

Conceptualising disability from a Samoan epistemological and cultural reference frame

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Certificate of authorship and originality of thesis (declaration)

The work contained in this thesis has not been previously submitted either in whole or part for a degree at CQUniversity or any other tertiary institution. To the best of my knowledge and belief, the material presented in this thesis is original except where due reference is made in text.

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Abstract

This research is concerned with the changing conceptualisations of disability in Samoa. The research also investigates fundamental cultural belief systems and contemporary ideologies that affect people with disability in Samoan society. Samoan policy reform within the area of disability has provided an alternate paradigm for society to view disability. Stakeholder groups have largely embraced recent policy reforms, endorsing a social disability model. However, due to a history of missionary involvement, colonisation and traditional cultural ideologies Samoa already has several conceptualisations of disability that challenge the philosophy of a social disability model.

The objective of this research is to establish a uniquely Samoan conceptualisation of disability through an examination of cultural epistemologies, discourse and global influences. Concerned with how Samoans with disability develop concepts of identity and belonging, the research examines the role of the *fa'aSāmoa* (the Samoan way) encompassing familial relationships, contribution, and status. The impact of discourse and terminology and the role of global influences are also examined to determine the factors that affect contemporary perceptions of disability in Samoa.

Using *Talanoa*, a culturally responsive research methodology, the success of the research hinged upon a respect for culture and a commitment to reciprocating the research. The participants revealed rich and diverse data indicating the scope of the experience of disability. An inductive approach was taken to data analysis. Participants verified identified themes, and a phase of data refinement ensued.

From this research emerged multiple realities of disability from a Samoan cultural frame. Various external influences, combined with the cultural underpinnings of the

fa'aSāmoa form a contemporary landscape of disability in Samoa. The absence of a shared understanding of disability is impeding the potential of a social disability model in Samoa. Perhaps more significantly, the social model of disability conflicts with several key aspects of the *fa'aSāmoa*. The disparity between emergent policy and cultural conceptualisations of disability represent challenges to identity development and concepts of cultural belonging for Samoans with disability.

The recent development of disability policy in Samoa demonstrates the recognition that people with disability in Samoa are marginalised and that progress is essential to societal inclusion and equality. This research reveals that multiple realities contribute to negative perceptions and attitudes of people with disability. Policy reform aligned with a social disability model is failing to incorporate essential cultural characteristics that ensure the development of positive cultural identities for people with disability.

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Glossary of terms

<u>Samoan</u>	<u>English</u>
<i>aiga</i>	family
<i>a'o</i>	learning and teaching
<i>afakasi</i>	person of part European descent
<i>Aitu</i>	ghost, spirits
<i>Ali'i</i>	Chief of aristocratic lineage
<i>alofa</i>	love
<i>aoga</i>	useful
<i>fa'aaloalo</i>	respect
<i>fa'alavelave</i>	cultural obligations such as funerals, weddings, births etc.
<i>Fa'amatai</i>	<i>matai</i> system
<i>fa'aSāmoa</i>	the Samoan way of life
<i>fagogo</i>	night stories
<i>faipe</i>	deaf
<i>fiapoto</i>	conceited, presumptuous, know-it-all
<i>fono</i>	village council
<i>iloa</i>	knowing
<i>kalofae</i>	an expression of pity or empathy
<i>logonoa</i>	hearing impairment

<i>mana’oga faapitoa</i>	person with disability
<i>ma’i</i>	sickness
<i>matai</i>	chief
<i>mea’alofa</i>	gift
<i>palagi</i>	person of European descent
<i>poto</i>	knowing what to do, and doing it well
<i>Talanoa</i>	to talk; a discussion
<i>Talanoaga</i>	the act of <i>Talanoa</i>
<i>tauasoa</i>	vision impairment
<i>Tauleasea</i>	traditional healer
<i>tautua</i>	service
<i>to’ona’i</i>	Sunday meal
<i>Tulafale</i>	orator, talking chief
<i>vā</i>	the space between people, in terms of relationships
<i>vāfealoa’i</i>	rules of behaviour, etiquette

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Abbreviations and acronyms

APTC	Australian Pacific Technical College
BMF	Biwako Millennium Framework
CA	Capabilities Approach
GNIPP	Gross National Income Per Person
ICF	International Classification of Functioning, Disability and Health
LDC's	Least Developed Countries
MDG	Millennium Development Goals
MESC	Ministry of Education, Sports and Culture
MoH	Ministry of Health
MWCSD	Ministry of Women, Community and Social Development
NGO	Non-Government Organisation
NOLA	Nuanua o le alofa (Samoan disability advocacy organisation)
PIFS	Pacific Island Forum Secretariat
SBS	Samoan Bureau of Statistics
SENESE	Special Needs Education Society (SNES) ¹
SIEDP	Samoa Inclusive Education Demonstration Program
SNEAC	Special Needs Educational Advisory Committee
UN	United Nations
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNICEF	United Nations International Children's Emergency Fund
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organisation

¹ The Special Needs Education Society originally had the acronym SNES, but adapted the acronym to SENESE to reflect the Samoan pronunciation of the consonants and vowels as Se-Ne-Se.

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Chapter 1: Introduction

This study sits within growing research and knowledge on Pacific ontologies that relate to culturally responsive approaches to people with disability. This study seeks to conceptualise disability from a Samoan epistemological and cultural reference frame. It investigates historical and contemporary practices and perceptions of disability, as well as examining current disability discourse. The research also reviews the perception of development in the area of inclusive policy.

The general aim of this research is to gain insight into the Samoan perception of disability from Samoan epistemological and cultural reference frames. More specifically, the aims are to determine a cultural conceptualisation of disability, with the objective of positioning disability within contemporary Samoan society. This encompasses an examination of cultural perceptions, and management strategies for people with disability, an analysis of discourse and an examination of the interaction between Samoan and global initiatives in the area of disability. The research focusses on disability conceptualisations in the Independent State of Samoa.

In the past decade the landscape for disability in Samoa has changed dramatically. With international consciousness centred on rights-based models for people with disability, Samoa is endeavouring to align policy and practice with international expectations. A government commitment to developing and practicing a rights-based approach has seen an extensive overhaul of the education system to ensure that settings are inclusive and that educators receive adequate training to overcome barriers for people with disability. In her investigation into the cultural responsiveness of educational policy in Samoa, Tufue-Dolgoy (2010) reports that



there is some resistance to inclusion due to lack of training and resources within the education sector. The development of the 2011-2016 Samoa National Policy on Disability (SNPD) and the ratification of the United Nations (UN) Convention on the Rights of Persons with Disability (CRPD) has left no doubt as to the government's reform agenda on disability. The social disability model is very much a driving force in an emerging disability discourse in Samoa.

The task ahead for Samoa should not be underestimated. Shifts in approaches to disability are aimed at long-term improved standards of living for people with disability within a barrier-free society. Yet there is much to be done in order for Samoa to be considered barrier-free and inclusive. As a nation, Samoa has shown that it is prioritising issues surrounding the inclusion of people with disability in society. The ultimate aim is equality and inclusivity for people with disability. Much of the information that drives these initiatives has been derived from international contexts. In an increasingly dual-motivated society, [a term originally used by Peggy Fairbairn-Dunlop in 1991 (cited in Kruse-Vaai, 1998, p. 44)] there is a place for loaned policy and practice. There is also significance in ensuring that the development of policy and practice is culturally responsive. It is necessary that future policy development and practice merge with the intentions and long-term outlook of Samoans. This will ensure people with disability have access to culture, as well as inclusion and equality. For this reason, it is essential to map the perceptions and issues raised by stakeholders; people with disability, carers, family members, support staff, educators, policy makers, and the government to ensure that the needs of all stakeholders are met in a culturally relevant and equitable way. Stakeholder voices have been represented throughout this research through active participation, publications and policy.



1.1 Background

Globally, disability is increasingly being viewed as a human rights issue where limitations lie within a barrier-ridden society, preventing equitable access for people with disability (Anastasiou & Kauffman, 2011; Bickenbach, Chatterji, Badley, & Ustün, 1999; Lang, 2007). The social disability model, underpinned by a human rights approach requires removal of barriers in society to increase independence and ultimately the rights of people with disability. A multitude of complexities create barriers for each individual in a practical sense. Whether physical, attitudinal, or cultural, barriers can limit a person's ability to access society on an equal basis. Barriers can also inhibit the establishment of a positive and secure identity.

The CRPD was initiated to globally redress the inequality experienced by people with disability. It has been well documented that people with disability have been, and continue to be, marginalised (Bickenbach et al., 1999; Lameta, 2013; McKinstry, Price, & Setareki, 2012; Ministry of Women Community and Social Development, 2009; Shakespeare & Watson, 2001; R Tufue-Dolgoy, 2010). Critical reflection on disability policy is initiating global policy reform that represents the ideology of the CRPD through a human rights model of disability. The human rights model, also known as the social model, is an ideological shift away from viewing the individual as problematic. Alternatively, it identifies existing barriers within society that prevent individuals from full participation and access to society. Globally, policy reform is targeting the shortcomings of society to enable unrestricted access and inclusion for people with disability. Fundamentally, enhancing access to society for every citizen is desirable, but the means by which individual countries do this should take into consideration unique socio-cultural circumstances. Ethno-specific beliefs and



practices need to be incorporated into the development of new policy to ensure that people with disability still have access to cultural identity.

Disability policy reform is a catalyst for social change in the perception of disability in Samoa. Pacific nations are increasingly aligning themselves with global economic imperatives. Traditional cultural beliefs are shifting to reflect a society that is both motivated by traditional practices as well as contemporary political, economic, and social factors. Policy development is an important part of global alignment, as developing and recently developed countries often rely heavily on international aid to implement the political changes necessary to reflect international standards. In 2014, Samoa graduated from the UN's list of Least Developed Countries (LDCs) (2015) but is still considered a "lower middle income country" (discussed further in Chapter 3) by the World Bank (2015b). Samoa is increasingly adapting disability policy to reflect global conceptualisations.

Incorporating the doctrines of the CRPD, the 2002 Millennium Framework (BMF), and the Salamanca Statement and Framework for Action on Special Needs Education (1994), Samoa has embraced an international ideology on disability. This is now reflected in policy reform (Ministry of Education Sports and Culture, 2006; Ministry of Women Community and Social Development, 2009). Samoa's response to the development of disability policy has been to endorse a human rights standpoint. Raising awareness on disability generally is seen as a priority.

Critiques on policy direction in Samoa represent the differing perspectives of global versus cultural ideologies. Tufue-Dolgoy (2010) conducted research into the implementation of inclusive education in Samoa. She reports that globally driven imperatives are a barrier to cultural inclusion and indigenous identity development.



Tufue-Dolgoy asserts that the *fa'aSāmoa* is incompatible with contemporary thinking around social disability theory. She suggests that promoting independence denigrates the cultural foundation of collectivism, which underpins cultural identity and inclusion. McCullough (2005), on behalf of the Pacific Island Forum Secretariat (PIFS), reviewed Pacific disability policy and legislation development, reporting that Samoa is a leader in the field of disability policy development.

Very little research documents traditional Samoan perspectives on disability. Previously conducted research still leaves several gaps in understanding disability conceptualisations in Samoa. Do traditional Samoan conceptualisations marginalise or celebrate people with disability? Do global ideologies reflect the lived experiences of Samoans? Do global mandates complement the *fa'aSāmoa*, and the development of a Samoan cultural identity? This research investigates the Samoan conceptualisation of disability, and how it interacts with global disability policy initiatives.

1.2 Purpose of the study

Tufue-Dolgoy (2010) conducted research to investigate the concept and application of inclusive education in Samoa. Her study was concerned with the beliefs, experiences, expectations, and practices of key stakeholders within the education sector. It has been documented that there is increasing awareness that barriers and stigmatisation exist for people with disability in Samoa (Lameta, 2013; R Tufue-Dolgoy, 2010). However, in-depth research is yet to be carried out to determine the origins of cultural beliefs around disability and how these perceptions perpetuate inequality for Samoans with disability. Understanding and contextualising cultural



conceptualisations is an important component in effective and appropriate policy development, not only in the area of disability, but throughout all domains of society and within government.

This research builds on the work of Tufue-Dolgoy (2010; 2012) through an investigation of community based beliefs and practices that illuminate how disability is conceptualised in Samoa. This research also explores the impact of identified conceptualisations on the place and status of Samoans with disability within families and in broader society. Furthermore, it examines language usage within community settings and the role of colloquial language in the perpetuation of cultural beliefs. This research also explores perceptions of international practices that are introduced through policy in Samoa. Through the findings of this research, further development of a uniquely Samoan model of disability is proposed.

Through this research, it is envisaged that a greater understanding of the way that the *fa'aSāmoa* impacts upon identity development for people with disability in Samoa will be reached. This research seeks to identify the issues that affect and impact people with disability, their carers, families, advocacy organisations, educators, policy advisors and other stakeholder groups.

1.3 Significance of the study

The potential significance of this research lies in its transferability to all government ministries and Non-Government Organisations (NGOs) in the development and strategic directions of future policy. Unlike other recent studies which focus on inclusive education (Lameta, 2013; McCullough, 2005; R Tufue-Dolgoy, 2010), this research identifies issues surrounding perception and stigmatisation from individual,



cultural and societal perspectives. Through determining the origin of societal beliefs on disability, policy development and practice can target the needs of individuals with disability. This can be achieved through inclusion, and the recognition of important cultural practices and beliefs that are implicitly linked to identity development and concepts of self-worth unique to Samoans.

Through an evaluation of belief, practice, and discourse, an image of perception, equality and inclusion for people with disability is formed. This will enable government and society to tackle issues that create barriers for people with disability. Additionally, the research identifies the perceptions of carers and families on the responsibility of providing care for a person with a disability.

The findings of this research also provide information about perceptions of introduced or borrowed policy and its relevance and impact on people with disability in Samoa. This aspect of the research makes the findings applicable to policy development in other areas, and also in other Pacific Island nations throughout the region.

1.4 Primary research questions

The research aims are intended to contribute to knowledge on the way Samoans perceive people with disability. The research aims to determine how people with disability are accepted into Samoan family and culture, the expectation of contribution, access to status, and the impact of traditional belief systems and practices for people with disability. The research also examines the relationship between traditional Samoan epistemologies and borrowed practice and policy in the area of disability. Through this, there is an examination of colloquial and emerging discourse that describes disability.



The objective of this research is to conceptualise disability, both in traditional and contemporary contexts. The research will navigate through the role of family, concepts of inclusion, and the means by which Samoan people with disability secure identity and achieve cultural belonging. There is also an investigation into language and discourse and the way these impact on conceptualisation of disability. Finally, the research will provide information on the influences and impacts of western derived practice and policy. The following research questions guided this study:

Research Question 1:

How is disability conceptualised from a traditional Samoan epistemological frame?

- What are traditional conceptualisations of disability?
- How do concepts comprising the *fa'aSāmoa* influence disability perception and practice?

Research Question 2:

Does having a disability affect identity development, concepts of belonging, and cultural inclusion?

- How do the concepts of the *fa'aSāmoa* impact upon perception of disability?
- How do conceptualisations of disability impact on identity development, cultural belonging, and inclusion for people with disability?

Research Question 3:

How is global disability policy and practice viewed from a Samoan cultural perspective?

- How do Samoans view borrowed policy initiatives?



- Is there a representation of traditional Samoan epistemologies and practices within policy and practice?
- Does current disability policy and practice represent ideal social, political, and cultural outcomes for people with disability?

Research Question 4:

How does Samoan language and discourse represent people with disability?

- What Samoan terms, either formal or colloquial, are used to describe disability?
- How does Samoan disability discourse affect general perceptions of disability?
- What are the options for, and implications of, disability discourse reform?

1.5 Research design

It was vital to this research that the methodology recognised and reflected lived experiences. The use of the *Talanoa* research methodology as a research method was essential to data collection (described in Chapter 5). It enabled the development of relationships, aiding the flow of data during *Talanoaga*² sessions. The advantage of the *Talanoa* approach is the allowance of time for researcher and participant to establish a relationship. This results in rich data collection where the participant reveals valuable information, and the researcher gains insight into culture through the gifting of personal and revealing experiences.

² In this thesis, the word *Talanoa* is used when referring to the research method and the word *Talanoaga* is used when referring to the act of *Talanoa* sessions within the Samoan context (Kolone-Collins, 2010; Milner, 1992).

This research was conducted with participants who reside in villages in the Apia urban area. The selection of participants was conducted using purposive sampling to maximise insight into the research topic. Participants were determined according to selected criteria. The *Talanoa* method was used to collect data from all participants. Usually this occurred in one-to-one *Talanoaga* sessions, but sometimes where appropriate, in family or group situations. Opportunistic sampling was also used to select participants. This reflected cultural responsiveness as well as injecting flexibility into the study regarding groups and individuals who would best inform the study. The criterion-selected participants provided referrals to other participants who also matched the set criteria, and who were “information-rich cases” (Merriam, 2009). An opportunistic sampling approach can be employed very successfully where it is difficult to access appropriate respondents (Fossey, Harvey, McDermott, & Davidson, 2002). Va’a (2011) employed this method of sampling in his study on Samoan migration in Sydney. While Va’a had tried various approaches to recruit participants, such as looking for Samoan-sounding names in the telephone directory, he found ‘snowball’ sampling to be the most effective and he relied heavily on respondents to supply him with new participants. Va’a revealed that this method results in the relative homogeneity of the sample in terms of ethnicity, social class, and origin. As he was seeking general characteristics, developments, and trends, rather than mathematical certainties, the ‘snowball’ method proved to be highly effective (L. F. Va’a, 2011). The ‘snowball’ method was appropriate for this research also as shared ethnicity and origin were required criteria for all participants, and only qualitative data was sought. This method also fits with Samoan culture as it relies on rich and diverse social and familial networks.



1.6 Theoretical framework

Qualitative research leads to the development of understanding about lived experiences (Fossey et al., 2002; Merriam, 2009). As a qualitative researcher, interest is centred on interpretation of experiences; how people construct their lived realities and what meaning they attach to these. Among the different research paradigms available, the most relevant to this research is interpretive research. The interpretive paradigm aims to understand and describe the construction of social meaning derived from language, culture, and daily experiences (Fossey et al., 2002). According to Merriam, interpretive researchers “assume that reality is socially constructed, that is there is no single observable reality. Rather there are multiple realities, or interpretations of a single event” (2009, p. 9).

The *Talanoa* research methodology is specifically designed to conduct collaborative and reciprocal research with Pacific people (Vaioliti, 2006, 2011). As a method for studying human phenomena and understanding the human experience from a cultural perspective, it is based on Pacific epistemological and ontological perspectives (Titchen & Hobson, 2005). Like phenomenological research, *Talanoa* seeks to reveal meaning. It is the sharing of mutual history, culture, and language to co-construct meaning from experiences.

Like phenomenology, *Talanoa* seeks to understand phenomena from within. The researcher’s commitment to representing the perspectives of participants is at the core of understanding the phenomena. It is essential that the researcher does not find the answers he or she seeks, but that a process of co-construction is undertaken (Merriam, 2009). Within phenomenology, three types of data collection are common; focus groups, interviewing, and participant observation. For *Talanoa*, it is appropriate to



hold unstructured conversations, both individually and within focus groups. It is essential to the authenticity and validity of *Talanoa* that the conversations are not conducted as formal question and answer sessions as this is not the nature of *Talanoa*. Formal question and answer interviews reduce the authenticity of the experience and ultimately the quality of the data. Straying from the nature of *Talanoa*, or having limited cultural knowledge has implications for the representation of reliable data. However, a more formal focus group, with a guided topic approach developed in conjunction with participants could yield reliable data. This is a strength of phenomenological research, and in turn *Talanoa*, as it is designed to be flexible. Conducting research within these parameters also enables the researcher to observe non-verbal communications, make immediate clarifications of topic content, and be able to explore participant responses more fully (Merriam, 2009).

The flexibility of *Talanoa* allows the researcher to incorporate the participants at a foundational level, ensuring the results reflect the social context. This co-construction between researcher and participants builds openness, honesty, and authenticity where participants feel their perspectives have been represented accurately and fairly (Fossey et al., 2002). The ultimate gifting of the research marks respect for culture and acknowledges the contributions of participants.

The use of ethno-specific research methodologies are becoming increasingly prevalent as awareness of the importance of non-western epistemologies emerges. It is important that Pacific research methodologies recognise Pacific values, and engage meaningfully with individuals and Pacific culture (University of Otago, 2011). Research methodologies specific to Samoan culture are making significant contributions to what is known about traditional Samoan practices, beliefs, and



histories. An area that has received significant attention in recent times is that of Samoan health both in Samoa and in New Zealand (McCarthy, Shaban, & Stone, 2011; Tamasese, Peteru, Waldegrave, & Bush, 2005). Research methodologies specific to the Samoan health sector have been developed and yield valid and insightful data. These methods are known as *Fa'faletui* and *Fonofale* and share similarities with *Talanoa*.

1.7 Cultural responsiveness

As basic principles of a Samoan collectivist society, collaboration and reciprocity are highly regarded (Thornton, Binns, & Kerslake, 2013; Thornton, Kerslake, & Binns, 2010; L. F. Va'a, 2006). Stories and experiences are not shared lightly, but given as gifts to people who share an understanding of and respect for reciprocity (Kolone-Collins, 2010; Vaioleti, 2006, 2011). In the context of research with Pacific people, truth emerges from mutual respect, love, and understanding. The cultural appropriateness of the research methodology is vital to the quality of the data to be collected (Vaioleti, 2006).

In the early 1990s, literature first began reporting a cultural and societal shift in Samoa (Fairbairn Dunlop, 1991; Kruse-Vaai, 1998). Factors such as changing economic conditions, motivational goals, and 'hybridised' language were identified as contributors to significant cultural shifts. These factors were reportedly impacting upon the way Samoans developed identity and related to collective kinship groups. This cultural shift has continued and more recent research by Thornton et al. (2013; 2010) has reported that the Samoan family is now adapting to cultural shifts related to concepts of contribution, obligations, and unity. As Samoa increasingly



participates in a global economy, individuals are increasingly engaging with societal activities that can conflict with family obligations.

In a traditional sense, at the core of Samoan culture are concepts of family and belonging. The notion of family is a collaborative relationship based on mutual reciprocity and contribution. This forms deep-rooted bonds that tie all members of the family as one. It is part of an honour code of inclusion, love, protection, and respect in return for contributing to the prosperity of the family (Kolone-Collins, 2010; Kruse-Vaai, 1998; Lui & Dowland, 2003; Seiuli, 2012; L. F. Va'a, 2006). As Samoans are increasingly participating in contributory and reciprocal relationships with broader society, individuals are becoming distanced from the obligation of collaboration within kinship relationships (Thornton et al., 2013; Thornton et al., 2010). These changing circumstances have implications for people with disability as perceptions of disability fail to progress at the same rate as other aspects of society. This research does not prioritise either cultural or global influences as having inherently more value over the other. However, it aims to highlight the need for an evaluation of both culture and imported policy. It is proposed in this thesis that an evaluation of culture and imported policy should be undertaken through the lens of human well-being, valued function, and the unique circumstances that each person with disability experiences.

1.8 Limitations and scope

This research identifies emerging areas for development in disability conceptualisation, policy, practice, and service provisions. It provides a thorough indication of current conceptualisations of disability in Samoa and how



conceptualisations impact upon equality and inclusion. It also reviews current terminology and discusses the dilemma of reform in the area of disability discourse. Finally, it investigates the perceptions and impact of borrowed disability policy and practice.

This study is limited by several factors. It does not represent all perspectives of disability as only a sample group of people were selected. The sample consisted of predominantly urban Samoans living in or around the Apia area. Due to a myriad of external influences, it is difficult to determine a Samoan historical perspective of disability. Many Samoans have ‘dual-motivational goals’ relating to employment, economic, and family ideals. Given the specific nature of this study, the relevance within an international context may be limited. Accordingly, the findings of this research need to be interpreted in light of Pacific cultural principles to determine the potential impact on perception, awareness, inclusion, initiatives, practice, and future policy development.

1.9 Explanation of terms

Concepts of disability and disability discourse continue to evolve. Terminology around disability has the capacity to empower or oppress. My choice of terminology in this thesis emulates current terms used in the SNPD, developed by the Ministry for Women, Community, and Social Development (MWCSD). It views disability as resulting from “the association between a person with physical, mental and intellectual aspects and the environmental and attitudinal barriers she/he may face in villages and wider society” (2009, p. iii). The policy uses the preferred term of “people with disabilities” explaining the usage of this term as a desire to “put people



first rather than disability” (2009, p. 7). I have chosen to use this term in this thesis to align this research with existing terminology in the SNPD. However, it is proposed in this thesis that a new disability model, the *Tutusa* model expand beyond seeing disability from a barriers perspective.

1.10 Personal research journey

This research journey has been the culmination of my academic interests stemming from my teaching career, and my cultural experiences. My first teaching experience was as a special education teacher in metropolitan Adelaide, South Australia. My career began teaching students with both intellectual and physical disability. During this time, I learned how to educate children who arrive at school with unique capabilities. One of the most rewarding aspects of my job was the relationships I was able to build with my students and their families. I saw how parents found it challenging to respond to all of their child’s needs. This frequently resulted in the development of collaborative families, with brothers, sisters, grandparents, aunts, uncles, and community groups all contributing to the development of the child. This collective model is one that Pacific communities are very familiar with in the building of prosperous and strong family units. My experiences with my first students and their families initiated a deep interest in the acceptance of people with disability, both in society and within their family.

In early 2005, I moved to Samoa. I was employed as a year three teacher at a local school. This initial teaching position was not a special education role, but my interest in special education remained. Being a teacher in Samoa provided many opportunities to become embedded in the community. I grew very close to many



families, many of them becoming close friends. Having built strong relationships with these students and their families I felt a strong sense of responsibility, obligation, and love for my students. This was reciprocated from the families through *fa'aaloalo* (respect), *fa'alavelave* (cultural obligations in time of need), and *alofa* (love).

In 2009, I became a mother. My *afakasi* (part European) son, Coen is my inspiration. Our Samoan *aiga* (family) and our extended community have always shown love and support to both Coen and I. Our acceptance within our *aiga* and community has strengthened our cultural identity and ensured that Coen will always know he is a son of Samoa. It is of highest priority to me as a mother to ensure that Coen remains connected to his cultural identity through practicing the *fa'aSāmoa* and the relationships he has with our *aiga*.

Throughout my time living and working in Samoa, I taught several children with disability. The ways Samoans perceived disability and how people with disability were included within families was of great interest to me. I began collaborating with students and families to provide support for students with disability at school. In establishing effective educational programs for students with disability, I spent time talking to parents and to students themselves about their experiences at school and at home. These informal *Talanoaga* sessions initiated an interest in the interaction between the *fa'aSāmoa* and disability. The underpinning concepts of the *fa'aSāmoa* such as love, respect, and contribution featured as ways that disability is conceptualised and managed in village settings. As my understanding of the *fa'aSāmoa* grew, so too did my appreciation for the strength of the collective identity and its role in inclusive practices.



Several questions were raised for me regarding the *fa'aSāmoa* and its interaction with disability and inclusion. I wanted to know what expectations were held for people with disability within the family setting. I wanted to know if levels of contribution impacted upon inclusion and acceptance for people with disability. I wanted to investigate the impact of global ideology on cultural practices for people with disability. I wanted to explore how discourse has shaped conceptualisations of disability in Samoa.

My experiences with people with disability in Samoa have been the impetus for this research. The intention is that it will add positively to the experience of people with disability and their families in retaining a strong sense of cultural identity while incorporating new knowledge.

I formally began this research in 2011 after living in Samoa for six years. Having the opportunity to conduct this research and collaborate with my participants has been an honour. I am humbled by the generosity of spirit and the friendships I have been offered by my participants who opened their families to Coen and I. We spent several months in 2012, and again in 2013 living in Samoa to collect data for this research. Being afforded the opportunity to live in our Samoan village with my participants gave me a deep sense of understanding through living within the *fa'aSāmoa*. During my research field trips, I volunteered at my village pre-school. Both Coen and I quickly became embedded in the practices of the *fa'aSāmoa* for our village and community. As a teacher I was afforded a high level of respect. As a mother, I was given endless support, friendship, and love. As a family member, I was given opportunities to contribute and reciprocate the generosity that was extended to me. Being part of a collective identity and feeling a sense of belonging highlighted the



value and importance of collaboration, contribution, service, honour, and love. I feel immensely privileged to have forged relationships that permitted rich *Talanoa*, facilitating the success of this research. More importantly, I am privileged to have the opportunity to secure my Samoan cultural identity with my Samoan *aiga*. This research is the gift of reciprocity to my Samoan *aiga*, and to all of my other participants whose voices will generate change for future generations.

My connection to Samoa is enduring, and my Samoan identity is something that remains. I have forged an unbreakable bond to the Samoan culture and its people. Spending time in Samoan villages conducting research has given me some of the most rewarding experiences of my life. It is a time of great pride and humility for me as I am finally able to give something back to my Samoan *aiga* and my Samoan community through my research. My research has presented an opportunity for me to contribute to the Samoan culture and to demonstrate my utmost respect and love for the Samoan people. The opportunity to conduct this research has presented ongoing opportunities to connect both Coen and I to the Samoan culture, helping us to maintain our Samoan identities. We will always be connected to Samoa, Coen through his blood and I through my heart.

1.11 Chapter summary

This chapter outlines the rationale for this research, identifying the aims, objectives, and research questions that guide this work. It also outlines the methodological framework and the importance of a culturally responsive research methodology to this research.



Throughout the chapters of this work, concepts of perception, familial relationships, and belonging are explored in relation to disability. Framing the Samoan context, Chapter Two provides a review of Samoan cultural underpinnings and the journey of the development of the nation of Samoa. This review examines the change and continuity of the Samoan culture and the ways that people with disability are affected by this change. Chapter 3 reviews disability in a global capacity to provide an understanding of the ways that disability conceptualisations have evolved in Samoa. Merging these two fields together, Chapter 4 reviews the history of disability development in Samoa and current initiatives into disability reform. Chapter 5 explores the concepts of *Talanoa* as a research methodology, and in its application to this research.

The interpretations of the *Talanoa* interviews are represented in Chapter 6, detailing the findings of this research. Identifying several key findings, this chapter explores concepts of conceptualisation, stigmatisation, inclusion, the impact of terminology, and perceptions of foreign influences on policy and practice. Reflecting on both political and cultural conceptualisations of disability, Chapter 7 identifies contributing factors to marginalisation and stigmatisation of people with disability in Samoa. This chapter also identifies pathways to continued community and stakeholder discourse on the ways in which terminology can be approached in future disability policy reform. Finally, Chapter 7 discusses how borrowed policy is perceived, how it interacts with culture, and how policy can incorporate both culture and borrowed policy. In providing conclusions on the research, Chapter 8 states the main findings of this research, provides recommendations, and suggests future research questions.



Chapter 2: The Samoan context

2.1 Introduction

The unique concepts of the Samoan way of life are interwoven to imbue a deep-rooted sense of culture, connectedness, and identity making up the cultural script of the *fa'aSāmoa*, literally the Samoan way. The concepts, described throughout this chapter bring to life a way of living that builds on an unshakable family bond. The *fa'aSāmoa* unites individuals to ensure strength, prosperity, and longevity for ancestors and future generations alike (Kruse-Vaai, 1998; L. F. Va'a, 2006). As a set of cultural guidelines, the *fa'aSāmoa* ensures the continuity of culture in what is now a changing Samoan society. The *fa'aSāmoa* is a beacon of conduct, law, education, identity, spirituality, relationships, economic exchange, status, service, and language (Kolone-Collins, 2010; L. F. Va'a, 2006). It acts as a compass to guide change as global influences interact with the concepts of the *fa'aSāmoa*. The changes occurring in Samoa regarding policy and practice for people with disability encourage a dialogue around the compatibility of the *fa'aSāmoa* and global influences.

This chapter describes concepts of the *fa'aSāmoa* and the role these play in Samoan identity development. Throughout this chapter, the value of the *fa'aSāmoa* to identity development and self-worth is highlighted. The concepts of the *fa'aSāmoa* are also evaluated within the frame of various models of disability that are present in Samoan society. This evaluation of cultural concepts, along with an evaluation of global disability models in Chapter 3 establishes a framework to develop a uniquely Samoan conceptualisation of disability. The *Tutusa* model, introduced in this chapter and further described and contextualised in Chapter 7 is a model of disability that acknowledges both cultural and human rights perspectives of disability.



2.2 Early Samoan conceptualisations of disability

The Independent State of Samoa is located in the South Pacific ocean equidistant to New Zealand and Hawaii, forming part of the Polynesian triangle in the wider Oceania region. It has a population of nearly 190,000 spread across the two main islands of Upolu, where the capital Apia is located, and Savaii. There are six smaller islands, some of which are inhabited. Samoans retain their indigenous dialect as the official language, with English also widely spoken. The Samoan diaspora make up approximately 300,000 people worldwide.

This research identifies multiple conceptualisations of disability in contemporary Samoan society. Concepts of disability from a Samoan cultural perspective have not been well defined for the time prior to colonisation. An examination of historical European conceptualisations of disability (discussed in Chapter 3) provides insight into how contemporary Samoans conceptualisations developed.

Colonisation of Samoa brought with it sweeping cultural change that impacted established belief systems and traditional practices (L. F. Va'a, 2006). It can be surmised that the period of early colonisation also brought change for people with disability as Christian and western ideology infiltrated Samoan society. A shift in conceptualisations of disability during the colonisation period is not documented. However, moral and medical conceptualisations prevalent in Europe during this period still feature as part of the disability landscape in Samoa.

In the 1830s, at the height of the medical disability model era, English missionaries and traders began arriving in Samoa in large numbers (Meleisea, 2012). Despite an established indigenous system of government, (the *fa'amatai*), external ideas began to influence the culture (Meleisea, 2012). Christianity was introduced to Samoa



despite indigenous spirituality already being fundamental to the Samoan cultural identity. When Christianity was not embraced wholeheartedly missionaries discovered that incorporating the support of the *matai* (chief) effectively enabled the dissemination and adoption of organised religion (Thornton et al., 2010; L. F. Va'a, 2006). The Samoan people felt that the principles of Christianity complemented the concepts of *fa'aSāmoa*. Approximately 99 percent of Samoans are currently identified as Christians (McMurray, 2006). Adopting Christianity eroded many traditional practices (Auva'a, 2003). Missionaries were encouraged to implement a new education system, dismantling traditional, non-formal practices as well as restricting the usage of the Samoan language in educational settings (Coxon, 2007; Kolone-Collins, 2010). Both moral and medical paradigms remain a part of disability conceptualisation in contemporary Samoan society. This is indicated through the various terms that describe disability in Samoa (see Chapter 4). The impact of moral and medical paradigms on cultural identity and self-worth are detailed in the findings of this research in Chapters 6 and 7.

During the period of colonisation, the experience of disability was not documented. Margaret Mead (1928) documented her experience in Samoa in 1928 depicting the integration of people with disability in traditional Samoan culture. Her research later became controversial, with Freeman (1983) arguing it should be discredited. No other evidence suggests that people with disability were either hidden from or embraced by society, nor does any literature indicate early education initiatives for people with disability.



2.3 Concepts of culture: Disability and the *fa'aSāmoa*

The development of identity for Samoans is guided by the *fa'aSāmoa*. The *fa'aSāmoa*, anchored in a hegemonic cultural script, is a complex set of social guidelines that shape individual and group identity (Horsley, 2011; Kruse-Vaai, 1998; L. F. Va'a, 2006). From birth, Samoan children learn about their cultural relationship within their kinship group, the system of hierarchy that gives relevance to all members of the *aiga*, and the nature of respectful relationships. The *fa'aSāmoa* provides a framework for identity development, incorporating concepts of respect, contribution, and love. These core beliefs and practices are known as the *fa'aSāmoa*, literally translated as “the Samoan way” (L. F. Va'a, 2006). For people with disability, securing cultural identity within the *fa'aSāmoa* has unique considerations (discussed in depth in Chapter 4).

2.4 The *fa'aSāmoa* : Cultural identity and well-being

In this section, the components of the *fa'aSāmoa* shed understanding on the importance and value of the Samoan culture and its role in identity development. This establishes a framework for contextualising the relevance of the *fa'aSāmoa* in the development of identity and in the continuity of culture. An evaluation of the *fa'aSāmoa* locates it in the context of the experience of disability from a human well-being standpoint. Figure 1 represents each of the components of the *fa'aSāmoa*, making up a continuum of cultural knowledge, expectations, and collective identity.





Figure 1. Core components of the *fa'aSāmoa*

2.5 Collective identity development

Kinship connections are a significant contributor to the development of identity for Samoans. Constructing a group self-image for Samoans is an important process in securing cultural identity (Kolone-Collins 2010). For Samoans, the concept of family is highly inclusive and broad; every member of a bloodline, no matter how distant, is part of the kinship group and subject to the responsibilities of the group (Kolone-Collins, 2010; Lui & Dowland, 2003; Tamasese, 2008, September 22-25). Kruse-Vaai (1998) describes the idea of collective identity and its relationship to the *aiga*:

The *matai* is the family, the family is the *matai*. This collective identity underpins a communal support system which accounts for each individual in the village...When a person does well, the members and *matai* of that family and village also take credit, since one's good reputation extends to one's village and family. In the same way, hardship and trouble for an individual are shared by the family and

village. A Samoan is seen by the rest of Samoan society – not only as an individual – but as part of the whole Samoan framework. (Kruse-Vaai, 1998, p. 35)

Concepts of the *fa'aSāmoa* such as hierarchy, respect, and contribution are observed as the basis of the Samoan identity (Coxon, 2007; Kruse-Vaai, 1998; L. F. Va'a, 2006). In pre-colonial times the *aiga* was part of an economic framework where families exchanged goods that were marketable in the wider economy (L. F. Va'a, 2006). While economic exchange still very much exists in contemporary Samoan families, the exchange is primarily cash based, and often families count a main source of income from remittance contributions (L. F. Va'a, 2006). Contribution is understood as obligatory and reciprocal. Responsibility to family is complemented by a sense of security in acceptance, belonging, and mutuality (Horsley, 2011; Lui & Dowland, 2003; McCarthy et al., 2011). Contribution is not exclusively financial, but is represented by a myriad of opportunities for the family to prosper. A respect for and acknowledgement of hierarchies is one such opportunity.

Within kinship groups there is an inherent understanding of the nature of respectful relationships (*vāfealoa'i*) and concepts of hierarchy (Kolone-Collins, 2010; Kruse-Vaai, 1998; Tamasese et al., 2005). In pre-colonial Samoa, the *matai* system (*fa'amatai*) provided a system of leadership and governance within families and villages (L. F. Va'a, 2006). The government is elected through a formal Westminster system; but a traditional chiefly administration is still relevant to contemporary Samoan society.

The *matai* system in general reaffirms the concept of family, belonging, and respectful relationships for Samoans. Its intention is to provide unity, security, and



leadership (Kruse-Vaai, 1998; L. F. Va'a, 2006). *Matai* are elected members of the *aiga* whose responsibility it is to represent the perspectives and needs of their branch of the family at village *fono* (council). This ensures equitable wealth distribution, settlement of disputes, and the upholding of honour (Kruse-Vaai, 1998; L. F. Va'a, 2006). There are varying *matai* titles which represent different roles both within the village and the *fono*. A *tulafale* title requires the *matai* to be the speaker and decision maker for the family and village. An *ali'i* title represents an aristocratic link within ancestry (Kruse-Vaai, 1998; L. F. Va'a, 2006). It is imperative for each family member to recognise their role, responsibilities, and status within the *aiga*.

The *matai* is the dominant authority who has the power to make decisions that affect all members of the family. The *matai* also ensures the well-being and protection of every member of the *aiga*. This collectivist mentality encourages a sense of self, rooted in the prosperity, security, and reputation of the entire family. This brief overview does not intend to minimise the importance, relevance, and complexity of the *matai* system.

The concept of hierarchies, collective identity, and contribution impact upon the way disability is conceptualised from a cultural reference frame. The concepts of the *fa'aSāmoa* that underpin identity development are examined through this research to determine the impact of cultural beliefs and practices on people with disability. One of the objectives of this research is to ascertain the impact of the *fa'aSāmoa* on cultural inclusion. It is proposed that concepts of hierarchy, status, and respectful relationships play a significant role in the inclusion of people with disability in Samoa.



This research has explored the interaction between hierarchical relationships, and beliefs and practices around disability. Being included as part of an *aiga* group has many obligations and responsibilities. This research examined the nature of inclusion for people with disability in relation to attitudes towards capability and functioning.

2.5.1 Contribution and *vāfealoa'i* (respectful relationships)

Strength and security can be derived from being a part of the collective. Being a part of the collective also entails significant responsibility. Contributing to the strength, prosperity, and status of the collective is an essential element in ongoing inclusion. Understanding the role of respect and contribution is the foundation for achieving self- and group-worth. Identity for Samoans is intrinsically linked to contribution to the family (Seiuli, 2012). Contribution is not limited to financial offerings, but also encompasses upholding family values and maintaining codes of behaviour and conduct.

Traditional Samoan society relied on systems of exchange as a form of currency. Families and villages would exchange goods as part of a subsistence lifestyle. Goods and services would also be exchanged as part of obligatory cultural contributions at times of *fa'alavelave*. In traditional Samoan societies wealth was accumulated through the extent of social contributions (L. F. Va'a, 2006).

In contemporary Samoan society, the extent to which an individual contributes is still an indicator of status, wealth, and respect. The practice of contribution and systems of exchange have evolved significantly in recent years. The notion of contribution itself is firmly embedded in the *fa'aSāmoa* and still has significant relevance in contemporary Samoan society. The concepts of contribution are not exclusively used



as a form of economic exchange, but also as means to secure status within the collective. Current economic and social conditions have affected the way the *fa'aSāmoa* is viewed and practiced. Contribution is increasingly being viewed as a burden (Auva'a, 2003; Kruse-Vaai, 1998; Thornton et al., 2013; Thornton et al., 2010). Diminishing familial contributions generally, due to a shifting social context, reduces the prosperity of the *aiga* group. It is vital to the success of *aiga* groups that hierarchies are respected. Within the hierarchical social structures of Samoan families, it is important to recognise the respectful relationships that arise from status. This is the *vāfealoa'i*. The *vāfealoa'i* is based on respectful behaviour, reciprocity, and an understanding of connectedness to others (Kolone-Collins, 2010; Lui & Dowland, 2003; Seiuli, 2012; Tamasese et al., 2005). The interplay between family members and the acknowledgement of reciprocity secures one's identity in relation to others (Kolone-Collins, 2010; Kruse-Vaai, 1998). It is important that all *aiga* members contribute to the prosperity and good standing of the collective through appropriate conduct. *Aiga* members must ensure shame is not brought upon the collective.

Changes to the value and perception of contribution have implications for familial structure. Historically, security and prosperity had been tied to levels of contribution, but also concepts of obligation and love. This raises the question of how people with disability secure their position within the *aiga* group in changing social circumstances. Where contribution and obligation are necessary to inclusion and acceptance, what constitutes contribution for people with disability?

As a concept of the *fa'aSāmoa*, contribution is a means of cultural identity development. This research explored the impact of the cultural beliefs of obligation



and contribution in light of a social disability paradigm. For Samoans, identity is not individualistic, nor is it motivated by self-promoting goals. It is based on a collectivist philosophy that determines identity in the light of family and community (Tamasese et al., 2005). Fundamentally, self-worth is determined by the capability to contribute. In turn, contributing is reciprocated through inclusion and security. In exploring concepts of the *fa'aSāmoa*, issues emerge regarding the identity, belonging, and inclusion of people with disability within a rapidly evolving social and political landscape in Samoa.

The concepts of *vāfealoa'i* and contribution present opportunities for individuals to make valuable contributions to strengthen *aiga* connections and social standing. In recent times, Samoan kinship groups have been experiencing conflict over religious beliefs. Thornton et al. (2013; 2010) report that family cohesion is being threatened by members of *aiga* groups who are leaving church congregations in search of less financially demanding congregations. This has resulted in conflict within the *aiga* where secular religious practices are an expectation (Thornton et al., 2013; Thornton et al., 2010). Thornton et al. claim family members who seek out alternate congregations have land entitlements reduced. It is of great value to the *aiga* that there is a sense of shared direction, belief, and understanding about how the family should conduct and present themselves within society. The shared direction and belief of the group facilitates unity. Representing the family in a positive way is an expectation of the collective. Having a shared understanding promotes unity. Achieving a united belief system in terms of the conceptualisation of disability is a challenge, particularly in a society that has multiple and conflicting conceptualisations. This research has evaluated the ways contribution and inclusion for people with disability are conceptualised within the framework of the *fa'aSāmoa*.



This research also evaluated concepts of the *fa'aSāmoa* through the lens of existing paradigms of disability present in Samoan society.

2.5.2 Being knowledgeable (*poto*) and useful (*aoga*)

The *fa'aSāmoa* is imparted as part of cultural continuity. It establishes collective identity, ensuring prosperous *aiga* groups. The imparting of epistemological concepts and cultural transmission are founded upon the principles of the *fa'aSāmoa*. Early education practices in Samoa relied heavily on an oral tradition. Learning was a spontaneous daily occurrence, responsible for the passing on of collective knowledge and skills aimed at the maintenance of cultural and physical survival. In this way, the objective of education was continuity of identity and culture (Coxon, 2007; Malietoa von Reiche, 2010). Learning was experiential; through listening, memorising, observing, and doing (Coxon, 2007). Traditional learning in Samoa was similar to other methods throughout Polynesia with the basis of knowledge acquisition being for the benefit and advancement of the collective. Tongan epistemological frameworks were explicated by Helu-Thaman (1988) who introduced the concepts of *ako*, *'ilo*, and *poto*. The concepts are transferable to concepts that underpin indigenous learning for Samoans and will be referred to in the Samoan terms of *a'o* (learning and teaching), *iloa* (knowing), and *poto* (knowing what to do and doing it well). In Samoa, this traditional learning teaches young Samoans about the concepts of the *fa'aSāmoa*; love, respect, honorifics, service, and honour. Early learning reinforces concepts of both culture and identity.

For young Samoans the acquisition of knowledge is essential to the continuity of culture, where identity is derived. Having cultural, historical, technical, and spiritual knowledge ensures each member of the *aiga* is *aoga* (*useful*), and can provide a



valued function to the collective. Knowledge of complex social behaviour and relationships, as well as functional skills to provide service to the *aiga*, facilitates inclusion and acceptance (Auva'a, 2003; Coxon, 2007; Malietoa von Reiche, 2010). Learning is a method of nurturing young Samoans to become both *aoga* and *poto* (Kolone-Collins, 2010). Much of early learning occurs through observation, listening, and imitation (Coxon, 2007).

The advancement of the collective and the maintenance of culture are still valued concepts in contemporary Samoan culture. The experience of cultural and social shifts impact upon the functioning of the *fa'aSāmoa* and in turn, the role of the *aiga* in the development of cultural identities. Fundamental to the prosperity of *aiga* groups is the value that each individual contributes. The strength and unity of the collective relies upon each individual being *aoga*. Being *aoga* establishes security within the family, and ensures reciprocal relationships. From a cultural perspective, *aiga* members are required to be *aoga* for the strength and prosperity of the collective. Failing to be *aoga* risks lack of reciprocity, in turn, threatening inclusion, identity development, and self-worth. Being *aoga* is a highly valued function within the *aiga* group (Kolone-Collins, 2010).

The recognition of people with disability as equal and productive members of society is promoted through a social disability model (discussed in Chapter 3). Within this context, the concept of useful is flexible and inclusive. The Capabilities Approach (CA) which will be explained in detail in Chapter 3, features two core concepts: capabilities (what a person can actually do), and functioning (what a person can do in light of their circumstances). As a paradigm of disability, the CA recognises that the concept of useful is impacted upon by a range of variables such as age, gender, and



health. The CA sees functioning as being impacted upon by effective facilitation of available resources. In this sense, it is the responsibility of the individual as well as the collective to evaluate usefulness in light of capability and in terms of what resources the collective has made provision for. Effective provision and recognition of capability ensures that all family members can achieve *aoga*. When a person with disability is provided the resources to effectively contribute, the capability to achieve a valued function for the collective can be realised. However, in a Samoan sense, valued functions are evaluated within a collective framework. The function needs to be of value to the entire *aiga* group. In this way, the valued function becomes a contribution.

Considering the value of being *aoga* raises the question of how people with reduced capability are accepted and included within *aiga* groups. The evaluation of disability within the framework of cultural conceptualisation questions the availability of equality and inclusion.

Poto is having the ability to apply knowledge and skills. It is essential to *poto* that knowledge and skills are carried out in such a way as to bring benefit to one's *aiga*, and that the individual carries it out with competency and success (Vaiotele, 2011). *Poto* benefits the *aiga* through a commitment to accept the cultural responsibility of bringing honour to the family and having the capacity to contribute (R Tufue-Dolgoy, 2010). Being *poto* does not simply mean being able to do something, or having certain knowledge. It is imperative that the knowledge and skills are acquired at a high level. Merely having the knowledge and skills does not mean that a person carries them out successfully. This is central to the concept of *poto* and brings with it a high level of regard within society. While being competent and knowledgeable



is desirable, being humble is a highly valued trait for Samoans. Being overtly proud is viewed as *fiapoto*; conceited or presumptuous (Milner, 1992). The challenge for people with disability is having the capability to execute valued functions for the *aiga*. For people with disability, knowing what to do is achievable. Executing a valued function, and doing it well may pose a challenge due to a multitude of potential barriers.

2.5.3 Discourse: From past to present

As a link to cultural identity, indigenous languages provide a sense of belonging and enable an outlet for cultural expression (Kolone-Collins, 2010; Sanga, 2004; L. F. Va'a, 2006). Having the capability to speak the language of the group ensures belonging and facilitates membership into a cultural group (Amituanai-Toloa, 2010; Sanga, 2004). In her study on Samoan night stories (*fagogo*), Kolone-Collins found that *fagogo* is more than merely storytelling for entertainment. It is a tradition of imparting knowledge, values, rituals, beliefs, and cultural practices in a shared language that develops a sense of identity, belonging, respect for culture, and understandings of hierarchies and one's role in society (Kolone-Collins, 2010; Wilson, 2010).

The Samoan language came under scrutiny during the period of colonisation. German missionaries introduced German language lessons into formal education (Coxon, 2007). This practice devalued and marginalised traditional learning, culture, and identity (Merriam, 2007). Later the New Zealand administration restricted the use of English as the language of instruction “to avoid the creation of a western-educated elite that might threaten New Zealand's political authority” (Coxon, 2007, p. 277).



The popularity and relevance of the Samoan language has seen a resurgence in the past several decades. Va'a (2006) suggest that 90 percent of grandparents in Samoa can speak their mother tongue although this is diminishing. The significance of the Samoan language to culture and identity has been acknowledged by the Ministry of Education, Sports and Culture (MESC) with the aim of policy development to be in the advocacy of bilingualism while recognising that English is established as the language of educational and economic opportunities (Ministry of Education Sports and Culture, 2006). The Samoan language is maintained in home settings, but Va'a reports the employment of code-switching between Samoan and English is increasing as culture and language are impacted by external practices.

Kruse-Vaai (1998) describes this change in language as a “hybridisation of language” that is not necessarily a negative cultural shift, but one that incorporates changing social, cultural, and economic conditions. In this sense, the merging of Samoan and English into a “hybrid” language reflects the changes to the Samoan identity in contemporary Samoan culture.

Very little documented evidence exists to track terminology and discourse around disability in Samoa. It has been reported by Tufue-Dolgoy (2010) and Lameta (2013) that terms to describe people with disability in Samoa has evolved from moral and medical models. This research, in part, aims to examine the shared understanding of disability that has emerged from the established terminology. The research also examines the complexities of discourse reform. These concepts are explored in more depth in Chapter 7.



2.6 Global citizenship: Change, continuity, and compatibility

This chapter has provided an overview of the essence of the *fa'aSāmoa* and the elements of the Samoan cultural identity. These concepts still hold a high level of relevance in contemporary Samoan society. However, culture is an evolving concept. Contemporary Samoan culture reflects change while maintaining a commitment to continuity in all aspects of culture. Since reclaiming independence in 1962, Samoa's cultural journey has been a weaving of the traditional, the borrowed, the innovative and progressive, and the celebration of both cultural continuity and change.

In the 50 years since gaining independence, the Samoan economy has gained in strength and diversified. National development is a priority for the Samoan government. Six developmental priorities have been identified (Ministry of Finance Economic Policy and Planning Division, 2005):

- 1) Strengthening the private sector;
- 2) Agricultural development;
- 3) Tourism development;
- 4) Community development;
- 5) Education development; and
- 6) Health development.

However, despite a strengthening economy, it is suggested that there are increasing numbers of people living below the poverty line (Thornton et al., 2013; Thornton et al., 2010; F. Va'a, Va'a, Fuata'i, Chan Mow, & Amosa, 2012; L. F. Va'a, 2006). Va'a (2006) reports that several groups in Samoa are vulnerable to marginalisation, including people with disability.



The 2011 census reported Samoa's population has reached an all-time high of more than 187,000 people (Samoan Bureau of Statistics, 2011). The emigration rate is also a steadily growing figure with New Zealand hosting some 144,000 people who identify as Samoans (Statistics New Zealand, 2014). The United States of America hosts more than 120,000 Samoans (United States Census Bureau, 2012). Samoan migration to Australia has increased dramatically in the past decade with nearly 40,000 Samoans now calling Australia home (Australian Bureau of Statistics, 2011). Samoa and Samoans rely heavily on remittances sent from relatives that have migrated overseas. Remittances account for 20 percent of Samoa's gross domestic product.

Political changes in Samoa are reflected in the fabric of Samoan society. Samoan culture has withstood many attempts to marginalise traditional ontologies and practices, and traditional culture still remains a central feature of identity. In contemporary Samoan society, however, traditional epistemologies share space with more contemporary outlooks. The coming together of Samoan and other cultures has seen fundamental changes in Samoan society affecting identity and community. This marriage of cultures has been referred to as "dual-motivational goals" (Fairbairn Dunlop, 1991), effectively globalisation. From economy to identity, these changes to Samoan society have far-reaching consequences that both benefit and constrain society.

Following several decades of active pursuit of national development, economic factors are contributing to cultural transformations (Thornton et al., 2013; Thornton et al., 2010; L. F. Va'a, 2006). As Samoans increasingly exist in a "hybridised" society (Kruse-Vaai, 1998), concepts of contribution and obligation are moving away



from a collective approach in favour of more individualistic goals. With increasing global influence, this concept of family is beginning to take on new meaning and with that, a new set of expectations. This has implications for identity development where collectivism is no longer seen as the only means to advancement.

Despite a move away from a kinship-based economy of goods and service exchange, Samoans still respect the tenants of the *fa'aSāmoa*. Generous monetary exchange, both in remittances (WST\$328.4 million in 2010) and contributions to *fa'alavelave* and church obligations (WST\$52 million in 2010), demonstrate a commitment to familial and cultural traditions (F. Va'a et al., 2012). The concept of contribution is one taken very seriously by Samoans, as it represents a cultural practice linked to inclusion and identity. It is considered every member of the family's responsibility to contribute to the prosperity of the *aiga*, which in turn raises the status of the *aiga*. The greater the contribution one makes, the more unshakable the level of acceptance one has. A family member who chooses not to contribute, or has little means of contributing has a more tenuous position in the family. This has implications for access to customary land, titles, and familial inclusion (Thornton et al., 2013; Thornton et al., 2010).

Thornton et al. (2013) report that increasing numbers of urban Samoans are opting out of customary reciprocal relationships in pursuit of increased independence. With restricted access to customary land, urban Samoans purchasing freehold land effectively reduce the necessity to contribute to collective prosperity. This has consequences for the fundamental aspects of traditional kinship relationships.

It has been reported that people with disability in Samoa are disadvantaged and marginalised socially and economically (Lameta, 2013; McKinstry et al., 2012;



Ministry of Education Sports and Culture, 2006; Shakespeare & Watson, 2001; R Tufue-Dolgoy, 2010). Va'a (2006) suggests that particular demographics are more susceptible to disadvantage in light of shifts in kinship relationships. Va'a reports that people most affected by hardship are landless families, the unemployed, families with a single income, large families, people who are geographically isolated, and people with disabilities. For vulnerable groups, such as people with disability, the collective support system provides security. Changes to family structures, coupled with traditional perspectives of disability contrive to create an uncertain future for people with disability.

National and regional development goals are aimed at improvements to the health and education sector, as well as general community development. The recognition of human rights has been prioritised and for people with disability this has facilitated a level of equality in society. The capability to exercise rights and freedoms may potentially be hampered by pervasive societal beliefs around disabilities, but also aspects of the *fa'aSāmoa* that are incompatible with individualism. Examining aspects of culture, along with assessing aspects of introduced practice through a human well-being stance can assist in determining the value and relevance of societal practices. A review of traditional cultural practices and beliefs, and an evaluation of disability (which is undertaken in Chapter 3) provide an opportunity to assess how Samoan epistemologies interface with introduced disability frameworks. This promotes thinking about the structure of families and society in Samoa in a positive way. It enables a pathway to emerge that critically reflects upon both concepts of culture and the changes that have occurred throughout Samoan society. It is proposed that a Samoan model of disability can provide a critical framework to assess culture and change. This new framework, the *Tutusa* model, rooted in the *fa'aSāmoa*,



proposes a uniquely Samoan model of disability from both cultural and human rights stances. It has a capacity to critique and celebrate culture, in what is a constantly evolving familial, social, and political space.

2.7 The *Tutusa* model of disability conceptualisation

The word *Tutusa* means “to be the same, equal” (Milner, 1992). It can be concluded, through a review of the *fa’aSāmoa* concepts, that a Samoan concept of ‘equal’ must incorporate concepts of hierarchical relationships, contribution and responsibility, and being *aoga* to the collective. Achieving group- and self-worth is derived from respecting and adhering to these cultural concepts. For people with disability, developing a cultural identity incorporates these concepts also, despite the challenges and barriers they may present.

The *fa’aSāmoa* is not based upon egalitarian concepts, so equality is not a concept that fits well within it. Within the context of the *fa’aSāmoa*, contextualising *Tutusa* incorporates the acknowledgement that hierarchical social structures will precede any new concept of equality. However, gaining a level of equality within *aiga* groups is a necessary aspect of inclusion and protection. In this sense, equality is earned as reciprocation for contribution to strength, well-being and prosperity of the collective. Having equality within the *aiga* group does not necessarily equate to being equal, or having equal relationships with others. It is the ability to contribute on an equal basis with others. It incorporates being *poto* and acknowledging that contributions must be *aoga* to the collective. The contribution must be both valuable and worthy of reciprocation. This questions how contributions are received by the collective where the contribution has been achieved with significant modification. Modification, or



barrier removal, is a central feature of a social disability model (discussed in Chapter 3). The concepts of inclusion and acceptance are quite separate to equality. Inclusion and acceptance are features of the *fa'aSāmoa*, and being a part of the collective ensures love and protection. But for people with disability to achieve a sense of equality, rather than just acceptance, valuable contribution is essential.

Developing a uniquely Samoan model of disability, such as the *Tutusa* model, presents an opportunity for Samoans to shape conceptualisations of disability that respond to shifting cultural and political circumstances, while retaining cultural epistemologies. It is proposed that a *Tutusa* model could be developed through facilitating the CA as a filter for valued aspects of culture, in interaction with concepts of human rights and disability paradigms. The CA will be explored in detail in Chapter 3. As an overview, and in its application to the *Tutusa* model, the CA focusses on human well-being and development (Bakhshi & Trani, 2006; D. Clark, 2006; Terzi, 2005). The premise of the CA is that all humans vary in their need for resources. The CA emphasises lived experience and acknowledges circumstances unique to individuals. Within the CA, the focus of achievement is on what a person values doing (Mitra, 2006). Two concepts are central to the CA; capabilities and functioning. Capability describes what a person can actually do and functioning describes what a person can achieve in light of circumstances such as health, access, nutrition, and social and cultural factors (Reindal, 2010). Functioning also includes what a person values doing (Mitra, 2006). The CA, in its application to disability, enables the person with disability to determine what achievements are valuable.

It is proposed throughout this thesis that the CA is used to evaluate aspects of both culture and human rights perspectives. This evaluation can determine what concepts



are valued in formulating a uniquely Samoan model of disability. In the context of the *fa'aSāmoa*, the CA can evaluate capability and functioning in terms of other important concepts such as hierarchical relationships, useful contributions, collective identities, and cultural concepts of equality.

The *Tutusa* model is proposed in this thesis as a way to conceptualise disability through blending Samoan and global ideologies. The application and development of the *Tutusa* model as a functional conceptualisation of disability will be further explored in Chapter 7. It will be evaluated in comparison to existing disability paradigms to ascertain its relevance and practicality within the Samoan context.

2.8 Conclusion

Reviewing the concepts of the *fa'aSāmoa* in relation to acceptance and inclusion highlights the unique perspectives that Samoans bring to conceptualising disability. Cultural identity and well-being are implicitly connected to kinship ties, making acceptance and inclusion essential aspects of the *fa'aSāmoa*. Acceptance and inclusion are not reliant upon acts of contribution, rather they are fundamental offerings that strengthen and promote *aiga* groups through love and protection. However, obtaining a Samoan concept of equality is dependent on acknowledging the existence of hierarchical social structures, and making useful contributions to the collective. Despite significant familial and social shifts in recent years, the concepts of the *fa'aSāmoa* still provide a basis for identity development. For people with disability, navigating the concepts of the *fa'aSāmoa* in achieving equality represents many challenges. From challenges of contributing, to stigmatising discourse, disability is yet to find a comfortable place in Samoan families and society.



Chapter 3 will review the history of disability conceptualisation globally. It will also review current conceptualisations of disability that endorse a human rights standpoint. The various disability frameworks will be positioned within a Samoan context, demonstrating the diversity of disability conceptualisation in Samoa. However, none of these conceptualisations incorporate the unique Samoan cultural context. This chapter has proposed the application of a uniquely Samoan model of disability conceptualisation, the *Tutusa* model. There is still great value and relevance in the *fa'aSāmoa* in contemporary Samoan society. Embedding concepts of the *fa'aSāmoa* in progressive societal shifts ensures retention of identity and the continuity of culture.



Chapter 3: Global disability conceptualisations

3.1 Introduction

Disability conceptualisation from a Samoan perspective has been heavily influenced by borrowed ideologies and epistemologies. This chapter will review the history of disability conceptualisation globally, from pre-industrialisation to contemporary paradigms. Establishing a frame of global disability conceptualisation provides a foundation to examine historical and contemporary Samoan contexts of disability, discussed in-depth in Chapter 4. An examination of the journey of discourse and policy in the area of disability in Samoa will also be discussed.

This study is not intended to compare the Samoan context to global ones. Samoans have unique conceptualisations of disability based upon cultural epistemologies and a history of external influences. These influences continue to be an experience of contemporary Samoan society. An examination of disability history from a western frame of reference is relevant to contextualising disability from a Samoan cultural perspective. Included in this chapter is an overview of moral and medical disability paradigms as both of these paradigms feature as part of a Samoan conceptualisation of disability.

3.2 Conceptualisations of disability

What defines disability from a political standpoint is determined by a complex set of factors incorporating culture, societal perspectives, and relevant policy. The lens through which people with disability have been viewed at different times throughout history has reflected societal and political agendas. The genesis of disability constructs emerges in relation to societal norms throughout history (Laracy, 2014).



To use Foucault's theory of normalisation, conceptualisations of disability at different times in history are a result of the views of the powerful minority (Laracy, 2014; McNay, 1994). Concepts of shared understanding can be based upon power relationships that exist in both historical and contemporary societies. In Table 1, each of the paradigms profiled in this chapter are summarised. The normalisation of concepts of disability has been imparted through discourse, policy, and service provision. Perpetual societal beliefs influence conceptualisations of disability and impact upon the identity of people with disability (Laracy, 2014).

The two paradigms of disability that feature as historical global conceptualisations throughout this chapter are the moral model, (sometimes referred to as the religious model) and the medical model. In the proceeding descriptions of these paradigms it can be seen that the genesis of these paradigms can be located in the broader philosophical underpinnings of society during the same time period. This too can be said for the social disability paradigm and the CA that will feature later in this chapter, and also feature in Table 1. Consistent with Foucault's normalisation process, Samoan conceptualisations of disability have been influenced by societal experiences. Despite a broad push to adopt a social disability paradigm, the moral and medical paradigms still linger.



Table 1. Summary of disability models

<i>Models</i>	Moral	Medical	Social	CA
<i>Eras</i>	Pre-industrial	1700s-1970s	1970s-present	1980s-present
<i>Paradigms</i>	Religious paradigm	Scientific paradigm	Human rights paradigm	Well-being and diversity paradigm
<i>Indicators</i>	Disability is seen as a curse or punishment from God.	Disability is an illness requiring medical treatment.	Disability results from limitations and barriers in society.	Disability results from reduced capability and functioning.
	Fear, stigmatisation, and ostracism.	People with disability viewed as useless and unproductive in changing labour markets.	Equality and inclusivity for people with disability.	Equality and recognition of capabilities for people with disability.
	Sometimes disability was seen as an opportunity to witness the power of God.	Rise of institutions and use of restraints and sedation.	Civil and political rights are prioritised.	All human rights are equal and cannot be prioritised.
	Agrarian lifestyle promoted inclusion.	The segregation of people with disability.	Adoption of the UN's Convention on the Rights of Persons with Disabilities.	Human diversity and recognition of culture and local circumstances.
<i>Terminology</i>	Natural fool Cripple Feeble-minded Cretin Mad	Lunatic Idiot Imbecile Insane Mental	Impairment Disability Participation Barriers	Functioning Capability Human diversity Well-being

(Anastasiou & Kauffman, 2011; Brown & Brown, 2003; Clapton & Fitzgerald, 1997; Creamer, 2012; Garrick Duhaney & Salend, 2010; Kudlacova, 2008; Lang, 2007; Shakespeare & Watson, 2001; Terzi, 2005; Wizner, 2006)

3.2.1 The moral paradigm – pre-industrialisation

What is documented on the treatment and perceptions of people with disability throughout Europe prior to industrialisation constitutes a diverse combination of both persecution and acceptance (Brown & Brown, 2003; Clapton & Fitzgerald, 1997;



Kudlacova, 2008). Religion provided a paradigm through which people could make sense of their world (Brown & Brown, 2003; Clapton & Fitzgerald, 1997; Creamer, 2012; Kudlacova, 2008). In this highly religious and conservative environment, it was often thought that a person with disability had been punished by God, or that disability was the result of witchcraft or sin (Clapton & Fitzgerald, 1997; Creamer, 2012). Conceptualising disability as a curse often resulted in stigmatisation and ostracism (Creamer, 2012). Certain religious groups believed that there was a cure for disability by way of exorcisms to rid people with disability of evil spirits (Clapton & Fitzgerald, 1997). Other groups viewed disability as an opportunity to witness the power of God during this period (Clapton & Fitzgerald, 1997; Creamer, 2012; Kudlacova, 2008). Caring for a person with a disability may have been interpreted as a test of faith, or as an opportunity to inspire compassion or faith in others (Creamer, 2012). Another interpretation of disability may have been that a person with a disability was blessed, as a disability represented the suffering of Christ (Clapton & Fitzgerald, 1997). This research found that one Samoan conceptualisation of disability also incorporates these beliefs (discussed in Chapter 7).

In the European pre-industrialised era, existence was of a collaborative nature and the care of people with disability would have reflected accepted kinship arrangements (Bewley, 2008; Brown & Brown, 2003; Clapton & Fitzgerald, 1997). People with disability were assigned tasks to complete to promote the survival of the family. An agrarian existence would have promoted inclusion of all family members as subsistence lifestyles required a delegation of labour (Clapton & Fitzgerald, 1997). For people with mild disability, inclusion and assimilation into village life may well have been the norm (Brown & Brown, 2003; Clapton & Fitzgerald, 1997).



Care of people with disability occurred within a home environment and quality of care relied upon positive personal relationships, as well as spiritual and religious values (Brown & Brown, 2003). At times throughout this era, a person with a disability would have been viewed as less fortunate, or a blessing to others, attracting acts of charity (Brown & Brown, 2003; Clapton & Fitzgerald, 1997).

In pre-industrial times, disability was not well understood and it was not uncommon for people with disability to be ostracised or ridiculed, and on occasion used as a source of public entertainment (Brown & Brown, 2003; Clapton & Fitzgerald, 1997). Stigmatisation had the potential to threaten the effective running of the family by driving out people with disability and their families, due to a belief that people with disability were sub-human (Clapton & Fitzgerald, 1997).

During the moral model era, disability discourse reflected a deficit perception with the employment of such terms as natural fool, cripple, lame, lunatic, feeble-minded, cretin, and mad (Brown & Brown, 2003; Clapton & Fitzgerald, 1997; L. Clark & Marsh, 2002; Garrick Duhaney & Salend, 2010). Discourse plays an important role in collectively describing disability. Foucault's normalisation theory impacts the role of discourse as a source of knowledge about the conceptualisation of disability. Clark (2006) asserts that language is a reflection of societal belief and perception. Terms that characterise the moral paradigm depict disability from a deficit perspective, and the normalisation of this discourse instructs individuals and society on how to reflect upon and interact with disability.

The moral model is one of several conceptualisation of disability in contemporary Samoan society. Sections of Samoan society share characteristics with agrarian lifestyles in pre-industrialised European communities. Collaborative living is still an



important factor in family prosperity for many Samoan families and care of people with disability is frequently undertaken within a home environment.

3.2.2 The medical paradigm – 1700s to 1970s

The first missionaries to Samoa arrived in the early 1800s (L. F. Va'a, 2006). They brought with them religious and moral beliefs that were adopted by the Samoan people. Along with missionaries, other Europeans began arriving in Samoa to trade and establish businesses (L. F. Va'a, 2006). These Europeans came with a view of the world where religion was not the only explanation for phenomenon.

With the onset of industrialisation throughout Europe, philosophical interpretations began to shift as the era of enlightenment provided a forum for rational thought and reasoning (Garrick Duhaney & Salend, 2010; Kudlacova, 2008). Empirical and scientific knowledge became the basis for theories of disability. Doctors rather than priests took on the responsibility of disseminating beliefs on disability (Clapton & Fitzgerald, 1997). The belief that people with disability were the result of moral or religious misdemeanours was diminishing. In a society that began to highly value labour productivity on an individual scale, people with disability were increasingly being viewed as useless and unproductive (Garrick Duhaney & Salend, 2010; Wizner, 2006). As family members gained paid employment outside of the home, institutions were established to house and ostensibly educate people with disability (Braddock & Parish, 2001). This had additional societal benefits of releasing families from the responsibility of caring for family members with disability. In contemporary Samoan society labour markets affect family structures (Thornton et al., 2013; Thornton et al., 2010). These societal shifts influence the ongoing management strategies for people



with disability. Disability is conceptualised, in part, as an illness. This research found that from a Samoan cultural perspective, families are considered responsible for the care of people with disability.

During the medical model era, individuals were viewed as inferior as they could not meet societal obligations. Institutionalisation was also sometimes sought as means to distance the family from the person with a disability for fear that dishonour would be brought upon the family (Braddock & Parish, 2001). It was common for people with disability to be housed in institutional facilities and be subject to medical experiments including sterilisation and shock therapy (Braddock & Parish, 2001). Mechanical restraints were utilised as well as a variety of treatments including cold baths, and oral drugs used to sedate people with disability or mental illness (Bewley, 2008). A pervasive societal belief existed that invasive medical treatment was the answer to managing and eradicating disability. However, treatment of people with disability or mental illness was increasingly being seen as abusive. By the mid-1800s, doctors were assigned the roles of supervisors and inspectors of institutions in an effort to reduce abuse and eradicate the use of restraints as concerns mounted regarding ill treatment in state-run facilities. Under this new arrangement provisions were made to restrict people with disability and mental illness from challenging their detention (Bewley, 2008).

In the early twentieth century support for asylums and institutions waned throughout Europe. The need for new legislation to meet the needs of people with disability and mental illnesses became apparent (Garrick Duhaney & Salend, 2010). In England, the Mental Deficiencies Act (1927) came into effect to endorse supported care for individuals in home environments. This represented a philosophical shift in



perception of disability, promoting skill acquisition and education. In Australia, while not subject to the English Mental Deficiencies Act, each state enacted separate legislation for people with disability throughout the 1930s. The legislation still reflected a medical model standpoint with legislation titles such as the 1934 Lunacy (Amendment) Act (NSW), the 1938 Backward Person's Act (Qld) and the 1935 Mentally Defectives Act (SA).

An educational agenda existed throughout the medical model era, but it had not been fully embraced. The provision of basic education in institutions was largely vocational, effectively transforming institutions into workhouses. It had become apparent that special education programs needed to be implemented more effectively.

The early years of the twentieth century brought educational change by way of the establishment of special classes in state-run schools (Garrick Duhaney & Salend, 2010; Wizner, 2006). Special classes discarded traditional curriculum and delivery and adopted a more flexible approach to education. A high proportion of enrolments consisted of people who were termed at the time as the deaf, blind, hard of hearing, undernourished, crippled, academically maladjusted, mentally retarded, speech defective, and the tubercular (Wizner, 2006). During this period of change, specialist personnel were employed, including input from psychologists, health workers, and school support staff. Despite policy and practice being developed to protect and educate people with disability, there was still a pervasive societal belief that people with disability had little to offer greater society (Wizner, 2006).

The rise of human rights movements throughout the 1950s and 1960s saw a shift in fundamental beliefs about disability, particularly in the education sector. Rather than segregating classrooms, it was becoming increasingly supported that people with



disability should be integrated into mainstream classrooms under an ethos termed inclusive. (Garrick Duhaney & Salend, 2010; Wizner, 2006). This new human rights approach to disability led to the establishment of the Union of the Physically Impaired Against Segregation (UPIAS). The premise of the human rights approach to disability was that societal organisation was a disabling factor (Union of the Physically Impaired Against Segregation & Disability Alliance, 1975). The recognition of this concept paved the way for societal equality for people with disability.

The past decade has seen significant reform to disability discourse and agendas in Samoa, yet a medical conceptualisation still has a pervasive presence throughout society. Treatment of people with disability in Samoa has largely been influenced by medical conceptualisations, seeing disability as an illness. This has resulted in what the MWCSD define as the “protective approach” (Ministry of Women Community and Social Development, 2009, p. 4) to disability management. In Samoa, the adoption of a social disability model aims to create a paradigm shift to locate disability within society, rather than with the individual. The impact of a medical conceptualisation of disability in Samoa is discussed in Chapters 6 and 7.

3.2.3 The social paradigm of disability – 1970s to present

The recent adoption of the social disability paradigm in Samoa has been driven by human rights and international obligations. This paradigm shift aligns Samoan conceptualisations of disability with international perspectives. In Australia, England, and America the social disability paradigm has been the driving force of policy and practice for decades.



A critique of the medical model of disability along with the civil rights movement in the United States of America changed the way that disability was conceptualised. By the 1980s most developed countries had enacted legislation to complement a social model of disability. Limitations were no longer viewed as being with the individual, but with society's inability to facilitate equal participation for all citizens (Clapton & Fitzgerald, 1997). Underpinning the philosophy of the social model was the recognition that disability was neither a fault of the individual nor an undesirable medical condition, but rather a combination of societal barriers and negative social attitudes (Anastasiou & Kauffman, 2011; Lang, 2007).

Social attitudes had posed a significant barrier to societal inclusion, resulting in discrimination of people with disability (Anastasiou & Kauffman, 2011; Lang, 2007). An important turning point in the construct of disability was the development of inclusive discourses. In 1975, UPIAS provided the first conceptualisation of disability as a social construct through its definition of the terms "impairments" and "disability" (Anastasiou & Kauffman, 2011; Lang, 2007). As one of the first disability advocacy organisations in the United Kingdom, UPIAS defined "impairment" as a physical dysfunction (Anastasiou & Kauffman, 2011; Lang, 2007). The term "disability" was defined as a social construct whereby individuals are restricted or disadvantaged from full and equal participation in society, resulting from a lack of provision being made by social organisations to enable people with physical impairments to participate in society (Union of the Physically Impaired Against Segregation & Disability Alliance, 1975). This was a defining point in the development of socio-political constructs of disability, which has seen the social disability paradigm provide a foundation for legislation and policy development. In re-conceptualising disability, it was essential that people with disability had a



presence in society. Under a medical model paradigm, people with disability were institutionalised. The social model dismantled this practice, leading to mass deinstitutionalisation. Driven by the principles of normalisation, the rationale behind the deinstitutionalisation of people with disability was to establish disability as a community based issue (Dixon, Marsh, & Craven, 2004; Rosen, 2006). With increased scrutiny of the relevance and success of institutions, and changing social attitudes, people with disability were reinstated within the community. The shift in ideology from the medical paradigm and institutionalising people with disability, to a social paradigm where people with disability were ostensibly included in society did not immediately impact the delivery of service. Rosen (2006) reports that in Australia throughout the 1980s, despite 90 percent of people with severe mental illness being housed in community based settings, 90 percent of funding was still allocated to hospitals.

The social paradigm for conceptualising disability is still highly regarded as a contemporary ideology of disability and is the foundation for the CRPD. The Convention, adopted in 2006 and enacted in 2008, emphasises the construction of disability as a result of societal barriers. Samoa became a signatory of the CRPD in 2014. A paradigm shift from moral and medical models to a social disability approach has been evident in Samoan policy since the 1990s, and more decisively in 2009 with the introduction of SNPD.

The social model has been widely accepted globally. However, some argument remains that identifying society as the limitation for people with disability does not recognise and acknowledge the personal experiences of people with disability. The denial of difference is in itself problematic. Clapton and Fitzgerald (1997) argue that



rights-based discourse has instigated change at a strategic level but it has not fundamentally changed the lives of people with disability. There is a high level of international support for the CRPD, but ongoing critiques of rights-based ideologies demonstrate that the area of disability is still undergoing philosophical and epistemological scrutiny. The CA has been suggested as an alternative paradigm to the social disability model (Shakespeare & Watson, 2001; Terzi, 2005). The CA evaluates levels of functioning and capability from an individual perspective. It acknowledges societal barriers yet focusses on the actual individual experience of disability. This will be examined in more depth later in this chapter.

3.3 International disability policy

Samoa joined the international community of signatories to the CRPD in 2014. Disability policy reform from a social model paradigm had been introduced in 2009 with the SNPD. This signified a commitment to a human rights standpoint. The context of international disability policy provides a frame to examine Samoa's motivations and actions in endorsing a social disability paradigm.

The social model of disability has been critically influential in shaping a modern discourse of disability. This has been reflected in recent political and social movements aimed at reform to disability legislation and practice. Advances in global understandings of human rights for minority groups has culminated in an international disability movement characterised by human rights, inclusion, and social change. In recognition of equal rights, the development of the CRPD has instigated institutional change to policy worldwide.



The CRPD, adopted by the UN's general assembly on December 13, 2006, is intended as an international guarantee of equality, dignity, and liberty. As stated by the UN:

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. (Article 1, para 1, United Nations, 2006)

The CRPD has been very well received and supported, and currently has 159 signatory countries, including Samoa. In signing the CRPD, countries are bound by obligations to enact the principles of the Convention. The general obligations of signatory countries, are set out in the CRPD (Article 4, United Nations, 2006) and are summarised as:

- adopt appropriate legislation;
- take measures to abolish existing discriminatory legislation, customs, and practices;
- protect and promote human rights for people with disability in policies and programmes;
- eliminate discrimination on the basis of disability;
- undertake and promote research;
- provide accessible information about assistive technology; and
- promote training of professionals to enhance provision of assistance.

The intention of the CRPD is the endorsement of equal participation in public and cultural life. It also establishes benchmarks for inclusivity, adequate standards of



living and social protection, and quality healthcare. Fundamentally, the CRPD is a tool for reshaping political ideologies of disability.

In observing the obligations to the CRPD, it is envisaged that an environment that abolishes discrimination and creates an equitable society for all citizens will be established and promoted. The CRPD acknowledges prevention as an essential element to overcoming discrimination and promoting equity for people with disability through health care, education, research, and technology. Samoa has politically embraced the ethos of the CRPD. This thesis highlights the way that the CRPD and a social disability paradigm challenge aspects of established cultural belief and practice. This will be examined in further detail in the following chapters.

3.4 Terminology: Creating a shared understanding of disability

Creating a global shared understanding of the concept and complexities of disability is a challenging task. Throughout the moral model era discourse approaches to disability reflected normalisation processes. Disability was constructed as a deficit. Medical descriptors were used during the medical era, reducing disability to a set of symptoms. Such discourse is now considered stigmatising and limiting (Bickenbach et al., 1999). Debate continues over appropriate terminology for contemporary disability discourse. As has been the function of disability discourse throughout past eras, terms that occupy current discourse are aimed at establishing a shared understanding of the current political standpoint on disability. The issue of discourse is a particularly important one in the examination of disability from a Samoan cultural standpoint. The development of disability discourse in Samoa has been a focus of this thesis. The findings on discourse and terminology relevant to disability in Samoa



are discussed in Chapter 7, highlighting the value and complexities of establishing a shared understanding.

The labels assigned to particular disabilities have the capacity to be derogatory even within modern frameworks of disability. There is a danger of overgeneralising the experience of disability and reducing individuals to a set of descriptors that are a checklist of symptoms and consequences of disability (Barton, 2009; Eayrs, Ellis, & Jones, 1993; Madden & Hogan, 1997). Eayrs et al. (1993) suggest that terminology that is perceived as derogatory can impact negatively on parental perceptions of a child with disability. Clark and Marsh (2002) assert that language is a reflection of what people think. Within a political paradigm, terminology is viewed as a necessary administrative tool for the development of policy and the application of service provisions (Madden & Hogan, 1997; World Health Organisation, 1997).

To facilitate a standardised framework of disability, the World Health Organisation (WHO) developed the International Classification of Functioning, Disability and Health (ICF). The ICF specifies guidelines for standard language and terminology for use within the development of policy and legislation, research, economic analysis, intervention studies, and in the identification of environmental barriers (World Health Organisation, 2001). The WHO views the ICF as a scientific tool used in the measurement and comparison of disability globally, providing a consistent framework to collect data on the experience of health and disability (World Health Organisation, 2001). The focus of the ICF is on the impact of disability and levels of health, rather than emphasising disability. The ICF is based upon a “biopsychosocial” model of disability; an integration of both the medical and social models, representing



biological, individual, and social perspectives of disability. In defining disability, the ICF puts forth the terminology described in Table 2.

The CRPD seeks to construct a global conceptualisation of disability as human rights become the foundation for policy development. Simeonsson et al. (2000) assert that one of the stumbling blocks to effective provision of service is in the lack of a common classification for disability. This results in flaws in documenting the epidemiology of disability in order to make international comparisons. Barton (2009) also suggests that a lack of uniform terminology has resulted in unreliable statistical data on the prevalence of disability globally.

Table 2. Terminology guidelines adapted from the International Classification of Functioning, Disability and Health (ICF)

Terminology	Description
Body functions	Physiological functions of body systems (including psychological functions).
Body structures	Anatomical parts of the body such as organs, limbs and their components.
Impairments	Problems in body function or structure such as a significant deviation or loss.
Activity	The execution of a task or action by an individual.
Participation	Involvement in a life situation.
Activity limitations	Difficulties an individual may have in executing activities.
Participation restrictions	Problems an individual may experience in involvement in life situations.
Environmental factors	The physical, social, and attitudinal environment in which people live and conduct their lives.

Source: International Classification of Functioning, Disability and Health (p10), by the World Health Organisation, 2001. Geneva: World Health Organisation.

The introduction of the ICF and its employment in legislation and policy worldwide creates a picture of disability from a health impact perspective. The ICF intends to shift the focus of disability from both an individual deficit perspective, and from a societal barriers perspective, synthesising these concepts to focus on outcomes.

The development of an international classification of disability was intended to create a global shared understanding of disability. More importantly the intent of the classification system was to create consistency in the measurement of disability prevalence. It is argued in Chapter 7 that the ICF is less applicable to countries where English is a secondary language, such as Samoa. For non-English speaking countries to apply the ICF effectively into pre-existing cultural, political, and social models, terms must be translated. This risks the essence of the definition becoming misinterpreted and making the purpose of the ICF and shared understanding problematic.

3.5 Post social disability model: The Capabilities Approach (CA)

The social disability model has been a highly effective tool in re-shaping a global public perception of disability, and has undoubtedly changed the political rhetoric of disability. Despite its broad application and acceptance, the social disability model has not been free from critique. The CA is emerging as a model of disability that both complements and challenges aspects of the social model.

Critics of the social model suggest that a preoccupation with the removal of social barriers has failed to recognise the reality of impairment (Crow, 1996; Shakespeare & Watson, 2001; Terzi, 2005). Shakespeare (2001) asserts that the social model is



outdated, and that it fails to recognise individual difference and personal experience. Crow (1996) concurs that the social model rejects the experience of impairment in a negative capacity, and the focus on societal barriers is a key obstacle for people with impairment. Critics of the social model do not deny the barriers that policy and society present to people with impairments but suggest that the social model ignores the many other complex factors that impact upon the experience of disability (Crow, 1996; Shakespeare & Watson, 2001; Terzi, 2005). Future disability models will need to examine not only social barriers, but also issues of biology, psychology, cultural and socio-political factors, as well as personal experiences that contribute to disability.

The CA has emerged as a useful paradigm with which to view disability. First conceptualised by Amartya Sen, the CA is a model of moral evaluation, human development and welfare economics (D. Clark, 2006; Nussbaum, 2006; Sen, 1979; Terzi, 2005, 2014). The premise of the CA is that all humans are inherently different and human diversity is a natural state. Focusing on human well-being, the CA has become a useful tool in the assessment of poverty, inequality, and human development (D. Clark, 2006; Terzi, 2005, 2014). The CA recognises that all humans differ in their need for resources and in their ability to convert resources into functioning (Harnacke, 2013; Munsaka & Charnley, 2013; Nussbaum, 2006, 2007; Saleeby, 2007). The application of the CA in the development of a disability model provides a paradigm to recognise, measure and make provision for the diversity of disability. The CA emphasises two key concepts: capability and functioning, explained in Figure 2.



<p><u>Capability:</u></p> <p>The ability of a person. The real opportunities and freedoms to achieve valued functions. A person's practical opportunity to participate in a valued activity.</p>
<p><u>Functioning:</u></p> <p>The achievement of a person. What a person manages to do given their resources. What activities a person values. Functioning is influenced by personal and social factors such as age, gender, health, access to medical services, nutrition, education. Functioning refers to the effective facilitation of the available commodities.</p>

Figure 2. Defining functioning and capability within the Capabilities Approach (D. Clark, 2006; Nussbaum, 2007; Terzi, 2005)

In providing an example of functioning and capability, it can be suggested that a person may value learning and recognise the value of education. The person's capability to achieve this functioning may be impeded by social conditions that inhibit a person's practical opportunity to achieve this valued activity. Alternatively, a person may not value learning and choose not to attend further education on that basis. However, the choice to access further education must be available and achievable.

The CA aligns many of its guiding principles with a social disability model in that it recognises human rights and diversity as fundamental aspects of human development. As a specific paradigm for disability, the CA has been advanced by Nussbaum (Harnacke, 2013; Nussbaum, 2007). Nussbaum's CA recognises that the ability to convert resources to functioning varies for each individual (Harnacke, 2013; Nussbaum, 2007).



In Nussbaum's interpretation of the CA, a list of minimum standards of justice has been formulated as a benchmark of capabilities including: *life, bodily health, bodily integrity, senses, imagination and thought, emotions, practical reason, affiliation, other species, play, and control over one's political and material environment* (Nussbaum, 2007, pp. 23-24). Nussbaum's CA views the listed capabilities as equal; none is of higher value than another (Harnacke, 2013; Nussbaum, 2007). She also contends that capabilities transcend culture, tradition, and local circumstances (Harnacke, 2013). However, it has been argued by Harnacke (2013) that it is not feasible to achieve all rights simultaneously and therefore it is important that rights be prioritised, as they are within a social disability paradigm.

Nussbaum's approach represents an interpretation of the CA, but the general principles of human well-being and diversity are in sympathy with social disability paradigms. The CA aims to broaden the scope of societal perception to view people with disability as individuals requiring support in the same way that every other individual requires support. Reindal (2010) identifies "functioning" as being imposed upon by concepts of quality and inequality such as:

- Personal differences in constitution, impairment, health, gender, and age;
- Climatic diversity, pollution, and disease;
- Variations in social climates and conditions such as infrastructure, education, health, crime, and violence;
- Differences in cultural codes of conduct; and
- Differences in familial organisations, beliefs, and conduct.

The CA does not regard disability as a deviation from the norm, thus no celebration of diversity is necessary. It sees disability as a variable in an equation to determine



well-being, functioning and capability. Mitra simply states, “Whether the individual is actually disabled depends on whether the impairment places restrictions on the individual’s functioning. The focus is on what the individual values doing” (2006, p. 241).

Mitra (2006) argues that the CA is a useful lens through which to view disability globally. It conceptualises disability via an analysis of the interactions between individual characteristics, available resources and physical, social, economic, and political environments. As yet, the CA has not been explicitly used in policy reform in Samoa, but the value of using a CA as a filter for culture and human rights in the development of the *Tutusa* model is discussed in Chapters 7 and 8.

The CA framework enables researchers, analysts, and policy makers to evaluate disability in terms of economic causes and consequences, standards of living, personal well-being, quality of life, and poverty (Mitra, 2006). In alignment with the CA approach, Lang (2007) claims that impairment is “simply a bodily state” (p. 8) and disability is a result of the organisation of social conventions including work, transport, and leisure activities.

The CA was not specifically designed as a paradigm for disability, but it provides a useful lens to examine a socio-cultural context impacting upon individuals’ experiences of impairment. As a framework for global comparisons and data collection, the CA has the advantage of examining functioning and capability in light of the specific socio-cultural conditions of any particular society. It has become globally important to report global statistics on the prevalence of disability with the adoption of international agreements such as the CRPD. However, collecting valid statistical data on prevalence of disability has proved to be a complex and difficult



task. The hegemonic ideology of any given society has an overwhelming impact on the defining of disability, as well as the type of economic structure that is in place (Lang, 2007). Conceptualisations of disability are in no way globally uniform, therefore the reported prevalence of disability does not represent the actual incidence of global disability. Bakhshi and Trani (2006) suggest that disability prevalence rates are a reflection of a country's willingness to recognise disability within a globally accepted social paradigm, thus promoting enhanced healthcare, early intervention, and research. Bakhshi and Trani endorse the CA for developing countries as there is potential to incorporate gender, religious implications, family dynamics, living conditions, and labour market variations into concepts of functioning and capability (Bakhshi & Trani, 2006). The importance of culture to the identity of Samoans is discussed in both Chapters 2 and 4. The CA represents an ideal opportunity for Samoa, as a lower middle income country (World Bank Group, 2015b), to evaluate circumstances of culture, living standards, as well as religious and family structures in the future development of policy, particularly in the area of disability.

The scope of the CA to largely transcend concepts of culture and circumstance makes it an ideal lens to examine the restructuring and modification of policy and practice in developing countries. It has the capacity to enable societies to attach appropriate and relevant values to capabilities. Enabling policy to reflect the unique circumstances of a given community ensures access to opportunities that are contextually valuable. With links to a human rights paradigm, yet free of rigid ideologies that fail to represent cultural contexts, the CA can counter the gaps created by the introduction of foreign policy. Chapter 7 examines the way that Samoa could facilitate the CA as a filter for cultural concepts and aspects of the social disability model. Through an analysis of these factors, the *Tutusa* model can be further



developed, establishing a uniquely Samoan model of disability. In facilitating the CA, it is possible to develop the *Tutusa* model to incorporate all of the motivations of Samoa, including global obligations, human rights, and cultural identity.

3.6 A worldview of disability: prevalence, economics, and global politics

The global profile of disability has been significantly raised through the adoption of the CRPD. Signatory countries are bound by global expectation of endorsing and promoting a human rights standpoint both in legislation and policy, and in action-based initiatives. Identifying and categorising people with disability globally has not been a straightforward process, and to date, accurate global statistics have not been reported on disability. Accurate statistical data on the prevalence of disability provides a useful tool in the delivery of funding, services, and in the allocation and distribution of foreign aid. This is a significant issue for Samoa as a recipient of foreign aid. As signatories of the CRPD, Samoa is well positioned to attract foreign aid. However, the receipt of aid is largely dependent upon meeting the global obligations of the convention. In the absence of a national shared understanding of disability, prevalence statistics do not necessarily reveal an accurate landscape of disability in Samoa.

In constructing a framework of disability prevalence, global statistics will be presented in this chapter. The statistics aim to illustrate the variance of reported disability prevalence, which has implications for funding and service provisions, particularly for a lower middle income country such as Samoa. There are several limitations impacting on the accurate collection of statistical data. One potential limitation of the collection of data on the prevalence of disability is the way in which



disability is conceptualised and defined. This can vary considerably from country to country, so global statistics cannot be valued as a definitive source of the prevalence of disability.

To deliver an estimate on global disability prevalence, the WHO combines the findings from two surveys: The World Health Survey and The Global Burden of Disease Survey. The World Health Survey, undertaken by 70 countries, is a face-to-face household survey to measure the prevalence of disability among people over the age of 18 years. The Global Burden of Disease Survey (originally commissioned by the World Bank to assess the relative burden of premature mortality and disability) provides an overall picture of disability globally. Both of these surveys used the ICF as a tool for measuring disability prevalence.

The combined results from these two surveys are reported in the WHO World Report of Disability (World Health Organisation, 2011). However, the WHO advises against interpreting the report as definitive due to limitations of data collection. Outlining these limitations, the WHO identifies variations to measurement techniques, the aspects of disability that were examined, the variation in definitions of disability, and the quality of reporting sources (World Health Organisation, 2011). Significantly, statistics on disability prevalence in Samoa are not reported in the WHO World Report on Disability.

Taking these limiting factors into consideration, this section reports global estimates taken from the WHO World Report on Disability, as well as sampling a range of other country-reported statistics on disability. Table 3 illustrates the significant disparity between reported global disability prevalence, according to the WHO World Report of Disability, and individual country statistics. For Samoa, which reports disability



prevalence at 3 percent of the total population, data collection techniques could pose a significant limitation. The impact of underrepresenting disability prevalence could be felt through the allocation of foreign aid, or the distribution of services. The development of effective policy may also be undermined as the reality of disability prevalence in Samoa may not have been realised.

The WHO World Report on Disability excluded the USA, UK, Australia, and New Zealand from the survey. These countries have been used as benchmarks of global disability in this thesis due to their historical and ongoing political relationship with Samoa. To report disability prevalence statistics for countries not represented in either the World Health Survey or the Global Burden of Disease Survey, the WHO World Report of Disability has included an appendix of worldwide statistics taken from either country census data or disability surveys, depicted in Table 3. There is a complete absence of reported statistics for the Cook Islands, the Federated States of Micronesia, Nauru, and Tuvalu.

The WHO World Report on Disability estimates global disability prevalence at 18.2% (World Health Organisation, 2011). This figure is accurately reflected in countries where the gross nation income per person (GNIPP) exceeds US\$12,736, giving them a WHO classification of “high income countries”. Australia, New Zealand, the United States of America, and the United Kingdom report estimated figures based upon census or independent country survey data. Each of these countries used aspects of the ICF as a tool for standardisation of disability identification and classification.

The Pacific countries profiled in Table 3 have a classification of lower middle income countries with a GNIPP of between US\$1,045 and US\$12,736 (World Bank Group, 2015a). With the exception of Fiji, each of the profiled countries reported figures that



are significantly lower than the global average. Statistics reported from Kiribati, Fiji, Solomon Islands, and Timor Leste were taken from a United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) survey (United Nations Economic and Social Commission for Asia and the Pacific, 2010). Aspects of the ICF were employed. The relatively low incidence of disability statistically reported across these four countries may reflect limitations of data collection, including the identification and definition of disability at a local level.

The variations to reported prevalence of disability have implications for lower middle income countries through access to health, educational and social provisions, the development of appropriate policy, and as the recipients of international financial aid. Fiji's reported disability prevalence varies from 0.25% to 19.25% depending on the region. The United Nations International Children's Emergency Fund (UNICEF) identifies factors that may impact upon reported prevalence, including general development in regions, nutrition, environmental factors, and socio-cultural perceptions (UNICEF, 2011).



Table 3. Sample of global disability prevalence

Region	WHS report	Census data	Disability surveys
Worldwide	18.2% ³		
Australia		4.4% ⁴	18.5% ⁵
Fiji		1.4% ⁶	
Kiribati			3.8% ⁶
Marshall Islands		1.6% ⁷	
New Zealand		20.0% ⁸	
Samoa			2.0% ⁹
Solomon Islands			2.9% ⁶
Timor Leste			1.2% ⁶
Tonga			2.8% ¹⁰
United Kingdom		17.6% ¹¹	27.2% ¹²
United States of America		19.3% ¹³	14.9% ¹⁴
Vanuatu			1.4% ¹⁵

Source: See footnotes

³WHO. (2011). World Report on Disability. Malta: World Health Organisation.⁴ABS. (2006). People with a need for assistance: A snapshot. Australian Bureau of Statistics, Canberra. Retrieved from <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4450.0>⁵ABS. (2011). Disability, Aging and Carers: Summary of findings, Canberra: Retrieved from <http://www.abs.gov.au>⁶UN. (2012). Disability at a glance: a profile of 28 countries and areas in Asia and the Pacific. Bangkok: Economic and Social Commission for Asia and the Pacific.⁷Republic of the Marshall Islands Census. (1999). *Census 1999*. Majuro.⁸Statistics New Zealand. (2001). *Disability Counts 2010*. Wellington.⁹Asia-Pacific Development Centre on Disability. (2006). Country Profile: Samoa. Bangkok.¹⁰Tonga Department of Statistics. (2006). *National Disability Identification Survey*.¹¹United Kingdom National Statistics. (2010). Retrieved from <http://www.statistics.gov.uk>.¹²European Commission. (2007). Living conditions in Europe: data 2002-2005. Luxembourg: Eurostat.¹³United States Census Bureau. (2000). *Census 2000*. Washington.¹⁴United States Census Bureau. (2007). *American Community Survey*. Washington.¹⁵Pacific Island Forum Secretariat. (2009). *Vanuatu: Disability country profile*. Suva

Australia, New Zealand, and Japan all make significant aid contributions to the Pacific region. Pacific Island countries are increasingly obligated to meet the agenda of regional and global initiatives. Foreign Aid is distributed for a variety of development priorities such as social or economic infrastructure, production, and program assistance, or as emergency relief. Aid is aimed at country and regional development. The significant financial contributions made to Pacific Island countries encourage a relationship of reciprocity and accountability from recipient countries. However, targeting appropriate policy for Pacific countries where disability prevalence data is yet to be confirmed emerges as a challenge for effective development outcomes. Statistics were not available for the allocation of specific funding for disability development in Samoa so the outcomes of disability initiatives and development are inconclusive. A report on development and governance in the Pacific claims that Pacific countries are generally not on track to meet the Millenium Development Goals (MDG) stating:

The report finds that the Pacific as a whole is significantly off track to meet the MDGs by 2015. Some countries are translating economic growth into reducing poverty and meeting the MDGs. However, overall the Pacific is stalling and falling short of the goals. Despite large investments in service delivery, public spending by Pacific governments is generally not leading to better development outcomes.

(Australian Agency for International Development (AusAid), 2009, p.

1)

A report compiled by PIFS states that Samoa has made significant progress in policy development, service provision and NGO collaboration (McKinstry et al., 2012). Yet other literature points to policy resistance, as emergent policy development has failed



to incorporate culture (Lameta, 2013; R Tufue-Dolgoy, 2010). An ideologically diverse environment such as Samoa, where politics, economics, and culture are all deemed priorities, presents a challenge to meeting the obligations of the CRPD.

3.7 Conclusion

The various disability paradigms promoted throughout historical eras highlights the influence of the process of normalisation. Reflected in contemporary Samoan society is a culmination of paradigms, reflecting the process of normalisation. Reminding ourselves of the history of disability demonstrates the fluidity of perception and that social disability paradigms are not an end point, but a step towards human well-being. Through its history of indigenous beliefs, as well as influences from religious, medical, and social paradigms of disability, Samoa demonstrates a flexibility in conceptualising disability. This flexibility will be a valuable asset to future policy reform seeking to incorporate human rights and cultural standpoints.

Using the CA, disability policy can reflect the unique needs of different societies. It can evaluate diversity, well-being, and valued opportunities. It can recognise the different needs and outputs of individuals. It can measure the experience of disability in environments that share a likeness. Above all else, it recognises the value of human rights, making its application a vital aspect of fostering diversity and well-being.

For Samoa, a process is currently underway to homogenise societal perception to a social disability paradigm that aligns with recent policy reform. This thesis identifies a number of factors that impact upon the acceptance of the social disability paradigm with Samoan cultural practice. The strength of the CA in its application to Samoan disability paradigms is its ability to transcend culture and circumstances. For



Samoans, this can facilitate self-determination of the value and priority of capabilities in light of unique cultural norms.

With increasing political obligations to both the CRPD and as foreign aid recipients, Samoa's disability policy development reflects global ideologies. For Samoa, reconciling historical perspectives and contemporary paradigms is a multi-faceted process. The CA presents an opportunity for culture, local circumstances, and lived experiences to be incorporated within policy. This can promote the development of the *Tutusa* model, locating disability as a human rights issue, but also an identity issue, providing Samoans with disability the capability to make choices about what is valued in both cultural and global senses.

In Chapter 4 the unique context of disability in Samoa will be examined, identifying the diversity of disability conceptualisation and the conflict of traditional and contemporary ideologies. The chapters in this thesis that review the literature on the Samoan cultural context (Chapter 2), the global disability context (Chapter 3) and the Samoan disability context (Chapter 4) construct a frame for developing disability theory unique to Samoa, the *Tutusa* model. It recognises the valued place of culture within a human rights paradigm, and incorporates the concept of functioning and capabilities essential to the recognition of the actual experience of disability.



Chapter 4: The disability context in Samoa

4.1 Introduction

Disability in Samoa has exhibited increased social and educational prominence in the past decade. In recent years, Samoa has been the recipient of foreign aid aimed, in part, at addressing the MDGs to improve standards of living and the promotion of basic human rights. Part of Samoa's obligation to the international community has consisted of addressing human rights issues for people with disability. In 2014, after several years of planning and preparation, Samoa became a signatory of the CRPD. This demonstrated Samoa's commitment to the promotion of inclusion for people with disability. It also ensures the reflection of an international human rights standpoint in Samoan legislation. This chapter examines the journey of disability in Samoa including historical conceptualisations, contemporary contexts of disability, and innovations to disability policy, employment opportunities, and service provision.

Samoan contemporary society has experienced significant societal shifts in the past two decades (Fairbairn-Dunlop, 2000; Macpherson & Macpherson, 2010; Thornton et al., 2013; Thornton et al., 2010). Traditional belief systems are being increasingly influenced by progressive economic and political circumstances. The conceptualisation of disability has also been impacted by these influences. To assert that there is a single, definitive Samoan perception of how people experience disability would be an inaccurate representation of the complex factors that influence people's belief systems around disability. This research does not seek to provide conclusive data of the entire Samoan population. It presents a sample of the variances



in belief that co-exist within Samoan society, impacting upon cohesion of ideas and perceptions surrounding disability.

4.2 Colonisation and the history of disability in Samoa

As discussed in Chapter 3, the history of colonisation in Samoa has impacted concepts of disability. Global socio-political constructs, as well as the influence of Christianity, add to the complexity of conceptualising disability in a traditional Samoan ontological frame.

Some accounts of pre-colonisation religious perspectives have been documented. Much of the documented history of Samoan cultural practices are reflections of non-Samoans, so examinations of Samoan history need to take this into account (Auva'a, 2003). There has been very little documented about pre-contact Samoan perspectives on people with disability. Barradale (1907, as cited in Auva'a, 2003, p. 14) reports that Samoans were “religious and very superstitious”. Margaret Mead reported incidences of disability, describing the way a village treated one man with disability as “universal gentleness and toleration by his relatives and neighbours” (Mead, 1928, p. 221).

During the early years of colonisation in Samoa, the concept of disability was tied to moral and medical conceptualisations. Societal perception reflected fear of people with disability, particularly those with intellectual or behavioural disability (Creamer, 2012). Language such as “*feeble-minded, mentally defective, or mentally diseased*” (Mead, 1928) inferred that inadequacy lay with the individual rather than with society. European missionaries were influential on Samoan philosophies and Samoa developed an association with a moral model of disability. The arrival of missionaries



saw the partial dismantling of traditional Samoan cultural belief systems, to be replaced by Christianity (Auva'a, 2003). What has become the legacy of modern Samoa is the lingering moral and medical perception of people with disability. It is still not uncommon for Samoans to call on Samoan healers to provide traditional medicine in times of sickness. Traditional healers may attempt to cure illness through massage, traditional medicines, prayer, and religious rituals. A belief still exists that certain illnesses are caused by possession of spirits (*Aitu*) and treatment from a traditional healer (*Tauleasea*) is sought (Enoka, Sili, Peteru, Tago, & Blignoult, 2013; McCuddin, 1974). This research explored the concept of curses and its relationship to conceptualisations of disability in Samoa. The findings regarding moral conceptualisations of disability are discussed in Chapters 6 and 7.

A medical model has provided another paradigm for perceiving and defining disability among Samoans. The medical model, from a Samoan perspective, assumes that disability came about through disease, trauma, genetics, or that the person with a disability was the victim of circumstance and deserves pity.

Within a Samoan collective society, it is the responsibility of family members to care for people with disability (McCullough, 2005). Tufue-Dolgoy (2010) asserts that Samoans see caring for their elderly as an honour or blessing. Caring for family is part of obligatory and reciprocal cultural practices of the *fa'aSāmoa*. This research has also found that caring for family members with disability can be viewed as an honour, blessing, or obligation. This is discussed further in Chapters 6 and 7.



4.3 Non-formal education

Traditional Samoan cultural practices shared a likeness, in terms of societal organisation, to agrarian societies in pre-industrialised Europe. Education took place in non-formal settings within home or village environments. Educational output was aimed at contributions to immediate family and village life, possibly giving people with disability a valid place within the community.

Prior to colonisation, Samoans had functional educational systems and well-established epistemological frameworks. Education practices were framed within cultural, family, and community practices. Education was a life-long process aimed at the transmission of knowledge around societal structures, roles, responsibilities, and hierarchies (Auva'a, 2003; Coxon, 2007; Malietoa von Reiche, 2010). The basis of education was oratory and was a means of passing on collective knowledge and traditions for the primary function of ensuring cultural continuity. For students, learning occurred through listening, memorising, observing, and doing. Teachers were elders within the village (Coxon, 2007). This oral system of education taught skills and knowledge such as manners, cultural conduct, manual skills, philosophical beliefs, roles, and responsibilities (Auva'a, 2003; O'Reagan, 2006). An important aspect of traditional oratory education was imparting myths and legends. This practice, *fagogo* (night stories), often delivered in the evening was a means of transferring cultural and pre-colonial religious beliefs. Imparting the knowledge of myths and legends helped shape Samoan identity through connectedness between people and histories (Kolone-Collins, 2010).

In the years after colonisation, education became the domain of missionaries. The intent was to disseminate the principles of western administrators, including religious



beliefs, ignoring established cultural systems of transmitting knowledge (Ma'ia'i, 1957; Malietoa von Reiche, 2010). Post-independent Samoa established its own education system but curriculum and policy was still very much based on western values (Malietoa von Reiche, 2010; R Tufue-Dolgoy, 2010).

Educational reforms of the 1990s had been devised in collaboration with developed countries such as Australia, New Zealand and Canada. Unlike missionary educational reforms, there has been some policy commitment to represent Samoan culture and the rich learning environment that existed prior to the implementation of formal education. As part of this commitment to recognise and celebrate Samoan cultural practice the Strategic Policies and Plans (2006-2015) incorporates policy on non-formal education. This initiative was based on the findings of a 2005 government commissioned study of non-formal education practices. In a society that is becoming increasingly influenced by international practices, formal education is viewed as an excellent pathway to future economic success. The contemporary value of non-formal education should not be underestimated however, as the practice of educating people at a village level is still a legitimate way of transmitting culture. Collaboration is fundamental to the notion of family and identity for Samoans. Where learning and teaching is conducted in a village setting, both the individual and the community is promoted. This provides opportunities for identity development, inclusion, contribution, and cohesion (Ministry of Education Sports and Culture, 2006). The non-formal education policy does not make specific reference to how it fits into the framework of inclusive education policy, nor does it specifically indicate that traditional non-formal education caters for or includes people with disability. In reviewing traditional, non-formal education, the value and relevance of traditional practices and epistemologies is emphasised.



4.4 Contemporary conceptualisations of disability in Samoa

Understanding a Samoan perception of disability requires an intense familiarity with cultural organisation and practice. This research has incorporated a culturally responsive research design with the intent of acknowledging and respecting indigenous knowledge (Filipo, 2004; Merriam, 2007; Sanga, 2004). Using a *Talanoa* approach, an authentic frame on disability perception from a Samoan perspective was built up through a co-construction of knowledge.

Gradual cultural shifts have been impacting cultural beliefs and practices in all aspects of Samoan society. For the conceptualisation of disability, change is also occurring. An imperative of Samoan government and advocacy organisations is to reshape perceived negativity around the perception of people with disability (Ministry of Women Community and Social Development, 2009). To progress with disability advocacy it is essential to contextualise the current social context of disability. This ensures that future conceptualisations and practices of disability respond to the needs of Samoans. New disability frameworks need to take into account a myriad of factors including cultural identity, discourse, inclusivity, education and employment, public access, and the actual experience of disability.

Language and the development of a cultural identity are inextricably linked (Horsley, 2011; Kolone-Collins, 2010; Merriam, 2007; Thaman, 2009). In Samoa, references to people with disability are grounded in both medical and moral models. This discourse has developed through a belief in curses, perceiving disability as an illness. There is little distinction between types of disability in the Samoan language. A colloquial umbrella term that is favoured is *ma'i* (illness), although there are other



terms that provide a more specific description of particular impairments (McCuddin, 1974), discussed further in Chapters 6 and 7. *Ma'i* may be caused by physiological, psychological or spiritual factors. *Ma'i* is a term that enables a shared understanding within a Samoan context, but the term is becoming increasingly offensive and outdated (Lameta, 2013). New terms are currently being developed, but this is an extensive process and one that is yet to be made uniform across all agencies. This makes the dissemination of a preferred discourse a challenging task for advocacy organisations.

In the development of disability policy in Samoa, terminology does not reflect guidelines set down by the ICF (McCullough, 2005). The 2011 Samoan Housing and Population Census collected data regarding different types of disability, resulting in a range of categories reported on in the English language. The terms, as depicted in Figure 3 indicate that the ICF was not consulted.

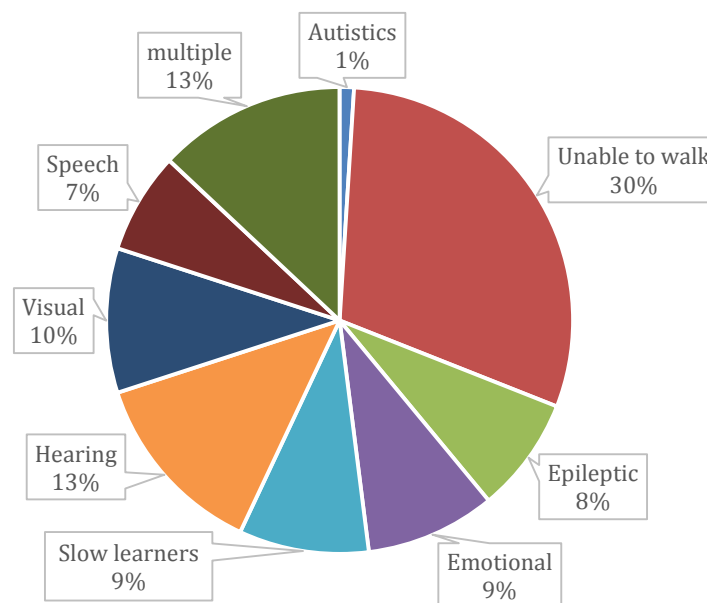


Figure 3. Types of disability in Samoa (Samoan Bureau of Statistics, 2011, p. 64)

In developing the SNPD, the MWCSD recognised perceptions of disability in Samoa did not reflect global trends, and in fact perceptions were reinforced by government welfare approaches to disability (Ministry of Women Community and Social Development, 2009). The SNPD aims to approach disability through a social model, empowering people with disability and their families through support and knowledge (Ministry of Women Community and Social Development, 2009). The new wave of social policy has not been free from critique. Tufue-Dolgoy (2010) asserts that the MESC Strategic Policy and Plans (2006-2015) still approaches disability from a medical standpoint, through the endorsement of special education units, promoting segregation. The Samoan Situational Analysis on Inclusive Education reports that the social theory approach of the SNPD does not recognise the lived experiences of people with disability (Lameta, 2013; Shakespeare & Watson, 2001).

4.5 Terminology usage and development in Samoa

People with disability have been referred to by a variety of terms throughout history. Determining the necessity for, and impact of labelling has posed a challenge in defining disability. There are equally compelling arguments on both sides of the coin around labelling disability. Does labelling create a culture of stigmatisation, alienation, and social distance (Eayrs et al., 1993; Osterholm, Nash, & Kritsonis, 2007)? Does providing a label add to a shared understanding of disability, enhancing service provisions and progressing scientific enquiry (Eayrs et al., 1993; Madden & Hogan, 1997)? According to Eayrs et al. (1993) it is a commonly accepted notion that labels are inherently negative and have a damaging effect on people with disability due to negative and derogatory connotations. Further, these writers assert that a hegemonic discourse of disability devalues people with disability. Eayrs et al.



and Osterholm, Nash and Kritsonis (2007) argue that labelling lowers self-esteem, and exacerbates negative attitudes leading to self-fulfilling prophecies (Eayrs et al., 1993). However, the idea that a shared understanding of disability can result in improved service provisions is also a compelling argument.

Language for disability based on the social disability paradigm began emerging in the mid 1970s with the UPIAS publication “Fundamental principles of disability” (1975). This report established a shared understanding of the terms disability and impairment. This shift in discourse was a starting point to view disability from a social perspective; that barriers existed in society rather than with the individual. This ended a long history of using language stemming from medical and moral models that reduced individuals to descriptors and limitations (Madden & Hogan, 1997). The distinction between disability and impairment is made clear in the following passage:

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 (Union of the Physically Impaired Against Segregation & Disability Alliance, 1975, p. 14).

The philosophical underpinnings of a social model of disability are fundamental to the CRPD. The CRPD defines disability as follows:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in



society on an equal basis with others. (Article 1, para 2, United Nations, 2006, p. 4)

The language used in the UPIAS and UN definitions of disability draws attention to the barriers present within society rather than limitations of the individual. Intrinsic to the understanding of disability, in this sense, is defining impairment. According to Lang (2007) and Shakespeare (2001) these definitions still create a culture of oppression. Without taking into consideration gender, religion, culture or other variables, for many people with disability oppression itself is what unites them as a cohesive group (Lang, 2007). Much of what is constructed in policy is based on a western notion of disability, culture, and empowerment. This calls into question the appropriateness of international policies for developing or recently developed countries where concepts of identity are intertwined with kinship and collectivist mentalities. In some instances, individual empowerment can be in direct contrast to cultural behaviours (Lang, 2007).

The WHO has developed a discourse away from disablement, and towards the recognition of individuals' capabilities and participation. According to Lang (2007) the new classifications incorporate factors that may be relevant to the barriers faced by people in developing and recently developed countries. In the context of health conditions, the WHO defines impairment as "a loss or abnormality of body structure or of a physiological or psychological function" (World Health Organisation, 1997, p. 19). Activity is defined as "the nature and extent of functioning at the level of the person. Activities may be limited by nature, duration and quality" (World Health Organisation, 1997, p. 20). Participation is defined as "the nature and extent of a



person's involvement in life situations in relation to impairments, activities, health conditions and contextual factors" (World Health Organisation, 1997, p. 21).

Policy in Samoa is beginning to adopt a social disability paradigm, evidenced by discourse within policy development. However, this has yet to be formalised or made uniform across agencies. The dilemma for stakeholders of disability in Samoa is how to approach disability language into the future. There is significant dichotomy between the development of ethno-specific terminology, given the link between culture, language, and identity, and the drive to adopt international notions of disability.

Very little has been documented regarding the discourse of disability in Samoa. It is certainly evident in MESC's Strategic Policies and Plans (2006-2015) and the SNPD that government departments are attempting to embrace the language of a social disability paradigm. However, the presence of community language that represents cultural beliefs and conforms to notions of collective identities still has relevance in Samoan society. Tufue-Dolgoy (2010) examined discourse among stakeholders of inclusive education in Samoa. She concludes that contradictions of conceptualisation partly exist due to different perspectives on the meaning of definitions for inclusive education, resulting from a lack of education and awareness (R Tufue-Dolgoy, 2010).

The SNPD draws on international conceptualisations as a platform for local investigations into the prevalence of disability and the provision of service. The policy, effective since 2009, defines disability as resulting "from the association between a person with physical, mental and intellectual aspects and the environmental and attitudinal barriers she/he may face in villages and the wider society" (Ministry of Women Community and Social Development, 2009, p. iii).



Calling for stakeholders to unite in advocacy, the policy endorses human rights and a barrier-free society for people with disability (Ministry of Women Community and Social Development, 2009). There is evidence within the policy of significant consideration and discussion of the development of a Samoan discourse for disability. Lang (2007) suggests that rigid social theory dictates the term ‘disabled people’ dismissing the term ‘people with disability’ as an outdated relic of the medical model era. Despite the SNPD’s commitment to the social disability paradigm, the decision to use the term ‘people with disabilities’ is justified by asserting that this rhetoric places people before disability; that it is not about limitations of the individual but rather limitations presented by social barriers. The policy defines impairment as referring to “physical, social, sensory, psychological, and medical conditions” (2009, p. 7). Environmental barriers are defined as “limitations on a person’s participation, expression of personal opinions in society, education; employment; religion; family life; human rights, freedom of movement and access to buildings and inclusion in decision making” (2009, p. 7). As discussed in Chapter 1, it was decided that the term ‘people with disability’ would be the preferred term for this thesis to align with current terms being used in Samoan policy documents.

In Samoa, colloquial language is still very much part of a shared understanding of disability. The focus on moral and medical models within disability discourse has come to be oppressive and derogatory. This research indicates that descriptive language for people with disability based upon moral and medical models, (including words such as *kalofae* expressing pity or empathy, and *ma’i*) are generally considered caring rather than offensive. Existing terms reinforce a medical model by describing the limitations of the individual rather than focusing on the capabilities of the



individual. Medical model language depicts people with disability as sick, and this is a limitation in itself.

Samoan language has attempted reform of disability terminology from purely medical terms such as *ma'i*, to terms that intend to raise awareness through reducing disability to a set of descriptors. Lameta (2013) claims that negative discourses are being phased out within government schools and this has had an impact on the stigmatisation of children with disability, although no research has specifically targeted this. The challenge now is how to transform language to represent both cultural perspective and the human rights perspective within policy development.

4.6 Innovations in disability in Samoa

Contemporary Samoan culture is an evolving combination of traditional and global ideologies. There is evidence of a governmental and societal drive to reflect contemporary global agendas through recent policy reform. Local policy documents are informed by international policy, but how do such policies represent traditional Samoan social values?

Until recently, the Samoan Constitution (Government of Samoa, 1960) was the only binding legislation for providing rights for people with disability. The small section addressing the needs of people with disability (Part 2, Article 15) provides little guidance as to the manifestation of this in political and social forums:

- (1) All persons are equal before the law and entitled to equal protection under the law.
- (2) Except as expressly authorised under the provisions of this Constitution, no law and no executive or administrative action of the



State shall, either expressly or in its practical application, subject any person or persons to any disability or restriction or confer on any person or persons any privilege or advantage on grounds only of descent, sex, language, religion, political or other opinion, social origin, place of birth, family status, or any of them.

(3) Nothing in this Article shall-

(a) Prevent the prescription of qualifications for the service of Western Samoa or the service of a body corporate directly established under the law; or

(b) Prevent the making of any provision for the protection or advancement of women or children or of any socially or educationally retarded class of persons (1960, p. 13).

Fundamentally the constitution makes provision for the protection and advancement of people with disability, but until recently there have been no policies that specifically address disability at a social level.

In the past two decades, Samoa has extensively engaged with regional and international agencies to transform the landscape of disability policy and practice. This recent history demonstrates Samoa's commitment and progress in disability rights, although getting the correct 'cultural-fit' is still in a development phase.

In understanding the journey of disability perception and policy development in Samoa it is useful to look at the phases of ideological models that have influenced public cognisance. Determining a traditional Samoan epistemology on disability is almost an impossible task due to the influence of colonisation and introduced religion, both of which have impacted heavily on contemporary perception. However, tracing



the recent history of disability perception provides some insight into both a historical perspective of disability and how the practices of *fa'aSāmoa* shape the unique Samoan perception of disability. The genesis of disability conceptualisation from a European standpoint was reviewed in Chapter 3. In this chapter, historical disability conceptualisations are framed within the Samoan context.

4.6.1 A social model of disability in Samoa

Samoan society of today is a dynamic and evolving culmination of traditional culture and global trends. Samoan society represents all paradigms of disability, so the process of instigating a perceptual change to align all citizens with the philosophies of a social model is a complex and daunting task.

Ultimately, it is the desire of the government, NGOs, educators, and other stakeholders involved in the area of disability that a social model of disability be fully embraced by society. This will enhance promotion of a social paradigm in affecting social perceptions, attitudes, and behaviours towards people with disability (McKinstry et al., 2012; Ministry of Women Community and Social Development, 2009). Promoting and acknowledging the rights of people with disability as equal is a collective responsibility of society to make reasonable accommodations and modifications to ensure equal participation in society for every Samoan. Lameta (2013) asserts that fundamental concepts of the *fa'aSāmoa*; *alofa* (love), *fa'aaloalo* (respect), and *tautua* (service) support a social model on disability, quoting a Samoan proverb: *e leai se tagata e vale* (there is no one who is of no worth or use). Conversely, Tufue-Dolgoy (2010) believes that the *fa'aSāmoa* is incompatible with



a social model. She asserts that hierarchical concepts of power manifest in different treatment according to concepts of status, contribution, and reciprocity.

The *Review of disability legislation in the Pacific* reports that significant progress has been made in Samoa regarding policy development, service provisions, and NGO collaboration (McKinstry et al., 2012). Concern exists over the acceptance of new policy as it replicates external policy rather than responding to Pacific Island culture (Lameta, 2013; McKinstry et al., 2012; R Tufue-Dolgoy, 2010). Challenges still exist in terms of societal perceptions and the acceptance of disability policy in Samoa (discussed further in Chapters 6 and 7).

4.6.2 Policy mandates

As a whole, the Asia-Pacific region is undergoing dynamic change as it rallies to make the necessary political, ideological, and physical changes necessary to meet the criteria of international expectations of human rights for people with disability. Samoa's commitment can be demonstrated through the extensive list of global mandates that the Government of Samoa have endorsed (shown in Table 4).

Significant obligation to the global community is attached to the endorsement of international agreements. For Samoa, this has required an overhaul of policy to address issues not only of disability itself, but of disability and poverty, disability and gender, and disability as it relates to access issues in a recently developed country. This is a significant and complex undertaking. Samoa's response to international agreements has been to develop local frameworks to begin the process of aligning policy, practice, and societal perception within global initiatives.



Table 4. Global mandates endorsed by Samoa

Year	Mandate
1989	United Nations Convention on the Rights of the Child
1990	United Nations Educational, Scientific and Cultural Organisation (UNESCO) Education for all
1994	The Salamanca Statement and Framework for Action of Special Needs Education
2000	United Nations Millennium Development Goals (MDG)
2001	Pacific Island Forum Secretariat, Forum Basic Education Action Plan
2003	The Biwako Millennium Framework for Action: Towards an inclusive barrier-free and rights-based Society for Persons with Disabilities in Asia and the Pacific (BMF) 2003-2012 Asia Pacific Decade for the Disabled Person 2003-2012
2008	United Nations Convention on the Rights of Persons with Disabilities (CRPD)

This process started in 1992 with the National Building Code of Samoa under the Ministry of Works Act with provisions for accessibility (although adherence to this code is not always evident in Samoa). The Compulsory Education Act was also implemented in 1992, including provisions for inclusive education. This was the beginning of a significant shift in policy and practice. In 1998, the Special Needs Educational Advisory Committee (SNEAC) was established. This initiated compulsory pre-service teacher training in special needs at the National University of Samoa, with the first special needs qualified teachers graduating in 2000. During that year, MESC conducted a nationwide survey to determine the numbers of children (0-14) with disability. The analysis of this data led to the employment of a Special Needs Coordinator within MESC. While MESC had been proactive in addressing inclusivity in government schools, the need to address issues of inclusion and equity in the broader society still exists. The 2002 Adult Identification Census (cited in



Ministry of Women Community and Social Development, 2009, p. 3) aimed to provide information on adults with disability and levels of access to education, employment, and public spaces. These investigations provide some information on the prevalence of disability in Samoa, but MWCSO asserts that it is not a definitive figure. MWCSO suggests that many people with disability in Samoa are “hidden from view” (Ministry of Women Community and Social Development, 2009, p. 2). There is great uncertainty around accurate statistics both in Samoa and internationally. A WHO estimate suggests 18.2 percent of the international population have disability (World Health Organisation & The World Bank, 2011), while Samoa identifies only two percent of the total population (Faafu-Taalogo, Lene, Nuanua o le Alofa, & Inclusion International Asia Pacific Region, 2002).

In the absence of specific policy for disability, and in light of recent findings into the prevalence of disability, the Samoan Government designated the MWCSO as the focal point for initiatives for people with disability. In 2008, a taskforce was established, headed by the Chief Executive Officer of MWCSO, to develop the SNPD through consultation with stakeholders throughout Upolu and Savaii. Upon establishment of the policy, it became the responsibility of the taskforce to review, assess and report on the implementation of the policy. The taskforce also makes recommendations to the MWCSO minister to strengthen and modify the policy based on identified necessary accommodations for people with disability. In 2009, MWCSO published the SNPD. This was a significant turning point for people with disability as it was the first policy of its kind in Samoa’s history. This policy demonstrates a commitment by the Government to acknowledge Samoans with disability and to begin planning for ways to redress inequality within society. The



SNPD was developed as mounting international engagement highlighted Samoa's welfare approach to disability. The SNPD raises challenges of inclusion, stating:

It is now recognised that many of the disadvantages they face resulting in exclusion are not due to the individual disabilities, but rather a function of the reaction (attitude) of society to that disability plus the physical (environment) and cultural (protective approach) barriers they live with and face in society (Ministry of Women Community and Social Development, 2009, p. 4).

Statistics from the Samoan Adult Disability Identification Census (Faafeu-Taalogo et al., 2002) prompted the suggestion that people with disability have reduced access to education and employment (Ministry of Women Community and Social Development, 2009). The role of traditional education and employment, even in contemporary Samoan society should not be overlooked. The majority of formal education institutions are located in the Apia area. The majority of people with disability (80 percent) are located in rural areas with limited access to services (Ministry of Women Community and Social Development, 2009).

Despite the developments in policy, the MWCSD is still concerned with societal perception and equality, stating:

But the question is, how can we make the society inclusive? It is like we are asking the population to include people with disability in their lives. When we should be focusing on empowering people with disabilities as an intention to shift people's perception of disability (Ministry of Women Community and Social Development, 2009, p. 7).



There seems to be little consensus on the stance of recent policy. Tufue-Dolgoy (2010) argues that policy is grounded in the medical model thus reinforcing stigmatisation of people with disability. McKinstry et al. (2012) suggest that there has been a recent shift from a charity to human rights model in Samoa, evidenced by changes in policy. Another perspective, proposed by Lameta (2013) is that policy does not recognise the lived experiences of people with disability, creating a barrier of both perception and access to service provision, an argument advanced by Shakespeare (2001), as discussed in Chapter 3.

4.6.3 Inclusive education

The reform leading to the current education agenda in Samoa began in the early 1990s. As a relic of colonisation, the education system had become increasingly irrelevant. MESC began seeking assistance from international parties to develop innovative and progressive education policy. In 1993, MESC developed Education Policies and Educational Strategies (1995-2005), followed by the Strategic Policy and Plans (2006-2015) with advisory, technical, and funding support from Australia, New Zealand, China, Canada, the European Union, and the UN.

Until the development of the MESC Policies, educating people with disability had been the primary responsibility of NGOs. Even with the implementation of the Compulsory Education Act (1992) people with disability sat under the umbrella of an entirely different educational framework. The need to regulate policy for people with disability became apparent. The current MESC Strategic Policy and Plans (2006-2015) provides guidelines for the education of people with disability. As a model of best practice, the policy promotes inclusive classrooms, schools, and communities,



yet it identifies some shortcomings in the realisation of the policy in educational settings. Within the policy it is identified that there is a need to develop an understanding about the philosophical underpinnings of inclusive education, as this presents a significant barrier for inclusion if teachers and support staff are inadequately informed (Ministry of Education Sports and Culture, 2006). It was also identified that raising awareness on the acceptance of people with disability attending local school was an important factor in individuals themselves valuing and accessing education (Ministry of Education Sports and Culture, 2006). With inadequate links between education, health, and NGOs, a lack of early detection and intervention, and limited on-site support, the commitment to inclusive education is yet to match the intentions of the policy framework. The recognition of these barriers by MESC indicates a commitment to addressing the limitations of the implementation of the inclusive education as part of a long-term strategic plan.

The Government of Samoa has created a partnership with Australian Aid to develop the Samoan Inclusive Education Demonstration Program (SIEDP) targeting the cost-efficient and culturally responsive delivery of identification and support services for people with disability. The SIEDP develops programs for MESC and NGOs to provide services and programs for people with disability, focussing on sustainable service provision. NGOs that provide services for people with disability in Samoa have historically operated independently but newly established links are strengthening and promoting the quality of service provision.

Tufue-Dolgoy (2010) questions how effective the implementation of policy has been by teachers, schools, and communities. She asserts that contemporary Samoan classrooms still emphasise cultural epistemologies and practices that are incompatible



with an inclusive education framework. She identified two significant barriers to effective inclusion: the perception of the capabilities of people with disability, and lack of knowledge and training on inclusive education practice and policy. Essential to the development of future inclusive policies and practice is the utilisation of local expertise in the development of a culturally responsive model of inclusive education. Tufue-Dolgoy recommends that further investigation be undertaken to determine the relationship between the *fa'aSāmoa* and disability and how practices and beliefs of the *fa'aSāmoa* impact on negative attitudes towards people with disability.

4.6.4 Service providers

In Samoa, NGOs are a powerful driving force for providing services, support, and advocacy for people with disability. These organisations are recognised by the government as instrumental in the provision and delivery of services to the community. Organisations such as *Loto Taumafai* and the Special Needs Education Society (*SENESE*) have been able to secure international funding to promote and provide services for people with disability. They also provide recommendations to the government for future initiatives. *Nuanua o le alofa* (NOLA), an advocacy group for people with disability, secures independent funding to advocate for equal opportunities and rights. The rights of people with disability are becoming increasingly well represented with numerous NGOs facilitating services and representing the voices of a diverse, disabled community. Not all NGOs are highlighted in this review.



4.6.4.1 Loto Taumafai Society for people with disabilities

Before the Samoan government had made a commitment to the development of education for people with disability, the *Loto Taumafai Society* for people with disabilities were pioneers in special needs education. The *Loto Taumafai* Special Needs School was established in 1981, aiming to provide quality education for children with disability, as well as instigating vocational services and early intervention outreach programmes. Today, *Loto Taumafai* has secured funding from Australian Aid and provides a range of support services for the community, as well as collaborating with other NGOs, MESC, and the Ministry of Health (MoH). *Loto Taumafai* has a strong commitment to raising awareness in the community and shedding the negative perceptions that have attached themselves to the school. Under the SIEDP, *Loto Taumafai* is responsible for training staff to provide appropriate early intervention, and to develop an awareness program that targets knowledge and understanding of cerebral palsy. The school caters for more than 130 students who attend the *Moto'otua* campus, as well as supporting over 150 students through the outreach program (Lameta, 2013). The outreach program is delivered by locally trained staff who visit homes to support families and communities in caring for and educating people with disability. The outreach staff collaborate closely with existing services such as MoH, MESC, and other NGOs, as well as community groups such as church congregations, community preschool teachers, and community leaders. It is reported that *Loto Taumafai* see the inclusion of their students into village schools and the ultimate closure of their facility as a long-term goal (McCullough, 2005).



4.6.4.2 *Special Needs Education Society (SENESE)*

In the early 1990s, there were limited educational options for people with disability in Samoa. A group of parents formed the NGO *SENESE* in 1992. Originally a stand-alone educational institution, *SENESE* merged with the Robert Louis Stevenson School in 2006 as part of a long-term goal to provide people with disability in an inclusive educational setting. *SENESE* has a focus on students from birth to 18, providing support to local schools in the provision of inclusive education. In recent years, *SENESE* has expanded significantly and is now a leader in the field of inclusive education. The organisation is a recipient of Australian Aid funding, managed through SIEDP. *SENESE* is contracted to specialise in support and provision of resources for people with disability, their families, and the community. Their role is in early intervention and support, teacher support, in-service training, and the management of funding for the MESC Inclusive Education Advisor role. *SENESE* employs many people with disability who contribute a wealth of knowledge and experience in the area of disability. *SENESE* has partnered with the NSW Institute for Deaf and Blind Children, and is the main provider of support for people with sensory disability in Samoa. *SENESE* conducts research that contributes to the body of knowledge on disability and inclusivity in Samoa. They attract expertise from overseas by way of volunteer services.

4.6.4.3 *Nuanua o le alofa (NOLA)*

Several organisations offer educational facilities for people with disability in Samoa, but NOLA are the sole advocacy group that provide support for people with disability. NOLA is a not for profit organisation focussing on awareness, advocacy, and equal opportunities. Founded by people with disability in 2001, NOLA is run by an elected



board and seeks independent funding. NOLA's main work centres on advocating for people with disability where discrimination, negative attitudes, limited accessibility, and inequality present barriers for achieving a standard of living free from economic or social restrictions. NOLA's staff frequently present seminars to educate the community on issues of inclusion for people with disability. They also lobby the government to achieve equal rights for people with disability. Their work also extends to assisting people with disability in the employment sector and in advocating for government welfare for people with disability who are unable to work given current societal constraints.

4.6.4.4 Australian Pacific Technical College

The Australian Pacific Technical College (APTC) funded by Australian Aid has become influential in the area of disability throughout the Pacific. The introduction of the Australian recognised qualification of Certificate III in Disability is nurturing pathways for careers in the disability sector. The 12-month course is establishing links with other agencies within the sector through the relationships and contacts the students themselves bring to the course. The course combines the notion of 'best practice' (using Australia as a benchmark) with the knowledge and wisdom the students bring to the classroom of Samoan culture, field experience through prior work placements, and personal experiences of disability. This combination of formal and informal knowledge creates a notion of 'best practice' that reflects the Samoan landscape and ensures that Samoan culture has a voice in newly emerging practice for disability.



4.7 Education and employment for people with disability

Identity, contribution, and acceptance are interconnected concepts within the *fa'aSāmoa*. It is reported that people with disability are well accepted members of Samoan society (Samoan Bureau of Statistics, 2011). The results of this thesis and previous research (Lameta, 2013; McKinstry et al., 2012; R Tufue-Dolgoy, 2010) indicate that barriers still exist in the effective social and cultural inclusion of people with disability. In the 2011 Housing and Population Census, people with disability were defined as “anyone with a condition (physical/emotional) causing great harm to one’s life hence making it difficult to live life to the fullest without support from others” (Samoan Bureau of Statistics, 2011, p. 62). Representing a moral and medical approach to disability, the report alludes to a societal perception that people with disability are dependent on their family for care, housing, financial support, and social participation as a result of impairment. The report states that general employment rates stand at 41 percent. This is a declining figure as increasingly people become unemployed, or move to ‘non-economic activities’ defined as domestic duties, courses or training, or being elderly, or disabled. The reported unemployment figure of 6 percent only accounts for those individuals who were actively seeking work through sending applications or attending job interviews in the seven days preceding the collection of data for the census (Samoan Bureau of Statistics, 2011). The Housing and Census Report (2011) identified the high volume of school leavers in a declining economic environment as a contributing factor to the increasing unemployment. It suggested that many school leavers go back to subsistent living. This makes for a highly competitive job market for people with disability, adding to the complexity of gaining paid employment and making contributions to society.



Table 5. Types of work activity for people with disability

Type of work activity	Male	Female	Total	%
Paid Work	26	12	38	1.3
Income Earner	22	11	33	1.1
Assist family work activities	647	757	1404	48.9
Student	159	153	312	10.9
None	504	583	1087	37.8
Total	1358	1516	2874	100.0

Source: Samoa National Policy for Persons with Disabilities (p.5), by the Ministry of Women, Community, and Social Development, 2009. Samoa: MWCSD

The Adult Disability Identification Census (cited in Ministry of Women Community and Social Development, 2009, p. 5) specifically identifies the main work activities of people with disability, depicted in Table 5, indicating the incidence of employment for people with disability (2.4 percent) is well below the national percentage of employment (41 percent).

4.8 Conclusion

This chapter provides a summary of current conceptualisations of disability in Samoa. It highlights the influence of global agendas and its impact on cultural values. Samoa is in a phase of prolific innovation in disability. This review has outlined the rationale that has driven these innovations as well as providing a review of the critiques of the emerging policies and systems.

Essential to any understanding of perception of people with disability in Samoa is the tracing of both recent history and the traditional Samoan way; the *fa'aSāmoa*. While perception of disability from a Samoan standpoint has yet to be researched in-depth,



it is the intent of this research, and of this review, to provide knowledge and understanding of the pathways to innovation.

A cultural lens provides an understanding of Samoan conceptualisations of disability and the implications of perception on education, employment, and inclusion. As reported by Tufue-Dolgoy (2010), concepts of collective identity, general societal perceptions, and some of the concepts of the *fā'aSāmoa* are incompatible with social disability models. The combination of factors create circumstances for people with disability that are difficult to navigate. These include cultural beliefs on disability, concepts of protection, status and collectivism, and progressive social models that endorse independence, equality, and individualism. These circumstances are driving people with disability to have to measure the value of their cultural identity against their identity as a person with a disability within an emerging social model environment. In the recommendations of this thesis, the further development of the *Tutusa* model is offered as a new paradigm of disability in Samoa. Its capacity to blend ideologies and recognise how people experience disability provides a framework for people with disability to fulfil their human rights and retain a Samoan cultural identity.



Chapter 5: Methodology

5.1 Introduction and overview

This chapter examines the research principles and methodological framework used to conduct this research. The research uses methods that combine reliable phenomenological methodologies with cultural epistemologies. The culmination of these two frameworks results in a culturally contextual, inductive approach. The methodology, *Talanoa*, draws on fundamental concepts and practices of the *fa'aSāmoa*, requiring the researcher to be immersed within the Samoan culture. This chapter will discuss the considerations of conducting research within Pacific communities. The chapter will also discuss the phenomenological foundations of the *Talanoa* methodology, as well as appraise other Pacific methodologies and their relevance to this particular research. Finally, the chapter describes methods of sampling, data collection, analysis, and ethical considerations of the research.

5.2 Researching as a ‘*Palagi*’

Researching disability in Samoa required a commitment to cultural responsiveness. I have contemplated my role in this research since its inception. Pasifika researcher Tuhiwai-Smith (2005) poses the question “What defines indigenous research?” (2005, p. 89). She hypothetically suggests that the research itself must have the capability to arouse social and institutional transformation towards a Pacific view and address issues of inequality and power relationships with outsiders (Tuhiwai-Smith, 2005).



Palagi (person of European descent) research does not always have a good track record in the Pacific. The classic example is Margaret Mead's work, taken as a conclusive truth on nature versus nurture when it was published in 1928 (Freeman, 1983). Her professor, Franz Boas, sent the then 23-year-old Mead to Samoa to settle the great intellectual debate of eugenicists and anthropologists on whether human nature is the result of biological or social factors. Mead's conclusion supported Boas' belief that "much of what we ascribe to human nature is no more than a reaction to the constraints put upon us by our civilisation" (cited in Mead, 1928, p. 6). Much of Mead's work has since been refuted, with revelations later surfacing that some of her participants deliberately misled her as a form of protest against her methodological approach and her 'outsider' status. Historically, formal research has not been a part of Pacific traditions. It has been viewed as a colonial tool to obtain power and control over indigenous issues (Tuhiwai-Smith, 2005). An aversion to research has begun to abate as culturally responsive research methods are developed and, increasingly, indigenous scholars undertake research opportunities (Robbins, 2004; Tuhiwai-Smith, 2005). Research agendas are often at the crux of resistance with concern that research will be used as a commodity to re-shape Pacific communities to conform to global directives (Taufe'ulugaki, 2001; Tuhiwai-Smith, 2005).

In the past, research had been viewed as a tool of the colonisers to meet economic and political imperatives that were not in the best interest of Pacific Island people (Robbins, 2004; Sanga, 2012; Tuhiwai-Smith, 2005). Reclaiming a Pacific worldview has incorporated a growing cohort of indigenous research scholars whose commitment to constructing indigenous dialogues has seen the development of Pasifika research methodologies. Increasingly, people of the Pacific are embracing research as researchers themselves begin to respond in a cultural capacity (Sanga,



2012; Taufe'ulugaki, 2001). In Sanga's literature of Pacific research capacity, he promotes the link between research capacity and national development, and emphasises the need to move away from a neo-colonial agenda to fully realise these objectives (Sanga, 2012). But does this mean that non-indigenous researchers have nothing valuable to contribute to the field of Pacific research? Increasingly, non-indigenous researchers are being viewed as bringing value to the field. Taufe'ulungagki (2001) suggests that while outsider researchers are effective contributors to Pacific research, the fundamental aim of any research needs to be in "transforming Pacific societies, but in accordance with Pacific values and aspirations" (p. 11). Tuhiwai-Smith (2005) echoes this sentiment emphasising the need to "critique the rules of practice" (p. 90), by examining assumptions, ethics, purposes, funding, and agendas.

The answer to Tuhiwai-Smith's question on what defines an indigenous researcher is not simply someone who is indigenous. The emphasis of indigenous research needs to be focussed on enhancing national development through the construction of a Pacific worldview.

Research in Samoa is becoming increasingly prevalent, with an assortment of indigenous Samoans, Samoan diaspora, aid organisations, and "outsiders" researching a diverse range of disciplines. Not all research has a Pacific worldview approach or national development agenda. However, culturally responsive research makes valuable contributions to a developing landscape of national development that creates a 'Samoan worldview'. Kolone-Collins (2010) conducted research on Samoan *fagogo* (night stories). Using culturally responsive methodologies and creating a Samoan worldview, Kolone-Collins' work is an excellent example of



indigenous scholars contributing to a national developmental agenda. While Kolone-Collins emphasises the benefits of conducting *Talanoa* in Samoan, she at times felt that her ‘Samoanness’ made it difficult to elicit accurate responses, as knowledge of family, culture, and language brought with it expectation of prior understanding. *Palagi* researcher, Bridget O’Reagan (2006), recognised that it was essential to devote a great deal of time to relationship building with her participants, and to the development of her understanding of cultural research protocol. Nurturing relationships and developing a Samoan worldview enabled O’Reagan to promote the validity of her research. Her enthusiasm and devotion to acquiring knowledge on culture improved her status and acceptance. Participants acknowledged that O’Reagan was not merely conducting the study for her own personal gain, but her intent was one of reciprocity, collaboration, cultural sensitivity, and respect. O’Reagan felt it was advantageous to her study to be a *palagi* and to have a developing knowledge of Samoan culture, as participants were willing to provide information about cultural nuances as gaps in O’Reagan’s knowledge presented themselves.

The intimate process of conducting interviews with my participants was a critical turning point in the realisation that my role as ‘outsider’ researcher was as a collator. My role was to provide a means to have these vital stories told from a Samoan worldview. I have interpreted the data within a Samoan cultural frame, and the research belongs to my participants who shared their stories with a mutual goal of reclaiming culture in both social and institutional senses.

I recognise that the voices of my participants present an invaluable contribution in the field of disability in Samoa and that my research may act as a catalyst for further



research for the benefit of Samoans with disability. At every stage of this research I have adhered to ‘rules of practice’. I believe, like ‘outsider’ researcher Robbins (2004), that my research is not an end point, but the beginning of further research that will contribute to culturally responsive national development and capacity-building for people with disability in Samoa.

5.3 Methodological framework

This research was designed to contribute to a Samoan worldview on disability conceptualisation. My cultural advisors and participants have provided guidance and support to ensure that the outcomes of this research are driven by a Pacific agenda and contribute to national development and capacity building. It was essential that this research fit within a Samoan cultural frame while simultaneously recognising societal shifts and global human rights agendas on disability. This has, at times, been challenging, as some of these objectives are seemingly contradictory.

The defining factor in culturally authenticating this research was the incorporation of my participants and cultural advisors at every stage to ensure community ownership of this work. At times, I humbly accepted my limitations as an ‘outsider’ and sought the assistance, advice, and support from those around me. Meaning was co-constructed through a process of questioning and clarifying. There was a mutual desire to represent a Samoan conceptualisation of disability as accurately as a rapidly changing landscape would allow.

This research journey began with *Talanoa*, a rich oral tradition that has been transformed into a valid and reliable research tool. Figure 4 depicts the phases of research development from conceptualisation through to the reporting of findings. As



illustrated in Figure 4, the initial phase of research development was conceptualising the research idea, which occurred through accessing literature, but more importantly through an initial process of *Talanoa*. All refinements to research, sampling and recruitment, interview questions, and findings underwent rigorous clarification to ensure the reliability of the research throughout each phase.

The *Talanoa* research methodology has its roots in phenomenology, where meaning is co-constructed. Phenomenology fits within an interpretive paradigm aiming at understanding the meaning of phenomena and how they fit within a social, cultural, and political context (Flood, 2010). The role of the researcher is not merely to interpret data, but to co-construct it with participants. It is necessary for the researcher to shed preconceived ideas, and to become embedded in the co-creation of information. The *Talanoa* research methodology adopts the interpretive and flexible nature of phenomenology, blending it with cultural protocol and practices to obtain the most valid data of phenomena that exists in Pacific communities.



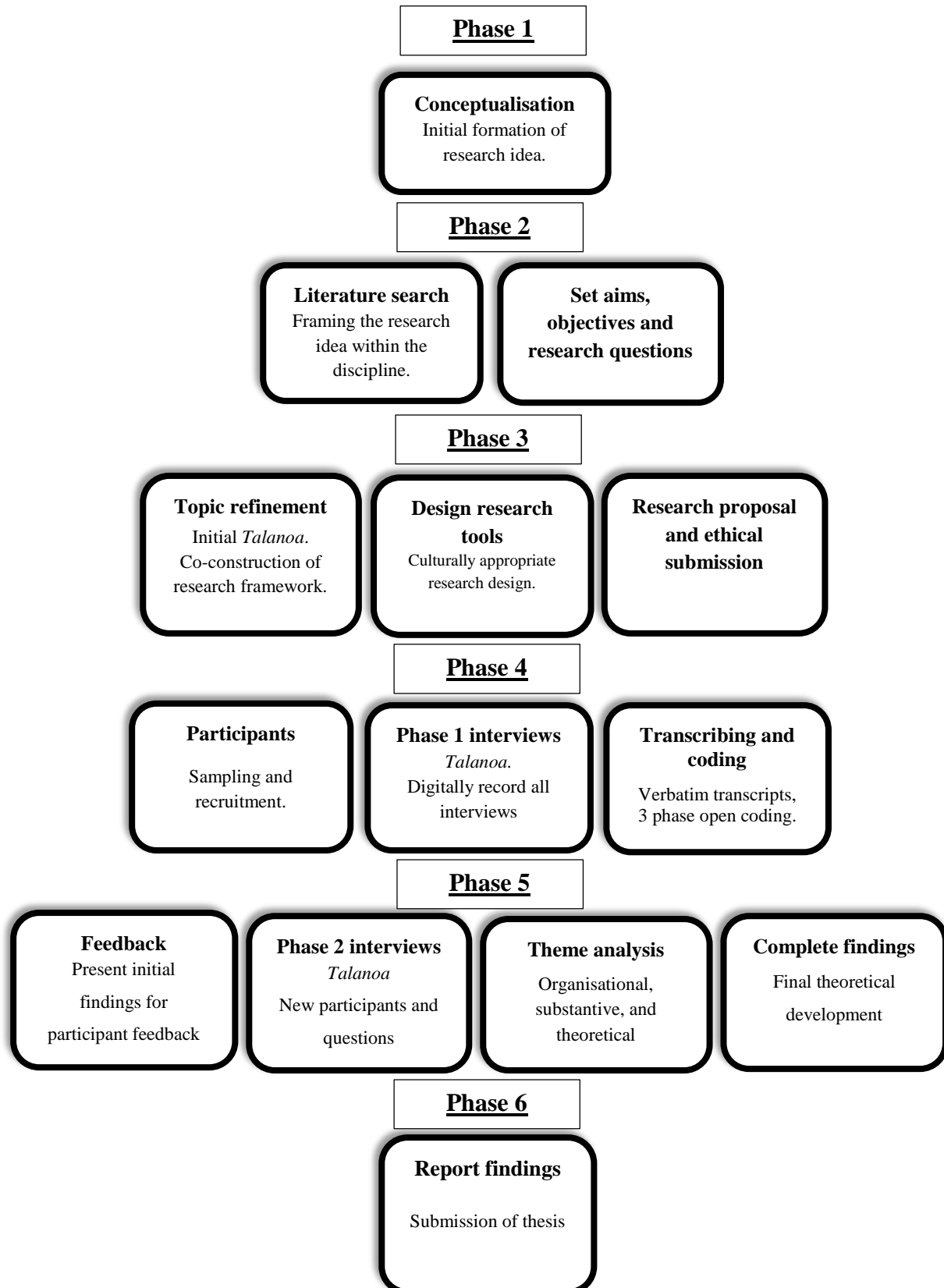


Figure 4. Phases of research development (adapted from Rasela Tufue-Dolgoy, 2012)

5.3.1 *Talanoa*

Talanoa has roots in most Pacific countries and continues to hold a significantly valuable place in Samoan society.

Talanoa, as a research methodology is specifically designed to conduct collaborative and reciprocal research with Pacific peoples (Vaioleti, 2006, 2011). As a methodology for studying human phenomena and understanding the human experience from a cultural perspective, it is based on Pacific epistemological and ontological perspectives (Titchen & Hobsen, 2005). Like phenomenological research, *Talanoa* seeks to reveal meaning. *Talanoa* is the sharing of mutual history, culture, and language to co-construct meaning from experiences (Flood, 2010). The *Talanoa* research methodology comprises three components: the act of *Talanoa* itself, awareness of protocol and *Tui Kakala*. The methodology is incomplete if one of the components is not incorporated, reducing the validity of the research. Figure 5 depicts the three components of the *Talanoa* research methodology.

The three components of the *Talanoa* research methodology are essential components in ensuring the development of a Pacific world view. The first component of the *Talanoa* research methodology is *Talanoa* itself. The act of *Talanoa* has deep roots in Pacific culture. The word itself literally explains what *Talanoa* is. *Tala* is to tell, relate, command. *Noa* is of any kind, nothing in particular. *Talanoa* is a discussion; a conversation between participant and researcher that has little structure, and requires input from both parties (Otsuka, 2006; Vaioleti, 2006, 2011). Māhina (2008) also defines *Talanoa* as simply “talking critically, yet harmoniously” (2008, p. 80), but critics of the process may consider *Talanoa* to be merely random conversations.



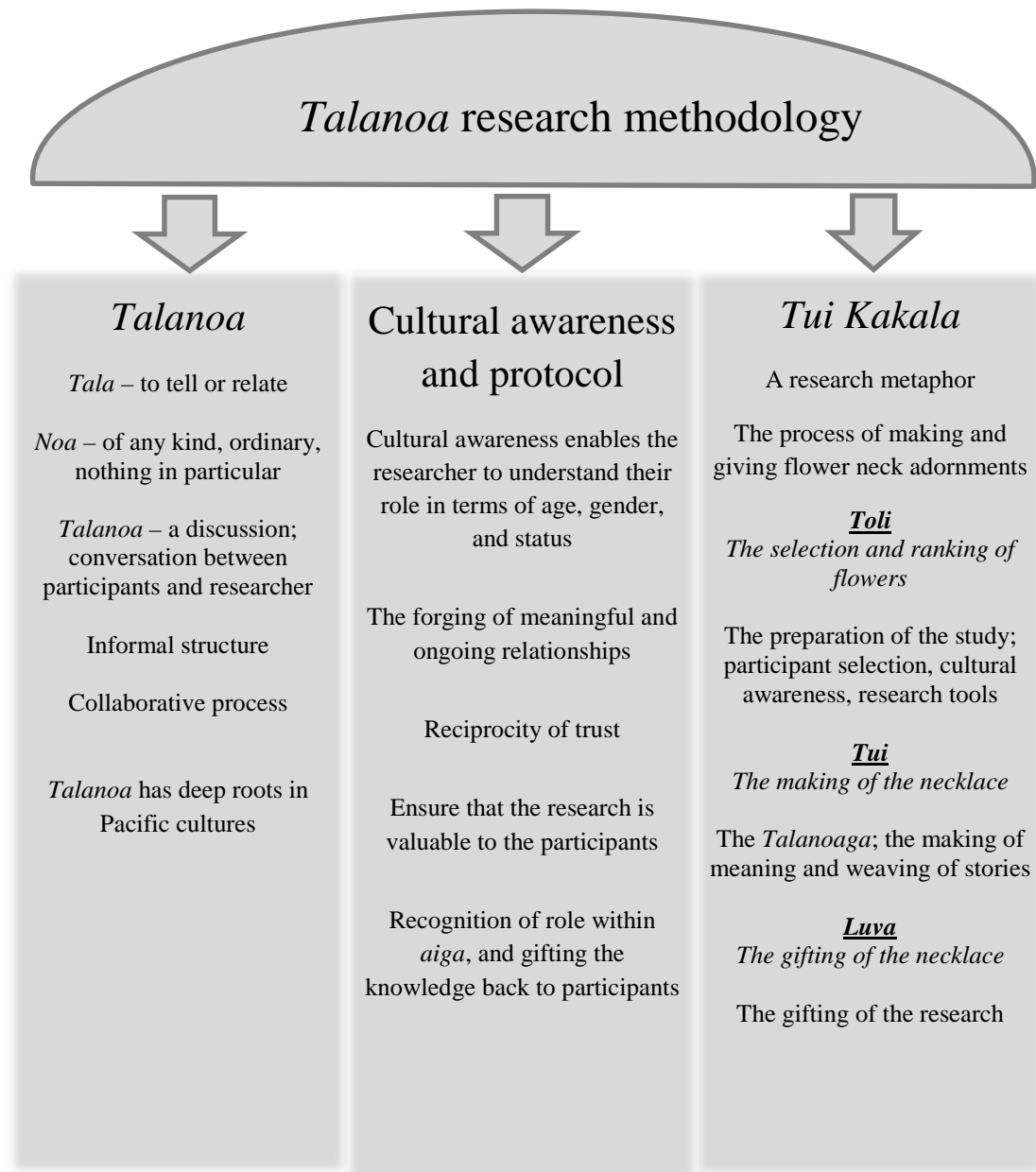


Figure 5. The three components of the *Talanoa* research methodology (Thaman, 1988; University of Otago, 2011; Vaioleti, 2006, 2011)

Pacific communities see it as a tool for gaining and sharing knowledge, strengthening and maintaining relationships, and maintaining stability within family units. Vaioleti (2011) outlines the myriad of ways that *Talanoa* may be adopted for different purposes (summarised in Figure 6). While all of these modes of *Talanoa* are not

necessarily applicable to a research context, it brings a deeper understanding to *Talanoa* as a cultural concept and practice.

In this context, the research methodology is known as *Talanoa*. In Samoa, the word *Talanoa* is a verb; it is the act of having a discussion, or talking to someone. The word *Talanoaga* is a noun that provides the label for the act of *Talanoa*. The term *Talanoaga* has been used when reference is made to a context that is specifically Samoan, as opposed to the umbrella term of *Talanoa* to depict the research methodology.

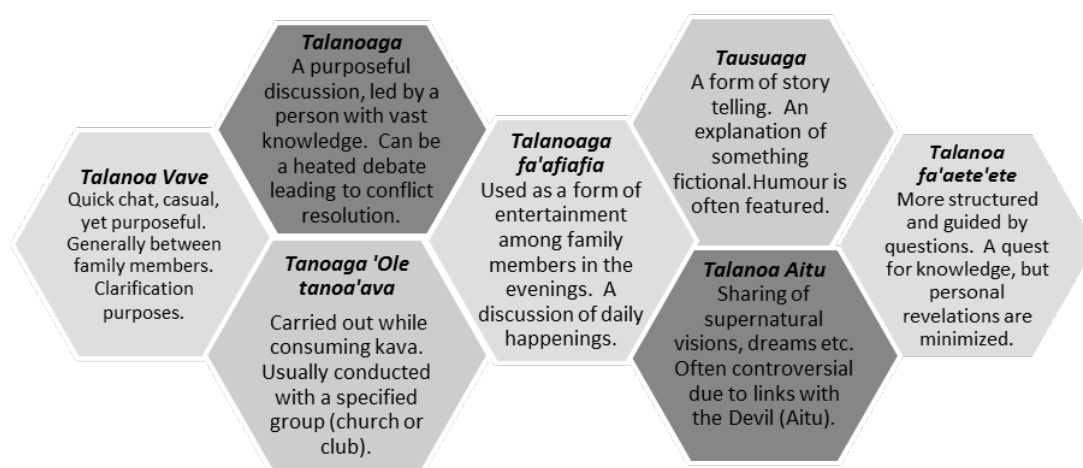


Figure 6. Types of *Talanoa* (adapted from Vaioleti, 2011)

5.3.2 Cultural awareness and protocol

The second component of the *Talanoa* research methodology provides a framework for the application of cultural concepts. The basis of *Talanoa* is cultural understanding, the observance of protocol (described in Table 6), respect, and reciprocity. To conduct *Talanoa* research, the researcher must have a deep

understanding of cultural practices and beliefs. This deep sense of cultural awareness allows the researcher to understand how he or she is perceived in terms of age, gender, and community standing. It also enables the researcher to forge meaningful and ongoing relationships with participants.

The University of Otago, has developed a list of protocols for conducting Pacific research. This includes family links, community, responsibility, love, spirituality, charity, obligations, service, respect, humility, gerontocracy, and reciprocity (University of Otago, 2011). These protocols are aligned with concepts of the *fa'aSāmoa*. Observance of the protocols ensures that research meets cultural and academic guidelines whilst building relationships for collaborative research. The protocols are not necessarily an exhaustive list, nor specific to any particular Pacific culture. However, the protocols provide sound guidelines for Pacific researchers.

5.3.3 *Tui Kakala*

The third concept of the *Talanoa* research methodology is the metaphor of *Tui Kakala*. *Tui Kakala* is literally the practice of making and gifting of flower neck adornments. As a metaphor, *Tui Kakala* metaphor is made up of three parts. Firstly *Toli*; the selection and ranking of flowers. Secondly *Tui*; the actual weaving and making of the necklace. Thirdly *Luva*; the giving of the necklace. In relation to *Talanoa* research, the *Toli* is the selection of participants, the preparation around the study, and the efforts to understand cultural practices. The *Tui* is the relationship building, the actual conversations, the making of meaning, and the weaving of stories. The *Luva* is the way the researcher disseminates the information so as to provide solutions to the community that the researcher worked with. The *Luva* is the gift of



co-created knowledge from researcher back to the participants (Thaman, 1988; Vaioleti, 2006, 2011). The application of *Tui Kakala* provides the framework necessary for *Talanoaga*. Practising *tolu* through nurturing relationships revealed important cultural information regarding hierarchies, respect, and collaboration. Engaging in the practise of *tolu* facilitated and enhanced the experience of *tui*, providing an interface of trust between my participants and myself. The process of *tolu* and *tui* embedded a deep sense of collaboration and reciprocity, making it an honour to practise *luva*.

5.4 Method application

The *Talanoa* research methodology is most appropriately employed with Pacific communities as the research process is culturally contextual. The data collection methods provide Pacific peoples with an opportunity to voice opinions within a method that respects cultural practices and cultural protocol. When research is conducted with the aim of increasing knowledge of and for Pacific communities, researcher and participants gain a sense of collaboration, whereby knowledge is co-constructed.

5.5 *Talanoa* and the Samoan context

The *Talanoa* research methodology has been used very successfully in a number of research studies. Kolone-Collins (2010) conducted research in Samoa on the role of Samoan night stories in traditional educational practices. Kolone-Collins remarked on her choice of methodology in her thesis, stating,

Since this study is located in the context of Samoan language and culture, the *talanoa* approach that stems from a culture in which



oratory and verbal negotiation have deep traditional roots, is most appropriate. The verbal communications that exist as part of Samoan life are a base for building respect and trust within relationships (Kolone-Collins, 2010, p. 34).

While Kolone-Collins is a fluent speaker of the Samoan language, and conducted her interviews in Samoan, the methodology can be used successfully by non-Samoan speakers, as shown in research conducted by Bridget O'Reagan (2006). It was essential for O'Reagan to devote a great deal of time to relationship building, and to the development of her understanding of cultural protocols.

5.6 Application to research

In the embryonic stages of research design, significant consideration was given to what methodological approach would most appropriately achieve the research objectives.

In selecting an appropriate research methodology for this research, an investigation into other available Pacific research was conducted. Three other methods were examined, alongside the *Talanoa* research methodology. They were the Kaupapa Maori Approach (Bishop, 2005), *Fa'afaletui* (McCarthy et al., 2011), and *Fonofale* (Pulotu-Endemann, 2009). Each of these methodologies rely on a process of *Talanoaga*. The *Talanoa* research methodology was ultimately selected as it provided for a broader application of findings. Both *Fa'afaletui* and *Fonofale* were designed for use within the health sector. The Kaupapa approach was designed specifically for research conducted with Aotearoa Maori communities. In its entirety, the *Fonofale* method was not applicable to this research, but as shown in Figure 7,



the foundation of the research design incorporates fundamental cultural perspectives that have been incorporated into this research.

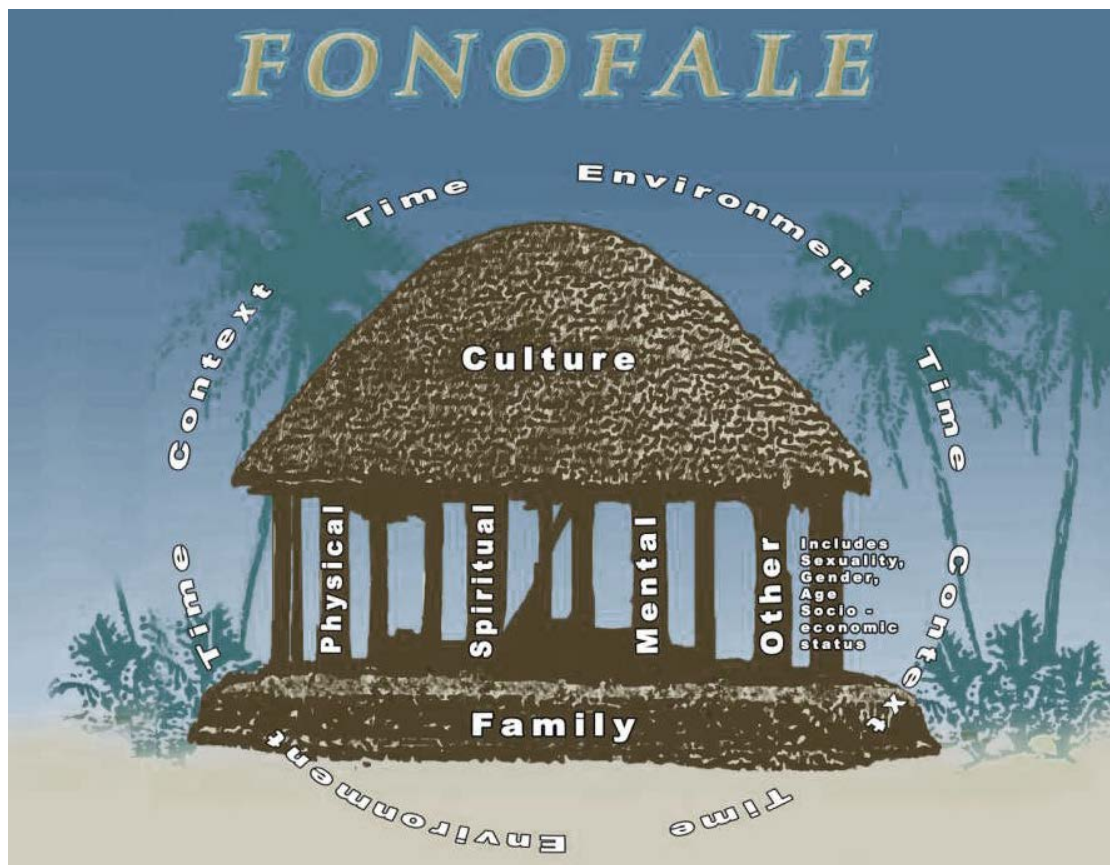


Figure 7. Fonofale research method (Pulotu-Endemann, 2009)

5.7 Procedures

In conducting *Talanoa* research, observing cultural protocol is highly valuable. It is important to take into consideration several guidelines when designing and implementing *Talanoa* research. The guidelines are depicted in Table 6.

Table 6. Cultural considerations for designing *Talanoa* procedures

Context	Protocol	Guideline
Flexibility	No single model of <i>Talanoa</i> is appropriate in all situations.	<i>Talanoa</i> can occur in various contexts and through a variety of modes.
Cultural Awareness	Being responsive to cultural concepts and ascribed powers.	Recognition of social (reciprocity, obligation, collaboration) and hierarchical structures (rank, title, status).
Relationships	Development of relationships.	A commitment to developing personal relationships with host communities. This potentially involves residing in a village and participating in village activities.

5.8 Research sample

5.8.1 Purposive sampling

Purposive sampling was the most effective means of recruiting participants for this research. The questions that form the basis of this research are specific to Samoans with disability. Insight into disability perception was critical in determining an accurate picture of how Samoans with disability interact within families, communities, and society. The selection of participants required significant consideration around how and where each person was located within the research field. The initial sample was determined according to criteria that would elicit the most accurate depiction of perception and experience of disability in Samoa. Selected participants were required to meet the criteria that they be:

- of Samoan descent;
- embedded in Samoan cultural practice;
- located in Samoa and live with extended family members;

- a close or extended family member of a person who has a significant physical or intellectual disability, or;
- self-identified as a person with disability, or;
- employed within the disability sector, and
- able to provide opportunistic pathways to other participants.

Purposive sampling was the initial method of recruitment. Opportunistic sampling, or snowball sampling, was anticipated as the next tier of sampling through the wide and varied family and social networks of initial participants. This approach enabled flexibility and on-the-spot decision making about groups and individuals in determining future participants.

The sample (see Table 7) was made of three groups: family members with direct carer responsibilities for people with disability (referred to in the results as ‘carer, family member’), people with disability (referred to in the results as ‘person with disability’), and extended family members without disability (referred to in the results as ‘family member’).



Table 7. Participant sample distribution

Participant	Carer, family member	Person with disability	Family member	Disability sector stakeholders
1			✓	
2			✓	
3			✓	
4			✓	
5		✓		
6		✓		
7		✓		
8			✓	
9	✓			
10			✓	
11	✓			
12			✓	
13			✓	
14	✓			
15		✓		
16	✓			
17		✓		
18				✓
19				✓
20				✓
21				✓
22				✓
23				✓
24				✓
25				✓
26				✓
27				✓
28				✓
29				✓
30			✓	
	4	5	9	12

The first group (carer, family member), were all women ranging in age from 27 to 65+. Most participants in the (carer, family member) group were mothers, although one participant was a daughter of a person with disability. Some of the (carer, family member) participants resided in the village where I was staying, and some were part of the snowball sample, residing in other villages in the Apia urban area. Of the participants with disability (person with disability), only two lived in my host village.

Both of these participants had a physical disability. The other (person with disability) participants were part of the snowball sample. The (person with disability) participants ranged in age from 21 to 65+ and the sample was made up of both males and females. The other (person with disability) participants were vision impaired. Participants from the extended family member group (family member) were all recruited from the initial sample. The (family member) group all resided in the host village. There was an equal proportion of males and females in the (family member) group. Extended family members ranged in age from 24 to 65+. The (family member) group consisted of brothers, sisters, aunts, uncles, and cousins. The (disability sector stakeholder) group was exclusively recruited through a snowball sample that made use of my own established networks, as well as the networks of my participants. The participants in (disability sector stakeholder) group were aged from 21 to 65+. All of these participants either worked within the disability sector, or were studying a Certificate III in Disability Studies through APTC. The (disability sector stakeholder) group were both males and females.

5.8.2 Snowball sampling

Participants who adequately matched the recruitment criteria were asked to refer me to other participants who also matched the criteria, and who would be “information-rich cases” (Merriam, 2009). The snowball approach can be employed very successfully where it is difficult to access appropriate respondents (Fossey et al., 2002). Va’a (2011) employed this method of sampling in his study on Samoan migration in Sydney.



There is indication that a hidden population of people with disability exists in Samoa (Ministry of Women Community and Social Development, 2009). Facilitating the networks of existing participants, I was able to effectively utilise a snowball sampling method to access participants who met the recruitment criteria (see Figure 8).

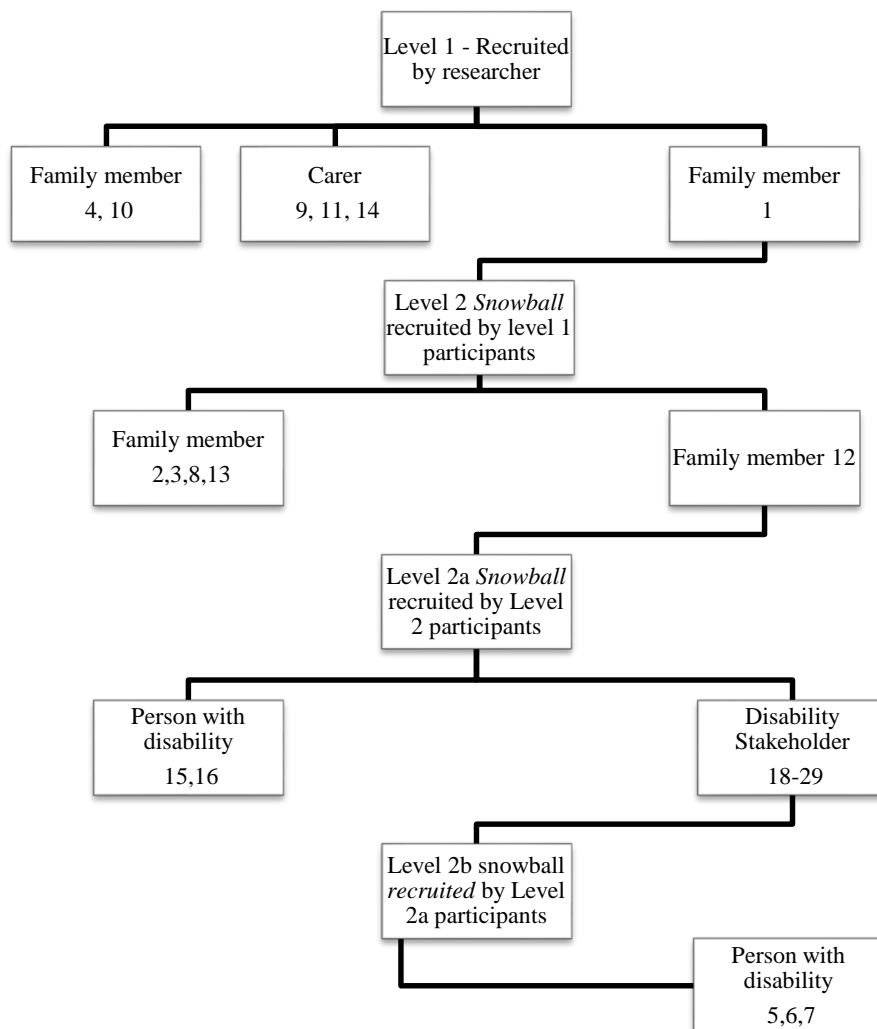


Figure 8. Snowball sampling method

The snowball sample incorporated networks and contacts of participants, as well as established networks through my teaching role in Samoa. All members of the snowball sample met the criteria of the initial sample, with the additional criteria of

being able to provide expert knowledge on policy development and national initiatives in relation to disability.

5.9 Research design

Qualitative research leads to a development of understanding about lived experiences (Fossey et al., 2002; Merriam, 2009). A qualitative researcher is interested in interpretation of experiences; how people construct their lived realities and what meaning they attach to these experiences. An interpretive paradigm aims to understand and describe the construction of social meaning derived from language, culture, and daily experiences (Fossey et al., 2002). According to Merriam, interpretive researchers “assume that reality is socially constructed, that is there is no single observable reality. Rather there are multiple realities, or interpretations of a single event” (2009, p. 8).

Like phenomenology, the *Talanoa* research methodology seeks to understand phenomenon from within lived experiences. At the core of understanding phenomenon is the researcher’s commitment to representing perspectives of participants. It is essential that the researcher does not find the answers he or she seeks, but that a process of co-construction is undertaken (Merriam, 2009). Within phenomenology, three types of data collection are common; focus groups, interviewing, and participant observation. For the *Talanoa* methodology, it is unstructured conversations, both individually and within focus groups, that form the basis of data collection. It is essential to the authenticity and validity of *Talanoaga* that the conversations are not conducted as formal question and answer session as this does not respond to cultural protocol. However, a more formal focus group, with a



guided topic approach that has been developed in conjunction with participants can be a useful and appropriate data collection technique. This is a strength of phenomenological research, and in turn *Talanoa*, as it is designed to be flexible. Conducting research in this way enables the researcher to observe non-verbal communications, make immediate clarifications of topic content, and be able to explore participants responses more fully (Merriam, 2009).

The flexibility of *Talanoa* allows the researcher to collaborate with participants at a foundational level, ensuring the results reflect the social context. This co-construction between researcher and participants builds openness; honesty and authenticity (Fossey et al 2002). Participants feel their perspectives have been represented accurately and fairly. The gifting of the research marks respect for cultural protocol and is an opportunity for the researcher to demonstrate reciprocity to participants.

5.10 Methods of data collection

5.10.1 Relationship building

My first field trip to Samoa in 2012 was the culmination of two years of planning in preparation for data collection. I had been invited to live in the village of my participants with my then three-year-old son. One of my contributions to my host *aiga* was to volunteer time at the village preschool where lessons were conducted in Samoan. Over the period of three months, I worked at the preschool daily. This provided invaluable opportunities to network with other community members and to develop my Samoan identity. This was intrinsic to gaining access and acceptance within the family and community. Through my work at the preschool opportunistic



pathways presented themselves to recruit additional participants. The hospitality of my host village provided an excellent basis for me to develop relationships necessary for effective *Talanoaga*. I was given opportunities to share experiences as one of the family. I was expected to contribute, collaborate, and to reciprocate, further developing an authentic Samoan identity for both my son and myself. In return, we received inclusion, respect, and love. I had many opportunities to conduct scheduled meetings as well as informal *Talanoaga* that helped to build a profile of participants. I gained insightful knowledge of cultural practices and beliefs around disability. There were also occasions of observation that assisted in developing a frame of culture, identity, and disability.

The development of relationships with participants provided opportunistic pathways to other people who met the recruitment criteria. These included government officials, representatives of NGOs, and educators. The rich and extensive sample represents varied sections of Samoan society.

I travelled to Samoa again in 2013 to present initial research findings to my participants. I also continued *Talanoaga* sessions to gain clarification on aspects of the findings. I maintained close relationships with my participants and my initial research findings were well received. Participants were particularly interested in initial findings that highlighted the existence of multiple conceptualisations of disability. There was also considerable interest in themes that explored concepts of policy and culture. This process of re-visiting the participants provided opportunity to receive invaluable feedback, critiques, and confirmation of findings in preparation for a re-coding phase of data analysis.



5.10.2 Individual interviewing

Individual interviews (in the form of *Talanoaga*) played an important role in data collection. These opportunistic conversations with participants provided the scope to reveal rich data about cultural conceptualisations. It is widely recognised by Pacific people that *Talanoaga* is an effective tool for gaining and sharing knowledge, as well as developing and maintaining relationships. In his descriptions of the various types of *Talanoaga* (as shown previously in Figure 6), Vaoleti (2011) highlights that incidental conversations are often an excellent source of information sharing and gathering, building upon cultural protocol as space is created for collaborative knowledge development.

Prior to conducting individual interviews, permission was sought and gained from the village *matai*. He approached participants to request verbal consent prior to seeking formal, written consent. This was an essential part of observing cultural protocol and validating myself as a responsive researcher. Participants were then approached to arrange a time for *Talanoaga* that suited the participant's schedule (often in the evening after village contributions and prayer time had been observed). The collection of data through individual interviews required a high commitment of time. *Talanoaga* sometimes took hours, or was conducted over a series of sessions.

The *Talanoaga* had to be very flexible both in terms of procedure and time. This was largely driven by the participants' willingness to give their time, and their openness to discussion. *Talanoaga* was frequently conducted in a one-on-one scenario. Occasionally small family groups were interviewed simultaneously, facilitating opportunities for families to learn more about each others' perspectives, providing a unique insight into family roles, perceptions and communications.



5.10.3 Focus group interviewing

Part of the snowball sample consisted of a group of students undertaking a Certificate III in Disability Studies through APTC. The students were predominantly Samoan with personal and professional connections to the field of disability. Due to the significant number of student participants, these interviews were conducted in a focus group interview setting. Participants imparted their own ideas and opinions, while group discussion resulted in a consensus of beliefs and practices. Research conducted in Samoa by Tamasese (2005) utilised a *Talanoa* approach, selecting leaders of each focus group who would then attend an additional meeting to share and debate what was discussed in each meeting. I also employed this technique in order to gain the most uniform insight. Having transcribed the interviews, I asked participants to correct or clarify aspects of the data. After initial coding, I revisited selected participants who had been nominated as group leaders to assess the codes and themes in preparation for a re-coding phase.

5.10.4 Participant observation

Field notes derived from participant observation have been used in this research to add to the data generated during *Talanoaga* interviews. During *Talanoaga* sessions, I was able to discuss and clarify my observations with participants.

Having the opportunity to share time and experiences with my participants provided me with a unique opportunity for acceptance and inclusion. Schostak (2010) describes the value of participant observation in research highlighting cultural immersion, stating:



To know the world of others – to understand a particular group – involves joining them in some way, being with people in their everyday locations and activities, and learning how to do what they do in the ways that they do it in the locations where they do it (2010, p. 443).

Derek Freeman, a New Zealand-born anthropologist who spent several years in Samoa depicted his experiences of village life. He had bestowed upon him a chiefly title as a result of relationships that he developed and nurtured (Freeman, 1983). Other Australian researchers, such as O'Reagan (2006) and Gough (2009) had similar experiences of being embraced by participants. O'Reagan remarked, "I was truly welcomed into their lives and treated as a member of the family" (2006, p. 1). Gough stated "...to the many Samoans who generously shared their stories with me – your openness inspires me" (2009, p. xxi). These comments speak of the way in which Samoans embrace outsiders who show respect for their culture. My own experience confirms the warmth and hospitality of the Samoan participants involved in this research.

5.11 Methods for data analysis and synthesis

5.11.1 Coding

Unlike quantitative research, data reduction did not occur in the handling of data throughout the analysis phase of this research. Value and insight lay in the abundance of data. A process of data transformation ensured rigour throughout the coding phases. This process, described by Richards (2005), entailed transforming data through coding, theme development, and analysis. Richards suggests a three-level



coding process to arrive at a detailed understanding of the data in preparation for general theory development. The three-level process includes descriptive coding, topic coding, and analytical coding. The aim of this is to transform the data through an organisational and effective data storage phase, a data sorting phase, and finally an analysis phase determining the relevance and meaning of data. Richards states, “qualitative coding is about data retention. The goal is to learn from the data, to keep revisiting data extracts until you see and understand patterns and explanations” (Richards, 2005, p. 94).

From early coding and identification of themes, a codebook was established to guide future coding. The codebook provided detailed descriptions of codes, criteria of inclusion and exclusion, and real text exemplars for each theme (Ryan & Bernard, 2000). The codebook was a perpetual work in progress as categories were refined. This facilitated purposeful data analysis while ensuring uniformity in data coding. Excerpts from the codebook are featured in Table 8.



Table 8. Excerpts from the codebook

Code	Working definition	Full definition	Example passage
Acceptance	The acceptance of people with disability either in the family or in society.	The perspectives of the level of acceptance of people with disability within families and within broader society. Inclusion in family and societal activities is a component of acceptance.	<i>So we accept whatever, we accept him whatever he has done, or the way he play so we accept him and then we understand him what his condition is.</i> (Family member)
Explanations	The descriptions or reasons given to describe disability.	The ways in which people describe or explain disability. This may be religious, superstitious, moral, medical, social, or cultural and may be sympathetic, empathetic, or pitiful, or understanding, accepting, or knowledgeable.	<i>Some people give birth and the baby is blind. Some people think of what the Bible says, when your parents do something bad when the woman is carrying the baby, then the child is blind. It's a punishment.</i> (Person with disability)
Language	The terminology and discourse used to describe disability.	Any term that is used within the context of disability to either describe a disability or to create a shared understanding of disability.	<i>The term 'mentally retarded' is used in some policy and legislation. In Samoa, there are no specific terms in Samoan.</i> (ID)
Western influences	Non-traditional influences that have changed, adapted or influenced society.	Influences from non-Pacific countries that have changed, adapted, or influenced society. Changes may be attitudinal, behavioural, political, practical, cultural, or societal.	<i>As Samoans, we can study and try to make others aware of western attitudes towards people with disability through human rights and showing people the value of the person as an individual and that they have self-worth.</i> (Person with disability)

5.11.2 Data analysis

A more in-depth analysis occurred through a data storing, data sorting, and preliminary code analysis phase. The data analysis phase complemented a hermeneutic perspective where the construction of reality came from the participants'

experiences. Using a general inductive approach, the data was analysed to develop theory where themes emerged from the perspectives and experiences of participants.

During data collection it was necessary to take an adaptable approach to interview questions to develop a theory that best represented the emic focus (Ryan & Bernard, 2000). Research questions were broad, and led to further discussions to narrow the data. Ongoing analysis was conducted throughout data collection. I transcribed, open coded and refined the data collection tools in preparation for follow-up interviews. This enabled clarification and continued theory development.

A general inductive approach to data analysis facilitated the development of themes. These themes became the foundation of theory development. The data generated multiple realities reflecting the viewpoints and experiences of the participants. Through this process of data analysis, it was necessary to apply validation techniques to ensure theory development was in accordance with the intended meaning of the participants.

A three-phase process was utilised in the development of a theoretical understanding using the participants' views to build codes, themes, and ultimately theories. Maxwell (2013) proposes three phases of analysis which refine raw data through analysis, and ultimately to theory development (see Figure 9).



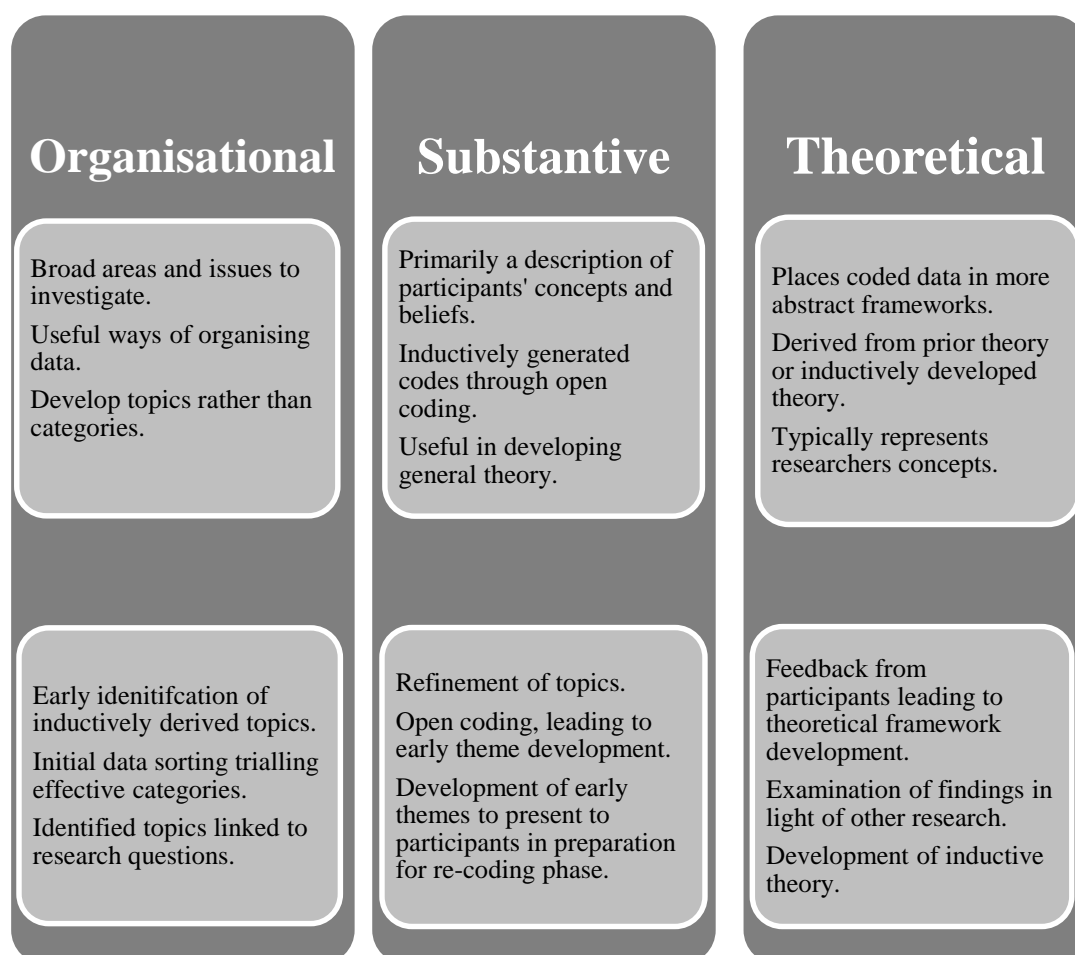


Figure 9. Process of data analysis (adapted from Maxwell, 2013)

5.12 Validating the data

There were valuable opportunities to validate the data throughout the phase of enquiry. Validations were achieved through member checking. *Talanoaga* sessions provided extensive opportunities for instant clarification with participants. Initial coding and analysis phases generated findings that were subsequently summarised and presented to participants for the purpose of clarification.

The data collected for this research was rich and extensive. A codebook ensured that data coding and theme development were consistent. My supervisory team provided feedback on coding. This critiquing transformed the data from a series of quotes to a

developed theory. These findings were presented to my participants for member validation.

The initial organisational coding phase of the *Talanoa* interviews developed several key themes. The key themes were discussed with participants, facilitating the development of the broad themes. The identified themes represent aspects of each research question (a sample of the organisational themes are depicted in excerpts of the codebook, previously shown in Table 8).

Utilising member checking throughout the theme development phase assisted in theoretical development. Participants were able to provide feedback on cultural understanding, the depiction of ideas and beliefs, and the space between emerging ideas and theory. In some instances, participants were asked to reflect on verbatim interviews and in other instances participants were selected for follow-up interviews to clarify codes, themes, and theory. Member checking was not only a reliable way to validate the data, it also provided an invaluable opportunity to re-visit participants. The invitation to further collaborate provided reassurance that the research was being culturally embedded and that the outcomes would provide a framework for future development for people with disability in Samoa. An essential aspect of effective research with Samoans is that the researcher acknowledges that the research is a *mea'alofo* (gift) to participants, as opposed to a means to a personal gain. This is the *luva* of the research (Thaman, 1988). From this, it is essential that participants be included in every aspect of research, from design to dissemination of results. It was essential that participants were continuously consulted to ensure that meaning was accurately constructed.



The substantive phase of analysis transformed the broad topics into themes. At this point of analysis, the themes linked back to the research questions. The participants were invited to provide feedback during the substantive phase, enabling necessary recoding and further refinement of themes.

5.13 Ethical considerations

This research was supported by the disability community in Samoa as well as my host community. In particular, Tino Tiufea, a Samoan *matai* of the village of Taufusi, provided support for this project from its inception. Tino, a Samoan-born *matai*, had been employed as the Educational Coordinator for the Samoan Advisory Council in New South Wales where he resided for six years. He also held positions within Disability Services with the Department of Community Services in NSW, assisting young people with disability. Tino had significant input into the Learning and Homework centres established and run by Professor Mike Horsley in various venues throughout Sydney over a ten-year period. These learning centres catered for Samoan, Tongan, and Niuean students to establish positive relationships between formal education settings and students and parents. Tino acted as cultural advisor as well as providing language support during data collection.

Sadly, Tino died in January 2014. His contributions to this research were intrinsic to the collection and analysis of the data. During my 2013 field trip Tino was unable to provide support as cultural advisor. Momoe Malietoa von Reiche provided cultural and language support for me for the remainder of the research. Momoe, a well-known Samoan artist and academic allowed me to stay with her and her family on my field trip in 2013. I have known Momoe for many years and she has provided both cultural



and academic advice to me throughout my research journey. In her role as cultural advisor, Momoe has provided extensive translation services. She is a NAATI-certified (National Accreditation Authority for Translators and Interpreters) translator. She has also liaised with stakeholder groups to establish professional networks for this research. Her input in this research has been invaluable for its cultural authenticity.

This research was granted ethical clearance from the Human Research Ethics Committee at CQUniversity in July 2012. Gaining formal ethical clearance was only one part of obtaining ethical approval. Navigating cultural ethical considerations and seeking approval from village *matai* was essential to my acceptance into the village, and in the recruitment of participants. Cultural ethical clearance was required to validate my research. Cultural consent was given orally from the village *matai*, permitting me to approach participants within the village. A meeting had been held prior to my arrival to inform potential participants of the purpose of the research, the proposed outcomes, and the expectations of participants in choosing to participate in the research. Upon approaching participants, I first obtained oral consent followed by a request to sign formal consent forms approved by the Human Research Ethics Committee. Living alongside many of my participants facilitated ease of clarification about the research and their role within it.

The *Talanoaga* sessions conducted for this research were predominantly conducted in English. On a couple of occasions, a translator was required. My cultural advisors were able to provide language and translation support, either by accompanying me to interviews, suggesting a suitable translator, or translating audio transcripts. Both of my cultural advisors, Tino and Momoe, provided opportunities to debrief after each



Talanoaga session to clarify content, to assist with providing knowledge and advice on culture, and in the translation and explanation of language.

Ensuring confidentiality and anonymity of the participants was of great importance. Providing a sense of protection enabled participants to reveal sensitive information during interviews. In focus group scenarios, the need for confidentiality among participants was discussed. This idea was reinforced by *matai* or group leaders. It was also discussed with my cultural advisors, particularly during translated sessions.

5.14 Conclusion

The *Talanoa* methodology has provided the scope for this research at every level of development. The concept of *Talanoa* has provided a fundamental framework to ensure the results of this research reflect the views of participants. Within the framework of *Talanoa*, and more broadly through the lens of Samoan culture, I was able to build strong relationships with the participants. This brought a high level of validity to the results. The richness of data generated from this research is an indicator of the success of the application of *Talanoa*, despite my outsider status. The relationships that were secured throughout the duration of this research have facilitated a sound basis for continued research into disability in Samoa. Through ongoing collaboration with participants, the findings of this research reflect the views and experiences of people with disability in Samoa. In Chapter 6 the findings are reported, and they are further discussed in Chapter 7.



Chapter 6: Findings

6.1 Introduction

This research has sought to answer four main research questions (detailed in Chapter 1, and in each part of this chapter). The findings for this research are thematically presented in this chapter. The research questions will be explored in four parts under the broad headings “Conceptualisations of disability in Samoan society”, “Cultural conceptualisations of inclusion”, “Terminology and discourse”, and “Perceptions of western influences”. Each part explores the concepts of a group of themes represented in the data.

6.2 Part 1: Conceptualisations of disability in Samoan society

One of the most significant barriers to inclusion and acceptance of disability in Samoa is the lack of congruency in the perception of disability. This creates issues of a lack of shared understanding and stigmatising attitudes. Part 1 of this chapter will examine the varied explanations of disability present in Samoan society to construct a frame of disability conceptualisations. These will be represented through established disability models, and by examining how these models interact in contemporary Samoan society. Part 1 will also explore how attitudes towards disability have facilitated stigmatising attitudes, incorporating aspects of the *fā’aSāmoa* and traditional spiritual beliefs. The themes from Part 1 and their links to the research questions are presented in Table 9 and provide a structure for Part 1.



Table 9. Theoretical theme development: Part 1

Part 1: Conceptualisations of disability in Samoan society		
Research question	Theoretical themes	Sub-themes
Question 1: How is disability conceptualised from a traditional Samoan epistemological frame?	Explanations of disability	Moral model
		Medical model
		Social model
	Stigmatising attitudes	Curses
		Shame and blame
		Pity
	Positive perceptions of disability	

6.2.1 Explanations of disability

The conceptualisation of disability from a Samoan cultural standpoint is at the core of this research. This section examines cultural perceptions and explanations of disability and how they fit into established models of disability conceptualisation. It has been identified through this research that disability perception is very much an evolving concept reflecting diverse beliefs and practices. Drawing on three predominant models of disability (moral, medical, and social disability models which are discussed in more depth in Chapter 4), this section explores how disability is represented and perceived from a Samoan cultural standpoint.

6.2.1.1 *Moral model*

The moral model of disability (sometimes referred to as the religious model) is a paradigm of viewing disability within the frame of spirituality. The data revealed that a religious philosophy towards disability is a feature of disability perception in

Samoa. The data highlighted that within a moral disability model, some participants viewed disability as a blessing and as an opportunity to witness the power of God.

Christian families value disability, our belief shows how marvellous thy God can be. Having a child with a disability is not a curse, but it is a blessing. It is a blessing. Coming from my own point of view as a mother with a daughter with a disability, that's my perception of my child. It's a gift. It's a gift. (Carer, family member)

Translated as:

O 'āiga kerisiano e faatāua mana'oga faapitoa, o le mātou talitonuga e faaalua ai le matuā matagofie o le Atua. O le iai o sa'u tama e iai ni mana'oga faapitoa e lē se mala, a'o se faamanuiaga. O se faamanuiaga. O la'u vaaiga lea faaletinā e iai sana tama teine ma ni mana'oga faapitoa; o la'u vaaiga loloto lea i la'u tama. O se meaalofoa. O se meaalofoa. (Tausi ma'i, sui o le aiga)

I feel that I have been blessed beyond measure. I have given beyond measure and I have given up my business life, my home because of taking care of (child), financially I have been depleted, but the blessing surmounts all of that. I think part of that is my family, my children, I have taught them something that not many people get to learn. Giving of myself over and above and being blessed in return and not looking at the limitations but stepping outside of yourself to help someone outside of your family. (Carer, family member)

After the operation, I had no pain. I rely on God. He heals me. He told me that it was the right thing to do. God loves me; he takes care of me when my feet were cut off. Many people wondered why I had both of my legs off in one day. Other men and women who had just one leg off were screaming in pain, but God looked after me because I asked for help. (Person with disability)

These participant comments are reflective of a moral disability model, and are aligned with aspects of the *fa'aSāmoa* that emphasise love, protection, kinship connections,

and spirituality. For these participants, viewing disability through a moral model lens provides an opportunity to develop and maintain a spiritual identity and to secure a positive relationship with God. For highly religious participants, care of people with disability fosters positive religious connections.

While several participants reported positive connotations attached to religious perspectives of disability, many other participants revealed more negative perceptions of disability associated with concepts of sin, punishments, and curses. This will be examined in detail later in this chapter.

6.2.1.2 *Medical models*

It has been reported that the medical model of disability has been the philosophical paradigm on which much of Samoan disability policy is based (Ministry of Women Community and Social Development, 2009; R Tufue-Dolgoy, 2010). The data from this research indicated that this belief is still very much at the core of conceptualisations of disability in Samoa. When asked how Samoans perceive disability one participant responded:

People always thought evil, everything started from evil. For example, before when (daughter) was sick we thought it was evil, and it was the demon or spirit but we finally got the answer that it was the veins, but before we just thought it was evil spirits. That's what people thought before, it was a curse, but when Christianity came now they're strong in their faith and they don't think anything like that, they know it's just a sickness. (Family member)

Translated as:

O tagata sã māfaufau leaga i taimi 'uma, o mea 'uma na 'āmata mai le leaga. O le faata'ita'iga, ina 'ua ma'i (tama teine) sã mātou faapea o se mala, o le tēmoni, poo se agaga, 'ae maua a'e le tali o nēula; 'ae

muamua lava na faapea o ni agaga leaga. Na faapenā māfaufauga o tagata anamua e faapea o le mala, ‘ae ina ua oo mai le faakerisiano ua mālosi lo lātou faatuatua, ma ua lē toe manatu ai faapenā, ua lātou iloina ua nā ose ma’i. (Sui o le ‘āiga)

The shift in the development of disability conceptualisation from moral to medical paradigms is strongly indicated in this data. It suggests that a medical model perception is considered progressive. One participant described the fundamental difference between the conceptualisation of disability from medical and social standpoints:

Whenever I heard someone in my village call my daughter *ma’i* (sickness), I say you know there is a difference between *ma’i* and disability. *Ma’i* there is a cure, disability you can only give support in the way that they need. It’s a medical term, *ma’i* is a medical term that discourages, it discourages a child with a disability, it is the end of the light, can’t do anything, won’t be able to do anything, and their disability stops them from doing things. That’s a medical description. (Carer, family member)

The idea that disability is considered a sickness has initiated a societal response that incorporates many aspects of the *fa’aSāmoa*. Concepts of love and protection are central to the prosperity of *aiga* groups and ultimately the collective identity. However, viewing disability as a sickness encompasses other beliefs that reduce the value of contributions that people with disability can make to their family and society. This problematises the ability to develop a positive cultural identity within the *fa’aSāmoa*.



6.2.1.3 *Social models*

The data from this research indicates that Samoan society is still very much in an ideological transition phase regarding disability conceptualisation. Incongruent understanding and perception around disability still exists. Participants of this research who either provide home-based care for a family member with a disability, who have a disability, or who study or are employed in the disability sector, perceived disability from a social model paradigm.

I wouldn't say my mother is sick; she's got a disability. She can't walk. My dad is sick. He has cancer. That's the difference between disability and sick. (Carer, family member)

It's not the same now. People know everyone has rights and there is equality. (Disability sector stakeholder)

Translated as:

Ua lē toe *tutusa* nei taimi. Ua iloa e tagata e iai aiā tataua a tagata 'uma ma ua aiā *tutusa* fo'i. (Sui o le vaega o mana'oga faapitoa)

The biggest barrier is people's attitudes towards people with disabilities. They don't consider them. What we're hoping is that they give them some emphasis on people with disabilities that they would give to any other sector of the community. The elderly, yes they value elderly, women, yes they value women. That sort of mentality should be extended to people with disabilities. With the *ma'i* thing, (the thinking is) give them a thing full of money and they'll be happy. It's not just a handout for one, you need people to respect and value you as a human being as an ongoing thing. (Person with disability)

This group of participants recognised the value of people with disability and the contributions they make. For identity development, it is of great relevance that Samoans can contribute to their *aiga* and that the contribution is seen as valuable.



From the data, three main cultural perceptions about the impact or experience of disability emerged that challenge the acceptance of a social disability model. The three perceptions that, in part, make up a Samoan conceptualisation of disability are: belief in curses, concepts of shame and blame, and attitudes of pity. These three perceptions contribute to stigmatising attitudes and have contributed to the restriction of people with disability engaging with broader society.

6.2.2 Stigmatising attitudes

The research data indicated that a significant barrier to societal inclusion was negative attitudes about disability. When asked about attitudes towards people with disability, some participants reported negative attitudes:

Families don't want to talk about disabled; families don't know what to do to consider the rights of the disabled. (Disability sector stakeholder)

Translated as:

O 'āiga e lē fia *Talanoa* e uiga i mana'oga faapitoa. E lē iloa e 'āiga poo leā le mea e fai e faatatau i aiā tataua a ē e iai mana'oga faapitoa. (Sui o le vaega o mana'oga faapitoa)

We need to work on changing the mentality of people towards people with disabilities. Some other families have branded their child with disability. (Carer, family member)

I think when children call people who are blind names, they are not to blame. They are young; they have limited exposure to people with disabilities. A child wouldn't approach a person with a disability. There is a need for more awareness and exposure of people with disabilities. (Person with disability)



It's challenging to change attitudes. People look at disability differently. We have to work on attitudes and how legislation can help us to move forward. (Person with disability)

The attitudes of the general community vary for different disabilities.
(Person with disability)

Negative societal attitudes were not the only barrier to equality. One participant reported that one barrier to cultural inclusion is in the promotion of disability and the special treatment that they may attract:

She's (niece) not only lazy, but she's taking advantage of her disability. She takes advantage of her disability so that she can get things that she wants. (Family member)

Translated as:

O lo'u (niece) e le gata i le paiē, ae nate faaaogāina fo'i ona mana'oga faapitoa. Na te faaaogāina ona mana'oga faapitoa e maua ai mea e mana'o ai. (Sui o le 'āiga)

Within the framework of the *fa'aSāmoa*, reciprocity is a necessary component of collective living. This participant saw the promotion of disability as a means to extricate oneself from the responsibility of contribution and reciprocity, and disrespecting the natural order of hierarchies, status, service, and respectful relationships.

6.2.2.1 Concepts of curses

All participants of this research acknowledged that curses were a primary means of understanding disability in Samoa, however many participants denounced this conceptualisation. Nonetheless, the data revealed a pervasive cultural belief that disability results from curses. The essence of the belief is that a child with disability



is delivered as a punishment to parents who have committed a moral or criminal wrongdoing.

The popular belief that babies that are deformed are cursed. It is explained by suggesting that the parents had done something wrong.
(Disability sector stakeholder)

Some people say it's a curse, but some people don't say that. I've heard if you do something bad your baby will be disabled. But I don't believe that. (Carer, family member)

Translated as:

E iai tagata e fai mai o le mala, ae iai fo'i isi e lē fai mai faapenā. Na 'ou faalogo e faapea 'ā 'ē faia se mea leaga e lē atoatoa le malosi o le tino o lau pepe. (Tausi ma'i, sui o le 'āiga)

Some people give birth and the baby is blind. Some people think of what the Bible says, when your parents do something bad when the woman is carrying the baby, then the child is blind. They think that's what she gets when she doesn't do the right thing to a *matai* or a pastor. If you hide something from the *matai* or from your family that's what you get. It's a punishment. (Person with disability)

Stories of people with disability resulting from curses have become something of folk legend in Samoan society. When participants were asked about curses, many incidents of disability were related to animals, ostensibly resulting in the person with a disability taking on features of different animals.

The story of the curse, they say that when the mother was pregnant the father found a cat eating food off the dining table. He threw the cat into boiling water, so the girl was born looking like a skinned cat. Her parents hid her; I found her cowering in a church. (Carer, family member)

Translated as:

O le tala i le mala, fai mai 'a'o tō le tinā na maua atu e le tamā le pusi o soa'ai mea'ai i luga o le laulau. Na tago loa togi le pusi i totonu o le 'ulo vaivela, ma na fānau mai le teine ua fōliga pei o se pusi ua leai se pa'u. Na nanā e ona mātua; oute maua atu o lafi i totonu o le falesā. (Tausi ma'i, sui o le aiga)

Samoans don't believe in curses unless someone confesses themselves, that's when they'd believe it, like in the case of Penina. Also there is a couple, they were looking after church things, and they sold the things. They would never tell the truth about it, and then their daughter had a pig eye, black and hairy. Then the dad confessed, so people think it is a curse. He admitted that he used to sell the pastor's pigs. I never believe in them unless people confess that they did something really wrong. (Family member)

One high profile case in Samoa of a child with disability has received extensive positive media attention in recent years. The child is referred to in this section by the pseudonym Penina. Due to exhaustive and unrelenting efforts on the part of the child's carers, this particular child has become a much-loved and included member of Samoan society, despite many still believing that the child's disability is the result of a curse. When asked about the Samoan perception of Penina, participants responded:

People think disability comes from a curse if the disability is there at the time of the birth. Like Penina, she has a genetic disfigurement; people still think the parents ate the pastor's pig. (Person with disability)

The popular story about Penina is that her parents stole the pastor's pig – as a curse Penina was born to look like a pig. (Disability sector stakeholder)



Translated as:

O le tala lauiloa e uiga iā Penina e faapea na gaoi e ona mātua le puaa a le faife’au – o le mala na pa’ū ia Penina na fānau mai ua fōliga i pua’a. (Sui o le vāega o mana’oga faapitoa)

In the Samoan context they say that she is a curse. She was born so disfigured. She was born with so many abnormalities. She was labelled as half-human, half-pig. She has a cleft palate, little ears, three nostrils, little slits for eyes, tiny, little head, and she did resemble a pig. She had a lump caused by the spina bifida which they said was a tail, and the story goes that in their village the father stole a pig from the pastors and the family partook of it. They had it for their meal and the pregnant mum also had part of this stolen pig. When Penina was born they said “well, that’s the curse, that’s why this child was born so disfigured, looking half human and half pig, because of the mother”. The father said he did take the pig, but they didn’t steal it. Apparently it was carved up and left in the pastor’s freezer, so he went and took what was told to be their share by the pastor’s wife. So he went and took their share of the pig and took it home and that is what they had. But that is their story, that’s Samoan superstition. (Carer, family member)

Despite a strong assertion from most participants that they themselves did not believe in curses, the data reflects that some Samoans use a moral paradigm to frame disability. The idea that disability is someone’s fault places people with disability in a position where their existence is a manifestation of a moral or criminal misdemeanour. The disability becomes the physical representation of a family’s shame.



6.2.2.2 *Shame and blame*

The medical model of disability is considered an obsolete model of disability conceptualisation in developed countries. In Samoa, in some cases, describing disability from a medical standpoint is considered progressive, compassionate, and empathetic. Participants were more accepting of medical explanations of disability, considering this perception to be progressive. When asked about the Samoan perception of disability, participants responded:

I don't feel embarrassed about my disability. It's not my fault. It's just my time to get sick. (Person with disability)

Translated as:

Oute le mā i o'u mana'oga faapitoa. E lē o sa'u mea sesē na fai. Pauā ua oo i le taimi 'oute ma'i ai. (Tagata e iai mana'oga faapitoa)

We all understand that (sister-in-law) is sick. We understand the situation. (Family member)

However, in some cases the data indicated that a medical paradigm is used to lay blame on individuals for behaviour that is perceived as resulting in disability:

Maybe if you hit the woman when she was pregnant. Or drinking or drugs, high with marijuana, and talk to (the child) while he's inside. (The child) can't understand the language. He can't understand language. (Family member)

Samoans would say his disability is a curse. We think it's because it runs in the blood from the Dad's family. We don't think it's a curse, but some Samoans do. (Family member)

Translated as:

E fai mai tagata Sāmoa o lona maua ai i mana'oga faapitoa o le mala. Mātou te manatu e iai i totonu o le toto o le 'āiga o lona tamā. Matou te lē talitonu o se mala, 'ae iai lava isi Sāmoa e talitonu iai. (Sui o le 'āiga)

The idea that an individual is at fault, or caused a disability to occur within an individual has the potential to generate attitudes of blame and shame. While this philosophy provides an alternate explanation of disability, it neither fits comfortably with the ideology of the medical model of disability, nor the concepts of the *fa'aSāmoa*.

Some participants discussed that shame was something families of people with disability may experience when outside of the immediate village environment. When asked about how families feel about having a family member with a disability, participants responded:

I personally believe that families were ashamed only when outsiders were concerned. When visitors would come into the house, they'd feel shame and make excuses. (Disability sector stakeholder)

Translated as:

O lo'u ā talitonuga faaletagata, e faato'ā maua lava 'āiga i le māasiasi pe'ā a'afia tagata mai fafo. 'Ā ō mai mālō i le fale ona mamā lea ma fai tala e pupuni ai. (Sui o le vaega o mana'oga faapitoa)

Samoans share a collective identity, so shame born by one family member is an experience of the entire family group. A participant who suggested that shame is brought upon the collective when people with disability enter public spaces raised this issue:

We are not ashamed of (niece), we are ashamed of her sitting in front of the shop. If she is sitting there all day from nine o'clock people are saying the family doesn't care. These are the things I am concerned about. (Family member)

For people with disability, entering public spaces can inadvertently attract negative attention. The data indicated that concerns exist that negative attention could result



in a reduction of status and respect. It was raised as a concern that other families could develop an opinion that obligations to family members with disability are not being upheld. The rapid development of the social model of disability in Samoa, which encourages people with disability to enter public spaces in an independent and equal way, can act as a source of shame and blame for people with disability. This is one of the ways that the social disability model is incompatible with aspects of the *fa'aSāmoa*.

The acceptance of external assistance for people with disability within villages is undermined by concepts of shame. Some participants expressed concern that external support services were not able to provide effective support to people with disability as, potentially, families felt exposed. The data reported that some families felt that allowing external support agencies to provide services or financial assistance highlighted a failing on the part of the family. Concern was also raised that outside assistance potentially identified the family as financially at risk, attracting shame and stigmatisation. When asked about support services, one participant responded:

Some families they just don't want anything to do with us. They want privacy. They feel the help we do for them stressed their incompetence, they should care for their own people. Most cases they are very appreciative of the work that we do. Samoan pride and acknowledgement of responsibility. In villages they don't want people seeing the car coming to the house and asking who was that? Why were they here? Then they have to explain. Another negative thing is that we are doing things like giving aids, wheelchairs, prams for mobility to make things easier and to help with the disability, but it's been received as us thinking they're poor and we're giving them all the attention. (Disability sector stakeholder)



I stopped a group last year. We accepted the offer to take photos, take it to get funding. But they'll say we are the poor family in Samoa. They'll promise a wheelchair, but never brought it. I'm fully aware of that program, so I said from now on I won't accept your group here. You're just taking photos to spread around the world that we are one of the poor families of Samoa, so that they will get the funding but we will never get anything. (Family member)

Families do not want negative attention brought upon their village, thus shame can act as an inhibitor to people with disability achieving equality. The risk to identity development is that people with disability must contribute to their family through maintaining a low profile, so as not to affect the status of the family group.

6.2.2.3 Pity

In recent years the MWCSO has been concerned that a welfare approach to disability was contributing to stigmatising attitudes. The data from this research supported this concern, finding that some Samoans with disability experience attitudes of pity that restrict access to equality and empowerment. One participant talked about his experience of pity attitudes:

I think Samoans take a pity attitude towards people with disability. They might overfeed them, or shelter them, keep them at home and sometimes even neglect them. It makes the disabled person dependent. (Person with disability)

Translated as:

O lo'u manatu e o'otia loto o tagata Samoa i tagata e iai mana'oga faapitoa. E pei e manana'o e so'ona fafaga, pe tausii puipua, tuu i le fale, ma e iai foi taimi e tuu lafoa'i ai. Ma e afua ai ona ola faamoemoe le tagata e iai mana'oga faapitoa. (Tagata e iai mana'oga faapitoa)

Negative pity has an impact on identity development. For example, I might take advantage of people's pity, like they might say, 'here's an ice cream'. They wouldn't normally do it but offer it because I'm blind, but I will say 'yes'. (Person with disability)

Attitudes of pity encourage overprotective behaviour, reducing access to cultural identity. The ability to contribute is a significant aspect of developing a collective identity. For people with disability this cultural norm is inhibited by an inability to demonstrate reciprocity due to a belief that disability is a sickness. It reflects poorly upon families who are seen to be accepting obligations from a person with disability. This attitude is a major inhibitor of the effective acceptance of a social disability model that sees equality and inclusion on all levels as a basic right.

6.2.3 Positive perceptions of Samoan cultural practices for people with disability

The data indicated several instances where Samoan beliefs and practices around disability were perceived as having more inherent worth or value than introduced practices. When asked about how Samoan families and society address issues around disability participants responded:

The community would also perceive the person as their responsibility as well, the community, the church, you know it's a positive thing that I reckon that we do better than overseas. Or money to help, I think that is a very positive things as well. (Person with disability)

Translated as:

O faalapotopotoga e vaai fo'i i le tagata e pei o sa lātou lava tiute vaavaaia faapea foi ma faalāpotopotoga, le 'au lotu; e te iloaina, o se mea lelei 'oute iloaina e sili atu ai tātou ai lō atunuu i fafo. E oo i tupe fesoasoani , o lo'u manatu ose mea lelei fo'i. (Tagata e iai mana'oga faapitoa)

I think if you ask some, I think one of the things we can actually do better than western is being able to mobilise communities, to have in Samoa, like if we have a disability program that we can extend to the village it is easy to have workshops and things and it's still got that unique sense of community, community togetherness, sort of thing where it is easy to deliver a message rather than just the internet, I don't know how effective that would be to transfer that into Samoan culture. (Person with disability)

This data reflects the positive attitudes and practices that Samoans bring to issues of disability. The strength of collective and collaborative relationships can promote the effective facilitation of inclusion, cultural identity development, and appropriate service provision. The collective identity can provide a secure and caring environment for people with disability. In some cases, people with disability are prioritised for care and consideration, as reported by these participants:

The Samoan way they will put them to the first priority, because they have a disability, so when we have food the people will say give the first food to the disability. (Family member)

Translated as:

I le faaSāmoa e 'ave iai le faamuamua ona e iai o lātou mana'oga faapitoa, ma 'ā iai ni mātou mea'ai, e faapea mai tagata e 'ave muamua mea'ai i ē e iai mana'oga faapitoa. (Sui o le *aiga*)

The tenets of the *fa'aSāmoa* can provide an ethos of care and protection for people with disability. For people with severe and/or multiple disabilities this environment would provide a high level of care and service provision. The shared responsibility and obligation of family members establishes an inclusive environment whereby people with disability are accepted at a family level.



6.2.4 Conclusion of Part 1

This section reported on the results of Samoan conceptualisations of disability. The data indicates that the conceptualisations of disability are currently evolving. A political push to promote disability as a social issue is still in its infancy, enabling moral and medical models of disability to be drawn on as a source for explaining disability within society. Moral and medical explanations of disability are derived from early European influences, but also from the *fa'aSāmoa*. The factors that influence perception of disability in Samoa include non-indigenous beliefs and practices, concepts of love, contribution, collective identities, and hierarchical structures. They have all played a significant role in developing moral and medical models of disability that are unique to Samoa. With increasing exposure, a social disability model is beginning to be adopted. However, promoting this ideology throughout the entirety of Samoan society is a challenging process, and one that conflicts with fundamental aspects of the *fa'aSāmoa*.

6.3 Part 2: Cultural conceptualisations of inclusion

The themes in Part 2 explore belonging and acceptance of Samoans with disability. Underpinning all of the themes represented in Part 2 are the concepts of the *fa'aSāmoa*. The theme of cultural conceptualisations of inclusion of people with disability incorporates several sub-themes, depicted in Table 10.



Table 10. Theoretical theme development: Part 2

Part 2: Conceptualisations of cultural inclusion		
Research question	Theoretical themes	Sub-themes
Question 2: Does having a disability affect identity development, concepts of belonging, and cultural inclusion?	Contribution	Obligation
		Identity
		Acceptance
		Status access
		Overcompensation
	Impact on family	
	Societal inclusion	

6.3.1 Contribution

The ability to contribute to one's *aiga* is a highly regarded trait and one that reinforces concepts of collective identity and belonging (Lui & Dowland, 2003; McCarthy et al., 2011; L. F. Va'a, 2006). Contribution within the *aiga* in a Samoan context is a mutual expectation that builds solidarity, capacity, and status. Contribution secures one's place within the *aiga* as it represents love, respect, and a desire for the *aiga* to prosper. From this perspective, an inability to contribute threatens one's ability to access collective identity and cultural inclusion. The data indicates that people with disability feel that exclusion from full contribution impacts identity and cultural inclusion:

People can be isolated by their disability. The contributions that they make can be seen as having less worth than others, but it depends on the contribution and the community. (Person with disability)

Translated as:

E faatu'i'esea tagata i ō lātou mana'oga faapitoa. O saofaga lātou te faia e lē tāua pei o saofaga a isi, ae tuu lava i le itūaiga o le saofaga ia ma le faalapopotoga. (Tagata e iai mana'oga faapitoa)

While I was strong I looked after my family. They loved me but now I am disabled. Before I was sick I was the one that did all of the things. I'd always be the first to plan everything. My family missed me when I had no feet, I couldn't go. In the Samoan way the wives are always in the kitchen, and I'm old enough so I was in charge, I'd tell them all to go. Now it's my cousin's responsibility. (Person with disability)

Contribution for Samoans is intrinsically linked to self-worth (Kolone-Collins, 2010; Seiuli, 2012). People with disability are not always expected to extensively contribute, but the data indicates that Samoans believe that some contribution is necessary to secure familial inclusion. Contribution is a means of developing a positive sense of self-worth and cultural identity.

It's disability, not inability. So despite your disability you can still contribute to your family, you can still be an active member of the family. Disability can't stop you from contributing. (Carer, family member)

He does chores, like cleaning the river, taking the rubbish, cutting the trees. He really likes doing that. He's really good at doing the chores. Those jobs are his contribution; they give him a place in the family. (Family member)

Contribution is not only the provision of money or material goods. As one participant describes, contribution encompasses any *tautua* (service) to the *aiga* that enhances prosperity.

Contribution is not just about doing work. But the better contribution is to be a role model, to change the mentality of the people. It is not just contributing in terms of money or work. (Carer, family member)



Translated as:

O le saofaga e lē nā 'o le fai o gāluega. 'A'o le saofaga e sili atu o le 'avea o le tagata e fai ma faata'ita'iga lelei ina ia sui ai māfaufauga o tagata. E lē nā 'o le saofaga e ala i tupe poo gāluega. (Tausi ma'i, sui o le 'āiga)

In the absence of the ability to contribute financially, people with disability can be relegated to a powerless position with their only available contribution being conforming to the authority of others.

If [my niece] obeys and respects, that is her contribution. If she obeys and respects then she will get a treat. (Family member)

Translated as:

'Ā usita'i (lo'u niece) ma faaaloalo, o lona sao lenā. A usita'i ma faaaloalo na te maua se meaalofo. (Sui o le *aiga*)

Conforming to concepts of expectation and respect may increase the level of acceptance and belonging that a person with disability can achieve as part of a collective identity, but has little place within a social model of disability.

6.3.1.1 Obligation

The concepts that form the Samoan construct of obligation are indicative of a reciprocal relationship within a collective identity (Kolone-Collins, 2010; Kruse-Vaai, 1998; Seiuli, 2012; L. F. Va'a, 2006). Obligation in a Samoan sense, is not resented but recognised as a contribution that secures reciprocity within a collective family environment. It is an honour to be included within the collective. The data indicated that obligation is a feature of providing care for people with disability.

To me, I didn't want to leave my job and care for my parents for the status, it's my job to do that because of what they have done for me,



and our family, but yea, sometimes I think I deserve from the family, but I can't do that. (Carer, family member)

The mother believes it is everyone's responsibility to sacrifice and help the disabled sister, as she cannot do anything. Her quality of life is diminished, and she is their sister. The family tie is very important. (Carer, family member)

Translated as:

E talitonu le tinā o le tiute vaavaaia a tagata uma le tuu o isi mea 'ae faaavanoa le taimi e fesoasoani ai i le uso/tuafafine e iai mana'oga faapitoa, ona 'ua na lē toe mafaia ona fai se mea. Ua faaifoifo fo'i lona ōlaga ma 'o ia o lo lātou uso/tuafafine. O noataga faale'āiga e tāua tele. (Tausi ma'i, sui o le 'āiga)

The concepts of reciprocity and love that exist within the *aiga* provide a framework for providing care for people with disability. Caring for a family member with disability can be an obligation that can be perceived as a celebration of the ties that bind the family together.

6.3.1.2 Identity

Constructing a group self-image for Samoans is an important process in securing cultural identity, as Kolone-Collins states “when the identity of a person is grounded firmly at an early age, the sense of belonging and pride in one's identity remains secure for life” (Kolone-Collins, 2010, p. 61). Practising respect and contribution is the foundation for achieving self- and group-worth.

Identity for Samoans is intrinsically linked to concepts of family, responsibility, and honour (Kolone-Collins, 2010; Kruse-Vaai, 1998; Seiuli, 2012; Tamasese, 2008, September 22-25; R Tufue-Dolgoy, 2010; L. F. Va'a, 2006). As one participant commented, identity and familial connection are intrinsically linked:



In the Samoan traditional sense, you are not an individual, but you carry the name of your family. If you act out it reflects on your family, it's collective. (Person with disability)

Translated as:

I le faaSāmoa e lē 'o 'oe 'o se tagata e ola to'atasi, 'ae e te tau'aveina le igoa o lou aiga. 'Ā 'ē faafitāuli e atagia ai le tou aiga, e faitele. (Tagata e iai mana'oga faapitoa)

A collective identity is a responsibility shared by all members of the *aiga* with the goal of maintaining community status, financial stability, and a network of people to provide support in times of *fa'alavelave* (Kolone-Collins, 2010; Kruse-Vaai, 1998; Seiuli, 2012; R Tufue-Dolgoy, 2010). A strong *aiga* is a united one. Each individual *aiga* member has a responsibility to the collective. The *aiga*, in turn, demonstrates reciprocity through love, protection, obligation, and inclusion within the collective. Being a part of this collective identity is a privilege that needs to be earned and maintained through appropriate conduct, contribution, and respect (Coxon, 2007; Kruse-Vaai, 1998; L. F. Va'a, 2006). Acceptance into the collective identity is not assured, but gifted to *aiga* members who have earned the right to inclusion through adhering to the concepts of the *fa'aSāmoa* and the beliefs of the community.

Developing a frame for the examination of identity development incorporated the analysis of Samoan perceptions of disability and the impact of cultural ontologies on identity development. When asked about identity and belonging, one participant responded:

It is part of the Samoan culture that they take care of their people whether they have a disability or not. So that's why it's hard for them to get their independence, but it is hard for them to even consider the person with a disability having the right to go out and be independent in the family. It is really hard for them to exercise that right within the

family environment, because there are always people that will help, take them around, feed them, do all of the things that they need to be done for them. (Person with disability)

The combination of medical model conceptualisations and concepts of the *fa'aSāmoa*, (such as love, care and protection, contribution, and hierarchical roles) facilitates an environment of forced dependence, relegating people with disability to submissive roles. Participants with disability were asked about their experience of having a disability:

If I have somewhere I want to go to but I can't go, I feel sad. I feel angry with the person who pushes the wheelchair who won't come and take me. The only thing that comes to mind when someone teases me is to hurt that person in front of me. I just want to punch them in the mouth. Sometimes they give a mean face, and not talk nice to me. Makes me feel bad. Maybe they're just joking or playing around. They make fun of me, like when they say sick, they say, 'look at that sick thing', you know, talk like that. It makes me feel bad, makes me get mad because someone is making fun of me or teasing me. I always say, 'I'm not crazy'. (Person with disability)

Translated as:

'Ā iai se mea 'oute fia alu i ai 'ae lēmafai ona 'ou alu, ona 'ou faanoanoa lea. 'Oute ita i le tagata e tūleia lo'u nofoa auā e lē sau e 'ave a'u. Pau lava le mea e oo mai iā te a'u pe 'ā faalili a'u e seisi o lo'u mana'o e faamanu'a le tagata lea i o'u luma. Na 'o lo'u mana'o lava e tu'i lona gutu. E iai taimi e pupula leaga mai ai ma fai mai tala leaga ia te a'u. Oute faanoanoa ai. 'Ai ā na 'o le toē ma tausua solo. E taufaifai mai a'u; pe 'ā fai mai ma'i, ona fai mai lea, "vaai i le mea ma'i lale," e te iloa, tala faapenā. Oute faanoanoa, oute ita ai ona e iai le tagata lā e fāifāi ma taufa'alili mai iā te a'u. O la'u ā tala, "Oute lē valea". (Tagata e iai mana'oga faapitoa)

Attitudes towards the blind motivate me but it also frustrates me. Why should I have to prove myself? People should accept me for who I am. I think people with disabilities sometimes overdo it trying to prove themselves. (Person with disability)

The views and experiences of participants with disability, as reported in the data, indicate feelings of frustration, sadness, and a sense of needing to justify their identity and disability. Social and familial perceptions and practices around disability have contributed to people with disability feeling powerless. It was reported that this affects self-esteem and personal worth. A sense of belonging for people with disability is affected by a perceived reduction in their capacity to contribute.

6.3.1.3 Acceptance

Acceptance within the family is an integral part of a collective identity for Samoans. Acceptance enables family members to carry out their responsibilities as well as be a part of reciprocal relationships that ensure concepts of security, prosperity and self-worth (Horsley, 2011; Kolone-Collins, 2010; Lui & Dowland, 2003; McCarthy et al., 2011; Seiuli, 2012). When asked about acceptance of people with disability, most participants reported that people with disability are unquestionably accepted within the *aiga*. The data revealed that the cultural beliefs regulating acceptance and contribution are sometimes modified to enable people with disability to access a collective identity.

So we accept whatever. We accept him whatever he has done, or the way he plays. So we accept him and then we understand what his condition is. (Family member)

The family give the priority to the sick people to fulfil their needs and a chance to save for anything they want, so that there is no barrier.
(Family member)

However, the important distinction between acceptance and inclusion was questioned. The data reflected that while often people with disability are fundamentally accepted by their *aiga*, they are not always fully included.

There is a difference between acceptance. Acceptance is more broad; you agree to involve them in activities, giving the person a sense of belonging. (Carer, family member)

A disabled person will be accepted by the immediate family, but will be kept hidden from broader groups such as church or guests in order to maintain status. (Disability sector stakeholder)

Translated as:

O le tagata e iai mana'oga faapitoa e taliaina e lona lava 'āiga, ae nanā mai faalāpotopotoga faalaua'itele e iai 'au lotu poo mālō asiasi ona o le tausia o le mamalu. (Sui o le vaega o mana'oga faapitoa)

The social model of disability recognises societal barriers as limitations, with the removal of barriers facilitating increased societal inclusion (Anastasiou & Kauffman, 2011; Lang, 2007). From a Samoan epistemological stance, removal of barriers can in some instances reduce an individual's capacity to access the cultural capital necessary for cultural inclusion. When asked about acceptance, some participants revealed that equal treatment, rather than barrier removal was the contributing factor to inclusion.

I've always treated my daughter with disability the same as my other children. If I want my daughter to have equal opportunity, equal access into the family, same as my other children, then I have to treat her the same. (Carer, family member)

Translated as:



‘Oute tausia lo’u afafine e iai mana’oga faapitoa e pei lava o isi o a’u tamaiti. ‘Ā ‘ou mana’o ina ia maua e lo’u afafine se avanoa e *Tutusa* ai, ma iai sona sao i totonu o lo mātou aiga, e pei o isi tamaiti, ona ‘ou tausia lea o ia e pei o isi. (Tausi ma’i, sui o le ‘āiga)

My elder sister is also blind. My parents never treated us any differently to our other siblings. (Person with disability)

We treat him the same as everyone. (Family member)

The data indicates that within a Samoan ideology, equal treatment is an important aspect of accessing and maintaining cultural identity. Equal treatment does not necessarily encompass equality or barrier removal. Equal treatment, rather than equality is seen as a means of developing a level of independence and personal strength. In some instances, full contribution is the essence of effective collective identity development and inclusion. An ideological conflict is evident between concepts of the *fa’aSāmoa* and barrier removal.

6.3.1.4 Status access

Samoan disability conceptualisations are layered with fundamental Samoan cultural beliefs and practices including hierarchy, protection, love, and pride (Kruse-Vaai, 1998; L. F. Va'a, 2006). When asked about access to chiefly titles for people with disability, participants responded:

A *matai* title in the Samoan culture is having a specific role in the village and the family so with someone with an intellectual disability they won’t be able to have a *matai* title. (Carer, family member)

A disabled person cannot be a *matai*. Being a *matai* is a very big job for the family. (Family member)

Translated as:



E lē mafai e seisi e iai ni mana’oga faapitoa ona *matai*. O le ‘avea o seisi o se *matai* o se gāluega tele lea i se ‘āiga. (Sui o le ‘āiga)

If we have a family discussion then the *matai* would walk to other families to let them know, so if the *matai* is not walking then who can go and tell. (Family member)

However, participants who supported a human rights approach to disability saw disability providing few barriers for *matai* duties. Contribution and the ability to be accountable were identified as being more significant factors in title bestowal.

If we look at it from a rights-based approach, the people with disabilities are entitled to the right to the title, but that’s what I think should happen. I don’t see any reason why people with disabilities can’t have titles but it depends on their disability and their village. There are *matai* who have disability. Within our organisation, we have 5 people who are *matai* and also have disabilities. It depends on the type of disability, and it also depends on how you contribute and how your contribution is recognised. Being a *matai* is not for everyone, being a *matai* means you are prepared to be accountable and all the responsibilities that come along with that. It needs careful consideration of their education, their contribution and their disability. The disability is not the barrier, but the person with a disability needs to consider if they are able to be accountable. (Person with disability)

I think the older people who have a disability but are active in village life have the opportunity to access titles and status. I’ve never heard of a blind *matai* though. Samoans look at your disability first, instead of looking at you. I know of a quadriplegic through an accident that is a *matai*. The family and village should view every person just as a person, not as a disabled person. They need to think “What do they need to be able to contribute?” (Person with disability)



The pervasive cultural perception that disability is an illness (discussed in Part 1 of this chapter) has resulted in a protective attitude towards people with disability. The data indicates that families avoid permitting work and community engagement of people with disability. This restriction is imposed to avoid harsh judgements from others for not providing adequate care and protection. This is not restricted only to chiefly duties, but also to activities outside of village life.

6.3.1.5 *Overcompensation and paternalism*

The roles and responsibilities of families in caring for people with disability can take the form of overcompensating behaviours and attitudes. The data revealed that families take responsibility for family members with disability out of love. However, there is also a sense of obligation to reduce the impact of societal stigmatisation, in what the MWCSA refer to as ‘the protective approach’ (Ministry of Women Community and Social Development, 2009).

I think sometimes the family can restrict their people with disability because they spoil them to the point they don't want them to go out because they're *ma'i*, they might get hurt, in the eyes of other people outside the family they are making them do all of these chores when they are sick, it all revolves around the sick thing. They are embarrassed in the village if people see them instructing their people to weed the garden or do any other chores. It happened in my family as well, some of my relatives who we don't live with, they would see Mum being hard on me about doing chores, they say they are pushing me when I am sick. (Person with disability)

[She] asked the boys to take her to the seminar, or to drive her in front of the shop so I stopped her going there. So that's what her sister is saying, "You're sick, you're not allowed to go there, or go anywhere".

It's a burden for people to take her, especially at night. That's why she was upset. *Ma'i* is supposed to stay home. She can go to Church or to the Youth meeting, good, but visiting friends, not good. Everyone is seeing her at the shop, like a nightwatchman, like the security of the shop; they see that she is disabled. Everyone is seeing her at the front. (Family member)

It was suggested that overcompensating attitudes can lead to family resentment, further reinforcing stigmatising attitudes and behaviours:

Her grandfather always took her wherever she wants. They said 'Give her what she wants'. But sometimes I don't like the way the grandparents looked after her. When they passed away no one liked her because they think she is greedy and selfish. The grandmother said to me the reason she loved her so much was because she is sick, she can't walk. (Carer, family member)

Translated as:

E 'ave lava e lona tamā matua iai soo se mea e mana'o ai. E fai mai ā lā'ua, “ ‘Ave iai soo se mea e mana'o ai.” ‘Ae iai ā isi taimi ‘oute lē fiafia ai i le tausiga o ia e mātua o ona mātua. Ina 'ua maliliu, e leai ma seisi na alofa iai ona o lona loto faapito, ma lona faaloloto. Na fai mai lona tinā matua ia te a'u, o le mea e alofa tele ai iai ona e ma'i, e lēafiai ona savali. (Tausi ma'i, sui o le 'āiga)

One participant described an early experience of unwanted overcompensation and its interaction with culture:

I've experienced rejection in school. The principal didn't realise I could be included or accepted. Other students took my things, other kids would play with my typing machine, and when I would ask who did it no one would take the blame. Some of my marks were recorded without me even taking the exam. The school didn't think I would find out, so they just gave me a pass grade. Being totally blind makes you the most disadvantaged. The school did it wrong on my favourite subjects, my marks looked wrong to me. I was disappointed and I tried

to fight back. My dad was the minister, but I didn't get through to him, he was trying to respect the other ministers at the school. Dad said to forgive them. I was given the extra task of proving everyone wrong, which I did. It was a motivation but a sad thing. They thought I had no potential, nothing, no hope. (Person with disability)

Based on the data, two disparate themes emerged around the inclusion of people with disability. Firstly, that inclusion can only truly occur when equal treatment, but not necessarily equality, is rendered (this theme is represented through the *Tutusa* model discussed in Chapters 2 and 7). This attitude sees disability as a problem of the individual, and removal of barriers reduces the value of contribution to family. Secondly, that inclusion is realised through overcompensation. This attitude sees disability as necessitating the removal of all barriers in order for people with disability to achieve inclusion. This stance discounts the real functioning and capabilities of people with disability. Both positions represent aspects of the *fa'aSāmoa* and are contrary to the philosophical underpinnings of a social disability model.

6.3.2 Impact on family

Disability can be seen as largely the experience of the person with disability. However, the Samoan concept of collective identity shares the experience among the entire *aiga* in different ways. The impact may be through stigmatising attitudes and behaviours, or through carers' responsibilities. When asked about the impact of caring for a person with disability, participants responded as follows:

Every time I see my child, my little girl having a seizure I cry because to overcome this I need to do something about it, but I couldn't. The only thing that helps control the seizure is the medicine, and I always ask myself what I can do to help. I couldn't do anything. (Carer, family member)



This comment reflects a high level of willing obligation and reciprocity despite the immeasurable challenges physically and emotionally for the carer. In this instance, the carer at times feels helpless despite her significant contribution to her daughter's development. Another participant also spoke of the extensive obligations that exist as a carer:

It has really changed me since mum got sick. Sometimes I think it is too hard, it's too hard for me, I can't do it but then I manage to do it, because I have to do it for my parents. I rely on God for my strength and good thoughts. When I'm stressed I just go and do other chores. If Mum wants me to do something I have to tell her to just wait, so patience. (Carer, family member)

Translated as:

Ua matuā 'ou sui lava talu ona ma'i lo'u tinā. O isi taimi 'oute faapea ai ua matuā faigatā lava, matuā faigatā ia te a'u, oute lē gafatia 'ae i'u ane lava uaafiai ona 'ou faia, auā e tatau ona 'ou faia mō o'u mātua. 'Oute faamoemoe i le Atua mō lo'u mālosi ma o'u māfaufauga lelei. 'Ā 'ou lagona loa le mamafa o lo'u māfaufau, ona fai lea o isi fe'au. 'Ā mana'o Tinā 'oute faia se mea mō ia, 'oute fai iai e faatali, ma 'onosa'i. (Tausi ma'i, sui o le 'āiga)

Increasingly, traditional village life is adapting to global and economic influences, drawing people into the paid workforce (Kruse-Vaai, 1998; Thornton et al., 2013; Thornton et al., 2010). Disability care giving becomes the responsibility of *aiga* members remaining at home in the village, despite a potential inadequacy to provide suitable care. When asked about the impact of caring for people with disability in the village, one participant reported:

We have a cerebral palsy girl; her mother left her with her grandmother. Imagine an old lady taking care of a very severe adult CP person. All she does is lie on the floor. (Disability sector stakeholder)

Participants working in the Samoan disability sector reported the impact of stigmatisation on willingness to accept external support:

Some families they just don't want anything to do with us. They want privacy. They feel the help we do for them stresses their incompetence. They think they should care for their own people.
(Disability sector stakeholder)

Translated as:

E iai isi 'āiga e matuā lē mānana'o lava iā mātou. E mānana'o ia nā 'o lātou lava. O lātou lagona o fesoasoani mātou te faia mō i lātou e faailoa ātili ai lo lātou lē tagolima. O latou manatu e tataua lava e i lātou ona tauti o lātou tagata. (Sui o le vaega o mana'oga faapitoa)

Care of people with disability in villages is influenced by traditional beliefs and practices that align to concepts of collective identity. The *fa'aSāmoa* obligates families to care for people with disability with little or no support for fear of the family being stigmatised. However, in a changing social context, the social disability model advocates services aimed at providing support. The support services may be carried out in the village, or as outreach, and also in established centres that require people with disability and their families to enter public spaces. Traditional beliefs and practices of disability may present a barrier to service provision and support.

6.3.3 Social inclusion

In contemporary Samoan society, social disability model advocates are actively addressing concepts of inequality through promoting a barrier-free society. MWCSO identifies stigmatisation as a barrier to inclusion (Ministry of Women Community and Social Development, 2009). It has been a challenge to reassure people with disability and their families that broader society is a place of equality, inclusion, and



acceptance. When asked about the level of societal inclusion experienced by people with disability one participant remarked:

I'm never, never shy to share my child to people. I'm never ashamed to show my child to anyone. (Carer, family member)

Translated as:

‘Oute lē tāi lava ona ‘ou mā e faasoa atu la’u tama i tagata. ‘Oute lē māasiasi e faailoa atu la’u tama i soo se isi. (Tausi ma’i, sui o le ‘āiga)

This comment highlights changing attitudes towards disability as people with disability become increasingly accepted. However, societal inclusion and acceptance is not necessarily just the presence of people with disability in public spaces. For this participant, experiences of societal inclusion come from a sense of belonging in the community:

Lots of people come to visit me. The women’s committee, some from New Zealand, doctors, nurses, members of St Vincent de Paul, the deacon and his wife, and my sons come every week. They bring money to buy food. (Person with disability)

For this participant, community support and care provided a sense of collective identity. Despite the inclusion occurring in a private, rather than public, domain this participant experienced acceptance and inclusion as part of broader society.

6.3.4 Conclusion of Part 2

The themes of conceptualisation and inclusion report on the relationship between the tenets of the *fa’aSāmoa* and disability at both a family and a societal level. The data generated from this research suggests that Samoans with disability are generally included in both family and society but that there are range of factors inhibiting unencumbered equality, inclusion, and access. The data primarily reiterates Tufue-



Dolgoy's (2010) assertion that the *fa'aSāmoa* is incompatible with policy and practice initiatives in Samoa influenced by social disability models.

Additionally, the structure and belief systems of the *fa'aSāmoa* view equality in ways that conflict with the social disability model. For this reason, acceptance, inclusion, and access are impinged upon by traditional beliefs. This has substantial consequences for the identity development of Samoans with disability.

6.4 Part 3: Terminology and discourse

Language, terminology, and discourse have played a pivotal role in the shaping of perceptions of disability in Samoa. Disability discourse has evolved largely from conceptualisations of disability stemming from moral and medical models. Progressive political agendas have directed attention at making changes to disability language, but this research indicates that the issue of developing a Samoan discourse that reflects a social disability model is still very much a work in progress. A shared understanding has yet to be achieved.

There are three themes that emerged from the data that contribute to the complexity of developing a new Samoan discourse of disability. These three themes, detailed in Table 11, will be discussed throughout Part 3, establishing a frame of how the Samoan language depicts and propagates perceptions of disability.



Table 11. Theoretical theme development: Part 3

Part 3: Terminology and discourse	
Research question	Theoretical themes
Question 4:	Representation of disability through discourse
How does Samoan language and discourse represent people with disability?	Indigenous terminology development
	New disability discourse

6.4.1 Representation of disability through terminology

Disability discourse in Samoa is the culmination of moral, medical, and social models that have left society adrift of what constitutes disability. This has been a contributing factor in stigmatisation and isolation for people with disability. One of the themes that emerged from the data centred on the conceptualisation of disability from a medical model standpoint, resulting, in part, from terminology that described disability as an illness. One term in particular, *ma'i* (meaning illness or sickness), is widely recognised as a descriptor for disability. When asked about the term *ma'i*, participants had mixed responses regarding the appropriateness of its usage:

Ma'i is a phrase to recognise that someone has a disability, but it is not necessarily negative. (Disability sector stakeholder)

Translated as:

Ma'i o se 'upu leaga e faamatala ai le lē malosi. 'Ā 'ē faaleoa faauigā, o le 'upu leaga. (Tausi ma'i, sui o le 'āiga)

There are different ways of using *ma'i* in Samoa. If you have a headache, or if you have a pain in your leg. The other way is if you are using drugs, especially boys who are using marijuana, people will say that to them. (Family member)

It is a word they use to describe disability because they don't have an understanding about the different terms. In terms of disability there is no exact translation for disability and if there is a child with disability they go "*ma'i*" because they don't know the exact type of disability. (Carer, family member)

The data indicated that there is a disparity in understanding of what disability actually is, and in the appropriate usage of the term *ma'i*. The general and broad nature of the term *ma'i* has resulted in uncertainty about whether the term is offensive or merely descriptive. Participant data indicates that *ma'i* is a commonly used term to describe disability and that its shared understanding emerges from a medical paradigm.

Ma'i is an umbrella term to describe disability. Other labels to describe particular disabilities are still rooted within medical explanations. When asked about specific terms to describe disability, several phrases and words that played a role in a shared understanding of disability in Samoa were indicated:

I know some words that people use, like *valea*, or *o le vale*, which is a stupid person, out of their mind. Or they might say *maufaufau*, which is a polite way, like the mind is sick. (Person with disability)

Another word to describe blind people in a negative way is *tauaso*, which means "broken eyes". I find that comical, not offensive, although it is not the right word to use to describe being blind. (Person with disability)

Your vision is dark, *po le vaai*, you have dark vision. (Person with disability)

Leaga le ulu is just a description of sick people. There are polite words now to avoid being rude to mental or disability people. (Family member)

Translated as:

Leaga le ulu ua nā o se faauigaina o tagata lē malolosi. O lea ua iai
‘upu faaaloalo e fō’ia ai le lē mīgao i tagata e lē ‘āto’atoa māfaufau ma
ē e iai mana’oga faapitoa. (Sui o le ‘āiga)

Leaga le ulu, I do hear people say that. It means crazy. (Carer, family member)

Another word is *faipe*. *Faipe* is a bit rude when you say it. A polite way to say it is *taliga tuli*. *Taliga* is ear; *tuli* is those drums, so affected drums. *Pe* is the waste that comes out of your ear, like if you have affected drums of your ear and something smelly, the waste that comes out smells, so that means *pe*, so *faipe* is not appropriate. *Fai* means caused the problem in the ear. (Family member)

This range of descriptive terms have resulted in disability being conceptualised as an undesirable medical condition. This contributes to stigmatisation. The data indicated that these words are still active within the community, but are increasingly acknowledged as inappropriate and offensive. Frequently, participants reported that the acceptance of these words hinged upon two important factors: relationships and tone:

Ma’i goes both ways. It depends how you say it. It’s a pivot point, if something positive or negative is said before or afterwards; it changes the tone and meaning. (Disability sector stakeholder)

Ma’i is ok to say inside the family. But if you are not in the family, if you are an outsider it is right to say *gasegase*. (Person with disability)

The term *ma’i* can be perceived as empathetic or derogatory, depending upon the tone that is employed, or the relationship between the person with disability and user of the term. When the term *ma’i* is used by someone outside of the family, the usage of the term can convey uselessness. Within the family, the use of the term could be



considered empathetic and understanding. However, it is not always appreciated by people with disability, and is frequently received as pity:

It's ok to say *ma'i*, some other people joke about the word *ma'i*. If (sister with disability) is very angry and she talks over someone then they say *ma'i*. She doesn't like it. (Family member)

Whenever I heard someone at my village call my daughter *ma'i*, I say you know there is a difference between *ma'i* and disability. *Ma'i* there is a cure. Disability you can only help and give support in the way that they need. It discourages the child with disability, it is the end of the light, they can't do anything, won't be able to do anything, it stops them from doing things. That's a medical description. (Carer, family member)

The data for this research identified pity as a theme in perception of disability. The term *kalofae*, meaning to feel sorry for, is frequently used to express empathy towards people with disability. However, this term is often received as unwanted pity, or an indicator that the family has reduced status due to having a family member with disability:

Kalofae, it means the person is sorry for you. So as a mother with a daughter with a disability, I don't like that word with that tone. *Kalofae* sounds like my child is worthless, it sounds like my child is useless. It is something really, really, really bad that has happened to her that we can't do anything about. (Carer, family member)

Translated as:

Kalofae, o lona uiga ua o'otia le loto o le tagata iā te 'oe. O lea lā ona o a'u o le tinā e a'afia lana tama teine i mana'oga faapitoa, oute lē fiafia i le 'upu lenā ma lona faaleoga. O le Kalofae lea e ta'u mai o la'u tama e lē tāua, e ta'u mai o la'u tama e leai se aogā. O se mea matuā leaga, leaga, leaga lava na tupu ia te ia ma e leai se mātou mea e mafai iai. (Tausi ma'i, sui ole 'āiga)

Some people say *kalofae* which means ‘poor you, it’s a pity’. I say ‘I love you too’, I make humour of it. (Person with disability)

Kalofae is generally accepted as a polite way to express empathy for people in a range of situations. When applied to disability, the term can be interpreted as pity, making it highly offensive to people with disability and their families. The data indicated that while this word was connected to disability discourse, it was not used exclusively in this way. However, its usage within disability discourse acts as an indicator of disability perception and attitudes.

The data indicated a significant lack of congruency in meaning and intent of terms currently in use to describe disability. Specifically, disability discourse is considered either too broad, as in the case of the word *ma’i*, or a reinforcer of a medical model of disability. The data indicates it reinforces negative stereotypes of disability in Samoa.

6.4.2 Indigenous language development for disability discourse

Outdated terminology has been identified as an area for development within policy in Samoa. Progress is being made in the development of new terms that reflects a more positive outlook on disability in Samoan society. Despite the adoption of a social disability model, Samoa has few resources to draw on regarding indigenous language development. The International Classification of Functioning, Disability and Health (ICF) provides guidelines for disability terminology in policy documents, but guidelines for the development of indigenous terms for use within society are non-existent. When asked about the need for development in the area of disability discourse, participants reported:



With the imminent ratification of the Rights of Persons with Disability in this country I believe it is a must for government and others, including the medical profession to come up with these terms. It's very much on the agenda. (Disability sector stakeholder)

There is an advocacy organisation that are making sure that part of their job is that terms are being used to describe people with disabilities. (Person with disability)

The data for this research revealed that terminology in Samoa represents disability from moral and medical models. Most participants supported descriptive terminology to better target service provisions, and to dismantle stigmatising attitudes that have flourished with medical model language. When asked about the level to which terms should describe disability, participants reported:

To describe disability we would need to create long phrases, or make new words. Or we could make English words into Samoan. (Disability sector stakeholder)

I hope language will adapt because cerebral palsy, autism, all go under *le atoatoa* – 'there's something wrong', or it could end up being *ma'i* because there is no Samoan word for Autism. So in the long run I hope they will adapt these words. You know one word in English could equal a whole sentence in Samoan. (Person with disability)

Translated as:

Talosia (o le gagana) o le 'ā sui 'ona o le cerebral palsy ma le autism e o 'uma i lalo 'o le lē 'āto'atoa – "e iai se mea e lē o sa'o", poo le i'u a'e fo'i ua ma'i auā e leai se upu Sāmoa mo le Autism. O lea talosia ia o le 'ā iai ia 'upu. Ua e iloa fo'i, e tasi le upu igilisi e tusa o le fuai'upu 'āto'atoa i le faaSāmoa. (Tagata e iai mana'oga faapitoa)

It was widely acknowledged that language needed to reflect a social disability model, but it also needed to reflect cultural identity through the use of indigenous language.

One of the identified difficulties with translating English words into Samoan terms was the complexity of descriptions that resulted in entire sentences being formed to describe each disability:

There is a need to remodel language and reshape culture to understand disability. (Disability sector stakeholder)

If they could make a description, a phrase not a sentence of disability then I would prefer that to adapting an English word that people will have no idea what it means if you were telling me. Otherwise we would have a bunch of people who will need explaining what the word means. Even Down's syndrome, cerebral palsy, intellectual, it's a lot. It's bad enough trying to learn the English words and trying to adapt terminology to Samoan. Make a whole bunch of Samoan words to make sure the meaning come across in the Samoan language. (Person with disability)

The complexities of creating a new discourse of disability through the development of new terms will require collaborative input from a range of agencies and stakeholders. This will ensure the development of a new disability discourse that effectively represents people with disability in both a cultural and human rights capacity.

6.4.3 Culture, shared understandings, and a new disability discourse

New disability discourse should reflect not only the desired shared understanding of disability, but also established ideologies of cultural identities. One participant described the implications of changes to terminology in light of ingrained cultural ideologies:



In the Samoan way of proper speaking, it takes away the actual meaning of the trueness of the word. It is simpler if you just speak the normal, everyday language instead of trying to use polite terms, *logonoa, po le vaai*. I agree it makes the person with disability more important, more inclusive, but when you talk about yourself you don't say *po le vaai*. What I'm saying is we should be trying to look into having cultural values integrated with overseas policies for the betterment of people with disability in Samoa, because, and I am speaking on behalf of myself, the Samoan way you don't speak politely about yourself, you don't praise yourself, other people do that, so when you say *tauasoa*, or *po le vaai* it sounds silly, it doesn't sound right in the Samoan way. But the reality is we are slowly changing. (Disability sector stakeholder)

Respect, and concepts of hierarchical relationships emerge as a consideration of language development. Future development of a Samoan discourse for disability would have to take into account levels of respect and humility that are built into the foundation of the Samoan language. This idea was presented to other participants, generating these statements:

Whenever a word has been introduced, then it is our responsibility to put in polite words to make sure it is proper. If you bring in a new word then I will have to ensure that there is right meaning on it, so I would have to put polite words in to it. (Family member)

I reckon it refers to other situations. Say I ask you, 'What is your name?' and I say, '*o'e lou igoa?*' and you say, '*suafa*' because *suafa* is the respectful term, the *fa'aaloalo* term, and if you say to me, 'my *suafa* is Catherine' then that would be insulting in the language. I don't think it applies to people with disabilities. If I said, 'I'm blind' in the respectful term, *po le vaai*, I don't think I'm actually being disrespectful because I'm using a term that not only referring to myself but others with disability with their eyes. Not even that there are many

respectful, deeper terms in Samoa for disability. So *po le vaai* is like you are blind but there is no historical respectful term, like *suafa* for your name so there is nothing like that for disability. I don't think it is any way insulting. (Person with disability)

Other participants did not necessarily confirm the inappropriate nature of using polite terms to describe oneself with a disability, but did verify that respectful terms are a significant feature of the Samoan language. As there is no historical basis for polite disability terminology, there is an opportunity for the development of ethno-specific terms to take into consideration the three factors in the development of a unique Samoan discourse of disability.

6.4.4 Conclusion of Part 3

Part 3 explores the relationship between terminology and discourse as it contributes to negative perceptions of disability in Samoa. The data reflects a lack of a shared contemporary understanding, contributed to by diverse terminology usage. The data indicates that current disability discourse is contributing to the reinforcement of a medical model of disability conceptualisation.

6.5 Part 4: Perceptions of western influences

In Samoa's increasingly dual-motivated society, outside influences and practices are generally well tolerated. Political trends in Samoa have mirrored global initiatives. However, tradition is still close to the hearts of Samoans and cultural retention is high on the agenda. Data from this research indicated concern over the level of cultural representation in policy development and service delivery. The questions for future policy development are: Should culture adapt to global political shifts? Should global



policy ideas be shaped to fit culture? Or should development focus on how the two can form a blended conceptualisation of disability that represents a progressive Samoan worldview? The themes for Part 4 and their connection to the research questions are displayed in Table 12.

Table 12. Theoretical theme development: Part 4

Part 4: Perceptions of western influences	
Research question	Theoretical themes
Question 3:	Positive attitudes of western influences
How is global policy and practice viewed from a Samoan cultural perspective?	Concerns of cultural erosion
	Blending ideologies

6.5.1 Positive attitudes of western influences

Recent developments in the area of disability, such as renewed policy and the ratification of the CRPD were driven by increased concern over human rights for people with disability. There has been a demonstrated commitment in Samoa from Government and NGOs to elevate social circumstances for people with disability, using international standards as a springboard for change (Ministry of Education Sports and Culture, 2006; Ministry of Women Community and Social Development, 2009). Issues such as education and societal inclusion have been prioritised to reduce barriers for people with disability (Lameta, 2013; McCullough, 2005; Ministry of Education Sports and Culture, 2006; Ministry of Women Community and Social Development, 2009). These changes have been well received by people with disability as Samoa attempts to replicate barrier reduction in developed countries.

When asked about perceptions of western influences in the area of disability, participants responded:

The influence of western culture has had a positive impact because of the way they can see people do it. They need to access services and participate fully. It's a human rights thing that everyone should access. It's not a negative. (Person with disability)

Translated as:

O le a'afiaga o tātou I aganuu mai fafo, o se fetaia'iga lelei ona o lātou vaaiga i 'auala eafiai ai ona faatino e tagata. E tatau ona faaaogāina 'au'aunaga faataatia ma ia 'āuai 'āto'atoa fo'i. O le aiā tatau a le tagata e tatau ona faaaogāina. E lē se mea leaga. (Tagata e iai mana'oga faapitoa)

What they bring to Samoa, their skills and expertise, we learn a lot from those people, not just now, even years ago. (Family member)

The paradigm shift from medical to social model has considerable appeal to many Samoans, as the ideologies promote accessibility and equality. When asked about the positive contributions that international policy and practice make to disability management in Samoa, a participant responded:

Internationally, policy puts the person before the disability. It promotes positive, accessible environments to enjoy equal rights. (Person with disability)

As Samoans we can study and try to make others aware of western attitudes towards people with disability through human rights and showing people the value of the person as an individual and that they have self-worth. (Person with disability)

Translated as:

Ona o tātou o Sāmoa, tātou te su'esu'e ma taumafai e faailoa atu i isi uiga o tagata mai fafo e faaalua i tagata e iai mana'oga faapitoa, e ala

lea i aiā tatau a tagata, ma faaali atu i tagata le faatāuaina o le tagata
lava ia ma ana ‘oa faaletagata. (Tagata e iai mana’oga faapitoa)

In some instances, a positive perception of global disability paradigms has instigated criticism of Samoan attitudes and practices, prompting one participant to report:

We have our own ideas but our own ideas don’t meet the needs of the disabled people. When we talk about mental and disabled people, we need experts, people who have already been educated in those fields.
(Family member)

All of the participants expressed the need for change. The basis for this change is the signing of the CRPD, signalling not only a political commitment to change, but also a progressive paradigm shift towards recognising human rights. For one participant, progress hinges on the ratification of the CRPD:

This country needs to ratify international conventions to ensure people with disabilities are received well by the community. There have been significant changes over the years, but it will take time to be accepted equally. There are huge challenges ahead. (Person with disability)

The support for human rights and the CRPD were well reported by participants throughout this research. However, reservations were noted. The CRPD and new disability policy has made considerable progress towards rights, equity, and access in Samoa, but there is growing concern that culture has not been embedded in borrowed policy.

6.5.2 Concerns about cultural erosion

As discussed in Chapter 4, borrowed policy is not always culturally responsive. There is growing recognition that change is necessary to progress, particularly in the area of disability where equality and human rights have been a source of concern in recent



years. As a starting point to reshape Samoan conceptualisations of disability, policy development has drawn heavily on social disability models and the CRPD. As these conceptualisations and policies are further embedded into contemporary practice in the area of disability, questions are being raised as to the level of cultural continuity represented through this emerging paradigm. Tufue-Dolgoy (2010) identified the disparity between the collective values that drive the *fa'aSāmoa*, and the individualistic objectives of a social disability model. When asked about the impact of external influences on culture, some participants expressed concern that cultural erosion was a consequence of unadapted borrowed policy:

The negatives of borrowed policy...it kills our culture by making it more open. Disability carers coming into the house to wash and care, that's the families' responsibility. I respect the western ways but certain bonds it steps over. (Disability sector stakeholder)

Translated as:

O itū le manuia e maua mai i tulāfono nonō mai fafo... e oti ai le tātou aganuu. O ē tausia tagata e iai mana'oga faapitoa ma o i totonu o fale e faatā'e'ele ma tausī, o le matāfaioi lenā a 'āiga. Oute faaaloalo i tū mai fafo, ae sosopo tuā'oi fo'i. (Sui o le vaega o mana'oga faapitoa)

Another participant expressed the need to be critical of borrowed policy to assess their cultural relevance before implementation:

The western teaching from overseas, if I know it is not suitable to my family and my community, then I will just forget it. But if I know it is fruitful then I will use it for the benefit of the community. Western teaching is not always perfect, it is not always suited to the community, but there are things that you can use and there are things that you can just let go. (Family member)

Borrowed policy is vulnerable to discerning attitudes that do not entirely embrace the external ideology. This attitude thwarts acceptance of policy and undermines change.



While still in a developmental phase of disability conceptualisation from a social model stance, Samoa has begun a journey to overhaul disability perception and practice through the implementation of borrowed policy. Opening up this dialogue of change provides an opportunity to now take the next important step of blending ideologies.

6.5.3 Blending ideologies

This section of the research has looked at the way Samoans perceive outside influence on policy and practice in the area of disability. Overwhelmingly, a social disability model is endorsed. However, some reticence exists regarding the lack of cultural continuity and representation. The data reflected an attitude that borrowed policy has been helpful and useful in an early developmental stage of creating a new Samoan conceptualisation of disability. The data also indicated that a new wave of development should focus on incorporating fundamental cultural values:

We can't just put laws straight in. It's the same aim but we have to look at how we can fit it into our culture. We can't go straight from international policy to schools and villages without the process of applying culture. (Disability sector stakeholder)

Translated as:

E lē mafai ona faaofi sa'o i totonu ni tulāfono. O le 'auga ā e tasi a e tatau ona tātou tilotilo pe faafelea ona ofi i totonu o le tātou aganuu. E lē mafai ona tātou ō sa'o mai tulāfono faa- le- vā o mālō i ā'oga manuu 'ae le'i faatūlagaina tulāfono faa- le- aganuu. (Sui o le vaega o mana'oga faapitoa)

Western education has had a positive impact. They have all the materials to educate people, it is a step forward. Life is moving forward and we cannot confine ourselves to traditional education. We have to step out of our comfort zone. We need to take things into

consideration but we need traditional thinking at all levels. (Person with disability)

Like the MESC's Strategic Policies and Plans (2006), which are adapting and changing in response to calls to embed culture in policy, disability policy development has reached a critical stage of development. Disability policy and the adoption of a new disability paradigm have been well accepted by society generally, but the next phase of development will be to merge global conceptualisations of disability with local Samoan conceptualisations. This affords opportunities for Samoans with disability to access equality and inclusion, while retaining a strong sense of cultural purpose, identity, and inclusion.

6.5.4 Conclusion of Part 4

The data for the theme of western influences suggests that non-Pacific ideologies are well embraced and appreciated. As western-influenced disability policies become further developed, it has become increasingly evident that Samoan epistemologies are not prioritised within them. The data indicates that incorporating culture into policy and practice is a valued aspect of development in the area of disability. There is concern that global ideologies do not represent traditional Samoan practices leading to cultural erosion. The data suggests that the ideal political standpoint on disability is one that blends together traditional practice with global ideas on human rights and disability.

6.6 Chapter conclusion

The data from this research has found that the development of Samoan conceptualisations of disability have implications for individuals, families, support



services, policy development, and society at large. Recent societal and economical shifts, along with changing family dynamics, and the introduction of global mandates each affect the perception of and management approach to disability.

Reshaping the way people view disability is a complex process that requires a clear direction from a political standpoint to guide a new societal conceptualisation of disability. Policy reform has a number of objectives. In this case, policy reform in the area of disability primarily promotes human rights and equity. Recurring concerns emerge that outside ideologies are prioritised over traditional epistemologies, leading to an erosion of cultural identity. This research indicates that prioritising Samoan culture is a valuable component of policy acceptance.

Further examination of the issues surrounding disability in Samoa highlight the need for policy to support changes in the perception of disability in society and addresses concerns of stigmatising attitudes and discourse. In Chapter 7, the *Tutusa* model is presented as a viable model of policy transformation, incorporating social disability model policy initiatives alongside cultural practices and beliefs.



Chapter 7: Discussion

7.1 Introduction

The aim of this research is to investigate the cultural conceptualisation of people with disability from a Samoan perspective. This research specifically examined four key areas: disability conceptualisation, concepts of identity and belonging for people with disability, Samoan discourse of disability, and perceptions of western influences.

Research conducted by Tufue-Dolgoy (2010) on the effectiveness of the newly adopted Inclusive Education Policy in Samoa found that cultural epistemologies are still highly emphasised in Samoan classrooms, creating barriers to the effective implementation of inclusive education pedagogies. She also found that teacher and parent perceptions of people with disability and their capabilities affect successful inclusion in Samoan classrooms. She identified a number of factors contributing to these perceptions and practices. These included a lack of knowledge and training in inclusive education, lack of local expertise, and a lack of cultural responsiveness within policy. Her recommendations included the need for further investigation in determining the relationship between the *fa'aSāmoa* and disability.

The findings and implications of this research are discussed in this chapter in five main sections. They are: the effects of conceptualisations on identity; the development of a Samoan disability model, the *Tutusa* model; cultural access and disability conceptualisations within the *fa'aSāmoa*; the consequences of stigmatising terminology; and merging divergent cultural and social paradigms.



7.2 The effects of multiple conceptualisations on identity

One of the objectives of this research was to examine the role of the *fa'aSāmoa* in shaping conceptualisations of disability. This research found that there are multiple conceptualisations of disability in Samoa stemming not only from the *fa'aSāmoa*, but also through a long history of foreign influences. Samoan conceptualisations of disability synthesise many of the components of moral and medical models of disability, as well as incorporating concepts of the *fa'aSāmoa*. The variety of disability models in Samoan society has contributed to a lack of congruency of disability understanding. It has resulted in a lack of uniform terminology, and is a contributing factor in marginalisation and stigmatisation. Throughout this chapter, the various disability paradigms manifest in Samoan society will be discussed. Previous discussions on the *fa'aSāmoa* in Chapter 2 will assist in framing the implications of the various paradigms on inclusion, equity, and identity development for people with disability. The beliefs and practices that have emerged from the interaction between the *fa'aSāmoa* and various paradigms of disability conceptualisation will also be evaluated within the frame of current political standpoints that endorse a human rights discourse.

7.2.1 A moral paradigm: Curses and blessings

This research identified two manifestations of a moral conceptualisation of disability. The first manifestation is that disability is a curse resulting from wrongdoing. Viewing disability as a curse can be attributed to a moral paradigm of disability, but this perspective also has links to the *fa'aSāmoa*.



The belief that disability is the result of a curse (placed on an individual for wrongdoing) is still prevalent in Samoan society. As part of this paradigm, it is thought that individuals or groups who do not adhere to concepts of the *fa'aSāmoa* are subject to spiritual punishment through the birth of a child with disability. This child then becomes the embodiment of sin, bringing shame and disrepute to the collective. The data from this research indicates that this conceptualisation of disability has undoubtedly contributed to the stigmatisation of people with disability in Samoa.

Within a moral paradigm, it is thought that having a child with disability is a result of misconduct within the *fa'aSāmoa*. Misconduct is a departure from contributing to the prosperity and status of the collective. Within the *fa'aSāmoa*, contribution provided an early economic system of exchange where contributions added to the prosperity and good standing of the family (Kruse-Vaai, 1998; R Tufue-Dolgoy, 2010; L. F. Va'a, 2006). Contribution still forms the basis of family solidarity. A demonstrated commitment to contribution exhibits a desire to promote the prosperity and status of the family and will be reciprocated (Kruse-Vaai, 1998; L. F. Va'a, 2006). Contribution is a tool not only for economic prosperity, but also to gain familial security and inclusion (L. F. Va'a, 2006).

Demonstrating a high level of commitment to contribution complements deeply embedded concepts of respect and status, forming the foundation for collective relationships (Kruse-Vaai, 1998; Seiuli, 2012). A lack of participation in contribution has repercussions within a village setting, including the potential to restrict land access (Thornton et al., 2013; Thornton et al., 2010). The notions of contribution, respect, and status strengthen families and ensure belonging, self-worth, and honour



are maintained (Kruse-Vaai, 1998; R Tufue-Dolgoy, 2010; L. F. Va'a, 2006). Where the moral paradigm exists, people with disability are marginalised from access to cultural identity and not perceived as a useful and valued member of the collective. These aspects of the *fa'aSāmoa* illuminate the origins of a moral perspective on disability from a cultural standpoint.

This research identified a second manifestation of the moral paradigm where disability is viewed in a spiritual capacity; providing an opportunity to demonstrate love, compassion, and honour to a higher spiritual entity. It is thought, within this moral manifestation, that disability is a blessing; an opportunity to both witness the power of, and demonstrate worth to, a higher spiritual power. This links to concepts of the *fa'aSāmoa* through love and contribution. The unconditional love that one imparts to other members of the *aiga* is an essential demonstration of commitment to the *fa'aSāmoa*. Love promotes unity, which in turn contributes to a strong, prosperous *aiga* group. Honouring one's *aiga* through love, care, and compassion is not only an opportunity to contribute, it is also an opportunity to improve one's relationship to a higher spiritual power. An inability, or reduced capacity to contribute can be viewed as a weakness or flaw. Through a demonstration of compassion and love for members of the *aiga* who are compromised, tolerance and humanity are exhibited. This paradigm of disability reflects a perspective that disability is a blessing for people who are provided with the opportunity to demonstrate compassion. It is also an opportunity to contribute to the acquisition of knowledge and understanding on the positivity of disability. Contributions of compassion and the provision of service are contributions to the *aiga* group that act as facilitators to belonging and inclusion. Demonstrating these virtues becomes a contribution to the collective status, prosperity, and strength.



Research conducted by Meredith (2009) concluded that the perception of disability in Tokelau and Samoa incorporated concepts of curses. Meredith reported that younger members of the population were unlikely to perpetuate this view, but her research did confirm the presence of a moral model of disability in Samoan society. Likewise, Tufue-Dolgoy (2010) confirms the presence of a moral paradigm, noting that a curse conceptualisation can reflect negatively upon the collective.

Viewing people with disability from a moral standpoint has serious implications for positive identity development, both culturally and socially. However, many of the beliefs surrounding a moral conceptualisation of disability are rooted in fundamental aspects of the *fa'aSāmoa*, making the development of identity for people with disability complex and tenuous. Overcoming some of the more negative aspects of a moral model that stigmatise people with disability will require an intensive investigation into aspects of the *fa'aSāmoa* which endorse and facilitate a moral disability model.

The findings of this research regarding moral conceptualisations of disability highlight the need for continued promotion of alternate conceptualisations of disability. One of the strategies that could assist in the eradication of the moral paradigm would be through educating religious groups to advocate for a human rights stance. Another possible strategy, and one that is becoming increasingly relevant in Samoa is the use of the internet and social media to advocate for a shift in disability conceptualisation. In a recent article, Mittler (2015) proposes the value of the internet in promoting a paradigm shift as disability advocacy is not only the responsibility of governments, but also of civil society.



7.2.2 A medical paradigm: Care, protection, and restriction

The medical model paradigm locates disability as a “problem” with the individual. Within this paradigm people with disability are considered less useful, as a perceived inability to gain paid employment or cash income compromises societal inclusion (Garrick Duhaney & Salend, 2010; Wizner, 2006). From a Samoan perspective, the medical paradigm views disability as a weakness. In this sense, a person with disability is dependent on others for care, protection, and security. This research has identified a strong societal association with the medical model of disability, viewed as a progressive model for disability conceptualisation.

Samoan families, through their cultural systems of obligation and contribution, take on the responsibility of caring for people who are sick, disabled, or elderly (McCullough, 2005). As Tufue-Dolgoy (2010) notes, caring for elderly family members is considered a highly honourable task . But caring for people with disability within the village is not entirely altruistic. Like other examinations of disability in Samoa (Lameta, 2013; McKinsty et al., 2012; Meredith, 2009; Ministry of Women Community and Social Development, 2009; R Tufue-Dolgoy, 2010), this research confirms that shame is associated with disability. Shame could emerge from a moral conceptualisation that the family has been subjected to a curse. In the case of shame associated with the medical model of disability, shame arises from a perception that the family is not meeting their obligations by providing adequate care to a person with disability. This attitude develops from several assumptions. Firstly, that the family cannot provide support for a family member with disability due to financial constraints. Secondly, that the family is being morally judged for not providing adequate care. Finally, that families are neglecting care by allowing a family member with disability to carry out obligations, or enter public spaces. This



research found that some families restricted the freedoms and activities of family members with disability to reduce the possibility of being perceived as neglectful. The assumption that a person with a disability is suffering a sickness requires the family to provide care, support, and services as part of the *fa'aSāmoa*. The data reflected a concern that allowing people with disability to participate in activities outside of the village, particularly unaccompanied, may provoke assumptions of neglect. This potentially attracts a negative stigma and judgements upon the collective. The MWCSO term this perception of disability as the “protective approach” (Ministry of Women Community and Social Development, 2009). This cultural belief and practice, based in the medical model paradigm, contradicts the principles of a social model of disability. This creates a significant challenge for people with disability to overcome cultural limitations in order to access and benefit from social model legislation and policy. It also has implications for belonging, self-worth, and cultural identity. From a medical model paradigm, a person with disability is compromised in making contributions to the *aiga*. Limitations are placed upon people with disability as to how they are able to contribute. One particular limitation is a reduced liberty to act independently, particularly outside of the village environment. This research found that within a medical model paradigm some villages required people with disability to act in a compliant manner as a specific contribution to the strength, prosperity, and honour of the collective. In making this contribution, access to reciprocity is not threatened. However, in this sense, cultural identity and belonging can only be achieved through acquiescence.

The implications of a medical conceptualisation affect concepts of cultural identity, self-worth, and access to society. In turn, this reduces opportunities for people with disability to access education and employment. MESC have addressed educational



exclusion through policy development. However, employment access for people with disability in Samoa is limited. The Samoan Bureau of Statistics (SBS) reports a general employment figure of 41 percent (Samoan Bureau of Statistics, 2011). For people with disability, the figure is significantly lower at only 2.4 percent. With increasing unemployment generally, due to a declining economic environment, and higher volumes of school leavers, the employment market is highly competitive (Ministry of Education Sports and Culture, 2006). When collecting statistics on the prevalence of people with disability in Samoan society, the SBS define disability as “causing great harm to one’s life hence making it difficult to live life to the fullest without support from others” (Samoan Bureau of Statistics, 2011, p. 62), reinforcing concepts of a medical model paradigm. Va’a (2006) reported that people with disability are among the groups of people in Samoa most susceptible to disadvantage. The social and economic disadvantage felt by people with disability, arising in part from a medical conceptualisation is reinforced in other research into disability in Samoa (Lameta, 2013; McKinstry et al., 2012; Ministry of Education Sports and Culture, 2006; R Tufue-Dolgoy, 2010).

7.2.3 A social paradigm: Equity, shared belief, and belonging

There have been conflicting reports on the successful integration of a social paradigm in disability policy in Samoa. A review of disability legislation in the Pacific (conducted on behalf of PIFS) claims that recent policy shifts throughout the Pacific have discarded charity models in lieu of a human rights model (McKinstry et al., 2012). Tufue-Dolgoy (2010) opposes this claim noting that policy still reinforces a medical model. Lameta (2013) claims that policy has adopted a social model paradigm, but reports that a social model discourse fails to recognise the lived



experiences of people with disability. This research found that a social disability model, advocated in a political capacity, has emerged as a societal conceptualisation of disability but is yet to become widespread in Samoa. Research participants who were sympathetic to a social model stance, widely reported that a social model conceptualisation supports the basic rights that people with disability are entitled to.

However, Tufue-Dolgoy (2010) recognised a disparity between the ethos of the social model and the tenets of the *fa'aSāmoa*, recommending further research to determine the relationship between the two. This research indicates that concepts of the *fa'aSāmoa* heavily influence people's attitudes, beliefs, and practices in relation to people with disability. Attitudes, beliefs, and practices that come from cultural, moral, and medical conceptualisations are incompatible with the social model of disability (as discussed previously in this chapter). To adopt a social disability stance in their actions, beliefs, and practices people with disability require support from the collective. In the absence of a shared belief in a social disability model, people with disability have their sense of familial belonging placed at risk. Thornton et al. (2013; 2010) conducted research in Samoa into land rights and religion stating that the maintenance of village harmony relies on shared religious beliefs. Due to economic factors, some Samoans are opting out of mainline churches causing dissension within the village. A shared belief system is of great importance to the strength of the collective. For people with disability to overcome the beliefs and attitudes of an entire village represents a significant challenge, and one that may risk their cultural identity and belonging. For people with disability who live in villages that endorse moral and medical conceptualisations of disability, exercising the ethos of a social model of disability could be viewed as risking the honour of the family and challenging the collective for personal gain. The findings highlight the complexity of identity



development for people with disability in Samoa. Choosing between a cultural identity, and equality within a social disability model challenges established global concepts of human rights.

7.2.4 The interaction of the *fa'aSāmoa* with contemporary cultural conceptualisations of disability

The social disability model sees disability as a series of barriers that exist within society, limiting access for people with disability. Equality is a core concept of the social model paradigm, with all people entitled to social access, inclusion, education, employment, health care, and basic human rights. This research found that while aspects of the *fa'aSāmoa* are compatible with aspects of the social disability model (support, love, acceptance, inclusion) there were also many cultural practices that are in direct conflict with the social disability model. Cultural practices, motivated by tenets of the *fa'aSāmoa* such as status and hierarchies, concepts of respect, expectations of contribution, and a collective honour system, challenge the effective adoption of the social disability model in Samoa.

This research also found that multiple conceptualisations of disability are a factor in challenges to the society-wide adoption of a social disability model. The lack of shared understanding about disability facilitates discord about the direction of attitudes, beliefs, and practices around disability. Shared understanding has been shown to be a useful tool in the targeting of service provisions, and in the development of discourse and terminology (Madden & Hogan, 1997). The diverse interpretations of religion, the impact of global influences, and the beliefs and practices of the *fa'aSāmoa* have contrived an alienating environment for people with disability.



The development of a Samoan political framework of disability has prioritised a rights-based discourse. It is proposed that a rights-based discourse has not fundamentally changed the lives of people with disability globally (Clapton & Fitzgerald, 1997; Lameta, 2013). Tufue-Dolgoy (2010) reports that current policy does not reflect cultural beliefs and practices. To make a fundamental difference in the lives of people with disability in Samoa, a challenge is presented for the development of Samoan policy. These challenges include the presence of multiple conceptualisations of disability, a lack of cultural representation within policy, and the idea that rights-based discourses do not effectively engage with the actual experience of disability.

The idea that the social disability paradigm does not represent the experiences of people with disability has been raised in critiques of the social disability model. It has been suggested that the social disability model places too much emphasis on barriers, and does not address the very real needs and realities for people with disability (Crow, 1996; Shakespeare & Watson, 2001; Terzi, 2005). In this highly developmental phase of political reform in the area of disability in Samoa, societal barriers are still numerous. Failing to recognise the day-to-day experiences for people with disability reduces levels of equality and societal inclusion. The data for this research indicates that the actual lived experiences of people with disability needs to be carefully considered. The complexity of factors related to Samoa's general infrastructure, the level of development and resources, and cultural beliefs of individual villages and families need to be taken into consideration when devising policy reform.



7.3 A Samoan paradigm: The *Tutusa* model

The cultural practices and beliefs of people in Samoa is a critical aspect of an examination into Samoan conceptualisations of disability. As discussed in Chapter 4, Samoan conceptualisations of disability have been influenced by a range of sources. The concepts of the *fa'aSāmoa* have become embedded in moral and medical models of disability. This research identified a uniquely Samoan conceptualisation of disability, the *Tutusa* model influenced by a social model paradigm and framed within the *fa'aSāmoa*. This is a critical finding of this research because, although this new model is not yet refined, it represents an opportunity to develop a disability paradigm that simultaneously advocates for the value of cultural identity development and human rights.

Introduced in Chapter 2, this new paradigm, the *Tutusa* model is based upon Samoan concepts of equality. From this research, the early development of the *Tutusa* model was identified. The embryonic model of *Tutusa* had emerged in pockets of Samoan society as an alternative paradigm of disability conceptualisation. It is proposed in this thesis that the *Tutusa* model be developed to better both cultural and human rights perspectives.

Enduring an era of medical conceptualisations that reduced the functioning of people with disability (through a protective approach), the *Tutusa* model emerges as a progressive conceptualisation of disability in its recognition of equality. However, as discussed in Chapter 2, concepts of equality from a Samoan standpoint incorporate hierarchical relationships, obligatory contributions, and collective identities. Equality, in this sense, is divergent from social model concepts of equality. Achieving equality from a Samoan standpoint is making a contribution in an equal



capacity to others, despite challenges or barriers. It represents a willingness to accept equal responsibility. It is recognising one's place within family and social hierarchies. It is prioritising the valued functions of the collective above personal interest. Adhering to these concepts earns a sense of equality; the right to inclusion, reciprocity, and protection. From this stance, barrier removal diminishes the value of the contribution, reducing the level of equality that is achievable.

The *Tutusa* approach sees the concept of contribution as highly relevant to identity development. Within the *Tutusa* model, contribution is seen as an essential element to inclusion and equality. An individual can only gain unequivocal inclusion, respect, status, and honour through contributing in the same capacity as everyone else, despite the barriers that may exist. Removal of barriers suggests that the person with disability is in some way inferior to the collective. The development of an equitable cultural identity requires a person with a disability to contribute in the same capacity, regardless of functioning or capability.

This early conceptualisation of the *Tutusa* model contradicts many aspects of the social disability model. The development of identity within the framework of a social disability model sees people with disability valuing and celebrating independence. The social disability model endorses people with disability to engage with society. The social disability model sees the removal of barriers as the key to people with disability reaching their potential. These ideas conflict with the ways Samoans develop cultural identities. Independence is not a valued trait within the *fa'aSāmoa*. Acting on behalf of the collective is what underpins identity. Samoa's commitment to the CRPD obligates the government to eradicate practices and beliefs that are discriminatory (Mittler, 2015; United Nations, 2006). It is therefore necessary that



cultural concepts, along with aspects of the social disability model, be assessed and evaluated in order to develop a disability model that values culture and human rights, yet undermines neither. It is proposed in this thesis that the merging of ideas in the development of the *Tutusa* model can be achieved through the facilitation of the CA as a paradigm filter.

As an example of the interaction between disability and the *fa'aSāmoa*, the 2011 film *The Orator* (Tamasese, T., & Fitzgerald, C., 2011) explores concepts of hierarchy and disability from a Samoan cultural standpoint. *The Orator* provides insight into how hierarchical social structures impact upon individual functioning. It is evaluated here in the context of the CA. The evaluation of *The Orator* is specifically undertaken within the frame of the two core concepts of the CA: capabilities (what a person can actually do), and functioning (what a person can do in light of their circumstances). Written and directed by Samoan Tusi Tamasese, the film tells the story of Saili, and his wife, Vaaiga. Vaaiga had been banished from her village for giving birth to a baby out of wedlock, bringing shame to her family. Vaaiga marries Saili and goes to live in his village. Saili, a man with dwarfism has experienced discrimination and stigmatisation. It is a perception of Saili's village that he has reduced capabilities. This has resulted in Saili being denied his family's *tulafale* title. Saili's social position within the village manifests in limited opportunities for him to exercise his capabilities. When Vaaiga dies, her estranged family claim her body. Vaaiga had told Saili that it was her wish to remain in his village. A feud develops between Saili and Vaaiga's family. As an untitled man, and a man considered disabled, Saili has no authority to act against Vaaiga's family. Saili requests that his village bestow him with the *tulafale* title. Seeing his passion, and the lengths he was prepared to go to in recovering Vaaiga's body, his village bestowed Saili with the *tulafale* title. As a



tulafale title holder, Saili's status enables him to be heard by other *tulafale*. It provides him with the capability to fulfil a valued function. Vaaiga's body is returned to Saili's village for burial. Saili is able to demonstrate strength to his *aiga*, proving that he is useful and that his contributions are valuable.

This vignette demonstrates the achievement of active identity development within the *fa'aSāmoa*. It also shows that cultural concepts can be flexible through an assessment of functioning and capability, achievable through the *Tutusa* model.

7.3.1 The Capabilities Approach: A paradigm filter

In Chapter 3, the CA was discussed in the context of its application to disability conceptualisation and policy reform. Having explored the variety of disability conceptualisations present in Samoan society it can be concluded that none of these reflect nor promote Samoan cultural epistemologies.

To revisit the CA, it is a model of human development that assesses and evaluates human well-being (D. Clark, 2006; Nussbaum, 2007; Sen, 1979; Terzi, 2005, 2014). The CA is not designed specifically as a disability paradigm, but can be shaped into a functional tool in assessing and evaluating disability. The concepts of functioning (what a person manages to do given their resources such as age, gender, disability, access to service, nutrition, etc.) and capability (the real opportunity to achieve valued functions) are what drives the conceptualisation of disability within the CA. The focus of the CA paradigm is on what the individual values doing, so disability is not seen as a series of barriers to overcome. Rather its focus is on what activities the person him- or herself values doing. In the Samoan context, the CA could be a practical tool to merge current cultural conceptualisations with social



conceptualisations. Bakhshi and Trani (2006) suggest that the CA can be particularly applicable to developing countries as there is capacity to incorporate a range of influencing factors including family dynamics, religion, living conditions, labour market conditions and of course, the capabilities and functioning of the individual and their family. The CA does not celebrate disability, nor does it see any human state as the norm. Every individual situation can be viewed from a capability and functioning standpoint. What is disabling for one may not be disabling for another. By relocating disability to the individual (or to the collective, as may be the case in Samoa), rather than conceptualising disability as a series of societal barriers, people with disability can be acknowledged and accommodated within the context of cultural norms.

The CA paradigm has the capacity to make global comparisons of disability through its focus on the examination of socio-cultural factors that impact upon functioning (Terzi, 2005). The collection and reporting of statistics of disability is part of the commitment to the CRPD. In relation to data collection, Mittler states, “Not to be counted can be considered an extreme form of discrimination” (2015, p. 85). This has presented as an issue in data collection in Samoa. The reported statistics from the Samoan Adult Identification Survey (3 percent of the population) fall well below WHO global estimates of 18.2 percent. Reluctance to be identified and the quality of enumerators could be contributing factors in people with disability not being counted in data collection efforts in Samoa. In using a CA model for analysis and comparison, developing or recently developed countries are no longer compared to developed countries where standards can be immediately unachievable.



Facilitating a CA paradigm for policy development in Samoa enables the merging of a human rights discourse with cultural conceptualisations of collective identities, further developing the *Tutusa* model. Although in many ways the CA focuses on the functioning and capabilities of the individual, the strength of this paradigm is that it can be remodelled to represent the functioning, capabilities, and best interests of the collective also.

The CA alone is not immediately applicable to the Samoan context. Its capability to incorporate factors such as family dynamics, culture, and living conditions is propositional. Transforming the CA into an appropriate and functional model of disability conceptualisation requires the assessment and evaluation of valued concepts and desired outcomes. In this way, the CA becomes a filter for valued concepts.

The lack of congruency in the conceptualisation of disability in Samoa has created a complex environment. Conflicting paradigms of disability conceptualisation have created a circumstance where people with disability must choose between either an identity as a person with disability, endorsing the ethos of a social disability model, or a cultural identity, maintaining the status quo of their village.

The endorsement of the *Tutusa* model has great capacity to represent the perspectives of both a human rights discourse and a cultural standpoint through a CA filter. As shown in Figure 10, the CA model can be used as a filter for cultural concepts and the concepts of a social disability model.

The role of the CA in this approach to the development of the *Tutusa* model is to assess and evaluate concepts to determine their relevance within the Samoan context.



The CA, in Nussbaum's view, does not prioritise capabilities (Nussbaum, 2007). In its application to the Samoan context, the CA is an ideal tool to combine cultural epistemologies with the social disability paradigm, affording equal value to both. What are considered valued aspects of culture would need to be the subject of extensive research and consultation. Determining the relevance and necessity of aspects of the social disability model would be guided by obligatory obligations set out by the CRPD.

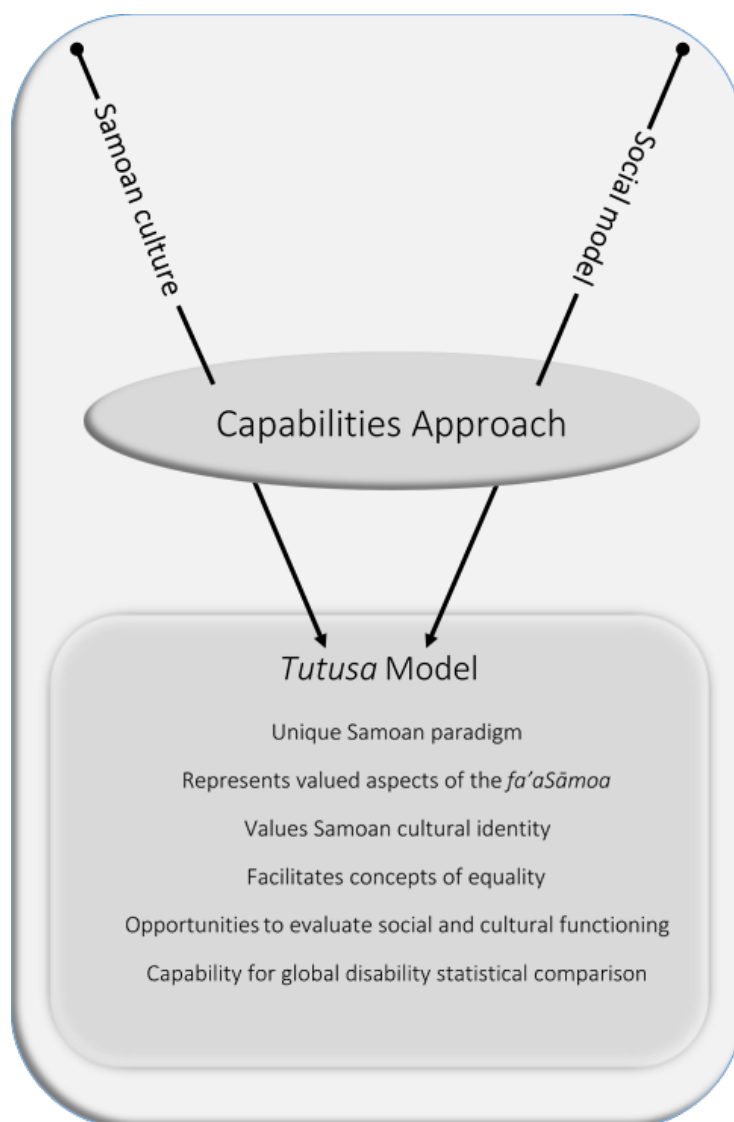


Figure 10. The development of the *Tutusa* model facilitating a Capabilities Approach filter

In the assessment and evaluation of the valued functions for disability policy development, Table 13 illustrates the strengths and disadvantages of each of the disability paradigms that exist in contemporary Samoan society. Through the facilitation of a CA filter, the *Tutusa* model can blend models to establish a unique Samoan paradigm of disability through a self-determination approach.

The development of a uniquely Samoan conceptualisation of disability mitigates many of the implications that a social disability model has on identity development within the *fa'aSāmoa*. Developing and implementing the *Tutusa* model into disability conceptualisations provides a unique opportunity for Samoa to uphold obligations of the CRPD to the international community, while recognising disability within the cultural context of the *fa'aSāmoa*.

7.4 Cultural access and disability conceptualisations within the *fa'aSāmoa*

Conceptualisations of disability, and resulting practices, greatly affect the development and maintenance of identity for people with disability. The development and maintenance of identity is impacted upon by factors such as culture, marginalisation, and political reform. This research found that cultural identity development and maintenance can be threatened by the ways Samoans conceptualise disability, and by a changing political and social landscape of disability.



Table 13. Assessment of disability paradigms in Samoa

	Cultural concepts	Social disability model	<i>Tutusa</i> model
Type	Moral, medical, and protective paradigms.	Human rights and social equity paradigm.	Cultural and human rights paradigm.
Premise	Disability results from curses or illness, and people with disability need to be protected and restricted.	Disability is a result of barriers that exist in society.	Disability is a human experience that incorporates culture, human rights, and lived experiences.
Capacity	No capacity to collect and report comparable data.	Capacity to collect and compare data globally, enabling effective service and funding provision.	Capacity to compare data to similar circumstances and also make global comparisons to target valued functions.
Focus	Focus on the impact of disability.	Focus on societal barriers.	Focus on valued cultural functions within a human rights frame.
Outcome	Does not celebrate disability, resulting in stigmatisation and marginalisation.	Celebrates diversity and equality, but does not acknowledge the lived experience of disability.	Recognises equality and functioning within an assessment of valued cultural practices.

7.4.1 Identity development and cultural access

As discussed previously, this research identified a diversity of representations of disability in Samoa, ranging from the total removal of expectation, as in the moral and medical models, to the maintenance of expectation, as in the *Tutusa* model of disability. The concepts of the *fa'aSāmoa* are represented within moral, medical, and cultural paradigms through love, contribution, and service. Within these paradigms the onus of responsibility for contribution, and ultimately identity development is altered. The onus of responsibility determines access to, and extent of cultural identity.

For people with disability who are subject to a moral or medical model of disability, their role in identity development is passive. The research indicates that moral and medical perceptions of disability see people with disability as dependent. The role of the family is to provide care for people with disability out of love, but also out of obligation to ensure the honour of the collective. In reciprocation, the person with disability must comply with the requests of the family. Contribution is seen as a form of currency that permits increased rights and responsibility, thus increasing status. Contribution is not always financial, but can include the sharing of knowledge, physical activities, and leadership. The data from this research indicated that for people with disability the development of identity is restricted through limited opportunities to practice contribution, service, and honour.

Within the paradigm of a medical model, people with disability are viewed as sick and the responsibility of the family is to provide care. A perception exists that families will be judged harshly by society for expecting a person with disability to carry out tasks that contribute to the family's prosperity and status. This belief impacts on identity development, as people with disability are restricted from contributing, resulting in an exclusion from the highly significant act of reciprocity.

In circumstances where moral and medical models are practiced, contribution for people with disability is by way of compliance, ensuring that the honour of the family is not challenged. There is limited opportunity for people with disability to take an active role in identity development. However, through the *Tutusa* model, identity development and the achievement of equality is an active pursuit. For people with disability to actively contribute facilitates authentic identity development and a sense of equality within the collective context.



7.4.2 Marginalisation and stigmatisation

It has been reported that Samoans with disability are marginalised (Lameta, 2013; R Tufue-Dolgoy, 2010; L. F. Va'a, 2006). One of the objectives of the social disability model is barrier removal to create an inclusive society. This objective is being addressed in Samoa through policy, and indeed in the acknowledgement that people with disability are marginalised. The key conceptualisations of disability in Samoa play a pivotal role in the marginalisation of people with disability. Marginalisation is an issue that is not exclusive to Samoa. Globally, marginalisation of minority groups, and particularly people with disability, is still a critical issue. In Samoa, marginalisation manifests through a lack of physical access, a lack of effective service provision, a lack of trained personnel, reduced access to targeted education programs and health care, reduced access to employment, and perhaps most significantly, stigmatising attitudes.

Within a moral paradigm, stigmatisation arises through perceiving disability as a curse, indicating that the family have committed an act of transgression. Stigmatising attitudes in this case, are directed not only at the person with disability themselves, but at the entire collective identity. This potentially results in families experiencing shame and blame. In extreme cases, it has been suggested by participants in this research that some families hide people with disability to avoid judgement but it was reported that this is becoming increasingly infrequent. From a medical model standpoint, stigmatisation is manifested largely through pity and a sense that people with disability are useless and unproductive (Garrick Duhaney & Salend, 2010; Wizner, 2006). Stigmatisation in Samoa resulting from the medical model paradigm can be experienced by the person with disability themselves, as they are excluded from the act of contributing due to the perception that they are incapable. In the event



that a family does permit a person with a disability to fulfil contributions, there is a perceived risk that this will result in the family being judged for expecting a ‘sick person’ to carry out obligations. The research indicates that the medical paradigm places people with disability in a tenuous position. Shame could be brought upon the family if independence is exercised. Alternatively, cultural identity is placed at risk due to restrictions to contribution. Again, this does not provide opportunities for people with disability to pursue active identity development.

The social disability model, in support of self-determination, equality, and inclusion actively acknowledges stigmatisation as a barrier to societal inclusion. A social model conceptualisation of disability was developed around ideologies of society celebrating individualism and egalitarianism. This is not the case in traditional Samoan societies where collectivism and social stratification are highly regarded. Again, people with disability find themselves faced with a dilemma. Choosing a social disability conceptualisation denounces many of the aspects of the *fa’aSāmoa*. This risks the development and maintenance of cultural identity and inclusion. Choosing cultural preferences repositions disability as a fault of the individual, attracting shame and stigmatisation. This quandary between individualism and culture forces people with disability to choose between a collective identity and a human rights standpoint.

This research identified several key inhibitors of positive identity development for Samoans with disability. The perception of disability from a moral paradigm attracts stigmatising attitudes for all members of the collective. The medical model paradigm restricts people with disability from accessing society. It is widely acknowledged that the moral and medical models of disability need to be phased out of Samoan



conceptualisations of disability (Lameta, 2013; McCullough, 2005; Ministry of Education Sports and Culture, 2006; Ministry of Women Community and Social Development, 2009; R Tufue-Dolgoy, 2010). These models have little relevance to people with disability in contemporary Samoan society. Despite aspects of these models being represented through the tenants of the *fa'aSāmoa*, such as love, service, and obligation, they do not address the rights of individuals to societal inclusion and equality. The social model paradigm does not recognise the unique cultural aspects of Samoan society, forcing people with disability to choose between a cultural identity and an identity as a person with a disability.

The social model of disability has raised the profile of disability in Samoa and has addressed fundamental issues around the human rights of marginalised groups. However, up to this point culture has not featured as a crucial aspect of policy development for people with disability. In fact, the CRPD actively endorses the modification of customs and practices that either directly or indirectly discriminate against people with disability (Mittler, 2015; United Nations, 2006). Identifying factors that stigmatise and marginalise people with disability illuminates the importance of active identity development.

7.5 The role and implications of terminology

One of the objectives of this research was to determine how terminology and discourse represent disability and to what extent they impact on conceptualisations and identity development. Before discussing the findings of this research, and the impact of terminology on disability conceptualisation in Samoa, a discussion on



language development will assist in the framing of discourse and terminology within the Samoan context.

Language itself is a tool for communities to express thoughts and feelings. Moreover, language has a social function in creating speech communities (Finegan, Besnier, Blair, & Collin, 1992). Being a part of a speech community is the sharing of meaning. Speech communities share not only a dialect, but a code of structure, organisation, expression, and frequently, the attitudes and opinion of the collective that result in shared understand (Finegan et al., 1992; Morgan, 2004). Clark and Marsh state, “the language that people use reflects what they think” (2002, p. 1). Language varieties, or registers, have a level of flexibility that enables them to be easily transferable depending on a range of variables. These registers have changing applications in different circumstances. For example, registers can reflect activity or topic, they can reflect status and power, or they can reflect the purpose of the language (Finegan et al., 1992). Registers can also incorporate the use of slang terms, which have a legitimate role in language (Finegan et al., 1992). In the examination of the development of language for disability in Samoa, it is worthwhile to consider the registers that feature as part of language generally. The development of a disability register in Samoa requires consideration of the political, social, and cultural functions that have emerged from recent policy reform. Moreover, it requires an evaluation of the topic of disability itself, the role of all of the participants in the development of disability discourse, and the perception the terminology and discourse will perpetuate.

Language is a contributor to one’s social identity (Changjuan, 2013; Finegan et al., 1992; Morgan, 2004). It reflects identifying characteristics such as region, gender, social class, and age. It establishes shared meaning among the speech community,



facilitating shared opinions, attitudes, and judgements. In this way, language has the capacity to be stigmatising (Finegan et al., 1992). This is evident in the historical discourse of disability in Samoa. Terms that contribute to a sense of shared understanding within the speech community about disability has reflected a deficit understanding of it.

The development of a register of disability in Samoa will inevitably incorporate the current political context, but this research indicates that incorporating the Samoan language is of significant value. Standardising disability discourse will contribute to shifting societal attitudes on disability, as well as addressing issues of the impact of terminology and discourse on identity development. In some instances, the utilisation of a language guardian can ensure that a new register is effective (Finegan et al., 1992). For example, the selection of language in the Samoan context would require an evaluation of the dialect to be used. A language development community or the appointment of a language guardian in Samoa could also ensure the standardisation of language through the establishment of consistency, and in the promotion of terminology (Finegan et al., 1992). The development of a new disability discourse would also require a process of codification, where the language development community or language guardian would be responsible for eliminating or restricting particular language choices. Finegan et al. (1992) assert that it is of particular importance that technical terminology be subject to the scrutiny of codification in order to develop a register that accurately reflects the desired shared understanding.

Language is in a constant state of change (Finegan et al., 1992). Frequently, this occurs spontaneously to reflect societal shifts. However, calculated change may be a necessary feature of reshaping public perception, as is the case in Samoa. Tufue-



Dolgoy (2010) identifies current colloquial discourse, based on medical descriptors, as a contributor to promoting deficit perceptions of disability in Samoa. Lameta (2013) suggests that the use of medical model language is diminishing, although it still does exist. This research found that the affective meaning that has been constructed in Samoa is associated with negative feelings and attitudes about disability, impacting upon positive identity development. McKinstry et al. (2012) state that law and policy needs to reflect the recognition of human rights and dignity of people with disability throughout the Pacific. The reports cites the 2002-2003 legislative review in summarising the first Asia-Pacific Decade for Disabled People, identifying a key issue of “changing antiquated and devaluing language” (McKinstry et al., 2012).

7.5.1 Language and belonging

It has been widely acknowledged that there is a fundamental link between culture, language, and concepts of belonging and self-worth (Kolone-Collins, 2010; Merriam, 2007; Taufe'ulugaki, 2001; Thaman, 2008, 2009; L. F. Va'a, 2006). Being a part of the language of the cultural group provides opportunities for membership and inclusion (Amituanai-Tolua, 2010; Sanga, 2004). Speech communities, and the registers that are used have the potential to be stigmatising (Finegan et al., 1992). With no uniform way to describe disability in Samoa, confusion exists around the conceptualisation of disability itself. Is it a medical issue? Tufue-Dolgoy (2010) argues that the MESC policies still approach disability from a medical model. Is it a social conceptualisation? The SNPD represents disability from this paradigm. Or is it a cultural model? Some NGOs are developing ethno-specific terms in developing a disability register. The lack of shared understanding between agencies and ultimately



within society is a significant contributing factor in the continued marginalisation of people with disability. Not only is there no uniform way to conceptualise disability, there are no uniform terms that reinforce a shared understanding.

This research found that a number of factors contribute to societal barriers and stigmatisation, and the existing register of disability contributes significantly to both. The existing disability register in Samoa blends colloquial discourse with introduced terms. Colloquial terms such as *ma'i* have become derogatory in a political capacity, but this research indicates that colloquial terms are still frequently used within families as a tool of shared understanding. Medical terminology that describes specific impairments such as *faipe* (hearing impairment) or *leaga le ulu* (intellectual disability), are also part of a shared understanding, particularly for speech communities that conceptualise disability medically. This type of labelling contributes to reinforcing an inherently negative shared understanding of disability. This research found that some terms to describe disability were not well understood resulting in confusion within speech communities regarding whether particular terms are considered polite or offensive. In the case of the word *tauaso* (vision impairment), the research indicated that some participants understood the word to be polite, meaning that both eyes were without vision. Other participants found the word highly offensive, meaning “broken eyes”. In place of increasingly offensive language, an initial register has been developed, but has not been uniformly used throughout policy.

Developing a disability register is a challenging task. The purpose of the terminology must be examined. Is it to develop global uniformity for data collection? Is it to better direct the provision of service? Is it to reduce stigmatisation and remove



societal barriers? Is it to create a shared understanding of disability? Is it to enhance feelings of belonging and self-worth? Or does it represent a combination of these purposes. The issue of discourse is multi-faceted and the development of terminology and discourse needs to take all of these factors into consideration. The process of how this could be approached is an issue for future research.

This research identified some dilemmas in the development of ethno-specific terms. Suggestions from participants included the translation of English terms, although it was acknowledged that this could amount to entire sentences in Samoan, which is not entirely practical. There was also the suggestion that English words be transliterated (as in the case of words such as *spooni* for spoon, or *balooni* for balloon, and it was suggested *autesima* could be used for autism). This suggestion places Samoan discourse within international comparability, but does not address the issue of shared understanding without significant public education on specific impairments. Samoans increasingly engage in code-switching (L. F. Va'a, 2006), or what Kruse Vaai (1998) refers to as hybridisation of language. The idea that disability discourse can share features of both English and Samoan is certainly viable. Another suggestion was that an entirely new, ethno-specific discourse be devised for use in policy and within the community. In some ways, it is a process that has already commenced. While this option certainly would address the issue of cultural identification, it fails to address global comparison issues. The dissemination of any newly established register is an essential aspect of its success. Finegan et al. (1992) assert that “it is particularly important that terminology for technical subjects...be standardised” (p. 421). They suggest that standardisation can be achieved through the appointment of a language guardian responsible to oversee the selection, elaboration, codification, and ultimately the dissemination of a newly established register. An interesting point



raised throughout the data of this research is that Samoan language in general is based upon a hierarchical structure, facilitating the use of language and terms that denote respect and status. The issue raised by some participants was that the development of new terms based on a social disability model would fail to take into consideration the roles of the participants in the interaction, or the *tenor* of the register. Tenor is concerned with the relative power and status that exists between language participants. Terminology choice can be an indicator of social characteristics, and the interplay between members of the speech community. In Samoa, traditional concepts of respect and status will impact upon the development of disability discourse. It was raised as a concern in this research that developing a disability register based on a social disability model challenges aspects of the *fa'aSāmoa*, forcing people with disability to refer to themselves with terms that would be considered self-promoting, rather than collective and respectful. This was not a widely held view, but nonetheless highlights the need for further investigation into the issues surrounding discourse development in Samoa.

Other factors that need to be taken into consideration in the development of a new Samoan discourse of disability include the issues that are relevant to discourse reform worldwide. The argument of whether labels are relevant or necessary presents valid arguments for both positions. It has been reported that the process of labelling, whether it be for disability or other minority groups, is inherently negative (Eayrs et al., 1993; Lang, 2007; Shakespeare & Watson, 2001). A label can overgeneralise disability, reducing a person to a mere set of descriptors, which can come to be a source of deficit identity development (Barton, 2009; Eayrs et al., 1993; Madden & Hogan, 1997). Conversely, labelling is an effective tool in shared understanding, in the provision of service, and in the measurement of disability prevalence globally



(Madden & Hogan, 1997; World Health Organisation, 1997). The value and purpose of discourse development in Samoa needs to be ascertained to ensure it meets the needs of all stakeholder groups.

Ultimately, the intent of any discourse reform is to address all of these issues: the development of a shared understanding of disability; the reduction of marginalisation; and the measurement of disability in the allocation of services. In the case of Samoa, this will involve blending ideologies that reflect global disability initiatives, while retaining a sense of cultural identity.

Internationally, disability terminology has been guided by the social model paradigm. The ICF provides guidelines for the standardisation and codification of disability terminology. Developing an appropriate register that considers current political agendas, social circumstances, and cultural factors in the representation of disability has yet to come to fruition in Samoa. Policy development on disability in Samoa has focussed on inclusion and equity, with little emphasis being placed on a unique Samoan register of disability. The terminology of policy in Samoa has been a culmination of ideas but has resulted in a lack of consistency between documents and agencies. Evidence of the usage of the social disability discourse is present throughout the SNPD. The intention of the language used in the policy is to shift the focus of disability from the individual to the limitations of society (Ministry of Women Community and Social Development, 2009). It is stated within the document that “the policy should discuss people in the context of their environment, their community and their family” (Ministry of Women Community and Social Development, 2009, p. 7). The policy suggests that adapting terminology doesn’t ensure inclusion, raising the concern that change may be viewed as an attempt to



plead with society to include people with disability (Ministry of Women Community and Social Development, 2009).

The SNPD has selected terms of usage based upon a social model paradigm as a means to shift public perception of disability. However, the language uses English terms. Some Samoan terms have been developed by NGOs to describe disability (such as *mana'oga faapitoa* meaning person with disability, or *logonoa* meaning hearing impairment) but these are not used in a consistent manner across agencies. The issue emerges that discourse is perpetuating marginalisation of people with disability through a lack of shared understanding. There is no consistent way of describing disability, therefore no consistent way of conceptualising disability. English terms have been used in favour of developing ethno-specific terms (such as in the Population and Housing Census report). So, if, as suggested by Clark (2002), language is a reflection of perception, then careful consideration needs to be given to the development of disability terminology in Samoa. This research identifies a significant dilemma for policy development. Using English terms exclusively does not enable an opportunity for people with disability to relate to or be represented by culture. However, there are certainly merits in using a globally aligned terminology framework such as the ICF in the development of a disability register in Samoa. The collection of data is an important tool in attracting funding and international aid, as well as in the provision of service. Using exclusively Samoan terms does not enable terminology to be used as a benchmark for statistical purposes. Despite using English terms, data collected by the SBS has little application to international comparisons as the terminology employed has few links to either Samoan or international policy (terms such as autistics, slow learners and emotional disability). The use of the ICF



could be beneficial in determining the prevalence of disability in Samoa. In turn, this may have an impact on the provision of service and in the allocation of foreign aid. However, the implementation of ICF discourse does not reflect Samoan culture and language, an important factor in identity development, belonging, and self-worth. These options do not present viability in ensuring cultural well-being while simultaneously meeting global expectations.

7.6 Merging divergent conceptualisations: Culture and the social disability model

The social disability model has experienced great success as a paradigm for viewing disability in western countries. The basic ethos, that disability is located in society, not within the individual removes the sense of blame and shame associated with previous paradigms. Since the 1970s, legislation has promoted the equitable access to society for people with disability. But has this reduced the experience of disablement?

It has been argued that a rights-based discourse associated with a social disability paradigm has not effected a change in the actual experiences of people with disability (Clapton & Fitzgerald, 1997). It has also been suggested that the preoccupation of the social disability model in identifying and removing barriers has failed to acknowledge the reality of impairment (Crow, 1996; Shakespeare & Watson, 2001; Terzi, 2005). Furthermore, the heavy promotion of a social paradigm of disability can in fact result in further marginalisation, as people with disability play down impairment to avoid challenging the ideology of the social paradigm (Crow, 1996; Shakespeare & Watson, 2001).



In a review on disability legislation in the Pacific, Samoa was cited as being a regional leader in disability policy development, as Samoan policy aims to align with global initiatives (McKinstry et al., 2012). The adoption and recent ratification of the CRPD has had an obvious impact on raising the profile of disability issues in Samoa. An example of the way in which Samoa demonstrates their commitment to and leadership in global initiatives is through the MESC Education Policy. The policy recognises the need for language, skills, and knowledge that best prepare students to enter global economies, while simultaneously celebrating culture through incorporating non-formal learning practices and bilingualism (Ministry of Education Sports and Culture, 2006).

There has been time to reflect on the success of a social disability paradigm in Samoa since the publication of the SNPD. This research has identified some areas for consideration in future policy development incorporating global obligations, human rights, cultural identities, and the functioning and capabilities of people with disability. This research found that people with disability still experience marginalisation despite a recent shift to a social model ethos. While policy reflects a human rights stance, people with disability report that they still experience barriers such as access to services, employment, transport, education, as well as basic needs such as hygiene and sanitation. It is not only attitudinal barriers that present barriers to society for people with disability. The physical environment is problematic to inclusion and equity also. This research indicates that lived experiences for people with disability can still present challenges as accessibility issues contribute to dependence for people with disability.



The social disability model also fails to take into consideration many of the barriers experienced by people with disability as a result of social and economic factors unique to developing and recently developed countries. Samoa is a lower middle income country (World Bank Group, 2015b). The changes to infrastructure necessary for full barrier removal are extensive and challenging. Political developments in Samoa have reflected global ideological standards, but consideration of the physical and environmental barriers have not yet been prioritised. Stigmatising attitudes have been the focus of barrier removal, but attention has not been focussed on the very real physical experiences of people with disability that act as barriers to social inclusion. Recognition of the physical experiences of people with disability is something that the social disability paradigm does not prioritise. In a recently developed country such as Samoa, and in other countries throughout the Pacific generally, the physical environment poses significant barriers. Some potential barriers include access to toilets, the absence of vision impairment traffic lights, lack of adequate footpaths, limited access to public transport, and insufficient built environments around homes (including restricted inside sanitation and access to electricity). New policy reforms are not specifically targeting these physical barriers. Policy has identified physical barriers, but the actual physical experience of disability is yet to be impacted.

There are global obligations that Samoa must meet regarding human rights and the adoption of disability policy. One report suggests that Pacific island countries are not on track to meet the MDGs despite Australia having provided significant financial aid for this purpose (Australian Agency for International Development (AusAid), 2009). One of the ways that Samoa is required to meet their international obligations is in the reporting of disability prevalence. Accurate statistics on disability prevalence assists the government in the allocation of service provision, education, health care,



and in the application and distribution of foreign aid. The success of a human rights discourse is an awareness of the magnitude of disability prevalence to ensure that people with disability are positively affected by policy.

Perhaps the most significant opposition to a rights-based paradigm in Samoa is culture itself, and the concepts that underpin the *fa'aSāmoa*. Tufue-Dolgoy (2010) recommended that further research needs to be conducted into the interaction between the social disability model and the *fa'aSāmoa*. She concluded that the success of inclusive education policy has been hampered by perceptions of disability and cultural concepts incorporating hierarchies, power relationships, and contribution. In investigating the cultural conceptualisations of disability, this research confirms the incompatibility of the *fa'aSāmoa* and the social disability model. The nature of hierarchical relationships, concepts of service and contribution, and the importance of attracting honour to one's family all conflict with a social disability paradigm.

It was reported that there is a high level of resistance to the inclusive education policy as it does not respond to Pacific island culture (Lameta, 2013; McKinstry et al., 2012; R Tufue-Dolgoy, 2010). This research supported these findings and found that a process of acculturation needs to be adhered to in order for Samoan people to embed value within it. Acculturation is by no means a new concept to Samoans. The value of progress to Samoa is evidenced by the myriad of partnerships Samoa has forged with Australia, China, and other countries in the Pacific region in pursuit of sustainable development. This research found that while Samoans respect international political and practical assistance, a passion for the *fa'aSāmoa* remains. Policy that is not based upon Samoan cultural values has the capacity to erode the fundamental cultural concepts of the *fa'aSāmoa*. This is already being reported



through the impact of changing family structure due to economic factors (Thornton et al., 2013; Thornton et al., 2010). Research carried out by Thornton et al. (2013; 2010) reported that as Samoans increasingly deviate from cultural norms in favour of global economic practices, concepts of the *fa'aSāmoa* are eroded. This changing space has implications for people with disability. It is essential to ensure that people with disability are not further marginalised due to emerging policy that does not incorporate culture. It is of equal importance that people with disability are not marginalised from culture due to the cultural limitations of policy. The choice for people with disability should not be between culture or policy, but the choice to effectively engage with dual identities.

7.7 Conclusion

This chapter has examined the themes identified through the research process. From this research emerges a uniquely Samoan cultural conceptualisation of disability, as well as identifying other factors that influence perceptions. The research has drawn conclusions from five main findings. Regarding disability conceptualisation, the research found that multiple disability conceptualisations impact upon positive identity development for people with disability. The assumption that curses and illness are catalysts of disability has instigated an attitude of shame, blame, and protection. Where these attitudes are exhibited, they have limited the capabilities of people with disability. From an examination of the conceptualisations of disability in Samoa, the research found that the existing moral and medical paradigms were incompatible with a human rights standpoint, currently politically endorsed through a social disability model. It also found that a social disability model was incompatible with the *fa'aSāmoa*.



From the research, the *Tutusa* model was identified, and it is proposed in this thesis that further development of the *Tutusa* model (through a CA filter) be undertaken to effectively blend valuable cultural concepts with a human rights standpoint. A CA filter will facilitate the assessment and evaluation of concepts that would advance the *Tutusa* model in cultural and human rights capacities.

One of the most significant findings is the impact on identity development for people with disability as they are increasingly forced to choose between shifting cultural and social circumstances. The research found that active identity development is challenged by conceptualisations of disability. The findings of this research indicate that where moral and medical approaches are brought to disability conceptualisation, identity development is imposed upon through restricted opportunities to contribute and participate in society. This has resulted in marginalisation and stigmatisation of people with disability.

An examination of discourse found that Samoan terms contribute to marginalisation and stigmatisation. Recent discourse reform has attempted to address the issues of stigmatising language but concerns still exist around lack of uniformity and the usefulness of English terms in policy documents. Finally, this chapter has explored the perception of foreign influences and the impact these influences have on personal identity, and economic and political positions. The development of a political position on disability in Samoa has been rapid and necessary. Part of the obligatory reform of the CRPD is the modification of discriminatory customs and practices. In this instance, evaluating cultural beliefs and practices through a CA paradigm may provide a useful tool in future policy development. The further development of the



Tutusa model can be achieved through evaluating the aspects of culture and of a social disability model that reflect a relevant Samoan standpoint on disability.

Overall, the findings of this research indicate that combining the ethos of a social disability model with cultural concepts such as collective identities, belonging, and contribution will enhance the experience of disability, and support culturally responsive political development.



Chapter 8: Conclusion

8.1 Introduction

The purpose of this research had three core directions, resulting in five main findings. Firstly, to explore the concepts which underpin a unique Samoan conceptualisation of disability and the impact of this on cultural and social identity development. Secondly, to determine how discourse represented disability, both in a colloquial capacity and through policy. Thirdly, to examine the perceived value of introduced cultures and discourses on the development of disability policy, practice, discourse, and conceptualisation in Samoa. Disability in Samoa has been a rapidly evolving area of development both in policy and practice in recent times. The findings of this research provide a basis for ongoing research that can guide the development of culturally responsive and globally relevant policy and practice.

8.2 Summary of main findings

In determining how Samoans conceptualise disability, the research found that multiple conceptualisations of disability exist in Samoan society resulting in a lack of shared understanding of the concept of disability. Multiple conceptualisations of disability have contributed to marginalisation and stigmatisation of people with disability. From the identification of multiple conceptualisations of disability, the research found that a uniquely Samoan conceptualisation of disability, the *Tutusa* model has emerged, facilitating the blending of cultural and human rights concepts.



The research also identified a conflict between the interaction between the *fa'aSāmoa*, established disability paradigms, and identity development. This conflict has perpetuated stigmatising attitudes.

In determining the role of language in disability conceptualisation, the research identified terminology as a contributing factor in the perpetuation of stigmatising attitudes towards disability. Finally, the research identified an incompatibility with current global initiatives of disability (currently endorsed through a social disability model in policy in Samoa) and concepts of the *fa'aSāmoa*.

The research found that multiple conceptualisations of disability exist throughout Samoan society. Samoa has blended conceptualisations from a range of influences including religion, colonisation, and more recently global and economic factors. This has resulted in a lack of shared understanding of the concept of disability. The three most predominant conceptualisations of disability (moral, medical, and social) in Samoan society have contributed to stigmatisation of people with disability.

The research found that a moral paradigm was one of the dominant conceptualisations of disability in Samoa. Perceptions of disability from a moral perspective, blended with concepts of the *fa'aSāmoa* have resulted in disability being perceived as shameful. Although this research suggests that this belief is diminishing, it has significantly contributed to marginalisation and stigmatisation in Samoa. Within the context of the *fa'aSāmoa*, moral perspective sees disability as a consequence of misconduct or wrongdoing. The physical manifestation of misconduct is disability, advertising the occurrence of wrongdoing. Where misconduct is seen as a failure to contribute to the status and prosperity of the collective, it results in reduced reciprocity and inclusion. The consequence of disability from a moral paradigm is



felt not only by the individual, but by the immediate family, and even the entire *aiga* group. Aspects of the *fa'aSāmoa* that emphasise contribution and usefulness impact upon the way that disability is conceptualised.

Disability as a curse represents one perspective of a moral paradigm. Another perspective is that disability is a blessing. Coming from a place of love and compassion, perceiving disability as a blessing has been found in this research to have links to both moral and cultural concepts. Disability conceptualised as a blessing presents an opportunity for care providers and family to gain approval from a higher spiritual entity. This research found that from a *fa'aSāmoa* frame, the perception of disability as a blessing incorporates unconditional love, promoting unity and collective strength. Within this perspective, contribution from a person with disability is not an expectation. However, a perceived inability to contribute due to disability is recognised as a weakness requiring collective compassion.

This research also identified the presence of a medical paradigm of disability conceptualisation. Within a medical paradigm, disability is seen as arising from underlying medical conditions, disease, or trauma. People with disability, from this perspective, are seen as less useful due to a perceived reduced capacity to contribute to either family or society. Fundamental aspects of the *fa'aSāmoa* such as love, contribution, and obligation impact upon the medical conceptualisation of disability, as families see a person with disability as sick and requiring extensive care. This highly nurturing attitude can act as an inhibitor to independence. Where people with disability are considered sick, families can restrict contribution. This research found that when people with disability are given the opportunity to exercise independence or make contributions, a concern exists that other families or society in general would



assume that adequate care was not being rendered. This perception of the care of people with disability potentially results in shame being experienced by the family. This research found that the medical paradigm restricts people with disability from contributing, and compromises the ability to positively develop concepts of self-worth. This conceptualisation has a significant impact on identity development for people with disability as it acts as an inhibitor to personal development. In the case of the medical model paradigm, people with disability find themselves in a vulnerable position. Independence for people with disability can be viewed as neglect on the part of their extended family. The choice that arises for people with disability is between a culturally secure, but dependent identity, and a progressive, independent identity, potentially risking family exclusion.

The Samoan government, in collaboration with other stakeholder groups, has developed policy to challenge moral and medical perspectives and introduce a new model of disability. Influenced by global disability models, the Samoan government has developed the SNPD based on the premise that societal barriers are what disables people. One of the main barriers identified through the policy is negative attitudes and perceptions of disability. This research has built upon Tufue-Dolgoy's (2010) thesis that the social disability model is incompatible with Samoan cultural practices, specifically the hierarchical nature of Samoan culture and concepts of collective identity and contribution.

The data from this research found that in many instances, the *fa'aSāmoa* and the social disability model did not complement one another. However, an emergent conceptualisation identified through this research, the *Tutusa* model, attempts to blend both the social disability model with cultural underpinnings. The *Tutusa* model



requires extensive remodelling to ensure that disadvantage is not experienced as a result of aspects of culture that inhibit contribution and identity development. In doing this, a new disability paradigm for Samoa can facilitate inclusion within a cultural context, securing identities that simultaneously represent culture and equality. The *Tutusa* model could be developed through a CA framework, as described in Chapter 7. Using the CA as a filter would enable the evaluation of priorities unique to individuals, families, and Samoan society generally. This process of developing the *Tutusa* model within a CA framework would recognise cultural beliefs and practices, human rights standpoints, and the experiences of disability itself. The application of the *Tutusa* model and the CA is discussed in more detail in the recommendations later in this chapter.

In achieving positive cultural identity development the research found that for people with disability, passive identity development arises within moral and medical paradigms. Passive identity development results from a lack of opportunity to contribute, resulting in dependence, and a lack of equality. An opportunity to contribute would enable active and positive identity development. However, contribution from people with disability could attract shame to the collective. The research found that the interaction of various disability models and the *fa'aSāmoa* contributes to marginalisation and stigmatisation of people with disability. In this space, a complex dilemma arises for people with disability; choosing active identity development aligned with a social disability models at the risk of cultural identity and acceptance, or choosing a passive cultural identity, challenging basic human rights.

This research also found that a lack of uniform terms is a contributing factor in the marginalisation and stigmatisation of people with disability in Samoa. Colloquial



language, derived from moral and medical models has become increasingly offensive. However, there is still a high level of shared understanding within its usage. As a social disability model is promoted, it is becoming increasingly recognised that current discourse is not reflecting social rhetoric for disability. Attempts by government agencies and NGOs to reshape discourse have yet to become a coordinated effort. Several dilemmas exist around the development of a disability register: the need for shared understanding and effective public education on disability; consistency of terminology between all agencies, departments, and service providers; and whether terminology will be developed in English or Samoan. This research identified discourse as a central aspect requiring reform in order to shift a deficit disability perception. The ICF is an excellent resource for terminology usage and data collection and reporting for English speaking countries, but it is less applicable to Samoa. Using ICF terminology without ethno-specific modifications prioritises a social disability model, but disregards cultural belonging. Alternatively, using ethno-specific terms exclusively restricts the capacity to collect and report on disability prevalence, affecting the distribution of service provision and the allocation of foreign aid. Further research is required to determine the impact of discourse on identity and belonging. An assessment and evaluation of current terminology will help to determine the most effective strategy to develop appropriate discourse.

Finally, this research found that Samoans generally are highly receptive to borrowed policy and ideologies. However, underpinning policy with Samoan cultural concepts is highly valued. This research confirmed the findings of Tufue-Dolgoy (2010) that the *fa'aSāmoa* and the social disability model are incompatible. The research found that despite implementing a social disability paradigm, barriers still impact significantly on the experience of disability. Full barrier removal presents an



overwhelming challenge for developing and recently developed countries. For example, barriers that have yet to be prioritised in recent policy reform include access to and availability of public transport and toilets, education and employment conditions, and more basic issues such as access to water and electricity. These issues present significant barriers in achieving equality and independence. The changes to both economic circumstances and cultural practices require assessment of the position of people with disability to ensure fair representation in both emergent policy and changing social platforms.

The facilitation of the CA in further development of the *Tutusa* model could assist Samoa in achieving global expectations of social disability frameworks while still retaining a sense of culture. Finding middle ground between cultural identity, equality, and each individual's unique circumstances will ensure people with disability have the best opportunity to access society and retain concepts of cultural identity.

8.3 Implications of the research

The findings of this research describe the rich current conceptualisations of disability, and how these perceptions impact upon cultural identity development, belonging, and human rights. The disability models currently present in Samoan society are impacting upon cultural identity, belonging, and human rights. This identifies future development in the area of disability as a priority. This research highlights the need for policy to be revisited to determine how current conceptualisations can be blended to ensure that people with disability have the opportunity to develop and maintain cultural identity within a human rights paradigm.



The research identified a unique Samoan conceptualisation of disability, the *Tutusa* model. The implications of this finding are relevant to future policy development in the area of disability. Having identified the *Tutusa* model, it is evident that there is value in the blending of cultural and human rights concepts. This is of critical importance to the retention of cultural identity for people with disability. Shifting public perception on the way that a social disability paradigm can interact, and even complement, the *fa'aSāmoa* ensures cultural continuity, inclusion, and equality.

The research also identified current discourse as a factor in the stigmatisation and marginalisation of people with disability in Samoa. There is a high level of diversity of current discourse ranging from deficit medical model terms, to ethno-specific descriptors, to terminology influenced by the social disability model. This diversity has created confusion over what terms are polite or offensive, resulting in disability being reduced to labels and descriptors that have no tangible meaning across society. This research identified a number of challenges in disability discourse reform. The link between language and culture is a highly significant one (Merriam, 2007; Taufe'ulugaki, 2001; Thaman, 2009; R Tufue-Dolgoy, 2010; L. F. Va'a, 2006). The initiative of NGOs to develop specific terms for disability ensures that people with disability can secure positive cultural identities through the use of reliable discourse. However, ethno-specific terminologies have limitations as a global data collection tool, which in turn impacts upon the provision of service and foreign aid. Alternatively, the use of international standard terminology derived from a social disability discourse fails to represent Samoan people with disability within a cultural frame, reducing access to cultural identity and belonging. This research identified this dilemma as a priority for future development. It will contribute to the reduction of stigmatisation and the promotion of cultural identity and equality.



This research has confirmed the positive attitude that Samoans have towards foreign ideologies that impact upon policy development and general practice. However, the research revealed a strong desire to underpin all policy with Samoan epistemologies and ontologies, as evidenced through the *Tutusa* model. This has implications not just for the future development of policy and practice for people with disability, but for future policy development in all fields. The application of a CA filter could be evaluated for use in other disciplines also. The introduction of foreign policy without modification contributes to issues of stigmatisation and marginalisation of minority groups. It reduces opportunities for individuals to retain cultural identities as policy relocates minority groups away from local culture and into a global platform. The *Tutusa* model can incorporate the valued aspects of foreign policies to develop policy and practices that recognise culture and lived experiences as a vital component of cultural identity.

It is hoped that this research will prompt future research on the relationship between policy and the *fa'aSāmoa*. Further research will ensure that minority groups are provided with the best opportunity to gain equality and secure an identity within the framework of cultural practices and beliefs. It is also envisaged that this research can inform future policy development targeting the further development of the *Tutusa* model. The *Tutusa* model will address the capabilities of people with disability in Samoa while simultaneously addressing global obligations.

8.4 Limitations of the study

This research has contributed to knowledge on Samoan conceptualisations of disability, the role of discourse in perception, and the general perception and impact



of policy development for Samoans with disability. Using a culturally appropriate research methodology and collaborating extensively with participants ensured the validity of this research, giving it the scope to contribute to change and progress within disability development in Samoa. However, there are some limitations of the study that need to be taken into consideration to contextualise the value of the research.

This research has focussed on a sample of participants across four categories: people with disability, carers of people with disability, extended family members, and people studying or employed within the disability sector. The participants were both male and female, and ranged in age from 21-65+ years. Some participants were recruited through a criterion based sample, and others were part of a snowball sample. All participants lived in the urban Apia area. The recruitment of participants was discussed in detail in Chapter 5. All of the participants had experiences of disability to differing degrees. My role as a researcher was to collect their stories (through *Talanoaga*) to derive meaning in the context of the aims of this research. The findings were inductively derived, but it is relevant to acknowledge that the sample does not necessarily reflect the full Samoan experience. A number of factors contribute to this limitation. Firstly, the research was conducted in the Apia urban area, although there are proportionately more people with disability spread across the island of Savaii (Lameta, 2013). Secondly, all of the participants had personal connections to a person with disability, potentially representing a differing opinion to groups who have no connection or investment in disability as a personal or social issue. Thirdly, some opinions expressed in the data of this research may be obsolete due to the rapidly changing social dynamic in Samoa, along with advocacy and promotion of disability.



As a limitation in itself, the changing landscape of disability in Samoa is rapid and ongoing. Political progress, as well as action-based initiatives of NGOs are largely aimed at reshaping public perception of disability, so these factors may already be impacting Samoan conceptualisations of disability. Therefore, the data may not accurately represent changing views into the future.

It is impossible to determine a purely Samoan conceptualisation of disability due to a myriad of external influencing factors. The influence of foreign ideologies has shaped contemporary Samoan society to a large extent. Colonisation and religious affiliations have contributed to historical and current conceptualisations of disability. Current disability policy has been shaped by borrowed political paradigms that present challenges to cultural underpinnings. These external factors play a role in shaping contemporary perspectives on people with disability, disability practice, and policy. While it can be argued that these influences are part of what makes up the Samoan identity, for the purpose of identifying a traditional epistemological perspective, the research was limited in this way. A collection of conceptualisations have been identified through this research, but they do not necessarily represent a historical or traditional experience of disability.

As this research looks at Samoan epistemologies and ontologies, findings may have less relevance within a global context. The findings of this research will need to be interpreted by Pacific island people in order to determine their relevance in relation to disability perception, practice, and policy.

The research may possibly have an application in other political forums, or other Pacific island countries. This is especially true of the application of the CA in assessing and evaluating policy in other political domains. The exercise of evaluating



culture is a contentious issue, and one that would require extensive further research and public consultation.

8.5 Recommendations

This research has been highly successful in identifying disability issues in Samoa. They can be addressed by further research and action strategies. Several recommendations emerge from this research.

It is recommended that future development reform in the area of disability be carried out to assess the valued aspects of both culture and a social disability stance. It is achievable to incorporate valued aspects of both cultural and political standpoints in the development of disability policy in Samoa. The *Tutusa* model emerges from this research as a disability model with the potential to incorporate culture and human rights. This can be achieved through the facilitation of a CA filter. The CA (discussed in detail in Chapter 3) provides a basis in determining well-being from a variety of stances including economic impacts, standards of living, quality of life, and the implications of poverty (D. Clark, 2006; Terzi, 2005). The CA has been promoted as a useful framework for developing countries as it has the scope to incorporate concepts unique to each circumstance, as well as acknowledging lived experiences (Bakhshi & Trani, 2006). The CA takes into consideration what activities and functions are valued, and what opportunities are available to achieve these functions. The CA has several strengths in its application to Samoan disability policy reform. Using a CA filter as a framework to further develop the *Tutusa* model allows policy to be shaped according to unique circumstances. It also enables the reporting of statistics to be comparable to other similar socio-political environments, resulting in more effective service provision. A CA filter can provide a lens for Samoans to



evaluate valued aspects of culture, politics, and economics. The further development of the *Tutusa* model can incorporate cultural and social frameworks, and reflect unique circumstances from a well-being stance.

Further research can provide an analysis of the ways people with disability can access a social disability paradigm given the available resources. In developing and recently developed countries where accessing equity can be challenged by physical, cultural, and environmental factors it is important that these issues are reflected in policy. The findings from this research suggest that lived experiences of people with disability can be greatly enhanced by combining concepts of culture and human rights. It is therefore recommended that a CA filter could greatly contribute to future disability policy reform.

The lack of uniform and consistent terminology in the area of disability has emerged as an area for further development. However, the aims of this research did not intend to recommend how this process would occur. This research has identified discourse as contributing to stigmatisation and marginalisation. Therefore, it is recommended that further research be conducted into the most appropriate strategy for implementing new terms across all disability agencies in Samoa. This research has identified several dilemmas that exist in the development of uniform terminology, indicating that a community dialogue needs to occur in consultation with stakeholders to determine the best way to proceed.

Finally, this research, like Tufue-Dolgoy's findings (2010), identified a strong conviction that policy must be underpinned by culture, despite a high level of acceptance of borrowed policy. The government has several factors to consider when



assessing policy and its implications. Factors such as global obligations, national and regional development, economics, and the application of foreign aid all impact upon the government's ability to meet the expectations of all stakeholders. It is recommended that further research be conducted to determine and compare the ongoing value and relevance of cultural beliefs alongside the value and importance of global ideologies within the Samoan context. Proposed in this thesis is the facilitation of the *Tutusa* model, developed through a CA filter as a framework for further policy reform. Several future research questions emerged from this research that may act as a guide for future disability policy development:

1. How could the *Tutusa* model be further developed to reflect valued culture and global ideologies?
 - 1.1. What are valued functions from a cultural standpoint?
 - 1.2. What are the real opportunities to exercise valued functions?
 - 1.3. How can policy be made more accessible for people with disability?
2. What is the value and purpose of developing ethno-specific terminology?
 - 2.1 Could ethno-specific terminology and the development of a Samoan disability register be used as a tool for reporting disability prevalence?
 - 2.2 Could a process of transliteration effectively represent disability in a cultural capacity and still be an effective global data collection tool?
 - 2.3 What disability model would form the basis of an ethno-specific discourse?
 - 2.4 How would shared understanding of disability be achieved to assist in a consistent conceptualisation of disability?
 - 2.5 What role could the ICF play in discourse reform?



3. What are the valued cultural functions of Samoans and how can these be incorporated into future policy development?

3.1 What are the non-negotiable aspects of Samoan culture that policy reform must incorporate?

3.2 What are the negotiable aspects of culture that have become irrelevant to contemporary Samoan lifestyles?

3.3 What are the compatible aspects of culture and policy that can be built upon to establish a culturally responsive disability paradigm in Samoa?

Continued research into the development of disability conceptualisation and policy in Samoa will ensure that people with disability are fairly represented in society. A commitment to constructive and relevant development in the area of disability needs to reflect cultural identities as well as notions of equality. The *Tutusa* model can be further developed to shape a unique Samoan conceptualisation that values cultural identity as well as concepts of equality. The further development of the *Tutusa* model has a valued application to policy development and can provide a practical tool for communities to respond to disability.

8.6 Conclusion

The aim of this research was to determine traditional Samoan conceptualisations of disability. Through the research it was found that multiple conceptualisations are present in Samoan society. This has resulted in an absence of shared understanding of what defines and characterises disability. A lack of shared understanding has fundamental implications for positive identity development, societal inclusion, and the acceptance of new policy. In identifying the uniquely Samoan *Tutusa* model, the



research found that blending cultural and human rights concepts is supported. The blending of cultural and human rights concepts has the capacity to develop policy and practice that addresses global and cultural obligations. It is acknowledged that in recommending the development of the *Tutusa* model further research is required. The *Tutusa* model has potential to blend relevant cultural ideologies with global expectations. The research also found that discourse and terminology are reinforcing marginalisation and stigmatisation, further thwarting the adoption of a new paradigm. Finally, the research found that current disability policy is not responding to culture, leading to the erosion of cultural identities for people with disability.

The research has achieved the initial objectives, but has also identified that there is a pressing need to prioritise a future analysis of the issues raised through this thesis. It is envisaged that this research will contribute to future development in disability policy reform in Samoa, and in other Pacific Island countries throughout the region. A CA could provide a useful paradigm to assess and evaluate policy in other areas of policy reform also.

The importance of the Samoan identity and its links to cultural belonging have been emphasised throughout this work. It is the right of all Samoans to secure a cultural identity that is exercised within families and society, and represented in policy and development. It is essential that the next phase of disability policy reform represents people with disability as having the freedom to express a cultural identity, without risking the right to equality and inclusion in a broader societal capacity. For Samoans with disability, this period of reform is an opportunity to reflect on the value of culture, and the significance of progress to reshape the political landscape of disability on the terms of the Samoan people, for the Samoan people.



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Appendices

Appendix A Proposed interview questions

Appendix B Participant information sheet

Appendix C Participant consent form

Appendix D Ethics approval



Appendix A – Interview questions

Guiding Questions for Focus Group Interviews

For all participants, I will be asking these questions:

1. How do you view contributions made to your village by a person with a disability?
2. Do you think having a disability plays a role in identity development for Samoans?
3. Do you think people with disability are limited to access of status, rank and titles as a result of disability?
4. How does having a disability (and possible inability to contribute skills, knowledge and/or monetary support) reflect upon your *aiga*?
5. Do you feel that western educational practices are an effective means of educating people with disability?
6. Do you think current education initiatives reflect in any way traditional Samoan practices?
7. How has western language and practice affected Samoan culture? What affect has it had on tradition and culture?
8. What terminology, specifically, is used to describe a person with a disability?
9. Has the English language and English terminology relating to people with disability had an impact on perceptions of people with disability?
10. What traditional practices are carried out to cater for or include people with disability?

Only the Elder *aiga* groups will be asked these additional questions:

1. What are traditional perceptions and explanations of people with disability?
2. What practices were traditionally carried out to cater for or include people with disability?



Appendix B – Participant information sheet

Participant Information sheet

Date information sheet produced: 11/09/2012

Talofa lava

My name is Catherine Picton and I am a doctoral student at the Central Queensland University. I am about to commence research for my thesis under the title of 'Conceptualising learning disability from a Samoan epistemological and cultural reference frame'. Having lived and worked as a teacher in Samoa for six years, I have an ongoing interest in Samoans with disabilities. I would like to invite you to participate in my study to share your experiences, knowledge and perceptions of disability in Samoa. Your participation will be completely voluntary and you can withdraw yourself from this study if you no longer wish to participate.

Purpose of the research

This research is conducted as part of a Doctor of Philosophy; specifically researching the Samoan perception and experience of disability. My supervisors for this study are Dr Mike Horsley who has conducted extensive research with Samoan communities in Australia, and Professor Bruce Knight, a Professor of Education, specialising in disability. The goal of this study is to explore the perceptions of Samoan people on traditional learning practices for people with disabilities, how western practices and ideas have influenced Samoan practice, and what language and discourse is traditionally used to describe disability experiences.

Selection

You have been selected to participate in this study as you have experience and knowledge of disability practices and of the Samoan language and the Samoan culture in general.

Research procedures

In this study, you will be sharing your experiences and perceptions of traditional learning practices, the role and perception of people with disabilities, descriptive language and terminology to describe disability, and your perceptions and experiences of the influence of western practices. I will meet with you as part of a small groups or sometimes individually at a time and location that is convenient to you to talk about your experiences. I will later analyse the data that I collect from our meeting and use it in my thesis and other papers associated with my thesis. In order to accurately represent the information given to me, I will audio-record our meetings as well as take written notes. I value your participation in all aspects of this research, and will provide opportunities should you wish to check, clarify or change any of the information provided to me.

Benefits

The information gathered as part of this study will be analysed to add to the body of knowledge on traditional Samoan epistemologies. It is intended that through this research, future policy development and practice for Samoan people with disabilities can be informed by the findings of this research to assist in the development of an inclusive and culturally responsive education system.

Privacy

The information provided to me will be used solely for research purposes. All data related to this study will be securely stored at my home or the Central Queensland University, Noosaville Campus until the completion of my work. For auditing purposes, the data will need to be stored until the time requirement expires. At this time, the data will be destroyed.



As the participants in this study may be known to each other, it may be possible to identify other participants from their stories. Therefore, it is not possible to guarantee your complete anonymity but all reasonable steps will be taken to protect your identity and you will not be referred to by name in any written parts of the study.

Participation

My contact details are provided in case you need further information and to confirm your participation in this research. Your participation in this study is entirely voluntary and you have the right to withdraw your consent or the information you have provided at any time until the completion of data analysis. Upon withdrawal, your data will be destroyed.

If you wish to participate in this research, please contact me via phone or email. I have included a consent form for you to read and sign before we meet for data collection.

Feedback

Throughout this research process I appreciate and encourage your involvement to clarify data and authorise the use of your data. I will also present findings to participants at the conclusion of the data analysis.

Questions and Concerns

If you have any questions or concerns regarding this research, please contact the Project Supervisor:

Dr Mike Horsley
Ph: + [REDACTED]
m.horsely@cqu.edu.au

Or the Cultural Advisor:

Mr Tino Tiufea
Ph: [REDACTED]
[REDACTED]

Researcher contact Details:

Catherine Picton
PhD Student
Ph: + [REDACTED]
[REDACTED]



Pepa o Faamatalga Faatatau mo le Sui Auai

Aso na maua ai le pepa o faamatalaga faatatau: 11/09/2012

Talofa lava

O lo'u igoa o Catherine Picton ma o a'u o se tagata aoga su'esu'e i le Faafoma'i o A'oa'oga (doctoral) i le lunivesite o Central Queensland. O le a amataina su'esu'ega mo la'u pepa faai'u (Thesis) ma o lona 'autu: ***“Conceptualising learning disabilities from a Samoan epistemological and cultural reference frame”*** (Vaaiga faalemafaumafau i a'oa'oga o mana'oga faapitoa e faatatau lea i vaaiga faapuna'oa o le iloa o loo faavaaina i le aganuu a Samoa) Ona sa ou nofo faia'oga i Samoa mo tausaga e ono, o loo iai pea lou agaga fia fesoasoani i tagata Samoa e iai o latou mana'oga faapitoa. O lea oute valaau atu ai ma le faaaloalo ina ia e auai i la'u su'esu'ega ina ia faasoa mai lou poto ma lou tomai e uiga i ē e iai lagona ma manaoga faapitoa i Samoa. O lou auai i lenei su'esu'ega e tuu atu lava i lou faitalia, ma e mafai fo'i ona faamutaina pe a e lē toe fia auai.

Uiga o le su'esu'ega

O lenei su'esu'ega o se vaega o le Faafoma'i o le Filosofia (PhD), ma e patino su'esu'ega i vaaiga ma aafiaga faaSamoa i ē e iai mana'oga faapitoa. O o'u faiaoga o Dr. Mike Horsley, o se alii ua lautele ana su'esu'ega i totonu o alalafaga o tagata Samoa i Ausetalia; ma Professor Bruce Knight, o se polofesa tau a'oa'oga faasino i mana'oga faapitoa. O le 'auga o lenei su'esu'ega o le lloilo lea o lagona ma vaaiga a tagata Samoa i faatinoga faaleaganuu e faasino i tagata e iai mana'oga faapitoa; a'afiaga o faatinoga faaSamoa i le fotua'i mai o manatu ma faatinoga mai fafo; gagana faaaogaina e faamalamalama ai a'afiaga o mana'oga faapitoa i totonu o nuu ma aiga.

Filifilia

Ua filifilia oe e te auai i lenei su'esu'ega ona e iai ou a'afiaga ma le iloa o faatinoga e faasino i mana'oga faapitoa, le gagana ma le aganuu faaSamoa.

Faatulagaga o le su'esu'ega

I lenei su'esu'ega, o le a faasoa mai ai ou manatu ma a'afiaga i: faatinoga o a'oa'oga faaleaganuu, le tofi ma manatu o tagata e iai mana'oga faapitoa, le gagana e faamalamalama ai uiga o mana'oga faapitoa, ma ou manatu ma a'afiaga i faatinoga o tu ma aga mai fafo. O le a ta feiloa'i pe a e auai i se talatalaga faavaega pe ta te feiloa'i fo'i na o ta'ua i se alalafaga ma se taimi e talafeagai mo oe. O le a lloilo loloto aoaoga faamaumau(data) o le a aoina mai ta fonotaga ma faaaogaina i la'u pepa faai'u (thesis) poo ni isi pepa e talafeagai ma la'u mataupu. Ina ia ma'oti lelei ma sa'o le faaaogaina o faamatalaga faatatau o le a tuu mai ia te a'u, o lea o le a faaoga ai se pu'e leo i a ta fonotaga ma tusi faamatalaga i lalo. E tūua ia te a'u lou auai i tulaga uma o lenei su'esu'ega ma o le a tuu atu fo'i le avanoa e siaki ai, faamalamalama, pe suia faamatalaga faatatau o le a tuuina mai.

Penefiti

O faamatalaga faatatau o le a aoina mo vaega o lenei su'esu'ega o le a lloilo loloto ma faaopoopo i le tino o tomai faaleaganuu e patino i puna'oa iloa o Samoa. O le naunauta'iga ina ia auala atu i lenei su'esu'ega se vaaiga i le lumana'i o tulafono faataatia ma le atina'e o faatinoga mo tagata Samoa e iai mana'oga faapitoa. O le a mafai fo'i ona ta'iala ni tomai o le a maua i lenei su'esu'ega e fesoasoani ai i ie atina'eina o se faiga faavae faalea'oa'oga e tali atu ai i mana'oga faaleaganuu ma mana'oga o tagata uma.



Puipuia

O faamatalaga faatatau o le a tuu mai ia te a'u o le a faaoga faapitoa i le su'esu'ega. O aoaga faamaumau e patino i le su'esu'ega o le a teu malu i lo'u fale poo totonu o le Central Queensland University, Noosaville Campus se'ia oo i le faai'uga o la'u galuega. O le a teu fo'i aoaga faamaumau se'ia mae'a iloiloga su'etusi ona faaleaogaina ai lea.

O le a iai nisi sui auai e masani i nisi sui auai ma o le a iloa gofie fo'i i a latou tala. O lea la e le mafai ona tuu poloa'iga atu le puipuia o lou faailoaina, ae ui i lea o le a 'ou taumafai e uia uma laasaga e puipuia ai 'oe ma o le a lē tā'ua foi lou suafa i soo se vaega o lenei su'esu'ega.

Auai ai

O a'u numera faafesoota'i na ua tusia atu ina ne'i e mana'omia ni isi faamatalaga faamaumau ma faamautū ai fo'i lou auai i lenei su'esu'ega. O lou auai i lenei galuega e tuu lava i lou faitalia ma e ia te 'oe lava le sa'olotoga e faamuta ai lou iai ma ave'esea ai au faamatalaga. O le a lē faaogaina fo'i au aoaga faamaumau.

A faapea e te fia auai i lenei su'esu'ega faamolemole faafesoota'i mai a'u i la'u telefoni poo le imeli. O lenei ua tuuina atu fo'i le pepa o le Maliega i le Auai ai, ete faitau ai ma sainia a e ta te le'i feiloa'i mo le aoina o aoaga faamaumau.

Manatu toe faaalia

I le faatulagaina o lenei su'esu'ega e faamalosia lou auai mai e faamanino aoaga faamaumau ma faasino le faaogaina tata o au aoaga faamaumau. O le a faailoa foi ni manatu ua maua i ē auai i le mae'a ai o iloiloga o aoaga faamaumau.

Fesili ma Atugaluga

A iai ni fesili poo ni atugaluga e uiga i lenei su'esu'ega faamolemole faafesoota'i mai le Faatonu o le Poloketi ma lo'u faaaloalo lava:

Dr. Mike Horsley
Ph: + [REDACTED]
m.horsely@cqu.edu.au

Faatonu Faaleaganuu

Mr. Tino Tiufea
Ph: [REDACTED]
[REDACTED]

Tagata Su'esu'e

Catherine Picton
PhD Student
Ph: + [REDACTED]
[REDACTED]

Appendix C – Participant consent form

Consent Form

Project title:

Conceptualising learning disabilities from a Samoan epistemological and cultural reference frame

Project Supervisor: *Dr Mike Horsley*

Researcher: *Catherine Picton*

- I have read and understood the information provided about this research project in the Information Sheet dated /2012.
- I have had an opportunity to ask questions and to have them answered.
- I understand the identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential.
- I understand that notes will be taken during the focus group and that it will also be audiotaped and transcribed.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that while it may not be possible to destroy all records of the focus group discussions of which I was part, the relevant information about myself including tapes and transcripts, or parts thereof, will not be used.
- I agree to take part in this research.
- I wish to receive a copy of the report from the research (please tick one) Yes No ☐ ☐

Participant's signature:

Participant's name:

Participant's contact details (if appropriate):

Date:

Note: The participant should retain a copy of this form



Maliega mo le Auai ai

Igoa Autū ole Poloketi

“Conceptualising learning disabilities from a Samoan epistemological and cultural reference frame” (Vaaiga faalemafaufau i a’oa’oga o manaoga faapitoa e faatatau lea i le puna’oa ole iloa o loo faavaaina i le aganuu faaSamoa)

Ta’ita’i o le Poloketi: **Dr. Mike Horsley**

O lē Su’esu’e: **Catherine Picton**

- Ua ou faitau ma malamalama i faamatalaga faatatau e uiga i lenei poloketi su’esu’e i totonu o le pepa o faamatalaga faatatau aso /2012.
- Ua mae’a le avanoa na fai ai fesili ma maua ai tali.
- Ua ou malamalama o tagata ta’itoa tasi matou te auai faatasi ma a matou talanoaga faavaega e fai, e tatau ona ou puipua mai lea i le faailoa faalaua’itele.
- Ua ou malamalama o le a tusiina faamaumaga i taimi faavaega ma o le a pu’eina fo’i leo ma faaliliuina.
- Ua ou malamalama e mafai ona faamutaina lo’u auai ai i soo se taimi ma ave’esea ai fo’i ni faamatalaga faatatau o le a ou tuuina atu ile poloketi, ae le’i mae’a le taimi o le aoina o aoaoga faamaumau.
- A ’ou alu ’ese ua ou malamalama o le a lē mafai ona faalēaogaina uma faamaumaga faavaega na ou auai ai, a’o faamatalaga faatatau ia te a’u, vaega o lipine ma o latou faaliliuina o le a lē toe faaaogaina.
- Oute ioe atu i lo’u auai ai i lenei su’esu’ega.
- Oute talosagaina se kopi o le lipoti mai le su’esu’ega (togi le tasi) ioe leai

Saini a le sui auai -----

Igoa o le sui auai-----

Numera fesoota’i a le sui auai (pe a talafeagai)-----

Aso:

Faailoa: E tatau i le sui auai ona taofi se kopi o lenei faamaumaga



Appendix D – Ethics approval



Secretary, Human Research Ethics Committee
Ph: 07 4923 2603
Fax: 07 4923 2600
Email: ethics@cqu.edu.au

Prof Mike Horsley
Acting head of Campus
Noosa Campus
P O Box 1128
Noosaville DC QLD 4556

Dear Prof Horsley

**HUMAN RESEARCH ETHICS COMMITTEE OUTCOME PROJECT: H12/06-129,
CONCEPTUALISING LEARNING DISABILITY FROM A SAMOAN EPISTEMOLOGICAL AND
CULTURAL REFERENCE FRAME**

The Human Research Ethics Committee is an approved institutional ethics committee constituted in accord with guidelines formulated by the National Health and Medical Research Council (NHMRC) and governed by policies and procedures consistent with principles as contained in publications such as the joint Universities Australia and NHMRC *Australian Code for the Responsible Conduct of Research*. This is available at http://www.nhmrc.gov.au/publications/synopses/_files/r39.pdf.

On 26 June 2012, the Human Research Ethics Committee of CQUniversity met and considered your application. The project was assessed as being greater than low risk, as defined in the National Statement. On 16 July 2012, the committee acknowledged compliance with the requested revisions made to your research *Conceptualising learning disability from a Samoan epistemological and cultural reference frame* (Project Number H12/06-129) and it is now **APPROVED**.

The period of ethics approval will be from 16 July 2012 to 1 November 2013. The approval number is H12/06-129; please quote this number in all dealings with the Committee. HREC wishes you well with the undertaking of the project and looks forward to receiving the final report and statement of findings.

The standard conditions of approval for this research project are that:

- (a) you conduct the research project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee;
- (b) you advise the Human Research Ethics Committee (email ethics@cqu.edu.au) immediately if any complaints are made, or expressions of concern are raised, or any other issue in relation to the project which may warrant review of ethics approval of the project. (A written report detailing the adverse occurrence or unforeseen event must be submitted to the Committee Chair within one working day after the event.)



- (c) you make submission to the Human Research Ethics Committee for approval of any proposed variations or modifications to the approved project before making any such changes;
- (d) you provide the Human Research Ethics Committee with a written "Annual Report" on each anniversary date of approval (for projects of greater than 12 months) and "Final Report" by no later than one (1) month after the approval expiry date; *(A copy of the reporting pro formas may be obtained from the Human Research Ethics Committee Secretary, Sue Evans please contact at the telephone or email given on the first page.)*
- (e) you accept that the Human Research Ethics Committee reserves the right to conduct scheduled or random inspections to confirm that the project is being conducted in accordance to its approval. Inspections may include asking questions of the research team, inspecting all consent documents and records and being guided through any physical experiments associated with the project
- (f) if the research project is discontinued, you advise the Committee in writing within five (5) working days of the discontinuation;
- (g) A copy of the Statement of Findings is provided to the Human Research Ethics Committee when it is forwarded to participants.

Please note that failure to comply with the conditions of approval and the *National Statement on Ethical Conduct in Human Research* may result in withdrawal of approval for the project.

In the event that you require an extension of ethics approval for this project, please make written application in advance of the end-date of this approval. The research cannot continue beyond the end date of approval unless the Committee has granted an extension of ethics approval. Extensions of approval cannot be granted retrospectively. Should you need an extension but not apply for this before the end-date of the approval then a full new application for approval must be submitted to the Secretary for the Committee to consider.

The Human Research Ethics Committee is committed to supporting researchers in achieving positive research outcomes through sound ethical research projects. If you have issues where the Human Research Ethics Committee may be of assistance or have any queries in relation to this approval please do not hesitate to contact the Secretary, Sue Evans or myself.

Yours sincerely,

Signature redacted

Professor Phillip Ebrall
Chair, Human Research Ethics Committee

Cc: Ms Catherine Picton (Student investigator) Professor Bruce Knight (Co-supervisor)
Project file

APPROVED