



# MONASH University

## **Quality of Life: A Phenomenological study of the experiences of Samoans with a disability in Auckland, Aotearoa New Zealand**

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## Abstract

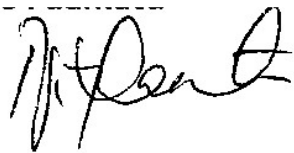
Quality of life is now at the centre of disability policy making and practice in many countries. This phenomenological qualitative study investigated quality of life conceptions and experiences of adult Samoans with a disability in Aotearoa New Zealand. Fourteen adult Samoans with a disability (i.e. physical and sensory) and eight of their partners and caregivers were interviewed. Analysis of interview data through Voice-centred Relational Methodology and Bourdieu's theoretical concepts of habitus, capital, field and doxa showed that Samoans with a disability describe and conceptualise quality of life in four interrelated ways. These are (1) independent living, (2) normal life, (3) connectedness to family and culture, and (4) performance of social roles. To enhance and maintain quality of life these participants and their families sought four interventions: cultural, biomedical, social and economic. Selecting one or more was determined by the nature and type of disability whether it was acquired or congenital. To facilitate the desired quality of life, disability funding policy and religious and social capital were identified. Disability funding policy, however, was a barrier for some who did not qualify due to the cause of their impairment. Other barriers to fostering their desired quality of life included personal grief over acquiring disability, mismatch of external caregiver support and Samoan traditional views of disability. This cohort held strong perceptions of the self and their image and identity as Samoans however this was consistently undervalued by other Samoans including extended family who equated their disability with *ma'i* (sick) or *malaia* (curse) and consequently not really a whole person and destined for a life of hardship and unhappiness. Bourdieu's theoretical concepts illuminated the embodiment of their habitus as Samoans and range of capital types accrued over time and space. His concepts made visible the interplay of habitus, capital, field and doxa particularly in accessing the interventions to enhance quality of life. It also made visible the contested spaces and sites of struggle when these participants position themselves in fields or social spaces to secure the desired quality of life. One of the

implications of this study is that Samoans with a disability conceptualise quality of life in a manner that is different to Western society. This has significant bearing in the formulation and implementation of disability policies and services, use of quality of life models and frameworks and level of cultural competency of staff and practitioners. This study contributes new knowledge that can inform policy makers and service providers interested in promoting the quality of life of Samoans with a disability and their families.

## Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Signature:

A handwritten signature in black ink, appearing to read 'Nite Fuamatu', written over a dashed horizontal line.

Print Name: Nite Fuamatu

Date: 31/1/2019

## **Dedications**

This PhD is dedicated to three special people who started this journey with me and were called home.

My father, the late Paepaelei Lameko Fuamatu. He toiled diligently for his family and extended family and served the church and village community well. His hope was that his children would make use of the educational opportunities in Aotearoa and that one of them would get a PhD.

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# **Chapter 1 Background to the study**

## **Introduction**

The notion of quality of life has been promoted in the disability policy context at the New Zealand and international levels (Lang, Kett et al. 2011). Current developments in most Western countries have been centred on policies and programmes aimed at increasing the quality of life for persons experiencing disability. This trend is situated within the global context marked by developed countries ratifying the United Nations Convention on the Rights of Persons with Disabilities and the influence of the disability rights movement (Priestley 2005, Priestley and Lawson 2015). In Aotearoa New Zealand, a former British colony, the inception of state initiatives such as Individualised Funding (IF) and Choice in Community Living (CICL) are designed to encourage people with a disability to exercise more choice and control over the types of supports needed to achieve their goals and to enable better lives (Appleton-Dyer and Field 2014, Evalua Research 2015, Conder and Mirfin-Veitch 2018). This study sought to explore the quality of life of Samoans, a migrant and transnational community, who are living with a disability in Aotearoa New Zealand. In this study, the Voice-centred Relational Methodology was used in order to make visible how Samoans with a disability conceptualise and experience quality of life in the Aotearoa New Zealand context.

The Voice-centred Relational Methodology (VCRM) is a qualitative approach that enables the ‘voice’ of those previously silenced or ignored to be heard in audible ways (Brown and Gilligan 1991, Brown and Gilligan 1993). The ways in which people speak of their experiences is multilayered, contextual and situated within relationships. Although VCRM is explored elsewhere (see Chapter 4), utilising VCRM in my study provided a specific platform of multiple readings and reflexivity to explore Samoan notions of quality of life vis-a-vis disability. Pierre Bourdieu’s theoretical concepts of habitus, capital, field and doxa were drawn on to frame and inform this study (see Chapter 3). His concepts serve to disentangle the

structure-agency continuum of Samoans with a disability searching to enhance their quality of life in the Aotearoa New Zealand context. By using both Bourdieu and VCRM, this study aims to provide a fresh perspective on policy, disability support services and models of practice in working with transnational communities. This begins by presenting key initiatives highlighting quality of life in the disability discourse at the international level to show how this has shaped disability policy and practice frameworks at the local level. Next I explore some initiatives and policies in Aotearoa and lastly, I discuss the significance of this research in relation to the disability policy context.

### **Disability in the international context**

The burgeoning body of disability literature highlights key moments into the nascence of disability on to the world stage. These moments represent a continuum of people with a disability responding to social injustice and maltreatment, and pioneering new perspectives on the conceptions and experiences of disability. This ranges from the emergence and practice of disability activism (Hughes, McKie et al. 2005, Soldatic and Chapman 2010, Pearson and Trevisan 2015, Hande 2018) and disability rights (Kelemen and Vanhala 2010, Meekosha and Soldatic 2011, Rioux 2011, Harpur 2012, Smith 2013, Soldatic 2018) to the advent, progress and criticism of the medical and social models of disability (Smith and Sparkes 2008, Peters, Gabel et al. 2009, Oliver 2013, Rudnick 2017). New perspectives spawned the birth and critique of Disability Studies (Söder 2009, Opini 2016, Vehmas and Watson 2016, Waldschmidt, Berressem et al. 2017), development of disability theories (Gable 2013, Garland-Thomson 2017), utility and critique of the emancipatory research paradigm (Hodge 2007, Sullivan 2009, Petersen 2011, Watson 2012, Genova 2015, Miettinen and Vehmas 2017), and interest in the notions of disableism and disablement (Oliver and Barnes 2012, Thomas 2012, Thomas and Milligan 2018).



Concomitant to these movements is the occurrence of various debates, for example, the centrality of the body in theorising disability (Hughes 2009, Rice, Chandler et al. 2018), situatedness of impairment in disability discourse and theoretical positions (Hughes and Paterson 1997, Goodley and Roets 2008, Hughes 2017), and articulation of disability scholarship using alternative or remodelled theoretical frameworks and critical perspectives (Campbell 2008, Meekosha and Shuttleworth 2009, Goodley, Hughes et al. 2012, Goodley 2013, Grech 2015, Garland-Thomson 2017, Soldatic and Gilroy 2018). Most of this literature has been promulgated by disability activists and academics from around the globe. International bodies and world governments have been influenced by such activists and disability scholars who were involved in propagating the disability movement from the 1960s onwards and inchoation of the discipline Disability Studies in the 1980s (Oliver and Barnes 2010, Watson, Roulstone et al. 2012).

### **Disability and quality of life in the international context**

Current developments in most Western countries have been centred on policies and programmes aimed at increasing the quality of life for persons living with a disability. For instance, in Australia, the promulgation and passing of the National Disability Insurance Scheme (NDIS) legislative policy in 2013 (Wiesel, Whitzman et al. 2017) is an overhaul of disability services designed to enhance the participation, inclusion and well-being of people with permanent and significant disability. International literature indicates similar trends have occurred in the United Kingdom, United States, Canada, Europe and Scandinavia particularly in the arena of funding policy whereby Individualised Funding (IF) (or direct payments, individualised support packages and self-managed care) is available to persons with a disability to assume greater control over their care and selection of support systems (Williams 2007, Chenoweth and Clements 2009, Power 2010, Dickinson 2017). Within this funding policy context both Aotearoa New Zealand and Australia have adopted a ‘social investment’ approach

to welfare whereby interventions (e.g. social insurance schemes) are introduced to reduce future public expenditure while maintaining long-term well-being (Dickinson 2017). Two international organisations, the United Nations and World Health Organization, are significant stakeholders in the arena of disability and quality of life (Lang, Kett et al. 2011). Over time the United Nations (UN) has been involved in spearheading several global initiatives, such as, the International Year of the Disabled Person (1981), UN Decade of Disabled Persons (1983-1992), Decades for Disability in the Asian, Pacific and African regions (1993-onwards), and World Programme of Action (1982). The latter was an attempt to devise a global strategy in the prevention of disabilities, provision of rehabilitation services and equalisation of opportunities (Lang 2009). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted by the General Assembly in 2006 and came into force in 2008 following ratification from several member states. The purpose of this international human rights treaty is "to promote, protect and ensure the full and equal employment of all human rights and fundamental freedoms by all person with disabilities, and to promote respect for their inherent dignity" (UN, 2008, p. 4). It is based on human rights principles, mainly the fundamental right of non-discrimination: people with a disability are not discriminated against because of their impairment and should enjoy the same rights and responsibilities alongside their non-disabled counterparts (Lang et al.,2011). The tenets of the social model of disability undergirds the UNCRPD. This Convention contains eight guiding principles, fifty articles and the Optional Protocol. Article 4 of the Convention describes the obligations of member states ranging from appropriate legislation and policy making to research development of technologies and training of staff and professionals working with people with a disability. Aotearoa New Zealand signed the Convention in March 2007 and later ratified the Convention in September 2008 (Stace 2007).

The World Health Organization is a specialised agency of the United Nations concerned with public health at an international level. The objective of the World Health Organization (WHO) is the attainment of the highest possible levels of health for all peoples (World Health Organization 2014). The WHO released the inaugural *'World Report on Disability'* (World Health Organization and World Bank 2011) and developed an international quality of life assessment tool (World Health Organization Quality of Life Group 1995). They define quality of life as “individuals’ perceptions of their position in life in the context of the culture and values systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL Group 1998). By developing this assessment tool WHO reaffirmed the organisation’s stance of promoting a holistic approach to health and health care, and the use of this tool to assess quality of life across cultures (World Health Organization Quality of Life Group 1995). The *'World Report on Disability'* is a comprehensive stocktake on the status of disability initiatives, policies and programmes across the globe derived from available scientific data and information. It covers topics, such as, health care, education, work and employment, rehabilitation, assistance and support and enabling environments. This report charts the way forward for governments and civil society institutions to consider and act "on measures to improve accessibility and equality of opportunity; promoting participation and inclusion; and increasing respect for the autonomy and dignity of persons with disabilities" (World Health Organization and World Bank 2011). Recommendation 9 is aimed at strengthening and supporting disability research to inform disability policy and programmes, efficiency in resource allocation, and increase public understanding of disability issues (World Health Organization and World Bank 2011). One of the areas identified is research into the quality of life and well-being of people with disabilities. This connotes qualitative research into understanding the lived experiences of people with disabilities focused on indicators of quality

of life and well-being. Aotearoa New Zealand has been a member state of the World Health Organization since December 1946.

## **Disability and quality of life in the Aotearoa New Zealand context**

The context of this research is Aotearoa New Zealand, which is located in the southern region of the Pacific Ocean and home to 4.5 million people of diverse cultures, such as, European, Māori, Pacific, Asian, Middle Eastern and African (Statistics New Zealand 2015). It is a democratic state with three official languages: English, Māori and NZ Sign Language. Wellington is the capital city and hub of the government and Auckland is the largest city. Historically, Aotearoa New Zealand is a British colony, and white settlers established residence and institutions associated with governance and management. Māori or *tangata whenua* (people of the land) are the indigenous people of Aotearoa New Zealand, and the Treaty of Waitangi was signed between Māori and the British Crown in 1840. Aotearoa means 'land of the long white cloud' and is the Māori name for New Zealand (May 2005).

In order to understand the spectrum of disability policy-making and service provision in Aotearoa New Zealand it is important to consider the role of the State. The State is a term used to describe the foundation and apparatus of political governance, and usually describes government institutions within a defined territory called the nation state (Matthewman et al.,2007). The development of the State was predicated on liberalism and state-centred socialism (influenced by British Fabian socialists) in the 19<sup>th</sup> century and this form of socialism supplanted both liberalism and Marxism thus embracing "the state as a means of providing for a more rational, equal and just society" (Belgrave 2012). The 1938 Social Security Act, introduced by the first Labour Government, ushered the modern welfare state into existence and formed the basis for social welfare, social security and social policy (Barnes and Harris 2011). The Aotearoa New Zealand State plays a critical role in the formulation of policies and provision of services for its citizens.

The significance of the State is contiguous with the rise and increasing profile of disability in Aotearoa New Zealand. The concept of need is ideological in the provision of support services for people with a disability (Belgrave 2004). Belgrave identifies the emerging role of social policy as an academic discipline that examines society's attempts to improve the well-being of its citizens on the one hand, and the study of various aspects of state intervention in housing, education, health and income support policies, on the other. Social policy is concerned with the way society meets its communal responsibilities through the enhancement of human development and the advancement of social well-being (Shirley 1994, Duncan 2007). Disability policy per se gradually surfaced through the 1970s and 1980s. Moore and Tennant (1997) observe that disability falls into three broad historical epochs. They classify the colonial period where persons with a disability were perceived to be dependent and in need of income maintenance, followed by the 19<sup>th</sup> century where specific disabilities were targeted for habilitation and rehabilitation, and the late 20<sup>th</sup> century (1970s) where specific disability groups grew in size and purpose and vocalised their needs for increased funding and accountability from the State's public sector. They suggest three existing ideologies during these historical periods: (1) dominance of the medical model of disability, (2) that people with a disability were primarily viewed as charitable cases, and (3) the growing frustration of people with a disability over the role of the State. Tennant (1996) identifies two key developments from the 1980s onwards which are relevant here: consumer voice and community care. The International Year of Disabled Persons in 1981 and a Telethon held that same year, raised the profile of people with a disability (Vickery 2003). The funds raised established the Disabled Persons Assembly (DPA) in 1983. The DPA, consisting of persons with a disability, became an important advocacy and support group by uniting different disability groups to fight for, and promote disability issues (Vickery 2003). Some policies such as 'normalisation' and integration into society were introduced where people who had been residing in institutions could now live in

the community. The 1992 government policy document *Support for Independence for People with Disabilities – A New Deal* (Shipley and Upton 1992) set out new goals for disability support services and the health sector took a lead role (Tennant 1996) in its implementation.

Traditionally, the State funded the health sector to provide hospital services for people with a disability and the social services sector (or welfare) to provide community care (Carter 1994). A review of funding policy and sector responsibilities led to the recommendation that the disability support system ought to respond to the individual's health, social and economic needs through a seamless provision of services (Carter 1994). Sullivan and Munford (1998) suggest that the State had raised ideas of 'consumer', 'choice' and 'flexibility' to give the impression that persons with a disability had access to a range of services which was not the actual case. The market environment, neo-liberal ideology and citizen participation permeated State policies (Sullivan and Munford 1998, Moriarity and Dew 2011, Dargan 2016) which meant the State sought to devolve its functions to charitable and community-based providers and contain financial expenditure. The health/welfare interface was heavily debated during consultations on the Health and Disability Services Bill (passed in 1993 and amended in 2001). Sullivan & Munford (1998) recount an experience of this consultation as to whether disability support services should go to health or welfare. Many disabled people [sic] rejected both sectors arguing that "one would medicalise them and the other would reduce them to objects of charity" (p. 185). They proposed disability support services as standalone "under the control of disabled people who would define, implement and monitor service delivery in partnership with nondisabled professionals and service workers" (p. 185). The portfolio of purchasing both health and disability support services was assigned to the health sector (Watson 1994, Sullivan and Munford 1998). The role of the State in formulating policies and provisions for its citizens with a disability has evolved and this can be attributed to the confluence of disability initiatives occurring across the world and rise in disability activism at the local level.

The social model of disability hails from the UK and has been adopted by many nations of the Commonwealth. Aotearoa New Zealand is one such nation that has embraced the social model of disability as a basis for key documents and which underpins the New Zealand Disability Strategy 2001 (Stace 2007). Other traces of the nation's focus on disability issues and rights is evident in the creation of the Minister for Disability Issues portfolio, establishing the Office for Disability Issues, and inclusion of disability in the Human Rights Act 1993 (Stace 2010). Many New Zealanders, persons with a disability and government officials, were involved in drafting the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Stace 2007, Moriarity and Dew 2011). Under the Convention's article 33, the New Zealand framework was established to promote, protect and monitor the implementation of the UNCRPD. Groups involved in the development of this framework were: the Ministerial Committee on Disability Issues, the Office for Disability Issues, Human Rights Commission, Office of the Ombudsman and Convention Coalition (coalition of eight Disabled People's Organisations). The latter three function as independent monitoring mechanisms and jointly publish biennial reports. Their latest *'Making Disability Rights Real'* report highlights five broad areas that require more attention to realise the rights in the UNCRPD (Human Rights Commission, Ombudsman et al. 2014, Barnett 2015). These five areas are - data, accessibility, building a people driven system, violence and abuse, and education. In addition, this report identified civic engagement of people with a disability vis-a-vis the policy-making apparatus, and the experiences of Māori and Pacific with a disability, as key monitoring priorities for the next report. Some Aotearoa New Zealand studies reiterate the significance of developing and sustaining an approach to disability policies and services that is culturally responsive and effective to the indigenous people (Bevan-Brown 2006, Harwood 2010, Bevan-Brown 2013, Higgins, Phillips et al. 2013, Wiley 2015, Hale, Bryant et al. 2018).

The quality of life in Aotearoa New Zealand is highly favourable. According to the OECD Better Life Index, which has been measuring well-being globally since 2011, New Zealand is ranked well across the 11 dimensions, such as, housing, civic engagement, subjective well-being and environmental quality and particularly high in health status and social connections (OECD 2014). The monitoring and reporting on the quality of life of New Zealanders is collected through the New Zealand General Social Survey, Social Report, and Quality of Life Project. The latter is a collaboration of territorial authorities representing six main urban areas (Auckland, Wellington, Porirua, Hutt, Christchurch and Dunedin). The Quality of Life survey is administered every two years, and the latest report shows 84% rated their overall quality of life positively and 30% noted an increased quality of life compared to 12 months earlier (Nielsen 2018). The survey data informs local government policy. The New Zealand General Social Survey (NZGSS) is the country's official survey of well-being, measuring individuals' perceptions of their life covering a range of social and economic outcomes, and administered every two years. The recent survey shows that the majority of New Zealanders rated their overall life satisfaction highly (Statistics New Zealand 2017). The Social Report provides a snapshot of the progress of social outcomes for New Zealanders and uses statistical and social well-being indicators in 10 domains, such as, health, education, social connectedness and economic standard of living, to monitor trends across key dimensions of people's lives at the micro and macro levels (Ministry of Social Development 2016). This report complements other government reporting mechanisms on economic development, indicators of family wellbeing, environmental health and sustainable development, and shows that the social well-being of New Zealanders has steadily improved over time. These documents, and the role of the New Zealand World Health Organization Quality of Life Group (NZ WHOQOL), dovetails into the global reporting and surveillance of the quality of life in Aotearoa New Zealand.



The NZ WHOQOL Group was formalised in 2009 and mandated to develop and promote the use of WHOQOL instruments in Aotearoa New Zealand studies (Billington, Landon et al. 2010). This group developed and validated the Aotearoa New Zealand version of the WHOQOL-BREF instrument (Krageloh, Billington et al. 2015) and set out to collect data on participants' ratings of the perceived importance of the facets contained in the WHOQOL-BREF in relation to the quality of life of New Zealanders and compared this with WHOQOL datasets from 14 countries (Krageloh, Billington et al. 2015). They concluded that the similarities of importance rankings with these datasets suggest the cross-cultural validity of the instrument is still current. One of the group's tasks is to develop ethnic and cultural specific modules and items, as appropriate and if needed, for Maori and Pacific peoples (Billington, Landon et al. 2010). Mason Durie and colleagues identify generic indicators of Māori quality of life, such as, Maori well-being, *whanau* well-being, culture and cultural identity, *te reo Māori*, the Māori asset base, *tino rangatiratanga*, *kotahitanga* and Treaty settlements (Te Puni Kokiri 2007). Several Aotearoa New Zealand studies on quality of life centred on disease, health conditions, and health related concerns. Studies were undertaken with people living with HIV (Grierson, Pitts et al. 2004), patients with axial spondyloarthritis (Jenks, Treharne et al. 2010), prostate cancer survivors on androgen-deprivation therapy (Keogh, Shepherd et al. 2010), and people with type two diabetes (Paddison, Alpass et al. 2008, Paddison 2010). Health related conditions included the oral health of children, teenagers and adults (Chen and Hunter 1998, Ukra, Foster Page et al. 2013), adults with narcolepsy (Campbell, Signal et al. 2011), adults with knee osteoarthritis (Abbott, Usiskin et al. 2017) and clients with panic disorder (Hamer, McCallin et al. 2009). Studies relating to health concerns focused on peoples' perceptions of the neighbourhood environment and well-being (Hill, Shepherd et al. 2012), medical students and doctors experiencing stress and burnout (Henning, Hawken et al. 2009), social supports as a protective factor for single mothers (Walker and Krägeloh 2016) and impact

of problem gambling (Rawat, Browne et al. 2018). Other studies examined the relationship between religious affiliation, academic performance of domestic and international university students and quality of life (Hsu, Krägeloh et al. 2009, Gardner, Krägeloh et al. 2013, Henning, Krägeloh et al. 2015) and the profile of quality of life for older Māori (Dyall, Kepa et al. 2014). Most of these studies utilised a survey research design in their methodology and administered either discipline-related national questionnaires or the WHO quality of life questionnaires (i.e. WHOQOL-BREF), or a combination of both. It is important to note that most of these studies reported low response rate of Māori and Pacific peoples. Anecdotal evidence suggests that postal questionnaires to Māori and Pacific households in Aotearoa New Zealand is an ineffective method of collecting data from these groups and that a combination of personal interviews and questionnaires is more appropriate (Dyall, Kepa et al. 2014).

Currently, there is an overall scarcity of research on the quality of life of people with a disability in Aotearoa New Zealand and more specifically of Maori and Pacific people. However, there are some studies that focus on older persons with a hearing or vision impairment (Good 2008, La Grow, Alpass et al. 2011, Zhang, Moyes et al. 2016). Other studies focus specifically on persons with a hearing impairment (Henning, Krägeloh et al. 2011, Looi, Mackenzie et al. 2011) or intellectual disability (Conder, Milner et al. 2011). Similar to the quality of life studies mentioned above, these studies also used survey research design and administered discipline-related questionnaires and the WHOQOL-BREF questionnaire. Zhang et al. (2016) found that hearing and vision impairment are both independently associated with lower quality of life. Family and friends emerged as the most important contributor to quality of life for persons with a vision impairment (Good 2008). La Grow et al. (2011) conclude that three variables are predictors of improved quality of life in their study on persons with vision impairment. These variables are satisfaction with life, ability to get around and number of diagnosed health conditions. In terms of studies specific to people living with a pre-existing

disability, Looi et al. (2011) establish, as part of the Southern Cochlear Implant Programme, that adults using cochlear implants rate their quality of life higher compared to those waiting to have cochlear implantation surgery. The former identified increased satisfaction with their independence, confidence and self-esteem. Henning et al. (2011) assessed the impact of accessing and using sign language interpreters on the quality of life of a cohort from Deaf Aotearoa. They were alarmed that 39% were unable to adequately access interpreting services. This discovery correlates to their other findings that access to good quality interpreters is associated with enhancing quality of life. Examples of quality of life is manifest in this cohorts' engagement of leisure activities, dealing with transport issues, access to health services and public information, and living in a health environment. Henning et al. conclude that their study has implications for policymakers and agencies particularly to ensure equitable distribution of essential services for all groups in Aotearoa New Zealand. Conder et al. (2011) report on the inclusion of persons with an intellectual disability as co-researchers in developing a quality of life tool. Although their paper does not report the findings, it provides key learnings on maximising participation of persons with an intellectual disability in disability research. It is important to highlight that most of these quality of life studies either did not report on Pacific ethnicity data or had low participation from Pacific participants. One of the studies (Henning, Krägeloh et al. 2011) acknowledges the over-representation of Pakeha (European) and suggests further investigations into quality of life issues with marginalised groups. Hence, there is a need for more studies into the quality of life of people with a disability especially migrant and Pacific ethnic groups in Aotearoa New Zealand.

### **Personal motivation for the study**

I am a Samoan woman born and raised in Aotearoa New Zealand. As a child of migrant parents, this country was considered 'the land of milk and honey' where education and employment opportunities were afforded to all. Most of my family and extended family worked on the

factory floor in the hope that the next generation would pursue tertiary education and secure better jobs. I am the first of this generation to pursue postgraduate studies. The topic of disability is an interesting one. In the Aotearoa New Zealand mainstream context, disability is spearheaded by a rights-based movement to facilitate the participation and inclusion of people with a disability into all facets of society and community life. In the Samoan cultural context, disability is something that you get as a result of sin and wrongdoing, and the punishment or curse is laid bare for everyone to see - and be reminded to live in an upright manner before God. A less prevalent co-existing view is that God has blessed the family with someone who has a disability or impairment so that the goodness of God may be demonstrated – such as patience, compassion and joy. My brother's children born with profound deafness, a symptom of Waardenburg Syndrome, brings to the fore familial concerns over the quality of life they will have in 'the land of milk and honey. ' I worked in several roles in the disability sector ranging from community support in residential services and brokerage of individual outcomes to research into autism and management of pan-Pacific and Samoan-specific disability initiatives. The dominance of Wolfenberger's social role valorisation theory and social model of disability underpinned the vision and operations of service planning, funding and delivery. The role of culture was deemed important in affirming the individual's ethnic identity and recognising that Samoan and Pacific people have their own worldview of doing and being in the world predicated on a belief and value system different to Aotearoa New Zealand Europeans. The clash of cultural values was often observed and spoken about and this took various forms. For instance, support staff were expected to encourage and foster the independent life skills of each person with a disability in the home and Samoan and Pacific staff found this incredibly difficult because their perception was that the person cannot do anything for themselves or for anyone else and that they ought to be cared for and looked after. For many, the culture of care was

primarily based on cultural values as an approach and model that undergirds a quality of life for this person.

My motivation to undertake this study was inspired by both personal and professional experiences. I am in a position to enter the research space to explore and delve into the quality of life of Samoans with a disability in Aotearoa New Zealand. This is a position of privilege: I am a Samoan non-disabled woman born and raised in a developed country, attained university qualifications and performed roles in both the public and private sectors. I am acutely aware of the opportunity to *tautua* (serve) my community by embarking on this research journey and contributing new knowledge about this sector of our community who are often overlooked and misunderstood. One poignant experience involved facilitating a *fono* (meeting) with Samoans with a disability and was immediately struck by the comment "having a disability makes being Samoan harder." This evoked emotional pain which stayed with me for hours. I undertake this study in order to make a positive contribution for Samoans with a disability living in the 'land of milk and honey.'

Research is not value-free. I come to the research terrain with my own set of ideas and assumptions on how it should be done, and much of this has been influenced by Pacific scholars, academics and researchers who share a common goal of engaging in transformative research. This study has the potential to actualise transformation. First, it is focused on a segment of the Samoan community who are 'invisible' and frequently excluded from participating in social and cultural affairs of the community. Second, it attempts to uncover the notion of quality of life and the relationship between ethnicity and disability from a cultural standpoint. Last, it examines how definitions of quality of life vis-à-vis the disability policy-making context impacts on this migrant, diasporic and transnational community in Aotearoa New Zealand. Research is also a catalyst for transformative change in the researcher. I anticipate my notions

of doing research and working with my community will effect profound changes in my thinking, skill development and outlook.

## **Statement of the research problem**

The research problem addressed in this thesis is the need to generate new knowledge on culturally-specific conceptions of quality of life from the perspective of Samoans with a disability, with a view to informing and shaping effective disability policies and service delivery.

Ideally, the policy and service delivery mechanisms reflect key drivers that enhance and maintain the quality of life for every person with a disability across the globe. Under the auspices of the rights-based approach to disability this is a highly desirable outcome for Māori, Samoans and the wider Pacific population in Aotearoa New Zealand. Research demonstrates the disparities between Maori and non-Māori in health, justice, housing, paid work, education and economic standards of living (Anderson, Crengle et al. 2006, Bishop, Berryman et al. 2009, United Nations Department of Economic and Social Affairs 2010). Māori are the indigenous people, *tangata whenua*, of Aotearoa New Zealand and the signing of the Treaty of Waitangi, *Tiriti o Waitangi*, between Māori and the British Crown in 1840 forged a relationship which was not without contention and debate as Aotearoa New Zealand developed into an independent nation state and free market player on the global economic stage (Mutu 2009, McCormack 2012, Belgrave 2014). Despite this Māori and non-Māori alike have sought to improve social, economic and health outcomes by articulating and promoting the incorporation of Māori worldview, perspectives and realities, frameworks and cultural values into mainstream policy and service delivery (Ellison-Loschmann and Pearce 2006, Kingi 2007, Ratima, Brown et al. 2007, Harwood 2010, Mark and Lyons 2010, Durie 2011). The implementation of Objective 11 in the New Zealand Disability Strategy specific to promoting the participation of disabled Māori [sic] was evaluated with Māori individuals with a disability, caregivers, service providers

and government officials. Wiley (2015) concluded that the evaluation, which included recommendations for more intersectoral collaboration and cooperation, more workforce development and increased community engagement, offers valuable lessons for indigenous peoples and governments in other countries when developing culturally comprehensive disability policy. Moreover, there is an increasing body of literature on Māori conceptions of health and well-being and quality of life (Panelli and Tipa 2007, Mark and Lyons 2010).

Many Pacific island nation states in the South Pacific have a historical relationship with Aotearoa New Zealand. The Pacific population resident in Aotearoa New Zealand have gradually acquired forms of social and political status not evident in other Western countries. For instance, the Ministry for Pacific Peoples (formerly Ministry of Pacific Island Affairs), with its own government minister, was established in 1990 and advises the public sector on policies and issues related to Pasifika communities. In 1975, the community set up the Pacific Island Advisory Council to address socio-economic needs and this led to the inception of education resource and multicultural centres. The community lobbied for its own stand-alone ministry (Whimp 2012). One of the major areas of concern has been the poor health of Pacific peoples. The significance of Bathgate et al.'s (1994) *'The Health of Pacific Islands People in New Zealand'* promoted an acute awareness of the negative health profile of Pacific peoples. This publication was the first of its kind to compile and document their health status, discuss the context of their health profile in Aotearoa, and explore the impact of socioeconomic factors, diet, lifestyle and nutrition on their health in Aotearoa. Poor health statistics indicated a need to address the burden of health on the State and Pacific communities. The 1993 health reforms, which created the purchaser/provider split, served as an impetus for Pacific health and medical professionals to establish services customised for the Pacific population. The concept of 'by Pacific for Pacific' was initiated and incorporated into the ethos, philosophy and practice of promoting and delivering accessible and culturally appropriate services to Pacific (Ministry of

Health and Ministry of Pacific Island Affairs 2004). A number of ‘by Pacific for Pacific’ clinics, health services and programmes working in parallel with mainstream equivalents, came into existence.

The recognition and inclusion of Pacific disabilities into the health portfolio emerged in the late 1990s. Even though Bathgate et al.’s 1994 publication provided important population-based information, very little was reported on the incidence and prevalence of disabilities. They do acknowledge the presence of disabilities such as physical, sensory, generic and acquired amongst the Pacific population and cite the limited availability of disability data about this population. First, the official reporting mechanisms (i.e. the Social Indicators Survey in 1980-1981 and the Household Health Survey in 1992-1993) did not extend to reporting Pacific-specific responses. Second, cultural reasons and they refer to a sense of shame and guilt Pacific parents have when they bear a child with a disability or impairment. Bathgate et al. (1994) surmise that this, as well as organisational and language barriers, can influence a behavioural pattern of Pacific non-use or low use of disability services. The *‘Tupu Ola Moui’* publication (Ministry of Health and Ministry of Pacific Island Affairs 2004) builds on Bathgate et al. (1994). It is a comprehensive review of Pacific health and reports on the incidence and prevalence of Pacific disabilities (using data from the 2001 New Zealand Disability Survey). They measure disability from a population health perspective and define disability in terms of functional and/or role limitation “requiring the assistance of another person or a complex assistive device to carry out everyday routines” (Ministry of Health and Ministry of Pacific Island Affairs 2004). Physical disabilities (mobility and agility) was identified as the most common type of disability followed by sensory (hearing and vision) disabilities, and that disease or illness is the most common cause of disability. The *‘Pacific Health and Disability Action Plan’* released prior in 2002 outlined strategic directions and was explicit in setting priorities in health and disability. Out of six priorities two were focused on disability: (5) to promote the



participation of disabled Pacific peoples [sic], and (6) to generate accurate and useful Pacific health and disability information and research (Ministry of Health 2002). The main goals of priority (5) is “to deliver disability support and health services that will enable disabled Pacific peoples to participate more fully in their communities” and priority (6) is “to develop Pacific research capacity that will inform policy, planning and service development” (Ministry of Health 2002). The *‘Pacific Peoples’ Experience of Disability*’ document was produced six years later, as part of reviewing the Action Plan, and incorporated data sets including actual experiences of persons with a disability. This document makes two notable points: (1) the difficulties Pacific peoples have in accessing and negotiating the complexities of disability support services, and (2) the absence of independent research into Pacific peoples’ experiences of disability despite evidence that 11% of Pacific peoples have a disability (Ministry of Health 2008).

In recent years there is an increase of the Samoan ethnic group in Aotearoa New Zealand. The Samoan ethnic group make up almost 50% of the Pacific population and the Samoan language is the third most common language spoken on a daily basis (Statistics New Zealand 2014). Pacific peoples in Aotearoa New Zealand are a heterogeneous and diverse population originating from Pacific Island nation states (e.g. Samoa, Tonga, Cook Islands, Niue, Tokelau, Tuvalu, Fiji, Vanuatu and Solomon Islands). The Pacific population compose 7.4% of the total Aotearoa New Zealand population and most live in Auckland and Wellington (Statistics New Zealand 2014). This population is projected to grow at a faster rate than the total Aotearoa New Zealand population (i.e. increase from 6.7% of the total population to 9.1% of the total population) in 2021 (Statistics New Zealand 2005). One of the problems faced by Samoans with a disability is the access to health care and disability support services (Huakau and Bray 2000, Neemia 2003, PIASS 2005, University of Auckland 2015). The findings of these studies converge on the issue of customising service delivery models to improve and

foster the relationship between the service provider and the Samoan with a disability and their family. However to iterate that these studies took a pan-Pacific focus and even though the sample size was proportionately representative of the main Pacific ethnic groups, it is not uncommon to undertake pan-Pacific research that incorporates some or all of these ethnic groups in Aotearoa New Zealand. Although interest in Pacific disability research has increased in recent years, the findings from these innovative studies act as a precursor to this study on the quality of life of Samoans with a disability. Very little is known about how Samoans with a disability conceptualise and experience quality of life in Aotearoa New Zealand. Akin to this is the formation, experience and perceptions of Samoan ethnic identity in Aotearoa New Zealand.

Many authors and scholars have written about Samoan and Pacific ethnic identities in the Aotearoa New Zealand landscape (Anae, 2010; Manuela & Sibley, 2015; Tamasese et al. 2005). Pitt and Macpherson (1974) document in their seminal text the emerging pluralism in the Samoan migrant community. They identify Samoan core institutions that shape, maintain and reinforce the cultural identity of Samoans in Aotearoa New Zealand. A new generation of Samoan scholars have expanded this literature. For instance, Anae (1998a) writes about the differences between Aotearoa New Zealand-born Samoans and their Samoa-born parents. She articulates these differences in terms of worldviews, lifestyles, identity pathways and that these reflect, in varying degrees, the exposure to urban, capitalist, humanist, individual, educational and consumer environments. It has been argued that a new and distinctive Samoan identity is evolving in Aotearoa New Zealand (Macpherson, 2004). The ramification of this claim is the existence of intra-group variations and perceptions of what constitutes ethnic and cultural identity. This ushers into the public domain a challenge to assumptions that the Samoan identity is static and fixed. For the cohort of Samoans with a disability in Aotearoa New Zealand, the literature on their experience and perceptions of ethnic identity is non-existent. To date, no studies have been undertaken that explore from their perspective how they perceive their ethnic

identity in conjunction with their disability. Inclusion of this perspective in this study can potentially bring into sharper focus how they conceptualise and experience of quality of life in Aotearoa New Zealand.

## **Purpose of the study**

The purpose of this phenomenological qualitative study is to investigate the quality of life experiences of Auckland-based Samoans living with a disability. The findings will inform policy and service delivery to meet the cultural and disability needs of Samoan and Pacific ethnic groups in Aotearoa New Zealand. Several studies on quality of life indicate conceptual variances in the definition of quality of life (Moons, Budts et al. 2006, Costanza, Fisher et al. 2007), the range of measurements and indicators used to assess quality of life (Saxena, Carlson et al. 2001, Skevington 2002, Sirgy 2010), and the conceptual construction of quality of life and life satisfaction in the policymaking context (Galloway 2007, Diener, Inglehart et al. 2012). Some of the work undertaken by the World Health Organization (WHO) includes the development of Quality of Life indicators. Most studies utilise assessment tools to measure quality of life, such as the WHO-BREF instrument. This is a short version, convenient for large research studies and clinical trials, and comprises 26 items measuring physical health, psychological health, social relationships and the environment (Skevington, Lotfy et al. 2004, Llewellyn and Skevington 2016, Suárez, Tay et al. 2018). Some local studies have used the WHO-BREF or survey instruments or both in their quantitative studies (Good 2008, Henning, Hawken et al. 2009, Hsu, Krägeloh et al. 2009, Henning, Krägeloh et al. 2011, Krageloh, Henning et al. 2011, Looi, Mackenzie et al. 2011, Zhang, Moyes et al. 2016). Although these types of studies provide useful data, very few qualitative studies have been undertaken with people with a disability in relation to their lived experiences of quality of life (Ahlstrom and Karlsson 2000, Shikako-Thomas, Lach et al. 2009, McDougall, Baldwin et al. 2016). Even

though one seminal study uncovered the paradoxical reality that people with a disability do have a good or excellent quality of life despite widely held perceptions that it is not possible (Albrecht and Devlieger 1999), there is a dearth of research on cultural perspectives of quality of life and subsequent transmission into the policy and service delivery contexts. In economic terms, the biggest areas of government expenditure in Aotearoa New Zealand is social security and welfare, health and education (New Zealand Treasury 2015) which suggests in broad terms that innovative approaches in policy and service delivery to curb this is warranted.

## **Research questions**

The aim is to explore the quality of life of Samoans with a disability in Aotearoa New Zealand through an examination of their lived experiences in Auckland. This research seeks to answer the following questions:

1. How do adult Samoans with various disabilities conceptualise and describe quality of life?
2. What factors are reported by Samoans with disabilities that facilitate or inhibit their quality of life experiences?
3. How do Samoans with disabilities perceive their ethnic identity in Auckland?

## **Significance of the study**

This study is significant in three ways. First, it generates a new body of cultural knowledge that can be used to provide professional development for practitioners in the health, disability and social service sectors working to improve the quality of life for this group. It is argued that a more informed approach based on research findings is more likely to yield meaningful outcomes for all parties concerned (Wiley 2015). Second, it revitalises the discourse on quality of life and disability in the policy-making context. Policy analysts and researchers can make inappropriate assumptions and arrive at flawed conclusions if they are insensitive to the diversity of people with a disability (Devlieger and Albrecht 2000, Albrecht, Devlieger et al.

2008). Third, it extends theoretical insights into the quality of life experiences of Samoans with a disability by rethinking this through Pierre Bourdieu's theoretical tools of habitus, capital, field and doxa. The application of Bourdieu's theoretical tools serves to examine, analyse, unpack and make visible alternative forms of re/framing and re-imagining empirical studies and new solutions (McKeever and Miller 2004, Agbenyega and Klibthong 2015). This study has the potential to make a practical contribution, impact on policy-making and add value to the scholarship of Bourdieu's theoretical concepts.

### **Scope of the research**

This study investigated the quality of life experiences of Samoans living with a disability in the Auckland region of Aotearoa New Zealand. The sample consists only of adult Samoans aged 18 years+ who have identified and live with a permanent disability in Auckland. To capture the range of quality of life experiences, the sample covers the following variables: place of birth (Samoa-born or Aotearoa New Zealand-born), marital status, gender, parenthood, and type of disability. This qualitative case study was conducted over a three- year period using face-to-face interviews in Auckland.

### **Structure of the thesis**

This thesis consists of eight chapters. Chapter One introduces the thesis topic and situates the study of quality of life of Samoans with a disability in the global and local discourse and literature. It provides the problem statement, rationale, purpose and potential significance of undertaking the study in the Aotearoa New Zealand context. The research questions driving the focus of this study are contained in this chapter.

Chapter Two is a review of the literature on current conceptions of both quality of life and disability. It provides a snapshot of empirical studies that have focused on improving the quality of life for persons with a disability, the facilitators and inhibitors to experiencing quality

of life in the disability policy context and the intersectionality of disability and ethnic identity in framing quality of life.

Chapter Three introduces the theoretical framework. It focuses on Pierre Bourdieu's relational thinking tools of habitus, capital, field and doxa utilised to investigate the quality of life experiences of Auckland-based Samoans living with a disability. It includes Bourdieu's intellectual enterprise of circumventing the agency-structure dichotomy in social sciences and the efficacy of his concepts to uncover and analyse social practices.

Chapter Four explores theoretical perspectives that undergird and influence the landscape of the research inquiry. It outlines the differences between quantitative and qualitative research, the nature and intent of selecting qualitative research and utilising interpretivism in my study. An overview of disability and Pacific research paradigms is also provided in this chapter.

Chapter Five outlines the methodology and methods of my study. It serves the following five purposes: (1) explain the theoretical orientation informing the methodology, (2) describes the methods and research design, (3) outlines the sample selection and data collection procedure, (4) describes the process of data analysis, and (5) identifies methodological issues and limitations of the study.

Chapter Six presents the findings from the interview data. The findings generated three interconnected themes and sub-themes which illuminate participants' lived experiences of living with a disability and the challenges in their quest to search for a meaningful quality of life. Bourdieu's relational concepts of habitus, capital, field and doxa uncover participants' types of capital and its deployment in specific arenas in order to optimise quality of life outcomes.

Chapter Seven is a discussion of the key findings in relation to literature and theory. It focuses on answering the research questions and highlights unique conceptualisations of quality

of life. The factors that facilitate or inhibit these participants' quality of life are identified as well as the intersectionality of disability and ethnic identity. Bourdieu's relational tools are brought to bear on the key findings. To ensure my study's trustworthiness three forms of reflexivity were used.

Chapter Eight is the final chapter. The implications and contributions of this study in policy, practice and theory are provided. Suggested recommendations for future directions in enhancing quality of life of Samoans with a disability are also provided.

## **Definition of terms**

**Agency:** the capacity of individuals to act independently and to make their own free choices.

**Agent:** Bourdieu uses this term to denote the individual person

**Aotearoa:** Aotearoa which means 'land of the long white cloud' is the Māori indigenous name for New Zealand. **Aotearoa New Zealand** is predominantly used to refer to country, **New Zealand** in relation to documents, organisations and groups proper, and **NZ** as abbreviated form of New Zealand.

**Capital:** "Accumulated labor in its objectified or embodied forms" (Bourdieu, 1986, p. 46) is acquired over time and appropriated by agents or groups of agents in social spaces.

**Disability:** A highly contested term which is dependent on the school of thought or model of disability that one subscribes to (Gronvik 2007). For instance, the medical model and social model have different definitions of 'disability.' The former defines disability as an individual pathology whereas the latter defines disability as the result of social structures that oppress persons with a disability.

**Doxa:** Taken for granted assumptions entrenched within social practices (Wacquant, 2006).

**Field:** Social spaces or arena of struggle between agents and institutions (Wacquant, 2006).

**Habitus:** A set of dispositions, norms, values and beliefs that is durable, transposable and designates a way of being (Bourdieu, 1977).

**Impairment:** A functional limitation of the body or some part of the body.

**Pacific or Pasifika people/s:** This is an umbrella term connoting people from Pacific Island nations residing in Aotearoa. These terms are used interchangeably. Pasefika is the Samoan word for Pacific.

**Quality of life:** A social construct and concept that defines the well-being and components of a person's well-being.

**Samoa terms and phrases:** These terms and phrases (e.g. fofo, ma'i, malaia, kagaka mama'i) appear in the latter chapters and are defined in the text.

**Samoa-born, Aotearoa New Zealand-born or NZ-born:** These highlight the birthplace of participants and growing up there during their formative years. This can influence habitus and accumulation of capital.

**Social structure:** An organised set of social institutions and patterns of institutionalised relationships that together make up society. It consists of multiple factors that determine or limit a person's agency and their decisions.

**Use of 'people first' terminology:** The thesis uses the 'people first' terminology (e.g. person with a physical disability, person with vision impairment) in recognition that they are primarily a person before any label is assigned to them. This contrasts with the UK terminology of 'disabled person' or 'disabled people.' The latter terms have been retained in the context of NZ and UK literature.



## **Chapter 2 Literature Review**

### **Introduction**

This chapter reviews the burgeoning literature on quality of life to inform and situate this study on the quality of life of Samoans with a disability. By looking at the conceptual and policy shifts concerning quality of life, the experience of living a happy and satisfying life is either facilitated or inhibited. These shifts help to define and contextualise quality of life experiences and emergent issues that impact on persons with a disability. A review of the models of disability is undertaken in order to juxtapose and further contextualise quality of life experiences. This study seeks to understand how Samoans with a disability experience quality of life. This chapter provides a historical overview of quality of life and looks at the facilitators and barriers to quality of life for persons with a disability. In this chapter, I also discuss the place of quality of life in disability policies particularly from the United Kingdom, United States and Australia to compare and contrast with the Aotearoa New Zealand approach.

### **A historical overview of the concept of Quality of Life**

Quality of life is an ambiguous term and its meaning can vary widely from person to person across a multiplicity of contexts (Warren & Manderson, 2013). For instance, it can be influenced by perceptions of health status, presence or absence of intimate and personal relationships, feelings of happiness, access to material wealth, and country of residence. Conversely, quality of life is often used interchangeably with well-being. Preference of one term over another is often based on the traditions of a discipline and the conceptual evolution of ideas, theories and models (Cummins, 2015; Dodge et al., 2012). However, in the interest of clarity, well-being is used at the individual level and refers to actual experience whereas quality of life is used at the community and societal level and refers to context and environments (Gasper, 2010). Gasper (2010) adds that well-being reflects the discipline of psychology, whereas quality of life is from sociology and social policy. Formal interest in studying quality

of life gathered momentum in sociology, psychology, political science, economics, medicine, nursing, philosophy, geography, management and health in the past six decades (Land, Michalos & Sirgy, 2012; Milton, 2013). According to Brown and Brown (2003) it is important to understand how quality of life has been approached and described. They identify three commonly used ways of approaching and describing quality of life, which are: “(1) quality of life of large populations, (2) health-related quality of life, and (3) quality of life in improving individuals’ whole lives” (p. 21) or individual quality of life. Brown and Brown (2003) define the quality of life of large populations as the attributes deemed to be important to almost every person and to society as a whole, usually referred to as social indicators (e.g. level of education, unemployment rate, access to health care, satisfaction with life). They assert the usefulness of social indicators when comparing multiple populations on aspects of life considered to be of value to most people across different geographical regions, and conducting a comparative analysis of urban or rural population over time. Conversely, they caution the limitations of social indicators and cite the challenges of using such data to compare countries, cultural and lifestyle differences between countries, and the reality that some indicators are not necessarily meaningful to all individuals in the population group.

Land et al., (2012) trace the development and evolution of social indicators in quality of life studies. They identify social indicators or systems of social indicators such as statistics, statistical time series and other types of evidence that can detect social change and evaluate the impact of programs over time. In other words, social indicators is a systematic approach to providing and monitoring data on social trends and emergent issues for academic, political and public consumption. The theoretical appeal of the quality of life concept emerged as part of the Social Indicators Movement in the late 1960s-early 1970s when social scientists in Western countries raised concerns over the predominance of economic growth as the goal of society at the expense of social costs and questioned whether “more” is equated with “better” (Land et

al., 2012). Glatzer (2015) reiterates this concern that historically social scientists focused on identifying and eliminating the negative features of society such as poverty, disease and oppression. Land et al., (2012) add that these social scientists incorporated the concept of quality of life into political and social policy forums as an alternative multidimensional goal that embraces many of life's domains. Social indicators serve the functions of (a) enlightening organisations, politicians, academics and the general public to describe trends; (b) policy analysis in guiding the formation and evaluation of public policies; (c) assessing the utility and development of medical interventions within a wider context of health and wellbeing; and (d) managerial interests in staff retention and service provision (Land et al, 2012; Land & Ferriss, 2006). The New Zealand General Social Survey, Social Report, OECD Better Life Index and Australian Unity Wellbeing Index are concrete examples of the use of social indicators in quality of life studies.

Health-related quality of life considers the importance of an individual's quality of life in medical and health treatments and shifts the focus from curing disease to include the individual's perspective on the impact of treatment, lifestyle and wants, their environment and pain management (Brown and Brown, 2003). Land et al., (2012) argue that the World Health Organization's (WHO) definition of health as a state of "physical, mental, and social well-being and not merely the absence of disease and infirmity" is a quality of life definition of health (p. 2). That is, it recognises other aspects of well-being and invokes a more holistic approach to the individual. Some of my indigenous peers have lamented the omission of culture and spiritual well-being from this WHO definition. However, it is conceivable that this has been incorporated into the World Health Organization Quality of Life (WHOQOL) project. For example, in their seminal paper, quality of life is defined as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" and six quality of life domains were drafted: physical

domain, psychological domain, level of independence, social relationships, environment, and spirituality/religion/personal beliefs (WHO, 1995, p.1405). At a global level the World Health Organization Quality of Life (WHOQOL) project was initiated as an international tool to measure quality of life and it was designed to be used across a multitude of settings (WHO, 1995). This brings to the fore the notion of subjective and objective dimensions and indicators of quality of life and well-being. Subjective well-being is a measurement which focuses on self-reported levels of fulfillment, pleasure and happiness (Costanza, Fisher et al. 2007). It describes a person's level of well-being based on their evaluation of their life and this can be both positive and negative such as reactions to a life event, and satisfaction with health, work and relationships (Diener and Ryan 2009).

In recent times, the concept of Quality of life (QoL) has expanded to incorporate other significant factors towards achieving quality of life and these are Health Related Quality of Life (HRQoL) and Family Quality of Life (FQoL) particularly in the area of intellectual and developmental disabilities (Cummins, 2010; Cummins et al, 2004; Hsieh, 2007; Kyrkou, 2014; Samuel et al, 2012). At a global level, the World Health Organization Quality of Life (WHOQOL) project was initiated as an international tool to measure quality of life and it was designed to be used across a multitude of settings (WHO, 1995). They define quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" and six QoL domains were drafted: physical domain, psychological domain, level of independence, social relationships, environment, and spirituality/religion/personal beliefs (WHO, 1995, p.1405). This definition incorporates a theoretical orientation towards culture as an integral part of understanding QoL in multiple settings and its cross-cultural validity in measuring QoL in relation to health (Saxena et al, 2001; Skevington, 2002; Skevington et al., 2004). Defining and measuring QoL, however, is still under debate.

There is little consensus on the definition of QoL (Barcaccia et al, 2013; Moons et al, 2006). Of the definitions that have been used in the literature, the two main ideas are related to: (1) “a life of quality based on individual needs, choices and control and it is experienced when these needs are met and there are opportunities to pursue life enrichment across the lifespan” and (2) “QOL includes subjective and objective aspects and is a multidimensional construct composed of personal and environmental factors” (Wang & Brown, 2009, p. 145). Many QoL studies have been conducted across different disciplines but only a few contained an original conceptual definition of QoL (Barcaccia et al, 2013). This means that the implication of not presenting a clear and innovative definition or an evolving definition can perpetuate the policy-making status quo of inhibiting QoL for marginalised groups.

A useful conceptual definition for this study is "QoL is a subjective, multidimensional experience of wellbeing that is culturally constructed as individuals seek safety and security, a sense of integrity and meaning in life, and a sense of belonging in one's social network" (Kagawa-Singer et al., 2010, p. 59). This recognises the role of culture and the socio-ecological context in framing and understanding QoL, and as such more likely to inform subjective well-being and life satisfaction measures in the policy-making context (Diener et al., 2012). Almost all of the QoL measurements have been developed in Western countries (Lau et al., 2005). Few studies have been undertaken that seek the perspectives of marginalised groups about the construction, constitution and experience of quality of life.

## **Disability**

The emergence of disability as an object of inquiry gathered momentum in the 1970s particularly in the UK and US when disabled activists and academics challenged the prevalence of the medical approach and introduced new conceptions of disability (Johnson, 2011; Peters et al., 2009). The disability rights movement was spawned from these revolutionary ideas and organisations mobilised their resistance to oppression, exclusion, environmental barriers and

cultural discourse (Shakespeare, 2006). Social conceptions of disability has influenced global organisations, such as, the World Health Organization (WHO) and United Nations (UN). The UN Convention on the Rights of Persons with Disabilities was adopted in 2006 and requires member states to regularly report on its implementation. Some countries like Australia, Canada, US, UK, Ireland, Aotearoa New Zealand and the European Union have reported on national legislation, disability strategies and policies (Harpur, 2012). Social conceptions have influenced the overhaul of key WHO documents and frameworks, such as, the 1980 International Classification of Impairment, Disabilities and Handicaps (ICDIH) and 2001 International Classification of Functioning, Disability and Health (ICF) (Barnes, 2012). The disability rights discourse has become significant over the years. This discourse is not without contention though when one considers the power of language in constituting and reflecting social order relative to social, political and cultural formations (Corker, 2000). In other words, disability rights discourse is predicated on a belief system which not only masks the hidden assumptions of that system but is privileged over alternative discourses and belief systems. The use of this discourse, though warranted and legitimate, is value-laden and likely to disaffect cultural communities that do not have a similar or varied view of disability or disability rights. Not all cultures share the same unitary conception of disability that underpins the social model of disability or International Classification of Functioning, Disability and Health (Shakespeare, 2011).

## **Conceptions of disability**

This section explores the conceptions of disability. Such conceptions are particularly evident in the creation of various models of disability which underpin, define and shape disability policies, programmes and interventions, public discourse and disability collective action across the globe. A number of models, such as, medical, social, economic, cultural, minority group, affirmation and Nordic relational have been documented in scientific literature (Degener, 2016; Retief & Letsosa, 2018). The medical and social models of disability have been particularly

influential in the English-speaking world (Degener, 2016). The three conceptions (i.e. medical, social and rights-based) outlined below are mainly relevant in the NZ context and associated discourses on disability.

### **Medical or Individual model of disability**

The medical/biomedical conception of disability is historically grounded in the late 18<sup>th</sup> century in Western civilisation as the advance of medical knowledge and professionalisation of medicine took shape and consequent approaches to disability focused on fixing or curing the person (Johnson, 2011). This focus on fixing or curing the person situated disability as something that the individual has and ought to be responded to through treatment, intervention or rehabilitation. This model views disability as pathology, dysfunction, disorder, deformity, defect, disease, abnormality and deviance that is located within the individual (Bickenbach, 1993; Smart, 2006) and has been called the 'individual model' or the 'personal tragedy theory' (Oliver, 1986). The philosophical dimension of this model is represented by etiology or the study of causation which produced diagnostic categorisations based on causes rather than consequences (Harlan, 1993). The central concern of making an accurate diagnosis of the person's 'condition' has facilitated the reliance of policy-makers on medical definitions of disablement to assess disability prevalence and the distribution of services and treatments (Marks, 2015). The diagnostic and definitional system of the medical model of disability accompanied with the underpinning tenets of scientific rigor and objectivity in medicine and medical science increased public acceptance of this model and influenced perceptions and attitudes towards disability (Smart, 2009). In other words, the predominance of this model permeated into the cultural fabric of society which standardised and legitimated a view that disability is a medical problem and propagated particular views of people with a disability. Some of the recent criticisms of the medical model of disability include (a) the inadequacy of the model to deal with other aspects of the person's identity, such as, cultural, linguistic and

ethnic, because it views the person as a biological machine devoid of subjective experiences; (b) the fragmentation of the disability community into medical diagnostic categories resulting in competition for resources and services; and (c) provides the sole basis to legislate payment systems and service provision thus inhibiting the consideration of factors, such as, maintenance of health and quality of life, access to education and employment and the onset of chronic conditions in ageing populations (Smart, 2006, 2009; Sullivan, 2011).

## **Social model of disability**

One of the social conceptions of disability is grounded in the social model of disability. It is important to discuss this model in depth because of its widespread presence internationally including Aotearoa New Zealand. The social model of disability, also known as the social barriers approach, originated in the UK and is premised on Marx's historical materialist analysis (Lang 2007). This analysis served as a way of looking at the social oppression of disabled people as fundamentally bound to the social relations of production in capitalist society (Thomas 2007). It is the social, political and economic structural arrangements in society that prevent and limit the full participation of people with a disability. The social model of disability and ensuing distinction between disability and impairment can be traced to Paul Hunt and Vic Finkelstein who were leading disability activists in the Union of the Physically Impaired Against Segregation (UPIAS) in the 1970s:

What was consistent in our view, however, was that our interpretation of 'disability' led us to focus on the nature and workings of society, **not** [sic] our personal or individual attributes (which we saw as related to impairments). We had started to redefine the meaning of disability (Finkelstein 2001).

Paul Hunt and Vic Finkelstein were central figures in authoring the UPIAS '*Fundamental Principles of Disability*' released in 1976. The British sociologist and disability rights activist, Mike Oliver, developed its main ideas into what is known today as the social model of disability. This seminal document revolutionised the nature and politicisation of



disability by making a sharp distinction between the concepts of 'impairment' and 'disability' (Sullivan, 2000). The UPIAS (1976) distinction is:

Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression (p. 14).

By making this distinction, the UPIAS redefined disability as a social construct that exists within the structural arrangements of society which results in restricting a person from participating fully in society and, as such, it is society that disables and disadvantages the person not the impairment (Thomas, 2004). To paraphrase a person has an impairment, disability exists in society in the way that it is structurally organised and configured based on ideological norms that do not take account of persons with a disability. In short, it is not the person's impairment that limits and prevents their participation, it is the barriers and attitudes of society that excludes and restricts them. Hence, disability was reformulated as a form of social oppression and this marked a radical departure from conventional perspectives and opinions that disability was primarily a welfare and medical issue (Thomas, 2004). The social model of disability reconceptualised and situated disability as an outcome of power relations and social barriers as opposed to an individual pathology or 'personal tragedy' (Barnes & Mercer, 2003). The key ongoing criticism (mainly in the academy) of the social model of disability is the impairment/disability dichotomy where proponents deny or neglect the subjective experiences or biological conditions induced by an impairment and thereby focus exclusively on disabling social structures and barriers (Shakespeare and Watson 1997, Swain and French 2000, Shakespeare 2006, Anastasiou and Kauffman 2013, Levitt 2017, Boxall 2018)

## **Socio-political model of disability**

Another social conception of disability is the socio-political model of disability. This was conceived in the US during the time of the Civil Rights and Women's Movement (Oliver & Zarb, 1989) and by the late 1960s the federal disability policy substituted the medical model with the socio-political or minority group model of disability (Scotch, 2000). Similar to the social model of disability in the UK which challenged the medical model, the socio-political model challenged the functional-limitations paradigm. This paradigm consisted of medical and economic perspectives of disability which measured limits on life activities and functionality in the workplace (Hahn, 1993). In this model, disability reflects Nagi's 1979 description of disability as "a form of inability or limitation in performing roles and tasks expected of an individual within a social environment" by emphasising the external environment and addressing these through laws and policies rather than focusing on improving the capabilities of persons with a disability (Hahn, 1986, p. 274). The external environment includes physical characteristics of the built environment, cultural attitudes, social behaviours, and the regulations, procedures and practices of private and public institutions (Scotch, 2000). To put another way, the socio-political model attends to the interaction between the individual and the micro and macro environment and uses the minority-group paradigm to promote and advocate for (1) social justice, (2) political parity as citizens and (3) civil rights protection. Smart and Smart (2012) assert that self-determination, elimination of discrimination, self-definition and rejection of medical categories are also part of this model. Hahn's analysis of disability broadened the scope in three ways. First, by including social forces, politics, social norms, values and attitudes that shape political discourse and ensuing policies that undermine full participation (Putnam, 2005). Second, by recognising the role of legislators, policymakers and service providers as part of the problem (Smart, 2009). Last, that the strategies to remedy this lies in the political realm of changing discriminatory attitudes, laws and policies (Bickenbach

et al, 1999). Some ongoing criticisms of the socio-political model include the problematic nature of this group as an interest group that lobbies alongside other minority groups, the extreme form of cultural determinism in defining disability, and the binary overtones from an epidemiological perspective that a person either has a disability or does not (Liggett 1997, Anastasiou and Kauffman 2010, Bickenbach, Rubinelli et al. 2017).

### **Rights-based model of disability**

The disability rights model is the recognition that persons with disability possess and can exercise their human rights. Disability is framed as a human rights issue (Retief & Lesosa, 2017). The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is the first human rights treaty with an express intent of protecting the human rights of persons with disability (Harpur, 2012). It has been argued that the UNCRPD is a landmark victory for the disability movement and represents a paradigm shift on how disability is viewed (Meekosha & Soldatic, 2011). Meyers (2014) remarked that the international disability rights movement hailed the passage of the UNCRPD as a platform in “giving voice” to countless persons with a disability and institutionalised an advocacy and monitoring role for Disabled Persons Organizations (DPOs). The rights-based approach is not merely restating the human rights of person with a disability but offers guidelines or intervention strategies on how to enable the exercise of their rights (Harpur, 2012). Degener (2018) makes two assertions: (1) the drafters of the UNCRPD moved beyond the social model and codified the Convention based on human rights model of disability, and (2) the UNCRPD is built on the premise of the social model (that disability is a social construct) but advances this further. She bases the latter on six propositions. Although all six are important, three of these propositions have a direct bearing on quality of life of persons with a disability. First, human rights is more than anti-discrimination in that this model “encompasses both sets of human rights, civil and political as well as economic, social and cultural rights” (Degener, 2018, p. 4). Second, impairment is accepted as human variation

and though this can reduce a person's quality of life it is part of humanity to experience life and value diversity (Degener, 2018). Third, the existence of different layers and forms of identity in that this model "offers rooms for minority and cultural identification" (p. 9) and intersectionality of identities. Although the rights-based approach is heralded as a significant step towards inclusion of persons with a disability in all facets of life, there are some criticisms of this approach. Some ongoing criticisms include the arguments that the notion of disability rights is a form of colonization and the Global North's presumption that rights has a universal appeal and can be applied in the Global South irrespective of historical and local context (Meekosha and Soldatic, 2011) and the implausibility of unifying concerns into a single unitary voice when reporting on a country's UNCRPD initiatives and progress (Meyers, 2014).

These conceptions of disability have bearing on how developed and developing nations approach and address the needs of its community of persons with a disability in its funding policies and service operations. Models of disability can significantly influence public perceptions of disability, public responses to persons with disability and even shape the self-identity of persons with a disability (Smart 2009, Andrews 2017). Smart (2009) asserts that all models are time-bound and culture-bound and are subject to modifications and refinement as society (and its people) evolves. There has been a shift from viewing persons with disability as defective to acknowledging a broader context of where the interaction of personal and environmental characteristics can impact human functioning and disability (Buntix & Schalock, 2010). It is generally accepted that models of disability have their own strengths and weaknesses, indeed any model, and that the uptake of selected model/s serves a purpose and function. However, the uptake of selected model/s can positively or negatively influence practitioner and professional approaches towards persons with a disability, if left unchecked (Buntix & Schalock, 2010; Retief & Lesosa, 2018; Smart, 2009). This has implications in improving the quality of life of persons with a disability.

## **Relevant studies**

A number of studies on the quality of life of persons with disability have been undertaken. This section reviews some key studies. The conceptualisation of quality of life was of poignant interest here, as were cultural conceptions and components of quality of life.

### **The interface of Disability and Quality of Life**

Quality of life in the field of disability has garnered interest particularly from within the intellectual and developmental disabilities arena (Simões and Santos 2016, Santoro, Shear et al. 2018). The operationalising of quality of life (QoL) in this arena has been articulated as a service delivery principle (Schalock, 2004), as a performance measure for disability services at the individual and agency levels (Kober & Eagleton, 2006) and its interaction with human functioning, disability and person-centred supports in professional development (Buntix & Schalock, 2010). The QoL framework has been used to guide service delivery, effect policies and increase positive outcomes for persons with a disability and their families (Wang & Brown, 2009). Some studies illustrate the importance of the support worker role regarding the enhancement of QoL for the service user (Marquis & Jackson, 2000), trialing QoL measures with people with post polio syndrome (Ahlstrom & Karlsson, 2000), and QoL experiences from adolescents with cerebral palsy (Shikako-Thomas et al., 2009).

### **Facilitators and barriers to Quality of Life**

Some studies have been undertaken to identify facilitators and barriers to achieving quality of life (Hammel, Magasi et al. 2015, Bossink, van der Putten et al. 2017, Smith and Papathomas 2017). These indicate that the environmental barriers in the community setting, lack of adequate transport and assistive technology, shortage of social supports, and inaccessible equipment prevented participation. These studies also show that social participation and physical activity contributed to their well-being and satisfaction. Parker and Fisher (2010) identified seven facilitators and barriers in their study on housing support policies for persons with a disability

requiring 24-hour care. These are (1) legislation, agreements and regulations, (2) funding and demand management, (3) interagency coordination, (4) range, flexibility and choice of housing support, (5) staffing quality, (6) informal carers, and (7) discrimination. Parker and Fisher (2010) highlight that these can be either facilitators or barriers that the person experiences which is intertwined with their set of goals.

## **Summary of the literature**

The studies reviewed for this research demonstrate that the construct of QoL is a value-laden term that varies from one cultural context to another. In this regard, to understand the cultural knowledge on how QoL is conceptualised and experienced from the perspective of Samoans with a disability a qualitative investigation is needed. The literature not only provided direction for the research but also showed that models of QoL and instruments to measure QoL are often developed and designed from Western conceptualisations of QoL, and although tested and validated across cross-cultural settings (e.g. WHOQOL, FQoL) implying that there are certain limitations. First, that models and instruments are viewed as generic and static and applied with little consideration that non-Western conceptualisations may be quite different. Second, the presumption that all persons with a disability, notwithstanding age, ethnicity, gender, impairment type and socio-economic status, have the same wherewithal to access resources and services that support their QoL also does not provide the whole picture. Third, the limited culturally specific knowledge of service providers and practitioners on improving QoL for persons with a disability can stagger person-centred goals and plans. Consequently, the literature reviewed in this chapter gave rise to looking at QoL from a different lens.

## **Chapter 3 Theoretical framework**

### **Introduction**

This chapter introduces Pierre Bourdieu's relational thinking tools of habitus, capital, field and doxa which were utilised to investigate the quality of life experiences of Samoans with a disability. The theoretical perspective or theoretical framing of a study is a philosophical stance that undergirds the methodology and deals with epistemology or what kind of knowledge can be attained in research (Crotty 1998). This chapter includes Bourdieu's intellectual enterprise of circumventing the agency-structure dichotomy in social sciences and the efficacy of his concepts to uncover and analyse social practices.

### **Critical social theory**

This study uses critical social theory from the point of view of Pierre Bourdieu as the theoretical framework. Critical social theory is "a multidisciplinary knowledge base with the implicit goal of advancing the emancipatory function of knowledge" (Leonardo 2004). Pierre Bourdieu's theoretical orientations are congruent with critical social theory particularly as the aim of critical theory is to redirect traditional agency-structure debates by foregrounding the notion that the actions, motivations and beliefs of individuals are influenced by forces that can be made visible (McKenzie 2014). Pierre Bourdieu was a philosopher, sociologist and French intellectual who developed a "theory of practice" (Bourdieu 1977, Bourdieu 1990, Grenfell 2008, Agbenyega and Klibthong 2015). This "theory of practice" is the culmination of his intellectual pursuits notably in the social science debate of the objectivism vs subjectivism binary. He sought to circumvent the divide between "the objectivist and subjectivist modes of theorising, between material and symbolic dimensions of social life, as well as between interpretation and explanation, synchrony and diachrony and micro and macro levels of analysis" (Wacquant 2006).

Bourdieu's dissatisfaction with structuralism of the Saussurean and Levi-Straussian traditions inspired him to re-introduce the notion of agent or social agent who “puts into action a system of dispositions *acquired through experience* which can vary from place to place and time to time” (Bourdieu 1990). Bourdieu had raised the possibility of individuals as social agents who operate and perform in the social world in fluid ways that is not necessarily prescriptive nor determined by compliance to rules. For Bourdieu "social reality exists twice, in things and in minds, in fields and in habitus, outside and inside of agents" (Bourdieu 1989). In other words, the structure-agency dichotomy is transcended when it is recognised that the creation of social reality is not mutually exclusive rather it is a combined effect of institutions shaping the individual and vice-versa. His relational "thinking tools" - habitus, capital, field and doxa serves as interactive concepts that can be used to analyse social practices (Wacquant 1989). These concepts will be utilised in this study to analyse disability services.

## **Habitus**

The first key concept from Bourdieu's theory that informs this study is *habitus*. He defines habitus as "the system of structured and structuring dispositions which is constituted by practice and constantly aimed at practical - as opposed to cognitive - functions" (Wacquant 1989). A “structured structure is a system of schemes generating classifiable practices and works and a structuring structure is a system of schemes of perception and appreciation” (Bourdieu 1984). On the one hand, structured structures depict traditional static synchronic forms of beliefs, values and norms often associated with primitive societies. On the other hand, the notion of structuring structure exemplifies the ability of societies to reify and impose dominant ideologies to maintain social control (Bertmann 2018). In this way, human dispositions, values and beliefs form part of the habitus which they use to formulate practices. In other words, habitus is the property of actors that is formed through past and present socialising practices, such as, personal biography and educational experiences, and is 'structuring' in that the actor's habitus helps to



shape current and future practices (Maton 2008). Bourdieu refers to this disposition as 'master disposition' where historicism, such as, geographical place, historical period, culture and socialisation instils a set of values and beliefs system and associated practices within the individual thus structuring their behaviour and practical sensibilities. The disposition is durable, transposable and designates a way of being (Bourdieu 1977). This is particularly relevant to this study. For example, the Samoan habitus is governed and determined through the transmission and practice of culture or *fa'asamoa*. Fa'aSamoa or 'the Samoan way' describes the cultural framework that depicts the enactment of Samoan values, such as, *fa'aaloalo* (respect), *tautua* (service) and *alofa* (love) into lived practices of being and doing in the family, extended family, church and village institutions (Pitt and Macpherson 1974, Anae 2010, Stanley and Kearney 2017). Although the presence of Samoan habitus within the confines of Aotearoa New Zealand life is visible, the habitus of Samoans with a disability is not and this study explores this: their perspective on identity formation where the compound of disability and ethnic identity is often viewed as a 'dual burden' or 'double oppression' (Lightfoot and Williams 2009) their conceptualisation and definition of quality of life and how this is navigated in relation to policy, families and caregiver support (Edwards, Parmenter et al. 2018), and their system of current and acquired dispositions to optimise personal positioning in the field (Park and Morris 2004).

## **Field**

The second key concept from Bourdieu's theory that informs this study is *field*. A field is 'a structured space of positions, an arena of struggle between agents and institutions, a sphere of life endowed with its own rules, regularities and forms of authority' (Wacquant 2006). Every human activity operates in social spaces or *fields*. Bourdieu (1977) conceptualised field in relational terms where different field actors interact in terms of their habitus and capital that produce certain practices. It is the relation between these structures that represent objective and

subjective realisations of the logic that each is mutually constitutive (Maton 2008). Disability is a contested field where individuals with a disability are in constant struggle with policy and service delivery. This struggle occurs between individuals and groups because each person brings different habitus and capital to the disability field which makes them more or less likely, or able, to engage in the stakes of the disability field. According to Bourdieu, “a field is simultaneously a space of conflict and competition” (Bourdieu and Wacquant 1992). The contestation between the positions occupied by individual children and groups within any given field results in the valuing of particular practices, which possess their own characteristics or 'logics' (Maton, 2008). Disability field contains some form of prevailing practices that exert a structuring influence upon persons with a disability within that field (McKeever and Miller 2004, Blackmore and Hodgkins 2012). The field of disability may be studied by identifying the practices associated with it, determining which service delivery practices are dominant and degrading or consultative and collaborative.

## **Capital**

The third key concept from Bourdieu's theory that informs this study is *capital*. Bourdieu conceptualises capital as accumulated assets in four forms – economic, social, cultural and symbolic (Bourdieu 1986). Economic capital exists in the form of money, investments, property and material assets; social capital is the accrual of social connections and networks via group membership; cultural capital is in the form of cultural goods, such as, books, instruments and machines, skills and educational qualifications; and symbolic capital is a designated effect of any form of capital (Bourdieu 1986, Wacquant 2006). A person's positioning in the field is determined by their possession of the overall volume of capital and the type of capital relative to the field (Bourdieu 1989). People with a disability generally have different types of capital and these can be generated and transposable over time and space, such as, family inheritance, car ownership and sports club membership. However, societal response to the inclusion of

individuals with a disability in the fabric of social and material life indicates that these individuals are rated as ‘second-class citizens’ and unworthy of status and recognition (Lang 2007). This equates to Bourdieu’s symbolic capital, minimal symbolic capital. The nature and form of one’s capital determines a person’s positioning within the disability field, and it is the interaction between habitus and capital that further determines the person’s positioning (identity) within the disability field (Byrne 2018, Frederick 2018). Examining the types of capital Samoans with a disability have will articulate how they navigate the access to and receipt of service provision as well as how they define their identities.

## **Doxa**

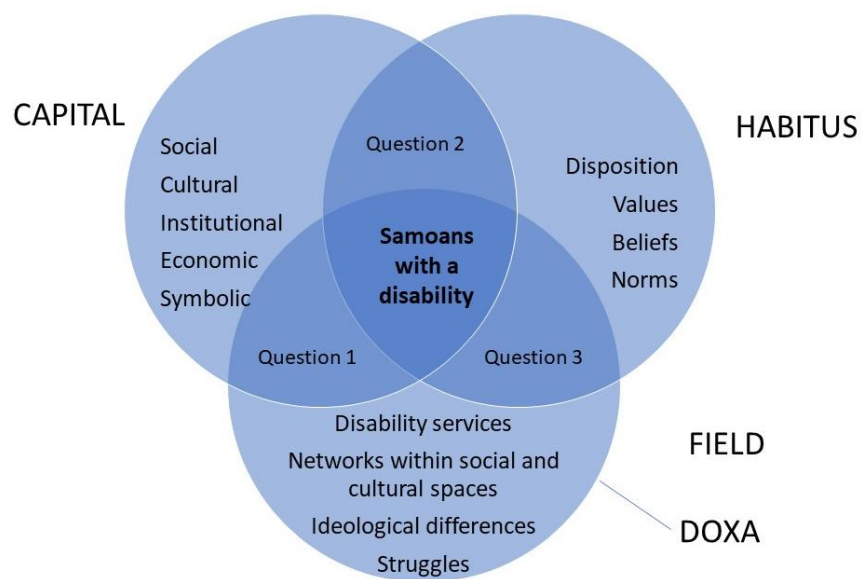
The fourth key concept from Bourdieu’s theory that informs this study is *doxa*. Doxa is “the relationship of immediate adherence that is established in practice between a *habitus* and the field to which it is attuned, the pre-verbal taking-for-granted of the world that flows from practice sense” (Bourdieu 1990). Doxa is the taken for granted assumptions, entrenched within social practices that are difficult to change as a result of dominant values and beliefs (Wacquant, 2006). The manifestation of doxa is expressed through ‘naturalised’ attitudes prescribed by prevailing universal norms of common practice (Supple 2013, Klibthong 2014). The disability field is a contested space of doxic attitudes where the rights-based discourse, policy-making context and expectations of quality service provision for Samoans with a disability are in conflict. The concept of doxa will unravel the institutional capital and disrupted/negotiated practices of the positions occupied by service providers and policymakers in relation to the quality of life of Samoans with a disability in the disability field.

## **Application of Bourdieu’s concepts**

Bourdieu’s four concepts are relational ‘thinking tools.’ Field and habitus are relational structures in that each is representative of a mutually constitutive logic of practice (Maton, 2008) and the relationship between field and habitus is fluid and ongoing. It is, on the one hand,

a relation of conditioning whereby the field structures the habitus and on the other hand, habitus contributes to constituting the field as a meaningful world (Wacquant, 1989). In other words the individual's habitus governs and guides a range of possibilities in the field, which in turn influences the field and vice-versa. Samoans with a disability enter the disability field with both habitus and capital. Maton summaries Bourdieu's conception of the 'unconscious relationship' between field and habitus as:  $[(\text{habitus})(\text{capital}) + \text{field} = \text{practice}]$  or "practice results from relations between one's dispositions (habitus) and one's position in a field (capital), within the current state of play of that social arena (field)" (Maton 2008). This equation is not lineal but multidimensional and illustrates the interaction between habitus and capital within fields. The utility of Bourdieu's concepts in this study was to identify, examine and articulate the positioning and interplay of Samoan habitus and capital within the network of socio-political relations in the disability field, a 'contested space of struggle.' Bourdieu's concepts and research variables are provided in Figure 3.1.

Figure 3. 1 Diagram of Bourdieu's concepts and key research variables



Research question	Key variable	Key theoretical concept	Method and data source
1. How do adult Samoans with various disabilities conceptualise and describe quality of life?	Meaning given	Habitus	Interviews
	Policy	Policy (field)	
	Family networks	Service provision (field)	
	Caregiver supports and service delivery	Doxa	
2. What factors are reported by Samoans with disabilities that facilitate or inhibit their quality of life experiences?	Service delivery	Capital	Interviews
	Structures	Doxa	
	Policy parameters	Habitus	
3. How do Samoans with disabilities perceive their ethnic identity in Auckland?	Perceptions	Habitus	Interviews
	Identity		

## Chapter summary

This chapter outlined Bourdieu's theoretical concepts in the framing of this study. His concepts are congruent with critical social theory particularly in the agency-structure debates of foregrounding actions and motivations and making these visible. The utility and application of habitus, capital, field and doxa were examined in light of this study on the quality of life of Samoans with a disability. These interactive concepts served as tools for analysing disability

issues in this research. The next chapter explores research paradigms and theoretical perspectives. I consider the offerings of paradigms and argue for the choice of interpretivism for this investigation.

## **Chapter 4 A review of theoretical perspectives and research paradigms**

### **Introduction**

A theoretical perspective is a “view of the human world and social life within that world, wherein such assumptions are grounded” (Crotty 1998). These philosophical assumptions underpin and govern the approach and trajectory of undertaking any research enterprise. Paradigms are metaphysical frameworks that enable researchers to identify and clarify their beliefs in relation to knowledge, reality, methodology and ethics (Mertens 2010). The choice of selecting a research paradigm is often based on the philosophical assumptions embedded within it. As this study seeks to understand how Samoans with a disability experience quality of life, there is an offering of paradigms to choose from. This chapter provides the rationale for situating this study within an interpretivist paradigm informed by Pierre Bourdieu’s theoretical concepts. It also explores theoretical perspectives and research paradigms considered in qualitative and quantitative research, and issues of validity, credibility and trustworthiness.

### **The nature of social research**

“A scientific understanding of the world must (1) make sense and (2) correspond with what we observe (Babbie 2008). Babbie relates these elements to the pillars of science: logic and observation, and to the scientific enterprise of theory, data collection and data analysis. In the social sciences, social theory aims to uncover patterns in social life or is a systematic explanation of observations that relate to particular spheres and dimensions of social life (Babbie 2008). The distinction between social and natural sciences is the subject matter (Bryman 2004). The former is about people and their social world and as such people possess the propensity to create and assign meaning in their environments; whereas the latter is about physical objects such as chemicals and gas in the natural world. It has been argued that this

distinction requires a different set of tools, methods and theories when undertaking research with people or physical objects (Willig 2001, Flick 2009). Social science is the enterprise of inquiry into social reality, the patterns or regularities of social life among groups and social research seeks to describe or explain social phenomenon (Babbie 2008). Bryman (2004) iterates that social research does not exist in a vacuum detached from social sciences rather practitioners and academics hold shared views on how to study social reality and in fostering the wider scientific enterprise of research praxis. The link between theory and research is characterised by the nature of explaining observed patterns or regularities (Silverman 2013). Grand theories (e.g. symbolic interactionism, critical theory and structuration theory) or middle range theories (e.g. labelling theory, normalisation process, role conflict) guides empirical inquiry and social research (Merton 1967). A paradigm is a frame of reference that underlies inquiry and theories and serves as a framework to guide observation and understanding (Maxwell 2008, Holloway and Galvin 2017) .

Social scientists have developed many paradigms to understand human social life and social behaviour. These paradigms hold to assumptions about epistemology, ontology, methodology and axiology. I draw mainly on Kivunja and Kuyini (2017) because of their express intent to guide postgraduate students undertaking research. They achieve this by demystifying and explaining key research terms and concepts for students to consider, understand and reflect on. Epistemology means knowledge and is concerned with the nature and forms of knowledge, how it can be acquired and communicated to other human beings (Kivunja and Kuyini 2017). It's the "how we know what we know" (Crotty 1998). In thinking about epistemology as a researcher Kivunja and Kuyini (2017) suggest three questions to ask oneself. These are: "(1) is knowledge something that can be acquired or something that has to be personally experienced? (2) what is the nature of knowledge and its relationship between the knower and would be known? (3) what is the relationship between me (the inquirer) and what



is known?” . They reiterate the importance of epistemology because it influences how I go about uncovering knowledge in my study. Ontology is about the nature and existence of reality. It is concerned with the study of being and “what is” in the structure and existence of reality (Chamberlain 2015) In thinking about the nature of being and existence as a researcher Kivunja & Kuyini, (2017) propose a set of questions to ask oneself. These are: “(1) is there a reality out there in the social world or is it a construction created in one’s mind? (2) is reality of an objective nature or the result of individual cognition? (3) what is the nature of the situation being studied?” . They assert the value of ontology because it requires me to consider what my belief systems and assumptions are about existence, being and reality, and how I make sense of the data in my study.

Methodology and method is often used interchangeably in the literature (Mackenzie and Knipe 2006) however they do not mean the same thing. Mackenzie and Knipe (2006) differentiate methodology as the approach to research that is linked to a theoretical framework or paradigm while method is about the tools and procedures employed to collect and analyse data. In thinking about selection of a methodology as a researcher Kivunja and Kuyini, (2017) propose a key question to ask oneself: “how shall I go about obtaining the desired data, knowledge and understandings that will enable me to answer my research question and thus make a contribution to knowledge?” . Axiology is about the nature of values and ethical behaviour in the research enterprise. In thinking about axiology as a researcher Kiyunja and Kuyini (2017) suggest a set of questions to ask oneself: “(1) what values will you live by or be guided by as you conduct your research? (2) what ought to be done to respect all participants’ rights? (3) what are the moral issues and characteristics that need to be considered? (4) how shall I secure the goodwill of participants? (5) how shall I conduct the research in a socially just, respectful and peaceful manner?” . They assert that this is principled on understanding that all humans have dignity and rights and to respect this. In contemplating these philosophical

assumptions I come to a place of critical awareness of who I am in terms of what my value system consists of, how I think about my reality and other peoples' reality, what counts as knowledge and how do I go about creating a credible study. A researcher usually aligns with one of the standard paradigms that best suits their assumptions and methodological preferences (Mackenzie and Knipe 2006, Maxwell 2008).

### **Positivist paradigm**

Positivism is an epistemological position that advances the idea that the methods used in the natural sciences can be applied to the study of social reality (Bryman, 2004). It is sometimes referred to as the scientific method of investigation (Kivunja & Kuyini, 2017) and originated from a rationalistic and empiricist philosophy associated with Aristotle, Francis Bacon, John Locke, Auguste Comte, Emmanuel Kant and John Stuart Mill (Mackenzie and Knipe 2006, Baronov 2012). Research located in the positivist paradigm rests on deductive and inductive logic, hypothesis and theory testing, experimentation and extrapolations which aims to explain and predict measurable outcomes (Bryman, 2004; Kiyunja & Kuyini, 2017). In other words, it looks at causal relationships and universal laws to generalise, control and make predictions. By doing so, these laws and predictions are expected to occur in other parts of the world. The objectivist epistemology and naïve realist ontology enshrined in the positivist paradigm assumes that knowledge can be gained to facilitate objective understanding of the world; and the world (or reality) exists independent of one's perception and it can be known through sense-experience (Kiyunja & Kuyini, 2017). The rise of post-positivism in the mid-1940s (Mackenzie & Knipe, 2006) is premised on four ideas. Baronov (2012) states these as: "(1) all knowledge statements are relative, (2) the basis for judging the truth of a knowledge statement is provisional, (3) one's understanding of society is largely shaped by a person's social and cultural background, and (4) knowledge production is not a linear process" (p. 79-82). The onset of post-positivism depicts evolving ideas and new questions about using positivism in

social research. Some of the characteristics of using positivism include the belief that knowledge is out there waiting to be discovered, context is not important, results of the study can be quantified, and theory can be used to predict and control outcomes (Kivunja & Kuyini, 2017). Positivist and post-positivist paradigms commonly use quantitative research methods (Mackenzie & Knipe, 2006). The interpretivist paradigm is a different approach to social research.

### **Interpretivist paradigm**

Interpretivism is an alternative to positivism and recognises the differences between people in the social world and the objects of the natural sciences (Bryman, 2004). The main endeavour of the interpretivist paradigm is to understand the subjective world of human experience (Guba and Lincoln 1989) In other words, to seek how people understand and interpret their world and the ways they make meaning according to their perspective within context. Interpretivism and constructivism are related concepts traced back to the work of Edmund Husserl's phenomenology (i.e. study of human consciousness and self-awareness) and Wilhelm Dilthey's hermeneutics (i.e. study of interpretation) (Chilisa and Kawulich 2012). Kiyunja and Kuyini (2017) and others reiterate the key idea that reality is socially constructed. Social reality holds meaning for people hence human action is meaningful by way of people acting on the basis of these assigned meanings to their acts and the acts of others (Bryman, 2004). The goal is to understand the lived experience from the perspective of people who live it (Schwandt 1998). Research located in this paradigm contrasts with positivism. For instance, the aim is to understand, theory does not necessarily precede and comes later, and researcher subjectivity in knowledge acquisition is permissible. The subjectivist epistemology and relativist ontology enshrined in the interpretivist paradigm assumes that knowledge is a cognitive process where the researcher makes meaning of their data shaped by researcher-participant interactions; and the situation under investigation consists of multiple realities (Kiyunja & Kuyini, 2017). The

role of the researcher is implicated because it is recognised that they enter the research arena as persons with a biographical history, set of values and these can influence the interpretation of data and its communication in the social world. Some of the characteristics of using interpretivism include the belief that knowledge is created by the findings and these can be value-laden, the existence of multiple and socially constructed realities, context and contextual factors is vital for knowledge, knowing and understanding, and causes and effects are mutually interdependent (Kivunja & Kuyini, 2017). Interpretivist and constructivist paradigms commonly use qualitative research methods or a combination of qualitative and quantitative methods (Mackenzie and Knipe 2006, Flick 2009)).

### **Making sense of Qualitative and Quantitative research**

The qualitative and quantitative approaches to research originate from 20<sup>th</sup> century philosophical thought. Each approach is distinctive in the aim and design of a social science research project or social research project. Creswell (1994) identifies quantitative as synonymous with terms such as traditional, positivist, experimental and empiricist; and qualitative as constructivist, naturalistic, interpretative approach, postpositivist or postmodern perspective. Denzin and Lincoln (2018) describe the quantitative approach as studies that emphasize measurement and analysis of causal relationship between variables whereas qualitative tends to emphasize the qualities of entities, meanings and processes which are not measured or examined in terms of amount, intensity, frequency or quantity. Numerous debates over many decades have ensued over the scientific merits of each approach. Mackenzie and Knipe (2006) and others make two notable points about the qualitative/quantitative debate particularly around the terminology and contradictory information that perpetuates confusion for inexperienced or novice researchers. First, that research texts and university courses discuss research in terms of qualitative or quantitative. Second, people will ask researchers whether their research is qualitative or quantitative or if they are qualitative researchers or quantitative

researchers. These two points resonate with me because I recall this debate in the 1990s as a postgraduate student and doing Pacific health research with my community. Almost always, the main question I got from research peers, friends and members of the Pacific community was 'is it qualitative research?' From this experience I formed the opinion that there was a qualitative/quantitative divide and associated with this was a status given to either depending on where one's interest lies. For instance, epidemiologists and statisticians might put value on quantitative whereas indigenous researchers in education and public health might put value on qualitative (Walter and Andersen 2013, Kovach 2015). Part of doing my study is to move beyond this dichotomy and to clarify in my own mind the strengths and weaknesses of each and to make an informed decision on the appropriateness of using either approach or combination of both approaches.

Qualitative research started as a countermovement to the empiricist or positivist tradition, through writers, such as Wilhelm Dilthey, Max Weber and Emmanuel Kant, of which Auguste Comte, John Stuart Mill, Emile Durkheim, and John Locke espoused in their work (Creswell 2013). The positivist tradition is a philosophy of science that facilitates the production and legitimation of scientific knowledge and scientific methods. Positivism is a philosophy that maintains that there is the existence of natural or general laws that govern behaviour of the natural world and that the goal of science is to discover them (Benton and Craib 2010, Hughes and Sharrock 2016). Green and Browne (2005) specify four key features which characterize positivism: empiricism, logical induction, realism and value-free nature of scientific enquiry. Empiricism is a belief that scientific knowledge can only be derived from observable data; logical induction is the process by which theories or laws about the physical world are inferred from repeated empirical observations; realism is the assumption that reality is stable, and exists independently or outside of any attempt to describe it; and the value-free nature of scientific enquiry is the notion that science should exist outside the influences of society, religious,

political and emotional values. The aggregation of these key features characterize the positivist philosophy that facilitates the production and legitimation of scientific knowledge and scientific methods (Willig 2001, Sarantakos 2012).

Green and Browne (2005) identify two different criticisms to positivism, and illustrate this through the ideas of Karl Popper, Alan Chalmers and Thomas Kuhn. The first criticism is that these features do not describe any kind of scientific research even those in the natural sciences, and to describe science in this way is naïve, simplistic and stereotypical; the second criticism is the inappropriateness in using positivism as a starting point in a study of human behaviour. They identify Karl Popper, who rejected this positivist view of scientific progress, and suggested that knowledge does not grow incrementally via repeated observations to develop laws about the world, but by a more creative process to include creativity, hunches and inspiration. Such creative processes lead to the generation of hypotheses and these should be tested. For Popper, it is the testability of hypothesis that characterizes scientific knowledge. For Kuhn, scientific knowledge does not increase incrementally but by radical changes in world views or paradigm shifts. To paraphrase, paradigm shifts occur as disciplines enter a critical mode to which there are competing explanations and existing theories that take account of new knowledge being generated. Hence new paradigms emerge to accommodate for new bodies of knowledge. Kuhn's ideas challenge the pure realist perspective; and implies that scientific knowledge of the social world can be explained and made sense of within specific paradigms (Maxwell 2008). It has been argued that the inappropriate use of positivism in social research is related to the notion of relativism (Alvesson and Skoldberg 2017). The relativist perspective believes that reality and knowledge of reality changes, is a socially constructed product of particular social, historical and political circumstances (Robson and McCarten 2016). The very idea that reality is stable and exists independently of societal influences, values and interests is central in rejecting positivism in social research (Hughes and Sharrock 2016). For instance, sociocultural and economic values

can influence and fuel topics of research interest and shape the kinds of answers sought. Concomitant with this perspective is the assertion that qualitative research emphasises the socially constructed nature of reality, the nature of inquiry is value-laden, situational constraints which can affect the shape of the inquiry, and the existence of the relationship between the researcher and that being studied (Denzin & Lincoln, 2003).

### **Deciding on qualitative research**

Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed view of informants, and conducts the study in a natural setting (Creswell 1998).

Creswell's definition of qualitative research encapsulates the nature, process and intent of qualitative research; and the role of the researcher. Qualitative research seeks to explore a human or social phenomenon by using an inquiry process or strategy of inquiry guided by an established methodological tradition. The researcher is tasked with formulating and executing an action plan involving the collection of data, the analysis of data, and its write up. Denzin and Lincoln (1994) offer a similar definition with the addition of data sources, such as, case study, visual text and life story, and adoption of a specific approach to the research topic, that is, interpretive naturalistic. Creswell's definition is useful because it is succinct, cogent and recognizes the existence of multiple methodological traditions of inquiry (whereas Denzin and Lincoln propagate a particular orientation to qualitative research). Qualitative research is a systematic process of uncovering, explaining, understanding and exploring a human or social phenomenon using scientific methods and procedures. The School of Chicago in Sociology was instrumental in pioneering work in urban community studies and established the importance of the qualitative inquiry into the study of human group life (Denzin and Lincoln 2003). This was prompted by a local orientation to social problems and concerns taking place in North America and the need to explore theories and methodologies to understand and explain a range of

phenomenon. Conversely in Germany, as qualitative research developed within its own borders two methods, the narrative interview and objective hermeneutics, emerged (Flick 2009).

Selection of either the qualitative or quantitative approach, or a combination of both, is subject to a range of factors and conditions. Creswell (2014) suggests the following criteria: the researcher's worldview, which they bring to the study will entail a preference for either qualitative or quantitative, the researcher's training and experience, the researcher's psychological attributes, the nature of the problem, and the audience for the research. Denzin and Lincoln (2003) offer similar criteria based on Becker's analysis of qualitative and quantitative approaches. These are the use of positivism and postpositivism, acceptance of modern sensibilities, capturing the individual's point of view, examining the constraints of everyday life, and securing rich description. In addition is the philosophical assumption that underpin either approach. These assumptions were discussed earlier and are presented here again. According to Creswell (2014) the ontological, epistemological, axiological, rhetorical and methodological assumptions pose different, interrelated and relevant questions for consideration. It holds significant implications at the research practice level. The ontological assumption is characterized by the view that reality is subjective, and multiple forms of reality exist. The central question is 'what is the nature of reality?' The epistemological assumption is geared towards the constitution, construction and theorizing of knowledge (Mertens, Holmes et al. 2009). This assumption appreciates the active relationship between the researcher and that being researched in the designation and movement of knowledge (Willig 2001). Constituting knowledge is a collaborative, dynamic and engaging process (Creswell 2014). The axiological assumption is characterized by the view that research is biased and value-laden – there is the presence of values at the micro and macro levels of the research. (Baronov 2012) The main question is 'what is the role of values?' The rhetorical assumption is a framing of the research to reflect, represent and reinforce a standardized reporting format; associated with informal and



personal styles of writing appropriate to the qualitative research discourse. The key question is ‘what is the language of research?’ The methodological assumption is characterized by the view that the research is context-bound, uses inductive logic, and acknowledges the flexibility of the research design. The research process, procedures and methods for carrying out the research is contemplated on. The main question ‘what is the process of research?’

Creswell (2014) suggests that the researcher is pivotal in determining the choice of approach to social research. The researcher’s outlook, research experience, and personal attributes are predisposing factors in selecting the best research approach. The philosophical assumptions are seemingly characterised, on the one hand, around a set of expectations of the researcher, and the validation of the researcher’s orientation on the other.

### **Disability research paradigms**

Social researchers and sociologists have been researching disability related issues since the 1950s (Barnes 2006, Barnes 2013). For instance, Talcott Parson’s sick role and Erving Goffman’s stigma. It is necessary to gain some appreciation for, and understanding of, the main disability research paradigms in social research. The three main disability research paradigms that have surfaced since the early 1990s are emancipatory, participatory and transformative (Sullivan 2009, Watson 2012). One of the earliest contact with social research in the UK was instigated by Le Court Cheshire Home residents (Barnes and Mercer 1997) in the late 1960s. These residents with a disability sought expert help in their struggle against a management regime for more autonomy over their daily lives which led to Miller and Gwynne conducting a three-year study (Watson 2012). The residents took extreme exception to being alienated from the research process, the rejection of their complaints and the study’s meagre recommendation of rearranging institutional practices. Discontentment with Miller and Gwynne’s research process and findings as ‘unbiased social scientists’ created a denouncement of academic social scientists; and some of these residents went on to set up the Union of the Physically Impaired

Against Segregation (UPIAS) in 1975 (Finkelstein 2001) Interest in how disability research ought to be conducted took shape in the late 1980s. In the late 1980s to early 1990s, the Joseph Rowntree Foundation funded a series of seminars which resulted in a gathering of interested groups and individuals at an inaugural national conference, and a special issue of the Disability, Handicap and Society Journal (later renamed Disability and Society) in 1992. One of the major contributions came from Mike Oliver who posited that disability research should focus on “critical enquiry, praxis or emancipatory research” (Oliver 1992). This focus paralleled the surge of literature that explored the potentiality of using critical social research from groups (e.g. feminists, educationalists and black writers) concerned with oppression, pedagogy, exploitation and notions of power and discourse (Barnes and Mercer 1997). Oliver (1992, 1997, 2002) is emphatic that the emancipatory research enterprise is a potentially useful paradigm for doing disability research.

### **Emancipatory research paradigm**

The development of such a paradigm stems from the gradual rejection of the positivist view of social research as the pursuit of absolute knowledge gained through the scientific method and the gradual disillusionment with the interpretative view of such research as the generation of socially useful knowledge within particular historical and social contexts. The emancipatory paradigm, as the name implies, is about the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs (Oliver 1992).

Oliver (1992) highlights two key ideas: the shortcomings of doing disability research using the positivist and interpretivist paradigm, and the political commitment to address the oppression that people with a disability encounter at all levels of life. He proposes that the emancipatory research paradigm can address these shortcomings by “redefining the problem of disability, challenging the ideology and methodology of dominant research paradigms” and “development of a methodology and set of techniques commensurate with the emancipatory research paradigm” (Oliver 1997). However Barnes and Mercer (1997) note that this paradigm is not aligned to any particular research method or technique. Similarly, Mercer (2002, Mercer 2004)

points out the shortage of methodological perspectives in the emancipatory research literature. Oliver (1992, Oliver 1997, Oliver 2002) argues for a change in the social relations of research production which means that researchers ought to put themselves in the service of those being researched and to relinquish or share control over the design, research procedures, analysis and distribution of results. Oliver identifies the unequal power dynamics of the researcher-participant relationship in favour of a more equitable and empowering arrangement. For him, research can facilitate and contribute to empowering people, and advances three fundamental precepts of the emancipatory research paradigm: reciprocity, gain and empowerment. The essence of emancipatory disability research is empowering disabled people through the transformation of social and material relations of research production (Barnes 2006).

The main criticism disability theorists have with ‘mainstream’ social science research is the rejection of disability as a form of oppression and disability (Mercer, 2002, 2004). For Oliver, emancipatory research must be located in the social model of disability (see Chapter 2). It rejects the medical model that a person’s impairment is the root cause of disabled people’s problems and shifts the focus to disabling environments, barriers and cultures (Oliver 2004). Stone and Priestly (1996) identify six core principles that characterise emancipatory research paradigm:

- (1) The adoption of a social model of disability as the ontological and epistemological basis for research production;
- (2) The surrender of falsely-premised claims to objectivity through covert political commitment to the struggles of disabled people for self-emancipation;
- (3) The willingness only to undertake research where it will be of some practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers;
- (4) The devolution of control over research production to ensure full accountability to disabled people and their organizations;
- (5) The ability to give voice to the personal whilst endeavouring to collectivise the commonality of disabling experiences and barriers; and

(6) The willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people .

These principles illuminate four aspects of the research enterprise, namely the usefulness of the study to its participants and community, accountability to participants, role of the researcher and choice of a suitable research paradigm. Stone and Priestly (1996) iterates the social model as the ontological and epistemological basis, and Sullivan (2009) echoes this as the basis for ethical disability research. In other words, the portrayal of reality and construction of knowledge is a mutually constitutive process involving researcher and participants coupled with the intent to change disabling policies and social structures. One of the criticisms of the social model is the absence of incorporating the role of experience (e.g. peoples' narrative and experiences) in the framework of emancipatory disability research (Barnes 2006). Paul Hunt pointed out that past reports have either been sentimental stories or tend to focus on medical and practical details of the affliction (Boys 2017). Barnes advises that any discussions of peoples' experiences or narratives are firmly situated within the cultural and environmental context and identifies disabling consequences of society. Watson (2012) asserts that despite criticisms over the emancipatory research paradigm it holds sway in disability research, and in recent times researchers have argued that this paradigm is still needed. Emancipatory research should be enabling, self-critical, reflexive, rigorous, and politically committed (Barnes & Mercer, 1997).

### **Participatory research paradigm**

Participatory action research focuses on generating knowledge for action (MacDonald 2012) It involves a collaborative approach between the researcher and participants (or research team and community) in an attempt to produce knowledge that translates into actions that will improve a situation or address an important issue. Baum, MacDougall and Smith (2006) identify the distinctiveness of this paradigm in three ways. First, the focus and purpose of the research is to

enable action. This can take the form of encouraging participants to be part of the data collection, analysis and dissemination of results. Second, attention is put on to power relationships and the intent is to share power. This can take the form of researchers acknowledging that participants are partners in every aspect of the research design, research process and setting the research agenda. Third, is the advocacy of research participants as active and equal partners. This can take the form of training participants on research methods, interviewing skills and report writing; and fostering their ability to critique methods and strategies that will not work in their communities. In disability research, the debate has centred on the social and material relations of research production. Over two decades ago Zarb (1992) also argued for a change in both the social relations of research production and material relations of research production (or control over resources to do research). He contended that until changes were made in these two arenas, the only research paradigm possible was participatory research. Although he acknowledges that material relations of research production are beyond the control of both researchers and the researched, he concludes that social relations of research production can be changed through participatory research. Zarb (1992) further argues that participatory research is all there is unless one wishes to return to positivist and interpretive approaches. Oliver criticises positivist and interpretivist approaches that have relegated disabled persons as inferior subjects and alienated them from themselves and from the research process (Sullivan, 2009). Oliver (1997) finds participatory research problematic. His main issue is that participatory and action approaches tend to reinforce existing power structures rather than challenging, confronting or changing them. Hence the relationship between social and material relations of research production remains untouched and unchallenged. Oliver's use of the game metaphor is particularly poignant here. Participatory and action approaches do not seek to change or critique the game but will entice people to take part, as they are, in the game. For him, emancipatory strategies are geared towards conceiving

and creating a different game, one that does not exclude people. In contrast, French and Swain (2004) who weighed into the debate maintain that researchers who adopt participatory action research are attempting to alter power relations and aim to ensure that research is owned and controlled by both researchers and participants. They highlight the role of non-disabled researchers, in developing qualitative methodology in participatory approaches, who desired to dismantle the traditional hierarchical researcher/researched relationship. French and Swain (2004) conclude that participatory research and emancipatory research are two distinct research paradigms and are not necessarily incompatible. Some researchers within disability studies are still critical of participatory research that reinforces the researcher/researched divide and does not confront oppressive structures and practices (Watson, 2012).

### **Transformative research paradigm**

The transformative research paradigm promotes ethical disability research (Sullivan, 2009). This paradigm is “a framework of belief systems that directly engages members of culturally diverse groups with a focus on increased social justice” (Mertens 2010). It emerged in the 1980s and 1990s in response to dissatisfaction with dominant research paradigms and that constructivism/interpretivism did not address issues of social justice and marginalised groups (Mackenzie & Knipe, 2006). The four basic belief systems that underpin this paradigm are axiology, ontology, epistemology and methodology and each have philosophical assumptions associated with each belief system. (Mertens, Holmes et al. 2009). They assert that the axiological belief system is very important because it drives how the other three belief systems are formulated. Its fundamental principles are to enhance social justice, further human rights and respect cultural norms (Mertens 2010). Sullivan (2009) undertakes a comparative analysis of the merits of the emancipatory research paradigm and the transformative research paradigm. Although both paradigms seek the emancipation of their research subjects, he identifies four elements that distinguish transformative research paradigm. First, it recognises markers of

identity (e.g. gender, ethnicity, class and age) and how these intersect with disability to highlight disadvantage. Second, that research participants are not necessarily in the state of readiness to assume leadership of their disability struggles nor the research project. Third, it consists of a systematic approach to conducting research and the use of mixed methods for data collection (i.e. qualitative and quantitative methods) to accommodate cultural and diverse needs. Fourth, it emphasises social justice for minority groups and collaborative partnerships to challenge structures of power with the desired outcome of transforming lives. Given the merits of the transformative research paradigm and the attraction it holds particularly in undertaking this study with Samoans with a disability, I contemplate Sullivan's adage. His adage is to learn from the debate amongst disability scholars to think carefully about what constitutes ethical disability research. That is, to consider how research participants (or subjects) are positioned within my study and to operate in a manner that enhances a shared humanity (Sullivan, 2009). As a Samoan, this is really important to me as I consider my own research and the scholarship of indigenous Pacific peoples.

### **Pacific research paradigm**

Indigenous scholars have, during and since the 'Decade of World's Indigenous Peoples' (1994-2004), challenged Western epistemologies and methodologies in favour of "a methodology of the heart, feminist postpragmatism that embraces an ethics of truth grounded in love, hope, care and forgiveness" (Denzin, Lincoln et al. 2008). Pacific scholars, academics and researchers embraced this challenge and pursued the development and implementation of Pacific-based, Pacific-oriented or ethnic-specific theoretical frameworks within the context of the academy, institutional bodies, and research endeavours. For instance, Fa'aSamoa methodologies (Tupuola 1993), Fa'afaletui (Tamasese, Waldegrave et al. 1997, Perese and Faleafa 2000, Tamasese, Peteru et al. 2005), O auala i le fa'aSamoa or Samoan pathways (Filipo 2004), Teu le va (Anae 2010), Talanoa research methodology (Vaiotei 2006), Uputāua therapeutic

approach (Seiuli 2016), *Pasifika education research guidelines* (Anae, Coxon et al. 2001) and revised *Pacific health research guidelines* (Health Research Council of New Zealand 2014). It would be extremely rude and arrogant of me to disregard the existence of these methodologies and frameworks and not consider their principles and concepts in my approach to this study with Samoans with a disability in Auckland. Taufe'ulungaki (2003) states that "Research in the Pacific must be aimed at transforming Pacific societies, but in accordance with Pacific values and aspirations" . She reminds me of my obligations as a Samoan in the research enterprise. That is to confer my energies, commitment and drive on the Pacific horizons of transparency of research practice, transmission of knowledge and transformation (or critique) of ideologies in the interests of promoting social justice whilst maintaining personal integrity as a Samoan. Sanga (2016) reports that the types of education research undertaken by Pacific students, scholars and researchers in the region between 2004-2014 focused on advocacy research, developmental research and transformational research.

I drew primarily on the work of two Pacific scholars: Kabini Sanga, a Solomon Islands educationalist, and 'Okusitino Mahina, a Tongan anthropologist/historian; for two reasons. First, their comments around theory and methodology resonated with me because of my growing interest in the utility of theory and theorising in Pacific research. Second, to grow in knowledge related to the philosophical assumptions undergirding indigenous Pacific research which I had wondered about for some time. Mahina (2004) laments the obfuscation of theory in research. He notes the unfortunate growing hostility that Pacific students and academics have towards theory and put this aside in favour of practice. His argument is couched in the wider discourse of Oceanic cultural democracy in knowledge production, critical thinking and the intellectual capacity of Pacific peoples to theorise problems in new ways and devise potential solutions. Mahina's staunch support of the role of theory in Pacific research is encapsulated in his work on *tā* and *vā*. As a critical anthropologist, he offers a sketch of a new social theory by



using the Tongan concepts of *tā* (time) and *vā* (space). He argues for a theory which critically considers, and integrates, time and space and its plausible application in ontological and epistemological ways (Mahina, 2004). In other words, *tā* and *vā* are indigenous prisms of what constitutes reality or being in the world and the construction of knowledge or ways of knowing. His Pacific oriented *tā -vā (time-space)* theory, which he developed to make sense of the world from an indigenous Pacific worldview, has been applied and extended in the Pacific and beyond (Tofuaipangai and Camilleri 2016, Koya-Vaka'uta 2017) Sanga (2004) explores philosophical ideas and assumptions in indigenous Pacific research.

Sanga's (2004) point of departure is premised on the notion that indigenous Pacific research is based on a philosophy of human nature with key assumptions underpinning this. His concern is twofold. First that "indigenous Pacific research needs to be more of itself, first ... to know more of what it really is and what it is not". Other scholars have raised the issue of using Samoan, Tongan and Fijian terms and metaphors to describe and justify their work as Pacific researchers (Suaalii-Sauni and Fulu-Aiolupotea 2014, Sanga and Reynolds 2017). Second that the academic legitimisation of indigenous Pacific research lies in conceptualising and developing its own set of philosophical orientations. Scholars have raised the perils of cluttering indigenous knowledge systems with ideas which are neither meaningful nor appreciative of what indigenous Pacific people value; and protracted use of creativity and individuality over scholarship and relationality when theorising indigenous Pacific research (Efi 2005, Sanga and Reynolds 2017). I return to Sanga's examination of key philosophical assumptions underpinning indigenous Pacific research. He identifies peoples from the Pacific as diverse and heterogeneous and have their own worlds that they influence, control, adjust and adapt to (Sanga, 2004). The set of presuppositions of indigenous Pacific research involve "the ideas of time, space, the self, self-image and attitudes towards others" and "peoples see time as integral to relationships" and "peoples see their ancestors as members of their worlds and masters of

their environments” (Sanga, 2004, p. 43). Some of these ideas echo Mahina’s ideas discussed above. These ideas conjure images of a cosmos – a world of systems, order, pattern and relationalism. Sanga, using Burrell and Morgan’s (1992) sociological approach that social science theories are based on philosophical assumptions of the social world and how the social world is investigated, offers an indigenous Pacific research perspective relating to ontology, epistemology, axiology and methodology. He describes these in the following ways. First, reality as subjective to context and people, particular to time and space and experienced in the locale. Second, the grounds of knowledge or understanding this social reality is relativist and inseparable from context and explanations are framed using metaphors and constructs particular to its own source of knowledge-making. Third, the social world and research of that world is value-bound: influenced by the researcher, participants, conceptual framework and situated in historical, spatial and social contexts. Finally, the purpose of methodology, methods and strategies is to garner rich contextual details, capture insider perspectives or the ‘voice’ and multiple realities. Sanga’s insightful delineation of Pacific research paradigms and Mahina’s *tā -vā (time-space)* theory provides a culinary of appetisers to stimulate the heart and mind, and make potential theoretical contributions, when considering research with one’s community. The question then is which paradigm to use?

### **Who should do disability research?**

To address the question “Who should do disability research? I consider the issue of awkwardness as a person without a disability undertaking this study. One of the concerns in disability research has been the commissioning of persons without a disability to conduct disability research. The criticism is that they lack understanding of the discrimination and oppression persons with a disability experience in their daily lives (Oliver 1996, Garbutt, Tattersall et al. 2010, Puyalto, Pallisera et al. 2016). Two relevant questions arise: Can a person without a disability connect and collaborate with participants in a non-hierarchical manner?

And are they prepared to share power and control over the design and execution of the research? These questions are poignant of disgruntled persons with a disability who felt marginalised and betrayed by mainstream researchers (Barnes and Mercer 1997) that sidelined their input and participation. Several points of contention have been raised and fiercely debated, such as, the researcher's accountability, chosen methodology, political commitment to the disability movement and associated groups, empowerment and autonomy of participants, researcher's personal reflexivity, forming research alliances and funding context (Morris 1992, Bury 1996, Shakespeare 1996, Barnes and Mercer 1997, Oliver 1997, Humphrey 2000, Sullivan 2009). As to be expected, there is no consensus amongst academics on whether the researcher should have direct experience of disability (Barnes 2013). These points are, however, duly noted and carefully considered, and actually run parallel to issues of non-Pacific researchers running Pacific research projects, in doing this disability research. I adopt a pragmatic view by leaning into the awkwardness. William Pua (personal communication, August 25, 2014), a social worker, educator and wise friend, recounted his experiences of working with disadvantaged and vulnerable groups and feeling ill-equipped to meet their needs. Rather than following the conventions of his professional knowledge he engaged heart, mind and depth of spirit to explore another space of beingness. He used this term of 'leaning into the awkwardness' as a socio-relational process of being and becoming more of who you are. I lean into the awkwardness.

### **A case for interpretivist paradigm and Bourdieu's theoretical concepts**

I once asked a learned friend Lita Foliaki (personal communication, October 10, 2007) whether I should use a Pacific or Western paradigm in my PhD. She basically said to go eclectic and draw on the strengths of both. I expected her to say 'Pacific' and took some time to reflect on her response. Another peer simply suggested to choose the most suitable paradigm and learn as much as I can about it, including the strengths and weaknesses, and utilise this. Considering the range of paradigms on offer mentioned above in disability research and amongst my Pacific

peers, this was a difficult decision to make. On the one hand, I would like to make a theoretical contribution to the scholarship of Pacific research, conceptualise its philosophical assumptions based on a Pacific research paradigm which Sanga (2004) advocates; and develop a Pacific oriented theory to make sense of our own world view similar to Mahina (2004). On the other hand, I am curious about the works of Western theorists and whether any of it can be plausibly drawn on or adapted to explain or elucidate a phenomenon in a non-Western group. I drew inspiration from my supervisor who discussed the possibilities and benefits of using Pierre Bourdieu's (Bourdieu 1990) concepts for my study. When I was an undergraduate student many years ago Pierre Bourdieu and Paulo Freire were the only theorists I remembered well into my adulthood. Somehow Bourdieu and Freire resonated with me. It is very apt and meaningful that I explore and utilise Bourdieu's thinking tools in this present study. Watson (2012) raises a significant point about the danger of overlooking the structure-agency dichotomy in disability research. In his view, studies on persons with a disability tend towards structure and omit the possibility that agency affects and influences structures. This view resonates with me also because the effects of the role of agency is sometimes obscured or undervalued in the macro scheme of overcoming disablement. Disablement refers to the social and economic processes that create both impairment and disability (Oliver and Barnes 2012). Bourdieu's relational thinking tools provide the analytic equipment to examine the structure-agency relationship of Samoans with a disability seeking quality of life. Selecting the interpretivist paradigm was a conscious decision based on the aim of acquiring subjective meanings of social action and infers the tradition of phenomenology (Bryman, 2004). I concur with Babbie's (2008) advice to choose the paradigm most useful. It can be argued that interpretivism falls short of any political commitment to challenge oppressive and hegemonic policies and structures. However, this can be countered by acknowledging that the researcher, regardless of using a single paradigm, can

adopt a flexible and nuanced approach to influencing tangible changes in policies and societal structures.

### **Issues of validity, credibility and trustworthiness**

Selecting a particular paradigm carries the connotations of which set of methodologies to choose from and utilise, and what is the criteria to assess validity, credibility and trustworthiness of the findings and overall study. Phenomenology, ethnography, grounded theory and narrative inquiry are examples of methodologies aligned to the interpretivist paradigm (Kivunja and Kuyini 2017). This study uses phenomenology because it focuses on the lived experience or lifeworld as one experiences it directly, and to gain a deep understanding on the meanings or nature of such experiences (van Manen 2014) In other words, this study focuses on a particular aspect of human experience (Finlay 2014) or quality of life, which is akin to asking the question: what is it like to experience a particular phenomenon? (Giorgi 2005). The specific use of Hermeneutic phenomenology in conjunction with the Voice-centred Relational Methodology is described in detail in Chapter Five. In terms of criteria to validate research employing the interpretivist paradigm, there are five criteria to establish rigour and trustworthiness. These are credibility, dependability, confirmability, transferability and authenticity Lincoln and Guba (1985). These are proposed as alternatives to the terminology of internal validity/validation, external validity/validation, objectivity and reliability commonly used in the positivist paradigm. Kivunja and Kuyini (2017) assert that despite initial challenges to Guba's criteria many scholars and researchers accept this criteria. Though beneficial for one's understanding of the rhetoric regarding criteria in positivist and interpretivist paradigms, I draw on Creswell's (2013) framework of validation strategies to choose which of these I can apply to ensure quality and rigour. He recommends selecting at least two from the eight strategies provided and I applied three strategies which were - rich thick description and clarifying researcher bias to ensure quality and rigour. Member check is explained in Chapter Five and rich thick description

is provided in Chapter Six. Clarifying researcher bias is discussed under the auspices of researcher reflexivity in Chapters Five and Seven.

## **Chapter summary**

This chapter provides an overview of social research and qualitative and quantitative research approaches. The philosophical assumptions underpinning different paradigms serve to articulate what and how these are to be considered in undertaking research. These also clarify in one's own mind the importance of selecting a suitable paradigm in view of the aim, purpose and intent of the research endeavour. It also hones into the idea that the researcher's outlook, research experience and personal attributes are predisposing factors in selecting the best research approach. By explicating the positivist, interpretivist, emancipatory, participatory, transformative and Pacific research paradigms, I come to a place of realisation. This realisation is of current (and ongoing) debates but more significantly an increase in my confidence to choose interpretivism and provide a strong rationale for this. I lean into the awkwardness of doing this study despite not having a disability. To ensure quality and rigour of the findings and study, I utilised member check, rich thick description and clarifying researcher bias (or reflexivity).

## **Chapter 5 Methodology**

### **Introduction**

The choice of a research methodology is based on the purpose of the research and research questions (Denzin and Lincoln 2018). The methodological choice is also derived from the researcher's assumptions about the nature of reality, attainment of knowledge and value system (Crotty 1998, Creswell 2009, Mertens 2010). Mertens asserts that the "exact nature of the definition of research is influenced by the researcher's theoretical framework" (2005, p. 2). This study sought to understand how Samoans with a disability experience quality of life. This chapter explains the methodology, methods, design, approaches to data collection and data analysis, and ethical considerations. It includes how the researcher attended to issues of validity, credibility and trustworthiness and argues why and how this study is situated within a phenomenological qualitative paradigm informed by Pierre Bourdieu's theoretical concepts.

### **The theoretical frame informing the methodology**

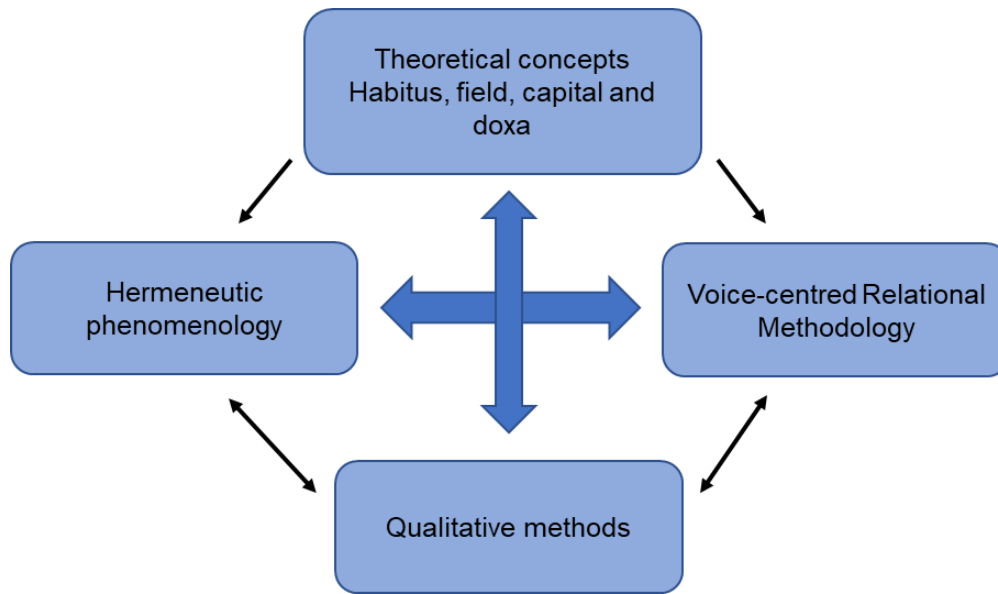
This study is informed by Pierre Bourdieu's theoretical concepts (see Chapter Three) habitus, field, capital and doxa. These interrelated concepts are positioned to inquire about the structure-agency continuum by foregrounding the notion that the actions, motivations and beliefs of individuals about disability are influenced by social and cultural forces (McKenzie 2014). The usefulness of Bourdieu's theory for framing the methodology of research on disability studies is the use of relational analysis. In terms of relationalism, the problem of disability can only be well-understood in context, as a part of a social structure and practices (Wacquant 1989, McKeever and Miller 2004). Thus, the meaningfulness of disability is determined not by the characteristic properties, attributes, or essences of the disability itself but rather with reference to the field in which the disability exists, practices, ideologies or activities within which they are embedded. Many researchers have used the concepts of habitus, field, doxa and capital to explore disability issues (Edwards and Imrie 2003, McKeever and Miller 2004, Bjornsdottir

2010, Blackmore and Hodgkins 2012, Purdue and Howe 2012, Supple and Agbenyega 2015). In this study the application of the concept of habitus served as a lens to unpack how Samoans with a disability conceptualise quality of life. In addition, types and ownership of capital, participatory levels across social domains and self-identity with reference to quality of life in Auckland have been explored through the interactive concepts of doxa, habitus, capital and field.

Given the theoretical orientation identified above, the researcher selected Hermeneutic phenomenology (Laverty 2003) and Voice-centred Relational Methodology (VCRM) (Cunningham and Cunningham 2013) as the most appropriate methodology to explore the quality of life of Samoans with a disability. This combination facilitates the capture of how people conceptualise, experience and interpret a phenomenon and foregrounds the person's embodied voice as they narrate their story. The following diagram (see Figure 5.1) shows Bourdieu's theoretical frame as the overarching umbrella which informs the selection of both hermeneutic phenomenology and VCRM. The link between hermeneutic phenomenology and VCRM is bi-directional because they synergise to shape and guide how this research was undertaken. This, in turn, informs the use of qualitative methods. All parts of the diagram relate to one another and show the interconnectedness of the theoretical frame, hermeneutic phenomenology, VCRM and the qualitative methods. These will be discussed further in this chapter.



Figure 5. 1 Diagram of the study's methodology



### Phenomenology as a methodology

Phenomenology emerged as a significant philosophical movement in the 20<sup>th</sup> century focused on human existence, the nature of being in and of itself, and the role of human consciousness and subjectivity (Giorgi 2005). Edmund Husserl, founder of phenomenology, contends that the human experience is implicit within the structures of consciousness and that the depiction of knowledge about reality/realities could be identified and described (Lavery 2003). Husserl's philosophy marked a radical departure from the positivist orientation of knowing and argued for a return "to the things themselves" which meant the characteristics, content and intentionality of human consciousness (Morris 2012). He asserts that "pure phenomenology draws upon pure reflection exclusively, and pure reflection excludes, as such, every type of external experience and therefore precludes any copositing of objects alien to consciousness" (Husserl 1917). In other words, phenomenology is the domain of how the structure and structuring activities of human experience appears or is presented in consciousness (Polkinghorne 1989, Giorgi 2005).

One of the key tenets of phenomenological inquiry is the notion that experiences in and of the world ought to be examined *per se* and in real time (Baronov 2012). Bourdieu argued human experience contributes to the formation of the habitus and capital within social fields (Maton 2008). For example, socio-cultural experiences contribute to the accumulation of cultural and social capital (Allen 2004, Agbenyega and Klibthong 2015). In this way, phenomenology can be said to have links with Bourdieu's concepts. The emergence of phenomenology served to redirect the focus on how human phenomenon is experienced and understood and that this was not possible when using the positivist paradigm (Mcphail 1995). Simmons and Benson (2013) reiterate this:

Phenomenology is the attempt to make sense - by way of description and analysis - of experiences as they are actually experienced. In this way, phenomenology (as much as possible) tries to offer a first-person account of experience. Instead of the third-person accounts offered by positive sciences that depend on data that is often understood as "objective," "neutral," and "repeatable," phenomenology is informed by the evidence of one's own experience (p. 33).

Although phenomenology can be perceived as anti-positivist or anti-empiricist, it complements the purview of Western scientific methods and discourse particularly in psychology, nursing and education (van Manen 1984, Polkinghorne 1989, Mcphail 1995, Giorgi 2005).

There are a number of philosophical ideas undergirding phenomenology. These ideas are indicative of key moments in the development and evolution of phenomenology. These key moments are: (1) realistic phenomenology, based on Franz Bretano's descriptive psychology and Husserl's early works, is premised on the idea of intentionality and consciousness in the structure of human experience; (2) transcendental phenomenology or descriptive phenomenology, based on Husserl's later works, is premised on the primacy of human intuition in knowledge-making and the essence of the lived experience; and (3) hermeneutic phenomenology or interpretive phenomenology, forged by Husserl's protégé Martin Heidegger,

is premised on the role of context in the lived experience (Moran 2000). Such ideas signify the different emphasis on how a phenomenological approach can be considered and undertaken. The main difference lies in what and how the human lived experience should be described, explained and interpreted. Therefore, it is important to distinguish transcendental and hermeneutic because it contextualises why hermeneutic phenomenology is applicable to this research.

## **Transcendental phenomenology**

Husserl's development of transcendental phenomenology stems from a strong interest in establishing and clarifying a scientific approach to the human sciences (Dowling 2007). More specifically, the formation and constitution of knowledge based on what and how something is experienced and the simultaneous presence of mind which brings an awareness or disclosure of these (Thompson and Zahavi 2007) into reality. In other words, the structure of consciousness is brought to bear on the constitution of knowledge. Although Husserl's brand of phenomenology focused on describing the essence in the structures of human experience, Martin Heidegger's hermeneutic phenomenology steered towards the experience of being human (Polkinghorne 1989) and stressed the critical role of interpretation in the human process of understanding something (Lavery 2003). Husserl's epistemological goal led him to devise the phenomenological reduction. This concept of "bracketing" or "epoche" means the suspension of presuppositions and preconceptions in order to describe and understand the primeval form of the phenomenon (Dowling 2007). For the researcher, the aim is to put aside one's assumptions and value judgements of the phenomenon and the person's narrative, and to explore and describe the person's experience as it is given in a non-prejudicial way. Giorgi (2007) identifies three key steps in Husserl's method of transcendental phenomenology: adoption of the transcendental phenomenological attitude, imaginative variation to intuit essence and description of the essence. The attitude refers to epoche and transcending the

‘natural attitude’ to reach pure consciousness. The imaginative variation to intuit essence is a creative process of determining the characteristics and aspects of a phenomenon to see what the essential features are, its essence (van Manen 2014). By naming the essence, the core meaning underlying shared lived experiences, the phenomenon is exposed (van Manen 2014). A careful description of the essence, how the particular experience is constructed, ensues (Daher, Carre et al. 2017). It is the attentive and rich description rather than its interpretation that distinguishes transcendental phenomenology from hermeneutic phenomenology (Horrigan-Kelly, Millar et al. 2016).

### **Hermeneutic phenomenology**

Heidegger’s ontological proclivities and recasting of Husserl’s ideas led to the subsequent development of hermeneutic phenomenology. Though both were concerned with the life world or lived experience, this study was framed using hermeneutic phenomenology. Heidegger pursued the question of ‘being’ and focused on *Dasein* which is translated as “the mode of being” or “the situated meaning of a human in the world” (Lavery 2003) in exploring the nature of lived experience. In other words, the state of being-in-the-world consists of a dynamic interplay between individual consciousness and encounters of and in the everyday world. Moreover, Heidegger claimed that nothing can be encountered without reference to a person’s background and their understanding of it, and how this influences their interpretation of the encounter (Lavery 2003). For him, the method of hermeneutic phenomenology serves to articulate and clarify the phenomenon of being (Giorgi 2007) which involves seeking the meaning of that phenomenon (van Manen 1990). For the researcher, phenomenological reduction is not possible because being-in-the-world implicates the researcher in relation to the participant’s being-in-the-world and Heidegger posits that:

Knowing is a mode of Da-sein which is founded in being-in-the-world. Thus, being-in-the-world, as a fundamental constitution, requires a *prior* interpretation (1996).

Hence hermeneutic phenomenology, following the motions of the hermeneutic circle, moves past description and embraces the critical role of interpretation in the human process of understanding something (Lavery 2003).

Hans-Georg Gadamer extended the purview of the hermeneutic interpretation process. Similar to Husserl's proposition that interpretation and understanding (*verstehen*) represent two sides of the same coin in the enterprise of being human and making sense of the world, Gadamer sought to clarify the conditions under which understanding occurs (Baronov 2012). His 'fusion of horizons' illuminates the role of historicity in the quest of understanding the self, others and the world (Holroyd 2007). In other words, one enters the mode of reflective thoughts and considers the impact of the intersection of personal biography and history on how a phenomenon is perceived, defined and experienced. Gadamer argued that it was necessary and important to identify one's preconceptions and prejudices because these would facilitate a more open and honest dialogue of how the process of understanding is reached (Lavery 2003, Dowling 2007). For him, understanding and interpretation are inter-related and that interpretation is an evolving process (Lavery 2003). To put in another way, there is no singular interpretation on any phenomenon as new knowledge emerges over time; and the hermeneutic circle requires a series of actions in constructing and producing knowledge. In addition, Gadamer asserted the role of language as a "universal medium of understanding" and that "it is through the framework of language that we experience the world and share our understanding" (Baronov 2012). It is through the use of language that shapes how one makes sense of their world and communicates this to others. For him, language is a pre-condition of understanding and that the world cannot be made known independent of language (Baronov 2012). For the researcher, there are three implications. First, this means confronting and taking stock of one's personal subjectivity and biases and how these can influence the interpretation of a participant's narrative. Second, that entering the participant's world is a dialogue of horizons and that

deciphering the meanings behind human action holds the potential to enhance and renew one's horizons. Third, that the participant's preferential expression of their world in a foreign language means that knowledge of that language as well as understanding its cultural nuances is needed (Tamasese, Peteru et al. 2005).

Therefore, this research uses hermeneutic phenomenology for the following four reasons. First, it is focused on understanding and interpreting the quality of life experiences of Samoans with a disability and takes into consideration the historical, social and cultural context that shape these experiences. Second, the importance of disclosing my personal subjectivity and biases and the bearing this has in how I interpret disability and quality of life experiences for this group. Related to this is the gaining of new thoughts and ideas to advance and renew my horizon or knowledge base of disability and quality of life. Third, that the construction and production of knowledge from this study is a snapshot of this group's experiences and ought to be viewed as one interpretation, within the temporal-spatial continuum, to further our understanding of their quality of life. Fourth, that language is a vehicle for communicative exchange of their worldviews and personal stories and that my fluency in Samoan and English as well as awareness of the cultural nuances and idiosyncracies is a precondition to understanding and interpreting participants' lived experiences of disability and quality of life. Although this study draws from hermeneutic phenomenology, it is also informed by the Voice-centred Relational Methodology and Bourdieu's relational thinking tools: habitus, capital, field and doxa.

### **Situating Hermeneutic phenomenology and the Voice-centred Relational methodology**

Voice is important to Bourdieu, because through the voices of participants researchers can enter into the reasons behind their habitus and social practices (Agbenyega and Klibthong 2015, Supple and Agbenyega 2015). Voice also acts as agency, which has been discussed in several

of Bourdieu's works (Bourdieu 1984, Bourdieu 2000). This positions the Voice-centred Relational Methodology strongly in this research. The Voice-centred Relational Methodology (VCRM) emerged in the psychology literature in the 1990s focused on the relational approach between the professional and client, and researcher and participant (Brown and Gilligan 1991, 1993). Brown and Gilligan proposed an alternative way of approaching qualitative methodology based on their concern that the voices of women had not been adequately heard or represented in studies (Petrovic et al., 2015). They draw attention to and emphasise the notion of 'voice.' By identifying the 'voice' they introduce the range of complexities that underpin how something is talked about and conveyed to the recipient. In other words, there is a context to the experience; and a person may experience contradictory ways of viewing and understanding an experience or situation, and how they speak or do not speak of it, in relation to themselves and relationships (Bright, Kayes et al. 2018). VCRM is instrumental as a relational approach that is 'responsive to the participant's voice, attuned to the body, the particularities of relationships and to societal and cultural contexts' (Brown and Gilligan 1991). It is recognised that knowledge forms are multilayered and contextual (Mauthner and Doucet 2003) and represent multiple constructions of reality (Berger and Luckmann 1966). For example, the discourse about disability and how different people experience it is contextual and multilayered. This is premised on the presupposition that the epistemological and ontological precepts of VCRM is closely intertwined (Bright, Kayes et al. 2018). In other words, the notion of actively listening to an embodied voice is situated in relationships, temporal spaces and contextual boundaries which is compatible with hermeneutic phenomenology – the enterprise of understanding and interpreting participant's experiences and the social construction and production of knowledge with reference to disability. Brown and Gilligan (1991, 1993) developed the Listening Guide as a heuristic tool in undertaking VCRM.

One of the key strengths of the Listening Guide is the relational act of interpretation. Although it is a given that there is a relational approach in meeting and engaging participants in the research setting, the Listening Guide attends to the particulars of the participant's experiences by focusing on the aspects of relating (or not) to the phenomenon. As Bright et al. (2018) put it, there is a "reading for relationship in the data and prioritizing relational issues within the analysis" (p. 3). In this research, the multiple readings of the participants' narrative attend to the following: their story, how they speak of themselves in relation to their disability, their experiences of the disability and the range of relationships surrounding and mitigating their disability, and the contextual factors that define, impede or facilitate their experience of quality of life (Brown & Gilligan, 1991, 1993). Supple's (2013) study on international students with a disability was drawn on because she used VCRM, which enabled silenced voices to be made audible and visible, and illustrated the advantages of the Listening Guide. These advantages include the following: a set of questions is asked during each reading which allows for a fuller picture of their story, reading and listening to their audio helps to attune to the tenor and emphases of their voice, attends to the researcher's biases and preconceptions, and the researcher's role in the co-construction of knowledge. Similarly, Bright et al.'s (2018) study on how rehabilitation practitioners engaged people after experiencing a stroke was also drawn on. Not only does she iterate the advantages of the Listening Guide but emphasizes a principle-based approach to analysis. As a heuristic tool, this Listening Guide supported my cognitive process to understand and interpret participant's experiences while attending to my own biases and personal reactions to their narratives. Therefore, based on the strengths of VCRM and its synergies with Bourdieu's habitus and the 'voice', this research employs the VCRM.

### **Bourdieu's relational thinking tools as a companion to knowing**

Pierre Bourdieu's seminal works in the mid-20<sup>th</sup> century led to the introduction of his theoretical concepts habitus, capital, field and doxa. These concepts are also described as "relational



thinking tools” to denote the distinctiveness and interrelatedness of these concepts (see Chapter Three). Bourdieu emphasised a relational mode of thinking which conceives of phenomena as the realizations of generative principles that are relationally defined (Maton 2018). In other words, “the real is relational” (Bourdieu and Wacquant 1992). There are horizontal and vertical dimensions in what he considers as relational. To paraphrase, the relationship between habitus, capital, field and doxa offers a prism of conceptualising and analysing the dispositions and attributes one possesses to negotiate and renegotiate their subsequent practice in a given social space. For example, the habitus of Samoans and accumulated capital makes visible how Samoans with a disability conceptualise quality of life, and how their range of actions to realising this is determined by context-bound social and cultural structural forces (field) and ideologies (doxa). His conceptual tools illuminate and foreground the structure-agency continuum of how Samoans with a disability negotiate and renegotiate their position in the field of disability support services in relation to quality of life. Bourdieu’s “thinking tools” unifies the strategy of inquiry consistent with the Voice-centred Relational Methodology (VCRM) at the epistemological and ontological level. The key term that underscores Bourdieu’s tools and VCRM is relational. In other words, this study investigates the dialectical relationships embedded and experienced by Samoans with a disability seeking a quality of life in Aotearoa New Zealand. Therefore, this study is informed by Heidegger’s hermeneutic phenomenology, Gadamer’s notion of interpretation process, and the relational analytic and conceptual tools provided in the Voice-centred Relational Methodology and the Bourdieuan approach. The following diagram (see Figure 5.2) shows the interplay of Bourdieu, hermeneutic phenomenology and VCRM.

Figure 5. 2 Interplay of Bourdieu, hermeneutic phenomenology and VCRM



### **Situating this study within Hermeneutic phenomenology and VCRM**

From an interpretivist paradigm, this study was guided by the hermeneutic approach in phenomenological research. The goal of phenomenological research is to uncover the belief patterns people hold which provides meaning, guides their actions and conveys how these have been constructed in the act of living (Mcphail 1995). Phenomenology recognises that peoples' experiences are deeply rooted in their perceptions, perspectives and understandings of a particular situation, lived experience or life world, and that the essence of the phenomenon can be extrapolated and made visible (Giorgi 1994, van Manen 2007). In using hermeneutic phenomenology, the interpretation of the participant's narrative focuses on the historical meanings of experience and their developmental and cumulative effects at the individual and social levels (Lavery 2003). Conversely, the fusion of horizons means that the interpreter enters and re-enters a dialogue with the self on preconceived notions and biases, and the participant or Other in co-constructing and producing knowledge about the phenomenon. Hermeneutic phenomenology also emphasises the role of language (Schmidt 2016). It is through the use and

exercise of language that shapes and directs how one makes sense of their life world and communicates these lived experiences to others. This makes it possible to actively listen to the participant's voice, communicate and reach a level of understanding between the researcher and participant.

This study aimed to understand how Samoans with a disability experience quality of life and to uncover the patterns of their experiences in the social, historical and cultural context of Aotearoa New Zealand. In accordance with this aim, their experiences needed to be interpreted in terms of the situated meanings derived from the socio-historical and cultural contexts of their life world. The notion of quality of life differs from person to person, and low knowledge of what this constitutes for persons with a disability is particularly evident. Very few qualitative studies have been undertaken with people with a disability in relation to their lived experiences of quality of life (Ahlstrom and Karlsson 2000, Shikako-Thomas, Lach et al. 2009, McDougall, Baldwin et al. 2016). Hence there is a need to gain a rich understanding from persons with a disability about their perceptions and perspectives on what factors constitutes (or not) a quality of life. A hermeneutic qualitative research approach is inductive, concerned with the person's being-in-the-world, identifies the meaning making of their subjective experiences in the world and attends to the researcher-participant interaction in the generation of knowledge (Reiners 2012).

To further investigate the quality of life experiences of Auckland-based Samoans living with a disability, this study incorporated the Voice-centred Relational Methodology (VCRM). One of the attractive facets of VCRM is how instrumental it is in privileging a relational approach that is "responsive to the participant's voice, attuned to the body, the particularities of relationships and to societal and cultural context" (Brown and Gilligan 1991). Working with or undertaking research with a marginalised group requires a methodological approach that is congruent with their values and the consequential rules of engaging with the group, such as, the

importance of trustworthy relationships and proper status accorded to the person (Health Research Council of New Zealand 2014). VCRM afforded a pathway where participants shared their stories in ways that gave full expression to the range of emotions embodied in their individual quality of life experiences as persons with disabilities in the Aotearoa New Zealand context. In advancing the ‘centrality of the voice’ the participant’s world of feelings and thoughts is expressed in a language that merges their psyche with culture (Brown and Gilligan 1991, 1993). As the Listening Guide is an analytic tool that accompanies the VCRM, the understanding and interpretation of the participant’s quality of life considers the social, historical and cultural context and how these can influence or inhibit their quality of life in Aotearoa New Zealand. Bourdieu’s “thinking tools” unifies the strategy of inquiry consistent with VCRM by illuminating the structure-agency continuum and the theorising of the quality of life of Samoans with a disability.

The research problem and the nature of questions guide the selection of the methodology. Incorporating the Voice-centred Relational Methodology (VCRM) alongside hermeneutic phenomenology was considered appropriate because of the philosophical compatibilities and the possibilities afforded by the combination as both facilitate the understanding and interpretation of subjective experiences, (such as, how people conceptualise and experience a phenomenon) and foreground the participant’s embodied voice vis-à-vis relationships and social, historical and cultural contexts. This study utilised hermeneutic phenomenology and VCRM to answer the following questions:

1. How do adult Samoans with various disabilities conceptualise and describe quality of life?
2. What factors are reported by Samoans with disabilities that facilitate or inhibit their quality of life experiences?
3. How do Samoans with disabilities perceive their ethnic identity in Auckland?

## **Methods and design**

This qualitative study employed the case study design. The main proponents of case study, Robert Stake, Robert Yin and Sharan Merriam, developed three approaches to guide, define and design case study and although each have different methods all seek to ensure that the topic is explored well and that the essence of the phenomenon is uncovered (Baxter and Jack 2008, Yazan 2015). In contrast to Stake and Yin, Merriam's version of case study was selected for the present study for the following reasons: its epistemological commitment to constructivism rather than positivism, use of interviews as a data source, purposeful sampling strategy to identify and recruit participants, constructing a theoretical framework and the use of analytic induction and strategies to ensure research rigour (Yazan 2015). Merriam (1998) defines the qualitative case study as "an intensive, holistic description and analysis of a single instance, phenomenon, or social unit" and that the 'case' is "a thing, a single entity, a unit around which there are boundaries" (p. 27). The study is focused on describing and analysing what and how Samoans with a disability from Auckland experience quality of life. From an interpretivist worldview, the case study design is compatible because it concerned with knowledge generation and understanding the world one lives in (Creswell 2014). The notion of 'meaning making' and 'context' is attended to in case study. In other words, as human beings interact with one another and engage with/in the world they live in they are constructing meanings and interpretations of that world garnered in a socio-historical and cultural context (Baxter and Jack 2008). As Samoans with a disability make sense of their world and their experiences in the world, they construct meanings and knowledge from these which not only accentuates multiple versions of realities and responses to it but illuminates the peculiarities within a context. Thus, Merriam's version of case study was applied to this research.

The qualitative data gathering methods used in this research was in-depth interviews with adult Samoans with a disability, their partner and support worker.

## **Individual interviews and developing the semi-structured questions**

The interview is a qualitative method of inquiry. Interviews are useful and relevant in eliciting in-depth information about the participant's views and experiences on a subject (Creswell 2009). As Seidman (2006) put it, “at the root of in-depth interviewing is an interest in understanding the lived experience of other people and the meaning they make of that experience” (p. 9). The interview was used to expedite an in-depth conversation about the participants’ personal experiences of disability and quality of life. The individual interviews contained two elements: the interview protocol and semi-structured interview schedule (see Appendix G-H). The semi-structured interview is an extended conversation between the researcher and participant about a topic and the researcher prepares a limited number of questions and plans to ask follow-up questions during the actual interview (Rubin and Rubin 2011). The interview schedule listed key areas to be covered in the interview, such as, the participants’ perceptions of acquiring a disability, experiences of living with a disability and its impact on them and their families, the types of help sought, being Samoan with a disability, definitions and concepts of disability and quality of life from a Samoan perspective. Also included were the factors that facilitate and inhibit quality of life, and the participants’ perceptions of their ethnic identity in Auckland.

The use of key areas rather than set questions was drawn from adopting the Life Story Model (Olson and Shopes 1991, Anae 1998) into the interviews. Not only was this model effectively used in studies involving Samoan and Maori people in Aotearoa New Zealand (Anae, Fuamatu et al. 2000, Edwards, Jensen et al. 2003, Edwards, McManus et al. 2005), it uses a non-invasive story-telling approach. The life history or oral approach has been adopted by researchers seeking to understand the lived experience of disabled persons in specific contexts (Barton 2005). Each participant was asked “can you tell me about yourself?” and he/she began to give a biographical account of his/her life in Samoa and Aotearoa New Zealand,

migration to Aotearoa New Zealand and shared personal experiences of acquiring and living with a disability. By using this model (Olson and Shopes 1991, Anae 1998), the participant was empowered to direct the pace and course of the interview and the interviewer actively listened and asked probing questions to clarify their response or raise one of the topic areas in the interview schedule (see Table 5.1).

*Table 5. 1 Sample of key areas and probing questions*

<b>Open-ended question</b>	<b>Key areas</b>	<b>Prompts</b>	<b>Elaboration</b>
Can you tell me about yourself?	Biographical account and family journey to NZ	Can you tell me more about living in NZ as a Samoan?	Is there anything else you would like to add to what you've already spoken about?
	Experiences of acquiring and living with a disability	Can you say more about what this meant for your family?  Can you say more about the supports you sought and received?	Is there anything else you would like to add to what you've already spoken about?
	Disability and quality of life	Can you tell me about what quality of life means? What is quality of life for a Samoan with a disability?	Is there anything else you would like to add to what you've already spoken about?

## Participants

Given that the focus of this study is about the quality of life of Samoans with a disability, the composition of participants were adult Samoans living with a disability in Auckland. Both men and women were selected to take part because of the importance of examining the range of

experiences from their unique perspectives. These participants were Samoans born in either Samoa or Aotearoa New Zealand. Moreover, there is a significant population of Samoans in the Auckland region (Statistics New Zealand 2014). The additional group consisting of the participant's partner, family member or caregiver was included in this research. It was rationalised that this group plays a pivotal role towards understanding what and how a Samoan with a disability conceives and experiences quality of life.

### **Sampling strategy**

This study utilised two strategies to recruit participants: purposeful sampling and snowball sampling. Purposeful sampling is advantageous in narrowing the selection of participants to those who have experienced the same phenomenon (Creswell 2009). This first strategy was used to identify and recruit Samoan individuals who have a disability and therefore able to share their conceptions and experiences of quality of life. Recruiting potential participants was undertaken through accessing personal, professional, social, church and family networks. Two of my friends, both with a disability, were instrumental in identifying and recruiting participants. Snowball sampling is one way to find hard-to-reach or hidden populations (Ellard-Gray, Jeffrey et al. 2015). This second strategy was also used and involved asking participants for help to recruit others they know of who may be interested in taking part in the study. The benefit of using both sampling strategies simultaneously was to promote interest and generate a reasonable sample of willing participants into this study. These participants were, in turn, asked to consider nominating a partner, family member or caregiver who would like to take part in the study. Although this was met with some trepidation, five participants expressed interest and supplied contact details.

A total of 22 participants took part in this study. Fourteen Samoan men and women with a physical or sensory disability were interviewed. Nine had a vision impairment and five had a physical disability. There were two couples where both had a vision impairment. The



participant age range was 23 years old to 60 years old. An additional eight participants identified by this core group of participants were also interviewed. Five were partners and three were caregivers (see *Table 5. 2*). Two of the caregivers were family members.

*Table 5. 2* Sample of participants

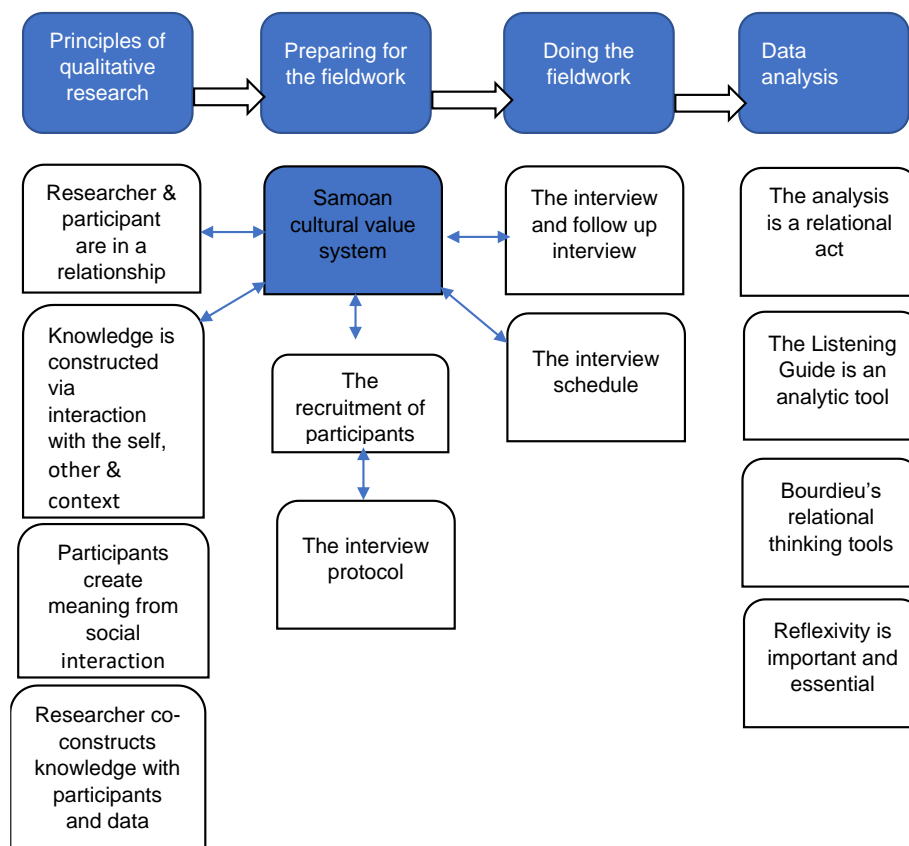
<b>Participant</b>	<b>Male</b>	<b>Female</b>	<b>Total</b>
Samoan with a disability	8	6	14
Partner of Samoan with a disability	2	3	5
Caregiver of Samoan with a disability	0	3	3
<b>Total</b>	<b>10</b>	<b>12</b>	<b>22</b>

## **Data collection procedure**

All of the data was collected using face-to-face interviews at a place of their choosing, such as, a workplace or other convenient location, at a mutually agreed time. An interview protocol was developed and enacted for this study. Having an interview protocol is critical because it covers a range of tasks. These include explaining the purpose of the study, the format and duration of the interview, drafting a script for the beginning and end of the interview, addressing confidentiality issues, answering any questions as well as conducting the actual interview itself (Turner 2010, Jacob and Furgerson 2012). There were two key drivers in drafting the interview protocol: the desire to effectively establish rapport and build trust with Samoan participants who have a disability, and the intent of generating data that would answer the research questions. A strong cultural dimension enveloped the ways of initiating contact, the face-to-face interview and follow up interview. Filipo (2004) identified six specific cultural values and concepts in his work with Samoans and these were drawn on to guide my code of conduct and relational approach as researcher-to-participant in preparation for and during the fieldwork. These inter-related concepts of *feagaiga* (code of conduct), *fealofani* (goodwill), *alofa*

(compassion), *loto maualalo* (humility), *aiga* (kinship and relationship) and *fa'aaloalo* (respect) form a system of cultural values in the Samoan context (Filipo 2004). These values govern social protocols and direct the nature of interactions amongst Samoans, and the purpose is to maintain kinship, communalism, the social relational identity and cultural exchange. For example, a *mea'alofo* (gift) is normally given as a reciprocal act of gratitude to someone for sharing their resources e.g. material goods, time. Incorporating these concepts into the qualitative process of this research is illustrated in Figure 5.3.

Figure 5. 3 Integrating Samoan cultural values into the research process



### Phase 1: Interviews

In this study, all participant interviews were conducted face-to-face at a place of their choosing, such as, a workplace or other convenient location. The interview time was mutually agreed on and the duration ranged between 45 minutes to two hours (totalling 22 hours and 22 minutes of interview data). Each participant consented to being audiotaped so that the interview could be

transcribed and their transcript handed to them for member checking (Creswell 2013). As per the interview protocol, I contacted each participant twice. The first telephone call was to establish contact and seek their interest in being part of the study. If interested, an interview time was scheduled. The second telephone call was to check their availability for the scheduled interview time. Even though the explanatory statement and consent form had been posted to them I took physical copies of these to the interview. The telephone calls were beneficial in assessing whether to converse in English or Samoan (or both) and which version of the forms to post and take to the interview. This also informed which language to use during the interview. A friendly manner and respectful tone was interspersed from the initial point of contact and beyond. This was reciprocated through the participant's hospitality of coffee, biscuits or cake and even lunch. In keeping with the Samoan concepts of *fealofani* (goodwill), *fa'aaloalo* (respect) and *aiga* (kinship and relationship) a *mea'alofa* (token of gratitude) in the form of a gift voucher was presented to the participants after the interview.

## **Phase 2: Follow up interviews**

A follow-up interview was conducted with five participants. The purpose of this interview was to seek additional clarification of information they had provided. The interview protocol was once again referred to for these interviews. These were conducted at a place of their choosing at a mutually agreed time. The interview duration ranged between 30 minutes to an hour (totalling 2 hours and 17 minutes of interview data).

## **Ethical considerations and translations**

The ethics approval for this study was obtained from the appropriate Ethics Committee (see Appendix I). Explanatory statement and consent forms were prepared in both Samoan and English and provided for all participants (see Appendix A-D). Given that this study was with Samoans, it was necessary to provide these in the participant's first language. All of the interviews, with the participant's consent, were audio-taped and transcribed verbatim; and the

transcript and audio recording were handed back to the participant. Participants were encouraged to check their transcript and audio recording for accuracy and to advise if there were any portions of content to omit from the transcript. For participants with a sensory disability, the audio recording was particularly helpful to them and most had access to software which reads documents aloud. Participants were also encouraged to provide additional information or clarification about the content in their transcript. All participants were satisfied with their transcript and did not request any additions or changes. An extra layer of consent was sought from participants which would grant me permission to use extracts from their transcripts for publications arising from this study (see Appendix E-F). In order to preserve confidentiality I used a coding system e.g. D0, D1, D2 when transcribing each person's interview, and their personal details was stored on a password-protected computer and signed consent forms stored in a locked room. As five of the interviews were done in the Samoan language, I drew on a Samoan study (Anae, Fuamatu et al. 2000) where Samoan transcripts were summarised into English rather than translating the Samoan verbatim into English. I also drew on a work experience where I contracted a professional translation service to translate a child safety resource from English into Samoan, Tongan and Niuean. The Samoan translation, in some parts of the child safety resource, was a literal translation thus obscuring the key messages and confusing the Samoan reader. I found the process of correcting and editing the translation of the child safety resource very time-consuming and labour intensive (van Nes, Abma et al. 2010). For each Samoan transcript in this study, I translated and summarised into English (in the third person) and enlisted a trusted mentor fluent in both languages to check the accuracy of the English translation. Then I provided these transcripts and English summary to the relevant participants to check its authenticity or potential loss of meaning and context, and coherence. In adopting the researcher/translator role, there was opportunity to closely attend to cultural meanings and interpretation and the 'meaning-making' context in the research process

(Temple and Young 2004). For Gadamer, language is a pre-condition of understanding and that the world cannot be made known independent of language (Baronov 2012).

## **Data analysis**

Compared to other qualitative strategies of inquiry, the phenomenological inquiry reveals and unpacks the structures, logic and interrelationships which are pertinent to the phenomenon being investigated (Polkinghorne 1989). As this aim is compatible with the Voice-centred Relational Methodology (VCRM) of foregrounding the participant's voice and deciphering meaning and contextual features of participant's lived experiences of a phenomenon, this study used the Listening Guide (Doucet and Mauthner 2008) as an analytic tool to guide the analysis (see Table 5.3). Based on the Listening Guide, each interview transcript was read at least four times and each reading had a different function (Brown and Gilligan 1991, 1993, Supple 2013, Bright, Kayes et al. 2018). The first reading consisted of listening to the story, plot, and drama (who, what, when, where and why of the narrative). This reading also involved a degree of reflexivity where I allow my reactions, judgements, opinions of the person's story to come to the fore. The value of doing this is to illuminate how these can affect the interpretation and understanding of the person's story. Gadamer argued that it was necessary and important to identify one's preconceptions and prejudices because these would facilitate a more open and honest dialogue of how the process of understanding is reached (Lavery 2003, Dowling 2007). The second reading involved listening for the "self" and "I" in the narrative paying specific attention to the ways in which the person is speaking about themselves. By doing so, an empathic encounter is heightened and I began to connect more sensitively to the person and on their terms. The third and fourth readings attended to the person's experiences of relationships and within relationships. It was from these readings that I examined relational conflict, institutional constraints, social and cultural norms, political resistance and contextual factors that impede or facilitate human expression.

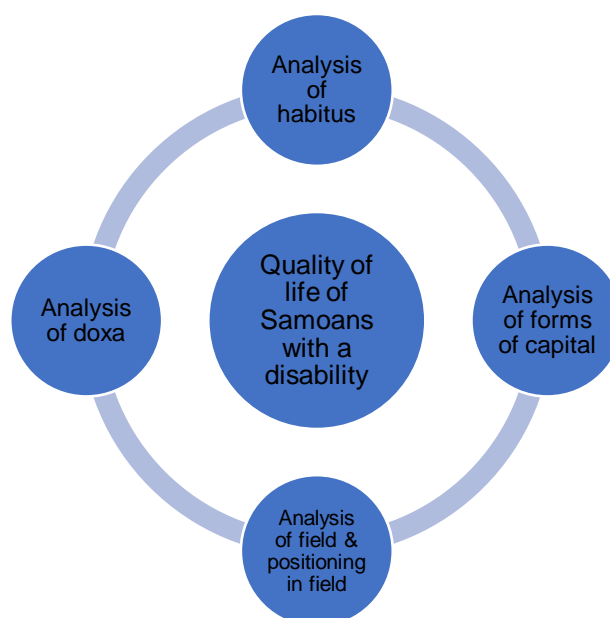
*Table 5.1* Questions guiding the Listening Guide Analysis

Reading	Questions
<b>1<sup>st</sup> reading</b> (person's story and my response)	What is going on here? What is this person's story? Any events, characters, subplots and metaphors mentioned? What is my personal reaction to the person and their story? How does this affect and influence my understanding and interpretation of their story?
<b>2<sup>nd</sup> reading</b> (self and I, person's voice)	Who is speaking? How does this person present their voice when speaking of themselves? How does this person feel, experience and speak of themselves? How does this person believe others see them? What opinions, emotions, reflections, desires and actions are represented or evident? What roles is the person performing? What is this person saying and doing? How do they expect to act? How do they do things and how did they acquire this knowledge? How do they perceive situations, words and action? How does this impact on action?
<b>3<sup>rd</sup> reading (relationships and others)</b>	Who is spoken about? What are the relationships, emotions and stories associated with each person spoken about? Who is related to who and in what way? How is this person positioned within these relationships and interactions? What is this person saying and doing? How do they expect to act? How do they do things and how did they acquire this knowledge? What roles is the person performing? How do they perceive situations, words and action? How does this impact on action?
<b>4<sup>th</sup> reading</b> (context)	What's the context? What are the broad social, political, cultural, professional and structural contexts surrounding the person's story, experiences, actions and interpretations? What is spoken and not spoken about? Whose voices are heard informing the situation? What and whose norms and values surround the interaction? Why do some people act in some ways and not others? What is institutionalised? What is the right way to do things? Where did this come from? How have different roles come about? What is privileged in talks and action?

The second tier of data analysis used Bourdieu's conceptual tools. His relational thinking tools: habitus, capital, field and doxa was employed to extend insights into the data. These conceptual tools have been used to frame and show how these interactive concepts have influenced research and practice in inclusive education (Agbenyega and Klibthong 2015). Bourdieu's theoretical concepts of habitus, capital, field and doxa also shed light on the notion of

‘meaning-making’ and ‘context’ (McKeever and Miller 2004) By using Bourdieu’s conceptual tools, the relationship between habitus, capital, field and doxa offered a prism for conceptualising and analysing the dispositions and attributes one possesses to negotiate and renegotiate their subsequent practice in a given social space. In this study, his conceptual tools were used to illuminate the interplay of habitus, capital, doxa and field in relation to Samoans with a disability and their quality of life. These thinking tools mitigated an approach to interpreting the data and theorising the complexities of identity formation, access to and receipt of disability service provision and hegemonic policies and practices in relation to quality of life (see Figure 5.4).

*Figure 5. 4 Application of Bourdieu’s conceptual tools*



## **Reflexivity as a method of validation and ensuring rigour**

The evaluation of validity and reliability in qualitative research differs to quantitative research. Qualitative research incorporates interpretive perspectives and a combination of multiple perspectives to signify a strong leaning towards understanding the subjective experiences of people and the consequential multiple realities that exist (Creswell 2013, Maxwell 2013). As an insider-outsider researcher, there was the ever present challenge of doing neutral value-free research with my own community. I am a member of the Samoan ethnic group undertaking

research with my community and therefore an insider researcher; whilst simultaneously an outsider researcher who does not have a disability and someone who is doing academic research. This dichotomy raised the issue of objectivity and bias – my objectivity as a researcher doing research with my community, and bias in showing favour and loyalty to my community. Even though undertaking neutral value-free research with one's own community is not a new issue, many scholars from diverse backgrounds have written and conceptualised new ways of navigating this terrain (Subedi 2006, Meo-Sewabu 2014, Wolfgramm 2016). To address this and uphold the rigour of this research, the concept of reflexivity was drawn on.

### **Positional reflexivity**

Reflexivity is a widely used method in qualitative research. It refers to the researcher turning back on themselves as a point of reference to raise critical questions about the power dynamics in the researcher-participant relationship, emotional investment in the research question, and whether the findings re/present what was originally sought (Cousin 2010). The usefulness of positional reflexivity is how it articulates the social, ideological and biographical location of the researcher in relation to the research, participants and analysis of data (Swart and Agbenyega 2010). As Mauthner and Doucet (2003) reiterate, it is important to be reflexive about how the data is interpreted, researcher's role in the analytic process and disclose preconceptions and assumptions brought to the analysis phase. Disclosure of my social and biographical location was undertaken by using Bourdieu's concepts of habitus, capital, field and doxa to examine my situatedness in this study. In doing this, the analytic process is uncovered for scrutiny and critique. The multiple readings from the Learning Guide, particularly the first reading, is a reminder that the researcher's reactions and judgements to the participant's story can reflect negatively on the interpretation of the participant's experience of quality of life.



## **Theoretical reflexivity**

Bourdieu's relational thinking tools frames the interrelatedness of habitus, capital, field and doxa in respect to the phenomenon being investigated. Theoretical reflexivity refers to the considerations on a researcher's world view and how these have influenced stages in the research from construction of interview questions, to data presentation, analysis and reporting of results (Swart and Agbenyega 2010). For instance, a person's habitus or set of dispositions are composed of biography, beliefs and values (Bourdieu 1989, Maton 2008, Supple 2013) coupled with possessing either high or low capital, such as, educational qualifications and social networks which can shape their action or inaction in the disability field, such as, contacting and receiving appropriate levels of disability support and care. The provision of disability support and care is determined by taken for granted assumptions entrenched in social practices or doxa of support services, such as, people having tacit knowledge about how to seek help and information and enabling them to confidently call a support service. Bourdieu's tools hold conceptual power and shifts the level of inductive analysis to consider the structure-agency continuum for Samoans with a disability seeking a quality of life.

## **Personal reflexivity**

As an insider-outsider researcher, undertaking non-partisan research with one's community was a challenge. Personal reflexivity is a reflexive state of mind that not only assesses the extent to which the questions posed have been answered but is also about self-appraisal about one's own personal performance as a researcher (Macfarlane 2010). The researcher is an active instrument throughout the research processes of data collection, analysis and write up. By engaging in personal reflexivity the insider-outsider dichotomy was more of a continuum. That is, that the researcher's identity is dynamic and constantly being negotiated (Labaree 2002). Although I made notes after each interview and reflected on these, the fact that I did not have a disability became redundant as participants were eager to share their stories, be part of the study and

wanted to help me get my degree. The shift has been the valuable offerings of stories to enrich my understanding of what it is like for Samoans with a disability to obtain a quality of life and to ask myself about what constitutes my quality of life.

Ensuring validation and trustworthiness drew on the concept of reflexivity. Member checking of transcripts and providing rich thick description were also used (Creswell 2014).

## **Ethical issues**

Two ethical issues presented themselves during the interview. The first issue was about consent. Some of the participants wondered why their verbal consent to being interviewed was insufficient. In other words, their verbal consent was akin to written consent. I explained that it was an institutional requirement in research involving people. They accepted this explanation, and that I might get into trouble, and signed the consent form. The second issue was about confidentiality. Some of the participants wanted their identity to be made known. In other words, they owned their stories and wanted people to know whose story it was. Though I understood their reasons, I felt bound by the tenets of institutional ethics in preserving anonymity and explained this to them.

## **Chapter summary**

This chapter outlined the methodology of this study. It was informed by Hermeneutic phenomenology, the Voice-centred Relational Methodology and Bourdieu's relational thinking tools (habitus, capital, field and doxa). A total of 22 interviews were conducted with 14 Samoans with a disability, and eight comprising partners and caregivers. The findings will be presented in the next chapter.

## **Chapter 6 Presentation of findings**

### **Introduction**

This chapter presents the findings from this study on the quality of life of Samoans with a disability. The three research questions in Chapter 5 formed the direction and impetus of this study. Face-to-face interviews undertaken with fourteen Samoans with a disability living in Auckland and additional eight interviews undertaken with their partner or caregiver formed the corpus of data collected for analysis. Utilising VCRM and Bourdieu's thinking tools provided a rich perspective on what and how a Samoan with a disability experiences quality of life. This chapter presents the findings from both groups.

### **Demographic information on participants**

The demographic profile of the fourteen Samoans with a disability living in Auckland showed that most had acquired their disability during adulthood (n=10) while others were born with the disability or acquired it during their childhood (n=4). The types of disability represented were vision impairment (n=9) and physical disability (n=5). In terms of place of birth, eight participants were Samoa-born and six participants were Aotearoa New Zealand-born. With the exception of one participant who migrated to Aotearoa New Zealand as a child, seven participants migrated in their late teens or during their adult years. These participants had lived in Aotearoa New Zealand for at least three or more years when data was collected. There was an even spread of adult women and men in this cohort and almost all of the participants (n=13) were married with children. There were two vision impaired couples who met, married and had a child each. Two men got married after acquiring their physical disability and one had a child with his wife. All of these participants had attended church as part of their upbringing (see Table 6.1 for profile). The cohort of partners (n=5) and caregivers (n=3) totalled eight participants. Two of the caregivers were family members, a sister and a daughter, and the third

caregiver was not related but had worked in the healthcare industry for 25 years. The partners were Samoan, Maori or NZ European, with the exception of one partner, had been married to their spouse for a period of 16-27 years when the data was collected (see Table 6.2 for profile).

*Table 6. 1* Profile of participants with a disability

Participant	Number	Age-range	Samoa born	NZ-born	Church background
Samoan women with a disability	6	28-54yrs	3	3	6
Samoan men with a disability	8	23-64yrs	5	3	8
<b>Total</b>	<b>14</b>	<b>23-64 years</b>	<b>8</b>	<b>6</b>	<b>14</b>

*Table 6. 2* Profile of partners and caregivers

Participant	Male	Female	Samoa	Maori	NZ European
Partner of Samoan with a disability	2	3	3	1	1
Caregiver of Samoan with a disability	0	3	3	0	0
<b>Total</b>	<b>2</b>	<b>6</b>	<b>6</b>	<b>1</b>	<b>1</b>

The data is presented using three broad themes to illustrate the findings which are informed by the research questions. These themes are: (1) Living with a disability, (2) Re/composing the self and (3) Forging a quality of life. The interview data is presented according to these themes foregrounding their lived experiences of living with a disability, the journey of identity formation as Samoans with a disability in Aotearoa New Zealand, and the facilitators and barriers experienced in the search for a happy, satisfying and meaningful quality of life (see Figure 6.1).

Figure 6. 1 Themes from the interview

Living with a disability	Re/composing the self	Forging a quality of life
<ul style="list-style-type: none"> <li>•The normal life</li> <li>•Disruption to normal life</li> <li>•Grief mode</li> <li>•Resiliency mode</li> <li>•Suite of interventions <ul style="list-style-type: none"> <li>•Cultural</li> <li>•Biomedical</li> <li>•Social</li> <li>•Economic</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>•The 'kalofa e' people</li> <li>•The narrative of 'ma'i'</li> <li>•Disability is not 'malaia'</li> <li>•Perceptions of identity</li> <li>•An instrument for advocacy</li> </ul>	<ul style="list-style-type: none"> <li>•Performance of role/s</li> <li>•Anchor of faith</li> <li>•Proper resources</li> <li>•Right carer supports</li> <li>•Connectedness to family and culture</li> </ul>

A short descriptor of the participant which consists of name, age, gender, disability type and relationship type is provided (see Table 6.3). Pseudonyms of popular Samoan names have been used to preserve confidentiality. Some of the quotes are presented as a summary of the participant's verbatim from interviews undertaken in the Samoan language (see Chapter 5).

Table 6. 3 Descriptor of participant quotes

Women	Descriptor	Men	Descriptor
Elena	37 year old with physical disability	Elia	28 year old with physical disability
Rasela	46 year old with physical disability	Lafaele	46 year old with physical disability
Malia	54 year old with vision impairment	Samuelu	51 year old with physical disability
Sina	54 year old with vision impairment	Ioane	59 year old with vision impairment
Elisapeta	52 year old with vision impairment	Tomasi	64 year old with vision impairment
Veronika	28 year old with vision impairment	Mikaele	23 year old with vision impairment
Elisa	Wife of Ioane	Tavita	41 year old with vision impairment
Mata	Wife of Lafaele	Peniamina	29 year old with vision impairment
Ruta	Wife of Samuelu	Isa'ako	Husband of Elena
Iuni	Sister and caregiver of Elena	Paulo	Husband of Rasela
Naomi	Caregiver of Lafaele		
Sarai	Daughter and caregiver of Rasela		

## Living with a disability

This theme focuses on the accounts of participants living with a disability. It provides a snapshot of their disability experiences. This theme explains what is considered as a normal Samoan life followed by the disruption of this normal life due to a disability. The inner workings of how

this disruption was processed, namely the grief and resiliency modes, is presented also. The suite of interventions is a range of actions that these participants and their families orchestrated in order to retrieve normality.

### **The normal life**

Living a life of normality alludes to the existence of a pre-defined social order. The work of Erving Goffman and Harold Garfinkel introduced a different perspective on normality (Misztal 2001). They viewed normality as a social construct “which is negotiated out of social conventions and rules in the local context” (Misztal 2016). In other words, normality is a values-based, context dependent and cultural specific concept (Freud 1999). For these participants, normality comprised of the ability to engage in full-time employment, pursue personal and professional goals, participate in social activities and perform familial roles. On the continuum of living a normal life all the participants had physical, mental and social capabilities to function in these domains. As one participant aptly put it *I’m a working person, I like to be up and doing things (Ioane)*. This sentiment was shared by ten participants who acquired their vision impairment and physical disability as adults. These participants were active in fulltime work or study, raising their children, contributing to the life of the immediate and extended family, and socialising with friends and community groups. However, this sentiment was not exclusive to these participants. Those who were born with or acquired their vision impairment early in life had similar motivations and aspirations:

*My goals when I was 18 was to get married, have children and write love songs and I’ve done all that. (Tavita)*

*I’m doing the storeman (job) but I don’t like it, I’m interested in this security job I think I can do it. (Mikaele)*

The conceptions of normal life for Samoans with a disability is not inherently different between these two groups. Both groups have a unified interest in living a normal life and this

notion of a normal life is influenced from a Samoan cultural perspective. This cultural perspective frames a series of values that shapes the life norms of a Samoan person, and as such, guides them in their attitudes, decision-making process and behaviour. In Bourdieu's terms – the Samoan habitus. Such values undergird the practices of engagement with employment, continuous participation in building the material and cultural prosperity of the family collective, and performance of ascribed roles as leaders and managers within the family collective. The 'normal life' articulated by these participants is similar to that of most Samoans who do not live with a disability. In the next section, this is made visible by Samoans who lead a normal life and then acquired their disability later in life. The disruption to their normal and otherwise active life brought to the fore a painful realisation that life was going to be remarkably different.

### **Disruption to normal life**

Most of these participants (n=10) had acquired vision impairment or physical disability later in life. Prior to the onset of this disability, they were either working fulltime or studying, going out and socialising with friends, attending church, taking part in family and community events, playing sport, travelling abroad, raising their children and meeting family commitments. They were living a normal life in Samoa and Aotearoa New Zealand. Although the variety of reasons for incurring the vision and physical disability ranges from personal health (diabetes, illness and stroke) and environmental health (work-related, domestic incident, medical mistreatment) to population health (rugby injury and car crash), the disruptive effect on normal life was felt in very similar ways:

*It's really hard e le faigofie i le tagata lea sa pupula muamua [it's not easy for someone who used to see] ae toe afaina lea lagona ia te a'u ua ola ae ua le atoatoa [and I felt that even though I am alive I was not a whole person. (Sina)*

*To me, le mea lea o le kauaso [blindness] it's really really hard, o makua'i faigaka lava [it's very very hard]. (Elisapeta)*

*It's not easy to be a disabled person or living with a disability. Being a disabled person is very sad because people look at you and the sighted people and they go 'oh kalofa e' [oh poor thing] and that's all I hear 'kalofa e' you know 'ma'imaui pe aga pupula, ma'imaui pe aga le po le vaai' [such a waste that they can't see, such a waste that they're blind]. This is all I get from sighted people. (Malia)*

*Everyone that sort of knew me before my accident, I wasn't comfortable meeting them. I didn't want them to see me in the position I was in. It's a lot better now than in the beginning. I perceive my accident as something so bad, awful you know. I thought I was disgusting to be around you know, who would wanna be my friend? (Elia)*

This contrasted with the views of Veronika, Mikaele, Tavita and Peniamina who were born with or acquired their vision impairment early in life and had learnt to accept it as part of their normal daily life. As Veronika conveyed: *It's life yeah that's what it is, you haven't known life any other way.* The acceptance of vision impairment during childhood and adolescence meant that these participants had embraced the challenges of living a normal adult life despite the limitations of not seeing the world. For participants acquiring their vision impairment and physical disability during adulthood, this interruption to their life course evoked the human process of grieving and finding ways to overcome the mental and emotional anguish of a loss.

### **Grief mode**

Mourning a loss in one's life is a natural human process (Neimeyer, Prigerson et al. 2002, Charmaz and Milligan 2006) and these participants experienced it in some form or another. There was a deep sense of anger and loss that life had changed dramatically and living a normal life was now out of reach. Grieving the loss of a normal life that one had been accustomed to for several years, even decades, took a considerable amount of time for the person to process. For some, this involved withdrawal from the public eye and into a private world of dark thoughts, and for others it was a gradual process of expressing sorrow and despair. The following quotes illustrate similar comments made by other participants:



*I was really down for 3-4 years, you feel helpless you're becoming a burden to other people, your own family and others. You're not able to help yourself so it's a sad very sad feeling. (Ioane)*

*After my injury you don't have time to think, you don't plan your life right there and then. The emotional side of things hit me later when I come home and that started to come out dribs and drabs. I think it's good to cry and let it out and I have done. It's an emotional experience. (Elena)*

The families also grieved. They too felt a sense of loss that their loved one had incurred a disability and this ruptured a quality of life (QoL) from that point onwards. This disruption impacted the routine life of the family, brought new uncertainties about the future, and fears of what lay ahead. Parents, children, grandchildren and spouses alike shed tears and mourned the end of a regular normal life for their loved one, for themselves and their families:

*My parents, it almost feels like they regret my accident more than I do. They've always wanted the best for me, for their children and it's a lot better now but the first early couple of years, I would always catch both of my parents crying. They always felt sad that my life was gonna be harder and they try and do as much as they can to make my life a bit more normal. (Elia)*

*I have my crying moments, my daughter and grandchildren know I'm having one of those days, they just come and cuddle and we cry together. (Malia)*

*Isa'ako (husband) he just looked like a broken man, didn't know where to turn to. (Elena)*

Part of this grieving mode prompted participants to take an introspective view on their disability and asked the questions – why did this happen to me? Why me Lord? Granted that people grieve in their own ways and the duration differs for each person, it was this question that created a lifeline for participants to find a way beyond the downward spiral of grief. Grieving people experience depression, anxiety as well as physical and psychological symptoms which can debilitate or be life threatening (Laurie and Neimeyer 2008). Continuing on a downward spiral of grief can significantly impact a person's QoL. As Shear et al., (2011)

illustrate, unresolved or complicated grief is associated with prolonged distress, impairment in social, work and relationship functioning, poor health outcomes and suicide.

### **Resiliency mode**

The questions of ‘why did this happen to me’ and ‘why me Lord?’ was asked on many occasions as participants sought answers about their predicament. Even though all had been raised in the church it was the older generation (n=7, 54+ years) that were attending church services. It was this generation that sought answers to ‘why me Lord’ and they framed their ability to bounce back from adversity in relation to God:

*I’m total blind but you cope ... like all the other vision impaired you say ‘why me, why me?’ and then it’s like getting an answer from God ‘why not you?’ It’s like ‘why not you? Get on with it (life).’ (Malia)*

*Summary of Samoan verbatim: His uncle took him to church and things started to change from there. It helped him to understand the will of God and it restored a sense of peace in his heart in the midst of turmoil. The burden was lifted from him. (Tomasi)*

*Summary of Samoan verbatim: He gives thanks to God despite his blindness that he’s physically able unlike others who are sighted and have some illness and feel pain in their body. (Elisa)*

The younger generation took a philosophical approach to ‘why did this happen to me?’ There were traces of a psychological resolve to accept they had a disability and overcome the tendency to dwell on negative emotions that their QoL has been disrupted. Strategies to overcome this involved a conscious decision of not entertaining these emotions, shifting to a positive and hopeful outlook on life and making plans that focus on a fulfilling life:

*I guess it’s a different life physically that is but mentally it’s not so much different. Well that really depends on the person itself, if there’s a will there’s a way but some people seems to be the end of the world when they get injured like this. It’s not an easy thing to go through you try and snap out of it straight away. Just have to move on and try and block it out and go to the next level. (Samuelu)*

*Well you go through highs and lows but my take on it was I knew I'd be going through a denial stage so in order to keep my head above water there were certain things I decided not to go anywhere near cos I needed to actually realign my life. Health and wellbeing was a priority. (Lafaele)*

*I've known a lot of people that have gone for surgery and ended up with less sight than I have and I'd just rather keep what I have. It doesn't mean you enjoy or find it easy being blind but to accept it makes it far easier, not to fight it I mean get on with life. (Veronika)*

The findings re-echoed the development of resiliency as part of being human. The array of challenges, crises and misfortunes form the fabric of human experience and individual responses to these is largely shaped from within a historical and socio-cultural context. To draw on Bourdieu, this indicates the presence of a religious habitus and Western habitus, and the disposition adopted took place from within these contexts. From these participants' responses the inevitability of living with a disability was matched with a resiliency to simply 'get on with life.' However to 'get on with life' does not occur in a social vacuum. A number of interventions were initiated and enacted to support how these participants could 'get on with life.'

### **Suite of interventions**

There was a suite of interventions or pathways that these participants experienced in order to 'get on with life.' The family was the principal driver in formulating a course of action, and this varied according to the participant's age and marital status. For five participants who acquired their disability during childhood and adolescence, it was their parents who determined the course of action. With the exception of one who was unmarried (at the time) and chose his interventions, eight participants consulted their spouses, siblings and parents about possible interventions. In terms of the interventions sought, these can be described as cultural, biomedical, social and economic. Five participants were living in Samoa at the time and sought cultural or biomedical intervention or both, and two travelled to NZ to continue the biomedical intervention. All five eventually moved to NZ and explored social and economic interventions.

Nine participants were living in Aotearoa New Zealand and sought cultural or biomedical intervention or both, and social and economic interventions. In Bourdieuan terms, these types of interventions represent the field of interventions or social spaces that these participants enter into and re/position themselves vis-à-vis agents and institutions in order to ‘get on with life’ (see Figure 6.2).

*Figure 6. 2 Field of interventions in Aotearoa New Zealand*

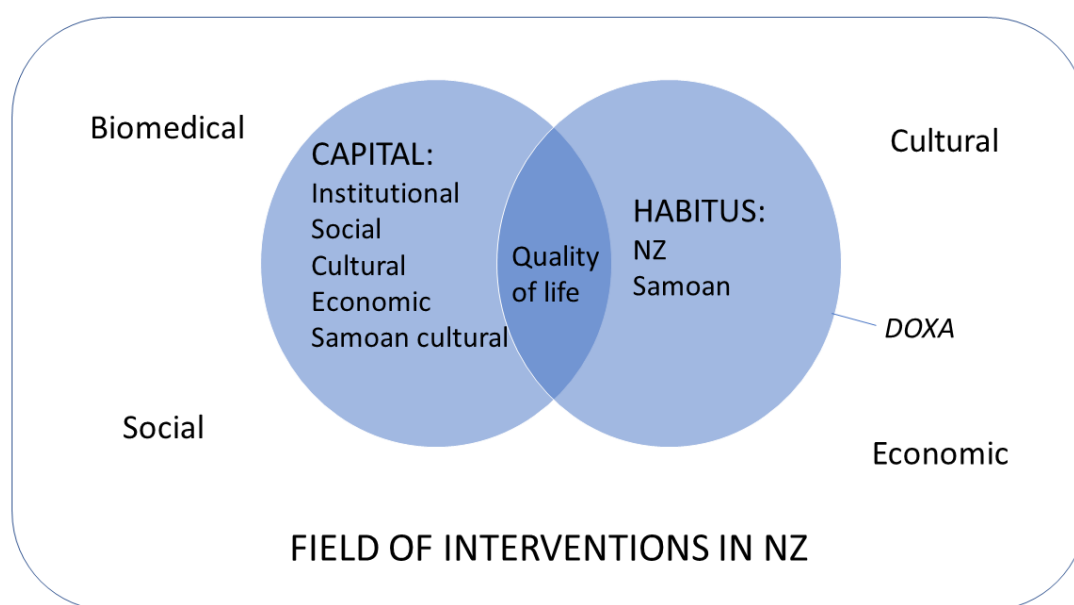


Figure 6.2 illustrates the cultural, biomedical, social and economic interventions that participants considered and engaged with to improve their QoL. The role of habitus, in the form of a NZ habitus and Samoan habitus, and forms of capital associated to engage in the field of interventions are interrelated. For instance, accessing the cultural intervention stems from a Samoan habitus accompanied by social (family and community networks), economic (money) and Samoan cultural capital (Samoan language proficiency, cultural knowledge and protocols). This exemplifies a logic of practice and doxa (Bourdieu 1977). Fields “are structured spaces of dominant and subordinated positions based on types and amount of capital” (Swartz 1997). The positioning of these participants in the field of interventions is framed by the field itself, its rules and the pre-requisite capital. For these participants the biomedical, social and economic

interventions are structured systems of power relations which can disempower and disenfranchise Samoans with a disability and their families. This can result in the dissonance of interventions to improve QoL.

### **Fofa**

Fofa is a Samoan cultural intervention. This is a generic word that means 'to doctor' (Pratt 1984), to apply traditional Samoan medical treatment and a person skilled at massage (Milner 1966). These specialist practitioners deal with one of two categories of illness: an illness with supernatural origins, and an illness with natural origins (Macpherson and Macpherson 1990). Not all participants went to a fofa and these participants reasoned that their disability created functional limitations to the body which could only be diagnosed and treated by the Western medical profession. Those who were born with or acquired vision impairment during their childhood were seen by several fofa and the desired outcome did not occur:

*My family brought two fofa from Samoa when we (she and brothers) were very young and when we were teenagers and it just cost them so much. I just wish they'd forget about it but as soon as they hear of someone or someone that healed someone they have to go and look for them, find them and bring them over. The fofas that dealt with us one said it was because of our dad's family, another fofa said it was because of our mum's family, they just have different reasons. (Veronika)*

*My family's done that I had Samoan medicine put on your ears, mouth, nose and eyes it's painful. Before you sleep you do that, wake up early in the morning have to do that you thought you're gonna wake up you're gonna see something. (Mikaele)*

Parents and families draw on their cultural knowledge and experiences in order to find a solution to a problem. This indicates that the frame of reference emanates from family habitus, a disposition steeped in values and beliefs and associated practices (Bourdieu 1977). This cultural intervention of the fofa was initiated, from a parental perspective, with good intentions that their child/children with a vision impairment will have an opportunity to 'get on with life' as sighted individuals in society. As the desired outcome did not occur, given the number of

fofo and increasing disappointment, these participants resolved to get on with life anyway with their vision impairment. Conversely, one participant with physical disability chose to have a fofo because it complemented his rehabilitation: *She (mum) brought a fofo over every night after my physio at the spinal unit. Fofo because it's a nerve thing (nervous system) it's more like trying to wake up the nerve(s) (Samuelu).* The biomedical intervention was instigated to gather information on how else to 'get on with life.'

### **Medical diagnosis and surgery**

This intervention of seeking Western medical expertise predominated the experience of those with an acquired vision impairment and physical disability. For those who were living in Samoa this expertise was sought in Aotearoa New Zealand because it was considered more advanced with better facilities for a diagnosis, treatment and surgery, and they had an established family network in Aotearoa New Zealand: *It was either gonna be here (NZ) or Australia and most of mum and dad's family is here (Elia).* It was the nature and type of disability that determined which medical experts were canvassed. Participants with the vision impairment visited medical doctors, eye specialists and had some form of laser surgery, ocular prosthesis (artificial eye) or corneal implant inserted. One participant had ten operations:

*Summary of Samoan verbatim: She had a work accident in 1994 in Henderson incurred burns from industrial chemicals and hot water to her body and this affected her eyes. One eye was affected but the other still has partial vision. She had surgery in 1995 and a cornea was implanted in her left eye and got some vision back but went to Samoa, returned and lost her vision. She went back to the hospital and has had around 10 operations. Today there's no vision but can make out shadows. (Elisapeta)*

Another had surgery:

*Summary of Samoan verbatim: He saw a specialist in Remuera and was informed that the blood vessels in his eyes had disintegrated. There was internal bleeding and he underwent laser surgery but was advised that this treatment would delay the blindness. His vision could not be repaired or restored and the treatment would slow the process of*

*becoming blind and give him more time to be a sighted person. He accepted this and underwent laser surgery on his left eye. After 3 weeks he had lost 60% of his vision. He wanted to do anything he could to delay blindness so that he could have more years as a sighted person. The operation on his right eye, to assist sightedness in his left eye, did not improve his vision. By the end of 1997 he lost 80% of his vision. (Ioane)*

Participants with a physical disability was largely attributed to a spinal injury. The spinal chord had been severely damaged which led to either paraplegia or tetraplegia. An injury of this nature required prompt medical attention, surgery and rehabilitation:

*It was on the field rugby game, got hurt keep on playing without knowing it was a serious injury so it didn't hit me until early hours the following morning I lost all my movements. I went to Whangarei Hospital they couldn't diagnose the scans so they transfer me to Middlemore. Well they send me to the MRI scan and they found that my neck was broken and I need to go under the knife straight away. (Samuelu)*

*They managed to identify that I've broken my spinal chord C5, C6, they told me that there's a chance that I will be paralysed. After all my major operations and being taken to spinal unit for rehab. (Elia)*

This biomedical intervention was instigated as a common sense response to a situation involving the physiological functions of the human body. To these participants and their families something dramatic had happened to the physical body and vision capacity. Considerable effort to obtain a medical diagnosis, undergo treatment and surgical operations was undertaken by these participants and families. Subjective well-being is integral to improving QoL. This relates to the person's cognitive and affective reactions to their life involving moods, emotions and life satisfaction (Diener and Suh 1997). An ethnic group's cultural values can influence a person's notion of subjective well-being (Ferriss 2006, Manuela and Sibley 2015) and direct specific courses of action. This concerted effort of utilising a biomedical intervention, however, did not restore full sight for those with vision impairment nor mend the spinal chord for those with physical disability. What it did do was to confront this

new knowledge of living with a disability and to explore new realities of how else 'to get on with life' in the Aotearoa New Zealand context. Accessing social and economic interventions played a critical role towards enhancing QoL as a person with a disability.

### **Support services**

The State offers wide-ranging support services to people with a disability. The national vision, enshrined in legislation, service provision and funding policies, and the New Zealand Disability Strategy 2001, aims to improve the QoL of all persons with a disability. Specific services accessed by these participants was dependent on their type of disability in conjunction with personal aspirations. Those with vision impairment accessed the Blind Foundation, Homecare Services, Manukau Institute of Technology, Auckland University of Technology, Disability Resource Services, Workbridge and Work and Income New Zealand. The Blind Foundation supported participants to develop independent life skills (use oven and kitchen appliances to cook and make a cup of tea, use microwave, do household chores, navigate the home), and mobility skills (use a cane and guide dog) when out in the community, shopping, church and catch public transport. The following quote illustrates similar comments made by other participants who had accessed the Blind Foundation:

*We have a process here at the Foundation where the services offered either maintain or establish a person's independence. Staff would help me find techniques that would help me cook. The same with mobility using techniques to allow me to walk around safely.*  
(Tavita)

The Blind Foundation provided a number of offerings to help transition these participants into living with a vision impairment and pursue their goals and dreams. Not only did the Foundation provide a library of Talking Books, it liaised and worked collaboratively with Manukau Institute of Technology (MIT). To improve language fluency and employability most did the English language course at MIT:



*Summary of Samoan verbatim: She attended an MIT course in the English Department over a three year period. There were tests and exams and this wasn't easy mainly because she was a mature student in her 50s. There are note takers and they do her notetaking but she doesn't solely rely on them because she's not sure if they're writing down everything. She records the lectures on the tape recorder and listens to it afterwards at home. She was happy to be able to undertake the course. It's the first time she's studied and appreciates the supportive classroom environment and the teacher's positive attitude. She's aiming to be a counsellor and believes she can do it and help others. (Sina)*

One participant who had worked for the New Zealand High Commission in Samoa for 20 years took a different route to improve his employability:

*Summary of Samoan verbatim: He did computer training at the Blind Foundation. He found that he couldn't write things down, write a letter or stay in contact but since the computer training a whole new world has opened up. Now he's able to re-establish contact through emails and use the internet to prepare documents. The computer has been a huge benefit to living again because it allows social contact. He's thankful for the Disability Resource Service and did a course last year at Auckland University of Technology. The Disability Resource Service makes enrolment and attending courses possible. He contacted the Blind Foundation for computer equipment to help with his course and was fortunate to receive a computer, printer, scanner and appropriate software. He uses the computer regularly. He finished his Certificate in Liaising Interpreting last year. Last week he submitted his cv to the Auckland District Health Board in order to register as a Samoan interpreter for their services. They have a need for Samoan interpreters in the hospitals, courts and similar institutions. He heard about Workbridge so applied to them. (Ioane)*

The Pacific Services in the Blind Foundation played a significant role for these participants. It was often the key port of call in seeking information and support. A defining characteristic of Pacific Services was its culturally responsive approach to working with Pasifika people. This involved actively liaising with MIT and facilitating a social support group:

*Summary of Samoan verbatim: She wanted to do a course and asked how this could be done. The Blind Foundation contacted the Disabilities Coordinator at MIT. The*

*Disabilities Coordinator and the Pacific Coordinator at the Blind Foundation made it happen. She's grateful for the Pacific Coordinator's support and service to Pacific people. (Sina)*

*This is where the Foundation comes in, they help you to accept your vision impaired your disability like when you go through PI (Pacific Island) group. We have a group we get together we just have a laugh have coffee do our little business. We enjoy each other's company mainly. (Malia)*

*It's good that there was a support group cos we've met other people. I've always wanted to meet other Samoans like us. It's good to know there are other people like us cos any palagi [European] would be different from any Samoan sighted or vision impaired. Palagi [European] vision impaired people are far different from us. (Veronika)*

Those with a physical disability accessed the Spinal Rehabilitation Unit, Rehab Plus, Homecare Services, Rugby Foundation and Vintage (pseudonym). Following surgery at the hospital they were transferred to a different institution for care and rehabilitation. Rehabilitation is generally understood as a “biopsychosocial process aimed at enabling people with conditions that impact on health and function to reach and maintain their optimal physical, sensory, intellectual, psychological and social abilities in order to live a meaningful life” (Bennett, McPherson et al. 2014). These participants spent on average one to six months in rehabilitation: *the support came from the Spinal Unit where I was housed for about 5 months (Elena) and I was hospitalised for about 2 months rehab for 1 month (Elia)*. Their primary focus was on regaining some physical functionality and planning for the immediate future. For instance, one participant and his family began the paperwork to obtain permanent residence, two sought to retrieve their independence through accessing relevant support systems while others looked at housing modifications. This shows initial acceptance of living with a physical disability but the emotional dimension was felt gradually over time.

Utilising Homecare Services consisted of staff coming into the home to provide personal cares, perform household chores, cook, drive to appointments and organise the

shopping. The uptake of these services differed according to views around life goals, preserving relationships and personal privacy. Three preferred family members, such as sister, wife and mother to act as carers. As one family member described it: *Elena asked us if we wanted to be her carers and without hesitation I said 'yeah of course I know you'd do the same for me.'* *Elena didn't want anyone really and when I think about it I don't want anyone other than my own family (Iuni).* The other two emphasised their life goals in relation to their spouses. Setting individual and shared goals and putting these into motion was a key factor in accessing Homecare Services. As one participant illustrated: *My perception is that Mata is my partner and my wife not my carer and not my nurse. I have to consider that my wife won't be there all the time I've got to allow for her to find a job and maintain it and not have to worry about me.* (Lafaele)

The Rugby Foundation and Vintage provided specific supports based on predefined criteria. Incurring a serious spinal injury from playing rugby determined eligibility to receive material and social support from the Rugby Foundation. One participant was eligible. This Foundation was notified of his serious injury and visited him at the Spinal Rehabilitation Unit. A programme of action was initiated which consisted of resourcing housing modifications, a vehicle, and the children's education. This contrasts with Vintage which another participant approached because he wanted to secure disability funding to purchase a vehicle. The vehicle was perceived as a vital resource for his law career and independence:

*It would make life a lot easier for myself for my family. I appreciate that the field that I'm trying to get into requires mobility from office to court and court to office, clients and that sort of stuff. It (modified van) would be a very good resource for me to try and live as normal as I can be and independent as I can. (Elia)*

The range of support services accessed varied according to the type of disability. The Blind Foundation offered practical, social and cultural supports that attended to the person's needs and aspirations. As a social intervention it addressed the transition phase of coming to

terms with life and vision impairment, fostered new life skills for independence at home and in the community, and collaborated with learning institutions on relevant courses to increase employability. The Pacific Services enhanced this social intervention by recognising and responding to diversity and cultural needs. In Bourdieu's terms, the Samoan habitus was incorporated into a mainstream institution. That is, the habitus of Samoans was recognised and re-enacted as "the strategy generating principle enabling agents to cope with unforeseen and ever-changing situations" (Bourdieu 1977). Staff at the Pacific Services were primarily of Samoan descent, shared Samoan habitus, possessed Samoan cultural capital and draw from these to support participants in the field of social intervention. The social intervention for those with a physical disability was intensive and somewhat fragmented. Eligibility for specific resources and equipment to enable a level of independence and 'to get on with life' was pre-set and fixed. This meant reduced equity and seeking alternative ways to overcome such barriers. Social and economic interventions are intertwined and this is particular to how the realities of 'to get on with life' is shaped.

### **Funding mechanisms**

Funding is an important aspect of improving the QoL of persons with a disability. The State's funding agencies are the Ministry of Health, Accident Compensation Corporation, Work and Income New Zealand, and Housing New Zealand Corporation. It is the nature of the disability event that determines the social and economic supports one receives. Participants that acquired their disability from an illness or disease have access to Ministry of Health (MOH), Work and Income New Zealand (WINZ) and Housing New Zealand Corporation (HNZC). On the other hand, those that acquired their disability from an injury in the workplace, medical operation and playing sport have access to Accident Compensation Corporation (ACC). ACC is a state agency that provides no fault accident insurance for personal injuries. Medical costs, rehabilitation services, home support, lost earnings and impairment of earning capacity and funeral expenses

are covered by this scheme (Henderson 1981, Flood 2000). ACC works with other agencies (e.g. Housing New Zealand Corporation, Rugby Foundation) as the need arises. Comparison of entitlements between those on ACC and MOH is shown in Table 6.4.

*Table 6. 4 Profile of funding agencies and entitlements*

Entitlements	ACC	MOH	WINZ	HNZC
Homecare	√	√	-	-
Disability equipment*	√	√	-	-
Vehicle funding	√	-	-	-
Housing modification	√	-	-	√
Income support**	√	-	√	-
Taxi fares assistance	√	-	-	-
Physio program/equipment	√	-	-	-
Computer	√	-	-	-
Course fees	-	-	√	-

\*covers bed, hoist, commode, wheelchairs

\*\*80% income from ACC until retirement otherwise WINZ benefit

Participants on ACC were eligible for homecare, disability equipment, vehicle funding, housing modification, income support, taxi fares assistance, physiotherapy programs and equipment and computer. In contrast, those on MOH funding were eligible for homecare, disability equipment, housing modification and income support. However accessing the latter two was subject to MOH funding conditions and its interagency partnership with HNZC and WINZ. WINZ provides income support in the form of invalid's benefit and disability-related allowances.

Participants with a physical disability on ACC were able to access resources and supports that fostered an ease towards improving their QoL and the QoL for the family unit.

Elena explains:

*I have the bed provided by ACC that one elevates my legs as well as the back of my head. I also have a hoist to help me out transfers for my chair to the bed. The commode is a shower chair that I use. This house that we're in now is a 4 bedroom place with a wet*

*area shower for my commode where I can just drive into and the kitchen is open plan with the lounge to moved around in the house. I can access all the bedrooms without bumps and that. I also have a back up manual chair which I'll use if my power chair kind of like dies out. ACC and Housing NZ had come together and put a plan in as to what I wanted which was quite good and this is what I had asked for. We're really happy with it we're able to hold things here like family get togethers and that because we can't do it elsewhere. Yeah that (van) was funded by ACC we were lucky at that time it didn't need anymore changes to it. It's done us really good and we use it all the time you know. (Elena)*

The social and economic interventions are intertwined. It was the nature of how one acquired their disability that fundamentally determined which funding regime they were classified under. Enhancing QoL (e.g. mobility in the home, modified vehicle, disability equipment, income support) proved to be more challenging for those not on ACC. Overcoming this barrier, by proactively looking for other funding sources and relevant services, was one of the realities to secure an independent lifestyle and 'to get on with life.' This required the accumulation of social capital, cultural capital, economic capital, institutional capital (English language proficiency, knowledge of entitlements, knowledge of funding pools, knowledge of other services) and adapting to a NZ habitus to confidently approach mainstream organisations (see Figure 6.2). For Samoans living with a disability the disruption of the disability event was felt more acutely when they had acquired it later in life. The impetus 'to get on with life' generated into the exploration of cultural, biomedical, social and economic interventions. The next theme is a by-product of living with a disability and delves into the murky waters of re/composing who one is in the Samoan and NZ context. The motivation 'to get on with life' is potentially impeded, or not, through a series of defining moments.

### **Re/composing the self**

This theme focuses on the participants' encounters of the terminology and labels used to define and describe them. These terms in Samoan and English influence perceptions of the self and it is the critical appraisal of its origins and context that marks how Samoans with a disability

define themselves. The process of navigating the discourse on cultural identity and the disability identity is strewn with challenges in the Samoan and NZ context. The following subthemes identify these challenges.

### **The ‘kalofa e’ people**

‘Kalofa e’ is a Samoan word which generally means ‘poor thing’ or ‘poor you’ that is used to express sympathy towards a person or situation. The use of this frequent expression was common across all of the participants’ encounters in a Samoan cultural context. One participant used this phrase to sum up how Samoans with a disability are perceived by Samoans without a disability:

*I still believe our people with disabilities are still the ‘oh kalofa e people’ cos it still happens, you hear that with our Samoan people. I hear that a lot. (Tavita)*

In a cultural context, the initial reactions to this perception is acquiescence and ambivalence. Participants would process their individual understanding of what this term meant and how it was being applied to them. The consensus was that Samoans with a disability are viewed as having suffered a misfortune, life will be sad and difficult, and it is acceptable to take pity and feel sympathy for them. Countering this consensus view invoked within these participants an equally sympathetic attitude that Samoans lacked understanding that people with a disability can and do have the capacity to lead a satisfying life:

*When we went to this church you will always hear people ‘kalofa e si kama’ [poor guy] and I kept thinking I probably have a better life than you do and you’re feeling that for me? Why you feel bad for me? Is there something wrong about me? (Elia)*

*I always get ‘kalofa e’ and I would always say ‘kalofa e what?’ I always hear that term ‘oi kalofa e, oi ma’imau’ [oh poor thing, oh such a waste]. I just kind of smile along with them it’s just that they don’t understand. I don’t get offended because they don’t know. (Elena)*

## The narrative of 'ma'i'

The word *ma'i* was identified from these participants as the primary term that Samoans employed to describe and define them. Ma'i is the Samoan word for illness, sickness or disease (Milner 1966, Pratt 1984). The usage of ma'i to describe Samoans with a disability was considered incorrect and improper for these reasons: disability is not an illness or disease that is contracted and curable, disability does not negate living an active normal life, and disability does not equate to being abnormal. The following quotes reiterate similar comments made by other participants:

*She'll (mum) class me as being ma'i and I'll always say to her 'what kind of ma'i? Do you think I'm ma'i? You know ma'i is like flu.'* (Elena)

*Call me sick when I've got the flu, when there's a reason to go to a hospital that's when I'm sick. The doctors told me that I can live a normal life there's nothing wrong with me besides not being able to walk. The perception out there is because you can't do normal functions.* (Elia)

*If you're vision impaired they think that your sight is missing so then there's something wrong with you, you're ma'i not normal.* (Veronika)

The use of *kagaka ma'i* (sick person) or *kagaka mama'i* (sick people) to classify Samoans with a disability was a blanket term that did not reflect their lived realities. Participants with a vision impairment shared a common perspective that despite the onset of partial or total blindness the body can still function, that they are physically able to perform daily and routine tasks inside the home, at work, and in the community. This was compared to sighted people who have some illness, feel pain in their body and are restricted from undertaking normal tasks over periods of time. Participants with a physical disability, on the other hand, acknowledged their bodily limitations and reliance on using a wheelchair to enable them to perform some daily and routine tasks inside the home, at work and in the community. As one participant relayed: *I use a wheelchair as an extra equipment that I wasn't born with, I don't believe I'm sick. There*



*are certain things that I can't do and that's the disadvantage, this disability that I have (Elia).*

There is a strong resistance to being called and labelled ma'i because Samoans with a disability are simply not ill or sick:

*We have this whole generic word of kagaka mama'i [sick people] and I guess even if you put that back into the English translation that's it very almost degrading for a person who has a disability. Those are words that I've heard that would associate for everybody with a disability. (Tavita)*

### **Disability is not 'malaia'**

This word *malaia* was identified from these participants as a correlation to their disability. Malaia is a Samoan word which generally means 'calamity' (Pratt 1984) misfortune and curse. There was strong opposition to being described as unfortunate and cursed and the rationale for this was framed in two ways: challenging cultural views that disability originates from a generational curse, and challenging religious views that disability is a punishment. There is a prevailing cultural perspective with supernatural undertones that malaia or the disability is tangible evidence that someone in the family has committed a wrongful act. Until this is addressed, the malaia will be passed on to other members and future generations. As one participant conveyed: *the fofos that dealt with us one said it was because of our dad's family, another fofo said it was because of our mum's family, they have different reasons (Veronika).*

The introduction of Christianity in Samoa in 1830 ushered a new religious belief system into the fabric of Samoan society. Belief in God permeated the hearts and minds and this was demonstrated through regular church attendance, participation in the life of the church community, reading the bible and daily family prayers. The opposing perspective that disability is not malaia reveals the dichotomy of culture vs religion. This culture/religion dichotomy in regard to disability brings to the fore the contradictions of belief systems but also the motivation to challenge assumptions. Many participants shifted their thinking to view the positive aspects of disability, and this is reflected in the following quotes *In Samoa they always say 'oh you're malaia, you're*

*cursed' but to me it's not a curse it's a gift. People think I'm crazy when I say it's a gift. They say 'is it a gift to be blind?' I said 'well it's better than saying you're malaia. 'I have a great belief (in God) but a lot of people say it's a malaia. I go 'why malaia? You make your own malaia, if you do something wrong you make your own malaia. (Malia)*

*For an ethnic minority that believes in Christ and all that they always look on the negative and I can't believe that crap. I say 'actually hang on, why is it something bad? Why isn't it something good? There's always a good side to things. (Isa'ako)*

Traditional perspectives and negative cultural conceptions about disability can hinder QoL of persons with a disability. At the service provision level, organisations providing supports to diverse groups may have inadequate knowledge and low awareness on deeply held beliefs these groups hold to. The resulting behaviours include 1) Samoans with a disability and their families do not access support services, and 2) Samoans with a disability and their families do access support services. These participants accessed services to improve their QoL. At the service provision level, without cultural understandings (Norris, Fa'alau et al. 2009, Faletolu 2010) the design and quality of the services offered can worsen or reduce their QoL.

On the whole, the majority of participants circumvented the notion of disability as a malaia and adopted a pragmatic view. This pragmatism was based on medical knowledge of their disability, parental responses and the positive effects of the disability:

*Oh no (not a curse) I manage to explain to everyone that it's because my spinal chord so the medical part of it has become introduced into my environment being family and friends. (Elia)*

*I think my parents felt it wasn't so much of a curse but that it was a challenge that was given to them in their own life. My dad has a philosophy 'what's happened has happened and let's deal with it rather than wondering why.' (Tavita)*

*I've learnt to accept it as a gift because if I was not blind vision impaired I would still be killing myself working 2 jobs, I wasn't taking care of myself. (Malia)*

## Perceptions of identity

The construction of identity is multifactorial and situated within a context of time, place and space. Half of these participants grew up in Samoa and migrated to Aotearoa New Zealand while the other half were born or spent most of their life growing up in Aotearoa New Zealand. The former were steeped in routine Samoan socialisation processes, for example: *I quite enjoyed growing up there sort of grounded in my roots taught me the values that I hold near to myself (Elia)*; while the latter also raised in similar ways contended with various definitions of ‘a real Samoan’: *for most of us born here especially half of the 50s to the latter stages of 60s we’ve had to pick and choose whether we wanted to be fobs (acronym for fresh-off-the-boat) or NZ-born, hopefully what I’ve done is actually not chosen one but both (Lafaele)*. Nonetheless they self-identified as Samoans.

There was a uniformity in that the family was the principal source of driving and developing the formation of the cultural identity. The Samoan habitus composed of values, belief systems and customary practices shaped subsequent attitudes and behaviour. This was evidenced through participation in family events such as contributing to fa’alavelave (significant events e.g. funeral, wedding, title ceremonies), travel to visit an ill parent, attend a funeral, lead the family court case, and active role in customary practices. Participants raised in Samoa were more likely to enact the Samoan habitus, which was informed by ascribed social roles and social status in the familial sphere:

*If there’s a fa’alavelave then I have to take a si’i [custom to show support] somewhere. Because I got a alii [high chief] title then I’ve got a kaule’ale’a [untitled male] to come and take it. It depends cause there are houses with steps so I can’t go in there so I make them come out to the van. (Samuelu)*

*Summary of Samoan verbatim: He returned from Samoa in February having attended a court case at Land and Titles. He prepared the family submission and had worked on this for over 3 months. He spent a great deal of time on the computer scanning documents,*

*writing the submission and adding attachments. He lead the family as the spokesperson for the case and the family won the case. (Ioane)*

However, the inception of disability introduced a layer of complexity into the constitution of the Samoan cultural identity for NZ-born Samoans. The reinforcement of their cultural identity through contributing to fa'alavelave and customary rituals was dependent on family perceptions of their ability to undertake this. For some the family selected a task appropriate to the person being able to undertake this with their vision impairment, while for others, the family waived the person's ability to contribute because of their vision impairment. For the latter, this was tied into cultural perceptions that a person with a disability is 'not whole' that the body, hence the person, is functionally restricted to perform normal activities:

*I really wanted to know how to do and learn all about Fa'aSamoa and then they (family) said 'yeah well we're gonna give you this part to do and you're gonna folafola the ava [announce the names of the person to receive the kava]' then they said 'oh but you're gonna have to learn' and I said 'oh yeah, nah I'll do it!' (Peniamina)*

*I've seen that when faalavelaves do come around everybody but me are expected to contribute. A couple of situations with my uncle I said 'cool just let me know when you guys are gathering everything up and I can contribute,' 'aua ke popole fua, ku'u ia o la e akoakoa lakou [don't you worry, leave it to the others they're whole]. There's still that perception 'don't ask him cos he's sick, leave him to look after his own money, money to look after him.' Well what difference am I with the next person whose struggling financially? (Tavita)*

In contrast, participants with a physical disability had been contributing to fa'alavelave and taking part in customary rituals and family events. The onset of the disability meant a reconfiguration of what commitments and events they could participate in. This new level of involvement was more to do with the accessibility of the venue in their wheelchairs and the weather: *Lafaele is likely as most people with paraplegia to get pneumonia we can't afford to get him wet so can't go, it does preclude Lafaele from a lot of things that normally he would be*

*an intrinsic part of (Mata).* The layer of complexity that disability adds to the Samoan cultural identity is markedly different between those with a vision impairment and those with an acquired physical disability. The convergence lies in the restrictions that prevent or exclude the person from full participation as a Samoan in cultural activities and commitments. It is the Samoan conceptions of disability which largely influences this. As one participant articulated:

*Being disabled still does diminish your identity as a Samoan. If I promoted myself as a musician and they (Samoan public) knew I was blind, I'm a blind Samoan musician. They would actually acknowledge my disability before my culture before my identity. I'm therefore known as a blind Samoan musician not a Samoan musician who happens to be blind. It does happen a lot. (Tavita)*

The labels and terms commonly used to define someone with a disability living in Aotearoa New Zealand was generally accepted. Most did not mind 'person with a disability,' 'disabled person,' 'person with vision impairment,' or 'vision impaired' in a formal situation of accessing a service, resource or venue. Vision impairment was preferred to blind because it acknowledged varying degrees of sightedness. There were reservations, however, in relation to internalising these terms. Two main reasons presented were: they don't see themselves with a disability because they still have the ability to conduct manual activities, and the authentic person becomes obscured when a disability, thus restrictions, is emphasised. This suggests an ongoing inner conflict in the structure-agency dichotomy, a resistance to external labels in favour of self-definition of one's strengths and abilities. The following quotes illustrate similar comments made by other participants:

*When it comes to formal stuff then I have to be put under the disability but knowing in my heart I'm still able-bodied person but I just don't walk. I can still do things. I can still talk and write yeah just do things sitting down in a chair. If I'm filling out a form or going to places you have to access because is it disability accessible then I put that kind of category. (Elena)*

*I like saying limited abilities cos we're not totally disabled, we just limited at the moment. Disability doesn't bother me because I just don't let it bother me. I still can get up everyday, vacuum my house, mop my floors, hang my washing out, the only thing is I do it slow. (Rasela)*

*Paralysed disabled I don't mind being called that. I don't mind being referred to as someone that has a disability. We've become a society that puts labels on so many things that if the label sticks to you then that becomes you and the real you becomes shadowed by it. There are instances where it's appropriate given the context. (Elia)*

### **An instrument for advocacy**

The negotiation of Samoan cultural identity vis-à-vis disability identity in the Samoan and NZ context is a continuous exercise of meaning-making for many participants. Advocacy was an outgrowth of this negotiation process. There were two types of advocacy and are classified as internal advocacy and external advocacy. Internal advocacy is oriented to raising new consciousness amongst Samoans about their loved ones with a disability and Samoans living with a disability. This is premised on supplanting the deficiencies model with a strengths-based capabilities model. The first set of particulars are the availability of supports, access to resources and technological advances to enable social contact, study and work: *what people don't realise is that disabled people themselves are quite wealthy, wealth in the context there are so many support mechanisms from the State. As a disabled person I get half price taxis through my mobility card, mobility parking card, I'm able to get free education and pursue any type of learning within reason (Lafaele)*. The second set of particulars are the family conceptions that a person with a disability is doomed to a miserable and unhappy life: *a lot of attitudes needs to change, disabled people here in NZ are lucky, they have so much support here. A lot of our families need to let go a little and to understand that well you've got a disability it's not the end of the world (Tavita)*. These participants were actively working in the disability sector at the community level.

A facet of internal advocacy emerged in the realm of social support groups. In this scenario the members of the Pacific Island support group for vision impairment met to discuss formalising the group. The conversations involved preparing a constitution. As the constitution included Samoan terminology and definitions there was considerable debate between the Samoan-born and Aotearoa New Zealand-born participants. The latter group lived with a vision impairment for most of their lives opposed the words ‘kauaso’ and ‘blind’ and favoured terms that were inclusive. They preferred ‘afaiga va’ai’ and ‘vision impairment’ to signal the varying degrees of sightedness from person to person. When asked by the Samoan-born, who had acquired their vision impairment, if they were embarrassed to be ‘kauaso’ they explained that from their lived experience it held negative connotations that propagated damaging perspectives of their personhood. To change Samoan attitudes of Samoans with a vision impairment it was considered vital to be unified on the terms that they wanted rather than accept long-standing and outdated terms: *We choose to be Samoan so we have to work with these Samoans and change their attitudes. If we’re gonna change the attitudes of other people we have to change ours first we have to be on the same line if we want to go out there (Veronika).*

External advocacy is oriented to speaking on behalf of Samoans and Pacific peoples with a disability in mainstream disability organisations and challenging mainstream perceptions of Samoans with a disability. It was from negative experiences of these mainstream organisations that precipitated self-advocacy and the confidence to advocate for others. As one participant relayed: *Yes he’s good because he (Samuelu) sticks up for himself. A lot of the island Pacific people won’t do that. He’ll get those phone calls from the Spinal Unit ‘can you please come and talk to so and so.’ You see they still in shock with their injury or sickness and no-one will tell them ‘look you have to speak up for this and this’ no-one will tell them (Ruta).* This view was echoed by others who recognised that Samoan and Pacific families were not receiving the entitled services and resources because they were not voicing their needs. As one participant

stated: *Elena and I would love to help out with Pacific Island people because they are the number 1 humble people in the world they just take what they're given and that's wrong. Our parents say 'oh no you shouldn't talk like that' well that's wrong. You've got to nowadays you have to stand up to what you're entitled to (Isa'ako).*

The five challenges show multiple layers of complexity in re/composing a strong sense of self. Opposition to Samoan terms of 'kalofa e,' 'ma'i,' and 'malaia' as well as 'kauaso' to define Samoans with a vision impairment and physical disability was prominent. In contrast the English terms 'disability,' 'disabled person' or 'person with a disability' was considered appropriate provided this was used in context however most did not rely on this to define who they envisaged themselves to be. Cultural identity and disability identity intersect and this was more pronounced for the Aotearoa New Zealand-born cohort. Advocacy stemmed from personal experience living with a disability or family exposure to living with a loved one with a disability. Internal and external advocacy highlight the acquired forms of capital to sustain an advocacy role. These are social capital, Samoan cultural capital (Samoan language proficiency, knowledge of culture and protocols), institutional capital (English language proficiency, institutional knowledge, disability rights). The quest to fashion a life of happiness and fulfilment as Samoans with a disability in Aotearoa New Zealand is presented.

### **Forging a quality of life**

This theme focuses on the components that these participants consider important in framing a life of happiness and fulfilment. The two previous themes form the basis of forging a good life, a QoL for Samoans with a disability. Bourdieu's concepts are used to decipher and unpack these components which facilitate and hinder a good life, a QoL. For Samoans with a disability 'to get on with life' there are elements of the Samoan habitus that is fundamental in conjunction with the accumulated forms of capital to restore a sense of normality.



## Performance of roles

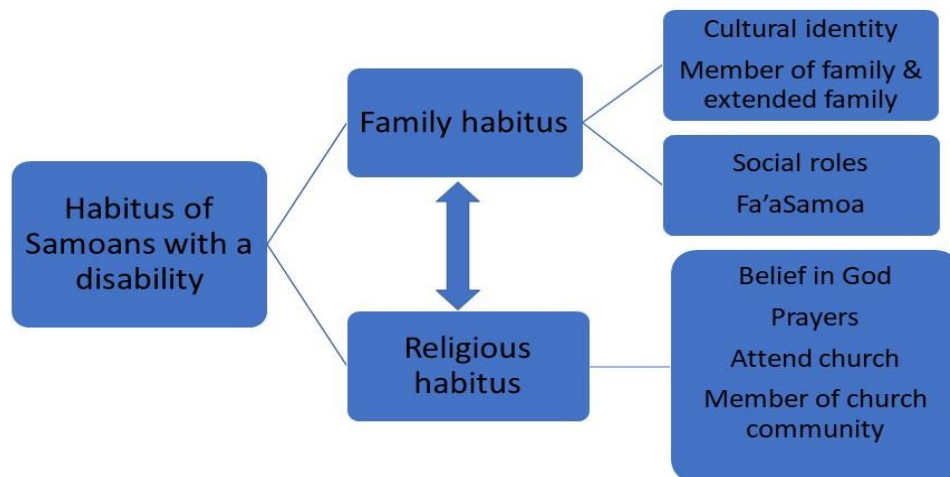
The data showed that these participants were leading active and productive lives. Those who had acquired their vision impairment and physical disability were particularly sensitive to carrying out their social and economic roles in the family. Most of these participants were wives, husbands, parents, and grandparents; and active in community, church and family activities. The motivation to re-enact these roles was framed in the context of the well-being of the family unit. As this participant's remark, and similarly voiced from other participants, illustrates: *Just making the most of what I've got now doing things differently what I did when I was able-bodied and just appreciating everyday as it is. I can't spend my energy moping around I need to keep me well and care for my family (Elena)*. It was shown in the second theme how two participants were fulfilling their social roles in the wider family collective. The social organisation of Samoan society is stratified in terms of the role of men and women (Meleisea 1987) and its complementarity in how the well-being of the family is prescribed and lived. The resiliency, gradual acceptance of the disability and moving forward with life was rekindled in the main by the religious life of faith and prayer. Family and church are two core institutions in Samoan society (Pitt and Macpherson 1974). Bourdieu's concept of habitus is used here to identify and explicate the habitus of Samoans with a disability.

Habitus is the set of dispositions, values, beliefs and norms that shapes and guides a person's behaviour and practices (Bourdieu 1977). The collective habitus of Samoans with a disability is composed of the family habitus and the religious habitus (see Figure 6.3). It is the family habitus that governs the socialisation of a person into being and acting and activates the sense of belonging to the family and extended family (Bourdieu 1984, Park and Morris 2004). Social roles, including gender roles, are characterised through the family habitus. As one participant relayed:

*Summary of Samoan verbatim: Mothers are the ones who provide guidance within their families because it's their role as mothers to develop the spiritual life (Sina).*

The practice of culture or Fa'aSamoa is a cultural framework that depicts the enactment of Samoan values (e.g. fa'aaloalo, tautua and alofa) into social and cultural practice. The religious habitus is the formation of belief in a powerful God and the gift of salvation. Attending church and joining the church community as well as praying are practices associated with this habitus. Performing roles is vital to the building and sustainability of the well-being of the family and extended family. For these participants, this is an essential component into propagating a fulfilling life.

*Figure 6. 3 The collective habitus of Samoans with a disability*



The collective habitus of Samoans with a disability is the embodiment of a socialisation process. That is, that the structures of the social world or world of Samoans is incorporated into the body which in turn structures perceptions of and actions in that world (Bourdieu 1977, Bourdieu 1998) and is expressed in the ways of speaking, feeling, thinking and being (Bourdieu 1990). The personal or individual habitus of these Samoans with a disability was initially

moulded from within the collective habitus however no two individual habitus are exactly the same. Each of these participants have a unique biographical history and corpus of life experiences. Their personal habitus is permeable and responsive to what is happening around them (Reay 2004) and as such it evolves when encountering a new and different world.

### **Anchor of faith**

The data showed that the role of religion and church instilled faith and trust in the goodness of God. Participants drew from the religious habitus to make sense of their vision impairment and physical disability. For most the religious capital of faith provided a source of inner peace and trust in God's lovingkindness and yet-to-be-revealed plans: *God closed one door for me and opened the other door for me and that's how I see it, if I was sighted I wouldn't be home I'd be out working then I wouldn't have my time with my granddaughter, looking after family and being there for my daughter (Malia)*. Faith, in particular an evolving faith, inferred from the narratives (e.g. move on and try, realign my life, get on with life) was drawn on in terms of fostering resiliency. As one participant reiterated: *Everything happens for a reason we got two beautiful kids they came out of this plus we gone closer and stronger everyday (as a family). With the right attitude you can overcome any hurdles and what life throws at you (Samuelu)*. One participant (husband) shared similar sentiments: *We always think there's reasons that there's a purpose for her to be doing other things. I think she has a purpose to be doing genealogy work or there's something that's being prepared for her. That's my own understanding because the Lord works in mysterious ways (Paulo)*. Bourdieu (1986) conceptualises capital as accumulated assets and these exist as economic, social, cultural, institutional and symbolic. Religious capital emerged as one of the findings. Religious capital is a combination of personal faith, prayer life, church attendance, and church membership. For these participants, they drew on religious capital as a source of meaning-making in living with a disability and as a platform of courage to seek a fulfilling life, a QoL.

## **Appropriate resources for independent living**

Permanent residency status and New Zealand citizenship facilitated a person's eligibility as to whether they could or could not access State services. Those who migrated to Aotearoa New Zealand were supported by their siblings and extended family there who started the paperwork to apply for permanent residence. It was the nature of the disability event or the cause of the vision impairment and physical disability which determined the level of resources and supports these participants could receive from the State (see Table 6.4). The Accident Compensation Corporation (ACC) provided a much higher level of support and entitlements and played an active role in liaising with other agencies (i.e. Housing New Zealand Corporation, Rugby Foundation) to attain the material resources (e.g. van, housing modification, income support, disability equipment) for some participants. As one relayed: *it's always been difficult cos for one absolutely no ACC it doesn't apply to me it would have made life a bit easier but can't dwell on things that you can't get (Elia)*. Seeking proper resources was oriented towards achieving an independent life as a Samoan with a disability in Aotearoa New Zealand. An independent life entails the ability to do things for oneself, to plan and pursue personal and professional ambitions and to have autonomy in decision-making. As one participant expressed, and this was shared by other participants with a physical or vision impairment: *I always value my independence well that's what all vision impaired people value is their independence (Malia)*. Independent living is a broad concept that embraces the full range of human and civil rights, such as, to have personal relationships, be a parent, equal access to education, employment, training, leisure activities and participation in the life of the community (Morris 1993).

For these participants, seeking and accessing material resources in the State's disability sector was determined by the cause of their vision impairment and physical disability. This distinction generated a raft of challenges in their quest to improve QoL. Bourdieu's concepts

of habitus, capital, field and doxa illustrate these challenges. Doxa is the taken for granted assumptions entrenched within social practices (Wacquant 2006) and field is the social spaces where different actors interact in terms of their habitus and capital and subsequent practices (Bourdieu 1977). There are three challenges (see Figure 6.2). First, the adaptation to the NZ habitus of the kiwi culture, individualism, rights-based environment informed by legislation and international conventions and the doxic attitude that one size fits all. Second, the need to acquire institutional capital such as fluency in the English language and knowledge of disability services, disability entitlements and disability policies to seek and access material resources. Last, the ideological differences amongst services, and the struggles for these participants to navigate (or not) the agencies especially when the conceptions of disability is remarkably different and services focus more on the individual rather than the individual within the family collective. In contrast the Blind Foundation Pacific Services offered a culturally responsive approach to participants in the field of social and economic interventions by recognising a Samoan collective habitus and Samoan cultural capital.

### **Right carer supports for independent living**

The carers support is an integral part to enabling Samoans with a disability to achieve an independent life. Being independent is an essential component of quality of life (Barnes 2003, Reinders and Schalock 2014). To iterate that an independent life entails the ability to do things for oneself, to plan and pursue personal and professional ambitions and to have autonomy in decision-making. These participants sought either internal support from family or external support from community-based homecare services. For some, this was subject to their permanent residency status and internal support was the only option. Matching of the right carer supports was critical for those who had acquired their physical disability. As one carer emphasised: *she had a caregiver that was looking after her but the caregiver would not let mum (Rasela) do anything. One day I came home and she was just sitting on the couch and the lady*

*was feeding her and I was really angry I mean I know it's her job but it just seemed wrong that she was treating her like a baby. After the caregiver left mum picked up really well she recovered on her own she's got a strong mind (Sarai).* This signifies that the right carer supports is a composite of knowing the role of the caregiver, treating the person with dignity, and getting to know the person. Another carer noted: *I know exactly that he's going to get angry at something then I'll just back off let him calm down then I make a joke to make him laugh. I come to love him very much like my own brother and it makes my work easy (Naomi).*

For these participants seeking to reacquire their level of independence and restore their life to one of perceived normality, the choice of internal and external care supports was shaped by personal preference and circumstances. The external care support staff are sourced and recruited by community-based homecare services and assigned to people who apply for this support. Community-based homecare services receive funding from the State. One participant (wife) defined the ideal caregiver: *someone that cares, loves doing what they're doing, someone that is his (Samuelu) hands and legs. Why be a caregiver if you don't care? A few selective people will do this type of job that has the patience and knowledge to help the person and then there are some people that do it because it's a job (Ruta).* This family's negative experiences of caregivers reached a stage where Samuelu started to ring and raise concerns directly with the CEO of the homecare services which prompted quick action. To voice these concerns, Samuelu would have had to consider using institutional capital (e.g. knowledge of disability support services, entitlements and disability rights), social capital (e.g. access to senior management in the service) and cultural capital (e.g. English language) in the field of interventions or home care services (see Figure 6.2). He positioned himself in the field vis-à-vis agents and institution to articulate his apprehensions and needs. By doing this Samuelu highlights this field of power as a contested site where there are ideological differences over the concept and practice of care, and differing conceptions about QoL particularly when a person with a disability desires

independence and autonomy. At the level of service provision, the absence of the following: QoL as an outcome measure (Kober and Eggleton 2006), the principles to guide and measure QoL outcomes (Verdugo, Schalock et al. 2005) and cross-cultural understanding of QoL (Schalock, Brown et al. 2002) can impact the effectiveness of services to enhance the QoL of persons with a disability.

### **Connectedness to family and culture**

The connectedness to family and culture emerged as a finding that facilitates quality of life. Quality of life is “conditioned by social structure and culture of the community” such as institutional composition and cultural patterns (Ferriss 2006). From the stories shared, the prevailing conceptions of disability is that a Samoan with a disability is *ma’i* (sick), *malaia* (cursed or punished) and worthy of pity and sympathy as ‘the *kalofa e* people.’ The common response to this person is isolation and exclusion from participating in social and family activities. As one participant remarked, and similarly other participants had observed this: *Our Samoan families they still have this big issue of isolation for our loved ones for our people. In terms of not being included in things and the easiest thing is to leave them in the corner (Tavita).* This is indicative of the collective Samoan habitus, which consists of family habitus and religious habitus, and its widespread uniformity in how Samoans with a disability are to be viewed and treated. For these participants recomposing the self has occurred in social and cultural spaces within the Aotearoa New Zealand context. The experience of living in Aotearoa New Zealand has exposed most in particular the Aotearoa New Zealand-born cohort to a NZ mainstream habitus and utilising advantages such as technological advances to live a normal life. One participant relayed: *we schooled here, reading braille, typing we were able to do things. There are things that have been adapted we can use computers go on the internet there’s talking software for phones so you can text, sports that have been adapted for blind people*

(Veronika). From this study, the Samoan habitus and NZ habitus are two sets of dispositions that Samoans with a disability draw from to live a satisfying life.

Both the Samoan habitus and NZ habitus are structured and structuring systems of disposition that constitutes and governs practices (Bourdieu 1977, Bourdieu 1990). They co-exist, intersect and operate in parallel ways depending on context. For these participants, the struggle to improve QoL is manifest in the field of interventions, home care services and Samoan cultural fields or sociocultural spaces. In their quest for a normal life or to enhance QoL, accessing material resources, disability services and homecare premised on organisational and staff recruitment policies, participants with the necessary capital will have a better ‘feel for the game’ than others. As one participant stated: *I think what people have to get around especially those who are disabled who are PI [Pacific Island] is the fact that they need to remember that they have equitable rights to living and what they need to re-embrace is their value (Lafaele)*. Accumulating institutional forms of capital is easier for the Aotearoa New Zealand- born cohort exposed regularly to the NZ habitus than their Samoan born counterparts. Although this latter group possess more Samoan cultural capital (i.e. Samoan language, knowledge and experience of Fa’aSamoa, social status) and tend to participate in family fa’alavelave or the Samoan cultural fields. The significance of connectedness to family and culture arose as a desired outcome for these participants to effect building an identity and foster a sense of belonging and wellbeing. At the service provision level, without an understanding of Pasefika indicators regarding wellbeing (Manuela and Sibley 2015), the heterogeneity of the Samoan identity in Aotearoa New Zealand (Anae 1998) and traditional perspectives on Samoans with a disability, the enterprise of delivering effective services can undermine their QoL.



## **Chapter summary**

The findings generated three interconnected themes and sub-themes. These identified the lived experiences, the process of recomposing the self and the components that constitute what a quality of life entails for a Samoan with a disability. The barriers and facilitators are explained. Bourdieu's relational thinking tools show that habitus, capital, doxa and field operate simultaneously and uncover the positioning and interplay of Samoan and NZ habitus and forms of capital within the network of socio-political relations in the field of interventions, home care services and cultural fields.

## **Chapter 7 Discussion of results**

### **Introduction**

The aim of this study was to explore the quality of life of Samoans with a disability living in Auckland, Aotearoa New Zealand. Data was generated from Samoan men and women with a disability and their partner or caregiver as outlined in Chapter 5. This chapter focuses on the findings, themes and discusses these in light of the research questions identified in Chapter 1. As this study was informed by Pierre Bourdieu's theoretical concepts: habitus, capital, field and doxa, this chapter illuminates the explanatory power of Bourdieu's concepts in relation to the quality of life of Samoans with a disability in Auckland. Bourdieu's concepts are relational thinking tools that form an interactional approach to looking at a phenomenon in relational terms (Maton 2003). That is, habitus, capital, field and doxa are interrelated and dynamic concepts which helps to unravel the structure-agency dichotomy. This is explained further in Chapter 3. The combined use of Bourdieu's concepts and the Voice-centred Relational Methodology (VCRM) is discussed enabling the hidden voices of the participants to be made visible. This chapter includes how the researcher attended to issues of validity, credibility and trustworthiness using theoretical, positional and personal reflexivity. Limitations of the study are also discussed in this chapter.

The findings are discussed in view of the three research questions. A summary of the key findings is provided in Table 7.1 to preface the discussion.

*Table 7. 1 Summary of key findings*

Research questions	Key findings	Data source
1. How do adult Samoans with various disabilities conceptualise and describe quality of life?	a) Independent living b) Normal life c) Connectedness to family networks and culture d) Performance of social roles	Interviews
2. What factors are reported by Samoans with disabilities that facilitate or inhibit their quality of life experiences?	a) Disability funding policy b) Personal grief over acquiring disability c) Religious and social capital d) Mismatch of external caregiver support e) Samoan traditional view of disability	Interviews
3. How do Samoans with disabilities perceive their ethnic identity in Auckland?	a) Affirmations of being Samoan b) Intersectionality of disability and ethnic identity c) Reframing cultural ideology	Interviews

The first research question is – **how do adult Samoans with various disabilities conceptualise and describe quality of life?** The key findings pertaining to this question are: independent living, normal life, connectedness to family networks and culture, and performance of social roles.

## **Independent living**

One of the emergent findings is that participants’ conceptualise quality of life as independent living. Independent living is a movement, originating in the USA late 1960s to early 1970s, that articulates the value of personal choice, independence and consumer sovereignty (Zarb 2004, White, Lloyd Simpson et al. 2010) for all persons with a disability residing in an institutional or community-based dwelling. As a philosophy, there are four main assumptions:

(1) that all human life, regardless of the nature, complexity and/or severity of impairment is of equal worth;

(2) that anyone whatever the nature, complexity and/or severity of their impairment has the capacity to make choices and should be enabled to make those choices;

(3) that people who are disabled by societal responses to any form of accredited impairment have the right to exercise control over their lives, and

(4) that people with perceived impairments and labelled ‘disabled’ have the right to participate fully in all areas, economic, political and cultural of mainstream community living (Barnes 2003).

In short, independent living means every person with a disability ought to be afforded the dignity, personal choice and control, and empowered to participate as humans and citizens in all areas of life, similar to others (Zarb 2004, Pallisera, Vilà et al. 2018). From participants’ narratives their notion of independent living arguably corresponds to the World Health Organization (WHO) definition of quality of life (QoL). The WHO, in their positional paper, defines QoL as “individuals’ perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations standards and concerns,” and conceptualised as “a broad ranging concept incorporating in a complex way individuals’ physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment” (World Health Organization Quality of Life Group 1995). Although it has been argued that the WHO definition of QoL is specific to the field of health-related quality of life (Barcaccia, Esposito et al. 2013, Van Hecke, Claes et al. 2017), it correlates with participant narratives in how they considered and valued their independent living in reference to these dimensions (e.g. physical, psychological and social) and domains (e.g. social relationships, spirituality and religion) that

feature in the composite of human life. As a socio-cultural construct, QoL or independent living, fulfils three universal needs of (1) safety and security, (2) sense of integrity and meaning in life, and (3) a sense of belonging in one's social network (Kagawa-Singer, Padilla et al. 2010). In other words, independent living embraces the person's human and civil rights, manifest in a variety of ways, such as, having personal relationships, being a parent, equal access to education, employment, training and leisure activities and to participate in the life of the community (Morris 1993). Perceptions of these participants' stance on independent living can be explicated in Bourdieu's habitus. Habitus is 'a socialized subjectivity' which is the process of internalising a structure that is structured by an individual's past and present circumstances (Maton 2008). Beliefs, values, norms and family upbringing are examples implicit in this structured structure of traditional societies. In other words, the individual's subjectivity has formed from within the realms of a social world. To note that 'socialized subjectivity' is part of Bourdieu's habitus. For many of these participants, they drew on their personal habitus to conceptualise independent living as QoL. Malia, Tavita, Ioane and Naomi's comments illustrate this, respectively:

*I always value my independence well that's what all vision impaired people value is their independence.*

*We have a process here at the Foundation where the services offered either maintain or establish a person's independence. Staff would help me find techniques that would help me cook. The same with mobility using techniques to allow me to walk around safely .*

*Summary of Samoan verbatim: He did computer training at the Blind Foundation. He found that he couldn't write things down, write a letter or stay in contact but since the computer training a whole new world has opened up. Now he's able to re-establish contact through emails and use the internet to prepare documents. The computer has been a huge benefit to living again because it allows social contact. He's thankful for the Disability Resource Service and did a course last year at Auckland University of Technology. The Disability Resource Service makes enrolment and attending courses*

*possible. He contacted the Blind Foundation for computer equipment to help with his course and was fortunate to receive a computer, printer, scanner and appropriate software. He uses the computer regularly. He finished his Certificate in Liaising Interpreting last year. Last week he submitted his cv to the Auckland District Health Board in order to register as a Samoan interpreter for their services. They have a need for Samoan interpreters in the hospitals, courts and similar institutions. He heard about Workbridge so applied to them.*

*You see that's the difference between him and other people (with a disability) he does it for himself. That's what I mean he's a very independent man, he wants to do it by himself not letting other people do it.*

## **Normal life**

The findings suggest that Samoans with a disability equate a perceived normal life with quality of life (QoL). The conceptions of normal life are, however, framed from values-based perspectives and driven by culture (Freud 1999, Sewell 2004). As a socio-cultural construct, the normal life for these participants emanates from a Samoan cultural perspective on life-course. The life-course perspective reiterates the social creation of meanings concerned with life transitions at the individual and family level within a socio-historical context over time and space (Bengtson and Allen 1993, Marshall and Mueller 2003, Alwin, Felmlee et al. 2018, Hutchison 2018). Similarly, life-course can be viewed as an age-graded sequence of social roles and events that are enacted and re-enacted over time (Elder and Shanahan 2006). It is salient that the Samoan life-course is iterated because it constitutes typical norms and expectations on how one progresses through life, identifies the age-graded sequence of undertaking social roles and that cultural values underscore and shape the meaning-making context. In this sense, culture “is a concrete and bounded world of beliefs and practices” and “one is assumed to belong to or to be isomorphic with a society or clearly identifiable group” (Sewell, 2004, p. 39). For these participants, the conceptualisation of QoL is synonymous with living a normal life: ability to engage in fulltime employment, pursue personal and professional goals, participate in family

and social activities, and perform familial and social roles. Their perception of QoL is further explicated through Bourdieu's habitus. Habitus is a 'socialized subjectivity' and the 'social embodied' which is the process of internalising a structure, that is structured by an individual's past and present circumstances; and structuring in the sense of shaping an individual's current and future practices (Maton, 2008). The Samoan life-course is an example of a system of dispositions that generates perceptions, appreciations and practices (Bourdieu 1990) and what is considered normal life. One of the participant's comments illustrate this:

*I'm a working person, I like to be up and doing things. (I felt) Abnormal in the sense that I was restricted in the things that I used to do but now I'm able to do much much more maybe not the same things but I'm able to do new things that I wasn't able to do before. I feel I'm a normal person now. I can't see but I'm able to do a lot more things (Ioane).*

### **Connectedness to family networks and culture**

Participants described and conceptualised quality of life (QoL) within socio-cultural milieus of family, extended family, cultural heritage and communalism. It is well-documented that the family institution (*aiga*) is a cornerstone of Samoan life (Pitt and Macpherson 1974, Fitzgerald and Howard 1990, Va'a 2001, Fa'alau and Jensen 2006). These participants were sons, daughters, wives, husbands, parents and grandparents and active in family, church and community activities. The principal trajectory in conceptualising QoL was predicated on maintaining the well-being of the family unit through the optimal performance of specific, ascribed and valued roles. Social functioning and fulfilment of kinship obligations are contributors to life satisfaction and happiness (Young-Leslie and Moore 2012, Aldersey, Francis et al. 2017). Maintaining relationships and connectedness to family and cultural heritage in conjunction with performing familial and social roles were critical aspects of how participants' conceptualised QoL. Culture is a dimension that cannot be ignored as a component of quality of life (Barcaccia, Esposito et al. 2013). It was discussed previously that these participants' conceptualise QoL as independent living and normal life, and this

conceptualisation of maintenance of strong ties to family networks and culture form an aggregate picture of what constitutes QoL. Connectedness to family networks and culture is inextricably linked to and situated within the scope of the wellness and well-being of family or family QoL. Recent studies in the field of Family Quality of Life (FQoL), particularly when a family member has a disability, shows that individual QoL is integral to family QoL and that separating the individual QoL from family QoL overlooks the ways family members contribute to the well-being of the family collective (Chiu, Kyzar et al. 2013, Aldersey, Francis et al. 2017, Boelsma, Caubo-Damen et al. 2017, Schmidt, Schmidt et al. 2017).

These studies also iterate that FQoL is a dynamic and relational concept. Bourdieu's idea of network relations, expounded in habitus and field, unpack the interface of individual QoL and FQoL. As a system of dispositions, habitus is a way of being and guides tendencies and inclinations (Maton 2008). The habitus of these participants embodies socialisation processes, norms and values and associated practices in accordance with the habitus of the family. These dispositions are durable and transposable (Bourdieu 1977). The participants' habitus corresponds to field or social spaces they engage with. Bourdieu conceptualises habitus and field in relational terms (Wacquant 1989). On the one hand field structures the habitus, and on the other hand habitus contributes to constituting the field as a meaningful world (Bourdieu and Wacquant 1992). For most of these participants, integrating individual QoL and FQoL is relational and necessary to improving QoL. Moreover, it highlights the fluid nature of network relations and importance of relationships. Elena and Peniamina's comments, respectively, demonstrate the process of movement that occurs across the life-course to foster QoL:

*We've also taken on a paper run just for family exercise. We're also in an organisation and it's a family organisation where four families are involved and it's to make changes to our lifestyle with being obese cos in our family we're quite overly large.*

*I really wanted to know how to do and learn all about Fa'aSamoa and then they (family) said 'yeah well we're gonna give you this part to do and you're gonna folafola the ava*



*[announce the names of the person to receive the kava]' then they said 'oh but you're gonna have to learn' and I said 'oh yeah, nah I'll do it!'*

## **Performance of social roles**

A key finding was how participants' conceptualised quality of life (QoL) in the performance of social and familial roles. This was briefly alluded to in the previous section of connectedness to family networks and culture. The four interventions that participants and their families explored to enhance QoL can be perceived as mechanisms to strengthen the integration of individual-referenced quality of life (QoL) and family-referenced quality of life (FQoL). More significantly, these interventions or pathways bring into sharp view how the performance of social roles within a family collective are manifested in the planning, decision making process and subsequent courses of action. Participants' families were the principal drivers in devising a course of action and although this varied for each participant (e.g. age, marital status) the family network were typically parents, spouses, siblings and extended family. Members of the family network lived in Samoa, Aotearoa New Zealand and other countries and offered practical support and assistance with any tasks that were required to help the participant regain body functionality and acquire material and financial supports and opportunities for independent living. Five participants acquired their impairment in Samoa and eventually moved to Aotearoa New Zealand. As Elia, Sina, Tomasi, Ioane and Mikaele respectively illustrate:

*It was either gonna be here (NZ) or Australia and most of mum and dad's family is here.*

*Summary of Samoan verbatim: Her siblings brought her (to NZ) because they were worried and they wanted to bring her quickly.*

*Summary of Samoan verbatim: He came on a visit to NZ and his family encouraged him to stay. They organised his papers for permanent residence.*

*Summary of Samoan verbatim: It was not an easy decision but thought about his children and inability to do things for them and decided to follow his family's advice to move to*

*NZ and explore new possibilities. They came in 2005. He greatly appreciated his family support, brothers and sisters in NZ, because he didn't come as a fit and healthy person with the ambition of providing for and looking after his family. Instead, he'd come as a sick person. His family were proactive in helping them settle and finding a place to live. Once they arrived, he began his quest for assistance, support and resources because this was the reason for moving.*

*I came here and went to Australia and Pakistan because I lead the blind cricket team. Some people in my family were quite surprised I went to Pakistan, they thought 'oh it's lucky to come here'.*

The performance of social roles within the family network indicates not only the participants' desire to actualise their social and familial roles but the role of the family network in sustaining the important feature of performing roles. Historically the interest in QoL reflects shifting perspectives of recognising that medical, scientific and technological advances are insufficient in improving life, the evolution of the normalization movement to the emergence of the consumer empowerment movement (Schalock, Brown et al. 2002, Verdugo, Schalock et al. 2005). The cultural, biomedical, social and economic interventions are reflective of these shifts. Schalock (2000, 2004) asserts that QoL is an over-riding principle that recognises the enhancement of a person's wellbeing and collaborative efforts to effect community and societal change. When QoL is conceptualised in this way, it signifies the prominence of the social, the context and the environment in improving QoL for these participants and their families. Collaborative efforts to effect change at the community and society level is made more visible when these participants are enabled to perform their social and familial roles. Bourdieu's concepts make visible the enactment of social roles and challenges in the journey to secure QoL. In Bourdieuan terms, these interventions (see Figure 6.2) represent fields or social spaces that they entered and positioned themselves vis-a-vis agents and institutions to seek a range of supports that would optimise QoL. Bourdieu's view on human action, which is evident in behaviours and practices, is generated from the intersection of habitus, capital and fields

(Swartz 2002). Empirical studies in inclusive education, health and social policy have documented the interplay of habitus, capital and fields (Bowman, 2010; Macaulay, Deppeler & Agbenyega, 2016; McKeever & Miller, 2004; Oldenhof & Wehrens, 2018). Findings from these studies show the cumulative effects of a logic of practice that influences behaviour and action, the strategic use of different forms of capital to optimise positioning in different fields (e.g. access medical services and resources), the amount of capital one possesses (e.g. economic, social, cultural, symbolic) can facilitate or hinder inclusion and participation, and propagation of social inequalities and disadvantage via the use of narrow frameworks in policy formation. Other studies illustrate the relationship between social capital (i.e. bonding and bridging), subjective wellbeing and identity for indigenous groups (Browne-Yung et al, 2013), potential distinctions between indigenous cultural capital and dominant cultural capital in mainstream society (Browne-Yung et al, 2013), and the transference of an ethnic group's habitus (e.g. Filipino) with associated forms of capital into a new country (e.g. Canada) particularly in identity maintenance and evaluating the types of capital to succeed in a mainstream or transnational habitus (Kelly & Lusi, 2006).

The cultural intervention, manifest in fofo, is shaped by the Samoan habitus. Fa'aSamoa or the Samoan way involves values such as the importance of knowing *aiga* (family) and *gafa* (genealogy) and demonstrating this through *fa'aaloalo* (respect) and *tautua* (service) are embodied and become part of the habitus (Park & Morris, 2004). This habitus is "ways of acting, feeling, thinking and being. It captures how we carry within us our history, how we bring this history into our present circumstances and how we then make choices to act in certain ways and not others" (Maton 2008). It is the embodiment of history and practices that are brought to bear on how to make sense, respond and form a course of action. Not all participants went to a fofo. Those that did were born with or acquired their vision impairment during their childhood and their parents took this course of action. This required the following forms of capital: (1)

social capital (e.g. access family and peer networks to find a fofo), (2) economic capital (e.g. money to fly the fofo from Samoa, financial gifting to and provision of food for the fofo), (3) Samoan cultural capital (e.g. Samoan language proficiency, knowledge of culture and protocols), (4) institutional capital (e.g. knowledge of how to make flight bookings, English language proficiency), and (5) symbolic capital (e.g. own a vehicle to transport the fofo, matai or chief status, house for the fofo to apply massage or Samoan medical treatment). Veronika's comments illustrate this experience:

*My family brought two fofo from Samoa when we (she and brothers) were very young and when we were teenagers and it just cost them so much. I just wish they'd forget about it but as soon as they hear of someone or someone that healed someone they have to go and look for them, find them and bring them over. The fofos that dealt with us one said it was because of our dad's family, another fofo said it was because of our mum's family, they just have different reasons*

The biomedical intervention predominated the experience of those with an acquired vision impairment and physical disability in adulthood. For participants living in Samoa at the time, medical expertise was sought in Aotearoa New Zealand because it was perceived to be of higher quality (e.g. facilities, diagnosis, treatment, surgery) and they had an established family network. The Samoan habitus was enacted, and a plan of action was initiated and put into motion. This required the following forms of capital: (1) social capital (e.g. access family and peer networks to learn what services were available, how to access these, identify family and contacts who can help liaise), (2) economic capital (e.g. money to fly to and from Aotearoa New Zealand, money for accommodation, money to pay for the services, money to acquire appropriate visas), (3) Samoan cultural capital (e.g. Samoan language proficiency, knowledge of culture and protocols), (4) institutional capital (e.g. knowledge of how to make contact with services and fill out forms, English language proficiency, map reading skills to travel to medical appointments and relevant venues), and (5) symbolic capital (e.g. a vehicle to travel, someone

to drive, matai or chief status or leadership skills). The accrual of these forms of capital differed for each participant (e.g. age, employment status, marital status, social status, citizenship or permanent residence status) and determined their positioning in the field of medical support and treatment. Although utilising this intervention did not restore full sight or mend the spinal cord, it meant that participants and their families had to confront living with a disability and explore avenues to facilitate QoL for the individual and family.

Accessing social and economic interventions was based on the type and cause of disability acquired in conjunction with their aspirations. The Blind Foundation supported participants to develop independent life skills (use oven and kitchen appliances to cook and make a cup of tea, use microwave, do household chores, navigate the home), and mobility skills (use a cane and guide dog) when out in the community, shopping, church and catch public transport. This contrasts with the focus on rehabilitation and utilising homecare services for participants with a physical disability (e.g. spend six months at the Spinal Unit). The dissonance of these interventions is captured from the type and volume of capital needed to position oneself favourably in the field, and the dominant ideology or rules of the game that determine who can and cannot participate (Bourdieu 1986). Participants had varying degrees of social capital, economic capital, institutional capital, cultural capital and symbolic capital to access different fields to secure the means to have a QoL in Aotearoa. This was not the case for all participants especially when the cause of the disability delineated the disability funding streams (e.g. Accident Compensation Corporation or Ministry of Health) and the subsequent material and economic resources one could access to live a satisfying and meaningful family life. Elena, Ruta and Elisapeta's comments, respectively, depict this:

*I have the bed provided by ACC that one elevates my legs as well as the back of my head. I also have a hoist to help me out transfers for my chair to the bed. The commode is a shower chair that I use. This house that we're in now is a 4 bedroom place with a wet area shower for my commode where I can just drive into and the kitchen is open plan with*

*the lounge to moved around in the house. I can access all the bedrooms without bumps and that. I also have a back up manual chair which I'll use if my power chair kind of like dies out. ACC and Housing NZ had come together and put a plan in as to what I wanted which was quite good and this is what I had asked for. We're really happy with it we're able to hold things here like family get togethers and that because we can't do it elsewhere. Yeah that (van) was funded by ACC we were lucky at that time it didn't need anymore changes to it. It's done us really good and we use it all the time you know.*

*The good thing when the Rugby Foundation help out and ACC. Rugby Foundation will help you with a car, with your children's education, they'll help out going to a private school or getting a good future for the children.*

*Summary of Samoan verbatim: There's a lot of support from ACC and the Blind Foundation. She has homecare which involves preparation of meals, cleaning the house and taking her out shopping. There's help with paying for taxis when she has appointments or goes to the hospital, and support from Blind Foundation where they taught her how to walk down the street, using the microwave to cook and cooking on the stove.*

These participants described and conceptualised QoL in four main ways. These four ways are interconnected and form an aggregate picture that QoL is conceptualised in a holistic manner. The facilitators and inhibitors of enhancing their QoL is discussed next.

The second research question is – **what factors are reported by Samoans with disabilities that facilitate or inhibit their quality of life experiences?** The findings pertaining to this question are: disability funding policy, personal grief over acquiring disability, religious and social capital, mismatch of external caregiver support, and Samoan traditional views of disability.

The findings underscore an ongoing process fraught with ups and downs and winds of change in the quest to secure a quality of life. This finding is consistent with Schalock and Verdugo's (2002) description of quality of life (QoL) as a dynamic concept which can change over time and this can result from changing environments. People's perceptions of their QoL

can also change according to the stage of life they are in (Schalock, Brown et al. 2002). Participants reported five factors that facilitate or inhibit QoL.

## **Disability funding policy**

Government and institutional policy guides and determines the allocation of funding and material resources. For New Zealand citizens and residents the nature and cause of their disability dictates which policy stream they fall under. It is primarily Ministry of Health or Accident Compensation Corporation (see Chapter 6). Accident Compensation Corporation (ACC) provides no fault accident insurance for personal injuries and those on the ACC scheme have better coverage (e.g. medical costs, lost earnings, and rehabilitation services) compared to Ministry of Health (see Table 6.3). Only three participants, acquiring their disability from an injury in the workplace, medical operation and playing rugby, were covered by ACC. Very few formal studies have been conducted comparing the outcomes of those on ACC and those not on ACC (Sullivan, Paul et al. 2010) however it has been argued that there is a disparity in service provision (Bennett, McPherson et al. 2014). In their recent longitudinal study on people with spinal cord injuries on ACC, many returned to the workforce (Paul, Derrett et al. 2013). Paul et al. (2013) conclude that being on the ACC scheme can mitigate against downward spiral of poverty and ill-health. It is inferred from their study that ACC eligibility can facilitate QoL. Elia wanted to secure a vehicle but was not eligible for ACC and Isa'ako makes light of the inequities:

*It would make life a lot easier for myself for my family. I appreciate that the field that I'm trying to get into requires mobility from office to court and court to office, clients and that sort of stuff. It (modified van) would be a very good resource for me to try and live as normal as I can be and independent as I can.*

*You have to fight for it and that's the difference between ACC and Ministry (of Health). With Ministry you have to fight for every little thing and with ACC just as long as you have an ACC number it's like the bank account's open. That sucks I don't think that's very fair. I always say to people that are on Ministry 'get in the car go have an accident then you'll be covered.' A person doesn't wear a seatbelt and he has an accident he's*

*covered and someone that has a genuine disability can't go have a shower in his own shower because he doesn't fall into the criteria, far out man! That's hard, so hard.*

ACC coverage was a facilitator of QoL for three participants and those ineligible for ACC found that this inhibited their QoL. Elia was one of the participants covered by Ministry of Health and in his quest to obtain QoL sought out additional agencies to secure resources. His journey led him to a disability funding agency (Vintage) and made application for a modified van:

*They told me that the policies that they have is that they would only fund a vehicle if I can prove that I can drive it myself.*

This scenario is troubling. Bourdieu's habitus, field, capital and doxa makes this visible. Habitus and field can be understood as relational structures and it is the relationship between these two structures that sheds light on understanding practice (Maton 2008). Field shapes habitus and vice-versa and is an ongoing process that is never complete nor static but continues to evolve. In order for Elia to secure a modified van he must enter the field of disability funding agency (or Vintage) with his habitus. However, Vintage is structured by its own structural mechanisms and relations (or NZ habitus) which is reflected in its policies and operations in the field (or rules to apply for funding). Elia has to make sense of these rules and position himself alongside other agents within this field and articulate a strong case to secure the van. There are vital forms of capital he needs to articulate his case especially if he is competing with other persons with a disability for this resource. The doxa or taken for granted assumptions he has to contend with may involve the presumption that applicants have a good command of written and spoken English, and credible proof that he does indeed have a disability. Elia is also expected to show that he can drive the modified van. This particular expectation is indicative of a hierarchy of impairments where some people have an advantage over others in procuring material support (hence fostering discrimination), and potential dis/ableism. Mortensen,



Hammell, Luts, Soles and Miller (2015) conclude, in their study with persons using power wheelchairs, that funding policies can be discriminatory and act as a barrier for those needing vital mobility resources to live life. They suggest a realignment of power relationships between the person and the organisation to increase a collaborative relationship and better reflect a client-centred approach. They advocate that organisations lobby for changes in the funding and provision of wheelchairs. It is inferred that lobbying for such changes applies to mobility and assistive devices which can contribute positively to one's QoL.

Shakespeare (2006) argues that the social model does not help to understand the complex relationship between the individual and environmental factors in the lived experiences of persons with a disability. Granted that the social model of disability underpins the State's disability policies, it is not mandatory for service providers and NGOs to adopt or incorporate this model into their organisational frameworks. Elia's situation highlights how other Samoans with a disability seeking similar resources have to get 'a feel for the game' and position themselves in the field with the necessary capital. The conflicts and struggles arise when a Samoan with a disability is perceived to have very limited or undervalued capital in the field and are overlooked in favour of others who have recognised capital. The implication is that Samoans with a disability and their families do not access support services and it is mistakenly assumed that they do not want nor need the services. Depending on the cause of the disability, disability funding policy can facilitate or impede QoL.

### **Personal grief over acquiring disability**

Participants report grief is one of the factors that can affect and impede quality of life (QoL). This was more pronounced for participants who had acquired their disability in adulthood. Bogart's (2014) study demonstrates that persons with a congenital disability adapt better to living with their disability than those with an acquired disability. In the former, this group had a higher disability self-concept (e.g. sense of identity, self-efficacy) and QoL compared to their

counterparts. Stress, crisis, loss and grief, body image, self-concept, stigma, uncertainty and unpredictability, and QoL are concepts to consider in the psychosocial adaptation of persons with a chronic illness or disability (Livneh and Antonak 2005). Shear et al., (2011) illustrate that unresolved or complicated grief is associated with prolonged distress, impairment in social, work and relationship functioning, poor health outcomes and suicide. Studies on persons acquiring a vision impairment show decreased mental well-being and a decline in social functioning (Thurston, Thurston et al. 2010), grief is a dynamic process rather than linear and this can differ according to the amount of time a person has lived with this impairment and the varying degrees of vision impairment (Murray, McKay et al. 2010) and reduction of social capital (e.g. relationships with friends, colleagues and community) (Bassey, Ellison et al. 2018). The findings in studies on persons acquiring a physical disability are congruent with the impact of grief on health and well-being. The occurrence and frequency of depression was identified (Dunn, Uswatte et al. 2009, Psarra and Kleftras 2013) as new realisations of living with a disability and its challenges set in. These studies are consistent with these participants' experiences of grief and loss following the onset of acquiring a physical or vision impairment. Grief was expressed individually (e.g. social isolation, depression, flow of tears, deep sadness) and collectively, even their families grieved. Ioane, Elena, Elia and Elisa's comments, respectively, highlight this:

*I was really down for 3-4 years, you feel helpless you're becoming a burden to other people, your own family and others. You're not able to help yourself so it's a sad very sad feeling.*

*After my injury you don't have time to think, you don't plan your life right there and then. The emotional side of things hit me later when I come home and that started to come out dribs and drabs. I think it's good to cry and let it out and I have done. It's an emotional experience.*

*My parents, it almost feels like they regret my accident more than I do. They've always wanted the best for me, for their children and it's a lot better now but the first early couple of years, I would always catch both of my parents crying. They always felt sad that my life was gonna be harder and they try and do as much as they can to make my life a bit more normal.*

*Summary of Samoan verbatim: The main emotion for her with his vision impairment was sadness that their family unit had changed. It was no longer the same, it's different and their lives have changed. Sad at the changes occurring and the decreased social contact because of the vision impairment.*

Laurie and Neimeyer (2008) emphasise that some cultures have a unique grief process and this suggests that (in relation to this study) parents, spouses and families are also experiencing profound grief and loss in less distinctive ways. Most of these participants had acquired their impairment in adulthood and had by that stage accumulated social, cultural, economic and Samoan cultural capital. They were active and comfortably participating in a range of fields (e.g. work, family, community, sports, church, culture). As Bourdieu puts it “when the habitus encounters a social world of which it is the product, it finds itself as “fish in water,” it does not feel the weight of the water and takes the world about itself for granted” (Wacquant 1989). The onset of personal grief following the acquired disability brought into sharp focus the reduction and stagnation of these forms of capital and the decline of taking part in these fields which they had been accustomed to for some time. Personal grief is a factor that can inhibit QoL.

### **Religious and social capital**

The church institution is a cornerstone of Samoan life (Pitt and Macpherson 1974, Lange 2005, Saada 2008, Thornton, Kerslake et al. 2010). Participants report that they drew from their religious capital as a source of hope and inspiration. Religious capital was one of the factors that facilitated their quality of life (QoL). Manuela and Sibley (2012) identified and incorporated religious centrality and embeddedness as a factor in their measurement tool, the

Pacific Identity and Wellbeing Scale. Religious capital is defined as “the patterns of beliefs and behaviours repeated over the human life-cycle, between generations and among family and friends” (Baker and Miles-Watson 2010). This coincides with the religious habitus mentioned in the previous chapter (see Figure 6.3). Participants’ narratives articulated three interrelated reasons which account for the significance of religious capital. These are: (1) to make sense of their physical disability and vision impairment, (2) as a font of meaning-making in living with the disability, and (3) as a platform of courage to seek QoL. Following a disability, people’s construal processes of how they assess, explain and draw meaning from their experiences represents an intentional act of finding a measure of happiness (Dunn, Uswatte et al. 2009) or subjective QoL. Holt, Schulz, Williams, Clark & Wang’s (2012) study reiterates that religious capital is a significant contributor towards positive emotional wellbeing. Conversely, Psarra and Kleftras’s (2013) study confirm the connection between the experiences of (and search for) meaning in life and positive psychological wellbeing. Dunn and Brody (2008) contend that there is a correlation between individual agency and communion with others that enables the good life. This signifies the combined effect of religious capital and social capital.

Some studies on the discourse of religious capital is accompanied with a focus on social capital (Baker and Miles-Watson 2010, Holt, Schulz et al. 2012, Yeary, Ounpraseuth et al. 2012, Grusendorf 2016). Apart from the obvious use of Bourdieu’s concept of capital to delineate religious, spiritual, social and symbolic capital in the fields of religion and public health, very little is mentioned about habitus. Habitus, field and capital is a triad of Bourdieu’s ideas on agency-structure and as a package it forms his conceptualisation of the logic of practice (Wacquant 2006). However, it is acknowledged that these authors had different intents and purposes. The religious and social capital of these participants emanates from their collective habitus which consists of family habitus and religious habitus (see Figure 6.3). To re-enter or continue their participation in social, cultural and religious fields they drew initially on religious

capital to find inner peace and trust in God, and to reappraise their lives as a person with a disability. Social capital was enacted as members of their family, extended family and church community. By capitalising on religious and social capital, participants found personal resolve and resiliency to ‘get on with life’ and increase QoL. As Malia, Paulo, Mata and Samuelu remarked, respectively:

*God closed one door for me and opened the other door for me and that’s how I see it, if I was sighted I wouldn’t be home I’d be out working then I wouldn’t have my time with my granddaughter, looking after family and being there for my daughter.*

*It’s only her parents that we ever look for advice and stuff. They’re the foundation of the family, members of their faith and because of that faith you tend to think ‘oh yeah, everything’s gonna be ok!’*

*What I’ve noticed in Pacific Island communities of disabled people is that they focus on solutions and there’s such a pervasive sense of not feeling sorry for yourself—just getting on with it. I’m not sure whether that comes from just a background of being stoic about problems in your life or whether it’s faith in God.*

*Everything happens for a reason we got 2 beautiful kids they came out of this plus we gone closer and stronger everyday (as a family). With the right attitude you can overcome any hurdles and what life throws at you.*

## **Mismatch of external caregiver support**

Some participants report the poor quality of homecare services or caregiver support received. This factor is an inhibitor to their quality of life (QoL). QoL has been described as a service delivery principle and basis for intervention and supports (Brown and Brown 2005, Schalock and Verdugo 2015). Studies show that the values of the family ought to be considered in promoting QoL (Brown and Brown 2003) and the role of the professional is to support the family to assume control and enact decisions that enhances and reinforces family and individual values (Wang and Brown 2009). The application of three QoL principles are relevant here, these

should: “(1) enhance a person’s wellbeing, (2) be applied in light of the individual’s cultural and ethnic heritage, and (3) enhance the degree of personal control and individual opportunity by the individual in relation to his/her activities, interventions and environments” (Schalock and Verdugo 2015). Negative experiences with external caregiver support can be attributed to the absence of applying these QoL principles in practice. Bigby (2006) suggests that the main focus is usually on day-to-day care and little regard is given to the vision for the person’s quality of life. Ruta (Samuelu’s wife) and Sarai (Rasela’s daughter), respectively, recounts such experiences:

*They come in late, want to finish early, they don’t want to do certain jobs that involve with personal cares, caregiving, physical parts or anything like that so why do the job? That’s why I get really angry with them, people don’t realise that you’re stopping our whole lives even if it’s just for half an hour to an hour. We have to plan things well ahead and sometimes if caregivers don’t come in then that plan gets demolished.*

*She had a caregiver that was looking after her but the caregiver would not let mum (Rasela) do anything. One day I came home and she was just sitting on the couch and the lady was feeding her and I was really angry I mean I know it’s her job but it just seemed wrong that she was treating her like a baby. After the caregiver left mum picked up really well she recovered on her own she’s got a strong mind.*

Bourdieu’s interactive concepts elucidate the experience of frustration and conflict. The caregiver’s habitus in conjunction with various forms of capital is conducting themselves in the field of disability support services. In other words, they enter the person’s home with their values and beliefs and perform a role as a trained professional. As a professional trained in caregiving supports, the ideology is to provide generic care and assistance. The participant and their family have their own habitus, which can differ significantly from the caregiver’s habitus (illustrated above), and forms of capital. The frustration and conflict arise at the systemic and practice level. Caregivers are structured into positions of power and these participants are perceived as passive recipients of care. Unequal power relations ensue and the agency of

participants is negated. These participants and family, however, have surpassed the notion of care and prefer supports tailored to meeting their individual and collective aspirations, and to enable QoL. In terms of models of disability, these negative experiences reflect the charity model (e.g. helpless and dependent) rather than the social model (e.g. social structures oppress and disable) which permeates key disability documents in Aotearoa New Zealand. The mismatch of external caregiver support was an inhibitor of their QoL.

### **Samoan traditional views of disability**

*I still believe our people with disabilities are still the 'oh kalofa e people' cos it still happens, you hear that with our Samoan people. I hear that a lot.*

Tavita's comment epitomises the consensus view of all participants in how Samoans with a disability are perceived by Samoans without a disability. '*Kalofa e*' generally means 'poor thing' or 'poor you' that is used to express sympathy towards a person or situation. By implication, the cultural ideology is that Samoans with a disability have suffered a terrible misfortune and are unlikely to lead satisfying and productive lives. The Samoan cultural discourse on disability contains terms and labels, such as, '*kalofa e*' (*poor thing/you*), '*ma'i*' (*sick*), '*kagaka ma'i*' (*sick person*), '*kagaka mama'i*' (*sick people*) and '*malaia*' (*curse*) that marginalise and propagate essentialist notions of Samoans with a disability. Participants' narratives reveal discontent and a strong distaste for these labels which undermines their personhood and inhibits their pursuit to foster quality of life (QoL). Agbenyega (2003) argues that labelling is a powerful tool in constructing disability and labels have the power to focus on deficits and overshadow potential capabilities of a person with a disability. The findings are consistent with previous studies which found that people with a disability do not wish to be viewed as objects of pity but as individuals who can make enormous contributions to society (Naemiratch and Manderson 2009, Cardona 2013, Owusu-Ansah and Mji 2013). Agmon, Sa'ar and Araten-Bergman's (2016) study on persons with a disability reveal culture-bound

assumptions of how Israelis with a disability are perceived. They highlight the Israeli cultural conditioning of normative personhood which consists of a strong functional body and mind and that to have a disability is to be less of a person. The notion of the flawless or perfect body is furthered in disability studies where a disabled body is devalued and considered inferior by societal norms that perpetuate structured inequalities and exclusionary practices (Edwards and Imrie 2003, Stewart 2016). Agmon et al's (2016) findings are congruent with traditional views of Samoans with a disability. In Bourdieu's terms, this exemplifies the very low positioning Samoans with a disability occupy in cultural spaces. They are perceived as either not a whole person or as people with limited or no capabilities coupled with scarce or non-existent capital. The doxic attitude inherent in cultural spaces or fields is that Samoans with a disability are sick, not a full person and unable to lead a normal life. Thus, they are accorded low or no status in their social worlds. Samoan traditional views of disability was an inhibitor of their QoL.

The third research question is – **how do Samoans with disabilities perceive their ethnic identity in Auckland?** The key findings pertaining to this question is: affirmations of being Samoan, intersectionality of disability and ethnic identity and reframing the cultural ideology.

I preface this section of the chapter in recognition, and anticipation, that this research question is a critical bridge to advance the discussion of the other two questions. The findings in this section are not isolated nor irrelevant, instead they are pervasive and intimately related to conceptualising quality of life (QoL) and the factors that facilitate or impede this.

### **Affirmations of being Samoan**

These participants self-identify as Samoans. Their conceptions of self-hood and ethnic identity is mirrored in local studies (Tamasese, Peteru et al. 2005, Anae 2010, Manuela and Sibley 2015). These studies converge on the centrality of context, socio-cultural factors and cultural values. Half of the participants in the present study grew up in Samoa whilst the other half were



born or spent most of their life growing up in Aotearoa New Zealand. The former were more comfortable and secure in their ethnic identity than their counterparts. Elia and Lafaele, respectively, highlight this contrast as well as the centrality of context:

*(I) quite enjoyed growing up there sort of grounded in my roots taught me the values that I hold near to myself.*

*For most of us born here especially half of the 50s to the latter stages of 60s we've had to pick and choose whether we wanted to be fobs (acronym for fresh-off-the-boat) or New Zealand-born, hopefully what I've done is actually not chosen one but both.*

To suggest that this latter group are insecure or unhappy about being Samoans is callous. On the contrary, there was pride and a sense of belonging derived from their personal and collective habitus (see Chapter 6). However it is erroneous to infer that this pride and sense of belonging was devoid of self-doubt, internal struggles and emotional turmoil. Two notable points are worthy of consideration: (1) the participants' perceptions of the self and identity (2) the participants' perceptions of how people see them and other Samoans with a disability. For a person with a disability, developing a positive sense of self and identity is a complex project based on self-recognition and the recognition from others (Shakespeare 1996) and can involve concurrently negotiating their impairment and assigning social meaning to it (Forber-Pratt, Lyew et al. 2017). Participant narratives indicate the challenges and difficulties of this complex project and it can vary, in form, duration and intensity, from person to person. Tavita and Veronika's comments illustrate the paradox of a positive self-image and identity and the low perceptions people have of their identity and generally Samoans with a disability:

*I've seen that when fa'alavelaves [crisis, unforeseen event] do come around everybody but me are expected to contribute. A couple of situations with my uncle I said 'cool just let me know when you guys are gathering everything up and I can contribute,' 'aua ke popole fua, ku'u ia o la e akoakoa lakou [don't you worry, leave it to the others they're whole]. There's still that perception 'don't ask him cos he's sick, leave him to look after*

*his own money, money to look after him. 'Well what difference am I with the next person whose struggling financially?*

*We choose to be Samoan so we have to work with these Samoans and change their attitudes. If we're gonna change the attitudes of other people we have to change ours first we have to be on the same line if we want to go out there.*

This is discussed more in the next section. One key distinction between the Samoa-born and Aotearoa New Zealand-born cohort is explained using Bourdieu's concepts. The cohort born and raised in Samoa embody a habitus that is structured by the conditions of their existence and generates beliefs, practices and feelings in accordance with its own structure (Maton 2008). This habitus is relational in that it "designates a mediation between objective structures and practices" (Wacquant 1989). In other words, the habitus of this cohort internalise and externalise social structures of Fa'aSamoa (Samoan way, ways of being) and engage regularly within fields of family, church, and village, with relative ease. These fields reinforce their habitus. A convoy of various forms of capital (i.e. cultural, social, economic, symbolic and Samoan cultural capital) has accumulated from their habitus and engagement in fields. Samuelu and Ioane's comment illustrates the forms of capital (mentioned above) that sustain and reaffirm ethnic identity in Samoan socio-political and cultural spaces in Aotearoa New Zealand and Samoa:

*If there's a fa'alavelave [crisis, unforeseen event] then I have to take a si'i [custom to show support] somewhere. Because I got a alii [high chief] title then I've got a kaule'ale'a [untitled male] to come and take it. It depends cause there are houses with steps so I can't go in there so I make them come out to the van.*

*Summary of Samoan verbatim: He returned from Samoa in February having attended a court case at Land and Titles. He prepared the family submission and had worked on this for over 3 months. He spent a great deal of time on the computer scanning documents, writing the submission and adding attachments. He lead the family as the spokesperson for the case and the family won the case.*

## **Intersectionality of disability and ethnic identity**

This follows on from the previous finding particularly in light of the disability identity. The findings indicate the presence of the concept of intersectionality in how Samoans with a disability perceive their ethnic identity. Kimberle Crenshaw (1989) introduced the term ‘intersectionality’ in her discussion on issues of black women’s employment in North America (cited in Yuval-Davis 2006). Intersectionality, in this regard, elevates the multiple markers of identity (i.e. black + woman) which interact to form a separate category of the experience of multiple oppressions (Mollow 2006). Similarly, the experiences of individuals who occupy multiple marginalised identities can be silenced by intersectional forms of oppression (Hernández-Saca, Gutmann Kahn et al. 2018). Mollow (2006) adds that “if race and disability are conceived of as discrete categories to be compared, contrasted, or arranged in order of priority, it becomes impossible to think through complex intersections of racism and ableism in the lives of disabled people of color” . Thus, intersectionality collates markers of identity (e.g. disability, gender, sexuality, race/ethnicity and class) not only to form theoretical responses but to consider how each marker supports the constitution of the other (Goodley 2011). For these participants, disability, ethnicity, gender, age, place of birth, marital status, citizenship status, social status and religion are markers of identity. Their ethnic and cultural identity can be considered as the master status “in the sense that it affects the person’s other roles all the time and for the person’s entire life” (Barnartt, 2013, p. 12). Earlier discussions on conceptualisations of QoL puts this into perspective. The onset and acquisition of physical disability or vision impairment introduced the marker of disability identity which did not sit comfortably with most participants. Most did not internalise the labels ‘disabled person’ or ‘person with a disability,’ though accepted its appropriation in context (e.g. accessing a disability support service, resource or venue) and felt that these labels overshadowed one’s

strengths, abilities, and authentic personhood. Elena, Rasela, Elia and Lafaele's remarks illuminate this, respectively:

*When it comes to formal stuff then I have to be put under the disability but knowing in my heart I'm still able-bodied person but I just don't walk. I can still do things. I can still talk and write yeah just do things sitting down in a chair. If I'm filling out a form or going to places you have to access because is it disability accessible then I put that kind of category.*

*I like saying limited abilities cos we're not totally disabled, we just limited at the moment. Disability doesn't bother me because I just don't let it bother me. I still can get up everyday, vacuum my house, mop my floors, hang my washing out, the only thing is I do it slow.*

*Paralysed disabled I don't mind being called that. I don't mind being referred to as someone that has a disability. We've become a society that puts labels on so many things that if the label sticks to you then that becomes you and the real you becomes shadowed by it. There are instances where it's appropriate given the context.*

*I think disability's just a trumped up word for disadvantage, it is another form of disadvantage whether it be physical or mental. It is a disadvantage so why blur the word? Why fragment the word to another level like disability?*

The disability identity is multifaceted, and these include feelings of solidarity and affinity with others with disabilities, disability activism, disability pride, and finding value, meaning and benefits in the disability experience (Bogart, 2014). Forber-Pratt, Lyew, Mueller and Samples (2017) reiterate this at the level of developing disability identity. They say that the disability identity can be considered as "a unique phenomenon that shapes individuals' ways of seeing themselves, their bodies and interactions with the world" and this identity takes shape when "the person with a disability simultaneously negotiates their physical impairment and the social meaning assigned to those impairments" (p. 204). Based on Bogart (2014) and Forber-Pratt et al., (2017) these participants reveal through their narratives that they have forged a preliminary disability identity in unconscious ways. Participants with a physical disability had

a different journey which contrasted significantly to their counterparts. Participants with a vision impairment found solidarity and affirmation of who they are through the active support of the Blind Foundation's Pacific Services. A defining characteristic of Pacific Services was its culturally responsive approach to working with Pacific people. In other words, this service and the participants had similar habitus (e.g. Samoan) and capital (e.g. cultural, social, Samoan cultural capital, symbolic) which enabled easier access to information and support (or field of disability support services). The habitus of the Pacific Services team had influenced and reconfigured the structural relations of the field and doxa and this transformed service delivery. In effect, these participants were positioned in a field that did not devalue their personhood and dignity nor compel them to compete for resources with others who had a vision impairment. This service also supported these participants to negotiate their vision impairment and explore the social meaning of this impairment. As Malia and Veronika comment, respectively:

*This is where the Foundation comes in, they help you to accept your vision impaired your disability like when you go through PI (Pacific Island) group. We have a group we get together we just have a laugh have coffee do our little business. We enjoy each other's company mainly.*

*It's good that there was a support group cos we've met other people. I've always wanted to meet other Samoans like us. It's good to know there are other people like us cos any palagi [European] would be different from any Samoan sighted or vision impaired. Palagi [European] vision impaired people are far different from us.*

The intersectionality of disability identity and ethnicity identity offers a lens on how categories are mutually constituting processes and serves to understand unique experiences at the intersection of multiple categories (Goethals, de Schauwer et al. 2015). Oliver and Barnes (2012) assert that it is important to recognise multiple identities however they caution that it must not distract attention away from a critical analysis of material and cultural forces that generate and sustain inequality and dependence. For participants born and/or raised in Aotearoa

New Zealand, the intersection of their disability identity and ethnic identity, reveals a raft of experiences that either diminishes or endorses their Samoan identity in different contexts and fields. Tavita's comment is an example of how cultural views of disability eclipse and minimise his strong self-concept of being Samoan:

*Being disabled still does diminish your identity as a Samoan. If I promoted myself as a musician and they (Samoan public) knew I was blind, I'm a blind Samoan musician. They would actually acknowledge my disability before my culture before my identity. I'm therefore known as a blind Samoan musician not a Samoan musician who happens to be blind. It does happen a lot.*

The material and cultural forces, Oliver and Barnes(2012) assert above, that generate and sustains inequalities is furthered by exploring the mechanisms that perpetuate this. There is an interplay of the Samoan habitus and NZ habitus which is enacted in behaviours and practice across various fields. Agents draw on their habitus or set of dispositions and explore how they can position themselves, with their acquired capital, in relation to other agents within a field or structured social universe (Maton 2018). Participants have encountered, adapted and incorporated the NZ habitus by living, schooling and working in NZ and as such have an additional set of dispositions to draw from. This involves acquiring the necessary capital (e.g. social, institutional, cultural, economic) to interact and participate effectively in different fields (e.g. workplace, classroom, community groups, self-employment). In terms of the Samoan habitus, the Samoan cultural capital (e.g. Samoan language proficiency, knowledge of culture and protocols) is essential in social, political and cultural spaces or fields. Struggles and inequalities arise when there are competing ideologies or doxa in relation to conceptions of disability. The following diagram (Figure 7.1) illustrates the intersectionality of disability and ethnic identity.

Figure 7. 1 Bourdieuan approach to intersectionality of disability and ethnic identity

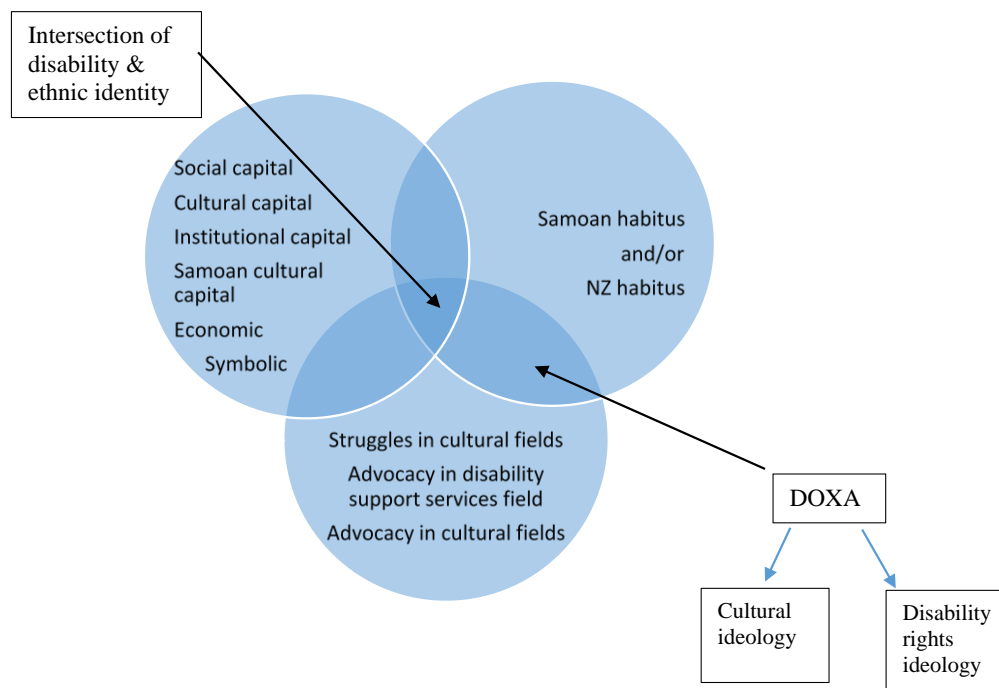


Figure 7.1 shows the relationship between the Samoan habitus and NZ habitus and the types of capital acquired to operate in the fields of culture and disability support services. The positions that these participants occupy in these fields is marked by the structure and volume of capital (Bourdieu and Wacquant 1992). For instance, the goal to secure material resources in disability support services fields requires cultural, economic, institutional and social capital. In the Aotearoa New Zealand context, the social model of disability underpins disability policies (e.g. ratification of the UN Convention on the Rights of Persons with Disabilities, launch of New Zealand Disability Strategy) and is further strengthened by the human rights approach (e.g. establish Minister for Disability Issues portfolio). The disability rights ideology is pervasive in Aotearoa. In contrast, only as recent as December 2016 did Samoa ratify the UN Convention on the Rights of Persons with Disabilities. The cultural ideology (discussed later) is pervasive in Samoa. Like many non-Western nations, the notion of human rights is new and foreign. Samuelu, Tavita and Veronika's comments, respectively, show aspects of this

intersectionality and ensuing tensions. They demonstrate three things: (1) the interplay of the Samoan and NZ habitus and competing ideologies which can explain inequalities, (2) the desire to strengthen ethnic identity and participate accordingly is minimised, and (3) embodiment of the interplay of the Samoan and NZ habitus, and capital to position oneself in order to raise consciousness and address inequalities, in specific fields:

*I mean it doesn't matter if you Tongan, Samoan, Maori or Palagi (European) once you're broke your neck we're all in the same category. We all got the same need, same equipment we need so it shouldn't be a problem. But it's just the Palagi can fight for what he wants and the island boy will sit back.*

*I couldn't participate in some of the activities related to the church because my disability overarched everything else so I couldn't participate in any of the Samoan stuff but as soon as dad passed away who did they (the church) call for support? It was just the sudden shock to my system because they were looking for direction from somebody ... apparently it had to come from a male representation in our family and my two older brothers, one of them having a matai (chief) title didn't know what was left and what was right. And it was lucky that my conversations with my mother helped me to remember a lot of the things that needed to be done and the conversations that were to be held on behalf of my father who could no longer speak for our family. It was just a major culture shock for me, and as to your question about what helps facilitate my own development – an event like that certainly did it. It helped me to be more prepared, better prepared and also to have an understanding around the Samoan culture when my mother passed away.*

*Difference between people who have just gone blind and people who have been blind all their life because we were sorting out our constitution last year to be registered and we were being really careful about that language. We didn't want the word kauaso in it at all and we suggested phrases like afaiga le va'ai you know that's much better your sight is impaired and the older ones who have just recently gone blind, they turn around and said to us who have been blind all our lives that we're ashamed of being blind We're like 'No we're not! We're not ashamed of being blind but you didn't grow up as a child at school, you didn't grow up as a teenager and hear people say 'you blind you blind' You don't have the attitude that we have and that's why we're more sensitive to it because there will be other blind children and teenagers that don't wanna be part of a group that's gonna*



*call them kauaso. 'So we had a big debate over it but we stood our ground because they're new to it, they don't have the experiences that we do.*

## **Reframing cultural ideology**

It was identified earlier that there is a cultural ideology that Samoans with a disability have suffered a terrible misfortune and are unlikely to lead satisfying and productive lives. The disability terminology is arguably a non-indigenous concept (King, Brough et al. 2013), its definition can vary widely across diverse indigenous groups (Hollinsworth 2013) and that some cultures simply do not have a word for disability in their native language (Hickey 2008). The existence and continual use of Samoan labels *ma'i* and *malaia* in cultural discourse shape and reinforce subsequent perceptions of Samoans with a disability. *Ma'i* is the Samoan word for illness, sickness or disease (Milner 1966, Pratt 1984) and many participants strongly objected to being described as *ma'i*. *Ma'i* did not accurately represent their disability condition and it projected negative connotations of their inability to lead an active robust life. It also heightened marginalising this segment of the Samoan community from being accepted as participating members in the life of the community. Even though there are Samoan terms to describe specific impairments (e.g. *kauaso* and *afaiga va'ai* = person with a vision impairment, *pipili* = person with a physical impairment or uses a wheelchair) these were generally more acceptable than *ma'i*. As Tavita put it:

*We have this whole generic word of kagaka mama'i [sick people] and I guess even if you put that back into the English translation that's it very almost degrading for a person who has a disability. Those are words that I've heard that would associate for everybody with a disability.*

*Malaia* generally means calamity (Pratt 1984) misfortune and curse. Most participants were also strongly opposed to being described as *malaia* or cursed. Recent studies show that non-Western cultures have similar interpretations that a disability is a curse from the gods for sins perpetrated by a parent or an ancestor (Naami and Hayashi 2012, Bayat 2013, Munsaka

and Charnley 2013). This finding is consistent with these studies and the implication is how this perpetual belief can seriously undermine efforts to promote the inclusion and dignity of persons with a disability as well as implementing the UN Convention on the Rights of Persons with Disabilities. Most of these participants circumvented *malaia* by adopting a pragmatic view that their impairment was a medical condition and reframed their impairment as a gift or simply another life challenge to overcome. Their narratives are precursors of challenging the cultural ideology: (1) challenging cultural views that disability originates from a generational curse, (2) challenging religious views that disability is a punishment, (3) challenging cultural views that disability is a sickness, and (4) challenging cultural views that disability affects the entire range of human capabilities and functioning (e.g. mental capacity, emotional affect, physical ability to perform routine tasks). As Samuelu, Malia and Iuni illustrate, respectively:

*Since the accident I meet a lot of interesting people. Before when you go to Manukau City or any mall they (people) look at somebody on the chair you don't take any notice of it but now you're on the chair and some people do look at you funny. Some people walking around just look at you, some people approach my wife and ask her 'how is he?' instead of asking me straight.*

*I've learnt to accept it as a gift because if I was not blind vision impaired I would still be killing myself working two jobs. I wasn't taking care of myself.*

*With my mum and sometimes family they think it's a curse that Elena got or she can walk again. Doctors have said that she won't walk again. They'll (mum and family) want to bring in their medicines and fofos and all that stuff. They think she's sick but she's not sick she just can't walk.*

Both the moral or religious model of disability and medical model of disability undergirds this cultural ideology. The latter relates to the idea that the body is impaired, dysfunctional, deviates from the norm of being able-bodied and incapable of participating in and contributing to the life of the community (Barnes 2012). The moral or religious model of disability regards disability as either a punishment for sins committed, test of faith or an

opportunity provided by God to develop character (Retief and Letšosa 2018). It has been posited that this model features prominently in cultures where religious or magical ways of thinking about the world predominates (Retief & Letsosa, 2018). Participants' narratives contest these models in favour of the human capability approach which focuses on a person's capability to achieve personally and socially valued functionings (Sen 1993, Burchardt 2004, Ruger and Mitra 2015) rather than on a person's deficiencies and limitations. Bowman (2010) argues that the capability approach complements Bourdieu's concepts to reveal insights into the processes and experiences of inequality. For these participants who focus on their capabilities and what they can do (e.g. perform daily and routine tasks at home, travel to Samoa to visit an ill parent or attend a funeral, lead a family court case) inequalities is experienced in social and cultural fields that devalue their physical capital (body) and other accumulated forms of capital (e.g. cultural, social, symbolic, economic). Hickey and Wilson (2017) argue that the medical and social model of disability is not relevant for many indigenous persons with a disability who have a relational, holistic and collective worldview. Participants' narratives strongly suggest congruence with and endorsement of this relational and holistic worldview. More recently, some service providers have attempted to influence community perceptions of persons with disability. To curb the negative stigmatisation and stereotype of Samoans with a disability, a pamphlet detailing appropriate Samoan terms was produced in Auckland (LeVa 2014). This exemplifies Bourdieu's agency-structure, in that the habitus of Samoans with a disability is interacting within certain fields (e.g. Samoan community, disability) and restructuring these fields and challenging doxic attitudes to reflect, and represent, their habitus or ways of being as Samoans in the Aotearoa New Zealand and Samoa context.

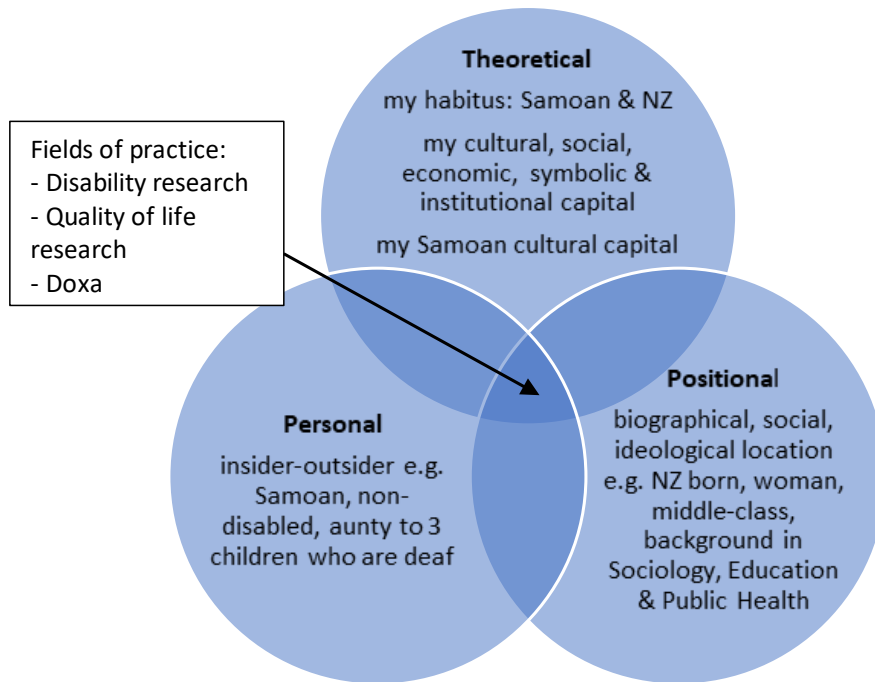
The implication of utilising Bourdieu's concepts in this chapter illuminates the structure-agency continuum. It is a relational mode of thinking about the QoL of Samoans with a disability. Habitus, field, capital and doxa are relational tools summarised in his equation

[(habitus) (capital)] + field = practice (Bourdieu 1984). Maton (2008) unpacks this in stating that “the practice results from relations between one’s dispositions (habitus) and one’s position in a field (capital), within the current state of play of that social arena (field)” (Maton 2008) . Bourdieu’s thinking tools clarify and contribute to theorising how these participants conceptualise and describe QoL and the ways (and challenges) of getting on with life and enhancing QoL. It also reveals a logic of practice whereby these participants and their families engage in a series of actions that is not fixed or prescriptive rather it is guided by practical strategies to operate in and transform social worlds. The following section is a foray into researcher reflexivity and delves into the efficacy of using and applying reflexivity in this study.

### **The imperative of reflexivity to account for trustworthiness**

The concept of reflexivity was drawn on to address the challenges of the insider-outsider researcher dichotomy and to ensure the academic rigour of this research. The insider-outsider researcher dichotomy raises the issue of my objectivity and bias in undertaking this study with my community. Similarly, the credibility and trustworthiness of this study is brought into question when my researcher positionality is not disclosed and clearly articulated. The questions surrounding reflexivity “is part of a broader debate on ontological, epistemological and axiological components of the self, intersubjectivity and the colonization of knowledge” (Berger 2015). Reflexivity is understood as the process whereby the researcher reflects on how their role in the study and their personal background, culture, socioeconomic status and experiences can potentially influence the interpretations of qualitative data (Creswell 2014). In pondering over the reflexivity concept, a series of philosophical questions came to mind about who I am, how do I see the world, what are my values and how do I know that knowledge about the quality of life of Samoans with disability is obtainable. I drew on three forms of reflexivity: theoretical, personal and positional, and the synergy of these approaches are illustrated in Figure 7.2. Each approach is explained in this section.

Figure 7. 2 Synergy of reflexivity approaches



## Theoretical reflexivity

Yet I am convinced that one knows the world better and better as one knows oneself better, that scientific knowledge and knowledge of oneself and of one's own social unconscious advance hand in hand, and that primary experience transformed in and through scientific practice transforms scientific practice and conversely (Bourdieu 2003).

One of Bourdieu's intellectual marksmanship in the terrain of contemporary social theory is his attention to reflexivity (Bourdieu and Wacquant 1992). His conception of theoretical reflexivity is couched within his broad sociological endeavours that calls for a return to the study of everyday life by replacing abstract armchair theorising with an experiential abductive way of knowing (Foley 2002). To put another way, Bourdieu recognised the importance of the researcher objectivizing their position in the academic or scientific field and the inherent biases (Wacquant 1989) that influence the production and reproduction of knowledge. As my study is framed in Bourdieu's theorisation, I draw on his key ideas of participant objectivation and epistemic reflexivity. Participant objectivation is "objectivizing the subject relation to the object" (Bourdieu 2003). In concrete terms, this is the researcher or knowing subject not only

examining their lived experience but the social and academic world that has contributed, consciously and unconsciously, to their formation and the subsequent positions they occupy in social and academic spaces. To enact participant objectivation in my study is to acknowledge that I am a product of external forces and influences which have shaped who I am, my worldview, values and belief systems, how I perceive and interact in the world across different settings and the social positions that I have had and currently occupy. Conversely, it signals that I am also a producer and reproducer of these forces and influences whether conscious or unconscious. Epistemic reflexivity is the critical assessment of the modes of knowledge construction and production. Bourdieu was cognisant of the biases a person brings into the study of the social world (Grenfell and Pahl 2018) and argued that theoretical and social conditions contributes to the possibilities of knowledge (Bourdieu 1977). He demonstrated this contention by developing and applying his theoretical tools of habitus, capital and field on himself to objectify the conditions that culminated into producing knowledge (Bourdieu and Wacquant 1992). In emulating his example (see Figure 7.2) I objectified my habitus, range of accumulated capital and doxa and fields of practice and discovered the interrelatedness of these concepts in shaping how I respond, act and situate myself favourably in the field. This prompted insights into how these concepts are possibly enacted in the participants' social practices of improving their quality of life. I also discovered the implausibility of the objectivism/subjectivism dualism in knowledge-building. By engaging in theoretical reflexivity, I moved back and forth between the concrete field of experience and theoretical explanations of that experience (Foley 2002). Positional reflexivity amplifies self-reflexivity and is discussed next.

### **Positional reflexivity**

Self-reflexivity is most identified with self-disclosure. Self-reflexivity acknowledges the researcher's role(s) in the construction of the research problem, the research setting and research findings, and highlights the importance of the researcher becoming consciously aware of these factors and thinking through the implications of these factors for her/his research (Pillow 2010).

Positional reflexivity brings to the fore the situatedness of the researcher during each phase of the research enterprise. A researcher's position is characterised and explored by categories, such as, gender, class, ethnicity, race, disability, sexuality, immigration status, personal experiences, beliefs, and theoretical, political and ideological stances (Cousin 2010, Cousin 2013, Berger 2015). In practical terms the researcher critically appraises how these characteristics influence and affect their approach, actions, interpretation of the data and presentation of the findings. The relevance of exploring positional reflexivity is how it articulates the social, ideological and biographical location of the researcher in relation to the research, participants, analysis of data and production of knowledge (Macbeth 2001, Swart and Agbenyega 2010). Bourdieu's reflexivity identifies bias within academic fields particularly how each discipline espouses a normative way of viewing their subjects and associated forms of inquiry (Bourdieu 2003, Grenfell and Pahl 2018). I incorporated his view when engaging in positional reflexivity. Not only did I critically examine my personal biography or habitus (i.e. bourgeois, heterosexual non-disabled Samoan woman, Aotearoa New Zealand-born and raised, socialised in Fa'aSamoa [way of Samoans]) but also the academic fields (i.e. Sociology, Education, Public Health) and professional fields (i.e. disability, education, injury prevention, public health). These facets of my experiences illuminated my social, ideological and biographical location. More significantly, it reaffirmed participant objectivation, the structural, policy and discourse influences in fields, these fields are fields of power, and the nature of my re/positioning in diverse fields over time. One of the tangible outputs in situating myself in this study occurred when preparing for the fieldwork (see Figure 5.3). The rules of engagement in the researcher to participant relationship stem from the Samoan cultural value system and recognises the importance of kinship and communalism. These rules addressed Finlay's (2002) caution that the researcher can embark on "an infinite regress of excessive self analysis and

deconstructions at the expense of focusing on research participants and developing understanding” (p. 212).

The choice to employ the Voice-centred Relational Methodology (VCRM) complimented positional reflexivity. I used the VCRM Listening Guide as an analytic tool to guide the analysis. To reiterate that the Listening Guide is a relational approach that attends to the person’s embodied voice within a network of relationships and sociocultural contexts and this approach required multiple readings of each interview transcript and each reading had a different function (Brown and Gilligan 1991, Brown and Gilligan 1993, Supple 2013, Bright, Kayes et al. 2018). The first and second readings involved a degree of reflexivity where I allowed my reactions, judgements, opinions of the person’s story to come to the fore and to connect more sensitively to the person on their terms. The value of doing this illuminated how these can affect my interpretation and understanding of the person’s story. Gadamer (1989) argued that it was necessary and important to identify one’s preconceptions and prejudices because these would facilitate a more open and honest dialogue of how the process of understanding is reached (Laverty 2003, Dowling 2006). By providing my reading of Ioane’s (edited) story in Appendix J, I disclose my impressions, insights and responses to his story which in turn begins to shape my interpretation and analysis of his quality of life. I have italicised portions to illustrate my initial interpretation of his story and this was mediated through my positioning as a non-disabled Samoan woman and daughter born and raised and educated in Aotearoa New Zealand. A key strength of the Listening Guide is the relational act of interpretation which attends to the particulars of each participant’s experiences by focusing on the aspects of relating (or not) to the phenomenon of quality of life. Personal reflexivity is the third approach to account for the trustworthiness of my study.

### **Personal reflexivity**

Insider research has to be as ethical and respectful, as reflexive and critical, as outsider research. It also needs to be humble. It needs to be humble because the researcher belongs



to the community as a member with a different set of roles and relationships, status and position (Smith 1999).

Personal reflexivity is explored under the auspices of the insider-outsider continuum. Informed by Bourdieu's reflexivity, he identifies the bias of personal identity (e.g. gender, class, ethnicity) and the narcissism of personal reflexivity to strengthen scientific claims (Bourdieu 2003, Wacquant 2006). The insider-outsider continuum makes explicit any perceived biases and highlights the ontological realisations that researchers occupy both insider and outsider status and the space in between. This space in between, denoted by the hyphen, acknowledges the complexities and ambiguities that the researcher navigates and negotiates (Dwyer and Buckle 2009). I argue that this continuum also addresses Bourdieu's third bias in his reflexivity that the intellectualist bias "entices us to construe the world as a *spectacle*, as a set of significations to be interpreted rather than as concrete problems to be solved practically" (Bourdieu and Wacquant 1992, italics in original). I became aware of insider-outsider research in the late 1990s and the prevailing view at the time was ethnic-matching of the researcher to the researched community in social science research. Anae (1998) addressed the concern of 'who is best suited to doing qualitative health research with Pacific peoples?' and considered the concepts of insider/outsider/native researcher, from an anthropological standpoint, as a space to discuss methodological issues. In short, she argues that the insider, outsider and native perspectives are equally important and ought to be integrated into the methodological approach. In a similar fashion I locate myself as a native and insider researcher in my study. As a native, I am part of the diasporic community in my study and committed to working with and for my community in the interest of promoting social justice and social equality. As an insider, I incorporated the outsider perspective of scientific objectivity, accumulated through the disciplines and discourse of sociology, education and public health; in tandem with my status set of identities (e.g. social, personal, ethnic, immanent, and circumstantial existential) in Figure 7.2.

The advantages and disadvantages of insider-outsider research when undertaking research with one's ethnic community has been documented (Kanuha 2000, Subedi 2006, Coloma 2008, Innes 2009). These scholars share personal insights, methodological issues and contribute to the insider-outsider debate particularly compartmental subjectivity, dynamics of power in the researcher-participant relationship and the validity and credibility of the study. As an insider, I had the advantage of automatic entry as a Samoan socialised in Fa'aSamoa and brought to the study a body of experience relevant to understanding Samoans in both Aotearoa New Zealand and Samoa. During my childhood my folks took us to Samoa several times to visit our grandparents and extended family, and we were immersed in the life there. Seiuli (2016) argues that a cultural insider brings a more relevant and grounded interpretation of the Samoan condition. As an outsider, I did not have a physical, sensory or any disability and was anxious that this would deter participants from taking part. I was entering the participant's world without a disability, had worked in the public and private sectors for 25+ years and was doing university research. By recognising these social and status markers of my identity I assumed these facets would be counterproductive in effectively engaging these participants to be part of my study. On the contrary, the participants were eager to share their stories, be part of my study and even to help me get my degree. I surmise that their willingness to participate was a combination of having their stories heard, recognizing the educational opportunities in the migrant journey to the land of milk and honey and the reputation of my peer network who recruited them. The insider-outsider continuum reveals how my researcher identity is dynamic and constantly being negotiated (Labaree 2002). In Bourdieu's terms, the continuum is reflective of the interplay of habitus, capital and doxa within fields.

To account for credibility and trustworthiness in my study I utilised theoretical, positional and personal reflexivity. These approaches in Figure 7.2 show the synergy of engaging in personal, positional and theoretical reflexivity in my study. The overlapping and

corresponding ideas discloses my situatedness and social location in all aspects of the research enterprise. Bourdieu's key ideas of participant objectivation and epistemic reflexivity opens up spaces to scrutinise scientific tools and practices used to describe and interpret social worlds and to unmask the logic of practice that agents adjust to, regulate or contest in their fields (Grenfell and Pahl 2018). In personifying Bourdieu's theoretical concepts of habitus, capital, field and doxa, it illustrates the relationship of these concepts in my arena of practice. Entering these two fields of disability research and quality of life research (and sub-fields) is determined by the structure and volume of my accumulated capital compared to that of other researchers also in these fields (Bourdieu and Wacquant 1992). These spaces are potential sites of struggle in competing for resources and highly valued status positions. Through engaging in theoretical, positional and personal reflexivity it became clear that subjectivity and objectivity as a researcher, in data interpretation and portraiture of knowledge, is a balancing act. It was not possible to be a detached, neutral observer, tabula rasa at critical junctions of the research process; nor was it feasible to be subsumed in a cycle of narcissism at the expense of producing quality research outputs. The synergy of these forms of reflexivity is an attempt to model Bourdieu's pursuit of blending theoretical and empirical rigour (Wacquant 2006).

## **Chapter summary**

The key findings from the three research questions were discussed. Quality of life (QoL) is described and conceptualised in four ways: (1) independent living, (2) normal life, (3) connectedness to family networks and culture and (4) performance of social roles. The five factors that facilitate or inhibit QoL were also discussed. These were (1) disability funding policy, (2) personal grief over acquiring disability, (3) religious and social capital, (4) mismatch of external caregiver support and (5) Samoan traditional views of disability. The affirmations of being Samoan, intersectionality of disability and ethnic identity and reframing cultural ideology were presented in view of the last research question. However, these findings pervade

and are inextricably linked to conceptualising QoL and the factors that facilitate or impede QoL. Bourdieu's concepts uncovered the relational aspects of these participants' lives in framing QoL and the quest to increase QoL in socio-political, economic and cultural spaces. Researcher reflexivity was examined to ensure trustworthiness of my study, which culminated into a synergy of theoretical, positional and personal reflexivity.

## **Chapter 8 Conclusion and Recommendations**

### **Introduction**

This final chapter contains concluding remarks about this study on the quality of life of Samoans with a disability in Auckland, Aotearoa New Zealand. As outlined in Chapter 1, the purpose of this phenomenological qualitative study was to investigate the quality of life experiences of Samoans living with a disability. The research questions sought to answer these questions:

- (1) How do adult Samoans with various disabilities conceptualise and describe quality of life?
- (2) What factors are reported by Samoans with disabilities that facilitate or inhibit their quality of life experiences?
- (3) How do Samoans with disabilities perceive their ethnic identity in Auckland?

It was envisaged that the findings will inform policy and service delivery to meet the cultural and disability needs of Samoan and Pacific ethnic groups in Aotearoa New Zealand. In this chapter, I provide recommendations that can enhance the quality of life of Samoans with a disability in the Auckland context focusing on policy and service delivery, the key contributions of this study particularly from a Bourdieuan theoretical perspective and suggest directions for future research.

### **Summary of key findings**

The main key findings of this research are presented in the following table:

*Table 8. 1 Key findings*

Number	Key finding
1	Quality of life is conceptualised in four ways: independent living, normal life, connectedness to family networks and culture, and performance of social roles
2	Personal grief over acquired disability in adulthood inhibits quality of life
3	Samoans with a disability possess cultural, social, economic, symbolic, institutional and Samoan cultural capital in varying degrees
4	Disability influences internal perceptions of the self and identity, and external perceptions of the ethnicity of Samoans with a disability

### **Study limitations**

There were three main limitations in this small study. The sampling strategies were not intended to yield a sample of participants who are representative of this population group. Even though there were Samoan-born and Aotearoa New Zealand-born Samoans, the number of men slightly surpassed the number of women. This study was a case design. Second, this is a small study and does not warrant any generalisations of this population group. Even though the purpose of this study was to investigate the quality of life experiences of Auckland-based Samoans living with a disability, the findings have potential reach to inform policy and service delivery to meet the cultural and disability needs of the growing Samoan and Pacific ethnic groups in Aotearoa New Zealand. Finally, conducting a qualitative study is a bit clumsy and loaded with the subjective experience of the researcher. This means, the researcher's perspective played a significant role in how the findings were interpreted. Yet, attention to reflexivity and detailed description of the research method provided trustworthiness of the research data and findings.

### **Key contributions to knowledge (practice, policy, theory)**

Despite the limitations enumerated above, this thesis makes a contribution in three areas: practice, policy and theory.

The 14 Samoan women and men with a disability represent a segment of the Samoan population who are often perceived as unfortunate souls deemed to live a difficult, unproductive and dependent life. Their stories cast a spotlight on the raft of quality of life experiences as a person living with a disability. The stories from their partner or caregiver is equally luminous on the shared challenges of actively pursuing a fulfilling and rewarding quality of life. Conceptualising quality of life in these four ways (see Table 8.1) suggests that this is perhaps not too dissimilar with how Samoans without a disability conceptualise quality of life (Sutter 1989). To put another way, Samoans with and without a disability share a similar outlook on what constitutes quality of life. The cultural, biomedical, social and economic interventions these participants and family explored and accessed emphasises these pathways as conduits to securing a quality of life. More importantly though is that these pathways reflect a logic of practice that is intimately linked to, and shaped by, their conceptualisations of quality of life.

At the level of service provision, the four ways in which Samoans with a disability conceptualise quality of life is informative and instructional. The application of this new body of knowledge is relevant in two ways: building a culturally responsive service, and developing a culturally competent workforce. When the specificities of this cultural knowledge is appropriated in the delivery of disability support services to Samoans with a disability and their families, it generates a properly informed approach on working effectively to improve quality of life outcomes. Moreover it creates a win-win situation of strengthening the capacity of both staff and service providers to work better with this ethnic community, and more broadly, diverse communities in Aotearoa New Zealand.

In the policy-making context the knowledge that personal grief over acquiring a disability in adulthood is important and needs to be acknowledged. Personal grief can overwhelm and dominate the person's wellbeing to the extent that it affects their quality of life, their psychosocial and emotional wellbeing. Granted that every person approaches and deals

with grief in their own way, if left unchecked or unacknowledged it can lead to complicated or unresolved grief which can worsen quality of life. Families are not exempt from the experience of personal grief. Furthermore, the permeation of social and rights-based model of disability in Aotearoa New Zealand is not necessarily understood or valued by Samoans with a disability and their families.

The application of Bourdieu's theoretical concepts: habitus, capital, field and doxa magnifies two areas of interest. First, it makes noticeable the different forms of capital Samoans with a disability have acquired and currently possess. These forms of capital (see Table 8.1) are either valued or undervalued in specific fields, and as a consequence, can positively or negatively affect their quality of life. Second, it makes visible the contested spaces of disability, policy and service provision which affects quality of life of Samoans with a disability. When these participants position themselves in a contested space to seek material resources or support services to actualise quality of life, the pool of resources becomes narrower as they compete with other people or they do not have the requisite capital and *nous* (or NZ habitus) to position themselves effectively in the arena. The participants with vision impairment, however, in their engagement with the Blind Foundation exemplifies the recognition of their habitus and capital. At a broader level, this illustrates the structure-agency continuum of individual agents (participants and staff) influencing the structure or organisation to accommodate the needs of diverse groups.

An additional contribution is more specific to my Samoan community. This study on a frequently overlooked segment of our community exposes the prevalence of the cultural ideology which influences negative perceptions of Samoans with a disability. Rather than using a capability approach to view the strengths and abilities of Samoans with a disability, the deficit model is unfortunately deployed often in unconscious ways. These participants' stories headline for our community their tenacity to be seen as real people with real feelings and a strong desire



to be accepted as equals. Their conceptualisations of quality of life signpost the high probability that this is very similar to most Samoans elsewhere. The Samoan traditional views of disability was a barrier that undermines and limits their quality of life as well as their ethnic identity. Samoans with a disability continuously navigate the terrain of affirming their ethnic identity in cultural fields. This is more pronounced for Aotearoa New Zealand-born Samoans who are confronted with low perceptions of their accumulated capital to participate in fa'alavelave and customary practices.

### **Recommendations for further action and research**

These suggested recommendations are specific to practice and policy towards improving the quality of life for Samoans with a disability and their families. Areas for further research are also suggested.

At the practice level, primarily in the arena of service delivery, workforce capacity and professional development, it is important to consider that Samoans with a disability conceptualise quality of life in four ways. These interconnected ways are independent living, normal life, connectedness to family networks and culture, and performance of social roles. Introduce these cultural conceptions into organisational frameworks, service operations and staff training. This multipronged approach is an enabler of building fruitful relationships with Samoans with a disability and their families, as well as developing the cultural competency of staff and practitioners in the health and disability sector. This is a step in the right direction of shaping a culturally responsive service that fosters the quality of life of Samoans with a disability. International studies support improved staff and practitioners' cultural awareness and responsiveness when working with ethnically diverse families who have a loved one with a disability (Brewer, McCann et al. 2015, Greenstein, Lowell et al. 2016, He 2016, Graf 2018).

At the policy level, new knowledge of personal grief over acquiring a disability in adulthood affects quality of life for the person and their family. Complicated or unresolved grief

worsens quality of life. The recommendation is review models, operational and resourcing policies to address the needs of the person and their family, as well as to increase the workforce capacity including training to identify and be mindful of the presence and impact of grief on a person's well-being and quality of life. This is confirmed through studies with persons acquiring a disability (Livneh and Antonak 2005, Klyce, Bombardier et al. 2015, Cichette, McArthur et al. 2016, Heatherley 2016). The inclusion and involvement of families and extended families into disability and rehabilitation services and policies will assist in developing appropriate policies and services and service provision. This is supported in studies where immediate and extended family members play a significant role in the life of a loved one with a disability (Kresak and Gallagher 2014, Wannarat, Horey et al. 2015, Lara and de los Pinos 2017).

There are three suggested areas for research. First, to undertake research with other Pacific ethnic, migrant and transnational groups who may have different conceptions of what quality of life entails. The richness of these studies serves to form a fabric of knowledge that enhances the inclusiveness and cultural adaptability of policies, programmes and services aimed at improving quality of life and well-being. Second, to consider research on the quality of life of persons with other disability types (e.g. developmental, intellectual, multiple). It is important to recognise that each person with a disability is worthy of living a great life and to ascertain what this entails from their perspective. Third, to contemplate the merits of research into grief following an acquired disability in adulthood particularly from a cultural standpoint. Complicated or unresolved grief can hinder a person's sense of well-being and their unique participation in the life of the family, community, place of employment and society. Lafaele's comment sums up these suggested areas for research:

*I put my case forward and I told them (Ministry of Health) that it wasn't that I wanted this chair it's because I needed this chair. They said 'oh you can't get what you want' and I said 'if I was to list my priority want – it's to get my life back. This particular chair is what I need to cope with a journey I'm about to embark on. This will minimise me having*

*to seek out counselling, optimise my self-esteem because I'm a very very people person and it will give me enough confidence and pride to wheel myself around.'*

## **Implications**

The implications of the findings show that Samoans with a disability conceptualise quality of life differently to Western societies. Their conceptualisations: (1) independent living, (2) normal life, (3) connectedness to family networks and culture, and (4) performance of social roles can be described as 'brown' conceptions of quality of life which is culturally derived and enacted in local contexts and particular ways of being (Raley, Casas & Coral, 2004). Despite the usefulness of generic QoL models and cross-cultural adaptation (e.g. WHOQOL tool) the intricacies, and complexities, of how quality of life is conceptualised and operationalised by diverse ethnic groups can be grossly overlooked and misunderstood. Bourdieu's theoretical concepts illuminate the habitus and capital of Samoans with a disability and their families and its deployment in fields of interventions in order to enhance quality of life. The four interventions (i.e. cultural, biomedical, social and economic) signal the pathways and the specificities of capital types required for an optimal vantage point. For instance, the Samoan habitus and Samoan cultural capital is more valued in cultural fields than in caregiver services. The wider implication of Bourdieu's concepts is that it raises an alternative way of viewing the interplay of a person's set of dispositions and their forms of capital in positioning themselves in structured spaces and how these in turn can lead to restructuring spaces and fields. Bourdieu called the habitus durable and transposable. An additional implication is that Samoans with a disability are viewed differently by the Samoan population. There is a prevailing cultural ideology that shapes this perspective and to which these participants were strongly opposed to and challenged. This ideology, across various settings and situations, had a negating effect on the person's perceptions of self, their image and sense of belonging as a Samoan. Being Samoan

was overshadowed and undervalued by peoples' visual and behavioural reactions to their disability.

## **Final thoughts**

This study contributes new knowledge of Samoan conceptions of quality of life from the perspective of Samoans with a disability. The combined use of hermeneutic phenomenology and the Voice-centred relational methodology in this study put an emphasis on the relational approach to understanding the participant's embodied voice within relationships and contexts. Their stories came from the heart and soul and denying my shared humanity with them would have stunted my personal growth. I leaned into the awkwardness as a person without a disability and became more of myself in the research process. Engaging in positional, personal and theoretical reflexivity revealed the insider-outsider continuum and that this continuum is reflective of the interplay of my habitus, capital and doxa in the research field. The utility of Bourdieu's concepts captured and brought into sharp view a way of examining patterns of social behaviour towards a phenomenon. Not only did it unpack the habitus and capital of Samoans with a disability but highlighted the challenges and struggles in navigating their various field positioning to enhance their quality of life. To conclude this chapter with Tavita's comments which summarises the aptitude and perseverance of these Samoans with a disability forging a quality of life:

*It really does vary in terms of peoples' perceptions and opinions of where their quality of life is at. I come across people who are very similar to myself, they just wanna get on with it. It all comes down to confidence for me. If you've got confidence in yourself and your abilities then the world's your oyster really. And people with disabilities needs to just stop taking others opinions into account in terms of making your own decisions. Focus a lot more on the positives rather than the negatives cos you can guarantee there's more positives than negatives.*

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# Appendices

## Appendix A Explanatory statement



26/10/2016

### Explanatory Statement for All Participants

#### Title: Quality of life of Samoans with a disability

Talofa lava,

My name is Nite Fuamatu. I am a full-time student doing a PhD at Monash University in Melbourne. For my PhD, I am doing a study which focuses on Samoans living with a disability. I am interested in learning about the experiences of our Samoan people especially when they live with a disability. The purpose of the study is to understand how Samoans with a disability live life, the impact of this on them and their families and the types of help sought. I feel that the perspectives of men and women are important and would like to focus the study on both Samoan men and Samoan women.

I would like to invite you to help me with this study by allowing me to interview you at a time and place that suits you. This will take 1-2 hours. A follow up interview might be needed and this will take approximately 30minutes.

The interview will focus on your life story especially your experiences and knowledge of living with or caring for someone with a disability. I will be using the results of this study to help with developing education programmes, informing policies and improving services for the Samoan and Pacific communities. At the end of this study, I will present the findings to everyone who took part in this research.

I would like to tape record our interviews. The tape can be turned off at any time during the interview.

All the information you provide will be confidential and your name will not be used unless you specifically request it. You may have a copy of your tape and transcript if you wish. You may withdraw from the study at any time up to the point at which the results are ready to be written up. All of the tapes, transcripts and forms will be stored in a locked filing cabinet for five years then they will be disposed of.

<p><b>If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:</b></p>	<p><b>If you have a complaint concerning the manner in which this research 1023 is being conducted, please contact:</b></p> <p>Reverend Alesana F Pala'amo (BTh, MTh.) Lecturer: Malua Theological College, SAMOA (on study leave) PhD candidate School of Social Work Massey University, Albany, NZ M: 021 0843 8387 E: <a href="mailto:a.f.palaamo@massey.ac.nz">a.f.palaamo@massey.ac.nz</a></p>
<p><b>Dr Joseph Seyram Agbenyega</b></p> <p><b>Monash University</b> <b>Senior Lecturer/ (Med) Course Pathway Advisor</b></p> <p><b>Early Childhood Education/Inclusion</b> <b>Building A, Peninsula, Frankston, Vic 3199</b> <b>Tel: +61 3 9904 4200</b> <b>Mobile: 0437959009</b> <b>Email:</b> <b><a href="mailto:joseph.agbenyega@education.monash.edu.au">joseph.agbenyega@education.monash.edu.au</a></b></p>	<p><b>Executive Officer, Human Research Ethics</b> <b>Monash University Human Research Ethics Committee (MUHREC)</b> <b>Building 3e Room 111</b> <b>Research Office</b> <b>Monash University VIC 3800</b></p> <p><b>Tel: +61 3 9905 2052</b> <b>Fax: +61 3 9905 3831</b> <b>Email:</b> <b><a href="mailto:muhrec@adm.monash.edu.au">muhrec@adm.monash.edu.au</a></b></p>

Thank you.



Nite Fuamatu



## Appendix B Explanatory statement (Samoan language)



26/10/2016

### **Fa'amalamalamaga Mo Lou Silafia O Lenei Su'esu'ega**

#### **Mataupu: Su'esu'ega o le Soifua Maloloina a Tagata Samoa o e e Le Atoatoa le Malolosi po'o le Fa'aaogaina o Itu Tino**

Talofa lava,

O a'u o Nite Fuamatu. I le taimi nei o lo'o o'u a'oga mo le fa'aailoga PhD ile lunivesite o Monash i Meleponi, Ausetalia. O la'u su'esu'ega e fa'apitoa lea mo tagata Samoa e le atoatoa le malosi po'o le fa'aaogaina o nisi o vaega o latou itu tino (se'i tulou). Mo se fa'ata'ita'iga, o e pipili, tauaso, tuapi'o fa'atasi ai ma le anoanoa'i o isi fa'afitauli ua fa'afaigata ai ona fa'aaoga nisi vaega o itu tino o le tagata soifua fa'anatura i tulaga e tataua ona iai. O le manatu autu o lo'o tuliloaina e lenei su'esu'ega o le fia iloa ma malamalama i uiga e fa'atino ma lagona fa'alemafaufau o tagata Samoa e le'o atoatoa le malosi po'o le fa'aaogaina o nisi o vaega o latou itu tino. E tolu ni vaega taua o lo'o fa'aaautu iai lenei su'esu'ega: Oa ni lagona ma ni fa'afitauli o lo'o feagai ma i latou nei. Oa ni a'afiaga o nei lagona ma fa'afitauli i o latou aiga. Oa ni ituaiga o auala tau fesoasoani e mana'omia, a'o fea foi e maua mai ai nei fesoasoani. Oute lagona e ese le taua o ni manatu e fa'aalia o i latou nei fa'atasi ai ma o latou aiga.

I le ava ma le fa'aaloalo, oute vala'auina aloaia oe ete auai i lenei su'esu'ega. O lou fa'atagaina o a'u tate talatalanoa i lenei mataupu taua. O lea e filifilia le nofoaga ma le taimi e tala feagai mo oe e fa'ataunu'u ai lenei talatalanoaga. O le umi o le taimi e fa'aaogaina o le 1-2 itula. A toe mana'omia nisi talatalanoaga mulimuli mai ai, pe mo le umi i le 30 minute.

O le ta talanoaga e fa'aautu lea i le tala'aga o lou soifuaga. Pe na e soifua mai lava ma lenei fa'afitauli, pe na mafai ose fa'alavelave fa'afuase'i, po'o se gasegase fo'i. O lea sou malamalamaga po'o ni a'afiaga o feagai ma oe i tulaga tau le soifuaga, talu ai le le atoatoa o le malosi po'o le mafai ona fa'aaogaina o ni vaega o lou tino ete ola ma soifua ai pei o le tele o tagata.

O tulaga uma o lenei su'esu'ega, o lea fa'aaoga lea mo le fa'aleleiga atili o auala tau fesoasoani e maua mai i isi o Fa'alapotopotoga aua le manuia ma le solo lelei aga'i i luma o tagata Samoa ma isi atumotu o le Pasefika. I le fa'ai'uga o lenei su'esu'ega, o itu taua uma o lea maua mai ai o lea tuisitusia uma lea ise lipoti ma tu'uina atu ia i latou o lea auai i lenei su'esu'ega.

O le su'esu'ega e fa'aaoga le la'au pu'e leo. E iai lau aia tataua e fa'amuta ai le fa'atalatalanoaga o lenei mataupu i so'o se taimi lava a'o fa'agasolo le su'esu'ega.

Oni finagalo ma ni manatu fa'aalia, o lea le mafai ona fa'ailoa atu i nisi, e o'o lava i suafa e le fa'ailoaina. E mafai ona maua atu kopi o lenei su'esu'ega mo i latou e talosaga mai. O lipine ma tusitusiga o lenei polokalame o lea lokaina i le nofoaga o le aoga ale lunivesite a Monash mo le lima tausaga ona fa'atoa fa'atamaia lea e le toe fa'aaogaina.

<p><b>A fia maua nisi fa'amalamalamaga atili e uiga i lenei su'esu'ega, fa'afeso'ota'i le Susuga ale Ta'itai o lenei su'esu'ega:</b></p>	<p><b>Afai e tulai mai ni fa'aletonu ona o le fa'asologa o lenei su'esuega 1023 fa'amolemole fa'afeso'ota'i le Susuga a le Fa'afeagaia ia:</b>  Reverend Alesana F Pala'amo (BTh, MTh.)  Lecturer: Malua Theological College, SAMOA (on study leave)  PhD candidate  School of Social Work  Massey University, Albany, NZ  M: 021 0843 8387  E: <a href="mailto:a.f.palaamo@massey.ac.nz">a.f.palaamo@massey.ac.nz</a></p>
<p><b>Dr Joseph Seyram Agbenyega</b>   <b>Monash University</b>  <b>Senior Lecturer/ (Med) Course Pathway Advisor</b>  <b>Early Childhood Education/Inclusion</b>  <b>Building A, Peninsula, Frankston, Vic 3199</b>  <b>Tel: +61 3 9904 4200</b>  <b>Mobile: 0437959009</b>  <b>Email:</b>  <b><a href="mailto:joseph.agbenyega@education.monash.edu.au">joseph.agbenyega@education.monash.edu.au</a></b></p>	<p><b>Executive Officer, Human Research Ethics</b>  <b>Monash University Human Research Ethics Committee (MUHREC)</b>  <b>Building 3e Room 111</b>  <b>Research Office</b>  <b>Monash University VIC 3800</b>   <b>Tel: +61 3 9905 2052</b>  <b>Fax: +61 3 9905 3831</b>  <b>Email:</b>  <b><a href="mailto:muhrec@adm.monash.edu.au">muhrec@adm.monash.edu.au</a></b></p>

Fa'afetai tele. Soifua ma ia manuia.



Nite Fuamatu

## Appendix C Consent form



### Consent Form for All Participants

**Title: Quality of life of Samoans with a disability**

**NOTE: This consent form will remain with the Monash University researcher for their records**

I have read the Explanatory Statement and have had the opportunity to ask questions. My questions have been answered to my satisfaction and that I may ask further questions at any time. I understand what the study is about and can withdraw myself or any information I have provided at any time. I will not have to give any reasons if I want to withdraw and there will be no penalty.

- ☐ I agree to take part in this study under the conditions set out in the Explanatory Statement.
- ☐ I agree to being interviewed.
- ☐ I agree to the interview being tape recorded.
- ☐ I would like a copy of my transcript and tape returned to me.

**Signature:**

**Date:**

.....

.....

**Print Full Name:**

.....

## Appendix D Consent form (Samoan language)



### Tusi Fa'atagaina e auai I lenei Su'esu'ega

**Mataupu: Su'esu'ega o le Soifua Maloloina a Tagata Samoa o e e Le Atoatoa le Malolosi po'o le Fa'aaogaina o Itu Tino**

**FA'ASILASILAGA: Ole a umia lenei tusi fa'atagaina e le researcher mai le lunivesite o Monash.**

Ua mae'a ona fa'amalamalama mai ia te a'u le autu o lenei su'esu'ega ma tu'uina mai le avanoa mo ni fesili. Ua fa'amalieina a'u i tali o fesili, ma o lo'o iai le avanoa e toe fesiligia ai lenei su'esu'ega i so'o se taimi lava. Ua ou malamalama i le autu o lenei su'esu'ega. O lo'o iai la'u aia tatau e fa'amuta ai lenei su'esu'ega i so'o se taimi lava e aunoa ma le fesiligaina o a'u i lona mafua'aga.

- ☐ Ua ou malie ma ioe oute auai i su'esu'ega i lalo o auala puipuia ua saunia ma tusia fa'apitoa mo lenei polokalame.
- ☐ Ua ou malie ma ioe i le su'esu'ega fa'atalatalanoaga.
- ☐ Ua ou malie ma ioe i le su'esu'ega fa'atalatalanoaga ae pu'eina i le la'au pu'e leo.
- ☐ Oute talosagaina tusitusiga ma lipine o lenei su'esu'ega e fa'afo'i mai ia te a'u.

**Saini:**

**Aso:**

.....

.....

**Tusia lou suafa:**

.....

## Appendix E Authority for the release of transcripts



### Authority for the Release of Tape Transcripts

**Title: Quality of life of Samoans with a disability**

**NOTE: This consent form will remain with the Monash University researcher for their records**

I have had the opportunity to read and amend the transcript of my interview/s.

I agree that the edited transcript and extracts from this may be used by the researcher, Nite Fuamatu, for her study and in reports and publications arising from the research.

**Signature:**

**Date:**

.....

**Print Full Name:**

.....

## Appendix F Authority for the release of transcripts (Samoan language)



**Tusi Fa'atagaina o le Fa'asalalauina o Tusitusiga ma Fa'amaumauga o lenei Polokalame**

**Mataupu: Su'esu'ega o le Soifua Maloloina a Tagata Samoa o e e Le Atoatoa le Malolosi po'o le Fa'aaogaina o Iu Tino**

**FA'ASILASILAGA: Ole a umia lenei tusi fa'atagaina e le researcher mai le Iunivesite o Monash.**

Ua mae'a ona ou faitauina ma siaki'ina fa'amaumauga o lenei su'esu'ega.

Ua ou fa'atagaina tusitusiga ma lomiga o lenei polokalame e fa'aaogaina e Nite Fuamatu mo sana lipoti tusitusia atoa ai ma le fa'asalalauina o le fa'ai'uga ma le taunu'uga o lenei su'esu'ega pea mae'a.

**Saini:**

**Aso:**

.....

**Tusia lou suafa:**

.....

## **Appendix G Interview schedule Samoan with a disability**

### ***Quality of life of Samoans with a Disability***

#### **Semi-structured Interview Schedule: Samoan with a disability**

First, I'd like to thank you and your family for giving me the opportunity to talk with you. Thank you welcoming me into your home.

This is a time where we can talk about your life here in New Zealand, how you came to this country, your experiences and in particular your experiences of living with a disability and the things that have happened since then. For instance, were there any changes at all in your lifestyle and if so, what kinds of changes, what types of help did you seek and how did you cope with the changes, if any. Your views and ideas are very important and if there are other things you would like to say please feel free to share this. By talking with you, I hope to get a better understanding of how our Samoan people with a disability are living life in Auckland.

Although the tape recorder is being used, your name will not be used in my study or in any reports. There might be something that you say which I might use as a quote in my study but don't worry because your name will not be mentioned. The tape will only be used for this study.

I'll be using this semi-structured interview schedule to guide our talk. Please don't let this put you off from expressing your views and thoughts that you might have.

Before we start, do you have any questions for me?

*In the interview situation, the researcher will use the life story model.*

- Can you tell me about yourself?

The researcher to ensure that the conversation covers the following areas:

1. The participant's perceptions of acquiring a disability.
2. The participant's experiences of living with a disability, its impact on them and their families, and types of help sought. And being Samoan with a disability.
3. Definitions and concepts of disability and quality of life from a Samoan perspective.

## **Appendix H Interview schedule Partner or caregiver/support worker**

### ***Quality of life of Samoans with a Disability***

#### **Semi-structured Interview Schedule: Partner and caregiver/support worker**

First, I'd like to thank you and your family for giving me the opportunity to talk with you. Thank you welcoming me into your home.

This is a time where we can talk about your life here in New Zealand, how you came to this country, your experiences and in particular your experiences of looking after someone with a disability and the things that have happened since then. For instance, were there any changes at all in your lifestyle and if so, what kinds of changes, what types of help did you seek and how did you cope with the changes, if any. Your views and ideas are very important and if there are other things you would like to say please feel free to share this. By talking with you, I hope to get a better understanding of how our Samoan people with a disability are living life in Auckland.

Although the tape recorder is being used, your name will not be used in my study or in any reports. There might be something that you say which I might use as a quote in my study but don't worry because your name will not be mentioned. The tape will only be used for this study.

I'll be using this semi-structured interview schedule to guide our talk. Please don't let this put you off from expressing your views and thoughts that you might have.

Before we start, do you have any questions for me?

*In the interview situation, the researcher will use the life story model.*

- Can you tell me about yourself?

The researcher to ensure that the conversation covers the following areas:

1. The participant's perceptions as a partner/family member and caregiver/support worker of someone with a disability.
2. The participant's experiences of living with and/or caring and supporting someone with a disability, its impact on them and their families, and types of help sought. And being Samoan with a disability.
3. Definitions and concepts of disability, quality of life and caregiving/support.



## Appendix I Ethics approval



### Monash University Human Research Ethics Committee

#### Approval Certificate

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

**Project Number:** 1023

**Project Title:** Quality of life of Samoans with a disability

**Chief Investigator:** Dr Joseph Agbenyega

**Expiry Date:** 26/10/2021

**Terms of approval - failure to comply with the terms below is in breach of your approval and the *Australian Code for the Responsible Conduct of Research*.**

1. The Chief Investigator is responsible for ensuring that permission letters are obtained, if relevant, before any data can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash letterhead and the Monash University complaints clause must include your project number.
6. Amendments to approved projects including changes to personnel must not commence without written approval from MUHREC.
7. Annual Report - continued approval of this project is dependent on the submission of an Annual Report.
8. Final Report - should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected completion date.
9. Monitoring - project may be subject to an audit or any other form of monitoring by MUHREC at any time.
10. Retention and storage of data - The Chief Investigator is responsible for the storage and retention of the original data pertaining to the project for a minimum period of five years.

Thank you for your assistance.

Professor Nip Thomson

Chair, MUHREC

## Appendix J VCRM Listening Guide Analysis of Ioane's story

Reading	Interview transcript
1 <sup>st</sup> reading (his story and my reaction)	<p>He is talking about his story on how he became blind in Samoa, the operations in NZ, working at the NZ High Commission, the 3-4 years of sadness following the total onset of blindness and moving from family home in Apia to the rural farm, his migration to NZ with his family prompted by his siblings in NZ in search of support and to find joy again, the fears of moving to NZ and the new opportunities he received from approaching the BF again. I feel privileged at listening to his story. He is a gentle man who shared his story openly and honestly. For instance, a Samoan older male sharing his feelings of being a burden to his wife, daughters and family and wanting to provide and continue providing for his family as the breadwinner. <i>I interpret his story of a strong Samoan man who acquired his blindness in his late 40s, led an active life at work, village, family and church settings prior to this and the blindness was a phenomenal challenge in continuing with all his commitments. As a Samoan, I identify with his goals of providing for his family and finding ways to live with the blindness and find a measure of normality to enable fulfilling his roles in the family and extended family.</i> My father had the same goals when he migrated to NZ but didn't have a disability as such. My father also acquired diabetes later in life which led to kidney and heart complications and limb amputation, and these had a profound impact on his ability to provide for the family and participate in church and village activities (his wellbeing was severely affected and had bouts of suicidal thoughts).</p>
2 <sup>nd</sup> reading (self and I, his voice)	<p>He speaks of himself in the first person and speaks candidly of his vision impairment, major changes in his life, self-imposed isolation, and fears of the uncertainty e.g. he had a life before vision impairment, moving to NZ, type of support he could get in NZ. He does not speak as an angry person who feels wronged but speaks as someone who has found hope and is ready to explore and embrace new opportunities to find normality again e.g. provide and serve the family, do a course and find employment, be part of the church community. He doesn't talk about how others perceive him and I get the sense that this is something that he worked through during the 3-4 years (they were dark times) and that it doesn't bother him what others think about him. <i>He doesn't talk about how he is expected to act and I surmise that he is very proactive and strong willed in</i></p>

	<p><i>determining his own actions and has a single-minded purpose of regaining a normal life, one where he is able to perform his roles. I also surmise that he has accepted his vision impairment and does not let this get in the way of finding a new way of living life and being happy.</i></p>
3 <sup>rd</sup> reading (relationships and others)	<p>He speaks about his wife, daughters, siblings, and mother. There is great love and care for them, one of his daughters is carer for his elderly mother. His siblings prompted him to consider moving to NZ and they supported him to adjust to the new country and to find a place to live. He is positioned as a family man who takes his responsibilities seriously and interacts within his family relationships based on this. He is the spokesperson leading the family in Samoa Court (Land and Titles) and was pleased to have done this and prepared the documents and to win the court case. <i>He is a person who values being part of the community and this was evident in Sunday preaching and his choice of completing the Liaising Interpreting course, and his role in Samoa prior to vision impairment.</i></p>
4 <sup>th</sup> reading (context)	<p>His family in NZ proposed moving to NZ. He has NZ citizenship granted under the Western Samoa Citizenship Act 1982 which meant he could travel freely to NZ for operations, contact the BF and access the other supports when the family moved. The support services in Samoa do not compare to NZ i.e. no appointment system to see the eye doctor so had to wait to be seen and this meant the whole day and still not see the doctor, the blind support service in Samoa was defunct, there is a school for the blind but didn't know anything about it and had low confidence in it. The Samoan cultural context of what are the causes of his blindness, he talked about 3 explanations – there are spirits on the rural farm (plantation) and that land was once a burial site and it's the evil spirits or ghosts that are punishing the person; a curse incurred by ancestors; curse or punishment because the family or parents converted to another religion. He says these are some of the explanations and isn't sure which one is applicable. He didn't seem to take these explanations seriously as he spoke about vision impairment on his mother's side i.e. grandmother went blind aged 55-60 years, great aunty was blind and that there are many causes for his condition. <i>It is primarily his voice and that of his siblings that informed his decision to move to NZ to seek new possibilities, a new journey to finding ways to support his important role as a Samoan family man, leader and breadwinner. The values undergirding this is Samoan, to perform expected roles for a man in the familial context. He is a husband, father, member of the family and extended family, son and one of the oldest in a family of 11. Although he does not speak of the interactions with NZ agencies</i></p>

	<p>and professionals and any negative experiences associated with this, I suspect that he had a good handle on approaching, requesting and obtaining the supports he needed e.g. understood processes and systems, spoke, wrote and understood English, articulate in making his requests known, had interpersonal skills in working with diverse groups of people and different agencies, visited NZ often to see family. <i>I know two of his brothers and they hold leadership and management positions at work, community and church and this suggests that he comes from an educated family with strong social and cultural capital.</i> In terms of what is institutionalised and the right way to do things, there is no mention of this and I surmise that he had the institutional knowledge and capital to be able to navigate systems, processes and different roles of personnel he was in contact with.</p>
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