MAORI
Concepts of
DISABILITY

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Donald Beasley Institute Incorporated

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Nga Mihi
Acknowledgments

This research project was only possible because of the willingness of the participants to share their knowledge, understanding, ideas, and life experiences. As they spoke, the korero was sometimes painful and agonising. At the same time it was inspiring and uplifting. The korero was indeed a taonga.

This project began as the result of a dialogue between the Donald Beasley Institute, a national institute for research on intellectual disabilities, and Ngai Tahu Maori Health Research Unit. The project was initiated by Dr Anne Bray, Director of the Donald Beasley Institute and developed with the assistance of John Broughton and Christine Rimene of Ngai Tahu Maori Health Research Unit.
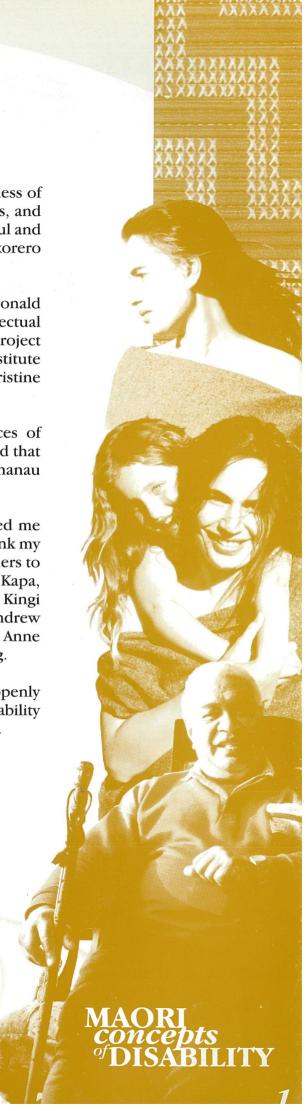
The documentation of the thoughts, feelings and experiences of people is qualitative research; research about people. It is hoped that this research project provides insight and information for both whanau and service providers about Maori people and disability.

Most of all I wish to pay tribute to those people who willingly, openly and honestly shared their whakaaro about disability; what disability means to them and how disability has impacted upon their world.

He mihi aroha ki a koutou katoa.

Jo Kingi

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"There are many kinds of Disability... It all depends on how you look at it!"

Te Korero Tuatahi
Introduction

How disability is perceived and diagnosed, scientifically and socially, shapes the way in which people with disabilities are treated as a group. Some perspectives start with the view that disability is inherent to the individual and that the problems experienced are medical in origin or a result of functional incapacity. Others view disability as a result of an individual's environment and that the disadvantages and limitations people experience can be altered externally (Rioux, 1996).

Each of these perspectives has a contribution to make in terms of understanding disability and ensuring that people with disabilities have the supports and services they need. It is, however, important to recognise that each approach makes fundamentally different assumptions about disability. Current policy as reflected in both professional and governmental spheres can be traced to these various approaches. Classification systems, labels, as well as the everyday use of language, shape and are also shaped by the various ways of understanding disability (Rioux, 1996).

Disability takes many forms, including limitations in mental and physical functioning, speech, vision, hearing and in emotional-wellbeing People with an intellectual disability have a cognitive or learning impairment. This means they master basic and social skills more slowly. While many definitions have emerged, these typically draw upon some combination of standardised psychological test results and measurement of functional capacity (Rioux, 1996). The Ministry of Health considers that a person with a disability will have at least a physical, sensory, psychiatric, intellectual or age-related disability (Ratima, Durie, Allan, Morrison, Gillies, and Waldon, 1995)

RESEARCH

Disability research has in the past reinforced the "medical model" of disability which means seeing the problems that disabled people have as being caused by their individual impairments. This, however, is not in accordance with disabled people's own explanations of their problems of disability which, they argue are caused by society (Oliver, 1997, cited in Barnes & Mercer, 1997). Again, consensus on the definition or nature of disability has yet to be reached. Where traditional definitions are based on the "medical model" the focus has tended to be upon illness and the treatment of illness (Ratima, Durie, Allan, Morrison, Gillies and Waldon, 1995). More recently, and at the instigation of people with disabilities themselves, definitions have been broadened to acknowledge the diverse nature and reality of disability and the importance of the wider environment, and the effect of belonging to an oppressed culture (Ratima, Durie, Allan, Morrison, Gillies and Waldon, 1995).

We are in a political time in which a middle ground has been farrowed for the sprouting of an acceptance of a subjective view or a qualitative methodology in research practice. Marginalised groups, such as Maori and people with

disabilities, have been sowing seeds into this ground and developing, validating and presenting their own research methodologies in contrast with, and complementary to the dominant world view. Central to the debate and discussion about research in a speciality area such as disability and Maori health research is the contention that there is only one "science" and that research methods are similarly universal. Any attempt to separate disability and Maori health research from other types of health research is therefore sometimes seen as subverting science and research for politically correct purposes. However the Maori-centred approach to research does not ignore the range of western research methods, nor the contributions which have derived from the medical and health sciences, but insists on and deliberately places Maori people at the centre of the research activity (Durie, 1995).

Much research into Maori health in the past has failed to demonstrate any benefits to Maori, so scepticism about the efficacy of research by Maori should not be unexpected (Durie, 1995). Too often research on Maori has focused on social pathology characteristics, cultural deprivation or the functional inadequacy of Maori (Bishop, 1994). Histories and lifeways have been recorded and documented by non-Maori researchers, an approach which historically has left a legacy of mistrust amongst Maori (Durie, 1992). Government systems have accepted unquestionably the findings of such (misinterpreted) research and the result of this has indoctrinated generations of New Zealanders to accept a distorted view of Maori society.

Research, both quantitative and qualitative, is the gathering of knowledge, not so much for its own sake, but for its use within a variety of applications. It is about control, resource allocation, information and equity (Te Awekotuku, 1991, cited in Teariki & Spoonley, 1992). Research is about power, and social science research is specifically focused on people, and is particularly pertinent to political management and political planning (Te Awekotuku, 1991, cited in Teariki & Spoonley, 1992). The social sciences have a lot to offer because they are reflexive and critical disciplines which facilitate cross-cultural discourse. They provide techniques for knowing and preserving the past as well as providing an understanding of non-dominant and dominant groups' structures. Consequently the social sciences have enormous potential in matters of policy development (Teariki & Spoonley, 1992).

In Aotearoa me te Waipounamu/New Zealand disability support services are funded under the umbrella of health following the 1993 Health and Disability Act. To access support and services people with disabilities have to be defined under a "medical model" of health. This not only defines people with disabilities as being "ill" but also alienates an indigenous or holistic analysis of disability support and services.

In recent years a number of models for describing Maori health have emerged and some seek to describe the component parts of individual and communal wellbeing while others are analyses of how Maori, as clients, providers and purchasers, can interact with modern health systems (Pomare, Keefe-

Ormsby, Ormsby, Pearce, Reid, Robson and Watene-Haydon, 1995). One of the models to be widely acknowledged is Te Whare Tapa Wha which is also known as the four cornerstones of Maori Health. This model describes four dimensions which contribute to wellbeing: te taha wairua, te taha hinengaro, te taha whanau and te taha tinana. Family, cultural heritage, identity and the physical environment are all described as a set of pre-requisites for health and are primarily external to the individual. Health continues to be defined by Maori with a broad definition and as such, many of the controversial and current measures of health and disability status fail to fully illustrate the "real" picture of Maori health and the utilisation of disability support and services by Maori.

This research project was a first step towards identifying appropriate provision of support and services to Maori whanau who are disabled. The main focus of this project was to establish whether disability, or the concept of disability, is viewed differently by Maori. If Maori do hold a differing view of disability than that of other groups then the question needs to be asked, "What does this differing view mean in terms of already established services for disabled Maori and for the future provision of disability services for Maori, health providers and clients alike?"

This research is an analysis and interpretation of the themes that have emerged from fifteen transcripts of korero with iwi Maori about their concept of disability. The research outcome has been the revelation of "a" Maori world view of disability. This cannot be regarded as "the" world Maori view of disability, if in fact such a view exists.

Te Tikanga
The Method

WHAT WERE THE AIMS OF THE RESEARCH?

To explore a Maori world view of disability.

To identify appropriate provision of support and services to Maori with disabilities and their whanau.

WHO WERE THE PEOPLE WHO TOOK PART?

The participants were whanau, friends and community networks. The project was discussed with them and they were invited to take part.

Twenty-three people were initially approached and fifteen were interested in participating in the project.

All but one person lived in and around the Otago region.

The youngest person interviewed was 22 years; the oldest was 65 years old.

There were eight men and seven women in the sample group.

Three of the men and one woman held kaumatua status.

All of the younger participants said they were committed, either through their mahi or their whanau, to working with and for iwi Maori.

HOW WAS THE INFORMATION COLLECTED?

The initial approach was followed up with an information sheet outlining details of the project, informed consent documents and a copy of the questions that would form the basis of the study.

A semi-structured, tape-recorded interview was conducted wherever people felt comfortable to korero. This was either their own home, a coffee bar or their work place.

FIVE QUESTIONS WERE ASKED DURING THE INTERVIEWS.

What does disability mean to you? Or what does the word disability mean to you?

Do you know anyone with a disability?

How do you feel about people with disabilities?

Do you think a Maori view of disability is different than a Pakeha view?

Do you think that whanau with disabilities needs are being met?

If you had an endless resource what would you change for whanau with disabilities?

HOW WAS THE INFORMATION ANALYSED?

The tape recorded interviews were transcribed. All participants then received the transcripts of their korero and were asked to correct, comment, add, remove or change any aspect of their korero.

The transcripts were then analysed for common themes.

A draft report was distributed to all participants seeking their comment. After feedback, consultation with other researchers, and conference presentations, this report was prepared.

THEMES

Many themes emerged from the participants' korero. Because qualitative data is dynamic and fluid it was difficult to "box" the korero, however for the purpose of this report the subheadings are as follows:

The Health Care System and Maori as Service Providers

Socio-Economic Influences, Alcohol, Drugs and Tobacco

The Impact of History and The Treaty of Waitangi

Traditional Food and Resources

Te Reo Maori and Maori Identity, Iwi World Views

The Differences Between Maori and Pakeha perceptions of Disability

Te Korero
Findings and Discussion

THE MEANING OF DISABILITY

The question, "What does disability mean to you?" or "What does the word or the concept of disability mean to you?" was generally answered from a "social model" perspective (disability as the result of disabling environments).

Rangatahi:

It's a disability to have your land taken off you, it's a disability to have your family dissolved and shifted into an urban environment, where you've never been before. It's a disability to be told that you can no longer grow your own food so you have to get a job in a system that has been set up by white people for white people to try and survive. We're a group of people who are brown living in a white system set up by white people, that is a disadvantage and that doesn't make it easy.

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Disability is not giving kids the right support ... their disability is that they don't know who they are in a sense that they don't know how to set goals for themselves.

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Not having the skills to be able to go forward and apply them and to take control of what's actually happening - your destiny. I mean that's sad and that's not knowing any better. For me it's a disability.

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I probably think people who are struggling and it's not their fault they're struggling. Just with life. Like being old, it's a disability.

Kaumatua:

Maoris are being brainwashed into doing things the Pakeha way - that's disability - it's got to be done the Pakeha way - brainwashed.

Our biggest disabler with the politicians is there is greediness, selfishness and they want to make their palace and they put a mana on certain things. The mana is for themselves not for you.

When participants were asked if any of their whanau had needs due to disabilities and were their needs being met, the people generally answered this question from a "medical model" view. This medical model view is typically a non-Maori concept of disability and although Maori use non-Maori definitions to express their concept it may not necessarily be their concept or understanding of disability. Two people demonstrated in their korero how non-Maori definitions of disability are used to describe their tamariki.

They call those kids, hyperactive kids now, calling them disability ... you've got to give him a pill because the big Pakeha doctors are saying let's analyse these kids because they are not working well in their homes, they must have a disability.

~ ~ ~ ~ ~

I suppose my son being deaf in his left ear that's considered a disability. People label him as disabled but to me it's not. I've got a friend who is slightly retarded and that's considered to be a disability as well.

THE HEALTH CARE SYSTEM AND MAORI AS SERVICE PROVIDERS

Most people were mistrustful and cynical of the recent health reforms and the state of the current health system. People were generally despondent about accessing health services and felt that a huge effort was required by individuals within the whanau if health and disability needs were to be met by the health system. Some people felt that accessing services equated with extra time, travel, lengthy appointments, money, parking tickets and generally a day lost to bureaucracy. One person believed that the government and its health and disability systems benefited from the assumed function and role of the whanau.

In a user pays society - what happens when the government says all right we don't want any more of this Maori stuff. Our structures - whanau, hapu and iwi - actually suits government policy because the more people that pick up the mahi, the less money the government pays and any shit going down - it goes back to the whanau and it suits the whole privatisation movement.

One person believed that to make an effort to access the health system for disabled whanau was of benefit to the whanau. This removed the burden of care away from the whanau especially if the family member had high needs. He believed that:

Another sad fact of what's happening to Maori - especially grass roots Maori is they don't like to burden their whanau with whatever problems they may have.

Another person also felt that the role of the whanau caring for elderly or disabled members of the family was a Romantic notion that needed to be realistically viewed. When asked if she thought a client would be happier or more appropriately attended to by his whanau in the North Island, as opposed to the residential home in Dunedin, her reply was:

I don't know. I mean there's two things that come up in that. Whether they (the whanau) want to do it (caregiving) and would they be capable of doing it, which may not be possible.

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The general critique by all who were interviewed was directed at Crown health and social systems and structures. However, one person also criticised those, both Maori and non-Maori, who hold Romantic views of Te Ao Maori or the Maori world.

Whanaungatanga, aroha, manaakitanga - all the words that we see splattered on posters in this contemporary world that we live in - it is romantic. Our own people are romanticising the Maori world. The disabilities korero that I have heard from whanau was if anyone is disabled in Maori society they were dead. That way it costs society nothing. Brutal and all - whatever English word that you want to define what it meant.

Whanau with disabilities, however disability was defined, were considered by most of the people as the same as everyone else. Whanau members were accorded the same respect on the basis that they were whanau and that they whakapapa. Some participants referred to their understandings of issues surrounding disability from accounts from whanau and the korero from tupuna. This directed the korero about how they viewed whanau with disabilities. One kaumatua had this to say:

Those who were mentally disabled, physically disabled and mongoloids - nobody seemed to treat them differently to the rest. They were just accepted as whanau - Oh that was back in the 40's.

Ratima et al. (1995) outline how services can be more appropriate and best meet the needs of Maori. Generally these frameworks are in response to already established western bio-medical systems. As with the first question in this project, questions were answered by the people either from a "social model" of disability or a "medical model" of disability. How to best meet the needs of whanau in terms of health systems was explained by this person.

A lot of the care that I received and other Maori people in that unit - it's not specific for Maori and I think that mistakes were made because of that ... my second time in hospital I greeted somebody Kia Ora and that was the first time I was offered Maori Mental Health Service Advocacy.

This person felt that as Maori we do go "the extra mile" when it comes to whanaungatanga and manaaki. She felt that whanau structure supplements or subsidises a health system that should be providing a total and whole service to every citizen in Aotearoa me Te Waipounamu/New Zealand.

Like we (Maori) provide the best, I have seen it. You drop everything and you go down to the Intensive Care Unit and you do your bit, you know. It may not be helping the person, but it's helping the whanau who are ultimately going to provide the majority of the care. I mean following that along we should actually have the highest health. Again it's the holistic view.

Many participants had a political analysis and view that not only highlighted how they see inequity within the health systems and service delivery but how they would restructure and create infrastructures in current systems. These particular people found token gestures, and "alternative options" or "cultural perspective" appendages to mainstream to be offensive and inappropriate. Equity and partnership between the Crown and iwi at the highest levels of policy and decision making were seen as the only solution for progressive and positive national development.

It's having a Maori service available, not just for Maori, but full stop. In that it recognises what is patently obvious, that it is of value and that the western system doesn't have all the answers.

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I think about establishing a Maori based disability thing that's community based - it's needed.

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There is still frustrations in training - some people just don't want to learn Maori ways.

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I think if they had a system set up to deal with Maori people with disabilities I think that you would find that a lot of people would use it.

SOCIO-ECONOMIC INFLUENCES, ALCOHOL, DRUGS AND TOBACCO

Poverty was also cited and described by most of the participants as being a disabler to Tangata Whenua. Although Maori collectively are over-represented in lower socio-economic groupings, there is nonetheless considerable variation between individuals (Durie, 1995a). The Maori/ non-Maori gap is wide but there is also an emerging gap between Maori who are employed and those who are unemployed. Health status and housing standards are likely to be reflected in that differential (Durie, 1995a). One third of the people interviewed mentioned the lack of money or "pingas" as having a disabling effect on them personally and on Maori generally. This person demonstrated through her korero that she believed poverty to be disabling to Maori.

I heard the poverty line is $ 20,000 a year - what does it mean when you are on $12,000 or $8,000 and be disabled - and be Maori. Anything that puts any person at some sort of deficit in society is a disability, and that could be financial, mostly financial really because the (low) income base immediately puts a person at a disadvantage which can be debilitating for their own progress, like educational opportunities, access to health, all those things.

Poverty was seen by many people as being more disabling than any physical, psychiatric or sensory impairment. Impairment was actually seen by one person as perhaps being a financial asset in certain situations.

Look at Steady Eddie, brilliant, he used it (his disability) as a tool. Now I couldn't go and do what he does. He's probably a millionaire that guy and I wouldn't make jackshit out of it would I? - Who's disabled?

This person did not consider Steady Eddie, a popular comedian who has cerebral palsy, to be disabled because of his ability to make money and therefore not be disabled by poverty.

Although conceptions varied everybody interviewed was aware of impairment on a physical, psychiatric and sensory level. However, they did not equate, or necessarily connect this with their view of the term "disability", or being "disabled". How the term disability was defined by each individual determined their responses to the semi-structured questions that followed. The word "disability" was described, explained and understood by individuals in a variety of ways. Alcohol, drug and tobacco use by Tangata Whenua were issues that were perceived as disabilities to Tangata Whenua.

Alcohol was first introduced in New Zealand in the late 1700's after Cook's initial landing. The name for alcohol - waipiro/stinking water -may indicate that when Maori were first exposed to alcohol they were repelled by it (Durie, 1998). However by the middle of the nineteenth century Maori were eager consumers of alcohol and the government of the time was concerned about drinking problems among Maori (Durie, 1998).

When alcohol, drugs or tobacco was viewed as the disabler then awareness and education about the effects on whanau and the appropriate support or intervention were perceived as being the disability support services required.

I suppose I am angry at alcohol - if there wasn't any alcohol in the world there would be a lot of happier people, alcohol is a disabler and people who suffer from alcoholism are disabled.

The suggested support service required for this disability was then described by this person as:

Well it's just so that we make people aware that we think it is uncool to be drunk.

Dispossession of land and language as early as 1860 in Te Waipounamu had a devastating effect on Kaitahu (Kapa, A., personal communication, May, 1999). Separation from land resulted in the fragmentation and urbanisation of iwi, hapu and individuals within the whanau. Many participants believed this process contributed directly to the increase in self-destructive behaviour and the high use of cannabis, alcohol and tobacco amongst Maori - both rangatahi and adults alike. One participant had this to say:

Alcohol and drug offending - it's pretty high up there. Just look at the statistics they are pretty high. Let's not destroy our whakapapa but we'll go and sit outside our marae and fag up, drink up and smoke drugs until they are coming out our ears.

His challenge to Maori working with whanau disabled by substance and alcohol abuse was:

Fire all the guys who are only words. Employ people that are prepared to back their mouth up and that are prepared to walk the walk and talk the talk in whatever field that they may be in - whether that's physical disabilities or psychiatric disabilities or alcohol and drug induced disabilities which quite frankly is one of our main ones.

Similarly, if disability was defined as a lack of parenting skills or behavioural issues with rangatahi then the perceived disability support service required was the awhi and understanding of parents by other parents in similar situations. Disability was described by several people as being deficient in the ability to function adequately as a parent and with the whanau. The majority of the people interviewed were sole parents of two or more children. One wahine had this to say:

Maori women talk their problems through with other Maori women and I've always had that support - if your kids are getting you down, you can go - ring up - this boy's getting me down and he's out of your face, he's had a day away, you've had a day away, you come back, you talk things through and you get on with life and he gets on with his things. That's support. I think support, honesty, whanau support, kid support, even if you're going to the pool and you've got another parent sitting there next to you, you can talk to, that's all you need eh?

THE IMPACT OF HISTORY AND THE TREATY OF WAITANGI

The history of colonisation and its wide-reaching impact on Tangata Whenua provides an important context within which to view disability and the concept of disability in whanau. Issues that were identified by the people as disabling could be attributed to the residual and current effects of colonisation. Colonisation literally means that a group of people has been passed through the colon of that of another people and deemed "waste" at the conclusion of the process (Ramsden, I., personal communication, November, 1998). Participants had varying views on the impact of colonisation and social change on iwi Maori and some people described how they saw this as having a disabling effect on Maori. In my initial analysis, colonisation was considered to be just one of the themes emerging from the data. On reflection and after further analysis I have come to regard colonisation, as stated by most of the participants, as the primary disability. All issues outlined by the participants could be directly attributed to and

considered as residual to the disabling effect of colonisation on iwi Maori. Their korero needs to be located within the historical context of the colonisation of Aotearoa me Te Waipounamu/New Zealand.

During the nineteenth century there was a dramatic depopulation and near genocide of iwi Maori (Durie, 1998, p.28). Tangata Whenua were forced to change from a tribal lifestyle to a new reality that was dictated by the social and political inconsistencies of Victorian Britain (Durie, 1998). Every person interviewed referred to or expressed their whakaaro on colonisation and the effect that it has had and currently has on the well-being and world view of iwi Maori.

One participant expressed how she felt about the social and political impact of the British culture:

The British ideal came and defined us and said, primitive, natives - let's civilise these people. So civilisation meant, kill our spirit. Drain it or crush it even. In fact don't have one (a spirit). I have to ask myself often, what the hell is civilisation. When you see our people that are hungry. When you see our people that are surviving on and dependent on the State.

In the first three decades of the nineteenth century, traders, whalers, missionaries and sailors introduced Tangata Whenua to the so-called advantages of a Western civilisation (Durie, 1998). Many participants related the current health, economic and social status of iwi to these imposed cultural practices. They related the alienating effect of colonisation directly to the use and consumption of drugs, alcohol, tobacco and gambling by Maori.

It is Maori who are largely affected by gambling because it's another addiction. It's like alcohol, it's like drugs - Maori - I mean there's no other way around it, Maori were dicked over basically and we are a recovering population and we are not recovering as fast as we should be. When the colonisers first came here, they offered guns tobacco and alcohol. Those are not good things to give people. It comes down to the same thing, ethics versus money and people want money, so Maori, they get dicked over - they lose their land ... Our land was paid for in vices - here we'll give you a whole bunch of vices which you can go off and annihilate your race with. I mean wasn't that the idea anyway, the Maori won't be here by 1850 if we're lucky, so then we can just take the whole sodding country. I think we're (Maori) still being affected by that.

This person also directly attributes high disproportionate prison statistics, specific to iwi, to colonisation.

I mean when you think we're only 13% of the population and 80% of the prison population, that definitely is a result of how we've been treated. Look at any country in the world that's been colonised, it has put us in a position where we're bad or we're worse.

Most people saw that the alienating and destructive effects of colonisation directly affected not only the identity and self esteem of Tangata Whenua but also the consumption and use of drugs, alcohol and tobacco by them. Some participants regarded these vices as forced upon them as a method of annihilating iwi Maori and controlling their greatest resource, land.

In 1840 Rangatira were encouraged to sign the Treaty of Waitangi on behalf of iwi and hapu and were persuaded and convinced that their futures were best placed under British protection because Tangata Whenua social systems had become irreparably eroded (Durie, 1998). Whanau or family structures were rapidly dismantled by the deliberate urbanisation of Tangata Whenua in the 50's and 60's. Many children of inter-relationships between Maori and Pakeha were adopted or fostered into predominantly non-Maori families, many of whom would today be considered dysfunctional. This process became, consciously or not, a vehicle for the Government's agenda of assimilation or the absorption of Maori into the dominant culture. Loss of identity, whakapapa and whanau links resulted in Tangata Whenua being brought up as Pakeha in a Pakeha compliant society which has had devastating results.

Tangata Whenua were destined either for extinction or to its social equivalent, assimilation (Durie, 1998). One woman explains her existence as a wahine being raised in such a family:

Colonisation said that we had to stick in a system that we didn't know nothing about and that we had to learn quickly and we didn't learn - because we had our own culture, our own beliefs and we only learnt half heartedly. That's how I feel about that. I mean look at me, I was brought up with a Pakeha family. I love my mother very much, I hate my stepfather very much. I don't know my Maori father at all. I only know my real Pakeha mother through telephone calls in Australia and I'm still for Maori people even though I have never been brought up around Maori people because it's who I am?

Another participant stated that:

I can't speak Maori to Pakeha people. They're not listening, the ears are off. That's a disability because they don't understand you.

Many participants saw the Government and layers of oppressiveness in terms of social policy as a disability to Tangata Whenua. Colonisation, assimilation and governmental policies have been suppressing Maori people for over 150 years. To remove a people's resource base over a period of a century and a half, to deny them access to the skills necessary in the post industrial society in which we all now live, and then to expect them to solve problems which have become systemic is to further past injustices (Smith, 1997). Throughout most of the interviews there were elements of mistrust and cynicism about any Crown or State intervention with Maori and a belief that the Treaty of Waitangi was not being honoured. Two participants had this to say:

Yeah - the Treaty of Waitangi happened, yeah good one Waitangi, it happened. Where does that leave Maori? The only walking bridge we've got in our own country is that document.

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If we are looking at the Treaty and talking Tino Rangatiratanga then there should be two houses (parliaments) that is the reason for the Kingitanga movement coming into being - a parallel structure alongside Pakeha.

TRADITIONAL FOOD AND RESOURCES

One kaumatua talked about diabetes being his disability. When I asked for his thoughts on why he thought Maori suffered the condition of diabetes he talked about how the kai had changed in his lifetime.

We used to go hunting and get our food - today it comes in tins and is wrapped up. We are not allowed to go and shoot this and shoot that. Even if you go and get kai moana they want to know what you got. They jumped on the paua, now mussels - they still don't worry about kinas because not very many Pakehas eat kinas or they can't - no they are not worried about kinas and I say bloody good job.

In a relatively short time social and environmental changes have occurred exhaustively and rapidly.

I can remember all the bush - used to be all beautiful bush and they (settlers, farmers, Department of Conservation) come along and burn it all to make farms - now you want to go chop a tree down they go bloody crook after what they done.

This feeling of alienation, powerlessness and the witnessing of contradictory behaviours of the dominant culture has fuelled an anger, resentment and frustration amongst differing age groups of iwi Maori.

Two participants spoke at length about the disabling effect of not being able to gather kai as we used to. They complained about the effect of pollution and enforced Department of Conservation (DOC) laws that have hindered and made inaccessible the appropriate kai for health and wellness. Different strategies and a sense of outwitting the powers that be were a common theme and a perceived solution to disabling environments. One person had this to say:

Yeah the rules change- that's one of my disabilities so I've got to hunt at night instead of the day - while they are all in bed.

Early nineteenth century Tangata Whenua were biologically and socially ill-prepared for the new morality that the colonialists imposed. If death did not occur through epidemics or muskets, then it was hastened by lifestyles that disturbed the balance between tapu and noa and links between Tangata Whenua and their lands (Durie, 1998). Less than a hundred years later Tangata Whenua are still being affected physically, emotionally and spiritually by this separation.

And if it's anything that's good, you're not allowed it, if it's got value on it. I'm not even allowed to go on to land that is mine and hunt an animal that is a noxious animal because the Department of Conservation came in on it. I'm not allowed to go out there and kill those deer. And they (the settlers) brought it in as a noxious animal. One minute I'm a deer culler, the next minute I'm a poacher. What's going on?

Alienation from the moana and the gathering of kai moana is also seen by some people as having a disabling effect on Maori.

Well I was disabled, they (police) disabled me. They disarmed me. I've had my guns taken off me and they also took my spear gun, so I couldn't shoot the fish. So what happens (laugh) I can easy go and get a net and catch ten times more fish than a spear gun will ever get.

The history of Maori and Pakeha relations since the signing of the Treaty of Waitangi has not been one of partnership, protection and participation of two peoples. It has been the development of a nation by the domination of Pakeha and the marginalisation of Maori (Bishop, 1994). The myth of our being "one people" with equal opportunities has been created to maintain the locus of power with non-Maori (Bishop, 1994).

TE REO MAORI and MAORI IDENTITY

General policies of assimilation and the promotion of English as the only language of progress and advancement have been blamed for the decline in the use of te reo Maori. Making it illegal to korero te reo Maori was one method used by the Crown for the assimilation of Maori and the maintenance of the "one people" myth. After 1900, legislation was introduced, which remained in force and forbade the teaching of te reo Maori in primary schools. This remained in force until 1967 with widespread corporal punishment. Its use provided a catalyst in the erosion , of not only the mana of Maori, but the identity of Maori (Durie, 1998). Vivid memories of this era were explained by one person:

I used to go to school - I used to talk Maori - I've lost all that - I should sue them (government) for that you know. You used to get fined if you talked Maori at school or you'd go and write one hundred times I must not talk Maori at school.

Recognition of Maori language as an official language will not by itself guarantee its survival and continuing use. It is the actual use of te reo Maori by Tangata Whenua and across all domains that is more important.

Te Kohanga Reo programs aim to provide a vehicle for the promotion of Maori language and to stimulate whanau centres and maintain a totally kaupapa Tangata Whenua environment by using immersion modes of learning. Objections to the establishment of Te Kohanga Reo have not been infrequent and are based on the assumptions that a total immersion environment would be detrimental to children when they moved on to English-speaking schools. One person had this to say:

Te Kohanga Reo wasn't supposed to survive. I know that, I've worked in government parties and so I know how that system worked.

Te Kohanga Reo was considered by one person to be a service that provides for a wide range of needs of Tangata Whenua.

Kohanga - it's totally accepting - it walks a fine line between what the government says has to be provided and what it will. So Maori whanau come in and they've got needs, with a disabled tamariki they (kohanga) just go yeah, stuff the roll, stuff the funding we'll take you in. They never say no to anybody, which is why they're always crowded and overworked. But in doing so they just make it (disability) a part of life. And when they do that they teach the children. But there is an accepting attitude in Kohanga Reo that just goes for anything. Any level of disability, whether it's financial, social or physical.

Most people spoke at length about the impact they believed that the process of colonisation has had on them, in particular the effect on identity and self worth. Most of the participants made reference to who they are as Tangata Whenua. This demonstrated the wide and varying realities amongst them and who they stated and acknowledge themselves to be as Tangata Whenua. Having little or no understanding or knowledge about who one is as Tangata Whenua and no turangawaewae were expressed as having a disabling effect on iwi Maori.

We have a tendency to think of people like in wheelchairs but I think from my understanding, and no doubt others, that disabilities is that people have lost that knowledge of whakapapa and how they are related to whanau, hapu, iwi.

During the Depression years, and post World War II, the Maori world was transformed into an urban society (Durie, 1998). The urbanisation of Maori was cited as having a disabling effect on our society by the people interviewed. One person attributed the lack of support amongst whanau to this rapid process of urbanisation.

There is no awhi - there is no manaaki and that's the problem with urbanisation.

The marae in the broad sense was mentioned by most people as being either their place of comfort or conflict. The diverse lifestyle realities and age ranges demonstrated how marae life was perceived and woven into the daily realities of the people interviewed.

One kaumatua expressed how lack of knowledge of oneself was a disability to Tangata Whenua.

I always go back to our maraes, to our meeting houses, to our meeting house because we've talked about people who have lost their way because they lack knowledge or understanding of themselves as Maoris and then the marae and meeting house is that thing that will help them to overcome those disadvantages that they've had. Because as we know the meeting house is a repository of everything that we as Maori identify with. It's that.

A younger interviewee explained that his identity of self as iwi Maori came through his whakapapa.

My grandfather was Maori, his mother was Maori, her parents were Maori. That makes me Maori. It makes me Maori whether I believe in things Maori or not. No one can take that away from me. No one will ever take that away from me, whether I believe in it or not. I don't have to wear a bone carving around my neck or have a moko on my face.

Some people who were adopted into non-Maori families experienced another reality and had a different perception again of what "disability" in terms of identity meant to them. Their understandings and perceptions of disability and disabling environments were a reflection of the two worlds within which they had to exist.

I say it's all right to be Maori. I go on the marae. I wouldn't say I went to the marae yesterday to my (non-Maori) Mum and Dad. They wouldn't know where it was, they're not interested. They don't care.

This person marvelled at how Tangata Whenua, although fragmented, urbanised and robbed of an economic, social and political resource base, could still foster and transmit a vibe or feeling of collectiveness and belonging. He passionately asked:

Why is it when you sit with a lot of Maori people you feel different? What is the power that makes you feel accepted? I can't answer that but it's there.

Prior to the Maori Affairs Amendment Act 1974, a Maori was defined as a person who was half or more Maori. Under this Act a Maori was defined as a person descended from a Maori and who elected to be known as Maori, cultural identity assuming a greater importance than biological make-up (Durie, 1994). The 1991 census determined both the numbers of people of Maori descent as well as those who identified as Maori. There was a

discrepency of some 76,000 and some doubt remains as to whether there are 511,278 (Maori descent) or 434837 (Maori ethnic identity) Maori in New Zealand (Durie, 1994). This change to the definition of what a Maori was/is affected the way statistics from earlier definitions could be used for statistical purposes. This change has also left a legacy of uncertainty about identity for many Maori. The Crown redefined and renamed Maori.

I was brought up in an era where I was illegitimate and not only that but Maori also, a half breed.

Throughout this person's korero he described with mamae the reality of this legacy. As society changes so do the labels and titles that are attached to marginalised groups of people. Such unsureness of self can potentially lead to destructive and disabling behaviours. This person however has reconciled who he is today and proudly acknowledges both his whakapapa and geneology.

To be truly whole you have to recognise who you are in all your being - if you have Pakeha blood you recognise that because you cannot be tuturu Maori unless you recognise your whakapapa. Whakapapa is not just Maori Whakapapa.

Perhaps the following person's korero is an example of the identity dilemma that still remains within iwi Maori.

I always wonder whether I would access a parallel or a Maori option in disability care and then I thought I wonder how many other people want to get more involved but are just too scared to because of the way that they look - not quite Maori enough.

Tangata Whenua are diverse in biological, social and cultural terms and more research is needed to unbundle the multiple associations and affiliations within which their realities are lived.

The common feeling amongst most who were interviewed was that disability comes in a variety of forms and that as Tangata Whenua our response to disability, however it was defined, was different. Tangata Whenua live in diverse realities so assumptions about lifestyle or world view cannot be made in respect of persons who opt for a Maori identity (Durie, 1995a). As each individual has their own lived experience and reality so too does each iwi. Each iwi maintains its own traditions concerning the beginnings of the world and maintains traditions pertaining to its own historical, environmental, political and social reality (Royal, 1992). It is understandable then that the people interviewed offered korero that was about certain issues that are reflective of their physical situations, their environment and their society. Woven throughout korero from people of Waikato was a definite sense of anger and mamae that perhaps mirrors the history and consequential effects of raupatu.

Participants from Taranaki spoke of a sense of loss and grievance in respect to

the history surrounding Parihaka and tupuna who were taken prisoners to Te Wai Pounamu. One person from Taranaki had this to say:

The hardships, like my great great grandfather - he was one that was imprisoned because they felt so strongly about the land - he was brought down from Taranaki to Dunedin - they did a lot of work out on the Peninsula.

Contemporary Maori realities and understandings of issues are very diverse and undefinable in many respects. This kaumatua attributed these differences to different iwi world views.

Each iwi have their own ways you know. Ngati Porou will sing about it as well and they'll laugh and everything - Te Arawa will do it another way. We're different people - we are not the same people - Maori is only a name, we come from all different parts.

Most people interviewed who whakapapa Ngai Tahu had a sense of control and autonomy in their korero. They had a measure of confidence in the iwi's ability to carve and develop a future with resources from impending claims settlement for their future and that of mokopuna.

One participant stated that she was both depressed and excited about being Maori.

I am depressed because I am Maori and excited because I am Maori. Depressed because .... we represent, statistically, inappropriate levels in all needs, be that health or education, or economic - all impacting on each other. Excited because I am able to work and they need more Maori people and Maori resources.

The different histories pertaining to each person created a wealth of insightful and precious korero and may have implications for how future research can perhaps be conducted within iwi by iwi.

One kaumatua believed that:

We are disabled in the Pakeha world - in our own world we're not.

MAORI PERCEPTIONS OF THE DIFFERENCE BETWEEN TANGATA WHENUA AND TAUIWI CONCEPT OF DISABILITY

Throughout the project differences in definition or perception of what disability is were demonstrated. Health and disability services are predominantly structured on western, non-Maori foundations so participants were specifically asked whether they thought a Tangata Whenua view of disability was different from the already constructed view. In the past support services have been based upon disability categories that are largely

medical in origin (Ratima, Durie, Allan, Morrison, Gillies and Waldon, 1995). Much of the interpretation of this difference has already preceded this chapter but many of the people's comments highlighted just how different Tangata Whenua and Tauiwi world views actually are.

Well I think the Maori health view is far more holistic than the pakeha health view - it takes into account the whole being and I believe the pakeha health view separates it - fixes one thing.

~~~~~

Well I know we are different because we accept people as they are, you know.

~~~~~

I think Maori - Maori are more spiritual aren't they?

~~~~~

We don't have a problem with homosexual people in the church, or even as ministers because they are whanau. Pakeha see homosexuality as a disability.

~~~~~

There were no such things as manic - depressiveness or schizophrenic in Maoridom...... You know the problem is that in mental hospitals they fill you up with all kinds of drugs and nobody will talk to you - a problem that not only Maori people have, but everybody has.

The majority of people believed that Tangata Whenua view people with disabilities differently from Tauiwi. However two people believed that the difference was not attributed to ethnicity or a difference between cultures and went on to state that:

I don't think it's a Maori/Pakeha issue, I think it's a person issue...Down syndrome in the Maori is the same as Down syndrome in the pakeha fellow. Down syndrome is Down syndrome.

Another person stated that:

Disability to me means something like intellectual disability or physical disability as opposed to anything else.

Amongst the varying concepts of disability some participants had this to say about people with intellectual and psychiatric disabilities that they worked with, lived with or knew as acquaintances or whanau:

Well I've pulled them into my house. I've had them around me and it actually gives me energy.

I guess I felt what I'd feel for anybody else. Sometimes they made me really angry - it used to really wind me up having to clean up after them......I believe they were perfectly capable of cleaning up after themselves.

~~~~~

Usually they annoy you. You really don't want them around, and it's a bummer because then they end up hanging out with people who aren't good for them.

~~~~~

They're gifted, they are not impeded, they are not handicapped, but they're gifted people and they must be looked after.

THE RESEARCH JOURNEY

Access to te Ao Maori and Maori community networks for the purpose of research comes with a set of obligations and responsibilities. There are expectations that research work with and for Maori will benefit whanau and contribute to the public good. Being a Maori researcher may rule out some variables that non-Maori researchers have to contend with but may also add others for researchers who have a whakapapa.

At the outset of this project I felt concerned interviewing whanau because I thought that a random sample would be more valid in terms of research. However the term whakapapa is one that speaks of genealogy, and more specifically about how closely one is related to the interviewee. According to Barnes and Stanley (1994), the closer the researcher is related to the person being interviewed the higher the quality of information from that person will be. The participants that were willing to be interviewed did so, I believe, because of who they understood me to be in relationship to themselves.

Most participants have stated that this particular research process has been a positive experience. Participants were able to articulate their thoughts and feelings about a multitude of issues that related to themselves personally and as members of the wider community. They expressed that they felt that their korero was valued and validated particularly by viewing, critiquing and holding their data and transcripts. However this process was also somewhat burdensome for the participants in terms of having to read many pages of text. Although some felt whakama about the way they expressed themselves orally, their grammar and the type of language that they used, most were encouraged by their ability to express their whakaaro. After the draft report was disseminated participants noted that their individual stories and thoughts were similar to that of others who participated. This made some people feel that they were not isolated in their thoughts, especially when the discussion involved Maori identity.

Te Ao Maori and a Maori world view was informed and validated by a theoretical approach that was set primarily in a qualitative perspective. In terms of rigour, reliability and validity this project has had to meet two different sets of expectations and several sets of analyses. One of the limiting characteristics of this type of research is the dual accountability that rests on the researcher as a result of both mainstream, and to some extent Maori, control (Cunningham, 1998). However, the potential of both world-views is to add insight to the lives of Maori people and the lives of other marginalised groups who are engaged in similar struggles and issues.

My views, beliefs, attitudes and political heritage are forged from the union of two distinctive yet similar cultures - Maori and Pakeha. To redefine or re-conceptualise the analysis of research data and the process of obtaining the data, we must highlight the "baggage" that the researcher brings to the research enterprise (Scheurich, 1995). The meaning of communication is inescapably situated and contextual, so we need to know who the researcher is. The ongoing process of colonisation and the consequences of this process have personally affected and coloured my views and responses to life and have invariably had an influence throughout my research practice, process and writing.

It is important to locate and unify the differences, conflicts and contradictions within ourselves. As a Maori and a Pakeha I choose to locate myself in two worlds. The korero surrounding disability links these two worlds because I have found that some Maori have a concept of disability that is defined by colonisation. Is this concept of disability unique to Maori or do other indigenous and colonised peoples share this view? Invariably more questions are often raised than answered in projects such as this, which perhaps highlights the continued need for future research.

CONCLUSION

Distinctions can be drawn between Maori health and disability services, and mainstream health and disability services that include a Maori perspective. Mainstream services have been encouraged to provide services which are likely to achieve good outcomes for Maori. Issues surounding power, control and equity need to be addressed to help develop services that reflect an appropriate relationship with Maori people (Durie, 1996b). As demonstrated throughout this research, disability is a symptom of wider and broader concepts within Maori society. Within the context of this project the common themes that have emerged concerning Maori need to be taken into account if appropriate services are going to be provided. Tangata Whenua concepts of disability are expressed in varying and diverse ways and they invariably issue a challenge to the health and disability sector and to our society generally. The loss of land, government policies, loss of knowledge of whakapapa and identity, and the on-going effects and process of colonisation and assimilation have all been identified by fifteen Maori participants as having a disabling effect on them as Tangata Whenua.

Although many of these issues are seemingly negative most of the respondents were not despondent about their personal lives or their future. There was a genuine sense of excitement amongst all who participated and an optimism about the future of iwi Maori. During the interviews participants shared how they were responding to a resurgence in taha Maori and reclaiming their tikanga and mana. They expressed and celebrated the unique ways that Maori, as a people, are beginning to achieve autonomy in most sectors of our society. However, continued education, training and the sharing and dissemination of information at all levels to empower whanau, hapu and iwi were perceived as being core solutions to the many issues that we face as iwi Maori.

Although the voices of these fifteen participants cannot conclude or answer the many questions that have been posed throughout this project, it is hoped that insight may be gleaned and that the actions of those in disability services and the consumers of services may be empowered by this korero. Again some of the themes could be perceived as being negatives that past research has already highlighted. However, as long as fundamental health and disability services within Aotearoa me te Waipounamu are constructed by the dominant Pakeha culture without equal participation by Tangata whenua, the same issues will continue to be restated through the research process.

Those interviewed have demonstrated that they have an insightful and deep understanding of not only te Ao Maori and te Ao Pakeha but of themselves - however their realities are presented. The benefit of using a qualitative approach in research is that the participants are able to articulate their feelings and concerns and contribute to an understanding around differing concepts of disability. Different histories pertaining to each participant have created a wealth of insightful and precious korero. This not only highlights the differing world view of Tangata Whenua and Tauiwi but also has implications for how future research can be carried out by, for and with Tangata Whenua.

The participants and the researcher for this project are located as indigenous persons in an on-going colonial world. To describe our society as post-colonial implies that colonial institutions of the past have been replaced (Spoonley, P. as cited in Pihama, L.,1996). Is colonisation therefore essential for an indigenous analysis?

Although there are commonalities that unify us with other colonised peoples, we have issues that are specific to Tangata Whenua. Smith, L. (1997) states that:

We cannot begin to describe the dilemma which faces us in our practice without first recognising that we exist in institutions which are founded on the collective denial of our existence as Maori. This not only actively continues to assimilate us, but more importantly it actively competes with us and the world views that we represent.

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Dominant Pakeha/western forms of analysis are maintained in the colonially constructed centre where assertions of kaupapa Tangata Whenua are continually being denied and located as marginal (Pihama, 1996). A Kaupapa Maori Theory provides us with a frame of reference that is premised on an assumption that te reo Maori and tikanga are valid and legitimate and as Tangata Whenua we are able to theorise, understand and represent our world from a place of centrality (Smith, G. as cited in Pihama, 1996). Kaupapa Maori has also been described as a quantum-jump rather than an extension of current western-based research (Cunningham, 1998). It has its own methodologies that may employ a range of contemporary and traditional methods.

FUTURE IMPLICATIONS

The health system and health and disability support services in Aotearoa me Te Waipounamu are generally founded and provided from a biomedical model and western ideology. Maori make up 15.1% of the population in New Zealand (Statistics New Zealand Ltd, 1996) and are subject to the dominant population and its culture that shape and form our society and therefore its health institutions. Likewise people with disabilities are generally defined by the bio-medical model of health.

In New Zealand disability support services are funded under the umbrella of health. To access these services people with disabilities have to be defined under a medical model. Not only does this box and define people with disabilities but it also alienates an indigenous analysis of health care and disability support services and shifts this analysis into the realm of "alternative".

Tangata Whenua needs are not being met if their concepts of disability which are different from that of the dominant culture are not recognised and considered a priority. We must critically look at the on-going effects of colonisation and its effects on the health, economic and social status of Tangata Whenua today. Tangata Whenua must manage their own initiatives and develop their own services so that they have the dignity of choice between mainstream or kaupapa Tangata Whenua services to support persons with disabilities and their whanau.

Glossary

Aotearoa me te Waipounamu	New Zealand
Aroha	love, sympathise, relent, pity
Awhi	embrace, aid, help, cuddle
Hapu	subtribe, pregnant, clan, conceive
Iwi	tribe, bone, people, race, nation, strength
Kaha	strength, persistence
Kai	food, eat, dine, nutrient
Kai moana	sea food
Kanohi	eye, face
Kaumatua	old man, elder, adult, become adult
Kaupapa	strategy, theme, level floor, fleet of ships
Kia ora	hello, thanks, may you have health
Kina	sea egg, erechinus chloroticus
Kingitanga	Maori king movement, Kingship
Kohanga Reo	Maori language nest
Korero	speak, news, narrative, quotation
Mahi	job, activity, undertaking, labour
Mamae	pain, ache, sore, stress, hardship
Mana	integrity, charisma, prestige, formal
Manaaki	support care for, show respect, hospitality, entertain
Marae	central area of village and its buildings
Mokopuna	grandchild
Noa	free from tapu, inexact
Pakeha	Caucasian, European, non-Maori
Paua	abalone, shellfish, (haliotis spp)
Rangatahi	modern youth, new fishing net
Rangatira	chief, landlord, team manager, noble
Raupatu	seize land, confiscate land
Tamariki	children, childish, a minor
Ta Moko	tattoo
Tangata Whenua	local people, aborigine, native
Tapu	sacred, forbidden, confidential, taboo
Taonga	treasure, property, apparatus, accessory
Tauiwi	foreigner, alien, gentile, heathen, infidel
Te Ao Maori	the Maori world
Te Reo Maori	the Maori language
Tikanga	custom, obligations and conditions (legal)
Tino Rangitiratanga	Kingdom, principality, sovereignty
Treaty of Waitangi	document signed between iwi, hapu and the British in 1840 at Waitangi
Tupuna	ancestor, grandparent
Turangawaewae	domicile, home, home turf
Wahine	woman, wife
Waipiro	alcohol, liquor, booze
Whakama	embarrass, shy, loss of mana
Whakapapa	genealogy, family tree, cultural identity
Whanau/Whanaungatanga	family relationships, networks
Whangai	nourish, care for/adopt child
Whare	house

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