All the little things:
The experiences of New Zealand secondary school teachers living with impairments and/or chronic illness.

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For you Mum.

It will not be simple, it will not be long
it will take little time, it will take all your thought
it will take all your heart, it will take all your breath
it will be short, it will not be simple
it will touch through your ribs, it will take all your heart
it will not be long, it will occupy your thought

~ Adrienne Rich (1991)
Abstract

Uncover me, my life is woven
Into the warp of impairment
The weft of chronic illness
Experience first-hand me living (Woven, LJS, 2014)

What are the experiences of New Zealand secondary school teachers living with impairments and/or chronic illness? This is the question I sought to explore through the storied experiences of Abby, Boady, Cleo, Elle, Garry, George, Harry, Jane, Kate, Lilly, May, and Sophie (not their real names), 12 New Zealand secondary school teachers. Working within a qualitative interpretivist paradigm, I drew from disability studies, disability studies in education, and arts-based educational research to frame this study. I conducted a qualitative exploratory survey and narrative interviews to produce the data. Thematic analysis of the opened ended survey questions provided strands of inquiry for the poetic text “I am, am I?” and the narrative interviews: Discriminatory practices/negative attitudes; disclosure; acceptance and support; impairment/chronic affects. After conducting a series of narrative interviews over a year, I drew on narrative and poetic inquiries to create an adapted holistic-content analysis framework to analyse the interview data. This involved three stages. Firstly, taking the position of storyteller, I co-created with the interview participants, storied accounts around their experiences of living with impairments and/or chronic illness. Secondly, an inductive analysis phase produced the major themes of diagnosis, teaching, and disability. Finally, poetic texts were created as a further iteration and level of analysis. The themes elucidate the complex, everyday doing and being for disabled New Zealand secondary school teachers. Teachers experienced levels of support from colleagues, and at times, school management accommodated their impairments. Participants also discussed the impact of stigma, isolation, and feeling like they were burdens. They highlighted attitudinal barriers associated with getting into, and staying in teaching. The themes, combined with the poetic and narrative texts, produce a space for creating understandings of disabled teachers experiences in New Zealand. This thesis provides a foundation for further research with and by disabled New Zealand teachers. It argues for social and political changes for disabled teachers if inclusive education is to be actualised. These changes may include both the celebration of and advocacy for and with disabled teachers through online forums and teacher union initiatives. Disabled teachers’ perspectives largely remain invisible and untapped sources for inclusion at both practical and theoretical levels. The stories of Abby, Boady, Cleo, Elle, Garry, George, Harry, Jane, Kate, Lilly, May, and Sophie have the potential to become vehicles for change.
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At the heart of this thesis are the stories and lives of the people who generously shared with me; they are embedded in every page of this thesis: Abby, Boady, Cleo, Elle, Garry, George, Harry, Jane, Kate, Lilly, May, and Sophie (not their real names). I am forever in your debt.

With these are the lives of those who have supported and shared with me their time, their wisdom, their encouragement, their patience; my wonderful supervisors Ruth Gasson and Alex Gunn, have supported me in such a way that I had the freedom to explore edges of my imagination and find my own academic pathway. Thank you to proof readers Fiona Stuart and Dr. Patricia McLean for bringing polish to these pages.

Throughout, my family have kept me grounded, reminding me that when all else falls away and finishes, they remain. I have appreciated their kindness, love, and support. To my Mother Denise, “my loadstar as I go and come”¹ your love and support shines brightly in my life. To my Father Chris, you probably won’t read this, but I will tell you about it when it’s all over! To my brother Matthew, the other side of the coin, I am so proud of you sweet man. I have a feeling I was your evil twin all along (muahahahahaaaaa). To Sue, from our shaky isles to your emerald one: Go raibh maith agat. To Elodie Rose, one day I hope to share so many stories with you under a blanket fort.

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*With all my heart, forever and sincerely, thank you.*
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Note on the illustrations.
The title page illustration is a papercut created by the author using the metaphors that some teachers used to describe themselves as teachers. From left to right: tug boat, figure with child representing grandfatherly, tree, three ducks representing Mother duck, vines and watering can representing gardener, arms that provide the structure represent a hug. Please see both chapter 6 title page and appendix A for the full co-created poetic metaphors. The blackout poems, theory, literature, and method were created by the author from a random page of key texts, inspired by Selina Tusitala Marsh’s blackout poems in Tightrope (Tusitala-Marsh, 2017), each end with the typed words to make sure they are visible to the reader.
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Glossary

**ABER:** Arts based educational research

**CCS Disability Action:** Formerly the Crippled Children’s Society

**CFS or Chronic Fatigue Syndrome:** also referred to as myalgic encephalomyelitis (ME), is a medical condition that causes uncontrolled levels of exhaustion over long periods of time ([https://en.wikipedia.org/wiki/Chronic_fatigue_syndrome#Definitions](https://en.wikipedia.org/wiki/Chronic_fatigue_syndrome#Definitions))

**CEDAW:** Convention on the Elimination of all forms of Discrimination Against Women

**Crip poetry:** An American movement of disabled poets writing in reaction to the disabling nature of society. For a full exposition please see: [http://www.wordgathering.com/past_issues/issue2/essay/ferris.html](http://www.wordgathering.com/past_issues/issue2/essay/ferris.html)

**DS:** Disability Studies

**DSE:** Disability Studies in Education

**DPA:** Disabled Persons Assembly

**ECNZ:** Education Council of Aotearoa New Zealand

**Endometriosis:** a medical condition that can be very painful for women and occurs when tissue similar to the lining of the uterus (endometrium), is found in places outside of the uterus ([http://www.nzendo.org.nz/about-endometriosis/](http://www.nzendo.org.nz/about-endometriosis/))

**IHC:** Intellectually Handicapped Children

**MS or Multiple Sclerosis:** A chronic degenerative, often episodic disease of the central nervous system. ([http://www.dictionary.com/browse/multiple-sclerosis](http://www.dictionary.com/browse/multiple-sclerosis))

**NZBORA:** New Zealand Bill of Rights Act

**PPTA:** Post Primary Teachers Association

**UNCROC:** United Nations Convention on the Rights of the Child

**UNCRPD:** United Nations Conventions on the Rights of People with Disabilities

**UNHCR:** United Nations Declaration of Human Rights
Chapter 1

All the little things get left out
Somewhere between mind and mouth
They leave as if unimportant
To the fabric of being;
Yet we are made up of all the little things
And little things make us, who we are.
(L.J.S, 10/03/14)
Introduction & Background

1.01 Introduction

The common saying, “all the little things” has inspired the short title of this thesis and the previous poem. It was used by several participants and has become a metaphor for the experiences of 12 secondary school teachers living in New Zealand with impairments and/or chronic illness. In this thesis I seek to explore the little things, the messiness of the lived experience, in order to create a space for understanding disabled teachers’ lives, with the view to the actualisation of inclusive education.

Disabled people’s experiences of the education system, including working within it, are important. They highlight the disabling barriers that continue to exist and be maintained by the physical and political structures of the education system.

In this thesis, I explore the experiences and stories of Abby, Boady, Cleo, Elle, George, Garry, Harry, Jane, Kate, Lilly, May, and Sophie (not their real names) through narrative and poetic inquiries. Their stories, voices, and experiences provide an insight into the “embodiment of fleshy life” (Titchkosky, 2007, p.12). They can and do ‘challenge’ the dominant view of teaching, of disability, of impairment, and of chronic illness as they reveal the often hidden and confronting aspects of being a teacher living with impairments and/or chronic illness.

Yet, by and large, stories of disabled teachers remain unheard, ignored, isolated, or viewed in patronisingly inspirational terms. The experiences of Abby, Boady, Cleo, Elle, George, Garry, Harry, Jane, Kate, Lilly, May, and Sophie provide a space for the disability experience where “even in matters as ordinary as everyday movement, disability can begin to be grasped as a place from which the culturally constituted boundaries between the expected and unexpected, the visible and the invisible, the doing and the non-doing of things can be considered.” (Titchkosky, 2003, pp. 17-18). These stories of the everyday create spaces for understanding the lives of disabled teachers, and potentially a place for the actualisation of inclusive education. In the following section I provide a guide to the structure of this thesis.
1.02 A Guide to this thesis

Although I write this guide in a linear nature, tied to the traditional structures of thesis and research writing, this belies the complexities and messiness of the lives represented in this thesis. Nevertheless, in the current chapter I seek to locate myself through a backstory of why and how I came to create this thesis. In Chapter 2, I outline and explore the theoretical layers that underpin this thesis. I begin with a brief discussion about the wider qualitative, interpretivist, and social constructionist frames. I then explore disability studies and disability studies in education (DSE). I then focus on the specific field of the sociology of disability. The final theoretical layer explores the arts-based aspects of this thesis including narrative and poetic inquiries. This theoretical framework has allowed for a flexible and inclusive worldview that privileges disabled participants and creates a space for understanding.

A review of the literature follows in Chapter 3. I focused primarily on the literature about disability experiences from disabled preservice teachers’ experiences of becoming a teacher, and of being a disabled teacher. This arc led me to explore the prejudices faced by disabled students and teachers. I also briefly drew on the key aspects of organisational bullying, workplace inclusion, and disclosure found in employment literature because there was a gap in the literature about disabled teachers, yet there were indications that these were important lines to follow in disabled teacher literature. The literature suggests that disabled teachers (primarily tertiary) are untapped sources of inclusion.

Chapter 4 describes the methods used for the collection of data including recruitment and analytic strategies. It further positions my role as a storyteller, not a story analyst (Smith & Sparkes, 2007). I describe the two phases of data collection; Phase one, a national recruitment survey from which the descriptive demographics of the participants are explored, and phase two, narrative interviews with 12 participants, 10 of whom were recruited via the survey. Chapter 5 draws on the qualitative responses from the national survey, and represents the data as a poem displayed at the beginning of the chapter as a prologue to a short anthology of stories. These stories represent the 12 interview participants’ narratives from phase two, describing what it is like to be a New Zealand secondary school teacher living with impairments and/or chronic illness. I continue the use of poetry in Chapter 6 as a part of an adapted holistic content approach to the interview data. A thematic poem illustrates an “iterative remix” (Wiebe, 2015, p.158) of each of the major themes: diagnosis, teaching, and disability.
Chapter 7 concludes the thesis, recognising the contribution of this research to the wider body of knowledge, and providing suggestions for future research including the establishment of networks either physical or online for disabled New Zealand teachers. This guide has given a brief overview of this thesis recognising that:

No real journey can happen without a foot on some piece of ground (or a bottom in some seat) and the wind’s kiss on skin. There is no philosophy in the absence of a sweating fear; no humor without hiccups; no love without blood in a beating heart. So get yourself comfortable, and let’s begin. (Hershey, 2011, p. 132)

1.03 Backstory: A bit about me

My story begins with my bottom in a seat, with sweating fear and hiccups, with blood in my beating heart (Hershey, 2011, p. 132). This backstory is not confined to this section of my thesis, it will echo throughout and within the research processes. It is hard to disclose any impairment or chronic illness, so I do not take the telling of mine or anyone else’s stories lightly. I do not speak for others, but rather with and alongside others. As a researcher, I am privileged to listen to and record the voices and stories of those who choose to participate. I have taken the position of story teller, not story analyst (see chapter 4). I view this research as an instrument through which participants can describe their stories to a wider audience. My own story is not meant to be a “sob story” but rather an acknowledgement of one of the many influences that led me to write this thesis (Campbell, 2009; Sanderson, 2011).

Most of my life I have been aware that I have had “ill health”, to the extent where the world I inhabited as a child and then a young adult came from books or images on the television wheeled into my room for “distraction therapy”: a world of imagination that, if I were honest, could be filled with life and stories or at other times a sense of limbo. It was as Janet Frame described:

. . . a territory of loneliness which I think resembles that place where the dying spend their time before death, and from where those who do return, living, to the world bring, inevitably, a unique point of view that is a nightmare, a treasure, and a lifelong possession. (Frame, 1984, p. 96)

My “lifelong possession” centred on stories or the reading and writing of them. I was lucky. I had the guidance and support of my mother, Denise. She instilled in me a love of literature, history, music, and art. She taught me the benefits of being inquisitive and gave me a passion for learning.
By the time my ill health was qualified by the medical profession as a severe
physical problem, I was thirteen. As a result of earlier medical intervention, I had
sustained a spinal injury. At the time, both my ill health and spinal injury were
considered implausible by the medical profession. For two years, I struggled with pain,
and the feeling that I had made it up, which was the true opinion of one man in a white
coat. I was finally diagnosed with a spinal injury.

Further medical intervention took place and failed. Looking back, as I now have
the luxury of doing, the diagnosis, or the need for one, was not sought for me. Rather, it
was needed in order for me to be accepted socially, by my peers, my teachers, and even
family. From a very early age I wrote poetry. One poem I wrote (that was published)
was written when I was seven, as a rebuttal to the students who thought I was “wagging
school”: “Being sick is no fun” (Southland Times, 29 May 1992, see appendix B). The
title was used as a repetitive refrain as if to convince my peers, a mixed classroom of
seven to 10-year-olds, that I was not wagging school. So, from a very early age I came
from a place of knowing impairment and chronic illness, and perhaps even a place of
poetry. My attendance at school was patchy at best, and I only attended high school for
a day, a term, and a year. I gained entry to university, where I have remained
surrounding myself with stories in history and classical studies, writing stories in
English and theatre studies, and examining narratives in child and youth studies, as well
as in Education. I recognise that:

My account of myself is partial, haunted by that for which I have no definitive
story. I cannot explain exactly why I have emerged in this way, and my efforts at
narrative reconstruction are always undergoing revision. There is that in me and
of me for which I can give no account. (Butler, 2001, p. 27).

Because I can only partially “account for myself”, why I chose this topic is also
important. The first real impetus outside of my personal experiences for this thesis came
when I was conducting the research for my Master’s thesis from 2009-2011.

Comments made by “Mrs. Black”, an interview participant in that study,
signalled not only the oppressive force of school for disabled students, but also for
teachers (Sanderson, 2011, 2012, 2013). She described professional isolation during a
peer teaching cycle. Although her qualifications were higher than most, her colleagues

1 As an aside I recognise that this backstory could also be seen as my re-storying of my experiences.
expressed little regard for her professional knowledge. Self-deprecatingly, she described her feelings of stigma attached to being disabled and teaching disabled students. Comments made by the Special Education Needs Coordinator (SENCO) suggested that Mrs Black was the only teacher committed to ideas of inclusion within the school. This suggested and emphasised the pedagogical differences between Mrs Black and her school (Sanderson, 2011, 2012).

I described my backstory here, because from the outset, in this thesis I have emphasised a collaborative, co-constructed, participatory research process. For some researchers an essential element in disability research is that the teller of the story, or the researcher, comes from a “place of knowing” (Sanderson, 2011, xi). I feel that my experiences of impairment and the disabling nature of society, enable a sense of knowing, if not place. Ultimately, teachers with impairments and/or chronic illness (disabled teachers) have not been represented within New Zealand educational research (Cahnmann-Taylor & Siegesmund, 2008). If we are to move forward and achieve a truly inclusive education system, then challenges to the status quo are required. Therefore, it is important to examine different narratives in order to understand why the actualisation of inclusive education has not been transferred from policy to practice. Narratives, like those of disabled teachers, challenge how we view the practice of teaching, and what it means to be a teacher. The next section briefly situates my ideological homes of disability studies, disability studies in education and arts-based educational research.

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2 This approach is championed by disability studies scholars like French and Swain (1997).
1.04 The (un)seeing world: Ideological homes

I have three umbrellas
Wide and encompassing
Two are similar but different
One is striped in multiple ways

On such a rainy day I ponder
Can I use all three at the same time?
Or will the wind turn them inside out?
I have three umbrellas

My first umbrella uses a theory of oppression
My second umbrella observes the first in education
My third umbrella creates colour in a black typed world
I have three umbrellas.

(L.J.S. 05/03/2014)

I wrote this poem pondering my use of two theories to frame this research, and wondering if I could or should add a third. By the time I came to write the third stanza, I realised that I needed to use all three, or parts of all three, to illuminate and elucidate my research position. Cahnmann-Taylor and Siegesmund (2008) stated that “every research methodology is a way of seeing the world – and every way of seeing is a way of not seeing” (p. 4). This section explores some aspects of my (un)seeing world, my ideological homes, disability studies, disability studies in education and arts-based education research.

I consider my first ideological home to be disability studies. Disability studies has been described by Thomas (2007) and Goodley (2011) as a large umbrella\(^3\) which is trans/inter-disciplinary. Considering the complexities of disability, it is understandable that no single discipline holds all of the knowledge or research regarding disability. The research within and across disability studies is used to promote the inclusion of disabled people, and to subvert long held disabling perspectives in traditional disciplines like medicine (Goodley, 2011).

My second umbrella is disability studies in education, which draws on disability studies, but refocuses on educational issues. My third and final umbrella is Arts-based

\(^{3}\) I acknowledge that I took this metaphor as my key concept in the poem at the beginning of this section.
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Education Research (ABER). ABER was new to me as I began this study. I discovered a theoretical home that challenged my own conceptions of what research should and could look like. My use of plain language is influenced by ABER where:

The use of ordinary, everyday speech in an arts-based research text may serve to attract a different readership than would ordinarily engage in the reading of educational research texts. Audiences for educational research may be thus broadened to include onlookers, such as nonresearcher educational practitioners, educational policymakers and even members of the general public. (Barone & Eisner, 1997, p. 97)

Most importantly, ABER challenged me to think in new ways, and made me engage in both my research and the research processes. The next chapter explores disability studies, disability studies in education, and arts-based educational research in more detail as part of my theoretical framework. Before exploring my research question, it is important to define the two key concepts of disability and inclusion.

1.05 Key Concepts: Disability & inclusion

From the theoretical perspectives of disability studies and disability studies in education come the key concepts of disability and inclusion. Defining and outlining what they mean in terms of this thesis speaks to both my theoretical and personal stance.

1.06 Defining disability.

What differentiates the oppression and discrimination of the disabled from other marginalised groups is that in one quick instant – a slip in the bathtub, a virus borne disease – anyone can join us …. In fact, at some time in our lives, each and every one of us, sooner or later, will be, whether for short term or long, in some way disabled. (Fries, 2011, p104)

Oppression and discrimination are just two parts of a complex ongoing and evolving discussion on what disability means. In light of the previous discussion of the theoretical umbrellas, defining or outlining what disability means within this thesis is important.

In this thesis, I view disability as a complex, evolving, and meaningful idea. It means different things to different people, and it can be both an identity and a label. Later, it will become clear that for the participants, defining disability or how they “label” themselves, has been an important part of their lives and identity. Accordingly, I have applied the wide definition provided by Carol Thomas (2007). Thomas (2007) describes disability as a social oppression, a sociological understanding of individual
identity, and a focus on the lived experiences of disablism. Thomas is not the first to incorporate identity into a theory of disability based on the BSM (Priestley, 2002).

For Thomas, the lived experience of disabled people is impacted by: 1) the barriers to doing, or the processes that restrict activity, including physical barriers; and 2) The barriers to being, or the processes that undermine psycho-emotional well-being (Thomas, 1999, p. 157). The barriers to doing and the barriers to being are impairment effects that have a direct bearing on disabled people’s experiences but, as Thomas explains, it is the social oppression that turns these into a disability. Like Thomas (1999, 2007), I argue that people with chronic illness can experience similar “barriers to being” and “barriers to doing”, due often to a lack of understanding or institutionalised disablism. People who experience chronic illnesses can face social oppression. Shakespeare and Watson (2002) note the difference “between impairments that people have and the oppression they experience” (p. 10).

However, theorists like Meekosha and Shuttleworth (2009) warn not to universalise these ideas of impairment and disability as universalisation can “oblige hierarchies of difference and oppressive social processes and social relations” (p. 61). Experiences are the key to understanding disability itself and how people construct and are constructed through their experiences.

In this thesis disability is seen as societal oppression of those who have impairments. Chronic illness is incorporated as a category of impairment and therefore viewed as having similar barriers to being and barriers to doing. This provides a flexible and broad meaning for participants to define themselves in multiple ways. It is complex, it is messy, it is full of little things that add up, and big things that overwhelm.

1.07 Inclusion

Inclusion in terms of this thesis is recognising the rights of all to participate in a society where difference and diversity are valued (Gordon-Burns, Gunn, Purdue, & Surtees, 2012). This definition allows for the acknowledgement of rights, of the disabling nature of society, as well as the barriers to doing and being. It also recognises that inclusion is not simply an issue for education.

Inclusion is a concept that both disability studies and Disability Studies in Education (DSE) have in common. For DSE, inclusion is situated specifically with educational issues in mind. Inclusion has moved beyond education and disability to intersect with gender, ethnicity, identity, and more (Slee & Allan, 2001). What it means to be inclusive and how inclusion of disabled people is enacted (or not) has had a long
history of theoretical debate, as pointed out by Davis, Watson, and Cunningham-Burley (2000), where inclusion has often been seen as solely the domain of education. The education focus of inclusion has resulted in its appropriation by special education pedagogy. Under the guise of inclusion, specialist education has appropriated the language of inclusion but not the ideology behind it (Ballard, 1999). An example of this is schools promoting inclusion, through segregation. When the concept of inclusion intersects with education, the literature is predominantly focused on the inclusion of disabled students through teacher pedagogy (Carrington & Brownlee, 2001; Carroll, Forlin, & Jobling, 2003; Garriott, Miller, & Snyder, 2003; Reber, 1995; Rutherford, Hale, & Powell, 2015; Shippen, Crites, Houchins, Ramsey, & Simon, 2005; Specht et al., 2015; Tindall & Culhane, 2014). By focusing only on students, schools, education systems and society are left without any responsibility for making changes (Glazzard & Dale, 2013). In doing so, this has not led to the development of inclusive practices but rather maintenance of the status quo. Instead of chasing the ideal or replacing one discourse for another, it is important to acknowledge that inclusion is a continual pursuit. Inclusion is more than disability (Allan, 2008).

In light of my theoretical position and how I have defined disability and inclusion, the next section explores my guiding research question.

1.08 Research question

What is it like being a secondary school teacher living in New Zealand with an impairment and/or chronic illness? I chose this as my guiding question, and indeed the vehicle for my research, initially out of curiosity about the messy and complex aspects that story the lives of disabled teachers.

In my previous research, I had established there was a need for the stories of teachers living with impairments and/or chronic illness to be heard (Sanderson, 2011). I wanted to address and explore the inclusion debate in education in a different way because of my previous research and experiences. I shifted focus away from disabled students where there is already a proliferation of research, including disabled students within educational settings (e.g. Sanderson, 2011), and non-disabled student-teachers’ beliefs about disability and inclusion, (e.g. Rutherford, 2015; Shippen et al. (2005), towards an area I saw as neglected.

The overarching question allows the participants to “talk about” their experiences with few limitations. My use of the terms ‘impairment’ and ‘chronic illness’ was to enable the greatest number of participants to identify with the socially
constructed label that they felt most comfortable to use. This inclusive stance is in line with feminist disability studies (Garland-Thomson, 2005). Additionally, my focus on ‘living’ and not ‘teaching’ recognises how participants construct themselves as, and perhaps even beyond, being teachers.

Finally, the most powerful aspect of asking this question, is the importance of simply asking this question. All the teachers interviewed and some of those who participated in the survey expressed their gratitude that someone was interested in their stories, in their experiences, in their lives.

1.09 Summary

This chapter was dedicated to introducing and outlining the background to my research. I positioned myself as coming from a place of knowing, through my own personal experiences of impairments and chronic illness. This provides insight into why research that privileges disabled people’s voices is important to me. Furthermore, I detailed how a participant (Mrs Black) in my Masters research signalled the need for disabled teachers’ voices to be heard (Sanderson, 2011). I moved from my personal experiences to my ideological homes by identifying the three umbrellas of disability studies, disability studies in education and arts-based educational research. I then presented my guiding research question: “what is it like being a New Zealand secondary school teacher living with an impairment and/or chronic illness?”

In the following chapter, I explore my theoretical framework. This includes the three broad foci of disability studies, DSE and ABER; and explores them in some depth. From a general qualitative-interpretivist approach, I detail each layer of my theoretical framework in three parts. Part one describes theoretical foundations using a qualitative-interpretivist approach with social constructionism. Part two explores disability studies and disability studies in education before narrowing the discussion to the sociology of disability. Finally, part three describes my foundation of arts-based educational research using narrative and poetic inquiries. The theoretical framework is flexible, participant centred, and inclusive. It provides a fitting tool with which to examine the complexities and messiness of impairment and chronic illness.
Impairment, disability, chronic illness, exclusion/herself
tiredness and pain/an embarrassment/living tragedy/ this does
not mean the experience of illness/marginalization,
stigmatization/ full inclusion intermeshing in the daily
experience.
Source text: Thomas, 2007, p.175
Underpinning ‘all the little things’: Theoretical framework

2.01 Introduction

In this chapter I explore the theoretical framework I have used to create an understanding of the lives of teachers living with impairments and/or chronic illness. Through the lens of a qualitative-interpretivist paradigm, I chose a framework that is inclusive, and responsive, and prioritises the lived experience. To do this, I used sociology of disability, alongside the arts-based educational research approach of narrative and poetic inquiry.

The experiences of teachers living with impairments and/or chronic illness is at the heart of this thesis. It was important to choose a theoretical framework that not only kept their experiences front and centre, but also did not impose strict boundaries of engagement. The theoretical underpinnings of this thesis can be viewed on different levels that sit within the overarching qualitative-interpretivist paradigm. Below is a visual representation of this framework. The visual shows the broad framework, and each layer is then discussed in this chapter which is divided into three parts. The first part explores the outer layers that explore qualitative, interpretivist and social constructionism. The second and third parts explore the inner circles labelled disability studies/DSE and sociology of disability and then finally ABER, narrative and poetic inquiries. Arts-based educational research (violet and pink) indicate they are on the same level as disability studies & DSE and sociology of disability, but that they differ from each other.

Figure 1: Theoretical Framework
2.02. Theoretical Framework: Part One

In this first part of the chapter I explore the outer layers of my theoretical model (as highlighted above). This includes a discussion about qualitative research, situating my research further within an interpretive frame and finally the use of social constructionism.

2.03 Qualitative Research.

“[qualitative research] draws on imagination—the ability to form images, ideas, and concepts of things both seen and unseen…” (Lutteral, 2010, p.8).

In order to draw on imagination, to form images, ideas, and concepts, qualitative research has certain criteria (Creswell, 2007; Lutteral, 2010). The criteria includes a focus on participants and an emergent design. The researcher is the primary research tool, studying phenomena in their ‘naturalistic settings’ and often employing multiple methods of data collection (Creswell, 2007). Qualitative research he suggested further, is holistic and takes account of the social-political context of the phenomena being studied. The researcher often uses an inductive approach to the analysis (Creswell,
In this study I utilised all these aspects of qualitative research. Qualitative research, as Creswell (2007) submits, starts with an assumption and a problem. In this thesis, my assumption is that the actualisation of inclusive education could be better served by incorporating disabled teachers’ perspectives. My problem was that there was no New Zealand research describing the experience of New Zealand secondary teachers living with impairments and/or chronic illness. This provided the research gap, and combined with my interest, led to the development of my research question: What is it like being a secondary school teacher in New Zealand living with impairments and/or chronic illness?

To answer this question, I have positioned myself as the research tool conducting a qualitative survey and interviews. I recognise that, as the researcher, I am both a “product and producer” of this research (Richardson, 1997, p. 2). In the previous chapter I acknowledged I come from a ‘place of knowing’. However, here I recognise that my positionality is not only marked by disability, but also by my gender, sexuality, and class. The analysis is discussed fully in Chapter Four, where I describe using an adapted holistic-content approach (Lieblich, Tuval-Mashiach, & Zilber, 1998).

In response to Creswell’s argument, that qualitative research should either add to the literature or provide a call for action, the research I have conducted does both. It adds to the small body of research found within disability studies and DSE about disabled teachers, and seeks advocacy for and by New Zealand disabled teachers. Creating an understanding of the experiences of teachers living with impairments and/or chronic illness is at the heart of this thesis. In the next section I outline interpretivism, a key aspect of which is understanding.

2.04 Interpretivism.

“…to bring us in touch with the lives of strangers” (Geertz, 1972, p. 16)

“To understand is always to understand differently” (Gadamer, 1970, p. 87).

Yanov (2014) describes interpretivism as characterised by research that seeks to understand the world of participants. Interpretive research starts with the supposition that reality is social and multiple. Interpretations of social and multiple realities are iterative and mediated through the experiences and interpretations of the researcher, participant, and the reader/or listener. (Yanov, 2014).
The key to interpretive research is to create understanding or *verstehen*. The concept of *verstehen* goes beyond simply understanding. It explores the complexities and multiplicities of social, cultural, and historical interactions (Lutteral, 2010; Goldkuhl, 2012). By doing so, interpretivist research recognises influences both from outside and within and it is the engagement with these influences that creates understanding (Yanov, 2014).

Research using interpretivism unfolds without a fixed theoretical framework. I began with a notion to conduct narrative research. This was expanded to include poetic inquiry. The influences of disability studies further shaped this thesis’s theoretical underpinnings. The theoretical foundations unfolded as the research did. Through an interpretivist lens, my research can be seen as striving to create understanding of inclusion through the lives of teachers living with impairments and/or chronic illness. Ultimately, it means to understand differently (Gadamer, 1970, p.87).

Interpretivism is considered a useful approach when seeking the voices of groups who have not been heard (Goodley, 2011). It also has the potential to highlight changing disability identity, and as such, challenge ablest social constructions. However, Goodley (2011) expresses a continuing critique of interpretivism, which is that there is the potential to “mask structural forms of disablism” (p. 55). Critics of interpretivism describe it in general as a “kind of disengaged contemplation or philosophical navel-gazing” (Yanov, 2014, p.22). This is because it does not explore issues of power. However, interpretivism does allow for “sustained empathetic inquiry”, and as such, provides a useful foundation for research that involves sensitive topics (Atwood & Stolorow, 1984, p.121 as quoted in Yanov, 2014, p. 22). The unfolding, responsive nature of interpretivism also allows for an ebb and flow to the research process.

2.05 *Social Constructionism.*

Social constructionism is a worldview in sociology that proposes that the everyday experiences of people and their interactions are mediated through language (Andrews, 2012). Views, ideas, people, and things are constructed within the context of society. There is no single voice because social constructionism recognises multiple voices, realities, identities, and the multiplicity of stories. Through these lenses, the taken for granted nature of the everyday can be grasped (Berger, Luckmann, & Zifonun, 2002; Gergen & Gergen, 2008). Understanding the everyday lived experiences of teachers living with impairments and/or chronic illness enables us to envisage “new,
different, and better ways of living” (Smith & Sparkes, 2007, p. 295). This is important because the research question interrogates the actualisation of inclusive education, which would be a new, if not better and very different way of living for disabled teachers.

Social constructionism is often considered unhelpful when examining issues that effect the individual (such as pain), because typically pain is constructed within the individual and is not shared by the wider social group (Siebers, 2001). In contrast, narrative identity, put forward by narrative inquiry, is useful for developing an understanding of pain as it is constructed within the individual. However, in order to explore the experiences of the individual within the wider social context I have also drawn from sociology of disability (Thomas, 2007). This enabled a theoretical approach that was inclusive and responsive to the experiences of teachers living with impairments and/or chronic illness (Corker, 1999). The sociology of disability and chronic illness is explored in relation to the next theoretical level, disability studies.

2.06 Theoretical Framework Part Two

![Figure 3: Theoretical Framework, Part Two](image-url)
In this second part I explore the theoretical framework as it relates to disability theory. Specifically, I view the broad ideological home of disability studies and disability studies in education before outlining the sociology of disability (Thomas, 2007).

**2.07 Disability studies**

To refuse to accept a normalizing conception of impairment rhetoric is to live differently with the terms and conditions of our bodies as living testimonies to the history they are made from and made to straddle. A new task for social justice praxis today is to stop killing the metaphors and to stop putting a lid on our capacity to imagine a different world. (Titchkosky, 2015, p. 16)

As Titchkosky (2015) posits, imagining a different world and the ability to change it is what I view as a key impetus for the use of disability studies. Disability studies is an umbrella term for inter-disciplinary research that explores disability either as a concept and/or experience (Goodley, 2011). Starting out as a reaction against paradigms that emphasise normalcy (Meekosha, 2004), disability studies is highly politicised, and often focuses on policy debates guided by disabled academics and theorists (Gleeson, 1997). It is a broad area of inquiry that has allowed me to draw on many perspectives – from personal experiences to literary perspectives like crip poetry (Rice, 2006, p. 253).

Tom Shakespeare (2009) suggests that research within disability studies needs to “capture the fact that impairment may not be neutral, but neither is it always all defining and terrible” (p. 191). The nature of the social and political struggle for rights, and at times to live, has perhaps created an unbalanced view of disability as a struggle. There is a lack of happiness represented in the disability experience (Bolt, 2015). I have not found it easy to maintain a balance of positive and negative experiences. This signalled need for a theoretical approach that is flexible and responsive to the experiences of teachers living with impairments and/or chronic illness (Corker, 1999). To achieve this, I have drawn on the perspectives from the sociology of disability and illness and feminist understandings of disability. I chose a theoretical position within disability studies that not only privileges the voices and experiences of disabled teachers, but also impacts lightly; in other words, a theory that does not impose strict boundaries of engagement. Sociological understandings (Thomas, 1999) explore the complexities of living with impairment and/or chronic illness. Through feminist perspectives the participants’ experiences become political (Morris, 1993).
A feminist disability perspective, as Vandekinderen and Roets (2016) suggest, can enable a space and place for rethinking “impaired bodies and minds as complex” (p. 44). Furthermore, feminist critiques of disability politicise the personal (Morris, 1993). Making the personal political enabled me to draw on personal stories of impairment and chronic illness without fear of individualising and re-inscribing these stories within the medical model. Feminist critiques also strengthen links with a human rights perspective. As Morris (1993) points out, “We all experience oppression as a result of the denial of our reality. If our reality is not reflected in the general culture, how can we assert our rights?” (p. 91). Likewise, Garland-Thomson (2005) notes that the inclusion of disability within feminist thought brings with it a complex understanding of how “social meanings … comprise narratives that justify practices that shape the lives of both disabled and nondisabled women.” (p. 1582). The narratives in this thesis show how social meanings shape the lives of disabled teachers, both women and men. How these stories are represented can be seen in terms of cultural reflection.

A form of cultural reflection is found in the work of disability poetics, poets with disabilities, or crip poets in America. Poetry is used as a medium and space to challenge, and to make the personal political, thus subverting the dominant culture of “normal”. For example, when discussing confessional poetry, Shelia Black (2011) noted that: “… far from being dominated by the personal, [it] often becomes a place where the personal and the political intersect in surprising, exciting and potentially subversive ways” (p. 206). Feminist and cultural/crip perspectives allow me to view disability from outside the discourse of medicine, and from outside the social perspective of disability. Taking a critical or questioning stance provides a space to highlight the celebration and the subversion of the “non-normative” body, recognising that disability experiences are “an important part of the diversity of the human experience” (Morris, 1993, p. 91).

Despite this, I am wary of using disability studies as untroubled and unquestioned. Scholars like Meeskosha and Shuttleworth (2009) point out that there has been an appropriation of disability studies by “specialists”, which they maintain, is often done without changing ideological perspectives. In reaction to this appropriation there have been two significant shifts within disability studies. Firstly, the shift from disability studies to critical disability studies (Goodley, 2011), then a further shift beyond critical disability studies towards a post-humanist understanding (Goodley, 2011; Meeskosha & Shuttleworth, 2009). Because my ideological home is disability studies, I have chosen not to go into detail about critical disability studies and post-
humanist perspectives. Other researchers have articulated their responses to these perspectives to a greater extent than I can do in the space of this thesis (Barnes, 2000; Biklen, 2000; Cameron, 2010; Goodley, 2007, 2013; Hughes, 2007). Briefly, however, the major tensions within and across disability studies, critical disability studies, and post-humanist disability perspectives centre on the construction of disability and the individual within it. Critical disability studies sought to reject the use of binaries between medical and social models, whilst a post-humanist perspective removes ‘the body’ and conceptualises a time when ‘the body’ might not be human (see Braidotti, 2009. 201Henders; Goodley & Cole, 2016).

I also chose to use a theoretical framework that emphasises social and relational aspects of disability, acknowledging that a:

Social theory of disability … should stand as the first and most significant attempt to produce, and interpret the concepts of disability and impairment from within the experience of disabled people... (Corker, 1999, p. 629).

2.08 Disability Studies in Education (DSE)

… the aim of DSE is to deepen understandings of the daily experiences of people with disabilities in schools and universities, throughout contemporary society, across diverse cultures, and within various historical contexts. … DSE works to create and sustain inclusive and accessible schools. (Connor, Gabel, Gallagher, & Morton, 2008, pp. 441-442)

Disability studies in education (DSE) became a subset of disability studies only in the last 20 years (Baglieri, Valle, Connor, & Gallagher, 2011; Connor & Gabel, 2013; Connor et al., 2008). Like disability studies, it arose in reaction to mainstream perceptions. For DSE it was in reaction to Special Education. DSE, as an area of both scholarship and a forum for activism and advocacy, has sought to further the debate about inclusion (Baglieri et al., 2011; Connor et al., 2008). DSE also incorporates elements of the trans-disciplinary nature of disability studies, which draws on multiple theoretical stances to promote understandings of disability and how these understandings relate to education (Baglieri et al., 2011).

The main unifying principle of disability studies and DSE is the view that disability is socially constructed. Other principles that characterise DSE but borrow from disability studies include a belief that there should be both a political and social
focus on disability research, framed within the privileging of voices, interests, and agendas of disabled people. DSE argues for inclusive educational opportunities, and full and meaningful access to all aspects of society for disabled people. It assumes the competence of disabled people to conduct their lives and rejects deficit theorising.

My approach to disability research is in line with disability studies and DSE by privileging the accounts of disabled teachers and seeking to challenge traditional methodologies. Thus, my research is methodologically eclectic. I agree with Connor et al. (2008) who suggest that what DSE explored in its infancy, is “only the tip of the iceberg” (p. 454). The research within the body of DSE literature still tends to focus on disabled students. Where it pertains to disabled teachers, it is predominantly in the traditions of special education (see, for example, Roald, 2002). Education settings are an important site or genesis of DSE. DSE is evolving to incorporate the consideration of education issues that may transcend the boundaries of educational institutions. Situating my study within the DSE and DS frameworks recognises that disabled teachers require the same considerations of social justice and advocacy as those recognised by DSE for disabled students.

2.09 The social models of disability.

The ‘social model’ of disability is a key concept and indeed a defining feature of research in disability studies. Often research encapsulates the ‘social model’ as a single theoretical positioning. However, there are multiple social models of disability and each views disability in a different way. The evolution of social models of disability underscores the plurality of theoretical assumptions found within disability studies and DSE. There are at least three major western iterations of the social model of disability. Situated geographically they are the British social model (BSM), the Nordic social model, and the North American social model (Goodley, 2011). In this section, I explore briefly the development of the British social model (BSM) to provide a context for the theoretical underpinnings of the sociology of disability and chronic illness.

The evolution of a social model perspective is at the heart of the evolution of disability studies (Meeskoka & Shuttleworth, 2009). Here it is simplified to situate this thesis firmly within a disability studies theoretical position. Disability studies is littered with debates about the pros and cons of the social models. I prefer the stance of Oliver (2013), who argues that a social model is a tool. It is a tool that also sits at the heart of disability policies both in international treaties (UNCRPD, 2007) and New Zealand policy making (NZDS, 2001, 2016). The evolution of the models of disability reflects
ways disabled people have been, and continue to be viewed, within western society. How a piece of research uses a social model tool signals its innate philosophical assumptions.

The BSM defines disability in terms of the oppression that society imposes above and beyond impairments, as noted in 1975 by the Union of the Physically Impaired Against Segregation (UPIAS) (UPIAS, last viewed 10/11/2017). The BSM’s development has been well-documented by disability studies researchers (Oliver, 2013). Briefly, it developed in reaction to the medical model of disability. Instead of viewing disability as an individual deficit or deviance, something to be cured or fixed the BSM views disability as a social oppression, separate from individual impairment (Anastasiou & Kauffman, 2013; Baglieri, Valle, Connor, & Gallagher, 2011; Barnes, 2000; Beckett & Campbell, 2015; Bickenbach, Chatterji, Badley, & Üstün, 1999; Oliver, 2013; Shakespeare, 2006).

More recently, disability theorising has moved beyond these dual ideologies to multiple models, interpretations, or reimaginings of the BSM itself. Mike Oliver (2013), a key theorist in the development of the BSM, described it as a tool rather than the encompassing framework that it is often described as. Through the geographically located models, the language and focus shifts slightly and is often tied to the political contexts.

However, the major critique of the BSM model focuses on its erasure of the “body”. This has led to researchers applying parts from different models, for example, Carol Thomas (2007) who incorporated relational aspects of the Nordic model with the BSM in her sociology of disability and then broadened both to include illness. It is important to understand that there is not one but many social models, yet they all carry the name of the social model of disability. Several key national and international treaties such as the New Zealand Disability Strategy (2016) align themselves with the BSM. The United Nations Convention on the Rights of People with Disabilities (UNCRPD, 2007) on the other hand, is aligned in language to the North American model.

This alignment speaks to what language is used, for example the BSM would say disabled person whereas the North American model uses people with disabilities. In this thesis, I have aligned the theoretical underpinnings with the sociology of disability (Thomas, 2007). Thomas (2007) aligns the BSM with a sociological perspective that sharpens the “blunt tool” (Shakespeare, 2009, p. 220) of the BSM through the lens of experience.
2.10 Putting back the body: Sociology of disability.

The sociology of disability (Thomas, 2007) brings together the social/cultural/political nature of disability with the individualised, and often medicalised ideas of illness, incorporating gender, race, age, and social class. Barton (2001) outlines the agenda for sociology of disability as “[a] political analysis which is inspired by a desire for transformative change and that constitutes hope at the centre of the struggles for inclusivity”. He then went on to say. “At both an individual and collective level a crucial task is to develop a theory of political action which also involves the generation of tactics or strategies for its implementation” (p. 3). However, the political aspect has been hard for researchers to implement (Allan, 2010, p. 604). Thomas (2007) furthers the agenda stating that the sociology of disability develops ways to overcome “disablist structures, systems, discourses, attitudes, practices and behaviours – wherever and however these appear…” (p. 182)

For Thomas (2007), any form of disability research should be situated within a social oppression model of disability such as the British social model of disability (BSM), and firmly aligned with disability studies. Importantly, in terms of this thesis, Thomas (2007) puts forward the argument that the lived experiences of both disability (socially constructed) and impairment (individual) should be explored. Illness then becomes a part of, not separate from, disability experiences. Indeed, chronic illness becomes a part of the impairment spectrum (Thomas, 2007).

To understand the experiences of teachers living with impairments and/or chronic illness I have chosen to draw on the sociology of disability, as proposed by Thomas (2007). This theoretical perspective incorporates chronic illness with the social model and the key aspects from disability studies explored earlier. Thomas’ (2007) sociology of disability enables an examination of the complexity, interwoven nature, and multiplicity of disability and chronic illness. It also recognises that:

Medicine continues to exert great influence on the social meaning of disability in general and the social valuation of various illnesses and impairments in particular. Whereas specific conditions may be socially valued, the overall category and label of disability connotes marginality and stigma. (Grue, 2016b, p. 957)

In part, it is because of these connotations of marginality and stigma that I felt it was important to enable participants to define themselves. I argue that the engrained medicalisation of disability has encouraged many of the participants to view themselves
in medicalised terms. Some use disabled, impaired, or diagnosis interchangeably. It is important, as Thomas (2007) explains, that research should “… give priority to the subjective experience of ‘disablism’, that is, to people’s encounters with social exclusion, discrimination and marginalisation.” (p. 177).

Chronic illness is conceptualised as a category of impairment as described by Thomas (2007) and as discussed in chapter one as I defined what disability means in this thesis. The sociology of disability is the core theoretical perspective of this thesis as I sought to engage with lived experiences of disabled teachers. This necessarily involved investigating the social structures of education and how these impacted on the social agency of disabled teachers (Thomas, 2007, p.181). The sociology of disability that Thomas (2007) promotes is one that includes disablism, impairment, and impairment effects. It is a stance that “can grasp the interrelationship between ‘the social’ and ‘the biological’….and engage with the sociology of ‘suffering” (p.182). The stories of disabled teachers in this thesis make explicit this interrelationship, and furthermore they reveal the engrained disablist structures of schools and political system. The sociology of disability makes visible the institutionalised disablism faced by the participants in this thesis. By viewing their experiences of impairments and/chronic illness within this frame it is possible to reconceptualise their stories in terms of the broader social oppression of disabled lives.
2.11 Theoretical framework part three

In this third and final part of this chapter I explore arts-based education research. I draw on narrative and poetic inquiries that enable, at times, a fractured and prismatic view of the lives of disabled teachers (Cannon, 2017).

2.12 Arts-based educational research.

So far, the unfolding theoretical underpinnings of this thesis have been focused on the wider context of qualitative research, interpretivism, social constructionism, and how disability is theorised through the sociology of disability. This section introduces Arts-based educational research (ABER) before exploring the specific frames of narrative and poetic inquiries. ABER, like DSE, is relatively new with just over 20 years of tradition to draw on (Sinner, Leggo, Irwin, Gouzouasis, & Grauer, 2006). Like DSE and disability studies, ABER stems from a broader interdisciplinary tradition of Arts-Based Research (Richardson, 1997).

The creative forms that ABER take are broad and can incorporate poetry, stories, drama, visual media, and music. Research that uses an arts-based foundation tends to be
research that “both finds its inspiration in the arts and leads to progressive forms of social awareness” (Barone, 2008, p. 34 emphasis in original). The production and reading of arts-based research also provides a “catalyst for the changing of minds” (Barone, 2009, p. 35). As I have set out to create awareness and to change and challenge minds, policy, and the education system about disabled teachers, ABER is appropriate for this project. Further to this, an arts-based approach connects with the wider theoretical framework of this thesis, including an emphasis on holistic research and a focus on bringing forward voices and perspectives of marginalised people (Leavy, 2018).

My thesis could be described as what Cahnmann-Taylor and Siegesmund (2008) call a hybrid text, which uses expressive everyday language to create space for the reader and promote empathetic participation. This is different to what they describe as ‘art for scholarship’s sake’, which is the creation and production of art that is stand-alone. The art in the form of poetry that I produced for this thesis could be read as stand-alone pieces, but as Cahnmann-Taylor and Siegesmund (2008) note, you have to be brave to pursue this line. At this point in my PhD, my courage failed me. Therefore, a conventional academic thesis structure of context and analysis is used to elucidate the research.

Through my burgeoning interest in ABER and poetic Inquiry, my thesis is punctuated with poems (Stewart, 2010). For me, “poems work with a sense of discovery and surprise, a showing rather than telling. They might hint, tease, captivate, shout; they rarely explain” (Stewart, 2010, p. 87). The poems provide potential spaces to evoke and provoke, spaces to create understanding and/or to disrupt and challenge the status quo (Leavy, 2018). I have used poems to highlight research processes, to challenge the status quo, to show what it is like being a secondary school teacher in New Zealand living with impairments and/or chronic illness.

The first use of poetry is through reflexive journaling, for example, Woven (abstract and Chapter 7), All the little things (Chapter 1), 3 Umbrellas (Chapter 1), and Ars Poetica towards the end of this chapter. Instead of a traditional journal, I found it easier and more effective to convey my thoughts, my struggles, and my triumphs through poetry. I began keeping track of powerful images from observations or thoughts

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4 I chose to use the term reflexive although I know it is a contested term (Gabriel, 2018). For me reflexive incorporates writing with purpose and a desire to reflect back on events or situations or thoughts and feelings.
to build on or from, to create metaphors. The images ranged from a poem inspired by
ews stories to everyday things noting, as Sullivan (2010) does, that poems hide in
everyday things (see appendix C for examples of these). This type of journaling is akin
to ethno-poetics (Chawla, 2008). Poems are also used in conjunction with narrative as
my forms of artistic re-presentations to “enhance perspectives” (Barone & Eisner p. 96)
and in turn, “... stimulate imaginative faculties, inviting the reader to fill gaps in the text
with personal meaning” (p. 97).

As I seek to question what inclusive education could look like, Slattery (2003)
reminded me that “the arts have often challenged dominant political, religious and
aesthetic conventions while serving as a lightning rod for social change” (p. 193).
Likewise, Barone (2009) observed that research that is arts-based is “engaged in an
ongoing quest to make the world of schooling a better place” (p. 102). Schools often
become or are disabling not only for students, but also for teachers; for all those who
reside in those institutional spaces and places. My research seeks in part to address this
disabling environment. Finally, I agree that the use of stories and poetry adds “joy,
meaning and impact” (Cahnmann-Taylor & Sigmunsen, 2008, p. 8) to the reading of
this thesis as it has in producing it.

2.13 Narrative and poetic inquiries.

I strove to use research approaches that would complement each other and
maintain the multi-faceted, person-centred, experiential, and polyphonic aspects that
relate to the broader umbrellas of disability studies, DSE, and ABER. I identified
narrative and poetic inquiry as capable of making these various aspects visible.

Narrative is considered as both a methodology and method (Clandinin & Caine,
2007). The arts-based functions of narrative have enabled me to explore the lived
experiences of disabled teachers within my unfolding theoretical framework. The use of
narrative inquiry is not generally common within disability studies and is a feature more
of illness narratives in medical sociology (Smith & Sparkes, 2005). Narrative inquiry
also features as a key methodology in the small amount of literature about disabled
teachers (see Chapter 3). It is rarely used in conjunction with disability studies because
of fears of re-inscribing individualistic, medicalised, disabling discourses (Frank, 1998;
Smith & Sparkes, 2005). I am mindful of this critique of narrative inquiry, and indeed,
the same critique of the broader interpretivist approach. However, for this research it
was important to access stories that had not been told within the New Zealand education
research landscape. Narrative has the power as both an advocacy tool and a catalyst for
change, allowing the stories within this thesis to become of greater ontological and epistemological concerns

Earlier, I described the social model of disability as failing to account for pain. Although narrative inquiry is not a social theory, it allows me to explore the experiences of pain and chronic illness through personal experience (Broyard, 1992; Daudet, 2002; Frank, 1998). Pain – physical or emotional – is a common feature of the stories in Chapter 6. Bringing these experiences forward further highlights the complexities and the everydayness that comes with a life lived.

I am very much influenced by how I came to poetic inquiry and ABER. In their introduction to *Essential New Zealand Poems*, Harvey, Norcliffe, and Ricketts (2014) describe contemporary New Zealand poets as having a “magpie-like enthusiasm”, taking their influences “from anywhere and everywhere” (p. 13). The metaphor of the magpie is appropriate for how I both create and use poetry in this thesis. I come from this creative tradition, my influences being both creative and research-based. Figure 5 below outlines briefly how poetry is applied in this thesis. Ethnographic poetry can be found in my personal poems, which are marked by my initials LJS. The data poems are concentrated in Chapters 5 and 6 in an evolving series of data poetry, all beginning with *I am*. They have a narrative focus as they seek to describe and explore the lived experiences of teachers living with impairments and/or chronic illness.
2.14 Why narrative?

Those that have no story that society judges as worth telling feel that they have no place in society (Frank, 1998, p. 201).

There continues to be an absence of the voices of disabled teachers surrounding inclusion in New Zealand. This is evident by the lack of research that identifies disabled teachers as participants (see Chapter 3). The teachers I interviewed expressed an unburdening of their stories, and an appreciation of being listened to and of being valued. The use of narratives ensured that the individual lived reality, or the storied experience, was the central focus of this research and took precedence, in other words, “because, experience” (Clandinin & Connelly, 2000, p. 50).
Narratives are both holistic and person-centred (Bruner, 1987; Polkinghorne, 1991). Although person-centred research has the potential to be individualistic, narratives are also capable of producing social change as they provide the space between, where a shared understanding can be reached (Squire, 2008). Stories hold power. They can convey understanding by transporting the reader or listener to a place they may or may not recognise. The telling of their stories provides an emotional and physical space where the tellers can relive, retell, and even re-imagine their lived experiences (Bamberg, 2012; Bertaux & Kohli, 1984; Bignold & Su, 2013; Blumenfeld-Jones, 1995; Broderick et al., 2011; Bruner, 1987; Clandinin & Connelly, 2000).

Importantly, I have used individual narratives to provide insight into participants’ lives, and the wider society in which they live (Bertaux, 2003). This approach recognises that “individual biography does not bring with it the isolated individual, but rather the awareness of the individual within society” (Plummer, 1983). The narratives in this thesis then can be concerned with the wider social and cultural representations of disability. Narratives can provide insights that reflect or refract parts of the wider phenomenon that is disability, yet, they still encapsulate individual storied experiences of impairment and/or chronic illness (Riessman, 2005). By acknowledging the social context of the individual stories; the tension found within disability studies in terms of viewing individual experience as (re)pathologising the individual, is lessened. Narratives viewed within a broader sociological understanding of individual experience can highlight and develop an understanding of disabled teachers as a social group and culture (Elliot, 2005).

The use of narrative allows for insider stories of organisations such as schools, as well as minority stories as they can help in the exploration of under or unrepresented lives (Squire, 2008). Disabled teachers are therefore seen as both organisational insiders, and as a minority. In other areas like psychology and some spheres of educational research, narrative is used as a form of therapy (Vickers, 2001). Although I did not set out with therapeutic catharsis as an aim, some of the participants used the time we spent together to unburden their anger and sadness, and describe their hopes. For my participants, catharsis has been an important aspect of telling their story, stories that should not be dismissed or taken lightly.

A participant Jane, told her story as something her children could read to create an understanding of her experiences when they are older, and when she may not be able to convey those experiences to them. This gives a tangible link with what Riessman
(2005) describes as “... the shifting connections ... [stories] forge among the past, present and future” (p. 189). These shifting temporal connections also represent the phenomenon as it changes over time. Thus, when exploring a single phenomenon, in this case the experiences of disabled teachers, the temporal nature can produce different and multiple stories from the same person as their experience and perspective of the phenomenon changes. Richardson (1997) notes:

The story of a life is less than the actual life, because the story told is selective, partial, contextually constructed and because the life is not yet over. But the story of a life is also more than life, the contours and meanings allegorically extending to others, others seeing themselves, knowing themselves through another’s life story, re-visioning their own, arriving where they started and knowing ‘the place for the first time’. (p. 6)

The re-visioning of a text through (re)reading and the (re)telling becomes a collaborative process. It enables re-inscribing the story with new meanings, recognising elements of ourselves, and creating a shared space for “a place of knowing”. Narrative enables the telling of many stories, not just a single “grand narrative” (Clandinin & Connelly, 2000). Consequently, Chapter 6 reflects these ideas and the commitment to participant voice through the findings as a small anthology of stories.

2.15 Why poetic?

… experimental writing helps to heal wounds of scientific categorization and technological dehumanization. With its aesthetic sensibilities, experimental writing can introduce spirit, imagination and hope (Glesne, 1997, pp. 214-215)

Glesne (1997) provides a powerful impetus for using poetic inquiry. Poetic inquiry is defined as a form of qualitative research in the social sciences that incorporates poetry in some way and is often centred on the human experience (Prendergast, 2009). Poetic inquiry has its roots in ethnographic, sociological, and anthropological research influenced by the post-modern turn late last century (Alder & Alder, 2008). Poetic texts are generally written free verse, but can also take specific forms. Examples include tankas, an ancient Japanese poetic form similar to the Haiku (Furman, Langer, Davis, Gallardo, & Kulkarni, 2007), and found poetry, which is the creation of a new text from another source text. Found poetry has been used to represent other researchers’ ideas in literature reviews (Prendergast, 2009). Often poetry is published context-free, with no explanation of how it was created or why it was created,
Experimental writing is risky (Cahnmann, 2003), yet poetic representations of data can become an act of advocacy by making voices more accessible than lengthy research texts (Kennedy, 2009). There is a precedence for creative writing forms, and poetic inquiry can be found in narrative (Smith & Sparkes, 2007), disability studies (Bartlett, Black, & Northern, 2011), ethnography (Chawla, 2008), educational ethnography (Eisner & Barone, 1997; Phipps & Saunders, 2009; Prendergast, 2006), and sociology (Richardson, 1997; Ward, 2011). I have been inspired by researchers who draw on poetic inquiry as a “method of knowing” (Prendergast, 2009; Richardson, 1997).

Poet-researchers describe poetic inquiry as a calling, and suggest that it makes other forms of inquiry one-dimensional and flat in comparison (Prendergast, 2006). This is because poetry can be evocative, powerful, transformative, and liberating (Lahman et al., 2010). It allows the reader to see, feel, and hear the participants: “Poetry is an imaginative awareness of experience expressed through meanings, sound, and rhythmic language choices so as to evoke an embodied experience” (Butler-Kisber & Stewart, 2009, p. 3). Invoking these types of feelings in the reader provides a space for the potential for positive change in education (Butler-Kisber, 2002).

Poetry is often used to elucidate a problem, theme, or concern. Considered “the emotional microchip”, poetry serves as “a compact repository for emotionally charged experiences” (Furman, 2007, p. 1). Conversely, as Richardson (1997) notes, “poetry provides a way out of the numbing, disaffected, disembodied, schizoid sensibilities characteristic of phallocentristic social science” (p. 166). In light of the research question, both Furman and Richardson provide interesting arguments for the way I have applied poetry in this research. Furman’s (2007) idea of an “emotionally charged microchip” suggests that poems have to be short with a focus on emotive language while for Richardson (1997), poetry challenges the status quo of the research body.

Poetry can illuminate our lives by providing new insights on familiar issues. The poet researcher can also make “the familiar strange”. The idea of “strangeing” the familiar to provide insight is in line with both feminist and disability perspectives. Beyond “strangeing”, a key aim for poetic inquiry is to provide a space that enables and promotes empathy through participation with the text because the empathetic
engagement of a poetic text creates a critical consciousness (Leavy, 2018). Indeed, through this process the emphasis is on humanness (Eisner, 1997).

The calling to poetic inquiry, as Wiebe (2015) implies, is a way of being. He describes five ways of “being” in poetic inquiry: 1) attending to and prioritising humanness; 2) expecting the unexpected; 3) holding multiple truths; 4) exploring literary form and theory; and 5) creating possibility through iterative remixing (p. 158). These five ways of being are key to understanding how poetry has influenced and transformed my thesis. Poetry is my ‘way of being’:

Poetry and I have history
That lies under trees
By different seas;
Playing Ophelia on rivers
With gravel boulder bottoms
Going beyond the bounded
Inside yellow stripe of bedroom walls;

Imagination cut open
To speak
For – to me
Filling the silences
Watching the dappled shadows
Waking in them;
Without poetry
There is no thought
There is no seeing.

Poetry is my hyoid bone
Poetry is my third eye
Poetry is my phantom limb
(L.J.S 09/09/14)

2.16 Summary

This chapter outlines and describes the theoretical framework that underpins my research to answer the question: “what is it like being a secondary school teacher in New Zealand living with an impairment and/or chronic illness?” In three parts, I have outlined my theoretical foundations that I have used in this thesis. As the diagram at the beginning of the chapter suggests, the framework is holistic, layered and multifaceted. It was important that my theoretical framework was trans-disciplinary, flexible, and inclusive so I began by situating the overarching theoretical paradigm of qualitative-interpretivist.

My theoretical foundations are situated within a qualitative approach to create holistic, participant-centred research. Interpretivism also allowed for the unfolding
nature of this research, the ebb and flow of the research processes. The key concept of verstehen, or understanding, highlighted the need to explore the lives of disabled teachers. Social constructionism was then explored as a way of making visible the taken for granted of the everyday.

Part two of my theoretical foundations was to explore my ideological home and to anchor it within a disability perspective. I drew on disability studies and disability studies in education, both providing a wide scope of theoretical understandings. I focused on exploring the foundations of the social models and disability-feminist perspectives before narrowing to the sociology of disability. DSE provided an educational lens and emphasised advocacy, albeit predominantly focused on disabled students.

The final sections of this chapter explored arts-based educational research, specifically my use of narrative and poetic inquiries. In these sections I argue that the use of narrative reflects my commitment to participant voice. Narrative combined with poetic texts, which include ethnographic and data poems, enable a (re)visioning of what it is like to be a New Zealand secondary school teacher living with impairments and/or chronic illness.
Illustration 2: Blackout Poem, Literature

Inclusive classroom/edge of empathy/transform teachers/social equality/diversity, disability/ faculties discouraged/enrich experience/encourage employ/teachers can create critical consciousness/inclusion broaden/educators enlighten.

Source text: Burns & Bell, 2010, p. 541
Literature Review: Disabled teachers

The disabled self is always a reader of his or her own body. The disabled body is a trifold pamphlet composed of medical terms, insurance jargon, social service lingo, self help verbiage, advocacy mottos, and more currently, ontological and epistemological rhetoric on the disabled everyman who will save us from post-modern burnout (DiPietra, 2011, p273).

3.01 Introduction

In this chapter I examine the research that spans from disabled pre-service teachers’ experiences to the experiences of disabled teachers. This largely international body of literature pinpoints the experiences of disabled teachers as a key inclusionary force (Anderson, 2006; Brueggemann, White, Dunn, Heifferon, & Cheu, 2001; Burns, 2015; Burns & Bell, 2010, 2011; Gabel, 2001). At the same time, the reality of their experiences shows that they are far from included in their school culture (Chenoweth, 1996; Officer, 2009). In the previous chapter I outlined and discussed the thesis’s theoretical framework, which aims to be inclusive and flexible in order to answer the research question: what is it like being a New Zealand secondary school teacher living with impairments and/or chronic illness? Guided by my research question, this chapter draws on a broad range of disability studies and DSE literature as it pertains to disabled teachers.

3.02 Pre-service experiences: Becoming a teacher

Pre-service teachers are those who are training to be teachers, and the experiences of disabled pre-service teachers signal the beginning of disabled teachers’ experiences. The research that explores disabled pre-service experiences introduces ideas like the impact of empathy on building relationships between teachers and students (Glazzard & Dale, 2013; Griffiths, 2012; Riddick, 2003). The research also exposes ingrained attitudinal barriers for disabled pre-service teachers. Indeed, the research suggests that assumptions about a disabled pre-service teachers’ capacity to work can be the most significant barrier to becoming a teacher (Broderick et al., 2011; Dvir, 2015; Gabel, 2001; Glazzard & Dale, 2013; Griffiths, 2012; Riddick, 2003). Attitudinal barriers are often created by academic staff who hold dismissive or prejudicial attitudes towards disabled pre-service teachers (Dvir, 2015; Gabel, 2001; Glazzard & Dale, 2013; Griffiths, 2012; Riddick, 2003). The research does not necessarily explicate what these attitudes look like, only that they exist. The potential
impact on the disabled teacher of these negative attitudes ranges from unemployment
due to assumptions of ability to fear of disclosure.

Despite these negative attitudes, disabled teachers and disabled pre-service
teachers are often considered an inclusionary force (Anderson, 2006). Research suggests
disabled pre-service and in-service teachers are often able to empathise with and build
relationships with their students. Susan Gabel’s (2001) study sought to highlight three
disabled student teachers’ understandings of themselves as emerging disabled teachers.
Gabel outlined their narratives, observing the interconnectedness of an emerging teacher
identity with an emerging disability identity. One of Gabel’s participants, Christina,
discussed how her worldview changed throughout her illness:

> My whole concept of myself has changed. I’ve always been polite to people. But
now it makes more sense to me. It’s like the scheme of things. What I do and say
doesn’t just affect me; it effects a whole different range of people. And even not
just in school, but at home. I’m not alone here. I’m this one little piece to this
whole scheme of things. I treat people the way I would like to be treated, with
respect. I’ve always done that, but I’ve never really thought about it. (Gabel,
2001, p. 41)

Christina felt she was more reflective and able to build confidence in her students
because of her experiences. Another participant, Martin, used his own experiences with
a “learning disability” (p. 41) as an empathetic tool in building relationships with a
student who was struggling in class. The literature suggests that empathy is important in
developing relationships with students (Gabel, 2001; Riddick, 2003). Because of their
heightened sense of empathy, the influence of the disabled teacher moves beyond the
classroom. It enables students to build empathetic relationships. This has the potential
for being a building block for the actualisation of inclusion (Gabel, 2001; Riddick,
2003).

Riddick’s (2003) study, is one of the few that looks at both disabled pre-service
and in-service teachers. Her study explored eight teachers, (primary to tertiary), and five
pre-service, or training teachers, all of whom self-identified as having dyslexia. She
traced participants’ experiences of schooling and explored how this influenced their
teaching. Riddick identified empathy as a core aspect of her participants’ decision to
become teachers. When asked where his empathy came from, one pre-service teacher
Participants also used empathy to find teaching solutions. Riddick questioned the notions of what makes a “good teacher” and suggested that the institutional “vision” of who should “become” a teacher plays a major role in teacher development. She proposed that looking at the experiences of disabled teachers could be a way for schools and institutions to “become” inclusive.

Sometimes, an institution’s vision can be a barrier to a teaching career. This is borne out in the research of McKay et al. (2000), which involved interviews with teacher educators from several New Zealand tertiary institutions. McKay et al. (2000) found that tertiary institutions were led by schools’ employment practices and teacher registration requirements. For the teacher educators, the “unwillingness” of schools to “take” disabled teachers played a role in whether the educators and institutions accepted disabled students as pre-service teachers. Some teacher educators related their disinclination to accept disabled students to a clause in the guidelines. In the words of one:

Teacher Registration is dependent upon being physically able to undertake responsibility of the education and care of a large group of children. It would be unreasonable to expect a blind, deaf, or wheelchair bound person to be able to undertake this task. Similarly, with learning disabilities the student must ultimately be able to teach a range of subjects as well as having personal strategies to cope with academic tasks. (McKay et al., 2000, p. 56)

However, the original text of the teacher registration reads as:

9 (f) is mentally and physically fit to carry out the teaching role safely and satisfactorily. (New Zealand Teachers Council, November 2007, p. 3)

The interpretation of the previous comment by the teacher educator shows a deep prejudice that people who had the specific impairments of being blind, deaf, or using a wheelchair would not comply with the fit for work ethic in section 9(f), and were therefore unable to teach. This prejudice is not limited to New Zealand teachers. Disabled teachers in Sandria Officer’s (2009) Canadian PhD thesis also described similar ‘fit for work’ barriers during recruitment. Like the teacher educator’s assumption, Officer’s participants described the greatest barrier at the recruitment stage for work placements was that their impairments were linked to issues of productivity or capacity to work. The international literature as it is explored later in this chapter has debunked the myth of capacity for work if you are Deaf or dyslexic, or have a learning disability. Since then the 2000 research of McKay et al., The New Zealand Educational
Council (NZEC) has developed a new code that outlines professional responsibility (NZEC, 2016). However, the participants in this study were registered teachers under the previous policy which prescribed a fit for work ethic.

Challenges and barriers are also a key focus for Givner and Ferrel’s (1998) case studies involving two disabled pre-service teachers (Meg and Stacey) who sought to teach in special education settings. The challenges that they faced related to field experiences, and relationships with educators and administrators. They were required to access disability support or self-advocate for access to field experiences, and the attitudes of the educators, administrators or agencies were often experienced as prejudicial or unhelpful.

The authors described Meg’s lack of assertiveness as a key barrier to her building relationships and experiencing success in field and course work. They acknowledged that there was no disability support system in place at her University, but they did not question the attitudinal barriers of the educators and administrators, explaining instead that “Meg stated that she was too afraid to confront this issue for fear of reprisal” (p. 65). For the authors, it was Meg’s lack of assertiveness that was creating a barrier for her.

The literature that speaks to and of disabled pre-service teachers’ experiences suggests that it is not the physical barriers that provide the greatest challenge to becoming a teacher. Attitudinal barriers, as suggested within the body of work, including those that suggest lack of capacity to work and learn, are key to understanding how disabled teachers experience of the accessing of employment as a teacher (Dvir, 2015; Gabel, 2001; Glazzard & Dale, 2013; Griffiths, 2012; Riddick, 2003). Interestingly, despite the focus on attitudinal barriers, the research about disabled pre-service teachers did not mention bullying explicitly. Bullying has, started to garner attention in workplace literature. The next section briefly segues from disabled teachers to general disability employment research. I seek to highlight practices that can equally apply to school settings as workplaces, but have often been left out of the conversation. This includes discrimination and bullying, and how they impact on disclosure of impairments and/or chronic illness.
3.03 Getting a job: Workplaces and inclusion

Illustration 3: Mojo Mathers by Tom Scott

In New Zealand disabled people are more than twice as likely as the general labour force to be unemployed. In 2017 statistics showed that 22.4 percent of working age (18-65) disabled people are in employment. This is compared to 69.3 percent of non-disabled people (Stats NZ, 2017). When I began researching this thesis, national headlines and political cartoons by cartoonists such as Tom Scott (Fairfax Media, 18/2/2012), told the story of Mojo Mathers, caricatured above. New Zealand’s first profoundly Deaf Member of Parliament (MP) who was initially refused the funding for closed captions\(^5\) during parliamentary debates. (New Zealand Parliament, 2012). This refusal highlighted a key issue for workplace inclusion: that is, the assumption that if you require support to work, such as closed captioning or even flat access, then you are not fit for work. Furthermore, it is assumed that the individual should adapt and change, not the workplace environment (Vick & Lightman, 2010).

The literature that attends to workplace inclusion and disability is characterised by a human rights/advocacy perspective. The literature reveals that one of the biggest barriers to creating an inclusive workplace is the negative attitudes or lack of understanding from employers or other employees (Charmaz, 2010; Critten, 2016;  

\(^5\) Closed captioning is the process where voice or audio is transformed into text to enable access for Deaf and hearing impaired people to audio-visual devices like television or in this case a live casting of parliamentary debates. A valuable definition of this can be found Wikipedia: https://en.wikipedia.org/wiki/Closed_captioning
All the little things | Literature Review

Kaye, Jans, & Jones, 2011; Krupa, 2011; Naraine & Lindsay, 2011). Gillies (2012) for example, has voiced frustration at the lack of research about the important transition between school (secondary or tertiary) and disabled students getting a job.

Having a job is important for social inclusion (Office for Disability Issues, 2014; Seeman, 2009). As Seeman (2009) points out, “more than almost anything else in modern culture, work defines individuals and provides them with an identity” (p. 9). Yet, the literature about disability and work often underscores a lack of meaningful opportunities for disabled people. In this thesis, I view the creation of inclusive workplaces and employment opportunities as a part of the overall complexity in the actualisation of inclusive education for disabled teachers. The importance society places on working and the shaping of identities converge in disability policies.

However, disability policies often imply that in order to be employed, disabled people have to be made “employable”, rather than removing barriers within workplaces (Hall & McGarrol; Hall & Wilton, 2011). What does it mean to be made “employable”? Hall and Wilton (2011) suggest that employability is tied to education and training schemes. But they also propose that making a person “employable” is often done without any thought to finding employment after the training has finished, and contend that there has not been enough focus on creating jobs for disabled workers.

At a basic level, teachers are employees and schools are workplaces. As stated in Chapter Two, it is important to view disabled teachers not just as transmitters of inclusion but also as recipients. The following section looks at workplace literature that examines aspects not addressed in the research about disabled teachers’ experiences, and is important for understanding how the workplace could impact on disabled teachers’ experiences.

3.04 Discrimination & disclosure: Disability experiences workplaces.

There is a common misconception that disabled workers:

... are not productive, they do not ‘fit in’ with other workers; they cost more than other workers, especially if they need accommodations; they require more supervision; they take more leave, and they are not likely to be especially useful.

… (Vickers, 1999, p. 258)

This section seeks to position workplace inclusion as key to understanding certain experiences, including discrimination, workplace/institutional bullying, and ultimately how these factors relate to the disclosure of impairments. As Hartley and Sutphin (2011) point out, “It is time for society to recognize their obligation to welcome
disabled workers into mainstream society, as well as in the employment arena. We have abilities to offer!” (p. 36).

The literature so far has suggested that there are certain attitudinal barriers for preservice teachers, but they have not described what these could be. In workplace literature it is clear that attitudinal barriers are predominantly the negative and prejudicial perspectives and treatment of disabled employees (Barnes, 2000; Charmaz, 2010; Critten, 2016; Fichten et al., 2012; Hall & McGarrol; Hyde, 1998; Kaye et al., 2011; Krupa, 2011; Madaus, Zhao, & Ruban, 2008; Naraine & Lindsay, 2011). There is a ‘fear’ about employing disabled people. New Zealand research into employer attitudes like that of Woodley, Metzger with Dylan (2012) revealed that employers felt “employing [disabled] people [is] scary” (p. 36). The researchers did not elaborate what “scary” meant, but because the employer went on to describe further negative attitudes, the assumption is that it could mean a fear of the unknown. The employer also expressed concern about the safety of other non-disabled staff. This type of attitudinal barrier is beyond physical accessibility of workplaces. Attitudinal barriers manifest in the literature under two broad interwoven themes of discrimination and disclosure. Drawing on national and international literature, I have identified different forms and stages of discrimination, which range from gatekeeping to bullying (Charmaz, 2010; Stanley et al, 2011; Vickers, 2009). The literature emphasises that these barriers are inherently relational as opposed to physical barriers.

Gatekeeping is the first such type of discrimination and is innately linked to disclosure and is the least discussed in the literature. As a form of discrimination, gatekeeping is defined as when a company or national policy is invoked in order to discriminate against a person. This type of professional gatekeeping, as described by Stanley, Ridley, Harris, and Manthorpe (2011), leads to the silencing of those with hidden impairments. Because of this official gatekeeping the authors noted that people were less likely to seek help or modifications, and were less likely to disclose impairments for fear of stigma being attached to their impairment. Furthermore, they were concerned about becoming isolated from their profession, or considered intellectually inferior (Stanley et al, 2011). The research also suggests that those who do disclose or have visible impairments risk being bullied by their colleagues (Farley & Sprigg, 2014).

There is a small body of literature that examines bullying as part of the disability experience in the workplace (Baker, 2013; Djurkovic, McCormack, & Casimir, 2004;
Figueiredo-Ferraz, Gil-Monte, & Olivares-Faúndez, 2015; Garrett, 2014; Hoel & Einarsen, 1999; Lewis & Orford, 2005; Margaret H Vickers, 2009; Margaret H. Vickers, 2015; Zapf, 1999). Bullying is a complex interpersonal conflict that is subtle and evolving ("the bully professes ‘concern’ for a target, enabling them to misuse other legitimate organisational processes as a part of the bullying” (Vickers, 2009, p. 262).

Targets of bullying in Lewis and Orford’s (2005) study talked about being ashamed. “They’ve [employers] shattered everything that I have ever believed in, that I have ever worked to try and put right. The relationship with colleagues, the relationship with family, my whole reasoning, everything” (Lewis & Orford, 2005, p. 40). Furthermore, there is often a struggle to gain recognition of bullying because organisations are likely to individualise bullying and place blame on the person being bullied by denying problems within the organisation’s culture (Lewis & Orford, 2005, p. 40).

In New Zealand there is a growing body of research that explores organisational bullying in general (Ayling, 2002; Gardner et al., 2016). The literature does not mention disability as it tends to be focused either on gender or ethnicity (Gardner et al., 2016). However, there is recognition of a silent culture of bullying that goes under-documented in New Zealand workplaces (Ayling, 2002; ; Gardner et al., 2016).

Employers’ perceptions and attitudes about disability in the workplace in a New Zealand context was explored through an online survey conducted by the EEO Trust (EEO Trust, 2005). The survey focused on the barriers faced by disabled people to finding and maintaining work. Their key findings included that people felt after they had disclosed their impairment, the perception of their impairment was a barrier to getting a job interview. Respondents felt that because they had disclosed their impairment on the job application they were not considered for the position. The survey also identified the attitudes of potential employer/interviewer as the second biggest barrier to finding work. Attitudes were not discussed.

International research identifies the link between relationships/attitudinal barriers and discrimination, and that this relationship is at its most precarious at the point of disclosure (Charmaz, 2010; Stanley et al., 2011; Vickers, 2009). Employee relationships can influence when, where, how, and if someone discloses hidden impairments and/or chronic illness (Charmaz, 2010). Yet, there is a paucity of research about disclosing an impairment and/or chronic illness across all of the literature about disabled people’s experiences and work. Vickers (1999) identified the reasons for and
against disclosing. For example, she argued employees need support and seek understanding.

Disclosure can enable this. In terms of not disclosing, Vickers found that employees felt that there would be a harsh social judgement on them or discrimination against them if they did disclose. She further suggested that perhaps “employers do not want to listen” (p. 247). Within the issue of disclosing impairments, research has also failed to address a potential right “not” to disclose. There is a dislocation between the literature about disabled people’s work experiences and disabled teachers’ experiences as employees. Teachers are not included in the literature around disabled employees, although as this thesis will show, they face similar issues.

3.05 Disabled Teachers

What makes a ‘good’ teacher? Mary Compton’s (1997) research with four Deaf teachers identified the following nine characteristics in the making a good teacher:
1. Understands
2. Listens
3. Questions
4. Shares experiences
5. Has a sense of knowing
6. Has high expectations of students and self
7. Respects
8. Cares
9. Empowers students

I begin this section with what makes a good teacher because, as the previous workplace literature suggested there is a belief that to be disabled is to not be productive in the workplace. What it takes to be a good teacher then is a useful frame of reference when exploring the experiences of disabled teachers. There has been a growth in research that explores disabled teachers’ experience due to a rise in interest about the impact of teachers’ lives and life stories in general (Vogel & Sharoni, 2011). The literature about disabled teachers is characterised by three facets: the methodology is often narrative (Burns & Bell, 2011; Compton, 1997; Dvir, 2015; Valle, Solis, Volpitta, & Connor, 2004); the research predominantly focuses on tertiary educational settings (Bell, 2015; Burns, 2015; Burns, Poikkeus, & Aro, 2013; Connor, 2012; McKay, Ballard, & Smith, 2000; Strnadová, Hájková, & Květoňová, 2015); and finally it focuses on specific impairment (Compton, 1997; Roald, 2002). The literature positions disabled teachers as
an inclusionary force (Anderson, 2006; Officer, 2009), recognising at the same time that their voices remain untapped and overlooked in terms of the actualisation of inclusion (Anderson, 2006; Gabel, 2001).

Disabled teachers’ experiences are not homogenous, the literature does suggest that disabled teachers are likely to experience similar barriers in the workplace, both institutional and attitudinal (Baker, 2013; Burns et al., 2013; Charmaz, 2010; Hall & Wilton, 2011; Hyde, 1998; Pinder, 1995; Roulstone & Williams, 2013; Szeto & Dobson, 2010; Vickers, 2001; 2015; Wilson-Kovacs, Ryan, Haslam, & Rabinovich, 2008). Attitudes are continually identified as the key barrier to getting employed and remaining employed. The hierarchical structures and often confrontational culture of a school create further barriers (Officer, 2009). As noted earlier, workplace attitudes tend to be negative and focus on assumptions about disabled peoples’ ability to work (Woodley & Metzger, 2012). This section explores the experiences of disabled teachers, including the attitudes of disabled teachers and the attitudes directed at them. These attitudes include discriminatory practices and teachers taking an empathetic role within the classroom.

Mary Compton’s (1997) research examined what she described as the fragmented narratives of four Deaf teachers in the United States. The participants – Rachel, Martha, Sarah and Tina – described how they constructed themselves as teachers. Rachel described listening to the students: “I feel like a counsellor. When the kids have problems I let them tell me why they are upset. I listen to them” (Compton, 1997, p. 358). Tina spoke of having high expectations for herself and students. While these expectations are not described in detail, Tina’s perspective debunks the assumption that disabled teachers have low expectations for themselves and for their students. Martha took an empathetic stance, believing that through her deafness she could “make learning easier” for her students (Compton, p. 358). Compton’s participants demonstrated that Deaf teachers do fall within the ‘good teacher’ criteria through their use of empathetic understanding. The fragments that Compton explored did not examine discrimination, unlike that of Reiser’s (2008) survey.

Reiser (2008) carried out an online survey of 35 of the 60 members of a disabled teachers group in the United Kingdom. The comments made by the participants signalled the barriers to doing and being, both as physical and attitudinal barriers. One participant said, “I could be wrong but I felt of less value, and that I am sometimes a burden to my colleagues, especially if I have time off” (p. 8). There is often an implicit
assumption that disabled teachers do not have the ability to teach. Nowhere is this assumption explored and contested more than in the literature about the experiences of teachers with dyslexia (Burns, 2015; Burns & Bell, 2010, 2011; Burns et al., 2013; Glazzard & Dale, 2013, 2015; Griffiths, 2012; Madriaga, 2007; Mortimore, 2013). In my introduction in Chapter One, I quoted Anderson (2003) describing disabled teachers as being integral to the actualisation of inclusion. This, however, belies the tension between disabled teachers being seen as a valuable resource or as a burden. As Griffiths (2012) argues, disabled, teachers with dyslexia, are, “often seen as threats to standards and a burden, requiring extra work rather than a valuable resource to promote understanding and acceptance of disability in schools” (p. 55). Burns & Bell (2003) explore the experiences of tertiary teachers with dyslexia and their developing professional identity. Their article described how disabled teachers negotiated their teaching identities, and found that for the teachers themselves, dyslexia “was not” a barrier but an imbedded and integral tool that could lead them to succeed.

Discrimination for Rieser’s (2008) participants, just as for those who have experienced discrimination in other areas of employment, took a number of forms – from feeling written-off to being demeaned: “The nature of my disability was belittled and I was subject to derogatory comments. Rather than providing support an investigation into my competence was started” (p. 9). Again, competency and capacity to teach were called into question in an unfair manner.

But how do you “deal with” a school culture that does not value diversity? Ferri, Connor, Santiago, Valle, and Volpitta (2005) used narrative inquiry to examine the lives of teachers. They interviewed nine teachers with learning disabilities in the United States and discovered that although their participants resisted the medical model, they still had to interact with it. Furthermore, participants who resisted often were viewed as the exception to the rule. When they embraced their impairments they were viewed as “exceptional” rather than as representing the norm. This enabled oppressive discourses to remain. The stories of these participants highlight conflicting ways they dealt with the school culture which could be hostile. Some participants chose to hide their impairments for fear of the stigma attached to them. Others sought to influence the culture of her classroom and became a “teacher-activist”.

Ferri et al (2001; 2005) warn of potential dangers of (re)pathologising disabled teachers by individualising them, even when the research seeks to disrupt traditional or

Illustration 4: Spectators by Jessica + Lianna Oddi
medicalised perspectives. In this thesis, there is the danger that the teachers’ stories could be viewed as individualising. I have situated the stories of my participants theoretically as described in the previous chapter. For example; I have identified that there is a need to explore the experiences of disabled teachers from their perspective and chronic illness is on the impairment spectrum (Thomas, 2007). Ferri et al (2001; 2005) point out that examining disabled teachers’ experiences could reinforce the medical model by singling out some teachers as being “not normal”. Although that is not the intention of this thesis, I am acutely aware that the stories could also be taken and used for what Stella Young (2014, TED Talk) calls “inspiration porn” therefore running the risk of (re)inscribing individualising perspectives. The concept has been illustrated by disabled bloggers Jessica and Lianna Oddi. Used with their permission and cited in the body of the text as they requested: “Spectators” by Jessica + Lianna Oddi of The Disabled Life www.thedisabledlife.tumblr.com.

In their article, Glazzard and Dale (2015) tell the life story of Kitty, a pre-service teacher with dyslexia, traces her educational experiences, and identifies the impact that these have had on her concept of self and professional identity. The authors note that

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6 Inspiration porn is further defined by Grue (2016a) who describes it as “ (a) an image of a person with visible signs of impairment who is (b) performing a physical activity, preferably displaying signs of physical prowess, and is c) accompanied by a caption that directs the viewer to be inspired by the image in question” (p. 2).
Kitty’s account illustrated how disabled teachers can be “creative, caring and empathetic teachers” (p 188). Disabled teachers are often described as empathetic through the use of their impairment/chronic illness as a pedagogical tool. For example, Kitty turns her fear of making a spelling mistake into a teachable moment: “One of my biggest fears throughout my whole teaching career has been that I might make a public spelling mistake” (p.186). It becomes a teachable moment as she gets her students to access a dictionary. Despite Kitty creating an inclusive, empathetic classroom, Glazzard and Dale (2015) warn that inclusion that only focuses on students within the classroom without moving beyond to staff, parents, and the school community is “not” inclusion. This assertion has implications for my thesis.

In the previous chapter I described inclusion as needing to recognise the rights of all to participate in a society where difference and diversity are valued (Gordon-Burns et al., 2012). Re-envisioning teachers as employees and a part of the wider school community is important, because once there is an understanding that teachers are employees, then questions about their rights and working conditions come into focus. For too long teachers have been viewed as the producers of inclusive classrooms without any reciprocity.

Disclosure is an important and reoccurring issue across the literature about disabled teachers, as well as in the employment literature discussed earlier. Valle et al. (2004), for example, explored the issues for a small group of special education teachers around disclosing their learning disabilities. Like the participants in the study by Ferri et al (2005), teachers who chose not to disclose did so out of fear of damaging their professional image due to the stigma attached to having a learning disability. Those who disclosed did so to empower their students, and in some cases the students’ parents.

Success and high expectations are key factors in many of these studies. Ingvild Roald (2002) who, like Mary Compton (1997), interviewed Deaf teachers. Roald found that the Deaf teachers from Norway’s first generation of Deaf students who had completed study in higher education institutions, also described the importance of attitudes especially respect. This manifested itself in part as high expectations. Despite having expectations and maintaining positive attitudes, disclosing invisible impairments remained difficult for the disabled teachers in Roald’s study.

The medicalisation of disability is so innate within western society that it is hard not to be drawn into describing oneself in medical terms, for example, one’s diagnosis. This can be seen in my backstory. Yet within the classroom, the impaired body is often
used as a pedagogical tool that produces a counter narrative as, “disabled bodies disrupt normal educational settings: enter guide dogs, sign language interpreters and motorized wheelchairs” (Anderson, 2006, p. 369). There is an increasing awareness from a feminist disability perspective of how the disabled body can be used as a pedagogical tool. This perspective was touched on by the participants in the previous studies, who sought to use their stories as a tool for empowering their students (Burns, 2015; Burns & Bell, 2010, 2011; Burns et al., 2013; Compton, 1997; Ferri et al., 2005; Ferri, Hendrick-Keef, & Gregg, 2001; Gabel, 2001). Brueggemann, Garland-Thomson, and Kleege (2005) take this awareness further in their academic conversations as they describe the body of the disabled teacher being marked for difference. They suggest that it is through the demonstration of difference that students learn about diversity, human rights, empathy, and essentially, inclusion. Disabled teachers, therefore, embody inclusion and in building relationships with students they promote diversity. Their bodies are pedagogical tools. Essentially inclusion can begin to emerge through the relationships that disabled teachers create. Most researchers tend to agree that relationships matter, “… ramps are not enough. I speak not only of bricks and mortar but also of relationships, stories of experience, even theory” (Anderson, 2006, p. 369).

Disabled teachers’ bodies, as pedagogical tools that move beyond classroom teaching, are explored in Sheridan & Kotevski’s (2014) study. Students’ attitudes, learning, and perceptions of a disabled tutor at a tertiary institution were gauged with the aim to “advocate for the potential role of people with a disability in academia” (p. 1162) and their findings echo that of previous studies mentioned in this literature review (Burns, 2015; Burns & Bell, 2010, 2011; Burns et al., 2013; Compton, 1997; Ferri et al., 2005; Ferri et al., 2001; Gabel, 2001). Indeed, Anderson (2006) acknowledges that disabled teachers offer important lessons through their embodiment of social justice, interdependence, and respect for difference. These embodiments are obtained primarily through empathy. Disabled teachers and the role of empathy was briefly touched on by Gabel (2001) and Riddick (2003) at a pre-service stage. Despite empathy being a major focus for disabled teachers, it is only discussed in terms of (pre-service) teachers’ feelings towards students. There is no evidence to suggest that empathy was reciprocal, i.e. that teachers and pre-service teachers had actually created a shared understanding.

It would seem that disabled teachers can be seen as exemplars of inclusion as long as they maintain standards (often high and inflexible) and are not a burden to the school, financially or by creating a strain on resources. In contrast to the pre-service
An educator who earlier in this chapter did not believe a disabled person could be a teacher (McKay, Ballard & Smith, 2000), Sheridan & Kotevski’s (2014) study included this student feedback: “… the world’s most brilliant mind is held by a man with a disability” (p. 1166). The student was describing Stephen Hawking, academic and teacher.

Once in the role of teacher, despite feelings of being (or made to feel) a burden to the school, some disabled teachers actively seek to empower their students. They do this in various ways, including telling their students about their impairment, incorporating disability into class topics, and building shared understandings of impairment.

3.06 Staying in teaching: Disabled teachers’ identity and resilience

Research about teaching identity is an area that is underdeveloped (Burns & Bell, 2011; Beijarrd et al., 2004). Burns and Bell (2011) and Bejarrd et al. (2004) note that research about teachers’ development often does not specifically seek the perspectives of those teachers with impairments. Teachers’ identity in this thesis is viewed as being socially and narratively constructed. This is in line with the theoretical underpinnings discussed in Chapter 2. Despite the lack of research undertaken about disabled teacher identity, there is a suggestion that its formation is tied to resilience and self-efficacy. These two aspects, which are both relational and context-specific (Beltman, Mansfield & Price, 2013; Burns et al. 2013), are briefly explored in this section.

There is an emerging body of work that focuses generally on (non-disabled) teachers’ resilience (Beltman, Mansfield, & Price, 2011). In this emerging research, resilience has been conceptualised as including dynamic interactions over time between people and their environments (Beltman et al., 2011). In their narrative study of six Finnish tertiary teachers with dyslexia, Burns et al. (2013) discussed resilience as being critical to understanding how disabled teachers view themselves and how they are viewed. Their study views resilience for disabled teachers in terms of resilience strategies, such as finding alternative methods or adaptation.

The four research participants - Kaisa, Liisa, Pekka, and Anne - sought to find alternative ways to teach. As Kaisa said, “this [dyslexia] is so ingrained that if I don't progress one way, I’ll find alternative methods” (p. 81). Adaptation as a resilience strategy has also been recognised by other researchers. Officer (2009) for example, noted that participants would adapt tasks and use a pedagogy that highlighted the experiences of disability. In the article by Burns et al. (2013), Liisa explained, “My
strength is when I have students with LD and I try to find alternative ways to work with them. It is easier for me to get a feel for their circumstances.” (p. 83). As described by Beltman, Mansfield & Price (2011) and by Burns (2013), resilience goes hand-in-hand with self-efficacy.

Self-efficacy is described by Bong and Skaalvik (2003) as what people believe they can do (p. 5). Self-efficacy is socially constructed. It is built on experiences, comparisons with other people, and how other people strengthen these comparisons. How disabled teachers sustained a sense of self-efficacy was identified by Burns et al (2013) in the comments made by Pekka who exclaimed, “My way of thinking is that I'm not going to hide in a closet because of this [dyslexia]” (p.82). Pekka asserted her strong sense of self-belief or self-efficacy. The other participants expressed similar positive comments about believing in themselves as teachers and being efficient facilitators of their students’ learning. Anne stated, “Someone might say he or she is a very effective teacher, although I haven't seen a perfect teacher yet. I just like teaching so why shouldn't I be allowed to do it.” (p. 81). Resilience strategies were individualistic and context-specific. However, Burns et al. (2003), noted that the strategies shared commonalities including the time, effort, and resources that disabled teachers put in to be able to teach successfully.

3.07 The body politic.

As stated earlier, disabled teachers and disabled people in general remain “an untapped resource” in discussions about the actualisation of inclusive education (Gabel, 2001, p. 39). As a resource, disabled teachers can challenge the status quo both within the classroom and within the wider community (R. C. Anderson, 2006). However, there is a distinct absence in these discussions about disabled teachers and their interactions with the political structures of the school setting (Officer, 2009).

The relationship of teacher autonomy to political structures was important in Officer’s (2009) mixed method study. Her research discovered that teachers were able to maintain a sense of autonomy within the classroom, but beyond that had little or no say in the wider workings of the school environment because of the structure of the school system. It is reasonable to assume that this would be experienced by most teachers, disabled or not. The lack of awareness of disabled teachers was exemplified through the neglect of disabled teachers’ rights, and the fact that individual teachers had to seek out any accommodations under disability legislation. Officer also found that disabled teachers often missed out on Professional Development (PD) due to issues of
access. As a result, she found that teachers began to compensate for their impairments by becoming over-qualified for their positions.

She also found that disabled teachers were often overloaded with work, and some tasks took longer. Disabled teachers often compensated for their impairments by taking wage cuts or reducing their hours of work. This, Officer argues, led to the undervaluing of their work and contribution to the school. Furthermore, she found there was a lack of mentoring and role models for disabled teachers. Disabled teachers often took on volunteer positions in professional and community organisations to promote empowerment and transition schools into inclusive communities.

**3.08 Situating this Study**

The body of knowledge I have sought to position this research within is small but well defined. However, there is a gap in the literature for New Zealand research at the time of writing that explores the experiences of disabled secondary school teachers. This is puzzling given the interest in New Zealand in disability, inclusion, and education research (see for example (Ballard, 1999, 2004; Gordon-Burns et al., 2012; Higgins, MacArthur, & Morton, 2008; Higgins, MacArthur, & Rietveld, 2006; Kearney & Kane, 2006; McKay et al., 2000; Rutherford et al., 2015; L. J. Sanderson, 2011; Woodley & Metzger, 2012). It is especially puzzling given the strong political interest in inclusive policies, such as the guidelines for inclusion introduced by various New Zealand governments.

In 2001, the New Zealand Government introduced the first New Zealand Disability Strategy (NZDS, 2001), and in 2007, New Zealand signed the United Nations Convention on the Rights of People with Disabilities (UNCRPD, 2007). Implementation of these polices has been described as ‘higgledy piggledy’ (Higgins et al., 2006). More recently, adding to the higgledy piggledy nature of disability guidelines and polices, a second New Zealand Disability Strategy was drafted and published (2016). A more comprehensive outline of socio-historic developments of disability in New Zealand, as observed through legislation and disability policies, can be found in Appendix D. However, the actualisation of inclusion in New Zealand has not been transferred from policy to practice, nor have the perspectives of disabled teachers been explicitly heard on the topic of inclusion. My study sits within the larger scope of inclusive education research in New Zealand and as such, it provides new voices and experiences.
In the international literature the review identified other gaps in the body of knowledge including the experiences of unemployed teachers. Here I return to the three characteristics of the international research about and with disabled teachers: 1) It is predominantly narrative; 2) It is usually carried out in tertiary settings, and 3) it tends to focus on a specific impairment (e.g. deafness, dyslexia, learning disabilities).

Firstly, using narrative as the key methodology: this study expands on this idea by incorporating narrative into an arts-based theoretical and methodological framework. The prevalence of narrative research to explore disabled teachers’ experiences shows that narrative interviews are a useful tool to gain the voices and depth of feeling for participants’ experiences (Broderick et al., 2011; Dvir, 2015; Fisher & Goodley, 2007; Gabel, 2001; Valle et al., 2004). As discussed in Chapters One and Two, I chose narrative as my initial “method of knowing”. I then drew on other arts-based education research, specifically, poetic inquiry. As Clandinin (2013) argues, combining narrative and poetic inquiry is growing in popularity as they provide complimentary creative spaces. Within disability studies, poetic inquiry is scarce, although the poems created for this thesis could fall within the crip poetry movement (Bartlet, Black & Northen, 2011). Whilst the two movements of poetic inquiry and crip poetry are different bodies of literature, they have points of convergence.

Secondly, regarding the prevalence of tertiary settings: I move beyond the perspectives of predominantly tertiary teachers to all teachers. This study began with disabled secondary school teachers because each level of education has its own challenges, including settings and institutional structures.

Thirdly, I sought to move beyond a focus on a specific impairment or type of impairment e.g. deafness or learning disability. My theoretical framework incorporated the idea of chronic illness on an impairment spectrum. This widens the concept of disability to allow for the greatest participation.

3.09 Summary

The literature explores the international experiences of disabled teachers in a way that responds to how their presence enhances the school. Disabled teachers make ‘good’ teachers (Compton 1997; Gabel, 2001). I traced the pathway to being a teacher, from disabled pre-service teachers to disabled teachers’ experiences. I also drew on literature that discusses inclusion in employment, focusing on issues such as organisational bullying. The literature provides some key realisations:
• Disabled teachers are an inclusionary force. Through empathy and adaption (their own adaption, not the schools) they can create inclusive classrooms.

• Their voices and experiences remain “untapped” despite over a decade of recognition of their potential in bringing about inclusive education.

• Issues like bullying, which are addressed in workplace literature, is very rarely discussed in terms of what disabled teachers experience.

• There is a continuing misconception about disabled people’s ability to work.

Finally, I explored a significant feature of undertaking this research – the inclusion of New Zealand voices. New Zealand disabled teachers have not yet been considered as a force to actualise inclusive education. The next chapter examines the research design (how the research was conducted). I begin by positioning this research within an ethical framework that includes procedural and narrative ethics. I then outline the research design including recruitment strategies, data collection, and conclude with my analysis framework.
Poetic speaking our story/flesh language/ poetic bypass prose/creates sound alone/ rhythm capture rhythms/show spaces through sound and vision/closer to voices silenced/poetic insights repeating, recurring, raw.

Source text: Faulkner, 2018, p. 215
Research design

“We begin in the midst and we end in the midst, of experience”
(Clandinin, 2013, p. 43).

4.01 Introduction

To understand the lives of disabled New Zealand teachers, in the previous chapter I have theoretically situated this research within a layered qualitative-interpretivist framework. In this chapter narrative and poetic inquiries play a significant role in the design and production of my research. This chapter begins by situating the research design ethically. I discuss both the procedural and narrative/relational ethics to foreground my research methods in an ethically responsible way. The recognition of both procedural and relational ethics recognises that relationships are important for the research process, going beyond lock and key ethics.

Narrative as a method has had the longest influence on my research design. I began with Narrative as my sole method of writing/knowing/telling (Richardson & St Pierre, 2005). In Chapter 2, I described the motivation behind using narrative. Here I have drawn on Clandinin’s (2013) justifications of personal, practicality, and social/theoretical (pp. 355ff) to highlight and foreground the ethical reflexive stance of showing not telling (Richardson, 1997). Firstly, attending to my personal justification, narrative interviews provided me with the ability to seek stories that mattered to the participants and me. For my participants, the research asked them to “give” something of themselves. I am eternally grateful for their giving of themselves. The stories produced in this thesis matter to me because of my earlier research, and my self-identification as having impairments and chronic illness. They speak to me of my own experiences just as much as they speak of the participants. In other words, this research is deeply personal.

Secondly, practicality is defined by Clandinin as the impact research has on practice. In this research listening to disabled teachers’ stories about their lived experiences has the potential to promote change at multistructural and relational levels for all teachers. At the very least, awareness of the diversity within the New Zealand teaching cohort may be recognised. Lastly, drawing on Clandinin’s (2013) social/theoretical justification, this study has the potential to redefine inclusive education. Narrative interviews make the participants’ stories important vehicles of change. Narrative, then, provides explicit justifications consistent with the overarching theoretical concepts discussed in Chapters 1 and 2, as to why narrative is important.
The key aspects of my research design explored in this chapter are ethics, methods that include; recruitment, data collection, introduction to the survey and interview participants, the interview settings, and data analysis. The linear layout of the following aspects of research do not overtly reveal their complexities, the “warts and all” aspects. It can not show the twists and turns of the research process as lived. Furthermore, although these processes are often presented as separate aspects of this research, they often overlap or are inter-related (Richardson, 1997; Vickers, 2001). Ethical considerations are a perfect example of this, as they are tightly woven throughout all aspects of this research.

4.02 Procedural Ethics

There are two strands of ethical considerations. Firstly, the institutional or procedural ethics that are required from the University of Otago and are considered in preparation of research. There are key considerations like informed consent, confidentiality, contact, data storage, and so on. Secondly, relational or narrative ethics emerge and are fostered in contact with potential and recruited participants. They include power relationships and vulnerability. In this section I examine the procedural ethics with the relational/narrative ethics discussed later in this chapter.

I sought institutional/procedural ethics approval the University of Otago Human Ethics Committee (reference number 12/136). In accordance with Otago University Ethical guidelines, I created and distributed information and consent forms to my participants for the survey and the interview (appendix E). The forms were either signed electronically with initials for the electronic survey, or signed by hand on paper copies for interviews and some surveys.

I designed the survey so the participants would be personally contacting me via email. This enabled me to pick up on some aspects of distress. For example, a participant described wanting to leave teaching and feeling glum (Survey FP15, Personal Communication). My responding email included links to free counselling service in an effort to provide her with an outlet to discuss her issues. My supervisors in turn supported me when I followed this up a few days later with another email. I am unaware of the outcomes as I never received a reply. It does, however, show the potential impact of the survey, and reinforces the importance of ethical considerations at every stage of the research process. It also highlights the importance of establishing a relationship with participants. In the interviews this is built on through informed consent.

Informed consent is ongoing, and participants were told that they had the right to leave the project at any time without any disadvantage. Survey participants were given an
information sheet. Interview participants were informed of their rights as participants and given the information and consent forms at the first interview. Before each interview participants were reminded of their rights, including to not answer an interview question, and the right to not continue with either the interview or the project. Questions they had were discussed before, during, and/or after the interviews.

At the beginning of the interviewing process I also discussed and included the information sheet and consent forms, and a brochure and information about New Zealand’s only free counselling service, Lifeline (appendix F). These were given at the initial interview and participants were reminded about the services at each interview. The incorporation of the counselling information was important because there was a possibility that through the re-telling of their stories, participants could re-live or re-experience painful memories. This included memories that may have been triggered by the interview, but that participants may have felt unable to share with me.

Providing participants with information about the resource enabled a discussion of Lifeline. At least two participants accessed this counselling, in part due to the memories that were highlighted in our discussions (Personal Correspondence, 2014). Any information shared with me was handled with the utmost respect. The sensitivity of the stories and the “small town” (Tolich & Davidson, 1999, p. 79) nature of the New Zealand teaching community highlighted the fact that confidentiality was a key issue.

The stories told are deeply personal. For the participants, the survey was the first time they had been asked about their lives and teaching in relation to their impairment and/or chronic illness. One participant (Survey, MP9) thanked me for the opportunity. Having his voice heard, even in a small recruitment survey, had been a powerful experience for him. Interview participants were also asked to provide a pseudonym, despite the fact that some participants wanted to retain their names. Moreover, I felt that it was important that they had the opportunity to choose their pseudonym themselves so that they maintained control of their identity within this thesis (L. J. Sanderson, 2011). Nevertheless, I did choose pseudonyms for those who requested it. Further to this is a commitment to respect participants’ confidentiality through changing or leaving out of some personal attributes, including impairment, to obscure their identity. This was done in collaboration with the participant as part of the construction of their narrative. Some participants asked for descriptions of their impairment to be left out and this was accordingly observed and respected.
Establishing and fostering relationships between myself and the participants was initially begun, then maintained via email. Relationships were fostered through emails by keeping an informal and polite tone and dropping a line. Although email is considered impersonal (James, 2007) all of the respondents preferred to keep in email contact, and in some cases we were able to carry out a conversation in very little time. Instant messaging was especially good for organising interview times and places. At times when email was not practical, for example, when a participant needed to postpone the interview or when the connection to the internet was limited or lost, texting was used. As linear in nature as this narrative appears, it belies the complexities experienced in establishing and maintaining relationships. Some relationships worked better than others. They relied a lot on the reciprocity and openness of both parties. There were times when significant life moments, for example the loss of a loved one, got in the way for either the participants or me.

Strong relationships were important in the collaboration of narrative stories (Chapter 5). The act of collaboration is ultimately a reflection of the underlying philosophical assumptions of producing a piece of research that privileges disabled voices. A strategy to further collaboration was to establish member checks. The transcription and the produced narrative were sent via email to the interview participants to be verified to see if their voices and stories were represented in a way that they wished. This allowed further collaboration with their narratives (Bignold & Su, 2013; Thomas, 2007). Procedural ethics stresses the security of the raw material (transcriptions), so each participant also had their own physical folder in my locked filing cabinet containing hard copies of their narrative and interview material. All efforts were made to ensure that the data was kept safe and secure.

4.03 Narrative ethics

“Narrative Inquiry does not allow each of us to walk away unchanged from our experiences alongside each other and alongside our participants” (Clandinin, 2013, p. 142).

Narrative interviews and representations effect the participants, the researcher, and the reader. It would be a challenge to read the participant stories and not be changed. In ways that I am as of yet unable to articulate, I felt changed by their stories, by our interactions throughout the interviews, and beyond. Furthermore, because of the transformative, and sometimes therapeutic nature of narrative (for participants), there is a “heavy burden of responsibility on the shoulders of the researcher” (Hunter, 2010, p. 45). I felt the responsibility the greatest in writing and analysing. The permanence of print, of
seeing as well as hearing, brings home this responsibility. Telling a story, telling your
story, and telling other people’s story is always risky. It makes public lives that may be
hidden from the everyday (Vickers, 2001).

Narrative Inquiry recognises that we all live storied lives (Clandinin, 2013). As
previously discussed in Chapter 3, research shows that there can be a justified fear of
disclosure for people with hidden impairments in employment, as well as for disabled
teachers. Someone has to go first; someone has to tell their story⁷, and by telling our
stories, we open the door for others to reciprocate (Hershey, 2011). We break down the
socio-historic constructions of impairment and chronic illness and begin to dismantle the
disabling stories imposed by others (Vickers, 2001). It is through the telling of our stories
that we situate ourselves; we make links, however tenuous with each other, and ultimately
through the collective power of these we can reject the “othering” stories (Washington,
2006). Acknowledging the risk, the uncertainty of “going first” nevertheless is a large part
of the ethical considerations for this thesis.

Close attention must be paid to how the stories are told and analysed. As Elliot
(2005) explained, it is the analysis of the stories that can do the greatest harm and
undermine the integrity of the research. Every effort has been made to make the research
processes visible with member checks. Member checks were conducted via email or face
to face contact. These played a large part in my commitment to the participants. This
process has been ongoing throughout the write-up stages. When parts of stories needed to
be changed I was able to do so in an open and honest way that respected participants and
their stories. Ultimately, member checks allowed me to produce stories that participants
wanted told. Furthermore, they allowed me to move beyond the story as an object to
analyse, and to explore the broader context as well as the individual story. At the same
time, the stories told to me and retold by me are just some of many stories that could be
told by the same person, and retold through the same data. Thus, the data is and was
narratively constructed within the social construction of the interview and data
reduction/analysis stages.

I wanted participants’ stories to be a mirror, reflecting how they wanted to be seen
within the thesis (Clandinin & Connelly, 2000) and, simultaneously, the stories were
intended to “break the silence” surrounding disabled teachers in order to “produce change
and share common experiences” (Smith & Sparkes, 2007, p. 24). I have chosen to present

⁷ I also recognise that people have equally the right not to tell their stories.
participants’ stories as a collection of storied and lived experiences in Chapter 5. Importantly, issues identified in this section, for example, confidentiality, reach far beyond the interview process. It continues throughout the writing of this thesis and beyond (D. J. Clandinin & Connelly, 2000).

4.04 Method

In the following sections I examine the method of how I conducted my research. First I explore the instruments of recruitment that I used to gain access to teachers living with impairments and/or chronic illness. I then describe the setting before detailing how I collected and analysed the data.

4.05 Recruitment

At the beginning of this research, because of my earlier research, I was aware that the recruitment and retention of research participants can be difficult when researching potentially sensitive topics (Sanderson, 2011). I was also mindful that my target population could be a hidden one, and not always forthcoming because of general attitudes towards disabled people (Ferri et al., 2005; Vickers, 2001). With these two issues in mind, I designed a recruitment survey as both an exploratory and recruitment tool. The survey was designed with self-identification processes in order to provide an unpressured choice as well as an accessible one for participants (Vickers, 2001). The survey was exploratory because at the time of the data collection no published research in a New Zealand context had been conducted involving self-identified disabled secondary school teachers. Their experiences and perspectives had not been sought. Therefore, this gap in the New Zealand research also meant that the types of issues disabled teachers faced were not known.

Facing the unknown, I was guided by the international literature discussed in chapter 3. I created a set of questions based on experiences of disabled teachers expressed in the international context. These included educational attainment, employment status, issues of disclosure, and the impact of impairment/chronic illness (see appendix E for a copy of the survey). Using the Education Counts website (Ministry of Education, 2004), I accessed the publicly available school administrative email addresses via the ‘Find a School’ search engine. I searched for Secondary Schools (year 7-15), composite schools (year 1-15), Special Schools and Correspondence Schools, totalling a list of 304 school administration emails.

On the 22nd of October 2012, a public holiday (Labour Day), I sent out 304 individual emails advertising for participants (not the survey) asking administrators to forward it to all staff members (see appendix E). Potential participants were invited to
email, telephone, or write to me to access the survey. Structuring the recruitment for the survey this way allowed me to establish communication with potential survey and/or interview participants. In fact, participants started sharing their stories with me via email, including describing their impairments and/or chronic illness, when they were diagnosed and so on. It was through this initial contact that I began building a rapport with individuals making sure to keep my emails prompt and friendly.

After the first week I had been contacted by 16 teachers in 11 schools. I emailed surveys to all of them. In that same week, I received four surveys that had been completed and sent back. I also had six respondents express their desire to become interview participants (two from previously established networks), and I received two rejection emails from school administrators who did not wish to send the email to staff (Data Collection Diary, 2012). I also advertised the survey in the November/December issue of the Post Primary Teachers’ Association (PPTA)\(^8\) magazine (see appendix E). Multiple paper copies of all issues of this magazine are sent to all secondary schools in New Zealand, and the publication is also available online (www.ppta.org.nz). Responses to this advertising came later when school had resumed in 2013. A total of 20 surveys were sent out with 18 completed and returned.

As Jansen (2010) notes for qualitative surveys, it is not the number of people who participate that is important, but rather the sense of “diversity” within the targeted group. Diversity, as Jansen described it, “establishes the meaningful variation (relevant dimensions and values) within [a] population” (section 2, para 6). Advertising for participants on a national scale has provided me with multiple points of meaningful variation including diverse geographical locations (North and South Islands), semi rural and urban, types of impairment and/or chronic illness, teachers roles and positions within the school, as well as in the size and type of school. The next section looks more closely at this diversity within the participant groups.

**4.06 Participants: Survey and Interview.**

In this section I briefly introduce the survey and interview participants. Participants will become known fully through the poetic and narrative accounts found in chapters 5 and 6. Here the 18 survey participants are viewed through the demographic material that they provided in the survey. 10 of the 12 interview participants were recruited via the survey.

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\(^8\) The Post Primary Teachers Association is a New Zealand Teachers’ Union. The PPTA displayed my half page full colour advert for free for which I am incredibly grateful.
The interview participants are referred to by their chosen pseudonyms. In this section I provide a description of the settings; of cafes, homes, and schools where the interviews took place.

4.07 Survey participants.

I recruited 18 self-identified survey participants who are represented in demographic material shown in Table 1, page 76. To indicate individuals, a number was assigned randomly rather than in the order in which they were recruited because of the small number. Of those who completed and returned the survey, 14 were female, and four were male. Their ages ranged from the late 20s to the late 60s. Participants self-identified their impairments and/or chronic illnesses in the following ways: six indicated multiple impairments, three medical, two chronic fatigue, one mental health, one vision impaired, one endometriosis, two mobility, and two hearing impaired. Ethnicities that they identified with are predominately New Zealand European (NZE), with one American, one NZE/German, and one who identified as being a New Zealander. The majority of participants held a graduate diploma in teaching as their highest education attainment although one held a Master’s degree. Two of the participants were retired teachers; two worked part-time, one was unemployed, and the rest were full-time teachers. Nine of the teachers held senior positions in their schools including Dean, Senior Management, and Head of Department. Over the page is the demographic data for the survey participants. The demographic sections are not linked to maintain anonymity. Following this, the next section introduces the interview participants.
<table>
<thead>
<tr>
<th>Gender</th>
<th>Years of birth</th>
<th>Ethnicity</th>
<th>Impairment/Chronic illness</th>
<th>Highest Qualification</th>
<th>Employment status</th>
<th>Years teaching and Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>F n = 14</td>
<td>1944-1985</td>
<td>1 USA/NZE</td>
<td>1 Mobility/Speech</td>
<td>3 B.A.</td>
<td>1 Unemployed</td>
<td>1 ½ years unemployed</td>
</tr>
<tr>
<td>M n = 4</td>
<td></td>
<td>1 European: German</td>
<td>1 Mobility</td>
<td>1 BSc</td>
<td>7 Employed</td>
<td>10 Years Coordinator Learning Support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 Other</td>
<td>1 Mental health</td>
<td>1 B.A. (hons)</td>
<td>1 Part time Special Ed plus relieving</td>
<td>15 Years Chemistry and Science Timetabling/Administration/4 classes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>15 NZE</td>
<td>1 Deaf/Mobility/Medical</td>
<td>7 Grad Dip</td>
<td>1 Part time HOD</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 Other: Endometriosis</td>
<td>1 TTC</td>
<td>3 Full time</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 Chronic Fatigue</td>
<td>1 Diploma</td>
<td>3 Secondary School Teacher</td>
<td>16 Years</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 Medical</td>
<td>1 Postgraduate</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 Vision/medical</td>
<td>1 PG DipSci</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 Hearing</td>
<td>1 Masters</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 Medical/Other/Badly broken arm on-going pain issues</td>
<td>1 NZDSS Level 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 Medical/Other: Diabetes T1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 Medical/Head injury/Chronic pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 Vision impaired</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1: National Survey Demographics
4.08 Interview participants.

As I mentioned previously, 10 of the interview participants were recruited for the interviews through the survey. The additional two were recruited via previously established contacts, thus making a total of 12 interview participants. The 12 interview participants are referred to throughout this thesis via their chosen pseudonyms. In alphabetical order: Abby, Boady, Cleo, Elle, Garry, George, Harry, Jane, Kate, Lilly, May, and Sophie. Their age at the time of interviews ranged from late 20s to late 60s. Their employment status ranged from seeking employment to retired. Nine were female, and three were male. Seven were from the North Island and five from the South Island of New Zealand. I describe the settings for the interviews in the following section.

4.09 Settings.

For the interviews, although geographically spread out, I drove or flew to the towns where Abby, Boady, Cleo, Elle, Garry, George, Harry, Jane, Kate, Lilly, May, and Sophie lived. This was self-funded. Most of the interviews took place at participants’ local cafes after school. For Lilly, Garry, and Harry their 2nd and 3rd interviews took place in their homes because it was convenient for them. For Jane and Garry, at their request, their second interviews were conducted at their schools in a conference room and in a classroom. For George, two out of three interviews were carried out at his school in a classroom and office. In the following sections I examine the individual settings. For each setting I begin with an evocative extract from my research journal.

4.10 Cafés.

Outside a school string quartet has set up, busking for the morning. The smell of cooked food hangs in the air, and the loud choking sound of coffee beans being pulverised competes with the string quartet as I sit in anticipation. (Research Journal, 2013)

The majority of interviews were conducted in a café of the participants’ choosing. The cafés were busy, bustling places. They were often noisy but my recorder had a clip-on microphone that could be concealed within the lapel of a shirt or other clothing, so after asking the participant’s permission, I used that to record their voice. Cafés provided a safe, public space to meet, but there were also problems. In some of the smaller towns, teachers recognised their former pupils passing by, and some did not feel comfortable because of the public setting, so they chose to be interviewed in their homes or other spaces like their school offices. As George noted, teachers (in small communities) are often well known in the community, especially after they have been teaching a number of years. There are often multiple generations that recognise the teacher (George Interview, 2014).
4.11 Homes.

The drive from the larger town took me beyond my knowledge of the local roads. Yet this new town feels familiar to me with its artery main road feeding into a round-a-bout heart. An adventure! The GPS on my battery dying phone spits out one last direction and one last text before ceasing all communication. Fingers crossed I am at the right place. (Research Journal, 2013)

Home settings were used for participants’ convenience, to ensure confidentiality, freedom to talk, and to enable greater participation. Homes provided confidentiality and freedom to talk, both concerns in the small communities where teachers are public figures. Interviews in homes also enabled participation for teachers who had other commitments like child caring. After the noise of the cafes, home settings were often quiet and contemplative places. Lilly’s home interview (2nd) came about because for the second visit I hired a car and was able to commute to her home (20 minutes away from the main centre). Lilly is legally blind and cannot drive. The area that she lives in (semi-rural) is a tight-knit, small community, so talking in her home allowed her to say what she wanted to say without fear of being overheard.

Garry’s home visit (again about 20 minutes from the main centre) came about because he was babysitting his granddaughter for the afternoon. Childcare was also the reason Harry was interviewed at home. His final interview happened during the school holidays, so he had to stay at home to look after his young children. They played and engaged with me and often interrupted – Harry himself looked on as I conducted a parallel conversation, one with him and the other with his daughter (Interview, 2014).

4.12 Schools.

I feel like an imposter, signing in, how will I know who I am meeting? I have no photo, no description. The Principal greets me, as he looks over my shoulder to see where I am from. Awkward. Smile. I state my name and shake hands with the Principal before I am gladly relieved to see a spark of recognition from the door frame dweller who has appeared from the staff room. (Research Journal, 2013)

The school settings for four interviews, two with George, one with Garry, and one with Jane were conducted in their non-contact periods and were requested by the participants. Interviewing them at school enabled them to participate. The schools offered a quiet place to talk, however participants were often cautious about what they said during the school interviews.
4.13 Data Collection

The survey and face-to-face interviews were the main methods of data collection. The survey had the twin foci of being both an exploratory tool and recruitment device. The data that it generated is expressed as a data poem at the beginning of chapter 5. The narrative interviews of the 12 self-selected participants form the small anthology of stories also in chapter 5. For the rest of this chapter, after briefly describing the survey, I explore how the narrative interviews were conducted and then in the analysis sections, how I created the stories and poetic texts.

4.14 The survey.

The first phase of my research involved the recruitment survey, previously discussed, as a recruitment tool. I designed the survey also as an exploratory tool. The survey in part guided and informed the interview process, to identify stories for comparisons, for example, stories about disclosing their impairments and/or chronic illness. For those who went on to become interview participants, I was able to expand on the information previously given in the survey. In this instance, the survey provided a foundation from which I could explore their narratives.

4.15 Narrative Interviews.

Speaking of…
I do not speak for
I do not speak to
I do not speak about or of

I speak with

(LJS, 2015)

I conducted a series of two to three narrative interviews over the course of a year (2013-2014) with Abby, Boady, Cleo, Elle, Garry, George, Harry, Jane, Kate, Lilly, May and Sophie. These lasted from 30 minutes to 1 hour and 30 minutes. Two participants had two interviews (Cleo and Elle), the others had three. At the first interview, the participants were also invited to keep a reflective diary to provide information about what happened beyond the interview, and to act as a potential interview aid. Due to the hectic nature of teaching, diaries were only used by three participants. This material was incorporated as part of their data for their stories, to respect the time taken to write them.
As interviewer, I adopted the role of an open listener (Polkinghorne, 2007). I did not go in with a set of semi-structured questions. In the first interviews I used a standardised, “Tell me about your life” approach that was often greeted with “where do you want me to start?” or variations of this (Elliot, 2005). Prompts or comments followed this to explore what they were saying (in greater or lesser detail).

The second interview built on the first, but also reflected where the participants were at that particular stage of the year. I asked them to reflect on what had happened since we met last. I also asked them to go into more detail about their days, their regular routines, and so on. The final interview asked participants to reflect again on their year, but also allowed for them to project into the future. The timing of the interviews was dependent on other commitments that participants had. Below is a chronology of the data collection.

October 2012- February 2013 Recruitment/exploratory survey
January 2013-May 2013 First round narrative interviews
July 2013- September 2013 Second round narrative interviews
November 2013- February 2014 Third round narrative interviews
Ongoing till the end Member checks

Figure 6: Chronology of data collection

I transcribed all of the interviews. To me, this was an important process, although laborious and time-consuming, taking on average six to seven hours per interview. I used a transcribing pedal and an open word document. It was through the act of transcribing my interview material that I began the analysis process. In turn, the transcription became an integral part of the research process for this thesis (Elliot, 2005; Tilley, 2003). I transcribed verbatim including any ums, ahs, or other utterances. Utterances like ums and aahs often produced a speech pattern, a flow that was particular to each individual.

I often relived the interview as I was transcribing, catching myself laughing at a joke made by a participant or welling up at the same points I had at the time of interviewing. Interviews were transcribed after some time had passed. I initially tried to transcribe on the road, but with a large amount of driving I found it physically difficult to transcribe and be interview ready after 4-9 hours of continual driving. Each decision I made about how I transcribed the interviews had a flow on effect with everything that
came afterwards, including the creation of the narratives (see appendix G for a sample page of a transcribed interview). I also created interview maps (Gunn, 2008) that allowed me to trace key aspects of each interview (appendix H). Narrative researchers often claim to give voice to participants (Juntrasook, 2013). In light of the importance of voice within this thesis, it is important to stress that I do not give voice, that I do not speak of, about, or to, but I speak with my participants in such a way that is appropriate within my theoretical positioning (see Chapter 2). In the following section I detail how these stories were created as part of the process of analysis.

4.16 Data Analysis

As Creswell (2007) noted, data analysis is “not off the shelf, rather, it is custom built…” (p.150). It is a process that I have developed and evolved throughout the research project. Further, when choosing a framework of analysis, Becker (1999) suggested that allowing the material to ‘speak to the researcher’ was a way to decide what type of analysis to use. In terms of this thesis, the analysis of the survey and interview texts involved and evolved into techniques drawn from both poetic and narrative inquiries. As such this thesis occupies a “scholarly world with faded disciplinary boundary lines” (Kincheloe, 2005, p. 683) disability studies and disability studies in education. Having already described these in chapter 1, my attention is now turned to the poetic and storied texts that were produced with the research question in mind: what is it like being a secondary school teacher in New Zealand living with impairments and/or chronic illness? Analysis and creation of the texts, both stories and poetry, are tightly entwined as the creation informs the analysis and vice versa. For the purpose of this thesis, I have tried to prise apart the interwoven processes of analysis and creation, although there will inevitably be some overlapping.

In the following sections I show the processes used to develop meaning from the data (Vickers, 2001). Both narrative and poetic begin with an in-depth understanding of the data through reading and re-readings of the transcripts or material. Figure 7 (page 82) graphically represents an overview of the twists and turns of the analytic process, firstly for the survey and then for the interviews (Figure 8, page 87) by way of an adapted analytical spiral as put forward by Creswell (2007).
Figure 7: Analytical spiral, survey

Figure 7 shows the simplified analytical spiral illustrating the analysis of the survey data. The spiral can be read either way. From the bottom, it shows the foundation of the survey data as it builds and spirals up from the reading to coding. The break point is where my analysis evolved to incorporate poetic inquiry. The analysis that this spiral represents is discussed in depth in the following section.

4.17 Analysing the survey.

Analysis of the survey data has been an emergent and data-led process, with the final analysis and creation using poetry to replicate the “microchip” of emotion as described by Furman et al. (2007) (see Chapter 2). In this section I describe the processes from the initial emergent theme analysis through to the final poetic text for the survey data poem.

Initially, I analysed the survey through open codes, exploring emergent themes using a general inductive and iterative approach (Thomas, 2006). Through this process I identified four broad themes:

1. Discriminatory practices and negative attitudes.
2. Disclosure: if they do or not and the reasons behind this.
3. Acceptance and support inside and outside of school.
4. How participants’ impairment/chronic illness affects their lives.
Themes are often used as a starting point for poetic transcription, (see Glesne, 1997). However, unlike Glesne (1997), I did not build my survey data poem from my previous thematic analysis, but rather directly from the survey data. This kept the poem participant centred. The themes discussed previously influenced my decisions about what to leave in or highlight in the poem. This was related to the occurrence of certain ideas within individuals’ survey answers, signalling their significance across their responses. Nevertheless, I tried to put previous thematic analysis aside, and eventually deleted it from my working document.

I started again, looking at my survey data afresh in order to view it from a new perspective, one that did not have thematic analysis as a core aspect. Initially I was influenced by the ethnographic concept of Creative Analytic Practice (CAP). CAP as I described in the second chapter is an ethnographic term for the holistic use of creative processes including poetry and story to reflect research findings (Richardson & St Pierre, 2005; Smith & Sparkes, 2007; Sparkes, Nilges, Swan, & Dowling, 2003). Further inspired by the keynote of Deborah Fraser’s (2013) New Zealand Association of Research in Education (NZARE) conference address and her call to use creative processes in education research (see chapter 1), I decided to try to represent the findings of my survey as a poem. At that stage I was relatively ignorant of the body of work that is poetic inquiry, having only touched on CAP described by Richardson and St Pierre (2005) as well as Smith and Sparkes (2007). I did not consider there were any conflicts with narrative by creating a data poem. In fact, there has been a move within narrative that explores poetry in conjunction with narrative or as narrative poetry (Clandinin, 2013). With hindsight I feel that a poem realigns the survey with the creative processes of prose in narrative inquiry (Blumenfeld-Jones, 1995).

Unlike many studies that used interview transcripts and oral material, the first poem created for this thesis is based entirely on participants’ already written material of the survey. This makes it more akin to found poetry (Butler-Kisber, 2002; Lahman & Richard, 2014; Prendergast, 2004, 2006). The poem, as it is meant to be read, is found at the beginning of the first findings chapter (Chapter 5). I designed it with a lot of white space to allow for reader interpretation (Lynn Butler-Kisber, 2002; Cahnmann, 2003; P. Carroll, Dew, & Howden-Chapman, 2011; Foster, 2012; Furman, Lietz, & Langer, 2006; Lahman et al., 2010).

After again reading and re-reading my survey data, I only took into consideration my over-arching research question, “What is it like being a teacher living
in New Zealand with an impairment and/or chronic illness?” and how to represent that from the survey data. I set out to create a larger poem than the one presented in this thesis, with a four-lined stanza per person to attend to the issue of voice and representation. However, this was clunky and unwieldy, and I felt that I was failing aesthetically. I recognise that the poetry within this thesis could be considered “good enough” for qualitative research. This is a tension that I found between creating a research thesis versus a creative exegesis (see chapter 1) and it may not be resolved. Perhaps this is best demonstrated through the differences between my own poetic musings which are imagery rich using “flowery” language, rich in metaphor (chapters 1 and 7) and data-led poetic texts which are experience rich, but utilise the plain language used in the interviews (chapters 5 and 6). The rich, plain language poetry of the survey and interview data signal my intention to place representation ahead of aesthetics.

A further problem was that the survey participants gave varying amounts of data. The first aim of the survey was to recruit participants; the data it produced tended to be deeply personal, but broad. Therefore, while I was able to create a stanza from one participant’s survey answers easily enough, there might have only been a couple of “usable” lines in another. Despite the sense of failure, writing the poem provided me with a creative challenge that I could not ignore, and I could see the potential of such an approach. I proceeded believing this ultimately would be the best way to represent the voices and experiences of the participants.

Within the literature about poetic inquiry, I found that very few poetic inquirers describe how they transformed the raw data into the poem or the poetic analysis, with the exception of Glense (1997) and Richardson (1997). Most poems are context-free, meaning that they stand alone and are not explained nor is the process of constructing described. In order to make this process more explicit, in Figure 8 I describe using a line by line comparison between the poem and the relevant statement in the survey data or the poetic transcription (Glesne, 1997).

Poetic transcription of the data, enabled the “data” to be shown and also captured the depth of feeling behind the words. A conflict that was raised when writing the survey data poem was between the survey poem and the interview stories, with a high retention of survey participants as interview participants. 10 of the 18 survey participants became interview participants. Economy of words was important when I was writing the data poem (Prendergast, 2009). This aided in preserving partial anonymity as I selected phrases carefully whilst also avoiding repetitition and
colloquial phrases that could be identifiable. I felt it was important not to use stories in the survey poem that participants later went into more detail about in the interviews. Because I had chosen to limit the lines, repetition did not happen. I also felt that if I had extended the poem, I was in danger of imposing unhelpful, or even obscuring, “padding” therefore weakening the overall impact of the poem. Examples of this can be found in my failed stanzas (or lines) in appendix I. Each stanza represents data from one individual.

Poetry is in a constant process of editing. It was through this editing process that included ideas like an economy of words, and the research question, that I tried limiting myself to just 18 lines, one per person. Through the creative processes, my aim became “to reveal the spirit” (Glesne, 1997, p. 30) or to highlight the most evocative aspect of an individual’s response across all of their survey answers. This involved reading and re-reading their answers using a process that Lynn Butler-Kisber (2002) described as “nuggeting” or “sifting” (Glense, 1997) words and phrases. The process was in part intuitive, Quinn-Hall (2016) describes this process, as she said:

I write poetry to try to unravel understandings about the world I engage in. Sometimes when I come to the end of a poem, I can say, “Oh, that’s what that was about”. Many times I come to the end of a poem and I can only say, “Oh.” And sometimes I come to the end of poem and sense there is nothing to be said because a poem is not always about the words. A poem is about the drift or the shift that happens between the words. (Quinn-Hall, 2016, p. 116)

There is a “drift and shift”, a disconnection between the raw data and poetic transcription. This speaks to the processes and its interconnectedness with method (Blumfeld-Jones, 2016). Appendix J shows the details about the processes of creating. This is beyond the step-by-step method and delves into the crafting process to be transparent with processes like the poetic devices I imposed on the data. These are interconnected and important as they can give a sense of the words. Ultimately, a poetic transcription can produce a unique representation of participant or participants’ voice. but also make visible the production of those voices by the researcher (Limes-Taylor Henderson & Esposito, 2017). The figure on the following page makes this explicit.
Figure 8: Poetic transcription

Closely related answer in survey (including question no.)
At times one feels very alone  FP5 Question 15

Sometimes I have to leave my class to use the toilet  MP9 Question 9

For a while the ‘timid’ year 9 girls stopped asking questions after I asked for a 3rd repeat of the question. MP7 Question 9

I feel guilty not disclosing it, but like I may be disadvantaged/viewed negatively (or just seen as giving ‘too much information’)  FP4 Question 14

is not information that is shared with everyone, as it is a private (taboo even) illness, FP6 Question 11

Bowel problems are not PC to talk about  MP1 Question 11

No longer allowed to leave school in non-contact time  FP10 Question 11

I feel quite dizzy and feel off the boil and unwell  FP2 Question 9

Sometimes a sugar low can force me to leave the classroom, or eat in the classroom, which often feels unprofessional  MP11 Question 9.

My hobbies over the years have been greatly limited by physical difficulties…. In saying that there are still many things that I can do and still many things that I take pleasure in. FP8 Question 10

I look o.k so no one really knows that I have MS  FP18 Question 11.

I felt my mana and dignity was not preserved  FP13 Question 11.

Red/brown colour blind. It is hard to mark material that uses both red and brown colours that normal vision people can see but I can’t. MP16 Question 9.

The constant battle to balance coping with work  FP3 Question 9

I have to balance work with coping, FP10 Question 9.

My life is very small because work took all of my energy  FP5 Question10.

Maybe it’s time to give up teaching  FP15 Question 17

During episodes I am at the wrong end of the depressive spectrum  FP2 Question 9.

I believe it has cost me the chance to meet love and marry someone  MP14 Question 10.

No, people accept me the way I am FP12 Question 10

Line in the poem

I am surrounded by people and yet I am alone

The bell rings, the lesson starts, and I rush down the stairs to toilet

Students ask and repeat; ask and repeat until they give up

I am silent

I am silenced, topics too taboo

A nap no longer allowed in a non-contact

Dizzy, I go off the boil.

Highs and lows, I crash because of classroom etiquette

Waiting, my hobbies fill some time, no work yet.

Always looking good, but no one really knows

Questions over my capacity, I lost my mana and dignity.

Red pens; a mark of invisibility.

Every day, the constant battle to balance coping with work

I want to give up!

I am at the wrong end of the depressive spectrum

Could I have loved and married?

In the end, people just have to accept me the way I am!
In this section I have endeavoured to describe my first encounter with “poetic transcription”, the beginning of the poetic turn in my research. From this poem my confidence grew, and I incorporated more poetic transcriptions with the interview material. In the later chapters, the use of both narrative and poetic inquiries combine to produce a multi-textual account as a part of a holistic approach. I have touched very briefly on both the poetic devices and research contained in the poem. Chapter 5 is the vehicle for the data poem; the research will be revisited in chapter 6 as I explore the stories produced from the interviews. Ultimately, “I am, am I?” recreates my own understanding and analysis as more than just an in-depth understanding of the data. For me it has created an empathetic understanding that moves beyond the page (Richardson, 1997). In the following section I turn to the processes used to analyse the interview material and create the texts found in the findings chapters (Chapters 5 and 6).

![Analytical spiral interviews](image)

**Figure 9: Analytical spiral interviews**

### 4.18 Analysing the interviews.

It was difficult deciding how to analyse interview participants’ stories. Jane Elliot, in her (2005) overview of the narrative landscape, identified three broad foci for analysis; content, structure or form, and a combination of content and form. Each of these has its merits and reveals different aspects of the narratives. For example, content can reveal detailed social accounts like those found in the research of Thomas & Znaniecki (1958). A focus on structure, as indicated in the work of Labov and
Waletzky (1997), reveals a chronological perspective using a framework of abstract orientation, complication action, evaluation, resolution, and coda. Narrative becomes a set of actions that we reproduce as we tell our story. My approach to the interview data, as described at the very beginning of this chapter, was guided by Becker (1999) who described allowing the material to “speak to the researcher” to determine what type of analysis to use. In light of my research question and my interpretivist framework, it was important that their narratives and my analysis be experience-centred (Squire, 2008).

I therefore decided not be a “story analyst”, described by Smith & Sparkes (2007) as having a single focus, for example, content, but a “storyteller” who looks at multiple aspects of the story including content and form. I have set out to to create a powerful piece of participant-centred piece of research (Smith & Sparkes, 2007, p. 20). In order to do this, stories are told from participants’ perspectives with their voice. I have drawn from multiple analytic tools within narrative and poetic inquiries to create multi-textual participatory research, to take an adapted holistic content approach (Lieblich et al., 1998).

This approach to analysis involves three stages after the initial transcription. The analysis incorporates aspects of content (the what) and structural (the how) in order to explore participants’ stories. My analysis approach included Polkinghorne’s (1995) “emplotment” (structural), emergent themes (content), and poetic transcription (content and structural). In the following sections I describe the processes I used to transform the narratives. This has the multiple aims of providing insight into how I created the texts as an issue of trustworthiness, academic visibility, rigor, and to ultimately acknowledge that my interpretive approach impacts on how the participants are represented (Tilley, 2003).

4.19 Holistic content analysis

“Storytelling is data with a soul” (Brown, 2010)

“Stories have a way of insinuating themselves into our conversations with each other and our self-dialogues. Stories weave sticky tendrils throughout our notions of how the world exists around us and how we are fastened within the world” (Quinn-Hall, 2016, p.110).

Storytellers attend to the “whats” and “hows” of a story rather than focusing on either or, and it is the story that becomes the analysis (Smith & Sparkes, 2007). This perspective allows for the complexities of stories to be revealed. Searching within
narrative traditions, it became clear that there was no one way to analyse my findings (Bamberg, 2012; Bertaux & Kohli, 1984; Bruner, 1987; Clandinin & Connelly, 2000; Gubrium & Holstein, 1998; Ollerenshaw & Creswell, 2002; Polkinghorne, 1995). In this section I describe how I adapted a holistic content approach to incorporate the social context of the stories and poetry, in keeping with my theoretical positioning described in Chapter 2.

A holistic content analysis seeks to encapsulate the narrative as a whole (Elliot, 2005; Lieblich et al., 1998). I drew from narrative and poetic inquiries with multiple goals in mind, including the privileging of disabled voices, and how best to answer the research question: What is it like being a secondary school teacher in New Zealand living with impairments and/or chronic illness? The adapted holistic content analysis that I used for this thesis is a multi-staged process. There are three rather than five distinct stages as described by Lieblich et al. (1998). The five stages as described by Lieblich et al (1998, pp. 62-63) are:

1. Read the material till a pattern emerges. They describe this stage as being intuitive.
2. Global impressions of the case put into writing including a focus on disruptive episodes.
3. Decide on foci or theme.
4. Mark in colours the themes reading repeatedly.
5. Follow each theme and transitions.

All of my analysis is founded in transcription, reading, and re-reading (stage 1) with an open mind and allowing the text to “speak” (Lieblich et al., 1998, p. 62).

My three broad stages:

1. Restorying (following Polkinghorne’s *emplotment*).
2. Search for themes (following Thomas’s inductive approach).
3. Poetic texts based on over-arching themes (following Glesne, 1997).
Below is a visual representation of my adapted holistic content analysis. These stages are explained in greater depth in the following sections.

4.20 Restorying

The **first** stage of my analysis involved the restorying of the interviews using Polkinghorne’s (1991) “emplotment” as an organisational tool. This ultimately helped me shape the narratives and can be compared to Lieblich et al.’s (1998) first and second stages as described previously. Interviews were read and re-read multiple times in order to gain an in-depth knowledge of the data that had been produced. They were then examined for key features of their plot that specifically addressed the research question. These were put predominantly in sequential order of (the interview) beginning, middle, and end. However, in some instances, in order to provide a better sense of coherence, they were re-arranged out of order although this was very rare. For example, Jane (p. 106) thanked me for the opportunity for telling her story. This was at the end of the first interview, but I placed it first because in my interpretation of the interviews it spoke deeply of her as a person. It also signals to the reader that this is a story that is being told. The stories that were produced are shown in Chapter 5 as the first findings chapter.

Creation of the narratives, through *emplotment* (Polkinghorne, 1991) was an important part of the research process, as stories are the essence of this thesis. *Emplotment*, as described by Polkinghorne (1991), is the “transformation of a series of events or a list into a coherent story with a point or theme” (p. 141). Using interview transcripts as well as participants’ journals as the “series of events or list”, the focus,
stories, were participants’ experiences of being a teacher with an impairment and/or chronic illness.

I have positioned participants as narrators of their own stories (Ward, 2011). The narrative, was created in participants’ own words (spoken and/or written). Material that related to the overarching research question was identified and used to further the “plot”. Material was also used to make the structures of the plot explicit, for example, material that provided a place to begin, a middle, or an ending, or talked about the telling of a participant’s story. This then provided a clear and flexible structure for each participant’s narrative. Material that did not answer or relate to the research question was excluded. This may be viewed as coming into conflict with data led research. However, because the research question is so broad, very little material was in fact excluded. Specific material that identified participants, for example, names of places, schools, and towns was taken out and/or anonymised. Examples of material that did not further the plot (Polkinghorne, 1991) or that pertained to protracted reciprocal exchanges during the interview, included rapport-building discussions for example, a discussion about a movie was also omitted.

The use of such broad criteria enabled the capture of the “whole” story as part of a holistic account. The criteria was also central in positioning the participants as narrators of their own story (Kraus, 2006). The narrative process emerged from the raw data and was updated after each interview. This led to the emergence of an evolving narrative that could be viewed as part of a continuing, living, narrative that moves beyond this thesis (Polkinghorne, 1991). The products of my analysis can be viewed in the first findings chapter (chapter 5). The survey poem “I am, am I” begins the chapter, followed by a two part introduction discussing the poem and introducing the stories. These stories and poems provide the answers to what the experiences of New Zealand teachers living in New Zealand with an impairment and/or chronic illness are; they are also highly evocative.

4.21 In search of themes

The second process of analysis focused on the themes found within the stories using Thomas’ (2006) idea of inductive thematic analysis. The use of an emergent thematic approach enabled cross-narrative comparison and sociological understandings that are important if disabled teachers are to be supported as a group within organisations like the Education Council of Aotearoa New Zealand (ECNZ) or the Post Primary Teachers Association (PPTA). Taking the stories as a whole, each story had its own dominant
theme, which provided me with 12 themes, one per person. These are: Unchanging, Strategy, Transformative, Balancing, Life Changing but not life defining, Understanding, Conflict, Perceptions, Loss & Gain, Support, Gender, and Educating. This was then condensed further to three even larger themes of diagnosis, teaching, and disability. The following table (Table 2, p. 93) describes each sub-theme and theme.

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<table>
<thead>
<tr>
<th>Individual themes</th>
<th>Definition</th>
<th>Major Theme</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Unchanging</strong></td>
<td>Came from the participant describing how her life is still the same. Her sense of her life not changing, a sense of limbo that surrounded her status as a teacher and her impairment and/or chronic illness.</td>
<td><strong>1. Diagnosis</strong></td>
<td>As a theme it relates to impairment effects (Thomas, 2007). All of the teachers described, to a greater or lesser extent, their impairments and/or chronic illness. I have also called these diagnosis stories. The impact of diagnosis is explored through stories of pain. It is tied to issues of disclosure and relationships that may or may not be accepting of the “diagnosis”. Diagnosis brings forth the engrained institutional disablism that disabled teachers interact with on a daily basis. Subthemes that are particularly indicative of this larger theme are: support, loss &amp; gain; life changing, unchanging.</td>
</tr>
<tr>
<td><strong>2. Strategy</strong></td>
<td>This came from the participant describing how she had to plan the day and who to disclose to, to be strategic.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3. Transformative</strong></td>
<td>In this theme the participant viewed their impairment as transforming both positively and negatively, their life as a teacher</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>4. Balancing</strong></td>
<td>Trying to find and trying to maintain balance, trying to work with their impairment</td>
<td><strong>2. Teaching</strong></td>
<td>As a theme, teaching sits between diagnosis (the individual) and disability (society). The theme of teaching explores ideas of empathy, of the disabled body as a pedagogical tool, of the barriers to “being” a teacher, as well as the barriers “to” teaching. Within the theme are ideas about how teachers can be inclusive/create inclusion but also how they can be excluded. These ideas can be found in all of the sub-themes but particularly in educating, transformative, gender, strategy and perceptions.</td>
</tr>
</tbody>
</table>
5. **Life changing but not life defining:** The impact of being diagnosed but moving beyond the diagnosis

6. **Understanding:** Understanding in school but also the lack of understanding

7. **Conflict:** In this type of theme or story, there is a conflict between wanting support but at the same time not wanting to be seen as needing the support therefore creating a conflict.

8. **Perceptions** How people’s perception of ability change when impairment becomes visible.

9. **Loss & Gain** Participant viewed the losses that came with the impact of impairment but equally the gains.

10. **Gender** The focus on how non-heteronormative behaviour challenged ideas of what it is to be a teacher.

11. **Support** Whether or not the participant had support regarding impairment and teaching. Support or not, could be from family, friends, and colleagues.

12. **Educating** In this sub-theme educating refers to using their body as a pedagogical tool and ‘educating’ wider staff and students.

3. **Disability** As a theme it relates to how an impairment/chronic illness is socially constructed. It situates the stories about how the participants define themselves, and the development of a disabled teacher identity. The theme incorporates the sub themes of support, education, gender, loss and gain, perceptions, transformative, unchanging, and strategy. These sub themes suggest a way of viewing disability which includes how disability is socially constructed by participants, and also how they are viewed and who is viewing.
These 12 individual themes were then examined for greater or lesser commonalities. Each story theme or type described an aspect of what would become the three larger themes. The broad themes of the narratives capture the messiness and the complexity within each story. The themes flow both to and from each other. The second findings chapter (Chapter 6) takes the three broad themes as the framework from which I begin a discussion of all of the findings (survey and interview). I had discussed earlier that my position is as a story teller not as a story analyst. As part of the holistic account, these themes act as an organising framework as much as an analytical tool.

4.22 Poetic texts

The third and final stage of my adapted holistic content analysis sought to describe the micro context. I explored each narrative and looked “for meaning in light of the larger narrative” (Glesne, 1997, p. 13). I settled on poetic transcription for this task (Glesne, 1997) as I had done so with the survey material. I “nuggeted” one line per person from the raw interview data that spoke of one of the three emergent themes: diagnosis, teaching, and disability. This allowed my analysis to be more than descriptive or thematic (Ollerenshaw & Creswell, 2002). Poetry has allowed me to retain emotion, and a sense of both the individual and universal experiences. I was able to produce an evocative “iterative remix” of the themes (Wiebe, 2015).

Poetry in general within this thesis has become a meeting point where disability, impairment, chronic illness, employment, voice, experience, and research intersect each other (Kuppers, 2013). Poetic forms produced in this thesis aim to, be a “poetics of witnessship” (Hartnett & Engels, 2005, p. 1051). This links with my aims of the incorporation of participants’ stories to bear witness to the lives of teachers living with impairments and/or chronic illness (Shuman, 2006). I feel my adapted holistic content framework allows the stories to speak for themselves. Ultimately, I chose to be a “storyteller” using these techniques, allowing the story and poetic texts to become the analysis, to theorise – to “show and tell” what it is like being a secondary school teacher living with impairments and/or chronic illness (Smith & Sparkes, 2007).

4.23 Summary

In this chapter I set out to describe the methods that have guided me in my research. I began with describing the recruitment processes using an advertisement for a survey that was sent to 304 schools via their public administration e-mail. This recruitment garnered 18 participants, 10 of whom became interview participants. I used
the survey as exploratory and a recruitment tool. An additional two participants were recruited through previously established links. They each had two or three face-to-face narrative interviews over a period of a year 2013-2014.

From the beginning, I decided that I wanted to feature the stories of Abby, George, Cleo, Kate, Elle, Sophie, Gary, Harry, Lilly, May, and Boady, and I have become a storyteller rather than a story analyst (Smith & Sparkes, 2007). The stories were created using Polkinghorne’s *emplotment* as a restorying tool. It provides a significant part of the holistic analysis process (Lieblich et al., 1998). I have developed and adapted this in order to produce data-led findings, allowing participant stories to invite the reader into their storied and lived experiences. The second process of my adapted holistic analysis was an emergent and inductive thematic coding of the stories. From this I produced the broad and large themes of diagnosis, teaching, and disability. I highlighted each of these themes using a poem created from the raw data. My aim with holistic analysis has been to explicitly show the complexities, and to bring forward the messiness of living with an impairment and/or chronic illness. I structured the following chapter differently, beginning the first data poem “I am, am I?” created from the survey which is on a single page. The poem is then followed by an introduction to a short anthology of the storied experiences of Abby, George, Cleo, Kate, Elle, Sophie, Gary, Harry, Jane, Lilly, May, and Boady. I end the chapter with a brief epilogue.
Chapter 5

“I am, am I?”

1. I am surrounded by people and yet I am alone
2. The bell rings, the lesson starts, and I rush down the stairs to the toilet
3. Students ask and repeat; ask and repeat until they give up

4. I am silent.
5. I am silenced, topics too taboo
6. A nap no longer allowed in a non-contact
7. Dizzy, I go off the boil.

8. Highs and lows, I crash because of classroom etiquette
9. Waiting, my hobbies fill some time, no work yet.
10. Always looking good, but no one really knows
11. The pain I live with.

12. Questions over my capacity, I lost my mana and dignity.
13. Red pens; a mark of invisibility.
14. Every day, the constant battle to balance coping with work
15. I want to give up!

16. I am at the wrong end of the depressive spectrum
17. Could I have loved and married?
18. In the end, people just have to accept me the way I am.
Teachers’ experiences living with impairments and/or chronic illness

“Poetry is power of words to effect change, to move people…” (Hershey, 2011, p.132).

... the story of how we live in the world is not really a single solid line. The story is not closed. The story is perforated; it has holes into which the world’s breath can whisper through (Quinn-Hall, p. 127).

5.01 Introduction

I have dedicated the space of this chapter to the survey participants (the previous poem) and the stories of Abby, Sophie, Cleo, Lilly, Jane, Kate, Harry, Elle, Boady, Gary, George, and May. Their stories directly attest to the experiences of New Zealand teachers living with impairments and/or chronic illness. I am, am I? is the first “iterative remix” (Wiebe, 2015, p. 158.) of data that I produced as a poem. It is then fitting that it is the first data poem that I explore in this thesis.

The poem created from the survey participants’ answers, stands on the previous page as a prologue to the larger stories of Abby, Boady, Cleo, Elle, Harry, Gary, George, Kate, Jane, Lilly, May, and Sophie. The poem can also be viewed as a “challenge” to the dominant view of teaching, of disability, of impairment, and of chronic illness as it reveals the often hidden and confronting aspects of being a teacher living with impairments and/or chronic illness. The survey participants are at the centre of the poem, so that the reader can see, feel, and hear them (Richardson, 1997).

I created this poem to capture the messiness, the lived, and the storied experiences. It is deliberately confrontational as all of the survey participants at some point in the survey expressed their anger, their sorrow, and their despair. It was therefore important to highlight it. The poem strips back the concept of “teacher” and allows for the reflection on some of the hidden aspects of workplace environments, the context of the classroom, and overall school structure. The narratives that follow this introduction make these hidden aspects more explicit.

The stories span a spectrum of employment in the teaching profession from Abby, who is an unemployed trained teacher to May, a retired teacher. I chose to order them this way to make explicit the varied ways in which impairment/chronic illness effects disabled teachers, as well as highlighting the temporality of their voices. The narratives between the poles of employment have tangible links that may require a “back and forth” reading (Clandinin & Connelly, 2000, p. 167). Therefore, although their stories stand alone, they also provide a context for each other. Their stories are
viewed as part of the stories found in a wider societal context; they are interlinked and interwoven experiences. The stories are personal, social, and political (Cortazzi, 1993). Ultimately, the stories contain insight into participants’ lived realities and listening to them and learning from them could potentially “expand the ways of thinking about and implementing school inclusion” (Biklen, 2000, p. 338).

I wish to acknowledge that in sharing their stories, Abby, Sophie, Cleo, Lilly, Jane, Kate, Harry, Elle, Boady, Gary, George, and May have laid themselves bare, risked everything (Hershey, 2011; The stories are not closed, nor are they linear. They have holes and spaces the world whispers through (Quinn-Hall, 2016). Furthermore, I have called this chapter an anthology, the collective noun for a collection of stories. The structure of this chapter reflects my commitment to a collaborative research process, as I wish to respect the story as lived and as told. Each narrative is in the first-person, and some have a non-linear aspect or no clear plot devices (Richardson, 1997). In the next Chapter 6, I examine the stories in light of the major themes of diagnosis, teaching, and disability, previously discussed in Chapter 4. So…

“What is it like being a secondary school teacher in New Zealand living with impairments and/or chronic illness?”
5.02 Abby

I am a philosophical kind of a person, I am constantly reflecting on my experiences but not just on my teaching, but on the whole life sort of thing. People I meet and why they think the way they do and various things. I’ve had a disability now for most of my life, and so I don’t really have any memory of not being the way I am. So, it has very much coloured the way I see the world and how I experience things differently.

Teacher training was a couple of years ago now; it’s gone by so fast. It was a good experience overall, mostly enjoyed it. It was still study, of course, so there are aspects of that that are boring as anything and other aspects that are good. There was P.C. nonsense, and a mixture of interesting new things to think about. The part that I enjoyed the best was working with the students. Yeah, I think I had, during my teacher training, I wanted to start off teaching because I wanted to talk about, wanted to interact with students, and teach them about my subject area. I’m very interested and passionate about, but as the year went on, it was more about I just want to work with teenagers. I feel that’s more important than what I’m teaching.

It is unfortunate because I haven’t been able to get a job, and yet I really feel that I would be able to work really well with teenagers. My experiences in life perhaps put me in a different place to some other teacher.

So, it’s kinda obvious that things in my life, have well, haven’t always been easy. So, I think sometimes it helps students, particularly teenagers because that’s the point in your life. I just think it perhaps removes one barrier possibly to students’ interactions, I’m trying to think of a better way to put that. I’ve almost, I wouldn’t say I’ve given up, but I would say, aside from signing up to the Ed Gazette for notifications every time my criteria are met; you know to get an email saying there’s a job. Other than that, I haven’t really been looking. And I so rarely get notifications of available jobs that I almost wouldn’t say forgotten about it, but sort of trying to think; what else can I do, if this teaching thing isn’t going to work out for me?

When I’m applying for a job I always feel that I am being forced into disclosing, which I hate doing, you know, because even if someone says we are equal opportunities, you just don’t know. There are two questions, and they are worded in such a way that they can get away with it, that is not illegal or unethical. I don’t know, but to me the way I read it, its forcing me to disclose my disability, and I thought I had the right to not to disclose if I chose to. These two questions are in such a way they could probably get away with it, but I still feel I have to. They use the word MAY. Do
you have an impairment, disability impairment, long-term medical condition that MAY affect your ability to carry out this job? Well the fact is that I do, MAY, I always circle that as well and I try and answer it in such a way that you know I manage my condition well, and I have been throughout my entire educational career as a student. I always feel more comfortable when a person sees you and talks to you face to face, um, I don’t want them to sort of bring up those questions and say well you put no, clearly you know. And the fact is, that it may, but then someone without a disability or impairment can break a leg, you know, can get stressed or whatever, and I don’t get stressed a lot. So I really find that those questions force me into disclosing. If I say no and I get to an interview stage, they might question my integrity or something like that. I have to talk about the fact that I need a wheelchair. And the other question that is a follow up to that is; do you have a medical condition, oh this is not exactly how it’s written, I can’t remember off the top of my head. But it’s along the lines of, do you have a long-term medical, disability, impairment, something like that, that MAY require alterations or special equipment in the workplace? And again, that’s forcing me into declaring myself. And my registration expires this year, and my referees are getting several years old now since Teachers College, so my chances are getting less and less of getting a job, and teaching.

I don’t know but I mean I don’t regret doing my teacher training or going to teacher’s college. I learnt a lot during that time, and not just about teaching, but you know, about myself, what I like to do and things that I can and cannot do. And it’s not bad, and I enjoyed my, I enjoyed the practical experiences, like going off to postings into schools the best yeah, so I don’t lose anything for not getting a job.

So, I’m just going with the flow I have no idea what I’m doing. Yeah, a bit of casual tutoring here and there I mean, but that’s not as satisfying in terms of work. Yes, you are working with teenagers, but it’s more about the academics and less about the interaction and social sort of aspects of teaching. It’s just about getting down to passing exams, which is fine because I’m good at tutoring students. And I’ve had good feedback, but you know, it’s just, academic stuff. I mean it’s somewhat enjoyable, but you know, the enjoyable parts are, teaching is having fun with your students and doing interesting things and practical stuff and, casual conversations you know, as casual as you can get teacher-student thing, but yeah, it’s quite formal tutoring. They want you to make sure they can pass.
At the moment, I don’t get up to a lot. I do get up at a reasonable hour in the morning, I get up at seven. I’ve learnt over the years when I have other times in my life where I haven’t done Ed or things, that it’s not good for your mental health if you sleep in all the time just because you’ve got nothing else to do. You know, most of my days consist of reading or finding other activities to keep my mind ticking over, just being content. Just taking it as it comes. There's no point in getting down about those things. Yeah, just see what's around the corner, you never know! And it may not be teaching, you know, I am open to other possibilities too, so you know, I’m not just focusing on that, clearly it hasn’t just suddenly happened, see what happens. The story hasn’t really changed.
5.03 Sophie
I was born and they didn’t know I was deaf. They didn’t screen me, and then when I was at kindy, they found out that I was deaf. I basically went to school to eat my lunch and play and go home. But I did quite well because I am blessed with a good brain, and I read and I learn from reading.

When I was in Standard 4 the government was just bringing in the new FM system, and my teacher kept pushing and pushing so eventually I got the FM system, and I was one of the first in New Zealand to get it and it was brilliant! It just revolutionised my education. Without it I would not have got through high school or university at all. And so for the first time I heard the teacher. That was good; it was embarrassing though, because it was very big, and you know what a teenager is like, very self-conscious. So I stood out a bit, but at the end of the day I had to think well I need this, I can’t get through my education without it and so that was the end of the story there. But nobody really aspired for me to be anything, because you know, a deaf person being in the mainstream was quite a rare thing. And so no one really knew what to expect of what they could do, so people had career options. Mine was just to finish school because that’s all my parents had for me, that’s all the teachers really had.

I got caught up on that dream of educational movement, and I was good at it, but I was good at everything, I just wasn’t allowed to do what I wanted to do. Then I got through Uni. I relied totally on my FM system. I would never have made it through Uni without it. Compared to the average deaf person I mean, I’m really only typical of the people who were mainstreamed who were deaf. We were the first of the ones that got mainstreamed. For most of it I had to rely on myself. Then I went through Uni. I did a B.Ed. degree thinking I would go into the mission field and work with poor people and stuff, so it was a bit of a surprise to end up in teaching because it was not my dream.

Ah, teaching was very, very, difficult for me. I started in a school that was co-ed, sort of a mixed range from very low decile to very high, so you had a range of people from one of the poorest communities in New Zealand to very wealthy, you know? And being Deaf I had a whole new set of challenges, being in the front of the classroom and so I had to again find strategies for myself that would work to help me as a teacher. I cried myself to sleep every night for the first year because it was just a challenging year – too challenging, I had so many, I had to create the resources, and I mean, of course you’d have more hours then, than we do now, so it’s a lot harder for first years back then, than it is now. But I, had to create all the resources plus deal with
management. The second year was bad as well, but I was gaining skills and by the third year we had changed the course, I had a lot of support, I knew the students, and got systems sorted.

At the beginning, sometimes I wasn’t sure if I should tell the students I was deaf or not. But I learnt from about third year of teaching that you are better off telling them you’re deaf so that you kind of take away a secret. They think there is something wrong with you. But you still have to deal with their rudeness, they can take advantage of you. But you have to teach them how you want them to respect you. And I think in order to survive as a disabled person in the secondary school sector, because you know, teenagers can be pretty brutal, in order to survive, you have to be confident in yourself. You have to respect yourself, so you can get that respect from them – you know what I mean.

Some schools, the parents when they found out that I was deaf, they were like “oh my gosh how is my child going to learn?” which is really stupid but you know, that’s how they think. I mean I had a student that said “I can’t learn from you” and I said “why not?” and she said “because you’re deaf!” I’m like I mean “hello what do you mean you can’t learn from me? I’ve taught other students!” But it’s an attitude, because some people have these ideas in their head that you can’t learn from anyone inferior to you, but you know, that’s just arrogance. And you have to slowly win them around so they can realise well hey, I’m a person and actually I have abilities!

I’ve got a cochlear implant and that’s just been wonderful! Absolutely wonderful! Gosh the first time they turned it on, I knew it was going to be Darth Vader with a mouse stuck in his throat, but when I heard it I just cried. It’s like you know when you give birth, you know it’s going to be painful, but nothing is going to prepare you for it, it’s just that kind of reality it’s just, you know. My hearing is getting better, although this one needs fixing. The right ear is still giving me trouble, so I have to fly back to [a city] to get it re-mapped. And it’s quite good because I took the term one off, and based on when my operation was, and all the remapping sessions, most of them have fallen in the holidays. So it hasn’t interfered with the school work, just term two. I mean the school has been supportive so they let me go and everything, but I have also been trying to reduce disruption by trying to put check-ups and operations into the holidays, or during that time. So it has worked out really well.

I’m hoping to try and do singing lessons, but that’s a bit of a challenge because I have to relearn what’s good, and what to do, so it’s a bit of a challenge for me but that’s
my challenge. I’ve found a really supportive music teacher and she’s prepared for the challenge. She knows it’s not just going to be like the normal singing student. I have to learn how to sing in tune. I’ve been calling people up on the phone and that, and slowly in school, sort of making more movement towards, you know, normality. But everyone has been supportive but although you are sort of on your own, you have to make it work. I have learned that with disability in any workforce you have to make it work.

I almost left teaching. If I hadn’t had the cochlear implant I would have, I probably would have left this year, it just got too hard. There’s not a lot of support for [the] disabled, but also depending on their disability, what can they do in teaching. For me, I was under a lot of stress last year because I couldn’t hear and I was trying to cope, and I didn’t realise how much until this year when I’ve got more hearing, you know? But the thing is, the other teachers don’t know what you’re going through. I think, though, and the reality is, unless there is a clear system of support, the reality of it is that most of us learn how to survive and we do what we need to do in order to survive. I mean nobody in my school, all my teaching years, none of them would know what to do to help me.

Don’t knock someone off because they have a disability and don’t put limits on them because they can be very wrong. Let the person prove, let them be who they are, and let them come up with solutions to overcome their disability in the situation. They can bring a unique side to education that a person without a disability may not. Because people put me in a box, and said oh you can’t do this, and you can’t do that. Well I could. I could do all of them! I just did it differently, you know. And I think that’s the thing, you know a disabled person can do everything, just some of the things they have to do a little differently but it doesn’t mean they can’t teach!
5.04 Cleo

You have to push yourself harder every day, when you are in pain or feeling exhausted from pain. You have to push yourself just that much harder to keep going. You spend a great deal of time hiding your disabilities or your impairments because you don’t want to be thought of as struggling to do your job, or not to be able to complete your job in some way. So you work twice as hard to be the best you can be, and yet still cover what’s troubling you.

The start of my disabilities really began in my early 20s, but probably because I wasn’t teaching then it didn’t really affect what I was doing. But then soon after I went back to teaching full time I ended having to have a series of operations, and a series of replacements. First off I had to struggle around the classroom, hobble around on sticks and accept the way that people looked at me differently, for that, both teaching staff and management and students.

I probably tended to over compensate during that time by doing a lot of extra things, like putting on a lot of extra outings for the students, extra out-of-school class activities, to show that I could manage perfectly well even thought I was on sticks. [Further] that I could [do] better than even just manage well, I could excel in the job because I could do all these interesting things for my students that other teachers weren’t doing. I tended to be sometimes running the department and it was important to me to feel, to show people, to signal to people that I could manage to run the department, and do all the teaching that I would normally do, and do all the extras that I was doing for the students at the time. So I had to push myself exceptionally.

Then there was choosing the right time to actually get my issues, my health issues sorted. I never felt that I could take school time off to do it, so I would do a lot of them in the school holidays to be the least inconvenience to the school as [I] can possibly manage. For my last series of operations, they have all been chosen to be in the holidays. I would have six full weeks to recuperate and then get back to school as if nothing had happened at the start of the year again. I am so busy coping with getting over the operation etc., that I don’t have good time to prepare my lessons, or even myself, for the start of the year again. I quite often go back to school exhausted and burned out from what I have had to do over the holidays just to get well. Then I don’t feel rested or well enough to cope, so I feel as though I start on the back foot, whereas everyone else has had lovely holidays and they are fresh, and I’m not.
I don’t feel supported at school. I think the administration were understanding in
the beginning but that sort of wears off. My head of department just looks at me like
I’m a liability rather than an asset. And yet I’m still doing, you know, a huge proportion
of the work, both in the department and out of the department, with parents and
students. I’m drawing students to the school because of what I offer. I’m putting on all
of those extras that I always have so that the students are getting a lot of extracurricular
activities. I’m still teaching valid subjects that allow the kids to achieve, achievement
standards. I don’t get any help around classroom comforts or conditions. There’s no
compromise or effort to even help in any way what so ever, it’s more like “oh good if
she’s unwell and she’s got problems maybe she will leave sooner!” And that’s just
because of her personal mind set and um, vindictive attitude.
I do consider [that] having disabilities of my own helps me understand others with
disabilities, [and] helps me to be more patient and understanding as a classroom teacher.
I think I have, I had plenty of empathy anyway, but I think I’ve got more empathy than
the average school teacher. The students don’t perceive me as being as daunting to
approach as some teacher might be. Some of the feedback I have from them is that I’m
understanding and that they feel they can tell me anything or come to me about anything
… that’s beneficial obviously, because I can build a better relationship with those
students and that can be exceedingly beneficial both for them and myself. I’m an
advocate for my students’ needs, um, they know that I respect them. … There’s a mutual
respect and trust between us and I think that should be at the forefront of any of my
dealings with them, and their dealings with me and anyone’s dealings in the
“department”.
A lot has happened this year. My boss has resigned, mainly because there had
been an audit done of the department and that revealed some flaws. You know those
flaws had caught up with her and people were asking her some uncomfortable questions
of her and I think that was her main reason. I was pleased in some aspects, because I
knew she couldn’t hurt me anymore, but she also left in a very, or left me to carry the
can to a certain degree for the year until she did put in her resignation.
I suppose the most exciting thing that has happened [is that] I’ve actually just been
appointed, newly appointed “to a senior position”. I had shown that I could run the
place I knew the place inside and out. I knew the kids, I knew the kids rely on me and
trust me um, I wouldn’t ever let them down, so I felt that I would be as good a candidate
as anyone to actually take over the position.
There's a lot of expectation. A lot more than there was of the last person; because she’s made mistakes, I’m going to be made to pay for them. Basically, because there’s going to be a lot more of a watchful eye on what I do and a lot more expectation of me to perform. I feel that people won’t be very patient or understanding. I think people will expect a lot of me straight away. More than what they would of a new person, they would allow a new person settling in time and I won’t be given that, that luxury, and because I am also doing the other part of my job as well as the teaching, it sets up a huge work load for myself.

I want to build a culture of respect in the “department”. I think that’s lacking, because there has been that bullying attitude if somebody didn’t fit the mould or somebody was um, what’s the word? Too much of a threat, they were bullied. I want to affect some change around how teacher aides work professionally in the classrooms. There is quite a lot of work to do to affect some areas of change. And I do want to have a much better interpersonal relationship between myself and the teacher aides, which is going to take some time to build as well.

I’ve only really just starting my beginning; I’m only just beginning at the start of my journey. The last journey I had was just a struggle. So now I’ve got the chance to show my potential and I’ve got the chance to go on the journey that I should have had ten years ago. So, it’s really just that I’m beginning my journey. … That I have time to prove myself and time to show others that I am the right person for the job and that I will build that culture of respect and I will effect change and I will make it a better place to be working in and going to school in. That’s it.
5.05 Lilly

Before I became a teacher, my disability was not an issue. I never had any problems with [my impairment], but once I became a teacher then it raised its head I guess you could say. I’ve come a long way and I want to hold on to what I’ve got. I have always had a strong will to succeed and to prove myself. It’s a bit of a battle … it never use to be but it’s getting harder as I get older. … When I was young I had this idealistic attitude that I wanted to be a teacher and that’s what I wanted to do. I enjoy teaching, I love the kids. It … came naturally to me, but as I’ve got older I’ve found it harder and harder to weather the storms.

My mother had toxoplasmosis when she was carrying me … she thought she had a cold at one stage … what happens is that it destroys [the] central parts either of your hearing or your eyes, usually your eyes, and its destroyed … the optic nerve that goes to my brain. So it’s right in the back of the macular. The most important part of the macular is destroyed completely. … I was about 12 months and I had little tiny glasses and … then I graduated to milk bottles when I was at high school, then I got contacts when I was 18.

To begin with I never said anything to any of my classes [about my impairment]. I just let them pick up on things but now, right at the beginning of the year I tell them straight up that I’ve got a vision impairment, I’m going to have to hold things close. They find it hard too, to tell if I’m looking at them, so they look behind them, so I learn their names as quickly as I can.

I’m the dumping ground for a lot of the disabled kids. They tend to put them all in my class because I’m disabled or have a disability. Then I think that sounds harsh and I am quite happy to have them, but I think they kind of assume that if you’ve got a disability you know how it is. Some of them are completely different from my one. I have got an epileptic boy and that’s a bit scary for me, because apparently, I’m supposed to look for signs, facial changes and whether he gets pale.

I’ve had to do a lot of writing stuff out, being ultra-prepared for my classes, so making sure I’ve got my planning in large print, so I can refer to it easily … and answer questions I’ve written out before hand in large print. There’s not books that, or text books that have been adapted like that. I have found the technology side a real challenge. [It] takes me a long time to plug everything in, to zoom up my screen on the laptop to the magnifier, then I’ve got to hook it up to the data projector, then it comes up big and all the kids say it [is]…. The school to be fair has tried to accommodate me,
accommodate me! And they think that they’re doing pretty well but there is still a way
to go and I’ve been there [a long time]. A couple of years ago a student walked out of
my class because we had a disagreement … she told … the principal or one of the
senior principals that I didn’t see her leave the class. Now it wasn’t because I didn’t
SEE as in physically, I didn’t SEE, because she actually snuck out of the class. The
Board wrote to me and said they thought I was a health and safety risk.

[Last year] I had to go part-time because I was under so much stress of having to
cope with all this stuff, and they gave me a couple of subjects that I hadn’t taught, and a
lot of family stuff. Now I don’t seem to be able to claw my [way] back into full time
again. There is a certain amount of discrimination that you have to cope with. I think
there is a feeling that OK, so you’ve got a disability, but people don’t understand
exactly what that disability is, and the extent of it. If she can teach class, why can’t she
read notices on the notice board or judge at the swimming sports? So people expect me
to do the same, but sometimes that’s just not possible. They can’t see how having a
disability can make you a teacher.

This year I actually feel that they are seeing a different side of me. I’m happier
and I feel that I can manage things; I’m getting my confidence back, which I had lost. I
think they are using me to, my experience, to actually get in there and put some new
ideas in there and do these things and they move me on to somewhere else, where they
need new ideas. Even the Head of the department, all of her memos and things that she
sends to me, are in large print so that’s good. There’s people in the department that have
got glasses that struggle with the tiny writing and stuff, yeah so I was really stoked
about that.

People probably don’t see me as tough at school. They think oh Lilly she’s
pretty weak, she’ll never be a senior manager or anything like that. I don’t have a strict
teaching style because that’s just not my way. But underneath I’m really tough; really
tough. You have to be. You couldn’t be where I’ve got to without being tough and
taking the knocks from colleagues and students. A lot of people still think that I’m not
disabled. They think, well Lilly is getting off these things, but she can do the job. She
can see you know, um they don’t actually realise how much I can’t see. But then again
I’m proving that I can see. Yeah so what, so this is what I have struggled with all along
how much; Ok, on one arm I’m saying I need the support, and on the other arm I’m
saying keep away because I can do the job. That’s the balance. That’s what it’s always
been.
5.06 Jane

This is a great opportunity to say hey, this is my story. These are my experiences. I know when you have a disability you want, you don’t want to be seen as having a disability. You want to be just fine. You want to walk on your own and you know, depending on personality, some people … cope totally differently because a disability is a weakness in some people’s eyes. I think it’s that when you have a disability and you are aware of the fact that you’re not going to live forever; other people think they are, don’t they? They think that they are invincible. It’s a real blessing because you look at life so different.

When I was first diagnosed I couldn’t type, I couldn’t write, couldn’t [do] all those kind of things, I couldn’t talk properly. I sounded fine to myself, but one of my very close friends goes “Jane you’re slurring your words.” I wasn’t aware of that and I was like “what are you talking about!?!?” [It was] August, I can’t remember the exact date, but August 2009 and I hadn’t had any earlier symptoms, I was fine.

I was at school, and I was walking up the steps and one of the DPs or the DP was behind me and he goes “what’s wrong?” He could see that my gait wasn’t right, and he asked me what’s wrong, and I said “I don’t know, I just don’t feel right”. So, my husband took me to the emergency room, and a friend met me there. They said I’d had a stroke because my right eye vision was a bit distorted, my voice was slurred, and my right arm was a bit less able, you know, just the strength was not there. In the end they did an MRI – Boom! I was covered in lesions, with MS – down in my spinal cord and the largest one or the most active one at this stage is the one in my cerebellum, so this effects my balance and motion. I was there in hospital for nine weeks. I just went down, down, down, down, down, down! It was terrible. Its forever impacted the way I teach, the way I relate to people, because we’re not, not that I thought I was invincible up until then, but you’re living – you don’t really know, you don’t think I might not see tomorrow or whatever.

Students and staff alike have always been very supportive and helpful. I have never felt or been made to feel ashamed … to feel bad for having a disability. I don’t know how my experience would be different if I was somewhere else, but I have, I am really blessed with the people I work with, ten years I have been there, they’re beautiful people, they love me and I know that so it was O.K. I felt safe to tell them. [So] I went to the staff meeting. We have staff morning briefing every morning, and my boss John
said: “Jane wants to talk”. I just broke down and I told them, at that stage it was still very painful.

My students are really funny, they didn’t know anything, and my boss came to see me, and he said: “what do you want me to tell your students?” It’s a really small school, 300 kids, and we lived at the time right behind the school, so he came to see me and said: “look what do you want me to tell the kids, they think you’re pregnant!??!” All my kids, all my year 12s, I explained to them about what was happening and that is all. They had probably never had someone close to them have something like that happen to them. Honestly it did feel like I’m telling them like I’m going, I didn’t know.

Totally changed the way I teach the same stuff, but there’s so much more of me because I can, I always ask them the question what makes you get up in the morning? And they go, my year nines, went “I’m hungry”. Yes, that gets you up, but why do you want to get up? Most people cannot answer that, or most students cannot answer that so I tell them about me. I want to get up because I’m breathing today. I can turn my head without getting nauseous. I can hold my kids. Teaching, I find, particularly in my subject area, just emotionally, spiritually draining. You are never not working, you’re never not teaching, you’re never not thinking about the lesson tomorrow or what did work today or that student that is driving you mad, it’s just so all consuming.

I was made full time for 10 days [at the beginning of 2013] as I have been part time for five years. But because of the small class size, it was merged so I was back to part time— I want to be full time, I know I have the brain but I just don’t have the energy so in the end I was grateful that I didn’t have to cop out. Because right now I pour everything into school, and work that when it comes to being at home, sometimes I’m not my best. It’s just little thing, little things that are not, they’re not big things.

One of the issues for me is memory. I’m having, had real issues, no probably had it for a long time but I am aware of it, not remembering things, not major things, I was like “aaaah am I losing my marbles?” I was really mourning my brain; that my brain doesn’t work the same way. So, ok it works. It works well enough, I have a job. Yet as each month ticks by, like all this crazy, and I don’t have a relapse, I get kind of, I mean like I say “YAY”, but at the same time I’m like, oh my goodness, what does that mean? Does that mean I am closer to another one? There’s a lot of anxiety that still, like even I’m really well and people telling me “oh my goodness you look really well” and I go yeah I know, don’t jinx it. There’s a wee bit of apprehension because if I was having, if I had a relapse then I would know OK done. I’ve had one. There’s a pressure on
myself pressure, and then like I would feel guilty if I had a relapse because I would feel like I didn’t do something right. I’m not going to stop doing something like, whatever it might be, because oh I might have a relapse if I do that I might just sit at home doing nothing and then I wouldn’t be happy, or I wouldn’t feel fulfilled or that I was contributing to the world or anything.

So I’m much more aware of those around me that are struggling in some way or yeah any. Yeah, just they are struggling whether it be a disability or just a bad day. I am so much more aware. I think it’s a blessing that I’m going through my own struggle or my own journey. [It] sounds like I’m going to win a beauty pageant, but you know, I want to contribute, and I want to make the world a better place. And when I say the world I mean my world. So the people I meet, I want them to be better for having met me, regardless of them knowing that I had MS or regardless of that, just me as a person, I want that.

It’s been really good to have a purposeful reason to talk about it. To talk about living day-to-day life with MS, being a teacher, being a mother, you know, all those things because I am often very ill. I don’t want that to define me, and so I shy away from talking about it like “oh hi, hi, I’ve got MS!” I don’t, I don’t want it to be what defines me. It’s been really good to reflect back on, oh my goodness, how far I have come. So four years and to really think about it and to be reminded of how darn good life is, you know. I’m still trying to figure out how my story is, how the MS, how it all fits, you know. I would rather [my children] remember, or to know I’m not dead, but to have memories that are enjoyable, fun, full of life. Knowing that I have a degenerative disease and I am aware that one day maybe I go back to hospital, maybe I’m throwing up, it is kind of hard to look towards the future. It’s been quite a journey.
5.07 Kate
I don’t, I don’t like to talk about it very much. Here I am talking to you, but I don’t like to talk about it very much because I find that it doesn’t help anything. I don’t tell people that I’m not having a good day, you know I just box, I just get on with it. There’s not a lot of room for weakness in teaching I don’t think. I have chronic fatigue syndrome and I’ve had that now for 17 years. In an ideal world, there would be more media about chronic fatigue syndrome, and about what it is, and the effects of it, but there's not. It’s quite an unspoken about kind of condition, and so that has affected how I have been able to share it, or not share it. It’s nice that someone is interested because I don’t talk about it a lot myself. I don’t even with my own family, I don’t really talk about it, just because I don’t want it to be the thing that is foremost in my mind all the time. I’d rather it was just a background thing. It’s good to think about it from an outsider’s perspective, I suppose, and um, I’m not sure my story is going to be helpful or interesting to anybody!

I am dealing with my chronic fatigue, I’m dealing with that on a daily basis and most people don’t even see that. I don’t want it to define who I am. It’s a part of who I am, but I don’t like it to be the defining part of who I am. I just box on because I know it always goes in waves. It might be bad, but it will get better and yeah, so I just have to, I have to pace myself a lot and I have to say no sometimes to things. Probably not as good at that as I should be as a woman.

When I first got it, I got it very suddenly, which is unusual but also very helpful and I had six months in bed – so six months I had to take off. I don’t look sick, and if I am really bad people can see it … all around my eyes goes very dark and they can see if they are looking for it. But um, other than that it’s quite an invisible illness, and because most of the time I am very energetic and outgoing people would think, really! I doubt it! They [the school] were supportive, but I knew there were things going on in the background. I was told about, you know whispers in the background, they thought maybe that I was just weak. … They never said that out loud, and um, but the people who had known me for a wee while knew that I was a good teacher and they didn’t want to get rid of me, and they wanted to support me. So that [was my] first experience of getting sick, of being unwell

I guess the thing that I have been the angriest about in the whole course of my illness is that a lot of people, because they know nothing about it, they tend to jump to the conclusion that it’s a psychological illness. And when I was first very sick they, you
know people thought I had had a mental breakdown, which is not true at all. It’s got nothing to do with psychological, it’s very physical, hormonal, chemical. It’s an illness of the malfunction of your adrenal glands and your immune system response. So it’s a very complicated illness and I understand that people don’t understand it. I guess um, I would like more people to be educated about it. But until you meet somebody who has it, and spend time talking to them, you wouldn’t know anything about it.

I told my principal, two of my, my head of departments and another colleague who is probably the best supporter of me at school, and yeah, I mean they were all gobsmacked and surprised. I told um, those people closest to me, and they were very supportive and yeah, so it’s kinda out there now. I don’t think parents know. I wouldn’t want them particularly to know. I don’t share with my students because I don’t want them going home and telling their parents and them saying “oh she shouldn’t be in front of my child!” You know because of the whole misunderstanding around it. You know, and it might be fine, but it might also be not fine. It doesn’t really affect my teaching, well I don’t let it affect my teaching too much. I told my own children last year, I hadn’t told them until then, and I don’t think that they really do understand. I’m not feeling very well, and they just know to leave me alone, and let me sleep, and not to bother me. Yeah, they are quite well trained in that regard! I don’t make people more aware of it because I don’t, I don’t like making it a central part of me. I don’t like, I don’t like it to define me. So I rather, I would rather prefer that it was something that I managed mostly on my own, and I do. I do manage it mostly on my own.

I did have a bit of a crash. The following year a management position came up and that was a position I had always aspired to. I had been in a “senior position” before when I was at the previous school, before I had children and I loved “it”. It’s definitely my calling as a teacher so I thought dammit, it’s a little bit too soon, but I knew that it only comes up very seldom and I needed to take the opportunity. So, I applied, and I got it! All this time nobody at school knows that I have chronic fatigue syndrome so, so I got the position. So, I felt confident then that they knew I was worth keeping and a good teacher blah blah blah. So, in the first year of “it” I still didn’t tell anybody, and you know, I did struggle. So, I had to take days off occasionally when I just wasn’t managing um, and then last year I had a particularly difficult um, cohort, and it was a particularly stressful year, it was quite bad.

I had quite a big um, relapse in the middle of last year, towards the end, well term three of last year. It was so bad I knew I had to tell people because I thought I was
away and away, and people didn’t really understand why and um, I would say I had a migraine, so you know a migraine is you know it’s a condition that people accept as being valid. And what I have is similar to a migraine in some ways, so instead of having to explain the whole chronic fatigue syndrome which requires a large explanation, I would just say that I had migraines.

Our schools, they don’t help in a lot of ways, in that there are constant meetings, meetings before school, meetings after school, things are programmed in lunch time, to meet students in the lunchtime. There’s very little um, downtime. A lot of the time very little recuperation between, you know, teaching. I enjoy the teaching. I always enjoy the teaching. My frustrations this term has been technology. But you know at the end of the day, you’ve just got to roll with the punches and just get on and do the best with what you’ve got.

It’s great we have the holidays. I can have two weeks of just complete rest. So that’s the good thing about teaching in that it is you do have those kind of restorative periods, but yeah, it is fairly high stressed job and you know more than what people, non-teachers would think; Its bloody hard work! I guess the only thing is that for people who … do have any kind of chronic condition, I think that it’s really important that we, you know make balance a really important part of our priority. So you have to prioritise balance in your life. I do my job and I’m happy to do my job well, that’s the job I signed up for. I use a gratitude journal (I teach my students this as well) it’s just to try and keep my head in a positive space. It’s about mindfulness, being aware of the good little things that happen each day, just little things, yeah, just little things, sometimes I just have to write that I am grateful that the day is over!
5.08 Harry

I would consider myself a creative person. For a creative person teaching is actually stifling, I find whilst I’m creative with some things like coming up with ideas and stuff for shows, its stifling in the fact that other creative ideas and outlets that I might have, I don’t have time to pursue.

I kinda came into teaching relatively later in the piece. I had done a performing arts course at [a tertiary institution]. Then I got diabetes, shortly after I had finished. My Mum said, move home, come home and stay with me, because I took it quite hard. I was young, get out and have a good time kind of guy. And I guess I found it really hard to cope with. … I had bad habits … all of those things I set up over my lifetime. I was quite depressed at the time, so I moved back home with Mum and got a job, did some performance work in local shows in [my hometown].

I meet [my wife] during performance stuff which was cool, and we hit it off and got married a year later. I think everyone though “God they’re all crazy!” I ended up working at a bar … I was there for a while and you know, I was getting paid ten dollars an hour at the age of 24/25 I’d just … got married and I sat there. There is no way that I can ever support a family or even think about having a family on ten dollars an hour! And so that’s when – you know for a long time I had actually thought about coming a teacher, but I’d been put off by the fact that men kind of had, were fairly persecuted in the education [system], or certainly a lot of men had the magnifying glass on them. And because I was … fairly dramatic I didn’t feel the need to draw any more attention to myself by becoming a teacher. Crazy thing is now that I am married, and I have a family, I’m perceived to be acceptable, you know. But hang on – if I was a bad in the first place, I’m no different now that I am married!

I’ve had diabetes now for, this is my 13th year and I kinda pride myself on the fact that I have never been hospitalised. And that’s a big thing for me, and my wife knows that too. So usually if she thinks I’m getting a bit daft she has on a couple of occasions said to me I will get on the phone, and I will call an ambulance, and I will take you to the hospital if you don’t sort it! I can sense it coming, and well that’s one of the things if you sense it at quarter past ten and you’re in the classroom, I don’t want to leave the classroom for five minutes to go and have food, and whatever else, so I kind of sit there and go I’ll be fine, I’ll ride it out till 11 o’clock.

At that moment I get really tingly and numb across my chest … my tongue would go numb, my lips. Certainly, when it goes the other way you kind of feel like
everything is seizing, its kind of like [cracking sound] and I sit there and go and you know, you are desperate to go to the loo cos I’m a bit slack because I don’t have my injection in the middle of the day. And I get home, I’m feeling it, and you test and it’s well and truly in the 20s, and you sit there and go, uh huh.

I guess the hardest thing for me, I don’t like to regard myself as having a disability. With my background in drama, I’m a firm believer for not making excuses, and just getting out there and doing you know. Dancers get out there and perform if they have sore feet or whatever. … I say to my drama kids, there is no excuse for not turning up and doing a good performance. The only time you have an excuse ever is if you’re dead! If you are actually not able to get there because you are dead, and that’s the only good excuse, and that’s kind of my mantra you know. I have on-going issues with depression, which you know, in whatever size shape or form, and so I had a bad, when I was first at drama school I had a particularly bad bout of it and the school director took me to psych services and put me through the system and put me with this counsellor to talk to. So I say with the kids, I’ve been and talked. Often you have the answers. The answers are in your head, they were sitting in there, but I couldn’t get to them clearly because it was in a big muddy pulp I guess. But I say shop, shop around until you find someone. I’ve had some sort of experience with it and you can relate with kids because you know how they are, how they feel – then why wouldn’t you empathise? Why wouldn’t you talk to them? … One thing I have learnt in life is that I kind of I don’t know, try not to supress stuff. I just kind of you know and everything for me is quite close to the surface … if I talk about something it might upset me at the time, but that’s ok, I’m alright. … I’ve got to the point that I know the things that I know I need in my life to keep me balanced out, to keep me stable and on an even keel.

I don’t know if teaching is something I see myself as doing forever. I can see how it can very easily come all consuming, because you eat, sleep, breathe school. I must say, I sometimes sit there and go what I wouldn’t give to have six months in a job where you get up and go to work at nine and you come home at five or whatever.
5.09 Elle

I think the physical and emotional in my story are very closely linked. I have had endometriosis for a really long time. Since I was 14, so as a student even school was sometimes really hard [with] pain that’s quite indescribable. I would describe it as debilitating, and it is not just at the time you’re in pain, and that pain is horrific, you just want to be dead when you are in that kind of pain. To be totally honest, those feelings don’t go when the pain goes.

When I was 28 I went to the doctors constantly, and was told that just some woman have this kind of pain, and that I was mentally unhinged. I just knew in my heart that something physically was wrong, but once you’ve been told for years and years and years, over and over that there’s nothing wrong, you’re just a bit crazy. Eventually you just think “wow I really am”. You start to buy into what you’re being told. I became very depressed; I was dealing with chronic pain so the depression was exacerbated by that.

When I started teaching maybe in my second or third year, I thought this is just ruining my career. I felt so embarrassed that I was having to go home or leave my class and go to sick bay. I was thinking, oh my god I can’t even work. I eventually let my HOD know. Everyday school life is really enjoyable. I really love my job. It can be really stressful, and I think that’s where having an on-going illness can be really hard.

So I have had a few surgeries over the years. Two since I have been teaching. So that required time off. I feel that asking for any more than a week would be asking a lot. So, I would only ask for a week. The last time I had this really full on crazy bout of depression. … I told my HOD and other people that I needed, and they were supportive. They didn’t ask me to do extra bits and pieces. People don’t want to know that your inside, your female insides, don’t work or that they have problems. They don’t want to think about, it’s not pleasant for them. You feel like you’re saying, oh I’m sick again, and you just don’t want to. So you’d rather take a nap on the vinyl floor out the back, and you just get through the day. I don’t want to be known as that person. I don’t want to be seen as some unreliable or can’t do the job. It’s the kind of job where you have to be the kind of person that shuts it down. If you wanted to you could work 24/7 as a teacher, and plan to the nth degree. But if you want to stay healthy and sane you need to say that’s me for the day, I’m done.

I’m quite empathetic with my students, there are actually girls out there that really going through something a lot more serious, so that kind of helps make me
sympathetic. If I have known a girl that has been diagnosed with the same condition, [and] if I think that it will help them to have someone to talk to then I do. Depression is a bit more acceptable to talk about, so I’ve been someone that they can talk to about that, that’s one thing I’m really open about.

Then this amazing thing happened. I knew I was bit sort of late, you know but I wasn’t really sure. I thought oh maybe I am having early menopause or something, because that was my thoughts about how likely it was you know, that we would conceive. So I started to feel a bit sick, and a bit off, and really tired. I sort of remember on a Monday, I got to lunch time and I just sort of said to my work colleagues oh I’m just so tired I can’t eat, which is really weird for me because like I really need my food. I must eat to keep going, and they were all like yeah I’m really tired, I’m really tired too, and I thought oh it’s just the middle of the term and we’re all a bit tired. And on Tuesday I was driving home, and there is a chemist on the left hand side by the roundabout before we go right off to where we live. And I indicated to pull over to get a test. And then I flicked the indicator off. And I was like oh don’t be ridiculous so I did, so I thought no and I went home.

And on Wednesday, I was still feeling quite sickly, nauseous so I thought oh I’ve just got to discount it you know, like it won’t be. So I actually did the test in the bathroom at school in the middle of the day, and it just came up straight away, and I just could not believe it. I was just in total disbelief and shock, and just I was really happy and excited but I was still like no, that, it can’t be! But I went out to the staff room and one of my best mates from work and said I need to talk to you, and um because I just had to tell someone. So I told my friend at work and she was really excited because last year she supported me a lot through all of the sadness and grief of the idea that it wasn’t going to be part of our life. Life’s going to be totally different and it’s really exciting and I can’t wait to meet him and be with him, but at the same time, it’s like, it’s a big change from what I have now.

I’m trying to put things in place now that will help me [with depression], so I had a really great chat with the midwife who does the acupuncture. And she actually put me on to a counsellor who I am going to start seeing in a few weeks’ time. Yeah, just over that time, just before and after he’s born, just to, because I know talking with someone will just help me you know, keep things on the level. And yeah, other than that I think looking after my body is well, is quite key for me, like getting enough exercise
and good food and rest and stuff. So I am going to have to have a bit more of a think of how I’m going make those things workable or put things in place I guess that will help

It’s still, my friend at work, probably my best friend at work, and even day to day she goes “do you not sometimes believe it, like it’s just so surreal?” I was like “totally, I think just like what!?!?” It’s not real; you know it’s like just so surreal. I think especially after sort of a year and half of letting go, feeling like I had to let it go and move on and get over and just be ok without. So yeah every now and then I’m like oh my god! Is it really happening! You know it’s crazy, it’s cool.

Everyone loves a baby. No one loves endometriosis, though everyone loves a baby. You know, it’s just so much more easy to, you know, if I don’t feel well to go. Whereas in the past it would have been like, no you just have to tough it out, get through it kind of thing. It is harder to talk about [endometriosis] because it’s related to your self-image, femininity, and being a whole proper working woman. It’s a really serious disease for many people. Maybe if it was out there it would be more easy to talk about, … we can all talk about prostate cancer and erectile dysfunction, but I can’t talk about heaving bleeding and period pain … there is still a bit of a taboo around it and it’s a shame in that way. It is lonely, but I don’t really want to get together with other people and talk about how horrible it is, and how is your pain? And how’s yours? It doesn’t sound like a good time for me, or useful. I would rather have fun, you know, take my dog for a walk! It is a big part of my life and who I am, but I don’t like that but —.
5.10 Boady
I’ve been, I’ve had a sick mentality, I’ve been sick since I was a baby so I was treated like a sick person when I was growing up, I’ve always felt sick and sometimes I had been really sick if you know what I mean. So I can’t say how different I would be if I was a healthy person. Although I have had some long health stretches like, you know, in my 20s and 30s. I actually felt well a lot of the time. It just is all the extra effort you need to put in to do your basic job and I think that’s the problem. And I have found my work mates really supportive so you know that that’s been good and I can see how it can be quite different. You know, so I suppose some people have really quite negative experiences, depends who you end up with. You know but it’s just all that extra effort. I think probably the deafness is the worst thing of all. And because I’m never quite sure I’m hearing what people are saying correctly, and that’s the responsibility when you’re in a job.

I do relief teaching as well with special needs and like, I’ve got some really nice people that I work with at the special needs unit here [at my school]. And they are aware, you know, that I’m a bit delicate, so they take special care and they realise I don’t hear properly. Like one of the teacher aides asked me the other week to mind this girl who is in a wheelchair and is partly disabled and I’m in the habit of saying “oh yes” when someone asks me a question when I don’t really hear or listen. And then I went off and did something, and when she came back there was no one minding the girl. So now they know they have got to really check that I have heard. So that’s quite good and the staff are pretty good, because it’s a small town mentality but you know the mainstream school is a bit hard to deal with.

Rheumatoid arthritis goes for every bone, I’ve got arthritis in the bones of my jaw and its sort [of] like effecting the whole side of my head and it makes me extremely tired. I’ve got it in my feet too and my knees and virtually every joint you might say is effected but the hands mainly. And yeah, various other bits get attacked at different times. I have [had] this chest thing, for my whole life I was mollycoddled and told how sick I was all the time, so I grew up expecting people to look after me, which they didn’t once I’d left home.

I don’t think I’m a very good teacher actually, but I am very patient, because of all the things that I’ve had wrong with [me]. I think that helps on that level, but I’m not a very good teacher unfortunately. I’m better than some possibly but, I yeah I try and do my bit. I’m quite conscientious so that’s good.
I started relief teaching at the primary school and the high school, and then eventually I just stayed at the high school ‘cos I’ve if you’re in one school you keep getting asked all the time, so I did that for a number of years. And just a couple of years ago I stated doing the special needs.

I’ve got 2 ½ students and um, one of them is leaving next week. It’s the end of the seniors and she’s turned 21 at the beginning of the year. So that will be end of her, and because I’m not capable, I can’t take on any of the new students. Oh well, there is one new student coming but I can’t have him because, you know, he needs physical restraint. You have to run after him, you know and things like that so I just couldn’t do it. That’s only 6 1/4 hours a week, but I’m there about 15 or more. And then I will get a phone call two or three hours maybe of relief, so I’m there most of the time more or less, except I am trying to take days off because, you know, they are sort of all those jobs that are endless.

So I will be left with one and a bit students, and the bit I do mainly paperwork for because she’s severely disabled and I can’t look after her either mmm, so my work is diminishing – probably good for me if I can spend sort of less time working actually, but not so good for the pocket. But it will be different because we’ve got a new student who is quite a handful and a couple of new teacher aides, so it will be a lot more difficult probably, with a lot of new people in there.

It’s amazing like because I’m only meant to do, what its 6 ½ hours or something, and its going to be 5 hours this year, but that takes up the whole week. And you know my days off I have to go into meetings, so like I end up working a whole week, but you know I’m enjoying the time by myself. I am feeling a little bit jaded. It’s really difficult because no matter how much equal standing in the education thing, they put everyone else in their classes and your student doesn’t get class choice. So even if you get in early they say oh no we’re full up already, so it difficult so we try and you know the students, in practical classes

I think I’m not doing it as well as others, because you know I don’t hear what they are saying I can’t always make it up the stairs to the staff meeting, various things that I probably should be doing. … I am trying to put in that extra time to do it properly but you don’t get any bench mark so that’s something

Sometimes relationships between the adults is not great as it is in any work place, so it’s not always a good idea to have morning tea there really. So some make a point of not having it there so staff dynamics is interesting in any workplace. In our
special needs unit I like, keep my ears, as good as they are, open as to what's going on so I can report to the boss who is really busy and isn’t in as much. It’s a pity that I’m not good in the ear department, but at least I can see. Yeah so I tell them that I’m a spy sometimes so they are aware, I tell them I will tell on you but you know its interesting working based on that. The atmosphere, sometimes it’s stressful and sometimes I think, you know, should I be bothered doing this work, but yeah but I keep telling everyone that I’m retiring when I’m 65, I think I will.

Just two years yeah, so not next year but the year after, probably at the end of the year if not before, depending on my health I suppose. The time slips by and you sort of get more mortal feeling at my age. But life begins at forty; I mean that’s a cliché. But it’s good to — it’s a bit of a challenge, it’s just I don’t want, my brain can’t handle all the ideas anymore. ... And I’m already so tired that I have trouble thinking clearly, you know, and I don’t have the energy to think creatively like you should be doing when you are in my kind of a job. So you know it makes you think rather negatively sometimes, and I’ve got to remind myself that a lot of stuff [is] in your mind and you don’t realise how your own attitude effects the way you are. I’m just grateful to be able to work and do things, and I feel like I moan a lot because I’m sort of not that sick, I’m just a bit sick. So, I’m not in a wheel chair or anything. Yeah, so any rate that’s about me!
5.11 Gary

I will start with the idea of [needing to get] hearing aids. Firstly, or [from ] two sources I suppose, firstly, at home my wife had enough [of] turning up, [and me] having the TV volume turned up way more comfortably up than what she wanted and having to repeat … instructions to me. Secondly, at school I was noticing that some of the year nine girls, especially at the back of the class,… might ask me questions as a teacher and I would be saying “oh pardon?” and after two or three pardons [they stopped asking] cos they were shy to keep on asking. So it’s not fair on my wife, it’s not fair on these students to have to ask to repeat their questions all the time, so I thought well we better do something about this. The principal said he could write a recommendation for me for the audiologist, to see an audiologist. They said “oh yes you are down”. The graph showed that [my hearing loss] wasn’t to do with damage like chainsaws or motor mowers or rock concerts or whatever … but it was something that was going to happen to me, possibly a kinda family, genetic, thing. So I was just getting deafer as of about ten years ago.

So I started wearing these hearing appliances and teaching and I think that just made a big difference. I still have to be careful about, listening to what I’m being spoken to about and paying attention. It enabled my job to become more efficient and … fair on the people I was involved with. I never regretted it. … Some people have a bit of a stigma about baldness, so they wear toupees, or some people have a bit of a stigma about wearing glasses, so they get contact lenses, and for me the hearing aids are little, but kinda discrete. Not really a social stigma thing to wear them, I think it’s quite good, and in fact some of the students that I’m most connect with are those that wear the hearing appliances too. I think it’s nice for them to see, like some people, some students might have that encouragement from having a teacher that has hearing aids.

I teach science and maths. It’s always been 60/40 or 40/60, just two classes of one, three of the other or vice versa, it just depends on what is needed in the time table … I have to keep conscious about … being aware of how noisy the class is … to keep it down, keep the control and in the science room.

I’ve had several staff ask me … what is it like wearing a hearing aid, and it just, I suppose it’s a bit like getting a new pair of glasses or you know, you’re taking that step towards showing your age, or supposedly, physical maturity (you don’t have to do it in behaviour). Many people are reluctant to do so, I don’t know why – I can’t imagine why
you wouldn’t want to see everything available to see, and I can’t imagine why you wouldn’t want to hear everything that’s available to hear. I probably sometimes go a bit low on them, one day I forgot them altogether and that was the best day, the day my class was on their best behaviour because I couldn’t hear anything! No it wasn’t like that, it wasn’t that I couldn’t hear anything but um, yeah it was no good thing because you know, I do like to communicate so my noise might have gone down a little bit, but my communication wasn’t so good.

Sometimes in the staffroom I still find like, we talk across a space of 8 meters sometimes, and we have some people that I find ah, talk as though they are talking to the person next to them in the conversation. I can actually hear ok. It’s probably like a person, like I mean I have glasses, sometimes for the phone book or something like and I can or like the newspaper and I can still read the newspaper and still read the phone. Or well I can’t read the phone book, but so, I can kind of manage but not so well.

So I can actually hear probably about 30, 40 per cent, 30 per cent loss I think it is. So I can actually hear but in terms of the quieter people, it’s just a waste of time really trying to hear what they have to say. But that was just one day, I forgot them, it was kind of crazy really. But I don’t do that very often, so leave my wallet at home, which I don’t do very often, or keys at home, which I don’t do very often, so it’s just one of those things that happened. It was an interesting day in the sense of it gave me a better understanding, a new appreciation of what I have with them, when I have the hearing appliances what I have with them and what I don’t have them when I don’t have them. Yeah, made me realise that I wouldn’t want to be like that all the time,

The work is going well here really. Some people say, because they’re quite out there really, some [of] the girls are very non diplomatic with what they say: “oh you’ve got pretty eyes sir!” You’re not supposed to say anything. But they just do anyway and so they say things like “are you deaf?” and I say “well Zac over there, is he blind?” “No.” “Well he’s got glasses!” “No, that just helps him to see”. So it kind of helps a little bit of understanding I suppose from people here who don’t have much contact with people with hearing aids before. But there's nothing, like I never feel like I’m too old or past it just because I am wearing hearing aids, any more than somebody with glasses might.
It’s wonderful really as a life for me and in personal terms I kind of feel like in the school sense. I like practicing my work. With my students, the year 12s said, “oh give us some maths puns sir”, I was talking at the time simplifying algebra fractions like 5 x over 5 squared or whatever and simplifying them down, and I said, “oh this work is a fraction too much difficult for you guys”, and they went “ha ha, that’s very good sir”. Well that got me through the morning today,

Anyway, this is just my story I guess. For many people it depends on their whole attitude, some people might think oh I’m getting hearing aids which means I’m getting deaf, which means I’m getting older. So they might take it as a winding down kind of thing almost, and some people might think I am getting older so I am winding down so I can’t do so much, but I will. It depends on one’s attitude I guess. I’m always like well I will do what I can and enjoy what I can, forget about what age I’m supposed to be. SO I enjoy having my hearing aids so I can hear better, and hear people, and get better involved.
5.12 George

Well I’m a carpenter by trade and I’ve built, you know, everything from houses through to dams and tunnels, and all that sort of thing, but I did get to the stage where I was probably a wee bit bored to be honest. I think, and you know … the trade is very subject to fluctuation of the economy wise. So I would have work one day and not [the next], and all that sort of stuff. I did have an inclination to teach when I first left school, but I was hopeless at school. Well not hopeless, but I couldn’t really be bothered. Um, so I couldn’t get to training college, so building was ideal for me. I started teaching 1997. [When] I trained I was 47 then, and I’m 63 now but in the interim, just after I started teaching, I knew that I had a faulty heart valve. It was a congenital thing. And it petered out at the age of about 52 I think, so they put the new valve in, which was great – it’s open heart surgery, all the drama! It was really good. It’s been going like a rocket. And then I had the inevitable prostate thing, which is a family thing. Got all that fixed up and then I got another pain in the pinny and it was bowel cancer. So I’m two years out of that now. Since I had the surgery for that, and I got a two year clearance in November um, well it’s about 18 months now isn’t? Um so that’s the size of aliment really.

The valve was probably the easiest part, although it was very painful and I felt so much better after it. Because you get used to something and think you are ok, but when they fix it up you realise how low you were. So that was a real lift, apart from having to have quite a bit of time off to recover, about eight weeks altogether, I think I was back at school and fine and working so that was great. During one of the surgeries, well before they got started fortunately, I had a heart block, this was about, you know, eight years afterwards, just stopped dead. I was completely oblivious; I slept through the whole lot. But they got it cracking again and I got, you know what do you call it? A pacemaker! That’s been quite ok because the results been 100 per cent, and I’ve come back to work, full of beans!

But the tummy thing is not quite so good. They’ve taken a piece out but it doesn’t function properly. So in the early days, you know, I would have to do these mad sprints out of my classroom across the quad you know, flat out! I always had several pairs of underpants and trousers stashed away somewhere. I would say to the girls, who are particularly good at this school, and say “well look I have some photocopying to do”, you know, “I will be back in a couple of minutes, just carry on with what you are doing while I tear out and come back!” And on one occasion I did that and it took me quite a while to get back because I had to do a bit of cleaning up and stuff, and then
come up the stairs went into the room and they hadn’t moved. You know they were still working quietly, and you know I came in and sat down and this voice came from the back “are you alright now Mr. G?” and they knew. They had sussed it all out coz it’s “a small town”. Somebody knew something and although I hadn’t told them they all knew what was going on. So to that extent they were very, very, good. But it was just, ah, the fear of being a smelly old man in front of a whole lot of girls, and all that sort of stuff that I found quite difficult um, and with a bit of medication and a bit of dietary stuff I managed to get that reasonably under control.

I didn’t make a big fuss about it at all. But it was obvious, it must have been fairly obvious, when I was disappearing in to the toilet a lot. Coming up we have to stay the night at the Marae as part of the training. But I won’t be able to stay the night … it would just be awkward for everybody, because I’m up a couple of times, and it’s not very pleasant sometimes. I will have to excuse myself from that, and possibly sometimes like when we have sport or something and we are away from school. I’ve got to suss out where we are to make sure I’ve got an escape route if I need it, that sort of thing. But to all intense purposes, I don’t think the school really realises what's happening.

It is something that is not obvious to outside that’s difficult, because if you are in a wheelchair people at least know what the story is. There are very few men here of course, so there is only one loo and it’s in the middle of the building, so you’ve got to make this dash, you know. But it hasn’t been so bad lately. I’ve managed to find a diet that works reasonably well and it will get better eventually. It just takes time apparently. But my real fear as I say, if I couldn’t have got um, passing wind and stuff under control, I would have had to give up. I couldn’t have stood it, you know I just wouldn’t have liked to be that bloke you know.

Of course, you are not supposed to leave your class, that’s the other thing. If something happens and you’re not there you’re in trouble. So that’s always, always in the back of your mind. That’s the story so far!
5.13 May

There is sort of element to chronic disease that gives you the opportunity to be the centre of attention which is perverse really. But it picks you out as being a little bit special, as different. A lot of people don’t want to talk about it, because it’s an embarrassing disease. People find the thought of having [my problem] disgusting; it’s not something that you talk about in civilised society. I was probably very lucky that I wasn’t diagnosed till I was about 50. The later you are diagnosed the milder the disease is, and my specialist thinks I probably had an underlying condition that, that relates back a long way [but] didn’t actually blow up until I was about 50.

I nearly had to have my colon removed but I think the threat of having my colon removed went some way in telling me to get better or get sufficiently well to go home. I think when you are obviously sick its actually easier for people to be supportive than when you appear for all intense [and] purposes to be perfectly ok and yet, you know … you are having to try and hold yourself and a department together, you can’t keep saying to people, [as] there comes a point where they reach saturation.

I have had a very supportive PR to whom I was able to talk and I think that was great. She was a bit of a mediator as far as I was concerned and we’re still good friends now that I am retired. I think looking back on it, she and I, looking back on it I think, “you were a really good friend and supportive and helpful person to me” and I think I should tell her that sometime, I suppose. When I was teaching I used to have to get up at about half past four in the morning, because that was the only way in which I could let my system sort it’s self out. I have to go to the loo eight times before I could go to work. But if I could do that in in some sort of peaceful environment, I would have breakfast, peaceful and not stressed out, then for the rest of the day I was fine. But it’s hopeless getting me up, and expecting me to, you know, be in the car in half an hour because I will be sick, for the rest [of the day] I would be in a lot of pain.

I was thinking about it yesterday, about the things you were likely to ask, and I wondered why I didn’t do school work. It would have been the obvious thing to do from half past four to half past six and do marking, I didn’t. I sat down and wrote a novel. One of the other side effects of ulcerative colitis is tiredness even when you are well, and I have been well now, basically since I retired, even then you get quite tired. I was absolutely exhausted so it was very difficult for me to do any work in the evening so I used to have to spend my whole Sunday doing school work to keep up.
I stopped being HOD when I was 63 and then I went part-time for a couple of years. Then I did a bit of relieving but that didn’t last very long – I didn’t really enjoy relieving so I finished that. I think I have used up my ability to cope with stress, because I find it difficult with a stressful situation. I think that the elasticity that you have in your system whereby you keep on bouncing back, I think I have used mine up somehow because it doesn’t take very much stress. It is as if I have had so much of it to cope with, that my system says “no thank you”.

In my retirement, I’m really enjoying that I’ve given up on support group but Citizens Advice is really, really good um, I’ve got usually just one shift a week and this week I have two shifts because we are a little bit short-handed. Sometimes we are not busy at all. But it’s stimulating because I am learning heaps of new stuff, every time I learn something new which is great.

You sit at a desk in front of a computer and you field requests and queries from people who just walk in through the door, telephone people and there is always two of you on so that you are safe because occasionally you get nutters coming in. I haven’t encountered one but you get recidivists [who] are forever coming in because they want a bit of company and ah, a bit of ah, reassurance about life I suppose, and that that’s fine. But no, the most common questions are questions about neighbours, neighbours who are a nuisance in one way or another. I spend time meeting lots of different people and ah, and we always have a laugh and so on, it’s a good thing to do. So no, no that’s going very well. I, as I said before I was secretary of the support group, I’ve given that away. I, I felt I had done my dash as far as that was concerned as there was an increasing drive, and quite understandably, to try and recruit lots of younger people. And I began to feel that perhaps my age group was being seen as a little bit redundant as far as the organisation was concerned and I thought, “oh well I don’t have to do this!, I shall move on!” But that’s alright, I mean it’s good to move on and do different things.

I’ve got a new passion, a new involvement. I mean it’s silly,…when I was with my sister, in Derbyshire, I went to a national trust shop and I’ve always been quite interested or thought oh well, one day I will do this, and that was to do a bit of research into the family tree. And I found this book that that gave you thousands of websites really, with comments about them, you know, whether they were free or not, under heaps of headings. [In] other words, a guide to discovering your family tree on the net, which is what I suppose I needed to get started.
Because the stress level has gone, I do think the treatment for ulcerative colitis is better these days but certainly stress is always an element there and um, I am much less stressed than I used to be and that’s one reason I’m so much better than I used to be. I haven’t had a flare up for a few years now. So, which is great yes, I mean it can come back unexpectedly, but also I think I suppose I can manage it better, but part of managing it better is being more relaxed um, and being able to take my time over things and having leisurely mornings.

I do miss very much the companionship and the sort of intellectual stimulus of teaching, but I have, I think, [been] getting used to retirement. It’s quite hard actually. But certainly my ulcerative colitis has been much, much better. I haven’t had a single flare up since my retirement.
5.14 Afterword & Summary

Narratives of the ghosts of lives
Lived away from the recorder
Their faces flicker within the imagination
As they whisper their words;
Hear me.
Hear me.
Listen.

*Listen.* (LJS, 2015)

My poetic turn for this thesis began because I felt that I had not captured participant voices, and in turn their stories, through traditional data representations. Poetry was not an instant answer; tensions still exist. The poem at the beginning of this chapter provides a depth of feeling for the collective experience. I wrote poems in order to evoke empathy and to highlight that the experiences of disabled teachers are isolated. The poem personalises the data for the reader. Mediated through the stories, they provide a space for a multidimensional relationship between participant, researcher, and reader. This is reminiscent of and in line with the goals of narrative as discussed in Chapter 2. I am, am I? “…invites us into the vitality of life, then pulls us out in brave ways.” (Finn, 2010, p. 5).

The larger stories of Abby, Boady, Cleo, Elle, Harry, Gary, George, Kate, Jane, Lilly, May, and Sophie provide a space that moves beyond the “conventions of polite silence” (Mairs as cited in Hershey, 2011, p. 132) and speaks loudly and deeply of their lives. Earlier I described how these stories could “expand our notion of inclusion”. They also expand the way we view teachers, as they provide a varied and rich picture of the lives of teachers with impairments and/or chronic illness. The stories stand as a testament to these teachers’ experiences. They explicitly show what the experiences of teachers living with impairments and/or chronic illness can be like. Their stories then become important vehicles of change: a beginning place for both promoting the understanding of New Zealand teachers with impairments and/or chronic illness, and advocating for change to bring about a new way to conceptualise inclusive education. The following chapter explores these experiences within the framework of emergent themes as described in Chapter 4.
Chapter 6

Cleo
I am a hug,
Something that wraps around and
envelopes
People with care and kindness,
That’s how I see myself as a teacher
That’s how my students see me,
They know they can always come to me
And that I will always care for them
And I will always listen to them
I’m kind first and foremost,
I am a hug.

Jane
I am a gardener
My students are little plants
And it is up to me to feed, water and
shed light on them.
Sometimes, I am not a good gardener
and neglect some plants
Or struggle to give them the specific
food they need to thrive.
Sometimes, I get wonderful results!
I am a gardener.

Kate
Like a mother Duck,
Although serene above the water,
Below I am frantically paddling
furiously
Trying to keep afloat
Leading my ducklings from the front
Showing them how they can navigate
I am urging them from behind,
No duckling is left behind
They get bigger and stronger,
I teach them how to fly,
And they do.

Gary
Grandfatherly
Respect firstly,
Love
Genuine expressions of:
Interest and love
Wisdom and experience

Boady
I am a tree
Steady
Wise
Growing

George
Being a builder,
The whole process:
Beginning with a really good
foundation
Then the vertical aspects of values and
goals
Need to be solid, plum, level, and
square
We can put the roof on with a bit
Of luck at the end of the year

May
Tugboats.
Tugboats can be relied upon,
Trusted to know and do their stuff
Even in the most adverse conditions.
Pushing and pulling, coaxing forces
much bigger than themselves
Sometimes into safe harbour,
sometimes out to face the rigours of the
ocean.
Tugboats often have to go against the
force of the tide,
Sometimes happily go along with it,
depending on their reading of the
situation,
They go about their work efficiently and
enthusiastically.

Illustration 6: Teacher Metaphors (see appendix A)
6.01 Introduction

A key motivation in creating this thesis was to create an understanding about the lives of teachers in New Zealand who live with an impairment and/or chronic illness. The stories in the previous chapter reflect the messy, the complex, everyday doing of the participants’ lived experience. The stories also can be viewed as vehicles for change: by creating a space for understanding them, the actualisation of inclusive education can be better served. In this chapter I use a thematic framework of diagnosis, teaching, and disability to create a space to continue the conversation about their experiences.

In the previous chapter, I kept poetic and narrative texts separate. Although they informed one another, I simply let the stories of Abby, Boady, Cleo, Elle, Harry, Gary, George, Kate, Jane, Lilly, May, and Sophie be told. The structure of these chapters aligns with my theoretical framework (chapter 2). The structure privileges the voices and stories of disabled people. Their stories bring the readers in touch with strangers’ experiences (Geertz, 1972, p.16) in order to create a space for understanding. The emotive poetic text that started the chapter, reflects the arts-based education research practices I have employed in this thesis.

In this chapter, narrative and poetic inquiries again intersect. The poems in this chapter are represented as a series of “I am” poems, beginning with “I am…” which explores diagnosis. Then “I am: never not” which begins the section of teaching, followed by the final poem “I am: able to[o]” which highlights the miss/conceptions of disability. They are again iterative remixes of the interview participants’ stories (Wiebe, 2016). The thematic poems share the same standalone status as the stories and the previous poetic texts. At the same time, the poems provide further glimpses into the complexities, messiness, and lives of New Zealand secondary school teachers with an impairment and/or chronic illness. The poetic texts orientate the themes with the voices and evocative images provided by the interview participants. The poems are also arranged with a lot of white space to allow for reader interpretation (Butler-Kisber, 2002; Cahnmann, 2003; P. Carroll et al., 2011; Foster, 2012; Furman et al., 2006; Lahman et al., 2010). Furthermore, it is important to note that unlike the 12 individual themes described in chapter 4, which sought to show what was different about each narrative, the broader themes used to structure this chapter seek to show what is similar. In other words, it makes visible the collective broader picture.
The three broad themes incorporate and highlight the lived experiences of impairment and disablism. They are purposively expansive. Each reflects a different aspect of my theoretical framework, for example diagnosis views the individual and medicalised aspects of their experiences. This is in keeping with my use of Thomas’s (2007) sociology of disability (see chapter 2). The theme of teaching explores the findings that relate to the individual within the social context of teaching, and the theme of disability which focuses on how the teachers in this thesis conceptualise disability. This is key to understanding how as a community, disabled NZ teachers, can be better served.

Following my analytical framework, the findings also provided the bounded narrative described in chapter 4. The experiences of the participants elucidate and provide insights into the subtle and not so subtle ways in which the New Zealand education system perpetuates exclusionary practices whilst maintaining a rhetoric of classroom inclusion. These teachers’ stories and experiences of living with impairments and/or chronic illness provide a “missing link” for the creation of inclusive education.

Diagnosis stories provide a starting point for exploring the experiences of participants as secondary school teachers in New Zealand. Diagnosis stories explore these connected experiences. Many are situated theoretically as impairment effects, e.g. pain. This theme includes the first aspect of disclosure. A key impact of diagnosis is often the judgement being made about the capacity to work immediately following disclosure of an impairment and/or chronic illness. Building on this theme is the theme of teaching.

Teaching locates the individual in and out of the classroom. The theme explores the impact of institutions. It illuminates how often participants use their bodies as pedagogical tools, the role of empathy, and the pressure to be well/to cope. I used a loose temporal structure across this theme, beginning with “getting into teaching”, then “staying in teaching”, and ending with the stories that talked about retirement in “getting out of teaching”. The temporality of this theme shows how barriers can impact differently at different stages of a teacher’s career.

The final theme, disability, draws on the interconnectedness of teaching and diagnosis in order to explore the wider perspective. In particular it examines how participants perceive themselves. This self examination enables participants to provide counter-narratives to the social model. Interwoven with these three broad types of themes are the reflections of the messiness of the everyday.
These reveal “exclusionary pressures”. It is the every day ‘doing of things’ that makes explicit the wider societal implications. It makes clear the “barriers to doing” and the “barriers to being” (Thomas, 2006). This chapter ends with a discussion about the actualisation of inclusive education. Through understanding the everyday lived experiences of teachers living with impairments and/or chronic illness then perhaps we can envisage the actualisation of inclusive education.
I am...

1. I haven’t known a life any different,
2. I had little tiny glasses, then I graduated to milk bottles
3. Just a bit sick, sort of not *that* sick,
4. Though they didn’t know it
5. The answers were sitting in there, in a big muddy pulp
6. Other people noticed before I did
7. Then I got this pain in my pinny
8. I had to struggle around the classroom
9. Then the threat of having my colon removed
10. I just went down, down, down, down
11. Always in waves; Bad then better; bad then better
12. Sometimes, I want to die, pain; indescribable, horrific, pain.
6.02 Diagnosis

“My body, the body of the teacher is inseparable from the curriculum. Perhaps the body of the teacher is the curriculum” (Orner, 2002 as cited in Jones & Hughes-Decatur, 2012, p. 51).

Diagnosis stories begin the journey of understanding what it is like being a New Zealand secondary school teacher living with impairments and chronic illness. Diagnosis stories start to reveal the deeply inner worlds of teachers and their lives, by moving beyond the pedagogical sites of classrooms. These deeply personal stories about being a teacher living with an impairment and/or chronic illness have no parallel in the literature about disabled teachers. Drawing on the theoretical framework as explored in chapter two, it is possible to view diagnosis stories as stories that can and do speak to the “interrelationship between “the social” and the “biological”” (Thomas, 2007, p. 182). Nowhere is this seen more acutely then when teachers described pain which is discussed later in this theme.

Diagnosis was, for most, a pivotal point in the participants’ lives, often encompassing the path towards and beyond it (Vickers, 2001). For example, Jane’s diagnosis story (p. 106) describes the very day she found out she had Multiple Sclerosis, reliving the fear of that day as she told me. She went on to describe the uncertainty of living with Multiple Sclerosis and carrying the weight of her mortality, in her words:

“It’s forever impacted the way I teach, the way I relate to people, because we’re not, not that I thought I was invincible up until then, but you’re living – you don’t really know, you don’t think I might not see tomorrow or whatever.”

(Jane’s story, p.109)

The opening words of this quote from Jane illustrate Orner’s (2002/2012) point perfectly. Diagnosis, impacts teaching and relationships. Potentially, diagnosis impacts on how impairment and/or chronic illness shapes a teacher’s identity. This sentiment of how an impairment or chronic illness impacts or challenges someone’s worldview was echoed in Gabel’s (2001) participant Christina. Gabel suggested that this was Christina’s turning point and the emergence of a disability identity.

I would suggest that the disabled, impaired, and chronically ill body challenges the status quo in favour of diversity and inclusion. The stories within this thesis confirm the idea that people with an impairment and/or chronic illness are more “adept in the areas of planning and contemplating in order to get the job done than those without” (Vickers, 2001, p. 92). This indeed was true for some of the participants and is
exemplified by the roles that the teachers in this study held at the time of interviewing. For example Harry, Garry, Cleo, Elle, Kate, Jane, and May all held (or had held) Head of Department and/or Dean positions alongside their teaching duties.

Diagnosis stories connect the inner and outer worlds, stories are also characterised by protracted interactions with the medical profession. By definition, diagnosis stories are indicative of the medicalisation of society. Teachers have to interact with medical perspectives whether they want to or not (Connor et al., 2008; Ferri et al., 2005). Interactions with the medical perspectives span both relational and organisational levels. By-storying their diagnosis, teachers interact and inscribe their lives with their specific medical perspective.

A medical diagnosis holds power; it places a name on ‘what is wrong’ (Vickers, 2001) and in doing so, dictates the social acceptability of the condition (Grue, 2016b). Sometimes, because of the institutional disablism people experience, the stigma attached to the label is not socially acceptable as Kate and Elle described in their stories. In fact, Kate replaced hers with a different label, creating a cover story:

I would say I had a migraine, so you know a migraine is you know it’s a condition that people accept as being valid. And what I have is similar to a migraine in some ways, so instead of having to explain the whole chronic fatigue syndrome which requires a large explanation, I would just say that I had migraines. (Kate’s story, p.113)

Kate’s cover story, suggests that some teachers living with impairments and or chronic illness are forced to hide their impairments and/or chronic illness because of the fear of marginalisation or misunderstanding. For teachers, this is innately linked with the school culture and the lack of workplace inclusion. Attitudinal barriers are predominantly the negative and prejudicial perspectives and treatment of disabled employees (Barnes, 2000; Charmaz, 2010; Critten, 2016; Fichten et al., 2012; Hall & McGarrol; Hyde, 1998; Kaye et al., 2011; Krupa, 2011; Madaus et al., 2008; Naraine & Lindsay, 2011).

Teachers in this thesis often felt they had to hide their diagnosis, impairments and/or chronic illness. Disclosure in this thesis has many connotations. In this theme disclosure can be seen as risky, potentially career damaging, and involving judgements of work capacity that can enable either exclusion or inclusion. Employee relationships influence when, where, how, and if someone discloses in particular hidden impairments and/or chronic illness (Charmaz, 2010). Yet, there is a paucity of research about
disclosing an impairment and/or chronic illness across all of the literature about
disabled people’s experiences and working. Vickers (1999) identified the reasons for
and against disclosing. For example, she argued employees need support and seeking
understanding. In terms of not disclosing, Vickers found that employees felt that there
would be a harsh social judgement or discrimination. She further suggested that perhaps
“employers do not want to listen” (p. 247).

The fear of disclosing impairments and chronic illness was briefly touched on in
the research of Ferri et al. (2005) who explored how participants felt that the stigma
around certain “learning disabilities” would impact negatively on their professional
image. In this thesis, Elle found that she gained social acceptability for her symptoms
when she became pregnant, so symptoms like exhaustion or general malaise were
tolerated:

Everyone loves a baby. No one loves endometriosis though everyone loves a
baby. You know, it’s just so much more easy to, you know, if I don’t feel well to
go. Whereas in the past it would have been like, no you just have to tough it out,
get through it kind of thing. (Elle’s story, p. 119)

The extended stories of Kate and Elle in Chapter 5 show the subtler ways the diagnosis
you get can be manifested. In Kate’s story, there is a very explicit feeling that schools
are competitive places and you must maintain a perception of “wellness”. Another
example is found in the survey:

I manage to conceal my illness most of the time except when I first [was
diagnosed] … my new DP thought I was mentally weak … she would have been
happy to ‘get rid of me’ (Survey Participant, Question 11)

The experience of hiding a diagnosis is a direct response to how impairments/chronic
illness is perceived within society (Ferri et al., 2005). With the idea of being “mentally
weak” and the stress of “wellness” and “ability” there is a fear that disabled teachers
will be viewed as unproductive, that they won’t fit in with others, they will cost more,
take more leave or won’t be useful (Vickers, 1999, p. 258). This is a common
misperception that can exacerbate problems. When employees feel they have to conceal
their impairment or chronic illness, they are less likely to seek help and/or modifications
that could potentially support them. (Stanley, Ridley, Harris & Manthorpe, 2011).

Jane and Garry both felt they could tell their school and they feel supported. As
Jane described:
Students and staff alike have always been very supportive and helpful. I have never felt or been made to feel ashamed … to feel bad for having a disability. I don’t know how my experience would be different if I was somewhere else, but I have, I am really blessed with the people I work with, ten years I have been there, they’re beautiful people, they love me and I know that, so it was O.K. I felt safe to tell them. (p.109).

In these stories the participants showed how they directly responded to the socially constructed world in order to live and work in that world. A diagnosis did not just impact directly on the individual. It was also used as a tool others used to judge the extent to which the teacher was socially acceptable, or capable of teaching. Diagnosis became a way to normalise, or to be fitted into a recognisable box. Diagnosis changes people’s perceptions of individuals in terms of ability. As Cleo described: “I had to struggle around the classroom, hobble around on sticks and accept the way that people looked at me differently, for that, both teaching staff and management and students” (p.104). She felt that the visual representation of her once hidden impairment left her as socially changed in the minds of others.

Often, participants in this study described isolation and lack of understanding as FP10 described: “… at times one feels very alone, as it is hard … to understand unless you experience [it]” (Survey participant, Question 15). While isolation can be seen as a feature of chronic illness narratives (Frank, 1998) it is rarely discussed in terms of teachers’ experiences. Diagnosis stories reveal explicit inclusionary measures like support, and exclusionary pressures like judgements on capacity to work. Schools can perpetuate certain images of how a teacher’s body should look and work. Diagnosis stories in this section, are often laden with emotion and nowhere is this more explicit then when participants described pain.

6.03 Pain

Most people with a disability understand that physical pain is an enemy. It hovers over innumerable daily actions, whether the disability is painful itself or the occasion for pain because of the difficulty of navigating one’s environment. The great challenge every day is to manage the body’s pain, to get out of bed in the morning, to overcome the well of pain that rises in the evening, to meet a hundred daily obstacles. (Siebers, 2008, p. 62)

The experience of pain, both physical and emotional has been a unique finding of this research. Despite the fact that pain can be a daily challenge, (Siebers, 2008) the
literature tended to ignore it. In this section, pain is viewed as physical and emotional. Participants’ stories suggest that the experience of pain is isolating and marginalising. A survey participant expressed the views of others when she said: “Initially I was in a great deal of pain as well and I just had to work through that as people didn’t understand that” (Survey participant, Question 9). Interview participants discussed pain in a number of ways from Elle who experienced extreme pain: “Sometimes, I want to die, pain, indescribable, horrific pain” (I am…., p.136); to George who understated the pain associated with bowel cancer as being “a pain in the pinny” (George, p.126); to carrying on teaching despite pain: “You have to push yourself harder every day, when you are in pain or feeling exhausted from pain. You have to push yourself just that much harder to keep going.” (Cleo, p. 103). These are unique insights. Stories that discuss pain and explain how teachers cope with pain while teaching is something that has not been directly discussed in the literature about disabled teachers. Instead pain is situated theoretically as Thomas (2007) concluded her book by calling for disability studies to take responsibility for suffering.

Pain was addressed within the theme of diagnosis because it expresses something that is individual. Pain, both physical and emotional, is often a feature of chronic illness narratives (Frank, 1999; Smith & Sparkes, 2003; Vickers, 2001). Feminist disability scholars like Morris (2014) and Brueggemann et al. (2005) have argued that ‘the personal is political’. When viewed through either a feminist disability or sociological perspective, pain provides a view of the individual within society that enables the status quo to be challenged. Experiences of pain have often been confined to medical perspectives and medical sociology and ignored by disability studies because of their fear of individualising perspectives over the political struggle (Siebers, 2008; Thomas, 2009).

Diagnosis stories and how and why we tell them, reveal the complexities of living with an impairment and/or chronic illness and ways participants and the people around them construct their identities in relation to a diagnosis. Exploring participants’ experiences of diagnosis enables exclusionary ideas like fitness for work to be identified and addressed. Furthermore, ideas that will be addressed in the next chapter, including the role of empathy, and the use of the disabled body as a pedagogical tool, have their origins in diagnosis stories. Diagnosis stories can become a platform from which to view other experiences.
**I am: never not**

1. I’m an advocate for my students
2. Communication with students was becoming problematic
3. That fear: The fear of being a smelly old person
4. Embarrassed, it was ruining my career
5. I needed the support but kept saying “keep away” because I can do the job
6. Looking sick: Its easier for people to be supportive
7. So we do what we need to do in order to survive
8. Tutoring here and there but it’s all about passing exams
9. Meetings: before school, after school, meet students in the lunchtime
10. And sometimes I think you know - should I be bothered?
11. I don’t know if teaching is something I see myself as doing forever
12. In a place where you are *never not*: working, teaching or thinking about that student
6.04 Teaching

The theme ‘teaching’ is large. I have divided it into three smaller subsections. These subsections reflect the narrative anthology’s temporal construction: getting into, staying in, and getting out. Stories in this study suggest that teachers’ identities shift and move within and beyond the classroom as well as between personal and professional spaces.

In terms of this study, teacher identity is viewed as socially and narratively constructed. Narrative construction of identity posits that an individual’s identity is constructed through the stories we tell, and through these stories we come to know our social world (see Clandinin & Connelly, 2000; Somers, 1994). Narrative identity incorporates temporality, which recognises identity shifts and changes over time. Narrative identity allows then, for the location of a multiple changing identity, through time.

Using social and narrative constructions together provides a perspective that allows for micro-macro connection. The social construction of identity views identity in macro terms (Ehala, 2018), whereas a narrative construction of identity sees the shaping and reshaping of identity in terms of what stories are told, by whom, and to whom. This is important when considering teachers as individuals within the broader context of schools and teaching.

Teaching too is a “socially situated practice that [is] deeply embedded in the emotional experience” (O’Connor, 2008). In previous research, professional identities for teachers have focused on “concepts of self”, teachers’ roles, and relationships (Beijaard et al., 2004). Teacher identity can be also be seen as a fluid and ongoing process of integrating the personal and professional sides of becoming and being a teacher. The broad literature surrounding teaching identities suggests that these identities are complex and relational (O’Connor, 2008). As with other studies, the stories that participants told reflect a ‘personal commitment to their profession’ (O’Connor, 2008, p. 118).

Professional identity is “not something you have, but something you use in order to make sense of themselves as teachers” (Beijjard et al., 2004, p. 123). The sense making of Abby, Boady, Cleo, Elle, Harry, Gary, George, Kate, Jane, Lilly, May, and Sophie in the “teaching” theme show how the “barriers to being” and “doing” change over time, from getting into teaching, staying in teaching, and finally getting out of
teaching. The theme of teaching also makes visible those moments of disablism, where teachers come into contact with the school as both a community and an institution.

6.05 Getting into teaching.

“When I was young I had this idealistic attitude that I wanted to be a teacher and that’s what I wanted to do. I enjoy teaching, I love the kids.” (Lilly, p. 106)

Getting into teaching and being a preservice teacher are the most widely covered aspects of disabled teachers’ experiences. The challenge of getting into teaching highlights the impact of attitudinal barriers (McKay, Ballard & Smith, 2000). Within the literature, it is also the most discussed aspect of teachers living with impairments and/or chronic illness. To a lesser extent the transition of disabled tertiary students into jobs is addressed (Gillies, 2012; Gillies & Pedlar, 2003). Transition into work is a focus of New Zealand policies like the Disability Action Plan, but it remains a problem for disabled teachers.

Abby’s story provides an insight into life after tertiary education, living as a qualified teacher and seeking work. The application process provided the first barrier. Abby’s experience highlights challenges potential applicants face before they can even be selected for an interview. A major difficulty Abby faced related in the use of “may”.

They use the word MAY. Do you have an impairment, disability impairment, long-term medical condition that MAY affect your ability to carry out this job? Well the fact is that I do, MAY, I always circle that as well and I try and answer it in such a way that you know I manage my condition well, and I have been throughout my entire educational career as a student (Abby, pp 97-98).

Use of terminology like this is part of a wider ingrained and institutionalised discriminatory practice that is enabled by key employment policies and documents.

Abby’s story highlights a problem for disabled postgraduate students who, as Gillies (2012) explained, lack access to “meaningful employment” after graduating. Participants in other international studies have also noted such practices (Critten, 2016). Indeed, participants in Critten’s 2016 study found that if they did get an interview it was an empty token gesture.

Although to many teaching is a calling, it is also wrong to assume that everyone felt that it was. Some participants had not set out wanting to teach.

I got caught up on that dream of educational movement, and I was good at it, but I was good at everything, I just wasn’t allowed to do what I wanted to do….

Then I went through Uni. I did a B.Ed. degree thinking I would go into the
mission field and work with poor people and stuff, so it was a bit of a surprise to end up in teaching because it was not my dream (Sophie, p. 101).

Sophie, described being swept up in the “education wave” after wanting to become a missionary or a pilot, finding her path blocked because of her impairment. The experience in getting into teaching is not a homogenous one. Sophie’s story suggests that teaching can be used to funnel disabled people away from other careers that they would otherwise seek. Teaching in this sense could be thought of as more socially acceptable than some other careers for people with some kinds of impairments and/or chronic illness.

Becoming a teacher can also be viewed as a life changing event. George had wanted to be a teacher when he was younger, but believed his school grades disqualified him, so he trained as a carpenter. With the carpentry qualification to support his application, and motivated by economic pressures, he retrained to become a teacher when he was 47:

Well I’m a carpenter by trade and I’ve built, you know, everything from houses through to dams and tunnels, and all that sort of thing, but I did get to the stage where I was probably a wee bit bored to be honest. I think, and you know … the trade is very subject to fluctuation of the economy wise. … I did have an inclination to teach when I first left school, but I was hopeless at school. Well not hopeless, but I couldn’t really be bothered. Um, so I couldn’t get to training college, so building was ideal for me. I started teaching 1997. [When] I trained, I was 47 then, and I’m 63 now (George, p 126).

Economic stability was also important for Harry. However, he described how he was expected to go into secondary school teaching and not primary, where his true passion lay. He found that in a female dominated profession, men, especially men who did not fit the socially constructed heteronormative vision of masculinity, were scrutinised more. The intersection of disability and gender is not often discussed in research especially surrounding disabled teachers (Meekosha, 2006), and is deserving of more attention. Harry described himself as “fairly dramatic”, and believed that his dramatic tendencies, combined with his disability and his then single status (unmarried), would have put him under the microscope had he applied for primary teaching, a career he saw as suspicious of males.

I’d been put off by the fact that men kind of had, were fairly persecuted in the education [system], or certainly a lot of men had the magnifying glass on them. And because I was … fairly dramatic I didn’t feel the need to draw any more
attention to myself by becoming a teacher. Crazy thing is now that I am married and I have a family, I’m perceived to be acceptable, you know. But hang on – if I was a bad in the first place, I’m no different now that I am married! (Harry, p. 115)

The engendered traditional roles and responsibilities can be an extra ‘barrier to being’ and ‘doing’ for those who do not ‘fit the mould’ of traditional gender stereotypes of atypical heteronormative male/female binaries. Research that includes the intersection of gender and disability remains a challenge for disability studies, as noted by Banks (2015) in relation to feminist disability studies (Banks, 2015). In this thesis, I recognise considerations of gender are integral to the goal of inclusivity and diversity (Gunn et al., 2011). The next section explores the experiences of being a teacher.

6.06 Being a [disabled] teacher.

The research has described disabled teachers as potential exemplars of inclusion. This was related to their ability to empathise and promote empowerment, and it was explained by their shared experiences (Compton, 1997; Brueggemann et al., 2005; Brueggemann & Moddelmog, 2002; Brueggemann et al., 2001). I started this theme with ideas and concepts from the literature about what makes a good teacher. The teachers in this study have articulated many of those qualities, but additionally they articulated the fear of being/becoming burdens. Participants’ teaching experiences often focused on how “they” could be inclusive, using their bodies and minds as what Brugemann et al (2001) described as pedagogical tools, incorporating their bodies into the curriculum in subtle ways. Their experiences highlight their resilience in the face of challenges and barriers. With a slightly ‘tongue-in-cheek’ attitude Boady claimed that she was not a good teacher, and yet she went on to describe empathy and patience as key to her teaching:

… I am very patient, because of all the things that I’ve had wrong with [me], I think that helps on that level, but I’m not a very good teacher unfortunately. I’m better than some possibly but, I yeah, I try and do my bit. I’m quite conscientious so that’s good (Boady, p.120).

Empathy, though little explored, is often discussed by disabled teachers as part of their teaching practice and teaching identity (Burns, 2015; Glazzard & Dale, 2013). Participants in this study described a variety of ways life experiences were used as a tool to develop their understanding of others, and also to grow empathy. In the words of Abby:
My experiences in life perhaps put me in a different place to some other teacher. So, it’s kinda obvious that things in my life, have well, haven’t always been easy. So, I think sometimes it helps students, particularly teenagers … I just think it perhaps removes one barrier possibly to students’ interactions (Abby, p. 97).

Cleo agreed that having an impairment contributed to her understanding of her students, but she added that the trust and respect that developed through empathy made her an advocate for her students.

The students don’t perceive me as being as daunting to approach as some teacher might be. Some of the feedback I have from them is that I’m understanding and that they feel they can tell me anything or come to me about anything … that’s beneficial obviously, because I can build a better relationship with those students and that can be exceedingly beneficial both for them and myself. I’m an advocate for my students’ needs, um, they know that I respect them. … There’s a mutual respect and trust between us (Cleo, p. 104)

Harry also agreed empathy was experience based. He reiterated that some issues, for example depression, were easier to address when they had been experienced.

I’ve had some sort of experience with it and you can relate with kids because you know how they are, how they feel – then why wouldn’t you empathise? Why wouldn’t you talk to them? (Harry, p.116)

Gary added that his impairment enabled him to be a role model for students with similar impairments.

I think it’s quite good, and in fact some of the students that I most connect with are those that wear the hearing appliances too. I think it’s nice for them to see, like some people, some students might have that encouragement from having a teacher that has hearing aids (Gary, p.123).

Empathy then is a key to promoting inclusive education. Yet as Lilly’s narrative demonstrated, teachers’ experiences are not homogeneous. Lilly, described and challenged the perception that a teacher with an impairment and/or chronic illness could necessarily identify with all students’ who have impairments. Describing her classroom as being a “dumping ground” for disabled students because of her sight impairment, she argued that those students were “not like her”.

Furthermore, there is no guarantee that the building of empathetic relationships with students, based on a shared experience, will be tolerated by school management as
survey participant FP15 found. FP15 was told to no longer discuss depression with students.

I have been categorically told not to disclose that I have and do suffer depression to students. I had a student with whom I had built a great teacher/student relationship as well as coaching them in sport, who was seriously depressed and hospitalised. I empathised and we talked about our experiences. When the student returned to school, our conversation got back to the management team and I was told not to discuss it (FP15, Question 14.)

A teacher is likely to be more willing to use his or her experience of impairment or chronic illness as a base for empathetic relationship building if s/he believes the impairment and/or chronic illness is socially acceptable. Elle felt the social stigma associated with her chronic illness made it harder to talk about, but she pointed out she made the effort if she thought talking about it would help a particular student.

If I have known a girl that has been diagnosed with the same condition, [and] if I think that it will help them to have someone to talk to then I do. Depression is a bit more acceptable to talk about, so I’ve been someone that they can talk to about that, that’s one thing I’m really open about (Elle, p.117).

The literature describes empathy building as a key process in broadening inclusion (Glazzard & Dale, 2013). It helps decrease the feelings of isolation that students may face. They will know they are not alone. The ability of the teacher to disclose is indicative of the status of inclusion within the workplace environment. Sometimes, as in Garry’s story, the pedagogical “teachable” moment happens at a staff level as well as a student one. Garry talked about his hearing aids with students, about reducing the stigma attached to deafness and he explained how he continued the discussion with his colleagues. In this positive role, Garry was able to encourage and promote acceptance of hearing impairments, and this was viewed as a benefit to others.

However, as Sophie pointed out “teenagers can be pretty brutal” and in a non-inclusive environment, disclosure can exacerbate exclusion. For participants like Elle, fear of reprisal means disclosure is not something she does:

I don’t share with my students because I don’t want them going home and telling their parents and them saying “oh she shouldn’t be in front of my child!” You know because of the whole misunderstanding around it. You know, and it might be fine, but it might also be not fine. It doesn’t really effect my teaching, well I don’t let it affect my teaching too much (Kate, p 117).
Kate’s fear of parents’ rejection of her as a teacher was realised by Sophie when she was told not only by parents but also by a student, that because she was deaf she should not be teaching. Sophie’s story shows that attitudinal barriers in schools come from staff, students, and parents.

Despite the challenges outlined above, and the danger associated with the idea that all disabled teachers will automatically be able to teach all disabled students, caring and empathy have been identified as important characteristics of effective teachers that promote inclusive practices (Glazzard & Dale, 2013). Yet, “caring” and empathy are often overlooked in the research regarding disabled teachers (Burns & Bell, 2011; Riddick, 2003; Vogel & Sharoni, 2011). The stories told in this thesis show that teachers placed importance on the role of their impairment/chronic illness, whether they disclosed it or not, in helping or aiding in building and maintaining their relationships with students, especially when it came to empathy. Empathy therefore, was regarded by participants as an important if not unique skill that they brought to their teaching practices because of their own experiences with impairments and/or chronic illness.

Often empathy is considered to go hand in hand with low expectations. This idea was debunked by Riddick (2003) whose study showed that disabled teachers held high expectations for themselves and their students. Similarly, in my research, teachers like Cleo empathised with her students, but also advocated for her students who were also living with impairments and/or chronic illness. An empathetic stance often takes the form of using their bodies – impairments and/or chronic illness – as pedagogical tools (Brugeman 2001; Compton, 1997).

Teachers who used their impairments/chronic illness as a pedagogical, advocacy or relationship building tool, found that it was important too, for the teacher-student relationship. This can be compared to the stigma (discussed in the previous theme of diagnosis) that participants experienced from their colleagues and management. This finding isn’t surprising when the discourse of inclusion has been so focused on classroom inclusion rather than school-wide/community inclusion (Biklen, 2000; Carrington & Brownlee, 2001). Because teachers are considered as the transmitters of inclusion and not the recipients of inclusive workplaces, disabled teachers can be left feeling isolated. The role of disabled teachers in bringing about inclusive education needs to be addressed holistically, beyond the classroom. They need to be supported so that the sole onus is not on them to adapt in order to remain teaching.
6.07 Accommodations & resilience.

There has often been a focus on what accommodations/adaptations employers have to make in order to hire or maintain disabled staff. However, there has been very little recognition of the (personal/physical) adaptations that some teachers have to go through to adapt to the school and to continue to teach. The motivation for these adaptations are twofold. Firstly adaptation could be viewed as a resilience and self-efficacy strategy (Burns et al, 2013). Secondly, teachers are often motivated to make these adaptations for fear of being a burden to their school. Sophie described needing and getting cochlear implants to continue to teach as her hearing aids were no longer effective. She personally raised the money to get a second one because only one is government funded. Interestingly, Sophie’s experiences can be directly contrasted with the study of Deaf teachers conducted by Burns & Bell (2010) where teachers went through a special education system and went to teach back into a special education system. The participants in Burns & Bell’s (2010) study were able to use sign language and did not have to have the surgery. Sophie is a mainstream teacher, teaching hearing students and working in a hearing workplace. Sophie grew up with her hearing impairment when oralism was the primary education method (see Appendix D). Therefore, she was discouraged from learning any form of sign in favour of lip reading and vocalisation. Despite the cochlear implant, she still preferred to lip read rather than force herself to hear (Personal Communication, 2014). Lip reading can be practical for one on one situations but with a class she needed to hear multiple voices at once and therefore was motivated by her teaching career, to get the implants. However, Sophie like Cleo expressed worry about taking time off work to have surgeries. Both participants went out of their way to make physical accomodations including getting cochlear implants and having surgeries in holiday times. Feelings of being a burden often directly related to feeling unsupported, for example Cleo:

Then there was choosing the right time to actually get my issues, my health issues sorted. I never felt that I could take school time off to do it, so I would do a lot of them in the school holidays to be the least inconvenience to the school as [I] can possibly manage. (Cleo, p.104)

9 In New Zealand only one cochlear implant is funded for adults see here for further information http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/hearing-and-vision-services/hearing-services/cochlear-implants.
Research on employment has found that employers are scared of hiring disabled people due to their being perceived as a burden (Bray, 2003; Brown, Hamner, Foley, & Woodring, 2009; Woodley & Metzger, 2012). Although in New Zealand through schemes like “Disability Confident” (2016/2017) there has been a concerted effort to ‘educate’ general employers about hiring disabled staff, there is no particular programme that is targeted for the education profession. This could be beneficial because tertiary institutions have the potential to drive inclusive education both through being an inclusive model and through school practices.

Being considered a burden to the school is a concept touched on by participants in Rieser’s (2008) survey, although it is not fully explored. In my study, there was a pattern where teachers who needed medical help put it off until school holidays. This was inspired by several reasons including loyalty to the school, feeling unsupported by the school, and feeling that the school saw them as a burden. Fear of being seen as a burden motivated teachers in this study to prove to their school that they could do better than other staff, and overcome any perceived weakness. For example Lilly said: “I have always had a strong will to succeed and to prove myself. It’s a bit of a battle … it never use[d] to be but it’s getting harder as I get older.” (Lilly, p. 106). Other participants like Kate and Cleo noted that they either “box on” (Kate, p112) or “push through” (Cleo, p. 104).

The stories within this research add to the body of knowledge about the relationships of teacher-student, teacher-parent and teacher-staff. Boady voiced the experiences of most participants when she stated: “sometimes relationships between the adults is not great …”. In this study there have been stories of bullying. For instance, survey and interview participants, FP2, FP13, Boady, Cleo, and Lilly (not the same people) described discrimination and institutionalised bullying. Cleo spoke of the systemic bullying that she received from her head of department who was complicit in inciting a “mobbing” atmosphere against her (Vickers, 2001).

My head of department just looks at me like I’m a liability rather than an asset. And yet I’m still doing … a huge proportion of the work, both in the department and out of the department, with parents and students. I’m drawing students to the school because of what I offer. I’m putting on all of those extras that I always have so that the students are getting a lot of extracurricular activities. I’m still teaching valid subjects that allow the kids to achieve achievement standards. I don’t get any help around classroom comforts or conditions. There's no
compromise or effort to even help in any way what so ever, it’s more like “oh
good if she’s unwell and she’s got problems maybe she will leave sooner!”
(Cleo, p. 105).
Cleo reported the “vindictive” attitudes of people in middle management. Similarly,
FP2 described destructive attitudes of people in middle management following a major
depressive period, and FP13 described the loss of her “mana and dignity” as she was
made to go through unnecessary processes to “prove” her capacity as a teacher.
Bullying was not just confined to management or staff. Sophie described being bullied
by students and parents who believed her unable to teach because she was deaf.
However, despite having sometimes considered leaving, teachers in this study persisted
even when faced with this type of institutional bullying. The teaching experiences of
bullying by staff, students, and parents highlights an aspect of school culture that has
not yet been described in the literature about disabled teachers. Bullying is a truly silent
issue that needs to be explored in more detail.

Other hidden stories include those that describe mental health. These featured
across interview and survey participants. For participants like FP15, Elle, Kate, Harry,
and Jane, mental health stories involved depression. New Zealand employers are scared
to employ people with certain impairment and/or chronic illness, citing mental health as
one (Woodley & Metzger, 2012). Depression as Elle said, is easier to talk about than
some other impairments and/or chronic illnesses but is still largely an invisible aspect of
disabled teachers’ experiences.

The title of this thesis is All the Little Things. It comes from some of the
participants describing how it is not one “big” thing that makes their lives either easier
or more difficult, or that creates barriers or takes them down, it is the little things. These
can increase the pressure and work load. Teachers living with impairments and/or
chronic illness have shown resilience in the face of all these little things. Burns et al.
(2013) maintained that key resilience strategies included the time, effort, and resources
that disabled teachers drew on to teach successfully.
In this study, participants’ resilience strategies span the day, from the moment
they woke up, to the moment they went to sleep. May explained that when she was
working she would have to get up at half past 4 in the morning to cycle through her
daily routine before she went to school:

…because that was the only way in which I could let my system sort it’s self
out. I have to go to the loo eight times before I could go to work. But if I could
do that in in some sort of peaceful environment, I would have breakfast, peaceful and not stressed out, then for the rest of the day I was fine. But it’s hopeless getting me up, and expecting me to, you know, be in the car in half an hour because I will be sick, for the rest [of the day] I would be in a lot of pain (May, p.128).

Teachers in this study, including those who only participated in the survey, had to show resilience in order to work and adapt. Many had been sustaining severe routines for years without support. Yet, when something happened that led to them feeling as though they were burdens to their school, they spoke about leaving. The next section of Teaching examines teachers leaving their employment.

6.08 Getting out.

“You are never not a teacher.” Jane’s words that ended the opening poem embody the physical and emotional responsibilities that are placed on a teacher. They also reiterate how deeply ingrained a teacher’s identity is in their everyday lives. There are many reasons why teachers may decide to leave teaching, including discrimination, the impact of impairment and/or chronic illness, and the growing demands of teaching as exemplified by Jane in the previous poem.

Elle, Jane, May, Boady, and Cleo all talked about the impact of their impairment and how the pressures of the schooling environment, coupled with impairment effects, led them to question continuing as a teacher. In this study FP15, Boady, Elle, Harry, Kate, May, and Cleo all described wanting to leave teaching or they did leave teaching. At the time of telling her story, Jane had not left school, but it was clearly on her mind. In 2014 she left her school to take up a “conventional” 9 to 5 job to allow her some time with her children before the degenerative effects of Multiple Sclerosis took hold (Personal communication, 2014).

The idea of a “conventional” job was also on the mind of FP5, Harry & Boady. FP5 described how her life had “become small” revolving around school. With that came a sense of managing and just coping with workloads. FP15 talked about wanting to give up. These stories speak to the stresses of teaching. Kate for example, talked about the lack of downtime:

Our schools, they don’t help in a lot of ways, in that there are constant meetings, meetings before school, meetings after school, things are programmed in lunch time, to meet students in the lunchtime. There's very little um, downtime. A lot
of the time very little recuperation between, you know, teaching. I enjoy the teaching. I always enjoy the teaching. (Kate, p. 114)

Flexible work environments are a key diversity issue in the literature about employment (EEO Trust, 2015). FP10 described no longer having the flexibility in her non-contact times to manage her impairment/chronic illness by having a rest. Teachers’ non-contact periods have the potential to provide a flexible time for teachers if they are supported to use them to address their particular needs.

Finally, the relief of retirement. May’s story emphasizes the positives and negatives of retirement:

I do miss very much the companionship and the sort of intellectual stimulus of teaching, but I have, I think, [been] getting used to retirement. It’s quite hard actually. But certainly my ulcerative colitis has been much, much better. I haven’t had a single flare up since my retirement (May, p.127).

At the time of interviewing, May was the only retired teacher. She described initial difficulties giving up her teacher identity. However, she also recorded the positive; the impact of retirement on her physical wellness. This suggests that for teachers to remain, there needs to be an organisational change in how they are expected to teach.

The temporal structure of this theme was designed to highlight the barriers to being and doing for disabled teachers. Teaching as a theme has reflected the discriminatory practices that meant teachers could not find work or they were funneled into areas of teaching they didn’t wish to go. It encapsulated ideas of bullying, being seen as a burden, the role of empathy, exclusionary attitudes, support, resilience, and accommodations made by disabled teachers in order to stay teaching. These are all part of the experiences of New Zealand secondary teachers living with impairments and/or chronic illness.
I am: able to[o].

1. You spend a great deal of time hiding your disabilities or your impairments
2. You don’t want to be seen as having a disability; you want to be just fine
3. It picks you out as being a little bit special, as different
4. Some people have a bit of a stigma
5. A lot of people still think that I’m not disabled
6. If you are in a wheelchair people at least know what the story is
7. You’ve just got to roll with the punches and do the best with what you’ve got
8. I can’t say how different I would be if I was a healthy person
9. I manage my condition well
10. I don’t like to regard myself as having a disability
11. I would describe it as debilitating or that
12. I am NOT DISABLED, I have ABILITIES!
6.09 Disability

Don’t knock someone off because they have a disability and don’t put limits on them because they can be very wrong. Let the person prove, let them be who they are, and let them come up with solutions to overcome their disability in the situation. They can bring a unique side to education …some of the things they have to do a little differently but it doesn’t mean they can’t teach! (Sophie, p.103)

Thomas (2007) called for disability research to attend to and indeed prioritise the experiences of social exclusion, discrimination and marginalisation and institutional disabling. This theme begins to explore how participants viewed themselves within the institutional disabling of schools with the view to the actualisation of inclusive education. Gabel (2001) identified in disabled pre-service teachers, the emergence of teacher and disabled identities. As current research predominately focuses on non-disabled preservice teachers’ views of disability, it is important to consider how disabled teachers perceive themselves. What disability meant to the participants can be seen in their stories. They spoke of how they viewed themselves not only as teachers, but as disabled (or not). Their disabled identity directly impacted on how they built relationships with students and colleagues.

For many, teaching was a calling. This could explain why, for participants in this study, their teaching identity was deeply ingrained. However, as noted earlier, participants struggled with their emerging disabled identity. The concept of disability is complex and multi-faceted. Conceptually it has been positioned within disability studies and disability studies in education, using the sociological position of Thomas (2007). Disability in this sense is a social oppression which includes barriers to doing and barriers to being. There is tension in incorporating chronic illness within the disability conversation, however, like Thomas (2007) I believe we need to acknowledge the barriers to doing and being that can come with chronic illnesses. Mental health, like chronic illness, has also often been left out of the disability conversation. Incorporating chronic illness and mental health into the impairment spectrum enables a comprehensive view of disability, one that reaches well beyond visible physical impairments. Alongside these ideas also runs their antithesis, of happiness and fleshy embodiments, and lives that are, no matter how different, full of wonder (Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015). They speak to the complexities of
defining disability within this thesis. It has been a key concern of mine not to
essentialise or focus purely on the negative aspects of impairment.

In this study, it has been harder for people with chronic illnesses to consider that
they have or could be socially oppressed in the same way a person in a wheelchair
might be. Harry for instance commented: “I don’t like to regard myself as having a
disability” (Harry, p.115). Participants with chronic illnesses sometimes talked about
themselves as being sick for example, Boady who said:

… I’ve been sick since I was a baby so I was treated like a sick person when I
was growing up, I’ve always felt sick and sometimes I had been really sick if
you know what I mean. So I can’t say how different I would be if I was a
healthy person (Boady, p. 120)

This can be compared with Abby’s statement about disability:

I’ve had a disability now for most of my life, and so I don’t really have any
memory of not being the way I am. So, it has very much coloured the way I see
the world and how I experience things differently (Abby, p. 97).

The emergence of a disabled teacher identity is often associated with participants
feeling isolated and alone. This was highlighted by comments made to me when
participants learned that they were not the only ones being interviewed. They often
responded with comments like, “I thought it was only me”. There is little recognition in
the literature that the social and cultural effects of impairment and/or chronic illness can
be “a political and cultural identity – one that is shared by others” (Yoshida &
Shanouda, 2015, p. 443). There is, a need for collaboration and education to help “break
the silence” and allow for “collective understandings and social change” (Yoshida &
Sanouda, 2015, p. 443). The stories and poetic texts explored in this thesis identify
understandings and experiences common to all participants. They are not alone.

Within each participant’s story there is a development of a disabled teacher
identity. Even if they did not disclose their impairment or chronic illness, each teacher
at some point felt that it helped their teaching by enabling them to take an empathetic
stance with their students (see the previous theme). Like the teacher activists described
by Burns and Bell (2010), these teachers often used their own personal struggles to
provide insight into the lives of their students. They felt that their impairment/chronic
illness gave them a unique perspective, and one that could not be replicated by teachers
who had not had similar experiences. Despite being separated by geography and
impairment/chronic illness, they all held this idea, which suggests that it contributes to a distinct disabled teacher identity. They are not alone.

Furthermore, the participants in this project reinforced Shakespeare’s (2009) view of disability, that it is not all defining and always horrific, and that lives are ordinary and messy. Abby for instance, acknowledged major challenges, but rejected doom and gloom:

You know, most of my days consist of reading or finding other activities to keep my mind ticking over, just being content. Just taking it as it comes. There's no point in getting down about those things. Yeah, just see what's around the corner, you never know! (Abby, p. 99)

Bolt’s (2015) article, discussed the role of happiness, and likewise Thomas (1999) and Shakespeare (2009) warned against essentialising the negative, depressive, doom and gloom aspects of living with an impairment and/or chronic illness. Sunderland, Catalano and Kendall (2009) reminded disability researchers that we should not silence the “full spectrum of human aspiration” (p. 713). Researchers such as Bolt (2015), critique disability literature and theorising, for linking disability to unhappiness.

The stories of Abby, Boady, Cleo, Elle, Garry, George, Harry, Jane, Kate, Lilly, May and Sophie are entwined with not necessarily big moments of happiness, but rather the everyday happiness. Their:

... bodies are moving, speaking, interacting in particular ways produce social spaces. Sometimes, the spaces produced are racist, sexist, misogynist, exclusionary, and oppressive, but when individuals work their own bodies as a site for self-transformation, they can move, speak, and interact differently and produce new social spaces – perhaps inclusion, acceptance and power. (Jones & Hughes-Decatur, 2012, p. 52)

Some teachers in this project were reluctant to use the disability label because of the connotations of ‘less than’ or ‘lacking’. They sought to reject the normalisation of their bodies (Morton et al; Young, 2014). They were not waiting to be cured (Savarese, 2009). They were living, teaching, doing, and being. Happiness happens: it happens both beyond and within the disabling interactions of society. Jane even considered her MS a blessing:

I think it’s that when you have a disability and you are aware of the fact that you’re not going to live forever; other people think they are, don’t they? They
think that they are invincible. It’s a real blessing because you look at life so different (Jane, p.109).

The lived experiences of teachers with impairments and/or chronic illness, explored in this thesis are stories of struggle, of pain, and of happiness, of everydayness, of living. They signify that the disabled body is “not” one that should be just accommodated. It should also be valued. It has much to teach us. “People with disabilities challenge our notions of what a classroom should look and feel like (Anderson, 2007, p. 374). I would go further and say that disabled teachers and employees challenge our notions of what workplace environment should look and feel like.

There is a danger however, that this research could be turned into inspiration porn where the lives of Abby, Boady, Cleo, Elle, Harry, Gary, George, Kate, Jane, Lilly, May, and Sophie are held up as something “other”. Teachers that have gone before have, some secretly, eked out their teaching careers, normalising their bodies and their minds. They have adapted to the spaces, and changed their ways of being and doing in such a way that personal is not so much political, it is simply personal (Oliver, 1996). So:

Perhaps it is time to refuse to shut down the world that disability metaphor is ready to open for us and attempt to straddle disability by understanding it as a way of being that could incite a critical imagination (Titchkosky, 2015, p. 16 emphasis added)

It may be time to “incite a critical imagination”, to celebrate a different but equally valid “way of being” to be included, valued, and accepted. As Anderson (2006) suggested: “More stories must be told by people with disabilities inside pedagogical spaces. Teachers with disabilities offer “bodies of possibility” that interrogate and transform the spaces of academe” (p. 378). There is the potential that through the stories here of diagnosis, teaching, and disability we can grasp the “bodies of possibility” and begin to change the organisational structures and relationships that are disabling. And by doing so, realising the actualisation of inclusive education.

6.10 The Actualisation of Inclusive Education

The themes within this chapter have shown, there are many barriers to doing and being for a teacher living with impairments and/or chronic illness. Aspects of teachers’ lives explored in this thesis have highlighted accommodations that could foster inclusive workplaces. They include support and acceptance, and also show that some accommodations bring benefits to all staff. For instance, Lilly spoke of
Accommodations being introduced as an across school initiative, (forms in large print), and others benefitting. As noted earlier, inclusionary measures and exclusionary pressures often made up ‘all the little things’ that participants were faced with every day. Exclusionary pressures were predominantly attitudinal. They included: stigma, isolation, questioning ability and presumptions of inability because of impairment and/or chronic illness. These went hand and in hand with institutional barriers including forced disclosure, inflexible non-contact times, and high workloads. This is consistent with the literature that had previously identified attitudinal and institutional barriers as being key to disabled teachers’ exclusion and preservice and tertiary students’ experiences (Anderson, 2006; Charmaz, 2002, 2010; Gabel, 2001; Gebrehiwot, 2015; Glazzard & Dale, 2013, 2015). The focus now needs to be on how to create awareness and shift perspectives in inclusive education beyond classroom inclusion. Support and acceptance should be the foundation of any workplace.

International literature about disabled teachers’ experiences in schools emphasises how the presence of disabled teachers in schools promotes inclusion (Anderson, Keller, & Karp, 1998; Officer, 2009; Rieser, 2008). It does not explore schools as a potential site for discriminatory practices. Therein lies the problem. Research has focused on what disabled teachers can do for schools, but neglected what schools can and should do for disabled teachers. This change of perspective is crucial for the actualisation of inclusive education. As Glazzard & Dale (2013) argued, inclusion that is purely student-in-classroom centred, that ignores staff, parents, and the school community, is not inclusion. Inclusive education has been identified in government documents (DAP 2014-2018; NZDS, 2001/2016) as being integral in achieving increased employment of disabled people. This is unquestionably woven into the overall vision of equal rights for New Zealand Citizens. Educational inclusion is also linked with transition into paid work. Making explicit, potential inclusionary measures and exclusionary pressures, is another step towards the actualisation of inclusion.

Who should be responsible for the actualisation of inclusion? For disabled students, the literature points to the classroom teachers (Alghazo, Dodeen, & Algaryouti, 2003; Carroll et al., 2003; Rutherford et al., 2015; Shippen et al., 2005). For workplace environment, the literature points to employers (Charmaz, 2010; Critten, 2016; Fichten et al., 2012; Hyde, 1998; Kaye et al., 2011; Krupa, 2011; Madaus et al., 2008; Naraine & Lindsay, 2011). Finally, for the employer, the literature points to
government policies. It would seem that at every stage, from the government to the classroom and vice versa, there is a responsibility that everyone should reflect inclusive practices.

At an organisational level, there are those who are meant to be held accountable for the inclusion of all staff (the employer). Inclusion within schools must have buy-in from all stakeholders at all levels, beyond lip service, beyond the classroom, and beyond physical environments. The actualisation of inclusive education requires meaning making, resources, and a cultural shift within schools, one that privileges the disability community including disabled teachers and their knowledge. Schools have the chance to be a site for societal change. Schools also, as showing, telling, feeling, and listening to what it is like to be a teacher in New Zealand living with impairments and/or chronic illness is a step towards creating awareness. Showing, telling, feeling, and listening to what it is like to be a teacher in New Zealand living with impairments and/or chronic illness is a step towards creating awareness.

6.11 Summary

The experiences of New Zealand secondary school teachers with impairments and/or chronic illness are complex, messy, relational, stressful, empathetic, dynamic, resilient, and involve adaptation. The experiences involve all those little things that are engrained within the institutions that are at their best supportive and at their worst, discriminatory. This is what it means to be a secondary school teacher in New Zealand living with impairments and/or chronic illness.

The first emergent theme discussed in this chapter was Diagnosis. There are three key aspects of diagnosis stories. Firstly, that they are deeply personal stories revealing the often hidden lives of disabled teachers. Secondly, disclosing an impairment and/or chronic illness goes hand in hand with ‘being diagnosed’. This can signal the social acceptability of an impairment and in turn impact on how a disabled teacher is treated. Thirdly, there is the impact of the unspoken issue of pain, both physical and emotional. Diagnosis stories are a key part of exploring the experiences of disabled teachers. These stories show how a diagnosis has impacted and shaped participants’ lives as teachers, and they ultimately challenge what it means to be a teacher.

Teaching was explored through the temporal structure of getting into teaching, being a disabled teacher, and getting out. The theme encapsulated ideas of bullying, being thought a burden, resilience, and accommodations made by disabled teachers in
order to stay teaching. It revealed an emerging, disabled teacher identity related to shared experiences.

The final theme explored was Disability. It focused on how teachers constructed their identities as disabled teachers. It addressed ideas about what a workplace should and could look like, if a higher value was placed on diversity and inclusion. This chapter ended with a brief exploration of the actualisation of inclusive education. It posited that the way forward for inclusive education is to create inclusive workplaces where teachers feel that they are working within a supportive, inclusive environment that values diversity.

Ultimately, the school has to become an inclusive site for disabled employees (teachers and other staff), as well as disabled students. This chapter, as with the previous chapter, reflects the experiences of the survey and interview participants living with an impairment and/or chronic illness. The following chapter is the final chapter in this thesis and it offers some concluding thoughts through the exploration of the significance and contribution this thesis occupies within the body of knowledge.
Chapter 7

Uncover me, my life is woven
Into the warp of impairment
The weft of chronic illness
Experience first-hand me living

(Woven, LJS, 2014)\textsuperscript{10}

\textsuperscript{10} Woven is a found poem, reference: Thomas, (2007). Original text: “Importance is attached to uncovering the first-hand experiences of people for whom impairment including chronic illness, is woven into life’s warp and weft” (p154)
Conclusion

7.01 Introduction

I began this thesis with “all the little things” and I end with woven voices pieced together to create a multi-dimensional picture of what life is like for New Zealand secondary school teachers with impairments and/or chronic illness. The lives of those who have shared their time and stories with me speak not only of the messiness and complexities of the every day, but also of the silences. They both confirm and challenge the research that has gone previously. The stories stand as a testament to Abby, Boady, Cleo, Elle, Garry, George, Harry, Jane, Kate, Lilly, May, Sophie and the survey participants’ experiences. Their stories have the potential to become important vehicles for change. They suggest a new way to conceptualise inclusive education.

In this chapter I briefly summarise this thesis and explore the implications and limitations of this study. The following section deliberately follows the form of my guide to this thesis found in chapter 1.

7.02 All the Little Things: A look back

Guided by personal experiences of impairment and chronic illness I set out on this research journey. I positioned myself as coming from a place of knowing and I reflected on my Masters research, specifically the influence of Mrs Black that led me to my research topic. I further positioned myself within my ideological home of disability studies, disability studies in education (DSE) and arts-based education research (ABER). This background plotted my journey towards the creation of my research question: What are the experiences of secondary school teachers in New Zealand living with impairments and/or chronic illness? Guided by this question, I sought to find a theoretical framework that would be inclusive, participant centred, and flexible. I outlined the underpinnings of my theoretical framework in Chapter 2.

To understand the lives of participants I used a layered theoretical framework. In three parts, the first part explored the wider foundations of my research that I described as qualitative, interpretivist, and social constructionist. I drew on Creswell’s (2007) criteria to outline the qualitative nature of this study. Creswell maintained that qualitative research should either add to the literature or provide a call for action. This study does both. It adds to the small body of research about disabled teachers and argues for greater advocacy for and by disabled New Zealand teachers. The interpretivist nature of the research required a “sustained empathetic inquiry” (Atwood
& Stolorow, 1984, p.121 as quoted in Yanov, 2014, p. 22). The unfolding, responsive nature of interpretivism also allowed for the naturalistic ebb and flow to the research processes. The social constructionist perspective of the thesis recognised the multiplicity of voices, realities, identities, and stories. Through these lenses, the taken for granted nature of the everyday can be grasped (Berger et al., 2002; Gergen & Gergen, 2008). Understanding the everyday lived experiences of teachers living with impairments and/or chronic illness enable us to envisage “new, different, and better ways of living” (Smith & Sparkes, 2007, p. 295).

In the second part I sought to position my theoretical framework within disability studies and disability studies in education, and was influenced by key theorists like Shakespeare (2009) who suggested that research within disability studies needs to “capture the fact that impairment may not be neutral, but neither is it always all defining and terrible” (p. 191). I then narrowed my theoretical perspective to the sociology of disability as described by Carol Thomas (2009). This allowed for a flexible definition of disability that incorporates chronic illness as part of an impairment spectrum. In the third and final part I then turned to the broad umbrella of arts-based educational research (ABER).

ABER draws from a broad range of mediums from poetry to drama and painting. I began with narrative inquiry and added poetic inquiry. The use of narrative ensured that the individual lived reality, or the storied experience was the central focus of this research, and that it took precedence. Poetry is also experience focused. It can illuminate lives by providing new insights on familiar issues. The incorporation of poetry was a direct response to my perceived need to find a way of retaining the evocative thoughts and feelings that were gained through data collection. The use of this theoretical framework enabled me to develop a piece of research that is holistic, person centred, flexible, and inclusive to better create an understanding of disabled New Zealand secondary school teachers.

Guided by my research question: What is it like being a secondary school teacher in New Zealand living with an impairment and/or chronic illness? I reviewed the research about disabled teachers’ experiences in Chapter 3. The international literature was characterised by three aspects 1) the methodology was often narrative (Burns & Bell, 2011; Compton, 1997; Dvir, 2015; Valle et al., 2004), 2). It predominantly focused on tertiary educational settings (Bell, 2015; Burns, 2015; Burns et al., 2013; Connor, 2012; McKay et al., 2000; Strnadová et al., 2015), and 3), and it
predominantly focused on specific impairment like Deafness or dyslexia (Compton, 1997; Roald, 2002). The literature positioned disabled teachers as an inclusionary force (R. C. Anderson, 2006; Officer, 2009). However, it also recognised that the voices of disabled teachers are an untapped potential, and are frequently overlooked in terms of the actualisation of inclusion (Anderson, 2006).

Having situated myself within the qualitative theoretical framework, the method chapter, in Chapter 4 I turned to describing the particular research methods used. I began by noting that the methods were grounded within a two-fold ethics approach, procedural ethics and narrative ethics. Procedural ethics addresses the procedures required by the University of Otago which stresses the security of the raw material for example transcriptions and recordings. Narrative ethics acknowledges the risks of telling stories and the relational impact of the research on the researcher and participants. I went on to describe the recruitment of participants and the demographic data. Following that, I described the settings for the interviews, and addressed data analysis.

To analyse the survey data I used an inductive thematic approach before settling on a poetic transcription which took the form of the poem “I am, am I?” To analyse the interview material, I chose to be a "storyteller” who looks at multiple aspects of the story including content and form. I adapted Lieblich et al’s (1998) holistic content approach. This had three stages: 1) emplotment 2) inductive thematic 3) poetic transcription. I set out to to create a powerful piece of participant-centred piece of research (Smith & Sparkes, 2007, p. 201)

This is reflected in the first of two findings chapters, Chapter 5. This chapter was prefaced with the survey poetic text called I am, am I? The poem can be seen as a “challenge” to the dominant view of teaching, of disability, of impairment, and of chronic illness as it reveals the often hidden and confronting aspects of being a teacher living with impairments and/or chronic illness. This was followed by the 12 storied experiences of the interview participants. These stories move beyond the “conventions of polite silence” (Mairs as cited in Hershey, 2011, p. 132) to speak loudly and deeply of participants’ lives.

Chapter 6. I used the framework from my inductive thematic analysis to structure the chapter: diagnosis, teaching and disability. These themes create a place to generate an understanding of the experiences of disabled teachers in New Zealand. The first discusses aspects of the individual experience through ‘impairment effects’,
including disclosure of a diagnosis to staff and management, which sometimes led to judgements about capacity to work. Other issues like pain, both physical and emotional, were deeply personal. This theme revealed the often-hidden lives of disabled New Zealand secondary school teachers. The second theme, teaching, traced the participants’ experiences of becoming a teacher to being a teacher and finally getting out of teaching. Discriminatory practices at an institutional level saw teachers face unemployment or being funnelled into teaching areas they did not choose to be in. This signals the status of disabled bodies in education. I argued that being disabled enabled these participants to empathise with and create relationships with their students. They used their disabled bodies as pedagogical tools. I concluded with the idea that the impact of sustaining connections whilst feeling unsupported led to early retirement for some teachers.

The third theme: disability, explored how teachers constructed their identities as disabled teachers. I argued that disabled teachers need to feel included and supported if inclusive education is to be realised. The experiences of disabled teachers can be used to show what a workplace might look like if we place a higher value on diversity and inclusion. Participants’ role in the actualisation of inclusive education was discussed at the end of this theme. If the education system is to enact meaningful inclusion, there must be a shift in how we view inclusion. Teachers, who are often viewed solely as the transmitters of inclusion, must also be recipients of inclusion in their workplace.

The rest of this chapter is dedicated to addressing the research implications and challenges of this thesis. As I view this research only as a beginning of creating understanding, through the experiences of disabled New Zealand secondary school teachers, the chapter ends with ideas for further research.

7.03 A unique side to education\textsuperscript{11}: Research implications & challenges

Someone, somewhere
Will hear your story and decide to fight
To live and refuse compromise
Someone else will tell
Her own story

\textit{Telling}, (Hershey, 2011, p. 135)

\textsuperscript{11} Taken from Sophie’s story (see page 103)
To understand the research implications of this thesis is to understand the enormity of simply telling a story. As a narrative inquirer or a “story teller”, my intention was to increase understanding (Clandinin, 2013; Sparkes & Smith, 2010) about the experiences of New Zealand teachers living with impairments and/or chronic illness. Each story has provided a unique insight. As we read the stories of Abby, Boady, Cleo, Elle, Garry, George, Harry, Jane, Kate, Lilly, May, and Sophie we can begin to understand the world of each disabled teacher, and the impact of the engrained and perpetuated misconceptions of the world they live and work in. They are stories of the 'everydayness' of simply living and, yet, they have “potentially wide-ranging consequences in the larger world” (Garland-Thomson, 2005 p. 1575). Perhaps, these stories can or have already become “a lightning rod for social change” (Slattery, 2003, p. 193). The act of storytelling is an act of advocacy and activism.

These stories push the conversation of inclusion beyond the classroom. They provide a “unique side to education” (Sophie, p. 103). The experiences of disabled teachers cannot be overlooked in an era of educational change and inclusion. They further our understandings of disabled teachers’ experiences at practical and theoretical levels. Ultimately, the insights and experiences of this small group, may provide motivation for meaningful inclusion for disabled people.

7.04 Implications for “the actualisation of inclusion”.

Practices and policies from tertiary teacher education to secondary schools as workplaces must seek to promote and enact meaningful change. Immediate action is required to realign employment contracts and hiring evaluation forms with human rights UNCRPD and NZDS documents in order to rid them of phrases and good character clauses that specifically ask for a disclosure of impairment and/or chronic illness that have little or no relevance on the applicants ability to perform, and are used as screening devices before job interviews. The use of phrasing like “may” continues to legitimise the oppression of disabled teachers and workers. It is a silent discriminatory practice that has gone on relatively un-noticed. This change would be in line with the New Zealand Government’s 2014-2018 Disability Action Plan which specifically targets employment goals.

This study highlights a need to extend the field of inclusive education to encompass not only disabled students and disabled teachers, but everyone in the school community and beyond. For the actualisation of inclusive education to become a reality, inclusion must happen at all levels, holistically. It must not be restricted to classroom...
practices. This is not a new idea – the holistic encompassing of the school, school system and society has been argued for some time (see for example Ballard, 1999). However, the role of disabled teachers within this has only been explored in a handful of countries and contexts. This is a potential area for future research.

As potential gatekeepers, the professional body needs to encourage disabled people to become teachers and to support them in that role. This is key to recognising valuing difference and diversity (Divr, 2015). Potentially tertiary institutions’ teacher education programmes have the power to foster the actualisation of inclusive education. Although tertiary institutions are not beholden to any inclusive education policy, there are guidelines for inclusion within tertiary institutions such as Kia Orite (ACHIEVE, 2007) as well as the key principal of UNCRPD of “lifelong learning” (UNCRPD, Article 24). Institutions need to ensure they are not undermining inclusive education through policy or practice.

A key recommendation is the establishment of a disability network for teachers. It should support, advocate, and provide resources for teachers without requiring them to disclose details of impairments and/or chronic illness. To enact this recommendation, an online forum could be established, either tied to ECNZ, PPTA, or independent of it, where teachers could share their experiences, explain what worked for them, and what did not, share resources and such. The development of structures that support teachers with impairments/chronic illness could benefit all teachers, to create work environments that are inclusive.

**7.05 Challenges.**

I wrestle with words
Until I submit
To the blurred lines,
To the aches and pains produced by my body
To that dullness of mind that never lets go

(LJS, 2014)

In this section I pause for a moment to reflect back on some challenges that I have encountered. These challenges reflect some potential limitations of this thesis. There is still much to be explored regarding disabled teachers’ experience that I have not been able to cover in this thesis. Disabled teachers have many stories to tell, both positive and negative. In this thesis, I have focused only on stories from 12 people. In this group of participants there was little gender diversity and no ethnic diversity. Of the 12 participants, all identified as being of European descent and only three were male. This
did reflect the national statistics at the time which suggested that teachers were predominantly white/pakeha women (Education Counts, 2017).

There were personal and financial challenges in producing this research. My own impairments have often hampered this research. Interviews where I have coughed the entire time because of pneumonia; interviews where I have shuffled in my chair constantly because of the invisible and unceasing pain; and long periods between transcriptions. This thesis has been produced amid several stopping points where I had to submit to my physical limitations. Stopping it made my writing up of research and indeed this thesis slower than I had hoped. Financially, this was a self-funded study. At times the economic pressures of conducting this study meant that despite all efforts to maintain complete flexibility, some trips could not be completely flexible for all teachers. Yet, they still gave of their time.

This research was, and is, for my sole benefit which is to gain an academic qualification (Henderson & Esposita, 2017). Beyond the physical challenges, I found balancing my voice with those of my participants a challenge. Elsewhere I have discussed the weight of participants’ words (see chapter 4). On reflection, I don’t believe I have found the right balance. My voice as the researcher has mediated their stories despite efforts to highlight participant voice and stories.

Academia has a history of institutionalising the oppression of disabled people (Morris, 1992) and as a part of an academic institution I recognise the potential for reinscribing such oppressive perspectives. As Barnes suggested, researchers need to make a commitment to action change (Barnes, 1996). I view this thesis as a call to action, yet, I am still aware it is an academic document, constrained by academic formats. The next section outlines some further ideas for future research and in the previous section, I called for action regarding key areas including the creation of forums and inclusive employment practices.

7.06 Future Research: An explosion of ideas

I set out to explore experiences that have very rarely been heard in educational research. This is as far as I am aware (at the time of writing) the only New Zealand study that has sought to explore the experiences of secondary school teachers living with impairments and/or chronic illness. The experiences so generously shared by participants have shown that there is a need to develop structures and networks to support teachers, and also encourage inclusion beyond the classroom.
The findings have implications in the areas of employment, disability studies and disability studies in education, teaching, and for teacher unions, and teacher education programmes. Ideas for further research include an expansion of the study, with greater emphasis on self-advocacy through arts-based educational research such as poetry, short films and visual diaries, to avoid the privileging of written and interview materials. The use of visual or video diaries could help address the problem of teachers having limited time to produce written thoughts about their experiences. Most teachers in my research found written diaries too time consuming.

Other ideas, like action research projects with schools and teachers could be used to highlight disabled teachers' ideas about creating inclusive school communities. In a climate of widespread and sweeping educational change, longitudinal studies that trace disabled teachers’ career development from graduation, and show the impact of major policy developments would provide valuable information on career pathways, as well as inclusion, within tertiary and employment spheres. This would be especially important if policies are to be reviewed and updated. For example, the issue and role of disclosure (both in applying for jobs and when teaching) needs to be examined closely in order to find a process that provides advocacy and support to applicants and teachers. More needs to be known about the role of teacher unions in relation to support of disabled teachers. This perhaps would be a pathway for growing inclusive education. It could lead to the development of professional development seminars and awareness campaigns.

Now at the end of this thesis, and in concert with answering the key research question, “what is it like being a secondary school teacher in New Zealand living with impairments and/or chronic illness?” I find that there are more questions than this thesis can answer. Participants’ stories challenge perceptions of teachers and people with impairments and/or chronic illness. Despite the barriers to doing and being, disabled teachers maintain busy and stressful professional lives. The experiences these participants have shared, highlight the everyday realities of living with an impairment and/or chronic illness. They are all the little things.
Presentations from this research

Sanderson, L.J. (2014). I am, am I?: Using poetry to reflect disabled teachers’ experiences. Verbal presentation at DSE, Melbourne, Australia
References


All the little things | References


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Garrett, L. (2014). The Student Bullying of Teachers: An Exploration of the Nature of the Phenomenon and the Ways in which it is Experienced by Teachers.


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All the little things | References


All the little things | References


All the little things | References


All the little things | References


Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability. *Disability & Society, 17*(5), 509-527.


Appendix A

Poetic portraits

At the end of the third interview and for some after I had conducted the interview via e-mail, I asked participants to reflect on what they were like as teachers, following Glesne (1997) I said:

“If I asked you to use a metaphor to describe yourself as a [teacher] what would you say you were like? Someone I asked said that she was a [gardener] and then told me why. What metaphor comes to mind?” (adapted from Glesne, 1997, p.207).

These are some of those self-portraits that were generated.

Cleo

I am a hug,
Something that wraps around and envelopes
People with care and kindness,
That’s how I see myself as a teacher
That’s how my students see me,
They know they can always come to me
And that I will always care for them
And I will always listen to them
I’m kind first and foremost,
I am a hug.

Jane

I am a gardener
My students are little plants
And it is up to me to feed, water and shed light on them.
Sometimes, I am not a good gardener and neglect some plants
Or struggle to give them the specific food they need to thrive.
Sometimes, I get wonderful results!
I am a gardener
Kate
Like a mother Duck,
Although serene above the water,
Below I am frantically paddling furiously
Trying to keep afloat
Leading my ducklings from the front
Showing them how they can navigate
I am urging them from behind,
No duckling is left behind
They get bigger and stronger,
I teach them how to fly,
And they do.

Gary
Grandfatherly
Respect firstly,
Love
Genuine expressions of:
Interest and love
Wisdom and experience

Boady
I am a tree
Steady
Wise
Growing
George
Being a builder,
The whole process:
Beginning with a really good foundation
Then the vertical aspects of values and goals
Need to be solid, plum, level, and square
We can put the roof on with a bit
Of luck at the end of the year

May
Tugboats.
Tugboats can be relied upon,
Trusted to know and do their stuff
Even in the most adverse conditions.
Pushing and pulling, coaxing forces much bigger than themselves
Sometimes into safe harbour, sometimes out to face the rigours of the ocean.
Tugboats often have to go against the force of the tide,
Sometimes happily go along with it, depending on their reading of the situation,
They go about their work efficiently and enthusiastically.
Appendix B

**Being Sick is no fun.**


Being sick is no fun
I miss school and there’s homework to be done
Being sick is no fun
I have to stay home with my Mum
Being sick is no fun
My head is not thinking and my tongue is numb
Being sick is no fun
I fell hot and bothered and sick in my tum
Being sick is no fun
I listen to the hailstones and can’t see the sun
Appendix C

Samples of “poetry hiding in the everyday”

Image of the day
Silhouettes of seagulls reflected
In the black glass of the inlet move
Against a darkening mercury sky before
Rain, which with each drop melts
The scene, disappearing in series of ripples

Thought of the day
I have become a collector
A collector of images,
Of thoughts
The Archaeologist's Business Card.

On the back of the archaeologist's business card
Trees still outline the last of the winter sun
Curls around
Public works and port-a-loos
A schematic for a clay drainage pipe
Which holds memories of
Glazing, that's how to judge the age of them
LJS 18/08/2014
Appendix D

Historical construction of Disability: The New Zealand context

No human group has ever been so subjected to violence, none so marginalized. In ancient Greece we were left to die in the cold mountain hillsides, in Africa we were food for beasts, in Europe dropped down a well. People forget the Nazis perfected their death machine before they moved on to the Gypsies and Jews … the only nation of the disabled is the nation of the abandoned and dead. History is not on our side. (Siebers, 2012, pp. 25-26, emphasis added)

The historical construction of Disability is important if we are to understand the broader connections to history that still impact on society’s construction of disability and disabled people. Scholars like Gleeson (1997), Watson (2002), and Officer (2009) have critiqued disability research for lacking recognition of the historical impact. Watson (2002) described disability research as needing to be “historically situated, socially composite and as part of multiple identities” (p. 513), whilst Officer (2009) viewed the silences within history, as fuelling the dominant discourses. Perpetuating the view of impairment as only a biological phenomenon located within the individual. While I agree with Titchkosky’s (2015) comment that Disability Studies has been too tied to recounting its own history, I also believe that recognising the historical construction of Disability is important because of the ingrained nature of these social constructions within society. They continue to impact how society views Disability and disabled people. This ranges from the language used and cultural representations of Disability. It also situates this thesis within the specific context of New Zealand.

Disabled researchers have generally not explored the history of disabled people in New Zealand. Institutions like the IHC, CCS: Disability Action, the Foundation of the Blind, and New Zealand Deaf Culture (McKee, 2004) have traced their roots with historiographies. Yet, there has been no collated history that provides an overarching examination of being disabled, by and for the disability community in New Zealand. Despite this, where it has been possible I have referred to any New Zealand context and New Zealand research. I do recognise that Pākeha/New Zealand European perspectives dominate the documentation due to the privileging of western culture and laws in New Zealand Society for over 150 years. I have chosen to encapsulate the social-historic construction in terms of a time line with key policies both national and international, and where possible, use New Zealand research to explicate the timeline. The words of Baglieri, Valle, Connor & Gallagher (2011) echo in this chapter, that disability is first and
foremost “… an idea, not a thing” (p. 270). What disability means as an idea, is often in a state of flux, changing and, evolving. A visual representation of the evolution of disability in New Zealand is found in the timeline on the following page followed by a detailed discussion of the time line.

This is based on information from the Office of Disability Issues. It is redesigned and dates put in sequential order. The legislation was cross referenced with databases like New Zealand Legislation (http://www.legislation.govt.nz/), Te Ara, New Zealand Encyclopaedia (http://www.teara.govt.nz/en), Archives New Zealand (http://archives.govt.nz), and Statistics New Zealand (http://www.stats.govt.nz/). The timeline and subsequent discussion of it will reveal the echoes and implications of the discrimination and position of disabled people in New Zealand.
1840-1900:
- 1846: Lunatics Ordinance set up the Asylum System
- 1840: Treaty of Waitangi - Tiriti o te Waitangi
- 1882: Imbecile Passengers Act
- 1880: Establishment of a Deaf school
- 1849: Immigration Restriction Act
- 1924: Pension for the blind
- 1924/25: Committee inquiry into mental defectives and sexual offenders
- 1911: Mental Defectives Act
- 1916: Census ceases to identify people with specific impairments
- 1929: Templeton Farm

1900-1989:
- 1899: Immigration Restriction Act
- 1882: Imbecile Passengers Act
- 1880: Establishment of a Deaf school
- 1846: Lunatics Ordinance set up the Asylum System
- 1840: Treaty of Waitangi - Tiriti o te Waitangi
- 1911: Mental Defectives Act
- 1916: Census ceases to identify people with specific impairments
- 1924: Pension for the blind
- 1924/25: Committee inquiry into mental defectives and sexual offenders
- 1973: Industrial Relations Act
- 1972: Royal Commission into Psychopaedic Hospitals Accident Compensation Act
- 1960: Disabled Persons Employment Promotion Act
- 1948: UNDHR
- 1929: Templeton Farm

1990-2016:
- 1975: DPCW Act
- 1979: CEDAW
- 1981: Telethon to raise money for people with disabilities
- New Zealand DPA formed
- 1989: New Zealand Education Act
- 2006: NZSL official language
- 2002: Office for Disability Issues
- 2000/1: NZDS
- 1990/93: NZBORA
- UNCROC
- 2008: NZ ratified UNCRPD
- 2014: DAP
- 2012: Think Differently campaign
- 2006: Disability Confident campaign
- NZDS consultation & redesign
- NZDS
- 1990-2016: Disability
- Designed & created by Lara J. Sanderson
- 2017
1840-1900: The beginnings

The first image on the timeline is a colourised version of the signing of the Treaty of Waitang/Tīrī o te Waitangi in 1840. This created a system of British control in New Zealand with three guiding principles of partnership, participation, and protection (Durie, 1989). In 2016, these principles were invoked in the redesign of the New Zealand Disability Strategy (2016). However, the first act that directly impacted on disabled lives was the 1846 Lunatics Ordinance and the establishment of the first asylums. Seacliff is one of these early asylums and is depicted in the second image, circa 1890. These asylums were initially directly tied to law and order and were the colony’s first government run social service. (Tennant, 2007). The asylums would have a lasting impact on the lives of disabled people which is evident in some of the later research conducted with former institutionalised patients in the 20th Century. For example, a research article written by Avis Hunter with Bridget Mirfin-Veitch (2005) describes Hunter's time in New Zealand institutions:

Sometimes I would hide under the mattress in the cold weather— wintertime.
I’d also hide under the building because I knew that was a really warm place.
The hot pipes would keep me warm. When they found me they would get me out. (p. 89)

In 2004, a report by the working group Te Aiotanga (Mahony, Dowland, Helm, & Grieg, 2007) finally conducted further research that explored the experiences of former patients, their family, and the former staff of institutions. Anonymised, the report describes the collective experiences of treatment regimens which included medication, electroconvulsive therapy (ECT), and seclusion. Participants described bullying tactics used to ensure compliance.

The report highlighted groups within the participants including those who were admitted into institutions as children and adolescents. Participants spoke about their childhoods spent institutionalised. Mahony, Dowland, Helm & Grieg (2007) noted that these participants described their lost, desolate childhoods. Participants spoke about how, as children, they were sent to asylums because they had epilepsy or were described as “wayward” or naughty and had moved through foster care and residential homes to psychiatric facilities. Overall, the former patients described the impact of their time in institutions as ranging from feelings of shame and anger to a sense of dislocation and poverty.
The asylum system in New Zealand formally end with their closure in 1999. This saw the establishment of smaller institutionalised living “within” the community (Mahony, Dowland, Helm & Grieg, 2007). Despite the processes of de-institutionalisation, recently (June, 2016) the case of Ashley Peacock came to light. Mr Peacock, had been in a “seclusion ward” of a mental health facility for five years (Johnston, 2016). Subsequently, there was an outcry on behalf of Mr Peacock, with a human rights complaint being processed at the time of writing. In July 2016 it was announced that the Human Rights Commission, with the backing of the United Nations subcommittee on the prevention of torture, would be launching a full inquiry to the use of “seclusion” for disabled people in New Zealand (Human Rights Commission, 2016)

Ultimately, the “lunatics ordinance” begun a long period of segregation through the institutionalisation of disabled people from their communities. Other legislation in the late 19th Century focused first on making any settlers with a disabled family member responsible for them in the “imbeciles” act 1882, imposing a one-hundred-pound fee and a commitment to that family member for five years. This then moved to an outright ban of disabled people from immigrating to New Zealand in 1899 through the Immigration Restriction Act.

Yet before these acts, New Zealand’s first school for the Deaf was founded at Sumner near Christchurch in 1880. This was influenced by the Milan Conference which favoured oralism, the practice of Deaf using lip reading and the “pure oral” technique rather than using sign language, and was adopted in New Zealand. In 1911, a census year, the Yearbook notes that the then Minister of Education, George Fowlds, stated:

It cannot be too often repeated that in this institution the deaf, who would otherwise be speechless, are taught both to speak and to understand (from the motion of the lips) the speech of others, and that they are thereby admitted not only to the benefits of communication with their fellow-men, but even very largely to the conceptions involved in human intercourse. (1911, Digitised Yearbook, New Zealand Statistics)

The first school house is the third colourised pictured. The idea of oralism persisted, leaving many Deaf adults unable to sign, including the only Deaf participant in this study who grew up and was educated in the 1970s and 80s (Personal communication, 2013). The school for the Deaf still exists although their focus has shifted to the use of sign language. It was renamed in 1980 to van Asch College after the first headmaster (van Asch College, Timeline). From the end of the 19th Century and persisting into the 20th
Century, the western world was gripped by the eugenics movement (Barrett & Kurzman, 2004). There is a somewhat disconcerting silence in New Zealand research about the impact of eugenics movement. There was a very small mention in Te Ara about the rise of eugenics movement Te Ara, last accessed 2017). The influence of the movement became explicit in legislation about the “unfit” and the “mental defective” that was implemented in the early 20th Century.

1900-1989: Decades of change and committees

The early 20th Century was a period of continuing institutionalisation for disabled New Zealanders, with the development of new ways of being categorised within the Mental Defectives Act (1911). People were classed along a continuum from unsound mind to epileptic. In the now digitised statistic yearbook for 1911 (Statistics New Zealand, Yearbook, 1911) it reported on two schools, the school for Deaf and the school “for boys of feeble mind” in North Otago. The segregation and concern about “mental defectives” had begun to turn to children. This “concern” was further legislated alongside the sexual reproduction of disabled people who were grouped with sexual offenders in the 1924/25 Mental Defectives and Sexual Offenders committee hearing. This led to the segregation of children and for those who were physically “capable”, Templeton Farm was established as a work-based segregated community in 1929 (Lemon, 2001). David Lemon’s (2001) Master of Arts in Sociology details Templeton Farm including the experience of Norman Madden, one of the “lost boys” who was wrongly institutionalised at the age of six in the 1940s.

Post-World War Two an establishment of a human rights perspective was seeded, yet disabled people were somewhat overlooked in the 1948 United Nations Declaration of Human Rights (United Nations, 1948). Disability then was considered as a temporary event, being compared to losing a job or becoming a widow (Article 25). Despite the seed of rights being sown, sheltered workshops and continuing segregation of disabled people from New Zealand communities persisted. In 1972 a Royal Commission began focusing on smaller institutions rather than the large traditional asylums.

In the same year, the Accident Compensation Act established that people injured through accidents on a case-by-case basis were allowed to apply for government assistance. In 1972 the Industrial Relations Act created an unequal pay system for disabled people who were then paid based on their “capabilities”. Three years later in 1975, the Disabled Persons Community Welfare Act meant that people could gain access to services and enabled disabled people to stay in the community. This furthered
deinstitutionalisation of people with disabilities. As with all of New Zealand’s disabled history, there a paucity of research about the lives of disabled people during this time. Internationally, in 1979 Women’s rights were acknowledged in the Convention on the Elimination of all forms of Discrimination Against Women (CEDAW, 1979).

There was, however, a growth in disability awareness to the point that a national telethon, where people would ring up and pledge donations, was held in the International Year of the Disabled in 1981. The telethon raised enough money to create the New Zealand Disabled Persons Assembly (DPA). The fourth colourised image on the timeline is the telethon board showing the total money raised. The awareness raising signalled a closer movement towards Human Rights for people with impairments and a move away from the social and historical injustices that disabled people had faced, towards social awareness and political activism. The 1980s closed with perhaps the most significant act, the Education Act, 1989. For the first time, since the 1890s this signalled that disabled students were given the right to be education within their own community.

1990-2016: Higgledy piggledy and reinvention

From 1990 to the present, the hap-hazard design of disability policy and its implementation has held a predominantly human rights perspective drawing on the social model of disability. As both Ballard (2004) and Oliver (2013) have noted, the social model and ideas about inclusion have been appropriated as framework to underpin many disability policies. New Zealand has a multitude of policies and legislation surrounding disability and inclusion that often takes for granted and appropriates the social model. The policies absorb the language of the social model with very little implementation of the ideology behind it. It is no wonder they have been described as “higgledy-piggledy” (Higgins et al., 2006) as they lack coherence. These policies often take a human rights perspective from international instruments like the United Nations Convention on the Rights of People with Disabilities (United Nations, 2007) to the New Zealand specific policies like the New Zealand Disability Strategy (NZDS, 2001, 2016). As a rights issue, disability is the last to be acknowledged after woman and children, (United Nations, 1979, 1989). Lawson (2007) posited that, “traditionally disability has been viewed not as an equality or human rights issue but as a medical problem” (p. 567). Therefore, the assumption was that any rights issues could be adequately recognised under other international declarations.

Nevertheless, in 1990 The New Zealand Bill of Rights Act (NZBORA, 1990/93) was implemented. NZBORA outlines all New Zealander’s rights and
freedoms, both civil and political. These rights include; the right not to be subjected to torture or cruel treatment, the right not to be subjected to medical or scientific experimentation, and the freedom from discrimination. It makes no special mention of disabled people, discrimination is considered as exclusive to race. The first policy of the modern era was the New Zealand Disability Strategy.

In 2000/2001, the New Zealand Disability Strategy was created and implemented. This document remained the blueprint for New Zealand disability policies until its redesign in 2016. The original strategy sets out the blueprint for the creation of an inclusive New Zealand. It had 15 objectives that specifically mentioned children, women, Māori and Pacific peoples. The Strategy lacked real teeth as it was not legislated policy but rather acted more as a guideline or yardstick or in the new strategy, a “map” (Draft Disability Strategy, p. 3).

Concurrently, the NZDS paved the way for the foundation of the Office for Disability Issues, an inter-disciplinary government department that sits outside of health and law. Furthermore, in 2006 New Zealand Sign Language (NZSL) became New Zealand’s third official language after Māori and English. This was in anticipation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which was ratified by New Zealand in 2008. A human rights perspective of disability that transforms disability into “disablism” which puts it on par with racism and sexism (Sanderson, 2011). Scholars such as Shakespeare (2009) viewed disablism as more complex when considering equalising provisions, including issues of access. Furthermore, civil rights campaigns of both gender and race have in the past used disability as a deficit and segregating term, distinct and apart from their movements (Titchkosky, 2015).

The UNCRPD sets out key areas that pertains to the inclusion and participation of disabled people and include education, the right to have a voice, and the right to express your views. UNCRPD is the first convention to make an inclusive education system a human rights issue (Article 24). The right to have a voice in Article 7 of the UNCRPD furthers the idea of voice from other conventions by including “assistance to realize this right” (24, para). This allows for assistive technology, Braille, or a support person. There is also a clear distinction made between right to have a voice and right to express thoughts and opinions.

The right to express views is found in every major international Human Rights document including UNCRPD and the UNDHR and it is enshrined in the New Zealand
Bill of Rights Act (NZBORA, 1990/1993). The right to freedom of expression also includes the right to “seek, receive and impart information” (UNCRPD, 21; UNDHR, 19; NZBORA, 14). This right continues to be problematical, for example, when I sent out a national survey as the first phase of this research and as a recruitment tool an e-mail I received back simply stated; “Sorry, to the best of my knowledge we do not have any staff who meet your requirements” (Personal Communication, 23/10/2012). As a result of this gatekeeping, staff members who may have had hidden impairments and/or may have not disclosed any impairments had their right to express their views by taking part in this research compromised. Furthermore, as survey participant FP2 pointed out, she was blocked from “impacting information” by her school about her chronic illness despite there being a need to show empathy during a difficult time for the students.

These two examples are part of a systemic lack of implementation and understanding of Disability rights. The Disability Action Plan (2014) coincided with criticisms levelled at the New Zealand Government about the lack of implementation of the UNCRPD (2007). It was designed to “advance implementation” of both the NZDS and the UNCRPD. The Disability Action Plan 2014-2018 provided a space in which to reevaluate how the country “does disability” and ties disability rights with citizenship and participation.

The Disability Action Plan (DAP) 2014-2018 was created with the over-arching vision that “all New Zealanders experience equal rights of citizenship” (New Zealand Office for Disability Issues, see Appendix D for an image of the DAP). The first priority is to increase employment and economic opportunities. The link with rights and citizenship reaffirms the socio-historical perspective that employment, citizenship, and social inclusion of disabled people are interwoven.

This is further exemplified by the criticism from the United Nations regarding New Zealand’s implementation of UNCRPD. In 2015 a United Nations report on the implementation of the UNCRPD criticised key areas being investigated in this thesis; the issue of disabled women, disabled employees, and disabled people in tertiary education. Since these criticisms were made, New Zealand has instituted a revision of the New Zealand Disability Strategy (NZDS). The revised NZDS uses a person-centred rhetoric, for example, the first line of objective one, “Our learning pathway supports us to develop friendships and social skills, as well as resilience, determination and confidence” (NZDS, 2016, p. 24).
While I commend the strategy for placing the person first, when in it is a government policy that is designed to promote inclusion, placing the person first runs the risk of “blaming” individuals and making inclusion the responsibility of the individual “not” society. The new strategy has eight objectives compared to 2001’s 15 objectives. A side by side comparison can be seen below in Figure 11.

<table>
<thead>
<tr>
<th>Objective</th>
<th>2001 NZDS</th>
<th>2016 NZDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Encourage and educate for non-disabling society</td>
<td>Education</td>
</tr>
<tr>
<td>2</td>
<td>Ensure rights for disabled people</td>
<td>Employment</td>
</tr>
<tr>
<td>3</td>
<td>Provide the best education for disabled people</td>
<td>Health &amp; Wellbeing</td>
</tr>
<tr>
<td>4</td>
<td>Provide opportunities in employment and economic development for disabled people</td>
<td>Rights Protection &amp; Justice</td>
</tr>
<tr>
<td>5</td>
<td>Foster leadership by disabled people</td>
<td>Accessibility</td>
</tr>
<tr>
<td>6</td>
<td>Foster an aware and responsive public service</td>
<td>Attitudes</td>
</tr>
<tr>
<td>7</td>
<td>Create long-term support systems centred on the individual</td>
<td>Choice &amp; Control</td>
</tr>
<tr>
<td>8</td>
<td>Support quality living in the community for disabled people</td>
<td>Leadership</td>
</tr>
<tr>
<td>9</td>
<td>Support lifestyle choices, recreation, and culture for disabled people</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Collect and use relevant information about disabled people and disability issues</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Promote participation of disabled Māori</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Promote participation of disabled Pacific peoples</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Enable disabled children and youth to lead full and active lives</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Promote participation of disabled women in order to improve their quality of life</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Value families, whanau and people providing ongoing support</td>
<td></td>
</tr>
</tbody>
</table>

*Figure 11: Objectives of New Zealand Disability Strategy 2001 and 2016*
Launched alongside the redesign of the NZDS in 2016 was an employment initiative called “Disability Confident” (Ministry of Social Development, 2016). This was aimed at making employers feel more “confident” in employing disabled people. Through the writing of this thesis it has become clear to me that there are laws surrounding the employment of disabled people that continue to perpetuate many stereotypes and fears including those found in pay rates (Minimum Wage Act, 1983).

I started this section with a quote from Tobin Siebers (2012), “history is not on our side” (p. 625). Despite efforts to make disabled people more visible there are still areas that society and institutions fail to address. They may not seem big, they may in fact be a single line in a 10-page document. What it does suggest is that history is not on our side! Disabled people will, despite this era of inclusion, continue to experience segregation, institutionalisation, discrimination, and unequal pay. History, it would seem, despite being cloaked in a new rhetoric of inclusion, will continue to repeat itself.
Appendix E

Information Advert and Survey

**PhD Research Study.**

**WORKING TITLE: WHAT IS IT LIKE BEING A SECONDARY SCHOOL TEACHER IN NEW ZEALAND AND LIVING WITH IMPAIRMENTS AND/OR CHRONIC ILLNESS?**

This PhD research study aims to explore inclusive education through the stories of secondary teachers living with impairments and/or chronic illness in an attempt to answer “what is it like being a secondary school teacher in New Zealand and living with impairments and/or chronic illness?”

I am looking for volunteers who self-identify as having an impairment and/or chronic illness, who are qualified secondary school teachers, and who are willing to answer a national survey that should take no longer than 15 minutes to complete. This initial phase seeks to examine the issues that affect teachers with impairments/chronic illness. If you wish to participate in the national survey or would like more information please contact Lara (see below).

Lara Sanderson

Postgraduate Offices, University of Otago College of Education,

P.O. Box 59, University of Otago, Dunedin

Ph: (03) 479 8804 or email: lara.sanderson@otago.ac.nz

This project has been reviewed and approved by the University of Otago Human Ethics Committee. Reference: 12/136
WHAT IS IT LIKE BEING A SECONDARY SCHOOL TEACHER IN NEW ZEALAND LIVING WITH AN IMPAIRMENT AND/OR CHRONIC ILLNESS? SURVEY

Please read the following information sheet about this project and then if you are willing to participate please sign the consent form and complete the survey.
WORKING TITLE: WHAT IS IT LIKE BEING A SECONDARY SCHOOL TEACHER IN NEW
ZEALAND AND LIVING WITH IMPAIRMENTS AND/OR CHRONIC ILLNESS?

INFORMATION FOR PHASE ONE SURVEY PARTICIPANTS

My name is Lara Sanderson and I would like to thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether to participate. If you decide to participate, thank you. If you decide not to take part there will be no disadvantage to you and thank you for considering my request.

What is the Aim of the Project?
This project explores inclusive education through the stories of secondary school teachers living with impairments and/or chronic illness. For the purpose of this study, inclusive education means recognising the rights of all to participate in society where difference and diversity are valued. Inclusive education is a part of rather than separate to the wider inclusion of disabled people within society. This project is being undertaken as part of the requirements for the Doctorate of Philosophy (PhD) in Education.

What will I be asked to do?
The following pages are a short survey, for the first phase of data collection. It should take no longer than 20 minutes of your time. If you do not wish to answer any of the questions please miss them out and go on to the next one. Further, if you require this to be put into a different form e.g. large type please contact Lara Sanderson (information below).

What Data or Information will be Collected and What Use will be Made of it?
The information that will be collected in this survey will be used in my PhD. It will also be used to identify any participants who may be willing to be involved in the second phase of the study. Further information about the second phase is at the end of this survey where you will also have the opportunity to provide your contact details if you are willing to take part in individual interviews. The results of the research may be published in articles and be presented at conferences. Finally, if you wish to participate in this survey please read the information and sign/initial the consent form on the following page.

Any Questions? If you have any questions about my project, either now or in the future, please feel free to contact either:

Lara Sanderson
Otago University College of Education
(03) 479 8804
lara.sanderson@otago.ac.nz

and/or

Dr. Ruth Gasson
University College of Education
(03) 479 4940
ruth.gasson@otago.ac.nz

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph. 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome. PLEASE DETACH AND KEEP THIS PAGE.
Working title: WHAT IS IT LIKE BEING A SECONDARY SCHOOL TEACHER IN NEW ZEALAND AND LIVING WITH IMPAIRMENTS AND/OR CHRONIC ILLNESS?
CONSENT FORM FOR SURVEY PARTICIPANTS

I have read the information concerning this project and understand what it is about. I understand that I am free to request further information at any stage.
I know that:-
1. My participation in the project is entirely voluntary;

2. If I feel any discomfort I can choose not to answer a particular question and I am free to withdraw from the project at any time without any disadvantage,

3. Personal identifying information will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for at least five years;

5. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my anonymity should I choose to remain anonymous.
I agree to take part in this survey.

.......................................................... ........................................
(Signature/electronic initials of participant) (Date)

Please print or type your name (for collection purposes only).
This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph. 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
All the little things | Appendices

Working title: WHAT IS IT LIKE BEING A SECONDARY SCHOOL TEACHER IN NEW ZEALAND AND LIVING WITH IMPAIRMENTS AND/OR CHRONIC ILLNESS?

NATIONAL SURVEY.

If this has been sent to you in PDF form please use the typewriter setting to fill in the form

1. Year of Birth:

2. Gender (please tick):
   - Female
   - Male
   - Other

3. Ethnic Origin(s) (tick at many as you like):
   - NZ European
   - NZ Maori
   - Australian
   - European (please specify):
     ______________________________________________________
   - Pacific Island (please specify):
     ______________________________________________________
   - Middle Eastern (please specify):
     ______________________________________________________
   - African (please specify):
     ______________________________________________________
   - Latin American (please specify):
     ______________________________________________________

4. Impairment/chronic illness:
   Do you have an impairment and/or chronic illness?
   - Yes
   - No

If your answer is no, thank you for taking the time to take part in this survey.
5. If yes, how would you describe your impairment and/or chronic illness? (Tick as many as you like)

☐ Deaf
☐ Hearing
☐ Blind
☐ Vision
☐ Specific learning
☐ Mental health
☐ Mobility
☐ Speech
☐ Temporary impairment
☐ Medical
☐ Head injury
☐ Other (please specify) _______________

6. What is your highest educational qualification?

__________________________________

7. What kind of work do you do? Are you employed/unemployed or retired?

__________________________________

8. How long have you been a qualified teacher and what is your current position?

__________________________________

9. Impairments affect people differently in different contexts. Briefly, has your impairment/chronic illness impacted on your professional life as a teacher? (If you wish to write more please insert a page at the end of this survey)

__________________________________

__________________________________

__________________________________
10. If yes, have you experienced similar or different in your private life, please explain.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

11. Have you ever experienced any impairment or illness related discrimination either in the workplace OR in your daily life? Please describe.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

12. If yes, did you seek any type of help or support and if so please describe and indicate if you received the outcome that you wanted.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

13. Are your colleagues or friends aware of your impairment/chronic illness?

YES/NO

14. Have you ever felt pressure to disclose (or not disclose)? your impairment/chronic illness? Please explain.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
15. Do you feel that your colleagues or friends treat you differently (positive or negative) because of your impairment/chronic illness?

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

16. If your workplace is aware of your impairment/chronic illness have they adjusted any area of your job or workplace in order for you to carry out your job? If so what?

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

18. Is there anything else you would like to add to what you have already written?

PLEASE TURN OVER/SCROLL DOWN.
The second phase will examine personal stories about living with an impairment and/or chronic illness and will involve three interviews throughout 2013 to be made at a time that suits you. It will also include some journaling either typed, handwritten or videotaped. How much journaling would be up to you and all materials will be provided.

If you are willing to take part in the second stage of this research and would like more information about it, please print your name and contact details below.

Name:
........................................................................................................................................

Postal Address:
........................................................................................................................................

Phone: [    ]...............................
E-mail:
........................................................................................................................................

Tick your preferred method of contact:

☐ Phone ☐ E-mail ☐ Post ☐ Face to Face

Thank you for completing this survey. Please return signed consent form and completed questionnaire in the prepaid envelope before the 10th December 2012 to:

Lara Sanderson, Education Postgraduate Office, University of Otago College of Education, University of Otago, P.O. Box 56, Dunedin OR email the PDF to Lara:
lara.sanderson@otago.ac.nz
Appendix F

Lifeline Brochure

What if we don’t have a Lifeline?

Lifeline caller demands keep growing. Lifeline is a confidential and non-judgemental telephone counselling service that has been offered FREE since 1964. To keep it running this way, we are dependent on the continued generosity and support of the community and our sponsors.

If you would like to support Lifeline see our website for details:
www.lifeline.co.nz

Always caring...
Always free...
24/7

For more information or your nearest centre, please visit our website:
www.lifeline.co.nz

Always caring...
Always free...
24/7

Lifeline is a counselling service accessed by telephone 24 hours a day, 365 days a year.

Talking helps - it may be that you just need support. You may want to talk to someone who won’t make a fuss. You may have something on your mind that you want to work out. We are not just a crisis service. Lifeline is here for anyone who simply needs to talk.

Making the first call takes courage but is the first step on the road forward.

Phone: 0800Lifeline
0800 543 354

Lifeline believes that:

- All people are to be valued.
- All people can change and grow.
- In times of stress and difficulties we all need to be listened to.
- Listening should be non-judgemental with respect as a first step.
- The aim is to encourage and restore people to worthwhile relationships.
- Lifeline Telephone counsellors must be professionally trained.

Lifeline counsellors are volunteers. Every Lifeline Telephone Counsellor is there because they want to be.

Lifeline centres are always looking for warm, caring, non-judgemental people. Training is offered by experienced and professional counsellors. The telephone counsellors are fully trained to standards accredited by Lifeline New Zealand.

If you are interested in becoming a telephone counsellor with Lifeline see our website for details.

www.lifeline.co.nz
Section of Jane’s transcribed interview 1 08/01/2013

Jane: Mmm three years it was um August, I can’t remember the exact date, but August 2009 and I haven’t had anything, any earlier symptoms so as far as I was concerned I was fine um I’ve had two big trips both overseas, one to America, I’m American by birth and went to see my parents, my kids husband and I and came home went straight over to Australia to Melbourne for a conference where I was speaking and Saturday night I had a splitting headache couldn’t like couldn’t think and I don’t get headaches and then I um I woke up on Sunday and just wasn’t right, I felt really anxious felt like I um yeah I’m not right, I’m not right but everything was fine, physically um flew home on Monday. Monday night, Tuesday morning I couldn’t walk straight, it happened so fast. In a matter of two weeks I was, I had an MRI cos I went to the emergency room because I couldn’t lift my right foot and I was at school and I was walking up the steps and one of the Dps or the Dp was behind me and he goes what’s wrong he could just my gait was right and um he said what’s wrong and I said I don’t know and I just don’t feel right and I went to stir my coffee and I could only go like that *backwards and forwards now circular* I couldn’t go around and um so my husband took me to the emergency room dropped me off because my daughter was two so he goes I’ll take you drops me off and a friend meet me there. I was there about eight hours and the last thing well they said you’ve had a stroke because my right eye was a bit distorted by my vision my voice was slurred my right arm was a bit less able you know just the strength was not there. And so in the end they said they’re going to do an MRI boom *snaps fingers* the covered in lesions so with MS and down in my spinal cord and the largest one or the most active one at this stage is one in my cerebellum so affects my um balance, motion and within a week from that I couldn’t stop vomiting I was just sick I couldn’t move my head, even opening my eyes like was sick as that was on the Saturday night and I went into hospital and I was there for nine weeks because I just went down, down, down, down, down it was terrible.

Lara: I’m sorry

Jane: Don’t say sorry, you know its

Lara: were you teaching at the time
Jane: I was, I was, I had just had, no I was I had been teaching two years since my daughter was born, so I had been two years and went off had my son two years I took off, I did my graduate diploma in Education then I came back, so I have been teaching about three years, five years total at that point, stage and um oh my students are really funny, they didn’t know anything and my boss came to see me and he said what do you want me to tell your students? It’s a really small school um, small 300 kids and we lived at the time right behind school, like right there so he came to see me and said look what do you want me to tell the kids they think your pregnant, they think, like they don’t think anything big, but they need to know so I said I need to go see them, and it was a really close community at school, where I teach and I went ah I went to the staff meeting. We have staff morning briefing every morning and we have a worship because we’re a Christian school so we have a worship and then um I said oh Bruce, my boss said Jane wants to talk and I just broke down I was like “huuhuuuuu” and everyone was like “what is wrong with you? And I told them, it just sounds like a death sentence at that stage it was still very painful, like I had just been diagnosed and I said “look I was diagnosed I think the day before um with Multiple Sclerosis and everyone was like “OH!” like the reaction was almost scarier than the reality you know I was like “oh is it that bad?” everyone was like “oh” I’m going to tell
Appendix H

Interview Map for Jane interview 1

“Jane”

Chronology of Interview 1.

J- Discussion about children and start of school, asks where I am staying
  L Discussion about staying and how I got to the café
  J Talks about the weather
  L & J Discussion about travel
    Shops and aquarium
  J – Consent forms
  L You can change your mind and discussion about journaling

J Sees people she knows and talks about couldn’t type and when she was first diagnosed
  L Asks how long diagnosed
    J Describes how she was diagnosed
      L Asks if teaching when diagnosed
      J describes how long teaching and telling people when she was diagnosed
      L due to topic shows concern
      J Thanks
      L reiterates that they can stop
      J Continues describing telling the people she works with
      L politely suggests for J to eat
      J Asks about schooling and a discussion about L’s high school and single versus co-ed schooling and childhood
        J Talks about her children, youngest child beginning school and her step son and birthday prep about Cook Island hair cutting ceremony for boys (J is married to a Cook Islander) cf for girls nothing
      L Apologises for making J talk and eat at the same time
J mentions survey and how it made her reflect on her experience at her school –
talks about how the school has been supportive and her routine, time with
children and relapses (p.12)

L asks about what causes relapses

J Discusses stress as the key factor. Not enough sleep. Guilt about
having to sleep instead of being with children. Talks about
dietary requirements and getting off coffee. Reiterates the support
from colleagues and family

“I have never been felt or made to feel ashamed…to feel bad
for having a disability”

L Mentions time off with M.S

J Talks about being paid and support of D.P. community and
friends and insurance then goes on to discuss about nationality
and rehab

L Comments about another rehab unit

J: Discusses in detail about her experiences and
friendships in the rehab unit, how her world view has
been impacted by her experiences and how in turn this
has affected how she teaches then moves to how it
impacted her children.

L Asks if they understand now

J Discusses how she has had to change her parenting and living in
the moment

L Asks about how she came to NZ

J Describes how she came to NZ, what she likes about NZ and her marriage

L Comments about 10 years and a discussion about special anniversaries
and citizenship

J Talks about refugee population of town, celebrating and family –
especially about Mum and parents. The focus on Mum then turns to what
she can’t do as a mum now – cycling a discussion about Tricycles and
costs. Then back to family and Mum coming out to be with J

Talks about her family’s reaction (overseas) including sister who thought
she was dying and cousins negative attitude because she didn’t look ill
after having chemo
All the little things | Appendices

**Moves onto symptoms - floaties**
L comments

**J Continues on symptoms and treatment and getting better.**

Seeing her students and the radical treatment of chemotherapy asks if L has to get steroids
L Comments
Discussion about steroids and effects
J Talks about vision if treatment fails and “well-meaning people”
L Comments

**J Appreciation of people/impact on children** and success of chemotherapy
L Asks about students
J Talks about challenging students and emotions
L Apologises
J Talks about empathy, world view and asking for help
L Comments
J Discusses counselling and cutting back on school commitments

L worried taking time up
J Continues about afternoons off and support of management
L Comment
J Time with children important for memories
L asks about new class
J discusses about the group of three students – thinking about the future
L asks J to revisit the loss she felt
J Grieving process – why she asked L about impairment. Everyday life and asking for help and focuses on the support of family and friends
A discussion of her blog diary and FB support group as part of her ‘therapy’ - **about sharing her story (p.33)**
Discussion about Google searching names and research

**Discussion about disability and different experiences** –
sharing of these p 34

Finishing up discussion about video dairying if needed because of relapses
Appendix I

Examples of failed stanzas for survey poem “I am, am I?”

I
Wrong end of the depressive spectrum
Lengthy time off work
“You are stronger than this”
No leeway

II
Dizzy, off the boil and unwell
Fine at home

(Draft, “I am, am I?” XVIII, 29/11/13)
Appendix J

Crafting scholARTistry: The poetic devices.

Even if the mind resists, the body responds to poetry. It is felt

(Richardson, 1997, p. 180, original emphasis)

In Chapter 2 I positioned this thesis within the theoretical space of poetic inquiry as I felt that it was a way in which could make the lives of New Zealand secondary school teachers living with an impairment and/or chronic illness be heard and felt. An integral part of poetic inquiry is the acknowledgement of the crafting and the poetic devices used in the production of the poetic texts (Cahnmann-Taylor, 2009; Faulkner, 2007; Percer, 2002; Piirto, 2009; Wiebe, 2015). Method and process are woven together and as part of the conventions of Poetic Inquiry it is important that I discuss the “literary form”, as the impact of the poetic devices of tone, voice are important part of the process. They speak to “how” and “why”. Furthermore, it makes explicit the construction and representation of the poetic texts. In chapter two I outlined five ways of being in poetic inquiry the ones that are perhaps pertinent to this chapter are “holding forth for multiple truths”, “exploring literary form and theory”, and “creating possibility through iterative remixing” (Wiebe, 2015, p. 158). In Chapter 1 I also acknowledged that I have an undergraduate degree in English, a large part of which focused on creative writing. Piirto (2009) extols the benefits of “knowing your craft”. In this section I seek to unpack the craft and make explicit the processes (linked with method as processes) of how I wrote the poetic texts in this thesis.

Further to this, Eisner (1991) asked arts-based researchers to think about what they have sacrificed for research in their artistic representations. This can also be viewed from another perspective – what have I sacrificed for the artistic representation? In the introduction of Chapter 2 I described how my bravery fails me in my attempt to produce a truly artistic exegesis, one without the safety net of traditional research qualities. In saying that, I do have to acknowledge that there is some “scholARTistry” in what I have produced throughout this thesis. I feel it is important to explore what I have sacrificed for both research and artistry. The processes of poetic transcription was described previously in this chapter, and I now turn my attention to the aesthetics or artistry of the poem and poetic techniques, bearing in mind that the writing process of this poem began with the data and in-depth knowledge of the data, but was written up in an “unfettered explosion” with only the data and my research question as a guide before refining techniques were...
All the little things | Appendices

applied. A further exploration of the poem will be incorporated into the discussion in Chapter 6, the final findings chapter.

Drawing on Faulkner’s (2007) work, who argued the importance of discussing the aesthetic qualities of research poetry, and acknowledging that I (as the researcher-poet) do have a stake in my own aesthetics (Faulkner, 2007), this section explores the poetic techniques used in the poem in an effort to be transparent about why I chose to structure it the way I have, and why I chose certain statements but not to reanalyse the poem. Laying bare the construction and crafting of the poem makes the “meaning leaning” more explicit; it is also important for the research process to ensure rigor and trustworthiness. I did not realise I had used many of the techniques explored here until I went back and critically examined what I had written. With a sense of mindfulness returned, I am able to view the techniques that I employed with some distance. In an arts-based study, the artistic techniques are as important as what data is used (see The Survey section about poetic transcription) from the title, to the order of the words to the commas, semicolons and full stops are important in creating the meaning, for imparting what it is like being a New Zealand Secondary school teacher living with impairments and/or chronic illness.  

Beginning with the short title of the poem, *I am, am I?*, this is inspired by Colin McCahon’s painting titled *Victory Over Death 2*, as it spoke to the idea of questioning identity both privately and publicly, of confidence, and also uncertainty or vulnerability. I had this title and the image in my mind even before I sat down to write the actual poem, influenced by my readings of the raw data. I think the statement “I am, am I?” helps, in terms of the poem, to break down traditional stereotypes that surround impairment and disability, if not teaching, then by immediately questioning any preconceived notions that the reader may have. I am also aware of a unit in New Zealand Secondary Schools year 9/10 English that is called “I am”, which explores students biographies through different writing genres, including autobiographical poems.

I wrote the poem as free verse. Free verse merely describes a poem with no specific rhyme scheme or formulae, in contrast to a sonnet, for example, which is a poem of 14 lines with distinct rhyme scheme and iambic metre. I included additional images like the bell ringing to orient the reader to the world of an imaginary school or schools. The participants used the personal *I* so it seemed logical to replicate this. The use of *I* in

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12 If you are not interested in the artistic processes used to create the data poetry in this thesis please feel free to skip to analysing the interviews
the poem has the effect of directly addressing the reader. Retaining the singular *I* instead of the pluralised *we*, created intimacy as well as an uneasy universality because the reader can become the *I*. This in turn has a “mile in your shoes” effect, making the personal political and the political personal. Politicising the personal is a key feature of both feminist and disability rights movements (Morris, 2014). “I am” ultimately reflects Eisner’s (1997) paradox, it universalises the particular.

The universalisation becomes even more explicit through the performance of the poem. I have presented the original I am survey poem twice at conferences – once at a Disability Conference (L. J. Sanderson, 2014a) and once at an ethnographic conference (L. J. Sanderson, 2014b). Each time I asked members of the audience to read a line each, at the Disability Conference, two lines were read out in American and Australian Sign Language respectively. Also at the Disability conference members also chose a line that spoke to them. But it was through the performance, the impact of reading and then hearing the poem, transformed the poem again – I becomes me, me becomes we.

The order of the lines was initially an intuitive act. It slowly emerged almost as a narrative, telling a fictionalised story of (a) disabled teacher(s), which simultaneously represents the individual but also the group (of survey participants). I do concede that the placement of “no work yet” was a concession to art rather than scholarly endeavour. The words themselves were suggested (Glense, 1997) as I examined individual qualitative survey answers for words or phrases, choosing words, phrases, or ideas that spoke to their experiences; as shown in the previous chapter via Figure 4. In the process, there were elements of participant’s stories that have been left out: “stories” they told to illustrate or expand on ideas, even ideas that were relevant to the larger picture but couldn’t be explored in a single line. However, their individual lines show a depth that could not be conveyed via traditional forms.

A single line per person also allowed me to use an “economy of words” that in turn provided impact and readability of the poem. For me, it was important that the poem had an element of readability so it would not alienate any reader (academic or layperson) through obscuring or complicated metaphors or excessive length. I recognise that poetry can be ambiguous – it takes a shared understanding or the creation of space for in order to bring understanding. To do this, poems should initially be recognised products of the poet-researcher’s construction, of time, of place, and I would suggest that is true of all research; poetry simply makes this more explicit/visible. It challenges traditional “knowledge production” and data representation (Richardson, 1997). Nevertheless, to
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lessen the impact of the ambiguous nature of poetry, I have tried to use plain language, white space, and the techniques previously described.

I tend to write poetry with the spoken word in mind, and as Cahnmann-Taylor (2009) described, these types of poetic devices have long been used to denote speed and intonation. With the spoken word in mind, techniques like rhyme and alliteration take on and create sound in an almost onomatopoeic sense. Alliteration in this poem focuses on the harsh consonant $t$ in “topics too taboo”. The alliteration reflects the anger, while the assonance resonance of double $o$ slows the pace down to emphasise the implications of being silenced. Essentially, all of these techniques are designed to provide space for the reader to observe, to think, to “taste the words” (Kuppers, 2013, p. 191). Ultimately, the use of literary devices aims to evoke and heighten emotion, thoughts, and feelings, recreating a sense of the experiences for the reader, allowing them to be felt (L. Butler-Kisber & Stewart, 2007; L. Richardson, 1997)

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13 Other poetic devices used include enjambment, repetition, rhyme/half-rhyme/end rhyme, and varied line lengths.
Disability Action Plan 2014-2018: cross-government priorities to make a difference

Ministerial Committee on Disability Issues’ priorities to advance implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) and the New Zealand Disability Strategy

All New Zealanders experience equal rights of citizenship

Vision

Safety and autonomy
I am safe in my home, community, and work environment. I feel safe to speak up or complain, and I am heard. Those assisting me (professionals and others) have high awareness, and I do not experience abuse.

Wellbeing
I feel dignity and cultural identity through a balance of family/community, mental, physical and spiritual wellbeing. I can earn and grow my wealth on an equal basis with others.

Self determination
I make my decisions myself based on my aspirations. I have access to information and support so that my decisions are informed.

Community
I feel welcomed by my community. I feel respected for my views and my contribution is received on an equal basis with others.

Representation
Disabled People’s Organisations (DPOs) represent collective issues that have meaning for me (based on lived experiences) in a way that has influence and impact. DPOs are sustainable with the capacity to deliver their role and evolve over time.

Person-directed outcomes

Increase employment and economic opportunities
This shared result focuses on building employers’ confidence to employ disabled people and provide accessible workplaces, opportunities for work experiences, entrepreneurship, and education achievement and skill development. It recognises obligations in the CRPD, particularly Article 9.

1. Priority: Increase the educational achievement of disabled children and adults.
   a. Build capability for inclusive education to improve delivery in the CRPD context.
   Lead: Ministry of Education

2. Priority: Increase the number of disabled people who transition from school and tertiary education into employment.
   a. Improve transitions.
   Lead: Ministry of Education

3. Priority: Increase the number of disabled people, including long-term unemployed disabled people, in paid employment and self-employment on an equal basis with others.
   a. Implement a long-term work programme to improve employment outcomes for disabled people including the development of guidelines on reasonable accommodation.
   Lead: Ministry of Social Development

b. Develop better alternatives to replace the minimum wage exemption, looking at existing and new schemes.
   Lead: Ministry of Business, Innovation and Employment

4. Priority: Increase the number of employees who are confident in employing disabled people, with the public sector taking a lead.
   a. Government to take a lead in employing disabled people and providing paid internships.
   Lead: Office for Disability Issues

Ensure personal safety
This shared result focuses on promoting systems and practices to protect disabled children and adults in all settings. It recognises obligations in the CRPD, particularly Articles 11, 12, 13, 14, 15, 16, 17, and 23.

5. Priority: Reduce barriers to disabled people making decisions to determine their own lives.
   a. Ensure disabled people can exercise their legal capacity, including through recognition of supported decision making.
   Lead: Office for Disability Issues

6. Priority: Reduce the number of disabled children and adults who are victims of violence, abuse or neglect.
   a. Educate disabled people about their rights not to be abused and what abuse is.
   Lead: DPOs

   b. Investigate funding of DPO partner programmes that support disabled people to speak up for themselves and ensure this is linked with victims of crime work.
   Lead: Office for Disability Issues

   c. Increase safeguards for disabled people who are socially isolated and develop initiatives to remove what is socially isolating them.
   Lead: DPOs

   d. Review the current care and support processes for disabled children who are (or are likely to be) subject to care under the Children, Young Persons and Their Families Act 1989 to establish whether they are being treated equally and fairly, and in their best interests, and if not, to provide advice on changes needed to legislation, operational policy, operational delivery and monitoring and enforcement.
   Lead: Ministry of Social Development

   Defined until 2015/2016:

c. Complete a stocktake of key reports, recommendations and findings on preventing violence, abuse and neglect, including the cultural context for disabled Maori and Pasifika.
   Lead: DPOs with the Ministry of Social Development and the Ministry of Health

7. Priority: Increase the responsiveness to disabled people of civil defence and emergency management arrangements.
   a. Promote implementation by local civil defence and emergency management sector of the guidelines for inclusive practice including learnings from experiences of disabled people in the Canterbury earthquakes.
   Lead: Ministry of Civil Defence and Emergency Management

Ref: A7514025  Date: 31 March 2014 – Office for Disability Issues

Approved by the Ministerial Committee on Disability Issues on 8 April 2014

First page of NZ Disability Action Plan 2014-2018
Minimum wage exemptions for people with disabilities

Minimum wage exemptions for people with disabilities: Information for employers
The Minimum Wage Act 1983 helps some people with disabilities to get work by allowing Labour Inspectors to give minimum wage exemptions in certain circumstances.

Labour Inspectors will issue a minimum wage exemption only if they think it is reasonable and appropriate to do so. They can refuse to issue one if they think the employee should be paid the minimum wage, or if the wage offered is unfair. (View the current minimum wage rates).

How to apply for a minimum wage exemption
Before you contact the Labour Inspector, you and the employee (or prospective employee) should discuss the job and possible wage rates. The employee should have the opportunity to have an independent representative or advocate present during these talks.

Labour Inspectors only become involved if the wage rate offered is less than the minimum wage. If you intend to pay a new employee less than the minimum wage you should contact a Labour Inspector as soon as possible.

When doing this, think about how you could help the employee to earn more by doing things such as:
- providing training
- tailoring the content of the job to the employee’s abilities
- providing supervision or support
- making physical changes to the workplace, or changing the way the work is done
- asking the employee to do a different job.

You and the employee have to negotiate the wage rate in good faith - that is, openly, honestly and without misleading each other.

Once you’ve negotiated a possible wage, you should contact a Labour Inspector in your region. The Inspector will visit your organisation to confirm that the wage and process is fair and reasonable. They will also check that the employee has a written employment agreement.

How do I show that the wage is fair?
You will have to give reasons for the wage level you have negotiated. To do this, you may find it helpful to use a wage assessment tool to estimate the employee’s job performance and to provide concrete evidence for why you think the proposed wage rate is reasonable. The Labour Inspector will need to be satisfied that the employee agrees with the rate.

Before approving the negotiated wage, the Labour Inspector will want to confirm that:

- the employee’s disability really stops them from earning the minimum wage
- the employee has had an independent representative
- the work is suitable for the employee and they will get appropriate supervision and training
- you are offering the employee an employment agreement that meets all other minimum employment standards
- the wage relates to the employee’s ability to do the work
- the wage is consistent with the wages of other people in similar circumstances who have exemptions for similar work
- you have done everything that can reasonably be expected to do to help the employee do the job well.

**What happens if employees are union members?**

If the employee is a union member with a minimum wage exemption permit, the union has to agree to the employee being paid at the rate stated in their permit, rather than at the pay rate in the collective agreement.

**Where can I get more information?**

Contact the Ministry of Business, Innovation & Employment through our website or call 0800 20 90 20 during business hours.

If an employee has any concerns about how the wage rate may affect their benefit or tax exemption they can contact Work and Income by calling 0800 559 009 or by emailing information@msd.govt.nz.
Appendix M

Artist consent forms
Dear Jessica and Lianna,

I am a PhD Candidate at the University of Otago in New Zealand, writing my thesis about the experiences of disabled secondary school teachers.

I am writing to request your permission to include the following material in my thesis, for which I believe you own the copyright.
I intend to use the material as follows:

1. In its original form in my literature review.
2. To illustrate the concept of inspiration porn
3. When completed, a print thesis copy will be deposited with the University of Otago Library.
4. An electronic copy will be deposited in OUR Archive, the university’s research repository. The completed thesis will be fully accessible on the Internet via OUR Archive

I am seeking a non-exclusive, worldwide, perpetual licence to use this material in the way described above. The work(s) will be fully referenced, including any copyright attribution as specified by you. If you consent, please complete the form below and return a copy to me by email.

Yours sincerely,
Lara Sanderson

________________________________________________________________________

I am the rights holder and grant permission for the use of the material as described above:

By [Name & Title] Jessica + Lianna Oddi (Creators of The Disabled Life Blog)
Date: January 12th, 2017
Company/Affiliation The Disabled Life (www.thedisabledlife.tumblr.com)

(Optional) Please attribute as follows, if different from standard academic acknowledgement:

“Spectators” by Jessica + Lianna Oddi of The Disabled Life
www.thedisabledlife.tumblr.com

Rossetti, C. 1890-1894 “Sonnets are full of love and this my tome” – This poem is my mother’s favourite I learnt it off by heart as part of an English paper called Victorian Literature in 2006 the full poem may be viewed here: https://www.poets.org/poetsorg/poem/sonnets-are-full-love-and-my-tome