

**Navigating Ever-Changing Seas:
Ageing with an
Intellectual Disability**

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ABSTRACT

Introduction

As a population, the ageing trajectory for people with intellectual disability is nearing that of the general population. Given that many individuals with intellectual disability continue to live into their middle adult years with someone they identify as family/whānau – this has implications for all parties. There is an emerging body of literature that identifies some of the challenges faced by this largely ‘hidden’ population. Whilst research about future planning is not necessarily a new phenomenon for this specialist field, the nature of ageing with intellectual disability, the characteristics and dynamics of caregiving and receiving within family/whānau, and the relationship this has to decision-making about ageing, has received limited attention. Hence the aim of this thesis was to explore perspectives about getting older and future planning for people with an intellectual disability and their family/whānau.

Method

The qualitative design for this study was based on Charmaz’s Constructivist Grounded Theory. This methodology was informed by the axiology of what is ethical (transformative paradigm), and the ontology of relativism both of which underpinned the interpretive constructivist epistemology embedded in this grounded theory approach. Non-probability and snowball sampling were used to recruit people with intellectual disability aged 40 years or older, living with someone they identified as family/whānau and whom they nominated to co-participate in this research. Memo writing,

interviews, concurrent data collection and theoretical sampling are features of a grounded theory approach that were used across participant groups. Photo elicitation was also used with participants who have intellectual disability to enhance and promote their contribution and inclusion in the research, and also served as a key theoretical sampling approach. Constant comparison data analysis was undertaken between and across participant groups.

Results

A total of 19 people with intellectual disability and 28 family/whānau were interviewed and the findings revealed a lifelong engagement with caregiving and receiving that was influenced by factors both internal and external to the living situation. Key features of this engagement were identified: Transitions across the individual and collective life courses were denoted in terms of decisions about the member with intellectual disability remaining at home and the subsequent changing roles, responsibilities and expectations within, and between, all in the network of care. Three categories exemplified this journey, namely; *Riding the Waves*, *Shifting Sands – Changing Tides* and *Uncovering Horizons*. Whilst these may appear to be linear, the perspectives and experiences expressed by participants both explored and demonstrated a reflexive interrelationship between these which is posited in *Navigating Ever-Changing Seas: An Emergent Theoretical Model*. This informs and illustrates the cyclical, evolving and reciprocal nature of caregiving relationships over time, identifies the influences thereto and the impact these have on the person with intellectual disability and those in their family/whānau system of care in terms of their view and experience of ageing.

Discussion

Navigating Ever-Changing Seas: An Emergent Theoretical Model provides a platform to understand the nature of caregiving and receiving for people who are ageing with intellectual disability and those they identify as family/whānau. The relationship of family/whānau who have a member with intellectual disability is seen to be complex, dynamic, and trans-generational. Each person has an experience and perspective of their identity and relationship with others which has been informed by the past and current philosophies of the caregiving network itself, as well as the wider, external community and socio-political context across the lifespan. As the territory for each person and life-stage changes over time, so does the constructed map (individually and collectively): This impacts upon the perspective and prospect of ageing, future planning, respective and projective roles and responsibilities. It is pivotal that these perspectives do not remain hidden as recognising them will enable and mediate the development of inclusive policies for each member of this caregiving network in regards to practice, research, service planning, development and delivery.

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LIST OF ABBREVIATIONS

APA	American Psychiatric Association
DSM IV – TR	Diagnostic Statistical Manual IV – Text Revision
DSM – 5	Diagnostic Statistical Manual 5
EGL	Enabling Good Lives
MOH	Ministry of Health
MSD	Ministry of Social Development
SIL	Supported Independent Living

CHAPTER 1

INTRODUCTION

“I didn’t get old on purpose, it just happened. If you’re lucky, it could happen to you” (Andy Ronney)

Regardless of culture or setting, the age of populations is increasing internationally as is the understanding of what is important in developing and sustaining health and wellness across biological, sociological, psychological and cultural domains. This is even more the case given the increasing awareness of the risk of multiple co-morbidities as people age (World Health Organization [WHO], 2015a). Healthy ageing is defined as a “process of developing and maintaining the functional ability that enables well-being in older age” and which is informed by “intrinsic capacity” and the extrinsic factors within one’s environment (WHO, 2015a, p. 28). Key concepts which drive health and aged care policy include the ability to make choices, to age in a place of one’s choosing, and limiting existing or potential inequities in the process. Reasons for the increase in global life expectancy are multifactorial ranging from the economic development of many countries to public health policy across the lifespan (WHO, 2015a). This is an acknowledged reality for New Zealand as those over 80 years of age for example constitute one of the fastest growing population groups whilst the birth rate has halved in the last 50 years (Ministry of Social Development [MSD], 2015).

People with an intellectual disability are included in the aforementioned global trends and whilst they too are living longer (O’Grady Reilly & Conliffe, 2002; Patja, Livanainen, Vesala, Oksanen & Ruoppila, 2000;

WHO, 2000), as a population they may also experience higher rates of ill health and mortality (Hogg, Lucchino, Wang, Janicki & Working Group, 2000; McCarron et al., 2011) and frailty at an earlier age than the general population (Evenhuis, Heermans, Hilgenkamp, Bastiaanse & Echteld, 2012). Further to this, age-related conditions tend to be either under diagnosed or masked by other unmet health needs (Bigby, 2004). Social disadvantage is also known to be highly prevalent amongst people with an intellectual disability which is an additional precipitating risk factor for physical (Emerson, Hatton, Llewellyn, Blacker & Graham, 2006) and mental health issues (Emerson & Hatton, 2007). Furthermore, social disadvantage and its sequelae may be heightened in developing nations due to possible differences in cultural cognisance of this population as part of the whole (Hogg et al., 2000).

Whilst there has been a drive over the last thirty-plus years for the deinstitutionalisation of people with intellectual disability and placement back into the community, it must be remembered that the majority of family/whānau resolved to keep their member at home (McCarron et al., 2011). As people with intellectual disability age, there are a number of individuals who have never sought assistance from specialist services. Defining the stage at which people with intellectual disability are seen as 'ageing' is a challenge (Bigby, 2004; Grant, 2001). Contemporarily, age 40 is more commonly seen as a starting point (Taggart, Coates, & Truesdale-Kennedy, 2012a). Hence individuals with intellectual disability past the age of 40 years who continue to reside with a parent have the potential for increased vulnerability regarding service access should the caregiving relationship breakdown or change (Dodd, Guerin, Mulvany, Tyrrell & Hillery, 2008).

It must be noted that age alone is not purely responsible for the increased risk of age-related conditions such as Alzheimer's type dementia for people with Down syndrome (Trisomy 21), but also includes a range of health

challenges faced by many with intellectual disability and associated conditions which may emerge at an earlier age (Evenhuis, et al., 2012; Glasson, Dye & Bittles, 2014). Despite the increasing research on the presenting health issues faced by this population, identifying what ageing means for people with intellectual disability, and to the family/whānau who care for them – has received little attention.

The concept of family and whānau means different things to each person and across cultures. New Zealand Māori for example use the word whānau which has a broader meaning to that of the biological family and refers to one's support networks. Whilst challenging to define, whānau embraces the notion of function in regard to people roles and relationships with each other, within and across generations. It includes individual and collective ancestry who share a common focus (Collins & Willson, 2008). Within cultures and communities family is also socially constructed and may denote the person or people with whom one has a kinship and may, although not exclusively, be based upon biological connections (Elliott, & Gray, 2000). The term family/whānau is used throughout this thesis to represent the understandings referred to as above, and unless siblings have been separated out in the narrative, reference to family/whānau includes them also.

Professional Background

In keeping with qualitative approaches, it is important to reflect back on and acknowledge the lenses brought to this research. It is critical to identify and acknowledge the personal and professional motivators for this study. I grew up in a household in which it was not uncommon for there to be a boarder at any point in time. For example, Jemima (not her real name) was just such an individual and lived with our family for just over two years. She

had a mild intellectual disability and came from a farming family who loved her very much and maintained frequent contact with her. The reason for the boarding situation was to enable her to access and attend a workshop setting for people with intellectual disability. In the time she boarded with our family there were several instances in which tension and conflict was observed between her and her family. The latter was usually in regard to her seeking permission from her parents to go to places, attend social events or skills-based training at a local technical institute. On several occasions, I observed and witnessed my parents advocating for Jemima by ascertaining what it was that she valued, what she was trying to do or achieve, and then speaking with her sibling(s) and/or parent. Given the concerns her family had for her safety, the goal was to try and reassure them by offering transport, supervision and/or making other arrangements. Despite this, there were many times I observed Jemima's sadness at not being allowed to participate in the community in a manner that she was aware other young women of her age group were able to do. My parents' attempts at advocacy, unintentionally, had the effect of modelling respect for Jemima as they sought to facilitate community access, participation and skill development – including responsible and informed decision making. However the experience of living alongside Jemima was not a sole driver for this study alone. As I embarked on my professional journey, as a nurse there have been frequent opportunities to reflect on the very same issues or concerns that arose with supporting Jemima in our family and which have been evident in the experiences and lives of those with whom I have worked clinically as well as those shared by participants in this study.

As a new graduate nurse (twenty years ago) there was no defining moment in which the specialist field of intellectual disability nursing became the passion that has fuelled a curiosity and respectful interest in how others

see, experience and understand the world. One of my earliest staff nurse positions was in a former institution for people with an intellectual disability. A number of key roles over time enabled the development of a range of skills including that of simply being with and alongside people with intellectual disability and those significant to them – in their own time and space. As transition co-ordinator during a deinstitutionalisation process, the responsibility of engaging with all parties in the system of care was a key focus. This ranged from the individuals themselves, their family/whānau, welfare guardians, prospective and newly contracted disability service providers, health funders and the staff (of all disciplines) who had worked with the person for many years or even – their whole life. A key element of this role was troubleshooting the accessibility of service delivery options, to ensure that what had been received to date – was available to the same or better degree in the community to meet the assessed needs of individuals.

The closure of the institution instigated a move from the above role to an interdisciplinary team and enabled involvement in the development of clinical and educational service systems as well as direct clinical engagement with individuals, their family/whānau and caregivers from a community perspective. A concurrent role for me included external involvement with the auditing of disability organisations over several years in which I was able to explore both service access and delivery. Whilst continuing in nursing practise I completed a Master's degree which researched issues affecting primary health care access from the perspective of direct support professionals, general practitioners and people with intellectual disability themselves. A growing awareness of the health care challenges and limitations faced by individuals and those who support them, further informed my practise.

In the years following deinstitutionalisation, my professional clinical interest evolved more specifically to thinking about the needs of individuals and communities of care for this unique population in the context of ageing. Of particular note, the community team with whom I worked saw an increase in referrals about the impact of imminent and/or sudden changes to people's living situation with family/whānau due to the death or significant impairment of caregivers. The resultant crisis, more often than not, meant other family/whānau were not in a position to assume caregiving roles which resulted in their brother, sister, nephew, niece, aunt or uncle being placed in some form of alternate, and often emergency care setting. Family/whānau sometimes raised concerns about the residential placements of their family member citing concerns over client mix, or not meeting individual needs and often being based on the availability of a vacancy at any given time.

According to funders and providers, the aforementioned same issue continues to arise when family/whānau decline planned options and prefer to wait until the 'right' one comes along. Whilst in the local context funders and providers acknowledge that there is a lack of choice, the timing of such transitions impacts upon all parties involved. Planning well may be further compounded by a lack of access to both historical and current information, differences in funding streams to respond to identified needs, and accessibility to relevant specialty services. It is conceivable therefore, that funders and service providers may still question the need for planned alternate care for the individual or family/whānau over time. It is this incongruence between the actual or perceived need as articulated by respective parties that spurred the inquiry which informed this thesis. Hence, in my professional journey there has been a parallel process of understanding and navigating disability service systems alongside the establishment of

community services following deinstitutionalisation and which has informed my perspective.

Positing Disability: A Theoretical Perspective

There has been both controversy and evolution over time in what constitutes disability. Over time the emergence and/or confluence of theoretical or philosophical approaches towards people with an intellectual or other disability have been explained through the application of models. These have informed and shaped society's understanding of (and response to) people with a disability. This section is not intended to provide a full chronological summary of the history of theoretical perspectives, but rather it serves to illustrate and highlight the emergent models which have informed the perception of people with an intellectual disability and their family/whānau in regards to ageing with an intellectual disability.

Historically, the medical model tended to be the main authority in determining what it meant to be a 'whole' person. The eugenics movement in the 1800s and early last century played a role in establishing the then value-laden diagnostic, caregiving, shunning and/or elimination practices of the time towards people with a disability. The latter was erroneously based on a view of a supposed degenerate nature that was deemed to be inherent and therefore representative of the 'whole' person (Burrell & Trip, 2011). That era also saw a multitude of labels assigned to such persons which, in the current day, are deemed to be both derogatory and disrespectful (Baynton, 2014). The medical model later formalised this connotation of disability as an illness, affliction, disease or condition from which the person needed to be cured and/or trained to overcome (Llewellyn & Hogan, 2000; Oliver, 1998). Over time this included legislation for the sterilisation of persons who were deemed to be non-productive (Harbour & Maulik, 2010; Scott, 1986). In the

current day, positivist approaches such as the science of reproductive technologies (Oliver, 1998) provides an example of the new challenges to the medical model in terms of philosophical and interpretive theories of what denotes humanity, for example through emerging opportunities for pregnancy screening (Miceli & Steel, 2007): In some quarters, this poses moral and ethical dilemmas once again about intentional selection albeit in another guise.

Over the last fifty years, the debate has simultaneously both focused and shifted insofar as recognising that those labelled as disabled are a person first and foremost in their own right. Attempts at understanding how this may be interpreted and how the individual is enabled led to the development of social constructions of disability. Moves to deinstitutionalise people with mental illness, physical or intellectual disabilities has been consistently upheld as beneficial, respectful and ethical (Mitchell, 1864; O'Brien, Thesing, Capie & Tuck, 2001; Scott, 2013). Hence normalisation became both a cultural and theoretical driver in making visible the rights of people with disabilities to live as others do in their community and society (Nirje, 1969; Wolfensberger, 1972). Despite the ideal however, there is evidence to suggest that what was deemed unacceptable in the institutions may unintentionally be replicated at times in the community (Burrell & Trip, 2011).

Social constructionists have thus sought to challenge the focus and ethos of the medical model and have engaged in the debate about what (or on whom) the focus should lie. The Social Model of Disability emerged from the Union of the Physically Impaired Against Segregation (UPIAS) which had produced the *Fundamental Principles of Disability* in 1976 (Chappell, 2001; Race, Boxall & Carson, 2005). Definitions of impairment and disability were respectively distinguished by reference to physical nature as well as being a socially constructed phenomenon (Carlson, 2010; Richardson, 2000) – which

refers to limitations that are intentionally or unintentionally imposed by society (Goodley, 2001). The United Nations Convention for the Rights of People with Disabilities (United Nations, 2006) went further by identifying that there are a number of external barriers which impede the ability of this population to engage meaningfully in society to the extent that is possible for them, and which barriers also impede the rights and freedoms that would facilitate this. The United Nations (2006) now requires signatory countries to report on their work towards achieving the articles contained therein. This is the first example of a global commitment to understanding and responding to the needs of people with a disability with a mechanism to monitor the way in which this responsibility is actively constructed and progressed. It is important to note that all frameworks and models stipulate what is known or understood about how people function in relation to others (Barnes & Mercer, 2004; Llewellyn & Hogan, 2000). However, such models in themselves do not constitute theory in the true sense of evidence-based replication of predictability, or reality nor does any one of them represent the needs of the whole to whom it applies. For the latter to occur, an understanding of the dynamics and factors in decision-making is needed. The aim of this thesis therefore was to explore perspectives about getting older and future planning for people with an intellectual disability and those nominated as family/whānau.

Thesis Outline

Chapter one has provided an overview of the emerging ageing context for people with intellectual disability and the personal and professional journey which has spurred my interest in the topic. Describing the theoretical drivers which have shaped the position of a largely vulnerable and

disenfranchised population is important insofar as it identifies the context which has influenced the choices that family/whānau and people with intellectual disability have made in relation to growing older. In chapter two the background literature further identifies and explains the populations in question by drawing together the research on the prevalence and ageing of people with intellectual disability and their family/whānau carers. What is known and understood about this largely 'hidden' population (Bigby, 1995; Grant, 2007; Hubert & Hollins, 2000) is further explored in reference to caregiving from the perspective of parents, siblings and the people with intellectual disability themselves. The factors identified in this section are posited in relation to the notion of future planning and are linked to current commentaries.

Given the diversity of existing perspectives about caregiving within and between the populations identified above, the challenge of how best to explore and capture these is explained in chapter three. It explores the paradigms that fuel the qualitative methodological approach of constructivist grounded theory. Whilst appearing hierarchical in nature, each provides intersecting and pertinent features upon which an understanding of their relevance and contribution to the grounded theory method is built. Axiology stems from the transformative paradigm of seeking what is ethical (Harris, Holmes & Mertens, 2009), the ontology of relativism requires the researcher to examine what is already known about a topic (Guba & Lincoln, 1994) and the epistemology of constructivism is the engagement of building an understanding of experiences. Hence, an introduction to constructivism as defined by Charmaz (2006; 2008a; 2014) is a key focus within this chapter. A brief introduction to perspectives of engaging people with intellectual disability in research is also provided. Critically, this then is seen to inform the place of photo elicitation as one of the data collection methods for this

study. Photo elicitation is offered as an approach in keeping with constructivism and contributes to the manner in which research with and for people with intellectual disability is conceptualised. Photo elicitation was first coined by Collier (1957) and initially was used to explore how families of different ethnicities adapted to residential and work environments. By way of comparison, interviews with and without photographic images have been used in subsequent studies resulting in the conclusion “that the photos sharpened the informants; memory and reduced the areas of misunderstanding” (Harper, 2002, p. 14). Hence this tool was used as part of the grounded theory methodology in an effort to include and develop the participation of people with intellectual disability in the research process. The remainder of this chapter explains the methods that have been applied to this study and which are in keeping with the principles of constructivist grounded theory. This includes exploring the ethical considerations for engaging in research alongside populations considered vulnerable and how this was applied in this context.

Chapters four to eight comprise the findings of this thesis. The first summarises the demographic data of the respective participant groups and their relationship to each other. A summary of the analysed and synthesised findings is also found here. In the second of these four chapters, the first theoretical concept, *Riding the Waves*, signals the way in which members of the family/whānau systems of care individually and collectively explain how they have continued to engage with life by taking it as it comes. Chapter six delves deeper into the experiences of participants which reflects the *Shifting Sands-Changing Tides*. This concept is about coming to terms with one’s own ageing as well as revealing the often unspoken but evident awareness of the interrelationship of roles and experiences and explains perspectives about planning for the future. The third concept, *Uncovering Horizons* comprises

chapter seven. This simultaneously evidences the intimidating yet hopeful perceptions of many participants about what is and/or may be important to consider when planning for the inevitable transition of care. The final results chapter concludes by describing the emergent theoretical model of *Navigating Ever-Changing Seas*. This model presents a convergence of the categories and demonstrates the interconnectedness of each in relationship to family/whānau system of care, decision-making, and ultimately, the people with intellectual disability themselves.

The discussion of this thesis is presented in chapter nine. As an emergent theoretical model, *Navigating Ever-Changing Seas* is further examined in regard to its relevance and application to both the intellectual disability and aged care sectors. The intrinsic and extrinsic elements embedded in the model are discussed in detail and illustrate the link between the socio-political drivers and the life course, all-the-while linking these to the individual and interwoven realities of people with intellectual disabilities and their family/whānau. The strengths, limitations and ethical considerations for this study are highlighted and are followed by recommendations for practice and research which have relevance for individuals, their systems of care as well as having implications for service providers. Finally, in chapter ten the conclusion to this thesis draws together the key challenges and opportunities which collectively identify and respect the experiences and expectations of the caregiving roles and responsibilities of people with intellectual disabilities and their family/whānau as they find themselves ageing whilst *Navigating Ever-Changing Seas*.

CHAPTER 2

BACKGROUND LITERATURE

Introduction

As with the general population, people with an intellectual disability are living longer. Not surprisingly there are a range of challenges facing the individual ageing with intellectual disability and those with whom they live and/or the family/whānau who care for them. Alongside the well-established increased longevity (for all parties in the caregiving relationship) and physical and/or mental health issues, changing roles within the system of caregiving and receiving over the lifespan provide opportunities for emerging conversations in regard to the future. This has implications for actualising choice and decision-making for the person themselves, as well as having ramifications for parents, siblings and others who are considered to be carers.

This chapter provides a synopsis of the known population constituting persons with intellectual disabilities as a whole and is then mapped onto the known New Zealand context in terms of health outcomes and ageing trajectories. The socio-political situation over the last two generations is then explained in regards to the societal perspectives which have influenced the positions and responses made by family/whānau over time in regard to their family member with intellectual disability. The resultant roles, responsibilities and well-being which inform each part of the informal caregiving system are then explored from the perspectives and expectations of the family/whānau unit, parents and siblings; this includes the possible emergent role of the person with intellectual disability in becoming an 'accidental' caregiver themselves. Research is limited in regard to the effects on siblings who are in a position to consider and/or take on the primary caregiving role for their

adult brother or sister with an intellectual disability and the parental decision-making which may inform or underpin this (Saxena, 2015). The above factors are seen to have informed and focused the aim of this research in New Zealand (NZ) which was to explore perspectives about getting older and future planning for people with an intellectual disability and those nominated as family/whānau carers.

People with Intellectual Disability: The Population

Definitions of what is understood as ‘intellectual disability’ have changed over time and represent an exposure to, and evolution of, self-advocacy, clinical expertise and socio-political contexts (Bray, 2003; Hogg, 1997; Schalock et al., 2007). It is commonly recognised that some of the key impacts of having an intellectual disability include learning challenges, the adaptation and application of knowledge, choice and relationships to name but a few: Difficulties in these areas may impact upon development and independence and be evident prior to adulthood (World Health Organization [WHO], 2015b).

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18 (Luckasson et al., 2002, p. 1).

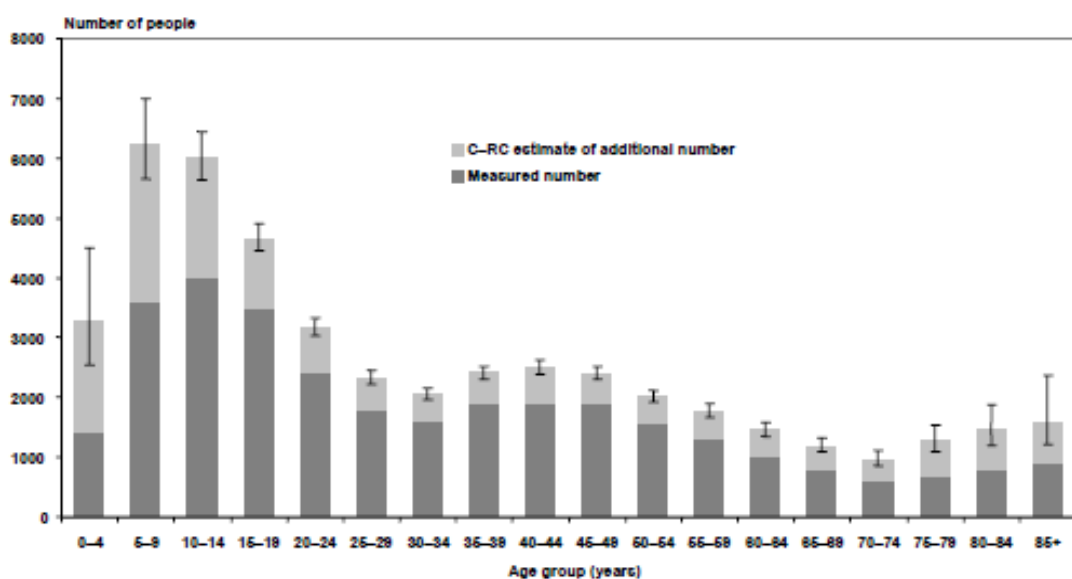
According to a meta-analysis of 52 studies undertaken by Maulik, Mascarenhas, Mathers, Dua and Saxena (2011) the prevalence of intellectual disability globally was deemed to be 1%. There are estimate fluctuations however as the countries with a higher prevalence of intellectual disability tend to be in the low-to-middle socio-economic bracket and data may be

influenced by the means of diagnostic capture as well as the target populations represented in the included studies (for example, child and adolescent populations) (Maulik et al., 2011). Intelligent quotient (IQ) is problematic due to problems in opportunity for schooling and terminology compounds the problem; for example, there is ambiguity around intellectual disability and learning disability which has skewed prevalence studies too. The measurement of adaptive functioning for ascertaining a diagnosis is also challenging in that it is value-laden to an extent. In some countries independence is not equally valued and co-dependence may sometimes be favoured depending on culture. There have also been recent changes from the DSM IV-TR (Diagnostic Statistical Manual IV – Text Revision) (American Psychiatric Association [APA], 2000) to DSM-5 (APA, 2014). Both editions have kept the focus on 10 domains within which adaptive functioning is assessed (each of which are comprised of subtests). However, there has been a broadening of the DSM IV-TR criterion that required any two or more subtests on adaptive functioning to be two or more standard deviations from the mean to the DSM-5 which requires one domain overall to be two or more standard deviations below the mean (APA, 2014). As uptake of the latter manual is only in its infancy, the impact of the potential broadening of eligibility, and the impact upon the assessment of populations and implications for service access and delivery is yet to be established. However, it is not the remit of this thesis to debate or resolve the diagnostic practicalities for this population. The reference to this is purely to establish the current understandings which are used to identify this population and which may contribute to variations in estimated prevalence. What is important, is to acknowledge that there has been a substantial move to shift from perspectives of limitation to those which seek to understand;

...disability as a function of the fit between the person’s capacities and the demands of the environment... Of course, it is not just how the construct is understood that is important; it is how the people so labelled both are perceived and perceive themselves. (Wehmeyer, 2013, p.124)

Establishing prevalence of intellectual disability in New Zealand based on actual diagnostic information is also flawed. According to Statistics New Zealand (2013), people with a primary intellectual disability comprise 2% of the total population (Figure 1). This has been dependent upon self-report or that of others reporting by proxy as to the primary disability as part of the census data collection. The data have been, to date, based on perceptions that the survey participants have of “their situation and memory of their experiences, rather than measurements of assessments conducted” (Ministry of Health [MOH], 2004a, p. 8): Survey participants were asked to record the most limiting or primary disability.

Figure 1: Estimated True Number of People with Intellectual Disability, by Age (Statistics New Zealand, 2013).



Source: Ministry of Health (2011). Study population capture-recapture estimates, 1 July 2007-30 June 2008. I = 95% confidence interval

The MOH (2011) document *Health Indicators for New Zealanders with an Intellectual Disability* also acknowledged there are limitations to these data as it only reflects those who accessed health services (as they are registered on a MOH database), and may not have captured individuals presenting with a mild intellectual disability or lesser disability level (as they may not identify as such) (Ali, Hassiotis, Strydom & King, 2012). Therefore a broad definition was used resulting in “people with moderate or severe intellectual disability who needed health and support services were more likely to have been identified” (Ministry of Health, 2011, p. xiii).

The lack of a reliable population profile presents significant implications for the planning and funding of timely and accessible health and disability services across the lifespan for people with intellectual disability. This population group have some of the highest health needs in New Zealand (three times the cost per annum of the general population in 2008) and make up 0.7% of the total population; however estimates place this at 1.0-1.2% (confidence interval 95%) (MOH, 2011). These figures are based on the 2001 Household Survey and recorded 2% for children and 1% across the age groups (MOH, 2004a). Regarding the latter figure, 50% were identified as having a severe level of intellectual disability. A staggering 89% of people with an intellectual disability resided in households at this time and a total of 71% of this population were aged under 45 years of age (Statistics New Zealand, 2001). Future systems planning is dependent upon having knowledge available about the populations concerned. Unfortunately the characteristics of the population of older persons with intellectual disability and the family with whom they live is inconsistent (Barron, McConkey, & Mulvany, 2006). Countries such as Ireland (Northern and the Republic) have a system in place whereby people with intellectual or other disabilities can be tracked longitudinally through health and social service registries (Barron et

al., 2006). This enables governments to generate information about a population in regard to geographical, health, education and social service needs, thereby enabling immediate and prospective planning to occur.

Population Trends: Ageing & Influences

Increasingly, there is a recognition that people with an intellectual disability as a population presents a shifting demographic alongside the general population in terms of longevity (Hogg, 1997) as life expectancy is increasing at the same rate as for those without intellectual disability (Ouellette-Kuntz, 2005; Patja et al., 2000). This can be attributed to a number of factors including deinstitutionalisation and advances in technology, as well as social and medical science which have resulted in an increasing longevity in both the western populations and in people with an intellectual disability (Hogg, 1997; WHO, 2000). Whilst life expectancy for people with intellectual disability is still lower, it is approaching that of the general population in developed countries; this has implications for healthy ageing given that, in the developed world, there are estimates that there may be up to sixty million people with an intellectual disability (WHO, 2000). Latterly, Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (2006) requires signatory parties to ensure that this population can access “the highest attainable standard of health without discrimination” (p.18) which will directly contribute to increased longevity.

In a retrospective stocktake of the life expectancy for Australians, Bittles et al. (2002) found a correlation between the level of intellectual disability (mild 54.7%, moderate 27.8% and severe 17.5%) and significance in the probabilities of survival at 74.0, 67.6, and 58.6 years respectively (p.M471). Factors such as the level of intellectual disability and complexity of co-

morbidities impact upon longevity. In Ireland the age at death between 1995 and 2001 averaged 45.68 years for people with intellectual disability (Lavin, McGuire, & Hogan, 2006) whereas this was 66.1 years for people with an intellectual disability who died between 1984 and 1993 in one state in the United States of America (USA). For the latter, the ratio was nearly one-to-three between those with a mild intellectual disability and those at a moderate to severe level (Janicki, Dalton, Henderson & Davidson, 1999), indicating the greater the severity of intellectual disability, the shorter the lifespan (Lavin et al., 2006). For people with Down syndrome, a review of data from 1983 to 1997 found that there had been an increase in the average age at death from 25 to 49 years respectively (Yang, Rasmussen & Friedman, 2002) or 55.8 years in the USA (Janicki et al., 1999).

The World Health Organisation (WHO) and the International Association for the Scientific Study for Intellectual Disability (IASSID) set out research priorities in the document on the *Better Health, Better Lives: Research Priorities. European Declaration on Children and Young People with Intellectual Disabilities and their Families*; (Emerson et al., 2012). The priorities are listed as follows and seek to:

- Protect children and young people from harm and abuse;
- Enable children and young people to grow up in a family environment;
- Transfer care from institutions to the community;
- Identify the needs of each child and young person;
- Ensure that good quality mental and physical health care is coordinated and sustained;
- Safeguard the health and well-being of family carers;
- Empower children and young people with intellectual disability to contribute to decision-making about their lives;

- Build workforce capacity and commitment;
- Collect essential information about needs and services and assure service quality;
- Invest to provide equal opportunities and achieve the best outcomes.

Naturally, it is anticipated that progress on the above objectives will inform service development approaches across the lifespan into the future as health in childhood is expected to be cumulative into adulthood. Of note, a number of these elements have already been identified in reference to the ageing individual with intellectual disability and those who support and/or care for them (WHO, 2000) and the comparison is evidenced by the following excerpt.

Disadvantaged subgroups of ageing adults with intellectual disabilities are at particular risk. In many nations, adults with severe and profound impairments are disregarded or institutionalized. Housing is often inadequate and health provision neglected. Older adults with mild impairments are often marginalised and not provided with minimal supports needed to be productive members of their societies. Rehabilitative services, vocational opportunities, and quality old-age services are not provided... Older adults with co-morbid conditions experience particular problems and their compound physical and/or mental health conditions not addressed. (WHO, 2000, p. 3)

Key targets for people with an intellectual disability included physical and mental wellness and the need to mitigate the risks which are heightened for individuals or groups with specific syndromes depending on their pre-existing or inherent levels of health, lifestyle, assessment, service access and

consent (WHO, 2000). Other targets specifically encompassed women's health, service access and behavioural disorders. Regarding the latter this may be as a result of the individual or collective impact of the former targets (WHO, 2000). The WHO also acknowledged that there needs to be a symbiotic focus with prioritising the provision of support to the caregiving setting as this is based on need, service availability and the culture within the family.

Intellectual Disability in New Zealand

By 2007 life expectancies for the general population in New Zealand had increased by nearly 11 years since the 1950s, and which was up from 67.2 years for males and 71.3 years for females to 79 years and 82.2 years respectively. Whilst the gap is closing, Māori (the indigenous population of New Zealand) continue to have a shorter life expectancy than non-Māori at 70.4 for males and 75.1 for females (Statistics New Zealand, 2009).

As in other countries, whilst longevity is increasing, life expectancy is still lower for people with intellectual disability. In New Zealand for males this is at least 18 years less (or 59.7) than the general population whilst for females, this is 23 years (59.5) (MOH, 2011). The reasons for this change in longevity may include but are not limited to improved health access and treatment across the lifespan. Lower birth rates and growing numbers of birth cohorts surviving into older age also plays a role. Estimates have indicated that in New Zealand, 12% of people with an intellectual disability will be over 65 years of age by 2020 (Janicki, 2009). There is a lack of definition as to what constitutes 'ageing' in people with intellectual disability (Bigby, 2004; Grant, 2001) and therefore it requires further exploration; 50 years of age has been proposed by some (Hogg et al., 2000) however latterly, it is generally deemed to be indicative from forty years of age (Taggart et al., 2012a). The

rationale for this reflects that people with intellectual disability may experience the same, if not a heightened incidence of health and age-related conditions compared to the general population albeit at an earlier age (Davidson et al., 2008; Leeder & Dominello, 2005; Tyrer, Smith & McGrother, 2007).

Health and People with Intellectual Disability

People with a physical or cognitive impairment experience lower levels of health screening compared to the general population (Reichard, Stolze & Fox, 2011). In keeping with this, studies have found that people with an intellectual disability experience higher rates of ill health (Davis & Mohr, 2004; van Loon, Knibbe & Van Hoeve, 2005) and mortality at an earlier age (Bigby, 2004; Leeder & Dominello, 2005; Tyrer et al., 2007). There are a number of reasons as to why this may be the case including socio-economic position (Emerson & Hatton, 2007; Graham, 2005), impact of the impairment itself (Ouellette-Kuntz, 2005), "health management by proxy" (Pomona, 2008, p.93), a lack of consistent and appropriate knowledge, skills and attitudes within primary health care (Sowney & Barr, 2004) and a lack of a co-ordinated approach (Kerr, 2004). The masking of health issues due to presenting behaviour is a critical issue (Davis & Mohr, 2004; Lennox & Eastgate, 2004) as is polypharmacy (McCarron et al., 2011; MOH, 2011) and exclusion from health promotion activities and living situations which do not nurture active and healthy lifestyle options (Haveman et al., 2011) all of which contribute to poorer health outcomes.

As people with intellectual disability age the tide is starting to turn in terms of not only improved health at an older age (Bittles et al., 2002) and increased longevity (Bigby, 2004; Emerson & Baines, 2010) but there is also growing evidence that the age-related conditions presenting in the general

population also negatively affect this group (Davidson et al., 2008). Over the last decade an increased awareness into the health disparities for this population has resulted in pocketed progress in regard to the establishment of policy in developed countries, which enables better access and treatment to a population already considered to be vulnerable and marginalised (Haveman et al., 2011). The POMONA II study for example (Haveman et al., 2011) gathered data from across fourteen European countries and measured eighteen health indicators previously identified for people with intellectual disability (Pomona, 2008): Across the age bands there was almost a 50% unemployment rate which included 37.7% for those over 65 years of age (of which 70% were unpaid); lifestyle factors included smoking (lower than general population – 6.0% compared to 28.3%); obesity was a factor as engagement in no physical activity was recorded for 51.8 per cent. In terms of health and ageing in the sampled populations for those over 65 years of age it was found that 12.7% had cataracts, 11.9% had a hearing aid, 10.8% were diagnosed with diabetes, 30.4% had hypertension, 12.7% had arthritis and 11.8% had osteoarthritis. Presence of malignant tumours were 2.9% higher and 15% experienced epilepsy which was half that of their younger participants. Constipation was relatively constant across the age groups at 26.5 per cent. As this constituted a pilot study across participating countries, it cannot be said that the results are indicative of the health status in either the respective country or across the European Union for people with an intellectual disability (Haveman, et al., 2011). Further, lower life expectancy is correlated with higher morbidity rates for those people with intellectual disability who have comorbid respiratory and neurological conditions (Leeder & Dominello, 2005) and they are at a higher risk for developing cardiac disease (van den Akker, Maaskant & van der Meijden, 2006).

Whilst it has been established in New Zealand that people with an intellectual disability may now be accessing health services more frequently than in the past, the general health outcomes have not improved for them (MOH, 2011). There remains higher rates of chronic conditions (over a third have been treated for coronary heart disease, respiratory or kidney disease and/or cancer), lower rates for mammography and cervical screening as well as reduced access to health promotion activities for this population. Dementias reportedly have a similar prevalence to the general population rate with the exception for those with Down syndrome who are at an increased risk of Alzheimer's disease (MOH, 2011). These evolutionary changes in both known prevalence, longevity and health outcomes may, in part, be attributed to and inform the changing socio-political milieu in which individuals and their family/whānau find themselves.

Socio - Political Context of Living in the Community

The closure of the last state-run institution for people with intellectual disability occurred in 2006 in New Zealand (Stewart, Gates, Milner, Mirfin-Veitch & Schumayer, 2008). Parents who were interviewed as part of this most recent deinstitutionalisation process retrospectively recalled their decisions to seek an out-of-home placement. Previously they tended to see placing their family member at the Kimberley Centre as the best option for their son or daughter. Family decisions for out-of-home placements were difficult and were traditionally based on the severity, realities and challenges of caring for someone with significant health and behavioural challenges and which impacted upon the family as a whole (Stewart et al., 2008). However it has not been widely researched as to why family/whānau, who were in the majority, chose to support their family member with an intellectual disability

to live in the community when institutions were the norm of the day (Beresford, 1996).

The drive to seek out-of-home placement is linked with contentment in family life and community integration; significance was found in regard to these factors being linked with multiple disabilities (Llewellyn, Dunn, Fante, Turnbull & Grace, 1999). In other words, the greater the contentment and integration of the family member with a disability both at home and in the community, the more likely family carers were to not consider alternative placement. For those contemplating or having completed this process, there were concerns about the impact on the family – including siblings compared to those who were undecided or simply not engaging in conversations about out-of-home placement. Llewellyn et al. (1999) clearly demonstrated that families have their own unique culture upon which values and beliefs form and which are held and develop over time. Skinner and Weisner (2007) extrapolated this further to suggest that the sociocultural context included the community at large. This signified that outcomes for an individual are not only dependent upon family and whānau but (as this system is socially constructed) other interactions arise in society which directly challenge both the resources available and the philosophies held regarding how these resources should be apportioned for people with a disability. This resonates with the social model of disability insofar as disability is only apparent when the abilities of the individual and the demands of the environment in which they live, are surpassed (Oliver, 1996; Putman, 2002).

The current New Zealand government funding guidelines allow individual access to a Residential Support Subsidy (RSS) for people who “have been assessed by a [Ministry of Health] contracted needs assessment service as having a need for the support due to a[n]... intellectual disability [amongst others]” (Work and Income Te Hiranga Tangata, 2012, p. 1).

Ironically, with this model, the more able individuals who are currently residing with someone they consider to be family and whānau may be hindered or disadvantaged from achieving the usual developmental stages of the lifespan of leaving home as their needs are met through family/whānau support. However, if needs are assessed as eligible, individuals may also have access to 'Supported Living' which provides a more independent option of having the required supports come into the home to meet specified support needs. Notwithstanding such fiscal implications, the issues remain for suitable and flexible housing options to be made available (Gilbert, Lankshear & Peterson, 2008) regardless of the location.

Over the last fifteen years, the drive to access meaningful support, employment, roles and services in the community has undergone a significant evolution. In the wake of deinstitutionalisation, the New Zealand Disability Strategy document was launched (MOH, 2001); this harnessed a vision for the full inclusion and participation of people with disabilities in every aspect of New Zealand society. Pathways to Inclusion (hereafter referred to as Pathways) was born from this strategy and sought to operationalise this vision further by promoting the restructure of existing vocational services to enable community access, employment and inclusion opportunities that were valuing for people with intellectual and other disabilities (Department of Labour, 2001). This was indeed a laudable and radical shift as on the one hand it ensured that, legally, people with disabilities had the same minimum pay and conditions as the general population, and on the other hand it demanded a redefinition of existing programmes such as those termed 'sheltered workshops.' Ideologically Pathways succeeded, to some extent, in creating the expectation for services to actively define the way in which they supported people with a disability to develop real life, employment and community access skills. The reality for others, not enrolled in such programmes, was

increased isolation in the community (Lord & Hutchinson, 2007). The evaluation report did however state that there had been an increase in the number of people having individualised plans, one-to-one time with staff, and integrated community settings (Ministry of Social Development [MSD], 2008). For those in employment and segregated environments, conditions had improved whereas for others no change was noted in the extent to which people with a disability were engaged as “active partners in the service” (MSD, p. 3).

Enabling Good Lives (EGL) is a recent initiative that seeks to build on Pathways through the introduction of a facilitated individualised funding model whereby people with disabilities would be enabled “to do everyday things in everyday places in communities, rather than on provision of ‘special’ places or activities for disabled people” (MSD, 2011, p. 2). Ideally this is the next step in flexible funding models, service access and delivery to reduce planning in silos and promote a whole of life approach. It is based on calls from the disability sector for greater choice and control to enable increased autonomy, participation and integration in the community (MSD). At the time of writing outcomes for this initiative are yet to be established.

Despite the opportunities highlighted above, through changing systems of service access and delivery in both the residential and community contexts, decision-making in regards to out-of-home placement continues to be complex for older adults with intellectual disability. Regardless of the rhetoric, family and whānau access to alternative placements for a family member with intellectual disability is still dependent upon several factors and may be considered fraught due to the limited availability and suitability of placements, the level of individualised support, and an appropriate range of community access opportunities and access to funding.

The ‘Hidden Population’: Older Adults with Intellectual Disability Living with Family/Whānau

As a result of changing population demographics and government policy the role of family and whānau across the lifespan of people with an intellectual disability has, increasingly, been given more prominence and scope. In regards to research, people with an intellectual disability are considered a hidden or hard to reach population: This may be because they are accessing generic rather than specialist services (Bigby, 1995) or they continue to reside within some context of caregiving relationship within a family and whānau system well into adulthood and/or are invisible to services (Grant, 2007; Hubert & Hollins, 2000; Ryan, Taggart, Truesdale-Kennedy & Slevin, 2014). Such individuals are primarily seen as vulnerable by virtue of their disability and consequently the potential power imbalance inherent in systems of care may both reduce an individual’s autonomy and/or limit their access to the community (Parley, 2010).

The natural life course perspective of launching (transitioning from one stage of development to another) has seen an increased co-existence (delayed launching) between adult children and their parents in the general population (Aquilino, 1990). Hence, on one level, it should come as no surprise that this is also the case for the population under discussion. Over the last twenty years, research has identified the need for increased cognisance of the issues faced by parents (Dillenburger & McKerr, 2009) and siblings who are caring for older adults with an intellectual disability (Dew, Llewellyn, & Balandin, 2004). From a life course perspective, as the family and whānau environment “is one of the most durable influences on the development and quality of life” for people with intellectual disability, recognition and attention to these relationships is important by those within the wider government, health, disability and social service systems with whom these members are engaged

(Esbensen, Mailick Seltzer & Wyngaarden Krauss, 2012, p. 387). There are a range of reasons as to why this delayed launching may have occurred, reflecting political, circumstantial as well as socio-cultural value systems. Yet, despite this, there are resounding concerns about the context in which families and whānau find themselves in regards to future planning. Dodd et al., (2008) cautioned that those with an intellectual disability who reside with a parent in their later adult years are at risk in trying to access services in the future should there be a sudden or gradual change in the nature of the caregiving relationship due to frailty or illness of the caregiver. This reflects the fact that throughout their lives family/whānau have communicated with services and advocated for people with intellectual disability to ensure their needs are met and to establish the choices available. Such processes often take time; if there should be a sudden or gradual demise in the health of family/whānau, appropriate alternative options may not be sufficiently informed. As a result, there may be adverse outcomes in terms of health, social connectedness, opportunities and the future trajectory for the person themselves (Cuskelly, 2006; Llewellyn, Gething, Kendig & Cant, 2003).

Caregiving & Family/Whānau

Statistics New Zealand (2006) has projected that by 2051 there will be an increase in the general population aged 65 and over to 800 thousand (from 500 thousand in 2005), and up to 320,000 people in the 85 plus age group. Given that there is an increase in longevity across the population in New Zealand, it stands to reason that the demand for informal care will rise in the wake of policy which embraces community living and ageing in place. There has been suggestion that society generally depends and relies upon informal carers and their networks (whose capacity is unknown) to continue in this role (Dillenburger & McKerr, 2009). Consequently, there needs to be sustainable development around how the needs of all parties can be aligned

given the limitations of funded caregiving models and the person requiring support (National Advisory Committee on Health and Disability, 2010). Statistically, 69% of all informal carers in New Zealand are aged between 30-64 years of age, 12% are above age 65 years and 63% of informal carers are female (MSD, 2008). Whilst the percentage of informal carers for older people with intellectual disability is unknown in New Zealand, in Ireland caregivers over the age of 65 years make up 32.7% (Barron et al., 2006). Adults with an intellectual disability who are not in care receive most of their help from informal care arrangements defined as “help or support provided by a family member, friend, or neighbour to a disabled, sick, or frail person. Informal carers are typically unpaid, although in some cases may be paid” (Office for Disability Issues and Statistics New Zealand, 2009, p. 1). Regardless of the situation, in addition to the actual or perceived responsibility for the relative with intellectual disability the carer is likely to have support needs of their own due to age and infirmity (Taggart, Truesdale-Kennedy, Ryan & McConkey, 2012b).

Caregiving can be defined as the “expenditure of time and energy in providing emotional, personal, and social care and support on a daily or intermittent basis” (Saxena, 2015, p. 210). It is acknowledged that a caregiving role between two or more reciprocal parties is often intense and may or may not be established by choice. For a range of reasons, many families have struggled over time both with the challenge of retaining their caregiving role as well as the relinquishing of it (Mirfin-Veitch, Bray & Ross, 2003). It is the elements of genuine care, kinship, duty or even foreboding of the alternatives that see this relationship form (National Advisory Committee on Health and Disability, 2010) or simply a commitment to the role (Maggs & Laugharne, 1996). Given that individuals with intellectual disability who are living with their family may have a range of abilities, Egan and Noonan Walsh (2001)

stressed that people with an intellectual disability are “[n]either children nor helpless dependents, they look to their families for an array of emotional and practical supports enabling them to direct the course of their own lives” (p. 28). Thus the true impact of having a family member with a disability is difficult to establish; research comparing parents with and without a child with a disability found “both groups perceived their families as having little marital conflict and low levels of family conflict and external locus of control orientation” (Mandleco, Frost Olsen, Dyches & Marshall, 2003, p. 384).

Australian researchers have noted that 10% of informal carers are older than 65 years of age, the majority have a family member with a severe or profound intellectual disability and 76% (of approximately 9700 carers) provide over 40 hours per week of caregiving (Llewellyn et al., (2003). In Ireland, just over 64% of those registered on the national database for people with a learning disability were living at home with a biological family member – 25% of whom had either a moderate, severe or profound intellectual disability and were over 35 years of age (Kelly & Kelly, 2011). Statistics on informal caregiving in the United Kingdom documented it was most common for 45-59 year olds and “people over the age of 70 [to] spend the most time on caregiving” (Dahlberg, Demack & Bambra, 2007, p.443). Compared to carers of adults with mental illness, the duration was twice as long for those caring for people with intellectual disability in Taiwan (Chou, Pu, Lee, Lin & Kröger, 2009a), 70% used no services and 80% maintained it was their preference not to pursue alternative placements and would rather keep their family member at home (Chou, Lee, Lin, Kröger & Chang, 2009b). Of note, those with a mild intellectual disability may have fewer supports and therefore be under-represented in the above statistics. Given that people with intellectual disability are living longer, an inference can be made regarding the likelihood that they will outlive their carers. Based on national data,

McConkey, Kelly, Mannan and Craig (2011) found that in 2007 a staggering 67% of carers anticipated that they would continue to care for their family member with intellectual disability for some time to come. The necessity and implications for appropriate service planning around ageing with an intellectual disability cannot be ignored (Kelly & Kelly, 2011).

As vigilance increases for the health of those receiving state funded services, the hardship for informal carers is an important consideration. Argyle (2001) explored the roles of the carer and recipient to better understand the challenges that this presents. Findings suggested that, economically, there were mutual benefits in regards to household income, a reluctance to seek entitlements, social isolation due to cost and lack of informal supports, change in traditional roles, a sense of being the preferred care option and issues of access to formal care options for which reduced family income is a factor (Parish, Seltzer, Greenberg & Floyd, 2004). The health status of familial carers cannot be ignored. Objectively, a cohort of middle aged and older female carers experienced “higher rates of arthritis, high blood pressure, obesity and activity limitations” compared to the general population (Yamaki, Hsieh & Heller, 2009, p. 429) which places them at greater risk for developing cardiovascular disease, stroke and diabetes for example. Of note, there is an association between age and physical health, however this was not necessarily the case with mental wellness (Llewellyn, McConnell, Gething, Cant & Kendig, 2010a). Moreover, their self-reported quality of life was equal to if not better than their peers (Yamaki et al., 2009). There is however recent evidence of an “association between self-esteem, stigma and depressive symptoms in parents of children with disabilities [which is] moderated by emotional support” (Cantwell, Muldoon & Gallagher, 2015, p.954). In addition to arthritis, Taggart et al. (2012a) found ageing carers also experienced cardiac issues, diabetes, depression and

anxiety. For some, their own needs and identity were linked to the family member with a disability (Williams & Robinson, 2001a). Despite the challenges, families have their own beliefs, culture, adaptations and ecology which inform and drive the way in which they interact and engage with each other, services and, socio-politically, with the community at large (Skinner & Weisner, 2007). Not negating the values held by family/whānau, the risk in not undertaking planning for the future may result in the inappropriate placement of people with an intellectual disability under emergency conditions (McConkey et al., 2011).

Parents as Carers of Older Adults

Previously, for those who were not placed in an institution, the caregiving roles in a family fell to parents, grandparents and extended family. In essence, these families have had a 'career' of lifelong caring for their family member and for whom there were individual rather than normative milestones (Llewellyn, et al., 2003). Taggart et al. (2012b) found the caregiving demands were stressful and aside from carers' own issues, presenting behaviour was an added concern for family carers. Factors which could possibly mediate the stressors for familial carers included health, resources, purpose or meaning as well as their own appraisal about ageing and their situation (Minnes, Woodford & Passey, 2007). Whilst not a factor in the previous study, the level of formal and informal supports deemed insufficient by the primary carers and their caregiving role may in fact impact upon their relationships with others internal and external to the family unit (Taggart et al., 2012b).

There are also a number of challenges experienced by family and whānau carers in regard to maintaining the role and relationship in which they are engaged; these include a focus of financial benefits directed towards

their needs as carers and/or to the person with intellectual disability, access to information and services and eligibility criteria which may exclude immediate relatives (Gilbert, Lankshear & Peterson, 2008). Additionally, the role of older family/whānau carers is extensive and may exist long into the adult lifespan of their family member with intellectual disability (Gilbert, et al., 2008). Hence it is important to remember that “caregiving dynamics are not static... the caregiver’s reality is constituted in involvement with others in the world” (Kellet, 1997, p. 62). That being the case, the ability of primary or other carers to balance their social roles and responsibilities therefore may be dependent upon access to other supports which may include respite care. Access to respite care serves a number of functions such as the provision of a planned break for carers, the opportunity for the individual to develop new skills and may deflect a desire to seek residential care if it was perceived as negative (Chadwick et al., 2013; Gilbert et al., 2008). Further, as caregiving has often been lifelong, access to alternative care and respite may only occur when a crisis arises (Haley & Perkins, 2004; Hubert & Hollins, 2000; Grant, 1986).

Stoneman (2005) has pointed out that it is difficult to fully capture the intricacies of the familial context. Whilst parents may not necessarily intentionally impose subsequent caregiving on the next generation (Hand, Trewby & Reid, 1994), given the increased longevity of people with an intellectual disability, the emergent or acquired role of siblings as the primary caregiver is being more widely recognised. The acquisition of such a role, whether planned or assumed, necessitates service systems to be aware of identified needs for current and potential caregiving sibling relationships (Arnold, Heller & Kramer, 2012).

Siblings as Carers of Older Adults with Intellectual Disability

A range of outcomes exists in the research literature in regard to the impact of having a sibling with an intellectual or other disability. Improved adjustment of siblings may be based on the degree of familial cohesion where independence is nurtured, whereas “social competence” and self-concept has been found to be inversely correlated with conflict and a lack of organisation in families who had a family member with intellectual disability (Lynch, Fay, Funk & Nagel, 1993, p. 94). In a review of the literature (which spanned 25 years) Damiani (1999) found, not unexpectedly, an increased level of caregiving activities for females than males. Further to this was the concern about future roles and caregiving needs in the absence of parents (Damiani, 1999). Despite the evidence of levels of impoverishment for this population, cooperative or assertive responses and self-control had a higher prevalence in those with a sibling who had a disability compared to those without (Mandleco et al., 2003).

Arnold et al., (2012) researched the support needs of siblings and found the average age of a cohort of 139 siblings was 37 years old and 34 years for their relative with developmental disability (75% of whom had intellectual disability). Forty-one percent of the latter group resided with parents, 8% with siblings and only 25% were in care. The remaining individuals lived either with a spouse, other family or lived independently. Egan and Noonan Walsh (2001) found no difference in either stress levels or future planning between siblings who were in either a primary or secondary caregiving role. Further, they suggested that a deficit focus in research may do little to assist in correctly identifying the factors that inform “successful intergenerational transfer of family caregiving” (p. 36). Until recently, research has been limited in regards to the impact on adult siblings of having a family member with an intellectual disability: A meta-analysis of the

literature from 1972 to 1999 by Rossiter and Sharpe (2001) identified this gap and posited that as adults, familial influence diminishes alongside of developed cognitive and social skills thereby allowing for improved responsiveness and purpose. In line with this Stoneman (2005) called for research into the sibling relationship to occur across developmental stages. Of note, given changing birthrates the pool of potential sibling carers may diminish in time to come (Bittles et al., 2002) and this will impact upon service planning and provision.

As the ageing trajectory increases, aside from outliving their parents, people with intellectual disability are likely to be unemployed, have limitations socially as well as in vocational, educational and recreational opportunities. Furthermore, as they are also less likely to have a partner and/or children to support them as they age this role is most likely to fall to their siblings (Dew, Llewellyn, & Balandin, 2004; Ryan et al., 2014). Siblings may or may not be involved in conversations about future planning or have knowledge about service systems as this may have been previously undertaken by parents. Despite this, involvement in activities related to disabilities, older age of a female family member with a disability, geographical proximity and support provided by siblings without a disability were significant predictors of involvement in planning for the future (Heller & Kramer, 2009).

For siblings, the role of carer for the adult family member with intellectual disability may be ascribed (Stocker, 1989 cited in McConkey et al., 2011), inevitable, unpredictable, acquired, anticipated or obligatory. This is more likely if the sibling is female and has proximity and is not dependent upon the level of disability (Burke, Taylor, Urbano, & Hodapp, 2012). Whether planned or incidental, the role may be a replication of what parents have previously modelled as the way of being. Alternatively, a new set of

expectations can evolve and develop in this new, sibling caregiving relationship; these may be dependent upon whether the sibling support is for social or recreational purposes or if it is in response to other demands such as ill health and/or death of parents, in-laws, the age of the sibling's children, or grandchildren (Dew et al., 2004). This can also be dependent upon the timing and the circumstances in which the transfer of care has occurred within the family setting as it is a complex process. Critically, it can be seen that intergenerational transfer has implications for service funders and planners (Wyngaarden Kraus, Seltzer, Gordon & Haig Friedman, 1996).

Compound Caregiving

It is important to define the difference between 'sandwich' and 'compound' caregiving; the former refers to those who have caregiving responsibilities for parent(s) or in-laws whilst taking care of their own children (Chisholm, 1999; Grant, 1986). The latter refers to those parenting an adult son, daughter or sibling with intellectual disability who then find themselves caring for additional family member(s) (Perkins, 2010); this was found to be 37% in a study conducted by Perkins and Haley (2010). The impact of this may depend upon the level of support needed for the adult offspring, the intensity and frequency of the compound caregiving demands (Perkins, 2010), and which may result in physical and emotional tiredness, feelings of isolation and may increase the likelihood of considering alternative placement options for the family member with intellectual disability (Perkins & Haley, 2010).

Health and disability services are predominantly funded and legislated on the basis of set, standardised algorithms measuring the needs of the carer and/or the person being cared for. However it is not always clear who is doing the caring, who is in need of support and whether it is about care of a

physical nature or simply companionship (Williams & Robinson, 2001b) and this will impact upon the type and level of support offered. Despite this, the nominated carer might still retain control over elements of the lives of those with or to whom the care is provided when it comes to financial matters (Grant, 1986) and relationships (Williams & Robinson, 2001a). In regard to compound caregivers, there needs to be a recognition of, and respect for their contribution not only to those whom they support but also their contribution to a nation's economy (Perkins, 2011).

Research of forty-one adults with intellectual disability living with family found that a mutuality of support existed. In other words, the person with intellectual disability may have been reluctant to look at alternatives for themselves as they identified their role as that of caregiver to another family member (Bowey & McGlaughlin, 2005) or were burdened by the restrictions on their own freedom given this role (Walmsley, 1996): From the sample, eleven individuals (27%) wanted to move and thirty (73%) did not. Participants had concern for their elderly carers regardless of whether they had previous experience of loss. Short breaks could either stimulate their interest and willingness to discuss alternatives or dissuade the notion. The same ratio of people indicated no awareness of the likelihood of the availability of the current parent or carers to them in the future compared to those who understood the need for alternatives to be considered (Bowey & McGlaughlin, 2005). Interdependence within the relationship based on the altered need of one is one of the most pertinent factors which may limit the planning for out-of-home placement (Bowey & McGlaughlin, 2005; Grant 1986).

Future Planning

Eighty two point six percent of family participants identified that living within the context of the family was preferable for the adult relative with intellectual disability and living with a sibling was endorsed by 52.6% (Taggart et al., 2012b), preferably in the family home (Black & Kendrick, 2010; Taggart et al., 2012b). The significance of the latter cannot be ignored in regard to the risk of compounded loss and instability for those with intellectual disability who may not only lose their primary carer and/or companion, but their home as well (Bowey & McGlaughlin, 2005).

It is not uncommon for family carers not to have undertaken any formal planning for the future (O'Grady Reilly & Conliffe, 2002). Prosser (1997) found that 82% of parents and half of the sibling carers had not made any plans for their family member with intellectual disability who was over 40 years of age. However, a study over three years showed that whilst it does not guarantee a placement, having a plan increases the probability of it occurring (Freedman, Wyngaarden Krauss & Mailick Seltzer, 1997). Heller and Caldwell (2006) noted that parents themselves may be reluctant to explore the conversation about future planning with other family members. There are many reasons for intentional or unintentional avoidance in making future plans and this may include; the sense of belief that the knowledge possessed (of one's family member) is not transferable (Grant, 1986; Williams & Robinson, 2001a), a recognition of their own fragility or significance of altered roles (Taggart et al., 2012b), perceived suitability of accommodation options for their relative with intellectual disability (Llewellyn, et al., 2003) as well as funding for appropriate caregiving support (Black & Kendrick, 2010; Weeks, Nilsson, Bryanton & Kozma, 2009). Moreover, there is often an expectation that they would outlive their relative and others (specifically family and services) will take planning responsibility (Prosser, 1997).

Sometimes there is the reluctance of the family member with intellectual disability to move (Bowey & McGlaughlin, 2005), or they are perceived as a perpetual child with associated concerns about behaviour and vulnerability (Williams & Robinson, 2001b). Concerns about policy, funding and service continuity (Cuskelly, 2006) also play an important role, as does the inevitability of the carer's sense of their own mortality (Heller & Caldwell, 2006; Grant, 1986), and mutual caregiving roles whereby neither the ageing relative or the adult with intellectual disability would be able to live independently without the other (Foundation for People with Learning Disabilities, 2010).

Few studies have explored the concept of future planning with people who have an intellectual disability and/or their family and two examples are provided here. Through the development and pilot of 'What the future holds', O'Grady Reilly and Conliffe (2002) identified that this tool enabled families to think about future planning in terms of what is desirable for one's life whilst ensuring that systems do not negate this when supporting transitions. Heller and Caldwell (2006) engaged families in a peer-support intervention that was based on the tool 'The future is now: A future planning training curriculum for families and their adult relatives with developmental disabilities' (DeBrine, Caldwell, Factors & Heller, 2003). They found that the peer-support approach was an important element for the family members as "was the inclusion of individuals with developmental disabilities in the planning process" (p. 198). Future planning should not be the sole responsibility of familial carers however: This role also falls to the government who holds responsibility for the funding of health and disability services. Government services need to consider not only the ageing population, but also the family and whānau who care for their older member with intellectual disability (Janicki, 2009) as there is a need to appreciate the fluctuating situations that

exist within such longstanding informal caregiving relationships (Black & Kendrick, 2010). Hence, whilst professionals may acknowledge the need to seek the wishes of individuals themselves, the focus may in fact remain bi-directional to include family/whānau (Williams & Robinson, 2001a).

Decision-Making & People with Intellectual Disability

Few studies to date have directly sought the personal perspective of older persons with intellectual disability themselves in relation to their own perspective of continuing to live at home with family/whānau and considerations about future planning as they age. O'Rourke, Grey, Fuller and McClean (2004) found that 37% of older adults with intellectual disability were satisfied with their living arrangements amongst their family. This included those who experienced difficulties such as the impatience of family members and altered levels of independence: Primary dissatisfaction for this cohort was access to activities and loneliness. For a population who are likely to have experienced exclusion and stigma during their lifetime, people with an intellectual disability are at risk of such experiences becoming compounded as they age (Janicki, 2009). As with the general population, people with intellectual disabilities have varied ideas or experiences of ageing or what death might be like and may not be included in rituals around death and dying (McEvoy, MacHale, & Tierney, 2012). It is important that these factors be acknowledged and that no assumptions are made that being involved may be unduly distressing for them.

Ageing-in-place is a well-established concept, the goal of which is to enable individuals to remain in their respective residence of preference by ensuring systems of support are in place to enable that to happen to the best extent possible. For people with an intellectual disability there may be friction

in setting this in place. Whilst ageing caregivers may be needing greater levels of support, the family member with intellectual disability may be at a stage where their primary goal is on developing choice and autonomy - hence the respective needs of each party in the caregiving relation may potentially be in conflict (Walker & Walker, 1998). Williams and Robinson (2001a) reported on conflicts (with carers) identified by participants with intellectual disabilities in which the tension was, primarily, about differences of opinion and belief regarding the need to develop skills to enable an increased level of independence. Further to this, such tensions were noted to still exist about perceptions held by family/whānau regarding the capacity of their member with intellectual disability which directly impacted upon the individual's role and right as a citizen to make decisions about their own life - including preferred accommodation and milestones (García-Iriarte, O'Brien, McConkey, Wolfe & O'Doherty, 2014). However a lack of exposure to life experiences and normative transitions can impede opportunities for self-determination, learning and skill development that people usually have across the lifespan in regard to ascertaining and discerning options available to them (Curryer, Stancliffe & Dew, 2015; Heller et al., 2011; Wehmeyer et al., 2011). It is acknowledged that (some) parents see it as their role to make decisions on behalf of their children and assert this under the defence of 'best interests' (Williams & Robinson, 2001a, p. 37). In light of emerging evidence about the changing role of caregiving within the family/whānau relationships (Ryan, et., 2014), it is important to note there is limited research about how family/whānau support autonomy of decision-making in adult family members with intellectual disability (Curryer et al., 2015). Therefore it stands to reason that decision-making processes in family/whānau across the lifespan may impact upon how considerations about future options are later discussed and undertaken.

Chapter Summary

This background chapter has provided a synopsis of ageing in society today (both generally and for the intellectual disability population). It explored the changing trajectory which represents both the evolution of an identifiable disability population and one of informal caregiving, and has unpacked the known issues with this interrelationship. Understanding what comprises and informs these hidden networks of support is imperative for funders and recipients alike if the needs of all parties are to be met in a balanced and appropriate manner.

“Relatively little is known about disabled people’s lives over time, their experience of ageing with disabilities, and what it means to cope with disabilities over many years” (Jeppsson Grassman, Holme, Taghizadeh Larsson & Whitaker, 2012, p. 95). This sums up the extraordinary challenge that is emerging as an increasing number of people with intellectual disability survive and thrive well into older age and the impact that this has upon their lives, informed decision-making process and opportunities. Ageing for and alongside people who have intellectual disability is a complex scenario. Factors which influenced the decisions of primary carers for example, the specific context in which they were made and which have implications both now and in time to come – not only for themselves as parents, siblings or carers but for their family/whānau with intellectual disability. As there is a paucity of research about the perspective about getting older and future planning for people with an intellectual disability and their family/whānau carers, these are the very perspectives that can and should be considered, and form the aim of this thesis.

CHAPTER 3

METHODOLOGY

Introduction

Historically, people with an intellectual disability were seen as objects of inquiry. In contemporary society however, they are increasingly involved as active participants in research due to the growing body of knowledge which expounds the benefits and validity of their inclusion within the research process. By ensuring that the voice of the person with intellectual disability is sought together with the perspectives of those significant to them, respect is both gained and implied for the perspectives they have of their experiences - individually and collectively.

The aim of this study was to explore perspectives about getting older and future planning for people with an intellectual disability and their family/whānau. Hence a qualitative grounded theory approach was used for this research and this chapter presents an introduction to the methodology. Charmaz's (2006) constructivist grounded theory is explained through the methodological foundations of axiology (the transformative paradigm or nature of ethics), the ontological perspective (that is the nature of relativism) and finally, the epistemology of constructivism. These conceptual commentaries inform the application of grounded theory in this thesis. The research design is then described in regards to the sampling techniques used to invite the participation of people with intellectual disability and those of significance to them. Inclusion and exclusion criteria are also identified and the rationale explained. The data collection processes are described in reference to Charmaz's (2006) approach of interpretive constructivism. This

section also includes ethical considerations for the inclusion of vulnerable populations, informed consent procedures and reference to the cultural foundations of research in New Zealand. The chapter concludes with an overview of the data analysis that has been undertaken and informed by Charmaz's (2005; 2006) convention of reflexivity in constructivism through grounded theory.

Disability Research: Emergent Understandings

It has long been considered that there are populations within society considered vulnerable and that their inclusion in research processes may heighten this vulnerability (Nind, 2008; Veenstra et al., 2010). People with intellectual disabilities are one such group. Traditionally, they were merely seen as static targets and objects of research; however there is now increasing recognition that they have the same rights to shape and participate in research as others (Atkinson & Walmsley, 1999; McDonald, Schwartz, Gibbons & Olick, 2015), can be reliable in the process (Stalker, 1998) and can identify the potential for benefit and harm for themselves as well as strategies to reduce the latter (McDonald et al., 2015). The phrase 'nothing about us without us' clearly represents the drive for greater understanding about and for people with impairments in the disability rights movement and is synonymous with the concept of inclusion (Stone, 1997). Nind (2008) reports on the emerging body of literature which informs the range of approaches that promote the active role of people with intellectual and other disabilities in identifying and defining research in this field. Participatory research is considered to be both emancipatory and inclusive as those with a disability are involved in research in a meaningful rather than tokenistic way at project conception (Northway, Howarth & Evans, 2015; Walmsley, 2004) through to the dissemination of results (Harrison, Johnson, Hiller & Strong, 2001). In other words it is based

on “equality within relationships and involvement” whilst simultaneously being mindful of the possible impact such involvement may have on the research and which may be dependent upon the topic, location and process (Northway et al., 2015, p. 574). There are three key principles which underpin participatory research: The equity in the relationship between those involved, the rights of individuals to “be consulted about and involved in research which is concerned with issues affecting their lives”, and the inherent assumption that their inclusion improves both the “quality and relevance” of the research undertaken (Stalker, 1998, p. 6). Participatory research is also seen to challenge existing discrepancies in both the perceived or actual power base and agendas of researchers who may experience pressure to achieve outputs in the face of the extensive time that inclusive research actually requires (Stalker, 1998). However it can be argued that these realities often overlook the fact that “individuals can speak with authority... from the validity of their own experiences” (Stalker, 1998, p.13) and as such, are often best captured through qualitative research – the premise of which is explained in the next section.

Qualitative Research

Historically qualitative research was not regarded as a pure science (Hallberg, 2006); however, it is now strongly acknowledged as a valid approach which encompasses a number of sound methodologies that enable flexibility whilst ensuring rigour in the depth of the phenomena sought (Polit & Beck, 2004). There are a number of qualitative methodologies which enable the interpretation of the individual and collective experiences of people across subject, place and time through different processes of meaning-making. Throughout the history of research, politics and discipline have both played a role in the evolution of the interpretive paradigms used, and which provide a

philosophical theory to underpin the qualitative approaches for example; positivist, feminist, Marxist, cultural studies, ethnic and constructivist (Denzin & Lincoln, 2011).

Denzin and Lincoln (2011) describe qualitative research as a contextual activity which “consists of a set of interpretive, material practices that make the world visible” to the observer. It is this contextualisation that allows for appropriate understanding of variations. Ideally such interpretive research occurs in real world settings as the researcher attempts “to make sense of or interpret phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, 2011, p. 3). It should be emphasised that personal meanings for research participants are not always overt, and it is the researcher’s engagement with what is offered by the individual which provides an opportunity to respectfully make visible that which is dynamic rather than static (Charmaz, 2004). These components of qualitative research are inherent within grounded theory and espouse the depth of experience sought and importance of participants to be involved in sense-making. It was based on this understanding that grounded theory was chosen in preference to other qualitative methodologies.

Grounded Theory as a Research Methodology

For the purposes of this study there is neither the scope nor intent to provide a full chronological exploration of the history and evolution of grounded theory other than to acknowledge the initial impetus and significance of those involved in its development. Glaser and Strauss are considered the founders of grounded theory. Research undertaken by them in the 1960s explored the interactions and processes around dying and resulted in the seminal text *The Discovery of Grounded Theory* in 1967. Their initial finding and recommendation was for researchers to await the emergence of

objective extant theory through the grounded theory process (Glaser, 1992). In other words, the researcher is to remain objective and separate themselves from what is occurring in the research process. This approach is to ensure that grounded theory is “systematically and inductively arrived at through covariant ongoing collection and analysis of data... [without] preconceived ideas of extant theory and then force them on data for the purpose of verifying them or rearranging them into a corrected grounded theory...” (Glaser, 1992, p. 15). To achieve this, a key element when embarking on grounded theory requires an avoidance of reviewing the literature in the first instance as this may impact upon the researcher’s ability to naturally and neutrally arrive at categories with properties clearly informed by the data (Glaser, 1992). They point out that the problem to be studied may be missed entirely if the researcher has a preconceived notion of what the issues are. Hence, in developing this approach, Glaser believed in the need for “...parsimony and scope. It accounts for as much variation in the action scene with as few categories and properties as possible” (Glaser, 1992, p. 18).

Over time, Strauss, whose background was qualitative in nature (compared to Glaser’s quantitative tradition of origin) teamed with Corbin: They explored a new direction in grounded theory which allowed an area of interest to be identified and which could provide opportunity to elaborate or develop that which is already known (Strauss & Corbin, 1998). Thereby, whilst the emergent theory was still sourced from the data, having some background enabled the research to use creativity to inform its development. Glaser (1992) contested Strauss’s independent development of the Basics of Qualitative Research and stated that it was far removed from their co-founding of grounded theory in that it perpetuated historical qualitative approaches in which data is forced and described. In comparing the respective stances, Walker and Myrick (2006) came to the conclusion that the

strength in grounded theory may not lie in a particular approach but rather “in the discourse itself” (p. 558). Over time there have been other permutations in which authors have sought to compare, contrast and develop the traditional Glaserian approach with that which evolved from Strauss and Corbin (Birks & Mills, 2011; Bryant & Charmaz, 2010; Charmaz, 2006; McCann & Clark, 2003; Mills, Bonner & Francis, 2006a).

In acknowledging the evolution of grounded theory, Charmaz (2006) respectfully challenged the status quo and added her contribution to the methodological developments. She maintained that the researcher cannot consider themselves separate from the interactions within which data is sourced as they come with experiences as well as personal and professional knowledge which inform their inquiry. Her approach encompasses the flexibility that grounded theory embraces, recommends principles rather than a prescribed process, and requires the researcher to be ‘reflexive’ or cognisant of the lenses that they themselves bring to, and engage with during the encounter with the participant (Charmaz, 2006; 2008a; Giles, King & de Lacey, 2013). In the context of the current study the researcher has both declared and clearly articulated her personal and professional influences from the outset. And, in keeping with Charmaz’s approach, engagement with the literature further contextualised and externalised the known and/or perceived issues facing the population in question which informed the research aim. In essence, acknowledging one’s lenses coupled with exposure to the literature guided and enabled the researcher to recognise the need for, and employ reflexivity - which is fundamental in constructivist grounded theory. The latter approach enables the social construction of experiences between those engaged in the research encounter to be illuminated (Charmaz, 2008) and for this reason was a key factor in determining the chosen grounded theory approach. During the collection of data in the current study for example,

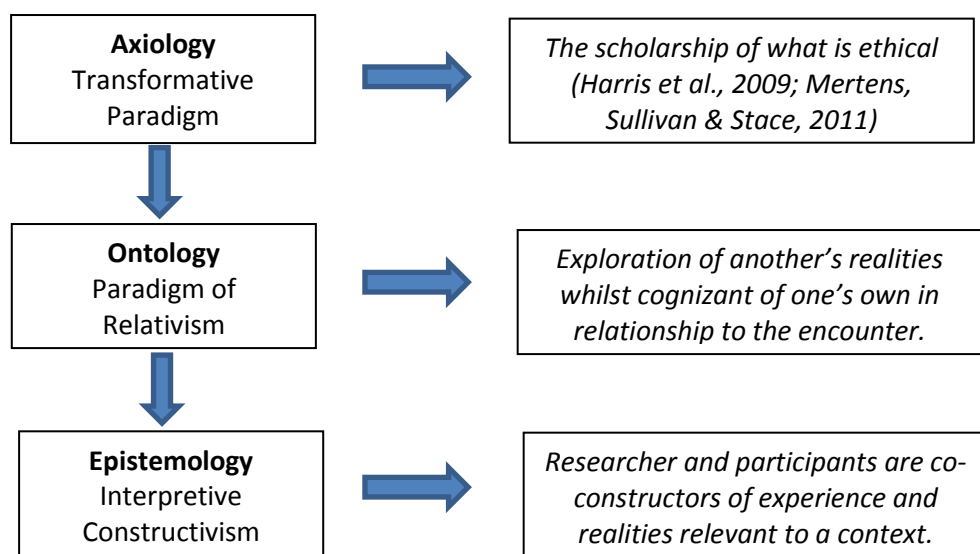
participants frequently provided information that was unintended or additional; through inclusive and exploratory interaction the original data became richer as such emergent ideas have the potential to alter the course or direction of the research path – regardless of which stage a study is at (Charmaz, 2006). A further key element within the grounded theory process is that of ‘memoing’, which Dey (2010, p.187) refers to as “an audit of the more metaphorical and narrative elements of the analysis”. Memos contribute to the development of a “coding framework” and work as a catalyst for the further development of codes.

To concentrate on developing theory Stern (2007, p. 118) encouraged the method of data collection as espoused by Glaser and Strauss (1967): In responding to transcripts brought by students, she describes the “search and seizure operation” as opposed to the traditional qualitative line-by-line approach. The aim of a grounded theory approach is to seek theoretical rather than descriptive findings to focus on the “accuracy of the discovered truth, rather than the less important what-did-they-say-exactly” (p.119). Charmaz (2008b) built on this foundation by articulating that grounded theory is not simply a vehicle to espouse the social constructions of research participants rather, the researcher is involved in a process of mutual construction throughout the study – not simply at a finite juncture.

In keeping with the constructivist tradition, the axiology of the transformative nature is unique and specific in its application to the disability sector and was the overarching paradigm which informed this grounded theory research process (Harris et al., 2009). For the researcher, the ontology of relativism is then recognised in regard to the potential impact for the researcher of engaging with participants’ realities and the constructs which inform them (Birks & Mills, 2011). Such paradigmatic awareness then culminates in the epistemology of interpretive constructivism in which all

parties, cognizant of their respective histories and experiences, co-create an understanding thereof and which informs a theoretical perspective about “*how* and sometimes *why* [emphasis in original] – participants construct meanings and actions in specific situations” (Charmaz, 2006, p. 130). These three interdependent paradigms are described below (Figure 2).

Figure 2: Summary of Paradigms Informing Grounded Theory



Axiology – Transformative Paradigm

Axiology is comprised of three assumptions within the transformative paradigm of research in the field of disabilities. Axiology refers to the scholarship of what is ethical (Harris et al., 2009; Mertens, Sullivan & Stace, 2011), seeks to know “what is intrinsically valuable in human life” and informs the transformative nature of inclusion in the creation of knowledge (Heron & Reason, 1997, p. 277). Its primary purpose is to question and understand the diversity and contentions within disability research and is based on;

...a framework of belief systems that directly engages members of culturally diverse groups while focusing on increased social justice... [for] people who are generally excluded from mainstream society. It strives to extend the meaning of traditional ethical concepts so that they reflect more directly ethical considerations in culturally complex communities (Harris et al., 2009, p. 108).

At its forefront the transformative paradigm thus instills in the researcher an awareness and drive to examine the potential realities of issues such as inclusion, access, quality, equity and fairness. This contrasts with, and is broader than, emancipatory research as it may stimulate the researcher to explore these realities in partnership with individuals and/or communities who experience some form of disability. This partnerships forges a pathway to challenge differential structures deemed to be limiting or oppressive (Harris et al., 2009). The focus is based on a developmental trajectory perspective which may include dimensions not only of disability but of ethnicity, culture, sexual orientation or gender for example and which differentiate this population from those considered to be 'privileged'. Mertens et al. (2011) added that in order to achieve the above goals the researcher must have a sound relationship with (and awareness of) the culture of the populations with whom they are engaged as this has ramifications for the utility and integrity of the research. Such axial awareness thus grounds the researcher and informs the establishment of parameters not only for their own realities but also for those with whom the research partnership has been established (Mertens et al., 2011).

Harris et al. (2009) noted that all researchers must have an understanding of the community with which they engage to validly explore the reality of its members. Hence, with over twenty years of nursing

experience working alongside people with intellectual disability and their family/whānau across the disability sector, I was attuned to a raft of realities unique to individuals within their social system of care in which they exist and/or participate in the community. Whilst this may be considered as a potential to bias or pre-empt the research process, it is contended that it enabled a deeper appreciation of the uniqueness embedded in the personal and collective experiences of prospective participants. It is further proposed that the ability to meet people in their own space and time enabled a process of engagement that is premised on an inherent respect for the person in their current reality and thereby reduces the risk of forming assumptions. To achieve this it was important to recognise my own assumptions (practically and philosophically) and not let knowledge of the phenomenon presuppose expectations or findings (Birks & Mills, 2011). A researcher's background knowledge may be considered a "filter of salience through which data are sieved" as "[t]heoretical sensitivity helps curb the potential bias from the researcher's background experiences and diminishes the risk of compromising the study through premature closure" (Schreiber & Stern, 2001, p. 60). Hence, the transformative paradigm provided an overarching philosophical lens which promoted and informed my reflexivity throughout the study (Charmaz, 2006; 2014) to engage both empathically and objectively. This form of engagement was further informed through the lenses ascribed to the ontology of relativism.

Ontology of Relativism

The naturalistic paradigm holds that a person's reality is their subjective interpretation of how they interact with the world over time and this is relevant to the context in which they find themselves (Polit & Beck, 2004). Because reality is constructed in the mind of the inquirer (Guba &

Lincoln, 1994), the ontology of relativism therefore requires the researcher to critique their existing knowledge or assumptions about the nature or reality of a particular phenomenon.

The researcher... has a responsibility to uncover the various versions of reality and to interrogate them to determine which version is most in accord with furthering social justice and human rights. This raises questions about how the researcher becomes competent in each cultural context in order to accurately reveal issues related to oppression and resilience. (Mertens et al., 2011, p. 231)

Health and disability service systems have often grappled with providing an appropriate reactive response to a crisis in the life of the individual and/or family/whānau system of care when some aspect of the caregiving relationship breaks down. Longitudinal knowledge of the rites, rituals and realities shared by family/whānau as they intermittently contemplated the future of their member with intellectual disability is critical – and in the current study was informed by a direct experience as a nurse in this field. Therefore, the realities and uncertainties were explored stemming from the participant's cognitive construction of the cultural and socio-political milieu upon which their memories, experiences and knowledge have been formed (Guba & Lincoln, 1994). Thus, the focus of any grounded theory study requires the researcher "to understand the shared basic social problem from the participants' perspectives. Their understanding of the problem must be revealed" and it is through the grounded theory process one comes to understand how they come to "resolve or ameliorate" it for themselves (Schreiber & Stern, 2001, p. 62). Therefore, when I, as the inquirer am aware of my own ontological stance, a position of "objective detachment" is formed and enables the unrestricted discovery of the reality of an individual's

phenomena as they engage in the process of discovery alongside others (Guba & Lincoln, 1994, p. 108). Such identity is seen as increasingly inductive rather than deductive (Charmaz, 2006; 2014) and as data is gathered, compared and integrated to form a theory or explanation of the phenomena (Polit & Beck, 2004) it remains grounded in the research.

Epistemology of Constructivism

The epistemological paradigm denotes the nature of relationships between those involved in the research encounter and reflects “a subjectivist and transactional” engagement with or about a particular phenomenon (Appleton & King, 1997, p. 14). Further, the application of interpretive-constructivism as a qualitative methodological approach engages the perspectives of persons and/or their communities to explore “how the social structures... influence... through a given set of social interactions” (Starks & Trinidad, 2012, p. 1374). This, in turn, may assist their own “navigation [of] complex and sometimes oppressive systems” (Ponterotto, 2013, p. 23). Here, the role of the researcher is that of a pivotal co-constructor of the experience alongside that of the participants. As a result of this engagement knowledge is formed (Bryant & Charmaz, 2010; Guba & Lincoln, 1994) which is based on the historical, cultural and social lenses but which constantly informs the interaction even as it is occurring (Crotty, 1998; Charmaz, 2008a). However, these constructions may be incompatible or in conflict with those of others as there are limitations as to the role experiential knowledge plays within this process (Heron & Reason, 1997). They may therefore be de-constructed or reconstructed as part of the research process individually or collectively to form a consensus of understanding (Lincoln, Lynham & Guba, 2011) and interpretive meaning (Crotty, 1998). In order to do this the researcher must consciously engage with and acknowledge the influences which inform and

underpin their perspective as they engage in the process of construction (Mills, Bonner & Francis, 2006b). Bryant and Charmaz (2010) described the researcher as an attuned participant who brings the data to life through their engagement as it is through this mutually facilitated story-telling that data is formed and new interpretations are established. The principles, elements and application of Charmaz's grounded theory constructivist approach are embedded throughout the methods section of this chapter.

Methods

The remainder of this chapter explains the method of recruitment and consent of participants who have an intellectual disability and their nominated family/whānau informants. The application of grounded theory is described in regard to theoretical sampling, data collection and analysis. Ethical considerations and strategies are also presented and which informed and enabled the meaningful engagement of all parties in this study including people with intellectual disability: These factors included consent, reliability, validity and trustworthiness.

Research Aim

The aim of this grounded theory research was to explore perspectives about getting older and future planning for people with an intellectual disability and those nominated as family/whānau.

Ethical Approval

A number of issues were considered to ensure that the ethical integrity of the research upheld the principles of respect, justice, beneficence and non-maleficence (Polit & Beck, 2004). These included; the imperative to ensure the

voice of people with an intellectual disability remained an integral focus of the study, their right to nominate a person of their choosing to be invited to participate and/or support them in the research process. This section provides an overview of the cultural foundations for research in New Zealand, principles for the inclusion in research and consent of people considered vulnerable, assent and informed consent, and access to visual media. This research was approved by the Upper South A Regional Ethics Committee, Ministry of Health, South Island, New Zealand (URA/11/02/004) (Appendix 1).

Cultural Context of Research in New Zealand

The Treaty of Waitangi was signed in 1840 and is the foundation document of the country which informs how Aotearoa - New Zealand recognises, engages with and works alongside Māori, the indigenous population. The principles of partnership, protection and participation are the cornerstones upon which the Treaty is based; in upholding these, respect of their interests were considered in regards to the design, implementation and relevance or application to research for a population considered vulnerable by its indigeneity (Kingi, 2007).

It is imperative to understand the history of Aotearoa – New Zealand in regards to the relevance today for an indigenous population. For example, Māori experience a higher mortality rate than non-Māori due to the incidence of diseases such as cardiovascular disease and cancer as causes of death (Ministry of Health, 2003). Moreover, there are identifiable disparities between Māori and non-Māori in both rates and outcomes for type2 diabetes for example (Ministry of Health, 2008). There are distinct similarities between the issues facing Māori and people with intellectual disability both in terms of the inequalities with health care access and subsequent outcomes.

Socioeconomic status and the impact of environment and lifestyle choices also lead people with an intellectual disability to experience poorer health outcomes compared to the general population (Emerson & Hatton, 2007) which are also predictors for New Zealand Māori (Ministry of Health, 2008).

To seek the inclusion of Māori in this study consultation was undertaken with Ms Elizabeth Cunningham, Research Manager Māori, University of Otago, Christchurch (Appendix 2) and Te Korowai Atawhai, Specialist Mental Health Service, Canterbury District Health Board, Christchurch. Recommended avenues were followed up by the researcher. Of note, the community based services who were contacted identified that they did not have anyone with an intellectual disability at that time accessing their service who was residing with family/whānau. This represents a significant shift over time in regards to the changing roles and make up of family/whānau within the Māori population itself. Whilst duty of care remains a core value culturally, diversity exists and the way in which responsibility for one's own is understood, experienced and/or expressed has, and continues to evolve in time, place and location (Collins & Willson, 2008).

Ethical Research & People with Intellectual Disability

Participation in research for people with intellectual disability is deemed to be fraught with ethical issues primarily as they are considered vulnerable, unable to consent (Polit & Beck, 2004) or their ability to contribute is questioned. Conversely there is the issue of not including them at all because of this (Iacono, 2006). Further to this, in regards to seeking their recruitment and inclusion in research processes, gatekeeping is often required or undertaken (whilst under the guise of protecting the individual) – it may exclude individuals from the opportunity to make a decision for themselves

to the extent possible (Iacono, 2006; McDonald & Kidney, 2012; Ponterotto, 2013). Family/whānau, carers and professionals may also weigh-up the potential benefit for all parties (including themselves) hence time is needed to form relationships to strengthen recruitment for vulnerable populations (Tuffrey-Wijne, Bernal & Hollins, 2008) and includes perceptions regarding decisions the individual is deemed capable of undertaking (Ponterotto, 2013). Alternatively, it may be deemed an imposition of time or, respectfully, a lack of understanding on their part to foster the uptake and involvement in research of their family member with intellectual disability. Notwithstanding, without such contact from and facilitation by others involved in the person's life, ability to access and participate in research would also be hindered (Lennox et al., 2005). Rigour remains a key element in constructing research well with existing participants (Hendricks & Blanken, 1992 cited in Spreen, 1992).

Informed Consent & People with Intellectual Disability

Ethical approval includes seeking participation for those who can consent, assent and/or require consent-by-proxy. For example, people with cognitive limitations may be able to assent in terms of willingness to contribute or be part of research however may not be able to provide informed consent (McDonald et al., 2009; Tuffrey-Wijne et al., 2008; Veenstra et al., 2010). Consent by proxy (Appendix 3) was also an option to enable people with intellectual disability to participate – given what is known about the individual by people who know them well (Freedman, 2001). Of course family/whānau may not be the best option (for a range of reasons) and there may be questions about the legal validity of such consent (Iacono, 2006). Of note, several participants did not want to be anonymous and preferred that their own name was used. Whilst a difficult and abstract concept for some to understand, they were all informed as part of the consent process that this

one of the 'rules of research' and it was to protect them by enabling them to speak without reserve (Tuffrey-Wijne et al., 2008) (Appendix 4: Consent form – Person with intellectual disability).

As it applies to the general population, people with intellectual disabilities "are assumed to have capacity to consent, unless it is proven otherwise" (Dye, Hendy, Hare, & Burton, 2004, p. 145; Freedman, 2001). Therefore, with individuals who may be considered vulnerable it is pivotal to reduce the likelihood of acquiescence which is defined as responding affirmatively regardless of the intent, content and/or complexity of communication (Finlay & Lyons, 2002) or suggestibility in which people accept, agree and apply information as it is communicated (Clare & Gudjonsson, 1993). Whilst not necessarily a conscious response, the person themselves may not comprehend the implications of either (Clare & Gudjonsson, 1993; Finlay & Lyons, 2002), hence clinicians, academics and family/whānau need an awareness of its purpose and function. Tools that were used to check the validity of individual responses included but were not limited to; reverse wording or question reframing, seeking examples, offering 'don't know' as a response options (Finlay & Lyons, 2002), using open-ended questions (Denzin & Lincoln, 2003) and allowing sufficient time for a response to be made. Generalising the experience of others was also used as way of engaging participants with the subject. As there was the potential for difficulty in participants' ability to understand what was asked of them or formulating responses due to some limitations in cognition or expressive language, a visual scale was available to aid responses (Appendix 5).

Each participant was offered the opportunity to decide where they preferred the interview to be held; their place of work, at home or at the Centre for Postgraduate Nursing, University of Otago Christchurch. For individuals residing outside of Christchurch, location was negotiated and all

opted that I come to them. All participants had the option of having a support person with them at each stage of the research process – including the establishing of consent (Appendix 6: Consent form - Family/whānau). Throughout the research process, consent was revisited at intervals with all participants to ensure it was still relevant and valid for them to continue with the process. It was this invitation to review informed consent which enabled one mother and son to withdraw from the study.

Sampling

A non-probability sampling approach (Polit & Beck (2004) was initially used over an extended period of time (exceeding twelve months) to invite prospective participants with an intellectual disability to engage in this study. Residential and vocational service providers from the intellectual disability sector were approached to ascertain whether people accessing their service met the general inclusion criteria. Those meeting the inclusion criteria were sent information by the service on behalf of the researcher. Services were required to contact the individual and/or their family/whānau/carer to discuss the research with them in the first instance before providing them with a copy of the 'Letter of Invitation' and the 'Information Sheet' (Appendix 7, 8 and 9) and 'Expression of Interest Form' (Appendix 10). Approximately fifty information packs were forwarded to the services who responded to the research request. Any individual who submitted an 'Expression of Interest Form' was followed up with directly by the researcher to engage and enable the consent and interview processes to proceed.

As those with intellectual disability who are older and living with or being supported by family/whānau are considered 'hidden' or 'hard-to-reach' (Bigby, 1995) flyers were sent out to eighty primary health care settings in the South Island of New Zealand to include individuals with intellectual

disability who were not already engaged in or may not have responded to the disability services referenced above. Advertisements were also placed in a religious publication, a carers newsletter as well as several public notices in local papers and websites to seek participants through secondary and tertiary health sectors (Appendix 11). Additionally, a weblink to the study was placed on the University of Otago website. The sampling approach of snowballing was initiated as another way of enabling research participants to use their connections within a certain population group to recruit further for the research being undertaken (Becker, Roberts, Morrison & Silver, 2006; Spreen, 1992). Snowballing has been used to recruit other minority groups such as the homeless, street workers and addicts (Faugier & Sargeant, 1997) due to the transient nature of their lives (Kaplan, Korf & Sterk, 1987). Although people with intellectual disability are not considered transient, their engagement within health, disability, education and service systems may be so. Whilst the majority of the participants lived within the immediate Christchurch city boundary, there were also a number of participants farther afield in South Canterbury, the West Coast and Marlborough regions of the South Island, New Zealand. Two to three follow-up contacts were made with each recruitment avenue to re-run the advertisements and, for example, to request services to check if the information packs forwarded to families had been received. It needs to be emphasised that the researcher was clear with services that the sole intent for the request for follow-up contact by the service providers was to ensure information had been received and in no way sought to further induce family/whānau/carers or individuals to participate.

Theoretical Sampling

Theoretical sampling is based on the premise that a range of participants may have experience of, or a perspective about the research

phenomena. The intent behind this sampling process is to inform the development of the emergent theoretical categories (Charmaz, 2008a). Saturation occurs when the data are found to be representative of the theoretical constructs that emerge through the concurrent analytical process (Starks & Trinidad, 2007). Theoretical sampling can take different shapes and forms; from a population that may have some similarities to that which is involved, to those whose role is external to the experience of the current members, or the seeking of “events, or information to illuminate and define the properties, boundaries, and relevance of [a] category” (Charmaz, 2014, p. 345; Corbin & Strauss, 2008). This occurs once analysis has been commenced as this informs the direction in which saturation is sought. This may be undertaken with existing research participants and is not dependent upon recruiting additional subjects (Charmaz, 2006). The purpose of theoretical sampling therefore is not about the population but rather to ensure the contribution of data to theoretical construction (Birks & Mills, 2011).

Theoretical sampling was conducted in a number of forms throughout the research process. Information obtained through the initial interviews provided a platform to explore angles in subsequent interviews between individuals and family/whānau participants. For example, during one interview, Lucy, a participant with Down syndrome commented that she was not looking forward to being in a coffin after she died because “it’s scary in there.” This was the first time that dying as a prospective experience of ageing had arisen as part of the interview process and hence, was drawn into other later conversations. Discussions were also held with those who expressed interest in participating despite not meeting specific inclusion criteria. Emerging concepts or codes from the data were further explored with new and/or existing participants through subsequent follow-up.

Critically, it is important to identify the fact that the recruitment period for this study commenced in January 2012, following a series of major earthquakes between September 2010 and December 2011 in Christchurch and Canterbury region of New Zealand. The contextual impact of these events on recruitment needs further exploration: On the one hand it may have impacted upon peoples' willingness and ability to participate, and on the other hand it may have made awareness of ageing and mortality more salient. Of note, the recovery process for the region was still underway at the time of writing up this study.

Inclusion Criteria

In regard to ageing, the parameters for inclusion of adults with intellectual disability, was those aged 40 years or older (Taggart et al., 2012b).

(a) Group 1: Participants with intellectual disability

- Aged 40 years and over with a mild to moderate level of intellectual disability with verbal or aided expressive language and who could consent or assent to an interview on their own behalf.
- These participants were to have resided with someone they identified as family, whānau or carer (not classified as residential care) for at least five years.

(b) Group 2: Nominated family/whānau

- Family, whānau or carers from the individual's care-giving network were invited by the participants with intellectual disability to discuss their perspectives on supporting their family member who is ageing with intellectual disability.

Exclusion Criteria

- Individuals who were not fluent in English.

- People with an intellectual disability who were unable to communicate their participation and/or assent or consent on their own behalf.

Data Collection

There are a number of interconnecting features of data collection in grounded theory which occur both individually and concurrently. Memo writing, conducting interviews, concurrent data collection and analysis – all of which are also informed by theoretical sampling. The latter is evidenced by the number and type of participants as indicated earlier and seeks rich data which includes participants' "views, feelings, intentions and actions" (Charmaz, 2006, p. 14) as well as specific events, the content and context from whence the information is gleaned (Charmaz, 2014; Corbin & Strauss, 2008).

Memo Writing

This enabled the capturing of ideas, perceptions and interpretations alongside the research process. It is not simply limited to the process of data collection, but rather it reflects the concurrent interchanges which occur internally (cognitive processing) and externally (interactive engagement) to the researcher (Birks & Mills, 2011; Charmaz, 2006) and which collectively form part of the bank of data. Hence researcher memos are integral to the analysis process and indeed form part of the overall data. The process of memoing is an engagement with the data and a noted reflexivity of the research process in which codes and categories simultaneously develop a conceptual depth whilst maintaining fidelity to the context in which the truths were conceived (Charmaz, 2014).

Concurrent Data Collection and Analysis

Interview data were gathered by the researcher and initial coding was done between interviews to explore the emerging content and which allowed for the exploration of ideas through subsequent interviews (Starks & Trinidad, 2007). It was beneficial to do the initial data collection alongside participants who represented some form of heterogeneity (Hallberg, 2006); this provided a baseline for others, who formed part of the wider theoretical sample. Through this interweaving of theoretical sampling and concurrent data collection it was possible to explore whether the experiences that emerged for individuals and their family/whānau about living with, caring for and growing older – were only relevant to those in a core sample or whether they were reflective of a broader group.

Semi-structured Interviews

Semi-structured interviews allowed for the collection of complex formal data which had the potential to be intertwined with informal delicate and personal issues. Furthermore, allowing participants to place such information into a relevant context sought to reduce the risk of misunderstandings (Gilbert et al., 2008). In a nationwide study about successful ageing one New Zealand organisation gathered the perspectives of stakeholders regarding the elements required for future planning both for people who access service and their families (S. Brandford, Personal communication, 09 March, 2010). The interview guideline for this study was further developed following a review of the literature on existing quality-of-life and family quality-of-life questionnaires. The Family Life Interview (FLI) is based on ecocultural theory which identifies and locates the needs of the family in relation to the connections and conflicts that may exist between them, the neighbourhood and the wider community: It has test-retest

reliability with a confidence interval of 95% (Llewellyn et al., 2010b). The Family Quality of Life (FQOL-2006) questionnaire explores importance, opportunity, initiative, attainment, satisfaction and stability across the domains of family life; health, finances, family relationships, support from other people, supported from disability-related services, influences of values, careers and planning for careers, leisure and recreation, and community interaction. It is deemed useful for assessing the need for, and scope of, services in the community, has a moderate internal consistency (Werner et al., 2009) and informed the development of the interview guide for this study.

It is imperative in grounded theory not to be prescriptive about the format: Pre-determined open-ended questions served as a guide only for the purposes of prompting a starting point to facilitate the sharing of experiences; this allows the interviewer to be truly present, focus on the content and use that to illuminate the process (Charmaz, 2006). In developing the semi-structured interview guide, draft questions were discussed with individuals who have an intellectual disability to check their understanding and interpretation and to establish the strengths and weaknesses thereof (Northway et al., 2015). The aim of using semi-structured interviews therefore was to facilitate, compare and contrast the perspectives of each party currently and/or potentially involved in the dynamic of ageing namely, people with an intellectual disability themselves (Appendix 12) and/or their nominated family/whānau (Appendix 13).

For the purposes of this study, ascertaining personal perspectives about ageing from people with intellectual disability themselves was a key starting point and which were then examined in conjunction with the realities of their family/whānau/carers with regard to future planning: This allowed family quality of life elements to be captured and reported in the context of both the individual and collective viewpoint of participants. Demographic

data were obtained for each group of participants and included age, ethnicity and gender, relationship between the ageing individual with intellectual disability and the identified informant (Appendix 14 and 15). Critically, the interview process included the use of photo elicitation, and parameters were established for interviewing participants with intellectual disability regarding the relevance of their chosen image, photo or item (Appendix 16).

Photovoice & Photo Elicitation

Photography has been used in recent history as a form of ethnographic data collection in the field of anthropology (Haddon 1898 cited by Hockings, 2003). This has been developed into a technique called photovoice in which a key component is that research participants (usually comprised of communities) are given cameras to record real life realities (Wang & Pies, 2004). It is a participatory, qualitative, action research method with three main goals: To enable people to record and reflect on the strengths and concerns in a community; to promote dialogue and increase understanding about community issues and to reach policy makers. Whilst it has often been used with groups it has rarely been used in health domains.

More recently, photovoice has been used in a range of research approaches from exploring child and maternal health (Wang & Pies, 2004) to the experiences of people with long term conditions such as chronic pain (Baker & Wang, 2006), the health of populations in rural Guatemala (Cooper & Yarbrough, 2010), health promotion needs for people with intellectual disability, (Jurkowski, 2008) and indigenous communities in Canada (Castleden, Garvin, & First Nation, 2008). These authors found that photovoice can be used very well with a group of people in one location.

Research is limited however regarding the use of photovoice as a methodology for facilitating the inclusion and contribution of people with an intellectual disability in health research (Jurkowski & Paul-Ward, 2007). Given that this population group has some of the poorest health outcomes compared to the general population (Davis & Mohr, 2004) it was interesting to note that photovoice has not been more readily applied in this field. However, it is gaining in popularity as an inclusive participatory research method (Povee, Bishop & Roberts, 2014). Jurkowski and Paul-Ward (2007) for example, used photovoice to explore health promotion and planning opportunities for Latinos with an intellectual disability. Given the nature of the current research, the population, recruitment process, costs and the potential diversity of locations, there were ethical and logistical considerations about using photovoice in its purest sense (Booth & Booth, 2003; Povee et al., 2014). For example time, educational set-up needed for participants, access to and the cost of getting the camera equipment to prospective participants and issues of consent should photos intentionally or inadvertently may be taken of members of the public. Further considerations included recruitment, the geographical spread, potential age and influence of family members in taking photos, the development of and access to prints. Hence, the challenge was to find a way in which visual images could still be used as a valid part of this research process: To this end, photo elicitation was chosen.

Harper (2002) explored the origins of photo elicitation which are also known to be rooted in sociology and anthropology. As a term, photo elicitation was coined by John Collier (1957) whose roots were in visual anthropology who informed that:

[P]ictures elicited longer and more comprehensive interviews...helped subjects overcome the fatigue and repetition of conventional interviews... it [has an] ability to prod latent memory, to stimulate and release emotional statements about the informant's life... (p. 848)

The premise of photo elicitation is that whilst there is cognitive memory, photo elicitation has the added advantage of evoking visual memory; this connects the person to an emotions-based recollection of an event through which they identify what the event represents. Harper (2002) suggested that this method bridges the gap between researcher and participant as the information to be elicited is "anchored in an image that is already understood... and may lead an individual to a new view of their social existence" (p. 20-21). Further, it "capture[s] the tangible and intangible aspects of [people's] lives" (Clark-Ibáñez, 2004, p. 1509). This provides a potential shift in any power imbalance in research in that the authority to inform and direct the research now lies with the participant rather than the researcher (Harper, 1993). There is, a yet more fundamental rationale to use this method in a population already compromised. The regions of the brain that process visual information are evolutionarily older than those which process verbal information (Guillemain, 2004). Participants may thus respond more readily to the symbolic representation of the visual image. Guillemain (2004) explored the use of other visual media such as drawing and found it beneficial as a method in its own right or alongside of others used in social research. Visual media (regardless of shape and form) initiates a process of harnessing subjectivity (Cooper & Yarbrough, 2010) as the image connects experiences with memories.

The core premise of photovoice is that the participants themselves choose the photographic image, what is documented and the way in which it

can be used (Boxall & Ralph, 2009, p.47). It is a guided process that allows other media, other than verbal, to stimulate or articulate the conversation around a mutual topic of interest. To date, photo elicitation as a methodology has relied on the use of photographs however, Harper (2002) discussed that whilst photos are deemed to be more concrete, other visual images that include drawings, prints and objects can also provide the same vehicle that aids discourse and elucidation. Hence the use of photo elicitation directly improved accessibility to, and facilitation with, the research process and was a key element in theoretical sampling (Charmaz, 2006).

Ethics & photo elicitation

Ironically, whilst there has been an exponential increase in the range and accessibility of digital imagery, this poses additional considerations in terms of ethical approaches. In exploring such issues, Boxall and Ralph (2009) cautioned that limits in appropriate access to visual media on the internet may be a further limitation to the inclusion of marginalised or vulnerable population such as those with intellectual disability. They challenge the research community to understand and embrace this as a “moral obligation” (p. 45). For the purposes of this study, participants with intellectual disability who brought a photo, image or object to the research interview were required to consent for it to be included as part of the study: Where the photo belonged to someone other than the participant, consent was sought from this family/whānau member (Appendix 16). A photograph was taken of all the visual items included in this study so that participants retained possession of the original material at all times.

Phase One: Participant Interviews

Initial contact was made by the person or agency who had initially provided prospective participants with a copy of the *Plain Language Information Sheet* (Appendix 8) and an *Expression of Interest Form* (Appendix 10). On receipt of the *Expression of Interest Form*, direct contact was made by the principal researcher to arrange the initial meeting between the prospective participant, their family/whānau and the researcher. Up to three face-to-face contacts were made with each participant in Phase One in order to achieve the following:

- i. Undertake introductions; establishing some common ground was seen as one way of establishing rapport. One example saw the principal researcher informing participants about herself as a nurse in the disability field. The first meeting enabled the research process to be discussed with participants, issues or concerns could be clarified as well as reviewing and completing the *Consent Form* (Appendix 4).
- ii. Engage in a semi-structured interview (Appendix 12): As part of this process, photo elicitation was used to explore the concepts of ageing (Harper, 2002). Participants were invited to bring a photo, image or object to the meeting that helped them think about getting older or ageing. Engagement with or reference to the chosen media was not covered immediately within the interviews. Rather, the principal researcher drew this through later as it enabled the opportunity to talk about getting older both without and then inclusive of photo elicitation. In addition, two static images, unknown to participants, were introduced by the principal researcher towards the end of each interview. The rationale for this was to reveal how “tangible” (Clark-Ibáñez, 2004, p. 1509; Harper, 2000) ageing was for participants using the abstract pictures - compared with their chosen image.

- iii. Discussion regarding the interview. The option of reviewing the transcribed interview with each participant was provided to allow opportunity to check relevance, currency and validity of the content.

Phase Two: Family / Whānau Interviews

Each informant was either self-nominated (as they had responded to the advertisement about the study), although the majority were invited by a participant from phase one to engage in the research. Regarding the latter, they may have also been the support person for the interviewee with intellectual disability and would have received the *Information Sheet* (Appendix 9) and *Family/Whānau/Carer Consent Form* (Appendix 6) at this time. Alternatively these were emailed or posted to the nominated family/whānau who then followed up directly with the principal researcher. It was anticipated that the family/whānau/ carer might prefer to make a separate time to engage with the interview process as they may also be the person requested to provide support during the interview process for participants with an intellectual disability. It was evident in each of the interviews that the process of engaging with the research topic informed theoretical sampling as the focus of the interviews tended to develop as the study progressed. This was caused in part by the nature of the topic, which precipitated an (unintentional) intervention in that family/whānau started to discuss individual or collective ageing and/or the implications for the future in ways they had not considered previously. Techniques were used to confirm the data elicited during interview and/or additional information from the individual or group and included externalizing the experience or phenomena with reference to what others talked about. Critically, this was found to be empowering to them in that it asked what they would recommend to others who are in the same position (Schreiber & Stern, 2001).

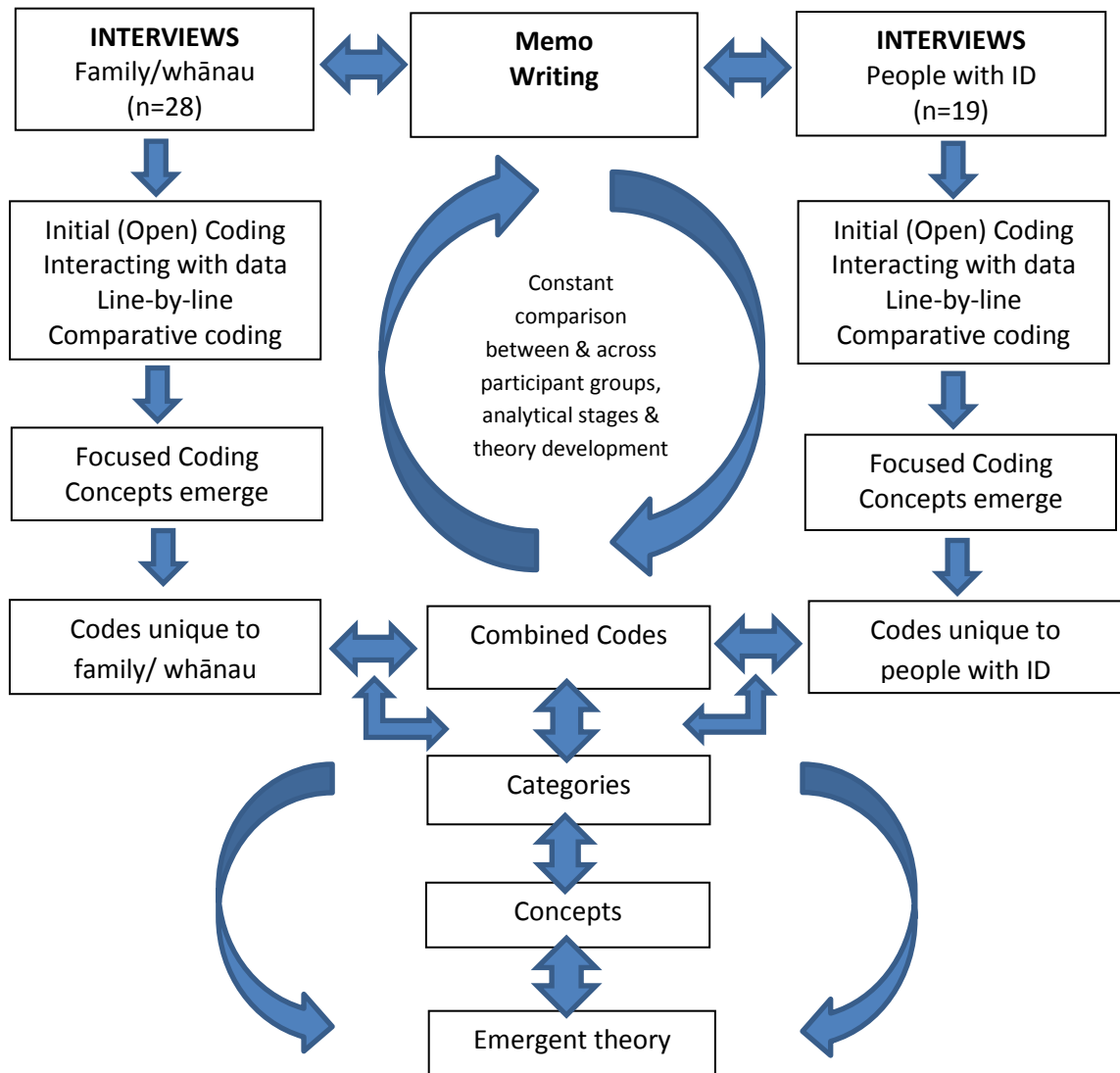
All participant interviews were digitally audio-recorded and transcribed verbatim by an independent person contracted by the University of Otago, Christchurch. The transcriber was required to complete a confidentiality form.

Data Analysis

In this section, the analysis is presented through a range of data collection points across the study (Figure 3). As stated earlier, photo elicitation (Harper, 2002) was used as a form of theoretical sampling to explore the subject of ageing alongside participants with intellectual disability. This method provided a vehicle to enable people with an intellectual disability (and other populations considered vulnerable) to more readily participate and contribute to the research process. Wang and Burris (1997) described a process of participatory analysis which involves three stages; (i) selecting the image(s), (ii) providing a context, and (iii) coding into themes (p. 380). In this study, this was done in a manner that enabled the participants to provide their own photo, image or object, and explored what it meant to them when thinking about getting older. Through the interactions between the participant and the researcher, this internal validation by the person was co-constructed into a commonly understood concept (Charmaz, 2006; 2014). In turn, the researcher then drew upon this within subsequent encounters for gathering further data and undertook this process externally by comparing, contrasting and coding the individual constructions alongside those of other participants. As separate processes, direct scientific claims cannot be made; however, the twofold process of internal and external replication of individual and collective construction was undertaken thereby

increasing the reliability, validity and trustworthiness of the emergent concepts in regards to ageing (Wang & Burris, 1997).

Figure 3: Constant Comparison Analytic Process



In keeping with ensuring reliability and validity all participants were also invited to review their transcribed interview. This was discussed both as part of the consent process and during the actual interview. Those who chose to do this were able to reflect on the meaning for themselves as to whether they were participants with intellectual disability or the nominated informant.

To illustrate the constant comparative approach and evidence the non-linear approach, there were five individual and interconnecting data sets in this study which comprised of:

1. Narrative interviews of people with intellectual disability.
2. Photo elicitation as part of the narrative interview for the above group.
3. Narrative interviews of family/whānau members.
4. Narrative interviews of parent(s) and others identified as family/whānau.
5. Narrative interviews of siblings.

The central component of the constant comparative process is illustrated in the above figure and occurred inductively across the data sets. The management of the data was undertaken as a manual process; a number of iterations were captured – initially through Excel spreadsheets and latterly in paper form: This determined that I stayed close to the data and consistently interacted with the data throughout the research process.

Constant Comparative Analysis

Mills et al., (2006a) refer to the process of coding through constant comparative analysis as necessitating the fracturing of the data: This process seeks to explore inter-relationships between the data and which enables it to be reassembled as the theory emerges. This ensures that the emerging codes and categories are grounded in the data (Charmaz, 2006; 2014). In this way, theoretical sensitivity is tested (where the data is checked against and towards an emerging core category) (Birks & Mills, 2011). A key part of this is to ensure reflexivity in separating out the influence of the researcher from that which is based on the data and corresponding relevant literature (Giles et al., 2013). Grounded theory that has been applied to data obtained through observation may include the use of recording media. From the perspective of

the researcher, "I act as an interpreter of the scene I observe, and as such I make it come to life for the reader, I grow it" (Stern, 2007, p. 115).

Codes are named in the active tense and are known as gerunds (Charmaz, 2006; 2011). These bring to life the actions and connections between the experiences of the participants within the research process by reflecting social and psychological processes and knowledge (Charmaz, 2011). "A code sets up a relationship with your data, and with your respondents... of what is this an example" is the question that must be consistently posed (Star in Bryant & Charmaz, 2010, p. 80). Codes are thus formed to stimulate the notion that whilst an experience in time has occurred, it is the gerund that evokes the notion that the experience is not a stagnant concept (Mills et al., 2006b): Critically codes (and what they represent) may be subject to change beyond the time and place in which they were originally conceived (Schreiber & Stern, 2001). Whilst conceptual in nature, advanced codes ultimately inform a core category but must also reflect the essence from which they were derived (Hallberg, 2006). Gerunds therefore induce sensitivity to emergent theory in which dynamic links are made with core ideas not previously seen, established or defined. Categories must evoke unique yet "crucial properties that make data meaningful and carry the analysis forward" (Charmaz, 20014, p.247) as it these which frame interpretation and inform relationships with the data. Iterations of the constant comparative analysis process were examined at regular intervals in conjunction with both academic supervisors as well as an expert in the field of intellectual disability. Such transparency of approach reflects the reflexive construction of the researcher with participants.

Initial coding

Glaser (1978) and Charmaz (2006) stated that data should be questioned and through initial coding one must challenge what is happening

and from whose viewpoint thereby enabling the researcher to remain receptive to emergent theory. In keeping with this requirement, several reviews of each interview transcript were undertaken. Words and phrases were highlighted and initial codes assigned. Memos informed both the historical and current context. Initially the visual images (both those provided by participants and the static images from the researcher) were separately coded to explore context and meaning. In this way increased familiarity with the realities articulated by each individual participant became evident. As previously noted, such coding enabled subjects to be identified that were then explored in subsequent interviews as part of theoretical sampling. The analysis was undertaken as a manual process which both informed and enabled the researcher to gain a greater appreciation of the data by frequently returning to the context from which content and depth emerged over time. Exposure to the data enabled the researcher to gain increased familiarity with the realities articulated by each participant. Furthermore, this process also identified content that could be explored further with subsequent participants and allowed for clarification to be sought as needed. Excerpts from interview transcripts were coded, and as part of the constant comparative process, were refined until data saturation occurred (Charmaz, 2014).

Focused coding

Focused codes, categories and concepts were mapped for each group and then the constant comparative process was followed as individual perspectives were then considered, compared and contrasted within and between groups. What was sought through this process was an exploration of the conditions in which the experience of ageing has (or was occurring) as well as establishing the relevant emotions and the impact of these (Corbin & Strauss, 2008). Thus, focused codes encapsulating similarities of perspective

became categories. Once again, categories were similarly analysed and concepts were formed (Charmaz, 2014). It is important to reiterate that this was not a linear process; this represents the constant comparative process across all levels of analysis. This constant comparative approach saw several iterations across combined and individual participant groups, the analytic process of which was captured and documented throughout using memos.

Theoretical development

Despite the arguments about the role of extant literature (to reduce access in predetermining possible constructions), Charmaz (2006; 2014) promotes the role of reflexivity in interpretive constructivism. Awareness of one's own theoretical sensitivity may be seen as an advantage within grounded theory as this identifies and enables the bracketing of existing expertise around the topic of concern and may invite greater objectivity (Birks & Mills, 2011; Giles et al., 2013; McGhee, Marland & Atkinson, 2007). As analysis in grounded theory is not a linear process, there is no defining point in constant comparative inquiry in which theory is said to emerge: Instead it represents an ongoing progression of evolving theoretical development until saturation is deemed to have occurred. The latter process ensures that grounded theory meets the social justice criteria of credibility, originality, resonance and usefulness (Charmaz, 2005; 2006). These elements safeguard the critiquing of the analysed data and emergent theory by revealing the nature of the substantive, logical and progressive contributions (Charmaz, 2005). In essence such research "is an integrated and comprehensive grounded theory that explains a process or scheme associated with a particular phenomenon" (Birks & Mills, 2011, p. 12).

Chapter Summary

The journey of grounded theory in relation to the current study has been positioned and informed by Charmaz's (2006) interpretive constructivist grounded theory approach. Through the interactive paradigms of axiology (transformative) and the ontology of relativism, which together underpinned the epistemology of constructivism, the applied relevance about meaningfully engaging with people considered vulnerable in research was made visible. The application of these paradigms have been explained through the interconnecting stages of the methods from theoretical sampling, memoing to the constant comparative analytic approach. These interconnecting stages individually and collectively allow for reflexivity in ensuring reliability, validity and trustworthiness throughout the research process. What follows are four results chapters; these illustrate the individual and collective findings informed by the subjective and objective constructions of ageing and perspectives about future considerations. Chapter four provides a descriptive narrative of the demographic data of research participants. *Riding the Waves* (the first of three categories) is reported in chapter five, *Shifting Sands- Changing Tides* in chapter six, and chapter seven brings together the remaining concepts which constitute *Uncovering Horizons*. At the end of the latter chapter, the emergent theoretical model is then presented.

CHAPTER 4

RESULTS

“The future depends on what we do in the present” (Mahatma Ghandi)

Introduction

The results of the current study are arranged into chapters (four through to eight inclusive) and each distils and presents the individual perspectives and those collectively co-constructed about ageing and future planning for the participants. At the outset of this study two participant groups were initially considered - people with intellectual disability and those they nominated as family/whānau. As the constant comparative process of analysis unfolded it became apparent that the roles, experiences and perspectives of siblings were unique to the wider family/whānau and illustrated an important contribution to the caregiving dynamic. There are key findings central to each group – yet, despite the perceived differences there are also intersecting, previously undiscovered commonalities which inform each party’s viewpoint in this unique system of care. This discovery exemplifies the application of the grounded theory approach which enabled the “hierarchies of power, communication and opportunity” to be explored in terms of those which “maintain and perpetuate such differences and distinctions” (Charmaz, 2014, p. 240) between and within each participant group involved in the caregiving system.

This chapter commences with a summary of the interview arrangements (Table 1), pseudonyms and relationships of participants (Table 2), demographic information of participants with intellectual disability themselves (Table 3) and finally, the demographic information of the

family/whānau participants (Table 4). For the latter, the interpretations of the connections they made when thinking about getting older are presented through the use of photo elicitation which both facilitated the construction of ageing as an idea and demonstrated the relevance of using photo elicitation with this population. The subjective relevance has been represented through the analysis of these images and integrated as part of the narrative interviews. The narrative interviews also provided a rich source of tacit meanings, the dynamics of which are illustrated through the metaphorical gerunds used. Such interpretation elucidates a depth of emotion and experience which reflects the dynamic nature of an experience (Charmaz, 2014; Fetterman, Bair, Werth, Landkammer & Robinson, 2015). An introduction to each the three co-constructed concepts is therefore provided namely; *Riding the waves*; *Shifting sands – Changing tides* and *Uncovering horizons*. Each of these is built upon a foundation of interrelated codes which form eight core categories. As each chapter progresses the meaning and intensity of each concept is defined and refined by examples from the data itself thereby illuminating perspectives and experiences which traverse both time and participants and resulted in an emergent model, *Navigating Ever-Changing Seas*.

Summary of Data Collection

Three people who responded to the invitation to participate, were ineligible to do so. Two were siblings of persons with intellectual disability and the third a parent. For one of the interested parties, they were outside of the region covered by the ethical approval, whereas for the others, their family member with intellectual disability had already been in full-time care for a number of years. A total of 58 interviews were undertaken to complete the semi-structured interviews with 47 participants. For those with an intellectual disability, five individuals requested to undertake the consent

process and interview within one meeting, and the remaining 14 over two meetings. The duration of the interview component of each meeting ranged from 30 to 139 minutes, with a mean of 61.68 minutes each. Table 1 illustrates how participants with intellectual disability chose to be interviewed: Six individuals undertook the interview independent of others, seven with a family/whānau member and a further six with other supports. With the exception of two participants, all chose to be interviewed within their own home. Twenty-eight encounters were undertaken with family/whānau participants and a similar timeframe was noted for the duration of the meeting (30-154 minutes) with a mean of 76.25 minutes.

Table 1. Summary of Interview Arrangements

<i>Variable</i>	<i>Number</i>
Total number of interviews	(n=47)
Participants with intellectual disability	(n=19)
Participants as nominated family member/s	(n=28)
Interviews of people with intellectual disability with family	(n=7)
Interviews of people with intellectual disability with other supports	(n=6)
Interviews of people with intellectual disability independent of others	(n=6)

Eleven participants with intellectual disability nominated one person in their family/whānau network to be invited to contribute to the study. The remaining eight participants chose more than one person. The range of relationships comprised of mother, father, brother, sister, sister-in-law, friend and aunt. In presenting the findings, pseudonyms are used which were chosen by, or given to participants and are listed below with the relationship between them provided (Table 2). For two families, one or other declined to participate: Bobby's sister and Lorraine's son. Hence for each of their encounters the voice of the family and the person with intellectual disability themselves respectively were not available for this study.

Table 2. Pseudonyms & Relationships of Participants

<i>Participant with ID</i>	<i>Family/Whānau</i>	<i>Relationship</i>
1. Samantha	Stephanie	Friend
2. Trevor	Adrienne	Sister
3. Bobby	<i>Declined</i>	<i>Sister</i>
4. Peter	Barbara & Jack	Parents
5. Leslie	Susanne	Mother
6. Kate	Isabelle & Richard	Parents
7. Frank	Natalie	Mother
	Eleanor	Sister
	Karina	Sister
8. Carol	Evelyn	Mother
	Mackenzie	Sister
9. Maddie	Carmen	Mother
	Deborah	Sister
10. Samuel	Maryellen	Mother
11. Stephen	Elsbeth & Murray	Parents
12. <i>Declined</i>	Lorraine	Mother
13. Preston	Julianne	Sister
14. Pauline	Jeremy & Mavis	Brother & Sister-in-law
15. Jacob	Melody	Mother
16. Jeffery	Alberta	Mother
	Rebecca	Sister
17. Mitchell	Melissa	Aunt
18. Jamie	David & Edith	Friends
19. Tony	Teresa	Sister
20. Cyril	Deirdre	Mother (<i>Withdrew</i>)

Demographic Data: Participants with Intellectual Disability

Nineteen persons with intellectual disability participated in the study; thirteen males and six females (Table 3). They ranged in age from thirty-seven to fifty-eight years of age; ten were between forty to forty-nine years and seven were in the fifty to fifty-nine year old age bracket. Seventeen participants identified as New Zealand European and the remaining two participants as Cook Island and Indian; they came from a range of locations across Canterbury, the West Coast and Marlborough regions of the South Island in New Zealand.

Table 3. Demographic data – Person with intellectual disability

<i>Variable</i>	<i>Type</i>	<i>Number (n=19)</i>
<i>Gender</i>	Male	13
	Female	6
<i>Age</i>	Range (37-58 years)	
	Mean (48 Years)	
	< 40 years	2
	40 – 49 years	10
	50 – 59 years	7
<i>Ethnicity</i>	NZ European	17
	Cook Island	1
	Indian	1
<i>Axis 1</i>	Anxiety	1
<i>Diagnosis</i>	Depression	3
	Borderline Personality Disorder & PTSD	1
<i>Axis 2</i>	Cerebral Palsy	2
	Spina Bifida	1
	Down Syndrome	6
	Arnold Chiari Syndrome	1
	Autistic Spectrum Disorder	1
	Intellectual Disability (Only)	10
<i>Physical Health</i>	Range of co-morbidities (0-4)	
	Asthma	2
	Allergies	2
	Epilepsy	2
	Arthritis	2
	High blood pressure	3
	Heart Murmur; Migraines; Pericardial Effusion; Diabetes;	1
	Hepatitis B; Neurofibromatosis; Hernia; ‘Superbug’; Diverticular Bladder; Hypothyroidism; Hirschsprung’s Disease;	(each)
<i>Living Situation</i>	Mother	9
	Parents	4
	Friend	1
	Sister	1
	Aunt	1
	Brother & Sister-in-law	1
	Other (Shared care / Supported Independent Living[SIL])	2
<i>Length of Time</i>	All their life	12
<i>Residing Together</i>	5 – 10 years	2
	11 – 20 years	1
	21 – 30 years	2
	N/A Other (Shared care/ SIL)	2

Ten participants self-identified as having a diagnosis of intellectual disability only, and the remaining participants either stated or were informed by their family/whānau that they had intellectual disability with one or more of the following; Autistic Spectrum Disorder, Spina Bifida, Arnold Chiari Syndrome, Cerebral Palsy (n=2) or Down Syndrome (n=6). Of note, only one participant had a formal psychometric assessment resulting in a diagnosis of mild intellectual disability. There are limitations as to the diagnostic data available in New Zealand – especially for older persons with intellectual disability. The reliability of the diagnostic label however that this was the case for the participants in this study is indicated by being in receipt of services targeted to people with intellectual disability over the course of the lifespan due to known functional and adaptive indicators including educational achievement.

Physical well-being played a significant role in people's lives as the range of co-morbidities in addition to the above was zero (n=3) to four (n=16). For the following conditions there were a total of two participants with each condition; asthma, allergies, epilepsy and arthritis. Three people identified as receiving treatment for hypertension and one person per condition was noted for the following; heart murmur, migraines, diabetes, pericardial effusion, hepatitis B, neurofibromatosis, hernia, diverticular bladder, Hirschsprung's disease, 'superbug' (not specified) and hypothyroidism. In terms of mental health challenges, one person self-reported they had a diagnosis of anxiety, another borderline personality disorder and post-traumatic stress disorder and three persons stated that they also experienced depression.

In terms of living situations with family/whānau; four people (21%) lived with both parents, nine with their mother (47%), one person lived with

their aunt, another their sister, and a third with their brother and sister-in-law. One participant lived in a flatting situation with a friend who was identified as akin to family. Two participants were living in other settings namely supported independent living (SIL) and the other in a shared care arrangement. The length of time individuals had lived within the identified settings ranged from five to ten years (n=2), eleven to twenty years (n=1), twenty-one to thirty years (n=2) and all their life (n=12). For the two remaining participants in other settings, the timeframe was not able to be defined although was thought to be more than five years in duration.

Demographic Data: Family / Whānau

A total of 28 family/whānau were nominated to be interviewed by participants with the intellectual disability. Five males and 23 females were comprised of friends (n=3), mothers (n=11), fathers (n=3), sisters (n=9), one brother-in-law and an aunt. Half this group were over 70 years of age, six were 61-70 years old, two indicated 51-60 years of age, three were 41-50 years old, two stated they were in the 25-40 year age bracket and one family member was under 25 years of age. Fifteen had lived all their lives with their family member with intellectual disability. Of note, 17 participants in this group received a government funded pension, six were wage or salary earners, two family/whānau were on an invalid's or disability benefit and another was a recipient of a student allowance. One person was self-employed, and the type of income for the remaining two participants was not specified.

Thirteen of the family/whānau participants were married, four were single and a further four were divorced. Two participants were separated and the same number were in a de-facto relationship.

Table 4: Demographic Data – Family / Whānau

<i>Variable</i>	<i>Type</i>	<i>Number (n=28)</i>
<i>Gender</i>	Male	5
	Female	23
<i>Age</i>	Range (20-83 Years)	
	< 25 years	1
	25 – 40 years	2
	41 – 50 years	3
	51 – 60 years	2
	61 – 70 years	6
	> 70 years	14
<i>Ethnicity</i>	NZ European	24
	Cook Island	1
	Other (Canadian, South African, Dutch)	3
<i>Axis 1 Diagnosis</i>	Phobia	1
	Depression	2
	Bo-Polar Disorder	1
<i>Physical Health</i>	Range of issues (0 – 6)	
	Good	21
	Fair	6
	Poor	1
<i>Highest Qualification</i>	Nil	6
	Secondary School	8
	Certificate / Diploma / Trade	6
	University Degree	6
	Other	2
<i>Marital Status</i>	Single	4
	Married	13
	Divorced	4
	Widowed	3
	De-facto	2
	Separated	2
<i>Income</i>	NZ Superannuation	17
	Student Allowance	1
	Invalid's & Disability Benefit	2
	Wage / Salary Earner	6
	Self-employed	1
	Other	2
<i>Length of Time Residing Together</i>	All their life	15
	5 – 10 years	4
	11 – 20 years	3
	21 – 30 years	3
	N/A Other (Shared Care / SIL)	3
<i>Relationship</i>	Friend	3
	Mother	11
	Father	3
	Sister (Includes sister-in-law)	9
	Brother	1
	Aunt	1

<i>Carer Support</i>	Yes Allocated (Range 20 – 103 days / year)	14
	Not able to use	5
	Nil allocated	2
	Non-applicable	3

The remaining three individuals were widowed. Of note, only 14 of the 19 families indicated that they received an annual allocation of carer support days (respite) five of whom advised they are not able to use them. Two families had no allocation whereas three considered this to be non-applicable. The health of family/whānau participants was also explored. They were asked to rate their health as good, fair or poor. Fourteen participants did not identify any specific health issues – including one person who indicated their health was poor. However, of the 21 family members who reported good health, two identified as having hypertension, and other individuals experienced one or more of the following; cholesterol, angina, Parkinson’s disease, arthritis, glaucoma, diabetes, depression, respiratory issues, memory issues, cardiac (not otherwise specified), and visual impairment. Within the group who stated their health was fair, the following conditions were self-reported; Parkinson’s disease, bi-polar disorder, cardiac issues, hypertension, eyesight, neurofibromatosis, depression, anxiety, phobias, and hypothyroidism.

Co-constructed Theoretical Concepts

The analysis of the 47 transcribed interviews was undertaken by comparing and contrasting the contextual data which formed the descriptive codes for participants with an intellectual disability and family/whānau. This same process of comparing and contrasting emergent descriptive codes continued and established the individual codes for, and commonalities between, each participant group. As this process of comparing and contrasting was occurring, advanced codes emerged which, on further analysis were synthesised to eight categories namely; Reciprocating

relationships, Emerging independence, Taking cognisance, Configuring ageing, Anticipating change, Entertaining possibilities, Creating a good life and Mastering decisions. In turn, from these categories three inductively co-constructed interpretive concepts were formed: *Riding the Waves*, *Shifting Sands – Changing Tides* and *Uncovering Horizons* (Table 5).

Table 5. Summary of Findings

<i>Codes</i>	<i>Categories</i>	<i>Concepts</i>	<i>Emergent Model</i>
Conceptualising family			
Continuing the duty	Reciprocating relationships		
Reflecting on roles			
Providing companionship			
Valuing autonomy	Emerging (in)dependence	Riding the Waves	
Acquiring skills			
Maintaining status quo			
Accommodating the disability	Taking cognisance		
Conflicting perspectives			
Rationalising the reality			
Reaching saturation			
Defining ageing	Configuring ageing		
Recognising altered function			
Dying is part of living			
Looming responsibilities	Anticipating change	Shifting Sands - Changing Tides	
Limiting factors			
Feeling disillusioned			
Letting go – Enabling others			
Unknowing explorers	Entertaining possibilities		
Evolving expectations			
Looking forward			
Changing circumstances	Creating a good life	Uncovering Horizons	
Having an identity			
Enjoying living			
Keeping well	Mastering decisions		
Connecting with others			
Knowing the person			
Facilitating ownership			
Engaging the system			

An added dimension to the data collection and analysis was the utilisation of photo elicitation with participants who have an intellectual disability. This approach both informed and facilitated data collection as part of theoretical sampling in terms of content rather than solely diversity of the included sample. The rationale for this was to provide the opportunity to both deepen and enhance the contributions of participants with intellectual disability with reference to something familiar and which bridged a range of abstract ideas within the study. Hence analysis of the data specific to the photos, images or objects proffered was undertaken in conjunction with, and integrated alongside of, the narrative interviews.

Riding the waves is comprised of three categories namely; Reciprocating relationships, Emerging (in)dependence and Taking cognisance. The codes which inform these represent the ebb and flow of relationships over time, the simple fact of being alongside and working with others of significance as one takes things as they come. Whilst some took stock of this, the majority of participants simply kept on with life as they knew it. *Shifting sands – Changing tides* however, reflected greater cognitive movement as participants were engaged with Configuring ageing and Anticipating change. These categories allow both the conceptualisation of what getting older may be like, and the factors which inform one's position or perspective about the inevitability of a future. Finally, *Uncovering horizons* reflects the permission-giving that participants may have for themselves or others to fathom something beyond the now through; Entertaining possibilities, Creating a good life and Mastering decisions. All of the latter are important facets of safeguarding and enabling the future to become a reality for all concerned. It is acknowledged that whilst these concepts appear to imply a linear and longitudinal process, this is by no means the case. Rather, the emerging theoretical model of *Navigating Ever-Changing Seas* embodies a multi-directional dynamic and

demonstrates an interconnectedness within and between the three concepts, and which informs the cyclical nature of relationships changing and time passing.

Aside from the combined viewpoints, unique properties were also uncovered for each group of participants; people with intellectual disability, family/whānau, as well as the siblings themselves whose contributions unveiled a distinctive lens. (Please note, unless there is a separate reference to the siblings as a distinguishable group, they are included as family/whānau). These viewpoints and properties reflect their experiences, perceived and/or anticipated expectations of ageing in regards to the future for themselves, each other, and/or service systems. Each of the subsequent chapters presents one of the aforementioned concepts. The links between the respective categories, and the advanced codes which informed them are explained in reference to examples from the transcribed data of the individual and combined participant groups. Of note, the impressions of all parties are evidenced including those of siblings to illustrate their unique outlook within the family/whānau system of caregiving. Chapter five presents the first of the three concepts – *Riding the Waves*.

CHAPTER 5

RIDING THE WAVES

Introduction

Riding the Waves is the first of the three concepts, and is defined as getting on with life from day to day by taking things as they come. It is comprised of three categories, which stemmed from a total of eleven focused codes. This is neither a stagnant state nor an impartial approach to life; rather, the waves represent the recognition of the challenges and opportunities that one must go through and have already experienced across the lifespan. *Riding the Waves* exemplifies and describes the continuous ebb and flow of relationships and interconnectedness experienced by the participants; it was seen to manifest through living alongside one another and was representative of each being with and to others over time. The ways in which this manifested for all participants was through the categories of *Reciprocating relationships* and *Emerging (in)dependence*. For family/whānau the interview provided an additional opportunity for *Taking cognisance* of the existing arrangements; the latter category explores their current realities in regard to caregiving roles and responsibilities (Appendix 17: Riding the Waves).

Reciprocating Relationships

Riding the waves evokes a personal quality and resilience, both of which emerge from the recognition and identification first and foremost of the strength of the bonds within the respective relationships which promoted this constant action. Instilled, derived or acquired roles were seen to denote connections within the caregiving system of support: Who is taking care of whom is the phenomenon that is the focus for this category of *Reciprocating*

relationships. The shifts between participant perspectives were filtered and reflected in the codes which form this concept and as such are based on the relationship-bonds that participants explained and which was coded as *Conceptualising family*. It is these connections which initiated and motivated members to be seen as *Continuing the duty* whilst simultaneously *Reflecting on roles*. It is important to recognise that such roles can be either ascribed or subscribed. These elements of reciprocal interaction were demonstrated by one or other party continuing their duty, reflecting on established roles, and which often resulted in *Providing companionship* for one or more parties in the caregiving relationship.

Table 6. Riding the Waves (Appendix 17: Summary of Examples)

<i>Code</i>	<i>Category</i>	<i>Concept</i>
Conceptualising family		
Continuing the duty	Reciprocating relationships	
Reflecting on roles		
Providing companionship		
Valuing autonomy		Riding the Waves
Acquiring skills	Emerging (in)dependence	
Maintaining status quo		
Accommodating the disability		
Conflicting perspectives	Taking cognisance	
Rationalising the reality		
Reaching saturation		

Conceptualising Family

What constituted family/whānau for individuals and their significant others was found to have developed over a considerable time involving both proximity and experiences. The defining sense of conceptualising connectedness with persons who fitted the ideal family or actual family was seen to be informed by memories or perceptions of missing out, stigma, isolation or that which represented the qualities expected when someone is called family. Whilst some of these experiences were negative for participants, others were laced with a firm conviction that, when all is said and done, nothing else comes close to or measures up to that which is conceptualised as family. The ability to recognise such associations is directly linked with one's role and responsiveness to engage in the *Reciprocating relationship*.

Nine parents and one aunt spoke about the perceived social shame that was experienced as a result of having a family member with an intellectual disability as the expectation at the time was to place children with intellectual disabilities into an institution. Evelyn was adamant that the latter was not an option for her daughter when, at two to three days old, her own mother offered to find a place; *"she [mother] got a very short sharp answer. But that was the thinking... you put them away..."* The impact and reality for parents and the family as to what or who could not be family was also acknowledged.

Susanne and Carmen respectively admitted feeling;

...a bit of self-pity sometimes... people staring... Nobody knew what Downs Syndrome was... [son] got into fights because someone would say your sister hasn't got a brain... (Susanne, mother)

I make excuses for her...sometimes I feel embarrassed by her, and I feel real bad about that. She embarrasses me, her behaviour and I do struggle with that.
(Carmen, mother)

For all family/whānau there was an acknowledged acceptance now in later years about not being invited out, of people making fun or professionals predicting the trajectory of the limitations that were to befall their family member. Without exception they all identified a point at which their role became one of informing, respecting and enabling, of seeking participation and opportunities for their family member to access the community. Five examples are evidenced below:

Now they haven't got a workshop anymore... things are not always planned out... He wants real things to do...he's missed out on a lot of learning and I would like him to have every opportunity. (Barbara, mother)

We always felt he needed to be socially acceptable... had he been given the opportunity that [literacy] would have been possible. (Elspeth, mother)

People have to talk plain English to Maddie and if I go to appointments with her at the hospital or whatever I say look she's got a disability, use plain words. You can't use fancy medical words... (Carmen, Mother)

And the doctor, who was lovely, came in and she said to me I want you to sign this [consent for operation]... and I said no I won't sign it. She was horrified... Not my choice, [daughter's] choice.... I said I was only trying you out to see what your reaction was. She said well I would have signed it if you wouldn't. (Evelyn, mother)

What got me frustrated... was the [institution would] say that I [Aunty] wasn't a suitable person to have him... social welfare said [nephew] can go to riding for the disabled – won't help him any... he used to sit on that horse almost lying down... but then he learned to sit up. (Melissa, aunt)

A tenth parent expressed her grief: Since the death of her own parents, she no longer had family who she could call upon to support or assist her in her caregiving role. Despite this, her son continued to be an integral part of her family.

...my family don't help me... Mum and Dad were the only ones that used to... I'd never really thought about it – he's always been there [son aged 49]. (Maryellen, mother)

Deborah (sister) was very clear that she did not want to become a carer in the future as first and foremost, she is a daughter and a sister. Whereas Mavis, who was already ensconced in the caregiving role, acknowledged that for them her sister-in-law with intellectual disability comes first; at times this means they miss out on family occasions should she not be willing to get out of the house. However when they do, unfortunately none of the wider family are willing to provide the level of personal care needed and which has challenged their concept and connection with their family/whānau ;

...when I came back [from a walk], here was Pauline in the toilet and nobody wanted to go in...she had to sit there and wait til I came home... They [other family] were laughing and saying I'm not going in there..." (Mavis, sister-in-law)

The awareness of giving up or losing out on what may be deemed normal milestones or having quality time with friends, parents or other family/whānau raised deep seated hurt for many participants. Mackenzie for example commented that her sister was always “*Mum’s plus one, we never get a look in – it’s always her.*” Having to leave school for example had an impact upon Julianne’s willingness as she was now in the role of shoring up the family in looking out for her mother and brother.

...not being heard is a big deal for me... I suppose my way of coping with things was to just box on... I was frustrated by more or less having to leave [school] because of financial pressures... I guess having Preston [brother] was sort of a drag in a way because... the relationship had always been more like – a parent to child because I was already babysitting Mum a lot of the time really.

These reflections were summed up by a fourth sibling who commented;

Sometimes I feel a bit why, why do we have to have him? But then I think every family’s got something...” (Karina, sister)

A fifth sibling simply saw this as part of growing up in family/whānau:

I don’t know what it would be like to have a ‘normal’ little brother... I would be telling lies if I didn’t say there have been times that I’ve wished – it was different... you go through a stage where it’s a bit embarrassing... some people would be downright horrible... absolutely awful.” (Rebecca, sister)

The narratives frequently revealed a duality of family/whānau connectedness: Siblings equally balanced their negative perspectives by also

being the strongest advocates for (and protectors) of their family member with intellectual disability when they encountered negative or stigmatising attitudes in others in the community. Jeremy remarked that when he would go and drop his sister off for respite *“it was dynamite... you feel like you are abandoning her.”* The latter shows an example of family role and duty. In a casino for example, when staff refused to talk to their family member with intellectual disability, MacKenzie (sister) responded that *“it’s her money, she’s making the decisions... this guy got replaced... and they came back and apologised.”* Closer to home, Deborah (sister) would be proactive and forewarn friends visiting the house about her sister by explaining she has *“an intellectual disability and she might say stuff that seems rude, but don’t take it to heart, it’s just who she is, she doesn’t necessarily mean it.”* Acceptance within families extended to Melissa’s recounting of her nephew’s experience of his brother Mitchell when he took him out to a nightclub, who, when he saw Mitchell enjoying himself and socialising realised that he *“was a person.”* Whilst siblings often saw themselves as missing out, the potential impact that having both a disability and a longstanding caregiving role may have on their family member with intellectual disability was also recognised. Adrienne reflected upon what her brother has either given up or may have missed out on:

My only, one concern I do have is that when Mum dies he [brother] might become just so much better and that would have happened years ago if they had been separated... in which case we might feel guilty about perhaps not breaking them up earlier [as] he will enjoy not being hen pecked all the time...” (Adrienne, sister)

Two participants with intellectual disability regarded their friend(s) as their family/whānau, and invited them to participate in the study: Samantha

described the meaning of the relationship one would expect from family/whānau and ascribed it to her friend:

I trust her more than family... She's my next-of-kin at the hospital... I said to Mum you've never been family since I was 10... you don't even know me..." (Samantha)

Family/whānau were also described by four others with intellectual disability in terms of the existence of an extended biological relationship. Two participants nominated nephews as people they could possibly make contact with should they need help. Preston commented:

I don't ring my nephews as much because you know they've got their own family... occasionally one might drop in because his son likes to see my train... I've asked Julianne [sister] could they help with doing the window seals... a bit of sanding of, possibly putting a new coat of paint...

Maddie believed that if she had a Dad, then she would have a family. The person she describes is a father which is different to a Dad:

He doesn't deserve to be called Dad at the moment... [A good Dad is] someone who is there every day.

How 'family' is conceptualised by individuals also emerged through photo elicitation as memories of people, places and roles were identified in relation to themselves. Who is important in one's life was signified in the stories shared by Jamie who brought a photo of himself with seven of his siblings. He described those he is estranged from as "*they don't come and see me*" and those

with whom he feels a connection now and into the future *“that’s all I have... they are important to me those two...”*

Figure 4. Carol and her Grandfather



Carol’s photo of herself with her Grandfather (Figure 4) reminded her that he built her a *“house in a tree”* and over the years, that he *“helped my Dad... on the farm.”* The connectedness of recalling roles (and inheriting reciprocal new roles) was overt in the memory Preston had of his father who was *“my rock as well – of course now I’m sort of rock for Mum...”* It was clear from all participants that the concept of family is not a static entity and

was jointly formed by experiences that were both external and internal to the family unit. Over time perspectives were shaped and their narrative demonstrated how the concept of *Riding the waves* influenced the interconnectedness between those conceived and deemed to be family/whānau. The category of *Reciprocating relationships* was thus seen to provide the foundations for relationships conceptualised as family/whānau and which then influenced the uptake of instilled roles which saw participants *Continuing the duty* of caregiving.

Continuing the Duty

Participants showed a degree of emerging awareness in their need to identify and maintain the caregiving position was either intrinsic, had been instilled, acquired or was evolving. This was demonstrated by the manner in which one was seen to be *Continuing the duty*, either by modelling expectations from those still in the primary caregiving role or by transitioning into it through time, space and circumstance. The narrative findings which form this code stemmed from family/whānau (including the seven siblings), as well as participants with intellectual disability. It is important to note that whilst some did not necessarily begrudge this 'dutiful' relationship, many were not cognisant of how they came to be continuing the duty, the point at which it was defined or whether in fact they had made an active choice in its undertaking. Notwithstanding, it was seen as an inherent necessity to all participants for a range of reasons.

The sense of duty clearly underpinned the need for at least nine parents to maintain the constructive role of a parent for day-to-day care. The age of the 'child' was irrelevant, and in part, it was something they recognised they had 'signed' up for long ago. For Lorraine (mother) it surmounted to "*just being here for him*" yet for others there were other parameters about why they are continuing the duty:

I feel it is my duty and I must do it... The first two times I sent her [to respite care] I felt as though I'd deserted her... They won't understand how I look after her. (Susanne, mother)

For me I've still got a child. I'll always have a child who is dependent. (Evelyn, mother)

I don't know, you just carry on and you don't stop to think. You get up in the morning and think well I've got another day ahead of me... (Alberta, mother)

Continuing the duty was recognised as a limitation by some family/whānau, and yet whilst this was identified as such, there was still neither scope nor discussion about how things could be different. For Barbara and Jack (Parents), whilst they hoped that would be able to continue for at least another five years, they also commented that:

We're very tied, coz we're home always...we can't just get away for a few days. Unless he goes away somewhere it's not easy to get someone to [look after their son] ...normally I put his clothes out for him, not as much now as I used to... He doesn't always know how to choose [his clothes]...

For siblings, the undertaking of this duty was more clearly defined and was based upon their situation or position within the family/whānau, picking up where parents had left off or, quite simply, being responsive to changing situations therein.

...mother does it [caregiving] to an extent... but for me there's just about something to be done every day for [brother], just about every day... (Adrienne, sister)

When my step-father [died]... he had done everything for them [mother and brother]... at first I was kind of the disapproving big sister – didn't fully understand [brother's] problems..." (Julianne, sister)

*She was a little doll...[Father] would probably be the one who mothered her...
No you can't get her to move out of that chair. Worst thing we ever did... [try
and replicate parental role]. (Jeremy, brother)*

*I said to Mum – you don't realise how much you do for him... how much you
oversee it and you put things in place for him to be able to look after himself.
(Rebecca, sister)*

*I felt obligated that it's my duty as the oldest one...my parents are gone. It's
up to me to look after my brother not anyone else... 90% of the choice is
mine... (Teresa, sister)*

For the three non-biological family/whānau members, there were similarities in their sense of duty both in relation to their friend as well as other caregiving responsibilities. Stephanie (friend) for example noted that she whilst had a sister...

*...she doesn't see Mum... So that makes life difficult too... it's a shame she
doesn't want anything to do with us but we've decided that's her choice... You
just have to get on with it...I touch base with [Mum] every day.*

Continuing the duty was also a highly emotive issue for six participants with intellectual disability as they demonstrated an awareness of a lack of choice about the responsibilities placed on them by significant others. These individuals felt resigned or trapped in what seemed to be a designated role as all that mattered was the here-and-now as is demonstrated in the following examples.

It was a case of having [live at home] to because of Mum's health. I had to stay living with her... I didn't have a choice no. (Bobby)

Probably no, not at the beginning [choice about staying at home]... I sort of had to be the man of the house [after Dad died]... Sometimes it is like a train station – people coming in and going... It is just the way it is for the time being until such time it all passes on... (Preston)

Ironically, whilst the sibling quoted previously (Adrienne) commented that there was something to be done every day for her brother (with intellectual disability) and their mother with whom he lives, his perspective below provided a unique contrast. Clearly being the eldest in the family/whānau demanded this sense of personal duty for another:

If anything happens [sister] gives us a ring to say 'will you do this?' I'm the older one... but sometimes they come over... and suggest anything they might like me to do... Sometimes I feel I could belt them up! No, it's not worth it...I wish it was someone else that could be older, not me... someone has to be responsible for Mum, might as well be me. (Trevor)

For Mitchell, his sense of responsibility was heightened as he experiences significant physical and communication impairments; he noted that he gets worried (about his ability to care) for his aunt who is over 70 years of age. Not only is she his primary caregiver, but “if she knocks something or fall over... [I] press alarm.”

In *Continuing the duty* within the caregiving relationship there was a sense of both acceptance and resignation to what was currently happening and/or required. Individuals and groups portrayed a tangible sense of having

to just get on with it by *Riding the Waves* of extrinsic expectations and intrinsic duty. Through this process a number of roles emerged, which were named by participants in this study and will be seen to be brought together through the next code.

Reflecting on Roles

Within the caregiving relationship, roles were sometimes neither nominated nor isolated, and whilst significant, were often hidden within reciprocal interactions. This code provides an insight to the current and/or anticipated roles undertaken by the majority of participants and itemises the components of the roles which comprised the duty of caregiving. Reflecting on these roles enabled a space for them to be both vocalised by participants and acknowledged by others within the network of support. Whether by choice, chance or evolution over time, naming roles provided an important reflection of who does what in this context.

Thirteen participants with intellectual disability identified key roles or tasks which they saw as necessary for them to undertake in order to maintain the reciprocal relationship alongside their family/whānau with whom they lived. Trevor and Bobby each noted that they vacuum, tidy their room, hang out washing, do the lawns, ensured their mother got her medication and were simply there.

She's blind she can't see but if anything happens I've got various telephone numbers I can use... if anything happens... she may snooze a bit and I zip out & water the garden...and zip back in again & see if she's alright and go out again... (Trevor)

Five participants stated that they were involved in preparing or cooking meals, Maddie provided care to younger siblings and Peter managed the firewood and would seek help for his parents if needed from a friend, neighbours or *“if Mother wasn’t feeling well, I would call an ambulance.”*

I started to vacuum, I cook, I give Mum some pills she has to take to keep everything honky dory... I make cups of tea and give her various meals and stuff. (Trevor)

Well I do me own room... I set the table... the dishwasher [load and unload]. (Kate)

I’ve gone half on the car with her... cos I knew she couldn’t walk or go any other way to get to places... I’m helping [flatmate] like that... She helps me when I need to go to the doctors or something. (Samantha)

Through photo elicitation

Preston reflected on a conversation with his father who said *“one day I won’t be around to take you out.”* Since his father’s death, Preston continued to live at home with his mother, who relied on him for many things. He reflected that because of this situation *“[i]t’s a 24-7 job you know day in day out...”*

Figure 5. Preston's Late-Father



Of course it was not all one-way as Maddie noted that her mother “*cooks my meals*”, as does Tony’s sister, and Stephen washes his “*hair first and dad puts stuff on... Mum does my shoes up for me,*” Mitchell noted that his aunt helps him with his self-cares and will “*wash my back – [as] that’s hard for me.*” In turn, familial carers reflected on their roles or that of the family member with intellectual disability which dovetail to benefit one or other party. Whilst this was heavily weighted in reference to the smooth running of the household, Melissa noted that her nephew “*won’t let me go on my own... that he doesn’t go because he thinks he’s missing out or it’s not safe.*” Elspeth (mother) was focused on enabling Stephen to achieve as much as he could: “*You don’t want to come right down to their educational level... I try to push his as far as I think he can go...*”

Notions of taking “*turn about*” for household chores and “*share the house work and gardening*” (Stephanie, friend), or “*needing each other*” (Rebecca, sister) were echoed by siblings not only in terms of the practicalities of managing the household, but also with a recognition of the individual’s ability to contribute in other meaningful ways. The reflection of roles within these reciprocating relationships was not limited to those between the family/whānau member with intellectual disability and their immediate carers. Two daughters clearly identified that part of their role included a sense of compounded caregiving in looking out for both their sibling (with intellectual disability) as well as for their mother with whom they stayed;

...you have to keep your finger on the pulse so that everything’s all right... it’s just another role. It is juggling... You become the parent – it evolves.
(Rebecca, sister)

I kind of feel like my role is to get her [sister] more space or freedom from Mum. (Deborah, sister)

This experience rang true for four other siblings who acknowledged the cost and/or benefit for all parties in the co-existence of their mother and their sibling with intellectual disability. The relief of this arrangement was overshadowed at times by the reality of having two or three family members with potentially, significant support needs – as they themselves as children or adults siblings – are ageing. *Reflecting on roles* acknowledged specific functions required for the benefit of either party and, to an extent, their success was dependent upon the interrelationship of those involved in the *Reciprocating relationship*. The awareness of the need to accommodate both the individual and household needs further revealed the extent that family/whānau and the person with intellectual disability themselves were *Riding the waves*. It is important to note that duty and roles aside, there is also a mutually identified benefit that this function is *Providing companionship*.

Providing Companionship

Providing companionship was found to be a natural outcome of the roles and duty brought about by the aforementioned reciprocating relationships. It was seen by all parties as a mutual benefit inherent both in the caregiving connection itself and that which is perceived and/or assumed from one to the other. It was noted however, that the longer this level of companionship was maintained, the more difficult it would be to extricate and form other meaningful connections which could sustain each member of the family/whānau in time to come. Notwithstanding this, the importance of the existing companionship should not be underestimated.

Seven family/whānau explicitly stated that having company was not just about having someone about the house, but reduced loneliness for both parties and provided the opportunity to do things together;

...we sort of go out a couple of times a week, sometimes three days a week... he seems to be happy. (Lorraine, mother)

We both get pleasure out of it – it's the company too yes. (Melody, mother)

I keep saying we need each other... I just keep saying I feel lucky that I've got him with me as company. (Alberta, mother)

Julianne recognised the possible impact for her mother should her brother not live there as “...[it] is the company I mean she'd be very lonely without Preston.” There was a sense expressed by some that this benefit was shared by the person with intellectual disability themselves:

She probably gets a bit sick of us at times and we probably get sick of her but... she is helpful... I think she likes being able to talk to us. (Isabelle, mother).

I needed her as much as she needed me. (Carmen, mother)

Having Mitchell kind of brought me out of myself... being able to give him the choice of experiencing the things he wanted to like horse riding... I've really enjoyed having him... I'm never terribly settled when he's not in the house. (Melissa, aunt)

It's rewarding to know that we are doing something worthwhile... We quite look forward to his visits. It's a bit of fun and something different – cos you can get into a rut when you get a bit older... (David & Edith, friends)

Siblings also recognised the benefit of companionship and were able to continue reciprocating the relationship that such companionship afforded. For example, McKenzie commented that growing up, her friends always included her sister with intellectual disability and *“they [still] expect her to be out with them if we go out for dinner.”* Even if they themselves were the primary caregiver, it was expressed that their sibling had become so much a part of their lives; *“he’s my friend, my companion ... I’ll be honest with you, when I leave him for more than three days – I miss him.” (Teresa, sister)*

For the people with intellectual disability themselves, the notion of providing companionship was simply a normal facet of living day to day. Kate thought it was good to have her mother there to talk to, Peter and Leslie acknowledged the company was important as they can play a game together. Living with family/whānau also enabled participants to get out into the community: *“I like living with [Aunt]. She takes me to school... Takes me everywhere” (Mitchell)* and facilitated ways in which time was spent during the day or evening by listening to music, watching television or for Jeffery - even knitting together.

She’s good to me [Mum]... she treats me well like going on walks, trains and things... And have coffee too! (Jacob)

Despite the enjoyment gleaned in describing how time was spent with his mother and her friends, the practicalities of being treated ‘as a child’ however was irritating for Bobby:

I had to behave... she was quite a strict woman... you'd go out for drinks and I'd spill something on my trousers and she'd say I only had those dry cleaned the other day blah, blah, blah... that was her.

One individual was more pragmatic about what the arrangement meant to him as *"it's cheap board I suppose!"* (Samuel). Overall, whilst companionship took many forms, there was one common denominator; being reciprocally connected to family/whānau. What differed was found in how this was personally captured by all participants.

There was a clear distinction between benefiting from companionship and the duty required in executing such caregiving roles and responsibilities. Such flexing and (re) negotiation of relationships occurred over time and clearly depicted what family/whānau and people with an intellectual disability in this study were doing to ride the waves in living day to day. This may pose a challenge to recognise emerging independence or further dependence for one or more persons involved in the caregiving relationship and is the focus of the next concept.

Emerging (In)dependence

Whether still anticipated or actualised, the stated formal goal of people with intellectual disability becoming more independent in society and in their identity, is largely based upon the perceived or known levels of dependence between all persons in the system – not just the person with intellectual disability. This was seen as a significant factor in thinking and planning for success into the future. Participants were neither wholly dependent nor independent rather, it was important to consider *Emerging (in)dependence* as an

adjustable scale and context specific. (The notion of inter-dependence is captured elsewhere for example in the previous category *Reciprocating Relationships*).

The codes which informed this concept can be seen to either help or hinder participants in *Riding the Waves*. Hence *Emerging (in)dependence* is built upon principles such as *Valuing autonomy* (compromised or actual), and the need or opportunity for *Acquiring skills*, which may result in some family/whānau simply *Maintaining the status quo* as this may be deemed the preferable way forward. The extent to which these principles are embraced determine the level of independence or dependence that ultimately emerges at any given point in time.

Valuing Autonomy

Inherently, autonomy is a valued notion which underpins self-determination. This was characterised by the majority of participants as either an experienced reality or seen as a compromise for family/whānau, and/or by those with an intellectual disability. The question needs to be posed; whose autonomy is being considered at any point in time? Hence the level at which autonomy was valued and able to be exercised correlated with the sense of identity, independence or dependence experienced.

Five siblings expressed concern as to the impact the unspoken future of their respective families/whānau may have on the ability of all members to make autonomous decisions about their lives (whilst simultaneously safeguarding the same for their brother or sister with intellectual disability).

Of course he looks after Mum – we really owe him right now because she'd be in a rest home otherwise... (Adrienne, sister)

...at times I probably thought why does he always come first? ...always had to keep an eye on him... it was always my job... that's one of my biggest bugbears is they [other siblings] don't check up very often. Yet, they can sit there and say oh perhaps this needs to be done... They wouldn't have a clue... (Rebecca, Sister).

This identified need for respect and autonomy included access to relevant health and disability services and was a key issue for Mavis in regard to safeguarding her sister-in-law's health.

I'm not scared of them [doctors and nurses]. I'm grateful for them... But sometimes you feel that ultimately I think that they wouldn't put much energy into it [responding to people with a disability]. I mean they would do everything they can but you just get the feeling that they wouldn't probably fight... She'd be walked all over. She'd just sit there quietly and put up with it, the poor little sod.

Whilst Isabelle did not wish her daughter Kate to be lonely, she noted that *"she has been proposed to twice (thank God she turned them both down otherwise I'd be worrying about having two instead of one person to look after."* In thinking about the impact of caregiving roles, Deborah was adamant that she did not *"want to take on [mother's] role, I don't think it's fair on me and I don't think it's fair on Maddie [sister]."* She was already feeling the pressure of this inevitability and vocalised her need to maintain her own autonomy about her life and about the place she has in the family/whānau.

Having time to oneself was challenging to negotiate between all parties in the caregiving system and was an issue for five family/whānau participants. For Stephanie it was acknowledged that the time spent apart is very little and when she spends time with her own mother, her flatmate with

intellectual disability can become “quite jealous or upset” (Stephanie, friend). For one set of parents the series of earthquakes in Christchurch forced a compromise as they negotiated who would stay home from their community engagements to ensure one was available to their son with intellectual disability. Another parent commented that by nature of the disability “you just can’t do anything what you’d like to do... Mind you, it’s not easy... being on a restricted income... [and] I can’t leave him on his own” (Lorraine, mother). Whilst adamant that caring for her nephew has been her decision, Melissa laughed;

...my life, what life? I didn’t have a life... [he’s] got the life – it’s me that hasn’t got the life because my life’s become involved with his... I wanted to give him the chance to be able to do what he wanted with his life.

More pragmatically, twelve participants with intellectual disability identified a number of factors that they considered were important for them both now and in time to come. These factors represented self-determination and autonomy over elements of their life which were critical for them to have control over. Maintaining some form of independence for example resonated for Trevor who said “Touch wood that’ll never happen. Touch wood” – in reference to not being able to drive, ride a bicycle or go out for meals. Mobility was also important for Samuel as a lack thereof signified having to move into a rest home. Whereas for Leslie, it would be important to be able to go “somewhere on me own all the time.” For Maddie and Jamie, being able to go out into the community denoted independence and Mitchell “sometimes [gets] a little bit frustrated” when people could not understand what he is saying or do not “take time” to listen: His difficulty with expressive language impacted upon his ability to be seen as being independent. Four participants believed that being able to manage their money and cook their own food would signify greater independence. Jeffery wanted to be able to “do that one day for myself

[get the groceries]. I want to cook meals." Being dependent upon others in order to access one's own money did not seem fair for Cyril and Preston. For Bobby, whose sister has Power of Attorney, this is also disempowering as he says he;

...can't go to the bank and get my money out, she's got to go with me and sign for it as well...It's a bit harder because sometimes she doesn't turn up... might be 2-3days before she turns up...

Kate sees *"everybody else is getting paid – but I'm not... I'd love a small paid job – that someone pays me."* Of note, she had previously been employed, was paid the minimum wage and saw that as valuing. Samuel however was comfortable that his money is managed as he knows his Mother has the cash flow card and *"they give me so much spending money... I'm happy she does it."* Being supported to access the community was another aspect of autonomy important for this group. Jacob was glad that staff at the day service 'let him' go to the library.

These examples about how autonomy was valued limited the ability of several participants to make decisions about how they spent their time and the feasibility thereof. One party was not always aware of what another hoped for, or was capable of, in regards to the significance of opportunities that denote autonomy. The drive to be independent (to the extent possible) within the caregiving network further demonstrated the adaptations all parties made when *Riding the waves*. It was acknowledged by participants that in order to recognise dependence and promote independence, the identification and promotion of meaningful skills is required.

Acquiring Skills

Acquiring skills was pivotal to recognising and promoting opportunities to foster *Emerging (in)dependence*. This code was about both the principle and process of learning and developing life skills. Whilst it may not be clear how the need to learn skills is identified or if so, how the decision is made for these to be fostered, this code encapsulated a range of attributes considered important in regards to nurturing independence. Whilst not pervasive, this code applied to at least a third of all participants.

The majority of family/whānau identified both skills of socialisation as well as home based activities of daily living as necessary for the son, daughter, sibling or friend with an intellectual disability. It was deemed that these core skills may set them up in time to come to manage more independently in the community regardless of the future setting:

...because of his inquiring mind and asking questions and talking, it doesn't always go down so well with the elderly men [at the bowling club]... If he was quiet it would be a lot better but he wants to help... (Barbara, mother)

...[daughter] can't cook, and I have tried, I tried and tried and tried and tried and tried. She's not interested... I've been trying to show her how to use the slow cooker... she can use that, is quite capable. (Carmen, mother)

Given time and opportunity, family/whānau also recognised the existing foundation skills that their member possessed and which could possibly be built upon and extended.

She [daughter] goes through the house with the cleaner, which takes her about a quarter of the time it would take me probably but it's done and that's fine... (Evelyn, mother)

...you wouldn't believe what he was like there [in the USA]...he was a way different person... Like there's nothing wrong with him. He talked faster, he acted differently... (Maryellen, mother)

We'd just let her [sister] do things herself, have a go. Point her at it and say go to it... they [people with a disability] can figure things out so it doesn't take them any energy... (Jeremy, brother)

Melissa spoke about her nephew having to learn how to make his own lunch as he would request it at 12 o'clock every day. In short, she told him to "do it yourself" which precipitated a new routine and an opportunity for Mitchell to learn the process for himself. Likewise, for five other individuals with intellectual disability, learning new skills was either out of necessity or for their own pleasure. Leslie identified her knowledge gap was using the telephone as it was hard for her to dial the numbers because she did not "know which ones to push... if the number's very big I can see." For Bobby, the skills were the aforementioned practical household chores:

Oh the first couple of times [mother was in hospital] I didn't cope too well because I didn't know how to use the washing machine... To clean the house... to make the bed... there was ironing and there was cooking...

For Samantha, the role of the support worker was pivotal in this as "she takes me swimming. She teaches me to swim... we go to the pictures... to the beach. Trying to get into something I can do." However, for another, their sibling had

commented to their mother about it being her responsibility to ensure the daughter with intellectual disability knew how to cook. Parents noted that the limitations imposed on their offspring learning skills of daily living were usually based on their parental concerns in terms of safety but admitted they had not explored ways in which to minimise the risk:

Isabelle ...probably my fault because I don't, I sort of do the cooking and don't really let Kate [daughter]...

Kate [Sister] always has Mum on about cooking, how I should learn and about one of these days you're going to go flatting you'll have to learn Kate, [sister] used to say to me.

Isabelle I get a bit worried with the elements...

Kate Oh Rose told me how to do it, she taught me how to do it. If you have a problem, if it catches light, flip that kitchen stove up there, flick it off

Isabelle I don't know, I'm just a bit scared she might turn things up too high...

The above example illustrates how a well-intentioned and protective caregiving system could be viewed as a limiting factor at times for a number of people in reducing their exposure or opportunity to acquire new skills. This was not an isolated example, and in fairness, concerns expressed by families were often real and reflected the known or potential vulnerability in managing finances or safety of their family member and which resulted in limitations being placed on community access for example as "he's got no sense of time." (Teresa, sister)

Whilst recognising and cherishing autonomy and levels of independence, it was also clear that some had few plans in place in looking

towards the skills needed to equip individuals for the future. Because skills can be seen as both static and dynamic there were several reasons given, ranging from the actual limitations of the disability to it being easier get things done without the person's input. Regardless of an awareness of the value placed on facilitating autonomy and choice, at least half of the parents, siblings, carers and the people themselves expressed a preference to maintain the status quo.

Maintaining the Status Quo

Keeping things as they are was, for many participants (including those with intellectual disability), was often considered to be in the best interests of all concerned. *Maintaining the status quo* is defined as the security of that which is known, and simultaneously acknowledging the fear and anxiety associated with the future; the latter instilled a sense of the unknown and intangible – a reality yet to be established. As reflected in the previous two codes this may or may not have an impact upon the extent to which *Emerging (in)dependence* is fostered.

For a third of family/whānau participants, there was an acknowledged sense that meaning and purpose was secure. For Carmen, not pursuing the future was because her daughter “*gave meaning to my life in a sense I felt needed*” whereas “*I’ve always been with him... he’s always been there*” for Maryellen (mother) was a concept of permanency. Similarly, Elspeth and Murray revealed that their son Stephen had, “*in lots of ways, kept us young really... he keeps us on our toes.*”

Understandably these sentiments were always coupled with a sense of pride in the care and commitment provided by family/whānau to the member

with intellectual disability in that such care was superior to what could be expected elsewhere;

...I think nobody can look after her like me... I didn't use to think about it but the other two children used to say well you really should get something organised and face facts because you're not going to live forever... It's in greater hands than mine... So I don't worry about my future. I just take it as it comes. (Susanne, mother)

I think I was running after him more when he was over there [in residential care] that what I did when he was here so wasn't any point in being away somewhere else. (Melissa, aunt)

I suppose I like the responsibility... could give it to someone else but... that would be like giving up and I would feel that they [Mother and brother] weren't getting the best I suppose... maybe I'm wrong there... (Julianne, sister)

Thinking about the future was not uncommon and not actually always acted upon or planned for. It often remained in the realm of thought only. Over half of the parents acknowledged that they have “*never really thought about it, because I keep healthy...just sort of take one day at a time ...we carry on regardless*” (Lorraine, mother). Several expected that they could “*carry on and hope the health holds up*” (Isabelle & Richard, parents) and would outlive their relative with intellectual disability hence planning for the future was not seen as a necessity. Barbara and Jack (who were in their early eighties at the time of the interview) commented that;

...while it's not something that you know you talk about really [the future], I mean as I say we hope we'll be around for many more years and able to look after him, which is not always, we realise the day will come but we hope it doesn't come too soon.

It was noted that, the anticipation of outliving the member with intellectual disability was paired with the expressed expectation that this person would inevitably die before key players in the family/whānau system of care. This promoted the notion of maintaining the status quo and applied to the majority of family/whānau carers:

Everybody's onto me about that [future planning]... I hope Mitchell dies before me. (Melissa, aunt)

I would prefer that he [brother] goes before me, that I've thought about... I just hope that I bury him before me... I just hope he will go before me if I'm honest. (Teresa, sister).

Two siblings noted that their family member has not been willing to engage in the conversation about the future or alternative living arrangements. Five siblings expressed a range of similar considerations in regard to keeping the arrangements as they are, albeit for different reasons;

...in the too hard basket at the moment. I don't want to have to deal with it, I don't think it would help [brother] or me really to try and walk down a road that's not there yet... (Julianne, sister)

Hope that she keeps on living. That she keeps on being the way she is. That we can manage. (Jeremy, brother)

[They] enable each other to live in their own home. Mum is enabling Jeffery to live independently... and he is enabling Mum to stay. At this stage – it's brilliant. (Rebecca, sister)

Despite the above sentiment, Rebecca also described the realisation of one's own mortality and the impact upon the family member with an intellectual disability:

I'd never thought about it if something happens to me ...don't want to think about that ...whether I'm going to die before [brother]... I don't know what my health will be like... I may not be able to give him the care that he needs.

The inevitability of being the older sibling was a strong consideration for Jeremy and Mavis in considering the future for his sister Pauline. Whilst they had already long taken on the role as second generation caregivers, they were planning to maintain the status quo by future-proofing the house with a ramp and a wet-floor shower. Their attitude was one of *"she's always here. [We've] got the best job."* For five participants with intellectual disability themselves, the status quo was seen as preferable and inevitable as things would *"stay the same"* (Samuel) or *"I could help them [parents] more"* (Peter). For Stephen the idea of living in care was seen as *"worse"* because it is *"better at home ...I see these two [indicating parents]."*

Hence the crossroads of emerging independence or levels of dependence were illustrated through the value placed on autonomy and the need to acquire skills for living elsewhere, despite some perspectives on maintaining the status quo. This further reveals the rationale, processes, and undertakings in caregiving systems as they are *Riding the Waves* in managing

the present and conceptualising what is needed for the future. Several members were already taking cognisance of the future and were willing to explore the factors which motivate, enable or disable such planning to occur.

Taking Cognisance

Four codes informed the category of *Taking cognisance*: This can be seen as a point at which factors converged and informed changing perspectives in which the future is considered for family members with an intellectual disability. Of note, this category evolved solely from interviews with family/whānau and demonstrated the extent to which accommodating the disability within families resulted in conflicting perspectives. Whilst a number of family/whānau engaged in rationalising their current realities, there was an acceptance in several about the existing dynamics which challenged changing positions as the sense of reaching saturation is described.

Accommodating the Disability

The question arises as to what extent the level of impairment explained, informed or excused the presentation and interrelationship between the family member with intellectual disability and their family/whānau. The majority of familial carers expressed a need to understand and be cognisant of how or why they accommodated the disability given the individual's presentation and responses at any one time. It was identified that these factors had a direct impact upon the relationship and is exemplified in the following examples;

...what it's like working with him [brother]? Sometimes it can be quite rewarding but sometimes it's terrible...he really will attack me quite often,

verbally. But he doesn't have the words to why he's annoyed... (Adrienne, sister)

...you get your frustrations when you wish she [sister] could move at your pace but you just have to accept that she doesn't..." (Mavis, sister-in-Law)

"I don't think we realised really how consuming his obsessiveness was ... it was just seen as [brother] was dragging the chain so slow... I understand now a little bit more... (Julianne, sister)

If you show him [brother] once he knows and then down the line maybe two or three weeks later he would forget so it means to show him again and has taken me a while...understand because I have to learn about him... (Teresa, sister)

Such efforts in accommodating the disability were not solely relegated to the siblings as other family/whānau also identified similar challenges:

She [flatmate] thinks it's all right for her to shut her door but if I shut my door that's a big no-no to her...she knows which buttons to push...that will set me off but she's very good at apologising later...she just needs time to think about it. (Stephanie, friend)

If you say a time we're going somewhere...he's there [son] standing there, got to go, we've got to go. And that is hard...It does become a pressure... then he gets really wild, he bangs his hands... and he'll yell at you and then he's forgotten about it. (Jack, father)

I don't think she tells lies, she imagines what she would like to happen, she says is going to happen or has happened... you've got to try and find where the truth actually lies... She was capable of learning to live with us, making

allowances for her disability but she certainly wasn't going to run the family.
(Evelyn, mother)

...he's [son] not really a problem just that he's got all his routines around the house and I've sort of learned to bite the bullet... (Maryellen, mother)

Of note, the need to feel in control of the situation and how it unfolded, was not isolated to the here and now. Natalie for example, was acutely aware from the outset of the potential impact of having a child with Down syndrome on both her and the family. She described that, despite not fitting the usual at-risk profile (she was in her twenties when she had Frank, her first child) she made a number of core decisions from the outset; to keep Frank within the family, and to undertake testing in all her subsequent pregnancies for possible disability as, *"knowing what I know now... possibly would not have continued with the [subsequent] pregnancy [fading voice – staring into space]."* She also made a conscious decision at the time to have more than one child as *"it would not be fair for there to be only one sibling... for the load to be shared..."* The latter comment suggests there was an intrinsic awareness of potential demands and that siblings may need to take up the caregiving role in time to come. However, the territory changed over time as did understandings of the roles and expectations within the adult family/whānau.

This concept of *Accommodating the disability* reflected the interpretations of family/whānau members in regards to their understanding the impairment and the impact on themselves or others. It is important to note that these perspectives on accommodating were not necessarily held by all members of the nominated caregiving network and did result in specific conflicts for some.

Conflicting Perspectives

Five family/whānau members expressed viewpoints that were reportedly at odds with significant others. It should be noted that, the 'others' to whom this refers were often those who had the least involvement with the child or sibling with intellectual disability. Naturally, this led to expressed concern or even trepidation among family/whānau about arrangements for the future.

The big one is going to be when Mum dies, where [brother] lives ...[as]... different family have quite different ideas about what that's going to be. So that's going to be fun and it's going to cause angst between me and my siblings... (Adrienne, sister)

So when she [Mother] broke down our brother came from Australia...he's very volatile – puts a lot of pressure on us...[brothers] were going to take over her care which I just thought...was very unsafe...I fought tooth and nail... (Julianne, sister)

As the interviews developed with family/whānau participants, articulating these frustrations was found to be a release for some. It enabled a process of taking cognisance to occur and to articulate their experiences to someone external to their lived reality. This process of engagement also enabled the rationalising of realities to occur for others.

Rationalising the Reality

The interplay of relationships, and the expressed being with and to others, provided an urgency or a sense of needing to rationalise one's own

reality. This was different to accommodating the disability insofar as it was a more reflective awareness of who each family/whānau member was and in relation to each other. Furthermore it also enabled parents, siblings and friends to verbalise why things were the way they are. Taking cognisance in this way was evident for all family/whānau participants.

I don't really begrudge Trevor much these days because we do owe him... Mum isn't in a rest home because of him... It doesn't make sense to break them up really but I mean there's something to look forward to as well you know because I think... I mean he will be lonely but he will enjoy not being hen-pecked all the time. (Adrienne, sister)

Sometimes daunting, is that the word? [Having a child with a disability]. Coped with it pretty well, but there are the odd occasions when you get a bit down...but you just get on with it...My faith. I would never be where I am today without my faith and it's something I'll always cling to... (Susanne, mother)

Sometimes she can just be a little over exuberant you know. I don't know whether sometimes she means to do it, even socially sometimes she might do it. I think 'cos it's a sort of a little attention-seeking... I'm honestly not sure about that. (Isabelle, mother)

I can't look after [brother] if I'm not well... I got a warning from the doctor... my diabetes wasn't controlled properly so I thought ok, that's it... I started going to the gym do everything right and I do it both for me and my brother. (Teresa, sister)

Because it's the best thing. It's the best thing you can do for someone, is to give them a good quality of life and caring for them. (Mavis, sister-in-law)

These examples illuminated differing perspectives due to the nature of the relationship or the duration of the caregiving role for each participant respectively. Taking cognisance by rationalising the reality is more reflective than consciously accommodating the disability. The question could therefore be asked as to what extent do values, beliefs and experiences dictate the response family/whānau carers have when it comes to accepting dynamics and connecting with their member with intellectual disability? Such considerations are likely to inform when and how family/whānau feel they have reached saturation.

Reaching Saturation

A third of family/whānau participants were found to be actively cognisant of their own limitations and ability to respond to the family member with intellectual disability over time. This was neither a constant nor finite experience, rather an intermittent occurrence which acted as a barometer of when they were *Reaching saturation*. Family/whānau were frequently taking cognisance of the potential for saturation to occur and were able to recognise triggers or indicators that this may be occurring and allowed them to monitor and manage their responses accordingly.

David (friend) for example knew that he and his wife “*have a shorter limit. I can get overdosed [with being available]. It's happened a couple of times...I felt terrible [about feeling that way].*” Whilst four siblings also felt bad about recognising this response in themselves - it did not deflect the reality for them. Adrienne and Julianne respectively recalled times when they were tired

and frustrated about what their respective brothers would be instructing or asking of them:

I feel like telling him to get stuffed and do it yourself and see how long he lasts without me...

He just sees everything as totally urgent so I get phone calls about everything...it takes a lot of my time... already handicapped by my own issues (sigh)... I just feel I'm always overloaded with Mum's things... don't want to speak badly of him, but he has some very annoying habits like standing around telling what to do and how to do it without actually getting involved himself...

Stephanie (friend) was more cognisant about recognising the need to act when reaching saturation and stated that:

I know things start to annoy me more. Little things... I can't be bothered with my other friends. You know I sort of think oh God, don't want to talk to you today, just leave me alone... I just feel like I've suddenly become overwhelmed with everything and I need some quiet peaceful time to myself, some space. And sometimes I'll go to Mum's, and she'll just know, she doesn't need to talk to me, ... I'll just have a cup of coffee with my Mum... I'm sort of de-stressing there.

This sense of saturation was two-fold for a number of other family/whānau and Deborah expressed it as experiencing it from both the sibling with a disability, but also from the wider community. As such, it reflects a 'no-win' scenario:

Sometimes when we're out, her disability comes out and she'll be acting like a child it just irritates me... and other people trying to advise Mum on how to deal with [sister]. And it's like well you don't live with her...just back off.

The opportunity of sharing this reality with the person with intellectual disability themselves was one way a sibling sought to bridge this sense of hopelessness:

"At one time – I was really stressed out... I would really cry...he [brother] said to me don't cry sister and I said I'm frustrated at myself for not knowing you because I want to understand you." (Teresa, sister)

Regardless of their relationship with the member who has intellectual disability, family/whānau were insightful as to the trigger points in themselves and cognisant of their response to these. The ways in which they recognised and responded to these recurring scenarios was by accommodating the disability, rationalising the reality and managing conflicting perspectives which could challenge or tip the balance of the manner in which they could be with and to others.

Chapter Summary

The category of *Riding the Waves* exemplified the journey of engaging in relationship by the wider family/whānau network of care with each other and members with an intellectual disability. Care was demonstrated in the formation of established and emerging ties and roles between all parties, be that duty and reciprocity, facilitating independence or negotiating continued interdependence. The realities of what it meant for individual family/whānau as well as the people with intellectual disability themselves was illustrated

through continuing cognisance and management of the tensions which exist. Needless to say, what has been described is not a linear process but a dynamic one and despite the tensions there was significant evidence about the opportunity for and/or actualisation of *Shifting Sands and Changing Tides* which comes together in the next category.

CHAPTER 6

SHIFTING SANDS – CHANGING TIDES

This concept reflects un-discovered realities about the past and the present, and/or those which are still emerging. The tangible nature of each reality is dependent upon a number of variables for each party in the family/whānau system of relationship. The discovery of such realities is based upon how the individual and those within the caregiving network are subconsciously or actively configuring ageing or anticipating changes at any point in time. The categories which comprise this concept are explored through the codes (which represent these realities) for each group of participants. A key finding began to emerge in regards to the presence of multiple realities within and between individuals and participant groups.

Table 7. Shifting Sands – Changing Tides (Appendix 18: Summary of Results)

<i>Code</i>	<i>Category</i>	<i>Concept</i>
Defining ageing		
Recognising altered function	Configuring ageing	
Dying is part of living		Shifting Sands – Changing Tides
Looming responsibilities		
Limiting factors		
Feeling disillusioned	Anticipating change	
Letting go – Enabling others		
Unknowing explorers		
Evolving expectations		

For at least ten people with intellectual disability, *Configuring ageing* was characterised through their choice of a photo, picture, image or object of significance that linked key facets representative of constructs or experiences of ageing in relation to experiencing altered function or increasing frailty. The concept of *Anticipating change* emerged solely through the family/whānau interviews and extrapolated evolving yet specific experiences: These informed the perspectives of this group, and identified possibilities for the future. For all participants there was a process of reviewing and editing, involving new and emerging information and the editing out of material which had become redundant due to the process underpinning *Shifting Sands – Changing Tides*.

Configuring Ageing

For some participants with intellectual disability, ageing in and of itself generally had not been extrapolated into anything more than the chronological aspects of getting older. However, when the notion of inevitability was explored with participants a number of distinct elements emerged and were named and which demonstrated an awareness of something greater than the individual had first conceived. For these participants explanations were realised and explored through the use of photo elicitation which provided a platform from which their formulation of ageing was evident. Three core facets of ageing became evident in configuring ageing: For those with intellectual disability, interpretations varied about defining ageing in terms of age or stage of life and which were linked to a sense of increasing frailty. Recognising altered function was found to denote a natural trajectory for all participants and dying was recognised as part of life. These codes are examined in this section.

Defining Ageing

Getting older and ageing are often mistakenly interchanged. Additionally they can each represent either a concrete dynamic (such as chronology) or they can reflect perspectives and abstracts. It is posited that 'getting older' is generally something which is constantly occurring for everyone. Commonly, generations of children hope for this and adults speak about it with mixed regard. By contrast, ageing is more traditionally linked to notions of a specific timeframe within one's lifespan and possibly more clearly includes the notions of maturation and decline. This code only captures the viewpoint of participants with intellectual disability for whom there was little distinction between the two; in fact, getting older was the turn of phrase used interchangeably to aid the understanding of ageing as an abstract.

For the majority of participants with intellectual disability perceptions of ageing were, predominantly, made in reference to a number. For Maddie, turning forty "*just seems old to me*" and Frank recognised the obvious in relation to himself with this statement "*I would say 40s and 50s, but I'm almost up to there, see.*" Four other participants reflected that 60 years of age was old, and a further six reflected that being in one's eighties or nineties defines it:

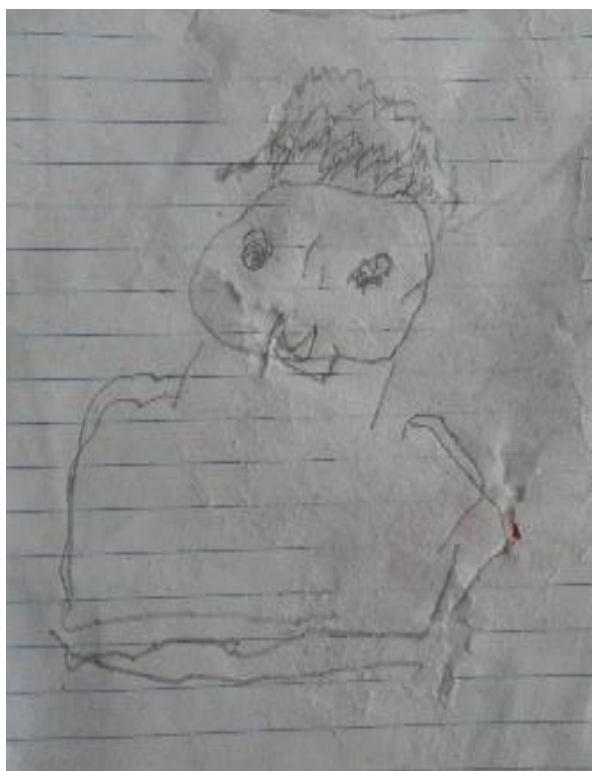
They [parents] are very old... dad's in his 80th year coming up, mother's in her 80th – that's very old... Retirement home nearly. (Peter)

Reasonably old (86 or 87). Well the woman across the road, she turns 99 in about a week and a half... If I was still around [at that age] they'd need to shoot me!(Bobby)

Beyond numbers, two women for example connected ageing with menopause as a hallmark feature of ageing, whilst Leslie had already experienced this. Kate noted that *“menopause that’s one worry... a lot of people have sweats, and hot and flush face, flushed whatever you call it.”* Two participants made a deeper connection in defining what ageing meant for them. Trevor for example stated that *“age is definitely there but I don’t know about old...because one minute you could be really fit... we all age eventually.”* Whereas Carol was emphatic that ageing was a lifelong expectation as *“we all get old – from when I’m born.”*

The conversation about getting older was difficult to generate or conceptualise for some with respect to their ability to link perspectives or experiences. However, defining ageing emerged more succinctly and personalised when making reference to an object, image or photo they had

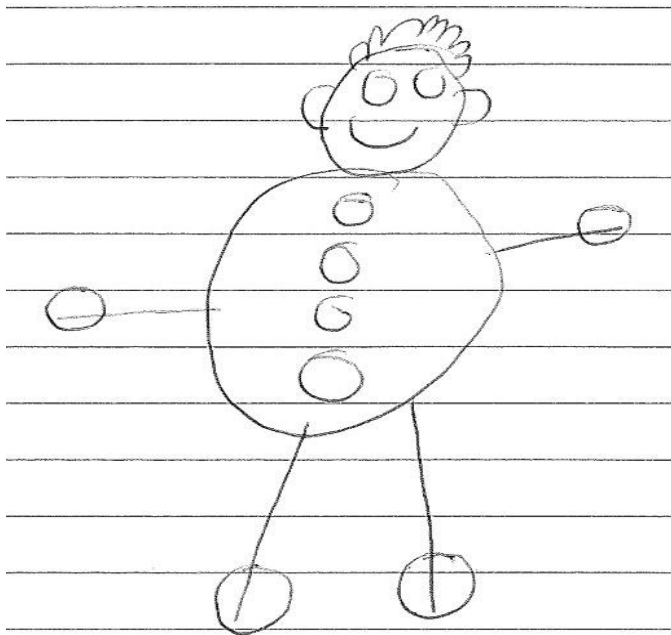
Figure 6. Tony's Drawing



chosen. Leslie and Tony, for example, saw changes in appearance as an inevitable part of getting older and were respectively linked to changes in the hair getting thinner and facial appearance. This sense of ageing was expressed as pictures that they themselves drew:

This is my face... what I’m trying to look like older. (Tony)

Figure 7. Leslie's Drawing



*That's me when I'm grown
old... all the hair around
there... It grows out. (Leslie)*

Figure 8. Stephen's Grandfather's Cap

In defining ageing, links were made by the individual with an intellectual disability to those people they considered to be old and this was also dependent on their relationship to a significant other such as a parent or grandparent. The association for Stephen was in the cap he brought along as it *"was old [and] belonged to my grandfather."*



Figure 9. Trevor's Clock



A sense of time was also pivotal: For four individuals, whilst telling time in itself was an issue, there was an inherent awareness of how time is qualified and the implications this has as one gets older. Trevor reflected the clock made him think about getting older as he would *“like to have perhaps another day...but it’s too jolly*

quick...I’d like to have a wand to slow it down but nobody can do that...” there was a clear sense of inevitability and of this being outside of one’s personal control.

The research approach included the use of a choice of generic static images as potential substitutes should individuals have forgotten or chosen not to bring a specific photo, object or image to the interview; they were also used to establish their potential utility to assist people with intellectual disability in generating ideas in regard to thinking about getting older. Of particular interest was the comparison between the response to these generic images and the insightful elements generated by the individualised photos, objects or images that participants themselves had selected for their interview. Two internet-based images were used for this purpose; one of an older person (Figure 10) and the other representing a composite of three generations of women (Figure 11). It was found that each of these images required significant prompting to elicit participants’ thoughts or ideas about ageing and what it might be like for them. Two participants thought the image of the

single older person in the picture did not look old and stated that she was young; one was unable to provide a response and one had withdrawn by the stage of the interview process in which the static images were used. For the image of the three women, two participants stated the opposite order of what constituted youngest to oldest. On checking their responses using reverse wording their responses remained the same.

Figure 10. Image of Older Person



Figure 11. Image of Three Generations



*Body will change, all wrinkles around their body and old and yeah, quite old...
No [nothing changes inside the body] (Cyril).*

Table 8. Static Images

Image	Yes	Comment	Did Not Know
Older person	(n=14)	“She looks old” due to:	(n=2)
		Wrinkles	(n=6)
		Grey hair	(n=8)
		Do not know why	(n=4)
		Age range 50-84	(n=7)
Three women			
(Youngest to oldest)	(n=12)	Wrinkles	(n=1) (n=4)
		Hair colour	(n=2)

Notwithstanding, the majority of participants with intellectual disability either through their own photo, object or image or those offered by the researcher, noted distinguishing elements which defined ageing (wrinkles and hair colour). A critical and significant facet of this was whether or not they could recognise the impending possibility of altered function for the person concerned. In *Defining ageing* participants recognised a number of factors from a chronological number to physical appearance, to connections with past and present. Poignantly, there was an articulated recognition of the impact such factors have in *Configuring ageing* and which are further illustrated in the next section. For all participants in this study, *Recognising altered function* was found to be a hallmark feature for people recognised as ageing.

Recognising Altered Function

Regardless of the stage of lifespan at the time of interview or prognostic trajectory for a person, getting older was seen by the majority as being inevitable. *Recognising altered function* elicited a recognition in most that ageing was both a foreseeable and inescapable reality. Similarities were found between participant groupings; for people with intellectual disability their perspective was largely informed by their knowledge of older others, and/or expressed through photo elicitation. For family/whānau, their own experiences of *Recognising altered function* added to their expressed hope for their own ageing trajectory.

Whilst not always specific in nature (aside from three participants with intellectual disability), getting older in terms of age was seen to correlate with *Recognising altered function* for the majority. For half of this group, it was the connection with knowing older people that informed their perceived current or anticipated changes and which therefore defined ageing for them. Examples included Bobby's neighbour who was 99 years of age and who had to stop driving, required a nurse aide and someone coming in to clean the house, mow the lawns and assist with groceries; these were all indicative of changing function by association with someone he knew. Three other participants identified mobility needs (walking) and sensory deficits (vision and hearing) as additional indications of altered function secondary to ageing:

They [older people] can't do much... Standing, walking and bending down [are harder]... They get in your way more... Wrinkly... They're slow in their thinking... You've got to yell - coz they're deaf... Going to that old people's home... They're really slow... (Maddie)

Not so good [being over 70]... Not steady on their feet... You! [Aunty] I see you wobble. I see you wobble before. (Mitchell)

Mitchell and Jamie however, believed that there was not much difference between being younger and getting older; they were of the opinion the level of support will not need to change and they anticipated living for a long time.

For three participants, function was a key element in getting older. Samantha initially stated that she did not know *"what about getting older is"*. However, when invited to bring a photo, picture or object, she brought her dog in to the meeting. When invited to talk about how this helps her to think

Figure 12. Samantha's Dog



about getting older, she likened it to their dog, being part of the family for many years, and the dog had changed. Samantha stated that a dog is *"older than humans sleeps a lot... [and] used to run around like a mad idiot – now not so much."* In addition, she reflected upon this and thought the dog was no longer as sociable as it had been in the past and concluded that her dog was like her - *"I am just getting older."*

Mitchell was cognisant of already experiencing altered function himself. For example, he was confined to a wheelchair, had limited muscle strength, and co-ordination. Hence he chose an image which was significant in terms of his

own physical well-being. The photo chosen was that of himself on a horse; it not only reminded him of being younger, and that he enjoyed riding and was able to sit up by himself in the past but which now poses some limitations for him as he gets older:

Figure 13. Mitchell on a Horse



"Yes I do [wish I had carried on walking but that was] a long time ago [not an option now]... no my legs closer – not right. Sometimes in my hand I get pins and needles... When in my wheel chair... my body that way... a lean" (Mitchell).

The inevitability of possible changes in bodily function was compared to that of a steam train (Figure 14) by Jacob as "...our bones become brittle... frail and brain becomes weak... it's [the train] got parts that works by steam and wood to make that engine go and it's the same with our body parts working." These parallels of getting old were linked, in life, to an uncle who became frail, and a grandmother who lived to 81 and 84 years of age respectively. Changes in function were not simply limited to bodily systems; several participants

identified that there is a cognitive element to ageing as well. Reference was made to people getting dementia;

"...they forget where the toilet is... they can't manage eating, someone feeds them... they all got to have mashed food" (Kate).

Figure 14. Jacob's Steam Train



Frank linked the experience of getting older to thinking and planning as *"when you're young you can plan ahead for days coming but when you get older... It's harder to plan... like Dad... he just forgets what's going on."* Frank brought a butterfly that he had made to the meeting – the importance of which he explained as

Figure 15. Frank's Butterfly



"...when you get older your mind starts to disappear on you." He explained the metaphor as connecting the flight of a butterfly to the changes in one's mind as one ages, and which may be difficult to capture or hold on to as one ages.

For family/whānau and siblings alike, recognising altered function was not simply focused on what they anticipated could happen, but was also on the level of function they aspired to as they themselves respectively get older. In recognising the likelihood of altered function, their expressed determination to age positively was not dissimilar to the member with an intellectual disability; this was exemplified for several who had goals of maintaining mobility and independence for the majority – *"taking the car away from me that was one [not good thing about getting older]... losing that"* (Melissa, aunt), *"and having your marbles [was] very important"* (Susanne, mother). Others concurred with the following goals; being financially stable, keeping good health, *"being able to engage in the community..."* (Julianne, sister) and *"keeping up interests and friends"* (Adrienne, sister) were equally important. These factors were summed up by an extra-familial participant (David, friend) who stated that:

I went to the doctor the other day...I've got a crook knee... I'm overweight. Well let's put it this way, I've got depression, I've got tinnitus quite bad. I've got a hernia. I've got a murmur. I get palpitations. Blood pressure's high... My thyroid don't work too good. Apart from that I'm great... I don't want to be gaga.

The aspiration for sustaining one's own autonomy and well-being, for a quarter of the family/whānau participants, was also tied up in reflecting upon having seen the experience of others' realities in growing old. One sibling, reflected that her husband is *"getting older before his time and that*

saddens me..." (Julianne, sister). For a mother, her experience with her own mother had made her determined that *"I don't want to be sitting in an armchair waiting to die"* (Evelyn). This drive to influence one's trajectory was tempered by a recognition by Jeremy (brother) that altered function is a natural part of getting older and slowing down is a certainty. In short, *"...the body starts letting you down. You have to start paying to have your hair dyed!"* (Alberta, mother). This reality was also not lost on the person themselves: *"Mum knows she's forgetting... more and more"* (Rebecca, sister). There was a respectful yet un-uttered recognition that irrespective of the individual specifics of *Configuring ageing*, a change in function and ways of being occurs over time and this introduced the notion for participants of dying being part of the journey of life.

Dying is Part of Living

For the majority of all participants there was an anticipation and acceptance that dying is an inevitable end part of living. The individual and collective perspectives all highlighted the uniform realities of death that had touched all participants over time. For family/whānau, there were additional expectations about what dying may mean not only for themselves but to their son, daughter, sibling, nephew or friend with intellectual disability.

Susanne, for example, was concerned that her daughter would outlive her: *"That Leslie's here after me – that's the only concern."* By contrast Jeremy stated that his belief is that his sister is *"probably going to see me out"*. Another sibling acknowledged that her mother will die one day but did not want to think about it in regard to what it would mean for her brother and them as a family (who were planning to take their sibling in – when their mother died). *"We hope not for a long time. But she [mum] will one day [die]. I don't want to think about that... We all will one day..."* (Rebecca). There were expressed concerns of

what death might mean for Mackenzie's sibling, Carol, due to family observing that when a character died on a television programme, *"she was very traumatised... And he [then] appeared on another TV programme. That threw her completely."* Furthermore, when their father died, Carol reportedly informed the family the day after the funeral that *"Mum can find a new husband now."* Insight as to what the experience of losing a significant other was reflected by Maryellen (mother) who noted that when her parents died, it was difficult for her son as he *"used to go there for 32 years every Friday."* Similarly, David (friend) reflected that Jamie's aunt, treats him *"far nicer than his siblings have done... she's the one thing [connecting him to his biological family], so when she goes it's going to be quite hard on him."*

There were a mix of ideas evident for the participants with intellectual disability when thinking about dying. Jacob, for example, was pragmatic in linking the image of a steam train with the physiological process of dying in that *"the upper body parts may shut down yes, before it's to sign off for death... That's how I know about getting old."* Conversely, four participants with intellectual disability were distinctly fearful or sad about the notion of dying. Both Leslie and Kate thought that dying would be scary and did not wish to be put in a closed coffin.

"I don't want to die. Not looking forward to dying... Going to be a bit scary... You die in your sleep... I don't want to be put in the coffin... Some people like to be cremated, but I don't want to be cremated. That's one thing I don't want to be when I die, I don't want to be cremated. When I die I want to be buried..." (Kate)

"It's going to be really sad to be that old – quite old... To have a walking stick because they're dying or don't want to live..." (Cyril)

For Leslie this fear was also informed by the fact that she had had experiences of going to funerals and did not like that *"because you cry too much... but they [parents] make me go... to get used to things. They make me go. They make me do it. They make me go..."* Despite her fear there was also a belief that *"it goes up there... Your soul [indicating skywards]. The body goes underground."* Kate and Frank by contrast, showed more concern about the unknown regarding how one might die; *"when you get older you might just one day pass away... Sometimes in bed I just don't like waking up. I say oh no, this is it."* (Frank)

Half of this participant group had experienced first-hand the death of a first degree relative. Kate thought her parents dying would be upsetting and was not sure of what she would do in this event. Jamie remembered feeling lonely when his father died and Bobby recalled the shock with the unexpected deaths of both parents despite him being aware of their significant health issues and the implications thereof. Carol referred to the photo of her grandfather and herself which prompted her to recall the facts that *"Granddad died first...he's the oldest, then my Gran... they died... He was 80..."* Having experienced the loss of grandparents, her father and a favourite horse, she was adamant *"I don't want to die no."* Notwithstanding, Carol equally knew that in the event her mother would die, she would live permanently in residential care. The significance of the clock and encounter with time was connected with a sense of how to deal with impending loss for Trevor as he lived with and cared for his mother; having more time would enable them to *"do more things...Perhaps go for more walks and have a look at more things and stuff."* Both experiential and anticipatory perspectives were seen to inform the understanding that participants with intellectual disability had of dying – as dying was associated with ageing. This was summed up by Samantha who stated *"Getting older makes me feel scared... I don't know – just scared."*

To both a greater or lesser extent, participants with intellectual disability demonstrated an ability for defining ageing in reference to themselves or encounters with significant others. All participants offered insights into the range of ways in which they recognised altered function whilst consciously or reluctantly embracing the reality that dying is indeed connected to living. In doing so, participants showed a sense of movement and awareness of the inevitability of ageing. This had implications for how people contemplated their role in regard to anticipating change.

Anticipating Change

The knowledge and understanding evidenced by participants in *Configuring ageing* further informed the extent to which they were *Anticipating change*. The conscious or unconscious expectation of change consistently evoked uncertainty that was unable to be quantified. Willingness to embrace or plan for change was found to be linked to a number of factors; a sense of looming additional responsibilities, intrinsic and extrinsic factors, and feeling disillusioned due to past encounters with health and disability systems. Whilst planning takes time, some families started to have a sense of 'letting go' to enable others to take on roles and which saw them cultivating new and different expectations about possible service delivery into the future. Of note, the six codes which form this category are solely linked to data from the family/whānau participants in this study.

Looming Responsibilities

The primary caregiving role was not limited to one generation and the question is posed as to where does the family/whānau responsibility start and stop? Whether defined or undefined, family and whānau had an awareness of

impending change and altered responsibilities. Over time messages within and between family/whānau had been assumed, presumed, imparted or distilled to eventually become a common accepted truth or consideration in terms of defining current or future caregiving roles for themselves. The result is that there is often either a limited or no definitive map for moving forward in planning for the future with and/or for the member with intellectual disability. Once again, there were different perspectives about what was looming - depending on where one was placed within the family system. The significance and impact of this variable in *Anticipating change* cannot be underestimated.

A range of projections were found in regard to potential future caregiving arrangements. For example, Lorraine (mother) had not “*thought about it at the moment. Who wants to?*” Whereas Susanne commented that her other children have already indicated this sense of impending change and said to her:

Well you've gotta organise it because if you died, we clean out the house, we do everything and get you buried dah, dah, dah... [And] oh what happens to [Leslie], where is she going? And that's really what started me on respite care.

On the one hand, parents were adamant that responsibility should not automatically fall to the other offspring as:

It's not fair for them to be responsible for [daughter] it's not their job... they've just started out themselves and that's what really started me thinking about it [making a plan]... no forward planning... it's [also] not fair on [daughter].(Carmen, mother)

I've always told the girls or the boys too for that matter, certainly keep an interest in [sister] but never have her living with you because it's not fair to either party. (Evelyn, mother)

On the other hand, there was an assumption that what had already been put in place is all that might be needed to secure the future for their family member:

They [siblings] will never put her anywhere she's not happy. There'll be money there ... and all that's organised through the lawyer... I've got no worry about her welfare after I've gone... (Susanne, mother)

I'm pretty sure [daughter] would take care of him she wouldn't put him anywhere... (Maryellen, mother)

Barbara and Jack (parents) illustrated both a recognition and acceptance of how circumstances constantly changes and their disappointment when anticipated possibilities were no longer on the horizon:

Our [other children] talked about building something... A bit of a flat for [son] but I don't think it's going to actually get off the ground... There will never be anyone come back to [town]... We'd always hoped that [daughter] would come and look after him but I'm afraid... she won't.

Seven female siblings, however, had given looming responsibilities quite some thought. The assumption of role was often ascribed on the basis of one's placement and gender in the family. In reference to looking out for the family member with intellectual disability and/or one's own mother, Adrienne and Rebecca felt that *"it's more because you're the daughter – I think it's*

an assumed responsibility." Deborah identified with this self-fulfilling prophecy of responsibility and added;

I think I'm going to be the person who holds this family together. I feel like there's a lot of pressure on me because my other sister isn't around... I feel like I have to make up for that.

In recognising the need to plan for the future, six siblings reflected upon what had either been instilled in them and what they saw as some of the key elements which may still need to be considered in time to come. The latter includes needing to reduce what is practically done for the family member with a disability within the existing roles in the caregiving network and ensuring that it is known and articulated what other offspring are needing or prepared to do:

...when we were kids, I think maybe our parents made us worry about the future... especially Dad "oh, [brother's] going to suffer" and all this sort of thing... (Adrienne)

Mum very much sees her still as her young child and... will do everything for her and I'm kind of like well you want her to move out, you can't keep doing everything for her, you need to get her to learn how to do things... (Deborah)

Mum really doesn't want to go into a rest home... we did have a recent breakthrough... [brother] telling me he was desperate for a break [as was I]... suggested again that she could have time in a rest home... this time she said oh yes that might be quite nice so I leapt on it (Julianne)

As indicated in the above example, the compounded sense of caregiving is evident where one daughter is not only thinking of needing to plan for their family member with intellectual disability, but also for the elderly parent with whom that sibling resides. Support roles therefore became multifaceted in planning or predicting what may be needed – even before there are timeframes around possible transitions. This was reflected by Rebecca (sister):

I rung Mum back and she couldn't remember what she'd rung for... that's a classic of where we are at the moment... that's when it hit me like a ton of bricks. What else is she forgetting?

However, it was not only the thought of feeling responsible for the mother, father, sister or brother, but rather the certainty of having to also 'manage' the community supports for one or both of them was a burden that is "still on my shoulders." For Julianne (sister), the view of 'still' was due to having grown "up with a sense of responsibility for them already because they [parents] weren't managing that well" – even when her father was still alive. Whilst caring for her brother was a current reality, Teresa had already experienced the reality of an ageing parent as "...it's not an easy life. I knew what I was getting myself into... a month before my father went into the home, my father was here; I was looking after my father." For one also ensconced in a compounded and parallel caregiving role as both daughter and sister, Mackenzie was clear to her mother that:

...If you die tomorrow, one of us [daughters] will still pick up the responsibility. I'm seriously thinking I will hand it over to [sister because] I do all the donkey work done here, she can have a turn...

Fairness and sharing the load was seen as a way forward for all these women who simultaneously felt that they were left to take charge but who were also cognisant that they cannot do it all on their own:

We need to have someone who we might be able to call upon, because I'm the second youngest of six so my family is getting up there. (Jeremy, brother)

The rest of the family will have to step up... because I will need a break. And they are going to have to put themselves out to do it, and it may not always be exactly when it suits them... you need to do it for your own mental health... I'm old enough to admit that now... I've also got a family to think of too... (Rebecca, sister)

In summary, the siblings all acknowledged their own ageing as well. This is significant in the context of all that may be looming and which may pose one of several limiting factors that impact upon family/whānau engaging in future planning for and alongside their family member with an intellectual disability. Thus, *Looming responsibilities* were seen to be informed by both actual and potential caregiving roles, and were informed by factors which may limit the way forward and be an integral part of the existing family/whānau system of support.

Limiting Factors

The extent to which the needs of the family member with intellectual disability impacted upon what the family/whānau caregivers can provide, and conversely, the limits that are imposed by same – is under researched. Such limitations are often intrinsic to the individual as well as extrinsically a function of the wider system of support. The factors which inform this code

were recognised in terms of their contribution to planning, enabling and *Anticipating change*. For example, the safety of the family member was always regarded as paramount, could not be judged nor discounted and was based on experience or longstanding, (although sometimes unsubstantiated) concerns. Barbara and Jack thus ensured their son has a microwave in his downstairs unit as they are;

...a bit nervous to give him a stove...because [they] couldn't guarantee that he wouldn't just walk out and leave it going.

She's very confident. We never leave her... you couldn't quite trust what she'd do in a crisis... She'd do things like hand the electric cord to the three year old to plug in the vacuum cleaner. (Evelyn, Mother)

Murray's son has, for the last 30 years, spent time with a particular football team; however he is not allowed to go out with them for a drink as, due to his health issues and allergies there are concerns that *"some of the guys would be fine... others would test the water... it is not worth it [to let him socialise with the team]."* Despite this, his son is acknowledged to be quite able to follow his parents' instructions about what he can safely eat and drink. Several family members acknowledged that they often do things for their family member rather than with them or expecting them to do tasks independently as it is *"easier and quicker"* (Lorraine, mother; Melissa, aunt).

As current or prospective future carers, siblings identified the actual or perceived lack of support from others limits the reserves that one might usually have to cope from day to day and impacts upon their life currently and/or may do so in the future.

A lot of people they could do it but they're scared to do it, scared to look after them, [people with disabilities]... They won't commit... They're scared of the responsibility because they think it's too hard or I think they're scared of themselves, that they wouldn't be able to cope." (Mavis, sister-in-law).

...and they [siblings] don't check up or anything. They don't really... I've got high blood pressure but it's managed with my medication... But when I go down I go down like a ton of bricks." (Rebecca, sister)

Despite the evidence about intentional or unintentional limitations that may be placed upon the family member with intellectual disability in the interests of safety or levels of existing supports, there was clearly an identified intention by many to plan for the future in some shape and form. However, despite the acknowledged limitations and looming responsibilities, individuals struggled to formulate or initiate plans on several levels. These variables were equally fuelled by external factors which all parties have experienced and which the majority felt disillusioned by.

Feeling Disillusioned

The lived experience over time of advocating for a family/whānau member with intellectual disability has resulted in a distinct mistrust in carers of the health and disability services that have been and/or are currently available; this, in turn, raised concern as to what may be sustainable for them in time to come. Six siblings and eight other family/whānau members echoed similar and often disparaging remarks about the challenges faced between the services or assistance that were sought and what was actually available and/or delivered to them. It was acknowledged that some of what was

occurring at the coal face was simply the result of changes at a national policy level:

Well, can you make any plans because things change all the time? You know it's very difficult... They get the homes so far out, no transport... those kids miss out on a lot... (Jack, father)

I even found the plan the other day of these lovely little units they [organisation] were going to build... they're still not built... They ask [daughter] what she would like to (they want a goal put down)... well that's been 12 months but it's still coming! (Susanne, mother)

They abolished the Act that allowed them to pay less than the minimum wage... he [son] like all the other clients felt they were a vital cog in the big wheel. And now they're nothing... they all had their job to do... Some of them who haven't got a lot of ability to speak, they knew they had a role and that was their job. They felt very important. So actually I think it's been very detrimental... (Murray, father)

Reflecting on such changes in legislation and the implications for meaningful engagement during the day was noted by several family/whānau who sadly reflected on the remarkable negative impact on their family member.

[What was available]...slowed her thinking. I think it slowed her down quite a lot because the less she's done... the less she's actually motivated to do... we got told that as siblings we didn't want the best for [sister] in terms of the day base closing, we didn't know what we were talking about and all that kind of rhetoric... (Evelyn, mother)

They [organisation] don't look after their volunteers... But she was marvellous with him [son]. But unfortunately that doesn't last and you get somebody else... it changes all the time – It's very difficult (Barbara, mother)

This sense of 'service fatigue' saw families/whānau *Feeling disillusioned* due to the experience of repeatedly seeking entry into services and as services often changed in terms of scope, focus and length of involvement. Over time, this meant they have often become reluctant to re-engage with systems. Ten family/whānau participants expressed their frustration at the amount of time that it took to find out where to go and for what services in the disability sector; this exasperation included the responsiveness in exploring avenues of support.

It took a year to get [brother] assessed really and get the proper help... (Julianne, sister)

We couldn't even have got somebody to after her while we went [to a family wedding] because there's just nobody to get (Jeremy & Mavis, brother and sister-in-law)

You wouldn't believe the number of people we've spoken to about getting him into the system. Man it's been trouble... What do you want, why are you asking this? What do you want to do that for? Because we're his safety net now... there's so much red tape. It's unbelievable the amount of nonsense that goes on... (David, friend)

I had no help from anyone. I went to the disability people they didn't want to know me... For almost a year I had [brother] at home... (Teresa, sister)

For the latter family member (Teresa, sister), not being able to access services in a timely manner meant that she had to give up her job for that period of time. This experience of feeling disillusioned extended to and included disability residential and vocational service options as well as mainstream primary and secondary health care. It was thought bad enough to have to fight for meaningful engagement in the community through the disability sector; demanding this from the general public system raised concerns in the family/whānau; if it was not for involvement of family/whānau – then what would be the outcome for their family member?

Because [district nurses] didn't do it [manage brother's diabetes] properly resulted in him being hospitalised one time. They knew he was sick but they didn't tell us and it only so happened that one of use went round and saw he was sick... (Adrienne, sister)

I said no I need help now not tomorrow... so I waited and waited and waited and rung up the hospital and said have you got the referral note, they wen t no, rang the doctor a month later and I said have you sent that letter [referral] – oh no must do it... (Maryellen, mother)

He reckoned [sister-in-law] wasn't his patient... One of them reckoned she was a surgical patient and the other one reckoned she was a medical patient... they stood there and argued about that; nobody wanted to look after her... the nurses are quite up themselves really... I said no – she is not going to be zonged to the eyeballs just to keep her quiet... (Mavis, sister-in-law)

Feeling disillusioned had the potential to induce further reticence for family and whānau in thinking about and planning for the future alongside their friend or relative with intellectual disability. There was a longstanding experience for familial caregivers to see the ebb and flow of health and disability services over time in terms of constantly changing service provision and funding streams as well as their own willingness to engage with the systems they once advocated for. However, the impending shift in roles and responsibilities for family/whānau were also seen to be tempered with an awareness of needing to hand over the helm in time to come.

Letting Go – Enabling Others

Despite the aforementioned disillusionment, there were at least eight family/whānau participants who, albeit cautiously, asserted the possibility and/or inevitability of (positive) change in time to come. Changing the focus of caregiving roles to letting family members themselves develop further autonomy and/or reluctantly embracing what services have to offer – is the essence of this code. *Letting go – Enabling others* is acknowledged to possibly be within the family/whānau system itself and/or be community based and external to this.

In moving forward in supporting greater independence for their family member Mackenzie (sister) acknowledged that “...*we take a risk with her bussing because you have no idea who she’s coming across but it’s a risk you’ve got to take.*” Caution was expressed in regard to the option of using a shared care facility as “*it’s also again that fine balance about them [service] not taking over that role [of taking sister to the doctor] ...it’s about that fine line of how much do you give over.*” Carmen (mother) also embraced the notion of the shifting sands of responsibility and what that would mean for herself as it would be up to the carer to manage “...*the day to day stuff. The nonsense. The behaviour.*”

Jamie's friend was keen to explore opportunities for what a support worker could offer in lieu of himself and his wife and wanted to ensure as smooth a transition as possible and hoped that they will *"co-ordinate with us – and see what we do and sort of follow on in the lines that we've done... I just want a continuation of what we do... [then] we can just be friends..."* Similarly, for Preston's sister Julianne, there had been a comparative process, although this had been actualised as the support worker *"has taken a very long time and a very delicate approach to become his confidante... but she's of course got the experience and she's not a family member."* This experience of *Letting go - Enabling others* was a relief for this sibling who was equally aware of the fragility of the relationship and the risk of further unsettling change in the future.

Maryellen (mother) had finally found a release in entrusting care to others, through a respite basis as there had been a history of unsustainable alternative caregiving arrangements throughout her son's lifetime. Susanne (mother) however was adamant that waiting was not an option and firmly believed there was a parental responsibility to put things in place:

...it's important that they [families] get organised because we think that we're gonna live forever... I think as long as they [parents] don't have their head in the sand about not providing for them, or arranging what will happen if the parent dies...

A mix of caution and relief was evident in the narratives that gave rise to this code as every member of the family/whānau system made decisions that were based on their lifelong experience as a primary carer. Whilst not all possible eventualities can be accounted for, those contemplating future options for themselves and their family member resemble *Unknowing explorers*; the destination is not yet established although the journey has long

since commenced and time must be taken to plan for both current and opportunities.

Unknowing Explorers

What information is needed and where do the interested parties obtain that in order to enable individual and/or collective 'mapping' of the possibilities? There were many frustrations identified (both intrinsic and extrinsic to the family/whānau system), resulting in a sense of being *Unknowing explorers* in the topography of health and disability systems: These were informed by previous experiences and were coupled with the perceived inertia of the time required for such planning to occur.

Parents and siblings alike expressed anxiety about knowing where to go or who to talk with in the event they wanted or needed to explore support options including in-house, future accommodation or other community-based supports: *"We've done a lot of spadework and he's not in the system... once we're not here we don't want him to hit the floor..." (David, friend)*. Seven family/whānau had either never had to use services so do not *"honestly know what other services are out there... [or] we don't know what to ask for..." (Richard, father)*. Contact options identified by family/whānau participants included the internet, the general practitioner, or a local needs assessment service.

I've got a glimmer of hope... where they [service] have different levels of care... I think [brother] might be more open to that suggestion now (Julianne, sister)

Now that she's deciding that she doesn't want to go places, I'm going to have to get somebody, and preferably somebody who will come here (Mavis, sister-in-law)

The latter example demonstrated the reality for second generation carers; Jeremy and Mavis (brother and sister-in-law) have taken up the role since the death of the mother. Their needs and reality have altered over time as their sibling with intellectual disability ages and they were now finding themselves at a crucial planning stage as her needs are changing further. Such truths highlighted a perceived diminishing opportunity to explore or discover what may be conceivable in the future both for themselves as family/whānau and in regards to their family member with intellectual disability.

I don't know what's going to happen so I would like them [mother and brother] to decide what they want to do... (I want them to move here - UK), I'd like them to settle... I know she's [sister] not necessarily keen on having responsibility for looking after them, but if my Mum did die, I wouldn't want them to upset [brother's] entire world' (Eleanor, sister)

I hope that [sister] will get a place of her own, that she'll be happy and she'll be near places that are important to her... being relatively independent... having a carer come in and help her with grocery shopping and cooking if need be.(Deborah, sister)

In essence, some family/whānau did not know what they did not know or needed to know. Of note, once again, this sense of being *Unknowing explorers* was largely the domain of siblings and friends. Critically, this reflected the impact of inheriting a role as opposed to having been involved in the original decision-making at the parental level. For those that permitted themselves to 'go there', *Evolving expectations* in regard to themselves, towards others in the caregiving network of support or the wider system, became more overt.

Evolving Expectations

Through any change process, whether anticipated or actually planned, it was not unusual for there to be stated or tacit expectations. For twelve family/whānau in this study, the possible future scenarios for their family member with intellectual disability were either inherently understood or still evolving. The examples below will be seen to evidence that the execution of such prospects were considered to be paramount either for those internal to the caregiving system and/or the responsibility of external services.

The narratives show that there were clear beliefs evident from the first generation of caregivers as to where the expectations lie for family/whānau to embark on subsequent care arrangements:

I just hope she'll pass away before me... Failing that I have great faith in the two [other] children... that they won't just place her anywhere... and believe you me neither of them will let a situation arise that they don't stir up and kick about... (Susanne, mother).

I'm quite relaxed that if something did happen to us that he would be well looked after... [son or daughter would pick up guardianship] (Elspeth, mother).

...he's got good friends... I'm sure they would all see to that [support if something happened to aunt]... the whole thing changes [service configuration] all the time and he'd speak up for himself... (Melissa, aunt). All I know is that she'll have a support worker... She'll need someone to help teach her to cook... it maybe selfish but I see that as being [service's] job in a sense (Carmen, mother).

For the siblings, the uncertainty as to who would step up and when this would occur – was no less tangible but simultaneously one step removed from the context and belief system surrounding the original decisions. There were distinct similarities to the responses of the parents as above, including expectations of services to step up, and, ironically, the need to instil the same sense of responsibility in the next (or third) generation to support the family member with intellectual disability further into life and the future.

...where's the support for siblings who are now, like me, starting to step into roles... [and] are potentially getting too old to do... I guess as we get older we'll just age with her... at that point you've got to rely on other organisations stepping up and taking over (Evelyn, mother).

Hopefully we've set a precedent for the others to follow. It seems to be. They [other family] seem to be quite caring (Mavis, sister-in-law).

...she's the mother of my granddaughter...I'm still Mum to her – I call her my daughter... and that's where he's [brother] going when I die (Teresa).

It was noted that the possibility of taking on the primary caregiving role for one's brother may not be one-sided in its effects and that there may be mutual benefit; this was the first suggestion in the narratives that the family member with intellectual disability may have something to offer others within the caregiving network:

He [brother] might come and live here and he might be extremely good help to me, because my husband's 12 years older than me. He might get sick... I might need help looking after him. So [brother] might be an absolute godsend to me (Rebecca, Sister).

The intergenerational positions regarding caregiving responsibility were seen to be both instilled (by parents) and distilled (by themselves through doing) for individual family/whānau and collective systems. Some were stated and others implied. For siblings who had already made informed choices about their future roles in regard to their brother or sister with intellectual disability there was a clear sense of being cognisant and being able to voice the imaginable implications. Support needs were identified for themselves as primary carer or guardian from both within their existing family, as well as from the health and disability sector to ensure a sustainable future for their sibling. Whilst previously noted that family/whānau might state that they have no expectations, these (expectations) were still evident and evolving for participants.

Chapter Summary

Whilst ageing and change is inevitable, this category of *Shifting Sands – Changing Tides* illuminated a non-linear trajectory of what constitutes getting older for all parties. The consequences of this posed an unsettling anticipation about what may need to be in place for family members with intellectual disability and for those who choose, are expected or resigned to being responsible for their futures. Whilst subtle, some family and whānau participants acknowledged the need to embark on further conversations to uncover what is or is not yet known about the options or opportunities that may be available in time to come: Others were not yet ready to commit. *Configuring ageing* and *Anticipating change* thus illuminated and clarified the challenges and tangible nature of *Shifting Sands~Changing Tides*. Despite the uncertainties of ageing and its resource implications for family/whānau, there was still a sense of hope and optimism for what might be construed as the

future. The final category *Uncovering Horizons* explores this further from the viewpoints of all participants.

CHAPTER 7

UNCOVERING HORIZONS

*The past is behind. Learn from it
The future is ahead, prepare for it
The present is here, live it
(Thomas, S. Monson)*

The accounts allowed for thinking beyond the here and now and uncovered a daunting yet potentially exciting move from an unforeseeable future to the inevitable future that held potential; this signalled a very real encounter of what facing the future may entail for all participants. *Uncovering Horizons* heralded tentative yet pertinent perspectives on key elements that inform how thinking unfolds and which may be predictive of the eventual trajectory into both the individual and collective futures (Table 9).

Table 9. Uncovering Horizons (Appendix 19: Summary of Results)

Code	Category	Concept
Looking forward		
Changing circumstances	Entertaining possibilities	
Having an identity		
Enjoying living		Category three
Keeping well	Creating a good life	Uncovering Horizons
Connecting with others		
Knowing the person		
Facilitating ownership	Mastering decisions	
Engaging the system		

This concept contains categories which reflected distinct and mutually agreeable participant viewpoints on daring to entertain possibilities, what it means to create a good life, as well as valuing the mastering of decisions. The experience and realities of engaging with that which is both known and yet to be discovered was seen to require constant adjustment and realignment of roles, expectations and perspectives by the majority of participants.

Entertaining Possibilities

For many, the category of entertaining other possibilities in one's life solicited a range of responses from those that may be preferable to the current situation, to those that evoked doubt and speculation. Looking forward invoked two meanings, one that related to future planning and the sense that engaging in change allowed one the unadulterated excitement of experiencing other opportunities. How one understood these was potentially informed by a recognition of changing circumstances together with a recognition of what is important to one's continued sense of self or identity.

Looking Forward

It was evident that, despite the apprehension experienced when anticipating change, participants were still able to conceptualise what was important for them. For participants with intellectual disability, there were clear expectations or feelings of anticipation about the possibilities that the future could hold. Three siblings, three parents and the three friends described seeing the future as something that was tentatively going to enable them or the family member with intellectual disability the opportunity to enjoy and take charge of their own destiny as far as was realistically possible. *Looking forward* was not only about seeing the person with intellectual

disability move on, but was also about 'owning' where they were in relation to the person whom they support.

I think once [friend] gets her scooter... she'll go out on her own a bit more and I think that will be very good for her... then probably I'll have a bit more time to myself... and she might enjoy that too – not having me there (Stephanie, friend)

...if you start [making decisions based on sister's needs] then what's my life worth? I think you have to be careful there about whose life you are living... (Evelyn, mother)

We're actually preparing [daughter] to move out this year... I'm looking forward to starting my life... even though she's still here the ton of weight's already been lifted off my shoulders... (Carmen, mother)

Thirteen participants with intellectual disability were more specific about what they perceived the future may hold for them. Generally speaking, looking forward by this group signalled new opportunities to engage with life as well as identifying possible realities awaiting them as they themselves age. There were a range of abilities to either conceptualise what getting older might mean for them in time to come or, whereas others felt that reflecting on the moment was just as significant. Four participants fell into the latter group as Trevor, for example, expressed the belief that *"I think the future's here now."* The other three were quite satisfied with their current life and found it difficult to project what the future might look like as illustrated in the following examples:

I'm quite happy what I'm doing. I can't think of anything I want to do for the future. (Kate)

[Not looking forward to getting older]... No idea why - I'm not there yet"
(Maddie)

For nine participants, the idea of looking forward allowed them permission to entertain goals of how things may be different to their current situation. What was apparent is that a number of participants were not able to do things currently that they would prefer and hence are still waiting to attain these goals at a later date.

Going out more [when older] (Mitchell)

Going on a plane for one thing... Not pushing trolleys. I'll be enjoying retirement... that's in about 14 years away (Jamie)

I want to be a chef and artist... they all teach me how to spell, read and use the phone... (Cyril).

The notion of retirement was also considered by four of the nine above participants and formed a key element of looking forward. This supports a recognition of the natural developmental stages that are seen to usually coincide chronologically with ageing: Retirement was clearly correlated with either not working or there being a reduced requirement to work. As demonstrated in the stories and quotes, this is observed to be linked with changes in one's circumstances and in doing other things (other than maintaining the status quo).

...we jokes and say we'll be in the same home together (Samantha)

Retire... going into an older people's home... they get the benefits... don't work... Looking forward to being unemployed, to play more bowls in the week (Peter)

...Maybe a small job. Retirement. I like the opportunity to probably get out more, go on a holiday because there are some parts of New Zealand I haven't seen yet... (Preston)

Figure 16. Kate and her Sister



However, for Kate, the significance of looking forward also held the uncertainty of what was yet to come as she has been told that when she gets “a bit older [you’ll] have to go and find a flat... It was quite a shock and I felt frightened... they’re really hard to get – real flatmates. I don’t mind being by myself... But you’ve got to find the right flatmates that you can

get on with.” This verbalised recognition of the inescapable was prompted by a photo of her with her sister who has initiated conversations about the future. Whilst this pre-empted discussions about inevitable changes as she gets older, she also reflected the hope that this is “a long way down the track yet.” Whilst cognisant of such inevitability, Kate was the only participant who overtly voiced the realisation that the direct impact of losing her parents may yet have on her current and future circumstances.

There were therefore a myriad of perspectives in this code which depended upon inherent knowing and acquired learning in the presence or absence of personal goals and aspirations. This signalled a deeper grasp of what would be important to each and every participant and which was for most, a previously untold or unknown ambition. Of note, this consideration about the future has been largely characterised thus far by the respective family/whānau through the earlier concepts. The participants with intellectual disability themselves were, however, able to express what may have meaning for them in time to come and this was extrapolated further in the next code.

Changing Circumstances

Whilst *Changing circumstances* was inevitable and necessary, the opportunity to contemplate this had been minimal for participants with intellectual disability; their accounts and perspectives are solely represented in this code and are clearly linked to the concept of *Entertaining possibilities* and For those participants with intellectual disability, who chose to be interviewed with the support of family/whānau, their ideas were new to their caregivers. At least fifteen of the nineteen members verbalised some vision for preferred alternative living arrangements. There were those who were currently in the role of caring for their mother, for example, who vacillated between being more independent and yet still feeling ill-prepared:

...if I had a big enough house, I'd live there by myself. I'd get people in... to do the lawns and the garden but I'll do the rest... I think I'd just travel New Zealand... If it was a nice day I'd probably be walking... come back and get my tea and watch TV for a while. Just have to wait and see...(Trevor)

I didn't really want to move and [neighbour] he's a guy that I trusted, he got me in one day to have a chat because he knew it [the move] was coming up and he offered to help... neighbours were popping in with cakes. (Bobby)

...if Mum goes I wouldn't be able to stay here... [sister] would probably help me with some things but I think this house would probably have to be sold... So whether or not I could [manage on his own]. (Preston)

For five participants, how any change in circumstances may be actualised, was clearly dependent upon support from others. This recognition sometimes came through their own awareness of their abilities, confidence, or experience over time or was seen to be based on messages which have filtered down to them over time.

If Mum and Dad were died, my sister and brother will come down and take me to one of the homes... hopefully they would help me (Leslie).

Whatever happens to Mum and Dad, I'll probably be staying with my sister for a while. (Kate)

Coming here to live [at sister's house]... Long time [before it happens - Mum dies]. (Jeffery)

Oh I just think when I get older... I'll be living in a rest home [as his father did]. (Tony)

Stephen expressed the hope that he would go and live with his brother if he was given the option. The reason he gave is that his brother “*is great fun... gives me home brew beer.*” The remaining participants either wanted to live alone (n=3) or in a flat with at least one other person (n=4).

A range of responses informed this code and these were constructed either spontaneously or throughout the participant's lifetime and reflected messages they have received or, in some cases, their own aspirations. Regarding the latter, these had not been previously expressed let alone shared with their family/whānau until the interview occurred for this research. What this reflected was an inherent individual personage that was unique to each and every participant and *Having an identity* was integral to this.

Having an Identity

For some participants with intellectual disability there was an acceptance of the inevitability of getting older, whilst for other this raised considerations and uncertainties about the role of identity over time and place. It is only this participant group which is represented in this code. For four individuals, connecting significant memories through their chosen photos was poignant in revealing their sense of *Having an identity*; this provided a unique insight in coming to terms with, verbalising and understanding their current reality.

Over the course of 28 years for example, Bobby was the head painter in the service in which he worked (Figure 17). With philosophical shifts and the resulting contractual changes within the wider disability sector he was made redundant. Hence the choice of this picture by him spoke directly to his identity *"that was my life as a painter, as a toy painter... It was a good life...I did it for 28years virtually... I liked the job – you know what I mean..."* The opportunities also now seemed diminished for Cyril who fondly recalled working in a bakery; the photo of him standing behind a table of baked goods reminded him of what he could do when he was younger contrasted to his belief now that he is *"a lot older now, getting older."* (Figure 18)

Figure 17. Bobby as a Toy Painter



Figure 18. Cyril as a Baker



Figure 19. Maddie in Hospital



The impact of connecting significant memories in revealing one's sense of identity was reiterated by Maddie who, at the age of five, sustained a head injury and broken femur when she was run over. In describing the event, her key rationale for selecting this photo was that *"it brings back memories about what happened to me... there's a mark on my head where the wheels ran over me."* In other words, she sees it as

the reason she has experienced the limitations of a cognitive disability throughout her life and which *"haven't been much fun."* In getting older, continuing to exist because of this is a challenge as she saw the accident as a defining feature in the trajectory of her life.

For a further thirteen participants, their need to be recognised as an individual with skills and someone who has something to contribute – was unequivocally noteworthy. The reflections which were volunteered as part of the interviews were based upon past roles that had value to them personally and/or perceived value to others. Having an identity encompassed a sense of meaningful roles and being connected and these are illustrated in the following examples:

Actually I was at day care when I was working, no at kindergarden... I worked there part time when I was at the workshops... I love kids (Samantha)

I'd love a small paid job... I don't mind working at [rest home] but I want to get paid for it... talking to the oldies and having cups of coffee with people I work with – workmates (Kate)

I go to the library and see my friends there. Spend time with them (Frank)

I call out the numbers [when at the day service weekly] (Samuel)

I worked for [name of company] – did the luxing, mop the floor, did the rubbish... it was pretty good though... someone else has taken over (Pauline)

I like to draw pictures there... Abstract drawings... I like to be happy with people there... and the tutors like me because I'm the best (Jacob)

Jeffery, who had part-time work, was hoping for full-time employment: *"If I retire yet... I'll go working earn my pay... Yes – more hours – would love it."* In contrast, Preston has *"enjoyed not working because then I've got time to do things that I want to do like there's my trains and I like going out a lot..."* The above reflect a sense of worth of themselves and hope for that either to continue or actually happen for them again. This sentiment was no different for Jamie who has had the same job of collecting trolleys for nineteen years, and whilst he enjoyed meeting people, he would like to be able to try something else.

The value of personhood was clearly evident in this code as the majority of participants expressed what is or had been important to them and which instilled a sense of *Having an identity*. Having the ability and opportunity to contemplate *Entertaining possibilities* was informed by the expectation that one's circumstances would change in time to come. Hence,

many participants, both family/whānau and people with intellectual disability, gave themselves permission to explore their perspectives and to look forward as they were individually and simultaneously *Uncovering Horizons*.

Whether the roles which formed one's identity were self-made, afforded them or limited by others, there is no negating the value of what these roles represented for participants. It is posited that having such functional roles enabled participants to entertain possibilities of *Looking forward* regardless of the autonomy they felt they possessed or did not possess and in spite of the potential or actual realities of *Changing circumstances*. This construct of achieving an 'identity of consequence' contributes to what it means for people with an intellectual disability to create a good life.

Creating a Good Life

The codes *Enjoying living* and *Keeping well* underpin this category and were poignant for participants with intellectual disability who were eloquent in attributing the factors which they thought would enable life to be good for them. These factors are seen to be in contrast to the factors aligned with the concept of *Configuring ageing* as the focus is now about what is needed to reduce the likelihood of frailty and maximise opportunities in this category of *Uncovering Horizons*. These codes offered and reflected hope as to the prospects which may await those with intellectual disability as they strive, in the most part, to think beyond the here and now and maintaining wellness in the process.

Enjoying Living

The majority of participants explored and identified what would make life good for them right now or into the future. Thinking about getting older and *Enjoying living* was comprised of preferable activities, the levels of support required and/or the health status needed to achieve these. There were a myriad of images that surfaced in reference to what life is like now and in the hope that life would not be squandered in time to come. The hope of being able to appreciate life even more and/or in different ways was explored by at least half of this group. For Jamie this was deemed possible as he had a *“Kiwi saver and a retirement fund... would be sleeping in. Enjoying life.”* By virtue of having a job, Jeffery also maintained that *“I work hard, earn my pay”* which allowed him to *“save more on a holiday – I love that.”* At least four other participants also aspired to explore other horizons which included specific destinations such as Paris (Frank) and *“go to see The Bill... Go to England”* (Stephen). Part of enjoying life included a sense of freedom as Bobby commented that *“sometimes you feel like you just want to be by yourself when you get older.”* Whilst this was desirable Leslie thought that she would still *“need someone”* with her *“all the time”* and similarly, Preston thought he would *“still need help even after Mum passes on...”* The hope of getting married was tangible for Carol, finding someone to help him get a job was a priority for Cyril, whereas Peter saw *“being unemployed [as an opportunity to] play bowls more days a week...”* and having the opportunity to choose his own flatmates as things that would make living more enjoyable for him.

Enjoying life at the present time was just as important for participants and was expressed by describing things they do now and ranged from spending time at the farm as *“there’s friendly people out there... I’ve got my best friends at the farm”* to the church as *“there’s good people there too”* (Peter). Critically, this also exposed the idea of relationships as being integral to

enjoying life. Existing activities such as going to the airport or to school (Mitchell), or when with their vocational service “*we go in the van and we just ask and [they] take us anywhere*” (Tony) were seen to be still important for now.

However, the notion of enjoying living was not so evident for two other participants with intellectual disability. In fact, their sense of living into the future was quite the contrary: Maddie was adamant that “*I just hate life in general – that’s all*” whereas for Preston this was more concrete; he was worried about the possibility that he, like others could get cancer and “*no I wouldn’t be looking forward to that – no.*” Hence, the motivation for, or ability to embrace or create a good life was buoyed by many factors and was primarily dependent upon *Keeping well* which forms the next code.

Keeping Well

Eight participants with intellectual disability recognised the need for and/or identified their ability to manage their own health and wellness as being important for nurturing the notion of having a future with hope. There was a mix of internal and external influences for *Keeping well* which were informed by what health professionals may have previously said to them or their own experience of managing their existing health conditions.

The accounts also revealed the presence of different levels of motivation. Four of this group, for example, had an established awareness of the need to be cognisant of their mental health history and how it manifests and impacts upon them: Maddie, for example, noted that her “*depression’s not that good... I wish I was dead... Taking my pills [helps],*” and this also helped Samuel. Being monitored by the doctor was reassuring for Jamie as “*she said there’s nothing else wrong with me.*” Cyril spoke of seeking out a nurse should he become unwell again due to his past history of experiencing “*all the voices*” and he valued that he can “*just talk to her how what’s going on for my mind.*”

The remaining five participants who commented about keeping well for the purposes of a *Creating a good life* did so in a number of ways; restricting sugar, going for walks or dancing to maintain fitness, not smoking, and Jeffery expressed the view that he was “going to lose weight too.” Managing his diabetes was important for Trevor as it has been difficult to get under control; “...but it’s good now... if I don’t exercise doctor once said my diabetes will get worse by the time I reach 60... So I exercise sometimes every day.”

Once again, participants with intellectual disability were surprisingly articulate and aware of the factors important for them in *Keeping well*, and which had enabled them to get on with *Enjoying living*. This group’s accounts clearly shows how they were uncovering their own horizons – albeit often in private as these hopes and preferences had not previously been explored with them.

Physical and mental well-being were found to be key contributors to the prospect of *Enjoying life* both now and/or into the future. Having such personal future goals demonstrated that people with intellectual disability are wanting to have a good life and can recognise the limitations for this now and can generate ideas about how to overcome identified future obstacles. One such obstacle was, for some, the extent to which family/whānau grappled with their own sense of role and responsibility in regard to this significant other: The latter will be demonstrated in the next category *Mastering decisions*.

Mastering Decisions

When is the right time to take the next step? Whose interests are at the forefront, and who is included in the process? In *Mastering decisions* these are the questions and accounts that individuals and their families considered in regard to contemplating future roles, needs and goals for all concerned.

Factors which both strengthen and illustrate the resolve of family/whānau in enabling future planning, include *Knowing the person*, *Facilitating ownership* and *Engaging the system* and which comprise three of the four codes in this category. For all participants, *Connecting with others* signified the importance of having natural relational supports by connecting with, and feeling uplifted by, others; this enabled links to be made in the processes of choice-making and are skills identified as being needed in *Uncovering Horizons*.

Connecting with Others

This code is richly filled with both a recognition and acceptance by all participants about the existing natural and potential supports that are integral now as well as being potentially available to the life of the family member with intellectual disability. It is also critically aligned with identity formation as previously discussed. The people themselves nominated relational connections within and external to their own family/whānau who, in turn, saw this as an extension of themselves and enabled them to contemplate what the future may hold.

For five participants with intellectual disability, this sense of belonging was rooted in their existing family – specifically siblings – and was based on time spent, existing roles, and knowing they could make contact if necessary. At this stage for Leslie it was about spending time with her sister when “*I go and stay with my sister for a couple of hours*” and for Preston connecting was in regard to getting things for his mother and “*anything that’s going to help... medical appointments.*” For eight others, a strong sense of relating to others was reflected through connections with friends (n=3), respite care (n=5) or services in the disability community or public arena such as the chemist (in managing medication).

The neighbours over the road keep an eye out... in the house either side, they keep an eye out too. (Trevor)

I go to Carer Support sometimes to give Stephanie a break... I quite like it. It's different people and you get used to stuff. (Samantha)

He's like a Dad [respite carer]. It's just their house is like home... A home is where you feel welcome and the people in it like you to see you there..." (Maddie)

I'm the boss [laughing]... Hard woman... Bossy woman too [aunt also laughing]... Ring my friend up [to] help me [if Aunt not able]. (Mitchell)

Similarly, the family/whānau themselves reflected upon the links both internal and external to the relational caregiving network. Many of these connections were either a constant reality or had evolved over time. Stephanie, for example, was acutely aware that the relationship with her flatmate was pivotal;

...[what flatmate needs] it's the friendship it's the knowing that she actually belongs to something or somebody. Even though it's not – we're not normal family to her it is a family and it's that connection that we do have. And it is something we will always have, no matter what happens...

Eleanor recognised the potential need for her brother having more contact with the extended family but which does not occur often at the present moment. This connectedness was more tangible for Deborah who was heartened that her sister Maddie had on the one hand found this sense of belonging with a maternal uncle, and on the other hand, had equally “more or

less helped raised me [as] she's always been there for me... she's almost like a second mother to me..." Given the limitations of what the family/whānau setting could offer in terms of stimulation, three parents took comfort in the roles (and associated connectedness) their son or daughter had in the local church community as:

They all make a great fuss of her as church... People are lovely to her.

(Susanne, mother)

If there's any cleaning at the Church or anything, he [Peter] will always go around and help. He likes to be part of, and he is capable of doing... He also has a ringing list, he has to ring all these people... some of them are our friends... He rings them more often than we do! (Barbara, mother)

The wider community was also evident in the accounts as providing a function of inclusion for four others; Mackenzie thought her sister “*seems to have friends everywhere... she's got an amazing ability to know people – and people know her.*” This example was also akin to that of Murray's experience for whom a bus ride was an eye opener regarding the importance of familiar strangers in regard to his son Stephen;

...we didn't realise that all the people on the bus keep an eye on him... he got off the bus one day and went the wrong way... the bus driver had parked his bus in the bus lane and came back because two or three of them [passengers] said he's going the wrong way.

However, the accounts also revealed a more concerning aspect for four family/whānau as they were each worried about their friend, son or daughter being lonely without the adequate support of family/whānau or disability

services. Hence whilst for the majority of participants the tacit connectedness they experienced from one to the other was not limited to this arrangement, it did instil a need to appreciate what is important in discerning decisions about the future.

“No he doesn’t have any friends, no. Like nobody will ring him up and talk to him... I want him looked after big time... because he’s not my husband’s child... (Maryellen, mother)

I’d like to see him not lonely I guess... he’s had a lot of interests in his life hobbies of various sorts... but the model railway’s one that has stuck... he’s got in with a group of men who seem to be quite kind to him so he doesn’t seem to be as lonely... (Julianne, sister)

Carer at a house that was up there for retarded people. And he used to go here an awful lot [for companionship]. She’s been a really good friend to him but when that place closed, when it emptied, he had nothing... (David, friend)

It was clearly identified that all participants had some sense for themselves about what is or would be important in time to come. Essentially meaningful relational connections (both internal and external to the family/whānau system of care) pre-empted ideas about what may be needed when one is *Mastering decisions* about the future. Central to this was *Knowing the person*.

Knowing the Person

This code, as for the remaining two, were informed solely by responses of the nominated family/whānau participants. Each delves deeper into the cognisant perspectives which consciously, or unintentionally, facilitated

continued decision making with, and for, their family member about *Uncovering Horizons* beyond the here and now. Elements of protectionism were found to drive the under or over-estimation of families' perceptions of the extent to which a family member could contribute to discussions about their own future. Equally intrinsic within and underpinning this knowing is the fear, anxiety and anticipation of individual needs and nuances and which may potentially make (or break) future caregiving options. Whether a barrier or facilitator, the quintessential knowing of the person by family/whānau underpinned the expectations they have of themselves or prospective others who may become part of their family member's life.

Such knowing about the identity, connectedness, roles, rituals and responses that family/whānau recognise in their family member with intellectual disability was seen to influence the trajectories of day to day living. These factors were considered to inform the quality of life, meaningful and respectful engagement in the home and community. Susanne for example reported that it is hard to know when her daughter Leslie is sick because "*she doesn't really complain. She's got to be really on deaths door to get her to the doctor*" or some family/whānau worried how to respond if "*she [Pauline] fell over, then she goes into a faint and nobody can shift her*" (Jeremy, brother) and when upset Samantha will "*just go to her room... I just let her go and she'll come out - when she's ready*" (Stephanie, friend).

A further nine family/whānau positioned their responses about knowing the person by describing their personality and skills as well as what might be possible for them. Deborah acknowledged that her sister "*tries her best to help, even if it doesn't always come out as she intended it's always well-meaning and she's always really sincere in what she does.*" The need to "*always have a routine*" (Maryellen, mother), and wanting to keep busy (Murray), builds on Julianne's hope that her brother Preston can live with others if the

situation was “*carefully managed [as] he does seem to blossom when he’s in a family situation where he’s accepted and can have fun...*” This may not work for everyone as Rebecca maintained that her brother can look after himself provided he is in a familiar environment, otherwise “*he wouldn’t have a clue.*” Murray reflected several parents’ concerns about their family/whānau member not having “*a great concept of money... he’s got a very good memory but no comprehension with time...*” Notwithstanding this, the sons, daughters, siblings, nephew or friends were all considered incredible individuals in their own right and were described as generous, honest and personable. However these positive attributes contained concerns about the risk of the individual being vulnerable to more others:

He’s got a most beautiful personality... he can judge people and it there’s something about that person I can tell if he doesn’t want to answer a question he’ll change the subject... (Melissa, aunt)

He is one of the nicest people. He’s clean, his flat is clean... He makes sure his clothes are always clean and ironed... just his cooking isn’t great... He is honest... He can’t lie. He’s punctual, he gets to work on time... and he is helpful especially to long term customers. (David & Edith, friends).

The perspective that family/whānau held was based on both their personal experience and attachment to their family member. It informed how they prioritised opportunities in the current setting and in thinking about the future. Many family/whānau were intensely aware of the need to ensure this did not subjectively cloud the manner in which they engaged with each other and thereby were attempting to ensure that their role changed over time to a role characterised by *Facilitating ownership*. This showed a need for sharing in

– the mastering of which would facilitate *Uncovering Horizons* for one or more parties in the caregiving relationship.

Facilitating Ownership

Ownership is not static in form, time or the place in which engagement occurs, an individual's ability to make choices ebbs and flows over the lifespan, as does the opportunities. *Facilitating ownership* linked the perception of the person's ability with the practice and manner in which choices are made for, with and between family/whānau members. Interestingly, of the eleven family members who specifically spoke about how decisions were arrived at, half of the responses were from siblings. The approach from siblings, regardless of the decision to be made, was one of guiding and checking how their family member feels about what is under discussion and to:

Give him [brother] time to think about it and not present it like it's just got to be that way, he's got to be respected... plant a seed really... I know some of the decisions he's made prior to having help not – I was not really in agreement with but then he's entitled to live his own life... (Julianne, sister)

You kind of have to guide her [sister] to the decision in that case but you're not making the decision for her, you're being more like – how do you feel about it? (Deborah, sister)

Teresa was surprised by her brother's unexpected response to needing to go into respite care so she could have a break as she "thought he would be devastated [not to go away with her] but ... he said to me I think it's good sister because you're going to have a break from me and I'm going to have a break from

you." The parents also expressed similar thoughts as to how they facilitate decisions, from offering two choices and revisiting the options up to a day later, to recognising the importance for including their family/whānau member in all aspects of the process:

I suppose I make them [decisions]... she's [daughter] quite happy to fall in with what I say I suppose... I gave her a choice the other day... would you like to go to [service] or would you like Dad to come and stay here with you for the weekend. She said 'I'll think about it'. So I asked her a few days later and she said "No, Dad can come." (Susanne, mother)

One time – we hadn't fully included him [son] in the family discussion. And he just stormed out of the room and I followed him and I got the biggest whack across the face... the next day he [apologised and] we had a chance to sit down and talk about what was going on. (Murray, father)

The accounts showed the intent to include the individual to the extent possible despite a number of parents acknowledging that they generally make the decisions. Although the idea of giving time to process was a useful strategy, it did not necessarily avail good decisions to be made as *"they're not actually able to make wise choices"* (Evelyn, mother). As such all family/whānau participants were aware of the need to include the member in decision-making conversations – especially in regards to the future options, however the ideal was not necessarily the reality and they recognised that reasoning required more than just including their family member.

It was important not to judge or be challenged by the individual and collective responses from the family/whānau participants on this aspect as there was genuine reflection by family/whānau as to how decisions were

facilitated. Rather, it was pivotal to recognise that as primary carers they have conceded much in the time that they have been in the current role to accommodate and adapt both to the changing needs of their family/whānau member with intellectual disability, and the system with which they have, over time, sought to engage. The majority however identified that they could or were in the throes of *Engaging the system* once more for the purposes of *Uncovering horizons* with and for their family member.

Engaging the System

Despite their earlier voiced misgivings, family/whānau still placed a great deal of trust and expectation on 'the system'. This code is not an indication of a definitive time and place when engagement occurred but rather reflects the fluid process of intermittently engaging with the 'system'. This was seen to be three-fold: an appreciation of past engagement and resultant services, a tentative appreciation of what might yet be possible, and lastly having to make a start at putting things 'in place'.

For ten family/whānau participants there was an echo of feeling grateful for what they were already receiving through the system – and possibly would in the foreseeable future. Forms of engaging the system ranged from ringing disability information services directly, "*if things are really going haywire... She's very good at getting back to us... there's always psych services*" (Stephanie, friend) to "*finding out things as we go along*" (Melissa, aunt). Whilst access to services was generally seen as a positive contribution to the household as the "*district nurse would be here [when sister-in-law] is sick... because the district nurse knows*" (Mavis, sister-in-law), however Elspeth (mother) was not the only one who commented on feeling as though they "*swallow a lot of things that come through the system and think well he's at least got a placement so shut up.*" Such comments reflected cynicism and resignation that

stemmed from previous negative encounters and seemed too much for Julianne (sister) to consider as she found herself contemplating engaging two different systems – disability and aged care; the question of motivational inclination and overlapping concerns for more than one family member was evident in this instance given that her brother and mother were residing together and is reflected in the following statement;

...it's quite awkward sometimes to get the right people... someone will ask you something and you think oh, haven't they done that full assessment... to be honest it's sort of in the too hard basket at the moment. I don't want to have to deal with it, I don't think it would help [brother] or me really to try and walk down a road that's not there yet... (Julianne, sister)

On the other hand, if services were coming in to help with her nephew, do the gardening, housework or “clean the bowels out” Melissa wondered what she would do as “I always feel I can do it myself.” For two other participants, whilst either having made arrangements or knowing that these could put one’s mind at ease, still raised further questions for those concerned. Kate’s parents explained that a legal executor had been appointed for the estate *but “we hope they won’t make [Kate] go... they can’t make her leave this house – can they?”* For these participants engaging the system was less about their knowledge of content and process, and more about their readiness of when this could or should occur. In doing so, horizons were still being uncovered at differing stages of the journey.

Chapter Summary

The concept of *Uncovering Horizons* reflected the over-arching notion that had been both thought about and lived in the lives of participants with intellectual disability as well as their family/whānau. The categories of *Entertaining possibilities*, *Creating a good life* and *Mastering decisions* denoted movement beyond that which was originally anticipated and which showed how such goals may be actualised in time to come. Three of the four codes which informed the latter category were exclusively the domain of family/whānau and may intentionally or unintentionally have acted as either barriers or facilitators of future planning depending on individual circumstances. Notwithstanding, there was still clear evidence in the remaining codes of the importance in recognising and including all participants in the processes and opportunities that will ultimately affect everyone's lives.

The ebb and flow of the identified realities posits roles and responsibilities for all family/whānau members and demonstrates that no clear linear process exists for considering or undertaking future planning. In effect, this recurred across the lifespan and was affected by the age and stage of participants in this study. *Navigating Ever-Changing Seas* will be seen to emerge from these results as a theoretical model which illuminates this recurring cycle of life and which affects all parties across the lifespan. The latter is informed through the inter-relationship of three categories; *Riding the Waves*, *Shifting Sands-Changing Tides* and *Uncovering Horizons* and is explained in the following conclusion on the development of an emerging theoretical model.

CHAPTER 8

NAVIGATING EVER-CHANGING SEAS

“The map is not the territory” (Korzybski cited by Bateson, 1973, p. 423)

This conclusion to the results chapters draws together the three concepts of *Rising the Waves, Shifting Sands – Changing Tides* and *Uncovering Horizons*: These concepts consist of the properties of the cyclical and evolving trans-generational relationships, and illustrate the journey that individuals and their family/whānau experience as they find themselves *Navigating Ever-Changing Seas*. Irrespective of how relationships were and/or are established, construed or identified, these realities are at the heart of this model. As with all models, encapsulating the identified properties into one model tends to imply that there is finite set of elements that often follow a linear process which hold true for all participants and, (in this instance), cover the journey of caring, perceptions of ageing and planning for the future. However, the current study contends that this is not always the case as “the map is not the territory” (Korzybski cited by Bateson, 1973, p. 423). Hence *Navigating Ever-Changing Seas* reflects the unspoken yet natural trajectory of an evolving map that intersects with the changing maps of others’ lives. As a map itself is a static entity it can only provide a tentative indication at a specific point in time of the possible or anticipated limits across the lifespan but it cannot denote the lived, dynamic territory. Maps and their subsequent subjective interpretations are drawn, redrawn and re-sized based on “differences [which] are the things that get onto the map” (Bateson, 1973, p. 426) as a result of the continuous ongoing journey. Such differences refer to how events are represented and interpreted through the stages across the lifespan and/or the

practicalities of time and place throughout the life course and which inform how and why decisions are made: The former are characteristics unique to individuals whereas the latter refers to the social context of participant groupings (Shanahan & Porfelli, 2002) (in this case people with intellectual disabilities, siblings, parent(s) and others denoted as family/whānau). The 'territory' is what emerges from the differences between the expectations of the map versus the experiences of participants (based on their existing knowledge, perceptions and relationships). However, as people's roles change, their identity changes and with this the opportunities and expectations change too and thus the map is continually, in a state of flux. Having a map is important but as the destination is largely unknown, the territory - and the navigation thereof - continues to evolve over time.

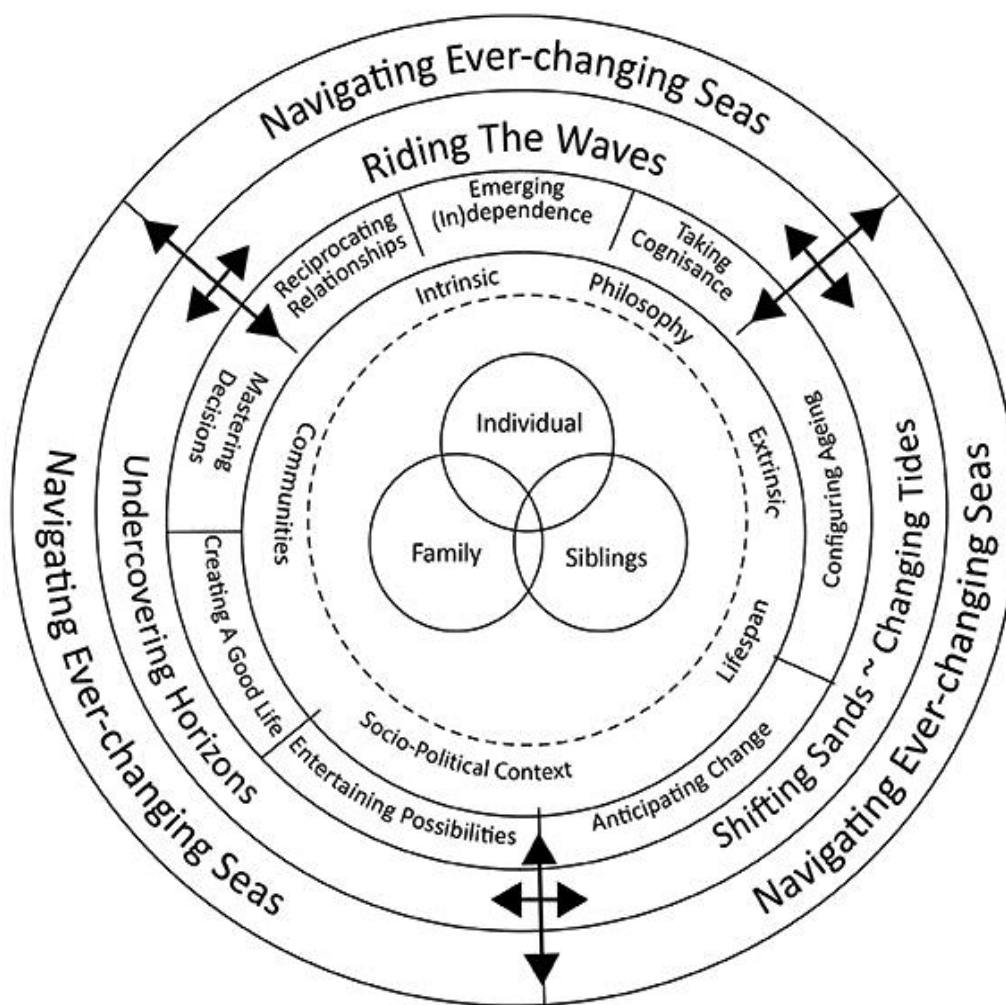
Family/whānau and people with intellectual disability may not always understand where they are at in terms of identities, roles and stages, what has informed their beliefs or position, why these are important and which factors may help or impede them in moving forward in a preferred direction. *Navigating Ever-Changing Seas* (Figure 20) provides a flexible platform from which families explored the interchange of their respective territories through the concepts of *Riding the Waves*, *Shifting Sands – Changing Tides* and *Uncovering Horizons*. The properties of the first concept denoted an intrinsic awareness of potential demands, balanced against an openness to simply take life as it comes by dealing with each challenge as and when it arises. The second concept delineates differences which may exist in recognising the current territory of one or other party in the caregiving system and which instigates a need to identify and adjust one's perspective to accommodate this. Hence through *Shifting Sands – Changing Tides* there are constant opportunities created for an unintentional yet self-determined emergence of either common or distinct territories; these find their expression in *Uncovering*

horizons. In doing so, new territories may be established but which will require a re-visiting and re-charting over time. Hence, *Navigating Ever-Changing Seas* provides both a personal and an all-encompassing perspective through which the direction or construction of individual and family maps and/or territories may be reconfigured as the member with intellectual disability matures and grows older. These elements can be individually reconstructed and recur through the system of care across the lifespan. The application of this model is crucial both developmentally and chronologically at each stage of an actual or perceived transition throughout one's life; caregiver(s) and care recipient(s) can use this model as an external framework and process through which one can identify and communicate their current or desired future territory. Of course, as demonstrated in this study, role-confusion and identity-confusion occurred when it was not always clear as to who was the caregiver and who was the recipient. The model is thus beneficial to all parties within the caregiving system – including the family member with intellectual disability.

The emergent theoretical model is illustrated by three circles in the centre of the model (Figure 20) to signify the interrelationship of the family/whānau system, siblings (indicating their own and subsequent generations), and the people with intellectual disability themselves. Whilst each have their own unique qualities and possible autonomy, the spheres of influence are seen to wax and wane between each and across all groups. The circle with the broken line signifies the fluidity between the parties in the caregiving relationship(s) and the factors that influence their individual and collective lives namely; philosophy, socio-political context, communities, factors intrinsic and extrinsic to each party across the lifespan. The impact of these factors is dependent upon a number of variables; setting, timing and magnitude (of the perceived or actual experience). Whilst the properties are

linked to the respective elements, the four-way omnidirectional arrows between each represent the permeability and flexibility between static and dynamic factors across the respective territories. The properties therein are constantly seen to be subject to change.

Figure 20. Emergent Theoretical Model: Navigating Ever-Changing Seas



There are a number of inherent drivers evident over the lifespan for families/whānau and their family member with intellectual disability in respect to how life maps were and are formed. It was seen that the value system intrinsic to the system of care is critical to this process.

Simultaneously, the extrinsic factors imposed by society were seen to strongly shape the lived experience or territory for people with intellectual disability and those within their caregiving network.

The territories therein both reflect and are responsive to retrospective and prospective considerations. Without exception, the influence of changing government policy over time significantly impacted upon how and why decisions were made by participants at core points. The discussion that follows will draw these influences further through the socio-political backdrop of disability policy in New Zealand which provided the context in which individuals and their family/whānau found themselves and offers a platform for understanding their approach to decision making or *Navigating Ever-Changing Seas*.

CHAPTER 9

DISCUSSION

Life is a journey not a destination (Ralph Waldo Emerson)

Introduction

This study provided a unique insight into the perspectives of people with intellectual disability and their families as they age and focused on adult individuals who are still residing with those they consider family/whānau and who thus constitute a largely hidden population. Ageing is both inevitable and an integral part of living. For people with an intellectual disability and their family/whānau, this may pose a number of additional challenges and opportunities particularly when the former continue to reside with the latter into their middle-adult years. The aim of this study was to explore perspectives of getting older and future planning for people with an intellectual disability and those nominated as family/whānau carers.

An interpretive constructivist grounded theory approach was used to explore what the future and ageing might mean for all those involved in the relationship of care-giving and receiving. This methodological approach enabled the individual and family perspectives to be shared via accounts and which allowed participants to co-construct their individual and collective realities across both time and with other participants in the study. The previous four results chapters illustrated the journey of participants from their individual and collective viewpoints. Critically, constant comparative analysis of the findings resulted in the emergence of a theoretical model, *Navigating Ever-Changing Seas*: This not only represents the experiences of

participants across the lifespan but provides a prospective inter-generational life course approach.

This discussion chapter commences with a description of the theoretical model *Navigating Ever-Changing Seas*, explores its properties in regard to the literature, and an evaluation is then provided of the model to demonstrate its elevation from a conceptual to theoretical level. It is then posited that the results demonstrate both a consolidation and contribution to the existing philosophical and socio-political approaches that have informed, and drive the disability sector. The intrinsic and extrinsic factors that are embedded in *Navigating Ever-Changing Seas* are discussed in terms of their contribution to new perspectives in understanding ageing and future planning for people with intellectual disability and their family/whānau. A critique is then provided of the methodological design which included photo elicitation as a means of enhancing the participation of people with an intellectual disability and informing the process of theoretical sampling. Through the constant comparative approach, photo elicitation data were integrated and thematically analysed alongside the narrative interviews. Ethical challenges, strengths and limitations are appraised later in the chapter and are followed by recommendations for future research, application to clinical practice and a focus on ensuring meaningful lives for all concerned. These considerations are seen to extend beyond family/whānau systems of care and pose a number of implications for health and disability service providers, funders and policy makers.

The conclusion chapter then brings together the key elements which have underpinned this study and have evolved as a result thereof. This includes the validation of a constructivist grounded theory approach, the contribution of photo elicitation as part of this process and the elucidation of the internal and external drivers which have informed decision-making for

people with intellectual disability and their family/whānau over the lifecourse; these are embedded in *Navigating Ever-Changing Seas*. The need for further research is explained in regards to establishing the application of this emergent theoretical model to other populations considered vulnerable the ultimate goal of which is to promote respect for people with intellectual disability and those of significance to them.

Navigating Ever-Changing Seas – An Emergent Theoretical Model

There was clear evidence in this study of an enduring parallel process for participants with intellectual disability and their family/whānau in recognising their role within the system of care as well as the unique features which shaped that over time. Hence it is essential that caregiving for families/whānau alongside members with an intellectual disability is recognised as dynamic and reflexive rather than a linear process. *Navigating Ever-Changing Seas* distinguishes the elements which comprise the interconnecting realities of all participants on the journey of living, ageing and planning for the future. Further, it provides a flexible map by which the respective territories of the individual and collective outlooks continue to be identified, acknowledged, engaged and shaped. This notion of perpetuating engagement needs to be considered as it applies not only to the study participants but to others in the intellectual disability sector and their family/whānau (regardless of age and stage of life).

This study therefore informed a gap in the literature in regard to the perspectives of individuals with intellectual disability and their family/whānau (in terms of ageing and future planning) and which demonstrates the complexity of the caregiving relationship between each party and the wider communities of influence. To date, research has identified

the impact of the relationship between parent(s) and/or siblings with their daughter, son, sister or brother with intellectual disability and the corresponding influences which may shape these (Stoneman, 2005). Whilst the factors which affect these relationships have been acknowledged (Heller & Caldwell, 2006; Simplican, Leader, Kosciulek & Leahy, 2015; Stoneman, 2005) there is limited research about how these relationships develop, are shaped, and evolve over time. Simplican et al.'s (2015) ecological model of social inclusion recently identified levels that "can promote or impede social inclusion" (p. 26). The levels are nominated as individual, interpersonal, organisational, community and socio-political conditions. A key recommendation for the proposed ecological model was to explore the social inclusion of families including; the "opportunities and obstacles for social inclusion" and conditions "such as family culture, socioeconomic status, and social capital..." (Simplican et al., 2015, p. 27). It is important therefore to explain the difference between that model and *Navigating Ever-Changing Seas*.

Whilst the levels identified in Simplican et al.'s (2015) model are acknowledged and evident in *Navigating Ever-Changing Seas*, the latter goes further by illustrating an integrated non-linear and reflexive process and describing constantly evolving cultures within families. It is these cultures which inform the interactions of all family/whānau members (including those with intellectual disability) with social communities and society at large. In other words, *Navigating Ever-Changing Seas* recognises the fundamental influences of biological and social conditions as well as "environments in which cognitive processes develop and operate" (Bates, 1972, cited by Hutchins, 2010, p. 706). This refers to the contextual nature or circumstances in which experiences are formed and upon which subsequent interactions occur, and it is these which were established in the current study.

The objectives of grounded theory are reflected in the way in which the emergent theoretical model demonstrates the constant yet evolving complexity of the interrelationships between adults with an intellectual disability and their family/whānau carers. *Navigating Ever-Changing Seas* encapsulates the key facets which are expected in the development of a theoretical perspective as all the identified concepts are inextricably connected. Furthermore, this linkage informs the awareness participants have of their social situation. As a metaphor *Navigating Ever-Changing Seas* ascribes to Schreiber and Stern's (2001) commentary that a viable theory "must fit the data, and must compellingly illuminate the action and interaction surrounding the phenomenon of study" (p. 78).

For each participant in the caregiving system perspectives were seen to be formed by intrinsic and extrinsic influences and interactions; these were also seen to be driven by the philosophical principles embedded within the socio-political context and communities with which they engaged over time. These interrelationships occurred individually, collectively and concurrently across the lifespan. In other words, all parties in this study acknowledged, recognised and/or demonstrated personal perspectives on ageing and future planning and which reflected values that were either in their nature or nurtured and which were (in turn) shaped by intrinsic and/or extrinsic influences. Having a reflexive map therefore emphasises the need to be able to access core information that will address the caregiving needs within and between the person with intellectual disability and their family/whānau. However, the fact that the map is not the territory (Korzybski cited by Bateson, 1973, p. 423) is a critical reminder that there is a juxta positioning between the proposed notions about getting older versus the lived reality: To an extent, each person draws and re-draws their own map across the lifespan as information is required and acquired. However the literature and accounts

identified in this research have shown that (in the field of intellectual disability) there is a clear predisposition for caregiving systems to 'draw' the person's map 'for' them – often as a response to perceived notions of vulnerability. There is however a transactional and ever-changing context stemming from intrinsic and extrinsic influences and which can create opportunities for transitions and evolution to occur (Jokinen, Janicki, Hogan & Force, 2012). Intrinsic influences refer to one's sense of support from others in the family/whānau (Resch et al., 2010) and includes personal resilience, hopes, and the bank of experiences which inform the 'truths' for each party. Extrinsic influences include philosophical shifts which are characterised by the prevailing socio-political context. These impact upon the individual experience of intellectual disability in relation to one's family/whānau and/or community, the services available and the accessibility thereof (Resch et al., 2010). This, in turn, is seen to affect the intrinsic experience of living with (and being to) each other as the context continues to evolve over time (Grant, 2007).

Critically, *Navigating Ever-Changing Seas* should be seen as an emergent theoretical model concerned with an interactive process of factors which both enabled and disabled the engagement of people with intellectual disability and their family/whānau in conversations and/or processes about ageing and planning for the future. It draws together the key categories from each of the three theoretical concepts (*Riding the Waves*, *Shifting Sands-Changing Tides* and *Uncovering Horizons*) and which illustrate the ever-moving inter-relationships between all parties in the caregiving system. Encapsulating the categories into the theoretical model of *Navigating Ever-Changing Seas* demonstrates that there exists a core set of elements that, if accessed, will identify and/or inform the knowledge and processing gaps that exist in the journey of living, ageing, planning for the future and dying.

In this study, those who did not appear to be making decisions about ageing and the future were seen to either not know how to do this, or sought the 'right' decision to be made on their behalf; this was often informed by their upbringing, conditioning and/or the culture of their family/whānau in relation to perspectives on disability. The latter was different for each party across the lifespan as perspectives were subject to change throughout the course of the journey. As people age transitions may "be marked by progressively more complex and socially significant life events... change in residence... acute ill health or the onset of chronic conditions, and loss of death of family and friends" (Jokinen et al., 2012, p. 60). Transitions were seen to occur and be informed by the prevailing value systems or expectations within the respective family/whānau, or were signalled by preconceived ideas articulated by society. What makes the difference is how messages and expectations around ageing and transitioning are formed, checked and communicated within the systems of care – and the extent to which they are open to revision across the lifespan.

The application of grounded theory to this study invited the opportunity to articulate a personal yet interconnected narrative which resulted in the emergent theoretical model of *Navigating Ever-Changing Seas*. This latter model is deemed to be credible, original, useful, and resonated (Charmaz, 2006) with participants' accounts of explicit and tacit meanings, as evidenced by:

1. The commonality of thinking that was found in all participants between past experiences, present realities and perspectives about ageing and future planning.
2. The interwoven multiple realities and interpretations within a single caregiving system and in which participants were and/or became

emotionally present and cognisant of their roles and responsibilities in regard to each other.

In and of itself *Navigating Ever-Changing Seas* promotes an inherent respect and recognition of the journey for all recognising both the territories mapped to date, and those yet to be charted. The model acknowledges the dynamic nature of the interrelationships that exist intrinsically as well as the extrinsic influences which permeated these relationships and experiences. The intrinsic stimuli are discussed as they applied to participants and as influenced by the lifecourse for the person themselves with intellectual disability and those they identified as family/whānau. The extrinsic factors are presented in terms of the philosophical and socio-political basis and context. A discussion follows on how these factors are adopted, assimilated and evolve and then, in turn, inform once more the intrinsic realities for members of these unique family/whānau over time.

Influences Intrinsic to the Family/Whānau System of Care

The nature, context and identity of individuals within family/whānau systems of care plays a significant role in the expectations and experience each have of themselves and generations to come. Regardless of who was nominated as family/whānau for this study, there was a realisation by most participants that roles and identity evolve over the course of the lifespan and these strongly influence the future trajectory and perspectives of persons with intellectual disability and their caregiving systems of support.

The uptake of roles and caregiving responsibilities was clearly demonstrated in this study and were seen to be based upon inherent values and beliefs. Such values and beliefs both instilled and sustained caregiving roles within family/whānau; critically, the participants' accounts showed that

these were neither innate nor solely biologically triggered. Victor (2005) reflected that “over the lifecourse individuals belong to a variety of kinship and social groups, all of which bring interactions and relationships with family, friends and neighbours” (p. 187). The acculturation and attributes of kinship were signified in the current study by participants’ commonalities of interest both in individual well-being and for those considered part of and connected to a family/whānau or wider community. Whilst Dunbar (2015) argues that the level or intensity of the connectedness experienced between family/whānau is based on the “degree of genetic relatedness” (p.103), those in the current study who provided a long-term caregiving role but had a non-genetic connection were found to demonstrate no less a commitment to this caregiving role and may clearly be deemed to be “families of choice” (Victor, 2005, p. 227). Ultimately, this connection resulted in the member with intellectual disability remaining within a family/whānau system of support rather than alternate care. Aside from the inherent and existing cultures within family/whānau, caregiving decisions were also found to be informed by principles of faith-based values or as a challenge to medical or societal perspectives at the time about the value, place and humanity of their family member. The evolving and changing nature of relationships with and between family/whānau represent the socially institutional nature of families which in and of themselves are not static entities (Victor, 2005). Regardless of the degree of relationship, decision making by family/whānau was found to have been often based on what was perceived to be in the ‘best interests’ of all concerned and the implications thereof: This included the perceived or actual support available both for and by family/whānau and siblings, the stigma that could be associated with having someone with a disability living at home (Power, 2008; Werner & Shulman, 2013), or indeed identifying as someone with an intellectual disability (Ali et al., 2012). It is important to note, that the planning and decision preferences for several participants with intellectual

disability also reflected a contentment with remaining 'at home' and was often informed by the degree of exposure to other settings and/or simply the sense of connection with those denoted as family/whānau (Bowey & McGlaughlin, 2005; McConkey, Sowney, Milligan & Barr, 2004). Regardless of their personal the journey to this point, all family/whānau maintained that remaining within the family/whānau had been the best decision for their member with intellectual disability and themselves.

What clearly emerged through this study was recognition of both the current and potential future impacts that the decision to keep their family member with family/whānau was now having on all parties in the caregiving relationship due to each member experiencing ageing themselves. The decisions made at birth were seen to not only impact now but also occurred at many other junctures across the lifespan within each family/whānau; the latter was seen most clearly in whether opportunities for skill building were accessed or not. Increasing longevity of persons with intellectual disability has resultant caregiving implications. Subsequent or prospective family/whānau carers in New Zealand for example are growing up in a society where formal large congregate institutions (and the services they offered) have now closed. However this latter generation may still be dealing with or responding to the legacy of the historical options faced and original decisions made; hence the importance of knowing the history is relevant for not only family/whānau but also for subsequent generations as well as the funders and service providers with whom they engage. A Belgium study into the perspectives of young siblings (6-14 years of age) of children with intellectual disability for example identified nine defining quality of life indicators namely; joint activities, mutual understanding, private time, acceptance, forbearance, trust in well-being, exchanging experiences, social support and dealing with the outside world (Moyson & Roeyers, 2012, p. 93).

For siblings in this current study, the future triggered the past as they found themselves again planning, prioritising, making adaptations and accepting their lives based on the needs of the family member with intellectual disability and for some, the needs of their ageing parent(s). It is important to be mindful that decisions made along the journey to date are not judged as either positive or negative, but that they are seen to represent a contextualised and meaningful place and time and which is respected and unique to those to whom they apply. Decisions made with and by individuals and/or communities are based on a culture of shared values and experiences which inform their perspectives (Wehmeyer et al., 2011). Hence, reflecting upon the intrinsic nature of *Navigating Ever-Changing Seas*, this study has demonstrated a lifetime of mapping and re-mapping the territories by individuals and their family/whānau and which has been symbiotic in nature. Of note, whilst siblings identified that there was likely to be a caregiving role for them, whether currently established, prospective or not yet discussed (Bigby, 1998; Coyle, Kramer & Mutchler, 2014; Greenberg, Mailick Seltzer, Orsmond & Wyngaarden Krauss, 1999), some vocalised their expectations for the future (in some cases fourth) generation to care for or look out for their family member with intellectual disability should the need arise. Whilst the siblings identified this as a preference, they had not yet embarked on this conversation. Regardless of the emergent and changing roles over time and across generations, it is helpful if family/whānau are mindful that they “do not automatically have either a legal or moral right to be involved in [the] life decisions” of the member with intellectual disability (Bigby, 1998, p. 18). However, the accounts in the current study revealed that this can be difficult to keep in mind when family/whānau have taken over the role from the original caregivers.

Gill's (1994) notion of a bicultural framework in which disability can be understood posits the view that the identities of ethnic minorities can be compared to those with a disability (and their family/whānau) using the perspective that both groups are, generally, surrounded by a majority culture. This is seen to inform the manner in which the cultures of family/whānau develop, evolve and transform over time due to both intrinsic and extrinsic forces (Fujiura & Parish, 2007). One of the fundamental foundations of *Navigating Ever-Changing Seas* therefore is acknowledging both the established and prospective systems of care and seeing the need for clear and shared communication in the inter-generational "transition of care" (Coyle et al., 2014, p. 310). It is not simply the fact that there were differing approaches to decision-making about the future within each family/whānau in this study, rather it is how these were identified, ratified and undertaken by each system. Consequently, there is an imperative need to explore the positioning of the third (and potentially fourth) caregiving generations as there may be diversity and difference in their perspectives about their roles and responsibilities towards subsequent caregiving within the family/whānau (Victor, 2005). The current study also illustrates that there may not be biological or sequential generations involved in a person's life. Given the decreased birth-rate and mortality (Vincent, 2003), together with changes in the geographical proximity of family/whānau, smaller families, and an increasing number of women in employment, there may be an increasingly smaller pool of naturally occurring and/or inclined caregivers in time to come (Fujiura & Parish, 2007).

Engaging with the Life Course

Life course represents the "series of stages (or social roles) ... individuals pass through as they age" (Victor, 2005, p. 37); it is both complex

and multi-dimensional. The majority of family/whānau in the current study reflected upon their relationships, realities and transitions which imparted both a resignation and recognition of the impacts these have had in the formation of their current roles and future caregiving. In the natural order of things, the hope for the majority of families in this study was that their family member with intellectual disability would die before them: However this is becoming less likely (Cairns, Tolson, Darbyshire & Brown, 2012), especially for siblings who are also recognising and dealing with the demands and the inevitability of their own ageing process (Coyle et al., 2014). The accounts in *Navigating Ever-Changing Seas* demonstrate that individuals and their family/whānau were regularly posing questions for themselves across the life course in relation to themselves and each other; thus individuals and families were seen not to just occupy one level of element of the model at any given time, but instead often occupied simultaneous and multiple levels in this model due to the fact that the complexity of informal caregiving “does not progress in a uniform manner” (Gaugler & Teaster, 2006, p. 146). Family/whānau demonstrated via their narratives that they are constantly buffeted intrinsically and extrinsically between *Riding the Waves*, *Shifting Sands-Changing Tides* and *Uncovering Horizons*. If this were not the case individuals and systems would become stuck or immobilised and run the risk of being unable to focus, make decisions and/or give themselves permission to fathom and explore what may be possible. Hence, the notion of an informal caregiving career for family/whānau is comprised of a “variety of stages” that unfold as the relationship progresses and in which “individuals may experience a change in status, or role expectations and responsibilities” (Banks, 2003; Gaugler & Teaster, 2006, p. 142-143).

Participants in this study also clearly demonstrated that there was an ebb and flow in their ability over time to consider the significance of the

present arrangements, and which were informed by the past and have implications for the future. Even for those who maintained that they had not or did not wish to contemplate the future (for themselves and/or their member with intellectual disability), their willingness and act of engaging with the subject for the purposes of this study indicates their awareness of the dynamics at play.

Making adjustments are often informed either by one's own ageing, or that of others in the caregiving relationship and/or the wider family/whānau (Coyle et al., 2014), was dependent upon one's perceptions of existing services, expectations of other informal caregivers within the system of care (Chou et al., 2009b) and adaptive coping mechanisms available over time and which may include support through existing networks (Llewellyn et al., 2010a). Hagerty Lingler, Sherwood, Crighton, Song and Happ (2008) explored concepts involved in the nature of care giving and receiving - two of which were clearly evident in the current study: Reciprocity and "a constellation of caregivers" (p. 359). The latter refers to the consultation required between family/whānau members to enable decisions to be made. The third concept was identified by Hagerty Lingler et al (2008) and referred to intergenerational resources of care which was both inferred and anticipated by participants in time to come. An interdependence clearly existed between participants with intellectual disability and those they identified as family/whānau – the impact of which is largely unknown; there is thus a need for this to be examined further alongside siblings specifically in regards to their emergent role as carers across the lifespan (Dew et al., 2004; Heller, 2008). Additionally, there is a need to question the degree to which the apparent interdependence is influenced by the level of perceived need or dependence by the carer towards the family member with intellectual disability (Parley, 2010) or vice versa. Formal supports are seen as those

requiring assessment and/or funding from an agency whereas informal supports are traditionally based on relationships in which roles, and obligations may be stated or evolve over time (Victor, 2005) and which may include neighbours (van Alphen, Dijker, van den Borne & Curfs, 2009). In so saying, the level of formal supports that are in place may not necessarily decrease the demand on the informal carer(s) who are commonly recognised as integral to the maintenance of community living for members of society across the lifespan (Victor, 2005).

The concerns for the future of participants was also reflected in the challenges they each faced in terms of their own physical and/or well-being (Caldwell, 2008). The self-reported health issues experienced by participants were significant in that some caregivers often minimised or put aside their concerns in order to focus more on their respective roles and responsibilities in the caregiving arrangement: Having purpose and meaning is known to be a key mediator of stress for carers whilst ensuring personal wellness and the needs of the family member with intellectual disability are seen as contributors to carer stress (Minnes et al., 2007). Conversely, stress is inevitable and imminent when the carer's needs outstrip the available intrinsic and extrinsic resources (Resch et al., 2010). As seen in the current study, participants reflected the same level of co-morbidities as their counterparts within the sector half of whom (for example), were older than 70 years of age and had lived with their family member for almost the whole of the person's life to date. For siblings specifically, they were "no longer caring [or going to be caring] for their sibling with a disability but for their ageing sibling with a disability" (Coyle et al., 2014, p. 306). It has been identified that, as for the general population, health, social connectedness (Buys, Aird & Miller, 2012) function and "active engagement with life" (Heller, 2008; 2011) are pivotal factors in ageing well for people with intellectual disability. Whilst

providers within the disability sector have been found to experience difficulty in differentiating between normative ageing and that which is disability specific, there is concern about the lack of expertise in the mainstream aged-care sector to cater for the needs of this disabled population (Buys et al., 2012) or the appropriateness of this setting in terms of assessment, resources and service provision (Bigby, Webber, Bowers & McKenzie-Green, 2008).

Aside from the health status of the primary caregiver, access to respite care may be related to the perceived or actual severity of disability; the older the person and more severe the disability the greater the need for access to respite is noted (McConkey et al., 2011). For some family/whānau in the current study the more able the family member with intellectual disability, the less likely respite care was sought or able to be accessed. The issue was not only about continued accessibility to information and funding entitlements for carer support, but also the ability to access the services through which it can be used (Mansell & Wilson, 2009; Resch et al., 2010). The impact of the availability of respite care, for example, on the health and well-being of individuals and their family/whānau is well documented and can be said to directly impact upon the sustainability of informal caregiving arrangements (Nankervis, Rosewarne & Vassos, 2011). The question must be posed as to whether the timing of engaging with formal services impacts upon the experience or outcomes for informal carers (Gaugler & Teaster, 2006).

Previous research has noted that “[t]here is a lack of preparation across the life span for families and individuals dealing with disability” (Banks, 2003, p. 368). As previously noted, until recently, the natural trajectory or lifespan for a person with intellectual disability was significantly shorter when compared to the general population. Clearly the latter is very dependent upon the level and type of disability, but the reality is that (as a

population), people with intellectual disability are generally living longer and are now expected to live almost as normative a lifespan as the general population. This poses some challenges as western societies are now starting to grapple with how to support and sustain healthy and meaningful lives for this group (Dew et al., 2004) alongside of other vulnerable populations.

Normative transitions and role changes in the life course are reflected in the notion of mutuality of support (Banks, 2003; Grant, Nolan & Keady, 2003). It could be argued that this research introduces and supports the notion of the person with intellectual disability sometimes acquiring the role of primary carer for an ageing parent and hence should be formally recognised as such when these roles are reciprocated. Critically this is not simply defined as just undertaking their share of running the house, but acknowledges that their contribution actually enables the continued independence in the community for their ageing family/whānau. Therefore there is the need to quantify the type of care respectively given and received which constitutes “mutual assistance” (Banks, 2030, p. 378). Without the latter the issue remains that both the individuals and their family/whānau potentially “experience a double jeopardy of being old and intellectually disabled and are rarely coherently provided for by agencies [which] compounds their disadvantage” (Ryan et al., 2014).

Putman (2002) provided a unique yet pivotal narrative comparing ageing theory against disability models. Whilst the focus is on people with physical disability, there are a number of important considerations that can be applied to the field of intellectual disability. For example, there are key differences between those who have experienced a lifelong or acquired disability early in life to those for whom this occurs later in life (depending upon the disability model of the time). The former group are more likely to have a been recipients of disability specific services which promote autonomy

and self-advocacy and the latter more likely would encounter a model of care with a greater medical focus (Putman, 2002). Hence *Navigating Ever-Changing Seas* represents an intersection of these two platforms of service funding and delivery which identify and describe the dynamic between the individual and the mutual needs of those in the caregiving relationship (Williams & Robinson, 2001a). Drawing on the social models of disability, Putman goes on to explain the elements therein from which gerontology can build, namely; separating out the impact of the individual's limitations from environments which disable the individual, and thus recognising that both "have adaptive capabilities" (2002, p. 804) to improve their social worth through a broader view of assessment of the life course of the individual.

A useful connection needs to be made between understanding the nature of ageing and the presentation of disability: Both of these represent an experience of different trajectories over the lifespan. For example, "[a]ging is a lifelong and developmental process... multifactorial, reflecting the cumulative impact of decades of decisions and behaviors that affect function and health outcomes later in life" whereas "[d]isability has long-term health and functional consequences... [it] is not a static condition but rather a process of continuous adaptation to changes across the life course" (Sheets, 2010, p. 2). The former infers that people do have some control over the likely course of their life and the latter, is a reminder that there are elements which may be constant but yet may fluctuate over time. Ageing well is thus dependent, in part, upon what has occurred across the life course (Heller, 2008). This notion of an ongoing yet constantly evolving existence was represented in this study through the categories which comprise the model namely; *Riding the Waves*, *Shifting Sands-Changing Tides* and *Uncovering Horizons*.

It stands to reason therefore that both ageing and disability have some degree of flexibility to be influenced over time. Building on this synergistic

view participants' accounts in this research finds some truth the old adage that the past informs the future. If individuals and family/whānau have felt unable to take true ownership of their respective lives and decision-making over time due to intrinsic or extrinsic influences, it follows then that one could query what sense of ownership they might feel they have or do not have over the future. Thus, those who were not making overt or tangible plans for the future were seen to be remaining in the here-and-now, doing what needs to be done today for their son, daughter, nephew, friend. True decision-making and ownership therefore requires (and demands) that an individual is connected to, and engaged with, the surrounding world. For such meaningful engagement to occur in society for people with an intellectual disability, O'Brien and Lyle (1986) recommended five core accomplishments which continue to be absolutely pivotal and relevant today. Choice (for preferred decisions, knowledge of available options and the ability to exercise this); Respect (for the right to make choices, to be treated with dignity and the expertise they have about their own lives and person); Community presence (to actively be acknowledged as an individual who has a contribution to make – both within and external to the family/whānau context); Community participation (to access the community, engage and utilise the available resources both disability specific and mainstream settings); Skill acquisition (to be supported within the scope of one's abilities and opportunities to learn through the above elements). The application of these accomplishments is critically dependent upon the interactions between all parties. Whilst originally formulated as accomplishments for the individual with intellectual disability, they can now also be demanded as essential key attributes in caregivers and health systems as they engage with the person throughout their life course. These principles continue to be relevant, underpin true inclusion, and promote quality of life as well as integration for people with an intellectual disability and their family/whānau in living and ageing in the

context of community. As demonstrated in this study, experiencing or achieving these accomplishments in a consistent manner has often been elusive to varying degrees for this population. Notwithstanding this fact, this study has shown that the principles and accomplishments as identified by O'Brien and Lyle (1986) clearly provide a crucial and the necessary link which enables normalisation, social role valorisation and the values inherent in the social model of disability to be nurtured and extended by family/whānau as they individually and collectively inform social change for themselves and across and between generations (Bengston & Allen, 1993).

Extrinsic Influences: Promoting or Excluding People with an Intellectual Disability

The philosophical and socio-political context has informed the focus and principles upon which services have been funded, developed and remodelled over time. This occurs not only in disability systems but has implications for the aged care sector and the wider health industry. As a result, access and engagement with current and future disability and aged care supports may be fraught for persons with an intellectual disability and their family/whānau system of care. In this study, the individuals and their carers expressed concern about the resources available and responsiveness of disability and aged care services to respond to their individual and collective needs. These interdependent extrinsic influences are discussed in the next section.

The Socio-Political Context

Family/whānau with a family member with intellectual disability have experienced multiple changes in the socio-political territory over their lifetime and see it continuing to do so. The evolving philosophies within the disability

sector informed the socio-political context for study participants and the model that emerged from this study. *Navigating Ever-Changing Seas* charts the continuing impact, adaptation and implementation of these philosophies by participants over the passage of time. It acknowledges the effect on the life course of all parties within the caregiving network and how this affects the inclusion of people with intellectual disability in society. The key focus of this section is to demonstrate the link between the philosophical influences of deinstitutionalisation, normalisation and social role valorisation and the emergent model of *Navigating Ever-Changing Seas* and recognises the direct impact these have had upon the progression of funding models and services structures over time.

As seen in this study, normalisation is what families were doing when they opted to keep their family member at home and which was personally valid for them during a time when society and services expected them to place their family member into a care facility. All families experienced this tension regardless of whether their family member had remained at home all their life or had spent some time in other places (including institutions). Despite the majority standing up for what they saw was in the best interests of their family member with intellectual disability (by ensuring they were brought up as an integral part of the family/whānau), many experienced ridicule, stigma and isolation as a result of their decision. It should be noted that this was in spite of the fact that community living for people with an intellectual disability is not an entirely new concept and that, at certain times in the past, living in private settings was indeed preferable (Mitchell, 1864). The advent of care institutions “reinforced the devalued role of such individuals who have externally driven social, economic and political restraints imposed upon them, thereby limiting the experiences and opportunities they may otherwise gain from” (Burrell & Trip, 2011, p. 178).

The second half of the twentieth century the philosophy of normalisation saw a shift towards deinstitutionalisation (Harbour & Maulik, 2010); this process saw countries (including New Zealand) moving people with intellectual and other disabilities into other settings – the conditions of which were considered to be in keeping with those normed against the wider community (Nirje, 1969; Wolfensberger, 1972). This shift did not just focus on settings, but included making choices, participation in schooling, meaningful vocational activities, work, and leisure through accessing facilities in mainstream society – all to the extent possible for the individual (Nirje, 1969). This experience was sought by all family/whānau in this study for their family member and the reality of actualising this vision was exemplified in the category of *Riding the Waves*.

The concept of social role valorisation by Wolfensberger (1980) built on Nirje's work and purported that normalisation needs to be culturally normed. Hence, having value attached to the roles one has in society would enable social role valorisation to occur (Wolfensberger, 1983; Wolfensberger & Tullman, 1982). By working to establish socially valued roles, it was thought that society would then be challenged to redress systems which hindered citizenship and therefore enable access. The current study demonstrated that for some, membership within family/whānau actually facilitated and promoted social role valorisation (to an extent) for participants with intellectual disability: Growing up in a culturally normed environment, they acquired, developed and experienced socially valued roles both within their community (attending school, church, work, vocational services) as well as at home (as a son, daughter, brother, sister, nephew, or friend). For the majority of participants, roles evolved over time and, for some, eventually included becoming both an informal caregiver and providing companionship in a reciprocal manner. Whilst the value placed on the latter roles are variable in society at large (Goodhead & McDonald, 2007), it was clearly identified as

significant in the context of family/whānau in this study. The aforementioned features of living in the community were also informed by changing funding models and corresponding service structures. The evidence of these is seen in the accounts of *Shifting Sands ~ Changing Tides* expressed by participants; for some there was a complacency and hesitancy about planning for the future due to an expectation and likelihood of further changes in both the funding and services available for their family member – something which they had seen occur several times in the past.

Whilst the value of social integration continues to be desirable and a core goal, it remains elusive as a norm despite multiple efforts at many levels (Lemay, 2006). Philosophically, normalisation and social role valorisation should not be seen as individually exclusive of each other nor as a hierarchy of individual influences. Rather they represent a confluence of mutual and complementary principles over time. The social model of disability built on these principles and foundations and called for society to differentiate between providing interventions for concerns resulting from an individual's impairment to interventions designed to support the adjustment of the person to the environment or which seek to dissolve or resolve the external or disabling barriers (Northway, 1997; Northway & Thomas, 1999). Hence, the barriers experienced by individuals may be due (in part) to the assumptions held by society and which are based on perceptions of dependency or incapability (Goodley, 2001; Race, Boxall & Carson, 2005). Such limitations represent "barriers both to personal and collective autonomy" (Richardson, 2000, p. 1392). In other words, one is considered disabled by the response of external factors to one's impairment. A significant finding of this study was that one of the greatest challenges for participants with intellectual disability lay not only in the disablement experienced in society through changes in policy over time, but the extent to which they may have been enabled or further disabled by the decisions and perspectives of family/whānau. The latter was illustrated in

the category of *Shifting Sands, Changing Tides* in the frustration experienced by family/whānau carers who struggled to get on with living and consistently experienced challenges of service access, support and availability, coupled with societal expectations both internal and external to their situation and occurring across the lifespan.

Participants constantly alternated between hope and uncertainty – and the stress and incongruency of that for participants is best understood by further exploration of the political context. In New Zealand this population traditionally attended what were known as ‘sheltered workshops.’ Under the Disabled Persons Employment Promotion Act (1960) exemptions existed in regard to minimum wage and holidays for people with disabilities compared to the general population. In 2007 this legislation was repealed and, whilst exemptions can still be applied for under the Minimum Wage Act (1983), Pathways to Inclusion (Department of Labour, 2001) was already forging new expectations of employers and opportunities for people with a disability in these settings (which latterly became known as ‘vocational services’). The goal was to improve flexibility and reduce inequalities by requiring services to be clearly demarcated as those assisting with employment and/or enabling community participation for example, activities, education and training. Further evidence of the ongoing evolution of services is seen in the current model of ‘Enabling Good Lives’ (Office of Disability Issues, 2011): A three-year pilot is currently underway in two areas of New Zealand; the goal is to facilitate greater choice and control for people with disabilities by managing their own funding and therefore have more flexible access and engagement with services to achieve their personal goals for participation in ordinary life outcomes. Whilst a relatively new project, there are anecdotal concerns being raised that there is no new funding allocated and that existing funding must therefore be diverted from existing contracts. Several issues were raised for participants of this study: Firstly, no-one was aware of the

pilot; secondly, this specific group are not eligible to access it, and finally, there is the potential impact this project may have upon the existing supports for meaningful engagement by this group in the community. Again, whilst such initiatives are laudable, the lack of inclusive planning and delivery thereof gives rise to the possibility of further disenfranchisement of an already vulnerable population. As a result, in planning for the future, participants may once again find themselves going through the cycle of *Riding the Waves, Shifting Sands – Changing Tides* and *Uncovering Horizons* – the elements of which inform the experiences already captured and denote how they have been *Navigating Every-Changing Seas* across their lifespan.

As a result of such policy changes disablement potentially continues in terms of how some participants with intellectual disability in this study were able to meaningfully fill their day. Whilst participants with intellectual disability and their family/whānau applauded the stated intent of changes in legislation, their realities reflected an incongruous sense of hope for future possibilities against the uncertainty of possibly losing that which was known. The latter experience was captured in *Uncovering Horizons*. The sense of purpose, opportunities for socialisation and identified roles that some individuals had fostered when attending the sheltered workshop, was often replaced with increased costs, uncertainty, isolation, decreased satisfaction and/or boredom. Whilst difficult to quantify, several family members believed that there was a direct correlation between the aforementioned and negative policy changes over time with the loss of motivation and functional skills for the person with intellectual disability

The most recent development in philosophical frameworks which underpin and inform socio-political approaches is the United Nations Convention for the Rights of People with Disabilities (United Nations, 2006) – to which New Zealand is a signatory. The Convention identifies responsibilities for signatory countries and reiterates that “disability results from the interaction

between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (United Nations, 2006, p. 2). However the reality for several participants in this study, both family/whānau and those with intellectual disability, is that there continued to be intrinsic and extrinsic limitations in the degree to which they were able to function in regard to progressing their own lives in their respective communities. Despite this, *Uncovering Horizons* illustrated that many individuals and their family/whānau still identified the need to regularly consider values, choices, future preferences and options as important.

Access to Current or Future Aged Care & Disability Supports

In addition to the socio-political context discussed above, there is a further layer of service access and delivery to be considered for study participants and the disability sector. Argyle (2001) recommended that formal service provision needs to be flexible thereby enabling people with disabilities to age in place. Coyle et al. (2014) reiterated the challenge of enabling “this population to successfully age in place” (p. 310) given the “age-related changes in the functioning of... siblings with I/DD are outpacing the ability of service systems to respond” (p. 310). Further, as the future is dependent upon the decisions made in the present, there is the need to mutually support ageing and the preferences of family/whānau caregivers and adults with intellectual disability themselves (Heller et al., 2005). Therefore, the challenges of receiving timely, relevant and adequate information and services about relevant in-home supports and out-of-home accommodation options also requires attention (Bowey & McGlaughlin, 2007). Silos are seen to exist between the aged care and disability funding streams and which prevent flexibility of access and yet there are similarities of intent in regards to the respective government strategies which inform policy for both streams. For example, the New Zealand Disability Strategy Making a World of

Difference: Whakanui Oranga (Ministry of Health, 2001) has specific objectives regarding funding equity, long-term supports, affordable housing and access to appropriate health services. The New Zealand Positive Ageing Strategy (Ministry of Social Development, 2001) also seeks the same to enable people to 'age in place' – to the extent possible for the individual. The objectives within this strategy are also applicable to those who may be younger than 65 years of age whose needs are akin to older counterparts. In 2002 a progress document on the former identified the goal for people with a disability was to “to live in the community with necessary supports to meet their personal, medical and social needs” (MSD, 2002, p. 18). Similarly, The Health of Older People Strategy: Health Section 2010 to Support Positive Ageing (MOH, 2002) made reference to the “relatively smaller number of people under the age of 65 who have health and disability support needs more commonly experienced in older age, notably Māori and Pacific peoples” (p. 11). To Have an 'Ordinary' Life (National Advisory Committee on Health and Disability, 2003) and the Guidelines for Specialist health Services for Older People (MOH, 2004) further delineated the need for the respective populations to be assessed for, and have access to, adequate health and housing which meets their specific needs. Currently, people with intellectual disability in New Zealand still may struggle to access relevant aged-related services unless the presenting issues are demonstrated to be attributable to their chronological status rather than the disability. Hogg et al. (2000) debate that this population should be resourced as part of the wider ageing population rather than funders continuing to promote funding or specialty silos.

In seeking alternative accommodation, family/whānau may be “criticised if they do not make plans for their son or daughter’s future, but [often feel] unsupported by the system when they do take positive steps to seek [alternative] housing for their offspring” (Grey, Griffith, Totsika & Hastings, 2015, p. 55). However, of the family/whānau in the current study who had carer support

hours allocated to them, a third could not access respite care. According to the Office for Disability Issues and Statistics New Zealand (2009) in 2006, eight percent of families who had funding allocated for respite were unable to use it and 41 percent with a child identified this as an unmet need. Ironically, the access to respite options may be seen as an investment that enables family/whānau to provide quality care and remain in the caregiving role longer (Ministry of Social Development, 2014). Moreover, the importance of this is the recognition that initiating access to temporary (respite) alternative care arrangements is often a stepping stone for families in embarking on the process of gradually relinquishing care versus planning towards out-of-home placement (Nankervis et al., 2011). It is important to note that gradually relinquishing such care is in keeping with promoting further independence, whereas planning for out-of-home placement does not naturally include this aspect. Concurrently, the question must also be asked as to whether the disability service is able to provide age-related support needs or the extent to which aged care services can accommodate disability. These concerns relate to both relevant expertise, as well as contractual funding obligations. Factor, Heller and Janicki (2012) suggest a need for workforce development to better meet the health and support for this population and research to evidence this to increase awareness at a policy level. Greater flexibility and co-ordination is thus required between the disability and aged care sectors (Washko, Campbell & Tilly, 2012; WHO, 2000) as existing resources from the respective sectors may (in isolation) be insufficient for one or both parties to age in place. Should responses to increasing care needs occur only at the point of crisis there is a risk of further increasing their vulnerability (Eley, Boyes, Young & Hegney, 2009) as it fuels the imbalance in the power distribution in the respective relationships (Glendinning, 2008). The New Zealand Carer's Strategy Action Plan for 2014-2018 identifies five objectives to improve the opportunities for carers to; know what respite options are available, have access to resources to maintain health and well-being, for other services or disciplines to

develop a greater understanding about the carer's role and to "improve pathways to paid employment for carers and support for whānau, aiga, family and carers to balance their work, life and caring role" (MSD, 2014, p. 22). Whilst these are all factors that have been shown in this study to impact upon the intrinsic nature of caregiving, the reality for family/whānau is that these strategic directions appear to have limited traction despite there being a call from the National Advisory Committee on Health and Disability (2010) for greater flexibility between funding streams to reduce fragmentation and improve accessibility for all in the caregiving relationship. This is ironical given that one of the strongest systems of care available, namely family/whānau, is the one that has the least legislative direction (Dunbar, 2015).

Future Planning

The socio-political context played a significant role in shaping the intrinsic and extrinsic influences which demarcate and continue to shape the respective territories for participants in this study. The hallmarks of developmental or typical ageing are usually determined by key domains in a person's life across the lifespan, (Vincent, 2003) for example, upbringing, health, children, grandchildren, relationships, career, finance, bucket list and/or regrets. For people with an intellectual disability, some of these domains may or may not have been visible, understood or, experienced, let alone discussed, which may impact upon how the future is conceptualised both for (and by) them (Grant, 2007). Choice was seen to be a key element for this group of participants both in terms of the current arrangement and/or future opportunities – and this resonates with the recommendations of O'Brien and Lyle (1986). The imperatives of seeking and being afforded the "freedom" and opportunity to make choices about one's future (Walmsley, 1996, p. 334), including living circumstances, is embedded within the United

Nations Convention on the Rights of Persons with Disabilities (2006). As explained in the previous section, having the support to be meaningfully engaged in their own lives and the opportunity to learn the skills necessary to be present and participate in communities was important (Buys, Boulton-Lewis, Tedman-Jones, Edwards & Knox, 2008) and is based upon inherent respect (O'Brien & Lyle, 1986). More than two-thirds of participants with intellectual disability in the current study were able to articulate in the interview some of their aspirations and where they wanted to be in the future. However, these dreams and goals, were often not previously known to many of their family/whānau. This is a significant finding in that it demonstrated that active and direct questions and valuing an individual's perspective served as a platform that enabled both the individual and family to entertain possibilities irrespective of the degree of autonomy needed to actually achieve them (Wyngaarden Krauss et al., 1996). Notwithstanding, given that autonomy is a dynamic process, this needs to be frequently reviewed as each chance to exercise it is unique and presents differing opportunities to engage with new information and/or acquired experiences (Jeppsson et al., 2012). It would also be advantageous for individuals and/or their family/whānau to explore future planning issues and needs alongside others who may be at a similar stage of life (Heller & Caldwell, 2006).

In contemplating the future for all members of a family/whānau system of care there tends to be a significant reliance on both the members themselves and engagement with the community at large (Bigby, 2004). Siblings in this study vocalised an expectation that other members of the family would need to step-up and be supportive of any role they had or would take on; however, the latter was not necessarily their reality. Stoneman (2005) summarised this interplay from a sociological and developmental perspective:

...we have a vested financial interest in socialising children to develop into adults who are willing to provide life-long care for their siblings with disabilities after their parents relinquish their role. Parents often share this goal. Many adults with disabilities, however, want self-determined lives that are not controlled by parents or parent-surrogate siblings (p. 344).

Bigby's (1998) study, which explored the role of siblings as substitute carers for parents, noted that this responsibility became more instrumental, informative and facilitative in nature over time – especially following the transition to other settings. Dillenburger and McKee (2009) identified a number of important cautions with regard to the value and impact of “high quality care given freely and willingly” (p. 14) by informal caregivers: They recognise society has a reliance on the inevitability of this role which may create fiscal savings but recognises that it decreases the ability of providers to adequately plan to meet future care needs. Furthermore, low levels of personal or natural supports impact upon those with intellectual disability when family/whānau carers move on (Buys et al., 2012; Dillenburger & McKerr, 2009) and also plays a role in the stress these same carers encounter when engaging in planning for the future (Dillenburger & McKerr, 2010, p.35).

It has been estimated that a third of carers in the United Kingdom are over 70 years of age. As a result, the Department of Health's White Paper (2001) *Valuing People* proposed to implement indicators for people with intellectual disability to have an agreed future plan. The value of this is evident not only for the person concerned, but for all members of the family/whānau as well as relevant services in the actual or potential planning

needs for this population. In this study half the family/whānau carers fell into the age group of concern. Importantly, whilst siblings or other nominated family/whānau may already be involved to a greater or lesser extent, their willingness to engage in future planning processes may vary (Egan & Noonan Walsh, 2001) and may be dependent upon the anticipated likelihood of caring for others in the future (Perkins & Haley, 2010).

In the current study, the more able the individual the less likely they were to have support to plan for their own future – and which included out-of-home placement options. *Navigating-Ever-Changing-Seas* clearly illustrates that in order to identify and foster a recognition of the evolving roles, expectations and values as one ages within the caregiving relationship, knowing the journey thus far affords an additional understanding of how the future may be conceptualised by various parties – including service providers (Weeks et al., 2000). Families are seen to relinquish care for a number of reasons, including level of disability and associated support needs (severe or profound 75%) and/or challenging behaviour (64.5%) that result in safety concerns for siblings (Nankervis et al., 2011). Familial exhaustion and stress was also identified as playing role (particularly for mothers as primary carers) and there was a recognition of natural lifespan milestones suggesting that young adults should move out of home (Nankervis et al., 2011). Hence, knowing the population and its composition is pivotal in enabling meaningful planning and funding to occur. Gathering such data would inform funders and policy makers as to the changing demographics of individuals, their family/whānau and caregiving arrangements in relation to the population of people with intellectual disabilities (Hogg et al., 2000).

The Research Methodology

The philosophical paradigms underpinning the methodological approaches of this study were critical in eliciting participant perspectives. From an axiological viewpoint, the transformative paradigm enabled the discovery of a distinct yet recurrent familiarity with perceived injustice for people with intellectual disability and/or their family/whānau. This ranged from longstanding isolation within their identified communities, to issues of equity and fairness in accessing reliable services across the lifespan, as well as in regard to the establishment of negotiated roles within the family/whānau system of care. Such perspectives were tempered by the naturalistic paradigm through the ontology of relativism thus allowing participants and researcher to collectively examine their own assumptions as to what informed such identified injustices. These paradigms underpinned and informed the application of grounded theory through the epistemology of constructivism.

It is acknowledged that the resulting constructions may (at times) be incompatible or in conflict with those of others due to the limitations that experiential knowledge plays within this process (Heron & Reason, 1997); they may be constructed, de-constructed or reconstructed as part of the research process individually or collectively to form a consensus of understanding (Lincoln et al., 2011) and interpretive meaning (Crotty, 1998). Co-constructivism is thus the intersection of the subjective experiential participation of each party to find an objective agreement of perspective; the latter informs the development of further opportunities for conceptual evolution. In order to do this the researcher must consciously engage with and acknowledge the influences which inform and underpin each perspective as they engage in the process of construction (Mills et al., 2006b). From a social justice perspective, a constructivist grounded theory approach elucidated the realities of individuals and their family/whānau in this study

in terms of “fairness, equity, equality, democratic process, status, hierarchy... individual and collective rights and obligations. It signifies thinking about being human and about creating good societies...” (Charmaz, 2005, p. 510).

From the outset, a key focus of this study was not to simply seek the participation of people with intellectual disability and their family/whānau, but to actively gain their involvement and engagement in the research process. The constructivist lens of grounded theory enabled the latter process. Results were captured through the reflexive and relational nature of the grounded theory approach of interpretive constructivism – an approach in which symbolic interactionism plays a key role (Hall & Cullery, 2001; Charmaz, 2014). A key element of this approach is the use of gerunds which reflect the dynamic nature of an experience. These may be metaphorical in nature and inform data analysis (Charmaz, 2014) and are now known to reflect “emotional understanding” (Fetterman et al., 2015). The findings evidenced from the data were socially formed, intrinsic and extrinsic in example and reflected intensely personal occurrences. The elevation of findings to emergent theory has been informed through the interpretive grounded theory process of reflexivity in which the literature provided both a backdrop and a lens through which *Navigating Ever-Changing Seas* can be understood.

Whilst thinking about ageing and the future had been an unspoken subject for some, the concerns and stories they shared enabled other questions to be posed for others. Throughout the research process, the valuing of individual perspective and interaction created a safe harbour for individuals and family/whānau to voice their individual experience of *Navigating Ever-Changing Seas* over the course of their lives.

Photo Elicitation

Historically, the inclusion of people with intellectual disability in research was constrained by the known or perceived limitations about the individual or population rather than focusing on finding a research approach that could enhance inclusion in research (Booth & Booth, 1996). As a methodological approach, there has been limited use of photo elicitation within intellectual disability research. Hence, grounding the research process for this study in visual imagery facilitated an increased level of engagement for the participants with intellectual disability; it was clearly evident that their contribution on the topic under discussion was rooted in a relationship with what was already known through their tangible memory and existence (Harper, 2002). The interviews, therefore, were “anchored in an image that [was already] understood” (Harper, 2002, p. 20). Their connection with time and how it has been experienced was found to be linked to their memories of significant people, places and events (both actual and anticipatory). The accounts and conversation were triggered and captured through the participants’ choice of a photo, image, object or picture which brought to the fore a deep rooted sense of the person’s own reality – what was, is, or will be important for them as they age. It was evident through each of the interviews that the ability to generate insights on ageing with intellectual disability would have been significantly limited if photo elicitation had been absent regardless of the timing in which it was included in the interview (Hurworth, 2004). Not only did photo elicitation allow the researcher gain a different view, it also provided a platform for the participant to explore a new perspective on their existing reality: This has been coined “breaking the frame” (Harper, 2002, p. 21). The sharing of a photo, picture, drawing or object is viewed as an invitation to a stranger to come alongside, to explore and interpret the photo together. Notwithstanding this, the individuals who

opted not to choose an image were still offered the opportunity to meaningfully contribute: Their ideas about ageing were (in part) generated from the additional and static images offered to each participant with intellectual disability. This process, an extension of photo elicitation, sought to provide a commonality of exposure to a stimulus on the topic of interest.

As a visual methodology, photo elicitation was evidenced in this study to be an approach which can positively and effectively engage people with intellectual disability: It bridges communication challenges, builds rapport and enables depth of content and context (Hurworth, 2004). Critically it is proposed, that it provides agency to populations that are considered vulnerable (Prosser & Loxley, 2008). Such vulnerability may be due to cultural isolation, language, literacy and/or a range of cognitive or other impairments. The priority with this type of research is to enable individuals to “express their beliefs and priorities in the context of their own lives through [visual] imagery” (Jurkowski & Paul-Ward, 2007, p. 364).

Ethical Challenges

The literature abounds with reference to the ethical challenges of undertaking research alongside people with intellectual disability. First and foremost is the philosophical requirement to discuss ideas about prospective research with the individuals themselves and those involved in their lives. As part of planning for this study, meetings were held with a range of individuals representing a cross-section of the health and disability sector and which included people with intellectual disability, family/whānau, funders and providers of disability services as well as those with expertise in the aged care sectors. The purpose of these conversations was to identify some of the commonly understood issues about ageing with intellectual disability before a specific aim was formulated. This approach does not encapsulate all that is

understood by inclusive research, and whilst it was a key step in this study, the lack of a greater inclusive process is identified as a limitation for the study.

A key issue in undertaking research in this specialist field is the possibility of gatekeeping or needing to access information about prospective research through a third party. Difficulties were encountered at times in directly accessing a hidden population such as people with intellectual disability. Whilst advertising was channelled through the public sphere (Appendix 11) as well as health and disability avenues, direct contact was only able to be made with participants once their family/whānau or service provider had discussed it with them. The level of research uptake when gatekeeping is present, is dependent upon a number of variables (Lennox et al., 2005) and, whilst gatekeeping has its place in terms of limiting the risk of further vulnerability, the respectful inclusion of this population in scientific endeavours is an equally important part of community inclusion (McDonald et al., 2009). Gatekeeping can also introduce a power relationship regarding decision-making and can sometimes reduce the likelihood of the person with intellectual disability accessing and participating autonomously in opportunities deemed preferable (Parley, 2010). Ironically, for the majority of family/whānau, their participation in the study was equally dependent upon the individual's decision about who could be included in the research.

Assent was actively sought as part of consent. There was an option for consent by proxy for those who were deemed by family/whānau as unable to undertake full informed consent. Only one of the 19 participants was unable to provide full informed consent for themselves. Throughout the research process, a number of clear opportunities were given at each stage to allow each person with intellectual disability and/or their family/whānau to withdraw at any time. The one family who chose to withdraw after

commencing the research (due to the demands of earthquake recovery) consented for data that had been already collected up until that point to be used. When there were indications that participants were too tired or distracted they were invited to consider whether to continue with the interview at that time or not. Most opted to continue and some rescheduled to complete the interview process at a later time.

A further key focus in this study was ensuring that the voices of people with intellectual disability were heard and represented whilst taking care that strategies were in place so that individuals were “not further exploited by engaging in yet another encounter with someone outside their day-to-day life” (Munford, Sanders, Mirfin Veitch & Conder, 2008, p. 346). All participants with intellectual disability had the option of having a support person with them during the interview process. Whilst some declined and wished to meet independently, several chose a family member (who they nominated for interview) and a third group sought this support through their existing disability supports. Acquiescence or suggestibility was a common vulnerability in those who chose to be supported during the interview by their family/whānau. To check the validity of responses and to ascertain the gaining of a true perspective of participants with intellectual disability under these conditions, a number of techniques were used: Reframing of questions, time delay in repeating key concepts, reflecting responses, and observation of body language. Regarding the latter, it was noted that these respondents often employed a visual glance, tilt of head or verbal intonations to subtly check their own responses with their chosen family/whānau member. Frequently they were either reassured with a returning nod of the head, minimal encouragers or corrected. It is important to note, that it is not clear whether this was heightened for some due to the novelty of the research encounter or

was in fact the standard manner in which the family/whānau most commonly engaged with one another.

Access to and use of visual images was acknowledged as having the potential to be ethically problematic. However, for those persons who chose a photo which included another family member consent was sought for it to be used within the published study directly from the person with intellectual disability or, if the image was not their own, from the relevant family/whānau. Furthermore, at no time were photographs removed from the participant or location and instead a photograph was always taken of the image and checked with the participant.

Whilst identified in the next section as a limitation of recruitment to the study, the act of undertaking research and seeking participation during the unprecedented earthquake events of 2010-2012 in Christchurch may also be considered an ethical challenge. For example, prospective participants may have wanted to contribute to the research process but may have felt unable dependent upon how affected they were at the time. Equally, several participants identified that they chose to engage with the study as it was a good distraction from the realities of the disruptions precipitated by the earthquakes and subsequent recovery processes.

Limitations of the Study

A key factor that impacted upon recruitment for example was the time and place in which it occurred. From September 2010 through to the end of 2012 there were a series of significant earthquake events in the Canterbury region of New Zealand which resulted in 185 deaths as well as catastrophic damage to and loss of homes, destruction of the central business district, and other infrastructure. These factors may have impacted upon people's willingness and/or ability to participate. Notwithstanding this, two-thirds of

participants came from this critically affected region. There was an expressed perception by several family/whānau that they felt that they did not have anything to offer the research and for this reason a number declined to participate. Whilst others initially thought this to be the case for themselves, they still consented to have a conversation.

The location in which the interviews were conducted may have also posed a limitation. Whilst the majority of participants with intellectual disability opted to have their interview at home, and given that some of them were supported by a family/whānau member, it is not clear to what extent this impacted upon their autonomy to freely express themselves. Conversely, it may have facilitated communication as several needed someone who knew them well. Families were largely respectful of the opportunity and actively supported their family member with intellectual disability to participate as independently as possible.

Evidence of precise diagnosis for intellectual disability was a further challenge. There is a presumption that if people are accessing intellectual disability services that clear standardised evidence already exists of eligibility for government funded services. Whilst the majority of information in this regard was sourced from family/whānau participants, some individuals self-identified as having an intellectual disability and even allowed the researcher to view a copy of an assessment report which validated the same.

A number of contact points were required to engage with participants for the purposes of consent and interview – ironically this may also be a strength of the study. Further, the prompts given to those with intellectual disability to bring a photo, image or object (that represented ageing for them) to the interview may have been open to bias. There is a risk that the family/whānau member supporting the individual to attend and participate

may have influenced (consciously or unconsciously) the selection of a visual image. However some participants only made their photo, object or image selection when the researcher returned to conduct the interview. Further to this, the request for participants to choose a singular item may have also reduced the breadth of potential opportunity to explore the subject at hand – ageing and future planning. Furthermore, not knowing the participants' ability (or level of intellectual disability) is a variable to be considered in regards to the conclusions made about responsiveness to the generic images used in this study.

Inclusivity is increasingly considered best practice and as such, active involvement in all aspects of the research process is an important consideration rather than simply seeking the reality of those being studied (McDonald et al., 2006; McDonald et al., 2009; Northway et al., 2014; Tuffrey-Wijne et al., 2008). The lack of a greater level of inclusion of people with intellectual disability and/or their family/whānau in the design and execution of this study is a limitation. It is recognised that both the disability and research communities are shifting their philosophical understandings about engaging with each other by identifying priorities deemed relevant to the populations concerned, of what is researched and how it is undertaken. It is important however that this is not hindered further by gatekeeping practices or perceptions which directly link autonomy with capacity to consent (Lai, Elliott & Ouellette-Kuntz, 2006).

It is proposed that the identified limitations have little bearing on the emergent model *Navigating Ever-Changing Seas*. For example, regarding recruitment for the study, findings indicated a number of longstanding experiences and deeply held beliefs for participants and were therefore not influenced by being situated in a post-earthquake region. Information pertaining to the diagnosis of intellectual disability may have an impact on

the generalisability of the findings and potentially, the model itself. Whilst clear differences were noted in the receptive and expressive communication of participants with intellectual disability all were able to engage in the research to the extent possible for them; this included those who were denoted by family/whānau or significant others as likely to not be able to contribute to the subject of ageing and future planning.

Strengths

It is my professional opinion and belief that prior knowledge and experience of the health and disability sector directly enabled me to encounter all participants in a different role and respond to their realities as they presented and had relevance both within and external to the family/whānau. The use of multiple points of contact and an awareness of techniques with which to engage participants was also important in this research. Critically, having an understanding of the functional communication of behaviour allowed me to remain present and responsive to participants' needs whilst engaging in the research process. Finally, having a knowledge of the intellectual disability sector, the resources available, systems and processes also facilitated a therapeutic connection as participants (particularly family/whānau) felt heard. It has been argued in the past that such a shift in role during research may impact upon the nature of the research, it can equally be argued that providing a response "can constitute reciprocity wherein relationships with participants are marked by a sense of mutuality and trust" (Hall & Callery, 2001, p. 267). It was imperative that I did not leave families in distress when the nature of the conversation triggered concerns and uncertainty for participants when I sat with knowledge that could assist and inform them. Hence, the application of grounded theory offers learning in real time as the nature of reflexivity presupposes and enables

understanding of the research process and thereby enables the researcher to recognise and respond to what is emerging whilst it is occurring (Schreiber & Stern, 2001). Furthermore, the research approach resulted in “anchor[ing] agendas for future action, practice, and policies in the *analysis* [emphasis in text] by making explicit connections between the theorised antecedents, current conditions, and consequences of major processes” (Charmaz, 2005, p. 512) for all concerned (including myself as a researcher).

Recommendations

The results of this study present a number of challenges and opportunities across the domains of practice and research. Whilst appendix 20 provides a summary of the recommendations, the associated narrative in this section explains the identified gaps, some of which are further informed by existing evidence. The emergence of each recommendation is a reminder that whilst several are not necessarily new, they have arisen through this study. Collectively they illustrate the range and number of issues which continue to confront caregiving and receiving for and by people with intellectual disability and their family/whānau networks of support.

Implications for Policy and Practice

As evidenced in the current study, there was an interdependence for some participants hence it is important to also assess the family structure (Ryan et al., 2014) to establish who is looking after whom. Equally important is to identify those who are not yet known to existing services so as to reduce the risk of transitions only occurring in the event of a crisis (Gilbert et al., 2007; Ryan et al., 2014).

Critically, all members of the caregiving system, including the person with intellectual disability, should regularly engage in planning conversations

to discuss imminent natural milestones and the future. As demonstrated in this study, individuals and/or their family/whānau may need permission and practical support to discuss this between themselves as well as with key service links, and they may face ethical dilemmas about how decisions are made and by whom within systems of care (Banks, 2003). To this end, the meaningful involvement of family members with intellectual disability in the decision-making processes within family/whānau systems of care needs to be more explicit, flexible and creative. Knowledge of what is desirable or possible, in any given context, impacts upon the sense or ability to self-determine available outcomes (Wehmeyer et al., 2011).

Information should be provided to individuals and their family/whānau at pivotal stages of life regarding considerations and entitlements for disability needs, services, and accessibility given that funding and parameters change over the life course (Chou et al., 2009b). As people in New Zealand are often dependent upon information from a needs assessment service or their GP, this would facilitate more timely planning and thereby reduce the acuity for some transitions. Timely planning would also facilitate meaningful access to, and engagement with the community, to ensure suitable and sustainable opportunities for support across the lifespan and “ensure that inevitable future transitions are well managed” (Jokinen et al., 2012, p. 64).

Knowledge of what information individuals and their families would like to have readily available to carers, professionals and planners is important. Collating information, both past and present, is pivotal in terms of capturing the personal health and social history, as well as the values, nuances or idiosyncrasies which are specific to the person with intellectual disability that would support the future planning needs should another carer

(including family/whānau) take on this role. This is separate to, or could be part of a formal advance-care-planning process.

To identify the limitations for a family in regard to future planning and explore the possibilities whilst *Navigating Ever-Changing Seas*, the following points provide a compass for all ages and stages of life. The key elements listed below reflect the information and perspectives held by individuals with intellectual disability and their family/whānau which were discovered and informed the development of the emergent model in this study. In so doing a record may be kept of the journey over the lifespan and which prompts the following exploration:

- a. What information do I / we have about (the topic under consideration)?
- b. What information do I / we need? What is the reliability of the source?
- c. How motivated am I / are we?
- d. Whose needs are being met by engaging (or not) in this process?
- e. How ready am I / are we? How will I / we know?
- f. Identify the existing resources and what may be needed or expected as part of planning a process. Resources may include but not be limited to; funding, location, personnel (carers, support, collaborators, community networks) and time (required as well as timeframe).
- g. Explore the values, language and schema (underlying, unconscious drivers which inform planning and reactions) internally and externally which are identified as influencing self, or others.
- h. Planning for end-of-life care (Banks, 2003).

For some of the participants with intellectual disability in this study, there was not always an environment which concentrated on supporting them to learn meaningful skills in anticipation of future needs relating to ageing. Hence education regarding actual life stages may actively support the

sense of ageing that people with intellectual disability have alongside of their family/whānau who may also be ageing (McEvoy, 2012). It should include health literacy (Heller, 2008; O'Connell, Bailey & Walker, 2003) and also target family/whānau carers (Caldwell, 2008). Further to this, a key recommendation calls for family/whānau carers to engage with the family member who has intellectual disability to develop new skills or building on existing skills that furnish functional abilities of daily living. People with intellectual disability would benefit from "information and training... to help educate them regarding their rights and responsibilities to make decisions about research, treatment, and other important issues affecting their daily lives" (Freedman, 2001, p. 138). It stands to reason therefore that key family/whānau would also benefit from developing their own knowledge and skill base about the rights of their family member with an intellectual disability (O'Grady Reilly & Conliffe, 2002) and how to facilitate informed choice with this person (Curryer et al., 2015).

A national strategy could be developed which guides transitioning processes via local leaders who "establish linkages with appropriate agencies and service providers to facilitate successful transitions, identify gaps in services and supports, and build community capacity" (North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities, 2009, p. 22) and this would ultimately serve to reduce the invisibility of informal carers (Grant, 2007). A key focus of this plan is on reducing silos of care and connecting funding structures to further promote and respond to all in the caregiving relationship. Existing structures and resources that are currently available for the general population as a response to normative ageing needs, should also be made available and accessible to older people with intellectual disabilities (WHO, 2000). To

achieve this, the formal training of health and disability professionals would be essential (Cairns et al., 2012).

In order to achieve the above, a structured and formal assessment is needed of the total caregiving responsibilities within the family /whānau system, including family members with intellectual disability and which identifies compound caregiving roles (Perkins & Haley, 2010). The need for this is based on the notion of intergenerational caregiving as this included not only grandparents during earlier phases of life (Mirfin-Veitch, Bray & Watson, 1997), but contemporarily also the parents, siblings or friends (and for some in the current study) potentially a fourth generation. Moreover, as demonstrated in this study, the support needs of the people with intellectual disability themselves also need to be addressed as they may also be providing a level of support to others in the family which enables the continued independence of other family/whānau. Hence carers at all levels, regardless of the relationship, need to have an “assessment in their own right” (Bowey & McGlaughlin, 2005, p. 1383) to ensure “real choices exist”, that all parties are involved and to enable services to be implemented which acknowledge and “respond to the changing nature of their [caregiving] relationship” (Williams & Robinson, 2001, p. 61). Aside from establishing the range of caregiving tasks, part of such an assessment needs to establish the impact of the demands this places on those concerned (Taggart, 2012b). As found in this study, those who find themselves in the role of primary carer for a family member with intellectual disability may already have had (or be anticipating) future caregiving responsibilities (Perkins & Haley, 2010). Whilst the likelihood of this may not be deemed onerous for some, for others it does have implications for planning at a government level about caring for carers (National Advisory Committee on Health and Disability, 2010). New Zealand

would be advised to scope the extent of existing and prospective caregiving needs of people with an intellectual disability and their family/whānau.

It is also imperative to reduce barriers between the aged care and disability sectors (Washko et al., 2012). Service funding streams differ radically and may inhibit ready access to community base in-home supports. Planning for future health care and accommodation is possible and contains the ability to calculate, monitor and maintain information regarding people who are born with or acquire intellectual and/or other impairments across the lifespan (Dillenburger & McKerr, 2009).

Furthermore, to reduce the risk of compounded loss of identity in the community, it is critical that providers ensure that new models are well established before existing services are discontinued as this will ensure accessibility to, and transferability of, funding streams. Such models also need to pay attention to existing theories of ageing and disability whilst simultaneously seeking to develop greater cohesion between them.

Implications for Research

As evidenced, the above is not isolated to the latter stages of life and signifies that many of the current or potential issues identified by individuals and their family/whānau have been a factor across the lifespan. Given the model which emerged as part of this study, and the projective claims made regarding its applicability, it would be essential to evaluate *Navigating Ever-Changing Seas* for other populations which may include but are not limited to; younger people with intellectual disabilities living with family/whānau, and those in residential and supported independent living (SIL) settings. It is proposed that this model would also have relevance to the aged care sector in targeting those who are living with children who are caring for older family/whānau. Whilst reference has also been made to the compounded

nature of caregiving, tracking the model across a range of specific caregiving arrangements would be critical. A key comparative similarity between the disability and aged care sectors is that both are experiencing increased complexity in population due to increased longevity, co-morbidities, and the later stage at which people may present or come into formal care situations.

Participation in research is the right of any citizen. This study has highlighted that people with a disability should be considered competent to assent or consent to participate; the challenge for researchers and ethical bodies is whether the option of being able to opt-out is as valid as opting-in (Tuffrey-Wijne et al., 2008; Veenstra et al., 2010). Whilst both laudable and understandable, gatekeeping of participants in having access to knowledge about projects for which they may have an interest, may equally reduce their autonomy and reinforce stereotypes about whether people with a disability have a meaningful contribution to make to knowledge in society (Morgan, Cuskelly & Moni, 2014; Northway, et al., 2014; Tuffrey-Wijne et al., 2008; Veenstra et al., 2010). The issue of challenging whether maintaining anonymity reduces the voices of individual stories as part of a collective experience also needs further debate (Tuffrey-Wijne et al., 2008).

'Nothing about us without us' (Harrison et al., 2001; Stone, 1997) is a long established term commonly used both in mental health and disability sectors to signify the right to inclusion. It challenges the status quo and requires that all people have the opportunity to be involved at all levels of citizenship in society and to the extent possible. A key recommendation therefore is to undertake inclusive participatory research. This necessitates clinicians, academics, institutions and research teams to facilitate processes which promote inclusion (Becker et al., 2006) and directly involve people with intellectual and other disabilities as co-researchers in all stages of the research process (McDonald, Kidney & Patka, 2013; Ollerton, 2012). This reduces the

risk of simply doing research 'to' participants rather than enabling emancipatory engagement of processes with populations considered vulnerable (Goodley & Lawthom, 2005). To do inclusive research well means engaging people with intellectual and other disabilities either as paid consultants to a project (Stalker, 1998), as part of the reference group for a project, to undertake an active role within the research team, and/or including them in the ethics, recruitment and data collection processes, analysis, authorship and dissemination of the results.

In the current study the importance of autonomy was identified as a necessity for all parties as it underpinned their individual and collective roles and perspectives which inform *Navigating Ever-Changing Seas*. As in other areas of life, autonomy may be further empowered, negotiated or interpreted through inclusive emancipatory research (Allen-Leigh, Kata, Rangel-Eudave & Lazcano-Ponce, 2007). The research community would be remiss not to use and apply a range of alternative and augmented communication approaches to ensure the inclusion of those with a greater level of impairment within the disability community who experience even greater disenfranchisement than the majority (Becker, et al., 2006). Whilst ideal and not without its challenges, these issues to inclusion can be overcome (Inglis & Cook, 2011; Northway et al., 2015). Snowballing as a sampling technique can assist in achieving this goal and is deemed to be a valid sampling technique to reach and seek the inclusion of hidden populations in research. Whilst this may pose problems with representativeness, it may still form one of a range of approaches to directly access populations considered vulnerable and/or hidden (Atkinson & Flint, 2001). Photovoice also lends itself well in this regard (Povee et al., 2014).

"Photovoice provides an avenue for people with intellectual disabilities to reflect on their lives and communicate their perspective to people who make decisions that influence their daily lives." (Jurkowski, 2008,

p. 7). Hence, further research is warranted into the application of both photovoice and photo elicitation to facilitate greater inclusion in research of people with intellectual disabilities. An important consideration would focus on how individuals are prompted and supported to engage. For example, with photo elicitation, it is important to establish whether there is a singular or more comprehensive understanding which informs and elucidates the subject of interest as this may inform the depth or otherwise of the research. Furthermore, in regard to seeking perspectives about ageing and future planning, it would be beneficial to use this methodological approach in the younger generation of people with intellectual disability. Given the possibility of inter-generational differences about perceived or actual caregiving roles as individuals age, it would be pivotal to explore whether the expectations are similar or different.

There is a plethora of recommendations here which highlight opportunities for people with intellectual disability themselves, family/whānau carers, health and disability services systems. These clearly demonstrate the ongoing challenges individuals and their systems of care persistently face whilst *Navigating Ever-Changing Seas*. The approaches identified in this study would facilitate a greater understanding in regard to each of the populations in the caregiving relationship who are both vulnerable (Veenstra et al., 2010) and who are also ageing.

CHAPTER 10

CONCLUSION

Given the competing demands philosophically, developmentally and practically (Banks, 2003) a number of inherent drivers over the lifespan were identified for families/whānau and the people with intellectual disability in respect to how they perceived ageing and the territories and subsequent maps they formed to understand the ageing process and future for themselves. Without exception, the influence of philosophical approaches in shaping the socio-political context over time significantly informed participants' decision-making capabilities. Identifying the values and beliefs intrinsic to the trans-generational system of care also proved critical: Simultaneously the extrinsic factors imposed by society strongly moulded the lived experience or territory for people with intellectual disability and those within their caregiving network who are *Navigating Ever-Changing Seas*.

Maps of decision-making and ageing were found to be dynamic and could be re-drawn and reconstructed. Regardless of whether the map (or the interplay between caregiving and care-receiving) is individually or mutually defined, the respective territories may not always have been fully explored or acknowledged. Prior to this study, these families had individual stories of a single shared experience and through the grounded theory process, these were able to be shared and so gave a more equal voice to the numerous realities of individuals. Photo elicitation was seen to strengthen the participation of participants with an intellectual disability: It relies heavily on metaphors and related definitions and thus allows for a shared understanding of other people's emotional experience of an abstract notion or event (and

which would otherwise have been difficult to articulate for the person with intellectual disability). It has been demonstrated that for all members of the caregiving network, knowing the journey thus far informs their perspective of ageing to varying degrees.

Navigating Ever-Changing Seas as a proposed emergent theoretical model was shown to be a platform for exploring learning, being and engaging with individuals about their life experiences, expectations, processes and decisions which are important to them particularly in regard to ageing: Thus it will be essential to further test its properties and parameters within and for other populations who are also considered vulnerable. The emergence of *Navigating Ever-Changing Seas* demonstrates that co-constructivism is the intersection of the subjective experiential participation of each party, and which makes a valid contribution to a collective objective and creates opportunities for conceptual evolution. The experience of growing up with someone who has an intellectual disability, for example, was different for siblings and parents respectively - and contained roles that repeatedly shift over time as each party passes through life stages as they respectively age. For some, the process of engaging with this study precipitated a deepening awareness of differences in existing maps and territories and the determining of new directions. For others, there was a reticence due to a lifetime of needing to be both persistent and consistent in *Navigating Ever-Changing Seas*. It is posited that whilst unintentional, the interview process provided a platform for an intervention to occur in the form of a conversation about that which was previously unspoken. For others, it sometimes reinforced their own need to hold off making any plans. Maggs and Laugharne (1996, p. 247) stressed the need to “plan alternative care arrangements for the older adult with [intellectual disability] so that crisis are avoided or, at least, anticipated... [and is] based on a good understanding of the relationship” of

those involved in the system of care. Regardless of one's perspective and positioning about the present or the future, all participants hoped to retain an ability to function well and socialise with others as they aged (Jeppsson et al., 2012).

The perspectives of ageing often reflected tentativeness, variation, uncertainty and sense of impending responsibility and reflects the emergent recognition that there is a mutuality in caregiving relationships, and which demands both a lifespan and intergenerational lens (Burke et al., 2012; Mirfin-Veitch et al., 1997). For participants with intellectual disability, whilst the map had often been partly drawn for them, it did not preclude their own need nor want for autonomy in re-drawing and planning the territory for themselves. Despite this need, there was also evidence that whilst the majority of participants could acknowledge their preferred territory, there was both ambivalence and ambiguity about the future and/or perceived powerlessness in ageing. Traits which inform interpretation and responses may be intrinsic to the disability or stem from individual personality and other conditions which inform the journey: Overall it remains an individual process. Despite the individual nature of perspectives there were also shared perceptions about getting older such as slowing down. For those who were indecisive about making decisions this reflected either a lack of knowledge and/or uncertainty about the 'right' decision to be made: It is argued that for participants with intellectual disability there are extrinsic factors such as upbringing, experience and beliefs of the family/whānau which influence expectations and decision making around ageing and which may be at odds with their own intrinsic needs. Mistrust represented a universal experience for the majority of family/whānau carers when they considered access to services, the availability and ability of health, disability and social services to provide the right care for their family member when it was needed (Cairns et

al., 2012). This prospective experience was different for each party across the lifespan as perspectives changed through the course of the journey.

Hogg et al. (2000) reflected that the principles espoused by the United Nations for older people (independence, participation, care, self-fulfilment, dignity) be equally promoted and inclusive of people with intellectual disability. In time to come, the aged care sector will need to become more aligned with the social model of disability in order to engage, empower and promote the autonomy of the older person regardless of lifelong or acquired disability. There is forever an anticipatory nature to the existing caregiving relationships which is confounded by anxiety about the current realities whilst simultaneously weighing up future possibilities (Bowey & McGlaughlin, 2005; Grant, 2007).

In summary, the need to recognise existing perspectives, experiences, and interdependent caregiving roles was evident for participants with intellectual disability and their family/whanau. The value of, and need for, autonomy in decision-making processes around ageing and future planning was underestimated for all concerned. Furthermore, it is imperative that the intrinsic and extrinsic influences which impact upon these hidden caregiving relationships across the lifespan – are not ignored. In working with people with intellectual disability and their family/whanau, such considerations are vital for health and disability service systems to enable inclusive policies to be developed which are responsive to each member of this unique caregiving network. To achieve this, systems must be aware that the aforementioned elements may not be fully acknowledged, recognised or understood by the family/whānau – in as much for themselves as for their sibling, child, grandchild, niece, nephew or friend – as they individually (and collectively) continue to find themselves *Navigating Ever-Changing Seas*.

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Appendix 1: Ethics Approval Final 11-04-2011
Ministry of Health Upper South A Regional Ethics Committee



Upper South A Regional Ethics Committee

c/- Ministry of Health

250 Oxford Tce

Christchurch

Phone: (03) 372 3037

Email: uppersoutha_ethicscommittee@moh.govt.nz

11 April 2011

Ms Henrietta Trip
Christchurch School of Medicine
University of Otago
P O Box 1274
Christchurch 8140

Dear Henrietta Trip,

Ethics ref: URA/11/02/004 (please quote in all correspondence)
Study title: Ageing with an intellectual disability in New Zealand:
Experiences, perspectives and future planning for
individuals living with family/whānau
Investigators: Ms H Trip, Dr L Whitehead (supervisor)

This study has been given ethical approval by the Upper South A Regional Ethics Committee. A list of members of the Committee is attached.

Approved Documents

Information sheet and consent form, version 2 dated 20.03.2011

Information sheet and consent form – family or whānau , version 2 dated 20.03.2011

Statement by relative/friend/whānau , version 2 dated 20.03.2011

Consent for the release of picture or photo, version 2 dated 20.03.2011

Letter of invitation, version 2 dated 20.03.2011

Expression of Interest form, version 2 dated 20.03.2011

Advertisement/poster/flyer, version 2 dated 20.03.2011

This approval is valid until 30 September 2015, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by 30 April 2012. The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

Requirements for the Reporting of Serious Adverse Events (SAEs)

For the purposes of the individual reporting of SAEs occurring in this study, the Committee is satisfied that the study's monitoring arrangements are appropriate.

SAEs occurring in this study must be individually reported to the Committee within 7-15 days only where they:

- are *unexpected* because they are not outlined in the investigator's brochure, and
- are not defined study end-points (e.g. death or hospitalisation), and
- occur in patients located in New Zealand, and
- if the study involves blinding, result in a decision to break the study code.

There is no requirement for the individual reporting to ethics committees of SAEs that do not meet all of these criteria. However, if your study is overseen by a data monitoring committee, copies of its letters of recommendation to the Principal Investigator should be forwarded to the Committee as soon as possible.

Please see www.ethicscommittees.health.govt.nz for more information on the reporting of SAEs, and to download the SAE Report Form.

We wish you all the best with your study.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Alieke Dierckx'. The signature is fluid and cursive, with the first name 'Alieke' written in a larger, more prominent script than the last name 'Dierckx'.

Alieke Dierckx

Administrator

Upper South A Regional Ethics Committee

Uppersoutha_ethicscommittee@moh.govt.nz

Appendix 2: Consultation with Māori



8 December 2010

Dr Lisa Whitehead
Centre for Postgraduate Nursing Studies
University of Otago, Christchurch

*Mā te rangahau hauora e tautoko te whakapiki ake te hauora Māori
All health research in Aotearoa New Zealand benefits the hauora (health and wellbeing)
of tangata whenua*

Tena koe, Lisa

Thank you to Bev Burrell and Henrietta Trip, for taking the time to meet with me at the University of Otago, Christchurch on 6th December 2010, to discuss your research study titled:

*Ageing with an intellectual disability in New Zealand: Experiences, perspectives and future
planning for individuals living with family*

I note that your research is a PhD thesis to explore the concept of getting older with people who have intellectual disability living with a relative.

You mentioned also "Maori may care for their family/whanau at home longer than the general population: It would be interesting to compare the similarities and differences between Maori and non-Maori about the needs and challenges of the caregiving relationship between the ageing caregiver, the family member with an intellectual disability and disability service streams".

It was heartening to hear that you have already spoken to Cherlyn Brown and Rik Ehau, well known in the Maori disability circle. Such people should be relatively accessible and well placed to advise you as to a relevance of your research and the outcomes which can be achieved for Maori health and the population overall.

We also discussed the relevance of the research in regard to improving Maori health status and referred to the HRC's *Nga Pou Rangahau Hauora Kia Whakapiki Ake Te Hauora Maori 2004-2008 – The Health Research Strategy to Improve Maori Health and Well being 2004-2008*. The other reference that is available is *Hauora Maori Standards of Health IV: A study of the years 2000-2005* by Bridget Robson and Ricci Harris, Maori Health Research Unit, Wellington School of Medicine. All provide Maori specific information on a range of health issues.

The recent publication *Tatau Kahukura: Maori Health Chart Book 2010*, Ministry of Health, 2010 (2nd edition), is an update relating to the socio economic determinants of health, health status and service utilisation of the Maori population. Further references are available from the HRC's *Guidelines for Researchers on Health Research Involving Maori* (page 22), www.hrc.govt.nz.

It is also advisable that researchers review and refer to the District Health Board Annual Plan and/or the current Health Targets published by the Ministry of Health (1 July 2009).

Research Office, Department of the Dean
University of Otago, Christchurch

PO Box 4345, Christchurch Mail Centre, Christchurch 8140, New Zealand
Tel +64 3 364 0237 • Fax +64 3 364 0525 • Email research.uoc@otago.ac.nz
www.uoc.otago.ac.nz

Page 1 of 2

It was agreed that there is a need to acknowledge the issues pertaining to ethnicity and to consider how ethnicity data will be collected in your study. Also, given the poor ethnicity data collection in hospital databases this information should be collected in demographic information as part of the research. Through our discussion the Census 2006 ethnicity question was considered to be the preferred tool in recording ethnicity.

It is a requirement of the ethics approval process that a final report be submitted when the research is complete. A copy of the report should be provided to me at that time as findings from this project may contribute to the development of future research hypotheses or projects. It is therefore important that appropriate Maori organisations, Maori health professionals and Maori researchers are aware of your findings. The Research Office of the University of Otago, Christchurch and in particular myself as the Research Manager - Maori would be willing to assist in the dissemination of your findings once your project has reached a successful conclusion.

My suggestions do not necessarily relate to ethical issues with the research, including methodology. Other committees may also provide feedback in these areas. I hope this letter will suffice in terms of the application. Please contact me should you need any other information that may not have been included in the letter relevant to our conversation.

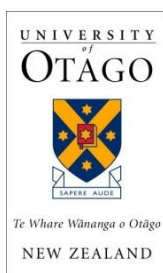
I wish you well in your research.

"Mo tatou a mo ka uri a muri ake nei" Ngai Tahu 2025

Ka nui tonu nga mihi



Elizabeth Cunningham
Research Manager - Maori



Appendix 3: Consent by Proxy

Ageing with an Intellectual Disability in New Zealand

STATEMENT BY RELATIVE/FRIEND/WHĀNAU

Lay title:

Ageing with an intellectual disability in New Zealand

Principal investigator:

Henrietta Trip

Participant's name:

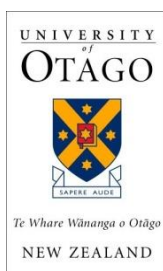
I have read and I understand the information sheet dated 25.01.2011 for people taking part in the study designed to seek their perspectives about what it is important them and the family/whānau/carers who support them. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I believe that _____ would choose and consent to participate in this study if they had been able to understand the information that I have received and understood.

I understand that taking part in this study is voluntary and that my relative/friend may withdraw from the study at any time if they wish. This will not affect their continuing health care.

I understand that their participation in this study is confidential and that no material which could identify him/her will be used in any reports on this study.

I know whom to contact if my relative/friend if anything occurs which I think they would consider a reason to withdraw from the study.



Appendix 4: Consent Form - People with Intellectual Disability

Ageing with an Intellectual Disability in New Zealand

I have been invited to talk about getting older with an intellectual disability and living with my family/whānau.

- What I say is important and private
- I can stop the meeting if I want to
- I can change my mind about being in the study. This is my choice.
- The meeting will be recorded. Only Henrietta will listen to the tape.
- Reports will be written. No one will know what I have said because my name will not be in the report.
- The information may help others with an intellectual disability to think about getting older and what is important to them (and those who support them)



I would like to talk about getting older and what is important to me.

I would like someone with me



YES

OR



NO

If YES, I want the person to be _____

- There may be 2 or 3 meetings
- Each meeting may take between 1-2 hours
- I can bring a photo or picture with me to the meeting that makes me think about getting older
- I can choose if I want to check what has been written down from our meetings
- I can choose one or more family members for Henrietta to talk to about helping me as I get older

I want the meeting to be at:

HOME _____



OR

WORK _____

OR

OTHER _____

My Name _____

My Phone Number _____

My Family Member _____

Their Phone Number _____

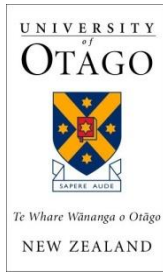
My Signature _____



If I have any _____ questions I can contact Henrietta:

Phone (03) 339 2860

Email trihe953@otago.ac.nz



Appendix 5: Visual Scale



1

No



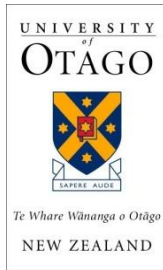
3

Don' t Know



5

Yes



Appendix 6: Family / Whānau Consent Form

Ageing with an Intellectual Disability in New Zealand

I have been invited to talk about my expectations and future planning needs as I support or care for a family member with an intellectual disability as they get older.

- I know I can stop the meeting if I want to AND
- I know I can change my mind about being in the study

The meeting will be recorded and/or notes will be taken. Aside from Henrietta Trip, the only persons who will access the data are her supervisors. As a requirement of such research, it is expected that the results will be presented at appropriate conferences and papers may be written for publication. My information will be anonymous and unidentifiable.



I would like to talk about my expectations and future planning needs as I am involved in supporting or caring for a family member with an intellectual disability as they get older.

I would like someone with me



OR



If YES, I want the person to be _____

- There may be one or two meetings
- Each meeting may take up to an hour
- I would like to review the transcript to review the content and make any adjustments that are needed



OR



I would like the meeting to be at:

HOME _____ OR

WORK _____ OR

OTHER _____

Name _____

Phone Number _____

Family Member _____

Phone Number _____

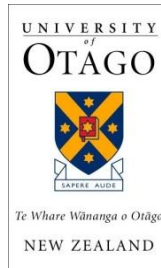
My Signature _____

If I have any questions I can contact Henrietta:

Phone (03) 364 3857

Email henrietta.trip@otago.ac.nz

Thank you Henrietta Trip, RN, PhD Student
 Centre for Postgraduate Nursing Studies
 University of Otago, Christchurch



Appendix 7: Letter of Invitation (A)

Ageing with an Intellectual Disability in New Zealand

DATE

NAME

ADDRESS

Dear

Re.: Study on Ageing with an Intellectual Disability in New Zealand

Thank you for your interest and response. The aim of this study is to understand what people with an intellectual disability think about ageing. For their family/whānau, this is an opportunity to discuss current realities and hopes for the future in regards to their family member with an intellectual disability.

Attached is an **Information Sheet** and **Expression of Interest Form** to discuss with your family/whānau/friend.

Please return the **Expression of Interest Form** in the attached stamped self-addressed envelope and I will make contact to set up a time to meet. The **Information Sheet** is to be kept by participants.

Should you have any questions, please contact me directly on (03) 339 2860.

Yours Sincerely

Henrietta Trip
Registered Nurse, PhD Student
Centre for Postgraduate Nursing Studies



Appendix 7: Letter of Invitation (B)

Ageing with an Intellectual Disability in New Zealand

- Do you *or* a member of your family/whānau have an intellectual disability who is aged 40 years or more?
- If so, do you / or they live with other family/whānau (for at least the last 5years)?

Then it would be great to talk with you.

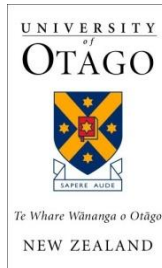
- The aim of this study is to find out what people with an intellectual disability think getting older might be like.
- For family/whānau/siblings/carers, this is an opportunity to discuss supporting an adult family member with an intellectual disability; your realities, plans, and/or hopes for the future.

It will involve meeting a couple of times and you are welcome to have a support person at each meeting. This research has been approved by the Upper South A Ethics Committee.

If you and/or your family/whānau would like to take part please contact:

Henrietta Trip
RN, Lecturer, PhD Student
Centre for Postgraduate Nursing Studies, University of Otago, Christchurch
Phone (03) 364 3850 027 294 6488
Email henrietta.trip@otago.ac.nz

THANKS FOR YOUR CONSIDERATION



Appendix 8: Information Sheet – People with Intellectual Disability

Ageing with an Intellectual Disability in New Zealand

Researcher: Henrietta Trip, PhD Student

Centre for Postgraduate Nursing Studies, University of Otago,
72 Oxford Tce, Christchurch. Phone (03) 364 3857

Supervisor: Dr Lisa Whitehead, Director

Centre for Postgraduate Nursing Studies, University of Otago,
72 Oxford Tce, Christchurch. Phone (03) 364 3850

You live with your family and are invited to be in a study to talk about getting older: Your thoughts and plans.

What is this study about?

1. To learn what is important for people with an intellectual disability as they get older.
2. To learn what your mother, father, family / whānau think is important as you get older

You can join in the study if:

- You are close to 40 years or over, have intellectual disability and can speak for yourself
- You have been living with a family member for the last 5 years or more

What will joining in the study involve?

We will meet two or three times. This could be either at your home, at work, or you could come to our office.

- At the first meeting we will talk about your consent or choice to join in. You will be invited to bring a photo, picture or drawing to the next meeting.
- At the second meeting, we will talk about what getting older is like, supports you have, things you like to do, your health and the future.
- If you want to check what has been written down, I will come and meet with you a third time. This is your choice.
- If you have to pay for parking to meet with me, this will be given back to you.
- You are invited to choose a family member for me to talk to about supporting you as you get older.
- **You can have a support person at any of the meetings**

Will the information I give you be kept private?

- This study has been approved by the Upper South A Ethics Committee
- Your information is private. I will only talk to the people in your family you say it is okay for me to talk to.
- Your information will be stored in a locked filing cabinet.
- As part of the study I will share what has been said to health professionals who work in aged care and services for people with intellectual disability. **YOUR INFORMATION WILL STILL BE PRIVATE. NO NAMES WILL BE USED.**
- I will need to write reports. **YOUR INFORMATION WILL BE PRIVATE. NO NAMES WILL BE USED.**

How much time will be needed? What are my rights?

- Each meeting may take up to 1 hour.
- You can ask me any questions about the study.
- You can finish each meeting at any time.

- You can change your mind about being in the study. It is your choice.



YES - I would like to join in the study:

Please fill out the **BLUE** form **AND send** to Henrietta Trip in the **FREEPOST** envelope (NO STAMP REQUIRED)



NO - I don't want to join in the study

- It is your choice to meet with me or not.
- You do not need to do anything if you don't want to take part.



NOT SURE?

If you have any questions please contact me:

Phone : (03) 364 3857

Email : henrietta.trip@otago.ac.nz



THANK YOU

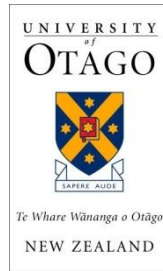
Henrietta Trip, Registered Nurse

Centre for Postgraduate Nursing Studies

University of Otago, Christchurch

If you would like to know more about your rights about joining in this study you may want to contact a:

- ❖ **Health and Disability Consumer Advocate**
Telephone :0800 555 050
Email : advocacy@hdc.org.nz



Appendix 9: Information Sheet – Family / Whānau

Ageing with an Intellectual Disability in New Zealand

Researcher: Henrietta Trip, PhD Student

Centre for Postgraduate Nursing Studies, University of Otago, 72
Oxford Tce, Christchurch Ph. (03) 364 3857

Supervisor: Dr Lisa Whitehead, Director

Centre for Postgraduate Nursing Studies, University of Otago, 72
Oxford Tce, Christchurch Ph. (03) 364 3850

You have been invited by _____ to
join in a study to talk about your experiences, expectations and
future planning needs as you support or care for a family member
with an intellectual disability as they get older.

What is this study about?

1. To learn what getting older may mean for people with
an intellectual disability
2. To hear what family/whānau/carers identify as
important – when they have a family member with
intellectual disability who is aged 40years or over

You can join in the study if:

- You have a family member with an intellectual disability
who is close to age 40 years or over
- This person has been living with yourself or another family
member for the last 5 years or more

What will joining in the study involve?

You may choose to meet with me individually or meet together with other members of your family/whānau for this discussion.

We would meet one or two times. This could be either at your home, at work, or you could come to our office.

- At the first meeting we will talk about the study and complete the Consent Form.
- At the second meeting we will talk about family roles, formal and informal supports, your health, concerns, goals and expectations you may have in caring for your family member with intellectual disability as they age.
- You are welcome to revise the transcript of the interview once this is available. This can be posted or emailed to you and you may indicate any changes you wish to have made at this time.
- Parking costs for the purposes of this research will be reimbursed to participants on receipt of coupon.
- **You can have a support person at any of the meetings**

How much time will be needed? What are my rights?

- Each meeting may take up to one hour.
- You can ask me any questions about the study.
- You can finish the meeting any time you like and we can make another time.
- You can choose to withdraw your consent to participate and your information will not be included.

Will the information I give you be kept private?

This study has been approved by the Upper South A Ethics Committee.

Your information is private and confidential both during the research process and in all publications pertaining to this study. All the data collected will be stored in a locked filing cabinet. This information will be retained for ten years.



YES - I would like to join in the study:

Please fill out the **CONSENT** form **AND send** to Henrietta Trip in the **FREEPOST** envelope



NO - I don't want to join in the study

It is your choice to meet with me or not. You do not need to do anything if you don't want to take part.



NOT SURE?

If you have any questions please contact Henrietta:

Phone : (03) 364 3857

Email : henrietta.trip@otago.ac.nz



THANK YOU

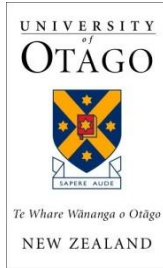
Henrietta Trip, RN, PhD Student

Centre for Postgraduate Nursing Studies

University of Otago, Christchurch

If you would like to know more about your rights for joining in this study you may want to contact a:

❖ **Health and Disability Consumer Advocate**
Telephone :0800 555 050
Email : advocacy@hdc.org.nz



Appendix 10: Expression of Interest Form

Ageing with an Intellectual Disability in New Zealand



YES - I would like to be in the study and talk
about getting older

-
- Please fill this out (or ask someone to help)
 - Post in the envelope provided (NO STAMP REQUIRED)

If you want to ask about the study please call me on:

(03) 364 3857 or Email: henrietta.trip@otago.ac.nz

When I receive this letter, I will contact you to make a time to meet. I look forward to meeting with you.

Thank you for being willing to meet with me. Henrietta Trip

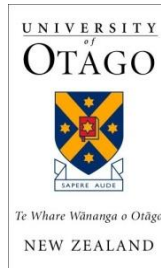
Name : _____

Address : _____

: _____

Phone Number : _____

Comments : _____



Appendix 11: Advertisement
Invitation to Participate in a Study about
Ageing with an Intellectual Disability in New Zealand

- Do you *or* a member of your family/whānau have an intellectual disability who is aged 40 years or more?
- If so, do you / or they live with other family/whānau (for at least the last 5years)? Then it would be great to talk with you.
- The aim of this study is to find out what people with an intellectual disability think getting older might be like.
- For family/whānau /siblings/carers, this is an opportunity to discuss supporting an adult family member with an intellectual disability; your realities, plans, and/or hopes for the future.

It will involve meeting a couple of times and you are welcome to have a support person at each meeting. This research has been approved by the Upper South A Ethics Committee.

If you and/or your family/whānau would like to take part please contact:

Henrietta Trip

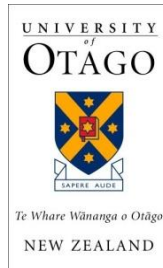
RN, Lecturer, PhD Student

Centre for Postgraduate Nursing Studies, University of Otago, Christchurch

Phone (03) 364 3850 027 294 6488

Email henrietta.trip@otago.ac.nz

THANKS FOR YOUR CONSIDERATION



Appendix 12: Interview Guide – People with intellectual Disability

Ageing with an Intellectual Disability in New Zealand

VISUAL MEDIA REFLECTION: (Photo/Visual/Lifespan Picture)

1. Tell me about the picture/photo/drawing that you have

1a. *If they do not have a visual image:*

Can I show you a picture that I have? (And go to No.5)

2. Did you make/take it yourself?

3. Where did you find it?

4. Why did you choose this picture?

5. What do you see in / like about the picture(s)?

6. How is the picture(s) important to you? Tell me about this picture

7. If someone is 'old' – What age might they be?

8. What do older people look like?

9. Do you know anyone who is old? What is being old like for them?

10. What changes have you noticed as they got older?

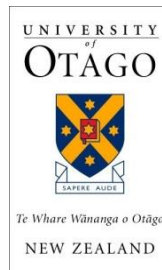
11. What happens when you get older? Does anything change?

12. What are you looking forward to as you get older?

13. What are you not looking forward to?

QUALITY OF LIFE & FUTURE PLANNING QUESTIONS

1. How would you describe yourself as a person?
2. Who else lives here with you?
3. Tell me about your family/friends? Who is important to you?
4. Tell me what you do during the day/week at home?
5. What do you enjoy doing during the day/week in the community?
 - a/ List all the things that make life good for you now
 - b/ How important are each of these (Scale 1-5)
 - c/ Overall, how happy are you right now?
 - d/ If any of these things were not in your life, for whatever reason, how would your rating change? (Scale 1-5)
6. If you could draw a picture, what would a great 'every day' look like? **
7. What support / help do you get now?
8. Who provides that support? How are they helpful?
9. Tell me about your health. (Medication/Specialists)
10. What might change in your body as you get older?
11. Is there anything you would like to know about getting older?
12. What do you think about getting older? (Easy/Difficult)
13. Do you have any plans? Where would you like to be and what would you like to be doing?



Appendix 13: Interview Guide – Family / Whānau / Carer

Ageing with an Intellectual Disability in New Zealand

1. We all have different ideas about ageing; What is “good” ageing and what is “not good” ageing?
2. Tell me about what it is like for you to care for your family member with intellectual disability?
3. What help/support do they need from you?
4. What are their strengths? Things they do themselves
5. What other caregiving responsibilities do you have or anticipate?
6. What practical/social supports do you have in place?
7. What do you see as the roles of other family members in regards to the future care needs of **X**?
8. Tell me about your health.
9. What information do you have about what to expect for your family member as they get older?
10. What services have you accessed in the past? Currently?
11. What other information or services do you think you will need to continue caring for **X** within the family family? Are there any plans in place / underway?
12. How are decisions about X made?
13. How does having **X** living within the family context impact on your life? Others lives?
14. If you wanted to explore other caregiving options, what is currently available for your family member?
15. What do you want or expect to be available for your family member as you and they get older?
16. How do you recognise caregiving stress in yourself?
17. What things do you do to take care of yourself given your caregiving role?
18. What impact has your caregiving role had between you and your family member? Other relationships?
19. What would a great ‘every day’ / the future look like for your family member **X**? For you?
20. Anything else you would like to add?

7. Income & Employment (Please tick all that apply)

- | | |
|---|---|
| a/ <input type="checkbox"/> NZ Superannuation | b/ <input type="checkbox"/> Working for families |
| c/ <input type="checkbox"/> Unemployment benefit | d/ <input type="checkbox"/> Domestic purposes benefit |
| e/ <input type="checkbox"/> Sickness benefit | f/ <input type="checkbox"/> Student allowance |
| g/ <input type="checkbox"/> Disability allowance | h/ <input type="checkbox"/> ACC income support |
| i/ <input type="checkbox"/> Wage / salary earner | j/ <input type="checkbox"/> Self employed |
| j/ <input type="checkbox"/> Other Please State: _____ | |

8. I have lived with _____ for: All their life No. of years

9. My relationship with _____ is: _____ (Please state)

10. They attend work/community activities: YES / NO

_____ (Please state type)

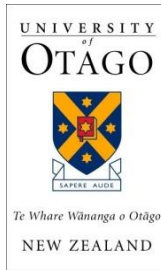
10a. Number of hours per week _____

11. Carer Support / Respite Care YES / NO

11a. Number of hours allocated per year _____

11b. These hours are able to be used YES / NO

If No Why _____



Appendix 16: Consent for the Release of Picture, Photo or Object Ageing with an Intellectual Disability in New Zealand

I have been invited to talk about getting older with an intellectual disability and living with family/whānau

I can bring a photo or picture to the meeting that makes me think about what it might be like to get older.

PLEASE COMPLETE A or B

A. The picture belongs to me



YES



NO

You can take the picture with you



YES



NO

You can use the photo/picture when you write up what we have talked about in the meeting. It may be in the report and I know that no one will know it is mine.



YES



NO

B. The picture belongs to my family



YES



NO

You may need to ask if you can take a copy with you
or to use it when you write up what we have talked
about. Please contact

Name _____

Relationship _____

Phone Number _____



My Name _____

My Phone Number _____

My Signature _____

I can change my mind about letting you use my photo/picture at
any time.



If I have any _____ questions I can contact Henrietta:

Phone (03) 364 3850

Email henrietta.trip@otago.ac.nz

Appendix 17. Examples from the Data: Riding the Waves

Category	Concept
<p>Reciprocating relationships</p> <p>"[Mum's] putting more pressure on Preston... Amazingly it did come to a place where [brother] has become a caregiver for Mum – something I never thought would happen... He's done a darn fine job..." (Julianne, sister)</p> <p>"I think we really care about each other - Like an old married couple... You've always got a bit of company in the house... [Flatmate's] a really good friend... Most of the time she's happy and we can have fun. Yeah. Do a few things together" (Stephanie, friend)</p>	<p>Riding the Waves</p> <p>"...years ago we were never invited out... people just didn't understand... [Other son]... could never have any friends or anything because Peter would be there... it wasn't easy... my sisters-they all thought he was [just] spoilt" (Barbara & Jack, parents).</p> <p>"... as a kid we certainly thought that every family was just like us and they all had a Carol... it's hard to tell what... your life would have been like without her..." (Mackenzie, sister).</p>
<p>Emerging (in)dependence</p> <p>"We'd just let her [sister] do things herself, have a go. Point her at it and say go to it... they [people with a disability] can figure things out so it doesn't take them any energy..." (Jeremy, brother)</p> <p>"I can't go to the bank and get my money out, she's got to go with me and sign for it as well... It's a bit harder because sometimes she doesn't turn up... might be 2-3 days before she turns up..." (Bobby)</p>	<p>"I sort of do things myself and take everything in my stride. I used to get a lot of help from one of my sisters when he [son] was younger, so that was really good... The weekend respite care is really good – it gives me a bit of a break and I think he gets a break from me" (Lorraine, mother)</p>
<p>Taking cognisance</p> <p>"... it gets a bit hectic at times or wires will be crossed and things won't be communicated and someone will get annoyed, and we'll have arguments but at the end of the day it's all right, we all get along... Usually just miscommunication or things that haven't been explained properly or misunderstood... and then someone gets the wrong end of the stick..." (Deborah, sister).</p>	<p>"It hasn't been plain sailing at all..." (Carmen, mother)</p>

Appendix 18. Examples from the Data: Shifting Sands ~ Changing Tides

Category	Concept
Configuring ageing	<p data-bbox="430 604 478 1097">Shifting Sands ~ Changing Tides</p> <p data-bbox="510 268 638 1097"><i>They don't like getting old [parents as it means] going into an old people's home... when they sit around doing nothing" (Peter)</i></p> <p data-bbox="654 268 798 1097"><i>[When people get older] ... they start to get grumpy... Cos back then [when younger] you can calm yourself down... They start getting more wrinkles on the face (Frank)</i></p>
Anticipating change	<p data-bbox="845 268 957 1097"><i>I think it will be changes [in health] I don't... want it to... I'd rather stay younger (Tony)</i></p> <p data-bbox="989 268 1133 1097"><i>Me and Mum were sitting down and talking about things and I was like it's not that I don't love[sister], but I don't want the responsibility when you die... Probably go to the internet – I don't know much about where to go for the next step in helping her..." (Deborah, sister)</i></p> <p data-bbox="1165 268 1348 1097"><i>It's not that easy to just up and leave because that's what [we] have done a lot, we move a lot... And I'm sick of it ...it's a lot of hard work (Stephanie, friend)</i></p>

Appendix 19. Examples from the Data: Uncovering Horizons

Category	Concept
Entertaining possibilities	Uncovering Horizons
<i>I want to live my life and make my decisions and do what I want when I want to do them, not when she [Mum] thinks that I should be doing things... She listened to me and said actually, I think you're right, and that won't be fair on you... (Deborah, sister)</i>	<i>"My hope is that he would be able to live with other people, someone who or a small group of people... I think her probably could but I'm not sure the other people could [live with him]" (Julianne, sister)</i>
Creating a good life	<i>"But he didn't have a choice... that was because of me and I said no you stay here with me so I started explaining you know Mum and Dad are gone... I'm here, I've got no-one here with me you can stay here and I look after you" (Teresa, sister)</i>
Mastering decisions	
<i>As long as she was included in activities... and not left sitting. She'd have to be – quite involved... And treated as normally as you'd treat anybody else... (Isabelle, mother)</i>	

Appendix 20: Summary of Recommendations

Domain	People with Intellectual Disability	Family/Whānau Networks of Support	Health & Disability Systems
Practice	<p>Conversations about ageing in place...</p> <p>Collation of information; life histories...</p> <p>Development of advance-care plans...</p> <p>Education: rights & responsibility, life skills</p>	<p>...involving people with intellectual...</p> <p>... update & preferences (bio/psycho/soc)</p> <p>...with each party in caregiving relationship</p> <p>...health literacy & facilitating choices.</p>	<p>...disability in decision-making</p> <p>...to enable timely planning</p> <p>...across disability & aged care systems</p> <p>Support & enable access.</p> <p>Increased flexibility (funding & service delivery in aged care & disability services)</p> <p>Assessments which acknowledge & respond to the caregiving relationship.</p> <p>Provision of information about service access & delivery across the lifespan.</p>
	<p>Evaluate <i>Navigating Ever-changing Seas</i></p> <p>Develop existing formal & informal</p> <p>Explore opportunities to voice choices & plan for one's future.</p> <p>Engagement with photovoice & photo</p>	<p>...across age groups, residential care, SIL</p> <p>...networks of support.</p> <p>Engage member with intellectual disability</p> <p>...elicitation. Decrease gatekeeping &</p>	<p>Disability & aged care</p> <p>Evaluation of programmes implemented</p> <p>...in future planning</p> <p>Scope the extent of informal caregiving for individuals & family/whānau</p> <p>... increase inclusive participatory research across range of abilities</p>
Research			