

“This journey has definitely changed me”

An ethnographic narrative exploring disabled peoples' lives
through embodied experiences and identity negotiation

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Abstract

Following calls from both disability studies and anthropology to provide ethnographic accounts of disability, this thesis presents the narratives of nine people living with disability, focusing on what disability means to them, how it is incorporated into their identities, and how it shapes their lived experiences. While accounts of disability from disability studies often focus on the social model of disability (Shakespeare 2006) and emphasise social stigma and oppression (Goffman 1967, Susman 1994), anthropological accounts often emphasise the suffering and search for cures (Rapp and Ginsburg 2012) that is assumed to accompany disability. Both approaches have their benefits, but neither pay particularly close attention to the personal experiences of individuals, on their own terms.

By taking elements from both disciplines, this thesis aims to present a balanced view that emphasises the lived experiences of individuals with disability, and uses these experiences as a starting point for wider social analysis. The primary focus of this thesis is understanding how disability shapes an individual's identity: what physical, emotional, and social factors influence how these people are perceived – by themselves and others? Through my participants' narratives I explore how understandings of normal bodies and normal lives influence their sense of personhood, and investigate the role of stigma in mediating social encounters and self-concepts. Furthermore, I undertake a novel study of the role of technology in the lives of people living with disability. My work explores how both assistive and non-assistive ('general') technologies are perceived and utilised by my participants in ways that effect not just the physical experience of disability, but also social perceptions and personal understandings of the body/self.

I argue that although the social model of disability is an excellent analytical tool, and one which has provided tangible benefits for disabled people, its political nature can sometimes lead to a homogenisation of disabled experiences; something which this thesis is intended to remedy by providing ethnographic narratives of disability, grounded in the embodied experiences of individuals.

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Chapter One: Introduction

“Uh, who am I? I’m Alex...”

I’m Alex, that’s it. I don’t introduce myself as ‘Hi I’m Alex, I’ve got cerebral palsy’”

Throughout the course of doing research for this thesis, I sought to gain a greater understanding of “the disabled experience” as it related to technology use. I spent time with a group of individuals with varying physical impairments, playing wheelchair basketball with them, casually chatting with them, emailing them, observing them and interviewing them. As my fieldwork stint came to an end, and I began to write up my findings on “the disabled experience” I found myself struggling to synthesise my participants’ experiences – with one another and with relevant literature. I found “the disabled experience” to be a misnomer; implying a level of homogeneity that simply does not exist.

Through multiple attempts at writing, trying to make sense of my research findings, and trying to get both of these to align with related literature; I have found what I consider to be the most interesting issues in my research. Despite my initial focus on the importance of technology in their experiences my participants (with a few notable exceptions) had little to say about their relationships with technology. Rather than a uniform set of understandings about technology and the life experience of living with disability, I found instead a diverse range of different relationships with technology, understandings of the meaning of disability, and attitudes towards both personal and social identity.

This shift in the focus of my research has proven fertile; it raises important points regarding experience, identity, and representation that have not yet been fully explored. Thus, this thesis seeks to address a relative dearth of individual experiential accounts within disability research by focusing on individuals’ lived experiences of disability, with an explicit emphasis on identity.

Background

In October 2013 I spoke to a PhD candidate from the University of Auckland who was studying young men with Duchenne Muscular Dystrophy (DMD) and their attitudes towards digital technologies; particularly videogames¹. I had initially wanted to investigate the importance of videogames for disabled people, focusing on the potential for physical rehabilitation, social interaction, and quality of life; however, after discussing this with colleagues I decided on an exploration of the role that technology (as a general category) played in the lives of disabled people.

As mentioned above, the initial results were not what I had expected, but proved useful in developing my research and led to some interesting issues worthy of further study. These issues centred on self-concepts and general disability-related experiences more than technology, but there were some fascinating overlaps which will be explored in later chapters. Given these unexpected results, my core questions were reformulated as: is the category of 'disabled people' as homogenous as it is often made out to be? How diverse are the lived experiences of these people? How and why do disabled people manage their identities and assert their status as full persons? And, what is the role of technology in the lives of disabled people?

Considering these questions, I aim to present the diverse life experiences of my participants to support my argument that the homogeneity assumed by some proponents of the social model of disability is problematic. Regardless of whether an individual identifies as disabled or not, such identifications are not necessarily harmful for their sense of self or social involvement, and the physical impacts of impairment cannot be overlooked. Following this, I argue that an emphasis on ethnographic accounts of disabled individuals provides a richer, more comprehensive view of the lives of disabled people, and can prove fruitful for further disability research.

¹ Due to the degenerative nature of DMD, many young men ended up bedridden with little voluntary movement and videogames were a way of providing some quality of life. One quote from a participant really stood out, and it was paraphrased as "If I can't play this game, I might as well be dead".

Terminology

Before moving forward I will take the time to introduce and clarify the terminology used in this thesis. The use of terms such as ‘disability’, ‘impairment’, and ‘disabled people’ are highly contested within disability studies and in contemporary usage; thus far, I have assumed that the reader has understood these terms in a common-sense way. However, as I am about to engage with a range of varying literature surrounding disability – in which a lot of authors do not agree on terminology (see Gleeson 1997) – it is worth explaining how I use these terms.

Firstly, ‘disability’, ‘handicap’, and ‘impairment’ are often defined as distinct terms, however, in recent years handicap has fallen out of usage as it is seen as unnecessary and carries a significantly negative connotation, and as such I do not use this term. The separation between disability and impairment has been attributed to the Union of the Physically Impaired Against Segregation (UPIAS) in their discussion of the “Fundamental Principles of Disability”, summarised in 1976. In this document, UPIAS state that,

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS 1976:4)

In this statement (which also led to the formulation of the social model of disability) UPIAS marked a clear separation between disability and impairment. Contrary to popular understandings of the term disability – that is, synonymous with impairment – UPIAS defined disability as the lack of opportunities and involvement due to social structures, ranging from the immaterial (prevailing negative social attitudes), to the physical (a lack of accessible infrastructure). Impairment was defined in physiological terms, that is, a physical lack, loss, or abnormality – all of which carry negative connotations. The most neutral term available to describe impairment is ‘difference’, which is often far too vague, and thus the negatively coded words are most commonly used. I maintain this distinction between impairment and disability in my writing wherever possible; however, the reader can consider them interchangeable as there are many situations where it is hard to untangle the social from the physical.

Within academia, the difference between impairment and disability is often maintained, and is rarely challenged; however, terms used to describe individuals and collectives are still a contestable area. Similar to the preceding terminological debate, there are three main terms: 'the disabled', 'disabled people', and 'people with disabilities'. 'The disabled' is no longer considered acceptable as it is dehumanising, and overly homogenous, bringing to mind images of some incomprehensible other, a collective of beings indistinguishable as individuals. We are left with two acceptable terms to use when describing impaired individuals or groups: 'disabled person/people' and 'person/people with disabilities' (PwDs).

The debate between the terms 'people with disabilities' and 'disabled people' is less clear-cut. Many disabled people prefer PwD because it is more humanising, and it "puts the person first", however some academics are opposed to this term as it implies that disability is something that an individual has, in clear opposition to social model thinking. Alternatively, some academics and advocates oppose PwD on political grounds, as the term is,

a retrograde terminological change which effectively depoliticises the social discrimination that disabled people are subjected to. He [Paul Abberley] is not prepared to accept the displacement of the adjective 'disabled' until disabled people are actually permitted to experience social life in fully human ways (Gleeson 1997:182)

Although the term 'disabled person' implies a label that is ascribed to a passive (non-agential) recipient, in its academic usage it focuses on disabled as a verb rather than an adjective: rather than disabled people being "people who *are* disabled" they are "people who *have been* dis-abled". Following this, I refer to those with impairments as 'disabled people' as I believe it is worth making clear that disablement is a complex social issue, one which involves physiological difference but cannot be reduced to it.

During this discussion on terminology, I have touched on two important historical factors which have influenced disability research: UPIAS's "Fundamental Principles of Disability" (1976) and the social model of disability. Below I will expand upon these to provide a historical context of disability issues.

History and context

Although it is difficult to locate the exact date in which disability studies sprung into existence as a fully-fledged academic discipline, it is clear that academic works relating to disability have been around for at least the past five decades². Certainly, questions about disability and ‘the abnormal’ have shown up throughout the centuries, yet it was not until the twentieth century that these questions multiplied, following other civil rights movements of the time.

Two key historical moments for the formulation of contemporary ‘disability studies’ field took place on opposite sides of the Atlantic. In England during 1975, the Union of the Physically Impaired Against Segregation (UPIAS) and The Disability Alliance (TDA) met to discuss the fundamental principles of disability, concluding that disability was not a physiological issue, but rather the result of social process that denied impaired people access to equal opportunities in almost all areas of life. Summarised in 1976, this meeting had implications for disability research and advocacy on a global scale, particularly due to its distinction between impairment and disability, thus locating disability in social structures rather than individual bodies. Fifteen years later in the United States, the Americans with Disabilities Act (ADA) was enacted, which aimed to “provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities” and “to ensure that the Federal Government plays a central role in enforcing the standards established in this Act on behalf of individuals with disabilities”³. While there have been many other important events, these two events are considered to be those that have had global implications in recognising the importance of an inclusive society, and creating a legally justified space for disability studies.

Moving to a more local, contemporary setting, I will now outline the current situation for disabled people in New Zealand. In 2013, 1.1 million people (approximately 24% of the population) reported identifying as disabled (Statistics New Zealand 2014a), and these

² Some scholars state these works are indicative of a cohesive field (for example, Gleeson (1997)) while others argue these works have “only recently recognized [themselves] as a political, discursive entity” (Davis 2006; xvi) - whatever the case, disability studies is still a relatively recent academic development.

³ Americans with Disabilities Act, 1990, Pub. L. No. 101-336, 101st Cong., 2nd. Sess. (July 26, 1990) U.S. Government Printing Office

people are afforded state-recognised protection and freedoms from a number of sources. Firstly, there are two non-disability-specific acts that ensure basic human rights (Human Rights Act 1993; New Zealand Bill of Rights Act 1990) for the entire population; however, recently two additional disability-specific initiatives have been adopted.

In 2000 the New Zealand Disability Strategy (NZDS) was introduced to provide “a framework to guide government agencies making policy and services impacting on disabled people” (Office for Disability Issues, n.d.) and in 2008, New Zealand ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which aims to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (UNCRPD; Article 1, n.d.). Although both of these disability-specific initiatives essentially restate universal human rights - albeit with explicit emphasis on disability - the importance of these documents lies within their designations of responsibility. The Minister for Disability Issues (with the help of the Office for Disability Issues) is required to provide an annual progress report to Parliament on the implementation of the NZDS, and signing the UNCRPD makes the state accountable to the United Nations. Although there are debates surrounding the actual benefits of such institutional protection⁴, they are generally considered to be beneficial, at least for exposure’s sake.

However, for my participants these institutional protections were often not recognised – not for lack of awareness, but because they were seen as essentially unnecessary. For example, although Carly acknowledged difficulties in finding employment, she did not consider it a violation of her human rights; and Alex stated outright that “our human rights aren’t getting violated or anything”. Indeed, Alex highlights an issue that is perhaps more important, at least for my participants;

We’ve had to... try and fight through the pain and have a disability and do it every day and own it – we don’t get no money for that. They offer you a fuckin’ disability allowance which is sweet fuck-all

⁴ Many question to what extent the government actually enforces these acts, for example, citing the difference between employment rates of non-disabled (72%) and disabled (45%) adults (Statistics New Zealand 2014b).

Funding is a significant hurdle for a number of disabled people, particularly considering low employment rates. Although Alex admits he earns too much to be eligible for the disability allowance, he implies that it is unjust - he still has his disability and the associated costs. As a note, the “rights” Alex talks about above are not the basic human rights set out in the above legislation, but rights to a basic level of disability-specific support.

In New Zealand, the Ministry of Health is responsible for providing practical assistance to disabled people through its Disability Support Services (DSS). For the most part, in order to be eligible for any support from DSS, an individual’s disability must “limit [their] ability to function independently, *to the extent that ongoing support is required*” (NZ Ministry of Health, n.d.; emphasis mine), and if this criterion is met they are then subject to a needs assessment to determine the level of support they will receive. Individuals with certain neurological conditions, developmental disabilities, or a disability co-existing with another injury or illness may also be eligible for funding, although the Ministry of Health does not provide a list of examples, instead calling on individuals to have a needs assessment carried out to determine eligibility. The Ministry of Health is currently trialling a range of new services, however, all of these trials are taking place in regions other than Wellington, and as such my participants appear to have no knowledge of - or at least no thoughts about - such trials. Overall, many are grateful that these support systems exist, although they have also expressed frustration at the eligibility criteria which they consider to be a little “out of touch” with the realities of the situation.

This contextualisation serves an important purpose: even though I argue for a greater understanding of, and engagement with, individual experiences, such experiences are shaped by the historical advances made by disability organisations, and the current state of legislative and financial support and protection. For the most part, my participants expressed relaxed acceptance of their situations, and I believe it is partly because of the support systems outlined above that they are able to do so; indeed, as the reader will see later, Amir’s narrative expresses this quite explicitly as he explains the response to impairment in New Zealand compared to Iraq.

Finally, in order to give the reader some sense of direction, this thesis is arranged as follows: in the second chapter I establish my theoretical framework, drawing from disability studies, anthropology, and identity theory to outline how and why I study individuals; in the third chapter I explain my research methods and some of the methodological and personal issues that arose, how I dealt with them, and what they revealed to me about this work; the fourth chapter introduces my participants and gives a brief description of them, as well as the individual and shared attitudes of self-identification; the fifth chapter focuses on individuals' lived experiences and the physical and attitudinal elements of disability; the sixth chapter discusses the related concepts of personhood, normalcy, and stigma as they relate to my participants' understandings of the relationship between social and personal identity; chapter seven is a novel discussion of the role of technology in the lives of my participants, something which is often overlooked in disability research; and chapter eight includes a summary and synthesis of the preceding three chapters, before I summarise the main points of the thesis, reflecting on what I have found, and outline potential directions for future research. The second and third chapters are constructed in such a way that they attend to the first half of my argument theoretically, showing how and why homogenised accounts of disability are problematic, while providing a justification for my individual emphasis. Chapters four through to seven address the second half of my argument, by providing an ethnographic account of individual experiences of disability in order to present an alternative understanding of disability.

Chapter Two: The theoretical lens

Disability studies has been a crucial discipline in formulating a theoretical framework and in this section I will provide a brief overview of the main theoretical approaches that I have used. Similarly, anthropology has been important in providing a different viewpoint from which to observe some of the issues related to disability. Thus, while focusing on the two key areas that prove most useful for all aspects of my thesis - disability and identity – I will draw from both disability studies and anthropology, and explore the relationship and overlap between the two. There are, of course, other theoretical areas of importance and they will be contextually situated in later ethnographic chapters.

For the purposes of my research, the single most important concept that has been discussed within disability studies is the social model of disability (referred to previously, and hereafter, as simply “the social model”). The social model, as explained earlier was first formulated – albeit not labelled as such – by UPIAS in 1975, with the assertion that disability was a social issue rather than an individual, medically defined one. The latter idea of disability being located within individual bodies is referred to as “the medical model”, and entails an “undue emphasis on clinical diagnosis” (Brisenden 1986:173) and management and treatment of impaired bodies. These two models are often dialectically opposite, and the medical model is heavily critiqued in disability studies. Although the social model has some shortcomings (and the medical model has some benefits) it is still the main framework in which almost all disability studies work is situated - sometimes unconsciously (Brisenden 1986; Gleeson 1997; Söderström 2011; Shakespeare 1994, 2006).

However, despite the prevalence of social model approaches it has not been accepted uncritically. Critiques of the social model have come from both disability scholars (Shakespeare 2006) and social scientists external to disability studies (Whyte & Ingstad 1995; Lupton & Seymour 2000). Below I will outline the three main critiques of the social model that have been apparent in my research and influenced my theoretical position on this topic – they are:

- (1) The social model, with its emphasis on the disabling conditions of society and fervent rejection of the medical model, often overlooks the physical, embodied effects of disability/impairment;
- (2) The social model assumes a level of homogeneity - in both experience and belief - amongst the disabled population which simply does not exist;
- (3) The social model (although a creation of 1970s England) is considered to be a universal explanation for disability, failing to account for culturally specific understandings of both impairment and disability – that is, what physiological “deficits” are considered impairments, and what impairments are considered socially devalued or limiting.

Below I will address each of these criticisms in turn, explaining why I find them problematic for my work and how they have influenced my theoretical approach.

The not-so-social model of disability?: Bringing the body back in

The experience of impairment is not always irrelevant, neutral or positive. How can it be when it is the very reason used to justify the oppression we are battling against? How can it be when pain, fatigue, depression and chronic illness are constant facts of life for many of us? (Crow 1996: 57)

Liz Crow, in her rethinking of the social model succinctly summarises the argument that there is often an overwhelming emphasis on the social construction of disability in social model approaches. This focus on society is certainly well-placed; however, it is not the only cause of disablement and this emphasis can cause some significant theoretical and practical issues for disability work.

One of my participants was already relatively well acquainted with the social model and although she agreed that the medical model was often too simple an explanation for her life experiences, she admitted that the physical issues that she faced in daily life simply could not be accounted for by the social model. It is not society that stops her from being able to enjoy exercise; it is her lack of leg function. Other participants expressed similar

opinions despite having no knowledge of the social model, that is, most other participants admitted that societal expectations and infrastructure shaped what they were able to do, but they also acknowledged that even in an open-minded and accessible utopia they would still be unable to do many things that they enjoyed.

It is in my attempt to 'bring the body back in', that I turn to another theoretical approach, one which plays a supporting role in my thesis: embodiment. Embodiment "requires that the body as a methodological figure must itself be nondualistic, i.e., not distinct from or in interaction with an opposed principle of mind" (Csordas 1990:8). In other words, an embodiment approach focuses on the preobjective perceptions and experiences of individuals who "are simply in the world" (Csordas 1993:137). Such an approach is intended to avoid "objectifying bodies as things devoid of intentionality and intersubjectivity" (Csordas 1994:4) and this is especially relevant to my work, as much work on disability – from various disciplines – tends to treat the 'disabled body' as an object set against social and cultural forces, rather than a lived-in subject that actively engages with them.

Furthermore, because physical disability – like chronic pain - is "something quintessentially lived and experienced in the body" (Jackson 1994:201) exploring the embodied aspects of my participants' experiences is essential. As Csordas (1990) explains, individual understandings of self-identity are products of a culturally-informed process of self-objectification, thus in order to understand how identities are negotiated I must examine, as best as possible, the preobjective physical experiences of my participants as they play a significant role in this process.

This bodily awareness is demonstrated in Tom Shakespeare's' (2006) critique of a "barrier-free utopia" (201); the notion, once again implicit rather than explicit, that disability as it is currently theorised will cease to exist once an enabling environment exists, free of imposed limitations. Whilst a more actionable 'solution' to disability this is extremely difficult in practice due to resource constraints, and is complicated by the assumed homogeneity of the disabled community. As Shakespeare (2006) explains, different impairments may require conflicting solutions as "blind people prefer steps and defined curbs with indented paving, while wheelchair users need ramps, dropped curbs,

and smooth surfaces” (201). Furthermore, there are variations ‘within’ impairments too, for example, “some visually impaired people access text in Braille, others in large print, audio tape or electronic files” (201). Shakespeare furthers this critique by asking what this utopia would look like for people with learning difficulties or autism spectrum disorders, which cannot be addressed by infrastructure developments.

The second critique of social model thinking outlined above - that of an assumed level of homogeneity across all disabled people - seems at odds with some of the goals of the model itself. How are assertions of individuality reconciled with a unified movement when they open the door for an understanding of disability as an individual problem?

As mentioned earlier, in 2013 the disabled population in New Zealand was approximately 1.1 million people; although this number comes from self-reporting (thus they all identify as disabled), I believe it is unreasonable to assume that roughly one quarter of this country’s population share the same view of their situation. Assuming such a level of homogeneity appears contradictory to claims by advocates about respecting the individual experiences of disability, and the push for the term ‘people with disabilities’ as a humanising method. Certainly, this homogeneity has both political and psychological benefits for disabled people, as it provides a sense of unity and belonging, and allows for a united front to be presented in politicised debates (Shakespeare 2006). However, aside from causing a tension between personal and political identification, this homogeneity is also intimately tied to a problematic aspect of the social model.

This aspect initially caused me trouble when I began my fieldwork, particularly due to my internalisation (and even expectation) of it as fact; “[T]he social model assumes what it needs to prove: that disabled people are oppressed” (Shakespeare 2006:201). One is hard pressed to find disability studies literature where disabled people are not portrayed as, or explicitly stated to be, oppressed. There is no doubt that many disabled people *are* oppressed, but to imply that *all* disabled people - regardless of geographical location, social status, income, race, and gender - are oppressed, is too broad a generalisation; not everybody in my research even considered themselves disabled, let alone oppressed.

Because the social model defines disability in terms of negative societal (re)actions, it “defines disability as oppression” (Shakespeare 2006:201; emphasis mine). This definition’s circular logic creates issues in disability research as “it is logically impossible for a qualitative researcher to find disabled people who are not oppressed” (Shakespeare 2006:201).

The final critique of the social model comes from a more anthropological position, arguing that the social model is seen as universally applicable, despite cultural variation in definitions of impairment and social disablement. In their article outlining the “Principle of Normalization” (1982), Wolfensberger and Tullman succinctly summarise not only the distinction between difference and deviance, but also the fact that social definitions of acceptable bodies are culturally constructed:

Thus deviancy is in the eye of the beholder, and is also culturally relative... different cultures define different types of human manifestation as deviant (Wolfensberger & Tullman 1982:132)

Although their concept of normalisation has been criticised by disability scholars, it is their assertion that the category of ‘deviant bodies’ is culturally informed that is important for this discussion. Since their article was published, multiple scholars from various disciplines have echoed these sentiments, arguing that impairment and disability (to use the social model terms) are both culturally defined, and to talk broadly of ‘disability’ is to ignore this diversity⁵. Below I will turn to anthropology to expand on this critique.

Anthropology and disability

Considering anthropology’s fascination with “what it means to be human” (Rapp and Ginsburg 2012:166) it is surprising that disability research within anthropology is often

⁵ Others (such as Whyte & Ingstad (1995)) have argued that the usage of “disability” is not intended to be universal, but rather refers specifically to the West [referring to developed countries exemplified by those in North America and Europe].

confined to the subfield of medical anthropology, and predominantly focuses on “the search for healing and cures” or “suffering” (181). Although medical anthropology has been a “hospitable home” (166) for disability research, Rapp and Ginsburg call for an expansion through greater cooperation between anthropology and disability studies. This thesis is an attempt to bring disability into the mainstream of anthropological work, and to shift the emphasis away from the negative aspects of disability, toward a more positive understanding of disability as a life experience.

Rapp and Ginsburg reflect on the benefits anthropology can provide, citing previous works that explore the importance of cross-cultural and ethnographic approaches, and – perhaps unwittingly - contributing to a critique of ethnocentrism within disability studies. They state that,

What “counts” as disability varies across social contexts as do the practices by which children and adults with disabilities are integrated, sequestered, shunned, or denied an integrated life. These vary enormously with other sociocultural rationalities (and cruelties)... “global” statements have very little efficacy in daily life at the local level, a point that underscores the significance of ethnographic research (169)

To any social scientist (anthropologists in particular) this statement likely seems straightforward – different people have different definitions of disability, and global solutions are not one-size-fits-all – however, the fact that this statement by Rapp and Ginsburg echoes a similar statement made by Susan Reynolds Whyte and Benedicte Ingstad back in 1995 indicates that progress in this area has been slow. In their introduction to an edited volume, Whyte and Ingstad (1995) wrote that “it is timely and instructive to examine some of these issues in a cross-cultural perspective” (4). They argue that there are global benefits to studying disability cross-culturally, citing Marcus and Fischer’s (1986) “cultural juxtaposition” - the idea that studying other cultures gives us a new perspective from which to view our own. I will briefly outline some cross-cultural understandings of disability to show that disability studies’ homogenising approach is not necessarily the best one to take, particularly if we wish to enact change for all disabled people, rather than only those living in the West.

In the opening paragraphs of their 1993 article “Multiculturalism, Chronic Illness, and Disability”, Nora Groce and Irving Zola argue that in order to better serve those with chronic illness or disability, “it is imperative that we understand the cultural beliefs and attitudes that determine behaviours, guide decisions, and effect interactions with the broader society” (1048). They follow this argument by providing a range of different cultural understandings of disability, broken into three main sections: causes of disability; expectations of survival; and appropriate social roles for disabled people (1049). For example, in contrast to the prevailing Western understandings of disability, Groce and Zola note that in many cultures disability is strongly linked with witchcraft and family curses, in which the disabled person is a victim (1049). Alternatively, Southeast Asian groups who believe in reincarnation consider disability a direct example of previous wrongdoings and as such as wholly deserved by the individual. Consequently, these culturally patterned understandings of the causes of disability lead to different ‘treatment’ of the individual – both medical (physical) and social. For example, social treatment of disabled people in cultures who believe in reincarnation usually involves the simultaneous avoidance of disabled people due to transgressions in previous lives, while they are urged to live ‘better’ lives in future. This has direct implications for the medical treatment of these individuals as they are “[A]nswerable to both the past and the future” thus “too little time and energy are often devoted to improving life in the present” (Groce & Zola 1993:1049).

Patrick Devlieger (1995) explored the way the Songye of Zaire understand disability and found that Western notions of disability are only occasionally compatible with Songye understandings. Devlieger uses “abnormal children” as his case study, explaining that,

Deviations in the body can induce a higher, lower, or undetermined status in comparison with able-bodied people. Therefore, not all deviation is stigmatizing, and not all persons with disabilities are marginalized because of their disabilities (95)

The Songye define three groups of abnormal children: ceremonial, bad, and faulty. Ceremonial children are those born unimpaired but in special circumstances, for example, twins; bad children are children who are born with visible physical differences such as albinism or dwarfism, and these are seen as supernatural beings with a link to sorcery;

faulty children are children who are the closest to what we would call “disabled” in the West. Ceremonial children have a higher social status due to the circumstances of their birth, bad children are given only basic care as “they did not come to earth to live but to die” (Devlieger 1995:96), however, faulty children are not considered socially inferior or superior, in fact they are undetermined. This results in the children occupying a liminal state due to their impairments (Murphy 1987) that entails both positive and negative aspects; faulty children are not ascribed a less-than-human status and thus are free to pursue their own development, yet they are encouraged not to overexert themselves – to be aware of their limitations and live with them, rather than attempting to surpass them. Interestingly, Devlieger notes that unlike Western questions about disability, the Songye must know the reason for their impairment, and none of these are medicalised in nature. The Songye search for the causes of disability through a deep analysis of interpersonal relationships, Devlieger explains,

Relationship with the physical environment will be examined, as will relationship with family members through sorcery and bridewealth, and finally relations with the ancestors. If none of these relations can be identified as distorted, then God is seen as the cause of the disability (1995:98; emphasis in original)

Furthermore, the cause that is arrived at through this investigative analysis is not set in stone – over time more information may surface, or information may be disregarded and thus the cause of disability may change.

Through the brief cross-cultural examples given above, I believe it is clear that even if the field of disabilities is concerned solely with the contemporary Western context, there is still much to be learnt from engaging in cross-cultural research on impairment and disability as it elucidates the similarities and differences that exist worldwide. Despite the limited cross-cultural work in this thesis, I aim to balance the influence of social factors with individual experiences by being aware of the boundaries of sociocultural categories of impairment, disability, and person, and by considering what personal traits are considered positive or negative in a given context. Although most of these are in line with current disability studies literature, given how similar New Zealand is to the United

Kingdom and United States, being consciously aware of these and investigating how they shape individual experiences is essential.

Thus far the construction of my theoretical framework has been predicated on a critique of disability studies; however, I will make it clear here that I am not opposed to disability studies approaches or the social model but rather these theoretical approaches are not clearly reflected in my fieldwork. The critiques I have put forward above are thus all based on the disjointed relationship between my findings and the approaches presented in the disability studies literature. Below I will discuss the second major theoretical area which my thesis draws from – identity.

Identity

Throughout my research I have been interested in the way my participants constructed their identities, and while conducting my research it became clear that ‘identity’ is far more complex than I had initially assumed. Identity is a broad – and somewhat vague – analytical category, therefore I now turn to a discussion of what I mean by identity and how I will use it in this thesis.

The history of identity as an analytical tool is often traced back to Erik Erikson’s work in the middle of the twentieth century (Weigert 1983). Erikson approached studying identity with a “neo-Freudian” (Weigert 1983:184) psychoanalytical approach while studying children going through adolescence. Erikson found himself drawn toward social anthropology (Erikson 1956:56) and subsequently found a way to incorporate, and make his research accountable to, both psychoanalytical and anthropological theory. One of Erikson’s most referenced concepts is that of “ego identity”⁶, yet it is one of his more general statements about identity that I find to have (more or less) held up to scrutiny over the past six decades:

⁶ Erikson uses this term to “denote certain comprehensive gains which the individual, at the end of adolescence, must have derived from all of his pre-adult experience in order to be ready for the tasks of adulthood” (Erikson 1956:56).

The term identity expresses such a mutual relation in that it connotes both a persistent sameness within oneself (self-sameness) and a persistent sharing of some kind of essential character with others (Erikson 1956:57)

This “mutual relation” is often characterised as a divide between private and public ‘selves’ in contemporary identity research, such as in Martin Sökefeld’s (1999) description of identities as “fragmented... essentially fluid and many-sided... or populated by multiplicities” (417).

Although there is little debate surrounding identity’s reformulation as no longer singular or static; issues of self, identity, and personhood as separate entities are often discussed. Sökefeld puts forward the idea that the way “a particular individual acts in situations involving contradictory identities requires a concept of a self... that is capable managing the respectively shared identities” (1999:417), and – importantly – that aside from “any culture-specific attributes, this self is endowed with reflexivity and agency” (417). In this way Sökefeld constructs the self as a universal feature of identity management and links the concepts of self and identity in a symbiotic way. This intimate link between a ‘solid’ self and multiple identities appears to fit well with my findings.

However, other authors (Brubaker and Cooper 2000; Leve 2011; van Meijl 2008; Hall 1996), argue that treating ‘identity’ as an analytical category can be problematic. The general argument in these works is that identity is too broad an analytical category, and its use can often complicate matters, or conversely, trivialise them. While the multiplicities of identity are accepted by these authors, they are all – in varying degrees – wary of the concept of unity, which so often accompanies this position. They caution that it is too simplistic and potentially misleading to assume there is a consciously constructed unity expressed throughout and between these diverse “I-positions” (van Meijl 2008:179). For the purposes of this work I argue that this lack of unity is true of my participants, but this does not imply they are confused about who they are; instead it allows them to occupy multiple conflicting ‘I-positions’ without encountering existential contradictions.

A further issue with identity is that it occupies an ambiguous position (Brubaker and Cooper 2000), simultaneously a category of practice (involving ‘folk’ or common-sense

understandings) and a category of analysis (an area of theoretical importance) – however, it is precisely because of this I choose to continue using the broad term ‘identity’. Due to its ambiguous position, ‘identity’ can be understood in general terms as well as in academic terms. This is important as I do not wish to distance my analysis of identity from the very people whose accounts made it possible.

So while I still talk broadly of ‘identity’, I differentiate between using identity as a category of practice, and as a category of analysis. Identity as a category of practice refers to my discussions with participants, in which they interpret ‘identity’ in response to my questions; it is a common-sense understanding of who one is. Identity as a category of analysis refers to my analysis of my participants’ responses, focusing on processes of identification, categorisation, and ‘groupness’ rather than identity as a reified object. In this way I aim to be accountable to both my participants and the call for analytical clarity put forward by Brubaker and Cooper (2000).

Furthermore, I will avoid - wherever possible - making any claims as to the identities of my participants; that is, I will avoid concluding my analysis by detailing certain properties that make up the identities of my participants. This is influenced by a critique of the social model’s emphasis on generalisation (and by extension, homogenisation). As Brubaker and Cooper state, regarding top-down ascription of identity,

why should we assume it is “identity” that is constructed in this fashion? To assume that it is risks conflating a system of *identification* or *categorization* with its presumed result, *identity*. Categorical group denominations – however authoritative, however pervasively institutionalized – cannot serve as indicators of real “groups” or robust “identities” (2000:26; emphasis in original)

Lauren Leve (2011), in her work on the complexities of Nepalese identity politics, also identifies the ambiguity of the term ‘identity’. In Leve’s analysis, the “identity machine” (516) is a tool of the neoliberal state in creating and maintaining new forms of sociality for its own benefit and it does so by taking advantage of the ambiguity of the term ‘identity’ – particularly the relationship between personal identity and group identity:

It is this indeterminacy that makes it possible to personify groups, allowing us to speak as if collectives had wills (“what women want”) and also to think of them as having histories that are common to all members regardless of whether any on individual has, in fact, taken part in every aspect of collective experience (Leve 2011:519)

This personification of collectives creates a powerful political force, at the expense of individual accounts and experiences – an issue that my participants revealed in their narratives. It is precisely this homogenisation of identity and experience that this thesis seeks to alleviate by focusing on individual experiences. However, this must be carefully balanced with Hall’s (1996) assertion that because “identities are constructed within, not outside, discourse” we need to acknowledge the historical and institutional influences present in these constructions, and remain attentive to the fact that they are often the results of specific power relations.

Taken together, the above authors have influenced my approach to identity in some key ways: firstly, identities are multiple, or in constant flux – or both – but they are never singular; secondly, there is not necessarily a unity of identities within or between individuals; and thirdly, ‘identity’ is not purely “intra-psychological”, but a “relational phenomen[on] that transcends the boundaries between inside and outside, between self and other” (van Meijl 2008:179). Following this, I must remain attentive as to how “multiple differences within individual actors [can] be acknowledged without representing their identifications as negative, damaged or in crisis” (van Meijl 2008:178). However, in keeping in line with embodiment, there is one important caveat to the above theorisation: although identities may be discursively or narratively constructed, they always begin with embodied experience. Particular aspects of identity are conditional according to certain bodily configurations, indeed, as will be seen later in the thesis; my participants’ identities were constructed around their bodily experiences – both as they are lived and reflected back on them via scientific and social ‘facts’ – an example of what Joseph Dumit (2010) calls “objective self-fashioning” (367).

In sum, identity as it is used in this thesis can be defined as follows: it is a broad term used to explain the result (or more accurately, the ongoing process) of negotiating a sense of self in relation to others. It is multifaceted or fluid, and not necessarily a unified entity; it

is grounded in embodied experience in the world; and it is dialogically constructed, deconstructed, and reconstructed. It is not necessarily who or what a person *is*, but who or what they and others see them as in particular social contexts.

Chapter Three: Methods (and madness)

In the following section I will outline the methods involved with this research project. I will discuss the methods I utilised in collecting, sorting, and analysing data, as well as some of the major methodological issues that I encountered during my fieldwork. I discuss how I responded to some of these issues, and how these shaped further fieldwork and analysis.

Firstly, however, I will justify my focus on physical disability rather than ‘disability’ in a broad sense, or intellectual disability specifically (as Robert Edgerton (1984) has called upon anthropologists to study). Two of the three factors in this decision were matters of practicality: firstly, as a relatively inexperienced researcher, I believe that working with people with intellectual disabilities would have simply been too difficult to do alone; and, considering the difficulties I had in recruiting participants with physical disabilities, I believe there would have been further issues with recruiting intellectually disabled people (see Lennox et al. (2005)).

I attempted to recruit participants via a number of disability organisations in the Wellington region, however, all but two of the organisations I contacted did not respond. The first was willing to help me find participants as long as I modified my research goal to better align with their goals; while the second was willing to help, contacting relevant participants on my behalf and reproducing an information sheet in their monthly newsletter, however, I received no messages of interest.

In terms of data collection, I planned to utilise the two cornerstones of anthropological data collection; in-depth, semi-structured interviews, and participant observation. Alongside these methods, I also aimed to collect data through “go-along” (Carpiano 2009) interviewing, and “disability simulation” (Herbert 2000) – potentially combining the two if at all possible.

My choice to do semi-structured interviews came as a result of the practicalities of my fieldsite and the timeframe of a Master’s thesis, but also as a result of arguments for its usefulness by multiple authors (Krefting 1989; DiCiccio-Bloom & Crabtree 2006; Leech

2002). All of these authors emphasised the relatively informal nature of semi-structured interviews as a way to make participants more comfortable, break down the traditional interviewer/interviewee power relations, and place the interviewee in the expert position - identified by Laura Krefting (1989) as important conditions for disability research. Furthermore, they all identified semi-structured interviews as providing richer detail, as well as more “digressions [which] can be very productive as they follow the interviewee’s interest and knowledge” (DiCicco-Bloom and Crabtree 2006:316).

Following Beth Leech (2002), I chose to construct my interviews in such a way that they were as casual as the topic allowed, to ensure my participants felt as comfortable as possible. I structured the interview questions to allow me to focus on the areas I saw as most important for my research, without being so specific as to elicit a particular response. I encouraged my participants to go into as much detail as they felt comfortable with, and they had the option to refuse to answer a question or end the interview at any point if they were uncomfortable.

Due to the nature of a semi-structured interview, I chose not to send them a copy of the questions in advance as I wanted to balance participant comfort (by sending the questions early) with raw detail (not allowing participants to construct answers in advance). I achieved this via my introductions with participants: when I introduced myself I told them about myself and my research, and the sorts of things I was interested in exploring. Subsequently, those who wished to take part in an interview were told again what my research interests were when organising a time for the interview. In this way I gave them some idea of what I wanted to discuss, and what sort of general questions I would ask, without allowing them the option to write a counter-script.

Participant observation was an approach I considered non-negotiable, however, it posed significant issues when doing research with a group consisting exclusively of physically impaired people. All but three of the people I did my research with lived at an assisted

living facility (ALF)⁷ in the Greater Wellington Region, and only occasionally left the facility although this varied with level of impairment, family support, and individual motivation.

For the most part, however, much of 'daily life' took place within ALF, often within individual rooms and as such did not lend itself to in-depth observation, let alone participant observation. General observations were made in the public areas of ALF, as well as brief notes upon first entering a participants' room and I also engaged in participant observation with a local wheelchair basketball team for two hours a day, once a week, as their training calendar specified.

Of course, observations need to be written down to be useful. I had originally toyed with the idea of keeping two separate notebooks, one for 'objective' observations, and the other for more personal observations and interpretations of events. Considering the complexities of note-taking (or note-making as the case may be) I ultimately decided to keep the two together, as in reality it is impossible to separate objective notes from subjective interpretation and analysis – in fact, keeping the two together allows for a more reflexive 'construction' of events and makes explicit my presence in the interpretation of them (Clifford 1990; Wolfinger 2002). Notes were written at the time, as far as the situation allowed, and comprehensive notes were written, based on memories and shorthand notes, the following day. Since most observation sessions took place in the afternoon and evening, and since I had short notes to jog my memory, I do not consider this delay significant enough to affect the integrity of my data. All notes were dated and stored in chronological order.

Disability simulation (Herbert 2000) and the go-along interview method (Carpiano 2009) were both approaches I considered for doing my research, but these ultimately proved inappropriate. Disability simulation is fairly straightforward, and it is for this reason that it receives a lot of criticism from social scientists and disabled people themselves. As the name implies, it is simply the act of simulating a specific disability; in this case I intended on using a wheelchair to understand some of the physical aspects of being disabled, whilst conducting go-along interviews with participants. The go-along method would also

⁷ For privacy reasons I will refer to this particular facility by the acronym ALF - this is fitting since this particular ALF is often referred to by its own specific three-letter acronym

help understand physical and social aspects of disability, as it would take place in a public space and inevitably elicit issues of accessibility and stigma according to the environment. However, as mentioned above, many participants were not very outgoing, and as such there were very few opportunities to actually conduct the go-along method, and so that idea was discarded.

This posed issues for the simulation approach. Simulating disabilities in public has the potential to go awry quite easily, especially if one is not used to using a wheelchair. Were I to get stuck, or worse, somehow fall out of the chair I would risk exposure as a non-disabled person masquerading as disabled. Aside from the personal issues related to simulation, there are also many academic critiques levelled at simulation as a method of inquiry. Gary Kiger (1992) provides a brief analysis of the benefits and potential pitfalls of disability simulation, noting that although disability simulation has the potential to be beneficial for both the simulating researcher and disabled people as a result, it is something that must be carefully considered. Although disability simulation can result in empathy and understanding in non-disabled individuals, it can also lead to negative value judgements of disabled people. For example, a researcher may feel anger or frustration at having to navigate an urban environment in a wheelchair, and may not cope very well with all of the attention they receive, and may project these feelings onto disabled people. More commonly however, a non-disabled researcher thrown into a wheelchair for a day with no prior experience may find themselves overwhelmed, and may focus on the negative aspects of the simulation (and thus their understanding of disability). This could lead to feelings of pity and sadness for those who live that kind of life on a daily basis, or on the other hand, it may lead researchers to valorise disabled people because they take such things in their stride. Kiger's main critique sums up the previous points excellently, stating simply that,

It is one thing to simulate disability by, for example, using a wheelchair; it is quite another matter to convey how having a disability is central to one's experience and identity. Some researchers view simulation as *demeaning* for this reason (1992:72, emphasis mine)

I have highlighted *demeaning* in this quote, as it relates to my initial feelings about simulation as masquerading – I felt that if I were to engage in simulation, I would simply

be 'playing disability', or at least be seen that way. It is for these reasons outlined above, including the decision not to conduct go-along interviews, that I decided not to engage in structured disability simulation.

However, despite this decision, while conducting observation with the basketball team I was invited to join in, and I leapt at the opportunity. I reasoned that it would be a great way to build rapport, and understand – even at a very simple level – the physicality of being in and using a wheelchair. In the cases where this took place I considered it informal simulation; being explicitly asked to take part, and only focusing on the physical nature of being in a wheelchair helped alleviate some of my anxieties around being a respectful and sensitive researcher, and the experience as a whole helped me understand a few key elements of wheelchair use.

Overall, I conducted six planned and recorded interviews, alongside multiple informal discussions of which notes were taken but were not audio-recorded. The shortest of these interviews was just fifteen minutes - an issue which I will discuss shortly – and the longest was just over two hours. In total I collected six hours and twenty-five minutes of audio-recorded interviews, comprising seventy-five pages of word-for-word transcripts (including pauses, silences, and notable non-verbal interaction), and produced thirty pages of fieldnotes based on my participant observation.

Despite my choice to focus purely on physical disabilities, I was unprepared for many of the issues that arose during all stages of my fieldwork. After receiving ethics approval I was struck with the first issue: gatekeeping. Being a non-disabled researcher, gaining access to participants was much harder than anticipated as many disability organisations that I approached for assistance were reluctant to allow me access to 'their' people. I found it difficult to shake my frustration at what I perceived to be aggressive - and somewhat paternalistic – gatekeeping, I thought, surely if I could just speak to the people themselves perhaps they would be interested. Unfortunately, in most cases this was not possible, however, I was able to snowball participants somewhat through the wheelchair basketball team.

Once I had gained entry to a fieldsite, and had recruited enough participants to start researching I came across another challenge in the form of communication. I had assumed that by focusing on physical disabilities I would largely avoid communication issues, however, my idea of physical disability was too specific – I had envisioned a clear separation of cognitive/physical disability, and one where disability was defined essentially as a loss of mobility. Of course in reality, disabilities are complex and multi-faceted, and communication with three of my participants was a challenge. Jenny and Grant are residents at ALF, both in their early fifties, and both have difficulty verbalising. Jenny was diagnosed with Cerebral Palsy (CP) at a young age and as a result has significantly lessened muscle control, whereas Grant suffered a brainstem stroke in his forties leaving him with little voluntary movement and weakened facial muscles. Both Jenny and Grant are capable of communicating verbally, but it is difficult for newcomers like me to understand. In these cases verbal interviews were out of the question, as I did not have enough time to develop the necessary skills to be able to consistently understand what they were saying, and especially because verbal communication for Jenny and Grant was quite taxing; requiring a huge amount of concentration and conscious engagement of facial muscles to produce the correct sounds. Although both Jenny and Grant are capable of typing to communicate more easily, due to their muscular impairments this is a slow process: Grant has to type with one finger using his non-dominant hand, whereas Jenny has to use her feet.

Considering these issues, it was decided that I would send Jenny and Grant a modified interview schedule and they would be free to answer in their own time. Unfortunately this meant I lost out on some of the richness that comes from a back-and-forth discussion, and the interview became more of a survey or questionnaire. This is not to say that I did not receive some excellent responses from both Jenny and Grant, simply that it was less than ideal.

However, even this approach was not without its issues; ambiguity as to what my questions were really asking resulted in some confused answers. In order to give Jenny and Grant some freedom in answering questions, each question had multiple parts and I made clear in my instructions that they could answer just one, both, or neither if they

were uncomfortable. Unfortunately, these closely related questions resulted in confusion for both Jenny and Grant. One question in particular caught both of them out – following a question about what technology they use regularly, I asked, “How did you determine or define what ‘technology’ meant in that question? / Why did you choose those technologies?” Grant separated out the two questions, giving an excellent definition of technology (“any process or thing that will simplify or streamline our existence”), but interpreted the second question as “why did you choose *to use* those technologies?” rather than “why did you answer the previous question with those specific technologies?” Jenny did not answer the first question at all, and interpreted the second question in the same way, replying,

Well, first I had an old laptop, and then it had played up second I barrow [sic] a P.C. from [ALF] and then bought my own twice

Although not the answer I was expecting, Jenny’s reply exemplified just how important having access to a functional computer was to her, even paying for her own computer twice. Similarly, although Grant also misinterpreted my question, his somewhat romantic answer also proves just how important technology is to him – his narrative is almost exclusively about the importance of technology, so this is no surprise. Answering why he chose specific technologies in response to the previous question, Grant replied,

I didn’t they picked ME many decades ago. I’m just doing what I know, what I’m good at and what’s worked for me previously that’s all

The final issue with data collection was once again to do with communication; however, this issue was easily solved and proved extremely useful for thinking about the relationships between disability, technology, and identity. One of my participants is deaf and blind - or deafblind – as it is commonly called. Paul is a middle-aged man who was “struck down” with bacterial meningitis in 2008, and was left deafblind as a result, making my prospects for interviewing him very limited. The only way I knew of communicating with him was via hand-signing, also known as manual sign language, which is essentially a modification of New Zealand Sign Language (NZSL), where the ‘speaker’ makes the signs directly on the hand of the ‘listener’. Learning NZSL is hard enough by itself, and learning to do it on somebody else’s hand (often needing to reverse all left-right movements)

made it impractical given my time constraints. I did not want to rely on the staff of ALF or one of Paul's family members for interpretation and was close to giving up when one of the staff members mentioned I could talk to him via his "Braille thing". I will go into more detail about Paul and his "Braille thing" (a BrailleNote Apex) in a later chapter, for now it is enough to state that this made communication with Paul possible - and convenient.

Initial contact with Paul was, admittedly, incredibly uncomfortable for me. As with all of my participants the plan with Paul was to introduce myself in an informal setting, give him some information about my work and get a feel for how the interview would work. Peter, ALF's personal trainer and physiotherapist, had a similar style to Alex when dealing with me: baptism by fire. Alex had suggested I speak to Paul because of his unique situation, and I managed to track him down to the gym where he was working with Peter. I approached Peter and told him what my goal was, and he suggested that I accompany him as he helped Paul head back home (Paul lives in a standalone house on ALF property). I was subsequently left to fend for myself in conversation with Paul, despite having picked up a guide for the deafblind manual alphabet less than twenty minutes prior.

I managed to sign "Hello Paul my name is Callan" after approximately five minutes of fumbling with my printout of the deafblind alphabet, Paul's hands, and my own. Luckily, and quite amazingly, Paul has what was jokingly described to me as "predictive text" in that he is often able to complete words during signing, which made my job a lot easier. Paul replied to me verbally (since his deafness is acquired, not congenital) and offered to talk to me via email or text message as he could quite clearly tell that we would be there for hours if I were to try and explain my research through hand-signing. I was surprised to receive an immaculately typed email shortly after sending through the details of my research to him, as it was not until I returned a fortnight later to interview Paul that I actually learned how his BrailleNote worked in regard to translating text to Braille and vice versa.

The interview itself was quite surreal, as we were both seated right next to each other in his bedroom, yet were not directly communicating. I would send a text message to Paul's phone, which was connected to his BrailleNote via Bluetooth, which would then translate the message into Braille for Paul, and then he would answer aloud. Although I cannot

speak for Paul, the entire situation felt quite strange, as there would be long periods of silence in which all that could be heard was the quiet clicking of his hands on the BrailleNote buttons, and the metallic tapping of the BrailleNote rearranging its Braille keys for him. In the entire ninety-minute 'interview', I did not say a single word. It is likely Paul is used to this sort of interaction, as his responses to my questions were long and elaborate. He was not afraid to drift off into tangential stories, which proved useful for me, especially since my questions were fairly short and straightforward to make it easier for Paul to answer. This worked surprisingly well for me, as I had to distil my questions into a concentrated form in order to get to the essence of my question, and it also encouraged active listening on my part, as I could not interject to ask for clarification or steer the interview. It was also beneficial that Paul's answers were expansive as he often answered related questions as he spoke, and his long, unbroken segments of narrative benefited from freedom of interruption and were often richer and more detailed than other interviews because of this.

Although this research proved more problematic than I anticipated, the issues that arose helped me think about my overall aims and gave me multiple opportunities to evaluate and refine my focus. In the following chapter I will introduce my participants and provide some brief ethnographic detail to let the reader 'meet' them, before moving onto my ethnographic analysis of identity.

Chapter Four: Setting the scene

Meet the participants

“One should never creep when one is compelled to soar”. That would be me... That’s a Helen Keller quote... But yeah, that would define who I am now. In spite of what’s happened to me I cannot allow, and I refuse to allow, myself to be restricted in any way, to be limited – in spite of the journey

(Paul)

My participants’ experiences of disability varied significantly according to personal situations, however, one thing that remained the same for all of my participants was a lack of feeling oppressed. This caused some issues for me in the early stages of my research, as I have mentioned earlier, but it also served to open my eyes to their experiences, and to help me rethink my approach to fieldwork. Below I will introduce my participants and outline their feelings toward disability before turning to a discussion and analysis of my findings in relation to the key theoretical points I outlined above. All quotes in this section come from interview transcripts or written communication⁸ – repeated verbal ‘clutter’ such as “umm”, “uh”, and stuttering has been omitted, everything else is a complete and direct quote. All names used (previously and henceforth) are pseudonyms.

Paul

My counsellor in the early days, he told me right from the outset, he said to me “Paul,” – he said – “are you disabled? or are you enabled?” and that resonated with me big time and I’ve always kept that right at the forefront of my thinking. I’m not disabled; I don’t see myself as disabled. I refuse to accept that I’m disabled; you might say “that’s totally crazy! You’re deaf, blind, and in a chair” – I don’t see myself as deaf, blind, and in a chair... my

⁸ One participant, Grant, who I will introduce shortly, has compiled multiple books and other documents about his experiences, and these have proven invaluable for my work. Also, as mentioned in my methods chapter, all communication with him was in written form, thus all quotes from him are direct reproductions, including all errors.

world is very dark but I don't choose to look at the darkness – I choose to fill my mind with whatever I can, of what I can achieve – and the dreams are pretty, pretty big
(Paul)

Paul is a balding, middle-aged man of average build, living in a standalone house connected to the ALF with his wife and two children. His room is very tidy, and most of his things are stored in specially-arranged storage units on the walls for easy access, and he has a large but sparsely populated desk at which he spends a fair amount of his time. He is welcoming and very friendly, always willing to chat, and is very motivated (and motivational). Paul also has the uncanny ability to make eye contact while talking, despite his impairment – this lends him a Zen-like superhero aura. As is somewhat necessary for someone with his level of impairment, he is quite open, to the point that I felt a little uncomfortable going to talk to him, as I simply let myself into his room and put my hand on his shoulder to let him know I was there. He is, as he states in the above excerpt, deaf, blind, and in a wheelchair following a sudden and nearly fatal illness; in 2008 Paul was “struck down” with bacterial meningitis, which left him in a coma for almost three weeks before he awoke to his new, dark world.

In spite of these extreme circumstances Paul does not consider himself disabled, and he is aware that this sounds strange to outsiders – after all, the level of impairment with which Paul lives is what many non-disabled people would consider life-ending. With the help of various support people, his family, and his faith, Paul bounced back from his illness with a renewed sense of purpose; to motivate and inspire people to push their own limits. Interestingly, Paul separates impairment from disability, and reframes disability as a personal attitude, telling me that “we all have limits in our lives”, but he makes a concerted effort to not “limit [him]self in any regard”. For Paul, disability is simply a limitation – we all have limitations but they do not define us, it is how we respond to these limitations that defines us.

These twin concepts of disability - as simply a limitation, and as a state of mind - came up frequently in my interviews, and are somewhat problematic for the social model of disability. Unlike social model approaches, my participants still located disability within

the individual – but rather than identifying it as a physiological issue, they presented it as mental, attitudinal issue.

Alex

My key informant, Alex, when asked whether he identified as “disabled” replied,

No, I actually forget my limitations, and I think a lot of people I work with after some time forget that I have a disability as well... but nah, I kinda don't find limitations – other people wanna give you limitations

Alex is a well-built man in his mid-thirties with a shaved head and piercing gaze – and “the worst critic to disabled people”. He is strong and skilled; previously competing in ‘disabled powerlifting’ and bench pressing 165 kilograms, and is currently able to make distance shots in basketball that many non-disabled people are incapable of, despite not being able to use leg drive while shooting (at a regular-height basketball hoop, no less). I first met Alex when I sat in on a wheelchair basketball training session at a local sporting centre, and despite being seated in a wheelchair he commanded the presence of someone twice his normal height. My first trip to the sporting centre was pure observation as a way for me to get a general lay of the land, so to speak, but it was clear very early on that Alex was the one in charge. During my second visit I gathered the courage to speak to Alex, and found that despite my initial unease he was incredibly helpful, even when he only knew the bare minimum about me and my research. Within minutes of meeting him, Alex had welcomed me and offered to help me find participants, and suggested I do my fieldwork at ALF.

I was surprised to see him get out of his wheelchair at one point during basketball training and this served as a stark reminder to me of the realities of impairment for some people. Although Alex does not require a wheelchair, nor does he ever prefer to use one (except, obviously, for wheelchair basketball) there are those whose impairments are not so severe that they require a wheelchair, but it is simply easier to use one. Although he can walk unassisted, due to CP the left side of his body is weaker than the right, and this is

most apparent in his gait; Alex walks with a significant limp, and his left leg is twisted into an abnormal position that further impedes movement. Despite this, Alex considers himself in a much better position than many others at ALF, and does not use any assistive technology at all.

Alex's views on disability as it relates to his identity appear, at first glance, to be fairly straightforward – he simply does not see himself as disabled, although he does acknowledge he is “different” in the eyes of non-disabled people. However, shortly after making the statement in the above excerpt, the conversation shifted and it became clear Alex was negotiating social distance through his narrative. Despite initially denying a disabled identity, Alex included himself in the category of born-disabled and distanced himself from disabled people who acquired their disabilities, creating two separate categories of disabled people,

They've had the so-called 'normal' life and no – nothing's been a problem. They can run, play, catch, fetch – do whatever it is they choose to do, whereas we've had to struggle to fight to have the right to do that anyway, and we continue to fight that and yet we're born that way (emphasis mine)

Carly

Carly is a woman in her early thirties who lives in a self-contained flat at ALF with her cat, Bella. She is a bright, bubbly individual with short dark hair and a perpetual smile, and is always eager to have a chat. At the time of writing she is currently studying at a tertiary institute in Wellington. Much like most of my participants, Carly seems younger than she actually is; I had initially estimated she was in her early twenties and was surprised to find she was in her early thirties. This was most likely due to Carly's attitude, combined with a penchant for social media, knitting, and cats, which remind me very much of someone in my circle of friends.

Carly was born with Spina Bifida, and as a result is paralysed from the waist down; in contrast to Paul and Alex, Carly identifies as disabled, however, she tells me this was not always the case – in fact, she had not really thought about it until I asked her,

Now that's an interesting one, because, growing up I went to mainstream schooling and was always – there's no one else in my family with a physical disability, or a noticeable physical disability, and I'm adopted so my parents always sort of pushed me to do everything. So when I moved here, with other physically disabled people, for a number of years I refused to partake in things – I refused to accept that I was 'like them'. But as I've grown up I've more accepted that, and I – I would know consider myself disabled, yes

Carly's upbringing emphasised 'normality' and as such she did not feel any affinity towards disability as an identifying feature; it is only in recent years that she has embraced her difference and identified as disabled. This would appear to be a victory for the social model, as Carly was given all of the same opportunities as non-disabled people growing up and consequently did not feel disabled. However, Carly expressed regret at being mainstreamed, as she believed that had she gone to a special-needs school she would have been surrounded by people like her and it would have been easier on her and her parents⁹. Further, Carly appears to value the disabled identity as a form of acceptance; however, she is conflicted and has trouble articulating exactly how she feels,

I don't know if I'd gone to somewhere like Kimi Ora – you know, a school for people with disabilities – I wouldn't have had the same struggles and I would've accepted my disability more. And it's not, I find – you know – I find accepting my disability different to like, some people here who have acquired their disability through accident. I mean, I've always had my disability, so I don't know if me just getting on with life and, you know – if that's denying that I've got one or that's striving to just overcome it. But since being here I've sort of hung out with disabled people, and it's not that I didn't dislike disabled people before, I just... I dunno

⁹ This comment is very similar to debates surrounding the choice to mainstream deaf children; weighing up educational, social, and cultural (i.e. Deaf culture versus 'mainstream' culture) factors (see Bathard 2014; Kent 2003)

Joe

With short dark hair, bright eyes, a strong jaw and rugged stubble, Joe is a traditionally handsome young man. Alongside his looks, Joe is also a kind and soft-spoken individual, and for these reasons he is very well liked – as such, the story of his impairment is perceived by all who know him as a personal tragedy; an undeservedly cruel twist of fate. Although the disability literature has much to say about this type of portrayal¹⁰, for those close to him it is nearly impossible to avoid framing his accident as such. In 2011, a “freak accident” at a friend’s house left Joe with a serious spinal injury resulting in paralysis from the chest down, landing him in a specialist hospital for seven and a half months. Joe found it difficult to adjust to life in hospital, and had an even harder time adjusting to ‘normal’ life upon returning home. Joe led a very active lifestyle before his accident, and has tried his best to keep that alive, throwing himself headfirst into rehabilitation including one situation where,

I went to the gym the first time – this was after seven and a half weeks in bed – and I got in to the gym for a bit and did a few exercises. But, of course my brain – uh, I went straight into exercise mode and pushed myself so hard that I was – I threw up [laughs]

Joe’s understanding of his situation was a little different to the others mentioned thus far, perhaps because of how recent his accident was. Although he did not explicitly address whether or not he identified as disabled, it was apparent he viewed himself as *temporarily* disabled. The above excerpt helps illustrate this, as Joe has always been a very active person, and he firmly believes in the merits of hard work and perseverance. Joe repeatedly made mention of regaining his lost abilities, however, he was well aware of the limitations of his situation; he accepted that he would never return to pre-accident physical ability, but he was determined to get as close as he could, and this was framed primarily in terms of independence.

¹⁰ For example, Jackson (2005) on the “moral deservedness” of chronic pain, injury, and impairment

Steve

Like Joe, Steve did not explicitly state whether he felt, or identified as, disabled yet it was quite clear he did not consider himself as such. In fact, when I first met Steve I had no idea he was impaired until he asked if I would like to speak to him about my research. Steve is a man in his late thirties - although he looks about a decade younger¹¹ - with short dark hair and, when I met him, a days' worth of stubble. He is of average height and build, and was dressed in an all-black chef's uniform, minus the hat. He gave off the impression of a sort of 'generic everyman' – possessing no distinguishing features to speak of.

When Steve asked if I would like to talk to him, I froze for a second; I was not quite sure how to tell him I was really only interested in talking to someone who was impaired. Obviously, Steve picked up on this hesitation and raised his shoulder above his head to reveal an empty sleeve. When he was twenty, Steve was involved in a motorcycle accident, after which he had to make a choice – one that led to the amputation of his arm from the shoulder down. He recalls that,

it basically didn't work, it was paralysed – the nerve endings had been ripped from my spine. I pretty much hit something with my shoulder and it kept going and so it ripped off without it being 'off', I suppose. I spent a few weeks in hospital and yeah, but it didn't really, I mean it – it wasn't – it was a life changing thing obviously, but it – you just can't – you just gotta move on

Steve explained to me prior to the interview that it was an easy choice to make in theory, but hard to accept in reality. His arm was still attached, and appeared mostly intact, but internally it was beyond repair. Steve did not see the point in having an arm that did not function, hence the decision to have it amputated – however, the reality of having a part of himself removed was tough to deal with. Steve believes that he is lucky - in a sense - that it happened relatively early in his life as he was young enough to learn to adapt. Because of this, Steve has been able to accept it and “move on”; he does not associate

¹¹ Considering my constant misjudging of peoples' ages I assume this is just an issue with my age estimation skills, rather than impairment or ALF being some sort of fountain of youth

with being disabled, jokingly explaining to me, “that’s my biggest challenge – trying to use the Playstation”.

Amir

In contrast to my other participants, Amir’s narrative was primarily political, and focused on the importance of assistive technologies, particularly in his home country of Iraq. Amir is a shaved-bald, middle aged man who lives in a self-contained unit at ALF where he spends most of his time. He can usually be found cooking or sitting at his desk in the main room of his unit watching television and writing poems (a few of which he has sent to various Prime Ministers since arriving in New Zealand). He is usually found wearing a *taqiyah* (skullcap) and a string of prayer beads around his neck. Usually calm and thoughtful, Amir occasionally got emotional when talking about the current state of disability support back home in Iraq, and elsewhere in developing countries. For example, he was very animated when explaining to me that,

It’s so, so, so, so important. Like, there is no word to describe the importance of this wheelchair... there is thousands of disabled people, if not millions – would be thousands of thousands and they do need this wheelchair... [they] cannot get out and socialise with the society and feel – feel their existence... this would be great solution to give them life

Amir originally arrived in New Zealand as a stowaway on a shipping vessel, and was granted asylum-seeker status. Despite surviving two separate desertion attempts while serving¹² in Saddam Hussein’s Republican Guard leading up to (and during) the Gulf War, it was a traffic accident shortly after arriving in New Zealand that left him paralysed.

Amir was the only participant who expressed a serious concern with finding the reason for his impairment. Initially, he could not understand why this accident had occurred, and

¹² I use the term ‘serving’ very loosely here, Amir tells me he had no wish to fight, hence the desertion attempts. He was caught following his first attempt and spent approximately three months in jail, fearing execution every time he heard footsteps. Eventually he was freed, on the condition that he returned to the Guard – whereupon he promptly deserted again. Amir told me this story twice, and although it is incredibly interesting, there is not enough space, nor enough reason to repeat it in full here.

was especially angry at those “faithless” people who told him Allah had created him to be disabled; however, his search eventually led him to understand that,

the purpose of the great Allah or God for ordering the truck driver to crash my car - to encourage ACC or the government to pay me 87 thousand. So the purpose of the great Allah or God ordered the truck driver – is a reason to make me rich. To make me wealthy, to make me worth something

Amir, like the others mentioned above, did not explicitly address whether or not he was disabled. It was clear from the language he used, however, that he did consider himself to be disabled. Unlike the others, I got the impression that he had not fully accepted this aspect of his life; however, he was very happy to be living in a country where he was well looked after, stating that the support - the “mercy” - he received in New Zealand was a direct manifestation of Allah’s will.

Aaron

Aaron has an air of invisibility about him – I get the impression that he is not often (and appears to dislike being) paid much attention. When I was first introduced to him he was sitting by himself playing a game on one of the computers in the corner of the dining room at ALF. He has short, black hair, black rimmed glasses, and a black wheelchair, and when I met him he was wearing a black hoodie, black pants, and black shoes – my kind of style. When I spoke to him it became clear he valued his privacy, and judging by the way I was thrust into a conversation with him this may be at odds with the service and care ALF seeks to provide.

Aaron’s answers to my questions were very short, and due to my interviews’ reliance on active participant engagement and elaboration, my interview with Aaron was short – approximately fifteen minutes in length. Aaron was reluctant to answer certain questions, so I do not know his age, or any details about his impairment other than he was born impaired and requires a wheelchair for mobility. Although it was clear Aaron was not

particularly interested in talking to me, he still had some interesting things to say about his situation.

Aaron told me that he feels like he lives a normal life, and although he did not mention how his impairment factored into the concept of normalcy, or whether he considered himself disabled, it appears that he does identify – at least implicitly – with being disabled. Aaron’s narrative was perhaps the most contradictory, and relied heavily on an outside/inside distinction, both in a social sense and a physical sense. Unlike my other participants, Aaron was much more openly ambivalent about his situation. He initially told me that, “I know deep down inside I’m normal... but physically I look disabled”, but a short time later he followed with, “sometimes I wish I wasn’t the way I am... I wish I was like everybody else”. Most tellingly, despite giving me the impression of someone who wanted to be left alone, Aaron expressed a desire to be praised – in contrast to my other participants and the general attitude within disability literature. When I explained the concept of a “supercrip” (Kama 2004) to Aaron, he replied that “it’d be awesome” to be seen as one. A supercrip is, according to Kama, a particular ‘image’ of a disabled person in which their actions – mundane or extraordinary – are celebrated as achievements. Such images are usually viewed positively by the general public, however, they carry the implication that disability is located within the body and can be overcome by hard work and discipline. Even when I explained a ‘regular’ supercrip – one who is praised for carrying out basic daily tasks – Aaron’s opinion was unchanged.

Grant

Grant was the very first person I met at ALF, and after being unceremoniously thrust into Grant’s room by Alex, we shared a moment of awkward silence before I introduced myself. Grant is a man in his early fifties with short, jet-black hair – something he is very proud of, and he assures me it will stay true until the day he dies. He gives off an aura of seriousness thanks to his rugged stubble, impressive moustache (which he appears to have been born with, looking through his older photos), tattooed arms, and intense gaze

– indeed, when I initially met Grant I got the impression I was intruding, however, that changed when I got him talking about technology.

Grant was a self-made millionaire before becoming impaired, having capitalised on the computer technology market shortly after it was established in New Zealand. I use the past tense *was* because after suffering a brainstem stroke in 2011, Grant had to quit work and his wife had to dedicate her time to caring for him and their children. Understandably, Grant is a little upset by this, but is grateful that because of his hard work he has been able to pay off all outstanding debt relating to his condition – albeit at the cost of his personal vehicle collection and his “man-caves”. Technology is his life, and he tells me that this statement is all the more true now that he is disabled, as he relies on it for daily functioning and enjoyment.

Due to the damage caused by his “catastrophic” stroke, Grant is totally paralysed from the waist down, and has very little movement above the waist too. He is able to move his head relatively freely, and can control his wheelchair with his non-dominant hand but – vexingly, for both of us – he cannot speak. Grant is able to vocalise, and his wife is able to understand for the most part, but these vocalisations are not yet at the level of being considered ‘speech’ – and this is something Grant is working on. Considering his situation, Grant identifies as disabled, but stresses that he prefers the term “physically impaired”, imploring me to “note brain is perfect only body broken”. This distinction between being physically and mentally “broken” is vital for Grant, and this is something I will return to later.

Jenny

The final participant with whom I conducted an ‘interview’ is Jenny, a small woman in her fifties from South Africa. She considers herself an artist and is a very determined, self-supporting individual. Jenny is a bit shorter than the average and quite skinny, both of which are partly due to serious health complications at a very young age, which resulted in CP. Jenny was not expected to do anything but lay on her back her whole life, and in

direct defiance of this, Jenny's parents enrolled her at Brown's School, "a special school to help [her] develop". In 1985 she got involved with 'sports for the disabled' in South Africa, and over the following twelve years managed to amass a collection of no less than twenty-two gold medals¹³.

Like with Grant, interactions with Jenny could not be considered interviews in a real sense, but closer to open-ended questionnaires or surveys, and for a similar reason. Due to her CP, Jenny has muscle tone issues and as a result her body – notably her arms and hands – are stiff to the point that they are very difficult to use. This has led Jenny to "use [her] feet insert [sic] of hands", a skill which she acquired at Brown's School.

Jenny's self-identification has elements in common with Carly and Grant, namely that there is a sense of ambivalence or uneasiness about how 'disability' defines her, as well as that she prefers a different term that marks a distinction between a medical condition (CP) and a 'category of existence' ('disabled'). Jenny identifies as disabled, and it "doesn't worry [her] at all", but later tells me that her disability does not define her; like Carly, she sees herself as disabled, but resists external attempts at labelling her as such. Directly after identifying as disabled, Jenny answered the question "Would you use a different term?" by saying, "I would use a different term, I suffer from Cerebral Palsy". Like Grant, and perhaps related to the previously noted ambivalence, Jenny specifies her disability; rather than simply being 'disabled', Jenny has CP and has to deal with its specific problems – she is not the embodiment of disability as a category.

For all but one of my participants, identifying with disability is not a simple decision. Some participants refused the label outright, while others avoided discussing such a label at all, or accepted it on the grounds that specific attention was paid to their impairment. While such a range of attitudes cannot be easily reconciled, there are a few potential explanations that can account for these views.

Despite the fact that none of my participants considered themselves particularly political in their experiences with disability, it is possible that they consider such a term politically charged; it is not enough to passively accept the label of disability, but it must be actively

¹³ Jenny did not specify which sport(s) she played, but achieving twenty-two gold medals is an impressive achievement regardless.

embraced. Alternatively it could be argued that the ambivalence toward identifying as disabled is grounded in the understanding that such a term is negatively charged in contemporary Western society. Furthermore, most participants preferred to be identified in relation to a medically defined, physiological issue; indicating that, although the physical lived experience does not change, the social response to it does. Being 'disabled' effects the entire lifeworld of an individual, whereas a physiological issue can be separated from the self, objectified as something to be managed or treated, and is only relevant in particular contexts where it becomes troublesome. Perhaps the explanation is even simpler; maybe my participants did not see any benefit to identifying with disability in a country where their civil rights are protected and state assistance is provided, regardless of disability status.

The first part of this chapter has served to introduce my participants, and briefly establish their stances on identifying as disabled. It is clear that far from being a simple semantic issue, such a label has consequences for personhood and lived experience. I have explained what these narratives can tell us about the ambivalent nature of identity for disabled people, and have introduced some key issues which will be discussed in later chapters.

Below I will describe the ALF in detail to establish the setting in which the majority of my research took place, and to give the reader a sense of my participants' daily lives as they are shaped by this environment.

Welcome to ALF

ALF is, despite the sterile connotation of the term 'facility', a cheerful community nestled between the base of a mountain range and a gently flowing stream. It is located at the end of a quiet and relatively affluent cul-de-sac, apparently blurring the boundary between public and private property, having no fences or gates separating it from the rest of the street. The reception area has been renovated in the last few years, and although indistinguishable from the rest of the buildings from the outside, the bright, modern

interior is in contrast to the functionalist aesthetic of the rest of the facility. It was here that I waited for my key informant, Alex, to arrive and give me the “grand tour”; due to the independent nature of the facility, this consisted of being shown to the staffroom to drop off my belongings, through to the dining room, outside to the gym, and out back to Alex’s office. Every other area in ALF was either a personal residence or considered (by Alex) irrelevant for my work (laundry, kitchen and other ‘utility’ areas).

The staffroom, located directly beside the dining room, was neatly arranged and frequently in use. Directly opposite the entrance is a slightly expanded kitchenette, comprising a simple linoleum-topped bench, a hot drink machine capable of dispensing coffee, hot chocolate, hot water, and sugar (which I was given full use of but felt too guilty to ever use), a toaster, a microwave, a refrigerator and a dishwasher. It was simple but effective, emphasising form over function, which was the general feeling I got from ALF as a whole. To the left of the kitchenette were two tables and matching chairs, one of the former always providing a bowl of fresh fruit and more often than not some form of baked goods. Along the wall were three rows of lockers for storing belongings, and various health and safety posters adorned the walls – most of them emphasising stringent sanitation rules due to the often-compromised immune systems of the residents.

Upon leaving the staffroom there is a small courtyard in honour of the ‘founding mother’ of ALF, and to the right is the dining room. The dining room is a large open room with tables and chairs scattered around the room. I never saw the room in use, but was told by members of the staff that the layout changes when everyone is present for a meal. When I entered from the courtyard, a few hours before lunch, to the right was a small table with another hot drink dispenser identical to the one in the staffroom, and nothing else. A bit beyond the table, along the right-hand wall was the main entrance, accessed via the covered walkway that connects all of the residents’ rooms. Directly opposite where I entered was the kitchen, which was modestly sized with a yellow-tinged, off-white paint scheme in contrast to the blues of the rest of the dining room. Accessed via the dining room were a number of other rooms, including a small alcove housing two public computers for the residents, a private telephone area, a meeting room, a few staff-only

areas, and an office that served as an informal information centre for residents and visitors alike.

Alex's office is, it appears, simply a modified garden shed. It is clearly not a permanent fixture, and is rather small despite serving as office space for up to three members of staff. It is situated at the back of ALF, and in wet weather a rather large puddle forms directly outside the door that needs to be navigated to gain entry to the office. Every time I went past the office, there was a pair of ducks ambling about outside the office which I later came to know were referred to playfully as either 'pets' or 'friends'. The interior of the office was rather cramped, mostly comprising desks, filing cabinets, computers, and lots of loose sheets of paper. I imagine it was (perhaps uncomfortably) cosy on rainy days.

After being let loose on ALF, I wandered around in an attempt to get my bearings and found that ALF is not particularly large, due in part to the arrangement of resident housing; the first impression I got when exploring, was that of a motel. With the exception of six or seven self-contained abodes, residents lived in units arranged in blocks of four, all connected by a covered walkway. Each unit was simply a room with an attached bathroom containing a shower and a toilet. The main room functioned as a bedroom and living room, and it was in these rooms that a lot of residents spent most of their time. These rooms were relatively customisable, according to residents' wants and needs, with a few containing bookshelves, kitchenettes (essentially a mini-fridge and a kettle or toaster), desks, or cabinets. The bathrooms were designed with accessibility in mind, and as such were fairly large "wet-rooms" and contained hoists for those unable to stand. Likewise, most beds were adjustable via remote control, with most having some form of hoist to provide residents with easier access, and with special mattresses to prevent bedsores and other pressure-related ailments.

The final area of importance for my research was the gym. Situated on the opposite side of the dining room from the staffroom, the gym served multiple uses. The gym building housed two distinct areas; firstly the gym proper, and secondly the music room. To the right directly upon entering was the gym itself, containing a combination of both disability-specific and non-disability-specific equipment. The former including things like a hoist and parallel bars, designed to facilitate rehabilitation for walking or to allow

residents to stretch out and relieve pressure on the body; a “disability Bowflex”, named for its likeness to a complicated home-gym system involving pulleys, cables, and handles, and which allows wheelchair users to be strapped in to avoid injury; and “the table”, something that was no doubt originally designed for torture. The table is simply a minimally padded wooden table, at a low enough height for most residents to be able to access relatively unaided. It is used for stretching and practising ‘transfers’ – moving from wheelchair to table and vice versa – an essential technique for many wheelchair users. In addition, suspended above the table is another table, similar to a bunk-bed arrangement, and on the underside of the top table is a metal grid. This grid is used for attaching bands of various resistances in order to facilitate even more stretching, or to provide additional support for transfers. My comment that it looked like a torture device was met by a grin from the resident personal trainer and physiotherapist who replied that many residents thought the same thing.

Finally, the music room is accessed by turning left immediately upon entering the gym building. Significantly smaller than the gym room, the music room contains a small desk with a computer and ableX system¹⁴, a piano, a few scattered chairs and a smaller room in which all the instruments (and some other items I could not recognise) are stored.

My initial observation that ALF was similar to a motel was somewhat jarring; a motel is not somewhere I would wish to spend a significant period of time. However, upon talking to my participants they all agreed that such a setup was probably the most balanced in terms of independence and access to support.

Alex, although wary of institutionalisation admitted that it is often easier for both the disabled person and their family to move into assisted living, provided that they continue to live as independently as possible and avoid complacency. Similarly, although expressing a desire to be living at home with his family, Grant accepted that – aside from the fact that his house is not particularly accessible – due to the level of support he requires, it is much easier on his family for him to live at ALF. Finally, Carly admits that life at ALF is a lot better than she previously gave it credit for. Initially, Carly likened ALF to a retirement home, and overemphasised the support that was provided, considering it rigid

¹⁴ <http://www.im-able.com/system/>

and stifling. However, she now accepts that she does require support from time to time, and that her freedom is not actually limited like she previously thought.

This final section of the chapter is an important contextual element for my study, as it not only gives the reader some idea of the spaces in which my research was carried out, but it also provides a description of the spaces in which most of my participants spent most of their time. This context helps explain my participants' identifications with disability; perhaps due to living at ALF, with the balance of support and independence it provides, as well as immersion in a community predominantly comprising disabled people, my participants simply do not experience 'disability'. Understanding the space in which my participants live and the support that is offered to them is crucial, as these inevitably shape their experiences of disability and how they interpret and incorporate such experiences in their personal and social lives.

Chapter Five: Lived experiences

“We come as a complete package, sorry!”: Subjects, objects, and bodily boundaries

The following analysis is primarily based within an identity work framework, by which I mean the “activities individuals engage in to create, present, and sustain personal identities” (Snow and Anderson 1987: 1348). More specifically, I regard my interviews as “*narrative* identity work” (Ibarra and Barbulescu 2010:137; emphasis mine) in the sense that by engaging with me in an interview setting, they have made “social efforts to craft self-narratives that meet [their] identity aims” (137). In this case, ‘narrative’ refers not to an overarching life story in which the participants attempt to make sense of their entire social existence, but is simply a “sequence of events with the purpose of making a point” (137). Narrative work alone is not sufficient to provide a comprehensive view of identity; as such I supplement my analysis with observations from my fieldwork, including casual conversation with and about participants. Furthermore, by focussing on narratives I do not intend to ignore the physical reality of identity management; although many argue that identities are primarily negotiated through discourse, such discourses are made possible through – and limited by - the lived body.

My wheelchair is part of me, yup. I can take my wheelchair off, so to speak, by getting out of it, but it’s my legs, you know? So it – we come as a complete package, sorry! [laughs]
There’s no leaving the wheelchair in the car – and if you do – if you wanna leave the chair in the car you leave me in the car too. So yeah, I agree it is an extension of me
(Carly)

This excerpt from my interview with Carly demonstrates an interesting aspect of her bodily boundaries; she provides an example of what Havi Carel (2007) terms an “extended body” (108). Carel explains that this concept is drawn from Merleau-Ponty’s phenomenological discussion of a “blind man’s stick” which,

has ceased to be an object for him, and is no longer perceived for itself; its point has become an area of sensitivity, extending the scope and active radius of touch, and providing a parallel to sight (Merleau-Ponty 1964:143)

For Carly, her wheelchair has become a part of her – it is more than just a chair that provides mobility; it is her legs. Although, to use Merleau-Ponty's words, she still perceives her wheelchair for itself in social situations - where it is most visible - in everyday life it is simply her legs. In direct contrast to the extended body exemplified above, Carly also demonstrates a kind of 'retreating body' in describing an exercise in primary school where she,

drew a picture... and my picture was of me – no it wasn't even of me, sorry I lie, it was of my mum. It was this yellow sort-of-stick-figure, and this yellow sort-of-stick-figure had a head, a body, two arms, and feet – but no legs. So for me, my legs are just pfft, not really part of me

What I found most fascinating about this excerpt was not that Carly drew a picture of a person without legs – after all she was born impaired and has no feeling below the waist – but that the picture was of somebody else, somebody non-disabled. Carly's experience gives us an interesting view into the way some people understand their own bodies; although Carly could see her legs, and knew other people walked on theirs, she did not consider them to be a part of her. What I found even more interesting was although Carly did not give her stick-figure mother any legs, she did give her feet. Coincidentally, directly after the above quote Carly began to explain the troubles she had had with her feet over the years,

when my foot gets cellulitis – notice I say “my foot gets cellulitis” and not “I get cellulitis in my foot” – I become very, I talk about my foot as if it's not part of me because for me, having no feeling from the waist down, they're just there... for a while there it was flaring up all the time and the doc kept saying “oh well we might need to take the foot”, I was like “sweet, take the foot, take the foot” and people were really worried that, you know, “oh how would you survive with no foot?”. I was like “sweet, it's not like I use them”, you know? And I kept saying “oh it's just the foot” like it's not part of me. I was talking to my aunty the other day and was saying that I'd gone into hospital and she was like “oh what

was wrong?" I said, "oh, just the foot" – she's like, "what do you mean 'just the foot'?" I was like, well, to me you just can't feel it, and I don't get sick with it or anything

These events have influenced Carly's recollection and reconstruction of past events, and help shape her understanding of her relationship with her body in the present.

Furthermore, the above excerpt helps to explain why Carly's drawing looked as it did: when parts of our bodies function as they 'should' we incorporate them into our subjective, agential selves, yet when they malfunction or cause us pain, or otherwise interrupt our wholeness of self, we tend to objectify them. It could be said that in Carly's situation, her legs are neither subject nor object as she has no feeling in them, and they do not (and have never) operate(d) normally. However, Carly's feet – like her legs – have never had any feeling, yet they have malfunctioned due to cellulitis. Although having no felt effect on Carly, cellulitis causes her feet to "dys-appear" (Leder 1990); that is, Carly's feet are "thematized at times of dysfunction or problematic operation" (Leder 1990:85). Carly's narrative quite clearly addresses the theme of embodied boundaries and subject/object distinctions, and despite being apparently complex issues, these seem to have little felt impact on Carly's identity.

Carly's comments to the doctor, that her feet should be removed if they continue to be troublesome, are echoed in Steve's narrative. Steve told me of a situation very similar to the one Carly faced above, however, it appears that his understandings of bodily boundaries were relatively normative following his decision to have his arm removed, and adaptation was more of a concern for him. Thus I will now turn to the adaptation¹⁵ that my participants underwent, and enacted upon their surroundings in order to manage these physical disturbances.

¹⁵ In the following discussion I use the terms adjust(ment) and adapt(ation) interchangeably

“My biggest challenge – trying to use the Playstation”: Reasons for, and methods of, adapting to impairment

A lot of Steve’s narrative referred back to the idea of adaptation, of how he managed to get by in the world with one arm. Steve stands out from the rest of my participants due to the nature of his impairment, as all of my participants were either born impaired or acquired impairment due to spinal or brain injuries - Steve “just” lost his arm. Everyone else I spoke to had systemic impairments – that is, their impairments were not restricted to simply one organ or limb – whereas Steve’s was localised and perhaps this is why his adaptation narrative appeared as it did. Certainly, my other participants all spoke of adaptation, as it is a part of life for disabled people, yet Steve’s adaptations were ‘simpler’ as he was coping with the functional loss of a limb, rather than dealing with an uncooperative body. This by no means diminishes Steve’s efforts; rather I draw attention to this distinction to once again return to my argument that a homogenous view of disability and disabled people does not do justice to the variety of life experiences of these individuals. However, Steve’s experiences did not occur in a cultural vacuum, and it is perhaps due to contemporary medical technology and understandings of the body that his adaptation is considered simple in comparison.

Adaptation to chronic illness and impairment can be understood as a “creative response” (Carel 2007:104) to a negative “movement between the biological and lived body” (99). Through this adaptation “a new relationship can emerge” (99), in which both practical and philosophical aspects of impairment work in tandem to produce a new understanding of the “body-subject: the body that is both a material object and the seat of subjectivity” (99). In the below examples the reader will see creative responses to impairment and the reasoning behind such responses, as well as a continuation of the matters discussed in the previous section; that is, the ways in which my participants view themselves as bodies and subjects – attempting to reconcile the two into an embodied body-subject.

Although Steve was offered a prosthetic arm, he quickly discarded it as he “found it easier to not have one and just learn to adapt”, mentioning how, with power steering, he was able to drive an automatic (transmission) car and how people he knew were able to ride a

motorcycle with one arm. I explained to Steve the background to my research and some of my interests, and we ended up discussing videogames, which turned out to be a fairly important part of Steve's leisure time, he explained,

Umm, had to learn to use a Playstation with one hand, yeah. Yeah, well I got an Xbox now but you can sort of like – you just have to sit it on your leg and kind of use all your fingers. You can't really use the thumb, it's – you're not as good as you could be obviously but you can still play... but yeah that, that's probably my biggest challenge [both laugh] – trying to use the Playstation. 'Cause they'd only recently started coming out then too, so it was – yeah. Felt like I was missing out [both laugh]

The idea of adapting to impairment to avoid “missing out” is something that is common amongst those who have recently found themselves impaired due to accident or illness, however, these adaptations are often more to do with basic functioning and social participation than leisure activities. Steve presents himself through his narratives as a laid-back man, more concerned with enjoying quality downtime than worrying about past events. This attitude could be considered an expression of idealised ‘kiwi bloke’ attitudes, and the fact that Steve considered using the Playstation his “biggest challenge” for comedic effect supports this.

However, such a ‘minor’ adaptation was not possible for all of my participants; Paul, Jenny, and Grant had to make significant adjustments. Paul and Grant are the two participants in my study who were the most seriously affected by their impairments, at least physically. Paul, who I have already introduced, suffered from bacterial meningitis which left him deaf, blind, and paralysed; Grant's illness was equally debilitating¹⁶. Jenny stands out from the previous two, as she acquired her impairment very early in life, and has made one incredible adaptation in particular in order to maintain her independence.

She explains this adaptation as she introduces herself,

My name is Jenny. I come from South Africa and I am living a home [sic] called [ALF] and in studio 21. I have Cerebral Palsy and use my feet insert [sic] of hands. I am an artist

¹⁶ I say this not to rank my participants on some sort of suffering-scale, but to acknowledge that out of all my participants, Paul and Grant were the two whose self-reports indicate that impairment caused the greatest disturbance in their lives

While this brief introduction provides some insight into how Jenny perceives herself in the world, here I will be focusing on her extraordinary adaptation. Upon meeting Jenny, and reading an information sheet she had prepared earlier, I was blown away by the way she had adjusted to her impairment. When she was just two or three months old, Jenny contracted whooping cough which led to brain damage and subsequently caused CP. At the time, Jenny's parents were advised that she "would never be able to do anything" for herself except lay on her back, but Jenny "proved the doctors wrong". As a result of these early health complications Jenny started at a special school at just nine months old which was designed to "help [her] develop". It was here that Jenny,

was taken to someone who also used his feet to do things. He showed me how to use my feet. I carried on with using my feet by myself getting more able all the time to do things with my feet instead of my hands.

I went to Brown's School for 18 years. Then I went to a home called Pevensey Place. It was a home for adult with disabilities [sic] and people with cerebral palsy to live and work. I did all sorts of things like handicraft, gardening, housework, laundry and pantry

This early start, combined with a supportive environment for eighteen years, enabled Jenny to develop an effective adaptation to help manage her impairment. Furthermore, Jenny pushed beyond simply adapting to her impairment, and got heavily involved in sport shortly after arriving at Pevensey Place;

I became involved in South Africa Sports for the disabled in 1985. I joined the Natal Team in 1986 and won two gold medals. In 1988 I became a Springbok and won three gold medals. In 1997 I won gold medals and three trophies. I have now 22 gold medals and I enjoyed my sports very much. I travelled around South Africa and saw many places. I retired because of the changes and have carried on with my life

Despite these early positive experiences, Jenny's adaptation serves to make her incredibly noticeable in social situations, putting her in an unenviable situation. Jenny explains,

the physically environment has it's challenges [sic] especially because I use my feet for everything. For examples, I avoid doing my shopping without a staff member as I would need to use my feet to get things off the shelf and I know this is not a social norm. In situations like that I worry a little about what people think

Public outings become stressful for Jenny as she is acutely aware of how she is perceived by others in a social setting. For Jenny, there is little room to exercise full agency; she either takes advantage of her learned adaptations and risks making herself highly visible and open to scrutiny, or she is accompanied by a carer which reinforces the perception of Jenny as dependent. It is clear that in Jenny's case adaptation to impairment is not enough to overcome disability, and that allowances need to be made to enable disabled people to exercise full agency.

Furthermore, these outings reflect my other participants' experiences with public interaction and are well documented in the social science literature on personhood and stigma. When talking of personhood, I mean the negotiation of my participants' status as persons; 'persons' in this sense are not to be confused with 'humans' – as individual biological organisms – but rather the term refers to a cultural category of things¹⁷ (Morris 1994) that are assigned social significance (La Fontaine 1985). I will discuss the concept of personhood in more depth in the following chapter, but as this is an important thread that runs throughout my thesis it has been briefly introduced here.

Arguably, in the West, in order to be considered a "full person" (Luborsky 1994:239) one must be able to "fully perform normatively valued activities and roles" (239). In the West, such activities and roles are often "systematically reinforced by portrayals in the media and through selection in the social, economic, and political dimensions of life" (Ablon 2002:S3) and are linked with personal traits such as "individualism, good physical health, external beauty, vocational accomplishments, and athletic achievements" (S3) – most of which are difficult at best for physically disabled people.

For Jenny, physical adaptation is confined by existing social structures; despite having learned an excellent adjustment to disability Jenny is incapable of using it in a public setting as it draws attention to her differences and contributes to her feelings of stigmatisation. For others, adaptation occurs in private where social structures have less of an impact, although social ideas of desired traits still factor in to these adaptations.

¹⁷ Morris (1994) chooses to use 'things' to make the point that, in certain cultures, animals and (what we consider to be) inanimate objects can be considered persons. However, in a contemporary Western context the category of person is usually reserved for human individuals.

Below I will briefly discuss some of the personal and introspective adaptations that my participants have made.

While Jenny's adjustments are predominantly physical, and Grant's are more attitudinal (as I will discuss shortly), Paul's adjustments are both physical and mental, and both centre on technology. Very early on Paul identified learning Braille as a necessary first step on his road to recovery, and so he,

propped myself up in bed and started learning the basics of Braille, right in those early days, within about three months of – yeah, entering the rehabilitation centre. So that's six years ago, and now I'm working with the technology I've got and working with it has changed my life massively, hugely, yeah

For Paul, learning Braille was necessary for communication purposes, and it enabled him to access certain technologies which themselves served as gateways to greater participation. Learning Braille and subsequently being able to use specialist Braille keyboard technology, Paul is able to "connect in so many ways now with the world" and this 'connection' is vitally important. Paul has also had to learn to adapt to life in a wheelchair, with all of the problems that come with it, although he is making steady progress toward "exiting [his] chair".

Paul structures his illness and recovery narrative by framing it as a "journey" and this concept has allowed Paul to make some attitudinal adjustments, as he explains,

I've learnt as I've gone on that – not to get annoyed at people because they may have feelings or they may treat you in a certain way, or have thoughts towards you in a certain way. Sadly it's just where they're at on their journey – everybody's at a different level on their journeys and they've got learning to do

Paul's Zen-like calm is a testament to his perseverance, and his ability to accept his impairment, adapting to his "new life". Paul's narrative focuses on the positive changes that his impairment has brought about, and he explores these by recounting the journey so far;

Yeah, this journey has definitely changed me. I was a very confident, very strong person in my old life, and knew what I was doing – wouldn't tolerate anybody messing me 'round... I

wasn't a very patient person in my old life, uh, anybody who, yeah, messed me around – I'd get pretty annoyed and pretty irritated and I'd flick them I suppose, and go elsewhere for whatever I needed... I've lived in an incredibly frustrating world for a long, long time. Incredible – used to make my blood boil because I came from a world where I could have anything I wanted pretty much instantly... I could do anything I wanted to; I was a free person... Uh, but when I entered this world – *nah* - you know? In the early days everything had to be done for me. Yeah, I couldn't care for myself, I had to be helped with everything until I've got to the point now where I can care for myself... but that's taken a long time to get to where I have, and I've had to learn so much patience – but patience doesn't come very easily [laughs]. If you'd seen me in my early days, I used to just wind myself like a tightly coiled spring ready to unfurl – and be careful if you got in my way man, 'cause I'd knock you into outer space, yeah. I just about knocked myself into outer space a few times...

So, I put patience right at the top of my list, yeah.

Like Paul, Grant's adjustments also primarily focused inward, emphasising internal adaptation rather than physical; an emphasis which is more noticeable in Grant's case. In 2011, after experiencing "the whole damn pre-stroke shebang" and being told he was at risk of a "major cardio event", Grant suffered a catastrophic brainstem stroke; against all odds (and despite some medical missteps) Grant survived. Although Grant defied some tall odds, his survival came with a significant cost – he narrowly avoided locked-in syndrome¹⁸, but was left with very little voluntary movement, an inability to regulate body temperature, and significant issues with verbalisation, among other things.

Grant's adaptation was limited due to the level of his impairment, and although rehabilitation proved very successful, Grant's adaptations were more mental than physical. Physically, the biggest trial for Grant in the early-to-middle stages of his recovery was to regain the ability to use computer technology (and navigate his way around it with one, non-dominant hand) as it played a vital role in his life. However, mental adaptation

¹⁸ This is a somewhat common condition among survivors of brainstem strokes, wherein an individual is left with negligible voluntary movement, often only able to move their eyelids – despite being lucid and cognitively sound.

was equally important, Grant explains that the transition from pre-stroke to post-stroke was the,

Hardest thing I've had to do. From impulsive money making go getter to an invalid on benefits needing assistance with everything. Having to learn patience, having to rely on others, often with inferior intellect when I can't 'talk' them through it is uber-frustrating

Coming to terms with post-stroke life was essential for Grant; the biggest issue was learning to be patient with himself and others, accepting his level of impairment but not being confined by it. Both Grant and Paul's narratives spoke of the end of an "old life" and a new beginning, and although both suffered the loss of their 'go-getting' businessman selves, they accept this loss as it brought about more important personal gains. Both men commented on how they are far more patient and tolerant post-illness, with Grant attributing his newfound cultural awareness to his post-stroke recovery.

Grant acknowledges that the support of his family, care staff and his eleven years in the army have "given [him] the goods to survive and manage this condition". Grant's gathering of "goods" to help manage his condition, and his life, is reflected by many of my participants who state that living with impairment has caused them to develop or strengthen certain positive personality traits – some of which may be seen to be lacking in non-disabled people.

"The goods to survive and manage this condition": Resilience and positive personality traits in response to impairment

These traits are an integral part of disabled peoples' identities, and the majority of my participants were able to offer up, or identify when asked, certain traits or skills they had developed due to – or despite – their impairments. Acknowledging these traits helped my participants make sense of themselves and their impairments; they provided a sense of satisfaction despite the issues that participants faced in everyday life, and allowed them to narratively reconfigure their current selves in reference to past events via a "springboard effect" (Pals 2006). Some of my participants considered these traits a badge

of honour, proof of their ability to accept or surpass their limitations, and something that was unique to those with impairment or disability. To me, these responses indicate one of the ways in which my participants overcome the “biographical disruption” (Carel 2007) that impairment can cause, and are demonstrative of the fact that it “is possible to suffer objective ill health and yet be subjectively well” (Carel 2009:218).

Out of these skills and traits, the single most common trait is patience. Interestingly - if somewhat unsurprisingly - patience was a trait that was brought up almost exclusively by my participants who had acquired their impairment, in contrast to those born impaired or who acquired impairment early on, who often talked of resilience¹⁹. As outlined above, both Grant and Paul struggled with coming to terms with their impairments and the issues that accompanied them, citing “learning patience” as one of the most important coping mechanisms. As these men have lost the ability to fully look after themselves, they are reliant on other people to help and this causes frustrations, something still fresh in Joe’s mind,

It was frustrating at the start, I couldn’t move my arms properly. Couldn’t even lift them over that – kind of, mid-chest height. Yeah those things were kinda frustrating, especially my um – I was doing occupational therapy and they had this kind of exercise where you had to put rings on, like, a wooden tree. Um, a vertical column with perpendicular horizontal branches coming off the side and you had to pick up rings and put it on [sic], and at the start I couldn’t even put the rings on the bottom and that really, kind of got me very frustrated...

It sucked [laughs], to be quite frank; it does suck still, quite a bit. Um, but initially before my accident I was very independent, I hated people doing stuff for me, I always wanted to do things myself, and going from that to – especially a hospital environment – where I couldn’t move my arms much and to people doing pretty much everything for me...

Joe ends this quote by explaining how he slowly started to regain his independence in the area of personal cares as a response to this frustration at becoming dependent on others. It is clear from Joe’s account that dependency, especially for those who had previously been essentially independent in daily life, is very disruptive to sense of self and is often

¹⁹ Although, in this case adapting to a traumatic incident which leads to impairment can also be seen as an example of remarkable resilience, thus it is a theme that runs throughout this section.

fought against. However, this fight for independence is mediated by sense of patience; all of these men accept that it will take time to adjust. These adjustments often come in the form of a renegotiation of the body and a better understanding of future potentials – in other words, acceptance. Although acceptance was identified by all of my participants as being important, definitions of it varied.

Joe's narrative frequently returns to rehabilitation, his "mindset", and his aims to be more independent and "have the able body". However, this is not to say that Joe has unrealistic expectations for recovery, rather Joe has accepted his current situation but refuses to be restrained by it – he has renegotiated what able-bodiedness is and strives to be the best he can be. When asked whether he had felt any pressure to "fix" himself, he replied,

Sort of – not really pressure, but I definitely do miss - in a heartbeat want to go back to the um, yeah have the able body eh? Be able to get up, play hockey, and do stuff, I suppose. In terms of pressure, not really. I mean I found my friends and family and stuff have been yeah, really accepting of everything and awesome around that. Um, personally I have been in the gym a lot to kind of get as good, strength-wise, as I can and get as mobile as possible to – for independence's sake as well. In a way it's – there's acceptance for a few factors but in other ways there is - not a lot of pressure - but I do aim to get as much as possible, to what I was capable of doing before my accident

Joe states that rather than external pressure to overcome his condition, most of the motivation comes from within. Furthermore, he understands that there are limits to what he can achieve, but he does not want to simply accept these limits as rigid and unchangeable – Joe is determined to test these boundaries. The reasons for all of his hard work are pragmatic: by gaining strength Joe will be able to get around in his wheelchair more easily, he will be able to transfer himself, and generally be more mobile, contributing to a marked increase in personal autonomy and independence. His narrative makes it clear that these traits are something which he values highly, and that his pre-accident identity was predicated on notions of strong self-sufficiency.

However, this kind of fluid acceptance is not the only way in which the concept is conceived by my participants. For most of my participants who were born impaired, acceptance was essentially a given, as these people felt no significant sense of loss. There

was very little discontinuity of self and body; however, acceptance was still a feature of their lives, especially when confronted with events which drew attention to their differences. Steve's stance on acceptance occupies an in-between state: he felt a profound sense of loss, but was able to accept this and "just... move on". This sort of attitude towards acceptance appears to be second-nature to people born impaired, and is often a late-blooming attitude for people who have acquired impairment and fought against it and the loss it represents. Accepting limitations, living within and around them, and focussing attention to other more changeable aspects of life is something that academics and advocates alike have suggested. This acceptance, it is argued, is not a concession, nor is it a sign of weakness; it is a sign of strength of character and the willingness to move forward rather than dwell on the past. Above all, it is a sign of resilience, a trait that is shared by all of the participants in my research.

Although resilience is internalised and expressed by my participants in individually variable ways, this process is influenced by a society in which resilience, (self) determination, and independence are considered positive traits and important markers of full adult personhood. Bearing this in mind, below I will discuss my participants' individual instances of resilience.

Acceptance of impairment by those who have acquired it through traumatic means can be seen as a sign of resilience, both to physical pain and the sense of loss and end of a "previous life". For those who had been born impaired, this resilience was more of an integral part of personal identity – conscious or otherwise – rather than an acquired response to trauma. It appeared as though these people had a near infinite source of energy in reserve, able to bounce back from almost anything, even issues unrelated to their impairments. Both Carly and Alex expressed this idea in their own way,

The majority of the time I have a lot of 'get-up-and-go', and determination to do – to live life, and to just get on with it. You know, there are so many doubters in this world – well, stuff you I'm gonna go to Uni and I'm gonna get a diploma, and I'm gonna – you know?... I just think, you know, a lot more energy...

(Carly)

Every day's an awesome way to wake up and enjoy your day. I think the day I wake up and I don't want to be here anymore's gonna be a pretty stink day, but it's not gonna be because of my disability – that's just a thing that I have to, I've adapted to and have to overcome, and, you know, use. If my legs pack out I'll get a wheelchair, my arms stop working I'll use my fucking end or something, you know?

(Alex)

This resilience is also apparent in more physical ways, as Carly explains,

When life has thrown me curveballs with health and things I do have the ability to, or stamina to go “Yeah, nah fuck you life, I'm just gonna keep on going”. Years ago I got an abscess on my spine and was chucked on bed-rest for three months and I think the average person – disabled or not – you know, wouldn't survive mentally. They'd go completely bananas – yeah I went completely bananas but I didn't let it get to me, you know? So I think, I just got on with life, you know? It was really crap but yeah, we just hunkered down and went with the flow... I think being born with a disability you are slightly more - or learn to be slightly more - resilient...

These narratives demonstrate not only how resilience is a feature of daily life for disabled people, but also that they actively incorporate it into their identities. Furthermore, as Carly's second excerpt shows, resilience does not necessarily follow from disability, that perhaps, in the words of Joe it is “a bit of a mindset”. These positive traits are essential in the shaping of meaningful identities for the people in my research, and it is especially interesting to note that although many of my participants were very much aware of the negative perceptions surrounding disabled people, nobody attributed themselves with explicitly negative traits.

The story so far: Embodiment, lived experiences, and identity

This chapter has been dedicated to presenting a range of narrative thoughts and feelings about the lived experiences of disability, including senses of bodily boundaries, tensions between the self-as-subject and the self-as-object, and adjustments to impairment. These

ethnographic snippets build upon the introductions of my participants earlier in the thesis, and serve to situate some of my theoretical work within individual and collective bodies.

It appears that the physiological reality of my participants' impairments had little impact on whether or not they identified as disabled, however, it had a significant influence on the level of adjustment or adaptation that they engaged in. These adjustments in turn affected the traits that my participants perceived themselves to possess or have learnt, and these traits – which were overwhelmingly positive – helped shape their understandings of themselves as complete persons and social actors. It is a bit of a stretch to state that the self-identification of my participants regarding disability was arbitrary as these identifications were clearly rooted in reflexive understandings of their selves in relation to their bodies, and to others *through* their bodies. Yet, contrary to claims that identifying as disabled is a political move, none of my participants that identified as disabled had overt political goals – instead, participants were more interested in living fulfilling lives, however they chose to define them.

It is beyond the scope of this thesis to propose some formulated understanding of identity management for disabled people, but I do hope this section has allowed the reader a greater understanding of how disabled people engage with their everyday lifeworlds. Through interviews my participants engaged in processes of narrative self-making, constructing personally meaningful identities which were grounded in their embodied experiences, while emphasising the positives of their experiences and downplaying the negatives. Thus they constructed themselves as resilient, resourceful, and independent social actors, for whom the term 'disabled' was more descriptive than defining.

These varied experiences and opinions on what it is to be disabled, illustrate that a homogenous view of disabled people often presented by advocates and disability scholars – even if unintentional – is not entirely accurate; and that perhaps more detailed ethnographically-grounded work exploring the experiences of individuals with disability is required. However, such works, similar to what I have attempted here, must also remain attentive to the historical and cultural contexts in which they are situated. While this

thesis has presented some interesting, phenomenologically grounded points thus far, I remain attentive to the cultural contexts that shape the lives of my participants.

In the following chapter, I will turn my attention toward some issues that scholars within disability studies and medical anthropology have often assumed when researching disability, namely stigma, oppression and normalisation.

Chapter Six: Acceptable identities; personhood, normalcy, and stigma

“Don’t talk to that person ‘cause you might pick up their disability”: Stigma and discrimination

Although recent debate has seen stigma criticised as a lens through which to view disability, there is little doubt that stigma is present in the lives of disabled people in both explicit and implicit ways. Stigma, Erving Goffman (1963) states, is the result of an individual “possessing an attribute that makes him different from others... *and of a less desirable kind*” (2-3; emphasis mine). As a result of this ‘negatively charged’ difference, such an individual is “reduced in our minds from a *whole and usual* person to a tainted, discounted one” (3; emphasis mine). I have emphasised certain statements in order to draw attention to two key points in my conceptualisation of stigma: firstly, a difference in itself is not stigmatising, but it becomes so when it is perceived negatively by society; and secondly, that stigma necessarily entails an erosion of personhood.

It should come as no surprise to those living in the West that physical (and moreover, intellectual) disability is considered stigmatising (Watson 1998; Charmaz and Rosenfeld 2006). Following this, I will discuss some of the instances of stigma that my participants have experienced, and how they manage these negative assessments of themselves.

Reflecting on her past experiences, Carly discussed some particular events where the judgements of others made her hyper-aware of her impairment and her perceived place in society. Interestingly, in the following excerpt Carly implies that her mother found these events harder than Carly did herself,

She found it really hard when I would go to discos and stuff, and no one would dance with me or hang out with me. You know, they were all willing to hang out with the poor little girl in the wheelchair during P.E. to get out of doing stuff, but not – it wasn’t socially cool. Um, you know, like my sixth form ball, yup I took a partner – I took my cousin. You know, which, I mean he hung out with me the whole night and was great and it was my last day of sixth form that I revealed that “actually he was my cousin” [both laugh]

This quote from our discussion is quite revealing; Carly admits that she was not really aware of the stigma associated with her impairment except when confronted with obvious, overt instances of avoidance, or when she reflected on past experiences. Although more literature is focusing on the positive 'uses' of disability status by disabled individuals, in the case of the P.E. example, we see the use of disability status by non-disabled individuals is a source of upset. Reflecting on more recent events, Carly discussed some of the issues she deals with in daily life, and although these are often more covert in nature, as Carly has gotten older she has become more aware of them.

[I] haven't been excluded from stuff, I mean, like – with getting a job and things that side of things hasn't been particularly normal. I feel employers need to accept disability a bit better, you know? I'll apply for a job, get an interview, you know, not tell them I'm in a wheelchair – because why should I? – I'll turn up and all of a sudden someone's more qualified for the job

Despite instances such as this Carly is confident she has a “pretty damn good life”, and – like others I spoke to – believes that attitudes toward disability are improving over time.

I think, actually kids these days are getting it really good because they have more – it's more part of their everyday life. Whereas my generation – our generation – it was a bit more sort of, hush-hush “don't talk to that person 'cause you might pick up their disability”, which is crap

However, even though the stigma associated with disability may be decreasing as a result of increased exposure and advocacy work, Carly is still aware of some of the more covert workings of stigma that exist. She admits that these are not necessarily very harmful, and that often many people are unaware that their actions are potentially stigmatising, but it is clear that despite Carly's personal experience of these actions they perpetuate certain negative evaluations of disabled people as a whole. Below I will present two final interactions from Carly's narrative before comparing her experiences to others'.

When I was going to Vic Uni, [I] handed in an essay and half the class handed in their essay late. I remember the lecturer, not intentionally – well, sort of intentionally – she was trying to make a point, singled me out in class, you know. Pointed out that if I could get my essay in on time, coming in – being disabled, coming in from the Hutt and getting

my essay in on time, then why the fuck can't the rest of the class do it, you know? So there, yeah there is occasionally that, you know "if Carly can do it why can't you guys get your arse into gear?"

This is an example of what Kama (2004) refers to as a 'regular supercrip'; a disabled person who is venerated or used as an example of great achievement for simply doing something that is understood to be a given for any 'normal' person. Such representations carry the implicit assumption that disabled people are automatically disadvantaged by virtue of their impairment, and are less capable than their non-disabled counterparts, thus non-disabled people should feel shame at failing to keep up. Not only does this reinforce negative views of disabled people, but it can also cause harm to those with 'invisible' disabilities - such as learning disorders - who would be more disadvantaged than someone whose "legs don't work". Although events such as these are problematic at a general level, for Carly this was not such a big deal – especially as events such as these were, and still are, fairly rare for her.

However, more common in Carly's daily life are protective interventions from outsiders; and Carly has learnt to deal with these instances due to their unfortunate frequency.

My um, personal trainer at Les Mills, he and I get on really well he'll totally piss-take and people have walked past and been absolutely gobsmacked at shit he's giving me. I mean, I'm sitting there taking and giving it right back but they're like "My God! You can't speak to her like that!" It's like, why? Because you think I'm some poor little girl in a wheelchair? Yeah, whatever. But I say, yeah, you have the ones that wanna wrap you up and treat you with the bloody kiddie gloves, and then you have the people in my life who I get on really well with because they just treat me like, you know, one of the crew

Events such as these were reported quite often by my participants, and they reflect the paternalistic attitude that a lot of people hold toward disabled people; viewing them as somehow childlike or lacking full adult personhood. Some participants implied that many people make these comments in public places in order to appear more caring and considerate in the eyes of passersby, and although definitely feasible, in these cases it is impossible to know the true intentions of strangers on the street.

Regardless of how these stigma-charged encounters are perceived by individuals, they are clearly shaped by prevailing social understandings of disabled people, their abilities, and their perceived level of personhood and independence. However, although these encounters were recognised by my participants as being instances revealing stigmatising attitudes, few of my participants felt a sense of oppression which is often assumed to be a universal presence in the lives of disabled people. Therefore I argue that although stigma is a universal feature of 'the disabled experience', it is not always felt by individuals with disability, and when it is felt, it does not necessarily follow that they feel oppressed²⁰. These instances reveal that although discrimination (primarily in terms of providing services and employment) is legislatively prohibited, such changes do little to change public perception of disabled people.

In contrast to Carly's experiences of 'supercripping', Aaron expressed a longing for such treatment. Aaron told me that in terms of being congratulated or praised, "it hasn't really happened to [him]", and stated that "it'd be awesome" – even for mundane tasks that are expected of any non-disabled individual.

Perhaps Aaron's relative 'invisibility' - as commented on in his ethnographic introduction - could be a factor in why he considers praise "awesome". Nevertheless, these differing attitudes toward expectations and praise indicate that labelling particular interactions as inherently negative fails to take individual feelings into account.

The first few times that I went out, I saw a lot of looks and – yeah, that I was quite self-conscious of. But um, as I was saying it might be perceived, it might be real, I wasn't – [or] if I'm just used to it now. But I've found recently in the last wee while, people kind of [are] more willing to go out of their way to help, to be helpful for the things that I can't do or struggle with. I suppose it's a matter of how you personally approach it, if you kind of forget that you're in a wheelchair yourself and just go and meet people, or when you meet people – um, then they kind of see that as well... I have experienced both ends of the scale, yeah, especially - I have met people that been a bit tentative and nervous but

²⁰ Does it make sense to say that a disabled person who belongs to a society that is considered oppressive (toward disabled people) is oppressed, despite not feeling so? Conversely, is it fair to say that oppression does not exist simply because they do not feel it? These are complex issues well beyond the scope of this thesis, so I have chosen to use the phrase "feel oppressed" rather than "are oppressed" to reflect my emphasis on the felt experiences of my participants

um, that has been the minority which is pretty cool
(Joe)

Joe's comments reflect the issue of uncertainty that is sometimes debated within disability studies. Although there is much to be said of the tension in social interactions between disabled and non-disabled people, I do not intend on getting involved in such a debate here, rather I think situations such as Joe described are interesting in that they reveal a kind of pseudo-stigma.

Joe made very little mention of being discriminated against or ignored, but rather that some people – albeit a minority – were quite tentative around him. According to Susman (1994) stigma is “any persistent [sic] trait of an individual or group which evokes negative or punitive responses” (16), and it is debatable as to whether the encounters Joe described could be considered explicitly negative (as they are most definitely not punitive). In this case, both parties are aware of the perceived differences between them, with the non-disabled party unsure of how to approach or acknowledge these differences. It could be argued that the non-disabled party is revealing a negative attitude in their attempts to avoid offending the disabled party, perhaps due to an underlying belief that disabled people are more delicate or prone to taking offence. However, I do not consider this to be an example of stigma in the strict sense of the term; but it is clear that there is something influencing these interactions, which are not particularly comfortable for either party.

Once again, I believe this ethnographic approach is enough to demonstrate that a more individual, micro-level approach to disability experiences and related issues is much better at capturing the diversity that exists within the (real or imagined) disability community. A more critical reading of the disability studies literature, one that looks past the assumed homogeneity – while still attending to overarching sociocultural structures – and explores distinct areas of concern is an important companion to such an approach, and together these can paint a more grounded analysis of a range of disabled experiences.

Although such narrative descriptions of stigma do not appear to have any lasting effect on my participants' sense of self-identity, they are significant enough to remind them that they are different – not quite 'normal' – in the eyes of wider society.

"I already am living a normal life": The concept of normalcy and processes of normalisation

In the following section I will explore how my participants feel about the concept of a 'normal' person; whether or not they believe such a thing exists, to what extent (if at all) they are willing to engage in processes of normalisation, and how they negotiate and manage their own normalcy.

A: The thing is they know they're different; you get it smashed into you all the time... You can't put people in boxes and push them to do – what is normal? But I mean, even disabled people push that and say they want to lead "normal" lives – they're not gonna lead "normal" lives, you have a disability, you're gonna be different. You're different in that way for a reason.

C: So it's like they have – normal for them is not what an able-bodied or non-disabled person would consider normal, and it's sort of – there's this bit of a weird disconnect... they're sitting there thinking "I'm already living –"

A: I already am living a normal life; it just has different challenges and different ways of doing that

This quote from my interview with Alex is a good insight into how the majority of my participants considered normalcy; it is hard to define normal, but regardless of the definition they believe they are all living normal lives. Whereas most disabled critics of normalisation claim that many disabled people feel less-than-complete and are pressured into measuring up to a non-disabled norm, my participants appear to feel 'normal' and although some of them do aim towards rehabilitation or other improvements which bring them in line with the norm, none feel pressured to do so. My participants' understandings

of their lives as 'normal' echoes B.J Gleeson's (1997) summary of Paul Abberley's work, in which he states that,

disabled people do not desire the current social standard of 'normality', but rather seek a 'fuller participation in social life'. For many people... the predominant bourgeois mode of social life is neither 'normal', nor one to which they aspire (Gleeson 1997: 185).

Gleeson continues that this concept of 'normal' lives and people is a result of "normative political theories which have effaced the critical fact of human social difference by presupposing abstract, homogenized notions of human subjectivity" (Gleeson 1997: 185).

Most of my participants fell into one of the following categories when talking about normalcy: either everybody is normal, and thus there are no problems regarding what constitutes a normal life; or nobody is normal, therefore a distinction between normal and abnormal becomes untenable – everybody simply 'is'. These categorisations show that for my participants the concept of normalcy and the accompanying processes of normalisation were of little lasting concern, a fact which serves to reinforce Gleeson's (1997) argument.

Normalisation is a much maligned concept within disability studies, specifying a set of processes in which an individual makes "an attempt to adjust to society, and as such, it is linked to internalization of socially devalued personal identities" (Susman 1994:20; emphasis in original). While normalisation is still a debated topic²¹ - usually depicted as social model versus medical model - Mankoff, Hayes, and Kasnitz (2010)²² remind us that "there may not even be a 'right' problem to tackle or a 'right' approach to take" (8). Although in the following section I argue that my participants appear to have resisted internalising negative societal attitudes, they still engage in activities that are perceived – by academics – as normalising. Rather than attribute an internalisation of stigma to my participants to account for this, I seek to understand what factors are involved in their decisions to act in this way.

²¹ See Wolfensberger and Tullman (1982) and Susman (1994) for examples of two contrasting approaches.

²² This quote was originally used in the context of debates surrounding the development and use of assistive technologies, but there are clear links between assistive technologies and normalisation (restoring 'normal' function).

Although my participants felt like the concept of normalcy was of little concern for them in their daily lives, it was clear that they were still very much aware of what other people considered normal to be. For example, Alex's assertion above that, "they're not gonna lead 'normal' lives" is in direct contradiction to his position in the following statement that "I already am living a normal life". The latter quote is based on Alex's personal definition (or lack thereof) of 'normal', whereas the former quote identifies a 'different normal' – a conception of normalcy that he recognises as being held by (non-disabled) others in society. Likewise, when asked whether her life was 'normal', Carly simply replied "Yes", yet when talking about visits from her niece and nephew she says "it's really cool – they come here and they see all these people in wheelchairs and with different disabilities and they just think it's normal, you know?" Carly's wording here implies that seeing disabled people just getting on with their lives is not considered normal by the wider public, her niece and nephew "just *think* it's normal".

The social model states that disability is located within a society that does not meet the needs of impaired people, and thus any disabled person is automatically oppressed – it is logically impossible for a disabled person (opposed to an impaired person) to be unoppressed (Shakespeare 2006). Following this logic, any disabled person who undertakes rehabilitation is subjected to normalising processes which are informed by the prevailing view that disability is a deficit that must be corrected (Lupton and Seymour 2000; Brisenden 1986). In contrast to these views my participants do not consider themselves oppressed, nor do they aspire to the dominant understanding of 'normal'. My participants acknowledge their differences and difficulties, and understand they will most likely never reach the 'norm' and as such focus on improving themselves in the areas that they can excel in, and negotiating their own sense of normal.

In fact, it could be argued that the social model instils feelings of despair and hopelessness for some disabled people; if normalisation just reinforces the perception of disabled people as at fault, then it is not worth taking part in. However, if one does not normalise themselves, they remain part of a disadvantaged population that has very little power to influence social change. In this case it may be best for one to remain in care as they have their needs met without the negative effects of normalisation; unfortunately

this can lead to institutionalisation and a withdrawal from social engagement. This institutionalised shrinking of disabled peoples' lifeworlds is an issue that Alex has experienced first-hand and is very passionate about; in fact, it is what his role at ALF is all about.

For me it's to inspire these guys that they can think outside the square and actually, they can achieve a lot more than what they give themselves credit for. But when you've been pampered for a very long time it's really hard to break these guys out of their insecurities... And I guess that's one reason why I was employed to come here is because I do everything that any of these guys could do – I mean some of them walk better than I do, it's crazy [laughs]

For Alex, this inspiration and his 'taskmaster' ethic are not rooted in aims to restore normalcy to these people, but instead to help them achieve their full potential – within the physical limits imposed by their impairments. Alex believes that a lot of disabled people are "pampered", and explains that it is often against their will, but over time they become institutionalised and are unwilling or unable to leave their comfort zones (which have shrunk, ironically, due to the high standard of care that they receive). Alex agrees that this is influenced quite heavily by the internalisation of pervasive negative stereotypes and admits that he has now gained a greater understanding of the challenges that disabled people face, yet these have not dissuaded him.

C: ... this whole normal thing again, how, you know, they're different, they're not normal and that they've sort of internalised that and-

A: yeah, they've – they take that on board, so if – especially some of the ones that have been here very, very long term or anyone in an institutional residential care facility, if their families go "Oh no, you know it's a lot safer if you go into care and everything's done for you and you're well looked after", decisions don't need to be made. The money's there, you know, they just exist and everything's catered for them and then they get these small wounds or they hurt themselves and it's the end of the world, you know?... They haven't had the joys of leading a life, of going flatting or holding down a job, or having to pay a power bill or catch a bus, or – and actually try that. I mean there's some here that would love the opportunities to do that and it's not gonna happen, um but again that's the families wanting them to be safe, you know, they're very precious to

them and I understand, I kinda get the concept. Before I came here I kinda wasn't, you know, I was like "ah fucking disabled people should be out there doing it" you know, until I came here and realised that not everyone's in that boat. I guess that opened my eyes a lot to, you know – and it's their own insecurities and they're very vulnerable to people taking advantage of them so I kind of understand the concept of that so then I make programs around them to enrich their lives

For Alex, the work that he is involved in is not about making disabled people normal, but is about working with them in order to enrich their lives. Part of this enrichment in Alex's eyes is physical mobility, because the more mobile someone is the easier their life will be, and they are more likely to be able to engage in meaningful social interaction. If, Alex states,

You keep using and working it, and keep those muscles going – you'll get some improvement... you'll get better mobility out of everything. But if you wrap them up in bubble-wrap and almost treat them too friggin' soft, they are gonna lock up, they are gonna seize up, they are gonna end up in a wheelchair

This approach to 'fixing' impairment is often criticised as being heavily influenced by the medical model, situating normative ideals of a successful body as the standard against which all others must measure up (Davis 2002, 2006; Edgerton 1984; Shakespeare 2006). Kathy Charmaz (1995) argues that this "struggling with" (663) impairment can be harmful as it leads individuals to resist embodied experience by distancing themselves from their own bodies, stating that it is better to accept bodily limitations and "surrender" to disability (672). Furthermore, Nick Watson (2002) argues that some writers "suggest that this struggle to attain 'normality' and eliminate the existence of impairment adds further to the oppression of disabled people" and that disabled people are "in effect, stigmatising themselves" (521-522) through such actions.

In contrast, Alex believes there is a point where acceptance becomes harmful; it is one thing to accept one's impairment and the unavoidable limitations of it, but it is a different matter altogether accepting the inevitable future in the present. Alex sums this up in his usual, no-nonsense way,

The body's gonna do what the body wants to do... people need to accept that they have a disability and move on with it. Things are gonna get harder as you get older, but there's no miracle cures²³

Returning to Gleeson (1997), I argue that my participants' aspirations and understandings of normalcy are not in line with the current tacit social understanding of normalcy. Thus, in this context it makes little sense to refer to my participants' actions to improve their bodies, attitudes, and overall identities as part of a top-down process of normalisation. My participants display their agency in their reconfiguring of not only normal persons, but normal lives.

I've met some crazy-arse people in my life man, and uh, I just don't know what normal is anymore, you know? [both laugh] What is normal? Maybe what's normal to you is not normal to me

(Alex)

Alex is not able to come up with a universal definition of normalcy, however, he acknowledges – consciously or not – that there does exist some shared social concept of normalcy when he states that disabled people are “not gonna live normal lives”. Clearly this conflict between a personal sense of normalcy and the socially understood sense of normalcy has little impact on Alex's life, and although this could be explained away by saying he has only known life with impairment (so naturally it seems normal), even those who have acquired impairment due to injury consider their lives normal.

How do you define normal? Who is normal? Uh, even before this happened to me I used to say “who's normal?” We've all got different, uh, disabilities that we live with, even able-bodied people. Their disability may not be so visible as someone like mine, but we all do have limits, limits in our lives

(Paul)

Paul constructs difference as a defining feature of normalcy. Like Alex he has a hard time defining normal but chooses to focus on disability, which he understands to be a

²³ Charmaz defines 'struggling against', 'struggling with', and 'surrendering to' disability as related but exclusive processes. However, as this quote shows, these boundaries are not as rigid as they are made out to be

particular manifestation of a limitation – something that everyone has. In this way Paul denies the socially understood norm of an un-limited or de-limited body, and flips it on its head by implying that the limited body is the norm. Paul thus challenges existing notions of normalcy, and creates a space for any-body to be normal.

Contrary to the above two excerpts which emphasised the difficulties in defining normalcy, Aaron's thoughts on the matter of normalcy were incredibly straightforward; he simply believes that everybody is normal.

C: It might be a difficult question to answer, but do you feel like your life is "normal"?

A: To me, yeah, I think so

C: Yeah, so do you think maybe somebody else might think it's not?

A: Well, I know when I was little someone thought I'm not like everybody else, yeah

C: Yeah? So how do you think they would define normal then?

A: Uhh, to them they would think, um, people that can walk around and – yeah. Do stuff that wheelchair people can't, yeah

C: Yeah, obviously not the case. Um, so would you have a different definition then?

A: I'd say, no matter if you're disabled or not disabled, you're like, the same, you know?

C: Yeah, so everyone's normal really?

A: Yeah

Aaron believes – fairly accurately – that the dominant social understanding of normalcy is closely tied with typical physiological functioning; that is, being able to carry out the full range of 'natural' human actions. His definition appears to simply be an appeal to humanity, we are all human, we are all individuals, and we are all normal – physical ability (or lack thereof) does not change this fact. This understanding of normalcy allows Aaron to live his life as he sees fit, and still be able to claim 'normal' status.

Similarly, Carly's understanding of normal is fairly uncomplicated; both she and her life are normal. Carly explains normality has nothing to do with physical ability or impairment instead stating,

Normal is what – you know, I eat, sleep, drink, have friends, go out. Um, I mean teen years probably wasn't particularly normal, but life is what you make it

Carly's definition of normalcy is perhaps closest to what is understood by the greater society, yet it is broad enough to include everyone at ALF. Interestingly, this excludes people with severe impairments who are unable to eat or drink in a normative sense (being fed intravenously for example), but also non-disabled people who have no friends or who do not leave their houses. However, it is worth reiterating here that there is no universally agreed upon definition of normalcy, and the dominant social understanding is not static or fixed. Likewise, I believe that my participants have reconfigured normalcy due to changes in their lives as a way to maintain consistency of self – if Carly were to suddenly lose her ability to eat I do not think she would consider herself doomed to a life of abnormality.

These examples of the different ways my participants conceive of normality and where they locate themselves in relation to this concept shows the diverse range of attitudes concerning the experience of disability in the social sphere. All of my participants considered themselves normal according to their definitions, even if they could not agree on what normalcy was, and despite being aware that their understandings of normal conflicted with the prevailing understandings of normalcy. They acknowledged they were different, but not abnormal, and some took pride in this difference. None of my participants considered themselves abnormal, and although they did pick up on certain stigmatising encounters, they considered these to be a failing in the individual 'doing' the stigmatising, rather than a reflection of negative social attitudes.

In sum, my participants did not see themselves as belonging to an oppressed group; they saw themselves as normal persons, who chose (or refused) to improve themselves through their own volition rather than external pressure to measure up to an idealised norm. They displayed agency by constructing their own understandings of normalcy, and

by identifying or distancing themselves from disability – or sometimes both. Through their narratives they reconfigured normalcy in relation to disability, and in doing so emphasised their status as full persons. These identifications as normal, full persons help my participants counteract narrative disruptions that can co-occur with impairment, and allow them the agency to construct their selves as unique social actors.

The processes of identification that my participants engaged in were not purely individual but also culturally informed, and this has impacts on establishing a valued identity. Presenting oneself as strong and independent only provides benefits as long as such traits are assigned positive status as markers of personhood. In this context, possession of these traits allows my participants to distance themselves from the label of disability, ‘de-normalising’ self-improvement and lessening the impact of stigmatising encounters. Although my participants serve as a living critique of certain issues within the social model – such as the (now contested) homogeneity of disabled persons, the lack of attention to physical aspects of disability, and the circular logic that results in oppression being considered a universal experience for disabled people – it must be kept in mind that such critiques are not intended to assert the irrelevance of the social model. Rather, I focus on individual accounts in order to present an alternative view of disability grounded in embodied experiences that is inspired by – and has the potential to extend – the social model.

I now turn to a discussion of the role of technology in my participants’ lives, in order to draw attention to its importance and how it shapes their lived experiences. I believe this is quite novel and goes some way toward presenting a diverse range of disabled peoples’ understandings of a topic which is often overlooked in disability studies. Discussion of technology in relation to disability is uncommon and usually focused on assistive technology, often framed in terms of the medical model and normalisation. My work focuses on whatever technology my participants deem important, which includes – but is not limited to – assistive technology, and emphasises conscious engagement with technology and the subsequent effects it has on life experiences and self-identity. Far from simply being practical tools or instruments of normalisation, “technologies

participate actively in every existing realm of anthropological interest” (Downey, Dumit & Williams 1995:267).

Chapter Seven: “This wheelchair is life!” **(The role of technology in peoples’ lives)**

I said – I think yesterday – to one of the workers, I said to her it’s a great ideas for the people making the electric wheelchair. It’s uh, a solution for disabled man. So it is a great idea and it is a great mate, yeah so it is beautiful... without wheelchair I don’t think I could live... this is a great technology and beautiful mate for all human beings, not just in New Zealand – this wheelchair what they make it’s needable around the world and desperately needed

(Amir)

Throughout our interview Amir’s focus returned again and again to the importance of his powered wheelchair, and even if he had not stated it explicitly – multiple times – it was evident that this particular piece of technology was quite literally of vital importance to him.

Despite Amir’s connection to his chair, he admits he is “not a computer man” and did not offer up a definition of technology when asked – rather, he told me that when he was offered a computer training course he simply could not keep up with what he was being told. This answer, combined with the fact that he identified his computer and his cellphone as the only items of technology that he uses on a daily basis, shows that Amir understands technology in a way that is fairly standard and consistent with my other participants.

Alongside Amir, I have selected three more participants whose discussions of technology I found particularly fascinating – Steve, Paul, and Grant – three men, all of whom acquired their impairments. Those who were born impaired had very little conscious engagement with (assistive) technology, often referring only to digital technologies such as computers and cellphones. Perhaps this is due to early and persistent exposure to technology, in fact, as mentioned previously those who were born impaired seemed to have different conceptions of bodily boundaries than those who had acquired impairment; often breaking down the barrier between human and technology. Conversely, those who acquired their impairments often reinforced these subject-object boundaries, even

applying them to their own bodies with comments like “note brain is perfect only body broken. i refer it as my broken shell” (Grant) and “it isn’t dictated by the outside, that’s only just a shell” (Paul).

“If I catch up to you I’m tipping you out of your chair”: Wheelchair basketball as an intersection between body, technology, and identity

As I mentioned very briefly earlier in this thesis, a significant part of my research involved observation of a local wheelchair basketball team. This observation was mainly non-participatory for obvious reasons, but later in the fieldwork I was invited to participate in trainings with them. Initial fieldwork with this team was carried out as a way to meet some potential participants, and I had originally considered it to be fairly unsuccessful as a data gathering approach in itself. However, upon reflection it appears that what I observed has close links with the topics I have engaged with in this thesis; primarily relating to the relationships between persons and technology, but also earlier discussions such as embodiment, subject/object distinctions, and even identity negotiation. As such, below I will provide an overview of the work I conducted and will analyse this work in relation to the main themes of this thesis, primarily focusing on the relationship between persons and technology - in this case represented by the wheelchair.

When I first arrived at the sports centre and saw how enormous it was - twelve full-sized basketball courts, six on either side of a wide central walkway - I was worried that I would have difficulty finding the team, luckily, however, they were training on the court directly opposite from the entrance. I sat down on the uncomfortable plastic seats lining the court and simply observed.

The very first thing I noted was how natural everyone looked, and how easily they manoeuvred around the court, avoiding each other, making and receiving passes, and taking shots. The second thing I noted was that they played on a full size court, with full height hoops; when I spoke to Alex later, he explained to me how wheelchair basketball

differed from the original sport²⁴. Although played on a regular court with a regular setup, there are a number of modifications made to suit those in wheelchairs: players are allowed to touch their wheels twice before needing to bounce, pass, or shoot the ball; contact is allowed, primarily in defending roles, however, purposefully restraining or tipping another player is not; and players are graded on their level of impairment, and teams are not limited by number of players but by the sum of their grades²⁵.

This grading system is interesting for my research in two main ways: firstly, it has an impact on how players understand their own impairment; and secondly – although it appears contradictory – it allows players to negotiate their impairment. The following excerpt from Alex exemplifies both of these points,

It starts going on your limitations, so for me I have three elements for my disability: so, weakness on one side, I have a bent spine, and I have the weakness in my legs and abdominal weakness so I get dropped down to a two. Um, and it's all gauged on how you play and how you handle your chair and everything when the assessors are watching, so I mean, the more broken you play the better

In the context of the wheelchair basketball grading system, people understand their impairment as an inventory of functional issues, and the perceived impact these have on the functioning of their bodies. Rather than internalising a view of their bodies as fundamentally flawed, players can take advantage of the ambiguity of certain physical aspects by 'acting up' their impairments and lowering their grading to free up space for less impaired players. In this case it is clear that players understand the 'real' limitations of their bodies and take advantage of this discrepancy between subjectively lived and 'objectively' perceived limitation. Furthermore, this 'gaming' of the grade system can be enhanced or offset by utilising different wheelchair configurations.

During my second visit, I overheard two players discussing a potential re-grading which could change the entire team dynamic. Kelly, a skilled teenaged girl with a position in the B-grade team, was explaining how she had recently been to a specialist who had made a

²⁴ These rules vary by country, and in training the rules are simplified

²⁵ Individual grades range from 1 to 4.5, with 1 being significantly impaired and 4.5 being unimpaired. The sum of players' grades on the court cannot exceed 14.

re-evaluation of her abilities, potentially changing her “from a two to a three”. Although there is no way to play the system when it comes to a specialist evaluation, in some cases it is possible to use technology to ones advantage by utilising a wheelchair that makes it more difficult to play – or at least appears that way to an assessor. In cases where the assessment could go either way, purposefully using a chair that does not suit your abilities can tip the scales in your favour.

For example, although all basketball wheelchairs are designed roughly the same – essentially being a normal wheelchair but lighter, with thinner and outward sloping wheels, leg guards, caster wheels to minimise tipping, and straps to hold the player in – they come in different heights, often described as “high/low-pointer” chairs. Although Alex is relatively unimpaired, he is rated as a two due to the “elements” of his disability – a grading that may be challenged by an opponent who sees him walk onto the court without issue. Alex can reassert his status as a two by showing his inability to play well in a high-pointer chair - although in his case it is not acted but legitimate;

A lot of our guys get to sit a bit higher, whereas for me, to have stability I need to be low and grounded so I can have that stability to shoot and be blocking and stuff. I’ve tried sitting higher and I just get all over the place and fall out – yeah, no fun

The role of the wheelchair in the ‘grade-politics’ of wheelchair basketball highlights some interesting things about technology in relation to disability; technology is often received ambivalently (Lupton and Seymour 2000; Cromby and Standen 1999), and in a more novel sense it exemplifies the different views on ‘cyborgification’. The above authors are just a few examples of the many scholars working on the ambivalent nature of technology for those living with disabilities, and although they cover some diverse topics the general theme across all of these works is that disabled people,

live life through bodies that are configured with assistive technologies in particular ways that have implications for how their bodies are socially identified and personally experienced. Technologies are a source of enablement for people with disabilities, but at the same time technologies structure human interactions and contribute to marking disabled persons as ‘other’ (Gibson et al. 2007:15).

This ambivalence can be seen throughout my work; as such I will not discuss it explicitly here.

In terms of the 'disabled cyborg' there are two main understandings of the form it takes and the associated connotations: the disabled person is less than human and requires a technological component to be complete (Howe 2011); or the disabled person is a complete person, and the incorporation of technology makes them more-than-human (Christie and Bloustien 2010). In my observations of the wheelchair basketball team, the former understanding is absent (unless we consider a 'basketball-playing-person' which requires a specific piece of technology to exist), whereas the latter appears in a weaker form in which a person is made 'more complete' by swapping to a custom-made piece of technology that enhances their abilities. Interestingly, the politics of grading introduce a third concept of the cyborg, in which a complete person incorporates technology (diagnostic or assistive) to lessen their completeness.

Returning to the title of this section, I will conclude by discussing my personal experiences in the wheelchair. One evening before training began, I asked Alex if there was anything I could do to help out; to my surprise he offered me the chance to train with them – an offer I immediately accepted.

After fifteen minutes of fumbling around trying to find a suitable chair and matching wheels (the bodies and wheels were stored separately, and it was not until later that I found out they were number-coded for easy matching), and after accidentally sitting in someone else's chair – crossing some serious personal boundaries – I managed to wheel myself out onto the court. Despite my complete inexperience, Alex did not hold back and I was subject to his usual no-nonsense approach to training, with the added incentive (for both the other players and myself) of a ten dollar bounty on my head for whoever could tip me out of my chair.

We started the warmup by following a course around the court, and it was here that the skill of these players shone through. I was going at roughly half the speed as everyone else, constantly veering to the right, and turning the wrong way around corners - and subsequently overcorrecting, spinning out, and getting in everyone's way. The former two

issues were down to having an underinflated right tyre as identified by another player, but the latter was all me. Shortly after inflating my tyre I encountered another issue, one I had previously observed among the other non-disabled players:

most of the time we rock back and forth, going from back caster to front caster while we roll. This is ineffective and slows us down. If we shift our weight forward, we can't get our arms far enough back to produce a good push, and if we lean back to get a good push we end up shifting our weight on to the back caster and essentially spinning the wheels in the air

I had barely gotten used to moving in straight lines when Alex initiated an exercise in which we had to pass the ball in a set pattern around the court, constantly taking the place of the person we had just passed to. Despite appearing to be a basic exercise, the complexity of it soon shone through: I noted that,

the constant push-pass-steer-catch-push-bounce-push-pass-catch-push-shoot got very complicated, and it was during this exercise that I made the most mistakes, spinning out, dropping balls, and fumbling passes – generally slowing it down and getting in everyone's way

Alex, being Alex, decided to add another ball to the exercise, increasing the speed and complexity. Needless to say, I did even worse when the second ball was added, but this time I was not alone. Shortly afterwards, Alex decided that it was perhaps a bit much, and instead separated us into two groups – which I later found out were the B-grade competitive team and the C-grade social team – to do some basic drills. We ended the training with a friendly game between the teams, and as to be expected it was a massacre. I still had not learned how to properly control my wheelchair by the time the training ended, despite being drenched in sweat with a numb arm, bruised hand, bleeding nails, and friction burns on my palms.

That particular training session made clear just how 'connected' these people were with their wheelchairs. Although being a relatively fit, non-disabled young man, I was totally outmanoeuvred and outplayed. I could barely control my wheelchair most of the time, let alone handle a basketball in a stressful environment, while keeping track of friend and foe, and making good game-related decisions. It is clear that in order to be successful in such a

sport, the control of the wheelchair must be second-nature, in a similar way to that of a non-disabled person's legs. For these people, some more than others, the wheelchair was definitely an extension of their bodies – particularly those who use a wheelchair on a daily basis. Returning to Kiger's (1992) discussion of disability simulation, initial responses can be overwhelming and lead to skewed perceptions and interpretations. This has been taken into account, and despite participating in multiple trainings I never got the hang of controlling the wheelchair smoothly. Certainly, I improved, but controlling the wheelchair was always at the forefront of my mind and I still made basic control errors from time to time.

In the context of wheelchair basketball, the direct relationship between technology and person is fairly straightforward for two reasons: firstly, the wheelchair is only used for a very specific purpose; and secondly, the majority of the players already used standard wheelchairs on a daily basis, so the transition from standard chair to basketball chair was very smooth. Although these players' use of their basketball chairs appeared to be automatic and prereflexive for the most part, they were not considered 'legs' in the same way that a standard chair was. Because their basketball chairs were only used in specific spatiotemporal settings for the express purpose of basketball, they were simply transferred in and out of as needed and not 'lived in'.

Perhaps more interesting are the ways in which embodied experiences, diagnostic and ability criteria, and technology usage all intersect in the grading system. Returning to Dumit's (2010) concept of objective self-fashioning, we can see how these players negotiate their identities and understand their bodies; embodied experiences take a back seat in the grading process, whereas medical assessments of bodily function and the use of certain technologies (in a certain way) are more important. For example, Alex does not associate with being disabled, but in the context of the wheelchair basketball grading system he is "a two". Non-disabled Alex disappears, and Alex-the-two appears; someone who has "three elements for [their] disability" and as such is little more than a catalogue of impairments. However, this identity is not assigned solely by an assessor, but is constructed through clever manipulation of one's body and use of technology. Furthermore, players are able to keep their embodied identities and their graded

identities separate because these graded identities are only relevant in a particular context, and one which is shared almost exclusively with other disabled people.

This discussion of my participant observation with a wheelchair basketball team has retraced some of the key themes in this thesis, such as the embodied experiences of technology as an extension of the body, and has shown explicit links between technology and identity, in the way that diagnostic (passive) and assistive (active) forms of technology interact in negotiating a context-specific disabled identity, and different understandings of the self. When set against previous work on identity in this thesis, it becomes clear that such identities and understandings of self are not necessarily harmful, that they are constructed by self-aware social actors, and that they may coexist with other - often contradictory – understandings of the self. Below I will return to my discussion of technology as it is present in the lives of my participants at ALF.

“Everything is interacting with everything else now”: Defining and making meaning of technology

When asked what came to mind when discussing technology (a question I asked every participant), Steve replied,

Yeah um, new technology obviously – like cellphones and tablets and the way things are going everything is interacting with everything else now. Or um, assistive-type aids and stuff, which was the first thing that came to mind when you said people with disabilities and technology. Probably the first thing I thought was how they would use the technology that’s out now

For Steve, technology is “obviously” digital and he emphasises connectivity, although he does not define technology explicitly. His comments show he distinguishes between assistive and non-assistive technologies, and although he does not provide examples of technology that he uses on a daily basis, he later mentions his prosthesis and his Xbox – examples of assistive and non-assistive technology respectively – which I will discuss shortly.

Paul's understanding of technology is similar to Steve's, but differs in a few respects. In response to a question about his daily technology use, Paul gave me a detailed rundown of what he uses and why.

I've got a BrailleNote Apex²⁶ which is what I'm reading your texts off here. It's connected to an iPhone – uh I do use the iPhone a little but I do most of the navigation on the BrailleNote... I also do it on the laptop as well... I do have a, a cochlear implant... which does allow me to hear uh some limited amounts of hearing

Paul identifies four key technologies²⁷ – two assistive and two that fit in the 'general' category of technology, that is, digital technologies - and like Steve, he does not offer up a definition of technology. For Paul, technology as a category includes both assistive and non-assistive (digital) technologies.

Despite the fact that Paul "never was really a techo" he has thrown himself headfirst into learning about technology, and endeavours to always be abreast of up-and-coming assistive technologies such as,

The camera I can use to take photographs of things and that gives me a readback on various articles which is quite cool. It's not always perfect but it does give you a brief description of items around the house

And

New technology made with polyurethane that's got a Bluetooth membrane inside the polyurethane that you can actually put inside the soles of your shoes... which connects with your iPhone... what it does is it gives you the ability to be able to navigate your way using your iPhone – a blind person – uh 'cause the membrane will vibrate. And so, you could set your GPS system... set it to the route you wish to travel and it will give you, as you travel along, it will cause various vibrations... to indicate you need to turn to the right

Both similar yet distinct to the previous two, Grant's understanding of technology is of great significance to his sense of self. Perhaps the greatest example of the important roles technology can play in the lives of disabled people, Grant told me outright that he

²⁶ See: <http://store.humanware.com/hus/brailnote-apex-bt-32-braille-notetaker.html> for more details

²⁷ Interestingly, the cochlear implant appears to be of more use for Paul in blocking out tinnitus rather than for hearing sounds; an example of the technological exaptation somewhat common among disabled people.

“would’ve given up in ICU if survival meant the two [technology and life] were mutually exclusive”. Grant was the only participant in a wheelchair to identify it as technology, and the only one to explicitly define technology, which he states is,

any process or thing which will simplify or streamline our existence. It will have the ability to process information quickly, consistently and tirelessly which otherwise may take us lifetimes

It is clear that Grant considers technology’s importance to stem from its utility and practical benefits – echoing both Schön (1967) and Pfaffenberger’s (1988) definitions – and both his examples and his definition identify digital technologies as representative of technology in general. However, despite the similarities between Grant and the others mentioned above, there are some crucial differences in Grant’s relationships with technology.

While Steve does not use any assistive technology, foregoing the use of a prosthesis because of the (somewhat ironic) impracticality of it, he enjoys using non-assistive leisure technology (his Xbox) but admits there are significant, and unexpected, accessibility issues;

You’re not as good as you could be obviously, but you can still play... I mean I’ve had a go at the Kinect [a hands-free, camera-based controller for the Xbox], I didn’t really like that very much. I don’t think the technology’s quite there – not quite right. Especially having one arm, it expects you to have two – there’s no sort of option so there’s some things you can’t do

Overall, Steve does not use or even require assistive technology, so his relationship is mostly based on leisure activities and although important, he is not reliant on technology.

In contrast, although technology is not required as long as he has somebody with him, Paul considers it to be “very much an extension of [his] life, without it [he’d] be very limited”. Moreover, Paul’s relationship with technology could be described as symbiotic, and he feels obligated to use his technology for good, rather than “selfish reasons” because,

It's [technology] caused me to be a lot more outgoing person... at one point I was caught in my own little world – trapped. It's causing me to look further and further afield and I want to use my technology to change the world. I'm a firm believer that I've got the ability to do what I can for a reason, I was left on the planet for a reason and my brain left intact for a reason. So I need to use this technology to the best of my ability... So as much as it's changing my life and giving me so much more positive energies inside, I'm wanting to, and I'm endeavouring to use it to inspire other people

Unlike Steve, Paul's technology usage is almost entirely limited to the practical realm, as being unable to see or hear makes most leisure technologies redundant, however, Paul does get great joy out of reading – something that is helped by technology.

An interesting aside that was raised in a very brief discussion with Paul's wife, Jamie, regards methods of communication. While preparing for the interview Jamie asked if I was going to hand-sign with Paul, and when I explained I was going to text-message him, she told me that she often has to make similar decisions on how she communicates with Paul. If she is tired or otherwise distracted her hand-signing can often be a little forceful which Paul interprets as a sign of anger or frustration; on the other hand, Jamie feels that sending him a text message for him to read on his BrailleNote is easier and more to the point, yet it also seems too mechanical and impersonal – she prefers the human-to-human contact, particularly when discussing sensitive topics. Jamie often has to decide between getting her point across easily and without misinterpretation, or going for a more personal approach which may be a little more difficult.

Returning to Grant's relationships with technology, while there are some obvious similarities in that Grant enjoys leisure technology greatly (like Steve) and relies on assistive technology (like Paul), his relationships with assistive and non-assistive technologies are more personal. In fact, Grant sees the boundaries between the two categories as inappropriate.

Computers and tablets ARE assistive when the correct s/ware is chosen, ESPECIALLY if unable to vocalise. Being able to communicate thru emails, blogs, etc and being able to type what I require has given me more independence and pure enjoyment (not leisure) than the specialised items you speak of ["wheelchairs, braces, modified cutlery etc."]

To this extent, Grant has dedicated an appendix in his latest book, “Tech Wreck”²⁸, which is “ESPECIALLY FOR VICTIMS LEFT UNABLE TO SPEAK”. In this appendix Grant provides a short list of free apps which are perfect for communication and learning to regain control of facial muscles to facilitate speech. He opens the section with an introduction, explaining that,

Yin and yang. While I blame computers for the sedentary nights and the 3a.m. mornings, and are largely to blame for the state I now find myself in, they have been my crux, my first aid kit, responsible for the pace of my rehab and again my constant companion. Computers give me independence, freedom, a reason to want to get up each morning... It is my vehicle now, my world trip, no, universe. And everything in between. My opening to the vast beyond, my escape. Yes, it always has been but MORE so now. I am at a loss, grounded, lost without it. Above all though, it's my VOICE!

The above two quotes from Grant align well with Alex's reflections on normalcy and the importance of technology for disabled people, particularly at ALF;

When you say technology, I think straight back to computers. It has opened them up to the world to communicate, and that is the one biggest thing that you've got. And the thing is the specialists, or the people, wanna see them out there in the communities and socialising and doing community-based activities. These guys are rocking it out on the computer, like, chatting to people like you wouldn't believe. They've become “isolated” – amongst the other 2.5 million New Zealanders that are online; dating services, computer chatting, Facebooking, everything else as everyone else. It's given them an opportunity, and a voice to speak out is your biggest – it's the biggest thing

Grant's close relationship with technology grew out of his attachment to computers in the late seventies. As an army-trained electrical technician, Grant was introduced to computers in 1978 and “never looked back” – starting up his own retail store, consulting the New Zealand Government, and pioneering what appears to be the first online store in Australasia using a Bulletin Board System (BBS) before the internet as we now know it existed. Grant has a fascination with old tube radios and speakers, and spent lots of time

²⁸ This book, along with others he has written is available for free in .pdf format from his website, <http://www.imstroked.com/home.html>. Grant is aware of the implications for his anonymity that accompany the sharing of this link, but wishes his work to be shared regardless.

and money buying and restoring many of them – his large collection unfortunately having to be sold to pay for ongoing medical costs. Grant identifies technology as being somewhere around the centre of his universe before his stroke, and it is for this reason that it has retained, if not increased its importance for Grant post-stroke.

If Grant's words alone are not enough to express his deep relationship with technology, his room at ALF certainly is - and this is to say nothing of the four "man-caves" full of technology back home. The first thing I noticed upon entering Grant's room was the impossibly huge (66-inch) television hanging from the ceiling opposite the doorway. Slightly below and to the left was another large television (50-inch) seated on a desk with Grant's computer, which was itself seated to the right of a large cabinet filled with DVDs, Blu-Rays, and videogames – flanked by two large, 8 kilowatt tube speakers.

The attitudes toward technology illustrated by these three men indicate that technology use in itself is not particularly important in shaping an identity, but rather it is the way this interaction is interpreted. Steve does not require assistive technology, and prefers to use leisure technology, constructing himself as a capable individual who enjoys his free time like any other. Paul uses technology in order to reach out to others and motivate them, rather than for "selfish reasons"; thus he creates himself as a good Christian man who values – and is valued for – helping others. In contrast, Grant's technology use is for himself, he does not aim to 'correct' himself or present himself in a certain way, rather he simply enjoys using technology; he defines himself in both past and present, as someone whose life has been shaped by technology.

Returning to the man who opened this section on technology, Amir's relationship with technology is different to all three of these men mentioned above. Although Amir is eternally grateful for the technology that he has, due to the physical mobility and emotional satisfaction it provides, he has experienced the other side of technological development. While the other three men I mentioned were all born in New Zealand, and although all had differing financial backgrounds, all were able to get the technology they required. Amir tells me that the story in Iraq is very different.

I know a man who was disabled, he was disabled – he’s old man – like, since he was a child and he’d been disabled [he was] on a pushing wheelchair. Not like this, a pushing one. And I could imagine how that man would be so happy and would feel he’s alive if he have electric wheelchair. He will feel he’s alive and part of the society, and he can connect himself to the society whatsoever - poetry organisation, literature organisation – any organisation, he can connect himself. But because his father old man and he don’t have a brother or a sister – so only he open cafe... and people can – they like the man, he’s an educated man naturally. Allah make him educated and make him loved by lots of people so he have a friends and he do ask his friends for pushing – for example he like to watch soccer... If he have no friends he would be so desperate to satisfy himself, but if he have electric wheelchair then he would not feel he would be desperate to watch the game, and not relying on his friends to push him

Despite Amir’s story taking place in a context quite different from the usual North American or English contexts in which disability is often discussed, he echoes what many disabled people, scholars, and activists all agree on – disabled people want and need greater social involvement. However, in a departure from Western views, this is not only a social issue but a very real physical one. The environment can be quite harsh, and this man’s impairment was severe enough that he was not able to get around by himself – if he were less well-liked he would, according to Amir, simply lay in bed all day. Amir believes this is far from a rare occurrence, and believes that powered wheelchairs would be an excellent “solution for a desperate people”.

I am a hundred percent – I know am very sure how the electric wheelchair is so helpful. So helpful for people like the man I know. And there is all around the world, same as him. I mean lots of them – there is lots of people around the world, they do desperately – particularly in the Middle-East; no electric wheelchair. And, people, they desperately need the wheelchair and I know people they disabled when Saddam – in Saddam time when everybody in the army and for a war with Iran and with Kuwait, he invade Kuwait and America come too. So the war was between Iraq and America so I know for sure hundred percent there is thousands of people – they crying for electric wheelchair

For Amir, the importance of assistive technology is more than simply improving mobility, or facilitating social involvement; it is a political issue, and a humanitarian one. As a result

of being dragged into a war in which the Iraqi people were massively outgunned – something Amir is all too aware of, as he was a member of Saddam Hussein’s Republican Guard²⁹ - many Iraqi people were left disabled and the state did nothing to alleviate their suffering, something Amir is furious about. As Amir continued his narrative, he got increasingly distressed, fulminating in an angry outburst directed at the Iraqi government.

They desperately want to make them feel alive, they do need wheelchair but no, they don’t have and stupid ignorant government was led by Saddam and now by another ignorant. They don’t think about the disabled people, and they have to help the nation to make them feel alive, and make them feel - make him feel he’s important, like, disabled people is important to the nation. And the government help them, give them electric wheelchair. Iraq can get millions of wheelchair, and have millions – billions of money! Have oil, have potassium, have gas, have gold, have lots of chemical stuff. Iraq could have the universe, could have the universe to be survive for a long time just from the money or the wealth in Iraq. The universe could be alive with the wealth in Iraq! And they cannot – they don’t - get wheelchair for disabled people. Look how ignorant they are! And how stupid they are! And how they motherfuckers they are!

Perhaps Amir has underestimated the cost of supplying powered wheelchairs, or perhaps he has overestimated Iraq’s wealth, however, his comments reflect the historical shift in attitudes toward disability, influenced by the social model of disability and related civil rights movements. Such shifts in public perception have established alleviating disability (not impairment) – by providing a basic level of care and maintaining respect and dignity – as a “humanitarian duty”.

Amir’s experience with disability is that the powered wheelchair is essentially a solution to disability, because above all else it enables independence. Although Amir’s narrative often overrode my interview questions, judging by his responses and the importance he placed on a single piece of assistive technology, I believe that in Iraq the situation for disabled people is different. According to the social model, disability in a Western context is primarily seen as a stigmatised condition and results in significantly reduced social

²⁹ Amir defected despite the threat of death, and was later captured and jailed for three months pending execution – which he feared every time a guard walked past. When war broke out, Amir was spared from execution, instead being forced to fight for Saddam once more, although luckily he managed to escape *again*, and this time for good.

interaction and life opportunities, but from what Amir told me, it appears that (physical) disability in Iraq is primarily a mobility issue.

The disabled man in Amir's story was able to freely take part in social activities and even started his own business, but the limiting factor in his life was his inability to independently get around. Amir did not go into detail about the social attitudes towards disabled people, simply telling me that the government often ignores disabled people and considers them less-than-complete humans, however, he did explain that disability is often explained as Allah's will. Although Amir vehemently opposes this view this attitude de-responsibilises disabled people – Allah's will is unquestionable, and if He chooses someone to be disabled that is simply the way things are. Presumably this has the effect of reducing stigma; however, Amir did not explain whether disability could be considered a punishment from Allah, so the extent of this reduction is unclear³⁰.

I have explained Amir's relationship to technology primarily in the way it intersects with society and politics. Obviously, this is not the only way Amir interacts with, or understands technology – indeed, before being impaired Amir had no idea just how important a powered wheelchair could be. Like my other participants who use assistive technology, the independence and mobility aspects were heavily emphasised, but there was one example Amir gave me in particular, which was very powerful.

Look, Callan, I tell you truth. When I have a car crash in 2007 I was in, I was not here [ALF]. I was in a place – a house, a two-people house and three people in the house with me in Waterloo. I had no electric wheelchair. Now sometime I get up – three-o'clock or two-o'clock in the morning and I desperately want to go to the toilet to get my stomach empty. I screamed to the worker, and [there were] no workers – they work at eight-o'clock and I believe the house will be empty until eight-o'clock. So... I shit on myself. In the bed. And when the worker came in the morning and they came in, they smelled the thing and they say "what's that Amir?"... You can imagine how important is this wheelchair! I shit on

³⁰ While an interesting topic, the intersection of religion and disability was not one which I explored particularly deeply. Other authors, such as Selway and Ashman (1998) provide more in-depth accounts of this intersection, for example; reporting that in certain passages in the Quran "special compensation is granted to the blind, lame and ill in regards to their civic responsibility... and their social responsibility" (1998:432). However, the authors provide no discussion of disability as a punishment in Islam, although they caution that more work is needed in this area before such broad claims about religious attitudes toward disability can be made.

myself like a baby... It is not simple thing when I'm telling you shitting on myself. It's not simple thing but this is how much is important – very, very, very – life! This wheelchair is life!

Amir's wheelchair "is life", without it Amir would not be living, simply existing. His wheelchair is essential as it enables him to look after himself, and carry out actions considered prerequisites for full adult personhood - if Amir did not have this wheelchair he would be infantilised, reduced to being "like a baby", unable to care for himself. Not only that, but it is quite literally required for survival – Amir needs his wheelchair to move around so he can feed himself – an issue that cannot be resolved by improving social attitudes towards disabled people. Telling me this story was not easy for Amir, but he deemed it necessary to give me an understanding of just how important technology was to him, and it is clear that in Amir's case the physicality of his impairment, or the consequences of this, was a huge factor in how he conceived of himself as a social actor.

Finally, Amir does not consider his situation unique, in fact, he recognises that he is just one out of millions and acknowledges that he is privileged to have access to such technology. He is eternally grateful to "the great Kiwi nation" for providing him with a "solution to life" but he does not distance himself from the less fortunate – he cannot remove himself from the social context in which he grew up.

Through the world there is thousands of disabled people, if not millions – would be thousands of thousands - and they do need this wheelchair to stop shitting on themselves and pissing on themselves and... [they] cannot get out and socialise with the society and feel, feel their existence... they don't have that... they do need this wheelchair and this would be great solution to give them life

In this section I have explored some of the ways in which disabled people interact with technology, and how this affects their lives. I have focused mainly on Amir, as his narrative was richly detailed and provided an overview of the personal, social, and political aspects of the relationship between humans and technology. Furthermore, Amir's narrative provided an interesting cross-cultural perspective of disability. As "the significance of disability is culturally produced" (Reid-Cunningham 2009:107), cross-cultural studies of disability are important if we want to present a more balanced view of

disability as a general concept. Through Amir's narrative we see that the concept of disability in Iraq differs from the contemporary Western take; it appears disability is heavily linked with mobility rather than social structures. According to Amir, disabled people are still included in social life – including employment – and mobility issues are the more limiting factor; in fact, in the absence of assistive technology it is social support which allows disabled people full involvement in everyday life.

This focus on technology was also intended to provide in-depth, personal accounts of – broadly speaking – the life experiences of being a 'disabled person', from a novel perspective. This is partly based on my critique of the social model; which, I reiterate, does not suggest a replacement of this model, but rather to build on its weaknesses and draw attention to areas which have been overlooked. This approach is also due to anthropologists' calls for more ethnographic detail in accounts of, by, and for disabled people. Such ethnographic accounts can draw attention to processes of identification and narrative self-constructions in ways which can provide a more nuanced view of disabled people. For example, this discussion of technology shows that technologies are not simply received ambivalently, but are actively incorporated into – or distanced from – the self in ways that shape not only how individuals are perceived by others, but how they perceive and experience their own embodied selves.

Chapter Eight: Concluding remarks (The End)

Summary of the living critique

To conclude, this thesis has been an attempt at providing a more personal account of the experiences of disability. The voices of my participants have been balanced with my own, and the analysis has been carefully tied in, for better or worse³¹, in favour of presenting relatively untouched accounts of the experiences of disability. Through narrative, I have explored what effects the concepts of stigma and normalcy have had on my participants' sense of personhood, and how this has affected their processes of self-identification. I have explored the multifaceted roles that technology has played in the lived experiences of my participants, and I have analysed these primarily in relation to the above processes of self-identifications in order to present a range of diverse understandings of disability in the lives of these individuals.

In using this approach, I have found that assumptions made based on the social model were not always aligned with my participants' experiences. Few of my participants considered themselves systematically oppressed, and although most were aware of the stigma associated with disability, they often saw it simply as a spatiotemporally bounded response within particular interactions. In Alex's words, "our human rights aren't being violated or anything".

Although there were occasional contradictions in self-perceptions of identity, these were often ignored or reconciled with no lasting effects on sense of self or personhood.

Participants discussed the physical issues they faced with their impairments, and considered these to be quite serious in some cases – and they all agreed that physical impairment had a very real impact on their lives.

Despite engaging in actions that could be seen as constituting processes of normalisation, none of my participants expressed feeling any pressure to become 'normal' or attain

³¹ One notable omission is the discussion of accessibility. This is due to a lack of space, but more importantly because this is a topic which has been covered in almost every discussion of disability to date; by academics, disabled people, advocates, urban planners and so on.

some arbitrary standard of functioning – rather they set themselves reasonable goals in order to improve themselves in ways of their own choosing. Furthermore, those participants who did not consider themselves normal redefined normalcy to suit themselves and their own unique experiences. Technology was invariably seen as important to all of those who took part in this work, however, the reasons for this varied wildly between participants.

There were complex personal, social, and political reasons for involvement (or lack thereof) with particular technologies, the implications of which I have not had the space to expand upon. The importance of technology is something that I believe could be investigated further, particularly to cover the relative dearth of work that addresses all technology, not simply assistive technologies.

The ethnographic focus of this thesis has served as a critique of the social model of disability, as well as prevailing social stereotypes about disabled people, by grounding discussions of such matters in the lived experiences of my participants. I have argued that the social model, despite its positive influence in the field of disability studies and general societal knowledge, has a tendency to homogenise experiences of disability and to put perhaps too much of an emphasis on the social construction of disability. While this serves to position the social model as a great rallying point for political action by and for disabled people, it can also be detrimental to disabled people who are not concerned with politics and just wish to “get on with life”. However, it must be reiterated that the social model was instrumental in disability rights movements, which go some way in explaining the social context in which my participants now live, and legislation which has made it possible for my participants to reject feelings of oppression.

I consider this approach the first step in a more ethnographically informed understanding of disability and its position within contemporary society. Future developments in this area have the potential to reshape how we view disability and disabled people, and perhaps more importantly, how we engage the topic of disability and issues that accompany it, as this is an area of life that affects us all.

Final points, future directions

Tom Shakespeare (2006) argues that one of the shortcomings of the social model is that it is too political, and whilst I agree, we must remember that it originated from the politics of the Union of the Physically Impaired Against Segregation (UPIAS). The issue lies in the fact that ‘the social model’ is a term coined by academics, and it is most often used in the literature as an analytic lens through which to view disability and the social attitudes surrounding it. Yet, it has not been able (or willing) to shake its political roots and this can lead to overly political and polemic academic accounts – as Shakespeare says, its benefits “as a slogan and political ideology are its drawbacks as an academic account of disability” (2006:200).

As I have demonstrated with my ethnographic accounts, experiences and understandings of disability can vary wildly from person to person and this diversity appears at odds with providing a unified political front. Thus, while I believe in the analytical power of the social model, the intense political nature of some works serves to undermine their academic integrity. I do not wish to see the social model depoliticised, but believe that a clearer demarcation between the analytical and political ‘sides’ of the model would benefit both purposes. Furthermore, I find it somewhat ironic that a theory which focuses on the social construction and reproduction of disability does not appear to acknowledge the fact that it was conceptualised in a specific sociohistorical context, and that other conceptualisations of disability exist.

In this thesis I argued that identity for disabled people is far from straightforward, as many people with impairments did not consider themselves disabled, while some embraced the disabled identity, and others did not hold to one specific disabled state. The identifications of my participants reflect Brubaker and Cooper’s (2000) comments that categorisations (such as labelling people ‘disabled’) do not accurately reflect group identity, as these self-identifications were influenced by personal, social, and political factors and in some cases appeared counter-intuitive. Yet, inconsistent or contradictory identities were either ignored or reconciled by my participants, and some were used for specific purposes (such as identifying as disabled for financial assistance, but denying

disability in order to be treated like “one of the guys”); echoing both Sökefeld ‘s (1990) “fluid and many-sided” (417) identities and van Meijl’s (2008) diverse, non-unified “I-positions” (179). Furthermore, although these self-identifications were grounded in embodied experiences, they were constructed dialogically through narrative explanations of life experiences, and as such express my participants’ efforts to “create, present, and sustain personal identities” (Snow and Anderson 1987:1348) as unique individuals not defined (solely) by their bodies.

My discussion of stigma and normalcy was similarly linked with my discussion of identity, as I sought to question whether my participants all considered themselves part of a disadvantaged group. As I discovered, all of my participants were aware that being labelled as disabled carried a certain level of stigma, yet they did not all feel the effects of this. There appeared to be a difference in the perceived level of stigma along two separate axes; firstly the length of time one had been disabled, and secondly, the severity of the impairment.

Those who had been impaired since birth, or very early in life, did not feel terribly stigmatised and they all stressed that things have gotten better as they have aged, and they only experience stigma or discrimination in specific situations. Those who had acquired their impairment relatively recently (within the last ten years or so) were more aware of the stigma associated with disability, but acknowledged that it was not an ever-present feature of life.

Understandably, the level of perceived stigma increased with the severity of the impairment, and how visible it was – interestingly almost all of my participants who used wheelchairs expressed irritation at the fact that many people would speak to them as if they were also mentally impaired. Grant found this especially infuriating as he is unable to vocalise, which further adds to the perception of him as being cognitively impaired.

Recognising that many of my participants did not see themselves as particularly oppressed is important for a few reasons. Attributing oppressed status to disabled people who might otherwise consider themselves perfectly normal and ‘welcome’ in society, may cause them to internalise this oppression. As Alex explained, multiple people he worked

with at ALF were more 'able' than him, yet preferred to live their lives in relative isolation and relied on technologies they did not necessarily need because they were told they were disabled - that life would be hard, and that they needed this help. Assuming all disabled people are necessarily oppressed serves to undermine their agency, and reduces them to passive subjects, in some cases serving as a self-fulfilling prophecy.

Similarly, my participants were unfazed by discourses of normalcy; they considered themselves normal or else reconfigured normalcy to suit their experiences. None of my participants considered themselves abnormal outsiders – yes, they admitted they were different, something they claimed they would be stupid to ignore – but this difference was not negative, and it certainly did not make them lesser persons. Somewhat tellingly, however, a few participants demonstrated an understanding of normalcy outside of their own definitions. This appeared to be unconscious, as they would slip into talking about how they were different to 'normal' people, despite previously asserting their own normalcy.

What shone through in these accounts of stigma, normalcy and personhood, was a sense of agency and of resilience. Although individual situations varied - sometimes greatly - none of these people were passive recipients of social judgements, and were prepared to challenge (consciously or not) the commonly held perceptions of disabled people. For example, many participants expressed pride in the fact that being impaired had allowed them to develop desirable traits that non-disabled people often lacked, portraying disability in not just a non-negative light, but an expressly positive one – attributing a level of prestige to disability. In some cases this was not truly a choice, but rather a requirement in order to avoid being rendered as a passive recipient of care and pity.

While initial narratives of identity focused on the concept as a broad understanding of oneself in relation to others, emphasising the *construction* of the self, the ways in which my participants managed stigma and normalcy emphasised a *negotiation* of the self. The former relates to a sense of "self-sameness" (Erikson 1956:57) within the individual, whereas the latter appeared to be the "marking of difference" (Hall 1996:4); difference from the 'norm', difference from 'other' disabled people, or difference between internal "I-positions" (van Meijl 2008:179). Both the construction and negotiation of selves are

situated within a specific cultural context in which individuality, independence, resourcefulness, resilience and self-discipline are all considered positive traits to possess. Furthermore, my participants' experiences of disability, normalcy, and stigma are shaped by the current social context in which disabled people are offered social, financial, and legislative support; due in part to the work of civil rights campaigners utilising the social model.

Finally, I explored the relationship between persons and technology in the context of disability. Many participants relied on assistive technology for daily activities, and as expected these technologies were considered beneficial for the independence they granted (Söderström 2011). However, these technologies also served to make my participants and their impairments more visible (Gibson et al. 2007), and certain technologies such as wheelchairs were limited by infrastructure in public spaces – one participant referred to his wheelchair as “like a cage”; it provided safety, but also imposed limits. In this sense, there was an obvious level of ambivalence toward these technologies, although most participants viewed the independence these technologies granted as outweighing the negative aspects.

Beyond the assistive side of technology, participants discussed non-assistive or leisure technology and its importance in their lives, with Grant being the main example of this. Grant's narrative was especially interesting as he broke down the (admittedly somewhat arbitrary) boundaries between assistive and non-assistive technologies, arguing that there were technologies that occupied both categories, and made it clear that assistance and leisure, or “pure enjoyment” are by no means mutually exclusive.

While there has been much work in anthropology and elsewhere concerning the relationships between humans and technology in an increasingly connected world, and while there has been significant work undertaken in disability studies concerning assistive technologies, there appears to be a fruitful area left almost entirely untouched at the intersection of these two areas; disabled people's interactions with technology in general. I believe, if my brief discussion of this was any indication, that there is much to be learnt from studying this intersectional gap.

In sum, this thesis has problematised some of the taken-for-granted aspects of the social model, such as the overemphasis on social construction of disability whilst neglecting the physical reality of it; the homogenisation of a diverse range of impaired bodies, persons, and their experiences; and the focus on the political aims of the social model over the academic benefits it offers. In response I have taken on calls from within disability studies and anthropology to provide a more detailed, ground-level view of the experiences of disability, in order to present an alternative understanding of disabled peoples' embodied experiences, their negotiation of meaningful identities, and their interactions with technology. I believe this thesis could serve as a point of departure for the study of disability as although the political aims espoused by some social model theorists are admirable, perhaps a more detailed account that accurately and sensitively presents the lived experiences of individuals living with impairment – similar to the one presented here, but in greater depth and breadth – would be of greater benefit for academics, advocates and disabled people themselves.

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