

**Brain Injury Whānau Action Project (BIWAP):
Increasing the capabilities of families of adults with brain injury
to live their lives in the ways they have reason to value.**

Elisa Lavelle Wijohn

A thesis submitted to the Auckland University of Technology in fulfilment
of the requirements for the degree of Doctor of Philosophy (PhD)

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Dedication

In loving memory of

Margaret Oakes

Acknowledgements

This project has relied on a large community of support from academics, family, friends and community.

My thanks go to Professor Kath McPherson for providing my first research home at AUT, and for developing a research programme that felt relevant to, and respectful of people with disabilities and their real rehabilitation needs. Professor Jane Koziol-McLain has fostered this project and my well-being as a person and a researcher over many years. Thank you for being there all the way, and for your warmth, encouragement, rigour and wonderful laugh.

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Ngā mihi nui ki a koutou katoa.

Abstract

This PhD was prompted by my concern about the lives of families after an adult sustains a serious brain injury. We have long known that brain injury impacts families, but our supports within Aotearoa New Zealand have been focused on individuals. I was concerned that an individualistic focus caused unnecessary suffering for families and was a remediable injustice. Our systems were a particularly poor fit for Māori whānau (families), given that Māori understandings of health and well-being have a strong focus on the well-being of whānau. As a non-Māori researcher I wanted to work in a way that is ethical, effective and respectful.

The Capability Approach has provided the theoretical framework for this research and was chosen because of its understanding of disability, or capability deprivation, and the focus on human rights and how people are able to live their lives in actuality. The methodology used is Māori-centred Community-Based Participatory Research. This gave me a way of working that respected Māori values and processes, focused on building solutions from the flax roots up, and is designed towards the possibility of influencing policy change.

The question asked in this thesis is: How can we increase the capabilities of families of adults with serious brain injury to live their lives in the ways they have reason to value? A community-academic partnership was established with the Auckland Brain Injury Association. A number of family members (co-researchers) from South Auckland then gathered over some months to explore the situation of whānau living with brain injury, to determine action that could increase the capabilities of their own and other whānau. This work brought the co-researchers to the determination that they wanted to educate and strengthen themselves, in order to educate and strengthen others. The action project chosen was a wānanga, which brought together a wider group of whole families (including people with brain injury, children and elders), to learn from each other and from selected health professionals, at the ancestral marae of one of the co-researchers. This work, and the process of our research was evaluated by co-researchers and wānanga participants. It has resulted in many other spinoff benefits

including relationship building with like-minded groups and is having a direct influence on policy.

The action of the wānanga is at the same time new and not new. Wānanga are a cultural tool with a long history of use amongst Māori, yet this method of learning and support has not been researched for working with families with brain injury. To understand why this type of support and learning process had not happened earlier, the next research stage was a reflective process considering government strategies and the United Nations' Convention on the Rights of Persons with Disabilities (CRPD). This thesis argues that in order to increase the capabilities of whānau with brain injury we need to develop Māori-centred, community-driven actions at the individual and whānau level. At the same time our government organisations need to uphold their commitments under both Te Tiriti o Waitangi and the CRPD.

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Glossary

hakari	feast
hapū	a collective of families with a common ancestor, subtribe
hinengaro	mind
hui	Meeting, which typically involves some formal processes such as opening and closing karakia
iwi	a very large collective of families with a common ancestor, tribe
kai	food
kanohi ki te kanohi	face to face
kapa haka	cultural (performance) group
karakia	blessing or prayer
kaumatua	an older person with knowledge and status
kaupapa	purpose
kaupapa Māori	Māori processes, Māori way of carrying out activities, research methodology that refers to research that is 'by Māori, for Māori'
koha	contribution
kohanga	early childhood centre based on Māori principles
kōrero	talk, converse
kuia	an older woman with knowledge and status
mahi	work
mana	status and respect as a result of whakapapa and actions
mana whenua	people with authority in that particular rohe (region)
manaakitanga	generosity, the process of hosting
Māori	indigenous peoples of Aotearoa New Zealand, normal
marae	ancestral home which includes meeting house and other buildings
matua	adults who are parents or in a parental role, uncle
mokopuna (moko)	grandchild – which can include grand nieces and grand nephews
Pākehā	New Zealanders of European descent
poroporoaki	formal process of closing of a hui
powhiri	formal process of welcome
puha	wild greens
ringawera	“hot hands” - kitchen and other workers at a marae function
rohe	region

tangata whenua	people of the land
tangata tiriti	treaty partners
tautoko	support
te ao Māori	the Māori world
te reo Māori	Māori language
Te Roopu Waiora	
tika	process of things being “correct”
tikanga	correct processes
tinana	body
waiata	song(s)
wairua	spirit
wānanga	learning place and space
whakapapa	Geneology - ancestry
whānau	family group but can also refer to a group that connect through a shared purpose
whānau hauā	People with disabilities – where ‘hauā’ refers to “changes in our natural environment, as in the wind. Sometimes the wind is breeze-like and other times like a tempest. As the forces of nature cause us to bend and change, the changes in our individual situation and the environment in which we find ourselves has an impact on the collective.” (Auckland UNCRPD shadow report group, 2014)
whānau	Family, which includes extended family
wharekai	Dining building which also houses the kitchen
wharemoē	Sleeping and meeting house (also known as wharenuī)
wharenuī	Meeting house

List of Abbreviations

ABI	Acquired Brain Injury - includes brain injury as a result of stroke or disease as well as traumatic brain injuries
ACC	Accident Compensation Corporation
BI	Brain injury
BIA	Brain Injury Association
BIA-AKL	Brain Injury Association of Auckland.
BIWAP	Brain Injury Whānau Action Project
BoRA	Bill of Rights Act
CA	Capability Approach
CBPR	Community-Based Participatory Research
CRPD	Convention on the Rights of Persons with Disabilities
CYFS	Child Youth and Family Services
GCS	Glasgow Coma Scale
GDP	Gross Domestic Product
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICF	International Classification of Functioning
IMM	Independent Monitoring Mechanism
MoH	Ministry of Health
NZDS	New Zealand Disability Strategy
ONAC	Ōtara Network Action Committee
PAR	Participatory Action Research
PPPR	Protection of Personal and Property Rights Act
TBI	Traumatic brain injury
UNCRPD	United Nations Convention on Rights of Persons with Disabilities
UNDHR	Universal Declaration of Human Rights
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples
WHO	World Health Organization
WINZ	Work and Income

Chapter 1 – Introduction



**Traumatic Brain Injury
and your whānau**

**How's the family coping
with brain injury?**

What would help?

We're starting a project to look at the needs of whānau/families of adults with brain injury to see how we can work together to make lives a bit better.

Contact: Elisa Lavelle
elisa.wijohn@gmail.com
Ph/text 0800 TBIWHANAU
0800 824942
or Brain Injury Association in
Otago 09 2722272

Headway
BRAIN INJURY | PICKLANDS
The Brain Injury Association (Auckland) Inc.

AUT
UNIVERSITY
15 SOLOMAN ROAD | AUCKLAND 1010

Figure 1: Recruitment flyer

I came to this work knowing it as much from the personal as the theoretical.

In my first year of university, I lost count of how many visits I made to the neurological ward of our city hospital. While my friends and I were attending lectures and parties, one of our closest friends was in a prolonged coma. During breaks between classes, I would walk from the university to the hospital, often with another friend, and we would talk with her, massage her hands, brush her hair and play the music that she loved.

She looked as if she was simply asleep without a single bone injured or even a scratch on her. We watched for signs of her return to consciousness, and I still remember the tears of elation when we found out, four months after the car crash, that she'd spoken her first word. But, this waking up from a coma didn't work like the movies. For the whole of that year she was in hospital where she learned again, as so many survivors of brain injury must, to walk, talk, eat and dress herself. And also to reconnect with each of us. Her life was forever changed, as was her mother's.

From the moment that any whānau learn of the situation of their injured family member, they are thrown into emotional turmoil. One of intense hope, grief, frustration, guilt and exhaustion. The grief that is encountered from brain injury is complicated (Kreutzer, Mills, & Marwitz, 2016). The injured person is still alive, and people from within the wider circle of friends and family will often comment on how lucky everyone is that the injured person has survived. But the ongoing reality for both the injured person and their family can feel far from lucky. Families and caregivers experience significant stress and reduced well-being. They can also end up dealing with bureaucracies which brings its own added stressors.

Background to the research

Fifteen years after my initial experiences in the neurological ward, I started working in post-acute brain injury rehabilitation. Prior to this I had worked in community mental health teams where I predominantly worked with people who struggled with depression, anxiety and suicidal behaviours. I had developed a reasonable level of competence and confidence in knowing that

I had tools that could generally help mental health clients to lead improved lives. The challenge in working with brain injury was that I did not feel that I could reliably achieve improvement. The life the person had after brain injury was likely to be significantly more challenging. What we could hope to achieve as health professionals was to set the individual and their family on a path of greater recovery than they would have achieved had they not come to us. Within this, clinicians have been aware that while early comprehensive rehabilitation is extremely important and found to lead to improved results (Andelic et al., 2012), our involvement is brief, and it is the family who will be impacted for life by the injury and who will play an enormous role in the long-term well-being of the person with the brain injury. I believe that we are extremely fortunate in Aotearoa New Zealand to have reasonably comprehensive rehabilitation for the individual with the brain injury, but this has not been adequately extended to the family. I see this lack of support for families as causing unnecessary suffering. It was for this reason that I wanted to see if I could use my PhD project as a way of improving the lives of people who I saw as experiencing the collateral damage of the brain injury.

Personal background

Before outlining the research design it is important to locate myself as researcher. I come to this research as a Pākehā woman who has grown up with educational privilege from my family of origin, and has worked as a Clinical Psychologist which also connotes professional privilege. While this privilege can be a barrier to working with more marginalised groups, to work only with those groups with whom I share that same background of being female, Pākehā and from a professional background would feel ethically indefensible to me, given the health disparities within our communities and the need for research to focus on reducing these. I am concerned that our current systems further advantage Pākehā, especially those from families with greater resources who are better able to interact with systems which can put up barriers to less resourced individuals. I believe that we each have a responsibility to reduce unnecessary suffering and, as a psychologist, our Code of Ethics includes the responsibility of “addressing

and challenging unjust societal norms and behaviours that disempower people at all levels of interaction” (New Zealand Psychological Society, 2002 Principle 4).

In line with the wishes of the Auckland Brain Injury Association (BIA-AKL), the research was conducted in South Auckland which meant that the people who were drawn to participate came largely, though not exclusively, from lower socioeconomic backgrounds. While there were Pākehā participants and co-researchers, most were Māori and some were of Pacific Nation or other ethnic groups.

In choosing to conduct research in areas that are outside of my own heritage and upbringing, I also bring more than 20 years of being in connection with te ao Māori through my husband and our children. My Pākehā whakapapa is now entwined through our children to Tūhoe, Tuwharetoa, Te Rarawa and Ngāpuhi. Our children have been and are educated within kaupapa Māori, bilingual and mainstream mediums and our lives operate in an urban bi-cultural manner. While I walk in both worlds, I am mindful that both of my feet are Pākehā and I therefore step carefully. I have also worked to increase my cultural safety and competence with other cultures through travel, reading, and professional and friendship relationships.

In terms of my relationship to families of people with serious brain injury, I am situated as a professional who also has a close relationship with my life-long friend who sustained a serious brain injury when we were in our late teens. A close group of friends now act in the role of family to support her, particularly when she needs to deal with bureaucracies, to lead the life that she chooses.

The problem/motivation

In deciding to embark on PhD research, I wanted to make a difference in the area of long-term outcomes. Within my clinical work, I often worked with family members as much as the person with the injury. I worried particularly for the wives and partners, knowing that while the early weeks could be a time of enormous turmoil, the longer-term outcome for the mental well-being of partners and family could be as difficult, or worse, than for the person with the injury. I could

also see that families had hugely differing levels of skill and success in managing the systems that they were now engaged with, including our own rehabilitation service and the key funder, the Accident Compensation Corporation (ACC).

I wanted to conduct research that could make a difference for partners and families, but I was concerned that as a Pākehā professional, the sorts of solutions I would likely come up with myself might be of little benefit to the people who struggled most within these systems. In seeking to make a difference I sought to conduct research that would help to improve the lives of partners and families, including the ones who I would engage with within the research. I also wanted to contribute to knowledge and have the possibility of influencing policy to improve the lives of families with brain injury.

Epistemological and theoretical position

This thesis project worked with a group of families in South Auckland who have adult members with serious brain injury. The purpose of the project was to develop action together that would lead to families having greater capability to lead their lives in the ways that they have reason to value. In order to embark on this action we first worked together to establish the concerns, strengths and goals of the group. Alongside of this we established how we would work together as a group, i.e. as co-researchers, and what would be the important structures and processes. While the project was a part of my PhD, the co-researchers as a group determined the aims of the group, the action we would pursue, what data we would collect and how the data would be analysed. The co-researchers have been involved in dissemination to the community and in establishing how to turn the Brain Injury Whānau Action Project from a research project to becoming a sustainable community organisation.

The epistemological position of the research is critical constructionist. From the constructionist frame, knowledge is viewed as constructed, rather than discovered, and this construction occurs as people attempt to make meaning of the world (both social and physical) that they are in (Crotty, 1998). The critical aspect of the epistemology reflects the emphasis on

the role of power in determining which meanings come to be most accepted, or in Crotty's words:

It emphasises that particular sets of meanings, because they have come into being in and out of the give-and-take of social existence, exist to serve hegemonic interests. Each set of meanings supports particular power structures, resists moves towards greater equity, and harbours oppression, manipulation and other modes of injustice and unfreedom. (Crotty, 1998, pp. 59-60)

The theoretical framework that I chose is the Capability Approach (CA). The appeal of CA is the focus on injustice and unfreedom, its links to human rights, and conceptualisation of disability. These concepts have relevance for this project as I see the situation of families of people with serious brain injury to be one of remediable injustice. CA is a deliberately underspecified approach (Robeyns, 2011) which considers concepts of justice and equity in terms of the ways in which people are able to live their lives in actuality, or whether people are able (have the capability) to live their lives in the ways they have reason to value (Nussbaum, 2011b; Robeyns, 2011; Sen, 2010).

The methodology which guided the project and the PhD is Māori-centred Community-Based Participatory Research. A key goal in embarking on this project was that the research would be 'respectful' and 'effective'; effectiveness being a tangible facet of respect. As a person who considers Te Tiriti o Waitangi to be the founding document of our nation, which gave my ancestors the right to co-exist with Māori in Aotearoa, it was important to me that the project would be respectful of Māori and conducted with awareness of the harm that research and intervention can do, and has done, to Māori and other marginalised groups (L. T. Smith, 1999, 2012). The ethics of Māori-centred research sits between Mainstream research and Kaupapa Māori research (Hudson et al., 2010), and is appropriate for this project given that I am Pākehā and working with families from a mix of ethnicities. The Māori-centred ethical frame sits comfortably with Community-Based Participatory Research (CBPR) which seeks to conduct research with an emancipatory intent, and has also been developed to be mindful of the risks of research with marginalised groups (Minkler & Wallerstein, 2008a; Viswanathan et al., 2004). CBPR sits under the umbrella term of Participatory Action Research (PAR) which is often

described as existing on a continuum from a more managerial focus, which links to the work of Kurt Lewin (Burnes, 2004; Lewin, 1946) and is referred to as the Northern tradition (Wallerstein & Duran, 2008), to work which has an emancipatory intent, linked to the philosophy of Paulo Freire (Freire, 1998, 2000) and is referred to as the Southern tradition (Wallerstein & Duran, 2008). While each project and each partnership need to determine their own guiding principles and processes, there are nine principles which CBPR projects need to be mindful of and seek to achieve at the level appropriate to the project (these are outlined in the Community Participation section).

The project

This project was conducted in phases. Prior to developing the research proposal I engaged in a lengthy pre-research phase which started by working with two Māori women, as mentors, who shared their knowledge of brain injury and its impact on whānau. To gain greater understanding of the community I then spent eight months volunteering alongside the Auckland Brain Injury Association (BIA-AKL) Liaison Officer for South Auckland (Michael). The first research phase was focused on building the Brain Injury Whānau Action Project (BIWAP) group, establishing our ground rules and building our shared understanding of the effects of brain injury and the process of research. Following this, in order to focus on what we could develop as an action project we looked at “What’s worked?”, “What’s not worked?”, and “What do we want?” As we started to consider what action we would engage in the project was forced to take a break as I dealt with the diagnosis and treatment for breast cancer. This resulted in an eighteen month break. During this time I was able to maintain some contact, and we did send some co-researchers on a comprehensive brain injury rehabilitation training course, that came highly recommended by another one of the co-researchers. Moving from the extremely under-resourced area of charitable support for people and families with brain injury, to the highly supported area of breast cancer was also interesting in terms of thinking through the possibilities of the range of supports that can be offered by a well-resourced sector.

The second phase of the research started with a recap of what we had covered and a rebuilding, as it was important to re-engage with community groups and we also needed to re-recruit due to the loss of some of the co-researchers from the first research phase. The action of running a wānanga for whole families to learn about brain injury was determined early in the second research phase. We then set about planning, running and evaluating the wānanga and setting up for the ongoing sustainability of BIWAP.

The wānanga

The action project chosen was a wānanga (a live-in teaching weekend) on the marae of one of our co-researchers. The idea for the wānanga came from this same co-researcher who told me, when we met at her recruitment interview, of her long-held idea of bringing families together on the marae to learn from each other.

The actual event was successful beyond our biggest hopes. Wānanga participants spoke of how much they had learned, but perhaps more importantly they experienced a feeling of universality (Yalom, 1985) apparent in the comment that we heard throughout the weekend of “we are not alone”. In line with CBPR principles, the project resulted in the development of new or increased skills amongst all of us (myself, the community partner and other co-researchers). Sustainability was planned for from the outset and the ongoing work of BIWAP is now having the influence we had hoped, and planned for, in relevant policy design.

Significance of the project

This research project is significant for the information that it shares about the situation of whānau of adults with serious brain injury and how their capability to live their lives well can be increased. The project group developed an effective intervention that has been valued by many whānau and is able to continue to share information to others. The project also demonstrated an effective way of conducting research that has direct relevance to the community of concern. By partnering with the local brain injury association the resource of research time and knowledge was put to effective use. Further the project demonstrates that with careful and

respectful partnership it is possible for a Pākehā researcher to conduct respectful and effective research with a predominantly Māori group using a Māori-centred ethical frame.

As is the intention with Community-Based Participatory Research, the project has resulted in sustainable action, demonstrated by numerous further projects and plans for ongoing work. A sustainable community-academic partnership has also been formed with a new partnership project with a different area of the university.

Use of language

Whānau

The interest through this project is on the impact of an individual's brain injury on families. The project is Māori-centred, which is explained in the Methodology chapter. The "family" tends to refer to the Western concept of the nuclear family (Mum, Dad and children). The word 'whānau' connects to a broader understanding of family for Māori. Mason Durie (2001) notes that whānau can refer to the nuclear family, to a broader kinship structure where everyone has a common ancestor (though this may also include partners related by marriage as well) and to groups with a common interest, or a kaupapa whānau. From the commencement of this project the use of the word whānau has referred to whoever the people considered to be their family. This has included partners, children, aunts, uncles, cousins, nieces, nephews and grandparents of the injured person, as well as those people who act in the role of family by being support people because of their friendship relationship. As seems to occur throughout many areas within Aotearoa New Zealand, the word whānau was embraced by all cultures for this project, and does not necessarily distinguish Māori from non-Māori families.

Serious brain injury

Definitions of levels of severity of brain injury will be explained in the literature review. My interest is in the brain injuries that cause significant change in the life course of the person and the family. These tend to be classified as moderate to severe brain injuries, although significant outcomes can also occur for people who experience multiple mild injuries. These life changing

brain injuries are referred to as 'serious brain injury'. It is not intended through the use of this term to suggest that mild brain injuries should not be taken seriously, as all brain injuries do concern me.

Within brain injury, references are made to traumatic brain injury (TBI) which occurs as the result of a blow to the head, and acquired brain injury (ABI) which is a broader term referring to all brain injuries that occur after birth and can be a result of both TBI or illness, tumours or vascular events such as strokes. The bulk of the people involved in this study were affected by TBI, but the research did not exclude people with other forms of brain injury.

Auckland Brain Injury Association

The community partner in this project was the Auckland Brain Injury Association which is also known as Headway Auckland and Brain Injury Auckland. At the commencement of this project, the Auckland association had recently distanced itself from the national association, and the national association at the time had no connection to this project. When referring to the Auckland Brain Injury Association I have used the abbreviation BIA-AKL, and when referring to the national association or to other Brain Injury Associations I have used only BIA.

Te reo Māori

In keeping with this research being Māori-centred, there are a number of terms which are used from te reo Māori (the Māori language). Where these words are in common use within Aotearoa they are not translated, but a Glossary of all Māori words is provided. Less commonly known words are explained in terms of their use within this project within the text. I have referred to Aotearoa New Zealand somewhat interchangeably using either Aotearoa, or New Zealand or both.

Academic language

Given the style of research and the importance of it being directly relevant and beneficial to the participants, it is also important that this written aspect of the PhD is also accessible. The PhD is written very much as the story of the project and is laid out in the chronological order in which it occurred.

Privacy and confidentiality

From the outset, co-researchers were aware that they were entitled to privacy and confidentiality, but that aspects of their anonymised stories would likely become a part of the data of the PhD. At the same time, with the intention of this being a project that would engage with a wider community and be sustainable, they also understood that some might choose to be public with their involvement. The level of anonymity and openness varies across co-researchers. One in particular, Leeanne, has taken a leadership role as the Chairperson of the Brain Injury Whānau Action Project and now engages on behalf of our group in policy development work with the Accident Compensation Corporation.

Chapter outlines

The research project and parameters have been introduced in this first Introduction chapter.

Literature Review: The Literature Review outlines the situation of families of adults with brain injury, with a focus on Aotearoa and Māori. Within this chapter I explore brain injury and how it effects the injured person and those closest to them. Models of rehabilitation, including Māori models of well-being are outlined, before moving on to the rehabilitation situation in Aotearoa. As noted the bulk of people involved in the research were effected by TBI, and this is predominantly funded via the Accident Compensation Corporation (ACC). The impact of ACC in rehabilitation is therefore significant, and the guiding principles, changing philosophies and the impact of these on whānau are noted. This is looked at in terms of the gap between our understanding of brain injury as a family injury and the individual focus of service delivery.

Philosophy: The Capability Approach is the philosophical framework for this project. It was drawn upon because of the links between human rights, economics and the lives that people are able to live in reality. The capability approach, as a theory of justice, considers what people are able to do and be in their lives, and prioritises addressing situations of injustice over trying to establish a utopian framework for justice. CA is considered in terms of its framing of disability, and of the human rights arguments that can be made through the CA lens.

Methodology: The Methodology chapter covers both the Māori-centred ethical framework as well as Community-Based Participatory Research which jointly guided the practical application of CA. Research with Māori, when it is conducted by someone who is non-Māori has definite risks and pitfalls. The principles of Te Ara Tika, an ethical framework for researchers engaging with Māori are laid out, and the position of this research as Māori-centred, which sits between Mainstream research and Kaupapa Māori research is established.

Method: CBPR research is often described as cyclical and iterative which can make the distinction between Method and Results somewhat arbitrary. Deciding what we would do, and how we would do it, are both methods and results. In the first phase we developed a shared understanding of the situation of whānau with ABI in order to determine an action that the co-researchers considered would help whānau with ABI to live their lives in the ways they have reason to value. The Method chapter covers the setting up of the project and the establishment of the first phase of the research. The focus of this chapter is what we did, without talking too much about what we found.

Results: The results chapter continues the story of the research phase starting with what we found in Phase I, and then moving into what we did and found in Phase II, as well as the later stages of dissemination and sustainability planning.

Reflections: In reviewing the results of the project I was still left with questions, which will no doubt continue well beyond the PhD. As I have already noted, my concern that triggered this research was that while academic research had established the impact of the brain injury on families, and had also looked at effective treatments for families, this had not led to a change of practice in New Zealand. While I was analyzing and writing up the results of our project we ran a second wānanga, and it was after this that it was remarked upon by both a strategy consultant and a rehabilitation Professor that the way that we had worked with families “changes everything”. This took me back to the question of “Why, when we know that families are impacted by brain injury and when we know that whānau is central to Māori well-being, would working with whole families in a Māori-centred way be seen as something that was new?”

It seemed to me that, while I had not anticipated the action project that we did decide on, the way in which we had worked made a great deal of sense. The particular project we chose clearly reflected the Māori-centred nature of the work and the fact that the project had been driven by the needs and experience of whānau with ABI. This thinking led me back to documentation from ACC and from Ministry of Health relevant to disabilities, brain injury and Māori, as well as to returning to the Convention on the Rights of Persons with Disabilities and its monitoring in New Zealand. All of this revealed the absence of a voice for brain injury, and also that the presence, absence and strength of Māori voices was highly variable and dependent on those at the highest levels of power.

Discussion: The Discussion chapter draws the threads of both the results and my reflections together. This project adds further weight to the adage that “brain injury is a family injury”, and problematizes the situation of it being treated as an individual injury. I argue that it is time for our government organisations of Accident Compensation Corporation and Ministry of Health to embrace their roles in upholding our commitments under both Te Tiriti o Waitangi and the human rights instruments of the United Nations Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities. Through these instruments our government have committed to protecting the rights of Māori and protecting the family as a unit, especially when it is impacted by disability.

Chapter 2 – Literature Review: Brain Injury and its Rehabilitation Within Aotearoa

Write down on separate pieces of paper:

two activities you love doing,

two people who are important to you, and

two things you “can’t live without”.

Yes, reader, I actually want you to do this.

Whenever I do this exercise in staff training for workers in brain injury rehabilitation, people then share these aspects of their life. It’s a fun warm-up activity, we get to know each other better and share some laughs. We find out that people love getting out in nature, reading, and watching TV. Their children, partners and parents are so important, and they “can’t live without” food, coffee, their phones, faith in God, cooking, or walking their dog.

The feeling in the room changes when I say “now turn to the person next to you, and they will remove, at random, two of your papers”.

In order to understand the changes in behaviour that can occur after a brain injury it is vital to understand the losses and grief that brain injury causes. A brain injury is an injury like no other, as it is our brain that allows us to create, to think and to move, and also allows us to feel and to be. Most importantly, to me, it allows us to connect. The idea that brain injury is a family injury has been understood for decades. The reality that it has largely been rehabilitated as an individual injury is the concern that drove this research project.

Going into this research, I took my experience of post-acute residential brain injury rehabilitation and my knowledge and concerns, informed largely by academic literature, of the community situation. In this chapter I will outline the effects of brain injury in terms of who is injured, some of the costs of injury and how brain injury impacts on both the injured person and those who are in close relationship to them. Consideration then turns to rehabilitation and the systems that it occurs within. In understanding this context it is important to look at who is

injured, the inequities that exist within our country and our health systems, and the impact these have on our more marginalised communities. This survey of knowledge, and gaps in knowledge, will bring us to the question which I have asked: How can we increase the capabilities of whānau of adults with serious brain injury to be better able to live their lives in the ways they have reason to value?

Demographics

Not only does brain injury have a major impact on each individual and the people close to them, it is also significant within our health system. Traumatic brain injury (TBI) accounts for a significant portion of disability for individuals and their families as well as for health costs globally (Barker-Collo, Wilde, & Feigin, 2009). Recent research in Aotearoa New Zealand gives us a much fuller picture of who is being injured and some of the costs of these injuries.

How are people injured?

For moderate to severe injuries amongst the general population, the bulk are caused by falls and road crashes (39% each), and then assaults (14%) with a smaller number as a result of exposure to mechanical force (4%) (Feigin et al., 2013). TBI due to assault is more common for Māori than for non-Māori.

Who is injured?

Until recently, we had little accurate data on the incidence of TBI in Aotearoa NZ. A comprehensive year-long study (known as the BIONIC study), which sought to capture every incident of brain injury from mild through to fatal, was conducted in 2010 within the Waikato area. This area was seen to offer a discrete sample that was reasonably reflective of the ethnic and urban/rural mix of the country (Feigin et al., 2013). From the BIONIC study, it was estimated that there were 11,301 first ever incidents of traumatic brain injury (TBI) in 2010 in Aotearoa NZ, with 530 of these being in the moderate to severe range, and that in total, 527,000 people had experienced a TBI at some stage in their lives (Te Ao et al., 2015). An increase in these numbers

of more than 20% is expected by 2020, when it is estimated that there will be a further 13,591 initial injuries and a total prevalence of 641,104 (Te Ao et al., 2014).

A breakdown of the totals shows that males sustained serious brain injury at almost three times the rate of females (61 compared with 22 per 100,000 person-years), with the peak incidence for males occurring at 15-34 years, and a second peak for over 65 year-olds. For females, the peak incidence of serious brain injury occurred in the over 65 year-old age group (Feigin et al., 2013). As is found globally, the incidence of injury within the indigenous population is higher than that for the general population, with Māori rates of moderate-severe brain injury occurring at a higher level to the European NZ (Pākehā) population (60 per 100,000 compared with 49 per 100,000) (Feigin et al., 2013). Māori rates of all brain injuries due to assault were higher than for Pākehā, and this was particularly noticeable in the 15-34 year age group (Feigin et al., 2013). Serious brain injuries were found to be 2.5 times more prevalent in rural populations than in urban (73 compared with 31 per 100,000 person-years) due largely to the higher rate of injuries as a result of transport accidents (Feigin et al., 2013). While the data for moderate-severe brain injury were not separated out, rates of all forms of brain injury for people of Pacific Island descent were also higher than for the Pākehā population (1242 per 100,000 compared with 842 per 100,000) (Lagolago et al., 2015).

Given higher rates of injury for Māori, for males and for rural populations, I have wondered how well our health-workforce is able to support these clients. I am also well aware that high rates of injury for males correlates with high rates of caregiving for females (Anderson, Simpson, & Morey, 2013; Bellon et al., 2015).

What are the costs?

The economic burden of TBI is significant (Faul, Wald, Rutland-Brown, Sullivent, & Sattin, 2007; New Zealand Guidelines Group, 2006). The costs of injury for the BIONIC study were evaluated by Braden Te Ao for his PhD research. The average first-year health system costs of moderate-severe brain injuries in 2010 in New Zealand were estimated at \$31,855, with average estimated lifetime costs of \$54,605. Hospitalisation was required for 88% of moderate-severe injuries; the

average cost of these hospitalisations was \$16,500 with a maximum of \$109,317. With an average first-year cost for moderate-severe TBI of \$31,855, and an estimated 530 people sustaining injuries at this level in 2010, this equated to a total first-year cost of \$16,882,996. There are significant ongoing costs for many people with brain injuries. From the BIONIC study it is estimated that the total costs for all TBIs (i.e. those that occurred in 2010 along with the costs of all already existing TBIs) was \$151.1 million in 2010, and it is predicted that this cost will be \$182.7 million in 2020, with a quarter of these costs being attributable to moderate-severe TBIs (Te Ao et al., 2014).

The estimates above were based on costs of hospitalisation and therapies and are therefore useful for planning health system costs. They excluded less measurable costs such as those borne by family members and caregivers, and there seems to be no significant research that addresses the economic costs to families (Humphreys, Wood, Phillips, & Macey, 2013). Te Ao and colleagues also noted that these costs are for those people who accessed treatment, and that many people, especially those from rural or marginalised communities, are underserved by health services. They also noted that their modelling may not have adequately taken into account the costs of the longer-term cognitive decline and increased dementia that frequently results from brain injury (Te Ao et al., 2014).

Effects of brain injury

When families ask for a prognosis, I often tell them there is a common phrase in brain injury rehabilitation: “When you’ve seen one brain injury, you’ve seen one brain injury”, and that my own experience also tells me “when you’ve met one family, you’ve met one family”.

The brain can be seen as a last frontier within science. The complexity of the organ is truly awe-inspiring, and our knowledge of its inner workings is limited and changing. The brain controls everything from our perception of a breeze across our face, our ability to understand what our eyes see, the sensation of pain, the movements that we make in order to feed ourselves, drive a car, or caress a loved one. It controls our communication – what we

understand from others' speech and the words we read, and not only *what* but *how* we communicate. Our frontal lobes which, given their location, are especially vulnerable to deceleration injuries (the sorts of injuries which typically occur in car crashes), play a major role in decision-making and our personalities (Stuss & Alexander, 2000).

When the brain is seriously injured, from a medical perspective there are both immediate and delayed effects. The immediate effects are the result of the tissue damage that occurs as the brain collides with the bony structures of the skull, causing bruising or bleeding, as well as the twisting (or shearing) that can occur causing damage to axons throughout the brain. The delayed effects occur as a result of the swelling of the brain, putting greater pressure on various structures within the brain, as well as the metabolic reaction that takes place causing a cascade of chemical reactions in areas emanating out from the initial damage (Bigler, 2007; Leon-Villapalos & McLernon, 2012). Through this process, an area of the brain that is not initially damaged can have changes in functioning, which may, or may not, recover at a later stage.

To me it seems that the relational effects for whānau have similarities with the process occurring within the brain. While the person who is actually injured is usually, due to their decreased level of consciousness, unaware of their situation, those who are close to the injured person are typically in a state of very high distress as they receive the dreaded news of the injury. There is, literally, a significant chemical response happening in the brains of loved ones as a reaction to the injured person's situation. There are the acute effects of this situation as family gather and many are told to expect the worst, and there are also significant delayed effects as people grapple with rebuilding a relationship with a person who can be quite changed from the person they previously knew.

The following section considers first some of the biological effects of brain injury, in order to make sense of the neuropsychological effects, and then the impact of these on both the injured person and their whānau.

Damage to the brain

Our brain:body ratio is the largest of all the mammals and corresponds with the greater social connectivity that humans exhibit (Buzan, Kupfer, Eastridge, & Lema-Hincapie, 2014). Over time the human brain has developed with a greater volume, particularly in the frontal and parietal regions, compared with any other primates, and while our newborns have relatively large brains, given the size of human infant bodies, they also have a greater level of post-natal growth than any other primates (Neubauer & Hublin, 2012). The frontal regions allow for complex cognitive processing, including that needed for decision-making, social interactions and understanding others, and the parietal regions facilitate the integration of information from throughout the brain.

Our brain is packaged in three layers of protective tissue: the pia mater, the arachnoid and the dura mater, which cushion it against the inevitable bumps and bangs that can occur within the snugly fitting skull. The skull develops as our brain develops through childhood, so that the fit is perfect, although some shrinking of the brain as we age results in a looser fit, and therefore greater vulnerability of the brain as we age (Bigler, 2007). All of this works well for the human activities of running, jumping, dancing and even milder physical scuffles, but not so well for high-speed deceleration injuries that occur in a car crash, or the high impact of a serious assault to the head.

With a single mild injury, effects can be relatively transitory and most people experience full recovery within 3-12 months (Carroll et al., 2004). Severity of injury is measured by length of the initial period of confusion (post-traumatic amnesia; PTA) and degree of reduction in consciousness (generally measured by the Glasgow Coma Scale; GCS). Moderate to severe injuries are more likely to cause lasting effects and are the focus of this thesis. For Aotearoa New Zealand, the Accident Compensation Corporation (ACC) defines moderate to severe injuries (referred to as “serious brain injury” in this thesis) as injuries accompanied by PTA of more than

24 hours, or a noticeably reduced level of consciousness i.e. GCS score of 12 or less (New Zealand Guidelines Group, 2006).¹

While I have noted the adage that “if you’ve seen one brain injury, you’ve seen one brain injury”, this does not deny that there are common patterns of injury that are a result of the basic physics of how our brain is attached to our neck and located within our skull. If you can picture the inside of the skull you may be aware of the numerous bony protuberances, as well as the ridges that hold our brain in place. The physics of the sort of injury that occurs in a car crash means that the very front (anterior) of the brain (prefrontal cortex), and the lower (or basal) area of the frontal lobe, as well as the anterior and basal areas of the temporal lobe are particularly vulnerable (Bigler, 2007). This gives us the classic difficulties with memory, fatigue, awareness of behaviour, and other difficulties with executive functioning (Lezak, 1986). While there can also be physical difficulties due to injuries in other areas of the brain such as the motor cortex and the initial bruising that can occur in a coup-contrecoup injury causing damage to the cerebellum (located at the rear of the brain), families tend to report that it is shifts in mood and personality that cause the most distress (BurrIDGE, Williams, Yates, Harris, & Ward, 2007; Lezak, 1988; Norup & Mortensen, 2015; Yeates, Gracey, & McGrath, 2008).

Ongoing effects of brain injury

The following section will take you through the impact of brain injury from the time of injury through to the effects some years down the track, and look at the ways in which many people can be affected by the one injury.

In the very early stages after a serious brain injury, the focus is on getting the person medically stabilised. Their level of consciousness is usually measured using the Glasgow Coma Scale - which assesses the person’s eye opening, verbal and motor responses. What is being looked for is whether people can show these responses independently, with prompts (including pain), or not at all (Teasdale & Jennett, 1974). There may be complications which require

¹ GCS scores range between 15, for someone who exhibits full consciousness to 3, for someone who shows no conscious response.

surgeries to remove bone fragments or dead tissue, or to remove a section of the skull to allow for the brain to be able to swell without causing further neurological damage. At the same time, the person can have sustained other injuries with broken bones, chest, spinal or heart concerns. Their family is thrown into a potentially life-or-death scenario. Predicting outcome at this early stage is yearned for by families, and pressured for by funders, yet lacks great accuracy (Carter, Hutchinson, Kolas, & Menon, 2016; Kalanuria & Geocadin, 2013).

While the family is going through this highly stressful situation, the patient may be unaware and will never regain memories of the time when they were unconscious, or of the time of post-traumatic amnesia which follows. Family members initially deal with the nurses and doctors in the hospital. Later they will begin to deal with a range of organisations such as the Accident Compensation Corporation (ACC) if the injury was the result of an accident, or the Ministry of Health if not, the person's employer or school, and perhaps the Ministry of Social Development. There may also be Police involvement if the injury was due to a car crash or an assault. Depending on their level of familiarity and comfort with these institutions, they will likely experience different levels of stress. They may experience direct racism within the health system (Harris et al., 2006), or may question whether the system is designed by or for people like themselves.

Once the injured person is medically stable, they may return home, but those with higher rehabilitation needs may move to post-acute residential rehabilitation. Aotearoa New Zealand has centres of excellence for brain injury rehabilitation in four of the main centres (Auckland, Wellington, Christchurch and Dunedin). A family living at a distance of more than 40 kilometres from a centre, may be able to access support for their transport costs, if they know to request this support. In Auckland, the centre is located in Ranui, West Auckland, which is approximately 34 kilometres from the South Auckland hospital of Middlemore. Most of South Auckland is just within the 40 kilometre range which means that many whānau experience transport barriers in being able to support their family member. Family members are often under financial pressure at this stage. ACC's compensation for loss of earnings may not have

come through, and working partners or parents may have used up all of their own sick leave, or annual leave, supporting their injured family member in hospital.

Within the rehabilitation setting, the person will often go through the process of re-learning to walk, talk and eat while working with a team of physiotherapists, occupational therapists, speech language therapists and possibly social workers and psychologists. Current rehabilitation practice tends to be guided by goal-setting, where therapists work with the family, if the person is not yet conscious or able to make decisions for themselves, to find out what the injured person would want to achieve (Prescott, Fleming, & Doig, 2015). The purpose of this is to ensure that the process is client-centred, which is a shift for many from a more medical model, which can be seen as more therapist or service-centred. While the physical effects of injury can dominate the individual's and family's concerns in the early stages of recovery (Oddy, Humphrey, & Uttley, 1978), it is the neurobehavioural changes that tend to cause more lasting difficulties for both the injured person and their families (Ponsford & Schönberger, 2010).

The lived reality of brain injury – Post-acute stage

In the early post-acute stage following a serious brain injury, maintaining the person's medical stability is still the first priority, followed by their comfort and building their level of awareness. An injured person may shift from the hospital still needing support for breathing, with wounds that need specialist care and with risks, such as blood clots, through a lack of ability to move. Alternatively they could be fully mobile and able to converse, but completely unaware that they have been injured and are in need of significant oversight and support to maintain their safety. Families can be dealing with someone with high medical needs, cognitive needs and/or behavioural needs; a person with a broken leg or poor balance who needs assistance to get out of bed and to walk, but believes that they are completely able to do this on their own. As bystanders, we can only imagine the distress of this for the injured person as they find themselves in a strange place, with a stranger who insists on looking after them as they go to the toilet or have a shower. In some settings they may have been restrained in their bed to

prevent them from falling, or from striking staff or family members who are attempting to feed or clean them.

The rehabilitation setting can be a very foreign environment to anyone not used to dealing with medical and allied health systems. Cultural barriers can significantly impact the ability of whānau to engage with services, which can impact the rehabilitation outcomes (Durie, 2001) through misunderstandings and even people leaving the service earlier than recommended. Calls for greater numbers of Māori health workers within services to shift this relationship so that it is more positive for Māori whānau are common (e.g. New Zealand Guidelines Group, 2006). Financial barriers related to travel and time away from employment can impact whānau involvement. We would often see South Auckland families who had been highly involved when the injured person was in hospital locally, having little engagement with the more distant post-acute setting. Provision of affordable whānau accommodation can help to overcome this barrier, as can financial support for travel.

During the stage of post-traumatic amnesia, the injured person is unable to reliably make new memories. In the early stages, or in particularly severe injuries, they may not know who they are or who their family members are, let alone where they are or who the staff are who attempt to care for them. Their behaviour can also be disinhibited, which can result in a person behaving in a way that is different from their usual character. I have spoken with many distressed wives who have felt embarrassed or mistreated by a usually respectful husband's sexualised, racist or aggressive behaviour, and injured clients can be embarrassed or disbelieving, once they emerge from PTA, to learn of their earlier acts.

The majority of injured people emerge from this confusing time, but they have no memory of these significant events that have occurred in the lives of themselves and their families, and that have impacted on their relationships. The dynamics of relationships have been significantly altered (Bowen, Yeates, & Palmer, 2010). Adults may have been spoon fed and washed by their family members. A young adult who had been building independence, suddenly

needs physical support to walk and may not be judged to be making sound decisions, although she may fully believe that she is able to.

The injured person can be experiencing pain, headaches and alterations in sleep patterns as well as a level of fatigue that they have never encountered before. Much like a toddler, as they become fatigued their mood and ability to control their movements and behaviour can decline, but an adult being told to have a sleep can feel resentment at being treated like a child. In working with challenging behaviour, we know that managing both fatigue and the environment is effective (Willer & Corrigan, 1994). Workers become skilled in de-escalating behaviour and setting situations up at the right level of challenge so that the injured person can experience a manageable level of challenge and a high chance of success. Memory for information is improved, for example, through processes such as errorless learning, where people are supported to make the correct response with less and less assistance, rather than attempting to learn through trial and error when they are unable to actually recall their errors (Baddeley & Wilson, 1994). A family that does not have the skills and support to manage the many changes and is faced with aggression from an overtired adult, can back away from making demands, which can tend to reinforce the aggressive behaviour.

The person with the injury may not be aware that they have had a brain injury – seeing as it is the brain that helps us to understand our body and how we are operating in the world. They will, however, need to find a way to make sense of the situation. An electrician who is not yet aware of what day it is, or holding on to any new information for more than a minute, may explain to me that he is in the locked house in order to inspect the electricals, and a businessman may believe that he is there to offer advice on how to run the programme. Someone with a criminal or drug-using background will tend to associate the term “rehab” with drug and alcohol rehabilitation and demand their right to leave. Many will pack their bags whenever they are in “their” room, including removing any pictures that families have put up to make the place more familiar. Working with issues like this takes a level of skill and experience in knowing when to gently steer the person towards a correct understanding of their situation, and when to simply

change topic, in order to not give incorrect information, but also to not provoke conflict. Families interpret behaviour based on their own experiences of the person as well as their experience of the rehabilitation setting. For anyone who is not of the dominant, Pākehā culture, there will likely be situations where they feel a cultural clash.

During the early stages of post-acute rehabilitation, recovery is rapid with noticeable shifts occurring daily or weekly. While families can be stressed at the medium and long-term prospects, generally optimism and hope are high. Therapists may be aware that the longer-term journey is likely to be very difficult, but there is a balance to strike in terms of maintaining hope and helping the family to plan for the future. Changes in behaviour that are apparent to therapists, such as disinhibition, may be seen by the client and the family to either be normal e.g. “he would always joke around”, or due to the situation of being in residential rehabilitation, with the family believing that everything will return to normal when they get home. We know through research that higher levels of hope correlate with high engagement in rehabilitation, but also with greater disappointment at the one year stage (Riley, Hough, Meader, & Brennan, 2015).

Transitions of any sort can be stressful. In brain injury there are major transitions between hospital to rehabilitation, and later between the rehabilitation setting to home which can have a strong impact on families (Piccenna, Lannin, Gruen, Pattuwage, & Bragge, 2016; Turner et al., 2010). In the setting in which I worked, a major effort was made to smooth the transition from hospital to rehabilitation. The family/whānau would have most likely met an acute rehabilitation coordinator (now called a Brain Injury Nursing Specialist), whose role it was to smooth the transition, and the rehabilitation team would have often been aware of the injured person’s progress within the hospital and have a reasonable idea of some of the key issues for the person and their family before their arrival. The transition from rehabilitation to the community does not have the same consistent level of coordinated and skilled support. While we know that the early stages of rehabilitation are extremely important to the overall

rehabilitation outcomes, it is the community stage that really counts, as this is where people return to rebuild their lives and even their identities.

The transition from residential rehabilitation can be one of great challenge (Piccenna et al., 2016; Turner et al., 2010). Most injured people will return to their home, but for some there will be a move to residential care if the person is not seen as being able to manage with the level of supervision and support that can be provided in their home setting. This decision may be against the wishes of the person with the injury and does not always reflect the hopes of the family either. In many families there will be disagreements as to how, and by whom, the injured person should be supported. For those who do return home there can be stresses for them and their families in understanding the systems that they now need to engage with and in having the right level and quality of support in the home and the community.

Long-term issues

Over time things will start to stabilise and people seek to return to previous roles or develop new ones. It used to be considered that meaningful recovery would only occur in the first two years (Gronwall, Wrightson, & Waddell, 1990), but it is now better understood that cells are continuing to replace themselves, through a process known as “neuroplasticity” and that ongoing recovery is possible with the right support and stimulation (Berlucchi, 2011; Khan, Amatya, Galea, Gonzenbach, & Kesselring, 2016). While improvement in functioning is important, so is the process of grieving, acceptance and rebuilding of identity (Cloute, Mitchell, & Yates, 2008; Ownsworth & Haslam, 2016; Ylvisaker & Feeney, 2000). By this stage the effects of the injury may not be immediately apparent to people in more distant relationship with the injured person, but may be becoming increasingly apparent to the individual and their whānau. This is why brain injury is often described as an ‘invisible injury’ (National Council on Disability, 2011).

Losses and identity

"He is no longer the man she married. She misses him so much even though he is alive in front of her." (Steward, 2011)

For those who move through the period of confusion and the inability to create new memories, what they are now faced with is the reality of their losses. For the first six months this will include not being permitted to drive, which has obvious effects on independence, but also can be just one of many losses that chip away at a sense of identity (Liddle et al., 2012). When we think of how we understand ourselves, it is very much entwined with our roles, our abilities and our relationships, as well as with our history and our memories. For the person with the injury all of this is changed, but with their reduced awareness, it can be extremely confusing for them to understand who or what has changed. It can seem that it is everyone else who has changed. They may perceive themselves to have the same skills and personality as before the injury and be at a loss to understand why others are limiting them in important areas of independence, such as driving, cooking and looking after their children. While increasing awareness of limitations is a sign of progress, it is often, unsurprisingly, accompanied by depression as the person begins to understand the reality of their losses and changed functioning.

The loss for family members is also difficult to process. There may be enormous relief that the person has lived, followed by enormous fear and anxiety about who they have actually become, and who they will be. Guilt gets mixed in as people feel that it is not a situation where grief is allowed, since the injured person is actually still alive. This is often referred to as 'ambiguous loss' (Kreutzer et al., 2016) and is compounded by the fact that the loss goes on forever. The person with the injury and their family can re-experience grief and loss as they watch friends achieve milestones, such as completing studies, finding competitive employment or having children, that the injured person may no longer be able to achieve, or may achieve very differently to how they would have if the injury had not occurred (Bruce & Schultz, 2002). A particular worry for the parents of a previously independent injured adult, who may now need life-long support, is what will happen when the parent is no longer able to be that support (Knox, Douglas, & Bigby, 2016).

The challenge in the longer term is often described as rebuilding a new identity which involves grieving for what has been lost, and working with the current abilities to establish new

roles and goals, and build (or rebuild) relationships (Bowen et al., 2010; Gracey, Evans, & Malley, 2009; Yeates et al., 2008; Ylvisaker & Feeney, 2000). The ability to return to previous work roles can be compromised not only by cognitive decline, such as reduced memory and slowed processing speed, but more importantly by reduced abilities with social communication (Douglas, Bracy, & Snow, 2016). Following injury, many men can find themselves moving from the role of the primary earner to taking on more domestic and caring roles, which involves rebuilding their identities in order to value these roles (J. A. Jones & Curtin, 2011). The non-injured partner can find their role shifting from a partnering role to one that is more akin to parenting, which impacts on both partners and the relationship (Braine, 2011).²

Changes in personality and behaviour

With the combination of headaches, fatigue, reduced memory, chronic pain and the increased risks of seizures, diabetes, incontinence and other difficulties (Murphy & Carmine, 2012), it is not surprising that emotional functioning can be challenging for the person with the injury. Changes in personality that can be characterised by reduced awareness and insight (Prigatano & Johnson, 2003), and difficulty in understanding the emotions of others (C. Williams & Wood, 2013), as well as increased disinhibition, self-centredness and apathy (Lane-Brown & Tate, 2009), naturally also take their toll on close relationships (Blais & Boisvert, 2007; Bowen et al., 2010; Burrige et al., 2007; Kreutzer, Marwitz, Hsu, Williams, & Riddick, 2007; Lane-Brown & Tate, 2009; C. Williams & Wood, 2013).

While challenging behaviour frequently occurs in the early stages of confusion after injury, it remains worryingly common into the chronic phase (Wood & Thomas, 2013), and is strongly predictive of the family and caregivers suffering their own distress (Anderson et al., 2013; Sander, Maestas, Clark, & Havins, 2013). Families dealing with challenging behaviour have higher rates of separation and experience high emotional turmoil, including deep feelings of loss

² I'm aware that the family experiences I'm writing of are somewhat heterosexist, but while I've occasionally worked with gay couples I haven't come across any research on brain injury and gay couples. I am not aware of any of the participants, or any of their injured family members identifying as gay. There was one transgender woman who attended the wānanga as a whānau support person.

and loneliness and worries for the future of the family and the person with acquired brain injury (ABI)³ (Braine, 2011). In dealing with aggression, people worry for both the person with the injury and for other family members, and remain vigilant for situations which could cause an outburst in order to avoid difficulties (Tam, McKay, Sloan, & Ponsford, 2015). Working with challenging behaviour requires knowledge, consistency and the ability to maintain your own well-being (Fisher, Lennon, Bellon, & Lawn, 2015), which is extraordinarily difficult to achieve and may account for higher rates of separation, especially in younger families (Kreutzer et al., 2007).

We know that brain injury can affect mood. In particular, people with brain injury are at high risk of depression (Rapoport, 2012), as are their carers (Douglas & Spellacy, 2000). Over the longer-term we are aware that emotional functioning of families tends to decline, with well-being at five years found to be lower than at two years (Ponsford & Schönberger, 2010). Isolation is a very common outcome, both for the injured person and for the family. The injured person may be reluctant to be in social situations due to difficulties such as sensitivity to light and noise, as well as the cognitive overload that can occur when trying to manage a conversation within a group setting. Friends may also withdraw due to the changed behaviour of the person (Charles, Butera-Prinzi, & Perlesz, 2007; Gill, Sander, Robins, Mazzei, & Stuchen, 2011), especially if this involves inappropriate or disinhibited behaviour.

Effects on couples

In the situation of a partner (or spouse) of a person with significant TBI, the partner has often lost their primary emotional support and the relationship can shift from its previous balance to one in which the non-injured partner assumes more of a caregiver role and takes greater responsibility for decision-making (Knox, Douglas, & Bigby, 2015). After a moderate to severe brain injury, interpersonal communication difficulties are often present within the couple relationship (Bracy & Douglas, 2005). Research suggests that it can be helpful for partners to

³ Acquired brain injury refers to any brain injury acquired after birth and includes traumatic and non-traumatic injury which can occur from medical conditions such as cardiovascular events, disease and tumours.

adopt particular personal characteristics such as coping flexibility and an effective attitude, rather than using avoidance, in order to enhance the stability of the marriage (Blais & Boisvert, 2007; Katz, Kravetz, & Grynbaum, 2005) and the independence of the injured person (Van Baalen et al., 2007). Sexual functioning and the intimate relationship is also impacted for many (Gill, Sander, Robins, Mazzei, & Stuchen, 2011; Sander, 2013; Sander et al., 2016), although this is an area that clinicians often fail to discuss with clients or their partners (Moreno, Arango Lasprilla, Gan, & McKerral, 2013).

There is rather conflicting information on marital stability following TBI, but this may in part be due to some research looking at the full range of TBIs (mild, moderate and severe) and not finding high rates of relationship breakdown (Kreutzer et al., 2007), compared with other research finding high rates of relationship breakdown following severe TBI (Tyerman & Booth, 2001). The impact of the injury can depend on numerous factors including the age of the couple (Layman, Dijkers, & Ashman, 2005) and the level of insight of the injured person (Burrige et al., 2007). Impaired interpersonal skills are often linked to poor emotion-recognition skills and treatment is now being explored in this area (Radice-Neumann, Zupan, Babbage, & Willer, 2007). From work researching the effects on families it would also seem that the stage of rehabilitation has a big impact on the needs of family members (Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007). These changing needs mean that the supports that are needed also change.

Children

Children of adults with brain injury can go through a particularly challenging time. They can be dealing with the injured person's difficult behaviours, the distress of the uninjured parent, as well as extra jobs and responsibilities as the family system adjusts. Alongside this they can be grieving for the parent they once knew, even though the parent is still alive (Kieffer-Kristensen, Teasdale, & Bilenberg, 2011; Tiar & Dumas, 2015). What is lost can feel confusing and be linked with guilt as others talk of how well the injured person is doing, how lucky they are that they survived, and the need for the child to support the adult (Kieffer-Kristensen & Johansen, 2013). The quality of parenting they receive from both parents is negatively impacted. Research shows

that children receive less positive parenting from both the injured and uninjured parents who demonstrate less love and acceptance, give less praise, have less involvement and interest, and also have less fun with their children (Tiar & Dumas, 2015). A comprehensive Finnish study found that children of parents with brain injury used mental health services at a higher rate than the rest of their cohort (Niemelä et al., 2014).

It has been my concern that in neglecting to support families as whole families, there are many risks for the children and adolescents of adults with brain injury. The savings that may be made by ACC or MoH in the short term could well be borne by justice, health and welfare as the parent's injury impacts the young person's emotional development, peer relationships and educational achievement, leading on to further difficulties as adults. Given that we already know that Māori and other minority ethnic groups, as well as lower socioeconomic groups, are both disproportionately more likely to be injured (Feigin, Barker-Collo, Krishnamurthi, Theadom, & Starkey, 2010; Feigin et al., 2013), have poorer long-term outcomes (Gary, Arango-Lasprilla, & Stevens, 2009) and that mainstream services are less likely to deliver health services effectively, if at all, for these groups (Cameron, 2004; Harris et al., 2006; Harwood, 2010; Signal et al., 2007), inequitable outcomes become sadly inevitable.

Assessments and cultural bias

Assessments of the person with the injury guides much of the rehabilitation process. The assessments we use, however, have strong cultural biases, as they are largely developed by and for US and UK populations (Ogden, 2001). Independence is highly valued, as is demonstrated even in the name of a major tool, the Functional Independence Measure, by which many rehabilitation centres and their clients are measured (F. C. Wilson, Wheatley-Smith, & Downes, 2009). The suitability of a focus on independence, rather than interdependence, is questionable when working with cultures that have less of an individual focus (Judd, 2003).

The neuropsychological assessment can have a strong influence on the level of support that will be given and on how much the individual's difficulties are seen to be the result of brain injury rather than a reflection of pre-existing issues. Both the results and the experience of

assessment can be inappropriate for Māori (Dudley, Wilson, & Barker-Collo, 2014). The conclusions drawn from such assessments have the potential to be harmful for Māori clients and whānau. There is a strong risk of underestimating previous functioning for Māori (Ogden, 2001), which has the potential to impact both the compensation and the rehabilitation that the individual is entitled to.

Research notes that even within countries with strong public health systems and high availability of rehabilitation, families report high levels of caregiver burden and unmet family needs in the chronic phase after brain injury (Doser & Norup, 2014, 2016). Families and injured individuals who are more likely to cope well tend to have a background of higher education, socio-economic status, pre-morbid intelligence, workforce participation and family functioning, as well as being from majority cultural backgrounds (Ponsford, 2013). Research on predictors of emotional distress note links between the severity of injury, impairment in executive functioning, the amount of support needed and the ability of the injured person to participate (Sander et al., 2013).

At the more extreme ends of the chronic outcomes of ABI, the risks of homelessness (Topolovec-Vranic et al., 2012) and of suicide (Bahraini, Simpson, Brenner, Hoffberg, & Schneider, 2013) are also higher than for the general population, and these need to be managed with a particular combination of skills and resources which are often difficult to access. A person with substance abuse difficulties, for example, is less likely to be able to access support services if they have a brain injury (West, 2011). People with brain injury also make up a high proportion of the incarcerated population (W. H. Williams et al., 2010).

Brain injury rehabilitation

How rehabilitation is delivered in Aotearoa is affected by the dominant models of disability and the directives of ACC. In the fifteen years that I have worked in this field, I have seen a deliberate intention to shift away from a medically dominated model to a more client-centred one, which is often termed *person-centred* (Prescott et al., 2015). The very naming of this shift shows its

individualistic focus, which can be a poor fit for many Māori, who are more likely to operate from a more collective or family-centred worldview, and services give varying levels of attention, funding and staffing to deliver rehabilitation which is culturally appropriate for Māori clients. Within rehabilitation guides, the ability to work effectively with Māori seems to be perennially lamented and, one would hope, incrementally improved as the small number of Māori clinicians and researchers gradually increases. I have also seen swings in the emphasis and cover provided by ACC. The following sections will look first at rehabilitation models, including Māori models and then at the role and influence of ACC.

Models of disability

Internationally, the dominant models in the area of disability are medical, social and biopsychosocial (Mitra, 2006). Within Aotearoa it is also important to understand Māori views of wellness and of disability, which have links to indigenous models internationally.

Under the medical model, disability was historically viewed as a deficit, understood solely in terms of the body of the person. Rehabilitation was focused on rebuilding the reduced function in the individual, which could involve relearning to walk unaided, or the use of a prosthetic limb. A person with reduced mobility in their arm would be prescribed exercises to improve this function. Challenges to this model came in the form of the social model of disability, which looked at the impact of society on the ability of a person with a disability to function in their community. Barriers to participation were seen as the problem, rather than the focus being purely on the person's body (Oliver, 2013). In order for people to be able to live their lives well, they needed an accessible and supportive environment which did not impede their participation (Burchardt, 2004).

The dominant model, at present, is the biopsychosocial model which looks at the interaction between an individual's biological and psychological functioning alongside the social factors which are present in the environment. The World Health Organization's International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) draws from the biopsychosocial model, although it should be noted that the ICF is a classificatory

system rather than a model. The ICF was developed with the goal of standardising classifications of disability in order to facilitate both research and policy development. While it is argued that it categorises largely according to a medical view of functioning, such as breathing, digestion, mobility and reproduction, it does take into consideration the impacts of the social and environmental world of the person with the disability; albeit from the perspective of a standard environment. However, it fails to take into account the individual's values, preferences and aspirations (Trani, Bakhshi, Bellanca, Biggeri, & Marchetta, 2011). Some other limitations that have been raised are the enormous detail of the system, which can make it unwieldy for clinicians (Tate & Perdices, 2008), although this has been improved with the development of a core set of classifications for TBI (Laxe et al., 2013), and the critique that it does not pay sufficient attention to relationships and families (Bowen et al., 2010). The extreme level of categorisation fits with Durie's explanation of Western thinking as being analytic and dissecting, in contrast with a Māori worldview which he considers to be more integrative and holistic (Durie, 1985).

Some recent writings on the ICF have approached it from the perspective of the Capability Approach (CA). With its roots in welfare economics, CA views disability from a non-medical lens. From a CA perspective, disability is understood in terms of the gap between an individual's aspirations – what they wish to do and be in terms of living a life they have reason to value – and how they are *in reality* able to live their life. This application of the broader framework of CA considers the personal, social and environmental factors (known as conversion factors) that are present in each of our lives and impact on the way in which we live our lives (Robeyns, 2005). Disability, or capability deprivation, as a result of injury or illness, sits alongside the limitations that an individual can experience as a result of poverty, low education or gender discrimination (Mitra, 2006).

While ICF has some compatibility with CA, a number of writers have noted the ICF pays inadequate attention to the resources available to the individual as well as the individual's values or intentions in terms of how they wish to live their life (Mitra, 2006; Reindal, 2009; Siegert & Ward, 2010; Trani et al., 2011). These writers argue that the CA offers new

conceptualisations of disability and rehabilitation by bringing a way of considering diversity and the reality of people's lived lives into the conversation. This conceptualisation fits with writings examining disability and identity amongst Māori (Henare, Puckey, & Nicholson, 2011; S. J. Hickey, 2008). CA will be revisited in greater detail in the "Philosophy" chapter of this thesis.

The intentions of models, and the uses that they are put to can, however, be two different things. Social welfare reforms within the UK, for example, have ostensibly been based on the biopsychosocial model, but disability activists and academics argue that in times of financial challenge different emphases have been used to advance different causes. Tom Shakespeare and colleagues (Shakespeare, Watson, & Algaib, 2016) note the increased focus on the psychological components of disability has been used to pressure people out of their entitlements for conditions such as low back pain. The difficulties are argued to be psychological, which is seen as being less real than medical (biologically based) limitations. Rather than the environmental, or social, aspects of their difficulties being addressed (surely the intention of a bio-psycho-social model), they are simply forced back into the situations which resulted in the limitations in the first place (Shakespeare et al., 2016).

Māori models of well-being

There are a number of Māori models of well-being such as Te Whare Tapa Wha, Te Wheke and Ngā Pou Mana. A common thread through these models is that whānau, hapū and iwi are considered central to Māori well-being (S. J. Hickey, 2008) and a holistic worldview is apparent in each of the models (Durie, 2001). In Te Whare Tapa Wha, knowledge is defined by kaumatua (elders) and health is consistently framed by four interdependent cornerstones: "te taha wairua (a spiritual dimension), te taha hinengaro (a psychic dimension), te taha tinana (a bodily dimension), te taha whānau (a family dimension)" (Durie, 1985, p. 483). In outlining this worldview, Durie noted the contrast between Māori and Western world views (Durie, 1985).

Sir Mason Durie argues that in order to understand an issue via the Western scientific method, it is dissected into smaller and smaller parts to be analysed. Whereas a Māori method for gaining understanding is described as holistic and integrative, as the enquirer moves

outwards from the presenting issue to broader realms in order to increase understanding (Durie, 1985). To understand a brain injury, a neuroscientist, might consider the locations and extent of tissue damage (a pure focus on te taha tinana), or perhaps also consider cognitive and emotional functioning (tapping into te taha hinengaro) but without a more holistic framework, the realms of wairua, and whānau could well be overlooked. From a Māori perspective, it would make little sense in the context of this project to seek to improve the well-being of an individual with a brain injury without considering the well-being of the whānau. This would almost be akin to trying to grow a single healthy plant without considering the soil or the other plants, insects, air quality and water surrounding it.

Durie has also connected the importance of a holistic view to how we might address health inequities (2001). He argues that deprivations of health are rarely the result of a single cause, but tend rather to come from a range of causes both past and present. He notes further that “threats come from many quarters, often traceable to the process of colonisation and its almost universal accompaniments: depopulation, violence, dislocation, poverty, and cultural repression” (Durie, 2011, p. 35). More recently, the importance of relationships (whanaungatanga) has been confirmed to be more important to Māori than to other groups in New Zealand via a detailed survey (Te Kupenga) of life satisfaction for 5,549 Māori in 2013 (Statistics New Zealand, 2015). This survey also showed that Māori living with children were more likely to show increased life satisfaction, which contrasts with other population groups. My concern is that the largely individualistic focus of most rehabilitation delivery is particularly inappropriate for people with a whānau-centred way of being.

Hinemoa Elder challenged the central position of rehabilitation thinking relative to the marginalised position of indigenous knowledge (Elder, 2015). She has drawn on the knowledge of kaumatua and kuia (elders) as well as whānau to develop a model that prioritises understanding of the significant wairua component of brain injury (given that the head is tapu, or sacred), and sees whānau knowledge sitting alongside medical and rehabilitation knowledge (Elder, 2017). Rather than training whānau to be more like rehabilitation practitioners, the two

sets of knowledge and practice instead balance each other out and contribute equally towards the well-being of the person with brain injury. While this elegant and practical model has been developed by Māori for Māori, I would anticipate that its use would be embraced by many families who can feel somewhat swamped by the medical and rehabilitation systems, and also want their family knowledge to be valued, and the family impact to be understood.

The Aotearoa environment: ACC, inequalities and structural discrimination

ACC provides universal, no-fault, comprehensive compensation and rehabilitation cover for injuries that occur as the result of an accident to any individual in Aotearoa. In order to understand the impact of ACC's relationship with families of people with serious brain injury (referred to through this thesis as whānau with ABI) it is useful to take a look at its history, principles, and the political issues that have surrounded it, and those that dominated at the commencement of this project.

Accident Compensation Corporation (ACC) history

The history of ACC reflects the changes in dominant political ideologies over its 50 years of development and operation. The Royal Commission on Compensation for Personal Injury in New Zealand was set up in 1966 to consider worker's compensation. Sir Owen Woodhouse chaired the commission and wrote the final report (New Zealand Royal Commission of Inquiry into Compensation for Personal Injury, 1967), generally known as The Woodhouse Report. This report outlined, in beautifully simple language, the problem of workers' compensation and, going well beyond the commission's terms of reference, mapped out the principles and design for an Accident Compensation Commission.

Sir Owen viewed serious injury as an inevitable and unfortunate product of modern society; the consequences of which he thought should be shared by society as a whole:

“The toll of personal injury is one of the disastrous incidents of social progress and the statistically inevitable victims are entitled to receive a co-ordinated response from the nation as a whole” (New Zealand Royal Commission of Inquiry into Compensation for Personal Injury, 1967, p. 19).

He was appalled by what he described as “the forensic lottery” of compensation being delivered by Common Law. Sir Owen noted that for an award of compensation to be made, there needed to be a single party that could be found to be at fault. He described the need to apportion blame to a single defendant as ill-suited to the reality of industrial accidents, which were typically the result of a number of errors (both human and systems). This common law process worked in the favour of the defendant (for whom it could often be successfully argued that they were not solely at fault) and against the injured worker.

Instead, the commission recommended that a scheme of universal, no-fault cover be available to all. The principles (often referred to as The Woodhouse Principles) that were to guide this service are:

Community responsibility: In the national interest, and as a matter of national obligation, the community must protect all citizens (including the self-employed) and the housewives who sustain them from the burden of sudden individual losses when their ability to contribute to the general welfare by their work has been interrupted by physical incapacity;

Comprehensive entitlement: All injured persons should receive compensation from any community financed scheme on the same uniform method of assessment, regardless of the causes which gave rise to their injuries;

Complete rehabilitation: The scheme must be deliberately organised to urge forward the physical and vocational recovery of these citizens, while at the same time providing a real measure of money compensation for their losses;

Real compensation: Real compensation demands for the whole period of incapacity the provision of income-related benefits for lost income and recognition of the plain fact that any permanent bodily impairment is a loss in itself regardless of its effect on earning capacity; and

Administrative efficiency: The achievement of the system will be eroded to the extent that its benefits are delayed, or are inconsistently assessed, or the system itself is administered by methods that are economically wasteful (New Zealand Royal Commission of Inquiry into Compensation for Personal Injury, 1967, p. 39, para 55)

Sir Owen noted that society as a whole benefitted from the production of the worker, and also stood to gain from the worker being returned, as quickly as possible, to their previous productive capacity. The Woodhouse principles have largely guided the ACC throughout its duration, though the level of attention has varied according to the political inclination of the time (see Accident Compensation Corporation, 2010b; Pricewaterhouse Coopers, 2008). While Community Responsibility has been seen as the central philosophical principle (Palmer, 2004), Administrative Efficiency was also crucial in terms of its enactment. The scheme required no extra money, as there was significant expense in the previous litigation-heavy process that was now able to be diverted to rehabilitation and compensation (Palmer, 2013).

Political football

Over time, ACC has been somewhat of a political football. National-led governments have tended to view it from a commercial insurance lens, and Labour-led governments as one of social insurance. National would often focus on reducing the costs to employers and introducing alternate insurance options, with Labour at times expanding what is covered. As Sir Geoffrey Palmer has noted these are two very different things. On the one hand the “Woodhouse scheme is about the social goals and social purposes of a compassionate society” (Palmer, 2013, p. 80), while the commercial insurance model is based on the efficiency of competition which he describes as “a triumph of optimism about private enterprise over very poor New Zealand experience in this field” (Palmer, 2013, p. 80)

Support for self-inflicted injuries, for example, used to come under health funding, then ACC, and now there seems to be a split across the two, with physical rehabilitation being funded by ACC, and psychological support supposedly covered by the public mental health system.⁴

Prior to this research commencing there was a shift for ACC’s funding base to move from a pay-as-you-go model to one of full funding. In the first option, the levies that were collected in a year needed to cover the costs incurred in that year, but in the full-funding option, ACC

⁴ The current range of services that ACC state are covered can be found at <http://www.acc.co.nz/making-a-claim/what-support-can-i-get/index.htm> accessed on 9 May, 2017

needed to have sufficient funds to cover the life-time costs of each claim (Palmer, 2013). Sir Owen Woodhouse described this move as “uncaring and predatory”. He made the analogy to family finances: “If you have children you'd be concerned if you found that they estimate your child will be at school for so long, will or won't go to university and will cost so much, and that that full cost has to be paid at the age of 5 when they start school”, to explain what he saw as its absurdity (Collins, 2009). This shift in accounting led to the determination that ACC was financially unsound (Accident Compensation Corporation, 2010a), and coincided with a much higher proportion of people’s claims being disentitled (Theunissen, 2012).

Disentitlement

Coinciding with the goal to achieve balanced books under these new standards there was a notable shift in what was defined as injury. Older people’s injuries were increasingly determined to be the result of degeneration or ‘wear and tear’, rather than due to the accidents that had occurred. In terms of brain injuries, clinicians were being asked to determine the proportion of people’s difficulties that were due to injury rather than pre-existing difficulties, and people whose claims had previously been accepted by ACC found themselves suddenly disentitled.

Claimants and NGOs became wary of referrals to particular specialists who derived significant income from ACC assessments and were seen as being more likely to determine that a person’s difficulties were not due to injury, and therefore not compensable under ACC. For those with adequate means, it could be possible to get a second opinion if they could find a clinician willing to do this work. But for less resourced families, disentitlement would largely prove to be a decision that they were unable to challenge. The Woodhouse principle of Administrative Efficiency, was being eroded through these processes, and the intention to remove the cost of litigation, was clearly threatened by these processes (Duncan, 2008).

ACC's support for families

Throughout the shifts, the focus and funding has been on and for the individual with the actual physical injury⁵. At the time of the inception of ACC, brain injury rehabilitation knowledge was in its infancy, as far fewer people survived the serious injuries. Brain injury has, as noted earlier, been understood as a family injury for decades now, and ACC rhetoric, in the form of its guidelines (New Zealand Guidelines Group, 2006), acknowledges the family, but the funding for family support has, in my experience, not been consistently available.

While my understanding was that ACC would only fund supports for the individual, there was the possibility for couples therapy, on the general proviso that the injured person must be present for treatment. This is not something that would be advisable in the situation where, for example, the uninjured partner is experiencing violence from the injured partner. Anecdotally I would hear of case managers who would tell therapists to simply do what worked – a sort of ‘don’t ask, don’t tell’ policy, which would require vague or slightly fudged reporting between the clinician and the case manager – but the effect of this is that supports are inconsistently available. When I complained to colleagues within ACC that families were not able to access support, I was often told that ACC did a lot to support families. This didn’t fit with the experiences that I would hear related, of families being denied support for family members. I assumed that how you asked, who it was that did the asking, or who supported you in your asking, made a difference as to who was able to access ACC support in actuality⁶.

While the bulk of people dealing with brain injury will have compensation and rehabilitation via ACC, some will be covered by the Ministry of Health (MoH) instead. In the case

⁵ I first became aware of this in dealing with the situation of the post-traumatic stress symptoms being suffered by a family member who had been present, but not physically injured within the car crash that left another family member with a brain injury. Despite the person suffering these symptoms as the result of an accident – the fact that their symptoms were a result of witnessing the injury to another, rather than themselves, made them ineligible for support.

⁶ During the time of this project support under ACC’s Psychological Services contract, which was established to support survivors of sexual abuse, was made available to families to be able to receive counselling to support them in managing the changes that have occurred in their family member. This information was not initially widely known amongst ACC case managers, or Brain Injury Association Liaison Officers, but it is now being offered to family members on a more regular basis.

of a traumatic brain injury, this can occur when the injury is sustained while the person has been out of the country for more than 6 months. Other people who find themselves in this category have acquired brain injuries as the result of medical issues such as strokes, tumours or illness (e.g. encephalitis and meningitis). The level of support that is available via MoH is markedly lower in terms of rehabilitation, where the person is reliant on whatever health services are provided by their local public services, and there is no financial compensation beyond what can be accessed via Work and Income (WINZ).

Solutions: What can be done to improve the lives of family/whānau?

Given that we know that brain injury impacts whole families, rather than just individuals, and that the funding of service delivery has been focused on individual treatments, my next questions were:

- What would work?
- Are the solutions economically viable?
- How can we get them implemented?

What would work?

Supporting the family/whānau of people with serious TBI is beneficial for the injured person (Verhaeghe, Defloor, & Grypdonck, 2004) and can also benefit the family (Kreutzer, Marwitz, Sima, & Godwin, 2015; Straits-Troster et al., 2013). TBI guidelines typically emphasise the importance of rehabilitation being based on the goals of the individual and their family, and that family support is an integral part of rehabilitation (Luauté et al., 2016; New Zealand Guidelines Group, 2006; Royal College of Physicians and British Society of Rehabilitation Medicine, 2003). Family information and support is a strong feature of these guidelines and strong family functioning is acknowledged as improving outcomes (Perlesz, Kinsella, & Crowe, 1999).

As has been outlined earlier, changes in psychological and interpersonal functioning after injury tend to have the greatest long-term effect. Improvements in these areas of relational functioning rely on the people close to the injured person learning effective ways of responding to inappropriate behaviour as well as supporting the individual to regain healthy

psychological functioning. This often requires the development of new skills, and a level of energy and well-being in the family members for them to be able to deliver effective support. Holistic neuropsychological rehabilitation models, which require family involvement, are well-established and well-researched (Ben-Yishay, 1996; B. A. Wilson, 2011; B. A. Wilson, Gracey, Malley, Bateman, & Evans, 2009). Relational rehabilitation is a newer model which focuses on the effect of the injury occurring in the relationships between people (Bowen et al., 2010). Both of these models show promise in helping all those affected by the injury to move closer to leading flourishing lives, yet ACC funding parameters, with the focus on providing treatment only to the injured person, have made these forms of rehabilitation extremely difficult to offer.

Multi-family groups have been found to be effective in helping people to connect with others, increase their knowledge and re-establish a sense of themselves as individuals and as families (Couchman, McMahon, Kelly, & Ponsford, 2014). Peer mentoring both for people with recent, serious TBI and their significant others has been shown to be beneficial particularly for people with TBI (Hanks, Rapport, Wertheimer, & Koviak, 2012). The results were a little less positive for family members, where it was thought that the experience of the mentor, who was further down a path that tends to become more difficult, may have negatively impacted on the optimism of the mentee family member. This outcome fits with Sander's call for assessments of family needs to occur over a longer-time frame and for it to be recognised that family needs do not finish simply because the more intensive phase of rehabilitation has finished for the injured person (Sander et al., 2013).

Within developing countries, work has also been done in training lay volunteers as supports for people with brain injury, which has been offered for people dealing with emotional and behavioural problems (Judd, 2003). Work with people with aphasia (communication difficulties) has shown that it is more effective to train not only the person with the injury, but also the people that they communicate with most often, i.e. their communication partners (Simmons-Mackie, Raymer, & Cherney, 2016).

Economics of rehabilitation

From an economic point of view, holistic neuropsychological and neurobehavioural rehabilitation programmes do require intensive resources in the short-term, but this form of spending money to save money has been shown to be cost-effective over the long-term (Feeney, Ylvisaker, Rosen, & Greene, 2001; Wood, McCrea, Wood, & Merriman, 1999). Many of the savings made are in the area of societal costs (Faul et al., 2007) which are valued differently depending on whether the dominant insurance model for ACC is social or commercial (St John, 2010). When ACC operates as a social insurer, savings made in the area of social costs can be seen as a benefit to all of society and are therefore a valid outcome; whereas under a commercial insurance model, the cost-benefits relate more narrowly to the costs and benefits to ACC alone, and the impacts on wider society tend not to be part of the analysis. Making a successful argument for change, therefore, is highly dependent on which political/economic ideology is prevailing at the time of the argument.

Human rights: Family entitlements to be able to live reasonable lives

An argument for change based on the human rights of family members can provide powerful leverage for change. This has recently been highlighted in the case of the rights of disabled adults and their family carers in *Ministry of Health v Atkinson (2012)*⁷. While this case was largely won on the grounds that families and disabled people experienced discrimination; an aspect of the decision is relevant to families of adults with serious brain injury. The High Court commented that the current government policy did not reflect the intentions of the United Nations Convention on the Rights of Persons with Disabilities in that persons with disabilities and family members should receive the necessary “protection and assistance” to enable families to contribute to the full and actual enjoyment of the rights of persons with disabilities” (United Nations, 2006, Preamble (x)).

⁷ Ministry of Health V Peter Atkinson (on behalf of the estate of Susan Atkinson) (2012) NZCA 184

Following a serious brain injury there is significant suffering that occurs for many people. This invisible collateral damage can be viewed as “third-party disability” (World Health Organization, 2001, p. 251) as family members are effectively disabled by the health condition of another person. This concept has been explored in the situation of spouses of people with aphasia (Scarinci, Worrall, & Hickson, 2009). If the view is taken that family members themselves experience disability, then rights under the United Nations Convention on the Rights of Persons with Disabilities could be argued to be relevant to the family members. Even without the concept of third-party disability, however, Article 16 (3) of the United Nations Declaration of Human Rights states that: “The family is the natural and fundamental group unit of society and is entitled to protection by society and the State,” thereby providing a level of protection to each and every family.

Within Aotearoa, the needs of family members are noted in the New Zealand Disability Strategy (NZDS) with Objective 15 being to: “Value families, whānau and people providing ongoing support” (Minister for Disability Issues, 2001). From the annual progress reports of government departments on this Strategy, it would seem that the bulk of progress cited in this area has been the development of the Carers’ Strategy (Ministry for Social Development, 2008). While this is clearly very necessary work, especially given that unpaid carers in private homes have fewer rights than the rest of the population due to being excepted from employment protections in the Human Rights Act (Waring, 2010a), it only covers one aspect of family/whānau roles and could be perceived to neglect other relational and emotional roles of partners and whānau.

These protections of the family by conventions and declarations can contrast with the reality of family lives, which are unnecessarily fractured and distressed by laws and practices based on the individual, and neglecting of the family and whānau. The rights-based approach is supported by the conceptual framework of the Capability Approach, which brings together an understanding of human rights and ethics when measuring activities that are perceived to be of value.

While the rehabilitation, economic and human rights arguments each have significant merit, it would seem that decades of information from the rehabilitation argument has not led to actual changes in rehabilitation service delivery, and that the economic argument is vulnerable to the fluctuations in government perceptions of the role and scope of ACC. The human rights argument has shown its power in a recent court case, and merits further exploration in the situation of unnecessary suffering and remediable injustice that whānau/families of people with serious brain injury find themselves in.

The question

The question that is asked in this thesis is: How can we increase the capabilities of whānau of adults with serious brain injury to be better able to live their lives in the ways they have reason to value? This question is framed within the language of the Capability Approach, which is outlined in the following chapter, and has a deliberately Māori-centred focus.

As has been outlined in this chapter, it has been long known that brain injury impacts not only the injured person, but also those people that they are in close relationship with. In Aotearoa NZ we are fortunate to have comprehensive, no-fault accident insurance cover for every person who sustains an injury as a result of an accident via the ACC. This system has resulted in the delivery of reasonably sound brain injury rehabilitation to people who are injured as a result of an accident but our supports for family/whānau do not yet match our knowledge of what is needed. Given the differing needs and experiences of Māori compared with non-Māori, the question is focused on whānau, recognising that Māori are particularly poorly served by health and other services.

Chapter 3 – Philosophy: The Capability Approach

The situation of families of people with serious brain injury has struck me as being unjust. We have known for decades that brain injuries don't just affect the person who is injured but that, due to the nature of the injuries and their impact on memory, thinking and personality, they also affect families and other people in close relationship with the person (e.g. Bowen et al., 2010; Brooks, 1984; Cavallo & Kay, 2011; Lezak, 1988; Perlesz et al., 1999). Research has also shown that there are many ways to support families through interventions such as therapy and education (e.g. Ben-Yishay, 1996; Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011; Kreutzer et al., 2009). Yet it has been my experience and the experience of liaison officers throughout the country that families in Aotearoa NZ have struggled to access these supports. The damage that is caused to the brain of the individual cannot be reversed, but the further harm that is caused to families is, I believe, a situation of unnecessary suffering and a remediable injustice. In choosing to embark on a PhD in this area I wanted to conduct research which was effective and respectful. In thinking through what effective and respectful would actually look like I was clear that I wanted to work in a way that would increase the possibility of change occurring. I was disappointed at the lack of impact that much applied research seemed to have on policy within my field and concerned that those who took part might not gain any direct benefit for themselves. My perception was that participants' involvement in research is often altruistic, with the intention that the research will contribute to knowledge that will benefit others. I sought a way of working that would, at the least, make a difference to the families that I engaged with and the community that we worked in and, ideally, would provide a vehicle for working towards policy change.

My intention to both challenge and disrupt, places my thinking and work within a critical constructivist framework. From my early quantitative background I had learned to seek truth and answers that were immutable, testable, and replicable. Later in life I had come to see that truth seemed to change and was contestable, and that power had a lot to do with what 'truths'

came to dominate. I learned, thanks to Feminist therapy teaching from Ruth Jackson, to look for “the loose brick” – the perhaps small thing that you could do, even if you had little power, which would have a bigger impact on a system. This reflection on the impact of power on knowledge, and understanding that knowledge is constructed, led me to look for ways that could increase the chances of the knowledge of families of people with serious brain injury being gathered in such a way that it could improve their lives. I realised it was unlikely that there would be *one* way of improving people’s lives, as the changes that result from brain injuries are so variable, and individual and families have such diverse needs, values and aspirations. My supervisor’s words that “one size fits one” felt very apt, despite working in an environment where people were often seeking the “one size fits all” through endorsements of evidence-based practice and striving for global measures. I sought a way to consider the situation of families that could take into account this diversity and could work with possible outcomes of multiple solutions.

As a neuropsychologist I had some nervousness about moving away from quantitative research, despite finding that much of this research actually seemed to have little impact on my own practice. Within my work, the clients and families where I struggled the most to make a difference were people who often had had challenges throughout their lives. As Huhana Hickey had written, brain injury was at times another layer of disability on the background of other disabilities experienced through poverty, racism, substance abuse and the lack of opportunities that had, for many, characterised their pre-injury life (S. J. Hickey, 2008). When I was first contemplating this research in 2010, I attended a conference and listened to a paper where of 160 participants who were screened only 24 met criteria of having no history of mental health issues, substance abuse or other physical difficulties, and had a good level of English literacy. This made me question the validity of the evidence-base that we were being exhorted to use to guide our practice. I wanted to conduct research that reflected the situations of families who struggled within our current systems, rather than focus on those clients and families who were already the most resourced.

Other work that appealed to me during this preparation time was Sir Michael Marmot's writing on health inequity. As the chair of the Commission on Social Determinants of Health, he wrote of the ways in which the distribution of power and social structures impacted on mortality and quality of life with people on low incomes, both globally, and within each society having poorer outcomes than other citizens (Marmot, Friel, Bell, Houweling, & Taylor, 2008). Marmot wrote of the ethical imperative to create the conditions for people to be able to lead 'flourishing lives', a term which particularly appealed to me, and that, in order to make the greatest gains, it was important that our focus was on those with the least (Commission on Social Determinants of Health, 2008; Marmot, 2007). Through his research and that of Tony Blakely's research group in Aotearoa NZ (Ajwani, Blakely, Robson, Tobias, & Bonne, 2003; Tobias, Blakely, Matheson, Rasanathan, & Atkinson, 2009), I could see the life and death effects of inequity. Discussions with local community workers assisting people with brain injury also showed these patterns in our own backyard in Auckland. Liaison officers talked about the stress of the lack (or inadequacy) of social services, and how this led to unmanageable stress causing family breakdown, homelessness, further injuries, ill health and preventable deaths occurring for clients who had fallen through every crack in service delivery, and who lacked family support, often as a result of their personality and behaviour changes following brain injury⁸.

While I was grappling for the philosophy and methodology that would underpin this research I attended some talks focused on social justice where I kept hearing the name "Amartya Sen", and was advised that his writing and the theoretical framework of the Capability Approach would be a fit with my thinking and the situation that I was looking to explore and address. Marilyn Waring noted that "what is important in the capability model is not what people are or what they do, but what they can or cannot be, and what they can or cannot do, given the opportunities or the freedoms" (Waring, 2010b). Manuka Henare also spoke to me of his interest in the application of the Capability Approach to the lives of Māori and in particular children (later

⁸ Some people were estranged from family already through a lifestyle (involving addiction, gangs and/or criminality) which had led to them having the brain injury.

outlined in Henare et al., 2011). The major appeal to me of considering the situation of families through the lens of the Capability Approach is that it considers both human rights and economics within its discussions of well-being and justice, and looks at how people are able to live their lives in actuality, rather than at whether systems or structures are technically fair or not. The Capability Approach deals with how to *increase the capabilities of individuals to live their lives in the ways they have reason to value* with the aim of enhancing justice and reducing injustice (Sen, 2010). For the field of disability, the Capability Approach also offers the advantage of thinking specifically, and quite centrally, about differing levels of ability and access to resource, with a number of basic examples within the approach being focused on disability and how this can impact the reality of people's lives.

The rest of this chapter explores the Capability Approach, how it relates to the lives of people with disabilities and the families of people with serious brain injury, its relationship to human rights, issues around operationalisation, and its links with community and participatory research.

What is the Capability Approach?

What are people able to do and to be? And are they *really* able to do or be these things, or are there impediments, evident or hidden, to their real and substantial freedom? Are they able to unfold themselves or are their lives, in significant respects, pinched and starved? (Nussbaum, 2007, p. 5)

The CA has been pioneered by Amartya Sen, the 1998 Nobel prize-winner for economics. His basic premise is that the role of development (and he sees all societies as developing) is to expand the real freedoms of each person. In thinking about what it is that societies should seek to maximise Sen disputes that it should be production, which is at best a means to an end, or an aggregated measure of happiness, which can have some doing well at the expense of others. Rather, the CA is a framework which offers a way of viewing people's lives in terms of what they are able to do and be, and the degree to which they are able to *lead lives that they have reason to value* (Robeyns, 2005). Philosophically, the CA maintains that the well-being and dignity of each individual is of paramount importance. The well-being of the few cannot be traded for the

benefit of the many. In terms of freedom it is the real and actual freedoms that people have which are important and are outlined further below. Sen makes the distinction between theories of justice which seek to describe an ideal world with ideal institutions and his own stance in which he seeks to reduce injustice, regardless of whether ideals can be agreed upon. He also makes a distinction between just institutions and just outcomes. He links this to *nyaya* and *niti* - two different Sanskrit words for justice. *Nyaya* is focused on outcomes, which he argues as being superior to a more simplistic focus on simply the rules and institutions as in the concept of *niti* (Sen, 2010, 2012).

Martha Nussbaum is also recognised as a major contributor to capabilities thinking (Robeyns, 2005). In particular she linked Sen's work to Aristotle and has strengthened its philosophical underpinnings noting that "At the heart of the CA is an idea that it borrows from and shares with most of the world's great religious traditions: the idea that all human beings are precious, deserving of respect and support, and that the worth of all human beings is equal" (Nussbaum, 2007, p. 10). Both Sen and Nussbaum consider it important to distinguish between the rules of justice and the actuality of justice. Sen and Nussbaum diverge, however, in terms of its application.

It is worth noting that the CA is an approach rather than a theory. The CA has developed in response to the shortcomings of Gross Domestic Product (GDP) as the dominant measure of how well a country is performing. While international economics may seem a long way from the needs of whānau of people with brain injury, the principles of economics at a global level flow through to policies (for example in health and rehabilitation) at a national level (e.g. Levack, 2009). At a general level, the CA is held to be a more relevant framework to that offered by opulence, utilitarian and libertarian economics (Alkire, 2005; Nussbaum, 2011b; Robeyns, 2005; Sen, 1999). In the following section CA is considered in terms of these different theories, before I move on to its relevance, as a theory of justice, to the situation of whānau with ABI.

Opulence

Opulence economics focuses on what people are able to acquire (often referred to in the form of a basket of commodities) with an assumption that commodities equate to well-being. Amartya Sen argues that GDP (a primary opulence measure which is often equated with standard of living) is inadequate for a number of reasons, but largely because it is an aggregative measure which does not take distribution into account, and ignores the level of real freedoms which people are actually able to achieve. In terms of opulence economics, a country can be judged to be performing well if their total measured production (GDP) is increasing, regardless of the level of freedom of the citizens or whether the wealth resulting from the production is distributed throughout the nation or concentrated in the hands of a few. In looking at the adequacy of measuring via commodities baskets, Sen often gives the example of a person with a disability requiring more commodities to be able to achieve the same level of functioning (Sen, 2010). For example, an individual may require a wheelchair or walking stick to achieve mobility and may need personal assistance in order to achieve other tasks of daily living. Their level of commodities would therefore not reflect their standard of living, given that a person without a disability with the same basket of commodities would be likely to have a higher standard of living. The reality of diversity within populations are therefore poorly accounted for if GDP is used as measure reflecting standard of living.

Utility

Utilitarian economics holds that the purpose in acquiring commodities and of production is to be able to achieve desirable states. These states have been termed happiness, satisfaction or choices by various theorists and are subsumed under the one term of "utility" (the desirable state that you gain from the thing). Within utilitarian economics it is theorised that each person seeks to maximise their own utility and that the goal for a nation is increased utility. Again the distribution of this utility is not considered. As with opulence economics and libertarian (to be briefly outlined next) this focus on the total without regard for distribution indicates that within these theories it is acceptable for some people's opulence/utility/liberties to be sacrificed in

order to increase the total amount of opulence/utility/liberty. The CA argues, however, that it is the role of society to increase the capabilities of each individual which is of paramount importance. Whereas current economics has focused on the ends of increased opulence or utility as being sufficiently important as to override many concerns about the means towards this achievement, Sen regards these capabilities as both the means and the ends.

William Levack (2009) has argued that utilitarianism should be used as an ethical framework for the allocation of rehabilitation. His position was that a clinician should consider the total rehabilitation resources available, and the benefits of rehabilitation of the individual in front of them to the whole community, when determining how much resource should be put in to achieving their client's goals. While he noted that this could lead to some people, whose lives are undervalued within communities missing out, he maintained that this is not a critique of utilitarianism per se and reflects instead, a lack of knowledge which, he argues, could be corrected with greater understanding of the quality of life that people with very severe disabilities experience. This thinking assumes that research and reported experience will actually convey the lived reality of marginalised people (in this case people with disabilities) to decision makers, who tend to be people from non-marginalised groups and not people with disabilities, and also assumes that inequities will be reduced if people have correct information, rather than that inequities reflect already existing power differences for different sections of our community.

Libertarian

The focus of libertarian economics is on liberty or personal rights, which at first glance could therefore seem to align with the CA. The driving theory is that increasing freedom of, amongst other things, the market, will lead to increased competition and an improved economy. Martha Nussbaum (2007) respects the focus on the individual and the promotion of freedom of choice within libertarian thinking. She sees it, however, as inadequate in ensuring that minimal levels of well-being are supported through state provision of education, health care and the protection of basic human rights to safeguard against discrimination and unsafe or unfair employment. She

also sees it as lacking accountability to the reality of people's lived lives as the focus is on whether a freedom exists in principle, rather than whether people's lives reflect that they have such freedom in reality.

Nussbaum notes that while mainstream economists believe supports should be provided they see this as coming from the charitable sector, rather than the government. While she is not against charities providing some support, she notes that the responsibility ultimately lies with government to ensure that the conditions are met for all people to lead sufficiently flourishing lives. "Unlike libertarianism, the CA holds that the purpose of government is to promote a set of core necessary conditions for reasonably flourishing lives, lives worthy of human dignity. If that purpose has not been fulfilled, government is ultimately to blame, and minimal justice has not been achieved" (Nussbaum, 2007, p. 24). This has real relevance to the situation of whānau with ABI in New Zealand where the national Brain Injury Association collapsed in 2011, and took five years to be re-established, leaving the sector without a strong voice to advocate for the needs and rights of individuals and families living with brain injury.

Capability Approach

Amartya Sen's focus within the CA is on expanding the real freedoms of each and every individual. His purpose in doing this is to enhance justice and remove injustice (Sen, 2010). This approach does not deny the importance of developing economies as measured by increases in production, incomes and access to goods but it sees these advances as part of the means towards the ends of expanding freedoms and reducing injustice. If we hold with the idea that 'what's measured is treasured' then it would seem that the measures present within opulence, utility and libertarian economics suggest that the expanding economy has taken precedence over the well-being of each individual that an economy is surely supposed to serve. Within rehabilitation the parallel situation often exists, where funders can have a great deal of interest in the changes of scores of functioning without looking at whether these scores reflect shifts in the person's well-being or in their or their family's ability to live their lives in the ways they have reason to value.

Within the CA a high priority is placed on actual freedoms, but it is the types of freedoms considered which are different to those focused on in the libertarian model. In illustrating this, Amartya Sen often refers back to an incident which occurred in his own childhood (e.g. Sen, 1998) where a financially poor Muslim worker who was bleeding profusely stumbled into the Sen family's courtyard having been fatally stabbed. This occurred during a time of Muslim-Hindu rioting in his city and the man, Kader Mia, had come into their largely Hindu area in order to earn very low pay as a labourer. Before he was taken to the hospital he explained to Sen's father that his wife had not wanted him to work in that area but he needed to work in order to be able to feed his family. Amartya Sen notes the *economic unfreedom* that this man had. Regardless of what freedoms or rights this man may have had on paper, he was not free to choose to work in a way which offered both a reasonable degree of safety and enough money to feed his family.

The freedoms which Amartya Sen is interested in are known as *substantive freedoms* and refer broadly to the freedom to actually do and be those things which one has reason to value. Manuka Henare and colleagues (2011, p. 14) have outlined the five instruments of freedom involved in Sen's approach:

1. Political freedom – opportunities for effective political participation and dissent.
2. Economic freedom – opportunities for people to access and use economic resources (including finance) for purposes of consumption, production, or exchange.
3. Social freedom – access to health care and education, which influence people's ability to live well and be an effective participant in economic activities.
4. Freedom to deal with others – transparency guarantees involve the freedom to deal with members of a community under conditions of certainty, disclosure, and lucidity. This freedom aims to prevent irresponsibility, corruption, and fraud.
5. Protection – a social safety net for vulnerable people who suffer adverse circumstances.

While Sen has stated that he is not particularly keen on the idea of a prescribed list of capabilities, as he believes rather that such lists need to be developed for and by the communities concerned, Martha Nussbaum has developed a list of central capabilities which

she asserts that policy could be measured on (Nussbaum, 2007, 2011b). Her list includes: Life; Bodily health; Bodily integrity, Senses, imagination and thought; Emotions; Practical reason; Affiliation; Other species; Play; and, Control over one's environment. While she sees this list as being open to change it seems that this would be difficult to reconcile with lists that have been developed from within varying communities. For example, Matthew Will conducted grounded theory research with a group of people living in an area of conflict in the Phillipines which resulted in the following list of what people needed to be able to have a good life: Fear of and faith in Allah; Love and help one another; Respect one another; Peace in community; Education; Work; Shelter; Good health; Take part in the government; Mobility and travel (Will, 2014). In considering the situation of whānau with ABI and models of Māori well-being, which are introduced in the following chapter, any list would likely need to include a spiritual (wairua) component. While Nussbaum's list can be seen as aspirational, and therefore likely to differ from those that people living with severe deprivation would construct, it is surely important that basic rights tools focus first and foremost on the needs of those who are most at risk of their rights being overlooked.

Human rights

So an advantage of the concept of capability, is that it is directly linked to the concept of dignity (and rights) and therefore reminds policy makers, health practitioners and the community, that people with disabilities' inherent worth is reflected in just outcomes and possession of the capabilities to live a life chosen by them – one that can be fulfilling (Siegert & Ward, 2010, p. 2144).

Rehabilitation in Aotearoa NZ is inextricably linked with human rights. Our accident rehabilitation system is based on the principle of community responsibility and in establishing this system we traded off our right to sue. The decision to do this was based on the belief that it would be a great deal more cost-effective to fund rehabilitation and compensation than to pay for lawyers to argue over what should be covered (Hon George Gair⁹, personal communication, 23 February 2011) (Duncan, 2008).

⁹ A Minister at the time of the introduction of ACC

My sense that the situation of whānau of persons with an ABI is a rights issue means that an exploration of human rights is necessary. Human rights are basic entitlements that communities and indeed the global community have agreed on that are essential for maintaining the dignity of each person. How they are enacted and upheld, and whether or not they actually exist is, however, up for debate. This debate within the CA, and the relevance of it to the situation of whānau, will be discussed in this section.

Martha Nussbaum views human rights and capabilities to be somewhat overlapping and classes capabilities as a “species of human rights” (Nussbaum, 2011a, p. 23). Her stance draws on Dworkin’s idea of human rights being trumps, all other things being equal. She asserts that the benefit of the use of the language of capabilities is that it brings the focus closer to the way in which people are actually able to live their lives. Coming from a legal philosophy background, her preference is for a list of capabilities, linked closely to the Universal Declaration of Human Rights (UNDHR), which she believes each nation should adopt and enshrine in order to afford statutory protection of the capabilities (Nussbaum, 2011b). This aligns with her assertion of the power of rights ‘as trumps’ as they override the claims of other forms of legislation, though our own governments do seem to have a habit of knowingly legislating in conflict with our own Bill of Rights Act, as was demonstrated in *Atkinson & Ors v Ministry of Health* (2010)¹⁰ and the related court cases and legislative changes¹¹.

Amartya Sen, however, grapples first with the intellectual grounding of rights, which he acknowledges are seen by some as being intellectually flimsy¹². Sen’s position is that as rights have significant moral appeal, their power, along with the power of capabilities, is determined through public reason (Sen, 2004). From Sen’s perspective, CA offers a framework for analysing some, but not all, rights (Sen, 2005). He notes that the language of rights or capabilities cannot subsume the other. In line with his belief in public reason he is not in favour of the development

¹⁰ *Atkinson & Ors v Ministry of Health* (2010) NZHRRT 1

¹¹ See p 44 for earlier discussion of these cases

¹² He refers to Bentham’s dismissal of the idea of natural rights. “Bentham insisted that ‘natural rights is simple nonsense: natural and imprescriptible rights, rhetorical nonsense, nonsense upon stilts’, by which, I take it, he meant some kind of an artificially elevated nonsense.” (Sen, 2010, p. 356)

of a universal list, but does believe that lists of capabilities can be developed for specific tasks, as in the work that he did on the Human Development Index (Sen, 2004, 2005, 2010)

So the power of human rights relates both to the degree to which they have been enshrined in law, and to the power they have within public reason. At the global level we have the United Nations' Universal Declaration of Human Rights (UNDHR), and at the local level our rights are protected by the Human Rights Act and the New Zealand Bill of Rights Act (BoRA). For people with disabilities there is the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to which NZ became a signatory in 2007, ratified in 2008, and signed the Optional Protocol for in October 2016 meaning that individuals or groups can now make complaints to the United Nations Committee on the Convention on the Rights of Persons with Disabilities. Prior to this we were reliant solely on the New Zealand Disability Strategy.

Families have protection under Article 16(3) of the UNDHR which states "The family is the natural and fundamental group unit of society and is entitled to protection by society and the State." This protection is echoed in the UNCRPD which also notes that "persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of person with disabilities" (United Nations, 2006, p. preamble). The UNCRPD is seen as "a milestone for the promotion of human rights and equal treatment ... worldwide" (COFACE-Disability, 2012, p. 4).

The power of New Zealand's protection for disabled people and their families has been tested by a group of families who sought equal pay, with non-family members, for their work in caring for family members with disabilities (*Atkinson v MoH (2010)*¹³, *Spencer v Attorney General (2013)*¹⁴, *Attorney General v Spencer (2015)*¹⁵¹⁶). It was interesting to see the power of their rights being tested out and battled over between the families, the courts and Government.

¹³ *Atkinson & Ors v Ministry of Health (2010)* NZHRRT 1

¹⁴ *Spencer v Attorney General (2013)* NZHC 2580

¹⁵ *Attorney General v Spencer (2015)* NZCA 143

¹⁶ A similar situation was also played out through the courts in Canada in *Hutchinson v. British Columbia* with the courts ruling that both the daughter, who needed care, and her father, who gave care had suffered a loss of dignity when the daughter had been unable to hire the careworker of her choice (her father) and when the father had been unpaid for his work (Waring, 2010a).

When the courts ruled that the practise of not paying family members, or paying at lower rates than non-family members, for their work in looking after people with disabilities was discriminatory, the government sought to change the legislation to stop the courts from pursuing this examination and to limit the number of families who would be able to seek redress (Geddis, 2013, 2015). Despite this, the courts have repeatedly ruled in favour of the families. While the Attorney-General declared that the legislation that was being passed was in conflict with the Bill of Rights Act (Finlayson, 2013), the legislation still passed with one argument being that it was not for the courts to decide how scarce funds were to be allocated as that was the domain of the government, an argument drawn from the 'progressive realisation' stance of the International Covenant on Economic, Social and Cultural Rights.

For me, this begs the question as to how the Attorney-General believes courts can ever uphold citizens' rights, when they are infringed by government, as these infringements will frequently be the result of government attempts at cost-saving¹⁷. As Sen states "The confusion in dismissing claims to human rights on grounds of incomplete feasibility is that a not fully realized right is still a right, calling for remedial action. Non-realization does not, in itself, make a claimed right a non-right. Rather, it motivates further social action." (Sen, 2010, p. 385)

While it would seem that the immediate power of rights may be somewhat at the mercy of the government of the day, the UN also has a monitoring role on how well the rights are being upheld given that we are a signatory to the UNCRPD. In the concluding observations of our first report the UN Committee recommended "that the State party reconsider this matter to ensure that all family members who are carers are paid on the same basis as other carers are, and recommends that family members who are carers be entitled to make complaints of unlawful discrimination in respect of the State party's family care policy." (Committee on the Rights of Persons with Disabilities, 2014). To me this situation demonstrates both the power of human rights, when they are supported by our domestic legislation, and the importance of external

¹⁷ This has also been the case with the Child Poverty Action Group's court case to fight for the same tax credits for homes with children where the parents are not in paid employment compared with parents in paid work.

scrutiny which can motivate governments to, at a minimum, be seen to be doing the right thing for groups whose rights have been violated.

Within this project, my concern has been that the rights of families to the protection of the state is not being upheld, as families suffer through lack of supports which causes increased family breakdown, stress and a situation of unnecessary suffering. As Sridhar Venkatapuram notes "there is something particularly alarming when the onset and experience of impairments and premature death are linked to social arrangements" (Venkatapuram, 2011, p. 5). The family is entitled to protection under both the UNDHR and the CRPD, but the reality of people's actual lived lives is that families suffer as a result of brain injury to a family member. There is family break-up which is sometimes as a result of personality change and sometimes as a result of difficulties in accessing sufficient funded support for the person with the injury. There is also break-up, or overwhelming stress and distress, as a result of lack of education and psychological support for family members, which has come about as a result of the history of ACC supports being for the individual with the injury, and not taking into consideration the disability that the wider family experiences as a result of the individual's injury. Even when supports do become available at the institution level, this information has been historically difficult to access and supports have not been universally applied. The pattern that I have noticed of better-resourced families accessing more supports than more marginalised families fits with the literature (Stephens, 2010) and shows that this is a pattern that needs action to ensure that those who are most in need actually access resources that they are entitled to.

Capability Approach and disability

"the CA can provide a new understanding of disability, which is more in line with policymaking requirements" (Trani et al., 2011, p. 146)

A feature of the capability approach, as distinct from other theories of justice (Harnacke, 2013; Sen, 2010), is the deliberate focus on diversity (Binder & Binder, 2016; Ibrahim, 2014), and within this, disability. Given that Sen is interested in the rights of every person to be able to live their life well, the suffering of a few cannot be written off as unavoidable or a side issues in achieving

a utilitarian aim of the greatest good for the most. He notes that “If the demands of justice have to give priority to the removal of manifest injustice ... then the prevention and alleviation of disability cannot but be fairly central in the enterprise of advancing justice” (Sen, 2010, p. 259). He contrasts this to Rawls thinking about disability which is dealt with through “special correctives for ‘special needs’” (Sen, 2010, p. 241) something which Sen seems to regard as a fundamental weakness in Rawls model. So while Sen has not developed a model of disability, he is very clear on the importance of any model for justice, or economics, being able to take into account this diversity. This is not surprising given his focus on remediating injustice and the known correlations between disability and poverty (Article 33 Convention Coalition Monitoring Group, 2015; Lang, Kett, Groce, & Trani, 2011; Mitra, 2006).

Sen writes specifically about the needs of people with disability being greater than those without for them to be able to achieve the same levels of functionings and capabilities:

in the developing world, the disabled are quite often the poorest of the poor in terms of income, but in addition their *need* for income is greater than that of able-bodied people, since they require money and assistance to try to live normal lives and alleviate their handicaps. The impairment of income-earning ability, which can be called 'the earning handicap', tends to be reinforced and much magnified in its effect by 'the conversion handicap': the difficulty in converting incomes and resources into good living, precisely because of disability (Sen, 2010, p. 258).

While he writes of the developing world he also refers to Wiebke Kuklys’ UK-based research which recognises that, as a result of disability, individual’s earnings are often reduced (earnings handicap) while their material and support needs are often increased (conversion handicap). Within Aotearoa there have also been clear findings of the links between disability and poverty, where people have expressed feeling doubly shunned by wider society for being both poor and disabled, although others noted that having a visible disability helped others be less judgmental towards their poverty (Article 33 Convention Coalition Monitoring Group, 2015). Within CA, disability is conceptualised as *capability deprivation* which can result from poverty, discrimination, low education, injury, illness or other disadvantage (Mitra, 2006).

By bringing in an individual’s (or a family’s) aspirations, CA considers disability in terms of the gap between how someone is able to live and how they aspire to live – the capabilities,

or lack, to live their lives in the ways they have reason to value (Robeyns, 2005). This contrasts with other models¹⁸ which can focus on the gap between an individual's functioning and a norm, or basic standard. Tania Burchardt has explored the compatibilities of the social model of rehabilitation and CA and argues that the two are complementary, with the CA offering a broader theoretical framework in which to situate the social model, and the social model providing a practical application of CA (Burchardt, 2004). Nussbaum's CA, however, has been critiqued for its limitations when considering the situation of people with severe disabilities because some people's lives are unable to encompass all of the items on her list which she considers part of what is essential for living life as a human (Harnacke, 2013).

CA has been criticised for its focus on the individual. Sen claims that this does not represent methodological individualism¹⁹ but is a necessary theoretical focus, as it is individuals who determine what lives they have reason to value, although these are inextricably linked to their society in terms of both what is permissible and what is seen as desirable (Sen, 2010). Looking solely at the life of the *individual*, however, does not always work for someone who does not have free agency and, when considering disability, Trani and colleagues argue that it works better to consider the household rather than the individual (Trani et al., 2011). I agree with their household focus, as this takes a step towards acknowledging the interdependence of our capabilities, not just that they are influenced by society but that, for example, the capabilities of a person with a disability are impacted by the capabilities of their caregivers or others in their household, and those people's capabilities are influenced by the capabilities (which are often limitations) of their family member with a disability. Thinking in terms of

¹⁸ Discussed in the Models of disability section of the Literature Review

¹⁹ CA distinguishes between ethical individualism and methodological and ontological individualism "Ethical individualism makes a claim about who or what should count in our evaluative exercises and decisions. It postulates that individuals, and only individuals are the units of moral concern" (Robeyns, 2003, p. 44). Ontological individualism is more along the lines of Margaret Thatcher's idea that there is no such thing as society as society is only the sum of individuals and their properties "The capability approach embraces ethical individualism, but does *not* rely on ontological individualism" (Robeyns, 2003, p. 44)

households also sits better with communities that have more of a family or community focus rather than a purely individual one.

Operationalisation

The capability approach is based on a reasonably simple idea – that what is important is people’s lives and how much they are able to live them in the ways they have reason to value. The beauty of this idea is that it allows for great diversity in terms of what is valued (capabilities) and what is done (functionings). The difficulty for operationalisation is that it allows for great diversity in terms of what is valued and what is done. Ibrahim explains that one of the advantages of other dominant paradigms, such as neo-liberalism, is that measures and policies are simpler (Ibrahim, 2014). If we believe that people’s lives are improved via expanding measured production, then we can measure GDP to check if the right things are being done to improve people’s lives. If we want to look into the detail of people’s varied lives to understand both their lives and whether development efforts are improving them, then it gets more difficult. While it is acknowledged that CA is not easily put into practice, it has, however, been used as the basis of measures such as the Human Development Index and also in a range of development and disability studies (Robeyns, 2006).

Aside from the technical difficulties, at the time that I commenced this project, I also had a concern as to whether CA’s beliefs in the importance of developing bottom-up processes were being enacted with sufficient knowledge. It is pleasing to see recent writing looking at links between Sen and Freire’s thinking as this could move some way towards remedying this situation (Glassman & Patton, 2014). Since the commencement of the fieldwork for this project I have also been pleased to see new writing from a CA perspective looking at communities (Ibrahim, 2015; Ibrahim & Tiwari, 2014; Will, 2014), and issues relevant to indigenous peoples (Binder & Binder, 2016; Bockstael & Krushil, 2016), as well as participatory research with indigenous groups (Yap & Yu, 2016). The question remains open as to the relevance of CA to indigenous populations with researchers noting its propensity to be used in ways that can be

either harmful or good (Bockstael & Krushil, 2016). The greater analysis of power, and understanding of the risks of colonisation and damage through outsiders conducting research with marginalised groups, that is found with both CBPR and literature considering the risks of researchers contributing to colonisation (L. T. Smith, 1999, 2005, 2012), has a lot to offer to the capabilities approach.

For the reasons above, in this study, CA has framed the research question and therefore frames the understandings that are drawn from the project. The practical application, however, is guided by Māori-centred ethics and Community-Based Participatory Research practices and principles. These choices fit the environment of Aotearoa, and were made because of the more developed understandings in these two approaches of the role and impacts of a researcher from the dominant culture attempting to engage respectfully and effectively with a more marginalised community.

Summary

Use of the Capability Approach as the philosophical framework for this thesis brings a human rights focus and the ability/intention to look at people's lived lives in actuality. The question that is asked in this research is a CA question: What would increase the capabilities of whānau/families of people with serious brain injury to live their lives in the ways they have reason to value? CA has been seen as a valid framework for much work within the area of disability policy because of its attention to diversity and its human rights foundation. While CA has great appeal in terms of its normative dimension, it is acknowledged to be challenging to operationalise, and practitioners will often combine CA with other approaches. The Methodology chapter will outline the Māori-Centred, Community-Based Participatory Research approach that has been used for this project.

Chapter 4 – Methodology: Māori-centred Community-Based Participatory Research

Choosing a methodology was a process of coming to understand my own thinking and beliefs around what constituted knowledge and what processes would shape the research project that I was to commit to. As a Clinical Psychologist specialising in neurorehabilitation, with a strong background in behaviourism, my training, which fitted also with my upbringing, was strongly quantitative and positivist. Through my early training I was only partially aware of this, as the hegemonic nature of these epistemologies meant that I struggled to accept that there were alternate, valid worldviews.

This knowledge and training, albeit with a broader consideration of emotions, thoughts and an understanding of holistic well-being, still underpins the behavioural side of my clinical work. And a strong tenet of behaviourism that *learning equals behaviour change* was part of what led me to this topic. I was aware that the knowledge of the impact of brain injury on partners and families was well established, that there was also an understanding that comprehensive rehabilitation, while it could be expensive in the short term, saved money in the long term, and yet our system delivered supports to the injured individual but offered little to support the well-being of the family. While the knowledge was there, the behaviour change had not followed. I wanted to conduct research in a way that would lead to change. As a PhD student I was aware that this apprentice piece of research would not change the world, but I still truly wanted it to be of benefit. When confronted with overwhelming structures in the past, my approach has been to cope through a personal 'ripple out' philosophy. I may not be able to change the world, but my work and my actions can have a positive effect on those I'm in immediate contact with and I hold the hope that the effects could go wider.

Research intentions

From the outset of this project I wanted to work out how I could do research that actually achieved change. After many years of attending conferences where impressive amounts of data

were presented that described situations that I was already aware of, I was often left disappointed that there had been little to help me work better with those people and their families who were dealing with serious brain injury. Money had gone into the research, interventions had been piloted and then everything had stopped, when the researcher had moved on or the student had finished. I learned that some academics had tested out how to work with depression with a group of clients with no pre-existing mental health issues, no difficulties with substance use, easy access to the university clinic and adequate English literacy to complete the programme. These were not the clients that I struggled with, and little of the research delved into the issues that caused me the greatest concern. This frequently-repeated situation has led some researchers to challenge the viability of randomised controlled trials, the pinnacle of positivist research in my field, for neurological rehabilitation (Kersten, Ellis-Hill, McPherson, & Harrington, 2010).

Within my own work in the residential post-acute stage of rehabilitation I was aware that we were in many ways involved in the 'easy' part of the journey. Injured people were making progress every week, and this progress gave families energy and hope. I was troubled that many whānau who had been very involved while their family member was in the hospital in South Auckland, were less involved once the injured person came to our service in West Auckland. In trying to arrange family meetings – which occurred on-site at our service – I would see therapists become impatient at people not attending. Then I would talk to family members who described how arrangements to attend - a whole patchwork of borrowing the car from one family member, money for petrol from another, and organising childcare and school pickups with someone else had fallen through. This situation was not something experienced by the well-resourced families in Auckland, and also not an experience familiar to many of our therapy team. So despite our service being freely available under the universal, no-fault insurance scheme of ACC, its accessibility depended on many factors beyond the service, factors that are considered to be social determinants of health. The differences were also apparent at discharge,

when I could see that well-resourced families were so often able to organise for higher levels of support than less-resourced families.

Partners and families were often offered the support of psychologists within our team while their family member was in residential rehabilitation, but it was then very difficult for them to access this same support once their family member had returned home. I was also aware that I knew very little of what happened to families once they left our service. The literature told me that life tended to become progressively more difficult in the years after injury. Paid supports tended to diminish, and socialisation with friends tended to dwindle, leaving many people with brain injury more and more reliant on family members²⁰ who became more and more strained with decreasing mental health of their own.

A support letter from a family friend who was a lawyer (on their letterhead), or who was also a senior health professional or had other powerful connections, often seemed to make the difference between a person with an injury getting sufficient support to live at home or being placed in institutional care. When it came time to define a PhD topic I was aware that where I would choose to put my time and energy was a political choice. I had considered researching aspects of programmes that had already been developed within the service that I worked in, but felt compelled to work to make a difference to how families were faring in the community.

My initial thoughts were that I would seek to understand the needs and experiences of partners of people with moderate to severe brain injury, as I was concerned that the lack of community support to non-injured family members was detrimental to the partners, to the person with the injury and potentially to the wider society. My concern for partners also stemmed from my own similarity to the partners. Most of our clients who were injured were men, and many of the support people were women. As a mother, with a husband and three children, I felt a particular connection with the hopes, fears and grief of the women. I was concerned that the lack of support contributed to increased suffering for families and that some

²⁰ My sense is that this situation tends to be experienced as more problematic in smaller nuclear families than it is for larger Māori whānau.

of this suffering could be reduced through better support and education. While the Brain Injury Association (BIA) charity offered some support, many of the women who I suggested attend the partners and caregivers support group, located in an affluent area of Auckland, did not feel able to connect with what was on offer. With the BIA being a struggling and diminishing charity it was hard to see how it could offer much more, but I was struck again with the impression that what few services were available seemed to meet the needs of middle class Pākehā families more than those of Māori, Pacific and low-income.

Impatience of a clinician

With these many thoughts swirling in my head I sought to construct a piece of research that could make an actual positive difference. The guiding thought in my head from my first day at the university was that I wanted the research to be *effective and respectful*, and to be consistent with the values of kaupapa Māori²¹ in order to be accessible to Māori. Despite the faculty being based on the North Shore, I was clear that I did not want a 'North Shore solution'.

With these thoughts in mind I set out to find an appropriate methodology. My initial expectations of my research fitted within my quantitative background as I considered surveying the needs of partners and perhaps interviewing a smaller group to gain more in-depth understanding. Discovering the array of methodologies open to me was both mind-boggling and somewhat threatening as I was concerned that the research that I would put years of effort into might not be accepted by my research peers in the field of neurological rehabilitation.

I was impressed with the beauty of many academic stories told and explored through a phenomenological lens and toyed with the idea of focusing on the stories. I am aware that change can occur through people becoming aware of these stories which we often see through advocacy journalism. A story of injustice shown to enough viewers at prime time can bring change for that person, and can also be the stimulus for an examination of policy. But it seemed that in terms of research, the policy change was a secondary effect and that while many

²¹ At this stage my understanding of kaupapa Māori was through family and school experiences of bilingual education, and not a formal understanding of the Kaupapa Māori research model.

participants spoke of the benefit of sharing their story with a listener, that benefit was also not a primary focus. As a clinician I was aware that I had a strong driver to achieve change and that I brought a critical lens to the work that I did. Projects that I had been involved with within my work role had come out of listening to clients to see what they wanted and then building an intervention from this. I was curious to find a way that this practical and effective work could also be research.

I initially thought that I would want my role in the research to be that of a servant researcher, as I was concerned about not exerting power over the people that I sought to work with. I was concerned that if I were to have a dominant voice then this could have the effect of taking my North Shore knowledge to South Auckland and imposing solutions that would not be effective in the local community. The role of servant however, would mean subjugating the knowledge that I had developed which also did not seem in the best interests of the project (Ristock & Pennell, 1996).

A partnership model allows instead for each partner to bring the skills, knowledge and experience to the project in order to create synergies, so that the final project is different from and greater than what could have been achieved by any one party. This, I believe, is what was ultimately achieved through a methodology of Māori-Centred, Community-Based Participatory Research.

Working effectively and respectfully with Māori

In choosing to work with Māori, I was making a choice to 'return the indigenous to the centre' (DeSouza & Cormack, 2009). Most Western research tends to privilege Western thinking, values and ways of being, and in NZ this is paralleled with most research and practices having a taken-for-granted Pākehā bias. As Ann Milne notes, the background of a blank canvas is white (Milne, 2009), and it is from this position that most mainstream research begins. While my intention was to work with a general population that would include Māori, Pākehā, Pacific Nations and possibly other ethnicities I deliberately drew on Professor Russell Bishop's tenet that while

what's good for mainstream is not necessarily good for Māori, what's good for Māori does tend to be good for everyone (Bishop & Berryman, 2009).

As a non-Māori researcher I was also aware that this choice placed me on 'tricky ground' (L. T. Smith, 2005). The following section looks at some of the choices that Māori and non-Māori have available when conducting research, and then highlights the principles and questions of Linda Smith, and the ethical framework of Te Ara Tika that guided my pathway through this ground.

History of dangerous research

I commenced my search for an appropriate methodology aware of the risks of services not providing appropriately and adequately for Māori. My own beliefs were that it was important for Pākehā not to speak for Māori, and important for Pākehā to make space for Māori voices. I recognised how it was so easy for our voices to dominate, even in settings where we were the minority, if we did not step in mindfully and with awareness of tikanga. As a neuropsychologist I was very aware of how measuring Māori, or their intellectual functioning, with our Western tools could bias our assessments negatively, given that these tools correlate significantly with the degree of cultururation or assimilation into the dominant culture (Ogden, Cooper, & Dudley, 2003; Ogden & McFarlane-Nathan, 1997)

It was during 1987, that we all learned of the horrors of medical research being conducted without the awareness of its subjects, resulting in the unnecessary deaths of women who were unknowingly placed in the 'no treatment' group when they attended our local women's hospital for cervical cancer (Coney & Bunkle, 1987). I learned of, and preferred, Māori models of health such as Te Whare Tapa Wha (Durie, 1985) which held a holistic view of health as encompassing our wairua, body, mind and whānau, as well as the well-being of the land (whenua) that we live on or, often more importantly, that people don't get to live on. Durie contrasted this holism with the Western focus on seeking to understand through dissection of a matter into smaller and smaller parts. Searches for treatments in many areas of medicine,

including neurology, look more to the cellular level in the pharmaceutical quest for the pill to treat (much more profitable than a cure), while holistic approaches are often regarded with a strong degree of scepticism.

While I had been aware of land confiscations especially in the home area of my mother-in-law (Tūhoe, Ngati Tawhaki), I had not connected this to the conduct of research and the links between research and the system of colonisation imposed throughout the globe by the European empires. Reading Linda Smith's *Decolonizing Methodologies* (L. T. Smith, 1999, 2012) I learned of so many more ways in which research had been used for the benefit of the settler government and had framed Māori, and Māori issues, as problems using a deficit-focused approach.

Much Pākehā research does not include Māori and this tends to happen either through oversight or through caution. Oversight can occur when a researcher does not deliberately think about how to include Māori or how the results will impact Māori. Research sampling methods such as the snowball technique can, with many of our communities being somewhat segregated, result in participants all coming from a rather narrow demographic that will likely match that of the researcher. When researchers fear perpetuating the harms of research, or that they do not have the skills to work with Māori they can also decide that the most prudent action is not to include Māori in the research – a situation termed Pākehā paralysis (Tolich, 2002).

I experienced some trepidation as a Pākehā researcher in choosing to conduct general population research with a deliberate and explicit Māori focus. During the time of my clinical training (early 1990s) the predominant message was that research of Māori should be done by Māori. The outcome of this thinking however would mean that at the time that we were also being exhorted to conduct evidence-based treatments, much of that treatment, even if it were researched in NZ, would not have included Māori. As the mother of Māori children, this stuff is personal. My children were being taught within bi-lingual settings, yet they were often required to be measured as if they were mono-lingual learners due to a lack of attention to collecting

data for bilingual learners. The effects of not including Māori in research could clearly also cause harm, albeit in a different way to Pākehā stepping in to conduct research “on” Māori.

I was aware that there were many ways in which I could get this work wrong and I risked setting myself up for significant criticism. I knew, however, that predominantly Pākehā services were not meeting the needs of Māori, and I believed that the individualistic focus of ACC caused unnecessary suffering to all families including Māori. Looking around I could not see that there was a Māori researcher about to pick up this task. So I therefore needed to find a way to work respectfully and effectively on this tricky ground.

Safer ways of working with Māori

Through the 90s, Tolich (2002) noted that the advice that was taught to students was that the best way to be culturally safe was to not work with Māori. I was taught that the role of Pākehā was to be allies, by supporting Māori as they pushed for change and being aware of the power that we did have in order to change systems. I heard the story of one therapist who decided that the best way she could support the work in her area to be practiced more effectively for Māori was to resign so that the organisation could hire a Māori staff member in her place – unfortunately, the hiring did not occur, but her intentions are illustrative of a dominant discourse. My own position at work and at home was to be extremely careful not to speak on behalf of Māori – despite living a relatively bicultural life especially around the education of our children. I was asked to stand for the school Board of Trustees and explained that I would stand, but only if I was not standing in the way of a Māori parent who wanted to represent our unit.

However, I was also nervous from experiences of being in Māori immersion education settings, in my role as a parent, and having ‘the tikanga card’ played to silence my opinion both on topics that I saw as tikanga related, such as kapa haka practise, and non-tikanga related, such as adequately heating the kōhanga (early childhood centre and language nest). My reaction tended to be to defer to Māori parents or kuia, especially if I was in a full immersion setting, rather than a bilingual setting, and especially if the alternate view came from someone older

than me. If these instances happened again, then I would tend to send my Māori husband to the meetings. The experience, however, of being in the minority is something that I have found interesting and valuable. As we have deliberately placed our children in Māori educational settings, I have been keen not to overly impose my Pākehā views. So while I don't want to shirk from the work that needs to be done I tend to seek to place myself in a servant role rather than one of leadership. Within some areas of school politics, the work that I have been asked to do has been around policy. Typically this has involved defending our unit from the harms that can be caused by mainstream policy changes which can have downstream effects (it's hard to know whether these have been intentional or not) of placing our unit at risk. These experiences influenced my thinking around what role I might take as a researcher.

This project

In conducting this project I drew on Linda Smith's cultural values (L. T. Smith, 1999) which Fiona Cram (2001) had translated into guidelines for researchers²². While the guidelines are directed towards Māori, Cram acknowledges that they may also be of use to non-Māori seeking to conduct research which is tika and therefore safe. The following table quotes the "Community-Up" Approach to Defining Researcher Conduct" (L. T. Smith, 2005, p. 98) in the first two columns and shows how it was intended to be applied to this research in the third column.

Table 1: Cultural values and guidelines for researchers applied to this research project

Cultural values (Smith, 1999)	Researcher Guideline (Cram, 2001)	Application to this research
Aroha ki te tangata	A respect for people – allow people to define their own space and meet on their own terms.	Flexibility in how and when to meet with people in order to maximise participation will be important in this project. It is recognised that people may want to be involved but may not always be able to attend scheduled meetings. Individual catch-ups along with written feedback will be needed to supplement the main contact processes and the explicit expectation will be that the ability to commit can fluctuate over time.

²² While my work drew strongly on these academics and the guidelines of Te Ara Tika, it is noted that the development of research ethics for working with Māori is seen as having commenced with Ngahua Te Awekotuku's 1991 discussion paper "He Tikanga Whakaaro: Research ethics in the Māori community (Fiona Te Momo, personal communication, 13 September 2017).

Cultural values (Smith, 1999)	Researcher Guideline (Cram, 2001)	Application to this research
He kanohi kitea	It is important to meet people face to face , especially when introducing the idea of research, “fronting up” to the community before sending out long, complicated letters and materials.	Face to face meetings with interested parties are prioritised in order to build relationships. Once the relationships are more solid then it could be expedient to use other forms of communication but I will remain mindful that sometimes saving time can cost time if it results in miscommunication.
Titiro, whakarongo ... korero	Looking and listening (and then maybe speaking). This value emphasizes the importance of looking/observing and listening in order to develop understandings and find a place from which to speak.	I believe this principle is especially important for participatory research as it is important that the community voice is heard and that the academic researcher voice contributes without dominating.
Manaaki te tangata	Sharing, hosting, being generous. This is a value that underpins a collaborative approach to research, one that enables knowledge to flow both ways and that acknowledges the researcher as a learner and not just a data gatherer or observer. It also facilitates the process of “giving back”, of sharing results and of bringing closure if that is required for a project but not to a relationship.	Sharing kai and giving koha will be part of the process of this research. The project will not function without the generosity of the participants in sharing their knowledge, ideas and time. This knowledge and time will be valued by the researcher through maintaining accountability to the group and the community organisations supporting the research.
Kia tupato	Be cautious. This suggests that researchers need to be politically astute, culturally safe, and reflective about their insider/outsider status. It is also a caution to insiders and outsiders that in community research, things can come undone without the researcher being aware or being told directly.	I am mindful of my insider/outsider status as a professional and as a Pākehā but also as the supporter of a person with serious brain injury. In order to enhance my reflexivity in this area I will draw on support from Māori mentors as well as from my peer-supervision group.
Kaua e takahia te mana o te tangata	Do not trample on the “mana” or dignity of a person. This is about informing people and guarding against being paternalistic or impatient because people do not know what the researcher may know. It is also about simple things like the way Westerners use wit, sarcasm, and irony as discursive strategies or where one sits down. For example, Māori people are offended when someone sits on a table designed and used for food.	Miscommunication can easily occur and part of what I will do will be to acknowledge my eagerness to learn, the likelihood that I will make mistakes and the desire that I have to be corrected, so that we can work effectively together in order to develop strategies to improve the lives of partners and whānau.
Kaua e mahaki	Do not flaunt your knowledge. This is about finding ways to share knowledge, to be generous with knowledge without being a “show-off” or being arrogant. Sharing knowledge is about empowering a process, but the community has to empower itself.	This is an especially important principle as I find that it is easy for people to be overly impressed by the idea that you’re doing research or a PhD student which needs to be managed so that all whānau are able to recognise their own knowledge, power and ideas.

Te Ara Tika

Alongside these cultural values, the other key guide for the research was Te Ara Tika Guidelines for Māori Research Ethics (Hudson et al., 2010), an ethical framework for conducting research with Māori which is endorsed by the Health Research Council of New Zealand (2010). I found

the concept that establishing ethical research is a process of moving from tapu to noa to be helpful, as it acknowledges the ongoing nature of these processes as well as the importance of setting up strong foundations. The guidelines explain that the starting point is *kia tūpato*, which is a place of caution, a warning to be careful in order to move the project from a place of restriction, *tapu*, to a place of unrestricted, *noa*, from which the research can proceed. Through using practices of careful consideration (*āta-whakaaro*) and robust discussion (*āta korero*) a consciously determined foundation (*āta whiriwhiri*) can be achieved, which will allow the project to proceed with understanding (*āta haere*) (Hudson et al., 2010, p. 5).

The framework outlines each of the principles and the expectations for minimum standards, good practice and best practice for each principle, which equate roughly with Mainstream, Māori-centred and Kaupapa Māori research. The four tikanga principles (Figure 2) which are given primacy in the framework are *Whakapapa* (relationships), *Manaakitanga* (cultural and social responsibility), *Mana* (justice and equity), and *Tika* (research design). The following section looks at how each of these were considered in the design of this research.

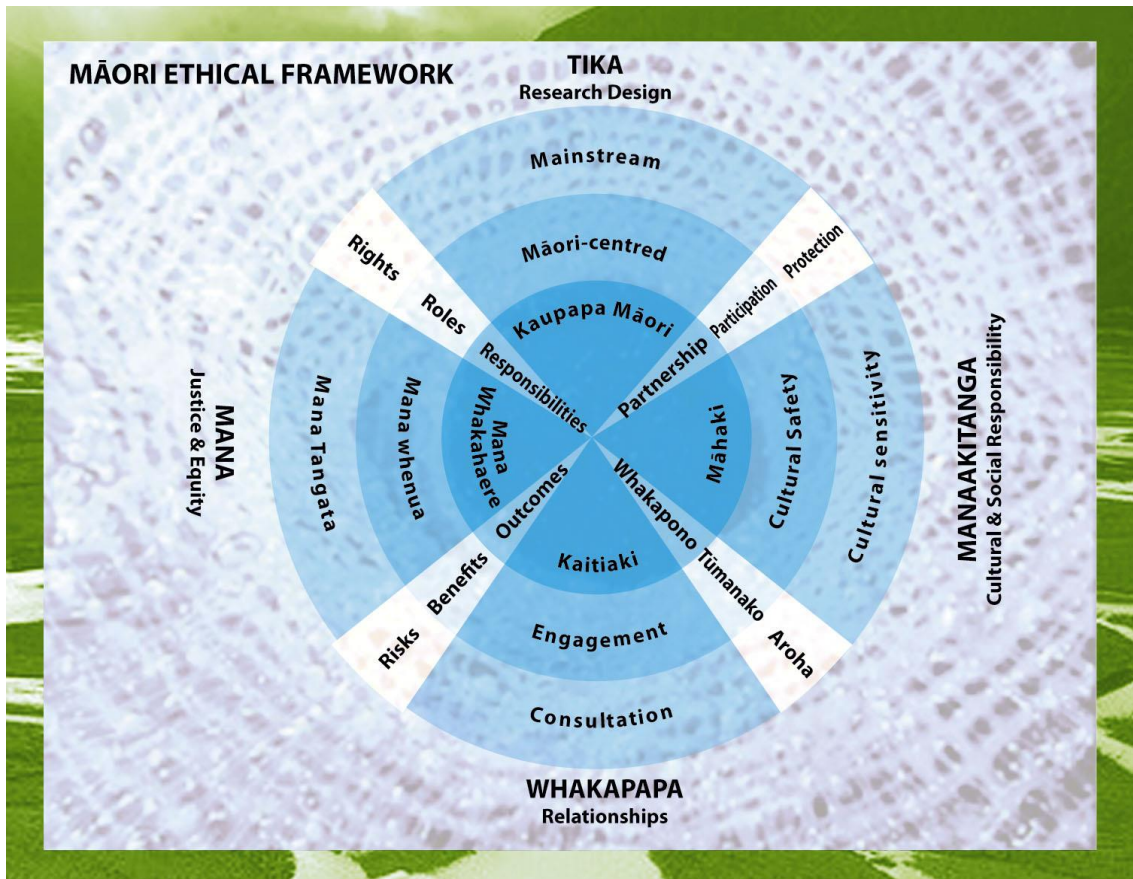


Figure 2: Te Ara Tika framework (reprinted with permission from Hudson et al, 2010)

Whakapapa – He aha te whakapapa o tēnei kaupapa?

The key question for Whakapapa is “What is the genesis of this project?”

In this context the genesis refers to both the origins and purpose of the project. The primary concern of the Whakapapa section of Te Ara Tika is relationships, with consideration as to how and why they are formed and how they are maintained and monitored. At a basic level the researcher is expected to exhibit care through a basic level of consultation. At a good practice level the researcher will move beyond consultation to a higher level of engagement with a focus on ensuring that the tangible benefits of the project align with the aspirations (tūmanako) of Māori participants. The best practice level is termed Kaitiaki, which connotes both caretaking and a level of leadership.

As noted above, the origins of the research came from my concern that additional suffering was occurring for the partners and families of people with serious brain injury as a result of the lack of appropriate supports for partners and families. The intention of this project was to operate at the good practice level of Engagement from the outset, and to strive towards

Kaitiaki through its development. Care was taken throughout the consultation process which began early and reshaped the project from the beginning. Consultation occurred with Māori mentors who I met with via my initial placement within a rehabilitation research team, and who in turn directed me to another woman with strong links with the community of Māori with disabilities and (whānau hauā) and with mana whenua.

Throughout the project, the importance of relationships with Māori and community was central at all stages, as is discussed further in the Community-Based Participatory Research section below and throughout the thesis. Relationships with and within the research group were nurtured and monitored through the project.

Tika - Me pehea e tika ai tēnei kaupapa?

The key question for Tika is “How will the project proceed correctly?”

Tika connects to the concepts of being good and being correct. Within Te Ara Tika it is concerned with the design of the research and embraces how the project will be of benefit to Māori, ways in which it could cause harm, and the involvement and/or leadership of Māori at the various stages of the project. In Te Ara Tika the minimum, good and best practice standards are named Mainstream, Māori-centred and Kaupapa Māori, respectively. During the development of this project I thought through the following of Linda Smith’s questions (L. T. Smith, 1999, p. 173) which have been used within the tika principle of Te Ara Tika.

- Who defined the research problem?
- For whom is the study worthy and relevant? Who says so?
- What knowledge will the community gain from this study?
- What knowledge will the researcher gain from this study?
- What are some likely positive outcomes from this study?
- What are some possible negative outcomes?
- How can the negative outcomes be eliminated?
- To whom is the researcher accountable?
- What processes are in place to support the research, the researched, and the researcher?

While these questions are used in determining whether research meets the best practice standard, Linda Smith recommends that they are appropriate to be asked when working cross-culturally.

Within this project the research was defined in consultation with Māori mentors and the Brain Injury Association (Auckland). The study is relevant to whānau of people with serious brain injury (whānau with ABI), and relevant to the brain injury rehabilitation research community, practitioners and funders. It was also deemed to be of relevance to local and whānau hauā communities, via consultation with Māori mentors, Ōtara Network Action Committee, Te Roopu Waiora and Mana Whenua I Tamaki Makaurau.

The anticipation at the outset was that the community would gain knowledge through a greater understanding of how to increase the capabilities of whānau of people with serious brain injury to live their lives in the ways they have reason to value. Given that the research is participatory it was also anticipated that the co-researchers would gain skills and knowledge in conducting research, working together to determine action, carrying out whatever action would be chosen, determining proper processes for data collection and evaluation and building skills and confidence in speaking to others at the dissemination stage. As the researcher, I expected to gain knowledge in working effectively with communities and how to conduct research in a way that was respectful and effective. I hoped that we would together develop knowledge in effecting change within systems.

The positive outcomes that were anticipated from the study were an increased understanding of the needs of whānau and an actual project that would help to address some of these needs. I also hoped that we would begin the development of a sustainable project that would have ongoing benefits to whānau. From my knowledge of brain injury and behaviour change it is my expectation that by improving the well-being (or capabilities) of whānau we would also improve the well-being and capabilities of their family members who had serious brain injury.

One negative outcome that I considered was that given that much of the research would focus on the needs of people who are part of groups who have been marginalised (Māori, Pacific and low-income) there was a risk that those groups would somehow be blamed for exhibiting their particular needs, as this has been a dominant discourse in cross-cultural research in the past. By including co-researchers who were Pākehā and not from a low-income background, I felt that it would demonstrate that the needs were shared by whānau from across the range of social and ethnic backgrounds of our community.

I was also concerned that the co-researchers could be exploited within the research project, and that the act of participating in the research would not be beneficial. My biggest fear was that the project would collapse before completion as I had read of research projects, including PhDs where projects were not completed. In order to eliminate these risks the research budget had a strong focus on koha for participants, and each meeting included a generous, healthy and (largely) home-cooked meal as well as tea, coffee and cake. Throughout the project we checked on the relationships within the co-research team and people were clear of the importance of this as a part of the whole design.

As researcher I considered myself to be accountable primarily to the co-researchers who agreed to participate in the project. Additionally I was clearly accountable to the Health Research Council, Auckland University of Technology, my supervisors and mentors, the Brain Injury Association (Auckland), Mana Whenua I Tamaki Makaurau and with the project being based in Ōtara, to the Ōtara Network Action Committee. Supports that were put in place for the research and the researcher included supervision and mentoring. Counselling support was available through both AUT and the Brain Injury Association (Auckland) for co-researchers.

The fact that I sought to work at a high standard in each of the areas of the tika principle does not, however, make this Kaupapa Māori research. While I am clear that it is possible for Pākehā to develop and conduct research with Māori, and that it is important for this to occur, for the reasons outlined above, this does not make the research Kaupapa Māori research. This research is appropriately located within the Māori-centred level of the tikanga principle. Good

care was taken throughout the project to have a significant level of Māori participation as well as accountability to Māori from the pre-research phase through to the action phase and dissemination.

Manaakitanga – Mā wai e manaaki tēnei kaupapa?

The key question for Manaaki is “Who will ensure respect is maintained?”

Manaakitanga focuses on ensuring that the mana of everyone involved in the process is upheld and links also to the protection and recognition of wairua, or the spiritual well-being of each person. At a minimum standard, termed “Cultural Sensitivity”, it is expected that each person’s dignity is acknowledged and that there is reasonable care. A good practice level is termed “Cultural Safety”, and research at this level will likely involve collective participation, the opportunity for the inclusion of whānau, and the incorporation of Māori values and protocols. The best practice standard is “Māhaki” which links to a higher level of understanding and practice in terms of deeper relationships, drawing on spiritual knowledge and understanding, as well as sound knowledge of Māori philosophies which allow for sound practice on spiritual matters.

Māori values and concepts were paramount throughout this project, with the concept of most importance being whānau and strong values of aroha and manaakitanga that were talked about through all stages of the development. The strength, importance and role of whānau was felt through all stages of the project. Co-researchers attended as the result of an injury to a family member and also often brought whānau members to our project hui, whether this was a husband or sibling for support and to increase their engagement and knowledge of brain injury, or a moko who could learn and contribute and also needed to be fed and looked after for the evening. People had strong and sometimes differing ideas about the project development but were guided in working through these ideas by the importance of respect and aroha. As the project developed to being a wānanga to be held at the marae of one of the co-researchers, it also became important that we all had adequate understanding of tikanga Māori to uphold the mana of both the marae and of the project.

Privacy and confidentiality has been determined by co-researchers, with some co-researchers choosing to maintain the confidentiality and privacy that was assured from the outset, and others choosing to take a more public role in their advocacy for the well-being of whānau of people with serious brain injury.

Māori protocols were observed through opening and closing karakia for each hui, and karakia kai before each meal. While it had been my intention to offer karakia at these times, it also came from the co-researchers that these practices were considered to be important for the safety of the co-researchers and for the protection and betterment of the project. It was considered whether kaumatua, kuia or a priest would be able to have a beneficial role for the research group, but the group decided to proceed with the co-researchers who had come forward through the recruitment process. Kaumatua were recruited later on when they were needed for the action stage of the research in order that we could participate on a marae appropriately.

Throughout the PhD stage of this research, the project has operated at the good practice level of Cultural Safety, though towards the end of the project, as relationships were built and strengthened it would have operated at the best practice level of Māhaki.²³

Mana – Kei a wai te mana mō tēnei kaupapa?

In the Te Ara Tika framework, mana relates to justice and equity, and the key question is “Who has control over the project?” At the minimum standard level (mana tangata) the focus is on the mana of the individuals who choose to be involved as participants; the good practice level (mana whenua) includes involvement, consultation and respect for the local iwi and hapū, or the mana whenua. At the best practice level (mana whakahaere) the project will have significant Māori control.

In this project, I came in as an outsider and chose to partner with the Brain Injury Association (Auckland) which has a history of being a Pākehā-led and dominated group. They

²³ Future plans for the project will likely take it to a Mahaki level

asked me to work in South Auckland with the Liaison Officer who is also Pākehā. The intention and action throughout, however was to develop a project that would work well for Māori, with the expectation that this focus would also be effective for non-Māori. Māori mentors helped to influence the shape of the project, but did not have control. They linked me to the support provider for Māori with disabilities in South Auckland, Te Roopu Waiora, whose CEO was a committee member for Mana Whenua I Tamaki Makaurau, which is a collective group which brings representation from the many iwi that have jurisdiction within the wider Tamaki Makaurau rohe (region). The relationship during the development of the project was purely with this one person, and it was recommended that the appropriate level of involvement was for me to inform mana whenua of the project developments.

During the project, through one of the co-researchers, we built stronger links with Waikato Tainui, initially through the wānanga that was conducted at her marae (Weraroa Marae in Waikaretu). As our work, through the Brain Injury Whānau Action Project (BIWAP), continues to develop, these links are being strengthened, with the intention of this building to a partnership relationship. While the project was researcher-initiated, which meant that it was non-Māori initiated, we have worked to ensure that the role of participants is one of co-researchers, and that the co-researchers together determined the direction of the project, contributed to the collection of data, ratified and modified much of the analysis, and are integral in the dissemination phase. This ensured that the research has relevance to Māori. With the ongoing development of the project the leadership roles of BIWAP (Chair and Secretary) are now being carried out by Māori women who were formerly co-researchers.

This project has been conducted at the Good Practice level of Mana Whenua. While the relationships with mana whenua were at a somewhat arms-length level to start with, these relationships are deepening. One of our goals has been to maintain collaborative relationships with other organisations who seek to support individuals and the families of people with brain injury, and the suggestion is now coming through strongly that our role in working with a Māori focus is strongly appreciated by the Brain Injury Association and they wish to see our work

continue. In order for the work not to be taken over by a mainstream focus, the Auckland manager thinks it will be beneficial for us to maintain a co-operative relationship but to form our own independent charity so that we can continue to serve whānau.

Community-Based Participatory Research

Community-Based Participatory Research (CBPR) provided the framework to explore how to increase the capabilities of whānau of adults with serious brain injury to live their lives in the ways they have reason to value. CBPR is seen not as a method, but as an orientation (Minkler & Wallerstein, 2008b). At its core the focus is on a partnered enquiry between the community, who are affected by an issue, and researchers who share the purpose of achieving social change that will reduce health disparities (Wallerstein & Duran, 2010).

CBPR was a natural fit with the ethics of Māori-centred research and the philosophical framework of the Capability Approach. Each of these paradigms share the focus on respecting, listening to and developing from the ideas and values of the community (or whānau, hapū, iwi), and the purpose of achieving change to benefit peoples lives in actuality. The Capability Approach reflected and further shaped my thinking about the unnecessary suffering of whānau with serious brain injury being a remediable injustice, and framed the research question of how whānau could better live their lives in the ways they have reason to value. The Māori-centred ethical orientation is right and tika for conducting whole-population research in this land, with its constitutional founding of a partnership treaty. Community-based participatory research brought the tools and thinking for putting these ideals into practice.

I knew that I was on the right path with this combination when I read Graham Smith's writing about Freire (a key philosopher that CBPR draws on).

"A key understanding here with respect to the relationship between Māori resistance and Freire's ideas, is that Māori did *not* go out and buy Freire's book and *then* apply his ideas as some kind of recipe for liberation and emancipation. On the contrary, most Māori (and this was certainly my own experience) came to Freire after they were well involved in resistance and struggle. The point is that for many Māori, Freire's writings provided support, direction, validity and confirmation of what they were already doing. Thus, Freire's manifesto, *Pedagogy of the Oppressed*, provided a theoretical

reinforcement for and an intellectualisation of the struggles which for the most part were already happening on the ground." (G. H. Smith, 1999, p. 36)

CBPR falls within the broader framework of Participatory Action Research (PAR). The idea of research which had an action focus had enormous appeal to me as a clinician as it would allow me to do, and to research the doing. My hopes were that this would result in a project which was, at the least, useful to the people and community involved in it and ideally that would also contribute to the knowledge base for both clinicians and researchers. Achieving this goal, however, relies on a solid understanding of how communities and academics can partner in ways that are of sufficient benefit to both that there is a reason for the partnership to continue, and that other communities may also be inspired (and feel safe enough) to engage in this style of academic research. The following section outlines the development of CBPR and how this influenced the pathway within this methodology that I chose. The principles and processes that guided my thinking, and were shared with the co-researchers, and later used by our group to evaluate the way in which we had conducted CBPR in the Brain Injury Whānau Action Project, are then outlined.

Development of CBPR

Amongst CBPR academics, participatory research is often described as having two traditions; a Northern and a Southern, with the Northern tradition linked to the work of Kurt Lewin and the Southern to the work of Paulo Freire (Wallerstein & Duran, 2008). Kurt Lewin was a German Jewish scholar who left Germany when Hitler came into power and continued his work in management systems in the United States until his death in 1946. Kurt Lewin's initial work has been further developed within the field of management and education. His work was revolutionary within the social sciences as he sought the input of subjects, rather than simply observing them and looked both at the object of his interest and the environment in which it was located (Adelman, 1993). Within CBPR circles his work is often seen as conservative and of benefit to management processes, rather than the subjects. It was interesting to me to learn that Kurt Lewin's work did have a clear intention of community change, with his focus on anti-

racism and in particular anti-semitism during World War II. His methods have been used in action research. Lewin's belief was in the process of research, action and education, and that education would lead to change – if people know then they will change. This work operates on an assumption that those with power (such as managers) will listen to those with less power (such as workers). This model of how change can occur aligns with functionalist theories of change (Stoecker, 2007). When the focus is on the things that those with power want, such as increased productivity, then it can be understood that this can happen, provided there are insights from one end of the process that had not been apparent to those with control over the process. But when the change that is being sought is wanted by those with less power and not wanted by those with power then it is hard to see how this can occur. The lesson for me, in learning of this history is how work that is developed with one intention can be co-opted for other purposes. This idea is explored further in the section on Risks of CBPR.

Paulo Freire's work, in his lifetime, had an explicit emancipatory intent. He taught farmworkers to read through a process that had a deliberate intention of causing them also to think about their situation and through this to seek change. This awareness raising, of their own situation, he termed *conscientization*. While Freire and other emancipatory researchers and theorists have been more aligned with conflict theory, it is the process of both action and reflection which Freire terms "praxis", which is seen as essential to achieving sound change:

"The insistence that the oppressed engage in reflection on their concrete situation is not a call to an armchair revolution. On the contrary, reflection - true reflection - leads to action. On the other hand, when the situation calls for action, that action will constitute an authentic praxis only if its consequences become the object of critical reflection. ...Otherwise, action is pure activism." (Freire, 2000, p. 66)

While Freire's emphasis is on reflection leading to action, Graham Smith has noted that this process may be circular as he believes that it is just as likely that action can lead to reflection (G. Smith, 2004).

One warning of Freire's, which I am particularly mindful of, is the risk that outsiders from the dominant class can pose when they are involved in seeking social justice for marginalised groups:

"...certain members of the oppressor class join the oppressed in their struggle for liberation, thus moving from one pole of the contradiction to the other. Theirs is a fundamental role and has been so throughout the history of this struggle. It happens, however, that as they cease to be exploiters or indifferent spectators or simply the heirs of exploitation and move to the side of the exploited, they almost always bring with them the marks of their origin: their prejudices and their deformations, which include a lack of confidence in the people's ability to think, to want, and to know. Accordingly, these adherents to the people's cause constantly run the risk of falling into a type of generosity as malefic as that of the oppressors. The generosity of the oppressors is nourished by an unjust order, which must be maintained in order to justify that generosity. Our converts, on the other hand, truly desire to transform the unjust order; but because of their background they believe that they must be the executors of the transformation. They talk about the people, but they do not trust them; and trusting the people is the indispensable precondition for revolutionary change. A real humanist can be identified more by his trust in the people, which engages him in their struggle, than by a thousand actions in their favor without that trust." (Freire, 2000, p. 60)

CBPR acknowledges these risks, and has developed principles that hopefully help to counter them.

CBPR principles

A set of principles have been developed as a general guide for conducting CBPR (Israel, 2005; Israel, Eng, & Parker, 2013; Israel et al., 2008) with the understanding that each project community will also need to develop its own guidelines and determine what principles are important for that community.

The following principles (Israel et al., 2008) used in the development of this project were discussed with the co-researchers and later used to evaluate our own CBPR project:

1. CBPR recognizes community as a unit of identity
2. CBPR builds on strengths and resources within the community
3. CBPR facilitates collaborative, equitable partnerships in all research phases and involves an empowering and power-sharing process that attends to social inequalities
4. CBPR promotes co-learning and capacity-building among all partners
5. CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners

6. CBPR emphasizes public health problems of local relevance and also ecological perspectives that recognize and attend to the multiple determinants of health and disease
7. CBPR involves systems development through a cyclical and iterative process
8. CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process
9. CBPR requires a long-term process and commitment to sustainability.

These principles seek to actively work against the pitfalls of much previous social research which had tended to highlight perceived weaknesses in marginalised communities and imposed solutions by outside experts. The principles work to achieve sustainable community-developed changes that benefit participants, their communities and the researchers. While the principles emphasise balancing research and action, it was Randy Stoecker's (2005) emphasis on getting involved at grassroots and embedding yourself in the community that guided my first steps.

Working with indigenous people

A strong appeal of CBPR was its focus on how to work effectively with marginalised groups. CBPR draws on the concept of cultural humility of Tervalon and Murray-García (1998) which I had found a useful concept as a clinician. LaVeaux and Christopher (2009), from their work with Native American communities, examined the principles listed earlier in terms of the literature on working with indigenous people and added the following specific principles for using CBPR within the indigenous context:

1. Acknowledge historical experience with research and with health issues and work to overcome the negative image of research
2. Recognize tribal sovereignty
3. Differentiate between tribal and community membership
4. Understand tribal diversity and its implications
5. Plan for extended timelines
6. Recognize key gatekeepers
7. Prepare for leadership turnover

8. Interpret data within the cultural context
9. Utilize indigenous ways of knowing

While my work already drew on a Māori-centred ethics and was influenced by my reading of Kaupapa Māori research principles, I deliberately drew on the first principle by specifically discussing the term “research” in order to draw out people’s experience of this alongside their experiences of brain injury. Interestingly the principle (7) of preparing for leadership turnover has not proved to be an issue within the community in terms of our indigenous connections, but has been much more relevant to our links with ACC.

Finding the starting point and balancing power

In order to gain approval for the project I needed to engage with stakeholders at a community organisation level – the CEO and managers of the organisations of Ōtara Network Action Committee, Brain Injury Association (Auckland) and Te Roopu Waiora. From my reading, a natural next step from this was to set up a Community Advisory Board of key stakeholders to guide the community engagement and the research project (CDC/ATSDR Committee on Community Engagement, 2011; Newman et al., 2011; Quinn, 2004; Strauss et al., 2001; D. Wilson & Neville, 2009). This plan was, however, challenged by an academic reviewer of the research proposal as being too directive, which she foresaw could work against true ground level community participation. This had me grappling to find a proper starting point.

Jones, Koegel, and Wells (2008) note that the preparation phase is essential and that there can be significant lead time. Their focus on community-partnered research, which they distinguish from community-based research was important for this project. A partnership is a relationship, and relationships take time to develop as each party becomes clear about what they want, how much they trust, what will foster trust, and what they can and are prepared to contribute. My concerns in both finding the starting point and balancing power were well-founded. I was aware of many projects that had failed, and had read a great deal about the risks of outsiders stepping into areas that are not their own in order to help .

Given that CBPR is frequently used to work with marginalised communities and to address health inequities (Wallerstein & Duran, 2006) and that there are many barriers for people from these communities to pursue academic careers, it is often the case that the academic is white and from a privileged background while community members are predominantly from lower socioeconomic groups and indigenous or non-white immigrant backgrounds (Stoecker, 2008). This sets up a situation that is rife for misunderstandings and the risk of researchers seeing problems as due to deficits in the communities and solutions needing to come from the outside (Chávez, Duran, Baker, Avila, & Wallerstein, 2008).

Working in South Auckland as a Pākehā PhD student with a professional background meant that there were several layers of privilege (ethnicity, professional and socioeconomic), which I did not want to intrude into the research. I initially considered that my role should be one of a servant researcher. Reading Ristock and Pennell convinced me of their idea that "To use power responsibly as researchers means to strengthen, not diminish, our capacity to affect the world while holding ourselves accountable for our actions" (Ristock & Pennell, 1996, p. 10). Working out the 'how' of achieving this I explored the advice of many writers and organisations (CDC/ATSDR Committee on Community Engagement, 2011; Cervin, 2001; Cooke & Kothari, 2001; Jordan, 2003; Kemmis & McTaggart, 2000; Labonte, Polanyi, Muhajarine, McIntosh, & Williams, 2005) but drew most from Vivian Chávez and colleagues (Chávez et al., 2008) and Randy Stoecker (Stoecker, 2005, 2007, 2008, 2013). Various methods were described to ensure that academics and community members did not fall into the familiar patterns of people with privilege telling people with greater challenges how to better live their lives.

It was sadly interesting to see this very situation played out in Ōtara when a wealthy, overseas-based, Pākehā businessman announced, with a great deal of publicity, that he would be putting \$8 million into Ōtara for community projects to increase community strength and well-being. One of his first actions was to bring in a US expert to speak to locals on asset-based community development. Many of the local community workers I met with were strongly sceptical of this outsider coming in, even before the difficulties with the trust that was to provide

the funding became apparent. While Owen Glenn had clear ideas about which projects he would fund, it also had the effect of other projects having greater difficulty accessing funding because of the perception that their community was now awash with money. Ultimately only a small amount of the promised money was delivered as the businessman put his attention to another, larger project where he sought to solve a different nation-wide problem of child abuse, through his money and his hired expertise (Theunissen, 2014).

The advice that seemed most practical was to see the work as “a social change project of which the research is only one piece” (Stoecker, 2008, p. 111). This stance allowed me to think in terms of how best each partner could contribute to the project. In order to achieve a community-driven project I attempted to start with as blank a canvas as possible. While the agreement to partner occurred with the General Manager of the Brain Injury Association (Auckland), the actual real work was with the frontline worker (Michael) who had relationships with local community organisations and people with brain injury and their families. I believe the success of this project was helped by the trusting relationship that Michael and I built. By the time we commenced the project we had worked together for eight months and had come to understand each other’s styles and values. He had shown me the reality of his work in the community and had seen that I was unafraid of the challenges, and willing to work in a way that could make a difference within his community.

A remaining hesitation for me was around the concept of the research project being able to build community capacity. In general the examples of capacity-building that I had read of (e.g. Israel et al., 2010; Stoecker, 2013) included community members being recruited to conduct data collection through tasks such as surveys, interviews and mapping. I questioned whether the communities in which the research was conducted really needed more research skills – when what they may have needed was more housing, better food outlets or better air quality. Attending the CBPR Institute for Health Equity at San Francisco State University in June 2013 helped me to see the power that the community-academic partnership could have. A number of partnerships presented their highly practical work which had achieved step-wise

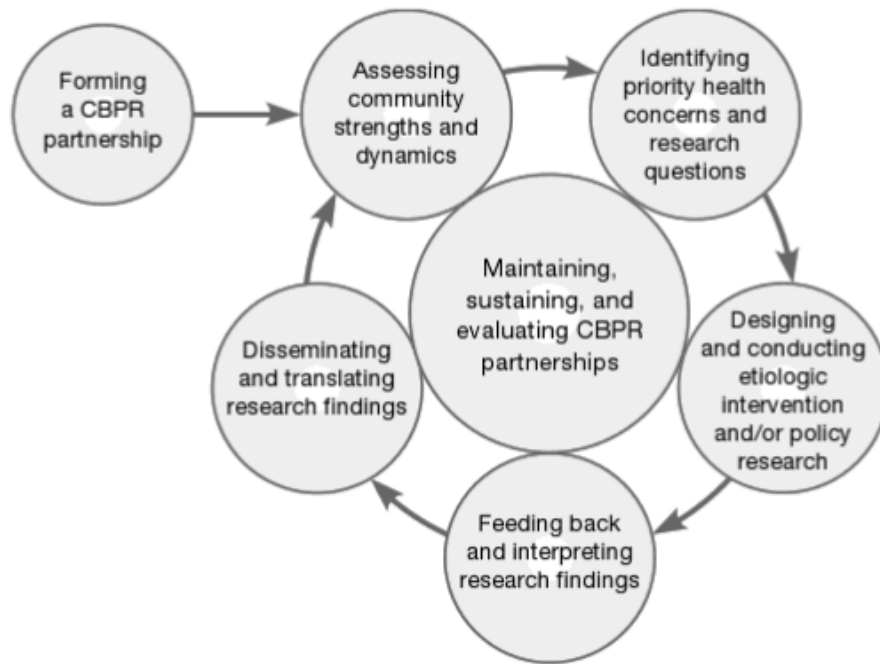
policy change through the combination of powerful stories and sound data on areas that were of high importance to local communities. We learned of worker safety standards in Chinese restaurants being implemented, air quality in a low-income area being improved by re-routing truck routes, and the parents and families of juveniles in the justice system taking charge of the ways in which their own stories were told in order to advocate for policy change. People became tellers of their own stories, and designers of their own programmes for research and intervention. Each presentation was a partnership presentation which modelled the way in which I would later seek to do much of the community dissemination about our own project outcomes.

CBPR core components

At the commencement of the project, I had some hesitations and some fears. My biggest fear was that the project would fall apart before completion. I had read of many projects that had started with good intentions, but due to either time constraints or relationship dynamics, did not achieve their goals. Researchers would then, at times, write about the processes rather than the action (e.g. K. Williams, 2001). This made me uncomfortable, as it had the effect of shifting participants from their intended role as co-researchers to the researched, which seemed to me to be a betrayal of the principles which I had chosen to align with for this project. In order to reduce the likelihood of this negative outcome, much attention was placed on the principles outlined above, and the core components which are shown in the following section.

Drawing on Israel and colleagues again (2013) gave us the step-by-step process for the development of the project.

Figure 3: Core components/phases in conducting CBPR



Source: Israel, Coombe, & McGranaghan (2010)

The diagram above (Figure 3) was presented to co-researchers for their understanding of what we were trying to achieve, and a simplified version (presented in the “Method” chapter) was also used in order to convert to lay-person language. The central focus on *maintaining, sustaining, and evaluating CBPR partnerships* was emphasised as I knew that it was important we attend to both process and action in order for the project to be successful and achieve meaningful outcomes.

Pre-research phase

Randy Stoecker talks of the importance of building the relationship with the community, especially if you are coming in as an outsider (Stoecker, 2013). Within the university system, I struggled to know where the actual starting point was in terms of what required ethical approval as research, and what was pre-research and community-building.

I thought a lot about what would be important to sustain a group through the very many meetings to take this project from an idea to action. I was aware that a lot can happen in people's lives and that in any group, people can have varying levels of commitment and energy. One analogy that seemed particularly sound was Jones, Koegel and Wells (2008) idea of 'the bus' which acknowledges that not everyone will be on the journey for the entire duration of the project, and that people could join and leave as they needed and as the project needed. We discussed this idea from the first groups and acknowledged that we might bring in people in different roles, i.e. not necessarily co-researchers, depending on what would contribute to whatever action we chose.

University requirements meet CBPR principles and practice

In order to become a doctoral candidate, the university expects to know what a student researcher intends to do, and that the student has the capacity to conduct the research ethically and effectively, and within a reasonable time frame. CBPR has challenges in two of these areas. Time frames for both community work and respectful work with indigenous groups are known to be longer than typical academy-based research expectations (Chávez et al., 2008; Stoecker, 2007). For the researcher to be completely prescriptive about time frames would involve a level of control and imposition that could detract from a community-partnered approach. Knowing exactly how the research will proceed would also mean that the researcher was not being guided by the community. As noted above, the risk of projects not being completed was also an issue, and this risk was explained to co-researchers at the outset.

Ethics

University ethics processes can be quite a challenge within Community-Based Participatory Research. While the university processes are designed to ensure the ethics of what will happen, before it happens, the iterative nature of community-based participatory research means that what will happen cannot be known in advance. Co-researchers were aware that we would need to obtain ethical approval for the action that we determined, and a two-stage ethics process was built into the design.

Tying it all together

A natural compatibility exists between Māori-centred research and Community-Based Participatory Research as was discussed by Graham Smith in his assessment of the parallels with Freire's work. Sen's work too fits in with this methodology in a way which is both compatible and complementary. This compatibility has been explored by Glassman and Patton (2014), who note that the work of both Sen and Freire are grounded in beliefs that the knowledge of local people, especially those from oppressed or marginalised groups, is essential in developing solutions. From Freire's perspective these solutions exist through emancipation and conscientization which occurs as a result of a reflection – action – reflection cycle (praxis) (Freire, 2000), and from Sen's they increase freedom through increasing people's capabilities to live their lives in the ways they have reason to value (Sen, 2010).

The Capability Approach brings a human rights agenda and the understanding that where an injustice is observed we have a responsibility to address this. Māori-centred ethics acknowledges tangata whenua and mana whenua, as well as bringing clear guidance around nurturing respectful relationships. CBPR focuses the research project on community-based action that contributes to social justice. My experience has been that each of these knowledge bases have contributed synergistically, so that learning from one area, has added to my understanding within an other.

By using CBPR principles and a declared Māori-Centred approach, with awareness of working respectfully with indigenous and careful attention to power, the project naturally moved to a place that upheld more and higher values in terms of the Te Ara Tika framework. I believe that the location of the project being on the marae – and the idea of the project coming so powerfully from a community member, enhanced the power balance towards whānau, as did our situation of all being learners in putting together the project.

Chapter 5 – Method: "OK, so what shall we do?"

In explaining the project to others, and also to the co-researchers, as we built our understanding of what Māori-centred CBPR would look like for us, I would often tell people that it was really about getting a group of people together, with a shared interest or concern, and then saying “OK, so what shall we do?”

With Māori-Centred Community-Based Participatory Research as the methodology, it was important that the methods reflected the tikanga principles of Te Ara Tika, that the cultural values outlined by Linda Tuhiwai Smith were demonstrated in practice, and that the principles of CBPR were upheld. The following section shows how each of the Tikanga Principles and the CBPR Principles outlined in the Methodology Chapter were applied to this project. The actual steps that were taken during pre-research and Phase I are outlined. Given that this research is participatory, which is iterative and cyclical, the concepts of “method” and “results” then become somewhat blurred as what we find determines what we then do, which leads to more findings. The Results chapter starts with the findings from Phase I, and then moves into the doings and findings of Phase II, as well as outlining the community dissemination steps and actions to build towards sustainability.

Tikanga principles

Whakapapa

The first step in any human process is connection, to meet and greet. How this is done can shape the tenor of the whole process. My primary motivation for this project came from the relationships, at various levels, that I had with individuals and whānau of people with serious brain injury, linking back to my close friend who was injured 30 years ago and her mother. Within this project the first relationship to re-establish and formalise was with the Brain Injury Association of Auckland (BIA-AKL), and with the Liaison Officer in South Auckland. I met with the general manager of the BIA-AKL to discuss the possibility of the research. From the outset he was supportive of the idea and the project and recognised the value that could be achieved

through partnership (Appendix E). The general manager was keen for the work to commence in South Auckland which fit with my goal of developing solutions with a community who were less well-served. To formalise this relationship he requested a one-page summary for the BIA (Auckland) Board (Appendix J).

Mentor relationships were established with Charmeyne Te Nana-Williams, who I had known for many years prior to the start of the project (Appendix D) and Dr Huhana Hickey, who I came to know through working at AUT University (Appendix F). Charmeyne Te Nana-Williams, following her husband's serious injury, has established a business supporting whānau with high support needs to have whānau-friendly packages of care. Dr Huhana Hickey is an academic who focuses on the experiences and needs of Māori whānau hauā (Māori with disabilities). Through their mentorship, I was introduced to Tania Kingi who worked as the CEO of Te Roopu Waiora, a support organisation for whānau hauā. The process of meeting with Tania Kingi, demonstrated her commitment to the well-being of her organisation and the people that they serve. Prior to meeting with me she asked me to respond to the questions that her organisation ask of any researchers who wish to engage with them (Appendix G). The focus of the questions was on how the project will uphold the principles of Te Tiriti o Waitangi, and how it would benefit participants. Many of her questions bore a striking similarity to the cultural values that Linda Smith (1999) considers important to conducting research, which were outlined in the Methodology. Tania Kingi also provided the link and liaison with Mana Whenua I Tāmaki Makaurau (Appendix H and Appendix I).

Community relationships were built within Ōtara through discussions with the Ōtara Network Action Committee (ONAC) CEO, followed by a presentation to their committee once our project had started (Appendix K Appendix L). Further discussions with staff at the Ōtara Library, and Ōtara Health, and links built with local board council members, council staff and other active citizens within the community strengthened the community links for the project.

Tika

In order for Māori-centred research to meet the criteria of being “tika”, it is expected that Māori will have significant roles throughout the research, including design, conduct, data collection, analysis and dissemination. While the research project was Pākehā-initiated, following consultation with Māori mentors it was re-designed, and it was ultimately defined by the co-researchers who were a mix of Māori, Pākehā and Pacific Nations.

This project was designed so that it would have significant engagement with Māori. Throughout the various stages of the project half, or more, of the participants have been Māori. The project has been designed in partnership, and this partnership resulted in the research question shifting from looking at the needs of the partners of people with brain injury, to looking at the situation of whānau. The final action project of running a wānanga on the marae of one of the co-researchers, reflects the collaborative nature of the design and conduct of the research.

For a design to be tika, there is an expectation that the project will benefit Māori as participants, researchers and advisors. The participants in this project worked in the role of co-researchers. Financial acknowledgement (koha) of their knowledge and time contribution was in the form of \$50 petrol vouchers. Other planned benefits were in the area of capacity-building as our group developed the skills to pool ideas, analyse situations, plan a major event, source sponsorship and evaluate feedback. Further capacity-building was demonstrated as co-researchers also became speakers at the wānanga in our roles as hosts, and in ongoing activities where we have fed back information to the community groups and providers who have supported the project.

Manaakitanga

The questions which are central to respecting the tikanga principle of manaakitanga are:

- Are Māori values or concepts used within this research project?
- How will Māori protocols be observed as part of the research project?
- Are whānau able to support participants within this project? (Hudson et al., 2010, p. 12)

The primary concept in this project was whānau and the primary value was respect, which was evidenced through listening and effectiveness. Māori protocols were observed in how we came together. Participants joined this project and became co-researchers as a result of their role of supporting a whānau member who had a serious brain injury. Throughout the project co-researchers brought family members along to our meetings - at times this was a moko who was staying with them, a husband so he could attend when the woman was not able to attend, a sister for support and because she was interested. For the action part of the project, whole families attended the wānanga, some brought only one family member and the largest had seventeen attend from their whānau. In the ongoing mahi (work), whānau involvement and purpose remains crucial.

Mana

In order to honour the concept of mana, relationships were built to ensure that the right people's and groups' ideas shaped the project from the outset. A relationship was established with Mana Whenua I Tāmaki Makaurau via Tania Kingi so that mana whenua were aware of the research being conducted and able to consent to or challenge the research. At the community level of Ōtara, a relationship was also established with Ōtara Network Action Committee for this same purpose. Prior to commencing recruitment, the research idea was discussed with clients who had sustained brain injury and were supported by Michael Denton, the Liaison Officer for Auckland Brain Injury Association, at one of their regular monthly meetings. As the project progressed and it was determined that a wānanga would be held at Weraroa Marae in Waikaretu, the relationship with this group/hapū was formalised through our co-researcher, Leeanne, who belongs to this marae.

These same groups have since been re-contacted in order to update them on the action that did occur and for them to have an opportunity to be involved in the ongoing work of BIWAP.

CBPR principles

1. CBPR recognizes community as a unit of identity

The initial community that the project linked with was the Brain Injury Association of Auckland. Through this connection I was directed to the South Auckland BIA Liaison Officer and we jointly worked to recruit whānau who had an interest in improving the lives of whānau with brain injury. In effect the project connected with a community, and then built a section of that group into a community of its own.

2. CBPR builds on strengths and resources within the community

The key strength and resource that this project was built on was the passion and commitment of the whānau members involved in the project to achieve positive change for themselves and other whānau. Local speakers from the university partner contributed to the programme, as did people who had connections to BIWAP co-researchers. The wānanga was based at the marae of one of the participants. The café owners near the marae supported the project through opening their glow-worm cave to be one of the children's activities and supporting the children's bushwalk activity. Co-researchers also tapped into their own networks for food and prize donations and for kitchen and clean-up workers (ringawera).

3. CBPR facilitates collaborative, equitable partnership in all research phases and involves an empowering and power-sharing process that attends to social inequalities

Throughout each of the phases of the research, decisions have been made in consultation with others. Initial decisions about the intended scope of the project were made with the community partner (BIA of Auckland) and mentors, and once co-researchers were recruited then decisions were made through project meetings. From the first meetings it was determined that decisions would be made via consensus, rather than through majority, so that each participant would feel that decisions made and actions planned fitted with their own motives for involvement. In order to attend to power-sharing within the group – especially around discussions – group processes, such as getting people to write thoughts down before each person shared their ideas and we moved to general discussion, were used to reduce the normal group situation of some members ideas being more dominant than others.

4. CBPR promotes co-learning and capacity building among all partners

Capacity building occurred through the range of activities that people were involved in. These included fund-raising, seeking sponsorship, thinking through the activities that were needed, meeting speakers and planning the timetable, planning the children's programme, establishing contracts, co-developing evaluation forms and, in the dissemination phase, participating in public speaking.

5. CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners

Throughout the project, the benefit of partners was seen as paramount and research was built around developing a sustainable project to benefit the whānau of people with serious brain injury, starting with the whānau of the co-researchers.

6. CBPR emphasizes public health problems of local relevance and also ecological perspectives that recognize and attend to the multiple determinants of health and disease

Through exploring the words that I had pre-determined to be important to the project (Family/Whānau, Brain Injury, Research, and Partnership), and discussing in-depth the situation of whānau of adults with serious brain injury, links were apparent between determinants of health and the situation of whānau.

7. CBPR involves systems development through a cyclical and iterative process.

The initial stages of the project took the form of meetings through which we built understanding of the situation of whānau and discussed the sorts of actions that could lead to increasing the capability of whānau to live their lives in the ways they have reason to value. From this process we were able to recognise a range of goals and determine the action of running a wānanga as our initial project.

8. CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process

As was outlined to community partners and contacts from the beginning, the dissemination process has involved coming back to the community with the co-researchers. Various members have presented to our primary sponsor for the wānanga to thank his organisation for their support, to the Ōtara Network Action Committee to recognise the base from where we worked, to the University of Auckland's Centre for Brain Research Brain Day to reach a wider audience, to the liaison officers for Brain Injury Association from around the country to demonstrate what can be done within their own communities, and to the Northern Regional Provider Group when we sought sponsorship for our next wānanga.

9. CBPR requires a long-term process and commitment to sustainability

The BIWAP project is continuing in its Mission of "Educating and strengthening the community to improve the lives of whānau with brain injury". Since the research project occurred, we have sent 10 whānau members to a four-day training in brain injury rehabilitation and have supported the Brain Injury Awareness Day in Rotorua, organised by a whānau that we connected with through our project. Some members of our group have also run an education session at the primary school of one of co-

researcher Leeanne's mokopuna. We have also opened our Facebook page up to others. At a meeting to gain information about becoming a charity, it was decided instead that the invited speaker²⁴ and Leeanne would be nominated to the board for the Auckland Brain Injury Association, on which they now serve.

Through the action project and its evaluation, the vision, values and mission of the group have been more clearly defined and the group is setting itself up for sustainability.

Getting ready: Pre-research and community connection

In order to determine the action for this research, there was a significant preparation and development phase. This began at the very early stage of developing a research proposal, i.e. well before recruitment, through engagement with Māori mentors who had strong community knowledge. The initial partnerships and mentoring have been outlined in the Whakapapa section above and led to the decision to shift the research focus from partners to whānau.

Consultation with mentors

The pre-research phase began with the initial focus on research that would improve the lives of *partners* of adults with serious brain injury. As I have noted, through my clinical work at ABI Rehabilitation, I had worked with people in the early post-acute phase of rehabilitation. Clients would come to our service, from the hospital, as soon as they were medically stable, and would be discharged as soon as their rehabilitation could be better carried out in the community, or their home, rather than in a residential setting. Given the distribution of who is injured, clients tended to be male, and their supporters who visited were predominantly female. Education and support was often offered to families however, given the very early stage of recovery, families were typically in a state of exhaustion and shock and not necessarily able to take on much in terms of learning or supportive therapy. Knowing the impact of brain injury on family and

²⁴ This was my husband Leon – one of the co-researchers had seen a newspaper article on him so learned of his role in Māori accounting and asked him to present to us on governance. He had also attended the wānanga as support for my friend who has a brain injury and was keen to be a part of the wānanga.

caregivers I was extremely concerned as to how the partners and families would cope after discharge.

I met with my mentors to discuss the idea of conducting research to see how partners could be better supported. From the beginning of the conversation they talked about the importance of whānau and their experience that “partners don’t stay”. One mentor felt that the idea of working with partners drew more strongly on Western concepts of the nuclear family, whereas shifting to whānau would allow for partners and any other involved whānau to participate as co-researchers (Mentors meeting, 13 July 2011).

Volunteer phase

Prior to the recruitment phase, I spent eight months volunteering with Michael Denton, the South Auckland Liaison Officer for the Auckland Brain Injury Association, in order to ensure that I had local knowledge and to increase my understanding of the issues that were faced by whānau of adults with serious brain injury in South Auckland (whānau with ABI). Within the volunteering phase I was involved with meeting clients alongside Michael to discuss their support needs, advocating with ACC, delivering food parcels, volunteering as a collector (shaking the bucket) and recruiting other collectors, supporting Michael at family meetings, attending the monthly client group, helping at the summer picnic, assisting people to find accommodation, assisting clients to get into community or residential rehabilitation, supporting Michael at home visits that he thought were too unsafe to do on his own (these typically involved gang members, or ex-gang members). We also met with people from other organisations who worked with some of the clients that Michael worked with such as Public Trust, Salvation Army, Auckland Disability Law in the Mangere Community Law Centre, Ōtara Health, Child Youth and Family Services (CYFS), and the Stewart Centre. Attending the monthly client group meeting felt like a particularly important part of the pre-research focus. When I explained the research to the group, the feedback was that they were positive that the research would be based in South Auckland and would focus on the needs of whānau as many had noticed how the injury they had

sustained had also impacted on their wider whānau, and had been troubled by the lack of support that had been available.

This experience revealed the common stresses and situations that families and Michael were dealing with. It was very clear that he was often dealing with very basic needs of food and shelter. It often felt that Michael was the only ambulance at the bottom of the cliff. Tasks such as organising emergency accommodation while dealing with the enormous difficulty of accessing funding for the accommodation were common, and he spoke of clients who had died, which he attributed to the lack of available and appropriate supports.

Phase I

Recruitment of co-researchers

Once ethics approval (Appendix A) was gained, recruitment was able to begin. Recruitment involved:

- delivering flyers and information brochures to the groups and people that I had met during pre-research
- informing ACC of the project through existing contacts, and meeting with the Serious Injury team at ACC – I had hoped to recruit people via ACC as I was concerned that the whānau who we met through BIA were largely whānau who had had difficulty with the system, which tended to prompt their first contact. I also felt that it was important that ACC have an involvement with the project during its development, rather than simply hearing from us after the completion. If we were to make suggestions for improvements it seemed that this could be heard better if there was already some relationship with the project.
- an interview with the local newspaper resulting in a photo and article (Figure 4). While I had attempted to get a story in the paper through a press release, the news outlet insisted that they would interview and write the story. The upside of an interview was that we did also have a photograph, which generated some interest, but the downside was that the wording and some of the information were not quite what I would have liked. Referring to *people with brain injuries* as “brain injured” does not fit with a philosophy of seeing the person first and the disability second, and the article also did not make it clear that we were seeking the whānau of adults with brain injury. As a result I did have a number of enquiries from whānau of children with brain injury, and I

endeavoured to link them to appropriate supports. The reporter also omitted the 0800 number which allowed people to make phone enquiries at no cost.



Families of brain injured wanted

By ADRIAN EVANS

Families affected by serious brain injury are needed to take part in a study on the challenges they face in surviving cerebral damage.

The study group is led by clinical psychologist Elisa Wijohn and will meet fortnightly at the Brain Injury Association office in Otara.

"I believe that brain injuries are family injuries and know that for many families a brain injury can cause a great deal of stress and difficulty," she says.

Ms Wijohn has an extensive background in brain injury and mental health and is concerned for families after their loved ones leave the rehabilitation unit.

"I believe that families are the experts and if we're going to look to

create some change then this needs to be driven by the families that are most affected and also the most knowledgeable of the situation."

Brain Injury Association liaison officer Michael Denton sees firsthand the effects of brain injury on individuals and their families.

The project is approved by the Auckland University of Technology ethics committee, is supported by the Brain Injury Association Auckland and Te Roopu Waiora and is funded by the Health Research Council through the Disability Placement Programme Award.

■ The brain injury whānau action project is recruiting until May 30. Contact Elisa Wijohn 027 295 8831 or email elisa.wijohn@gmail.com for more details.

Figure 4: Local newspaper article for recruitment

- and meeting with anyone and everyone who the Liaison Officer thought might be interested. As Michael Denton has worked in the community with individuals and whānau dealing with brain injury since 2005 he has extensive contacts and is well-known in Ōtara and beyond. The Auckland Brain Injury Association did not have a database, so contacts tended to be made through word of mouth, i.e. if Michael thought of, or came across, people he thought could be suitable he would discuss the idea of the project with them.

Once a person had expressed an interest in being involved I would arrange to meet with them kanohi ki te kanohi at a place of their choice, which included people's homes, the meeting room which we used at Ōtara, at cafes and at Friendship House in Manukau. At this meeting we would chat to get an understanding of the journey that the person or whānau had been through and their connection to serious adult brain injury. I would then outline the idea of the research project and the principles from which it would operate including that, while the project was

intended to look at the needs, and work to improve the situation of the range of families of adults with serious brain injury, it would operate from a deliberately Māori-centred stance. From this conversation we would jointly work out whether the person or whānau were a match for the project in terms of their interest and ability to commit to an ongoing involvement. The koha (a \$50 petrol voucher for each meeting) was also discussed.

Koha

It was important, in terms of reciprocity, that koha was at an appropriate level and the decision was made with my supervisors that it would be equivalent to two research assistant hours. Some people do seem to get a bit tied up in knots over koha – linking it to inducement, but it was a very necessary part of maintaining the project, and many co-researchers said how much they valued it. If they didn't completely need it for themselves, co-researchers would give it to other family members, and one group member handed hers back in the meetings leading up to the wānanga, in order that we could gift them to speakers attending the wānanga.

Through the recruitment process, I spoke with 32 potential participants. Two of these made contact because of their own injuries, and three because of the injury of a child. Ten of the potential participants made contact after reading the article in the Manukau Courier or Eastern Courier, one was referred via a potential participant who I had already spoken to, and the remaining 21 were contacted via their connection to Michael Denton. I met face-to-face with 26 people from 21 families. At these meetings potential participants received an information brochure and a Participant Information Sheet. From this process some were clear that they were not currently able to commit to the project or, in one case, that their personality would not suit a group situation as the woman was aware that she needed to be the centre of attention. It was also explained to people that while we hoped that people would remain involved throughout the duration of the project, it was possible that people would leave at various times and that new people might join as their own circumstances, and the needs of the project, required.

Building the Brain Injury Whānau Action Project (BIWAP)

Initial meetings: Establishing the group and processes

At the first project meeting four of the ten people we were expecting actually attended. Of those who did not attend, three had texted to say they were unwell and one had a WINZ appointment that she had to attend. We later found that one other person was unwell and there was one person that we did not hear from at all. The focus of this meeting was ground rules and introductions as well as some discussion of the style of the research (Figure 5; Appendix P). Through this process the participants were introduced to their role as co-researchers. From the beginning, the group agreed that meetings would be opened and closed with karakia and that the food would be blessed. The group, at this meeting, consisted of three women whose link to brain injury was through a son, a brother and a mother, and one man whose wife had sustained a serious brain injury while the family were visiting from Samoa.

The ground rules (Appendix O) which were established focused on:

- **respect** - listening when others spoke and allowing space
- **confidentiality** - people could talk to people they were close to about our research, but that they were not to divulge names or other people's personal stories²⁵
- **safety** - people would look after their own well-being and stress within meetings, for example they could leave the room if they felt this was necessary, but would ensure that they also returned. Discussion was had as to whether we would involve kaumatua or a priest in the group to support the safety and carry some leadership within the group.
- **consensus** - the group decided that it was important to work as a group, and that decisions needed to be agreed to by everyone rather than using a majority to determine action.

²⁵ I am aware that classic group formats speak of confidentiality – which can be experienced as a blanket ban. From the outset it was discussed that people might choose different levels of confidentiality and anonymity in their role as researchers. Some would want to be publicly recognised in the work that we would come to do, but might not want their particular stories linked to them, others would choose complete anonymity. Anonymity has been given in this project, unless the co-researcher has stated that they would like more of a known presence.

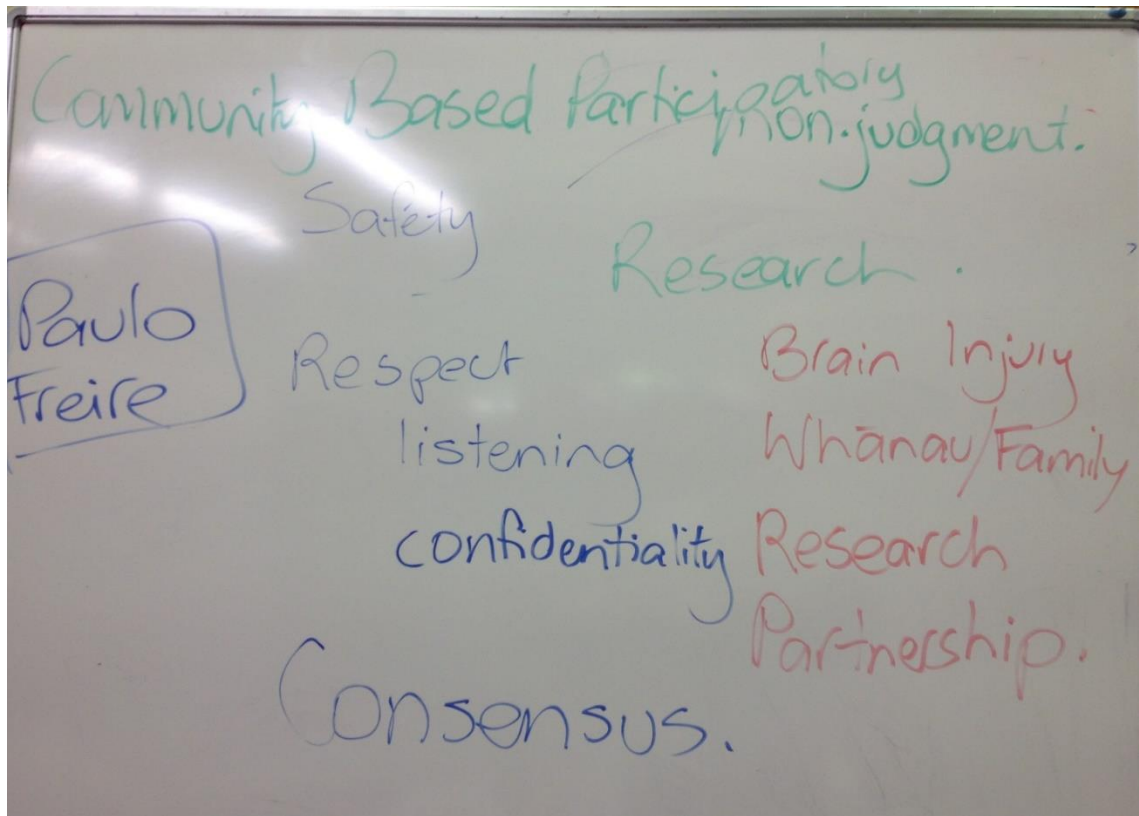


Figure 5: Developing ground rules

Meeting formats

Meetings were opened and closed with karakia. I had started the first meeting with karakia, and the group also brought the idea of karakia in when we discussed safety. A non-denominational karakia had been offered to me by a Māori colleague at AUT. This was offered to the group, and either this would be said by all of the group, or a co-researcher would lead a karakia of their choosing for the group. Any food shared was also blessed with a karakia kai.

Each meeting started with people arriving and having a cup of tea or coffee and a snack. In the early meetings, I would lead an ice-breaker round in order to build connections and so that everyone spoke. These ice-breakers included starters such as “your name and where you’re from?”²⁶ in the early stages, through to “one good thing about your week” in order to bring some balance to the meetings once we progressed into heavier material as people shared more

²⁶ “Where are you from?” is a very typical first question when Māori first meet, as this helps to establish whakapapa and connection. Many of the participants expressed pride in being from Ōtara, the area that the research was based in.

of their stories and spoke about the real impact of brain injury on their lives. Generally at around the half-way mark in the meeting we would break for a meal.

Meetings were audio-taped, though there were occasions when I thought we were recording, but the recording had remained paused after the break. On another occasion an entire session was not recorded as the recorder was set to taping phone conversation, rather than sound from the room. If any of a meeting had not been recorded, I was aware of this at the end of the meeting, so would write down as much as I could from memory and check the information with the co-researchers via email (when possible) and at the next meeting. Ensuring the meeting was recorded became a group responsibility. As the purpose of these meetings was to determine action, verbatim recordings were not considered essential for this stage. They were, however, helpful as I could review the recordings and listen for contributions that I may have overlooked at the time in the busyness and intensity of the meetings.

Co-researchers were aware that while the *focus* of the project was to determine and carry out action that would benefit families, the stories and ideas that were shared were also data which might be evaluated. I was clear that I had come across projects which had collapsed before there was action, and that in these cases the content and process data were evaluated, despite there being no action to evaluate. This was discussed in the context of us setting up sound processes, so that we would not experience a collapse, and also so that people understood the different forms of data we could draw on within the research project. Ownership of the project was also discussed. I explained that my intention was that the Brain Injury Whānau Action Project would belong to the whole group, and that we would be jointly involved in dissemination, but that the PhD was my responsibility, and that because of this I would need to retain ownership of how it would be written. This conversation also ties in with a conversation with the university's research ethics advisor²⁷. He had wondered whether participatory research could truly qualify for a PhD, as the work is not the outcome of an

²⁷ This conversation took place when I was the sole participant at an AUTECH workshop *Ethically Managing Unexpected Moments in Research*, run by Charles Grinter on May 4 2015

individual endeavour. I disagreed with this position as it would be difficult for any academic endeavour to be truly individual, and because of the separation that occurs within the literature searching, thinking and writing that the researcher must, certainly within a PhD, take responsibility for (Journal note, May 4 2015). In future projects with this group the sharing of responsibility for writing will be able to be reconsidered, in order to work out what is best for BIWAP.

Initially, Phase I meetings were minuted, recorded, but not transcribed, as the focus of this stage of the project was to share ideas and experiences in order to develop action that would increase the capabilities of whānau to live their lives in the ways they have reason to value.

Contact between meetings

Maintaining the numbers in groups through texting, emailing, facebooking, and phoning was extremely time-consuming. There was no one way of being in contact with all the co-researchers, instead I used phone calls, texts, emails, Facebook and getting in the car to pop in at people's homes. Initially visits were with Michael, as he was known to each co-researcher, but once I was also known to everyone the visits were on my own. We had a 0800 number to reduce the cost barrier of people calling me, but that did not get around the barriers of phone numbers changing, and phones being lost or shared between family members.

Ongoing meetings

At the second meeting, two of the women returned and one brought her husband along, as she would be away for some future meetings, and wanted his involvement so that they could continue to contribute. This was a disappointing turnout, as we had again expected more to attend. Between the first and the second meetings, I had been out of the country for a training course in CBPR²⁸ and so had not managed to do as much follow up, connecting with and

²⁸ My purpose in attending the institute was to get confirmation that what I was doing was CBPR. At the CBPR Institute I met with Nina Wallerstein to talk through the project and, at a breakfast meeting (27 June 2013), she confirmed that my partnership was starting in exactly the way that these things typically

reminding of people between the two groups as may have been needed. As had been planned, we continued with the development of the project by discussing and using Post-it notes to brainstorm the key concepts for the project, namely: Brain Injury, Family/Whānau, Research, and Partnership. We also set a goal that we would have six people at the following meeting in a week's time.

Following the second meeting, all participants were re-contacted. It became clear that some were not going to be able to continue with the project and that there was no one time when everyone could meet. It was decided therefore that there would be two sessions run for each group in order to involve as many people as possible. A further member joined the group, although the usual recruitment process was not followed as she was unable to meet prior to the group to discuss the aims, ethics and style of the group. This later proved to be an issue, as it became apparent that her own beliefs were not compatible with the Māori-centred framework of the project.

For the third meeting a morning and an evening session was run, and each session had eight participant co-researchers representing six different families. In both of these meetings there was a brief catch up and discussion of the ground rules, followed by much longer post-it note and discussion session on the key words of Partnership, Family, Research and Brain Injury. An example of the post-it feedback is shown in Figure 6. The information shared in these meetings, and our themed understanding of this information, is presented in the "Results" section.

start. I explained that the academic partner was basically me, feeling like a one-woman band, and she assured me that this was entirely normal.



Figure 6: Example of a post-it discussion board

The core components and phases of CBPR were introduced in the day and evening meetings that were run as Meeting 4a and Meeting 4b, using two diagrams. The first (Figure 7) draws directly from CBPR literature, and the second (Figure 8) was my own translation of the concepts into language which was relevant for our group.

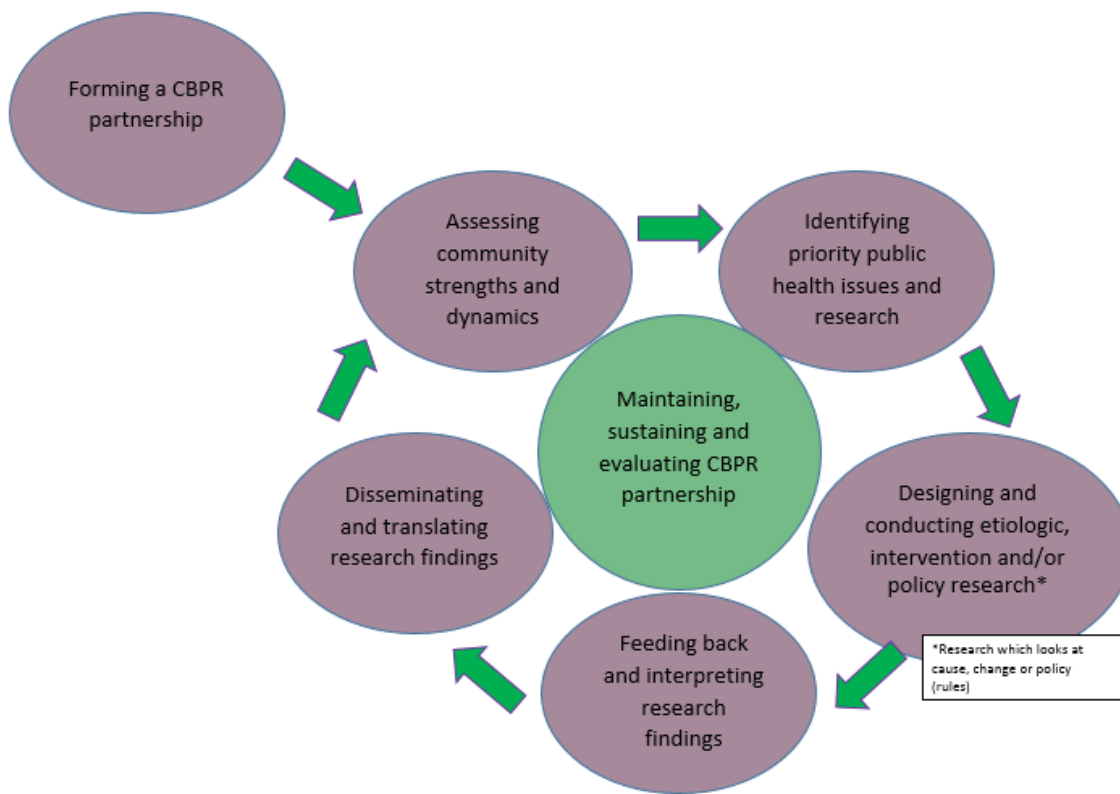


Figure 7: The core components and phases of CBPR research (adapted from Israel, Eng, & Parker, 2013, p,12)

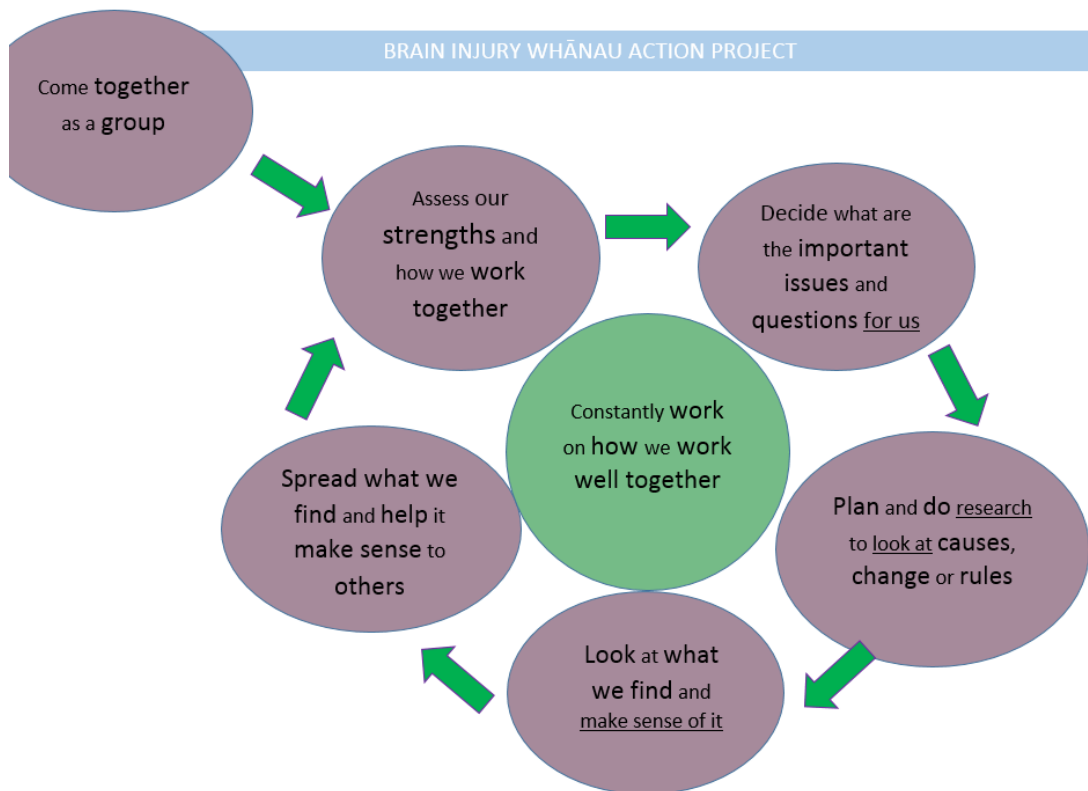


Figure 8: The core components and phases for the BIWAP research project

For the rest of Phase I we ran two groups and there were ten people who reliably attended or sent apologies. We explored the experiences of families by brainstorming and discussing the following questions which I had pre-planned prior to commencing the research as a way of information-gathering in order to develop our action project:

- What's worked?
- What's not worked?
- What do we want?

The purpose of these questions was to gather information about the range of co-researchers' experiences and ideas for possible action projects that would address the concerns of whānau and meet some of the goals (i.e. "What do we want?") that were emerging through the discussions. As per the CBPR model, attention was paid to the group dynamics through a pen and paper review of how the group process was going, as well as through discussion of the experience of being in the group.

At the 5th meeting it was decided that Michael Denton would be invited to join the groups. Initially it had been my decision that he should not be part of the group. I was unsure as to whether some of the group might have issues with the way in which the Brain Injury Association was delivering service, so did not want to limit discussion through his inclusion. As it turned out, discussions often included how much Michael had helped the individuals or their whānau, and despite recruiting through a range of avenues (newspaper, ACC, other community groups), all of the co-researchers who remained with the group had a strongly loyal relationship with Michael. There were also times in discussions, as we considered the projects we might take up and any information gaps that we had, where Michael's community knowledge was considered to be useful. The confidentiality rule that we had set up had also meant that I was unable to discuss any issues from the group with Michael. If co-researchers raised issues where Michael could be of assistance to their family situation, they would then need to discuss this again with him. From the outset, Michael had expressed his interest, as a family member of an

adult with a brain injury, in being in the group. His participation in the project was therefore valid both through his community and his family experience.

The first person I met in the recruitment phase was Leeanne, whose brother had been injured as the result of an assault about eight years previously. At the time of our first meeting, Leeanne had said that she had wanted to have a wānanga at their marae, where lots of families could all be together and learn from each other, so this was a possibility for our action project. Another option that the co-researchers considered was a movie fundraiser, as a step towards supporting a bigger action project. Michael and I had attended the movie *The Crash Reel* at the Auckland International Film Festival, along with a couple of clients, and been extremely impressed with the way it portrayed the impact of brain injury on the individual and the family. The movie was highly compelling and through the focus on, and great footage of, snowboarding, appealed to an audience outside of those who normally have an interest in brain injury. In considering this option we decided to all watch the video at a meeting.

The meeting where we watched the video ended up becoming the second to last meeting of Phase I, as I also needed to inform the group that I had been diagnosed with breast cancer and would need to take leave for surgery, chemotherapy and whatever other treatment might be indicated. While I intended to see if it was possible to continue with meetings between chemotherapy treatments, the group encouraged me to focus on achieving a strong and full recovery.

Maintaining contact

We had one more meeting, in September 2013, following my surgery. My supervisors encouraged me to take 12 months leave of absence, and I was aware, given the amount of energy that it took to prepare for, run and maintain the groups that it was important that I not try to do this until I was back “at the top of my game”. In reality it took 18 months before I was cognitively able to do this. While I was nervous about leaving the project just when we had got

started, Michael reminded me that “nobody was going anywhere” because brain injury would still very much be a part of their lives.

As our group goals had started to centre around “educating and strengthening ourselves in order to educate and strengthen others”, it was decided that, during my leave from the project, some of the research money could be used to support co-researchers to attend a four-day comprehensive training in brain injury rehabilitation that was run by Professor Barry Willer and Associate Professor Duncan Babbage. This 4-day course, known as “Whatever It Takes”, is run for health professionals and ACC case managers and is offered to people with brain injury and their family members at a significantly discounted rate (which remained out of reach for many whānau members). One co-researcher had attended the training several years previously and was a strong advocate for people to attend. In November 2013, three co-researchers attended the course, and one attended in November 2014. This course added to people’s knowledge, and their confidence in their knowledge, and also helped to shape people’s thinking in terms of what information they thought would be important to share with others and how this could be done by the Brain Injury Whānau Action Project. Interestingly the feedback from one Pākehā co-researcher focused on her experience of the other students, who were predominantly ACC workers: “some of them I could have hit their heads ... the bigotry (of one of them) was so bad I had to speak to the lecturer, and time and time again they weren’t getting it ... the prejudice and homophobia (exasperated sigh) ... and in terms of families they just didn’t get it.”

Group contact was also maintained through occasional emails, texts and phone calls, as well as seeing people at the Auckland Brain Injury Association annual picnic in February 2014 and February 2015. Michael and I also kept some contact and he sought out my assistance when one of our co-researchers was being deported.

Reconnecting and rebuilding

Starting the project back up felt like a version of the initial start. I reconnected with the research by listening to all of the meeting tapes and transcribing much of their content, as well as creating

mindmaps of information that was shared. Alongside this, I re-engaged with the individual co-researchers who had been involved, and the various communities. I was invited to the Brain Injury Association's National Liaison Officers conference where I presented a workshop on "Engaging with Research". Through this workshop I was able to bring some of the ideas of Linda Smith and CBPR to the Liaison Officers who advised me that their experience of research was often burdensome and irrelevant.

As noted earlier, transcription had not been intended at the outset, but transcribing allowed me to re-immersify myself in the earlier work and discussions. Through this process, I was able to listen with some distance to the ideas that had been talked about. There were a few different action possibilities that had been talked about, and I considered how we would narrow these down to an action project that would help whānau to increase their capabilities to live their lives in the ways they have reason to value. Project ideas included movie fundraiser/family evening, education through wānanga, navigators (people to assist whānau to deal with health and social service bureaucracies). One person who I re-engaged with prior to re-commencing with was Tania Kingi. When I mentioned the idea of navigators to her, her response was to point out strongly that if a system needs navigators then there is clearly a problem with that system.

Phase II

Two of our core group members were unable to rejoin the group. One had been deported as the injury that had occurred to his wife had taken place while they were in New Zealand as visitors, and one other couple had moved away from Auckland. Through supervision, it was decided that the co-researcher who had had an inadequate recruitment process was not suitable to the project because of an incompatibility around the research ethics and her own beliefs. Michael and I met with her to explain that the group was starting back up again and to discuss the lack of fit between the direction that the group was heading and her own goals and worldview. One older couple who had attended, but said very little through the meetings, were

informed that the group was recommencing. Given their minimal previous contribution, I did not pursue a vigorous follow up to maintain their involvement, and they did not re-engage for this phase of the research.

In the next chapter, the information that was shared through the meetings and the process of determining the action project are discussed.

Chapter 6 – Results I: What we found and did

While this chapter is being named “Results” it is more of a chronological record of the doings and findings that occurred throughout the research. Within CBPR the conversations and decisions in one phase, determine the actions in the next, and those actions can elicit more results, which determine further actions. The separation of “Methods” and “Results” then becomes somewhat arbitrary. This chapter is therefore more of a progression from the initial phase of setting BIWAP up. The findings from the discussions of the key concepts and questions are covered first. These discussions led to the action of running a wānanga which was evaluated by participants. Co-researchers then evaluated both the wānanga and the entire CBPR process. Consistent with the CBPR model, we then moved into the phases of community dissemination and planning for sustainability.

Key concepts – Building shared understanding

Once the ground rules had been established the group spent time looking at key concepts that I had considered important for the project. The purpose of this was to begin discussions around these words in order to build some shared understanding of people’s lives, as well as to explore ideas related to the particular style of research that we were engaging in. From reading about how the term “research” was considered a dirty word (L. T. Smith, 2005), and consistent with the guidance for conducting CBPR with indigenous populations (LaVeaux & Christopher, 2009), I decided that as part of building the foundation for our work it was important we talk through terms that would be central to the project. The concepts that were discussed were Brain Injury, Family-Whānau, Research and Partnership.

Each concept was written on a flip chart and all four charts were placed on the table. Post-its were given and each person was asked to jot down the words or phrases that came to mind, related to the key concepts. We then discussed each concept, one at a time, and the post-its that people had written. This exercise was initially done over three meetings. Using Mindjet

MindManager, I organised the post-it ideas by listening to the meeting tapes, transcribing some of the discussion, and grouping the words and phrases into themes.

Following the 18 month break in the research project, the concepts were reviewed as a way to bring people back up to speed with the discussions that we had previously had, to incorporate one new co-researcher's ideas, and to get feedback on the themes and organisation that had been developed from the original discussion. New comments were added and some previous ones were changed or deleted by the Phase II co-researcher group. The purpose of organising the words into themes was to facilitate the reviews and discussions, and the purpose of the discussions was to help our group move towards determining what our goals would be as a group and what action would meet those goals. The following is a summary of these early discussions and all of the mindmaps can be found in the appendices.

We spent time discussing first, the concepts of family/whānau, brain injury, research and partnership, and then moved on to What's worked? What's not worked? and What do we want? The process of the discussions was one of building shared understanding. People commented on both the similarities in their stories and their differences

The conversations about brain injury (see Appendix Q) and family/whānau (Appendix R) focused on the lived reality of people's lives. While co-researchers had written down words and phrases, within the discussions they then also shared their stories, and it was this process that really built the understanding. When the post-its for "brain injury" had been completed I asked "What do you notice?" The first response was "it's all quite depressing", which others agreed with. A number of people had commented on anger, frustration, loneliness, stress, and anxiety. There were feelings of grief, isolation, and sorrow, but in the discussions these feelings were mixed in with guilt. Frustration was expressed towards the person with the injury, which focused especially around the changes in personality. These changes included a loss of initiation (the ability to get started on an activity), as well as the self-centredness, and lack of emotional and behaviour control, which are all common following frontal lobe damage. People also talked

about the overall loss of relationship which resonated, for me, with the concept of third-party disability:

they get very egoistic, they think more about themselves, whereas you were able to talk about day to day things – you can't do that cos they just switch off, cos you've had your 2 seconds worth that's it, brain gone, and it's all about me again (laughs) ... Whereas before if you had that empathy from other people, and you could talk about things, that was a way of getting rid of your stress and everything else, and you haven't got that, then you've got to look after yourself (Meeting 3b)

For me personally, it's like a chain reaction. I see myself as much of a victim as my brother is, for me our whole life changed, switched, but it's not just the change, what I have to do for my brother, it's what I lost. Cos he was my older brother, supposed to look after me, not the other way around. Stuff like that I s'pose (Meeting 3b)

Co-researchers also felt for the person who had been injured with their losses in independence, hope and the goals they had previously had. There were parallels to the situation of sorting affairs after the death of a person, as partners needed to deal with the business activities of previously self-employed men, but this occurred alongside the bureaucratic red tape of needing to find supports for the life that the injured person now needed to live. Dealing with institutions and the medical system was compounded by the injured person's lack of understanding of their own limitations. A number of people commented about the situation of dealing with doctors and assessors, who would ask the injured person about their difficulties and take their answers at face value. The injured person might think themselves capable of many activities that they no longer performed. Their spouse, or family member, in protecting their dignity, or not wishing to experience their anger, would often not correct this information, assuming that the health professional would have enough knowledge of brain injury to recognise the person's lack of awareness. They would then have to deal with the effects of medical reports which overestimated the person's abilities and level of competence, which could have ongoing effects in dealing with ACC.

The discussion of family/whānau was notable for its overlap with brain injury, with a lot of discussion of similar emotions of pain, frustration, anxiety and fear. A number of people spoke of the difficulties they had as a result of their lack of knowledge about brain injury, and they

noted that the need for education and information extended to their whole family. This related to changes in family dynamics, with people noting that some family members understood better than others. Issues around safety were raised within this discussion. People gave examples of risks to the person with the injury from family, as a result of the potential for the injured person to be bullied by wider family members who did not understand, and risks to the whole family through the cognitive deficits which could result in risky situations such as leaving the house with the stovetop elements still on. Cultural issues were noted within this discussion, with two Māori women commenting on how their family member's relationship with their marae had changed, with one no longer knowing how to act appropriately and the other saying that her "mum lost her comfort on the marae". At the first two meetings where we did this post-it exercise, I noted the absence of the words "love" or "aroha", which surprised me in a discussion about family. One of the people at the first group, also attended the third meeting and brought these words into the discussion, which led on to more talk around working to achieve a sense of togetherness.

The concepts of "research" (Appendix S) and "partnership" (Appendix T) were discussed as a way to bring out co-researchers feelings and understandings of how they related to their lives and the project that we were embarking on. My purpose in these conversations were to help mark us coming together as something different to a support group. The post-it words and discussion focused on making a difference, telling the stories, and gathering quality data. These discussions also allowed for me to talk about the philosophies that underpinned the research project and in particular the ideas of Freire and Linda Smith, as discussed in the Methodology chapter, such as people making a difference to their world through the combination of reflection and action, as well as the risks of research to researched populations. One co-researcher raised the issue of "integrity" and talked of how when she told her story of how brain injury had impacted her whānau she was also telling her brother's story. While we had talked about confidentiality and privacy in relation to the co-researchers, this brought in their responsibilities

to their own whānau in terms of what stories they would choose to share and how they would share them.

My journal notes from one of the meetings:

“Discussion talked about avoiding drive-by research, idea of sustainability, likelihood of joint presentations of information, desire that research would lead to change ... links to policy change, discussed how good data can back up calls for change.” (Meeting 3a notes)

The partnership discussions were very interesting (Appendix T). The word was brought in because of the project being a community-academic partnership. Two women in one of the groups both commented on the difficulty they had in working on this particular concept. They felt emotional thinking about what partnership should be about while they were dealing with difficulties, that resulted from the brain injury, in their own intimate partner relationships. Another woman’s response was that the thing that came to mind for her around talk of partnership was the Treaty of Waitangi. Within this discussion she talked of “how we look at people as being a gift, our taonga, which is a gift, and how we look at the environment as being a gift also”.

In relation to the research partnership people spoke of the importance of working together, honesty and integrity and having proper processes around bringing other people and organisations into the work. Through all of the discussions, as a researcher endeavouring to build a team of co-researchers, I found myself turning comments about “you” into comments about “we”. For example group members would offer advice or make suggestions along the lines of “what you could do” or “have you thought about”, and I would keep shifting the conversation to “what we could do” and “what we could think about”.

Following this discussion, one co-researcher asked for me to bring in more information about the research process. For the next meeting I put together the diagrams of the core components (Figures 7 & 8) as well as bringing in the folder from the CBPR training course that

I had attended to show the overall process and to share knowledge at the different levels that people were requesting²⁹.

Group numbers and finances

Through this time I struggled with what would be good numbers for the group. Bringing more people in could enhance the diversity and sustainability of the project, but with the \$50 koha per meeting attended I also feared running out of money. Budget information was shared with co-researchers so that this too could be taken into account in the group's planning for action and the processes surrounding that action.

Key questions – Information to guide action

The next round of meetings were focused on the Key questions of “What’s worked?”, “What’s not worked?”, and “What do we want?”. At the meetings where these questions were discussed all three flip charts were placed on the table and people were given post-its to write their comments on. The information from these areas of discussion are presented next. From experience with groups who shared the common situation of brain injury I was aware that discussions would frequently move quickly to what was difficult and especially to the short comings of ACC, and those who were not covered by ACC would then explain how much worse their situation was with only having Ministry of Health cover. Because we wanted to effect positive change, it was important to look at what *had* worked for families so we could build on any positives within the system, as well as gathering information about what had not worked in order to move towards “what do we want?” to give us a frame within which we could consider alternative actions.

What’s worked?

In terms of what’s worked – the comments ranged from what worked at the individual level through to families/whānau and systems (Appendix U). At an individual level a comment which

²⁹ Two of the co-researchers were particularly interested in the academic side of the research as they tied in with their own studies in social work and Māori business development, and one of these students was able to combine some of our work into her own studies.

resonated with the group was, “remembering it’s the brain injury not the person”. People talked about the individual techniques that they used to cope with the effects of living with a person with brain injury such as “giving time”, “talking about it” and “lots of laughter”. “Distraction” was an important technique for when the person had become fixated on one particular topic, but it was also discussed that this needed to be done sensitively – so a person might change the topic of conversation but try to do this in a way that was not dishonest or disrespectful of the other person. For the person with the injury, having regular support “weekly/fortnightly follow up meetings with Neuropsychologists at home” was also seen to be something that had worked. Other things that individuals noted had been helpful included an Outward Bound course, medical care and faith. A topic that was mentioned repeatedly was “an understanding GP”. Group members specified that they needed a GP who understood brain injury, listened to the family as well as to the person, and also understood ACC. From a family perspective, people talked about the importance of telling the family the issues and the different ways that different family members came to understand and accept the injury.

Two people in the groups had managed to access some training and had found that this had been helpful for themselves, and to support their family including their injured family member. One of these women noted that the Family Care magazine was useful – and she then brought it in to a future group, which prompted us to access some materials for the whole group.

“Michael”, the liaison officer, was listed as something that had worked for people with one person noting “Michael’s help has worked with getting my son appropriate help with different agencies”.

Many people noted the importance of “group get togethers that understand”, with post-its including “this group”, “Concussion group helped”, “Sharing finding solutions answers for others to help cope, manage”, “support group – meeting others in the same situation and sharing ideas and experiences”, “collectively not individually” and “you need a network to fall back on”.

In terms of the system, comments included “the squeaky wheel gets more action”, “demanding help”, “advocates” and “locating the right help”. “Temporary Guardianship – taking financial management” had worked for one family and another family member talked about “lump sum compensation – when done right”. Reflecting the importance of meeting the most basic of needs was the post-it from one co-researcher of “adequate housing” and she talked about how important this had been as she had a large family with two family members who lived with disabilities. The research began at a time when ACC had been in a cost-cutting mode and a lot of people had been disenthralled – one person’s battle in this area was reflected in the comment “paying privately to get back on ACC” as they had had to pay for second opinions and gone through a lengthy process to get their weekly compensation reinstated.

When this mental map was reviewed at the beginning of Phase II, some of the new ideas that came through reflected the training that several members had managed to attend during the gap in the research process. People talked about the importance of “informing their community” and “informing police if lost”. Counselling was seen as important for both the injured person and close family members as it could improve confidence for both. Exercise was also seen as a way to improve well-being. Other things that had worked included “managing the issues”, “providing activities”, “breaking task down” and “getting right level of support”.

In listening to the discussion about what had worked it was interesting how often statements were qualified, such as “lump sum compensation – when done right” and “locating the right help”, as alongside these conversations there were the conversations about what hadn’t worked which often looked at “help” which had actually been experienced as being unhelpful.

What’s not worked?

This was the area of discussion that generated the most energy and comments (Appendix V). Many of these discussions were quite poignant, while others highlighted anger and frustration. An aspect that was highlighted in the Literature Review is the fact that brain injury can cause the person with the brain injury to lack awareness about their own behaviour, the changes that

the injury has caused, and how they come across to others (Gasquoine, 2016). This lack of awareness caused by brain injury, can get mixed in with the injured person's and at times other family members' denial about the effects of the injury (e.g. Prigatano & Johnson, 2003). One woman spoke of the difficulty that her adult son, who had worked alongside his now injured father, had in accepting and adjusting to his father's limitations.

Things that were noted not to have worked for the individual included lack of insight and awareness on the part of the client, which could lead to a reluctance to seek help. This lack of awareness impacted family members trying to get the person to access help, and also convincing agencies of the help the person needed as many agencies would go with the injured person's description of their abilities. "Unrealistic expectations for improvement" were seen as an issue for the person, ACC and also family members who had less understanding of brain injury. Whether or not awareness was impaired there were also difficulties in accessing help with people noting delays to get help, and the person being left without appropriate help and support in areas such as housing and health, as well as "Lack of focus on person's real wants".

Financial issues were a strong theme with it being noted that people with brain injury were vulnerable to door knockers and discussion about the way in which door-to-door sales trucks preyed upon low income areas. Some families also had the experience of injured family members receiving lump sum payouts despite their inability to manage their own finances which could lead to the money being spent very quickly and also, for the injured person having greater access to drugs and alcohol having received the money.

Under "What's not worked?" people talked about the injury itself with one person noting "the people driving the car" and another, "Second, third ... injuries" referring to later injuries that their family member had sustained. Unfortunately having a brain injury puts you at greater risk of incurring further injuries due to changes in functioning such as balance and visual processing.

A number of comments linked to the theme of **Whānau**, people wrote about difficulties from "Letting the person with a brain injury get to you – taking it personally" to "Unnecessary

Family break up – lack of education – lack of support at transition”. One person wrote “Families being shut out” and this linked to experiences others had of there being an “Individual focus rather than family focus” and “Barriers to family connection - \$ (money), - judgment, - hassle, - legal”. One person wrote of “Family/provider conflict” and another resented that their family member had become an earner for the provider, writing “Client/brain injury as a commodity” and “clients ‘trapped’ in residential – business taking ownership of family members”. “Long term help for whānau” was also grouped with these issues around “What’s not worked?”.

In discussion, a number of people agreed with the comment “Bully or racist” and spoke of experiences of being judged by the community and by ACC and other government departments. There were concerns about “the cost of injury – supporting family”, but also “Families judged – you’re only there for the money”. On this topic one woman spoke of the experience of wanting to be able to support her brother by having him home for weekends, but that there were times when the family was experiencing financial hardship which made the cost of petrol to collect him, and food to feed him difficult, yet when they asked that he be allowed to contribute to these costs from his own money, the family felt judged, shamed and angered by the response of the provider. Another issue that was presented was “slack workers” which was written in relation to residential providers but others commented in terms of their experience with community providers as well.

People spoke or wrote about government organisations in general noting “Mainstream services³⁰ working badly with brain injury”. This reflected the experiences that I had observed during the pre-research phase where I was surprised at how much the Liaison Officer needed to do directly. He informed me that his practice was shaped by so many experiences of people with brain injury being unable to get their needs met appropriately with organisations such as Salvation Army, WINZ and CYFS. In his experience clients had been asked to leave these offices when they became angry, and that they struggled to tolerate the long waits and questions that

³⁰ This referred to services not focused on brain injury, rather than mainstream not being kaupapa Māori

were asked without having a support person. This was also commented on directly by one person who wrote “WINZ – reassessments payments, - inflexibility, - work trial, - bureaucracy”.

As expected there was a lot of comment about ACC. At the time of our first meetings, ACC had gone through a period of cost-saving and many clients had been disentitled i.e. their weekly compensations had been ceased. So it was not surprising to see the following comments related to ACC of “Disentitlement”, “ACC terminating payment” and “Culture of fear to ask for help in case ACC determine entitlements should be disentitled”. It was also noted “Too much emphasis on independence → people living on their own and unsafe”. There were comments about ACC assessments including “Clinicians pressured into different (non TBI) diagnosis” this comment related to a family who had been through multiple assessments following a disentitlement as a result of a clinician determining that the older man’s change in cognitive functioning could be due to dementia.

A number of “What’s not worked?” comments related to assessments including “Lack of understanding with assessors – Taikura Trust”, “Repeating info to everyone – ACC, - Lawyers”, and “Drs neuropsych testing – over long, over difficult, - exhaustion”.

When the “What’s not worked?” mental map was reviewed at the beginning of Phase II the following points were made: “Alcohol and drugs” which were discussed as being a form of self-medicating, “Facebook” because the woman felt that her partner had become paranoid about her interactions on Facebook. Gangs were also seen as a problem as the person with the injury was “vulnerable” to being a “fall guy”, often “taken advantage of” and “asked to sell drugs ... and then in trouble”. “Over-medicating” in residential facilities was named, and adding to previous discussions about financial vulnerability, the issue of “trucks” selling goods to low-income families was again emphasised.

What do we want?

The purpose of the “What do we want?” flipchart and discussion was to open up the possibilities of change and to also work as a reference point for us to check back to, when we were determining the action project (Appendix W). Responses to this discussion were many, often

detailed and ranged from helping the person with the injury and supporting the family, to education for individuals, families, health and government workers. Given that the driving philosophy of the project was to explore ways to increase the capabilities of families of adults with serious brain injury to live their lives in the ways they had reason to value, I was aware that we might come up with a range of possibilities rather than a one size fits all, yet we would still need to pick one actionable project. A good project would tick many of the “What do we want?” boxes and allow families to increase their capabilities in multiple different ways.

There was a wide range of suggestions for supports for the person with the injury including to treat people holistically, group therapy, individual mentoring and strategies to reduce isolation in order to also reduce feelings of hopelessness, depression and risk of suicide. Co-researchers wanted education for their whole whānau, and for friends to also understand their family member’s injury. Supports for family members that acknowledged the trauma and grief were amongst the wants. Co-researchers saw it as important that families were supported both because they in turn support people with brain injury, and also because the needs of family members were high. In terms of support for family members, it was noted that whānau needed to be able to have conversations and counselling that was independent of the person with the brain injury, so they could be free to speak openly and to feel their feelings as their own, rather than only expressing their thoughts in terms of what was best for their family member.

There was much discussion of the need for education for a wide range of groups including for case managers and health professionals to learn about brain injury, and for brain injury workers to learn about family realities. Co-researchers wanted information to be widely accessible and available at places such as medical centres and schools, as many had experienced difficulty in knowing where to access support and information. Other supports that were wanted included “more liaison officers and resources to help support clients and families”, and “Good respite”. At a systems level the wants that were noted included better teamwork with

health professionals, for the government to have a greater understanding of the situation for families, and more choices and accountability in terms of service providers.

In the review discussion at the start of Phase II the new ideas that were added to the mental map covered building community awareness for individuals; activities for people to do, such as gardening; creating job opportunities for people with brain injury e.g. working bees or mahitahi (an organisation that supports Māori with disabilities); addressing family trauma, as was seen through the loss of the role model in a parent; creating a safety net for children; group for children; and, support for families to grieve and cope with guilt. The idea of the wānanga which had been floated earlier was considered and it was agreed it could help with more understanding of brain injury; teaching children; and, education about brain injuries.

We also considered some of the resources that were potentially available towards these wants and towards the idea of a wānanga. We had contacts with an ACC lawyer who could be approached, and we were aware of a Member of Parliament who had been exploring bringing a bill to parliament to create a list for people who do not want to be able to enter financial contracts with the mobile truck businesses. We had also looked at other supports such as Carers NZ and whether some of our stories could go in there, or whether they would have resources to support our work, and there was discussion around the legal rights of families.

The Crash Reel idea and evaluation

During the time of the brainstorm groups occurring, Michael and I, along with a few clients had attended the movie The Crash Reel which screened at the International Film Festival. The movie depicts a young snowboarder, Kevin Pearce, with Olympic gold medal prospects who sustained a serious brain injury in the lead up to the Olympics. We were both very impressed by the movie as it had a strong focus on the impact on the family and on the psychological as well as the physical effect of the brain injury.

At the following meeting we mentioned the movie to the group and the idea that I had that in the future, i.e. not as part of this project, I could see this movie being a worthwhile

fundraiser movie possibility for BIA-AKL. The group seemed to pick up on this idea and were keen that we do a fundraiser, as they were also aware that the research funding was enough to cover petrol vouchers and food for the meetings, but that we could also need to find further money for whatever action project we decided upon. This had the effect, I felt, of moving our attention away from what we might do as an action project, to focusing on a screening of the movie as a possible mini-action. In the meetings I found it at times to difficult to keep the focus on the experiences of whānau with ABI and what action we might do to increase capabilities, as people moved to the logistics of setting up a fundraiser. Memories of social psychology lectures drifted back, in terms of how groups can find it easier to focus on something smaller and concrete rather than larger and more abstract. The discussions also revealed differences in fundraising ideas and experience reflecting the different areas of the city and socio-economic groups that people came from. I had in my head that an “early win” could be a good thing for BIWAP, and was okay with running with the group idea, but noticed that discussions on the practicalities could eat into time for discussing key words and questions – and felt that we were possibly getting ahead of ourselves. I wondered whether the familiarity of fundraising, compared with research, drew the co-researchers strongly in this direction. Plus people wanted to do something, rather than just talk about their situations. In order to keep the research focus it was decided that we would watch and evaluate the film (Appendix X) as a group in terms of its usefulness as a research and education tool.

Overall people rated the movie as 8/10 (on a scale of 0 = Not useful at all, to 10 = Extremely useful) in terms of meeting their education needs about brain injury and how it affects families/whānau (Appendix Y). Co-researchers also rated it very highly in terms of its usefulness for educating their close family, wider family, health professionals and case managers, and commented on which particular aspects had made the movie useful. The purpose of this exercise was partly to introduce ways of evaluating, and that we could create our own evaluations to suit our own purposes.

One co-researcher had joined BIWAP as a result of her son's injury which occurred while he was snow-boarding, so it had particular relevance to her, and her son had found watching the movie to be a powerfully positive experience for him. During the break time from the research she and her son invited a group of his friends over for a movie evening to watch *The Crash Reel*, and they also filled in evaluation forms³¹

My needing to take a break from the project put an end to planning around this as a fundraiser. The planning did bring forward ideas of how we could both fundraise and build awareness, and that our preference would be to fundraise and do action in ways that work for people with brain injury as well as for non-injured. This would likely mean having alcohol-free events, as some whānau had found that alcohol and brain injury were a bad combination.

Phase II regrouping: Pre-research II

In order to recommence the research, I first reviewed the work that had been done in Phase I. The initial meetings were transcribed, which made the discussions immediately fresh for me again. I also reviewed the mental maps of the brain storm sessions and reread my research journals. Following this I was clear again that the dominant ideas coming through were around education and having navigators to help families to manage the various systems that they found themselves engaged with. I then began re-contacting co-researchers.

Re-contacting co-researchers

In total there were 12 families who had been involved as co-researchers in Phase I. One family had attended only once and while they were interested in the project, the times of the meetings were difficult for them to attend and they did not maintain their involvement. As noted above, one family was deported during the hiatus. Another family had moved out of Auckland, and although they are no longer actively involved the key co-researcher (a mother of an injured adult son) maintained regular email contact and followed up on *The Crash Reel* ideas around educating family and friends as described above. One other woman had participated regularly.

³¹ This was an independent activity from the research project

She was extremely shy during many of the meetings, but did contribute her thoughts and was often surprised at how much others valued her input and all that she had done to support her own family. When I visited her to discuss the project starting up again, she was extremely happy to meet again and there was a marked difference in her manner. She was noticeably more confident and positive. She was working as a volunteer Māori warden which had been a great boost for her, but unfortunately meant that she was unable to be involved in the group as once meeting times were determined to continue in the evenings³², she was unable to make these times.

There were two discontinuations that were decided on via supervision. One couple had attended irregularly through the first phase and spoke very little during the meetings, I had discussed in supervision whether it was appropriate for them to continue given their minimal input. The couple were invited to return and I had planned to have a conversation about the importance of contributing thoughts and ideas, but as they did not attend the first couple of meetings or make any independent contact I stopped actively pursuing their involvement. The other woman had joined the group without having an interview prior to her initial involvement. During recruitment interviews, with all other co-researchers, the philosophy and ethics of the research project were explained with emphasis on the fact that it was to be conducted as Māori-centred research. During the project meetings, and in conversations that occurred after some meetings in Phase I it became apparent that there was a clash in beliefs over this issue. While I had attempted to address this in Phase I through arranging meeting times for discussion of this issue, the co-researcher would cancel the meeting but then attend the project meeting. Michael offered to join me in meeting with her to discuss the next Phase of the project. We talked about the principles of the research and the strong possibility that the action project that the group could choose could be a wānanga held on a marae. She agreed that she would be very uncomfortable in this setting and, while she did not completely agree with my decision, she did

³² While I had run morning and evening meetings in Phase I, I did not see this as practical when it came to Phase II as it was too cumbersome for decision-making. I also didn't believe that it was sustainable in terms of my own energy.

accept it. Michael also discussed other projects that he was involved in that might be of interest to her. From an ethical position, although it was a big decision to exclude someone, it was important to maintain the project as Māori-centred in order to meet the goal of developing action that would be respectful and effective for Māori.

New recruitment

At this stage, of the original 12 members, we had five who had attended reliably and one who had attended unreliably but remained keen to be involved. We had also had Michael join the group towards the end of Phase I. Michael introduced me to two more women who he thought could be interested and effective. One of them was keen but was very recently diagnosed with breast cancer and, while she did not want this to be a barrier to her joining, her health did not allow her to become involved. The other woman was keen and joined our group. She is a young Māori woman with two young boys. Her partner had been injured in Australia while they were both working there and was therefore ineligible for ACC support. Because of the huge delays in the project, and mindful of the expected timeframes for completion of a PhD, I elected to go with a smaller group in order to be able to work quickly and effectively, and to not spend too much time on additional recruitment. Phase I had given us all a rich base of understanding from a good number of families, and the focus of Phase II was on designing and implementing the action phase.

Reconnecting with community groups

Prior to re-commencing the groups I made contact with both ONAC (Otago Network Action Committee) and Tania Kingi of Te Roopu Waiora and Mana Whenua i Tamaki Makaurau to let these groups know that the project was re-commencing. I had maintained engagement with BIA-AKL and delayed the re-start of the project until I had completed a community teaching commitment with them that we had started to discuss prior to Phase I. By chance, part of this family education session was filmed for a current affairs programme that was focused on the situation of a Rotorua whānau who had struggled to access appropriate help following the brain injury of a family member.

First meeting

Our group met at the same time on the same night as we had met during Phase I. For me everything from Phase I was very fresh as I'd transcribed the meetings and been thinking through everything that had happened. Coming back to the meeting people quickly re-connected and joined our new co-researcher into the project by introducing themselves and sharing their own stories, and then through reviewing the work that we had done in Phase I. The thing that I was struck by after the gap, was that people were tired. This was particularly noticeable for one woman, whose husband's injury had occurred about two years prior to our first meeting. Consistent with the literature, the difficulties had not reduced and her own mood and energy on that first night had lowered compared to Phase I.

I met with one other young woman, once our meetings had started again, who had been raised as the step-daughter of a man with multiple brain injuries. Her primary interest was in finding employment, and Michael had felt that the experience of the project may have increased her prospects, but difficulties around transport and childcare got in the way of her becoming a part of the project.

Planning the wānanga

At the end of the first meeting the decision was already clear that the action project that we would do was to run a wānanga, which meant that the following meetings focused on developing the wānanga programme and finding funding. Leeanne, whose idea it had been, was able to organise for the wānanga to be held at Weraroa, her ancestral marae in Waikaretu (a little over an hour's drive South of Ōtara).

Creating the vision

We looked at the areas that people wanted to learn in and what would be important in the wānanga. One exercise that we used was a relaxation exercise to create a vision of what each person would like. Co-researchers were asked to close their eyes while being instructed in relaxation breathing and then in projecting forward to picture the feelings that were happening

for them at the very end of the wānanga. The exercise triggered quite a lot of emotion for people, and a strong sense from some of just how important it was for them to have their families with them, so that the learning could take place as a family.

One young woman's response was:

can't wait for the day, to bring my kids along, create the awareness and education. You know educating ourselves and our families to make that change, I'm all for it. I've got a wish that [partner's name] would be here and his family ... engaging with one another in the quiet times – you're in the marae and you feel that richness come out with the stories.

Another older woman responded:

for me these are just words that came out - Family, sharing, accomplishment, learning, settled, joining in, being together, values, travel, the unknown, help and understanding. That's how it came out – having the families there – you know for the families to share in their experiences and their learning – to have the values – being on a marae, and to learn, the unknown is how is it going to happen – helping each other and the understanding of what it's like.

Another was clear that she wanted a lot of her family to be there as her connection to brain injury is through her mother's injury and there are many adult siblings. The exercise had crystallised her feeling of being alone and unsupported by her wider whānau. In sharing this experience she was upset and tearful, and received a great deal of support from the group.

I was left wondering if the exercise had been a mistake due to the level of emotion that it triggered, but looking back after the wānanga I think that it had pushed people to make sure that they did get what they needed from the wānanga and it strongly influenced our planning. At the time I noted in my journal my concerns about how triggering the process was and wrote “for families, the situation of brain injury is one of pain and grief and guilt. The injury is often talked of as an invisible injury, but it is an injury that has widespread ripples to the people close to the injured person”.

Over the following meetings it was apparent that co-researchers were taking more ownership of the project. People were bringing their own laptops to meetings to take notes, one co-researcher drew up catering contracts, and another initiated fundraising for, and

organising of, BIWAP t-shirts for the co-researchers and other workers to wear or be given as koha (thank you gifts). Both of these women sourced donations of food, or prizes for children.

Following on from the vision exercise we talked through what our goals were for the wānanga. While it had been talked about as a family event, it became clear that we were moving from the initial idea of everyone coming together and learning from each other to also bringing expert speakers in to boost the learning and continue with the philosophy of “educating and strengthening ourselves in order to educate and strengthen others”.

Upholding tikanga

Holding the wānanga on a marae had been Leeanne’s dream and immediately meant that we would be offering a different learning experience to running a seminar in a community or mainstream education setting. By holding the wānanga on a marae, we were prioritising Māori ways of joining and learning. This meant that there was new learning required for quite a few members. Michael noted that he had never actually said the words “kia ora”, as it was being explained to him that, as the only male in the group, and as the representative of the BIA he would need to stand up and speak in the marae, and that the beginning of his speech would need to be in te reo Māori. As a group, we also needed to learn waiata, to support speakers, and the proper processes that would occur on the marae.

Through Phase 2 there were 6 women who attended most meetings, along with Michael and myself, and one who was interested but generally sent her apologies rather than attending. Of the 6 women, four identified as Māori and two as Pākehā. One of the Pākehā women worked in the health sector and was confident in Māori settings and in her ability to generally be able to uphold tikanga. She reassured the other Pākehā woman who had no experience of going onto a marae.

Road trip

As part of our preparation, a few of the co-researchers took a road trip to actually have a look at Weraroa Marae. My journaling notes read:

Field trip to Waikaretu went really well. Beautiful warm feeling in the wharemoē – very well appointed marae – great kitchen, decent size wharekai, lots of covered outdoor areas that will be able to be used for children’s programme, there’s also a large mattress room with a single bed, and an excellent kaumatua room with small kitchen for speakers to use as prep area.

Leeanne brought up the idea of how can we give back more to families and started a discussion of other ways to get information out to families – like a booklet of things people wanted to know back when the injury first happened. (30 July 2015)

We were able to think through where we would have children’s activities, how the spaces would work, and how we could also offer a quiet space in order to manage fatigue for people with brain injury. The kaumatua room offered an excellent space, and the mattress room also contained a single bed that we would be able to offer to anyone who needed a rest.

After our visit we lunched at the local café which also offered a glow-worm cave tour as an attraction and had on-site accommodation. We wanted to have information about local accommodation options as we knew that some of the whānau were going to struggle with marae-style accommodation (sleeping in a communal room with mattresses on the floor) due to concerns about mobility or snoring. The café owners enquired about, and were very interested in, our project. Before we left they informed us that they wanted to support our work and would offer guided tours through the glow-worm cave for the children and also offered to support us by being guides for a local bush walk, as an additional activity.

The road trip took place the day before a scheduled planning meeting and we ended up stopping when one of our co-researchers, who was a keen forager and had been noticing watercress and puha all along the way, spotted a particularly big patch of watercress. We ended up with trousers rolled up along the water’s edge gathering bags of watercress, which were then cooked up with pork bones by the same co-researcher for our dinner the following night. This took the idea of being ‘in the field’ to a whole new level and was one part of a great day of bonding, as the Māori co-researchers taught Michael and I about picking watercress correctly.



Figure 9: Scenes from our trip to check out Weraroa Marae and local community

Planning the programme

From the various discussions, but especially the “What’s worked?”, “What’s not worked?”, and “What do we want?”, the group were clear that they wanted education for themselves and for others. The group had goals of educating doctors and ACC case managers as well as themselves, their families and others who were impacted by brain injury. The key topic areas were brain

injury, self-care and advocacy. We wanted the wānanga to be uplifting and for the experience to be one of holistic learning, and we were aware that we needed to cater for the needs of whānau with brain injury, and for children, as well as those who were there as caregiver family members.

We brainstormed possible speakers and then started to approach people. With no funding confirmed, we were looking for speakers who were motivated to get their message to people without being paid. The contacts largely came from my academic connections and Michael's community connections.

We expected that people would gain as much from meeting other participants as they would from listening to and interacting with the speakers, so in putting together the programme we talked about the importance of "less is more". We didn't want to overfill the programme to a level that people with brain injury would become fatigued or feel unable to participate. Based on Michael's experience of camps and taking people to brain injury related workshops, he expected that many of the participants who had serious brain injury would spend time together in the smoker's area rather than in the wharenuī listening to speakers. Ultimately we ended up with a fairly full schedule, but in order for it not to be overwhelming we gave each main speaker an hour to present and asked them to only prepare material for half of the time so that there would be time for people to ask a lot of questions.

A couple of weeks before the wānanga we came up with a list of questions for each speaker to consider in their preparation and presentation. Coming up with questions prior to the wānanga was a way of guiding the speakers to topics that people might have felt uncomfortable to ask about in an open forum. A key area was relationships. People wanted to know about anger, but didn't want to ask about it when they could be sitting next to the partner who had difficulties managing anger. Another woman wanted to know about managing her partner's reduced initiation (ability to get started on any activity), but again did not want to raise it in front of the partner, for fear of causing embarrassment. I also prepped the speakers to

pitch their talk so that it was practical for families, this was done through phone calls or kanohi ki te kanohi lunch meetings.

The speakers we invited (see Wānanga Programme Appendix DD) covered a wide range of issues for people with brain injury and for whānau including:

- an overview of rehabilitation
- advocacy - understanding your rights in dealing with agencies
- getting the most out of a neuropsychological assessment
- relationships
- managing fatigue.

We started with Tamati Paul, a motivational speaker who had suffered a serious brain injury, as we wanted to ensure that participants with brain injury were as well-catered to as whānau. The participatory nature of the planning continued into the wānanga as participants also asked if they could share their experiences. One spoke about her knowledge of posture and its links to well-being, another told the story of their own family's journey and her learning around aromatherapy and how this had benefitted her. The Crash Reel film did find its way into our work as an evening movie option (Appendix EE).

Planning the evaluation through clarifying our hopes

We wanted a simple way to gather information from participants about their hopes and experience of the wānanga. I sought advice from a Participatory Research peer group at my university and one suggestion of using post-its fit perfectly with the work we had done throughout our own development of the BIWAP project. Through our meetings, we had talked a lot about our hopes for the wānanga, but in order to get really clear on it, and to try out a data collection method together, we did a post-it exercise of writing down the three most important outcomes that we were seeking from the wānanga and then each speaking to these points (Appendix JJ).

The hoped-for outcome themes that came through from this exercise were

- Knowledge

- Connection/support
- Strategies
- Enjoyment
- Learning for children

The focus of “Knowledge” was on gaining more knowledge about the effects of brain injury in order to better understand family members with brain injury. “Connection/support” was about the co-researchers wanting to network and connect with others going through a similar situation in order to learn from each other, as well as to reduce isolation and experience a sense of togetherness. Connection and support was also seen as important in planning to collaborate on future projects. The “Strategies” theme reflected the wish of co-researchers to leave with practical strategies that they could use in their daily lives. In the post-it exercise this was focused on working with the person with brain injury, but in previous discussions it had also been linked to the advocacy topic. “Enjoyment” had been talked about a great deal, but was only included in the post-it exercise by the grandson of one of the co-researchers who wrote that he wanted “games, fun games and competitions”. In the discussion phase of this small exercise, people agreed on the importance of enjoyment, and that this had demonstrated how helpful it was to have the child perspective in this meeting. Learning for children had been a major goal throughout the development and discussion of the wānanga. We spent time together reviewing activities that the children would be able to engage in to learn more about the brain and how it is impacted by injury.

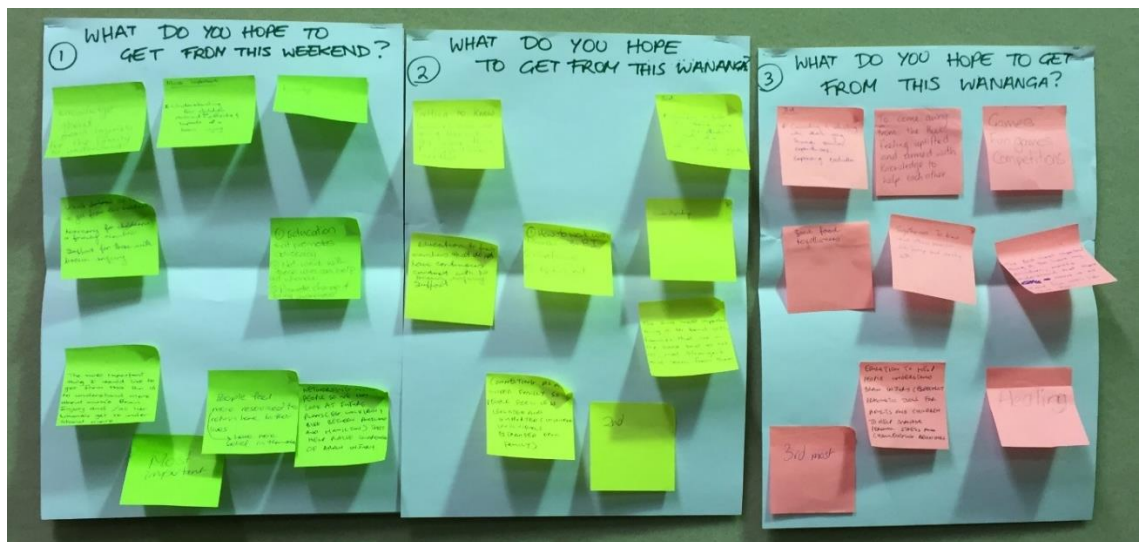


Figure 10: This photo shows the comments co-researchers had for what was the most, second most, and third most important to them in terms of their hopes of what they would get from the weekend.

It was decided that our own evaluation process would involve encouraging participants to use the post-its to contribute their thoughts throughout the wānanga, and that I would also conduct a verbal feedback session.

Filming the speakers

As part of wanting to get the information out to more people we decided that part of the budget would need to include filming the speakers so that we had a resource that we could continually share. Speakers were invited knowing that their kōrero would be filmed for this purpose of sharing (Appendix II).

With Leanne's challenge of how we could give more to families - which seemed based on her sense that as a group we were receiving/gaining a great deal from the project and she needed there to be a level of balance in terms of give and take – we talked through the idea of a booklet of people's stories. I introduced the group to a resource that I had found helpful in learning about breast cancer in which people (mostly who had been diagnosed and also some health professionals) had been interviewed on a range of topics and then the interviews had been compiled into brief vignettes with a range of people talking on each topic. This seemed like a doable project to make a start on, with our own group being interviewed and filmed by our cameraman. We recognised that we would only be able to make a start and that this could

be a future project to develop further, which fitted with the principle of CBPR developing sustainable projects rather than simply conducting drive-by research.

Finding funding

I had intended to access funding through community trusts or lottery funding, but given that the project was decided on in late May, with the plan of running it by the end of August this made the prospect of hitting application deadlines very tight. At the outset of the project, the Auckland BIA were aware that we would not ask them for funding, but would need to draw on their knowledge to access funding. To this end, I sat down with the General Manager to look at possible funds and to get advice on making applications. The key issue in accessing these funds was that we needed to be a charity and we would need to show we had two quotes for each expense, or a sound reason for only using one quote. Given that BIWAP was a community group rather than a charity, Auckland BIA were able to support us by putting through the application under the umbrella of their charity. The applications also required evidence that the Board of the charity had passed a resolution stating which fund we were applying to, and the amount that was being applied for. I was confident that we could meet all of these requirements and set about drafting a budget, gathering up quotes and requesting that the Board approve us to make the applications for the amount budgeted. I was encouraged by the General Manager to include everything we might want in the budget, and to give a one-page summary of the project, with a budget, for the Board to approve.

Unfortunately the Board did not approve us to apply for funding as I had not included two quotes for each item. I had not realised that the Board also required this and had thought that they would approve based on the General Manager's assurance that he would ensure that applications were complete prior to them being submitted. Given that the Board met monthly it was not possible to get their approval at the following meeting and still meet application deadlines for funding organisations that would be able to provide funding in time for the wānanga. This experience parallels advice from Stoecker (2013) on community deadlines

compared with academic deadlines, and the importance of academics learning to understand community processes.

In order to secure funding we therefore decided to approach businesses for funding (Appendix Z). With much trepidation, I sent the budget and a request for sponsorship to my former employer who, at the start of the project had pledged his support because the research area aligned with his own values and mission. I was enormously relieved when he agreed to meet and then offered to underwrite the basic budget. He did not seek recognition for his organisation's involvement, but did ask me to continue to seek funding from other possible sponsors in order to keep his own costs down. Approaches to ACC, another major residential support provider, and a service organisation who I had partnered with previously with BIA, all came to nothing. Both ACC and the service organisation were supportive of our kaupapa (the work we were seeking to do), but the timing of our approach did not fit within their budget rounds and we were encouraged to approach again in the future. The residential provider is a large commercial organisation and despite the manager's initial indication to one of our co-researchers that they would be keen to support us, ultimately he did not believe that their sponsorship would be visible to a sufficient number of people for it to meet their criteria.

One cost that came in after we had drawn up the initial budget of around \$10000 was for sign language interpretation. The adult daughter of one of the co-researchers had acquired deafness so in order for the wānanga to be accessible for her we would need to provide an interpreter at a cost of around \$3000 for the weekend. We sought direct sponsorship for this and the family also approached their case manager for funding so that the daughter could better support her father (who had the brain injury) through increasing her understanding of brain injury. While we were still trying to access funding, which was proving to be very difficult, the co-researcher informed our group that the family were not going to be able to attend. Throughout the process of developing the wānanga programme, I had wondered if this co-researcher would attend. She had seemed nervous about the project and I had not been sure if this was because of the cultural challenge of being on a marae, the possibility that co-

researchers could become speakers in the programme, difficulties over accessing funding for the interpreter, or some other reason. Regardless I was troubled that this barrier to participation, via the disability of deafness, had caused an additional hurdle for this family.

Co-researchers organised further donations with one approaching her employer for donations of beverages and food for the morning and afternoon teas, as well as for making up gift bags as koha, another approaching her daughter's employer and also approaching local businesses for prizes such as family passes to entertainment venues.

Ethics

As is common with participatory research, once the project had been finalised, it needed to go back for ethics approval (Appendix B) in order that the data could be used as part of this research. This two-stage process had been indicated in the first ethics application. In contrast with the warnings that I had come across at the CBPR training in 2013, the process was helpful and efficient. The Ethics Committee required separate child-friendly information for younger participants, and also required an alternate evaluation process to be available for people who might want to give feedback on the wānanga to BIWAP, the community organisation, without actually participating in the evaluation for the research.

Recruiting participants

With the date and funding sorted, the next step was to let people know. Our target was to run a wānanga for 60 people. We developed a flyer (Appendix AA) and let people know through the contacts we had built up during the project such as ONAC (Ōtara Network Action Committee), Te Roopu Waiora, and the BIA Liaison Officers. We also linked with the NZ Brain Injury Support Network – a group that had been set up by the Rotorua whānau who featured in the current affairs programme and that we had connected with through the BIA-AKL families' training that I contributed prior to the BIWAP meetings re-starting.

Our experience with recruitment for the wānanga was similar to recruitment for the project. Flyers were a tool so that you had something to email or leave with people, but

ultimately recruitment came down to personal connection again. While the programme and the project was Māori-centred, the wānanga was intended to be something that was for everyone – along the thinking of “what’s good for Māori, is good for everyone”. The reality, however, was that aside from Michael, other Liaison Officers perceived it to be something that was for Māori whānau and tended not to recommend it to non-Māori. During the wānanga recruitment process, Michael met someone from the local Māori Member of Parliament’s office, who stated that she might be interested in attending. In order to maintain positive links with ACC, and with a view to impacting at a policy level we informed the ACC Minister of the event and extended an invitation to her, and a request to meet if that was not possible (Appendix BB). We did not receive any form of reply to the invitation or request.

Regardless, we reached a point where we stopped recruiting when we became worried that we would have more people attending than we could cater for and accommodate.

Results II: What we did and found – action project and evaluation

The wānanga

We gathered for the powhiri at 10am at Weraroa on the 29 August 2015. Waiata sheets were handed out to people so that they could tautoko our powhiri speakers, which included Michael, a participant who attended because of his own brain injury, and a kaumatua friend of one of our co-researchers. Throughout the weekend 86 participants from 17 families came together and learned from each other, and from the scheduled speakers who were a mix of clinicians, academics, and brain injury survivors. The speakers expressed that they were honoured by the focus of participants, especially those with brain injury who were clearly hungry for the information that was delivered, and by the thoughtfulness of the questions that were asked, and stories that were shared.

From the first cup of tea to the lunch hakari on Sunday, our ringawera looked after people with delicious meals that were served and cleared away promptly, making for a very smooth-running programme.

Post-it feedback

During the registration time and welcoming cup of tea, participants were told about the method of post-it feedback. Four poster charts had been set up with different colour post-its for people to write down “things you’d like to get from this weekend”. The first three charts were for people to write down what was most important, second most important and third most important, and the fourth chart was for “other comments”. The way in which people used the charts was to write comments on the first three early on and during the wānanga, and other comments tended to be used for feedback and thanks towards the end of the wānanga. It is not known how many people put comments on the charts. All of the comments are collated and grouped in “Things you’d like to get from this weekend” (Appendix KK).

From this information it was clear that people wanted information, awareness and education with comments including people wanting general information, such as:

Education about BI.
Inspiration, connection tips

I'm wanting to learn more about what brain injuries do to people and how they manage to fight what they have and what they have been through

Knowledge about TBI

As well as more specific, such as:

I want to see my Dad finally understanding that what he did was bad in the past. But now in this time. He can learn from his mistakes and move on 😊
Oh and to get to know all you lovely people

Find out about obtaining driver's license.

A number (4) of comments related to wanting "Support for children" in terms of both the activities on offer for the wānanga as well as looking after the emotional needs of children who live with adults with brain injury, such as:

find a way to teach the children that no matter what happens and no matter what is said to them, from a brain injured person that they are the most important thing in my life

More fun activities for the children, animals, songs around bonfire

Five comments were grouped under the heading "Respite" and included:

A respite weekend with like minded whanau and parents how they cope

Peace of mind



Peace

food

People also sought out connection and suggested pairing up activities to improve learning:

Pairing non impaired members (whanau) with impaired (whanau) to do activities together so they can learn and understand how these amazing people are as a person

Friendship Networks

Enjoyment, kids, family

Verbal feedback

Throughout the weekend, a comment that was regularly heard from family members, children and people with brain injury was, "we are not alone", with many people commenting along the lines that while they knew that there were other families living with brain injury, it was wonderful to truly experience that they were not alone. An unexpected, but extremely

welcome, comment was relayed to me by one of the cameramen who filmed the main speakers. He had spent time talking with the kaumatua who had commented that the wānanga had “refreshed the wairua of the marae”.

The final session for the wānanga was the feedback session. This session did not include children, so no formal feedback was gathered directly from children, but many of the children were represented by the adults who attended. Seventeen people attended the session. Ten of these were at the wānanga as family members, six because of their own brain injury and the marae kaumatua also attended. The group consented to being audio-recorded and were reminded of the ethics approval for this session of the wānanga and for the audio-recording.

The actual time that we had for feedback was about 50 minutes, which was tight for this number of people. Each person was asked to sit and reflect before we started the feedback, so they could think about what it was that they wanted to share. Each person spoke at least once to give their feedback. An alternate feedback process was available for anyone who wanted to give written feedback to BIWAP without this becoming part of the PhD research (Appendix CC), but no participants used this option.

The themes that came through within this session resonated with much that the BIWAP co-researchers had talked about during the Phase I and II meetings. People wanted more awareness of brain injury in the community and talked about the need for this in places like WINZ and at family doctors. They wanted the awareness so that these organisations would deal better with people with brain injury, and also so that families would have more avenues to get information from when they found themselves in the situation of there having been a brain injury within the family.

Older man with brain injury:

“Yeah, I think more of this stuff getting back to um, organisations that are charged with supposedly looking after the families and the brain injured, um, perhaps it will open, ah, perhaps their vision will change.”

Father of adult son who sustained brain injury as a pre-schooler:

“it’s one thing that I think this nation needs is awareness out there, from people like WINZ, all those government agencies that deal with head injury without knowing it – and sometimes they know it but they don’t really understand it, and I think somebody (unclear – other background talking) something needs to be done about them being aware of what it is that we have actually been in touch with this weekend.”

A number of people also spoke of the desire to reconnect again. People spoke of wanting to reconnect face-to-face and through social media such as Facebook. The quality of speakers was praised and the fact that there was time for questions, with one participant noting how much the speakers had also valued the questions.

Wife of man with brain injury:

“having excellent speakers that people have been able to talk to and not talked at – I think has worked out extremely well. And you know, the ones that have done the lectures have commented on the questions and everything else because people are participating extremely well.”

Whole family teaching was commented on with family members noting how important it was that their children had also learned as well as the wider family

Wife of man with a brain injury:

“Kia ora everyone and kia orana³³. I just wanted to share that this whole experience has been just absolutely an eye-opener for, not just [name of husband], but for the whole rest of the family unit. What I love about it the most is that our children get to come along and share this whole experience and understand ... they just, that it’s you know, used to be a thing in the family, we’d kind of joke about it, it used to be a joke – but then, along the way it kind of used to upset him and you know, and then it was, you know, it wasn’t a joke. It’s actually quite hurtful and so, just for them to understand, that it hurts Dad and just being there as a family, you know, to come and learn, and for them to understand. It’s not a sickness, it’s not because Dad’s naughty or you know, something like that, but you know, that that’s ah, you know that we’re here to learn what it’s all about, to try and be equipped for it, so that we can, ah, make life a bit easier for us, so that we can maybe reach out to other people a bit in some ways.”

19 year old daughter of man with a brain injury:

“I just want to say, you know, this is my first time to come to a function like this, and you know, this has proved to me, myself, that it’s just not my Dad that’s going through it. I actually only thought it was just my Dad [father crying], don’t cry Dad – and you

³³ Kia orana is a Cook Island Māori greeting

know, but coming here, it's actually been quite lovely, you know and it's [interrupted with comment of "beautiful" from another participant and "thank you" from her Dad] ... But other than that, you guys are such lovely people and it would be lovely to see you guys again."

Her father later commented how he would have liked someone to check how he was doing:

"But that's one thing I would love. "How are things going for you?" "Is there anything not right for you at the moment?" or anything that's going on? How you feel? Or you think it should be a lot better. But nah, this is a really awesome gathering here. I love it. Thank you"

Sister of a woman whose partner had a brain injury:

"I personally ... found it quite insightful, to hear everyone's versions of their stories and what they were going through, and their battles and yeah, learnt quite a bit, in regards to how her partner would be dealing with things and reacts to certain things."

BIWAP reviews

The wānanga

At our meeting after the wānanga the group were very much on a high. People spoke about the weekend as having been life-changing for them as it had exceeded their expectations of what we might be able to do. Prior to the wānanga we had written down our hopes, and earlier on the group had developed a vision of how they would feel at the end of the wānanga. Feedback in this session included co-researchers unprompted comments and we also repeated the post-it exercise to review the weekend by writing down the most important, 2nd most, 3rd most and other comments on the topic of "How the weekend went". The overall feedback through the meeting was that we had exceeded our hopes and vision for the wānanga, as was epitomised in this comment:

"The wānanga was the best experience ever in regards to TBI, I came out feeling so high spiritually, mentally & emotionally. I left learning what I wanted, gaining so much more. It was truly amazing."

With the following comment covering a range of the areas of positive feedback:

"Having family together. No boundaries everyone the same. Great speakers. Friendly. Support for all. Great food."

The areas that stood out in the feedback were Connecting, Education, Exceeding expectation, Whānau, Holistic and Relaxed. We also collected comments on “Areas for improvement / future ideas”.

Under Connecting co-researchers spoke of there being a “sense of belonging” and emphasised the importance of “meeting all the children and parents that have a brain injury and how they lit up from the speakers”. This theme of “Connecting” aligned with a number of co-researchers mentioning the importance of hearing the comment, as well as experiencing the feeling of “we are not alone”. Education post-it comments included “My whānau were able to learn about TBI and issues relating to TBI”, “Knowledge, Education!!”, and “Education through speakers and talking to attendees.

All of the “most important” comments made some mention of connections whether it was through the concept of ‘belonging’, family, whānau or mentioning the importance of specific family members attending.

Review of the whole project

The highlight of the project for me was that as an individual researcher I would not have developed the concept or had the cultural resources to conduct the wānanga without partnering with both the community partner, in the form of Michael (the Liaison Officer), and the co-researchers. Each of these three roles contributed uniquely to create an outcome that was greater than any group could have produced on their own. The idea for the research came from the academic partnership, setting the research in South Auckland was a decision of the community partner, and the wānanga idea from the co-researchers. The topics that we sought speakers to cover, choosing to conduct whole family education and having a programme for children all came from the co-researchers. The availability of the marae and the ringawera were all thanks to one co-researcher. The contacts for speakers largely came from myself – through my academic and clinical links; Michael – through his disability community links, and also through serendipitous chance, as we drew on a connection to a Rotorua whānau made through the television programme.

Our meeting to evaluate the project as a whole looked at the work we had done and whether we had lived up to the principles of CBPR, as well as considering future plans. There were 5 of us present at this meeting. As we had often done, people wrote down their thoughts before sharing with the group. The questions we considered were:

1. What have we learned about supporting families of people with brain injury to live their lives in the ways they have reason to value?
2. Did we stick to our principles?
3. Did we achieve our aims?
4. What's worked?
5. What's not worked?
6. If you knew of another group wanting to do similar work – what would your advice be to them?
7. Individually - how has this experience impacted you?
8. Where to from here?

What have we learnt about supporting families with brain injury to live their lives in the ways they have reason to value?

The issues that came out on this were the wide range of needs, which required a wide range of responses.

“everyone’s an individual and will have different needs at different times in different ways, and that what works for one person may not work for another – depends how far along the journey they are”

“– it doesn’t fit into the whole prescriptive thing, it changes with different people. It’s having some flexibility which is really important ... People are wanting prescriptive stuff when we need to be moving away from that sort of model – and what it is about the brain injury that affects other things – not just physical, not just cognitive, but psychological the spiritual aspects – all those things, and it’s not stuff that’s addressed very well under a model with ACC because it’s all around medical.”

“I have learnt that people with brain injury need more wānangas, hui, togetherness with their families and just to have fun and learn knowledge and wellbeing within themselves”

In terms of the work we had done, people continued to talk about how happy they were with the outcome of the wānanga. They had also valued the process of getting there.

Did we stick to our principles?

When the group were asked how well we had worked within the CBPR principles, discussion was brief but all agreed that we had. My own analysis of how the principles were enacted have already been presented within Chapter 5 - Method.

Did we achieve our aims?

The group were very happy that we had achieved our aims with a representative comment being:

“Cos I noticed that yeah so many families and children were happy at the hui and we achieved a lot of togetherness and awareness. I mean even the kids were so happy. And I noticed a lot of those ones that had brain injury, they were focused, they wanted to learn. They really wanted to learn, and a couple of them come up to me asked me questions – and I just couldn’t give them any answers, I need to learn.”

What’s worked?

In terms of “What’s worked?” people focused on the group in terms of both the learning and support, and managing to get sponsorship.

“some individuals have really grown within the group, which is awesome, and some individuals have really needed this. You know, I’ve seen that for some people – it’s been really useful. So that’s brilliant”

What’s not worked?

Under “what’s not worked?” people commented on some logistical issues around the wānanga itself, but the main focus was around whether we should have had more co-researchers. One woman commented “*I thought everything we did, did work. But it was difficult having a smaller group falling off*”. Throughout Phase II we had a core group of about 8 (including me), but one woman seemed to drop out just prior to the wānanga due to other family issues, although her injured family member and another member of the whānau still attended the wānanga. Group numbers was always a juggle. It was a priority for me that we compensated people adequately for their time, which meant that I was a little nervous about getting too many in the group, as that could reduce the number of meetings we could afford. With the group being forced into

taking such a long break, I was also concerned that introducing too many more people would eat into the time available (in terms of university deadlines) and could take us back to the beginning, rather than being able to move forward with plans. We all agreed that the one new co-researcher had slotted in incredibly easily and been very effective within our team.

If you knew of another group wanting to do similar work – What would your advice be to them?

When asked about advice for other groups the main comment was “go for it”, but sort the funding.

Individually, how has this experience impacted you?

The significant individual impact on people had been talked about spontaneously in the wānanga evaluation meeting, and people added to this by talking about how it had increased their awareness of ABI. There was also discussion about the importance of the project being about support as well as action:

“I think it was both (support and action) really, because basically we were doing both weren't we. We were sort of supporting ... looking ahead – and I found that was quite good. Cos I think supporting each other is more or less the same as looking forward for what we can do to help others”

Where to from here?

The “where to from here?” discussion focused on everything from getting a logo (we'd been advised that we needed this to help with sponsorship on our next project), to when and where we would meet, as well as talking about future projects which some in the group were excited about, whereas others felt that they had completed what they set out to do and would therefore not be continuing. We also then planned a celebration of a dinner out at a nearby Thai restaurant which was a particularly lovely evening. A friend had put together some logo ideas and there was lively debate over them at dinner. We ultimately chose the design (below) that two of the whānau members with brain injury preferred the most, because it represented hope to them as they connected it to a soaring bird.



Figure 11: A new look for BIWAP: Logos agreed to by BIWAP co-researchers with involvement of some of the injured family members.

Trust the process

Throughout the entire process I was clear to organisations, our group, my supervisors and our funder for the wānanga that I did not know what I was doing. The key advice that I had from my supervisors was “trust the process”, and so I did. There was an enormous amount of energy put into the project, but it seemed that there were parts where everything flowed easily and productively. I noticed that when we spoke with people about what we were doing people were not only interested but they also wanted to help – which is how we ended up with outcomes on top of outcomes on top of outcomes. Each activity or event we were involved in seemed to lead to a new connection which supported another worthwhile outcome occurring. For example, as part of returning to the fieldwork I did two evening teaching sessions in a series of evenings that Enliven Presbyterian Support organised in partnership with the Auckland Brain Injury Association. This work ended up being filmed for a local magazine-style current affairs programme as part of a story focused on a Rotorua whānau who were seeking to build awareness of and support for families impacted by brain injury. This led to the family supporting our wānanga and us gradually building a strong connection between the two groups, which has also seen us supporting each other in work that both groups are now doing with ACC. Even further down the track (outside of the PhD research), Enliven became sponsors for our second wānanga run in 2016.

Outcomes on top of outcomes

We were thrilled with achieving our key outcome of running a wānanga for families that was evaluated by both the participants and the co-researchers as having met our goals. But then the outcomes kept coming.

The week after the wānanga we went to ABI Rehabilitation to thank them for the sponsorship which made the event possible. A group of co-researchers, children, and participants who were there as a result of their own brain injuries came along to share our experiences and our thanks as recorded in my journal reflection the following day:

We had the most beautiful encounter yesterday. After completing our wānanga over the weekend we went to thank our sponsor, ABI Rehabilitation. We'd put together a few slides of photos of the event and then people spoke about the weekend. The conversation evolved as the owner of the organisation talked about some upcoming work he's involved in. I was so happy to see four men, who've had very serious brain injuries, talking as equals with a man who they know can have influence in how supports are delivered. They were articulate, considered and heartfelt in their talk and were listened to with great and genuine respect. The thing I loved was that while for each of these men it is fairly immediately clear that they've had some difficulties, there was nothing patronising in the interaction - right down to the fact that we (the people without injuries who work in the area) had done nothing to prep them or their family members. We had a safe space, where enough time was given and it was a moving, beautiful and worthwhile encounter (journal entry, 3 September 2015).

Part of what made this thank you meeting so powerful was that one of the men who attended was the father who had wanted someone to ask "How are things going for you?" It felt as though this process had spontaneously and serendipitously met this need.

Through this event we were told of the owner's (Max Cavit's) impetus behind a project that ACC were picking up looking at the "rehabilitation pathway". Max's desire was for providers to communicate more for the benefit of clients and families and we were also keen to be involved in order to ensure that the family voice was well represented and that that voice included the experience of Māori and of South Auckland. Through Max, both Leeanne and I attended and achieved our goal of contributing to family matters being at the fore in this planning.

At the Pathways event I spoke to a general manager of one of the community rehabilitation providers and told her of our project and that we were wanting to raise money to support family members to attend the Whatever It Takes training in November. Her immediate response was to offer to sponsor two family members and to encourage me to seek more sponsorships at the event. Ultimately we sourced sponsorship for 10 people to attend the training – seven who were family members and three who had sustained serious brain injuries

in the past. By asking for sponsorship at this event we were also approached by a woman who was involved in a group mentoring women in business. She was keen for both Te Rina (of the Rotorua whānau) and myself to attend a lunch with this group in order to raise the profile of families living with brain injury and to fundraise for Te Rina's work with the NZ Brain Injury Support Network. At this luncheon I was introduced to Dame Rosie Horton, known as "the charity Queen" in Auckland, who is an ambassador for the Centre for Brain Research. She encouraged me to keep in contact and to build links with this Centre.

It certainly seemed that when we told people of our work there was a great deal of support and enthusiasm which could lead on to new opportunities. The data collection phase of the project was now complete but these next steps were important in terms of the sustainability of BIWAP.

Support through action

In reflecting on the meetings and the process, it was clear that while there was a lot of focus on action, the co-researchers also talked about experiencing a lot of support. Six months down the track from finishing the data collection we were again in a rebuilding phase and the balance between support and work came up again. Through discussing what we wanted, what had worked and what had not worked, the co-researchers shared their struggles and successes and received validation from others. At the same time, they knew that they were contributing to something bigger. While we did not have large numbers to do the work, people were motivated and inspired through the process, which is something that seems to drop away easily. It could also be linked to the fact that there was adequate koha each meeting to make it viable for people to attend, which was no longer available in the post-research phase.

Dissemination and sustainability

The final stage in the CBPR core components, or phases, for research is dissemination. Community groups (including the BIA community) often talk about researchers asking for help with recruitment and data collection, but failing to recontact with the results and talking about how the completed research relates to the community. The BIWAP group reported back first to

our sponsor, then to our local community of Ōtara through the ONAC meeting, and then to our community partner via a presentation to the Auckland BIA Board. Later on we supported a Brain Injury Awareness Day in Rotorua by having a stall and talking with people about the research, presented jointly with BIA at Brain Day run by the Centre for Brain Research, and also presented to the Brain Injury Association's Liaison Officer Conference. In keeping with what was demonstrated to me at the CBPR training, presentations include any co-researchers who are available, as well as myself. We jointly decide what the key messages are and how we will present.



Figure 12: Community dissemination: Presenting what we had done and our future plans to the Ōtara Network Action Committee

Sustainability of the project was very important to me in order to still not be doing drive-by research. The group has continued to meet, although the lack of petrol vouchers has made regular participation more difficult. The Facebook page that we used internally as one way of communicating has been opened up, and used as a way of disseminating videos from the wānanga and other information that we think could benefit whānau with ABI.

Following the wānanga, co-researchers had noted the impact that brain injury had had in some families on parenting. The group decided that a parenting course for whānau with ABI would be more helpful for people than for them to attend a standard community course. We partnered with The Parenting Place to run their course Building Awesome Whānau, with a view to one of our group becoming a trainer on this course and able to deliver it to our community on a more regular basis. A second wānanga was delivered in November 2016, and there are plans for future workshops including a Wahine Toa retreat where BIWAP are now the

community partners in another community-academic partnership with Occupational Therapy students. Other actions are lined up but on hold until the completion of this PhD, and other collaborators completing their own projects.

Sustainability has had its challenges, particularly in terms of funding. We have sought community grants, but as we are not yet a registered charity we have not had success in this area. The relationships we have built have, however, resulted in sponsorship and it is interesting to see that again it is relationship, built over time, that is leading to success in this area.

Policy impact

In contemplating research my goal was that it would be respectful and effective. The practice of the research achieved this on many levels, and has also begun to achieve the higher goal of impacting on policy. Through the BIWAP project we have become involved in ACC policy development via the Rehabilitation Pathways. In the time since the wānanga we have continued to build links with ACC, managing to secure sponsorship from them for our second wānanga, and now looking for future work to be supported via education, rather than sponsorship funding. BIWAP is also impacting the Auckland BIA as we now have a Māori co-researcher on their Board and she sits alongside another Māori board member (my husband) who became involved in this work through the BIWAP project. Their input highlights the need for brain injury organisations to consider Māori within their service delivery. Speaking to BIA Liaison Officers also shows this group that there are alternate ways of delivering education which are well-received by Māori and non-Māori, and has sparked conversations where we have been asked to take our work to different areas through the country. Our response has been that we would happily support, but would recommend that they start by connecting with their own Māori communities and listen to what they think is working, not working and what they would want, in order to develop projects suited to their communities.

Summary

In summary, the BIWAP project built understanding of the lives of whānau with ABI in order to develop an action project that would increase the capabilities of whānau to live their lives in the ways they have reason to value. The careful preparation before entering into the field, and then partnering with co-researchers resulted in a successful project. The result of the project was a clearly Māori-Centred and Community-Based action in the form of a wānanga which directly enhanced the lives of many whānau.

Chapter 7 – Reflections: But none of this is new

The final stage of this work is critical reflection on the consequences of our action. This reflection is my own, rather than the work of BIWAP as it draws back to the philosophy and methodology and has occurred while I have been writing up the results. At a later stage I will take this reflection back to BIWAP for their consideration as we continue to strategise ways of influencing policy as well as delivering projects to support whānau with ABI.

My question from the outset has been **“What would increase the capabilities of whānau of adults with serious brain injury to be able to live their lives in the ways that they have reason to value?”** BIWAP delivering a wānanga for whole families to learn and connect around life with brain injury was a new thing, in that such action has not been done before. Following BIWAP’s second wānanga, comments from both an ACC strategy consultant and an overseas Professor, ran along the lines of “this changes everything”. I was initially very excited by their feedback and especially by those comments, and the fact that the ACC consultant had taken on the range of concerns and suggestions made by whānau. Yet at the same time, when I reflected on the voiced experiences of whānau with ABI, and longstanding recommendations of Māori academics and clinicians, the same thought kept running through my head: “but none of this is new”. While on the one hand, the involvement of a co-researcher in ACC strategy development, and the fact that ACC have now attended and been a sponsor for a second wānanga made me feel extremely hopeful in terms of the project having met a goal of beginning to influence policy, on the other hand there was a nagging feeling that something was not quite right. I was aware that while what we had done and found had newness in it, the basic understandings of what would increase the capabilities of whānau was in many ways absolutely not new.

The idea of this project started because of my discomfort with the gap between the well-known research knowledge of serious brain injury impacting significantly on families, and the individually-focused policies which did not allow for real support of families. My reflection

now considered the gaps between rhetoric and practice, and between rights and policy. In reflecting on what we had found, and what we had done I was drawn back into reading to try to make sense of not only the gap between research and practice that is discussed in the Literature Review, but the gaps between how we have long known that brain injury is a family injury, *and* that Māori benefit from services that are designed and delivered by and for Māori, yet services have remained steadfastly mainstream and individualistic in their delivery.

In order to better understand the gap between what is known and what is delivered, I looked at a sample of Ministry of Health (MoH) documents focused on whānau well-being and disability strategies, and Accident Compensation Corporation (ACC) documents relevant to Māori and the delivery of rehabilitation for serious brain injury. In keeping with the Capability Approach's connection to human rights and whether these exist in actuality in peoples lived lives or only on paper, I then looked at monitoring reports related to New Zealand and the Convention on the Rights of People's with Disabilities (CRPD). I have not revisited the UNDRIP in this section due to both its current lack of real power in Aotearoa³⁴ and the already existing power that Te Tiriti o Waitangi has in the articulation of the rights of tangata whenua, and responsibilities of tangata tiriti. Overall this engagement revealed a series of forward and backward steps, and of policies being developed, ignored, and then developed again, often seemingly for the first time. In order to better understand the processes underpinning the non-implementation of knowledge, I re-engaged with the work of Heather Came looking at institutional racism found in health funding in Aotearoa. This chapter concludes with recommendations for what needs to be done to maintain and solidify the forward steps.

Review of ACC and disability-related documents

Reviewing the various strategy documents, guidelines and reports, summarised in Table 1 below, it was clear that there were a series of forward steps and back steps. An example of a forward step was the Ministry of Health's (1998) in-depth publication, *Whāia te*

³⁴ The UNDRIP has the status of a UN Declaration only, compared with a UN Convention, so the government signing of this Declaration signals only intent.

Whanaungatanga, which focused on the well-being of whānau, because it was understood that improving whānau well-being could improve the health of Māori. As one could reasonably expect, this work also resonated with the overall strategy of the time in terms of public health action (Ministry of Health, 1997). Unfortunately ensuring this follow-through between Māori and mainstream strategies is clearly not always a priority, as is demonstrated in the complete lack of connection between the current Māori disability strategy (Ministry of Health, 2012) and the broader New Zealand Disability Strategy (Office for Disability Issues, 2016).

ACC also provided examples of forward and backward steps, but here the issue was often more to do with gaps between the practice recommended by their guidelines and the practice that was possible in actuality as a result of their funding parameters. Alongside of this there are mainstreaming practices, such as the use of evidence-based reviews which ignore the fact that the research that their recommendations are based on, will be likely to be drawn from mainstream populations. Yet despite having little relevance or validity for Māori, they will be imposed on our whole population.

Table 2: Review of sample of government documents that relate to well-being of whānau with ABI

Document	Good points	Less good points	Summary
Ministry of Health: Whāia te Whanaungatanga (1998)	Recognises central role of whānau. Includes six whānau well-being principles. Mainstream document resonated with this document.		Forward Steps
ACC: TBI Guidelines (2006)	Recognised impact of brain injury on the family and the importance of considering family needs in rehabilitation planning. A chapter on Māori and TBI.	Practice did not match up with recommendations.	Great words but not enforced in practice.
ACC: Te Tūroro Māori me o mahi: The Māori patient in your practice – Guidelines on Māori Cultural Competencies for Providers (2008)	Thorough. Involved input of a wide range of respected Māori clinicians, academics and cultural experts. Highlights issues such as cultural barriers. Notes the importance of providers practicing in accordance with Te Whare Tapa Whā and meeting the needs of Māori claimants.	May not have been widely distributed. I worked with predominantly ACC claimants at the time and was not aware of the document.	Great document but may not have been widely distributed or known about.
ACC: Pragmatic Evidence-Based Reviews (2012) across a range of topics including community integration, substance abuse, depression, challenging behaviour and aging.	Practical range of topics	No mention of Māori needs. No mention of families/whānau International evidence base despite No noticing of the gap in attention to Māori well-being.	Likely to cause harm to Māori whānau through invisibilisation of their needs

Document	Good points	Less good points	Summary
ACC: Traumatic Brain Injury in Adults: Stakeholder Findings Report (Esplin, 2012)	Notes families' needs for supports, education and counselling are expressed by clients and recommended. Notes importance of recognising the individuality of each person's injury and situation, and supporting the needs of families and that these needs included the need for education and for support that may need to be separate from the person with the injury.	Lack of Māori participants ³⁵ . ACC staff key performance indicators had negatively impacted on their ability to work well with clients with longer term needs. Notes lack of staff knowledge.	While the researcher had sought to include adequate number of Māori participants this was not achieved
ACC: TBI Client Service Experience (UMR Research, 2012)	Notes families' needs for supports, education and counselling are expressed by clients and recommended. Notes importance of recognising the individuality of each person's injury and situation, and supporting the needs of families and that these needs included the need for education and for support that may need to be separate from the person with the injury.	Notes lack of staff knowledge.	Good summary of the experiences of clients throughout the client with a great deal resonating with the experiences of families we had worked with.
Ministry of Health: Whāia Te Ao Marama is the Māori Disability Action Plan for 2012-2017	Developed by the Māori Disability Leadership Group and involved in-depth conversations with over 200 people as well as engagement with services over 18 months. Recognised that "services that fail to take account of the significance of culture in the assessment and support of Māori disabled have the potential to create a greater likelihood of poor outcomes and reduced health gains" (p2). Comments on the ways in which whānau commonly care for family with disability, even when there is no financial support for this is also commented on.		While Whāia Te Ao Marama does not mention any particular disability, there was no sense of it not fitting with brain injury, because first and foremost, it fit with whānau and with Māori aspirations for flourishing lives.

³⁵ The recruitment method was to give local Brain Injury Associations a list of criteria which did seek a balance of age, ethnicity, time since injury and a mix of family/whānau relationships, but clearly this resulted in an overwhelmingly non-Māori bias, which reflects the overwhelmingly Pākehā makeup of most BIAs

Document	Good points	Less good points	Summary
Office for Disability Issues: New Zealand Disability Strategy (NZDS) 2016- 2016	<p>Strategy has three principles, namely:</p> <ol style="list-style-type: none"> 1. Principles of Te Tiriti o Waitangi 2. Principles of the Convention on the Rights of Persons with Disabilities 3. Ensuring disabled people are involved in decision-making that impacts them (page 17) <p>Recognises Māori as tangata whenua. Notes that with one in four Māori identifying as disabled it is important that inequality is addressed - "Māori world view needs to be woven into the implementation of this Strategy. This includes the cultural importance of whānau and a whānau centred approach which differs from Western concepts of family and disability" (p14).</p>	<p>Only one member of the 16 person reference group was Māori which is hardly adequate for a partnership principle.</p> <p>Ignored Whāia Te Ao Marama.</p>	<p>At first glance this document looked promising. But in reality it was a missed opportunity to build on the solid framework of the Māori Disability Action Plan.</p> <p>It did not put into practice its own principles or recommendations.</p>
Article 33 Convention Coalition Monitoring Group: Participation and Poverty (2015) and Acceptance in Society (2015)		<p>Reports made no comment on how their findings related to Māori.</p> <p>Both reports state: "One limitation of the first interview round was that Māori and Pacific people were not specifically engaged/considered as a target population" (p37).</p>	<p>Fail.</p> <p>This group is funded via the government to serve a monitoring role for the CRPD. There is no Māori voice and no voice for brain injury within either of these reports.</p>

Summary of issues within the practice-related documents

The review of these documents highlighted a number of issues relevant to upholding the rights of whānau with ABI, all of which can be seen as colonising, or mainstreaming, practices. Talking the talk of partnership, while only walking the walk of representation clearly results in Māori voices and concerns being side-lined, which was obvious in the shift that took place within the disability sector reports between 2014 and 2015. Only approving supports for an injured individual, and ignoring the known impact of brain injury on their whānau, operates against both knowledge of best practice for brain injury and established frameworks for Māori well-being. While the use of evidence-based practice reviews may at first glance seem like a sound and unbiased way of determining what treatments should be funded, there are clear racially biased effects of these practices. Within neuropsychology, we consider that it is not proper practice to use tests normed for one population on another, yet we impose rehabilitation models from a Western framework on to people whose understanding of health, and how to achieve well-being is based on a more holistic framework. The use of these reviews should only, therefore, occur with sufficient attention to what information is being left out, and the lack of suitability of these guidelines for people from cultures outside of those that the evidence-base is built from.

But what about human rights?

The purpose of human rights instruments is to ensure that governments can be held accountable for protecting the basic rights of their citizens. Given that the rights of whānau with ABI have not been evidenced to be a priority, I looked at the Convention on the Rights of Persons with Disabilities (CRPD) and the monitoring process that took place for Aotearoa in 2014-2015.

Convention on the Rights of Persons with Disabilities

The UNCRPD is recognised as a significant step in terms of the rights of people with disabilities, and a shift in people being viewed as recipients of welfare to being independent rights-holders. New Zealand signed and ratified the CRPD in 2007 and 2008 respectively, and the Optional Protocol, allowing parties to take claims of violation to the Committee, was acceded to in 2016.

While the focus of the CRPD is on individuals with disabilities, the role of families is noted in the Preamble (x) and a number of articles directly note the obligations of the State parties to support the family:

(x) *Convinced* that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities,

The entitlement of the family to protection by society and the State is also found in Article 23 of the International Covenant on Civil and Political Rights (ICCPR), making this an immediately enforceable right, rather than one which is only required to be progressively realisable.

In terms of indigenous people, the preamble (p) does express concern that some people face discrimination through multiple pathways:

(p) Concerned about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status,

There are, however, no articles to specifically protect the rights of indigenous with disabilities, which means that State's parties have not been required to commit to ensure specific protection for indigenous with disabilities.

Relevant articles

The articles which have strong relevance to our own work are:

- Article 8 – Awareness-raising
- Article 9 – Accessibility
- Article 16 – Freedom from exploitation, violence and abuse
- Article 23 – Respect for home and the family
- Article 25 - Health
- Article 28 – Adequate standard of living and social protection
- Article 30 – Participation in cultural life, recreation, leisure and sport

In the following section each article is outlined and its relevance to whānau with ABI is noted.

Article 8: Awareness-raising requires States “to adopt immediate, effective and appropriate measures ... to raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities.” This suggests to me that various groups supporting this aim should be able to access resources to raise this awareness. *Relevance to BIWAP:* financial support would be needed for awareness raising so that huge time and effort is not consumed in the fundraising process, when supporting awareness-raising is a State responsibility. In order for the State to ensure the relevance of the awareness-raising, and to uphold its own principles of ensuring active participation in decisions, and the general principle of “nothing about us, without us”, this work should be planned and delivered by and for whānau with ABI, as well as delivered to the wider community. Doing this would meet a BIWAP goal of educating families, GPs, case managers and the wider community.

The purpose of *Article 9: Accessibility* is “to enable persons with disabilities to live independently and participate fully in all aspects of life” and is generally discussed in terms of physical access for people who use mobility aids, and access to communication and information for people with sight and hearing impairments. The issue for access for people with brain injury relates to cognitive, behavioural and emotional limitations that result from the injury. Following a brain injury whānau experienced needing to engage with bureaucracies which family members found stressful, and people with brain injuries could find impossible. Difficulties with fatigue, comprehension and behavioural and emotional management could lead to people expressing distress in the settings where they were trying to access help, in ways that can be interpreted as aggressive or manipulative, rather than as being the expression of the disability that has resulted from the injury. This means that injured people need support people present when they engage, which can cause costs for family in needing to take time off work, or the need to rely on the overstretched resources of the BIA. I did not come across any writing on this form of impediment

to access, and wonder if it would be more apparent if there had been representation of the needs of whānau with ABI in the monitoring of CRPD.

Relevance to BIWAP: The concept of accessibility needs to recognise that for people with BI, alongside those who have physical and sensory limits, there are some for whom the accessibility limitations can be due to cognitive and emotional disabilities. Access for people with these limitations could be achieved through the provision of skilled support people, such as liaison officers or whānau, to be present when people with brain injury need to deal with bureaucracies.

Article 16: Freedom from exploitation, violence and abuse, brought to mind the many discussions that we had about how to protect individuals with brain injury from high pressure selling from trucks that prey on low-income neighbourhoods selling household goods via loans with exorbitant interest rates. We were also aware of situations of family members assaulting the person with the injury due to their inability to cope with the changes in their family member, and difficulties in accessing support. Article 16 is also relevant to the situation of people with brain injury in residential care. Clients are extremely vulnerable to abuse as people in care tend to be there because their cognitive functioning is at a level where they cannot make life choices for themselves. Many will have very poor memory for recent events and need skilled people to support them to manage their behaviour. When support people, whether they are family, residential workers, or workers who come into the home, do not have appropriate training or adequate support then the risks of abuse increase.

Relevance to BIWAP: Ensure that adequate training of paid and unpaid carers is available and accessible. Our experience in providing training within a low-income area is that training and support need to be provided at zero cost. This means ensuring that training is available for free for family members, with necessary supports in place to ensure that attendance is achievable for those on very low incomes. These supports may need to include travel, accommodation and paid cover for the support needs of the injured person or other dependents.

In the CRPD, *Article 23: Respect for the home and the family* clearly states that “States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities”, and that “In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.” This contrasted with the experience that BIWAP had of people struggling to get supports for their children to cope with the effects of their parents’ injury, and for parents with brain injury to be able to get support with parenting.

Relevance to BIWAP: Parenting support and teaching parenting skills needs to be available for parents with brain injury.

Article 25: Health states that “State Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.” COFACE, a European Union organisation which represents the interests of families, considers this statement in terms of the family, and advocates that family roles in healthcare of people with disabilities be understood and supported (COFACE-Disability, 2012). A Māori-centred perspective would also inextricably bring whānau into the understanding of health, along with prioritisation of physical, mental and spiritual well-being. Achieving health needs to be understood from each person’s understanding of what health means to them.

Relevance to BIWAP: The “highest attainable standard of health” needs to be understood in terms of what health means to each person. For Māori this would include the recognition that health is understood as a holistic concept, and needs to be understood in terms of Māori concepts of well-being.

Article 28: adequate standard of living and social protection was clearly not met for many people with brain injury. In order to orient me to his worklife in the pre-research phase, one of the first places that Michael took me to was the Salvation Army where he visited regularly in order to collect food parcels. He found he needed to do this himself as many of his clients did not cope with being in these settings (Salvation Army, WINZ, Housing NZ etc) without support

(a situation that links back to the Article 9 right to accessibility). A number of his clients, including BIWAP co-researchers and their whānau, were homeless or inadequately housed. I realised the seriousness of the housing situation when a social worker at CYFS was excitedly amazed that a couple had managed to get accommodation at the local caravan park, even though we all knew that this would not be a suitable place for the couple to be able to have their child stay with them.

Relevance to BIWAP: Ensure that the State uphold its responsibility for adequate standards of living and social protection by prioritising housing and social protection for people with disabilities, and ensuring that access to support services in these areas are accessible and effective for whānau with ABI.

Article 30: Participation in cultural life, recreation, leisure and sport, obliges States Parties to “take all appropriate measures to ensure that persons with disabilities: a) Enjoy access to cultural materials in accessible formats;” and prescribes the entitlement to “recognition and support of their specific cultural and linguistic identity”. Through our discussions, co-researchers had talked about the ways in which whānau had struggled to remain involved in their cultural lives as some had forgotten their tikanga. One co-researcher also perceived that participating in cultural life was not seen as a priority by her family member’s residential provider as she felt she had to jump through too many hoops to be able to take him on leave for this purpose, let alone access the staff support that would have made the participation more viable for her whānau member and less stressful for the wider whānau.

Relevance to BIWAP: For this right to be upheld. The State again needs to think beyond physical accessibility to cultural life. Being able to physically access, but also to stay on marae is an important way of participating in cultural life and therefore an important rehabilitation goal which needs the level of support that would be put in place for more accepted goals such as vocational goals. For a person with very high needs following a brain injury this can mean that the person needs the provision of a support person to attend to physical (such as toileting) and cognitive (such as wandering) needs, even while staying with family.

CRPD monitoring

The monitoring process involves the government preparing a State's party report and also supporting the process and report writing of an Independent Monitoring Mechanism (IMM). Alongside of this, other groups are able to submit shadow reports. All of these reports are considered by the UN Committee on the Rights of Persons with Disabilities, which comments and makes recommendations within their Concluding Observations. This process took place in 2014-2015, and the next reporting cycle will commence in 2018. In the following section the relevant reports from 2014-2015 are considered in terms of their relevance to whānau with ABI and the gaps that are apparent in the reporting as a result of the lack of consideration from a whānau with ABI perspective.

State party's report

The State party's report did acknowledge the overall disadvantage that Māori and Pacific peoples, including those with disabilities, have in terms of health outcomes, and that they also experience high rates of disability, unemployment and low incomes. The report notes that "Health and disability service standards recognise the values and beliefs of Māori and Pacific health and disability consumers, stating that the needs of individuals must be met in a manner that acknowledges individual and cultural values and beliefs" (New Zealand Delegation, 2014, p. 33). While this statement may be technically accurate in terms of what is documented, or recognised, it does not inform us how well these standards are met *in actuality*. The report goes on to note that "Disabled Māori have identified their right to access Māori culture and language is not always met" (p. 39) as there are many marae which are not accessible and that there are only three qualified sign language interpreters who are fluent in both te reo Māori and English. Also of relevance to the work of our group was acknowledgement of the inadequate number of sign language interpreters, specifically within the Courts and education system, but no acknowledgment of the cost barrier that could be present for community groups in being able to provide accessible support to whānau.

Independent Monitoring Mechanism (IMM)

The IMM for this round of reporting comprised groups who represent deaf community, blind citizens, people living with intellectual disabilities and with mental health issues, and the Disabled Person's Assembly (Article 33 Convention Coalition Monitoring Group, 2012), and was funded to carry out the consultation and report writing process. As noted above, the IMM's reporting up until 2014 actively considered the situation of Māori with disabilities. The opening sentences in the Second Report of the IMM are:

“Human rights in New Zealand have bicultural origins, a Tangata Whenua whakapapa that sits alongside tauwiwi (settler) beliefs about the importance of human dignity and rights. The Treaty of Waitangi was the promise of these two peoples to manaaki, to take the best possible care of each other. It is about us all, in all our diversity.”
(Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, 2014, p. 5)

It goes on to note the links between Te Tiriti, CRPD and UNDRIP stating:

“The Disability Convention shares some common underlying human rights principles with both the Treaty of Waitangi and UNDRIP. These include the importance of partnership, autonomy, close consultation and full and effective participation” (p. 7).

A key focus of the reports was the discrimination apparent in the State's efforts to continually ensure that family members, funded via MoH rather than ACC³⁶, were unable to be hired as carers for people with disabilities, which was litigated through several courts in the case of the Ministry of Health v Atkinson³⁷. They note the importance of people with disabilities having full choice of carers, and that it is especially important for Māori and Pacific peoples to be able to make this choice as it “involves all aspects of Te Whare Tapa Whā – physical, mental, spiritual and whānau health. Therefore whanaungatanga and whānau ora are integral to supporting Māori disabled” (Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, 2014, p. 63). These rights to a family life are considered from many angles within the 2014 IMM report, including noting the need to ascertain “how many children

³⁶ While people have been able to hire family members under ACC, this has often been frowned upon by case managers

³⁷ Discussed more fully in the Human Rights sections of both the Literature Review and Philosophy chapters.

are living with a disability or *being cared for by a parent with a disability*" (my emphasis p. 90). Restricted access to cultural life is also noted. The links between disability, being Māori, and poverty are made, including the importance of having access to adequate housing, and that New Zealand's rates of child poverty impact disproportionately on Māori and Pacific children as well as children with disabilities.

As with many other reports, the concept of access is discussed but focuses on physical access. For many of the whānau we engaged with, however, lack of access to services related to the challenges for the person with the brain injury of managing fatigue, reduced comprehension and being able to cope behaviourally and emotionally with the challenging nature of the bureaucracies that many people with disabilities and their whānau are forced into contact with. These difficulties create stress for whānau who need to make time to support and advocate for their whānau member in these settings. Representation from brain injury focused organisations could see a broadening of understanding of access and the supports needed for people to be able to fulfill this right.

Shadow reports

Auckland UNCRPD Shadow Report Group

Other groups are also able to submit reports. A significant shadow report, written from the perspective of people who are both tangata whenua and whānau hauā, spells out much of my discomfort with the processes that I have seen, and mainstream reports and strategies that I have read (Auckland UNCRPD shadow report group, 2014) and is therefore quoted extensively:

“Under the provisions of Te Tiriti o Waitangi, whānau hauā should have been able to expect the government's first action following ratification of the Convention to have been to seek advice from whānau hauā and their representative groups - providing space and resources for meetings with government officials to form a *partnership* [my emphasis] to determine what implementation of the Convention would mean for the first peoples of Aotearoa New Zealand, and then to provide the resources to facilitate that implementation in a kaupapa Māori (Māori way). Monitoring implementation would have been conducted in partnership with whānau hauā groups, and the government's report would have begun by acknowledging the first people of the land and their views of how the Convention had been implemented.

Instead, whānau hauā are largely invisible in the government's report. Disabled Māori are mentioned in passing as another disadvantaged group with poor health, education

and employment outcomes, and with limited access to culture and meeting houses” (p11).

“This omission is detrimental to the whole disability community in New Zealand and to the successful implementation of the Convention. Had our government engaged with whānau hauā in the way that Te Tiriti o Waitangi requires: in a spirit of protection, participation and partnership, it could have paved the way to creating a model for all disabled people in New Zealand to engage with government. Instead, most disabled people, but particularly whānau hauā, feel excluded, marginalised and overlooked by the government” (p11).

The Shadow Report Group’s key recommendation, from the shortcomings noted above, is that:

“The New Zealand government provide resources to whānau hauā and their representative groups to work with government to develop and put into effect a kaupapa Māori model of partnership to implement the convention” (pp. 4 and 12).

The body of the report covers many areas that are considered in the IMM report and that overlapped with issues apparent within the work of BIWAP. They recommend “dedicated support to disabled parents in the parenting of their children” (p. 8), and note that barriers to justice are influenced not only by the ability to pay for lawyers but also by the lack of lawyers knowledgeable in disability law. They express concern for the people working with disabled in terms of lack of training, low wages and poor employment conditions. PPPR legislation is touched upon and it is noted that it provides for substituted decision-making, when the preference of the disability community is for supported decision-making. It goes into detail on the situation of people in residential care, especially of young people being required to live in rest homes which are designed for, and populated with, older people. PPPR issues are of relevance to whānau with ABI because stress surrounding PPPR processes were raised as issues by co-researchers and wānanga participants alike, and were areas where both sought more information.

Again a major focus of this report is on the government’s knowing actions against the rights of people with disabilities through the passing of the New Zealand Public Health and Disability Amendment Act 2013 which took away the rights of people with disability to have their human rights assessed. The gap in this report was that while it had a strong voice for Māori

and, in particular for, whānau hauā, there was no clear voice for people affected by their own or a family member's brain injury.

Acclaim Otago

Acclaim Otago is an advocacy group for people who experience disability as a result of injury. While they note the integral role that ACC plays within New Zealand's economy and society, they also spell out some of its drawbacks, especially in terms of the CRPD.

Acclaim Otago's key issue is that the CRPD has not impacted the delivery of supports via ACC. They believe that many New Zealanders do not receive their full entitlements under ACC, and that the processes for review of compensation are unfair due to both the costs of making a legal challenge, and the fact that a company which is wholly owned by ACC conducts the reviews. The review process is dependent on the Reviewer's discretion which means that claimants who seek review are excluded from the usual judicial safeguards. They note that in 2014 ACC had a \$29 billion reserve, and that the interest in protecting profits and the reserve worked against the rights of claimants to justice. Acclaim Otago contend that this has been a driver in ACC not taking any steps to realise the reforms that should have occurred under the CRPD.

This strong sense of distrust with ACC³⁸ was evident for many co-researchers and people in the wider brain injury community as they dealt with disempowerment, reviews and multiple assessments. The lack of affordability of the review process, which may involve self-funding specialist assessments by neurologists, neuropsychiatrists or neuropsychologists, is an area of discrimination for low-income families, which I would consider to be a class-privileging practice.

Concluding observations of the UN Committee on the CRPD

Many of the concerns from the reports above are noted as recommendations of the Committee to the State party to make changes. Among these were concerns about many of the areas that had come through in our work which included difficulties with access to justice through the ACC

³⁸ This sense of distrust is evident even in ACC's own documentation as the Statement of Intent 2013-2016 focus includes to "rebuild trust and confidence in the organisation, improve the delivery of services to ACC's customers, increase the customer focus, and improve the culture and capabilities of the organisation" (Accident Compensation Corporation, 2013, p. 6).

review process, the lower standard of living for people with disabilities, and the disparity that exists between people with disabilities who are supported via MoH compared with those with ACC support. Of particular relevance to this thesis was the Committee's concern "that the Accident Compensation Corporation machinery lacks a human rights focus" (Committee on the Rights of Persons with Disabilities, 2014, p. 4), and the recommendation that "the State party examine the processes for the assessing of compensation by the Accident Compensation Corporation to ensure that adequate legal aid is available and that its processes are fully accessible to all claimants, and finally to ensure that this mechanism has a human rights focus" (p. 4). Given the human rights origin of ACC, via the Woodhouse principles, this recommendation is entirely compatible with Sir Owen's original intent. Embedding a human rights focus into legislation could offer greater security to more marginalised groups who can otherwise have difficulty gaining access. The ground level understanding of this lack of access was apparent from the frequent comments from middle-class Pākehā who wondered out loud along the lines of *if it's this difficult for us, how hard must it be for others*.

While there is no clause specific to indigenous populations in the CRPD, the situation of Māori, and in particular Māori children, was noted. The Committee expressed its concern "that Māori people have the poorest health outcomes in New Zealand ... that the prevalence of disability is higher in the Māori population as a result of poverty and disadvantages" (p. 7), and "that some children with disabilities, especially Māori children with disabilities, have difficulty in accessing some government services, including health and education services" (p. 3).

Summary of issues in CRPD monitoring reports

While the reports vary in their attention to issues that are of relevance to whānau with ABI, key issues that emerged for me were that the voices of Māori were frequently left out, or given inadequate attention, and that voices for brain injury were generally absent. The recommendations made by the Committee suggests that groups giving feedback on valid areas of concern will lead to pressure for the State to achieve change. Building a voice for whānau

with ABI in relation to the State's obligations under the CRPD is a valid strategy to achieve change, or at least to bring UN pressure to the state to deliver change.

Without there being a voice for people with brain injury or their families/whānau however, there are aspects which are missing, in particular the recognition that the disability of one family member can cause significant disability, not only at the income and time level, but also at a relational level through the particular effects of brain injury. Reading these reports and seeing the monitoring process gives hope that bringing representation of brain injury to these UN processes could cause the government to look more particularly at these situations. While the UN does not have the power to force governments to make changes, it is able to put them in the situation of having to justify their position, and allows a spotlight to be shone on areas of injustice.

Lack of intersectionality within CRPD

It has been noted by many that indigenous people are disproportionately impacted by disability and by poverty (e.g. H. S. J. Hickey, 2008), yet this situation of multiple disadvantages is not directly addressed through the human rights protections. It was only through looking to see how NZ was doing under the CRPD and experiencing frustration at the lack of attention to the dual issues of being indigenous and living with brain injury that impact on whānau with ABI being able to lead flourishing lives, that I became fully aware that the CRPD did not specifically, other than within the preamble, consider the needs of indigenous.

“Difficulties appear to be compounded for indigenous disabled people where disability remains an issue treated as something of causation rather than identity and where there is no article in The Convention. While indigenous disabled people are mentioned in the preamble, this was not developed further. Instead of having the ability to intervene in the planning stages of developing The Convention, indigenous disabled people were excluded and are subsequently facing invisibility through the lack of recognition of their identity as a specific marginalised group within an already marginalised group” (Article 33 Convention Coalition Monitoring Group, 2012)

So the lack of attention to indigenous voices goes up to the UN, as well as down to the lived lives. While my thinking had been that it was important to get New Zealand to live up to its

human rights obligations under both CRPD and Te Tiriti, it is interesting to note that these rights do not coexist within the one document at the UN level.

Reflections on reading so far

In trying to understand this dance of awareness of Māori disadvantage within health and disability, alongside the lack of sustained implementation, I wondered which factors correlate with the forward steps and which with the back steps. Given the historical differences in ACC ideology that occurred under National governments, compared with Labour, I had expected that this pattern might be the same for addressing the needs of Māori and whānau with ABI. This pattern did not hold. While I do not have the answers, a particularly noticeable factor was the leadership of Dame Tariana Turia³⁹. Under her tenure as Minister for Disability Issues, appropriate delivery of services to Māori was a priority, and this attention was present in mainstream as well as Māori-focused strategies. As soon as she retired, however, this attention disappeared as was evident in the contrast between the work of the Article 33 Coalition in 2012 – 2014, compared with their 2015 reports.

This cycle of reading and reflection led me to conclude that there are four key areas that need attention. These are 1) the repetitive dropping or ignoring of already established knowledge around ways to better achieve service delivery for tangata whenua; 2) the domination of non-disabled Pākehā (i.e. mainstream) thinking and practices even within the arena of disability issues; 3) the lack of a voice for brain injury leading to whānau with ABI not being heard; and, 4) the need for Brain Injury Associations to better reflect the full range of people, especially tangata whenua, who sustain brain injuries.

The lack of a brain injury perspective in the 2014 CRPD monitoring reports is understandable, given the lack of a national BIA from June 2011 to July 2016 (Denis Denton, former chair of BIA-AKL, personal communication). The inconsistent presence of Māori

³⁹ Dame Tariana Turia was the Minister for Disability Issues. She was initially a Labour party MP but broke away from this party, over the trampling of Māori rights on a land rights issue, and formed the Māori party which went into coalition with the National party.

perspectives in both CRPD monitoring along with ACC and MoH documentation, however, led me to consider whether this could possibly be due to oversight, which seems implausible given the concerns over Māori health and well-being statistics, or to something more deliberate. The final stage of my reflective process was to revisit Heather Came's work examining institutional racism in order to better understand the processes that led to the invisibilising of Māori perspectives.

Institutional racism

Heather Came has examined the situation of institutional racism within health funding and looks at the various processes that lead to racist outcomes, regardless of whether that was the intention. In terms of policy-making she argues that there are five "sites" of institutional racism that move policy away from what Māori clinicians and advisors would advocate and towards more mainstream policy, namely the tyranny of the majority, incomplete evidence, a lack of cultural and political competence from decision-makers, flawed consultation, and the impact of crown filters (Came, 2014; Came & Humphries, 2014). Each of these sites were evident in the documentation and processes that I considered through this reflection.

Tyranny of the majority was seen in Heather's research when there would be typically one, or at most two, Māori advocating in a group of non-Māori for Māori health concerns to be prioritised. While majority decision-making, much like utilitarian economics, can seem fair on the surface, it can also have the effect of repeatedly shelving the same minority interests, while decisions are constantly made in favour of the dominant group. These same majoritarian processes were seen in the disability strategy where Māori had representation of one advocate on a panel of 16. Given that Te Tiriti o Waitangi has a key principle of partnership, this process of the dominant group deciding that minimal representation is sufficient, has the effect of sidelining Māori health issues and treating tangata whenua as an interest group, rather than a partner.

Incomplete evidence operates via a similar process as majority decision-making. When policy makers set policy, a common first step is to draw on international evidence in order to determine 'best practice'. Within health settings this will tend to result in an overemphasis on bio-medical evidence which can have the effect of side-lining Māori health frameworks – even though all of this policy will often sit under a whakatauki (Māori proverb) talking about the importance of bringing together contributions from many people. Just as women were sceptical of the process of only conducting drug tests on men, as this did not offer evidence of how effective, or harmful, a drug would be for women, so too do we need to be sceptical of developing policy based on research that is relevant only to the dominant cultural group. As discussed above, this practice was clearly evident in ACC's Pragmatic Evidence-Based Reviews, which drew on international research, and did not comment on, or counter, the disappearance of Māori knowledge through this practice.

Cultural and political competencies are noted by Came (2014) to be required for health care practitioners, yet there is no such requirement for senior management or policy makers. For those of us who have grown up as part of the dominant culture it can take significant conscious efforts and training to see that our world view offers simply one lens, and that there are other valid views that can be ignored if we do not take care. Heather Came talks about people needing to understand their own culture, and to learn about social justice and an understanding of power, as well as Aotearoa's colonial history. This imbalance of required learning and understanding can lead to situations such as outlined above, with ACC documents pointing out the higher rates of injury for Māori and need for attention to whānau in one set of papers, and then commissioning research of client experiences, without even requiring the researchers to engage effectively with Māori. You don't need to connect many dots to then also see how much harder it is for Māori perspectives to even get to be in the evidence base discussed in the *Incomplete evidence* section above.

Flawed consultation was seen as a site of institutional racism when Māori health providers are asked to participate in advisory groups at significantly lower rates than

mainstream health providers (Came, 2014). This process is summarised as “asking the wrong people the wrong questions, often within the wrong timeframes” (Came & Humphries, 2014, p. 105). The very concept of a ‘consultation process’ is also troubling as it indicates where the power lies i.e. within the mainstream institution, and the level of influence that is available to Māori. Consultation is not exactly binding, and consultants whose ideas are too counter to the dominant group may well not be asked again for their consultative input. As noted the inclusion of only one Māori consultant in the 2016-2026 Disability Strategy showed that whether or not the person was the right person they clearly didn’t even reach the numerical threshold of consulting “people” with only one person.

Impact of crown filters refers to the practice of the political needs of the day over-riding the advice and development work done by Māori advisors. Came’s participants who had experience in policy development saw their ideas taken out or diluted through the various phases of report-writing, especially in the final stages of development. While my own experience, and review of documents has not included the development process, this practice nonetheless seemed to be evident in the gap between the TBI Guidelines (New Zealand Guidelines Group, 2006), commissioned by ACC, and the actual ACC funding practices. The Guidelines recommended supports for families/whānau, and had a whole chapter devoted to best practice in working with Māori, yet their policy of funding only the individual who had sustained the injury was in opposition to both supporting families and coming anywhere near to working in a way that acknowledges Māori well-being.

What needs to be done? – How do we solidify the forward steps?

The action-reflection cycle above suggests a range of actions that could be effective next steps, or iterations, for the action-research cycle. To increase the capabilities of whānau with ABI to live their lives in the ways they have reason to value we need to make changes at every level. These need to occur from the person with the injury, to the supports available to families and whānau, to the ways in which community groups offer supports and act as a voice for whānau with ABI, and to the national organisations charged with funding and delivering supports and

rehabilitations. The challenge however, is to find ways to ensure that forward steps do not turn into back steps, or disappear altogether. The simplest explanation I have of what needs to be done is that we need to live up to our already existing human rights commitments under Te Tiriti o Waitangi, the International Covenant on Civil and Political Rights (ICCPR) and the Convention on the Rights of Persons with Disabilities (CRPD). The other step in ensuring that back steps do not occur is to ensure that, at all levels of delivery, there are people who understand the situation of whānau with ABI.

Live up to our commitments

At the most basic level, we need the State to live up to our human rights commitments. Instead we have had a government that has legislated in breach of the Bill of Rights Act and CRPD (New Zealand Disabled Person's Organisations, 2014). If Te Tiriti o Waitangi principles of Partnership, Protection and Participation were upheld, i.e. if a Māori worldview had equal power to Western medical discourse, then the protection of whānau well-being would be unquestioned as an essential aspect of health and rehabilitation practice. A purely individual focus, especially in the area of brain injury, would be seen as antithetical to achieving well-being for the injured individual as well as for people in close relationship with that person. Supporting the development of resources from a Māori perspective is one way of enacting participation, as is seeing the relevance of supporting individuals and whānau to be able to participate within their cultural life. Partnership means, at a minimum, having an equal voice in policy decision-making rather than fighting for space amongst many other voices. Recognising the mainstream dominance that has occurred since colonisation and the difficulties that seem to exist for dominant culture policy-makers and executives to allow Māori perspectives to hold an equal place in decision-making, it is also necessary for these groups to support kaupapa Māori initiatives so that Māori voices are unimpeded by the domination of mainstream practices.

Within human rights conventions and covenants, the family is acknowledged as the basic unit of society and entitled to protection. This right comes from the International Covenant on Civil and Political Rights (ICCPR) which is therefore an immediately enforceable right, rather

than being progressively realisable. Practices that have not recognised the impact of brain injury on families, and supported the protection of the family could be argued to be in violation of Article 23 of the ICCPR. In order for these arguments to be made it is important that whānau with ABI build and maintain a strong advocacy role.

Under the CRPD there are a number of articles that clearly relate to whānau with ABI, but need stronger consideration from this perspective. Monitoring of New Zealand's performance under the CRPD will again occur in 2018 and it is strongly recommended that whānau with ABI contribute to this monitoring through the submission of a shadow report.

Strong voices for brain injury

While much work has been done within civil society to monitor New Zealand's performance under the CRPD none of this has had focus or input from groups representing the needs of whānau with ABI specifically. The lack of a national brain injury organisation has resulted in a lack of voice for brain injury, the absence of which was evident in the document review. The national BIA collapsed in 2011 and was re-established in 2016. The lack of a voice for brain injury was noted by ACC during the presentation of the TBI strategy to BIA Liaison Officers in 2015, and its absence is also notable within the disability strategies, and reports to the CRPD Committee. Strong representation for brain injury needs to be maintained at national policy level, and it is imperative that Māori voices have equal power within this in order for all whānau with ABI to be adequately supported in realising their capabilities to live their lives in the ways they have reason to value. Strong voices for brain injury could increase the understanding that a distinct feature of brain injury is how it impacts on the wider family, i.e. that brain injury is a family injury.

Strong voices for Māori to ensure strong, sustained action for Māori

We've tried using mainstream models for Māori and found them to be lacking. The reality is that the Western individualised model arguably does not work for Pākehā either, given the nature of the impact of brain injury on families. When we simply take mainstream models and attempt to adapt them for Māori by using the word *whānau* alongside family, this also does not

work. So perhaps it is time to recognise that, when it comes to working holistically, Māori have richer models and we could all benefit from starting with this base of knowledge which is likely to better suit Māori whānau, and then see how well it also works for Pākehā. Again, this is not a radically new idea. Whānau Ora was based on delivering services in a whānau-centric and holistic fashion and there are many other examples of effective service delivery which have been developed by Māori, and for Māori.

When partnership is proposed then it needs to be real partnership, i.e. 50:50, rather than a mainstream organisation being in control of the ways in which the Māori 'input' is allowed to be heard and implemented. Alongside partnership there should also be a place for 100% Kaupapa Māori organisations funded from the same pool as the current kaupapa Pākehā services. In order for partnership services to operate as true and actual partnerships, then proper understanding and support for this will need to come from the top, with executives and policy-makers, along with their staff, all being required to be trained in their responsibilities under Te Tiriti o Waitangi and how to implement services effectively.

Services such as ACC and MoH, which are charged with delivering equitable services to all need also to be held accountable for delivering services in the ways that are effective with Māori, which will mean measuring the quality, quantity and accessibility of services using measures that are acceptable to, and valid for Māori.

Conclusion of reflections

In trying to understand the feedback that the action of delivering a wānanga developed by and for whānau with ABI was something that "changed everything", I read practice-related documents, disability strategies and CRPD monitoring reports. This reading highlighted that understanding of brain injury as a family injury, and understanding of the importance of working with Māori through the lens of understanding of Māori health frameworks is extremely important and often overlooked. In order to increase the capabilities of whānau with ABI, brain

injury and its rehabilitation needs to be understood from a whānau perspective in order to support the well-being of the injured person as well as their wider whānau.

I am no longer naive enough to believe that change which benefits those with less power comes about purely through those with power being aware of the need for change to reduce the disadvantage of some groups. While I do concur with the notion that rights tend to be fought for, rather than handed over generously, I do not believe that a pure conflict stance achieves lasting change either. My focus rather, has been to think about what would motivate change? What would reinforce the change? This comes from a radical acceptance of the reality that those with power, have power, and therefore have the power to make, or refuse to make change.

Chapter 8 – Discussion: Increasing the capabilities of whānau with ABI

Brain injury is a family injury and the fact that rehabilitation has largely been funded as if it was an individual injury is a remediable injustice that has caused unnecessary suffering. An individualistic focused system is, I believe, particularly disadvantageous for Māori who have the right under the Treaty of Waitangi to expect that health and other services should be delivered in a way that fits with a Māori worldview and in particular with Māori health frameworks.

The BIWAP co-researchers focus of “educating and strengthening ourselves in order to educate and strengthen others” is a viable way to increase the capabilities of whānau with ABI to live their lives in the ways they have reason to value. Being able to achieve this in a way which takes into account Māori health frameworks and is therefore whānau-centric will require sustained commitment from government organisations. Forays in this direction seem to have been short-lived, the vagaries of which can be partially understood by Came’s study (Came, 2014) of the ways in which institutional racism can impact systems, whether or not that is intended. A human rights-based and Treaty-honouring approach from ACC, MoH and other organisations involved with families of people with brain injury could progress the sustainability of an approach that would be more Māori-centred and whānau-centred. There is ample evidence of the needs for and benefits of working with families (e.g. Doser & Norup, 2014, 2016; Kreutzer, Stejskal, Godwin, Powell, & Arango-Lasprilla, 2010; Luauté et al., 2016), and working with Māori in ways that Māori have determined to be helpful (e.g. Elder, 2017).

In exploring this situation and how to increase the capabilities of whānau with ABI, BIWAP co-researchers focused on “educating and strengthening ourselves in order to educate and strengthen others”. Through their knowledge and their many goals, the first step that was chosen for an action project was to deliver a wānanga so that many whānau and individuals could come together to learn from each other and learn from health professionals with expertise in the areas where the co-researchers sought education. By delivering the education within a kaupapa Māori framework of a wānanga on the ancestral marae of one of the co-researchers,

we were able to both educate and strengthen through a holistic programme that attended to the four pillars of Māori well-being – hinengaro, tinana, whānau and wairua (Durie, 1985, 2001). The mission of educating and strengthening the community to improve the lives of whānau with brain injury, opens up many other possibilities for action, some of which have already been piloted and others which are in development.

This chapter will first summarise the study and outline the major findings. These findings are considered in terms of the literature surrounding brain injury and its rehabilitation and impact on families, as well as philosophically and methodologically in terms of CA and Māori-centred CBPR. Implications for action and for research are then outlined. In a nutshell, the findings of the initial phase of the research was that co-researchers wanted to be able to “educate and strengthen ourselves in order to educate and strengthen others”. This goal has now been adapted to “Educating and strengthening the community to improve the lives of whānau with brain injury” as the ongoing mission of the Brain Injury Whānau Action Project. In answer to the question of how to increase the capabilities of whānau with ABI to live their lives in the ways they have reason to value the solutions are as multitudinous and varied as the whānau who are affected. At the national policy level they can be summarised as New Zealand and its government organisations need to live up to the commitments already made, and that they purport to uphold, under Te Tiriti o Waitangi and the relevant United Nations human rights instruments. At the community level, the process of the research, where a community was asked to develop action based on their own experiences, knowledge, and understanding of what was needed has also been shown to be effective. At the family level, the action of the wānanga offers one way of increasing capabilities for whānau with ABI.

Summary of the study

Overview of the problem

The problem that triggered this research was the experience that while brain injury was widely accepted as a family injury within the literature, this had not translated to rehabilitation or

support services being delivered to families and whānau in Aotearoa because of the funding for rehabilitation only being available to individuals. While my initial concern was particularly for the partners of adults with serious brain injury, my Māori mentors pointed out the Western thinking behind this view, and that in their experience brain injury became an issue for whānau, as so few partners remained with the person with the brain injury. I believed that supporting families made sense from a rehabilitation, economic and human rights perspective. The philosophy that fit with my thinking, and with my understanding of the issues was the Capability Approach. Through a capability lens, disability is understood as capability deprivation (Mitra, 2006), which fits with intersectional understanding of the multiple limitations and barriers that are experienced by marginalised (via ethnicity and income) communities that also experience, and are more likely to experience, disability (e.g. S. J. Hickey, 2008).

My understanding of the additional difficulties that Māori, Pacific and low-income families experienced is widely accepted and was evidenced by the sentiments of the middle-class Pākehā women and men who were co-researchers and who expressed their concerns of “if it’s this difficult for us, how must it be for other families”. While I am convinced that there will be economic benefits in supporting whole families, the argument for this support is not made from an economic angle in this thesis because this is not my area of expertise and it is so dependent on what is counted in terms of the total costs and benefits around brain injury and its rehabilitation. Instead the philosophical focus of this project has been on the human rights arguments for better support for whānau with ABI. Basically, as a nation we are committed to protecting the rights of indigenous through our founding document of Te Tiriti o Waitangi, and protecting the rights of disabled, and of the family through both the Convention on the Rights of Persons with Disabilities and the United Nations Declaration of Human Rights in the form of the International Convention on Civil and Political Rights (ICCPR) and the International Convention on Economic, Social and Cultural Rights (ICESCR).

Purpose statement and research questions

The purpose of this research was to ask the question: How can we increase the capabilities of families of adults with life-changing brain injuries so that they can live their lives in the ways they have reason to value? Ethically it was also important to me that the research process would be directly beneficial to the participants and conducted in a way that was acceptable and useful to the local community, mana whenua and the brain injury community.

Review of the methodology

From the outset it was my goal to conduct research that was respectful and effective. I saw effectiveness as one way in which respect would be shown, in that the ideas and passion and time that people contributed would not only be valued through koha, but also through real action that could make a difference to the lives of the co-researchers and to other whānau. In order to achieve this and to realise my goal of striving to conduct research in a way that was respectful and valid for Māori the project was guided by both Linda Smith's principles (L. T. Smith, 2012) as well as the Māori-centred ethics of Te Ara Tika (Hudson et al., 2010), along with the principles of Community-Based Participatory Research (Israel et al., 2008). Māori-centred research incorporates a respect for the mana of Māori participants and local hapū and iwi, as well as a respect for cultural knowledge and values. This respect and attention to proper processes should be evidenced from the beginning of the research design, and through all of the relationships which are established and attended to. Linda Smith's principles, some of which are incorporated within Te Ara Tika, focus on avoiding the colonising processes which can occur within mainstream research that involves or focuses on Māori, when proper attention is not paid to dignity and ownership of knowledge. Her work also offers sound guidance around how to be in relationship with participants (or in this case co-researchers) and other parties who have an interest in the research. CBPR prioritises working with communities and building on their strengths in order to achieve dual goals of research and action that are of importance to the local community. Attention to power within the processes in the research, and the broader

community is important, as are longer term benefits from the research through capacity-building and sustainability.

Major findings

Much of what our co-researchers spoke of was echoed by wānanga participants, and much of this resonated with already established research. Co-researchers expressed feelings of anxiety, grief, guilt, exhaustion and being overwhelmed as they dealt with the changes in their family member and the family relationships while also trying to manage to deal with various aspects of health and legal systems, including, for some, the racism within these systems. They felt frustrated by both their own lack of knowledge, and the lack of knowledge exhibited by people whom they thought should understand whānau with ABI. This could include brain injury professionals not understanding their situations from a family/whānau perspective, and other non-brain injury support services not understanding the impact of brain injury. In choosing to take part in research, they wanted to learn for themselves and make a difference for others. They wanted to do this in partnership so that the solutions were based on the reality of their own, and the experiences of their co-researcher colleagues.

In terms of what had worked and not worked, much of this related to social determinants of health, or having people's basic needs met. Whānau with ABI at the most basic level needed adequate housing and support for their families, and were stressed by financial issues and the lack of knowledge around how to work the system. On top of this, they were impacted by the stress of care-giving, and the changes in personality and behaviour of their family member. For those with children they were concerned about the effect on them. Many also spoke of feelings of isolation for both themselves and their injured family member. All of this speaks to the reality of brain injury in one person often resulting in impairments in the lives of people in close relationship, or third-party disability.

This study contributes to the knowledge base through demonstrating an effective way of working with whole families, through a culturally sound process to increase their education

and strength to live their lives well within the context of brain injury. Further it demonstrates effective processes for determining valid strategies for working with communities who may not relate to mainstream services. Finally it argues that our government is obligated to uphold the rights of whānau with ABI and outlines some effective ways of increasing the capabilities of whānau with ABI to live their lives in the ways they have reason to value.

Combining Māori-centred ethics with CBPR

Combining Māori-centred ethics and Linda Smith's cultural values with CBPR resulted in a relevant methodology for the cultural makeup of the Brain Injury Whānau Action Project. BIWAP co-researchers were a mix of predominantly women who were Māori and Pākehā, with some also having Pacific Nations ancestry. In the first phase the research included one Samoan man.

Operating from a deliberately and explicitly Māori-centred position meant that the project was always intended to work well for Māori whānau with the expectation that it would also be effective for non-Māori who were also welcome to join with this kaupapa. In order to maintain the project as Māori-centred it was necessary for one co-researcher to leave, as her views would have made it too difficult for her to be on a marae and to take part in tikanga-related practices, such as waiata and karakia, which were important for the proper functioning of the wānanga.

The Māori-centred ethics also resulted in the liaison officer, Michael, who had never previously even used the greeting, "kia ora", to reply to the marae hosts welcome in a speech which began in te reo Māori, and to experience Māori cultural practices within an authentic setting. While Michael had worked effectively with many Māori whānau from his stance of generosity and support, this whole experience deepened his cultural understanding. Māori-centred ethics' focus on relationship (whanaungatanga) and on honouring and respecting others is a strength that is well worth applying within any research.

"Trust the process"

Coming back to Phase II, while our numbers of co-researchers had diminished, the passion for making a difference to families had not. The process of working with the community from a

strengths-based perspective meant that we were able to draw on the ideas and resources from across the whole group. As a researcher this meant taking a stance of being interested in what would emerge from discussions rather than trying to control what would happen. Through this process, I believe that the discussions and action flowed in such a way that positive connections were made. This started with co-researchers being supported by their own or family member's employers with donations and continued with the café owners helping out with children's activities for the wānanga. The kaumatua feeling the positive impact of the wānanga being held at the marae helped to build further connections with mana whenua. Max Cavit of ABI Rehabilitation, the sponsor, was enthusiastic about the idea and the implementation of the wānanga which led to involving our group directly into the ACC Rehabilitation Pathways work. This strengthened our relationship with ACC, when our work and push for change could have just as easily been seen as a threat, and helped us to secure sponsorship and their participation at the next wānanga, which gave ACC direct experience and appreciation of whānau-centred support and its multiple benefits.

Findings related to the literature

As commented on within the Reflections chapter, many of the findings are not new, as they resonate with well-known aspects of brain injury, rehabilitation and disability academic literature, as well as with Kaupapa Māori research and strategies for improving Māori well-being.

Brain Injury research

Families

Phase I of the research confirmed the range of impacts of brain injury on families including changed dynamics within the family with much experience of stress, anxiety, guilt, isolation, and feelings of being overwhelmed (Anderson et al., 2013; Perlesz et al., 1999; Ponsford & Schönberger, 2010; Tam et al., 2015; Vangel, Rapport, & Hanks, 2011; Verhaeghe et al., 2004).

While I had anticipated that whānau with ABI would talk of difficulties dealing with ACC or MoH,

I had not anticipated that stress from dealing with bureaucracies would go much wider. For this reason while people sought knowledge in many areas, the need for knowledge around advocacy was as high as for the anticipated need for knowledge around brain injury (Bellon et al., 2015; Kreutzer et al., 2009; Tyerman & Booth, 2001). Needs for family support, and for this to be delivered as whole family support was very clear.

Given that brain injury impacts whole families, I was particularly pleased that the BIWAP action delivered to whole families. The reality is, that had we not included children within our wānanga, then I suspect that very few families with children would have had the capacity to attend. At the most concrete level this research has demonstrated a way of supporting families as families which include children, people with brain injury and elders. While research has previously been conducted with both people with brain injury and a family caregiver, using the structured format of Multifamily Group Therapy (Couchman et al., 2014), I am not aware of research which included whole families, including children, delivered within a culturally relevant setting such as a marae.

Impact on children

Co-researchers were very keen that children have opportunities for learning about brain injury and connecting with other children. This concern for children links to the developing literature on the impact of parental brain injury on children (Kieffer-Kristensen, Siersma, & Teasdale, 2013; Niemelä et al., 2014; Tiar & Dumas, 2015). At the actual wānanga it was incredibly heartening to see the connections that the children made, and to hear the “we are not alone” comments from children as well as from adults. As a result of the evaluation and observations of BIWAP co-researchers after the wānanga, we determined that another way to increase the capabilities of whānau with ABI would be to partner with a parenting training provider in order to offer a whānau with ABI-focused parenting programme which was piloted during August – September 2016. This observation of the co-researchers and the piloted action gives further evidence that whānau with ABI are in need of protection, as New Zealand has committed to under Article 23

of both the ICCPR and the CRPD, and that more needs to be done to support parents with disability in their role as parents.

Racism

Sadly one of the findings in this work relates to experiences of racism. Co-researchers talked of experiences of racism in terms of their treatment within health systems, including hospital, ACC and providers. This fitted with my own observations through my experience as a clinician and the member of a Māori whānau, as well as through conversations during the research. Racism exists in behaviour and systems whether or not that is the intention (Came, 2014), as it comes about through the dominance of one cultural and economic group over marginalised groups. The racism that individuals and families experienced and felt in direct interaction are known within the literature (Gary et al., 2009; Harris et al., 2006). These were apparent in the document review that I undertook for the Reflections chapter, and must be acknowledged and challenged if health funders, systems and providers are serious in their intent to reduce inequity that is found between Māori and non-Māori within health settings.

Third-party disability

A comment from one of our first meetings of “I see myself as much of a victim as my brother is” stuck with me throughout the research and articulates clearly the reality of third-Party disability. This came from a Māori woman in a larger family, and alongside her a Pākehā woman spoke of the isolation and loneliness that she had experienced within her marriage since her husband’s brain injury. Co-researchers also expressed concern about the impact that the adult brain injury had had on children within the family. The concept of third-party disability, explored first in terms of people with communication difficulties (Scarinci et al., 2009; Threats, 2010), has clear relevance to whānau with ABI. Some whānau involved in our work had multiple difficulties prior to injury, which is a not uncommon cause and consequence of the layers of marginalisation and deprivation within much of the community we worked in. Others, however, were at the time of the injury, living their lives in the ways they had reason to value, as young families who were working and raising children, or older couples enjoying grandchildren and looking forward to

retirement. The brain injury of the family member has caused enormous upheaval as people shift roles from partner to carer, or, particularly in younger families have had to separate due to the changes in personality and behaviour of the injured person. These complicated losses and changes that result from brain injury have significant ripple effects on whole families in a way that injuries to other parts of the body do not. If the impact of brain injury on the family is recognised as a third-party disability then this will add another plank towards the argument for the State's obligations to consider brain injury as a family injury, and to remediate this current injustice and deliver the comprehensive rehabilitation that is central to the Woodhouse principles.

Māori-centred Community-Based Participatory Research

The project demonstrated that Māori-centred research ethics offer valid guidance to a Pākehā researcher seeking to engage in health research with general population which includes Māori. By using CBPR principles and a declared Māori-Centred approach, with awareness of working respectfully with indigenous and careful attention to power, the project naturally moved to a place that upheld more and higher values in terms of the Te Ara Tika framework (Hudson et al., 2010). While Te Ara Tika offers three different levels at which research can operate (Mainstream, Māori-centred and Kaupapa Māori) I believe that it is worthwhile for all non-Māori health and social science researchers to challenge themselves in each area of Te Ara Tika to move from the mainstream level of practice to a Māori-centred level, especially when working in areas where Māori are over-represented within the negative statistics. While my particular background did make it easier for me to choose to conduct research at this level – setting this as a baseline for ethical research involving Māori, would mean reviewing the make-up of research teams and ensuring that researchers develop the cultural humility and competence to operate at this level.

I believe that this research can stand as encouragement to other researchers who want to directly benefit their participants. The pre-research phase (Stoecker, 2005, 2013) was an

essential aspect of this project as it allowed for time and shared experience, particularly with Michael as the community partner, to contribute and build trust. The importance of proper processes was demonstrated with issues with one co-researcher who joined without going through the proper recruitment process, which led to a situation of discovering that her views were in conflict with the ethics of the project. Clarity of expectations and roles, and attending to group dynamics was important throughout the project in order to ensure that everyone was able to contribute to the group conversations, regardless of whether they had a more dominant or more reticent personality. The months of volunteering and experiencing the range and severity of issues that whānau were faced with meant that I could engage with co-researchers with a reasonable level of community understanding. I believe that this reduced the degree to which I was experienced as an outsider, although I was clear about my own whakapapa and background, and saved the co-researchers from some of the burden of educating a naïve person of privilege that might otherwise have occurred.

Collaboratively establishing ground rules with the co-researchers and having a focus of working towards achieving change gave us a shared purpose and allowed people to bring in their variety of skills and resources to contribute to the project. Clarity of purpose was also important in re-focusing when we had, for example, become somewhat side-tracked by the possibility of showing an awareness-raising movie as a fundraiser, which would have achieved some goals, but not have covered as broad a range of goals as we ultimately achieved via the wānanga and its spin-off benefits. The purpose of this project was always to achieve change at the ground level, by offering something to co-researchers and hopefully also to other whānau, and ideally also at a policy level.

Sharing, shifting and enhancing power

Prior to the research I had considered what role I would assume as a researcher. My initial intention was to be a servant researcher, but I was later convinced that in order to be able to achieve real change, this project would need everyone to not hold back in contributing fully. At the same time it was important to be aware of ways of bringing people in that invited full

contribution. Linda Smith's advice (L. T. Smith, 1999) to look, listen and then, maybe speak (titiro, whakarongo ... korero) was helpful, even if I didn't typically achieve this at the level I would have liked.

I did notice the need to work explicitly and deliberately in order for co-researchers to take on co-ownership of the work. This was done through direct teaching of the CBPR process, and ensuring that decisions were made via consensus. When co-researchers came up with ideas along the lines of "you could do a survey", or "you might want to look at how families have coped with ...", I would 'correct' this language to "we" in order to be clear that this was partnership research. In doing this, I did use and acknowledge my power as the instigator of the research, and somewhat ironically the power used in pushing for this shift, but it was necessary in order to move others towards taking greater ownership. The shift in power became evident as other co-researchers asked for more detailed academic information to learn about the concept of CBPR, and then brought in folders to organise their materials, followed by laptops to take notes, and later took charge of tasks such as organising catering and t-shirts, and even running a fundraising raffle for the t-shirts completely independently from me.

The idea of The Crash Reel movie fundraiser gathered a steam of its own and for a couple of meetings seemed, from my perspective, to detract from some of the information-gathering process during Phase I. The balance between action and discussion and preparation is important and, like other CBPR projects it felt that some of our group were keen to get to action and making a difference before we had fully considered our purpose (Israel, 2005), what we hoped to achieve via action, and how the action would increase the capabilities of whānau with ABI.

The research tool of watching and evaluating the movie, in terms of whether or not it would be beneficial may have had some effect in re-focusing our team on the need for the action project to have greater goals than a social event and a fundraiser, in order to increase our chance of having a policy impact. The evaluation process also brought in the idea that we could create our own tools for the purpose of evaluation. The need for the project to take a break while I dealt with health issues put an absolute stop to the movie fundraiser plan, although it was

ultimately incorporated into the wānanga programme based on our evaluation of the movie as a somewhat useful tool for families to reflect on the impact of brain injury on families, and for the modelling that it showed around positive family communication.

Capacity building

Principle 4 of CBPR promotes co-learning and capacity building among all partners (Israel et al., 2010; Israel et al., 2008; Stoecker, 2013). I entered this research with a degree of scepticism around this possibility as the capacity-building that I had read of was generally around community members becoming research assistants. Given my scepticism around the usefulness of much research, I wondered if the world of whānau with ABI needed more research assistants, or in the case of this study co-researchers. The reality of the project was that we all witnessed significant capacity-building amongst the co-researchers. People valued the knowledge that they had gained from each other and from health professionals around living more effectively with the impact of brain injury in their whānau. Several co-researchers also felt that they had found a new purpose in life in being able to educate and strengthen themselves in order to educate and strengthen others. Their previous, and ongoing, difficulties, became sources of knowledge and learning that they could share with others. Their experience made them relatable to others, and they could see themselves becoming the people that they had needed as supports in their own most difficult times as they sought to adjust to the effects of their family member's injury.

Importance of sustainability

Principle 9 of the CBPR principles requires that projects have a long-term process and commitment to sustainability (Israel et al., 2008). It was important to me that this project would offer something more than drive-by research, and make a real difference within its community. From the outset of the project it was pitched as an action project that had a research component, and was intended to continue as a viable organisation, if that was the wish of the co-researchers and later participants. Sustaining a group through more than 20 meetings that ended up being spread across well over two years was assisted by a research grant from the

Health Research Council which covered the costs of petrol vouchers and food that were provided at each meeting. However, once the PhD research component was finished, so too did this funding. In working with a low-income community, it is necessary to fully cover the costs as co-researcher's personal time and money budgets tend to be too tight to manage the additional strain of committing time and transport costs. While we have delivered further projects, we have not had the same level of financial support for the BIWAP members who have done this work, so finding ongoing funding for this work will be important. This links to Nussbaum's assertion that protection of rights is a government responsibility, rather than one that can be left to the charitable sector (Nussbaum, 2007).

Capability Approach

This PhD did not seek to extend the theoretical framework of the Capability Approach, but rather used CA as a way of framing the question by focusing on increasing the capabilities of whānau with ABI to live their lives in the ways they have reason to value. The concept of capability deprivation was valid to this group, and to indigenous research on disability (e.g. S. J. Hickey, 2008). The whānau with ABI who engaged with this research dealt with different levels and layers of marginalisation, including the experiences of racism and the impact of poverty as revealed through insecure housing, food, transport and community participation, as well as experience of being outsiders within services that should be there for support. The human rights focus of CA (Sen, 2005, 2010; Siegert & Ward, 2010) was also used as a way of considering possibilities for leverage towards policy change, which are considered in terms of each of the relevant articles of the CRPD below.

CA's focus on how people are able to live their lives in actuality, as distinct from what institutions or policies exist which should allow people to lead lives of dignity and well-being, is relevant for this population, particularly those with low socioeconomic status and from marginalised ethnic groups who can have less access to supports than the dominant groups within society. While the relevance of CA to indigenous populations has been questioned (Bockstael & Krushil, 2016), I believe that the flexibility that it has, through prioritising what it is

that is valued by individuals and, in some situations, groups or collectives, allowed for this work with its Māori-centred focus to consider the mismatch that occurs when services are delivered through an individualistic-focused system to peoples who prioritise whānau and collectivity.

Human rights and supports for whānau with ABI

In line with CA's human rights focus, I considered the articles within the Convention on the Rights of Persons with Disabilities that have most relevance for whānau with ABI. If the Accident Compensation Corporation and the Ministry of Health were to adopt a human rights focus, as was recommended (at least in terms of ACC) by the Committee on the Rights of Persons with Disabilities (2014) then the actions that would be recommended from this research would include 1) a real embracing of the principles of Te Tiriti o Waitangi, which would be evidenced by true partnerships with tangata whenua in both policy development and service delivery and, 2) recognition that as government organisations they have responsibility to uphold the commitment to protection of the family.

This section reviews the CRPD articles that were considered in the Reflections chapter, and the actions that could occur if this human rights focus were adopted.

Article 5: Awareness-raising – Financial support is needed for awareness-raising so that families, and wider society who impact on whānau with ABI, are able to gain increased awareness of brain injury and its effects on individuals. From a BIWAP perspective this would allow for the training of GPs, case managers, WINZ workers and workers in vital NGOs such as Salvation Army, so that they are better able to support and work with people with brain injury. Funding of this awareness-raising by the State is in line with Nussbaum's assertion that this protection cannot be left to the charitable sector (Nussbaum, 2007).

Article 9: Accessibility – Accessibility needs to be understood in terms of the non-physical ways in which the brain injury can impact on an injured person's ability to participate in society. This can include people with brain injury behaving in challenging ways in the very places where they seek support. In order to increase accessibility for people with brain injury they need

supports to allow access, along with services being better educated about brain injury. When behaviour resulting from a brain injury is not understood as the disability that it is, then case managers can react to the behaviour as verbal abuse, for example, rather than emotional lability and behavioural disinhibition. Of course workers are entitled to safe workplaces as well, so accessibility in places which can deal with people with disinhibition would need to include support and education for workers, as well as support for clients.

Article 16: Freedom from exploitation, violence and abuse – Families repeatedly spoke of the risks of exploitation for the person with the brain injury. This came up with people with brain injuries becoming the fall guys within gang or criminal groups, and also with people taking advantage of the injured person when they had money via lump-sum, or weekly, compensation. BIA workers and whānau have spoken of the need for a process around ACC paying out lump sum compensation in the situation of brain injury which takes into account the person's financial decision-making capacity. Another area of exploitation which needs addressing is the vulnerability that people with brain injury have to the type of door-to-door sales methods which seem to particularly operate in low-income areas. Whānau need support to navigate processes such as Protection of Personal and Property Rights (PPPR) Act in order to better protect people with brain injury from financial exploitation.

In order to achieve freedom from violence and abuse for people with disabilities there would likely need to be a fuller evaluation of the current rates and risks. Provision of accessible staff and whānau training to increase understanding of, and skills in working with, the emotional and behavioural effects of brain injury would also be an important step to reduce these risks.

Article 23: Respect for home and the family – The requirement for the State's parties to respect the home and family, and in particular that parents are supported in their parenting role so that the disability of a child or the parent does not result in unnecessary separation, is clear. BIWAP have trialled partnering with a parenting training organisation in order to deliver parenting support tailored to whānau with ABI, and this is an area that clearly needs further research as well as support. While the literature has long acknowledged that brain injury is a

family injury, the research on the impact of parental brain injury on children is still relatively small (Kieffer-Kristensen et al., 2013; Niemelä et al., 2014). This project has not looked at the impact of brain injury via the lens of the rights of the child, but this would be a valid extension of this project.

Article 25: Health – The New Zealand Delegation’s report to the CRPD (New Zealand Delegation, 2014) noted that “Health and disability service standards recognise the values and beliefs of Māori and Pacific health and disability consumers, stating that the needs of individuals must be met in a manner that acknowledges individual and cultural values and beliefs”. Clearly for Māori this means delivering health services through a holistic framework such as Te Whare Tapa Whā (Durie, 1985, 2001), or Hinemoa Elder’s models for working in partnership with whānau with ABI (Elder, 2015, 2017). It would seem to me that current service delivery is an example of attention to these rights existing more on paper than in actuality, as this does not accord with the lived experiences of whānau with ABI. If services were delivered in accordance with the delegation’s statement then the well-being of whānau (te taha whānau) would be understood to be of significant importance to the well-being of the injured individual. Strengthening and educating whānau would be a given rather than an area requiring activism.

BIWAP have been encouraged by the listening ear of the ACC throughout this project. Further support for whānau with ABI initiatives will help to address this issue, but the needs of whānau with ABI need to have the same priority as attention to physical and cognitive issues following brain injury, and this priority needs to be given to all whānau regardless of their ability to work the system.

Article 28: Adequate standard of living and social protection – Evidence of breaches of Article 28 were apparent from my first engagement in the community at Ōtara. Unstable accommodation affected co-researchers, wānanga participants and many of the clients with brain injury who Michael worked with. The personality effects of some of the brain injuries can make it difficult for people to manage interpersonal relationships which can make sharing accommodation (and the costs of accommodation) more difficult. This can put family members

in the position of having to make tragic choices. Mothers have to choose between keeping their children and themselves safe from aggression, when their partner has difficulties with both emotional and behavioural control, and not allowing their partner to live with them, knowing that he may not be able to find safe accommodation for himself. Homelessness is not solely a problem for whānau with ABI. The multiple disadvantages that can coincide with, and accrue from, the injury, however, certainly make it more likely. Added to this, the reduced skills in managing bureaucratic systems to obtain food and accommodation, such as provided by Salvation Army can reduce the chances for a person with a serious brain injury to be adequately housed and fed.

Article 30: Participation in cultural life, recreation, leisure and sport – In order to enact commitment to Article 30, participation in cultural life would be recognised as a valid and important rehabilitation goal. If this goal is important then it would be included in measures of progress. Supports for clients participating in cultural life would be made available and widely accessible to whānau.

What is measured, is treasured. Measurements, and reliance on research, that ignore culture are common within mainstream services and systems and risk having the colonising effect of whitewashing practice and reducing the importance placed on cultural life. Ideally measurements built from frameworks such as Te Whare Tapa Whā (Durie, 1985) and Te Waka Kuaka me Te Waka Oranga (Elder, 2015, 2017) will be developed and will offer greater broadening and relevance of measurements compared with those that are currently available. Work in this direction has commenced with Whānau Ora research. Kaupapa Māori and Māori-centred knowledge could become the base for measures and practices, rather than the awkward add-on that, through lack of initial attention and valuing, then risk existing only on paper and being ignored in practice.

Methodological conclusions

BIWAP's work demonstrated the power of both Sen (Sen, 2005, 2010) and Freire's (Freire, 2000; Glassman & Patton, 2014) work. In examining their situation as family members

of adults with serious brain injury, and assessing their lives in terms of how they could increase their capabilities, co-researchers' consciousness of their situation contributed to meaningful action that increased both their own and others capabilities. The action/learning that they chose impacted on their ability to lead their lives in the ways they had reason to value. Increased understanding of brain injury, along with strategies to better support themselves and their family members in an environment where they experienced the shared understanding of their own and other's similar struggles was empowering and impactful. For those who have remained involved in order to impact the way in which services are delivered, via policy work, or via our own local work there is also a greater sense of being able to make a difference in their world.

Implications for action

This research further supports the need for ACC (and MoH) to embrace the human rights stance on which it was founded through living up to the commitments that the State has made under both Te Tiriti o Waitangi and the CRPD.

Accident Compensation Corporation

In order to not add to the grief and uncertainty that the brain injury of a family member causes, whānau need to know and be able to access the safety net that Woodhouse envisioned 50 years ago (Royal Commission of Inquiry, 1967). For ACC to be equitable, it needs to ensure that services deliver effectively for everyone, and not just for those who are already most advantaged (Hefford, Crampton, & Foley, 2005; Stephens, 2010).

As recommended by the Committee on the Convention on the Rights of Persons with Disabilities (2014), it is time for ACC to take up its role in upholding our government's commitment to this Convention as well as to other human rights instruments. From this project, the most important step within this would be to recognise the right of the family to protection, and that by providing rehabilitation and support only to the injured person, following a brain injury, the rights of the family to protection by the State are ignored.

In line with the goal of this research being to effect policy change, Leeanne, who is now the Chairperson for BIWAP, is already involved with ACC in policy development through being a

part of their Rehabilitation Pathways project. This was a direct outcome of this research and began through the connection of Max Cavit who sponsored the wānanga and instigated the Rehabilitation Pathways project.

Valuing feedback of family, from the full range of families, needs to become a part of how ACC assesses services. When people spoke of services wanted and received, there were often qualifiers as to the benefits of them, such as ‘home help – when it works’, or ‘lump-sums when done right’. This research has demonstrated, and co-researchers have voiced, that there is no one size fits all, but if individuals and whānau are valued, then case managers would seek to ensure that services are delivered in the way that suits the individual and the whānau – that home help, for example, is genuinely home help, rather than a hindrance, and that lump-sum payments have the intended effect of increasing the capabilities of people to lead flourishing lives, rather than increasing their risk of exploitation.

Māori health workforce

Case managers and brain injury advocates have both expressed concerns to me about low-income families becoming dependent on the carer income, which they fear could provide a disincentive for the injured person to become more independent. If, however, training results in everyone having increased skills, then if the injured person does become less dependent, the family members have gained greater skills, increasing their employability within the health sector.

Brain Injury Association

There are a number of issues to be addressed within the Brain Injury Associations, both regionally and nationally. At the national level there is clearly the need for a voice that represents brain injury to ensure that the particular needs of people with brain injury and their families are considered in disability, ACC and MoH policies. Nussbaum (Nussbaum, 2007) has argued that it is the role of government to protect the rights of the least powerful, as leaving it to the charitable sector is too tenuous. This was clearly demonstrated in the collapse of BIA which took place during the pre-research phase of this project.

A further issue with the Brain Injury Associations throughout the country is their lack of connection to Māori whānau with ABI. Although this was not a focus of the research, it was apparent through my experience: - as a clinician of sending young Māori women to the local BIA, only to have them feel a disconnect and then not feel able to engage with their supports; through the establishment of the NZ Brain Injury Support Network by a Māori whānau which was set up by whānau who had similarly felt unable to connect with their local BIA; and - evidenced in the Stakeholder Findings Report (Esplin, 2012) which had managed to engage very few Māori when recruiting participants via local BIAs. When I met with the liaison officers at their conferences, not one identified as Māori, although many expressed wanting to be able to work better with Māori. In order to ensure that Māori voices are heard, BIWAP nominated two Māori to our local board. Following attendance at the BIWAP wānanga, the previous chair of the Auckland BIA, who was working hard at the time to re-establish the National Board, has pushed for Māori to come forward for this National Board, but due to the lack of deep connections between Māori and BIA, this proved to be difficult. Just as ACC and MoH need partnerships, it may well be that BIA needs to partner with Māori-focused organisations in order to ensure that Māori have an equal voice, and that services and supports are developed that will deliver well to Māori.

Brain Injury Whānau Action Project (BIWAP)

BIWAP In order to fulfil the mission of “Educating and strengthening the community to improve the lives of whānau with brain injury” BIWAP will need to continue to develop. BIWAP currently works under the umbrella of the Auckland Brain Injury Association (BIA-AKL) as it does not yet have charitable status. Dissemination of findings has already started at a community level as we went back to our initial community partners and supporters. BIWAP seeks to work collaboratively with other groups who also support whānau with brain injury, and through these collaborative relationships will look to influence policy so that whānau with ABI interests are taken into consideration in policy development. It may be worthwhile to draw on the experience of groups such as Te Roopu Waiora and BIA-AKL in order to put together a whānau with ABI-

focused report to the Committee on the CRPD to highlight the special situation of brain injury as a disability and the needs that are present for both people with serious brain injury and those who are in close relationship with them.

As noted, one of the biggest challenges for BIWAP since completion of the research project has been to have enough people who are able to continue with the work now that we no longer have funding available for attending meetings and transport support. The people who are involved in BIWAP tend to be motivated to improve the situation for whānau, but at the same time they are living with a degree of strain as a result of the brain injury that has occurred to a family member. The group have a great deal of enthusiasm for continuing to deliver worthwhile projects, but will need sustainable funding to achieve this.

Further wānanga?

During the community dissemination process, BIWAP were asked to deliver wānanga in other regions in the country. There are a couple of issues with doing this. One would be finding the funding to deliver these effectively. The other issue is whether communities would benefit from wānanga, or whether we would be better to start by gathering a group of whānau with ABI and starting the process by considering the meanings of words and concepts that are important to them, and looking at what has worked, what has not worked, and what the group want. Through this process we could then co-determine the action that could increase their capabilities to live their lives in the ways they have reason to value.

Surprises

The key surprise for me in this project was the wānanga, and the way in which when a process that was sufficiently tika was followed, the doors seemed to just keep opening to more and more possibilities, and delivering more and more benefits. The synergy of the community-academic partnership combined with the lived experiences of co-researchers produced an action project that was well-received by participants, and sufficiently valued by providers that three were willing to sponsor a second event and to remain involved with our mahi. I was also surprised by

the degree of positive influence that the project had on the lives of some of the co-researchers, particularly those who described it as 'life-changing'

Other learning

An area where I had known that I would need to direct some attention was around fund-raising. I realised that the research budget would cover the first phase of the research, but that the group would very likely come up with action that would have additional costs. Fundraising was somewhat of a headache. Much like recruitment, the funding we have managed to secure for both the action project of this research and our subsequent projects has all been achieved through relationships that we are gradually building. Two of our second wānanga sponsors declined to support the first wānanga – this was partly due to budget cycles as people expressed being supportive of the idea, but unable to access any funding to put behind their support. Coming back to them a second time, with the history of having previously delivered a useful action, resulted in organisations being keen to support this work. While our work can be seen as challenging mainstream structures, we work to pitch it positively in terms of it addressing our shared problem of the recognised shortcomings of current supports. So rather than taking a confrontational approach to services, we work to include and partner while being very clear about our own mission and values, so that we can find ways that we can partner without compromising what it is that we seek to achieve.

Recommendations for further research

Further exploration of the concept of third-party disability from the perspective of brain injury would be interesting, especially if this can lead to greater leverage to improve the delivery of services to families. I am interested in whether the concept of third-party disability brings additional rights to whānau with ABI through the recognition that they experience disability in their lives and are therefore directly entitled to protection under the CRPD.

While much of the human rights attention within this thesis has been on the CRPD, it could be more fruitful to examine, and pursue, the protection that the family unit is entitled to under the ICCPR. Rights under this Covenant arguably have greater power than the CRPD, as ICCPR

articles are immediately enforceable. The experiences of co-researchers and wānanga participants demonstrate that these whānau have not been protected by the State, as family lives have, for many, been shattered by the injury, to such a degree that many are unable to live together, even though they would choose to with the right level of supports.

BIWAP have a number of areas where they would like to pursue additional ways of supporting whānau with ABI to increase their capabilities. We have conducted one pilot class of delivering an established parenting programme (Building Awesome Whānau) in partnership with BIWAP, with the idea that whānau could be more comfortable and derive more benefit from attending this course with a group that focuses on parenting within the context of brain injury. It would be worthwhile to conduct deliberate evaluation to establish the efficacy of this style of course for whānau with ABI. We also anticipate delivering a Wahine Toa (strengthening women) weekend this year, and have commenced engagement with Occupational Therapy students to assist with putting together a funding proposal and will look for links with researchers who could be interested in evaluating this work.

This work also highlights the importance of finding ways to engage directly with the community to produce effective and respectful research. While this is not a recommendation for a research topic, it is a recommendation for a research process. I believe that a great deal more research could be conducted from a Māori-centred position. In order to do this researchers need to consider from the outset the direct benefits to both the participants and the community to ensure that the research is relevant, beneficial and not exploitative.

Further exploration of the theoretical connections between Sen, Freire and Māori Potential Approach could be useful, in as much as they can help us to understand how each contributes to our ability to support environments that are conducive to individuals, whānau and communities building flourishing lives.

Leveraging change

In seeking to conduct research which would achieve change I have thought a great deal about how change actually occurs. What are the levers that can make shifts more likely? How can you ensure that positive change endures? My initial frustration was that research knowledge did not necessarily lead to change. Establishing that families were impacted by brain injury, and that there were valid family treatment programmes, had not resulted in family-focused therapy being available in New Zealand. In order to achieve change it seemed important to deliver at the community level, which has an effect of increasing capabilities (from a CA perspective) and conscientization (from a Freirean position). At an individual and a whānau level this change has been positive. However in order to increase capabilities at a broader level it is necessary to achieve broader change. We have sought to do this through building relationships with people and groups with the power to achieve change. We worked to both keep our sponsors happy, through delivering wānanga that they could see were worthwhile, and through profiling their organisations within our materials, as well as acknowledging their support when disseminating information, at the same time as using these relationships as a way to have a voice for whānau with ABI in order to achieve policy change. This seems to be having a positive effect.

Concluding remarks

In answering the question of “How can we increase the capabilities of whānau with ABI to live flourishing lives?” It is clear that there is no one answer. Brain injuries have varying outcomes, and the families that are impacted by them have highly diverse needs and aspirations. A basic stance of recognition that brain injury is a family injury and that people in close relationship also experience disability as a result of their family member’s brain injury and are in need of support that is appropriate to their situation, is required.

This project has demonstrated that it is possible and worthwhile to conduct research with marginalised groups that is both respectful and effective in terms of directly contributing to the well-being of participants and co-researchers, and that also contributes to knowledge. By laying very strong foundations with appropriate mentor relationships and community

engagement, right from the stage of the development of the research proposal, this research was able to flow in a positive way where it went from strength to strength. The sound processes that drew on both CBPR principles and tikanga principles helped us to work through difficulties as they occurred in order to achieve a positive action project.

By continuing to build on relationships as we highlight the research findings to those with power to make the changes that this research indicates are needed, we hope to be able to continue to contribute to policy development in an effective way. This work will proceed at multiple levels with partnerships with ACC, Brain Injury Association and a possible goal of submitting our own Shadow Report to the Committee on the CRPD.

The research makes a contribution to knowledge through demonstrating that whānau can learn from each other and professionals, as whole whānau, in a way that is educational, supportive, and culturally sound.

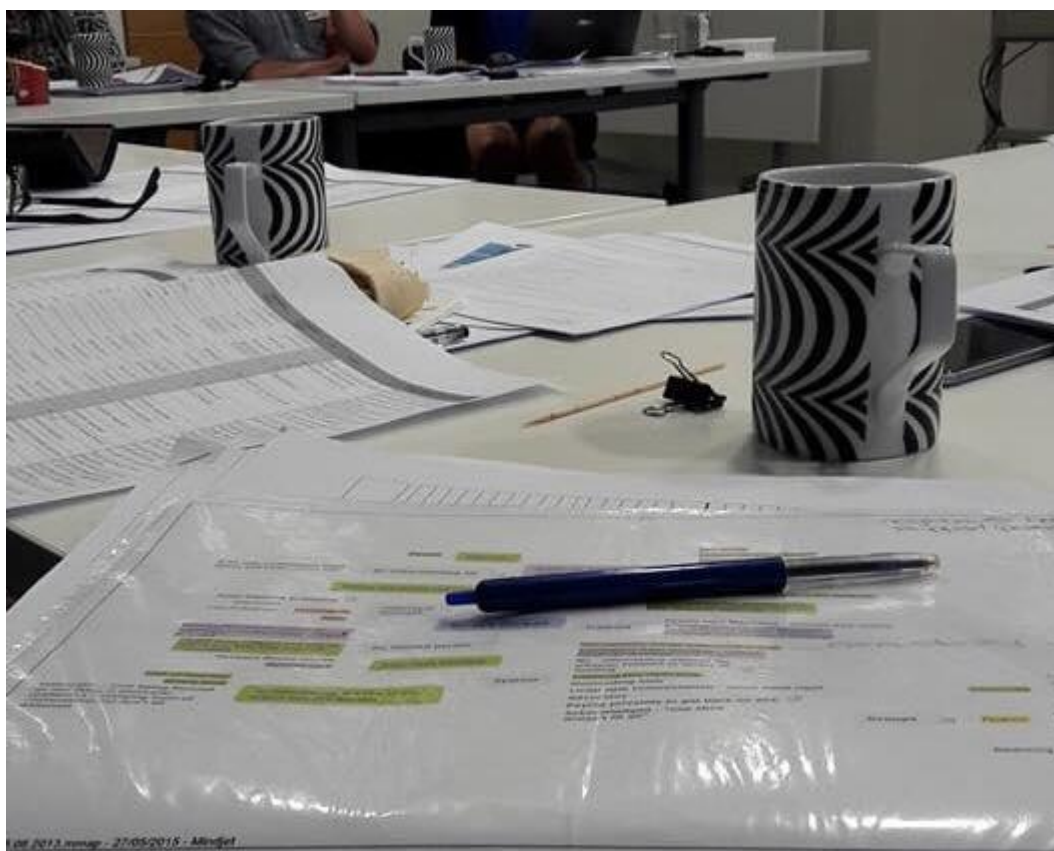


Figure 13 BIWAP data contributing to policy discussions for Rehabilitation Pathways project

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Appendix A: Ethics approval 1



11 April 2013

Marilyn Waring

Faculty of Culture and Society

Dear Marilyn

Re Ethics Application: **12/317 Short Title: Brain Injury Whanau Action project**

Working Title Developing strategies to better meet the needs of whanau/families of people with serious brain injury:

Thank you for providing evidence as requested, which satisfies the points raised by the AUT University Ethics Committee (AUTECS).

Your ethics application has been approved for three years until 9 April 2016.

This approval is for stage one of the research only.

As part of the ethics approval process, you are required to submit the following to AUTECS:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 9 April 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 9 April 2016 or on completion of the project.

It is a condition of approval that AUTECS is notified of any adverse events or if the research does not commence. AUTECS approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTECS grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

A handwritten signature in black ink, appearing to read 'Rosemary Godbold', written in a cursive style.

Dr Rosemary Godbold

Executive Secretary

Auckland University of Technology Ethics Committee

Cc: Elisa Lavelle elisa.wijohn@gmail.com

Appendix B: Ethics approval 2



AUTEC Secretariat

Auckland University of Technology
D-89, WA505F Level 5 WA Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

25 August 2015

Marilyn Waring
Faculty of Culture and Society

Dear Marilyn

Re Ethics Application: **12/317 Brain Injury Whanau Action project**

Thank you for providing evidence as requested..

The second phase of your ethics application has been approved.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 9 April 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 9 April 2016 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,



Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: [Elisa Lavelle elisa.wjohn@gmail.com](mailto:Elisa.Lavelle@aut.ac.nz)

Appendix C: ABI Rehabilitation Letter of Support



25th August 2010

Ms Elisa Wijohn (Lavelle)
13 Tirotai Cres
Westmere 1022
Auckland

Dear Elisa

Re: Application for an HRC Disability Research Placement Programme

We wish to very strongly support the application to the HRC for funding for the above.

1. On behalf of our organization I wholeheartedly commit to working with you and collaborating with you in supporting the research in any way that we can. It has been very good to see in your clinical work with us, the development of the focus on the needs of partners and families of people who had experienced a brain injury. More particularly, as practitioners, it is very exciting to see in New Zealand the growth of academic interest in research that has a direct impact on clinical practice and the real delivery of services to families. In the busyness of a rehabilitation programme it is easy to forget that the partners and whanau of clients essentially hold the key to ensuring robust outcomes for clients. The outcomes of clients are compromised to the extent that families are not included as partners within the rehabilitation team.
2. We also know that a key to successful rehabilitation is successful engagement with the client and whanau. Motivation has a major impact on outcomes and it is very difficult to achieve this without providing structured education and support to families.
3. Bringing together in a systematic way, and documenting and understanding the actual experience that people have along the rehabilitation pathway is arguably the real foundation for looking at quality in service delivery. Hearing people's stories is for us a crucial component of advancing knowledge. And yet we do not often do this systematically and with a research hat on so that we are critically evaluating our approaches and systems for the support of families.
4. I was very aware of the work you did while working within the specialist team to address these issues. I was also aware that your motivation in taking time away from clinical practice was to focus on bringing greater academic rigour to this particular area of work.
5. I think that you personally are in a very good position to advance an understanding of this area. You have had many years of clinical experience, solid demonstrated ability to engage and work with families, an ability to work across cultural boundaries, and great teaching and communication skills. However, in particular I am keen to support what you are proposing because you are grounded in the real and rather messy world of the realities around the rehabilitation clinical practice. In my view, the field of rehabilitation in New Zealand is in desperate need of research that can be applied at the coalface, and influence the

**ABI Rehabilitation
Management Ltd**

E: info@abirehab.co.nz

Rehabilitation Management

Level 3, 93 Grafton Road, Auckland,
New Zealand
P O Box 110095 Auckland Hospital,
Park Road, Auckland 1146
P: 09 373 7268 F: 09 358 3102

Intensive Residential Rehabilitation

180 Metcalfe Road, Ranui 0612
Waitakere City, Auckland, New Zealand
P O Box 70039, Ranui, Waitakere City 0655
P: 09 831 0070 F: 09 831 0071

development of standards of best practice. Among the many areas that need development, systems, processes and models to support families are close to the top of the list.

6. I also know from your own background, and the work that you did with us, that you have depth in your understanding of Tikanga Māori and the health needs of Māori within the TBI population. As in most areas, Māori are over represented in the brain injury statistics with double the incidence compared to their percentage of the population (27% of incidence, 13% of population). Poor engagement of Māori in health services is well documented. We are trying to develop other models that will establish greater trust and confidence on the part of whanau through which they will feel that there is value-based support rather than tick-box cultural safety. Given that your research and your clinical practice has looked at both the problems for partners and their families, and the strategies and solutions they come up with - the positive perspective makes a good change from research that only looks to identify what is wrong.
7. I have been particularly enthusiastic about the clinical work you have done with family groups and staff in the "Bringing out the Best Programme" and the Brain Interest Group which you established. I know you are interested in researching Group work with families and support systems for partners of clients with TBI. It is something that families frequently ask for, but again we are unsystematic in the way we provide for this need and we have little research base to work from. I am very much looking forward to seeing the results from your work.
8. As you know, our service provides specialist residential, community and advisory services to ACC, to other service providers as well as clinical coordination of the pathway for all people with traumatic brain injury from Northland to Waikato and in Wellington. Therefore we are vitally interested in the research that is being proposed.
9. The overall volumes of people with brain injury in New Zealand are known to be significant – even staggeringly estimated at around 30,000 per annum. TBI has been classified as the "Silent Epidemic". The impact of any research that goes right to the customer and their family could be significant.

We very much look forward to helping with this particular research project and I commit our organization to making a contribution of time and effort to work with you in any way that may be useful.

Yours sincerely



Max Cavit
Managing Director
ABI Rehabilitation Management Ltd

**ABI Rehabilitation
Management Ltd**

E: info@abirehab.co.nz

Rehabilitation Management

Level 3, 93 Grafton Road, Auckland,
New Zealand
P O Box 110095 Auckland Hospital,
Park Road, Auckland 1148
P: 09 373 7268 F: 09 358 3102

Intensive Residential Rehabilitation

180 Metcalfe Road, Ranui 0612
Waitakere City, Auckland, New Zealand
P O Box 70039, Ranui, Waitakere City 0655
P: 09 831 0070 F: 09 831 0071

Appendix D: Charmeyne Te Nana-Williams Letter of Support



25 August 2010

To whom it may concern

LETTER OF SUPPORT – ELISA LABELLE

This letter is to support Elisa Lavelle's proposal to undertake research in an area that is vitally important to the ongoing support of whanau with a disability in the community.

I have known Elisa for approximately 7 years. We met after my husband suffered a traumatic brain injury as a result of a boxing match. The support she was able to offer us as a clinical psychologist particularly around collaboration and training support teams was fundamental to the wellbeing of our whanau. In recent times I have again become involved with Elisa but in a professional capacity as part of a wider support team for individuals who have suffered a traumatic brain injury.

Elisa's wide range of expertise in working alongside families affected by TBI and her understanding of the cultural dynamics particularly of Maori whanau is exceptional. To be effective a partnership approach is fundamental and Elisa was able to develop and maintain solid relationships that enabled a process by which families and wider support groups could engage positively. These qualities and skills make Elisa the ideal individual to undertake a project such as that proposed.

The incidences of relationship break ups and failings after TBI are significant. The research Elisa is proposing is vital and would offer spouses the ability to access specialised services and support that could ultimately determine the success of a whanau to remain intact after a traumatic and life changing situation.

I would like to offer my personal and professional support to Elisa's proposed project. This is based on my personal experiences as a wife who has familiarity with such situations and as a professional who has worked alongside Elisa to support whanau afflicted by TBI.

If you have any queries please do not hesitate to contact me.

Mauri Ora

Charmeyne Te Nana-Williams

Director

Appendix E: BIA (Auckland) Letter of Support



8 Manukau Road
Newmarket, Auckland
PO Box 74323
Market Road, Auckland 1543
P 09 520 4791
F 09 520 5789
E stephen.jenkins@brain-injury.org.nz

19 August 2010

To Whom it May Concern:

Re: Elisa Lavelle

The Brain Injury Association of Auckland provides support and advocacy for people with brain injury and their families/whanau. Our association is an incorporated society which has endured for 29 years and is recognised and supported by a range of government departments and funding organisations. Our region extends from Te Hana in the north to Pokeno in the south, covering the district health boards areas of Auckland, Counties-Manukau and Waitemata.

We have four staff, comprising two liaison officers, a qualified social worker and a manager/qualified social worker based at offices in Newmarket, Otara and Albany. At any time we have between 220 and 250 persons receiving direct support and advocacy services. We make about 120 to 150 direct one to one contacts with clients or their families/whanau per month. In addition in any month, we typically make or receive over 1200 telephone calls, email, letters, or texts assisting or informing families and the general public about brain injury. On an as required basis we make presentations as to the extent and purpose of our services or as an 'entry level' awareness training for persons working as carers or assistants in the brain injury field.

Aside from one to one community based support for clients and families/whanau, our other most useful service is the provision of support groups. We have eight of these currently running and three are facilitated by clinical psychologists. These support groups are popular and effective way of developing post injury support, education and invariably encourages social networks. Some are 'over-subscribed' and we need to add at least another two groups to meet current needs. However our present groups are largely focussed on the person with the brain injury and we have long perceived a need for professionally facilitated support for families and carers, particularly for partners. We have provided low key coffee group style opportunities but it is very apparent that more focussed and expert facilitation is needed to meet the needs. This need is even more apparent in South and West Auckland where Māori and Pacific families have little or no access to useful education and support with understanding and adapting to the post injury consequences of traumatic brain injury.

In this context we welcome the opportunity to work with Elisa Lavelle whilst she undertakes research on "How can the needs of partners of people with brain injury be better met?" BIA Auckland has worked with Elisa for many years when she was employed as a clinical psychologist at Cavit residential rehabilitation centre. We look forward to working with Elisa to establish community based support groups to meet these needs and we will welcome the opportunity for our staff to co-facilitate some

presentations so as to develop their skills in turn. Ultimately the partners themselves would develop skills in research and in turn be able to assist others through their knowledge. In effect empowering the community to see that its own needs are better met.

BIA Auckland have a good network of referral agencies and enjoy a good working relationship with ACC and the Ministry of Health. Our current membership is over 300 and many members have been associated for many years. We have an extensive knowledge of the extent of the brain injury community in Auckland. We welcome the opportunity to support Elisa in her post graduate study. We see Elisa's research as meeting a vital need, whilst her skills in turn will enrich our ability to better inform and assist persons with brain injury and their families.

Yours sincerely,

Stephen Jenkins BA, Dip Crim, Dip Soc Sci (Social Work)
General Manager

Appendix F: Evidence of consultation with mentors

Dr Huhana Hickey LLb/BSocSci, LLm(dist), PhD
Director
Pukenga Consultancy
P.O. Box 23326
Hunters Corner
Papatoetoe 2155
Manukau
Phone: 0220597752
Email: huhana@gmail.com

25 November 2012

Attention: Elisa Wijohn
(elisa.wijohn@gmail.com)

To Whom It May Concern

Tena Koutou katoa

I am of Waikato Iwi, Ngatitahinga and Ngai Tai hapu, and I am a human rights lawyer, researcher and consultant with expertise in indigenous disability international human rights issues, I am also a survivor of a head injury and have the diagnosis of Multiple Sclerosis where I am a wheelchair user. I was engaged by Elisa to be an expert advisor and support for her research which is integral in gaining the knowledge of brain injury and whanau from a Maori perspective. This is particularly important as a disproportionate number of Maori acquire a brain injury at some stage of their lives.

I am also a part of Te Roopu Waiora with Tania Kingi who is also advising as is Charmeyne Te Nana Williams of Whatever it takes. We have all been providing culturally appropriate advice to Elisa around the framework for her research and around how to approach it from a kaupapa Maori perspective.

I wholeheartedly endorse this work and am aware that both Charmeyne and Tania also endorse this work of Elisa's with the hope it can increase knowledge of an under researched area of the brain injury. We wish Elisa all the best in her research and look forward to an ongoing relationship with her as we continue to provide critical support and advice to her throughout this project.

Nga Mihi nui

Dr. H. Hickey (electronically signed)

Dr Huhana Hickey

Appendix G: Tania Kingi questions

Tena koe Tania

As Huhana told you, I am a PhD student. My background is that my formal training was as a Clinical Psychologist and I have worked in the areas of adolescent drug and alcohol rehabilitation, community mental health and brain injury rehabilitation over the last 18 years. On the personal front, I am married to Leon Wijohn (Te Rarawa, Tuhoe, Tuwharetoa) and we have three children together. I am Pākeha, born in Wellington and grew up in Auckland.

The research that I will be engaging in is a Māori-centred Community-Based Participatory Research project. The focus of the research is to work with partners and whānau to first map out how things are going since their family member had a serious traumatic brain injury, in terms of people being able to live the lives they have reason to value. Following on from this, we will work together to develop a project which the community believe will increase the capability of partners and whānau to lead flourishing lives. Partnership with those who choose to become involved is the key mode of working throughout the project.

- Following a serious traumatic brain injury, it is clear that many more people are impacted than just the person who actually sustained the injury. The purpose of this research is to work together with partners and whānau of people with serious traumatic brain injury to develop strategies towards improving how they are able to live their lives.
- The process will be to meet with people in groups to map out the changes that have occurred in how they are able to live their lives since their family member's brain injury occurred and to look at areas where they can see that changes would improve their capability to live flourishing lives.

I do have formal mentor relationships with Huhana and Charmeyne, which so far has shifted the project from focusing on partners to working with partners and whānau. Their guidance has also led me to you and Te Roopu Waiora.

The way in which I am hoping that you and Te Roopu Waiora will link in will be to contribute in the design phase as part of ensuring that the project is appropriate for the community, through distributing information to partners and whānau of people with serious traumatic brain injury, and in any other ways which you feel would fit with the goals and aspirations of Te Roopu Waiora.

Nga mihi nui

Elisa Lavelle

Ph 027 295 8831

09 6200354

How will your research directly and/or indirectly assist whānau haua? (whānau experiencing disabilities)

- Given that the research will be Community-Based Participatory Research (CBPR) it is difficult to say exactly how the research will benefit whānau hauā. The purpose of the research will be to determine and then do an action/intervention of some sort which the participants believe will be of benefit. I can't yet say how this will exactly assist people until we get to determine what the action will be. The benefits will be driven by the ideas, wishes and actions of those who choose to participate. The sorts of actions or interventions that I could envisage this group wanting to drive could be anything from developing support groups that better meet their needs, developing information for other whānau through to advocating for policy change especially in the way in which rehabilitation funding is targeted to the individual without taking into account the impact of the injury on the whānau.
- Meeting together in groups can be hugely beneficial in terms of people building connections and feeling that they're not alone.
- Given that this is participatory research – i.e. the participants act as co-researchers – a lot of literature talks about the participants gaining skills in research. Now I don't know how much that happens in reality, or how many people want to gain skills in research.

How do you or how would you demonstrate your commitment to Te Tiriti o Waitangi in undertaking this work?

- I recognise Te Tiriti o Waitangi as the founding document of Aotearoa and as a guide for partnership.
- The research will be conducted as Māori-centred Community-based Participatory Research. If research is not explicitly defined as Māori-centred then by default it is Pākehā-centred or as Ann Milne names it “whitestream” (Families Commission, 2011).
- As you have noted, you have been poorly treated by researchers in the past, and this is not an uncommon experience for Māori in their role as the researched (L. T. Smith, 1999). For this reason I have explicitly chosen a research methodology (Community-Based Participatory Research; CBPR) which has been developed to work more effectively and respectfully with people from marginalised groups (Minkler & Wallerstein, 2008b). As a researcher within Aotearoa this naturally means that the focus has to first and foremost be on how to conduct research with Māori, given both their tangata whenua status alongside the health and socioeconomic realities which reflect their marginalisation.
- Pākehā conducting research with Māori has often been deficit focused and has not been of benefit to the research participants and I am aware that there are risks in going down this pathway. However, I also did not want to work purely

within my cultural group of birth as I get concerned about “middle-class capture”(Hefford et al., 2005) of services and believe that Pākeha tend to be better served anyway.

- In an effort to buffer the risks of a Pākeha conducting research with Māori I have set up a formal mentoring relationship with Charmeyne Te Nana-Williams and Dr Huhana Hickey. I also have other people whose input into my life and my knowledge of Te Ao Māori I value incredibly. Papa Tawhari and Whaea Kaa Williams meet with me, my husband and a few other learners to help us with te reo Māori. Dr Margaret Dudley (Clinical Psychologist) is a colleague and friend who I can talk through ideas with on a regular basis. As part of self-reflection, and a commitment to action, I will be taking part in a workshop series (Pākeha Challenging Privilege) through the winter.
- The principals of Partnership, Participation and Protection will be actively focused on within the research. The partnership is between the researcher and the research participants – this will need strong attention to power relationships in order to strive towards achieving partnership. Participation is the key focus of the design – if there is not strong participation (at the level that people who are often already stretched are willing and able to make) then this would likely mean that we are not heading down a path which is truly worthwhile. Protection comes in the form of being accountable to the research participants. Research participants are encouraged to be a part of data collection, analysis and interpretation as part of CBPR.

What tikanga practices do you apply when engaging Māori?

- Part of our initial planning and discussions will include how we ensure that tikanga is considered appropriately.
- To me the most important thing in working with anyone is to establish some sort of a relationship. Tikanga guides us in engaging with others and having the conduct which creates safe spaces for everyone. Participants can be from a range of cultural backgrounds, however I feel that respecting people and largely following Māori protocols creates a space that values all the participants.
- Along with more formal requirements, such as karakia, rules around food, tables, hygiene – I will be strongly guided in particular by the following Kaupapa Māori practices
 - Aroha ki te tangata (a respect for people)
 - Kanohi kitea (the seen face, that is present yourself to people face to face).
 - Titiro, whakarongo ... korero (look, listen ... speak).
 - Manaaki ki te tangata (share and host people, be generous)
 - Kia tupato (be cautious)
 - Kaua e takahia te mana o te tangata (do not trample over the mana of people).
 - Kaua e mahaki (don't flaunt your knowledge). (L. T. Smith, 1999, p. 120)I expect that I will make mistakes.

- With the focus groups/discussion hui – I will be looking at offering three different group options
 - Afternoon meetings
 - Evening meetings
 - Marae-based longer one-off hui
- I find that I prefer meetings that are opened and closed clearly – often with Pakeha meetings it can almost be difficult to tell if the meeting has closed. I am able to open and close meetings with simple karakia, though would usually start a meeting by asking if anyone would like to open the meeting. If a meeting is opened with karakia, I would ensure that it is also closed with karakia.

When do you expect to release your findings and if we consent to being involved will you provide a copy of your final report to Te Roopu Waiora?

- I anticipate completing the PhD in 2014 – though given that this will be a community-based project there is the possibility that it will take longer depending on the time-frames that work for the community.

Will you ensure that any whanau we may contact on your behalf to assist with your research will be provided at no cost to them any disability supports they may need?

- The supports which have been budgeted for include room hire (which I will ensure is accessible), childcare and a koha of \$30 per participant as a contribution to travel costs.
- With sufficient notice I would be able to engage a deaf interpreter

Will you ensure that they will also have full and appropriate access to your final report? (ie. Disability access)

- The PhD will ultimately end up on-line via AUT so will be accessible to anyone with internet access.
- PhDs, however aren't normally the sort of thing that other people want to read. Given that this will be a community-based participatory research project I will be guided by participants as to how they would like to have the information disseminated. I would be happy to write a summary of the research for community groups who are interested.
- I believe that at times there can be issues around any work being published prior to completion of the PhD (as PhD research has to look like a new contribution to knowledge) so there may be delays imposed on the release

What engagement or involvement would you propose to have with Te Roopu Waiora after your research has concluded?

- This would depend on what Te Roopu Waiora wished.
- My non-academic role is that of a Clinical Psychologist. Following completion of the PhD I am likely to return to some clinical work, but a key goal in

completing this research is to develop skills which can be of benefit to other organisations, particularly those with a social justice focus.

Appendix H: Mihi ki ngā Mana Whenua

14 May 2013

Tena koutou ki ngā Mana Whenua i Tamaki Makaurau

I am writing to respectfully inform you of a project which is commencing in your rohe. This project involves working with families and whānau of adults who have sustained serious brain injury, and is being developed as part of my PhD through AUT University. Brain Injury Association Auckland (BIAA) are the key supporters of this project. Through the development of this project I have received mentorship and guidance from Dr Huhana Hickey, Tania Kingi and Charmeyne Te Nana Williams. My university supervisors are Professors Marilyn Waring and Jane Koziol-McLain and the project has ethical approval from AUT.

I wish to inform mana whenua of the project and to be able to keep the committee updated on its progress and outcomes, as they develop. I am happy to receive any advice, or to answer any questions, you may have in terms of this project taking place.

Please find attached a one-page summary of the project, as well as the recruitment flyer, brochure and Participant Information Sheet.

Naku noa

Elisa Lavelle Wijohn

Appendix I: Summary for Mana Whenua

Brain Injury Whānau Action Project

Tena koutou ki te Mana Whenua ki Tamaki Makaurau

I am writing to respectfully inform you of a project which is commencing in your rohe. This project involves working with families and whānau of adults who have sustained serious brain injury and is being developed as part of my PhD through AUT university, with the support of the Brain Injury Association. Through the development of this project I have received mentorship and guidance from Dr Huhana Hickey, Tania Kingi and Charmeyne Te Nana Williams. My university supervisors are Professors Marilyn Waring and Jane Koziol-McLain and the project has ethical approval from AUT.

Who am I?

My professional background is that my formal training was as a Clinical Psychologist and I have worked in the areas of adolescent drug and alcohol rehabilitation, community mental health and brain injury rehabilitation over the last 18 years. On the personal front, I am married to Leon Wijohn (Te Rarawa, Tuhoe, Tuwharetoa) and we have three children together. I am Pākehā, born in Wellington and grew up in Auckland.

What does the project involve?

The project will use a type of research called Community-Based Participatory Research. This involves getting a group of people together who wish to develop a project that will be of benefit to families/whānau where an adult has had a serious brain injury. We will work together over the next year to develop the project and to evaluate it. Within this type of research the participants become co-researchers, so we will jointly decide how to evaluate the project and how to disseminate information.

Why is it being conducted in this rohe?

The Brain Injury Association of Auckland, who are partners with this project were keen to improve the ways in which services are delivered in South Auckland. I was also keen to develop a project that recognised the needs of groups of people who are often more marginalised. Many services are developed based on mainstream needs and tend to benefit those who are financially better off, and those who are Pākehā – largely because that reflects the make up of the groups who develop the services. By basing the research in South Auckland and linking closely with Brain Injury Association, which already has a strong understanding of the needs of whānau in this area, I hope that the project we will develop will be suitable for whānau in South Auckland.

Accountability

As a PhD student at AUT I am accountable to, and have ethical approval from, AUT. I have a formal mentoring role with Dr Huhana Hickey and Charmeyne Te Nana Williams. Through these two women I have also developed a relationship with Tania Kingi of Te Roopu Waiora, and have benefitted from her advice and insight into working with whānau hauā

Involvement with mana whenua.

I wish to inform mana whenua of the project and to be able to keep the committee updated on its progress and outcomes, as they develop. I am happy to receive any advice, or to answer any questions, you may have in terms of this project taking place.

Naku noa

Elisa Lavelle Wijohn

Appendix J: Research Summary for BIA (Auckland) Board

Brain Injury Whānau Working Group Research

Summary for BIA (Auckland) Board

The researcher

I am a Clinical Psychologist who has worked in the fields of adolescent drug and alcohol rehabilitation, community mental health and brain injury rehabilitation (since 2001). Through my work at Cavit (ABI Rehab) I came to know Stephen Jenkins and the work of Brain Injury Association (Auckland). While I worked at Cavit I enjoyed the opportunity of working with families as well as with the injured person, but I was very concerned as to how things would go for families after the residential stage of the rehabilitation. I am now enrolled in a PhD at AUT and this concern has become the focus of my research.

The research is supervised by Professors Marilyn Waring and Jane Koziol-McLain. Both of my supervisors have great experience in community research and action projects, as well as in looking at how to convert this work into policy change.

The purpose

The purpose of this research is to join with families of adults with serious brain injury, in South Auckland, to develop an action project that will be of benefit to families.

This is a little different to a lot of traditional research in that rather than the university coming in to try something out, the idea is to listen and build a team to work with first, and then to develop action from the ideas and goals of the family/whānau working group.

Steps in the project

Pre-research: I've already been getting familiar with the BIA's work in South Auckland over the last 6 months. This has occurred through me working alongside Michael Denton.

Recruitment: I will be distributing brochures and talking to groups in South Auckland, but the key focus will be finding families through those people who already link to BIA in South Auckland.

Working Group: Once the group is formed we will have regular meetings to share experiences and develop priorities and goals for the group. We will come up with a range of possibilities for the action project and will agree on a project that fits with the groups priorities.

Action Project: Once we have determined the action project, we will go back to Ethics committee at AUT for approval, and will also keep BIA (Auckland) up-to-date with what has been chosen.

Evaluation: Processes and methods for evaluation will be determined jointly by the researcher (Elisa) and the participants in the working group.

Write-up and dissemination: This research will be part of my PhD so will be written up and examined for this purpose. Outside of the PhD, the working group will be involved in determining how the results will be disseminated. I would expect that results will be shared through the BIA newsletter and at relevant conferences and forums (e.g. Brain Day). The

group may wish to share results with ACC or other interested groups. It will be over to the working group whether they choose to be anonymous at this point or whether they have their names included as author. Participants may want me to present the research, or may also choose to be involved in presentations.

BIA role

Stephen Jenkins and Michael Denton have supported me in learning to understand the work done by BIA (Auckland) in South Auckland through my regular involvement over the past 6 months. Through the office space in Otara, I will have access to the Tui room in the Otara Community Centre for meetings to take place in.

Risks

I do not foresee any direct risks to BIA (Auckland) with this research. I am aware however that many community groups have experienced researcher involvement as a drain on their services with no actual benefit to the service or their members. The research methods I am using (Community-Based Participatory Research) seek to work against this risk by focusing on the needs and wishes of the community in co-developing a useful project. It is possible that the Working Group will have suggestions for changes to policy which could be at a national level, or more at the level of operating of the BIA – hopefully any suggestions would be perceived as a benefit rather than a risk to the organisation.

Funding

I am aware that the finances of BIA (Auckland) are limited so I do not intend to impose any additional costs on BIA. The Health Research Council have provided some funding for this research which helps with costs around printing, koha for participants, and childcare (if needed). I am currently checking whether I will be able to get funding for an 0800 number, and for increased mobile phone minutes to support recruitment of and communication with participants.

Benefits

I am hopeful that this research will be of direct benefit to the people who take part. There will be likely to be benefits simply through the act of coming together and experiencing that others recognise and share aspects of the families' situations. While I do not know what project the group will determine is worthwhile, the focus will be on choosing a project which will increase the capability of families being able to live their lives in the ways that they value.

Current stage of the research

The project has been given ethical approval by AUT, and is in the final stages of gaining academic approval. I will be recruiting participants over the next weeks, so that the working group can be formed during May-June.

I am happy to be contacted for any further information about the research.

Elisa Lavelle Wijohn

elisa.wijohn@gmail.com

ph 027 295 8831

Appendix K: Research Summary for Ōtara Boards Forum

Brain Injury Whānau Action Project

Tena koutou ki te Otara Boards Forum

I am writing to respectfully inform you of a project which is commencing in your rohe. This project involves working with families and whānau of adults who have sustained serious brain injury and is being developed as part of my PhD through AUT University, with the support of the Brain Injury Association. Through the development of this project I have received mentorship and guidance from Dr Huhana Hickey, Tania Kingi and Charmeyne Te Nana Williams. My university supervisors are Professors Marilyn Waring and Jane Koziol-McLain and the project has ethical approval from AUT.

Who am I?

My professional background is that my formal training was as a Clinical Psychologist and I have worked in the areas of adolescent drug and alcohol rehabilitation, community mental health and brain injury rehabilitation over the last 18 years. On the personal front, I am married to Leon Wijohn (Te Rarawa, Tuhoe, Tuwharetoa) and we have three children together. I am Pākehā, born in Wellington and grew up in Auckland.

What does the project involve?

The project will use a type of research called Community-Based Participatory Research. This involves getting a group of people together who wish to develop a project that will be of benefit to families/whānau where an adult has had a serious brain injury. We will work together over the next year to develop the project and to evaluate it. Within this type of research the participants become co-researchers, so we will jointly decide how to evaluate the project and how to disseminate information.

Why is it being conducted in this rohe?

The Brain Injury Association of Auckland, who are partners with this project were keen to improve the ways in which services are delivered in South Auckland. I was also keen to develop a project that recognised the needs of groups of people who are often more marginalised. Many services are developed based on mainstream needs and tend to benefit those who are financially better off, and those who are Pākehā – largely because that reflects the makeup of the groups who develop the services. By basing the research in South Auckland and linking closely with Brain Injury Association, which already has a strong understanding of the needs of whānau in this area, I hope that the project we will develop will be suitable for whānau in South Auckland.

Accountability

I have built links with the clients of BIA in South Auckland and hold myself accountable to this group, as well as to Mana Whenua I Tamaki Makaurau. As a PhD student at AUT I am accountable to, and have ethical approval from, AUT. I have a formal mentoring role with Dr Huhana Hickey and Charmeyne Te Nana Williams. Through these two women I have also developed a relationship with Tania Kingi of Te Roopu Waiora, and have benefitted from her advice and insight into working with whānau hauā.

Naku noa

Elisa Lavelle Wijohn

Appendix L: Research Summary for Ōtara Network Action Committee

Brain Injury Whānau Action Project

Tena koutou ki te Otara Network Action Committee

I am writing to respectfully inform you of a project which is commencing in your rohe. This project involves working with families and whānau of adults who have sustained serious brain injury and is being developed as part of my PhD through AUT University, with the support of the Brain Injury Association. Through the development of this project I have received mentorship and guidance from Dr Huhana Hickey, Tania Kingi and Charmeyne Te Nana Williams. My university supervisors are Professors Marilyn Waring and Jane Koziol-McLain and the project has ethical approval from AUT.

Who am I?

My professional background is that my formal training was as a Clinical Psychologist and I have worked in the areas of adolescent drug and alcohol rehabilitation, community mental health and brain injury rehabilitation over the last 18 years. On the personal front, I am married to Leon Wijohn (Te Rarawa, Tuhoe, Tuwharetoa) and we have three children together. I am Pākeha, born in Wellington and grew up in Auckland.

What does the project involve?

The project will use a type of research called Community-Based Participatory Research. This involves getting a group of people together who wish to develop a project that will be of benefit to families/whānau where an adult has had a serious brain injury. We will work together over the next year to develop the project and to evaluate it. Within this type of research the participants become co-researchers, so we will jointly decide how to evaluate the project and how to disseminate information.

Why is it being conducted in this rohe?

The Brain Injury Association of Auckland, who are partners with this project were keen to improve the ways in which services are delivered in South Auckland. I was also keen to develop a project that recognised the needs of groups of people who are often more marginalised. Many services are developed based on mainstream needs and tend to benefit those who are financially better off, and those who are Pākehā – largely because that reflects the makeup of the groups who develop the services. By basing the research in South Auckland and linking closely with Brain Injury Association, which already has a strong understanding of the needs of whānau in this area, I hope that the project we will develop will be suitable for whānau in South Auckland.

Accountability

I have built links with the clients of BIA in South Auckland and hold myself accountable to this group, as well as to Mana Whenua I Tamaki Makaurau. As a PhD student at AUT I am accountable to, and have ethical approval from, AUT. I have a formal mentoring role with Dr Huhana Hickey and Charmeyne Te Nana Williams. Through these two women I have also developed a relationship with Tania Kingi of Te Roopu Waiora, and have benefitted from her advice and insight into working with whānau hauā.

Naku noa

Elisa Lavelle Wijohn

Appendix M: Participant Information Sheet

Whānau Working Group Participant Information Sheet



Date Information Sheet Produced: 7 May 2013

Project Title: Brain Injury whānau action project

An Invitation

It is well known that brain injury affects the whānau/families of people who have been injured, as well as the person with the injury. Even though the impacts are well known, the needs of families are often overlooked and we believe that this results in more difficulties for families than may be necessary.

We are developing a project to look at how the needs of whānau/families of adults who have had a serious brain injury can be better met. In order to do this we will be forming a community-academic partnership and bringing together a group of family members to consider what action can be taken to improve their lives. This group will become a Brain Injury Whānau Working Group and our task will be to work to think about the sort of changes that could improve the lives of families, and then to develop a project that will lead to some positive change for families/whānau. The researcher is Elisa Lavelle Wijohn and this action and research will contribute towards the completion of her PhD. If you choose to become a member of the Whānau Working Group your involvement is voluntary and you can pull out from the project at any time. Whether you choose to be involved or not will not affect your involvement with the Brain Injury Association Auckland.

The project is supported by Brain Injury Association Auckland and Te Roopu Waiora, and funded by Health Research Council (HRC) through the Disability Placement Programme Award.

What is the purpose of this research?

Action and Research

One purpose of this research is to achieve positive change (action) and another is to contribute to knowledge (research) through publications and presentations.

The positive change will occur through the development of a project which would be likely to improve how well families can live their lives after brain injury. We can't say what the project will be, as this will be developed with the Working Group.

The publications and presentations that could result from the project will include articles for organisations such as Brain Injury Association and Te Roopu Waiora, or for the local newspaper, as well as academic publications. Presentations could include community hui as well as academic conferences. This research will also be written up as part of Elisa's PhD.

How was I identified and why am I being invited to consider joining the Community Advisory Board?

You have been invited to consider joining the Whānau Working Group because you have been affected by an adult family member having a serious brain injury. In recruiting members, we have looked for people who have a passion for making a difference in this area, and who have the energy and skills to contribute to this group, and are willing and able to attend meetings on a regular basis.

What will happen in this research?

It is planned that the group will initially meet fortnightly, in order to determine the goals for the Whānau Working Group, and an action project that will support these goals. Meetings may reduce to monthly if that meets the needs of the project and the group. Meetings will be scheduled at a time and place which is convenient for most members. It is anticipated that meetings will take about 1 ½ hours with time for kai after each hui. It is anticipated that meetings will occur throughout 2013.

The focus of the Working Group will be to decide on what issues are important for whānau/families of people with brain injury and what changes we could work on that would help families be able to live their lives in the ways that are important to them. We will work together to determine our goals as a group and then to decide on an action project that we believe could make a positive difference to the lives of families/whānau. Once we're clear on the project we'll need to decide what measures would be worth using to decide if the project has been effective and then to get on with making the project happen. At different stages we will need to go back to the university to get ethical approval. The university ethics committee (AUTEC) has approved the set-up of a Whānau Working Group in order to begin this planning, and we will seek ethical approval again once we have decided on the next steps.

The meetings will be audio-taped and these tapes will be transcribed (written up) by me (Elisa). I'll spend time thinking about what ideas come through strongly in the meetings and bring these thoughts back to the group on a regular basis. These tapes could become data for some aspects of the research but the group as a whole will decide on how the information can be used.

What are the discomforts and risks?

You may find it upsetting to discuss the situations that some families are in as a result of a family member's brain injury, but you may also find it to be supportive.

How will these discomforts and risks be alleviated?

As a group we will discuss ground rules that will help people to work in the group without becoming overly burdened by being involved in the group. These ground rules will include attention to privacy and confidentiality for each member (which is discussed in more detail below). While the work that will be done by the Working Group will not be therapy, people can find it beneficial to talk with others in a similar situation. Elisa is a Clinical Psychologist who has experience in working with individuals and groups and will work with the group to develop ways of working together to meet the needs of the project in a way which will hopefully also be beneficial to everyone who is involved. As

noted above, the involvement is voluntary and you can also withdraw from the board if you find that the work is causing distress.

If the process of this research does cause you distress you will be able to access 3 sessions of counselling support via AUT Counselling, or through Family Court Counselling.

AUT Counselling:

Manukau Campus: 09 921 9303

City Campus: 09 921 9992

North Shore Campus: 09 921 9998

What are the benefits?

The Whānau Working Group will determine what action could best be taken, as part of this research, to **increase the ways in which whānau/families are able to live their lives in the ways that they want to**. It is hoped, therefore, that this research will lead to benefits to the participants and to others who are in similar situations. The Working Group will oversee the design of the action, its evaluation and the way in which information about the project will be spread (dissemination of results). One way in which the research information will be shared will be through the write up of a PhD and through articles in academic journals, but the Working Group may also wish to see information about the project being given to other groups with an interest in the areas of brain injury, rehabilitation, and the effects of brain injury on family members, as well as through spreading information to the general public.

How will my privacy be protected?

Anyone who takes part in research has the right to privacy and confidentiality. When people take part in research that involves groups the usual rule is that what is said in the group will stay in the group, so people are asked not to talk about individuals' stories and ideas once they have left the meeting. As the purpose of this research is to conduct an action project, however, there will be ideas and messages that the group do want to be taken out into the community. The initial meetings for the Working Group will focus on what the rules should be around deciding what should be kept confidential and what should be made public. Deciding how to operate together as a Working Group will be an important first stage of this project.

When the research is written up your name will not be used, unless you let me know that you want your name included. As the Whānau Working Group will be working to achieve change for families it is likely that people will know that you are involved in this project, but the comments and ideas that each person shares can be kept separate from their name.

What are the costs of participating in this research?

Working Group members will be asked to attend regular meetings. Koha of \$50 in petrol vouchers will be provided in acknowledgement of the time and knowledge which you will contribute.

What opportunity do I have to consider this invitation?

The first meeting will be in June (date will be determined based on times that most people are able to attend).

How do I agree to participate in this research?

If you would like to become a part of the Whānau Working Group, then please get in touch with Elisa on 027 295 8831 or through the Brain Injury Association offices (09 272 2272). We will also have initial information and discussion meetings where you will be able to hear more about the project and ask any questions on [*rooms will be booked after Ethics has been approved*]. If you would like to join the Working Group and believe that you will be able to contribute the necessary time then you'll be asked to sign a Consent Form.

Will I receive feedback on the results of this research?

Members of the Whānau Working Group will guide the project throughout all of its stages and will be aware and informed about each stage of the project. Rather than receiving feedback, you will be actively involved in achieving the results, analysing the results and interpreting the results.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Marilyn Waring, marilyn.waring@aut.ac.nz, ph 921 9661 .

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Dr Rosemary Godbold, rosemary.godbold@aut.ac.nz , 921 9999 ext 6902.

Whom do I contact for further information about this research?

Researcher Contact Details:

Elisa Lavelle Wijohn

Phone: Mobile 027 2958831 or 0800 824942 (0800 TBI WHANAU)

AUT 09 921 9999 ext 7663

BIA Otara 09 272 2272

elisa.wijohn@gmail.com

Project Supervisor Contact Details:

Professor Marilyn Waring 09 921 9661

marilyn.waring@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 11 April 2013 , AUTEK Reference number 12/137.

Appendix N: Consent form

Consent Form



Project title: **TBI Whānau Action Project**

Project Supervisor: **Professor Marilyn Waring**

Researcher: **Elisa Lavelle**

- I have read and understood the information provided about this research project in the Information Sheet dated 7 May 2013.
- I have had an opportunity to ask questions and to have them answered.
- I understand that opinions of my fellow participants and our discussions in the working group are confidential to the group and I agree to keep this information confidential.
- I understand that notes will be taken during the working group meetings and that it will also be audio-taped and transcribed.
- I understand that I may withdraw or retire myself or any information that I have provided for this project at any time prior to completion of the action project, without being disadvantaged in any way.
- If I withdraw, I understand that while it will not be possible to destroy all records of the working group meetings of which I was part, I may seek to have all the relevant information about myself including tapes and transcripts, or parts thereof, removed from the data.

- I agree to take part in this research.
- I wish to receive a copy of the report from the research (please tick one): Yes No

Participant's signature :

Participant's name:

Participant's Contact Details (if appropriate):

.....
.....
.....

Date:

**Approved by the Auckland University of Technology Ethics Committee on 11April 2013
AUTEK Reference number 12/137**

Note: The Participant should retain a copy of this form.

Appendix O: Ground rules

Respect

- Listening
 - Allowing space for each person
 - Not interrupting

Confidentiality

- People are likely to talk about their day, but don't bring names in
- It's okay to talk about your own reaction, your own feelings, what you personally said, but remember to respect the confidentiality of what other people talk about.
- Think about whether you'd be happy for other people in the group to hear anything that you say about the group.

Safety

- Take yourself out of the room if you need, but bring yourself back
- Will we include a kaumatua/kuia/priest or do we just work with the family members?

Consensus

- Need to work together as a group – not just one person doing things on their own.

Non-judgmental (in discussion)

- On reviewing the rules above one person suggested that being non-judgmental would be a good ground rule. A second person, who had arrived later to the meeting had felt that this might not be possible to achieve, an option for the group(s) to discuss is whether to include a rule about striving to not judge others but to ...

Appendix P: Principles of CBPR

1. CBPR recognizes **community** as a unit of identity
2. CBPR **builds on strengths and resources** within the community
3. CBPR facilitates **collaborative, equitable partnership** in all research phases and involves an **empowering and power-sharing process** that **attends to social inequalities**
4. CBPR promotes **co-learning** and **capacity building** among all partners.
5. CBPR integrates and achieves a **balance** between **research and action** for the mutual benefit of all partners
6. CBPR emphasizes public health problems of **local relevance** and also ecological perspectives that recognize and **attend to the multiple determinants of health** and disease
7. CBPR involves systems development through a **cyclical** and iterative



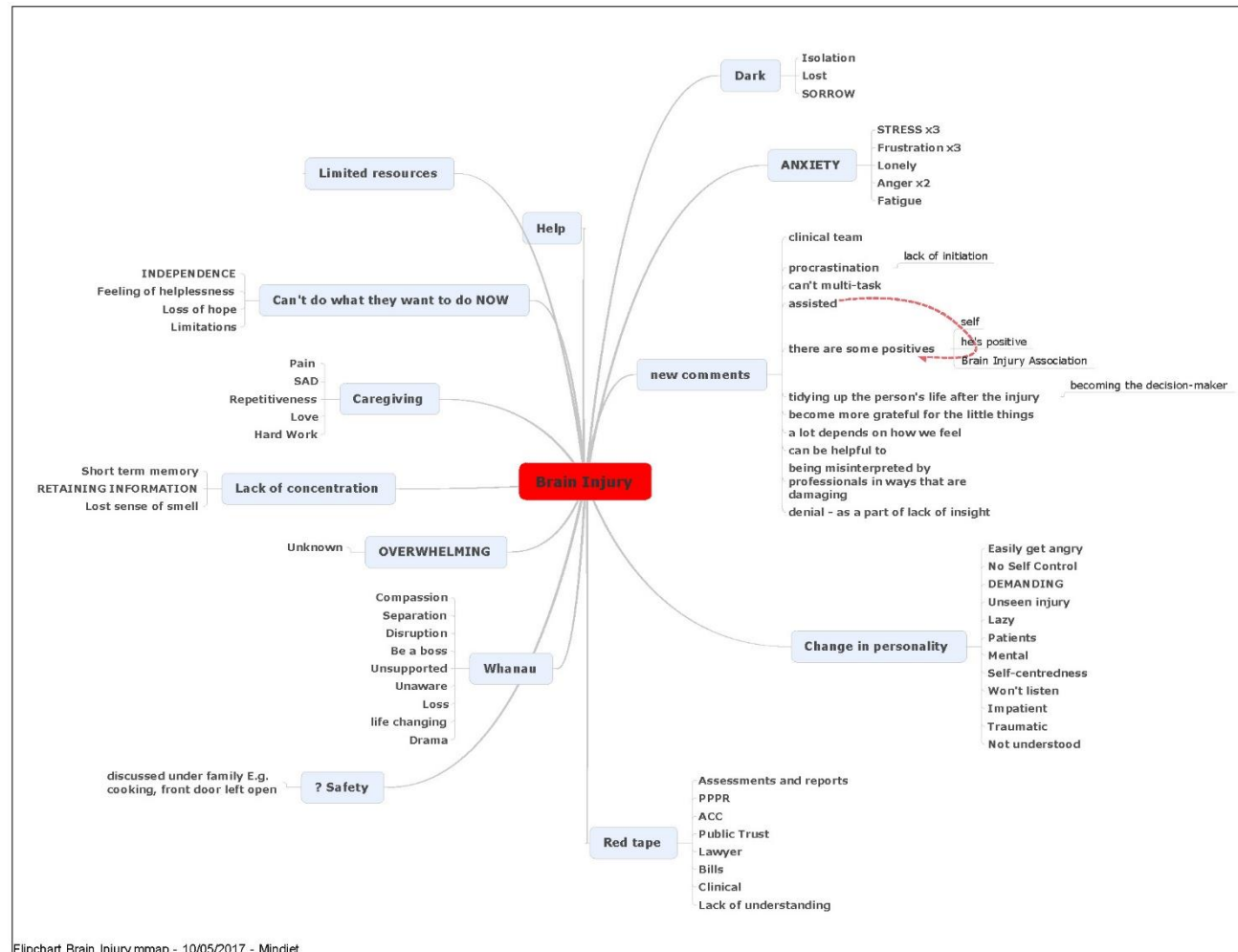
process.

8. CBPR **disseminates findings** and **knowledge** gained to **all partners** and involves all partners in the dissemination process
9. CBPR requires a **long-term process** and **commitment to sustainability**

What principles are important to you?

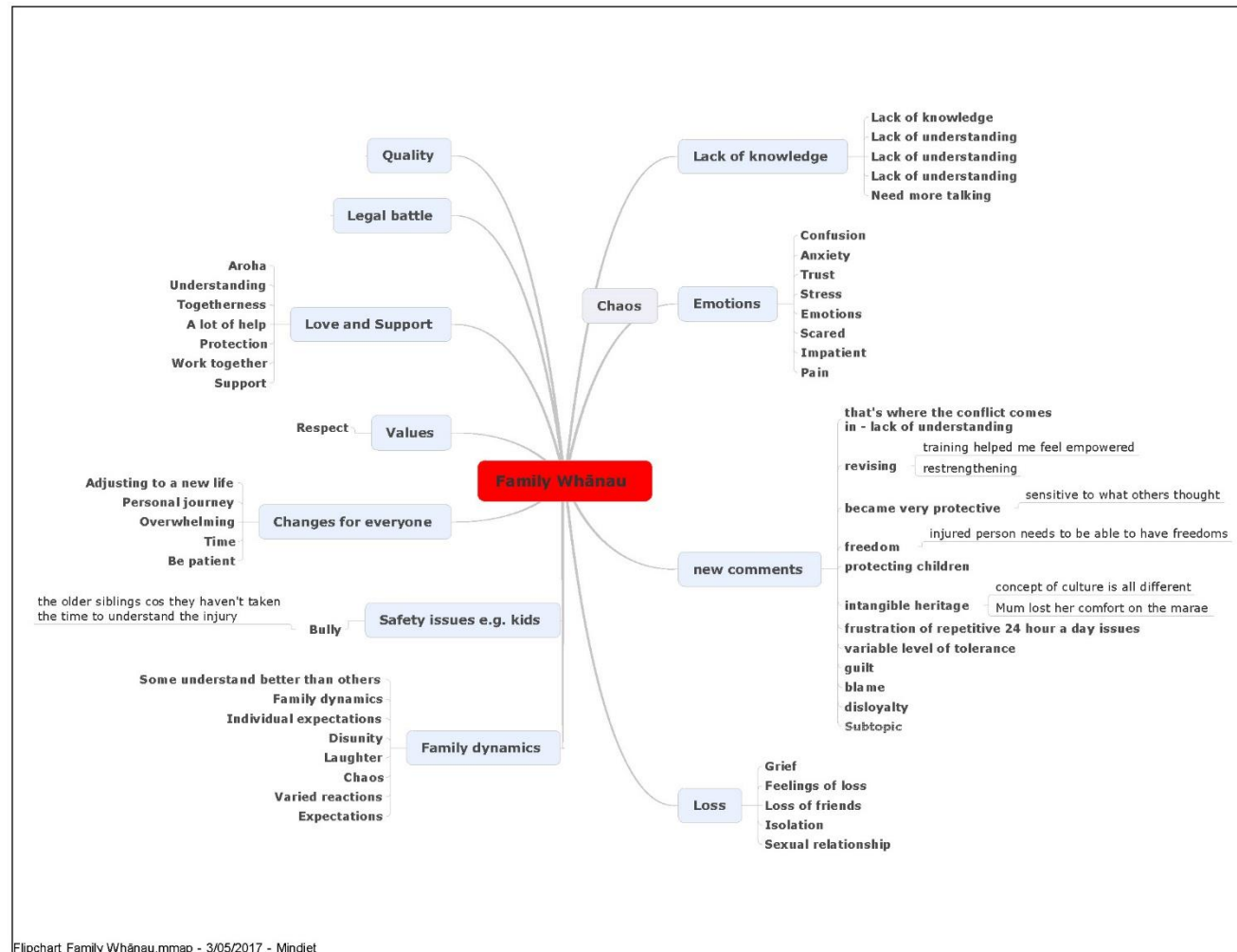
What principles will guide this group and project?

Appendix Q: Flipchart Brain Injury

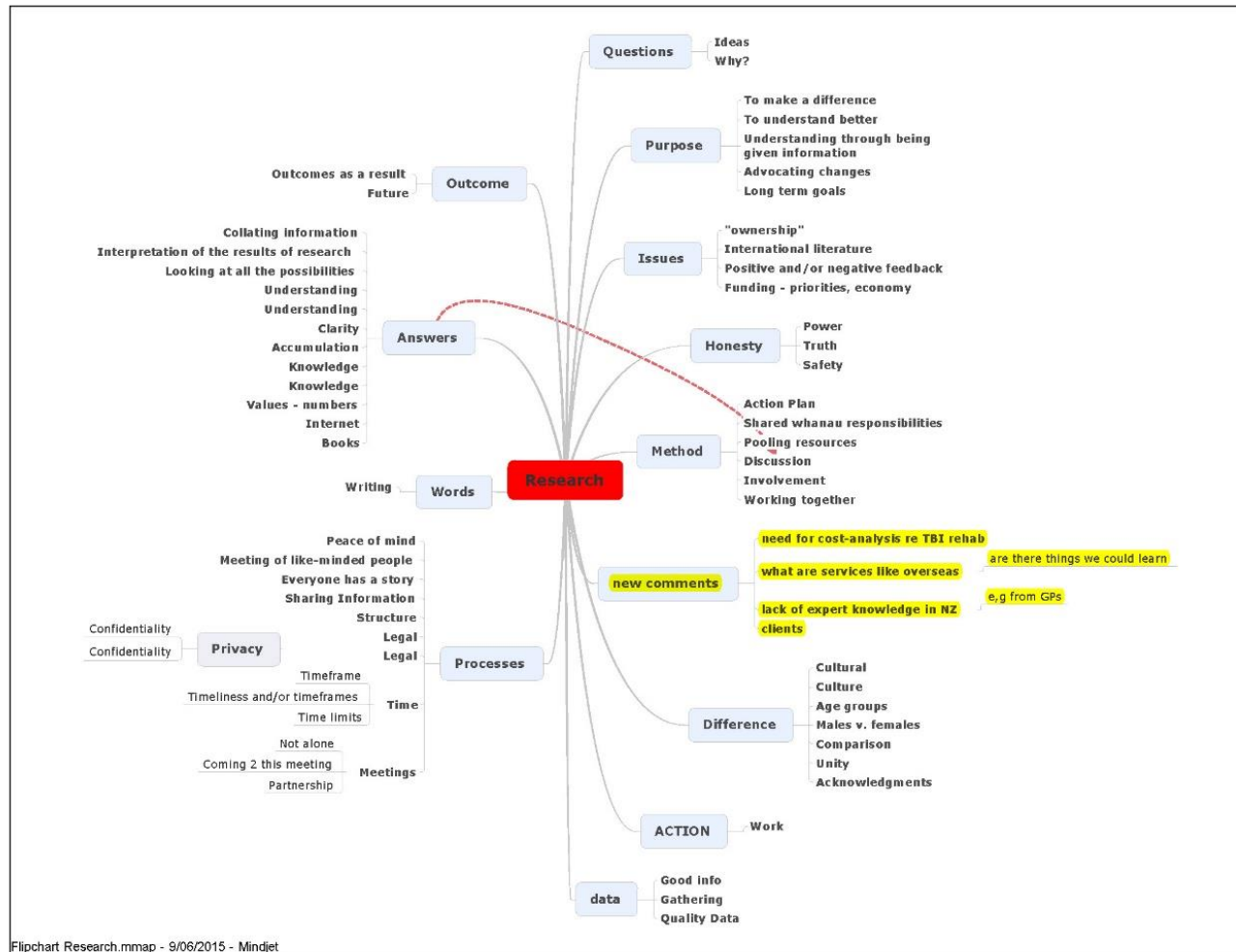


Flipchart Brain Injury.mmap - 10/05/2017 - Mindjet

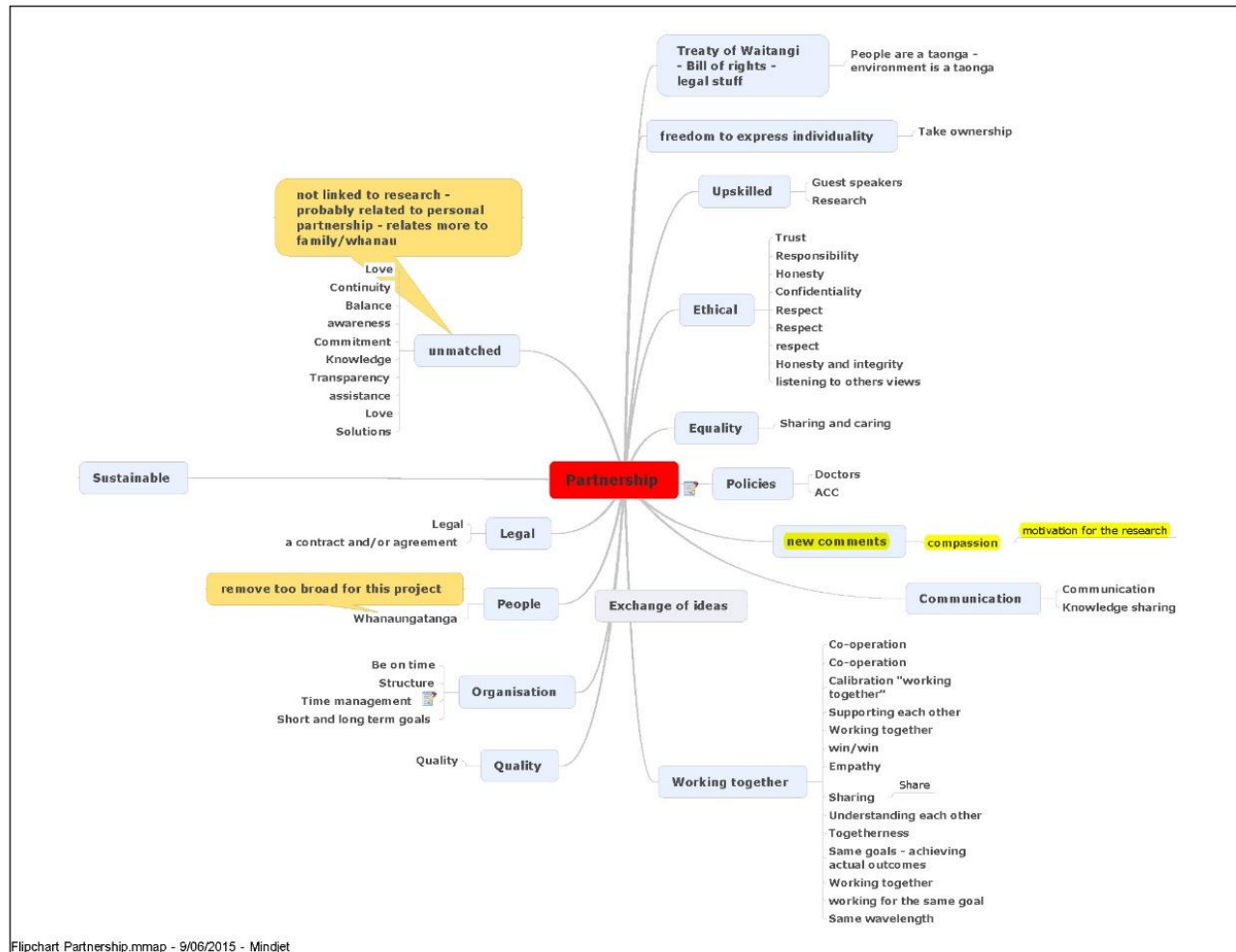
Appendix R: Flipchart Family Whānau



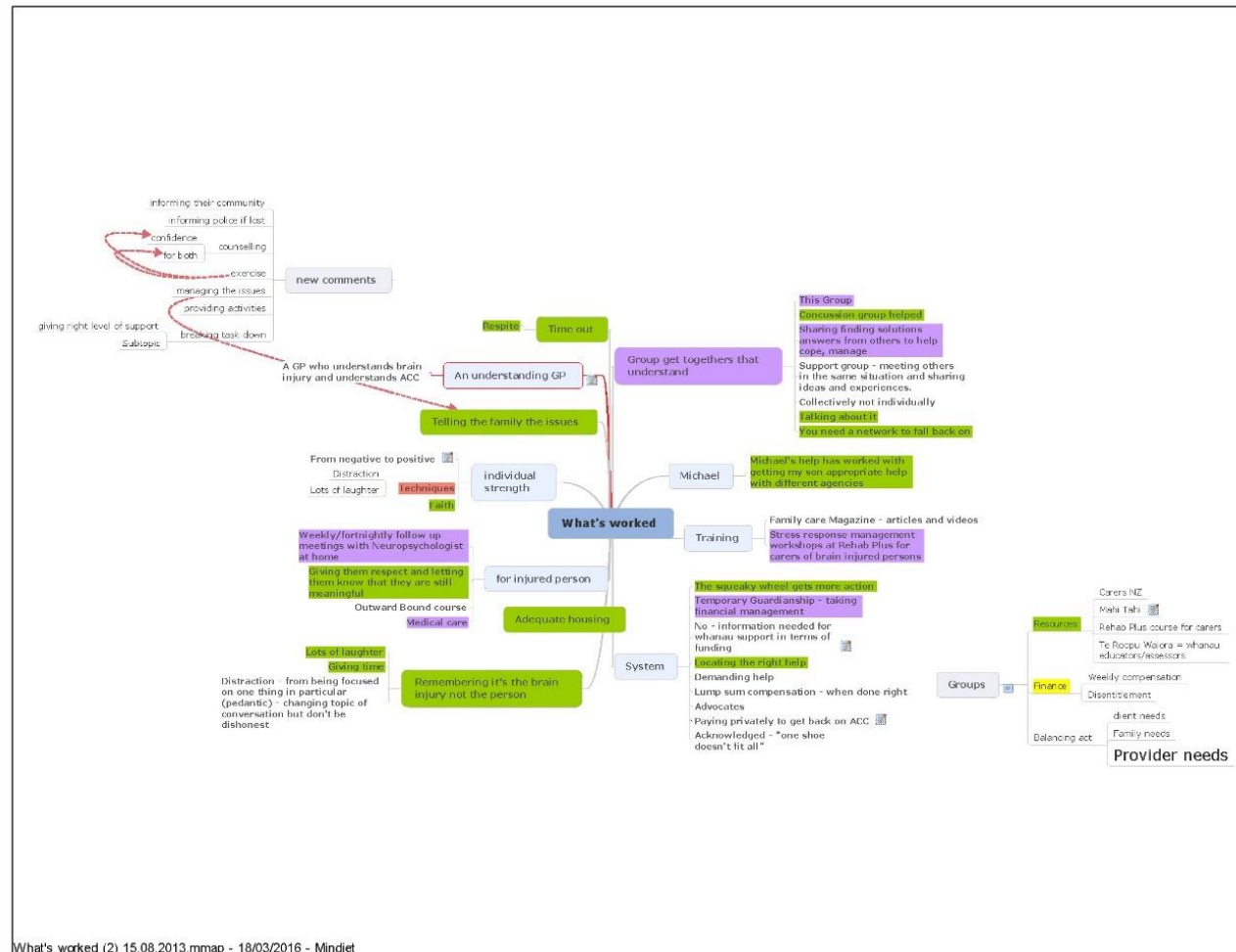
Appendix S: Flipchart Research



Appendix T: Flipchart Partnership

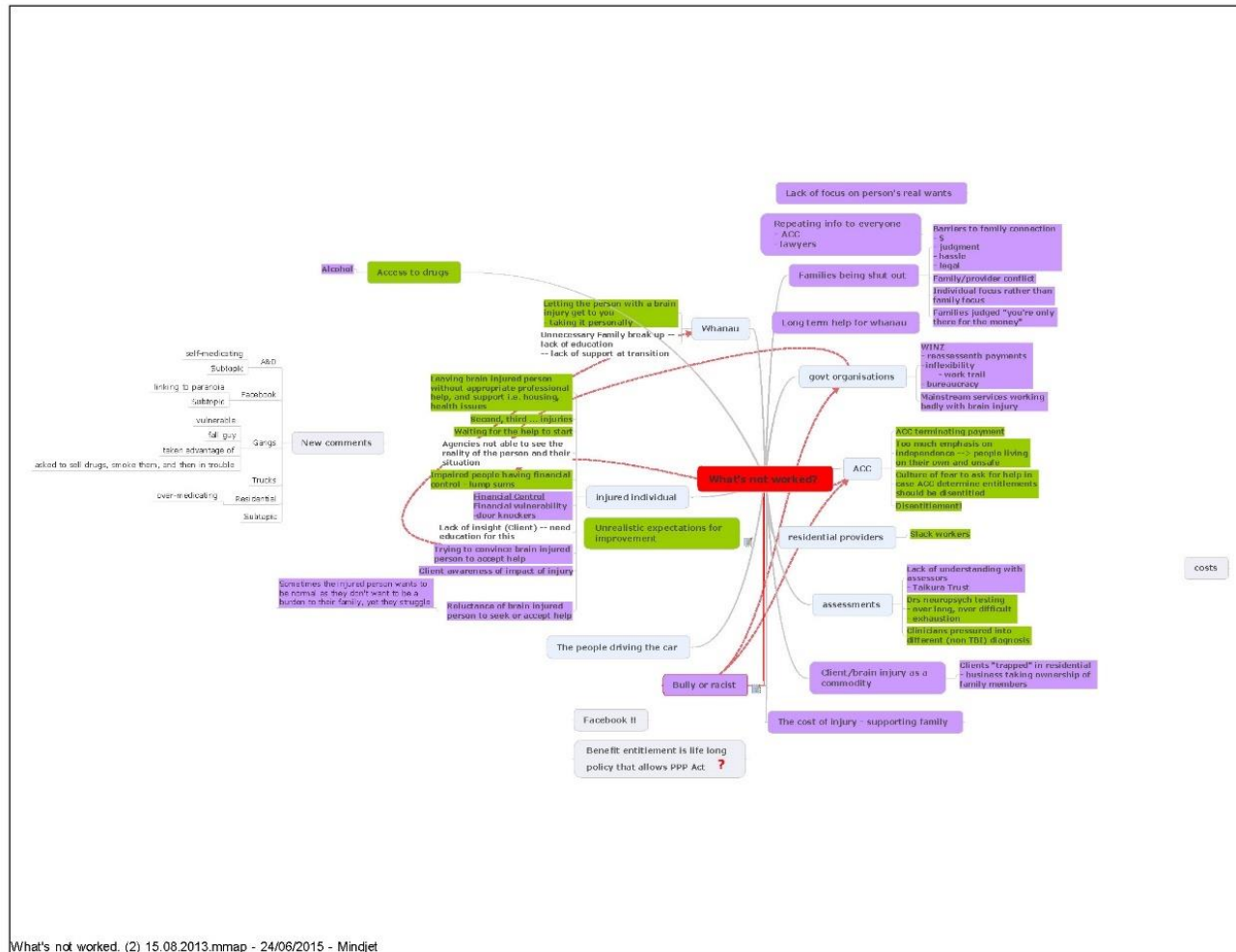


Appendix U: What's worked?



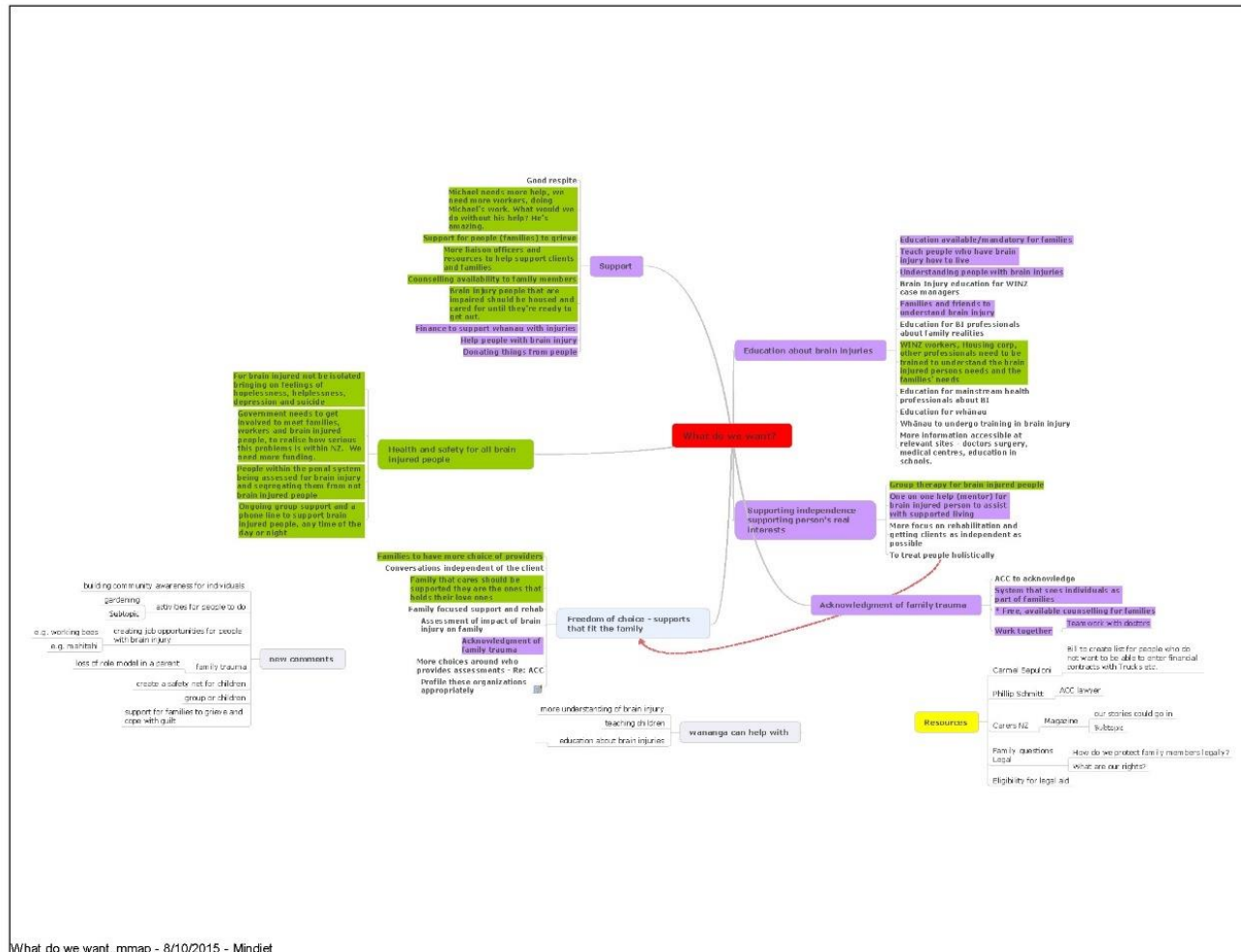
What's worked (2) 15.08.2013.mmap - 18/03/2016 - Mindjet

Appendix V: What's not worked?



What's not worked. (2) 15.08.2013.mmap - 24/06/2015 - Mindjet

Appendix W: What do we want?



What do we want_mmap - 8/10/2015 - Mindjet

Appendix X: The Crash Reel – evaluation form

Overall as a way of meeting your education needs about brain injury and how it affects families/whānau, how would you rate this movie?

0 1 2 3 4 5 6 7 8 9 10

Not useful
at all

Extremely useful

In what ways did this movie meet your needs for learning about the impacts of brain injury?

In what ways did this movie meet your needs for learning about how brain injury impacts families/whānau?

Are there any things you thought were particularly good about this movie?

Are there any things you thought were less good?

Thinking about our group's goal of supporting other families affected by brain injury how would you rate this movie in terms of its usefulness?

0 1 2 3 4 5 6 7 8 9 10

Not useful
at all

Extremely useful

Why did you answer in this way?

Who do you think should see this movie?

My own close family

0 1 2 3 4 5 6 7 8 9 10

Not important they
see this movie

Very important

My own wider family

0 1 2 3 4 5 6 7 8 9 10

Not important they
see this movie

Very important

Health professionals

0 1 2 3 4 5 6 7 8 9 10

Not important they
see this movie

Very important

ACC Case Managers

0 1 2 3 4 5 6 7 8 9 10

Not important they
see this movie

Very important

Who else?

Appendix Y: Summary of evaluations – The Crash Reel

The Crash Reel

Overall as a way of meeting your education needs about brain injury and how it affects families/whānau, how would you rate this movie?

0 1 2 3 4 5 6 7 **8** 9 10

Not useful at all Extremely useful

In what ways did this movie meet your needs for learning about the impacts of brain injury?

- Family
- Patience, encourage, understand
- Just showed me a lot of what I already knew. There needs to be more information for families, husbands/wives to be able to access
- Watching the changes that occur after brain injury
- Every person with brain injury would have different needs, lifestyle and whānau/friend(s) support to cope with their disability(ies). I gave the movie a 6 because whānau need different methods/tools to learn about brain injury – the 6 for me is really good. When I went with my brother Tom who has brain injury I wasn't allowed to accompany him when the doctors did tests on him. Seeing this young man's pain and at times lack of understanding to what's going on around him is really sad. As for meeting my needs, having completed the Barry Willer (Level 1) the movie is refreshing all that I was shown/taught to a point.
- It related well to Carl's BI due to the accidents both being on snowboards. Kevin's family had the same realistic concerns that we had when Carl decided that he wanted to go back on to the slopes and go snowboarding after his injury. We, like them, felt it was very risky. I remember feeling quite helpless and powerless to make him see sense. Also, the mother of the young man who thought it was quite comical to run over his sister on the bike, she was feeling quite inadequate which reminded me of myself at times in the earlier part of Carl's recovery process.

In what ways did this movie meet your needs for learning about how brain injury impacts families/whānau?

- That everyone needs help even the family themselves also need support
- Think positive, how to (teach) them
- It helped me to think about getting my family together to discuss things on a regular basis with my Brain injured son, to bring out our thoughts/feelings to support my son, in any way that we can.
- It showed how families were affected

- It's like reliving events that happen with my whānau, sometimes a blame game, some times wanting to walk away from all the worry and drama.
- It showed that Kevin's family was an ordinary family who had the same fears for their child as everyone else. I thought the movie flowed very well. It was obvious that Kevin had short term memory problems (not remembering his appointment with the interviewer). Also, you picked up on the fatigue and impulsiveness side effects. It made us very aware of the after effects of the impact of the injury with his long rehab process. Friends talking about additional injuries sustained after the initial one which has affected their lives.

Are there any things you thought were particularly good about this movie?

- Yes that head injury has a real impact on the whole family and friends
- Awesome family, good friends, good doctors around him
- Interesting hearing it from Kevin's perspective – his lack of awareness/insight
- It brought back lots of memories to the time when my son had his Brain Injury, I could relate to a lot of things, within this film. Also, reminded me to be more tolerant with my son, and his mood swings.
- Out of the mouths with those with disabilities as Down syndrome came the most honest comments and feelings
- The doctors explaining all the medical processes and how the whānau work with each other. I suppose the spiritual connection this whānau whare helped them and shows in the movie. The Dad acknowledged having to change sporting rules and upping safety. The danger of the sport and other sports such as bike and skateboarding.
- The movie flowed very well. A point was made about the increase in height to the half pipe where the competition took place and the danger of it being so high causing more accidents as well as the fatality of the young girl skier. The emotional plea from Kevin's Down Syndrome brother about how worried he was that Kevin would die if he went back snowboarding. It also highlighted the fact that he disliked his disability and his struggle with being different. The rehab support Kevin received from his brother who took time off work especially to help in his recovery. This relates well to young people.

Are there any things you thought were less good?

- Kevin wants to go back to do it again
- There needs to be more information shown on the DVD from the doctors, and I would have liked to see Kevin in his different mood swings.
- Showed how sports people are pushed to limits
- I think the movie is too long and would more useful as a tool if it were broken down in stages – example 15 min showing then stop and ask questions from whānau about that part of the movie. Some areas of the movie triggers bad memories for me – angry that doctors, healthcare and ACC took advantage of our brother and whānau. I believe health and safety issues should be put first that's where the 15 min showing comes into the above.
- Kevin is fortunate that he has been able to travel and retell his story and to work in an area that he feels comfortable with and loves (snowboarding commentary role). However, in the majority of BI cases, many struggle to go back to the work they did prior to the injury and even to find a meaningful job. I know Carl struggles with this.

Thinking about our group's goal of supporting other families affected by brain injury how would you rate this movie in terms of its usefulness?

7.4

Why did you answer in this way?

- We need more help out there for families to know what you would go through and also let them know that there is help out there. (10)
- Because we need to share ideas to them and support (6)
- Some of it seemed a little long and drawn out (8)
- Because there is not a lot of information out there about brain injury (6)
- Not all families have such support (7)
- The movie covers all perspectives – BI person, family members, friends, doctors, psychologists and other professionals. (10)

Who do you think should see this movie?

- Everyone should

My own close family **8.9**

My own wider family **9**

Health professionals **9.3**

ACC Case Managers **9.1**

Who else?

- I'm not sure but students should
- Players e.g. rugby players, boxers
- Maybe for some it would need to be subtitled
- All of New Zealand
- Anyone who does any sport or work where they may get a brain injury
- I believe (strongly believe) that children should not attend (0-10) reason being the movie is long and children wouldn't enjoy sitting through this. We want people to take in the message the movie has.
- Schools, universities, work places, sports clubs.

Rough notes re themes

Families are different but the same, they go through many of the same challenges. Families need support, people need information.

Appendix Z: Wānanga sponsorship request

Brain Injury Whānau Action Project: Request for Sponsorship

Wānanga August 29th – August 30th, 2015 at Weraroa Marae

We are a group of family members who are impacted by the serious brain injury of a loved one. We are working in partnership with AUT to look at how we can improve the lives of whanau with serious brain injury. We have been working to educate and strengthen ourselves in order to educate and strengthen others.

At the end of August we will be running a wānanga (marae-based education workshop) for families. In order for everyone to be able to benefit we will include adults, children and our whanau members who have had a serious brain injury. We hope to deliver the wānanga to about 60 people.

The areas that the learning and discussion will focus on are:

- Success stories from families
- Understanding brain injury
- Skills in advocacy
- Self-care – including mirimiri being available
- Information and activities for children

Running a project such as this will have a lot of expenses including food, accommodation, and care for the people who need extra support (children and people with serious disability), as well as koha for speakers. As we are working with a group that include people on very low incomes it is important to be able to provide the training at zero cost to those who are attending. We are also seeking to film the sessions so that the information can be made available to people who are unable to attend. We may also need to provide transport support to whanau who would otherwise find it too difficult to attend.

We would be grateful for any contribution that you could make towards this project through cash or product.

The Brain Injury Whānau Action Project (BIWAP) is a research partnership between Brain Injury Association (Auckland) and Elisa Lavelle Wijohn who is a Clinical Psychologist and a PhD student with AUT. The research side of the project is supported by a scholarship from the Health Research Council Disability Placement Programme.

If you would like any further information please talk to me (the person who has given this to you) or contact Elisa on elisa.wijohn@gmail.com or phone her on 027 2958831 or 0800TBIWHANAU.

Brain Injury Whānau Action Project Wānanga

Learning together as a whole family to thrive and survive with brain injury.

The Brain Injury Whānau Action Project invites you to a weekend of learning and sharing on living well with brain injury. This weekend is for the whole whānau and includes learning and activities for children.

We will learn about

- Effects of brain injury
- Self care
- Advocacy
- Whanau ora / Family wellbeing

Plus we'll spend time together sharing our stories, challenges, strengths and triumphs.

Supported by:



When: August 29th—August 30th

Where: Weraroa Marae, 34
Richardson Rd, Waikaretu

For registration

Contact: Elisa Lavelle Wijohn

elisa.wijohn@gmail.com

0800 824942 (0800 TBIWHANAU)

Appendix BB: Letter to Minister Kaye



Brain Injury Whānau Action Project

13 August 2015

Tēnā Koe Minister Kaye

The Brain Injury Whānau Action Project has been set up by a group of family members of people with serious brain injury. As you know brain injury has a significant impact on not only the person with the injury, but also on others with whom that person is in close relationship. Our group includes partners, parents, and siblings of people with serious brain injury who are working to improve the lives of whānau through educating and strengthening ourselves in order to educate and strengthen others.

Our first action project is that we will be running a wānanga on the 29th-30th August at Weraroa Marae so that whānau will be able to come together to learn, share and be inspired by our guest speakers, the environment and each other. We see this wānanga as a pilot that will be able to be repeated in other regions where there are families who also want to develop action which is by families, for families. For your interest, we have enclosed both the flyer and the programme.

Through our recruitment process the local MP for Hauraki-Waikato, Nanaia Mahuta, has expressed an interest in attending and we would be thrilled to have anyone who is in support of this kaupapa to attend. While we would absolutely welcome your involvement in this wānanga, we appreciate that at such short notice this might not be possible. We would, however, like to request the opportunity to meet with you in order to brief you on the group's activities. As our group is based in South Auckland we do not have the means to be able to visit you in Wellington, and therefore request a time to meet with you in your Auckland Central office.

Contact can be made with our group via Elisa Lavelle Wijohn on 027 295 8831, or via email elisa.wijohn@gmail.com

Mauri ora

Appendix CC: BIWAP Wānanga Evaluation Form

About you:

Are you here because: you have had a serious brain injury ? YES NO

you are supporting someone with a brain injury ? YES NO

Age group: (circle one)

8-12

13 -17

Adult

How helpful has this wānanga been for you?

1

2

3

4

5

☹ Very
unhelpful

Neutral ☹

Very helpful ☺

How helpful has it been for your family?

1

2

3

4

5

☹ Very
unhelpful

Neutral ☹

Very helpful ☺

How helpful has the training been for you to have: Very unhelpful neutral Very helpful

An increased sense of connection with others? 1 2 3 4 5

Increased knowledge of the effects of brain injury? 1 2 3 4 5

More strategies to support someone with brain injury? 1 2 3 4 5

More strategies to look after myself (self-care)? 1 2 3 4 5

More strategies to deal with systems (e.g. health, ACC)?

How would you rate your enjoyment of the wānanga?

Appendix DD: Wānanga Programme

Weraroa Marae, Waikaretu, Saturday 29 th – Sunday 30 th August 2015	
Saturday 29 th August	Sunday 30 th August
10.00 am	Pōwhiri Welcome on to the Marae.
10.30 am	Morning Tea
	Introduction Explain Post-Its
11.30 am	Tamati Paul – Shattered Dreams
12.00	Richard Seemann – Rehabilitation Physician – the brain and physical effects of injury
1.00 pm	Lunch
2.00 pm	Margaret Dudley – Neuropsychology - neuropsychological assessment
3.00 pm	Te Rina Ruru and Corina Colbert – The Ripple Effect
3.30 pm	Afternoon Tea
4.00 pm	Huhana – Practical tips around knowing your rights and successful advocacy
5.00 pm	Free time
6.00 pm	Dinner
7.00 pm	Karakia
7.10 pm	The Crash Reel (running time 1hr 48 min)
9.30 pm	Kapu Ti and a chat
	Karakia
	Breakfast
	Tess Liew – Mindful movement, Self-care and relaxation
	Nic Beets – Brain Injury and Relationships
	Morning Tea
	Alice Theadom – Self care and Managing Fatigue after brain injury
	Lunch
	Post-its evaluation
	*1.30 pm Feedback and future directions
	*3.00 pm Poroporoaki / Closing at the Marae and karakia
	Children’s programme includes special trip at Saturday afternoon

Appendix EE: Crash Reel Screening Rights



**Roadshow
Public Performance Licensing (NZ)**

Thursday 9th July 2015

Roadshow PPL quote for The Brain Injury Whānau Action Project

Dear Elisa

Thank you for contacting me in regards to acquiring a performance licence for a screening of *The Crash Reel*. I can quote the following licence fee,

\$120.00 + GST per film and screening

Please let me know if this is something you would like to proceed with and I will contact the studio for their approval.

Kind regards,

Michael Chal

Sales Co-ordinator NZ
Roadshow Public Performance Licensing

ROADSHOW ENTERTAINMENT (NZ) LTD
686 Rosebank Road, Avondale, Auckland, New Zealand Private Bag 19998, Avondale, Auckland, New Zealand. Telephone: 09 820 8800. Fax: 09 820 8801



Brain Injury Whānau Action Project Wānanga

Registration Form

Name:

Age (if under 18):

Address:

Contact phone number:

2nd contact phone number:

Email address:

Any dietary requirements we need to know about?

Do you have any physical support needs?

Anything else you would like the organisers to know?

Appendix GG: Wānanga Information Sheet

AUT

TE WĀNANGA ARONUI
O TĀMAKI MAKĀU RAU

Wānanga Participant Information Sheet

Date Information Sheet Produced: 28 July 2015

Project Title

Brain Injury Whānau Action Project Wānanga

An Invitation

The Brain Injury Whānau Action Project are happy that you're attending this wānanga and would like to invite you to also take part in some research in the form of an evaluation of the wānanga.

This project has been developed as part of the research that I, Elisa Lavelle Wijohn, am doing for a PhD qualification. But we also hope that through getting your hopes for, and feedback on, this wānanga it will help us to be able to develop future training opportunities for families.

Taking part in the evaluation is voluntary and anonymous.

What is the purpose of this research?

The purpose of the PhD research has been to develop action that would be of benefit to families of people with serious brain injury.

The purpose of the wānanga evaluation is to give us some information about what you would hope to get from the wānanga, and afterwards to tell us what your experience was actually like. We obviously hope that this wānanga will be a success and that the information that we learn from developing and running it will help us to run future trainings for other groups.

The publications and presentations that could result from the project will include articles for organisations such as Brain Injury Association and Te Roopu Waiora, or for the local newspaper, as well as academic publications. Presentations could include community hui as well as academic conferences. This research will also be written up as part of Elisa's PhD.

How was I identified and why am I being invited to participate in this research?

Everyone who is taking part in the wānanga is invited to participate in the evaluation. You were invited to take part in the Wānanga because you are, or are affected by, an adult family member who has had a serious brain injury.

What will happen in this research?

We are asking you to take part in participatory evaluation. Basically we'll ask you to write on three coloured post-its at the start of the wānanga to let us know what are the most important things you would like to get out of these two days, and then at the end we'll ask you to do the same thing to let us know what has been the most important aspects of the weekend. The post-its need to go on the large sheets of paper called "Most important", "Next most important" and "Third most important". Please use the correct colours for each page, as this will help us later when we analyse your responses by going through all the responses and grouping them into areas that seem to have something in common to find the themes of your feedback.

Through the two days we'll also have a space for "Any Other Comments?" where you can add post-its to let us know anything else you think we should know about.

At the end of the wānanga we will have a closing session where we will ask for your feedback. This session will be audio-recorded and transcribed by Elisa Lavelle Wijohn. If you do not want your comments recorded you can ask for the recording to be stopped. If you would like to give us some feedback, but not have it included in the research then you can also fill out an evaluation form.

What are the discomforts and risks?

Hopefully none in terms of the evaluation. If throughout the wānanga you have any concerns, please approach any of the Brain Injury Whānau Action Project team who are the organising team.

How will these discomforts and risks be alleviated?

If the process of this research does cause you distress you will be able to access 3 free sessions of counselling support via AUT Counselling

AUT Counselling: Manukau Campus, 09 921 9303; City Campus, 09 921 9992; North Shore Campus, 09 921 9998.

What are the benefits?

The benefits of completing the participatory evaluation (post-its pages) will be that you will get clear for yourself on what you'd like to get from this weekend and be able to see and discuss with others what they would hope to achieve. You will also be able to reflect on the weekend at the end through both the feedback session and completing the post-its again. This thinking ahead and reflecting back can help with later recall of the information.

The benefits of this research as a whole will hopefully be to increase understanding of how families who are affected by serious brain injury can be better able to live their lives in the ways they value. Through the evaluation of this wānanga we will be better able to deliver future trainings. We intend to also share the findings through various means such as conferences and newsletters, and through this to increase understanding of the impact of serious brain injury on whānau as well as individuals.

The benefit to the Brain Injury Whānau Action Project group members is that as a group we are continuing to develop our knowledge of how to improve the lives of families of people with serious brain injury, as well as increasing our knowledge in conducting and evaluating research. The research will also contribute to Elisa obtaining her PhD.

How will my privacy be protected?

The names of people who have participated in this process will not be included in the research.

What are the costs of participating in this research?

The only costs are a few minutes of your time to fill out the post-its and about an hour of all our time as we talk together at the end of the wānanga in the "Feedback and Future Directions" session.

What opportunity do I have to consider this invitation?

Very little. But we're here for two days, so if you do fill out the 'before' post-its and then decide that you don't want your comments to be included then you can remove your own comments, but please don't remove anyone else's.

How do I agree to participate in this research?

By giving us feedback through the post-its and the audio-taped feedback you are agreeing to participate in this research. We will remind you about the use of the audio-tape and that it will be used as part of the research at the beginning of the "Feedback and Future Directions" session.

Will I receive feedback on the results of this research?

If you would like to receive feedback on this research then please fill out your contact details on the form at the registration table.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Professor Marilyn Waring, marilyn.waring@aut.ac.nz, ph 921 9661

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?**Researcher Contact Details:**

Elisa Lavelle Wijohn elisa.wijohn@gmail.com

Phone:	Mobile	027 295 8831	
	AUT	09 921 9999	ext 7663
	BIA Otara	09 272 2272	

Project Supervisor Contact Details:

Professor Marilyn Waring 09 921 9661 marilyn.waring@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on *type the date final ethics approval was granted*, AUTEK Reference number *type the reference number*.

Appendix HH: Wānanga Child Information Sheet

AUT

TE WĀNANGA ARONUI
O TĀMAKI MAKĀU RAU

Wānanga Child Participant Information Sheet

Date Information Sheet Produced: 23 August 2015

Project Title

Brain Injury Whānau Action Project Wānanga

An Invitation

We know that brain injury affects whole families so we want to do something to support children and other members of the family, as well as the person with the injury. That's what this weekend is all about.

Our group, the Brain Injury Whānau Action Project have developed this family weekend and we will also want to know what people think of it. Was it worthwhile? Are there things that you think we should do differently? To find this out we will ask everybody to tell us a bit about the things that they think are important in supporting families who live with brain injury.

What is the purpose of this research?

The purpose of this research is to find out whether running wānanga like this weekend is a good way to support families living with brain injury. We also want to find out whether you have ideas for how we could improve what we have done. To start with, we want to know what you hope to get from this wānanga, and at the end of our time together, we'll want to know what you actually thought of it.

We hope that this wānanga will be a success and, if it is, we would want to share what we have learned with other groups, such as other researchers, and other groups who support people with brain injury or other issues. Elisa will share what we learn through talking with other groups and through writing about the research.

What will happen in this research?

We will ask you to write on three coloured post-its at the start of the wānanga to let us know what are the most important things you would like to get out of these two days, and then at the end we'll ask you to do the same thing to let us know what has been the most important aspects of the weekend. The post-its need to go on the large sheets of paper called "Most important", "Next most important" and "Third most important".

Through the two days we'll also have a space for "Any Other Comments?" where you can add post-its to let us know anything else you think we should know about.

At the end of the wānanga we will have a closing session where we will ask for your feedback. This session will be taped and then everything that is said will be written up by Elisa Lavelle Wijohn.

What are the discomforts and risks?

Hopefully none in terms of the evaluation. If throughout the wānanga you have any concerns, please come and see any of the Brain Injury Whānau Action Project team, in the BIWAP t-shirts, who are the organising team.

How will these discomforts and risks be alleviated?

If the process of this research does cause you distress you will be able to access 3 free sessions of counselling support via AUT Counselling

AUT Counselling: Manukau Campus, 09 921 9303; City Campus, 09 921 9992; North Shore Campus, 09 921 9998.

What are the benefits?

The benefits of doing the post-its exercise will be that you will get clear for yourself on what you'd like to get from this weekend and be able to see and discuss with others what they would hope to achieve. You will also be able to look back over the weekend at the end through both the feedback session and

completing the post-its again. This thinking ahead and looking back can help you to remember the information that was important to you.

The benefits of this research as a whole will hopefully be to increase understanding of how families who are affected by serious brain injury can live better lives. Your feedback will help us to plan and deliver future trainings. We plan to also share what we find out through different ways such as meetings with other researchers, with groups that help families, and with families. We will write up reports for all of these groups as well.

The benefit to the Brain Injury Whānau Action Project group members is that as a group we are learning how to improve the lives of families of people with serious brain injury, and also learning how to do research. The research will also help Elisa to get her PhD (university degree).

How will my privacy be protected?

The names of people who have taken part will not be included in the research.

What are the costs of participating in this research?

There are no money costs. All we are asking for are a few minutes of your time to fill out the post-its and about an hour of all our time as we talk together at the end of the wānanga in the "Feedback and Future Directions" session.

What opportunity do I have to consider this invitation?

Very little. But we're here for two days, so if you do fill out the 'before' post-its and then decide that you don't want your comments to be included then you can remove your own comments, but please don't remove anyone else's.

How do I agree to participate in this research?

By giving us feedback through the post-its and the audio-taped feedback you are agreeing to participate in this research. We will remind you about the use of the audio-tape and that it will be used as part of the research at the beginning of the "Feedback and Future Directions" session.

Will I receive feedback on the results of this research?

If you would like to receive feedback on this research then please fill out your contact details on the form at the registration table.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Professor Marilyn Waring, marilyn.waring@aut.ac.nz, ph 921 9661

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Researcher Contact Details:

Elisa Lavelle Wijohn elisa.wijohn@gmail.com

Phone: Mobile 027 295 8831

AUT 09 921 9999 ext 7663

BIA Otara 09 272 2272

Project Supervisor Contact Details:

Professor Marilyn Waring 09 921 9661 marilyn.waring@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on *type the date final ethics approval was granted*, AUTEK Reference number *type the reference number*.

Wānanga Video Consent Form



Project title: **TBI Whānau Action Project**

Project Supervisor: **Professor Marilyn Waring**

Researcher: **Elisa Lavelle**

- I have read and understood the information provided about this research project in the Wānanga Information Sheet dated 28 July 2015.
- I have had an opportunity to ask questions and to have them answered.
- I understand that my presentation to the wānanga will be video recorded.
- I understand that this video recording is for the purpose of dissemination of information to a wider audience, for example via the Brain Injury Association (Auckland)'s website and Facebook page, and is not for the purpose of collecting data for research.

- I agree to my presentation being video recorded.
- I wish to receive a copy of the report from the research (please tick one): Yes No

Presenter's signature :

Presenter's name:

Participant's Contact Details (if appropriate):

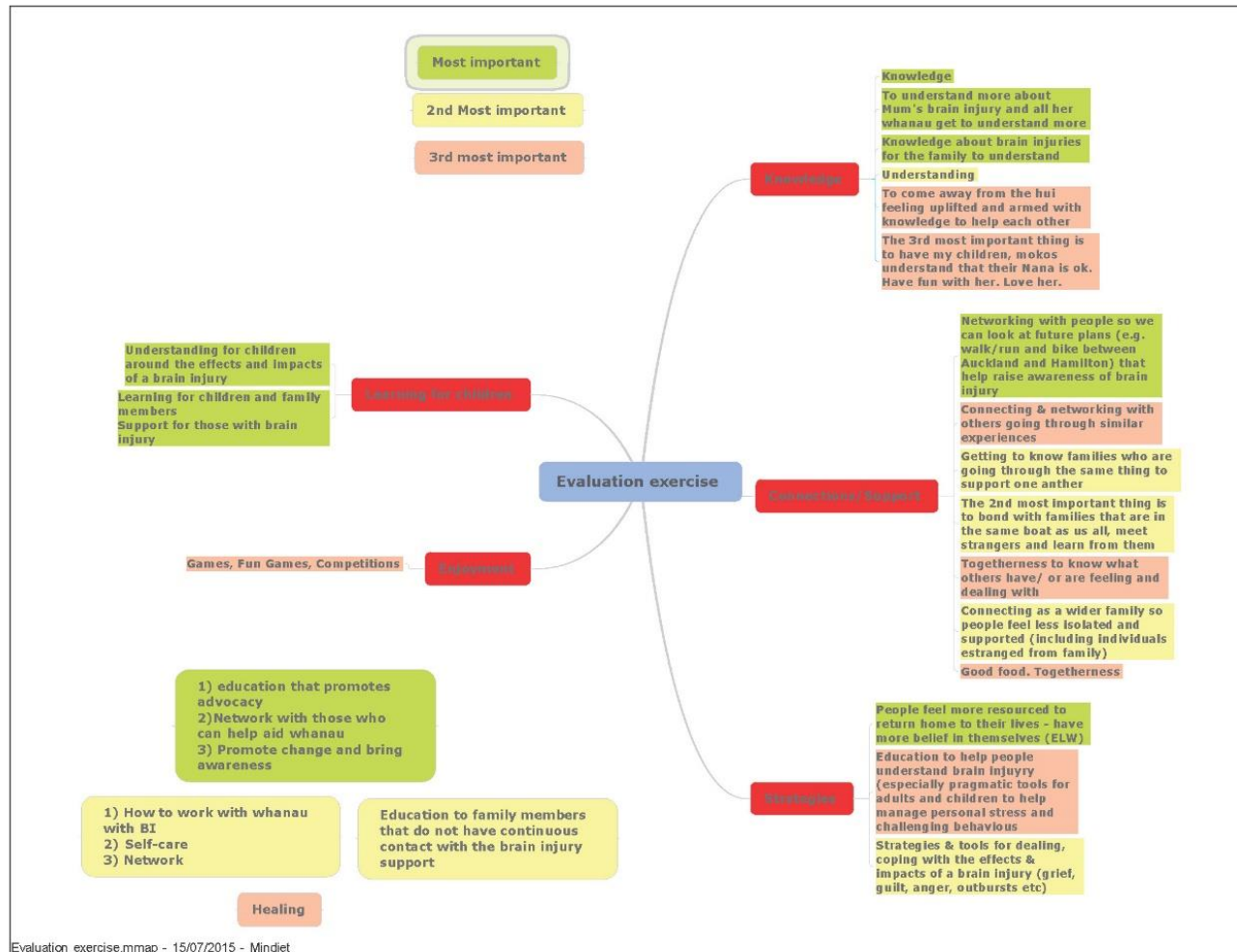
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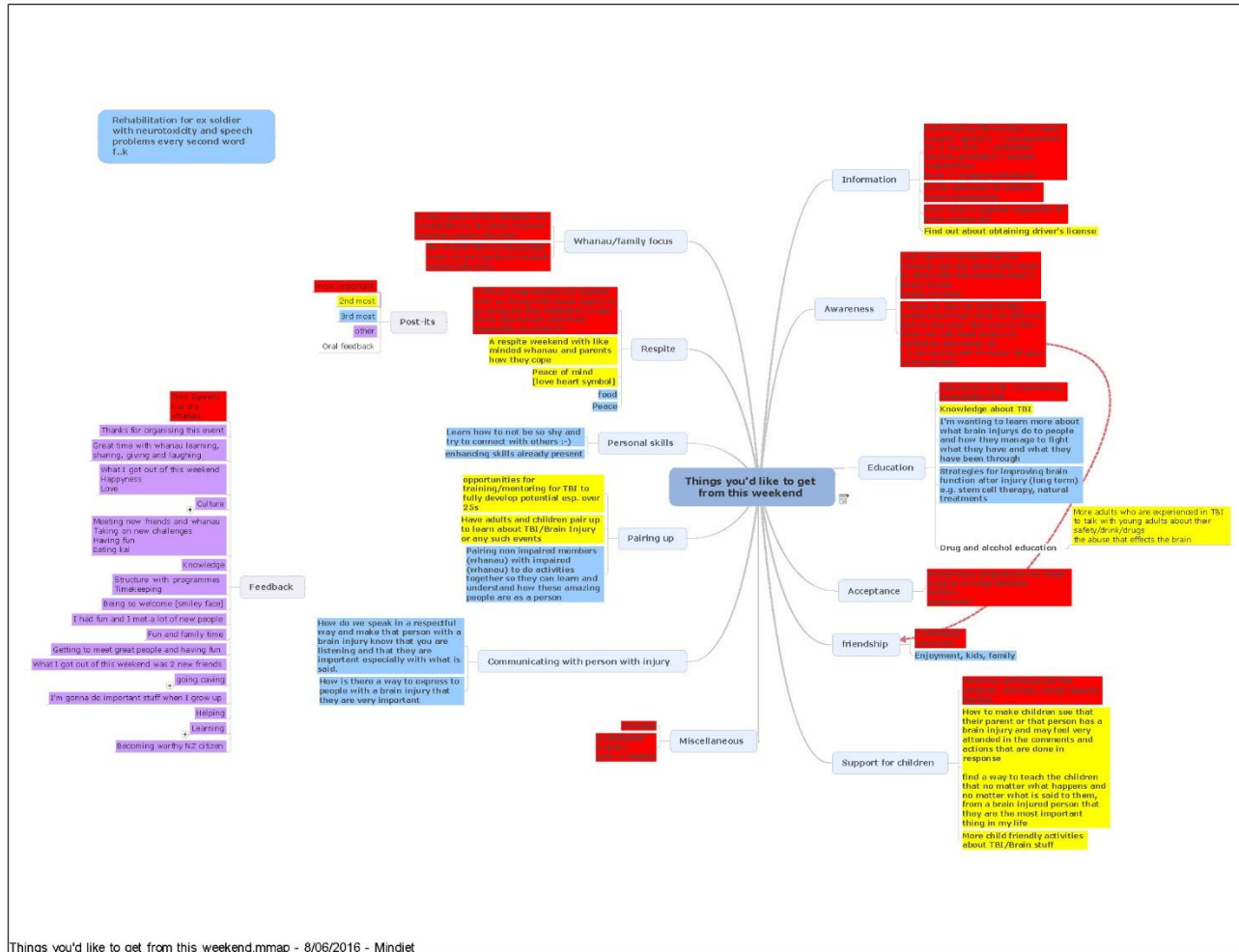
Approved by the Auckland University of Technology Ethics Committee on _____
AUTEC Reference number _____

Note: The Presenter should retain a copy of this form.

Appendix JJ: Evaluation exercise



Appendix KK: Things you'd like to get from this weekend



Things you'd like to get from this weekend.mmap - 8/06/2016 - Mindjet

Appendix LL: BIWAP brochure



HOW WE WORK

We get together on a regular basis for evening meetings and a kai to plan our projects. While our style of work makes us an action group, the people involved also find the group to offer a sense of support and community.

Upcoming projects include:

- Brain injury and parenting
- Healing with horses
- Wānanga 2016

GETTING INVOLVED

If you think you would like to be part of this project and work to improve the lives of whānau, then get in touch and come and join us.

 Find us on Facebook Groups **Brain Injury Whanau Action Project** and ask to join.

Thanks to our supporters:



Educating and strengthening the community to improve the lives of whānau with brain injury.



The Brain Injury Whānau Action Project was formed with local community members in partnership with AUT University and Headway: Brain Injury Association of Auckland.

VISION

To contribute to individuals and whānau of people with brain injury to be better able to live their lives in the ways they have reason to value.

VALUES

- Inclusiveness
- Action
- Valuing health
 - Hinengaro (mind/brain)
 - Tinana (body)
 - Wairua (spirit)
 - Whakawhānaungatanga (connections with people)
 - Whenua (the land)
- Working supportively and collaboratively with other brain injury support organisations
- Upholding the principles of the Treaty of Waitangi



GOALS

- Influencing policy
- Being a voice of whānau
- Spreading education information to whānau
- Increasing understanding and awareness of the effects of brain injury on whānau amongst health professionals and other groups who interact with whānau e.g. GPs, WINZ, ACC and schools.
- Sustainable funding

Our Mission: Educating and strengthening the community to improve the lives of whānau with brain injury.

RECENT PROJECTS:

Weraeroa Wānanga 2015

BIWAP was welcomed to Weraeroa Marae on the 29th – 30th August to run a weekend wānanga. It was attended by 19 families.

In total we had 95 participants, of whom 15 were there because of their own brain injury and 38 of the participants were young people under the age of 18.

Nine speakers shared their knowledge with our whānau. Through this training, families were able to learn together, build connections with other families, and have fun together.

Whatever It Takes training

BIWAP sent 10 whanau participants to this 4-day comprehensive brain injury rehabilitation training course run by Professor Barry Willer and Associate Professor Duncan Babbage.

This was achieved through the sponsorship of a range of rehabilitation and support providers.



MEMORANDUM

TO Elisa Lavelle

SUBJECT Psychological support for research participants

DATE 18th July 2012

Dear Elisa

I would like to confirm that Health, Counselling and Wellbeing are able to offer confidential counselling support for the participants in your AUT research project entitled:

"Invisible Collateral Damage: Developing strategies to better meet the needs of partners and whānau of people with serious brain injury."

The free counselling will be provided by our professional counsellors for a maximum of **three** sessions and must be in relation to issues arising from their participation in your research project.

Please inform your participants:

- They will need to contact our centres at
- **09 921 9992 City Campus** WB 219
- **09 921 9998 North Shore campus** AS104
- **09 921 9303 Manukau Campus** to make an appointment
- They will need to let the receptionist know that they are a research participant
- They will need to provide your contact details to confirm this
- They can find out more information about our counsellors and the option of online counselling on our website:
http://www.aut.ac.nz/students/student_services/health_counselling_and_wellbeing

Yours sincerely

Kevin Baker

Head of Counselling

Health, Counselling and Wellbeing

Appendix NN: AUT counselling support 2015



MEMORANDUM

To Elisa Lavelle Wijohn
CC
FROM Stella McFarlane
SUBJECT AUT Counselling services for research participants
DATE 12.8.2015

Dear Elisa

As manager of AUT Health Counselling and Wellbeing, I would like to confirm that we are able to offer confidential counselling support for the participants in your AUT research project entitled:

"Brain Injury Whānau Action Project Wānanga".

The free counselling, for participants who require it, will be provided by our professional counsellors for a maximum of three sessions and must be in relation to issues arising from their participation in your research project.

Please inform your participants:

- They will need to drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment
- They will need to let the receptionist know that they are a research participant
- They will need to provide your contact details to confirm this
- They can find out more information about our counsellors and counselling on our website http://www.aut.ac.nz/students/student_services/health_counselling_and_wellbeing

Current AUT students also have access to our counsellors and online counselling as part of our normal service delivery.

Yours sincerely

A handwritten signature in black ink, appearing to be 'Stella McFarlane', written over a horizontal line.

Stella McFarlane
Manager
Health, Counselling and Wellbeing

From the desk of Stella McFarlane

Health, Counselling and Wellbeing
Private Bag 92006, Auckland 1010
Main Entrance, 55 Wellesley Street, Auckland.

Tel: 09 921 9999 ext 8193