INTRODUCING DISABILITY CONCEPTS WITH INTEGRITY INTO TONGAN CULTURAL CONTEXT

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DEDICATION

This humble effort is dedicated to my beloved parents:

Talia mo Penisimani Takavaha Tu‘itahi.

Ko e hounga ho‘omo ‘ofa mo e mahu‘inga kiate au ho‘omo ‘Fakalotofale‘ia’

‘o lava ai ke fakahoko e ki‘i ngāue ni.

ABSTRACT

The case being advanced in this thesis is that "*Fakalotofale'ia*," a Tongan concept, should be adopted as a viable and supplementary practice framework for disability services support and delivery systems – within the context of the Pacific peoples of New Zealand – and most specifically for the Tongan segment of that population.

Fakalotofale'ia encompasses the holistic worldview of Tongan disabled people in terms of their cultural, physical, intellectual, socio-economic and spiritual well-being.

Research evidence has established that the participation of Tongan disabled in available disability support services in New Zealand - is low. This study examines the reasons for the problematic of this low incidence and then reaches beyond that to propose and recommend possible alternatives.

An integral part of this same exercise involves an examination of the practice of *Fakalotofale'ia* within the structure and values of the "*Kainga*," the most primary of Pacific kinship systems, processes and relationships. *Fakalotofale'ia* plays the widest possible and most pervasive range of roles and functions – from everyday maintenance of peace and good order, through to actual dispute resolution and as well as exerting a curative, preventative, educational, spiritual and economic influence on a Tongan's life and entire social universe.

Tongans both in New Zealand and in Tonga have followed the precepts of *Fakalotofale'ia* – and have thereby gained a much more enlightened perspective of the reciprocal effects of the interactions between disabled people and members of the *Kainga*.

It is equally of significance to point out that this study had also found that in a number of cases the practice of '*Fakalotofale'ia*' has been neglected due to some disabling factors and conditions of the new environment. This has had its obvious set-back effects.

For most of the disabled people and their *kainga* however, the practice of '*Fakalotofale'ia*' facilitates their needs and fills in certain very critical gaps experienced under current mainstream disability support services and delivery arrangements.

CHAPTER 1 PRELIMINARY MATTERS

1.0 Introduction

Participation of Pacific Peoples - and especially Tongan disabled people in available disability support services and delivery in New Zealand has been found to be low[1]. This is an issue of very grave concern and is at the centre of this study.

This thesis thus takes as its point of departure an in-depth and detailed examination of this problematic situation and as well as the many and varied reasons which have given rise thereto.

In the process the fundamental elements of the intricate multivariate relationships between the main parties in this equation viz. the government’s health / disability services; the care provision and delivery systems; and the Pacific / Tongan disabled population - as well the problems that arise there from – are examined in detail.

At the same time and on the basis of findings from previous research – possible solutions to and means of alleviating (if not perhaps altogether eradicating) these difficulties are explored.

In concluding its discussions this thesis then follows through with proposals for possible alternative approaches and solutions for the problems raised and discussed.

Most significant amongst these proposals is the cultural practice of “*Fakalotofale‘ia* [2]” – a concept of time-honoured utility within – and at the very root of the holistic universe of, Tongan culture, values and belief systems.

It is therefore the prime contention here that the cultural practice of “*Fakalotofale’ia*” affords us the best perspective from which to view the whole spectrum of disability-related support

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[1] Pome’e – “*PIASS Report 2000*” ” and Tahaafe – “*Study of Carers for Tongan Disabled People, 2001*.”

measures and services delivery. The case being made is that this process should be utilised right from the initial conceptualisation and formulation of disability related policies – through to all implementation, monitoring and evaluation of these policies.

1.1 The Problems

Research conducted by both disabled and non-disabled Tongans has brought to light a substantial body of evidence that confirms a widespread lack of participation on the part of Tongan people at all service levels.[3]

These studies – by Pome‘e and by Tahaafe (2000) highlight a number of salient features of disability support services used by both Tongan and other Pacific Islands disabled people – including but not limited to the following:

- low participation rates of Tongan disabled as consumers of disability services
- lack of appropriate information on and knowledge of disability support services
- very limited access to disability services
- incompatibility of mainstream disability programs with and to meet the needs of Tongan disabled people
- lack of Pacific/Tongan provider for disability support services
- Pacific/Tongan people being at a disadvantage due to their low socio-economic level
- the objectives of the National Disability Strategy do not sufficiently provide for the needs of Tongans because it does not cater for Tongan disabled people’s preference for a culturally based service delivery - and

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[2] “*Fakalotofale‘ia*” [literally – a combination of (the prefix) ‘*faka*’ meaning “*Way*” or “*The Way of*” / “*loto*” meaning “*inside” or* “*heart”* or “*the heart*” / and ‘*fale”* – or (its derivative) *‘fale‘ia’* meaning *“household*” or *“of the household – and its values and of its expected ethical standards and etiquette etc”*.]

[3] Pome‘e – “*PIASS Report 2000*” and Tahaafe – “*Study of Carers for Tongan Disabled People, 2001*.”

- the follow-up action plan is so very broadly stated that it does not therefore mean anything for Tongan disabled people - until the actions are transformed to address their needs appropriately[4].

In examining the nature, extent and impact of these problems there are several key questions that this thesis seeks to answer including:

- What are the causes for the low participation rates of Tongan disabled people as consumers of disability services?

- On the balance of probabilities, whereabouts in the complex web of interrelationships between the main parties in this equation, the government's health and disability services; and the Pacific/Tongan disabled population itself – can these causes be located?

- What possible factors have given rise to the lack of appropriate information on disability support services and delivery by the Tongan disabled population?

- Why are there so few Pacific / Tongan providers of disability support?

- Why is it that Pacific / Tongan people are at the lowest strata of the socio-economic make-up of New Zealand?

- What can be done to ensure that the objectives of the National Disability Strategy can sufficiently provide for the needs of Tongans?

Beyond the immediate practical levels the questions can then become:

- What possible useful contributions can the findings and analysis in this thesis make towards the existing theoretical corpus of knowledge on this subject?

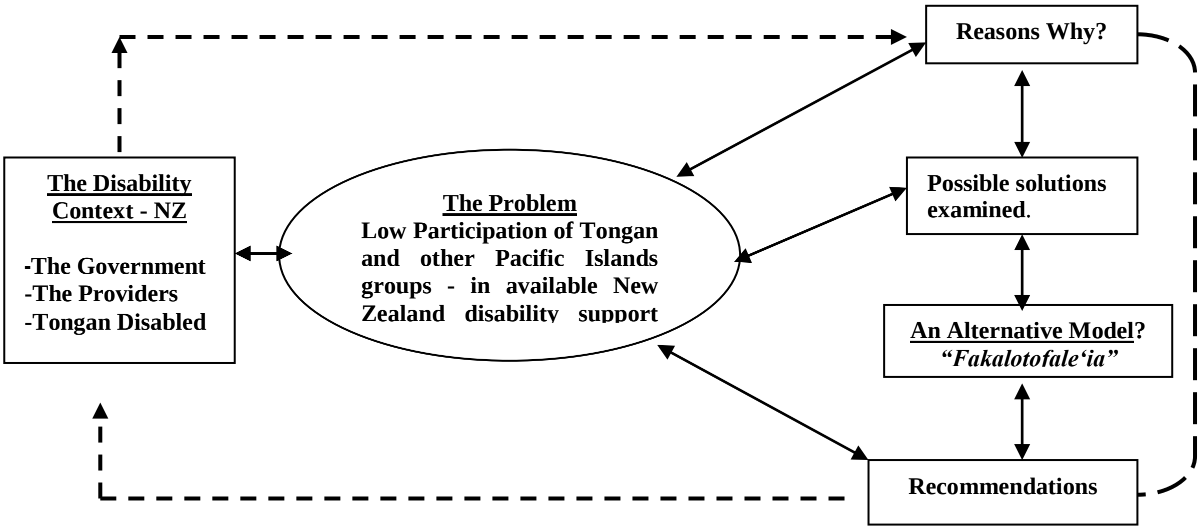
- If such theoretical contribution could be made, then would this help provide a possible other alternative frame within which the problems being examined in this thesis can be further clarified, explained and alleviated and/or solved?

- How can this thesis assist, inform and improve on the procedural issues as well as the substance of policy – from conceptualisation to assessment?
- What other possible areas can this thesis bring out into the light such as which would warrant further research and investigation?

1.2 Thesis Outline

Figure 1 below depicts in schematic form the basic configuration of the thinking and viewpoints being explored and advanced in this thesis.

Figure 1: A 'Mind Map' of this Thesis



As this '**mind map**' shows the central problem to be addressed is the low rate of participation of the Tongan disabled population – in available New Zealand disability support services / programs.

The box on the left-hand side of the diagram lists out the main parties in the context of the disability issues and services. These are:

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[4] Pome'e – "*PIASS Report 2000*" and Tahaafe – "*Study of Carers for Tongan Disabled People, 2001*."

- The Government of New Zealand which sees itself in the role of being responsible *inter alia* for the disabled members of the community – and acting accordingly;

- The Health and disability care providers; and

- The disabled community – notably the Tongan members – but whose low rate of participation in the services being provided by Government through various provider agencies has become the central focus of this thesis.

On the right-hand side there is set out a sequence of steps that this thesis follows through in dealing with the central problem of Tongan disabled low participation rate viz.:

- **Reasons** - In this section a very wide and diverse range of possible reasons for the perceived low rate of participation of Tongan disabled in the services available from the Government of New Zealand are raised and examined;

- **Possible Solutions** – In the process of examining these reasons the thesis also explores several possible solutions.

- **An Alternative Model** – "***Fakalotofale'ia***" – From out of all the possibilities examined the theorectical and practical framework of "*Fakalotofale'ia*" is then postulated as a viable alternative.

- **Recommendations** – As a result of all its analysis the thesis then offers a number of policy and practice-related suggestions – framed as recommendations towards improvements where/when necessary in the total context of disability issues and services.

Within this whole process - this thesis is then necessarily divided into several chapters, which are as follows:

Chapter One (Preliminary Matters) sets the scene by introducing the main problems at issue – giving a preview of the possible causes – and as well as highlighting possible 'solutions' including the Tongan concept of "*Fakalotofale'ia*".

Chapter Two (Disability Support Services) explores disability support services and policy in New Zealand together with its delivery systems –looking at relevant legal, policy and other instruments as well as the people involved in the various associated processes.

Chapter Three (Tongan People in New Zealand) describes and discusses the circumstances of Tongan people in general within the New Zealand context - highlighting how their low socio-economic status places them at a disadvantage and further marginalises them from participating in and accessing mainstream services.

Chapter Four (Tongan Disabled) explores the dynamics of Tongan disabled people.

Chapter Five (Causes of Low Participation of Disabled Tongans in DSS) discusses and elaborates further on the causes of the low incidence of Tongan participation in available disability support services and delivery arrangements.

Chapter Six ("Fakalotofale'ia" : The Alternative) highlights and offers the theoretical and practice framework of "*Fakalotofale'ia"* as a viable alternative.

Chapter Seven (Conclusions and Recommendations) is the closing chapter of the thesis. It brings the discussions together to their conclusions and then offers a number of possible policy recommendations for further consideration and study.

1.3 The Significance of this Thesis: The Theoretical Perspectives

This thesis has as its initial point of departure the perceived low rate of participation of Tongan disabled – and looks into the possible causes of the problem as part of that same exercise.

It then moves on into a next phase in which it offers some possible solutions.

Its ultimate objective however is to advance an alternative model and theoretical base to bridge what is seen to be a critical gap in mainstream policy. This view is manifest in the perception that this policy is either not sensitive to or does not give adequate recognition to certain cultural practices of Pacific and especially the disabled Tongan segment of the population.

This lack of a proper fit between the health and disability sector system and its intended beneficiaries is recognised in this thesis as being to a very substantial degree the main underlying cause of the low incidence of participation of Pacific and Tongan people.

This alternative model is best expressed in terms of the all-embracing Tongan concept of "*Fakalotofale'ia".*

In the attempt to explore the holistic dimensions of Tongan disabled people *Fakalotofale'ia* also provides an explanation of how they have coped despite the fact that mainstream service delivery and policy actions have not sufficiently catered for their needs. This has led to the identification and establishment of the following broad research objectives:

1. To explore the holistic context of Tongan disabled people and *kainga* identifying why their access and participation in mainstream disability support services have been low?

2. To explore how this situation could improve the access and knowledge of Tongan disabled people and *kainga* about disability support services both at government and community-based levels. What are the alternatives?

The Tongan practice framework brings a different perspective from the participants themselves and a real insight to their worldviews. It offers explanations of why participation and access to mainstream services have been low. The Tongan disabled choices of a culturally appropriate form of service delivery would be a welcome change for effective delivery of healthcare service.

1.4 Research Methodology and Literature

1.4.1 The Approach to Research

The methodology that guided this study has been influenced by many factors.

- The first, of these are the sets of objectives already stated (in Section 1.3 above);

- Secondly, the literature reviews and the theoretical analysis have informed and directed the process of the study. The theoretical perspectives that have emerged – primarily the discussions by Linda Smith (1999) on the dilemmas and appropriate approaches for the "inside researcher" - provided the framework that guides the approaches and shaped the questionnaire designs as well as the interview dynamics.

- The third factor is the influence of *Fakalotofale'ia* and how it dictates the sets of relationships that existed within *kainga* dynamics. The values that underpin *Fakalotofale'ia* as discussed forms the basis of how this study has approached its subject matter from a Tongan perspective.

These above factors served to guide and instruct the entire groundwork of this thesis right through from conception, data gathering, interviews, data analysis, and discussions and writing up.

In the process the following points of procedure were also given emphasis:

- Face-to-face communication
- Telephone communication
- Follow-up with written information
- Focus Group Meetings

The balance of this Chapter takes up discussions on the research questions (1.4.1). My role as a Tongan researcher is discussed in section 1.4.2. Section 1.4.3 focuses on participants, decisions for selections and processes of access. Section 1.4.4 profiles the *kainga* who participated in the research, while Section 1.4.5 discusses significant aspects of their characteristics. Section 1.4.6 then gives a profile of disabled members of the Tongan community and from among these *kainga.* Section 1.4.7 discusses the processes and procedures followed in data collection whilst Section 1.4.8 reviews the interview process. Ethical issues are considered and examined in Section 1.4.9. Section 1.4.10 then concludes the chapter with a summary of the discussions.

1.4.2 **The Research Question**

The key question for this study is when New Zealand mainstream policy action and delivery fails to cater sufficiently for the needs of Tongan disabled people, how do we establish the theoretical and practical means to address such failings?

In the attempt to address this question, one cannot pursue this study without the understanding of the holistic dimensions of *kainga* and the practice of *Fakalotofale'ia* as discussed in Chapter Four. It is very difficult to establish the relationships and influences on Tongan disabled people without a full understanding of the concepts of *kainga* and *Fakalotofale'ia*. Can it be argued whether a practice framework for social services delivery can be established for Tongan disabled people? During the interviews and in dialogue with disabled people and kainga a great deal of time and effort was devoted to the pursuit of possible answers to these questions.

1.4.3 **The Tongan Researcher's Role**

Fakalotofale'ia practice framework explains how Tongans interact with other Tongans. In approaching this study, the values of *Fakalotofale'ia* have major influences in my role as a researcher. For example, in placing myself within the context of *kainga*, "I must acknowledge this process takes much more than having to establish appropriate methodologies, it is highly physical, dynamic actions which an indigenous researcher hold serious responsibilities," Hu'akau (2000). My roles involved responsibilities guided by *Fakalotofale'ia* practice. For example, f*aka'apa'apa* – respect for *kainga* elders and disabled people were paramount for this study. *Fakatokilalo* – being humble / behaving with humility encourages forming of a good relationship between the researcher and the participating *kainga*. The researcher also earns respect and credibility of the *kainga*. Linda Smith (1999:139), "it needs to be humble because the researcher belongs to the community as a member with a different set of roles and relationships, status and position."

From a Tongan perspective taking yourself into the research process demands an expectation and respect of your community, therefore, you are expected to know better especially if you are put in an “expert position (researcher)” Linda Smith (1999). As an inside researcher, when entering the *kainga* dynamics, values of *Fakalotofale‘ia* as earlier demonstrated and Tongan cultural protocols guided the processes of this study. Linda Smith (1999) argued, a major difference between an outside researcher and an inside researcher, is “that the inside researcher has to live with the consequences of their processes on a day-to-day basis for ever more, and so do their families and communities.” Linda Smith further suggested that other support bases and systems must be built outside the family networks in order to develop some “lines of relating” to the specific project. For the purpose of this study some Tongan disabled people, both from participants and professionals groups, are part of these support bases for this study.

1.4.4 **The Participants**

The participants in this study involved *kainga* who have a disabled member. Disabled people were viewed in this study as part of the *kainga* dynamics and not as separate individuals. Participants varied from household to household, depending on the number of *kainga* members living there, and those who were present during the interview process. The sample selected was based on the purposes of the study. Because the disabled community is a minority within the Tongan community, some of the families were easily identified through my community connections. Some *kainga* participants were already known to me through my previous work at Auckland Health Care.

Because the aim of the study is to explore the holistic dimensions of Tongan disabled people, the selection of participants must represent these requirements (ethnicity and disability). Secondly, the *kainga* who consist of carers, family members (both nuclear and extended families) as disabled people cannot be viewed outside these contexts because the dynamics of *kainga* represent a clearer picture of their worldviews.

1.4.5 ***Kainga* Profiles**

The ten *kainga* consisted of five married couples and three in a solo parent situation. Seven *kainga* were all beneficiaries, two *kainga* had one full time worker, one as a factory hands and the other in a community health service. Their annual incomes ranged from $14,000 to $40,000.

Seven *kainga* live in the same locality (eastern Auckland central) and three live in South Auckland. All ten participating *kainga* have strong church affiliations. Two out of the ten participating *kainga*, had a formal tertiary educational qualification. The same households had children at a University. One had two and the other had one student at universities in Auckland. Formal Education qualifications for the rest of participating *kainga* are low.

1.4.6 ***Kainga* Characteristics**

The *kainga* households consisted between four to eight individuals including disabled members. All *kainga* members present during my visits were involved in the interviews and discussions. Participating *kainga* felt their day-to-day interactions have major impacts on disabled people. Therefore, participating *kainga* perceived the interviews and dialogues as part of their collective dynamics.

1.4.7 **Disabled People Profile**

Out of the ten participants, four had physical related disability, four had both physical and intellectual disabilities, one was age-related (passed away during the study) and one had an intellectual related disability only. The age ranges were between 10 and 74 years. Eight participants lived within their *kainga* while one lives independently and one lived in residential living arrangements, but both had strong *kainga* connections. Two of the participants had good secondary education background from Tonga. One participant had completed Secondary School in New Zealand but in a special disability unit and one participant was still at primary school level. Three were within final years in special disability schools. One had left school and was attending a workshop for disabled people twice a week. Two disabled participants had no particular activities; the severity of their disability contributes to the lack of appropriate educational choices.

1.4.8 **Data Collection**

The data colletion process involved face-to-face dialogue, story telling and interviews with *kainga* and disabled people. A semi-structured questionnaire (**Appendix 2**) used as a guide, contained items that were selected from assessment tools (NASC). Other items were included to cover the parameters of the study.. Demographic information about participants that was considered relevant to the study was also collected. The information was collected in written and audio forms.

The cultural dynamics of the study was a key factor that contributed to the richness of the data. Several issues emerged during this process created a feeling of connectedness between the participating *kainga* and the researcher. Duelli Klein (1983) cited comments from Worrall (1995) that a dialectical relationship between the researcher and the researched allows the participants to recognise connections between their different lives." My experiences as a Tongan woman, a mother, a family counsellor and a former needs assessor for disabled people allowed me to share appropriately with participants allowing me to draw on my wealth of experiences to address any issues that arose during the research. Every *kainga* was treated as unique. Nonetheless, it was very important that any preconceived assumptions be avoided and my focus on *kainga* issues not be clouded with my own experiences.

The use of the Tongan language encourages a good flow of communication. The context of how the conversation took place – " story telling is a focus on dialogue and conversations amongst ourselves as indigenous people, to ourselves and for ourselves. Such approaches fit well with the oral traditions, which are still reality in day–to-day indigenous lives," (Linda Smith 1999:145). Smith has pointed out that the oral traditions of indigenous cultures; like Tongans, handed down from generation to generation, are still very much alive.

It is acknowledged that although some of the disabled participants were unable to present their needs directly; their voices were heard and represented by their *kainga* members. Therefore, the stories, and data have come from the collective voices of *kainga* members, some disabled participants and the residential care giving staff.

Linda Smith (1999) pointed out, “It is common practice in many indigenous contexts for elders to be approached as the first point of contact.” And so it was here. The *kainga* structure is hierarchical and it is appropriate to acknowledge that it is normal practice to approach the elders (men and women) as the first point of contact. In order to hear the voices of disabled participants, I sought permission from parents and elders to talk to them either separately or with the *kainga.* The choice was left entirely to the disabled participants. I believe it is important that disabled voices are heard in cultural contexts where younger members have been taught to adhere to cultural norm, Taule’ale’ausumai (1997).

> The very process of doing research can begin the process of enlightenment for the families themselves, as power relations that they experience on a daily basis are revealed (Munford, 1989) cited in Worall (1996).

In this process, hearing the voices of disabled participants who were able to express their views was not problematic. *Kainga* members were quite open about information sharing and felt strongly that disabled members should voice their ideas, experiences and feelings.

For disabled people who were unable to speak directly, *kainga* members wanted them to be seen by the researcher. This was one part of the research process that made it enlightening not only for the *kainga* but also for myself as a researcher into disability issues.

Therefore, the process of data collection was not only highly interactive at the interviewing and dialogues levels but also observations of *kainga* being interactive with disabled people contributed significantly to enriching the data.

Two focus groups meetings were also held with the same participants. The first meeting aimed to outline key themes that had emerged from the study. The second one was for participating *kainga* to be kept informed on progress made and to invite them to share any concerns and ask any questions they may have.

The discussions of the focus groups were guided by the key themes highlighted from the one-to-one interviews and new issues that arose were also recorded as part of the data.

1.4.9 **The Interview Process**

The participating *kainga* were invited to take part in two interviews, with a maximum of two hours duration. Invitations were extended through telephone contacts and followed up with written information on the research and a home visit. At the first meetings with prospective participants, discussions of confidentiality and consent took place. This was considered to be an appropriate approach, especially when confidentiality and consent were key issues before the interview process could proceed.

Although the written information detailed the requirements of the study, it was very important that the participants were guided through so that they were well informed and had a clear understanding of the project. All the information was written in the Tongan language except for the questionnaire. The questionnaire was intended only as a guide.

The interviews took place at participants' homes because it was more convenient for participating *kainga* especially for those who had severe disability. It worked out very well both ways as a result. This process also painted a fuller picture of the disabled people's context.

At the end of each interview, the contents were relayed back to participants to check whether some comments needed correction. When audio- tape had been used, then transcriptions took place on the same day. Another Tongan person shared the task of transcribing, and therefore signed a confidentiality agreement (**Appendix 3**). Only half of the *kainga* participants were recorded due to technical problems with the tape recorder.

1.4.10 **Ethical Issues**

The ethical approval of this research was sought and obtained from the Massey University Human Ethical Committee before it was undertaken. As a Tongan woman, I have other ethical responsibilities that go beyond these University protocols. Linda Smith (1999) explains:

Indigenous researchers have to meet these criteria (Western) as well as Indigenous criteria, which can judge research 'not useful,' not indigenous,' not friendly,' 'not just'.

I feel that because disability can easily be associated with lots of negative issues, my approach to *kainga* deserved appropriate cultural protocols and respect. Special attention also had to be paid to disabled members as well. For these reasons, I am of the view that Tongans' collective identity meant that confidentiality and anonymity of each situation had to be highly protected. This was about family reputation and honour. The Tongan community is very small no information could be shared outside this study, which may lead to unwanted revelation of the identity of the participants.

Linda Smith (1999) pointed out that the "inside researcher has to be as ethical and respectful, as reflexive and critical as outside research. For me, I have to be critical about my own views and respect the uniqueness of each situation. For example, I had working knowledge in the disability area, but I had to hear it "as how participants understand it," – "test their own taken-for-granted views about their community." My awareness of the sub-cultures that exists within the broader framework of *kainga* helped keep this study in perspective and also assisted me to articulate my roles and responsibilities in this process.

1.4.11 **Summary**

In order to capture the central theme of this study, an indigenous approach was selected, as most appropriate. although of course Tongan New Zealanders are not indigenous to Aotearoa. Nonetheless as a Polynesian people and in minority culture within New Zealand, there is much common ground between Maori researching Maori and Tongan researching Tongan. *Fakalotofale'ia* has had major influences in the framing of this research. Other cultural frameworks have been considered useful. The indigenous perspective and theoretical contributions from Linda Smith affirmed some of the approaches that this research has taken.

The research question raised issues that were highly emotional within *kainga* – and which were also highly political in the broader sense - especially the nature of this study. Linda Smith (1999) writes:

> Negotiating and transforming institutional practices and research practices and research framework is as significant as carrying out of actual research programmes. This makes indigenous research a highly political activity.

I was aware that some of issues that arose from the discussions and interviews were much more serious than I had imagined. *Kainga* members talked about inappropriate disability services, not being able to participate in mainstream programmes and as well as about a whole litany of other failings of the current system.

As I continued to listen to these stories, I wondered how they have survived without the support of the mainstream systems. In this instance, questions were raised during the interviews. What has been significance was the identification of how cultural values and practices had contributed to the survival of the *kainga* participants. The contrasting worldviews of two cultures (Tongan and New Zealand) have led to some misconceptions of one another.

Sharing in these discussions made me realise that I had been affected more than anticipated. I went back to revisit some *kainga* I had worked with previously and to find them living in similar situations six years later, was very a difficult experience. Linda Smith (1999) suggests, "Like networking, sharing a process, which is responsive to marginalised contexts in which indigenous communities exist."

While I was aware of the broader context of this research, which was useful, it was more important to reaffirm the good stories that were shared at the *kainga* levels.

The process of writing this chapter has kept this journey in perspective.

2.0 Introduction

At a first glance, the health and disability sector in New Zealand is large and complex. Further investigation also reveals that in organizational and structural terms the functions assigned to different organizations for the purposes of delivering health and disability services are fragmented and in some quite significant instances overlapping.

This Chapter explores Disability Policies and Support Services in New Zealand, giving a brief overview of: Government's objectives for the Health and Disability Sector (Section 2.1), the relevant enabling Act and other relevant legislative instruments (Section 2.2) as well as the structure and organization (Section 2.3) of the sector. The Disability Strategies (Section 2.4) and the funding of disability support services (Section 2.5) will also be discussed illustrating how funding is distributed to various providers. The implementation of the disability strategies (Section 2.6) discusses the functions of various support services and what part of services they are responsible to deliver (Section 2.7). Section 2.8 examines access and entitlements in relation to services. Section 2.9 discusses the role of the Health Disability Commissioner highlighting gaps in policy responsibilities, and which in turn impact on consumers' rights to services and, as well as receiving of quality services.

2.1 Government Objectives

Disability policy became one of the main issues that the Labour Government emphasised and drew the attention of New Zealanders to - during both its campaign efforts in 1999 and subsequently. A direct result was the New Zealand Public Health and Disability Act 2000 – with a stated intention of pursuing a more inclusive policy in health and disability matters. This was further followed up with the launching of the New Zealand Disability Strategy (NZDS) in 2001.

Saucier in his review report in 2002 – Promoting a National Vision for People with Disabilities – Successful Policies and Enduring Barriers stated that the NZDS was:

“ a broad framework to guide disability policy toward full inclusion. The purpose of this project was:

- To assess the degree to which the disability system in New Zealand supports the inclusion and participation in society of people with disabilities;
- To determine whether the New Disability Strategy is an effective tool for achieving a fully inclusive society; and
- To identify remaining barriers to full inclusion and make suggestions for improvement”

2.2 The New Zealand Public Health and Disability Act 2000

The New Zealand Public Health and Disability Act 2000 introduced structural and management changes, which include the following:

- Establishing of the 21 District Health Boards (DHBs) to be geographically responsible for the health and disability services of their respective local population;
- Call for developing of the New Zealand Health Strategy and New Zealand Disability Strategy and for annual reports to be submitted to Parliament on the implementation of these strategies;
- Encourage co-operation and collaboration amongst the agencies in the sector to ensure delivery of better care and support; and
- Strengthening local community participation on health and disability support service decision – making through electing members to District Health Boards (DHBs).

2.3 Structure and Organization of Disability Support Services (DSS)

DSS originated from the establishment of the Department of Social Welfare (DSW) in 1971. **Figure 2** following gives a diagrammatic representation of the evolution of the Disability Support Services as explained by Saucier in his 2002 review.

Figure 2: Recent History of Disability Services (1971 – present)

1971 – establishment of DSW taking over program from the Department of Social Security such as:
- home help for the elderly;
- subside voluntary organisations for people with intellectual disability;
- income support programme to people with disabilities (sickness benefit, invalid benefit.

1975 – Disabled Persons Community Welfare Act (DPCWA) entitlement:
- New entitlements to a range of social supports for community living to be administered by DSW;
- Department of Health continued to fund institutions in NZ & other services with all types of disabilities (home nursing, home help, care hospital subsidies and prosthetic devices.

1990's – Market Oriental Health Reform with purchase/provider roles and de-institutionalisation policy)

1993 – 1996 – establishment of 4 Regional Health Authorities (RHAs) responsible for purchasing health services in a competitive market particularly health services with growing disability sector. Accessibility was through individual assessment replacing entitlement approach of DPCWA;

(Meanwhile the Dept. of Health also provided growing community-based services and on-going role in funding institution. Also DSW still retained vocational services for people with disabilities, income support programme).
1999 – full deinstitutionalisation;

2000 – New Zealand Health Public Health and Disability Act
- abolishing Health Funding Agencies, established District Health Boards to plan, fund and provide health and disability services;

July 2003 – to devolve age-related DSS to DHBs;
Before July 2004 – devolving of DSS for physical, intellectual and sensory disabilities to DHBs

Source: *Adapted from Saucier – Promoting a National Vision for People with Disabilities – Successful Policies and Enduring Barriers – August 2002 (pp 15 –17)*

The management of the Disability Policy and Strategies is fragmented (may be overlapping) amongst a number of government agencies meaning that different organisations deal with disability related issues such as education, vocational services, income supports, housing, and transport.

Table 2.1 Organisations and Type of DSS related Services

ORGANISATION	TYPE OF DSS RELATED SERVICES
Ministry of Health (Disability Services Directorate) or DSD	-Information, advice, personal care, assistance with household management, home-delivered meals, hospital based assessment, treatment and Rehab. Group homes, rest homes & continuing care hospital DSD purchases DSS through about 3,000 contractual agreements with providers. I) Purchase in-patient assessment, treatment and rehabilitation; ii) Purchase NASC from DHBs.
Ministry of Health (Mental Health Directorate	- provides through DHBs for those with most severe mental illness
Ministry of Health (Funding and Performance Directorate)	- Oversees devolution of personal health and other health funding to DHBs.
Office for Disability Issues (ODI)	- Responsible for NZ Disability Strategy; - Monitor coherence and equity of disability services across government
Ministry of Social Development (MSD)	- Administers invalid and sickness benefits, residential care subsidies and other disability allowances through Work and Income NZ (WINZ)
Ministry of Education	- Responsible for the education of children with disabilities.
Housing of New Zealand Corporation	- Collaborates with government agencies and community groups to develop group homes and other housing for people with disabilities.
Accident Compensation Corporation (ACC)	-Provides no fault compensation and rehabilitation to New Zealanders and visitors injured through medical misadventure or accidents, regardless of location.
Human Rights Commission	-Enforcing Human Rights Acts which prohibits discrimination on the basis of several categories, including disability.
Others such as Office of Health and Disability Commissioners, Ministry of Transport, State Service Commission, Lottery Grant Board, etc	

Source: Saucier – *Promoting a National Vision for People with Disabilities – Successful Policies and Enduring Barriers* – August 2002 (pp 13-14)

The research sample of Tongans with disabilities, the consumers, saw the changes that took place since 2001 within the Health and Disability Sector as leading to a greater fragmentation of services amongst a larger number of agencies, thus causing a lot of confusion. Nine of the respondents claimed that they do not fully understand where and how to get various forms of DSS.

Figure 3 below depicts the overall structure of the New Zealand Health and Disability Support Sector as in 2002 and their interrelationships.

Figure 3: New Zealand Health and Disability Support Sector 2002 - Overall Structure

Source: Ministry of Health Web site at http://www.moh.govt.nz

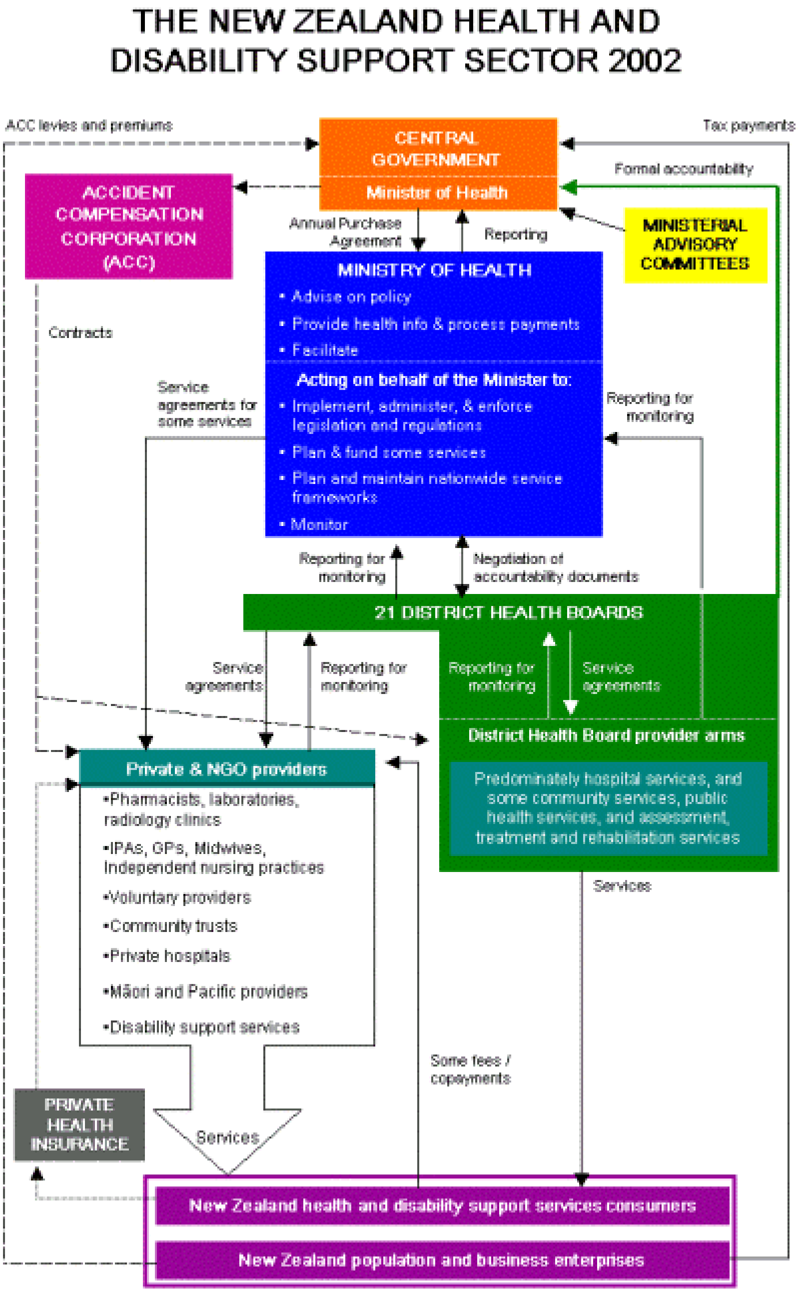
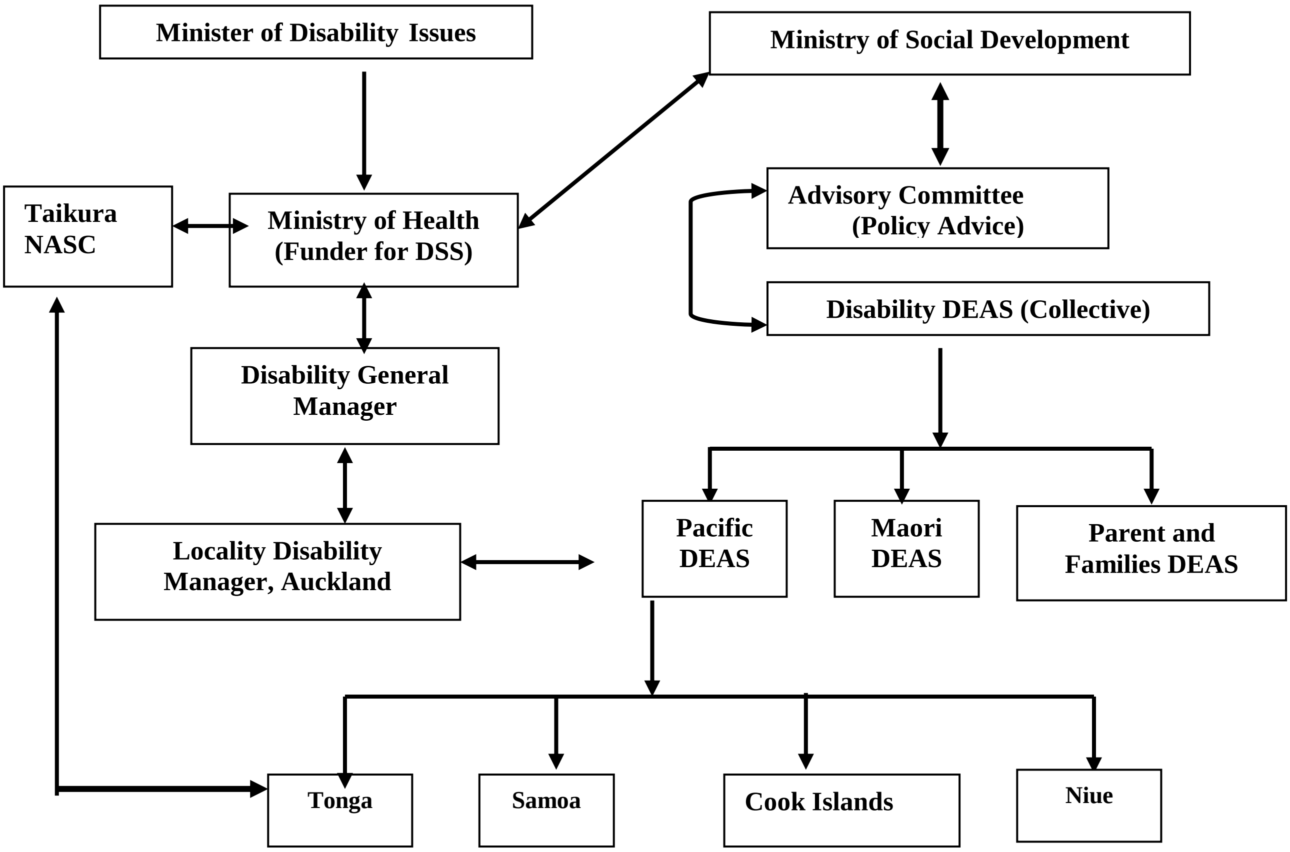


Figure 4 is a much more simplified diagrammatic representation aimed to provide a more easily comprehensible perspective on the working relationships between the two organisations, but even here the likelihood of consumers understanding how this works is minimal.

Figure 4: New Zealand Disability Sector - Simplified Diagram of Structure.



Source: *Adapted from various official and other publications on the Ministry of Health - and including from / adaptation of the chart in the Ministry of Health Web site at* *http://www.moh.govt.nz*

One fundamental aim of this thesis is to explore and explain the situation of Tongan disabled people and the informal roles played by their "*kainga*" in the provision of care and support for them. **Figure 4** therefore also depicts the flow of governance and resources for Pacific Island communities including Tongan disabled. The Disability General Manager and the Locality Disability Manager are responsible for contracting of disability services to various disability services providers.

The Pacific Information Advocacy Support Services (PIASS – Pacific DEAS – Disability Empowerment Advocacy Service) as shown on the above diagram is the first Pacific disability service established. The PIASS Trust caters for all Pacific ethnic groups such as Tonga, Samoa, Cook Islands, Niue, Tokelau and Fiji. The current emphasis is to provide appropriate information on disability issues, provide advocacy roles and support Pacific disabled people, their *kainga*, *aiga* and family groups. PIASS is still a developing service and although some good efforts are being made in meeting their goals, it is clear that a minimal workforce and inappropriate funding limit the service provision for the diverse needs of the Pacific communities including Tongan. The funding allocation will be elaborated further in section 2.3 of this chapter.

The DEAS partners as shown on the diagram had an original memorandum of understanding (MOU) with the Ministry of Health that policy matters on disability will be dealt with at that level. Because of the transitional process of disability resources to the Ministry of Social Development, the DEAS partner no longer has a role in policy advice to the Ministry of Health or Ministry of Social Development. The findings from the research suggest *inter alia* that in order to advise on Pacific disabled issues, a formal arrangement with the Ministry of Social Development needs to be established.

2.4 Disability Strategies

The New Zealand Disability Strategy 2001 was established after a broad consultation process that resulted in 15 Objectives:

1. Encourage and educate for a non-disabling society;
2. Ensure rights for disabled people;
3. Provide the best education for disabled people;
4. Provide opportunities in employment and economic development for disabled people;
5. Foster leadership by disabled people;
6. Foster an aware and responsive public service;
7. Create long-term support systems centered on the individual;
8. Support quality living in the community for disabled people;
9. Support lifestyle choices, recreation and culture for disabled;
10. Collect and use relevant information about disabled people and disability issues;
11. Promote participation of disabled Maori;

12. Promote participation of disabled Pacific peoples;
13. Enable disabled children and youth to lead full and active lives;
14. Promote participation of disabled women in order to improve their quality of life and
15. Value families, whanau and people providing ongoing support.

Attached to the above objectives were 113 action plans to be implemented.

Specifically, for the Pacific peoples who come under Objective 12 viz. *to promote participation of disabled Pacific peoples* the following plan of action was attached:

12.1 Increase access to, and quality of, both Pacific and mainstream service providers that deliver disability services to disabled Pacific peoples, their families and communities.

12.2 Support disability workforce development and training for Pacific peoples, by training Pacific peoples as providers of disability information and services for their local communities.

12.3 Encourage Pacific communities to consider disability issues and perspectives and further their own understanding of disability through the development of community-based plans for disability issues.

12.4 Support training and development of trilingual interpreters for deaf people.

12.5 Ensure the Ministry of Pacific Island Affairs undertakes a leadership role in promoting the participation of disabled Pacific peoples.

2.5 Funding of Disability Support Services

There are three main sources of funding for the Disability Support Services (DSS) with Ministry of Health as the major provider. The other two are the Accident Compensation Corporation (ACC) and the Department of Work and Income.

Vote Health is divided into two major categories – Departmental and Non-Departmental Appropriations. Allocations for DSS from each of these categories are reflected in **Table 2.2**

Within the Departmental Appropriation, Disability Issues accounted for about 11% ($12,548m) in 2001/02 fiscal years compared to 14.6% ($17.505m) in 2002/2003. The allocation for Disability Issues (within the Departmental Appropriation for 2002/2003 represents an increase of 39% from the previous fiscal year. The allocation for Disability Issues under the Departmental Appropriation is mainly for policy advice, negotiate and administer service agreements with disability support service providers. Specifically, allocation of DSS fund to from Vote Health to consumers is age related with disabled people in the age group of 0-64 can apply for DSS under the Vote Health – Departmental Appropriation ($17.5m)

Table 2.2: Vote Health Appropriations 2002 - 2003

MAJOR EXPENSES CATEGORIES	**2001/02 (000')**	**% of Total**	**2002/03 (000')**	**% of Total**
1) Departmental Output Classes				
Departmental expenses	115,271		119,190	
Information Services	34,083		44,502	
Sub-total	**149,354**	**(1.9%)**	**163,692**	**(1.9%)**
2) Non Departmental				
DHBs	5,017,129	(65%)	5,411,379	(62.6%)
DSS	1,347,682	(17.5%)	1,421,738	(16.4%)
Public Health Services	239,512	(3.3%)	221,682	(2.6%)
Other Non-Departmental	570,948	(7.4%)	688,860	(7.9%)
Sub-total	**7,175,271**	**(93.2%)**	**7,743,659**	**(89.5%)**
3) Other Crown Expenses	**37,558**	**(0.5%)**	**19,851**	**(0.2%)**
4) Capital Contribution	**336,405**	**(4.4)**	**718,291**	**(8.3%)**
Total Appropriation For Vote Health	**7,698,588**	**100%**	**8,645,493**	**100%**

Source: The Estimates of Appropriations for the Government of New Zealand for the Year ending 30 June 2003 – Vote Health 2002 / 2003

As for Non Departmental Appropriation, allocation for DSS increased by 5.5% from the level of 2001/2002 and accounted for a significant percentage of 16.4% in 2002/2003 total Vote Health. The $1.4 billion allocated under the Non Departmental Appropriation is for funding of disability support services from DHBs and other disability Support service providers. Disabled people of over 65 years old can apply for DSS from this allocation of $1.4 billion.

2.6 Implementation of Strategies

The *New Zealand Public Health and Disability Act 2000* gives the mandate for the Disability Issues Office to be responsible for the implementation of the New Zealand Disability Strategy. **Table 2.3** provides an update on the implementation of Disability Strategy Objectives – particularly Objective 12 for the Pacific People.

Table 2.3: Progress of Implementation - New Zealand Disability Strategy for Pacific Peoples

Objective 12	**Actions to be implemented ***	**Implementation status of actions as at 31 December 2002**
Promote participation of disabled Pacific Peoples		
	1. Increase access to, and quality of, both Pacific and mainstream service providers that deliver disability services to disabled peoples, their families and communities.	Appropriate frameworks, increase of Pacific workforce and cultural training must be compulsory for mainstream providers
	2. Support disability workforce and training for Pacific peoples, by training Pacific peoples as providers of disability information and services for their local communities.	Development of PIASS (Pacific Information Advocacy Support Service) to focus on the needs of the Pacific ethnic group by translating materials, radio programmes through ethnic radio programmes, co-ordinating of meetings for pacific disabled people. Still at an infancy stage (established in 2001).
	3. Encourage Pacific Communities to consider disability issues and perspectives and further their own understanding of disability through the development of community-based plans for disability issues	Need its own funding and workforce from specific ethnic groups to deliver, because of the diversity of Pacific groups.
	4. Support training and development of trilingual interpreters for Deaf people.	Need to be established and appropriate funding must be committed for implementation.
	5. Ensure the Ministry of Pacific Island Affairs undertakes a leadership role in promoting the participation of disabled Pacific peoples	Not active

Source: The New Zealand Disability Strategy – April 2001
* Direct extract from the NZDS document.

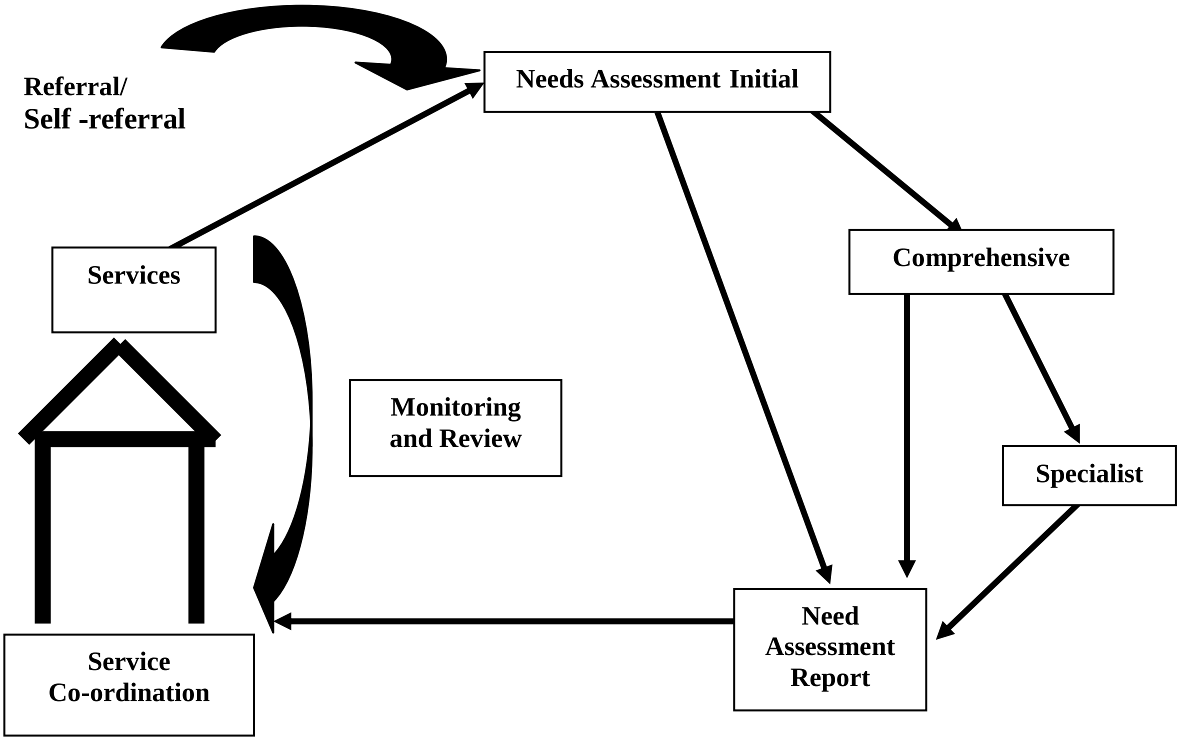
2.7 Delivery of Disability Support Services (DSS)

The main aim of the New Zealand Disability Strategy:

> … is to promote and maximize the independence of people with disabilities, provide effective habilitation and rehabilitation, and support opportunities for people to participate as fully as possible in their families, and community and society (New Zealand Official Year Book 2002:183).

The disability support services framework involves three processes that form the basis for publicly funded disability support services provision as shown in **Figure 5** below.

Figure 5: The DSS Framework



Source: Ministry of Health, (1994) The New Zealand Framework for Service Delivery – Disability Support Services – p. 12

These three processes are:

- **Needs Assessment** identifies and prioritises needs. The needs assessment process is intended to identify all of a person's care and support needs, irrespective of funding constraints and availability of services.

- **Service co-ordination** identifies the most appropriate services and support options to meet assessed needs of the clients. Where possible, the service co-ordinator also refers individuals to other agencies for needs not funded by the Ministry of Health.

Needs Assessment and Service Co-ordination (NASC) services are delivered by agencies that are funded by the Ministry of Health.

- **Provision of services** which include:

i) **Environment Support Service (ESS).**

The Ministry of Health funds the following ESS – home modifications such as bathroom alterations, vehicle grants, equipment for daily living (shower chairs), wheelchairs, seating solutions, communication and information technology equipment, hearing aid, vision supplements, etc.

ii) **Home Support:**

Home support is provided to assist a full-time caregiver to fulfil the physical needs of the disabled person. This includes home help and personal care services (e.g. lifting, bathing, dressing, eating and so forth).

iii) **Carer Support:**

Carer support is a number of relief care days allocated by the NASC service co-ordinator to give a full time unpaid/primary caregiver who cares for a disabled family member occasional breaks. (Respite services can be provided by a family / *kainga* at a home-based context or an option of a residential care facility). The Ministry of Health pays the carer support costs directly to relief carers.

iv) **Assessment, Treatment and Rehabilitation**

To restore functional ability of disabled people and / or people with age related disorders to enable them to live as independently as possible. Such services include provision of specialist inpatient clinic, services to people in their living / working environment, etc.

- help with household activities (e.g. cleaning, laundry)
- habilitation and rehabilitation services
- short- and long-term residential care

2.8 Access and Entitlements

Disability and eligibility for government funded disability services is covered by the following definitions:

> A person with a disability is a person who has been identified as having a physical, psychiatric, intellectual, sensory or age-related disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent functioning to the extent that ongoing support is required.
>
> Where a person has a disability, which is the result of an accident, which took place on or after 1 April 1974, their eligibility for entitlements from the Accident Rehabilitation and Compensation Corporation should be determined.
>
> Where a person has both a disability and personal health need, the services provided to address those needs are disability support services and personal health services respectively. However, any acute mental health services needed by people with a psychiatric disability are considered to be disability support services.

As previously mentioned (Saucier 2002 - and also borne out in findings from the field research) - the history of accessing disability support services has been quite difficult due to structural fragmentation issues and inflexible funding arrangements by the government. The purchases of disability services were divided between several government agencies. These arrangements resulted in people with disability facing difficulties in identifying whom to deal with and in the numerous agencies they were sent to seek support from.

However, there were major transfers of funding responsibilities from the Department of Social Welfare to the Health Department between 1993 and 1995 due to this confusion. During this time, disability funding was consolidated under the Regional Health Authorities, while nationally specified entitlements were replaced by individually assessed needs through the DSS framework.

2.9 Health Disability Commissioner

Although there is a Commissioner who is charged amongst other things to protect the rights of health and disability consumers, the functions of the position does not however cover the issues of access and entitlement to services. Therefore, if disabled people are not satisfied with service provision or having difficulties accessing appropriate services, they may either be forced into accepting inappropriate options or end up without service because of these gaps in the complaint process.

CHAPTER 3 TONGAN PEOPLE IN NEW ZEALAND

3.0 Introduction

This chapter discusses the situation of Tongan people in New Zealand in terms of their demographic composition, socio-economic situation, including education level, employment rate, income level, health as well as social cultural systems (kinship ties, social and religious obligations).

3.1 Demographic Trends

3.1.1. Numbers and Proportions

According to the latest census in 2001, the Tongan ethnic group is the third largest amongst Pacific Peoples accounting for 17.6% with a total population of 40,713 (20,421 males and 20,292 females) after Samoa (49.4%) and the Cook Island Maori (22.1%) (Table 3.1 refers)

Although Tongans in New Zealand represent a minority group; the total number of Tongans has increased rapidly over the past 10 years – a growth of 35% in 1996 and 28% in 2001.

Table 3.1: Number of Tongans in New Zealand (1991 – 2001)

	1991	% of Total	1996	% of Total	2001	% of Total
Total people of NZ	**3,345,813**	**100**	**3,466,587**	**100**	**3,586,731**	**100**
Male	1,648,239	49.3	1,698,099	49.1	1,747,752	48.7
Female	1,697,574	51.7	1,768,488	51.9	1,838,982	52.3
Total peoples of the Pacific	**167,070**	**5.0**	**202,233**	**5.8**	**231,801**	**6.5**
Males	82,404		99,834		114,153	
Females	84,669		102,399		117,645	
Tongan	**23,172**	**0.7**	**31,389**	**0.9**	**40,713**	**1.1**
Male	11,727		15,699		20,421	
Female	11,445		15,690		20,292	

Source: Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups*, (Table 2a)

3.1.2 Age Distribution, Births and Location

The median age of the Tongan population in New Zealand is 19.2 indicating that the Tongan ethnic group has a youthful population compared to 21 years for Pacific Peoples as a whole and 36.8 years for the Europeans. Around 43% of the total Tongan population in New Zealand is recorded as being aged between 1 month and 14 years old.

Almost all (98%) of the total Tongan population reside in the urban areas of New Zealand particularly in the Auckland region (about 80%) and 83.2% of Tongans were born in New Zealand.

3.2 Socio - Economic Situation

3.2.1 Education and Occupation

Close to 70% of Tongans either do not have any qualification (28.7%) or only high / secondary school qualification (40%) – with only about 12% having achieved tertiary and vocational qualifications. A similar trend in tertiary and vocational qualification is also observed with the other two major Pacific ethnic groups (Samoa – 14 % and the Cook Islands – 14.2%) – and as well as also for the Pacific Peoples (14.1%) as reflected in Table 3.2

Table 3.2: Level of Education 2001 - Selected Pacific Islands Ethnic Groups (Aged 15 and Over)

Ethnic Group	No Qualification.	5th & 6th Form Qlfcn.	Higher School Qlfcn.	Other Secondary School Qlfcn.	Vocational Qlfcn.	University Degree	Not Elsewhere included	Total
Samoan	17,865 (25.5%)	16,602 (23.7%)	4,434 (6.3%)	9,399 (13.4%)	7,530 10.8%)	2,262 (3.2%)	11,973 (17.1%)	70,059 (100%)
Cook Islands	11,409 (38.1%)	6,699 (22.4%)	1,380 (4.6%)	1,227 (4.1%)	3,252 (10.9%	693 (2.3%)	5256 (17.5%)	29,913 (100%)
Tongan	6,687 (28.7%)	4,503 (19.3%)	1,926 (8.3%)	2,892 (12.4%)	2,100 (9.0%)	780 (3.3%)	4,449 (19.0%)	23,334 (100%)
Pacific	41,520 (29.3%)	31,400 (22.2%)	8,643 (6.1%)	15,039 (10.6%)	15,333 (10.8%)	4,512 (3.3%)	25,098 17.7%)	141,654 (100%)
National	681,189 (24.5%)	668,424 (24.1%)	155,853 (5.6%)	163,509 (5.9%)	505,083 (18.2%)	290,340 (10.7%)	302,223 (11%)	2,776,624 (100%)

Source: Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups* (Table 14a)

The national figure on the other hand indicates a more educated population (close to 30% on vocational and university degree holders).

The level of academic achievement attained by the Tongan ethnic group is also reflected in the type of employment that Tongans occupy – such that 56% are employed in either lower paid and semi-skilled jobs such as clerical works, service sales, plant operators. Pacific islanders including Tongans are over-represented in less skilled manual jobs in secondary industries, and are under-represented in more skilled and higher status white-collar jobs in service industries, particularly professional and managerial occupations.

Table 3.3: Employment by Major Groups - Selected P I Ethnic Groups – (Aged 15 and Over)

Ethnic Group	Legis. / Admin. Manager	Profess Assoc.	Clerks, Service/ Sales	Agric. / Fishery	Trades Worker	Plt/Mac Operator/ Assembler	Elementary Occupation	Not elsewhere included	Total
Samoan	1,839	6,159	11,820	780	2,760	6,579	4,368	4,851	39,120
Cook Islands	810	2,133	4,569	564	1,224	2,733	2,118	1,710	15,867
Tongan	**441 (3.7%)**	**1,488 (12.4%)**	**2955 (24.7%)**	**426 (3.6%)**	**942 (7.9%)**	**2,025 (16.9%)**	**1,734 (14.5%)**	**1,962 (16.3%)**	**11,973 (100%)**
Pacific	3,630 (4.8%)	11,523 (15%	22,479 (29.3%)	2,208 (2.8%)	5,245 (6.8%)	12,804 (16.6%)	9,396 (12.2%)	9,573 (12.6%)	77,352 (100%)
National	215,046 (12.6%)	427,713 (30%)	456,306 (26.7%)	136,401 (8%)	144,138 (8.4%)	142,980 (8.3%)	99,807 (5.8%)	88,665 (5.2%)	1,711,056 (100%)

Source: : Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups* (Table 19a)

3.2.2 Employment and Income Level

Table 3.4 shows that of the total Tongan labour force (11,973), 83.4% are employed with a significant percentage of 16.6% being unemployed. The high percentage of unemployment compared to the national figure of 2.2% further reflects the education achievement of the Tongans (although some are voluntarily unemployed due to other factors such as taking up duties as caregiver for aged parents or disabled family member). This is further reflected in the data on source of income. There are 20,619 income earners indicating that some 8,646 Tongans receive income in various forms of benefit payments (**Table 3.5** refers).

Table 3.4: Work and Labour Force Status 2001- Selected P I Ethnic Groups – (Aged 15 and Over)

Selected Ethnic Group	**Work and Labour Force Status**							
	Employed Full Time (1)	Employed Part Time (2)	Total Employed 3)	Unemployed (4)	Total Labour Force (5)	Not in the labour force (6)	Work & Labour Force Status (7)	TOT. (8)
Samoan	31,236 (79.8%)	7,881 (11.2%)	39,120 (84.3%)	7,278 (15.7%)	46,398 (66.2%)	23,658 (33.8%)	3	70,056
Cook	12,564 (79.2%)	3,306 (10.8%)	15,870 82.0%)	3,477 (18.0%)	19,347 (64.7%)	10,566 (35.3%)	0	29,910
Tongan	**9,507** **(89.4%)**	**2,466** **(10.6%)**	**11,973** **(83.4%)**	**2,379** **(16.6%)**	**14,355** **(61.5%)**	**8,985** **(38.5%)**	**0**	**23,334**
Total Pacific	61,389 (79.4%)	15,963 (20.6%)	77,352 (83.8%)	14,910 (16.2%)	92,262 (65.1%)	49,389 (34.9%)	3	141,654
National	1,315,449 (76.9%)	395,607 (23.1%)	1,711,056 (97.8%)	137,727 (2.2%)	1,848,783 (66.8%)	917,814 (33.2%)	24	2,766,624

Source: : Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups* (Table 17a)

The next **Table 3.5** estimates that about 60% of Pacific Peoples' income is from paid employment and/or return on investments. About 55% of Tongans earn their income from paid employment and/or investment. The remaining 45% do not have any source of income (15%) or being paid under various forms of government benefits such as pension, ACC, sickness and invalid benefits, student allowance (30%) indicating significant dependence on government benefits due to unemployment, economic inactivity and health problems.

Table 3.5: Sources of Personal Income 2001- Selected P I Ethnic Groups – (Aged 15 and Over)

Sources of Personal Income	**Samoan**	**Cook Islands**	**Tongan**	**Pacific**	**National**
1. Wages, Salary, Commissions, Bonuses, etc paid by Employer	37,890	15,768	11,028	74,754	1,526,697
2. Self Employment or Business	2,841	1,086	903	5,688	449,817
3. Sub-total	**40,731**	**16,854**	**11,391**	**80,422**	**1,976,514**
4. Interests, Dividends, Rent, Other Investments	2,094	1,125	597	4,740	698,322
5. Regular Payments from ACC or Private Work Accident Insurer	669	288	180	1,320	43,770
6. NZ Superannuation or Veteran Pension	2,316	1,257	696	5,157	414,231
7. Other Superannuation, Pensions, Annuities (Other than NZ Superannuation, Veterans Pension or War Pension)	657	369	228	1,572	87,915
8. Community Wage – Job Seeker	7,092	3,735	2,325	14,856	176,925
9. Community Wage – Sickness Benefit	2,394	1,230	831	4,977	52,932
10. Domestic Purposes Benefit	4,320	3,030	1,227	9,870	105,465
11. Invalids Benefit	1,890	948	612	3,912	64,743
12. Student Allowance.	2,883	1,095	1,002	5,838	77,175
13. Other Government Benefits, Government Income Support Payments, or War Pensions	4,065	1,686	1,578	8,343	108,447
14. Other sources of Income including support payments from people living in other households	912	378	402	2,019	53,099
15. No Source of Income	7,035	2 610	2,886	14,028	150,021
16. TOTAL	**63,849**	**27,903**	**20,619**	**129,213**	**2,688,607**
17. Income earner but not employed*	**16,083** **(25%)**	**8,439** **(30%)**	**6,349** **(30%)**	**34,763**	**562,072**

Source: : Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups* (Table 15a)

Note: Totals not equal to sum of all columns since some have more than one source of income.

* (16 - 15) - 3 = 17 or (63 849 – 7 035) – 40731 = 16,083

Regarding level of income, the median income for Tongans is $11,800 compared to a median of $14,800 for the Pacific and $18,600 for the national level (refer to **Table 3.6**) indicating the income gap with the rest of the New Zealand population.

Table 3.6: Total Personal Income 2001 - Selected Pacific Island Ethnic Groups (Aged 15 and Over)

Selected Ethnic Group	Samoa	Cook Is.	Tonga	Pacific	National
Loss	1,185	372	312	2,049	16,764
No Income	5,007	1,953	1,950	9,996	120,000
$1 - $5,000	7,203	2,928	3,075	15,060	238,878
$5001 - $10,000	7,833	3,807	2,964	16,914	334,236
$10,001 - $15,001	6,531	3,441	2,136	11,730	391,365
$15,001 - $20,000	5,727	2,601	1,779	11,730	241,773
$20,001 - $25-000	6,201	2.454	1,614	11,763	206,913
$25,001 - $30,000	6,396	2,724	1,617	12,294	213,552
$30,001 - $40,000	6,507	2,778	1,545	12,612	309,753
$40,001 - $50,000	2,424	1,035	624	4,794	182,151
$50,001 - $70,000	1,290	528	330	2,544	162,615
$70,001 - $100,000	312	141	105	678	68,118
$100,000 or more	225	108	93	474	61,965
Not stated	13,212	5,046	5,193	26,682	218,544
Total	**70,056**	**29,910**	**23,334**	**141,654**	**2,766,624**
Median Income	**15,600**	**14,900**	**11,800**	**14,800**	**18,600**

Source: : Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups* (Table 16a)

3.2.3 **Housing and Household Necessities**

According to Table 3.7, the majority of the Tongans (68%) cannot afford to buy a home and are still living in rented accommodation – particularly state houses. This reflects a number of factors such as the low-income level of the majority of the people (around 70% earning about $20,000 or less), and / or having other priorities such as spending on social obligations (contribution funerals expenses, weddings and birthday feasts of relatives). At the same time a fairly significant high percentage of Tongans have access to other necessities such as vehicles and telephones.

Table 3.7: Percentage of Households with Access to Necessities

Pacific Peoples' Access to conveniences	**1991 (%)**	**1996 (%)**	**2001 (%)**	**Tongans' Access to conveniences**	**2001 (%)**
Household with access to a telephone	**….**	82.7	87.0	Household with access to a telephone	85.8
Households with access to fax	…	…	10.3	Households with access to fax	10.1
Household with access to the internet	…	…	20.3	Household with access to the internet	17.4
Household with access to vehicles	77.6	80.4	86.0	Household with access to vehicles	84.4
Household in Rented Dwellings	50.7	55.6	61.8	Household in Rented Dwellings	67.9
Households in Dwellings with / without a mortgage	49.3	44.4	38.2	Households in Dwellings with / without a mortgage	32.1

Source: : Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups* (Table 1c)

3.3 Socio – Cultural

3.3.1 Families and households

Table 3.8 depicts that two or more family household is not uncommon in the Tongan family system. It is also still the norm for Tongan couples to desire to have children. Average family size is about four yet there are many families who have more than four children. This trend of over-crowding in Tongan homes causes health problems due to sharing of facilities thus contributing to increasing of infectious diseases.

There is also a symptom of deterioration in the level of functional family as although couples with children still compose a majority, it has decreased from 69.2% in 1991 to 64.5% in 2001. The trend of one parent with children on the other hand composes a significant proportion of family type increasing from 24.7% in 1991 to 27.8% in 2001. One parent with dependent children has also increased from 29.5% in 1991 to 34.2% in 2001.

A household with extended family is part of the Tongan culture and kinship (*kainga*) system, where two or more families stay together for economic reasons as part of strong ties - and as well as of the extended family practice of caring for one another. The *kainga* system is still very strong with the extended family tracing back to three generations or more. The original idea of *kainga* was adopted and used because our family extends beyond the nuclear to include grandparents, many, many uncles, many, many aunts, and many, many cousins, nieces, nephews and so forth.

Overcrowding has also been an issue for some time now. This has become most noticeable with the influx of new migrant families who in turn need the extended family support system during their initial one or two years in New Zealand – before they can find their own feet financially.

Table 3.8: Structure of Families and Households (1991,1996,2001)

Percentage of the Peoples of the Pacific by	1991 (%)	1996 (%)	2001 (%)
Family Type:			
Couple without children	6.1	7.0	7.7
Couple with children	69.2	66.5	64.5
One parent with children	24.7	26.5	27.8
Dependent Children			
Couple with children	70.5	67.8	65.8
One parent with children	29.5	32.2	34.2
Average family size (#)	3.8	3.7	3.7
Extended Family			
One-generation	…	1.3	1.4
Two-generation	…	39.4	39.8
Three or more generation	…	59.3	58.8
Household			
One family household	80.9	74.5	75.6
Two family household	13.3	18.1	17.0
Three or more family household	2.1	3.4	2.8
Other multi-person household	2.4	2.4	2.8
One-person household	1.4	1.6	1.9

Source: Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups* (Table 1c)

Members of the *kainga* have well-defined roles. Women's roles are separated from the men. Men were traditionally the main income earners while women fulfilled the domestic roles of child care and house management. This division of labour between Tongan men and women is less clearly defined and has undergone increasing changes in the New Zealand environment. The research evidence has indicated that the many men still perceived women's job as being in the home. This assumption is reflected in the high percentage of women caring for the disabled.

3.3.2 The *Kainga* System

Kainga consists of a very large extended group, which includes relations of one's mother and father. *Kainga* is also hierarchical in nature. Ranks, roles and status are significant in understanding how members of the *kainga* relate to each other. It also determines how one behaves in a particular setting and function. For example, age, sex and position within the *kainga* determine one’s rank. The older members of each sex are revered and younger members often seek their wisdom. The eldest male member (*‘Ulumotu‘a*) has a leadership role within the *kainga* dynamic and often offers support to his your *kainga* members. His role involves the oranising of collection and distribution of production contributed by *kainga* and other lineages (see Havea 1996). *Fahu* is the eldest female of female lines. *Fahu* is the most elevated position a Tongan woman can hold. She has superior social status over her brother and his children. Her role involves the administration and management of *koloa* – mats, fine mats and tapa etc.

The relationships also involve very key aspects, which define members’ behaviours towards other members and interactions with each other. For example, the respect between a brother and a sister (*veitapui*) describes the degree of this relationship. This relationship involves certain aspects of *taboos* that must be respected. The brother and the sister cannot watch television together, especially if it shows any sexual scenes or the use of obscene language and so forth. The father is also highly respected by the children; daughters especially cannot provide certain personal assistance like bathing, and so forth. However, because of certain constrains of the new context, some families have uplifted the taboo system in order to accommodate the needs of the disabled member. As one informant explained:

Ko e talu ‘a e kamata ke toe kovi ange e tukunga ‘o Uili mo e si‘i tokoni mai ‘eku ta’ahine lahi. Kou u ‘osi lea tonu ange pe ki ai. ‘E maumaui‘i e faka’apa’apa kae.‘ata pe ia ki ai ke ne fakahoko e ngaue ki hono ki‘i tounga‘ane	*Since Uili’s condition started to continue deteriorating, my eldest daughter has been helping. I have spoken to her,that the taboo (veitapui) will be lifted to to enable you to care for your brother.*
‘Oku malohiange ‘enau fe‘ofo‘ofani pea fai ‘e he’ema ta’ahine e me‘a kotoa ‘o a’u ki he kaukau‘i. ‘Oku mahu‘inga ange ‘enau nofo fe‘ofo‘ofani ‘Oku ma fiemalie lelei pe kimaua ki he tu‘u tu‘uni.	*The love and compassion among my children is much stronger and our daughter does everything, even bathing. It is much more important to us. We are comfortable with our decision.*

Note : **The names used in these texts have been changed in order to protect the true identity of the participants.**

This is a very rare situation, but its existence needs to be acknowledged and in this case, the participant was very frank about breaking the taboo between the brother and sister. Again the practice of *Fakalotofale'ia* is evident in this case. *Fetokoni'aki* – interdependent among the members, showing of compassion – *'ofa* towards the disabled member are key aspects of this *fale*. However, it is acknowledged their decision of adjusting their family roles to cater for their needs in the new environment must be highly respected. This family was very open and honest about their collective decision to utilise their own members to meet the needs of the disabled member.

Although *kainga* is determined by blood ties, marriage, adoption, or others are determined through cultural lineages. Tongans referred to these lineages as *kainga* faingata'a (difficult *kainga)* and *kainga-'ofa* (generous, love), see Havea (1998). For the sake of further clarification it needs to be pointed out here – with regards to '*kainga faingata'a*' ('difficult' *kainga*) - that the connotation of 'difficult' is that the *kainga* relationships / linkages obtained are (others / 'outside') with whom there are no blood / biological relations. The beauty of the Tongan's special regard / respect for this non-blood based *kainga* linkage is that it is placed at a 'higher level' of 'sanctity and preference' than those normal linkages with close blood relatives. 'Difficult *kainga* must therefore always receive priority/preferential treatment when they come visiting in our household. They always get the best food and sleep in the best bed. Tongans would always have to make difficult decisions under such 'sacrificial' situations – to give up the best for the adopted *kainga*. It is not easy but is also highly altruistic, noble and brave.

The non-blood related lineage can also mean a very close and long-standing good neighbours or friends. These new adopted lineage were more evident with some of the participants, because their blood-related *kainga* were geographically distant. As one participant stated:

Ko e tokoni lahi kiate au, ko hoku kaunga'api.
Neongo ko e Ha'amoa, ka 'oku ofi ange ia
Pea faingofua ko 'ene ofi. 'Oku mau fu'u
feohi lelei 'aupito.

I get most of my help from my
neighbour. Although they are
Samoans, they are much closer
And it is easier because of its closeness.
We mix very well.

A Tongan community group can also be defined as *kainga* when blood related *kainga* are lacking. *Kainga* does not necessarily live in one place they are scattered in various places, back in the villages in Tonga, various places in New Zealand, Australia, United Sates and worldwide. Particular families and how they perceive their new context in Aotearoa defined kainga in this sense. For example, the above case highlighted her kainga as her Samoan neighbour.

Kainga is underpinned by these philosophical worldviews: ‘*ofa* – love, *uouangataha / fa‘utaha/ faaitaha* (collective), *fefua‘aki / fetokoni‘aki* (interdependent), *makafetoli‘aki* (reciprocal) and *fe‘ofo‘ofani* (harmony).

3.3.3. Religious Affiliation

About 85% of total population are Christians. A very high proportion of these Tongan Christians spend a very significant amount of their meager income on religious related projects such as construction of big church buildings, feasts and so forth.

This has drawn strong criticism from some New Zealand Members of Parliament. In 2002, one such MP (Matt Robson) criticised the Tongans' heavy spending on ‘religious-related' matters (actively encouraged and urged on by church ministers) because this is a drain on the majority of the people's meagre income and which thus contributes to further deterioration of the Tongans' economic marginalisation.

Other examples of these criticisms also include weekly letters to the editor in *the "Times of Tonga*" ("*Taimi ‘o Tonga*") newpaper from the likes of S ‘Akilisi Pohiva and Professor ‘I Futa Helu – amongst others of the Tongan Pro-Democracy Movement – who noticeably are themselves Tongan natural born citizens. They have raised the issues together with Mr M Robson.

The important point to note here is that it does not matter so much as to who is seen to be criticising the ‘system' / situation – as much as that there is a genuine concern that possible problems exist and need to be dealt with – in the interest of a fairly substantial segment of the Tongan population in New Zealand.

However, and at the same this is of course also a matter of freedom of choice and belief as well as of value to most Tongans. Thus whilst the mainstream’s measurement of well–being may focus on the material aspects (good accommodation, car, etc) - Tongans’ feelings on and interpretation of well-being on the other hand - take account more of kinship (compassionate and respect for each other) and as well as serving their Christian God by spending a lot of money on building churches where they can worship Him. Tongans’ total well-being must therefore be viewed in a ‘holistic’ manner because it encompasses the physical, spiritual, intellectual and socio-economic dimensions. The socio-economic development of Tongans and Tongan disabled people must take into account the ‘holistic’ or wholeness of all these interrelated elements. As another participant had reported:

> *‘Oku kau e lotu ia he tefito‘i me‘a mahu‘inga taha ki homau ki‘i famili. Ko e efiafi kotoa ‘oku fai ‘emau lotu pea fai ai e talatalaifale ki he fanau ke nau ‘ofa, fetokoni‘aki mo nofo fe‘ofo‘ofani tautefito ke nau ‘ofa mo tokoni‘i honau ki‘i tounga‘ane / tokoua faingataa‘ia.. Ko e tautefito eni ke mahino kiate kinautolu ko e ‘Otua pe te ne lava ‘o fakahaofi kinautolu mei he ngaahi fakatu‘utamaki ‘o e ‘atakai.*

> *Church is one of the very important aspects to our family. Every evening we say our prayers. We also have family discussions and teaching our children how to show compassion, help each other and live in harmony, especially their attitude to care for their disabled brother. The emphasis is to make them understand that God is the only one that saves them from all the troubles in the environment.*

The above family stated that church and their spiritual faith is a very import aspect of their survival in their new environment. It also guides them to teach their children good values and behaviour: to show compassion for each other, to help each other and to live in peace and harmony, especially to understand the special need of their disabled sibling. This family strongly believes that their faith in God will save their children from all troubles in the environment. This family also practice the value of *Fakalotofale‘ia,* such as *‘ofa* – compassion, *fetokoni‘aki* – help each other (interdependence), *fe‘ofo‘ofani* – harmony.

Kuopau pe ke fai e kavenga ia ‘o e lotu
he ko e me‘a pe ia ‘oku fai ai e mo’ui.
Neongo pe e fusimo‘omo ‘e feinga pe
ke fai e tokoni ki he ngaahi kavenga
‘o e lotu

We must fulfil our church obligation because
That what has kept us going? Although we are
financially stretched, we still try to meet our
church obligations.

For some participants, church donations must be fulfilled and whether or not they can afford it, it has to be given - a strong belief that families perceive their donations as offering to God a share of what He has blessed them with. This is part of maintaining their relationship with God. The spiritual aspect is one of the many values of *Fakalotofale‘ia.*

Another participant commented:

‘Oku tatai taha pe foki ha lava atu ia
ki he lotu koe‘uhi ko e tauhi ‘o e ta‘ahine ni.
Ka ko ‘ema lotu ai pe heni. Taimi pe ni‘ihi
‘oku lava mai ‘emau setuata, ka ‘oku lava pe
e lotu ia heni.

Being able to attend church is rare.
Because of my commitment to care for
my daughter. We pray at home. Sometimes, the steward pays a visit, but we
managed to pray here.

For all participants, the spiritual aspects were highlighted as very important, whether they attend church or stayed at home. There also seemed to be a variety of patterns, which emerges especially as to how participants responded to church financial obligations both at family level and church leaders. What has been highlighted from this section is that the spiritual dimension is one of the many values of *Fakalotofale‘ia.* Participants acknowledged that they practice it whether they are at church or at home.

3.3.4 Pangs and Pains of Adaptation and Cultural Assimilation in Aotearoa

The existence of sub-structures such as *kainga* and church which have some knowledge of such opportunities as are being offered under DSS however – does give support to these Tongans.

To put the total picture into proper perspective however, it is equally as crucial and thus needs pointing out that although this situation has had a positive impact – it still has had at the same also quite delimiting effects on the life of Tongans in New Zealand.

Quite serious problems with further aggravating dimensions have emerged and they too remain manifest in the taxing effects of what has come to be referred to by some scholars on the subject as being the wholesale transplantation syndrome[5]. This concept is based on and derived from reluctance / resistance to change and adaptation – particularly migrants in new environments.

Clear manifestations of these are seen in:

(i) Failures of Imported Traditional Institutions – The Church

As mentioned earlier Tongans value their spiritual health very highly indeed. They are very devout believers and devoted to their Christian God.

The problems start however when the place and role of the Church within the scheme of things spiritual - is called to question.

In terms of structure and management practices or indeed the lack of a proper system of it - the Tongan (version) of the (Methodist) Christian Church in Aotearoa has come to be perceived more and more as being a disabled and disabling institution – and whereas it is

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[5] Tu'itahi M F (1996) "*Adaptation in Akarana & Aotearoa: Support Networks for Tongans in Auckland*" Master of Arts Research Essay, Department of Development Studies, University of Auckland.

often perceived as being a prop and source of support - it is also now beginning to be seen as being more of a burden upon its adherents and followers than anything else[6].

- whatever social action it takes – if any at all - for and on behalf of its flock is almost always out of sync with the members' needs ;
- ignorance is bred and perpetuated by the teachings, examples, attitudes, action / non-action of many of its leaders (the so-called "spiritual leaders") – and this serves not to dissolve but to provide a substitute for as well as perpetuating misunderstanding – particularly of the true priorities for life here in the new environments of New Zealand.
- Very strong opposition to changes in the New Zealand environment – especially where it is perceived that such new changes would upset the (albeit 'imported-from-Tonga' *status quo*)[7]

It is of note that there are notable exceptions

As another participant had said:

'Oku sai 'aupito homau siasi 'o
mautolu he 'oku mahino ia ki
he'emau setuata. 'Oku ne pehe 'e ia
'oku mahu'ingaange ke totongi homau
ngaahi mo'ua pea ka toki toe ha me'a
pea ka 'ikai pea sai pe.

Our church is good because our
Steward understands the situation in
New Zealand. He thinks it is more
important to pay our bills and only
gives if there is anything left. If not,
it is okay.

The above case shows that some of the church leaders are starting to shift from the strong emphasis on the material requirements of the church and are realising that the new environment has different financial demands that should be met by the families. Therefore, as a leader he is releasing some of the pressures from the families.

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[6] Witness the present on-going case in the High Court involving the Tongan Methodist Church (Otahuhu) splinter group vs. (i) The main Otahuhu Methodist Church (ii) NZ Metodist Church .

[7] Witness for example the recent case of the Supervising Tongan Minister of the Tongan Methodist (Auckland – Manukau) Parish – whom the last Conference of the New Zealand Methodist Church has ruled / directed to be repatriated to Tonga in early 2004.

(ii) **Other Community Institutions / Support Networks**

Some other attempts to build direct links with the mainstream have been in the form of community based charitable trusts, providing a variety of social services.

These however have failed due to lack of proper management skills and or highly questionable motives, objectives and practices.
As a result the majority of Tongan people have thus come to begin to lose faith and trust in even their own so-called ‘vanguards’ and ‘representatives’. This is a very sad situation indeed.

In sum these factors contribute in a very unfortunate combination to the already low participation of Tongans in many other areas of the available services in mainstream culture.

3.4. **Tongans in New Zealand:**

The low participation of Tongan people in the available disability services is not entirely due only to structural and policy deficiencies. Indeed part of the problem also arises from the economic, social and cultural status of the Tongans in New Zealand.

3.4.1. **Social Economic Condition**

The latest Census in 2001 highlighted the average income ($11,800) for a Tongan person as the second lowest amongst the Pacific Island peoples when compared to an average of $14,800 for the total and $18,600 for the whole nation. The low average income for the Tongans strongly correlates with the level of educational achievement of many Tongans (28% with no qualification and 48% of college qualifications). This is further reflected in:

- a high unemployment rate of 16%; and
- those who are employed, occupy mainly clerical works (24%), factory workers (17%); elementary occupation (14%); and
- about 40% Tongan income earners are on some kind of benefit payments.

The level of education of Tongans in New Zealand is rather antithetic to the oft-quoted educational achievement records of Tonga in the Pacific. Tonga (with the exception of NZ, Australian and the Indians of Fiji) is reputed to have the highest number of tertiary level graduates.

3.4.2. Tongan Migration into New Zealand

A brief background of the history of Tongan migration further illustrates their profile and how the pattern of adaptation and acculturation has occurred at many diverse levels. Prior to the late 1960s, there were only a few Tongan families in New Zealand, most of which were mixed marriages, and a small number of Government sponsored students pursuing further education and training. (Joris de Bres & Campbell 1975)

The more substantial initial influx of Tongans to New Zealand started in the 1970s, which was a response to the increased availability of jobs in New Zealand (Joris de Bres & Campbell: 1975). In their 1975 study of migration between Tonga and New Zealand – entitled "*Worth their Weight in Gold"* - Joris de Bres and Rob Campbell, pointed out there were 17,422 temporary migrants between 1965 – 1975 coming from Tonga to New Zealand, over 15,000 since 1970.

It is estimated that between the periods of 1970 – 1975 one in every four Tongans between the age of 15 and 60 had been to New Zealand for temporary visitation under the circumstances described above (Joris de Bres & Campbell 1975).

However, since visas were only short-term and temporary, at the end of three or six months, many overstayed as illegal immigrants because they had not achieve their objective in coming to New Zealand. As Whiteheads explained the reasons for coming to New Zealand were to (a) build a house (b) finance education of children in Tonga and (c) because of underemployment in Tonga (Whiteheads, 1974).

This situation then further evolved into applications for permanent residency in New Zealand, which was a much-preferred option to the harsher subsistence existence in Tonga. Tonga's economy was then and still is predominantly subsistence – characterised by severe resource constraints and limited employment opportunities, an environment in which Government service is the sole major employer.

The Tongans who flooded to New Zealand in the 1970s and up to the early 1980s were predominantly those who did not make it at school to be able to get a lowly paid job in government. The opportunity for temporary entry to New Zealand was thus a way out for these Tongans to find better economic opportunities and as well as improved living standards for themselves and their families. Even Civil Servants at clerical levels visited New Zealand on short holidays and stayed illegally, then later getting their status legalised through macro amnesties offered by the New Zealand Government.

Table 3.9 : Patterns of Tongan Migration to New Zealand (1971 - Present)

Year	Scheme	Amnesties	Tongans in NZ	Tongans in NZ General profile
1971	Hutt Valley Chamber of Com. (6 months permit)			Predominantly young, able Bodied males but with very low educational levels
1974	New Zealand-Tonga Government Work Scheme – arranged / agreed between the NZ and Tongan Governments.	Macro Amnesty		Same as above but with more low education females joining in 9 but not as part of the government arranged scheme
1976	Labour Scheme (11 months)	1976 Macro Amnesty		In mid 1970's a number of Tongans civil servants came for holidays and stayed on.
1981			7,055	Early 1980's more Tongans came for tertiary education on scholarships and some of them stayed on in NZ
1986		1986 Macro Amnesty		
1987	Visa free experiment	Many Tongans entered NZ		Late 1980's with MERT Scholarship youths left Tonga for further education in NZ and more stayed on.
1991			23,194	Continued
2001			40, 713	Continued
1996 – present	General skills – NZ residency awarded highly skilled Tongans			Hundreds of highly educated Tongan families migrated to NZ seeking better jobs and new life.

Source: Compiled, adapted and consolidated from **:** (i) Joris de Bres, (1974), *How Tonga Aids New Zealand: A Report on Migration and Education:* South Pacific Action Network, Wellington (ii) Joris de Bres & Rob Campbell (1975), *Worth their Weight in Gold:* Auckland Resource Centre for World Development

(iii) Statistics New Zealand, 1995, *Tongan People in New Zealand* : *A Statistical Profile,* Statistics New Zealand, Wellington (iv) Statistics New Zealand, 2002, "*2001 Census of Population and Dwellings : Ethnic Groups"* Statistics New Zealand, Wellington, New Zealand.

Note :

Despite increasing numbers of highly educated Tongans moving to NZ in the 1900 to the present, there is still a consistent flow of lowly educated Tongans coming to NZ at the same time and are still staying illegally in NZ at the present time.

The industrial expansion in New Zealand in the late 1960s to 1970s welcomed the ready-made unskilled labour workforce. A number of work schemes were arranged in 1971, 1974 and 1976 as depicted in Table **3.9**

According to de Bres an estimated number of illegal Pacific overstayers, between 4,000 – 7,000, were in New Zealand in 1974 (de Bres and Campbell 1975). Many of these faced the notorious dawn raids of that era – and which culminated in mass deportations. The resultant public outcry eventually led to the New Zealand government offering amnesty to many of these overstayer Tongans.

A second wave of migration from Tonga to New Zealand occurred in 1987, when the Government permitted Tongans to come to New Zealand for three months visa free. This scheme lasted only three months. A high proportion of those few thousands who came to New Zealand under that scheme were unemployed and had limited education.

The pattern of Tongan migration is therefore significantly characterised by a majority without qualifications, low educational achievement, and occupants of lowly paid factory or clerical jobs.

In order to survive in the new environment and a culture where money is the sole means of survival, getting any job was of top priority, and "to make ends meet." This situation was and is to a large degree still the order of the day for many Tongan families.

Gaining higher education, better job opportunities and higher living standards are thus ongoing challenges for many Tongans in New Zealand. At the same time since English is the official tongue in New Zealand, Tongans with low levels of education face communication problems and language barriers, which in turn have resulted in a low level of awareness and understanding of opportunities that are available in the mainstream system.

This also leads to a further low-level of participation in services such as DSS, which are available for Tongans with disabilities, their *famili* and *kainga*.

3.5 **Summary**

Tongans, alongside other Pacific groups are highlighted as one of the ethnic groups at the lowest of socio-economic status. The main defining characteristics of this situation are:

- Higher percentage (48%) in ‘no qualification and secondary school only’ level of education - relative to only 12% with tertiary qualification – and as compared to 48% and 39% respectively at the national level;
- This then translates into severely limited employment opportunities - most Tongans are employed either on lowly paid jobs or are on some form of government benefit;
- High unemployment rate of about 15% compared to 2.2% for all of New Zealand;
- Highest level of poor housing condition with about 68% still staying in rented houses (particularly State Houses);
- Living within extended family context is most common (which contributes to poor health status), but which arrangement nevertheless also demonstrates the compassionate nature of their *kainga* system;
- Highest crime rates (violence conviction 5.7% of Pacific population out of the total 12% of all convictions of violence);

This chapter has highlighted a number of factors that have worked to the disadvantage of Tongans in general and Tongan disabled people in particular. Firstly, there is all the statistical evidence of their low socio-economic status. Then it has also been identified that their perception of well being is in contrast with the mainstream New Zealand view of well being. For example, mainstream socio-economic and well-being development is based solely on the physical and material aspects. The perception for the development for Tongans is based on a holistic worldview as proposed by “*Fakalotofale‘ia”*. It encompasses the physical (*sino*), ‘*atamai* (intellectual), *laumalie* (spiritual) and *‘ekonomika* (economics).

Tongans in the study also maintained that fulfilling their family/*kainga* and social obligations makes them feel free. This involves family duties, financial contributions to the family, and church obligations. As this participant suggested:

Ko e lava ko ia ‘o mafua ‘a e kavenga, mo e fatongia, ko ‘ete ongo‘i tau‘ataina ange ia. Ko e kavenga ki he siasi mo e famili kuopau ke fakakakato.	*Once obligations for family and church have to be fulfilled. I feel much more free. The church and family obligations must be fulfilled.*

CHAPTER 4 TONGAN DISABLED

4.0 Introduction

This chapter deals specifically with disabled Tongans in New Zealand.

The main purpose and objective is to describe, discuss and highlight the condition of the Tongan disabled in the context of the Tongan ethnic group and as well as a component of the Pacific Peoples in New Zealand.

4.1 Key Statistics on Disabled Tongans

Due to limitation of official data on Tongans with disabilities (Disability Survey in 2001 was sorted only by main ethnic groups), the researcher estimates that close to 4,700 (12%) Tongans are disabled (this estimate is based on the given percentage of total number (28,100 or 12%) of the Pacific Peoples that were reported in the Disability Survey in 2001 as persons with disability.

Table 4:1 Profile of Disabled People in New Zealand – 2001

	Total New Zealand Population	**Pacific Peoples**	**Tongans (Estimates)**
People with Disability	**743,800 (20% of total NZ population)**	**28,100 (12% of Pacific Peoples)**	**4700 (12 % of Tongan people)**
Age	**Disability as % of total popn. by Age Group (%)**	**Disability as % of total Pacific People by age group**	**Disability as % of total Tongan people by age group.**
0-14	10	8	9
15 – 44	13	12	12
45 – 64	25	26	26
Over 65	54	53	53
Disability by Type	**%**	**%**	**%**
Physical	58	56	56
Other	35	42	42
Sensory	37	35	35
Psychiatric/Psychol.	13	18	18
Intellectual	4	8	8
Major causes of Disability	**%**	**%**	**%**
Illness	40	41	41
Accident/Injury	30	23	23
Unmet need for special treatment	12	13	13
Unmet need for some type of health service	Na	17	17

Source: Statistics New Zealand, (2001) New Zealand Census of Population and Dwellings: Ethnic Groups: Disability Survey - Snapshots 1 and 3

It is also estimated that the trend of Tongan disabled population (in terms of type, age, and cause) follows the same pattern as that for the Pacific. (Table 4.1 refers)

According to the New Zealand Disability Survey conducted in 2001 and reported in 7 snapshots, 1 in every 5 New Zealander is disabled compared to 1 in every 8 Pacific Islander /

Tongan. Disabled Pacific Peoples (including Tongans) are mainly physical related and in the age group of 65 years and over.

The main causes of disability were given as being through illness – and with 13% having had unmet needs for special treatment and 17% with unmet needs for some other types of health service.

4.2 Case Study on 10 Disabled Tongans

The researcher randomly selected 10 disabled Tongans in the Auckland area and interviewed them regarding the DSS to which they had access. The initial selection was aimed to cover the range of disability, gender, age and geographical, but because of the limited time factor, this sample was a convenient one.

Out of this group of ten - seven of the interviewees were females whilst there were only three males. Half (all three males and two females) suffered purely physical impairments whilst of the other half - four of the females suffered physical / intellectual disability. The tenth member (female) of the group suffered a physical / age-related disability. (**Table 4:2** refers)

Table 4:2 Disabled Tongans' Profiles

Age Group	**Male**	**Type of disability**	**Female**	**Type of disability**
0-14	0		2	Physical
15 – 44	3	Physical	4	Physical / intellectual
44 – 64	0			
65 and over	0		1	Physical and age related
Total	**3**		**7**	

Four of the interviewees have severe impairments and also regularly have to see the doctor, on medication and required specialised care and treatment.

The remaining six are considered to have less severe conditions. They only occasionally see the doctor when they are sick and do not require specialised treatment and care **Table 4.3** provides details of the participants' medical requirements.

Table 4:3: Medical Requirements

	Seeing the doctor (regularly)	**On medication**	**Requirement for specialised care and treatment**	**Other form of treatment (massage, herbs)**
Yes	4	6	4	4
No	0	1	4	3
Occasionally	6	3	3	3

4.2.1 **Family Support**

All participants resided with and are supported by their respective families, except one participant who lives independently with support from one of the disability support providers. Four participants claimed to have support from relatives as well as friends. This reflects the strong kinship ties amongst the Tongan families and the practice of *Fakalotofale'ia.* All participants clearly suggested their need for immediate family members to assist with the personal care of their disabled family members. They explained that an immediate family member would be more compassionate *('ofa*) and familiar than a paid caregiver (bearing in mind that a disabled person needs all the support - physical, psychological, spiritual and so forth) support he / she can get from her / his immediate environment (home).

Table 4:4 Levels of Support Available to Disabled Group

Data in **Table 4.4** below indicates the level of family support, awareness, access and exposure to DSS and level of economic situation that the disabled population as reflected in housing.

Family Support	**Stay with family**	**Support from family**	**Support from relatives, friends, etc**	
Yes	9	9	4	
No	1	1	6	
Severity of impairments	**Need personal care**	**On 24 hour supervision**	**Personal Need being met**	
Yes	7	4	3 (physical	
No	3	6	7 (emotional	
Awareness, Exposure to DSS	**Been assessed by NASC**	**Receive some form of DSS Service**	**Aware of DSS social groups, service**	**Fully informed of entitlements**
Yes	8	6	3	2
No	2	4	7	8
Benefits Type	**Invalid Benefit**	**Accommodation Allowance**	**Support from others - occasional financial support**	
	6	1	3	
Living conditions	**Live in Own home**	**Live in Rented Houses**	**Employed**	**Unemployed**
	0	10	1	9

The idea of a stranger looking after a Tongan disabled person appeared not to be acceptable to the Tongan families who participated in the study. All respondents in the case studies expressed their wishes to use family members as caregivers because they cater best for their needs. The mothers and children of participating families made the following comments:

‘Oku mau fetongitongi pe hono tokanga‘i‘ema ta‘ahine. ‘Oku ma ongo‘i ko homa fatongia , pea he ‘ikai te ma teitei tukuange ‘ema ta‘ahine. Kuo ‘osi felotoi homa ki‘i famili, ka hoko ha me‘a kiate au, kuo loto lelei ‘ema ta’ahine lahi ke ne hoko atu hono tauhi ‘ema ta‘ahine	*“We take turns to care for my daughter ... always feel responsible and will never give up on our daughter. My family agreed if something happens to me, my eldest daughter will continue to care for her sister.*
Ko e fengaue‘aki pe ‘eku ki‘i fanau ‘oku lava ai ke tokanga‘i lelei ‘a Mina.. ‘Oku fu‘u ‘ofa ‘aupito ‘a hono fanga tounga‘ane mo hono fanga tokoua ai pea ‘oku nau fu‘u tokanga‘i lelei ‘aupito	*It is through the co-operation of my children that we able to take good care of Mina. Her siblings really love her and take good care of her.*
‘Oku malava nai ke tokoni mai pe ‘a ‘eku ta‘ahine lahi ki he tauhi ‘eku ta‘ahine mahaki? ‘Oku fu‘u fiema‘u ‘aupito ke hiki holo. ‘Oku ou fiema‘u pe ke tokoni mai he oku faingofua ange ia pea he ‘ikai ‘ikai mai. ‘Oku ‘ikai foki ke ngaue. ‘E lava ‘ehe tafa‘aki ngaue ko eni ‘o fakangaue‘i pe ia?	*Is there a possibly that my eldest daughter could help me care for my disabled daughter? There is a lot of lifting involved and I prefer to use her because it is more flexible and will not say no. She does not have a job too. Can the Home Support people use her instead?*

The above comments reflected the wishes of participants to use members within their own *kainga* system rather than having a carer who many not speak their language and lack the understanding of their social and cultural background. For some participants, the members within their own *fale* – (house) managed to cater for the appropriate needs of the disabled person because of the significance of the *fakalotofale‘ia* values – compassion, co-operation, interdependence and so forth.

Others raised the issue of employment opportunities for members who have no jobs. Another key issue that had emerged from the views of some families is the degree of flexibility in this arrangement - to meet the needs of the disabled person.

4.2.2 **Awareness of and Exposure to DSS**

Table 4.4 indicates mixed responses from the participants. For instance, although eight have been assessed by NASC and six of them have received some form of home care service such as respite care (28 days). - when the primary caregiver is sick, only two participants were aware (partially) of the process and the criteria for accessing DSS. The rest of the participants did not fully comprehend DSS. This was mainly attributable to a number of factors such as:

i) Fragmentation of the DSS services amongst different government organisations. On top of this also are a number of problem areas in relationships with a contracted service. For instance, an assessment is conducted by an Assessor from the contracted NASC providers. Another staff from the NASC concerned will then come in and deal with service co-ordination and who will in turn contact the service provider This means – three different people are dealing with the consumer on a normal / non-complicated situation.

If the case is severe, a comprehensive assessment will be completed after the initial assessment and before referring the case to service co-ordination. For invalid benefit, the consumer will have to refer to WINZ (which is an arm of the Ministry of Social Development), and for transport assistance (adult), applications have to be lodged with Lottery. This kind of fragmentation is not only confusing, but also time consuming.

One caregiver had this to say on this issue:

> *Ko ‘emau tali fuoloa ki ‘asesimeni (NASC). ‘Ikai lelei e ngaahi fakamatala ki he kakai faingata‘a‘ia. Ko e ngaahi liliu mo e fokotu‘u tu‘u fo‘ou ‘oku fu‘u ta‘emahino ‘aupito. Na‘a ma kole ki he me‘alele pea ‘ikai tali pe ‘oku fekau‘aki mo e NASC pe ‘ikai, hei‘ilo!*

> *“... long wait for NASC, no consistent information on disability issues plus changes on new services is confusing. We also applied for a vehicle but declined by the Lottery; whether it had anything to do with NASC, I don‘t know?*

(ii) Participants were not fully aware that DSS are not entitlements, but are needs based. An assessment must be completed before any consumer receives any form of DSS. This was reflected in the data on the last time participants were assessed. Seven respondents said the last time they were assessed was in 2000 and 2001 and no follow assessments were done in 2002 as expected. There appears to be a big misunderstanding because unless NASC are approached, no follow up assessment will be made. In his review of the Disability Policies in 2002, Saucier wrote:

> At first blush, DSS look like a universal entitlement to disability and long-term care not found in the US, but the system operates under a capped budget, and individuals are not personally entitled to services. Some services are subject to waiting lists and prioritisation criteria. In some areas, NASC agency capacity cannot keep up with the demand for assessments, and wait for assessments can be six months or more (p13)

iii) Another very significant area of misunderstanding is caused by language barriers. Due to limited understanding (or lack of understanding) of the English language, many Tongan families with a disabled person(s) do not fully comprehend the various systems (including DSS) in New Zealand. Most of the information about services that they benefit from was passed on to them informally by word of mouth in Tongan, often by relatives. One respondent said:

> *‘Oku mau fiema‘u ha taha ngaue Tonga ‘Oku ‘ikai ke mau lava ‘o fetu‘utaki lelei mo e kau ngaue koe’uhi ko e palopalema lea. Ko ia ‘oku ‘ikai ke nau mahino‘i*

> *We need a Tongan Assessor, as we cannot communicate effectively with other Assessors due to language barrier. So they do not understand what we want, how we*

‘emau fiema‘u mo ‘emau ongo‘i pea mo e ngaahi tapu faka-Tonga.	*feel and the cultural taboos etc.*

4.2.3 **Benefit Type**

Six claimed that they received some form of benefit payments but were not too sure of the type or what they were called. One receives accommodation allowance and three occasional financial assistance from relatives. Of the caregivers (who are family members), only two are employed - the rest cannot work because they had to stay home and look after their disabled children/members.

The following are excerpts from the interview:

‘Oku fu‘u faingata‘a he ‘oku ‘ikai ke ‘i ai ha‘amau me‘alele pea ‘oku ma nofo ai pe ‘i ‘api he ‘aho ki he ‘aho.	*It is really hard as we do not have any vehicle/transport, so we are stuck at home day in and day out.*
Ko ‘emau tefito‘i ma‘u‘anga pa‘anga pe mei he penafiti. ‘Oku mau matu‘aki fakafalala ki ai he kuopau keu nofo ‘i ‘api ‘o tauhi ‘eku ta‘ahine.	*Our main source of income is from the benefit. We depend heavily on it because I must stay home and take care of my daughter.*
‘Oku ‘ikai lava keu ngaue au kae li‘aki ‘eku ta‘ahine, he ‘oku ‘ikai lava ke tuku tokotaha ia. Na‘e ‘ahi’ahi ‘ave ia ki he polokalama pea‘ikai ke sai‘ia Ia ai pea ‘ikai toe ‘ave ia. Ko e ‘atunga pe ia kuopau ai pe ke fakafalala pe ki he penefiti. Oku fu‘u fusimo‘omo ‘aupito.	*I cannot work and leave my daughter because she cannot be left on her own. She was attending a programme, but she did not like it and she was not taken there anymore. Well, we have to dependent on the benefit. The finance is very tight.*

The above comments were common for all participants. The families explained their financial situations were inadequate for the needs of the family, especially the disabled person. For most of the caregivers, employment was not a choice.

Ko e ki‘i seniti ki he mahaki ni‘oku $67 he uike. Na’a mo e napikeni, ‘oku ‘ikai lava ‘o ma‘u, tukukehe ‘ene me’akai’oku ‘ikai fe‘unga e ki‘i seniti ia ‘oku ma‘u mai mei he penefiti.	*The little money received is only $67 per week, even the nappy we could hardly afford it, let alone the food. The benefit we receive is not even enough.* .

4.2.4 **Dwelling**

Except for one, who has accommodation allowance, the remaining nine interviewees' families live in rented properties, mainly State houses. This is a strong indication of the economic situation that the families of the disabled persons (interviewed) are in. One interviewee said:

‘Oku mau toko valu kotoa ‘i ‘api ni
Ko hoku mali pe ‘oku ngaue. ‘Oku
fu‘u fe‘amokaki ‘aupito e me‘a
fakapa‘anga. ‘Oku vahe invalid
‘eku tangata‘eiki mo hoku
tokoua.

There are eight of us in this household..
My husband is the only one working.
Finance is very tight. My father and
sister are on the invalid benefit.

4.2.5 **Attitudes and Beliefs**

Attitudes and beliefs about the disability are also very important. Most of the interviewees intimated that their physical disability is due to some bad things or sins that they committed before and that God is now punishing them. This attitude and belief is still very strong with many Tongans irrespective of their religious beliefs or as part of these beliefs.

Three of the interviewees (two males and one female) said the following:

“ Past has been bad, pray to God to forgive and help me, give my life to God and make up for past mistakes – pray that my children will not suffer because of past mistakes..." (A disabled male)

“ Though the father is no longer involved, I know God helps to provide for the children. I know God helps because my children are very smart at school. Line always comes first in her class”. (A caregiver – mother)

“ I know this is a curse/punishment from God for my past sins. (A disabled male)

4.2.6 **Issues that Emerged from the Interviews**

During the interviews with the families of the disabled population, a number of issues were identified:

i) Payment for family members who do not seek employment but stay at home to provide personal care for their disabled family member (s).

At the present time, providers of DSS do not recognise the *kainga* who provide care and also who live in the same household with the disabled person - as eligible for payment. The *kainga* and family members who are in these circumstances see this as not being fair because there have been cases where the DSS providers pay for a *kainga* to provide personalised care – but who happen to reside in a different household or address. The differences in opinions regarding payments of relatives and other *kainga* members needed to be clarified between the disability service provider and needs assessment agencies.

ii) Cultural Differences:

There are differences between Tongan culture and the cultural experiences and upbringing of the workers of mainstream service providers and which is often manifest in frequent misunderstandings between mainstream service providers and their Tongan consumers. For instance, in Tongan culture, there is a very strict taboo governing brothers and sisters' relationships - and also generally the relationships between males and females.

In this system foul language particularly swearing, is not allowed – and as well as excessive exposing of body parts.

Within the context of this system of taboo relationships, daughters or mothers with disability who need 24 hours help, preferred mothers or daughters respectively to take care of their needs. Disabled males would prefer their wife, son or father to look after them. Home cares that are provided by DSS providers do no take into account these cultural matters.

Food is also another issue. With good intention, home carers provided by DSS providers prepare a balanced European diet, which is not preferable to a Tongan disabled, who would prefer Tongan food.

4.3. **Summary**

(i) About 12% (4,700) of Tongans in New Zealand have some form of disability - meaning one in every eight Tongans has some form of disability;

(ii) About 53% of Tongans with disability are in the age group of 65 years and above;

(iii) The main causes of disability are illness (41%) and accidents (23%);

(iv) Ten Tongans with disability were randomly selected for case study and the following were key findings from the interviews:

(a) Most of the disabled participants were cared for within their *kainga* - except for one who resided in his own accommodation with support form the ACC Department.

(b) *Kainga* claimed they experienced confusion due to the fragmentation of services they received from the Disability and Health providers.

(c) Flexibility of services were suggested; both from the caregivers who care for high complex cases and also the idea that *kainga* should be able to have options of culturally appropriate professionals and services that best suit their needs.

(d) Communication was a key factor for not accessing and participating in disability services. The majority explained these were due to language barriers and cultural differences.

(e) Participants clearly preferred to use *kainga* as caregivers, not only because they feel they have more cultural understanding and language skills (Tongan) but possessed Tongan values as outlined in the ‘Fakalotofale‘ia’ framework.

(f) The low socio-economic situation of disabled people and their *kainga* indicated economic difficulties and stress because a high number of participants who depended heavily on benefits.

(g) High unemployment figures were also evident due to family members / *kainga* having to stay home to care for their disabled members.

(h) The low educational levels of *kainga* contributed to several factors: the low income earnings, lack of understanding of the disability services, lack of confidence to participate in disability programmes and their low rates of participation in disability services and other mainstream provided services.

CHAPTER 5 CAUSES OF LOW PARTICIPATION OF DISABLED TONGANS IN DSS

5.0 Introduction

The focus of this chapter will be to analyse and draw out the causes for the low participation of disabled Tongans in DSS - through exploring the various parties and structures that are involved in DSS in New Zealand viz. Government policy and organisational systems and framework, the providers of DSS (Chapter 2); the circumstances of Tongans in New Zealand (Chapter 3) and the circumstances of disabled Tongans in New Zealand (Chapter 4).

In this exercise the following have been found as being critical:

5.1 Structural Changes

In the latest development of organisational structures for disability services, there are a number of separate organisations mandated to be responsible for different aspects of Disability Support Services.

As pointed out in Chapter 2, these organisations include the following:

i) Office for Disability Issues (ODI) – disability issues across government agencies; monitoring NZ Disability Strategy;
ii) Ministry of social Development (MSD) – administers Invalid and sickness Benefits accessed by people with disabilities;
iii) Ministry of Health Directorates such as Disability Support Directorate (largest Funder of disability services), Funding and Performance Directorate (supervises the transferring of health funding to District Health Boards);
iv) Ministry of Education – in charge education of children with disabilities;
v) Housing New Zealand Corporation – jointly develop with government agencies and community groups group housing for people with disabilities;
vi) Accident Compensation Corporation – support people who have disabilities due to accidents;

vii) Human Rights Commission – enforcing Human Rights Act that forbids discrimination against disability amongst other things;

viii) Office of Health and Disability Commissioner – responsible for grievances regarding DSS;

ix) Ministry of Transport -

x) State Services Commission and

xi) Lottery Grants Board – grants special vehicles for people with disabilities;

xii) Ministry of Pacific Island Affairs – to promote participation of disabled Pacific peoples, and

xiii) Service providers such as Need Assessment Organisations, providers of respite care, home service help, etc.

When the Labour-Alliance government took office in 1999, there was a major structural change to the Health and Disability sector. This was a change from the former system where Regional Health Authorities and then the Health Funding Authority were responsible for purchasing Disability Services.

In the new structure, although District Health Boards are the main Funder of DSS, there are also other organisations involved in DSS, which means fragmentation of disability services as well as overlapping of their functions in some cases.

Whilst this may be an issue with ordinary New Zealanders it is even more difficult for Pacific people with disabilities to deal with different organisations for different DSS services given their general level of education, language barrier and exposure to mainstream systems.

Overlapping responsibilities is another issue that causes confusion and uncertainty amongst Tongans with disabilities. For instance, there is overlap between the Ministry of Social Development and Disability Support Directorate of the Ministry of Health because many people with disabilities receive DSS also depends on income support from MSD. Similar situations also arise with ACC.

From the interview of the participants in the case study, it is noted that seven said that the last time they had any contact with DSS related agencies was either 2000 or 2001 despite their urgent and continuing needs for DSS. This was mainly due to lack of knowledge and confusion on whom to approach and whether they could again approach the organisations - or perhaps just wait for an assessor to come.

Some of the comments of the participants in the sample group when asked about their awareness and understanding of the DSS services included the following:

i) *" We do not know what is out there? There is a need to form a group for Tongan Disabled persons*".
ii) " *Do not have access to DSS because we are not aware of such services"* (two participants)

5.2 Policy Changes – Inappropriate Services

The New Zealand Public Health and Disability Act 2000 required a New Zealand Disability Strategy, which was successfully developed in 2001 on the basis of a series of consultation by all parties concerned. As already discussed in Chapter 2 the Strategy document is comprised of 15 objectives and prescribed plan of action (113).

The main thrust of the Strategic Plan " is to promote inclusion and participation in society to the extent that resources are available."

The objective for the Pacific Peoples is **to promote the participation of disabled Pacific peoples by trying to**:

i. Increase access to, and quality of, both Pacific and mainstream service providers that deliver disability services to disabled Pacific peoples, their families and communities;
ii. Support disability workforce development and training for Pacific peoples, by training Pacific peoples as providers of disability information and services for their local communities;

iii. Encourage Pacific communities to consider disability issues and perspectives and further their own understanding of disability through the development of community-based plans for disability issues;

iv. Support training and development of trilingual interpreters for deaf people;

v. Ensure the Ministry of the Pacific Island Affairs takes on a leadership role in promoting the participation of disabled Pacific peoples.

Whilst the Strategy marks a milestone of government’s support and dedication to the cause of the people with disabilities in New Zealand giving the sector a high profile and broad guidelines to work on, there are also limitations particularly on lack of new resources, deadlines and performance indicators to ensure that plans of actions are implemented and people with disabilities all have access to DSS.

For instance, there is no performance indicator for – “promote participation of disabled Pacific peoples” in terms of number of people to participate in DSS and the time frame for such target. The same goes for the plan of actions. The lack of specific targets for the objective and plan of actions has meant that it is now two years since the launch of the Strategy, and there has not been much discernible and positive impact on the ability of the Tongan disabled community to access DSS. Furthermore there has not been much satisfaction with the level and quality of service delivered. As evidenced from the results of the case study, the few who have received assessment and/or some form of support services were not satisfied.

Na’e ʻi ai e ʻaʻahi mai ka ʻoku ʻikai ke ʻaonga e tokoni ia ʻe niʻihi. Ko e haʻu pe e fefine tokoni ia ke fakavave ʻene houa ʻe taha pe ua pea ʻalu ia ki he ʻapi hoko mai, ʻoku si’i teʻeki ke ʻa ʻeku mahaki ʻaku peau siʻi fainga tokotaha ai pe.

Someone was sent to help but it has not been really useful. The helper just only come for one or two hours and then hurried on to the next family and my daughter is not up yet, so I struggle on with the rest of it on my own.

The above comment reflected on the inappropriateness of the home care service provided. It is not flexible enough to suit particular families, especially when they have high complex needs such as the above case.

‘Oku mau kei tali ki he ‘asesimeni. Na’e ‘omi pe e tohi ka ‘oku te‘eki ke ‘a‘ahi mai ha taha ia. Kuo ‘osi e ‘aho 28 ia, ka na‘e ‘ave ‘a e tangata‘eiki ia ki falemahaki he uike kuo osi ko hono suka pea na‘e fiema‘u ha taha ia ke ha‘u ‘o nofo mo e ta‘ahine ko eni kau tokanga au ki he motu‘a ko eni. Fu‘u fakahela ‘aupito.

We are still waiting for an assessment. We received a letter and no body has visited. Our respite care (28 days) has run our but dad was taken to hospital last week because of his diabetes, and I needed someone then, to care for my girl so I can focus on dad. It’s a real hassle.

The above family expressed dissatisfaction with the Needs Assessment Service, due to their prolonged wait for re-assessment and their need for respite care services.

Interviews in the case study revealed a quite disconcerting picture of the waiting time as in Table 5.1 following:

Table 5.1: Participants Waiting Time

Year	Number of disabled persons	Waiting time for an assessment
2000	1	3 years
2001	5	2 years
2002	3	One year
2003	1	

Source: Interviewing of 10 Tongan with Disabilities

The above table indicated participants were not satisfied with DSS because of the time lapsed before their next review and their confusion whether they should approach NASCs for reviews or wait until they came. The following participants pointed out that:

Ko e ‘osi eni ia e ta‘u ‘e 3, te‘eki ke toe
‘asi mai ha taha ia mei he potungaue
‘Asesimeni ‘o ‘asesi ‘ema ta‘ahine.

It has been 3 years, no one from the
Assessment service has been come
to assess our daughter.

Ko e ta‘u e 2, mo e ‘ikai te mau toe fanongo ki ha me‘a. ‘Oku te‘eki Ke fakafo‘ou e sea ‘o Sela, pea ‘oku fakatu‘utamaki ki ai, he tu‘o ua ‘eni ‘ene to ‘ana he sea.	*It has been 2 years, we have not heard anything. Sela’s wheel-chair has not been reviewed, it is too dangerous because she has fallen twice from it.*
Ko e fiha‘i telefoni atu ‘eni, mo e ‘ikai pe ke ha ‘u ha taha ia. Mahalo ‘oku saiange hono tuku ‘ona. Kuo faka‘au ke fakapiko e fa‘a fakahoha‘a ia ki ai.	*Many times we have telephoned no one came. Maybe it is better to leave it. We feel we are wasting time in hassling them.*

The comments from the above participants further illustrated the figures in **Table 5.1**.

5.3 Bureaucracy of providing DSS and Ineffectiveness of Assessment process

The bureaucracy of providing DSS for disabled persons is also a matter of concern – in terms of turn around time for delivering of service as well as creating confusion for the recipients.

In order for a disabled person to have support services, the following processes need to take place:

i. Contacting of the family of the disabled person to a social worker that they know;
ii. Referral by the social worker to the Need Assessment Agency;
iii. Conducting of initial need assessment;
iv. A comprehensive need assessment and to a specialist depending on the severity of the case;
v. Need assessment report;
vi. Service Co-ordinator to select the most suitable service for the recipient;
vii. Service provider specialist - on site assessment; and
viii. Providing of the service.

The turn around time for the process ranges from a few days, to weeks, even months. However, on a typical day – people with disability will make 115 applications for Environmental Support Services. The turn around time in many cases is quite lengthy which discourage seekers of DSS from participating. In his review of the DSS, Saucier (2002) pointed out that in :

> some areas, NASC agency capacity cannot keep up with the demand for assessments, and the wait for an assessment can be six months or more. … without assessment, services cannot be authorised.

This is also confirmed when the sample population in the case study were interviewed. One of the issues they were concerned with was the long wait for NASC assessment, particularly with requests for vehicle modification or special vehicle for disabilities. There are internal deadlines set by the NASC and priority cases, however, this has not eliminated concerns on turn around time of assessment – as pointed out in Saucier's report and the comments from the case study.

In order to improve accessibility and expedite the process of the assessment, communication is very important and NASCs could explore the following:

i) Create a fast track stream for simple and straight forward applications with turn around time of say – 2 days;
ii) Establish definite turn around time for other urgent cases but would take longer time – say 5 days; and
iii) For more complicated requests, consumers should be updated on a regular basis on the progress.

Having different personnel perform different tasks are arrangements that are also beyond the comprehension of Pacific / Tongan recipients of DSS. This creates confusion and is further exacerbated by language barriers between many Tongans and the service providers.

Na‘e ha‘u e tamasi‘i Tonga heni mei fe koa? Ke ‘ave ki he polokalama ‘a e Pasifiki. Na‘e ‘ave tu‘o taha pe pea tangi e fu‘u polio ia pea nau toe fakafoki mai. ‘Ikai ke mahino pe ko e fe koa e feitu‘u?

A Tongan man came here, I do not know where? To take to a programme for Pacific. They take her only one time and she cried so they brought her back. I do not really understand where?

I found out the above family were referring to a Pacific Team within the Spectrum Services and they provide social assistance and some activities. The family was not too sure which organisation. When asked for a card or information, they did not have either. It shows that families need to be educated that asking for a business card or some information from services providers who visit their families are of paramount importance.

‘Oku lahi ange pe ‘emau ‘ilo e ngaahi tokoni ‘e ni‘ihi mei he ‘api ako koe‘uhi ko e lahi ‘emau feohi. ‘Oku ‘ikai ha fu‘u loko mahino fekau‘aki mo e ngaahi ngaue‘anga kehe ka ‘oku monu‘ia pe ko e fu‘u maheni mo e kau faiako ‘a e ‘apiako ni pea ‘oku fakafiefia ‘aupito ‘enau tokoni mai.

We find out a lot of help through school because we have mix a lot. There is little understanding about other services but we are lucky because we know the teachers at school very well and we are happy they are helpful to us.

The above family shared that they knew a lot of services from their son’s school and teachers at school advocate for their needs. They also felt they were happy with the way the school had helped and would continue with that.

5.4 **Funding Limitations**

A $17.5 million budget is allocated to the Ministry of Health for Departmental Disability Issues and $1.4 billion for DHBs with an average of $67.7m per DHB.

As mentioned before, some of the DSS services are directly funded from the Ministry of Health and this includes DSS for disabled persons up to 64 years old, whilst the DSS for 65 years and over are funded from the $1.4 billion allocated to the DHBs.

The $17.5 million appropriated to the Ministry of Health covers administrative expenses, salaries and wages, training, service agreements with DSS service providers to disabled people of 64 years old and below.

The population of the Pacific Peoples is predominantly young with the median age of 21 years. The national figure for NZ is 36 years old. This relatively young population both at the national level and for the Pacific peoples indicate that a larger proportion of the people with disabilities have to share a very minimal budget of $17.5m compared to $1.4 billion allocated for fewer disabled people at 65 years and over.

Table 5.2 : Proportion of Pacific Peoples with Disability (by age group)

	Aged 0 - 14	**Aged 15 - 44**	**Aged 45 - 64**	**Aged 65 and over**	**TOTAL**
Total number	90,144	105,780	28,236	7,632	231792*
Estimated disabled**	7,211	12,693	7,341	4045	31,290
Disabled as % of tot. Population	8%	12%	26%	54%	100%

Sources:

Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups* (Table 3a) & Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups: Disability Survey - Snapshot 3*

* 9 counts short of the total appeared (231,801) in the total of Pacific peoples

** Overstated when age percentage of disabled Pacific Peoples given in the Snapshot 3 of the 2001 Disability Survey is converted into numbers. Therefore it is used only as an indicator.

According to the data on **Table 5.2** more than 50% of total disabled persons share the minimal allocation for DSS fund allocated under the Ministry of Health Department. Since most of the Pacific Peoples age group is predominantly young (median is 21 years for total Pacific and 19 years for Tongans) they are amongst many others who are competing for a very limited amount of fund, thus also lowering their participation in DSS.

This is further manifest in the approved budget for the establishment of the PIASS for the Pacific People with disability. The limited amount of funding allocated for staffing and implementation of programmes for all the Pacific people does not recognise the diversity of their populations. So far, the office can only afford to run limited programme for the three main ethnic groups (Samoa, Cook Islands and Tonga), but only in some areas of the Auckland area. For Tongans with disability, so far, there has only been one seminar in one of the Auckland suburbs with pamphlets translated into the Tongan language. There is a lot yet to be done – in terms of geographical coverage and activities to inform the communities and to establish support groups but these could not be carried out due to limited resources.

Table 5.3: Proportion of the Total New Zealand Population with disability (by age group)

	Aged 0 – 14	**Aged 15 - 44**	**Aged 45 - 64**	**Aged 65 and over**	**TOTAL**
Total number	820,107	1,547,361	789,864	429,096	3,586,731
Estimated disabled	90,212	201,157	197,466	231,712	743,800
Disabled as % of tot. population	11%	12%	24%	53%	21%

Source: 2001 Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups* (Table 3a) & Statistics New Zealand, (2001) *New Zealand Census of Population and Dwellings: Ethnic Groups: Disability Survey – Snapshot1*

Note: Percentages given in Snapshot 1 of Disability 2001 do not reflect the right number of people with disabilities in each age group. Use only as indicator.

CHAPTER 6 : *"FAKALOTOFALE 'IA" :* THE ALTERNATIVE

Introduction: Fakalotofale‘ia Defined

As has been pointed out earlier at various other points in this thesis – the main focus and thrust is to advance an alternative theoretical model and practice framework viz. "*Fakalotofale‘ia*" It is therefore the general concern of this Chapter – to pull together the main component elements of "*Fakalotofale‘ia" -* and on that basis to offer it up as a composite whole for those purposes.

The concept of "*Fakalotofale‘ia"* may be best understood within the context of its being a conglomeration with its main component elements being as follows:

- "***Faka****"* = The Way / The Way of
- " ***loto***" = Inside / Heart / the Heart */ Inside the heart*
- **" *fale*"** / "***fale'ia***" = House / Household / of the Household / within – inside of the household*" – and its attendant values and expected ethical standards and etiquette etc".*

Note further that "***fale‘ia***" also (especially with the addition of the suffix " ‘***ia***") takes on an additional dimension to its meaning viz. ‘**ia** = "*being full of" / "steeped in"/ "saturated with".*

Within the context of the focal proposition of this thesis – what one is being invited to be ‘steeped in' / ‘be saturated with' and be ‘full of' / ‘ become filled with' – is the attendant system of core *values and expected ethical standards and etiquette of the household and within the household.*

Thus in advancing from mainstream networks and infrastructures the normal fallback position for a Tongan is the cultural heritage of his origins. Within this context, being on familiar terrain the feeling takes on inspiration from the old adage that " … *we do it best when we do it ourselves and for ourselves."*

The comments of two among many of our interview participants confirmed this view:

He'ikai foki tatau e fakahoko e ngaue 'e he Tonga koe'uhi ko 'etau lea, mahino'i 'etau fa'ahinga mo'ui faka-Tonga mo e anga 'etau nofo	*Nothing compares when a Tongan professional does the work, because of the language, understanding of our way of life and the way we live.*
Ko e toki mahino eni kiate kimaua. *ko e ha'u e kau palangi, 'o 'ikai* *loko fai ha fetaulaki. Ko e mate* *tupu'a ai pe. Ta koe 'oku lava pe* *ke ha'u e Fakatonulea pe ko ha taha* *Ngaue Tonga.*	*We understand now. Every time the* *Palangi comes, we cannot connect.* *It is like trying to solve a riddle?* *Now we know an Interpreter can come* *or even a Tongan worker.*

The above participants acknowledge that in implementing NASC, and in comparison with other workers, a Tongan professional would be much more effective because she / he speaks the same language, and also understands the Tongan way of life.

Some may well argue that this is more a preferential situation - where Tongans may think to themselves " *... better (that we have to deal with) the devil we know* " – viz. that recognition and adoption of traditional and culturally-based (healing or care-provision) practices may only be preferred because '*palangi* medicine' is unfamiliar and that there is no other viable alternative.

The fact however remains that a willingness to at least start from a point of self-help is evident and is significant.

6.0 **The Gaps: Further Elaboration on the Theory behind the Policy Debate**

In its initial chapters this thesis has made it clear that one of its main concerns is the notion that there are critical gaps in current mainstream policy thinking. This Chapter focuses on and offers an alternative with which this gap may be bridged viz. "*Fakalotofale'ia* ".

6.0.1 **Introduction**

This section outlines and explores some of the major defining and underlying characteristics of the policy debate over disability support services and its delivery. In the course of this discussion it will elaborate the theoretical issues that help to explain what is happening on the ground level – in as far as the New Zealand disability sector goes.

This outline also affords an insight into the main problems that have affected almost every transaction and activity in this system – particularly as to their origins and as well as possible remedial options.

‘Oku ‘i ai pe foki ‘etau ngaahi ‘ulungaanga faka-Tonga ‘a kitautolu ‘oku ‘uhinga ai ‘a e fiema‘u pe ha kainga ofi pe famili ke ngaue ki ai. Hange ko e ngaahi tokoni fakahangatonu ki he fiema‘u ‘a e tokotaha faingata‘a‘ia; hange ko e kaukau, pe tokoni ki hono teuteu‘i ‘ema ta‘ahine. ‘Oku loto pe ia ke fai ‘e hono ta‘okete pe ko au (fa‘ee). Ko ‘etau ngaahi veitapui faka-Tonga ‘oku ‘ikai ke mahino ki he kau Palangi.

Some of our claims for close relatives or family members to help are based on our Tongan ways. For example, some of the personal care likes bathing and dressing of our daughter. She prefers her older sister or mother to do. We have cultural taboos that are not understood by the Palangi.

6.0.2 **Universal Assumptions and Categorisations**

One of the first main difficulties that Pacific islanders – including Tongans – do come up against is finding that mainstream disability policy and delivery systems are predicated on generalised universal categories that tend to be based mainly around dominant mainstream cultural assumptions and expectations about social structure and order. Over the years then there also have been developed a whole network and infrastructure of related practices that have become well established and which are clearly manifest in New Zealand Government policy initiatives, instruments and practices – that manifest this thinking.

Tongan disabled often complain that these policies are often mono-cultural or individualist. This they often argue is of course contrary to their (Pacific) collectivist view of the world.

It is also important at this point to note that the 'universalist' theory of the mainstream assumes a system of a somewhat legalistic order where rules and laws are formulated and administered to ensure that all citizens receive fair and equal treatment. This of course is based on the democratic system of majority rule – and it does have its merits.

The Pacific Islander's notion of 'universality' on the other hand, would argue for making sure that polices, rules and associated practices - give recognition to and take account of all the little finer details and peculiarities of unique cultural practices of diverse groups of different ethnic origins. The emphasis is on the 'group' rather than on the 'one'. It is an emphasis derived from the ubiquitous and all-pervasive extended family system

As a result of the above situation, a context of which he / she is very much a part - the Tongan disabled would naturally tend to feel lost, alienated, neglected, ostracised and left behind by mainstream services and delivery systems. This is more especially so when he / she perceives (or is, by the same token, not able so to perceive anything other than) ambivalence and ambiguities about just where / when he / she fits in as far as disability services go.

6.0.3 "**Fakalotofale 'ia": The Alternative Theoretical - cum - Practice Framework**

This dialectical situation of conflict described above would obviously mean that a Tongan, not being able to understand let alone accept mainstream policy and practices will naturally shy away. This then further aggravates their already low rate of participation in disability services.

However, the most crucial point here is the argument being advanced as the central thrust of this thesis – viz. that there is a viable complementary alternative in the concept and practice framework of "*Fakalotofale'ia*".

The definition has been laid out at the beginning of this chapter viz. "*Fakalotofale'ia*" is [literally] – a combination of (the prefix) '*faka*' meaning "*Way*" or "*The Way of*" / "*loto*" meaning "*inside" or* "*heart"* or "*the heart*" / and '*fale"* – or (its derivative) *'fale'ia'* meaning *"household*" or *"of the household – and its values and of its expected ethical standards and etiquette etc".*]

The Tongan then is able to follow "the ways" or "in the manner of" [***"faka"***] of his/her people – both past and present. He / she is able to call upon and enlist their assistance - and this they usually give with their whole "hearts" [***loto***] – all in the safety and security of their "household" ["***fale***" or also "***loto fale***"]. Here he / she is completely surrounded, protected and sheltered in the glow of the circle of warmth of his / her kin and loved ones. Here he / she is at home and he/she feels that he/she is filled up with that glow of recognition of kin and being recognised back and protected by them ["***fale' ia***"].

Here too, the Tongan is assured of and receives full recognition of other aspects of his / her cultural make-up.

'*Fakalotofale 'ia* – on a further level is also the practice framework used by the members of '*Kainga*,'(the wider extended family system) to remind themselves that actions and interactions come from the hearts of members, through the internalisation of values within the *fale* (house).

The conception of *Fakalotofale'ia* is based on and characterised by the following values among many others: *'ofa* (love or compassion), *fetokoni'aki* (interdependence), *makafetoli'aki* (reciprocity), *uouangataha* (collective), *faka'apa'apa* (respect), and *fe'ofo'ofani* (harmony / 'share-and-care'/ looking out for each other). The framework promotes the internalising of the said values among the members' relationships within the *kainga*.

'*Fakalotofale'ia'* is often invoked in times of crisis, because of its curative and preventative elements. For example, the care for disabled members of the '*kainga,*' can sometimes become very stressful, therefore, the members have a '*talatalaifale*' (counselling session) to discuss how this could be addressed. Often members will express their commitment to fulfil the '*fatongia*' (obligation) towards the disabled person, based on *'ofa* (love and compassion).

Siblings have provided for various needs of disabled people within the ‘*fale*’ and the interactions are based on the values enumerated earlier.

6.0.4 **Fakalotofale ‘ia and Disabled People**

The approach in *Fakalotofale‘ia* is not based on linear relationships but is viewed as interactive, interdependent and reactive. The Tongan pertinent expression is “*Ka lavea ha kupu ‘e taha ‘o e kainga, ‘e uesia ai pe e toenga ‘o e ngaahi kupu kehe hono kotoa”* [Lit. “ when a member of the *kainga* is injured, the whole *kainga* is injured”. The very same point has been emphasized by McGoldrick and Gearson (1989), viz. that “The physical, social and emotional functioning of family members is profoundly interdependent, with changes in one part of the system reverberating in other parts of the system.” Tongan disabled peoples are viewed in similar contexts. Interdependent values of *Fakalotofale‘ia* have influential effects when in practice.

At yet another level of expression it can also be seen that a most important feature of *Fakalotofale‘ia* is the way in which members are affected by actions of or what had happened to other members. Luterman (1984) wrote, “This notion implies that when a deaf child is born into a family, to some extend everybody is deaf.”

> *‘Oku mau fetongitongi pe hono tokanga‘i ‘ema ta‘ahine, tautautefito ki he ngaahi ‘aho Sapate. ‘Oku fiema‘ u ia ke tokanga ‘i houa ‘e 24, kae tatau ai pe pe koeha ha me‘a ‘a e famili ‘oku fai kuopau pe ke tokanga‘i ‘ene fiema‘u. Ko e Sapate ko eni ‘e nofo e tangata-‘eiki. Sapate kaha‘u ko e fine‘eiki, hoko hoku tokoua. Taimi ni ‘ihi ko hoku tounga‘ane mo hono mali. ‘Oku pau ke mau fengaue‘aki ‘a e kupu kotoa homau ki’i famili ke lava ‘o feau e fiema’u ‘a Heta*

> *We take turns in caring for my daughter; especially Sundays she requires 24 hours supervision, whatever we do as a family, we make sure her needs are taken care of. This Sunday dad will stay home to look after her, next Sunday it will be mum, next will my (older sister) turn. Sometimes, my brother and his wife will come here to look after her. Our.family works together to fulfil Heta’s needs*

The practice within this *fale* as emphasized by the participating *kainga* has been a normal routine. The sharing – f*evahevahe‘aki* of caring roles are reflected on the value that is promoted by *Fakalotofale'ia*. *Fetokoni'aki* – Interdependent values of members are important features of *Fakalotofale 'ia*.

Ko 'eku ta'ahine lahi mo hono mali 'oku na nofo pe he hala hoko mai. 'Oku na 'a'ahi faka'aho ma'u mai pe ke vakai kimaua.	*My daughter and her husband live in the next street. They visit almost every day to check on us to make sure we are okay.*

This particular participant expressed her confidence that the supportive attitudes from her *kainga* contributed towards their holistic wellness. It also serves as additional evidence that families were confident and comfortable to get help from their *kainga.*

6.1 Perceptions of Disability

This part discusses some of the participants' perceptions of 'disability'. Different cultures have different views on disability and Tongans have their own perceptions. Tongan disabled are viewed as valued members of the *kainga*. They are not treated in isolation from the dynamics of the *kainga*. Makasiale and Williams in O'Brien and Murray (1997), had this to say on the issue …

> A person with an intellectual disability can be viewed either as a valued member of the family who needs to be protected from the outside world, or as a punishment on the family for past sins."

Some of the participants in the research for this thesis had similar views with this suggestion from Makasiale and Williams. As one of them had stated:

Kou 'ilo pe ko e me'a 'oku hoko ki hoku 'ofefine ko e Tautea mei he 'Otua 'i he'eku ngaahi kovi he kuohili –	*I accept what has happened to my daughter is a punishment from God for my past sins.*

This particular participant was accepting that the cause of his daughter's disability was a punishment from God. The notion of divine retribution comes out very strongly – reflecting also the Tongans' very firmly and deeply-rooted belief in God

Ko e kotoa pe ia ‘ema ‘ofa mo e toenga ‘o e fanau ‘oku ‘ai ‘ia Sina, ‘oku fu‘u mahu‘inga ‘aupito kiate kimautolu ke ne ongo‘i ‘oku tauhi ‘aki ia e lelei taha pea ke mahino ko e memipa kakato ia ‘o homa ki‘i famili. ‘Oku mau fakafamili ma‘u pe pea ‘oku mau talanoa ai mo e fanau ke nau manatu‘i ma‘u pe ‘oku mahu‘inga kehe ‘a Sina, pea ‘oku ‘osi lea kotoa mai e fanau te nau fai honau lelei taha pea he‘ikai ha taimi te nau ‘ave ia ‘o tuku ‘i ha ‘api ‘o e pule‘anga.

All our love and the rest of the children are for Sina, it is very important to us that Sina feels she is cared for with best of our ability ensuring that she is a valued member of our family. We have family time regularly where we discuss with the children and reminded them that Sina needs special attention. All the children have spoken to us that they will do their best and they will never take him to a government placement.

This family clearly demonstrated the actions of *‘Fakalotofale ‘ia’* by practising the values of, *‘fe‘ofo ‘ofani* - harmony,’ *fetokoni‘aki* – help for each other (interdependent) and ‘*ofa* – love and compassion towards their person with disability. This reflected on the level of commitment that even if their parents may pass on, the rest of the siblings expressed that they will make the necessary sacrifices to care for their disabled member and would never put him in an institution.

For some disabled participants, it is like a ‘curse’ (*mala,*or *mala‘ia*) that has been passed down from ancestors who did wrong to God or another *kainga*. Some biblical beliefs also expressed that *mala* (curse) can affect a whole generation of *kainga*, unless if they ‘*fakatomala*’ (repent/confess) their sins to God through a Minister or Priest to reverse the ‘*mala*’ and ask God for forgiveness.

Ko ‘eku sio ki he me‘a na‘e hoko kiate au, na‘e ha‘u mo e fo‘i fekau keu liliu. Pea neongo ‘oku hange ha fo‘i mala, ka kou hoko au ko e tokotaha lelei ange mei he’eku mo‘ui ki mu‘a ‘osi e fo‘i fakatu‘utamaki

The way I look at this situation, a message came with it, for me to change. Although, it is like a curse, I have become a better person now, then before my accident

The above participant supported the notion of accepting some form of punishment and a God-sent message that he should change his ways. He believes he is now a changed man and that he is better than before he became disabled.

For some participants disability brings shame to some *kainga* based on the beliefs associated with social stigma, family reputation and rumour and from the attitudes and perceptions of the community.

‘Oku uesia ‘a e toenga ‘o e fanau, ‘i he me‘a ‘oku Hoko ki he ta‘ahine lahi – Ka ‘Oku fu‘u tokanga‘i lelei ‘aupito ‘e he tamaiki iiki ia honau ki‘i tounga‘ane. ‘Oku ‘ikai te na maa‘i ia ‘e naua –	*The rest of the children are affected by what happens to our eldest daughter, but my two younger children look after their little brother well. They are not ashamed of it. The rest of the siblings are affected by the older sibling’s disability.*
“*Ko e lavea ‘a e kupu ‘e taha ‘oku lavea ai ‘a e kupu kotoa*,” –	*When one is injured the rest of the group is injured.*

The collective identity of Tongans, impacts the whole group both in a negative and a positive manner.

Ko ‘emau ngaahi me‘a fakafamili kotoa pe ‘oku fai kuopau pe ke fakakau ai e fu’u polio ni, pea ‘oku ne ‘osi ‘ilo lelei pe ‘e ia e me’a kotoa neongo ‘oku ‘ikai lava ke lea mai. ‘Oku ne ‘ilo pe ‘e ia e taimi ‘oku mau talanoa kau ki ai pe ko ha’amau teuteu holo ke o ki ha feitu’u. Ko ‘ene sio pe teu ‘alu, kuo mata mamahi pea ‘ite‘ita ia ‘o longoa‘a.	*All family affairs are inclusive of our polio, she knows everything, although she cannot talk to us. When she knows we are talking about her or when she knows that I am going somewhere, as soon as she sees that I will go, she really look sad or she starts to get upset and makes funny noises.*

Some participants were however more comfortable with the medical explanations of disability.

Tongans in the study are beginning to form other perceptions about disability. The *kainga* members below are accepting ‘medical diagnosis’ as the alternative explanation of disability instead of feeling guilty because their parents sinned against God and have been punished. *Kainga* members also learn new information in their new environment. Some have sought to be better informed about disability, which therefore influenced their views and perceptions, is a medical condition.

Na’e ‘osi fakamatala mai pe ‘e he Toketa ia, kapau na’e ‘ikai ke to’o vai ‘ema ta’ahine, he’ikai ke mamatea ia.	*The doctor explained to us, “if our daughter did not have a lumber puncture, she will not be paralysed now.*

The pattern and trends that have emerged from this situation have been expressed in various ways, but the majority from the study (7 participants) believed disability was a “*form of punishment or curse from God*”. To these participants whether or not it was their personal beliefs, they all agreed this perception is generally accepted in Tongan society.

6.2 Fakalotofale‘ia in Practice

6.2.1 Introduction

The practice of various aspects of *‘Fakalotofale ‘ia’* emerge from the day-to-day functions of the *kainga*, as has been demonstrated at various earlier segments of this thesis.

However, in order to show and further articulate that this alternative approach does work and that it has indeed been successful in the maintenance of care provision for disabled people, two case studies will be used to further illustrate a typical *kainga* context and show *‘Fakalotofale‘ia’* in action.

6.2.2 Illustrative Case Study (A)

Background

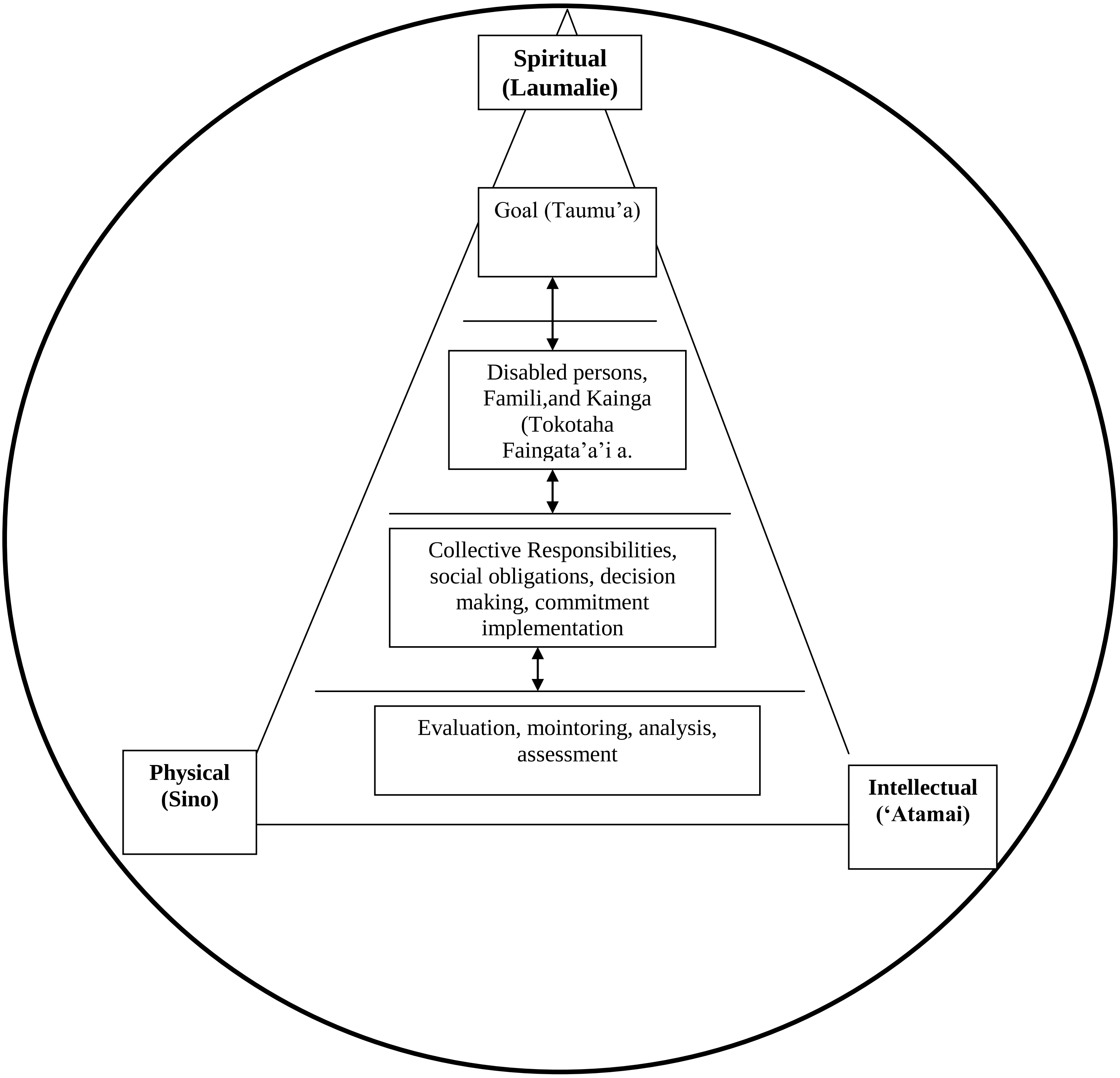
This situation involves Seini a young woman who has physical impairment and has to use a wheelchair to assist with her mobility. There are older and younger siblings, which gives a total of eight within the same household. The degree of her disability requires almost twenty-four hours supervision, requires assistance with all her personal care including transportation to her work twice per week. Other days she would be home with her own family. This young person is in her early adulthood (age between 25-30). She can communicate clearly and expresses her needs very well.

Family Dynamics

The interview revealed this family's typical function on a day-to-day, week to week and year-to-year basis reflected the practice of their Tongan values and way of life, which they believe is the reason why it is making the care of their disabled member successful. This family acknowledges specific skills and knowledge of members within their household and therefore, share particular roles from house chores, to making contacts with various services when needs arise, adjustments and negotiations to substitute roles and so forth.

This diagram depicts the idea behind the '***Fakalotofale'ia'*** Model, which encompasses the 'holistic' worldview of Tongan people. From conceptualisation, to formulation, to implementation, monitoring, analysis and assessment we must consider the philosophy of this model.

Figure 6: The SPI Model



The philosophy of this model is based on a 'holisitc' approach, which acknowledges that the total wellbeing of disabled people must be viewed within the context of their *famili* and *kainga*. Their approach to address the needs of disabled persons are based on the cultural values of *'Fakalotofale'ia.* It recognises and treats each family as unique and with integrity. As depicted in the above diagram, each *famili* / *kainga* has a goal or aim that shows an inclusiveness and collective effort by shared responsibilities and commitment from its members.

CHAPTER 7 CONCLUSIONS AND RECOMMENDATIONS

7.0 Introduction

From the foregoing examination of the various parties that are involved in delivering the DSS to the disabled community in New Zealand – viz. the government's health and disability services and office for disability issues on the one hand, the service providers as the deliverers and as well as the disability community as the recipients on the other - the following conclusions can be drawn:

7.1 Summary of Key Findings

- Government's policies on disability services (as well as in other areas / systems) are subject to changes according to what Governments may decide to be the best options at given times;

- The Labour-Alliance government constructed its Public Health and Disability Policy based on two main contributing factors. Firstly, disability was more or less historically regarded as predominantly a medical concern, where disabled people were institutionalised for treatment. In the recent past however, social researchers have revealed that besides being physically impaired, disabled people have the same basic needs of any other normal persons. They need to socialise, they have families and friends, and they have values and beliefs and are entitled to normal existence just like anyone else. Secondly, policies were intended to be inclusive and to offer the best health and disability services to the people of New Zealand;

- Government has taken the view that the way to deal with the needs of the people with disabilities is through provision of professional services (which involve a number of organisations in New Zealand – Ministry of Health, Ministry of Social Development, Office for Disability Issues, ACC, NASCs, Providers, etc) to act as enablers to meet individual needs of people with disabilities;

- This new structuring is now on to its third year, and there are indications that even with the best of intentions, the disability policy and organisational framework has not really worked for the Tongan disability community in terms of:
    - modest growth in number of Tongan consumers involved in DSS;
    - dissatisfaction regarding the turn around time of assessment/approval;
    - language and cultural barrier between caregivers and assessors which led to poor communication, misunderstanding;
    - Confusion caused by a number of organisations involved in disability related services.

- All parties involved have important roles in ensuring that DSS are delivered successfully. Whilst Government has a role to play in the society, its organisational and policy framework should be able to recognise the cultural diversity of New Zealand. Over the years, New Zealand has become host to a diversity of many ethnic groups – including Asians, Europeans, and Pacific.

- There are a number of contributing factors to which this low participation is attributable. Some of these factors arose in the study and can be directly related to some weaknesses in the policy framework and the organisational structure. Others are due to the delivery processes and some are due to the attitudes and level of understanding of the Tongan community in New Zealand;

- Whilst the main concern of this thesis is to highlight the need for cultural sensitivity of the DSS policy in New Zealand, other subject areas have come into light during the research – which merit further research and investigation. These subject matters include the efficiency of the current policy and organisational framework in terms of resource allocation, turn around time, customer service and satisfaction as well as cost benefit ratio (meaning how much does it cost to deliver the DSS to the intended beneficiaries). Although it is not dealt with herein in any significant detail, there is a question of efficiency and effectiveness of the current system given the number of organisations involved in DSS and disability related services and resource allocation.

7.3 Implications and Recommendations

Based on the above conclusions, the following recommendations are made:

RECOMMENDATION 1: Need for Reviews

The groundwork investigations carried out in the preparation of this thesis turned up and pointed to a number of key areas where there were critical needs for review. These include but are not limited to the following:

- Cost efficiency of the current structure (characterised by overlapping functions of government ministries, the lengthy process of assessing and delivering DSS to disability people);
- Performance of the contracted service providers - to ensure that they deliver quick and effective services to the intended beneficiaries;
- Definitive performance indicators need to be included as part of the Government's expectations from its contractors (NASC and providers);
- The current Disability Strategy needs to be re-examined to ensure that there are definite performance indicators and targets (time frame for implementation of plan of actions stated in the Disability Strategic Plan as well as the target number of consumers who are to benefit and so forth) - at least at the national level - to provide guidelines and to ensure that the objectives of the strategies are achieved. ;
- The budget allocation for the Pacific Islands Advocacy group would need to be readjusted to strengthen their network and "reach out" role to disabled people through active workshops and dissemination of information, thereby educating Pacific, including the Tongan community and disabled population, to be more aware of the DSS services and what is required of them; and
- The policy regarding the delivery of DSS to the ethnic groups including the Tongan community needs to be made more culturally sensitive and to recognise the differences at the micro levels. Readjustments in this area could include training of NASC assessors on the different cultures they would be expected to meet during the course of their duties.

RECOMMENDATION 2: Education / Training

It was clear from the evidence obtained in this study that in a very large number of instances there was a lack of skills and knowledge – which if accessed and taken advantage of would have most certainly enabled the Tongan disabled community to participate more meaningfully in DSS provision.

One effective way to remedy this situation would be through training and development programs/activities – including the following:

- To train *kainga*, disabled people and Tongan community to gain full understanding of the National Disability Framework (NASC – Needs Assessment and Service Co-ordination), as this is the entry to be serviced for their disability needs. The background study for this thesis showed that a number of participants were still confused about this Framework; and
- To educate and advise the *kainga*, disabled people and Tongan community about information relating to disability services and how to access such services - whether they are mainstream or Pacific providers.

RECOMMENDATION 3: Advocacy / Promotions / Supports

- To promote and advance the holistic needs of Tongan disabled people and *kainga* in terms of the physical, intellectual, spiritual development and wellbeing by recognising individual and collective strengths within their context;
- To improve the support choices provided to Disabled people and *kainga* in order to minimise the loss of employment and income; and
- To promote and recognise the preference of the Tongan disabled people / *kainga* to use their own members to provide the home supports and care roles.

RECOMMENDATION 4: Institutional Developments / Strengthening

- To establish community networks that will enable the Tongan disabled and *kainga* to link with the wider community, disability support services (Tongan, Pacific and Mainstream);
- To make specific cultural training as a compulsory requirement with mainstream organisations who serve this particular segment of the population – Tongan disabled people / *kainga*, or
- Alternatively, increase their workforce to reflect the percentage of the Tongan disabled population; or
- Establish organisational policies that identify key issues and protocols that are culturally safe and appropriate.

RECOMMENDATION 5: Respect of Values and Beliefs

- To maintain and respect disabled people and *kainga's* cultural values, beliefs and various forms of practices and options. For example, the use of herbal remedies, *Fotofota* – massages as complementary to Western approaches.
- To encourage disabled people and *kainga's* input into Disability policy level and service implementations by allowing feedback / suggestions from communities to Ministry of Health and Office for disability issues through Ministry for Pacific Affairs;

RECOMMENDATION 6: Communication

In order to improve accessibility and expedite the process of the assessment, communication is very important and NASCs could explore the following:

- Create a fast track stream for simple and straight forward applications with turn around time of say – 2 days;
- Establish definite turn around time for other urgent cases but would take longer time – say 5 days; and
- For more complicated requests, consumers should be updated on a regular basis on the progress.

RECOMMENDATION 7: ***Fakalotofale‘ia* as the Alternative**

Over and above all of the foregoing considerations, the main underlying thrust of this whole thesis has been and remains – to demonstrate that there is a lack of and therefore a need for greater cultural sensitivity in the whole framework of health and disability relationships here in New Zealand.

In view of this then, the whole program of recommended follow-up actions (review, training, advocacy / promotions / supports, institutional developments / strengthening, and respect for values and belief systems) - should be underpinned and be guided by the basic philosophy of "*Fakalotofale'ia."*

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APPENDIX 1 APPLICATION TO MASSEY UNIVERSITY ETHICAL COMMITTEE

1.1 Application Document

1. DESCRIPTION

1.1 Justification

"The combination of disability and ethnicity, race and/or cultural background often results in a double form of discrimination," Bryan (1999). Pacific disabled people experience marginalisation from mainstream service provision. Research has identified Pacific disabled people as having low participation rates in mainstream services, lack of access to information and as further disadvantaged because of their low socio-economic status.

The New Zealand 'Disability Strategy' highlighted that:

> "As a group, disabled people are likely to have lower and fewer financial and family resources than the general population. This economic disadvantage is compounded by financial cost of disability. The earning potential of families with disabled children can be curtailed by their need to provide support for their children or live and work in areas where they can access family or professional support."

This research is intended to explore issues of disability with Tongan disabled people, their famili (family) and kainga (ex-tended family) to establish:

- How their capacity could be strengthened and further enhanced within their cultural and socio-economic context in Aotearoa.
- How services could be improved through encouraging Tongan disabled people, famili.kainga and community to contribute towards shaping and establishing support services that more effectively meet their needs.

The research will explore the perspective of the receivers of disability support services at grass-root level, looking at the effectiveness of service delivery and identifying key issues both from community-based and government agency levels. Respect for participation will be preserved by linking perspectives to tangible outcomes for service delivery that provide value for future services to Tongan disabled people and by extension other Pacific people.

1.2 Objectives

1. To promote participation of Tongan disabled people, their famili/kainga and community.
2. To increase and improve access of Tongan disabled people, their famili / kainga and community to disability support services
3. To make recommendations from the outcome of the study that will add value towards the future development of services to Tongan disabled people and by extension other Pacific people.

1.3 Procedures for Recruiting Participants and Obtaining Informed Consent

Recruiting participants will follow the process:

- Identify disabled people through the community network of which I am a part i.e. Community groups, famili and kainga. As a member of this community and with considerable knowledge of the groups disabled Tongans in Auckland, I will chose potential participants through these existing networks. A list of individuals known to myself and to my networks will be developed and 15 people will be randomly selected from this list to be approached to participate. New names will be added to the list to make up for refusals.
- Personal visits to possible participants, famili and kainga to extend invitation to participate.
- A full discussion about the study with each family, and at the same time the written information will be handed over together with the consent form to make sure families are well informed, and feel the autonomy to make their own decisions about wanting to participate.
- The informed consent will be discussed during the time of the visits. Both verbal and written consent will be offered.

1.4 Procedure in which Research Participants will be involved:

Participants will be involved in a one-to-one interview and a focus group meeting.

This process will involve the following:

- An introductory meeting with possible participants, their famili and kainga to talk about the study and discuss their consent to participate. It will take up to an hour maximum.

- A second meeting with those who have consented to participate will be involved in an interview that may also involve a ‘holistic needs assessment’ analysis. This meeting will require about one and half to two hours maximum. This may lead to referrals to appropriate agencies.
- Further follow up visits or phone calls to participants as a routine check to inform them of the progress and basically to check how they are doing.
- A focus group meeting to discuss all information gathered and also for participants to raise any concerns or ask any questions they may have. This meeting will require two hours.

1.5 Procedure for Handling Information and Material produced in the course of the Research Including Raw Data and final Research reports.

My first and utmost concern is to treat the participant’s perspectives with great integrity and respect. The information obtained from the interviews will be acknowledged and I will make sure they are used entirely for the purpose we have agreed to. Participants will also be kept informed of the progress of the study. Because of the size of the Tongan community and the fact that we will be meeting in a focus group situation, it will be impossible to achieve total confidentiality and anonymity. The group will be asked to keep the discussions confidential. However, I will do my very best to ensure no personal information is compromised in any way or form. For example, no personal details will be identified individually.

1.6 Procedures for Sharing Information with Research Participants

The researcher proposes this option as an acceptable process based on her understanding of Tongan culture and experiences working with Tongan disabled people, their famili and kainga.

At the completion of the research, disabled people, their family and kainga will be invited to a closing celebration meeting where the summary of the findings will be shared in their mother tongue. A brief summary of the report will be provided to all participants. The written form of the ‘thesis’ will also be made accessible and available to those who would be interested to read the full report.

1.7 Arrangements for Storage and Security, Return, Disposal or Destruction of Data

All transcripts, notes and tapes from the research will be returned to participants, deposited in an archive or destroyed at the completion of the study as determined by the individual participant.

2. ETHICAL CONCERNS

2.1 Access to Participants

Access to participants will be through Tongan community groups, other informal network (families, kainga) and negotiated with the assistance of the mainstream disability providers will be considered if identification of some participants becomes difficult. The researcher will also explain to participants, families and kainga how their names were obtained to participate.

Action research is perceived as generating change and solutions to practical problems and has ability to empower practitioners (Meyer 1996), for ethnic minority groups who experience being marginalised from mainstream systems often welcome participating in these studies as a forum for implementing potential solutions for their own problems. Similar to the Tongan community, these meetings are perceived as forums to resolve some of the unresolved problems especially when a Tongan professional is involved.

2.2 Informed Consent

Informed consent (Collaboration)

This process will involve the researcher ensuring the participants are fully informed about the purpose of the research, the potential uses of the research and any potential impacts on them. The information will be offered in writing; in this case it will be in two languages (Tongan/English). It will also be offered in oral form and, in some circumstances, in the presence of the person's caregiver or an advocate.

Each participant, their caregivers, advocate or other recommended persons would sign consent forms.

Because I have practiced in the field and will be well known to most of the participants there may be some feeling that participants have an obligation to participate. I will be very clear will all potential participants that they should feel no such obligation and that a refusal to participate will not have any impact on services they may in the future require from any agency I am involved with.

Participants will also expect that by being involved they will receive some form of assessment or treatment through being part of the research. It is import to recognise this, and as a result, I will be undertaking assessments with the interviews where this is appropriate and agreed to.

2.3 Anonymity and confidentiality (Confirmation)

It is acknowledge that because of the nature of the qualitative study which tends to deal with relatively small samples of people and within a very close knit community, trying to conceal the identity will be quite difficult. It is very important to obtain the trust of the participants. From an indigenous perspective, the researcher is faced with a number of responsibilities (Hu'akau – 2000). One of the major responsibilities was to ensure the participants felt safe both from an "individual sense and a community sense." Participant's anonymity must be ensured and details and names must be deleted from any record of the interviews and their information must not be compromised in any way or form.

Complete confidentiality and anonymity can be maintained for individual interviewees.

The focus groups process must have clear ground rules around confidentiality at the beginning and at the end of each meeting, especially information shared within the group. Participants must also be informed of appropriate processes on how to deal with any complaints or grievances regarding any inappropriate approaches or actions.

2.4 Potential harm and risks to participants and researcher

One has to be aware that working people with disability who are relatively powerless.

It is very important that I am aware of the powers that exist in the relationship between the researcher and the participants. My attitude and approach will have a big impact in the research process. Therefore, there are issues that I need to acknowledge to ensure that my involvement with my community is not a view as an outside researcher.

Smith (1999) suggested, that, "one of the difficult risks insider researcher take is to "test" their own taken-for-granted views about their community. It is a risk because it can unsettle beliefs, values, relationships and the knowledge of different histories."

Similar situation could also be confronted with a Tongan researcher. Because I have been educated in the Western system my community may be suspicious of my involvement and perceived me as an Outsider. Therefore, my approach and actions would earn my creditability but most importantly the safety of those who choose to participate in this study. To express humility, respect and demonstrate that I have the understanding of my particular roles and relationships would deal with any threats or potential harm that may possibly felt by the participants.

Smith again argued, that, "convincing indigenous community to participate in such a study requires a thorough knowledge of the research paradigm and an ability to mount a sophisticated and honest justification."

The designing of the study also suggests a build-in safeguards like: the choice of participants to withdraw making sure the material about the research is accessible, an ongoing consultative approach with the participants (focus group meetings) and lastly to ensure my accountability to the community studies, the University Ethic committee and the school of Social Policy and Cultural Studies is maintained.

2.5 Potential Harm to Researcher

Potential harm would be due to over committing one's self and possible fail to completed the research adequately. This could result in conceivably damaging of my reputation in this community as well as a Professional.

2.6 Potential Harm to University

Similar to the above, if a research is not conducted properly it could create potential harm to the University. The approval from the ethics committee, proper planning and appropriate supervision should avoid this potential.

It is also intended that I will use a Team of Tongan people with disability, professionals and family/kainga (family/extended family) as my outside advisory support.

2.7 Participants' rights to decline to take part

Participants have the right to decline to take part, or to withdraw or renegotiate their involvement at any time up to three months before the thesis is completed if they do initially choose to take part. This will be discussed clearly on the consent form or first meeting.

2.8 Use of Information

With consent, I am hoping to use the information as an empowerment basis for the participants by making recommendations to providers of disability services.

2.9 Conflict of interest / conflict of roles

It is a known fact that boundaries within/among the Pacific community are often very blurred. The researcher is perceived to wear many hats: a researcher, an educator, an advocator, a counsellor, a family member and so on.

It is very important that the researcher has the balance of professional knowledge and cultural knowledge in order to be able to recognise when roles may be confused. To maintain rapport and maintain participants' interest throughout the process, their queries must be acknowledged and it is quite appropriate to inform them that although this study is separate to my work, information and contacts to the appropriate persons or organisations would be given to help particular families.

2.10 Other ethical concerns

A non-disabled person doing a research in the area of disability would be a concern?

I must always be aware about the fact and its potential distort both from a practice perspective and perception of others. Oliver (1999) argued, that all disability research must look to promote the empowerment and autonomy of disabled people and not to perpetuate oppression. Therefore, the researcher must ensure the inclusion of people

3. Legal Concerns

3.1.1 Intellectual Property Legislation e.g. Copyright Act 1994

This legislation is involved with accountability and acknowledgement of other people's work that you quote from. Will be adhered to.

3.1.2 Human Rights Act 1993

This relates to personal rights as a human being to be respected and treated with dignity, as an individual and it will strictly adhered to.

3.1.3 Privacy Act 1993

Will be adhered to.

3.1.4 Health and Safety in Employment Act 1992

Not relevant.

3.1.5 Accident Insurance Act 1998

No relevant as I am not doing this in paid employment.

3.1.6 Employment Contracts Act 1991

Not relevant.

3.2 Other Legal Issues

4. CULTURAL CONCERNS

None.

5. OTHER ETHICAL BODIES RELEVANT TO THIS RESEARCH

5.1 Ethics Committees

None.

5.2 Professional Codes

- Not applicable,

6. Other Relevant Issues

None.

1.2 Information Sheet

INFORMATION SHEET

Research Title: Applied Research, Introducing Disability Concepts with Integrity into Tongan Cultural Context

You are invited to participate in a research project concerned with Tongan disabled people, their famili/kainga and community. I am Tongan and have both qualification and professional experience in social work and counselling. I also have specific professional experience working as a Need Assessor/Service Co-ordinator in the disability field and have conducted other community projects within the disability area with Tongan disabled people, their famili/kainga and supporters. This study is undertaken for the purpose of a partial fulfilment of the requirements of the degree of Master of Arts (Social Policy): however, it is intended that it will ultimately contribute towards forms of service delivery that provide value for future services to Tongan disabled people and by extension other Pacific peoples.

Researcher: Seluvaia Le'ota Tu'itahi TAHAAFE
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A staff member from the School of Social and Cultural Studies at Massey University, a Co-supervisor from Koloto & Associates Ltd and Tu'uta Pome'e Manager of PIASS Trust and disability support will supervise my research project.

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Purpose of the study:

This research is intended to explore issues of disability with Tongan disabled people, their *famili* (family) and *kainga* (ex-tended family) to establish:

- How their capacity could be strengthened and further enhanced within their cultural and socio-economic context in Aotearoa.

How services could be improved through encouraging Tongan disabled people, famili, kainga and community to contribute towards shaping and establishing support services that more effectively meet their needs. Respect for participant will be preserved by linking perspectives to tangible outcomes for service delivery that provide value for future services to Tongan disabled people and by extension other Pacific groups.

Selection of Participants:

A random selection of up to 15 Tongan disabled people from age 0-64 who live in the Auckland area. *Famili, kainga* and supporters will also be invited to participate with their consent. The researcher will obtain parental consent if participants are under the age of 16. The researcher will explain to the participants that they have been selected either because they are already known to her or Pacific people in the community who have an interest in disability have given their names to her.

What will participants have to do?

Participants will be involved in a one-to-one interview and a focus group meeting. It is acknowledged that some participants may experience some difficulties due to their disability; therefore, information would have to be obtained from the parents or primary caregivers.

- An introductory meeting with disabled people, their famili/kainga and supporters to talk about the project and discuss their consent to participate. It will take up to a maximum of one hour.

- A second meeting with those who have consented to participate will be involved in an interview which may also involve a ‘holistic needs assessment’ and will require about one and half to two hours.

- A further follow up visit with participants to check through the information obtained from the first interview. This will be approximately1 hour duration.

- A focus group meeting to discuss all information gathered and also for participants to voice any concerns or have more input towards the study. This meeting will take approximately2 hours.

- The overall time anticipated for each participant will be 6 hours in total. This process is expected to take place over a period of 3 months period, (June-August 2002).

As a participant, time and venue will be negotiated to suit your individual needs. The focus group will be at times and venues most suitable to participants as a group. Participants may also contact the Researcher if transportation is required.

With your permission, the interviews and focus group meetings will be audio taped. All notes and recordings of interviews will be destroyed or it shall be returned to you at your request.

What can participants expect from the researcher?

My utmost concern is to treat disabled people, their *famili* and *kainga* with respect.

I will also make sure that your contribution and input to this study is adequately acknowledged by using the information entirely for the purpose you have agreed to.

You will be also be kept informed about the progress of the study and take time to answer any questions you may have. Because of the size of the Tongan community and the fact that we will be meeting in a focus group situation, it will be impossible to achieve complete confidentiality and anonymity. However, I will do my very best to ensure no personal information is compromised in any way or form. For example, no personal details will be identified individually.

As a participant you would have the right to:

- Refuse to answer any question and to withdraw from the study at any time up to three months before the thesis is completed. (Please note that in terms of the focus group, you will be able to withdraw your comments from being used, however, it is not possible after you have already participated to withdraw your total input and influence on the group).
- Ask any further questions about the study that you think of during your participation, and have your questions answered.
- Provide information on the understanding that steps will be made to achieve confidentiality and anonymity as far as possible, so that you cannot be identified in any reports that are prepared from the study.
- Be given access to a summary of findings from the study when it is concluded.

Thank you for your time in considering this. I welcome your comments and questions.

"This project has been reviewed and approved by the Massey University Regional Human Ethics Committee, Albany Campus, Protocol MUAHEC 02/042. If you have any concerns about the conduct of this research, please contact Associate-Professor Kerry Chamberlain, Chair, /Massey University Regional Human Ethics Committee, Albany, telephone 09 443-9799, email K.Chamberlain@massey.ac.nz."

Signed:

Researcher: Seluvaia Le'ota Tu'itahi Tahaafe

PARTICIPANT/CAREGIVER INTERVIEW CONSENT FORM

I have read/ have been read to me the information sheet for this study and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction, and I understand that I may ask more questions at any time.

I also understand that I am free to withdraw from the study at any time until three months before the thesis is completed, or to decline to answer any particular question in the study. I agree to provide information to the researcher/s on the understanding that it is completely confidential.

I agree to participate in this study under the conditions set out on the Information Sheet.

WRITTEN CONSENT:

PARTICIPANT

Your Name: ______________________________________

Signed: ______________________________________

CAREGIVER:

Your Name: ______________________________________

Caregiver's Name: ______________________________________

Caregiver's Signature: ______________________________________

Date: ______________________________________

VERBAL CONSENT:

(Please fill in section below if only verbal consent is given. E.g. blind consumer)

Your Name: ______________________________________

Interviewer's Name: ______________________________________

Interviewer's Signature: ______________________________________

Date: ______________________________________

I agree/disagree to audio tape the interview.

I request that the tapes and transcripts of my interview be:

(a) Handed back to me
(b) Depositing in a suitable archive with the following conditions of access:
Destroyed

APPENDIX 2 COMMENTS FROM THE PARTICIPANTS IN THE CASE STUDY

Home Care:

1) Need to recognise that family members are not seeking employment, as they need to take care of their disabled relatives. Therefore need to recognise the contribution of the family members who are caregivers in terms of formalised payments (5);

Communication:

2) Cultural Difference – Need to recognise the cultural difference, respect others culture and protocol, need to employ Tongans who understand Tongan culture (5)

3) Language barrier, gender issues, emotion (5)

4) To form a social group of Tongan Disabled persons, with wider propaganda and dissemination of information, translation of policies into Pacific ethnic languages, activities for people with disabilities, seminars meetings, support groups, etc (8)

Organisational

5) Do not know what is out there, with no consistent information on disability issues, need more explanation of services/clear information about DSS services (8)

Customer Service

6) Long wait for NASC, need to listen and understand disabled person's problems (5)

Cultural Beliefs

7) Beliefs – see disability as curse/punishment because of sins, etc (4);

APPENDIX 3 CONSENT TO TRANSCRIBE - CONFIDENTIALITY AGREEMENT FOR TRANSCRIPTION OF TAPE

I, the undersigned, -- agree to maintain respect and confidentiality throughout the trnscription process of these tapes. All materials concerned will be shared solely with the Researcher and no one else.

I am aware that I have legal responsibilities binded under this agreement and any bridge of this agreement and confidentiality will treated similar to bridging of the Privacy Act 1983.

Thank You.

S. L. Tahaafe
Researcher.

APPENDIX 4 QUESTIONNAIRE

Part A.

PERSONAL DETAILS

1. First Name/s: --------------------------------------- Surname: ---------------------------------

2. Date of Birth: ------------------------------------

3. Address: --- Tel: --

----

4. GP: --- Tel: --------------------------------------
Add: --
----

5. When was the last time you saw the GP?
____

6. How often do you see the GP/doctor?
____

7. School/Employer:------------------------------------Tel: --------------------------------------

8. Parent/s/Caregiver: ---------------------------------- Tel: --------------------------------------
----

Part B: Support System

1. Who do you live with?

----

2. What kind of support do you have access to?

----

3. Do you access any DSS support? If yes who?

----

4. What kind of support do you get from your famili/kainga? (emotional/practical)

----

5. Other supports:

----

6. What are some of the barriers re: physical safety?

____

____

7. How about cultural barriers?
____
____

8. Any other comments?
____
____

Part C:

FINANCIAL SUPPORT

1. Employment: ---------------------------------- Full-time----------- Part-time ------------

   Benefit: -- Specify: ---------------------------------------

   Earnings: -------------------------------------- DSS benefit ---------------------------------

2. Other Income: ------------------------------------ specify: -----------------------------------

3. Own Home/ Rent: ------------------------------- Costs: ------------------------------------

4. Do you get financial support from any other source? eg. famili/kainga.

   ----
5. How long have you lived here?
   ____
6. Do you receive/or entitle to some accommodation allowance?
   ____

Part D:

PERSONAL SUPPORT

1. Do you access Home care? If yes, who?

   ----
2. Do you need assistance with the following?:

   ☐ Walking
   ☐ Eating
   ☐ Bathing
   ☐ Lifting
   ☐ Other Specify: -----------------------
3. Do you need 24 hrs supervision? ☐ Yes ☐ No

4. Have you been assessed by NASC? If yes, who?

----

5. When was the last time?

----

6. Are your personal needs being met? Physically, emotionally, culturally and spiritually? Please explain.

----

7. Any other comments:

Part E:

RECREATION ACTIVITIES

1. What are your hobbies/interests?

----

2. Are you aware of dss social groups/community? If yes, specify.

----

3. Are there any specific activities you are interested in?

----

4. Do you involve in family activities? specify.

----

5. Any other comments?

Part F:

DISABILITY SERVICE

1. Are you currently receiving any dss service? If yes, specify. If No, why?

----

2. Are these services appropriately meeting/acknowledging your needs? culturally, physically and spiritually? Please explain.

----

3. If yes, or No to Q2. Can you specify how?

----

4. Are you fully informed of your rights/entitlements?

   ----
5. What are key issues you would like disability providers, policy makers or government Agencies to consider when establishing a disability service for Tongan disabled people?

   ----

6. Any other comments:

Part G:

CAREGIVER DETAILS:

Primary Carer:

1. First Name/s: -- Surname: -----------------------------
2. Add: -- Tel: ------------------------------------
   ----
3. Please explain your role?

   ----
4. Do your work? If yes ☐ Full-time ☐ Part-time
5. Other care supporters/: --
   Relationship: --

   ----
6. Please talk about your needs as a Caregiver?

   ----
7. Do you feel supported by the disability service? How?

   ----
8. Do you receive respite care? How many days?

   ----
9. How do you use your respite care? Please explain.

----

10. Any other Comments:

Part H:

MEDICAL DETAILS:

1.Can you explain your medical condition/diagnosis?

----

2. Are you on any medication? How often?

----

3. Do you require any specialist care/treatment?

----

4. Do you use other forms of treatment? Eg. Herbal, traditional medicine, therapy etc.

----

5. Any other comments:

PART I

CULTURAL ASPECT

1.What cultural issues do you think that has been in conflict with the way disability has been delivered? Please explain or give examples?

----

2. In terms of caring for the disabled person what are things that are normal in the Tongan way of life and how different it is in the New Zealand environment?

----

3. Can you talk about your perceptions as a disabled person/or as a caregiver?

----

4. Are there anything else you wish to talk about or comment on?