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*Experiences of care at the nexus of intellectual disability and
leisure travel*

A thesis
submitted in fulfilment
of the requirements for the degree

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Abstract

This thesis explores lived experiences of care at the nexus of intellectual disability and leisure travel, notably among a sample of carers and people with intellectual disabilities, whose voices are otherwise absent in much previous tourism scholarship. The originality of this research therefore lies in its approach, which favours the cognisance of situated, contextual and value-laden care experiences between self and other, privileging subjective and inter-subjective ways of knowing, and humanising the intricacies of the participants' individual, relational and emotional lives.

In this way, this thesis seeks to honour the participants' authentic voices, positionalities and subjectivities as they narrate their lived experiences. It offers, thus, a person-centred, strengths- and abilities-based approach to inclusive tourism research. As such, this research adopts a Heideggerian interpretive phenomenological approach, exploratory in its nature and qualitative in its design. The data has been collected through in-depth, semi-structured interviewing with fifteen carers and nine people with intellectual disabilities. The data was then thematically analysed, inductively eliciting a depth and richness of meaning embedded in the participants' experiential knowledge, iteratively and recursively negotiated with the theoretical knowledge.

Findings of this thesis define the leisure travel phenomenon both as a meaningful experience in and of itself, and as the situated context in which carers and people with intellectual disabilities make sense of, and ascribe meaning to, their lived experiences of care. The analysis reveals three key emergent themes: *giving*, *attunement*, and *(in)visibility*. Experiences of care at the nexus of intellectual disability and leisure travel, indeed, are a labour of love. They reflect a complex and dynamic (re)negotiation of the paradoxical tensions involved in being in between two worlds, and span practical, emotional and socio-political caring spheres. This thesis concludes with implications for (re)imagining the transformative potential of tourism through an ethic of care as an ethos to guide our social relations, wherein we meet one another morally.

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van Manen (1990) once said, “*to truly question something is to interrogate something from the heart of our existence, from the centre of our being*” (p. 43). Never stop learning about this weird and wonderful world we live in, and remember always, you hold an innate power inside of you, to turn out toward others, with care, compassion and conviction. With love and gratitude, I thank you.

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1 Prologue

To do research is always to question the way we experience the world, to want to know the world in which we live as human beings. And since to know the world is profoundly to be in the world in a certain way, the act of researching-questioning-theorising is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to *become* the world – (van Manen, 1990, p. 43).

I would like to open this thesis with a prologue, the intention being to foreground myself as situated researcher within this research (Ren, Pritchard, & Morgan, 2010; Westwood, Morgan, & Pritchard, 2006), which explores lived experiences of care at the nexus of intellectual disability and leisure travel. Traditionally, the researcher has been a largely anonymous, unidentified and genderless individual (Ateljevic, Harris, Wilson, & Collins, 2005), “able to identify, isolate and disengage their particular values, biases and emotions in order to record a more objective account of an independent reality” (Jones, 1998, 2). A conclusion drawn in this thesis is around the dehumanised (Feighery, 2006) view of much historical tourism scholarship and the disembodied (Westwood et al., 2006) view of many historical tourism scholars, and the assumption that research can remain value-free (Ateljevic et al., 2005) by abstracting the researcher (Feighery, 2006).

The researcher is a bricoleur, “gendered, radicalised, sexualised, embodied and emotional” (Coffey, 1999, p. 34), each researcher having their own individual histories, experiences and stories (Denzin & Lincoln, 2000). These embodied conditions of personal historicities (Ateljevic et al., 2005) shape our being in the world (Feighery, 2006). They are “a part of us, who we are and how we understand the world, and not something we can free or distance ourselves from” (Pocock, 2015, p. 35). They therefore frame our ontological positionality to, and epistemological intersectionality with, those we involve in our research (Alvesson, Hardy, & Harley, 2004; Ateljevic et al., 2005; Stanley & Wise, 1993). Through self-introspection and self-reflection, the research process is humanised (Dupuis, 1999), as we look to our inner world as researcher, and to the outer world, at those we research with (Ateljevic et al., 2005).

In this vein, I affirm that I cannot be distanced from this research – neither as researcher nor as author – “physically, psychologically or ideologically” (Foley, 1998, p. 110). I acknowledge that my personal historicity has undoubtedly shaped my interest in and decision to pursue this particular thesis topic (Dupuis, 1999; Janesick, 2000; Tracy, 2010), as well as the way in which I approach, conduct, interpret, and present this research (Ateljevic et al., 2005; S.A. Cohen, 2013; Wilkinson, 1988). I make known, therefore, that much of the text in this prologue consists of personal statements (Denzin & Lincoln, 1998), and that the thesis in its entirety is written in the first person, active voice (Ateljevic et al., 2005) rather than the third person, passive voice (Westwood et al., 2006).

To this end, the purpose of this chapter is for you, the reader, to know *why*. I detail my implicit assumptions and biases, perspectives and motivations (Feighery, 2006), and I share parts of my story – particular emotions and events – as openly and as honestly as I can. It is these experiences that have cumulatively contributed a number of lessons and learnings that I believe to have been formative and profound in my understanding of my being in and of the world (McConnell-Henry, Chapman, & Francis, 2009). This understanding continues to evolve, as I seek a greater understanding of the world we live in, which is why I have similarly included Chapter 9, ‘Epilogue’, for as van Manen (1990) remarked:

The question of knowledge always refers us back to our world, to our lives, to who we are ... the problem is that our common sense, pre-understandings, our suppositions, assumptions, and the existing bodies of scientific knowledge predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological question. (p. 46)

Who am I? I might describe myself as follows. I am twenty-seven years of age and of New Zealand European ethnicity. I have a female body and am of heterosexual orientation. I am from a middle-class family and have had a spiritual but not religious upbringing. I am a PhD candidate and researcher, and neither a carer nor a support worker. While I have lived experience with mental health issues, I do not personally identify as an individual with disability. Given that this research involves carers and people with intellectual disabilities, surely the preceding descriptors of my identity presuppose the possibility of a partisan difference with which I participate in the world and of a privileged lens through which I may see

the world (Beail & Williams, 2014; Higgins-Desbiolles, 2006; Locke, Spirduso, & Silverman, 1993).

I would argue that while it is important to consider the other identities we inhabit, and the differences these may present, it is just as important that we account for that which we may share or have in common. While descriptors and symbols may serve to prescribe an aspect of identity for individuals and for groups, the product of such labelling can be confining and disempowering, isolating and othering (Goodley & Runswick-Cole, 2016). I would also argue that such descriptors are a less representative touchstone of who we are as individuals or our being in the world, and fail to acknowledge the diversity, multiplicity and universality of the human condition (Ateljevic, Pritchard, & Morgan, 2007). Indeed, “our borders are much more porous than we usually imagine they are” (De Schauwer, Van de Putte, & Davies, 2018, p. 10). We are not a single identity or label; we are multi-dimensional beings having – or perhaps sharing in – a human experience. I prefer to describe myself as “being with and for the other” (de Laine, 2000, p. 16); an advocate for people with disabilities, and their carers (Coons & Watson, 2013; McDonald, 2012; Walmsley & Johnson, 2003). Like these individuals too, I am a daughter, sister, friend and member of the community (IHC New Zealand, 2016).

For as long as I can remember, disability has presented itself as something of a moral quandary between my mind and my heart, my thought and my action (Heidegger, 1927/2008). Growing up on a horse stud, I rode ponies throughout my child and adolescent years. A few falls meant several years of various musculoskeletal therapies for a recurring back injury and with this came a subtle albeit unrelenting phobia of immobility that contributed to my eventual decision to give up riding. Throughout this time, I struggled to soften into the discomfort that came with seeking the truth behind what I knew to be an unfounded fear; for the phobia was not so much the potential of paralysis itself, rather the perceived threat to the certainty of my non-disabled being in the world (Giddens, 1991).

My insight into lived disability began with my friendship with Lucy, the sister of a close friend of mine. Lucy had contracted neonatal meningitis following her birth, which resulted in infant brain damage and the subsequent diagnosis of acquired cerebral palsy. There is no denying her impairments were severe. She

spent the former part of her life in a wheelchair, attending a Conductive Education Unit, and the larger and latter part of her life in a hospital profiling bed, entirely dependent on 24/7 home care. She was non-verbal with severe mixed receptive-expressive communication abilities. Even so, she was more than the descriptor of ‘individual with disability’; she was a friend, sister and daughter, and she brought the notion of disability into my realm of normality. Her excitable shrieks and squirms, beaming smile and brightly lit eyes were all expressions of her happiness and love. Her being was beautiful and something those of us around her had always celebrated and not condemned throughout the seventeen years of her life. I always felt in awe of her resilience and strength – and, equally, of the courage of her family and carers, and the way they cocooned her in compassion and unconditional love. I was witness to evidence that their care knew no bounds.

What feminist care ethicist Kittay (2011) acknowledged of her disabled daughter and their own care relationship, I have experienced indirectly through witnessing Lucy’s care relationships. That is, “a knowledge of ... the extraordinary possibilities inherent in relationships of care toward one who reciprocates, but not in the same coin; one who cannot be independent but makes a gift of her joy and her love” (p. 57). Thus, it is the following passage from Kittay that deeply grounds my social justice-oriented motivation in pursuing this research (Janesick, 2000). Kittay (2011) wrote:

I have been learning about disability from the perspective of one who is unable to speak for herself; and it is from her and her caregivers that I have come to have a profound appreciation of care as a practice and an ethic. My daughter’s disabilities always threaten her with a life of diminished dignity. It is only with care, and care of the highest quality, that she can be included, loved, and allowed to live a joyful and dignified life. When I speak of disability, I think a great deal about the cognitive disability that marks her life, and my concern is that persons with such disabilities, as well as her caregivers, not be left out of considerations of justice and moral personhood. Coming to the question of disability from the position (or ‘role’) of a resolute carer of a beloved disabled person, I am invested in the idea that care is an indispensable, and even a central good – one without which a life of dignity is impossible and which is itself an expression of a person’s dignity. (p. 52)

In a different vein, I too have experienced deep compassionate care from others. As mentioned, I have lived experience with mental health issues, namely major depressive disorder and generalised anxiety disorder. Although mild to moderate in its severity, it has been a persistent force in my life for over fifteen years, and a battle I have largely fought in silence and invisibly, only disclosing what I was contending with and receiving diagnosis, medication and treatment over the last five years.

Pain affords perspective and adversity is a crucible. Only through the immense care, compassion and love I received from others have I been able to pick up the pieces of my former fragmented being, working toward a more nuanced understanding of myself and becoming increasingly whole. I feel compelled to show up for others in the same way, to bear the weight of their story, and to sit in proximity to, and walk with them through, their pain (Gustin & Wagner, 2013; Lipari, 2010). I cannot pretend to know another's pain, nor will I compare my experience to theirs as though it is the same. But it is the polarity within and of my own experiences that give me a sense of empathy, so that I may see myself in other people, recognise a need within me to help in their healing, and to hold compassionate space for them (Gustin & Wagner, 2013; Hoffman, 1987; Noddings, 1984). No one is a stranger to pain (Sontag, 2003); "suffering, like alterity, is both unique and universal, both particular and ordinary" (Lipari, 2009, p. 51). I think that if we can recognise the suffering in ourselves, then we can recognise the suffering in another – even if different – and we can feel the essence of another because we can feel it in ourselves. We all have a human heart that experiences anxieties and sadness, and in the same vein we all yearn to be seen, to be heard, and to belong. In this way, and in these times more than ever, I do not think we can be complicit in our care.

The final personal incident I share was a serious car accident I had during the course of my study. In what could have been a decisively fatal moment, fate had other plans, and I walked away physically unscathed. While I was immensely grateful to be okay and could not comprehend how or why I had been so lucky, I struggled for months afterward, with feelings of confusion and guilt. Just years earlier, I had been contemplating taking my own life and not living it, yet equally

and even worse, here I may have inflicted pain on, or taken, another individual's life because of my complacency and carelessness. I realised a heightened appreciation for the fragility of life, becoming more "sensitive to my place in the world" (Manning, 1992, p. 45). Also, I realised a heightened sense of my pathic knowledge (van Manen, 2007), becoming more authentic and intentional in honouring my responsibility as a caring individual and morally engaged agent (Black, 2005; Caton, 2014, 2016; Conroy, 2003; Koskinen & Lindstrom, 2013; Lipari, 2009). The meaning that an individual extracts from these moments of cognition in their life can shift them in an existentially defining way (Willson, McIntosh, & Zahra, 2013), and the eventual solace I found in confronting my mortality could be cathartic (Zahra & McIntosh, 2007), crystallising a sense of clarity in my conviction.

Academically, I completed an honours degree in management, majoring in tourism management. The degree was broad and the major was self-indulging, commensurate with what I perceived as employment and travel prospects, respectively. Studying tourism and having been fortunate enough to have travelled, I realised very quickly that the world we live in and the people we share it with are disproportionately vulnerable (Caton, 2014), and that tourism's managerial focus on advancing business aims (Caton, 2015) ahead of its social function (Higgins-Desbiolles, 2006) did not sit well with me. Providence came with a single lecture on accessible tourism by my then lecturer and current supervisor, Professor Alison McIntosh. Together with her guidance and encouragement, and the resonance in our mutual desire to lead a life of consequence (Caton, 2014), I decided to pursue a research trajectory in the critical tourism space (Pritchard, Morgan, & Ateljevic, 2011). This trajectory began with the completion of my honours dissertation, which examined stakeholder perspectives in the accessible tourism space (see Gillovic & McIntosh, 2015), and continues with this current doctoral thesis. My future research interests lie in the continuing examination of the embodied experiences of stigmatised and marginalised identities in tourism, and more generally too. In this way, my research will remain founded in critical tourism studies, seeking to challenge conventions and create alternate ways of knowing for human dignity, human rights and social justice (Richards, Pritchard, & Morgan, 2010; Rorty, 1999).

Practically, I sought to extend an outward focus to the individuals, groups and communities with which I was engaging in my research pursuits. I volunteered with several disability organisations. I carried out work experience with a public service department around a nationwide social change campaign challenging attitudes and behaviours toward people with disabilities. I interned with a national social change enterprise around a holistic framework for accessibility. I was a student advocate for a community network involved in sharing resources, knowledge and support around social issues, and I participated in various collaborative research projects between the health and disability sector and the university. Similarly, I wish to continue to enact agency, engagement and community involvement, advocating a more collaborative style of research: research embedded in industry priorities and processes for social change (Pritchard et al., 2011; N. Morgan, Pritchard, & Ateljevic, 2012; Willson et al., 2013).

In consideration of this intent, in carrying out this present research I have been guided by an ethic of caring (Campbell, 2002), for “research is a caring act” (van Manen, 1990, p. 5). We “act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences” (Ellis, 2007, p. 3). Thus, unveiling the lived experience of others represents but one medium that may lend itself to the humanising of life and its structures (van Manen, 1990) “to alert societies and individuals to alternate futures by providing an opportunity to hear the silenced or delegitimised voices of people at the social margins” (Milner & Mirfin-Veitch, 2012, p. 106). With this in mind, the thesis begins...

2 Introduction and literature

The purpose of this initial chapter is to introduce the thesis topic and, as such, the chapter begins by offering a statement of the thesis aim and research questions, as well as a note on language and terminology. The significance of the research is then clearly articulated and, in doing so, I suggest that a paucity of research exists at the nexus of care, intellectual disability and leisure travel. Following this, and forming the greater part of this chapter, is a succinct synthesis and review of the relevant literature at this nexus, which again emphasises the dearth of research that currently exists, and illuminates both the originality and contribution of this present research. I conclude this chapter with an outline of the thesis structure, before moving to Chapter 3, 'Background', which further supports the arguments made here.

In considering Chapter 2, 'Introduction and literature', and Chapter 3, 'Background' together, I have sought to provide a more holistic introduction to the foundations that have underpinned and framed this research. In this way, I value all knowledge, whether conceptual or contextual, rather than dividing them or privileging one over the other. It is important to note that neither the academic literature nor the background information need be viewed in isolation, for they respectively conceptualise and contextualise the thesis topic, and therefore should be considered as interrelated parts to a whole. The three somewhat divergent academic disciplines of care, disability and travel, and their personal, relational and societal dimensions form both a foundation and frame from which one can begin to understand the phenomena in question. I believe this to be a straightforward yet effective way of centring knowledge, and for subsequently knowing knowledge, since lived experiences, especially, cannot be easily separated or neatly structured, as more binary approaches to tourism enquiry might posit.

2.1 Statement of the thesis topic and research questions

The aim of this thesis is to explore lived experiences of care at the nexus of intellectual disability and leisure travel, as described and understood by carers and people with intellectual disabilities. Motivated by the following phenomenological questions, this research seeks to address:

1. How do carers and people with intellectual disabilities experience leisure travel, and what is the significance of this?
2. How do carers and people with intellectual disabilities experience care within this context, and how do they understand and ascribe meaning to this?

Hence, it is an intention of this thesis to offer an understanding of the ways in which these individuals make sense of, navigate and construct their contextualised leisure travel experiences, as well as the significance of them. It is also an intention to discover the ways in which these individuals experience care, and its manifestation, negotiation and/or transformation at personal, relational and societal levels. This thesis does not seek to define, conceptualise or theorise the phenomenon of care, because to do so would go against the philosophy of the research paradigm employed (J.A. Smith, Flowers, & Larkin, 2009). Rather, this thesis seeks to provide in-depth, preliminary and exploratory insights into the phenomenon, constructing but one possible interpretation of the nature of this particular human experience (van Manen, 1990).

An interpretive phenomenological approach to the inquiry was appropriate in order to examine a subjective view of experiences of care for an individual, within the unique context of leisure travel. This approach, with its phenomenological focus, sought the reflexive accounts of the participants, as they offered their descriptions and understandings of their lived experiences (Denzin & Lincoln, 2000) because “only through reflection can we appropriate aspects of lived experience” (van Manen, 2007, p. 16), and only from such reflection is the meaningfulness of this experience derived (Bain, 1995). This approach, with its interpretive focus, then sought to offer but one possible interpretation of lived experiences of care at the nexus of intellectual disability and leisure travel, from the perspectives shared by the carers and people with intellectual disabilities. I acknowledge the possibility and likelihood of multiple interpretations, and I therefore encourage the reader to reach their own conclusions and interpretations as I have done (Denzin & Lincoln, 2000).

I make a caveat here, as I caution the reader to the limitations of my perceptiveness as researcher, in that I cannot write legitimately on an experience that I have not lived first-hand. While as researcher and author I have necessarily composed the final thesis text presented at my discretion (Ren et al., 2010), I sought

to honour the participant voices (Harding, 1993), by way of offering a person-centred (N. Morgan, Pritchard, & Sedgley, 2015), strengths- and abilities-based approach to inclusive tourism research (see Gillovic, McIntosh, Cockburn-Wootten, & Darcy, 2018). It was important to me that I included and allowed for the authentic voice of each travelling companion, even if to varying degrees (Hamington, 2010). Consequently, the knowledge acquired in the thesis is largely articulated from the carers' perspectives, although articulations from the perspectives of the people with intellectual disabilities are also included if and where possible, despite the need to work through several ethical and practical considerations (see Gillovic et al., 2018).

Experiences of care are shared and relational (Keith, 1992), and therefore cannot be looked upon in isolation (Walmsley, 1993). Accordingly, the descriptions, understandings and meanings offered by each individual participant may have been shaped through, or constructed in relation to, their shared and inter-subjective experiences of care with their respective travelling companion, presenting an indexical context, or additional perspective (Bigby, Frawley, & Ramcharan, 2014; Burr, 2003; Stanley & Wise, 1993). Interpretations of the people with intellectual disabilities perspectives, then, could function as a way of deepening those of the carers, and vice versa, thereby contributing to a more holistic understanding and presentation of the phenomena. In this way, the approach favoured the cognisance of care experiences between self and other, privileging subjective and inter-subjective ways of knowing, offering a multiplicity of understanding, and humanising participants' individual and relational lives (Pocock, 2011).

2.1.1 A note on language and terminology

Having stated the thesis topic and research questions, and before moving forward to describe the significance, originality and contribution of this research, in relation to the current literature, I would like to make a comment on the language employed in this thesis. I draw your attention to the preceding paragraphs, which have so far identified the research participants with the descriptors of 'carers' and 'people with intellectual disabilities'. Given the thesis aim, these descriptors necessarily determined the scope of the sampling parameters for participation in this research (Ellingson, 2017), defined as follows.

‘Carer’ is a term that describes any individual who assists an individual with intellectual disability with their personal care, household duties, and everyday living, within their homes and out in their communities (Ministry of Social Development, 2014). It refers to those individuals who care in an informal/unpaid capacity, such as a parent, sibling, other family member or friend. ‘Support worker’ is a term that describes any individual employed in a formal/paid capacity by an organisation in the health and disability sector. Similarly, they “support, care for and encourage individuals with intellectual disability in their daily living situations, whether it be at home, work, day programmes or in social, leisure and educational time” (IHC New Zealand, n.d., para. 1). Under the term ‘carer’, I include the three ‘support workers’ that were involved in this research.

“There is a history of controversial attempts through research to standardise the signs and symptoms of intellectual disability into psychiatric diagnostic categories (for example, the Diagnostic and Statistical Manual of Mental Disorders)” (Gillovic et al., 2018, p. 54). The argument here is that much of the way this group of people are constructed and classified actually disempowers and others them, rather than treating them as valid members of society. Like much of the critical research that places the ‘individual with intellectual disability’ at the forefront of its concern, the thesis will use this term, and the plural ‘people with intellectual disabilities’, to describe any individual/s who self-identify or define his/her/their own way of living with intellectual disability. I “acknowledge, of course, that many people so-labelled prefer no labels whatsoever” (Goodley & Runswick-Cole, 2016, p. 14).

Additionally, the terms ‘leisure travel/traveller’ describe the type of travel engaged in by the type of traveller presented in this thesis. For all of the individuals who participated in this research, the purpose and nature of their travel was leisure and holiday, respectively. In this sense, the individuals mostly presented themselves as leisure travellers engaging in leisure travel experiences.

I provide further discussion of the terminology employed in the thesis in Chapter 3, ‘Background’. However, for the purposes of consistent signposting for the reader, I have included these descriptors – of ‘carer/s’ and ‘individual with disability/people with intellectual disabilities’ – in the first half of the thesis, to introduce the research topic, define its context, and outline its approach. As parts of

Chapter 1, 'Prologue', may have illustrated however, certain descriptors serve to prescribe an aspect of identity for self and groups, and the product of such labelling can be confining and isolating, disempowering and othering (Ellingson, 2017). Given my intention to be inclusive in the research approach (see Gillovic et al., 2018), I deliberated how I represented the individuals involved in this research, as well as the way I narrated their experiences (Caton, 2014). Notably, "the words we use, how we behave and how others talk to and behave with us have powerful effects on our sense of identity, agency and authority and on how others see us" (IHC New Zealand, 2016, p. 5). Thus, in the second half of the thesis, I introduce the participating individuals, contextualise their experiences of care, and present the research findings and wider discussion. Notably, the previous descriptors do not take precedence; rather I embrace and empower the humanity of each individual through the use his or her name wherever possible (McClimens, 2007).

2.2 Significance of the research

The previous section has offered a statement of the thesis topic and research questions, in addition to a note on the language and terminology used throughout this thesis. Importantly, before ascertaining the originality and potential contribution of the thesis, in consideration of the relevant literature presented, the very significance of this research must be determined. The following section succinctly suggests the significance of this research, signposting further elaboration in the ensuing Chapter 3, 'Background'. More specifically, that background consists of the contextual landscape of care and intellectual disability in New Zealand, in addition to the existing scholarship, its identified research gaps and suggested future directions, in relation to this current research. Here, I emphasise the wider scope of the thesis topic, illuminating the paucity of knowledge at the nexus of care, intellectual disability and leisure travel.

As Chapter 3, 'Background', discusses further, disability is ubiquitous worldwide. Estimations from the first 'World report on disability' (2010) suggested that there are over one billion people with disabilities, of whom nearly 200 million experience substantial difficulties in their functioning (World Health Organization, 2011). Disability affects less advantaged and more vulnerable populations disproportionately (World Health Organization, 2011), although in Western

developed nations alone, the average population of people identifying themselves as having an impairment ranges between 10 and 20 per cent (Daruwalla & Darcy, 2005).

Globally, the rising primacy of disability is attributable to increasing life expectancies and improving rates of child mortality (Bowen, Gibson, & Hand, 2002), as well as rising levels of chronic health problems and non-communicable diseases (Office for Disability Issues, 2001). Perhaps affecting this change most significantly, and virtually everywhere, is population ageing, that is, “growth in the number and proportion of older persons [affecting] the size and age structure of the population” (United Nations, 2015, p. 1). “Between 2015 and 2030, the number of people in the world aged 60 years or over is projected to grow by 56 per cent, from 901 million to 1.4 billion, and by 2050, the global population of older persons is projected to more than double its size in 2015, reaching nearly 2.1 billion” (United Nations, 2015, p. 2). Disability will inevitably enter into the lives of most people, be it in a temporary or permanent capacity, and whether directly for an individual or indirectly for someone close to them (Kittay, 2005; Philip, Rogers, & Weller, 2012; World Health Organization, 2011; Zola, 1982).

In this way, feminist care ethicists emphasise the commonality in our vulnerability and therefore our interdependence as human beings (Rogers, 2016). With disability then, comes the need for care (Beckett, 2007; Fine, 2004), and thus the right to both give and receive care is an issue of social justice (Fine & Glendinning, 2005; K. Lynch, Baker, & Lyons, 2009). “Caring is a basic human need and we cannot live without it if we wish to flourish as human beings” (Rogers, 2016, p. 54). Despite being a historical, universally lived experience (Schumacher, 2010), the practice of care will become an increasingly commonplace and fundamental aspect of our human existence (Noddings, 2002; Philip et al., 2012; Sevenhuijsen, 1998; Tronto, 1993). In contemporary society, demographic changes, like the ageing population, as well as economic and social trends, like delayed fertility, are changing the nature of care giving (Hirst, 2001; Schumacher 2010). As Tomkins and Eatough (2014) have elaborated:

A significant trend in contemporary demography is the emergence of a labour force of working carers who combine paid employment with unpaid caregiving. People with more complex

medical conditions are living longer, and there is pressure to support them in their own home rather than with institutionalised care. At the same time, the drive towards fuller labour-force participation means that families are expected to combine the provision of this home-based care with employment away from the home. ... The question of how to cope with this demographic time bomb is becoming more and more pressing. (p. 4)

“There has been a considerable evolution from a situation of inequality, difference and dependence towards greater equality, integration and independence of people with disabilities” (World Tourism Organization, 2016b, p. 53). Such economic and social integration has seen individuals who, once, were merely existing in their communities, now participating in and being a part of them (Novak, Feyes, & Christensen, 2011). As such, people with disabilities, are increasingly desiring and pursuing “the right of all persons to access, participate in and enjoy,” the phenomenon that is tourism (World Tourism Organization, 2016b, p. 1). This is particularly true in Western developed countries where, on the whole, individuals are experiencing a higher standard of living as a result of their increased labour market integration and income levels, translating into increased disposable income, as well as spare time, to spend on leisure and tourism activities (World Tourism Organization, 2016a, 2016b). There is much evidence to suggest that people with disabilities are representative of one of the most lucrative future tourism markets (Packer, Small, & Darcy, 2008). In fact, Burnett and Bender-Baker (2001) argue people with disabilities to be an untapped travel market, having stated that “few consumer groups have greater potential and are more ignored than the disabled” (p. 4). Yet, while “the spirits of tourists might remain young and strong, the vagaries of time and circumstances may cause the body and its sense to function with reduced capacity” (Foggin, 1999, p. 371).

2.3 Review of relevant literature

In identifying the significance of the thesis topic, the following sections offer an overview of the relevant scholarship existing at the nexus of care, intellectual disability and leisure travel, so as to explicitly identify and describe both the originality and contribution of the present research. Given that an interpretive approach to phenomenological research is ultimately concerned with the lived experiences of human beings (Holloway, 1997; Kruger, 1988; Kvale, 1996), I have structured the review of literature as follows. It is appropriate to map the way in

which tourism scholarship has traditionally and more recently examined the tourist experience, and how a critical tourism studies perspective has increasingly granted attention to previously overlooked touristic identities. Disability is then identified as a marginalised identity in travel, especially people with intellectual disabilities and their carers, who largely remain invisible to industry and scholarship alike, as do their experiences of care. It is here that a number of research gaps are identified and that the significance of this current research is reiterated.

2.3.1 An introduction to the tourist experience

“Tourism is a significant force in society. It is both shaped by and shapes the world we live in” (E. Wilson, Small & Harris, 2012, p. 51). The tourist experience, therefore, has been explored for some time (Uriely, 2005), and has increasingly been granted attention (Otto & Ritchie, 1996), mostly from economic and social perspectives (Quan & Wang, 2004). Tourism is a service industry (Otto & Ritchie, 1996) that exists within an experience economy (Pine & Gilmore, 1999). In many ways, the phenomenon has simulated the processes of industrialisation and commodification, modernity and consumerism (Dann & Cohen, 1991; Pearce, 1988). The industry as object delivers an experience as offering, from which the tourist as subject derives an experience as essence (S. Larsen, 2007; Volo, 2009). This economic approach is definitional and managerial (Moutinho, 1987; Swarbrooke & Horner, 1999). It emphasises an objective observation of a tourist and their behaviour (Parsons, 1951). It examines their motivation to partake in tourism (Crompton, 1979; Iso-Ahola, 1982), their consumption of a particular type of experience (Andersson, 2007; E. Cohen, 1979a), and their evaluation of its quality based on their level of satisfaction (Otto & Ritchie, 1996; Pearce, 2005).

A prominent example of this approach was E. Cohen’s (1972) initial conceptualisation of four primary tourist types, ranging from the overt, organised mass tourist or individual mass tourist, to the covert, explorer or drifter. To reflect a diversity within these tourist types (Obrador, 2012), and to form a basis for comparative study (E. Cohen, 1988), new and existing typologies were created and developed further (E. Cohen, 1979a, 1979b; Dann & Cohen, 1991; Pearce, 1982). A number of scholars, for instance, considered these tourist types in terms of their quest for the artificial or the authentic, and their respective consumption of staged

or genuine experiences in the physical and social environments of the tourist space (MacCannell, 1973, 1976; Pearce & Moscardo, 1986; Redfoote, 1984). Many scholars have since cautioned about typologies as a sufficient or sound tool with which to examine the tourist experience (S. Wearing, Stevenson, & Young, 2009).

Indeed, “the most elusive area in tourism ... is the experience itself” (Meyersohn, 1981, p. 1), and of course, “the figure of the tourist is neither neutral nor universal” (Obrador, 2012, p. 408). Yet, central to such historical ways of thinking about the tourist experience is the flâneur (S. Wearing et al., 2009). This portrays the tourist as a solitary male figure with a lonely gaze, passive and rational in a process of decision-making for individualised consumption and de-socialised encounters (Uriely, 2005; Veijola & Jokinen, 1994; B. Wearing & Wearing, 1996). More contemporary ways of thinking about the tourist experience realise that it is uniquely individual and intangible, better understood from the subjective, psychological perspective of the tourist himself or herself (Mannell, 1984; Mannell & Iso-Ahola, 1987). Since the 1990s, there has been a move away from such disembodied, masculinist, and managerial perspectives of the tourist experience (Johnston, 2001), toward constructing the tourist as embodied choraster (Schanzel & Smith, 2014).

This approach has emphasised the tourist’s mental state of mind (Crompton, 1979; Mannell, 1984; Quan & Wang, 2004); the thoughts and feelings experienced during a tourism episode (Mannell & Iso-Ahola, 1987); and the meaningfulness or memorability of such activity in recall (Dann, 2001; Uriely, 2005). Here, the tourist may be motivated to escape the ordinary routine of the everyday, to seek the extraordinary, novel and hedonistic (Crompton, 1979; Iso-Ahola, 1982; MacCannell, 1973; N. Wang, 1999). The mode of the tourist’s experience may be diversionary or recreational, existential or transformational (E. Cohen, 1979a, 2004; S. Wearing, 2001; Zahra & McIntosh, 2007). From a research perspective, then, scholarship has been shifting towards exploring the nature of the individual’s experience, as stated in the travellers’ own words, rather than categorical measurements (Harris & McIntosh, 2006).

Increasingly, tourism scholarship has not only examined the nature of the individual’s experience, but also acknowledged the multiple subjects of tourism

(Otto & Ritchie, 1996; Small, 2008). Still, there is paucity of research determining the effect that the tourist space and experience have on the meaningfulness of the relationships of and between these subjects as significant others (Durko & Petrick, 2013; Glover, 2018; Obrador, 2012). A couple of studies to this effect include, for instance, conference travel as a context in which relational issues exist (Yoo, McIntosh, & Cockburn-Wooten, 2016), or tourism as a social lens on family (Lashley, Lynch & Morrison, 2007). Such understanding, it is argued, is pivotal (Pearce, 2012), as the tourist is not only seeking the authenticity in or of the other, but also that within themselves, and of and between those they travel with (N. Wang, 1999).

Participation in the tourist experience has increasingly been associated with the bestowing of intrapersonal and interpersonal rewards (Iso-Ahola, 1982; Mannell & Iso-Ahola, 1987). Intrapersonal rewards relate to the positive outcomes for the mental and physical health and wellbeing, or quality of life and life satisfaction, of an individual (D. Gilbert & Abdullah, 2004; Sirgy, 2010; Uysal, Sirgy, Woo, & Kim, 2016), for instance, learning, competence or mastery, challenge or self-determination, and personal development or self-identity (Li, 2000; Pearce, 2005; S. Wearing & Wearing, 2001). Interpersonal rewards relate to the positive outcomes on the social relations of those individuals travelling as a group (Pearce, 2012), for instance, reconnection (J. Larsen, Urry & Axhausen, 2007). The social environment of the tourist space thus has been emphasised (Selstad, 2007). Such research has explored the micro and macro forces defining social situations (Dann & Cohen, 1991), prescribing integration or inclusion, and shaping encounters and interactions with others (Redfoote, 1984; B. Wearing & Wearing, 1996).

2.3.2 The subjective lived experience of travel

This growing body of scholarship, however, is largely representative of a “dominant way of understanding and being in the tourism world,” which offers “but one perspective” (Pritchard, Morgan, & Ateljevic, 2012, p. 2). It seems, in the main, that tourism scholarship “carries with it a subtle power to define; to skew; to objectify; to foreground some issues leaving others untouched” (Tribe, 2006, p. 375). Tourism scholarship, largely, has been remiss about its inclusion of the lived experiences of the many individuals and groups at the margins of society

(Humberstone, 2004; Kastenholtz, Eusebio, & Figueiredo, 2015). From an academic perspective, this research is possibly avoided due to its exploratory nature, for instance, the ease in having accepted for publication research about ‘common tourist populations’ rather than ‘new tourist populations’ (Poria & Timothy, 2014), or limitations in existing tourism scholarship and an unfamiliarity with appropriate or applicable theories from other related disciplines (Obrador, 2012). Or, alternatively, it may be due to a sample of research participants being regarded as a ‘difficult-to-access group’; the need to obtain ethical consent from a guardian or organisation to reach potential populations; or the requiring of an individualised research method or specialist expertise in order to carry out data collection (Gillovic et al., 2018). From an industry perspective, the lack of engagement with any such population is perhaps “due to it being considered a ‘minority’ market, requiring too much investment to ‘pay off’ and eventually also as an undesirable segment to include in the industry’s target market” (Kastenholtz et al., 2015, p. 1260).

Since the early 2000s, however, a group of critical tourism scholars have been realising a moral obligation to explore the perspectives of these otherwise overlooked populations (Macbeth, 2005; Pritchard et al., 2011; Schwarzin, 2012; Tribe, 2010); and to engage, understand and empathise with (Swain, 2004) under-represented or marginalised voices, and their identities and subjectivities, relationships and mobilities (Ateljevic et al., 2007; Pritchard & Morgan, 2007). Described as a ‘hopeful’, ‘critical’, and even ‘moral’ tourism turn (Ateljevic et al., 2005; Caton, 2012; Pritchard et al., 2012), such inquiry seeks to politicise research and is oriented toward advocacy (Ateljevic, Hollinshead & Ali, 2009; Pritchard et al., 2011). It is committed to “advancing tourism scholarship and industry knowledge” by way of “developing a more inclusive view of tourism and its impacts” (Poria & Timothy, 2014, p. 95). Critical tourism studies exist as an antidote to the domineering paradigms and binary traditions, and the neoliberal market ideologies and values, that have historically led tourism inquiry and understanding (Higgins-Desbiolles, 2006; Hollinshead, 2007; Pritchard, 2012; Pritchard et al., 2011).

Critical tourism studies pursues human dignity and human rights, promoting social capital and social inclusion in and through a just, conscious and answerable

industry and inquiry (N. Morgan et al., 2012; Pritchard & Morgan, 2007; Pritchard et al., 2011). The practice then, ethical and reflexive in its nature (Harris, Wilson, & Ateljevic, 2007; Macbeth, 2005; E. Wilson et al., 2012), involves blending co-transformative learning and pedagogy with collaborative engagement and interaction, critical thinking and action (Pritchard et al., 2012; Sedgley, Pritchard, & Morgan, 2011b). Ultimately, critical tourism studies seeks to “illuminate the spaces of the possible where we can work to sustain our hope” (hooks, 2003, p. xi). Where certain individuals and groups remain absent from or passive actors in, mainstream scholarship, as does the embodiment of their experiences, these different standpoints and their related cultural complexities are critical to our understanding of tourism phenomena, and especially the tourist experience (Ateljevic & Hall, 2007). Evidently, it is a hope of these scholars, among many others, to see that “issues of research silences, tensions and invisibilities, marginalised individuals and inequality of opportunity might be overcome” (Tribe, 2010, p. 31).

These scholars have given consideration to a number of individuals and groups (Caton, 2012; Small, Harris, & McIntosh, 2008; Richards et al., 2010), who share an underlying commonality, that is the subjugation and exclusion they face as ‘other’ (Schwarzin, 2012; Small et al., 2008), and who represent “foci of future tourism enquiry” (E. Cohen & Cohen, 2012, p. 2186). To illustrate, these scholars have examined previously unheard lived experiences in the following contexts:

- Gender and the body, and complexities of body size, tied to discrimination and inequality (Johnston, 2001; Pritchard, 2014; Small et al., 2008; Swain, 1995; Veijola & Jokinen, 1994).
- Sexuality, sexual identity or sexual orientation (Johnston, 2005; Pritchard, 2004), and sex tourism, sexual harassment and exploitation (Pritchard, 2014; Rydsik, Pritchard, Morgan, & Sedgley, 2012).
- Age, whether that be children, or the ageing population (Gladwell & Bedini, 2004; Sedgley, Pritchard, & Morgan, 2011a, 2011b; Small, 2008).
- Low socio-economic individuals, families and groups, and the prospect of social tourism (Belanjer & Jolin, 2011; M.E. Casey, 2010; McCabe, 2009; Minnaert, Maitland & Miller, 2009), as well as those living in poverty, and the prospect of pro-poor tourism (Chok, Macbeth, & Warren, 2007; C.M. Hall, 2007; Meyer, 2007; Zhao & Ritchie, 2007).
- Those living in areas of conflict or post-conflict (Buda & McIntosh, 2012; Novelli, Morgan, & Nibigira, 2012), as well as refugees, asylum seekers and migrant workers (Russell, 2003).

However, while this particular area of scholarship is growing, its scope has been limited. There are some individuals and groups who remain privileged, while others are excluded and ignored (Small, 2015; Tribe, 2006). Arguably, the lived experiences of people with disabilities, while emergent in critical tourism scholarship, remain relatively unheard in both academia and practice (Aitchison, 2009; Daniels, Rodgers & Wiggins, 2005; Huh & Singh, 2007; Hunter-Jones, 2006; Richards et al., 2010; Stumbo & Pegg, 2005), especially in terms of people with intellectual disabilities. Yet, a critical tourism studies perspective has significance to people with (intellectual) disabilities as a marginalised societal group, as well as to those who accompany their travel (Kitchin, 1998; J. Knight & Brent, 1998; Morris, 2001; O’Grady, Pleasence, Balmer, Buck, & Genn, 2004).

2.3.3 Disability as a marginalised identity in travel

While many tourists will face barriers at some level in accessing and participating in tourism experiences, these can be amplified and unique for people with disabilities (Daniels et al., 2005; Mactavish, McKay, Iwasaki, & Betteridge, 2007; McKercher & Darcy, 2018). Their participation is dependent on the interaction between the embodiment of their impairment and the accessibility of the industry’s physical, informational and attitudinal environments (Darcy & Dickson, 2009; Eichhorn & Buhalis, 2011; R.W. Smith, 1987). Despite the potential existence of such barriers to participation, many people with disabilities travel (Darcy, 1998), want to travel more (Ray & Ryder, 2003; Turco, Stumbo & Garnarcz, 1998), and are motivated to travel for reasons that are similar to those of the non-disabled population (Ray & Ryder, 2003; Small, Darcy & Packer, 2012; Yau, McKercher, & Packer, 2004). Like all tourists, they desire an experience to be individualised and reflective of their unique needs (World Tourism Organization, 2016b), although their planning and decision-making processes are generally more extensive and complex, and their subjective experiences may differ (Packer et al., 2008; Yau et al., 2004).

Arguably, with this demand for tourism experiences comes a demand for accessibility. Defined by Darcy and Dickson (2009), ‘accessible tourism’:

Enables people with access requirements, including mobility, vision, hearing and cognitive dimensions of access to function

independently and with equity and dignity through the delivery of universally designed tourism products, services and environments ... inclusive of all people including those travelling with children in prams, people with disabilities and seniors. (p. 34)

For a market that is currently significant in size and expected to grow, the tourism industry at large has been complacent in its consideration for and provision of accessibility (Daniels et al., 2005; Darcy & Buhalis, 2011; Huh & Singh, 2007; Robinson, Packer, Carter, Goddard & Muir, 2007). For the most part, the industry is developed and serviced with the non-disabled majority in mind. It delivers embodied, multi-dimensional experiences, contexts and spaces (Aitchison, 2009; Figueiredo, Eusebio & Kastenholz, 2012; Small, 2008), “marginalising those with different bodies and/or minds” (Kastenholz et al., 2015, p. 1262). The accessible tourism scholarship, although growing, is also reasonably narrow in its agenda (Hunter-Jones, 2006; Richards et al., 2010). As such, there is an evident need to encourage greater understanding around what accessibility is, and its meaningfulness as a business opportunity and social imperative (Foggin, 1999).

Mostly, scholarship has been oriented toward an economic, market-driven perspective (see Burnett & Bender-Baker, 2001; Gladwell & Bedini, 2004; Thornberry, 2005). The economic arguments supporting accessibility are well reported in tourism scholarship. Tourism products, services, experiences and destinations that are developed, delivered and managed in a manner that is accessible to all make good business sense, adding value and benefiting a business’s bottom line (Card, Cole, & Humphrey, 2006; G. Shaw & Veitch, 2011; G. Shaw, Veitch, & Coles, 2005). Reported benefits have included increased customer activity and loyalty, and rates of capacity occupancy or utilisation, in addition to heightened competitive advantage, market share and profitability (Robinson et al., 2007; Stumbo & Pegg, 2005; Yau et al., 2004). In addition, many people with disabilities will travel with companions (Darcy & Buhalis, 2011; Huh & Singh, 2007). Despite clear economic rationales supporting a significant, profitable and growing market (Huh & Singh, 2007), there is a lack of industry-based case studies showcasing the benefits of accessibility (Darcy & Buhalis, 2011). As such, people with disabilities represent a market that is largely emergent, underserved and

misunderstood by the industry (Huh & Singh, 2007; Robinson et al., 2007; Shelton & Tucker, 2005).

Much of the supply-side focus has also concentrated on particular sectors and their systems, and on how to better serve their respective markets, for instance, in attractions, hospitality or transportation (Bell, 2011; Poria, Reichel, & Brandt, 2010). Relatedly, this supply-side focus has further concentrated on barriers to and constraints on tourism participation, and the managerial implications of such accessibility-related issues (Blichfeldt & Nicolaisen, 2011; Eichhorn & Buhalis, 2011; Robinson et al., 2007; G. Shaw & Coles, 2004; R.W. Smith, 1987). Such barriers to and constraints on participation are environmental, informational and attitudinal (Turco et al., 1998). While many barriers and constraints are negotiable, others are not (Daniels et al., 2005); they are both intrinsic to an individual with disability, and interactive with the socially constructed tourism environment (McKercher & Darcy, 2018; Packer et al., 2008). Thus, we are cautioned to acknowledge the heterogeneity of disability; that is, not only is it extensive and varied, but that it exists along a continuum in terms of support that is required (Darcy & Buhalis, 2011; McKercher & Darcy, 2018).

There is a need to understand the value of the altruistic vindications supporting accessibility (Lovelock & Lovelock, 2013), which “goes beyond the commercial incentive” (Small, 2008, p. 773). A social perspective is somewhat missing from tourism scholarship, yet as Chapter 3, ‘Background’, will demonstrate, the global impetus for accessibility is rising in importance (Gladwell & Bedini, 2004; Robinson et al., 2007), as nations are increasingly recognising the strong correlation between age and disability (Darcy & Buhalis, 2011; Vila, Darcy, & Gonzalez, 2015), and what this means for their residents and visitors alike (Darcy, Cameron, & Pegg, 2010; Darcy & Dickson, 2009). Participation in tourism is especially beneficial to people with disabilities (McCabe, 2009; Pagan, 2013). It can afford both intrapersonal and interpersonal rewards, such as positive psychological and physical benefits for health and wellbeing, personal development and social inclusion (Blichfeldt & Nicolaisen, 2011; Daniels et al., 2005; Innes, Page & Cutler, 2016; G. Shaw & Coles, 2004; Yau et al., 2004). Still, there remains little conceptual and empirical evidence to particularise not only the economic constructs

of the accessible tourism phenomenon, but the relational and social constructs too (Carr, 2011).

Evidently, there is a need to contemplate this tourism market not only in terms of supply- and demand-side perspectives, but also in terms of embodied, lived experiences (Small et al., 2012). Some scholars have explored representations of the access tourist and their accessible tourism experience. Mostly, these representations have been from the perspective of people with mobility and/or physical impairments (Daniels et al., 2005; Darcy, 1998; Lovelock, 2010; Ray & Ryder, 2003; Shi, Cole, & Chancellor, 2012), and increasingly, more recently, on sensory impairments, especially vision impairment (Packer et al., 2008; Poria et al., 2010, 2011; Richards et al., 2010; Small, 2015; Small et al., 2012; Yau et al., 2004). As it stands, the accessible tourism agenda is not inclusive of people with other impairment types (O'Neil & Knight, 2000), for instance, psychological/psychiatric, such as people with dementia (Innes et al., 2016). People with intellectual disabilities and their carers are also under-represented in tourism scholarship. The originality of this research topic, therefore, lies in its focus on exploring experiences of care from the perspectives of carers and people with intellectual disabilities.

2.3.4 Examinations of care dimensions in lived experiences of travel

To varying extents, care has been demonstrated and subsequently explored within the context of travel. Geographically and spatially, this intersection of the two activities has been evinced in: landscapes of care (Conradson, 2005; D.M. Smith, 1998); mobilities of care and migrant labour (Andrews, 2004; Bettio, Simonazzi, & Villa, 2006; Conradson, 2003); and transnational families and aged care (Baldassar, 2007). Explicitly, the activity of tourism itself has also seen various manifestations of caring-related activity in certain niche markets, such as: medical tourism (V. Casey, Crooks, Snyder, & Turner, 2013a, 2013b; Kingsbury, Crooks, Snyder, Johnston, & Adams, 2012; Whitmore, Crooks, & Snyder, 2015); respite care and tourism (Hunter-Jones, 2006; Weightman, 1999); and volunteer tourism (Sin, 2010; Sin, Oakes, & Mostafanezhad, 2015; Zahra & McIntosh, 2007).

Specific to accessible tourism, there has been limited representation of those individuals accompanying the travel of people with disabilities, despite it being known that they typically travel with a companion, usually a family member or

friend (Darcy, 1998; Lehto, Luo, Miao & Ghiselli, 2017; Luo, 2014; Stafford, Samson, & Roy, 2001; World Tourism Organization, 2016b), and especially of carers and the care experience, which is relevant to the scope of this research topic (Gladwell & Bedini, 2004; Gladwell, Bedini, Byrd, & Cardenas, 2010; Hunter-Jones, 2006, 2010). This is, perhaps, not surprising, given that family members of people with disabilities are often neglected in research more generally (Green, 2007), especially mothers of children with disabilities (Topia, 2015). Family tourism scholarship, too, is largely remiss in not addressing the diversity and complexity of families in its conceptualisations (Schanzel & Yeoman, 2014), with the voice of mothers, for instance, being scantily addressed, despite the family being a common tourist segment (Small, 2005).

As such, carers, like people with disabilities, represent a marginalised group of individuals, and therefore the care perspective – given or received – has been somewhat disregarded (Hunter-Jones, 2006). Some scholars have suggested that this may be due to: the difficulties associated with gathering empirical data; the diversity of this population; the complexity in understanding the nature of the care experience and the travel experience; or the perception that this population is not representative of an economically lucrative market in comparison, perhaps, to the person they care for, or to other market segments altogether (Hunter-Jones, 2006; Kim & Lehto, 2013).

Research at this nexus, although limited (see Hunter-Jones, 2006, 2010; Lehto et al., 2017; Sedgley, Pritchard, Morgan, & Hanna, 2017), is beginning to emerge (Mactavish et al., 2007). Mostly, this research has adopted the perspective of either the carer (for example Hunter-Jones, 2010; Kim & Lehto, 2013; Nyman, Westin, & Carson, 2018) or the individual with disability or illness (Gladwell & Bedini, 2004; Gladwell et al., 2010; Hunter-Jones, 2006, 2010). This pattern mimics wider studies of care, where one individual is an active actor while the other is passive, rather than the two being examined together (Forbat & Henderson, 2003). Studies of the shared experience of the carer and the individual with disability, especially, are a rarity (Lehto et al., 2017). To offer an illustrative example, Small (2015) examined the organised tour experiences for paired sighted guides and people with vision impairment. After identifying that no previous research had considered the

experience of sighted guide, as companion and/or carer, or their intersecting, embodied mobilities with one another, she argued, “it is difficult to understand mobility without considering the interaction. Each person’s experience will be impacted by the other. Guiding and being guided are social matters” (Small, 2015, p. 78). Similarly, Richards (2013) had noted that “being guided is a physical and interpersonal act between two bodies which concerns primarily the sense of touch and hearing between the sighted guides, the vision impaired person and their surroundings” (p. 98).

Of the research that currently exists, studies have considered attendant relationships in leisure travel (Darcy, 2002), sighted companions and guides and people with vision impairment (Small et al., 2012; Small, 2015), carers of seniors and the ageing population (Gladwell & Bedini, 2004; Hunter-Jones, 2010), carers of cancer patients and individuals with serious illness (Hunter-Jones, 2003, 2006, 2010), and family carers of children and other family members with disabilities (Gladwell & Bedini, 2004; Kim & Lehto, 2013; Lehto et al., 2017; Mactavish et al., 2007; Nyman et al., 2018; Sedgley et al., 2017). Such studies have examined issues relating to: leisure travel entitlement and the implications of caring responsibilities as an impediment to travel participation (Bedini & Guinan, 1996; Gladwell & Bedini, 2004; Gladwell et al., 2010; Hunter-Jones, 2010); travel constraints due to disability and family decision-making (Nyman et al., 2018); psychological and physical benefits of travel (Hunter-Jones, 2010); and the role of respite care in facilitating the consumption of leisure travel (Hunter-Jones, 2006).

Relevant to the parameters of this present research topic were the following studies, which involved carers of people with intellectual disabilities:

- Kim and Lehto (2013) examined the travel motivation and travel activities of Korean parents of children with disabilities. This study identified several primary motivating factors for travel, as well as a number of principal activities that were engaged in. Mostly, these parents were motivated to travel in anticipation of the physical competence or mastery for their children, and most commonly participated in sedentary outdoor activities.
- Lehto et al. (2017) examined the ways in which Chinese people with disabilities (that is, individuals with hearing, intellectual, mobility or vision impairments) and their carers (that is, family members or friends) constructed a joint account of their shared tourism experiences. This study

employed a phenomenological approach and, through conversational discourse, interviewed each participant individually, then together, to uncover the processes through which they ascribed meaning and accounted for memorability. They concluded “that a memorable trip experience is perceived as a mutually rewarding experience with growth and mutual enrichment for those who are cared for and those who render care,” which stemmed from mastery of activities, emotions evoked, eudemonic outcomes, and social parameters (p. 182).

- Mactavish et al. (2007) examined the role of vacations in enhancing quality of life, from the perspectives of family carers of people with intellectual disabilities. They identified that fulfilling basic health needs, experiencing social connection with family and friends, and feeling a sense of control, independence and freedom, were significant contributors to their quality of life while vacationing.
- Sedgley et al. (2017) drew upon positive psychology to explore the emotional and everyday experiences during travel, of mothers of children diagnosed with autism spectrum disorder. This study illuminated the inherent challenges, coping strategies and benefits inherently involved in such experiences, contributing a unique perspective on autism disorder as being context-specific, and problematising the dominant hedonic discourse of tourism scholarship and practice.

Almost all of the scholars mentioned above have expressed a shared sentiment that their studies were merely representative of ‘the tip of the iceberg’ (Hunter-Jones, 2010), and that the seriousness of the paucity of research at this praxis lies in the fact that “the industry stands to lose both the individual with the disability as well as their caregiver” (Gladwell et al., 2010, p. 30). Therefore, the scope and value of future research in this general area was considered to be ‘immeasurable’ (Hunter-Jones, 2010), and a number of gaps and directions were identified accordingly.

Firstly, pertaining to care, scholars expressed a need for more diverse samples that account for specific types of disabilities and contextualised care relationships, across demographic and situational circumstances, as well as the use of qualitative rather than quantitative methods (Gladwell & Bedini, 2004; Gladwell et al., 2010; Hunter-Jones, 2006, 2010; Lehto et al., 2017; Nyman et al., 2018). In addition, scholars identified a need to explore the nature of caring responsibilities and their physical, psychological and emotional dimensions (Lehto et al., 2017; Sedgley et al., 2017), as well as the small-group dynamic that exists between the carer and individual with disability as a relational unit, as well as other travelling companions

who may not be the primary carer (Lehto et al., 2017, Luo, 2014; Nyman et al., 2018).

Secondly, pertaining to travel, scholars have expressed a need to explore “the multiple, complex and nuanced meanings” of leisure travel experiences (Sedgley et al., 2017, p. 22), such as perceptual and psychological barriers to travel; travel needs, preferences and decision-making processes; travel behaviour; and emotions and their impact during travel (Gladwell & Bedini, 2004; Gladwell et al., 2010; Hunter-Jones, 2006; Nyman et al., 2018). Ultimately, further research is needed in order to obtain a fuller appreciation and understanding of the meaning and implications of care within the context of travel, so as to better determine how the industry and the public sector alike can best meet and serve the needs of this group of travellers, by way of providing relevant, meaningful and inclusive experiences (Gladwell & Bedini, 2004; Gladwell et al., 2010; Hunter-Jones, 2006).

The originality of the thesis topic also lies in contributing insights that might assist in addressing these research gaps and, in this way, the thesis further contributes to this emerging body of scholarship, as the next section demonstrates. Evidently, care, disability and travel are cross-cutting issues of local and global importance (World Tourism Organization, 2016b), the intersection of which is a critical current and future consideration. That being so, the learning acquired through examinations of the tourist experience of such a population could contribute to awareness of, and action toward, important issues of human rights and social justice (Macbeth, 2005; N. Morgan et al., 2012; Pritchard et al., 2012; Reisinger, 2015). Moreover, this perspective is significant not only when looking through an industry lens but when looking through a societal lens, in terms of our interaction with other individuals and groups as relational beings. Given that “the relationship is the site for and context of experiences of care, and as such the relationship is always central”, the caring dyad is then central to tourism too (Forbat & Henderson, 2003, p. 1454). To this end, and unmistakably, there is “a need for further critical thought on the nature of travel and relationships” (Yoo, 2014, p. v). The question must be posed, “can tourism be used as a lens to gain insights into society” (Zahra & McIntosh, 2007, p. 118) or, even better, as a social force for change? (Hunter-Jones, 2010). Therefore, the very exclusion and vulnerability of

tourism experiences is an obvious research topic to pursue (Hunter-Jones, 2006, 2010), and is taken up in this thesis.

2.4 Originality and contribution of the research

At a conceptual level, this research positions itself as contributing preliminary and exploratory insights into lived experiences of care at the nexus of intellectual disability and leisure travel, as described and understood by carers and people with intellectual disabilities.

Firstly, this research contributes by representing the authentic voice/s (Harding, 1993) of carers (informal and unpaid or formal and paid) and people with intellectual disabilities, which addresses a scarcity of representation in existing scholarship on the nature of care and disability. By privileging their authentic voice/s and embodied experience/s, this research augments and advances current understandings of the tourist experience, and especially of the accessible tourist experience. The wider application of this approach is that it may be applicable to reconciling other previously silenced voices in tourism (Clear, 1999), who also “ought to be heard if the aim of scholarly inquiry is to conceptualise the tourist experience more comprehensively and responsibly” (Poria & Timothy, 2014, p. 93).

Secondly, this research contributes by way of the nature of the thesis topic’s focal point, that is, lived experiences of care, which related tourism scholarship has not yet directly addressed. By privileging the individuals’ subjective and inter-subjective experiences of care, this research unveils the nature and specificities of its practical, emotional, and socio-political dimensions, and promotes the ideological importance of caring activity and relations (Hochschild, 2003). While this research included the perspectives of formal carers (for example, support workers), there was a disproportionately greater representation of informal carers (and particularly, female family members), which potentially contributes a domestic and potentially gendered perspective.

Thirdly, this research contributes by way of incorporating both the perspectives of carers and people with intellectual disabilities, which addresses a scarcity of representation in existing scholarship, where individual experiences and outcomes are emphasised and presented separately, or not at all (Cockburn, 2005). “The

experience of caring is intimately bound up with being cared for” and hence the importance of this research is in contributing the individual and shared experiences of both the carers and the people with intellectual disabilities (Staden, 1998, p. 148). In this way, this research may reveal further insight into the wider tourist experience, for other individuals and groups travelling as a relational unit, which involves an aspect of considered care (Hibbert, Dickinson, & Curtin, 2013; J. Larsen, 2008; Yoo, 2014).

At an operational level, this research positions itself as contributing to furthering the accessible tourism agenda, by way of advocating for its moral imperatives (Higgins-Desbiolles, 2006; N. Morgan & Pritchard, 1998), namely around illuminating vast and diverse experiences of care and their personal, relational and social dimensions. The new insights acquired may stimulate an awareness of, or build a sense of identity among and stimulate engagement with, this group of travellers. It may then contribute to the development and delivery of more appropriate and meaningful tourism products, services and experiences, thereby aiding the development of a more accessible and inclusive industry (Kim & Lehto, 2013).

While tourism may be a seemingly trivial extension of the trials and tribulations of this group of individuals’ everyday lives, tourism holds the possibility of being a transformative force for social change (Hunter-Jones, 2010). In this way, the thesis presents a challenge, to academia and industry, to: move away from binary understandings of disability, clear out limiting beliefs and dominant mindsets; raise a new standard and push to be better; and transcend the status quo by being open to the possibility of seeing and doing things differently. Perhaps ideologically, the thesis premises an analogy of hope, born from the cultivation of a collective consciousness of, and conviction to, care. It accentuates care as integral to tourism activity development and knowledge; care as a central tenet of our lens on the world, where *giving*, *attunement* and *visibility* are aspired to and embodied by all, and where we meet one another morally (Noddings, 1984). In doing so, the originality and contribution of this research ultimately lies in (re)imagining the transformative potential of tourism through an ethic of care (Gilligan, 1982; Kittay, 2011).

2.4.1 An ethic of care

Morality, or ethics, as a philosophical study, has a long masculinist tradition (Hekman, 1995), “guided by Logos, the masculine spirit” (Noddings, 1984, p. 1). To this effect, Hekman (1995) has explained:

The public realm is the realm of culture, rationality, and universality, of the universal citizen who rises above the particularities of his situation; this realm has been defined in exclusively masculine terms since the beginning of Western philosophy. The private realm, by contrast, is the realm of the body and nature, irrationality and particularity, the situated individual; this realm has been identified as the sphere of the feminine. (p. 35)

Where such thinking has dominated approaches to and understandings of moral reasoning (Noddings, 1984), developmental psychologist, Carol Gilligan (1982), introduced an alternative perspective, “the more natural and perhaps, stronger approach ... through Eros, the feminine spirit” (Noddings, 1984, p. 1). In her classic and influential text, *In a Different Voice* (1982), Gilligan identified this contrasting approach to moral reasoning when navigating the way in which young women dealt with both imaginary and true moral dilemmas (Hekman, 1995). Through her revelatory examination of such decision-making, she suggested that moral reasoning was gendered, where an ‘ethic of justice’ pertained to men, while an ‘ethic of care’ pertained to women (Black, 2005; Fine & Glendinning, 2005). Controversially, this finding contradicted the otherwise dominant and widely-accepted finding of Kohlberg (1981), who had earlier declared women as inferior to men, deficient in their degree of moral development (Gilligan, 1982; Hekman, 1995). Instead, Gilligan argued women to have been overlooked in such studies of moral development, and pronounced them equal to men (Hekman, 1995; Kohlberg, 1981). In effect, “she propose[d] a dual vision of the moral realm, one in which two interacting and intertwining voices replace[d] the unitary view,” thus arguing for dialogue between the two (Hekman, 1995, p. 5). Deeply feminine then (Fine, 2004; Noddings, 1984), an ethic of care placates oppressive gender norms (Day, 2000).

Where an ethic of justice is explicitly premised upon self, and on notions of independence and sufficiency, fairness and equality, in comparison, an ethic of care necessitates an empathic concern for and respect of, other, and an orientation toward

relationship (Slote, 2004). In this way, an ethic of care considers the impact of one's decision-making upon another, meaning that one seeks to not only identify and respond to another's needs, but also to avoid inflicting harm and instead seek to alleviate suffering (Black, 2005; Day, 2000; Gilligan, 1982; Fine, 2004; Noddings, 1984). In this way, a moral voice is characterised by caring, as it sustains the intimacy and connectivity that contributes to relational wellbeing. As Wolf-Devine (2013) explained, an ethic of care "values taking responsibility to care for others (especially the vulnerable) resolving conflicts by communication rather than violence, and preserving the network of relationships within each person is imbedded by giving loving attention to the needs of those particular individuals" (p. 209). Care, then, is seen as a positive ethical disposition (Fine, 2004, 2005), that morally guides our thinking, feeling and behaviour (Noddings, 2002). The reckoning of moral logic is through the practice rather than the consequences of, care (Black, 2005; Philip et al., 2012). This practice is cognitive, affective and indexical (Noddings, 2002; Tronto, 1993). It emphasises the values of commitment and respect, attentiveness and responsiveness, openness and dialogue, reciprocity and mutuality (Black, 2005; Held, 2006; Henderson & Forbat, 2002; Widdershoven, 1999). It ultimately enhances the lives of self and of other, and cultivates a collective life (Gilligan, 1982; Noddings, 1984).

An ethic of care has undoubtedly transformed the once male-dominated discussions of moral philosophy and, naturally, has received both praise and critique (Hekman, 1995). Critics have argued that an ethic of care is "methodologically unsound, theoretically confused, and even antifeminist" (Hekman, 1995, p. 1). The focus on care itself, and particularly its goodness, has been considered a major flaw (Allmark, 1998), and an ethic of care overall has been seen as oppositional to an ethic of justice (Philip et al., 2012). In fact, proponents of an ethic of care have actually suggested that "an alternative strategy is to see justice and care as, in some ways, and to some extent, compatible or integrated, and that both may be necessary for a systematic theory of morality and ethics" (Philip et al., 2012, p. 7). Proponents have also argued that that these caring values are emotional rather than rational (Tronto, 1993), and that such activity has been marginalised to a gendered order (K. Lynch et al., 2009), subjugated and contained to the realm of the private (Fine, 2004; K. Lynch et al., 2009). They instead seek to

politicise care, promoting its moral and social value, arguing that it should rightly gain centrality and greater recognition within the public sphere (Gilligan, 1982; Noddings, 1984; Sevenhuijsen, 1998; Tronto, 1993).

An ethic of care, as a key theory, can assist in framing understandings of the relational nature of lived experiences of care, and has particular value to examinations of disability (Tronto, 1993). Ultimately, an ethic of care recognises the inherent vulnerability of the human condition and, therefore, our dependency upon, and responsibility to, one another as relational beings; that it is only through care in relationships, that human life can be sustained (Gilligan, 1982; Noddings, 1984; Philip et al., 2012; Sevenhuijsen, 1998; Tronto, 1993). When an assertion of a collective life is recognised and maintained, there is a certain “intentionality for living as a caring individual” (Black, 2005, p. 417). Relational experiences between the self and other are humanised; cognisance of the giving and receipt of care is favoured; social undercurrents are comprehended; and the embedded, interconnected and interdependent nature of individual lives is emphasised (Black, 2005; Gilligan, 1982; Milligan, Atkinson, Skinner, & Wiles, 2007). Much like the critical tourism studies agenda, an ethic of care is both hopeful and future-oriented (Black, 2005), and aligns well in theoretically framing the direction of this thesis. As Gilligan (1982) explained, it shares:

A vision that self and other will be treated as of equal worth, that despite differences in power, things will be fair; the vision that everyone will be responded to and included, that no one will be left alone or hurt. These disparate visions in their tension reflect the paradoxical truths of human experience – that we know ourselves as separate only insofar as we live in connection with others, and that we experience relationship only insofar as we differentiate from self. (p. 63)

2.5 Thesis structure and chapter summary

The thesis is presented in the following structure:

Chapter 1, *Prologue*, has briefly introduced and situated myself as the researcher in the thesis, acknowledging my desire to pursue this particular topic, and describing aspects of my lived experience, which may have shaped the subsequent research approach I have taken.

Chapter 2, *'Introduction and literature'*, has provided a statement of the thesis topic and research questions, as well as a note on language and terminology. This chapter has examined the tourism scholarship relevant to the research topic and uncovered the knowledge gaps that remain neglected, and has therefore illuminated the significance, originality and contribution of this research. Finally, it has introduced an ethic of care as a relevant theory which can guide considerations of the thesis aim.

Chapter 3, *'Background'*, provides the contextual background in which the thesis topic is set. It offers a detailed account of the past and present state of disability in New Zealand, as well as the informal and formal provision of care and support. In addition, it briefly presents a conceptual framework for disability, and a theoretical framework for care.

Chapter 4, *'Methodology'*, focuses on the philosophical and methodological approaches underpinning the thesis. It covers the paradigmatic debate, the philosophical and theoretical bases, and respective research design, data collection methods and analytic processes. It concludes with a description of sampling strategy, methodological reflections and ethical considerations.

Chapter 5, *'Context'*, presents an introduction to the individual participants presented in the thesis. Further, it offers a contextualisation of the experience of leisure travel. The purpose of this chapter is to help the reader develop a more detailed understanding of the nuances and unique lived experiences of each participant represented, and affords authenticity to their individual voice/s.

Chapter 6, *'Findings'*, presents the findings of the research, which have emerged inductively from the data and manifested themselves as three key experiential themes, that is, the experience of care as *giving*, *attunement*, and *(in)visibility*.

Chapter 7, *'Discussion'*, presents a wider discussion around both the significance and implications of the research findings, as supported by existing theories and extant literature.

Chapter 8, *'Conclusion'*, provides a summary of the key findings and discussion points. It highlights the suggested contributions of this research to wider scholarly

knowledge, as well as further theoretical and managerial implications. The chapter ends by exploring possible limitations of the research, sharing recommendations for future directions.

Chapter 9, '*Epilogue*', offers a final reflexive commentary.

3 Background

The purpose of this chapter is to both contextualise and conceptualise care, disability and travel, the concepts that form the foundation of this thesis. Here, I provide the wider historical and socio-cultural context in which the thesis is set, presenting the current landscape of disability, with reference to care and tourism. Notably, I explore this research within a localised context, which is New Zealand. Nonetheless, I draw benchmarked comparisons with other Western developed nations, as much anecdotal evidence and academic research indicates that patterns and issues of disability are commensurate with that of other countries worldwide. As such, this localised context is both a significant and justifiable case study.

The chapter begins by briefly reporting on the degree of pervasiveness of disability and its demographic characteristics. A conceptual framework for disability then identifies prominent models of disability that have contributed to the prevailing discourse. Following this, sections detail a short history of disability in New Zealand, as well as the current legislative environment in which it exists, and the disability support services provided within the health and social systems, one area being care. The next section then describes disability issues affecting this population group, especially with regard to the disparate economic and social outcomes they face. This chapter concludes with the suggestion that access to and participation in travel is potentially a further disability issue, one which captures the nexus of care, intellectual disability and leisure travel, and therefore recognises the country's tourism industry and its current consideration for accessibility.

3.1 Degree and demographics of disability

Since 1996, the New Zealand Government has conducted four national Disability Surveys (Statistics New Zealand, 2017a), which are the official and most comprehensive sources of data on people with disabilities living in households, group homes and residential care facilities in New Zealand (Ministry of Health, 2005). The data provides information regarding the degree and demographics of disability (Statistics New Zealand, 2017a); the cause, duration and nature of disability; the type and level of support needed; and, disability issues affecting day-to-day living (Careerforce, 2017). This data allows comparison between the disabled and non-disabled populations on measures of economic and social

outcomes (Statistics New Zealand, 2015a). The latest survey took place during the national Census of Population and Dwellings (2018), with the results yet to be published (Statistics New Zealand, 2017a).

The recent Disability Survey (2013) identified 1,062,000 people with disabilities, representing just under a quarter (or 24 per cent) of New Zealand's population (Statistics New Zealand, 2014). The rate of disability had increased (by 4 per cent) across the twelve-year period since the preceding survey (2001) (Statistics New Zealand, 2015a). This was attributable to population ageing and the increased willingness of individuals to identify with and report their experiences of disability (Statistics New Zealand, 2014). The rates of disability across the main ethnic groups of Asian, European, Māori and Pacific, varied (at 13, 25, 26 and 19 per cent, respectively) (Statistics New Zealand, 2014).

Overall, the rate of disability among the total disabled population was similar for both men and women (at 49 and 51 per cent, respectively), as it was among Māori (at 27 per cent and 25 per cent, respectively) (Statistics New Zealand, 2014). As expected, a strong correlation exists between age and disability (Social Statistics Division, 2002), where adults aged between 44 and 65 years, and adults aged 65 years and over, report greater affliction with disability (at 28 and 59 per cent, respectively) (Statistics New Zealand, 2014). This latter age group will likely double over the next 20 years to 1.2 million in 2036, and the number of older adults with disabilities will experience considerable growth (by 60 per cent) by 2051 (Ministry of Social Development, 2014).

The most common causes of impairment among the country's adult disabled population was disease and illness, followed by accident or injury, and ageing (at 42, 34 and 31 per cent, respectively); and among children the most common cause was conditions existing since birth (at 49 per cent) (Statistics New Zealand, 2014). The most common type of impairment among adults was physical, and among children was learning-related (at 64 and 42 per cent, respectively) (Statistics New Zealand, 2014). Over half (at 53 per cent) of the country's total disabled population identified as having more than one impairment, and this likelihood increased with age (Statistics New Zealand, 2014).

The survey (2013) identified 89,000 people with intellectual disabilities living in households, representing a small proportion (or 2 per cent) of New Zealand's population (Statistics New Zealand, 2014). The rate of disability had increased (by 1 per cent) across the twelve-year period since the preceding Survey (2001) (Statistics New Zealand, 2014). The rates of intellectual disability across the main ethnic groups of adult European, Māori and Pacific, varied considerably, for both adults (at 73, 20 and 5 per cent, respectively), and children (at 64, 27 and 5 per cent, respectively) (Ministry of Health, 2005). Overall, the prevalence of intellectual disability among the adult and child populations were disproportionately higher for men than woman (at 40,000 and 27,000 adults, respectively), and for boys than girls (at 16,000 and 6,000 children, respectively) (Statistics New Zealand, 2014).

3.2 A conceptual framework for disability

While these statistics provide a measure of disability, it is equally important to have a conceptual framework to guide our understanding. Within an international and local context, two models of disability have dominated the discourse – the medical model and the social model – and determined the meaning of ‘impairment’ and experience of ‘disability’ (Aitchison, 2009; Statistics New Zealand, 2015b). This section discusses these models, with particular reference to the framework informing New Zealand's disability discourse.

Historically, the perspective of the medical model largely determined disability discourse. Here, impairment was represented as a reduction in or absence of, a person's functional ability (Oliver, 1990, 1994; Shelton & Tucker, 2005), due to some inherent bodily ‘abnormality’, ‘dysfunction’, or ‘illness’ that was deemed problematic and tragic to the individual (Barnes & Mercer, 2005; Howson, 2004; Hughes & Paterson, 1997; Oliver, 1996). This ‘deficit’ in an individual was considered a deviance from normality (De Schauwer et al., 2018; Oliver, 1994). It thus became a medicalised problem, perpetuating a dependency of an individual's ‘special’ needs upon a government's health system and medical professionals for a treatment or cure, intervention or correction, and upon a social system for accommodation (Barnes, 1996; Office for Disability Issues, 2001; Statistics New Zealand, 2015a, 2015b). Institutionalisation was one example of the way in which people with disabilities were “cast in the role of the other and cast out” (Hughes &

Paterson, 1997, p. 325), effectively ‘hidden away’ because of their ‘flawed existence’ (Barnes & Mercer, 2005; Hughes, 2007).

Defiance toward the medical model surfaced during the late 1970s and early 1980s, with a rise in political constructions and rights movements (Abberley, 1987; Hughes & Paterson, 1997; Oliver, 2004). This pushed for the reconceptualisation of disability as a social tyranny of oppression and subjugation (Barnes, 1991; Winance, 2007), giving voice to experiences of discrimination and prejudice (Morris, 2001). “Disability was not an outcome of bodily pathology, but of social organisation: it was socially produced by systematic patterns of exclusion that were – quite literally – built into the social fabric” (Hughes & Paterson, 1997, p. 94). In this way, it recognised disability as being a social construct, necessitating a social resolution (Gleeson, 1999; Shakespeare, 2006; Susman, 1994). Disability became a political problem that required the remedy or removal of barriers to participation in the spatial and social worlds (Hughes & Paterson, 1997; Oliver & Barnes, 2010; Paterson & Hughes, 1999; Titchkosky, 2003). Therefore, disability was as much about the functioning of an individual as it was about the functioning of a society (Statistics New Zealand, 2014). “At different times and places, the dominant worldview affects the position of disability within the social context” (Darcy & Buhalis, 2011, p. 21), and today, the perspective of the social model largely determines disability discourse.

While the models provide an initial grounding upon which one can begin to fathom the convolution of disability, naturally, both models have received their share of critique. Essentialist and constructivist tensions exist between the two models (Shelton & Tucker, 2005), which largely consider impairment and disability as “universal, fixed, unchanging trans-historical social phenomena” (Thomas & Corker, 2002, p. 19). The mind/body dualism that creates binary distinctions between impairment and disability, and therefore a divide in the medical and social models, is problematic (Hughes & Paterson, 1997; Meekosha & Shuttleworth, 2009). There are innate complexities and subsequent complications in reducing impairment/disability to the dichotomy of a unitary model (Corker, 1999; Pinder, 1997). To illustrate, the social model somewhat neglects impairment in the ontology of disability and, consequently, this disembodied approach (Finkelstein, 2004;

Pinder, 1995), “defines disability principally in terms of sociological categories, including exclusion, discrimination and oppression” (Hughes, 2007, p. 674). Perhaps the most significant attempt to address such critique, and to expand upon such discourse, was the argument to consider a ‘sociology of impairment’ (Freund, 2001; Hughes & Paterson, 1997), and an ‘embodied ontology’ of disability (Shakespeare & Watson, 2002). Phenomenologically, this acknowledges that “disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning” (Hughes & Paterson, 2006, p. 101). A person therefore faces barriers to ‘doing’ and to ‘being’ (Thomas, 1999); “bodies are lived in; but in the social settings that they inhabit” (Goodley, 2013, p. 635).

It is important to also mention the significance of language and its relevance to these two models. Conceptualisations of the dominant discourse determine distinctions between the meaning of ‘impairment’ and ‘disability’, and the use of ‘disabled people’ or ‘people with disabilities’, ‘non-disabled people’ or ‘able-bodied’ (Harpur, 2012a; Oliver, 1990; Reeve, 2002). “An impairment is an individual specificity, while a disability is a social reality” (Winance, 2007, p. 230). Impairment refers to an abnormality of structure or a lack in function in an individual, and disability refers to any identified restriction or lack of ability of an individual to perform some action because of that impairment (Darcy & Buhalis, 2011). Linguistically, among the disability community and disability studies scholars alike, there is much contention over the use of these terms, and their implications for identity politics (Butler, 1990; Mallett & Runswick-Cole, 2014; Shakespeare & Watson, 2002), where each essentially argue for recognition of an individual’s humanity over and above their impairment. As an example, some scholars dispute the use of ‘disabled people’ as it identifies an individual by their impairment, and instead maintain the use of ‘people with disabilities’ as it emphasises an individual by their humanity rather than their attribute (Harpur, 2012b; Jaeger & Bowman, 2005). Conversely, other scholars insist on the use of ‘disabled people’ as it frames aspects of disablement to society rather than the individual (Clark & Marsh, 2002; Shakespeare, 2006).

Considering these perspectives and the localised context of the thesis, New Zealand's Disability Survey (2013) defines 'impairment' as a long-term (six months or longer) and limiting effect (a restriction or lack of ability to perform) on an individual's ability to carry out their day-to-day activities (Statistics New Zealand, 2014). Further, New Zealand's Disability Strategy (2016-2026) views 'disability' as:

Something that happens when people with impairments face barriers in society; it is society that disables us, not our impairments. ... It is something that happens when the world we live in has been designed by people who assume that everyone is the same. ... Every human being is a unique individual. Even if we have the same impairment as someone else, we will experience different opportunities and barriers because of where we live and how we are treated by those around us. The time and context in our lives when we may acquire our impairments also informs what barriers or opportunities we may experience. (Office for Disability Issues, 2016b, p. 12).

To reflect the personhood of the participants in this research, as well as representing the wider humanity of people more generally, before their disabilities, I have employed the descriptor of 'people with disabilities' throughout this thesis, and previous research. Given the thesis aim and its sampling parameters for participation in this research, the identity descriptor of 'people with intellectual disabilities' should also be conceived within this conceptual framework. The World Health Organization (2011) defines 'intellectual disability' as follows:

Characterised by diminished higher mental functions. This reduced ability has an overall but not homogenous effect on aspects like mobility, perception, comprehension, language and affective skills, amongst others. As a common characteristic, these people may have communication difficulties, orientation problems in unfamiliar situations, or they may behave in a way that is not socially expected from a person of their age. (p. 30)

Common to most definitions of intellectual disability is the onset, cause, duration and nature of impairment (Careerforce, 2017). In most instances, the onset of impairment is prenatal, perinatal or postnatal (that is, conditions existing before birth, during or since birth, or during early childhood, respectively) (Bray, 2003; National Advisory Committee on Health & Disability, 2003). Prenatal conditions are often the result of chromosomal or genetic information (resulting in, for instance,

Down syndrome, Fragile X syndrome or Prader-Willi syndrome) or other factors related to illness, poisoning or trauma (resulting in, for instance, foetal alcohol syndrome), transferred from parent/s to baby during pregnancy (Careerforce, 2017). Perinatal conditions may be the result of premature arrival, complicated or prolonged labour, or multiple births (Careerforce, 2017). Postnatal conditions are usually the result of a child's developmental growth and – if affected by a brain injury or tumour, a severe allergic reaction or poisoning, severe malnutrition or other illness – may result in an intellectual disability (Careerforce, 2017). Onset may also be the result of an impairment acquired through accident or illness during late adolescence or adulthood (National Advisory Committee on Health & Disability, 2003). In many instances, the cause of impairment is unknown and is referred to as general developmental delay or intellectual disability, and in almost all instances, the duration of impairment is life-long (Careerforce, 2017).

The nature of the impairment is reduced intellectual and social functioning, and individuals face varying difficulties related to their communication and interaction, learning and literacy, understanding and problem solving, and health and mobility (Careerforce, 2017; National Advisory Committee on Health & Disability, 2003). The presence of these difficulties and the extent to which they occur have implications for an individual's navigation of a cognitively complex world (National Advisory Committee on Health & Disability, 2003), and their ability to “live in a safe and socially responsible manner in their everyday lives” (Careerforce, 2017, p. 2). Subsequently, people with intellectual disabilities will likely require support – whether minimal, moderate or high level – to enhance such navigational ability (Bray, 2003; Careerforce, 2017). Formal, paid support workers or informal, unpaid carers (Jorgensen, Parsons, Jacobs, & Arksey, 2010) typically offer such care, as their “effort, understanding and compassion support people to live with dignity and participate more fully in society” (Ministry of Social Development, 2014, p. 4).

Evidently, disability is a dynamic concept that has evolved over time, and will continue to evolve as society progresses (Office for Disability Issues, 2001, 2016b). Firstly, disability has become prevalent due to increased survival rates and longer life expectancies coupled with the increased medicalisation of people with

disabilities, and demographic changes have seen a gender balance and population ageing (Office for Disability Issues, 2001). Secondly, trends of best practice have contributed to themes of change over time, for instance, trends in medical treatment or service provision once favoured have now been disregarded (Office for Disability Issues, 2001). Thirdly, perceptions of people with disabilities have improved. Recognised in the past as weak or lesser members of society by others, in more recent times there has been a greater willingness to explore these negative attitudinal barriers (Office for Disability Issues, 2016b). A modern perspective of disability recognises people with disabilities as part of the vastly diverse human experience, and acknowledges, understands and celebrates their multiplicity (Office for Disability Issues, 2001).

3.3 A brief history of disability in New Zealand

To better understand what is happening now and to look ahead to what might be, it is important to know what happened in the past. (National Advisory Committee on Health & Disability, 2003, p. 3)

While a conceptual framework illustrates the bounds of disability today, a short history can provide the reader with a greater understanding of the current legislative context and structure of the health and social systems in which disability exists in New Zealand. Historically, people with disabilities have experienced systemic discrimination, since New Zealand saw its beginnings as a nation, from 1840 onward (Convention Coalition, 2012). Through policy and legislation, the Government sought to contain, and preferably discourage, the numbers of people with disabilities settling in New Zealand (Office for Disability Issues, 2016a). Financial aid was minimal and met only by the voluntary sector, and care was met informally by the individuals' families (Office for Disability Issues, 2016a). Some institutions offered support for orphaned children, single mothers, people with mental illness and the elderly, and some people with disabilities found residence here (Office for Disability Issues, 2016a).

The 1900s saw social beliefs around racial fitness rise as part of the eugenics movement (Office for Disability Issues, 2016a). This saw the segregation of children perceived as defective, from mainstream services to institutions, and the prevention of adults perceived as ill or weak from having children, through their

removal from society to gender-segregated institutions (Office for Disability Issues, 2016a). During this time, medical knowledge and technological advances increased, emphasising the premise for the medical treatment of people with disabilities, and of returned veterans experiencing mental illness and physical impairment (Office for Disability Issues, 2016a).

The passing of the Mental Defectives Amendment Bill in 1928 saw the institutionalisation of people with intellectual disabilities (Convention Coalition, 2012). Over the next 50 years, the residents of these institutions were isolated and abused, and their rights to independence, choice and privacy were violated (Convention Coalition, 2012). Throughout the 1950s and 1960s, organisations began to establish day centres, vocational services and residential homes to challenge this proclivity towards institutionalisation (Office for Disability Issues, 2016a). Yet, institutionalisation reached its pinnacle in 1964, with over 10,000 people with intellectual disabilities and/or mental illness housed across the country in 13 institutions (National Disability Authority, 2011). In 1985, a new policy directed at community living for people with intellectual disabilities (Convention Coalition, 2012) signalled a move away from collective living toward deinstitutionalisation (National Advisory Committee on Health & Disability, 2003; National Disability Authority, 2011). The Kimberley Centre in Levin was the last institution closed in 2006, marking the completion of deinstitutionalisation (National Disability Authority, 2011; Stace, 2015). The implications of this historic abuse are ongoing for the affected individuals and their families and, as such, there are urgent calls for a major enquiry (Stace, 2015).

From the 1970s until the early 2000s, and in alignment with the disability rights movement internationally, the Government's approach to people with disabilities became increasingly community- and rights-based, working towards ending discriminatory practice (Convention Coalition, 2012). There was recognition of the need for community-based supports, smaller residential facilities, mainstream education and employment opportunities, and financial assistance to people whose cause of impairment was accident or injury (Office for Disability Issues, 2016a).

The 2000s have seen the inauguration of New Zealand Sign Language as an official language (Office for Disability Issues, 2016a), and the appointment of

people with disabilities in high profile Government roles (Convention Coalition, 2012). Further, the Christchurch earthquakes emphasised a turning point in the consideration of disability, as the destruction exacerbated inaccessibility, televised Civil Defence announcements were in Sign, and the representation of people with disabilities in the rebuild was mandated (Convention Coalition, 2012). The Government has continued to introduce and develop programmes, strategies, policies and laws centred on a regard for citizenship rights and improving the lives of people with disabilities through the offering of more equitable outcomes (Convention Coalition, 2012; National Advisory Committee on Health & Disability, 2003).

3.4 Current legislative context

Reflecting this shift in focus is the disability policy rhetoric, which is built upon the premises of the social model (Stace, 2015), recognising that people with disabilities should have the same citizenship and human rights as non-disabled people, and aspiring to a vision of inclusion for all (Office for Disability Issues, 2011). The Government's efforts to accommodate people with disabilities are validated throughout national policies and legislation, initiatives and strategies (Office for Disability Issues, 2011). New Zealand has generally sound legislative prescriptions in theory yet, in practice, these prescriptions are restricted in their influence and need better compliance and enforcement (Convention Coalition, 2012).

Perhaps the most fundamental pieces of legislation are the Bill of Rights Act 1990 and the Human Rights Act 1993 (Convention Coalition, 2012). Together they assert New Zealand's commitment to ensuring the human rights of all citizens (National Advisory Committee on Health & Disability, 2003), promoting harmonious relations between the diverse groups of society (Human Rights Commission, 2018), and prohibiting discriminatory behaviour (Office for Disability Issues, 2011). Other pieces of legislation reflect a number of disability-related issues, for instance, accessibility, communication, education, employment and transportation (Office for Disability Issues, 2011; Stace, 2015).

Further, there are a number of pieces of legislation exclusively directed at people with disabilities, their family members and whānau. New Zealand signed on 30

March 2007, and ratified on 26 September 2008, the United Nations Convention on the Rights of Persons with Disabilities (Office for Disability Issues, 2016a, 2016b). New Zealand played a leading role in the initial negotiations surrounding the convention's development (Office for Disability Issues, 2011, 2016b). Robert Martin, a New Zealander with learning disabilities, was the first person with such impairment to address the United Nations through these negotiations (Convention Coalition, 2012), and he has more recently attained successful candidacy to the United Nations Committee on the Rights of Persons with Disabilities (Office for Disability Issues, 2016b). The convention serves as a benchmark to guide policy and its analysis, and to ensure that mainstream services and support are accessible and delivered in a non-discriminatory manner (Office for Disability Issues, 2011).

The Office for Disability Issues originated in 2002 to ensure a cross-government sector focus on disability, and independent monitoring and active implementation of the United Nations Convention on the Rights of Persons with Disabilities in New Zealand (Office for Disability Issues, 2011, 2016b). The bases of its implementation are the New Zealand Disability Strategies and the Disability Action Plans (Office for Disability Issues, 2016b). Each successive Disability Strategy has guided the Government's commitment to and leadership in improving the lives of people with disabilities (Office for Disability Issues, 2011, 2016a). The vision, always, is to realise an inclusive, non-disabling society (National Advisory Committee on Health & Disability, 2003) that acknowledges, understands and celebrates people with disabilities as "part of the vast and diverse human experience" (Office for Disability Issues, 2016b, p. 13).

The current New Zealand Disability Strategy (2016 – 2026) also holds the vision of a society where people with disabilities "have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen" (Office for Disability Issues, 2016b, p. 6). It emphasises a rights-based framework, informed by the principles of the Treaty of Waitangi, Te Tiriti o Waitangi, and the United Nations Convention on the Rights of Persons with Disabilities, and is guided by twin-track, whole-of-life approaches (Office for Disability Issues, 2016b). The key outcome areas cover issues of accessibility, attitudes, choice and control, education, employment and economic security, health

and wellbeing, leadership, rights protection and justice (Office for Disability Issues, 2016b). The Disability Action Plan (2014 – 2018) is a strategic framework that, through a series of action points and priorities for outcomes, offers guidance to cross-government sectors, agencies and disabled people’s organisations (Office for Disability Issues, 2015). The plan’s vision is that people with disabilities experience equal rights of citizenship, especially around community, representation, safety, wellbeing, autonomy and self-determination (Office for Disability Issues, 2015).

Similarly, the New Zealand Carers’ Strategy Action Plan (2014 – 2018) is directed toward carers of people with disabilities. This strategy emphasises that “caring should be something people do with pride and feel supported when they do it,” and therefore holds the vision of enhancing the support offered to those people in roles of caring for people with health conditions or disabilities (Ministry of Social Development, 2014, p. 8). The strategy sets out a strategic framework informed by principles of recognising diversity, and being proactive, enabling and inclusive (Ministry of Social Development, 2014). The action plan covers a five-year period and sets out objectives to be achieved, actions required to be taken, and resulting key outcome areas (Ministry of Social Development, 2014). Here, too, the plan recognises the potential and far-reaching impact a commitment to care can have on individuals’ health and wellbeing, social connectivity, employment and economic security, and future (Ministry of Social Development, 2014). Therefore, it emphasises that carers must “realise true inclusivity and dignified participation in all aspects of life,” and hence key outcome areas relate to general health, learning and wellbeing, respite, access to information, pathways to employment, and public awareness of their social role (Ministry of Social Development, 2014).

3.5 Health and disability sector and disability support services

Responsibility for the facilitation of these fundamental outcome areas for people with disabilities lies with both the public and private sectors. In terms of the public sector, the Ministry of Health and associated District Health Boards support daily living needs; the Ministry of Education supports disability-related education needs; and the Ministry of Social Development supports income, employment and vocational needs (National Advisory Committee on Health & Disability, 2003; National Disability Authority, 2011). These three key ministries primarily have

authority for the funding and administering of competitive contracts to the private and not-for-profit sectors (Te Pou o te Whakaaro Nui, 2016). These non-government agencies and organisations deliver a number of community-based, disability support services to people with disabilities (National Advisory Committee on Health & Disability, 2003). Such services and support may include things like home and community support, residential care, and respite services; special education (Ministry of Social Development, 2016); and day centres, employment pathways and vocational programmes (National Disability Authority, 2011). A range of services and support is available to carers too, from financial assistance or home help, to respite care or travel and transportation (Ministry of Social Development, 2016).

Given the focus of this research, one relevant example of services and support available to carers and people with intellectual disabilities, is ‘respite’, defined as “a period of rest or relief” (Ministry of Health, 2017, p. 1). For carers, respite can serve as an important reprieve from care work, beneficial to their mental health and wellbeing as well as the individual with disability, and the continued longevity of the care relationship (Ministry of Health, 2017; Ministry of Social Development, 2016). Facilitating access to respite for carers is a Carer Support Subsidy (a contribution to the cost of a break) or Individualised Funding (a contribution to the cost of directly purchasing support) (Ministry of Health, 2017; Ministry of Social Development, 2016). Alternative provision of respite for people with intellectual disabilities is home support (one-on-one assistance), host-family respite (a break in the home of another family/whānau) or facility-based respite (a break in a dedicated respite facility, or a residential or rest home) (Ministry of Health, 2017; Ministry of Social Development, 2016). Access to respite is dependent upon the carer’s needs, the individual with disability’s needs, and the availability of services (Ministry of Health, 2017; Ministry of Social Development, 2016). Depending on circumstances pertaining to a particular care relationship, respite may be available for anywhere from a few hours to a 24-hour overnight break, or a short period to several weeks (Ministry of Health, 2017; Ministry of Social Development, 2016).

The Government’s approach to respite is one of social investment, recognising the invaluable role and contribution of carers to the lives of people with disabilities

(Ministry of Health, 2017). Yet, the current model is requiring of improvement, particularly around the need for greater choice, control and flexibility for the carer and their diverse needs, as well as greater accessibility to and availability of a range of high-quality respite staff and services (Jorgensen et al., 2010; Ministry of Health, 2017; National Advisory Committee on Health & Disability, 2003).

Still, the health and disability sector provides services and support that are somewhat prescriptive and life-defining, constrictive and custodial (IHC New Zealand, 2016; National Advisory Committee on Health & Disability, 2003). Operationally, the services and support an individual may have access to or receive reflects a medical model of disability, as it is dependent upon their eligibility in meeting requirements in addition to their ability to navigate an intermittent, fractured delivery of these services and support (Stace, 2015). Therefore, not every individual with a disability receives the services and support of this sector, for they may be ineligible, the demand may be unmet, or there may be a service gap (National Disability Authority, 2011). This places limitations on the extent to which people with disabilities can access, participate in and contribute to community life (National Advisory Committee on Health & Disability, 2003). Consequently, there are deep-seated sectorial issues, principally in relation to service and support provision, and workforce development (National Advisory Committee on Health & Disability, 2003).

Firstly, New Zealand Government funding of the sector is inadequate, and consequently the standard and quality of services and support supplied is inconsistent (Convention Coalition, 2012). Demand exceeds the capacity to supply (National Disability Authority, 2011), and both the provision of and access to services and support is disconnected and fragmented, and limited in its variety and scope (Convention Coalition, 2012; National Advisory Committee on Health & Disability, 2003). The health and disability sector needs to move toward effective coordination between the agencies and organisations delivering the different services and supports, so as to offer ease of access, navigation and flexibility to its clients (Office for Disability Issues, 2016b). Further, there needs to be greater emphasis on the individual, with the objective of an approach that is both person-centred around the particular “preferences, strengths, aspirations and needs”

(Enabling Good Lives, 2018, para. 1) of an individual and their family, and whole-of-life in that these considerations will naturally evolve long-term (Care Matters, 2017).

Secondly, the workforce of the sector is one of the most critical determinants of the input and effectiveness of the services and support provided to people with disabilities (National Advisory Committee on Health & Disability, 2003). Yet again, there are inherent issues principally relating to the demographic profile of the workforce, the skills and capabilities of its staff, the nature and conditions of the work itself, and the perception of the sector.

A support worker is any individual employed by an agency or organisation in the health and disability sector, and whose role is “to support, care for and encourage individuals with an intellectual disability in their daily living situations, whether it be at home, work, day programmes or in social, leisure and educational time” (IHC New Zealand, n.d., para. 1). This takes place in a range of settings, from personal or group homes, to residential or nursing care (Ministry of Social Development, 2016). Support workers play an integral role in the lives of many people with disabilities, caring for and supporting them to lead ordinary lives and realise aspirations of a good life (IHC New Zealand, 2016; National Advisory Committee on Health & Disability, 2003).

Evidence shows that the demographic profile of the workforce lacks diversity (Te Pou o te Whakaaro Nui, 2016). A typical staff member is a non-disabled European woman, between 45 and 54 years of age (Te Pou o te Whakaaro Nui, 2016). The workforce is ageing, and poorly represented in terms of men, Māori and Pacific peoples, and people with disabilities (Te Pou o te Whakaaro Nui, 2016). It has tended to be unqualified or poorly qualified (Convention Coalition, 2012), although the uptake of health and disability-related qualifications has improved in recent years, especially among staff employed in small- to medium-sized rather than very small or large organisations (Te Pou o te Whakaaro Nui, 2016). In addition, there are poor opportunities for training or career progression (National Advisory Committee on Health & Disability, 2003).

The nature and conditions of the work are reflective of an undervalued workforce (National Advisory Committee on Health & Disability, 2003). Staff are often paid the minimum wage or an average hourly rate that is usually lower than that of the country's average hourly rate (Te Pou o te Whakaaro Nui, 2016). Hours of work are not always guaranteed, are minimal or varied, and usually within a part-time capacity (Te Pou o te Whakaaro Nui, 2016). As such, agencies and organisations have faced long-standing issues with the recruitment and retention of staff (IHC New Zealand, 2016; Te Pou o te Whakaaro Nui, 2016), and there is a high rate of staff turnover (National Advisory Committee on Health & Disability, 2003).

Increasingly, there have been calls to the Government to action a full enquiry into the planning and development of this workforce (Convention Coalition, 2012; Te Pou o te Whakaaro Nui, 2016). The future of this sector is dependent on a number of factors, as follows: greater demographic and ethnic representation; recruitment, development and retention of a capable and skilled, qualified and culturally competent workforce; preservation of institutional memory, knowledge and understanding; and negation of attitudinal barriers toward the valuing of the workforce and sector (Convention Coalition, 2012; IHC New Zealand, 2016; Te Pou o te Whakaaro Nui, 2016). A recent move toward these priorities was the historic Care and Support Workers (Pay Equity) Settlement Act, which came into effect in 2017. This Act mandates an increase (of between 15 and 50 per cent) in the average hourly wage (to between \$19 and \$27 per hour) for 55,000 support workers, dependent on their qualifications and/or experience (Ministry of Health, 2017).

3.5.1 Informal care

More often, it is unpaid carers delivering the necessary help or support (Norman & Purdam, 2013), “for anything up to 24 hours, 7 days a week” (Jorgensen et al., 2010, p. 9). A carer is any individual who assists an individual with intellectual disability with their personal care, household duties, and everyday living within their homes and out in their communities (Ministry of Social Development, 2014). In 2013, New Zealand's Census on Populations and Dwellings identified there to be nearly half a million New Zealanders (or 490,000) with caring responsibilities for people with poor health and disabilities (Ministry of Social Development, 2014).

Yet, the term carer “does not adequately reflect the diversity of those who take up the role, the special relationship they have with those they care for, and the sometimes-tough circumstances in which they live” (Ministry of Social Development, 2014, p. 2). Often, they are parents, siblings, children, or other family members of an individual with an intellectual disability (Ministry of Social Development, 2016). They “may also be paid or unpaid persons with no kinship connection with the cared for person” (Beckett, 2007, p. 364). While carers represent a diverse group of varying ages, cultures, ethnicities and lived experiences, a typical carer is a Māori female family member of working age, who is looking after an older person with poor health or disability (Ministry of Social Development, 2014).

Carers comprise both an informal component of and interaction with the health and disability sector (Beckett, 2007). They, too, have cited difficulties in accessing the services and support provided formally, being “forced to negotiate a complex maze to access services and support, endure endless assessments and long waiting lists and often have to be in crisis before they can get help if they get help at all” (IHC New Zealand, 2016, p. 4). The most significant of these issues is the fragmented nature and provision of information that is often neither accessible nor up-to-date, and a lack of access to funding, whether for reasons of ineligibility based on an individual’s diagnosis or of difficulty in navigating paperwork and bureaucratic environments.

Informal carers, too, are a marginalised identity that is being increasingly granted attention in a broad sense, politically, economically, and sociologically. The seeming selflessness involved in placing the wellbeing of another ahead of that of one’s self can come with a cost (Day, 2000; Sevenhuijsen, 1998). Mostly, this is the result of the personal economic and social costs carers face (Fine, 2005). Economically, they face additional financial costs associated with their care activity, such as the purchasing of personal care products, medication, special food, as well as additional utility expenses. If there is a need to reduce or relinquish paid employment, for instance accepting a position with lesser hours or lower pay, or declining a promotion, then these costs are amplified (National Advisory Committee on Health & Disability, 2003). Similarly, a carer will relinquish

opportunities related to the realisation of their own ordinary or good life pursuits (Ministry of Social Development, 2016). Socially, carers describe experiencing the compromising or breaking down of familial and social relationships (Gladwell & Bedini, 2004; National Advisory Committee on Health & Disability, 2003), as they have “little free time for their own life, such as going out, isolation from work, lost social contacts and loss of a partner to talk with” (Jorgensen et al., 2010, p. 13).

Much of the literature has centred on the burden of care upon the carer, where they feel concern, worry and anguish for the cared for (Henderson & Forbat, 2002). The time-intensive and demanding daily tasks they must undertake (Hubert, 2011) contribute both psychological and physical distress to their wellbeing (Gladwell & Bedini, 2004; C. Lee, 1999; Pinguart & Sorensen, 2006). Carers desire “more financial assistance; flexible and reliable respite provision; the opportunity and ability to be in paid employment; one national place for information; and recognition for their caregiving roles” (Jorgensen et al., 2010, p. 13).

Support workers and carers offer an invaluable contribution to the lives of New Zealanders with intellectual disabilities, the health and social systems, and the wider society, yet they largely go unrecognised. “At some stage in our lives, most of us will care for, or be supported by, someone” (Ministry of Social Development, 2016, p. 2). This care or support might be required with a sudden onset or occur gradually over time, and its duration might be temporary or life-long (Ministry of Social Development, 2016). Yet, as the population ages and the prevalence of disability increases, the availability of informal care and support continues to diminish while demand increases (Jorgensen et al., 2010), placing increased pressure on formal funded services and support (Disability Investment Group, 2009). Support workers and carers alike must be valued and supported, both materially and psycho-socially (Jorgensen et al., 2010).

3.6 Disability issues

While the health and disability sector works to implement measures that the Government has put in place to achieve a non-disabling society that values and augments the participation of people with disabilities, the extent to which this occurs in actuality is questionable (National Advisory Committee on Health & Disability, 2003). Many people with disabilities, and especially people with

intellectual disabilities, still face barriers that prevent them from reaching their full potential, and from participating in and contributing to their communities on an equitable basis with others (Morris, 2001; National Advisory Committee on Health & Disability, 2003). As IHC New Zealand (2016) has put it:

Without a doubt there have been significant advances for people with intellectual disabilities in New Zealand but progress has not been good enough. ... There are too many gaps and there is a way to go before we can say people with intellectual disabilities are living valued and good lives as citizens where no voice is unheard and no rights ignored. (p. 2)

At a minimum, every New Zealander should have equal access to their citizenship rights and the guarantee of an ordinary life, and at an ideal, the space to fulfil their life potential in the pursuit of a good life (Care Matters, n.d.; National Advisory Committee on Health & Disability, 2003). The use of the word ‘ordinary’ is the recognition “that all people, whatever their level of impairment, have the same fundamental human needs and expectations” (National Advisory Committee on Health & Disability, 2003, p. 5). An ordinary life is one where people with disabilities “are supported to live an everyday life in everyday places ... regarded as citizens with opportunities for learning, employment, having a home and family, and social participation” (Care Matters, 2017, p. 2). Hence, people with disabilities being able to realise their rights to citizenship means being able to exert autonomy over the decision-making in their lives, being able to live in a place of their choosing, having access to good education, being able to contribute through employment and acquiring financial stability in doing so (Care Matters, n.d.).

A caveat, however, is that the extent to which an individual is able to realise their rights to citizenship is often determined by the nature and extremity of their impairment (National Advisory Committee on Health & Disability, 2003). Where some individuals are very restricted across all aspects of their functioning, others may be relatively unrestricted in their functioning, having had life experiences and desiring to achieve aspirations similar to those of many non-disabled people (National Advisory Committee on Health & Disability, 2003). Some individuals simply want to feel present in their communities, while others want to belong, participate in and contribute to them (Office for Disability Issues, 2016b). While these simple measures of an ordinary life are taken-for-granted among much of the

non-disabled population (Care Matters, n.d.), there is a tendency in New Zealand society to place conditions and limitations on these defining life domains because of a perception of lower life expectation and a reality of lower outcomes for people with disabilities (Care Matters, n.d.). Only when we as a society can acknowledge that people with disabilities also have their own vulnerabilities and safeguards, needs and wants, likes and dislikes, and hopes and dreams, will we afford a good life for them too (Care Matters, 2017, n.d.).

In addition to the social barriers described above, issues arising for people with disabilities are usually attributed to a lack of access to disability support services, health and wellbeing, education, employment and economic security, accessible housing and transport, social inclusion and participation, sport and recreation, leisure and tourism (CCS Disability Action, 2013; Convention Coalition, 2012). Notably, an experience of discrimination or inaccessibility in just one of these areas has flow-on effects which can further adversely affect their experience in another area (Convention Coalition, 2012).

Firstly, income and economic security, employment and education, are important measures of economic outcomes. Being able to contribute to one's community through paid employment generates income and enhances quality of life (Bishop & Allen, 2003; Jacoby, 2002), but also can develop skills, foster a sense of purpose, and cultivate confidence and social connection (IHC New Zealand, 2016). Compared with the non-disabled population, people with disabilities are more likely to receive lower levels of income (Office for Disability Issues, 2001; Stace, 2015), and be dependent upon a government welfare benefit (Statistics New Zealand, 2017b). In 2013, a significant proportion of people with disabilities were receiving less than \$20,000 per annum or between \$20,001 and \$50,000 (at 44 and 37 per cent, respectively), and a small number were receiving more than \$50,000 (at 18 per cent) (Statistics New Zealand, 2015b). In 2017, the average weekly income received from all sources by people with disabilities was less than half of the income received by the non-disabled population (at \$458 and \$833, respectively) (Statistics New Zealand, 2017b). People with intellectual disabilities were even more likely to receive a lower income, and in 2001 a considerable number were receiving less than \$15,000 per annum and a small number were receiving between

\$15,000 and \$30,000 (at 63 and 14 per cent, respectively) (Ministry of Health, 2005). Many adults with intellectual disabilities had a Community Services Card and/or received the Disability Allowance and/or the Invalids Benefit (at 74, 27 and 27 per cent, respectively) (Ministry of Health, 2005).

Compared with the non-disabled Māori population, the Māori people with disabilities experience poorer outcomes across almost all measures, and disparities in material wellbeing are the most marked. In 2013, they received lower incomes than non-Māori people with disabilities, with a significant proportion receiving less than \$30,000 per annum and a small number receiving more than \$50,000 (at 68 and 14 per cent, respectively). In fact, a number of Māori people with disabilities felt as though they did not receive enough income to afford everyday goods and services, compared with very few non-disabled Māori holding the same view (at 25 and 8 per cent, respectively). An even greater number of them felt as though they received just enough income to afford everyday goods and services, compared with a number of non-disabled Māori (at 42 and 32 per cent, respectively) (Statistics New Zealand, 2015a).

Compared with the non-disabled population, people with disabilities are less likely to be in paid employment (Stace, 2015). In 2017, one quarter of people of working age with disabilities were participating in the labour force, compared with almost three quarters of the non-disabled population (at 25 and 73 per cent, respectively). Just under one quarter of people of working age with disabilities were employed and over one tenth were unemployed (at 22 and 11 per cent, respectively), compared with almost three quarters of the non-disabled population who were employed, and very few who were unemployed (at 69 and 4.5 per cent, respectively). Compared with the non-disabled population, people with disabilities in employment worked less hours per week and received lower average earnings per hour (Statistics New Zealand, 2017b).

Compared with non-disabled Māori, Māori people with disabilities are less likely to be in the labour force (Statistics New Zealand, 2015a). In 2013, just over half of Māori of working age with disabilities were participating in the labour force, compared with over three quarters of the non-disabled Māori population (at 53 and 76 per cent, respectively). Māori people with disabilities also experience higher

rates of unemployment (17 per cent, compared with 11 per cent for the non-disabled Māori population) (Statistics New Zealand, 2015a).

New Zealand's future economic growth will likely be constrained by an overall labour shortage, as well as shortages in skilled labour. The low rate of employment for people with disabilities is representative of a considerable loss in potential economic and social contribution (Office for Disability Issues, 2016b). Lower levels of educational attainment, difficulties in seeking and attaining employment and the older age profile of people with disabilities have contributed to these employment disparities (Statistics New Zealand, 2015b). Compared with the non-disabled population, people with disabilities are more likely to have lower levels of educational attainment (Office for Disability Issues, 2011; Social Statistics Division, 2002), often reflected in fewer formal qualifications at the secondary and tertiary education levels (Statistics New Zealand, 2015b). For instance, in 2001, just over half of all adults with intellectual disabilities had no educational qualifications, just under one fifth had a school-related qualification, and just over one tenth had a post-school-related qualification (at 51, 18 and 11 per cent, respectively) (Ministry of Health, 2005).

Secondly, societal attitudes and connectivity are two examples of important measures of social outcomes. People with disabilities encounter negative attitudinal barriers from individuals and groups in society (CCS Disability Action, 2013). These often manifest as negative discrimination, stereotyping or stigma (Office for Disability Issues, 2011), and hinder community inclusion (Convention Coalition, 2012). "Being seen as people first and being connected in their communities and culture is the essence of what has been long called for by people with intellectual disabilities and their families and Whanau" (IHC New Zealand, 2016, p. 5). Being able to experience connectivity along with loving friendships and relationships with others is essential to any individual, contributing to their wellbeing and quality of life (Enabling Good Lives, 2017a, 2017b). Further, having these social roles – of partner, sibling, friend or colleague, for instance – affords a sense of value and a feeling of belonging for a person (CCS Disability Action, 2013). Still, many people with disabilities report feelings of loneliness and experiences of social isolation (Statistics New Zealand, 2015b), at best lacking basic connection with others, and

at worst never experiencing friendships or intimate relationships with others (Enabling Good Lives, 2017b).

Measures of social outcomes are particularly marked for people with intellectual disabilities and, often, a contributing factor is believed to relate to their living arrangements (National Advisory Committee on Health & Disability, 2003). People with intellectual disabilities tend to have limited choice or control regarding “where they live, the people they live with, and what happens in their home” (National Advisory Committee on Health & Disability, 2003, p. 22). People with intellectual disabilities were more likely to live in the most socioeconomically deprived areas of the country (Ministry of Health, 2005), and a number were living in group homes or residential care facilities, and together these circumstances were particularly constraining on their ability to access and participate in the social world (National Advisory Committee on Health & Disability, 2003). In particular, many people with intellectual disabilities struggle to make and maintain friendships or relationships with others, often requiring support to do so (Ministry of Health, 2005; National Advisory Committee on Health & Disability, 2003). Some individuals only have relationships of a professional and transactional nature, as client-staff, and for others, their families have estranged themselves (Enabling Good Lives, 2017b).

The opportunity to get out and about and to participate in a range of leisure and recreational pursuits is an important contributor to a person’s quality of life and life satisfaction (Browder & Cooper, 1994), yet there is little opportunity for people with disabilities to engage in such pursuits (National Advisory Committee on Health & Disability, 2003). Socio-demographic constraints of ethnicity, limited employment opportunities and minimal disposable income exacerbate an individual’s access to and participation in such pursuits (Convention Coalition, 2012; Mactavish, Schleien, & Tabourne, 1997). In addition, they face a lack of acceptance by other individuals and groups in society (Vash, 2001), as well as difficulties in both accessing and moving around a community with ease and independence (National Advisory Committee on Health & Disability, 2003), for instance, due to a lack of appropriate transportation (Cavinato & Cuckovich, 1992).

3.7 Access to and participation in tourism

A further example of a measure of inequitable social outcomes for people with disabilities is travel (Foggin, 2011). This section offers a brief introduction to New Zealand's tourism industry, which is necessary to provide further localised and contextually relevant information at the nexus of care, intellectual disability and leisure travel, and forms the foundations of the thesis topic itself. It also determines the current awareness and provision of accessibility within the industry, suggesting the extent to which people with disabilities are able to access and participate in the travel experience. The previous Chapter 2, 'Introduction and literature' has offered an elaboration upon this point from a scholarly perspective.

The contribution of tourism to New Zealand's economy is irrefutable, as the following statistics illustrate. For the year ended March 2017, the tourism industry maintained its position as the country's largest export earner, contributing just over one fifth (or 20.7 per cent) of the total exports of goods and services. Total tourism expenditure grew (by 1.9 per cent) to \$36 billion dollars. Its direct and indirect contribution to total gross domestic product accounted for \$14.7 billion dollars and \$11.3 billion dollars (or 5.9 and 4.6 per cent), respectively (Statistics New Zealand, 2017c).

International tourism arrivals grew considerably (by 9 per cent) to 3.68 million, accounting for \$14.5 billion dollars of total tourism expenditure and generating \$1.5 billion dollars in Goods and Services Tax revenue. The industry saw a considerable growth in its arrival numbers from the inbound markets of Australia, the United States of America and the United Kingdom (by 6.2 per cent to 1.5 million, 26 per cent to 325,472 and 14 per cent to 244,384, respectively). The inbound cruise market also experienced considerable growth (of 12.5 per cent) accounting for \$306 million dollars of total tourism expenditure. Of the 222,000 arrivals, the median age was 65 years, while three quarters were aged between 50 and 80 years. Half of these arrivals were from Australia, nearly one fifth from the United States of America/Americas, and nearly one tenth from the United Kingdom (or 50, 18 and 9 per cent, respectively) (Statistics New Zealand, 2017c). Domestic tourism expenditure grew (by 4 per cent), accounting for \$21.4 billion dollars of total tourism expenditure and generating \$1.8 billion dollars in Goods and Services Tax

revenue. In addition, the industry supported nearly 230,000 jobs, accounting for nearly one tenth (or 8.4 per cent) of the total labour force. There was an increase (by 10 per cent) in the overseas trips made by New Zealanders to 2.79 million, these trips being mostly for the purpose of holidaying or visiting friends and relatives (at 43 and 37 per cent, respectively) (Statistics New Zealand, 2017c, 2018).

In New Zealand, like elsewhere in the world, there has been little attempt to determine the proportion of both the domestic and international tourism markets made up of people with disabilities and their travelling companions (Rhodda, 2012). “Nothing is known about the number of visitors with disabilities in and to New Zealand; and little is known about their wants and needs” (Rhodda, 2014, para. 2). This is despite it being acknowledged as a potentially sizeable and growing group (Rhodda, 2014), given that New Zealand’s domestic market and many of its inbound markets are ageing (Gillovic & McIntosh, 2015). Similarly, there has been little attempt to approximate the economic value of this market, possibly because of the minimal disability-specific and travel-related statistics that are collected at a national level (Rhodda, 2014). One group of scholars did in fact provide a conservative estimate of the total expenditure of the country’s ‘domestic access market’, to the value of \$317.5 million dollars. This was calculated from the percentage (55 per cent) of the total number of people with disabilities (584,710) who took one holiday away in the 2012/2013 year [Disability Survey, 2013], the domestic tourist’s average nights away (three nights) and average spend per night (\$181 dollars) [Domestic Travel Survey, 2008]. It then considered the multiplier effect of 2.2 – a figure cited across international literature, for the average number of people travelling with an individual with disability – which saw the value increase to \$700.5 million dollars (see NZ Tourism for All, 2015).

Regarding tourism scholarship, Gillovic and McIntosh’s (2015) research was one of the first published studies to examine accessible tourism in New Zealand. It explored the perspectives of industry stakeholders, offering insight into the current and future scope of accessible tourism in New Zealand, and concluding that the access market remains decidedly underserved and misunderstood (Gillovic & McIntosh, 2015). In addition, it emphasised the significance of a co-ordinated and collaborative whole-of-industry approach, in addition to a wider cultural shift in

perception, from disability to accessibility (Gillovic & McIntosh, 2015). Gillovic and McIntosh (2015) called for a meeting in the middle of the industry, and explained:

Whilst there are ‘two sides’ of the coin’ and each side undoubtedly has their own pertinent roles to respectively play, participants felt it is about the industry recognising and valuing the interconnectedness and interdependence of one another. It is incumbent upon each and every individual organisation to play their part, but to be conscious that concurrently, one is limited in control over their own environmental spheres, as well as their influence at a larger scale. (p. 234)

A champion is “a person who enthusiastically supports, defends, or fights for a person, belief, right, or principle” (England’s Inclusive Tourism Action Group, 2016, p. 1). An accessibility champion is “the driver behind developing access for all and should ensure that everyone works positively to provide inclusive customer experiences ... promoting equality and diversity” (England’s Inclusive Tourism Action Group, 2016, p. 1). They are inspired and passionate role models and advocates (Gillovic & McIntosh, 2015). Indeed, champions are showcasing their success stories and leading by example, forging paths for others to follow behind them, building the momentum to demand change (Gillovic & McIntosh, 2015). Gillovic and McIntosh’s (2015) study suggested that awareness was beginning to rise and dialogue was beginning to open up at the industry’s operational levels, the scholars believing traction was starting to manifest, with change makers championing the provision of access. They explained that accessibility champions:

Envision and are acutely aware of the ‘kind of world’ they want themselves and others to live in; they demonstrate aspirational leadership in their endeavours to transform access hopes and dreams of the future into today’s reality ... To better themselves and embolden others, pushing the boundaries through: challenging of policy, processes and entrenched ideas; having the difficult but necessary conversations; shifting organisational culture and mind-set; empowering staff; and championing change. (pp. 231-232)

An example of this in practice is Be. Accessible. This is a nationwide social initiative and holistic framework for accessibility, which has been a stimulus in this shift toward making New Zealand an accessible country for all. Securing government funding, their initial objective was to garner accessibility buy-in from

tourism businesses in Auckland, in preparation for the hosting of the Rugby World Cup in 2011. It was acknowledged that much of this inbound market would be of retiring baby boomer age or older, and would likely benefit from the provision and delivery of accessible tourism products, services and experiences. Since then, the organisation has gained increasing traction, seeing a number of businesses, as well as those in other sectors, committing themselves to the cause. Through their 'Be. Welcome' consultancy programme, they have assessed the accessibility of businesses and organisations across the country, which are given an accessibility rating and online profile, and then offered recommendations and ongoing support in their pursuit of a higher rating (Be. Accessible, n.d.-a).

Be. Accessible “allows people to find new common ground with each other and it encourages a community where we all take responsibility for creating the best and most accessible world imaginable, individually and collectively” (Be. Accessible, n.d.-b, para. 1). Their work has “cultivated the profile of accessibility, placing it upon the industry’s agenda, leaving a legacy which to this day, both current and future accessibility provision is grounded upon” (Gillovic & McIntosh, 2015, p. 233).

3.8 Chapter summary

This chapter has provided an overview of the situated context of the thesis topic, providing the background information relevant to disability, care and tourism in New Zealand. The next chapter will provide an explanation of the philosophical and methodological underpinnings of this thesis that have both framed and informed the way in which this research has been approached and designed.

4 Methodology

The purpose of this chapter is to articulate the epistemological and methodological approaches and theoretical insights that underpinned the thesis and informed the research design and methods implemented to collect, analyse and interpret the data. It begins by describing the ways in which two predominant paradigmatic methodologies have contributed to understandings of truth and reality, and governed our inquiry into knowledge. Mostly, it discusses the evolution from functionalist, positivist inquiry to naturalist, interpretivist inquiry, detailing their respective philosophical assumptions. It includes a discussion of the fundamental philosophical underpinnings of phenomenology, and illustrates how an interpretive phenomenological approach, inductive and qualitative in its nature, has appropriately framed this thesis aim. That is, to explore lived experiences of care at the nexus of intellectual disability and leisure travel. The method of qualitative, semi-structured interviewing is then detailed, and the chapter concludes by presenting methodological reflections, research limitations, and ethical considerations.

4.1 A paradigmatic debate

Paradigmatic contention has permeated the philosophy of knowledge (Berger & Luckmann, 1966; Patton, 2002). Paradigms are basic sets of assumptions and beliefs (Guba, 1990; Maykut & Morehouse, 1994) illustrating the convictions we hold as members of any given community, and sculpting our perceptions and understandings of the natural and social worlds (Ayikoru, 2009). In an effort to understand the world, and to address the elusive yet revered concepts of truth and reality (Baginni, 2017; Gergen, 2001; Lincoln & Guba, 1985), metaphysical assumptions concerning questions of ontology, epistemology and methodology are considered (Kafle, 2011; Pernecky & Jamal, 2010). These assumptions “are connected in such a way that the answer given to any one question, taken in any order, constrains how the other may be answered” (Guba & Lincoln, 1994, p. 108).

Ontology questions what is knowable, in reference to the nature of being and the constitution of reality (Ayikoru, 2009; Creswell, 2013; Hughes, 2007). Epistemology questions how we know what we know (Kafle, 2011), in reference to the origins of knowledge (Lincoln & Guba, 1985). It considers the relevance of,

and relationship between, the knower and the known, the researcher and the researched (Guba & Lincoln, 1994; Veal, 2011). For instance, objectivity asserts the researcher's orientation to an object, from a stance which they can remain true to, while subjectivity asserts the researcher's orientation to the object in a personal manner, discerned through perception and insight (van Manen, 1990). Lastly, methodology questions our pursuit of knowledge (van Manen, 1990), in reference to the framework guiding our inquiry, and the methods of data collection and analysis utilised (Guba, 1990). Quantitative methods may include experiments, structured observations or surveys, while qualitative methods may include participant observation, interviewing or focus groups (Oakley, 1998).

Because these metaphysical assumptions determine that which is important, legitimate, or reasonable (Patton, 2002), the truthfulness of a given paradigm can neither be proven nor disproven (Guba & Lincoln, 1994; Scotland, 2012). As such, the tenets of a given paradigm are often incompatible and irreconcilable with another (Bryman, 2012), and this premise has given rise to the science and culture wars (Gergen, 2001). The empiricist positivist and naturalist interpretivist sciences are perhaps most illustrative of the paradigmatic debate (Bryman, 2012; Guba & Lincoln, 1994). This debate is characterised by dualistic tensions between the former and the latter, for instance, quantitative-qualitative, hard-soft, masculine-feminine, objective-subjective, nomothetic-ideographic, deductive-inductive, and explanation-interpretation (Oakley, 1998; Platenkamp & Botterill, 2013).

Influenced by Thomas Samuel Kuhn's classic text *The Structure of Scientific Revolutions* (1962), positivism has been pervasive in the natural and social sciences (Guba & Lincoln, 1994; Lincoln & Guba, 1985; Reason & Bradbury, 2001). Positivism discerns the world to be highly composed and structured, ordered under the governing dictations of the natural and social worlds (Jennings, 2010) that emphasise universal laws of cause and effect (Henwood & Pidgeon, 1993). Hence, through a process of trial and error, one "could make a list of purported facts about the world and tick them off as true, false or unknown" (Baggini, 2017, p. 18).

Ontologically realist, positivism contends there to be a single tangible reality (Lincoln & Guba, 1985) and a single objective truth (Gergen, 2001) determined by indisputable natural laws, structures and mechanisms that are time-independent and

context-free (Guba, 1990). Epistemologically dualist (Henwood & Pidgeon, 1993) and objectivist (Lincoln & Guba, 1985), the relationship between subject and object is separate and detached (Dupuis, 1999); the subject is “capable of studying the object without influencing it or being influenced by it” (Guba & Lincoln, 1994, p. 110). Through rigorous procedures, the subject prioritises rational thought over affective thought (Dupuis, 1999), emphasising impartiality, neutrality, and value freedom (Gergen, 2001; Lincoln & Guba, 1985; Oakley, 1998). Methodologically deductive and reductionist, it follows an experimental scientific method (Gubrium & Holstein, 1997; Lincoln & Guba, 1985). Here, hypotheses are formulated and tested (Phillimore & Goodson, 2004) through conditions of control and manipulation (Guba & Lincoln, 1994; Henwood & Pidgeon, 1993), and measured against conventional criteria of internal and external validity, reliability, and objectivity (Shenton, 2004).

Positivism’s essential metaphysical assumptions (Hammersley, 1995) have met with criticism (Phillimore & Goodson, 2004). In privileging the inquirer as knower and expert, the known is merely an object of their mechanical conjectures of stimulus and response (Guba & Lincoln, 1994; Oakley, 1998; Sandberg, 2005). Equally, in asserting quantitative method as the ideal if not essential source of rational knowledge, positivism disregards the vast and varied nature of the human experience (Kolakowski, 1993). For these reasons, I have dismissed the positivist paradigm from my search for an appropriate approach to framing this research, given that the thesis aim is to explore lived experiences of care from the subjective perspectives of carers and people with intellectual disabilities.

Influenced by the work of German philosophers Immanuel Kant and Wilhelm Dilthey, naturalist interpretivist paradigms present an antithesis to the dominant empiricist paradigms (Henwood & Pidgeon, 1993). Interpretivist paradigms demonstrate “a variety of ways of discerning and describing social reality, a virtual medley of approaches to understanding the contemporary complexity and dynamics of lived experience” (Gubrium & Holstein, 1997, p. vii). Common to all of these approaches is the phenomenological basis upon which they are founded, that is, the inseparable relationship between subject and object (Berger & Luckmann, 1966; Giorgi, 1992; Schutz, 1945). Thus, Kant’s classic texts *Critique of Pure Reason*

(1781, 1787), *Critique of Practical Reason* (1788), and *Critique of the Power of Judgment* (1790) argued the importance of the human being in the construction and conception of reality (Rawls, 1980), while Dilthey argued that *verstehen* (meaning) is fundamental to the understanding of social phenomena (Schwandt, 1998).

As an example, interpretivism is ontologically relativist (Lincoln & Guba, 1985), and adherents of interpretivism argue that there is no single objective reality (Tribe, 2007) but, rather, that multiple realities exist (Hammersley, 1995). Epistemologically subjectivist and transactional (Lincoln & Guba, 1985), adherents of interpretivism argue that humans are cultural beings who make sense of their world through their culturally-specific and historically-positioned experiences (Guba & Lincoln, 1994; Henwood & Pidgeon, 1993; Scotland, 2012). Therefore, one individual's particular construction of reality may be shared with many other individuals, or just as easily constructed in a very different way (Hammersley, 1995). In an inquiry, then, a dialogic and interactive process takes place between the researcher and the researched, leading to the co-construction of knowledge (Greene, 1990). Methodologically, various inductive, qualitative methods enable the researcher to access both tacit and propositional knowledge (Ayikoru, 2009; Denzin & Lincoln, 2003; Lincoln & Guba, 1985; C. Marshall & Rossman, 2006).

While interpretivist research endeavours to question real-life social incidences, it is characteristically descriptive (Coles, Duval, & Shaw, 2013) and highly contextualised (Greene, 1990). The inward looking and in-depth focus on the researched lends interpretation to the description of espoused values versus actual actions, and does not necessarily account for wider socio-cultural influences and constructions (Scotland, 2012). However, such constructions could be fundamental to exploring lived experiences of care at the nexus of intellectual disability and leisure travel, particularly the relational and social dimensions. For these reasons, I have dismissed the interpretivist paradigm from my search for an appropriate approach to framing this research.

The social constructionist paradigm also challenges the empirically essentialist and realist hegemony of positivism (Burr, 2003). Social constructionism "holds that all tenable statements about existence depend on a worldview, and no worldview is uniquely determined by empirical or sense data" (Patton, 2002, p. 97). By contrast,

it seeks to reveal that which is taken-for-granted in understanding (Burr, 2003). Ontologically relativist (Lincoln, 1990), social constructionism assumes and honours the pluralities and multiplicities of reality (Lincoln & Guba, 1985). Epistemologically subjective, the relationship between the researcher and the researched is democratised (Burr, 2003; Millman & Kanter, 1975), as knowledge is dynamically and interactively co-created (Caton, 2013; Gubrium & Holstein, 1997). Methodologically, the inquiry is dialectic and hermeneutic (Gergen, 2001; Lincoln, 1990). Given language is itself a social construction (Berger & Luckmann, 1966); there is interest in communication, deconstruction and discourse (Alvesson & Sköldberg, 2009; McNamee, 2004). Rather than exploring external patterns, sociocultural constructions and historical backdrops of care, the thesis aim is focused on exploring the subjective, experiential dimensions of care in each participant's lifeworld. For these reasons, I dismissed the social constructionist paradigm from my search for an appropriate approach to framing this research, suggesting a phenomenological approach would be a better fit.

4.2 A phenomenological approach

Phenomenology is an overarching term that describes philosophical doctrines and movements, research approaches and methods (Berríos, 1989; Maykut & Morehouse, 1994). Ultimately, a phenomenological perspective holds “the potential to penetrate deep to the human experience and trace the essence of a phenomenon and explicate it in its original form as experienced by the individuals” (Kafle, 2011, p. 183). Phenomenology appreciates the rich and complex diversity of subjective human experience, and prioritises a need to delve deeper into that which is ordinary or taken-for-granted (McManus Holroyd, 2007). Much phenomenological research has conformed to one of two classical approaches, those of German philosophers Edmund Husserl and Martin Heidegger, the two subscribing to the goal of either describing (transcendental phenomenology) or interpreting (hermeneutic phenomenology) lived experience of phenomena, respectively (Giorgi, 2007; Langdridge, 2007; McConnell-Henry et al., 2009).

Recognised as ‘the father of phenomenology’ (Crotty, 1996; Dreyfus, 1988; Kafle, 2011), Edmund Husserl, and his texts *Logical Investigations* (1901), followed by *Formal and Transcendental Logic* (1929) and *Cartesian Meditations*

(1931), formed original phenomenological (transcendental or descriptive) conceptualisations (Moran, 2000; Moustakas, 1994). Husserl challenged the natural sciences disregard of human consciousness as a means of accessing knowledge (Burrell & Morgan, 1979; Lopez & Willis, 2004). Knowledge is derived from lived experience (Bahdra, 1990; Lavery, 2003), and access to the *Lebenswelt* (life world) (Koch, 1995; LeVasseur, 2003), or as Husserl described, *zu den sachen selbst* (to the things themselves) (Husserl, 1972), is attended, perceived, recalled, and thought about through consciousness (Lavery, 2003). Husserlian (transcendental or descriptive) phenomenology therefore attests that “all we can ever know must present us to consciousness. Whatever falls outside of consciousness therefore falls outside the bounds of our possible lived experience” (van Manen, 1990, p. 9).

A descriptive phenomenological inquiry is directed toward unveiling the essential and intrinsic structures of consciousness and experience (Pernecky & Jamal, 2010). The study of such structures is described as the *eidae* or *eidōs* (Husserl, 1973), that is, the essential nature of phenomena (Kleiman, 2004; Sanders, 1982; van Manen, 1990). As such, the essence of any human experience is common to all (Lopez & Willis, 2004), as “what is possible for one is possible for another” (van Manen, 1990, p. 62). In seeing things as they are (Lavery, 2003), the essential structure of a phenomenon when described in its purest form (Streubert & Carpenter, 1995) holds that absolute certainty and truth are a possibility (Kafle, 2011; Solomon & Higgins, 1996). Intellectual seeing is intentional (Husserl, 1973). “Phenomenology asks starting-from-scratch style questions such as: what does it mean to be conscious? How do mind and body come about? How are things experienced?” (Tomkins & Eatough, 2013, p. 259). Sandberg (2005) explained:

Intentionality means that individual as consciousness is not closed but open and always directed toward something other than itself. ... The intentional character of consciousness has a constitutive power. It constitutes the meaning of reality, that is, the meaning of reality that appears to us in our experience. (p. 48)

This is referred to as a horizon of meaning (Husserl, 1973), understanding that the intentional conscious mind is indivisible from the experiencing person as the object (Gallagher & Zahavi, 2008; LeVasseur, 2003; McConnell-Henry et al., 2009; Schmidt, 2005). To reach this meaning of reality, however, the natural attitude characteristic of the human mode of being requires transcendence to a

phenomenological attitude reflective of a pure state of consciousness (Giorgi, 2007; Kafle, 2011; Lopez & Willis, 2004; Merleau-Ponty, 1962). To achieve this, phenomenological reduction employs techniques of bracketing or epoché to neutralise personal pre-conceptions, bias and opinion (LeVasseur, 2003; Lopez & Willis, 2004). The role of the researcher, then, is one of detachment and objectivity (Annells, 1999).

Recognised as a ‘disciple of Husserl’, Martin Heidegger posited a divergent conceptualisation of phenomenology (hermeneutic or interpretive) in his texts *History of Concept of Time* (1925) and *Being and Time* (1927), a conceptualisation which was later synthesised and developed further by a number of philosophers including Hans-Georg Gadamer, Paul Ricoeur, and Max van Manen (Kafle, 2011). Heidegger builds on Husserl’s phenomenological conceptualisations, arguing that this reality of existence and experience (Steiner, 1978) is mediated through space and time, and is culturally, historically, linguistically, and relationally situated (Sandberg, 2005). We exist and are enmeshed within a lifeworld that has shared and become, over time, pre-inherited by all (Guignon, 2012; Lavery, 2003; Lopez & Willis, 2004). We have pre-understandings, pre-judgments and pre-reflections embedded within us (van Manen, 1990, p. 43), and Heidegger premises this capacity of historicity (Pernecky & Jamal, 2010) on fore-structure; that our knowing, understanding and interpreting of something is guided by and founded upon something that has already existed (McManus Holroyd, 2007; Seale, 1999).

Ontologically existential, then, Heideggerian phenomenology constructs a truth and realness to our *Da-sein* that is our being in and of the world (Pernecky & Jamal, 2010; van Manen, 2007). *Befindlichkeit* describes facticity or the way one finds oneself, both living-in and living-with (Heidegger, 1927/2008), dwelling alongside others in the world (Conroy, 2003). Our intelligibility (Lingis, 1996), then, is “how we make sense of the world, our place in it, and how we become aware of this place” (Conroy, 2003, p. 38). A phenomenological experience has passed and been lived through before it can be reflected upon and made sense of (van Manen, 1990). Yet, meaning always exists (McConnell-Henry et al., 2009), and humans as self-interpreting beings (Conroy, 2003), are able to “intuit the meaning of being”

(McManus Holroyd, 2007, p. 3). In this way, interpretive phenomenology moves from description to interpretation (McConnell-Henry et al., 2009).

Epistemologically inter-subjective, the researcher has an integral role to play in this meaning-making of an individual's experience (McConnell-Henry et al., 2009). "Every experience is unique to that person, in that context; however, experiences might still resonate with that of another" (McConnell-Henry et al., 2009, p. 12). In contrast with Husserl's approach, Heidegger (1927/2008) argued that the researcher's consciousness cannot be separated, as they "are always and already part and co-constitutive of that world" (Ateljevic et al., 2005, p. 17). Indeed, the practice of bracketing (Koch, 1995; LeVasseur, 2003) is unnecessary, counter-productive, and a practical impossibility (Annells, 1999; Craig, 2007). As the researcher and researched come together, their familiar lifeworld meets the other's unfamiliar lifeworld, which challenges their personal historicities and taken-for-granted assumptions (McManus Holroyd, 2007). Still, the researcher comes into the inquiry with an openness oriented toward the experience of hermeneutic understanding, which is when we transform our prejudgments through interpretation, a fusion of horizons of meaning (Berg, Skott, & Danielson, 2006; LeVasseur, 2003; Moustakas, 1994). As the researched offer an implicit narrative account of their subjective lived experiences (Coffey & Atkinson, 1996; Glover, 2003; Lopez & Willis, 2004; Schwandt, 2001), the hermeneutic circle opens and evolves into a hermeneutic spiral (Heidegger, 1998; Hoy, 1993). Through such interactions, the researcher is necessarily involved in the interpretation and reinterpretation of an ontological perspective of the participants' experiences (Heidegger, 1927/2008). Hence, the aim is one of *verisimilitude*, which is an appearance of truth or realness (Heidegger, 1927/2008).

Phenomenology has grown in popularity within the social sciences and, more recently, in tourism scholarship too (Hayllar & Griffin, 2005; Li, 2000). While positivism has traditionally held prominence, tourism scholars have increasingly acknowledged the ineptness and rigidity in its reductive, objective and quantitative methods (Szarczyz, 2009). Instead, scholars have used a phenomenological approach to describe and understand the human existence and experience within tourism

phenomena. The most significant avenue of inquiry, perhaps, has been the nature and meaning of the tourist experience (Pernecky & Jamal, 2010; Szarczyz, 2009).

The earliest cited examples of phenomenological tourism research were the works of Eric Cohen and Stanley Plog during the 1970s (E. Cohen, 1979a, 1979b; Plog, 1974). E. Cohen first contributed a theoretical approach to understand tourism phenomena through tourist typologies (E. Cohen, 1979b), and later contributed a continuum of tourist experience typologies (E. Cohen, 1979a). Plog (1974) contributed a psychographic classification system of tourists that determined the extent to which their personality type was psycho- or allo-centric. Through the late 1980s and early 1990s, further publishing of phenomenological scholarship occurred (E. Cohen, Yeshayahu, & Almagor, 1992; Dann & Cohen, 1991; Mannell & Iso-Ahola, 1987), and, more recently, it has become increasingly prominent (for example Curtin, 2006; Jamal & Hill, 2002; Jennings, 2005; Lengkeek, 2001; Obenour, 2004; Pernecky, 2006; Uriely, 2005).

Despite the growth of this approach in researching the tourist experience, Pernecky and Jamal (2010) have described the body of research itself as ambiguous. Indeed, Szarczyz (2009) has asserted:

A select few who erroneously make claims about reality, aspire to a form of objectivity, engage in impractical 'abstraction', and 'generalise' from sample to population. They appropriate, in other words, the prerogatives of scientific inquiry while, officially, disowning science. The appropriation is, no doubt, unwitting. (p. 48)

Pernecky and Jamal (2010) supposed that much of this previous research has taken a descriptive rather than interpretive phenomenological approach, placing emphasis on seeking the essence of phenomena while disregarding the specifics of context and interpretation. Such an approach could serve as a valuable tool to describe and understand the meaning of situated and embodied tourist experiences, especially in "exploring how experiences may be gendered, classed, sexed, raced, aged and how these pre-givens dictate how we experience tourism" (Pernecky & Jamal, 2010, p. 1071).

As an example, an individual with intellectual disability might experience strangeness during a particular travel occurrence; the meaning of such experience

may be derived according to the individual's own socio-cultural and historical background (Platenkamp & Botterill, 2013). Yet, as the researcher, I too may meaningfully interpret the experience, according to my socio-cultural and historical background and frames of reference (Pernecky & Jamal, 2010). For, as Heidegger argues, it is not humanly possible for the researcher, as both the instrument for data collection and analysis, to produce interpretive research that is objective (Crotty, 1996; McConnell-Henry et al., 2009). Accordingly, throughout the thesis – and particularly in Chapter 1, 'Prologue' and Chapter 9, 'Epilogue' – I have sought to reflexively offer an honest exploration of my personal values and their potential influence (Primeau, 2003). In this way, an interpretive approach, as Platenkamp and Botterill (2013) explained:

Counts as a self-reflexive way to include biases, which stem from hidden background assumptions, into a contextualising effort to get at the richness of various contexts in this tension between the global and the local. Within the tradition of '*verstehen*', this tension is crucial for contextualisation. (p. 117)

In respect of the thesis aim, a descriptive approach would have focused on an essential truth of the care experience at the nexus of intellectual disability and leisure travel. It would have focused on the commonalities of the participants' experiences rather than the inherent intricacies in the subjective lived experiences of each participant, in addition to the contradictions between their experiences. Instead, this research sought to acknowledge and privilege the personal historicity that shaped the participants' individual experiences and subsequent understandings of them. For these reasons, I dismissed descriptive phenomenology from my search for appropriate approach to framing this research, suggesting instead an interpretive approach as a better fit.

The following phenomenological questions motivate this research:

1. How do carers and people with intellectual disabilities experience leisure travel, and what is the significance of this?
2. How do carers and people with intellectual disabilities experience care within this context, and how do they understand and ascribe meaning to this?

The thesis aim is to explore lived experiences of care at the nexus of intellectual disability and leisure travel, as described and understood by carers of people with

intellectual disabilities. I seek to offer my own description and interpretation of the nature of these human phenomena as but one possible construction (van Manen, 1990).

4.3 Research parameters, population and sampling

In what follows, I explain the decision-making process surrounding the refinement of the research sample, and subsequent recruitment of the participants. Twenty-four carers and people with intellectual disabilities participated in this research. I have defined these identifying descriptors – ‘carers’ and ‘people with intellectual disabilities’ – in Chapter 2, ‘Introduction’. Given the thesis aim, these descriptors necessarily determined the scope of the sampling parameters for participation, as follows.

The following criteria determined the carers’ eligibility to participate. They were to reside in New Zealand, have had a personal and/or professional relationship with an individual with an intellectual disability for a minimum of six months, and have accompanied this individual’s travel within the twelve months prior to interviewing (in February 2017). To capture the immediacy of experience, and to facilitate the ease, accuracy and thoroughness of their reflection, this one-year period was deemed appropriate (Pocock, 2011).

For the people with intellectual disabilities, the primary nature of their impairment/disability was to be intellectual, as this defined the one homogenous aspect of identity necessary for sample membership (Beail & Williams, 2014; McDonald, 2012; Milner & Mirfin-Veitch, 2012). Yet, I welcomed the heterogeneity of disability, and the unique lived experiences and worldviews that came with each individual. For this reason, I neither prescribed nor excluded certain types of intellectual disability. That is, for example, I did not actively seek out the recruitment of individuals with Fragile X syndrome, nor did I explicitly exclude the recruitment of individuals with cerebral palsy. In addition, it is important to note that many people with intellectual disabilities do not necessarily have a specific diagnosis, as was the case with a number of the individuals in this research (Coons & Watson, 2013).

Given my desire for valued contribution rather than tokenistic involvement, there were certain criteria which prospective participants were to meet. They were to identify as having a mild to moderate intellectual impairment/disability (Ottmann & Crosbie, 2013), as opposed to a severe or profound, high or complex intellectual impairment/disability (Coons & Watson, 2013). Firstly, this criterion was imposed given the qualitative nature of the interpretive phenomenological approach and its demands for rich textual narrative (Kafle, 2011). The hope was that a participant would be able to verbalise a comprehensible and reasonably detailed narrative, commanding a certain level of expressive and receptive communication abilities (Beail & Williams, 2014; Nind, 2008). Secondly, I imposed this criterion because of potential issues surrounding a participant's capacity to comprehend the notion of, and communicate, their consent (Boxall & Ralph, 2010; Cameron & Murphy, 2006). This communicative criterion: ensured that a participant could express queries and concerns; avoided acquiescence in response; minimised actions of indecency; minimised vulnerability; minimised the skills or training required by myself in order to administer augmentative and alternative communication approaches; and allowed me to more accurately interpret the data (Coons & Watson, 2013; Ottmann & Crosbie, 2013; Sullivan, Bowden, McKenzie, & Quayle, 2016). Lastly, a participant was to be an adult of eighteen years of age or older for the requirements of the University of Waikato's ethics approval.

Participants were recruited regionally from six major New Zealand hubs – Auckland, Bay of Plenty, Waikato, Wellington, Canterbury and Otago – chosen as regions with the highest rates of disability, and regions with an international airport (Statistics New Zealand, 2014). To reach the participants, this research employed purposeful and professional criterion sampling (Lincoln & Guba, 1985; Patton, 2002). There was value in this technique as it sought a range of informal and formal carers and people with [varying] intellectual disabilities, that is, participants with a diversity of perspectives and experiences (S.A. Hall, 2013). Further, it was self-selecting, meaning that participants were more likely to be committed to the research (Altinay & Paraskevas, 2008; Milner & Mirfin-Veitch, 2012; Nicholson, Colyer, & Cooper, 2013). Sampling occurred until February 1, 2017, the point at which data saturation was achieved.

I made email contact with regionally and nationally prominent umbrella disability service and support organisations (see Appendix B – Email request for participant recruitment assistance). As time went by, I made email contact with a number of other intellectual disability-specific organisations. Building relationships with these organisations as gatekeepers and intermediaries was of considerable significance in negotiating access to prospective participants (Altinay & Paraskevas, 2008). It was important to build these relationships on trust and a mutual understanding of one another's role, expectations and responsibilities (Iacono, 2006; Nicholson et al., 2013). As advised by disability scholars (for example McDonald, 2012; Nind, 2008), the organisations were asked to circulate a 'Call for participants' in both written and visual forms (see Appendix C – Written call for participants and Appendix D – Visual call for participants). The organisations disseminated this call through their established networks and/or databases, and via their desired communication channel/s (for example, in mail-outs, newsletters, magazines, websites and social media platforms).

Expressions of interest regarding participation in the research came directly to myself from the carers. I followed-up these expressions of interest by email or phone call, to: introduce myself; orally communicate what the research was about and what it would involve; answer questions and address concerns; and assess the eligibility of both the carers and the people with intellectual disabilities. All of the prospective participants met the desired criterion. Via email, they then received the 'Information sheets', 'Consent forms', 'Accommodation and supports form', and 'Demographic information sheet' (see Appendices E-J).

As required for the University of Waikato's ethics approval, I made sure that I reiterated the voluntary nature of the project, making it known once more that the communications, both current and ensuing, did not necessitate their involvement, and that they could withdraw their interest at any time. Together these information sources provided the prospective participants with sufficient information with which to make an informed decision as to their (non-)participation in the research.

Furthermore, I offered the participants the optional activity of a 'Meet and greet session', which could take place prior to the scheduling of their interview/s (see Gillovic et al., 2018). This served as an opportunity for the participants to meet with

and ‘get to know’ me face-to-face, in an informal setting of their choice (Arksey & Knight, 1999). It also allowed me to verbalise the contents of each document they had received via email, with the purpose of: making it clear that they were not compelled to participate; further assessing their eligibility against the criteria; answering questions and addressing concerns; and, to obtain their consent in person (Cameron & Murphy, 2006). Whilst not mandatory, the objective was to establish trust from the outset, and to contribute to the building up of rapport (Altinay & Paraskevas, 2008). Only three of the participants ended up taking part in these sessions. The cultivation of social closeness and establishing of quality research relationships was a lengthy process that I believe was just as effective through the extensive phone and email contact I shared with all of the participants, as has been evidenced by other disability scholars (for example Nicholson et al., 2013; Stalker, 1998).

The ‘Information sheets’ served to be a primary point of reference for the participants, in terms of acquiring information about the research and related activity (see Appendix E – Information sheet for carers and Appendix F – Information sheet for people with intellectual disabilities). These sheets detailed the: research purpose and goals; nature of data collection and participant involvement; recording of data; plans to distribute the data; participant access to a summary of the completed research; confidentiality clause; ways in which a participant could refuse to answer a particular question; participant’s right to withdraw involvement; and contact details of myself and my supervisors. The fundamental difference between the two versions of sheets was to ensure that the information was communicated in an accessible manner for the people with intellectual disabilities (Boxall & Ralph, 2010; Coons & Watson, 2013). As recommended for this sample, simple measures around accessibility, such as the incorporation of plain language and bullet points, enhanced inclusivity (Walmsley & Johnson, 2003).

Consent was achieved using the ‘Consent forms’, which requested the written or electronic consent of the participant, affirming their desire to participate (see Appendix G – Consent form for carers and Appendix H – Consent form for people with intellectual disabilities). There was a statement with a tick box, where the participant consented to the audio recording of their interview; and a statement with

a tick box, where the participant consented to the publishing of findings in academic publications and conference proceedings. Once more, the fundamental difference between the two versions of the forms was to ensure that the consent form was communicated in an accessible manner for the people with intellectual disabilities, again achieved through both written word and imagery (Milner & Mirfin-Veitch, 2012).

To facilitate a comfortable and enjoyable interview experience, I offered the participants an ‘Accommodation and supports form’, as suggested by disability scholars (for example Bigby et al., 2014; Chappell, 2000). This allowed the carers to identify any accommodations or supports required during the interview/s, either for themselves or for the people with intellectual disabilities (see Appendix I – Accommodation and supports form for participants). Lastly, the ‘Demographic information sheet’ allowed the participants to be profiled, which is illustrated in the following sections (see Appendix J – Demographic information sheet for participants).

The following sections introduce the research participants as the individual carers and people with intellectual disabilities who have described their lived experiences of care at the nexus of intellectual disability and leisure travel. In this chapter, I provide the demographic profile of the participants to offer some contextual background to the presentation of them that follows. My intention is to humanise the research by acquainting the reader with the participants, and allowing them to come to know these twenty-four individuals as I did, introducing them as the ‘real’, emotional and complex human beings that they are, in Chapter 5, ‘Context’. In this way, I prioritise their personal historicities and contextualise their leisure travel experiences, which is central to informing an understanding of Chapter 6, ‘Findings’, and Chapter 7, ‘Discussion’, that follow.

4.3.1 Presenting the demographics of the research participants

This section summarises the profiles of the total sample of participants, which comprises of the carers and the people with intellectual disabilities. It does this by capturing their demographic profile, and is illustrated in the ensuing tables and supporting descriptions (see Table 1 and Table 2). These demographic characteristics have been included in an effort to provide the reader with a sense of

who the participants were, rather than “to suggest any causal relationships or broader sociological observations” (Sedgley et al., 2017, p. 17).

The sub-sample of carers comprised of fifteen individuals who *care* in an informal or a formal capacity. This sample was mostly representative of female carers. In fact, this sample consisted of nine mothers, an aunty, a sister, a female friend and two female support workers. The sample consisted of one male, who is a support worker. In terms of the age of the carers, three were aged between 25 and 44 years, seven were aged between 45 and 54 years, three were aged between 55 and 64 years, and two were aged between 64 and 75 years. The majority of the carers were living in their own home, with three residing in Auckland, one residing in Otago, three residing in Wellington, and five residing in the Waikato. The remaining three were renting, with one residing in the Bay of Plenty and two residing in the Waikato. In terms of the employment of the carers outside of their informal caring responsibilities, eight were employed in some capacity (casual, part- or full-time), and four were unemployed. The remaining three carers provided care in a formal capacity, employed as community support workers. Often referred to as ‘staff’ by their ‘clients’ [people with intellectual disabilities], the length of their care relationships ranged between one and three years for two of them, and between three and five years for the other. The carers’ income ranges per annum at the time of interviewing varied. Four were earning less than \$20,000, six were earning between \$20,001 and \$40,000, two were earning between \$40,001 and \$60,000, two were earning between \$60,001 and \$80,000, and one was earning more than \$100,000.

The sub-sample of the people with intellectual disabilities was comprised of four males and five females. For three of the individuals, their disabilities were undiagnosed and they were considered to have general intellectual disabilities. For six of the individuals, their disabilities were diagnosed, and the nature of such disabilities were varied and sometimes multiple. They included attention-deficit-hyperactivity-disorder, brain injury, cerebral palsy, Down syndrome, epilepsy, foetal alcohol syndrome, Fragile X syndrome, polyarthritis nodosa, and visual impairment. In terms of the age of the people with intellectual disabilities, three were aged between 18 and 24 years, three were aged between 25 and 44 years, and

three were aged between 45 and 64 years. In terms of their living arrangements, four lived with their parents, and five lived in residential and supported living services, with two residing in Auckland, two residing in the Bay of Plenty, one residing in Otago, and four residing in the Waikato. In terms of employment, seven individuals were unemployed with a current income range of less than \$20,000 per annum, and two individuals were employed (in a casual capacity), earning between \$20,001 and \$40,001 per annum.

This research refers to seven additional people with intellectual disabilities, who are presented in this research as a silent sample (see Table 3). They are included because they represent the people with intellectual disabilities in the care relationships of six of the carers involved in this research, but who were unable to participate for various reasons. The degree of their intellectual disabilities was considered more severe, and the nature of their intellectual disabilities varied, including autism spectrum disorder, cerebral palsy, global developmental delay, and Prader-Willi syndrome. Their names are marked with an asterisk (*) throughout the thesis.

In terms of the total sample of participants – that is, the carers and the people with intellectual disabilities – and their experiences of leisure travel, five had travelled domestically, five had travelled internationally, and fourteen had travelled both domestically and internationally.

To ensure the research findings remain person-centred, each participant is fully introduced in Chapter 5, ‘Context’, along with their expressions of the significance and meaningfulness of travel in their lives.

Table 1 – Summary of the sub-sample of carers

Pseudonym	Type of carer	Gender	Age	Lives	Housing arrangement	Occupation	Income range	Traveller with intellectual disability	Length known	Travel
Alyssa	Mother	Female	45 – 54 years	Waikato	Own house	Unemployed	Less than \$20,000	Sadie	N/A	Domestic and International
Aroha	Support worker	Female	45 – 54 years	Waikato	Renting	Employed	\$20,001 – \$40,000	Maggie	Three to five years	Domestic
Ashleigh	Mother	Female	45 – 54 years	Auckland	Own house	Employed	More than \$100,000	Brooklyn	N/A	Domestic and international
Ava	Mother	Female	64 – 75 years	Auckland	Own house	Employed	\$20,001 – \$40,000	Francesca*	N/A	Domestic and international
Cassie	Mother	Female	45 – 54 years	Otago	Own house	Employed	Less than \$20,000	Mason	N/A	Domestic and international
Gemma	Friend	Female	25 – 44 years	Auckland	Own house	Unemployed	\$20,001 – \$40,000	Chloe	Less than one year	International
Georgia	Mother	Female	45 – 54 years	Wellington	Own house	Employed	Less than \$20,000	William*	N/A	Domestic and international
Harriet	Mother	Female	64 – 75 years	Wellington	Own house	Unemployed	\$60,001 – \$80,000	Ethan*	N/A	Domestic
Jade	Sister	Female	45 – 54 years	Waikato	Own house	Employed	\$40,001 – \$60,000	Liam	N/A	Domestic and international

Pseudonym	Type of carer	Gender	Age	Lives	Housing arrangement	Occupation	Income range	Traveller with intellectual disability	Length known	Travel
Lily	Mother	Female	55 – 64 years	Wellington	Own house	Employed	Less than \$20,000	Noah*	N/A	Domestic and international
Mia	Mother (adopted)	Female	45 – 54 years	Waikato	Own house	Employed	\$60,001 – \$80,000	Anastasia	More than five years	Domestic and international
Nathan	Support worker	Male	25 – 44 years	Tauranga	Renting	Employed	\$20,001 – \$40,000	Jacob and Oliver	Three to five years	Domestic and international
Phoebe	Support worker	Female	25 – 44 years	Waikato	Renting	Employed	\$20,001 – \$40,000	Gracie*	Less than one year	Domestic
Shelby	Mother	Female	55 – 64 years	Waikato	Own house	Employed	\$40,001 – \$60,000	Emma and James*	N/A	Domestic and international
Sophia	Aunty	Female	55 – 64 years	Waikato	Own house	Unemployed	\$20,000 – \$40,000	Emma and James*	N/A	Domestic and international

*This individual with intellectual disability did not participate in the research, although is presented in the thesis in reference to their carer.

Table 2 – Summary of the sub-sample of people with intellectual disabilities

Pseudonym	Gender	Age	Lives	Housing arrangement	Occupation	Income range	Carer/support worker	Length known	Travel
Brooklyn	Female	18-24 years	Auckland	Living with parents	Employed	Less than \$20,000	Ashleigh	N/A	Domestic and international
Chloe	Female	25 – 44 years	Auckland	Living with parents	Employed	Less than \$20,000	Gemma	Less than one year	International
Jacob	Male	45 – 65 years	Bay of Plenty	Residential/supported living service	Unemployed	Less than \$20,000	Nathan	One to three years	Domestic
Anastasia	Female	18 – 24 years	Waikato	Living with parents	Unemployed	Less than \$20,000	Mia	N/A	Domestic and international
Liam	Male	45 – 64 years	Waikato	Residential/supported living service	Unemployed	\$20,001 – \$40,000	Jade	N/A	Domestic and international
Maggie	Female	25 – 44 years	Waikato	Residential/supported living service	Unemployed	Less than \$20,000	Aroha	Three to five years	Domestic
Mason	Male	18 – 24 years	Otago	Living with parents	Unemployed	Less than \$20,000	Cassie	N/A	Domestic and international
Oliver	Male	45 – 65 years	Bay of Plenty	Residential/supported living service	Employed	\$20,001 – \$40,000	Nathan	One to three years	International
Sadie	Female	25 – 44 years	Waikato	Residential/supported living service	Unemployed	Less than \$20,000	Alyssa	N/A	Domestic and International

Table 3 – Summary of the silent sample of people with intellectual disabilities

Pseudonym	Gender	Age	Lives	Housing arrangement	Occupation	Income range	Carer/support worker	Length known	Travel
Emma*	Female	25 – 44 years	Waikato	Living with parents	Unemployed	Less than \$20,000	Shelby and Sophia	N/A	Domestic and international
Ethan*	Male	25 – 44 years	Hawkes Bay	Residential/supported living service	Unemployed	Less than \$20,000	Harriet	N/A	Domestic
Francesca*	Female	25 – 44 years	Auckland	Living with parents	Unemployed	Less than \$20,000	Ava	N/A	Domestic and international
Gracie*	Female	25 – 44 years	Waikato	Residential/supported living service	Unemployed	Less than \$20,000	Phoebe	One to three years	Domestic
James*	Male	25 – 44 years	Waikato	Residential/supported living service	Unemployed	Less than \$20,000	Shelby and Sophia	N/A	Domestic and international
Noah*	Male	25 – 44 years	Wellington	Residential/supported living service	Unemployed	Less than \$20,000	Lily	N/A	Domestic and international
William*	Male	18 – 24 years	Wellington	Living with parents	Unemployed	Less than \$20,000	Georgia	N/A	Domestic and international

*This individual with intellectual disability did not participate in the research, although is presented in the thesis in reference to their carer.

4.4 Data collection

The research largely manifested itself as an inductive and exploratory qualitative inquiry. In order to explore lived experiences of care at the nexus of intellectual disability and leisure travel, as described and understood by carers and people with intellectual disabilities, qualitative interviewing was employed. This is considered to be an appropriate data collection method with which to explore lived experiences in interpretive phenomenological research (Kafle, 2011; Tong, Sainsbury, & Craig, 2007), one that illuminates a richness and depth of meaning, rather than breadth of information (Berry, 1999; Clear, 1999; Rubin & Rubin, 2005; Westwood, 2007). This method involved two components: (1) in-depth, semi-structured interviewing, individually with the carers; and, (2) person-centred, semi-structured interviewing with the people with intellectual disabilities.

Qualitative interviewing “begins with the assumption that the perspective of others is meaningful, knowable, and able to be made explicit” (Patton, 2002, p. 341). Through a dynamic and iterative process, narrative, experiential and theoretical knowledge are negotiated (Pernecky & Jamal, 2010; van Manen, 1990), leading to the experience of dialogic moments in which researcher and participant acquire a plurality of knowing (Clark, Holland, & Ward, 2012). Fundamental to the researcher and the participants within this process is their relationality as an ethical caring relation, and their orientation toward dialogic listening as an ethical act (Helin, 2013; Koskinen & Lindstrom, 2013; Lipari, 2010; Shotter, 1980). Listening is an active responsiveness (Bakhtin, 1986) to the words expressed by “‘one’ in relation to the ‘other’” (Voloshinov, 1986, p. 86), which creates a ‘we-ness’ in the intersubjective stance (Cunliffe, 2011). “Listening is thus a dwelling place from where we offer our ethical response, our hospitality, to the other and the world” (Lipari, 2010, p. 350), with the intent of them experiencing the genuine “feeling of being heard” (Shotter, 2009, p. 21).

For the sub-sample of carers, in-depth, semi-structured interviews were decided upon (Morse & Richards, 2002). A semi-structured interview guide was loosely prepared to allow for some structural guidance, and represented the basis of the interviewing with the carers (Patton, 2002) (see Appendix K – Interview guide for carers). In keeping the interviews relatively semi-structured, and using open-ended

questions wherever possible, I could prioritise and unveil the participants' subjective and situated lived experiences (O'Connor, 2007), and embrace any opportunity to be flexible in developing emerging ideas (Berry, 1999; Coles et al., 2013; Glover, 2003; Wengraf, 2001). In order to meet the aim of the thesis and to address the research questions, I developed the interview guide following a review of previous care, disability and tourism scholarship (Whitmore et al., 2015). It covered questions relating to the following broader categories of: introductory remarks; dynamics of care relationship; experience of giving care; experience of leisure travel; emotion; and, concluding remarks. To explore and illuminate the heart of the thesis topic (Kvale, 1996), I sought detailed descriptions of what their lived experiences of care were like and what they meant to them (Whitmore et al., 2015), followed by their understanding and interpretation of such experiences (Berg et al., 2006; Crotty, 1996; Johnson, 2002; Laverty, 2003; Nagel, 1974).

I was alert to the possibility of disruption or surprise, aware always that the tone and trajectory of the interview(s) could often differ from what had been planned or expected (Johnson, 2002; Rubin & Rubin, 2005). Where appropriate, probes, prompts and follow-up questions were offered for further understanding (Berry, 1999; Bryman, 2012; Rubin & Rubin, 2005). These usually manifested as detail-oriented questions, asking 'who', 'what', 'when', 'where', and 'how' (Patton, 2002), rather than 'why' questions. They also manifested as clarifying questions, asking 'could you elaborate on...' or 'could you provide an example of...' (Berg et al., 2006). Leading questions assisted in member-checking, and were an important medium in which to both clarify my own interpretations of the participants' experiences, and to confirm the reliability of their answers (Dupuis, 1999).

People with intellectual disabilities do not represent a homogenous group, rather a heterogeneous group that is individualistic and idiosyncratic, complex and diverse (T. Gilbert, 2004; S.A. Hall, 2013; Nind, 2008; Walmsley & Johnson, 2003). For the sub-sample of people with intellectual disabilities, semi-structured interviews were decided upon as a proven method for engaging in research with this population (Ottmann & Crosbie, 2013). In favouring a person-centred, strengths- and abilities-based approach (see Gillovic et al., 2018), I adapted both content and process to ensure the participants remained visibly present at the centre of the research, as

suggested by a number of disability scholars (for example Bigby et al., 2014; Hillier, Johnson, & Traustadottir, 2007; McDonald, 2012; Milner & Mirfin-Veitch, 2012).

Disability scholars have discerned that it is not always easy for people with intellectual disabilities to communicate conventionally, due to poor language and conceptual skills, and as evidenced in their expressive and receptive communication abilities (Beail & Williams, 2014; S.A. Hall, 2013; Milner & Mirfin-Veitch, 2012). Perhaps “the label ‘intellectual disability’ is most usefully understood as an umbrella term, which brings together individuals with a diverse range of communication preferences” (Hollomotz, 2018, p. 157). This was true of the sample of this current research and, as such, based on an extensive review of previous research, I considered the way in which communication occurred, the nature of the interview, and the types of questions posed (Coons & Watson, 2013). I prepared a general semi-structured interview guide, which outlined the key themes to cover (see Appendix L – Interview guide for people with intellectual disabilities). In order to meet the aim of the thesis and to address the research questions, the guide covered questions relating to the broader categories of: introductory remarks; dynamics of care relationship; experience of care; experience of leisure travel; emotion; and, concluding remarks. This again was informed by previous studies and theory. Each individual’s guide was then personalised, to concede their autonomy in expressing themselves freely (McDonald, 2012).

Where appropriate and/or necessary, there were a range of general communication measures and creative techniques that I drew upon, as suggested by a number of disability scholars (for example Boxall & Ralph, 2011; Hillier et al., 2007; Nind, 2008; Ottmann & Crosbie, 2013; Schleien, Brake, Miller, & Watson, 2013; Stalker, 1998; Westwood, 2007). In following these suggestions, I asked structured, concrete questions to provide clarity, as well as open- rather than close-ended ‘yes’ or ‘no’ questions to avoid acquiescence and encourage free recall. Similarly, I placed emphasis on the wording of questions, using clear, uncomplicated language free from jargon, and minimised the use of abstract concepts and temporal dimensions. I orally spoke out the questions, and for a couple of participants, I also had them written down in plain language, accompanied by images. Visual prompts, such as photographs or personal belongings provided by

several of the participants, also facilitated conversation; however, I did not photograph and include these in the thesis in order to maintain the guarantee of their anonymity. Above all, I endeavoured to offer an open and encouraging communication space (Milner & Mirfin-Veitch, 2012, p. 106) and, most importantly, I had “faith in their ability to give the most accurate and meaningful account of their own subjectivity” (Hollomotz, 2018, p. 168).

In seeking to offer safety and security, convenience and flexibility – wherever feasible and practicable – all interviews took place at a date, time and physical location of the participant’s choice (S.A. Hall, 2013; Hillier et al., 2007). Ideally, the venue was somewhere familiar to the participants and/or easily accessible by public transportation. The majority of the interviews took place at the participant’s home, with the exception of a few that took place in public libraries. In an attempt to foster genuine inclusion and facilitate full participation throughout the data collection phase, I made various accommodations, as outlined in the ‘Accommodations and support form’. Further, I provided refreshments at all interviews, considering the participant’s disclosure of any dietary requirements specified (McDonald, 2012; Nicholson et al., 2013). At the conclusion of the interviews, I reimbursed participants for their travel with petrol or public transport vouchers. I made sure to impart affirmation that the participants had done well, thanking them expressively for their time and effort (Lincoln & Guba, 1985; Patton, 2002). When the participant’s involvement in the research ceased, I sent by post, a handwritten ‘thank you’ card as an expression of my gratitude for their contribution. I treated all participants and their data with the utmost respect, dignity and confidentiality throughout the entirety of the research process, in an environment conducive to equality, reciprocity, transparency, trust and understanding (Oliver, 1992; Ren et al., 2010; Savin-Baden & Wimpenny, 2007).

4.5 Data analysis

Data analysis “entails classifying, comparing, weighing, and combining material ... to extract the meaning and implications, to reveal patterns, or to stitch together descriptions of events into a coherent narrative” (Rubin & Rubin, 2005, p. 201). It is an inductive process (Locke et al., 1993), involving the construction and reconstruction of parts of interaction, into meaningful wholes of interpretation

(Lincoln & Guba, 1985). “The themes, patterns, understandings and insights that emerge from fieldwork and subsequent analysis are the fruit of qualitative inquiry” (Patton, 2002, p. 5). The ensuing section outlines the process of thematic analysis, which was deemed to be the most appropriate method in considering the thesis aim.

Thematic analysis is a widely employed method of qualitative data analysis, particularly when exploring the data produced by way of qualitative interviewing (Joffe, 2011). Thematic analysis offers “a way of making sense out of seemingly unrelated material, a way of analysing qualitative information, a way of systematically observing a person, an interaction, a group, a situation, an organisation, or a culture” (Boyatzis, 1998, p. 4). The exposition of both implicit and explicit ideas leads to the elucidation of patterns of cohesive meaning within a set of data, emerging inductively, and recognisable at direct and observable, or indirect and underlying levels (Braun & Clarke, 2006; Patton, 2002; Wengraf, 2001).

In alignment with the thesis aim and the interpretive phenomenological approach that framed this research, the method of analysis was contextualist. A contextualist method allowed me to recognise the ways in which the participants ascribed meaning to their subjective lived experiences, while also considering how the historicity of the broader socio-cultural and historical context could impinge upon the meanings described (Braun & Clarke, 2006). An interpretive phenomenological approach requires an interpretation of the construction of meaning and, therefore, this thematic approach not only describes the semantic data but also offers a deeper, more comprehensive engagement with the data at a latent level (Braun & Clarke, 2006; Joffe, 2011). The data was recursively analysed in a systematic and transparent manner (Joffe, 2011). The analysis was data-driven rather than derived from my own theoretical perspectives, seeking to affirm subjective lived experience by way of deriving rich detail of personal meaning (Denzin & Lincoln, 2003). It was reflective in that I had to consider my positioning within the interpretation, for instance, thinking about ‘what was important to the participants?’, and ‘how that importance was understood?’ (Laverly, 2003).

To carry out the practicalities of the thematic analysis, I followed Braun and Clarke’s (2006) ‘Phases of Thematic Analysis’, namely ‘Phase one: Familiarising

yourself with the data'; 'Phase two: Generating initial codes'; 'Phase three: Searching for themes'; 'Phase four: Reviewing themes'; 'Phase five: Defining and naming themes'; and, 'Phase six: Producing the report'. Whilst the description of the following phases is presented in a somewhat linear and step-by-step manner, the analysis process was in fact inductively data-driven, iterative and recursive, with many aspects of the data collection and data analysis undertaken concurrently (Boyatzis, 1998; Braun & Clarke, 2006). It is important to note that the data analysis in its entirety was carried out manually and by myself because, as Patton (2002) has explained:

The analysis of qualitative data involves creativity, intellectual discipline, analytical rigor, and a great deal of hard work. Computer programs can facilitate the work of analysis, but they can't provide the creativity and intelligence that make each qualitative analysis unique. (p. 442)

Phase one: Familiarising yourself with the data

To ensure thoroughness and accuracy of analysis, all of the interviews were audio-recorded with the permission of the participants. At the conclusion of each interview, I recorded by hand, in the ledger of the participant's interview guide, any initial thoughts I had, forming field notes which could later be referred back to, as they were kept in a clear file folder until the completion of the data collection phase. At the completion of the data collection phase, I then sought to transform the data from verbal to written form, manually transcribing the audio-recorded interviews into readable typed transcripts (Bryman, 2012; Guest, MacQueen, & Namey, 2012; Legard, Keegan, & Ward, 2003; Nierse & Abma, 2011). I checked each transcript against its initial audio recording, to meet a high standard of detail and ensure accuracy of representation.

I began the analysis by reading all of the transcripts multiple times, from beginning to end as a whole, before exploring the constitution of their parts (Berg et al., 2006; Kleiman, 2004). This enabled me to develop an initial sense of the background context of each participant, and to generate emergent insights (Patton, 2002), as I attained a naïve understanding of the expressed meaning (Lindseth & Norberg, 2004). While carrying out this immersive process of reading and re-reading, typing and checking back against the recordings, I began to scribble down

a number of ideas in a notebook, which formed the basis of initial words I utilised for coding in the succeeding phase (see Figure 1). These words largely conformed to the three standards set out by Owen (1984), namely recurrence, repetition and forcefulness.

Recurrence refers to an idea that appeared at least twice within one interview and across several interviews; repetition refers to the repeating “of key words, phrases or sentences”; and, forcefulness refers to “vocal inflection, volume or dramatic pauses” (p. 275). This was particularly evident in the interviews with the sub-sample of the people with intellectual disabilities. There was a high presence of verbal and non-verbal cues, for instance, animated facial expressions or gestures, or upward vocal inflection when an individual was describing their experiences in a positive manner. Each transcript was printed twice, the first intact and unmarked copy stored in a clear file folder, and the second copy available to be marked with pen and highlighter, ready for coding and analysis (Maykut & Morehouse, 1994). Having two copies of each interview transcript offered ease in working as well as the ability to cross correlate in comparing parts to the whole.

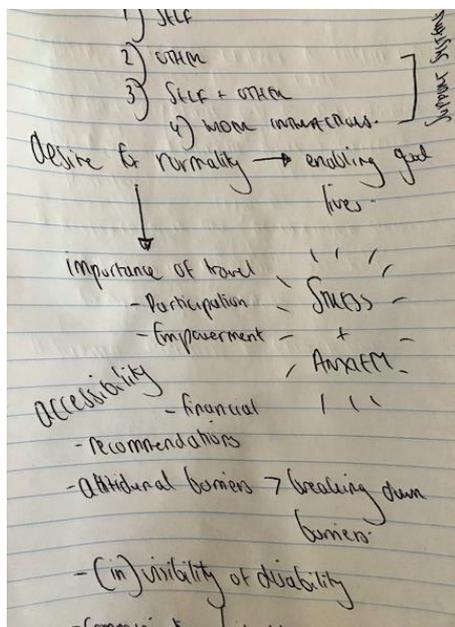


Figure 1 – Example of field notes

Phase two: Generating initial codes

Given that there were twenty-four participants involved in this research, each with interviews lasting anywhere between fifteen minutes and two hours, the typed data was sizeable, comprising around 145,000 words. Again, in an attempt to re-familiarise myself with each participant and their individual nuances of expression, I simultaneously listened to the audio recording of their interview, and read their interview transcript. I gathered a sense of their narrative as a whole, and then as parts of that whole. As I read the transcripts, I asked myself, in regard to my participants, ‘what were they trying to tell me?’ and ‘what was important to them and why?’ (Laverty, 2003). Adhering to the frame of this research and in an effort to collapse the data into a more manageable working corpus, I then sought to systematically work through each typed transcript, pulling from them, data extracts, which were labelled as ‘units of meaning’ (Berg et al., 2006; Kleiman, 2004). I sought to find not only patterns of commonality but also the “vagaries, uncertainties, and ambiguities” of the data in all its uniqueness (Patton, 2002, p. 437).

Patterns of meaning laid the foundation upon which I could generate the units of meaning, and contributed to the eventual confirmation of the ‘overarching themes’ and ‘key themes’. Units of meaning could comprise anything from a single word or a sentence, to an entire paragraph of narrative. Importantly, these data extracts constituted manifest content (that which was explicitly referred to within the data) as well as latent content (that which was implicitly referred to within the data) (Boyatzis, 1998). The latter, of course, helped “to identify or examine the underlying ideas, assumptions, and conceptualisations and ideologies ... theorised as shaping or informing the semantic content of the data” (Braun & Clarke, 2006, p. 84).

I recorded the units of meaning in an Excel spreadsheet, incorporating the sub-sample of the carers and the sub-sample of the people with intellectual disabilities (see Table 4). Simply, there were three columns: ‘participant name’, ‘unit of meaning’ and ‘key idea/s coded for’. The inclusion of the participant name column allowed for quick referencing back to the clean and intact interview transcript. This was deemed necessary if any additional clarification needed to be derived, or if the contextual entirety was to be provided (Maykut & Morehouse, 1994). As mentioned,

the unit of meaning included the extract of data and, not surprisingly, given the sheer volume of the data, there were 655 units of meaning for the carers and 190 units of meaning for the people with intellectual disabilities. Lastly, the 'key idea/s coded for' column included the associated code/s for each unit of meaning.

I did not disregard or impose limitations around what or how many codes were included for each unit of meaning (Braun & Clarke, 2006). Rather, the inclusion of all potential 'key idea/s coded for' meant I could more readily see the occurrence of codes, note patterns within codes, and allow for comparisons to be made against each code (Maykut & Morehouse, 1994). Initially, there were 43 'key idea/s coded for' in reference to the coding frame (see Table 5). As evidenced, only a handful of these codes featured distinctively and exclusively in either of the participant samples. The final themes presented in Chapter 6, 'Findings' and Chapter 7, 'Discussion', were the product of this iterative and inductive process of amalgamating the units of meaning that were coded for.

Table 4 – Example of ‘units of meaning’ and ‘key idea/s coded for’

Pseudonym [carers and support workers]	Unit of meaning	Key idea/s coded for
Shelby	<i>I have always been very active in finding out what’s available, and if it isn’t available, making it happen anyway. Also, about sharing it with other people. Giving people hope that things can be achieved. I’ve done a lot of presentations at conferences, and taken Emma* and James* to them. Because it’s easy for people to stand up and say their kids have done this, that, and the other, but when you can’t visualise the person... So, Emma and James have gone to things. Yeah, it’s about sharing what I’ve learnt, about making it a positive journey, and just having a good life.</i>	<ol style="list-style-type: none"> 1. Advocacy. 2. Enabling good lives.
Sophia	<i>I think a lot of them don’t realise she has a disability. Some people are obviously disabled, like Down Syndrome and those sort of people, and James* with his Cerebral Palsy. Generally, I will wait until most people have got off the aircraft before we get off. If you’ve got somebody sitting by the window and we’re in the aisle bits, they want to get out. Of course, if people start talking to Emma, she doesn’t know what they’re saying to her, so there’s a bit of that.</i>	<ol style="list-style-type: none"> 1. Breaking down barriers. 2. Attitudes of others.
Jade	<i>And there was a lot of support by the people in the resort. Lots of international people but there were two New Zealanders actually there... She was an American actually, living in New Zealand. They be-friended us. They were probably a similar age, maybe a bit older, and they be-friended us. They’d hired a car and came around and said, “would you like to... I am going in to find some black pearls [it was], do you want to come for a ride and look in the town or whatever?” And she was quite aware of his needs, and in fact, we’ve exchanged emails and addresses, but because we’ve been away... We’ll be able to visit, and she indicated to me... So this is really good, that we can have a link. Because that’s the other thing for Liam, because he’s got a very narrow span of friends. This to me is a plus out of the trip, in the fact that we will be able to go and visit these people, they live in Waihi actually.</i>	<ol style="list-style-type: none"> 1. Support systems. 2. Connection.

Table 5 – Example of ‘coding frame’

‘Key idea/s coded for’	Carers and support workers	People with intellectual disabilities
Accessibility	✓	✓
Activities	✓	✓
Advocacy	✓	✓
Attitudes	✓	✓
Breaking down barriers	✓	✓
Burden of care	✓	✓
Care as work	✓	✓
Communication	✓	✓
Comprehension	✓	✓
Connection	✓	✓
Coping strategies	✓	✓
Cost as a barrier	✓	✓
Critical incidences	✓	✓
Disability-disclosure	✓	✓
Disability-specific	✓	X
Disney	✓	✓
Decision-making process	✓	✓
Definition of care and support	✓	✓
Dependency	✓	✓
Desire for normality	✓	✓
Emotional intelligence	✓	✓
Empowerment	✓	✓
Enabling good lives	✓	✓
Familiarity	✓	✓
Food	✓	✓
Guilt	✓	X
Identity	✓	✓
Importance of travel	✓	✓
(In)visibility of disability	✓	✓
Love	✓	✓
Occupancy	✓	✓
Planning	✓	✓
Recommendations	✓	X
Relational	✓	✓
Resistance	✓	X
Respite	✓	X
Routine	✓	✓
Sacrifice	✓	✓
Space	✓	✓
Stress and anxiety	✓	✓
Support systems	✓	✓
Toileting	✓	X

Phase three: Searching for themes

In this phase, I condensed, refined, and transferred the units of meaning and their associated 'key idea/s coded for' to a more manageable format. This written Word document was again substantial in size, comprising over 60,000 words (see Figure 2). In carrying out this process, I could now sort the numerous codes cited in the previous phase into tentative overarching and key themes, by way of including each theme and its respective units of meaning as excerpts of textual data from the interview transcripts. These overarching and key themes arose through my ruminations around what I interpreted as being perceived by the participants as important, and their understandings of why these overarching and key themes were important. From here, I coded for this process, which aligned with four tentative overarching themes, and their respective key themes and key ideas coded for (see Table 6).

Figure 2 – Example of Word document containing ‘tentative overarching themes’, ‘units of meaning’, and ‘key idea/s coded for’

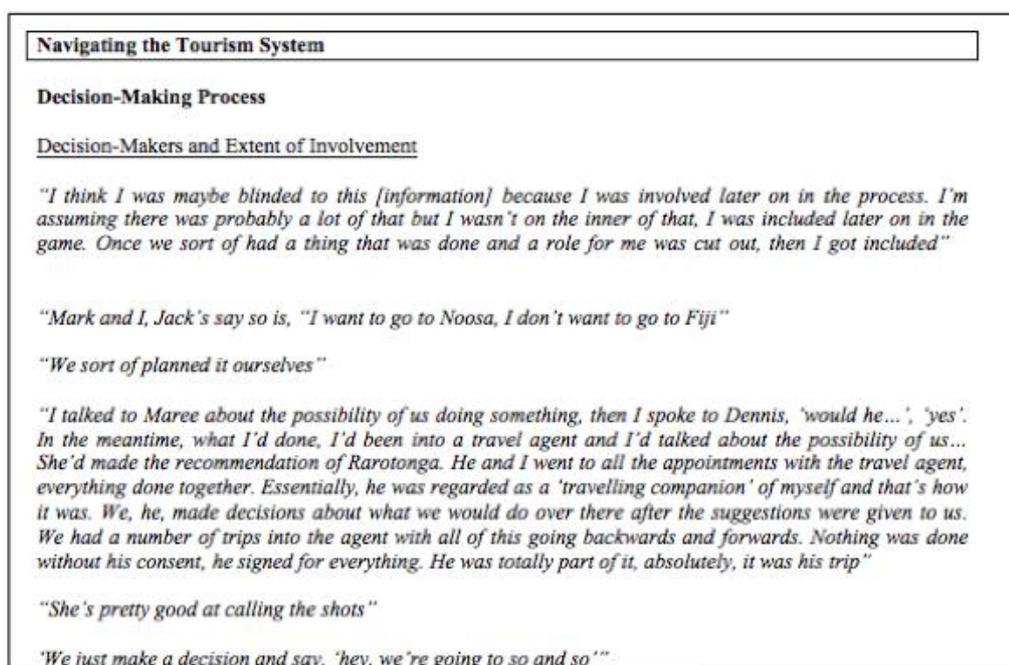


Table 6 – Example of coding for ‘tentative overarching themes’, ‘key themes’ and ‘key idea/s coded for’

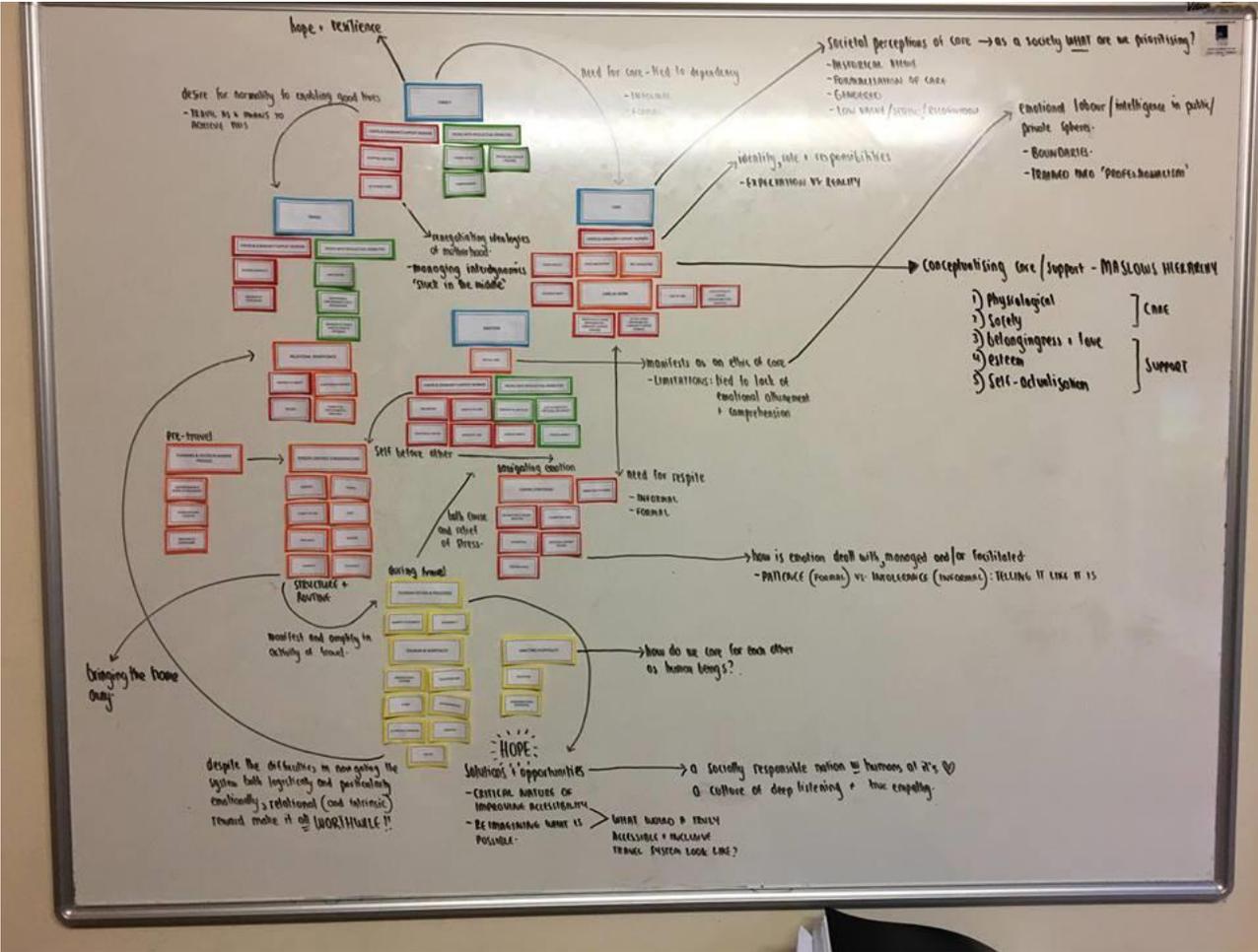
Tentative overarching theme	Key themes	Key ideas coded for
Contextualising the leisure travel phenomenon.	Planning.	Ease.
		Familiarity.
		Flexibility.
	Decision-making process.	Logistics.
		Decision-makers and extent of involvement.
		Assistance of online and alternative information sources, residential and supported living services, and travel agents.
	Person-centred considerations.	Creating occupancy.
		Structure and routine.
		Personal care.
	Communicating decisions.	Communicating decisions.
		Resistance and compromise.

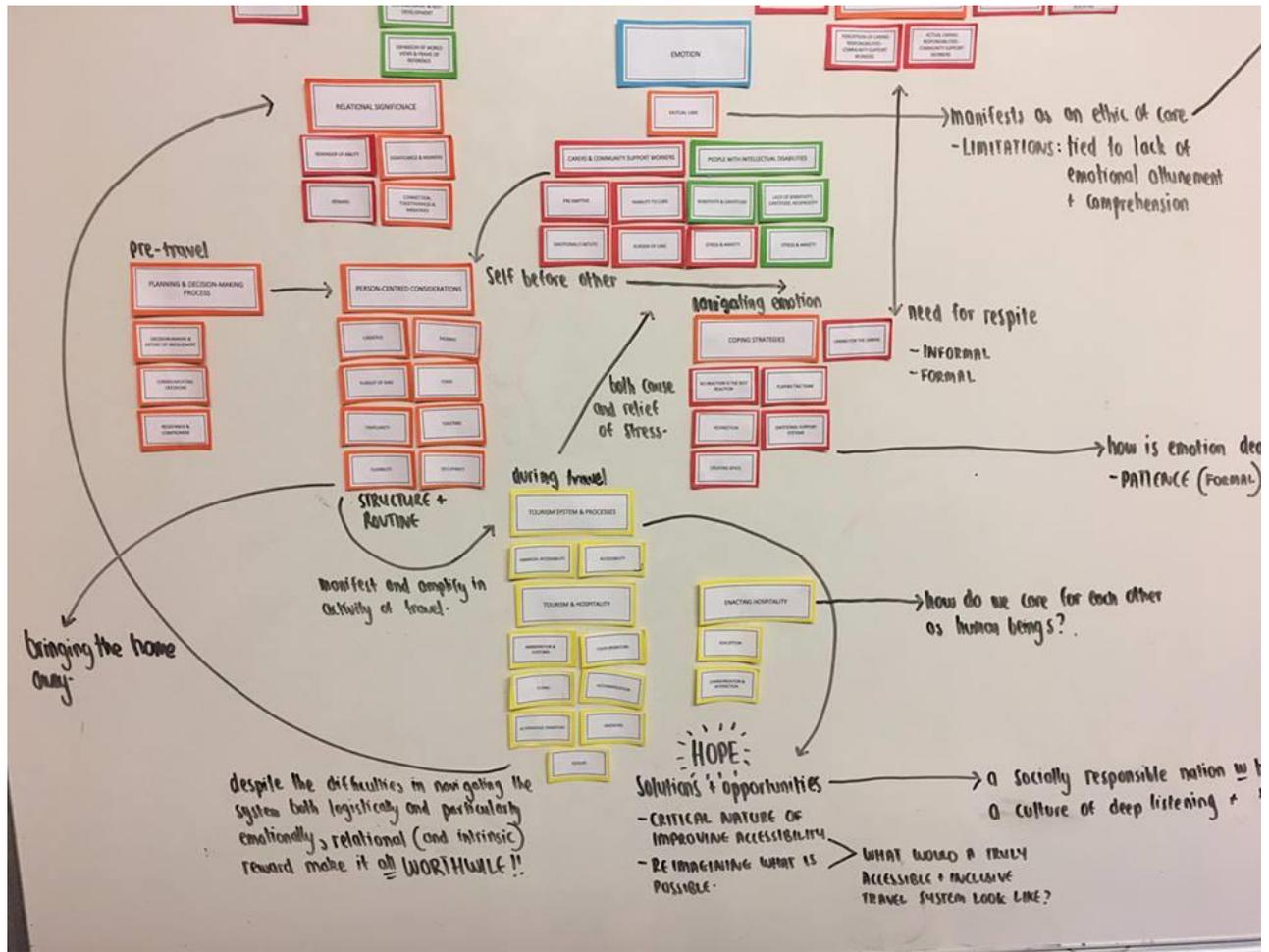
Phase four: Reviewing themes

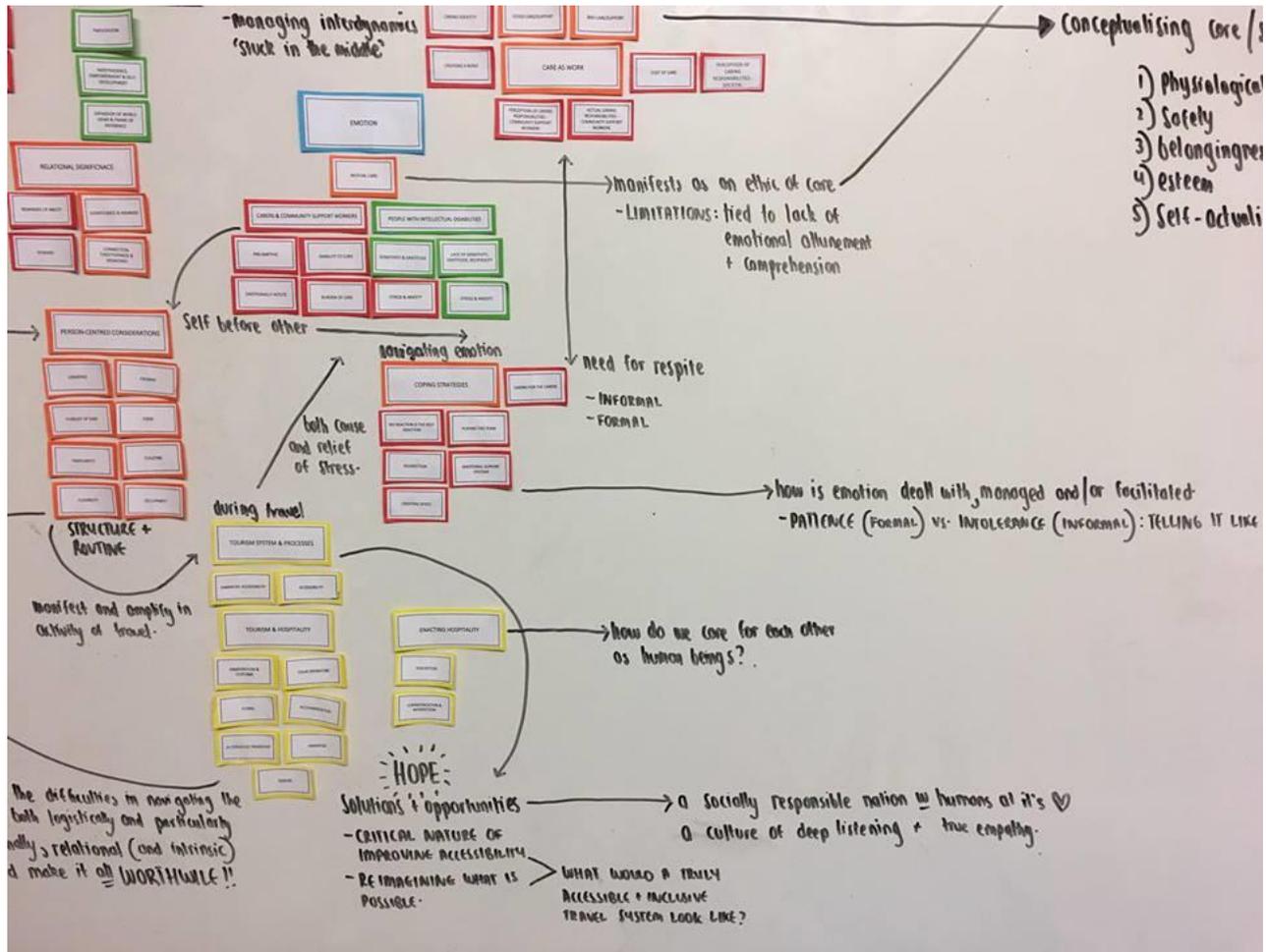
Utilising the outputs of the above phases, I was then able to create a ‘thematic map’ (Braun & Clarke, 2006). The thematic map enabled me to visually communicate the fundamental ideas that were emerging, and the inter-relationships between the broader tentative and emergent overarching themes of ‘care’, ‘emotion’, ‘family’ and ‘travel’. I typed, printed, and then subsequently colour-coded each overarching and key theme. The overarching themes were blue. The key themes and key ideas coded for were divided into theme piles. These theme piles were also categorised by colour, firstly in terms of who it affected, namely the ‘carers’ (red), the ‘people with intellectual disabilities’ (green) or the ‘care relationship’ (orange), and then, secondly, in terms of the context itself, which was the ‘leisure travel phenomenon’ (yellow). This broad categorisation of the codes allowed for further refinement of what I had previously contended were the overarching themes, key themes, and key ideas coded for. Here, it became more obvious that these provisional themes were indicative of emerging patterns, illustrative of the rich data set in its entirety.

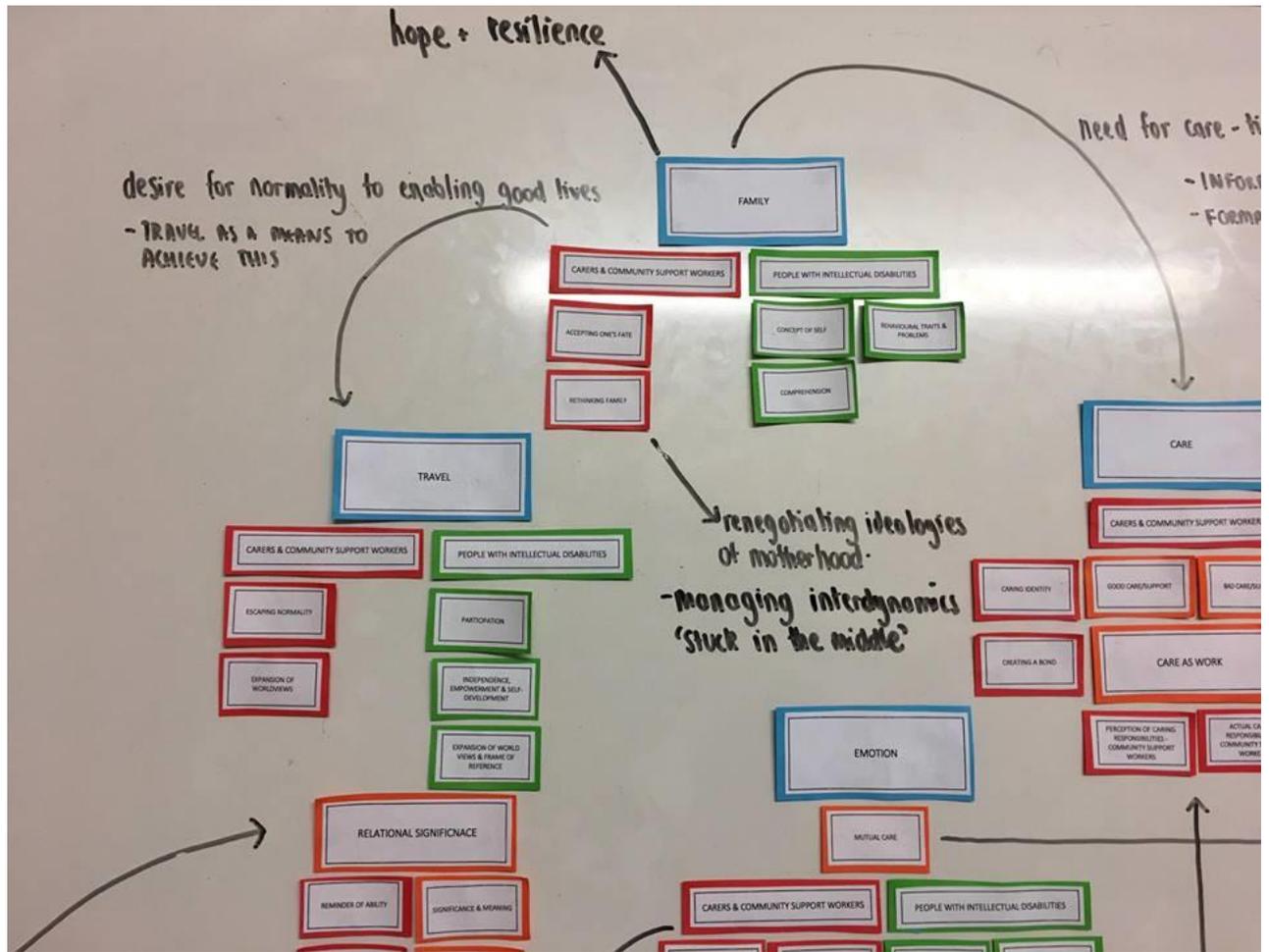
Using a large tabletop, I began to place each theme accordingly. As I sought to add each piece of paper, I consulted against what was already existing, and included it if it was entirely new, amalgamated or inextricably linked it in some way if it was similar, or discarded it entirely if it was no longer deemed relevant. Once I confirmed each theme’s placement and positioning, they were then attached to a whiteboard to create the visual thematic map. This method still allowed for any further movement with ease, although there was very little. It also allowed for the writing, with a whiteboard marker, of any inherent links between each idea and the inclusion of my written thoughts beside them (see Figure 3). Here, I felt as though I had a sound understanding of what my themes were, their interrelatedness to one another, and the data as a whole (Braun & Clarke, 2006).

Figure 3 – Example visuals of ‘thematic map’









Phase five: Defining and naming themes

From the visual thematic map of the data corpus, the themes were further refined and named, before being written up as Chapter 6, 'Findings', and Chapter 7, 'Discussion'. The overarching themes, key themes, and key ideas coded for were confirmed, and illustrated, for the most part, what the subsequent chapters would capture and unveil (see Table 7). Certainly, these themes were not mutually exclusive; rather, they overlapped and linked to the thesis aim. The inclusion of both key themes and key ideas coded for was especially "useful for giving structure to a particularly large and complex [overarching] theme, and also for demonstrating the hierarchy of meaning within the data" (Braun & Clarke, 2006, p. 92). These confirmed themes offered a rich thematic description of the data set in its entirety, illustrating the originality of this under-researched topic of inquiry.

Table 7 – Confirmed ‘overarching themes’, ‘key themes’, and ‘key ideas coded for’

Overarching themes	Key themes	Key ideas coded for
Contextualising care and support.	Defining the notion of <i>giving</i> care and support.	Definitions of ‘caring about’, ‘caring for’ or ‘supporting’ people with intellectual disabilities. The <i>givers</i> of care and support – formal and informal. The historical socio-cultural context of care and support.
	Historicity of mothering disability.	From guilt to unconditional love. Managing the nuances of family dynamics. Affording agency in manifesting a ‘good life’.
Contextualising leisure travel.	Defining the leisure travel phenomenon.	Definitions of ‘leisure travel’ as a context, and as an experience.
	Contextual factors determining participation in leisure travel.	The dependency of the people with intellectual disabilities on the carers to travel. Availability of finance and the financial (in)accessibility of the industry.
The experience of leisure travel.	Significance of leisure travel to the people with intellectual disabilities.	To be able to participate. To foster independence, empowerment, and self-development. To expand upon one’s worldviews and develop new frames of reference.
		Significance of leisure travel to the carers
	The importance of the planning and decision-making process.	The extent of involvement in the planning and decision-making process. The communication and negotiation of the planning and decision-making process. The pursuit of ease, familiarity and flexibility.
Person-centred considerations.		You before me. Bringing the home away. Seeking occupancy. Personal cares.
The experience of care as companionship.	In the <i>giving</i> of care and support, the carers are <i>receiving</i> .	The fluidity of the carer identity. The notion of mutual reciprocity.

Overarching themes	Key themes	Key ideas coded for
		Camaraderie in the care relationship
The experience of care as hospitality.	Nature of encounters with 'others' [travellers and host community].	General disability awareness. <hr/> (In)visibility of disability. <hr/> The carers reflections on personal historicity. <hr/> Managing behaviour in public spaces.
	Nature of encounters with 'others' [industry personnel].	Navigating the process of flying. <hr/> Navigating the process of customs and immigration.
The experience of care as compassion.	The emotions felt during experiences of leisure travel.	The emotions of the people with intellectual disabilities. <hr/> The emotions of the carers.
	The emotional awareness of the carers.	Cognitive empathy. <hr/> Emotional empathy.
	The emotional management of the carers.	Compassionate empathy. <hr/> Caring for the carers.

Phase six: Producing the report

The final stage involved the production of the thesis, which manifested as the write-up of Chapter 6, 'Findings', and Chapter 7, 'Discussion', structured by utilising the confirmed overarching themes and key themes alluded to in phase five. On an Excel spreadsheet, I recorded an audit trail of the participants' verbatim quotations used, categorised into 'carers' and 'people with intellectual disabilities', and then again into 'in-text quotations' and 'stand-alone quotations' (see Table 8).

In carrying out an analysis of the data and in formulating findings and the wider discussion, "the interpretive examination of lived experience has this methodical feature of relating the particular to the universal, part to the whole, episode to totality. Lived experience is the starting point and the end point of phenomenological research" (van Manen, 1990, p. 36). For instance, Chapter 6, 'Findings', perhaps unveils what may be common or unique to this particular travelling care relationship, in comparison with other travelling relationships. In this way, I do not suggest that such interpretations are representative or generalisable (Sedgley et al., 2017). Consistent with the research paradigm, rather than seeking to represent definitive truth(s), the themes represent those experiences

considered both influential and meaningful in the participants’ own reflection, in dialogue with myself (Pocock, 2015). For, “meaning is negotiated mutually in the act of interpretation; it is not simply discovered” (Schwandt, 2003, p. 302). Rather than prescribing what the reader should (or should not) think, I encourage them to form their own interpretation, as I have offered but one possible interpretation (Annells, 1999).

Table 8 – Example of ‘record of participant representation’

Theme	Pseudonym [carers and support workers]	In-text quotations
Contextualising care and support.	Aroha.	<i>Full experience.</i>
	Ava.	<i>It wasn't a carer taking a client, it was like we were family going out on holiday.</i>
		<i>Incredibly close and loving relationship.</i>
		<i>Know when to step in.</i>
		<i>Overdoing it.</i>
	Harriet.	<i>The life we have and we make the most out of it.</i>
		<i>We're a team.</i>
		<i>He always wants to be with me and around me; he's like a shadow.</i>
	Lily.	<i>You get good caregivers and bad caregivers. You know that no one is going to look after a family member as you would, and you're always perhaps going to find some fault along the way.</i>
		<i>He makes me feel complete.</i>
<i>We belong together.</i>		
<i>I'm mum. It's not care and support. This is my role as mum. It's what I do.</i>		
Sophia.	<i>My pride and joy. I think he makes me who I am.</i>	
	<i>Supervisory.</i>	
		<i>What happens when I'm not able to do it anymore? Who is going to do it then?</i>

4.6 Methodological reflections

This section gives a reflexive account of the challenges faced in the field, and limitations in the research design and execution. Such issues include research parameters and sampling, participant representation and trustworthiness of the research, and they are elaborated upon further in Chapter 8, 'Conclusion'.

Research parameters and sampling

The qualitative nature of an interpretive phenomenological approach to inquiry is typically small, with a modest sample size so as to offer sufficient insight into the personal meanings of particular phenomena (Szarcyz, 2009). The risk of a larger sample size is that it then becomes difficult to offer sufficient voice to each individual participant, or to attain an in-depth interpretation of the research as a whole (Jennings, 2010). Ultimately, a phenomenological researcher must make a discerning judgment about the size of their sample (Taylor & Bogdan, 1998).

Twenty-four participants were involved in this research. While this may appear to be large, the sample of carers was comprised of fifteen participants, of whom twelve were carers and three were support workers. The sample of people with intellectual disabilities comprised of nine participants. I believe I was able to achieve a sufficient richness within the data, and represent both my samples effectively (Taylor & Bogdan, 1998). According to Patton (2002, p. 245), "the validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected," and, indeed, the personal and in-depth perspectives that were both sought and attained exhibit rigour in the conclusions drawn (Pocock, 2011). It is important to note that this research did not seek common or definitive findings; it is both historically and contextually situated, local and personal, and is in no way generalisable across or representative of a population (Szarcyz, 2008).

In terms of the sampling parameters of this research, a limitation may be the decision to exclude the involvement of individuals with more severe or complex intellectual disabilities. I rationalised this exclusion on the grounds of there being potential confines to their receptive and expressive communication abilities. It could be argued, however, that a number of augmentative or alternative

communication (AAC) measures could have been used in an attempt to improve the conveyance of communication (Nind, 2008). In addition, I could have drawn upon the aid of an individual's carer, support worker, family member or friend, in an attempt to facilitate the interview process through 'proxy response' (Cummins & Laraine Masters, 2002). It is important to note that for some people with very profound intellectual disabilities, the interview process, irrespective of the availability of alternative communicative and/or visual strategies, still would not be possible (Nind, 2008). Even so, given the interpretive phenomenological approach framing this research, I sought to hear the individual's uncompromised voice and unveil a rich subjective narrative of their experiences (Nind, 2008).

Participant representation

I was particularly attentive to the ease of misinterpreting or misrepresenting the participants' data. As a process of participant validation, and to further enhance the credibility and trustworthiness of the data (Lincoln & Guba, 1985), I engaged in checking back (Novak et al., 2011) or member checking (Shenton, 2004). The carers were offered the opportunity to read their interview transcripts, allowing them to verify their data in terms of its degree of anonymisation, and the legitimacy of the actual content as an account of their experience (Mays & Pope, 1995; Nicholson et al., 2013). In this way, I could ensure that no data was included that a participant would later be uncomfortable with, or that they felt misrepresented them (Walmsley, 2001). The carers were able to exclude, amend or add content as they saw fit (Decrop, 2004). I encouraged the participants to take ownership over their data, to react to it, comment on it, and essentially develop it further (Braun & Clarke, 2006). Oftentimes, I was also able to ask any further questions I had, or request clarification as necessary. Together these actions enhanced the research protocol, signifying that the participant had signed off on their data, and that it was ready to be analysed (Milner & Mirfin-Veitch, 2012).

Unfortunately, there are practical challenges in member checking with people with intellectual disabilities, and this activity is often neglected or rejected. Instead, I made active efforts during the interview to relay the participant's responses back to them, along with my interpretations, to seek confirmation that this was what they had said and that they agreed with the interpretation (S.A. Hall, 2013; Nind, 2008;

Shenton, 2004). Again, the level of understanding and interpretation that could occur between the reader and the text produced in the thesis itself may be limited.

The incorporation of the voices of people with intellectual disabilities presented me with a significant ethical conundrum. Interpretive phenomenological research represents its participants with rich text, yet I found this difficult to achieve because of the varied expressive and receptive communication abilities within this particular sub-sample of participants, and even across their diverse and messy transcripts. I grappled further with an evident imbalance between the thick descriptions offered within the sub-sample of carers, in comparison to that of the people with intellectual disabilities. For me, this raised concerns regarding the way in which I represented the diversity of the participants' voices. I deliberated extensively as to how I might better be able to incorporate the perspectives of the people with intellectual disabilities, but nonetheless contend that they have been included at a subtler level within the thesis. I did make explicit, however, that the thesis aim is to uncover the lived experiences of the carers, and that the lived experiences of the people with intellectual disabilities are complementary to this purpose.

Participant voice

Another important aspect of interpretive phenomenological research is the way in which we write the presentation of data in the findings and discussion (Sanger, 2003). Through my academic positioning, I have necessarily made the final decisions surrounding theoretical insight, methods, and the inclusion of narrative that surrounds the compilation of the thesis. I choose to write the thesis using an active voice in the first-person. This decision reflected my self-awareness, acknowledged my role as the researcher (Patton, 2002), and emphasised my embodied voice (Ateljevic et al., 2007). A critical point, however, is how I relate to and voice the experiences of my participants in the written thesis (Harris et al., 2007). The "extent to which alternative voices are heard is a criterion by which we can judge the openness, engagement, and problematic nature of any text" and hence, the credibility of this research is augmented as follows (Lincoln & Guba, 1985, p. 283).

Reflexivity encourages poly-vocality, and aligns with the interpretive phenomenological approach informing the thesis. A poly-vocal perspective allowed me to write the text in my voice, while ensuring the voices of the participants were heard in the text (S.A. Cohen, 2013; Sanger, 2003), by way of offering plausible and persuasive elicitation of the meanings embedded within their experiences (Kafle, 2011). The nature of interpretive phenomenology allows for people to share their stories, and interpret and therefore find meaning in them. I have presented the thesis in the hope that the reader will engage with the carers and people with intellectual disabilities in a profound way, like I did. I have favoured the unique voice of each individual participant, and privileged the intricacies and complexities of their experiences (Lavery, 2003). Like Pocock (2011), I too felt some discomfort in elucidating the participants' perspectives and experiences: "while I preferred to let the data speak for itself ... I inevitably had to offer an interpretation of these stories, thus reasserting my own voice over theirs" (p. 336). I do not claim to understand their experiences; rather I acknowledge that mine is but one possible interpretation (Oakley, 1998) of a potentially "messy matter of infinite interpretive possibilities" (Hollinshead, 2004, p. 63).

The language employed and the style of writing is reflective of the research's rhetoric, and delineates a unique oratory of depth and richness (Kafle, 2011). Appropriate to this, then, is a mode of language that is informal in its tone, and inclusive of adages, maxims and idiographic expressions (Kafle, 2011). The text is written with thick description and in the participants' own words where possible (Pernecky & Jamal, 2010), privileging their 'positionality' and 'subjectivity', and aligning with the rich textual element of an interpretive phenomenological approach (Riessman, 2000). For instance, in Chapter 7, 'Findings', each theme opens with the presentation of a 'vignette' from an individual participant, and is then supported with the inclusion of direct verbatim quotations from the other participants. Together, the themes are illustrative of the participants' "depth of emotion, the ways they have organised their world, their thoughts about what is happening, their experiences and their basic perceptions" (Patton, 2002, p. 21). It may be argued that the inclusion of such 'thick description' is one means in which trustworthiness, verisimilitude and plausibility can be substantiated, thus enhancing the credibility of the research (Tracy, 2010).

Trustworthiness of the research

According to Lincoln and Guba (1985), important questions to consider in any inquiry, are:

How can one establish confidence in the ‘truth’ of the findings of an inquiry for the respondents with which and the context in which the inquiry was carried out? How can one determine whether the findings of an inquiry would be consistently repeated if the inquiry were replicated with the same (or similar) respondents in the same (or similar context? How can one establish the degree to which the findings an inquiry stem from the characteristics of the respondents and the context and not from the biases, motivations, interests, and perspectives of the inquirer? (p. 218)

Therefore, “the gathering, analysis and interpretation of data is always conducted within some broader understanding of what constitutes legitimate inquiry and warrantable knowledge” (Henwood & Pidgeon, 1993, p. 15). The natural sciences operate under the criteria of precision, exactness and rigour (van Manen, 1990), and measure internal and external validity, objectivity, and reliability (Hammersley, 1995; Kvale, 1989, 1995; Sandberg, 2005; Shenton, 2004). In the human sciences, quality is difficult to assess under such criteria (Clark et al., 2012; Kafle, 2011). Instead, in qualitative research the criteria of authenticity, credibility, dependability and confirmability are often applied (Lincoln & Guba, 1985; Patton, 2002). As aforementioned, this research employs an interpretive phenomenological approach. Here, truth “is neither an objective endeavour nor something awaiting ‘verification’ or ‘confirmation’ through a set of methodical tools. Truth is an interpretive construct, and involves assessing the trustworthiness or credibility of the researcher’s interpretation of the participant’s experience” (Pernecky & Jamal, 2010, p. 1068).

Further, an interpretive phenomenological approach does not include any particular methodological prescriptions (Pernecky & Jamal, 2010). Mostly, there is flexibility in adopting “a creative approach to understanding, using whatever approaches are responsive to particular questions and subject matter” (Laverty, 2003, p. 28). van Manen (1990) recommended that the process is inter-subjective, systematic, explicit, and self-critical. Similarly, Kafle (2011) asserted that several principles guide process and unveil understanding of phenomena, maintaining the

inquiry's quality. These include "commitment to an abiding concern, oriented stance toward the question, investigating the experience as it is lived, describing the phenomenon through writing and rewriting, and consideration of parts and whole" (p. 191). In selecting, designing and carrying out the process of data collection, I sought to follow this guidance. The process was inter-subjective in that it involved dialogic interaction between myself as the researcher and the participants as the researched. In a systematic manner, the process followed the functions of focusing, questioning, intuiting and reflecting. Through the analysis of the data and the formation of text, I endeavoured to be explicit in the enunciation of the meaning embedded within the lived experiences of the participants. In addition, the approach was self-critical, in that I continually (re)addressed the purpose and process of the research (van Manen, 1990).

An interpretive phenomenological approach, too, does not include any particular analytical specifications (Kafle, 2011). The intention, then, is to ensure the contextual features of the research are reported on (Henwood & Pidgeon, 1993), and that interpretive descriptions are offered, demonstrating a completeness or fullness of detail (van Manen, 1990). In fact, van Manen (1990) asserted, "a rigorous human science is prepared to be 'soft', 'soulful', 'subtle' and 'sensitive' in its effort to bring the range of meanings of life's phenomena to our reflective awareness" (p. 18). Finally, Jamal and Hollinshead (2001) suggested that further evaluations of quality ask:

Did the multiple points of view, narratives and emotions described in the text offer the reader an in-depth, substantive understanding of the topic? Does the writer demonstrate an ethos of self-reflexive attention, not just to the moral obligation and ethical responsibility of the writer/researcher to the study, reader and interview participants? (p. 76)

4.7 Further ethical considerations

The University of Waikato's Human Research Ethics Committee granted full ethical approval for this research (see Appendix A – Approval of ethics application), and I conducted this research in a manner that fully complied with the ethical standards articulated. As L.M. Smith (1990) explained:

Ethics refers to that complex of ideals showing how individuals should relate to one another in particular situations, to principles of conduct guiding those relationships, and to the kind of reasoning one engages in when thinking about such ideals and principles. (p. 141)

Given the nature of this research, participation was neither likely nor expected to impose any significant risk to the participants or their daily lives. I minimised any possible risk on a case-by-case basis, and took every conscious precaution to ensure that the preparation, conduct and analysis of the research was of a sensitive, non-offensive, and culturally safe manner. The research environment was ethically appropriate, and conducive to understanding, trust, transparency and reciprocity. I granted particular consideration to issues around attaining informed consent, and the guarantee of anonymity.

Informed consent

Attaining the informed consent of the ‘people with intellectual disabilities’ was a significant ethical consideration. A historical perspective is that people with intellectual disabilities lack the competence and capacity to give their consent (McDonald, 2012). As discussed, I evidenced their explicit decision to participate in the written provision of their signature on the ‘Consent form’ and the audio-recorded offering of their verbal consent at the interview. Both the ‘Information sheet’ and the ‘Consent form’ were available to read and touch as desired.

To achieve the process of consent, I allowed the participants time and flexibility, among other strategies suggested by disability studies scholars (Iacono, 2006; Pitts & Smith, 2007; Stalker, 1998). I elucidated what was required of the participants, used plain language or language that was familiar to them, and offered repetition where needed (Cameron & Murphy, 2006; Coons & Watson, 2013). I then encouraged each individual participant to express their understanding of consent, in their own words. It was important that I felt confident that the participant understood: what was being asked of them; what the research was about; that the nature of their participation was voluntary; that they could withdraw their participation at any time before February 1, 2017; and that they actually wanted to participate.

To assess consent, Cameron and Murphy (2006) offer a number of positive and negative, verbal and non-verbal indicators, which I considered in my approach. For example, a high level of engagement would see an individual making eye contact and demonstrating positive body language, whereas a low level of engagement would see lack of eye contact and the appearance of being indifferent. Positive verbal responses saw relevant elaboration, that is, verbal expression and comments that were indicative of their willingness to take part. Contrastingly, negative verbal responses were acquiescent, where the participant would simply agree without evident understanding. Finally, positive non-verbal responses were actions such as nodding one's head or smiling, whereas other non-verbal responses were ambivalent, with negative facial expressions, such as tilting or turning.

I appreciated consent to be “an interactional, contextually informed construct” (McDonald, 2012, p. 36). Whilst the capacity of an individual with an intellectual disability is static, their consent to participate was a dynamic, ongoing process (Cameron & Murphy, 2006; Coons & Watson, 2013; T. Gilbert, 2004; Pitts & Smith, 2007), monitored carefully through the comments they expressed, tone of voice, facial expressions and gestures (S.A. Hall, 2013). In the best interests of prospective participants' vulnerability (Hillier et al., 2007; Ramcharan, 2006), the preceding actions assisted the assessment of consent, suggesting that it was in fact informed and avoided the participants simply acquiescing (Nind, 2008). As it transpired, however, all participants were able to give their informed consent to my satisfaction.

Guarantee of confidentiality

From the very outset of the research process, and throughout its entirety, I took measures to ensure that I protected the participants' identities, respected their privacy, and maintained their confidentiality (McDonald, 2012). It was fundamental that I accounted for both external (organisation) and internal (participant) confidentiality, given the relational and social nature of the research, particularly when both members of the care relationships were involved (Guenther, 2009). In the interest of external confidentiality, throughout the thesis I have simply named the organisations that were involved in assisting the recruitment process as a 'care/disability' 'service/support' organisation. I have endeavoured to disguise and protect participant identities as best as possible and, for this reason, I employ

pseudonyms. Methodologically, the use of pseudonyms ensures a higher level of rigour than would have otherwise been achieved with the use of real names, as with the latter I was more likely to conceal identities “at the expense of making convincing, nuanced arguments” (Guenther, 2009, p. 413). Further, the assurance “of confidentiality can be an empowering experience, allowing individuals to speak candidly without concerns about attribution or retribution” (Guenther, 2009, p. 414). Notably, I could not guarantee anonymity, given the nature of the qualitative, face-to-face interviewing data collection method.

4.8 Chapter summary

This chapter explored paradigms, methodology and methods. Specifically, I articulated the research approach, design and methods that were implemented in the collection, analysis and interpretation of the data. I discussed how I engaged in an interpretive phenomenological approach to meet the thesis aim and address the research questions. I then detailed the collection of data through use of qualitative semi-structured interviewing, firstly with the carers and secondly with the people with intellectual disabilities. Thematic analysis was used to identify the ‘units of meaning’ contributing to the identification of overarching and key themes, and through which the data could be interpreted and discussed. The chapter concluded with a brief account of the methodological limitations and ethical considerations of this research. Chapter 5, ‘Context’, which follows next, ‘sets the scene’ for the presentation of the findings. In introducing the research participants, the preceding research process is humanised, as their personal historicity provides the necessary context in which to explore the thesis aim.

5 Context

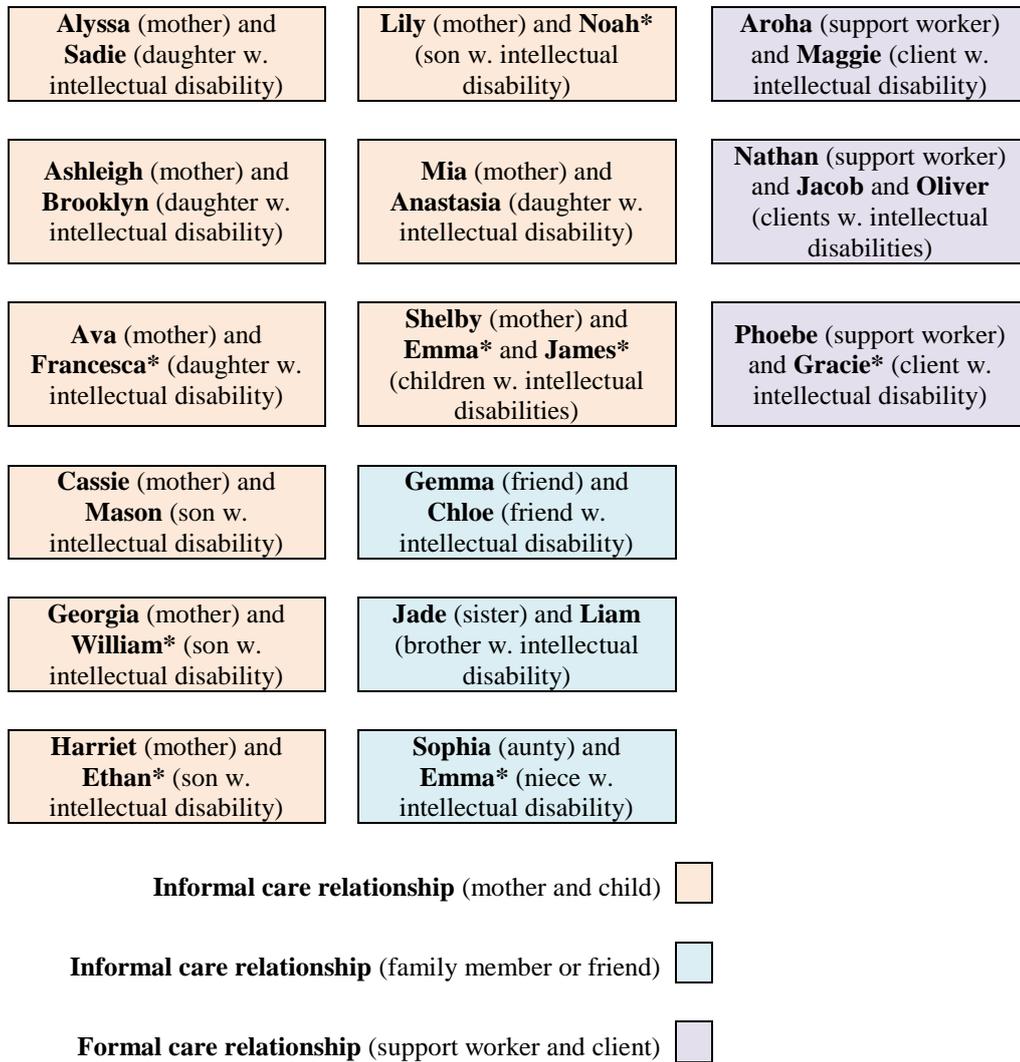
The aim of this thesis is to explore lived experiences of care at the nexus of intellectual disability and leisure travel. The purpose of this chapter, therefore, is two-fold. The first aspect of the chapter's purpose is to offer a human element to the demographic profile of the research participants detailed prior, in Chapter 4, 'Methodology'. The second aspect of the chapter's purpose is to offer insight into the travel element of this research, that is, to contextualise the phenomenon of leisure travel in an effort to describe, understand and interpret the participants' experiences of care in the context of that travel, in the later Chapter 6, 'Findings', and Chapter 7, 'Discussion'. Taking these two aspects together, this chapter has relevance both for humanising the research and for centring the significance and meaning of being able to partake in travel, as described in the carers' and people with intellectual disabilities' own words.

5.1 Introducing the research participants

This section necessarily foregrounds the research participants (Westwood et al., 2006), and provides the subjective contextual background of each individual. It offers a brief unpacking around who these individuals are and what makes them unique (Westwood et al., 2006) – their struggles and triumphs, their relationships, and the presence of disability in their lives. This allows the reader to 'get to know them', which better positions the reader to draw their own interpretations of the lived experiences of care presented in this thesis (Willson et al., 2013). These personal narratives are elaborated upon in further detail in the subsequent sections of this chapter, as I detail the participants' expressions of their travel experiences, staying true to the rich, textual element of interpretive phenomenological research, and ensuring each individual's voice and lived experience is not lost among the themes (Glover, 2003; Schmidt, 2005; Willson et al., 2013).

The following figure offers a visual to illustrate the total sample of participants and the care relationships that exist within this research, namely 'informal care relationships' (mothers and children), 'informal care relationships' (family members or friends), and 'formal care relationships' (support workers and clients) (see Figure 4).

Figure 4 – Visual of total sample of participants and their care relationships



* This individual with intellectual disability did not participate in the research, although is presented in the thesis in reference to their carer.

At the time of interviewing [February 2017] ...

Alyssa [mother] is in her early 50s. She has been married for nearly thirty years, and is the mother of four children in their early twenties. She and her husband own and live in their family home in Hamilton. Alyssa is returning to full-time study in early childhood education (March 2017) and her income is less than \$20,000 per annum. Alyssa's husband works in the health and disability sector as a community support worker, and the three eldest children are all at university.

Sadie [daughter with intellectual disability] is 25 years old, and is the eldest child. On discussing Sadie's disability, Alyssa explained:

She was a very bright, precocious toddler and then, just before she turned 3 years old, she had her first seizure. It became apparent reasonably quickly that, all of a sudden, her development was slowing down. She does not have a specific diagnosis. She has her epileptic syndrome, which is very similar to one called Lennox-Gastaut syndrome, as she has followed the pattern of that with seizures, which are almost every kind of seizure. They were all over the place, difficult to control as a toddler. They gradually became more easily controlled so that now she only has a seizure once every six months or so with medication. All the other intellectual and behavioural problems have become more pronounced over time.

Sadie has lived in a residential and supported living service in Hamilton for the past seven years. She is unemployed and her current income range is less than \$20,000 per annum, primarily received from government benefits. Sadie attends a vocational service three times a week where she enjoys participating in arts and crafts, music and dancing, and exercise. She also enjoys playing on her laptop, going shopping, and attending concerts with her sister.

The family travel domestically regularly during long weekends and holidays, going on "*road-trips*" and staying at their family beach house in the Bay of Plenty. Alyssa and her husband recently experienced their first "*big trip*" travelling Europe for six weeks. Shortly after, Alyssa, Sadie, and her sister Poppy spent two weeks in Paris, France.

Ashleigh [mother] is in her late forties. Originally, a New Zealander, she became a solo mother to **Brooklyn** [daughter with intellectual disability] in Sydney, Australia where they lived for eight years before moving back to New Zealand. Ashleigh then reconnected with her friend Laura, and their relationship grew. They have since owned and lived together in their family home in Auckland, and got married one year ago. Ashleigh is in full-time employment in the I.T sector and her current income is more than \$100,000 per annum. Laura has been a university lecturer for over twenty-five years.

Brooklyn has Down syndrome, is 19 years old, and lives with her parents. In casual employment, she works as a waitress for a local cafe, and her current income range is less than \$20,000 per annum. Brooklyn is in “*mainstream schooling*” and enjoys participating in dancing and swimming lessons, reading and creating art, and spending time with her friends. On discussing her daughter and their relationship, Ashleigh described Brooklyn as “*someone who has always been curious about things and able to try lots of new things; she is quite independent and her biggest quality is the ability to organise herself.*” She explained further: “*my primary role as a mother is helping Brooklyn, as much as possible, to reach her potential as an independent member of society.*” The family have shared a colourful life together, living abroad and travelling extensively, both domestically and internationally. Travel is high on their values, representing the opportunity to connect and share in experiences that are new, unique, or unusual in their nature.

Ava [mother] is in her mid-sixties. She has been married for over thirty years, is a stepmother to her husband's son and mother to **Francesca*** [daughter with intellectual disability]. She and her husband own and live in their family home in Auckland with Francesca, and their son lives overseas with his partner. Although a teacher for over thirty years, Ava is now a software trainer for a classroom programme that she delivers in primary schools and her current income range is \$20,001-\$40,000 per annum. Francesca is 30 years old, with mild cerebral palsy and global developmental delay. On discussing her daughter's disability, Ava explained:

When we had Francesca, our lives changed. It certainly has had its pressures and its ups and downs, but it is the life we have and we make the most of it. I think in terms of the restrictions on her life, she cannot read or write, and she cannot be left alone. She has independence away from home but she always has to be with someone. She's fine if everything is going okay, but the moment something goes wrong she loses the ability to think rationally.

Francesca is unemployed and her current income range is less than \$20,000 per annum, received from government benefits. On discussing her daughter and their relationship, Ava described Francesca as being *"incredibly sensitive and usually very kind."* She explained further: *"we have a very loving relationship, it's not a stressful relationship; it has its moments of stress and is sometimes very tense, but it is generally very loving, with lots of friendship along the way."* The family have travelled extensively together, both domestically and internationally, and mostly for the purpose of visiting family and friends.

Cassie [mother] is in her late forties. She is married and is the mother to two adolescent daughters and one teenage son **Mason** [son with intellectual disability]. Cassie and her husband have recently sold their family home where they live in Clyde, and are currently building a new home in Alexandra. Cassie has always worked in the travel sector, as a travel agent and a customer service representative. She is currently in part-time employment working as a tour operator, and her current income range is \$20,001-\$40,000 per annum. Her husband works overseas in the mining sector. Mason is 18 years old and has Fragile X syndrome. On discussing her son's disability, Cassie explained:

He's eighteen and he can't really read or write; the attention span is there of only sort of a few minutes at a time. Socially, he is okay if he is with familiar people but he is lacking in friendships. He takes Concerta Ritalin, and that rather helps to slow him down a bit, and to think about what he is up to. Very repetitive with his speech ... Things out of context ... Whatever flies into his mind ... You could be talking about catching a bus and suddenly he is going for a swim or he is back on holiday in Australia at the zoo.

Mason lives with his parents, is unemployed and his current income range is less than \$20,000 per annum, primarily received from government benefits. He attends high school and enjoys participating in swimming, team sport and training at the gym. On discussing her son and their relationship, Cassie described, "*We have a fantastic relationship; we are like two peas in a pod. I know him inside out and I can read him like a book; I know exactly what is coming before it happens.*" The family enjoy travelling regularly, both domestically and internationally, mostly for the purposes of relaxation and escape.

Gemma [friend] is in her mid-twenties, has a partner and does not have any children. She owns and lives in her Auckland home, and spends most of her spare time renovating. She is currently unemployed, is a PhD candidate in psychology and her current income range is \$20,001-\$40,000 per annum, received from university scholarships. **Chloe** [friend with intellectual disability] is in her thirties. Chloe has spastic quadriplegia cerebral palsy, which presents as a mild intellectual disability, although she has relatively high functioning and independence. She lives with her parents in Auckland, and is one of five siblings. Chloe is in part-time employment, working in the health and disability sector as a writer, and her current income range is less than \$20,000 per annum.

Gemma and Chloe met at the university three years ago. Gemma coined their friendship, “*a coffee and chocolate biscuit relationship*,” where they catch up every three to four weeks. On discussing Chloe, Gemma described:

First words, sheer determination; I really admire her. It is going to sound wrong, but her ability to just put herself out there and continue. ... It gets heightened in disability because you end up being put in a fair amount of embarrassing situations, but she just powers on through and lives really strongly.

On discussing their relationship, Chloe explained:

Our strengths are that we are very strong at communication, and fundamental to that, is that Gemma doesn't take any shit from me; she calls a spade a spade and she tells me when I am doing things that are inappropriate, ignoring my health needs or putting undue stress on her.

Chloe recently asked Gemma to accompany her on her travels around Europe for three weeks, as “*friend and caregiver*.” They both reflected fondly on this shared experience, and expressed their desire to engage in more travel together in the future. Gemma has since travelled to the United States of America with her partner.

Georgia [mother] is in her mid-forties, married, and the mother of three teenage children. Originally, from the United Kingdom, they live in their family home in Wellington. Georgia has always worked in the education sector as a primary school teacher; however, she has recently moved into the health and disability sector where she is in part-time employment working as an administrator, and her current income range is less than \$20,000 per annum. Georgia's eldest child is **William*** [son with intellectual disability] is 18 years old and has Prader-Willi syndrome. His disability mostly presents as autistic spectrum characteristics and behavioural issues. He also has physical disabilities in respect to his very low muscle tone. William is unemployed and his current income range is less than \$20,000 per annum, primarily received from government benefits. He attends mainstream schooling, with funding for support from a teacher aide. The family enjoy travelling back to the United Kingdom, as well as to other domestic and international destinations, and recently travelled to Argentina. William, however, has experienced heightening anxiety around travel, which has seen the family's travel aspirations change somewhat.

Harriet [mother] is in her late sixties. She is the mother of four adult sons to her late husband, the stepmother of her current husband's adult daughter, and the grandmother of ten grandchildren. She and her husband own and live in their family home in Wellington. Harriet is currently unemployed; however, she has dabbled in part-time employment over the years, in both the insurance and travel sectors. Her current income range is \$60,001-\$80,000 per annum.

Harriet's youngest child **Ethan*** [son with intellectual disability] is in his late thirties and has Fragile X syndrome, which he received a diagnosis of when he was 21 years old. As a young toddler, Harriet and her late husband had noticed that his development was progressing somewhat slower than that of his older brothers, and although they could not obtain a specific diagnosis, the presence of an intellectual disability was evident. The family supported him through special early and primary education, but with the passing of his father, Ethan moved into a residential and supported living service in Hawkes Bay, where he has since lived and been educated. Ethan is unemployed and his current income range is less than \$20,000 per annum, primarily received from government benefits.

Until recently, Ethan would travel home each holiday break, Harriet would travel to see him, or they would go away as a family to their beach house in Eastland. As time has progressed, however, Ethan's autistic spectrum characteristics and behavioural problems have become more pronounced and severe. Because of his increasingly elevated anxiety and unpredictable behaviour, their travel aspirations have changed somewhat, becoming more infrequent and more localised. Harriet and her husband still travel together often, both domestically and internationally. On discussing her son and their relationship, Harriet explained:

He's been very close to me, and I wondered whether it was maybe because he lost his father. When he's home with me, he always wants to be with me and around me; he's like a shadow. We did lots of fun things together; we had certain things that he enjoyed and we used to do all those activities. ... Those dynamics have changed in the last couple of years; it's almost like a love-hate ... I shouldn't say a love-hate relationship. ... He wants to talk to me all the time on the phone. He wants to come home. I go up there quite a bit to see him, to take him out. In the last couple of years, I'd go to pick him up and he'd run a mile. It's a bit difficult at the moment; we have good visits and not so good visits.

Jade [sister] is in her early fifties. She has been married for over thirty years, and she and her husband live in their family home in Hamilton. They do not have any children. She is one of five siblings, and her younger brother **Liam** [brother with intellectual disability] is a twin. Jade is very involved in Liam's life and the day-to-day management of his care, particularly since their parents passed away and because their other siblings now have families of their own. Jade is in full-time employment in the health sector, working as a nurse, and her current income range is \$40,001-\$60,000 per annum.

Liam is in his late forties. He became unwell with polyarteritis-nodosa when he was eight years old, and then had two strokes when he was 16 years old, which consequently presented as brain damage and an undiagnosed general intellectual disability. Liam lives in a residential care and supported living service in Hamilton. He is unemployed and his current income range is \$20,001-\$40,000 per annum, received from government benefits. He enjoys participating in the weekly house outings with the other men he lives with, and riding his scooter around the lake. Jade and her husband travel often, both domestically and internationally, and Liam has travelled to Australia and the United Kingdom. Jade and Liam recently travelled to Rarotonga, and are planning to cruise around the Pacific Islands together.

Lily [mother] is in her early sixties. She is married and is mother to two adult sons and grandmother to two grandchildren. She and her husband own and live in their family home in Wellington. Lily is in part-time employment in the education sector working as a librarian at a primary school, and her current income range is less than \$20,000 per annum. **Noah*** [son with intellectual disability] is in his late thirties and has cerebral palsy, which presents as moderate intellectual and physical disabilities. On discussing her son's disability, Lily explained:

It completely and utterly affects him. The physical stuff, like not being able to walk, he has learnt to live with; it does not bother him. However, the speech thing would be a big problem for him; it really does bother him, because even socially that is hard, people are frightened because they do not understand him, so rather than stopping and trying, they just say 'hello' and keep going. He cannot feed himself... He is relying on other people, which bothers him; he has no independence. He's totally relying on other people for everything.

Liam has lived in a residential and supported living service in the Lower Hutt for the last five years. He is unemployed and his current income range is less than \$20,000 per annum, primarily received from government benefits. Liam enjoys participating in boccia, singing and watching sport on the television. On discussing her relationship with her son, Lily described:

He's my pride and joy; I think he makes me who I am. We feel like a team; we feel like we belong. He's just a pleasure to have around; he's happy to be obliging and to be involved. We have lots of fun together and we do silly things. He's just full of life.

Lily and Noah travel relatively often, for leisure and recreational purposes, as Noah competes in boccia tournaments. Lily also travels with her husband, both domestically and internationally.

Mia [mother] is in her early fifties. She is married, the mother of two adult sons in their late twenties who live in the South Island, and one teenage daughter who lives with them in their family home in Hamilton. Mia owns and manages her own business training dogs for agility, and her current income range is \$60,001-\$80,000 per annum. **Anastasia** [daughter with intellectual disability] is 19 years old. Mia and her husband adopted Anastasia from Russia when she was a young child. Anastasia received a diagnosis of attention-deficit-hyperactivity-disorder, foetal alcohol syndrome and general intellectual disability, upon their return. On discussing Anastasia's disability, Mia described how, "*she's pretty capable; she can look after herself and she can get around.*"

Anastasia is unemployed and her current income range is less than \$20,000 per annum, primarily received from government benefits. She is in her final year of schooling in a special education unit. She enjoys leading an active lifestyle, participating in sport, singing and dancing, and volunteering at a disability organisation. She has a pet dog and loves to spend time with her many friends. The family travel often – both with and without Anastasia – to their family beach house in the Coromandel, as well as other domestic and international destinations. Their travel is mostly for the purposes of visiting family and friends, and to escape and relax. Anastasia particularly enjoys travelling on her annual school camps, which are typically to a domestic or an Australian destination.

Shelby [mother] is in her early sixties. She is the mother of three adult children and the grandmother of two granddaughters. She owns and lives in her family home in Hamilton with her partner. Shelby is in full-time employment in the health and disability sector, working as a community support worker, and her current income range is \$40,000-\$60,000 per annum. **Emma*** and **James*** [children with intellectual disabilities] are in their late thirties and mid-forties, respectively. They acquired significant brain injuries at birth, which presented severe intellectual disabilities, in addition to autism spectrum disorder and cerebral palsy, respectively. Emma has lived with Shelby's sister **Sophia** for the last ten years, and James lives in a residential and supported living service in Hamilton. They are both unemployed and their current income range is less than \$20,000 per annum, primarily received from government benefits. On discussing her children, Shelby described, "*whenever I think about the kids, all I see is a big heart.*" Shelby values the experience of travel and believes in working hard to facilitate this for her children as they enjoy it. She and Sophia love to take the children on holiday, regularly staying at their family beach house in the Bay of Plenty, or travelling to Australia, Fiji, and Hawaii.

Sophia [aunty] is in her early sixties. She is divorced and does not have any children of her own; however, over the last ten years has been the full-time carer for her sister Shelby's daughter **Emma*** [niece with intellectual disability]. They own and live in Sophia's family home in Hamilton. Sophia served in the Royal New Zealand Air Force for over twenty years, at both New Zealand and overseas bases. Following this, she spent twenty years in the hospitality sector where she owned and managed several catering businesses. She is currently unemployed and her current income range is \$20,001-\$40,000 per annum, primarily received from government benefits. On discussing her niece's disability, Sophia explained:

She is on the autism spectrum and there are certain aspects of autism that show up quite dramatically, like everything being in order. If I go to the cupboard and get the biscuit container out, she will always go back and make sure it is in the right place, level, even, and squared up. There is a certain amount of brain damage. ... She knows a lot of things but she doesn't understand or comprehend a lot of it.

Emma is in her late thirties, unemployed and her current income range is less than \$20,000 per annum, primarily received from government benefits. She attends a vocational service several days a week, and enjoys relaxing at home or spending time with her brother James and younger cousins. As mentioned above, Sophia and Shelby enjoy taking Emma and James on holiday, whether that be regularly staying at their family beach house in the Bay of Plenty, or travelling to Australia, Fiji and Hawaii.

Aroha [support worker] is in her early fifties. She has a partner, is a mother of four children and a grandmother of two grandchildren. From the East Coast originally, Aroha is an iwi citizen of Ngāti Porou, although is now renting in Hamilton. Having attained a Diploma in Business Management and a Bachelor of Social Work, she has spent over thirty years working in the hospitality sector, and the last ten years in the health and disability sector. She is currently in full-time employment working as a community support worker, and her current income range is \$20,001-\$40,000. Considering herself a carer by nature, she explained:

I think I've always been a people person; I have spent most of my life looking after someone. I am like my mum; my mother has always been a carer. My grandmother whānaued me; she adopted me and many of my cousins. My children are my world, my grandchildren are my universe, and everything revolves around them.

Aroha has known **Maggie** [client with intellectual disability] for three years, as the staff at the residential and supported living service where Maggie lives in Hamilton. Maggie has an undiagnosed general intellectual disability and an unnamed visual impairment. Maggie is in her early forties, unemployed and has a current income range of less than \$20,000 per annum, primarily received from government benefits. Maggie attends a vocational service where she enjoys participating in music and knitting. She has a close relationship with her mother who she regularly texts, and visits weekly in her Hamilton home. On discussing her client and their relationship, Aroha explained:

I met her in the first house I was at; everyone kind of informed me that she was like the General of the house, the Commander, the one that liked to boss everyone around, and it was like that straight away. It's very strong, her personality; I find her very independent in that way, strong-headed. She's really awesome. She's not afraid to do things, and she's been more independent as the years have gone past, as every year she's exposed to something new, she takes it on board and she runs with it. It's really awesome to watch her grow.

Aroha and Maggie recently travelled to Wellington to fulfil Maggie's desire to travel by plane and train, and to experience a number of attractions and activities. Besides supporting Maggie's travel, Aroha has not engaged in much leisure travel herself.

Nathan [support worker] is in his late twenties, is single and does not have any children. He is renting in Tauranga. Nathan has been a community support worker for the past three years and is a musician in his spare time. His current income range is \$20,001-\$40,000 per annum. Nathan has been staff for **Jacob** and **Oliver** [clients with intellectual disabilities] at the residential and supported living service where they live in Tauranga. Both men are in their early sixties and have undiagnosed intellectual disabilities. Jacob is unemployed and his current income range is less than \$20,000, primarily received from government benefits. He enjoys getting out, going to the gym, making models and playing computer games. Oliver is currently in casual employment, working in the industrial sector as a cleaner, and his current income range is \$20,001-\$40,000 per annum. Oliver enjoys creating art in his spare time and watching videos on YouTube. Nathan recently supported Jacob's travel to Christchurch, and Oliver's travel to Melbourne. Outside of work, Nathan often travels, both domestically and internationally, for the purposes of relaxation and escape.

Phoebe [support worker] is in her mid-thirties. She is married and the mother of five young children. She has recently returned to New Zealand after living in Australia and is renting in Hamilton. Although Phoebe has had an extensive career in the events sector, working in corporate functions, for the past year she has been in full-time employment working as a community support worker, and her current income range is \$20,001-\$40,000 per annum. Phoebe is staff for **Gracie*** [client with intellectual disability] at a residential and supported living service where she lives in Hamilton. Gracie is of Māori descent and is in her late thirties. She has an unnamed genetic disorder, which presents as general and undiagnosed intellectual and physical disabilities. Phoebe discussed Gracie's disability, explaining that "*she has 24/7 care, personal cares, communicating, everything. ... She needs double staff. Her disability affects all aspects of her life but even though it does affect her life, she does not let it affect her life as well.*" Gracie is unemployed and her current income range is less than \$20,000 per annum, primarily received from government benefits. Phoebe and Gracie recently travelled to Wellington where they attended a conference and engaged in leisure. Phoebe also travels regularly with her own family, mostly domestically, for the purposes of escape and relaxation, and to promote familial connection.

5.2 The significance of leisure travel as a meaningful experience

For all of the participants involved in this research, the purpose of their travel was leisure, and the nature of their leisure travel was a holiday. In this sense, the participants mostly presented themselves as leisure travellers engaging in leisure travel experiences. For almost all of the carers and people with intellectual disabilities presented in this research, the experience of leisure travel was meaningful and significant. Ultimately, the pursuit of the leisure travel experience, and the intrinsic benefit in the nature of such participation, were about enabling a 'good life'. These situated experiences of leisure travel, then provided the context in which the participants' experiences of care could take place, and allowed for their subsequent sense making of such experiences. Together, both the context and the experience of leisure travel relate directly and indirectly to the three key themes of the thesis, thus setting the scene for their exploration in Chapter 6, 'Findings', which follows on from this chapter.

5.2.1 Travel as a meaningful experience to the people with intellectual disabilities

This section explores the significance of leisure travel as a meaningful experience for the people with intellectual disabilities, as described in their own words. Almost all of the carers expressed the people with intellectual disabilities' love of travel, describing them as deriving a considerable joy from such experiences. Similarly, almost all of the people with intellectual disabilities verified the carers' perspectives, expressing a "like" or "love" of travel, and a desire to travel again and more often in the future. The people with intellectual disabilities conveyed this perspective through comments like, "*I really love going to holidays,*" and "*to be honest, it was so much fun; I love travelling and I wish I could go back.*" Also, "*I did love it and I want to go on another trip; go to other places I haven't seen,*" and "*I love travelling a lot in the world; it's my big thing, I've realised I love going so much.*" In addition, several of the people with intellectual disabilities described their travel aspirations for "*next time.*" As an example, Anastasia commented, "*so far I am thinking about travelling overseas. America, the stars in Hollywood... Disneyland, Orlando, Universal... And, just a side-trip to Australia if I can.*" As a further example, Oliver expressed:

Probably go on the cruise. Probably go on the trams. Might go on the trains and all sorts. Probably go and see some animals... Elephants. Probably go and do the markets. I might stay with staff and a couple of friends over there for a month because America is a big city, or a big country. Probably just got to save up to go to 2020.

From the expressions shared by the people with intellectual disabilities, it seemed that the nature of their participation in travel served as a positive antithesis to their everyday life. The people with intellectual disabilities commented, for instance, *“just relax and have a break,” “it’s a bit of a change and a bit of a highlight,”* and, *“it’s a good thing for me to do it; to do all these things I’ve never done before.”* Lily verified this perspective for Noah, commenting, *“He likes the excitement of something different because his life can be pretty boring otherwise.”* It appeared from their responses that the attractions they visited and the activities they engaged in were the most memorable aspect of their travel experiences. The activities participated in included: the zoo; eating out or shopping; boating, swimming or snorkelling; art galleries, museums or performances; camps, conferences or sport tournaments; and, gardening or hiking. Theme parks, in particular, were an experience many had participated in, and those that had not wanted to do so. Anastasia expressed:

I love Dream World, it’s lovely; I love all the rides there and I love the animals, except the tigers. That’s the only one where one of the rides got shut down, so that’s a bit sad. Sea World is my second favourite. Wet and Wild is my third – obviously my favourite, but my third – but then Movie World, because there’s a lot of things to do there.

From the perspective of the carers, the significance of travel as a meaningful experience for the people with intellectual disabilities was three-fold. Firstly, ‘to be able to participate’, secondly, ‘to foster independence, empowerment and self-development’, and thirdly, ‘to expand upon one’s world views and develop new frames of reference’. Offered below are the carers’ descriptions and explanations of these understandings.

To be able to participate

Mostly, the carers described the travel experience as representative of an unparalleled, *“one in a lifetime opportunity,” “the trip of a lifetime.”* They

elaborated upon how memorable such experiences were, through comments like, *“he/she has made memories for the rest of his/her life,”* and *“he/she remembers holidays even if he/she can’t verbalise them.”* As an example, Aroha expressed:

I know that for Maggie the Wellington trip was memorable because she’s still talking about it today and she’s excited for the next one. I see that with Maggie, a person that’s hungry for excitement, hungry for adventure; she enjoys everything.

As a further example, Phoebe recalled the excitement Gracie expressed when travelling by plane and staying in a hotel for the first time. She described, *“she was so excited and happy, and she loved it the whole time that we were there; she was like that the whole month leading up to it, looking forward to it.”* Phoebe also explained how the nature of Gracie’s physical disabilities meant that she required a hoist into her airplane seat, and revelled in how this gesture had made her *“feel like a normal person.”* In a similar vein, Nathan described how he would allow Jacob and Oliver a little more freedom than they might otherwise have in their everyday lives, for instance, *“a wine or something, treats or just nice food, nice restaurants; it’s just things like that because you’re away on holiday.”*

Some of the carers described how the desire of many of the people with intellectual disabilities to participate in experiences of travel stemmed from comparison. They explained how often an individual with intellectual disability would make a statement of comparison against what non-disabled siblings were able to do or were doing, or against a former non-disabled life. Alyssa, for instance, described how Sadie experienced gratification in asserting, to herself and her siblings, *“that independence that she can do it.”* She explained, *“I think for Sadie it was, ‘this is something special that I’m doing’, which she doesn’t get to feel very often I don’t think.”* To be a part of this experience as it unfolded was a *“highlight”* for Alyssa. Similarly, to be able to successfully partake in travel was especially meaningful for Liam, given he had acquired his disabilities later in life, after living his adolescent years as able-bodied and -minded. Travel, it seemed from Jade’s responses, was a medium in which he could reclaim part of his old identity, an identity he felt as though he had lost. Jade expressed:

I think for him, it’s something he is able to do and accomplish; is to participate with other people. It’s important for me, to be able

to participate in things that are important to him. He is a social person really; he likes to get out and about and I think he likes to do that activity because he's not able to do other things. It is important because of the limited other leisure activities, and also the fact that he probably can't do things independently or as he chooses, which is ideally what he would love to do.

Many of the carers, who are mothers, described the encroaching nature of disability upon the people with intellectual disabilities' "*active participation*" in life. The carers shared examples of their longing for social connection, to drive a vehicle, to attend school or university or to attain employment, which was often made in comparison to what a "*normal*" life might look like. The carers explained how they themselves acknowledged having lived an experience of an alternative reality, and how this had once translated into the belief that the people with intellectual disabilities may not lead an "*ordinary life*"; a life that they had once believed, and that some still believed, would be "*better*." As an example, Alyssa expressed:

There's always that slight element of guilt I guess, that her life could be a bit better, easier, whatever; it's hard to know what would make a difference to her and, in an actual fact, there's probably not much that I can do.

The mothers described how, with time, they understood their child's experience to be relative and not necessarily "*lesser than*," recognising that their experience could still be a "*full experience*." To illustrate, Shelby articulated how "*they don't know what the experience would be, so I always try to bring myself back to their experience; their experience is the experience they're having, they don't see anything else*." To illustrate further, Alyssa expressed:

It's that certain lack of awareness on her part which can sometimes be a good thing; she doesn't see it as something's different, so she probably doesn't realise some of the limitations that are placed on her. It's sort of reminding her what she can do and what independence she can have.

Essentially, it seemed from the carers' responses that, although many "*normal*" aspirations might no longer be feasible, a diversity of unique yet all the while positive experiences were feasible, with leisure travel being but one example. In short, many of the mothers felt personally accountable for their child's disability, and questioned whether their efforts as a mother were "*enough*." To this end, they

felt a sense of responsibility in affording them a “*good life*,” and demonstrated resilience in accepting their fate, understanding “*it certainly has its pressure and ups and downs, but this is the life we have; we make the most out of it.*” Shelby expressed:

They’ve always come first, that’s why I’ve never had a life. It was too important to me that they have a good life; that they lead an ordinary life but one that’s really interesting. That they get to experience lots of things. Just because they have very significant disabilities, it’s still really important that they get to see lots of things. I have always been very active in finding out what’s available, and if it’s not available, making sure it happens anyway. It’s about sharing what I’ve learnt, giving people hope that things can be achieved, making it a positive journey and just having a good life.

To foster independence, empowerment and self-development

The experience of travel also facilitated a context in which the carers could encourage an increased sense of independence, empowerment and self-development among the people with intellectual disabilities. As an example, Chloe expressed:

I never used to think I had the ability to be spontaneous until I went to Europe, tranced up a medieval castle, and went to a sculpture park in Oslo. Cos you just do it, cos you have to. You don’t actually have travel guardian angels who swoop in and fix everything for you; but that’s important too, because in real life you don’t have people fixing everything for you. Personal growth ... Emotional growth ... Your sense of competency in yourself and confidence in yourself, and your ability to realise that you can exist as an adult in the world. Travel is the best way to learn a new language of confidence, I believe anyway.

To illustrate further, some of the carers described how several of the people with intellectual disabilities had achieved personal goals they had set themselves while travelling, and many of these examples were also verified by the people with intellectual disabilities. Sadie was determined to try snails and frogs’ legs in France. Gracie presented at a national conference in Wellington. Noah travelled “*on his own, without his mum*,” instead going with a group of fellow clients and staff from his residential care and supported living service to the South Island. Brooklyn would set herself a “*new challenge*” with each successive holiday, stating, “*My*

next new challenge is to eat spicy.” Similarly, Anastasia recalled how she overcame her fears with each successive school camp she attended. She expressed:

When I first started going to Australia, I couldn’t do the Giant Drop but I did it anyway. And then the second time I went, I couldn’t do the Bustle but I did it anyway. I’m scared to get over my fear of heights but I’m actually going to go bungee jumping off the bridges.

Maggie acquired a deeper comprehension of the relationship between “*saving her money*,” in order to facilitate future travel. Aroha expressed:

The night before we left, she was like, “man, I can’t believe that we’ve got to go back,” and I was going, “yeah, I wish you were richer and then we could stay longer.” We went for three days; it was only for three days. I was cracking a joke with her because she paid for the trip and I was taking the mickey out of her because I felt guilty. I was going, “man, I wish I was like you,” and she was going, “well, if you do your budget like this...” I was getting her to talk about her finances and it was good, it worked. She was like, “oh, I want to go again; I want to go to this place,” and I was like, “how much will you budget for,” and she was like, “oh, I’ll have to budget for this much and for this long.” So, she’s even learning how to manage her own finances, because it’s something she wants to do; if you get her in the space where she’s excited and she wants to do something, she’ll use that as motivation to learn how to manage her money.

In a different vein, Anastasia described how her increasing travel experiences in the Gold Coast – and especially visiting Sea World – had cultivated a growing passion within her, and helped her to develop direction around a potential future career path. She expressed:

I love Sea World; I think it’s the dolphins. It just inspires me to do a bit of biology to do with the marine life. How these guys adapt in the wild; I wouldn’t say that they live in the wild, these guys ... They’re so used to just doing tricks and living in the closed area, like dolphins in particular. These guys are really well trained ... Basically, that’s what I want to do, studying and training, but I just have to move ... If I am not careless like Steve Irwin and kill myself! I could just study what they eat and how they adapt in the wildlife. But no, I also love stingrays; they’re really nice, except when they get really aggressive. It’s not just stingrays, it’s fish and dolphins ... How they adapt when they get caught in the nets and stuff, and how I could, as a biologist, prevent that. They are endangered; all the dolphins at Sea World are endangered. So that’s what I want to do.

A number of the carers also described that those people with intellectual disabilities who had engaged in sequential experiences of travel acquired an increased familiarity with, and autonomy in, navigating the processes of the travel system. They explained how they evidenced this learning through activities like completing their forms for immigration or making their way through the e-passport photo recognition technology. As an example, Ava expressed:

She now has it pretty well sussed; she knows what to do. She can go through the self-check in with the passport, and she knows the system of when to stand at the lights and when to carry on; she knows the routine for checking her luggage in and picking it up at the other end. She's learnt that over a number of trips; the first time she didn't get it right but someone helped her and that was okay. It does empower her and she feels really good that she knows how to be able to do that. For someone that can't read, theoretically, she's surprisingly good at finding her way around places.

To expand upon one's worldviews and develop new frames of reference

The carers described how experiences of travel enhanced the perspectives and worldviews of the people with intellectual disabilities, and explained how it offered new frames of reference for them to draw upon. This was not withstanding the fact that the comprehension of such learning, *"even if it is only intrinsic and it's not specific,"* meant, *"their view of the world had expanded in a limited sense, but it had expanded through travel."* The carers conveyed this perspective through comments like, *"I just think they've got a different perspective; to see how other people live and to experience different things,"* and *"it's more educational, it's more understanding of the world; more awareness that the world is much bigger than our little place where we live."* Brooklyn verified this perspective, describing, *"I love travelling because I love history a lot, and new culture, new people, and new, different ways, when you travel a lot."* Chloe verified this perspective, and expressed:

I think travel should be considered not so much as a luxury item but as a fundamental aspect of expanding your horizons, even if it's just domestic travel or travel within your own city. The ability to do it enhances yourself and your sense of psychology and wellness.

Many of the carers also spoke to the idea of developing new frames of reference, sharing specific examples. Alyssa described Sadie's ability to recognise a number of major attractions and icons of Paris, though affiliating them with various forms of pop culture she was familiar with, excited in knowing that she had visited and experienced these places in real life. Ashleigh described feeling hopeful that Brooklyn would be able to reflect upon her travel experiences and share her knowledge during her studies at school, commenting, "*Brooklyn this year is starting geography. How wonderful for her to say, 'I've been there' and remember whatever she remembers; that must be a fantastic feeling for her, that other experience.*" Some of the other carers also described the potential for there to be favourable opportunities for the people with intellectual disabilities to communicate their experiences to others. They explained how such communication, where travel experiences were a reference point and topic of common ground, could help form connection with others. They conveyed this perspective through comments like the following: "*It brings up things to talk about; the fact that he/she went away and that he/she participated,*" and "*he/she can be a part of that conversation, a part of that dialogue; a part of something, he/she has done something good.*" In addition, "*they can come back and talk to people, people can talk to them about it; they can share their experiences with other people.*" As an example, Chloe expressed:

I've found now too, particularly because I've been to Europe, that I can have dialogue with my friends that are on par with them. When I say, "have you seen the amazing sculpture park in Oslo," they are like, "oh my gosh, yes, it's amazing." That's a dialogue I wouldn't have been able to have if I hadn't travelled. It puts me in a different frame of reference. I'm not just "the poor disabled person," I am somebody who has done some of these things and experienced some of these things, and have valued them as equally awesome.

5.2.2 Travel as a meaningful experience to the carers

For most of the participants presented in this research, their experiences of travel were regular, and for a few of them, it was novel. Whilst appreciated as not being a necessity, almost all of the carers described the context of travel as representative of a potential space for 'escaping normality and expansion of worldviews', and 'travel as an enabler and strengthening connection' with the people with intellectual disabilities. Ultimately, the carers explained how they perceived the travel

experience to be an effective medium through which they could enable a ‘good life’ for themselves, as well as for the people with intellectual disabilities. Whether this activity came about for the purposes of visiting family and friends, to participate in new experiences, or to simply spend quality time together away from the everyday routines of home life, travel was valued as a positive and enriching pursuit. The carers conveyed this perspective through comments like, *“just quite joyful times really,”* and *“travel is a positive part of our life; it has enhanced life for all of us.”* Nathan expressed:

I define travel as, leaving your normal place where you reside and going somewhere that would involve new experiences. I think it is a valuable thing. I think it’s quite normal for people to experience that from time to time; otherwise, life would maybe feel a bit more stagnant or something. It can make you feel more alive as well.

Escaping ‘normality’ and expansion of worldviews

The carers personally ascribed the significance of leisure travel to escaping normality and expanding their worldviews. The carers described how the travel experience offered escapism, which they conveyed through comments such as, *“doing things you wouldn’t normally do,”* *“I absolutely love the excitement of going somewhere new,”* and *“that feeling of motion or moving; where you feel like something is happening in your life.”* They also described the potential for feeling a sense of release from the constraints, norms and structures of the everydayness of their home and working lives. The carers commented, for instance, about *“not having to work to a timetable; not having to work to a schedule,”* and *“just leaving the everyday routine of life behind; forgetting about that for however long you are away for.”* In addition, *“we just enjoy getting away,”* *“having a break away from the normal and recharging,”* and *“just for relaxation really, to be away from home; even if it’s just for a few days, you are just away for that period of time.”* Ashleigh, as an example, stated, *“I feel a sort of happiness because I am free and I can see and do stuff; I’m not working.”* Interestingly, while many of the carers described the travel experience as representing an escape from normality, for a couple of mothers, the experience of travel represented an opportunity to re-instil a sense of normality into their lives. Georgia expressed:

I actually feel with travel though – like going places and doing things – that actually puts some normality back into my life. It’s probably why I still insist on doing it. I don’t want to sort of give up and say, “oh well, we’re not going anything because we have William.” It’s the doing things – even though it doesn’t always end up being much fun – it just gives me something to look forward to, going away. I get annoyed and frustrated by it sometimes, because I feel like the holiday can be ruined; at the same time, I am still determined to have one because travel is quite important to us. I’ve had lots of places in life that I’ve wanted to go.

Many of the carers also described how the experience of travel contributed to an expansion of their worldviews, which they attributed through being immersed into the experiences of other people, their cultures and ways of life. The carers conveyed this perspective through comments such as, *“To see how other people live and to experience different things,”* and *“it certainly enhances your worldview, to experience other cultures and things.”* In addition, *“I do enjoy seeing other countries, experiencing different cultures,”* and *“I think it’s important for us to have that experience of a different culture; different food, different language, different music, different dancing, different routines during the day.”* To illustrate, as an example, Nathan expressed:

To me, it represents motion and life, reflection and growth, broadening and changing your perspective. It makes you realise, things are a lot bigger than your normal surroundings. Often you remember colours, sights, sounds and smells; things like that that are different.

To illustrate as a further example, Gemma expressed:

That wonderment and wow, that feeling of awe. Travel for me, is really trying to experience culture; I’m always fascinated by different landscapes, different architecture, all that kind of stuff. It’s always really interesting to see what’s different from where I grew up. Perspective; it opens your eyes; it gives you an idea of how similar everyone is across the world and how different.

Travel as an enabler and strengthening connection

In addition to the escape from normality and expansion of worldviews, the carers ascribed the meaningfulness of leisure travel to its intrinsic reward and relational benefit. All of the carers described how their shared experiences of travel delivered value and meaning, in the sense that it served as a reminder of the abilities of the

people with intellectual disabilities. The mothers, in particular, explained how they often became cognisant of themselves as either an enabler or disabler in their child's life, and emphasised the importance of rendering the former possible, through travel. To illustrate, Mia explained, *"I think sometimes as parents, we actually limit them a little bit because we think they're only capable of doing certain things; she's probably more capable than we think."* Similarly, Alyssa described how she was "amazed" by Sadie's physical and mental capabilities to "handle things" during their travel, expressing, *"it was actually a good reminder of what she is capable of."* She explained that not only was Sadie *"treated more like an adult,"* but also the experience itself allowed the space in which she could prove this to herself. She elaborated that, upon their return, this learning could be utilised at home in everyday life, where, *"you can say, 'remember that time where you were capable of doing this [or] enjoyed doing that?'"* Alyssa continued, *"She was just taking a bit more responsibility and standing a bit taller for a wee while."*

Many of the carers expressed a sense of gratitude for their shared travel experiences with the people with intellectual disabilities, describing a feeling of pride in having enabled and supported such an experience to take place. Aroha articulated it like this: *"I was glad that she had a good time, it made me feel good; 'oh wow, she enjoyed herself,' I enjoyed myself too."* Phoebe described *"Just seeing her happy; just feeling like you really have done something good for someone that they are going to remember for their whole life."* Gemma explained, *"I was twenty-four when I did it. I got a kick out of her thinking that I was the right person to do that; there was that kind of 'yay' I suppose."* To illustrate further, Nathan expressed:

For you as well, to walk away just feeling like you've done okay. All this money, time, organisation, you just want it to be a positive experience for everyone; if it's positive, then it's really positive. I don't experience what the other person has experienced but I just pray that hopefully it's a cool, memorable experience for them. It can become tiring and stuff but it's also a real blessing. It's a mixed thing. It's like an adventure. Some things are a little challenging, and some things are pretty cool. You feel pretty privileged to be able to support someone to do all that stuff; stuff you normally wouldn't be able to do.

The carers also described the significance of the shared nature of the travel experience with the people with intellectual disabilities from a *“relational perspective.”* The carers comments included, for example, *“spending that time together,” “it’s just a way of having some really quality time together,” “it was just nice to be away; just the two of us to do things together,”* and *“just to go away and enjoy each other’s company in a nice, relaxed environment.”* Lily expressed:

When we’re in our hotel room too, there’s usually two double beds in the room; he can lay in bed and I’ll sit on my bed and read a book, and we’ll just talk until he goes to sleep. Just being able to give him that extra bit of company that he wouldn’t normally get; that’s quite a nice feeling. We always have our stash of chocolate.

In addition, *“getting new experiences as well,”* and *“just making new memories and having new experiences.”* Nathan expressed:

One day we were going to go out on the dolphin watch but the times were funny. We ended up just getting a kilogram of mussels at this café or bar thing; it was in a big bowl that they cooked it in and we were just sitting at this window looking out at the bay. We sat there, ate all the mussels and just hung out. That was pretty cool, just hanging out, strolling along, chatting to people, going to all the different shops.

The carers explained how they attributed the meaningfulness of this shared experience to facilitating and strengthening connection. The carers commented, for example, *“I think it just makes relationships stronger probably,” “for our bond to strengthen; sometimes you just need to go away together for that to happen”* and *“real special times that we treasure.”* Nathan, for instance, indicated, *“I think that’s true; the bonding, the camaraderie, and all that sort of thing just gets stronger.”* Aroha also recalled moments of connection she experienced with Maggie:

She even farted in the room because she got gas the first night we were there. I was like, “oh hello no Maggie, open that door, hang your arse that way and fart out the window.” We were laughing about it; it was like having a conversation with my own family, with my kids or something. She was laughing forever. She was on her phone texting her mum, telling her about stinking out the room and she thought it was funny. She’s funny, you know, I didn’t realise how funny she was until this trip, she actually likes

cracking jokes; she's such a bossy britches, you don't see that side of her.

A few of the carers described how they would often reflect upon their shared experiences of travel with the people with intellectual disabilities, commenting how *"it's just helped the relationship; it does give us more to sort of chat about, other things to talk about."* They conveyed this perspective through comments such as, *"we can refer back to those memories, photos, references and things like that,"* and *"we'll bring the photo albums out and chat about that holiday, what we did and whom we went with."* Nathan elaborated upon this communicative element, describing how it did not just benefit the care relationship, but their interaction with others too. He articulated, *"It's something to talk about; I think it's something cool and positive to share with the families and staff too."* As an example, Sophia expressed:

We just seem to have a lot of fun together. When we go to the Gold Coast, we do so many things. A funny thing is when her and I went over for a long weekend when she'd just turned twenty-one. The hotel we stayed in had a deal with a hire rental car. It was one of those real old danger things; her side door wouldn't open, the boot wouldn't open, and it conked out at the stop signs and things like that. That tickled her fancy. For years she talked about the car that conked out; that's probably one of the things she's always remembered.

5.3 Chapter summary

This chapter has humanised the research by way of introducing the research participants. In addition, it has contextualised the phenomenon of leisure travel, defined as both a significant and meaningful experience, and as the context in which care experiences could take place for the care relationships presented in this research. The experience of leisure travel is meaningful for the carers and the people with intellectual disabilities, in the sense that it affords them with a sense of living, and ascribes them with a sense of learning and strengthened relational connection. Leisure travel, it seems from the participants' responses, equates to wellbeing, dignity and enabling a 'good life'. In considering both the context and experience of leisure travel, and the experiential dimensions of care, the following chapter presents the key findings of this research, under the following themes, *giving, attunement, and (in)visibility*.

6 Findings

The purpose of this chapter is two-fold: firstly, to present the findings that inductively emerged through thematic analysis of the data; and secondly, to signpost the following discussion of the wider implications of these findings in exploring lived experiences of care at the nexus of intellectual disability and leisure travel. Three key themes emerged from the data analysis that represented the participants' experiences of care as *giving*, *attunement*, and *(in)visibility*. This chapter is mostly written by articulating the voice of the carers, however the voice of the people with intellectual disabilities is also presented where possible, further substantiating the themes. Further, like Small et al. (2012) who explored the tourist experiences of people with visual impairment, the findings of these carers and people with intellectual disabilities too, "are deliberately descriptive ... given their relative omission from the research literature and the importance of understanding these experiences to inform tourism industry practice" (p. 944). In this vein, this chapter therefore offers but one possible interpretation of the participants' reflections, and offers but one possible construction of the phenomenon of care during travel (van Manen, 1990).

These experiences, as described and understood by the carers, seem to evoke a certain ambivalence, as elucidated in the interpretation that now follows (Finlay, 2012). As stated in Chapter 4, 'Methodology', the thesis seeks to explore that which is significant, unique and meaningful, rather than to offer generalisations. As such, in this research, the carers' experiences of care were not mutually exclusive, rather multi-faceted, both relationally and contextually intricate and entangled. A number of commonalities, however, did in fact exist across their experiences. Each of the three themes described below illuminate the nuances and complexities of, and meanings ascribed to, their situated experiences of care during travel. As Kearney and Griffin (2001) have attested:

The themes are not to be viewed in isolation, but rather grasped and understood within the context of the whole phenomenon. ... They should be viewed as parts of a dynamic whole which shift and merge and are interwoven to the degree of becoming dependent. (p. 585)

6.1 Theme one – giving

This quote, “*if all is happy and calm in their world, then all is happy and calm in everyone else’s world,*” represents the first key theme that inductively emerged from the participants’ responses, the experience of care as *giving*. In the vignette below, Cassie captured the essence of, and many nuances imbued within, this theme.

It’s about picking the right things that are going to work, and that he will enjoy. The recipe for a good holiday is doing what Mason wants and how he wants to do it; if he is getting stressed out, then it is easier to fit in around him. That’s why we do one trip, which caters solely to him, and then we leave him behind on the other one – which took me a long time to get my head around, that that was okay. It’s a fine line between not letting him get his own way the whole time, because I wouldn’t do that ...

Across the participants’ data, the nature of giving was a prominent and recurrent theme. Where leisure travel represented a meaningful experience for each of the care relationships, it also represented a unique context through which experiences of giving care played out, away from the comforts and familiarity of their everyday life at home, which was very much practical and functional, yet driven entirely out of a deep concern for the other. The carers described how the giving of care included nuances such as the need to acknowledge the necessity of care and carer for people with intellectual disabilities, and their dependence on care and carer, in order to travel. This saw the carers driven by a mentality of ‘you before me’, prioritising the needs and wants of other before those of self. This is not to say that the carers’ experiences of care were entirely altruistic, but that the people with intellectual disabilities were always at the heart of the experience. In the pursuit of ease, such expressions of care lent themselves to extensive planning and preparation, structure and routine, compromise and resistance, and occupancy. Ultimately, a positive experience for an individual with intellectual disability generally translated into a positive experience for a carer. The following sections present these complexities and subtleties, and provide examples to illustrate the experience of care as giving.

6.1.1 Necessity of, and dependency on, care

This section describes the necessity of care and carer for people with intellectual disabilities, and their dependency on care and carer, in their day-to-day lives at

home and therefore in their shared and situated experiences of care during travel. Because, as Jade explained, there is *“a recognition that he can’t function in society as it is, without some assistance.”*

At a lower level, the carers described the notion of care through comments like, *“seeing to the basic functions,” “to make sure that all their needs are taken care of”* and *“ensuring daily needs of life are met.”* That is, *“understanding what one needs in order to keep one’s self safe, clean and fed.”* The carers explained how this level of care was around reasonably attending to an individual’s principal physiological and safety needs at all times, which included examples of personal care, medication, mobility and security. To illustrate, Chloe articulated her care needs supported by Gemma as *“getting help to do the essentials in the morning; so, getting dressed, having a shower, getting ready, preparing myself to leave for the day.”* In addition to these aspects of functionality, the carers emphasised *“respect”* as being an integral component of care. This was conveyed through comments like, *“I think one needs an understanding of the person and a consideration of where they are in life; respectful and not patronising”* and *“treating her with respect and dignity; as a person with rights, acknowledging her needs and not being critical.”* Some of the carers elaborated upon how a lack of care at this level could present itself as *“negligence,” “neglect”* or *“abuse.”* From the carers’ descriptions and understandings of care, one could suggest that this lower level of care reflects the notion of a ‘duty of care’, of a carer in relation to an individual with intellectual disability.

The carers described the notion of care at a higher level, as moving beyond the more apparent standards and functionality of health and life, to support an individual to fulfil their esteem and self-actualisation needs. Here, care was ultimately about *“enabling”* and *“empowering”* an individual *“to do as much as possible,” “to have a normal life”* and *“to have a good life.”* Crucial to enabling such a life, the carers explained, was how this enabling was achieved through a number of *“actions”* centred upon *“providing a platform for their own independence,” “supporting them in their decisions,” “encouraging self-determination”* and *“fostering self-reliance.”* To illustrate, Alyssa expressed:

It's just putting the things in place, providing the assistance so that she can actually do what she's capable of doing, and with any luck, extending what she's capable of doing; it's just help to do the things she needs to do but also the things she would like to do.

To illustrate further, Gemma expressed:

It's enabling somebody to do what they need to do, to achieve their goals; to help them to achieve what they want to achieve. To help them meet the goal of life and health, and to be able to successfully support them in being able to achieve what they want to achieve.

The carers emphasised "*autonomy*" as being an integral component of care; that "*everyone has their own autonomy,*" and that it is at the discretion of an individual as to "*whatever shape that takes*" or "*whatever form that may be.*" To illustrate, Gemma shared an example of what she described as being "*a minor level of support*" for Chloe, articulating, "*sometimes it's letting her wheel herself even though it's slower than my walking pace; letting her wheel herself when she wants to wheel herself and letting her go where she wants to go.*" Some of the carers explained how there was a fine line in affording an individual with intellectual disability too much or not enough autonomy. Too much autonomy was "*neglectful,*" where carers gave examples like, "*doing the bare minimum slash not enough*" or "*not sort of following through on things; not seeing opportunities to make a difference to the person.*" In the same vein, not enough autonomy was "*overbearing,*" for instance, "*fussing too much,*" "*to take over*" or "*overdo it.*"

A couple of the carers elaborated upon the need to find a responsible level of autonomy, "*without being overly intrusive to someone's personal freedoms and wellbeing,*" or "*imposing, because you can, your ideas of what somebody should do, or should want to achieve.*" Instead, to care was to take on more of a "*supervisory role,*" being "*perceptive*" enough to "*know when to step in,*" "*as in, when needed.*" Here, care could achieve a balance of autonomy-responsibility through the actions of "*prompting*" or "*reminding,*" "*directing*" or "*guiding,*" and "*suggesting*" or "*role-modelling,*" in addition to offering "*motivation*" or "*encouragement.*" From the carers' descriptions and understandings of care, one could suggest that this higher level of care reflects the notion of a carer acknowledging the dignity of risk to an individual with intellectual disability.

While the carers described varying degrees in the level of “*help or support*” required by the people with intellectual disabilities presented in this research, common to all was the fact that they were necessarily dependent upon either an accompanying carer or companion if they were to partake in the travel experience. This was conveyed through comments like, “*she would have to have someone with her,*” “*he would not be able to travel on his own*” and “*I can’t imagine her ever being able to travel anywhere by herself.*” Chloe for instance, articulated how “*I will travel with companions for the rest of my life. I will always be at this level of independence; there is going to be no cheesy Hallmark movie of my grand recovery.*” For some of the people with intellectual disabilities, their dependency was around their functional mobility and/or personal care, while for others – the majority in this study – it was around their communicative and cognitive capacities, as illustrated in the following section.

Capacity for comprehension

For almost all of the people with intellectual disabilities, their dependency on the need for care was around their expressive and receptive communication abilities, as well as their cognitive capacity for comprehension. Although all of the people with intellectual disabilities presented in this research were aged eighteen years or older, the carers described many of them as having “*the thought process*” or “*the intellectual understanding of maybe a six- or seven-year-old.*” The carers explained how, during experiences of travel, this limited capacity for communication and comprehension became more pronounced for the people with intellectual disabilities, emphasising the necessity of care and their dependency on it. The carers commented on how time, place, money and safety were abstract concepts that were especially difficult for some to comprehend, as were the general processes of the tourism system.

In terms of place, the carers described how some of the people with intellectual disabilities did not seem to understand that geographically they were somewhere else. Spatially, this limited comprehension of place offered an interesting perspective, which contrasted somewhat with the emphasis the carers placed on travel as a significant and meaningful experience for the people with intellectual disabilities. To this effect, Alyssa articulated, “*She obviously didn’t appreciate the*

enormity of being on the other side of the world; we could have been in Auckland.” Similarly, Shelby articulated, *“I don’t know if she has any concept of, say if we go to Australia that we’ve actually gone to another country; in her mind, Australia may as well be Otorohanga.”*

In terms of money, the carers described how there were problematic issues around money management for some of the people with intellectual disabilities. Therefore, the giving of care entailed a need to enforce *“strict rules”* around spending, especially as some of the individuals misapprehended the very concept and value of money. The carers conveyed this through comments like the following. *“They don’t understand how much they’ve got and they don’t understand the value; five dollars equals five hundred dollars, there’s no difference.”* In addition, *“they wouldn’t know what a twenty-dollar note is, but if I say a green one, they can bring me a note.”*

In terms of safety, the carers commented on how some of the people with intellectual disabilities were neither *“street wise”* nor able to *“necessarily understand the dangers of being in strange places.”* They explained a need to direct their attention to the actions of getting in and out of cars, crossing roads and navigating traffic. In contrast, a couple of the people with intellectual disabilities themselves expressed concerns around their safety and a heightened sense of some danger, even if unfounded, illuminating notions of risk and vulnerability. Jacob, for instance, articulated that *“you’ve got to be scared of them plane crashes.”* Similarly, Anastasia expressed:

I get a bit worried, especially in Australia where there are those pesky animals. I thought I saw a red back spider in my cabin and in the bathroom when I went to the toilet; I know that they’re red backs and poisonous because they have a little bit of red on their back. American point of view is the big Hollywood sign; I would really love to go up there but it’s a big trek and it says in the grass that there are poisonous spiders and stuff. I’m not really good with bites actually; I’ve never got bitten but I just have to be cautious. Same with rattlesnakes; they will tell us straight away; you know they are there because of their tails, because they rattle. I know that I need to be aware that there are rattlesnakes breeding somewhere, so just don’t stand on them or “boom,” you’ll get bitten.

Mostly, the carers described how the people with intellectual disabilities had limited capacity to perform straightforward activities in their day-to-day lives, “*let alone [in] navigating the travel process.*” The “*logistical aspects*” of the travel process and systems – whether that be “*money, passports, finding directions, accessing information,*” “*looking at signs*” or “*seeing or hearing boarding calls*” – were explained as being “*challenging*” and “*far beyond his/her capabilities.*” Considering that a number of the people with intellectual disabilities “*probably wouldn’t understand what was going on,*” the carers explained how the experience could amplify a “*loss of ability to think rationally*” and spur on emotional responses like “*stress,*” “*anxiety,*” “*worry*” and “*panic.*”

The potential implications of such emotional responses lent themselves to notions of risk and the necessity of the carers in “*essentially taking full responsibility.*” This was conveyed in their experiences of giving care through comments such as, “*it’s just sort of knowing when to step in,*” “*making sure she is safe,*” “*to keep her safe because she doesn’t necessarily understand the dangers of being in a strange place*” and “*to ensure dangerous boundaries are not crossed.*” Some of the carers explained how many of these concerns were just as prominent in their day-to-day lives, and that tied to notions of responsibility was a lack of control over the potential risk involved, a recognition that “*anything could happen.*”

As such, the carers emphasised the necessity of and dependence on care, in order to be able to travel, which was conveyed by the carers through comments like, “*it’s just not an option; it’s just not something we would do*” and “*there’s no point in unnecessarily putting someone through that; a situation that’s maybe going to be stressful or frightening.*” As an example, Aroha articulated, “*It’s the constant worrying about, ‘did they take on what I said? I know that I have my limits with them but you’re kind of slightly panicking; that’s where the drainage comes with the job.*” As a further example, Ava articulated, “*we don’t leave her alone at all, it just doesn’t work, which is a real shame for I would love for her to have some more independence in that sense.*” From the carers’ descriptions and explanations, it seemed that the giving of care presented a tension between responsibility and

potential risk, which was at odds with their ideal of care in encouraging independence. To this effect, Cassie expressed:

He flew to Wellington with his sister. My husband and I put them on the plane at this end [Queenstown], and then at the other end they were met. We were checking the weather; we just had everything crossed that they were going to get there. We just think back to last Christmas when we tried to fly to Wellington; we left Queenstown, we were just about to land, and they aborted the landing and took us back to Christchurch. That's the kind of thing that we just couldn't take the chance that it was going to be okay; because there is no way that he could cope by himself, he just wouldn't understand what was happening. We had to wait around in Christchurch; we were sent out to a hotel for a night, given a taxi chip. It's just, what would happen in that scenario? There is no way known that that would work; we would have to be in the car on our way to Christchurch to meet them immediately.

Financial dependency

A further nuance reported by the carers in the giving of care related to the fact that, in order to participate in the travel experience, not only did the people with disabilities have a dependence on care, but also on access to finance. The carers described the travel experience as being largely inaccessible to people with intellectual disabilities, and that they were often financially dependent as a result. They explained how, in their day-to-day lives, most people with intellectual disabilities typically face high rates of unemployment, receive government “funding” or “benefits” or “have no income.” This “limited budget” usually covered the cost of their disability support services and medical needs, before considering the cost of travel. This was conveyed through comments such as, “a lot of it comes down to cost” and “the cost really does restrict it a lot,” or “money is a big thing,” “it is just financially a challenge for so many” and “the financial side is the biggest hurdle for them.” Some of the people with disabilities offered their agreement with this perspective, describing “money” and “finances” as being noteworthy barriers to their participation in travel. They explained how they needed to “save up in a safe way” and be “very financially astute” as travel is “very expensive.”

Further, some of the carers elaborated upon the disparity between the costs of travel for people with disabilities in comparison with that of the non-disabled population, which was conveyed through comments such as, *“it costs a lot more to travel than it would for you or me”* or *“they’ve got to pay a lot more.”* The carers attributed the additional increase in cost to their dependency on care, which they conveyed through comments like, *“it’s financial if you require a care person”* or *“if they go, they have to take somebody with them.”* To illustrate, Lily articulated, *“he used to have to pay the whole whack for the carer; so, as well as their food, he’d have to pay their fares and accommodation, plus his own.”* Similarly, Gemma expressed:

So few people can afford to travel and pay for someone else’s travel; it’s like having to pay business class but only going economy class, and then being in a position where you can’t afford to fly economy but having to go premium economy.

Overall, the carers relinquished that the financial inaccessibility of care and travel meant that for many people with intellectual disabilities, they *“wouldn’t be able to afford to go;”* *“it’s just not doable.”* They questioned what could facilitate greater financial accessibility of those people with intellectual disabilities who might like to travel, and who indeed might require the support of a carer. They maintained that participation in travel could be more *“cost effective”* for people with intellectual disabilities and *“cost neutral”* for carers, for instance, *“free,” “discounted,”* or *“subsidised”* admissions, fares, rates and package deals. Chloe spoke to the first point and articulated, *“I can’t sit in an economy seat because of my blood circulation, so I had to go into premium economy and pay the price. No concession, no whatever.”* Gemma spoke to the second point and articulated, *“I think that it should be fair, that the carer is cost neutral, especially when you are travelling in a professional sense, but also, if I can travel for leisure, why can’t someone else just because of a disability?”*

In recognising this, the carers seemed to appreciate that, as a sample, they were potentially representative of a minority, *“lucky”* to have the financial means with which to facilitate and engage in experiences of leisure travel. This was conveyed through comments such as, *“in order for him/her to travel, it would always have to be us paying for things probably”* and *“he/she is in a unique position where his/her*

parents could pay for his/her trip and a lot of mine.” Jade articulated that *“finance wasn’t a problem, we were financially able to do that, and that’s a big compromise for some people.”* To illustrate, Shelby expressed:

I have always worked full time so that I have been able to fund the children’s trips and enable them to do that; not every family are in a position to have been able to do that, but then that has been my choice, to work hard to provide that for them.

To illustrate further, Paul offered an explanation as to how funding of formal care to support the travel of people with intellectual disabilities works. He expressed:

I think the family pays for a lot of it to be honest; the family pays for all the person’s savings. Our cost would be the travel cost and then the cost for all of our hours. That’s something that has to be negotiated; you could basically say 24/7 but that would drive the cost up heaps. Man, if we got paid 24/7 hours a day - that would just be crazy, we would get so much money it’s silly. Most of the staff will just come to sort of agreement, it’s just part of the deal. I just don’t even worry about it too much, it’s one of those things where it’s give and take. We get to go on holiday, there’s bonuses for us too; we get to go away and do something that we wouldn’t normally get to do, and we’re getting paid. We can’t really complain.

Not only was it about the carers being financially able to support the travel of the people with intellectual disabilities, but it was about their willingness to *give* the care too. The carers offered mixed descriptions of their care relationship. Two of the three support workers expressed, *“a support person but also a bit of a comrade”* and *“it wasn’t a carer taking a client, it was like we were family going out on a holiday; she wasn’t like a client at all, she was like whānau.”* In comparison, the third support worker Phoebe suggested that she felt somewhat compelled to accompany the travel of her client Gracie, contending that the travel experience simply would not have been a possibility for her otherwise. She expressed:

I just felt that with everyone else, they just weren’t interested at all, and if I didn’t volunteer, she wouldn’t have gone. I just thought, ‘what’s a few days;’ that could make her happy for a whole lifetime because she’s got those memories.

Then, in terms of the informal carers, one mother stated, *“I’m one hundred per cent caregiver”* while another mother stated, *“I’m mum, it’s not care and support; this is my role as mum, it’s what I do.”* A couple of the other carers who were also mothers described a desire for another carer to travel with their children. However, they raised concerns around a need *“to have a really strong relationship with that carer; to have a lot of faith and trust in that person”* and *“a person genuine in their affection and in wanting what was best for them.”* In addition, there were a couple of other carers who described a desire for a friend rather than a carer or support worker to travel with the people with intellectual disabilities. To illustrate, Lily expressed:

I had always wanted Noah to have somebody else, a friend or a mate to do it with; it’s never happened so it’s become me. I would miss it if it wasn’t me but if the right person came along, I’d be more than happy for him to have somebody else in his life, but it’s very hard to find that person. None of the others have actually got a friend going with them, they’re all taking staff; I would rather it be me than staff. The staff here are friends but only because they’re staff; if it was a real friend that would be different.

Gemma too described this desire, in addition to explaining the fluidity of her care identity, as formal-informal. She expressed:

It kind of slipped from one to the other depending on what I was doing; first thing in the morning I was carer, part way through the day at the museum or whatever, I was ‘friend.’ Because also at that point, I wasn’t really required as a carer and she probably could have got around without me, so it was at that point that I became friend. I think it’s important also, that it was legitimate for her to be able to have gone with a friend as well, because I was thinking about it and it would also kind of suck, to have to go with a care worker that you didn’t get along with purely because they were a qualified care worker. We’d be travelling but we slipped into friendship right, and that part of it was really important for her. So she should be able to travel with whomever she wants and anybody in the future.

Travel was representative of an important medium through which the carers could facilitate the enabling of a ‘good life’ for the people with intellectual disabilities.

6.1.2 For him/her

With an emphasis on trying to facilitate independence for the people with intellectual disabilities, there was a ubiquitous undercurrent of the travel experience being primarily *for* them, a further nuance revealed from the giving of care. Across the participants' responses was a prevailing understanding that at the heart of their participation in the travel experience was a priority toward the people with intellectual disabilities. The carers conveyed this perspective through comments like, "*it was completely for him/her*" and "*this trip was all about him/her.*" Or, "*he/she was totally a part of it, absolutely; it was his/her trip,*" "*this was his/her trip, I went away knowing that it was his/hers*" and "*it's what he/she wants to do; it's his/her dream holiday.*" It seemed experiences of care, then, were about prioritising the needs of other (individual with intellectual disability), ahead of self (carer). In this way, expressions of care were seemingly one-dimensional, which was conveyed through comments like, "*It's very much a one-way thing,*" "*I'm very happy to accommodate him/her*" and "*I'm pretty much doing it for love.*" To illustrate, Alyssa expressed:

We were very conscious that all the decisions, everything, was going to be what Sadie wanted and what was going to work for her best. I don't know many people that go to Paris for eleven days and spend five of them at Disneyland.

To illustrate further, Jade expressed:

I think that's probably the main thing about it, is that by him and I going, it was individualised for him; taking into account what he was needing, wanting, choosing. He and I went to all the appointments with the travel agent, everything done together. Essentially, he was regarded as a 'travelling companion' of myself, and that is how it was. We ... He ... made the decisions about what we would do over there after the suggestions were given to us. We had a number of trips into the agent with all of this going backwards and forwards. Nothing was done without his consent, he signed for everything; we had full control over the planning and decision-making, both of us, it was a two-way thing.

Planning in the pursuit of ease

This notion of being for him/her was in the main, centred on extensive planning, prompted in the pursuit of ease in the giving of care. The carers described how they engaged in "*lots of planning*" and conveyed comments like, "*I'm the one that*

always has everything planned; everything has been done ahead of time” and *“it’s getting more prepared each time.”* Mostly, they explained how this was in an attempt to minimise the complexities involved in getting to and from the destination, which they conveyed through comments like, *“it’s the whole rigmarole of getting there,”* *“just doing it, just getting where we need to go”* and *“the light’s at the end of the tunnel, we’ve just got to get there first.”* Georgia stated to this effect, *“it is masterminded down to the last minute.”* Further, many of the carers questioned how ‘leisurely’ the process of travel actually was, instead contending it to be *“mentally-draining,”* *“continuous hard work”* and *“certainly not as relaxing as it could be.”* Mia articulated, *“people think of travel as this grand relaxing experience and it very rarely is.”* To illustrate, Cassie expressed:

You are pretty much dreading getting from A to B; it’s such a tedious, long nightmare of a trip. It’s just like travelling with a toddler; you’ve got to do everything for them, and you’ve got to be watching them the whole time. You’ve got this appendage with it, that you’ve got to constantly be looking after him the whole way through. There are so many things I would love to be able to do but it’s just logistically, “how on earth is that going to work?” I think there so many things we would do if it were easier; there are lots of things that I don’t do because it’s in the ‘too hard basket’.

Ultimately, planning for and then carrying out travel was reportedly in the pursuit of ease. This was conveyed through comments such as, *“it’s just thinking of all those things that are going to make it easier,”* *“just making it as easy and as stress-less as possible,”* *“it’s almost like you’re trying to streamline it, so everything just runs smoothly”* and *“really just being organised to try and keep it easy.”* A number of the carers elaborated upon the lengths they would go to in determining the finer details of their travel, *“finding out as much as possible”* and *“doing a lot of research.”* This included for example, consideration of the most direct, timely flight paths, and the likes of check-in times, transfers, layovers and time zones. To illustrate, Cassie explained, *“I will spend a lot of time shopping around finding the easiest, most direct flights that get us there at a sensible time.”* In a similar vein, Jade articulated, *“the flights were early in the morning so that probably wasn’t achievable; now he’s not a good morning person, not able to get up in the mornings and hasn’t done for years.”*

The carers also explained how ease in terms of the practicalities of travel often meant that cost became secondary, offering the examples of paying for a sky couch on a long-haul flight if that meant it was more conducive to sleep, or paying for an airport transfer rather than taking public transport if that meant minimising stress. Such perspectives were conveyed through comments such as, *“we are paying the extra and we are doing the simplest thing,”* *“it would be the easiest option as opposed to the cheapest option, without a doubt,”* and *“that worked well; that was worth paying the extra money for him/her to have that.”*

In addition, many of the carers described how planning in the pursuit of ease often meant incorporating familiarity, both in process and in place. Some of the carers explained their tendency to visit destinations that they had visited in the past and had reflected upon as being a positive experience. They were therefore inclined toward attempting to emulate such travel. The carers conveyed this perspective through comments like, *“if we find somewhere that’s good, we stick with it”* and *“we have found what works, why should we reinvent it?”* Also, *“knowing where I am going, being familiar with where we are heading to”* and *“it’s familiarity, that’s what you need; you’re better off, him just doing exactly what he knows, it’s all easy.”* They elaborated upon the benefit this had for the people with intellectual disabilities, in terms of knowing what to expect and of enhancing memorability, and for the carers in being acquainted with the destination, the activities and attractions they could participate in and visit, and the type of transport and accommodation they could utilise. To illustrate, Cassie expressed:

If we are going away to Noosa for a week, Mason will know that we will go to the beach, walk down to the coffee shop. Even more to the point, where is good to eat, even down to the scones he likes at ... We’ve had the same house the last couple of years and he just knows it; he walks in the door, knows where to unpack his bag and we will walk down to the shops. Its familiarity, that’s what you need.

The need to know

A number of the carers described the importance in communicating plans of travel to the people with disabilities, which was due to a *“need to know in advance what was going to be happening”* or *“going on.”* The carers explained how both the timeliness and the nature of such disclosure were significant considerations

within this. In terms of timeliness, they elaborated upon when the most appropriate time was to tell of the forthcoming travel, given that some of the individuals needed time to mentally process and prepare themselves. To illustrate, Alyssa commented, *“you can’t just spring something on her, you’ve got to sow the seed and give her time to process a holiday,”* although the emotional responses of the people with intellectual disabilities varied *“if told too far in advance.”* Where one individual with intellectual disability could not contain his or her excitement, another individual’s anxiety would heighten in the build-up that came with waiting for the travel to take place. In terms of the former perspective, Mia articulated, *“she needs to be told obviously, and that’s a bit tricky as to when you tell her because, sometimes, if you tell her too far in advance, she just gets so excited about it, but she does need to know.”* In terms of the latter, the carers conveyed this perspective through the following comments. *“I actually won’t tell him/her pretty much until it’s about to happen because otherwise it’s a sense of getting all anxious in the build-up of it”* and *“you have to try and explain things in a way he/she doesn’t get anxious because he/she is waiting for something to happen.”*

In terms of the nature of disclosure, the carers elaborated upon how they would communicate the forthcoming travel verbally and visually. They offered examples of their use of tools like a *“daily schedule”* or *“holiday spreadsheet,”* *“books”* or a *“holiday diary.”* They conveyed the benefit of such tools through comments like, *“preparing a sense of interest,”* *“keeping him/her involved in what we were doing,”* and affording the *“feeling of having some control over what was happening.”* To illustrate, Alyssa expressed:

We pretty much kept her involved as everything happened; we wrote it all down for her so she could see it and show people, we printed off a map that actually had icons of the major attractions, ‘which of these do you want to see?’ and then, ‘let’s plot out what might be a good timetable’.

Mostly, the carers understood that communicating plans of travel to the people with intellectual disabilities was important given their ‘need to know’. Yet, also given the people with intellectual disabilities’ need for structure and routine, any change in plans or variance from what was scheduled would heighten anxiety or be met with resistance. The carers conveyed this contention through comments like, *“he/she doesn’t react well,”* *“it would be tantrum time and it would take a bit to*

settle him/her down,” and *“it backfired; he/she would get a bit anxious when it changed.”* Georgia expressed:

Sometimes you just have to change your plan. He just sort of has that inflexibility where he can be very stubborn; he did go through a phase where he would completely refuse to do anything if he didn't want to do it.

Here, some of the carers described a tension of inflexibility-flexibility that came with the need to plan but, in the same vein, a need to have some space for movement within this. As an example, the carers conveyed this perspective through the following comments. *“I think it's good to plan activities but not necessarily every day; the point was that I planned it so it wasn't so jam packed that there was no room”* and *“when you plan it, you plan it not to be too stressful I think; I think in some ways, planning less, having free time to do things.”*

As an example, Alyssa explained:

We didn't pre-book too much in terms of having to be somewhere at a specific time; we only booked the Eiffel Tower and the ballet one afternoon. Again, the tickets were cheap, so if we didn't make it, it wouldn't have mattered so much. We deliberately didn't book a lot of stuff to do because you just never know what mood she's going to wake up in, or if she has a seizure. ... She does tend to have seizures when she's stressed; if she had a seizure, we might not have been able to do much stuff. We were very aware that some days we might just have to sit in the apartment, but it didn't end up happening, thank goodness.

The carers described how there was benefit in *“spontaneous relaxation,”* and *“not feeling like, ‘oh god, we've got to do this.”* In a similar vein, a couple of the people with intellectual disabilities verified such perspectives, which they conveyed through comments like, *“you have got to have rests sometimes; you can't go out all the time”* and *“you're sort of obliged to be spontaneous because you don't really have a choice; there are no reference points.”* Relatedly, the carers described the benefit in seeking to be more patient and tolerant, taking their time and being in flow, where possible. The carers conveyed this perspective through comments such as, *“I guess we are all just in that space to be a bit more obliging than usual; happy to compromise on things,”* and *“we're not in any hurry,” “we've got plenty of time”* or *“we always allowed ourselves masses of time.”*

Furthermore, many of the carers described how a tension of inflexibility-flexibility around the need to know and the need for structure and routine also held dimensions of restriction and compromise in the pursuit of ease. Some of the carers explained how a dimension of restriction could manifest when attempting to meet the people with intellectual disabilities need for routine, and in minimising the stress that could otherwise ensue. The carers conveyed this perspective through comments like, *“all of your usual coping strategies and normal routines are thrown out the window”* and *“you are constantly exposed to new things every day rather than a routine.”* The carers’ descriptions and explanations suggested the need to alter or abandon their own or their family’s own wants and needs. To illustrate, Cassie expressed:

We had the idea that we could take him to Fiji this year with the girls. We book it all and nope, not going to work. You can’t really send him an idea of something new. We did think that we would just do it, just get to the airport and say, ‘surprise,’ but it’s just not worth it and it would backfire. Mason has just said time and time again, “I don’t want to go; I’m not going.” We’ve just thought, “really, what are we doing?” I thought that he’d love it once he got there and we’ve been trying to sail the idea to him, but it’s just not worth it. He has categorically said, “no, I don’t want to go,” so what is the point? All it will end up doing is potentially ruining the holiday for everybody else.

As a further example, Georgia described William’s preoccupation with *“not missing anything,”* and especially *“not missing school.”* She explained how she felt as though she and her family should be able to travel, but at the same time recognised the need to acknowledge his anxieties around not breaking away from his routine, expressing, *“it’s probably the thing I find hardest to deal with, a lack of sensitivity; he loves routine; he hates change.”* This incongruity meant the need for compromise. She commented, *“we have adapted what we were going to do; meeting him halfway and thinking about his needs.”* This resulted in cutting down what had been tentatively planned as a five-week holiday to Argentina, Bolivia, and Peru, to a two-week holiday during the school term break to Argentina. Georgia articulated, *“We decided that from now on we wouldn’t do any trips where he misses school because he just doesn’t cope with it.”*

To elaborate upon the above examples, where each carer and individual with intellectual disability wanted to go, or what they wanted to do, could differ, this

variance could impose a dimension of restriction on the carer. It seemed that the carer would seek to reach agreement or compromise their own needs and desires. To this effect, for Ava it was in relation to the safety and suitability of a particular destination. She expressed:

Where we can go is restricted because of her; I would like to go to other places but I just think it would be stressful for Francesca and too stressful for me; to go to places where I wasn't sure of her safety; places that aren't suitable for her to go.

To illustrate further, Alyssa recalled a couple of instances of resistance and compromise with Sadie. She articulated, "*Sadie had very definite ideas about what she wanted to do,*" and "*we were always clarifying what we were doing and what she wanted to do; it was all within the realms of what she wanted to do.*" She described how resistance came about if Sadie perceived a threat – such as time constraints or a change in plans – to achieving these activities. Alyssa explained how "*a perfectly rational decision*" that might have led to a time constraint or a change in plans was met with resistance, where Sadie would "*get really snotty, 'oh, I suppose we're not going to...'*" or "*you're going to ruin my trip completely.*" Alyssa conceded that such resistance necessitated compromise on her part, but emphasised a lack of compromise on Sadie's part. She articulated, "*There were a couple of things I would have liked to have done that she was adamant she didn't want to do, so we didn't.*" She then conveyed the lack of compromise through comments such as, "*so again we changed plans; we made that happen*" and "*she sounds like a spoilt brat, which she was; that was the decision though, we've spent however many years trying to get her to compromise on things.*"

The dimension of restriction and compromise also implicated the other family members of some of the carers, and the intricacies involved in accommodating the needs of each individual or in managing certain relational dynamics. As an example of accommodating the needs of each individual, Cassie described how as a family, they would like to travel back to the United Kingdom, where they are from originally. She explained, however, that their ability to achieve this was restricted in that "*it's too far to go,*" both in terms for the length of travel time for Mason and, additionally, to the length of care time required for him at home, if the rest of the family were to go. She relinquished that idea, saying, "*it's kind of limited what*

we're able to do with his sisters; that is sort of hindering it at the moment." The compromise was their decision to wait until a later date.

To illustrate an example of managing certain relational dynamics, Harriet recalled an incident at their family holiday home, where Ethan had *"lashed out"* and hit her eldest grandchild. She described how his escalating anxiety and behavioural problems meant that she *"had to make the decision that he couldn't cope with holidays with the grandchildren."* While she acknowledged that his exclusion was necessary and in the best interest of all other extended family members, she expressed a sense of loss in having done so, explaining how his entire life they had experienced these annual family holidays together. To illustrate further, Jade recalled a time where she grappled with the decision of who would travel with Liam, on a holiday to Rarotonga. She expressed:

My husband didn't go, he said it was his trip. The other thing is a threesome is not so easy; his needs are quite difficult and there are some inter-dynamics about it all. If the three of us were away, I would feel sometimes 'in the middle,' but then [husband] probably feels in the middle of Liam and I, and Liam probably feels in the middle of us two. We make it work; I am very fortunate that [husband] is so considerate to make it work but it's not always easy.

Bringing the home away

In order to minimise the stress of being away from home, the nature of giving care was reportedly a need to be organised and take up 'occupancy.' To illustrate, Georgia articulated how *"I will always have a bag of tricks and they are always with me; it's just what you need to do with a toddler really, it seems very baby-ish but that's just the way it is."* They explained how this could be a mechanism of distraction or to minimise boredom, irritability and stress, both during the travel process and at the destination. To illustrate further, Jade expressed:

Liam, due to his problems, chooses, or is not able to, sit back, kind of relax, and kind of do nothing; in the fact that he doesn't read a book, he's not so keen to sit and sort of be aware of time going by, like if you're at a beach or something. So, if you're travelling, one needs to be aware of, and ensure that there is good occupancy so that he's not bored, because that's what would happen.

For the most part, during the travel process, the carers frequently described the increasing availability of in-flight entertainment as a form of occupancy. The carers conveyed this perspective through comments like, *“he/she loves screens; he/she can watch a screen for hours”* and *“he/she is just in heaven really, with his/her own remote control and choice of movies.”* In addition, the carers described various other mediums such as reading material, activity books, knitting, music, and electronic handheld devices. To illustrate, Ava expressed:

She can decide what to pack in her bag and take as far as activities go; often we’ll go shopping and she’ll choose something that she wants to take on the plane with her to do, usually she chooses one of her soft toys.

The people with intellectual disabilities verified such perspectives, which they conveyed through comments like, *“my cell phone to play games or to listen to music,”* and *“headphones; I like my music. I love my iPad. I like colouring in, so much fun.”* It was understood that in preparing for occupancy, *“you keep him/her comfortable”* and *“happy,”* and thus the pursuit of ease was made more attainable. This notion of keeping the people with intellectual disabilities comfortable and happy also related to the element of packing as an important consideration before during and after travel. The carers conveyed such considerations through comments like, *“packing the right sort of clothes,”* *“taking cognitive note of all their possessions”* and *“making sure that everything was packed up.”* A few of the carers elaborated upon this perspective, describing how *“packing for themselves; doing their own packing,”* could be empowering for the people with intellectual disabilities, affording them with a sense of ownership over the process. To illustrate, Jade articulated how she would pack an alarm clock for Liam to set and be responsible for, in terms of getting them up and ready to *“achieve what had been planned.”* To illustrate further, Ava expressed:

She gets pretty involved in the packing of her bag that she takes with her on the plane and making sure that we’d covered all contingencies. We’d have wipes, a mat that I put under her when she goes to sleep in case she wets her pants, a change of clothes, and have some little snack in there because sometimes it’s a long time between meals.

Sophia provided an interesting perspective around the way in which packing could also lend itself to implementing aspects of their routine at home, while away. She expressed:

If there's a little chest of drawers or something there, she likes to have her clothes all there in the drawer rather than live out of her suitcase for the week. The suitcase then goes in the wardrobe and her shoes all go in there. She likes it to be like it is in her bedroom; everything set out in drawers or hung up. So that is very much like the routine here in the bathroom and that if she can put deodorants, shampoos and all that upon on top of a little shelf or something, she will.

A few of the carers also described a range of person-centred considerations they had around the principal care needs of the people with intellectual disabilities. Mostly, these seemed to surround personal care, and particularly in regard to food and toileting. A couple of the people with intellectual disabilities had specific dietary requirements that needed adhering to while away, as they would at home. To illustrate, Georgia elaborated upon how it was not always easy to follow, and that she appreciated that travelling was a rarity. She felt therefore, that she could offer some leniency, and explained:

He does have a particular diet when he's at home; I do sort of stick to it but I'm not fixated on sticking to it. There are some times when something takes his fancy and I don't say, 'no you can't have it'.

To illustrate further, Ashleigh elaborated upon Brooklyn's coeliac dietary needs and how it was essential to organise around them: *"Is there food here that she can eat? Maybe we should bring something that she can eat with us?"* She did however acknowledge that aside from not being able to eat *"street food,"* her intolerances did not present any major limitations and, as a family, they sought to be resourceful while also attempting to try the different local foods of the destinations they visited. She said:

We had to buy bread in the pharmacy. We had to have our own gluten-free pasta, which was no problem for any restaurant to cook for us, you know, we just gave them a bag and said, "Just put some tomato sauce and cheese on it," and they would say, "no problem, no problem." But we had to provide it; that was a big one in Italy.

6.2 Theme two – attunement

This quote, “*trying to pick up on their emotion; staying in tune with how they’re feeling,*” represents the second key theme that inductively emerged from the participants’ responses, *attunement* in the care experience. In the vignette below Ashleigh captured the essence of and many nuances imbued within this theme.

I think what is important, is trying to build an understanding of one another, and then something that is more difficult, is to act upon that understanding, and to understand what the triggers are. In terms of emotional responses, it’s quite essential to understand what triggers other people’s emotions and work with that; we’re not always successful with that, but we try. It’s very important, in order to build a good relationship, that you show that other person that you love them and that you’ll be there for them no matter what the difficulty is.

Across the participants’ data, attunement in the care experience was a prominent and recurrent theme. What this theme revealed was that attunement was a natural inclination or disposition of the carers to be present with the people with intellectual disabilities and their emotions, in the expression of their experience. Attunement therefore referred to the perceptiveness and responsiveness of the carers; that is, their ability to intuit, sense and feel the emotional needs and moods of the people with intellectual disabilities. Simultaneously, attunement meant that the carers were perceptive of their own emotional needs and moods, responsive by way of managing or suppressing the expression of these, if they were to attune sensitively to the potential reactivity of the people with intellectual disabilities. In this way, attunement is affective and expressive, as it is mediated through and constitutive of a closeness and connectedness of care relationship; it brings both an immediacy to and a mindfulness of the expression of care, which in turn evokes a certain presence and feeling of being ‘at one’ with another being.

6.2.1 ‘Mothering’ disability

Nine of the 15 care relationships presented in this research were mother and child. In addition, a sister and an aunt described their care relationship with their brother and their niece, respectively, as comparable to that of mother and child too. Sophia for instance stated, “*she is pretty much like a daughter to me.*” These carers offered rich narratives of their personal historicities, as they candidly shared their

experiences of what I have termed ‘mothering’ disability, as much of the data suggests a gendered nature of care. While much of this data specifically offers insight into their lives – past and present – at home, importantly it helps to frame their experiences of care while away. That is, it illustrates the relational dynamic of their care relationships, and the motivations driving their pursuit of leisure travel experiences.

Many of these carers described a feeling of “*guilt*,” as they themselves felt they were to blame as the cause of or reason for, their child’s impairment. This perspective was conveyed through comments like, “*I don’t know if maybe there was a little bit of guilt in thinking, ‘oh god, it’s my fault that they’re like that’*” and “*there was that little tinge of guilt there that meant I always made sure they came first.*” They seemed to have offset some feeling of this guilt with an understanding that they could have neither known nor prevented their child’s disability, which they conveyed through comments like, “*well no, it’s not my fault,*” “*it was just one of those things*” and “*I think a strength would be being positive, because I never thought anything could beat me.*” To illustrate as an example, Cassie described how she had not known that she was a carrier of the hereditary Fragile X syndrome that her first child Mason was born with, until his birth. She explained how, with successive pregnancies, her and her husband had decided to find out through Chorionic Villus Sampling whether their two daughters were carriers, and the subsequent action that they would take. She articulated, “*we were very black and white about what we would do; whilst we wouldn’t swap Mason for the world, we wouldn’t knowingly bring another child into the world with an intellectual disability.*” To illustrate a further example, Mia described how disability had not been anticipated in adopting Anastasia from Russia. She explained:

We knew there would be some aftermath from being at an orphanage, but we didn’t expect the Foetal Alcohol Syndrome and intellectual disability. It was a few years before we got her diagnosed; she was pretty challenging from the moment we got her but we just thought that was the trauma of moving away and not really seeing life and things beforehand.

A number of these carers described the nature of their child’s disability and consequent dependency, and explained the intensity of this care work, through comments like, “*it’s hard work, or not so much hard work, but it’s always there*

when its seven days a week; it's basically just 24/7, you're pretty much doing it for love" and "as a mother, you've got that commitment from the day they're born; that you'll just look after them no matter what." They did not seem to resent their circumstances, however; for instance, Sophia articulated, *"there's nothing that I think, 'oh, I wish I could go and do that'; there's nothing there that I want to do so desperately that I feel hindered by the fact that I'm looking after Emma."*

These carers also described how their maternal caring role would be ongoing throughout the course of their child's lifespan. Rather pragmatically, they conveyed this perspective through comments like, *"it's very much a 'take each day as it comes'"* and *"we need to be involved for the next, well ... forever, and that is quite a daunting thought sometimes."* They did express some concern as to who could provide care in the event that they were unable to do so, and were resigned to the likely reality of care in a residential care and support service. They commented, *"if my husband and I disappeared tomorrow, there's not going to be many other options,"* *"I know him/her inside out, which is a good way to be but it's also a dangerous way, because if I'm not here, how is he/she going to be?"* and *"what happens when I'm not able to do it anymore, who is going to do it then?"* In addition, *"that is potentially where he would have to go, to an accommodation service"* and *"she doesn't seem particularly interested in going into a residential service; she just thinks she is going to live here forever."*

In a different vein, some of these carers described a feeling of guilt that came with trying to serve the best interests of each family member individually and their family unit as a whole. They explained that the presence of disability meant managing what could sometimes be both a demanding and difficult relational dynamic when another child or partner was involved. As an example, Georgia described how the communication demands of her son's disability were met with disengagement from his siblings. She explained how her other son *"doesn't really have the understanding, patience or tolerance, so they don't really engage or have too much to do with each other,"* and that her daughter *"will try to talk to him, but it will get to the point where [Georgia] needs to redirect things."*

As mentioned earlier in this section, the dependency and demands that came with disability, and therefore with care, were greatly disproportionate to that of the carers'

other children. The carers recognised this tension, which they conveyed through comments like, *“he/she is still more dependent on us than our boys/girls are”* and *“we haven’t got the luxury of being able to concentrate on the boys/girls.”* As an example, Harriet described how she could rectify this, *“having someone coming into the house to support him or having him taken care of outside of the family home.”* As another example, Georgia, described how she thought her other children sometimes felt as though their brother received preferential treatment, for instance, when it came to the types of activities he had access to, yet acknowledged that they knew his circumstances were fundamentally different to theirs. She explained:

If we have to give William some money to do something fun with his caregiver, then the other kids see that as, “what are we going to do.” So, there’s little things like that; they don’t see it as fair. Sometimes it seems that William, you know, gets Riding for the Disabled for years, and they don’t get to go horse riding. ... They don’t mind too much, they’re not too bad; they do understand that he doesn’t have a great life in many ways.

Still, these carers sought to manage this tension, primarily by way of directing their attention equally and as best they could, to all their children. They explained this perspective through comments like, *“I like to be very involved with all the children; I’ve been very conscious the whole way through, to give individual time to the children”* and *“I think it’s important to keep the family somewhat together, and to do things and give time to the other children.”* To illustrate, Cassie explained:

I didn’t want Fragile X to be the ruler of everything we did, so I am very careful about making sure that I’ve got time for each of the children to pursue what they want to do, and not just say, “oh well, we can’t do that because Mason can’t do it.” We sort of make a way.

These carers expressed a desire to instil some sense of ‘normality’ in their family life – especially for their non-disabled children – yet simultaneously acknowledged that their reality was not necessarily congruent with that of the norm. The carers conveyed this perspective through comments like, *“so that they can lead a reasonably normal life”* and *“our family life is quite different to other peoples.”* These carers explained that this sometimes meant being attuned to, managing and sometimes relinquishing wider relational dynamics or activities with extended family and friends. As an example, Georgia explained:

I'm not sure we'd ever go and travel with friends though; I feel it would impact on their holiday, so we don't do that. I could travel with another family who had a child like William, that would be fine; but we don't really travel with other families, which is something we might do if we didn't have William.

As another example, Cassie explained:

As Mason was growing up, I was very tuneful of where we could go for a barbeque and everything would be fine, and where it would just be, "oh, we need to go home." I've chosen to socialise with people that are accepting, and I've got some friends that I am really good friends with but I know there is no point in taking him along to something because it's just not going to work. My parents – Mason hasn't had a meal at their house ever because they just don't get it at all, so we just choose to spend very little time in their company. It took me going to a counsellor to have someone say to me, "they haven't embraced him in eleven years, they're not going to, you need to get over it."

These carers also described the varied and multiple ways in which their children with intellectual disabilities experienced life as a divergence from notions of normality. They acknowledged disability as being "*all encompassing,*" "*having a huge impact*" and "*affecting every aspect of life.*" They explained, for instance, how socially their children had trouble with both their communication with others and their lack of friendships. In terms of the former, the carers commented, "*sociable in that he/she is very chatty and friendly, but doesn't really know how to go about a conversation; he/she has very poor social skills*" and "*very repetitive with his/her speech, things out of context, whatever flies into his/her mind; the attention span is there only sort of a few minutes at time, so very spontaneous and not relevant to what you're talking about.*" In terms of the latter, the carers commented, "*she would love to have a group of friends but she really doesn't,*" "*he doesn't really have friends or anything like that, so he is a bit of a loner really*" and "*socially he is okay if he is with familiar people; that is probably one of the major things, the lacking of friendships.*" To illustrate, Cassie explained:

He's very trusting, probably too trusting at times. He thinks everybody is his friend, to the point where if somebody shows him a bit of niceness, he will think they are his best friend; where in an actual fact, they are only doing it on the surface. That can be quite heart wrenching for me.

These carers tended to make comparisons between their disabled children and their other non-disabled children, describing the types of experiences one might typically have in transitioning through adolescence to adulthood. They conveyed this perspective through comments like, *“I just wish they could have experienced what all the other young ones their age would have been doing on their big overseas experiences”* and *“he’s not out there doing what an eighteen-year-old should be doing, you know, playing rugby, driving a car, getting into girls, going to pubs, going off to university ...”* While it seemed that these carers were subscribing to and measuring against normative social scripts, they expressed an understanding that the experiences of their disabled children were not actually comparable with that of their non-disabled children. To this effect, Alyssa explained:

On the other hand, it’s that certain lack of awareness on her part, which sometimes can be a good thing as she doesn’t see it as, “something’s different.” So, in an actual fact, she probably doesn’t realise some of the limitations that are placed on her. It’s sort of reminding her what she can do and what independence she can have; just trying to make it as normal as possible.

Further to this effect, Shelby explained:

They won’t have experienced all that kind of thing; that used to upset me but they don’t know what that experience would be. So, I always try to bring myself back to their experience; their experience is the experience they’re having, they don’t see anything else.

Ultimately, these carers recognised that their child’s experience was relative and not necessarily *“lesser than”* that of a non-disabled child’s, and in fact could be a *“full experience.”* Even so, these carers expressed a feeling of guilt around not doing enough, and wishing they could do more, for their child. Harriet, for instance, articulated, *“sometimes when he’s home, I just get upset; especially in recent times because we would love to do so much with him but we can’t.”* To illustrate further, Alyssa explained:

I also feel guilty about not doing enough for her; I think possibly there’s other things that we could be doing that might help her live a better life but on the other hand, everybody says, “oh, stop beating yourself up about it.” There’s always that slight element of guilt I guess, that things could be, or her life could be, a bit better, easier, whatever. On the other hand, she probably

wouldn't know if it was; it's hard to know what would make a difference to her, and in an actual fact, there's probably not much more that I can actually do.

This notion of guilt appeared to have manifested as a heightened sense of selflessness and of responsibility. The carers spoke to the former, with comments like, *"I tend to put them first, before myself sometimes,"* and *"I've always made sure that they come first; that's why I've never had a life, it was too important to me that they have a good life."* The carers spoke to the latter, through comments like, *"it certainly has its pressures and ups and downs, but it's the life we have and we make the most of it"* and *"every so often you get whiney and you think, 'if only things were different,' but they're not going to be different, it's just about making things good."* To illustrate, Shelby explained:

To me it's been really important that all three children lead an ordinary life but one that's really interesting; that they get to experience lots of things. Just because they have very significant disabilities, it's still really important that they get to experience lots of things. I have always been very active in finding out what's available, and if it's not available, making it happen anyway. Also, it's about sharing what I've learnt, about making it a positive journey and just having a good life; giving people hope that things can be achieved.

To conclude, this section demonstrates attunement in the care experience as a narration of these carers' understanding of the reality of their experience of 'mothering disability', defining its meaning positively, and in relation to their values and beliefs, their hopes and their dreams. Evidently, these carers recognised to some extent, that their family life deviated from the norm, yet understood that this did not necessarily equate to a life that was 'less than'. While the presence of disability was sometimes met with demand or difficulty, the carers were attuned to the practical and emotional needs of each child individually, and the family as a whole. They were practical and realistic, humble and positive, negotiating a new normality amidst understandings of disability, and seeking to enable a 'good life'. In sharing their experiences of 'mothering' disability with me, what became apparent were the subtleties in their expressions of vulnerability, resilience, and hope. These emotions and qualities, it would seem, help to form the cornerstone to not only survive but also thrive, both home and away.

6.2.2 Attunement

What also became clear through these carers' stories was the deep love and connectedness in their relationships with their children with disabilities. These carers described feelings of gratitude through comments like the following. "*My pride and joy,*" "*my only child and my precious child*" and "*when I think about the kids, all I see is a big heart; I can't live for long without seeing them.*" And, "*I think he makes me who I am,*" and "*I probably feel most complete when I've got him at home; we feel like we belong.*" A few of the people with intellectual disabilities described similar feelings, suggesting a shared sentiment. Brooklyn, as an example expressed:

She is just the dearest, sweetest mother in my life for all the years. She is gorgeous, so beautiful, and my step-mum. ... I feel like a very lucky one to have two darling mothers in my life. I adore them; I am very proud of them.

These carers described the closeness of their relationship through comments like, "*we have a fantastic relationship; we have a very close relationship,*" and "*it's a very loving relationship, it's not a stressful relationship; I mean, it has its moments of stress and is sometimes very tense, but it's generally very loving, incredibly close.*" This closeness manifested as friendship, for instance: "*we feel like a team*" and "*we are like two peas in a pod.*" They commented further, "*he's just a pleasure to have around,*" "*he's great fun; I know exactly what he laughs at, what he likes and doesn't like*" and "*we have lots of fun, we do silly things; he is just full of life, happy to be obliging, to be involved.*" Also described was an intensity to this closeness at times. As an example, Alyssa on her relationship with Sadie, described, "*the first thing that comes to mind is 'prickly', so maybe it's like a Velcro strip or a couple of those biddy bids that are intertwined but annoying each other; we're stuck together, we don't always like it.*"

The natural inclination of a mother to attune to the needs of her child or, in the case of this research, another family member, as mentioned in the previous section, was apparent. What I found surprising however, was that the remaining four carers (three support workers and a friend) fulfilled aspects of caring intent and action that one might expect to see from a family member. I felt this was important to note when considering what might otherwise have been a more dispassionate and formal

professional relationship between carers and people with intellectual disabilities, as staff and client. Instead, it seemed as though they gave care freely, “*genuine in their affection.*” They were outwardly intentional in “*wanting what was best for them,*” and enabling a good life. In this respect, these carers described how it is “*really important*” to nurture “*strong relationships,*” and to then “*keep the relationships quite positive*” with the people with intellectual disabilities that they support. They expressed recognition of the fact that “*building up rapport,*” “*trust and understanding*” could take “*time,*” and therefore “*patience*” and “*tolerance*” were key. The result of this can be that, as Aroha stated, “*we formed a really good strong bond, and we understand each other.*” To illustrate further, Phoebe explained:

It’s just getting to know them, spending more time with them, understanding their needs, the way they communicate and building trust. I took the time to learn, where with other staff, they would come in and didn’t take the time.

All of the carers in this research described the importance of nurturing the development of relationship, explaining that intrinsic to this was an ability to attune themselves to the emotional needs and moods of the people with intellectual disabilities. Attunement, was understood as “*trying to pick up on their emotion; staying in tune with how they’re feeling*”. That is, to be “*perceptive,*” “*intuitive*” and show “*initiative.*” Attunement was of course important while at home, but more particularly while away within the context of travel, where the people with intellectual disabilities experienced increased stress and anxiety. “*To travel well with someone with a disability, you have to be very emotionally astute,*” and therefore, “*keeping anxiety levels low is the main thing to travelling.*” All of the carers described the importance in not only being aware of and attentive to the emotions an individual was experiencing, but simultaneously being alert and able to pre-empt what that individual was thinking and feeling. These traits, they explained, enabled them to exercise some control by pre-empting, seeing “*this is what’s going to happen,*” and therefore diffusing a potentially problematic situation before it actually presented itself, essentially “*nipping everything in the bud.*”

Attunement of the carers

As illustrated in the paragraphs above, the ability of the carers to attune was a result of experience and knowledge, as well as a cognitive understanding and

perceptiveness. To this effect, the carers made comments like, *“I guess over the years you just get to know”* and *“we get to know somebody enough to try and make accurate and perceptive calls.”* To elaborate, the carers suggested that we were able to *“read”* the people with intellectual disabilities, commenting for instance, *“I feel as though I am really good at reading him and his moods”* and *“I can usually read him and I can sense if there’s something wrong.”* They explained how, as a result, they felt as though they could tell what an individual was thinking, feeling and likely to say or do. They commented, for instance, *“I generally know what he wants before he wants it, and I’ve already delivered it to him”* and *“when I’m around, I know exactly what he’s talking about; if you ask him a question, I know exactly how he’s going to answer.”*

In fact, many of the carers described how changes in an individual’s body language, general demeanour and mood, were telling indicators of the deeper stresses and anxieties they were feeling, whether that be, *“retreating into silence”* or *“getting a little bit watery-eyed.”* As an example, Cassie articulated, *“he’ll shut down and go into himself; go into the bathroom and shut himself away. He won’t talk to me for a little while, for a few hours, and then he will come out of it.”* As another example, Alyssa articulated, *“she usually has all these signals for when she’s not happy about something; so we are just attuned to, ‘this is what’s going to happen’, she’ll go quiet and then she’ll start.”*

A number of the carers described how, even if it was apparent that something was wrong, that did not necessarily mean they knew what it was. The carers conveyed this perspective through comments like, *“I don’t always quite know what it is; it’s just body language that indicates there might be something”* or *“we’d have massive meltdowns, tears and tantrums; you couldn’t get near him and you couldn’t work out what was wrong.”* In addition, *“somebody or something has upset him; sometimes we don’t even know what it is,”* and *“sometimes it might be several days later that she’ll say something.”* They expressed an increased attunement to the individual through simple strategies, commenting, *“I just have to keep an eye on her”* and *“I guess you just check-in without being overbearing, ‘did it go all right today?’”* Even so, some of the carers explained how, in some cases, they were resigned to the fact that there was *“nothing they can do.”* The third theme,

(in)visibility, explores many instances of this, but as an example, Georgia articulated, “*when he has a meltdown or when the anxiety has just got too much, then you can’t really do much except for ride it out and wait for him to calm down.*”

The carers seemed to understand that some people with intellectual disabilities have difficulty in expressing how they are feeling in a way that is discernible by another. To this effect, they made comments like, “*maybe their ability to express things is not quite the same,*” “*might be the anxiety or maybe a bit of frustration, perhaps he can’t express himself and how he’s feeling*” and “*he can’t say, ‘I’m upset, I’m going to leave the room and go and have quiet time’; he just lashes out.*” To illustrate, Alyssa explained:

She will suddenly get upset or talk about something that’s annoying her, and you’re like, “why are you even talking about that, there’s obviously an issue but you’re not willing to tell me what it is, so you’re rabbiting on about something else.” She will suddenly get annoyed about something that happened hours ago, it’s like, “okay, what are you actually getting frustrated about here?”

To illustrate further, Georgia explained:

He sort of has autistic spectrum type behaviour, and the main behavioural problems we find hard will be where he is very impulsive and he can’t really explain why. He cut up all our passports, ripped them up; he saw them, he acted impulsively, and once he starts, he can’t stop that behaviour. He wasn’t annoyed; there had been no conflict beforehand. I couldn’t believe it. He just has those moments; he’ll do lots of stuff like that, which just come out of the blue sometimes. He’ll be very apologetic after he’s calmed down, and we’ll finally get to the bottom of things and he’ll say, “I wish I hadn’t done that, I don’t know why I did it.”

In a similar vein, Harriet explained:

Thirty-odd years of coping with him, and he’s probably hit me half a dozen times in the last two years; it’s just with an open hand, a slap on the face. It hasn’t hurt or anything, it’s more the shock of it. You can’t react in any way because if I get cross with him or upset, that would make it worse, that would make him more upset. As soon as he’s done it, he knows he shouldn’t have done it.

Not only did the carers describe a need to attune to the emotional needs and moods of the people with intellectual disabilities, but a need to attune to their own emotions, so that they were able to then exercise management over them accordingly. They explained how, despite the fact that they too could be experiencing *“all sorts of emotions,”* they sought to *“to try and bottle all those emotions up; to try and keep those in check.”* As Nathan articulated, *“you can deal with all sorts of things on your own but the idea that you put someone else under pressure, under stress...”* Other carers commented, *“even if you’re a bit stressed out, you just try to act calm and not take it out on the other person,”* or *“I just have to take a deep breath and stay calm; I deal with it afterwards and have a glass of wine when it’s all over.”*

The reason for such management of their emotional expression, they explained, was that an individual with intellectual disability might have some awareness of the carer’s emotive state, which could heighten their own emotional reactivity in response. This perspective was conveyed through comments like, *“he/she picks up on stress; sometimes other people’s stress stresses him/her,”* *“if I’m getting cross, impatient and frustrated; if I show it, straight away he/she will pick up on it”* and *“again we had to be quite deliberate about not getting stressed; if I get stressed too, he/she will get even more stressed.”* In actuality, this was not always achieved with ease, despite having the best intentions. Georgia articulated, for example, *“your children can push different buttons so I am not always as patient as I’d like to be; you always feel bad when you get cross or whatever.”* To illustrate further, Cassie explained:

Queuing up the stress levels go right through the roof. I am as placid as anything and can take and take and take, and then finally, “will you shut up!” It takes me a lot to lose my rag. Even last year coming to Queenstown for the winter festival, there was traffic and it took us an hour and fifty minutes to get from the airport. He must have said a million times, “oh my god, this queue is driving me mad, when are we going to get there?” There were fireworks.

Many of the carers also expressed a certain consciousness around how their general mood might indirectly have an impact on the people with intellectual disabilities experience. To illustrate, Nathan explained:

I was going through a bit of anxiety when I was on that trip. I remember thinking at the time that I didn't want anything I was thinking or feeling to affect his holiday, just because of the way I was personally.

To illustrate further, and in reference to the importance of building trust mentioned earlier, Aroha explained:

When we first arrived, there was probably a touch of anxiety for her. I think that was when I was like, "okay, I've got to pull my shit together, let's do this." She knew it was the first time for me too and I don't think she really had that much confidence in me when we first got there. It was about making sure I followed the map and we got to where we were going without any hiccups. She felt secure then; it was all right for her to follow me around and for me to take her places, knowing she would get there.

It seemed that the carers were very self-aware, conscious and conscientious in their influence on the care experience, feeling a practical yet especially emotional responsibility. Practically, a number of the carers considered themselves to be "*insular in and of one's selves.*" To this effect, they made comments like, "*stress, anxiety, and not quite fear, but the whole, 'until we get there,' that constant level of anxiety,*" and "*sometimes stress, a little bit of worry; it's full on because you're doing a lot of the organising, the thinking.*" Emotionally, it seemed as though the carers genuinely wanted to, and perhaps felt responsible for, facilitating the best possible experience for the people with intellectual disabilities. Mostly, the carers described their intention around being both positive and present. In speaking to the former point, they made comments like, "*to try and keep things positive,*" "*to keep moving forward*" and "*you just go with the flow.*" Nathan, for example, explained:

I think a lot of it is just positivity; positive experiences, positive reinforcement, positive encouragement. Just to not seem too worried, and keep the vibe positive on the trip; trying to have fun and enjoy the days, not being too harsh and stuff. You're maybe quite responsible for a lot of that kind of thing, otherwise it's a lot of battling; like, if you had a bad attitude the whole time, it would probably have a negative effect. At times, you are tired or you are wondering if the other person really is enjoying it, because you want them so much to, and you're thinking, "I really hope they are."

Humour, as an example, was one such tool in which to garner positivity, as the following quotes illustrate. "*He/she would get smart and I would crack a couple of*

jokes,” and “sometimes we have to act a bit silly, just to kind of get the ball rolling, just to try and change the mood; I guess that’s why we have little jokes and stuff, it just lightens things up.” In speaking to the latter point, they made comments like, *“we’ve just got to try and be more aware,”* and *“being able to really focus; just to be more present and involved, more thoughtful,”* to avoid being *“distracted by something when maybe you could have been paying attention over here or something.”*

Reciprocity of attunement in the care experience

In addition to what the carers shared, in my interviews with some of the people with intellectual disabilities, a certain level of their own attunement in relation to their carers was evident. Mostly, this was at a minor level, where they expressed feelings of gratitude toward their carer, for supporting their travel. They commented, for instance, *“yeah, she helped me a lot,”* *“a present; a pot plant to say thanks,”* and *“she very generously agreed to be my support person, and I feel very grateful for her.”* To illustrate, Maggie explained:

I said, “Aroha, do you feel happy having me?” and she said, “Yeah, I do.” It was nice for her to come with me; she was happy to do it. I said, “thank you for having me on the trip.”

To illustrate further, Chloe offered a more elaborate explanation of an incident that occurred during her travel with Gemma, where she gained, upon reflection, an increased awareness around her own emotional responsiveness. She explained:

We had a communication breakdown when I tripped and fell out of a bus in Finland. I have reduced sensation so I didn’t really feel it. I figured that I was fine, and then I realised I had a massive bruise down my leg. Gemma was quite upset by that because I had trivialised it. I had said I was fine but I genuinely didn’t perceive that she might not have been fine. I know my limits, I know what it looks like, and I knew I wasn’t broken in any major sense. I should have recognised the obligation of me as the recipient of care, and the ramifications of how she felt as a caregiver, seeing me injured. I worked that out simply by apologising and realising I had made a mistake; I had made a presumption that wasn’t true. As Gemma articulated it to me – and I always take this away – is that I can’t automatically assume that people perceive my situation as I perceive my situation. Therefore, I need to be more articulate than I may necessarily think I need to be. So, for example, rather than say, “I’m fine,”

be more specific and say, “as far as I know, there’s no damage, but this is what I’m going to do to mitigate the effects.” Because I may not be fine. ... So it’s to give people the confidence in what I am saying, because “I’m fine” is the ultimate, sort of dismissive, kiss-off type phrase that people use when they want to get out of communication. It’s the coward’s way out, basically; and it shouldn’t be, particularly in a caregiver dynamic.

Some of the other carers described an inability of the people with intellectual disabilities to attune to the needs of others, considering them “*emotionally removed and emotionally naïve,*” and “*self-centred*” or “*ego-centric.*” Jade explained:

I am not sure I am right on this but it’s my thought; that they cannot be cognitive of what that other person is kind of doing or how they’re feeling, because it’s enough to think of themselves. The fact is that it takes them so much more to cope and to be able to function in life.

Georgia explained:

He doesn’t think about what other people might want to do or how they might be feeling about it; it doesn’t really enter his thinking. It’s more about his anxieties about everything, and he can’t sort of get past that.

Some of the carers, however, described an ability of the people with intellectual disabilities to attune to their emotional needs. They commented, for instance, “*these guys are pretty perceptive though; but they were cool with me, they tolerated me,*” “*he keeps me calm; he just keeps me calm*” and “*she’s pretty good at noticing if I’m not happy and at making me happy.*” To illustrate, Aroha described how travelling was an entirely new experience not only for Maggie but for herself too. In reflecting upon their experience of flying, she expressed a recognition of their being somewhat of a role-reversal in their care relationship. She explained:

I had a great fear of flying. Right up until the day I was like, “oh god, I don’t know how I’m going to cope.” It was funny because when we got to the airport I was talking, “chat, chat, chat, chat, chat,” and usually she’s the one that’s talking all the time, and you can’t shut her up, you can’t even get a word in. That day I talked all the way on the flight to Wellington. She just kept looking at me and looking at me. We got there and I was like, “phew, we’re here, finally,” and she was like, “well yeah, thank god for that, you did nothing but talk the whole way.” Then I realised it was me; she was actually the calm one and I was going on and on, talking the whole way. She wasn’t freaking out or

anything – which I wouldn't have known how it would have affected me – but it was almost like she was looking after me on the plane. It was very unusual but after that I kind of got a grip, and then hopefully made the rest of the trip enjoyable for her.

Ultimately, the carers acknowledged a reciprocity of attunement in the care experience, where being attuned to the needs of one another had mutual benefit, for instance, “*we're good at cheering each other up; I think it just comes with caring for each other.*” Ashleigh articulated, “*Brooklyn's ability to be happy and to be light-hearted about things is helpful; I will quite often try to be light-hearted myself so that she gets lighter-hearted, and then I feel lighter-hearted.*” She elaborated, “*I feel like there are situations where we depend on each other; moments where we feel very connected because we depend on each other.*” It seemed that the novel context of travel therefore provided a unique platform for interdependence. Chloe, recognised this, and explained:

We needed to form a cohesive unit – and that's the fundamental truth – they help you, you help them; it's a mutually beneficial situation, or at least it should be. You need to be respectful of their needs as well; their entire reason for existence isn't solely to support you, or it shouldn't be.

6.2.3 Care for self, to care for other

As illustrated in the previous section, the carers expressed a strong sense of self-awareness and were attuned to their own needs. Another aspect of attunement that they described was seen in the various instances in which they would seek the support of others, create space or have respite. Essentially, such instances were described to be coping strategies, important in avoiding the type of burnout that could potentially impact upon the care relationship in its entirety. They unveiled their vulnerabilities and strengths to me, in describing the difficulties they faced in everyday life, as well as their travel lives. To illustrate, Mia explained:

The vulnerability I guess would be that I am an only child and I do find her continual moving and excessive talking gets a bit much at times; she's just got to be always talking loudly and making noise. You have to be quite strong. On a daily basis we still get tantrums and things like that; she gets angry and you've just got to walk away.

To further illustrate, Georgia explained:

I actually can feel quite burnt out just in normal life. I feel there are times when I can get quite down about things with William. If I have a particularly bad day, sometimes it all just gets a bit much. I will sometimes get anxiety; I get little panic attacks as well at times. It's been okay lately, it's sort of under control at the moment, but every now and then I have little episodes with William where I can just feel the anxiety coming back.

Phoebe described how, for her, the vulnerabilities that she experienced at home within the capacity of her role as a support worker were magnified during travel. She explained:

In the home that she stays in we are double staffed, and because I went down single staff, well, that was like 24/7 for three days. It was overwhelming; I was extremely exhausted. To top it all off, on the last day my back went out as well; because of the equipment and because we usually have two people to help with her cares and supporting her, and I was doing it on my own. I still had to carry on with my back like that because there was no one else to do it. I didn't think it was fair on me at all, or Gracie. I have never put my needs before hers; I always put her needs first. Not while I am at work; that's why I am there with her all the time. Even when we were in Wellington, because I feed her – she takes about half an hour, forty minutes to eat – I could be really hungry but that doesn't matter; I just wait. Sometimes it went till like eleven thirty at night – I haven't had anything to eat, I haven't had a shower – you've just gotta do it.

Some of the carers were travelling with somebody else – usually their partner or another child – and they described how they were able to draw upon this support, commenting, for example, *“we work pretty well together; I think a lot of the strength lies in that we both help each other out.”* They explained how together they were able to play *“tag-team”* in terms caring for the people with intellectual disabilities. This could mean having someone else to *“provide a lot of the hands-on care,”* or having someone else who *“knows the travel processes,”* or *“having that other person who could stay with him/her while I approached the hotel desk or the airport counter; one of my biggest fears was that I'd lose him/her.”* It also enabled them to draw on one another's strengths, for instance, when attempting to reason or negotiate with an individual with intellectual disability. Emotionally, they explained how this strategy created a sense of space, where one person could redirect a certain behaviour or situation, while the other recovered. Mia articulated, *“If we're having a difficult day then he will kind of take over. We are pretty good*

at managing between us; if one gets stressed, the other can usually stay calm.” In addition, this support person could also manage the relational dynamic between the carer and individual with intellectual disability too. To illustrate, Alyssa explained:

I’m so glad Poppy [daughter] went; it was just the absolute best decision because she sort of deflected Sadie when we started getting antsy with each other. Poppy being there just gave Sadie a different perspective on things, and a different outlook. “But Sadie, just look at what’s in front of you now; we’ll worry about that later,” whereas I would probably be trying to answer her questions.

Having another support person was not always described as being a positive thing, however, and could actually create more emotional work for the carers, who not only needed to be attuned to the people with intellectual disabilities’ emotional needs and moods, but that of the other support persons too. The carers conveyed this perspective through comments like, *“I guess one of the things about him being there, is there are times when I have to say to him, ‘just stay calm, go and sit somewhere else or walk off.’”* To illustrate, Georgia explained:

I don’t find it necessarily less stressful because my husband is not so patient with William; he will get even more cross, “no, you will do this now.” They end up having a confrontation, so that doesn’t really help me because I’m stuck playing piggy in the middle.

Even those carers who were not travelling with anyone else expressed a sense of gratitude in having support from afar, whether that be from their partner, family, friends, manager or staff, who were contacted via audio/video call and social media and who served as *“avenues for decompression.”* Gemma, for instance, articulated, *“he was the only person I contacted while I was away; I’d quite often call him on Viber and we’d just chat. That sort of cured the homesickness a bit; I missed him terribly.”*

Another aspect of attunement described by the carers was creating *“a bit of space,”* whether that be *“time out,” “downtime”* or a *“little break.”* It was suggested that the care experience within the context of travel held an inherent intimacy for both the carers and the people with intellectual disabilities, where *“whatever you’re doing, you’re doing as a group; it’s tiring,”* and *“to be constantly in each other’s space isn’t always that easy.”* A number of the carers described how

oftentimes the creation of space was planned and intentional, and they commented, *“it’s part of thinking about it beforehand,” “to have some time in the day to do that”* and *“allowing some time for that.”* Such space could mean doing nothing, having a lie down, reading a book, playing on a phone, watching television, participating in an activity or going out for a meal; *“to retreat to their own little world.”* To illustrate, Alyssa explained:

So, although we couldn’t be physically removed, when you have a bit of time, it’s okay to sit on your phone and play games, read a book, have nobody say anything for an hour; just not a problem, and we definitely needed that.

Again, the carers reinforced a notion of being present and in the moment. As an example, Ashleigh explained:

There are things that cause frictions but it’s just time. After a while, it’s silly to be annoyed because you’re on holiday; you’re in this train and you see this beautiful landscape, and things just get buried in the sand and that’s that.

For the carers especially, the creation of space seemed to be a coping strategy of sorts. Some of the carers described how even if the creation of space was not planned, it could necessarily be obtained. Lily for instance articulated, *“if I actually just wanted time for me, I could get it; he’s not demanding, and one of the other carers would take him if I needed it.”* Other carers described how the creation of space was not even a consideration, but if pertinent, they too could obtain some sense of space in the form of a small reprieve. To this effect, they commented, *“we went out for a meal and he/she was just pushing all the buttons; I was going to get really agitated, so walked out for some fresh air,”* and *“I’d just take a little break, that’s all I could really do; just take a little break and get back to it and know that it wasn’t going to be forever.”*

To illustrate, Lily explained:

If I do get tired, I do want to put my feet up, I do want him to just shut up. ... It doesn’t get that bad but sometimes you just think, *“oh shit, he wants to go to the toilet again,”* and so you just do it.

To illustrate further, Jade explained:

I never got to the stage where I thought I needed space out, but I couldn't have space out. I had known you do not go into these things not knowing; you have to know that this is what it's going to be, so I don't see any negativisms.

Gemma elaborated on her care experience, articulating, *“it was an incredibly intense experience for me as you can imagine; waking up as a caregiver, spending the day as a friend, and then going to bed as a caregiver.”* Gemma expressed a tension between feeling as though she had been selfish in prioritising her own needs before those of Chloe's yet recognising that she needed to care for self in order to care for other. She explained:

I like space and I need time; I just need time to regroup myself, and that's how I really eased myself back into being happy and relaxed again. I think about half way through I was kind of burning out a little bit, just emotionally going a bit crazy. I think I pushed myself too hard, too quickly. I think that is when I probably sacrificed a part of her trip, just so that I could kind of make it through. I knew it was important, otherwise I would have got too tired. I deal with migraines a lot; if I was to overdo it and trigger major outbursts of migraines, then I'm potentially going to become incapable of taking proper care of her as well.

As she shared this experience, she also acknowledged that Chloe was likely attuned to her emotional needs and moods. She explained:

We never explicitly had any conflict, but when I created the space, I think what she really wanted from me in those times was to hang out with her; I think she picked up on that and she sort of eased up and gave me my own space and more time. It didn't feel personal to her and we didn't have any kind of personal issues; I think that was sort of an unsaid occurrence and it was so important.

Interestingly, Chloe verified this as she described her own attunement to Gemma's emotional needs and moods. She explained:

Gemma became dependent in about the middle of our trip; in the sense that she needed me to take on more responsibility so she could rest. I think she felt a bit of burnout after the first leg, so we needed to modulate that. There was the lack of, “you're really pissing me off, and I am going to storm off and do nothing,” she had to come back to me. I mean, we didn't really have any major blowouts because we are fundamentally good communicators and friends, but she probably would've wanted the option.

This desire to create space was also relevant in home and working life, where the carers described requiring respite. Carers in a formal capacity described the importance of respite, stating for instance, *“you need to have a break, rejuvenate and recharge; you come back to work and you feel a lot better, you do your job better.”* To illustrate, Nathan articulated, *“I think it’s a healthy thing to do; you feel refreshed and you’re able to really focus when you’re here. Just to be more present, involved and thoughtful; not drained, not feeling like a need for escape.”* Carers in an informal capacity, described the importance of respite personally, through comments like, *“having some management over your own life,”* and relationally, through comments like, *“important in any family unit”* and *“offering reconnection and that time with one another.”* Once more, for these carers a tension seemed to present itself, when seeking to manage family life and relational dynamics, for example in prioritising the wants and needs of the partner or other children. To this effect, they made comments like, *“we could take her, it would be easier not to, and we don’t want her getting into the habit of expecting to come too”* and *“we’re fortunate we’ve got a grandma that can step in, we are able to get a night away and stuff like that; we’re doing that more now, I have made sure we get away.”* To illustrate, Georgia explained:

What I would like is longer periods where William could be left for a weekend or something. That sort of respite. To go tramping with the other two [children] or something like that; just do those sorts of things because the other two are outdoorsy, sporty sort of kids. I just feel like we’re missing out on doing those sorts of things with them.

To further illustrate, Ava explained:

It’s hard to really go overseas on our own because you have to have a long period of care; it would be lovely to be able to do more travelling – just the two of us [Ava and her husband] – but it’s not so practical.

Many of these carers described the difficulty in actually accessing respite, whether in an informal capacity (through the family members, friends or other caregivers) or in a formal capacity (through disability related support and service organisations and funded respite schemes). In terms of informal respite, these carers explained how it was *“hard finding people that are free and can look after them,”* as well as *“finding that person or people that he is happy to be with.”* Some of the

carers had expressed gratitude in how “fortunate” they had been in having access to the appropriate support person who could “step in as a caregiver,” and facilitate opportunities of respite. Cassie, for instance, articulated, “we are able to do that because he is very able and very happy at home, as long as there is an adult there to supervise”. Other carers expressed comments like, “I’m not sure who else we could use quite frankly,” “his/her grandparents are getting quite elderly now, so it is getting more difficult” and “our parents now, I’m not sure they’d be able to look after her/him anyway ... they wouldn’t cope, they wouldn’t want to get cross with him, they’d get extremely stressed by it.”

In terms of formal respite, the carers described the service as being highly sought after but undersupplied, commenting for instance, “we had so few opportunities for respite when she was younger; when we needed it.” In addition, they explained that even if it were available, it would likely be inaccessible, as they would personally be constrained by time and expense. Harriet explained:

Of course, there was a huge demand on respite care, so you would have to book weeks ahead. I remember one time in particular, I was just at my wits’ end; I thought, “I’ve got to get some respite for him” and they said, “we’re sorry but we can’t give you respite until six weeks out.” Well, what happens in the meantime? You have a breakdown.

Some of these carers have had experiences with formal respite services, commenting for instance, “my experience of respite services hasn’t been good; there may be good respite services now, I don’t know,” and “you get good caregivers and bad caregivers; no one is going to look after a family member as you would, and you’re always perhaps going to find some fault along the line.” Again, the carers expressed a sense of guilt around a selfishness in seeking respite, at the potential detriment to the people with intellectual disabilities. Ava explained:

We took her through the front door and there were just these people sitting around doing nothing; there was a couple of non-verbal people in wheelchairs and stuff. I felt absolutely terrible leaving her there because I just knew it was going to be absolutely dreadful. The lady that looked after her said, “she was okay but missing home.” To me, that was treating Francesca so disrespectfully because I was putting her in a situation just because I wanted to go away somewhere, and that situation was not offering her anything.

She continued, by providing a comparison with a different type of respite, expressing: “*when she goes to camp, she’s going to something that’s fun, with people that she likes; she’s got her friends, and she’s having a real life.*”

6.3 Theme three – (in)visibility

This quote, “*you feel like everyone is watching you,*” represents the third key theme that inductively emerged from the participants’ responses, the (in)visibility of the care experience. The essence and many nuances of this theme are captured in Jade’s vignette below.

At one side of this restaurant, there was a library and a place where you could sit down and have a barista made coffee. These beautifully made up ladies arrived – four of them in their fifties/sixties... Here I am, as they are speaking to me, and he’s at the loo. He’s been there for absolutely ages – some of it’s due to bowel problems – he’s really slow; you’ve got other people there, and also, one needs to be aware that it’s all cleaned up. How do you manage a toilet when he’s there for over half an hour, it’s a mess, and there’s some bright looking ladies who might follow him in? He comes out and I think, “Oh god, I need to go in there.” Unisex toilet... Sure enough, I need to do a bit of a clean-up; so, I duly do it. So awkward!

Across the participants’ data, (in)visibility was a prominent and recurrent theme. Where leisure travel represented a meaningful experience in and of itself, it also represented a unique context where experiences of care played out due to the (in)visible nature of intellectual disabilities and care. Yet, such experiences were not confined to the privacy of a carer and an individual with intellectual disability. Rather, as they navigated the travel system, they negotiated their place – their being in the world – in this often liminal yet public space, alongside and with others (whether that be travellers, industry personnel or host community). It was here that the carers acknowledged how they became (in)visible, exposed to the discernment of others, subject to their assumptions, expectations and judgment. Under this gaze, the carers negotiated the tensions of their inner world, in order to present, to a degree, a performance of care, to and in accordance with the outer world.

6.3.1 (In)visibility of disability

In a general sense, the carers described how they believed there to be some societal awareness around and acceptance of disability, but that this consideration did not include disabilities of an intellectual nature. Hence, the nature of giving care was rendered visible in the context of what are often invisible disabilities, “*because the disabilities aren’t always obvious*” or “*immediately apparent.*” For some of the people with intellectual disabilities, there was a certain visibility to their disability, which was conveyed visually (through age and/or appearance), verbally (through oral spoken word), or nonverbally (through body language, facial expressions and mannerisms). For the other people with intellectual disabilities, there was a certain invisibility to their disability. Sometimes, there was need for the visibility of a disability “*to be made known to a degree,*” which was conveyed verbally (through prompting the individual’s spoken word, or the carer’s spoken word), or non-verbally (through action, such as taking the individual’s arm and escorting them).

To illustrate, Nathan explained his conscious efforts to modify his own behaviour in a way that could amplify the visibility of Jacob’s disability. A subtlety around normalising his care work and their care relationship as staff–client could be inferred and, by extension, so too could disability as part of the diversity of the human condition. That is, certain actions in one’s behaviour could be exacerbated in an attempt to normalise them. He expressed:

You can project a certain energy that’s real awkward, like you’re uncomfortable; you don’t want to be there and you feel like everyone is watching you. Whereas, if you just put out this energy and body language where you look comfortable, that’s like, “this is a person, we are just here, and this is normal,” then it’s almost like, people maybe respond to that without really realising it.

Some of the carers described, how when there was a certain visibility to an individual’s intellectual disability, it served to communicate a message to others that the individual was approachable. These carers explained how, as a result, they would experience more favourable encounters and positive engagement with others. In such instances, the visibility of disability served to “*break down barriers.*” To illustrate, Gemma elaborated upon how Chloe’s power chair presented a tangible visibility of her cerebral palsy to others and was understood to portray the perception that she was “*personally approachable and accessible.*” Gemma

evidenced this in the “warmness” she felt, where “*people talked to her a lot more, smiled at her a lot more.*” To illustrate further, Shelby articulated how James was “*a really good ambassador for disability.*” She elaborated upon how his extroverted nature and verbal ability to initiate conversation – albeit having very limited expressive-receptive communication abilities – meant that he could “*break down those potential barriers*” of others who might otherwise be “*a bit stand-offish,*” which she felt “*enhances not only his life but changes other people as well.*”

Some of the other carers described how, when there was a perceived invisibility to an individual’s intellectual disability, that this would translate into less favourable, more neutral encounters with others, which gave rise to both overtly and covertly apathetic attitudes and behaviours. The carers conveyed these attitudes as “*ignorant,*” “*intolerant*” and “*couldn’t be bothered.*” The carers conveyed these behaviours as “*looking away*” or “*moving away;*” and, “*giving funny looks,*” “*looking at them blankly,*” “*staring*” and “*pointing.*” The people with intellectual disabilities gave mixed descriptions of their encounters with others, some being more positive or somewhat positive, than those more neutral or negative. They conveyed positive attitudes as “*friendly,*” “*very nice,*” “*lovely*” and “*peaceful,*” and they negative behaviours as “*being shoved out of the way*” and “*pushed around.*” They expressed their feelings of being “*unwelcome,*” experiencing “*annoyance,*” “*frustration,*” “*anger*” and “*upset.*” Exemplifying this perspective, Anastasia articulated, “*they don’t care that I am there; I am not invisible.*”

6.3.2 Assumption and expectation

The carers also described how the perception of (in)visibility gave rise to the making of various assumptions and expectations around the presence and nature of disability and/or the care relationship. To illustrate, Lily elaborated upon how others were presumptive around the type of care relationship shared between herself and Noah. She expressed:

I feel like people see me as a caregiver, and in fact I’ve been quite known to say “this is my son,” because I want people to know we’re mother and son. If I think that they’re thinking I’m a caregiver, I’ll tend to butt in and say; it’s usually if we’re in a group and it’s a group conversation, “you people are marvellous at what you do.”

To illustrate further, Gemma described how others were presumptive around the type of care relationship shared between herself and Chloe. She explained how initially this presumption was that she was “*a sister and not her friend; there in a professional not a personal sense,*” and that upon realising that the relationship was neither familial nor professional she was praised, “*what a good person,*” which she named, “*the whole ‘hero’ mentality.*” Gemma understood this discernment of others as reinforcing the normative thinking that relegates people with disabilities as objects of pity, while exalting those who support them. She expressed:

But we absolutely have to move a little bit beyond the kind of, only considering it’s a good thing when somebody is being an inspiration; I was honoured to be there, to have been invited, and it was an incredibly generous gesture.

In a similar vein, Chloe conveyed another aspect of the normative thinking around disability and notions of inability and dependency. She expressed:

People offer to help you, people want to help you – very nobly – but it doesn’t give you a sense of self-competency, confidence or coping; because you’re not expected to cope, and when you travel all you do is cope. I think they presume a certain level of incompetency until I prove myself, which is not particularly fair but it is the reality of the situation. I think it works in the same way in the sense that if you have an invisible disability, people presume competency and confidence, and then if you don’t meet it their perception of you goes down the toilet. So at least I can surprise people and meet their competencies; I feel more grateful that I have a visible disability than an invisible disability.

As Chloe detailed above, where an individual with intellectual disability may have presented as being physically able or as having their mental faculties, the reality was that they in fact had underlying complexities that were requiring of ongoing support. This presumption of competence could then add an element of difficulty to the travel process, and especially the formal systems within it that largely cater to “*mainstream tourists.*” The carers described the “*officious*” nature of customs and immigration personnel, who, “*because they don’t see anything as being wrong, they just expect him/her to be able to do that,*” or “*I think because he/she looks so able, perhaps if he/she had Down syndrome or something, people would think, ‘oh, let’s give them a hand’.*” The carers put forward several examples, for instance, going through separate queues for facial recognition software or

separate aisles for immigration, being questioned with an expectation of verbally communicated answers, and getting random drug-tested where medication causes a positive result. Another example shared was the issue that came with mother and son having passports with two different nationalities, and confounded by demands to sign a passport despite being illiterate. Cassie expressed:

I'm on a British passport and Mason's on a New Zealand passport, so you've got to go through different aisles. His passport is not signed because his signature is never the same, so I have to get dispensation from my lawyer to say, "He's not signing it because of this..." Because he doesn't look any different, they don't tend to look at what's going on to realise why. Then of course he gets anxious and he's all flustered. You know, stuff like that makes you think, "what do I need, a big sign across my forehead?" It's there in the notes; they need to be looking at those before opening their mouths sometimes.

In addition, a few of the carers described instances where the visibility of disability was apparent yet encounters with others, specifically industry personnel, led to experiences that the carers and the people with intellectual disabilities conveyed as 'debasing' and 'disembodying'. To illustrate, Sophia recalled an instance where she had borrowed a wheelchair at the airport for James. This example suggested that material goods or resources were valued over the dignity of a human being. She expressed:

From the moment we had checked in, the staff just told us to go straight to departures where we ended up shunted in this little departure lounge all on our own; we just had to sit there, I couldn't get him anything to eat. They were concerned about the wheelchair; well, the wheelchair's not going to go any further than departure. But no, they insisted because we had one of their wheelchairs.

To illustrate further, Chloe recalled the treatment she received at the airport, as she was consigned to object and her wheelchair to subject. She expressed:

It drives me mad and it drives my parents to be absolutely ropable, that [airline] – not to bash a company – refers to me as, "the wheelchair's coming." So it's a sense of dehumanising the identity, and that's often the issue with travel; it's becoming a bit of a spectacle, so you're not just the fellow traveller, you're the awkward one that gets carried everywhere, and it's not a particularly pleasant experience.

As such, the carers expressed the need to instil a sense of humanness into the travel process. They described how, instead of being reactive and responsive, if industry personnel were proactive and considered, an achievable and considerable difference could be made. They explained that such attention could take the form of prompting, explaining or demonstrating. Lily expressed:

I think that sometimes too, it's about the staff, the personnel there; recognising a situation where a little extra attention might be needed, just knowing that sometimes a little bit of support might be required. I think this could apply in any situation, people, personnel, to just be a little more watchful, and if there are people who look a little undecided about which lane to go in or what documentation is needed ... not making a big deal about it but just to offer that sort of help, "are you alright?" "would you like a hand?" "do you know where you are going?" Just to be a little more proactive rather than people getting distressed; people often just stand back and wait till we're in crisis.

Critically, the carers understood their personal experiences to have reinforced the basic human right of being "*treated sensitively,*" and "*treated with dignity and respect, like everyone else.*" To illustrate, Alyssa articulated, "*it's possibly more a societal thing; if you can expect them to just participate more fully in society, then they should be catered for if there are identifiable ways that they can be.*" The carers therefore emphasised a "*need to raise disability awareness,*" "*to develop pathways for there to be more understanding in the industry of what disability means and what it doesn't mean*" and "*being educated as to the actual help that's needed.*"

6.3.3 Behaviour and performance

Adding a further dimension of the complexity of the (in)visibility of disability and care was the sheer stress induced in navigating the travel process, both for the carers and the people with intellectual disabilities. This was particularly relevant for the people with intellectual disabilities, and was demonstrated by their behaviour, which called upon the carers to manage such behaviour due to their visibility in the public space of the travel context. In this context, there were three layers of performance, the behavioural performance of the people with intellectual

disabilities, the performance of care by the carers, and the judgment of the performance at the discernment of others.

The people with intellectual disabilities, in particular, described their apprehension in relation to certain aspects of the travel process, such as the compactness and confinement of transportation. They conveyed this perspective through comments like, *“It’s a little bit stressful waiting,” “I don’t like the queues,” “I don’t like getting on it, I don’t like getting off it”* and *“too many people, too noisy, too busy, oh so crowded.”* Many of the carers agreed with this perspective, which they conveyed through comments like, *“being on a plane that is very claustrophobic and small; it’s the anxiety, he gets himself so worked up”* and *“we were at the gate and he sort of stormed off in the other direction, he was refusing to get on the plane, ‘I’m not going’.”* In addition, *“queuing up the stress levels go right through the roof”* and *“she has an aversion to doing up seatbelts so was screaming for about forty minutes straight.”* Many of the carers, however, suggested that such manifestations of stress were more characteristic of their intellectual disabilities and associated behaviour problems. They commonly described difficulties with *“arguing,” “being cross,” “lashing out,” “throwing things,” “a screaming match”* or *“massive meltdowns, tears and tantrums.”* As an example, Harriet described:

He’s probably hit me half a dozen times in the last two years and it comes right out of left field or when I’m trying to tell him not to do something. We were standing on the footpath talking to friends and he started to step back; he was going to go right out onto the road, so I said, “Ethan, please come back onto the footpath.” He obviously objected to being told what to do; he didn’t know the reason why I was telling him, he couldn’t understand that, so he just lashed out and hit me. It’s just with an open hand, slap on the face; I mean, it hasn’t hurt or anything, it’s more the shock of it. You can’t react in any way because if I got cross with him or upset with him, that would make it worse. He knows as soon as he’s done it that he shouldn’t have done it. Might be the anxiety or maybe a bit of frustration; perhaps he can’t express himself, how he’s feeling.

All of the carers described how they were often able to pre-empt the behaviour of the people with intellectual disabilities, which meant that they could attempt to *“diffuse,” “divert”* or *“nip in the bud”* what might otherwise present as a problem. *“I can usually read him/her pretty well and I can see where he/she’s getting a bit*

worked up; I sort of just have to calm him down,” or “I can read him/her like a book; I know exactly what’s coming before it happens and I know exactly when to think, ‘oops, we need to get out of here right now’.” Most of the carers explained their intent on keeping situations as “low key” and as “calmed” as possible. As Ashleigh articulated, *“to avoid any conflicts is very important, and if you have them, know how to manage them.”* They conveyed a hyper-awareness of and hyper-vigilance around, *“How will or won’t he/she behave?” “What’s the worst that could happen or go wrong?” “How are we going to deal with it?”* This anticipation and management of behaviour evoked expressions of care as a performance, conveyed through comments such as, *“they’ve got to be constantly watched and supervised,” “you’ve got this appendage with it; you’ve got to be watching the whole time.”*

Emblematic of this was a tendency of the carers to liken the people with intellectual disabilities to young children, conveying for instance, that *“it’s just like travelling with a toddler.”* To this effect, the carers made comments like, *“there was a three-year-old little boy there who was starting to have a little tantrum; you could understand it with him but people were looking at us,”* and *“people are looking and thinking, as you would do with a toddler who was about to have a bit of a tantrum.”* What these carers highlighted, however, was a disparity in the way that others would approach such behaviour; sympathetically if it was a young child, but unsympathetically if it was an individual with intellectual disability. Ava spoke to this point, and articulated, *“people with young children are moved through, and sometimes I feel like one of those as well – because it’s like having a young child – but I don’t get the advantages of having a young child.”*

In addition, a number of the carers described how they were “mindful” that what others might be denoted as being socially appropriate might differ from the way in which the people with intellectual disabilities are in the world; that is, *“there can be some behaviour that is not congruent with social norms that need supporting.”* As an example, Cassie described how Mason has a propensity to *“completely phase out and stare,”* a characteristic common of people with Fragile X syndrome. She explained an incident where his staring was ill-received by a restaurant patron; *“this woman stood up and shouted in his face: ‘What are you staring at? What’s the*

matter with you? Will you stop him staring?’” In this particular instance, she had challenged the woman by saying, “*he’s got a disability, what’s your excuse?’*” As she continued to explain, she evoked a sense of frustration for her son, who would typically be very upset, ruminating on the rudeness of others while “*worrying that he himself had been rude yet he hadn’t done anything wrong.*” In the same vein, she evoked a sense of empathy toward the woman and her reaction. She seemed to reconsider her own emotional response more cognitively, insinuating a notion of responsibility. Cassie expressed:

It was likely just the perception that there was a big eighteen-year-old lad staring at her. The whole staring thing, I do need to distract that; I am very conscious of that, it’s not right, you don’t sit there are stare at people.

To illustrate with another example, Nathan explained:

Sometimes he really likes the shirts and stuff that women wear, or a woman might wear a nice necklace. He’s so innocent but he just wants to walk up and grab it and be like, “wow, it’s a great necklace,” and I might be like, “there’s no threat, it is all good.” Most people are usually pretty fine, it’s just one of those things where you try and not make it awkward or anything. Another one might be, you’re waiting in line somewhere and someone might say something to somebody and they don’t really know how to respond, or the person you’re supporting might ask something unusual; you might jump in and say something that just sort of makes it known you are there, you might just help smooth it out somehow. Sometimes you might even leave it, you might not jump in. We’re always learning; none of us are perfect.

Aware of the judgment of others, many of the carers described the behaviour of the people with intellectual disabilities as, at best, creating a “*disturbance*” or “*disruption*” and, at worst, as being “*threatening and destructive.*” To illustrate such performances, many of the carers offered examples, a few of which follow. Harriet described how “*he wouldn’t sit down, he just wouldn’t cooperate, not putting his seatbelt on; the plane was taxiing down the runway and they said, ‘do you want to get off,’ he said, ‘yes’, so the plane turned around.*” Alyssa described how “*she’ll raise a fist and threaten to punch me in the face; in a public place, it’s interesting and quite confrontational for other people, and definitely not something that can be explained easily or quickly.*”

A couple of the carers even admitted that it was their own behaviour that could cause a performance. Cassie articulated, *"I am as placid as anything and can take and take and take, and then finally there are fireworks; in the end I just lose my rag."* Oftentimes and despite their best efforts, the carers understood that their performances of care may have been perceived by others as an inability to *"cope,"* that *"there was nothing [they] could do."* To illustrate, Georgia recalled an incident where she faced difficulty in managing William's behaviour, which rendered his invisible disability visible to the gaze of others. She expressed:

There was a moment on holiday where he was cross with me, where he just behaved really badly. He was walking around town and knocking over all the signs outside the shops; he'd go into a shop and knock over a pile of shoes, knock things off the rails. I literally had to grab him by the arm and march him out of town because he was being so destructive. He then decided he was going to scream a really high-pitched scream at the top of his voice; constantly he would walk, stop, do a huge scream, walk on and do another big scream. The streets were quite crowded and it was so unbearably loud that everyone around him literally stopped, put their hands on their ears.

To illustrate further, Harriet recalled a number of different scenarios where the same patterns of Ethan's behaviour would play out. Here, too, his invisible disability became visible to the gaze of others. She expressed:

He starts to get anxious, call and lash out, bite himself and sort of bang the window. He absolutely spins out. I would leave in tears because of the way he'd perform; I used to get the feeling that people would look at me and think, "look at that undisciplined child, why isn't the mother dealing with it?" Because he looked normal, people didn't understand that there actually was a problem, and that it wasn't simply a discipline problem.

Common to all of the carers, regardless of the (in)visibility of disability or care, was that a spectrum of interaction and reaction in the public sphere of their everyday home lives was just as present, if not heightened, in their novel away lives. In reflecting upon this, they revealed elements of their personal historicity, explaining how emotional responses of 'disappointment,' 'embarrassment' and 'vulnerability,' had once been felt, yet were lessening with time as they acquired an aptness and developed a 'resilience' through negotiating these experiences with others, both home and away. They conveyed comments such as, *"I have become hardened to*

it,” “I am able to let it go,” “I don’t generally bother explaining to anyone, I just deal with it and they can come to their own conclusions,” and “I am now able to ignore what other people around me are doing or thinking.” Such fortitude was not without frustration however, as illustrated in the following comments. *“I just want to put him in a t-shirt that says something like, ‘stop staring, I am this...’” and “there are times where you want a badge or a card or something, where you can say, ‘well actually this is...’”* In addition, *“to some extent we are like, ‘this is what a disabled person looks like; she’s not causing you any harm, so just put up with it people’.”*

6.4 Chapter summary

This chapter has presented the three key themes that emerged from the participants’ data, which were experiences of care as *giving*, *attunement*, and *(in)visibility*. To summarise, the leisure travel phenomenon saw experiences of care situated within three main contexts: firstly, the individual, subjective frame, that is the lived experiences of the carers and the people with intellectual disabilities; secondly, the relational, inter-subjective frame, that is the care relationship between each carer and individual with intellectual disability; and thirdly, the social, inter-subjective frame that is the care relationship and their encounters with others in the wider tourism system. To conclude, this chapter has presented the subjective, lived experiences of care, and the meanings ascribed to such experiences, as described and understood by the carers. I now move toward a wider discussion around the significance of these themes in Chapter 7, ‘Discussion’, offering but one possible interpretation.

7 Discussion

The major focus of this thesis is to explore and understand the multiple ways in which carers and people with intellectual disabilities experience care during leisure travel. Chapter 5, 'Context', and Chapter 6, 'Findings', offered descriptions of the participants' experiences of both travel and care, which inductively emerged through thematic analysis of the data. Such descriptions illuminated the significance of leisure travel as enabling a 'good life', and three key themes pertaining to their experiences of care, which were *giving*, *attunement* and *(in)visibility*. The purpose of this chapter is to present my understanding of these findings before moving forward to present but one possible interpretation of this construction of the care phenomenon during travel, by way of discussing the wider implications of such findings in Chapter 8, 'Conclusion'.

7.1 Experiences of leisure travel

The purpose of the first half of this chapter is to address the first subsidiary research question of the thesis:

1. How do carers and people with intellectual disabilities experience leisure travel, and what is the significance of this?

Leisure travel represented both an experience in and of itself, as well as the context where experiences of care played out for the carers and the people with intellectual disabilities involved in this research. The findings tell us about the significance of travel for the participants as a unique and meaningful, mutually rewarding experience; an experience that, fundamentally, is sought in pursuit of, and has potential to contribute toward, an enabling of a 'good life'. Fundamentally, the experience of leisure travel relates directly and indirectly to the three key themes presented in Chapter 6, 'Findings', as it is here that the participants' situated experiences of care as *giving*, *attunement* and *(in)visibility* materialise.

7.1.1 Travel as a meaningful experience for the people with intellectual disabilities

Tourism scholars have noted that the travel experience positively enhances the quality of life, wellbeing and life satisfaction of people with disabilities (Luo, 2014; Modell & Imwold, 1998). The people with intellectual disabilities involved in this

research were motivated to travel for reasons comparable with those of other people with disabilities, and with non-disabled people too. These motives were to have a break and relax, or to engage in new and novel experiences (Dominguez, Fraiz, & Alen, 2013; Packer et al., 2008). These individuals derived considerable joy from their travel experiences, and expressed a desire to travel again and more frequently in the future (Dominguez et al., 2013). Indeed, the carers involved in this research confirmed that, for the people with intellectual disabilities, the travel experience was not only representative of a positive antithesis to their everyday lives but was an unparalleled life experience. Travel, it seems, affords a reprieve from the restrictions and frustrations of the everyday, as well as an opportunity to traverse into a perceived realm of the ordinary and the normal, which together account for an extraordinarily full experience.

The travel experience was meaningful for the people with intellectual disabilities in that it facilitated intrapersonal outcomes, namely “intellectual, creative and emotional growth” (Kim & Lehto, 2013, p. 19). As an example, Luo (2014) pointed to self-identity as an important positive outcome of the travel experience for people with disabilities. It was suggested that an individual could acquire a greater sense of understanding of self in relation to the world they lived in, feeling ‘normal’ if and when this self-identity was enhanced. Relatedly, Innes et al. (2016) suggested that, for people living with dementia, the travel experience minimised feelings of agitation, apathy and dependency, which were often associated with their day-to-day lives. In speaking to these points, for some of the people with intellectual disabilities involved in this research, to be able to partake in the travel experience was a rite of passage to feeling normal or experiencing normality. For others, to be able to partake liberated them from the constraints of a more mundane everyday life. For many of these people with intellectual disabilities, their desire to partake had stemmed from comparisons made with a non-disabled sibling or a former non-disabled life. Their participation, then, afforded them a sense of gratification and self-assertion that came with not only having the opportunity to experience travel but also successfully partaking in travel and, by extension, (re)claiming a sense of self-identity.

Many tourism scholars have noted that the novel travel experience facilitates learning opportunities for people with disabilities, which is conducive to their personal growth and development, and renders a sense of independence, accomplishment and fulfilment (Kim & Lehto, 2013; Lehto et al., 2017; Luo, 2014). In this research, travel enhanced the awareness, perspectives and worldviews of people with intellectual disabilities. Further, the experience facilitated opportunities for and moments of learning, which meant they had new frames of reference to draw upon both at home and away (Minnaert et al., 2009). It was through travelling that these people with intellectual disabilities sought to set and achieve personal goals, uncover new interests and inspire future dreams.

It has been suggested that, through the travel experience, people with disabilities are uniquely provided with intellectual development (Lehto et al., 2017; Luo, 2014). The carers involved in this research also suggested that travelling encouraged a sense of independence, empowerment and self-development within the people with intellectual disabilities. They noted, however, that such positive outcomes were generally shorter-term and usually confined to the duration of the travel experience, whereas Luo (2014) and Lehto et al. (2017) suggested that these outcomes were longer lasting, being impactful after their return home. Even so, it is important to note that those people with intellectual disabilities involved in this research who engaged in sequential travel experiences acquired an increased familiarity with and autonomy in navigating the travel processes and systems.

It could be inferred, therefore, that the travel experience uniquely affords people with intellectual disabilities with an effective medium through which learning moments can take place. As Lehto et al. (2017) commented, “a unique factor for individuals with disabilities is that tourism experiences provided intellectually disabled children with superior learning occasions ... more appealing, easier for the children to comprehend, and more effective compared to traditional learning methods” (p. 6). The experiential nature of travel and the different environment that it takes place in transmits tacit knowledge for the people with intellectual disabilities. That is, it gives a tangibility to their thought process and understanding, which might otherwise be conceptualised in an intangible and abstract way. Notwithstanding the fact that the comprehension of such learning is specific rather

than intrinsic, this finding could potentially have implications around opportunities for recreational programmes, retreats and camps for school children with disabilities, facilitated through tourism.

Further, the travel experience was meaningful in that it facilitated positive interpersonal outcomes for the people with intellectual disabilities, as tourism scholars have suggested. The travel experience can facilitate social inclusion and enhance social skills and effectiveness (Hunter-Jones, 2003; Kim & Lehto, 2013), improving an individual's ability to understand and get along with others (Kim & Lehto, 2013). It also aids learning around social norms and representations (Lehto et al., 2017), as the diverse, the unfamiliar and the strange are integral elements of the tourism experience. As an example, Lehto et al. (2017) noted that through such experiences, "breaking down barriers, and challenging boundaries and stereotypes that are associated with disabilities are an important part of meaning-making for travellers with disabilities" (p. 182).

In many respects, the social aspects described were inferred by the participants involved in this research, but were not so explicit across the majority, possibly given their limited expressive and receptive communication abilities, which are described in Chapter 4, 'Methodology', and Chapter 5, 'Context'. What was particularly evident, however, was that the travel experience provided a space and place for favourable social interaction, both home and away. At home, the people with intellectual disabilities then had an especially significant reference point – that is, having travelled – which was affirmed through their interaction with others. The fact that they had travelled established common ground and subsequently facilitated their connection with others. This connection generated in them feelings of confidence and belonging, as other tourism scholars have noted (Kim & Lehto, 2013; Lloyd, King, Lampe, & McDougall, 2001; Lord, 1997). Photographs, for instance, were drawn upon as a conversation aid, as the exchange of photos and stories with others facilitated interaction, as Lehto et al. (2017) also noted. Disability scholars have drawn upon visual methods, such as photovoice, to foster greater participation and inclusion in their research involving people with intellectual disabilities (see Schleien et al., 2013). Tourism scholars in the mainstream have considered photography as a means of reflecting on and sharing

memories, and the photographed tourist experience often becomes a predominant element in the narrative of a person's life (Baerenholdt, Haldrup, Larsen, & Urry, 2004).

7.1.2 Travel as a meaningful experience for the carers

As much tourism scholarship has suggested, for disabled and non-disabled families alike, travel offers an escape from the everyday and it establishes a sense of normality (Britton, 1991; Sedgley et al., 2017). This research concurs with these points and, in addition, indicates that the pursuit of travel is more a necessity than a luxury for many families (Lehto, Soojin, Yi-Chin, & MacDermid, 2009), appreciated as an important aspect of their family lives (Gladwell & Bedini, 2004; Kim & Lehto, 2013; S.M. Shaw & Dawson, 2001). The carers involved in this research, however, acknowledged that they had both the resources and the power to facilitate such an activity, suggesting that this may not be the norm in terms of other families with members with disabilities (Mactavish et al., 2007).

I think this point is important to emphasise for two reasons. Firstly, as it may contribute to dispelling the common misconception that people with disabilities and their families (or, their formal carers) do not travel, and which also supports the economic rationale for accessible tourism in that there is a multiplier effect. Secondly, as it may contribute to strengthening the argument for a social tourism programme with an agenda toward achieving greater social inclusion (Belanjer & Jolin, 2011; Schanzel & Yeoman, 2014). Such programmes could assist in facilitating the financial and structural accessibility of travel for disadvantaged families with people with disabilities, who might not otherwise have the resources to do so themselves (Minnaert, Diekmann, & McCabe, 2012).

Scholars have attested that, for families with and without disabilities, the motivation to travel is premised on its offering of escapism (Britton, 1991; Sedgley et al., 2017). Ironically, perhaps, the pursuit of leisure travel is often framed as a hedonic experience, a promise of rest and relaxation (Leiper, 2004), and as recovery from the stresses and demands of daily life (Plog, 2005; Valtonen & Veijola, 2010). As Kim and Lehto (2013) explained, "coping with the stress of parenting a developmentally disabled child can be a challenge but the shared leisure experiences of family members seem to allow a modicum of relief for some of the

stress and tension” (p. 19). This was certainly reflected in this research, where the carers perceived travel as offering a sense of reprieve from the busyness and constraints, structures and routines, of their everyday home lives (Kong & Loi, 2017). In addition, where many carers perceived the leisure travel experience as offering a potential sense of escape from normality, for others, interestingly, it represented an opportunity to instil a sense of normality into their lives, which Sedgley et al. (2017) also identified.

Despite having the intention to leave behind the gender imperatives and associated domestic obligations of home life (Schanzel & Smith, 2011; Small, 2005), the responsibilities of carers (or parents, and especially mothers) would cease to alleviate stress while away, and could actually exacerbate stress (Backer & Schanzel, 2013; Sedgley et al., 2017). Scholars have suggested that gendered domestic roles (Keith, 1992; Traustadottir, 1991), behaviours and constraints are extended into the tourism context, where women typically continue to care for others (Aitchison, MacLeod & Shaw, 2000; S.M. Shaw, 1994). Even so, this research concurs with Sedgley et al. (2017) who noted in her study on mothers with autistic children that, overall, travel was valued as a positive, enriching pursuit, offering a considerable sense of pleasure amidst the stress.

Some scholars have suggested that participation in leisure activity, particularly that of travel, may be restricted, compromised or relinquished for individuals or families with disability-related care responsibilities (Chenoweth & Spencer, 1986; V. Wilson, 1990). Such responsibilities might necessitate, for instance, the redirection of discretionary time and income (Innes et al., 2016; Kong & Loi, 2017). Even if carers were to travel without the individuals that they cared for in their everyday lives, they would still incur financial and emotional costs. Financially, this comes from having to fund an alternative care arrangement for the individual with disability (Chesson, 2001). Emotionally, it might arise from feelings of concern for the individual who is at home, which can negatively detract from their own travel experience while away (Gladwell & Bedini, 2004).

As an example, Bedini and Guinan (1996) described how, although carers “desired and accepted leisure in their lives, their ethic of care created barriers to accessing it. ... [They] viewed leisure as a privilege rather than as a right, often

placing it low on their priority lists” (p. 236). This ethic of care was explained as a “sense of responsibility to their care recipients [that] far outweighed their responsibility to their own personal and leisure needs” (Bedini & Guinan, 1996, p. 235). The above was not dominant among the participants involved in this research, nor for Lehto et al. (2017), who noted that “none of the caregiver respondents articulated sentiments of unchosen obligation or burdens” (p. 182). For this reason, I believe it is important to emphasise the point, as it may contribute to more positive focus on the dialogue around the care experience more generally.

Similarly, many scholars have attested that travel enhances a person’s life satisfaction and brings about health and happiness (Figueiredo et al., 2012; McCabe & Diekmann, 2015). In fact, a positive and enjoyable tourist experience stems from the sociality of being together (Baerenholdt et al., 2004; Carr, 2011; Gram, 2005; J. Larsen, 2008;). Indeed, all of the carers involved in this research placed considerable value on the pursuit of leisure travel, perceiving it as an experience through which a ‘good life’ could be enabled (Hermsen, Embregts, Hendriks, & Frielink, 2014). They ascribed meaning to both the intrinsic reward and relational benefit that could ensue from such an experience. Firstly, travel offered the opportunity to spend quality time together and to share in a memorable experience. Such an experience facilitated friendship, strengthened connection, and formed deeper relational bonds. Accessible tourism scholars have also noted positive outcomes around social development, in the sense that through shared memorable experiences, friendships are enhanced and deeper relational bonds are formed (Kim & Lehto, 2013; Lehto et al., 2009; Luo, 2014).

Secondly, the travel experience served to remind them of their own role in enabling or disabling opportunities in the lives of the people with intellectual disabilities. With such cognisance, the importance in enabling a ‘good life’ through travel was realised, and they were afforded a sense of pride and gratitude (Lehto et al., 2017). As discussed in the next section of this chapter, the carers largely interpreted the meaningfulness of their care experiences from the lens of the people with intellectual disabilities (Kim & Lehto, 2013; Lehto et al., 2017). Similarly, scholars have noted that travel is experienced through relationship, can enhance relationship and is mutually rewarding, which therefore reinforces the presence of

an ethic of care within such a situated context (Backer & Schanzel, 2013; Luo, 2014).

This research contributes to the tourism scholarship that emphasises exploration of the domesticity, relationality and sociality that inherently exists within the tourist experience. It also emphasises the need to better recognise and acknowledge, rather than discredit, the everydayness of travel, as well as the extraordinariness of this activity. It is important to be cognisant of, rather than take for granted, the fact that what may be considered as ordinary to one traveller, is indeed considered extraordinary by another (Lehto et al., 2017). In addition, that the spheres of home and the spheres of away are often inseparable, informing and not at variance with one another (J. Larsen, 2008; Obrador, 2012). It is here in the taken-for-granted – the assumed and unquestioned – aspects of everyday life, where the power lies (Ellingson, 2017). Scholars have argued that it is the very ordinariness of an experience that renders it extraordinary and, similarly so, in seeking to explore and understand what is extraordinary (Baerenholdt et al., 2004; Lehto et al. 2017), we can also explain that which is ordinary in an experience (Small, 2008).

Family tourism scholars, for instance, have considered the inter-relationship between everyday life at home in comparison with travel life while away (Uriely, 2005), as well as implications of the place of family and of home, in and opposing the dominant ways in which tourism is understood (Lashley et al., 2007; Obrador, 2012). The tourist gaze of a family – and/or of a care relationship – then, might offer insight into “the ‘extraordinary ordinariness’ of intimate social worlds” (Haldrup & Larsen, 2003, p. 24). Indeed, this research would concur with the arguments of these family tourism scholars who argue for the “need to confront such prevailing distinctions and reappraise thick sociality and relations of domesticity as integral to the contemporary tourist experience” (Obrador, 2012, p. 409).

7.2 Experiences of care

Where leisure travel represented a meaningful experience for each of the care relationships involved in this research, it also represented a unique context through which the participants’ lived experiences of care played out. Experiences of care at the nexus of intellectual disability and leisure travel were multi-faceted,

contextually intricate and relationally entangled (Philip et al., 2012), representative of, *giving*, *attunement*, and *(in)visibility*. These three themes illuminated the nuances and complexities of, and meanings ascribed to, situated experiences of care during travel. In this way, the carers' experiences captured an everyday life; the practical and emotional caring spheres, which seemed to be 'care-full' (Rogers, 2016). But they also afforded us a glimpse into the broader and more violent socio-political caring spheres, which arguably are 'care-less' (Rogers, 2016).

This section briefly summarises the findings of this research, before continuing the chapter by way of offering but one possible interpretation of the data (Oakley, 1998; van Manen, 1990). This research contextualised the phenomenon of leisure travel, defining it as both a significant and meaningful experience, and as the context in which care experiences took place. The experience of leisure travel was meaningful for both the carers and the people with intellectual disabilities, in the sense that it afforded them a sense of living, learning and connection. Travel, it seems, equates to wellbeing, dignity and enabling a 'good life', which much research across several fields of scholarship (namely, leisure studies, tourism studies and disability studies) has referred to.

The experience of care as *giving* was ultimately about the pursuit of ease, and in turn, the minimisation of stress, through a person-centred approach to care. It was therefore a strategy of sorts, representative of the practical caring sphere. *Attunement* in the care experience was ultimately about an emotional reactivity and responsivity, considerateness and connectedness; the bridging of one another's inner and outer worlds. As interpreted in this research, it was representative of the emotional caring sphere, significant and meaningful to one's being (Heidegger, 1927/2008), likened to care work as a labour of love (Finch & Groves, 1983; Kittay, 2011; Traustadottir, 1991). The *(in)visibility* of the care experience was ultimately about the current 'care-less' spaces of tourism and hospitality, which in fact could be care-full; hospitable and human. Indeed, tourism need not be a site of reproduction or resistance but, rather, a potential site of transformation, as will be suggested in Chapter 8, 'Conclusion', and Chapter 9, 'Epilogue'.

7.2.1 Giving

Travel represented a unique context through which experiences of care played out away from the comforts and familiarity of everyday life at home. To this effect, the experience of care as *giving* illuminated a practical caring sphere, that is, “where day-to-day care is carried out relationally” (Rogers, 2016, p. 2). This was both contextual and particular to environment and person, as an ethic of care also denotes. In this research, giving related to a need to acknowledge the necessity of and dependency on, care and carer, of the people with intellectual disabilities, in everyday life but also in order to travel. As scholars have suggested, for the carers, the concerns and stresses faced in functioning at home are mirrored while away. For the people with intellectual disabilities, “if travel represents a temporary escape of everyday routines for an average traveller, travel to this group represents a magnified everydayness as travellers continue to be challenged with limitations due to a disability” (Lehto et al., 2017, p. 181).

Care is both a disposition and a practice (Tronto, 1993). The nature and execution of giving care (Kittay, 1999) is understood to manifest at two levels, mirroring the groupings of Maslow’s (1943) goals of basic needs and tailored always to the individual receiving it (as cited in Hermesen et al., 2014). Firstly, at a lower level giving care is about attending to an individual’s principal physiological and safety needs (Noddings, 2002), and aspects of their functionality in life. Here, an acknowledgement of an individual’s personhood and rights is emphasised as an integral component of care, as are values of respect and dignity (Gustin & Wagner, 2013). Hermesen et al. (2014) identified that, through their ‘professional loving care’ approach, carers (or support workers) who evoked a sense of reliability and trustworthiness fostered feelings of safety and security for an individual (or client). The consistency of such an approach over time conveys a message to the individual (client) of: ‘I am here for you’, ‘to help’ and ‘to defend’ you (Noddings, 2002). These findings were also evident among the participants in this research. At this lower level, giving care reflected the notion of a ‘duty of care’ – of carer in relation to individual with intellectual disability – as described by scholars in care and disability studies alike (Kittay, 2011; Twigg & Atkin, 1994).

Secondly, at a higher level, giving care is about supporting an individual to fulfil their self-esteem and self-actualisation needs, which really was about enabling and empowering an individual to lead an ordinary, and ideally, ‘good’ life. Here, this is achieved by way of the carers providing the people with intellectual disabilities with a platform of independence, supporting them in their decisions, encouraging self-determination, and ultimately self-reliance. Here, too, autonomy is emphasised as an integral component of care (Kittay, 2011). This relates to definitions of empathic concern, where a carer encourages both the aspirations and individuality of an individual, which “thus plants the necessary seeds of autonomy” (Slote, 2004, p. 302). The exercising of autonomy seemed to walk a fine line, however, as it necessitated a balance of autonomy–responsibility. This balance was perhaps more pertinent within the travel context where the vulnerability and dependency of the people with intellectual disabilities was heightened (Fineman, 2004; Kittay, 2002). At this higher level, giving care reflected the notion of acknowledging ‘dignity of risk’ – of a carer in relation to an individual with intellectual disability – as described by scholars in care and disability studies alike.

Within the tourism industry and society more generally, there is an assumption that we can all be independent and autonomous, but this simply is not the case (Wendell, 1996); the way people see things and the way they are in the world differs. Generally, the dependency of the people with intellectual disabilities on the carers, was tied to personal care, functional mobility and, most significantly, their cognitive capacities for comprehension and expressive-receptive communication abilities. Such dependency at home was not only mimicked but became more pronounced during travel (Lehto et al., 2017), due to the abstract nature of time and place, money and safety.

In addition, the logistical aspects involved in navigating the travel system and processes more generally were challenging and often beyond their capabilities. Consequently, this could impede their ability to think rationally, amplify their vulnerability and cause stress and anxiety as an emotional response. Other accessible tourism scholars have also identified that the unfamiliar, sensory-overloaded travel context (Richards et al., 2010; Sedgley et al., 2017) can engender feelings of anxiety, fear, tension and stress among some people with disabilities

(Durko & Petrick, 2013; B.K. Lee, Agarwal, & Kim, 2012; Small et al., 2012). This emotional state, in turn, held the potential to implicate their ‘dignity of risk’. Therefore, in the precarious tourism environment, as risk is heightened for an individual with intellectual disability, responsibility is heightened for a carer, which can in turn amplify their own anxiety (Kingsbury et al., 2012). To this effect, and as argued in Chapter 8, ‘Conclusion’, the tourism industry needs to be more cognisant of its ‘duty of care’ to people with intellectual disabilities.

The giving of care also meant giving in a financial sense. In order to participate in the travel experience, the people with intellectual disabilities were dependent upon access to finance, which typically came from the carer, in the same way that a child is dependent on their parent (Blichfeldt, Pederson, Johansen, & Hansen, 2011). To understand experiences of care during travel first “requires an appreciation of the broader social context ... in which the holiday takes place” (Small et al., 2012, p. 947), which is elaborated upon in Chapter 3, ‘Background’. In everyday life, people with disabilities and their carers often experience lower measures of socio-economic outcomes (G. Shaw & Coles, 2004). They face higher rates of unemployment, and are therefore financially restricted (Hunter-Jones, 2010; McKercher & Darcy, 2018). Their principal income stream is usually in the form of government benefits, which tend to go toward medical needs and disability support services well before beginning to consider discretionary spending on travel. Even if discretionary income is available, financial concerns might exist in terms of the “costs attached to hiring specialist equipment, inflated single-room occupancy rates, and an inability to access last minute deals” (Hunter-Jones, 2010, p. 175).

Understandably, then, there is an assumption that people with disabilities cannot afford to travel. For the individuals involved in this research, however, it was uniquely rendered possible. Indeed, the carers involved in this research acknowledged that they were somewhat representative of a minority, in that they could financially afford to facilitate the travel experience, but that for others, as the majority, it is financially inaccessible, a finding which Mactavish et al. (2007) also raised. Disparities around the cost of travel and the additional cost of care were also pointed out (Freeman & Selmi, 2010; Kastenholtz et al., 2015; Yau et al., 2004).

Compounding the cost of travel and of care was the fact that a carer actually needs to be willing to both give care and travel. Together, these points raise a pertinent argument in favour of the case for social tourism policy (Belanjer & Jolin, 2011; McCabe & Diekmann, 2015), and potentially some sort of volunteer tourism programme. From a rights-based perspective, too, if travel is representative of an important medium through which carers can facilitate the enabling of a ‘good life’ for people with (intellectual) disabilities, then private, public and not-for-profit sectors alike need to be doing more to facilitate the exercising of these individuals’ citizenship, and assist in offering access to both care and finance.

From a practical perspective, giving care saw the carers being driven by a mentality of ‘you before me’, where the needs and wants of other were prioritised before those of self. Kim and Lehto (2013) have also suggested that families travelling with a child with disability are driven by a “strong child centred focus” (p. 19). Care ethicists have recognised this sensitivity to, and emphasis upon, the needs of others, as a feminine selflessness, which has long represented an oppressive gender norm (Day, 2000; Gilligan, 1982). In this respect, Small (2005) referred to an ethic of care as being reflective of the experiences of the women in her study, who defined themselves relationally and considered their responsibility to their children’s safety and happiness before their own needs and desires. She continued, “it appeared that what the women wanted was a change in their circumstances, to be removed from their children, removed from a sense of duty and obligation so that they did not have to behave responsibly” (Small, 2005, p. 149).

In a different vein, Lehto et al. (2017) had commented, “a striking finding is the selflessness exhibited on the part of the [carers]” (p. 182). They continued, “the wellbeing of the care-recipient almost single-handedly determined the experience satisfaction of the [carers]” (p. 182). Similarly, Kim and Lehto (2013) commented on the wellbeing of parents as carers being ‘closely tied’ to the wellbeing of their children with disabilities, and that the travel context amplified the closeness of their relational dynamic. These comments resonated with the findings of this research, where, put simply, positive experiences of both travel and of care for an individual with intellectual disability correlated with positive experiences for a carer. For, in

giving care, the carers were receiving, and this reciprocity as a form of mutuality (Noddings, 2002; Walmsley, 1993) is elaborated upon in the succeeding sections of this chapter.

In considering this mentality of ‘you before me’, it was important that the ‘dependent’ – in this case, the people with intellectual disabilities – maintained a position of centrality in the decision-making process (Hunter-Jones, 2010), although it was ultimately the carer who would make the final decisions. Family tourism scholars have also noted that while the children certainly influence the planning and decision-making process, it is the parents who, in the end, decide (Bronner & de Hoog, 2008; Gram, 2005; Seongseop, Choi, Agrusa, Wang, & Kim, 2010; K.C. Wang, Hsien, Yen, & Tsai, 2004). In mainstream family tourism scholarship, it seems that there is more room to navigate family dynamics and tensions, and to adapt and alter between the conflicting needs and wants of each family member (Lehto et al., 2009; Schanzel & Smith, 2014). To this effect, Mactavish et al. (2007) suggested that a focus on the needs and wants of an individual with intellectual disability can impose limitations on the nature, frequency and spontaneity of travel, necessitating compromise within a family. It was relatively common for the carers involved in this research to compromise their own travel desires in favour of fulfilling those of the people with intellectual disabilities (Kim & Lehto, 2013), but also those of the other family members (Hibbert et al., 2013). Nyman et al. (2018) explained how competing demands within a family might necessitate compromise in the sense that the parents opt to take two separate holidays, one for the child with disability, and another for the non-disabled child. This was evident among a couple of the families involved in this research. Ultimately “parents often invest considerable resources of time, energy and money in family vacations motivated by their ... idealised notions of family bonding, quality time and togetherness” (Hilbrecht, Shaw, Delamere, & Havitz, 2008, p. 542), yet perhaps nuances of care and disability idealise notions of ease, first and foremost.

The notion of the travel experience being primarily carried out for the people with intellectual disabilities prompted the carers into an extensive planning process in the pursuit of ease. Like other accessible tourism scholars have identified (Gladwell & Bedini, 2004; Mactavish et al., 2007; Packer et al., 2008), the carers

“invested significant time, energy and emotional labour” (Sedgley et al., 2017, p. 22). It could be inferred therefore, that the pursuit of travel is more stressful than it is alluring (Sedgley et al., 2017). Interestingly, where Gladwell and Bedini (2004) perceived the extensive time and energy involved in such process as an obstacle, Mactavish et al. (2007) suggested that by engaging in the process in such a way, it actually enabled a more positive travel outcome, which this research too confirms.

Detailed and intensive, the purpose of such a process was in an attempt to mitigate any practicalities or tensions that the carers anticipated. Therefore, stress reduction was favoured, meaning that cost became secondary. This finding perhaps adds weight to the argument that people with disabilities spend more money during travel. Where most of the stress for the carers involved in this research lay in actually travelling to and from the destination, for Sedgley et al. (2017) the stress seemed to become more prominent once at the destination itself, where the mothers of children with autism emphasised their planning around “the destination; the journey; the type and layout of accommodation; meal arrangements and daily activities” (13). This research builds on the idea that “unlike more familiar conceptualisations of tourism, [carers] are particularly challenged to create order and routine in unfamiliar environments” (Sedgley et al., 2017, p. 18).

Like Lehto et al. (2017) and Sedgley et al. (2017), the carers in this research also granted significant consideration to ‘home-like’ structure, routine and occupancy while away, which involved compromise and resistance yet facilitated predictability and familiarity, in both process and at place. As an example, the carers would select the same destinations to repeatedly travel to, and they would seek to emulate past travel experiences that they had deemed successful. There was benefit in the people with intellectual disabilities knowing what to expect and the carers being already acquainted with the destination and its activities, attractions, accommodation and transportation, as well as enhancing the memorability of the shared experience. Indeed, as Sedgley et al. (2017) attested, “spontaneity, surprise and cultural immersion [were] not found in these women’s tourism lexicons; instead their language [was] one of repetition, comfort and familiarity” (p. 18). This perhaps reinforces the argument that people with intellectual disabilities specifically, and those they travel with, are loyal as a market segment (Burnett &

Bender-Baker, 2001; Patterson, Darcy & Monninghoff, 2012). In comparison, Nyman et al. (2018) suggested that families of children with physical disabilities, namely wheelchair users with cerebral palsy, choose to travel to new destinations.

Relatedly, the carers emphasised the importance of communicating plans of leisure travel to the people with intellectual disabilities, given their ‘need to know’, and contended that both the timeliness and nature of such disclosure were pertinent. Similarly, Sedgley et al. (2017) attested that the mothers in their study found need in “psychologically preparing their children for the holiday” (p. 18). There were, however, implications in seeking and communicating familiarity, as any variance from what was planned was met with anxiety and/or resistance. Sedgley et al. (2017) commented, “holidays are desirable spaces of family relaxation, yet they simultaneously create enormous pressures as the predictability of the everyday is something to appreciate” (p. 18). Tensions between familiarity-inflexibility and spontaneity-flexibility could therefore prevail, which challenged the ‘discourse of spontaneity’ (Sedgley et al., 2017). In comparison, other scholars have noted the importance of flexibility and adaptability, that is, the capacity to react to change and achieve a sense of cohesiveness (Lehto et al., 2009; Muir & Strnadova, 2014). Indeed, giving care was a strategy of sorts, and while carers had described their motivation to travel as an escape from the everydayness of their home lives, they in fact seemed to reproduce many aspects of this life, effectively bringing the ‘work’ of home away (S.M. Shaw & Dawson, 2001).

7.2.2 Attunement

As elaborated upon in the previous section, where *giving* illuminated a practical caring sphere, *attunement* illuminated an emotional caring sphere, that is, “where love and care are psycho-socially questioned” (Rogers, 2016, p. 2). This caring sphere saw attunement manifest as attunement to self (the carer was attuned to their own emotional needs and moods); attunement of self in-relation-to other (the carer was attuned in-relation-to the individual with intellectual disability) (Noddings, 2002; Tronto, 1993); and, attunement to other others (the carer, representative of the care relationship, was attuned in-relation-to other others) (Hochschild, 1979).

Attunement relates to the natural inclination of a mother to care for – that is, give love and nurturance to – her child (Traustadottir, 1991), and as individuals “our

sense of caring and being cared for starts at home ... probably, in parental love” (Noddings, 2002, p. 1). Traditional understandings of mothering have conceived the mother as primary carer, responsible for performing care work, and held accountable for a child’s moral, psychological and physiological development and wellbeing (Chodorow, 1978; Malacrida, 2009; Read, 2000). Much of the motherhood scholarship attests that women are thought to feel both morally and culturally bound to place the needs of other before self, and this is a central tenet of an ethic of care (Bolton, 2009; Fineman, 2004; Kittay, 1999, 2002; McKeever & Miller, 2004; Tronto, 1993). Indeed, whether biological, adoptive or self-professed, the carers involved in this research as mother or maternal figure (Brock, 2015; Topia, 2015; Noddings, 2002) were “preoccupied not with herself but with another” (Ruddick, 2007, p. 376); “that ear always tuned for the sound of emergency, of being needed” (Rich, 1976, p. 37). Selfless and self-sacrificing (Day, 2000; Sevenhuijsen, 1998), these carers were engaged in the time-consuming, emotionally involved (Bassin, Honey, & Kaplan, 1994; Green, 2007) ‘labour of maternal thinking’ (Ruddick, 1989) or ‘intensive mothering’ (Hays, 1996).

As Topia (2015) described, “mothering, in all its complexity, can be seen to be a contradicting mix of emotions and states of being” (p. 22); “good days and bad days, boring and mundane, joyful and exhilarating. It is pressure, pain and challenge, cuddles and love” (p. 44). This was certainly true of the carers involved in this research, who shared their experiences of mothering, continually ‘historicising’ their past as a reference point against which to describe their present and look forward to the future (Heidegger, 1927/2008). In many ways, this was a sense-making mechanism which illuminated the presence of disability in and progressing throughout their lives, as well as the relational dynamic of their care relationships. This frame seemed to help them in understanding and interpreting the value they placed on leisure travel and, in many ways, informed how it was experienced. What became apparent in their experiences of attunement in mothering disability were the subtleties in their expressions of care as vulnerability, resilience and hope. These emotional subtleties, it would seem, helped to form the cornerstone to not only survive but also thrive, both home and away.

Despite the all-encroaching and unrelenting nature of disability and care, the carers did not seem to feel hindered by or resentful of their circumstances; rather, they were pragmatic in recognition of, and in responsibility for, their maternal caring role (Traustadottir, 1991). They were practical and realistic, yet all the while optimistic about what they hoped to achieve with and for their child. Over time, they grappled with and renegotiated a new normality amidst both their own, as well as societal understandings, of ideologies around disability and motherhood. They pursued and enabled whatever a ‘good life’ looked like for each of them personally, which seemed to be a common theme through the experiences of mothering children with disabilities (Brock, 2015; Ryan & Runswick-Cole, 2008).

To some extent, this outlook may be representative of an innate characteristic of each individual’s personality – a feature of how they have been and who they are – and perhaps not easily or quantifiably replicable. In any regard, the ability to view from a positive frame what others may perceive to be a deviation from the norm, and as having potentially negative circumstances, built resilience and inspired a sense of living from a place of unconditional love and devotion (Hubert, 2011; Levine, 2009; Traustadottir, 1991). It could be inferred that their boundless love and deep sense of connectedness was integral to the care experience (Grant, Ramcharan, & Flynn, 2007). Indeed, this ‘fierce love’ came through so strongly during the data collection (Hubert, 2011) where, to borrow a description from Kearney and Griffin (2001):

It was clear that their children were a source of joy [and] admiration ... they were animated and enthusiastic ... and their voices were full of pride and love. They spoke of their children in glowing terms and used words such as ‘beautiful’, ‘affectionate’, ‘generous’, ‘cheerful’. (p. 586)

For the carers, this was not to deny the presence of inadequacy, guilt, scarcity or fear, but to acknowledge that, and appreciate what is and hope for what would be. To summarise, intrinsic to the carers’ attunement in giving care was the ability to ascribe positive meaning to and rise above situations of circumstance. As identified by many motherhood scholars, within this relational context of care, these mothers expressed a great sense of happiness and joy, and satisfaction and pride. Mothering disability as an expression of attunement in care, they found, was a rewarding, fulfilling experience, despite the many and varied challenges faced along the way

(Hubert, 2011; Khanlou, Mustafa, Vazquez, Davidson, & Yoshida, 2017; Traustadottir, 1991). These experiential elements, that were both positive and negative (Kearney & Griffin, 2001), were parts of a whole, and suggested a complex co-dependency (K. Knight, 2013), mutuality and reciprocity (Hubert, 2011). When “something is given ... something is received” (Cushing & Lewis, 2002, p. 179), and “in serving others, one is serving one’s extended self, and self-actualisation occurs in relationship” (Spiller, Erakovic, Henare, & Po, 2010, p. 159).

As a moral orientation, caring is neither specific to the private or public sphere, nor to gender nor biological relation (Noddings, 2002) and, as such, whether informally or formally, non-biological women and men can perform the work of a ‘mother’ with a strong disposition to care (Ruddick, 1989). I felt this was important to mention when considering what might otherwise have been a more dispassionate, formal and transactional relationship between the carers (as staff) and the people with intellectual disabilities (as clients). While presumably an individual seeking this line of work would embody such qualities, I still was somewhat surprised and delighted by this, as I had envisioned a more sterile or clinical staff-client type of relationship. Yet, in any case, such attunement would be dependent upon the connection that existed between two individuals (Noddings, 2002).

Instead, it seemed as though the carers involved in this research gave care freely. They were genuine in their affection, open and full of empathy, wanting what was best for people with intellectual disabilities, and outwardly intentional in seeking to enable a ‘good life’ (Hermesen et al., 2014). Indeed, an ethic of care sees caring relationships as empathetic, emotionally considerate, open and responsive (Chanter, 2001; Simola, 2003). The carers emphasised the importance of attunement in nurturing strong, positive relationships, and recognised that building rapport, trust, mutual respect and understanding was a timely process (Kittay, 1999), requiring of temperance, tolerance (Hermesen et al., 2014) and a distinctive thoughtfulness (Ruddick, 1989), especially in the case of intellectual disability, where expressive-receptive communication could add unique challenges (Tronto, 1993).

Over time, the sharing of emotion, and trusting in one’s judgement and discernment in reading another person, enabled a closer emotional connectedness. Emotionally invested and relationally entangled, these carers shared all of

themselves and embodied a ‘professional love’ (Hermsen et al., 2014). They derived considerable fulfilment through their care work and, ultimately, the interpersonal relational dynamics that they cultivated (Henderson & Forbat, 2002) were mutually beneficial and reciprocal (Cushing & Lewis, 2002; Luo, 2014), which facilitated an enjoyable and fulfilling care experience during travel. From witnessing such a ‘love’ in these carers, in a non-intimate or non-familial sense, I agree with the following statement, that “professional loving care goes further than the professional care relationship and should be embedded in a caring society and caring network around the client” (Hermsen et al., 2014, p. 227).

All of the carers involved in this research emphasised the importance of nurturing relationships, and intrinsic to this was their attunement of self in-relation-to other. Once again, I reiterate that being attentive and attuned is neither an autonomous or generic action; rather, it is defined by the dignity of person and context of a situation’s specificities. The meaning of attunement, in this respect, was essentially an instrumental and cognitive attentiveness to what was needed in terms of the nature of giving in the care experience (Kohler, 1929), as described in Chapter 6, ‘Findings’. It was also a deeper knowing and exercise of one’s moral sensibilities, as it illuminated the carers’ feminine capacities to intuit, sense and feel the emotional needs and moods of the people with intellectual disabilities (Stotland, 1969). Indeed, care work is considered to be attentive and intuitive, thoughtful and intentional (Kittay, 2002; Noddings, 2002; Skeggs, 1997). It is an “ability to be present, to be reflective, to attend to mutuality of being and centring one’s consciousness and intentionality toward caring” (Watson, 1997, p. 51).

Attunement, therefore, was about listening to and looking out for the subtleties and nuances of another’s emotions and emotional cues, whether overt or covert, to capture a sense of what that person was thinking and feeling, needing and wanting, and essentially experiencing, in that moment (Noddings, 2002), and to meet them in that place of vulnerability with empathic compassion (Gustin & Wagner, 2013). This required “stepping out of one’s personal frame of reference into the other’s” (Noddings, 1984, p. 24), and feeling one’s self into their experiential world (Hoffman, 1984) through their proximity and presence (Gustin & Wagner, 2013; Hoffman, 1984; Stotland, 1969). An embodied intent, solicitous attention, and

affective action, attunement is therefore phenomenological, in alignment with a Heideggerian concept of care, or *sorge*.

Despite the fact that the carers could experience a juxtaposition of emotive states at any given point in time (Davidson & Smith, 2009), the carers were attuned to them, and therefore to self. That is, the carers had a certain self-awareness and conscious caring intent around the ways in which their own emotive state could influence their expression of care, the individual with intellectual disability, the care relationship as a whole and, ultimately, the leisure travel experience. This meant being able to suppress the expression of their own emotional reactivity to a given circumstance or situation. The necessity for such emotional regulation and management was that if the people with intellectual disabilities had an awareness of what the carers were experiencing, they could then react by way of their own emotional responsiveness. It seemed that this ability to be able to, firstly, identify and acknowledge one's emotions and, then, to conjunctively see oneself in-relation-to another rendered them able to be emotionally open and available, responsible and responsive, in such a way as has been described above.

The people with intellectual disabilities, too, even if at a more minor level, demonstrated a certain level of their own attunement in-relation-to their carers'. At a superficial level, most of the people with intellectual disabilities expressed feelings of gratitude toward their carers for supporting their travel. At a deeper level, a few of the people with intellectual disabilities seemed to gain an increased awareness around the emotional experiences of their carers, as well as their own emotional responsiveness, upon reflection on their travel experiences during the interview, which the carers recognised as being something of a role-reversal in their care relationships (Noddings, 1984).

At the same time, however, the carers recognised a certain limitation in terms of the extent to which the people with intellectual disabilities were able to attune to their emotional needs, considering them to be somewhat emotionally naïve and removed. This was largely attributed to the nature of their impairment being intellectual. Even so, there was acknowledgement of a reciprocity and mutuality in the attunement of the care experience (Henderson & Forbat, 2002). Being attuned to the emotional needs and moods of one another had mutual benefits, and it seemed

that the novel context of travel was conducive to providing a unique platform for such interdependence to be appreciated. That is, attunement was rendered necessary in order to form a cohesive unit in which to navigate the experience, and it evoked a sense of security and solidarity, closeness and connection, and belonging and togetherness.

In many ways, attunement in the care experience relates to ‘emotion work [or] labour’ (Hochschild, 1983), which has been discussed in relation to care, mothering and disability (D.H.J. Morgan, 1996; Ruddick, 1989; Staden, 1998; Steinberg & Figart, 1999). Emotion work has been defined as the “act of trying to change in degree or quality an emotion or feeling ... to ‘work on’ an emotion” (Hochschild, 1979, p. 561). To ‘work on’ an emotion is to employ cognitive, bodily, affective, and expressive techniques to suppress, manage or evoke an emotive state (Hochschild, 1979). Such techniques involve ‘deep acting’ or ‘surface acting’, where the former manages the feeling, while the latter modulates the expression of it, in seeking out a particular response of another, through one’s own behaviour (Hochschild, 1983). In this research, what became apparent were mostly affective and expressive gestures of emotion work, and both deep and surface acting: altering the feelings of one’s inner world, as well as its manifestation in the outer world (Hochschild, 1979).

In the public, proximate and interactional spaces of tourism and hospitality (Beckes & Coan, 2011), “social factors affect how emotions are elicited and expressed” (Hochschild, 1979, p. 555). That is, social norms, practices, rules and values (von Scheve, 2012) demarcate the intensity, duration, direction, and object of emotion appropriate in a given situation (Hochschild, 1979; Thoits, 2004). The carers involved in this research demonstrated an emotional fluency in their ability to navigate the tourism environment, intentionally attempting to regulate their emotion to meet normative socio-cultural expectations (Mauss, Bunge, & Gross, 2008; von Scheve, 2012). They were self-aware, able to self-manage, and had social awareness (Gardner & Harmon, 2002; Levine, 2009). Such emotion work as an expression of attunement is elaborated upon in the next section of this chapter.

In tourism scholarship, where self and the care of self has typically been prioritised before that of other and the care of other (S. Wearing & Wearing, 2001),

this theme contributes a relatively unique perspective. Indeed, as a services industry, the supply-side of tourism and hospitality sees a certain performance of emotional labour in relation to meeting the needs of the tourist as a customer (Urry, 1997). Emotional labour in this industry is witnessed, for instance in a waitressing role in a restaurant (Paules, 1991) or an air stewarding role on a plane (Hochschild, 1983), being willing to serve and appearing approachable and friendly throughout their exchange with patron or passenger (G. Marshall, 1986; Warren, 1999). This emotional labour is very much for a functional purpose and arguably is a 'staged authenticity' (MacCannell, 1973), whereas the attunement evident in this research is more an 'existential authenticity' (Cook, 2010; Reisinger & Steiner, 2006), subjective and relational, as Sedgley et al. (2017) also alluded to.

This theme may also contribute insight into the emerging scholarship on the 'feminisation of work' (McDowell, 2009) and 'hostessing' (Veijola & Jokinen, 2008) in tourism and hospitality. The very essence of 'new work' is a feminine "performance of social identity" (McDowell, 2009, p. 49); that is, the embodied, emotional and aesthetic labour involved in service work (Bell, 2011), and the performance of social identity" (McDowell, 2009, p. 49). Similarly, 'hostessing' describes "a skill and performance experienced and embodied by both women and men ... but not necessarily in similar terms and consequences" (Veijola & Jokinen, 2008, p. 166). Like an ethic of care, the bases of such relations (Noddings, 2002) are those that are usually seen in the private sphere (Fine, 2004), affective and communicative in nature (Veijola & Jokinen, 2008). Where an ethic of care considers the feminine and its difference from the masculine, Veijola and Jokinen (2008), too, consider this concept to be gender contingent also, where 'hosting' is masculine, and 'hostessing' is feminine; the former, an act and a practice, the latter a 'being' rather than 'doing' (Bell, 2011).

Evidently, where relational dimensions of care have largely been overlooked (Henderson & Forbat, 2002), this research offers an important contribution to tourism scholarship through attunement as a consideration of an ethic of care in regard to the spatially and relationally negotiated elements of the tourist experience. It offers interesting insight as to how we might better approach our touristic encounters with the other through attunement as a consideration of an ethic of care.

“In encounter, obligation happens” (Noddings, 2002, p. 50) and, in this respect, an ethic of care not only pays attention to the situated context and its particularities wherein self finds itself with others, but it also directs our attention toward the need for responsiveness in our relations with others (Noddings, 2002). That is, our attunement to the other is requiring of rational thought and emotional response, together. This might see a consideration of self in-relation-to other at a more intimate, direct level, or a more general, indirect level, through considerations of attunement in the care experience (Noddings, 2002). In terms of the former, it could for instance refer to, the capacity of the carer to look past their own immediate needs (as well as their desires) in order to take on, as their own, the needs (and the desires) of the individual with intellectual disability (Noddings, 2002). In terms of the latter, it could, for instance, refer to the development of an emotional awareness of and capacity for the other in our broader touristic surroundings.

This thesis encourages the development of such emotional awareness, so as to move beyond a conditional obligation (or, emotional rigidity) to an unconditional attunement (or, emotional agility) (David, 2016), from ‘caring-for’ to ‘caring-about’ other/s (Noddings, 2002), in our touristic encounters. We learn what it means to be ‘cared-for’, initially through a mother’s natural attunement, and through the ‘relations of affection’ we have with those who are close to us intimately; with time and by extension, what it means to care for and to care about others enlarges our caring disposition toward strangers (Kittay, 2011; Noddings, 2002). As Noddings (2002) elaborated:

Caring-about moves us from the face to face world into the wider public realm. If we have been well cared for and have learned to care for a few intimate others, we move into the public world with fellow feeling for others. We are moved by compassion for their suffering, we regret it when they do not experience the fruits of care, and we feel outrage when they are exploited. (p. 22)

In situations of encounter in tourism, this might then mean that where the other might behave in a way that might draw one’s attention to them, one would consciously endeavour to be less critical, calculative and conclusive as to what the situation might be, and instead would seek to take a more considered, caring approach (DeVault, 1990; Preissle, 2007). Compassion would be central to such an approach where one would seek to be less judgmental and more accepting and

understanding (Gustin & Wagner, 2013). If there is a ‘takeaway’ from this research, to crystallise the message, then it is simply this. As Ava reflected:

I’ve learnt to be patient and I’ve learnt to be tolerant; to try to not be too judgmental of people. Everyone has a story and we don’t necessarily know what that story is; you can’t judge them because you don’t know where they’re coming from.

Attunement is powerful. If we are oriented toward and bring an authentic presence into our encounters and engagements with others, we create a sense of spaciousness wherein we can render the other as seen and heard, and afford them a feeling of acknowledgement and acceptance (Gustin & Wagner, 2013). Even if an encounter represents a mere moment in passing, the simplest of gestures – a warm smile or engaging eye contact – can speak volumes. In this way, this theme both considers and contributes to the minimal consideration of empathy within critical tourism studies scholarship, as emotional attunement is empathic. Tucker (2016) attested that empathy is an ‘emotional pre-requisite’ for engaging with others which, as Pedwell (2012) attested, “recognises and respects the subjectivity and agency of others” (p. 165). Where cognitive empathy refers to one’s capacity to perspective take, that is, to imagine and therefore understand what it might be like to be in the experiential world of the other (Davis, 1980; Hogan, 1969; Kohler, 1929), affective empathy refers to one’s capacity to feel oneself into that world (Davis, 1980; Eisenberg, 1986; Hoffman, 1987). The significance of empathy as an aspect of attunement in the specific and situational context (Davis, 1994/1996) of tourism lies in the notion of “being there” or “being in proximity to the other” (Tucker, 2016, p. 40). This means that tourism could aid the cultivation of empathy, and that empathy as an ‘altruistic emotion’ could engender social justice, healing and transformation (Pedwell, 2012; Tucker, 2016).

There is a need to embrace the innate feminine capacities within all of us to care. Such capacities can engender nurturing emotion and relationship where one seeks “to form open, trusting, creative bonds with others” (Love & Shanklin, 1983, p. 279). As Noddings (2002) explained, “the best we can do is to care directly for those who address us – those we actually encounter (... this includes strangers) – and indirectly for others by working to establish social conditions in which we can flourish” (p. 47). Empathy as an attribute of attunement in the care experience is

further touched upon in Chapter 8, 'Conclusion', and Chapter 9, 'Epilogue', where some dialogue is offered in response to the following questions that Tucker (2016) called upon tourism academia to consider:

What does it mean to attempt to empathise with another's plight through tourism? Who benefits from the production of empathy in tourism contexts, and also, what, if any, are its limitations and risks? What does it mean to think that to empathise with another is possible? (p. 33)

Lastly, attunement in the care experience also related to an attunement to self, and the critical significance in caring for self in order to care for other. It is widely cited in scholarship, that carers – and particularly, parents of children with disabilities in comparison with parents of non-disabled children – are more likely to experience boredom and fatigue, decreased social interaction and isolation, emotional and physical exhaustion, stress and depression (Hubert, 2011; MacDonald & Callery, 2007; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Singer, 2006; T.B. Smith, Oliver, & Innocenti, 2001). Relatedly, other scholars have described various ways in which carers 'cope' with the experience of giving care, given the potential of such emotional responses (Staden, 1998, p. 148). Many of the carers in this research alluded to personally experiencing much of the above. Further, it could be inferred that their cognisance of this was heightened given the precarity and risk that the travel context could pose, and that many of the supports they might have at home were simply not an option while away.

Expressing a strong sense of self-awareness, the carers were attuned to their own emotional needs and moods, recognising that the vulnerabilities they experienced in everyday life were magnified in their travel lives. Tourism scholars have recognised that the nature of the travel experience lends itself to a context in which travellers spend a greater length of time together, and in closer proximity to one another, than they perhaps would have at home. Such a context provides an inherent intensity and intimacy of "an interactive space that represents a reconfiguration of interpersonal distance" (Lehto et al., 2009, p. 463), which can potentially lend itself to negative travel outcomes and memories (Durko & Petrick, 2013). Creating space, then, was emphasised by the carers as a coping strategy of sorts, which could potentially mitigate the type of burnout that could impact not only themselves but, ultimately, the individual with intellectual disability and the care relationship in its

entirety. The carers described various instances where the support of others was sought or respite care was desired, essentially creating space as an expression of attunement.

The needs of the carer were often placed second to those for whom they care for (Khanlou et al., 2017), yet, in creating space, the carers expressed a sentiment of guilt, feeling selfish in perceiving themselves to be prioritising their needs first. This, however, was offset with a recognition that in caring for self, they could provide better care for the other (P. Gilbert, 2005). In this way, attunement was affective and expressive, as it brought an immediacy to and a mindfulness of their expressions of care. Such expression, it seemed, evoked a visceral presence and connectedness of relationship in the care experience, and brought the relationship into harmony, a feeling of being 'at one' with another. This was also important in instances where the creation of space was unable to be facilitated. Here, the carers emphasised the need to come back to themselves, acknowledge what they were feeling, and then recognise the impermanence of that and of the care experience at large, within that context of travel.

There was some sense of a juxtaposition of context where, despite what seemed on the one hand to be an over-stimulated and highly stressful experience, on the other hand the carers found themselves in (or in need of) a state of flow. In a way, this related to what other tourism scholars have described, that emotions and emotive states are not static at a point in time, rather they are subjective and qualitative, fluid and changing, regulating and evolving (Gao & Kerstetter, 2018). In this state of flow, then, it was as if the notion of time was lost through what was an often-intentional slowing down of pace and a mindful opening up to one's surroundings. In many ways, the carers were then able to stay grounded in a sense of spaciousness that such presence could bring. It seemed that this state of flow was possibly an inherent part of who the carers were, as evidenced in the following paragraphs of this section. It is inferred, therefore, that to attune optimally is to neither be in the past, ruminating in a place of guilt or regret, nor to be in the future, wrapped up in anxiety and overwhelming feelings, but to simply be where they themselves are, and meet others where they too are at.

As an element of this expression of attunement, the carers could create space by drawing upon the emotional and social support of others. Those carers travelling with someone else – be it a partner or another child – were able to draw upon their support in giving care. This meant they were able to utilise one another’s strengths and abilities, manage the relational dynamic between carer and individual with intellectual disability, and emotionally engender a sense of space to recalibrate the feelings they were experiencing – and, sometimes, even physically facilitate a space to recoup. Other motherhood studies scholars, too, have identified the importance of others as emotional and relational support systems (Hubert, 2011), suggesting that they are “mostly effective, mutually supportive with the inevitable stresses acknowledged and usually contained” (Hubert, 2011, p. 219). The presence of an additional person was not always considered positively, however, as it could create more emotional work for the carers, who felt the additional pressure of not only needing to be attuned to the emotional needs and moods of the people with intellectual disabilities, but those of the other persons too.

The creation of space as an element of attunement in the care experience was as relevant at home and at work as it was for its potential as being a pursuit of leisure. For the carers involved in this research who were employed as community support workers, respite represented a critical means through which they could have a break, recharge and rejuvenate, for they maintained that if they felt better, they would in turn work better. In caring for self, they could essentially care for other, bringing a greater sense of presence and conscientiousness to their work (Gustin & Wagner, 2013). For the carers involved in this research who were mothers or other family members, respite represented a critical means through which they could attain a sense of management over their lives, which in turn could strengthen the quality of time and connection with the people with intellectual disabilities. Respite was considered a necessity, emphasised as being in high demand but undersupplied at a formal level, and difficult to source at an informal level.

Even if formal respite was available, it was often inaccessible at a personal level where the carers were constrained by lack of time or finance, and those carers who had utilised such respite services did not recall their experiences in a positive light. Hence, it could be suggested that this research might add weight to an argument in

favour of facilitating respite and/or in bridging accessible tourism with health and wellness tourism, as elaborated upon below and in Chapter 9, 'Conclusion'. Indeed, Small (2005) highlighted "the need for the industry to provide opportunities for mothers to be relieved of domestic work and to have the time and space to experience the recuperative, stimulating, or empowering benefits of leisure that holidays can offer" (p. 152). From a social justice perspective, this is especially pertinent given female carers experience lower wellbeing than male carers, and carers have the lowest collective wellbeing of any group of people (Cummins & Hughes, 2007).

7.2.3 (In)visibility

The *(in)visibility* of the care experience illuminated the socio-political caring spheres of disability and of tourism, that is, "where social intolerance and aversion to difficult differences ... played out" (Rogers, 2016, p. 2). The body as the face of encounter "is material but it is also socially constructed with bodies differing in their social images, meanings, values and worth" (Small, 2015, p. 76). Central to the experience of disability then, are psycho-emotional dimensions of disability (Reeve, 2002), that is, embodied encounters of prejudice, stigma and discrimination (Hughes & Paterson, 1997; Thomas, 2007), which carers too face, by association (Goffman, 1963). In the socially constructed spaces of tourism and hospitality, such encounters can manifest as inclusion-exclusion, welcome-unwelcome, hospitality-hostility (P. Lynch, Germann Molz, McIntosh, Lugosi, & Lashley, 2011; Selwyn, 2000). Because tourism does not 'exist in a social vacuum' (Small, 2005), the social restrictions that people with intellectual disabilities and their carers face in everyday life (Thomas, 2007) can therefore be imposed and internalised while away (Eichhorn, Miller & Tribe, 2013; Holt, 2007, 2008; Sedgley et al., 2017).

The findings from this research suggest that the intellectual nature of impairment and the degree to which it is discernible to others visually contributes a further consideration – an element of *(in)visibility* – to current scholarship on tourism as a site of marginalisation and inequality (Gladwell & Bedini, 2004; Lehto et al., 2017; Luo, 2014; Preston & Rajee, 2007; Sedgley et al., 2017) but also as a potential site of resistance and transformation (Eichhorn et al., 2013; Pritchard et al., 2011). While the carers involved in this research had believed there to be some societal

awareness and acceptance of disability more generally, this consideration did not extend to impairment of an intellectual nature. It was suggested that, like vision impairment, intellectual impairment, too, could appear hidden or is in fact invisible (Packer et al., 2008; Small et al., 2012). Indeed, as the carers and the people with intellectual disabilities navigated the tourism environment, “the reaction of others was often dependent on the degree to which the person’s ... impairment was obvious” (Packer et al., 2008, p. 21), recognisable and identifiable to others (Brock, 2015). Depending on such discernment in others, disability and/or the care relationship was rendered (in)visible (Cockburn, 2005; Topia, 2015).

Some of the people with intellectual disabilities involved in this research had a certain visibility to their disability, which the carers suggested communicated a message of approachability and resulted in positive engagement in their encounters with others. Whereas in comparison, the carers suggested that an invisibility to an individual’s disability lent itself to less favourable encounters with others, as accessible tourism scholars have similarly identified for people with vision impairment (Packer et al., 2008; Small et al., 2012). Motherhood scholars have reported that the visibility of disability can communicate both a positive image of the ‘good disabled child’ (Brock, 2015), or a negative image of difference and deviance from the norm (Topia, 2015). The negative reactions of others to such visibility could range from the more covert avoidance and disregard, to staring and pointing, or overt judgment and discrimination.

In an effort to avoid such negative reactions and facilitate more favourable encounters, the carers involved in this research described the ways in which they could make the disability and/or care relationship known to a degree; an offer of disclosure, as accessible tourism scholars again identified (Packer et al., 2008; Small et al., 2012). Not only could such disclosure lessen the potential reactions of others, but it could minimise feelings of embarrassment or misunderstanding (Brock, 2015; Innes et al., 2016) for the carers and people with intellectual disabilities. These disclosures of disability and/or care relationship did not necessarily need to be direct, and often they occurred in more subtle and indirect ways. Motherhood scholar Topia (2015) described how a mother used a pushchair rather than a wheelchair for her disabled daughter in public, as the “wheelchair

objectified her daughter's difference' and she wanted to "look like any other mother and toddler" (p. 48). In making this change in equipment and therefore visual appearance, "she could blend in and walk down the street in a customary fashion like other mums and babies, unified in their sameness; albeit momentarily. ... It was a way of being able to belong" (Topia, 2015, p. 48).

Irrespective of whether or not disability and/or the care relationship was made known, others could affect the carers and people with intellectual disabilities with their ignorance (McKercher & Darcy, 2018) by imparting their unsolicited advice or asking that they prove or defend their impairment (McKercher, Packer, Yau, & Lam, 2003; Poria et al., 2010; Richards et al., 2010). Mostly, (in)visibility at the discernment of others manifested in their assumptions of (in)competence, and expectations of (in)ability and (in)dependence (French, 1994; Keith, 1996). To illustrate, if an individual with intellectual disability visually appeared to be physically able and/or as having their mental faculties, the assumption and expectation of others would be around competence and independence, respectively. A lack of visibility of a disability or illness, for instance, could lead to an assumption that a person was able or well (Wendell, 1996) whereas, in actuality, that person may have been doing their best to cope, while experiencing underlying complexities that were requiring of ongoing support.

In comparison, if an individual with intellectual disability did not visually appear to be able and/or as having their mental faculties, then an assumption and expectation of others would be around incompetence and dependence (Hughes, 2007). Typically, others would seek to assist an individual until the need was shown to be otherwise; this however, was not considered to be conducive to an individual's sense of confidence or self-efficacy (Richards et al., 2010). To illustrate, Packer et al. (2008) described how people with vision impairments were assumed to have multiple disabilities. Others (namely, industry personnel), would therefore presume "the need for a wheelchair or the need to be spoken to slowly or loudly" (p. 21). Packer et al. (2008) explained how such assumptions could leave an individual feeling disrespected and humiliated, especially because assumptions tended to be made without consultation. To further illustrate, Richards et al. (2010) shared an example from their study and explained:

The disability policy of an airline effectively stripped them of their dignity and their independence and made them feel ‘a fraud’ when they were travelling. As people with low vision, they were forced to sit in a wheelchair in order to be assisted through the airport and to the aeroplane, during which time they were also left in the dark – presumably because the employee assumed that they had no sight at all. (p. 1107)

Despite having developed a certain resilience in negotiating their encounters with others over time, such fortitude was not without frustration and, ultimately, the attitudinal barriers of others determined the extent to which the travel experience was positive or negative (Packer et al., 2008; Small et al., 2012). Much of what the carers involved in this research relayed was in alignment with what other accessible tourism scholars have also described. The carers deemed the attitudes of others – especially, the industry personnel – as apathetic and ignorant, insensitive and lacking empathy and understanding, patronising and condescending (Gladwell & Bedini, 2004; Packer et al., 2008; Richards et al., 2010; Small et al., 2012). Small et al. (2012) attested, “while the ignorance of the public could be forgiven, the ignorance of the service providers was less excusable” (p. 946). The carers called for a sense of humanness to be instilled in tourism spaces (Richards et al., 2010). They emphasised the need for greater proactivity, attentiveness and consideration, a need to seek to be more discerning of situations in which support may be required, and to then be patient and tolerant in delivering this (Innes et al., 2016). Ultimately, the carers simply expressed a desire to be treated sensitively, with dignity and respect, as other accessible tourism scholars have also identified (Packer et al., 2008; Small et al., 2012).

As described in earlier sections of this thesis, emotion is central not only to the care experience (Held, 2006; Kittay, 2011; Milligan & Wiles, 2010; Traustadottir, 1991), but also to the travel experience. It is highly complex and multi-faceted, intersubjective and not easily disentangled (Hunter-Jones, 2006; Sedgley et al., 2017). As in other accessible tourism research, the carers and the people with intellectual disabilities experienced a spectrum of emotive states, as well as an intensity to such emotions, in navigating an unfamiliar, overstimulating and challenging tourism environment (Durko & Petrick, 2013; Kingsbury et al., 2012; B.K. Lee et al., 2012; Lehto et al., 2017; Packer et al., 2008; Richards et al., 2010; Sedgley et al., 2017; Small et al., 2012; Small, 2015). Their emotions – the more

positive and the more negative – could conform to create a binary experience, often feeling simultaneously, both “stress and escapism ... pleasure and apprehension” (Sedgley et al., 2017, p. 22), “exuberance, pride and awe ... distress, frustration and humiliation” (Lehto et al., 2017, p. 181). Irrespective of the more negative emotions felt, however, the carers never perceived them to be significant enough of a deterrent in preventing them from seeking out future travel. Similarly, Lehto et al. (2017) described the positive as “a more terminal state of emotion, overriding the negative sentiments” (p. 182).

Even so, “emotions are socio-spatially mediated and articulated” (Richards et al., 2010, p. 1100). In public spaces of tourism and hospitality, the carers were not only attuned to their own emotional needs and those of the people with intellectual disabilities, but also to those of others (Sedgley et al., 2017), even if others were not attuned to them (Steinberg & Figart, 1999), which was evident in their discernment of (in)visibility. They were especially cognisant of the behavioural problems that could manifest with particular emotive states of the people with intellectual disabilities, and that rendered the care relationship visible. This emotional work of the carers was a performative act, to and in accordance with their outer world (Goffman, 1959; Steinberg & Figart, 1999). They were intent on keeping situations as calm and conflict-free as possible, hyper-aware and hyper-vigilant of how the people with intellectual disabilities might behave, what could occur as a consequence, and how to manage, which Sedgley et al. (2017) identified too. As an example, they were mindful of what they might deem to be the ‘unwritten rules’ of socially appropriate behaviour, as the behaviour of the people with intellectual disabilities could present an incongruence with this, and some social needs therefore needed to be supported (Innes et al., 2016). They were subjected to the invalidating watch and judgment of non-disabled others (Foucault, 1977; Hughes, 1999; Reeve, 2002), “being seen, in full sight, detected, obvious, distinguishable and in view. Being visible is about being seen by others, being noticed, under the gaze of others in a particular way” (Topia, 2015, p. 45). Consequently, if the behaviour of the people with disabilities and the performance of the carers, by extension, was unsuccessfully managed, the disapproval of others could be internalised (Sedgley et al., 2017, p. 20).

Family scholars too, have noted the performative display of doing family, and the degree to which such performance reinforces or affirms normative understandings of family (Heaphy, 2011), or does not align with such prevailing parameters. Travel is an example of such parameters, where the experience is symbolic of ‘good parenting’ in contemporary society, and therefore parents face the societal pressure to behave in a manner in which they can give the impression (S.M. Shaw, 2010) of having a ‘happy holiday’ (Carr, 2011).

Motherhood scholars, too, have noted the performance of women, and especially mothers, in the demarcation of public and private space, and as “pivotal actors in the sphere of social reproduction” (Chodorow, 1978, p. 11). Women face much societal pressure to be domestic workers and do domestic work, and as such their care as an expression of their femininity and maternal disposition is on display (Butler, 1990; Hager, 2011; Keith, 1992). This display is mediated and judged by others against the ideologies of motherhood (Skeggs, 1997; Stoppard, 2000), for instance, the ‘good mother’ and ‘intensive mothering’ (Hays, 1996). It is not uncommon for mothers, and particularly mothers of children with disabilities, to experience discomfort, guilt or shame as well as ‘mother blame’ in the public space (Grinker, 2007; Sousa, 2011) or, in tourism, where “holidays were thus another site in which women could be judged good or bad mothers” (Small, 2005, p. 150).

Generally, care work is neither seen nor valued, let alone the care work of mothers of children with disabilities (Blum, 2007; Home, 2008; Landsman, 2009). Women therefore, “negotiate their role as carers and mothers – often on the margins, often invisible” (Brock, 2017, p. 2). They occupy a liminal space in the broader contexts in which they live and travel, and in the societal attitudes of others which they encounter (Small, 2005), which all too often are those of indifference and intolerance, discrimination and exclusion (Joosa & Berthelsen, 2007; Topia, 2015). It is ironic that academia and industry alike place such emphasis on the idea of authenticity. Surely, we all, in our perceived or actual (in)visibility, should be able to simply *be*; authentic in the ‘resoluteness’ of our *being* (Heidegger, 1927/2008), rather than offering an inauthentic performance, created and staged to negotiate normality and to placate the other’s reactivity (see Butler, 1990; Goffman, 1959). Conclusively, the (in)visibility of disability and/or the care relationship was

somewhat exacerbated in the public space and, in many respects, tourism was both a site of reproduction and marginalisation, but also of resistance and transformation (Eichhorn et al., 2013; Small, 2005).

7.3 Chapter summary

Throughout this thesis I have offered a description of the perspectives of a group of carers and people with intellectual disabilities, who candidly and generously shared with me their lived experiences of care, disability and travel. Borrowing the words of Landsman (2009):

These are not, as stereotypes might lead us to expect, stories of tragedy, nor even of ‘triumph’ over tragedy... [They] were willing to tell their complex stories – of hope, sorrow, betrayal, challenge, transformation and, unscientific though it sounds, of love – is a gift the full value of which perhaps they alone can understand. (p. ix)

Lived experiences of care at the nexus of intellectual disability and leisure travel, it seems, are paradoxically defined, bound in the tensions and complexities of being in between two worlds. A main finding of this research, however, is that despite the inherent vulnerabilities in their experiences of care, the value of intentionally expressing such caring, through *giving* and *attunement*, to facilitate the leisure travel experience, is fundamental. This sometimes ‘messy’ and embodied nature of care (Rogers, 2016) is a natural inclination or disposition, affective interaction and performative endeavour. Ultimately, experiences of care at the nexus of intellectual disability and leisure travel are reflective of emotional caring work (Rogers, 2016); that is, work done from the heart, with heart.

It is important to now consider whether and how these experiences of care as *(in)visibility* translate into the travel processes and systems of the industry. And, as has been suggested, in such care-less spaces, it is equally important that we consider the essence of such care, in describing *how we are* (our being, and how we got to be this way). But, perhaps more importantly, we must consider *how we can be* (that is, all that we are preventing ourselves from becoming).

8 Conclusion

The purpose of the final chapter of this thesis is to present the reader with some reflective commentary and concluding remarks in response to the thesis aim and research questions. The thesis aim was to explore lived experiences of care at the nexus of intellectual disability and leisure travel. The subsidiary phenomenological questions guiding this aim were:

1. How do carers and people with intellectual disabilities experience leisure travel, and what is the significance of this?
2. How do carers and people with intellectual disabilities experience care within this context, and how do they understand and ascribe meaning to this?

This thesis has sought to offer but one possible interpretation of lived experiences of care at the nexus of intellectual disability and leisure travel, as described and understood by the carers and the people with intellectual disabilities involved in this research. Informed by this interpretation of the key findings and their discussion, what I offer here, similarly, is but one possible construction of the phenomenon of care, as “research does not ‘represent’ reality but rather indexes the various ways reality might be produced” (Martin & Kamberelis, 2013, p. 672). In Chapter 5, ‘Context’, I presented the data that was relevant to the first question. This was an interpretation of the participants’ descriptions and understandings of their lived experiences of care, as they developed within the context of leisure travel. In Chapter 6, ‘Findings’, I presented the data relevant to the second question. This was evinced in the three key emergent themes of experiences of care as *giving*, *attunement*, and *(in)visibility*. Lastly, in Chapter 7, ‘Discussion’, I offered dialogue around these findings in relation to wider scholarship. In this chapter, I now put forward the significance and contribution of this thesis overall, namely, (re)imagining the transformative potential of tourism through an ethic of care as an ethos. Following this, I briefly acknowledge the methodological limitations of this research, as well as theoretical and practical implications, and recommendations for future research directions.

Experiences of care at the nexus of intellectual disability and leisure travel were fundamentally about *giving*, *attunement* and *(in)visibility*, which spanned practical, emotional and socio-political caring spheres (Rogers, 2016). The stories shared by

the participants involved in this research reflected a dynamic interaction with and negotiation of the subtleties and complexities of the tensions involved in being in between two worlds – that is, their inner world and the outer world. Away from the comforts and familiarities of their private everyday lives at home, their experiences of care within the context of leisure travel, were indexical and relational, situational and contextual. While away, in the public and precarious tourism world with others, their experiences of care rendered a certain – and often, paradoxical – fluidity and intensity and, indeed, were a labour of love (Finch & Groves, 1983).

Drawing upon this particular construction of the phenomenon of care, I now consider how things are, in terms of the knowledge epistemology that currently exists. That is, I reflect upon the ‘care-less’ encounters and environments (Rogers, 2016) at the nexus of intellectual disability and leisure travel. I then proceed to contemplate the transformative potential of tourism – its becoming (Martin & Kamberlis, 2013) – if we are to (re)imagine an industry (or wider society, even), where care is ontologically at its centre. That is, I consider the ‘care-full’ encounters and environments (Rogers, 2016) at the nexus of intellectual disability and leisure travel. The thesis contributes, therefore, a new way of being in the world with others.

8.1 Care-less experiences at the nexus of intellectual disability and leisure travel

Many of the points that are raised in the sections that follow, were also raised by the participants involved in this research. They were elaborated upon in Chapter 6, ‘Findings’, and Chapter 7, ‘Discussion’, in respect of the third key theme, *(in)visibility*. This research therefore contributes to the existing arguments of accessible tourism scholarship. It offers new insight around the practical and functional aspects of care during travel, through the first key theme, *giving*. It both agrees with and reinforces the existing arguments of the social model of disability, emphasising the implications of the social environment – and specifically, the attitudes of others – through the third theme of *(in)visibility*. This in turn amplifies the emotion work of the carers, through the second theme, *attunement*. This research therefore, illuminates the necessity of and potential for a more inclusive and enabling tourism environment, the wider implications of which, I now detail.

From the perspectives of a social model of disability and the tourist experience as socially constructed and embodied, this research suggests that experiences of care at the nexus of intellectual disability and leisure travel are ‘care-less’ yet have the potential to be ‘care-full’ (Rogers, 2016). This research reiterates what other tourism scholars have suggested; that, for the most part, the industry is developed and serviced with the non-disabled majority in mind, delivering embodied, multi-dimensional experiences and environments (Aitchison, 2009; Figueiredo et al., 2012; Small, 2008).

People with disabilities face many constraints to their participation in travel, which can make for an “emotionally, socially and physically challenging” experience (Small et al., 2012, p. 947). The most significant constraints are considered to be structural (environmental and attitudinal barriers), as opposed to intrapersonal (impairment) or interpersonal (relationships) (Daniels et al., 2005; Darcy, 1998; Daruwalla & Darcy, 2005). Some tourism scholars have suggested that it is the attitudinal barriers of the socially constructed and embodied touristic environment that serve as the greatest deterrent to participation in travel (Innes et al., 2016; Oliver, 1989; Richards et al., 2010; Small, 2015). Scholars have noted, for instance, that “closely related to the negative attitudes of the service providers were the attitudes of other individuals on tours and in public places” (Gladwell & Bedini, 2004, p. 691), and that “many people with visual impairments simply choose to opt out of the anxiety and stress of travel because of the lack of empathy of the sighted world” (Richards et al., 2010, p. 1111). Despite all of the potential barriers to accessibility – physical, informational, and otherwise – the social barriers were the most profound and impactful for the participants in this research too.

As scholars have suggested, there is a lack of industry knowledge (Darcy & Pegg, 2011; Patterson et al., 2012; Small et al., 2012); “the industry is complacent and responsive, oblivious to the need in being pre-empting and proactive” (Gillovic & McIntosh, 2015, p. 229). There is little tolerance of or acceptance for people with [intellectual] disabilities (Bell, 2007b); “negative attitudes focus on negative behaviours, such as avoidance of people with disabilities, obsolete and derogatory labelling, paternalistic behaviour toward people with disabilities and apathetic behaviour in which people behave as if individuals with disabilities do not exist”

(Robinson et al., 2007, p. 165). It is this lack of awareness, understanding and openness of others that serves as an impediment to achieving accessible experiences in spaces of tourism and hospitality (Bell, 2007a) and, importantly, as Rogers (2016) argues, “to look away and deny difference is inhumane and care-less” (p. 5).

To facilitate more positive and fulfilling travel experiences, and therefore promote social inclusion (Innes et al., 2016; Richards et al., 2010), many accessible tourism scholars have emphasised a need for an increased acknowledgement of and awareness around disability among industry personnel and society at large (Gladwell & Bedini, 2004; Innes et al., 2016; Luo, 2014; Small, 2015). Accessible tourism scholars have argued that education is one tool with which to achieve greater social cognition of this. The development and delivery of disability awareness and sensitivity training programmes could provide an understanding of the dimensions and degrees of impairments, and the necessary assistance required in order to anticipate and meet the heterogeneity of such varied needs (Gladwell & Bedini, 2004; Luo, 2014; Richards et al., 2010; Small, 2015; Turco et al., 1998). Considering this particular group of people’s access needs when navigating the travel experience could extend to and enhance the participation of a more far-reaching, inclusive array of people, especially if approached with an ethic of care, as this research argues in the sections that follow. I would emphasise that such education would necessarily extend to a consideration of the invisibility of disability, for instance, people with intellectual disabilities or mental health issues, as well as care relationships and their associated caring activity. Quite simply, however, it comes down to recognising the citizenship right of all to travel (Darcy & Dickson, 2009; McCabe & Diekmann, 2015; Minnaert et al., 2009; Ray & Ryder, 2003) as an ethical issue (Small, 2015).

It has been argued that a ‘social lens’ of [tourism and] hospitality can serve as a conceptual approach (Bell, 2011; Lashley et al., 2007) with which to better understand society (P. Lynch et al., 2011; E. Wilson, Harris & Small, 2008). Tourism and hospitality are both a cause and an effect of the social relations that structurally and spatially govern everyday social life (Crang, 2006; Larsen et al., 2007; P. Lynch et al., 2011). Tourism and hospitality can thus serve as a means through which “societies change, grow, renew and reproduce themselves” (Selwyn,

2000, p. 34), as it is in these ‘public places’ where we might learn to live with difference through our everyday experiences with strangers (Degen, 2008; P. Lynch et al., 2011).

Tourism relies on bodily displacement and an immersion into unfamiliar environments (Gibson, 2010), while hospitality relies on negotiating rich encounters with others (Crouch, 2000) as “different individuals with different biographies from different cultures and life-spaces viscerally collide” (Caton, 2015, p. 1). It is here, in these liminal and precarious spaces of tourism and hospitality (Sheringham & Daruwalla, 2007), that an informal and indirect public hospitality manifests (Bell, 2007a, 2007b). These encounters are immediate and geographical, affective and embodied (Gibson, 2010), and mostly fleeting, so these “flickering moments of interpersonal interaction” (Bell, 2011, p. 146) lend themselves to a mere acknowledgement of rather than a meaningful engagement with difference (Valentine, 2008).

Human encounter necessitates an obligation of self to open up to other (Noddings, 2002) and there is a “special mutuality of immediate social interaction” (Goffman, 1963, p. 16). In this respect, to think of hospitality as an unconditional act of welcome offered by stranger to other, without rule or condition (Bell, 2007b; Lashley, 2008; P. Lynch et al., 2011), is certainly alluring. The polarity, however, (Sheringham & Daruwalla, 2007) is that inhospitality renders unwelcome and exclusion (Kitchin, 1998; P. Lynch, 2017); it is conditional (Still, 2013), “governed by explicit, moral and unwritten rules” (Cockburn-Wooten & Brewis, 2014, p. 117). In fact, Thrift (2005) has gone so far as to caution us “to think more carefully about whether we really have it in us to just be unalloyedly nice to others at all times in every single place, [as] most situations can and do bring forth both nice and nasty” (p. 140).

Indeed, spaces of tourism and hospitality, as they stand, are inept at supporting caring and care relationships. Within such a context, and through encounters with others, expressions of care (or rather, a lack of such expressions) reproduce and reinforce the dominant hegemony and cultural discourse that currently exist around disability and care. The implications of such a normative framework sees the sociality, structures and systems of tourism as masculine and ‘care-less’. In relation

to disability, as with many other aspects of sectionalism, it seems that we experience discomfort with difference; “we no longer interact with each other as one human to another, we lack care and concern for others in an interactive and relational way. We are care-less” (Rogers, 2016, p. 30).

Whether out of our own fear and ignorance, or borne through our socio-cultural conditioning, we have created, learned and sustained this rigid thinking and behaviour, which creates an oppressive reality. Binaries based on self-other, inclusion-exclusion and, as evinced in this research, visibility-invisibility are perpetuated in spaces of tourism and hospitality. For those of vulnerable identities, the territory comes with discrimination, inequality and exclusion. For those of dominant identities, the territory comes with privilege and agency. If a critical tourism studies approach is concerned with the nature of and inequalities in power relations within the tourist experience (Small, 2015), then it is important that experiences of care at the nexus of intellectual disability and leisure travel, too, are addressed. Otherwise, one could argue that tourism’s “full potential is squandered and its promise of many powerful benefits for humanity remains unfulfilled” (Higgins-Desbiolles, 2006, p. 1193).

Not dissimilar to the ways in which knowledge inquiry at large has disregarded the soft sciences in favour of the hard, our patriarchal ‘masculine’ society and its individualistic thinking as ‘power over’ has devalued that of a more matriarchal ‘feminine’ society and its collaborative ways of thinking as ‘power with’ (Graham, Rawlings, & Rigsby, 1994; Watson, 2009). Wider society, more generally, has been described as “a culture which has lost its way: a culture void of humanity and authentic human caring relationships, and void of meaningful communication and connections” (Watson, 2009, p. 468). It seems that we are somewhat behind in developing and extending the empathic capacities and relational qualities that are reflected in the philosophies of tourism’s ‘critical’ and ‘moral’ turns (Ateljevic et al., 2007; Caton, 2012), that is, for instance, in being oriented toward moral encounters, social inclusion and social justice (Eichhorn et al., 2013; Richards et al., 2010). In a spirit similar to that of Watson’s (1979) caring philosophy and science in nursing, “new horizons of possibilities have to be explored to create space whereby compassionate, intentional, heart-centred human caring can be practiced”

(Watson, 2009, p. 480), and perhaps tourism could be representative of such a space.

To this effect, the thesis unveils the depth and richness of the lived experiences of carers and people with intellectual disabilities, “a group of individuals who dwell on the periphery of public consciousness,” more generally (Brock, 2017, p. 3), and in tourism too. Indeed, their experiences of care, as both virtue and as practice, are often relegated to the private, domestic domain (Kittay, 2011). Yet, care need not be only a personal quality but a relational practice as well and, in this way, it can serve a political function, firstly in recognising our mutual interdependence and strength in our human solidarity, but also in dislodging the ways in which we other.

Through illuminating insight into the practical, emotional and socio-political worlds of the participants in this research, we might then create space in which to reflect upon the social norms that tourism has become indebted to, and is governed by, and seek to reconfigure our social relations. To this effect, some scholars have considered ‘hospitality as a doing’ (Bell, 2011), that there is critical ‘social work’ that happens in spaces of hospitality; the “flickering moments, little islands, magic touches, thrown togetherness, now you see it now you don’t stuff both constitutive of and constituted by society” (Bell, 2011, p. 149). In this way, the participants’ experiences of care might indirectly inform a “values guided epistemology and ethic” within tourism (Watson, 2009, p. 480), to engender a more ‘caring society’ and world (Hermesen et al., 2014), where ‘it is possible to be good’ (Noddings, 2002).

The antithesis of caring is the current way; the disregard and despondency, the disassociation and disconnection, the care-less faces in care-less spaces (Rogers, 2016). From a phenomenological perspective, Heidegger attests that “Dasein is always what it can be and how it is its possibility. Dasein concerns the ways of taking care of the ‘world’ ...of concerns for others and, always present in all of this, the potentiality of being itself” (2010, p. 139). The potentiality of our becoming is our capacity for caring relationship and this, I believe, is a beautiful way of being. “This might seem too much to ask, but if we collectively do not reach for the stars, aim for a caring, care-full and human society, then we do not have hope” (Rogers, 2015, p. 1442).

8.2 Care-full experiences at the nexus of intellectual disability and leisure travel

This thesis contributes ontologically to tourism's 'emotional', 'relational', 'critical' and 'moral' turns (Ateljevic et al., 2005, 2007; Caton, 2012), by way of (re)imagining the transformative potential of tourism through an ethic of care as an ethos (Gilligan, 1982; Kittay, 2011). Critical tourism scholars have called upon the academy to ask and to address the "bigger questions about how we can be good in tourism" (Caton, 2014, p. 28), and "to consider the way discourses and practices of [tourism and] hospitality create their own contexts in which certain ways of being together, caring for one another, or excluding the other are normalised and reproduced" (P. Lynch et al., 2011, p. 14). That is, tourism scholars have been asked to contemplate, for instance, "what the tourism encounter is about and how we might shape that encounter into a space that better reflects our moral goals" (Caton, 2014, p. 21), or "what is enabled through tourism encounters by feelings and acts of empathy, and what is disabled by acts of empathy?" (Tucker, 2016, p. 33).

Where tourism scholars have called for an ethic as a practice grounded in concern for people (S. Wearing & Wearing, 2001), comparably, hospitality scholars have actually professed hospitality as an ethic, born out of principles such as, altruism and beneficence, exchange, mutuality and reciprocity (Lashley, 2000; P. Lynch et al., 2011). Other academic disciplines related to this current research have also called for such moral deliberation in their scholarship. Feminist care ethicists called for an ethic grounded in care and oriented toward social change (Cole & Coultrap-McQuin, 1992). Similarly, disability scholars argued that "the human in being human ought to be at the heart of caring and ethics" (Rogers, 2016, p. 26), and called for an ethic that might morally rectify the discrimination that harms the dignity and wellbeing of people with disabilities (Kittay, 2011).

Common to all is the alignment with an ethic of care, and its innately feminine and inclusive, intentional and impactful qualities (Willett, Anderson, & Meyers, 2015) which define the parameters of a fundamentally moral form of relationship, and a moral approach to life (Slote, 1998; Tronto, 1993). An ethic of care offers an expression of the many significant and varied ways in which we matter to each other, and through (re)imagining such an ethos through tourism, we might nurture and value the very 'salience of care' (K. Lynch et al., 2009, p. 2) as intrinsic to our

intimate, social and global relationships (Gilligan, 1982). An ethic of care as an ethos, then, perhaps can render “a more care-full, ethical and moral way of doing caring” (Rogers, 2016, p. 22) and, indeed, an affective and empathic way of ‘doing’ tourism and hospitality.

As Gilligan (1982) emphasised, “we know ourselves as separate, only insofar as we live in connection with others, and that we experience relationship only insofar as we differentiate other from self” (p. 63). As relational beings, we exist in relation to and for, the other, which is what Heidegger termed *being-with* (Heidegger 1927/2008). The reality of our everyday existence is one that takes place among our encounters with others; these interactions impact upon us, as our own thoughts, words and actions impact upon them (Heidegger 1927/2008). We are “always affected by and affecting each other” (De Schauwer et al., 2018, p. 10); we are “bound together in a mutual entanglement of becoming with each other” (Davies, 2014, p. 16). It is not enough to disregard the seeming ambivalence of our affect-filled lives; we must also consider seriously, the centrality of affect embedded in our encounters with others. And we must do this while particularly cognisant of the “social consequences that arise when people from different backgrounds encounter, represent, perform for, and make sense of one another” within the context of tourism (Caton, 2014, p. 128).

An ethic of care recognises care as being an ethical orientation, that is, one’s responsibility for and accountability to, the other (Noddings, 2002). The caring self is fundamentally directed toward the other, as moral agent with moral duty that is not dependent upon some sense of moral equality (Noddings, 2002). This is because an ethic of care arises from the realisation that one’s own vulnerability (and, wellbeing) is never entirely independent of the vulnerability (and, wellbeing) of others. Therefore, “when we acknowledge a need, we may be called upon to do something, to give up something, or to respond sympathetically and effectively to someone, whereas acknowledgement of a right often means leaving people alone, not interfering” (Noddings, 2002, p. 57). Because the human condition is one of interdependence and connectedness, and because we are bound in our affective connections to one another, there is need to move toward ‘caring-about’ the suffering and – and indeed, the betterment – of others (see Noddings, 2002).

Tourism has been described as a ‘morally loaded territory’ (Caton, 2014). Yet, the topic of moral transformation is under-addressed within tourism scholarship, as is the moral development and growth of us scholars as moral agents (Caton, 2015). Critical tourism studies scholarship has contributed, in part, to tourism’s moral development, and much of what it is oriented toward and advocates for, too, is in alignment with various aspects of an ethic of care, and its principles and practices. To reiterate, such scholarship and its scholars are representative of an ‘academy of hope’ that is “pro-social justice and equality and anti-oppression” (Ateljevic et al., 2007, p. 3); a ‘co-created’ pedagogy and practice that is ‘values-led’, premised on fairness and equity, respect and understanding, partnership and reciprocity (Ateljevic et al., 2007; Pritchard & Morgan, 2007; Pritchard et al., 2011). It seeks to “nurture open minds and open hearts” (Ateljevic et al., 2007, p. 5), and offers implicit insight in terms of our relations with others, not only within academia and industry, but also in our personal lives, communities and societies more generally.

That is, at both an individual and a collective level (Richards et al., 2010), these scholars and this scholarship, respectively, may offer “an increased recognition of the need to live consciously and to promote self-acceptance, self-responsibility, self-assertiveness and personal integrity” (Ateljevic et al., 2007, p. 4), as well as “enhanced consciousness, tolerance [and] global citizenship” (Caton, 2015, p. 2). We must bear in mind the following caveat, however, which I elaborate upon in Chapter 9, ‘Epilogue’: “People can hope for a world with greater justice while simultaneously failing to understand the need to confront the role their own privileges can play in reproducing injustice” (Higgins-Desbiolles & Powys-Whyte, 2013, p. 428).

I believe this to be pertinent and have provided a brief reflective account examining my own privilege, in Chapter 1, ‘Prologue’, and Chapter 9, ‘Epilogue’. I recognise that this is a continual journey of (un) learning, and I am committed to being conscientious of the role I play through my own research in reproducing or resisting such injustices. Walker (2004) has argued that, too often, “research seems to be conducted for its own sake” (p. 1). Indeed, a constant concern of mine has been whether this research will ‘make any real difference’ to or engender ‘meaningful change’ for the participants and/or their wider identities (Higgins-

Desbiolles & Powys-Whyte, 2013; Warr, 2004). This (re)imagining of tourism through an ethic of care as an ethos might be just that – an ideological fiction of my imagination. Nevertheless, I have succumbed to the fact that I cannot simply surrender this ‘ambitious agenda’ (Higgins-Desbiolles & Powys-Whyte, 2013), or relinquish my “responsibility to do meaningful work” (Madison, 2005, p. 135). Any incongruence or inaction of mine, in now having this awareness, would morally be doing a disservice (Caton, Schott & Daniele, 2014). All I can do is continue to interrogate and evolve my awareness, and to embody that in action. I have a role to play, we all do, in engaging our minds and our imaginaries morally (Caton, 2014). After all, “new tourism enquiry is more than just a way of knowing, an ontology, it is a way of being, a commitment to embracing moral discourse” (Pritchard & Morgan, 2007, p. 24).

Humans are moral beings, which means we hold the inherent capacity and, therefore, the responsibility, to act in ways that contribute decidedly to the good of the world in which we live (Caton, 2016). We are not inseparable from the parts of the system that we agree/do not agree with or choose/do not choose to be a part of; we are a part of its implications – both positive and negative – in their entirety. Equally then, we can contribute creatively and consciously, to a solution. As Higgins-Desbiolles and Powys-Whyte (2013) have attested, and perhaps ironically, it is “only by constant contextualisation in the wider struggle for human dignity and wellbeing can we ensure that we demand that tourism fulfils its promise and bears its responsibilities in generating a better world for all” (p. 432).

Even so, there is “every reason to imagine that embodied experiences in this unique context might have an effect on individuals’ ... conceptions of the responsibilities they bear in living relationally with their fellow human beings” (Caton, 2015, p. 5). This thesis thus calls upon a sensitivity in how we perceive and treat others, in order to ‘meet one another morally’ (Noddings, 1984). The applicability of a seemingly relational and personal ethic to societal and necessarily impersonal contexts – like tourism – has been questioned (Cole & Coultrap-McQuin, 1992). An understanding of an ethic of care, no matter how immediate, parochial or emotional it seems, notably, is as integral to our partial and asymmetrical relations as it is to our impartial and symmetrical ones too (Noddings,

2002). An ethic of care as an ethos offers a novel yet important lens through which we can view the complex local and international, moral and socio-political contexts in which tourism engages, and our relational responsibility and responsivity to the other.

P. Lynch et al. (2011) have posited the very ‘concept of hospitality’ “bear[s] on some of the most pressing, social, cultural and political questions of our time” (p. 3). Tourism, specifically, is both implicated by and implicates (Higgins-Desbiolles & Powys-Whyte, 2013) many ‘moral conundrums’ (Caton, 2014). Consequently, tourism has a pertinent role to play as ‘global citizen’ (Caton et al., 2014, p. 126). Here, it becomes quite clear that an ethic of care could be an integral and critical consideration in the transformative potential of tourism (Higgins-Desbiolles & Blanchard, 2010). Within such a context, then, an ethic of care as an ethos might appease to the alleviation of the prejudicial relations (Ben Jelloun, 1999; Valentine, 2008) and oppressive conditions that perpetuate injustices and breaches of human rights (Caton, 2014; Derrida, 1999, 2000; Dikec, 2002; Higgins-Desbiolles & Blanchard, 2010). Fundamentally, then, an ethic of care has implications for the many marginalised identities stigmatised in or through tourism, for instance, the homeless (Bolland & McCallum, 2002), refugees and asylum seekers, migrants and ethnic minorities (Ahmed, 2000; Ben Jelloun, 1999; Rosello, 2001).

If spaces of tourism and hospitality govern human interaction and social relations, and if care sits at the heart of humanity, then it is care, I believe, that can disrupt our ways of knowing, and reconstruct a more ‘care-full’ way of being in the world with others (Heidegger, 1927/2008; Rogers, 2016). On that account, this research radically ‘opens up’ “the possibility of doing togetherness differently” (P. Lynch et al., 2011, p. 14); the possibility of (re)imagining tourism’s becoming through an ethic of care as an ethos (Gilligan, 1982).

8.3 Limitations and future research directions

It could perhaps be argued that this research faced limitations in terms of its research parameters and its participant representation. I detail these potential limitations below, and I outline brief considerations of how these limitations could be adapted or addressed in the future. Like other accessible tourism scholars have suggested, and as was identified in Chapter 2, ‘Introduction and literature’, future

research could “include larger and more diverse samples, specifically with regard to financial means, disability type of the care-recipient and cultural background” (Gladwell & Bedini, 2004, p. 692).

In this research, the sub-sample of people with intellectual disabilities was included as an all-encompassing group. Moving forward, this research could examine intellectual disability by specific impairment type, such as people with Fragile X syndrome. This research could also examine the different generational perspectives of people with intellectual disabilities. For instance, where older generations were typically institutionalised and then subsequently integrated into community living situations, younger generations have typically lived with their families and attended vocational day services or participated in mainstream schooling/employment systems. Their respective perspectives on care, disability and leisure travel, therefore, could differ somewhat.

Similarly, the carers were also included in this research as an all-encompassing group that included both informal carers (that is, family members or friends) and formal carers (that is, community support workers). While it was not intentional, this research mostly offered informal, maternal perspectives of the lived experiences of care, as most of the participants who volunteered were mothers, or were other female family members who self-professed their undertaking of a ‘maternal role’ (Noddings, 2002; Ruddick, 1989; Traustadottir, 1991). Notably, it has been well-documented that the lived experiences of mothers more generally are under-represented in qualitative research, both nationally and internationally (Ryan & Runswick-Cole, 2008). At the nexus of care and disability, they further “occupy a liminal position because they are often not disabled” (Ryan & Runswick-Cole, 2008, p. 199).

The more formal and paternal perspectives of the lived experiences of care were somewhat limited, despite extensive recruitment efforts regionally and nationally, through pan- and specific-disability and care organisations. By no means did this research seek to diminish the significance of the voices or experiences of fathers or other male family members undertaking a ‘paternal role’, nor that of the voices or experiences of formal male carers employed as community support workers. Yet, this thesis is suggestive of a gendered nature of care (Keith, 1992). Moving forward,

this research could examine the gendered nature of care, and consider, primarily, the male community support workers' experience, or the fathers' experience, as scholars have expressed a similar need in family tourism research (Schanzel & Smith, 2011).

During the very initial stages of my doctoral journey, I had intended on carrying out memory work as a means in which to explore the social construction of care. Understandably, however, this proved to be difficult, given the carers' lack of time due to the intensity of their caring commitments, as well as the near-impossible logistics involved in coordinating the expansive national geographical spread of participants. I would like to pursue this direction in the future, however, and believe the best way in which to do this would be to collaborate with one of the larger disability support service organisations, such as Community Living or IHC New Zealand. In doing so, I could call for volunteers from their team of community support workers specifically, and carry out the data collection at the organisation's premises, in order to work in with and around the rostering of their shifts and to keep the participants geographically contained. Such a strategy, too, could lend itself to more creative and collaborative approaches to obtaining more comprehensive data from the people with intellectual disabilities, where the support workers could act as proxies, and in addition have access to client-specific knowledge and resources. Relatedly, in speaking of method, the findings of this research, and their wider implications, could be advanced upon and corroborated through employing a larger sample size, perhaps using a mixed methods approach.

The care relationships that were included in this research were representative of any carer who responded to the 'Call for participants' and the individual with intellectual disability that they cared for. Moving forward, this research could explore the lived experiences of care from a relational perspective, placing parameters around the specificities of care relationships existing between particular individuals, for instance, community support worker-client with intellectual disability, father-child, entire travelling families, or all individuals travelling in a group (Joosa & Berthelsen, 2007).

Almost all of the carers and the people with intellectual disabilities presented in this research were Caucasian. Given New Zealand's ethnically diverse population,

it would be both interesting and important to explore the lived experiences of care from different ethnic perspectives, and also to acquire deeper insight into the influence of their respective cultural understandings and practices of the notions of care and caring. Māori peoples, for example, are disproportionately prominent in the statistics of New Zealanders living with disabilities, as well as the New Zealanders engaged in care work. Albeit unintentionally, a Māori care perspective was also underrepresented in this research, although Aroha offered her cultural understanding of care which, from the moment of listening to and learning of this understanding, has stuck with me and resonates with the wider argument of this thesis. She explained:

For me, to care for someone is covering everything; it's the whole holistic feel. It's the Te Whare Tapa Whā – the whole person, the spiritual side, the emotional side, their way of thinking, their body, all of it – that's always been the model that I've followed, that's how I work. It's a natural thing for Māoris' though, it always has been. We don't only class blood family as family, we class everyone that we associate with as family. We don't have a boundary, everyone is 'bro', 'cuz', 'love'.

Notably, the Māori people's relational worldview (Spiller et al., 2010) shares much alignment with that of an ethic of care (Gilligan, 1982). This relational ontology means 'to be is to belong' and, as such, "rests upon a profound commitment to developing reciprocal relationships of respect, in which the intrinsic worth of all aspects of creation [are] recognised" (Spiller et al., 2010, p. 155). Their values system is grounded in notions of care in order to engender a sense of belonging, for instance, through manaaki (respect and kindness), aroha (empathy and love), hau (attain and maintain vitality), kaitiakitanga (stewardship and guardianship), and hapai (uplift others) (Spiller et al., 2010). Ultimately, they call upon one another "to be kaitiaki, caretakers of the Māori, the life principle, in each other and in nature" (Spiller et al., 2010, p. 155).

The carers in this research were not only interested in participating in the leisure travel experience, but had the financial means with which they were able to do so. Moving forward, this research could explore lived experiences of care from a socio-economic perspective, that is by working with those carers and people with intellectual disabilities who are socio-economically disadvantaged, to propel arguments in favour of social tourism (Belanjer & Jolin, 2011). By extension, it

would be interesting to then consider the interest of formal carers in supporting the travel of people with intellectual disabilities living in residential care and supported living services, who might not otherwise have access to an informal carer or the opportunity to participate in the travel experience. This, similarly, could present opportunities to consider the facilitation of experiences of care and travel, as a social and volunteer tourism programme (Minnaert et al., 2012).

As disclosed elsewhere, interpretive research at large is considered to be implicated in the way in which meaning is found, where my interpretation – which is undoubtedly influenced by my own personal historicities and lived experiences – could differ significantly from that of someone else’s. Here, I state once more that what I have written is but “a construction, and not a representation, of the reality it is ‘about’” (Stanley & Wise, 1993, p. 218). Throughout this research process in its entirety, I have continuously engaged in robust conversations with my supervisors, questioning, relaying, and reflecting upon my interpretations, while considering their own. They have concurred with this interpretation and construction of the phenomenon presented. In addition, I believe that, if the carers themselves were to read the findings of this research, they too would find, in their own experience, a resonance with that which has been shared. Thus, “these constructed meanings can offer great insights into participants’ embodied worlds” (Ellingson, 2017, p. 112).

I too acknowledge that listening, speaking and interacting are gendered, and therefore recognise the potential for misinterpretation as a limitation (DeVault, 1990). Saldana (2014) has cautioned us to “remember that the original meaning of datum is ‘something given.’ Data is a gift, so be thankful for it when it’s given to you and treat it with respect” (p. 979). Always, I was aware of the way in which I was both subjectively interpreting and subsequently representing the participants’ lived experiences, and cognisant of this in seeking to position their voices as primary and central (Olesen, 2005). Even so, whether intentional or not, as the researcher and as the final author of the thesis text (Stanley & Wise, 1993), I am reminded of the ‘ethics of representation’ (Preissle, 2007), that such writing is a political act of ‘authorial power and control’ (Ellingson, 2017), where our ‘narrative privilege’ is exercised (Bolen & Adams, 2017). We “choose the words, we choose the placement of the words on the page, we choose the moment to capture, we guide

the gaze of you, the reader” (Honan, 2014, p. 11). Therefore, I have sought to uphold my responsibility to the research participants (Ellingson, 2017). In this way, I have been guided by an ethic of care in carrying out this research, with a view toward a more embodied, humanised and value-driven approach.

One of my initial motivations to carry out this research was social-justice oriented (Janesick, 2000): to engender change. Where tourism scholarship at large has been remiss in its considerations of disability and care, this thesis contributes an exploration at this nexus, by way of contributing a depth and richness of data, of the individuals’ lived experiences. I hope that I have made visible the largely invisible lived experiences of carers and people with intellectual disabilities; that their personal experiences may move from the margins to occupy space in domains of the public and the political (Fine, 2004; Stanley & Wise, 1993), the industry and the scholarly (Richards et al., 2010).

I would hope that, within the realm of our tourism scholarship, this research encourages us as scholars to cast a more critical eye over the issues of inequality and injustice that tourism may perpetuate, but also on the ways in which tourism offers possibility and potentiality to transform. I also hope that this research raises awareness more generally, and that it may contribute to the current and wider debates around care and disability (Richards et al., 2010). I hope that there is some serious recognition of travel as an important means with which to enable and contribute to a ‘good life’ for people with disabilities and their carers. In a similar vein, while the thesis topic explored lived experiences of care within the novel and situated context of tourism, I hope there is some broader consideration around the implications of the gendered, devalued nature of care work that continues to persist (Beckett, 2007; Keith, 1992; Leiter, 2004), where carers “often are poorly paid, marginalised and socially restricted” (Philip et al., 2012, p. 1).

In consideration of this current research, there are a number of directions which future research could take, so as to advance knowledge on the key themes of the thesis and the wider implications of such findings. Broadly, research could consider, continue, critique or challenge, an ethic of care within tourism specifically, and in other social, cultural and political contexts more generally.

An area of interest to me personally is experiences of care within tourism as a potential bridge between accessible tourism scholarship and aspects of the emerging and growing scholarship in the areas of health, medical, spa and wellness tourism. I wonder, too, whether these relatively siloed areas of tourism scholarship and practice – including accessible tourism – could be considered in a more coordinated and collaborative manner, and in this way move farther from a primarily market-driven focus to realise their potential as a tool for social justice. Given my personal interest in social advocacy and policy, as well as the largely unexploited potential in crossing academic disciplines as well as industry sectors, this is something that I would like to pursue further. I especially believe that it would be both interesting and important to consider an examination of respite care, either within the context of, or as relating to, the leisure travel experience. Given the significance of respite as a necessary and desired service, as well as tourism being attributed to enhancing the psychological wellbeing and quality of life for carers (Mactavish et al., 2007), such an examination could potentially have wider implications for policy and the development of a social tourism programme in New Zealand.

Respite care is variously and broadly defined, although typically refers to an offering of temporary relief of care work, either home-based or residential services (Chesson, 2001; Wilz & Fink-Heitz, 2008), in the form of a structured short-term break, “be it for a couple of hours, or for a longer period such as an overnight break” or longer (Hunter-Jones, 2006, p. 41). The primary purpose of respite care is the intention of “sustaining the wellbeing of carers as well as ensuring the continuation of caring itself” (Pickard, 2001, p. 441). The benefits of this lie in alleviating carer burden and depression, and encouraging coping, while enhancing their subjective wellbeing (Pinquart & Sorensen, 2006). Further, benefits extend to the individual with disability as well as the other members of the family, and, ultimately, it is (or should be) a positive experience for all involved (Cowen, 1994).

Tourism scholars, in the main, seem to have dismissed this opportunity, possibly because the nature of respite’s delivery in an everyday context might seem difficult to facilitate or attain within a travel context (Chesson, 2001), or because of variance in the period of time that respite is offered or sought (Hunter-Jones, 2006). Within

care scholarship, Pinqart and Sorensen (2006) have drawn attention to the importance and necessity of respite of a recreational nature for informal carers. Despite some minor acknowledgement of respite care and/or tourism, there is both a need for and significance to tourism scholarship and practice alike, in addition to public sector policy, in recognising, examining and enabling such an opportunity for carers and people with disabilities (Hunter-Jones, 2006; Weightman, 1999). An example specific to tourism that is related to and comparable with respite care is assisted vacations for carers and their care recipients, for instance, carers of people with dementia (Perry & Bontinen, 2001).

In terms of industry practice, Gladwell and Bedini (2004) gave an example of the Marriot Corporation's assisted living and special needs facilities. Assisted vacations are essentially a shared experience of leisure travel. They are designed to both facilitate shared activity and create space and time for oneself. Again, the positive benefits for the carers' health and wellbeing were cited, as was the reduction and potential alleviation of physical and psychological stresses (Wilz & Fink-Heitz, 2008). Assisted vacations, therefore, enable "a process of regeneration, recuperation, and relaxation in a nice and calming environment" (Wilz & Fink-Heitz, 2008, p. 115). "Despite sustained demand, assisted vacations are an important type of potential support for family caregivers and are still too rarely available" (Wilz & Fink-Heitz, 2008, p. 115), and very little research currently exists on this subject (Perry & Bontinen, 2001).

I wonder, as very simple example, whether there are grounds to suggest an examination of the feasibility of developing 'Care Clubs' or 'Respite Rooms' in a manner comparable to the various ways in which we accommodate needs associated with age or religion through the likes of 'Kids Clubs' in resorts or 'Prayer Rooms' at airports? In addition, such places could have benefits for the people with disabilities too, especially those with impairments of an intellectual nature, that typically come with sensitivity to the overstimulating sensory environments of tourism. Within a more complex and ambiguous context, there is a considerable need to examine the feasibility of offering respite for carers travelling with medical tourists/patients, as well as the very notion and provision of care in such precarious settings (see Whitmore et al., 2015).

It has been well-documented, in the main, that travel can engender an array of benefits for a person's health and wellbeing (Hunter-Jones, 2006). Spa and wellness tourism, for example, are premised on an offering of physical, psychological and spiritual activities and experiences to promote relaxation and healing, and, therefore, to enhance the health, wellbeing and quality of life of an individual (Didascalou, Lagos, & Nastos, 2009). Wellness tourism, for instance, has been premised as a potential tool with which to work through and heal from mental health issues, such as stress, anxiety and depression (Didascalou et al., 2009). Surely, then, there is a case for closer examination of the facilitation of respite and care (Sutherland, 2010) through tourism, especially given arguments in favour of participation in respite care are premised, fundamentally, on a recognition of the positive benefits for an individual's health and wellbeing (Gladwell & Bedini, 2004; Hunter-Jones, 2006; McNally, Ben-Schlomo, & Newman, 1999). In terms of the findings of this research, the notion of care for self in order to care for other is emphasised as being an integral component of *attunement* in the care experience. Surely, then, the opportunity to participate in respite care through tourism would directly contribute to one's own sense of wellness, and by extension, could indirectly contribute to another's sense of wellness, ultimately enhancing the care experience at large.

8.4 Chapter summary

This chapter has provided a summary of the key findings and discussion points of this thesis, emphasising the contribution of this research to wider scholarly knowledge. In addition, it has identified possible limitations of the research, and considered future research directions. The following chapter concludes the thesis by way of offering some final reflexive commentary.

9 Epilogue

Over the years, I remember feeling disappointed by my thinking around disability. That is my ‘pre-understanding’ (Heidegger, 1927/2008); the nature of my personal beliefs and sensibilities coupled with hegemonic historical and social antecedents (Craig, 2007; Kitchin, 1998). This wider discourse had served to underpin my childhood fear of impaired mobility or paralysis, which I had perceived to “constitute a risk to [my] ontological security” (Hughes, 2007, p. 680); to my embodiment (Shakespeare, 1994). This was despite the fact that impairment – and, disablement as its effect – is or will likely be a salient condition of most people’s reality (Bichenbach, Chatterji, Badley & Ustun, 1999; Shakespeare & Watson, 2002). Disability, for the normative, prompts us “to explore the vulnerability at the heart of the ideal model of the body/self,” and then “disrupt that binary by being all too human” (Shildrick, 2002, pp. 54-55).

“Caring and dependency, far from being dichotomous, are on a continuum. We are all dependent to a greater or lesser degree on others” (Walmsley, 1993, p. 131). Such dependency is understood to be “complex and multi-faceted taking many different forms and developing differently over time – psychological, physical, emotional and economic” (Bolton & Skountridaki, 2017, p. 502). Yet, we fail somewhat to acknowledge the universality and inevitability of disability, and of care (Kittay, 2005; Philip et al., 2012; Zola, 1982); that as human beings, we share a common fragility – and therefore, a mutual interdependence – with the embodiment of our contingent, precious existence (Oliver, 1989; van Hooft, 1996; Watson, 1997).

Critically, then, as our vulnerability to suffering traverses the journey of our lives, care is not only a presupposition for human life, but fundamental to its continuation (Philip et al., 2012; Tronto, 1993; Turner, 2003). Every encounter with another, serves as an exposure of our own vulnerabilities and a recognition of that same essence of suffering, even if differential, in another (Gustin & Wagner, 2013). Having compassion for our shared humanity means that we ‘bear witness’ to another’s suffering (Batson, 1991; Frank, 1995; Koskinen & Lindstrom, 2013). Rather than turning away from another, we turn toward them (Lipari, 2009), and we commit to an act that might alleviate their suffering in some way (Bauman, 2007;

Wispe, 1986). An ethic of care therefore emphasises the relational ontology of our human connectedness (Gabriel, 2009). To illustrate this call to attention in our human encounters, Noddings (2002) explained:

When I attend in this way I become, in an important sense, a duality. I see through two pairs of eyes, hear with two sets of ears, feel the pain for the other self in addition to my own. My initial self is vulnerable, and it will be changed by this encounter. Knowing this, I may resist giving my attention. (p. 15)

Hughes (2007) argued, “because we are all impaired or will all become impaired does not mean that we are all treated in the same way [or] that disablement is or even will be the destiny of each and every one of us” (p. 678). It is, ironically, our society that is disabled – emotionally. I believe that the participants’ experiences in this research have indirectly drawn attention to the larger systemic ways in which ableism operates in a landscape of alterity (Lipari, 2009). This non-disabled/disabled dichotomy (Meekosha & Shuttleworth, 2009), is based on binary logics of us-them, normal-abnormal, sameness-difference (Rose, 1995; Shildrick, 2002). Though it is not necessarily chosen (De Schauwer et al., 2018), the disability discourse that we create, learn and sustain, produces a negative ontology of otherness and oppression for the non-normative, sub-ordinate other (Hughes, 2007; Paterson & Hughes, 1999).

This thesis argues for a move away from the dualistic vectors of tourism and hospitality that are also demonstrative of aversion and ignorance, minimisation and dehumanisation. Caton (2016) argued, “we need not be the same as one another, nor hide from discussions about our differences. But we do need to expend more creative energy in thinking about our connections” (p. 56). Indeed, in the spirit of hospitality, we must recognise both our independence of and our indebtedness to the other (De Schauwer et al., 2018; Koskinen & Lindstrom, 2013). For it is “only when we have cultivated an outlook that dissolves the barriers between ‘us’ and ‘them’ – that promotes an inclusive citizenship of the whole – will we have set the foundations for a truly sustainable approach to tourism” (Caton et al., 2014, p. 126). To this effect, this thesis contributes some moral consideration of the role tourism might play “in encouraging people to think and live relationally with their fellow humans” (Caton, 2015, p. 4).

“If we are to work affirmatively with difference ... we need to be aware of the ways normativity is at work on us and through us” (De Schauwer et al., 2018, p. 9) if we are to deconstruct our privilege and our participation in the patriarchy (Higgins-Desbiolles & Powys-Whyte, 2013; Meekosha & Shuttleworth, 2009). We need to confront our assumptions, the distinctions of difference we make, and the binaries they create (Meekosha & Shuttleworth, 2009); we need to “move beyond binary thought, beyond clichés, beyond judgmental thinking, and beyond abjection” (De Schauwer et al., 2018, p. 18). We might live by the paradigms we know, but we are not tethered to a particular way of being – rather, we can disrupt and dislodge (Davies, 2014) – we can untether ourselves to (re)frame our becoming. As Lipari (2009) remarked:

I listen for and make space for the difficult, the different and the radically strange ... it is only when we *listen otherwise* to the unknown and unrecognisable face of alterity that we can hear the voice of ethics whispering, drawing us beyond the limitations of our subjective understandings of the world so that we may shed, like a snakeskin, our old views and certainties about the world.
(p. 57)

Because our evolution is dependent upon our relations with others (De Schauwer et al., 2018), it therefore “involves hard epistemological and ontological work to enable the not-yet-known to emerge in the spaces of encounter” (Davies, 2014, p. 5). “Listening is thus a dwelling place from where we offer our ethical response, our hospitality, to the other and to the world. Listening then becomes an invitation, a hosting” (Koskinen & Lindstrom, 2013, p. 147). As we enter into an exchange of the narratives at every side of these many divides, then perhaps we might shift the wider cultural rhetoric around who we see, hear and value. Indeed, vulnerability in the face of fear and disengagement is the catalyst for care and connection. It is, as Davies (2014) attested, “how we accomplish our humanity; it is how the communities, of which we are part, create and recreate themselves [for] we are not separate from the encounters that make up the community but, rather, emergent with them” (p. 10). We need not shy away from encounter, but show up ethically (De Schauwer et al., 2018). With open minds and open hearts, we must resolve to face the very real possibility of affecting and being affected by the other (Davies, 2014). As De Schauwer et al. (2018) argued:

Research (and indeed life) lies in the capacity to affect and be affected, a capacity that enables each of us to go on reaching beyond ourselves and beyond the constraints of any given conditions of possibility. The human subject can actively crack open its own boundaries, welcoming its own vulnerability as that which makes it much larger than itself, creatively evolving, capable of taking it beyond itself, and also capable of recognising its own limiting practices, and modifying them. (p. 17)

To come full circle, I am humbled in acknowledging the inherent privilege sewn into the fabric of my social world, and my passive role in the patriarchy and in ableist power (Kitchin & Law, 2002). I am sure, for instance, that I have communicated unintentional ableist slurs, passed uninformed judgment, and expressed uneducated opinion that would disappoint me now (Goffman, 1963). Oftentimes, I have struggled to live up to my own page; and still, I am potentially problematic. Still, my advocacy means nothing if it does not include everyone. I cannot advocate against disability-related prejudice while directly or indirectly perpetuating covert or overt prejudice toward some other issue of sectionalism. My sensibilities must be around a sense of collective responsibility to all (Higgins-Desbiolles & Powys-Whyte, 2013).

I do not have the answers, but I am learning to live with the questions. Standing strong in my integrity, as the organising principle of my life, I am committing to be more consistent in my hypocrisy; to truly ‘walk the walk and talk the talk’, as my supervisors would continually put to me. Honouring my ‘process of becoming’ (Ateljevic et al., 2007) as a ‘phenomenology of practice’ (van Manen, 2007), I am open always, to a ‘renunciation of self’ (Lipari, 2009), open to the possibility of expanding upon my own perceptions, to acknowledge that which I do not know, to be considerate of alternative perspectives and curious of new knowledge. “Everyone influences the surrounding environment, creates reality and is responsible for life” (Reisinger, 2015, p. 4). Therefore, where ignorance might have been the condition, bigotry is a choice. I can no longer be benevolent or benign in my care for other. “And so, dear reader” (Stanley & Wise, 1993, p. 173), I hope the thesis has raised questions like these within others, and you seek to answer them too. We then might be discerning enough to be unapologetic for change; to address fundamental questions that could push the parameters of possibility beyond the ‘status quo’ (Caton, 2016; Richards et al., 2010).

I thank you for being a tourist in my story, but more importantly, in the stories of these twenty-four beautiful, caring humans. Their experiences of care were indeed expressive of emotional work – a labour of love (Finch & Groves, 1983) – and we have much to learn from their messaging. Care is a selfless act, but a sharing one too. It is only in giving (without expectation or condition) that we receive. It is in attuning oneself to another that we not only acknowledge but see them, honour and be with them. It is in surrendering into vulnerability, and embracing authenticity, that we render and are rendered visible, while navigating the sometimes-harsh (tourism) world. Listening to what the participants in this research have said, and the way they have said it – whether that be, minimal and fragmented or comprehensive and coherent – has touched me deeply (Helin, 2013). These stories, rarely told publicly, were each, in their own right, compelling; and, collectively, these individuals speak a narrative of femininity (Tomkins & Eatough, 2014), of gratitude and resilience (Levine, 2009), perceptiveness and presence, vulnerability and authenticity, and most of all, hope. To offer the words of Bauman (2007):

People who dedicate their lives to the care of others, and particularly such others as have been failed by the society upheld precisely by their invocation of humane compassion and care, are the frontline troops of humanity. On their courage and determination depends not only the well-being of people in their care, but also the humanity of the society we share. (p. 60)

Like me, I hope you too recognised that while each of their experiences was unique and extraordinarily their own, they were commonly and ordinarily the experiences of all. What this research evokes, and as Ellingson (2017) reminds us, is that “life is lived at the intersection of common stories with the specific embodied moments in the ebbs and flows of a particular life” or lives (p. 179). What I realise now is that the diversity of our difference represents the particular and the universal; “we are simultaneously both many and one” (Caton, 2014, p. 128). Like everything in this world, humanity is a sum of all its parts. The paradox, perhaps, of collective action is that, individually, our existence – our being in and of care – matters. Care in the microcosm of our individual encounters serves to function as a locus for change and the catalyst for care in the macrocosm of the wider relationality of the tourism industry, or even society (Held, 2006; Tronto, 1993). I sincerely believe

that through (re)imagining this ethic of care as an ethos by which to live is how we might serve to transform the world through tourism. To conclude, in the words of Zeldin (1994):

It is in the power of everybody, with a little courage, to hold out a hand to someone different, to listen, and to attempt to increase, even by a tiny amount, the quantity of kindness and humanity in the world. But it is careless to do so without remembering how previous efforts have failed, and how it has never been possible to predict for certain how a human being will behave. History, with its endless procession of passers-by, most of whose encounters have been missed opportunities, has so far been largely a chronicle of ability gone to waste. But next time two people meet, the result could be different. That is the origin of anxiety, but also of hope, and hope is the origin of humanity. (p. 472)

10 References

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Appendices

Appendix A – Approval of ethics application

WAIKATO MANAGEMENT SCHOOL
TE RAUPAPA

Waikato Management School
The University of Waikato
Private Bag 3105
Hamilton 3240
New Zealand

Amanda Sircombe
WMS Research Office
Phone +64 7 838 4376
Email amandas@waikato.ac.nz
www.management.ac.nz



Brielle Gillovic
Highview Stud
1544 Kakaramea Road
Hamilton

1 November 2017

Dear Brielle

Ethical Application WMS 16/90
'Exploring the personal and social care dimensions of carers accompanying people with intellectual disability during travel'.

The above research project has been granted Ethical Approval for Research by the Waikato Management School Ethics Committee.

Please note: should you make changes to the project outlined in the approved ethics application, you may need to reapply for ethics approval.

Best wishes for your research.

Regards,

Amanda Sircombe

Amanda Sircombe
Research Manager

Appendix B – Email request for participant recruitment assistance

Waikato Management School

Te Raupapa



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Email Subject: Meeting Request – PhD Research Assistance

Email Message:

Dear Sir/Madam,

I would like to take this opportunity to (virtually) introduce myself. My name is Brielle Gillovic and I am a postgraduate student at the University of Waikato in Hamilton. I am currently eighteen months into my Doctorate of Philosophy, under the supervision of Dr Cheryl Cockburn-Wootten, Professor Alison McIntosh, and Professor Simon Darcy.

I was hoping you would be able to direct me to the most appropriate person in which to talk to, regarding the likelihood of meeting with and explaining my study in further depth and detail, with the intention that your organisation might be interested in assisting me with the recruitment of participants. That is, be involved in the capacity of a gatekeeper/intermediary, disseminating a call for volunteers. Any communication content for this purpose will be provided by me and can be distributed via your desired communication channel/s. For example, featuring a research brief in your mail-outs, newsletter, website or social media platforms. In the interest of confidentiality, time, and to further the recruitment process along, we would simply request that any interested prospective participants then contact me directly. In an essence, your involvement would be about providing me with access to your established networks of possible participants. I have attached a participant information sheet to provide you with a brief introduction to my research 😊

There is absolutely no pressure to be involved of course, I only hope that you're willing to have a chat over a coffee at your convenience; if nothing more than to network and engage with like-minded individuals who too, **are passionate and committed to the cause of making meaningful improvements to the lives of New Zealanders with disabilities and their carers.**

I would like to express my sincerest gratitude to you in advance, for taking the time to respond or pass on this email to the relevant persons, as any insight in this respect will be greatly appreciated.

Kindest Regards,

Brielle Gillovic

P: 027 3919 020 E: bsg6@students.waikato.ac.nz

Appendix C – Written call for participants

RESEARCH OPPORTUNITY!

Do you live in Auckland, Bay of Plenty, Waikato, Wellington, Canterbury or Otago?

Do you have an intellectual disability? And are you over 18 years of age? OR Do you care and support (paid or unpaid) somebody with an intellectual disability?

Have you travelled together (domestically and/or internationally) during the last year?

If you answered 'YES' to all of these questions, you have a unique opportunity to have your say!

Brielle Gillovic, a PhD student at the University of Waikato, wants to hear your stories, and has asked us to distribute this message to you.

This study hopes to explore the idea of '*care*' during travel. To achieve this, we need to understand the relationship between the *care giver* (informal carer or formal support worker) and the *care receiver* (individual with intellectual disability), important as significant people in one another's lives.

The aim of this study is to develop a more holistic understanding of what care means to your lives, in the hope that we can further support and enable independent travel for other carers, support workers and people with intellectual disabilities.

Brielle would like to hear about your *perspectives* and *experiences* of travelling together domestically and/or internationally, whatever they might be. She will ask you, for example, what your *travel aspirations* are, the *challenges* you face, and what '*care*' *personally means* to you.

Please feel free to pass this message on, if you know of someone else who can answer 'YES' to the questions above.

If you are interested in being a part of this study, please contact Brielle at bsg6@students.waikato.ac.nz or on 027 3919 020

Appendix D – Visual call for participants

 **RESEARCH**
OPPORTUNITY

Do you live in Auckland, Bay of Plenty, Waikato, Wellington, Canterbury or Otago? ✓

Do you have an intellectual disability? ✓

OR... Do you care or support somebody with an intellectual disability? ✓

Have you travelled together domestically or internationally during the last year? ✓

If you are interested in being a part of this study, could you or your carer/support person please contact Brielle at bsg6@students.waikato.ac.nz or on 027 3919 020

If you and your carer/support person answered **'YES'** to all of these questions, you have a unique opportunity to have your say!

Brielle Gillovic, a PhD student at the University of Waikato, wants to hear your stories, and has asked us to distribute this message to you. We encourage you and your carer/support person to participate in this research, if you are able, so that together we can improve the care experience for others who travel. Please feel free to pass this message on, if you know someone else who can answer **'YES'** to all of the questions too.



Appendix E – Information sheet for carers



Waikato Management School
Te Raupapa

Thank you for expressing your interest to participate in this study ☺

Brielle Gillovic, a doctoral student at the University of Waikato, Hamilton, will carry out this study. Dr. Cheryl Cockburn-Wootten of the University of Waikato, Professor Alison McIntosh of Auckland University of Technology, and Professor Simon Darcy of the University of Technology, Sydney, will supervise Brielle.

This study hopes to explore the idea of ‘*care*’ during travel. To achieve this, we need to understand the relationship between the *care giver* (informal carer or formal support worker) and the *care receiver* (individual with intellectual disability), important as significant people in one another’s lives. **The aim of this study is to develop a more holistic understanding of what care means to your lives, in the hope that we can further support and enable independent travel for other carers, support workers and people with intellectual disabilities, and raise awareness of the valuable ‘work’ you do, in wider society too.**

We would like to hear about your *perspectives* and *experiences* of travelling together domestically and/or internationally, whatever they might be. We will ask you, for example, what your *travel aspirations* are, the *challenges* you face, and what ‘*care*’ *personally means* to you.

Your participation in this research will involve:

a) **Interview:** The individual face-to-face interview is designed to be open and conversational, as you share your perspectives and experiences of caring for an individual with intellectual disability, whilst travelling domestically and/or internationally. Whilst Brielle will ask you a number of questions, you will also be encouraged to raise any additional ideas or topics that you feel are important. You are of course able to refuse to answer any questions. We should need between 60 minutes and 120 minutes for the interview.

The interview will be carried out at a **time, date and location convenient for you**. Brielle will *reimburse your travel* with *petrol or public transport vouchers*, and *refreshments will be provided*.

The interview will be **audio-recorded with your permission**, to ensure that you are happy with the information collected. Brielle will provide you with a **typed interview transcript**, to allow you the opportunity to verify that what has been typed and interpreted, is a true representation of what you have said or had meant to say. You will have the freedom to *add in any new detail or request for any detail to be removed*. Brielle may also ask to **take photos of any photos, personal belongings or written memories** to assist with her analysis. **These will not be published anywhere.**

Please be aware that all of your responses and any information gathered by Brielle will be **confidential**, accessible only, to herself and her three supervisors. Brielle will store all data and information on a **password-protected computer in a lockable office**. While *direct quotations may be used* from the interview and memory-work, they **will not be associated with any personal or identifying information**; a number of actions will be taken to **safeguard your confidentiality**, for example, using a pseudonym instead of your real name.

Brielle will produce a **PhD thesis** containing the findings of this study, combining it also with academic literature. You are welcome to contact Brielle at the completion of the thesis if you would like an **'Executive Summary' of the key themes** to be sent to you. Findings of the study may also be featured in **academic publications and conference proceedings**. To allow for such activity, all data will be **destroyed within five years** following the submission of the thesis, that is, **before the 1st of November 2022**.

You are welcome to **withdraw your participation** from this study **up until the 24th of February 2017**, at which point Brielle will begin the data analysis stage.

If you have any specific questions you would like addressed, or any requests for further information, please don't hesitate to contact Brielle (researcher) or Cheryl (chief supervisor) via the following:

Researcher's name and contact information:	Supervisor's name and contact information:
Brielle Gillovic P: XXX XXXX XXX E: XXX@students.waikato.ac.nz	Dr Cheryl Cockburn-Wootten P: XXX XXXX XXX E: XXX@waikato.ac.nz

Appendix F – Information sheet for people with intellectual disabilities



Waikato Management School
Te Raupapa

Do you enjoy going on holiday? Help us to share your stories!

WHAT IS THE STUDY

- Brielle is a student at the University of Waikato. Cheryl, Alison and Simon are her supervisors.
- Brielle will interview you for her study. Cheryl might help her interview you.
- The study is about your experiences of travelling on holiday with your family, carer or support worker.
- By helping us with our study, we can help other people travel with their families, carers or support workers.

WHAT WILL YOU BE ASKED

- Meet with Brielle for a friendly and relaxed interview.
- The interview will take place at a location where you feel comfortable and at a time that suits you.
- The interview will take 1 hour to 1 and a 1/2 hours.
- A light snack and drink will be offered to you during the interview.
- Brielle will ask you questions about travelling with your family, carer or support worker on holiday.
- Brielle will also encourage you to share your stories and to bring along any special photos or personal souvenirs from your holiday.

WHY ARE WE ASKING FOR YOUR CONSENT?

- To share your stories, we need to have your permission in writing and in person.
- We will not publish your name, photos or personal souvenirs anywhere.
- We will record the interview to make sure you are happy with what has been talked about.
- You do not have to answer every question. Your answers to the questions will be kept confidential.
- If you change your mind and want to stop taking part in this study, you can contact Brielle before the 24th of February 2017.
- Brielle will provide you with a summary of the study in writing.

WHAT TO DO NEXT?

1. Read this information sheet.
2. Talk about this information sheet with your family, carer, support worker or a person you trust.
3. Complete the consent form.
4. Ask Brielle any questions you have.

Thank you for offering to take part in our study 😊

If you have any questions about taking part in the study or about giving your consent, contact us at:

Researcher's name and contact information:	Supervisor's name and contact information:
Brielle Gillovic	Dr Cheryl Cockburn-Wootten
P: XXX XXXX XXX	P: XXX XXXX XXX
E: XXX@students.waikato.ac.nz	E: XXX@waikato.ac.nz

Appendix G – Consent form for carers



Waikato Management School
Te Raupapa

I have read the **Information Sheet for Participants** for this study and have had the details of the study explained to me. I agree to participate in this study under the conditions set out in the **Information Sheet for Participants**. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I also understand that I am free to withdraw from this study at any time up until the 24th of February 2017, or to decline to answer any particular questions in the study. I agree to provide information to the researchers under the conditions of confidentiality set out in the **Information Sheet for Participants**.

I am happy for my interview to be audio-recorded:

I am happy for any of my photographs, personal belongings, or written memories to be photographed, and understand that these will not be used in academic publications:

I agree to participate in this study under the conditions set out in the Information Sheet for Participants.

Signed:

Name:

Date:

Researcher's name and contact information:	Supervisor's name and contact information:
Brielle Gillovic P: XXX XXXX XXX E: XXX@students.waikato.ac.nz	Dr Cheryl Cockburn-Wootten P: XXX XXXX XXX E: XXX@waikato.ac.nz

Appendix H – Consent form for people with intellectual disabilities



Waikato Management School
Te Raupapa

	I have read the information sheet.	✓	YES	x	NO
	I know what the study is about.	✓	YES	x	NO
	My questions about the study have been answered.	✓	YES	x	NO
	I know that I can ask more questions at any time.	✓	YES	x	NO
	I know that I don't have to answer all the questions.	✓	YES	x	NO
	I know that it is my choice to take part in the study.	✓	YES	x	NO
	I know that Brielle will not use my name or other details.	✓	YES	x	NO
	I know that the interview is being record.	✓	YES	x	NO
	I know that I can stop taking part in the study before the 24th February 2017.	✓	YES	x	NO
	I am happy to take part in the study?	✓	YES	x	NO

Name:

Signature:

Date:

Appendix I – Accommodation and supports form for participants

Waikato Management School
Te Raupapa



Brielle would like to make the interview experience as enjoyable as possible 😊

All interviews will be carried out on a **time and date that is convenient to you**, and in a **location that is accessible for you**.

To assist Brielle in preparing for the interview, could you please list any **personal care or support needs** – be it physical, social, cognitive, sensory or otherwise – that *you or the person you care for, may require during the interview process*. Please describe the way in which Brielle can **best accommodate and serve these needs**.

For example:

- *Do you or the person you care for require an accessible car parking space or a ramp/step-free entrance?*
- *Do you or the person you care for have any food allergies or intolerances?*
- *Do you or the person you care for require any visual aids or devices in order to communicate with Brielle?*

Who would like support? What are their support needs or preferences? How can Brielle best accommodate this need or preference?

If you would like to discuss any of this in greater detail, please do not hesitate to contact Brielle (researcher) or Cheryl (chief supervisor) via the following:

Researcher's name and contact information:	Supervisor's name and contact information:
Brielle Gillovic	Dr Cheryl Cockburn-Wooten
P: XXX XXXX XXX	P: XXX XXXX XXX
E: XXX@students.waikato.ac.nz	E: XXX@waikato.ac.nz

Appendix J – Demographic information sheet for participants

Waikato Management School
Te Raupapa



For the purposes of categorisation only, it is asked that you please complete the following questions. This data will be kept **confidential** with **no personal information or identification attached** to your responses.

What is your gender? M F T

What is your current age? 18 – 24 YEARS 25 – 44 YEARS 45 – 54 YEARS
55 – 64 YEARS 64 – 75 YEARS 75 + YEARS

Where do you currently live in New Zealand? AUCKLAND BAY OF PLENTY
WAIKATO WELLINGTON CANTERBURY OTAGO

What is your current housing arrangement? RENTING OWN HOUSE
LIVING WITH PARENT/S LIVING WITH PARTNER
LIVING WITH FAMILY OTHER (PLEASE SPECIFY) _____

Do you currently work? YES NO
If yes, what is your occupation? (PLEASE SPECIFY) _____

What is your current income range? LESS THAN \$20,000 PER ANNUM
\$20,001 - \$40,000 PER ANNUM \$40,001 - \$60,000 PER ANNUM \$60,001 -
\$80,000 PER ANNUM \$80,001 - \$100,000 PER ANNUM MORE THAN
\$100,000 PER ANNUM

What is your relationship to *insert name*? PARTNER PARENT CHILD
SIBLING FAMILY MEMBER FRIEND COMMUNITY SUPPORT WORKER
PAID CAREGIVER OTHER (PLEASE SPECIFY) _____

What is *insert name* gender? M F T

What is the current age of *insert name*? 18 – 24 YEARS 25 – 44 YEARS
45 – 54 YEARS 55 YEARS – 64 YEARS 65 – 74 YEARS 75 + YEARS

Where does *insert name* currently live in New Zealand? AUCKLAND BAY OF
PLENTY WAIKATO WELLINGTON CANTERBURY OTAGO

What is *insert name's* current housing arrangement? RENTING OWN HOUSE
LIVING WITH PARENT/S LIVING WITH PARTNER
LIVING WITH FAMILY OTHER (PLEASE SPECIFY) _____

Does *insert name* currently work? YES NO
If yes, what is his/her occupation? (PLEASE SPECIFY) _____

What is *insert name's* current income range? LESS THAN \$20,000 PER ANNUM
\$20,001 - \$40,000 PER ANNUM \$40,001 - \$60,000 PER ANNUM \$60,001 -
\$80,000 PER ANNUM \$80,001 - \$100,000 PER ANNUM MORE THAN
\$100,000 PER ANNUM

What is the nature of *insert name's intellectual disabilities*? ANGELMAN
SYNDROME ASPERGER'S SYNDROME AUTISM SPECTRUM DISORDERS
CEREBRAL PALSY NEURO-MOTOR DISORDERS DOWN SYNDROME
APERT SYNDROME FRAGILE X SYNDROME PHENYLKETONURIA (PKU)
WILLIAMS SYNDROME BRAIN INJURY UNDIAGNOSED
OTHER (PLEASE SPECIFY) _____

How long have you cared for *insert name*? LESS THAN ONE YEAR ONE TO
THREE YEARS THREE TO FIVE YEARS MORE THAN FIVE YEARS

Where have you travelled with *insert name*? WITHIN NZ (PLEASE SPECIFY)
_____ INTERNATIONALLY (PLEASE SPECIFY) _____

Appendix K – Interview guide for carers

Nature of question/s	Example of question/s
Introductory	<p>Can you tell me a little bit about yourself?</p> <p>What would you perceive your strengths and vulnerabilities to be?</p> <p>Can you tell me a little bit about [individual with intellectual disability]?</p> <p>What is the nature of his/her disability?</p> <p>Can you describe to me, [individual with intellectual disability's] ability to travel on a typical domestic/international trip? How are his/her experiences of travel affected by his/her disability?</p>
Dynamics of the care relationship	<p>Can you describe one to three things that would provide me with a little insight into your relationship with [individual with intellectual disability]?</p> <p>If you could use an image or metaphor to describe your relationship, what would you use?</p> <p>How do you build upon a good relationship?</p> <p>Can you describe a typical communication between yourself and [individual with intellectual disability]? Do you have any examples of instances where the two of you experienced good/bad communication? How might you facilitate more meaningful interactions?</p> <p>Were there any moments where you felt a strong sense of (re)connection?</p> <p>Were there any benefits derived from your experiences of travelling together? Were there any short- or long-term changes in your relationship, as a result of your travel experiences?</p>
Giving care and support	<p>How would you personally define the concept/s of care and support?</p> <p>Can you give me an example of what 'good' or 'bad' care and support might look like?</p> <p>What would you consider your role and/or responsibilities to be in supporting [individual with intellectual disability's] travel? Does this differ in any way from the day-to-day care and support he/she receives at home?</p> <p>While travelling, what are the care and support requirements has and seeks from you? How do you recognise and meet these needs of him/her?</p> <p>Do you believe you meet his/her expectations of care and support? How does [individual with intellectual disability] express recognition and fulfilment of these expectations?</p> <p>Are you able to describe a time where you may have put your own needs before the needs of [individual with intellectual disability], and vice versa? What might have been some of the demands you placed on one another?</p> <p>Is there any reward for you personally, in <i>giving</i> care and support to [individual with intellectual disability] during travel?</p> <p>Are you grateful for your experiences of travel with [individual with intellectual disability]? Has he/she expressed gratitude to you?</p>
Experience of leisure travel	<p>How would you personally define travel, and what does it mean to you?</p> <p>Do you think that the experience of travel contributes to a person's quality of life or self-development? Can you provide any examples relevant to yourself and [individual with intellectual disability]?</p> <p>What motivates yourself and your family to pursue certain travel experiences? What motivated you to take this particular trip?</p> <p>In comparison with a non-disabled person, do you believe [individual with intellectual disability] has experienced a loss of leisure opportunities, because of his/her disability? Have your own leisure opportunities or motivations for travel experiences changed as a result of <i>giving</i> him/her care and support?</p> <p>Can you tell me the key one to three differences in terms of travelling with [individual with intellectual disability] or with someone else?</p>

Nature of question/s	Example of question/s
Experience of leisure travel [cont.]	<p>Can you describe the key one to three things you have to do pre-travel in terms of planning? How much control/involvement did each of you have over the planning and decision-making process?</p> <p>Can you recall any incidents where there were instances that meant either of you had to compromise on choice? Was there much room for flexibility/spontaneity?</p> <p>Can you describe the key one to three things that happen during travel? Can you describe the nature and pace of a typical day of travel for the two of you?</p> <p>Describe your most memorable travel experience (good or bad)? Did you face any challenges or conflicts during your travel together? Were there any critical incidences?</p> <p>How did you feel being in one another's company and space? Was this level of intimacy heightened while travelling in comparison with being at home?</p> <p>In terms of the tourism industry, how prepared were they, or able to provide, appropriate services and support for people with intellectual disabilities and their carers and support workers, as a group of tourists? How would you define hospitality?</p> <p>In terms of other tourists you encountered, how did they perceive or respond to [individual with intellectual disability] while travelling? Was his/her disability or the nature of your care relationship visible to others? How did you feel? Did you feel accepted and included, dignified and respected? Were there any instances where you felt excluded or unwelcome? How could we facilitate more positive travel experiences, or better compensate for the negative ones?</p> <p>After the travel is completed, what happens?</p>
Emotion	<p>While travelling, what were some of the emotions you felt or experienced? What about the emotions [individual with intellectual disability] may have felt or experienced?</p> <p>What was the impact of these emotions on your experiences of travel and of <i>giving</i> and <i>receiving</i> care and support? How did you cope with or manage these emotions?</p> <p>Can you recall any instances where you felt as though you needed to manage the behaviour of [individual with intellectual disability] because you were in a public setting?</p> <p>Was there any emotional or physical impact of <i>giving</i> care and support on you personally? Did you feel burnt-out at any stage during your trip? How did you moderate or negotiate these feelings?</p> <p>Did you draw support from someone or something during your travel? Or, did you seek any support from [individual with intellectual disability]? What did this support look and feel like?</p> <p>Have you ever considered the opportunity to travel as an opportunity to attain some respite? What is your experience with, of opinion of, respite services?</p> <p>If you were to leave [individual with intellectual disability] with a carer or support worker while travelling yourself, how would you feel during this time? Could you relax yourself from the grip of your 'caring work'?</p>
Concluding remarks	<p>Looking into the future, what are your personal/family's travel aspirations?</p> <p>What would you hope the future of travel looks like for other people with intellectual disabilities and their carers or support workers?</p> <p>Is there anything I have not asked or understood that you feel I should know or wish to clarify?</p>

Appendix L – Interview guide for people with intellectual disabilities

Nature of question/s	Example of question/s	
Introductory	Can you tell me about yourself?	
	What are your hobbies and interests?	
	Can you tell me how your disability affects your life?	
	What are some things that you are good at? What are some things you find hard?	
Dynamics of the care relationship	Can you please tell me about [carer or support worker]?	
	Do you get along well with [carer or support worker]? Do you have a good relationship with [carer or support worker]?	
	What are [carer or support worker's] best/worst qualities?	
	How do you and [carer or support worker] communicate with each other? Do you and [carer or support worker] agree/disagree sometimes?	
	Did you like travelling with [carer or support worker]? Did [carer or support worker] like travelling with you? Did travelling together make your relationship better?	
	Are you thankful for travelling with [carer or support worker]? How do you show or tell [carer or support worker] that you had a good time travelling? How does [carer or support worker] show or tell you that they had a good time travelling?	
	What did [carer or support worker] do to help care and support you while travelling? Did you help care and support [carer or support worker] while travelling?	
Giving care and support	Have you ever travelled with anyone else? Would you like to travel on your own?	
	Can you describe what travelling is?	
Experience of leisure travel	Do you like to travel? Does travelling make your life better?	
	Do you think that you have more, the same or less chances to travel as other people?	
	Where did you travel? Who did you travel with? Where did you stay? What did you do? What did you see? What transport did you use? What food did you eat?	
	What is your (least) favourite memory of travel?	
	Who planned your travel?	
	Who made the decisions when travelling? Did you get to make some decisions when travelling?	
	What things did you need to travel?	
	What made travelling easy/good? What made travelling hard/bad?	
	Did you and [carer or support worker] face any challenges?	
	Did your disability make it hard to travel sometimes?	
	Were people nice and friendly to you while travelling? Did other people make you feel included/unwelcome?	
	Emotion	How did you feel when you were travelling? How did [carer or support worker] feel when you were travelling?
		How did you cope with these feelings? How did [carer or support worker] help you to cope with these feelings?
		Did you need to take breaks to rest?
Concluding remarks	Where else would you like to go travelling?	