Auto-mobile: Disabled Drivers in New Zealand

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Abstract

Mobility parking spaces can be found in cities and towns throughout New Zealand and in countries around the world. Despite this, there has been very little academic examination of the meaning or importance of driving for people with mobility impairments. What research exists on disabled drivers is almost entirely concerned with safety concerns of allowing disabled people to drive. Cars have been excluded from conceptions of assistive technology and the existing literature on driving and transport generally fails to acknowledge the fact that disabled people do drive cars. Following on from the assumption that disabled people do not drive, car-centric transport systems have even been presented as restricting disabled people’s mobility. A considerable volume of research has been published on transport as a social determinant of health, as well as its role in facilitating social participation and inclusion. This transport literature frames social participation and inclusion in terms of public transport, and acknowledges, but does not address, the inaccessibility of public transport for many disabled people. This thesis seeks to address the knowledge gap regarding social participation and inclusion among drivers with mobility impairments.

This thesis draws upon the author’s own experiences of being a disabled driver. It is written in the context of increasing concerns about global climate change and fluctuating (but rising) fuel prices, both issues which have put pressure on many people to reduce their car use. The aim of this qualitative study was to investigate the transport experiences of work-aged physically disabled drivers in New Zealand. Participants were recruited through the national issuer of mobility parking permits. In-depth interviews were conducted with 27 physically disabled drivers between the ages of 18-64 in New Zealand’s two largest urban centres, Wellington and Auckland, and in various parts of a semi-rural region, the Wairarapa.

The main barriers and enablers of car use identified were funding, the physical environment, and appropriate vehicle modifications. When unable to drive, participants relied on family or friends, as taxis were too expensive, and the alternative
was being housebound. While some participants could and did use public transport, most could not, or would not due to their own or others’ bad experiences.

The participants saw cars as enabling them to perform tasks and social roles that they would not otherwise have been able to, due to the lack of other viable transport alternatives. Cars were also used as social and life markers, as driving could influence peoples’ identity and sense of self, including their perception of disability and ‘normality’. As modern societies are based around a system of ‘automobility’, disabled drivers found driving particularly meaningful because they were able to move around environments that are built for cars, in the same manner as non-disabled people, which made the world a less disabling place.

Overall, this thesis finds that cars play a vital role in improving social participation and inclusion for people with mobility impairments. This speaks to Amartya Sen’s capability approach whereby emphasis is placed on the ability to live a life ‘one has reason to value’. In order to achieve this life, people need to be able to access appropriate transport. On this view, present funding models in New Zealand, which create inequalities of access to appropriate transport on the basis of whether a person’s impairment(s) arose from illness or accident, need to be addressed. This study has shown that the voices of people with impairments provide rich insights into meanings of mobility, participation and disability.
Before writing this thesis I was a disabled driver with a background in political philosophy. I wanted to do disability research, but had not settled on a topic for my PhD. I thought about which of my experiences related to being disabled were interesting enough to spend three or more years thinking about, that were the most under-researched and the least depressing.

This thesis began, in part, as a 80000 word love letter to my car. Learning to drive a (slightly modified) car at age 19 was a life-changing experience. I loved driving for its own sake. I loved being able to leave my house of my own volition, being able to go to the supermarket by myself and buy things that I wanted. I loved being able to go and visit my friends, drive them round or hang out with them in public spaces. I did not love driving to work with the same intensity, but I would have not been able to get to my job any other way.

Some of the hardest times in my adult life were times when I was unable to drive. These times were not hard because I could not drive, but they were made harder by being largely housebound and having little independence outside my home. In those periods, getting back into my car meant that life was getting easier and I felt that I was getting my life back.

While writing a love letter to my car was part of my initial motivation that is not what this thesis is about. I believe in the political act of giving people space to tell their own stories. I identified strongly with some of the stories that the participants in this study told, but I was also surprised, delighted and saddened by many other stories. I was convinced at the beginning of this thesis that driving personally my life better, but I wanted to find out what other people’s experience of driving was, if it had affected them similarly, or if driving meant very different things to them.
I believe that understanding the experience of being a disabled driver can contribute to our understanding of disabled peoples’ lives as well as the mobility and participation of all people.
Acknowledgements

This thesis is dedicated to amazing the people who told me their stories and gave me their time: without your generosity this thesis would not exist. Thank you so much – I tried hard to do justice to your insights.

Thank you to my supervisors Philippa Howden-Chapman, William Levack and Sunny Collings for all your guidance on, and enthusiasm for, my project. I appreciate every minute of your time and every kind word.

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I probably have the best friends in the world (thank you all), but I would particularly like to thank Grace, Livvy, Suse, Zac, Jo, Em, Jennybell, Kate and Kim, for getting me through 2008 and 2009 in (more or less) one piece. Again, thank you to Grace Millar for being the best friend a girl from Wellington, who wrote a thesis, could ever have. Thank you to my parents Eva and Glynn Woodbury, not just for being ridiculously amazing and reading through my thesis more than once, but for everything, ever. I love you.

I also dedicate this thesis to the cars I have driven and loved – past, present and future. I promise to clean you more often now that I have finished my thesis.
Statement of Contribution

My thesis supervisors, Philippa Howden-Chapman, William Levack and Sunny Collings, individually and collectively discussed the development of this research project with me and advised me throughout the course of my PhD. My supervisors commented on my ethics approval and on a draft of my interview schedule, as well as providing general advice on how to recruit and carry out interviews. My supervisors read and commented on my interview transcripts. I discussed my methodology with William Levack in particular and had a session with him where we brainstormed the organisation of categories and codes that had emerged from the data collection. My supervisors discussed my ideas and read and commented on all my chapters.

I had many discussions with Kate Amore and Grace Millar about my ideas and how to present them. Grace Millar also gave suggestions about structural elements of several chapters. Eva and Glynn Woodbury made grammatical corrections and suggestions for clarity of expression.

All other data collection, writing and analysis was done by me.
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<td>ACC</td>
<td>Accident Compensation Corporation</td>
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<tr>
<td>MOH</td>
<td>Ministry of Health</td>
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<td>NZDS</td>
<td>New Zealand Disability Strategy</td>
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<td>SMD</td>
<td>Social Model of Disability</td>
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<tr>
<td>UPIAS</td>
<td>Union of the Physically Impaired Against Segregation</td>
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<td>WHO</td>
<td>World Health Organization</td>
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“They get heaps… WINZ benefits, a special ramp, even their own Olympics. Enough’s enough.”

Introduction

“Everywhere in life is somewhere else, and you get there in a car.”

– E. B. White, One Man’s Meat (1950)

Auto-mobile: Disabled Drivers in New Zealand

This study is concerned with the experiences of disabled drivers and how driving affects their well-being, identity and their ability to participate in society. There has been little academic research on the experiences of disabled drivers. For this project, semi-structured interviews were conducted with 27 work-aged drivers living in New Zealand who had long-term mobility impairments.

Background to the Research

My research on ‘disabled drivers’ (drivers with physical or mobility impairments) involves trying to understand how the phenomenon of driving differs for people who are disabled by society, and how disabled people use cars to make the world a less disabiling place. Driving provides disabled drivers with opportunities for mobility, participation and an accessible
alternative to active and public transport. As well as having difficulties with active transport, many of the disabled participants in this study and other disabled people in the population find public transport difficult or impossible to use (New Zealand Human Rights Commission, 2005). For some people with mobility impairments, travelling by private car is one of the only forms of mobility available to them outside of their home (Rosenbloom, 1982).

Participation is often considered to be a key part of creating an equal and just society. The capability approach, a major influence on this project, is also concerned with people being able to participate, as understood through a conception of capabilities (real opportunities) (Nussbaum & Sen, 1993). In New Zealand, the aim of the New Zealand Disability Strategy is to promote full participation for disabled people. There is some government provision of vehicles and vehicle modifications, but inequities exist between those disabled people whose impairments originated from accidents and those that are non-accident related.

Traffic injuries and deaths are serious concerns for public health researchers, as are air quality and other environmental effects of car use (Featherstone, 2004; World Health Organization, 2000). However, there is also a body of research on the effects of Transport-Related Social Exclusion, that has looked at people with limited access to transport being unable to participate in society, including how disabled people are susceptible to these effects (Casas, 2007; Church, Frost, & Sullivan, 2000; Lucas, 2004; Rose, Witten, & McCreanor, 2009).

This study was partly inspired by an awareness of rapidly rising fuel prices shortly after the turn of the 21st century and an increase in discussions about the negative environmental and health effects of car use. These financial and environmental pressures prompted popular media, (some) government discourse and academics to pay closer attention to efforts to reduce car use. However, proponents of car reduction have not always considered the differential effects that car reduction would have on groups such as disabled people, and what the alternatives to car use would be.
History and Symbolism of Cars

Cars have a long history of being loved and hated: they have been associated with freedom, status, danger, sex, pollution, death, sanctuary, masculinity, family life, work and leisure. They have been seen as the status symbols of the elite, as a necessary tool for workers and as a dangerous form of technology. But, cars have also suggested possibilities for people that have inspired novels, poems, films and songs.

In his article on the experience of African-American drivers in the mid-20th century, Seiler (2006) discussed how automobility both resisted and reinforced the transport exclusion that African Americans faced under Jim Crow laws. Seiler linked ideas of African-American citizenship to automobility, as cars were an escape from the humiliation and dangers of segregated public transport and were used as a means of resistance during bus boycotts. The segregation of the public transport system pushed those African-Americans who had the financial means, into private motor vehicles. However, access to cars was limited and the systems that supported automobility, which included petrol stations, mechanics and roadside restaurants, were still segregated. I believe Seiler’s narrative has parallels with some of the experiences of disabled drivers—those for whom public transport has the potential for humiliation, danger or exclusion (albeit for very different reasons) and for whom cars can offer mobility in a way that meets their needs.

Disabled Drivers

While there has been a significant rise in research on car cultures and ‘automobility’ in humanities and social science research, most of it has been with a view to reducing car usage. There is little research on the driving experiences of work-aged disabled people. There is some literature on the public transport experiences of disabled people, although it has mostly highlighted the ongoing issue of many people with impairments finding it difficult, or impossible, to use public transport on a consistent basis (Jolly, Priestley, & Matthews, 2006; Massie, 1988; New Zealand Human Rights Commission, 2005; Schmöcker, Quddus, Noland, & Bell, 2008). There are mobility parking spaces in many countries around the world, and their presence hints at the important role that cars have played in the mobility and
community participation of disabled people. Additionally, there have been a number of studies on the benefits of driving for elderly people (Fonda, Wallace, & Herzog, 2001; Marottoli et al., 1997, 2000; Metz, 2000). These studies provide a useful starting point for analysis, however there is a difference between being a work-aged disabled driver and being an elderly driver who may or may not have a mobility impairment.

Concepts and Language of Disability

This thesis comes from the perspective of the social model of disability, which asserts that people are disabled by society, not by any individual impairment (Oliver, 1990). Therefore, when talking about people who are affected by disabling practices and attitudes in society, I use the term ‘disabled people’ or, relating specifically to this thesis, ‘disabled drivers’. However, different terminology is used in literature about disability; for example, the use of terms such as ‘people with disabilities’, and I have left all such instances in quotes intact. I have used the terms ‘impairment’ and ‘mobility impairment’ to refer to an individual’s functional limitations.

Aims of the Research

This research seeks to develop an understanding of the practices and meaning of driving while disabled. The research question of this study was to explore how disabled drivers experience the relationship between driving and their ability to meaningfully participate in society. The specific aim of this research is to construct a substantive theory about the experiences of disabled drivers in relation to the effects of driving on participation in society, the effects of driving on well-being, and the economic effects of driving.

Shape of the Thesis

Chapter Two is a review of the literature which considers the scant amount that has been written about disabled drivers and puts it in the context of some of the ways disability and driving have been separately theorised. In the chapter, I discuss the origins and debates around the social model of disability, a theoretical framework for understanding narratives
about impairment and how they shape cultural and political responses to impairment. I also discuss Sen and Nussbaum’s capability approach (Nussbaum & Sen, 1993; Nussbaum, 2006; Sen, 1999), which asserts that inequities in society can be addressed when people have the capability sets (real opportunities) to live lives that they value.

Chapter Three considers methodological issues and the framework and the constructivist grounded theory method I used, and contextualises it within existing thought on disability research methodologies. I specify the methods I used to gather and analyse my data and briefly describe the participants in my study. I also include a brief personal statement on my own experiences as a disabled driver and as a researcher.

Chapter Four is the first of three results chapters and presents a description and analysis of the significance of driving for the participants of this study, including what activities and roles they felt driving enabled them to perform and how driving made them feel.

Chapter Five presents a description and analysis of the financial, attitudinal and environmental barriers and enablers to driving that participants experienced.

Chapter Six presents a description and analysis of situations where participants were unable, or chose not to drive, including their experiences of public transport, taxi use, getting lifts from other people and being housebound.

In Chapter Seven, I summarise and discuss the results of my study and present my theory of disabled driving. I discuss my findings in relation to existing knowledge and describe the implications of this research for policy makers and other theorists. Finally, I make recommendations for policy changes and consider what further research needs to be done in this area in the future.
2

Literature Review

“Transport is an enabling technology.” (Knowles, 2006, p. 408)

Although there are mobility parking spaces in every city and town in New Zealand, as well as government funded schemes to help (some) people with mobility impairments to purchase vehicles to increase their mobility, there has been practically no research done on how, or why, driving is important for people with mobility impairments in New Zealand. Standard database searches on disabled drivers in New Zealand yielded no results, although there has been some research on disabled people and various aspects of their transport issues. Internationally, the experience of drivers with mobility impairments has also been neglected. This chapter will examine the existing research and what is known about the experiences of disabled drivers in New Zealand and internationally. It will also touch on other bodies of research that can inform discussion of the experience of driving a car for someone with a mobility impairment.

Literature Searches

I performed electronic searches for literature on disabled drivers in two large databases and in selected journals. The articles were then screened for relevance based on a review of their title, firstly, and then abstract (where the title was ambiguous). Articles were deemed relevant to the study if they met the following criteria: research on disabled drivers, including the effects of the ability to drive on the lives of people with mobility impairments, or the effects of the ability to drive on their ability to participate in their communities; or, the meaning or experience of driving for people with mobility impairments. The articles’ bibliographies were also checked for any additional references. Additional articles were also identified and discussed here, which did not meet the inclusion criteria. These additional studies looked at:
safety aspects and crash rates of disabled drivers (from the perspective of clinicians or insurers); technical discussions of vehicle modifications; licensing or assessment criteria of disabled drivers; monitoring of mobility car parks; and, articles on the ability of disabled people to access public transport and its effect on their lives and participation in society. The related articles on the safety and assessment of disabled drivers often focused on a single type or source of impairment, including: diabetes, arthritis, spina bifida, cerebral palsy, stroke, epilepsy, vision impairment, traumatic brain injury, Parkinson’s and Alzheimer’s.

I searched the Web of Knowledge database using the key terms: “disab* OR handicap* AND driv* OR car OR automobile”, over all time periods. The Web of Knowledge search yielded 493,499 results, which I then refined by limiting the results to those that specifically included the term “driver”, this reduced the number of results to 1,074. Finally, I limited the results to English language only which reduced the number to 929. I reviewed the results and found two articles that matched the inclusion criteria. I used the same search terms in the Scopus database and applied the same filters. The original search yielded 4991 results which I again refined by the term “driver” (1439 results) and by English language (1213 results). Reviewing the titles and abstracts I found the same two relevant articles.

I performed an electronic search of the archives of journals that I identified as being well regarded in their discipline and relevant to my research topic, such as Disability & Society, Disability & Rehabilitation, Disability Studies Quarterly, Transportation Part A: Policy and Practice and Transport Policy.

I searched the archives of Disability & Society (including the archives of its former incarnation Disability, Handicap and Society) using the terms “driv* AND car OR automobile OR vehicle”. This resulted in 227 articles, none of which met my inclusion criteria. I then searched the archives of Disability & Rehabilitation again using the terms “driv* AND car OR automobile OR vehicle”, this yielded 462 results, with one article meeting my inclusion criteria. I performed an electronic search of the archives of Disability Studies Quarterly, using the search terms “driving OR driver AND car OR automobile”. This yielded 40 results, none of which met my inclusion criteria.
Similarly, I performed an electronic search of the archives of *Transportation Research Part A: Policy and Practice*, using the search terms “disab* OR handicap*”, this yielded 153 results, none of which met my inclusion criteria. I also performed an electronic search of the archives of *Transport Policy*, using the search terms “disab* OR handicap*”, this yielded 110 results, none of which met my inclusion criteria.

**Reviewing the Literature**

In this review, I will first look at what is known about disabled drivers in New Zealand, and I will then consider what has been written about disabled drivers internationally, both in peer-reviewed journals and in grey literature. However, because this body of research is so small, it is necessary to look more broadly at relevant theories of disability, including concepts of disability, social participation, mobility and technology. I will also consider theories of driving in general, including the links made with health, the environment, and issues of social participation and justice. Finally, I will discuss what is absent from these fields of scholarship and why the literature might look the way it does.

**Part I**

**Driving and Disability in New Zealand**

New Zealand has one of the highest rates of car ownership in the world, third only to the United States and Saudi Arabia. There are approximately 4.4 million people in New Zealand (Statistics New Zealand, 2012a) living across approximately 268,000 square kilometres, and in 2009 there were approximately 2.8 million registered cars (New Zealand Transport Agency, 2009a), with car ownership rates at 0.574 cars per person in 2005 (New Zealand Transport Agency, 2009b).

According to Statistics NZ’s *Disability and Travel and Transport in New Zealand in 2006* report (Statistics New Zealand, 2009), which took data from the New Zealand Disability Survey: an estimated 388,600 (72%) of all disabled adults were drivers and 506,800 were drivers or
passengers (94%).\(^1\) Disabled women (65%) were less likely to be drivers than disabled men (80%), and disabled Pacific adults were the group least likely to be drivers (48%). In this study, I am principally concerned with people with mobility impairments who drive vehicles, at least in part, because of their limited mobility, which I take to be the same population as the Statistics New Zealand (2009) definition ‘mobility disability’:

> “Difficulty with or inability to: walk about 350 metres without resting; walk up or down a flight of stairs; carry an object as heavy as five kilograms for a 10 metre distance; move from room to room; or stand for periods for longer than 20 minutes” (2009, p. 49).

This definition was slightly different from the CCS Disability Action (CCSDA)\(^2\) criteria for a mobility parking permit, but used a similar concept of mobility limitations. CCSDA’s criteria for a permit specifically requires people to have difficulty walking even relatively short distances (200 metres), with, or without, the use of a mobility aid.

The *Disability and Travel and Transport in New Zealand in 2006* report (Statistics New Zealand, 2009) estimated that there were approximately 539,200 disabled adults in New Zealand, 285,000 who had a mobility disability (53%). Of the adults with a mobility disability, 182,600 were drivers (64%). The report discussed only the travel and transport patterns of disabled people living in households and not those living in residential facilities. Approximately five percent of disabled adults lived in residential facilities and so the numbers of drivers with mobility impairments may have been slightly higher if data had also been collected from them. However, in comparison, a UK Office of Population Censuses and Surveys report from 1989 found that of disabled people living in residential facilities in the UK who travelled in cars, only 3% drove themselves (OPCS, 1989).

The *Disability and Travel and Transport* report also looked at disabled peoples’ met and unmet needs around transport, including private vehicle ownership, vehicle modifications, parking needs, public transport and taxi usage. Although public transport and taxi usage are not

\(^1\) 2006 census data is used throughout this thesis. New Zealand’s 2011 census was cancelled due to the 2010-2011 Christchurch earthquakes.

\(^2\) CCS Disability Action administer New Zealand’s national mobility parking permit scheme
strictly relevant to disabled driving, some disabled drivers are able to use public transport and taxis in addition to driving their cars, while others may be completely unable to do so. Additionally, having data about other forms of transport provides some context about transport options for disabled people. Therefore, I will include some relevant parts of the report’s analysis of the ease of making short and long trips in transport other than private cars.

In the 12 months prior to the survey, an estimated 23,000 disabled adults (4%) needed to buy a vehicle because of their condition or health problem, but 6,000 (26%) of those people had been unable to. Lack of affordability was the main reason people were not able to buy the vehicle they needed. The report also estimated that 6,100 (1.1%) of the disabled adults surveyed had had modifications made to a private motor vehicle, but another 4,300 people (0.8%) had an unmet need for modifications to enable them to drive. Cost, or affordability, was the main reason these modifications had not yet been done.

The report estimated that 129,100 disabled adults (24%) needed to park close to their destination; however, in the six months prior to the survey, almost half of those, an estimated 61,100 disabled adults (12%) reported having problems finding a car park on at least one occasion. The most common problems encountered were: finding a park close to their destination; car parks meant for disabled people being used by non-disabled people; and the available car parks being too physically awkward to use.

Approximately 142,400 of disabled adults (26%) had used public transport for one or more short trips in the previous 12 months. However, of those who had used public transport for short trips, an estimated 12,400 disabled adults (9%) experienced difficulties because of their condition or health problem. The three most common difficulties with public transport experienced by disabled adults related to getting on or off, standing in the vehicle while it was moving, and getting to, or finding the stop. A further 36,600 of all disabled adults (7%) were completely prevented from using public transport for short trips because of their condition or health problem.

The link between those who could drive themselves and those who worked was also made clear. Of the estimated 225,400 disabled adults in employment in New Zealand, 139,700
(62%) drove themselves to, or from work in a private car, truck or van, with a further 18,000 (8%) driving themselves to or from work in a company car, truck or van. Another transport option, taxi use, was used by an estimated 7000 of all disabled adults (1%) every day, or almost every day, and a further 26,700 disabled adults (5%) used a taxi every week. An estimated 21,400 disabled adults (4%) had used half-price Total Mobility Scheme taxi vouchers in the previous 12 months.³

Many disabled people, who needed private transport to meet their mobility needs, used their own finances to acquire a vehicle, doing so without government assistance. Meeting the costs of private transport can be very difficult, but the criteria for providing governmental financial assistance to help disabled people purchase a vehicle can also be very restrictive. Further, the criteria differ depending on how people have come to their impairments. In New Zealand there is a split between the agencies that cover people who have impairments acquired through an accident (these people come under the jurisdiction of the Accident Compensation Corporation⁴) and impairments that are hereditary or develop from an illness (these people come under the jurisdiction of the Ministry of Health).

If someone with a mobility impairment comes under the funding jurisdiction of the Ministry of Health, they qualify for financial assistance for the one-off purchase of a vehicle if they require a car to get to a fulltime job (which they have already secured) or if they are in full-time tertiary education for the first time. If a person with a mobility impairment qualifies for assistance to modify a vehicle through the Ministry of Health, they can apply for up to a maximum of $12,165 (Enable NZ, n.d.; New Zealand Ministry of Health, 2007). In addition to assistance with modifying a vehicle, the Ministry of Health can also provide up to $12,165 towards the purchasing of a vehicle (Enable NZ, n.d.; New Zealand Ministry of Health, 2007). To put this in context, the cheapest new car available for purchase in New Zealand would start at approximately $20,000 (Automobile Association of New Zealand, n.d.-a).

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³ The Total Mobility scheme provides vouchers to people with mobility impairments which allow them to pay half price for a taxi fare, with the other half paid for by the New Zealand Ministry of Health.
⁴ The Accident Compensation Corporation (commonly known as ACC) is a state-owned Crown entity that provides no fault personal injury insurance for citizens, residents and temporary visitors to New Zealand. ACC covers all work and non-work related injuries and the legislation prevents individuals from suing any at-fault party. Few individuals pay levies directly to ACC, as it is funded through taxation on income and through employers (one of the exceptions is the self-employed). ACC has existed since 1974 (then called the Accident Compensation Commission). In its 1990 annual report ACC recommended that coverage be extended to people affected by illness as well as injury, but this was rejected by the government of the day.
Given that the Ministry of Health will only fund the purchase of a car once in a disabled person’s life, and only under some circumstances, the likelihood that a second-hand car will not last as long as a new car is of some concern.

**Accident Compensation Corporation**

People who come under the jurisdiction of the Accident Compensation Corporation (ACC) have slightly different entitlements to those under the Ministry of Health, as ACC was created under legislation that specifies entitlements:

> “Depending on the claimant’s needs, they may be entitled to one or a combination of eight social rehabilitation options provided under the Injury Prevention, Rehabilitation, and Compensation Act 2001. These options [include]: transport for independence (including vehicle purchase and modifications).”

The purpose of ACC is to provide rehabilitation that will allow people to “regain their health, independence and therefore their ability to participate in their usual activities as far as practicable.” This independence specifically includes the capacity for mobility and use of transport (ACC, 2004).

While the academic literature on the experience of driving and disability is almost nonexistent, one masters dissertation project in New Zealand looked at young disabled people learning to drive. In her unpublished thesis, Terrell (1992) surveyed 50 young people with cerebral palsy (who did not have a severe intellectual disability), with a questionnaire that included some scope for people to add free comments. Terrell found that learning to drive was an important signifier for being viewed as an independent adult.

> “For a group of people who are seen as dependent by society, gaining a drivers licence is likely to help them to gain independence physically and socially” (Terrell, 1992).
As well as the perception of independence, being able to drive a car made an enormous practical difference to the young disabled people surveyed, as this skill gave them a huge increase in mobility, and thus more choices about their lives.

“Drivers have more options of being independent in their living arrangements. Drivers are also more integrated into the wider community through employment and leisure time activities” (Terrell, 1992, no page).

This new mobility and autonomy was very specifically linked to driving and was spoken of in contrast to other transport modes that did not meet the needs of the participants of the survey.

“[One] person comments, “Before I could drive I was isolated because I couldn't use public transport and taxis were too expensive” (Terrell 1992, no page).

People who had learnt to drive attached great significance to driving and having a car that extended beyond their immediate transportation needs, “A car means something more to me than just a way of getting from A to B” (Terrell, 1992, no page).

Although Terrell’s masters project did not contain a huge amount of data on the experiences of driving for people with mobility impairments, it does suggest some interesting areas for investigation: the meaning of cars for disabled drivers, their practical uses for disabled drivers and how they offer transport alternatives for people with mobility impairments.

An article by Jones and colleagues (1991), that had a New Zealand context, discussed the modification of vehicles for drivers with arthritis. While the article was concerned with the technicalities of driving for disabled people (see more below), the authors discussed the importance of driving for physically disabled people, with a particular focus on the local geographical and transport context. Jones and colleagues pointed to a lack of mobility as one of the biggest issues for people with arthritis, causing problems with accessing work, shopping, and social interaction, as well as maintaining independence. Jones and colleagues thought this was particularly an issue in New Zealand, with its small population and limited
public transport: “if arthritic individuals can drive, 'the world is their oyster'; if they cannot drive, their horizons may extend only as far as the corner shop” (Jones et al. 1991).

As I will discuss later in this chapter, Jones and colleagues’ unstated assertion of the value of cars for disabled people seems to be in the background of other (international) research into the technicalities of vehicle adaption, driving and parking. Perhaps it is because the value of private vehicles seems to be taken as read that there has not been further investigation into the experience of disabled driving. However, this has meant that there has been little research into broader conceptualisations of disabled driving or the barriers and enablers to car use.

Part II

Disabled Driving (And Parking) Internationally

The international disabled driving literature is considerably more substantial than a review of the New Zealand literature would suggest. However, much of what is known about disabled drivers internationally is contained in government-produced or funded research reports, many of which were written to inform transport policy in the UK. These reports were concerned with disabled people and transport in general, often focusing on the barriers that disabled people faced when using public transport. However, the reports did briefly discuss disabled drivers.

An early example of governmental focus on transport for disabled people came from the European Conference of Ministers of Transport in 1991, which recognised “the desirability of providing assistance to disabled people for whom the purchase and operation of a car is essential for their work or to enable them to live in the community.” Furthermore, the participants of the conference agreed that “where disabled people receive financial help with car purchase, adaptation and/or operation, this should be made available by governments regardless of whether or not the motorist uses the car for travel to/from work” (European Conference of Ministers of Transport Working Group, 1991, p. 14).
In 2008, the UK Department for Transport commissioned a qualitative report, *Travel Behaviour, Experiences and Aspirations of Disabled People*, for people with various kinds of impairments (Penfold, Cleghorn, Creegan, Neil, & Webster, 2008). This report contains the research most closely aligned with the concerns of this thesis, and even though the data collected on disabled drivers was small and not peer-reviewed, the areas covered are very similar to ones that will be examined in the results chapters below. Penfold and colleagues found that disabled people experienced considerable transport disadvantage, were unable to use 70% of buses and 40% of the rail network and yet half of disabled people were totally reliant on the public transport system. Despite the difficulties with accessing public transport, 60% of disabled people lived in households without a car. Of the people in the study with physical impairments who had access to a car, “car access was described as being ‘fundamental’ to maintaining mobility and independence.” The people with physical impairments were concerned that they would be “unable to work, access services, fulfil their caring responsibilities or [would] become socially isolated” without a car, as even when having ‘bad days’ they could still use a car (Penfold et al., 2008, p. 13). In a parallel story told by one of the participants in this study, one of Penfold and colleague’s participants described being especially dependent on her car after taking early retirement, because she had lost a lot of social networks after leaving work and would become depressed if she was unable to see anyone (Penfold et al., 2008).

The financial difficulties of running a car were also expressed by the participants in Penfold and colleague’s study, and although people relied on the financial support of the UK’s Disability Living Allowance, they felt that use of their cars was such a high priority that they would cut down on other expenses before they reduced or stopped using their cars. However, alongside their car-based mobility, participants said they would have liked to be able to access more public transport, partly due to the cost of car use and partly because of concerns about the environment (Penfold et al., 2008).

The participants in Penfold and colleague’s study found the Blue Badge (the UK’s mobility parking) scheme particularly helpful for being able to access the services and places they needed to, particularly for those who needed a door-to-door method of transportation. They
also discussed the difficulties they had experienced when the parks were used illegally (Penfold et al., 2008).

Researchers in Leeds University’s Centre for Disability Studies synthesised data from multiple existing data sets to examine disabled people’s use and experience of public transport for the UK’s now defunct Disability Rights Commission. Despite the clear focus on public transport, some data were gathered on disabled drivers – most notable was that car driving was the most commonly reported mode of transport and the most common mode for travelling to work (Jolly et al., 2006).

There are a few instances of academic literature on disabled drivers. Casas (2007) took transport data and examined whether, and in what ways, disabled people in one city in the US were socially excluded through their transport options. While transport-related social exclusion is often looked at through concepts such as transportational deprivation in a specific geographical area, disabled people are not necessarily clustered in a particular location and their inability to access transport might not have anything to do with a lack of public transport options (Hine & Grieco, 2003). Casas found that disabled people (in Buffalo, NY) had limited mobility when accessing opportunities, but that mobility was less limited for those who were young, male, from a small household, and who held a driver’s license and a job (Casas, 2007).

Carr (2004) observed that transport and access problems result in popular mainstream leisure activities being considerably more difficult for people with impairments to participate in. However, many more opportunities were available for people who had their own car, or who could use the car of a family member or friend. Carr also noted that the high value of cars, for many people with impairments, arose because a great deal of public transport was inaccessible, and using taxis or drivers regularly was not affordable (Carr, 2004).

One Swedish study looked at the driving experiences of four people re-assessed for driving safety following a stroke, including two participants who were work-aged (Patomella, Johansson, & Tham, 2009). Although the study did not specify whether the participants had any mobility impairment resulting from stroke, the study highlighted several interesting ways that participants experienced driving and the prospect of not being able to drive, which they
described as ‘untenable’. Driving was seen as a sign of continuity of their lives before stroke, as an integrated and positive part of their lives, and one which enabled them to participate in everyday activities, as well as work and leisure. The re-establishment of driving following stroke gave participants confidence in their future and their sense of self. From reading Patomella and colleague’s article it is difficult to gauge the mobility of their participants and whether they would match the conception of disabled drivers proposed in this thesis, i.e. drivers who have mobility impairments, however the study highlights the importance of the lived experience as well as the functional abilities of people with impairments.

Rosenbloom (1982) has noted that despite policy debates over public transport in the form of buses and train versus provision of paratransit services (she was speaking primarily of the US, though her research has been conducted in many countries, including New Zealand), most disabled people make the majority of their journeys in private vehicles. However, as Rosenbloom (2007) pointed out, this has not prompted researchers or policy makers to consider the barriers to car use. Massie (1988) also noted that private car use was the most effective way for many disabled people to travel, but focused on the public transport needs of disabled people.

Aldred and Woodcock (2008) discussed transport and disabled drivers in terms of the social model of disability (see below) and automobility (see below). Aldred and Woodcock’s focus was on the environmental effects of car use and although they acknowledged that cars can offer mobility to some people with impairments inside a highly motorised system of transport, they contended that cars are also ‘disabling’ because of the large numbers of disabled people in the UK who do not have access to a car. Aldred and Woodcock (2008) disagreed with the UK Disabled Persons Transport Advisory Committee (DPTAC) and their advocacy of private car use, and instead favoured increases in accessible environments and increases in walking and cycling by people with impairments, including the use of handcycles.

While I found that academic researchers have not generally focused on the experiences of disabled drivers, there have been many investigations into the safety of disabled drivers and how their vehicles can be modified (Henriksson & Peters, 2004; Wilson, 2003). As well as Jones et al.’s Driving and Arthritis article mentioned above, three separate articles written by
Murray-Leslie in the early 1990s were concerned with information about, assessment of and provision of modifications which would enable physically disabled people (particularly arthritic people) to be able to drive independently.

Two separate studies, Prasad and colleagues (2006) and Henriksson and Peters (2004), surveyed a total of 1366 disabled drivers on their safety records (when adapting to non-standard controls) and accident rates and found no significant difference in accident rates between disabled and non-disabled drivers. There were also a small number of authors interested in the technicalities of tetraplegia and car driving (Kiyono, Hashizume, Matsui, Ohtsuka, & Takaoka, 2001) and access to, and information about, modifications and aids to assist driving (Babirad, 1989; Jones et al., 1991; Murray-Leslie, 1990, 1991a, 1991b).

Despite the focus of researchers on the technical aspects of driving, all the above authors briefly commented on and assumed the high importance of driving for mobility impaired people, who were able to operate a car. Prasad and colleagues noted that “driving is an essential component of independence and employment for many disabled people” (2006, p. 445). Murray-Leslie’s based his interest in the assessment and provision of modifications which enable disabled people to drive, on the assumption that cars help physically disabled people “maintain their independence, social contact, employment or education”, as well as helping to “restore their self-esteem and reduce their frustration and sense of being disabled” (Murray-Leslie, 1991, p. 54).

Older (Disabled) People and Driving

The conceptual separation of the needs of younger disabled adults and older disabled adults is common, and although the issue is complicated, some of the reasons for the distinction have to do with the conceptualisation of aging, function and normality. Priestley and Rabiee (2002), after looking at issues common to older and younger disabled people, through a survey of organisations focused on the needs of older people, argued that there should be more links between groups that advocate and make policy for older and younger disabled adults.

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5 The line between older adults and younger adults in literature on driving is generally considered to be on either side of 65 years of age.
people because they have more in common than they have differences. Many older people have impairments that mean they are disabled by society and many disabled people are elderly. However, there is often very little linking or identifying of common issues between disability and elderly groups or theorists. Priestley and Rabiee acknowledged that this is partly due to issues of identity. Older people and groups may try to explicitly distance themselves from ‘disability’ discourses and present themselves as people functioning ‘normally’ as part of the aging process, so discussions of disability discrimination or a social model of disability are often absent (Priestley & Rabiee, 2002). Younger disabled people may also differentiate their experiences from those of older disabled people because they prefer not to associate themselves with elderly people and instead wish to see themselves as having many of their major life experiences still to come.

There are other reasons that younger disabled people and older disabled people might distance themselves from each other. Both the terms ‘disabled’ and ‘elderly’ carry negative associations, so that older disabled people may want to position themselves as separate from a stigmatised ‘disabled’ identity and younger disabled people may want to distance themselves from being ‘elderly’. However, there is a difference between being disabled in similar ways and having similar life experiences of disability. Older people with impairments have, in all likelihood, had different experiences of work, family life, leisure, and social interaction. They could also be in very different financial situations, if their impairments became apparent at an older age and did not affect their earning capacity while they were of working age.

Older and younger people are conceptually separated in policy, research and community organisations and movements, and the effect on research into mobility impairments and driving can be seen. There has been considerable research on elderly drivers (defined as aged 65 year and older) and their ability (or inability) to keep driving. Although the research is not framed in this manner, it is actually about people with mobility impairments and not about age as such. This conceptual separation occurs simply because it is assumed that mobility impairments are the domain of the elderly.

There are a very small number of exceptions to the separation of elderly and disabled people in academic transport literature. Schmöcker and colleagues looked at what mode of transport
elderly and disabled people used when they made shopping trips in London. While noting that many of the participants in their study primarily used private cars as transport (either as drivers or passengers), they found that there was more public transport use among the non-disabled elderly (Schmöcker et al., 2008). One other article combined elderly and disabled people in its analysis. However only four percent of those included in the study were work-aged disabled people, and there was no discussion of the differences between the groups (Gant & Smith, 1988).

When researchers describe why they are investigating driving reduction or cessation it becomes clear that the literature on older drivers is actually concerned with mobility impairments. Marottoli and colleagues (2000), who were interested in out-of-home activities, noted that older people are dependent on cars for transportation and drew on notions that younger people are associated with high degrees of mobility, while old age is associated with mobility impairments.

> “Younger people, with fewer physical limitations, may have a wider range of transportation options including walking, biking, and using public transportation. Older persons with limited mobility may be less able to utilize these options, especially in inclement weather” (Marottoli et al., 2000, p. 335).

Fonda and colleagues (2001) also looked at driving cessation amongst the elderly and found that it was associated with worsening depressive symptoms. Their description of old age, however, could easily be used to describe mobility impairment, with its, “stigma of dependency and/or the constriction of access to necessary and recreational activities” (Fonda et al., 2001, p. 349).

Similarly, Metz’s conceptualisation of mobility and quality of life for older people was explicitly concerned with increased rates of ‘age-associated disability’ in the population, specifically mobility impairments and how they limit travel behaviour, as well as the relationship between mobility and quality of life. For Metz, conceptualisations of mobility for older people needed to focus on issues such as provision of transport services through subsidy or regulation, “inclusive design” in transport design, assistive technology associated with mobility, and the accessibility of services such as clinics and community centres (Metz
2000, 150). All of these elements would be equally appropriate to consider when conceptualising mobility for (younger) people with mobility impairments.

If the research on elderly drivers can be seen as being also relevant to younger people with mobility impairments, then there is a considerably wider knowledge base to be incorporated into our understanding of disabled drivers. The main foci of the literature on elderly drivers and driving cessation are: the psychosocial consequences of reducing or stopping driving such as increased depressive symptoms; reduction in quality of life or life satisfaction, reduction in perceived control; as well as the associated reduction in out-of-home activities and the economic factors that contribute to access to private transport. This literature is rich with insights into driving and well-being, which I will now summarise.

Depression

Fonda and colleagues (2001) specifically looked at depressive symptoms and their association with changes (i.e. reduction or cessation) in driving patterns. They hypothesised that depression could follow the reduction or cessation of driving, because, as there is a decrease in mobility, decreased social participation and depression are likely to follow. The follow-on reduction in access to resources that reduce the likelihood of depression, such as paid or voluntary, health care services, religious or other communities and friends, make people more susceptible to depressive symptoms (Fonda et al., 2001). Another possible hypothesis was that driving was an everyday activity and the sudden loss of being able to perform such an everyday activity made depressive symptoms more likely.

Marottoli and colleagues also explored the increase of depressive symptoms following cessation of driving over a six-year study. Even after they adjusted for sociodemographic and health-related factors, driving cessation was the strongest predictor of depressive symptoms among the older people in their study (Marottoli et al., 1997).

Quality of Life/Life Satisfaction

As well as the studies that dealt specifically with depression, a number of studies discussed the way driving affects quality of life or life satisfaction, independent of depressive symptoms
(Cutler, 1972; Fonda et al., 2001; Metz, 2000). Cutler (1972) was interested in the relationship between life satisfaction and levels of social activity, and found that a loss of car-related mobility was associated with low levels of life satisfaction as it constricted ‘life-space’ (an actual or perceived physical boundary for activities) and narrowed the social world of the aged. Similarly, in Metz’s (2000) article, mobility was associated with quality of life, specifically that loss of mobility was equated with a decline in well-being when peoples’ movement was significantly affected by age-associated disability.

Perceived Control

In an article on perceived control and depressive symptoms related to driving cessation, Windsor and colleagues made the claim that it is the feeling of having autonomy and control over environmental interactions that makes driving so important to people of all ages (Windsor, Anstey, Butterworth, Luszcz, & Andrews, 2007). In their discussion, they identified expectancy of control as playing a significant role in the relationship between driving cessation and depressive symptoms. One of the theories proffered as to why this might be was that, if there is a lack of perceived control over other environmental interactions in their lives, this may increase the significance of driving to people with mobility issues (Windsor et al., 2007). The relationship between perceived control and depressive symptoms associated with driving was unsurprising when driving and independence are so closely linked in our society (Marottoli et al., 1997). So for people with mobility issues, having a sense of control over their environment is affected by any limiting of independence that being unable to drive may cause.

Mobility and Out-Of-Home Activity

All the articles on driving cessation and older people concentrate on the central role that mobility plays in ensuring physical and mental health and well-being. Mobility ensures access to health care and other out-of-home activities. In Marottoli and colleagues’ research, out-of-home activities, which driving allowed, were seen as significant factors in physical health status and lowering mortality risks. They found that driving cessation decreased out-of-home activities, which in turn affected participants’ health status and well-being. The study cited other research where activity levels were associated with health promotion behaviours
Inactivity was shown as a risk factor for increase in disability. They also hypothesised that the inactivity may relate to increased depressive symptoms associated with cessation of driving.

Economic Factors

Many of the articles on driving cessation in the elderly mentioned economic factors as being one of the reasons that driving may have to be reduced or stopped. The cost of running a car on a lower income, common to many elderly people compared to younger age groups because of retirement and sickness, was noted as being relevant to transportation usage. However, none of the articles went into any further detail about the economic effects of driving, or how income could be a significant barrier to continuation of driving.

Disabled people are more likely to live on lower incomes, either because they are unemployed or work in lower paid jobs. In 2001, this meant that 13% of disabled people in New Zealand had a median household income equal to or less than $15,000, which was double the rate (6%) of the non-disabled population (Statistics New Zealand, 2002). In comparison, the median household income for all New Zealanders in 2001 was $39,600. As well as lower incomes directly affecting transport options, incomes could also influence where disabled people could afford to live, which has a further bearing on transport options (Preval et al. 2010).

Mobility Parking Schemes

There are mobility parking schemes in many countries in the world. In the European Union, parking permits for people with mobility impairments can be used throughout the region, regardless of which EU country they were issued in (provided the permit holder adheres to the parking rules of the country they are in). While parking entitlements vary from one country to the next (or in some countries, even one state to the next), a widespread problem seems to be people without permits parking in spaces reserved for those with permits. There is even a body of research on how to prevent people illegally parking in mobility car parks (Cope & Allred, 1991; Fletcher, 1996). The subtext of this research seems to be that if the
parks are not available, the disabled people who could be using them are prevented from functioning independently and are more likely to be socially isolated (Fletcher, 1996).

Motability is a UK charity with close links to government, which provides modified (and unmodified) vehicles to disabled people on a lease-to-own basis (Motability, n.d.). People applying for a Motability vehicle need to qualify for the Higher Rate Mobility Component of the Disability Living Allowance (HRMC of the DLA), which goes directly towards paying off their vehicle. The HRMC of the DLA is not means tested, so people qualify for it whether they work or not. As part of the hire purchase contract with Motability, the insurance and servicing costs of the vehicle are covered. However, if a vehicle is especially costly, there is an upfront lump sum required to be paid by the person receiving the vehicle, though there is also the potential for help with paying this cost through the charity.

The literature that exists on disabled drivers internationally is scattered throughout broader transport research projects and is almost entirely contained within government reports, and not peer-reviewed research. What it does, however, is provide some ideas for further exploration of key areas in other bodies of literature. Although very little has been written on disabled drivers, there is a great deal more written on driving and disability separately. Literature on various aspects of driving, disability and assistive technologies can give us an interesting context from which to view the research that is the core of this thesis.

Part III

Driving

In the next section I will discuss literature on disability, but in this section of my literature review I will reflect upon what has been said about driving and drivers, and how it relates, or does not relate, to drivers with mobility impairments. The increasing academic interest in driving and car use in the last 20 years has been largely spurred by a desire to reduce the

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6 It should be noted that at the time of submitting this thesis in 2012 there were on-going changes being made to the social welfare system in the UK. The Disability Living Allowance (DLA) was due to be replaced by Personal Independence Payments (PIP) in 2013, with fewer disabled people eligible for income support. The Higher Rate Mobility Component was also being reviewed, with a significant percentage of disabled people, who currently qualify for it, expected to be no longer eligible under the new criteria.
environmental impact of traffic congestion and fuel emissions. The ‘green’ push of moving away from car-oriented transport to public transport, began to be expressed as a concern in the 1970s (Hine & Mitchell, 2001), but has gained increasing traction in more recent years. This can be seen in the growing body of literature from transport researchers trying to understand and conceptualise car use in order to encourage people to cut down on their use of cars for environmental and health reasons.

Automobility: The Sociology of Car Use

In 2005, Featherstone, Thrift and Urry edited a book which examined the concept of ‘automobilities’, or systems of (car-based) self-directed mobility, and looked at the way a system of automobility has been created – with its roads, cars, drivers, and fuel production and distribution. The authors also looked at how people and landscapes were affected by “the modes of mobility that automobility generates and presupposes”, as well as the relationships people have with cars and driving (Featherstone, 2004, p. 2). Urry’s description of the system of automobility, entailed: having access to a vehicle, the symbolic value of cars, the support structure that makes driving what it is, its difference/dominance over other forms of transport, the culture of car use, and the environmental issues surrounding it (Urry, 2004, pp. 25–26).

This concept of automobility is particularly interesting in reference to people with mobility impairments; who are often labelled as having a disability because of walking difficulties. However, it is clear that mobility impairments do not merely prevent people from walking easily; lack of access to buildings, public spaces and modes of transport can also mean that people with impairments frequently lack autonomy over their mobility. For disabled drivers, however, some self-directed mobility can be accomplished through their cars. Although cars cannot solve all mobility issues that a disabled person might encounter outside their home, with adequate environmental planning and access to appropriately modified and resourced vehicles, disabled drivers can be mobile in their cars where other people might walk or use public transport, if it is available.
In Dant’s ‘The Driver-car’ he described the car as “a mobility aid for the able-bodied” (Dant, 2004, p. 62), which is an apt description, but which also underlines that he had not considered the place of the car as a mobility aid for people who are not ‘able-bodied’, i.e. people who often require the use of mobility aids. Dant also discussed the embodied relationship between the driver and the car, as a car can provide the mobility and motility of using one’s legs, but travel faster and farther, without requiring the same effort (Dant, 2004, p. 65).

Although it did not refer to disabled drivers, Sheller’s article on ‘automotive emotions’ the emotional aspects of driving cars was explicitly concerned with the feelings associated with car cultures, within a context of human bodies and cars, how they interact, and how they move (or do not move) through space (Sheller, 2004, p. 223). Sheller’s work was interested not in the way that cars move bodies around, but the way that this mobility affects people’s relationships and feelings. Not only could cars provide feelings of “liberation, empowerment and social inclusion” for their drivers (Sheller, 2004, p. 230), they could facilitate the care of children and loved ones alongside job demands or change the locations and ways that families spend time together through ‘Sunday’ drives and family holidays.

Largely due to environmental concerns about car use and how to decrease current levels of car use, considerable research has been published on the sociology of car driving – particularly why people drive cars rather than use alternatives such as public transport (Ellaway et al, 2003; Hiscock et al, 2002; Nolan, 2010; Gardner & Abraham, 2007; Eriksson et al., 2008; Anable & Gatersleben, 2005, Sheller, 2004). Several studies have looked at utilitarian or instrumental, affective and symbolic factors that influence car use (Steg, 2005; Steg et al, 2001; Gardner & Abraham, 2007; Anable & Gatersleben, 2005, etc). Eriksson et al (2008) even looked at whether moral motivation about environmental concerns could decrease people’s car usage. One study found that utilitarian and affective reasons for using private cars were closely entwined and that while utilitarian reasons were often given to explain instances of car use, they were often underpinned by affective reasons, such as a desire for a feeling of control (Gardner & Abraham, 2007). However, there has also been research that acknowledges that many people find the act of driving pleasurable in itself and that these affective and symbolic factors contribute to the utility of driving (Steg, 2005).
Unsurprisingly, the studies that looked at affective and symbolic reasons for car use, including those ones that compared these to instrumental reasons, did not consider the views or experiences of disabled drivers in their research, and so the assumption was that all people who were driving cars could choose to use other modes of transport. While Steg (2005) examined symbolic reasons for car use, such as cars giving their drivers prestige, the frame of reference could be potentially quite different for disabled drivers – prestige for a person with a disability might simply mean that driving a car makes a disabled driver feel like other people, when, in many situations they may feel different and stigmatised. Likewise, the instrumental reasons that Steg looked at, such as not being dependent on others, could take on completely a different meaning for a disabled person, who may already have an identity attached to them by others of ‘being dependent’. Similarly, studies on the psycho-social benefits of car use showed that cars could provide drivers with feelings of autonomy, protection, mastery, self-esteem and prestige (Hiscock et al., 2002; Ellaway et al., 2003), which could be especially important for disabled drivers, because driving may be one of the limited ways that these psycho-social affects could be achieved for people with mobility impairments.

Although the above studies do not specifically consider the needs and experiences of disabled drivers, they were interesting in their analysis that there were multiple reasons why people use cars and, while the instrumental ones were often considered to be of utmost importance, the symbolic and affective associations of cars and their psycho-social benefits were also salient.

Freund and Martin’s (2007) discussion of the concept of ‘hyperautomobility’, appeared to be analogous to ‘automobility’ as conceived by Urry (2004), in that it was a system where there was both a large dependence on private vehicles, and where communities, facilities and opportunities were largely structured around mobility through car use (see also Beckmann, 2001). Furthermore, Freund and Martin argued that when people were unable to access a car they were excluded from society, and that disabled people were particularly vulnerable to this.
“While mass motorization has led to greater mobility for many, it has created new accessibility problems for those who do not drive (i.e. the disabled…)” (Freund & Martin, 2007, p. 38).

Freund and Martin made a similar claim in their earlier work (Freund & Martin, 2004) and used the social model of disability as a framework, but described the transport exclusion of people without impairments. Although Freund and Martin (2007) made an interesting point about accessibility problems for people who do not drive, they assumed that driving was an exclusively ‘able-bodied’ activity (although in Freund’s earlier work (Freund, 2001) he acknowledged that some people with mobility impairments drive). Freund and Martin (2007) contended that for disabled people (it was unclear what kinds of impairments they were referring to), systems of driving were necessarily exclusionary and disadvantageous, because they made disabled people appear even slower than they might have been in comparison to an ever faster paced world.

The central critique of Fruend and Martin’s hyperautomobility (2007) was that increasing use of private vehicles creates social exclusion and public health problems. They theorised that people were isolated because they either could not interact with others or access communities and opportunities without a car, and that there were public health implications because people in car-centred societies did less walking. In a forthcoming article, Goodman and colleagues (2012) also examine exclusion through the social gradient of car-ownership and its relationship to health, theorising that in car-dominated environments socio-economic advantage means that people are less ‘disabled’ by transport. In fact, other theorists of mobility and automobility have also seen these two issues, social participation and public health, combined with environmental damage, as the central concerns of car use.

Mobilities, as theorised by Urry, have changed rapidly in the last century due largely to the growth in use of the automobile. Urry and others have argued that the widespread desire for and the use of cars, combined with government and transport planners that have funded and placed emphasis on transport systems based around the car, have meant that a system of ‘automobility’ has become the dominant form of mobility. Automobility has become so ubiquitous that car travel is assumed when accessing most workplaces, homes, community amenities, shopping centres and leisure activities. Theorists of automobility have talked about
the difficulty at this point in time of reconfiguring transport systems, communities and people’s lives in a way that makes them less focussed around car travel, as cities and towns have been built around cars and people are emotionally, as well as practically, tied to their cars. Transport and mobility theorists’ major concerns about automobility, aside from what they have seen as the fracturing of face-to-face interactions that are afforded by walking and public transport, have been the polluting effects of carbon based emissions and the unsustainability of fossil fuels (Freund & Martin, 2007).

For Urry and others, a move towards lower carbon mobilities is inevitable in our future, with the consequences that people will have to change their conceptions of their own mobility, as well as their means of mobility. Automobility, in their estimation, is a negative social phenomenon which isolates people, causes pollution, destroys neighbourhoods and is entirely unsustainable from an environmental perspective. However, a move away from a carbon-intensive system of automobility will have differential effects on different groups depending on their ready accessibility to other forms of mobility, their economic situation, the location of their home, and what familial and other responsibilities they have. I believe that more consideration of the experiences of people with mobility impairments in the analysis of mobility theorists, would bring a complexity and more complete analysis to their arguments.

Environmental Concerns about Car Use

Over the last decade there has been growing public and policy awareness of climate change science and calls for reductions in emissions. A major focus of emission reduction has been the emissions produced by private car use. Consequently, initiatives to reduce car travel have become more urgent and public and active transport are promoted by many environmental and health organisations and academics. Indeed, the concept of ‘sustainable transport’ is synonymous with transport systems not organised primarily around the car.

Many theorists of car use have therefore talked about the various ways that policy makers can try to get people out of cars and position public and active transport as attractive alternatives to private car use. In an effort to do this, Steg (2005) investigated the various
reasons that drivers drove their cars, including the symbolic and affective reasons for cars use as well as the instrumental reasons.

There has also been valuable research done on how cities can be built so as to best meet the needs of people as they go about their lives, with easy access to work places, schools, shops, recreation areas and community and health facilities (Witten, Abrahamse, & Stuart, 2011). Environmentally conscious city planners aim to influence the way that cities develop over time so that people have less commuting time and costs, while still being able to access services, even if they live on what is generally considered the outskirts of urban centres (Howden-Chapman, Stuart, & Chapman, 2010).

However, most discourses about the reduction of car use and the promotion of public and active transport have assumed that people can access public transport easily and safely, and/or are capable of walking or cycling to public transport depots or to the places they need to access reasonably priced food, healthcare, employment, social networks and support, as well as other destinations required for participation in society. But this is not always the case, and for both people with mobility impairments and other transport disadvantaged groups, their social exclusion is partly generated and maintained through their lack of appropriate transport options.

There has been some movement in the discourses around public transport however, such as the 2010 Bangkok Declaration on Environmentally Sustainable Transport. One of their goals was to adopt “social equity as a planning and design criteria”, which consider the transport needs of elderly and disabled people and included indicators such as accessible public transport vehicles and depots, and footpaths (Bangkok 2010 EST Forum).

Lucas (2006) has examined the tensions between policy initiatives which seek to reduce car use and those that seek to reduce social inequalities through transport programmes. Because of the heavy reliance that many people have on cars, it is extremely difficult to attempt to create a transport policy that minimises environmental degradation without limiting access to social and economic opportunities to the very rich (and physically able).
While there is some hope that technological advances will in the future create vehicles that emit few or no climate changing gases, the replacement of the existing car stock would take a considerable time, as polluting cars would exist in the lower cost, second-hand market for many years afterwards. Furthermore, attempts to try and price people out of cars with taxes and duties would affect people on low-income most severely and create more social injustice through limiting their mobility. However, Lucas has seen some progress in the UK, with local councils undertaking ‘accessibility planning’ initiatives which seek to ensure local accessibility to key activities and services alongside public transport planning (Lucas, 2006). In New Zealand, the Auckland Council’s draft discussion document on its spatial planning strategy specifically asked for feedback on the needs of disabled people in Auckland and recognised barriers to transport, and the physical environment, including attitudinal barriers.

Transport, Social Justice and Social Exclusion

“In most modern societies, some form of transport is usually necessary if an individual is to gain access to education, employment, shops, essential services, leisure and the other social activities that are necessary to securing a good quality of life” (Lucas, 2004, p. 10).

Although written in the context of the US and UK, Lucas’ assertion holds true in New Zealand – that where there is an assumption of a high degree of transport mobility, those who cannot access appropriate transport, and therefore lack mobility, are denied access to a wide range of services and opportunities, with serious consequences. Lucas, and her colleague Clifton also pointed out that, in a highly mobile population, lack of appropriate transport limits access to employment, education and training opportunities, which severely affects a person’s financial independence, and consequently, their ability to participate fully in society. Lack of appropriate transport also limits access to food, healthcare and social services which intensifies health inequalities. Furthermore, inadequate transport creates a risk of people becoming housebound and isolated, cutting them off from important social networks. All of these factors affect people’s quality of life and can even weaken social cohesion (Lucas & Clifton, 2004, p. 29).
Social exclusion has received a lot of academic and policy interest since the mid-1990s, particularly in the UK and Europe, and the WHO has identified it as a key determinant of wellbeing. While it has been a contested term, social exclusion is often closely linked to material resources, but has been differentiated from poverty (Hodgson & Turner, 2003) because it involves being excluded through multiple systems, groups and institutions, not merely through lack of money. Transport inaccessibility has been strongly linked to social exclusion through its relationship to accessing employment, housing, healthcare, education, political involvement, and social and cultural participation (Kenyon et al., 2003). This lack of transport and mobility can either enforce or reinforce exclusion from participating in society, as those who are most excluded often have the least opportunity to access transport, “Social exclusion can be a direct result of lack of mobility, or lack of mobility can exacerbate existing experiences of exclusion” (Kenyon et al., 2003 p319).

While New Zealand’s “dominant transport mode is unquestionably the private motorcar,” (Rose, Witten, & McCreanor, 2009, p. 192) a report by the New Zealand Ministry of Transport also found that “purchasing, running and maintaining a car” was not affordable for many households without “severely compromising other areas of household expenditure” (Rose et al., 2009, p. 193). This has serious implications for people being able to access the “places, goods and services they require to participate fully in economic, social and recreational activities” (Rose et al., 2009, p. 192). Living in a low income household or in a deprived area, which many disabled people in New Zealand do (New Zealand Ministry of Health, 2004), means being especially vulnerable to transport-related social exclusion.

Although there is public transport in many parts of New Zealand, it is extremely limited outside the main centres and even in main centres public transport can be inadequate to many people’s transport needs (Rose et al., 2009). Qualitative research in New Zealand found that people experienced public transport as deficient in terms of its “coverage, frequency, regularity and reliability” (Rose et al., 2009, 198). For disabled people, access to public transport in rural areas was even more difficult with 54% of disabled adults reporting that they could not easily get to a public transport depot (New Zealand Ministry of Health, 2004). This difficulty in accessing transport in rural areas is concerning considering that, according to an Australian study, disabled people in rural areas were already likely to suffer
disadvantage because of difficulty accessing health and rehabilitation services, appropriate housing, education and employment opportunities (Gething 1997).

As well as difficulties with being able to get to public transport depots, some participants in Rose and colleagues’ study found many work locations difficult to access by public transport, essential services such as health care and affordable food difficult to reach; and, in general, found the cost of public transport to be prohibitively high (Rose et al., 2009). This was on top of the finding that public transport was inaccessible for many elderly and disabled people, who found it difficult or impossible to get on and off public transport, ride on it safely, or overcome the many other barriers to its use (Rose et al., 2009).

Public transport has long been identified as not meeting the needs of many disabled people and the consequences of this for their ability to participate in society are that public transport is both a symbolic and a physical barrier. Hodgson and Turner argued that the built infrastructure of the transport environment “explicitly communicate[s] messages from the dominant culture about the societal value of users of that environment” (2003, 268). The social exclusion of disabled people, who cannot use a transport system that is designed for the public, is built into one of the key systems that is supposed to facilitate social cohesion and inclusion.

Isolation from networks and activities has been cited as a key component of social exclusion – hostility from institutions, groups or individuals can mean that people intentionally isolate themselves further from people and society (Hodgson and Turner, 2003). When considered through a transport lens, that hostility could be felt through physically inaccessible, unsafe or uncomfortable modes of transport, unhelpful or impatient transport workers, or even through a physical environment that is hostile to some people’s bodies.

Geographical location has also been tied to social exclusion, as Farrington and Farrington (2005) pointed out. Accessibility “is fundamentally about… life opportunities…It is not a sufficient condition for social inclusion and social justice, but is it a necessary one” (Farrington and Farrington, 2005, pp. 11–12). Although Farrington and Farrington were largely talking about accessibility to opportunities for all people living in rural areas and not specifically for disabled people, they elaborate on the idea that the spatial elements of social
justice must be understood in any attempt to reduce inequality in society. Being situated in a rural setting was one way that the spatial and structural elements of exclusion could interact to produce social injustice (Farrington and Farrington, 2005). For disabled people, whether they live in a rural setting or not (although perhaps especially if they live in a rural setting), their spatial isolation from opportunities to participate in society means that if they have inadequate transport they are extremely vulnerable to social exclusion.

Health Effects of Car Use

Transport has been identified as one of the social determinants of health. The World Health Organization (WHO), in their Transport, Environment and Health report (2000) stated that transport is key to accessing jobs, education, services and leisure. However, the report also linked car use to a number of negatives consequences such as road injuries, respiratory illness, cardiovascular disease, sleeping problems, hearing impairment, reduced child cognitive function, aggression, nervousness and social isolation. These negative health indicators were in contrast to studies that have shown the individual health benefits of having access to a private car (Macintyre, Ellaway, Der, Ford, & Hunt, 1998; Macintyre, Hiscock, Kearns, & Ellaway, 2001). In the WHO’s Health in the Green Economy, it was noted that “[c]ities and neighbourhoods that are not designed to meet the travel needs of disabled people are, in fact, more likely to exacerbate health inequities” (World Health Organization, 2011, p. 34). The report acknowledged that a lack of accessible transport excluded disabled people from services and social contact, and that it is a problem which is often ignored in transport planning. Despite this acknowledgement, cars were absent from the WHO’s conceptions of accessible transport and inclusive cities.

Although the specific health effects of disabled people driving cars have not been studied, there have been studies, notably in the UK, of the health statuses of people with, and without access to cars. One study found that “generally, irrespective of tenure or class, those without access to a car have worse health” (Gould & Jones, 1996, p. 863), and this research was followed up by a Scottish study which found that “car access was still a predictor of health after controlling for social class” (Macintyre et al., 1998, 2001, p. 330). The psycho-social benefits of car use were also examined and cars were shown to provide protection,
autonomy and prestige. More specifically, cars were shown to be particularly beneficial if people had children, or had been ill. In a systematic review of the health impacts of road transport policies and interventions Thomson et al. (2008) found that while there were interventions that could affect traffic injuries, more research was needed on the social and environmental health effects of transport.

Qualitative research on the psycho-social benefits of having access to a car found that after people became ill, a car could be a protective factor and people’s lives did not alter as significantly as they might have done without car access (Hiscock, Macintyre, Kearns, & Ellaway, 2002). Many participants found public transport almost impossible to use due to having to access bus stops by walking, being uncomfortable waiting at stops and the pain of sitting on a bus.

Interviewer: ‘What couldn’t you do without a car?’

Respondent: ‘I couldn’t get out…I could get out and walk up and down the street, but I couldn’t do much else… I could probably walk down to [the bus stop] but by the time I come back in I’d be extremely tired (Hiscock et al., 2002, p. 129).

Being physically able to access public transport or walk a short distance was not a sufficient factor in ensuring meaningful mobility after people had become ill (Hiscock et al., 2002).

Part IV

Disability

Because of the limited amount of (academic) literature on disabled drivers, and the lack of discussion of people with impairments in driving and transport literature, in the following section I will discuss what has been written more generally about disability. The mobility and transport needs of disabled people have been theorised by many people, although the focus has largely been on the simultaneous need for, and difficulties of using public transport. There are also several other relevant areas of discussion of disability, including issues of disabled peoples’ exclusion from and participation in society, the mental health vulnerabilities
of disabled people, various conceptualisations of disability itself, as well as issues around the use of, and access to, assistive technology, which can mean disabled people are ‘able’ to do things. This section will also consider how general theories of disability relate to general theories of well-being and human development such as the Capabilities Approach.

The New Zealand Disability Strategy

The 2001 publication of the New Zealand Disability Strategy laid out 15 objectives to improve the participation of disabled people in New Zealand society. Objective 8, which aimed to “support quality living in the community for disabled people,” specified as one of its actions, “moving around the community”, which included:

- Requiring all new scheduled public transport to be accessible in order to phase out inaccessible public transport.

- Encouraging the development of accessible routes to connect buildings, public spaces and transport systems.

- Developing nationally consistent access to passenger services where there is no accessible public transport. (New Zealand Office for Disability Issues, 2001)

Given that “moving around the community” was a specified action which would support “quality living in the community”, and that many disabled people use private vehicles, disabled drivers are notable in their absence within the New Zealand Disability Strategy, even though passenger services (where disabled people are driven by a community and/or state-funded agency, often in groups) were mentioned. However, public transport was mentioned, which can also be seen in much of the literature on disability and mobility.

Disability, Mobility and Public Transport

Although many countries have had a policy of making gradual changes in the design of public transport vehicles for many years (Vintila, 1996), many disabled people are still unable
to use public transport because of environmental barriers (New Zealand Human Rights Commission, 2005; Penfold et al., 2008; Rosenbloom, 2007). Knowles (2006) described how, despite an awareness of the discriminatory implications, accessible transport has been seen as too big a financial burden to remedy the situation quickly. In the UK, the Disability Discrimination Act 1995 required public buildings to be fully accessible by 2004, but public transport was exempted from the legislation because of the cost of adapting buses, trains and railway stations (Knowles, 2006).

In 2003, the New Zealand Human Rights Commission announced an inquiry into the accessibility of public land transport in New Zealand for disabled people. The report, *The Accessible Journey*, found that journeys were made up of multiple ‘links’ and that if any of the links did not work for people then they could not complete their required journey:

> “Having an accessible bus on a route is not enough to guarantee access and egress for wheelchair users. Unless bus stops are appropriately sited and maintained, and footpaths are of the required height and width, the bus effectively becomes inaccessible” (New Zealand Human Rights Commission, 2005, p. 39).

The Inquiry considered four aspects of transport situations, to assess whether they were viable for disabled people and how they could be improved: accessibility, availability, affordability and acceptability. Submissions were received from various groups and individuals, focus groups were conducted and comparative international research was done to provide the basis for the findings and recommendations of the Inquiry. The Inquiry found that a lack of accessible public land transport was “one of the biggest barriers to active participation in society faced by disabled people today” (New Zealand Human Rights Commission, 2005, 1).

There were 129 submissions to the Inquiry from government agencies, community advocates, providers and individuals, as well as information provided by the private sector providers of public land transport. The Inquiry found that disabled people in New Zealand were faced with systemic discrimination when accessing public land transport. The Inquiry recommended key strategies that would help reduce the systematic discrimination of disabled people in regards to public land transport. These included direct participation of disabled
people in planning processes, mandatory national accessibility design performance standards and industry wide training in disability awareness and competency.

The Inquiry also considered data gathered from the 2001 Statistics NZ Household Disability Survey, and found that as well as having a huge unmet need for transport, many disabled people would use buses were they able to: “46,000 adults who had access to a bus service, but had not made any short trips by bus in the previous 12 months, said they would travel on buses if they were easier to use” (New Zealand Human Rights Commission, 2005, p. 34). However many more disabled people did not have easy access to buses, with an estimated 139,300 (24%) of disabled adults not easily able to get to a bus stop or a railway station from where they lived (New Zealand Human Rights Commission, 2005).

Many researchers looking at the issues of transport-related social exclusion, have noted that disabled people are highly likely to belong to a group of people who are socially excluded through transport.

“Transport difficulties compound the structural disadvantages of many disabled people in relation to education, employment, household income and living standards. Adults with disability are … less likely to be employed, and more likely to have lower personal incomes, than adults without disabilities… Disabled people are more likely than people without disability to live in the five most deprived areas in New Zealand” (New Zealand Human Rights Commission, 2005, pp. 34–5).

In 2009, the Human Rights Commission updated their website on progress made towards the recommendations in their inquiry, they reported that: design standards for urban buses and for wheelchair accessible vans had been improved, and design standards for information services were being developed; all new applicants for the driver’s licence necessary to drive buses and taxis must undertake disability awareness training (New Zealand Human Rights Commission, 2009). In their 2011 Briefing to the Incoming Minister for Disability Issues, the Human Rights Commission also noted that the number and proportion of accessible buses had increased, accessibility requirements had been established for purchases of new urban buses bought with government money, and regional councils had begun to include disabled people in their transport planning (New Zealand Human Rights Commission, 2011).
However, the HRC were still recommending to the Minister for Disability Issues that the Ministry of Transport and the New Zealand Transport Agency develop a systematic work programme to improve the accessibility of all public land transport services (2011).

The 2006 United Nations Convention on the Rights of Persons with Disabilities specifically recognised the need for personal mobility for disabled people and asserted in Article 20 that state parties shall take measures to ensure personal mobility, including by “facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice” and “facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies… including by making them available at an affordable cost” (United Nations, 2006). Accessibility and its relationship to full participation of disabled people in society is also discussed in Article 9 of the Convention, including the identification and elimination of obstacles and barriers to transportation and community facilities and services. The Convention on the Rights of Persons with Disabilities was ratified by the New Zealand Government in 2008.

Through the 1980s and 90s there was increasing awareness about the need for transport solutions for disabled people and in the mid-1980s, groups such as the European Conference of Ministers of Transport (EMCT) were formed. The EMCT Working Group published reports on the problems of transport for people with mobility impairments and the various solutions proposed by its member states, including an acknowledgement that cars can give disabled people independent mobility (European Conference of Ministers of Transport Working Group, 1991).

While there has been research noting that access to private cars, especially for disabled drivers has been important for independence and participation (Rosenbloom, 1982), many researchers on the transport needs of disabled people have focused on public transport provision and the problems that disabled people face with it. This makes sense for a number of reasons, for disabled people who cannot drive independently, even with modifications to a vehicle, alternative forms of transport are needed that are driven by someone else. Public transport already exists in many places including New Zealand and is supposed to be a public

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7 In 2006/7 the European Conference of Ministers of Transport formed into the International Transport Forum, based at the OECD, and New Zealand is now a member.
service, so making it more accessible to people with mobility impairments has been framed as a civil right (Langan, 2001), as those with mobility impairments have the right to not be excluded from a public service.

Physical Impairment and Mental Health

People with long-term impairments and chronic illnesses are more likely to be affected by poor mental health than those who are not (Vilhjalmsson, 1998). People with physical impairments have been shown to have about three times the risk of presenting with significant depression, as those without physical impairments – irrespective of age, sex, education level or income (Turner and Noh, 1988). These results have been linked to stressful life events and chronic stress, as well as to degrees of mastery and social support (Turner and Noh, 1988). Social support has also been linked to psychological well-being in other studies; Fitzpatrick et al. (1991) found that for physically disabled people social integration was important for good mental health, particularly where social relationships were diffuse, but that those who had mobility difficulties were most likely find social integration difficult. As with many studies done on physical impairment, there tends to be a great deal of emphasis on the elderly disabled population. A 2001 review of the literature on depression in older disabled people (65 years plus) had 66 separate studies to consider (Lenze et al., 2001).

Participation

To understand why participation is important and in what ways participation can be enabled, we need to understand what participation actually means for disabled people. After the WHO moved from ‘handicap’ to ‘participation’ in the International Classification of Functioning (World Health Organization, 2001), researchers began to question what ‘participation’ actually meant. Hammel and colleagues (2008) conducted a series of focus groups with 63 disabled people and sought their views on what it meant for them to ‘participate’ in society. What emerged was that participation was not a particular set of activities, but more a reflection of the participants’ values: “Working, family, recreation, spiritual aspects…each of us based on our own value systems has more or less interest in pursuing them” (Hammel et al., 2008, p. 5). Some of the things that people valued were
‘being a part of things’; having choice and control over how and when to participate; having access to opportunities (which was closely linked with social inclusion) and resources (such as income and assistive technology); being able to be involved in and to contribute to the community; and being able to make physical, mental and social connections with others. It is important to identify some of the ways that disabled people have themselves described participation in society as disabled people. However, it is also interesting to consider this in light of how academics and policy makers have been talking about similar ideas of social justice, and social inclusion or exclusion in society, particularly as disabled people have a high risk of being socially excluded. Disabled people are also more likely to be economically excluded than the rest of the population (Jan, Essue, & Leeder, 2012; Statistics New Zealand, 2001; Zaidi & Burchardt, 2005), and economic exclusion causes health inequities (Van Lenthe et al., 2004). Work has been done in New Zealand by Carroll and colleagues (2004) looking at how the effects of illness and impairment are amplified by poverty. Carroll and colleagues looked how to intervene at different levels so as to lessen health inequalities between groups, including how the effects of ill health and impairment on socio-economic position can be minimised through appropriate supports.

Social Model of Disability

The social model of disability (SMD) has become hugely influential in the field of disability studies and other areas of study that have as their focus people with impairments. Since the 1976 publication of the UPIAS (Union of the Physically Impaired Against Segregation) guidelines Fundamental Principles of Disability, disability theorists have been concerned with the idea that:

“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, p. 3).

This idea was expanded upon and developed into the Social Model of Disability by writers such as Mike Oliver in his 1990 book The Politics of Disablement. Tregaskis (2002) has described the social model as an explicit critique of the oppression of people with
impairments within capitalist societies; that people who “do not conform to mainstream expectations of appearance, behaviour and/or economic performance” are placed into an artificial and exclusionary category of ‘disability’ (Tregaskis, 2002, p. 457).

In the last 20 years, the SMD has become both widely accepted, and also critiqued, by many disability theorists. The SMD is often contrasted to a medical model of disability, where disability is understood in terms of functional deviation from a ‘normal’ or ‘healthy’ body. The medical model of disability is a description of (usually) practitioners looking at an individual in terms of what they can and cannot do in society and how medical intervention may be able to bring the disabled individual into line with standard ideas of functioning. This is different to a social model approach which looks at the way society is organised in ways that create barriers for people with impairments, and seeks to get rid of the barriers, rather than either changing the impaired person, or accepting the barriers as permanent and fixed.

The SMD is informative for research such as mine as it takes a structural and not an individualist approach to the ‘lived’ experiences of people with impairments and it puts the onus back onto those with power in society to address the disabling forces that prevent people with impairments from living the life they choose, as well as achieving equitable health or well-being outcomes. It also gives those people with impairments an opportunity to understand their experiences from outside their individual circumstances and make the connection between themselves and others who are disabled by society (Crow, 1996).

The SMD has also been criticised by Corker (1999) and others, for not taking into account the lived experiences of many people with impairments, such as those who, as well as having impairments which limit their ability to do things because they live in a disabling world, have to deal with the other, more private, consequences of impairment. A common example of the aspects of impairment that the SMD cannot not ‘account for’ comes from people who experience chronic pain or fatigue, or those who cannot function in a way that is important to them specifically, and not just because it is expected that people function in certain ‘normal’ ways.

Critiques of the SMD often claim that it is not a comprehensive enough model because, as some theorists have argued, even if society eliminated disabling attitudes and organisational
and physical structures, some people would still be left dealing with the lived experience of their impairments, such as pain, fatigue or anxiety about the future of their bodies (Corker, 1999; Shakespeare, 2006). However, the SMD can be used to analyse some of the structural elements of people’s lived experience: whether people have access to appropriate pain killers or treatments that could alleviate their discomfort, whether people have access to support that could enable them to expend limited energy on things that they most wanted to do. Even anxiety about the future of someone’s body could be affected by attitudes towards disability and whether they think they will be able access the resources they might need and be able to cope with the attitudes of the people around them. What the SMD cannot do is eliminate these problems; it can only be used to identify and analyse problems, and find ways in which these problems can be alleviated. To bring this idea back to UPIAS’s original conception of disability and impairment, the SMD relates to disability, not impairments – because “disability is something imposed on top of our impairments.”

Part of Corker’s argument was that the (theoretical) elimination of structural barriers affecting disabled people would not necessarily be enough to make ‘disability’ disappear. Corker (1999) pointed to groups, such as women and black people, who have had several decades of various forms legal protection from discrimination and yet who still face discrimination. However, addressing structural barriers does not merely amount to introducing legal protection from discrimination. In New Zealand, the Human Rights Act 1993 made discrimination against disabled people illegal, and yet structural barriers to full participation for disabled people still exist in New Zealand.

Although theorists have argued over the value of personal narratives about impairment, having a way to explore the structural creation of disability is very important. Personal narratives about impairment are important in their own right, because they are stories not usually told or heard. But to create social change, people have to work collectively.

Marks (1999) argued that theoretical debates about the value of the SMD arise from tensions between approaches which encourage people to talk about and consider the individual experiences of being disabled and those that are only concerned with systematic oppression of disabled people. Those who encourage personal narratives about the experience of being disabled are seeking to alleviate situations where disabled people have to simultaneously cope
with public systematic discrimination, as well as privately cope with the particular difficulties that arise solely from their impairment. Marks gave the example of Finkelstein (1996), as someone who saw personal or psychological narratives about impairment as deflecting attention from real world changes that could be made to create a less disabling society, and instead being closer to a more medical model, or ‘personal tragedy’ way of understanding the world. Shakespeare (2006) has also criticised many proponents of the SMD for their refusal to engage with individual’s experiences of the negative effects of impairment, while insisting that only structural understandings of disability matter.

In reality, personal narratives and structural understandings of disability do not work in opposition to each other; they actually work to inform each other by helping people to identify common experiences, barriers and solutions. Crow pointed out that, “the social model has never suggested that disability represents the total explanation or that impairment doesn’t count” (1996, p. 65). The criticism of the SMD, that it does not take lived experience into account enough or solve the problems of lived experience, is a slightly misleading one because, again, the model is an analytical tool that can be used to create help create social change and is not intended to solve every problem. People who use that tool need to use it to critique the ways that society affects and creates lived experience. It is also a tool that, by exposing the social construction of disability, can offer some solutions for the reconstruction of society in a way that does not disable people. The lived experience of disability exists in the social context of the person experiencing it and the goal of the SMD is to critique and hopefully to change the social context. The SMD cannot eliminate negative experiences of impairment, but it can argue for the practical steps that be taken to lessen the effect of these experiences.

Some disability theorists have looked at the SMD through psychoanalytic theories around the oppression of disabled people. Theorists, such as Shakespeare (1994) and Morris (1992), have drawn attention to conceptions of disabled people as a group of either pathetic or disturbing ‘others’, whose bodies are feared and hated because they are a reminder that bodies are fallible, base and mortal. This perspective links into a more materialist social model approach by describing a societal conception of disabled bodies as tragically, individually flawed, an image which deflects attention from the reality of disabled people
living in a society where bodies that deviate from an impossibly idealised ‘norm’ are excluded and oppressed.

Whether or not the SMD can describe and theorise all aspects of the experiences of people living with impairments in a disabling world, it is a tool that can be used to expose the assumptions and limitations of a society where those with impairments face (often easily solvable) human-made barriers to participation and well-being. The SMD is not the only tool that can be used for the benefit of disabled people, but it is an important one.

Assistive Technology

Although there has not been a qualitative exploration of the use and meaning of car driving for people with mobility impairments, in Technology, Selfhood and Physical Disability Lupton & Seymour (2000) reported on qualitative findings from interviews with physically disabled people about their use of, and attitudes towards, technology in general. While technology can potentially have much to offer disabled people, all people (with and without impairments) use technology to enhance their capabilities. While Lupton and Seymour stated that almost everyone in “contemporary western societies” (2000, p. 1852) has a close dependency on technologies in their everyday life, they ignored the fact that people in all cultures use technology. However, they also pointed out that many of the technologies we use are not often seen as extending our physical capabilities. Two examples are the use of glasses to improve vision and cars to make us more mobile. However, for disabled people specifically,

“Technologies may be regarded as offering a tangible way of addressing sociocultural disadvantage and marginalization…by augmenting or substituting particular bodily functions and transcending time and place, new technologies offer people with disabilities the possibilities of facilitating entry into and participation into previously inaccessible activities and domains” (2000, 1853).

Lupton & Seymour found that the technologies that their participants accessed could give them a sense of autonomy and control which were closely connected to their sense of independence. Participants talked about enjoying the experience of being able to master and
accomplish things themselves with the help of technology and how it could enable them to fulfill other roles, which gave them even more independence and a sense of control, such as entering into paid employment. Being able to enter the work-force also gave one participant financial independence, social connection and status. The psychosocial benefits that participants got from technology were sometimes most obvious when they were absent. One participant, who used a computer to work and communicate with people, commented that: “One day I was without the computer for a whole week and I nearly went mad!” (2000, p. 1857).

Whether the technology that participants in Lupton and Seymour’s study used was originally made for ‘mainstream’ use, or was designed for use exclusively by disabled people could make a difference to how acceptable the participants found it. While participants talked about both kinds of technologies, several said that they found ‘mainstream’ technologies particularly useful. Using ‘mainstream’ technologies could also be ‘normalizing’, while technology designed especially for disabled people could increase feelings of stigma. If the technology was visibly different to technology that non-disabled people used, it could draw further attention to disabled participant’s feelings of difference, and therefore ‘invisibility’ of technology was seen as a very positive thing. The invisibility of technology for participants of the study could just mean using technology that non-disabled people used, but using it in a slightly different way, such as was the case with a visually impaired person using an electronic ‘business memo’ speech recorder rather than writing something down. The participant who used the sound recorder experienced a neutral or positive reaction from other people when using this kind of technology, but experienced a negative reaction when using a cane, which was highly associated with visual impairment, to move around. Another participant with visual impairment preferred having a guide dog, which she believed to be “completely and utterly socially acceptable”, to using technology such as a sonic pathfinder, which might include a “head band with ear plugs and a big thing across the forehead” (2000, p. 1858).

Because disability is stigmatised, devices used solely by disabled people were stigmatised and the participants who used them sometimes felt that the rest of their identity was erased when people looked at the ‘disabled’ technology they used. However, as one participant pointed out, his use of a wheelchair drew attention to his ‘difference’, but also gave him mobility and the opportunity to interact with people and these competing factors needed to be balanced.
This balance was described particularly well by another participant: Kate explained that the technologies she used must address,

“What I need them for[,] but also they have to fit into my view of myself and the way that I want to present myself to the community” (2000, p. 1859).

The requirements for technology to meet disabled people’s practical needs as well as making them feel as if their identity was not negatively associated with technology, is interesting in the context of disabled drivers. In Lupton and Seymour’s study, disabled people who used the internet to communicate with people had a very similar experience, because the people who they were communicating with only knew they were disabled, if they revealed it themselves and this meant they “were able to avoid, to some extent, the discriminatory attitudes they otherwise encountered” (2000, p. 1859).

Lupton and Seymour also discussed how participants had varying levels of access to technology because of the cost involved in purchasing the most appropriate kind. New technologies were prohibitively expensive for many of the disabled people who might benefit from them, although they could give disabled people independence in many areas of their lives (Brooks, 1991; Lupton & Seymour, 2000, p. 1859). One of the in participants Lupton and Seymour’s study talked about the social injustices that could occur when disabled people did not have access to technology that would enable them to do interact easily with other people.

“[A computer] for a person with a disability might mean the difference between communicating and not communicating… to me, there’s an injustice somewhere and there’s not a recognition that that for people with disabilities it is more need than want. The benefit there is it can be really life-changing, not just a help or something” (2000, p. 1860).

However, even if they could access some forms of technology, Lupton and Seymour found that because their participants relied on external agencies to fund their technology needs, the participants at times had to accept technology that they would not have chosen, and was not as helpful to them, as other technology would have been. This could occur, for example, if a
funding agency would approve one type of wheelchair, but not another type of wheelchair, even if the second wheelchair was easier to use and was preferred by the person who had to use it. Not being able to make decisions about the type of technology used meant that the benefits of technology could be reduced or could completely disappear (2000).

Lastly, the people in Lupton and Seymour’s study talked about the consequences of technology breaking down or failing, and they found that “feelings of autonomy, self-control, independence and normality that have been painstakingly achieved are challenged and disrupted” (2000, p. 1860). Not being able to use the technology could mean the person was thrown back into a situation where they felt dependent, frustrated and burdensome.

Overall, Lupton and Seymour found that although there were technologies that participants resisted and that they resented being dependent on, there were many acknowledged benefits that technology could bring them, including:

“Communication with others, mobility, physical safety, personal autonomy, control, independence, competence, confidence, the ability to better engage in social relationships, the workforce and participation in society” (2000, p. 1860).

This list of positive associations with technology in general is strikingly similar to the associations that participants in this study attributed to their ability to drive their cars, as will be seen in the results chapters.

There appear to be subtle differences between the uses of the terms ‘assistive technology’, ‘assistive devices’, ‘adaptive technology’ and ‘advanced technology’. Scherer, in a special edition of Disability and Rehabilitation which focused on assistive technology, argues that the common definition of assistive technology, which comes from 1988 US legislation and is used by academics.

“Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities” (Scherer, 2002, p. 1).
According to this definition, cars could be considered assistive technology, but they have not been talked about in terms of assistive technology. Scherer (2002) gave examples of assistive technologies such as wheelchairs, scooters and canes that were used for mobility and also mentioned related products, such as lifts on vehicles. These examples of assistive technologies were referenced in relation to the mobility of disabled people, and it was also noted that “more people use assistive technologies related to mobility… than any other general type of assistive technology” (Scherer, 2002, p. 1). Yet cars, a form of technology that so many disabled people use for mobility, were omitted.

Harris, on the other hand defined ‘assistive technologies’ as “specialist devices designed purposively to assist disabled people” (2010, p. 428). Harris also talked about ‘advanced technologies’, which she used to mean “devices (often electronic) both mainstream and ‘specialist’ that assist disabled people at home” (2010, p. 428). This definition was interesting as seemed to posit that the technology, even if it was simultaneously ‘mainstream’ (by which she meant it was used by non-disabled people), somehow changed or took on a special additional dimension when it was used by disabled people to ‘assist’ them in their lives. Harris gave an example of a mainstream technology that could be used by disabled people, an electronic device such as an iPod, which could be used by disabled people as a reminder that they need to take medication. This ‘mainstream’ product “obviates the need for ‘specialist’ devices and avoids potential stigmatisation of the users, as well as unnecessary financial outlay” (Harris, 2010, p. 428). However, a reminder function on an iPod is something that many people, not only disabled people, would use. For Harris, this ‘advanced technology’ took on assistive qualities through its use by a disabled person for something related to their disability, as opposed to non-disabled people using a device for secondary uses (the primary use being for playing music). Another factor that Harris did not touch on was that a device such as an iPod is a desirable item in itself, as well as performing a useful function related to its owners’ disability; not only could a disabled person avoid the stigma of using a specialist medication reminder and instead have a device that is not linked to disability or illness at all, but it also played music as well as other types of media, which could bring pleasure to its disabled owner, as it would to any other owner. This is an important point to consider, because technologies can have more than one layer of use and meaning for the person that uses them.
Scherer (2002) also noted that while rehabilitation practitioners were concerned with the non-use of assistive technology, assistive technology was most likely to be used if its selection was based on how well it satisfied the client’s needs and preferences, as well as its attractiveness and appeal. For example, Pape and colleagues (2002) discussed the personal meaning that people attach to assistive technology and how this was connected to the integration of the technology into their daily life.

As well as reconceptualising what ‘disability’ means and how the world should be ordered, the social model of disability has affected how assistive technology is considered by rehabilitation theorists. Rehabilitation professionals have traditionally been concerned with the physical functioning of their clients more than their ability to do the things in life that contribute to general well-being. However, if a ‘social model of rehabilitation’ is used then a different kind of rehabilitation outcome could be measured, for example “[a] person’s satisfaction in being able to get to where they want to go, whether by walking or some other means, rather than just by the functional capability to do so” (Scherer, 2002, p. 3).

One interesting thing to consider about assistive technology is how it relates to other technology: Danny Hillis, a computer scientist, has described technology as “the stuff that doesn’t really work yet” (Mackintosh, 2005). Hillis’s argument was that once a technology has become normalised by a population – it almost always works – it is not even considered technology. It is not perceived as ‘new-fangled’ or unreliable and is accepted as an everyday fact of life. This has interesting implications for my assertion that theorists of assistive technology for disabled people do not talk about the car as assistive technology. An argument could well be made that cars are not considered technology because they are an everyday fact of life for many people with mobility impairments – just as electricity is not discussed as an assistive technology.

If it is true that the failure to identify and ensure the availability of cars as assistive technology comes from the assumption of their ordinariness, then it is important to make explicit the need for cars and their role in people’s lives. This relates specifically to groups that have a particular need for a technology, and who are also at risk of not having the means to acquire that technology as easily as other people.
Part V

The Capability Approach

In their capabilities framework (or approach), Sen and Nussbaum have asserted that the social, economic and environmental disadvantages that people experience need to be addressed by enabling people’s capabilities (meaning the genuine opportunities that they have available to them) and their functionings (the specific things that they want to do or be) (Nussbaum and Sen, 1993).

As previously discussed, the social model of disability differentiates between an individual’s impairment(s) and the disadvantage and loss of opportunities that people with impairments experience in society (disability). Because disability originates in society, it is a matter of social justice that society be reconfigured so that people with impairments have the opportunities to participate in society as they see fit. The capabilities framework has been similarly concerned with whether people have the substantive opportunities, or capabilities, to be and do their chosen ‘functionings’ (Burchardt 2004, Sen and Nussbaum 1993, Sen 1999). People might not want to be or do any ‘functioning’ in particular, but for those functionings that they do value, they should have the capabilities to achieve them. The capability approach places emphasis on people being able to live a life that they value, rather than their being able to achieve ideals or norms in society. The opportunities to be and do the things that people value add up to a set of capabilities, which is one way of measuring their well-being.

While Sen and Nussbaum developed and wrote about the capability approach together, they also wrote about it individually. Amartya Sen is a professor in political economy known for his work on international development, and Martha Nussbaum is a professor in political philosophy and law who has also written a considerable amount on disability and aging.

For Sen, the capability approach sought to ensure that people live a life that they have reason to value. The beauty of Sen’s approach is that it was not prescriptive; while he argued that there are many things that people should have a real opportunity, or capability, to have or be, people have different wants and needs. In Sen’s Development as Freedom (1999), the expansion
of freedoms are not only the ends, but also the principle means by which people, groups and communities can hope to develop. Development constituted the removal of un-freedoms that denied choice and the opportunities of agency, such as poverty, systematic social deprivation and intolerance. Sen saw freedoms as important in themselves, but also that freedoms were connected and one can strengthen and enable other freedoms – social freedoms could enable economic participation (Sen, 1999). While there are a variety of freedoms that people aspire to, for Sen they are all desirable as a means for people to be able to live the lives that they have reason to value (Sen, 1999). To achieve these lives requires substantive opportunities.

Nussbaum’s *Frontiers of Justice* (2006) put the capability approach in the context of Rawls’ discussions of social justice, which she saw as being admirable in almost all respects, but which fell short in relation to understandings of disability or other kinds of human frailty, such as dependence or illness. Nussbaum considered that for Rawls, the ‘disability question’ must be accounted for, not within basic notions of social justice, but as an add-on through legislative practice. Nussbaum also noted that Rawlsian notions of social justice were predicated on the assumption that all people who entered into the social contract had no impairments.

> “While citizens do not have equal capacities, they do have, at least to the essential minimum degree, the moral, intellectual, and physical capacities that enable them to be fully cooperating members of society over a complete life” (Rawls, 1996, p. 183).

The inference was that to be entitled to social justice, people needed to be productive members of society, and those that were not considered to be productive posed a practical question of what they might be entitled to, instead of being included in basic understandings of social justice. The consideration of who is a ‘productive member of society’ and to whom notions of social justice apply is not merely an academic aside to this study, because productivity is most often a central concern when considering who has the right to entitlements that help bring about some level of equity and participation. Certain kinds of government assistance, including transport assistance for people with impairments, are commonly targeted towards those who are the most ‘productive’ members of society, in the sense that they are able to earn money and/or raise children. This is problematic for two
reasons: it excludes people who may be able to become productive if they are given support, because they do not meet the criteria of already being productive; but more importantly it is problematic because it implies that people who are not considered productive do not have the same rights to participation or the ability to live a life that they, as individuals, value.

Nussbaum has written on many aspects of disability in terms of social justice and the capability approach. For her, the capability approach has succeeded in some of the ways that Rawlsian conceptions of social justice failed, as it has accounted for the experiences of people with impairments and fulfills more notions of social justice (Nussbaum, 2006).

Capability and Disability

The capabilities approach, and Sen and Nussbaum, have become highly influential. Mitra (2006) has written about the influence of the capability framework on disability policy makers and how she saw it as closely aligned with the WHO’s International Classification of Functioning. Baylies (2002) described connections between ideas of the social model of disability and the capabilities approach, and Burchardt (2004) has also described the compatibility of the social model of disability and the capability framework, as imagined by Sen and Nussbaum.

The conceptualisation of capabilities generally focuses on the importance of ends rather than means – how a person is able to achieve an activity or state of being is not of utmost importance, but merely that they have the opportunity, or means, to do so. Burchardt (2004) used the example of mobility to elucidate her point; most people value some amount of mobility, but what is important is that they have the opportunity to be mobile, not that they achieve mobility in a specific way which might be the same way as many other people. Whether by walking or moving in a wheelchair, people are able to be mobile in their home and whether by catching a bus or driving in a car, people have the opportunity to be mobile in the community.
Mobility and Capability

Interestingly, the capability approach has also been taken up by many disciplines, including ‘mobilities’ theorists. Uteng has theorised mobility in terms of the capability approach and pointed out that unlike many other kinds of capabilities, mobility is a readily observable ‘realized capability’ (2006, p. 445). Kronlid’s ‘Mobility as Capability’, developed this idea considerably and talked about mobility as “a capability generally… and a part of what people are able to do and to be.” Kronlid also addressed ideas of mobility as capability from a policy perspective: mobility needs to be seen, firstly, as a broad and ideal concept where people’s potential and desire for mobility might be considered, but secondly, mobility needs to be considered in a way that takes specific contexts and limitations into account (2008, p. 22).

A further question that Kronlid posed was around whether mobility had value in itself and/or if its value was in service to other functionings. Several theorists of capabilities, have tried to operationalise the capability approach by proposing lists of basic capabilities, with some including mobility on their lists (Robeyns, 2003). While it is clear that mobility can enable other functionings, Kronlid also referred to Cresswell’s assertion that the need to be mobile is a very human one, and one that is required to experience the world (Cresswell, 2006).

Mobility and Disability

While disability theorists and mobilities theorists have both considered the capability approach, they have largely ignored each other. One exception, Imrie (1996, 2000) argued that the assumption of certain bodies and certain kinds of mobility reproduces structural inequalities in movement and mobility patterns (Imrie, 2000). Imrie’s work is one step in building a bridge between the disability and capability theorists and the mobility and capability theorists which I believe is useful to help to understand and explain the experiences of disabled drivers and to show how they fit into wider conceptions of participation and social justice. Imrie (2000), in particular, has discussed the assumptions that mobility theorists and planners make about the kinds of bodies that exist in mobility discourses and systems, where people with mobility impaired bodies are largely absent from mobilities discourses.
However, I would go further and say that in some cases, people who are seen as having impaired bodies are more than absent from discourses on Mobilities; they are actively excluded. For example, one mobilities theorist, Cresswell, claimed that “to be human…is to have some kind of capacity for mobility”, and that “mobility is a capacity of all but the most severely disabled bodies” (2006, p. 737). While is difficult to know specifically which bodies Cresswell was excluding from mobility when he described ‘the most severely disabled bodies’, he nonetheless made it clear what he meant by mobility:

“I take mobility for the purposes of this paper to refer to the brute fact of movement (getting from A to B) taken together with the social narratives that attach meaning to it and insert it into frameworks of power” (Cresswell 2006, 735, emphasis added).

Assuming Cresswell understood mobility (‘getting from A to B’) as meaning something more than one individual body walking unaided without shoes, then it follows that mobility can be aided by technology (for example the use of shoes to facilitate walking) and forms of transportation, whilst still entailing ‘mobility’. And if he allowed for mobility to be aided by technology, then even for people who might be considered the most ‘immobile’, such as with the example of someone who is largely paralysed, they could still move around in a wheelchair or in a bed with wheels and might experience the sights, sounds, smells or the feelings of movement, and get ‘from A to B’. Furthermore, if the same person could communicate which ‘B’ they wish to get to, then they could have mobility that is only limited by their social and physical environment, much as everyone else’s. Yet Cresswell could not conceptualise the mobility of a person with a severely disabled body, and without this capability he denied them their humanity, even while admitting the importance of movement’s social narratives. Creswell and other mobility theorists have considered little of how disability interacts with mobility, how cars might work for people with mobility impairments as well as how, and why, they might create different meanings.

**Conclusions**

The shape of any literature review is constrained by the available resources. This chapter was shaped by the extremely small amount of academic literature on ‘disabled driving’. I have
therefore widened its scope beyond disabled drivers and also look at what has been written about disability and mobility, disability in general, and what has been written about driving.

It might be interesting to consider why the various bodies of literature examined in this review look the way they do. Although there was considerable research on driving for older people, with a largely implicit assumption that many of them will have mobility impairments, the literature did not generally discuss issues of disability at all because it came almost universally from the field of gerontology.

The transport situation of disabled people has been considered by some transport researchers, though the focus has almost entirely been on public transport and how it can be made more accessible for disabled people. This is assumedly a reflection of the research interests of transport theoreticians and environmental policy priorities of many governments, that car use should be universally reduced.8

Some government departments, most notably in New Zealand and the United Kingdom have commissioned research on the travel needs and experiences of disabled people, some of which applies directly to disabled drivers. Statistics New Zealand painted an interesting statistical portrait of disabled drivers in New Zealand, but nothing is known about the experiences of driving with a mobility impairment for those people. A UK Department for Transport study into the travel experiences and aspirations of disabled people revealed a small amount of extremely interesting data on the experiences of disabled drivers, which also provides a starting point for considering what kind of data should collected for this study and how it should be collected.

8 One of the markers of this thesis suggested that a reason that disability researchers may have focused on public transport and disability is that they may be more likely to either come from or live (and travel) in urban centres, where public transport is more common.
Methodology Chapter

The focus of this thesis is on how disabled drivers experience the relationship between their driving and their ability to meaningfully participate in society. This chapter will describe the methodological orientation of this thesis and outline the methods of data collection and analysis. The chapter first puts the research into the context of contemporary discussions about ways of doing disability research, and explains the theory and practice of constructivist grounded theory as it pertains to this research project.

Part I

Disability Research

Alongside other methodology concerns in this thesis, I had to consider what it meant to be doing research relating to disability and impairment. People with impairments have a history of having research done on them by people without impairments, who have not shared many of the experiences that they are investigating, have framed disability as a ‘personal tragedy’, and who have failed to consider how society creates disabling barriers for people with impairments (Stone and Priestley, 1996). It has also been suggested, by Stone and Priestly (1996) among others, that some of the (non-disabled) researchers did not have any investment in the processes and effects of research, beyond publication and career opportunities. This critique arose from a considerable amount of frustration from those in disability communities who had been researched on, as well as from researchers (with and without impairments) who viewed these practices as exploitative (Oliver, 1992, 2009).
Research with, by and for disabled people was demanded, and the phrase ‘nothing about us, without us’ became a call in the disability community in the 1990s. The phrase was used in reference to self-determination ideals, to mean that disability research should not be done on people with impairments, but with and by people with impairments, for people with impairments, and this kind of research was also expected to incorporate the goals and expertise of people with impairments into the research process (Charlton, 1998). This is not to say that disability research done by non-disabled researchers who share a commitment to improving the social conditions of people with impairments is not considered valuable or desirable, but that it is expected that the research be done in partnership with disabled people (Barnes, 1992, 1996; Oliver and Barnes, 1997).

Goodley and Moore (2000) have discussed the tension between the agendas of the disability studies of academia and the disability rights movement, where there are issues of making research accessible and useful to people with impairments, as well as meeting the demands of academia. Shakespeare (1996) has also noted the complexities of balancing academic independence and relationships with the disability rights movement: he explains his positions as having a commitment to the movement but not being accountable to it.

Disability studies and disability research in the UK, as growing bodies of work in the last few decades, have been hugely influenced by the Social Model of Disability. Although the SMD was first written about in academic terms by Oliver (1990), the principles were initially developed by disability rights organisations, such as the UPIAS (Union of the Physically Impaired Against Segregation), from the mid-1970s. Oliver (1990) originally argued that disability studies, by its nature, must have an underpinning of social justice and, at its best, is informed by, and informs, the disability rights movement, which has at its core a commitment to social justice and ‘making things better’ for disabled people. Although nearly 20 years after this optimistic statement Oliver (2009) expressed considerable skepticism about the benefit of disability studies and research for many disabled people. Oliver partly attributed this perceived failure to structural elements of the funding and institutional requirements of research, as well as to disability academics that he believed focussed on communicating their ideas to other academics rather than to the majority of disabled people.
Participatory and Emancipatory Research

After much criticism of disability research, particularly research carried out in the late twentieth century, disabled activists and theorists began to question how disability research could be done in a way that provided better outcomes for disabled people, and did not leave them feeling that research was merely a parasitic enterprise (see Stone and Priestley, 1996). In light of the social model of disability, and because of the anger of many disabled people who felt exploited, appropriate ways of conducting research on disability have been discussed extensively in the discipline of disability studies as well as in other disciplines (Kitchin, 2001). Many of the discussions about research methods have centred on how to conduct research that does not replicate exploitative research practices, in which the research does not benefit the disabled participants, but merely advances the careers of the researchers (Oliver, 1992, 1997; Shakespeare, 1996; Stone and Priestley, 1996; Zarb, 1992).

Participatory and emancipatory research are two paradigms that have been most commonly associated with the changing nature of disability research. Participatory research methods require the researcher to invite participants with impairments into the research, so as to create a shared knowledge about disability (Goodley, 2010). Walmsley (2001) summarised the differences between participatory and emancipatory research and described the characteristics of participatory research as being: interested in getting inside the experiences of research subjects; likely to come from a perspective of the social model of disability; research done in partnership with disabled people (particularly at the data collection stage); where the researcher is seen as an expert or as sharing expertise with research subjects; research about issues that are of relevance to the lives of disabled people, and; accountable to funders. Participatory research is an attempt at a greater amount of power-sharing between the researcher and the research participants.

However, while participatory research has been a considerable improvement on previous practice, many disabled people’s groups and academics do not think it goes far enough towards giving disabled people ownership of their own experiences in research settings (Barnes and Mercer, 1997). One of the other ways that disability researchers have responded to criticisms of exploitative research is through an approach called emancipatory research.
Emancipatory research, by one definition, needs to have a social analysis of disablement, include political action that benefits disabled people’s movements, and be academically rigorous (Stone and Priestley, 1996). Emancipatory research has also been seen as a process of investigation that does not just take (data) from the participants and force a research agenda upon them, but instead allows participants to shape the research. Oliver (1992) described emancipatory research as needing to be focused on reciprocity, gain and empowerment. However, Barnes and Mercer (1997) have pointed out that reciprocity is difficult to put into practice and Oliver (1997) himself admitted that empowerment cannot be provided by people in power such as researchers; but must be created by people who have less power, namely, people with impairments. In later years, Oliver’s (2009) view of disability research became even more Stone and Priestley (1996) have also noted that the emancipatory paradigm is daunting in the face of constraints on, among other things, the material conditions of academic research, and they noted that few if any researchers claim to have participated in purely emancipatory research.

It was not my intention in this project to make any claims that it is an attempt at doing emancipatory research. I consider my project to be participatory research, emancipatory research being an aspirational goal to work towards. I was committed to giving the participants an opportunity to share their experiences and provide the basis of the research. However, as someone who has experienced being a disabled driver, and who knows that there is a gap in knowledge on this topic, I hoped to gather data in specific areas to begin to address that gap. My intention in producing this research was to theorise the experiences of disabled drivers and through doing this to identify enablers and barriers to the mobility and social participation of people with mobility impairments. By producing this research I hope that I, as well as others, may to use it to begin to dismantle these barriers.

Because I wanted to represent the self-described experiences of disabled people, constructivist grounded theory was an appropriate method of theory generation for this research project, as it is a methodology which focuses on keeping the data (the experiences of people with mobility impairments) at the centre of the analysis. Situating the research within the context of other theorists is important, but more important is maintaining the integrity of the lived experiences of participants.
In terms of who shaped the research agenda in this study, I constructed the interview questions to be as open-ended as possible, so participants could shape the research and that a variety of experiences could be captured. However, I also wanted to make sure that some specific aspects of experience were considered by the participants. An example of targeting specific experiences was where I asked participants to discuss their economic experience of driving.

One of the key tenets of emancipatory disability research is that the participants who have impairments should be regarded as the expert-knowers alongside the expert-researchers (Barnes and Mercer, 1997). This is a complex issue as researchers are almost always the people who perform the analysis and write up of research and the quality of their work is judged by (and therefore, to a certain extent, accountable to) their academic peers, and not just by people involved in the study. This issue is further complicated by who is leading the research. In this piece of research I am both a researcher and a driver with a mobility impairment.

I did not return to my participants with transcripts or seek their feedback with the analysis of my research, and although I asked the participants to contact me after the interview with any more thoughts they had about the interview or the research, only one did. I committed to presenting the findings of my research to participants and disability organisations at its conclusion, so that participants and other members of the disability community could see what they had contributed to. I also told participants that I would attempt to disseminate the findings as widely as possible so as to make their concerns and stories heard.

While I believe that research should aim to make the world a better place, I agree with Shakespeare (1996) that research alone, without collective will and work, will not create significant change. One intended outcome of this thesis is to gather the stories of disabled drivers together so as to view their experiences collectively and to be able to understand them in context. The other intended outcome of this research is to make recommendations to policy makers based on the results of the study and to broaden academic debates about the mobility of people with mobility impairments and car use, so as to benefit people with mobility impairments. However, the power to change the lives of people with mobility impairments for the better is not realistically within my control.
Part II

Qualitative Research

Because of the dearth of research on disabled drivers and social participation, qualitative research was judged to be the most appropriate way of investigating what the main areas of interest would be. Additionally, shortly after I began this research project, Statistics New Zealand released a report of the transport and travel situations of disabled people in New Zealand. Quantitative analysis of some of the results of this research may be useful in subsequent studies, but in the meantime these studies complement each other.

In March 2009, before I began the data collection stage of this research project, I participated in a transport forum run by the Christchurch branch of the Disabled Persons Assembly (DPA) New Zealand. The focus of the forum was on public transport in Christchurch and members of DPA discussed their experiences of public transport. A representative from the Christchurch City Council also presented their public transport strategy and received feedback on it from the members of DPA. Additionally there were discussions about the built environment and its effect on mobility, and of people’s experiences of the use and misuse of mobility car parks. I had a number of conversations with members of DPA about their experiences of transport and this informed my ideas about the focus of my research.

The paucity of research in this area meant that in-depth interviews provided an opportunity for an exploration of the various issues associated with disabled driving and social participation. Although the research was exploratory, I was interested in some general areas of inquiry in the interviews, and broad questions were settled upon. An example of a question posed to participants related to the financial implications of driving and whether car use was perceived as a financial benefit or a burden – or if economics did not enter into their decisions about car use. I asked the participants about how their finances affected their car use and if prompting seemed appropriate, I would reframe the question, for example, “What are some of the costs of driving? Are there any financial benefits to driving? Do you have to make choices about your car use?” Depending on their responses I could then ask further...
questions, or ask for specifics: “How does your job affect your car use?” One benefit of conducting semi-structured in-depth interviews is that the interviewer and participant have opportunities to ask for more details about an answer, or a question, and can move sideways on to other areas of conversation easily.

**Epistemology**

**Constructivism**

The epistemological perspective of this thesis is constructivist as it focuses on the experiences of disabled drivers: how they experience disability, driving and their mobility, and what meaning they have constructed about them. The epistemological stance of constructivism simply means that as academics, we do not purport to present the world as a singular reality but to analyse and present the multiple worldviews and the many ways that people interact with and interpret the world, and what these understandings and interactions mean (Patton, 2002).

**Symbolic Interactionism**

The theoretical perspective that underpins constructivist grounded theory is symbolic interactionism. Patton described symbolic interactionism as the way that “people create shared meanings through their interactions, and those meanings become their reality” (2002, 112). Charmaz pointed out that people can and do actively interpret their experiences individually, and collectively, that “meanings arise out of actions, and in turn influence actions” (2006, 189). In the context of this study, participants’ experiences affected how they thought about driving, and the meaning that they and other people attached to driving, shaped their actions.

“The viewer creates the data and ensuing analysis through interaction with the viewed... the ‘discovered’ reality arises from the interactive process and its temporal, cultural and structural contexts. Researchers and subjects frame that interaction and confer meaning on it” (Charmaz, 2000, pp. 523–4).
In this thesis, meaning is constructed by both the participants and myself. As a researcher investigating disabled driving, I have already constructed disabled driving as a phenomenon to be studied. As someone with a mobility impairment, I have interpreted my experiences as 'being disabled' (through my interactions with other people), and that furthermore there are things that make 'being disabled' harder or easier for me, such as being a driver. Through my experiences of being a driver with a mobility impairment I have come to think about driving in certain ways: that because I have limited physical mobility, having a car gives me more mobility; that because I am disabled, my driving experience is slightly different than for many other drivers, and that I will be more concerned, for example, about access issues such as the location and physical layout of car parks.

The people I talked to in this study had also already given meaning to their experiences of mobility and car use (whether in an implicit or explicit sense), including by making considered decisions about their mobility and car use in their lives. During the interviews the participants were encouraged to interpret their experiences of driving, and no doubt they continued to construct meaning about being ‘disabled drivers’ after being interviewed on this topic. Some of the people I interviewed noted that they felt that the research was important, because they were very aware of their reliance on their cars, and how much their cars meant to them.

Part III

Methodology

The methodology of this research is based on constructivist grounded theory as outlined by Charmaz. The reason for choosing constructivist grounded theory as an approach to this research is that, given the nature of the study and the situation of the researcher, it allowed for the notion that “…people, including researchers, [to] construct the realities in which they participate” (Charmaz, 2006, 187).

Charmaz’s (2006) constructivist grounded theory is something of a redevelopment of classical grounded theory, and her articulation of the methodology is one that she sees as
addressing changing ideas about positivist methodologies in the 21st century. Although Glaser and Strauss originally developed the grounded theory methodology together in the mid-1960s, their views on grounded theory diverged and they parted ways. Glaser and Strauss took their versions of grounded theory down different paths, with Strauss beginning to publish on grounded theory with Corbin. The history and development of grounded theory is one filled with controversy (Charmaz, 2000), but in every permutation the essence of grounded theory is that repeated forays into data analysis mean that any theory must rise to a high conceptual level while staying grounded in the data.

Constructivist Grounded Theory – Rationale

Disability Research

Because of the dearth of research on the experiences of disabled drivers, qualitative research is appropriate because it can be used in an exploratory manner. Grounded theory in particular places the data, in this case the experiences of disabled drivers, in the centre of analysis – as any theory generation has to be grounded in the data. Given the history and criticisms of research done on, rather than with disabled people, where disabled people’s voices were not placed at the centre of analysis, using a grounded theory methodology impels the researcher to maintain the integrity of the data – the experiences of disabled drivers.

Having a researcher with the same type of impairment as the participants in the study provides an opportunity for the researcher to develop theoretical sensitivity in the analysis of data through prior knowledge of the topic (Charmaz, 2006). Constructivist grounded theory is in this way is a particularly appropriate methodology with which to conduct a study where the co-construction of meaning between the researcher and the participants and the data are recognised as valid and enriching to the theory creation.

Personal Statement

It is important to acknowledge that I did not begin this research process from a purely theoretical perspective; I have had a mobility impairment for 29 years (from a very young
age) and have been a driver for 15 years. I have relied heavily on my car for many things: work, study, socialising, a degree of independence, and generally going about my life. This has naturally influenced the way I went about conducting this research. For me, the question was never: does being able to drive my own car affect my mobility and participation in society, as someone with a mobility impairment? I already knew that it affected it, but what specifically did it affect, why was it important, and what were the things that made driving difficult or easier? What were the commonalities of being a disabled driver? Did other disabled drivers have similar experiences to my own, or were they slightly, or completely, different? These questions naturally influenced the starting points of my research, from the kind of methodology I would use, to the areas of enquiry I would begin my research with.

Although I almost always use my car when leaving the house there have been (thankfully relatively short) times when I have been unable to drive due to surgery or injury, and these times, where my mobility was considerably compromised, were frustrating and isolating for me. Consequently, I was interested in exploring both disabled drivers experiences of driving and disabled drivers experiences of not driving.

These experiences affected the starting points of my research and undoubtedly they also affected my data collection, analysis and development of theory. However, Charmaz (2006) has stated that this as natural: that the theoretical sensitivities that researchers bring to their research help to move analysis beyond the raw data that researchers are presented with. Almost all research is conducted because researchers have a particular interest or knowledge of a topic; however, having acknowledged my position within the area of this research, I believe that my position adds strength to the analysis rather than weakening it.

Characteristics of Constructivist Grounded Theory

Use of Literature

The role of literature reviews within grounded theory is highly contested, with many theorists of grounded theory, including Glaser, insisting that prior knowledge of an area of inquiry overly influences the researcher when formulating ideas, and that therefore the development
of a theory would be less ‘grounded’ in the data and instead forced into fitting with preconceived ideas. However, Charmaz (2006) has noted that it is often impossible to be able to begin a body of research without familiarising yourself with the field of study enough to be able to apply for funding, and in the case of this project, acceptance into an academic department and ethics applications both require familiarity with major texts. Charmaz (2006) has aligned herself in favour of prior reading, but only as a starting points for research, and not for preempting the coding or analysis of data. Instead, Charmaz considered ‘theoretical agnosticism’ an appropriate stance to take, meaning that researchers should be able to understand previous research to the extent that they can make a critical assessment of it. In the instance of this project, while I had experience of being a disabled driver myself, there had not already been research on disabled drivers, and this lack of literature contributed to the framing of the project. Despite the absence of research on disabled drivers, there had been research on some topics similar to this project, such as: the meanings of driving for non-disabled people; public transport issues for disabled people, and the role of car use in older people’s well-being. Being aware of this gap in knowledge about the experiences of disabled drivers was helpful in locating the starting point of the research. The absence of research also contributed to my analysis when generating theory, as it encouraged me to question: why this gap existed, why disabled people’s experience of car use might be different from other people’s car use, and why experiences of public transport might be different from car use?

Once data collection has been completed and the analysis is well under way, Charmaz (2006) has considered it appropriate to return to the literature to shed light on findings and to deepen analysis. This can be done by placing your own analysis alongside that of previous scholars, or using others’ research to articulate parts of your analysis.

**Constant Comparative Method**

The constant comparative method of grounded theory means: “(a) comparing different people… (b) comparing data from the same individuals with themselves at different points in time, (c) comparing incident with incident, (d) comparing data with category, (e) comparing a category with another categories” (Charmaz, 2000, p. 515). These comparisons, which occur
throughout the data collection, analysis and writing, produce insights into the field of study, in this instance individual’s experiences, and provide pathways for conceptualising and developing theory.

Coding

An important first step in analysis of data is the coding process. This means simply that the data are examined in detail – and broken down to component parts and those components are used to build theory. The theory needs to be conceptually coherent, but it also needs to encompass all of the components of the data, so that it is grounded in the data.

“Coding starts the chain of theory development. Codes that account for our data take form together as nascent theory that, in turn, explains these data and directs further data collection” (Charmaz, 2000, 515)

Although coding begins the analysis and theorising process, it is not only done at the beginning of analysis. Coding is built upon, through more than one iteration of coding, as more data collection is done and then during the process of theorising.

Memo Writing & Theorising

Memo writing is another important tool when employing the constant comparison during the grounded theory process. Writing memos immediately after and in between bouts of data collection provides an opportunity for reflection on the similarities, differences, unexpectedness and complexities of the data, as well as on the process itself and what new avenues for investigation are produced. It is also particularly useful to write memos whilst theorising, so as to make explicit any burgeoning theories – these memos can then be used by returning to the data to consider their appropriateness by “linking analytic interpretation with empirical reality” (Charmaz, 2000, 517). This process of memo writing is also intended to move writing beyond the descriptive and into the abstract and theoretical (Charmaz, 2006).
Theoretical Sampling

Theoretical sampling means gathering data from targeted sources about an area of theoretical interest. Because of the use of semi-structured interviews, even during an interview I was able to probe into ideas more thoroughly as they were revealed, or refer back to similar ideas in previous interviews. Using the data gathered in earlier interviews I could use theoretical sampling to probe into the experiences of participants living in geographically diverse locations and in different family situations.

Theoretical Sensitivity

Theoretical sensitivity, in grounded theory, simply means that a researcher is capable of identifying the important elements of a body of data and is able to make connections and build upon the data to create a substantive theory. One way to develop theoretical sensitivity is through immersion in the data.

“Line-by-line coding sharpens our use of sensitizing concepts – that is, those background ideas that inform the basic research problem. Sensitizing concepts offer ways of seeing, organizing and understanding experience” (Charmaz, 2000, 515).

Theoretical sensitivity can also be aided by some prior knowledge of the subject matter, however, as previously described, the researcher must be careful to avoid coding the data automatically merely based on this prior knowledge – codes must earn their way into the analysis.
Part IV

Data Collection

Design, Setting & Sample

This project is a qualitative study done in New Zealand on the experiences of work-aged disabled drivers. The data collection consisted of a series of individual, in-depth interviews with work-aged, long-term disabled drivers. The interviews were held in Wellington, Auckland and in the Wairarapa region over the period September 2009 to February 2010.

Ethical approval

Ethical approval was granted by New Zealand’s multi-region health ethics committee in February 2009. Approval was conditional on the basis that participants were under no obligation to be part of the study once approached, could drop out of the study at any time without giving a reason, and were given contact details for the Health and Disability Commission in case they were unhappy with the research process. Furthermore participants’ interviews would be kept confidential and any reference to information gathered from the interviews, or about participants, would be kept anonymous. To this end, only myself and the transcribers of the interviews listened to the interviews, and my supervisors and I read the interview transcripts. Participants have been given pseudonyms for the purpose of this thesis\(^9\) and some potential identifiers have been removed (for example, references to a region have been kept intact, but references to a suburb, or small town, have been made anonymous).

Recruitment

Recruitment of participants was done with the assistance of CCS Disability Action, a New Zealand disability organisation that “work[s] with, and support[s], all disabled people to have the same right to relationships, learning, recreation, work and community as everyone else.”

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\(^9\) Pseudonyms were selected from the character names of companions in the television series Doctor Who.
CCSDA was the most appropriate organisation to work with because it is the nationwide body that administers the Mobility Parking Scheme. The scheme allows people with mobility impairments to park in disabled car parks when displaying a current Mobility Parking permit. This scheme has nationwide coverage and relates to car parks designated for disabled drivers in both commercial car parks and public car parks. The ubiquity of the orange Mobility Parking permits and the ‘disabled car park’ signage (a stick figure in a wheelchair, in white on blue) means that it is likely that most people who would be eligible for a Mobility Parking permit would also be aware of disabled car parks. However, an awareness of disabled car parks is not the same thing as an awareness of how to obtain a Mobility Parking permit, or having the ability or willingness to pay the $50 for a long-term (five year) permit.

After I had discussions with a number of people from CCSDA (who themselves had impairments) about the nature and objectives of my research, the National Office of CCSDA agreed to help recruit participations and gave me permission to engage with individual regional offices. Each regional office sent out information about the study with every Mobility Parking Permit renewal reminder in one month, and the Wairarapa regional office also mentioned it in their newsletter.

As well as recruiting through CCSDA, I used a snowballing recruitment method, where participants tell other potential participants about the study. This method was particularly useful in Auckland where only half of the participants were found through information sent out by CCSDA’s Auckland regional office. The remaining participants in Auckland contacted me after hearing about the study through one participant, Rose.

In 2009, prior to the recruitment stage of my thesis, I was interviewed by Attitude TV, a New Zealand television programme on disability. The episode I was featured in aired just before recruitment and a couple of the participants in my study mentioned having seen the segment on my research. This may have also encouraged participants to engage in the research.
Eligibility of Participants

People of working age (18-65), who held a current long-term (five year) Mobility Parking Permit issued by CCS Disability Action, were eligible to participate in the study. The criteria that CCS Disability Action have for issuing Mobility Parking permits must be certified by a general practitioner:

“[Mobility Parking Permit holders] must: be unable to walk and be reliant on a wheelchair for mobility, or; rely on mobility devices (e.g. crutches, walking sticks, walking frames), or; be unable to walk more than 200 metres unassisted because of the nature/severity of [their] condition.”

The reasons for making the eligibility criteria for this study match the Mobility Parking permit criteria was due to convenience sampling – that there was already an agreed upon definition of a ‘disabled driver’ in New Zealand. However, the eligibility criteria for this study were further narrowed to include only work-aged drivers with a long-term (five year) permit. Work-aged participants were sought for this study because, although there are a considerable number of studies done in the U.S. on driving, health and social participation in the elderly population (Cutler, 1972; Fonda et al., 2001; Marottoli et al., 1997, 2000; Metz, 2000; Windsor et al., 2007 etc), no studies on work-aged drivers with mobility impairments currently exist. The gap in knowledge that this creates is significant because of the social roles that work-aged people are often expected to fill, such as: working, parenting, finding a partner, as well as more nebulous concepts of ‘being an independent adult’. Furthermore, ‘work-aged’ implies those who are expected to support themselves financially and this has implications for the economics of driving. The ability to work or generate income in any way is often affected by a person’s transportation needs. As well as this, car driving has many associated costs, which can be particularly difficult to fund if someone is on a low income, as disabled people are more likely to be (Statistics New Zealand, 2001). Some older drivers may be on a low income but have previously been on a higher income and had the opportunity to set aside assets or money for expenses such as cars, as they have anticipated some of the extra costs that a lack of mobility or function in later life can create.
Additionally, only drivers who held a long-term Mobility Parking permit were sought as participants in the study on the basis that it implied a long-term mobility impairment and not a temporary change in mobility. This project was interested in the transport issues of those with a long-term mobility impairment in respect to how social participation was moderated by driving a car.

The characteristics of participants are shown in Table 1 (below). The sample was broadly representative of adult disabled drivers in New Zealand in terms of gender, age, and ethnicity.

Table 1 Characteristics of disabled drivers in the study sample (n=27) and the 2006 New Zealand Disability Survey

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Study participants % (n)</th>
<th>NZDS 2006 %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>44% (12)</td>
<td>54%</td>
</tr>
<tr>
<td>Female</td>
<td>56% (15)</td>
<td>46%</td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24 years</td>
<td>4% (1)</td>
<td>6%</td>
</tr>
<tr>
<td>25-44 years</td>
<td>30% (8)</td>
<td>31%</td>
</tr>
<tr>
<td>45-64 years</td>
<td>67% (18)</td>
<td>63%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pākeha/European</td>
<td>85% (23)</td>
<td>71%</td>
</tr>
<tr>
<td>Māori</td>
<td>11% (3)</td>
<td>11%</td>
</tr>
<tr>
<td>Asian</td>
<td>4% (1)</td>
<td>Not available</td>
</tr>
<tr>
<td><strong>Region of residence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wellington</td>
<td>48% (13)</td>
<td>Not available</td>
</tr>
<tr>
<td>Wairarapa</td>
<td>30% (8)</td>
<td>Not available</td>
</tr>
<tr>
<td>Auckland</td>
<td>22% (6)</td>
<td>Not available</td>
</tr>
</tbody>
</table>

Notes:

1. The NZDS statistics presented here relate to all disabled adults, not exclusively those with mobility impairments; data restricted to people with mobility impairments were not freely available.
2. The denominator for the NZDS age group statistics is people aged 15-64, approximating the age restriction for the present study (18 to 65);
3. The denominator for the NZDS gender and ethnicity statistics is the total population of disabled adults who drive a motor vehicle. The gender and ethnic profile for the population restricted to ages 15-64 were not freely available;
Ethnicity data for both samples were prioritised in the following order: Māori; Pacific; Asian/Other; European.

Sources: Statistics New Zealand (2009), Statistics New Zealand (2006)

After being interviewed, all participants received a $20 petrol voucher as a token of appreciation for participating in the study. I also gave the participants my contact details again and asked them to contact me if they had any thoughts or questions that they would like to discuss. I explained that I would present the findings of the research once I had completed it, at a variety of venues that they would be invited to.

Locations

I decided on the interview locations because, as well as looking at the transport issues for disabled drivers in large cities, they enabled a comparative study of transport issues for disabled drivers in more provincial settings. At the time of data collection the Auckland region had an estimated population of approximately 1.46 million, the Wellington city, Lower and Upper Hutt territorial authorities had an estimated population of approximately 341,500, and the Wairarapa region had an estimated population of just 40,280 across three territorial authorities (Statistics New Zealand, 2012b). These differences in population density, as well as geographical differences in the size and makeup of the regions, meant that the transportation needs and opportunities of people living in different regions were going to potentially be very different.

Wellington was partly chosen as a location for convenience sampling reasons, as I lived in Wellington during this research project. However, it was also chosen as it is a mid-sized New Zealand city (as compared to Auckland or other smaller cities such as New Plymouth) and it is commonly considered to have better public and other transport infrastructure than the largest city in New Zealand, Auckland. The Wairarapa region, whilst also being reasonably close to Wellington, is a rural and semi-rural area which I have taken to include the districts of Masterton, Carterton and South Wairarapa. The Wairarapa area is generally sparsely populated (Masterton, the largest town had an estimated population of 23,400 in 2010
(Statistics New Zealand, 2012b)) and the area has quite limited public transport between the towns.

**Interviews – Methods**

As the location of the interview had to be physically accessible for me as well as for the participants, and because I wanted to be of as little inconvenience to them as possible, I offered to interview participants at a variety of venues. The proposed venues included: their home; their workplace; my place of study; in an office of CCS Disability Action (in the Wairarapa and in northern parts of Wellington); or in another public place of their choosing. One participant even volunteered her home as a location for an interview between myself and another participant that she knew, because I would have been unable to access the second participant’s home.

**Interviews**

I started the interviewing process by doing a practice interview with a colleague who had a mobility impairment, but was not a driver. Although I had to modify or skip some questions, the interview, like all the interviews I would do, highlighted a few keys issues. One of these issues was the importance of enquiring into experiences of mobility in the past and thoughts and expectations of mobility in the future.

The interviews, including the practice interview, were recorded using a digital voice recorder. Once the interviews had been completed the recordings of the interviews were transcribed by a professional transcribing service. The decision to use professional transcribers was made for reasons of time, and to minimise the amount of typing I would have to do and the discomfort it would cause, as each of the 27 transcripts was between 5000 and 11,500 words long. The interview schedules received feedback and approval from my supervisors. Transcripts of the interviews were also given to my supervisors and discussed at regular meetings.
Having a Disabled Researcher/Interviewer

There has been much discussion in the field of disability studies about disabled people’s involvement in disability research, as active participants and researchers. However, the reality of doing research as someone with a visible impairment has elicited less discussion. Although it is not possible to know how this particular piece of research was affected by having a physically disabled person as the researcher/interviewer, because the sole interviewer/researcher was disabled, it is interesting to consider the ways in which the participants in this study verbalised their view of my disability in reference to their own.

My status as a disabled researcher was specifically mentioned in the information pack that I sent out with the consent form for participation in the study before I met any of the participants. I also made initial phone contact with all the people I interviewed to arrange a time and place for the interview to take place. This involved a negotiation of an accessible (no stairs) location, for my own benefit as well as, at times, their own. These conversations about access made it clear to the participants from the onset that I had an impairment that affected my mobility, just as their inclusion in the study made it clear that they had a mobility impairment that made them eligible for a mobility parking permit.

Several participants made unprompted comments, during, before and after the interviews, about my use of crutches or my physical appearance in relation to my impairment. One of the reasons that it is useful to consider how participants regarded their own and my disability is because in our society ‘disability’ is associated with stigma and therefore what people may or may not say about their experience of feeling stigmatised or that they belonged to a stigmatized group could depend on who they are saying it to. Although the participants in my study had all already self-identified to a certain extent as ‘disabled drivers’, both by applying for a mobility parking permit, and by responding to a request to participate in a study that involved talking to ‘disabled drivers’, not all the participants necessarily in general saw themselves as disabled or identified with other disabled people.

At times, the participants’ self-view of themselves as having a disability showed itself through their comparison of themselves to me, and my status as a person with a disability. For Amy, my disability would be “obvious to people who looked at [me]” and she stated that she
imagined that this would affect how people behaved towards me. Amy compared her own experience of having a reasonably invisible disability, which many people would not necessarily notice, with my disability that was partially sign-posted by my use of crutches.

Amy: “I try to live my life as if I am not disabled and because, I mean you look disabled, but I don’t look disabled unless you see underneath the clothes, so a lot of people don’t notice that I am disabled.”

Surprisingly (for me), when another participant described herself having an invisible disability, she also hypothesised that for people with a visible disability, such as my own, although people might be more likely to see me as different, they might also be more likely to think I had a minor injury rather than a mobility impairment.

Martha: “It certainly gives you a, yeah, empathy for people who have outward disabilities, see you’re fortunate in some ways, ‘cause you have got crutches. People would assume that you have got a bung foot, which may not be anything like that, but people just assume ‘cause it’s the easy option: ‘Oh, she must have sprained her ankle or something’, you know?”

For me this was an interesting comment to make, because it seemed to imply that ‘other people’ might view me as someone with an ankle injury not a permanent impairment. But the comment was also interesting because it made it clear that Martha had concluded that the severity of our various impairments and our experiences of being disability were very different. Martha narrated her own experience of having a largely invisible disability as difficult for her because, as people could not always recognise her impairments, they questioned why she was entitled to assistance with things such as mobility car parks.

Rose made comments during her interview that demonstrated that she saw me as having very similar experiences to her own, that we belonged to a similar group, and that we could relate to each other’s lives. Rose first suggested (correctly) that we had similar past experiences of the difficulties of geography and accessibility in Wellington.
Rose: “I got really frustrated because all my friends live up hills, and you must know that too.”

Rose’s identification with me also meant that she could assume that I had similar levels of knowledge to her own in regards to institutions.

Rose: “As you probably know it’s very hard to get funding out of Ministry of Health for things...I am preaching to someone who has known it their whole life.”

Before beginning his interview Mark mentioned feeling like his participation in the research was contestable because he was not ‘really’ disabled, or at least not compared to me – he mentioned his lack of easily recognisable mobility aids (in contrast to my crutches) and minimised his impairment as only affecting one part of his leg. By saying that he was not very disabled, and that by comparison I was, Mark was establishing a hierarchy of disability, which, because of the place of ‘the disabled’ as a stigmatised group in society could mean that he was assuring himself that he was in a less ‘unfortunate’ situation. However, in the context of the study that he was participating in, where I was looking for disabled drivers as the ‘experts’, his status as ‘less disabled’ than me might create a different hierarchy, where I was more of an ‘expert’ than he was, not only because of my status as researcher, but because of my status as ‘properly disabled’.

In contrast, Melanie, in a casual conversation immediately after the interview had ended, suggested that my perspective on some aspects of disability might change after I had been disabled for a number of years: in other words that I was reasonably new to the experience of disability (or at least was significantly newer to disability than her). She was surprised when I disclosed that I had had arthritis for 27 years, as I was in turn surprised that someone would conclude from looking at me that I had not been disabled for a considerable period of time. Unlike Mark, Melanie seemed to see herself as more of an expert than me, that she was both ‘more disabled’ than me and, more accustomed to having to think about issues of disability.
Deciding on the appropriate number of interviews in a qualitative study – or rather deciding when a sufficient amount of data has been collected and it is appropriate to stop interviewing – is a contentious issue in the field of qualitative inquiry. Mason (2010), when writing about qualitative PhD research, suggested that the sample size of qualitative studies should be sufficient to uncover most or all of the relevant perceptions, but that if the sample size is too big data can become repetitive and even superfluous. Discussions about when to conclude qualitative data collection invariably centre on the concept of ‘saturation’. Mason surveyed other qualitative researchers’ opinions on appropriate sample sizes and found that three grounded theorists considered 20-30 (Creswell, 1998), 30-50 (Morse, 1994) and ‘at least 25’ participants (Charmaz, 2006) appropriate.

Grounded theorists have asserted that when categories are saturated, it is no longer useful to collect more data (Mason, 2010). Charmaz (2006) stated that “categories are ‘saturated’ when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories” (2006, 113). However, how to evaluate when the data is saturated is a matter of considerable debate and skepticism. Guest and colleagues (2006) have argued that while theoretical saturation is consistently considered the gold standard for determining sample sizes, equally consistent is the absence of description of how saturation is reached. Charmaz (2006, p 114), whose methodological framework was used in this study, has stated that if the study is not making grand claims about human nature or contradicting established theory, then 25 participants may be sufficient for saturation.

When deciding when I should stop interviewing, I firstly noted that I had interviewed 27 people across the intended age range, across different geographical locations, from different social economic groups, in different living situations, with and without children or dependent family members, and of (some) different ethnicities. The basis upon which I decided that I had reached theoretical saturation, to the degree that further interviews would be superfluous, was based not upon people relating similar or different experiences, of the same phenomena to me, but that they were relating the same phenomena. Participants had different experiences, but they had difference experiences of the same things. One example
of this was how participants spoke of other people’s perceptions of them when they were driving in their cars; these (assumed) perceptions evoked different responses for the participants, but were a matter of interest and discussion for many of them.

Part V

Analysis

Use of Literature

As described previously, Charmaz believes that it is most appropriate to comprehensively review literature at a later stage of theory development, once a researcher has already articulated their own ideas and analysis. At this point literature can be used to enrich the researchers’ own analysis. In the case of my research, the only possible choice was to conduct the majority of the literature review towards the end of the research because of the lack of literature specifically related to the topic. Once a large part of the analysis had been done I was able to research various aspects of the concepts and phenomena that had emerged from the data.

Although I had done a scan of literature on ‘disabled drivers’ at the beginning of the research process, being unable to find any significant body of literature had been simultaneously encouraging, intimidating and liberating. It was encouraging that I was considering an original question and that my research would genuinely generate new knowledge of an important subject. However it was also intimidating in that the research would be entirely exploratory, meaning that I would have to start from scratch and make decisions about what aspects of this research I would be able to explore, what could and could not be covered within the scope of the project and how it would be framed. Finally, it was liberating to be able to approach the project with the knowledge that this unexplored topic could be shaped by the participants sharing their experiences.
After I had conducted the data collection and I was formulating a theory of the experiences of driving with a mobility impairment, I began to consider the ways in which my theory could relate to existing theories. At this point I expanded the literature searches to encompass some of the themes and experiences that had arisen from the data.

**Constant Comparison**

The process of forming the initial questions to be used for data collection is not unique in that all researchers bring their own beliefs and values and interests to their research. However, as a researcher, with experience of being a disabled driver myself, I was able to identify factors, such as parking, which might be relevant to participants.

Even though the interview topics did not change, analysis during the interviews was possible through talking (anonymously) to participants about ideas and experiences raised by other participants. For example, Ben mentioned wheelchairs on the outside of cars and even though Harry had a different conclusion about the visibility of wheelchairs, their stories showed both that participants had different experiences and opinions, but that the visual presentation of their cars and disability were meaningful to both participants in terms of their identity.

The interview questions were constructed so as to open up specific topics of conversation in a reasonably neutral way, with extra prompts to potentially use, depending on the initial responses of participants. Although the questions did not substantially change throughout the five-month period during which the interviewing took place, the interviews did change. I asked more ad hoc questions as connections began to emerge between the themes of the participants’ stories. While in the earlier interviews I could engage with the participant’s experiences based on my own experiences, as the interviews continued, I could also engage with them on issues raised in earlier participants’ experiences: ‘Did you also experience *this*, as someone else has mentioned?’ There is an advantage to this form of interviewing, as these types of prompts could stimulate further discussion of a shared issue, or could highlight differences between people experiences.
To develop a grounded theory Charmaz (2006) has described the process of creating codes from raw data, then organising the codes into categories, raising the categories to concepts, and then raising the concepts up to a grounded theory. But the end product of a grounded theory comes from the sorting and presenting of the data, and not from imposing order on it.

To generate a theory about the data required an initial round of theory generation, merely to be able to talk about the data in a coherent manner. There were multiple rounds of this stage of the theory generation because the different ways of grouping the data had to be at a high enough level able to encompass all the data, but also be able to say something relevant to people’s specific experiences.

All coding was done with NVivo software using the transcribed interviews. Using NVivo enabled me to keep track of when codes had been created and in what order. I coded solely with the software but wrote memos in conjunction to consider more theoretical coding. I created codes by reading through transcripts and labelling things that seemed relevant or important, both to myself as a researcher, and to the participants. In total, over the 27 transcripts, I created 100 codes, some of which occurred in one transcript only once, and one of which (parking) occurred in all 27 transcripts a total of 204 times.

Although I had been writing memos since the beginning of interviews, I did not begin to systematically code in NVivo until after I had done the first fifteen interviews. In total, the coding process occurred over six months. To begin with, I coded the transcripts of eight participants in one continuous period, in order to get the feel of coding in general, and of the subject matter, and also to establish a substantial set of codes to draw on. During this process, I did not stop and go backwards in a transcript, or to previous transcripts, and code things which I realised matched the new codes I was creating. In the first transcript I created 34 codes alone, some of which had a high rate of recurrence in subsequent transcripts and some which were particular to that transcript alone. Some of the codes with a high rate of recurrence were in some ways related to key areas in the interview schedules. An example of
this was ‘driving/mobility in the future’. However, even having an interview prompt about ‘driving in the future’ came about because of Jack’s comments in the first interview.

By the end of coding eight transcripts I had created 64 codes. Part of the reason that so many of the codes were established near the beginning of the transcripts was that there were many fairly broad codes that were identified in the data, such as ‘cost of running a car’, or ‘parking’. During the middle part of coding, the original codes were still used but the new codes were more likely to be conceptual. In the last month of coding only thirteen new codes were created as the data came closer to saturation point.

After the initial coding of eight transcripts I then stopped and reflected on the codes I had created thus far. I noted that some of the codes were quite simple or practical codes relating to the driving experiences of participants (“parking”, “petrol”) and other codes were more conceptual (“independence”, “choice”, “freedom”). The variety of codes were interesting because of their different natures and I temporarily wondered if I was ‘doing it right’ when identifying what I thought were relevant codes. However, I decided that the different kinds of codes were both important and how they worked together would become apparent later. After re-evaluating the initial coding I went back through the first eight transcripts and re-coded sections that I had ‘missed’ on my first pass through. In this way, concepts that I realised were significant, and justified assigning a code to in the sixth, seventh or eighth transcripts, and which were present, but not ‘picked up’, in the first few transcripts could then be coded appropriately. An example of a code that emerged from the data and I then had to go back and code in earlier instances was ‘getting lifts from family and friends’. The importance of this code was not apparent in the first couple of transcripts during my first attempt at coding, but as multiple mentions of family members giving participants lift occurred, I created a code and realised I would have to go back and identify these sections. In the initial period of coding, discussions of being driven by family members rather than driving themselves were coded as ‘reliance’ or ‘independence’, because these were the concepts that people explicitly or implicitly referred or alluded to. It only occurred to me during the coding process that the specific modes of transport that participants used when not driving were extremely significant themselves.
Memo writing immediately after interviews gave me an opportunity to reflect on how the interviews had gone – whether there was information conveyed non-verbally, how I had interacted with participants, what questions or prompts I had asked them, and how the interviews were similar and different from each other. Memo writing between interviews meant that I could reflect upon and record unexpected things or particularly interesting things that participants mentioned and could consider incorporating them into future versions of the interview schedule or discuss them more with participants who brought up a similar point in future interviews. Writing memos during the coding, categorisation and theorising process was an opportunity to externalise analysis as it occurred and to note down patterns and thoughts that could be re-examined in relation to the data. As well as memo writing, I met regularly with my supervisors during and after the interview period to discuss the interviews and emerging ideas.

After I had finished coding the transcripts of the interviews, I had to move from looking closely at the raw data in each interview to engaging more with the emerging concepts and categories. This theorising was an iterative process. Even though the codes were not in any way ‘equally weighted’ as some were mentioned multiple times by all almost all participants, while others were quite specific experiences that possibly only one or two participants mentioned. However both types of codes provided insight into the experiences of driving and together began to create a more nuanced picture. Because the codes described different kinds of experiences of car driving (such as practical coping strategies, emotional reactions, social and economic contexts) and the codes and ideas interacted with each other in different ways, they did not need to necessarily have to recur in multiple interviews to make them a significant part of theory creation. One example of this was the code ‘cruising for chicks’. Although this idea came up only once in the interviews, it was instrumental in understanding the role that cars could play in identity formation, participant’s notions of normalcy and social relations and participation. However with other codes, such as ‘parking’ or ‘changing abilities/needs’, the fact that they occurred in almost every interview transcript underlined the central role they played in the experience of being a disabled driver, and how parking issues or changing needs could create serious barriers to mobility and participation.
Although they remained evocative of the stories that participants told, looking at the codes separately from the interviews themselves enabled me to consider the data on a more conceptual level as the process of analysing the interviews could be approached from a different perspective.

Developing Theoretical Sensitivity

The experience of identifying and assigning codes to the different aspects of a participants experience was an essential part of my analysis and also of my understanding of the methodology of grounded theory and, eventually, of my own grounded theory. I believe that being a disabled driver helped me to develop theoretical sensitivity to the data as I was able to reflect on personal experience and how the experiences of participants mirrored and differed from my own. However, this ‘prior knowledge’ is only useful in so far as it is ‘sensitising’ to the data (Charmaz, 2006). Coding, conceptualising and theorising must only proceed from the data itself. The process of coding also helped me to develop theoretical sensitivity, firstly by making me familiar with interviews to a minute degree, and then subsequently, by also considering the codes separately from the interviews, I could think of the data more conceptually. ‘Getting lifts from family and friends’ is an example of how coding a portion of the data could begin as simply the labelling of a recurring motif that seemed interesting, and develop into a deeper understanding of the complex meaning of mobility and impairment.

Categories, Concepts & Theory

As my codes built up and my analysis of the data deepened, I could see how the stories that participants told could simultaneously reveal a multiplicity of meaning about their individual experiences. The data also began to reveal patterns of shared and individual experiences. In this way I could see that getting a lift from a family member or friend, at the same time as simply being a way that people got around their community, was also an important strategy for coping with having a mobility impairment, and it became part of an individual’s experiences of close relationships and feelings of independence or reliance on others. Whether a participant mentioned being driven by family or friends could also potentially indicate something about their relationships and their connections in their communities. The
way that people moved around their community, employed coping strategies and felt about their own independence or reliance on others could, in turn, also affect their identity. Although this was only one of many codes that had links to other codes and concepts, it is an example of the process of how early coding builds upon itself and can develop into deeper analysis. As I continued to code, some of the codes became more conceptual as I was already beginning to make connections within and between the stories that participants had told me.

Once I had coded all 27 interviews I had 100 codes and at this point I took time to step back and find a way to synthesise the large amount of data I had. It was clear that all the codes were connected to at least some other codes, and usually were connected to many other codes in, at times, quite different ways. What was needed however was a way to organise the codes into manageable, and analytically useful, groups. Because the participants in this study were so generous when telling stories from their lives, and the accounts that they related were so rich with information and genuinely fascinating, it was at first hard to let go of individual’s stories and consider them as a conceptual whole. There were many stories that did not make it into this thesis because of space and the need to avoid repetition of similar experiences between participants.

After completion of the coding, it became apparent that breaking down the data into codes had clarified how, when viewed collectively, the participants’ individual experiences held many similarities. The codes could be grouped together into categories that revealed their chief interests and concerns regarding their driving experiences. After consideration and discussion with my supervisors I sorted of the categories into three groups, each with a conceptual focus. These three conceptual groupings of the data, or explanations, subsequently became the three results chapters: the meaning of driving; the barriers and enablers to driving, and; what the absence of driving, and the mobility it provided, meant for participants. Grouping the categories this way helped to make sense of the seemingly disparate threads in the data, and meant that the theory generation within and across these three sections could continue to be refined without any of the codes being left behind, as all the categories fitted into these concepts.
Writing a Substantive Theory

Charmaz’s view of constructivist grounded theory has been that it must “dig deep into the empirical and build analytic structures that reach up to the hypothetical” (2006, 151). A substantive theory interprets or explains a specific issue within a particular area. The writing of a substantive theory is itself part of the iterative process of theorising, as writing generates analysis which can then be used to return to the data.

My substantive theory is an interpretation of how and why disabled drivers in New Zealand experience car use and mobility, and it also highlights issues and questions for other theorists of mobility and transport. As will be seen in the discussion chapter, locating this substantive theory inside grander theories of disability and human development shows how exploring one (reasonably small) phenomenon can also deepen our understanding of those theories.
Results: The Significance of Cars for People with Mobility Impairments

“It’s my legs, if you know what I mean.” - Adam

One of the key areas of discussion in the interviews I conducted for this study on disabled drivers’ experience of car use was the significance their car and driving held for them. In this chapter, I draw together the ways in which cars, or the ability to drive, were important to the people interviewed. The chapter is divided into two parts. The first looks at the significance of the car based on practical matters of social participation, or what participants felt that their car enabled them to do. The second part examines the relationship between driving and mental health and sense of self.

Some of the issues that will be examined in this chapter were experienced and discussed by many, if not all, of the participants in this study, whereas other issues discussed came from their unique perspectives or experiences of car use and related only to their particular circumstances. The role of participants’ cars and driving in shaping and enabling social participation varied across the sample, based on physical abilities, age and life situation, but there were recurring themes that emerged in the data and which reflect general societal expectations of life roles.
The first part of the chapter looks at the major social participation categories which were oriented around the role of the car in participating in work, education, family and/or domestic life, socialising and/or leisure, and other car-related reciprocal social roles. The second part of the chapter looks at the role of the car in the participants’ identities, issues around ‘normality’ (as described by participants), as well as discussing their experiences of depression and anxiety.

Part I

What Driving a Car Enabled Participants to Do

Being able to drive enabled the participants in this study to accomplish a variety of activities such as working, studying, transporting personal items, caring for or keeping in contact with their family and socialising. These activities were all related to ideas about participating in society; some were vocational, such as working or studying, but many of the other activities were related to daily living or socialising.

Work

The interaction between driving and work varied considerably between the participants as not all of the participants worked, some felt that their unemployment was because of their impairments, and some were not working for unstated reasons. Of the participants who were working, some used their cars to travel to and from work, some worked with cars and others drove as an integral part of their job. For the participants who were not able to or did not wish to be in paid employment, some did voluntary work which they saw as a crucial contribution to society, as well as to their own well-being, and to do this they required access to a car.

For those who were in paid employment, many saw a direct relationship between their ability to drive and their ability to have a job or career, either because driving a car was their only

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10 Although I believe that ‘work’ or ‘labour’ includes a great range of activities beyond paid work (including amongst other, childcare, domestic duties and voluntary work), because of the social and monetary value ascribed to paid work, I will discuss this as ‘work’ and will discuss other forms of work (such as child care) separately.
way of getting to and from work or because they drove as part of their job. For quite a few of the people I interviewed who were working, driving was a component of their job:

Steven: “I drive pretty much for a living... a lot of my work is travelling from site to site.”

One participant, who also used public transport and a taxi to get to work, talked about the crucial role her car played in getting her to the train station to be able to catch her train.

Barbara: “If I couldn’t get to the railway it would be nearly impossible to get to work.”

Because of Barbara’s difficulty with walking, her car enabled her to connect to the other forms of transport that she needed to get her to her workplace, and in this instance, driving herself was one link in the travel chain.

For some participants, having the mobility that driving provided was a crucial part of their job, it had enabled them to secure employment and they depended on being able to continue driving to stay employed.

Rose: “If I didn’t have my car, I wouldn’t have the successful journalism career I have.”

While for Rose, having a successful career quite obviously benefited her financially, there are other, non-monetary reasons that people find work important. As will be discussed below in the section on depression, Dorothy needed her car to do voluntary work when she could not manage to do paid work in order to feel useful and enjoy the social contact that workplaces often bring. The effects of the absence of this social contact can be seen when River talked about how difficult she found having to leave her job, as she was suddenly a lot more socially isolated.

River: “Work is a social thing as well, you know, and yeah, particularly when you’ve been somewhere for nine years. I found that really hard.”
The fact that the participants who worked, generally relied heavily on driving meant that the significance of their car could be linked to both their financial and emotional well-being.

Study

For Katarina, a student, her car was a means of getting to classes without the pain and exhaustion of travelling in another vehicle.

Katarina: “The car has been instrumental in [studying at university], I couldn’t have gone if I didn’t have the car because I couldn’t have handled for a start the taxis, for the seating which was the problem and I couldn’t handle going on to the public transport system just because by the time I would get there I would have been flat on my back and worn out, completely exhausted just from having to deal with the pain of the journey.”

Having a car meant that Katarina could conserve her energy, control her pain levels and reduce the physical cost that getting to her place of study incurred. These factors in combination meant that she had more physical and emotional resources to be able to complete her course of study.

The distances that participants had to travel to get to their places of study varied, although whatever the distances, access was still an issue. Melanie studied outside of the town where she lived and needed her car to be able get to classes.

Melanie: “I’ve done a lot of study, and I wouldn’t be able to do that without the car, because I had to go to [another town] for it.”

Although there was limited public transport throughout the Wairarapa region, the combination of a lack of access vehicles, as well as Melanie’s specific physical needs, meant that the significant distances she needed to travel for study were only manageable in her car. However, the distances travelled could be extremely small and still only be manageable by car. Although River lived right on the campus at university when she was studying, she used her car to get to all of her classes, even though they were very close. Her limited mobility
meant that the distances that many other students could easily make on foot were only accessible to her because of her vehicle.

River: “I lived in the halls of residence, which are actually on the campus, but they were still quite a distance from some of the lectures. Or, you know, we’d have practical sessions down in the orchards and stuff like that. So I would still, I would take my car up to the lectures.”

Family and Domestic Life

For some participants, the role of the car in facilitating their family and domestic life was a key one. However, the role their car played depended on people’s family and household makeup. To divide these spheres of car use into two separate but frequently overlapping categories enables us to show the separate significance of family and domestic life, as well as the relationship between the two. While some participants lived in the same household as their family, others lived separately, but stressed the importance of using their car to visit or care for their family.

The role of the car in domestic or home life was significant as almost all participants talked about their cars enabling or assisting with tasks such as shopping. For some people, their ability to drive was essential because it meant they were able to access some of the basic necessities of life. For other participants, domestic life and family were intimately linked because they lived with other family members with whom they either shared or provided domestic duties. Five of the participants had one or more dependent children living with them at the time of the interviews, and many others lived with partners with whom they shared domestic duties. Some of the participants who did not live with their families felt that their car enabled them to connect them with their family.

Domestic Duties

For some of the participants, using their car for in the domestic realm was important for feeling independent or that they were making an adequate contribution to the household.
Zoe commented on her husband’s willingness to do things for her such as grocery shopping, but being able to do such tasks herself meant that she could feel that they had separate identities and that she was an equal partner in their relationship.

Zoe: “I go and do all my shopping and do everything I can. [My husband] would do it all for me, I know he would. Run around and do everything for me, but I don’t want him to. He works too; we’ve both got a life.”

There is potential for activities such as shopping for oneself, or for a household, to be considered as ‘merely’ a matter of pride for people with impairments, but I believe it is important that they are able to make their own assessments of what boundaries they placed around relying on family and friends or being independent of them. The independent mobility of disabled drivers can also increase the independence of friends and family members.

Interaction with Family

Most of the participants in the study talked about how contact or interaction with their family was facilitated by driving. For Donna, who had an elderly parent who was very unwell and a grown child who herself had dependent children, the onus was on her to travel to see her family.

Donna: “It gets me to be able to see my grandkids because they can’t come down to me so I’ve got to go to them and yeah it gets me out to see my mum as well.”

Even though Donna had significant mobility limitations, her situation meant that she had more time and ability to visit her family than they had to visit her. Although Donna could not work, she had a role in caring for and spending time with her family members.
Contribution to the Household

There were a variety of ways that driving was seen to contribute towards family life. For some participants, driving meant being able to support their family by working; for others, it meant being able to share household jobs with their partner and to feel that they were on a more equal footing with other members of the family.

Harry: “You may only be out with one of the kids, you might be out with all the kids, so again, as a family. It made you an operating member of that family.”

Because he could drive his children around, Harry felt he could contribute to the household in similar ways to his wife. The feeling that people with impairments are active and contributing members of their families is a powerful one as they are often considered to be dependent on others.

Parenting Role

Harry was not the only participant who used his car when parenting. Five of the participants in this study had children who lived with them and others had grown children whom they had raised whilst being a disabled driver. For some participants, driving children around was considered a part of the expected role as a parent. As children got older and went through different stages of development, transporting them involved different activities. While their children were very small they needed to be driven everywhere but as they got a little older, parents could help them towards independence by driving them from where that they could transport themselves.

Vicki: “I used to drive my daughter to school, but now I drive her to the bus stop.”

For Vicki, driving her daughter to the bus stop was analogous to another parent walking their child to a bus stop. One participant talked about how the practice of driving their children round was more than functional; it was part of the relationship that they developed with their children and was a sign of being involved in their lives. A father talked about being
able to get involved in his children’s sporting activities. Although he could not participate in their sport or practices, he could be involved both by transporting his children and by being present at their games.

Harry: “When I had young children, they all played sport, so you took them to soccer on a Saturday and you followed them at their sport. You went to school things, you know running and athletics and all those things… you connected with your children.”

For Harry, spending time driving his children around meant engaging in their leisure activities and interests. As well, this aspect of parenting could also provide an opportunity to connect with other parents and the community.

Many of the participants saw transporting their children as one of the core functions of their car; that they needed to “do necessary things like drop my daughter off.” The necessity of being able to drive children around did not only mean that they had to drive them to essential services or to travel long distances, but because the option of walking even short distances was not available to many participants, their car became vital in their role as a parent.

Dorothy: “When my son was growing up, as I say he’s nearly 20 but he had to go to sports things and so we were living in [a nearby suburb]… but I couldn’t walk him to [the local] Park, I had to drive him.”

The idea of losing the ability to drive was upsetting for a lot of people, not only because of their own loss of mobility, but also as parents, their dependence on their vehicle included being dependent on being able to transport and look after their children. In this situation, losing their car would mean they would lose the ability to parent in the same way or with the same ease.

Grace: “When you’ve got two children that do things and have to get to school and have all these after school things, and I just, yeah. I mean it would just be catastrophic.”
Being able to drive their children, generally gave participants the ability to parent quite independently. Even Rose, who needed help getting her young daughter in and out of the car, still felt that driving enabled her to “be a sort of, a mother… it means that I can just participate in everything.”

Shopping

A very common task that almost every participant mentioned was that their car enabled to do shopping, particularly food shopping. Being able to shop independently seemed to be very important to participants, not just because they needed groceries to sustain themselves physically and liked being able to make choices about what they consumed, but because it was often synonymous with independence and capability in general.

Dorothy: “Even silly things like going to the supermarket, [my husband] and I… we do the shopping together and things like that but there is other times when I go and do it and if I can’t go and do it then I get quite pipped, ‘cause… I want to do it, I don’t want to sit back and let life just pass.”

For many participants, shopping symbolised the minutiae of life, the idea that everyone did it, everyone had to do it and to not do it was to be dependent. The attitude that providing for oneself and others was an important role was particularly true of women.

Socialising

Alongside some of the essential ways that cars facilitate independent living, such as enabling people to work, parent, shop and take care of their health, many participants talked about how important socialising and participating in their community was and the vital role that their car played in allowing them to do this.

One participant, Mark, explained that although he had lost some of the physical capabilities that he had previously had, he did not want to lose his connections to people and institutions such as his church:
Mark: “My injury has certainly forced me to be less active because there is pain with it so I can’t be terribly active, but I can be socially active.”

Socialising and being involved in the community did not just mean that he was able to go out and see people and attend church; being able to drive a car also enabled him to transport his friends to social events, which was good for the group's well-being as well as his own.

Mark: “I have two friends here that are more disabled than I am and I take them to a meeting once a month…it helps me to stay connected yeah. I’ve been pretty lonely because it has been too painful to walk too far from my house and I get quite isolated, which wouldn’t be a good idea, and which is one of the reasons why I help these chaps out. Because I don’t want to see them getting too isolated and I want them to be able to enjoy some of these evenings that we have.”

In this way, Mark’s passengers, who had even more mobility restrictions than he, were transported, enabling them to participate and Mark felt good that he could provide support for others. This communal transport also gave the men an opportunity to connect over their shared experiences.

Going to Visit Friends

For many participants, all of whom had a range of mobility difficulties, being able to visit or meet up with their friends was very important to them, particularly if they had difficulties participating in more physically active pastimes. For Ian, having contact with his social group had always been important, but maintaining this social contact now required using his car.

Ian: “I have always been a fairly sociable kind of guy but to get to a social meeting, I would need my car in a big way and there was a time when I was younger that I used to walk everywhere, but not anymore.”

For Katarina, having a car meant she was able to get to university which facilitated more than just her study; it also gave her the opportunity to meet other disabled students to whom she could relate and get to know in a social context.
Katarina: “Being able to meet other people, make connections with people, meet other people with disabilities was fantastic, you know. And other people that looked like me, that looked fine on the outside, but that was really struggling with things and then other people that were even more so and just the whole range of things.”

Driving Friends

For Adam, who, at the age of 18 was the youngest participant, his car not only facilitated his participation in society generally but also allowed him to develop friendships with his peers that were not complicated by feeling dependent on them for inclusion in social activities. Having a car and being able to drive himself and his friends was also a practical help to his participation in group activities.

Adam: “A lot of my friends were only on their restricted and stuff so someone would text me or something and say everyone’s going here but none of them could pick me up because of that reason so it’s good having that and also I’m allowed to take passengers to help me in and out of the car and stuff.”

Being able to drive himself and his friends independently made Adam feel like he was on a more equal footing with them and that they were all just ‘hanging out’, rather than having a dependent relationship with his friends having to care for him. He felt more confident that his friends enjoyed being with him and did not have to deal with any sense of obligation that might arise if they had to always facilitate his transport and mobility.

Adam: “I get to spend more time with people without feeling like they’re caring for me if you know what I mean. So it more feels like I’m hanging out with people instead of people coming to pick me up because they have to sort of thing.”

This desire for friendship based on feeling equal and competent and able to do all the things expected in a peer group was echoed by Jack who had also been a teenager growing up with a disability. As described below, Jack felt that his car enabled him to be ‘one of the boys’, and just one of the people in his social group who could give lifts to other people.
Driving as a Social Activity

Some participants talked about the ways in which over time, cars were involved in their social lives. For those who had had impairments from a relatively young age or from birth, being able to drive was one way that they could participate on an equal footing in social activities because they could transport themselves to where other people their age gathered. Jack talked about how as teenagers, he and his friends did not have a lot of options for recreation in their spare time, but driving rounding looking at girls was something they could all do together.

Jack: “[It was that] cruising mode that teenagers got in to and always got in to since cars were invented and so, but it just meant that I could get down town with my mates on a Friday night and hang out in the streets and watch the girls go by sort of stuff.”

Having a car at a young age could also potentially be a social advantage when meeting people, as other younger people were less likely to have their own car and could be given lifts. One participant talked about how having a car was a resource and sharing his car was a way of showing friendship to someone his own age. Travelling together on a long journey in a car gave Jack and an acquaintance an opportunity to get to know each other and become friends.

Jack: “On the way up there cause I found somebody else was going to Waikato university and offered him a ride and so been friends ever since basically.”

For other participants, going for a drive with a friend fulfilled the same function as going for a walk with them. While walking would keep active people warm, a participant could shelter in their car to keep from getting cold if they were unable to walk far or quickly.

Romana: “I go out to lunch once a week with a friend and we often go to the lake and both say how therapeutic it is just to stare at some water…lately we’ve been
getting out of the car and you know, sitting on the bench and talking about the doves and stuff. Through winter we tended to sit in the car.”

Having a car afforded Romana and others an opportunity to get out and enjoy public spaces and amenities but without the same requirements of having to physically walk there or to stay warm through exercise. For some participants, their car could also provide a more comfortable place to sit than park benches.

Driving and Leisure

Driving was part of people’s leisure activities in a variety of ways from making it more accessible and more comfortable to being the central focus of it. For a couple of participants, cars or motor sports were themselves a leisure activity. Adam fixed cars and belonged to drag racing clubs and Steven was part of the crew for his family’s racing car team.

For Steven, participation in his family’s racing car team was a significant aspect of his life outside of work. Family gathering were based around motor sports and gave the family an opportunity to meet up in various parts of the country and spend family time together that was focussed around a common interest.

Steven: “We went to Stratford and Wanganui one weekend last year, it was absolutely great, racing all weekend. But yeah, the driving does very much help with my pastimes and leisure activities, ‘cause yeah it pretty much involves driving and motor sport.”

For Adam, who was also involved in driving related pastimes, his ability to drive himself meant he was able to attend club meetings with his friends and travel away from home for the weekend with them. This was perhaps particularly significant for them as a group because they were in their late teens, a time when for many people independent travel is very important.
Adam: “I’m in a mini-trucking club and then a club that we drag for in [another town]… we’ll drive up for meetings and shows and different things that clubs put on and what not.”

For many participants, however, cars were vital to their leisure simply because they allowed them to get to places where they could join other people in a shared hobby. Whereas Adam’s social activities involved meeting up with other people who generally did not have a disability but were focussed around a common interest, other participants mentioned the importance they attached to being able to meet up with other disabled people.

Several participants from Auckland became involved in this study because they knew each other through a sporting organisation specifically for people with impairments. Being involved in such groups is important, not only because it provides entry to a leisure activity that might otherwise be inaccessible for disabled people, but also because it gives them an opportunity to do a physical sport. It also gives them an opportunity to interact and socialise with other disabled people in a form that focuses on their abilities, rather than one that is medicalised or focused on their physical limitations. All of the participants who were involved in this organisation said that enabling leisure was an important use of their car, and that they would not be able to participate without one.

Protective Environments

Participants also talked about how cars could fill the role of being protective or a supplement to physical environments that were not accessible or friendly to their physical needs. Cars could afford some protection from the weather or could be used as a known and comfortable resting place.

Katarina: “Having the car, I like to be out in nature so I have been able to, it’s given me a little bit more access to be able to get to like the beach …just to be able to be by the beach and that sort of stuff with the dog. I still find it uncomfortable walking on the beach because of the uneven ground, but that’s okay.”
Katarina also talked about taking how, despite finding being at the beach difficult, she was able to use her car to transport things that would make her time there more comfortable and enjoyable. Although she could not sit on the sand, she could take a chair that supported her back appropriately which allowed her to sit outside and enjoy being at the beach. Katarina could also rest for a while in the car if she got tired and kept a blanket in her car for such occasions. This meant that she could stay out on an excursion longer.

**Flirting in Cars**

One participant, Ben talked about his experiences of having women smile at him and flirt while stopped at a traffic light, “You can pull up to some lights or something and have a bit of a highway romance.” Ben felt that he was an ‘equal’ in a car because other people did not know that he used a wheelchair outside of it. Ben also spoke about participating in a drag race against a car full of young women and how, when he met them later they did not believe that he used a wheelchair at all. Even after he pointed to his wheelchair in the back of his car, one woman continued to disbelieve that he used one and said it must be a pram.

**Driving, Depression and Social Connection**

Some participants talked about their experiences or fear of being depressed because of feelings of social isolation and the inability to leave their house easily. Often participants had experienced a period of being confined to their house, which they had found very difficult and were extremely anxious about finding themselves in that situation again.

Tegan: “I think I’d get very depressed if I didn’t have a car to drive. I mean I enjoy my own quiet time and time on my own – that’s why I send my husband off fishing every now and again when he stays away – but if I didn’t have access to get out I think that would really bug me, because I sort of enjoy being with people on my terms.”

Another participant talked about how she had experienced depression after she acquired a disability and had become increasingly housebound. Donna thought that getting access to a
car had contributed to her emerging from the depression because, although she was still unwell, she was less isolated.

Donna: “It helps you get out there and socialise, which is something I didn’t really do. I shut myself away for a long time, so yeah, so it does help.”

Similarly, River saw her ability to drive as the most significant enabler of her social participation. The importance of her car was particularly highlighted during periods when she could not drive and found herself unable to leave the house. During these times, she felt increasingly isolated and depressed. River talked about how isolation was a vicious circle that was hard to escape from, as socialising and participating in the community became much harder emotionally for her after she had experienced a period of isolation from people. River was very aware of the fact that her mental health was negatively affected by her isolation.

River: “If I couldn’t drive I wouldn’t, basically wouldn’t participate at all. I have had a couple of times where I haven’t been able to drive for different medical reasons… the first time I wasn’t allowed to drive for 12 weeks…Basically over those periods I really didn’t do anything so yeah… [I]went stir crazy… I find the less I see, I don’t go out, the less I want to go out as well and… yeah I don’t think it’s good for your mental health.”

Katarina talked about a similar experience of finding it much more difficult to socialise again after a time of isolation and depression and theorised about why this was. She felt that because a lot of social interaction was dependent on the sharing of experiences with other people, conversation was severely limited after an extended period of isolation.

Katarina: “I saw the neighbour’s cat coming in. It did a crap on my lawn. Yeah, or I watched television.”

So when Katarina was unable to go out or do many things, not only did she not see many people to interact with but felt as if she had less to say of interest to people, when she did see them.
Katarina: “When you don’t have those choices and those opportunities to get out and about people do become depressed and that whole social isolation thing. And they don’t have anything to talk about with somebody when they meet them.”

Individually, each of these women’s stories of depression and isolation reveal the effects of mobility or immobility on their well-being. When the stories are considered together, they indicate how important it is to have the right tools to be able to live a life of value.

The Value of Social Connection

One participant expressed frustration at the fact that, although having a car meant that she was able to leave her house and socialise with friends in an independent and normal fashion, factors such as these were not taken into account when funding bodies made decisions about which people received funding. To qualify for any kind of Ministry of Health funding to purchase a car, there were certain criteria that had to be met, such as being in full-time work or study. For Melanie, who was near retirement age and unable to work because of her disability, having a car funded would have kept her more independent and prevented further social isolation.

Melanie: “Being housebound for me is a biggie very much and I don’t like, I mean I’m becoming isolated now and I don’t like it… if you just want a car because you want to go out to [a nearby town] to have a coffee with friends you know you don’t stand a chance.”

Melanie was in the process of losing the social connection that she had depended on for many years, because she could not easily drive the vehicle she had. However, she was not the only participant who was very aware of vehicle funding being tied to indicators such as employment status and not to a need for social contact.
Driving as Carrying

Although it is quite common for non-physically disabled people without cars to find transporting groceries difficult, common solutions such as taxis would not work for some physically disabled people, because of the other ways that cars helped them with the shopping process. Having her own car enabled Romana to take plenty of time with her groceries, as she could pause and rest when she got to her car and could rest in her house in between carrying shopping inside.

Romana: “I bring in my frozens and I put that away and then I sit down and rest, absolutely true. And then I stagger out to the car and bring it in and lay it all out in the kitchen and then it probably takes me the next two to three hours to put it away, because the actual carrying of the shopping is just hard work.”

Romana was able to shop for herself, but could only achieve this by pacing herself and being able to break the task down into components. While some people with mobility impairments might qualify for help to perform tasks such as shopping, others would not. Some had the support of family members or friends or wanted to maintain their independence.

The Car as an Extra Set of Arms

Some participants not only had an obvious mobility impairment of difficulty walking around but also could also not easily carry heavy objects. Some talked about leaving frequently used things in their car to avoid carrying them as much as possible.

Romana: “My painting stuff stays in my car all the time and I wouldn’t bother taking it inside and one of the hardest things I do is… my shopping, just the carrying of it, the weight of it really.”

Because of River’s impairment, her car essentially functioned as a handbag, or at times, a substitute for pockets.
River: “Probably one of the best descriptions of my car is like a glorified handbag, because I can’t reach my pockets or anything like that I tend to travel light but I have a lot of things in my car that most women would carry in their handbag.”

River did not only use her car in this way; like the other participants, she required it for her general mobility, including frequently to travel short ‘walking’ distances. Using it had enabled her to develop strategies to alleviate other aspects of her impairment.

Driving Over Time

What cars enabled people to do could change over time as their bodies or their circumstances changed. Many participants talk about how they had experienced an often dramatic reduction in their mobility and how being able to drive was important for recapturing some of that mobility and the activities that were associated with it.

Dorothy: “Prior to being this bad I walked everywhere, I mean I just, I was walking five kilometres to work and home every day. Didn’t think anything of it you know, I was playing water polo, I was doing gymnastics, I was competitive swimming so overnight that just disappeared.”

After this dramatic change, driving suddenly became key to Dorothy’s life and to her mobility in a way that it had not been. However, Rose, who learnt to drive as a teenager with a disability, went from having limited mobility and independence before learning to drive to having much more freedom and mobility. The role of Rose’s car, though not the importance, changed quite markedly after she became a working parent. When Zoe had been younger, having a child with a number of impairments meant that driving was vital to being able to care for her child and keep her family functioning. In later years, when Zoe no longer had responsibility for caring for a disabled child but had a mobility impairment herself, she still relied on her car for aiding her mobility, but did not see driving as important as it had been.

I believe that the various tasks and roles that driving enabled participants to accomplish equate to some of the things that people mean when they talk about social participation,
‘independent living’ or capabilities. Just as the concepts of ‘social participation’ or ‘inclusion’ in the New Zealand Disability Strategy are undefined, these terms are kept vague for good reason. What ‘participation’, ‘inclusion’, or even ‘independent living’ means for people with impairments is different depending on an individual’s circumstances and preferences. For the participants in this study, being able to drive their own car, increased their opportunities to do the things they needed or wanted to do with their lives. The second half of this chapter will discuss how the participants felt about driving.

Part II

How Driving Made People Feel

The other way that the participants in this study saw their car as being significant was how it affected their sense of self in relation to the world around them. In this section, I will discuss how participants felt about their cars, their bodies and their personal identities and how driving affected their feelings of independence, mastery, depression and anxiety. I will also consider the relationship that participants described between driving and a sense of normality and continuity in life.

Cars and Bodies

Some participants had experienced a considerable change in bodily function when they acquired or developed a mobility impairment and this, in turn, affected how they thought of their cars. Dorothy talked about how, when her impairment began to prevent her from doing the things she previously had, her car began to take over some of the functions that her formerly very active body had performed and that this process had changed her relationship with her car.

Dorothy: “It’s the extension of my feet and legs.”

In this way, driving became much more than just using a vehicle and Dorothy’s body and its functions were supplemented and extended through her ability to drive. In a similar way,
River talked about how her car meant she was able to inhabit a physical space where she felt comfortable and was able to protect herself from other people’s curiosity about her body and its functions.

River: “Mobility aids and stuff like that, you know, you don’t carry them round with you every time you go anywhere, but for example like dressing and toileting and stuff I use a [device] and you can’t exactly, even if you did have a handbag, exactly tuck it in it. It’s quite long and people always ask what it’s for, so I don’t tend to carry it round, but I leave it in the car.”

The privacy of her vehicle could afford River a form of bodily integrity in that she had more control over how much information about her body was available to the public.

Driving as a Means of Independence

Almost all of the participants in this study talked explicitly about how being able to drive themselves around, gave them a sense of independence that they valued very highly. In fact, one of the key fears that people talked about for their future was that they would lose more of their independence than they already had. Independence is valued very highly by most segments of the population and this was reflected in how people talked with pride about the independence that they had, particularly when that independence was hard won.

Melanie: “I don’t know if you’ve come across any Polio’s before, but we are fiercely independent and don’t like relying on anybody for anything. And I mean, I was at home all the time, I certainly couldn’t take [my baby] on buses, couldn’t cope with that with a push chair, so yeah, I mean having the car I was just able to have a normal life. And I mean, I used to go and pick my husband up from work as well, which was suitable for him but, it enabled me to go places, do things that I wouldn’t have been able to do if I didn’t have the car.”

The independence that Ben’s car gave him was described as more important than many other significant things in his life. In the past, he had moved to Australia where he could not afford
to buy and modify a car to get around. While he was living there, without the governmental, family and social support that many people with impairments rely upon, he achieved what would be seen by many as a high degree of independence. However, Ben talked about how it was the specific loss of independence which came from not being able to drive a car that made him decide to move back to New Zealand.

Ben: “It’s basically the reason I left Australia was I missed my car more than I missed my friends and family. It was just being able to do what you want, when you want, all that kind of stuff, it’s that key to independence.”

One participant described how using a car enabled an independence that went beyond simple mobility. The sense of isolation she experienced when she was housebound and not able to go out independently, affected in a much more holistic sense and her whole world, not just her physical world, shrunk. Katarina felt that regaining her mobility independence through driving a car again, expanded her intellectual and social independence as well.

Katarina: “It’s just regaining an independence of thought and being out there meeting people, meeting people and talking, you know. I hadn’t realised how much I had missed all that.”

Although for some participants, driving signified the regaining of independence after losing other forms of mobility, for other participants whose illnesses were progressing rapidly, driving was one of the last elements of independence that they still had, and were trying to maintain.

Michael: “It’s not much of an independence, but it’s still a little bit of independence that I have got left and that’s the stuff that I try and hold on to. I don’t want to lose it, I want to retain everything.”

As well as being able to perform tasks independently by driving his car, Michael also valued maintaining the ability to drive independently, in itself.
Driving and Mastery

Driving a car afforded opportunities for achieving a sense of mastery for participants who had grown up with a disability or acquired one in later life. For those people who learnt to drive with a disability, the process of learning to drive gave them a chance to master a physical skill that many of their peers were mastering at the same time, even if this sometimes meant learning to drive in a slightly different way. One participant talked about how, when he learnt to drive 40 years ago, the modifications available on a car were quite basic and although he had hand controls, they were difficult to operate and required simultaneously performing several different tasks with each hand.

Jack: “The main challenge was actually operating the clutch and changing gear at the same time with both hands. So, one hand on the clutch, one hand on the gear lever and no hands on the steering wheel. But the thing is that with a bit of skill, a bit of practice it was no problem. So got them to pretty slick gear changes.”

Further opportunities for mastering new situations or challenges could arise when anything went wrong in a car, as Jack found when his car stopped on a deserted stretch of road because of vehicle modifications that had broken. He had to work out a way of getting to the next town with the hand controls in his car malfunctioning. Even though he had learnt to drive without using his legs, he had to be resourceful in an emergency situation and teach himself to drive using a combination of the hand controls that still worked, and his one good leg.

Jack: “The strange thing about polio is… some muscles work and some don’t and it’s completely random… just so happens that the muscles that I need to push the brake work and to push the accelerator work so I was able to use my foot for the brake and still use the twist grip for the throttle. So after a couple of hours of just sitting on the side of the road practising going from one to the other I plucked up enough courage to get over this hill and did it successfully.”
For people who had previously been drivers before an accident or the onset of illness, getting back into a car and driving could show a different kind of mastery. They also needed to increase their stamina for driving longer distances.

Martha: “I had to drive up Taranaki, up to New Plymouth… and that was a major for me to do and it was all part of that – well I want to prove I can do it, ‘cause I have got friends up there and what have you.”

Overcoming physical difficulties and/or learning new skills, with bodies that had changed or were considered difficult, could give people a sense of achievement and command over their lives and their bodies.

**Driving and Normality**

Driving promoted a sense of normality for participants for several reasons. In their cars, people felt that they looked like other drivers in contrast to when they used other forms of mobility aids, such as wheelchairs. Participants were involved in an activity that is considered normal for the majority of New Zealand adults, and they could perform tasks that were considered normal with their cars, such as shopping, working or transporting their family. Using a car to do normal things could either mean doing activities that other ‘non-disabled’ people consider ‘normal’, or it could mean doing ones that participants have considered ‘normal’ in their past.

Wilfred: “I use it for everything. So yeah, from transporting the family, groceries, going sailing, meetings, I just use it as anybody else would.”

More than one participant talked about appreciating the feeling that they looked ‘normal’ while driving in their car, as people could not see any mobility aid, such as a wheelchair, that might distinguish them as being different.

Wilfred: “When you’re in the car you’re, yeah how do I put it in to words, I suppose when you’re in traffic you’ve got a perception of being normal, you know you’re in your little capsule and as far as everybody else is around they don’t… other people
aren’t looking at you with that degree of what is it when people look at you?
Curiosity I suppose, so you’ve got that levelling of being in a vehicle.”

Participants also drove in a similar manner, obeying the same road rules and encountering the same obstacles barriers and frustrations as all other drivers – as well as the same enjoyable experiences of “cruising” on a sunny day, listening to music or spending time in their car alone or with friends. This idea that driving itself was normal was also commented on.

Wilfred: “I suppose also enjoy the fact that you’re doing something that’s normal, perceived normal.”

For some participants, being able to drive and having that form of mobility made them feel that they were getting back to a state of normality. Martha described her wanting to start driving again after a time of being unable to.

Martha: “I battled on regardless because... it was about... I want some bit of normality and driving in my car allowed me to have that, even whether it was safe or not… No one said I couldn’t drive, or could drive, and it was just me, I want to feel normal so I am going to try and see what I am like driving.”

Martha’s struggle to recover from a sudden illness, which had left her with a variety of impairments was extremely hard on her mental health and had altered her perception of her life and identity. Driving was one important symbol of who she had been prior to her illness.

For Rory, being able to drive again after an accident that had left him with a traumatic brain injury and mobility problems, was also a link to some of the things that he had lost and he saw it as one thing his peers had that he could recapture.

Rory: “I wanted to get better, I want to get stronger you know and try and get back to work… when I went to work half days, four days… I saw my friends, they had cars, they had transport, I wanted something, even still, you know?”
For Jack, who had grown up with a mobility impairment, learning to drive was a part of the normal process of growing up. It meant learning a skill and gaining a level of independence in a similar way to his peers. Driving gave Jack the opportunity to participate in a rite of passage which meant that he was growing up in the same way as friends and that they had that shared experience.

Driving and Construction of Identity

Because Adam’s hobby was driving, fixing and racing cars with his friends, his identity was even more closely tied to his car than for many of the other participants in the study.

Adam: “It’s my passion. So not only my freedom, but cars are like my hobby and stuff, so all my mojo is in my cars. So I’m not too worried about how much I have to pay or what I have to pay you know, I just pay as much as I can to get it going and get out and stuff.”

Adam’s identity, as something of a ‘boy racer’, was able to be constructed through driving and the fact that he had a mobility impairment did not prevent this. Having an identity that was separate from being disabled was important to some participants, but not to others. Some participants, who used wheelchairs, but transported them on the inside of their car, rather than mounting their chairs on the top or back of their car, talked about how they liked feeling more anonymous when they were driving in their cars. Because other people could not tell that the driver of the car was disabled, they did not attract any extra or unwanted attention.

Rose: “Nobody knows, because I am fortunate that I can put my wheelchair and myself in, I don’t have to have a hoist stuck on to the roof. And so I am just amongst everybody in the traffic or driving down country and people don’t have a second look.”

However, Harry commented that although he had met many other disabled people who did not like having their wheelchair attached to the outside of their car because they felt it
identified that they had a disability, he personally had no objection to having had his on a roof rack. In fact, Harry felt quite strongly that there was no point hiding a disability while inside a car, when the disability immediately became recognisable and public once outside the car.

Harry: “When I first had my accident I didn’t care that I had my wheelchair… on my roof, I would meet younger people with a vehicle going, “oh, never put it, have a hoist.” Why? “Oh, people see I am in a wheelchair.” Whew! Okay, so what? “Well I don’t want to be seen like that.” Well, they are going to see you like that when you get out of your car into your chair, so why not get over it?

There was a difference between Harry’s attitude and the attitudes of other participants in the study towards the appearance of their car as one driven by a ‘disabled driver’. These attitudes could potentially be attributed to differences in personality and also possibly to differences in life stages. It is perhaps worth noting that Harry acquired his disability as an adult with a partner, a family and a career and although he changed his job after his accident, he worked in a similar area and had the continuing support of his family. He had had more of an opportunity to form a sense of his adult identity before he acquired a disability, and afterwards still had many of the things that identity is often hinged upon for adults – a partner, a family and a career. In contrast, some of the other participants, who had talked about appreciating the fact they did not look disabled when driving, had acquired their impairments as late teenagers or young adults when their sense of identity was still developing and they did not have other elements in their lives to hang their image of themselves on.

Cars and Continuity of Life

For people who had had an accident, who had acquired an impairment later in life or whose impairment had decreased their mobility over time, their vehicles could be seen as providing a degree of continuity between their former and current lives because it enabled them to continue do similar activities in their everyday lives.
For Katarina, having a specific type of vehicle meant that she had a degree of continuity between her activities before and after the accident that left her with a mobility impairment. Her family bought a campervan, which enabled her to continue camping, an activity she had previously enjoyed. The campervan ensured she would have a firm mattress to sleep on and a seat with the appropriate cushions. It also meant that she could go and rest in the back while her husband drove long distances.

Katarina: “I can’t camp anymore and you know, it’s just too difficult. ‘Cause you couldn’t put up the tent, somebody has to do that for you and that sort of stuff. So the camper is the ideal solution, you just pull up and park and yet be able to be there.”

Although there was a difference in the way Katarina did things after her accident, she could still manage do them. This is one example of how a car could help to alleviate a sense of loss and allow participants to feel that their impairments did not completely prevent them from living the life they had been living previously and the life that they wanted to live.

Driving and Personal Space

The fact that a car is a private mode of transport was extremely important to some participants. Susan spoke about her car as if it was an extension of her home where she felt very comfortable; she could leave her belongings in there, both for convenience and because it made her car a more pleasant and comfortable environment to be in.

Susan: “Well my own car is just a mess because it is an extension of, you know I leave books in the car, I leave CDs…”

For people who had to find ways of getting through periods of pain or tiredness, public scrutiny of these methods could be potentially stressful or awkward. Katarina talked about not wanting to wait in a doctor’s waiting room because she knew that she would not be comfortable and might have to lie down on the floor, which would attract unwanted
attention and possibly require explanation, whereas in her car, she could make herself comfortable and have some privacy.

Katarina: “If you have got your car you can recline your seat, relax, listen to your music and actually it becomes your little mini lounge in some ways because it is a space that you can relax in as well as drive in.”

Having personal space could give participants opportunities to rest or prepare themselves for any effort that they would have to expend once they got out of their vehicle.

Driving and Depression

Some participants had become depressed upon acquiring a disability because of their loss of movement, pain or general mobility. For some of these participants, having access to a car helped them feel less isolated and could broaden their total mobility in the world.

For other participants, the act of driving itself could make them feel less depressed. Even if they did not have a destination, the physical acts of leaving the house and driving around could distract people and bring them pleasure.

Steven: “Yeah it’s, it sort of lifts my spirits, just getting in it and going, just going anywhere. I will be sitting there and feeling a bit down or whatever and I just go for a drive around [the neighbourhood] and just the noise, rumbling along in it, it just feels good.”

Participants, who had had to give up work because of their disability, also talked about missing having a purpose and the social interaction that came with work and about experiencing depression and the feeling that they were missing out on life because of their mobility impairments.

Dorothy: “I was doing voluntary work at the hospital, so I had to get there and not getting there meant that I missed out on having the morning tea with the other ladies, and talking to the patients, and taking the smokers out for a ciggie and things like
that. I missed out on that and I, because if I couldn’t get there and I found that doing voluntary work… sort of keeps you going, so if you can’t get there it’s actually, it’s quite depressing.”

Cars and Anxiety

While some participants talked about experiencing depression, other participants had expressed anxiety about being largely housebound.

Tegan: “I think in those initial days I was probably quite happy to sit there and do my own thing for a little while but once I started to feel better and got more mobile that’s when I started to get a bit anxious and say well get me out of here.”

While Tegan was anxious about staying relatively immobile, Michael talked about the fear that accompanied thoughts of what losing his car in the future would mean for himself and for his family life. Michael considered the possibility of his car breaking down as having serious implications for his and his partner’s ability to keep their children at school and therefore to continue to parent them at all.

Michael: “We’re stuck, we’re stuck. The kids won’t be going to school, they will probably be with CYFS – government intervention.”

It is unclear whether the government department, Child, Youth and Family would indeed take children away from the care of their family when they had such complicated transport barriers to sending their children to school. However, it is a strong indicator of the significance of the role of the car for providing for the necessities of Michael’s children’s lives and his level of anxiety about maintaining access to a car.

Another participant, Jack, had anxieties about what he anticipated would be his changing transportation needs. Jack could use his car at the time of the interview, but believed that to continue driving in the future he would need significantly more modifications and possibly a new vehicle.
Cars Alone Not Eliminating Isolation

Although the majority of participants in this study spoke about the important role that driving played in facilitating their lives and about the personal significance of having independent transport, one participant, Martha, did not feel that her car saved her from isolation.

Martha: “Having the car hasn’t given me a lease on life…it’s got me out, I go in to the supermarket, go in to Westfield for what I need to get down there, but I am not out every day. I could have three days and not go out the house, so for me… yeah it hasn’t opened up a whole new world of possibilities for me.”

Martha acknowledged that her car was still useful to help her do necessary activities such as food shopping or collecting her medical supplies but felt that the car did not reduce her isolation, because she did not have enough places to go in her car where she felt welcome. Without a desirable destination, she could not participate more in society, even with her car, in fact it made her feel more isolated.

In terms of general well-being and mental health, participants clearly felt that being able to drive themselves provided elements of protection or relief from some disabling attitudes in society and made the embodied experience of having mobility impairments easier.

Conclusion

The overwhelming message about the significance of the car for participants in this study was how important their cars were to them and what the physical and emotional benefits of driving were. The mobility that cars gave people enabled them to do a huge range of things that they would be unable to do otherwise, or would find substantially more difficult, and this knowledge had implications for how they felt. Participants expressed how driving affected their identity, their social and economic participation and their mental health. The significance of driving also changed over time for participants because their bodies, lives, expectations and understanding of their disability changed over time, all of which altered the
meaning of driving. For many participants who had experienced the inability to drive for a short or medium length of time, they feared a return, or descent, into a reduced mobility and what it would mean for their lives. This absence of mobility will be explored in a later chapter; however, the next chapter will explore the practical enablers and barriers to driving that the participants faced.
In the previous chapter, I examined why driving was important and the ways in which it was meaningful for the disabled drivers in this study. These reasons ranged from what driving enabled the participants to do to how driving affected participants’ emotional well-being and identities. In this chapter, I examine the barriers and enablers that participants encountered when driving.

All the participants in this study talked about the specific, though varied issues that they faced in relation to their ability to use their car. These have been divided into issues related to the built environment, particularly parking, economic issues associated with the cost of vehicles and physical issues related to the need for vehicle modifications or self-management of chronic conditions.

Part I

The Built Environment

Driving could not exist outside of the built environment, without roads and transport systems. For the participants in this study, parking was the major concern that they had about the built environment. Indeed the issue of parking was understandably a significant part of almost every interview with the participants of this study. For participants, being able to find an accessible car park close to their destination was a key factor in being able to go anywhere and having mobility options. Some participants specifically talked about the car parking factors that made up the total journey such as whether there were disabled car parks and how many there were, the park availability, location, and the physical environment they were situated in and whether the parks were adequately monitored against abuse.
There were different views on whether there were enough mobility car parks for people to park in. Some participants were happy with the number of car parks and felt that there was adequate provision while others felt very strongly that there were not enough for the number of Mobility Parking permits issued. All felt that there would be enough if they were not abused. For those who felt that there were not enough, some considered the proportion of mobility car parks in any one area was not proportionate with the number of people with mobility difficulties, who would need to access the areas that the car parks serviced.

Vicki, was also concerned with the pressure on the limited available disabled car parks becoming more extreme in the future, as New Zealand’s population aged.

Vicki: “I think with these baby boomers all starting to retire they’re all going to start wanting these disabled parking permits. Well, many of them will probably, and there is not enough parks for them, or anyone you know? I mean it’s hard to get one now, so there is going to need to be more parks, otherwise there will be a real problem for people.”

Vicki feared that the resource which facilitated her mobility was already limited and could become increasingly difficult to compete for, as population changes meant that there would be more people eligible for mobility parking permits. This concern that a population change would affect the availability of mobility car parks, was a legitimate one as CCS Disability Action, who operate the mobility parking scheme, estimate that three quarters of the people issued with parking permits are aged 75 years and over. This age group is one that the ‘Baby Boomers’ (the population ‘boom’ of people born in the 15-20 year time period after the Second World War) will enter in the next 10 to 15 years which will significantly boost the size of that cohort. Assuming that rates of car usage and disability in the elderly stay the same, this will mean that many more people will qualify for mobility parking permits and the number of car parks will also need to increase significantly. Forward planning will be required by councils and city planners so that mobility is not further restricted for those people with a mobility impairment.
One participant, Martha talked about how she would prefer to take her car to work every day but that it was made difficult by the lack of parking available around her workplace. This meant that she relied on public transport, which was difficult to get on quickly and crowded and did not always enable her to sit down while she was travelling.

Martha: “I started taking my car in initially so I can get a park outside and I was getting too many tickets and there was no disabled parking….so no I couldn’t, I wouldn’t intend taking my car in on a regular basis no. It would be preferable, but it won’t be happening. So if I collapse on the train, I collapse on the train.”

Abuse of Car Parks

The abuse of mobility car parks (where people who did not have a mobility parking permit or were illegally using someone else’s permit, parked in a mobility car park) was a concern for many participants, although some commented on how abuse of disabled car parks was variable and could depend on the time of day or the location of the car park.

Steven: “Between the hours when parking meter maids might be around that, people are very wary about parking in disabled car parks, but after hours it’s just the normal car park as far as they are concerned.”

This is a concern because it suggests that people who abuse mobility car parks ‘after hours’ have experienced little risk of penalty for illegally parking outside of normal business. More worryingly, the message that disabled people require mobility in the evenings and weekends is not being understood. Although it is more likely that people illegally park in mobility car parks because they perceive that they can do it with impunity, it points to a need for more monitoring of parks during off peak times. Although it did not specifically come up in this study, it would be interesting to talk to disabled drivers about their experience of rates of abuse in mobility cars parks that primarily service after hours venues, such as movie theatres.

Although some participants said they would not for reasons of safety, others talked about at times challenging drivers who appeared to be illegally parked in disabled car parks, and the
various responses they received, ranging from indifference to aggression to mild embarrassment. Some non-disabled drivers who were parked illegally in a mobility car park displayed indifference when challenged by participants. One such incident was related by Steven.

Steven: “They just don’t give a damn and I’ve asked people, ‘Where is your card?’ And they just ignore you and walk off.”

The other way that people abused disabled car parks was when a driver had a mobility parking permit in the car, which had not been issued to them, which they used to park in disabled car parks even if the passenger with a disability was not getting out of the car.

Barbara: “You’ve got an able bodied driver, he pulls up in to the disabled park, he will jump out go to the shop, get whatever he wants and jump back in the car and his consideration for it is he has got the disabled person with the mobility card sitting beside him and I get really anti that sort of person.”

Another participant talked about how displaying a valid mobility parking permit properly was important for other disabled drivers, as they would know whether a disabled car park was being legitimately used or not.

Tegan: “I couldn’t see any mobility thing and the person sitting in the driver’s seat could obviously see me looking and the next minute he put down his sun visor and there it was on the sun visor. So I felt a bit silly.”

Because there was potential for a lot of frustration for a driver when people were parked illegally in a mobility park they wanted to use, disabled people who were in a car park but had not (yet) displayed their permit were likely to be glared at or asked to leave the park.
Placement of Car Parks

Participants discussed not just the number of available mobility car parks, but also where they were situated and what kind of access to destinations and services the parks gave to disabled drivers.

Susan: “In New Zealand mobility parking are few and far between or clustered in one place and when there is not an actual need of it.”

This approach to the distribution of mobility car parks seemed somewhat ad hoc to some of the participants as they thought that places which should have mobility car parks nearby, did not and other places had multiple mobility parks that did not appear to be close to the facilities they wanted to use.

However, some people felt that the placement of mobility car parks was not always the only relevant part of what the permit allowed disabled drivers to do. It also allowed drivers, who did not need the extra width that mobility car parks usually provided, to stay longer in non-mobility car parks and cost them less money.

Ian: “I do use [mobility car parks] but it’s very handy to be able to park anywhere and not worry about change and all that sort of thing.”

Ian, who lived in the Wairarapa, also felt that the placement of mobility car parks was excellent and that the council had carefully considered what the car parks would give disabled access to.

Ian: “The mobility parking system in Wairarapa is brilliant... there are a lot of disabled parking places in Wairarapa, in [my town] anyway... and they are in good places and they are well thought out.”

There appeared to be a greater consensus in the Wairarapa that there were usually enough mobility parks so that participants did not often struggle to find a park close to where they were going. There was less consensus for those participants who lived in Wellington and
Auckland, many more of whom felt that there were not enough mobility parks to provide access to the places they wished to go.

Accessible Environment Around Car Parks

Some participants talked about how it was not just important to have reserved mobility car parks to facilitate mobility, but that the environment around the car parks needed to be accessible as well. An example of the requirements for an accessible parking environment related to vehicles that had hoists or ramps for wheelchairs; these vehicles needed a car park that was significantly wider than the standard car park.

Wilfred: “The vehicle that I have now has a side ramp so I always have to find a park that is going to give me two metres on the left side of my vehicle and even a disabled, a lot of disabled parking or mobility parking doesn’t achieve that so sometimes I have to try and find a park on the end of car parks or on the side of the road.”

Not all participants who needed wide car parks had to negotiate a wheelchair; they merely required the ability to open their doors fully to be able to get their legs out of their cars easily. Although not all disabled car parks were wider than standard car parks, many of them had at least some extra room.

Steven: “The great thing with the disabled parks is they are nice and wide for wheelchairs and what have you, it’s also good ‘cause I can open my door right up. If I go in to a normal car park I can’t get out of the car.”

However, there was also some frustration about disabled car parks being widened to allow for vehicles with ramps or hoists on the side. One participant commented on the number of mobility car parks decreasing as they were widened in the area near her physiotherapist’s rooms.

Amy: “You could actually squeeze four cars in there if one was you know, the two on the end were right up against the pavement. And so with the new design they have
done they have made room for just two disabled cars, but they have got these huge gaps around the cars which is great... like if it was a van and you were trying to get a wheelchair out of the side, I can see that that would be really useful. But what it's done is that it's meant that there is only room for two cars, so I've actually gone down there on several occasions and I haven't gone in to do my rehab, because there is no parking.”

One participant talked about how the parking meters on the Auckland waterfront, which issued pay and display parking tickets were positioned too high up on posts for most of the members of the local disabled sailing group to reach, as many were in wheelchairs. The parking meters were also on poles that extended out over the edge of the wharf by approximately 30 centimetres. Because of the difficulty of reaching them, many of the group's members had been given parking infringement tickets or had their vehicles towed away. The board members of the sailing group had asked the Auckland city council to make the parking meters on the wharf where they sailed more accessible for disabled drivers and to provide more mobility car parks in the area. While the council did provide more mobility car parks, it did not change the meters, so the board members developed a relationship with the tow truck company that monitored the Auckland waterfront and explained to them the problems that disabled drivers were experiencing with tickets. This informal arrangement greatly reduced the number of disabled drivers' vehicles being towed away.

Wilfred: “[It’s] been highlighted and when we were first, or as [the group] was developing and we were needing more parks we approached them also about providing more disabled parks which they have done as well. But the towies know us a little bit better now and they tend to be a lot more lenient to us.

Interviewer: “So the council haven’t really solved the issues, but you’ve kind of sorted out your own?”

Wilfred: “They haven’t solved the parking meters not being accessible, but they kind of turned a blind eye to where we park. On the occasion we do get the odd car towed.”
Interestingly, Ben had a similar experience of parking wardens accommodating his difficulty with the lack of accessible parking around his workplace. He did not have a park provided by his work and parking in the area was difficult, so he frequently had to park illegally to be able to get to his work. When Ben explained his situation to the local parking warden, the warden volunteered to not ticket his car or have it towed away. Even after the parking wardens changed, when he explained his situation and the informal agreement with the previous warden, the new warden was happy to continue ‘turning a blind eye’ to Ben’s vehicle.

Public Versus Private Car Parks

Several participants commented on the difference between the monitoring of abuse of the mobility parking scheme in public versus private spaces. Mobility car parks that were created by local councils and monitored by their trained parking wardens were generally considered by the participants to be abused less than mobility car parks off public streets that were not monitored, or only very infrequently monitored. Participants expressed frustration that parks in retail areas such as supermarkets or attached to off street public facilities such as swimming pools, were the most likely to be abused because other drivers knew that they were likely to avoid an expensive fine or to have their car clamped.

Vicki: “You will get them downtown, but like go to the swimming pool, you are not going to get a parking warden there you know.”

On the other hand, one participant described his experience of the monitoring of mobility parking in some private car parks as being inappropriately overzealous, when even with a valid mobility parking permit, he repeatedly had his car clamped.

Craig: “On the street car parking you’ve got the council parking wardens walking around, while in the malls and stuff you’ve got those private contractors that are looking to clamp anyone as soon as they can.”
Craig attributed this to the fact that he did not superficially look as if he had a mobility impairment and was assumed to be abusing the car parks.

Craig: “When I’ve come back and saying why clamped me, I’ve had all sorts of reasons from the people, saying that your permit isn’t registered to you, to ‘there is nothing wrong with you, why are you using this park?’”

Craig thought that this was not so much the case with council trained parking wardens, who seemed to be more aware of the actual rules of mobility parking permits and more conscious of the range of people who might use them. This may have been because of differences in the training of public and private parking wardens and it could be a worthwhile exercise to improve the understanding by parking authorities of the diversity of disabled drivers.

Driving to a Parking Destination

For some of the participants, their decisions about where they would drive to were completely moderated by their knowledge of the parking availability at their destination.

Susan: “For me what is really important is to have parking spaces available, wherever I want to go so because sometimes I won’t go to places where I know that I can’t park so I will take a taxi or I will ask someone to take me there and then pick me up or take taxi back or whatever it is. I found that you know it is really important for me, it is important to drive, but it is important to park.”

This essentially meant that the freedoms afforded to the participants by being able to drive themselves were curtailed by the lack of parking at their chosen destination. In Susan’s case this meant that she had to use alternate forms of transport. However, being aware of the frequent scarcity of parking, other participants took a proactive approach to finding parking at their destination and if possible would ring ahead and see whether parking was provided or available nearby.
Dorothy: “I would actually ring up and find out, just you know say, ‘Look you know I have, have you got you know? What’s the parking like?’ Cos I mean, I don’t have a problem with ringing up a particular shop and saying, ‘Look I am coming in, I have trouble with mobility, can you tell me where the parking is or what parking is closest to you?’”

This practice is interesting because, as Dorothy describes, it took her a long time to work out various ways to manage her transport needs. This relates back to ideas of how needs and attitudes change over the life of an impaired person. It may also signal a difference in identity and comfort around the public face of disability – by explicitly telling people about her needs and asking for help, Dorothy was able to better manage her needs. Of course, the problem with this form of solution is that not everyone will reach a level of ease in proactively asking for accommodation of their needs (or even be aware of what will make their lives more manageable). Ideally, there should be publicly available resources to help navigate parking availability.

Extra Time or Planning to Find a Park

For those who had difficulty in finding parks where a minimal amount of walking was required to carry out tasks outside of the home, participants, particularly those who did not work full time or had variable shift work, talked about planning their trips around the times of day that would be the quietest and when non-disabled drivers would be least likely to be in areas where they needed to park.

Dorothy: “You get to know the times of the day where there is, parking is available. So it’s taken 20 years of checking it all out and making sure.”

This was a very useful way of ensuring that if someone had limited energy for running errands it was not wasted on a trip where they would not be able to park their car and do the things they needed to. However, being able to be flexible about getting to a destination was not always possible and having an appointment at a particular time meant that participants had to allow extra time for any mobility difficulties they might encounter in getting there. For
some participants, this time allowance when planning for a journey was often influenced by whether there was disabled parking in the vicinity.

Ben: “If I have to be somewhere really important in town I will leave half an hour earlier and allow myself an extra 15 minutes to actually find a park. Which, generally if I do that I find one first time and spend 15 minutes twiddling my thumbs, but yeah that’s one of the tough, minor annoyances.”

For Wilfred, knowing that there was not accessible mobility parking near his intended destination would mean it was very likely he would not go, and each time he had to go to a new destination he would have to work out a different parking solution.

Wilfred: “If I know there is good parking close I wouldn’t hesitate to go. And if it’s somewhere new that I’m going quite often, I will call and just find out if there is you know parking handy or if they have any other suggestions for me.”

Melanie, who lived in the Wairarapa, found that if a car park was not immediately available, one was likely to become free, if she took the time to drive around the area for a while and that most of the time this approach suited her.

Melanie: “Usually I find if I persevere and go around the block something will crop up. There has been the odd time when I’ve wanted to go somewhere and not been able to get a park, but for time constraints I’ve probably not been able to drive around and around.”

This seemed to be a more common attitude amongst the Wairarapa participants, possibly because there was a smaller volume of vehicles and people competing for car parks. There may also have been an expectation from drivers that because more time needed to be allotted for travel as the distances were frequently greater, taking longer to get a park close to their destination was not a problem.
Attitudes Towards Mobility Car Parks

There were considerable differences in the participants’ attitudes towards mobility car parks. These included defensiveness about their use of mobility car parks, a resentment or suspicion of other permit holders or a concern with being a considerate, disabled driver. Some of the people who I interviewed were somewhat suspicious about why other disabled drivers needed to have mobility parking permits, as some either did not have a mobility aid or an obvious disability.

Ben: “I think there is an issue with the amount of card holders out there and what the rationale is for them because I see a lot of people that have them that I am like, what the hell do you need that for you know, why do you need to be close?”

This frustration felt by Ben was intensified by what he felt was a scarcity of mobility car parks, combined with people sometimes illegally parking in them. When he saw people who looked as if they could be illegally parking in mobility parks, he was frustrated even if they did have permits.

Ben: “[There are] more people out there with parking permits than there are parks, you know quite often it will be like ‘Oh shit’ and they are all actual cardholders.”

However, many more participants had either felt judged or had been verbally abused by members of the public who thought they should not be using mobility car parks because they did not use a visible mobility aid, or looked ‘disabled enough’.

Katarina: “There are times when I’ve deliberately not parked in disabled parks even though there is one there and it’s available, because of that whole thing that people look at me as like, ‘Well hang about, you have got no crutches or a walking stick or whatever, what are you doing parking there?’ And yet I know that my access can be just as difficult.”
Because he looked younger than most people’s perceptions of a disabled driver and did not use a mobility aid, Craig was frequently questioned by the public about the validity of his permit. Another participant described being upset when she was confronted by a passerby whilst getting out of her car, because she had not yet gotten her crutches out of her car and therefore did not look ‘disabled enough’.

Dorothy: “He goes, ‘And which one of you has got a handicap?’ I just looked at him and said, ‘Beg your pardon?’ He said, ‘Well it doesn’t look to me like you need this car park.’ I said, ‘Oh really?’ I thought, you arrogant old prick, so and so you know and... I was still on crutches, I had both feet operated on for the second time and I was still on crutches!”

Some members of the public appeared to have taken on a monitoring role around the use of mobility car parks, and would challenge drivers whom they thought should not be parked in them. This was possibly because members of the public placed a high importance on the role that mobility car parks played in the mobility of disabled people. However, whatever their reasons, passersby were not in a position to be able to judge the legitimacy of a driver parking in a mobility park by looking at their appearance and not at whether they had a valid permit. The effect of their policing was more likely to reinforce ideas about what disability was supposed to look like.

Interestingly, the type of car that the participant drove affected people’s attitudes towards the legitimacy of parking in a mobility car park. For one participant, having a slightly sporty car meant that his car attracted attention and suspicion as to the legitimacy of his permit. Craig felt that there was a dissonance between the conception of a person who drives a sporty cars and someone with mobility difficulties and that there was an expectation that disabled drivers drove small, economical, ‘practical’ cars. When Craig drove his sister’s ‘practical’ car, he felt that his mobility parking permit was more accepted and although this did not prevent him from using his own car (out of necessity), it did dissuade him from using his permit with his own car.
Craig: “Now I don’t even use [a mobility parking permit] at all in the Hutt Valley whatsoever because, again because the type of car I have. I drive like my sister’s car which is a nice little small Mazda, little Familia and nothing flash about it and I use my parking permit on that, not a problem, even if I am walking without a limp or anything like that, not a problem. As soon as I put my Subaru in there, that’s it.”

Another participant, Steven, discussed feeling that work vans were not necessarily considered legitimate to be parked in mobility car parks either, and that people would look more closely for a permit than they would if another car was parked in a mobility park.

Steven: “I will get out, get out of the vehicle and then reach in and grab me thing and stick it on the window and you see them ah. But yeah it’s, people have a perceived view of somebody with a disabled car park permit, they drive a Honda or a Toyota Corolla, yeah they don’t think that we should have a work van.”

It is interesting to consider why it might be the case that a work van does not conceptually ‘fit’ in a mobility parking space, whether that is because there is a perception that people in work vans are more likely to misuse mobility car parks or generally park illegally more often than other people, or that people with mobility issues do not drive vans or have jobs that come with a work van.

Harry, another participant, felt there were different kinds of disabled drivers. Some used disabled car parks because they needed the extra time that a mobility car park would allow them or they needed one to be close to a particular location, such as the entrance to a supermarket or bank, to avoid walking too far to carry out the tasks they needed to do. This type of disabled driver was contrasted to those drivers who very specifically needed mobility car parks because they had a particular type of car vehicle that required a car park with extra space on one side or at the back for modifications such as hoists or ramps.

Harry: “I need that wider park for the side ramp and that and there is a little old lady parked in there who just needs to get to the shop but there was another park right next door that she, a conventional park so there to my mind we are missing the point, there is a mentality because I have the park, the disability car park card I must park in
a disability car park, no it should be to give me a compensation for over parking, being slower, that sort of thing unless I need the access for a chair or a walking frame or something.”

Interestingly, this idea had occurred to at least one of the other disabled drivers I interviewed, who did not need an especially wide car park. She acknowledged her own need for the ease of access that mobility car parks provided, but that, if possible, she would not use one with extra space for modified vehicles.

Katarina: “I know that my access can be just as difficult and you know, but I always, I have always thought you know if somebody comes in that’s, if there is a few car parks around the area I will always take an un-disabled car park because I think somebody may be coming along in a wheelchair and need all that area around and all that sort of stuff.”

Some participants mentioned not parking in a mobility parking space if there was another park available, either because the car park was closer to their intended destination or because they wanted to leave the mobility park for another disabled driver who needed it, or needed it ‘more’, as there were such a limited number of mobility car parks.

Because of their limited number, one participant talked about how she would decide on the day whether she needed to use a mobility car park, based on how she felt physically.

Dorothy: “If I am having a bad day and it’s not, it’s bad I can’t move very well but I can drive, I will use the disabled ones if they are, right I will use those. If I am having a day where I am actually not so bad and I have got to go somewhere, I won’t use them, because I figure there is someone that’s going to have a worse day than I am.”

River told a similar story of not parking in a mobility car park in order to leave the designated mobility park available to other disabled drivers, and instead, to park nearby. However, a member of the public had reprimanded her for not parking where they believed she should be parking because they saw her as taking up a ‘normal’ park that they were being prevented from parking in.
River: “I don’t like using mobility spaces if I can leave them free for other people, if there is you know not many of them and stuff. And I once had someone leave a dirty note under my windscreen telling me I should be using the mobility spaces not the normal ones.”

This anonymous person seemed to be implying that mobility parks were not there to facilitate ease of mobility for disabled people but must be used by someone with a disability, even if they were not necessary or useful for mobility at that time. The note-leaver defined general parks as a limited resource and that disabled drivers were not entitled to that resource if they had access to mobility car parks.

For Melanie, her beliefs about what ‘disabled’ meant affected her perception about the people who used mobility car parks.

Melanie: “They’re not just physically disabled people that can use the parks, I mean you can get disabled stickers for various other things, not just obvious people like you and I.”

While Melanie thought the drivers had a right to be parked there, she did not seem to think people who parked in disabled car parks legitimately were actually really ‘disabled’ unless they had a wheelchair or other walking aid.

Mobility Parking Overseas

A few participants talked about their experiences of disabled transport overseas, the mobility parking schemes that they had experienced whilst living in other countries or how they used their New Zealand mobility parking permit in Australia while they were on holiday. Tegan had intended to apply to the Australian provider of mobility parking permits while visiting on holiday, but then found that the parking wardens she encountered seem to regard a New Zealand mobility parking permit as an adequate substitute.
Tegan: “We were told from the disability place here that supplied them that, ‘Yes,’ but we had to apply for one when we got there. But the first day we were there we were in a big parking mall and we parked in the disabled park and there was a warden there and we said, ‘Is this ok?’ And he said, ‘Yup ok just go ahead and use it from New Zealand, it’s perfectly ok.’”

This was an interesting situation and suggested that the principles behind who qualifies for a parking permit are reasonably standard; so that if a person has been provided with a permit in one country, they will be highly likely to qualify for one in another country that has a similar scheme. In Australia, there have only recently been moves towards a nationally consistent parking permit scheme, as each state and territory has had their own scheme with different criteria (Australian Department of Families, Housing, Community Services and Indigenous Affairs, 2010). While the Australian Disability Parking Permits are currently being issued, they are still administered by state and territory agencies based on a variety of criteria and negotiations about nationwide criteria are continuing.

Despite this, there may be at least informal acceptance of other countries’ permits, particularly between countries with close ties such as New Zealand and Australia. However, in a situation like the one described above by Tegan, the physical appearance of the individual could affect the reaction of the monitors of mobility parks. Visual signifiers of a mobility impairment, such as a wheelchair or walking stick are more likely to present a universal picture of someone who is entitled to use a mobility park, so that someone who is challenged in their own country about the validity of their permit is likely to be challenged in a country they are visiting. In European Union countries, an agreement has been reached that having a ‘parking card for people with disabilities’ from your home country automatically entitles you to being able to park in mobility car parks in other European Union countries. Each country issues permits based on their own criteria and drivers must adhere to the specific mobility parking rules of the country they are visiting.

Much of Zoe’s experience of using disabled car parks in countries other than New Zealand came from transporting her disabled son around in Australia, when her family lived there for
a time. She felt that there was more abuse of mobility parks by the public and disabled drivers were more frustrated by the lack of mobility parks.

Zoe: “Yeah parking [in Australia] was abused a lot more. Mind you it was a bigger population I suppose, so we saw it being abused a lot more. And these people get frustrated then, because there’s a bigger need for it. And it used to make you mad because you couldn’t get a park. And it was the access too, because Tony had the wheelchair and you needed the wider parks to get him in and out and people don’t allow for that either. They never think of that you know, they squash in.”

Local Councils and Mobility Car Parks

Some participants had engaged with their local councils on the provision of disabled car parks in their local areas and been frustrated at the lack of understanding of the needs of disabled drivers. One example given was a city council’s belief that mobility car parks were only required during ‘business hours’.

Susan: “I had a discussion with the Auckland city council ages ago because I want a mobility parking space at the shop in Allen St… anyway they proposed… to have the mobility parking 8 to 6 Monday to Friday. So I wrote back to the woman, I said, “Why 8 to 6? You know it means that… before 8 or after 6 you are able bodied and you can…?” She replied back, “To be consistent with the parking spaces around there.””

The participant who related this experience was frustrated by the attitude of the council representative because as Susan demonstrated, there was a need for mobility parking in the area after normal business hours. The implication of this kind of policy, that people with limited mobility only required parking in an area during the day, meant that there was an expectation that people with mobility impairments, either would not use the area after hours, or that there was no need for specially designated parking after hours. If there was a need for a mobility park to change to a non-mobility park, this implied a demand for parking in the area in the evenings, in which case there should be mobility park for those with limited
mobility. However, this was the only reported instance in the study of participants encountering mobility parks which were only available during business hours.

Part II

Economic Issues

One of the requirements of driving is the ability to afford the initial and ongoing costs of a car. There were a number of factors in the total cost of transport for the participants, whether that cost included a mixture of public and private transport or running their car exclusively. The effect that the cost of transport had on the budget and transport options of the participants varied as some felt that the cost of transport did not influence their transport options, while others felt that they were making difficult budgeting decisions every time they drove their car. The effects of the cost of transport on participants also seemed to change over time, as circumstances made the affordability of transport a greater or lesser stress on participants’ lives. The financial burden of transport was sometimes affected by big financial events such as needing a new car or modifications or an expensive car breakdown, but even ongoing costs of running a car, such as buying petrol or keeping a car registered, could become more or less difficult as other financial variables changed.

Cost of Petrol

Petrol prices have fluctuated frequently in the last 10 years, although they largely trended upwards. In September 2008 the price of 91 octane had was approximately $2.02 per litre. In September 2009, when interviews for this study began, averages prices for 91 octane were approximately $1.55 per litre and as of Februray 2012, 91 octane was approximately $2.16 per litre (Automobile Association of New Zealand, n.d.-b, n.d.-c). These price rises, as well as being affected by inflation, have risen because of international petrol prices and flat tax increases on petrol in New Zealand.
While some participants in this study were not necessarily happy when fuel prices went up, they did not feel that the cost made any difference to their purchase of petrol; they would buy it when needed and drive as much as was required or was desirable.

Vicki: “I notice petrol going up and down, but I can still drive, it hasn’t really impacted me personally.”

However, for participants who were on a low or limited income such as a benefit, the cost of petrol had an effect on the use they made of their car and fluctuations in petrol prices meant that the amount of trips they could take in any given week had to be calculated accordingly.

Melanie: “When you’re on a limited income it makes a big difference and how often you go out of town, especially the way petrol has been. I mean you have to restrict and think twice as to you know whether you are going to go.”

For one participant, the amount of petrol used in any individual trip had immediate repercussions for other trips that needed to be taken, as well as other items in the household budget. Because of a limited amount of money for petrol, Michael had to balance the current and future transport needs of himself and his family with other budgetary considerations.

Michael: “You are always constantly looking at that petrol gauge: have I got enough, am I going to be chipping in to this, am I going to be sacrificing this trip…?”

One participant felt that the kind of fuel used made a big difference to his freedom and mobility. Wilfred had changed from petroleum to diesel fuel and the decrease in cost meant he felt able to use his car more frequently, which enabled him to participate more in his community.

Wilfred: “My latest vehicle, which is diesel, it tends not to hinder me so much, it’s quite economical to run.”

For Wilfred and Michael, there was an explicit link between the cost of filling up their vehicles with petrol and how much mobility they had in the community. Having to spend a
larger amount of their income on petrol every week meant that they adjusted how often they could leave their house and what they would leave their house for.

Cost of Buying a Car

Private motor vehicles are an expensive financial outlay for anyone purchasing one. However, many consumers have some flexibility around the need they have for a vehicle whether this is because they can share a vehicle or because they do not have very many specifications for the kind they need. Some participants already owned a vehicle before they became ‘disabled drivers’, which meant either that they drove a car before they developed an impairment or that their impairment only started to affect their mobility after they had become drivers. However, over time as participants’ cars broke down or if their physical or circumstantial requirements changed, replacement vehicles needed to be purchased and the cost of buying a car had to be addressed.

There was a variety of experiences that the participants described around purchasing a car and this was partly related to their nature of their impairments. While some participants had an impairment or impairments caused by an accident, others had impairments that came on gradually through illness or hereditary factors. The level of impairment of the participant affected their requirements and entitlements to help with purchasing an appropriate vehicle to drive. Participants who had one brought on by an illness could potentially receive funding through the Ministry of Health, though this depended on what their life situation was at the time. Melanie talked about how she had purchased vehicles at different times in her life.

Melanie: “When we moved down here, I was working and I got a social welfare car grant, or part towards a car, and then I got that. And then the next one, when I changed that I paid for it myself, and then the next one I was still working and I got a thousand dollars or something from social welfare. And I got a van with a lottery grant.”
For those participants who had acquired a mobility impairment through an accident, ACC provided whole or partial funding if they needed to purchase a modified vehicle for their mobility.

Ben: “When I first had my accident, [ACC policy] was a new car every five years, ‘cause they want to keep you in a reliable car, I think the only stipulations were: it had a cap on how much you could spend and it has to be within five years old and have power steering.”

However, Ben described his experience of ACC’s policies around entitlement to funding of vehicles changing, as he found it more difficult to get approval for funding of new vehicles over time and had some doubt about being able to replace his vehicle in the future.

Ben: “By the time [the proposed time for updating the vehicle] came round in five years time they changed the rules on me. So I ended up taking it to review... and it took about a year but they kind of caved and got me the second car. I just don’t know about the next five years.”

Interestingly, another participant, Harry, found that ACC funded a larger percentage of the purchase of vehicles that he made over time. Immediately after the accident that left him with a mobility impairment, Harry received a lump sum payment from ACC as compensation of which more than half went towards purchasing a vehicle that could be modified for him to drive. ACC paid for a quarter of the cost of purchasing the vehicle and also paid for the modifications. Its contributions to the purchase of vehicles seemed to increase as Harry’s income increased.

Harry: “The next time it was half the cost each to buy it and they did the hand controls and the hoist and the time after the same thing. So there was a top up; if I wasn’t in a good paid job... that would be not an easy thing for lots of people.”

Because of changes in his mobility, Harry’s vehicle modification needs also changed over time and his most recent vehicle had to accommodate many more modifications than previous vehicles. ACC had fully funded the most recent vehicle.
Harry: “The vehicle is insured for $110,000... all I had to do was sell the car I had and give them that money, so here is the biggest, one of the biggest cost contributions they’ve ever made and they just gave it to you and I was just blown out the water, I was like, not to say that’s not how it should be, but whew! I am going to sell my Hyundai, I might get $5000, that’s all, and half of that is theirs and half of that is mine in reality if you wanted to say depreciation and whatever. All they are saying is give us that and here is a running vehicle all fitted all kitted.”

At the time of his interview for this study, Harry’s annual salary was more than the purchase price of his latest vehicle cost and he attributed this fact to ACC’s decision to fully fund his latest vehicle, “ACC want to keep me at work... If I wasn’t working I wonder what their answer would be?”

Sometimes the type of vehicle that was able to be purchased made a difference to whether people could learn to drive or continue to drive. A common example of this was whether the car was a manual or automatic, with many people saying that automatic cars were much easier for them to drive. For people who became disabled after the acquisition of a car and came under MOH and not ACC funding, the cost of modifying their car themselves could be beyond their means and meant they did not have access to an appropriate vehicle.

Craig: “[I drive] a manual car at the moment… it’s because of the type of car I’ve got and how long I’ve had it more than anything else. If I did have it I would prefer to have an automatic car for a day-to-day basis definitely, it would just make life so much easier.”

For those participants who had an impairment that was not caused by an accident, there was a chance to receive a grant from the government to help fund the purchase of a vehicle through the Ministry of Health (MOH). To qualify for the grant, they needed to prove that they were either in full-time tertiary study, or working more than 25 hours in a paid position. One participant described his experience of applying for funding to purchase a vehicle.
Adam: “They said I could get funding for a van when I’m working over 26 hours a week. So I could now, but I already saved up and bought a ute that worked for my chair and stuff. So did it myself, instead of waiting around I guess.”

Although Adam managed to save enough money to buy a vehicle, he was lucky that he was in situation where this was possible as working 25 hours a week or less could make this difficult. In fact, because the funding criteria for help to buy a vehicle are partly dependent on their work situation, some participants talked about how their need for a vehicle and their work situation were at times at odds with each other. Not having a job (which meant not qualifying for help to purchase a vehicle) also meant that participants struggled to afford saving for, or paying off, a vehicle.

Melanie: “It’s very tough if you don’t actually fit into that criteria. I mean it’s not our fault that we’re disabled, that we can’t work.”

Adam also discussed the restrictions on the type of vehicle that the Ministry of Health would allow to be purchased through its scheme.

Adam: “I don’t really see how a van would work for me to drive it, ‘cause I can’t pull myself up into the driver’s seat being higher, but like they’d have the hoist in the back of course, which meant I could get my electric chair around, but I wouldn’t be able to get to the driver’s seat. So I’d have to rely on someone to drive it.”

Although Adam explained his physical limitations to Enable NZ, the organisation had certain perceptions about what vehicles were most physically appropriate for people with mobility impairments. Although Adam was offered help to fund the purchase of a van with a hoist for his wheelchair, Enable NZ were reluctant to fund the purchase of a coupé utility vehicle (a ‘ute’).

Adam: “They were like, well you know, you’ve got this amount for the car and this amount for that and it doesn’t really match up, if you know what I mean, sort of thing. So I just sort of passed and got everything sorted myself. I guess you know what you need exactly and you can go out and find the vehicle that suits you.”
Fortunately, despite his frustrations, Adam had the ability to bypass the funding inflexibility of the Ministry of Health’s scheme by using money that he had already saved and was able to purchase the vehicle that he felt made it easiest for him to use in conjunction with his other mobility aids.

Family Help

Some of the participants had originally learnt to drive because they had received family support to purchase a vehicle when they were young. Jack was left money by a family member and bought a car when he was at high school, River had a vehicle purchased for her by her parents and Rose’s uncle supplemented the support she received from ACC to purchase a car. Family members had identified the benefits that that these three would gain from having the mobility of a car and were able to offer financial support.

Cost of Modifications

For the participants of this study, there was a variety of experiences related to the ease of driving any particular vehicle. Many participants had had minor or major modifications done to their vehicles, ranging from special cushions or seatbelts for management of pain when driving, to hoists or ramps to get into and out of a vehicle or hand controls for control of the vehicle.

In general, participants found it considerably easier to get funding for modifications than for the purchase of a vehicle. Although not all the participants who needed modifications to their vehicle got full funding, the vast majority had received at least partial funding. There seemed to be a difference between ACC and MOH funding for these; while several participants mentioned that there was a $12,000 cap on funding through the MOH organisation, Enable NZ, ACC generally seemed to fund whatever modifications people required as a result of an accident.
Grace: “Unfortunately coming under Ministry of Health and not ACC I don’t have much money, $12,000 worth of funding which won’t go very far and that’s where it all stops.”

Disabled drivers who came under the MOH funding stream and had used up their allotted $12,000 would at times then have to make a decision between self-funding the remainder of the modifications that worked best for them, or opt instead for modifications that were less expensive, but not would meet their needs as adequately.

Grace: “My condition has progressed to the point that I can’t really operate the hoist independently ‘cause it involves walking around in the back of the vehicle, putting the wheelchair on and off... at the moment I am trying to figure out what I am going to, how I am going to do that.”

Essentially, Grace’s independent mobility had disappeared and as her condition had changed, she needed a vehicle she could drive without transferring in and out of her wheelchair. She currently had to get her co-workers or children to load her wheelchair onto the external hoist of her vehicle and so could only travel to a destination when accompanied, or where she knew someone could assist her at either end of her journey.

One participant said that although she had not received government funding for modifications, she did not explicitly pay for them either because when she bought a new car from a dealership, she made an agreement with them to put hand controls into the car as part of the total cost of purchase.

Susan: “When I buy the car I make part of the contract that they have to pay for [hand control modifications].”

Although being in a financial position to buy a brand new car appeared to be rare, negotiating modifications with a car dealership that sold new cars seemed to be easier as a dealership might generally cater to customers, who would want their car tailored specifically. This particular situation seemed to be a very uncommon arrangement, as most participants
talked about buying their cars second hand and then having them modified through Enable or ACC.

Although it was not explicitly a financial burden, one participant, Wilfred, also talked about the amount of time required to get his vehicle modified. The contract for the modification of his vehicle was with a company at the other end of the North Island and Wilfred had to travel by plane to get his vehicle modified to his needs and stay in a motel while it was being fitted. The costs of the plane fares and motel room were covered by ACC, but as well as the physical difficulty of travelling, it was a disruption to his family life.

Cost of Vehicle Maintenance

The participants in this study had a variety of financial situations so the impact of the cost of running and maintaining their vehicle also varied significantly. To better illustrate the financial pressures of maintaining a vehicle for those participants who found the cost of their vehicle difficult to sustain, I will differentiate between common, ongoing maintenance costs of vehicles such as those associated with warrants of fitness (WOFs) such as new tyres, oil changes or brake pads, and more expensive maintenance costs when something major happened to their vehicle.

Craig: “For my next warrant I needed four new tyres, that cost me $650, yeah now that is a hell of a lot of money for someone that’s on a static income yeah so but that’s the cheapest I could get them for, I am just lucky my brother works at a tyre shop otherwise it would have cost me close to $1000 at least... And then when the warrant comes around there is the unknown of what needs to be fixed on the car as well, average mechanic bill will be anywhere from $250-300 every single time that I’ve taken it down.”

Although he had very limited mobility, Michael's efforts to keep the cost of vehicle maintenance down was aided by his doing as much of the servicing of his car as he could, with the help of family and friends.
Michael: “I do as much as I can motor-wise. I do all my own services. Takes me a day to change the oil and the filter and that, but it saves me $100. Sometimes I get a bit stuck and I have to go and get the neighbour and, ‘can you wrench on this?’ I just ain’t got the power in my arm and he is quite good – he will come and help me. My wife does a lot of, taught her a lot about cars, servicing, changing tyres... saves a lot of money.”

Cost of Breakdowns

Several participants in the study talked about the anxiety they felt about their car breaking down because they felt dependent on their car for mobility and because they were concerned with their ability to afford to pay for major work to be done on it. It was clear that participants felt that the older the vehicle, the more likely it was to need serious work done on it or to break down altogether.

As well as the general financial issues that are associated with a car breakdown, one participant talked about the added effect that car modifications could have on the cost of keeping a car functioning.

Wilfred: “I also find that the more modifications that actually make it easier to use the vehicle, you’re relying on those modifications more. So the more things you do, the more chances you have of something breaking.”

Insurance

The last participant that I interviewed, mentioned that a considerable additional cost for him was his car insurance, which had to cover the expensive modifications done to his vehicle by ACC.

Wilfred: “Because of the modifications of the van were expensive to do I have to insure it for replacement cost, so you know, it’s putting up the, making the vehicle
close to $100,000 worth of machinery which is expensive to insure. And that’s a cost I have to burden… at the moment nearly $160 a month.”

Although I did not have the opportunity to ask further participants about how modifications affected their insurance premiums, this would have been significant for other participants with highly modified vehicles and would be a factor in the cost of operating a vehicle for disabled drivers that could be investigated further.

Budgeting

For participants who found the cost of transport hard to fund, fluctuating petrol prices meant they had to adopt various strategies to keep themselves mobile, such as limiting their travel, cutting spending on other household items, or diverting their savings towards their vehicle expenses. To deal with the financial costs of keeping their car going, one participant, Michael, described limiting the amount of driving he and his partner did and setting priorities for what they would use their car to do.

Michael: “With the cost of the fuel it’s like I have to budget every kilometre for the fuel, so we sacrifice our social life for the kids’ schooling and their social activities.”

There were also transport consequences to other budgeting decisions Michael and his partner had made. Because they had moved to a more remote area to save money on rent, there were flow effects on their transport costs due to the distances travelled and their distance to the nearest public transport.

Michael: “Went to the cheap part of the town to rent and in doing that I’ve halved my access to the public transport.”

Although Michael would have found it very difficult to use public transport himself, his family was also very restricted in their ability to use it because of the location of their home. The distances that Michael and his family needed to travel by car had also increased, because of their location and this affected petrol usage.
For some participants, balancing other costs against the cost of car use was not always a priority, but depended on their circumstances at the time.

Rose: “At the moment it’s a bit tough, when it was just me, single and things, it was okay. But yeah, I am now married and we’ve got a business which is struggling and a little daughter and I’ve just… I am going to have to get my car registered and warranted, and with increased petrol I really notice it. So I, now I have to really budget and not do other things or buy other things, I have to really think about it.”

For participants who considered their car a high priority, a restriction in their financial situation meant that either they had to spend less on their transport costs, or less on other expenses. A strategy that some participants used was having a set amount of money that they would spend on petrol in a time period and then not using the car after that. Although this was a good way to predict spending on petrol, it could mean that their mobility varied with petrol fluctuations.

Melanie: “I’ll go and put $30 in probably once a fortnight and that’s my limit.”

Romana talked about having to take into account the cost of being able to drive in the future when making budgeting decisions.

Romana: “I have some savings and I think that if I was doing some major planning I would always keep car money before anything else, before anything else.”

Meeting the costs of driving week to week was a struggle for some people, but to also have to anticipate future costs of vehicles and maintenance put people in precarious financial situations and under a great deal of pressure.

Institutional Inequities

Many of the participants in this study talked about the differences between receiving funding from ACC or the Ministry of Health. There was a lot of agreement among the participants that generally those who were entitled to ACC funding were in a far better position than
those who came under the jurisdiction of the Ministry of Health. Grace talked about the Ministry of Health’s cap on funding for the modification of vehicles, which in the case of her vehicle “only just cover[s] a very basic hoist like a mobility taxi has.” This kind of hoist was difficult to operate for someone who had little strength and although Grace could operate it independently at the time of the original modification, she could no longer do this and had to rely on someone helping her at either end of her journeys.

As well as feeling that the funding could not cover the best kind of modifications for her mobility impairments, Grace also found that she only just met the criteria for any funding entitlements by the Ministry of Health. It was likely that Grace would not be able to meet the same criteria for funding in the future because of her deteriorating condition, which could affect her ability to work.

Grace: “I’ve had [funding for a vehicle] approved because I fit the criteria, which I think is pretty tough criteria: you’ve got to work more than, I actually think it’s more than 30 hours a week, I only work 20 but I have got two small children, so I get it through that. But I think it’s a big ask for people that, you know, people with challenging conditions that they would have to. It seems like pretty tough criteria to me.”

This was in contrast to Wilfred’s experience of receiving funding for vehicle modifications from ACC, where: “any modification as far as keeping your independence is all covered by ACC.”

Jack who came under the Ministry of Health funding scheme, found that he did not have too many problems, because he knew exactly what he was entitled to and felt confident when dealing with the funding application processes.

Jack: “I’ve managed to kind of manage my transport needs because of knowing my way through the system quite well.”

Jack was aware that not everyone was in the position to be able to negotiate and advocate for themselves when dealing with institutions in relation to their disability.
A couple of participants, who came under ACC funding, talked about how acutely aware they were of the disparities between ACC and MOH funding and how they were in a privileged position, because of the nature of their disability.

Rose: “As you probably know it’s very hard to get funding out of Ministry of Health for things and I feel that someone like [a friend who comes under MOH funding], his need is far greater than a lot of people under ACC and just yeah that struggle, it’s just a two-tiered health system... [some] people get all the bells and whistles and then I look at people with Ministry of Health who get absolutely S.F.A. [Sweet Fuck All].”

Participants saw the institutional inequities between MOH and ACC as meaning that depending on how an impairment originated, people's ability to drive their car was dramatically affected.

Part III

Physical Issues

The third issue that participants had to contend with was the demands of being able to physically drive a car. Although some people had no difficulties with driving any car, others needed small or complex modifications to their vehicle, or could only drive a particular kind of vehicle. The ability or inability to manage chronic illness was also an issue for some participants who had to negotiate variable levels of energy or pain in their daily lives and balance their need for mobility with physical comfort and safety concerns.

Type of Car

Although many participants had extra modifications done on their vehicles, picking an appropriate vehicle in the purchasing stage could make a good deal of difference to the ability to drive and for the vehicle to perform the roles it was required for. One participant, River, needed a car that suited her specific physical needs so that she could transport herself around in it but also one that fitted the needs of the animals that she showed in competitions.
in her spare time, “I was involved in a lot of dog showing and racing and the vehicle I wanted was actually an ex-police dog wagon, but it still had the cages in it and everything.” River had difficulty finding a car that suited her body’s physical requirements and found that there was not one make of car that would repeatedly meet her needs over time; instead she had to try out a large range of cars every time she needed to replace hers.

River: “What I’m driving at the moment is a Subaru Forrester and the later ones are actually slightly higher off the ground, which are just that bit too high for me and things like that, so next time I replace it I am going to have to go back to the drawing board again and look at everything to see what suits me the best.”

Adam also had specific requirements for the type of car that he needed to buy in order to drive, which included facilitating his actual ability to drive and his ability to transfer his wheelchair in and out of his vehicle. However, he talked about how he encountered resistance from the funding agency that he came under to buy the kind of vehicle, a coupé utility vehicle, that he thought would best suit his driving and wheelchair transferral needs. The Ministry of Health did not consider a coupé utility vehicle an appropriate vehicle, despite the fact that Adam, the intended driver, did.

Adam: “[The Ministry of Health] said I could get funding for a van when I’m working over 26 hours a week. So I could now, but I already saved up and bought a ‘ute’ that worked for my chair and stuff, so did it myself instead of waiting around I guess...”

Self-management of Impairments

Not all the barriers to driving and mobility were external to the person wanting to drive, although many were. While many physical difficulties of driving could be overcome with modifications, or by changes to the built and funding environments, the physical reality of their impairments could at times be a barrier to some of the participants. Just as all drivers have to be aware of their physical limitations, so too did the participants, so that they could comfortably and safely continue to stay mobile. For some participants who were on, or had
been on medication that could potentially impair their ability to drive safely, self-management of safety while driving was important, particularly when they had received no specific guidelines from medical practitioners.

Martha: “Nothing was said to me about whether I could drive or not, or when I could drive. And I was told, ‘You have short-term memory loss with all the anaesthetics you’ve been under.’ But no one has actually quantified what that is and I have actually noticed it obviously a lot, but I don’t know the extent of the damage.”

Not knowing how the anaesthetics were affecting her cognition and ability to drive safely, was a concern for Martha, and one that she had become increasingly aware of after she began to drive again after her illness. Similarly, Barbara talked about the very dangerous (when driving) side-effects of medication she had taken in the past and how they had prevented her from driving at times.

Barbara: “When I have a relapse and I am on steroids… one of my symptoms is double vision and of course you’re not allowed to drive when you’ve got that.”

Having double vision was a clear indicator to Barbara that she was unfit to drive, and this was a straight forward assessment to make. However, for other people who took medication that could cause drowsiness or slightly change their cognitive function, it was a more subjective assessment that they were making of their ability to drive safely. One participant talked about how, at the time of the interview, she was temporarily abstaining from driving her car, because of a change in her medication and its effects on her cognitive functioning and her ability to drive (or to feel that she was driving) safely.

Melanie: “I’m on morphine-based medication now and I’m just about to go on a stronger one tonight, so yeah I mean it doesn’t make me a zombie or anything like that, my bodies used to it. There’s no way I’ll get behind the wheel of a car, especially if I’ve had a bad night as well.”

The link that Melanie made between the effects of her medication and the effects of lack of sleep highlights that these judgement calls were similar in kind, though not necessarily to the
same extent, as decisions that non-medicated drivers make about whether they are too tired to drive or not. Melanie talked about how she had previously had to self-monitor her ability to drive safely due to her medication and how she had managed the situation and self-tested her ability to drive over a period of time.

Melanie: “When I first went onto morphine it was only a low dose, well for the first week I wouldn’t even drive the car, purely for safety sake. I would probably have been alright, but I just thought no, I’ll get used to the medication. And then I did sort of drive a bit, and then I had to take it during the day as well. So I sort of had another week where I waited for my body to get used to it, and yeah that will be the same when I change it tonight, you know, I probably won’t get behind the wheel for a week.”

Managing Bad Days

Just as Melanie assessed her ability to drive based on her medication, the amount of sleep she had had and her sense of cognitive ability, other participants talked about how they had to manage their pain and energy levels and balance them against their need to be mobile and get the things done that they needed to do.

As previously discussed, some participants would conserve energy by planning their shopping or errand trips around the quietest times so they would be more likely to find a park. On bad days, some participants might decide not to go out in their car at all. But one participant also talked about using good days to do multiple-park trips that would enable him to get all the errands he needed to done at one time, so he would not need to expend the energy and deal with the physical pain from going back to town again the following day.

Craig: “If I’ve got to go from one end like where the supermarket is to the post shop, for example, I will park my car at one end, go to do my shopping at the supermarket then drive my car down to the other end to go to the post shop.”
These micro-stops depended on the ability to get parks at each point, but were effective for managing walking distances, even within shopping centres such as malls.

Modifications

When participants talked about modifications, they generally meant the machinery or devices they had added to their vehicle for comfort, safety or ease of use, or the restructuring of the interior which enabled them to get in and out of the vehicle independently. These modifications should be seen as part of a spectrum of alterations that vehicles have gone through since they were invented. Cars and other vehicles are constantly evolving as technology develops and car design progresses to make them easier, safer and more comfortable for all drivers to use. Electric windows, power steering and airbags are increasingly standard on new vehicles. These features are not installed in cars specifically for disabled drivers, but they can make vehicles accessible to a wider range of bodies and abilities. Some of the participants in this study required extra modifications to be able to drive which ranged from special seats to hand controls, to vehicles that had seats removed, ramps added and wheelchair fixtures installed.

Changes in Participants’ Modification Needs

A very common theme that emerged in discussions about modifications was how, over a period of time, the ability of participants to drive depended on different modifications and, or vehicles.

Grace: “When I learnt to drive I was probably pretty fine and just drove you know normal vehicles and things then as my condition progressed my issue is being able to get in and out of vehicles and things… And so yeah progressively I would have, you know, changed vehicles according to the changing needs of my condition.”

Frequently, if a participant’s condition became more severe and more extensive, modifications were needed on a vehicle to keep them driving and their need to drive became greater to maintain some level of independence and mobility. Some participants had current
problems with their ability to use their vehicles and felt that different modifications were already needed so that they could drive independently then as well as in the future.

Grace: “I’ve got this massive issue at the moment because I have a new wheelchair. I currently drive a car that’s completely unmodified and has a platform hoist at the back which I put the wheelchair on to but the new wheelchair is too heavy for the hoist.”

Sometimes, the modifications in their vehicle currently met the needs of a participant, but they were aware that in the future, they would need to be more extensive. One participant felt comforted by the mere fact that she knew that there were options available for modifying her car in the future, when progression of her impairment meant that driving would probably become more difficult.

Barbara: “I was lucky in a way that in my first job I worked with somebody who was quite disabled, she couldn’t use her legs and she had to have a knob on her steering wheel and she had the hand controls for the breaks and the accelerator and I used to drive that sometimes, when she wasn’t feeling up to driving. So I am actually well aware that if I deteriorate, which I hope I don’t, but probably will, I am aware there are other options to keep me driving.”

Barbara was one of several participants who talked about being aware of modifications, which could be future options for them as they got older and their bodies found the strain of compensating for existing impairments increasingly difficult. Jack talked about how his independence could massively decrease over time if he could not get appropriate modifications in the future that would enable him to get himself and his wheelchair in and out of a vehicle independently.

Jack: “Getting in and out of the car depends on my ability to manhandle the wheelchair in and out of the car and so forth. So I have got to watch that I maintain that ability [and] it’s going to become a bit more of an issue as I get older… I saw this van with all the mod cons in it the other day [and] somehow or other I have got to
acquire one of those… Cause the thing is that… even as it is, at the moment… my independence is reliant on the good will of my partner.”

The consequences of not being able to change to a vehicle that suited his needs as his physical needs changed over time were apparent to Jack; it would put a strain on his shoulders, his relationship and his independence.

Changing Safety Standards of Modifications

One participant talked about how modifications on cars for disabled drivers had become more regulated over time and that when she was learning to drive, there was little to no monitoring of the modifications done on cars to make them useable for disabled drivers.

River: “My dad realising that I was going to need a car with some adaptions anyway purchased a car for me before I was 15 and did the modifications on it himself. We’re dating back to a period where you didn’t need them all approved and what not.”

The lack of regulation of vehicle modifications meant that River and her father experimented through trial and error what could be done to make a vehicle useable for her specific needs. Having a father who was willing and able to do the modifications himself was fortunate for River as it enable her to transport herself independently at a very young age.

River: “The original Minis you could adjust how far the seat was forward and back, but because of how I sit in a car most seats actually slope sort of downwards, you sit in the seat, not on it and that sort of throws me back from the wheel so with the old Mini seats because they pivot to get people in the back what we did with that we just put it forward and put a block under the back so it didn’t go back down as low so it was just really stupid things, silly little things like that but yeah but now you would never get away with that because it’s not an approved modification.”
While it is obviously very important that safety standards be applied to cars driven by disabled drivers, the cost of modifying a vehicle themselves was lower than it would have been to have it done professionally.

**Appropriateness of Modifications**

As well as making sure that disabled drivers can drive their cars, modifications need to be done in a way that ensures the vehicle still suits the wider needs of the person driving it. Grace described how her family situation and social network were affected by the modifications on her vehicle.

Grace: “The problem is then that you end up, you are going to get some van then you’re coming in through the back of the vehicle; cause that’s where the hoists go, so then you’ve got to take all the seats out so you end up with a huge van with two seats, well with one seat in it ‘cause the other driver seats have been taken out. I mean, I’ve still got two children to accommodate and friends and things so.”

Grace’s role as a parent meant that transporting herself and her children was a significant role that she required her vehicle to play in her mobility and participation in society. Having a vehicle that was modified in a way that it could only transport herself and her wheelchair would have been grossly inadequate to Grace’s needs.

**Changing Technology of Modifications**

For participants who had been disabled drivers for a number of years and who had owned a number of modified vehicles, the advances in the technology of modifications were obvious; they could drive their vehicle more easily or simply were reprieved from losing the ability to drive because of decreases in strength or agility related to their impairment. However, being able to take advantage of these advances in vehicle modifications generally required access to funding for the modifications, because they could be expensive. A good example of the technological changes in vehicle modifications can be seen through the different vehicles and modifications that Harry had access to in the three decades since the accident that gave him a
mobility impairment. In Harry’s first modified vehicle, which was originally modified in the 1980s, he had to manually pull his wheelchair into his car once he was inside it.

Harry: “To get in the car… I would get in from the passenger side, get into the passenger seat, transfer across to the driver’s seat, had the passenger’s seat adapted so that it folded down, as it would normally do, but it was unbolted from the floor except the hinges at the front and the whole seat then pushed forward against the dashboard. And then I pulled my, lent out and pulled my chair in to that space and seat-belted it in. Today’s standard it wouldn’t pass anything, they would be highly dangerous.”

The effort required to get himself and his wheelchair inside the car was considerable but manageable for Harry, who was then in his 30s and who had the necessary upper body strength to carry out this task. However, Harry’s vehicle did not meet all his needs and the space that his wheelchair took up in the car meant that Harry could not easily transport other members of his family, which was problematic as he had a wife and three small children at the time. One of Harry’s later vehicles had a wheelchair hoist added, which put less strain on his shoulders and left more room inside the vehicle for his family.

Harry: “Most of it was practicality; definitely there was a ergonomics in terms of the chair and that on the back and with my wife. And as I sort of got older and that the problem of reaching out of the car to pull your chair in, yeah that, my left arm was probably my worst arm and that would have been just repetition type stuff.”

However, it is interesting to compare his earlier vehicles to Harry’s current vehicle modifications, where getting into and out of his car does not require leaving his wheelchair at all. The technology involved has advanced considerably and the design of the vehicle has been modified with an eye to the future, which has meant that Harry can drive now with his current mobility impairments, as well as assuring his ability to get in and out of his vehicle and to drive in the future.

Harry: “The ramp comes down, I go up that, a tight turn in to the bay, lock down, push the button, ramp comes up, door closes, car won’t start until that mechanism is
finished. If the chair doesn’t lock in to that locking position there is a buzzer sound goes off then you have got to just give it a, so to make sure the safety. I have a hand control now in there that is now only the brake and the accelerator is a ring behind the steering wheel that I can either pull or push with my fingers.”

Harry also talked about the benefits of new technology for alleviating the fatigue and discomfort of driving longer distances. Cruise control, which was a feature available to drivers of some models of cars and not specifically intended for the benefit of disabled drivers, was an example of how makers of cars look to solve the difficulties that all drivers may experience, but in doing so, can be particularly helpful to drivers with mobility impairments.

Harry: “The other big advantage on this vehicle that I never had on the others is that it’s got cruise control, so boom to set it, especially if you are going somewhere and you then can take your hands off the accelerator and move around a little bit.”

For many of the participants in this study, a commonplace, essentially built-in modification of having automatic rather than manual gears, was essential to their being able to drive. Eleven of the participants specifically made reference to needing to drive an automatic car. However, even more participants were likely to have relied on automatic gears as they drove cars with hand controls. Additionally Craig talked about how if he could afford to replace his present car, he would definitely opt for one with automatic gear change

Craig: “An automatic, most definitely it would be a lot easier especially with the leg work and hand work… I did have an automatic car at one stage and that was absolutely brilliant.”

Other participants talked about the advantages of the evolving technologies of cars in general, with people describing features such as power steering and electric windows and mirrors as making driving easier, safer or possible at all.

Melanie: “As cars have become newer they have become easier for, well certainly for me to drive, you know with electric windows and you know power steering, being
you know more standard things like that and I know the car I’ve got at the moment has a lot of adjustment in the seat compared to the original cars and things like that.”

**Conclusion**

As described in the previous chapter, having the ability to drive a car or other vehicle for their mobility was very significant to participant’s ability to participate in society. However, the practical considerations of car use were what made the difference between being mobile or immobile. The main factors that enabled participants to drive their vehicles involved whether their vehicles were properly modified to suit their physical and other needs; the physical environments that their vehicles existed in – their ability to find a park and get in and out of their vehicles in those parks; and the economic situation they found themselves in – whether they could afford to buy, modify and run a vehicle, either without forgoing other necessities in life, or without placing themselves at a considerable economic disadvantage to the rest of the population. However, there were also attitudinal barriers to participant’s auto-mobility, in particular when interacting with the public in relation to parking spaces and when dealing with institutional beliefs about who qualified for funding and what could and could not be funded.

The good thing about the barriers that the disabled drivers in this study have described is that, the transport systems that private vehicles exist in are constructed by people and can therefore be remedied by people to provide mobility to a greater range of people than they currently do. Transport is affected by the economic situation of people who wish to transport and be transported; the modes of transport; and the physical and policy environment that people exist in. These factors can all be changed through effective policy that minimises the disabling effects of society.

In the next chapter, I will describe participants’ experiences of not driving – whether through choice or circumstance – and what the implications of not driving were for them.
Out of the Driver’s Seat

This study has primarily focused on the driving experiences of physically disabled people. However, to better understand the significance of and the barriers to driving, participants were asked to discuss what experiences they had of not driving, as well as what, if any experience they had had of using public transport. All of the participants interviewed in this study drove but most of them had experienced a short or medium period of time when they had not been able to drive their car. Participants could be without the use of their car for a day or so because of car maintenance or for a period of up to several months because of surgery or hospitalisation. There were various responses to not being able to drive, and the subsequent loss of auto-mobility, which were partly dependent on the reason for the loss of car use.

When they were unable to drive, participants had to consider other options to stay mobile. The short-and-medium term alternatives to driving personal cars that participants discussed will be examined in this chapter. However, these alternatives were not only used when the participants could not drive their own car; sometimes people chose to not use their cars and instead to stay at home, or they chose to use a combination of driving themselves and other transportation methods. Using a combination of transportation methods was commonplace for a few participants, but many others would only use alternatives to driving their car if there were unanticipated problems.

Generally, when not using their private vehicle to drive themselves, participants did one of four things: they were given lifts from family members or friends, they took taxis, they took public transport or they stayed at home. For some participants, one or more of these ‘alternatives’ to driving were not possible – some participants could not physically use public transport or taxis, did not have people who could drive them, or had difficulty staying at
home because they needed to get to their workplace – but on the whole, participants had employed one or more of these alternatives to driving and related them here.

In this chapter, in addition to presenting the alternatives to personal car use, I have also included the participants' attitudes on environmental concerns and driving. Participants were asked about this issue because there is considerable concern from many quarters, including a significant amount of research from those in the discipline of public health, on the effect of car emissions on environmental health and climate change. Although there is a good argument for placing these results in the previous chapter when looking at perceived barriers to car use, I placed them in this chapter, because they conceptually hang together with the ‘alternatives’ to car use. If people reduce personal car use, then the ‘alternatives’ such as public transport and taxis must be relied upon to maintain some level of mobility in the community.

There is also the fact, as discussed below, that if local and national governments were to put measures in place to discourage car use by the public, then those disabled drivers who currently rely heavily on their vehicles would be marginalised unless steps were taken to avoid their further exclusion from society.

Part I

Lifts from Family or Friends

Because of the many ways that cars facilitate mobility such as a door-to-door method of transport, participants would often try and stay mobile with other people’s cars if they could not drive themselves. For many participants, including Craig, their first choice of transport (where they had the option) was to be driven by a relative or friend.

Craig: “I try to get my friends to come and pick me up or my brother or sister, parents, try to get other people to pick me up or I will drive to someone else’s house and then they will drive to where we have to go.”
While Craig actively wanted his family members to drive him, Dorothy only wanted family support when she was not able to drive. In these situations, she benefited from her son having his own car.

Dorothy: “If for some reason I can’t drive… my son will come round and, or his girlfriend will come and pick me up.”

Dorothy felt most comfortable being driven by her family, who knew her and understood her mobility impairments. As discussed in Chapter Four, driving with family and friends could afford an opportunity to spend quality time with loved ones.

Another alternative to driving themselves that participants mentioned, was being driven in their own car by someone else. However, this could be a temporary and less than ideal solution to not being able to drive independently. For one participant the situation arose in a work environment.

Steven: “The boss did hire a trainee when I was at my, when I first came back to work. And I let him drive a couple of times and I am like, “I will drive.”

Steven’s experience of not driving himself lasted as short a time as possible as he could manage and he resumed driving as soon as he was able.

Not everyone who was driven in their car by someone else was uncomfortable with the situation. Vicki talked about how she enjoyed going for a drive with a friend to get out the house and do something that did not involve walking round. As she tired easily, she would sometimes have them take over the driving for a while so that she could relax and still get out and about and see the scenery.

Vicki: “It’s good to be able to go out and see friends. I think it’s, I mean, you know, sometimes you get very tired so I can’t drive and sometimes I will have a friend take me for a drive and I know that sounds old granny-ish, but gosh, it’s kind of nice eh?”
For Vicki, the most important thing was to be able to get out of her house and have some time to spend with friends, and in that instance, driving her own car was not necessary.

For Adam, getting a lift to work from his mother was a more economical alternative to driving his own car every day. While he considered the lifts to be an acceptable alternative to driving himself, his caveats were that he was being driven by someone he knew and that his work was close to his mother’s workplace.

Adam: “I get dropped off in the morning by my Mum and then she works in town as well. So she just drops me off and picks me up, just. It works like that, but definitely if I wasn’t working close by and anyone that I knew... It’s like, so much better to have a car.”

One reason that Adam may have felt comfortable about being driven to work by his mother was that he did not have to travel anywhere else during his work hours. He could assume that he would not need his own car during the day and that because of their relationship, he could expect his mother to drive him somewhere if there was an emergency.

Some participants talked about being driven around by other people when they were having a ‘bad day’, when they were not allowed to be driving their vehicle for temporary disability-related reasons or when they knew that they would not be able to easily park near their destination. The participants seemed to consider getting lifts from friends and family as being the closest thing to driving themselves around independently.

Dorothy: “If I was having days where I couldn’t drive, any one of my friends would come and get me and take me to where I needed to go. You know, hospital, doctors, groceries. So I have been really lucky, I have never actually been without access to a vehicle.”

For Dorothy, having people who were close to her, drive her around meant that even when she could not personally drive, she maintained access to a vehicle, which was important to her.
Sometimes, participants who had particular difficulties with walking would either drive themselves or be driven to their destination and wait there while someone else parked the car.

Dorothy: “Maybe [my husband] will like, take me to where I want to go, drop me off and he will go and park the car, come back and meet me, do what we have to do, he will go back and get the car.”

In this way, participants could still have the convenience and comfort of their own vehicle, or could drive their car to their destination themselves without having to cope with finding a park, walking in crowds of people or bad weather. Some of the advantages of having someone else do the parking part of the journey were the same advantages as travelling in a taxi.

Another participant, Craig, actively sought people to drive him places instead of driving himself and would sometimes drive to other people’s houses to get a lift from them. As he found driving himself physically tiring and stressful, he would only do it when he could not get a lift from other people.

Craig: “[Getting a lift] just it makes life so much easier cause you are not under whatever time pressure, stresses and all that sort of stuff.”

Generally speaking, however, many participants did not like relying on other people driving them and preferred to drive themselves. As well as a loss of independence in their transport timing and decision-making, there was a reluctance expressed by some participants around opening up the potential for people to be unreliable, or for other interpersonal relationship issues to manifest themselves in a situation where they were dependent and someone else was doing them a favour. Even when participants felt that the person driving them did not mind, there seemed to be resistance to relinquishing control over their mobility.

Barbara: “I just really hate not being able to get in the car and go somewhere. So that’s sort of really, you know, it just limits you totally, irrevocably. And I get quite
grumpy about it, even though other people will drive me, I just, you know – it’s a loss of freedom, it’s pretty bad.”

Despite her reluctance, Barbara did have people driving for her when she could not drive herself. However, another participant talked about the physical discomfort of having other people drive her, compared to when she drove herself and could brace herself against the steering wheel and hold her body in a more comfortable position. When she was a passenger, Katarina could not make the decision to drive more slowly or take corners differently so as to limit jarring herself.

Katarina: “You drive differently than being a passenger, being a passenger you have got nothing to brace yourself on, you have to sit there and I would be holding on to the dashboard and the side whereas if you are holding a steering wheel you have braced your body and you are nicely set.”

This reflected other participants’ stories, where they described feeling that they could control the motion of the vehicle better when they were driving. One participant mentioned that while she drove locally to do reasonably short everyday trips, she was generally a passenger when going on longer car journeys, because after a period of time she would become uncomfortable and tired at the wheel.

Tegan: “In most cases my husband drives, because I find I get very uncomfortable sitting for any length of time driving. So about an hour and a half is tops for me driving, then I’ve got to stop.”

Tegan’s pain and discomfort in a car would only became an issue after some time and the solution for her was to accept her limitations and not drive from that point to allow her more energy to move around at her destination.
Part II

Active Transportation

The alternatives to private car use as a transportation system are usually described as ‘public transport’ and ‘active transport’. Active transport is defined as people using their bodies, with or without other technology, to get from place to place, such as walking, riding bicycles, skateboards, or scooters – and of course using a wheelchair. It is generally espoused as an environmentally sustainable and healthy (calorie burning) way for people to use their bodies rather than using fuel and private vehicles to get from one place to another (Haines et al., 2009).

By definition, the disabled drivers, who had a valid mobility parking permit from CCS Disability Action and were part of my study, had some form of mobility difficulties and had a doctor's certificate to confirm that they must:

- Be unable to walk and be reliant on a wheelchair for mobility, or

- Rely on mobility devices (eg. crutches, walking sticks, walking frames), or

- Be unable to walk more than 200 metres unassisted because of the nature/severity of their condition.

So the participants’ ability to utilise active transport was generally limited by their inability to walk medium-or-long distances. Although all people interviewed for the study qualified for a parking permit and some could not walk independently, other participants could walk or walk further if they were having a ‘good day’.

The participants whom I spoke to for this study had a range of mobility abilities, some were in manual wheelchairs or power chairs, others had walking aids such as crutches or walking sticks and some used no obvious mobility aids to help them walk. Many of the participants used a walking aid or wheelchair at some times and not at others, or used a different walking aid or wheel chair.
Harry: “[I use] a motorised chair, which I moved into this year. I use that definitely for work, to locations where I know I can go. Other than that I would then take my manual chair.”

Harry was able to use his manual chair as active transport under certain conditions. However, it appears that using a wheelchair in this manner could affect the long-term mobility of wheelchair users and Harry’s shoulders had permanent injuries from the stress of operating his wheelchair. Rose had a similar experience of using her wheelchair as ‘active’ transport.

Rose: “I’ve been a paraplegic for 23 years and I am wearing out all my muscles and I used to always staunchly wheel for miles and miles, but now my arms and shoulders and neck will ache. So I unfortunately, not by choice, use my car more.”

While I did not specifically ask about active transport, there was one participant who mentioned that he had used a bicycle occasionally since acquiring a mobility impairment. Although Steven could at times walk well and at other times found it painful and tiring, he used different muscles when he was riding a bicycle than when he was walking.

Steven: “I can ride a push bike, I have done it a couple of times lately, it’s a bit of a laugh. I can get on, I have got to get on from the one side, get on the bike and start pedalling and I am away laughing, but when I stop I have got to make sure I go to the right side – to the left, the correct side – cause if I try and put this leg down to hold myself up it doesn’t really work. So yeah, that gets a bit hairy, but yet most of the time I just take the car. If I have got to go down the dairy, I'll take the car, it’s easier.”

Dorothy talked about active transport being her most frequently used form of transport in the past, but that after she developed a condition that left her with a mobility impairment, this was no longer an option.

Dorothy: “I would like to be able to say that I can walk everywhere, but yeah anywhere I have to go I need the car. I just can’t, I’ve tried, but it’s just, it’s hopeless, I can’t do it. As I say, prior to being this bad I walked everywhere. I mean I just, I
was walking 5 km to work and home every day, didn’t think anything of it you know.”

Dorothy’s experience of using active transport a lot of the time when she was younger and able to walk long distances, affected her opinion of other people utilising it now. She believed that young and able bodied people should walk if they could and not rely so heavily on cars.

Dorothy: “I get really annoyed when I see these young ones and they say I have got to have a car, I need it, and I am thinking oh you’re young you can walk, yeah use it now before it disappears you know.”

In summary, although active transport was seen by participants as an option for other able-bodied people, or in some cases something that they might have utilised prior to becoming disabled themselves, it was generally not considered a viable option for them in their current circumstances.

Part III

Public Transport

Public transport is made up of various transportation modes such as buses, trains, trams, ferries or airplanes, where people share a vehicle with members of the public to travel around. This is different from other forms of transport sharing methods such as car-pooling as it does not rely on pre-arranged travel with specific people. Like active transport, public transport is generally regarded as an environmentally friendly alternative to private car use because of the pollution caused by fuel emissions from petrol. Although public transport could also produce emissions, the emissions created were relatively less when transporting a larger a group of people than when an individual car produced emissions. Public transport is also seen as a more efficient way to transport groups of people, cutting down on congestion, traffic and eliminating the need for more roads to be built.
A minority of the participants in this study used public transport. Although the reasons participants gave for not using it were varied and in some cases, the problems faced were unassailable, some of the reasons given highlight ways in which public transport could be improved so as to make it more usable for physically disabled people. People talked about the safety issues, how comfortable they felt when travelling in it, the distances that they had to walk to access it, the convenience of using it as opposed to using a car, the difficulties of getting on and off it and the attitudes of the drivers and other passengers to themselves and their impairments.

Some people, such as Wilfred, had used public transport in the past, but had decided to no longer use it, for a variety of reasons. His reluctance was to do with the difficulty of actually being on public transport when it was in motion.

Wilfred: “I have tried, I’ve caught the train a few times and I’ve caught the bus once and I wasn’t comfortable, I was kind of, didn’t think it was a safe situation in my chair.”

Wilfred, along with some of the other participants, particularly those who had acquired their impairments later in their lives, discussed using public transport when they were younger.

Wilfred: "It had been a while before, but I used to rely on it totally, I don’t know maybe 20 years earlier, before I had a car."

Wilfred’s previous positive experience of public transport probably meant that he was more likely to attempt to use it after his accident, as he knew it had previously met his needs. While he seemed to view it in a positive light, particularly for those who, unlike him, had always or could still use it easily, other participants did not like or had ever liked it, regardless of their physical mobility.

Steven: “Never been a fan of public transport, I used to catch a bus to school… for college every day.”
This comment and others could possibly mirror the attitudes of other, non-disabled, members of the public and their ambivalence towards it. Steven associated it with being young and not having other options. In popular culture, cars are often portrayed as being “cool” and symbolising independence, adulthood and financial means.

Attitudes towards Using Public Transport

Overall, there was not a lot of enthusiasm for public transport amongst participants. This is not necessarily surprising as the participants were all, by definition, drivers who had mobility difficulties and as discussed in my literature review, people with impairments are more likely to find it especially difficult to use. I anticipated that at least some of my participants would be unable to use any form of public transport, and in fact, only a few of the people I interviewed used it on a regular, or semi-regular, basis. Many others said they would never use it, because it could not meet their transport needs because of their mobility impairment.

In Auckland, public transport was not generally seen as a practical option for the people I interviewed, although as one participant pointed out, this attitude was also often shared by non-disabled people in that city. Susan expressed the view that the problems with public transport in Auckland were multiple and systemic and not just problems with accessibility or ‘disability-friendliness’.

Susan: “Public transport in Auckland is abysmal… they don’t take you where you want to go.”

Another participant in Auckland spoke more specifically about public transport not covering the areas that she needed to travel between, but acknowledged that she had not tried to catch any public transport herself and that this sentiment could be partially her own perception of the limited coverage.

Grace: “Generally those buses are not going where probably I need to go. I have to be honest, I’ve never really checked it out, but I would assume maybe not or you would have to go to the bus station and maybe change buses or something.”
Regardless, Grace felt that there was not much advantage in investigating where public transport routes were because, as a wheelchair user, she knew that her disability would make public transport extremely difficult as she would have to deal with getting her wheelchair on and off buses or trains.

Other participants spoke with more certainty, based on past experiences about how public transport could not meet their transport needs. Participants were conscious of the various ways in which it would be difficult to use it and how it could not give them the mobility that they gained from driving a private vehicle.

Wilfred: “There’s no public transport that could achieve what I am doing [driving my own vehicle], there is quite a distance for me to catch a bus.”

While attitudes towards public transport use in Auckland were generally very negative and it was seen as inadequate as well as inaccessible, in another region where there was a low level of public transport, participants were not so much negative as indifferent to it.

In the Wairarapa, many participants seemed to not really consider it as a viable option for getting around their neighbourhood. Some participants travelled to Wellington by train, but for everyday trips, they always used their own car.

Romana: “I use the train to go to Wellington and I drive to the station, I get picked up at the other end so anything that doesn’t involve walking I can do.”

The differences in attitude to public transport in the Wairarapa in comparison to Auckland could well reflect different general attitudes in the region towards it. There was very little traffic congestion in the Wairarapa and therefore, public transport would not be conceptually framed as a way to reduce that congestion. Instead, it was simply seen as a way for people to get around when they were not using cars or walking.

Some participants seemed to have a complicated relationship with how they felt about it. Frequently, people had both physical (disability related) reasons for not being able to use public transport as well as a general dislike of it. One participant talked about his difficulty
with managing pain on public transport when he was unable to drive, but also talked about
how it was something he used to use only before he could afford a car of his own. He
viewed it as undesirable, to be avoided for himself, if not for other people.

Steven: “I used to bus around [the city] ‘cause we couldn’t afford to own a car while
we lived in the city, but once we moved out to [a different suburb] bought a car,
house. And yeah, since I’ve had cars… public transport is something you put the wife
on, drop her at the train or at the bus.”

When Steven used public transport, he was not only vulnerable to more pain but he was also
unhappy about just being on it as opposed to driving himself in his car. However, it should
also be considered that having had negative experiences on public transport in the past, or
hearing about others’ negative experiences could very easily colour peoples’ attitudes towards
it and mean that they had cultivated a permanent distaste for it. Even if a particular public
transport mode was reconfigured to make it more accessible and ‘disability-friendly’, some
people with mobility impairments could continue to view it negatively and perceive it as not
being able to meet their transport needs and the needs of other disabled people.

Physical Difficulties of Using Public Transport

Participants talked about the physical difficulties of using public transport. Many of these
difficulties stemmed from getting on and off buses and trains. One participant talked about
finding it difficult to climb the stairs on a bus and to do it quickly enough to be secure in
their footing by the time the bus started moving. This was essentially a matter of the bus
driver not taking the time to ensure that they were securely seated before pulling out of a bus
stop.

Dorothy: “You know buses... and trains, you can get in, if you have noticed the door
stop and the train starts and you haven’t got to your seat and for some when you’re
not too steady that can be a real, that can actually be quite dangerous... I mean these
bus drivers, the way they drive these days. I mean you pay your money and they put
their foot down and it’s like well can you wait? I need to get to my seat.”
Dorothy’s negative experience of public transport, when she had been put at risk of serious injury, also meant that she had become wary and was not prepared to use it again.

For participants in wheelchairs, getting on and off public transport was difficult and meant they needed to be able to access buses and trains with ramps. Although not all buses had ramps and not all trains had attendants who would be able to operate their ramps, some wheelchair users had discovered that, as individuals, they could ring the bus or train company and organise for special assistance on a train or could request an accessible bus at a certain time and on a certain route.

Adam: “I think what we did is just rung up and said I’m going to work at this time and leaving at this time and they’d sort of send the bus. But then, like I had a couple of occasions where there was a rugby match in town that night, so they’d send the bigger bus with the ramp to the rugby match and send a bus with stairs.”

Although making special arrangements for accessible vehicles was not always successful, Adam still tried to use public transport on occasion. He also described how he learnt out that members of the public could ring up bus companies and ask that a wheelchair accessible bus be put onto a particular route at a particular time.

Adam: “I think one of the bus drivers actually told me about that and so once I got home I rung the operator and stuff.”

This sometimes worked well for Adam, but it was not an ideal solution as there was not widespread knowledge of the availability of this kind of service amongst participants, the system might not work as well if more people knew about it and it was not necessarily a service provided by all bus companies.

Even small obstacles to getting on and off public transport could prevent some people from using it. Donna talked not just about the problems of getting onto a train, but also the problem she had of even getting onto the platform.
Donna: “I would catch a train, but it means I’ve got to walk up a steep runway, or whatever you want to call them, to catch the train and I can’t do that, it’s too much for my legs.”

Aside from the difficulties getting on and off public transport, riding on buses could cause pain both during the trip and after.

Michael: “I broke my pelvis in seven places, broke my femur in four, my tib’ and my fib’, shattered my forearm, severed my ulna nerve, fractured my skull, jaw – who knows. So pretty full on. And I mean, getting up [onto a bus, it’s] the big step ups on to them. They are uncomfortable seating, just aggravates the pelvis something shocking, just all the jarring and the roughness.”

Steven also talked about the potential for pain involved in using public transport, because he could not always control his physical environment in a public space and could be thrown around by the vehicle's movement, or be jostled by people bumping into him.

Steven: “If I have got my car I don’t have to wait for public transport, which for the first three years of having this [disability] my wife always sat on the side of me if we were in a public area ‘cause I was very tender and having people knock in to me was not good. And they think that the things you are hanging on to [crutches] are for decoration.”

Even when buses did have ramps for wheelchair access, one participant found that the ramps did not always work. Rose tried to catch buses but was put off by her experiences and gave up on them after she encountered more than one bus ramp that broke when she tried to use it.

Rose: “I’ve tried and it’s been very unsatisfactory in general because they either don’t bother to stop or when they do stop their ramps are used so infrequently that on two occasions when they went to put the ramp down the ramp fell off, the bracket had rusted.”
Although Rose said that she would not continue to try and use public transport because she did not feel that it was reliably accessible, Adam was optimistic that it could be improved in the future and that this would allow him to rely more on it than he did in the present.

Adam: “When I was working in [a Wellington suburb] there was no train to and from. And also the ramps aren’t that good onto trains, but I think they’re modifying them so they could get better.”

Even recent bad experiences did not put him off the possibility of using public transport in the future. One of the specific areas that Adam thought could be improved was the ramps. Although trains were more likely than buses to have functional ramps, some of the ramps on the trains, which were supposed to be used by people in wheelchairs seemed as if they were primarily designed for push chairs and were not necessarily appropriate for wheelchairs as well.

Adam: “It was a bit difficult though, like the ramp was too thick to get under the chair, so I sort of had to tip it back slightly or take some of the weight off the front. So they weren’t made too good for electric wheelchairs, I think they were more made for prams and stuff, but it worked if we needed it.

With assistance, Adam could get his wheelchair onto a train, though he could not do this independently. Another participant, when commenting on getting on and off public transport, mentioned having had a similar experience of kneeling buses.

Melanie: “[They are] supposed to have those, what do you call them? Kneeling buses. So if I had somebody with me I would be able to go in my wheelchair, but on my own, no.”

For Adam, having to rely on a support person while using public transport made it less desirable than being able to drive independently.

Although Zoe had not experienced all of these issues, she knew the limitations of her body and was able to anticipate the difficulties she would be likely to face on a bus.
Zoe: “I would have a lot of trouble getting my legs up off and on a bus, so I don’t even try.”

Some participants knew, even without direct experience, that inaccessible public transport would not meet their needs or be appropriate transport because of their physical limitations, particularly if the vehicle had not been modified.

**Parenting and Public Transport**

Participants frequently needed to transport others as well as themselves and this was particularly complicated when they had dependent children. Public transport, which could be difficult to navigate with a mobility impairment, could be even harder when having to look after children at the same time.

Melanie: “I was at home all the time I certainly couldn’t take him on buses, couldn’t cope with that with a push chair so yeah I mean having the car I was just able to have a normal life… it enabled me to go places, do things that I wouldn’t have been able to do if I didn’t have the car whereas an enabled body person probably wouldn’t have worried because they would have just jumped on the bus with their kids and led a normal life.”

Vicki, another participant, did not use public transport herself, but saw the benefit of it and talked about her young daughter using it. She hoped it would allow her daughter to be independent in the future, even if she herself was dependent on her car.

**Safety**

For the participants who used public transport, or who had used it in the past, some were concerned about theirs and other's safety while travelling on a vehicle such as a bus. This was particularly true for those in wheelchairs. Wilfred mentioned feeling concerned about going round sharp bends and his wheelchair tipping over, or that he might be thrown from his chair altogether if the bus stopped suddenly, as there was nothing to secure his chair to.
Wilfred: “Just doesn’t feel like I was locked down, you know I was kind of at the mercy of the way the bus rolled and was holding on… the bus driver doesn’t tend to slow down because there is somebody in a wheelchair and you’re really relying on the brakes on your wheelchair to stay situated.”

Because people in wheelchairs did not have a seat belt on the bus, have their seat bolted to the floor or even have a seat in front of them to hold onto as many other bus passengers had, they could be particularly vulnerable to injury.

There was also mention of the limited room on a bus. Participants could feel as if they were blocking the exits for other people which, as well as being awkward and slowing down the bus, could potentially create safety issues for other passengers. Getting on and off public transport was also considered a safety issue for some people as they did not necessarily have the stability or strength to right themselves if they stumbled.

Donna: “I have already fallen off a couple of buses so, and I can’t, I am too far away from a bus stop as it is.”

Difficulties with getting on and off a bus could be exacerbated by having to walk to the bus stop and possibly becoming tired before even trying to get onto it.

Attitudes towards Disabled People on Public Transport

Some participants who used public transport were very aware of being in a public space and of the attitudes of the people they encountered, both those who worked in the system and those who used it. Some of the participants who were reluctant to use it remarked on the attitudes of the workers, such as the bus drivers or train conductors. When they needed assistance, they were dependent on the goodwill of the staff.

Adam: “I’d say the train people were more friendly than bus people definitely, but the bus was easier… they’re just always in a rush so I’m sort of a hassle when I get there
you know what I mean, they’re not as – probably in part of their job if they’re driving they have to help.”

The attitudes of the people who worked on public transport affected how Adam felt about using it as he knew that only some of the drivers would be helpful and patient when he needed to get on a bus.

Adam: “It sort of made me not want to use it anymore. I don’t know, it just got really annoying and stuff. But after a while I got to know a couple of them from occasions and certain days I was working and just hoped that they were on.”

This uneven experience of Adam pointed towards more training being needed for public transport workers about the differing needs of their passengers.

Donna’s experiences of falling on buses meant that she was reluctant to use them again, not just because of the potential for more injury but because when she had fallen, no one had offer to help her get up again.

Donna: “I wouldn’t trust another bus, not after falling off a couple of times.

Interviewer: “That’s really scary.”

Donna: “And embarrassing. And when they won’t help you...”

However, negative experiences affected more than just that one specific disabled passenger. Other disabled people’s negative experiences also affected how a disabled person might feel about whether they would try to use public transport.

Grace: “I know enough people that get buses around Auckland that tell me what a nightmare that is and half the time the drivers don’t want to get the ramp down, so they just drive past the person in the wheelchair, leave them at the bus stop. So yeah, probably not something I would like to try to be honest.”
Another participant offered an explanation for some bus drivers being annoyed and others being helpful to disabled passengers. She believed that their attitude depended on the time of day and whether the bus was running late or not. If there was plenty of time, drivers seemed happier to have someone in a wheelchair or on crutches take longer to get on a bus and settle safely.

Rose: “Some of the drivers are lovely, the ones that I think are on time and it’s not at rush hour, but when it’s at rush hour the last thing, my interpretation is the last thing they want is a disabled person that’s going to take a bit of time to get organised.”

However, disabled people also needed to be able to use public transport at peak hour times and did not always have the flexibility to travel during off peak times. Bus drivers being impatient with disabled passengers during busy times was one part of the exclusionary attitudes that could prevent people with mobility impairments from considering public transport as a viable option for transporting themselves.

Rose also talked about feeling uncomfortable on public transport because some passengers, who were perhaps unused to seeing a person in a wheelchair in that situation, would stare or act inappropriately.

Rose: “When it’s a pretty full bus it’s quite intimidating women with prams and they don’t want to move out of the space for wheelchairs and everybody is staring, just not a comfortable experience at all.”

Having people stare, made Rose and other participants more reluctant to travel on public transport rather than being in the privacy of their own car.

**Distance to and from Public Transport**

Some of the participants I interviewed were able to use public transport by combining their car use and public transport together to satisfy their transport needs. Although she could not walk or catch a bus to work, one participant could drive to and from the train station and
then use the train to get to her work. Another used the same configuration of car use and train travel when she was visiting people in another town. However, for other participants, while they could use public transport in the sense that they could physically get on and off it, the distances they had to travel between the public transport and their origin or destination prevented them from using it on a regular basis.

Romana: “If it involved walking at one end or the other it wouldn’t be on, I couldn’t do it. So I mean public transport only works if it went from my door to the door of where I wanted to go, it’s the only way it would work and it doesn’t happen.”

It was the total journey that participants had to consider when deciding whether they could or would use public transport and not just the physical difficulties of being on or using any particular transport mode.

Lack of Availability of Public Transport

In the Wairarapa in particular, participants spoke about the limited amount of public transport contributing to their decision to reject it as a practical option for their transport needs.

Romana: “Public transport in [my town] is tricky, because I don’t know what time the buses go or anything, but they obviously don’t go into the [...] suburbs at all so public transport in [my town] would do me no good whatsoever... public transport is not really a factor.”

Similarly in Auckland, some participants discussed feeling that even apart from accessibility difficulties, public transport did not provide participants with enough options for dealing with their transport needs because there were not enough routes. The geographical coverage of public transport was particularly important if participants were working. Dorothy whose workplace location changed from day to day explained,
Dorothy: “If I couldn’t get to work I wouldn’t do the job, I wouldn’t get paid so, and the type of work that we do you are not going to the same place every day so you need a vehicle to get to where you’re going, and yeah that’s, it’s not, I mean... you can’t get there on public transport anyway.”

Participants made complex decisions about how transport was going to best meet their needs. When work entered into the equation, travel could not be as flexible in timing and people could not make a decision to go to a different location because of the ease of transporting themselves there. Participants also wanted to be able to control their time of departure from somewhere so that they could make best use of their energy or how their body felt at a particular time and public transport sometimes made this difficult.

Martha: “[Driving my car rather than using public transport] would be preferable yeah because, you know, you don’t get bound, if you need to leave or go, you can go – as opposed to having to line up with 1000 other people when the trains are delayed etc and not feeling well.”

Although Martha did use public transport for various reasons, to get to work, she felt that it was not ideal for her body’s needs since developing her disability and she would change her transport mode if she could.

Preference for Driving

Although some participants had disability related reasons for not using public transport, they also mentioned wanting to use their car independent of any difficulties with public transport.

Ian: “I would rather use my car, or I would see the bus stop is a reasonable distance away from where I live and I would rather scrounge a ride with somebody else until my car got repaired or sort of got another car if it was written off or something like that. But I wouldn’t use public transport in Wairarapa at all if I had no other way… I just prefer using my car.”
As might be expected of able bodied people, people with mobility impairments had a variety of reasons why they did not use public transport. For the general public, choosing to use a car over public transport came with many advantages and disadvantages that they had to weigh up. For people with mobility impairments, there were also extra considerations to do with environmental, social and attitudinal barriers, as well as personal physical considerations associated with it use.

Ecological Concerns

When participants were asked about any thoughts or concerns that they had about driving or car use in the future, none of them independently raised ecological concerns. However when questioned about the environment, there appeared to be two common responses from participants. The first was that participants did not think about or particularly care about the ecological impact of car use, and the second was that although they were concerned, they felt that they had no choice to using their car because they felt their disability gave them few or no other options. For the second group of participants, there seemed to be some hope, that in the future, technology would create cars that were less polluting so that people could continue to drive them without the negative ecological implications.

While some of the participants who stated their indifference to or frustration with ecological concerns about car use, did not comment further on their replies, others elaborated somewhat on their perspective.

Dorothy: “Couldn’t care less about the environment, I will be six foot under before that bothers me, but no this is all me, me, me. You know, when it comes to moving around, cars and things.”

This statement of Dorothy’s about driving and its ecological effects could be taken as a statement of the over-riding importance of driving for her as a person, whose impairment meant that her mobility depended so heavily on car use. However, it could also potentially be seen as indicative of wider societal attitudes towards car use and ecology. In the context of her interview, it was clear that Dorothy’s mobility revolved around car use and she would not
make the effort to participate in her community if she did not have a car. It is perfectly reasonable to consider that Dorothy’s attitudes towards cars and ecological concerns may encompass both positions – that because of her impairment, she had an arguably greater need to be able to drive than other people, regardless of the ecological effects and that she would not care about the ecological effects of car use if she did not have an impairment.

Other participants expressed similar sentiments about their driving and ecology. When asked if she had any concerns about driving and the ecology in the future, Zoe merely responded, “No.” While another participant was interested in preventing ecological pollution, she did not feel that claims of climate change were completely convincing and therefore did not warrant a general encouragement to reduce car use.

Susan: “I am not totally convinced about climate change, I think there are still arguments for and against… I have always been that mindful and I don’t believe in [wasting] energy, but I wouldn’t limit myself to drive my car because of pollution… no way.”

While Susan was in favour of recycling and was concerned about the wastage of resources, her ecological concerns did not relate to her car or her driving habits and this, combined with her strong sense of dependency on her car, meant she had no intention of changing those habits for ecological reasons.

The few participants who said they had ecological concerns about driving, all commented that they felt that their need to drive their car overrode the feeling that they should stop driving.

Amy: “Like most other people I have environmental concerns about [driving my car] but I still do it, you know? I have a car which is relatively economical on petrol and I mean, I keep it serviced so that it’s not badly polluting the atmosphere, but I take plane trips and plane trips must be the worst in that… so yes, I have environmental concerns and I still drive a car.”
Interestingly, Amy believed that most other people had environmental concerns about driving their cars. At any rate, her experience of both having environmental concerns about certain kinds of behaviour but nevertheless continuing them could be an attitude which is commonly shared in a society where people are increasingly being asked to reduce their reliance on cars and petrol.

Jack talked a little about his belief that environmental concerns about the effects of car driving should primarily be addressed by non-disabled people, who would find it easiest to use public transport or use other methods of travel that did not involve cars such as active transport.

Jack: “Yep environmental things do affect me, but the thing is that I think that in the scheme of things that there is that kind of, sort of issue between people who drive and people who can use public transport so.”

Although Jack was concerned about the environment, he thought that climate adaptation should begin with those who were the most able to physically adapt. This is a similar argument in some ways to the idea contained in the Kyoto Protocol (United Nations, 1998) that ‘developing’ countries should have longer to change their production to less polluting methods than ‘developed’ countries, because ‘developed’ countries have already benefited from those highly polluting production methods. An analogy might be that because able bodied people already have multiple transport systems that give them high levels of mobility, those with mobility impairments should be given more leeway to use forms of transport that pollute more than public transport.

Jack was also concerned about moves by local government in his area to reduce the number of cars in the central city, because he feared they were not recognising the needs of disabled drivers who could not easily or at all get around the city if they could not park close to their destination.

Jack: “[They are proposing] a kind of a shared pedestrian vehicle type pathway if you like, and kind of restricting the number of vehicles that can go in to inner city areas, and those type of issues has got to be a balance of access for people with disabilities,
so that people who need to use vehicles can have access to those types of areas and park without being penalised too much.”

He pointed out that when councils fail to create an accessible environment in which to facilitate driving for physically disabled people they are effectively geographically and socially excluding disabled drivers from participating in society. As discussed in the previous chapter, making it difficult for disabled drivers to park their cars creates similar issues to not having a car at all.

For Rose, continuing to drive a car was not negotiable, but she acknowledged that she would prefer to drive a less polluting car if she had the financial means to purchase one and have it appropriately modified.

Rose: “In an ideal world I would like a hybrid car in the future, because I always need to use a car, so I would like it to be as environmentally friendly.”

For hybrid cars to be accessible to disabled people, especially those on lower incomes, they would need to be affordable and readily available in the second-hand car market.

Another participant talked about how he would like to be able to convert his current vehicle into a more fuel efficient car and that he had future plans for making his car less polluting.

Craig: “The whole idea of hybrid cars going to electronic cars which is about time, even the water based engine… that sort of stuff should have come out a long time ago, should have been off petroleum, should have been off diesel… I mean I’ve got a turbo car, but if I could convert it in to a hydro-electric or whatever I would, but otherwise I will most likely look at some form of green vehicle.”

Interestingly, one participant mentioned being worried about regulatory steps that the government could decide to take in the future to address environmental concerns about pollution from cars. Barbara felt that owning an older car that might not meet emissions standards in the future could mean that she would lose the ability to drive, as only cleaner vehicles would be able to be registered to be on the road.
Barbara: “My major concern is all the modifications they are making to cars to make them more non-polluting and I can see a stage where I am not going to be able to keep any one car for a long period of time because they are going to just push the older cars off the road and make you have these new ones…”

The cost of buying a newer, more efficient car felt prohibitive to Barbara and she was also aware of having to modify any new car that she bought. The combination of these two costs made her fear that pushes to have people drive less polluting cars could mean that in the future, she would no longer have the financial means to drive.

Ian discussed his thoughts on the future of cars and felt that in the foreseeable future, car manufacturers would produce non-polluting models and that consequently, there would not be any need to reduce car use for reasons relating to fuel emissions.

Ian: “I think the day will come when every car is environmentally sound, I don’t think that day is far off... I believe that will happen in the next 10-15 years, every new car that’s produced will be environmentally sound.”

He commented that although, in ten to fifteen years all new cars produced would be non-polluting, the number of cars already on the road, together with those that would continue to be produced up till then, would still be creating pollution for many years in the future. However, because Ian believed that there would be an eventual end to pollution from cars, he felt alright about driving his car now.

While many participants expressed the view that that they were not at all concerned about the environmental impact of cars, those who did engage with the question implicitly suggested that, on the basis of their impairments, they should be held to different standards than the general population. Of the participants who were concerned, none said that these concerns would prevent them from using their cars to enable their mobility.
Taxis

Taxis were used by some participants as an alternative to driving their own car, although they were generally considered a very occasional and prohibitively expensive one. There were differences in experiences of using taxis as some participants found them physically easier to travel in than their own car, while others found them much harder. Similarly, some people considered using taxis to be more convenient than driving, while others found travelling by taxi to be an inconvenience. People also talked about issues such as safety, whether using taxis was more economical than running a car and the role of taxis in enabling disabled children to attend school.

Physical Difficulties of Using Taxis

Although taxis were an alternative to private driving or public transport for some disabled drivers, some of the participants in this study had difficulties being driven in taxis because they did not have the supports they needed (and had set up in their own car) to be able to sit comfortably without pain.

Katarina: “I couldn’t sit in a taxi ‘cause it was just too uncomfortable cause the seats were sloping back and by the time you got your paraphernalia that you needed, and then they would drive so erratically.”

For Rose, taxis were acceptable to use occasionally, but they did not have the specially padded seat that her own car had and this would cause extra difficulties through skin rubbing if she travelled in them more often.

Rose: “I have a suitable seat in my car for my skinny bum and if I get taxis all the time it wouldn’t be good for my skin.”
Being able to tailor their own car to their needs and comforts meant the difference between pain and tiredness and ease of driving and therefore mobility for some participants. However, taxis would be more comfortable for other participants, because they could relax and not have to do the driving themselves which could also prevent tiredness.

Safety

One participant, who was a wheelchair user, described feeling unsafe in taxi vans, which were often sent when a taxi was ordered. Because the taxis had hoists, passengers would stay seated in their wheelchairs for the duration of the trip. Although such vans had restraints for the wheelchairs, Ben said he felt unsafe and unstable when travelling this way.

Ben: “Sitting up in the wheelchair, it feels wrong being in your wheelchair moving, yeah I have fallen over in a couple of them and don’t like them anymore.”

For this reason, Ben preferred taxis which were unmodified so that he could transfer in and out of a regular seat and store his wheelchair on a seat or in the boot of the car. This accommodation was not possible for all wheelchair users, so issues of safety when travelling in a wheelchair in taxi-vans are relevant. However, no other participants in wheelchairs mentioned this issue.

Taxi Driver Attitudes towards Disabled Passengers

Although participants did not generally use taxis very often, it was surprising that one of the reasons that they did not use them was due to the attitudes of some taxi drivers towards their impairments. Katarina found being in a car uncomfortable and although she could modify her own car to be more comfortable by getting help with some slight adjustments, she found this difficult when travelling in a taxi because the drivers often viewed adjusting the seat as inconvenient for them and did not want to help her.
Katarina: “I could be comfortable but you can’t lie down in the taxi you know and they almost get offended if you ask to make changes or modifications for the seats and then they won’t do it for you.”

Rose found it difficult at times to even get a taxi driver to accept her as a passenger during busy periods. She felt that because she was a wheelchair user, taxi drivers could see that she might take a little longer to get in and out of the vehicle which could slow their turnover and prevent their getting more fares.

Rose: “…Especially late at night down at the waterfront, down at bars in Auckland. Been out with some friends and there will be a lot of people around, taxis queuing up and the drivers don’t want to have to bother to get out, so they will try and drive on and say ‘No, no, no, cannot take wheelchair.’ And that sort of thing, so now I take their numbers and ring their superiors.”

Although not all participants who used taxis reported having negative experiences, taxi drivers' attitudes could potentially add to a reluctance on the part of the participants to feel that they could rely on taxis as a way of transporting themselves.

Cost

Many participants considered taxis to be so expensive that they were essentially not a transport option at all, and this was expressed as the major, and at times, total, barrier to taxi use. When Romana talked about taxis being the only transport option she could physically manage other than driving herself, she equated this with not being able to leave the house.

Romana: “There is no other way, apart from cabs, to get to places so… if I didn’t drive I would be house bound.”

Many people similarly dismissed taxi use as a financially viable alternative to using their private vehicle. However, one participant believed the expense of taxis to be partially a function of living in Auckland, because of the geographical size and layout of the city. The
long distances needing to be covered and the fact that the city is spread out meant that car travel frequently took considerable amounts of time, making taxis very expensive compared to smaller cities or towns.

Grace: “The other thing with Auckland, everything is very spread out and you know the whole taxi thing, I mean occasionally get a taxi but you know get stuck in some traffic jam and suddenly the bill is up over $100 pretty easily actually so and yeah long, long distances to travel.”

There was a differing opinion amongst participants on whether they would choose to use taxis more frequently (or at all) if they felt that they were more affordable. One person stated that she would always prefer to use them because that would overcome the need to find a car park as well as having the advantage of being able to be dropped off close to her destination.

Amy: “Probably you know if I had plenty of money I wouldn’t bother to car, I would just ring up a taxi and get delivered, much nicer.”

The cost of using taxis compared to the total ongoing costs of cars was discussed as well. One participant had been told that it was more cost effective in the long run to use taxis rather than pay for the ongoing running costs of a car. However, she felt that whether or not that was true, given her transportation needs, spending money on taxis felt like more of a financial hardship than paying for the costs of her car. She also felt freer to use her car than she would to call a taxi to go somewhere, because taxis were a more immediately measureable cost.

Amy: “I did far more things when I had the car than when I had to take taxis and maybe it’s just that somehow I wasn’t aware of the money that went on the car whereas I was painfully aware every time I paid a taxi.”

Being able to immediately assess the cost of a taxi journey through its fare felt different to thinking about the more hidden running costs of a car. For Amy, this meant that she regarded her car as a lower cost option, thus allowing herself to go out more in it. The perception that paying for a taxi was different from paying for the running costs of one's
own car could also be because the car owner regarded this cost as being an investment in their own asset and their ongoing mobility.

Convenience or Inconvenience of Taxis

Although many of the participants in the study felt that taxis were a convenient way to get from place to place, most participants still felt that having their own car at their disposal was more convenient for reasons of time comfort and sense of independence.

Susan: “I want my car. I want to be free… I don’t want the inconvenience to call a taxi, wait, go there and come back and then call another one to come back. I want to be independent.”

While Susan simply did not like waiting for a taxi and wanted to be flexible in her movements, Harry felt that when travelling by taxi to work, he had to plan well in advance, with limited options for arrivals and departures, and hope that there would be no complications or delays.

Harry: “[A taxi] got me to work, but it was totally frustrating because I had to be ready by the time I told them I want them at my door. They couldn’t be at my door after a certain time or before a certain time because they had the school runs, and I was dependent on linking. So the ability just to go as and when you wanted, you lost that freedom.”

While Katarina found the timing of travelling by taxi difficult to manage, she also had the additional problem of not having somewhere to wait that would cause her the least amount of discomfort if she could not sit in her specially designed car seat.

Katarina: “You would always turn up to your appointment early cause you didn’t want to be late but because you were in a taxi you didn’t have anywhere you could rest or be quiet, you would have to go and sit in the waiting room and uncomfortable
chairs or whatever and then they would look at you weirdly if you lay on the floor and you know so whereas if you have got your car you can recline your seat, relax.”

Amy talked about taxis being more convenient and noted that she used them when she wanted to go to a place where she knew there were likely to be many people and limited or no disabled parking.

Amy: “I might take a taxi or get somebody else to take me because like I couldn’t imagine going to a really big public event you know if, because it’s just too difficult having to get from parking that’s miles and miles away to where it is you want to go.”

This use of taxis was likely to be infrequent, but was important because it could make a big difference to whether someone could participate in a public event with the least amount of pain or fatigue.

Temporary Replacement for Car

Some participants felt that although taxis were not affordable or practical as a frequently used form of transport, they were useful and necessary at times, particularly when participants could temporarily not use their own cars. A common example of being temporarily without one’s car was when they were being serviced or getting a warrant of fitness.

Rose: “I get the garage to drive me to my work place and then I ring work beforehand and say I can’t go out on a job today unless you get a taxi.”

This temporary use of taxis, rather than self-driving in a private vehicle, seemed to be the most acceptable to participants, because there was a time limit on when they could go back to driving their own car. In this way it was similar to being able to use a taxi occasionally for reasons of convenience.
Ministry of Education Taxis

For many young disabled people, taxis were a familiar transportational mode because the Ministry of Education provides taxi rides to children, who are not able to get to school by walking or catching a school bus.

Jack: “From the third form to the fourth form of school, I started going to Gisborne Boys High School and I was getting taxis to and from the school.”

Another participant also talked about the taxi service provided by the Ministry of Education to enable her severely disabled son to be transferred to and from school. Zoe discussed what she described as a highly unsatisfactory situation when a bus was temporarily substituted for taxis to take a number of disabled children to school.

Zoe: “I said he’s not going [to school] again [until you] put the taxis back on. I rung the Ministry of Education and the taxi was back the next day. I said it doesn’t work, you’ve got no seatbelts. I said they can’t, never mind getting him off the bloody bus, bring the taxis back now and the taxi’s back the next day and so did [other parents]. Because you can’t put kids like that on a bus with no seatbelts, they can’t sit up properly some of them.”

For the parents of disabled children attending the same school as Zoe’s son, a taxi with seat belts, and close supervision by the school for the pick-up and drop-off, was considered as the only possible form of transport that would keep them safe. After Zoe and other parents raised these issues with the Ministry of Education the taxis were reinstated.

Part V

Staying at Home

When participants could not use their own vehicle they sometimes sought out alternatives forms of transport to get themselves (and/or their family) into the community. However,
sometimes these alternatives to car driving were not appropriate because of physical
limitations or pain, were too expensive, unavailable or inconvenient, or in some other way,
did not meet the needs of the participants or their families. In such cases participants
sometimes found themselves housebound for varying periods of time.

For many people, who had had an accident or had been hospitalised for an operation, there
was frequently a period of time when they did not even want to leave their house and
participate in society outside of their homes.

Tegan: “I think in those initial days I was probably quite happy to sit there and do my
own thing for a little while. But once I started to feel better and got more mobile,
that’s when I started to get a bit anxious and say well, ‘Get me out of here!’”

As they recovered, there was generally an impetus for at least some participants to want to
regain some aspects of their former lives and this was often marked by a need to leave the
house. If they were not able to drive, often other transport options were also too difficult for
people. Tegan’s inability to drive meant she was also likewise unable to use any kind of
public transport or even be driven around by friends and family because of the physical
discomfort.

Tegan: “I literally stayed at home because I couldn’t drive for two months and…
some of my friends… said, ‘Come on we’ll take you out for a drive.’ But just the
physical effort of actually doing it was quite difficult in the earlier stages.”

The cost of using his car was the biggest factor in Michael's decision about staying at home,
and he saw this as being explicitly linked to the cost of petrol.

Michael: “I have been stuck at home for the last year because of the fuel prices.”

Although he did not want to be at home, he knew that he had a very limited budget for
transport and had to save his petrol for trips that were not optional such as appointments
with his doctor, supermarket trips and taking his children to school. Any other kind of trip
was a luxury for Michael and his family.
Michael: “We want to go and do something, but that means we, you know... And it’s like, oh there is always an excuse not to do it, but it’s not – it’s using your fuel wisely... We would be at the beach, we love the beach, be at places like that, in the open and... there is only so much you can do around your own house...It’s alright, ah get sick of it, get sick of the house you know, ‘cause stuck in it all the time.”

The consequence of not being able to freely leave his house and enjoy being out in the world, was that Michael felt depressed and frustrated, a sentiment which was shared by another participant, who was also unable to leave the house at times because of financial constraints.

Donna: “Sometimes I just can’t go anywhere ‘cause we can’t afford it... the money is important cause it keeps the house going; me getting out of the house is just as important. But if it comes to [my husband] having to get to work then yeah I will stay home, I will just have to.”

When people could not leave the house for whatever reason, they frequently suffered emotionally and socially. River talked about feeling less able to leave the house the longer she stayed at home, as her confidence levels about socialising would go down and she would begin to dread it.

River: “Oh went stir crazy, it’s like a version of cabin fever I think yeah. Yeah you hear of these people in Alaska and that in winter getting sort of cabin fever and it was just like that you know, you just, and the less, I find the less I see, I don’t go out, the less I want to go out.”

Tegan had a similar experience to River’s and attributed it to becoming more insular the longer she was unable to leave her house. It was not until she had broken the cycle and begun socialising outside her home that she became more comfortable interacting with other people and wanted to go out more.

Tegan: “The fact that you’re house bound, your whole world just sort of shrinks and you do become very insular. And I think you sort of get to a state where you couldn’t
care less about what’s happening outside your own place and it’s not until you sort of get out and see there is still the world out there, that you realise how locked in you’d been.”

Katarina had experienced a very similar series of events to those described by Tegan and River. Unable to drive, she had become isolated because of being at home all the time and then not felt capable of going back out into the world and interacting with people again. However, when Katarina talked about re-engaging in society, she explicitly linked this process with requiring tools, such as her car, to make it happen.

Katarina: “When I think about the road that you know gone through, of depression and that whole social isolation and that whole thing of gradually your social circles get smaller and smaller and people. You don’t go out for dinner, you don’t want to have a dinner party and you know, you get more and more removed from society, unless you make a real concerted effort to make sure that you can get the things that you need to get yourself mobilised and out there.”

The fact that many of the participants talked about the difficulties they experienced when they were not able to drive was significant in itself, as it also served to highlight the important physical and emotional support their car provided in enabling their mobility and their ability to participate in society.

**Conclusion**

The participant’s transport choices did not and could not always involve driving their personal vehicles. However, while not driving their own cars was sometimes an acceptable situation, it frequently did not work for the participants for a variety of reasons. Alternatives such as public transport were often not as comfortable and at times not as safe as their own cars, even when participants were able to get on and off them independently. Taxis were expensive and although some people preferred using them to driving their own car, others found them uncomfortable, inconvenient or felt that they were treated rudely by drivers.
For some people, getting a lift from family or friends was the closest transport option to driving themselves in a vehicle – in fact, at times they might drive part of the journey themselves. However, being driven by family and friends could put participants in a difficult situation where they were dependent on people with whom they already had a close relationship which could complicate their relationship or add further pressure if they were unreliable.

The final alternative to participants driving their own car was not leaving their house at all. Most participants talked about a time when they were unable to leave the house because of physical or financial reasons, or because they did not have a car, whether this was temporary or for a medium period of time. Being completely housebound was generally talked about as a very difficult time for participants when they became depressed and isolated. Other people chose to stay at home for financial reasons and were not completely housebound, but could only use their car for essential journeys such as shopping for food, going to the doctor and taking their children to school. In this situation people missed the social interaction and participation and the mobility that their car could enable.

While participants had different views of all of these alternatives to driving their car, many participants made it clear that they felt very strongly that their lives were greatly improved by being able to drive themselves. The implications of all the difficulties of the alternatives to driving will be synthesised in the next chapter with the significance of self-driving and the enablers and barriers to car use.
Discussion and conclusions – a Grounded Theory of Mobility Impairment and Car Use

Introduction

In the preceding chapters, I have described the context within which this research was conducted, including why this particular project was undertaken. In a survey of literature relating to disability and driving, it became apparent that the driving experiences of people with mobility impairments had not previously been considered, despite recognition of the importance of transport and mobility, the insufficiencies of the public transport system and some acknowledgement that for many people with mobility impairments, car use was in many instances, either their primary, or most appropriate, form of transport.

Having identified what appears to be a new area of research, I began to explore the mobility experiences of disabled drivers by interviewing 27 people with mobility impairments in urban and rural areas of New Zealand, who held long-term mobility parking permits. The interviews were semi-structured and began by exploring the story of how the participants became ‘disabled drivers’. Participants were then asked what they used their car to do, how much access to a car they had, the ways in which cars affected their participation in society and their well-being, how practical considerations such as finances and the physical
environment affected their ability to drive their cars and finally, what thoughts they had about driving in the future. Participants were also asked to talk about any experiences they had of public transport.

In the results chapters of this thesis, I ordered and conceptualised the experiences of the participants and divided the results into three main ideas: the meaning of driving for participants, the barriers and enablers to driving and the alternatives to car use, which largely dealt with the consequences of being unable to drive. In this chapter, I present a constructivist grounded theory of disabled drivers and mobility from the synthesised and conceptualised results of my study. After presenting my theory, I discuss a number of assertions that arise from my theory in the context of existing ideas of social participation, justice and mobility. I will discuss some of the implications of this research on policy and on other areas of scholarship such as public health, disability studies, and transport and mobility studies. I will also make recommendations on policy changes and future research. Firstly, however, I will reflect on the methodology I used.

Part I

Reflections On The Method and Methodology

Recruitment of Participants

Recruitment was carried out primarily through CCS Disability Action, however the snowballing method of recruitment was extremely beneficial in finding some participants for this study, particularly the younger participants, and those from the Auckland region. If carrying out another recruitment process in New Zealand in the future however, I would approach Māori community organisations with the specific aim of significantly increasing the proportion of disabled Māori participants. Māori are both over-represented in the number of people with impairments and are overwhelmingly affected by health inequalities.
Constructivist Grounded Theory

Constructivist Grounded Theory was a very productive methodology for this particular project as I began the project with an intimate knowledge of my own experiences as a disabled driver, yet with the awareness that there was no existing body of data, or theoretical understanding of the experiences of disabled drivers. Constructing a ‘theory’ of the experiences of disabled drivers required a methodology that was exploratory, took the experiences of participants seriously, and yet acknowledged that I did not come to the study in a tabula rasa state as an impartial ‘outsider’. Indeed, I believe coming from an ‘insider’ perspective on the topic was hugely beneficial to the research, as the rapport I was able to develop with participants was partly based on having had many similar experiences in relation to mobility difficulties and driving.

One-on-One Interviews

The data collection method of one-on-one interviews allowed me to build rapport with each individual participant and also allowed a great deal of flexibility in arranging accessible venues for each interview. Although this did not allow for participants to officially interact with each other during the data collection, because I am also a disabled driver, there was always an opportunity to discuss similarity or dissimilarity of driving and mobility experiences. As well, some of the participants knew each other, or at least knew other disabled drivers, so they could reflect on their experiences in comparison to other people. The semi-structured interviewing meant that I could be responsive to unexpected comments or new areas of interest, but also meant that if, during a discussion with one participant they were unsure of how to answer a question, I could (anonymously) talk about an example of the driving experiences of one of the other participants to see whether it resonated with them or if their experience was completely different and why that might be.

Participants’ Reactions to Interviewer’s Impairments

The way that participants reacted to my impairment made me think critically about how I was interacting with them and about how they might see themselves and understand
disability. Although I had no other option but to conduct the face-to-face interviews in this study as a researcher with a visible mobility impairment, it is still worth reflecting on what this might have meant for my data collection. As discussed in the methodology chapter, some participants were vocal in their reaction to my mobility impairments. This could have had the potential for awkwardness and embarrassment on my part, either because a participant could make remarks about me that made me feel particularly ‘abnormal’, or because they could make remarks about themselves that I did not know how best to respond to.

Having an impairment myself held the potential for participants to compare their impairment with mine in a way that made them minimise their mobility difficulties. This was apparent with Mark who made comments about how he ‘wasn’t really that disabled’, or at least, not compared to me. Although I assured Mark that his experiences were important regardless of the severity of his impairment, I cannot be sure that other participants did not have this, or the opposite reaction (that I could not understand their mobility difficulties because mine were not ‘as bad’).

When participants vocalised comparisons between our bodies and experiences, they were drawing attention to my body and personal history in a way that could, and sometimes did make me feel slightly uncomfortable. However, I feel that presenting myself as a ‘disabled researcher’ and ‘disabled driver’ worked to my advantage in some respects – it placed me on more of an equal footing with the participants, which I think engendered trust and openness. But the consequences for presenting myself in these terms were that I opened the door for a discussion about disability and then potentially to questions about my own body and experiences. This was an interesting and often positive experience as a researcher, because it gave me an opportunity for sharing my experiences with someone who had some similar mobility difficulties, just as the interviews had given participants that opportunity.

Luckily, in almost all of the instances where participants initiated a conversation about my bodily experiences or history, an enjoyable and interesting conversation ensued. Interestingly, the majority of the conversations that participants initiated either about our shared experience of disability or direct questions about my personal experiences or thoughts about disability, happened outside of the ‘official’ recorded part of our interview. Often,
participants began to ask questions of me after I had concluded the interview and had begun to pack up my recording equipment. They might begin to talk about other aspects of having a disability or more about their history in a way that invited reciprocity, or they might ask me directly about my research and my life.

Participants could assume that there was at least some shared experience of mobility difficulties, which is likely to have made them reasonably comfortable about talking about their own difficulties. I could also encourage this by verbally or physically signaling when I had similarly experienced something.

Researcher with Mobility Impairments

The limitations placed on me as a researcher with a chronic illness and a mobility impairment had to be managed so that I was able to gather data in an appropriate way, and talk to appropriate people. My strategy of negotiating with participants about a mutually appropriate and convenient venue, giving them a variety of options, seemed to work well. In this way, it was an advantage that both the participants and I had mobility impairments and so had reasonably similar access needs and could at least understand the kinds of access that would be easiest and why it was important. A few participants lived in homes with stairs, which I could potentially have had difficulty accessing, but these participants agreed to be interviewed at another location. For one of the interviews I conducted, the participant and I agreed to meet in a public place, which worked well as he did not have to travel far and the venue, a café, had easy access for us both. However, if the study had been of a more personal nature, the arrangement to meet in a public place would not have been appropriate and further options would have been considered. None of the participants who contacted me about being involved in the research were unable to be interviewed because of either of our physical constraints.

The initial conversations about the location of interviews also gave the participants and myself an opportunity from the outset to negotiate aspects of the research. Negotiating and checking-in was a good precedent to set, and in many instances continued into the interview with conversations about the physical comfort and needs of participants and at times about their level of comfort about revealing information.
In the analysis stage of this thesis, the discipline of substantive theory creation made me reflect on my own experiences of being a disabled driver in the context of this study. While there were commonalities of experience between myself and some participants, there were also differences of experience and interpretation, and I actively worked to prevent blurring of our experiences.

Part II

Key Findings

When taken together, the three previous results chapters present a picture of driving as experienced by drivers with mobility impairments. The chapters are ordered to focus on the individual as well as shared experiences that make up the three main concerns of the participants in this study. This previously underexplored area of research examines the opportunities and problems that disabled drivers encounter in their daily mobility. The experiences discussed in these chapters are in some instances peculiar to people with mobility impairments, or those people whose difficulties with mobility is exacerbated by impairment, and in some instances are shared with other groups of drivers who may be vulnerable to transport-related social exclusion, such as those on low incomes.

The conceptual organising of participants’ experiences into thematically distinct results chapters goes a certain way towards the development of a theory of driving for people with mobility impairments. However, there is a further step that needs to be taken, to more fully understand the experience of being a disabled driver. To develop a theory of mobility impairment and driving requires stepping back from the individual experiences of participants and assessing what the key experiences of being a disabled driver are and how they interact together in a way that explain these experiences. Reflecting on relevant literature also suggests ways in which to approach a theory of disabled drivers. Placing the results in the context of the Social Model of Disability and the Capability Approach helped to frame some of the ways in which cars function specifically for disabled drivers. In the following section I present my substantive theory of disabled drivers and the assertions that arise from my theory.
A Grounded Theory of Disabled Driving

Driving a car does not just enable people with mobility impairments to be mobile and live their lives; it enables them to be mobile in the same manner as non-disabled people, which makes society less disabling.

Disabled drivers use their cars to facilitate their mobility, which enables them to live their lives. For disabled drivers, driving a car is a ‘normal’ way to be mobile, when other aspects of their mobility are not necessarily considered normal. Driving is also what enables them to be included in society and do ‘normal’ things with their lives. Furthermore, for many disabled drivers there are few, if any, other options for transport and mobility outside of the home. These elements make driving highly significant for them, as access to automotive mobility can make for a less disabled life. However, they are also likely to face barriers to this mobility, that are either unique to people with impairments, or are exacerbated by their impairments. Economic, societal, environmental, as well as physical factors, are barriers to car use for disabled drivers and given the value that driving holds for them, concerns about new and ongoing barriers to future mobility are particularly acute.

I will now discuss five assertions that I believe arise from the substantive theory that I have developed in this thesis:

I. Being able to drive a car is important because of what it enables disabled drivers to do and how it makes them feel.

As discussed in Chapter Four, cars can provide people with mobility impairments the ability to perform a large range of tasks and roles that they would either be completely unable to achieve without the ability to drive independently, or else would need to depend on others to a far greater extent. The tasks that people with a car were able to perform were as varied as the lives they led and the needs and desires that they had. One very straightforward kind of
task that a driving a car could enable was getting to an appointment in a timely, dignified and comfortable manner. However, being able to drive enabled an extremely wide range of tasks that were more complex and/or slightly more unexpected. Mobility could enable more than a particular task; it could mean that various life roles were able to be performed – being a parent to children, a carer to elderly parents, a friend, an independent person, a ‘normal person’, a worker. The ability to perform these tasks and roles gave people feelings of control, normality or independence.

Figure 1 Disabled Driver and Mobility

I would argue that while having a mobility impairment can shrink people’s sphere of experience through lack of mobility, access to the physical environment, pain, depression or other people’s reactions to their disability – however, having access to a car can broaden disabled people’s sphere of experience. If people can drive, they are able to go out into the community, transport themselves further and in a manner that they can have some control over. Where people cannot walk very far, they can drive; where other forms of transport may be difficult to access or painful to use, cars can be modified for an individual's comfort; and they can choose when they are best able to go out and drive.

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However, as will be discussed in more detail below, despite meaning the difference between the ability or inability to leave the house and move around in the community, being able to drive did not always mean that people were able to do all the things they wanted. Participants made it clear that physical, emotional, environmental, economic and societal barriers could still cancel out the mobility that driving could provide and leave them feeling almost as isolated, dependent and immobile as they would be without it. The ability of people to participate in society requires many elements, and mobility is just one (key) element. There may be many other reasons why a person cannot participate in society, but if a person lacks mobility, it will be extremely difficult for them. Figure 1 describes how for disabled drivers, driving a car facilitates mobility and mobility facilitates participation in society, the object of which is living a life that they value.

II. Disabled drivers’ interactions with cars can change over time, as their needs, lives, identities, and mobilities change and interact in ways that are not commonly expected or accommodated.

As with any person, the needs, circumstances and abilities of disabled people change over time. However, what is different for people with mobility impairments is that their abilities, needs or circumstances may change in ways that are generally not expected, or accommodated for by society. It is not a new or unique claim that the meaning of, or patterns of, mobility change for people over the course of their life. But while many people may experience a change in transportation needs and circumstances on assuming a new role such as parenthood, this change does not commonly coincide with pre-existing, or potentially worsening, mobility difficulties that occur in a society that creates disabling barriers for people with impairments. It is this confluence of factors that can make changing mobility needs over time note-worthy for people with mobility impairments. Similarly, many other groups of people experience barriers to mobility, such as financial constraints, but for people with mobility impairments, it is the combination of impairment, general barriers to mobility and other societal barriers, such as the increased probability of having to live on a lower income, that combine together to create a particular experience of driving.

As disabled drivers are often only able to accomplish some everyday tasks because of the mobility their cars provide, having an appropriate and reliable vehicle is essential to their
independence, security, confidence and well-being. People who can walk easily may base their lives around the certainty that this will continue and this is the kind of certainty about mobility that should be associated with vehicular mobility for disabled drivers.

Life Stages

Although it is true that everyone moves through different stages in their lives, where their needs, identities and abilities can change, these are generally seen as ‘normal’ changes and there are, to a certain extent, accepted ways of managing them. For people with impairments, however, changes throughout a life span can be qualitatively different in effect and rapidity.

The roles that a car plays in the life of a disabled driver can change along with their circumstances as they move through different stages in their lives. As people move in or out of study or employment, their transportation needs also change and their car may be important to enable career aspirations or economic participation. If a disabled driver has children, a car may help them perform their role as a parent, particularly while their children cannot transport themselves independently. As well as being life changing, disabled drivers’ impairments can change significantly over time and this can affect how much and in what ways people may be able to drive.

Different Stages of Experiencing Disability

For someone who has either acquired an impairment suddenly, or experienced a period of particular difficulty with a chronic condition, there can be a period of time where their desire or ability to participate in society becomes secondary to their more immediate physical needs. As could be seen in this study, this can be a very isolating and depressing time and if they have been unable to be mobile during this period, the prospect of driving can represent more than just mobility for disabled drivers – it can represent independence, freedom or normality. At such times, being able to drive can take on monumental significance. In contrast, for someone who has been a disabled driver for a length of time and has not had their ability to drive threatened in any way, a car may be a (very important) tool, like any other, that allows them to go about their daily life, but it is something that they are able to take for granted.
Changes in Identity

As being disabled is a stigmatised identity, many people have an investment in not identifying themselves as disabled and try and minimise the chances that others will label them as disabled (Goffman, 1959). For people in this study, who commented that they did not really see themselves as disabled, being able to drive could help them to hold onto this self-image, as their car meant they could perform tasks and essentially not mean that they were dis-abled from anything that they wanted or needed to do. At other times, wanting to identify as ‘normal’ might not be so important, but going about their daily activities was still of utmost importance to them. People could even incorporate the mobility that a car could give them into their bodily identity and see their cars as an extension of their bodies or their legs. Some people had such a strong identification with their car that the thought of losing the ability to drive was as life changing as another person’s understanding of losing their arms or legs.

There were also identities other than ‘disabled’ or ‘not-disabled’ that driving a car could affect. Steven and Adam described themselves as being ‘boy racers’ for which being able to drive was of central importance. Although they could still be car enthusiasts without being able to drive, the fact that they were able to, meant that they could participate in a sport and were actively included in their peer group.

III. Economic, societal and environmental, as well as physical factors, are barriers to car use for disabled drivers.

The physical inability to drive was one of the most straightforward barriers to car use that participants described. This could result from either body pain or fatigue, post-surgery or medication safety restrictions preventing them from driving for a time, or it could mean that they did not have an appropriately modified vehicle. The barriers that pain, fatigue or medical restrictions presented were usually temporary, but often affected individuals significantly, leaving many frustrated at being largely immobile. However, for some others, these barriers made them reluctant to drive even when they were able, despite they acknowledgement of their dependence on driving. Not having an appropriately modified vehicle was, in many respects, the easiest or at least the most straightforward barrier to eliminate. However, many people struggled with this obstacle because they could not afford
the required modifications or an appropriate vehicle, and had difficulty finding, or were completely unable to get funding assistance.

There were other economic barriers to mobility and car use than the initial monetary outlay of a vehicle with appropriate modifications. For some participants, the ongoing financial costs of driving were the biggest barrier to their mobility. Having to try to cover the financial costs of vehicular mobility could mean putting extra pressure on a person’s emotional wellbeing due to the stress of budgeting around such a key aspect of their mobility that, in turn, affected their physical, emotional, social and economic wellbeing.

The environmental barriers to car use that participants experienced were almost entirely related to being able to move around their environment once they arrived at their destination. Not being able to find an appropriate park could mean that it there was no point in being able to make a journey in the first place.

While it was clear that practical restrictions of physical, environmental and economic barriers could prevent mobility and participation, in ways that could or could not be overcome, the emotional and societal barriers to mobility were more subtle, complex and difficult problems to deal with, although they overlapped with the other barriers. Environmental barriers to being mobile in the community, such as a lack of accessible mobility car parks, could easily prevent a disabled driver from being mobile and moving around in a community. However, even where there were sufficient parks, having other people park in them illegally meant that they were unusable. Likewise, being continually challenged about whether a disabled driver looked sufficiently ‘disabled enough’ meant that some participants found the emotional costs of dealing with mobility parks were too high. For other participants, the barriers to mobility that they experienced were due to feeling that they did not have anywhere to go where they would be wanted and treated as normal people. For some, an extended period of isolation because of their impairments had resulted in a lack of confidence about reengaging in social interaction.

IV. The alternatives (or lack of alternatives) to driving reinforce the importance of driving for disabled drivers.
It is when considering the alternatives to driving, for disabled drivers, that the importance of access to appropriate private vehicles is most apparent. Participants discussed using public transport or taxis, getting lifts from friends and family, or staying at home when they could not drive. Although the ability of the participants to access these other forms of transport could differ, and difficulties involved with each form of alternative transport could also vary, it is clear that losing the ability to drive their cars would be almost universally devastating. While alternatives to driving are exceedingly important, they should be available alongside access to cars, if at all possible.

Figure 2 Non-disabled Drivers

There is a lot of pressure for non-disabled people to use cars (see automobility) but there are often alternatives, such as public transport and active transport (Figure 2). However, for many disabled drivers, public transport is difficult to use and for even more disabled drivers, active transport is not an option, so driving is the primary means of mobility (Figure 3).

Figure 3 Disabled Drivers

When the ability to drive becomes so central to a person's mobility, the lack of that ability has consequences that manifest in a multitude of ways, such as feeling that one's life is
considerably narrower and holds fewer opportunities. Other consequences could be to make life more complicated and incur extra costs, so that disabled drivers may have to balance energy or pain levels, close relationships or budgets much more closely, merely to be able to leave their homes.

While public transport is not an option for some people with mobility impairments, public transport could potentially be made be far more accessible for a variety of people, including ‘disabled drivers’. Even if some people with mobility impairments could not use public transport all the time, there could potentially be more scope for them to incorporate some use of it into their mobile lives if it was more accessible. However, while there are increasing numbers of buses and trains that enable wheelchair access, having a ramp so that a wheelchair user is able to board a public transport vehicle is only one issue of accessibility. Physical issues, such as public transport sometimes being a painful, uncomfortable or potentially hazardous experience and the distances between home, bus or train station and destination can all be significant deterrents. The attitudes and practices of some people working or travelling on public transport experience can also contribute to making it an unreliable and difficult experience. These factors make private car use all the more important to prevent people with mobility impairments from being more disabled than they would be otherwise.

V. Being able to drive is even more important for people with mobility impairments because it enables them to be mobile in the same manner as other people, inside the system of automobility – and consequently they are less ‘disabled’.

To the extent that this society is one where people move around inside a system of automobility, where cars are the dominant form of transport, the significance of driving becomes even more pronounced for those whose mobility is already limited. Not only does being able to drive a car give people with mobility impairments a greater degree of mobility, but this mobility is accomplished in the same manner as for other people. The built environment is generally not designed for people with mobility impairments which can make navigating around it difficult, time-consuming, awkward, tiring, painful, embarrassing, stressful, or impossible. Being given something of a reprieve from those difficulties when driving in a car is extremely important to many people and it works in quite a unique way.
Although there are mobility aids available to people with mobility impairments, they are generally made only for the use of people with mobility impairments and must still operate within an inaccessible built environment. However, the car operates in an environment that is built almost entirely for itself: with roads and car parks, suburbs and cities that were designed almost solely with the car in mind (although not with disabled drivers in mind). While many people lament the hegemony of car-based transportation, it nevertheless means that disabled drivers have the opportunity to get to many more destinations, at the same speed, whilst essentially resembling everyone else on the road.

Moving around inside a system of automobility, in an environment that is purpose built for car drivers is important to disabled drivers from a practical and a symbolic perspective. From a practical point of view, being able to drive means that many destinations are immediately accessible that would not otherwise be. Because so many cities and towns, neighbourhoods, shopping centres and facilities are designed with the assumption that people will reach them by car, mobility is somewhat standardised; roads are built to be accessible to automobiles. Giving people with mobility impairments entry into this system of mobility means that they can access homes, workplaces, social and leisure opportunities, political life, and can perform other roles that they may choose. The knowledge that driving to a destination will almost assuredly be an unimpeded journey opens the way for a different kind of mobility than people with mobility impairments would usually be able to access.

This discriminatory accessibility is not true for drivers, as all cars travel on roads which were built with cars in mind and their speed is regulated not by individual physical capability but by roading policy. For a group of people who live in a world that is, in many respects, excluding and disabling, driving can mean that they are made more equal and able because they are participating in (or are ‘inside’) a system where there is a standardisation of motorised mobility.

Symbolically, being able to move around in a system of mobility in the same manner as everyone else is also highly meaningful and can create a feeling of normality, equity and independence for disabled drivers. Being mobile can bring joy to anyone, whether it is in service of any particular destination or not, and this feeling can be intensified when other forms of mobility are compromised. In addition to moving around the same, looking the
same as everyone else and taking up the same kind of space as other vehicles whilst driving in a car has further symbolic value for people with mobility impairments who are often stared at and treated differently because of how they look.

For its original theorists (Beckmann, 2001; Urry, 2004), discussion of automobility is a critique because such a high dependence on cars is seen as unsustainable due to the burden of climate change and the finite supplies of petrol to fuel cars, but also because the dominance of cars pushes other means of mobility and community interaction to the periphery. However the results of this study suggest a re-reading, or parallel reading, of automobility is useful.

Automobility has a different meaning for drivers with mobility impairments, and automobility has a different meaning because of people with mobility impairments. While I do not believe that automobility will always, or should always, exist – particularly in its current form – automobility highlights how transport systems can be more and less disabling for different groups of people. I believe the importance of this reading should not be underestimated when trying to understand how driving makes for a less disabling world for disabled drivers and how systems of mobility work.

Part III

Findings in Relation to Existing Literature on Disability and Driving

I will now put my theory into the context of existing knowledge on disability and driving to ascertain its usefulness to scholarship.

The Findings in Relation to Existing Literature on Disability

The findings of this study shed light on and expand the scope of some existing bodies of knowledge, including older drivers and assistive technology, and provide real world examples of the application of the social model of disability and the capability approach.
Older Drivers

Although the importance of car use by older people (who are assumed to be disabled) has been explored, largely in the field of gerontology (Fonda et al., 2001; Marottoli et al., 1997, 2000; Metz, 2000), the significance of car use by work-aged people with mobility impairments has not previously been studied. This study has shown the links between the mobility experiences of older and younger people with mobility limitations, and has opened up a broader discussion of how mobility affects people’s ability to participate on multiple levels, as well as how driving can mediate a person’s identity, and their physical and emotional well-being. This study provides a theoretical framework to understand why driving is so important to disabled drivers, which is relevant to gerontologists studying disability and disabled drivers among the elderly.

Assistive Technology

Cars are assistive technology for disabled drivers and therefore drivers interact with cars in the same way that people do with other forms of assistive technology. While some people needed extra modifications to their vehicle to be able to drive, all the participants used their cars to facilitate their mobility and to perform tasks which they would not be able to or would find extremely difficult to perform without them. The findings of this study closely align with Deborah Lupton and Wendy Seymour’s research on assistive technology and their analysis of how people with impairments interact with various forms of assistive technology. The findings also emphasise how we need to take assistive technology seriously for its life changing potential and the potential for it to create an enabling world. As Lupton & Seymour (2000) described, assistive technology must meet the needs of the individual who is using it. Similarly, cars need to work for individual disabled drivers, which sometimes means the need for vehicle modifications to enable people to drive their cars, and sometime that modifications of vehicles would need to be changed or adjusted as drivers’ bodies or circumstances changed.

Lupton & Seymour’s (2000) ideas about the user acceptance of assistive technology from a cosmetic or socially acceptable point of view are also relevant to how disabled drivers feel about their cars. Cars can achieve a high degree of social acceptability as assistive technology
because so many people, who do not have any mobility impairment, use them. For the disabled drivers in this study, driving a car was not an unusual thing to do, so although they may use cars as assistive technology, in a way that other people did not, they did not feel ‘different’ when driving. There was some discussion about the desirability or not of having a wheelchair mounted on the outside of their car where people could immediately know that there was a wheelchair user inside the car. However, there was more comment on the fact that people do not generally look twice at a car, regardless of who is driving it and that this was a relief for people who felt that they were often stared at.

One of the interesting things about cars being used as assistive technology is that for the people with mobility impairments who use them as such, they may not have always been used in this way. While people who have acquired a mobility impairment may not begin to think of their car in this way, modifications and financial assistance to access an appropriate vehicle can still be prioritised by funders and rehabilitation specialists and theorists.

Most importantly, cars need to be included into our understandings of assistive technology and we need to consider why they are not already considered as such and what this tells us about how it is conceptualised. Assistive technology does not only mean technology that is used by people with impairments (as lifts/elevators are considered assistive technology), but the fact that cars are not considered assistive technology despite clearly being used as such, indicates that theorists need to re-evaluate our conceptualisations of assistive technology and begin to think about systems of technology as assistive as well as any individual items of assistive technology. Once we shift to thinking in terms of systems of technology it becomes clear that what we need to ensure is access to those systems for disabled people.

**Social Model of Disability**

The Social Model of Disability (Oliver, 1990) contains the theoretical underpinnings of this research: that aside from the presence of any impairment, disability arises from the failure of society to structure and organise systems and environments around anything but a conception of the infallible, idealised body. The findings of this study underline the importance and relevance of the ideas of the social model for understanding impairment and disability, and for considering how to reconfigure ideas about transport and mobility
generally, and about car driving specifically. The use of private vehicles for extending mobility is an example of the usefulness of the social model for the lives of disabled people. Being able to drive does not eliminate mobility impairments, but can help people with mobility impairments from feeling abnormal and excluded and could mean that they actually were less dis-abled in key aspects of their lives. Simply put, in almost all cases, participants found their mobility impairments less disabling when they had access to an appropriate vehicle.

The people interviewed in this study live in a society where they are disabled in many ways because of their mobility impairments. The way society is structured made many things more difficult for them, such as their ability to easily access food and medicine, to interact with people socially, and to participate in close familial relationships. The structure of society also frequently made participants feel isolated, more dependent than many of their peers, abnormal, or a range of other damaging emotions. However, some aspects of the negative consequences of living in a disabling society with a mobility impairment could be ameliorated by being aided in their mobility. Furthermore, at the same time as providing mobility, cars could ameliorate other negative consequences of living in a disabling world by providing privacy and a sense of normality. Making sure that disabled people have easy and affordable access to technology, such as appropriate vehicles, which can be operated in accessible environments is necessary for creating a more just and less disabling society.

Capability Approach

Disability theorists have already shown how the social model of disability and the capability approach are compatible in their focus on people being able to access the means or have substantive opportunities, to achieve lives that they have reason to value – the ‘ends’ (Burchardt, 2004; Mitra, 2006). In the context of this thesis, the capability approach can explain why cars have so much importance for disabled drivers, because cars act as a means to achieve a variety of ends.

Participants in this research repeatedly described how they used their cars to be able to live their lives. Just as their desired ‘beings’ varied from feeling like a good parent to feeling independent, the ‘doings’ that people desired in their lives ranged from being able to work to
being able to participate in their hobbies. However, the common experience of participants was that they all saw their cars as helping to enable these capabilities. Being able to drive could mean enabling other people’s capabilities, be they dependent family members or friends with impairments (this also gave the driver the capability to contribute in society). Without their cars, participants believed they would not have the same opportunities to participate in society in the ways that they did.

While being able to drive a car was the means to be able to achieve many other things for people with mobility impairments, there were also a variety of means required to be able to drive in the first place, as could be seen through the various barriers people faced. Sufficient money or external financial assistance were required to have access to and be able to run an appropriate vehicle and elements of the built environment needed to be accessible for any destination to be able to be reached. When these elements were in place, driving could then properly function as a means to achieve capabilities.

The fact that there were barriers to car use was problematic for many people, but it was the lack of viable alternatives that in many ways highlighted how, for a significant number of people with mobility impairments, cars were not just a means to mobility in their community, they were the means to mobility. As society is currently configured, some participants were only able to achieve crucial capabilities by having the mobility that came with being able to drive a car. The function that driving fulfils for disabled drivers means that the capabilities that cars provide need to be ensured both in the present and in the future as this mobility is a key component of social justice.

The Findings in Relation to Existing Literature on Transport

The theory that I have presented in this research is most relevant to scholarship on transport-related social exclusion and the ways that it challenges the assumptions of various theorists of mobilities.
Transport-Related Social Exclusion

The findings of this study reflect many of the ideas in the literature about transport-related social exclusion (Lucas, 2004). The ways in which cars enable social participation for disabled drivers, combined with the barriers to car use, show how easy it is for people with mobility impairments to face transport-related social exclusion and what the consequences are. Experiences of being unable to drive, severely affected disabled driver’s mental well-being and quality of life, as is similarly described in transport-related social exclusion literature (Lucas and Clifton 2004, 29).

Being ‘stuck at home’ can make it hard for disabled people to interact with the community when they have been away from it for a time. River’s description of being more anxious and depressed around other people than she had when she previously had a greater degree of mobility and was able to afford to drive more regularly, was significant to her mental well-being. But society in general benefits from enabling mobility and social participation through a variety of means. There are many people who are excluded from participation in society because of mobility, many of whom would not be considered ‘mobility impaired’ but merely isolated through distance, income, or family circumstance. A solo parent with a low income might face many similar psychological difficulties from being house bound through lack of appropriate and affordable transport, and while this is also a circumstance that should be remedied by reconsideration of transport systems, their experience is unlikely to be also compounded by having a mobility impairment and other experiences of stigmatisation by society because of how they look or move.

Not all disabled drivers experience some or any degree of transport-related social exclusion. While some participants talked about feeling extremely isolated and excluded, in large part because of the constraints on their driving and its effect on their transport or mobility, some had no constraints and felt that they had plenty of mobility because of their car. Still others expressed the fear that, although they had mobility now, they would be socially excluded if they were unable to drive in the future. These differences were influenced by economic, social, and physical factors, where the more financial security and social support people had (and to a certain extent the less severe their mobility impairments were), the less likely they
were to experience isolation. The inequities in the New Zealand disability funding landscape could be a major factor in the economic pressures on disabled drivers, those who came under MOH funding did not have the same opportunity to purchase or modify a car as those people who qualified for ACC assistance.

Transport-related social exclusion refers to those who lack adequate transport, but, even for disabled drivers with cars, there were still significant barriers to adequate transport and this affected their social participation. Not being able to afford the costs of running a car (or having strict financial limits on destinations), needing modifications or an alternative vehicle to be able to drive independently and difficulties with the built environment or parking (even when there were mobility car parks), meant that disabled drivers could be socially excluded and alienated from participation in society, despite having access to a mode of transport. Viggers and Howden-Chapman (2011) have also talked about how in New Zealand’s largest city, Auckland, public transport is only practical for people living reasonably close to the city centre. Participants in this study, such as Michael, talked about facing financial pressures to live in outer suburbs so as to be able to access lower housing, but the consequences were that they had less access to community amenities and public transport, and high petrol costs. Although disabled drivers may have access to a car, the costs of travel and the lack of alternatives such as public could make them, and their families, socially excluded. Being on a low income can intensify the effects of living in a disabling society, but this is not inevitable and intervention through appropriate support can mitigate these effects.

**Mobilities and Automobility**

This thesis challenges some of the assertions that mobility theorists have made about driving such as Fruend and Martin’s (2007) assumption that disabled people do not drive and are even more disadvantaged by a car-centric society than other people. It also highlights some of the gaps in understanding that exist with regard to the mobility of people with mobility impairments. Disabled drivers also subvert the discourse of many theorists of car-centred transport who argue that individuals need to prioritise making environmentally conscious choices about their transport and mobility decisions. Making a conscious choice to reduce car use implies that, as well as reducing ‘unnecessary’ car journeys, people also need to
choose alternatives to driving for their day-to-day mobility. For disabled drivers, their mobility is often dependent on car use for at least part of their journeys in the community, because it is their best or only form of mobility.

Mobility and automobility theorists see an inevitable reduction or end to automobility in the reasonably near future, because of the environmental damage of carbon emissions and the decreasing efficiency of fuel extraction (Anable and Gatersleben, 2005; Ellaway, Macintyre, Hiscock, & Kearns, 2003; Eriksson, Garvill, & Nordlund, 2008; Gardner and Abraham, 2007; Nolan, 2010; Sheller, 2004; Steg, 2005; Steg, Vlek, & Slotegraaf, 2001; Urry, 2004). It is also assumed that no other sources of fuel will replace petrol, particularly as the economics of electric cars have yet to be established. Disabled drivers are not part of the theorisations of car use and mobility. This means that when theorists make these claims, they do not consider what the differential effects on groups such as disabled drivers will be and are thus constructing a more disabling world, when they should be aiming for a less disabling one. This thesis shows that there needs to be a clear understanding of who would continue to drive, what the alternatives to driving would be and how they would work for people with a wide range of bodies and impairments. As transport systems currently stand, a wide scale reduction in car usage, particularly if it arises from increasing running costs, could mean that only the wealthiest people are able to continue to drive, and could easily result in many disabled drivers losing the mobility that they currently gain from their cars. Perhaps somewhat perversely, if cars were no longer the dominant mode of transport, then driving might no longer produce the same degree of mobility as it does now for disabled drivers. The mobility of disabled drivers is dependent on the whole system of automobility, without widespread use of cars the element of normality would disappear, as would the systems of parking, refueling, and car and road maintenance. A reduction or total abandonment of private car use is likely to significantly affect disabled drivers’ mental health, their financial situation and their ability to participate in society.

As described in the literature review chapter, the ‘system of automobility’, as theorised by Urry (2004), is made up of a number of different elements which I will discuss in reference to the findings of this study. The first element of automobility is the vehicle with which to move around in. For disabled drivers, the cost of purchasing a car can be a financial stress,
especially for people on lower incomes, and the need for it to be modified can incur further costs. The symbolic value of the vehicle for these drivers can be distinguished from that of other drivers (a sign of being normal or minimally disabled), or intensified for them because the symbolic value of cars is not associated with disability (but rather independence, speed, attractiveness, or family responsibilities). The support structure required of a system of automobility, which includes the built environment and other vehicle-based industries such as car and fuel manufacturers, is necessary for all drivers. But the fact that support structures for automobility already exist is part of why it provides mobility for many disabled people. For example, car parks are available for cars, while ramps and curb cuts are often not available for wheelchairs. As well, the culture that equates driving with the good life means that the good life is not out of reach for disabled drivers. Cars are beloved by many people not just as a means of transport, but also as a recreational pastime. For the participants in this study, for whom their car also represented a substantial part of their leisure activities, this culture was something that they could share with their peers.

The final component of the system of automobility for Urry is the substantial environmental cost that it has occasioned. While the cars of mobility impaired drivers contribute to pollution, I would argue that, in this instance, consideration of environmental damage should be weighed against the fact that there are currently few accessible alternatives to the mobility that cars can provide for people with mobility impairments, and that losing access to car-based mobility would disproportionally limit people’s ability to participate in society.

Some mobility theorists have also made the link between mobility and the capability approach. Cars contribute to higher level functionings, such as feelings of independence and normality, but can also enable disabled drivers to buy food from shops which are cheaper, but further away, or live in housing that they can afford, but could only access by car. Because mobility is considered to be part of a basic capability set (Kronlid, 2008), appropriate ways of achieving this capability need to be put in place. This is a useful way of looking at disabled driving, because although cars cannot completely satisfy the mobility needs of disabled drivers, they can extend community mobility considerably, in a form available to many non-disabled people and can help people achieve other capabilities. In
order to achieve functionings, however, disabled drivers need appropriate vehicles and they also need to have access to appropriate parking spaces and other facets of accessibility.

Although the idea of automobility was originally developed as a critique of transport systems and urban design by mobility theorists, this system has provided the means for disabled drivers to expand and alter their mobility in a way that puts them on more of a level playing field with non-disabled people and grants them opportunities to live radically different lives than they would be able to without a car. My reconsideration of automobility is not merely extending the idea that cars give more choice and freedom of opportunity to individuals and extend mobility, it re-frames automobility as an example of system that can be less disabling.

Part IV

Implications for Researchers and Policy Makers

Because the experiences of work-aged drivers with mobility impairments have not previously been studied, the implications from the analysis I have provided are somewhat diverse as they relate to areas of scholarship and policy that overlap with this research. The implications for academics in public health and transport and mobility studies are simply that their analysis must be expanded to include the experiences and needs of a wider range of people, including disabled people, for society to be a less disabling place. Given the commitment of the New Zealand Disability Strategy to support quality living in the community, which includes enabling people to move around that community, this thesis provides clear guidance on one way to support disabled people to be mobile and enable quality living. A policy shift towards greater provision of vehicles and modifications for disabled drivers and a greater emphasis on accessible urban design is achievable and needs to be recognised as part of human rights.

Implications for Public Health Researchers

The link between social participation and health has been made by public health researchers, including how social capital and social networks can produce benefits in self-rated health and
predict longer lives (Hyyppä and Mäki 2003, 771). As was clear from the stories related by the participants in this study, one of the main ways that driving affected their well-being was through the way in which it enabled them to interact with people, and how this affected their sense of self and their mental health.

Public health researchers such as Marmot (2005) have talked about transport being relevant to health through the effect of active transport on the amount of exercise that people do and how a reduction in fuel emissions would create better air quality. However, people’s health and well-being have to be considered in context of their whole lives: “in many instances, activity limitations and restrictions in (social) participation are more important to the affected person than the underlying health condition” (Van Brakel et al. 2006, 193). Transport is a tool of social connectedness and the benefits of car driving for people with mobility impairments is an example of the way that the health benefits of transport could be viewed from a more holistic perspective.

Implications for Transport and Mobility Theorists

Transport researchers need to broaden their understanding of the effects of transport on the health and well-being of people. Currently, where there is research on transport and health, the focus is on how it affects people’s physical health through exercise or air quality. However, this study has shown that transport can have many flow on effects to other aspects of people’s lives that relate to social determinants of health, including employment, housing, education, and access to health care, as well as effects on their mental well-being.

Mobility theorists, particularly those writing on car use (Beckmann, 2001; Freund & Martin, 2007; Sheller, 2004; Urry, 2004), have not included drivers with mobility impairments in their conceptualisation of systems of driving and mobility. This gap in knowledge is a problem, both because of the lack of awareness of all the reasons that people rely on their cars and how this affects the social value that should be placed on cars, but also because, while not everyone has what could be classified as a mobility impairment, there are a range of reasons that independent mobility in our current society can be difficult or impossible without a car.
While cars are often seen as a private good for individuals, they are not seen as having a public good component. For people who cannot use public transport, cars should also be seen as a social resource and predominantly a public good. The concept of a system of ‘automobility’ was created as a critique of modern society. However, transport and mobility theorists need to think critically about why mobility is important and how different forms of mobility and immobility are created through their narratives. Cresswell’s (2006) discussion about the production of mobility through laws and discourses around the rights to mobility, inadvertently highlights the need for theorists to further consider the mobility needs of people with mobility impairments.

Implications for New Zealand Funders and Policy Makers

To be able to participate in society people need mobility. For disabled drivers, cars are often essential to that mobility and essential to being able to participate in a society that in many other ways limits their mobility. The lives, abilities and mobility needs of disabled drivers change in ways beyond the changing mobility needs that people without mobility impairments face. Furthermore, these changing mobility needs can be potentially expensive to accommodate, which is particularly difficult for disabled drivers on low incomes.

For some disabled drivers, being mobile means that they need government funding to purchase an appropriate vehicle. For others, vehicle modifications are just as crucial for them to be able to drive. In such situations, modifications that meet the needs of disabled drivers are as necessary as a vehicle itself, and government assistance may need to be provided. While there is currently some government funding provisions for disabled drivers to purchase and modify cars, some disabled drivers do not qualify for it due to the origin of their impairments or because of their employment status. As there is no difference in need, it is a clear injustice that some people do not qualify for financial assistance to purchase or modify a car because of the origin of their disability. Policy makers and funders also need to look beyond ‘productive’ reasons that people might need a car or modifications.

Kronlid (2008) has talked about the gendered nature of mobility discourses, particularly the emphasis on the “journey-to-work”. The Ministry of Health’s policies currently discriminate against those not in full-time paid employment. While opportunities for being in paid work or
looking after children are incredibly important, and indeed were valued by many of the participants in this study, some disabled drivers do not work or have dependent children and yet they still have a need for, and right to, mobility. Living full lives is contingent for some disabled drivers on the mobility that a car can provide.

In ‘The Right to Mobility’ Cresswell (2006) discussed how conceptions and practices of mobility are produced through discourses of rights, and through laws where “particular modes of mobility are enabled, given license, encouraged and facilitated while others are, conversely, forbidden, regulated, policed and prevented” (2006, 735). In the context of New Zealand, the provisions under the ACC legislation around the mobility of people who have acquired mobility impairments through accident are clearly laid out. Yet, for people who acquire mobility impairments through non-accidental means, there is no legislative framework and there is much less funding, which has created unjustifiable inequities between disabled people. Further funding inequities exist between drivers with mobility impairments who work, and those who do not. Funding bodies give priority to purchasing and modifying cars belonging to drivers who are in full time paid employment.

Steg (2005) discussed the different functions that cars can fulfill: they can have instrumental, affective and symbolic functions, or put another way, practical, symbolic and emotional effects. Participants in this study used their cars to participate in society in many more ways than just employment. Although making arguments for the practical benefits of car use for disabled drivers is very important, the affective and symbolic functions of cars, that they can significantly reduce disability, should not be underestimated for disabled drivers and funding should reflect this.

Implications for Operational Policy in New Zealand City Councils

There are several implications for city councils in New Zealand regarding the number, placement and monitoring of mobility car parks. While participants in the Wairarapa region were generally happy with the number of mobility car parks, many participants in Wellington and Auckland felt that the number of mobility parks was inadequate. It is important that the dimensions and accessibility of mobility parks can accommodate vehicles with wheelchair hoists and that parking voucher machines are accessible; but equally important is having an
adequate number of mobility car parks, both in areas where community facilities can be accessed and in spaces where people socialise and participate in leisure activities.

Adequate monitoring of mobility car parks outside of normal business hours is also required to ensure disabled drivers can be involved in the community in the evenings and on the weekend. An additional solution could be the employment of a smartphone application launched in Canada in 2010, called Parking Mobility, which allows users to take photos of cars parked illegally in mobility parks and automatically sends them to the local council who tickets the driver. The application also helps people find mobility car parking spots in places they are unfamiliar with.

Implications for Transport and Spatial Planners

The implications of this research for transport and city planners are that, whatever their vision for the transport and movement of people in their region, the needs of people with mobility impairments must be taken into account. Almost all participants in this study found public transport to be inaccessible, however the mobility that disabled drivers got from driving does not mean that the accessibility of public transport should not mean a priority. An increase in accessible vehicles and public transport depots would increase the ability of all people to use public transport and could open the way for people with mobility impairments to use public transport (including in conjunction with cars).

Furthermore, regardless of whether planners want to create a largely car free environment or not, disabled drivers need easy access to public facilities and spaces through means such as mobility parking, even in ‘car-free’ areas. Regional and city councils need to recognise that people with mobility impairments, like everyone else, have a broad range of needs and desires for their mobility and councils need to ensure that they adequately plan for mobility access and parking, particularly in areas where they are trying to discourage motorists. While easy access to essential services is very important, the ability to participate in social and recreational opportunities is also important, but this can be particularly difficult for disabled drivers when trying to access areas in urban centres. At the very least, there is an immediate need for disabled people to be represented on spatial planning committees and incorporated
into future planning initiatives so that systems of transport and spatial planning can be developed to be less disabling in the future.

Part V

Further Research

Self-Reported Health Benefits of Car Use for People with Mobility Impairments

While this thesis has developed a theory of the experiences of disabled drivers, in the context of participation in society and well-being, it has not measured any health effects of car use. Research into the self-reported health effects of acquiring a car or having a car modified could contribute to an understanding of disabled people. A study on the self-reported health status and general measures of social determinants of health could be sent to disabled people when they apply for vehicle funding. An identical follow-up survey would then be done 6 months after receiving a vehicle or modifications and a comparison made.11

Transport and Mobility for Non-Driving People with Mobility Impairments

One thing that is clear from this piece of research is that being able to drive their own car provided disabled drivers with a much greater degree of mobility and consequently, ability to participate in society. What this has highlighted is that more research needs to be done to consider the experiences of people with mobility impairments who cannot drive, and yet face all the other barriers to mobility as disabled drivers. Even at the initial ethics committee meeting for this study it was pointed out that, while this piece of research was needed, people with mobility impairments who were unable to drive were imagined to be in an even more excluded situation than disabled drivers. Research into the transport and mobility experiences of non-driving people with mobility impairments is an under-researched area.

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11 One of the markers of this thesis has also suggested a possible future research project using the main results of this thesis (not limited to health indicators) to conduct a small quantitative survey amongst disabled drivers in New Zealand and in other countries.
and could provide insights into people’s lived experience and potentially suggest ways that mobility could be expanded.\textsuperscript{12}

Disabled Driving Experiences Outside of New Zealand

This research project was carried out in a relatively small, industrially advanced country, with a low density population and a medium standard of living. These are some of the reasons that car ownership rates in New Zealand are one of the highest in the world. The social welfare entitlements of physically disabled people in New Zealand vary depending on the origin of the disability (a differentiation is made between acquired and non-acquired disability) and there were huge disparities between the financial situations of participants. However, there is a social welfare system and most people in New Zealand have access to what many would call the basics of life: food, shelter, education and a public health care system. In some areas of New Zealand (including in a semi-rural area, the Wairarapa, where some of this research was carried out) there is little-to-no public transport. This same research carried out in other countries with different population densities, average incomes, social welfare entitlements, attitudes towards disability and transport systems may have yielded different results and conclusions and could potentially stimulate more ideas for future transport systems.

Theoretical Understandings of Transport and Mobility

What I believe is most clear from this study is that there is a massive gap in our knowledge about the transport and mobility needs of people with impairments. While this thesis project has explored one specific area of transport and mobility and one group of people with impairments, I hope it will open up a discussion about disability and mobility. There is a need for a great deal more research on transport and mobility from disability scholars, but there is also a desperate need for the growing numbers of transport and mobility theorists to incorporate the perspectives of people with impairments into their research and theoretical considerations.

\textsuperscript{12} One marker of this thesis, also suggested possible further research into the transport experiences of people with (non-mobility) impairments who are excluded from driving because of concerns over the safety of their driving.
Part VI

Recommendations

I recommend that government agencies amend their funding models for the modification and purchase of vehicle for disabled drivers to reflect the fundamental need for mobility that all people have a right to. In provisional of funding, differences in the origins of a person’s impairment or their earning potential should in no way affect their eligibility for funding or mean that only certain vehicles or modifications are made available to them. Furthermore, policies must ensure that funding to update cars and modifications is made available to individuals as, and when, their mobility needs change. This would mean that people should be eligible for funding to purchase a vehicle more than once in their life. Funding should also match real world increases in the costs of running a vehicle, such as petrol costs. One way to structure funding for disabled peoples’ transport and mobility could be through a system such as the UK’s Higher Rate Mobility Component of the Disability Living Allowance. This would mean that people with mobility impairments would receive guaranteed ongoing financial assistance which could either be used to lease an appropriately modified vehicle or cover other transport costs incurred by their impairment. Consideration could also be given to waiving individual taxes on private car use for disabled drivers, including registration fees, in recognition of the necessity of car use for everyday functioning.

I recommend that local governments move faster to make public transport vehicles accessible to people with mobility impairments. There should be compulsory training for people who work on public transport to politely assist disabled people when they need assistance and allow people adequate time to safely board and depart vehicles, as well as find an appropriate place to sit or stand while travelling. Not all people have obvious or visible mobility impairments, so systems should be put in place so an individual can easily signal to staff that they need more time or assistance to enter or exit the vehicle.

I recommend that disabled people are represented on all future transport and spatial planning initiatives. Where car-free areas are planned, people with mobility impairments
must still be able to easily access the areas at multiple points, including having nearby mobility parking places.

Part VII

Conclusions

Importantly, what this research shows is that it is relatively easy to substantially decrease, though in no way remove, all obstacles to mobility and participation for a substantial proportion of people with mobility impairments. For, whatever people claim about the merits or otherwise of the system of automobility, while we live in an era where cars are the dominant form of transport and many cities are built on the assumption of car travel, having access to, and being able to drive a car, is to be included in many aspects of mobility and participation. For disabled drivers to have access to a car (with any necessary modifications) means that their experiences of immobility and exclusion from society can be significantly ameliorated. Much of the infrastructure required for motorised transport by people with mobility impairments in a country such as New Zealand already exists: roading, a nationally recognised scheme for mobility parking permits, companies that import and service vehicles, facilities for vehicle modification. The New Zealand government already has some provision for the funding of and modification of vehicles for people with mobility impairments. All that is required is that the needs of all disabled drivers be recognised and met, regardless of the origin of their impairment(s) or their working or parenting status.

If society is concerned with reducing the effects of impairment (having a less ableist society), and if cars can mitigate ‘disability’, then society should ensure as many disabled people as possible have access to a car. The exciting thing about transport systems is that they are systems that have been created by people and can therefore be changed and modified to work for the widest possible range of human bodies and experiences. Transport is a specific form of technology that exists to help people move themselves and their cargo around further, and more easily, than they could on foot.
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Retrieved from http://www.sortclearinghouse.info/research/124


doi:10.1080/09638280802306539


doi:10.1080/02674649266780161
APPENDIX 1 – Participant Consent Form

The “Disabled Drivers’ Experiences in New Zealand” Consent Form

Participants Name ______________________________________________

Address and Phone Number ______________________________________

I have read and understand the information sheet on the “Disabled Drivers’ Experiences in New Zealand” for people agreeing to take part in the study on the experiences of disabled drivers.

I understand that:

- Taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without any disadvantage and without affecting my relationship with CCS Disability Action.

- The exact interview questions will depend on the way that the interview develops (like a normal conversation) and that if I am uncomfortable with the question(s) at any time I can choose not to answer that question(s), stop the interview and leave without any disadvantage.

- The interview will be tape-recorded and typed up, and the data will be kept in locked storage for ten years, and then destroyed.

- The results of the project may be published and available in the library but every attempt will be made to keep my identity confidential.

I have had the opportunity to discuss this study. I am satisfied with the information I have been given. I consent to take part in this study.

<table>
<thead>
<tr>
<th>Participant’s Signature</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Name</td>
<td></td>
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<tr>
<td>Date</td>
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This study has been approved by the Multi-region Ethics Committee.
APPENDIX 2 – Participant Information Sheet

Disabled Drivers’ Experiences in New Zealand
Participant Information Sheet

Hello, I am inviting you to take part in a study of Disabled Drivers’ Experiences in New Zealand being carried out through the Wellington School of Medicine, which is part of the University of Otago. The study is being conducted by myself, Esther Woodbury, a PhD student, who is also disabled driver.

During the ‘Disabled Drivers’ Experiences in New Zealand’ study, I would like to come and find out from you more about the different ways in which driving affects people with long-term physical disabilities. The study will look at the different experiences of the participants and pull them together to create an overall picture.

Why is the study being done?
Physically disabled people often have issues with mobility and many rely heavily on cars. While there has been a significant amount of research on the effects of driving on elderly drivers, there has been no published research where disabled drivers have discuss how driving affects their social participation. The study is also being done in part because of an interest in recent petrol price rises, which have been coupled with an environmental push towards increasing use of public transport. The ‘Disabled Drivers Experiences in New Zealand’ study is being conducted by myself as part of my PhD degree in Public Health.

Where is the study being done?
The ‘Disabled Drivers’ Experiences in New Zealand’ study is being carried out in Wellington, Auckland and the Wairarapa. The locations of the interviews will be completely accessible and parking will be provided if required.

When is the study going to take place?
The interviews will take place during the second half of 2009 and the beginning of 2010.

What will I have to do if I participate?
I will ask you to participate in a face-to-face interview with myself and talk about your experiences of driving and how it affects you. The interviews will need to be tape-recorded with your permission, so that they can be listened to again to make sure that I have your stories correct. The interviews should take approximately one hour to complete.

Because of the type of information I am trying to uncover, the interviews are going to work like a conversation. This means I don’t know exactly what questions will be asked, as these will depend on the way the interview develops. If you become uncomfortable with a question at any time you can choose not to answer that question, or to leave the interview without any disadvantage to yourself of any kind. To give you an idea of the kinds of questions that will be asked, the question that I will start the interview with is: “can you tell me about becoming a ‘disabled driver’?”
Will participating affect my relationship with CCS Disability Action?
No. Whether you decide to participate in this study or not, your relationship with CCS Disability Action will not be affected.

Can I change my mind about participating?
Yes. If you agree to take part in the Disabled Drivers Experiences in New Zealand study, you are free to withdraw at any time and do not have to provide any reason for doing so.

What information will be collected and what will it be used for?
The information collected will come from typed transcripts from the tape-recorded interviews. I will ask questions about your experiences of driving and how you feel this may have impacted on your social participation. Once you have been interviewed, your stories and those of the other participants will be viewed together, to create a bigger picture of the driving experiences of disabled drivers.

The only people to see the typed transcripts from the interviews will be myself, a typist and my research supervisors. Parts of the transcripts will appear in my final report, but your name will not appear anywhere in the written reports. The results of the project may be published and will be available in the library, but I will do my best to make sure that no one can identify you from the data.

To make sure that the information you choose to share remains private, I will keep the tape recordings and transcripts on a password protected computer and keep any hard copies in a securely locked cabinet for ten years, which only I can access. After 10 years they will be destroyed.

Can I find out the results of the Disabled Drivers’ Experiences in New Zealand study?
Yes. Although there will be some time delay between the interviews and the results being known, if you are interested I will send you a summary of the results of your interview.

Who do I contact if I want to participate?
Please contact Esther Woodbury either by filling in the consent form and posting it to:

Esther Woodbury
Wellington School of Medicine
23a Mein Street
Newtown
Wellington South 6242

Or contact Esther directly:

Esther Woodbury
Phone: (04) 3855541 ext 5076 or 0274046593
Email: esther.woodbury@otago.ac.nz

This study has received ethical approval from the Multi-Region Ethics Committee.
What if I have questions?

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a Health and Disability Advocate:

Telephone 0800 42 36 38 (4 ADNET)
Free Fax (NZ wide) 0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide) advocacy@hdc.org.nz

If you would like to discuss any part of this research, or your participation in it, please feel free to speak with either:

Student Researcher

Esther Woodbury (04) 3855541 ext 5076 or 027 4046593

Supervisors

Dr Sunny Collings (04) 3855541 ext 5660
Professor Philippa Howden-Chapman (04) 3855541 ext 6047
Dr William Levack (04) 3855541 ext 6279
APPENDIX 3 – Interview Schedules

Disabled Drivers Interview Schedule September 2009A

INTERVIEWEE RIGHTS

Interview Aim: “To find out what disabled people’s experiences of car use are.”

Disabled driver – Would you please tell me about becoming a disabled driver?
(Prompts: Did you learn to drive before you became disabled? OR Did you have a disability before you learnt to drive? How do you feel about that? What do you think about that?)

Role of car – Can you tell me about the ways in which you use your car?
(Prompts: Do you think you could do those things without your car? (How?) How do you feel about that? What do you think about that?)

Car access – How much car access do you have and has this changed over time?
(Prompts: Do you share the car you drive? Do you drive one or more cars? What does that mean or has that meant? How do you feel about that? What do you think about that?)

Participation – How does driving influence your participation in society?
(Prompts: How does driving influence your ability to do certain activities? e.g. Work? Study? Leisure? How do you feel about that? What do you think about that?)

Well-being and driving – Can you tell me about how driving affects your well-being?
(Prompts: Do you think driving affects your physical - social - psychological well-being? How do you feel about that? Can you tell me more about that?)

Money – Can you tell me about how money affects driving?
(Prompts: What are the costs? Are there any financial benefits to having a car? What kind of choices do you have to make? How do you feel about that? What do you think about that?)

Public Transport – Can you tell me about your experiences of public transport?
(Prompts: What do you think other people’s experiences of public transport are? What do you think are the benefits of public transport for people who can use it? Can you talk to me about picking between using your own car versus using public transport? How do you feel about that? What do you think about that?)

The future – Do you have any thoughts about your driving or your car in the future?
(Prompts: Cost? Environmental concerns? Changes in your life?)

Other thoughts – Is there anything else important about driving for you?

Weather: Parking: Ethnicity:

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Disabled Drivers Interview Schedule September 2009B

INTERVIEWEE RIGHTS

Interview Aim: “To find out what disabled people’s experiences of car use are.”

Disabled driver – Would you please tell me about becoming a disabled driver? (Prompts: Did you learn to drive before you became disabled? OR Did you have a disability before you learnt to drive? How do you feel about that? What do you think about that?)

Role of car – Can you tell me about the ways in which you use your car? (Prompts: Do you think you could do those things without your car? How? How do you feel about that? What do you think about that?)

Car access – How much car access do you have and has this changed over time? (Prompts: Do you share the car you drive? Do you drive one or more cars? What does that mean or has that meant? How do you feel about that? What do you think about that?)

Participation – How does driving influence your participation in society? (Prompts: How does driving influence your ability to do certain activities? e.g. Work? Study? Leisure? How do you feel about that? What do you think about that?)

Well-being and driving – Can you tell me about how driving affects your well-being? (Prompts: Do you think driving affects your physical - social - psychological well-being? How do you feel about that? Can you tell me more about that?)

Money – Can you tell me about how finances and driving affect each other? (Prompts: What are the costs? Are there any financial benefits to having a car? What kind of choices do you have to make? How do you feel about that? What do you think about that?)

Public Transport – Can you tell me about your experiences of public transport? (Prompts: What do you think other people’s experiences of public transport are? What do you think are the benefits of public transport for people who can use it? Can you talk to me about picking between using your own car versus using public transport? How do you feel about that? What do you think about that?)

How does the weather affect your driving decisions?

Does parking affect your ability to drive?

The future – Do you have any thoughts about your driving or your car in the future? (Prompts: Cost? Environmental concerns? Changes in your life?)

Other thoughts – Is there anything else important about driving for you?

Ethnicity: Age:
Disabled Drivers Interview Schedule November 2009

INTERVIEWEE RIGHTS

Interview Aim: “To find out what disabled people’s experiences of car use are.”

Disabled driver – Would you please tell me about becoming a disabled driver?
(Prompts: Did you learn to drive before you became disabled? OR Did you have a disability before you learnt to drive? How do you feel about that? What do you think about that?)

Role of car – Can you tell me about the ways in which you use your car?
(Prompts: Do you think you could do those things without your car? How? How do you feel about that? What do you think about that?)

Car access – How much car access do you have and has this changed over time?
(Prompts: Do you share the car you drive? Do you drive one or more cars? What does that mean or has that meant? How do you feel about that? What do you think about that?)

Participation – How does driving influence your participation in society?
(Prompts: How does driving influence your ability to do certain activities? e.g. Work? Study? Leisure? How do you feel about that? What do you think about that?)

Well-being and driving – Can you tell me about how driving affects your well-being?
(Prompts: Do you think driving affects your physical - social - psychological well-being? How do you feel about that? Can you tell me more about that?)

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(Prompts: What do you think other people’s experiences of public transport are? What do you think are the benefits of public transport for people who can use it? Can you talk to me about picking between using your own car versus using public transport? How do you feel about that? What do you think about that?)

How does the weather affect your driving decisions?

Does parking affect your ability to drive?

How much time do you spend driving? Do you enjoy it?

The future – Do you have any thoughts about your driving or your car in the future?
(Prompts: Cost? Environmental concerns? Changes in your life?)

Other thoughts – Is there anything else important about driving for you?

Ethnicity: 

Age:
Disabled Drivers Interview Schedule February 2010

INTERVIEWEE RIGHTS

Interview Aim: “To find out what disabled people’s experiences of car use are.”

Disabled driver – Would you please tell me about becoming a disabled driver?
(Prompts: Did you learn to drive before you became disabled? OR Did you have a disability before you learnt to drive? How do you feel about that? What do you think about that?)

Role of car – Can you tell me about the ways in which you use your car?
(Prompts: Do you think you could do those things without your car? How? How do you feel about that? What do you think about that?)

Car access – How much car access do you have and has this changed over time?
(Prompts: Do you share the car you drive? Do you drive one or more cars? What does that mean or has that meant? How do you feel about that? What do you think about that?)

Participation – How does driving influence your participation in society?
(Prompts: How does driving influence your ability to do certain activities? e.g. Work? Study? Leisure? How do you feel about that? What do you think about that?)

Well-being and driving – Can you tell me about how driving affects your well-being?
(Prompts: Do you think driving affects your physical - social - psychological well-being? How do you feel about that? Can you tell me more about that?)

Money – Can you tell me about how finances and driving affect each other?
(Prompts: What are the costs? Are there any financial benefits to having a car? What kind of choices do you have to make? How do you feel about that? What do you think about that?)

Public Transport – Can you tell me about your experiences of public transport?
(Prompts: What do you think other people’s experiences of public transport are? What do you think are the benefits of public transport for people who can use it? Can you talk to me about picking between using your own car versus using public transport? How do you feel about that? What do you think about that?)

How does the weather affect your driving decisions?

Does parking affect your ability to drive?

How much time do you spend driving? Do you enjoy it?

Do you think being a disabled driver in Auckland differs from being a disabled driver elsewhere in New Zealand?

The future – Do you have any thoughts about your driving or your car in the future? (Prompts: Cost? Environmental concerns? Changes in your life?)

Other thoughts – Is there anything else important about driving for you?

Ethnicity: _______ Age: _______
APPENDIX 5 – Codes from Interviews

ACC
Access to car
Accessible environment
Accident or Illness
Active transport
Adapting to car
Ageing
Alternatives to transport
Anxiety
Appearance, legitimacy of parking
Attitudes
Auckland perspective
Budgeting
Buying a car
Cabin fever
Car accidents
Car breakdowns
Car high priority
Car personality
Changing abilities or needs
Comments on interviewer’s disability
Community
Confidence
Control
Convenience
Cost of transport
Cruising for chicks
Demographics
Depression
Dog walking
Driving other people
Driving restrictions
Education
Energy
Enjoying driving
Environmental concerns
Exercise
Family
Financial benefits
Flexibility
Freedom
Frequency of driving
Future
Good or bad day
Grants for cars or modifications
Growing up
Health care
Housebound
Housing or location
Identity
Improvising
Independence or dependence
Isolation
Learning to drive
Leisure
Mastery
Medication and driving
Mental health
Mixed transport
Mobility card or park
Modifications
MOH
Motivation
Non-New Zealand
Normality
Other drivers
Other mobility aids
Pain
Parking
Parking tickets
Participation
Passenger
Perception of disability
Petrol
Physical aspects of driving
Planning journeys
Privacy
Public Transport
Public vs private parking
Reliance
Role of car
Safety
Security
Servicing Car
Sharing a car
Shopping
Socialising
Taxis
Total journey
Transporting things
Travel
Type of car
Unproblematic
Wairarapa perspective
Walking
Weather
Well being
Wellington perspective
Work
APPENDIX 5 – Ethics Approval

3 March 2009

Esther Woodbury
Wellington School of Medicine
23a Mein Street
Newtown
Wellington South 7343

Dear Esther,

MEC/09/02/013
Auto-mobile: The impact of driving on the health and well-being, social participation and economic situation of work-aged people with long term physical disabilities in New Zealand
Lead Investigator; Esther Woodbury

Thank you for the above application which was considered by Multi-region Ethics Committee at its meeting on 17 February 2009 and approved subject to the following conditions.

<table>
<thead>
<tr>
<th>Recruitment(National Application Form A4.1)</th>
<th>Please clarify your recruitment process including how you plan to utilize ‘snowballing’</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Application Form B10</td>
<td>Please provide further information on the inclusion criteria</td>
</tr>
<tr>
<td>National Application Form B11</td>
<td>Please clarify how you will recruit participants including participants</td>
</tr>
<tr>
<td>National Application Form D6 and Consent Form</td>
<td>Data needs to be stored for ten years</td>
</tr>
<tr>
<td>Interview Guide</td>
<td>Please provide</td>
</tr>
<tr>
<td>Locality Assessment</td>
<td>Please provide from CCS</td>
</tr>
<tr>
<td>Māori Consultation</td>
<td>Please provide from Ngai Tahu</td>
</tr>
<tr>
<td>Participant Information Sheet and Consent Form</td>
<td>Please rewrite providing more detailed information for the participants (refer to <a href="http://www.ethicscommittees.health.govt.nz">www.ethicscommittees.health.govt.nz</a> guidelines for completion of the National Application Form). Please ensure you detail how data will be kept confidential and who will have access to it</td>
</tr>
</tbody>
</table>

Administered by the Ministry of Health
Approved by the Health Research Council
http://www.ethicscommittees.health.govt.nz

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Please forward your response in letter format with amended information sheet/consent form or other required forms. Your response will be reviewed by committee members and if the above points have been addressed to their satisfaction, final ethical approval will be given by the Chairperson under delegated authority.

The Committee forwards the following comments, which do not affect the application's ethical approval status.

**Comment:**

| Consent     | The Committee suggest you consult with DPANZ and Donna Rose Mackie at the University of Otago |

If you have any queries, please contact me.

Yours sincerely,

Emalene Pearson
Multi-region Administrator
APPENDIX 6 – Māori Consultation Response

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
TE KOMITI RAKAHAU KI KĀI TAHU

11/11/2008 - 17
Thursday, 13 November 2008

Dr Collings
Public Health
Wellington

Thank you Dr Collings

Title: Auto-mobile: The impact of driving on the health, social participation and economic situation of working age people with long term physical disabilities in New Zealand.

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 11 November 2008 to discuss your research proposition.

The Committee considers the research to be of importance to Māori health.

The Committee notes that there is an intention to conduct interviews with participants, and so as this study involves human participants, the Committee strongly encourages that ethnicity data be collected as part of the research project. The Committee is aware that there are two different data sets and they recommend collecting both, that is the question on self-identified ethnicity and the question on ancestry that are contained in the 2006 census.

The Committee would ask if analysis by ethnicity will be carried out and if so they suggest including in the research team a researcher with expertise in analysing data by ethnicity.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

The Committee would also value a copy of the research findings.

The Committee notes that this proposal is already funded. In respect of consultation and collaboration it would be anticipated that the engagement process would have taken undertaken at the earliest possible stage, prior to funding applications.

The recommendations and suggestions above are provided on your proposal submitted through the consultation website process. These recommendations and suggestions do not necessarily relate to ethical issues with the research, including methodology. Other committees may also provide feedback in these areas.

Nāhaku noa, nā

Mark Brunton
Kaitakawaenga Rangahau Māori
Facilitator Research Māori
Research Division
Te Whare Wānanga o Otago

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtākou Incorporated
Kūti Huatanga Rānoka ki Pukekawa
Te Rūnanga o Moeraki