

MATAURANGA MOTUHAKE

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with Mere Berryman, Trevor Himona and Temapuoterangi Paul

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HE WHAKATAUKI

'He kai poutaka me kinikini atu, he kai poutaka me horehore atu, mā te tamaiti te iho'
'Pinch off a bit of the potted bird, peel off a bit of the potted bird, but save the inside for
the child'

The welfare of the child ensures the future strength of the people

MIHI

Tēnei te ara
Tēnei te ara o Ranginui e tu nei
Tēnei te ara o Papatuanuku e takoto nei
Tēnei te ara o Rangi räua ko Papa e takoto nei.
Nā räua ngā tapuwae o Täne- ki- raro,
Haere te pö, tēnei te ata.
Tihei mauri ora!

E ngā mana, e ngā reo, e ngā karanga maha o te motu, tēnā koutou katoa. Tēnā hoki koutou i runga i ngā tini āhuatanga o tēnei ao matemate. Kua mihia, kua tangihia, kua poroporoakitia te hunga kua riro ki tua o te ārai. Ko rätou wēnei e takahi ana te ara whānui e kore e kitea a kanohi, e whakangaro atu nei i a ratou ki te pö uriuri, ki te pö tangotango. Käti, ko te whakatau noa ake, waiho ake rätou kia tīraha mai, ko tätou te hunga ora ki a tätou. Nō reira kia ora tätou katoa.

Tēnei te mihi whānui ki ngā kairangahau, ki ngā whānau hoki, i whai kaha ai ki te whakatakato körero, ki te huakina mai o rätou ngākau aroha i runga i te whakaaro, a tōna wā pea ka tau i roto te hinengaro o ngā kaiako me ngā kaipupuri pūtea. Ko tēnei pukapuka te wharikitanga o ngā whakaaro, o ngā körero hōhonu hoki e pä ana ki ngā mahi āwhina, tautawhi ana a tätou tamariki hauā, tömuri haututu ränei, me o rätou whānau. Me ngā whakaaro puaki noa iho e pä ana ki ngā huarahi pai hei whāinga mā te katoa.

Nō reira e hika mā, äta pānuitia ngā tuhituhinga i takohatia e o tätou whanaunga o ia marae, o ia takiwā, kia piki ake te möhiotanga, kia whai mātauranga tätou katoa o roto ngā mahi tiaki, ako ränei i ngā tamariki motuhake. Käti ake, ko te tino wawata kia haere pai katoa ngā mahi tötika, kia piki ake te ora a tinana, a wairua, a hinengaro, a whānau hoki ki runga i a tätou tamariki katoa. E ai ki ngā kupu a kui mā, a koro mā:

Ko te manu e kai ana i te miro, nöna te ngahere;
Ko te manu e kai ana i te mātauranga, nöna te ao.

Noho ora mai rä i raro i ngā parirau o te mea ngaro.
Tēnā koutou, tēnā koutou, tēnā tätou katoa.

Kerehi Waiariki
Pukenga mö Te Rünanga o Aotearoa mö te Rangahau i Te Mātauranga.

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To my own extended whanau of family and friends including Steve and Breaker Bay Records, thank you for your assistance and support through this special learning experience.

Margaret Wilkie
Kairangahau/Researcher

FOREWORD

In November 1999 I accepted a position with NZCER which included providing some of the project support for this report, Matauranga Motuhake. Much of my work was to transcribe interviews recounting the intimate stories of families who had embraced children with special needs into their lives. It was a daunting task. Pregnant with our second child, I found the stories a constant reminder that any pregnancy could produce a child with special needs, mine included.

I transcribed the last story for the project a week before the birth of my daughter, Rosa Therese. Twelve hours after Rosa Therese's arrival, she was diagnosed with Downs Syndrome. A week later it was found that she also had a severe congenital heart condition. We were flown to Greenlane Hospital in Auckland where Rosa Therese underwent heart surgery. While the operation appeared to be successful, we found that Rosa Therese was unable to be weaned off the ventilator. Her heart was too small to cope with life. In a private room in the Intensive Care Unit we took Rosa Therese in our arms, surrounded her with family, filled the room with roses, gentle music, shawls, and teddies and massaged her with oils. The ventilator was removed and we sang, crooned, prayed and waited. Rosa Therese died in my arms, two days later.

A shocking coincidence—our lives had become transcribable. I turned back to the stories I had transcribed. I found in them connection with other families who had been where I now was, and drew deeply and gratefully on their wisdom and inspiration.

In an unusual precedent I was asked to write the foreword for this report as someone closely involved with its creation who has also experienced a child with special needs. I write it as a Pakeha woman who has been inspired and nurtured by the stories of the Maori whanau who are at the heart of this report. I believe that the raw honesty and wisdom of these stories will guide many others who care for children with special needs. It is no easy thing to have a child with special needs. One can't do it alone. The support of family, and the health, education and welfare services, and acceptance and encouragement from the community are essential. It is support that must be accessible and appropriate. This report explores the experiences of Maori families with children who have special needs, and their ability to be supported by our country's systems and people.

Rosa Therese's life blessed us profoundly—"she is an angel born with wings hidden" is how I described my daughter. In the six weeks she was with us, we experienced many special needs but we also cherished many special graces. It is my hope that all those who care for special children may be given strength and support in order to cherish the graces which accompany the needs.

Rachel Nankivell (and family)

Mate atu he tete kura

Ara mai he tete kura.

When one fern frond dies,

Another arises to take its place.

SUMMARY

The title of this research report is 'Matauranga Motuhake', which translates into English as 'Special Education'. Originally called 'Special Education for Maori', the report title was changed to te reo Maori to signify that the research is Maori-focused and Maori-centred. Just as the case studies tell stories about the people and especially the children at the heart of this research, the title suggests the kaupapa Maori research process that is used here to present a uniquely Maori perspective on special education.

Statistics show that Maori are over-represented in indicators of special educational needs. Policy-making in New Zealand has not generally been inclusive of Maori so that, while policy may claim to be based on a philosophy of inclusion, it is more likely to have been developed outside of kaupapa Maori and without due regard to the Treaty of Waitangi. At the same time, there has been a lack of substantial research into many issues of importance to Maori, of which special education is only one. NZCER was contracted by the Ministry of Education to study Maori perspectives of Special Education 2000, as part of the Ministry's ongoing evaluation and development of the policy, and produced a report in 1999 titled, "*So—What's So Special about Special Education for Maori?*". This showed that Maori have not been included in policy development and that special education policy as it stands does not acknowledge the central role of the whanau in supporting special needs children.

The Matauranga Motuhake research takes the traditional concept of whanau and the place of the individual child within this context as a starting point for discussion of special education. In every case, parents and extended whanau were approached to speak on behalf of the children, who were not always able to speak for themselves.

The primary finding of this research is that the whanau is indeed the main pillar supporting children with special educational needs. It offers examples of successful support within the whanau enabling special needs children to access positive educational experiences, and details some of the additional support for whanau especially where schools and services are able to respond within a Maori kaupapa.

While all of the whanau stand tall and offer multi-layered support and love to their special needs children, all of the case studies show the difficulty whanau face trying to find and access help and support, including specialist services and appropriate specialist or mainstreamed schooling. There is a general dearth of information, and those living away from their home area without the help of extended whanau face a much steeper challenge to respond to the needs of their children. In other words, whanau with tangata whenua status in a given area find it generally easier to access support networks and services than whanau who are living away from their own area. Matauranga Motuhake reports on a range of problems and their solutions for whanau who have relocated with their children into different areas.

Even for those living in their home area the special needs of children and their whanau in isolated rural communities are exacerbated when the whanau feels isolated from their community because they have a special child who is regarded as "not normal". Matauranga Motuhake presents whanau-based responses where children are accepted and naturally integrated into their schools and communities. Where whanau have access to

services and support, enabling their children to experience education on a par with other children, an equitable solution has been reached.

It is difficult for whanau to access the appropriate information about resources and services available to support their children. Word of mouth and relying on knowledge within whanau networks appeared as a common theme to the stories. The need to develop policy ensuring equitable access to information about resources and support available for Maori whanau with special educational needs is apparent. Whanau made some very practical suggestions about how access to information could be improved for them and the schools and services that work with their children.

There are also difficulties for Maori whanau dealing with services or schools that are unable to recognise the unique needs of Maori in wanting a culturally appropriate response for their children. The lack of knowledge and information about Maori whanau, kaupapa and tikanga impacts on the ability of a service or school to respond appropriately. This research shows how culturally appropriate, whanau based interventions are often a useful and much appreciated way for schools and services to deal with needs and problems that arise.

There are innumerable stories elsewhere of special education children harmed, lost, and neglected. On the other hand, stories which offer solutions to the problems of special educational needs for Maori whanau are harder to come by. Sharing positive stories of whanau who respond to the needs of their children with the help of services, schools, and other supports adds to the body of knowledge about more equitable solutions for whanau with special needs children, and this is pertinent for all New Zealand families.

Matauranga Motuhake records both the problems and issues of special educational needs as defined and experienced by whanau, and the decisions they made in framing their responses to often complex situations. While the statistics can make depressing reading, these stories provide a positive record of solutions found by whanau themselves. The voices from each whanau are heard telling their own stories of the children as taonga, requiring extra special care or awhitanga, and the whanau strengthened in the process by their experiences.

The themes emerging from the analysis show aspects of kaupapa Maori in the strength of whanau, the importance of whakawhanaungatanga and respect, the frustration of whanau who have neither, the support of manaakitanga, and the spiritual values that can strengthen persistence in the face of ongoing challenges.

MAORI AND SPECIAL NEEDS

Research with information on Maori and special needs has only become available in recent years. In every report *with* ethnicity data, statistics appear to show a disparity between Maori and other ethnic groups in New Zealand. The Ministry of Health disability surveys shows a clear over-representation of Maori children. When other socio-demographic variables were adjusted for, Maori were over-represented by a factor of 35 percent among children with disability” (Ministry of Health, 1999b).

Evidence from the 1999 Massey University phase one report of their evaluation of the SE2000 policy showed that Maori students are disproportionately represented in all Special Education 2000 initiatives. With Maori representing 20% of the school population (Ministry of Education 2000) in the Massey survey, 26% of Ongoing Resourcing Scheme funded students were Maori, 37% of the Severe Behaviour Initiative roll and 16% of the Speech Language roll were Maori and 26% of those receiving support from the RTLB service were Maori students. Of all children referred to residential special schools, 39% were Maori. The Wylie review (2000) found that more applications were made for Maori for ORS funding and were less likely to succeed for Maori children.

Evidence of schools’ inability to respond to extreme behavioural problems may be determined by the rate of suspension of children from New Zealand schools. Ministry of Education (1998) statistics on suspensions showed that Maori were three times more likely than non-Maori to be suspended. While Maori comprise 20 percent of the total school population, they made up 43 percent of all suspensions in 1997. More recent figures appear to show a rise in these figures. In the period 12 July 1999 to 16 July 2000, the effects of the new procedures for managing serious student misbehaviour saw 13,272 students stood down from school and just under 5,000 suspended. Forty-eight percent of students suspended were Maori. Their rate of suspension was 3.6 times higher than that of Pakeha students. Forty percent of the stood-down students were Maori, a rate that was 2.5 times higher than Pakeha students. Children with special needs are more likely to be stood down especially at secondary school.

In 1998, I undertook research to identify the particular needs of tangata whenua in relation to the Special Education 2000 (SE2000) policy. The report concluded:

... that there is a definite Maori perspective about the education of children with special needs, and the majority of respondents considered that SE2000 policy failed to acknowledge this perspective. (Wilkie, 1999, p. vi)

The report identified a range of key issues for Maori whanau with special educational needs and these issues feature again in Maturanga Motuhake. They include the role of the whanau, the difficulties of access to special education services, the importance of

kaupapa Maori as a research and policy-making tool, and the need for services in New Zealand to be grounded in and to reflect the principles of the Treaty of Waitangi.

Whanau first of all identified a need for a wider understanding of the traditional concept of whanau and the place of the individual within the whanau. The word 'whanau', which means extended families across several generations and configurations, is not readily understood within the non-Maori context, where the concept of the family signifies a nuclear family unit. Joan Metge (1995) offers five descriptions of the traditional Maori concept of whanau based on kinship by descent and by marriage. These descriptions include whanau based on a set of siblings; whanau based on descendants of female and male lineages of a relatively recent ancestor, whether these whanau members are in contact with each other or not; whanau based on common ancestry where members are in close contact on a regular basis; whanau in contact and including spouses and adopted children; and, finally, whanau as a grouping of greater genealogical depth and breadth, often referred to as hapu and iwi.

There has been little information available on how whanau with children with special educational needs interact with helping services and agencies. This report puts a particular focus on the whanau as the main pillar supporting children with special educational needs, offering examples of successful support which is more likely to occur where schools and services are able to respond within a Maori kaupapa:

My philosophy is that I work from the realm that I have been brought up in, I work from te taha tinana, te taha hinengaro, te taha wairua, te taha whanau. The body is not healthy without the mind. The mind is not healthy without the wairua, and the wairua is not healthy without whanau. If you break any of those pillars, you break down the learning opportunities of the individual, whether they are special needs or not. (Public health nurse) (Wilkie, 1999, p. 16)

But however much the whanau does, and however much it provides, children with special needs require and deserve access to special services. Equity of access to available services and support is constantly an issue for Maori, and there are several areas of difficulty which are identified in this report. For example, there is a huge range in the types and ease of interactions between whanau with special needs children and both the mainstream education system and special schools in New Zealand. Generally, it is perceived that the non-provision for Maori of special education involves a lack of information about services and previous negative experiences with provision:

I wasn't sure what to do or where to go, I didn't know who to talk to.

There has been some service here but they seem to come and go and nothing consistent. There was one gentleman who works with SES and he's supposed to be doing speech therapy with Ben but he's not very thorough in his job, so Ben has missed out with a lot of those services.

(Mother, Te whanau o Ben)

It is also clear that financial difficulties impact directly on whanau with special needs children, and several cases show that financial hardship can reduce the ability of whanau to support their children with special needs.

Whanau with tangata whenua status in a given area find it easier to access support and services than whanau who are living away from their turangawaewae. In addition, those living in remote rural areas are less likely to be able to access physically special needs services. Where transience is part of the life experience of a child with special needs, the whanau also loses the support and accumulated knowledge of the extended family. These difficulties can be exacerbated when the whanau feels isolated from their community because they have a special child who is “not normal”.

Advice given by respondents in the 1999 report strongly supported direct consultation with tangata whenua about the issues of special education for Maori:

If you are targeting the tangata whenua, you can't go wrong. Target across the age groups, target from the kaumatua to the child, and also target the special needs parents and how they feel, and where they are. ... If you don't seek the knowledge, the wisdom, and advice from the tangata whenua then you are not working within the partnership role within tino rangatiratanga. (Public health nurse) (Wilkie, 1999, p. 27)

The research focused on Maori as tangata whenua and reports on a range of people of many ages, and parents of children with special educational needs in particular:

The consultation process needs to be with a range of people. Really if it's about children in education, parents have to be consulted first. Just your general Joe Bloggs, they may not have all the insight that the experts have, but as parents they have the gut feeling about their kids, they know what they want, they know what's good. Parents can tell others what works and what doesn't. (Urban Kura Kaupapa Maori) (Wilkie, 1999, p. 27)

It is about consultation. It is about listening. It is about coming to Maori people with open hearts really and listening to what we say. ... They need to come and listen to how Maori perceive the world, perceive their children, the expectations, and the aspirations for the children. It is really about whanau, hapu, and iwi development and then they can see how their expertise can assist. (Te Kohanga Reo National Trust) (Wilkie, 1999, p. 30)

Matauranga Motuhake presents each child within the context of their whanau and everyday lives. Common to all the stories is the recognition of each child as special in their own right, and the details of their life experiences, including their special educational needs, are part of what marks these children out for particular attention and support.

METHODOLOGY

Matauranga Motuhake is based on kaupapa Maori research methodology, offering a qualitative study based on tape-recorded, semi-structured interviews with whanau and education, health, and service providers in ten different locations throughout New Zealand. The research targeted Maori in remote, rural areas; urban whanau in three different cities, some of whom have relocated for special health and education services; Maori living in poverty; and Maori living in both the North and South Islands.

Kaupapa Maori Research

The term kaupapa Maori means Maori philosophy or agenda. When used in research it is both a world-view and a methodology which is underpinned by cultural safety, and Maori ethics, beliefs, and knowledge, e.g. tikanga and matauranga Maori.

Irwin (1994) and Smith (1999) argue that Maori should carry out research into Maori, for Maori, and with Maori. The Matauranga Motuhake research project team consisted of kairangahau, kairangahau awhina, kaumatua, and education professionals who are Maori, with the support of both Maori and non-Maori advisors.

Bevan-Brown (1999b pp 231-245) reviewed literature to identify the top ten components of Maori research: including the use of a Maori cultural framework, the presence of research expertise, and “commitment to the obligations, liabilities and responsibilities that are an integral part of Maori research”. The research for Matauranga Motuhake was based on Maori frameworks, in particular, the whanau and whakawhanaungatanga, (as advocated by Bishop, 1999), the wharenuui, and the Treaty of Waitangi. Details of the wharenuui model and logo created for the research project can be found in Appendix 4. The processes of whakawhanaungatanga, establishing a connectedness between the researchers and the whanau who contributed, was an essential feature of the research kaupapa and mention of the connections is made at the start of most of the stories. All whanau were interviewed by Maori with a range of research expertise, and cultural and ethical obligations were at the forefront of the whole project. The control and responsibility for the conduct of the research process rested solely with Maori researchers.

Bevan-Brown states that “the people being researched are active participants at all stages of the research process”. The Matauranga Motuhake research actively involved whanau who not only gave the information for the interviews, but also read transcripts and added to drafts before agreeing to publication. Bevan-Brown also states that “Maori research should empower those being researched. This empowerment should stem from both the research process and product”. In this kaupapa Maori research methodology there is a partnership between whanau and the research project team.

Having gained appropriate access to whanau, the research team discovered that in encouraging whanau members to think and talk about their situation, while being closely listened to, positive benefits emerged. Thus, whanau were enabled to participate within protective structures and tikanga, empowering themselves and the research team in the process, and thus helping to increase the potential for equitable access by all whanau to help with special educational needs. Whanau comments on their involvement in the research process appear at the end of some of the case studies.

Smith (1999) discusses issues identified as features of emergent indigenous research, including that of people “representing” themselves:

Indigenous communities have struggled since colonisation to be able to exercise what is viewed as a fundamental right, that is to represent ourselves. The representing project spans both the notion of representation as a political concept and representation as a form of voice and expression. Representation is also a project of indigenous artists, writers, poets, film makers and others who attempt to express an indigenous spirit, experience or world view. Representation of indigenous peoples by indigenous people is about countering the dominant society’s image of indigenous peoples, their lifestyles and belief systems. It is also about proposing solutions to the real-life dilemmas that indigenous communities confront ... (p. 151)

Matauranga Motuhake aims to give voice to Maori whanau with children with special educational needs and edited quotations make up the bulk of the case studies. During the process of the research, the plan to present case studies evolved to become the telling of the stories of the children in their own whanau, drawing on the strength of traditional Maori practice, using narrative to convey information and ideas. Some of the stories are very short because the special needs of the child were dealt with effectively. Others go into more depth where there are multi and intergenerational needs in situations that are more complex and which change over time.

The use of stories to convey information is a traditional Maori practice and the hope that other Maori whanau would benefit from the stories in the research was the main motivator for whanau involvement. All whanau were willing to share their stories so that other Maori whanau with special needs children would benefit.

The research was designed to enable whanau to korero Maori if this was their preferred language, and to present case studies in either te reo Maori or English. Two Maori kairangahau and two Maori kairangahau awhina wrote the stories, using their own styles. These individual styles have been retained. Bilingual capacity is an important element of kaupapa Maori research. Te whanau o Maui presents a version in te reo Maori and a version in English.

In kaupapa Maori research methodology, it is not only the fact that is important but also the emotional background, the hidden context. As Smith (1999) writes,

The framing of an issue is about making decisions about its parameters, about what is in the foreground, what is in the background, and what shadings or complexities exist within the frame. The project of reframing is related to defining the problem or issue and determining how best to solve that problem. (p. 153)

Matauranga Motuhake records both the problems and issues of special educational needs as defined and experienced by whanau, and the decisions they made in framing their own responses to often complex situations. The original aim of the report was to present a balance to the negatively framed over-representation of Maori with special needs and to show positive viewpoints which offer the solutions found by whanau themselves. The voices from each whanau are heard telling their own stories of the children as taonga, requiring extra special care or awahi, and in the process becoming stronger.

Access, Informed Consent, and Confidentiality

The children whose stories are told here were originally identified through contact with Maori people or services working with Maori in the field of special education. Some stories were accessed through the process of whakawhanaungatanga with contact made initially through existing whanau connections. The research aimed to have kairangahau awahina and interviewers working within their own iwi grouping and for the most part this was achieved. Two interviews were conducted by Maori staff of a special education support service and a special school then written into case studies by the kairangahau. The project accessed some stories with the prior informed consent of providers who have agreed to their actual names appearing, including the Kelston Deaf Education Centre (KDEC), the Specialist Education Services, and the Correspondence School (TCS). Schools, RTLB clusters, iwi organisations, and health services which also gave their consent cannot be named where this would lead to identification of any child.

As each whanau was identified, they were approached personally by trusted family friends, service, iwi, or school staff, and asked if they would agree to an approach from the research project. After they had given verbal consent, a formal letter outlining the project was sent to them by the Matauranga Motuhake research project (see Appendix 1). Eleven case studies were completed.

It was critical that whanau had ample time to consult and to consider their agreement to participate. The protracted timeframe required for kaupapa Maori research became apparent when tikanga was followed closely so that whanau had time for discussion with extended whanau and hapu members and could then give their full consent to enter a partnership with the researchers. The next response came from whanau who returned a written consent form to take part in the research (see Appendix 2).

Whanau were given a copy of the research questions several weeks before tape-recorded interviews were conducted (see Appendix 3). Each whanau was given time to consider research questions and in one case met with the interviewer to review the questions before a subsequent video-recorded interview. The kairangahau for Awhiro's whanau observed that giving participants time to get all of the information was “cup of tea” research. Interviews were often conducted as tape-recorded chat which covered the questions posed by the research project.

In most cases, these interviews were transcribed. A record was made from memory after one interview by a kairangahau awahina and the RTLB (Maori) who had opened the access to the site when the tape recorder did not work. At another site, tape recorder failure was compensated for by transferring the audio track from a video recording of the interview onto an audio cassette for transcription.

Full transcripts were made from the tapes and returned to most of the whanau who contributed. Where whanau did not read the transcripts for a range of reasons, rangahau and advisors have read the transcripts and commented. Whanau responded with comments on one copy of their transcripts, and these changes were taken into account prior to stories being drafted. The draft stories were then returned to whanau for comment and their final consent to proceed to editing and publication of the report. Additional and inspiring comments received from the whanau at this stage were included at the end of most stories.

In each story, details such as names have been altered to ensure anonymity for the children and whanau who have shared their stories for the research. It is expected that readers who think they recognise the whanau appearing here will respect this right of anonymity for the protection of the children.

It was not always possible for whanau to participate in the research after giving initial consent. Six case studies did not proceed, and the details are summarised here to illuminate some of the incidents impacting on Maori whanau and their special needs children.

The first such case was accessed through a whanau member working in Te Puni Kokiri. The whanau are tangata whenua with a 13-year old daughter who is an academic achiever at a remote, rural, area secondary school. This female leader for the school kapahaka group has a congenital bone deformity and her part-time caregiver for physical needs was her aunty. The death of a sister and aunty within the proposed interview timeframes terminated the research priority.

The second case study was accessed through an Iwi Trust Health Service operating outside of its own tribal area. The whanau are tangata whenua and one of two remote sites with multiple generation and special needs in the whanau. This service won new contracts and their work commitments increased. The kairangahau was able to complete only one of the two case studies planned for this area.

The third case study was accessed after a presentation to a national conference of Resource Teachers of Learning and Behaviour. One RTLB was interested in writing the story of a whanau who were not living in their own area. Hoani was 15 years old. He was whangai with his koro, the last living member of Hoani's immediate whanau, who was himself recovering from a mild stroke. Koro had agreed to the interview. An RTLB intervention at the decile 1 secondary school where Hoani had recently enrolled was Hoani's last chance, as he was under suspended sentence of detention at borstal for violent offences. The RTLB suspected multiple personality disorder and was attempting to arrange an assessment for Hoani. In the days prior to the scheduled interview, Hoani had "gone berserk" in the school grounds and been taken the next day by the RTLB and his koro to a hospital 60 minutes drive away, where Hoani was admitted. The RTLB feared disciplinary proceedings from the school for this 'unauthorised action'. Subsequent testing revealed a brain tumour. Hoani died before surgery could be scheduled.

A fourth case study was accessed through whanau connections of the kairangahau with a rural marae where the whanau are tangata whenua. Previously suspended from three schools and expelled at 14, this student continued learning with the Correspondence School. As a 19-year old, he returned to the area secondary school and achieved School Certificate passes as an adult learner. He is currently working as a teacher aide in the

same secondary school, teaching kapahaka, and acting as a mentor and role model for 'at-risk' Maori students. The first korero with the kairangahau was not recorded. Family circumstances changed and the respondent relocated with his whanau, travelling for one-and-a-half hours every day to continue working at the secondary school. There was not enough time to complete the second interview to meet the case study milestone.

The fifth non-proceeding case study was accessed through whangai connections of a kairangahau. The whanau are tangata whenua. Aroha is a seven year old graduate of kohanga reo. Maori is the language of the home, with both parents learning te reo through kohanga and kura matua classes. Aroha has been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and is partially deaf. The whanau decided to move Aroha from the kura to a special unit attached to a local mainstream primary school where immersion instruction would be available to her. The whanau met with the kairangahau to explain in person that they chose to withdraw from the research as they were no longer kura whanau and wanted to put their energy into settling Aroha into her new school.

The sixth case study was accessed through a Maori SES, Severe Behaviour Initiative case worker who contacted NZCER seeking a copy of the report, "*So—What's So Special About Special Education for Maori?*". The whanau are tangata whenua and 11-year old Rangi first came to the attention of SES through a request for assessment from a primary school principal. Rangi had been suspended from another primary school and had learning and behavioural problems. The SES worker had developed a close relationship with the whanau over a two-year period and SES supported Rangi attending a one-week residential taiaha training wananga to assist with anger management. Rangi started to receive one-to-one learning support with reading and writing. On one occasion, Rangi got angry and ran to a nearby hill with a stick, going through his taiaha stances. The school alerted police that a student was loose with a weapon and the SES worker was called in. He successfully intervened and explained what was happening. Rangi's performance at school lifted and the whanau was happy to share the story of his success. Rangi changed to intermediate school and the SES worker left the service to take up a position as a counsellor with a city secondary school. The transition and changes proved too much for Rangi who was suspended from his intermediate school. The ex-SES worker continues to keep contact with the whanau and transports Rangi every Sunday to a kapahaka group in the city which includes taiaha training. The case study was terminated as the deadlines could not be reached, and the new priority was to find another school for Rangi.

Selecting the Special Educational Needs

The special educational needs of the children in the study include physical disability (four children), behaviour and suspension issues (four children), and learning problems (two children). One child has a special circumstance of living remotely, and features in this report to make the availability of early childhood education through correspondence or distance learning known to Maori whanau who currently have no or limited access to early childhood education because they live in remote rural areas. Maori respondents agree that remoteness is a special educational need.

The Treaty of Waitangi

The research followed a kaupapa Maori research process using analysis based on the Treaty of Waitangi, and the principles derived from the Treaty developed by the fourth Labour government for use by government departments and agencies. These principles were designed to analyse the relationship between the Crown and the tangata whenua, and to ensure that the Treaty is being upheld. The principles used for the research are: partnership, participation, protection, empowerment, equity, and access. They are used as the basis of the analysis of the whanau stories and the research process.

Partnership

The research for Maturanga Motuhake was designed as a partnership between the kairangahau of NZCER and whanau who agreed to provide the case studies. In several instances, a connection was first made with larger organisations, including the Specialist Education Services, the Correspondence School, and three separate iwi runanga or iwi services to get agreement to proceed with approaches to whanau. Some of the case studies were created after invitations from school principals, or from Resource Teachers: Learning and Behaviour. In one case, the kaupapa of the partnership between the kura kaupapa Maori (KKM), the RTLB (Maori), and the RTLB Regional Co-ordinator enabled entry by whakawhanaungatanga for the researcher.

Whanau were approached through a process of whakawhanaungatanga, drawing on existing partnerships between schools, services, and whanau, and connections between kairangahau and whanau. In all cases, a verbal request was made to the whanau kanohi ki te kanohi by people who knew the whanau, to see if they would be interested to be part of the research. The approaches made to the whanau, grounded as they were in kaupapa and tikanga Maori, made partnership more possible between researchers and whanau. The process gave whanau several opportunities to agree to take part in the research or to withdraw from it, and to have input into the case studies as they appear here. They were also given time for consultation and discussion. In all cases, whanau were asked for their guidance as to who needed to be interviewed and they decided who would meet with the kairangahau for the interviews.

At the wananga to evaluate the research project, the point was made that partnership can be seen as power-sharing in relationships. At all times, the Maturanga Motuhake researchers respected the rights of whanau members and sought to share decisions, such as corrections and consent to use the drafts of the stories in the final report. In this way, the research was conducted within a partnership with an expectation that the researchers are accountable to the whanau at every step of the research process.

Participation

For ten of the eleven whanau who completed the research process, being part of such a research process was an entirely new experience. All of the whanau wanted to participate in the hope that sharing their experiences or stories could help other Maori whanau to find the appropriate education for their own special needs children.

Whanau decided who would participate in the interviews and tell the story for the special needs children, and the interviews were arranged by the kairangahau to suit the whanau, most often in the whanau's home or at school. One interview took place in a workplace with both parents.

Protection

In the context of kaupapa Maori, it was natural to have kaumatua and other whanau and staff members give karakia to protect the process of the interviews and the research project. The kaupapa of the research methodology was to have the kawa of tangata whenua followed and koha was a common practice. Kaumatua connected with the children and whanau themselves made sure that the participants were accurately portrayed, and other kaumatua acted as advisers and pukenga for the research process. In several cases, an iwi or hapu connection established a whakawhanaungatanga relationship between the researchers and the whanau, and the rights and responsibilities of those connections ensured that the whanau were protected. Conducting interviews in whanau homes was a safe and familiar environment.

The establishment of informed consent between researchers and participants is central to most research practice. Providing the time for whanau to familiarise themselves with all of the research requirements before they committed to participate was an essential and time-consuming step in the process. In addition, they could read and reread the drafts, and give consent to proceed or withdraw at any stage.

An essential understanding was that the research ethics ensured the protection and anonymity of the whanau and their children, with changes to details such as personal names, place names, and other identifying features in the stories.

Empowerment

Matauranga Motuhake presents case studies of Maori whanau who have a child with special needs caused by disability, learning and behavioural problems, and location, and the problems of accessing appropriate support in a range of situations. Presenting positive examples of solutions reached by whanau was aimed at empowering all whanau with special needs children, and all staff dealing with such whanau. The stories give information and options in a way that is easy to understand. Most whanau were empowered by voicing their own perspective of special educational needs in their own words, and by the research process.

In several case studies, whanau shared stories about their positive experiences with schools, health professionals, and other support agencies. In one case study with a negative outcome, the whanau felt that it was time to tell their story and that finally someone was listening to them.

For some of the kairangahau at the Matauranga Motuhake wananga, empowerment was believed to be integral to the principles of partnership, participation, and protection. Without the three prior elements, neither empowerment, equity, nor access for Maori whanau could be achieved.

Equity/Access

Positive stories about whanau who manage to meet at least some of their special educational needs with the help of services, schools, and supports can indicate ways of finding more equitable solutions for all whanau.

The Maturanga Motuhake research analysis aimed to make sense of the issues for Maori children with special educational needs. One of the major trends showing in all of the case studies was the difficulties whanau face in trying to find and access help and support, including specialist services and appropriate specialist or mainstreamed schooling. Whanau lack information, and for those living away from their home area without the help of extended whanau it is much harder to respond to their children's needs. Some of the Maturanga Motuhake case studies show iwi services working with health, SES, and non-government organisations like the Child Cancer Foundation, CCS (formerly the Crippled Children's Society), and special education providers for the benefit of the whanau and child. Some whanau were until recently unaware of state benefits and entitlement to services and support for their children, and others appreciated the essential help of the transport allowance in enabling their children to get to school.

Where the whanau have access to services and support that allow their children to experience education on a par with other children, an equitable solution has been reached. In most instances, the case studies show at least a progression towards equity or access. The inclusiveness and partnership of Maturanga Motuhake, as well as its bilingual nature, are also aspects of the equity and access offered by the kaupapa Maori research methodology.

Maturanga Motuhake Wananga

The kaupapa of the Maturanga Motuhake methodology included a wananga as the most appropriate process to start the analysis of the research data in a safe and Maori centered environment and kauapapa. The wananga was based at Hongoeka Marae near Wellington and followed the kawa of the tangata whenua, Ngati Toa, in the powhiri and the proceedings of the wananga over three days. Along with the NZCER pukenga and various kaumatua and kuia of the marae whanau, partners, children, and mokopuna of those attending joined in the wananga.

The Advisory Committee, kairangahau of NZCER staff, and the kairangahau awhina were presented with summaries of all of the case studies, and subsequent workshops looked at the individual case studies and the Treaty of Waitangi framework in detail. In addition to principles embodied in the Treaty of Waitangi, the wananga whanau adopted a culturally appropriate audit for Maori research (Bishop, 1995) to analyse the content of the case studies and to audit the research process. In this framework, an audit of the research is referred to by the acronym IBRLA, which stands for Initiation, Benefits, Representation, Legitimation, and Accountability. The next section, entitled 'Questions for Special Education Policy-makers and Providers' summarises the questions based on both the Treaty principles and the IBRLA principles for the use of services, schools, and agencies dealing with whanau with special needs children.

The applicability of each case study to the principles of the Treaty of Waitangi is presented at the end of the case studies.

MATAURANGA MOTUHAKA WANANGA AT HONGOEKA MARAE AUGUST 2000



Standing: Dick Grace, Pukenga (Ngati Porou, Whanau-a-Apanui); Waimirangi Mihitea (Ngati Whanaunga, Te Pirirakau, Te Aupouri, Ngati Kahu); Margaret Wilkie, Kairangahau/Project Leader TWKM/NZCER (Ngati Porou, Ngapuhi); Vyletta M Tapine, Kairangahau Awhina (Ngati Porou, Ngai te Rangi); Taina Tangaere McGregor, Kairangahau (Ngati Porou); Garrick W Cooper, Kairangahau (Ngati Whanaunga, Te Pirirakau); Te Kohitu Ruaköhä ((Ngati Whanaunga, Te Pirirakau, Te Aupouri, Ngati Kahu); Mere Berryman, Kairangahau SES Poutama Pounamu (Ngai Tuhoe); Wharehuia Hermara, Kairangahau (Ngati Maniapoto, Ngapuhi)

Kneeling: Te Mapuoterangi Paul, Kairangahau Awhina (Te Arawa, Kai Tahu); Trevor Himona, Kairangahau Awhina (Ngai Tahu, Ngati Raukawa, Ngati Kahungunu).

AUDIT OF THE MATAURANGA MOTUHAKÉ RESEARCH

Bishop's IBRLA framework was adopted at the wananga stage of the research and woven together with the principles of the Treaty of Waitangi in the analysis. In the korero over three days at the wananga, it was agreed that where partnership does not feature in relationships with whanau, none of the principles or the Treaty itself are being upheld.

Initiation

Bishop asks, "Who initiated the project?" Maturanga Motuhake was initiated as a result of the findings of NZCER's earlier report where not enough information is available about Maori and special educational needs and encouraged by discussions by other interested Maori staff of organisations including New Zealand Educational Institute (NZEI) Te Riu Roa and SES

Initiation also relates to how the kairangahau establish relationships with the research participants and how power is shared in the process. The methods of approach adopted by Maturanga Motuhake are described in the methodology, and in the context of each case study the sites of the kano ki te kano were chosen by whanau. The consent process gave whanau the right to withdraw at any time and to give final permission for the publication of the case studies. The tikanga of kaupapa Maori prompted the approach through whakawhanaungatanga, establishing connectedness to access Maori whanau. Tikanga also required a koha from Maturanga Motuhake as an acknowledgement of the contribution by whanau, and the value of their contribution to the research.

Benefits

Bishop asks, "Who benefits from the research?" The foremost benefit from kaupapa Maori research must be for the actual participants in the research. When Maori benefit, all of New Zealand benefits. Maturanga Motuhake aims to enhance understanding throughout all sectors of the educational and governmental systems about the very special educational needs of Maori New Zealanders in order to make the positive difference for them and their whanau.

Representation

Bishop asks, "Whose voice is represented in the research. Is it an adequate depiction of social reality?" Maturanga Motuhake presents the voices of the whanau who speak for the children with special educational needs. Acknowledging the importance of te reo

Maori, the research process offered bilingual rangahau and kairangahau so that the stories could be presented in the whanau's language of choice. Most whanau chose English and one story from kura kaupapa Maori is presented in te reo Maori. This is a small beginning.

Whanau were actively involved in the process of bringing the stories to print, so that the stories offer a true representation of the whanau's experience and knowledge. The results of this collaboration are seen in the body of the research.

Legitimation

Bishop asks "What authority does the text have?", and the answer to that question must come from Maori and readers of the text. In her foreword to this report a mother of a special needs child acknowledges the authority and wisdom within the stories of whanau. "Who defines what is accurate, true and complete?" Maori have designed and carried out interviews and analysis and participated in this project, with support from pakeke and pukenga. "Who theorises the findings and what happens to the results?" Whanau and Maori working as kairangahau analysed and theorised within kaupapa Maori frameworks and the result is in your hands.

Accountability

Bishop asks, "Who were the researchers accountable to?" Matauranga Motuhake kairangahau were primarily answerable to the Maori participants of the research, and to the kaupapa Maori process and to NZCER's quality standards. The processes followed in the research are based on kaupapa Maori and follow a clearly defined tikanga, overseen by wise kuia, kaumatua, pakeke and pukenga.

QUESTIONS FOR POLICY-MAKERS AND PROVIDERS IN SPECIAL EDUCATION

Preliminary analysis of both the case studies and the kaupapa Maori research methodology was conducted at a wananga for this specific purpose. Three days of consideration by kairangahau, kairangahau awhina, kaumatua, and advisers concluded that the presentation of information in the report could aid the informed formulation of recommendations for the improvement of special education provision for Maori. This process may best be undertaken by people whose roles are to develop policy or deliver services to ensure Maori have equal access to information, support, and resourcing.

A series of questions for services to consider about their own provision and support for Maori children and whanau with special educational needs is presented here within the framework of the principles derived from the Treaty of Waitangi and the IBRLA audit of the research.

Partnership

What is the nature of your relationship with Maori as tangata whenua?

Can you point to evidence of your partnership with tangata whenua?

How well-informed are staff about partnership practice?

Participation

How do Maori participate in your organisation?

What proportion of Maori do you have on staff?

In what way do you enable participation by Maori in your work?

Do you korero Maori?

Protection

What do you do to actively protect Maori children?

How conversant are you with tikanga Maori?

How well do you connect with Maori whanau, hapu, iwi, tangata whenua, and Maori from other regions in New Zealand?

Empowerment

What do you do to empower tangata whenua to solve special and all educational needs?

What is the nature of the power-sharing relationship between you and tangata whenua?

Equity/Access

What do you do to ensure equity for Maori as tangata whenua?
How do you enable equal access by Maori to your service or support?
How do you inform Maori of their available choices or options?

Initiation

How is contact or work with tangata whenua initiated?
What do you do to enable Maori to initiate action?

Benefits

Who benefits from your work?
How do Maori benefit from what you offer?

Representation

How are the particular needs of Maori accommodated in your work?
How do you uphold Maori tikanga?
How do you ensure that the concerns of Maori in particular are considered in the course of your work?

Legitimation

In what ways do you ensure that kaupapa Maori is upheld in your workplace?
Are Maori able to korero or communicate in te reo Maori with options for kanohi ki te kanohi in the practice of your work?

Accountability

In what way are you accountable to Maori?
When was the last time you talked about this with a Maori person?

MATAURANGA MOTUHAKE CASE STUDIES

**WHANAU EXPERIENCING SPECIAL EDUCATION
NEEDS BECAUSE OF DISABILITY**

TE WHANAU O MEI

Mei:	Maori spelling of May
Mariri:	Gentle—Mei’s mother
Koro:	Grandfather—Mariri’s father and Mei’s koro
Nan:	Mariri’s mother and Mei’s nana
Piki:	Helper - Public Health Nurse and family friend
Pakari:	Strong—Mei’s father
Wiremu:	William—Mei’s twin brother
Hemi:	James—Mei’s older sibling
Whaea:	Aunty—Mariri’s sister and Mei’s aunty
Lee:	Whaea’s son and Mei’s cousin
Mohe:	Soft—Mariri’s sister and Mei’s aunty
Jay:	Mariri’s brother and Mei’s uncle
Pae:	Mei’s younger sister

A premature arrival, 4-year old Mei attends a pre-school for the deaf with her twin brother Wiremu. Mei has multiple disabilities and special needs. Mei’s mother Mariri and father Pakari are profoundly deaf. Mei’s whanau moved from their own land as tangata whenua into a city where they are living away from their own land, and access a wide range of specialists and services. The extended whanau supports Mei. The story of Mei, and her siblings, parents, aunty, cousin, and grandparents is told in this inter-generational story.

Mariri’s Story

Mariri is Mei’s mother, she was born ‘in the wop wops’ in the far north, the first child of Koro and Nan. The reality of having a child with special needs in this whanau was intrusive and dramatic. Her deafness changed the destiny of the whanau and had a huge emotional impact:

Mariri was about 9-months old and starting to pull herself up and this particular day she was pulling herself up on the highchair. She was the one to pull the top off, she dropped it and it was the most awful noise and she just looked at me. I whipped her up off the floor, put my mouth in her ear and screamed at the top of my voice and then really went into deep depression right from then on. I’d actually had rubella, there had been an epidemic at school and I had mistakenly believed I had antibodies.

She was taken to the doctor about 35 miles away, it would have been about an hour then, before the shorter road. It was a specialist visit so we had to wait to see him. We took Mariri in and the first thing I noticed on the specialist was that he was wearing a hearing aid. I thought, ‘Well, he can’t be much good, he can’t hear himself’. The irreverent sort of thoughts that pop into your head but when you’re in grief and shock—you’re not thinking rationally at all. He just said, ‘I will make a referral to the school for the deaf’, and Koro and I just went home.

I know that that was the most terrible moment of my life and we just cried and cried and cried and cried, it was just awful. It was also because of the isolation. I didn't know anyone who was profoundly deaf and all I could think of was the future. I thought of ridiculous things like the piano we had, Mariri would never hear the piano. I focused on all those things, from my perception, that she would never be able to do. She won't hear our voices, there is so much that is special to you when you're a mum and a dad and she won't have those things.

The doctor referred the whanau to some of the available support services, including the Public Health Nurse and the Specialist Education Services:

There was a pair of peripatetic teachers of the deaf who would come every 6 weeks. Mariri had her first hearing aid fitted at about a year old. It had ear moulds, two cords and the microphone on the front, it was like a Berlei bra thing. That was just so awful, it was like putting a stamp across [saying], 'This child is different'.

Mariri did not like the equipment designed to help her hear:

Mariri used to ram porridge down the microphone or drop it or pull her earpieces off and throw them over the neighbour's fence. I remember crawling around looking for the moulds. She used to flush them down the toilet, chew the cords of her hearing aid but it was, 'Hey, sorry people, you're not getting a visitor for another 6 weeks'. These are the ones that travelled out to us; they brought us the new batteries and the new cords we had to replace. We were so isolated.

Life went on for the whanau, with increasing demands on Nan as the parent and teacher of Mariri:

The difficulty up there was, I'd been working. I spent as much time with Mariri after school—I didn't have time for me. I was always teaching and I lost the mother/child . . . I lost that very precious part where you do the silly stuff together, always we're doing the 'one-to-one matching'.

The pressure became too much for Nan, especially with the births of three more children—Whaea (11 months later), Jay (15 months after Whaea), and Mohe (two years later):

I was still teaching and pregnant and there was Mariri. The pressure was already there and that was the beginning of my depressive illness. I had high anxiety which eventually escalated into full-scale depression, which I had for 15 years. This was near enough all the time of raising Mariri and her three siblings. It was trying to attend to all of the children's needs too; in those days you just coped. The only way I got a rest was by having another nervous breakdown. That was the only time I'd go away to 'the home for tired mothers' and recover sufficiently to get back and wade in again. No time out, no helper support and we had no family down here, we were on our own and it was terrible. I was on a huge amount of anti-depressants and I had an addiction to tranquillisers. I had other things like agoraphobia and claustrophobia while trying to look after the kids.

The Public Health Nurse, Piki, was able to give Nan hope and to confirm her inner strength:

I always had the belief that somehow we'd get through, there would be light at the end of the tunnel and Piki said, 'Nan, you'll never ever believe this but you will get through, it will come to an end'. Well, it did and of course what I learnt along the way was precious.

When Mariri was 4-years-old, Koro and Nan decided to shift to the city so that they could have access to the school for the deaf:

We were told that if we wanted her to start school at 4 we would need to relocate, if she was to come as a boarder they would not take her until she was 5. Mariri was our reason for being here but at the time we thought, 'Just for her schooling and then we'll go back up to the far north'.

It was a hard decision, but in the midst of it, a small message of hope for the whanau arrived:

I was moved tremendously by a wonderful letter I got from the principal. He wrote that Mariri will be able to do lots of things, she'll be able to drive a car . . . I mean I hadn't got as far as thinking about that.

The move to the city was to affect the destiny of the growing whanau profoundly. Mariri's father, Koro, had always intended to take the family back north, but the children put down roots in their new home, and eventually the family decided to stay put:

In the meantime the other kids grew up, all of their friends are here. We just couldn't do that. We're still here now. We had the opportunity to go back home 4 years ago and I chose not to go. Too much time had gone by and there were others that I spoke to up there and felt that they were almost strangers. So much had gone on in between and they'd missed out on all of that. The children had missed out on the history back home.

While Koro was able to accept the change for the whanau, Nan felt bad about it:

It was worse for Koro than for me. I've been a wanderer on the face of the Earth but I recognised and grieved over what it meant to Koro, knowing about the attachment to the land that they'd struggled so hard to get in the first place.

Nan reflected that responding to the special need in the whanau could cause challenges to marriages and families:

I regard us as being supremely blessed that we are still married because so many marriages break up. I noticed the children at the school for the deaf—there were a few who were being cared for by their mothers, not all of them still had both mum

and dad. There would have been various reasons for that too; it may not have just been the handicap.

Mariri was educated at the school for the deaf and the whanau learned to adapt to her special needs. Mariri was taught to lip-read:

She would understand what you were saying and she could speak to you. The way in which Mariri was educated—it was talk, talk, talk and they will learn to lip-read. There was so much that we, as parents and siblings, were simply not able to express because sign language was not allowed. We were told to sit on our hands, you know how you make gestures, we were told, ‘No, keep your hands behind you and talk, talk, talk’. Well, the children lived in a world of compounding confusion but that was thought to be best at the time. We complained about it, we were angry about it. We had it emphasised to us the absolute cruelty that there is in denying access to language because that has also happened for the deaf. Ultimately, when Mariri began to be more proficient at lip-reading, we could converse.

The difficulties caused by a lack of communication between Mariri and her parents were keenly felt by Nan:

There are still all those years when a lot of really important stuff that belongs to each stage of growing has been missed. As parents we wanted to share all sorts of things with our children. We had the home-school notebook, we drew pictures and we had a caption underneath. Well, that expresses only a very small part of what you would dearly want and love to be able to say to your children and what you would dearly love to hear back from them.

Mariri’s siblings had their own means of communicating with their sister. Mariri’s sister Whaea recalled:

I think we had our own language because quite often Dad and Mum would call us in to see what Mariri was saying because they couldn’t understand her. It was left to us to figure out what she wanted us to do or tell us and that included TV. She couldn’t hear it so we had to explain what was happening. I remember a lot of times there was four of us sitting in front of the TV and Mariri would always be tapping me on the shoulder to say, ‘Hey, what’s happening?’ Thinking about it now that was actually quite cruel because she used to be able to lip-read it but she couldn’t really get the gist of what was going on.

New technologies were starting to make a difference for the whanau.

Nan:

The really wonderful thing that happened was the teleprinter because then Mariri could be an ordinary teenager and would tie up the phone for an hour-and-a-half like everyone else did. When we got a Teletext TV we heard her, I mean there were tears when we just heard her laugh instead of someone having to explain to her what was happening. She could read it and she’d laugh.

Whaea:

Now we've got Teletext but Teletext is not on all the programmes, it's only certain ones and that must frustrate the heck out of them because Mariri really likes TV.

After schooling, Mariri's life progressed with her whanau and friends and she eventually met Pakari, her future husband.

Whaea:

The deaf had their own community and that's how they met, most of the deaf couples of Mariri's friends, that's how they all met. They didn't go to school together but she knew of him through friends.

Mariri and Pakari eventually married and have four children.

Mei's Story

Mariri and her profoundly deaf, non-verbal husband Pakari are the parents of Hemi (aged 5), twins Wiremu and Mei (aged 3-and-a-half), and a new baby Pae (aged 9 months).

Wiremu and Mei have special needs. They were born 25 weeks prematurely and were not expected to survive.

Nan:

Well, Mei . . . was presenting a little foot. The doctors came out and they were briefing all of us, they just said, 'There is a possibility that she won't survive the birth'. She was so little, 700-odd grams. So we were warned then that the situation was grave. They were actually all right for a couple of days but then all sorts of things happened.

Whaea recalled:

They had to spend the first two months in the Neonatal Intensive Care Unit [NICU] and then they got put up into the Special Care Baby Unit [SCBU], getting ready to come home.

Mariri did not stay in the hospital with the twins but travelled to the hospital to feed them.

Koro:

She had to supply the new babies with milk—what little milk she had. She was just like a cow going to the shed on the dairy farm, she'd arrive at the hospital, go into a special room and you'd hear the milking machine going on.

Nan:

Mariri elected not to stay at the hospital even though we encouraged her to and promised our support. We believed it would be much better for the babies but in the end we had to recognise that Mariri and Pakari were the ones making the decisions and that we would support them in whatever decisions they made. Koro and I went in and I went in with Mariri every day. Given that they were so frail it seemed as though Mariri could have stayed there with them at the whanau room. She considered it.

Whaea:

We went down there to check out the facilities but I don't know if Hemi couldn't stay there with them or something happened. Mariri decided 'no' because she wanted Hemi with her all the time, she didn't want to leave him at home, which was quite understandable, she didn't know if her babies were going to survive. It was also because she was living in Auckland and first preference went to whanau that had to travel out of town—she would have to move if whanau came in and she just couldn't be bothered with it.

Nan recalled the care that was available for Hemi while his brother and sister were in hospital:

There was a very nice crèche at the hospital, he went into that and it was helpful for him, he did a lot of language development. The teacher was wonderful to him; Hemi began to settle in very nicely. It was an environment he hadn't had, a hearing environment.

Mariri and various members of the whanau were travelling 30 minutes to and from the hospital each day. The pressures mounted on the whanau. Nan continued:

Mariri and Pakari made the comment that—how did they say it? That the babies are not theirs, the nurse is doing all the work.

Whaea:

No, they didn't have a bonding because pretty much they had switched off.

It appears that the hospital service kept the whanau informed.

Nan:

We'd been told that each year there would be eight babies in the most severely ill category—and three to five babies who would survive. And the twins survived.

I remember saying to the paediatrician, 'You'll let us know if anything happens, you'll get in touch with us straight away?' He said, 'You don't understand, they're

on total life support'. Well, we didn't, we had no idea. We'd ring the hospital and say, 'How are the babies?' 'Oh, they're stable'. So we thought—that's okay, they're stable. We thought 'stable' meant 'good'. Then one day I said, 'Well, if they're stable, why are they having all these problems?' And they said, 'It means that there isn't anything that's too life-threatening happening at the moment'.

Mei developed hydrocephalus, she had head-bleeds which were grade 4, which I gather were the most severe. So her head just started to grow, we could see it.

Mei's whanau found ways to support her:

I remember them saying, 'We're going to have to do a lumbar puncture', and I said, 'I want to be there'. 'No, you don't want to be there for that', but I stayed, I said, 'I don't want her to be on her own'. And then it started on the head, they wanted to put the big needle in and draw the fluid out of there too and it was the same thing there—'No, you don't want to see this, you don't want to be here'.

I used to sing to her, I used to sing the same thing over and over again. I don't know if it's for her or for me but "Moe, Moe Pepe" and that one "E Runga Te Raupo" and "Hine e Hine". I've not been brought up in a really close family and what Mei did, she helped me to see the tremendous importance of connectedness, of hearing the voice, of feeling the touch, of knowing that someone's near.

Mei was blessed with signs, symbols, baptisms, karakia, matakite and faith:

It was such a terrible time that we needed signs and symbols almost. There needed to be things that were going to carry us all through. So we decorated the incubators. Apart from the baby books, we had all the family photos, the Guardian Angels, Pakari's family tapestried the twins' names and that gave me a pang, I thought, 'Oh hooray, Mariri and Pakari have got something if...'

Then I went into another stage which was 'we celebrate the day that is'. Every day that I'd go in there I would bless the door to the incubators so that every hand that entered that incubator would be a hand of healing and harmonising. Sometimes I wouldn't trust the hands that went in there.

Nan recalled:

The twins had a lot of baptisms, they were baptised before they were born, there were two priests came and blessed Mariri and the twins. Then Koro's brother who is a minister came down and he blessed them, brought the water from a spring on family land. It was a way to me of that connectedness with the land—the twins' whenua went back there, very close to the place that the spring came from, so there was a lot of connecting there. These little ones, even though they were so frail and so terribly ill, there were their ties, their bonding to their own was happening then.

Nan asked Koro how he felt when the whanau came down from the far north and brought the water from the tipuna. Koro recalled:

Just as well they didn't ask me because I would have said 'No' at the time but I thought, 'If that's what they want to do, well, they can go ahead'. I've never been superstitious, that's through the upbringing I had, of course, but that doesn't mean to say that I'd deny anybody else who wanted to do something because—oh, there might be something in that too. I wouldn't know because I wasn't taught about that—that's why I see a lot of these hoodoo Maoris, I think it's all hoodoo because after years I think all those people [tohunga] are not here, they're gone, those are the people that can do that thing.

Mariri identifies very strongly with her Maori side, as Nan recalled:

She hears things, she sees things, it happened there at the unit. Over here at our local church we had the congregation praying because the twins were just getting sicker and sicker—little Wiremu's heart being opened up again, Mei's head had been growing and there were times when they said, 'Don't even talk to her, she can't stand the stimulation', she was that sick. The church had been praying and of course me. 'Mei' can be looked at as a form of Mary and it was a big Mary feast-day that we had. I'd been humming the hymns in the room there but I was with Wiremu, Mariri only was allowed to touch Mei and they used to notice Mei's need for oxygen would decrease, the stress would decrease as soon as she felt her mother's hands. This day Mariri was cocooning Mei when she had these things that happen to her, it's almost like she's going into a trance, she becomes very warm and very sort of dreamy, she said she felt as though arms were enclosing her and the baby. I didn't know the prayer group that I belong to had been praying that Mei would feel arms surrounding her and caring for her every inch of the way. Mariri actually felt them—I suppose it might seem rather strange to some people—we just accept that she feels people.

Whaea saw Mariri's ability as "a sixth sense", Koro called it "matakite", and Nan recognised "the Celtic side":

I talked about signs and symbols—the priest who came in to give the babies their emergency baptism, we felt it was a sign because he said, 'I was one of twins born at the time we didn't have incubators. My grandmother popped us in the stove in cotton wool—you know the old farm stoves'. Those were the sort of things we needed to hear so once again we can move toward the light.

What it taught me in terms of faith was the importance of surrender, of being able to say, 'We love these children, we value them and we want to give them all the love we can for this day. We recognise it might be too much for them and they might choose to go. If we just sing to them and if they know that there's all this love surrounding them—this lovely warmth and the arms that they could feel, they might choose to fight'. We couldn't even hear them cry, they didn't cry, we all cried when they first cried, to actually hear them cry—that they had the energy to do it.

It's a different dimension of living that you're taken into. I think that was the thing that was important for me, the fact that when you stand by that incubator—sometimes I stood there 7 hours at a stretch—it was clear to me that surrender was the important thing, that we don't want to hold on to them at all costs, it might not be

best for them. So we had to be strong and able enough to let them go if that's what they wanted.

Nan recalled her interactions with other whanau in the NICU:

We became very close to certain people there, although you mightn't talk a lot we became close in the sense that we would look up and smile. There would be a connectedness through that because we were all going through exactly the same thing.

At last the twins were able to leave the NICU:

It's like the big promotion—you say, 'Yay, they're going up to SCBU', they went up in incubators. We all had a big birthday party and we were very happy, because they leave hospital when they arrive at what should have been their birth-weight.

Mariri and Pakari stayed with Koro and Nan during the twins' stay in hospital and for a while after they left the hospital:

When she eventually brought the babies back they were all living here, which was quite good in a way because even though they had apnoea monitors and what have you, they needed the ongoing support. They didn't actually want to be here, they wanted to be in their own place, which is perfectly understandable, but Mei had been through so much and was such a frail child and we knew when she came out of hospital she would be special needs.

When I would talk to Mariri she appeared to understand what it all meant. But then it's one thing to understand and it's another thing when the reality is hitting you. Pakari was continuing to go to work. They were having broken nights. Those babies had been tube-fed for quite a long time and when they were feeding it was kind of little and often. They weren't breastfed babies in the sense that Mariri put them to the breast, she didn't, she expressed and gave them breast-milk and then they went on to formula. The strain would have been too much for Mariri.

Finding the balance between offering support and the need for Mei's family to grow itself is an ongoing challenge for the whanau.

Nan:

We had a real problem around doing too much in that we were there pretty much every day at Mariri's place, offering support. We noticed it more so when she was pregnant with her fourth child, in that physically she couldn't do anything for the kids. She was actually really sick for all of three months. It was terrible, she lost about 10 kilograms, and she was being monitored regularly at the doctor for the blood pressure. So looking after the kids did fall to us. Pakari could only take so much sick days off work, in fact, I think he didn't have any sick days after a while. Pakari was doing his bit, as in keeping the household running, because Mariri couldn't go into the kitchen, she couldn't cook.

Nan recalled that the whanau was advised of available support services:

‘Right, now we’ll get a social worker in’, this is with an interpreter and of course these were the complications when you had special needs, that there had to be interpreters for the deaf. There’d be these big multi-disciplinary meetings and it was so hard to take in the information but it’s even harder when you’re deaf. It was really, really hard.

When it was said, ‘Now we’re going to get the social worker in because there’s going to need to be a special benefit for Mei’, I think that’s when it hit me, those were the moments of truth, you know—this is what we were facing. We knew that all this was a possibility but there was all the joy that the twins still lived because it had been so unexpected.

One thing they did say was, ‘We do not know how the brain damage will affect her’. What we were left with was—we will have to wait and see as she reaches the developmental stages, we will have to wait and see what she can actually do, we simply do not know.

At the time that the story was shared by the whanau, Mei was 3-and-a-half. There had been subsequent testing and she had gone through several developmental stages. Services were being provided for Mei and supplemented by therapy from Nan:

A child-development expert looks at the stages and looks at Mei’s ability to move, to sit, to climb, all that’s assessed once a year. The specialist makes recommendations, something like, ‘She really does need to have more speech therapy’. The speech therapist sees her every week. We have now gotten to the stage where Mei is rather sick of people sitting with her one-to-one and being all earnest. Having come through the talk, talk, talk and the patterned language, I take her over to the sink, she’s a little floppy doll but I sit her up there and I do things with her over there and we talk about what we’re doing. That’s what she likes to do, she doesn’t like saying words, she likes speech.

The whanau is concerned about changes to support in the future.

Nan:

We’re operating very much as a unit to offer support. What happens if some of the pillars (and we’re all pillars) go? Because that’s going to mean more for the others to do, bearing in mind that if it was just Mariri having to do this, if Koro and I dropped dead tomorrow, she would have to take responsibility for at least some of this.

Wiremu’s Story

Mei’s twin Wiremu is not officially classified as having special needs but Nan has a different view; she described some of the health problems Wiremu has experienced:

I think a usual thing with preemies [premature babies]—they're undeveloped and there's a hole there in the endomygium. It closed and then it opened and it had to close again. They were saying, 'We would much prefer not to have surgical intervention'. You wouldn't when they're so frail because Wiremu was the one eventually who started to lose weight, even from his 900 grams, he went down to 500. I was looking at him and thinking, 'He's not going to make it, he just doesn't look as though he's going to be able to live'.

He had this enormous hernia so he was operated on before he reached his birth weight and he had the worst lung damage of the two, that left him with a tendency to get colds very easily and to go down fast. He had a lot of ear trouble and he had a problem with reflux and he's a 'boy' boy—bang, crash, wallop, up, down and bouncing on the beds and of course vomiting all over the beds.

He bolts, he runs away. He's just so active, he wants to be out there, he doesn't like being in here, he hates it, and he likes to be outside or in the garage with dad. Even at home Mariri constantly has to say to him, 'No, don't go outside' because of his chest, he gets colds so quickly.

It was soon discovered that Wiremu also had a hearing problem, but a less profound one than his twin. This happened –

... via the grapevine through Mei's caregiver saying that Wiremu was being naughty and wasn't listening. I said, 'Well, how are they getting through to him?' 'Oh, they're signing to him', and I then picked up—'Oh hello, he isn't hearing properly'.

While caring for the twins, Mariri was pregnant with her fourth child and ill. The whanau took action to support her.

Nan:

I suggested then that I would do some of the hospital visits, it was really hard to find the people that you had to deal with. We just got used to a whole lot of stuff then it was a new ball game, it was different from having a deaf child. So Wiremu eventually got back to the hospital, he got grommets, then they came out and then it was hard to get another appointment, waiting times and all the rest of it.

Another series of services assisted with Wiremu's need:

The school for the deaf wrote a letter and the hospital looked at his ears again because he was always very adenoid or very throaty. I remember I tried to get through to the hospital, it took me an hour-and-a-half on the phone to get through to the people that we needed to be talking to. It all worked out well because the guy said, 'Okay, I've got an appointment, come in tomorrow'. He said he'd take Wiremu's adenoids out.

On top of the physical problems the whanua faced, and the emotional repercussions, simply getting Wiremu to the hospital was difficult for Nan:

On the day that I took Wiremu there I had to park over by the museum and walk a three-year-old child on a freezing cold day, a child with quite severe lung damage, across the park to get him to the hospital. By the time he was supposed to have the procedure he got a rattle in his chest again and they couldn't do it.

Wiremu's health problems continued:

They then began to suspect that Wiremu had sleep apnoea and that he wasn't getting enough oxygen. He was already a bit lung-damaged and it had shown up on the scans. Then the specialist said the adenoids are secondary, it's tonsils that are the big problem, so he's now without those.

If we're looking at the bigger view, he is a twin of a special needs child and he has special needs of his own regarding access of time and energy from people for play because his perception is—Mei's getting it all.

The whanau was in close contact and so was able to identify this problem.

Whaea:

Mum's actually really involved with little Miss Mei, as in speech therapy, she had chosen to spend that time with Mei because Mariri just physically could not do the speech therapy. We all had noticed that Wiremu was having pretty wicked behavioural problems, as in chucking tantrums and wobblies and he just does naughty things because he wants attention. So I talked to mum about it on a number of occasions and said that I would look after Wiremu, as in take him out—special outings, all by himself. I actually had started taking one of them out a week, like Mei on a Friday because she doesn't go to pre-school, then a week after that would be Wiremu's turn and Hemi usually comes over in the weekends. Wiremu was the one that I noticed and I actually got quite hurt, it must be because I identify with being in the middle and having had a sister who was special.

So when they come here we would look after him. We don't make it obvious, as in the other two go away while Wiremu comes here with us. It's more that we tend to look after him, take care of him and we can do that because we're a big family and there's usually an adult to each of the three of them.

Using the Services

Nan saw that the major difficulty for the whanau in trying to care for Wiremu was in accessing the appropriate services:

It took a long time to access the service in such a way that things started to fall into place. Your frustration lies in trying to get in touch with people, because members of the whanau are not hearing and having to use faxes, and the services don't always clear their faxes. How well are you able to care for a deaf client who needs your services when she has two special needs children?

Whaea explained how the whanau supports Mariri by dealing with the difficulties of access for her:

We do it now, things like phone-calls and faxes. I think it's actually quite insensitive, a lot of the places that don't give you fax numbers, they give you phone numbers. I mean, what's Mariri going to do with a phone number? She doesn't need a phone number. I put in bold, '**Profoundly deaf, use fax**'. 'Oh yes, but no one reads records.' I asked them to . . .

Mei's specialist treatment places huge demands on the whanau.

Nan:

We have [a] multi-needs child. You know how there are some special needs that are individual in the sense that you're deaf, you're blind. Well, Mei has got a range of needs. My diary is not really full of my own work stuff; it's full of Mei's appointments that I take responsibility for. There's physiotherapy, she has speech and occupational therapy, and they work six weeks turn and turn about. She has a yearly appointment with the neurosurgeon. She also sees the doctor for certain checks and she occasionally goes to the orthotic centre.

Nan subsequently wrote a fuller list of the specialist appointments to which the whanau was committed and the twins' ongoing need for services:

For both Mei and Wiremu:

Appointment	Frequency	Nan's Comments
Doctors' visits	Frequent	
Time in hospital	3 of 4 winters	Asthma
Audiology Centre	Yearly	They are <i>not</i> deaf
Hospital	Yearly	Specialist in child development
Early Childhood Development Service	Frequent	Occupational therapist & physiotherapists
School for the Deaf Early Childhood Centre	Mei—4 days per week with a caregiver funded for 3 hours per day Wiremu—5 days per week	Variety Club provided van for transport

For Mei only:

Appointment	Frequency	Nan's Comments
Orthotic Centre	Twice-yearly	For boots and splints
Neurosurgeon	Yearly	Shunt in head
Child Health Clinic	6-monthly checks	
Eye Clinic, Hospital	Yearly	Mei's eyes—watching squint
Early Childhood Development Service	Weekly	Occupational therapist and physiotherapist
SES Coordinator	Twice-yearly	Goal-setting with all involved
Special Needs Assessor	When needed	Benefits and other services information
Speech Therapist	Weekly	Nan also works 1:1 with Mei

The costs and challenges to the whanau are constant and varied.

Nan:

This is travelling we're talking about, this is time, energy, and money, and of course you do it because you love your mokos but it's also costly and for me it's not so much the money—you can always find money somewhere, it's the time and the energy.

Getting to the hospital, impossibilities of parking, it's absolutely hopeless. They've since said, 'Get in there by bus if you can or get someone to drop you off'. Mariri's got a baby to take with her too, plus Mei, who she can't carry, Mei can't walk yet. Once again it comes down to accessibility.

I never give up; we've learnt that though. But I'm not good at yelling and screaming, I mean some people can just do it and it's great and I wish I could do it too but I'm just dogged, I'll say, 'Well, put me through to someone who can help me. If you can't, who can?' And I'm also very good at reading leaflets and reading it back to them, what they're supposed to be providing us in the service. Those are the things you get through trial and error, I know, but because of the background I've got in mental health too, I'm very aware of the needs of consumers. People give up very easily if it's too hard to access the service.

Koro:

Why do they make these services hard to access, for ordinary people to have access to them, why should they?

Nan continued the story of accessibility to services:

The school for the deaf's pre-school is brilliant because they've got a mini-bus provided by the Variety Club of New Zealand, now, God bless them! Mei comes home on the mini-bus, the workers usually bring her up to the house, up a lot of steps.

In fairness to the physiotherapist, they always visited in the home but I believe it is better for Mei to go to the gym, they have a bigger range of things there and there's more room. She could throw the big ball and they've got the climbing frames.

I have nothing to measure [the Special Education Service] against but compared to what happened when Mariri was young, I think they have been wonderful. There is a co-ordinator who every so often calls a multi-disciplinary meeting with everyone involved in Mei's growth and development—so that's her caregiver over at the school for the deaf, speech therapist, occupational therapist, physiotherapist, who else? Us, that's right—whanau, Whaea when she's available, we're all in on that too and they set goals for the next little while. There might be speech goals but they're quite specific—she needs to be using more verbs, she's got enough nouns now, her sentences need to be longer—so we know exactly what to do with her and that's great.

When asked if the whanau felt comfortable or safe with the services and looked after by them, Nan replied:

Yes, I do actually, and I can honestly say that. I learned by trial and error that there are certain ways of asking questions which are, 'What do I need to know that perhaps I don't know because I've never come across this before'. Or, 'What are the options in this? What are the ramifications? What might that mean out there?' It might be quite difficult for people that haven't been around different systems or institutions.

Whaea's Story

Whaea is 11 months younger than her sister Mariri and has a son, Lee, a first cousin to Mei. She is a sole parent of a child with special needs.

When asked what she saw as special needs for Maori, Whaea recalled:

From our time in kohanga reo—the amount of children who came there with health problems and the whanau didn't know how to access health care. I think we were in kohanga when it was relatively new. Lee was 18 months when he started at kohanga and to me that was choice, it meant that I didn't have to rely on Mum and Dad to get me to the doctors with Lee because they just came straight there. The only problems I did see with that was some of the whanau actually waited, the kids would be sick and they waited for the van, they wouldn't or didn't know where to go. We'd be saying to the whanau, 'Hey, do something, the nose is running', and we knew it was glue ear but the whanau would say, 'The van's coming in three weeks' time'.

At one stage in Whaea's story, she returned to the far north:

When Lee and I moved back up north they had a doctor's service running at the school and the doctor would come in every Thursday and kohanga kids had access to it. I was working at kohanga and we would take the kids over and it would usually always be glue ear. The dental service used to come out with a mobile dental van which our kohanga kids had access to as well.

We didn't have that down here in Auckland, but Waipareira Trust have been great because they actually get the vans and go and visit the kids now. Once a month they have the Well-Health checks at Kura. Waipareira started that because they saw the lack of support, that there was nothing.

Reflecting on Lee's special needs, she said –

It was more behavioural. He was 8, that goes back to the break-up of my relationship with his dad. I knew there was going to be problems there and I wanted someone that Lee could talk to or that we could both go to but we didn't know where to go or who to go to. We didn't want to go into a system that wasn't going to cater for Lee because he's Maori and that's what he's comfortable with, that's what he's known all his life and that's what I wanted, someone that he was going to be comfortable with.

The whanau worked together to find a service for Maori, as Whaea's mother Nan recalled:

I looked through the phone-book, I looked for Maori Mental Health Services specifically. It didn't take me too long to find them.

Whaea:

Now I'm with a Maori children's service, they work on the whole family, it's a counselling service I guess. They do it the Maori way. It is really facilitation 'cause it's the whole group, it wasn't just taking Lee in there and having somebody see him for an hour, it was the whole whanau—me, Nan, Koro, and Lee.

You know this place is just so Maori you're comfortable as soon as you walk in. The lady that Lee sees speaks Maori to him so it's on his level. I don't understand what they're saying sometimes, that's probably a good thing because it is her finding out from Lee how he feels. Sometimes I couldn't do that because I was too close to the situation. That's what I liked about that place.

The other thing about it was that the last meeting we had included my ex-partner and myself. He said afterwards that it was just awesome. He had counselling because the courts told him to have counselling. He walked into this place and straight away he was put at ease and they did the mihi and there was a kaumatua there and a whaea and they did the whole thing—karakia, mihi, and just put him at ease.

While Whaea was visiting the Maori children's service with Lee, she was undertaking full-time study at polytechnic for a Bachelor of Nursing degree. In the year 2000, Whaea is continuing her nursing studies:

... but part-time this year, which means I've got more time helping out with Mariri and the kids. Mum and I work out—like with Mei's appointments or Koro's appointments—if she can't do them then I'll step in and take them. So it gives Mum a bit of flexibility to be able to do what she does. We work pretty good as a unit, don't we?

Nan agreed:

I think we do, and of course having had Mariri for all of those years and her siblings having all helped variously to take responsibility for their sister, that's continued on, it's almost like a progression.

Whaea:

I believe it needs to start with the individual educating themselves to be able to access whatever they need to access. I used to be there myself, I didn't do it because I didn't know how to and that was simply it. I wouldn't push myself because I didn't want to be knocked down or I didn't want someone just saying, 'Well, you know there you go, you just can't do it anyway, can you?' You've got to educate yourself these days because nobody else is going to do it for you. That's where I believe Maori have fallen down. It's okay if you've got a good support system within your whanau or hapu or iwi, but if you don't have that—and you know for somebody coming down from the bush to the city—if you don't have those links, you're pretty much lost.

One of the things they say to us in nursing is that it is our job as the primary health-care giver, like in a hospital situation, to be able to have that knowledge to pass on to our patient. You know that you're pretty much there as an advisor to them in whatever they want and whatever their needs are. And there's a box now in the forms when you're doing your assessments and it identifies you as Maori: 'Do you wish to have any of the Maori services that are in the hospitals?' And for a lot of Maori people, they didn't want to be identified as Maori because they didn't want to be a statistic, which meant that they didn't have the services offered to them. You know, they didn't want to have the kaumatua there to say karakia because it would identify them as being different, but I think in these times if you don't do that you're not going to get the services and that needs to change. One of the things that we have talked about in some of our tangata whenua papers is having information there, as in when you go into the doctor and the doctor's learning to say to their patients, 'Do you identify as being Maori, have you heard of the Waipareira Clinic? Have you heard of the Maori services? Would you like to know more about it?' A lot of them won't because it identifies them as being Maori and therefore you know—special—but I think that needs to be up to the individual.

We need the people here that are in the know to be sharing that. I mean, we do it for the whanau when we go back up north and if anybody's having a problem they'll come to us because they know that we've been there. But we freely give the information as well, we don't hold on to it. Today's buzzword is 'networking', [and] now of course whanau network. The marae is actually a network in a sense and of course the whole of Maoridom is a network because you're usually related to someone who's related to someone.

But in terms of the Pakeha aspect of networking, you've got to have a huge bundle of cards in a special book, you've got to have one of those diaries where you've got all of this stuff—your contact person is, the fax number is, the phone number is, the mobile number is, these are the times when you can phone them. We've had to run a special file. Now for the ordinary person, how in heaven's name are they going to do that?

Whaea reflected on her access to services for Mei and Wiremu:

Well, I'm not afraid of the hospital system. Nursing has been really good for that in that I know what we're taught about at school. All your focus is supposed to go into the patient and you're supposed to make things happen for them, they shouldn't find their time in hospital a trial and a lot of them do. A lot of it is Maori as well because they don't know what their rights are.

But usually with the twins, I haven't had many problems simply because I'm not scared to say, 'Hey, what's going on, why is this happening?' If Mariri's waiting for an appointment like she so often does, they say it'll be 6 weeks time and 8 or 9 weeks later there's been nothing. Usually it's because they've forgotten or it hasn't been entered into the records and that annoys me because that's not good customer service. I don't have the problems or if I do I usually get them sorted out pretty much straight away because I'm not afraid to have a go at anybody sitting behind a desk looking at me rather vaguely.

The whanau can access support because of prior experience and because they have mixed blood in the whanau, as Koro stated:

I must emphasise here—because of Nan being a European she knows which buttons to press.

Nan was not so sure:

I'm not always sure what to ask for. I think it's about learning how to find things out, the words to use. One thing I've discovered with the system now is you have to be very clear about what you need and for a lot of people, they're not. I've missed the bus on quite a few occasions because I haven't understood exactly what the requirements are. That's a difficulty with people who might struggle with communication. In terms of our whanau it was concerning me because I'd lived up north and we go back up quite a bit and I hear up there—'Oh, how's so and so?', 'Oh yes, they're not too good and this isn't too good', 'What is the doctor saying?'—

everyone looks rather vague, you know. I've noticed that with Koro's family, they don't actually talk about things like that, it's a much more general sort of moving in from the outside somewhere, it's a different style of communication.

The whanau is linked through all three generations back to the land of their own hapu. Mariri chose to give all of her children Maori names, spending "hours and hours" looking for their names, and they are immersed in Maori culture.

Nan:

Our young moko goes to kohanga reo at a large urban marae. We speak Maori to them, all the children know little bits here and there and even Mei—"What is my puku?" They're actually very bilingual because Wiremu's really into kapahaka. He's been taught at the school for the deaf, so he's singing. We always talk Maori to the twins and when they were in hospital we did.

When asked to give advice to other whanau in New Zealand, Nan was thoughtful:

I believe there's a role for the families who have dealt with a lot of these things, those who have survived, that have come through and you know—we're already doing this in the sharing of the stories but for people at local levels. Those who are struggling with the fact that their child is different in some way would understand. Well, they've got to start somewhere, so if they're really struggling and they can't get ahead with finding out what they need to know, maybe just talking to someone else makes them feel less alone in the meantime. From past experience it can be a long, slow process and you're going to need support because to me support is the greatest thing, it's what gives you the courage to keep going.

Koro agreed:

I think it's the only thing really—whanau support. With the Maori—they don't think of money, they think of life—life is important to them. Look for a Maori health facility where they've got the nurse, the nurse comes to see you, checks you out and tells you whether you need to go into the doctor, saves you a trip. Now these are good initiatives.

Whaea added her own suggestion:

I always thought it would be as easy as going into your phone-book and looking up 'Maori services' and finding whatever you wanted to, which of course it's not 'cause they all have different names these days, but something like that I would have thought benefited.

Koro is currently undergoing medical assessment involving visits with doctors and specialists. This creates an interesting situation for the whanau, as recalled by Nan, since it highlights again the issues of access, accessibility, communication, and support:

I'm now the translator; I'm the English translator for the English-speaking Maori. It's finally getting through to the doctors that Koro's way of expressing things, if you're prepared to wait there long enough, you're going to get it.

Whaea explained:

We've had to make that quite clear that English is not Dad's first language and even when Lee was doing speech therapy, you know—he'd been in a kohanga reo environment, speech therapy was totally, totally Pakeha. And all the words there, you know—looking at a picture of a sheep, Lee knew what it was in Maori but he didn't know what it was in English. And that was only because there were no Maori-speaking speech therapists at the time.

Nan:

I'm concerned that there are so few trained interpreters for the deaf who can also interpret in Maori. I don't know what's happening with regards to that as an extra resource for those with deaf whanau. Whanau need support. Part of any good support network is the fact that you know that people are going to be there for you when you need them, so it's accessibility and availability. It seems to me too that Maori in these sorts of positions are very much overtaxed because there's so few and everyone wants them.

The whanau had an opportunity to reflect on the transcript of the interview and wrote the following.

Mei's parents have been part of an institution where decisions regarding their disability and education were virtually made for them, recommendations would be made as to their suitability for the Special Unit or mainstreaming or staying at the school for the deaf. They don't have a background in decision-making, they don't have much experience at deciding what's required for Mei, they know about their own disability only and they haven't made the big assertive shift to 'This is what I want for my child' because they are unaware of the options. They live very much in dealing with the needs of the moment. It takes time for them to make informed decisions.

In a reference to the full interview transcript, Nan wrote:

About the 'aroha factor'. Why else would we all do what we do if we just didn't love these little ones to bits. It's not so much about what they know or their optimum for the future—it's about their individual preciousness and the unique place they have in our hearts because they are special. They bring that to us, which has developed our capacity to love and give even further.

Something special has been happening for us too in the opportunity you have given us to share our story—some more healing, some more harmonising, and a deepening of the gratitude that we have always felt that this is our story. In spite of everything, we have been spared to care for each other and our special ones.

Nothing in this world happens by accident and our special children have been given to us for a reason. Even though there can be hard times, how blessed we are and how our little ones bless us.

Arohanui—Mei's Whanau

TE WHANAU O ROSA

Rosa:	Spanish/Italian name meaning Rose
Ani:	Transliteration of English name Annie—Rosa’s mother
Te Ati:	The beginning—Rosa’s father
Mahingarangi:	Work of the sky—First teacher aide for the deaf
Rona:	Encircle—Second teacher aide
Tipene:	Stephen, younger brother

Rosa’s whanau moved from their own farm on their hapu land as tangata whenua to a major town and later to a big city where the whanau is separated from their extended family. Rosa is the fourth child born to her mother Ani and father Te Ati after three sons, and she has one younger brother, Tipene. Rosa has experienced a series of disabilities including deafness. Rosa is enrolled as a student at Kelston Deaf Education Centre (KDEC) in Auckland, and her story was told by whanau in an interview with a Maori teacher working from the KDEC's Ruamoko Marae.

Rosa is a special child for more reasons than one, as her father Te Ati explained:

My wish has actually come true, that I wanted a daughter and I got my wish.

When asked about special needs for Maori, Rosa’s mother Ani answered,

I don’t really know very much about it, well, very little actually, but I think there are special needs for Maori. As an example, for my daughter being totally deaf, her needs are sign language skills. You never see our Maori people bring out like the blind and the deaf very much at the marae, they’re always left at home, they never bring them out. The only one I see is my own girl; you don’t see very many Maori bringing their whanau out, with disabilities anyway. A certain person had his leg amputated and he didn’t want to show it, he didn’t want to go to the marae. Sure his leg was amputated, but he was at the marae all the time before then, he didn’t want to be seen that way, and that’s him. There’s always an individual or individuals that feel like that, some different to others, but I think that was a rarity.

Te Ati:

Special needs children just had to go through the mainstream and be left at the back on their own basically. That was something that I saw—that if you had a disability or handicap or whatever, you were classed as being dumb, no matter what it was. They were ignored, that’s all there is to it. Take me, for instance, I spoke Maori when I was small but I was strapped for talking it.

Ani found out early that there was something special about Rosa:

It was the doctors; they picked it up when Rosa was still in hospital at three months old. We were at the big city hospital then, but I can go back further than that. It was

actually when I was pregnant with her and admitted to hospital for about 2-months bed rest.

Te Ati:

It happened when the hospital said bed rest. Not after the boys, it was natural—she just went on the day, had baby, then come home. With Rosa she had to have that 2-month rest. That made me think, ‘Well, there’s something going on here’. They turned around and asked me, ‘Would you like to meet the baby?’ and I said, ‘Why so early?’ They told me that it was the heart. They had to bring Rosa out early, but they put it in a nice way in that they said would we like to meet the baby. We said, ‘Yeah’.

Ani:

As soon as they said there was a heart problem, that was the first indication that there was a problem, and that’s while she was in the womb. So on the 11th of April about half-past seven in the morning Rosa was born. The heart wasn’t okay, she had a hole in the heart, and she had renal kidney failure.

Te Ati:

That was the other part, after the heart we were told that Rosa also had renal failure, and then that’s when we got a bit worried. When Rosa was born, because of the heart we thought, ‘Oh well, we’ll just go with it’. It affected me more than her [Ani] because she didn’t know what was going on after the baby was born. I knew because I followed Rosa all the time, and it was frightening for me for the simple reason that Rosa went straight from mum on to the machine. The machine couldn’t help her, she actually went on us three times, she died three times, my baby. When the doctor just pushed all the machines away and did mouth to mouth, that’s when Rosa came back to life, and here she is now, it was thanks to the doctor, eh.

Ani:

Rosa was a real fighter, that girl, been a real fighter ever since, got lots of heart, eh. After three months they told us that our baby was profoundly deaf.

Te Ati:

I’ll go back a bit further—when she was born, well, the hardest part about it to accept was that we weren’t able to touch our baby for about 9 to 10 months. Weren’t able to hold her, carry her, or touch her. That’s how long she was incubated for, 9 months. Her eating habits were just—you wouldn’t believe what she can eat now—but at the time it had to be a little syringe, that was hard. It wasn’t through the mouth; it was through the nose, all that sort of thing. That’s the only time we saw her, was at feeding time when we wanted to feed her and that was for 9 months. But the care that the nurses and doctors gave her was just super, I couldn’t believe it, eh,

it was so beautiful to see that people care like that, it was the good part about it. So we basically stayed there with her for 9 months, we lived in the hospital.

I wouldn't wish it upon anyone else, but if you need that help it's there. If we didn't have that technology that they've got, well, I'd say we wouldn't have our baby, I wouldn't have my daughter, I wouldn't have my wish.

Ani:

I wouldn't leave her. You know if you want your baby to pull through, you got to be there, you had to be there to help that baby come through all that. You got to be there to help the doctors, if you want your baby to get well, the doctors can't do it by themselves, you got to be there, and that baby will know that you're there and you want them to come home.

Te Ati:

There were a lot of babies there, you know, that were sick just like Rosa and maybe more. But the families never stayed to support their babies, and then next minute their babies were gone, you know—they'd passed on. I always believed that if you've got a sick baby you stay there, that's what it's all about, that's the way I think, you know if you've got a sick baby you stay there and look after her. So it was from there that after 9 months we moved home, well, we moved to the big town hospital. Ani and Rosa had to both be transferred back and we were there for 3 months, so basically it was a year in the hospital.

Ani:

But that was good, the help was there for us. Then when we lifted our heads up and wanted something it was there, and they went out of their way to do it, you know, that's the great thing about it at both hospitals.

Te Ati:

We had a lot of help, you know, and we have the hospital services right up 'til now. She still attends the specialist every 3 months. We actually started thinking about it, Rosa's special needs, when she was maybe 1-year old. We started then; for the simple reason we really needed the help or someone to show us how to look after our daughter, knowing she was deaf. We'd had a lot of orientation; we learnt about what deaf people thought and what hearing does to balance. We had to know how to look after her, eh.

Ani:

She was really unbalanced. She couldn't sit up; we had to help her sit up. We had to get people in to massage her, and that was from a very early age, I had three different lots of people come in to help me look after her. The specialists from the hospital had to come home and do Rosa up every day.

Te Ati:

It started off at home, it would have been about 2-years old, and then the doctors appointed teacher aides, as well as a speech therapist and it went on from there. From Audiology they started contacting other people to bring in to teach Rosa at home. From age 2 onwards, we started getting a sign teacher in, and they were teaching her at home, as well as a physiotherapist. We were having them both together—while we were trying to sit Rosa up, the other teacher was trying to sign. We had them all together then, and then we had a teacher aide come in and she was learning to sign as well as us.

When Rosa was 2-and-a-half, she started attending a mainstream kindergarten.

Ani:

And then we had all those people go there with her, the signer and teacher aide. From there on she just went on to the big mainstream school, with those same teachers.

Te Ati:

But during that time, when she got a bit older in the pre-school side of things, they started cutting the support hours, so Rosa learnt to mix with the mainstream. They found out that later on Rosa wasn't doing well. The communication wasn't there so we had to get a deaf teacher aide to go in with Rosa every time she went. The teacher aide had to be at the kindergarten to meet Rosa and be there until Rosa left. So basically it was about 3 or 4 hours a day and then she used to come home.

Rosa made the transition into a mainstream primary school with support.

Ani:

She was never alone; she always had a signing teacher with her, right through until school finished. The itinerant teacher of the deaf might come in the morning and then in the afternoon she's got her teacher aide and that would carry her through the hours of school. If there's no-one in the afternoon, she comes home and I've got to be home, you know, they ring me and say, 'Oh, the teacher aide can't teach Rosa in the afternoon, will you be home, we'll have to bring her back', and that's how it used to go.

Te Ati:

Well, the problem after a while we could see it when she was about 7 or 8 years old. The teachers tend to have their time at a certain job, and then they want to take time out. And this is where it started. See, in my girl's eyes, I think it was seeing someone different all the time.

At 8 years the support staff started changing a lot and we could see the change in Rosa and then we started disliking it, I just couldn't understand why this was happening.

Ani:

Rosa had Mahingarangi as her first teacher since she was 2-years old and right up until she was 7. Then Mahingarangi took a break of a year and that's when I saw this problem starting to come up. So what Mahingarangi was trying to do was work in Rona to come up into Mahingarangi's place so when she takes her time out Rosa would be okay with Rona. Rosa was fine with Rona but hey—Mahingarangi's supposed to come back tomorrow morning and she didn't—in Rosa's eyes, waiting, signing, 'Where? Where's Mahingarangi?' So the school went and took Rosa to where Mahingarangi's working and Rosa didn't like that, Mahingarangi shouldn't be there, she should be back at school with Rosa. That was the problem and ever since then things were never right with Rosa.

Te Ati:

When Mahingarangi left she actually changed her job, she went as a consultant speech therapist and she worked in a school so she had an office at the school. Any time we wanted to know something we could phone her and one time we had to actually ring her to come down and settle our baby. The other eight staff couldn't.

Ani:

Rosa had another teacher aide Rona who came in, but oh, that's when the fights started. Rosa got really angry. There are only certain ones she likes, and the mainstream teachers, she'll pick her teachers.

Te Ati:

Halfway through the school year, the teacher in the class would change because, for example, Rosa's main teacher would stay home and do the business that she's taken a day off for, and then another new teacher comes in. Rosa used to leave school, just come home, walk home, because basically I was just around the corner, but that's what she did, if she didn't like anybody, well, any of the staff, she'd just go.

Ani:

Next minute, I'd be at home and I could hear this thumping coming, no-one else with her, Rosa comes in the back door and signs, 'Finished school'. I look at the time, it's not even twelve o'clock, and I said, 'Why?' 'Finished, no more'. Rosa put her bags down, went and got changed and sat down and we had a cup of tea. Next minute Rona comes in the back door. She said, 'Oh, have you got Rosa here?' I said, 'Yes, she says she's finished school, she's sitting down to have a cup of tea'. So we all sat down and had a cup of tea, and I said to Rona, 'What's going on?' Rona said, 'Oh,

there's a new teacher at school, she never smiled at Rosa, so Rosa decided to go'.
And that was it.

Te Ati:

Yeah, she's a hard girl. It was pretty hard, sometimes she'd want to go school, and sometimes she wouldn't. She'd play up in the morning. This is after all these changes started coming; she got real frustrated 'cause she didn't get what she wanted. When we'd tell her to go to school she didn't want to go to school, so she'd play up in the morning. We were actually forced to take her to school, and on the way to school she started having tantrums.

Ani:

And then we got reported.

Te Ati:

We were actually reported to the school and then I got a bit frustrated. Someone rung up and said, oh we're abusing our own child going to school, and Rosa was throwing a wobbly. I'd just walk in front of her and take no notice of her. The teachers knew what we were going through. But it was rung in anyway.

Ani:

I'd just take no notice of her because she'd just sit down on the ground and yell, you know how they scream, eh, yell and scream, and then you'd see everybody come to the door and apparently someone took notice and they rung the school.

Te Ati:

I got a bit frustrated because the principal and Rosa's teacher aide Rona come over to talk to us, and I said, 'Hey, that's my daughter, what I do to my daughter is my business, not anything to do with you'. I couldn't understand where they were coming from so I just turned and I asked the principal, 'Who reported it?' This was my main issue, I wanted to know but, no, he can't tell me. I knew what he was getting at about privacy. I just wanted to explain to that person why my girl was like that and if they knew that Rosa was deaf, and it was just a phase that she was going through they might have understood and kept their mouth shut. That's the whole thing, we've learnt through that, there's people out there that don't know what's going on and if they see that sort of thing they're only acting on what they think is happening to the child. I thought, 'Oh yeah, true'.

Ani:

We tried to get Rosa to school and that didn't work, so the teachers were coming to get her. Then it got to that stage they had to bribe her, like take her to McDonald's first before we go to school or go down and see the trucks or the boats and she'd use them that way, go and have a feed first before you go to school.

Te Ati:

Yeah, play down on those swings and everything. She'd use them that way, and she got them. Then next minute that wore off and then it was going down to the boats, oh, watch the boats come in and got sick of that. Every time she went downtown she was looking for something else for her to go to the next morning or feed the ducks, go to Georgie Pie and have little tantrums there but that's how they were getting her to school.

The whanau had heard of the Kelston Deaf Education Centre, a special school for learners who are deaf from Rosa's first teacher of the deaf, Mahingarangi. The whanau did not act immediately on the information, as KDEC is located in Auckland City, hours from where the whanau was living.

Ani:

What changed it all was the disruption Rosa was having at school, she didn't want to go to school. That's when we started thinking about Kelston, but we carried on for another few years. We sort of carried on for a few years and didn't like it after she started playing up.

Te Ati:

Part of the problem was that the other teacher aides [for the deaf] that had come on after Mahingarangi basically were only learners. Which made everything hard for us. I'd go as far as to say that I think I would have known more about the sign language than they did, and what my baby was getting wasn't what I wanted.

Now, this is where the other lot of parents came in and they started complaining about Rosa's teacher aides. This was parents of the deaf children as well, they said the aides weren't up to that level, they were not up to standard and weren't eligible for that money. Which was right.

Ani:

Now, there is where all the trouble started amongst themselves, and they were trying to move the teacher aides out and put someone else in, but we just didn't have enough teachers.

Te Ati:

What they were looking at was why are those teacher aides there that don't know anything about the sign language and the parents here that know more than they do? In other words, why aren't we the parents there teaching our kids? Well, how would you do that? No one thought how the parents are going to get paid for that and teach your child. What they said was that my girl Rosa will go to Mrs so-and-so, and her girl come to us, move them around onto the parents but I have her child and she has my children. I thought, 'Oh jeez'.

It wasn't possible to get services at the school. I'd say that the only service that was there was the time that she got with Mahingarangi the deaf teacher who came with Rosa. At the time it was good, when it went on it was good. Then we started to learn more and that's when we started to think more about our baby Rosa and what she was getting. The services were there to a certain point and then they started just fading out, and we could see it, my girl losing out.

Other factors started to impact on the whanau, including the implementation of the Special Education 2000 policy which was aimed at meeting the educational needs of all learners. As part of the policy, whanau were written to with details of the resourcing available for their own child.

Te Ati:

We started getting letters concerning the money that Rosa was given through the 2000 something policy. I looked at it, there's the money there for the resources for my baby and why haven't I got it? What I saw was, it's sad to say, but those teacher aides weren't up to standard for the amount of money that the school was getting from my baby. That made me change, that's when I said to Ani, 'I'm going to Kelston, that's where I'm going to take Rosa'. I'd sooner put that money back into Kelston and help that school and Rosa at the same time. That way we know where the money is, whereas we didn't in the schools. I know they were getting some of it and I wasn't getting what I was entitled to for it from them and that made me change. I said, 'Come on, let's go', and that was the big move, eh.

The whanau discussed the change with the mainstream school.

Te Ati:

We talked with the head principal of her school then and he asked why we were moving. We asked him why Rosa was like that. He knew about deaf children and he said it was time for Rosa to move on. So, we made that move. I said to him, 'Well, I'm going to move', I said, 'I'll move for her'. And that's how we came to be down here.

I'd just like to say no disrespect to the help that we had from those teachers that came on and did their best. The reason for moving wasn't because of that, it was just to better my girl Rosa's schooling and learning.

When Rosa was 9, the whanau made a journey to the city to visit KDEC.

Te Ati:

We had to come down here first to see if Rosa could fit into the school, whether the roll was full or how long we had to wait. So, we thought we'd come down, check that out first, and then look for a house.

The whanau were looking for the front of KDEC and turned into a driveway with a sign for Ruamoko Marae. The marae staff warmly welcomed the whanau as is usual for all marae visitors, and this special first 'face' of Kelston made a difference to the whanau.

Ani:

We made our minds up that day. When we came down to look for a house we actually put Rosa in to classes at KDEC, and just that week or two weeks we were here we noticed the difference straight away, the excited look on her face, she was happy, the happiness was there. She was different, she'd changed altogether, she was no worry.

Te Ati:

It was get up in the morning, get ready for school, have breakfast, and she's waiting for that car to take her to school. That's how it is now, it's half past six in the morning. She's just up, ready, had breakfast, by half-past seven she's waiting for that bus, it doesn't turn up until quarter-past eight! But she's out there, watching out for her bus, come back inside, have a cup of tea again. She is just so eager to get to school, and it makes it so easy for us, instead of dragging her around.

Ani:

She's got everything here [at KDEC], now she can get back into her Maori, she loves Maori, and you could see it when she comes home, she's doing the haka, she's got her poi and the voice is coming out louder.

The move has benefited the whanau in various ways. Te Ati is committed to learning te reo Maori:

I'm hoping to get back into it, I'm reading books at the moment. I can korero a little bit, until I know I can do it fluently I won't speak it.

It's very, very positive and the good thing about it is because we are all working now we can get things that Rosa needs and buy things that Rosa needs. It's not only for her and for our baby, my little one, and it's employment for us, you know.

Both Te Ati and Ani are continuing to learn New Zealand Sign Language. Their youngest son Tipene is very caring towards Rosa.

Ani:

He cares for his sister, he's very fluent on his sign, he's very, very, very good, actually quicker than us because he picks up a lot off her.

Te Ati:

In the mainstream, Tipene was good with Rosa at school. It's totally different now because they're separated, and he misses that and he's actually just drifted away a little bit from her. He's not as close as they were when they were going to the same school. He misses her, she misses him.

Ani:

But he needs his time and this is where I feel sorry for him sometimes, actually most of the time. He's learning now to not take any notice, just to take off and go away and play somewhere else, and there's nobody else for him to play with.

Rosa's whanau is well aware of their hapu and iwi links on both sides, and started out life as tangata whenua, on their own land. The relocations to town and then to the city meant a change of status and a distancing from close whanau ties. Much of what they had to do was to seek for support and the right referrals and help. They were lucky enough to get it.

Te Ati:

Nothing was used; nothing was asked for; nothing was taken to do with Maori. I don't know whether they've got access to what I had, for the simple reason that we went out to search for it. The thing that helped for our daughter was from our doctors, we really got in with our doctor and all he said was, 'I'll help you to do this, I'll help you to do that', and he got onto it. And that's how it went big.

Ani:

Well, that's the only way you can get your answers, was to ask and that's where we went—from the doctor at the top and then he started bringing it [support] out to us and that's how we got all this help.

Te Ati:

And in moving here [to the city], it's all here. All we get now is notification that what they're going to do here and what they're going to do there, what they need for Rosa.

When asked of their hopes for Rosa in the future, both parents were clear and optimistic.

Te Ati:

I would love her to have a career; I see her going that way. As I said, it's proved to me now. The first week Rosa was here, her face glowed, it's totally different, no worry, something was taken off her shoulders, and I'd like to say also off mine, or

ours. It was lifted off as soon as we got here and Rosa started at KDEC and we settled—it was gone. And my baby Rosa's career, I think she's going to go a long way.

Ani:

I think so. She's strong in what she does and she'll put her things across, what she wants to do. Very strong-minded, I reckon she is. She knows you don't let people stand all over you—you've got to stand up for your rights.

Rosa continues to thrive as a day pupil at the Kelston Deaf Education Primary School and the whanau has given consent for the publication of their story.

TE WHANAU O MARIHI

Marihi:	Precious
Tiaka:	Mother

Marihi is 12-years old with three younger brothers, and is part of an extended whanau living in three areas and belonging to one iwi. At the time of the interview, Marihi was in the care of her mother, Tiaka, who was supported by the Domestic Purposes Benefit and worked part-time in the local kohanga reo. Contact was made with the whanau through an iwi-based health and disability support service established in 1992 to develop education resources and initiatives for the people of the iwi. With over 50 children aged 0–7 years and 30 children aged 8 to 19 years of age on their books, the service has recently been extended to support kaumatua throughout the large rural area. The service is funded through the Health Funding Authority in a partnership with the local iwi, and offers support to Maori people and their whanau with special needs and disabilities. The interview with Tiaka was conducted by a manager of the service who has research experience to the level of a Masters degree. Tiaka and Marihi had a 6-year relationship with the service and iwi blood links with the staff. When Tiaka speaks of the help of her whanau, she is referring to the support of the iwi-based service as well as individual members of her family.

Tiaka had no previous experience of special needs in her whanau and Marihi's needs developed after she had turned 4:

Marihi's needs were first recognised through one of the doctors for her speech, that's where they picked it 'cause she couldn't swallow properly and they knew there was something wrong with the throat part of her. She was 4-and-a-half at that time, and it was one of the doctors that picked it up first. The doctor had picked up Marihi's speech problems and left-side weakness, so they said to me there was people out there who can help instead of going to the hospital.

Well, it all started through grommets. She went into the hospital for grommets and didn't wake up from the operation. About 24 hours later she ended in cardiac arrest and we were sent to a big city hospital the next day. Then they diagnosed her with a brain tumour, it was cancer. So that's where we are now. No one knows what really happened, I'm talking about that first operation now. All I know is that she had two anaesthetics for the operation and they rushed us straight up to the big city hospital and we stayed there for 8 weeks. She was in a coma and they gave me 24 hours after her 6-hour operation. They came down and said to me they don't think that Marihi will last 24 hours. Her brain was full of fluid and they weren't really worried about the tumour at that stage, it was just trying to drain out the fluid that was in her. They don't really know what caused it. They said it was quite a mystery. So from there she pulled through with a lot of help from the Māori in our whanau, we had all the karakia and from there she started picking up. After they transferred us to the big city hospital they put Marihi into a head unit. They said to me that her tumour is in the centre of the brain, that it was sitting on the nerves that control the heart and her

breathing so they can't remove it, but later they would look at radiation. From there the tumour is still in Marihi and she's just living day by day now.

While we were in the big hospital the doctors came and said they weren't sure Marihi would walk again, they weren't really sure what was going to happen to her. But she was a fighter and we found out that she couldn't walk at all, from her hips down she was paralysed. But the way she was going, she was fighting her sickness. The tumour was stable so they were just looking at the side effects of the actual tumour that hit her body. Marihi had gone back by a couple of years. She was 4-and-a-half years at that time but she had gone back to a 2-year-old. I had to train her again to go to the toilet, how to feed herself. So that's where they said to me there was some people out there that maybe they'll come in and help me.

So from there we left the hospital 4 months later, and we moved to a suburb in the city to stay with one of our whanau. I had to live here to do radiation with her, and from there they sent people out for physiotherapy, that was to try and motivate her legs. From then they said it was a possibility that Marihi may be able to walk again because it wasn't as serious as they thought. So I got help from physios, speech therapists, and the hospital themselves were paying my petrol from the suburbs to the hospital. That was every day for radiation or whatever we needed as ongoing therapy. Those were all the services my whanau got. Well, they gave us lunch money but that was just for the café and that was a help for us.

From there they put me onto Child Cancer and that was the only other service I got besides physiotherapy and speech therapy. As Marihi's been diagnosed with cancer, she is also under the Cancer Foundation. So from there they gave me a co-ordinator from the support service back here in my home town and they gave me a woman who works with the Crippled Children's Society [CCS]. So those were the support people they gave me for when I got back home.

Tiaka was not aware of the full range of support services and resources available to help her with Marihi until after she had left the city and returned to her own home town:

I didn't know there was a Disability Support Service here at that time until I went back and got information from the co-ordinator and the CCS worker. It was CCS who said to me they could put Marihi into taxis for her to go to school. At that time she was a year behind school and she couldn't walk far, and I didn't want her in a wheelchair. Apparently she started walking while we were in the city when she got hoha with her little brother and she started walking, chasing him to give him a hiding. And she couldn't walk fast. CCS was the first one to tell me about Special Education Services, SES. They put me on to two people who came for an interview to see if Marihi passed the criteria for transport to school. Before then I got a lot of help from my whanau. They were there, if I needed a car they were there, just a phone call away, you know, they'll just turn up.

Tiaka is very happy with the support available from the Iwi Support Service:

Yes, it's there so I don't even hesitate to ring if I need help or if I've got something to complain about, I just ring up. They helped me a lot with taxis for her for school 'cause I didn't have a car. At least when she goes I've got time to get the other two ready for school. So Marihi was quite lucky.

Tiaka was helped by both the Special Education Service and the staff of Marihi's school:

I was actually involved with SES when Marihi started at her school. I was involved with them quite a lot, especially for her schooling because she was a couple of years back. She needed a lot of help from her teachers one-to-one so we had Individual Education Plans [IEP] to see what level she was at for school. The headmaster at the school was really good with us. He pushed a lot for the workers from SES to come in and view Marihi's needs, especially for her academic learning and physical things. She couldn't sit at a low desk, she needed a special desk and a swivel chair, and ramps to get into the toilet if she needed it. Those were all the things we got as a help from SES. The teachers were great because they know I didn't want Marihi to rely on a wheelchair. They'll just put her in one of the staff cars and take her to the rugby park or swimming pools so we are quite lucky with the school.

There were some things Tiaka was not able to get through SES:

[It was difficult] travelling back to the city 3 hours away for ongoing treatment, so SES were able to help me to push the local hospital for transport help. I got a lot of those trips through the hospital, I'd just go up and tell them, 'I've got an appointment in the city', and they would arrange transport for us, like in an ambulance taking a trip to the city hospital with another patient.

It wasn't hard to find the help of services because I had support from CCS and Child Cancer. So whatever I needed if I was stuck, like I didn't know who to contact with SES, so I'd just ring one of those two services and they'd just give me the name of the person that I could talk to. They were good, excellent, just a phone call away.

Most of Marihi's life we've lived in this town. On holidays she'll go back to her grandparents, I think if she had it her way she'd live back there, but because everything is here, the hospital and the services, everything is here for us. Because my parents live rural, we couldn't get a lot of help there. I suppose it was there, but it was different to this town and I don't know whether I'd get the help for Marihi I'm getting now if she did attend the rural school. So I've found it easier to stay here.

Right now, Marihi's doing well but still getting a lot of help from SES. As she's getting older I rely on them a lot, especially in her intermediate years of schools. She is 3 or 4 years back from her age group so I need the help from SES a lot now. We're still getting taxis to and from school so that's good.

Marihi's tumour is stable and it has been stable for the last 7 years, but it's all the side-effects of the radiation that we're having problems with now. That's hormone problems as the radiation affected her thyroid and her growth hormones. She's on

injections everyday that used to go in her tummy, now they go in her bottom and that's to reduce her hormones because without that she'd have had big breasts and menstruating at the age of 7. Now, they have just put her on another injection to help her grow and she has this one every day. The other one stopped her growing, now this one helps her grow, because she's a bit too short to stop growing and it can affect her insides, so Marihi's on injections for the rest of her life.

Marihi is bilingual:

She can korero Maori when she wants to, she can understand, because me and everybody in the whanau speak to her quite a lot, the grandparents speak to her all the time in Maori. It's only me, I'm one of those half pai ones. Marihi likes to know her tikanga and her reo and it's up to me for Marihi to keep her reo and understanding of her tikanga.

Since the interview, Tiaka has relocated her whanau to a city and is no longer a customer of the iwi-based service, but continues to access support for Marihi from the Child Cancer Foundation and CCS. Tiaka has given her consent for this case study to appear in this report.

TE WHANAU O BEN

Ben:	The name of a family dog that ‘Ben’ can say
Tika:	Straight, direct—father
Fleur:	Flower—mother
Kereru:	Wood-pigeon—teacher aide
Koanga:	Spring—teacher
Hoa:	Friend—Ben’s friend at school
Urekehu:	Light-haired—principal

Ben was accessed through contact between Urekehu, a school principal, and the NZCER. Fifteen-year old Ben attends a remote rural primary school. Ben is “growth retardated” and has Section 9 and Ongoing Resourcing Scheme funding with a special Ministry exemption which allows him to attend primary school although he is over the usual primary school age. The whanau supporting Ben includes parents and the school working together. Ben has been educated in special units and was ‘mainstreamed’, as is told in the story. Four connected stories present the parents’, caregiver’s, teacher’s, and principal’s viewpoints. The whanau now accesses health services and benefits.

Fleur and Tika: Ben’s Parents

Fleur’s previous experience and knowledge as a nurse led to the whanau learning of Ben’s special needs:

I picked it up when he was a fairly young child because he had trouble feeding. Having a nurse’s background I knew what he should be doing. He would eat often but very small amounts and I sensed something wasn’t right but didn’t really know that it was going to be special needs. His condition was not picked up at birth.

Ben went into hospital at 11-months old. The doctor came in to see Ben, he was a paediatrician and he just growled at me that I had been underfeeding Ben and malnourished him and this is why he was so small. The next morning the doctor came back to me and apologised for his language and said that the blood tests had shown that Ben did have a condition. They say he’s growth-retardated—he’s only grown at half the rate of other children.

However, labelling Ben’s condition as “growth-retardated” did little to help the whanau understand:

It’s in the brain somewhere; they’ve never really pinpointed what it is and why he’s like that.

Ben’s condition was rare and unique in the rural area where the whanau lived, so Fleur had to observe Ben’s development over time to determine his needs:

We haven't really met any child that is of similar condition to Ben. He's behind with all his milestones—he can't write properly, he can't read, he can't speak, he says a few words. He needs a lot of help and support in everything he does really, with his eating, toileting, showering, and dressing.

When Fleur asked the medical profession for more information, she found out little more than she could observe for herself:

I asked the specialist and he said to me, 'Ben is going to do what he's going to do', and that's all they can really tell us. I mean he has shot up in the last few years, he's got taller and very strong physically but you put him beside another 15-year-old, he's very small.

Fleur, Ben's Pakeha mother, saw the benefits of the whanau structure into which Ben was born, which in their case was reconstituted through a second marriage:

That is an advantage with Maori whanau, it's an extended family.

Tika has two daughters from a previous marriage—they'd be 21 and 22, somewhere around there, so young Ben is our only child. Being Maori we've had a lot of family staying with us.

Tika:

My father died and my mother was sick, with my three sisters and one brother, so we brought them up for 8 years. Ben was born during that time and he sort of got to know them. Then there are my two children as well sometimes, my daughter was staying with us for two years and they both come up and visit.

Tika recalled some of the misunderstandings experienced in Ben's early years as he was the first child with major special needs in the whanau:

I think it was hard when Ben was growing up, we would go and visit relatives and Ben couldn't handle warm milk, he could only drink cold milk, so Fleur would give him cold milk and the old Maori would look at you. But they don't understand the situation, they think, 'No wonder he's small because they're giving him cold milk, they don't look after him'. We did get a fair bit of flak but that's the way you had to look after him and we just carried on because it was Ben first, not what anybody else thought. So we come away on top really because Ben goes back now and shakes their hand.

Ben's whanau moved around and his education has been in a range of different environments. The whanau was living in a city when Ben started school at a nearby primary school, as recalled by Fleur:

They had what they call 'satellite classes' that branch off the main school, so that's where we initially took him. The satellite class in the city was a special needs unit

and it was good, it was when we moved up north the class environment changed for Ben. This was still a satellite class linked to the school in the city but I used to get quite disturbed at the other children in the class that he was with. Ben started to pick up some of their little habits, like rocking. I wasn't comfortable with the environment that he was in. The teachers were very nice people, of course.

When the whanau moved to their present home, Ben was enrolled for a period of 2 years at another primary school with a special needs unit.

Tika:

He'd come home and usually he's a very joyful, happy boy, always excited and life is for living, but somehow you could pick up in just little pauses that something wasn't right with him there. You wonder what's been happening and those sorts of feelings, it's things that you more feel than know and so we decided to do something about it. Due to his lack of communication he couldn't tell us anything.

As Ben got older, Tika and Fleur wanted to find another place for him.

Fleur:

Ben was growing and I thought he had more to him than some of those children, he had more drive. I wasn't sure what to do or where to go, I didn't know who to talk to, I was a bit cautious about saying anything in case I upset anybody—I didn't want to upset people. Then somebody gave me the number of a parent with a special needs child and I talked to her about the situation. She recommended talking to the SES worker about alternative schools.

We made inquiries ourselves, we went to the high school, we visited the special class, we talked to a teacher there, and we talked to the principal. But we were just not settled in ourselves and even now we don't want to see Ben go to that high school. It's just too big, too vast, too much goes on there and we didn't want to expose him to that. So then we went to the intermediate school—we talked to the principal there but he wasn't very helpful, it wasn't right, we could just sense they weren't prepared for someone like Ben. I don't think anybody is, but I think it's a lot to do with the environment.

Tika and Fleur had considered Matariki School on the recommendation of other people in their community.

Tika:

People who have had children go to Matariki School had nothing but good things to say about it and I think somehow it's a school that has got its own uniqueness. Matariki had the environment with a Maori interaction. They have it all there and it's really a whanau one, it's a love one.

However, their lack of knowledge of the flexibility of enrolment enabled by Section 9 of the Education Act (1989) left doubt in their minds.

Fleur:

We had discussed Matariki School but we sort of wiped it because we thought, that's a primary school. Tika phoned and talked to the principal Urukehu and she re-contacted us towards the beginning of the term to tell us that they'd just extended the school to become eligible to do the Form 1s and 2s as well. That meant that Ben was eligible to go to that school. So that's when we thought, 'Right, that's where we want Ben, at the smaller area school', and, like Tika has said, for the Maori environment.

The opportunity for Ben to be included in the mainstream primary school was very attractive to the whanau, and it was soon possible to see a difference in Ben.

Fleur:

The other thing we wanted to do was to take him out of that special class setting and put him into a mainstream class so he could be mixing with other children and hearing normal speech. That was what we were looking for, that environment.

Quite quickly he seemed to be happier, he just seems more settled and his vocabulary has started to increase. He's started to hear more sounds and uses more words and a lot clearer speech.

Tika described how Ben's whanau is able to understand his needs:

He's got his distinct way of communicating and I know exactly what he wants now. I can talk in English to him to go and get something and he will do that. He's got a very good comprehension like that. Put it this way, he really knows what's happening. The more he's in an environment the more he starts to understand where things go. He works better if he knows what's going to happen next. When he gets up in the morning, he knows exactly what's going to happen to him before he goes to school. He likes routine.

Fleur continued:

Ben's very happy, he looks forward to going to school. Even on the Saturday I might be giving him a shower and he'll go, 'Mmm mmm', and that means, 'Am I going to school?' I have to explain, 'No school today, nobody's at school today'. Sometimes it takes a little while for him to understand.

While Ben is responding well to his new schooling experience, Fleur talked about the lack of specialist services in the rural far north:

There has been some service here but they seem to come and go and nothing [is] consistent. There was one gentleman who works with SES and he's supposed to be

doing speech therapy with Ben but he's not very thorough in his job, so Ben has missed out with a lot of those services.

At the time of the interviews, Ben was funded by the Ongoing Resourcing Scheme provided by the Special Education 2000 resourcing for high needs. The funding is dependent on ongoing assessment of the child and review every 3 years using at least two Individual Education Plans for each review. The whanau recalled the interaction between the Special Education Service assessment and the school:

When the Towards 2000 [SE2000] came in, there was an application form and they [SES] come up and do an IEP. Well, it's supposed to be every term but it always seems to be at the last week. I always get involved with that. At the last IEP the SES worker was saying, 'Now what are we going to do next year?' and I'm thinking, 'I've just got this year sorted out and I just wanted to have it one year at a time'. You can't think that far ahead as far as I'm concerned. I said to her, 'We'd still like to see him at Matariki School'.

Ben continues to grow, requiring an application for an exemption under Section 9 of the Education Act (1989) to enable him to continue his schooling at Matariki.

Tika:

We're very fortunate in the principal at Matariki because she was very helpful. I think without her help it would not really have come through. Now, going through the stage where he got older to the place where he's at high-school age, we had to apply again. Last year we had to get the approval from the Ministry and they allowed us to stay on this year. They talked to the Board at the school as well, just to get their approval and the Board agreed. We were very fortunate with the people involved; there was a good connection and a good rapport. I gather this is the first time this has happened in the North, with somebody like Ben staying on at a primary school.

Tika described other key people in Ben's life at Matariki School:

Another important person is Kereru, the teacher aide, she's been excellent, we're really pleased to have her. You know she cares and I think that's where it starts—Matariki cares, it's a caring environment and I think that's what contributes a lot to how well Ben's doing. That was one of our concerns about taking him into a mainstream class, he would then be allocated a one-on-one teacher and you know—stab in the dark—who are we going to get?

Like many whanau members who have previously experienced patchy access to information, service, and support for their child, Tika expressed a common viewpoint:

Ben's our boy, our responsibility, we'll bring him up and do the best for him and we don't expect others to really help. We've just carried on and we pray for him every day before he goes to school. I think it's been our choice that we haven't looked for other supports, since we've been able to look after Ben. That's where he's often missed out on some funding.

Central government provision for special needs includes a Child Disability Allowance paid to the child's parents. Although Ben's parents have fitted the criteria for this allowance since Ben's birth, the whanau was previously unaware of the available financial support, as described by Fleur:

I think we actually missed out on the handicap allowance. I didn't know about that until he was about 11-years-old and we missed out on it for those 11 years. Nobody told me we were entitled to that allowance.

At the time of the interview, Fleur was unclear who paid the allowances to the whanau but she was aware that these were government-funded. Ben's whanau is also paid a special needs transport allowance to cover transporting him to and from Matariki School. Fleur takes Ben to school and the school bus drops him home.

Fleur:

I do get a travel allowance, he's either eligible to a taxi or an allowance. I like to take Ben to school each day because it gives me that contact with the school. I can talk to Kereru and we can communicate about Ben. He can't communicate himself so talking with Kereru gives me that opportunity to communicate with the school.

The whanau's lack of understanding about the ORS funding paid to Matariki School for Ben was shown in Fleur's story:

I had been told there was funding allocated to Ben for resources and I haven't seen that funding so I asked Kereru if she knew, and she said, 'No', she didn't know. So then I went to the office lady, she didn't know. So then Kereru asked the principal and we found out it was going back into Kereru's wages.

In fact, the ORS funding allocated funds for .1 of a teacher equal to \$6,250 per annum. Under bulk funding this money went to Kereru for full supervision of Ben during play and lunchtime and for other duties, such as taking him to Riding for the Disabled.

Outside of school, the whanau faces constant threat of medical emergency.

Fleur:

As a baby Ben had the petit mal of epilepsy and it went to the grand mal. He had quite a few in his younger years and then later he had a spell of 5 years where he didn't have anything and he was still on his medication. But then, just about a year ago, he started having small seizures again. Just before Christmas last year, another one in January, then another big one in February this year. We went up here to the hospital first. The nurse didn't know what it was about; for instance, she didn't know the right size mask to fit things they should know and the doctors were learning about this different situation. I think typical of our young fella Ben—in a way he's old, he seems to be teaching everybody but he was very good. With this last seizure we were helicoptered down to the city because they felt the urgency to get him to the Intensive Care Unit at the hospital. We were there two nights, Ben was on the

respirator and I stayed with him. Tika was in another town at the time and he met us in the city, he pulled in as the helicopter arrived. They had Ben sedated overnight on the respirator and they took it off at ten o'clock in the morning. We sort of needed and wanted to be there because then he can recognise someone he knows straight off. They reviewed his medication and put him on a more up-to-date adult medication so we're hoping that that's sorted it out a bit.

The whanau carefully returns Ben to school when he is recovered from medical crises, and he is taken straight back in, included, and accepted.

Tika:

He loves the kapahaka, Matariki taught him the taiaha. He performed with the school down at the community centre; it was an interschool competition. Matariki does very well and they allowed Ben to be part of it. What was special about that—he'd just come out of hospital after having quite a big seizure. He came out of hospital and he sort of cut it straight down there and into it, you know. That was really neat. He was a bit out of line but he thoroughly enjoyed himself. I appreciated the fact that they were happy to allow him to be part of that.

The children, they're very open to letting Ben do stuff. That's a good thing. That's the other side of it, the school is such that the children are accepting of him, they must do something good.

Tika is able to korero Maori, particularly the dialect of the far north, and English:

We were brought up to speak English. My mother said that if we want to get a job, we'd better speak English but you couldn't help but learn Maori. They—my father in particular—spoke fluent Maori. I was brought up in the day where you got strapped for speaking Maori in the school grounds, so I spoke English to not get strapped.

Ben is used to hearing both languages spoken and will respond to instructions in both languages. Tika described the whanau as “marmalade and kina” to represent the mixed blood-lines in the family.

It is clear that having Ben has been a rewarding and wonderful experience for his parents and whanau:

I think peace is a big thing. Your peace is your umpire, if you like. I suppose that's part of being a Maori too; it's a part of being Christian. Some people say 'gut feeling' or those sort of instincts come into it very much because Ben's very much a young fellow like that and you've got to try and think for him that way. And I think it's a very feeling thing whether Fleur and I gel, or whether we feel right about and are open to hearing what she feels, what I feel and how Ben's interacting too before we make decisions. But it's a constant talking about it.

Fleur agreed:

A lot of the decision-making was instigated by us and we had to go and find out for ourselves. I guess that's what we've done for the benefit of Ben, that's what we wanted to do—find the best we could for him, that we felt happy with.

Fleur described the source of her strength that plays an essential role in being a primary caregiver for Ben:

I think the key for me with caring for Ben is that I know I've had that strength there that I get from knowing Jesus as my saviour. And that's where I have a heart for other mothers in my position because I can see the emptiness they have if they do not have this faith during the struggles that they have to go through. There's been many a time—I'm not ashamed to say it—I've cried and I've wept because of Ben's condition. Things that we've gone through with him and the times we've seen him nearly die and the times when he is suffering, you know—you can only do your best.

Tika continued:

I'd just like to say if you've got a child like this, it's an attitude thing, it's a mentality thing, and you can be either a part of the problem or a part of the answer. I think if you're part of the answer, you can turn a child like this into a gem. I mean Ben's a joy to have; I can't see myself going anywhere without him. He loves to go wherever you go and people love him, even grown-ups, from nanas to young children. I think it's an attitude that he's just expressing the input that he has had. If you have a child like that you can look at it as a unique opportunity rather than thinking, 'Oh, I'm missing out on something'. I'd just like to really encourage people that it's an awesome privilege to have somebody like Ben.

Kereru: Ben's Teacher Aide

Ben's whanau experience extends into his life at Matariki School, a small decile 2 primary school located in the rural delivery area of a remote rural town. Anecdotally Matariki is a school of choice for the whanau of about 120 children. The kaupapa of whanau encompasses every level of interaction within Matariki and extends naturally into the surrounding community with whanau who are predominantly tangata whenua.

Sitting in the homeroom for Ben's class while the other senior students were attending an inter-school touch rugby and netball competition, Kereru, Ben's teacher aide, shared her perspective on Ben's story:

My children have gone here for years, I waited until my youngest started school here and I saw the position advertised, I applied and was accepted and now do all sorts—helping children with their work and being supportive to the teacher, because they've got so much to do, they've got a lot of children in the Standard 4, Form 1, and Form 2 classroom.

Ben walked into the classroom and Kereru assisted him with a toilet break. Ben had a cold and Fleur wanted Ben to stay at school instead of joining his classmates in their

sports competitions. That day he spent his time with the Standard 3 class. The kaupapa of Ben's care is that he is part of the whole whanau of Matariki School and that Kereru is there as his main caregiver for specific tasks. Ben's programme is unique within the school:

Oh yes, he does float around a bit, last term he was with a class learning the kapahaka, then he'd go out and do the sports. They had a programme going and we tried to get him to sort of go away from me really, to not be so dependent on me. I don't mind being depended on to take him to the toilet and things like that. He's not by my side all the time he's here at school.

Kereru was not always so confident about being the teacher aide in support of Ben:

Well, I was a bit scared because I haven't come across someone like Ben before. I remember Urukehu asking me, she rung me up before the term started and said that there was a special boy. I've had experience, not personally, but we had an ADHD boy in the classroom I was in. The teacher though was fantastic, she really coped with him, she was very firm and she could handle him and he was a big boy. And I said, no, I didn't want to, and Urukehu sort of encouraged me that Ben wasn't like this other boy.

I was a bit apprehensive I think with my first day and didn't really know how to treat Ben and I think he was a bit apprehensive towards me too. But I found his behaviour strange. I remember sort of just putting my hand on his arm and he jumped back. So I presume that was from something before because he had been in special needs units all his life until he came here.

When he first came here he used to always go, 'Hey you!' or 'Hello, how are you?', like all day long. But you know that's all he sort of knew, and then in class he'd go, 'Oh man', hitting himself on the forehead. All I could do was look at him and think, 'Oh my goodness', but he's gotten out of that now.

I was sort of worried for him too. I treated him like a son really and if anyone gave him a hard time or teased him, just look out. You get it all, especially with new children coming in who don't know Ben and some of the little ones. In our class the children understood about Ben. The teachers and aides that were in the class always introduced Ben and told the class that he was special and how to treat him, that we were a whanau. Mind you, I thought that could have gone throughout the whole school, I could have gone to each class and spent time and maybe the teachers could have explained to their little children more about Ben, but instead the children are finding out a bit at a time in class and at intervals.

Kereru's role includes liaison with SES to complete the IEP, which is a requirement to maintain the ORS funding for Ben:

I do the IEPs with SES. We all come together, Fleur and I and Koanga, the teacher, all meet once a term. We make plans for Ben, just little steps at a time, very simple things, like making sure that he can pull his own undies up, those sort of basic

things. We had to give him just simple instructions like, ‘Remember to flush the toilet and wash your hands’; I have to remind him each time he goes. I say, ‘Have you forgotten something, Ben?’, then he’ll go back and flush the toilet, and if he forgets to wash his hands I’ll say it again, ‘Have you forgotten something Ben?’ ‘Horoī te ringa ringa’, and off he goes. So the IEPs are mainly for goal-setting for him—to go into the right toilet—the men’s toilet; or making his lunch—we did do a term with that, making his lunch.

He’s not able to do anything unless you’re there to supervise him, you know, like something constructive. He can make his lunch, how he likes it, but even the sweeping, if you’re not there beside him saying, ‘Ben you’ve got to sweep there’, that’s it, he’ll sweep and he’s gone. Especially if you want to see him complete a job for 10 minutes.

I think we can only do this for Ben because everyone is accepting, even the parents who are doing voluntary work at the school. When I ask them, they just take Ben along and they give him jobs to do. They’re not too bothered if Ben doesn’t do the job, whereas it does bother me.

Ben’s condition has other effects on his experiences at school:

His concentration span is very short and he’d rather be sitting here at the table with the boys, doing what they’re doing like maths, with his book. He can’t really speak properly either but I can understand what he’s saying and what he wants. He goes into the office and says, ‘Good morning’ to everyone and most of them can understand what he’s saying too.

Actually he’s involved with a lot of things, we try and get him involved with everything because I know he gets sick of me on him all the time, every day, which we’re trying to get away from. We had him with one of the caretakers who was building the chook pen, Ben would go over there every morning with two of the other children and help—that was the idea, to help, you know, he loves to do those sorts of things, hammering and helping.

We don’t have a rigid programme for Ben; it works best if he just does whatever we do. If I see the caretakers doing something interesting, Ben will come and say that he wants to go there. I’ll always ask the guys if it’s okay if Ben can come and help.

Kereru is aware that Ben’s whanau was very unhappy at the thought of him having to move onto the high school. The Board of Trustees agreed with the whanau and the principal to use the waiver from the Ministry of Education, to be part of a regular review of Ben’s progress, and to keep him at Matariki School, which is permissible up to the age of 19:

That would be wonderful, because the whanau just live up the hill there. Maybe Ben can come in and sweep or push the wheelbarrow—he just loves pushing that wheelbarrow.

Kereru recalled Ben's most recent admission to hospital and recounted her view of Ben's recovery to join the school kapahaka:

We were performing down at the community centre and I rung up to the hospital to see how Ben was. I told Urukehu that I'd be late because I wanted to stop in because it's on my way, to see him. I went in there to see him—me and my two children—and gosh, he performed and he cried, he wanted to come to school with me. Anyway, his mum brought him straight from hospital and put him in the piupiu. We were all outside just getting ready to go on stage and, oh, he was wonderful. And I tell you, I knew quite a few people in the audience and they just thought it was lovely that he was up there. Most of the adults that knew him and teachers from other schools have told me they felt proud too, to see Ben up there.

I did talk to Urukehu first and then to Fleur about how she thought about him going, being part of the kapahaka, being on stage. Knowing that some children will tease him and some adults too, I suppose his parents might feel funny that Ben's 'on show'. I didn't actually think of it myself, I think Urukehu mentioned it, but I didn't come from that perspective. The whanau were quite happy, they said, 'Oh no, we don't want to hide him'. No, he needs to be part of what we do every day.

Ben is also a part of everyday life in the small rural community his whanau lives in, as Kereru recalled:

We had an incident where we went to the skateboard bowl in town. I went with my daughter's class and I took Ben with me and transported some other children down there. There's always college kids or children who are out of college down there, they were skating about. So Ben sort of meanders around there and they'd always give him a turn on their boards. He must just go over there and ask if he can have a go and they'd give it to him and he was sitting on the board and going down which was fine. This little girl came up to me and she said, 'If Ben wasn't so silly in the head he'd be able to stand up on that skateboard wouldn't he?' and I sort of looked at her and I said, 'Yes, you're right', and she said, 'How did he get silly in the head?' and I said, 'He's not silly in the head, there's something wrong with his brain. When he was born I think there wasn't enough air that got to his brain, I'm sure he'd be able to stand up if he was like us'.

I found that quite interesting, how she looked at Ben and she was quite accepting of him after that. I think through his church, too, a lot of people know him.

There is a computer in Ben's classroom and Kereru supervises Ben's access to it:

If I was there reading a book, say if I went, 'Once upon a time', he'd sit there for quite a while if I did that, sort of read a line from a story and he'd pretend to type that. I tried for more than a year to get Ben to recognise his name on the computer—the letter 'B' actually and writing the letter 'B' for a whole year every morning. If you hold his hand and help him he can do that but he can't do anything independently. Sometimes first thing in the morning he could recognise the 'B', for his name, for Ben. I'd say, 'Show me where the B is', and all the kids who were in

the class used to encourage him as well, encourage him to speak properly, to try and sound their names properly.

He writes his own way. I usually make up a portfolio for him, bits of work collected through the term. I send the whanau his books. Ben just sort of types away to his mummy, that's his sort of work, not the maths, of course. He does circles and he can do that actually. We have tried it with the Correspondence School, they used to send things with dots on them and you had to join up the dots. If I gave him the sheet and said, 'Join up the dots', he wouldn't be able to; I'd have to say, 'Ben, put your pencil on this dot', and 'Ben, we have to take the pencil down to that dot'.

When asked about support with speech or language therapy from SES or any other provider, Kereru commented:

I never found the speech therapist very reliable myself, so we tried to help Ben and we don't know whether we are doing any good. Who really helps Ben? It's the kids in the classroom. A long time ago the therapist gave us a sheet of paper which I blew up and we put it on the blackboard. We had to record words Ben said clearly and the whole class was in on that. We just left it up on the blackboard and we used to write the word and they used to write what they thought he said. But most of the time it's just 'Hey' to me. I say, 'I'm not answering you, Ben—what's my name?' and he can say my name sort of. I remember him calling me Kereru, it sounded like Kereru, it was quite clear when he said it. I always remind him if he says 'Good morning', especially to an adult, to say their names properly, instead of going 'Hey'.

Kereru does not spend all of her time in the classroom with Ben and the school is looking to develop Ben's skills:

It's just life skills really because that's going to be a real priority soon. Not maths or reading or any of that, it's just that sweeping a bit and making his own lunch, making his own Milo, doing those sorts of simple things. Ben was in the outdoor education that we had here last term, where they learn to abseil and work as a group making hobo stoves. They had the opportunity to go on a camp overnight during the holidays, which I thought would have been wonderful for him and we told his mum, but they didn't go to it.

Although Ben is the only child at Matariki School receiving ORS funding, Kereru was able to identify many other children in the school with special needs:

We've got a lot of special needs children here in the school that need special help. Mainly behavioural problems, disruptions in the class, that's every day. I think they must have one in each class that do need one-on-one. We've got children here in this class and I personally feel they've been neglected at home. You can tell by the child, we've got children here that violence must happen at home because they come sometimes in a rage in the morning, swearing in the classroom. That doesn't happen often but to me that's special needs.

But there again, there are a lot of areas of special needs for Maori. You don't have to have something wrong with your brain or look dopey just to be a special need. And I feel, especially being a Maori too, that Maori people need a lot of help and maybe it's at home, counselling or whatever. None of us were taught how to be a good parent which is the most important job in the universe.

Koanga: Ben's Teacher

Koanga is Ben's classroom teacher. She has taught at Matariki School for "2 and a bit years" out of her 4 years teaching primary and 6 years teaching in an early childhood centre. She recalled her scant training with special needs during her 3 years at teachers' college:

I remember the course; it was a 6-week course, a couple of hours a week.

Ben was at Matariki for a year before he moved into Koanga's class. She recalled his arrival at Matariki School:

We were aware of him in the school, absolutely, from the day he arrived.

He came to me at the beginning of the year—so that's a term and a half, the kids just took him on board straight away. He was part of our family. I'm sure the class did a health unit explaining how Ben is and why he is but they've all looked after him, the fact that he doesn't quite operate at their level means absolutely nothing as far as I can see. They are all really proud of him. We went to a hui just recently, we had schools up doing their kapahaka things and Ben joined in with everybody. Our children were very accepting, I mean that was just Ben. Every time he hears kapahaka songs and all the rest of it, he's up and doing it. We could see the other schools looking at him like, 'What?' The adults noticed but our children didn't even notice the looks, Ben was just up doing what he does, Ben's just part of us, you know?

Koanga constantly referred to her class as a whanau:

I've always felt and always said that we are a family. A lot of our children are related or have grown up together. I do think the children see each other as family and they do really operate on that level.

Koanga reflected on the special nature of the staff at Matariki School:

We're all the kind of people that this job is really a huge part of our life, it is our lives. Three of us have come here from having worked together before and wanting to be together. We lost staff last year and they've come back in and then we've had new staff come in this year. Being a small town you only apply for the job that you know is going to fit you. We all have a sense of family and that's who we are and that's what we want in our teaching. That's just the way it happened and I think our parents have probably got a big part in that too, without them realising it.

Koanga's relationship with Ben's parents is slightly different from her other parents. Primarily, Fleur saw Kereru (Ben's teacher aide) as the right person to speak with on a daily basis:

I know Ben's mother; I don't have the same relationship with her that Kereru and Urukehu have. They obviously aren't tentative parents in this with Ben, I know that a lot of people with children with special needs are very anxious. I do make a real point of speaking to my parents and that's on the level of them coming through the gate. So I probably have pushed myself on Ben's mother more than she has approached me.

Koanga reflected on the positive effect of Ben's presence in the classroom and in the school:

These children's lives are quite hard lives. It's hard for them to look at other people and feel empathy or sympathy because they spend so much time thinking about survival. I don't even know if it would be half the class but I know a lot of them and I know the lives that they live. When they see someone like Ben and can see that this boy is happy and wonderful and they can be part of that as well, it seems to be not as hard. It's an easy relationship for them to have with Ben and I think it's something they can build on too, just to realise that there are other people out there with totally different issues, real hard too and there's ways of dealing with it and accepting it.

It's not hidden, it's here, but people are amazed when they come into our playground and see how Ben is just one of us. He's just not operating at the level that the other children are but that means absolutely nothing. As teachers we look at that in kids every day, so our children just accept it because it's there from a very young age and no-one's hiding it. It means nothing less or more than anything else does, it's just part of their lives, our lives, Ben's life.

Ben loves all the children here, but he's got one boy in particular—Hoa—who finds things really hard, just in his own personal life and being at school is really hard. Ben just adores him and if we ever need anything done it's, 'Go and see Hoa', and Ben goes and Hoa sorts it out for him. Hoa knows that that's his important role in the room and it's really quite neat. Ben is forever getting Hoa and trying to touse with him. I know that Hoa gets very frustrated sometimes but he actually just lets Ben do it. Occasionally he pushes him away but he really just accepts Ben and this is part of what he has to deal with.

Ben isn't functioning at a 15-year-old level so the kids appreciate that he may be older in years but in our family someone's always looking after someone else and everyone's looking after Ben. They do work really well together.

Ben functions at a different level to the other children and Koanga finds herself responding in a particular way to Ben's needs:

He often comes to me for ticks of his books, I don't know where he's ever seen that because I actually don't do that at all for any of them, and if they want to tick their work they can. Ben always comes to me, I've got to tick his book because I don't

have stamps or anything and I have to draw happy faces and then he's fine and off he goes.

I've been in teaching situations where there's been special needs children that really needed a teacher aide, they really were hard work, it was a whole different scene, but with Ben and the family he's got, he's just really easy to have. Not that I think we would accept him any less if he was a lot harder work. Maybe the freedom to move in and out of the classroom wouldn't be that easy, you'd really have to take each child's situation for what it is.

Koanga described her changing viewpoint of working with Kereru, Ben's teacher aide:

I think it was having another adult in the class that worried me, but in this relationship it's just not like that, it's been really wonderful. Ben was never going to be a bother because I knew that there was another adult there with him, it was just the fact of the other adult really because if you can't work with somebody then it's like, 'Oh, my goodness'.

When Kereru's working and Ben's working with her, she's also working with the other children. Kereru doesn't molly-coddle him. If he's at the table he's very serious so it's not just him she's helping, she does get around all the children. If they call her over she goes and Ben either goes with her or he sits with the boys and the boys are taking her role, I suppose.

When asked about accessing other services for Ben such as speech language therapy, Koanga laughed:

I wouldn't even bother asking because I'm fairly sure that when they came they'd only come for a little while and so there's no continuity, so why bother, especially with the speech and language?

The whanau and principal had both mentioned that when Ben started at Matariki School, he didn't speak. Koanga commented:

All of a sudden he started saying 'Hello' every day. He absolutely understands what you want from him, I mean he'll do messages for me. If I say, 'Take this to this certain teacher', he'll do it and bring back the replies. I didn't realise how verbal he was until we had a guy that comes doing abseiling and rock-climbing with the older kids and Ben was part of that, he just loved it. I had a chance to be out there for half-an-hour with them one day and Ben looked at this other child that he relies on and said, 'Hoa, help me get it off'. He had all the karabiners and everything on, he didn't want it on anymore and he said it. I just turned—I couldn't believe it, because he's never really spoken around me. I speak to him and then he usually just goes 'Yeah' and that's it, but he had a whole sentence there. Then after that we started noticing occasionally that given the right time and the right motivation Ben will actually speak in sentences. I gather he does more at home.

He has got Hoa here for him; Ben just loves him so much. Hoa is just like a big bear and he lets him do it all and he's the one Ben speaks to. He has relationships with other kids, but he does have that relationship and with Hoa moving on next year that really will be the test for Ben—can he build another relationship with someone else?

Matariki is looking at developing the life-skills Ben will need to survive in the world after school. As Koanga explained:

We talked with his SES person, she's talking about getting Ben lawn mowing and stuff, but you'd have to have somebody that had the time to do that with him. It would have to be the gardener. I really think that he's got things he probably needs but I haven't really sat down and thought about it.

Kereru and I talked last term and I said what would be the point in moving him on, I can't see any point in that. Ben's comfortable here, he really knows he fits in. I really think he's got it ideal, he can be a part of anything that goes on in the school and whenever there is anything special in any room, he can just go and be part of that. Out of all the children in the school, Ben gets the pick of everything, so I know he likes to be outside and doing that kind of stuff.

Koanga shared her thoughts from her experience of having this special needs child in her class:

The relationship has to be holistic. I don't know if we've made the parents feel at ease or what's happened beforehand but having a really comfortable relationship that goes the whole circle is really important. Having every teacher in this school accept that Ben's here and he's not just mine, he's all of ours, that has been the biggest part. I know that we have a good relationship amongst our staff and if there are programmes going on Ben can be part of it all. Everybody loves him, it's not just us in this classroom, it's not insular, and it's all of us.

If we'd had to keep Ben in this class all the time—like in the old days of teaching or maybe in other schools—and he wasn't able to move out of here or if he had to be doing the work that we're doing, it would just be a nightmare, he would hate it and nobody would be happy. But because he can be free to go and everybody knows that he's coming into their class, he's not told to go back to his own class, he's pulled in and that's the way it goes.

The success of Ben's matauranga motuhake is based on both the parents and the school operating as a whanau in support of Ben and developing an appropriate programme with achievable goals:

I have in the past had parents that really want that child to be sitting down, learning to read and write. For Ben it's not going to happen or it could. Instead of looking at your own child with a special need and worrying whether they're going to get this far ahead, it can be as relaxed as you want it to be. I'd love for my own children to be able to go to any room they felt like, whenever they felt like and feel free to do it,

wouldn't that be lovely for every child in this situation that Ben is in, I would love that for all children.

At Matariki we really like this idea of movement, just seeing what Ben can do, that's what we all wanted. We know that we're not conventional by any means, but I look at Ben and I know we can do it for him. People don't understand when we've got all these problems but you won't let us do it our way. We know that we've got huge problems up here and it is across the board. We can't do anything about it because there's just no help there and we honestly believe that the approach that we use with Ben would be beneficial for all these children, all the time.

Urukehu: Principal of Matariki School

The many layers of interaction with the whanau surrounding Ben are captured in the story told by school principal, Urukehu.

We know all our parents care for their kids, we know that because they're choosing to send them here at personal cost to themselves when there are other free options that are close or kura kaupapa. It's a dollar a day to transport their children, some of them carpool or whatever, but by hook or by crook they get their kids here. We obviously have intelligent parents because they can feed themselves and their family on \$150-\$200 a week. So we know our parents have the desire to be good parents and we uncork that desire, that passion, all the ingredients are there and they need to know that it's okay to love your kids, we've been increasingly upfront about saying, 'Look, there is no homework at our school but send us a child tomorrow morning who is loved'.

We know there are children who don't have a sense of being loved and parents who are perhaps thwarted in their opportunity to love their children generously and whole-heartedly. We have parents who have been dehumanised and damaged in some way so they can't love as freely as they would, but we'd go and do things like school camps and we'll end up with one adult for every three children.

Now in that setting, we're sitting there as teachers and teacher aides with our tamariki around a camp-fire cooking together, laughing, going for walks along the beach, for our parents to see these are the relaxed and beautiful relationships you can foster with children, you have a conversation and children talking rather than children just receiving instructions or a chastisement. Children just aren't recipients, they've also got a contribution to make in this relationship and it's got to be built on the bottom line of respect, not coarseness and rough, abrasive contact. So there are things that we can foster by example.

There are things we can foster through our genuine admiration for the stresses our families live with and how they still hold it together. I've been here 6 years now and I see people's hidden stories, of alcoholism and drug abuse and violence within the home. I've seen them moving towards getting up and getting their kids breakfast in the morning, moving to getting rid of the television, moving into study, drying up, attending church, becoming active in the marae, some even moving into the cloth

and one now a Maori warden. These are stories that span 5 and 6 years, who else is observing that?

It's kept quiet because of course nobody wants to admit the shame. They were so cool and wonderful when they were in a gang perhaps but they're actually cool and wonderful as dads as well. The same dads will be coaching and out there on that sports day with us today. I have no problem with those men being with the children from our school because I know their bottle has been uncorked and all the gifts they have flow freely.

In response to a comment that Matariki School offers an inclusive policy for special needs, Urekehu said:

Inclusive policy? Well, I suppose the air includes oxygen. It's what we breathe, it's not policy, it's what we breathe and how we walk. The carving out the front of our school there is just so rich in what our kaupapa is. We recognise our Treaty of Waitangi gives us all the right to be here in a mutually respectful way. If we can't meet and greet and work and support each other on this site as a microcosm of an idealistic society, then how can we hope that our children will grow into what our ideal of the wider society is?

Urukehu recounted her version of Ben's participation in the same kapahaka event mentioned by his parents and teachers, and generally in the life of the community:

We went to a function downtown to recognise the signing of the Treaty in this area and Ben was with us. We ended up being manuhiri in that setting, I don't know how, but that's how the day went, we were manuhiri and another school was being tangata whenua. As they sang to tautoko their speakers, Ben stood on our side at the back and followed through every action they did through their waiata. We could see as they moved their arms around, you know their singers were kind of disturbed, it really diminished them. We turned to see what Ben was doing and he was just beautiful, standing high with such dignity and with all his poise. He knew what he was doing and he did what he needed to. None of our kids were embarrassed by his conduct.

We had manuhiri arrive here at the school the other day and Ben stepped across our marae area to join them at the gate and came on with them, walked with these two men from the Ministry of Education, sat on the taumatua with them and remained a quiet constant presence and came through our hongī line to harīru with everyone at the end. Now, we don't say, 'Oh sorry, he's our special needs kid', and we don't say, 'Oh, he's not the full quid'. We don't have to excuse anything about Ben because he is beautiful and none of our kids are sniggering and scoffing, so we're learning.

The reason Ben's a treasure is he teaches all our other kids to tread carefully in this world, to look first rather than judge, to wait, to respond to everyone. We know that he's not a nasty person, we know he does no harm and why should we feel sorry for someone who can live so peacefully in this world? We've got lessons to learn from Ben.

Ben is really part of us. I can imagine Ben continuing to come here for the next 10 years. We feel an obligation to be providing his education, he could well become a supplementary worker within our school grounds and continue to be adored and feel comfortable for much of the rest of his life.

Matariki School provides a full-time teacher aide position in support of Ben:

The ORS funding doesn't give us Kereru full time. It falls short each term so we pick up the slack on that and the resource money of \$62 a term also goes into Kereru's wages at present, although I understand people might like to purchase some resources, but we see all our teacher aides as exactly that, teacher aides. Koanga as Ben's teacher has the responsibility for him. Kereru's job is to take up what requirements there are within the IEP that Koanga delegates to her. Koanga is also going to be interacting with Ben, it doesn't mean because you've got a teacher aide the teacher isn't there. When Koanga is addressing Ben's needs, that gives Kereru the opportunity to work as Koanga's aide as a compensation for the extra responsibilities she has with a special needs pupil in her class.

Kereru and Ben do our lunches sometimes here at school as part of Ben's education, and between the pair of them they pretty much cover our school canteen—you know, seven or eight pizzas heated up each lunchtime—that's part of his routine and it's functional and productive.

Urukehu's relationship with Ben and his whanau is part of her usual routine as principal:

In my mind I have the picture of Ben, his whanau, his home, and his needs and that's the same for every child that I've got on the roll here. I've got a picture of their wider family, who their previous teachers were if they've been at our school. I think my ideal is that I'm a servant. Now, if someone makes a request and I hear it and don't act upon it, I'm not a servant.

It's not for me to decide whether their request is valid or not. I think I'm obliged to know what the legal opportunities and the legal constraints are, but if there's an opening, it's an opportunity. I'm obliged to be as knowledgeable as I can in the areas that I'm claiming to the world that I know about, like the brain, like the Education Act, like the curriculum. These are areas where I must be as thorough in my knowledge as I would expect my GP to be regarding health.

I do recall that Ben's whanau expressed quite a fearful concern about his transition to college and I'm obliged to listen to that. I'm obliged to listen when parents express their fears. That is really the kindest thing they can do for me because they are giving me such vital information. If they withhold that information we're going to lose children and I'm not in the business of losing children. I mean losing children from life, losing children from society, losing children from their potential, we've got no room for waste.

We don't have a lot of information about Ben, I would expect that there's some paediatrician who takes a regular ongoing interest in him. I look at what he's producing on paper and it really hasn't progressed a lot. What hinders him is his fine motor co-ordination, what more can we do for him? If not in handwriting what about in buttering bread? What about in doing up his shoelaces? What about the next thing? So who's advising us with physiotherapy? No one! I mean this is not information we're getting, we're working on his academic progress and the bulk of the financial support for Ben seems to be through this school. Where is the medical support? That understanding of physiology, anatomy, that's not my area, mine is learning. Ben's non-verbal, somebody else has got to be able to explain that to me, someone in psychology—is he a volunteer mute? I don't know, I have not been given that information, I have been given the information that he's got ORS funding and he is non-verbal.

Urukehu discussed the training for Kereru, Ben's teacher aide:

Kereru has been a constant in Ben's life since he arrived at our school. Why has SES never offered her appropriate training to address Ben's specific need? She is his teacher's aide and has been right through. We've had another non-verbal child and his teacher aide had access to New Zealand Sign Language training. Now she's gone to train as a deaf communicator and has a specialised job in that field because she went so far with it. That was an opportunity of growth that she needed, it was applicable to the child she had. Somebody also said, 'This child will benefit from this course'. No one has said, 'Teach Ben sign language'. Maybe we're wrong, maybe we should have said, 'Yes, that's exactly what he needs', but then he's not deaf. Neither was the other child, the other child was non-verbal as well with perfect hearing. So who makes those decisions? We were following orders because we knew it came with the funding for that child. Maybe we've underestimated how proactive we should be.

Urukehu noted that better access to courses was made available to the school as a result of the SES's own review during 2000.

Matariki was recapitated to include intermediate years 7 and 8 and appears by word of mouth to have become a magnet school or a school of last choice for parents experiencing illicit 'kiwi' suspensions¹:

Last year it was really hard because we had kids who arrived to our newly recapitated school and they formed the vast majority of our senior school. Twelve Form 1 and 2 kids, eight of them suspended, or shifted sideways from elsewhere, they had not been welcome in their previous locations. We had a massive amount of work to do, which we did without additional funding and support. And it broke us. We actually lost 50 pupils through last year, partly because of that ugly, ugly influence right at the top of our school. They were so visible, they were new, they were big, they were loud, they were raucous and people thought, 'Why have they come to our school?' But they hadn't actually been officially suspended, so we had no right of refusal. A part of what I had to do was go to these schools and say, 'You

¹ 'Kiwi suspensions' occur when parents may be urged informally to remove their child from a school before action such as suspension or expulsion (exclusion) is taken.

are breaking the law, or you're sailing very close to the edge of it'. When Maori parents are told, 'Your child is suspended', they believe it, they don't ask for the paperwork. So, a school could let parents believe their child had been suspended or expelled, the parents come looking. There was no documentation that gives me right of refusal so of course in the door they came. In the end I went to the Ministry and to the Education Review Office and I reported the individual cases.

There has been no guidance and support. Fortunately now our local intermediate has a spare room that's been set up by social services. We completely tautoko that initiative because where you see problems on your own site, you address them on your own site. You can't just sweep children out to clean up your act and say, 'We've got this really tough zero tolerance, we've got our standards and people who don't meet them are out'. Sure, out of what? Out of our town? No. Those kids are still in our town. Out of our society? No, they will still be people in our society.

What happened was the impact of these older kids added to the stress levels of our staff and we lost some very valued staff members to burnout. With their departure we lost 50 pupils. I can't say all of them were down to that but that was a third of our roll we lost in about 6 months because of the whole string of events. That's okay, I mean it, we really like having our smaller school anyway.

When people commit to a school, especially under our Tomorrow's Schools models, the school is what we're going to make it. And if you can only stick it out through the good times and not hold fast through the stressful times, then you're best to move to where you're going to be happy. If you only want to invest 2 percent of your personal life in the school where your children attend, okay—find a school where 2 percent's enough. If you only want to invest up to 50 percent of your working life in this school and you're an employee here, well, find a school where that's enough because other people will be compensating for the shortfall.

We've got a really good team and having been through that together brought a heck of a lot of talk, debate, passion, because there were different solutions. There were hard-liners and then there were those of us who know what our carving means, what our charter means, what our community expectation is and we know we're living in a community that does not alienate the children.

Dealing with the educational bureaucracy is often problematic, as Urukehu described in relation to accessing a Resource Teacher: Learning and Behaviour designated Maori:

Specialist Education Services called a meeting at sort of 3-days' notice to say, 'Come down after school and we'll let you know how everything's getting on with SE2000'. About half of the principals gathered at this meeting which was not a 'keep-you-informed' meeting. This was: 'Here are the RTLBs. You've got a week to decide who their host schools are'. We said, 'What?'

Now, neither of the principals of kura kaupapa Maori had attended that meeting and it's the same with all small schools, how do we get representation at a meeting any organisation wants to call with 3-days' warning? Transport's a consideration, you have to prioritise, you've got other things on and this really didn't look like an

important meeting. We discussed that at the Principals' Association and this tagging of RTLB (Maori) was of particular concern because it was meant to be on a ratio of one to 500 pupils and the two kura together only had around a hundred or so, how would we do it? It would be ridiculous to try and speed that one person from one edge of the remote area to another involving hundreds of kilometres of road and the expense of that too.

One KKM principal was away and this whole decision-making thing happened while she was away with waka ama. It's 10 days when significant decisions were being made. I could see people eyeing up RTLB (Maori) as something that they were going to snaffle up, that they would use, that they would make an appointment and that once again our kura kaupapa would miss out on a resource that was their entitlement. I thought, 'If we don't get an RTLB Maori in our kura, then we're going to have crumbs around the edge of the table again'. So I've got all these meetings minuted because I was furious. I could see them playing with thirty pieces of silver, it was just scavenger stuff—'Wow, what a neat resource', and grab what they could. I could see one going to the college, one going to the primary, one going to the intermediate, as a right—because they were big. I thought, 'No!', because then we are again in this situation as we were with the previous system of the itinerant teacher, we'll be on the periphery, we'll have crumbs, we'll have scraps. I also said, 'I'm standing in a room here where all of you have sent me children you don't want and you will keep the resource provided for their needs, I don't buy it'. So, we secured the RTLB (Maori) and our school looks after her with the two kura kaupapa Maori.

Matariki works with two kura kaupapa Maori schools in the area:

We had no understanding when we signed our Memorandum of Agreement to be the host school and the management committee for the RTLB (Maori) position that we had to serve the three areas. We definitely had no expectation that she would be working with pupils anywhere other than in our three schools. We know that we've got a good deal but then the buy-off for all the other schools, with our seven RTLBs for the region, was they got better RTLB service, they got better ratios as well, so they didn't just go one to 500 plus an RTLB Maori—2 percent. So that was the trade-off with each other.

All of the other schools have access to our RTLB because she is designated Maori. We've since found that not only is she meant to serve this area, she is meant to service three big rural areas. I can't imagine how many pupils that one person is meant to stretch to. We secured a wonderful person, we headhunted her. We travelled a long way to get her, we knew that this was a resource that we weren't going to waste, we had to get the very best person we could find. Through the grapevine and through all our past experience we came up with a list of ideal people. We went through the process and we are more than happy with who we have, but of course she's addressing the needs of Maori and this is a crying gap. We've got other RTLB who are failing to bridge that gap.

Now we've got 18 months into RTLB they can see those gaps, and increasing calls are being made on our RTLB (Maori) to serve their needs as well. It's a wonderful resource but we don't have the personnel.

We were talking earlier about how SES or the government could put in a layer of scholarships for Maori in particular, or funding. Look now at seventh formers around the country, look at under-graduates. Look at people who have done a degree in psychology or appropriate areas. Go to the graduates of the Maori language departments in all the universities. Go to the graduates of the Teachers' Colleges and say, 'One more year, because we want you as a Speech Language Therapist' or 'We want you as psychologist'. For the sake of waiting one more year, or at the most 3 more years, we know we will have cultivated the people we need so that we have that harvest, that bumper crop.

There are going to be people we lose through these first 2 years of RTLB. Now, who will fill those positions? People also untrained as RTLB. RTLB could have come in as two tiers with people actually filling those jobs, side-by-side with another cohort who were training to be RTLB. It's a specialist job, it's attractive financially but if we say, 'Oh look, we gave them money for the resource' and there's nobody to employ, we've wasted the money. You can just feel that rubber band stretching right out, just keep on stretching; it's going to snap back on their fingers soon.

When 45 percent of this region's population is Maori, 45 percent of our RTLBs should be Maori and a hundred percent of them should have an empathy with the 45 percent, if not some proficiency in te reo, if not some understanding of tikanga, if not some courage and understanding.

Ben is the least of our worries. He's got funding, he's got resources, and he's got IEPs and people who make time for the IEPs. I don't understand, we've got \$622 for the first half of the year, some kind of supplementary funding to the RTLB and what am I supposed to do with \$622 for 20 weeks? So I can spend \$30 a week on something to address what? To address moderate learning and behaviour needs in our school—\$30 a week? It's not even going to shout my staff a decent morning tea for the additional hours they put in, the additional toll on their personal well-being, for the work they do in our school. I find that an insulting sum. I think that the Ministry could keep that money, you know, rather than spit at us.

It came into our cluster; it was the most expedient thing for some people in our cluster to make a decision on our behalf that whatever money your school generated under the formulas would go to your school. It's not even needs-based within our cluster, so somebody in a decile 8 school gets the same proportion of money as I do here and sure I guess being rich has it's own difficulties and problems.

In terms of tino rangatiratanga, we may be on the edge of that and it breaks my heart that we may fall out of the grouping with the kura because we are, on paper, a mainstream school. We do not believe we are mainstream, we believe we are as alternative as kura kaupapa Maori is. If you could spell it all with little words, if you spell it te kura kaupapa Maori, we have the kaupapa, we are Maori and Maori in the sense of—we are just ordinary, we are normal. We're fresh, life-giving, life-

maintaining, but we also know we're not in the mainstream state system because our parents aren't freeloading on us, they aren't here as a matter of convenience or expediency, they're here out of choice.

It's things like reporting to parents. Now, probably each week most teachers in our school would have reported to a third of the parents in their class, through those interactions, it's not just 'Good morning', 'Hello', it's those meaningful interactions you have, you're touching base.

I was listening to a decile 10 school from the city saying they wanted extra resources for their school, so they thought they'd charge their parents \$190 as school fees annually. I thought, 'Oh boy, we couldn't ever do that'. Imagine if you could just send out a bill for \$190 and the cheques came in. On reflection later, I thought that's what our parents are paying, that's what the transport costs. It doesn't appear as school fees in one lump sum, it appears as their daily dollar, as their weekly five dollars, so our parents, in decile 2, have at least as equal the commitment of any of those decile 10 schools. I mean, when that kind of light lights up in your head, you think, 'Man, these are remarkable people'. Why is there the belief that all our people drink beer and buy lotto tickets and beat their kids up?

Urukehu described the Matariki School charter, kaupapa, and governance structure:

When we were reviewing our charter, I said, 'Let's not put values in English and then go and find a translation in Maori. Let's name them first in Maori, let's use the vocabulary that already exists and not have to go and make up a word like "computer". What are the words for the values expressed in tikanga Maori and which of those will we hold on to?' It came down to five core values of aroha, manakitanga, whanaungatanga, whakamaramatanga and kotahitanga. Now, they're not transliterations from English, they are embedded in what we do.

We do have opportunities for younger children to work beside older children, for them to awhi each other. What's at the centre of our harakeke, why do we grow harakeke in our grounds? So our children can go out and see mother, father, and child and leave that unit intact, we take from around the edges. I mean the harakeke itself is a beautiful expression and we'll have some of our 5-year-olds taught here and within their own lives to karakia before they take those leaves. So you might see them at lunchtime with a pair of scissors, bow their heads, say their karakia, take the leaves they require, make whatever they're making, even if it's whips or putiputi or whatever they're making and they return their scraps back to that. Nobody scoffs, sees it as anything unusual, are alarmed by it, nothing like that, it's actually part of a natural rhythm, you know, like I was saying, oxygen is part of the air. It's what we breathe.

We've got to have the development of our grounds, so it's living. Our grounds are alive, they're alive with plants, they're alive with food, and they're alive with insects and birds. That kind of liveliness helps to relax people and open them up. We had visitors from the Ministry here and I took them down to our grounds and they enjoyed sitting down there, amongst all the mosaic and plants. Because they could see the varieties of plants, they starting talking about plants as well and I said, 'Now,

this is one of the ways we open up our school to receiving information. If we show you we value Tanemahuta, then when I let you talk, some of your talk will go that way.' Now, I've got more information freely given from them to me about the kawakawa plant and why we should have it and there's no doubt in my mind that's the next thing we're going to stick in the ground here. I will find a kawakawa plant from somewhere because it's got the story of these two visitors. Now, if we have a sterile environment—prefabs, asphalt, concrete, neat, tidy—people will respond to that as well, it says everything's orderly, speak when you're spoken to, get in line, shut up, be quiet, only one person talks at a time. A garden says much more, 'Hey, come on out here, the birds aren't putting their hands up before they sing'.

You know, so there's more unruliness. It does leave it unruly at times. It leaves it complex and difficult to understand. It leaves it frayed around the edges and you can feel, 'Oh, I'm losing control in this'. But we accept change at the beach; we accept change with the seasons. We don't think, 'Oh my goodness, all the leaves are falling off the tree and I need to stick them all back on'. We don't panic in response to the natural world and I think the more natural we can make our school, the more we will remove that panic, which is removing the fear. This opens us up to talk, to really talk to each other, to talk through the silence between us, whether that's culturally or in terms of class. If someone is feeling they're intellectually inadequate compared with someone else, you've got to talk through that silence as well.

Matariki School has a Board of Trustees with six members—a Pakeha chairman with two children attending, a Pakeha man who has one child at the school, a Pakeha mother who is a farmer with two children at the school, two Maori mothers with two children each at the school (one of whom had a child at the school about 20 years previously and has the historical view of the school), and the principal, Urukehu, who has three of her four children attending the school.

We have just invited the local marae committee to nominate someone that they would like to join the Board because in the past they've always provided us with one among our parents who are also on the committee. We happen to be at a time of between generations and there are only two families I think associated with our marae who have got children in our school at present. It shouldn't be an obligation upon them to be the ones, because if I didn't have the care and concern shown by our kuia and our matua in my work, it would be a whole different kettle of fish. The interest of those aged in their 50s, 60s, and 70s in the school is really important. They need the information. They want to be knowing where we're going and what we're doing. They want to know what they can do for us and also what we can do for them, so we advocate for each other on different issues and share resources.

While there are major concerns for Matariki School, it also has great strengths:

The fact that our roll has dropped is a concern. I think ideally we'd like to be sitting around 156 rather than where we are—around 120. I've felt really vulnerable through a goodly half of this year because of a financial deficit that we ended up in last year simply because we lost those kids and it affected our final quarter of funding. We'd been in such a hearty position in the first half of the year that as a

Board we'd agreed to overspend by \$17,000 and we came in at a deficit of \$14,000. We understand why but for 3 months there were a number of people who didn't understand why and didn't ask. I felt very much as if there was a suspicion of 'What's Urukehu done with the money?' To go through our audited accounts of course that's all vindicated, but it did leave a nasty taste because I am unaccustomed to working without trust and honesty and being upfront and saying what you mean and talking to the right people.

I sincerely believe we're in good heart and, despite the trials and tribulations that we might face as a Board, I believe we hold together because our focus is singularly for children, the children, we do not exist for anything other than the children.

A special quality of our school is that the vast majority of our children are living with both biological parents, their brothers and sisters are their full brothers and sisters. We're not playing Brady Brunch. We have a large number of people who attend church, a large number who would do anything when the call goes up at the marae, people who attend sport; we already have a community built on a strong sense of hauora, which is important.

We are happy to use the exemption for over-age children with special needs. I don't think any parent should use it to pressure a primary school to keep a particularly physically large or aggressive student on the grounds, because that's inappropriate. We've got a gentle soul in our setting and Ben does have a place here. He doesn't physically stand out at present and there's room for that. I think we've got so much to learn from Ben. Our children have got so much to learn from him, but if there was like a 12-stone aggressive character, it's a whole different story and that's why it's got to be that three-way partnership with the whanau, the Board and the principal. I think of the number of Downs Syndrome kids, we're a primary school, if this is where they've had their primary schooling, if they have that teacher aide to tautoko their mahi, they've got the watchful eye on them. I think it's a beautiful thing to do. I think if we are able to let schools know that it's possible, then that's a lovely thing for a principal like me, to be able to deliver to a really despairing parent good news, that is a delight, to say, 'Look, I've found a way'.

**WHANAU EXPERIENCING SPECIAL EDUCATION
WITH RTLB SUPPORT**

TE WHANAU O MAUI

E ngā mana e ngā reo e ngā karangatanga maha o te motu, tēnā koutou, tēnā koutou, tēnā koutou katoa. Ngā aitua o tēnā marae o tēnā marae kua wheturangitia, haere atu ki o tātou nei rangatira kua wehe atu ki te po haere, haere, haere. Ki a tātou te hunga ora o tēnei ao hurihuri, kia kaha, kia maia kia manawanui. Nō reira tēnā koutou, tēnā koutou, huri noa huri noa tēnā tātou katoa.

Tēnei te mihi ki te whānau i huakina mai tō rāua whare ki au, i runga i te wairuatanga me te aroha, ä, kia whārikihia, a rātou korero mo te mahi rangahau nei. Me te whakaaro kia whakatakoto te mahi rangahau nei i roto i te reo Maori. No reira tēna koutou te whānau.

*'He kai poutaka me kinikini atu,
he kai poutaka me horehore atu,
ma te tamaiti te iho'*

Ki a koe hoki te tohunga matua. Nga whakawhetai ki a koe i takoto te huarahi kia tutaki ai maua ko te whanau o Maui. Me o mahi whanui mo nga tamariki pera ki a Maui.

'Haere e whai i te waewae o Uenuku, kia ora ai te tangata.'

Timatatanga

He mahi rangahau tenei e pa ana ki tetahi tamaiti tomuri, tamaiti haututu hoki. Ko Maui te ingoa o te tamaiti o te rangahau nei. E whitu ona tau. I haere ia ki te Kura Kaupapa Maori o te rohe nei. Ko ana raruraru e whakatomuri ia i roto i ana mahi, na reira he tamaiti haututu ia. Kaore ia te orite ki nga tamariki pera ki ona tau, Na aua ahuatanga i whiwhi awhi ia mai i tetahi tohunga matua Maori, kei raro i te maru Matauranga Motuhake.

E noho ana te whanau i tetahi taone paku rawa te hunga Maori. Kaore ona whanaunga e noho i kora hoki.

He korero tenei mai nga matua o Maui, te ara kia whakatikatika, kia whakaangitu o raua tamariki. No te tohunga matua i tapiri, i nga korero hoki

Nga Kororerero

I te whiti te rä, he ruarua noaiho ngā kapua e iri ana i te rangi, ä, i purea mätou i ngā hau maiangi a Tawhirimatea. Ahakoa i ähua tio, ae he rä tino ätaahua tēra.

Ka tae atu māua ko te tohunga matua ki te whare o Maui. Ka tiro atu au ki ngā pätiti, he ataahua rawa atu, tino kakariki ana, he orite ki ngā papa takaro o te kemu korowha.

Ia rä koiane te papa takaro a Maui, ä, ko tana teina e mätakitaki ana i te pouaka whakaata. I nuku maua ki muri, ka tutaki ahau ki öna mätua. I korero okawa mätou mö tētahi wā poto,

Kei te pēhea koe?
He rangi ātaahua tēnei, ahakoa he āhua makariri.

A, i korero pērā mātou. I te koropūpū te ipu mo te kapu ti me te kapu kāwhe, kātahi anō ka timata ngā pātai.

I timatangia e au te ripene ta hei whakamau i ngā kupu a ngā pakeke nei. Ka ki mai te matua,

Me whakamātau te mihini tā kia tiro tātou mēna kei te pai te rere?

Ka whakahoki atu au i tana pātai.

Kei te pai, kei te hurihuri te tēpa, kei te pai ngā ahuatanga mö ngā mahi, me haere tonu.

I te mutunga o ngā pātai, kāore i mau ngā kupu kōrero ki runga i te ripene.

Kātahi te kairangahau küare – Pokokohua!!

Ae, ka tika ana te papa. Ka mohio au i mua o te timatatanga o ngā mahi me tīni ngā pākahiko. Nō reira aroha mai te whānau mo taku hara.

I te tuatahi i whakatakotonga e mātou nō whea mātou, he tikanga hei whakarata i a mātou, me te whakawhanaunga hoki kia kitea mēna he whanaunga nōku rātou. I oti ngā mihimihi, ä, ka rapua e au te nako, te matü me te hinu o ngā kōrero.

I möhio tonu ngā mātua o Maui i reira tonu he wāhi mo Maui, heoi anō, kāore räua i mohio ko wēhea tari tika mo wēra momo äwhina.

Tokoono o te whānau i noho tahi i te kainga. I whāngaitia, ä, i manaakitia e nga pakeke a Maui. Ko Maui te tuakana o ngā tamariki.

Nō räwaho kē te whānau nei. Kei tua atu o te taone to rātou whare.

I kite ngā mātua he raruraru to tā räua tamaiti. He raukura ia. I kimihia e räua he äwhina mö tā räua tamaiti a Maui, ä, I kitea he aha taua raruraru. He āhua pöturi tana mate, engari, nä taua ahuatanga ka pörarurarutia äna mahi i te kura.

I tirohia whānuitia mö te manākitanga. Ki a räua kōrero, i tino ngawari noa iho te kimi äwhina möna. Mä te pātai ki te kura me te hikoi o ngā ringaringa, ka whai manaaki.

He raukura hoki te kōtiro o tēnei whānau, heoi anō. kei tērā atu pito o te taumata. He tino mohio ia. Me whāngai tana hinengaro kia kore ai ia e whakahoha.

Tekau örau o te wä ka korero Mäori te whänau i te kainga. Ka körero Mäori ngä tamariki i ngä wä katoa i te kura.

Tokomaha ngä täkuta me era atu tängata i kite i a Maui. I haere ia ki tētahi tangata kia whakamātautia öna taringa. Ko te whakautu, käre ia i te turi. I kitea e tētahi atu täkuta mö aua momo mate, he tamaiti mätau ia. Ko te urupare, kei te pai tana möhioanga. Ia marama i haere a Maui ki tētahi täkuta mö ngä mate waewae. Tēnä, i whiwhi awhi ia mai i tētahi tohunga e mätau ana mo ngä momo tamariki pērā i a ia. Ko te tümanako o öna mätau, kia pai me te noho ora tonu tä räua tamaiti.

Ka haere ia ki te kura kaupapa Mäori o te rohe nei. I reira tētahi tamaiti pakeke ake i a ia, ka whai hoa ia. Ia rä, ia rä i äwhinatia, i manaakitia e te tamaiti pakeke nei a Maui, i whakahaneaneatia ia. I ngä wä o ngä Kapahaka i tü a Maui ki te taha o te tamaiti nei ka whai ia i a ia. I tētahi rä ka tau mai he kapua pouri.

I nekehia e te kura tana hoa ki tētahi atu karaehe. Na tērā ähuatanga ka tino hinapouri a Maui, nä te mea kua ngaro tana hoa. I mua i te neketanga o tana hoa, i whakapakaritia ä, i whakaangitütia ia. I kitea e öna mätau koira te hoki whakamuritanga a Maui. Kaore he hoa hei piri pono atu mäna.

Ko tētahi atu mate e pa ki a ia, käre ia i kaha ki te whakaputa i öna whakaaro. I tētahi wa i rangiruatia ia ä, i pērā anö i ana kupu. Mēna ka whakato i tētahi tamaiti ki a ia, käre ia i möhio he aha hei whakautu mäna, nö reira ka ruturutuhia, ka päkarukaruhia e ia ana taonga. Käre ia i möhio he aha ai ia i pēnei ai, nö te mea tata muri iho, i tana hokinga ki te kainga kätahi anö ia ka möhio i tana pukuriri.

He wahine ngakau mähaki, ngakau nui te whaea o Maui ki a ia. Ko ana wawata kia mätau ia ki ngä ähuatanga katoa e pehi rä tana tama, no reira, ka kaha ia ki te pänui i ngä pukapuka e pa ana ki aua momo ähuatanga. Ma tērā ka hikina ai ngä taumahatanga i ona pakihiwi.

I tētahi wä i pätai atu e tētahi wahine ki a ia mehemea he pörangi tana tama. I tērā tonu ka pa mai te pouri ki a ia, nö te mea ehara tana tamaiti i te tamaiti pörangi. I haehaetia tana ate, tana hotu manawa. Ka whakautu a te papa, kua e whakarongo ki tētahi atu tangata, kua e whakarongo ki te reo o te kuare.

I tētahi wä i hinapouri te whaea o Maui, na te mea i kite ia käre anö a Maui kia eke ki ngä taumata orite ki ngä tamariki o tōna reanga. I titiro whakaroto ia ki a ia anö mö ngä raruraru o tana tama. Heoi anö hoki, ki a ia koiane te rahi o tana aroha ki tana tamaiti.

I whiwhi tautoko te whänau mai i ngä kaiako tohunga mo ēnei momo ähuatanga e pa ana ki tētahi tamariki. Nä, tokorua o ēnei tängata i te awhina i tēnei whänau. I te timatanga i nuku tētahi o ngä tängata nei, ä, i uru mai ko tētahi atu. I hari koa, i häneanea te whänau mö tēnei tautoko i whiwhi rätou, me te möhio anö, a tōna wä ka taea e te whänau te kaw

i ēnei momo mahi mō Maui me ērā atu tamariki pērā. Koiane te painga mō tēnei whānau.

Ahakoia i ki te whaea o te whānau, he pai tonu mēna ka mutu te āwhina i a rātou, ēngari, i ki te tohunga matua ka hoki tonu atu ia ki te mātoro i te whānau. He tikanga anō tēnei ki te ao Māori. I waihangatia nga piriti i runga i te aroha me te manaaki i te tangata,

Oti ana aku pātai, i haere maua ko te kaiāwhina ki te kite i a Maui i roto i tana karaehe i te kura, kia mohio ai ahau i tōna wāhi ako me ngā āhuetanga o reira i kōrerotia e ōna mātua.

Nō to māua taenga atu ki tana karaehe i mihi mai ngā tamariki ki a māua. I pēnei ngā mihi.

Good Morning whaea (*Ingoa*)

Morena tamariki ma!!

Good morning matua (*Ingoa*)

Mōrena tamariki ma!!

I muri iho i noho māua i muri i te karaehe ki te titiro ki ngā mahi a ngā tamariki. I mahi a rōpu rātou.

Ko tētahi rōpu i te purei kari, ko tētahi atu rōpu i te tuhi pikitia, tētahi atu anō i te pānui i pukapuka, ā, ko te rōpu o Maui i te purei i ngā rākau tae. Ko aua rākau tae he rakau maa, he rākau arani, he rākau kahurangi me ērā atu tae. Ko Maui i te purei ko a ia anake me āna rākau kōmā. Kāore ia i te korero, i te whakaeneene i ētahi atu tamariki, engari i pau katoa ōna whakaaro ki āna ake mahi.

I kōrero māua ko Maui mō tētahi wā poto, ka kite au he tamaiti tumeke ia. He tino kamakama ia ki te korero ki ahau. Nā, i haere mai ētahi o ngā tamariki ki te korero ki a māua, ka puta a rātou patapatai.

I kōrero Māori atu māua ko te kaiāwhina ki a rātou. I ētahi wā, mēna i kōrero tētahi tamaiti i te reo Pākehā, i kohetetia ia e ngā tamariki. I pēnei ngā kōrero:

Turituri!

Kōrero Māori!

Kaua e kōrero pēnā!

I tino miharo ahau ki te mātakitaki i tēnei āhuetanga.

He tauira pai tēnei mā tātou te hunga pakeke, no te mea hoki, he tino māngere tātou ki te kōrero i to tātou reo rangatira. Arā, whakarongo ki te tauira a aua tamariki.

E rua rau pea ngā tamariki o tēnei kura, a, rua tekau ma rima ngā tamariki o te akomanga Māori, Ko te pakeke o ngā tamariki i roto i tēnei ruma – mai i te rima tau ki te tekau tau te pakeke. I riro he tamariki hei ranagtira mo ngā tamariki, I whakamana te nako o te whanau. I kitea e au ko ngā tuakana i te äwhina me te ärahi i o rätou teina. nā tēnei hoki, i ako rätou i ngā kupu kanga. I möhio a Maui te wä mö te whakahua i aua kupu. Tera pea ka mohio rawa atu ia.

I paku rawa te ruma i whakawāteatia mo te katoa o ngā tauira. na reira, i hiahia ai ngā tamariki o te akomanga Māori i tētahi ruma nui ake mo rätou katoa.
Na aua ähuatanga käre a Maui i whiwhi äwhina mo ngā tamariki pērā i a ia, ahakoa tonu, he nui ake ngā raruraru e pa ana ki tana karaehe katoa.

Ki öku whakaaro, me kaha kē ake ngā whānau me te kawanatanga ki te whakarite he akomanga Māori i roto i te kura tuarua, na te mea, kia puta ngā tamariki i te kura tuatahi käre he karaehe Māori hei whakauru atu ma rätou i te kura tuarua. Ka memeha noa iho to rätou reo i tēnei tüähua. Pēnei te ähua mö te nuinga a ngā kura tuarua i te rohe nei.

I puta ēnei whakaaro i te matua o Maui. Ka taea tonu e ngā kura tuarua te tonu mo ētahi putea mai i te tari mätauranga kia taea ai te whakatu he karaehe pēnei i roto i ngā kura tuarua. Ki öna whakaaro anö, kei te whiwhi tonu ētahi kura tuarua i tēnei momo pūtea, ëngari, kei te whakamahia kētia mo ētahi atu karaehe o te kura, ehara mo ngā kaupapa Māori.

Whakamutunga

I ahu mai i roto i tēnei tirohanga, ko ngā painga i puta ki te whānau mai i ngā tohunga matua i awahi, i manaaki i a Maui mo ngā ähuatanga katoa i pa ki a ia. Tētahi atu, kua tino mätau tēnei whānau ki ēnei momo mate.

He tauira tēnei ki ētahi atu whānau i heipu ana ki te whiwhi tamaiti pērā i a Maui.

Anei he huarahi awahi ngāwari, pätai atu ki te kaiako o to, waeatia ngā tari e awahi ana i ngā tamariki, pätai atu ki o hoa, ki to täkuta ränei. Ko te mea nui, kua e nohopuku, ëngari pätai atu.

Kupu Hou

Akito – Slow

Angitu – Confidence

Hikoi o nga ringaringa – Fingers do the walking (phone book)

Kemu Korowha – Golf

Okawa – Casual conversation

Päkahiko – battery

Tohunga matua Maori – RTL B Maori

Tüähua – circumstance

Whakahaneanea – Made to feel comfortable

TE WHANAU O MAUI: WHAKAPAKEHATANGA

Whakatauki

‘Haere e whai i te waewae o Uenuku, kia ora ai te tangata.’

“Go search for the footprints of Uenuku so that humankind may be nurtured.”

(Uenuku was said to be wise in things such as health, personal safety and welfare)

Maui:	Left
Kuini:	Queen—Maui’s mother
Tautoko:	Support—Maui’s father
Pono:	Truth—Maui’s friend at KKM

Te whanau o Maui live separately from their extended whanau in a small town in the South Island where Maori are a minority. Seven-year-old Maui attends Kura Kaupapa Maori and receives assistance from an RTLB (Maori). The details of the case study were written down after the tape recorder failed, and the version created in te reo Maori is for Kura Kaupapa Maori whanau, children, and teachers, and the Resource Teachers: Learning and Behaviour. The English or ‘whakapakehatanga’ version is for use by English-speaking education professionals. The style is a narrative which follows the story of Maui as a slow learner who misbehaved in class to a situation with which everyone is happy. This story, told by a kairangahau awhina interviewing Maui’s mother and father, is an account of what they went through to seek assistance for their son.

The sun was shining, there were a few clouds in the sky, we were touched by a little breeze from Tawhirimatea. Even though it was a bit nippy, it was indeed a beautiful day. I looked at the grass, it was primo, green as, everyday Maui plays here while his sister prefers to watch TV. I met the parents and we engaged in casual conversation for a while, then the jug was put on the boil for a cup of tea, and we started the interview.

I started the tape-recorder to catch the words of the parents. The father said to me, “You should test it to see if it’s working”. I replied, “It’s alright, the wheels are spinning, the settings look alright”. (Well, what an ignorant researcher!) At the end of the interview when I checked the tape, it hadn’t recorded. So now I know for next time, test the machine. Apologies to the family for my mistake that we solved by recalling the details of our korero together and writing draft stories, checked by our whanau, RTLB (Maori), and NZCER pakeke and kairangahau.

First, whakapapa were shared so that all present established who they were and where they were from, to familiarise themselves with each other and to see what whanaungatanga links existed. This is an important exercise to Maori. “Where are you from” is often the first question you ask somebody you have just met. We finished our mihimihi and then got into the essence of the story.

There are six in the immediate family. Maui’s parents look after him and it was his parents who noticed he was a special needs child, the problem being that he misbehaves.

The whanau looked far and wide for assistance for their child. They asked the school, rang various agencies, and with a doctor had a glue-ear check. Maui's ears were then checked by an audiologist to see if he was deaf, and tests showed that Maui wasn't deaf. Maui had an intelligence test, and the results were fine. He saw a podiatrist regularly because of his legs—the toes point inwards. It was discovered in the end that he was slow for his age, which leads him to misbehave. Then the KKM arranged for Maui to receive assistance from the RTLB (Maori). Kuini and Tautoko, like most parents, want only what's best for their child.

Maui goes to the kura kaupapa Maori in the area and there was an older student, Pono, who was a friend of Maui's. Every day Pono would assist Maui. He made Maui feel comfortable. When they had kapahaka, Maui would stand next to his mate Pono and follow him. One day, however, a dark cloud arrived—Pono had moved to a mainstream school. Maui became quite upset by this as he missed his mate. Before Pono moved away, Maui was making progress, he was building up his confidence. After Pono moved, Maui's parents could see that he was going backwards, there was no longer a peer for Maui to look up to.

Maui speaks slowly and sometimes mixes up his words but he does understand what has been said or what instructions have been given to him and he knows how to respond. He knows when other children are getting cheeky to him but he doesn't have any verbal comebacks. Instead Maui reacts physically, in one case breaking some toys. He didn't know why he reacted like this until he got home.

Without a doubt, Maui's mother Kuini has a big heart and strives to do what's best for her child. She works hard to build up her understanding of how to cope with her child, reading books to help him. She also carries a lot of the weight on her shoulders. One time a woman asked Kuini if her child was "crazy". It made her sad when she heard this. Maui isn't crazy. Something ate away at her stomach, her heart was sobbing. Maui's father Tautoko's response was to say, "Don't listen to other people, don't listen to people who don't know".

Sometimes Kuini would compare Maui to children the same age even though she knows that she has a special child. If she doesn't properly resolve some issues, like the toy-breaking episode, she feels that it is her fault even though it isn't. This shows the love that she has for her child.

The whanau accessed help from two RTLBs who are Maori. They had two RTLBs, the first one moved out of the area and they got another. They are happy and comfortable with the assistance they have received so far. Soon they feel that it won't be necessary for the current RTLB to check on Maui. This is beneficial to the family. They have searched for assistance for their child and from this they have gained some confidence to be able to put Maui on the correct path. They have gone forward again because of this RTLB. They have become familiar with and learnt about these sorts of problems. Even though they stated that it would be alright for the RTLB to cease visits, she would check on the family anyway because of the rapport that has been built up. They have built bridges on aroha and manaaki to the person.

TE WHANAU O NGATATA

Nga mihi ki te whanau o te korero nei. Nga mihi ki a koutou i huaki te tatau o to whare, o to ngakau ki ahau te kairangahau. Ko te tumanako o te rangahau nei, ka whakapakari ai koutou, ka whiwhi koutou te awhi ma koutou. No reira tena rawa atu koutou.

Ki a koutou hoki nga kaiawhina i whakatakoto te ara naaku kia whaainga. Nga mihi ki a korua mo o awhi me te tautoko ki a au me te whanau. No reira kei te mihi

Whakatauki

He aha te mea nui o tenei ao?

He tangata, he tangata, he tangata.

What is the most important thing in this world?

It is people, it is people, it is people

Ngatata:	Open
Papa:	Storm—Father
Peara:	Pearl—Mother
Kukupa:	Dove—Little sister at home
Rei:	Fang—Brother
Tara:	Sister who has been adopted out
Tohunga Matua Maori:	RTL B Maori
Kaiawhina Matua:	SES worker
Amanda:	RTL B

Ngatata is 8-years old and lives with his parents and two of his three siblings in rental accommodation in a small South Island town. Ngatata's whanau lives in an area with a low Maori population, and they have relocated to avoid criminal associates in a North Island city. The whanau is living in poverty, supported by the Unemployment Benefit with an accommodation supplement.

At the time of writing, Ngatata had been suspended from and left three of the five primary schools in the area, and after the interview was suspended by a fourth school. Access to the whanau was opened by the Regional Co-ordinator of the RTL B (Maori) or kaiawhina matua who attended the interview, with the kairangahau awhina and the RTL B (Maori) or kaiawhina Maori involved closely with Ngatata and his whanau. His special need is high to moderate behavioural problems and when he has one-to-one help, he makes progress. The interview highlights the problems of accessing help for Ngatata, and an instance when Papa, Ngatata's father, threatened to assault the staff of one school.

The whanau left their house and the region before they could see the draft case study and gave no forwarding contact details. Some of the information and language presented in this case study is disturbing, and after consultation and advice is presented as an authentic example of one Maori whanau.

A bright and captivating smile was waiting at the door, greeting us as we, the kaiawhina Maori, kaiawhina matua and kairangahau awhina, pulled into the driveway. Ngatata had

had a good morning, he had been given the day off school to see the kairangahau who was coming down from the big smoke to interview his whanau. The boy was huge for his age, a barnstorming prop if he were to play rugby, where he can let out all his frustration in a hard but fair and acceptable manner. I nodded to him and he rushed inside to tell his parents the kairangahau had arrived. I was ushered inside by the two kaiawhina to meet Ngatata's parents, Papa and Peara. The kaiawhina matua is currently the case-worker for Ngatata. Inside, Kukupa, Ngatata's little sister, was playing with some cards.

While greeting the parents, a koha was passed over, a show of appreciation to the family for their contribution to the Matauranga Motuhake research project. The kaiawhina Maori then volunteered to take the kids down to the park so that Ngatata could show off his new bike and the whanau could get on with the business at hand. By sharing our whakapapa, we established on which waka our respective whanau had come to Aotearoa and then it was time for the whanau to tell its story.

There are six in Ngatata's family: the parents, and two sons and two daughters. Ngatata is the oldest. Only five live at home as the parents adopted one child out, called whangai in Maori, to feed, nourish, bring up. The whanau has pictures of this child, Tara, and she in turn knows who her blood-family is. The family lives in a rental home described by Papa as a "suburban, low-class house for top-class rent".

They live outside of their tribal boundaries and do not have extended whanau nearby to provide different levels of tautoko, not necessarily financial support but manaakitanga and tiakitanga. Some members of the whanau sometimes speak te reo Maori in the home. The problems faced by Ngatata and the whanau are not seen by the whanau to be caused through a lack of care or love for their children. Like most parents, the whanau wants what's best for the children. But that's difficult without a job, as steady employment would solve some of their problems. Providing for a special needs child requires that much more effort and extra expenses than the average child.

It was a bit of a shock to the two kaiawhina to see Papa the father being very open with his dialogue. Most of the local services have had run-ins with Papa and have found him difficult to deal with, but not today. Perhaps something positive may come for their son Ngatata after all the running around they have been subjected to. Or perhaps it was the appearance of the kairangahau awhina. Maybe seeing a 'brown' face with dreadlocks had sent a different signal and lightened the mood.

When asked, "How do you see special needs for Maori", Papa replied:

That's the first time I've heard about it, I don't know much about it either.

Peara:

No-one tells us what we can use, who we can use, who can help us.

This highlights a problem that recurs throughout the Matauranga Motuhake case studies: there is not enough information readily available for whanau who need assistance. The family explained who first noticed that Ngatata had a special need.

Peara:

They noticed Ngatata's behaviour at kohanga, that's how everything started.

Papa:

Because we didn't know anything about these disorders until we met a friend of hers at the kohanga who's boy had ADD, so we just observed him for a bit and said, 'Yeah, our boy Ngatata's a bit like that'. He used to stress us out, we didn't know what the hell's wrong with him, he wouldn't obey us. That was 3 or 4 years ago, we've been here 6 years.

The whanau did not say whether there have been inter-generational special needs, but Papa talked about problems Ngatata's brother, Rei, has as well:

We think our little boy might have a speech problem because he stutters a bit.

The parents explained the progress Ngatata has made so far.

Papa:

It's getting a bit better, not much, but he's slowly progressing. The principal can actually pick out now what kind of mood he's in but his teacher can't. You look at him in the morning, just observe him for a bit and you can pick out what kind of attitude he's going to have, if he's going to play up all day or just a little bit, but his teacher hasn't picked that up yet. That's how I look at it, one's onto it and one's not.

Peara:

We used to get rung up to go down to the school and pick Ngatata up and that used to stress me out heaps, at the time I was still pregnant. It didn't help, you know, nearly due, that made it even worse. Yeah, it was horrible, 'cause you had to wait—about two o'clock I'd be looking at the phone and if it rung I'd be, 'It might be the school'. I didn't want to go and pick him up because, you know, I might have had a nice day already, waiting for the kids to come home and for Ngatata to stuff it up, sometimes I didn't want him to come home, not with that attitude anyway.

The parents and the kaiawhina matua/RTL B discussed his behaviour.

Papa:

See the teacher said, 'Oh, he's very good today', you know why? Because I gave him a hell of a hiding before he left for school—'Hey, you listen to those teachers', and that's how bad it has to get. Failing that, we get rung up to bring

him home, that's why most of the time he's alright, he doesn't want to get a hiding from me.

Peara:

And he hasn't had one for a while because he's actually been pretty good, not an angel but reasonable to teach.

Kaiawhina matua/RTL B:

Just even sitting here this morning and sticking those things on and writing his name, that's huge progress as far as concentration's concerned for Ngatata. When I was first involved he wouldn't listen to anything and now he's listening a lot more.

Papa:

Ngatata has a hard time just sitting there concentrating on stuff, that's what they say but you sit here with a Playstation going 8 hours or something and he'll sit there and, 'Oh, watch out, Dad, it's going to get you, behind you', you know. He'll sit there for that 8 hours, where when he's at school a half-hour's too much for him, 'cause it's boring to him. You gotta be up and moving and doing stuff.

At the time of the interview, the whanau was receiving support from an RTL B (Maori).

Papa:

Well, I think she was just part of the school, she wasn't actually assigned to us by anybody.

Peara:

And in the past it has to be a male, in fact, the kaiawhina matua/RTL B Maori, she's the only female so far that's gotten through to him.

Papa:

She can just say, 'Pick up those books or you're not coming in the car'. So he'll pick the books up 'cause she takes him out one hour a day or something, just time out from school a bit, as well as learning. She takes him shopping and stuff and she's the only other female that's gotten quite close to him.

Peara:

She actually handles him, usually someone goes, 'Oh no, I can't handle him, I can't deal with him, he's really stressing me out'. At school he's got two teachers

who don't want him back in their classes 'cause if they have to have him back they're going to resign, that's how bad it is. We want the best for our son but it's trying to get it that's the hardest.

The whanau has attempted to access a range of services and support in the past but they experienced disjointed and confusing information.

Papa:

Before, with SES, we had one guy, he was really excellent and they took him away from us, he had other commitments as a teacher's aide. Ngatata needs a teacher's aide, one-to-one all of the time.

See like, I'd go to Social Welfare: 'There's something wrong with our boy.' 'Oh, go see SES.' 'There's something wrong with our boy.' 'Oh, go and see CYPS.' 'There's something wrong with our boy.' 'Oh, go and see....' 'Oh, fuck you, who's going to fucking do something to help us, just answer the question?'

The whanau has been involved in early education and visited many organisations designed to help children. Here they explain the different services they have encountered, and the difficulties they have experienced which have clearly led to their having often angry and mistaken views about the various organisations.

Papa:

The kohanga reo started off alright but then they got too nosy. You know, kids being kids they push and shove everyone around and 'Donk', oh, got a bruise on your head. Send them to kohanga and they get CYPS out there and health nurses and 'Ooh, ooh, ooh'—trying to take him because he's got a ding on his head. Kohanga reo has got a thing with Social Welfare, if they can turn around and get CYPS to come and take your kids they get sort of a bonus but they don't say that.

And SES—they tried to deal with the boy but, oh yeah, they give him a pizza voucher. You keep giving him shit and he's going to expect more. If you're going to give Ngatata one, give the other kids one, 'Oh, nah', so we cut them on the head.

Social Welfare won't help shit, it's the same as CYPS. The only decent thing Ngatata's had is this kaiawhina matua (RTL) so far and the other teacher's aide that he used to have. There's three different schools he's been to. There's all the places that can't help, everyone sends us there and they can't do shit—'Oh, there's a government department, they help you', yeah, help you to send you to someone else.

Peara:

Children's and Young Persons tried to come in: 'Oh, we'll take the kids'. 'Yeah, on what grounds?' 'Oh, this one is playing up.' 'Yeah, what about the other one?' 'Oh, nothing wrong with him.' 'So why are you going to take him and not the other one?' 'Oh, we got no reason to take him actually.' 'Yeah.' Ngatata's one of those kids that if CYPS turned up and just took him, he'd be dead by tonight. Because he'll just sit here, he'll just cry and bring on his asthma and everything else that he's got and he won't let no-one touch him and he'll just go [cough, cough].

Papa:

He'll shit himself, he'll piss himself, for the fact is his mother and father's not there. He can't get it, he's still a bit young to understand, 'Look, you fuck up, boy, they're going to come and take you'.

Peara:

We tell him the truth, we don't tell him bullshit, we tell him straight what it is and why he can't do this and why we can't do that. 'How come we can't go here?' 'Oh, because we haven't got the money to go there, we have to buy you these and I can't buy them because we haven't got the money.'

The whanau requires things beyond the 'normal' things that government agencies provide.

Papa:

It's like 'Oh, can you help us?' 'Oh yeah, we're here to help.' 'Yeah, well, we got no beds, mate, Ngatata's been jumping on them, breaking 'em.' 'Oh, can't buy you beds.' 'Well, he rips his blankets.' 'Oh, can't buy you blankets.' 'I can't afford to buy him clothes, he's that size.' 'Oh, we can't do that.' 'Oh, what the hell am I doing here then?'

The whanau has also taken Ngatata to a specialist.

Peara:

That was a mission because he sabotaged the whole room and the only thing that was standing was this wall unit and he was looking at the wall unit and at the window because the window was a really big window. 'Oh no, it's alright, that's how we do things', but she turned around and said, 'Well, at least we know your son hasn't got ADD', oh yeah, okay, whew, she wrote that down and we say, 'What has he got?' We went to see another specialist and he did the same thing. Here's the major behavioural problems, I says, 'Oh yeah, okay, can I get that on paper?' 'Yeah', so they put it on paper, went back to Social Welfare and they still did that shit, oh this is what's wrong with him.

The parents spoke of the extended whanau.

Papa:

We're just hoping that my family up north will see Ngatata's name. 'Oh, that's my baby brother's family, better send him some stuff.' They did that when we were living up the road. We were like really strapped for everything for 2 months. 'Oh got any kai? Fifty bucks or something?' They turned around and sent down two boxes of crap, you know, one full of lollies and food and toys for all the kids.

Peara:

And that was a good thing what they did.

As the whanau has grappled with financial issues, the parents have taught the children to appreciate the things they have or earn and described how their experiences with SES seem to contradict this.

Papa:

Yeah, things mean a lot and that's what we've taught them, what you get you appreciate and he appreciates it from us, anybody else gives it and he'll expect more.

Peara:

Yeah—'Oh I can get more off you, oh choice'. The SES think they know him but his whole attitude changes all the time, his way of thinking changes all the time, 'Oh, we're onto that one, I'd better try this tactic', and he does.

Papa:

And Amanda [an RTL], Ngatata's got her around his little finger. 'I'm hungry, I want a pie', so she'll buy a pie. 'Where's my pizza voucher?' 'Don't show Dad.'

As well as having an appreciation of things, Ngatata is learning that on some occasions he has to earn his rewards. Here, the parents described one incident that demonstrates a change in Ngatata.

Papa:

Assembly at their school, it's like Fridays, two o'clock. All the kids' names on a little bit of paper are put in a hat, like sometimes through the week—'Oh, you did all your schoolwork, yeah pretty good', so you get a certificate, you get called out, you go up the front, 'Yah, yah', everybody claps. Then they say, 'Oh, pick a

name out of the hat' and he goes up and gets a prize. Then they ask, 'What was the saying for today?' And the saying on this day was 'Don't eat your lunch on the way to the lunch area, wait 'til you get there and eat it', but Ngatata said yesterday's one so he bummed out and he didn't get the lollipop. But what freaked me out is he didn't get all aggro like usual, he just sat there—'I missed that, I wasn't listening'.

Peara:

When we told Amanda that...

Papa:

She said, 'Oh, they should have gave it to Ngatata', but you can't have the school giving him a lollipop when he got it wrong.

Peara:

Amanda said, 'But he has the problem'. I said, 'It doesn't matter, he didn't get the answer, he tried and he missed out and he accepted it'.

Papa:

That's why I said to Amanda she's not to give him any more pizza vouchers. That's just teaching him, 'Oh yeah, I can do that with her'. I said, 'Well, you can't change him', 'cause you know he still manipulates some of the workers.

At school Ngatata has no friends.

Papa:

There's one boy that's got the same problem, he's not Ngatata's friend though, they're just like partners in crime.

Peara:

Ngatata's not the ring-leader, you know, the instigator. It's both of them, they must work out a plan, what are they going to do to their teacher. Not the headmaster 'cause he knows Ngatata quite well and he's onto them. I caught Ngatata one time when I was taking his lunch to school, Ngatata and his friend were in the classroom, the kids had gone somewhere and these two were in the classroom writing lines: 'I must obey the rules'. So funny, when I saw his lines—boy, I couldn't understand them, I knew basically what he was trying to say but some letters were around the wrong way. But it was good to see that he could actually be writing something, you know, he wasn't just scribbling.

In a meeting with the kaiawhina Maori to initiate this case study, she mentioned that, from her experience, teachers in her region expect Maori children not to perform well in the classroom and expect them to be naughty. They are constantly unfairly judged. The kaiawhina Maori is RTLB (Maori) for the region. In some cases where she is called in to assess a child, the child referred is not the offending party and more often than not the child singled out is Maori.

Ngatata learnt an unfortunate lesson when he saw his dad stick up for him as described by Papa:

I think the other half of the problem is the schools have got to get used to me. We had a bit of a raucous up there and Ngatata was really playing on it. He went to school on a Friday and he must have played up or something bad, he come home that day and said, 'Oh, the teacher went like that to me' [mimes choking hands]. 'What?' 'Yeah, the teacher—ahhh—like that to me.' We didn't think much of it, then Saturday morning we went to the fleamarket and saw Amanda and she said the same thing: 'Oh, they choked your boy at school'. 'What?' So Monday morning I went in there and I bailed all of those bloody teachers up and I was ready to smack somebody. 'Who touched my fucking kid? You ain't got no right to touch him.' 'Oh, he was playing up.' 'Hey, you got my phone number, I just stay around the corner, if he plays up leave him alone, we'll come and get him.'

They tried to grab him and said that he picked up the cricket bat and 'whack' across the principal. When the teacher came up, Ngatata booted her away. I just went ape-shit at all those teachers and my son was right there and he seen me go ape at those teachers. I think that's where he turned around and said, 'Oh no, I don't have to listen to you, my dad can beat you up' . You know, that's the attitude he had. I think he's just slowly trying to come out of that now.

Peara:

It's horrible, 'cause I know exactly what he's going to do, eh? And tell them and that and they're so scared of Papa.

Papa:

I only want the best for my boy, 'cause I haven't had shit, you know, I was in Mount Eden at 16. So yeah, we've had some ups and downs.

Financial reasons have caused many hardships for the whanau. Since finding out about Ngatata's special need, the whanau's problems have escalated.

Papa:

It gets that bad sometimes, me and Peara go without food for about 3 days. It gets even worse because we have to go down the market and steal shit. We find it hard because the system is not helping our boy, they just pissed me off.

Since we've found out what was wrong with Ngatata, we've never been ahead ever, we've always been behind. All our financial stuff has a big effect on the boy, too. We couldn't afford to pay the whole 4 weeks' bond and rent in advance to move into this place. We got Social Welfare to pay 2 weeks and we're going to pay extra on top. Instead of \$190 a week—\$240 and that's as much as the mother gets a week so that's all her money gone. I haven't had work the last week so we've got nothing. You can see the fridge, there's nothing in there, so that sort of stresses Ngatata out. So when he goes to school he just plays up, he don't give a shit 'cause, 'I don't care, I go home and there's no kai.'

And these are things we can't explain to him: 'We got no money, we gotta have a roof first'. That's where all his attitude comes out at school, try and tell these people that and, 'Oh no, it's his diet', how can you do his diet when you got no money to buy food? 'Oh, you should plan it like this.' What, 30 bucks a week on a diet like that? You just don't get it, a lot of us ain't got that kind of money.

Peara:

With WINZ and CYPs we go up there and say, 'Oh, really can't afford to buy my kids shoes every 3 months'. WINZ says, 'Well, you don't, you buy them every 6 months'. I says, 'Yeah, well, I can't afford to buy shoes every 6 months'. 'Go and buy those \$14 ones and pay it off over 3 months.' The thing is that we can't keep doing it. We never bought him clothes this year, at the end of last year we bought some and then someone stole half of them, so he's just got the shorts left. And he was really bummed out for that, you know, really disappointed because, like, 'I got some new clothes, they don't belong to no-one else but me, I'm the first person to wear them'.

Papa:

And all of that is like 80-odd dollars we've lost, wouldn't have been so bad if we still had his tops, you know. Because of his size—he's like size 12, intermediate girl sizes, so they just come and pinch them. We just can't keep buying him stuff.

Because the whanau has a track-record of getting extra money from Social Welfare to cover the basics, they discovered they were not able to access extra help for Ngatata. When they found out what was wrong with him and got it down on paper, the whanau went back to the services they had already visited to look for specific help.

Papa:

We went back to all these places like WINZ and they still did that shit, 'We found out what's wrong, surely we don't have to pay that money back 'cause we're trying to help our kid'. 'Nah, you owe us this money.' So 'cause we owe them back their money, like we can't get any advances or nothing at all really. I went to go and ask them for something— 'Oh no, you're \$2000 in debt'. 'Eh? No, no, no, no.' They had a look and, yeah, they had put what I previously owed and they doubled it, it's sorted out now.

Peara:

And when they want to come and visit 'cause they've seen us before, they go, 'Is Papa going to be there?' and I go 'Yeah'. He is the father, the kids have known him from day one, from the day they were born, he's been there from the start.

Papa:

We done it, everything we were asked to do, we were just getting jacked. Then they wonder why the father is so angry about all these places, 'Oh, go here for help'. They done shit, they can't give you nothing, we can't do much more.

Peara:

There's a lot of criteria before they can recognise the problem, so that was a problem as well.

Papa:

There's a school in a different town nearby, I think they deal with ADD people and kids like that. Went up there for, but waste of time—that's no good because like there's a couple of violent kids there and they just turn around and start hitting the teacher and stuff. So nah, 'cause then you teach my boy to do that, he'd just end up a bully, that school was no good.

The whanau has done everything in its power to seek help, as the father explained:

If you can find the services but they can't give the support, it's no good. One of the health nurses found us and she sort of started us off, gave us the proper nurse and doctor to go and see, found out what was wrong with him and alternative ways. But then she's left, so all our ideas sort of went with her and this someone else has got no clue what's going on. They automatically think, 'Oh, little boy, he should be alright, he's not really nasty, he's only a little boy'. Half an hour later, 'Oh, here's your boy back'.

The initial approach to te whanau o Ngatata was made because he had a history of special educational needs from moderate learning to severe behaviour, and at the time of the interview the RTLB (Maori) reported that Ngatata was making progress in terms of listening and concentration. The details of the life of the whanau, featuring poverty, unemployment, hunger, violence, aggression, suspension, and eventual relocation by the whanau have clearly impacted on Ngatata. It is not possible to present the evidence of this case study in a positive light.

He Whakatauki

Haere ana Manawareka, noha ana a Manawakawa.

‘Well-pleased’ goes off; ‘Bitter minds remain’.

The person who has received what was wanted goes away happy but the one who has given and perhaps had only promises in return is dissatisfied.

Haha uri, Haha tea

‘Desolate darkness, desolate light.’

According to Kohere, the saying means a policy, plan, or action that has not produced the hoped-for results.

**WHANAU EXPERIENCING SPECIAL EDUCATION
NEEDS BECAUSE OF SUSPENSIONS**

TE WHANAU O AWHIRO

Awhiro:	Hope
Rangimarie:	Peace—Grandmother

As a form one student in the Maori immersion class of an intermediate school, Awhiro was at risk of suspension because of his experimentation with marijuana. His story is told through the personal narratives of his grandmother and his teachers at the time. When he was in form three, Awhiro was able to access special needs funds because it was clearly necessary for him to be educated away from an area where he was constantly exposed to drug abuse in both his educational and social community.

His grandmother, Rangimarie, understood special needs to be any need that a learner has that may prevent them from getting the most from the educational opportunities provided for them, without some additional resourcing or support:

That's how Awhiro went to boarding school because he got that special needs grant. People were saying, 'How come he got it, he's not handicapped or anything?' and we said the special need is in the home. When he goes there, his dad is surrounded by drugs and he had a need that they could see. Somebody in the office could see he had the need and they gave the money to go away to school and he wasn't living with his dad, so that helped us a lot. Awhiro doesn't mind telling people he got his grant from special needs because he really felt he needed it.

Awhiro is the eldest in the family and lived during his form one year in a small rural community within his extended whanau of mother, siblings, and often his maternal grandparents who are tangata whenua in their area. Te reo Maori was the medium of instruction for Awhiro. The grandparents and kuia are all fluent native-speaking kaumatua.

His father who lived separately also had access to Awhiro. Marijuana which was at the root of the special need is predominantly a community rather than a family problem, but in this case the father's drug use was very much part of the problem.

Awhiro's story is a retrospective study that shows how one school, and some whānau members, were able to confront a drug problem in the school and in the community, through a culturally appropriate intervention in an informed and assertive manner, causing the least disruption to the education of the students involved. Awhiro is one Maori male who did not appear in the Ministry of Education suspension or expulsion statistics. The minority Māori worldview has historically tended to be marginalised in the majority European culture of the education system. The strategies employed in this situation are not often employed by conventional educational facilities.

Being able to access iwi, hapu, and whanau networks and commitment to whakawhanaungatanga were crucial to the success of this intervention and remain crucial for the participants and their lives.

A Culturally Appropriate Intervention

This intervention involved the school, three students, and their whanau in collaborative decision-making within a supportive learning context provided by a traditional hui or meeting (Macfarlane, 1998). All groups learned from the process, the outcome was seen by all to be just and equitable, and more importantly none of the groups (school, student, or whānau) lost mana. The personal narratives of the participants are used to describe this intervention:

Senior Teacher:

It was a Friday afternoon and the bell for home dismissal had just gone when one of the students from the class next door came running through. 'Oh, whaea, whaea, they've been smoking in the boys' toilets.' When I went next door the look on the teacher's face told me the seriousness of the situation. She said, 'It's marijuana. The smell is really strong'. I began to consider that whoever had been smoking had been very naïve. Not only had they smoked in the toilets at a time when people would be collecting bags in the cloak-bay and could smell the smoke, but they'd smoked marijuana. Anybody less naïve, who smelt the very distinct strong smell that wafted out from the toilet area, would know exactly what it was. The first priority was to accurately identify the perpetrators.

Classroom Teacher:

Well, I knew, because the smell was so strong in the toilets, that if I was fast enough they would still have the smell on them, so I actually was looking for kids. I was grabbing kids from my class and getting them to give me their hands and I would smell their hands. I got them to breathe on me. I got very close to their faces so I could smell and eventually I came across one boy who had the smell on his fingers, and from there he gave me the other names.

When questioned, the two who were named readily admitted their participation in the smoking of marijuana.

Senior Teacher:

My immediate concern was that senior management would kick the kids out. We had never had an incident such as this in the school and as a school we had just been through Assertive Discipline. This most likely meant that the parents would be rung and the students suspended. They could end up down the road, lucky to get back into the education system on an even footing again. This incident could mean a black mark against their reputation for the rest of their schooling.

I realised that as the syndicate leader I had to take some responsibility for what had and would happen. I wanted to do something positive to support the boys but at the same time help them to take responsibility for their actions. I rationalised that if the boys had realised the full implications of their actions they would never have lit up marijuana in the school toilet block.

The teachers were further concerned that these boys would be punished for something that was condoned and practised by others in the community:

From my background knowledge of the children's families, I knew that marijuana had played a big part in at least one family home. Parents had had previous convictions related to marijuana. For some, marijuana was fairly common in their homes, so it may be that in the home, smoking a joint was just like smoking a cigarette.

I believed that if they were experimenting, trying something out, then being kicked out into the community where maybe they could smoke it if ever and whenever they wanted, was not the best answer. Time could be better spent providing these students with more valid information about the physical consequences of smoking marijuana.

I can remember thinking that the option for the school was to suspend, possibly expel, these students, and what would that do for the boys? It would only put them in the community—labelled, and the label would not be that they had smoked marijuana; the label would be that they had got caught. So we could actually be exposing them to more of the same and more reason to participate in marijuana use. We really had thought long and hard about wanting to protect the boys and wanting to send some strong messages back to their home communities, in fact the school, our whanau community, our class, our syndicate community as well.

Both teachers believed that the boys had the potential to do well and that suspension and/or redirection to another help agency would not necessarily provide the best outcome:

We felt that these kids had potential and for this to happen—who knows—it could start a downward spiral. One of them had amazing potential for leadership in the future.

Both boys had come a long way in our lead-up to the cultural festival—they had learned taiaha. One had a leadership role in the haka, and he had become something of a role model to the others. He had been a problem for us, leading up to that, and the cultural group had given him mana, given him an avenue to put his energies into, and he responded to the kapahaka really well. I can remember one other boy was in Form I, and he stood out.

There was cultural leadership, but there was also sporting leadership, and none of them had learning needs—they were good all-rounders who were excelling at sport and culture.

Understanding that they could not act alone, the next step for the teachers was to speak with the principal:

There were two things in my mind when we went to the principal, and one was, why are we just punishing the boys when maybe this is a problem also in the community, in the home, and also there was the potential loss of the boys' potentiality.

By the time I went to the principal, it was about half past three and all of the other teachers had gone. I have to take my hat off to that principal because he had a lot of aroha for our kids as well. I explained what had happened and I promised that we would have a meeting with the boys on Monday morning and that I would have one family member for each of the three boys at that meeting. While this action was in line with Assertive Discipline, because we had never had an incident of this kind in the school before and no procedures were already in place, I suggested that maybe the people at the meeting could come up with a solution that could meet everyone's needs. The boys had been told that either they tell their parents or whanau—'You get them here on Monday or I will come and I will do it for you'. During that weekend, I also contacted the families and our kuia in preparation for our hui.

A grandmother shared how she first became aware of the incident.

Rangimarie:

On Friday when my grandson came home I was sewing and his mum was at polytech. I said to him, 'The kids been smoking dope on the bus? I can smell it on your clothes', and he said, 'It must have been'. On Monday morning his mum said to us, 'I've got to go to polytech and yet this kid's got into trouble at school. He's been smoking dope'. I said, 'Oh no, that's what I had smelt. You were actually smoking it?' And he said, 'Yeah. You didn't ask me if I was smoking it, you asked me if the kids were smoking it on the bus, so I didn't lie to you, Nan'. And I said, 'Okay, we'll go to school'. My husband came that first morning and my daughter. They both came and left. During that meeting a lot of korero came down.

The meeting was held in the room designated as the syndicate where wananga. The three boys, who each had at least one family member for support, attended the meeting. Rangimarie was there for her mokopuna Awhiro. The principal, deputy principal, senior teacher, classroom teacher, and the kaiarahi i te reo who was a respected local kaumatua also attended. The meeting began with mihimihi then karakia that asked for guidance and support, before a cup of tea was shared and the kaupapa of the meeting was jointly set. At that stage the principal, who had a prior engagement, gave his commitment to support the decisions made at the meeting then withdrew along with the grandfather and mother of one of the boys.

Deputy Principal:

No-one got injured, nothing got broken or smashed but it was an incident probably more like smoking cigarettes. (The damage was to themselves not to others.) OK, there needed to be consequences and being marijuana the consequences would have to be more involved with the parents because it is an illegal drug. At the time, the thought of suspension didn't actually cross my mind at all. There had to be, as I said, some sort of a consequence for the action.

Senior Teacher:

For me it was important that we had the family there, but also that we had representatives from the school, and also the boys—it wasn't going to be one of those meetings where we lock ourselves away and the boys are left to wonder what the heck is happening and go through that horrible uncertainty. Other than the meeting with our principal, every other time we met, the boys were present and their family members were present, and we asked and valued their opinions.

Because each of the boys and their whanau were Maori, it was important that we conducted that meeting according to Maori protocol. It was also important for me that our kuia was there because I didn't know exactly what was going to happen or what was going to come out of that meeting. I believed that she would guide us to maintain the integrity of the meeting and at the same time keep us, and the kaupapa of the meeting, safe.

Rangimarie:

That made me feel comfortable. It made my husband happy that he was leaving it in Maori hands, he could see that justice would prevail and he was able to take our daughter off to polytech happy.

Classroom Teacher:

It was a hard meeting, though, because nobody knew what the outcome was going to be. When we arrived we knew we were going to talk about what had happened and we were going to try and come up with a resolution but we didn't know what it might look like.

Senior Teacher:

That's why we had our kuia there because I felt that she would make sure that we didn't transgress kawa and that we would resolve the matter so that everybody was happy. There were a couple of people that weren't happy to be there. I can remember a dad in particular, he didn't think he should be there, he thought that the school should deal with it and he was actually I think quite angry that he had to come down. They had their baby with them, too.

Classroom Teacher:

I remember we did have some ideas about what we wanted to get from the meeting, what we wanted for the intervention for the boys, but our ideas were shared with the whanau, and the whanau made suggestions themselves.

Rangimarie:

Yeah, we came up with all sorts of crazy suggestions. I made one suggestion that was to give them a bald head and that I found out that's the 'in thing'. I didn't know

that. I felt that it would be a good idea because when we were kids if our brothers did anything naughty they were given a bald head.

Classroom Teacher:

They talked about possibly having a kaumatua spend a lunchtime with them to talk about kaupapa Maori, tikanga Maori and that holistic well-being. We didn't go into that meeting thinking that this is what we want to come out of it. We ran our thoughts past the whanau, and they ran their thoughts past us. So it was a combination of ideas.

Senior Teacher:

Absolutely, but they could also see that the alternative, if this didn't work, was that the boys could be suspended. They supported us right from the beginning, as a group anyway, some individuals I'm not sure, one particular mother—she just sat there, didn't seem to want to say much, was more of an observer almost, but perhaps she was tied up in the disappointment of what had just happened. I don't know, but those who spoke up, and most of them did, were very supportive and they wanted this to work.

Classroom Teacher:

I can remember that the meeting got heated a couple of times when we started—and by 'we' I mean the group, not just specifically the teachers—but when the talk about the possibility of the drugs being in the home became an issue, one dad in particular got quite upset.

I can remember him being very angry for part of the time. One of the things that comes to my mind was the fact that he wanted to go on this witch-hunt of other people's kids, I remember him saying, 'I know it's in this home, and I know it's there, and why aren't they here?' Yes, other names started coming into that, but they were unrelated to this actual incident, they were just people who he said also indulged in marijuana in homes.

When asked what they had wanted to come out of the meeting, the grandmother and teachers were quick to reply.

Rangimarie:

That the boys didn't get expelled or suspended.

Senior Teacher:

I didn't want the school alone to set the punishment. I wanted the boys to hear how concerned everybody was but I didn't want them to take all of the blame because I

knew that they had to have got that marijuana from somewhere. I wanted something positive to come out. That they learn from their mistake.

After much collaborative discussion, the consequences were decided and agreed upon by the group. The teachers and grandmother talked about these outcomes.

Teacher:

One of the outcomes of our meeting was in-school suspension. Before the meeting I remember thinking maybe that's what we could do. Once it was decided, I spent a lot of time developing resources using *Mana* magazines. I developed a unit on positive Maori role models. There was information on smoking. I developed a graphing exercise for maths. Their reading, health, everything was taken from my *Mana* magazines. I can remember making sure that there was plenty of work. It was sit down, shut up and think about what we've done and let's find out some real information about how drugs can affect your body but also let's have some information about some neat Maori out there who have succeeded. I believed we needed to give these kids some real information about drugs but we also needed to give them the positive stuff, the positive role models that Maori can be if they can rise above the challenges. I can remember you [speaking to Rangimarie] thinking in-school suspension would never work.

Rangimarie:

I'd been doing correspondence with the kids in the community helping to supervise and I thought maybe I could offer my services here and my husband thought, 'Oh well, you can give it a go', and yeah, we didn't think it would work in a school like that. But yes, I admired the programme you had done over that short time because, you know, when we came back on the Tuesday you had it all set up, you weren't just sort of floundering around but you had it all organised.

Teacher:

One of my aims was to give the children some genuine information so those lunchtime visitors were another outcome of the meeting. We had a medical person, someone who worked in drug rehabilitation, a Maori policeman, and we had a kaumatua. These people talked to the boys during the lunchtime on each of the four days. The boys also had to invite one of their whānau back for the lunchtime meetings. I remember that young dad, he resisted these outcomes very badly but he knew that his only option was to either attend those meetings, support the child on one of those days, or to have his son asked to leave, and I mean he could've said, 'Well, I'll just take him out of school', but he didn't.

The teachers and grandmother then talked about the intervention.

Teacher:

We made a space at the back of the classroom so each boy sat just apart from the rest of the class. We spread the boys out through the syndicate so that each of the teachers had one of the boys sitting down the back but we never talked to the other children about what had happened. They all knew but nobody talked about it, it was sort of an unwritten, an unspoken word. It was an amazing experience, to see the rest of the students distance themselves from the boys but still be there for them, still awahi them. They knew that they could help them through just being there. The adults rotated around the boys and around the classrooms. The boys had lunchtime and morning interval but their days and their timetable were at different times, in this way they were isolated from the rest of the students all day. Not only did they have a different timetable, they had a different programme.

Rangimarie:

I admired the way the children supported those boys. They didn't judge them or anything and I know that they helped them to actually bear what happened in those four days.

Teacher:

They did. One of the things I liked about this whole experience was that nobody lost mana over it.

Rangimarie:

But people paid what was due. You know it was, it was a very respectful process. I know one of the boys had to stay in that classroom, one in the other, and one was in another room. When it came to my mokopuna, he said he didn't know what to be with me because I'd been supervising him on correspondence. He just asked me questions but he always knew the answers so he thought I was just being a hoha, in his space. But he saw the day through and you know that was okay.

Teacher:

They had to do fitness even, they thought that they wouldn't have to do the fitness run but they had to do that by themselves, and they did that. They did everything that we asked them to that week and there were no frustrations from them, no telling us where to get off. They did everything as they were asked. Can you remember the lunchtime visitors that we had?

Rangimarie:

I went to three of them and I know the boys enjoyed them, they were sort of forced to listen but they enjoyed them, they endured them I suppose. Well, my moko did. He tells his little brothers how he'd been in trouble and he's not going to do it again. The next year when he was in form two he really stuck up for himself and resisted all

the temptations that came his way from the same people who'd been ahead of him. When his younger brother was at school, then too at intermediate, and then at college, they did the same sort of checking up on each other all the time.

Teacher:

One of the things that impressed me after that week was that there was never a mention of it. The principal said that if we could work it out in that room, then he would support us whole-heartedly not to have any stigma attached.

I can remember a couple of years later in one of the other intermediate schools, there were headlines in the paper, 'Principal Suspends Boys for Drugs', and my partner said to me, 'Look, read this, why didn't they do what you fellas did?'

Rangimarie:

Yes, we felt really sorry for those boys and thought what an opportunity this school had to introduce something like what we had done at your school. And how they are letting themselves down as poor teachers and letting those children down for their future. I know a teacher's job must be hard, they don't normally just teach, they've got to support all other things too like social work and guidance.

I felt my time with the boys was really valuable. I really enjoyed it. Just knowing that our children were doing something different from the other students. You had taken your time to write up a special programme for them and they enjoyed the programme because it was something new to them. They put everything they had into it and I know there was a little boy he did it and I took him for his maths. He kept asking me all the answers and I said, 'Hang on, you're the student, you look after yourself, you learn. I can give you the answers but how do you know to work them out?' He said, 'But I'm no good at maths. I'm never good at maths'. So I just gave him a few simple things and he knew the answers, of course, and I said, 'Now work it out yourself, I'm not going to do your sums for you'. He got those sums all right and the teacher had thought I had told him the answers. I said, 'No way'. He thinks about it himself and he buzzed out because he got all his answers right because I made him use his own brainpower and he was so happy he had done it himself.

Teacher:

That's excellent because the boys got a lot out of that week. They realised that they weren't stupid and dead beats when we think about what might have happened.

When the Grandmother was asked if she had any experiences with other relations being suspended or expelled from schools, she replied:

Yes. The kids get resentful. They go all yucky and they feel inadequate and inferior and we've had to build them up again. Like our three girls were expelled from college and when we wanted to get them into polytech, my husband and I went to the

college and asked them, 'Why have you expelled these girls?' They told us it was for their bad behaviour in class. We asked them to look at all of the positive things these girls had done in the past. They were worth their weight in gold but they weren't going to give them a good report to go to polytech. They ended up doing so. All those girls have now gone through the polytech and got jobs.

When asked what some of the differences were between the meeting for their grandson and the meeting for these girls, Rangimarie replied:

Well, I felt the aroha and compassion for the kids at the first meeting and at the college we were just a hoha. They had wanted to get them out into the community because they were older, they were 16.

They didn't care, they just didn't care. We took them back to our community and made them work on the marae. We were having a lot of marae programmes, people visiting, other schools, so we took the girls back and they were a taxi service using the tractors and bringing up everyone to the marae and looking after them in the kitchen. We made them do that and that made them feel good. And when they said they wanted to go to polytech they went to get their reports and they weren't given them. They were just refused. That's why we went and intervened on their behalf. We asked for a bit of aroha, a bit of constructive criticism to give them a feeling of being better than what they had been told they were. Just for one little mistake in all their 16-year old lives.

We had three meetings with the board staff and the Maori staff and one particular Maori lady who was just adamant they weren't going to get any reports on good behaviour for those girls. But we were convinced that there was more good in the girls than bad.

It took three meetings before we got the reports to bring to the polytech. There was this lovely lady at the polytech who said, 'It's the prospects of these children, not what they have been judged on, but what they can do with their lives'.

Because she had been through two different sorts of interventions by schools with drugs and within her own family, she was asked how she would like to see the outcome decided for Maori kids if it happened again:

Give those children a chance. Have a meeting and use that in-school suspension programme. Work with the whanau to sort out a solution. I think it should be set up in all schools to protect the children's future and I think it proved to myself and a lot of people that we talked to back home that good teachers didn't just say, 'You're a nuisance'. They say, 'I want to help you'. We came out of that meeting with a shared understanding of what was going to happen, and we all understood our roles, what our roles would be to make this work.

I guess it was that point of equal respect, wasn't it, because we respected them, they respected us back and being fair is very important to those kids. Treating everybody fairly. Those kids were pretty thankful. I don't know where they are today.

This incident happened seven years ago. The boys all finished college up to at least the end of the fifth form year. Awhiro, the youngest of the three boys, successfully finished his sixth form year having competed in top college sports and cultural teams throughout his secondary schooling. For these boys, no repeat incidents occurred throughout their schooling.

Conclusion

Olsen, Maxwell, and Morris (1994) identify four features crucial to pre-European Maori discipline. First, there is an emphasis on the whole community reaching consensus. Second, the outcome needs to be acceptable to all parties rather than merely to isolate or punish the offenders. Third, and upon an implicit assumption that there may have been problems in more than one context, it is important to examine the wider contexts for the misdemeanour. Finally, there is more concern with the restoration of harmony than with the wrongdoing. Macfarlane (1998) asserts that these four core functions, implicit in the traditional Maori discipline model (consensus, reconciliation, examination, and restoration), are quintessential to an effective school conference or hui. Those whose story this is all mentioned the importance of keeping everyone's mana intact. Drewery, Hooper, Macfarlane, McManemin, Pare, and Winlade (1998), theorising and writing about the kind of interactive dialogue that is required if suspension is to be avoided, also highly value a quality or principle that they term "the psychology of mana". Tate (1990) asserts that mana goes beyond personal magnetism to being a force that brings about change. Macfarlane (1998) adds that a conference leader with mana is much more likely to succeed in enforcing the limits, monitoring the situation and maintaining sound relationships.

The participants in this hui were looked after by such leaders. They were looked after by kaumatua who ensured that all of the appropriate traditional practices and protocols, including those implicit in traditional Maori discipline, were employed throughout, in order to ensure the safety of all and the ultimate success of the intervention. The reassertion of Maori cultural aspirations, preferences, and practices, supported and legitimised by kaumatua, can only lead to more effective participation and learning for Maori students (Bishop and Glynn, 1999), especially for those at risk.

TE WHANAU O MOANA

Moana:	Sea
Matiti:	Summer Star—Mother
Matenga:	Head—Father
Ngaire:	Tree—Little sister

Contact was made through whakawhanaungatanga. The relationship between the kairangahau awhina and the whanau is one of blood at hapu and iwi levels. The whanau lives on a main street in a small North Island town, and the interview took place in the whanau home.

Moana is the second eldest of five children living with her very caring parents. The whanau has experienced her lifetime filled with many difficulties. Moana's first special need was identified as hearing loss as a result of glue ear from the age of 2, and she continued to experience learning and behavioural problems and continuing low self-esteem. The whanau kept a file of information that tracked the details of Moana's life and referred to their records to recall small details of her story. Residing in a small town between two major districts, the whanau has to leave the town to access specialist support services as there are no agency services located in the town. The runanga of the local iwi is developing services in partnership with government agencies, such as the Strengthening Whanau initiative with the Ministries of Education and Health. From the whanau perspective, the schools—including one that provided the assistance of a teacher aide—did not deal well with Moana's needs. Moana's whanau learnt from their experiences and wanted to share their knowledge with other whanau who have special needs children.

Matiti:

We've actually got stuff on Moana from when she was 2. I've rarely gone back and read it, it's just that I've always kept it just thinking, 'I'm going to keep your life'. And you don't know what your life is, if our other children are going to be in that situation, we want to be sure that it doesn't happen for them. Maybe Moana might blame us for not preventing it from happening to her, but we tried. From her having trouble at school, Moana's first one was in 1992, so she must have been 6 or 7 years when she was first referred to Special Needs. The file goes into a lot of her own stuff, about what her problems were, and then how it spiralled.

The whanau first sought help for Moana from their local doctor when she developed glue ear.

Matiti:

We tried to help Moana, but too many antibiotics ruined her teeth, so she went through the yellowy teeth. I blame the antibiotics, she went through so many antibiotics that they reckon they're full of sugar. Well, over the years Moana ended up with hyper-plastic teeth, her second lot's come down and ended up with the top

four and bottom are good, but all hyper-plastic molars at the back so she could end up with false teeth before she's 19 or 20.

Moana's father, Matenga, added:

Those yellow teeth were a real stigma and another part of what Moana had to deal with. It wasn't until we started learning about the after-effects of continuously having the antibiotics, how they affect the teeth because of the lack of calcium getting through. They tried her on everything, she had so many different antibiotics that nothing worked, it just kept feeding the problem. So Moana went to hospital and ended up on a drip and got rid of it that way. Her health was just getting worse all the time.

Matiti:

Moana had got bad ears when she was 2 and it went on so we asked, 'Please, give her a chance, she's had such a bad time and she really wants to learn, how can you help me?' We knew her learning was low academically. I got a counsellor in for her before she went to school.

Matenga:

It was affecting her emotionally because she had such a low opinion of herself from the start, because she knew she was different to the other kids, because they knew how to read, they knew how to do their times-table and she didn't.

Matiti:

It was always happening, she knew that there was no way out without having to be embarrassed. One time she was questioned on her schoolwork and she didn't know it, so she just went down.

The whanau looked for help for Moana.

Matiti:

We tried to look at the health camp. We went through the doctors, and did the referral to the health camp through the specialist in [the nearest city one-hour drive away]. It was the only way we could do it with Special Ed. because it would be special education, see? The local runanga was another one—I rarely approached them until I got older and I realised that their service was available. But as for where Moana was at her time, I felt there was really nobody, apart from the referrals that we went to through the school and we went through the doctors.

Matenga:

It could have been her food that sparked her behaviour, but nobody here did any of that sort of stuff. But as we've all grown up and my kids have grown up, I've got

more time to realise what we could have tried to prevent my baby's suffering. To have got to 15 years old and she can't find anywhere to be a part of.

She was awesome, she started off absolutely awesome at college, and it was, 'Mum, no-one's picking on my ears, and my ears ain't running'. Because they used to run, and then they used to call her rotten ears, and dirty, real snide remarks, but Moana was so gullible she took it all so personally. We say, 'Tell them to be quiet, that you've got a medical problem'. But they don't understand at that age, at primary school, because you're different. The kids made fun of her. So she went to college and had a really good time there, and then it all fell apart. Her behaviour pattern had got to 'I don't care about anyone'. That attitude had come with all of the nastiness she had as a child. Moana had a run-in with the teacher at the college and before we knew it she was the worst kid in the world.

We went there, I went to the schools right from the beginning before Moana started at college and they offered all these services for us. Then she had a run-in with the principal, and it was a totally different issue but then it just blew her out and put her back to where she started. I did all the work, I spoke to all sorts of people. I went to see them and said, 'Well, my baby needs somebody, if she's having a rough time in the class'. They even got a special person, a teacher's aide to work with her there. To just follow Moana around and work with her and see how she was. She was only there for 6 weeks, but it just blew up and she was dumb.

Matenga:

But before that incident with the principal, she was bringing home reports of good behaviour and good work done, and that's all we were getting from the school.

Matiti:

But then the teacher put her into a Maori perspective. He's not a very nice principal, and Moana had got a Walkman from a friend of hers. The principal pulled her up and suspended her for theft. She said, 'Sorry mister, but my friend borrowed me the Walkman'. The principal goes, 'No, it wasn't your property'. He accused her of stealing that. The owner of the Walkman even come into the office with us and said, 'No, look, I'm sorry but I lent her the Walkman'. He wouldn't listen, he said, 'No, it doesn't belong to Moana and it shouldn't have been in her possession, and that's theft and you're suspended for 3 days'.

Matenga:

That was the only issue that was brought up there and then. It's the only issue that's ever arisen, then all of a sudden, they made up all this, 'She did this and this and this'.

Matiti:

That was never brought to our attention before, all we got was certificates for correct uniform, and being on time. As soon as the principal did this and I said, 'You're wrong'. He knew that she did not steal it, so therefore there isn't an issue, then the principal said, 'Oh no, I'm going to have her for behavioural problems'. He brought something else up because he knew he was wrong about the suspension. It was his stuff-up on the Friday, but by the Monday he'd gone back and accumulated all these things, things that were irrelevant. That she was late to class, or she was two minutes late, and because he knew that he was wrong, and he turned around and said to me, 'Oh well, you Maoris are just used to this and you should just let her go, most of the youth do it'. I said, 'I don't really want to go there with you. You just write my report and I will take it from that'. He wrote it out, classed her as a thief, and then we went and had a meeting with the Board of Trustees, I got my [Maori] Trustee's help. I had to drag Moana along to the meeting, and as far as the principal was concerned, in his eyes she was still a thief.

Matenga:

Even that chairman of the Board of Trustees was saying, 'Well, you define theft—I don't define that as theft'.

Matiti:

This is the Chairman of the Board agreeing with us, and the principal said, 'In my books, it is theft. If it's not her thing, and she's got it in her possession, that's theft'. And some of the Trustees just sat there ... It was chaos, it was chaos. And then the principal goes, 'Get out of my office, and you take that thief home'. Loudly. I mean, the school had just come out after school, so all the kids were in the courtyard and in the classroom and he's yelling. So then we left the school.

Three days later I put her back into school and everybody was accusing her for being a thief. Moana just went straight down, we got her esteem up, got her confidence built to get her all the help she needed, and they took her down. She was only there for about a couple of days and she was really terrible, I walked in and took her out.

Well, you're trying to be good, and because I'm her mother and you've got to be one-eyed. Moana always did a lot of stuff that was over the top. It always got her into trouble so I really grabbed onto the good stuff, and I held onto her. I knew sometimes that it weighed so heavy—the naughty stuff—that I just got too tired, trying to think nice things about my child. I used to say to her, because she drove me up the wall so often, I said, 'Look, at the moment, I love you, 'cause I'm your mother and I love you but I don't like you at the moment for what you are doing. So you need to go away and give me five things that I should like about you. It would make me feel so much better to be able to keep fighting for you when you are starting to fight me'. I had to do it, because it just got so frustrating because we defended her so often.

Matenga:

So often we were there at the school, and a lot of the stuff that she brought on herself, only because she had low self-esteem, low academic achievement and all the mixtures of knowing that she's going to fail. So therefore we're going, 'You're alright, you're alright', trying to pick her up, but we knew and she knew that the odds were against her, eh.

Matiti:

So she never gave up on us because we tried to help her, and she would still go to school. We'd get her back on track again, but then she would fall over and she might have fallen over for maybe being loud in class, so they sent her out. But they always did it, all the background was 'bang' hit her in the face again like, 'I remember when you did this, and you did that, you did this'. So the teachers were actually bringing up the last 5 years into the present and it's a habit and you get labelled. I've been trying to fight the label, and I used to go to school, 'Excuse me?', but they'd say, 'Oh, but that's what Moana's like, Matiti, okay'.

Matiti continued:

I just said, 'The thing is that you've sent me a whole lot of letters about stuff that she did, you gave her detention five times'. This particular day I went there and it was because she had non-regular shoes on. But she'd stayed at a friend's, and she called in to my work. 'Mum, sign me a note because I couldn't wear my school shoes.' 'Okay.' So I wrote her a note. I said to the teacher aide, 'Did my daughter show you her note?' 'Oh yes, but anyone could have written that.' I said, 'I wrote that note'. 'Oh, you're just saying that to stick up for her now.'

When they called her a thief we pulled her out of the first college. We just didn't want her to be put in that situation again, so we moved her to another college. It was only for 6 weeks, like half a term, and then she got suspended. I tried again, put her back into school but they just cracked. We got 12 phone calls a day, though the worst was one day I picked up the phone and this teacher aide said, 'I thought I'd ring you, Matiti'. I said, 'What's up?' 'Moana's standing outside the office and looking really suspicious, I don't know if she's going to go for a smoke or if she's going to get in a fight.' I said to the teacher aide, 'Is Moana doing anything?' 'No, no she's just standing up against the wall, so I don't know if she's going to run and wag school.' That was nuts, I lost it totally, and I said, 'I'll be there in 5 minutes'. 'No, no, no, you don't have to be here.' 'I'll be there in 5 minutes to see you', and I hung up. I went to the school and I said to the teacher aide, 'What are you doing? Haven't you got anything better to do than act like a private investigator on my kid? Was she smoking? Was she being naughty?' The teacher aide said, 'No, but I thought I knew what she would do because of what she's like'. Well, she looked like an idiot by the time I finished with her, because I didn't go in and totally lose it but I put her right where she belonged and said, 'Excuse me, but if my child was smoking, you ring me, if my child was being violent, then you ring me, do you ring other parents? There's some kids beating up on others, do you ring their mothers to say that their child is standing up against that wall over there? Would you have rung that child's

mother? No—so what’s the difference?’ There were a lot of kids standing up against buildings down there, because it was interval, everyone was doing the same sort of thing that my child was doing. ‘This is ridiculous. My daughter’s standing up against a wall and you ring me in the middle of a conference I had at work and you’re telling me this, you’re wasting my time and your energy, and I’m taking my child out of school.’ She said, ‘Oh, you can’t do that’. I said, ‘Well, I’m taking her’, and they said, ‘On what grounds?’ I said, ‘I need to keep my child safe, and those are the grounds I’m taking her out on. You can’t keep her safe so I’m going to keep her safe’.

Matenga added:

The thing that it all boiled down to was our brown faces, bro. I was hoping that it didn’t get to that stage, but it had. Other things had cropped up about the same issues about suspensions, and if they’ve only been Maori families it’s a worry.

The whanau lives in a small town, and the problems they were facing became common knowledge.

Matenga:

Even to the point where you go out the supermarket and the woman in the next aisle’s talking about your kid—that sort of rubbish. It’s absolutely nuts. We pulled her out of college, my baby doesn’t need this anymore, no-one’s keeping her safe, and her mum and dad’s going to keep her safe. So we had a big fight about it but the school signed her over and let us put her on Correspondence. Moana’s academic has picked up, she’s a lot better, it’s really good the Correspondence School with her. She’s been on for a year and a half.

Matiti:

For Moana I could have handled all of that to keep her safe, ’cause all I wanted her to do was to be a part of the children, to be a kid and make mistakes and get out there and get good friends. She never got that; Moana got robbed of that because she was labelled as being a naughty girl, right from the start. A lot of it was due to when she was small her ears started, her low self-esteem, and it just spiralled and it got worse and worse and worse. Now we know pulling her out of school was really good, we got her education up, positive in that sort of way. Moana still hates stuff, hates doing school work but I told her, ‘Bubby, you can keep hating it because you’re still bringing us in good marks’.

Matenga, referring to a report from the Correspondence School, said:

In her last report for English an A pass, and Science 97 out of 100. But we’ve got another downfall, she’s so lonely socially, because she’s grown up with adults, so her peers now are too young for her. If Moana hangs around with other 14-year-olds, they’re still doing 14-year-old things, they’re babyish and she’s moved on. She’s moved too big, she’s moved on into the alcohol and drugs and stuff. We’ve ended up

taking our child into a safe care just in the last couple of days, to take her away from it and to get her safe. Because her self-esteem is zero, she cut her arm and tried to end herself because of just how dumb she is, and this is where we are now. She went to the point where she's cut her hand, ended up with five or six stitches, and she got right to that point that nobody cared about her, and nobody gives her a fair go. She can't walk down the road without somebody picks on her and gets her into trouble. It's real hard, eh.

Matiti:

So the stigma is just crazy, I know it spirals from Moana being so low academically that she always ended up down there. She'd never feel like she could bring that gap together. Course, my bubba Moana could have been a different child today if only we knew more. We've got one more girl Ngaire with the same problem. There was a lot for her, we got onto it with her and Ngaire had glue ear like Moana as she grew up, but we worked with Ngaire and managed to have her ears fixed. We were looking at this one here, where we went wrong with Moana before.

Matenga:

We saw it with Moana, we tried not to make that mistake with this next child Ngaire and really got onto it. She's up on her peers, even though she's got a hearing problem, she's there, which is really good for us. And Ngaire's a real neat kid, socially she's got the skills to interact with people, not only her own mates but also adults, really nice.

Matiti:

Ngaire goes to specialists and she's been on all the antibiotics and she's got the hyper-plastic teeth. Same sort of thing, but by the time Ngaire came along we'd got a bit more wiser with experience of Moana, so we knew what to do with Ngaire. I went that extra mile to pick up all her homework to assist her, when she was a lot younger. But as Moana grew up she got angrier and we fought, because we couldn't come together to work, because she was angry with the world, and angry with us because she was dumb. With Ngaire it was a lot different because we worked together and made homework just an interaction that was normal to her. We knew that Ngaire would have slipped if we'd given her the chance, we made her get into the academic stuff. We couldn't do it with Moana because we didn't know what we were dealing with in the first place.

Matenga:

From that experience we saved another one, who would never go down the same track as our Moana did. And now we're looking outside of our family because there's a few kids at the school that have that same stigma. They're labelled kids, and those families need the help.

Matiti:

Ngaire is in total immersion, and whanaungatanga is a part of how we look after our kids. We're saying we belong to a whanau unit and yet we aren't whanau, we're not because we don't go and tautoko that family, or think, 'Jeez, I'm glad that kid's not mine'. I'd have loved it if they came in and said, 'Look, I'll take Moana for maths to help her'. I would love that. Knowing about our whanau as a whole in the classroom, we can keep them together. No one's to blame, it's just that we can still see how our kids will get lost in the system. We've lived it with our girl, calling them deficient or they're lacking, those sorts of labels.

Matenga:

So that's what happens and this poor one that we know through our school is going through the same thing. His mother's just beside herself, well, 'Who do I turn to? Where do I go? I need help'. But her boy's got a different type of health problem to put him where he is. He's got a lot of special needs, but the mother's done the work, and fighting to keep her boy. We're looking at her and saying we were lucky, because we had each other to keep one another sane, she's got nobody, eh. We're looking at this lady going down the same track we went down but we can help, we can help her because we know the pitfalls, of what actually went down or how to rectify the problem.

Matiti:

I felt angry with Special Needs, because there was a big problem in my life with my child, but I feel they didn't help, they came up with all the big answers, but we already knew those. What I felt was, what is their purpose? To tell me that my child's got a problem? Or is it a programme that says, 'This is what you need to do to get your child better'? That's what I needed, not to tell me that my child had a problem, they needed to have a programme or an intervention. This is what you need to be able to get your child going, you might need 6 weeks of special ed. with a teacher one to one. That's what my child Moana could have done with earlier on, not just to be told she's a year and a half behind in school.

Matenga:

And it would probably take 6 months and four meetings just to actually tell you that.

Matiti:

SES just told me that I've got a year and a half to catch up my child to get to where other kids her age are. I felt that was okay, Moana loved the SES person she worked with, it was really good that way, but it didn't progress into improving my girl's situation. So I think that with special education for Maori that everybody works so differently that it can't always be the same system. Systems don't always fit this one particular child, there's got to be a system that fits everybody and if there isn't then people in your area have got to develop one to suit their own area. Because we all

learn differently and we know that and this is what we feel that we need to be able to do. If you're in a situation to prevent this from happening to my child or the next child in other whanau, try and prevent it from happening by getting workshops or whatever they need to do to lift kids up.

Matenga:

What happens to a person in a town like this where we have so many different boundaries? We're at dead-end. We don't fit in [the district to the south] and we don't fit in the [district to the north], we all miss out. For Moana, we had to go away to [named city], one hour, too far. We miss out, and the programmes will never reach people with need in our town.

The whanau discussed aspects of underachievement amongst local Maori children.

Matiti:

They have to sit in class and it's boring. Who's going wrong, are we the adults setting that example of making learning boring for our kids? Are our teachers too structured? What is it, eh? I'm trying to find out how we can get our kids to really, really enjoy learning. I know when the kids go to kohanga and love it, wow! They sing and they learn, then you get into a school and sit behind a desk. What happens? Bang, totally switch off, eh, switch off. Because you're on your own at school, and that's you.

So then we make it right for us Maori by actually bringing our kohanga reo together and making a really good structure for them to come to. They're really eager to go to school, but once they get there, they're there for a couple of days and wanting to go back to kohanga, because it isn't fun anymore.

Matenga:

But we've learnt, we've made our kohanga reo in ways that we've learnt to structure our kids and enjoy it at the same time. So why can't us Maori be able to structure something, so that our Maori kids will carry on enjoying school. Because it should have already been implemented, eh, 'cause we implement it at kohanga then I feel that it goes back to the mainstream, the different kaupapa that we're on. So are we setting up our kids to fail? Or are we throwing them to the wolves and we don't really want to but there isn't any choice available?

Matiti:

Sometimes our hands are tied in those sorts of areas. The best example of a learning poutama would be kohanga reo, kura kaupapa and whare kura and then maybe to the wananga. And that should be the track that our kids go on, in an environment that's the same all the way through. And it's whanau orientated, and the tautoko's there and the wairua's right. But then again, are we segregating from the Europeans to what we think is good for us and what they think is good for them?

Matenga:

That's just a common fact, if you were to do a survey on our town, we are very low economic and stuff like that. In every aspect we miss out, on health, we're a third-world town for doctors. The runanga has a medical service, they've got a lot of vans that come around, like the blood, the one about contraceptives, those awareness campaigns.

Matiti:

That's what we are in our town, really low employment, isolated in every way. I work in a budget service and I know a lot of low-income families and how they struggle, I know their needs and problems, and I know all that sort of thing, so I've been there. And there's a lot of people just like me and Matenga that fight for a child that we've had to fix up, and there's just nobody there to help. We're the ones that go that whole hundred yards and these other poor people out there got no money, no food, and nowhere to go to help their kids.

Matenga:

You get back to the special needs again, that the whanau suffer because their nutrition is poor, their living is poor. We're going back to poor health, which affects our kids' learning to everything that we need to get our kids going.

Matiti:

You're not judging but let's get real, we've got pohara families that are legitly pohara, and our service hasn't got access to funds. They go and beg and scrape from all the charitable trusts around here to get the funding to help people. And then you get the government is saying, 'Well, you might just have to start turning people away'. Over my dead body, over my dead body! You tell this to a family that hasn't eaten for 3 days: 'I'm sorry, I can't help you'. There are a lot of people here with special needs and no matter what the areas are, if we can improve the health, improve the finance, our kids will be a lot better off. You get their heads up, they are confident. But in our town they're going around with their heads down, and looking at other people who are better off and getting angry. That's just another way that our kids spiral down. They don't want to learn because they're so different to the next person, and then they're going home saying, 'Well, my mate's got ham sandwiches, why can't I?'

Matenga:

Nowadays, bro, it's worse because they're going to school with no lunches, 'cause there's nothing in the cupboards at home for them. They say you got to get a full puku before you can learn. When you're not healthy or you're hungry you don't want to learn because your body's not healthy enough to keep you up with the education system. And worse if you are worrying about money at home, or dad at home with no job. Whatever the situation may be in that child's life, I really think

that's one of the main areas that we need to focus on the rural and remote and smaller towns, more than actually the big towns or cities because there is help in the big areas to go to.

Matiti:

A lot of our people go through it, and it's a shame because you want to help and I get really really tired because I'm fighting all the time for them. I will keep fighting because I know the effect it has on the mother, parents, to the kids, to their education, to their health. And then the problems are just getting bigger and bigger and out of hand, that we're running out of help for anybody. So it just needs the government to take a deep breath and look at what's happening to small communities like this, 'cause we won't be the only ones.

Matenga:

We're not the only ones, just imagine how other people are feeling in their community, with low employment and no post offices, and no banks. For special needs, we need really good programmes to start in areas like that to keep kids going and to pick up where parents haven't been able to. Just developing stuff that's readily available and make enough noise that families are aware of it.

Matiti:

I get a lot of people who don't know what we're doing ourselves, so we get downfall, no-one's really educated on where we can get help from our own services. We try and share it and we try and get it out to our people. Come on, we can do this, statistics are telling us just where us Maori are today, which is a real shame because we know we're there, we ain't all living in jail, we ain't all naughty, but the statistics are out there making this stereotype of us. It's the biggest label that we all wear as Maori. We're the tangata whenua and we're the ones with the labels.

Matenga:

We've got to meet in the middle, what we discussed was getting back to this whanau concept with our people. We need to go back to our grassroots to start again, to get a solid foundation we can build on that, support groups for families that need us, that type of thing. You need to go to the Maori people and let them know that you'll be there for them, 'cause there's nobody outside the districts going to be there for us. We're going to have to start ourselves, because in the meantime we're all falling over, everybody's feeling bad. So it's got to be a community effort. I know one area where we've picked up is with our community night patrol. All these old people driving around in cars late at night, keeping checks on all the little criminals, and it's helped stop all the burglaries at night, because our criminals all go to places out of town, bro. It's all free, people offer their time, to keep our community safe. It's been going for a couple of years, and look, there's really no support for them either. They're choice, our police, because they know they've got that support here now. Even if it's a little old lady or a little old man in the car driving around, they're eyes

for the police, or eyes for security. We've picked up in that area because our crime statistics are down in the community. We really need to go back to our grassroots to sort of build one another up before we can work with our kids, eh, help get them back up.

Matiti:

And that's the kaupapa we're on at the moment, because of how our girl Moana's been and how it's taken our lives to a whole lot of other kids in our own school that are going the same way. And how to prevent that one getting to this type of thing, but they need the support, parents of those kids need the support to help them.

Matenga:

It's really good to have other people become aware, so that they can help someone like Moana. There's going to be a lot more Moanas out there. We don't want others to go through the same situation that our family's been through. Everyone needs to be made aware like at our schools and at the doctors and at Te Runanga, and if they're willing to help our whanau, it's to show us where we can get help in our area. If you're not in the know, you'll never know. It's only because of Matiti being in the budget service that's opened her eyes to so many different things and so many areas that we haven't been able to tap into, but people if they don't know, they're never going to know.

Matiti:

For us there's been a lot more sadness. I wouldn't put it down to negativeness with Moana, but the positive is probably, she has picked up on the academic. She has suffered in a lot more areas that override that positive for her. I wouldn't have given a hoot about her academic side if I could have got our girl to stand tall, feel good about herself, then that's what I would have wanted to achieve. Now she is with Correspondence School, we moved her there and she's learning. We've now got her schoolwork up, but she's got nobody socially.

Matenga:

She hangs with a whole lot of kids that are in the same locker, eh bro. That's where her mates are, they're all around that 14 or 15 age group, and they all have lollies, drugs, alcohol, money, you name it, bro, Moana wants it. And it makes her feel good because if she gets wasted she doesn't live in the real world. And it takes her away from all the pain and all the anger she's feeling. She can believe whatever she wants when she's wasted, 'cause it feels good, so when she comes back to reality, it doesn't feel good anymore.

Matiti:

That's where the drugs have come in and alcohol and the running with the law, and look where she's ended up now. Moana is in respite care now and getting people to

work with her, we've got the department [CYPFS] working with her counselling. We're trying to get her self-esteem up and we're trying to get her going, which I wish could have happened before now. But it's always never too late. I've worked with the system for so long, that if you get them by the time they're 7 you can save your child, but after that they always carry a stigma. They find that they can't get rid of who they were before, so that's a bit of a shame. With Moana she'll have to be strong enough to deal with what's going to hit her the next day and the next day.

Matenga:

It's a really big part of getting children's confidence up when they're so low in a whole lot of different areas. Even when they're academically high, they still suffer because, again, they're still segregated because they're brainy and so they still get the same stigma. So you don't have to be low academic, you can still be highly academic and still get a stigma. They think they're too brainy and they don't want to know a brainbox. The rate of teenage suicides in our town is not about low achievers, it's about high achievers.

Matiti:

I don't think it's just Maori people. I think it's everybody, because I know a lot of European people out there obviously are going to be in the same situation. We know that if their self-esteem is right, people can conquer anything when they feel good about themselves. Even if they fail, they're still strong enough to deal with the failure.

To break a cycle we have to learn, the whanau have to get more educated. You need more patience with kids when you get children like Moana, because the patience wears real thin with four other kids and they're all among you at the same time. We're trying to deal with what Moana's going through, it just gets really hard. So it affects every one of us in our homes, when one of our children is down, because everything just spirals. We put so much energy to try to pick Moana up and our other kids still need the aroha and they still need the hugs. If they're onto it, or achieving what society wants them to, you tend to not spend as much time with the ones that are on the right track. It can be a real vicious cycle, you're trying to fix up the one that needs the help and you leave the ones that are okay. Those ones that are okay want to fall off so then they can get all our attention we're giving to the one that needs it. So you get that downfall in a big whanau, and it does affect all the kids. I'll get annoyed and go, 'What's wrong with you? You did okay at school today'. I have to sit back and think. I have to take that deep breath and say, 'Well, they just only want my attention because my attention's always with Moana'. So I have to pull myself out of Moana to pay my attention to my other kids. And it does get really, really hard.

Matenga:

We take a deep breath now and realise, 'Hey, it's just got to be done because we're the adults here'. It really needs to be addressed otherwise these kids are going to start

doing stupid things just to get the attention that they know they can get, by doing these crazy things. We've pulled our heads in now and our kids will walk in the door and we'll hug them just to let them know that we have that personal contact with them, we haven't lost that. They know we love them, they love us but we don't show it enough. Often as parents I think because we're so hooked up in our own lives trying to get the waka running, keep food in the cupboard, and the bills paid, they're the ones that miss a big part of us.

Matiti:

You don't always know how your children are doing if they keep hiding stuff. Like if their English is down, I guess you're so tied up in other things that you don't pick it up until it's too late. As an example, I'd spent too much time with Correspondence with Moana and our other daughter Ngaire was having real difficulty in her maths. At the end of the week Ngaire just burst into tears, she just couldn't cope with it, it made me think, 'What's wrong?', because Ngaire's really good at school, loves her schoolwork. It was only because she had too much homework that she couldn't finish, and she worked so hard. That wasn't Ngaire's problem; it was the teacher had given her too much work. By the time I sat down and pulled myself away from what Moana needed to look and focus on Ngaire's homework, I saw that it wasn't Ngaire's problem, it was the new teacher who'd given too much work for her. Ngaire is a kid that's got to finish things, and you give homework that they can appreciate and they can complete, but she couldn't, she was struggling to complete it, so then that took like a 2-minute phone call to sort out.

Matenga:

And Ngaire was one of the high-achievers, one of the top in the class, and she couldn't do it. She thought she was failing, but it made me realise that our other kids are important. They have to know they are good, they are doing their homework, and they are doing what we all want our children to do, but they still need our time. This is one of the reasons why Moana went away for respite care, for the rest of us to get that back together.

Matiti:

Moana had people to help her with her confidence and get her going again, and so then we can build up at home and get our energy back. Because over all these years that we've had Moana she's really drained us all the way through until we've got to the breaking point where we couldn't help her anymore. We tried every avenue from the department [CYPFS] to the police to the psychologist to the mental health. We took this child there to get her confidence up, so she can believe, she can achieve whatever she sets her mind to wanting to achieve. I don't care as long as she had a go at it, and didn't feel like she'd failed if she didn't get it, but I wanted her to be able to get into a frame of mind that she could actually try and achieve anything she puts her mind to. I just felt she was robbed of that, robbed of knowing that she's good enough to achieve.

Matenga:

We're trying to get her mana back, her wairua, that's what we were trying to do, we were hoping that all these other support places that were out there had the answers to help us to get Moana up academically. We were trying to build her self-esteem up, trying to keep her there, and she'd get there and feel really good and happy and cheery and then next minute, 'pow', she's right back down where she started.

Matiti:

It could be something stupid, like she was doing really well in Correspondence and that took me a year and a half to get her into it and working again. One day I said, 'What is wrong with you?' Moana had had some friends come in from school one day to visit. Moana spelt 'house' wrong. Because she's 15 and doesn't know how to spell 'house', they thought it was hilarious. 'You're dumb', and that was it. Moana felt she was dumb. 'Why should I bother?' Instead of telling me this is what happened, it's 'I don't care', but it really affects her. It wasn't until I was talking to her and she said, 'Well, I'm dumb and I'm not doing it, I can't even spell "house", mum'. I said, 'That's alright, we'll work on it', but then it all came out. We were doing really well together but it took somebody to walk in my door and read her work. Two minutes to undo a year and a half of work and Moana took a big fall with it, and she wouldn't pick it up because she didn't see it was worthwhile. I said, 'Girl, you did 95 out of a hundred for your maths, 48 out of 50 for your Maori, we know you're up there'. But she totally lost that focus to 'I'm dumb' because 'My mates are laughing'. So it is a teenage thing for the kids of needing that confidence to swing aside remarks like that, but because Moana's so low in herself, she takes it a lot more personal than swinging it.

Matiti:

We've tried, I would have cut my left leg off to put my girl into respite care. She needs it, it's a safe place for her, and she needs a bit of time out, and she's enjoying it, and that's the main thing. Moana has a structure that's really quite neat. When we put her in, a lot of families don't care about their children and they were blown away by us because we were there. I spent half of my time bawling because I didn't want to leave her, but I had to do it.

Matenga:

I just wanted to meet him, who our child was coming to. We felt that if she didn't want to go then we would bring her home. But the Maori fella walked in and he was just magic. He just walked in and it was like all this wairua and energy and laughter and happiness all walked in with him, 'cause he was laughing and carrying on and, 'Kia Ora', and he's talking like this. And in our minds thinking, 'Please come in and give her a good impression because that will be it'. I was praying he'd come in and make that impression that she liked. He blew her away.

Matiti:

Moana's really happy, I know a lot of people are working with her. They have to make that right impression or she will not open up, she will just tie herself in knots until she comes home so then we're not going to get anywhere. So we need to have that openness to make her feel a part of it to want to open up, because that was the only way I'll get my girl, or somebody to help her, because I want my baby to be able to walk in society and feel good. Moana doesn't have to be like the Jones's, I want her to be who she is, but happy. 'I can do it and I am good enough to belong to this.' To this town, or to wherever she wants to go. She'll go into the city and I guarantee if someone said, 'You don't belong here', she'd probably beat them up and then go. But she wouldn't walk away.

Matenga:

That's her little defence system though, eh, because she's been downtrodden, and stomped on so many times. She won't back down for anything or anybody, eh, just stand in their face until they deliver. She'll walk away and cry about it but she won't let you see. She'll mihi to people, and she'll do all that. Moana just doesn't treat anyone bad, unless she gets caught up in a situation. If you don't respect her she just won't respect you. It's even a big issue with her crying in front of us. She's so solid within herself that to shed a tear is a sign of weakness for her. She was never brought up like that. We always maintained that, 'No matter what, girl, we love you, don't you ever forget that'.

Matiti:

I think the night when she finally realised she was going into respite care was the first time I've seen her cry for ages. She looked at me and I looked at her and both of us cried.

Matenga:

I know that she's enjoying herself now, and that says more to me than it ever has because she doesn't stay awake. Moana is doing reality stuff, the normal living. I really believed she was going to ring me and, 'Come and get me', and be a real failure. But Moana rung us up and she's having a really neat time. I felt so much that's the answer that I've been looking for, just to know that she's somewhere she's happy. Before she was never happy, only pretending to be.

Matiti:

We knew that happy girl, we just lost her along the way. We know she's a good girl, but we started to doubt her because she was so negative, and I was holding onto those good things of hers, 'cause she just threw so much bad stuff at us. She fought the people she loved, because she's angry too. 'Why am I dumb, Mum?' 'Why can't you keep me safe?' and 'Why couldn't you get me educated?' 'Why couldn't I be clever?' I'm trying, Baby, I've done this, I've done that', but she's convinced she's

still dumb so I'm not doing my job as a mother. I should have done something to her, we're supposed to be the protectors and we should have looked after her.

**WHANAU EXPERIENCING SPECIAL EDUCATIONAL NEEDS
BECAUSE OF SLOW LEARNING**

TE WHANAU O MAHIKA

He mihi nui tenei e tukua atu ki nga whanau penei huri noa o te motu
Kei te mihi kei te mihi kei te mihi Mihi atu ki nga aitua kua whetu rangitia haere ki runga
I nga roimata o matou te hunga ora moe mai ra, a, tatou te hunga ora e ki a nei, Ko te
tumanako kia hapaitia nga tamariki haua I roto I nga kura me nga whanau huri noa na
reira tena koutou tena koutou, tena koutou tena tatou katoa

Mahuika:	A fern
Heather:	Mahuika's mother
Totara:	Tall tree—Father

Mahuika is an 8-year-old Maori girl who goes to a mainstream primary school in a city in the South Island. She and her mother Heather moved 3 hours away from their whanau so Heather could undertake teacher training in the city. They do not live with Totara, Mahuika's father. Mahuika's special educational need is slow progress in reading and failure in the overall system of schooling.

Transient whanau and whanau with mixed ethnicity are increasingly common. The challenges of relocation from remote rural areas to the cities away from immediate and extended whanau support are a factor for whanau with children with special needs. In Mahuika's case, help came from a link between her whanau and hapu which enabled her to receive assistance from a large iwi corporation. Mahuika is from a hapu of the iwi that lives far from the city, but she is also tangata whenua to the iwi which has structures in place to respond to hapu and whanau needs. It is through the support of her whanau, even though they are far away, that her special needs have been able to be addressed.

Mahuika lives with Heather in a beachside suburb on the edge of the city. Their cosy house is surrounded by many plants and trees. Mahuika was a bit shy to say anything to this kairangahau awihina from Wellington who had come to speak to her mother about her educational experiences. A happy, mischievous child, Mahuika was never more than two to three feet from her mother (and the tape recorder) during the whole interview. She also spent time drawing and playing with her toys in the adjacent room.

When asked about special education, Heather was unclear about its parameters but was relieved that Mahuika is starting to make progress:

Well, looking at that, because I am training to be a teacher, probably I have got some more knowledge, looking at the 2000 Special Education plan they have got out. It is looking at children that are physically disabled rather than children with lower achievement. They are looking at the more serious cases first. And the adults tend to see children with foetal alcohol syndrome rather than someone like Mahuika who's just a 'slow progressor'. [This is not correct.] I think in that aspect, it is hard to narrow out who gets funding and who doesn't. But they seem to focus more on physical disabilities and forget about the other ones, because she looks okay so she will fit into the system. Mahuika has got a difficulty with reading. I am feeling that her school is doing a lot for her but still she is 8 and I feel she is really behind in the system. There is only so much you can do and Mahuika has got special funding through the iwi.

It is making a difference for Mahuika now she is progressing, which is really good. They have got to have another look into what is causing the problem, I think.

When asked, “How was Mahuika’s special need first recognised?”, Heather discussed the effect of moving from the small area where she grew up with her family and the father’s whanau, and the confusion brought about by these changes:

Basically, I think what had happened is that Mahuika had been a year at school in our hometown, and she was fine and everything was fine. I was not with her father anyway and I moved over here to go to teachers’ college. We came over here and we do not have much support here. The change, and because I am doing it all by myself, and not having the support of her father here—I think she was getting behind. I did not have the knowledge to understand, or not that I did not understand but I was not aware. And it was until last year, Mahuika spent year 2 just pottering through and I thought she was fine. It was not until the school did an assessment at the end of the year when I realised that Mahuika was behind.

The assessment was to make sure that the children are progressing. A lot of Mahuika’s problem is the fact that she is younger than the other children in her class now. So the other children are over 9 and Mahuika has only turned 8 this year. And that is a lot to consider as well. But basically probably when she was 6 we realised and now she is 8.

I was noticing that she was struggling with reading and spelling and sentences. Back then I was only a first-year student, and did not have the knowledge and the problem did not seem to get any better. I had been out teaching and I had year 7 and 8 children and I know what it is like to have year 5. This year I had a section with little ones, 5-year-olds.

Heather commented on the challenges she faces being away from the support of her own and Mahuika’s whanau:

I have a cousin down the road and she is quite supportive. But the fact [was] that before moving to the city, even though her father and I weren’t together I still had support and he was still there and he was a big part in her life. And I had my family and his family who are still a big part of her life, but they are 3 hours away. And I cannot tell Mum that I am having difficulty, ‘Can you help Mahuika do this or that?’, it is a bit hard. Mahuika’s father’s whanau is huge, but they seem to have average ability from what I gather and his younger brother is very intelligent and my side of the family. I had difficulty reading at school but it was more just the fact that I hated, you know what it is like, that you had to get up and read in front of everybody and I was so terrified about making mistakes. And I think that was more my problem.

Finding funding to pay for private after-school learning was seen by Heather as the most significant factor in bringing Mahuika up to the reading level of her peers:

Last year Mahuika’s teacher had said to me that she had gone to Reading Recovery, when she was 6. And then last year she had specialist reading, and I tried as much as

I could to help and I just thought that I have got to do something, like they have got Learning Centres. So I rang up one of them, and they told me how expensive they are, and I said, 'Wow, I don't know about that'. I started talking to the service anyway and I asked whether there was a way Social Welfare would pay for it. The service said to me, 'No'. Then I said, 'Well, my daughter is part Maori'. The woman at the service said she was not sure but maybe the iwi could fund us, so that is when I went ahead. It has been great because I would not have been able to support Mahuika by myself, and she has progressed so much. At school she has specialist reading, where last year she went and read to an elderly lady who really just sat there and listened to her. So it was not really helping, until she had a one-on-one, and we are actually making advantage whereas last year it was just a classroom teacher plus this lady that listened to her read, which did not help.

The iwi was able to provide funding for a suitable intervention that targeted Mahuika's needs. An iwi literacy programme aimed at raising the reading levels of iwi children paid for her assessment and made contact with a private provider:

An iwi worker said to me that the iwi would fund Mahuika and then she assessed to see how bad Mahuika's need is. When Mahuika was assessed I had a meeting with somebody, I can't remember that lady's name, I just basically went with the iwi funding and I haven't really seen the other options for funding.

Heather described her experiences with the iwi and the after-school learning centre:

The iwi are really welcoming. . . . when I went and met the lady . . . she really did not have a clue and she put me on to somebody else. I thought that she was a bit rude, but the guy that I dealt with afterwards was good as gold. He said, 'Go and get Mahuika registered with the iwi', and I rang up Nana and she said that she registered all of the kids, she is definitely on to it.

. . . they got back to me with everything really good. I have not had much one-on-one contact with the Iwi Authority but I have just got a Review Report from the Iwi Authority at the end of term to let me know how Mahuika is progressing. They asked what I thought of the learning centre that she is being sent to. I said, 'It has been excellent'. Mahuika is into her second term, but there must be such a need for funding, and so they have only got her two terms. If I have to get funding next year, I have to look somewhere else for funding just to pay the fee. It's \$295.00 a term, \$29.50 a week for 80 minutes. Yes, that is a bit expensive, when you are on a stretched budget.

She is keen to improve Mahuika's facility with language:

Mahuika does korero Maori a little, more than me. A few of her uncles are quite fluent but her father isn't and she probably knows more than her grandfather does. Because I am a Pakeha I do not know a heck of a lot but I am learning through teachers' college and I use the odd command and greeting. Mahuika knows her numbers and she is in a kapahaka group in her school and she is fine at school. They had a performance yesterday, they do one in town every year and they get dressed

up. Mahuika has not been in kohanga reo or anything like that partly because they did not have one in our town.

In conclusion, Heather said:

Without the help of the iwi, we would still be struggling. Mahuika is still quite behind, but she has improved and she has got her reading level up, we are getting there. Her spelling is improving. I am not worried about her spelling at this stage, it is more the reading. You know what it is like yourself, you know you can read the words but when it comes to spelling you have to actually look at the dictionary. But as long as she can read and have the meanings, it is fine. The really good thing is the Trust will put her into the learning centre again next term and we can see how we go.

TE WHANAU O DANIEL

He mihi nui tenei ki a koutou, huri noa o te motu, nga whanau penei kei te mihi kei te mihi Ka huri te mihi nei ki nga aitua o ia marae, o ia marae haere k ringa i nga roimata o matou te hunga ora haere, haere atu ra. Ko te hunga ora me koutou te whanau me nga tamariki haua kia manawanui kia maia i roto i nga kura whanui o te motu. Tena koutou, tena koutou tena tatou katoa

Daniel**David:** Daniel's father**Jacob:** Daniel's grandfather**Ruth:** Daniel's sister

Twelve-year old Daniel is the oldest boy of a whanau in which his Maori mother has left her two sons and one daughter in the care of their Pakeha father and grandfather who together make up a three-generation whanau. David works full-time, and Jacob, their grandfather aged 72, is a superannuitant. Daniel is identified as making slow progress in reading and maths in his mainstream primary school and, along with his sister Ruth, is receiving special assistance from a government fund for literacy support administered by their iwi to access alternative after-school support. The whanau has minimal knowledge of the children's Maori heritage but, as the children were registered as members of the iwi, they were eligible for extra literacy support from a commercial learning support service.

The river running through the middle of this South Island city wound its way along the edge of the road and Daniel and Ruth (aged 7) were playing outside in the driveway of the whanau home, enjoying themselves. Met by the senior member of the house, the grandfather, the rangahau was welcomed into the home and spoke of the privilege it was to record their story for the benefit of similar families. The children were marshalled into the living room to meet this researcher from Wellington.

David:

Daniel is the oldest child of three. They all spend time with my mother, my sister and her children, and Daniel spends a lot of time with my brother. They also spend time with their mother.

Jacob:

They stay with my sister and her family, there are all those cousins on the other side [Daniel's mother's whanau]. We are not without support.

David:

So we are strong, we communicate between each other and we are protective of each other, very much so. Daniel does not speak the Maori language but we have his iwi affiliation papers there. Daniel's mother's whanau is tangata whenua.

When asked how the whanau saw special needs, David replied:

I am not sure if I understand the question about special needs. My children are important to me, I want them to survive and get into the workforce, but education has failed them. With my oldest boy Daniel, he lost 2 years with a particular teacher and when we had to take Ruth, my youngest child, for help, Daniel got it too. In two terms Daniel recovered his reading and maths skills for 2 years.

Grandfather Jacob added:

It is education and appropriate teaching. We proved that through Daniel being ignored for a couple of years and then getting the one-on-one teaching that he's had for 2 terms to bring him up to the standard that he should be and is at now. Special needs is education, that's the basic thing that I see. I am not a trained teacher and neither is David but we can see it would have slowly escalated as Daniel got closer to high school.

David:

As a parent I was aware that this particular teacher had not helped Daniel to the best of his ability because I am aware that he was capable of more. The school structure being as such, it is awkward for a parent to approach the teacher and say, 'I feel you are not doing it as well as it should be done'. When we needed to get help for my daughter Ruth, we were looking totally independent of the school. This offered Daniel a chance to be assessed too. So it was purely by accident that he got any help.

Jacob:

See, the thing was, I help Daniel with his homework. I used to come on Tuesday, that was his homework night and we used to get stuck into it. It became more and more apparent as time went on that he was given the homework for maths but it had not been explained to him properly, he didn't know the formula for working things out. I mean simple addition, he was just given it as homework, it is easy to say that, but you have to be taught how to add up—2 and 2 is 4, 4 and 4 is 8, and his education was lacking in that respect on the simple stuff. Daniel did not even know the times table. The essential thing in mathematics is the times table.

David:

There are needs in the family with Ruth too and we work with both of them at the same time, in terms of getting on to the after-school learning programme through the iwi. The kids have to be of a certain age. Ruth is 7 and she does the programme and we are paying for that ourselves because we found Daniel's improvement was so good. So Ruth did get a chance the same year Daniel did, it has only come for her at the beginning of this year.

Jacob:

And then again Ruth never had a problem with her teacher, she had good teachers. Their school itself happens to have won a top award last year, it's in a low-economic area, it has very good teachers and is a very small school, I think they have 200 places. The teachers have programmes in place for the kids who are lacking in reading, spelling, and maths. Lots of non-Maori kids fill those positions.

David:

Up until the iwi helped us into the programme, my dad and myself were fighting to improve my children's, his grandchildren's education by ourselves. We didn't have money to look at private organisations so we could only work within the methods of the school.

What I find annoying is that when my kids started school, they filled out the forms to enrol and there was an additional part, it asked if your children were Maori. The principal said that I did not have to worry about it because it only applied to Maori, they did not realise that my children were Maori because I'm European. Anyway, I finally asked, 'What is this additional part of the form for?' And she said, 'Those children that are Maori get additional funds—the school does'. I didn't have the kids with me but the point being that the school gets that additional money because my children are Maori.

We had some Somalis come in, and the teachers were taking the time out at lunch and in the morning before school started to teach them English, just to get them started in the classroom, and yet the school is getting funds from my children because they are Maori, and as a European I find it difficult to work with. At that time, which is 7 years ago, the school had the culture group and there were outside Maori people that came and ran that free of charge. I do not think that it should be. It annoyed me, one side that they were getting the money for my children being Maori and one side of me says, 'What about the European children that are in the school at the same time?' Why discriminate? I do not want discrimination with my children and so it is like a two-sided sword, do you understand what I am saying? And then we saw that these Somali children came in and take up the teacher's time anyway, and my kids were not getting any extra.

It is only as a parent with the understanding of the systems that I have seen in working through this problem. I am wondering if they cannot get information about what is available, or services established in your areas. How can people get help? I don't think there is a mechanism that can fix it but what I meant was what works in all areas, be it rural or town. We are lucky now, we are very comfortable with the service that we are getting now.

I know they have got the money, regardless of what may be said. I would like to see that it goes through the whole of New Zealand. I don't mean like the iwi fund for local Maori but I would like to see it happen throughout the whole of New Zealand for all Maori.

Jacob:

There is an aspect that I experienced in Japan, that these students can speak English and they would come over to visit our camp, get a good kiwi beer. And they were paid fabulous salaries to teach in the one particular field. They had 10 children in each class and the thing was they were only allowed 2% failure. But the idea was that those 10 children specialised and went out and they taught another 10 children and from the original 10 you finished up with 100 who had knowledge of specialised subjects, English, mathematics, and all those things. The students became the teachers, this is how the knowledge spread. What I would like to say is the people with special talents should be put back into a position where they can pass it on to other learners.

David:

That is not necessarily just in reading and writing. What concerns me as a parent is when I am in town at night and I see 10-15 Maori children or a mix of Maori and Polynesian children and you can see trouble coming before that night is out. They are bitter and they are angry and they need help. Unfortunately, the parents, for whatever reason, have also broken down on the system. So we need a mechanism that we can get these kids going again, we have got to help the parents too. It's serious and I really care about it. There is no blame involved here. It's the events that have happened through New Zealand history. But you have got these kids in the evening and they are good kids, they are smart kids, they are not stupid kids. You have got 10 kids there, you know that statistics are that 1 kid in 10 is stupid, then there are the other nine Maori/Polynesian kids who are bright but they are angry and bitter. You can't kick-start them without getting their parents involved and history has got us where we are now.

Jacob:

The thing is you get back to education. I am not talking about the 3Rs or anything, I am talking about general education, experience and knowledge. There is a wider suitcase you can carry and it will keep on going with you all your life. It will take you a long way, more so than anything else, education, knowledge, people being able to help other people to pass on the knowledge.

David:

I used to work in a young people's programme, for 6 years back in 1982. There was a boy, Takare, and he was in the Black Power. He came to me very angry and in trouble with the law for almost everything you could possibly imagine. I had worked 2 years before that with Black Power, I did not know Takare by sight but he knew who I was. Over a period of time, Takare opened up and became active, he was the youngest boy to go to Australia in the New Zealand Rugby League under 16. He was 15 at the time. Takare came to me and said, 'I've been picked to go to Australia in the under-16s but I can't, they've paid for me to go but I need money while I am away. What can you do?' I was the supervisor, I spoke to my superior and we

worked out that Takare had plenty of sick leave and Takare went away and that money was there for him when he came back. He did our programme for 6 months and I and my superiors got him to do another 6 months. He got away from the gang and he got his own flat, he had his own money, he would come to work in the morning and talk to these people without the hang-ups of whatever else was going on. And he really grew. Takare's sister was in Black Power, his younger brother was a prospect and his mother had connections. It took him guts to do what he did.

We could not take him for another 6 months, the best we could do was to get him on a programme elsewhere. He did that for 6 months. He went off that programme and the support mechanism wasn't there for him after that. In a very short time he slipped back to the place that was prepared to have him back again, the gang. There was a shooting here between the Black Power and the Mongrel Mob, Takare got shot and thrown outside the door of the hospital. He was shot four or five times and the end of his story is that he went into prison and he hung himself. To this day I have to wonder would he have been better off just being left where he was in the first place? Because I did not know at that time that the support mechanism was not going to extend far enough to look after this kid. If I had known that it was going to end the way it did, I would have seriously thought twice of working with any of those kids. If I had known that we couldn't support Takare any more than a-year-and-half, I would not have wanted him out of there. I had never had someone working under me hang himself. He just makes up the statistics of the Maori in prison.

You've got to keep them moving again, make sure that there is support for them at least a year down the track. If you get them going again, you be there for them and you will be there for a long time. All these kids are talented but to give them an opportunity and see how far they go.

Jacob:

It is no good, a short-term programme with no perceivable future. You've got to give them something of value to work towards. That is essential. The tragedy of that was that he was on the right. They just cut the ground underneath him, just said there are no more programmes. He looked around and, 'Where do I go and who is going to help me?'

David:

He was capable of looking after himself. The kid was 16 and he had an understanding of the work ethics. I just wanted you to know this because I am very aware of what is happening with Maori in New Zealand and I am a Pakeha.

Jacob:

We are New Zealanders and I am the fourth generation of our family here in this country. We cannot claim ancestry, you know, way back in Scotland somewhere long ago, we are New Zealanders, all of us. All my grandparents were in New

Zealand and my grandchildren are sixth generation New Zealanders with all of the family here.

**WHANAU EXPERIENCING SPECIAL EDUCATIONAL
NEEDS BECAUSE OF REMOTE LOCATION**

TE WHANAU O KOWHAI

Kowhai:	Flowering tree
Mamaku:	Tree fern—Mother
Kauri	Tall tree—Brother
Kaitiaki	Guardian—Correspondence School Early Childhood Service teacher

Four-year-old Kowhai is bilingual and lives in primitive conditions on whanau land in a remote rural area with her mother and brother amongst an extended whanau grouping. Kowhai receives early childhood education from the Correspondence School, and the connection between the whanau and the research project was made through the early childhood teacher at TCS. Kowhai was not enrolled as having special needs; she is eligible for the service because of the criterion for distance provision. It is common for TCS to have children enrolled for this reason, and particular learning or special needs become apparent as the relationship between the whanau and the service develops. When Maori whanau choose to live on their own turangawaewae, a need may arise for special educational provision for their children. With anecdotal evidence of more whanau returning from the cities to live on their whanau or hapu land, this may become a more significant issue in the future.

In the year 2000, Te Puni Kokiri (TPK) reported on the education status of Maori including pre-school:

Although there have been some improvements in the number of Maori enrolments in early childhood education, a considerable number are still not participating, with the disparity between Maori and non-Maori remaining significant. (p. 15)

At the time of the interview with te whanau o Kowhai, May 2000, the Correspondence School had 661 New Zealand children aged 0–6 years enrolled in Early Childhood Education (ECE) through the Early Childhood Service (ECS)—Te Ratonga Whakaako Puhou. Seventy-nine or 12% of these children were enrolled as Maori. This compares with a national average of Maori aged 0–4 of “19% of all early childhood enrolments in 1998” (TPK, p. 16) and the “[a]lmost 19% of all children attending childhood institutions [in 1999] identified as being Maori” (Ministry of Education, p. 19).

The rationale for the Correspondence School Early Childhood Service is –

... [that it] is a distance education service mainly for children between three and five who are unable to attend, or have limited access to, an early childhood service because of isolation, illness or itinerancy. Programmes are also available for children with special needs. (Ministry of Education, p. 18)

The Maori children enrolled in the ECS with TCS in 2000 are part of a very special education experience. Kowhai is one of those children.

There are no clocks in 4-year old Kowhai's story. It is the middle of the day and she is at home by the river when a 4-wheel drive vehicle pulls onto the grass behind the caravan she lives in. Kaitiaki, Kowhai's teacher from the Correspondence School, has come to visit.

With Kaitiaki is a kairangahau from NZCER who has come to gather information from Kowhai's whanau for the Maturanga Motuhake research project. Kowhai is a little bit shy of strangers and watches from a safe distance as about ten of the whanau greet and meet the visitors. A small aluminium dinghy pulls up onto a beach on the river's edge and Kowhai's brother, Kauri, aged 3, jumps out of the boat carrying a very large gutted trout. Fish and boy make a beeline for the teacher who receives the gift with great pleasure. Kaitiaki's relationship with the whanau spans 2 years and the children, their mother and whanau have eagerly awaited this, her first visit.

Korero by the river recalls how the whole whanau agreed to take part in the research and gave their informed consent because the story is being told by Maori for the benefit of Maori. Mamaku hopes that Kowhai's story may help more Maori whanau throughout New Zealand gain access to early childhood education through TCS. The whanau and visitors are called together for karakia to bless the food which includes smoked trout caught that morning, salads from their own garden, other home-grown fruit and vegetables, breads, and the small contributions from the visitors. The group sits to share the kai.

Kowhai has gained confidence and sits with Kauri and Kaitiaki playing with hand puppets, reading a story, singing a song, and investigating bugs with the magnifying glass provided by TCS in Kowhai's latest posting. Mamaku sits across the table from the tape recorder and the kairangahau and answers a set of questions being asked of all of the whanau contributing their stories to the research.

Mamaku described their living conditions:

I've got a caravan and we've built a lean-to over it. We all sleep in the caravan and the lean-to is the lounge and kitchen. We've got a little bathroom outside at the back. We've got all longdrops here; there's no power. What I've got now, which has been up for 3 years, is an absolutely luxury. Six years ago we were still cooking on open fires but now we're all hooked up to gas ovens which our uncle found and brought them up for our whanau here. We heat the rainwater off the fire. It's the perfect place.

There's 11 of us who live here permanently. There's my aunty and uncle—my uncle's the chairman of our marae, and my aunty's the secretary. There's me and the kids, Mum and Dad, and I've got another two cousins down the end there.

Mamaku is financially supported with the Domestic Purposes Benefit from Work and Income New Zealand (WINZ). Mamaku realises that not having to pay rent to live on their hapu land makes all the difference in her ability to manage on the limited income.

Located about 40 minutes from the closest town, the whanua's home is a difficult journey that includes 8 kilometres of very rough track. The community has no power or phone lines, but has a mobile phone:

I got mine for the doctor's sake and to ring the children's father, no other reason. I turn it off, unless someone goes, 'Oh Mamaku, can you leave your phone on?' I don't use it for people to ring me; I'm not into them, but just in case. We're not reliant on anything, even doctors. I've never had to ring them.

When asked, "Do you consider this to be a far out of the way place, or is it just town that's far away?", Mamaku replied:

I'm just used to the trip, but from what everyone else says it's remote, yeah. They find it a hassle coming and going, and to me, well, it's just a part of life. We're used to that rough terrain; you definitely need a 4-wheel drive, though. We get washed out twice a year, the land locks because of the rain and you can't go anywhere. It's a river that comes straight down that canyon. We're lucky to have the farm up the top, which belongs to our people so they bring their tractors down and unblock all the rivers. See, we're just used to it.

As Kowhai's story unfolded, it became clear from a whanau viewpoint by the side of a beautiful river that perhaps it is TCS and the Maturanga Motuhake research project which are located remotely from Kowhai's world and not the other way around.

Kowhai and Kauri exemplify the concepts of tangata whenua and turangawaewae; both were born on their own land. Mamaku recalled:

I had to leave here, and bubba Kauri was born on January 3rd. Being over the holidays I consciously got out; I had to go out of here to have him. I had both the kids at home, at their father's. I went up there and asked him to light his fire and we had the baby. I had a midwife, well, she come in when the baby was coming. And then they were brought straight back down.

The whanau is closely linked it to its own whenua and a hapu-owned farm operates on adjoining land. Drinking water is available from seven springs. Stories of the old days before major waterwork developments took over large tracts of the hapu land were shared with the kairangahau. When asked, "How long has your whanau been here?", Mamaku simply replied:

Since the beginning.

The aspirations of the hapu rest within the planned opening of their new marae on their own land. Because of this, whanau with kaumatua and other family members are returning from the cities:

We're expecting a lot of our kaumatua to come back. A lot of them have come once out of the city. We've got a couple of them back now, they're in their 80s, and I think a lot more of the old people will come back. I've made the conscious effort to learn about nutrition so that I can look after them. I just wanted more information than I'm not reliant on anyone.

Once our marae starts up, you know the concept of the marae being the baby. Our marae is the baby for our hapu, which means that our hapu isn't even born yet, so, and when she's born, that's when our people's heartbeat begins. Like our people aren't united at the moment, but they will. It only takes being united with our people and our marae's going to be up and when that starts, ah—it's endless.

Kowhai has limited experience of life away from her home; she stays with her brother and father on weekends. Mamaku plans carefully for trips to town and takes the children with her. These trips occur about every 3 weeks:

They come to town, we go and have lunch, go to the park and then we go and do our shopping. It's mainly for the children's own good to get a taste of it all. They don't know a lot about town. I've told them that they don't run out onto a road, but still I have to consciously keep an eye on them all the time. When you're in a town situation where there's constant traffic coming from all ways, they wouldn't know what to do.

Kowhai's story is like that of many Maori living in rural and isolated areas: access to information about early childhood education or services is haphazard. Although Mamaku experienced some of her own primary schooling through correspondence, she was unaware that TCS offered early childhood education. When asked, "how did you find out?", Mamaku explained:

My sister lived out in the wops, too. Her neighbour's children were on pre-school correspondence, and I said, 'Oh', and so I got the same. Their schoolteacher was Kaitiaki, too.

Anecdotal evidence from around New Zealand suggests that word of mouth, particularly within extended whanau groupings, is one of the most common sources of information about services for both special education and early childhood education. In the 2 years that Kowhai has been having correspondence, more of the whanau have become aware of and are intending to enrol for the service:

One of my aunty's mokos is coming up 2, so when he's 3 I think they'll sign up, and then she's got a form 2-year old and she's going to sign him up too.

Since the start of 2000, TCS has altered its application processes and now accepts applications for eligible children at birth.

Mamaku described the process she went through in choosing the right early childhood education for Kowhai. It was a choice between kindergarten, play centre, kohanga reo, and TCS:

[The closest town, about 30 minutes away, has] a kindy [kindergarten], they've got a REAP Playcentre, and a Playcentre . . . I used to do that though. It just used to open one day a week for 2 hours. There were about 10 kids. I actually got asked to take over the Playcentre but that was not right for me.

She checked out the options that would strengthen Kowhai and Kauri's reo:

I couldn't decide. First of all, I rung one Kohanga down town and it was, 'Hello'. Oh right! And the next one was, 'Hang on, hang on', and then the last one was, 'Kia Ora', and I went, 'Oh, this is the one'.

To hear te reo Maori spoken by a potential service provider gave Mamaku some hope, but her special needs caused by the remote location of her whanau could not be accommodated:

They wanted the 5-day commitment with the parent as well. I thought, 'Oh, that's a big ask', and I said, 'Can I make 4 days?' 'No, you have to make the 5 days, or your child's not coming, they're not allowed to come.' This was okay, but then I worked out, 'Oh, well, how am I going to get back, feed the kids, bath them?', because we had no bath and coming home in winter time. That all added up, and I was like, 'Oh no!' No, what I wanted was to have the education with me and the kids too, so it was one kohanga downtown or the Correspondence ...

My sister had these forms. Well, she didn't sign up, and I asked one of our kaumatua whether this was the right choice for my children. I said I wanted to know this because I had rung the three kohanga reo down in [named town 40 minutes away]. I was prepared to travel for my kids' education. Education for my children is a very high priority for us, so there was a toss-up. I said, 'Look, there's a kohanga reo or the Correspondence School', and I also got offered different places . . . at the different kohanga in town. But he told me Correspondence.

When asked, "Do you know why he made that suggestion?", Mamaku replied:

No. But he has wise, wise decisions.

To enrol Kowhai, Mamaku completed the application form that she picked up from her sister and sent it into TCS:

Oh yeah, they sent me this thing on isolation. That was the criteria that I fitted into. I sent them this invitation to my uncle's 50th birthday which had the map on it, and the terrain. It was instantly accepted. Because they [TCS] said that sometimes there's a long stand-down that you have to wait, we were really surprised when we got our first package [posting] about 2 weeks' later.

Saying that the posting arrived needs clarification. The posting is collected from the whanau letterbox on the main road over 8 kilometres from where the whanau lives. The mail service is provided by rural delivery and when asked if it is possible to return the postings from their home site, Mamaku commented,

I've never tried the mailbox, but they say you can put the thing out. I just usually give it to someone so that it gets into a post-box in town, 40 minutes drive away.

This is not always a straightforward exercise:

I get caught up a lot too. I've sent a couple of packages back to myself, a couple of times. They'll go by post but I've sent it back up here. One [posting] has been for a trip around the South Island and then it came back here in the wagon. Everyone in the community here can help to pick up the posting or sending it back to TCS.

The service provided by TCS offers many benefits to Mamaku and her whanau:

Well, I don't have to travel. I'm home with my kids in our own environment. With the building of our marae, Kowhai has to do a tukutuku board, bubba Kauri helps build. We're in the middle of our culture all the time.

When asked about the use of te reo Maori generally, Mamaku indicated that the main language spoken in the home is "Pakeha" or English. The reasons for this are simple and common for Maori whanau:

I think it's a respect to our Pakeha family who come and visit or live here. I mean, if we talk Maori, our other half of the family wouldn't be able to understand or communicate with us.

When asked, "Do some of you korero Maori together sometimes?", Mamaku responded:

I'm still learning; all of our old people all talk Maori, the whole lot of them all together. The mokos hear it spoken. And it's the language of this hapu. It is very important that the kids hear it spoken. Very much so. Some people say, 'Well, they're going to be left out in the mainstream if they don't know the transliterated Maori', and I said, 'Well, too bad, if we don't keep the old reo, well, that's another part of our culture dead'.

To develop her own reo, Mamaku draws on two sources:

Through my parents and through the resource sheets that Kaitiaki sends us. I rush over to Dad and say, 'Hello, have a look at this', and he says, 'Oh yeah, that's good'. He said that as long as you try, it doesn't matter what sort of reo it is, that's his way.

Kowhai turned 3 a few weeks after the application was made and was added to Kaitiaki's caseload. Mamaku is the designated supervisor for Kowhai's learning with TCS. Mamaku's mother is a qualified kaiako from kohanga reo and she does korero Maori with her mokopuna at every opportunity. Although the number of children on the hapu land is small, there has been some discussion about establishing a kohanga reo:

We've talked, I've had a talk to some of our people on our marae for kohanga, and that our marae fund it, or from one of the whanau funds so that we're not accountable to the government, we're accountable back to our own people. What they want is someone who's got te reo but who's also physically capable, because

you get a lot of kaiako that have got te reo but they haven't got the energy to keep up with the kids.

At the present time, TCS is offering the only pre-school education service to the whanau. When asked, "Do you feel that the Correspondence School is supporting you in this home-schooling with your kids?", Mamaku pointed to another benefit of TCS service:

It's supporting me as their first teacher, and it's even supporting me as a parent. For instance, I was finding it really hard to discipline the children. Kaitiaki sent me all this information on disciplining. Honestly I know nothing about kids, only what I've learnt and I've had to go out and find that information myself. It's hard telling someone that I'm finding it hard. I wrote to Kaitiaki and said, 'I'm finding it hard, I don't want to hit the kids. Is there another way?' Kaitiaki sent me all this information and it was like—oh, there is another way! I believe from the discipline information that respect and patience will be the foundations of my teaching for Kowhai and Kauri and, yep, it's working.

Mamaku agreed that she felt it was possible to ask for help from TCS particularly as she had developed a direct relationship with Kaitiaki, the ECE teacher:

If it's to benefit raising the children, yes, and for the parents they've got books available. I was deciding on whether to put Kowhai through school, I'm into having choices. All I know about is Correspondence School, so Kaitiaki gave me information on school itself, and they're all positive things, so I had two positive choices.

Mamaku ensures that the two children sit with her to correspond with Kaitiaki when they return comments about the resources and activities from TCS postings:

I ask Kowhai, and she helps me write the letters, that view that I send back on our life is the whole lot of us, I can't speak for Kowhai—I let her speak. I like the confidentiality in that what Kaitiaki expressed to me about her work as a teacher, I feel like Kowhai and bubba Kauri are getting a private tutor. I write what's happening in our lives. To me that's very personal and private, I open the communication up with Kaitiaki only because I knew that confidentiality was there too. So, for example, with Kaitiaki it's gone to a personal level, and I feel very confident, it's very professional.

With permission from Mamaku and TCS, an example of their communication follows:

Kia Ora,

Merry Xmas and New Year's greetings. Where to begin? First, Kowhai is well, slowly getting back into the rhythm of things. Still have the clown puzzle looking for one more piece found the clipboard will send the clip next time. Kauri is now 3 so I would like to sign him up. Mum and Dad look a bit under the weather with the continuous flow of celebrations. As for myself I have a new person in my life,

looking forward to having a healthy and happy relationship. He used to teach English and Maths and that sort of stuff in 4th form [named High School]. So we have help with their schooling, let's hope we can keep up with the timetable and what's expected of us. Kowhai starts school on May 10th we're still considering [named primary school], a fair bit of travelling on our behalf. I mainly feel inadequate to teach her how to read + maths plus Kowhai's not the easiest pupil to teach at the moment. 'I know' are her main words.

Kowhai stayed away for a night at her friend's place which was a big step for her. She didn't miss me, she was very proud of herself. She's slowly finding herself around strangers not so shy any more. Expressing herself well, asks 101 questions as soon as her eyes open, I get quite drained.

Finding it hard to discipline her. Will have to be more tactful. Looking forward to this year. I don't believe the millennium has started only that this year is to set the foundations for the next 1000 yrs.

Eating some wonderful food and drinking some beautiful wines, you really do have to drop in some time. If you know anyone who fishes they'll tell you where we live. Anyhow I'm sure you have another 100 more students to contend with, so all the best.

Mamuka, Kowhai, and Kauri

TCS has rules as a guideline for how the service works with eligible whanau. The communication between whanau and teacher is critical to the supply of appropriate resources for each child, and requires a commitment to return the resources at 2-weekly intervals. This poses challenges for Mamaku:

I usually tell Kaitiaki that I need them for a little bit longer, especially for the kids. I need about 3 weeks plus, to comprehend the whole lot, otherwise it's too swift. But then my partner said 2 weeks is long enough because the kids are like sponges at the moment, it soaks in and it just stays there.

Maybe it's just me that needs the 3 weeks. I think they can grasp it, but with me everything's new to me in teaching, I've even gone and got information for myself so that I can learn how to teach them so that they will understand it. They understand it; they can comprehend what I'm trying to get through to them, even though they say no, like tomorrow they would repeat exactly what I said. I get so much from the resource sheets that come along with the school work, and it takes me a while to get through that.

When asked if she felt that the Correspondence School offered real tautoko for herself and her children, Mamaku replied:

Definitely, it's my truth, it goes along with what I believe, and it's empowering parents to make some real decisions for their children's well-being, setting some strong foundations for when they get older, and I really believe that it begins now.

Like up to the age of 7, they say children complete 90% of their learning. I couldn't believe that. I said to Kaitiaki that the learning is unreal, and I am constantly learning with the kids.

Mamaku reflected on whether the Correspondence School pre-school service would help Maori whanau teach their own children. She considered the problem of the lack of information about available services as a major issue:

I believe if a mother's given a choice she'll take that learning with her kids. But I know a lot of mums who don't know the choice, they only know one way and that's wait for the mainstream primary. I've told a couple of friends up the road about pre-school Correspondence and now they're on it. One's got two children, and the other's got a daughter, and they were overwhelmed to know that TCS is there, they didn't even know it was available.

As well as sharing information about services through whanau and other informal social contacts, Mamaku suggested alternatives for dissemination of information about services:

For the other early childhood groups to have the information on all of the options so parents can have choices apart from their own groups. For example, the Playcentre to have information on the REAP Playcentre, or there's the Correspondence service for your child.

When asked how TCS could get information about the pre-school service out to whanau, Mamaku commented that radio would not work for her:

Well, I don't listen to a lot. One suggestion is to get the information out through marae.

When asked if she had any concerns about the need for bilingual resources for pre-school Maori children, Mamuka felt that TCS was providing well for her whanau:

Because it's not contradictory to kohanga reo, it's on a par with them, because te reo also comes through the Correspondence School. I was surprised because the majority of the Maori resources that are sent to Kowhai are all new. It was like they must have just got it in, and it's like, wow! My cousin said they may be just catering to Kowhai. I said I actually think it's by law that it has to cater for the Maori culture.

Mamaku expressed her concerns that not enough Maori whanau are accessing pre-school education for their children:

Well, Correspondence service begins about 3. I know some of the ways that we've been brought up; it's not arrogant, it's the ignorance of our own people, their belief is that school doesn't start until you're 5, so they don't start, they don't teach their kids until they're 5, because they don't know any better. The parents really need to be educated and educating their young kids.

Mamaku is delighted in how Kowhai and Kauri have taken to learning by Correspondence:

All of the holidays they want to do the schoolwork. They want to invite all their friends over, during the holiday time I get all the kids over home. It's like—oh what! But now Kowhai's cottoned on that this is really special and so that's for her and bubba Kauri, that learning.

Mamaku suggested that information about pre-school services should target parents and mothers, and that Maori parents or whanau would be able to handle teaching their own children:

The mothers, the ones who are looking after the children, have to take on that role as teacher. So you need to get to the Maori parents, not the kids. They only learn as much as the parents put in them.

Even if a Maori mother left school at 13, the support's there from TCS to teach. I've been taught how to teach my kids through the Correspondence. I've been taught how to read a book to a child, and now Kowhai will say what book she wants and who the author's written it, and the illustrator. It's beautiful, I didn't realise that there are ways of teaching a child that they will comprehend everything you say.

Feedback

Mamaku read the draft of the case study and requested several deletions, and added:

I hope the story will be of value to our young Maori children,
Arohanui, Mamaku, Kowhai, and Kauri.

ANALYSIS

THE PRINCIPLES OF THE TREATY OF WAITANGI AND THE CASE STUDIES

Partnership

The case studies in Maturanga Motuhake present a range of partnerships varying from successful to non-existent. Some whanau felt there was little sign of partnership between themselves and schools or services, and the negative results from this are evident in both Ngatata and Moana's stories. Boards of Trustees were involved with a positive outcome for Ben and a negative outcome for Moana. Involvement by principals was reported by whanau as positive in four cases and negative in two. Some partnerships involve a written contract, such as the one Kowhai's whanau has with the Correspondence School, and the Ministry of Education in partnership with parents and the school for a waiver in Ben's case.

Teacher aides assisted Ben and Moana, with other whanau wanting this one-on-one support for their special child. Resource Teachers Learning and Behaviour including those designated Maori in partnership with school clusters gave help in two of the case studies, with positive results in one case (Maui) and suspension as the outcome in the other (Ngatata).

Some whanau experienced a kaupapa Maori response with tikanga Maori and whanau-based services: one involved relationships with marae staff at a special school (Rosa); another involved a school with a whanau-based response (Ben); one was grounded in a Maori Immersion class (Awhiro); and two involved whanau in kura kaupapa Maori settings (Maui and Awhiro).

In three cases (Marihi, Moana, and Mei), the local iwi had entered into partnership agreements with the Health Funding Authority, including one case of positive support from a holistic Maori-centred service provided by an urban Maori trust (Mei). Iwi also offer services to Maori whanau (Mahuika and Daniel). Some iwi services offered co-ordination between the whanau and other services, while Mei's whanau co-ordinated their own responses including ongoing speech language therapy practice with a kuia at home who has many years teaching experience.

Successful partnerships are evidenced by well informed whanau and parents who are positively supported with their special needs children, and education and services provided within Maori kaupapa and tikanga were appreciated by whanau.

Participants at the Maturanga Motuhake wananga put forward the view that where there was no evidence of partnership in the case studies, none of the other Treaty principles were in evidence. Where partnerships in their many forms are evidenced in the case studies, other principles can also be seen operating positively for Maori whanau.

Participation

Matauranga Motuhake reports on extended whanau throughout New Zealand supporting the participation in education by children with special needs. Te whanau o Mei records positive and successful participation in support and health services by concerted whanau commitment and effort in the presence of multiple and inter-generational disabilities. In most of the case studies, successful support enabling participation in education for children with special needs required input from all concerned, the whanau, schools, and services.

While most whanau considered a range of options for their children, many had to rely on word of mouth as a source of information. Some whanau felt that a kaupapa Maori approach specifically enabled their participation in schools, for example, the hui whakatika following Maori tikanga in Awhiro's story, and the whanau-based kaupapa evident in Ben, Maui, and Rosa's cases. The availability of te reo Maori resources from The Correspondence School was valued by the whanau of Kowhai, and Maui and Awhiro received support within kaupapa Maori. Iwi health services offering information and practical assistance to the whanau enabled hospital visits for Marihi and health checks for other children in kohanga reo.

A range of government-funded support assisted special children within the mainstream setting, for example, the schools using an Individual Education Plan developed with SES staff to establish achievable learning goals for Marihi and Ben who are both supported by the Ongoing Resourcing Scheme. The transport allowance enables Rosa to participate in a special school that offers a range of education options for the deaf.

Many of the children were at various times in their lives unable to participate in school because of health or behavioural problems, Ben, Awhiro and Maui were supported by school whanau to participate in all school activities. In Moana's case, the whanau felt excluded from and alienated by the schools they approached.

Remote rural locations resulted in intermittent support in speech language therapy in Ben's case and the relocation by whanau to cities to access services by Rosa, Marihi and Mei's whanau. A whanau choosing to live on their own turangawaewae in a remote area successfully accessed participation in early childhood education in Kowhai's case.

Protection

Matauranga Motuhake presents cases of schools where all staff are committed to protecting children within a whanau model, and the school commitment to kaupapa Maori and whanau structures gives Maori whanau the confidence that their child is safe at the school. Language is protected by the schools and services where te reo Maori is spoken. Children are also actively protected where staff are trained for medical emergencies, e.g. epileptic fits in the case of Ben, or staff are qualified and fluent in New Zealand Sign Language in the case of Rosa.

Cases where kaumatua provide advice and protection to the whanau, for example with Awhiro and Kowhai, sit in stark contrast with Ngatata's whanau which is without protection, and Moana's parents, who felt that racist attitudes impacted quite significantly upon Moana and the whanau.

A difference in the ability of whanau to protect their special needs children was their status either as tangata whenua or as whanau living outside their own rohe. While Maori rely on word of mouth for a wider pool of information from within the whanau, sporadic access to services and supporting resources is evident. These whanau could however draw on whanau for both emotional and practical support for the care of their special needs children. Without the network of physical support and information available within the extended whanau, children with special educational needs are supported by whanau lacking resources and the support of services which could be available to them. Of the 11 case studies, six whanau were tangata whenua, living in their own tribal lands, including Kowhai living on hapu land, her turangawaewae. In all these cases, the extended whanau was able to support and protect the children. The remaining five whanau were living outside their own tribal area and in most cases removed from close connection with the extended whanau. Two of the whanau have Maori children living with single Pakeha parents who were able to access learning support with help from an iwi authority and maintain contact with the whanau. Two whanau moved to access health and education services for their children. One whanau was transient to avoid criminal associates or perhaps the consequences of criminal activities.

Medical professionals and health services supported many of the children, including SES co-ordination of delivery of services to the children within Mei's whanau, and an Iwi Support Service advising Marihi's whanau how to get the support they needed. Information is critical to whanau with special needs children, and the benefit of experience ensured that Moana's sibling benefited from the whanau knowledge of glue ear and how to access support.

A theme through most of the stories shows that whanau at times felt unprotected where schools and services were unable to provide solutions to the problems caused by the special needs (with Ngatata and Moana, for example). Most other whanau found help to protect their special children.

Empowerment

Whanau in the case studies demonstrated empowerment when they were confident that the school or service ensured the safety and happiness of their own child. For some, the use of te reo me nga tikanga Maori is an empowering practice for the whanau with the school or support service. Whanau were empowered when they saw improvement in their children and sometimes themselves, and where learning improves (verbal communication and life skills in Ben's case, and general confidence in the cases of Rosa and Kowhai). In the case of Maui and his improved behaviour, the whanau was informed and knowledgeable and felt empowered to look after him with no further help from an RTLB.

Several whanau strengthened their fluency in te reo and taha Maori and other whanau were assisted by the availability of bilingual resources and in one case New Zealand Sign Language. Maui's parents are confident that kura kaupapa Maori ensures his safety and happiness and Awhiro's story shows a kaupapa Maori intervention resulting in a successful social and educational outcome.

Information and experience empowered many parents to teach their children or support them in therapies. All whanau actively searched for advice, support, and services, and

case studies such as those of Mei, Rosa, and Marihi show the whanau empowered by the support services and resources which enabled the children to attend hospital appointments and school.

Rosa's whanau felt empowered by its move to the city, resulting in help for Rosa and employment for whanau members. One whanau has a member empowered by working and training in the health professions (Mei), and one felt empowered by training in education (Mahuika). Two whanau (Ngatata's and Moana's) felt disempowered by the nature of the local schools' relationships with the whanau.

Equity

Maori are over-represented in all areas of special educational need, and the disparity between rates for Maori and other New Zealanders is of concern. Any action taken to reduce the rates of special educational need for Maori, or to ensure that Maori can access support and resources, would be in the interests of equity. In the cases of Ben, Rosa, and Marihi, the whanau were happy with the support they were receiving with funding from the Ongoing Resourcing Scheme. Provision by the Correspondence School to Maori whanau in remote locations, or to those suspended or expelled from schools, was seen by whanau to contribute to a more equitable solution.

Schools willing to accept children suspended or expelled from other schools, or schools attracting special needs children, can become magnet schools and face particular difficulties where no extra funding is available to meet the higher demand for resources and support. In Ben's school, a shortfall in ORS funding is subsidised from the school's Special Education Grant for moderate needs to employ a full-time teacher aide. Maori are over-represented in demand for RTLB assistance and under-represented in RTLB staffing. Maui's case shows how a kura kaupapa Maori whanau found the necessary assistance with the RTLB (Maori). Moana and Ngatata's whanau experiences highlighted the need for schools to develop their ties with Maori whanau.

Some whanau including Marihi's, Rosa's, and Mei's found information about the services for their children available as the needs were identified, and others were until recently unaware of state benefits and entitlement to services and support. Increased knowledge of whanau rights in the process of stand downs and suspensions would benefit whanau, as shown in the cases of Moana and Ngatata. Increased awareness of health problems, e.g. the symptoms of glue ear, and what to do about them could benefit many children, as shown in Moana's whanau.

Access

In most cases, initial access to information about services was haphazard, with some whanau satisfied with their current access to services and support gained only after long or complicated experiences of learning what was available. Mei's whanau sees knowledge based on past experiences and linking to Pakeha systems through the Pakeha grandmother having worked in both education and mental health and an aunty training as a nurse, as keys to their access to services and support. The transport allowance enables access to school for Ben, Rosa, and Marihi. Two whanau relocated to access services, and Kowhai showed how a whanau living remotely can access early childhood education. It is

the case, however, that Maori are under-represented on the Correspondence School ECS rolls and, as in Moana's case, over-represented in the numbers of children suspended and enrolled with TCS. In some cases, the support of iwi services helped access transport to hospital, and entry to an out-of-school learning and literacy service. Some whanau were aware that there were agencies to help but were not sure where they were located or how to get in touch with them. Others are totally satisfied after gaining access to their Maori-centred support services.

INDIVIDUAL STORY TREATY ANALYSIS SUMMARIES

Analysis Te Whanau o Mei

A premature arrival, 4-year old Mei attends a pre-school for the deaf with her twin brother. Mei has multiple disabilities and special needs. Mei's mother and father are profoundly deaf. The extended whanau supports Mei. The story of Mei, her siblings, parents, aunty, cousin, and grandparents is told in this inter-generational story.

Treaty principles	Te Whanau o Mei
Partnership	<ul style="list-style-type: none"> ● The whanau receives support and assistance from a range of government-funded health and education services. ● Positive support from holistic Maori-centred service is provided by an urban Maori trust. ● The whanau provides its own support and response to the needs of its special children, e.g. ongoing speech language therapy practice with a teacher-qualified kuia at home.
Participation	<ul style="list-style-type: none"> ● The whanau has multiple special needs within three generations and all actively work to support each other. ● The whanau exemplifies positive and successful participation in government-funded services by concerted whanau commitment.
Protection	<ul style="list-style-type: none"> ● Medical professionals and health and education services give advice and delivery in support of the children. ● SES co-ordinates delivery of services to the children with the whanau.
Empowerment	<ul style="list-style-type: none"> ● The whanau takes responsibility for the care of its own members. ● Two whanau members are working and training in the health professions. ● Whanau members actively pursue support and services.
Equity/Access	<ul style="list-style-type: none"> ● The whanau sees learning from past experiences, the grandmother working in mental health and an aunty training as a nurse as keys to their current access to services and support. ● The whanau reflects total satisfaction with the Maori-centred support service.

Analysis Te Whanau o Rosa

Eight-year old Rosa is deaf and has experienced kohanga reo and mainstream schooling. Her whanau relocated twice to a town and then to the city to access services for Rosa who attends a special school for the deaf. The marae and Maori staff at the school made the whanau feel welcome. The Maori content of the school curriculum affirms Maori culture for Rosa. Rosa is happy and achieving well at the special school. The whanau communicates in three languages, English, te reo Maori, and New Zealand Sign Language.

Principles	Te Whanau o Rosa
Partnership	<ul style="list-style-type: none"> ● KDEC has Ruamoko Marae, Maori staff, and is committed to te reo and tikanga development for all staff and students.
Participation	<ul style="list-style-type: none"> ● KDEC offers a range of education options from pre-school, primary, intermediate and secondary levels for children who are deaf. ● A transition out of school and itinerant teacher services for the deaf are supported from KDEC. ● Rosa is transported to and from KDEC.
Protection	<ul style="list-style-type: none"> ● KDEC staff are qualified and fluent in New Zealand Sign, English, and some in te reo Maori. ● Ruamoko Marae gives whanau confidence that taha Maori supports Rosa.
Empowerment	<ul style="list-style-type: none"> ● The parents are delighted with Rosa's schooling and learning. ● The whanau is fluent in New Zealand Sign Language. ● The whanau is strengthening its fluency in te reo and taha Maori. ● Their move to the city resulted in employment for the whanau.
Equity/Access	<ul style="list-style-type: none"> ● Rosa's whanau had to relocate off hapu land to access the school. ● The whanau was well informed of options including KDEC at an early stage. ● The whanau accepts that the move to access KDEC has benefited Rosa.

Analysis Te Whanau o Marihi

Twelve-year old Marihi has three younger brothers, and lives with her DPB-supported mother Tiaka as tangata whenua in a small rural town. A local doctor was the first to recognise her special needs at age 4. Marihi has multiple physical disabilities and is academically 4 years behind her peers at her mainstream primary school. Marihi is living for each day with an inoperable cancerous brain tumour. An iwi education initiative created the service to support Maori with special needs and their whanau, and this service has co-ordinated access for Marihi to government-funded help from the school, hospitals, SES, and the Child Cancer Foundation.

Principles	Te Whanau o Marihi
Partnership	<ul style="list-style-type: none"> ● The iwi initiated a partnership with the Health Funding Authority to offer the Disability Support Service to local people. ● The Iwi Support Service offers whanau information and practical support and co-ordinates with local hospitals, SES, school, CCS, and the Cancer Foundation to support Marihi.
Participation	<ul style="list-style-type: none"> ● The Iwi Support Service offers information to the whanau and practical assistance such as arranging transport enables hospital visits. ● The school and SES used IEP to establish achievable learning goals within the mainstream setting.
Protection	<ul style="list-style-type: none"> ● The Iwi Support Service is available to advise the whanau to get the support needed for Marihi's needs.
Empowerment	<ul style="list-style-type: none"> ● Tiaka feels empowered by the support, services, and resources enabling Marihi to attend hospital appointments and school. ● Use of te reo me nga tikanga Maori is usual practice in the whanau and the Iwi Support Service.
Equity/Access	<ul style="list-style-type: none"> ● Information about the services for Marihi was available as the needs were identified. ● The transport allowance pays for Marihi to travel to school and the Iwi Support Service helped access transport to hospital.

Analysis Te Whanau o Ben

Fifteen-year old Ben attends a remote rural primary school. Ben is “growth retardated” and has Section 9 and Ongoing Resourcing Scheme funding with a special Ministry exemption to attend school over the usual age for primary school. The whanau supporting Ben includes parents and the school working together. Ben has been educated in special units and was ‘mainstreamed’ as is told in the story. Four connected stories present the parents’, caregiver’s, teacher’s, and principal’s viewpoints. The whanau now accesses health services and benefits.

Principles	Te Whanau o Ben
Partnership	<ul style="list-style-type: none"> ● The whanau, Board of Trustees, and principal have a Section 9 agreement enabling Ben's attendance at primary school at age 15 years. ● The school has a whanau-based response to the needs of special children. ● The whanau and teacher aide are in daily contact on Ben's condition.
Participation	<ul style="list-style-type: none"> ● The whanau chose the school from a range of options based on word of mouth. ● Ben is free to participate in any school activities at any level at any time of the school day. ● Ben is integrated into a class and has 100% teacher aide support funded by ORS. ● Ben receives no support in speech language or other therapies due to intermittent service delivery from SES.
Protection	<ul style="list-style-type: none"> ● Ben is free to be part of a range of activities, with all staff committed to that programme and protecting Ben at school. ● School commitment to kaupapa Maori and whanau structures gives whanau confidence that Ben is safe at the school. ● Staff are trained for medical emergencies with Ben, e.g. epileptic fits.
Empowerment	<ul style="list-style-type: none"> ● The parents are confident that the school ensures Ben's safety and happiness. ● Ben's verbal communication skills are improving.
Equity/Access	<ul style="list-style-type: none"> ● Maori are over-represented in ORS applications and under-represented in ORS funding ● School tops up ORS funding to enable Ben's teacher to have a full time teacher aide. ● The whanau was until recently unaware of state benefits and entitlement to services and support for Ben. ● The transport allowance enables Ben access to the school.

Analysis Te Whanau o Maui

Te whanau o Maui live separately from their own extended whanau in a small town in the South Island where Maori are a minority. Seven-year-old Maui attends kura kaupapa Maori and is a slow learner and was misbehaving in class. The benefits of KKM whanau kaupapa extending awhitanga to special children and the assistance from a Resource Teacher: Learning and Behaviour (Maori) have positive results for everyone.

Principles	Te Whanau o Maui
Partnership	<ul style="list-style-type: none"> ● Government funding of KKM and the RTLB (Maori) enables a tangata whenua kaupapa Maori response which is successful for the child, the whanau, and the kura. ● Whanau and RTLB (Maori) worked together to help Maui's learning and behavioural problems.
Participation	<ul style="list-style-type: none"> ● Whanau chose the kura based on kaupapa Maori and te reo Maori. ● Maui is integrated into a class and receives infrequent RTLB (Maori) assistance in class. ● The school has whanau-based kaupapa in the classroom. ● Lack of resources means that special needs children may not receive necessary assistance. ● Maui is able to participate in all school activities.
Protection	<ul style="list-style-type: none"> ● The school commitment to kaupapa Maori and whanau structures gives whanau confidence that Maui is safe at school.
Empowerment	<ul style="list-style-type: none"> ● The parents are confident that the kura ensures Maui's safety and happiness. ● Maui's behaviour has improved and the whanau is informed and knowledgeable and feels empowered to look after Maui with no further assistance.
Equity/Access	<ul style="list-style-type: none"> ● Maori are over-represented in demand for RTLB assistance and under-represented in RTLB staffing. ● The whanau was aware that there were agencies to help but was not sure where or who. ● The KKM whanau found the necessary assistance with the RTLB (Maori).

Analysis Te Whanau o Ngatata

Ngatata is 8-years old and lives with his parents and two of his three siblings in rental accommodation in a small South Island town. Ngatata's whanau lives in an area with a low Maori population, and they have relocated to avoid criminal associates. The whanau is living in poverty, supported by the Unemployment Benefit with an accommodation supplement. At the time of writing, Ngatata had been suspended from and left three of the five primary schools in the area, and after the interview was suspended by a fourth school.

Principles	Te Whanau o Ngatata
Partnership	<ul style="list-style-type: none"> ● The whanau receives support and assistance from a range of government-funded health and educational services. ● Negative feedback about SES, CYFS (CYPFS), WINZ. ● SES. Two teacher aides. First teacher aide provided assistance to the whanau until he was relocated. The whanau was unhappy with the methods of the second teacher aide. The whanau terminated his assistance. ● The whanau went to CYFS for extra financial assistance, but nothing came of it. ● The whanau went to WINZ and was told to go somewhere else to get confirmation of Ngatata's problem. They did this and when they went back to WINZ they were unable to help. ● The whanau now receives assistance from a dedicated RTLB mainstream teacher. Ngatata is making progress but home life makes it difficult. ● When Ngatata has one-to-one assistance, partnership is strong.
Participation	<ul style="list-style-type: none"> ● Ngatata has been suspended from four schools in the region. ● Ngatata receives assistance from RTLB mainstream. ● Ngatata's severe behaviour means that he would be more suited to full- time care rather than sporadic care, as this sort of assistance has proven fruitful for Ngatata and the whanau in the past. ● Ngatata's behaviour limits him from some school activities. ● Ngatata has been linked to several government departments. Until the assistance of RTLB, the whanau felt that nobody seemed willing to help them. ● The father is unemployed which escalates the problems of this whanau.
Protection	<ul style="list-style-type: none"> ● Because Ngatata has been to four mainstream schools, his needs are not being met and the whanau does not feel protected. ● Ngatata was allegedly choked one day at school by one of his teachers. The whanau did not send him to school so that he could be assaulted by school staff, although the case study shows there is violence in the home.
Empowerment	<ul style="list-style-type: none"> ● The whanau feels helpless considering they have taken all the necessary steps to find assistance for their son. ● When there is one-to-one assistance, the whanau feels empowered.
Equity/Access	<ul style="list-style-type: none"> ● The whanau feels they have done everything in their power to access assistance for Ngatata. They feel help from the government agencies named did not find its way back to the whanau. ● The whanau reflects total dissatisfaction with the system. "The system is not helping our boy."

Analysis Te Whanau o Awhiro

Awhiro's story tells of a whanau intervention which created an alternative to suspension for the use of marijuana at an intermediate school in a large North Island town. Whanau members who are tangata whenua attended a meeting with the Maori Immersion class staff to find a solution to the problem. An in-school suspension with extra programmes was created. Whanau members attended the programme sessions and the student continued at school and achieved well academically. Awhiro was subsequently funded from SES to attend boarding school for secondary schooling to remove him from the environment of drug use in the whanau and community. Awhiro graduated with Sixth Form Certificate. The kairangahau writer uses theoretical models from literature. The story is told retrospectively using spiral and narrative discourse.

Principles	Te Whanau o Awhiro
Partnership	<ul style="list-style-type: none"> ● The problem was owned by all rather than blaming the boys. ● The whanau and school agreed to collaborate in order to search for a solution that was agreeable to all concerned.
Participation	<ul style="list-style-type: none"> ● Because the context for the solution was to come from a Maori context, Maori whanau felt safe to participate. ● The solution sought input from all. ● Hui whakatika followed Maori procedures. ● Students, whanau, and teachers were all part of the developed solution.
Protection	<ul style="list-style-type: none"> ● Participation of kaumatua provided protection to the people as well as the processes. ● There was trust in the process and accountability to the whanau.

The elements of empowerment and equity/access are believed to be integral to the principles of partnership, participation, and protection.

Analysis Te Whanau o Moana

Moana is the second eldest of five children living as tangata whenua with both of her parents. At the time of the interviews, Moana was 15. Her first special need was identified as hearing loss as a result of glue ear from the age of 2, and Moana continued to experience learning and behavioural problems and continuing low self-esteem. After a suspension for alleged theft, her parents withdrawing her from another college, enrolment with the Correspondence School secondary service, and a suicide attempt, Moana is in respite care. The whanau applied their learning to Moana's younger sister Ngaire, to avoid the downward spiral of events. They aim to actively extend their support for special educational need children into the whanau of their kura kaupapa Maori.

Principles	Te Whanau o Moana
Partnership	<ul style="list-style-type: none"> ● The whanau felt there was little sign of partnership with the schools, but improvement was made when the iwi runanga was involved.
Participation	<ul style="list-style-type: none"> ● Moana missed school because of health problems. ● The whanau felt isolated and alienated by the schools.
Protection	<ul style="list-style-type: none"> ● The whanau at most times felt unprotected from the school which provided no solutions to Moana's special needs. ● Moana's sibling benefits from the whanau knowledge of glue ear, and accessing support, for example. ● The parents felt that racist attitudes impacted quite significantly upon Moana and this whanau.
Empowerment	<ul style="list-style-type: none"> ● The whanau felt disempowered by the accusing nature of the school's relationship with the whanau. ● The whanau relied on their own experiences and learning to empower themselves and the well-being of the wider KKM whanau.
Equity/Access	<ul style="list-style-type: none"> ● The whanau's experiences highlighted the need for schools to develop their ties with Maori whanau. ● Increased awareness of health problems, e.g. symptoms of glue ear, and what to do would benefit whanau. ● Increased knowledge of whanau rights in the process of stand downs and suspensions would benefit whanau.

Analysis Te Whanau o Mahuika

Mahuika is an 8-year old Maori girl living with her solo parent mother who is Pakeha, in a city in the South Island. She attends a mainstream primary school. Her special need is slow progress in reading and spelling. The whanau lives in a city where Maori are a minority of 8% in the regional population. Te whanau o Mahuika received assistance from the local iwi runanga which used government literacy support funding. Mahuika's reading has improved and now the whanau is working on her spelling.

Principles	Te Whanau o Mahuika
Partnership	<ul style="list-style-type: none"> ● There is evidence of local iwi runanga helping the whanau to access private after-school learning and literacy support. ● There is also an agreement between the iwi and the private support provider.
Participation	<ul style="list-style-type: none"> ● The mother participated in all steps of identifying the special need, e.g. attending a first assessment, managing contact and enrolment in the programme, and ongoing transport. ● The whanau is seeking more resources to continue attendance.
Active Protection	<ul style="list-style-type: none"> ● The iwi has established divisions to assist with specific support, in this example, literacy and learning needs. ● At every step the mother felt comfortable and safe with the personal advice and interaction with the iwi runanga. She described excellent liaison and extra effort given to her needs. ● The mother felt that the school worked hard but its efforts were not effective.
Empowerment	<ul style="list-style-type: none"> ● The mother felt empowered by the experience of working with the iwi and wants to continue with the extra support programme. ● Although the mother is Pakeha, she felt that when it was realised her daughter is Maori, she received assistance where eligible.
Equality / Access	<ul style="list-style-type: none"> ● The mother and child live away from extended whanau support. ● The mother is a student in a tertiary institution and finds her budget cannot stretch to continue her child on the programme. The mother felt left out of school discussions.

Analysis Te Whanau o Daniel

Twelve-year old Daniel is the oldest boy of a whanau in which his Maori mother has left her two sons and one daughter in the care of their Pakeha father David, and Jacob their grandfather, aged 72, who is a superannuitant. Daniel made slow progress in reading and maths in his mainstream primary school education and, along with his sister Ruth, was receiving assistance from the local iwi, to access alternative after-school support. The whanau has minimal knowledge of the children's Maori heritage but as the children were registered as members of the iwi, they were eligible for extra literacy support from a commercial learning support service.

Principles	Te Whanau o Daniel
Partnership	<ul style="list-style-type: none"> ● Whanau involvement with the iwi runanga developed a workable partnership. ● There is evidence of partnership between the iwi and the private training provider.
Participation	<ul style="list-style-type: none"> ● The whanau felt involved in the intervention, and happy with the levels of participation they experienced from pre-assessment to intervention programme facilities.
Protection	<ul style="list-style-type: none"> ● The whanau felt secure in the efforts of the iwi and the private literacy service provider. ● The whanau felt very safe that they had their children participate in the intervention programme.
Empowerment	<ul style="list-style-type: none"> ● The whanau felt empowered by the clear links to the programme that addressed the child's need.
Equity/Access	<ul style="list-style-type: none"> ● Māori are over-represented in low literacy levels. ● Intervention programmes are few and far between.

Analysis Te Whanau o Kowhai

Four-year-old Kowhai lives in primitive conditions on remote whanau land. Kowhai is bilingual and received early childhood schooling from the Correspondence School. She is eligible for special education services because of the remote location of her whanau. Kowhai was not enrolled as special needs which requires regular verification to keep enrolled. Kowhai's whanau has made a choice to live on the turangawaewae, their ancestral lands, and like other Maori children in similar circumstances she is without access to early childhood education. Lack of early education has been shown to make a difference to later learning, and therefore Kowhai has a special educational need. TCS supports the mother Mamaku as Kowhai's supervisor and first teacher. Resources in te reo Maori have been made available, and other whanau are now accessing the service.

Principles	Te Whanau o Kowhai
Partnership	<ul style="list-style-type: none"> ● The whanau has a written contract with TCS which both refer to as a partnership.
Participation	<ul style="list-style-type: none"> ● TCS enables participation in early childhood education for whanau living remotely. ● The extended whanau actively supports participation with TCS and word of mouth within the whanau has resulted in more Maori children enrolling with TCS.
Protection	<ul style="list-style-type: none"> ● A kaumatua advised the whanau to start correspondence learning. ● The TCS contract ensures accountability between the whanau and the service. ● The whanau has chosen to live on hapu land that is the turangawaewae from which they are safe to participate.
Empowerment	<ul style="list-style-type: none"> ● The mother feels empowered as parent and teacher to her children. ● TCS supplies resources in te reo and English.
Equity/Access	<ul style="list-style-type: none"> ● Maori are under-represented on TCS ECS rolls. ● Access to information about the service is haphazard. ● The whanau is satisfied with their own access to the service and appreciate one-to-one tutoring from Kaitiaki and the resources in te reo Maori.

CONCLUSION

Kaupapa Maori research processes opened the door to these stories and the lessons they hold for all of us. The principles derived from the Treaty guided the development of the research and enabled whanau to participate in a way that acknowledged them as the centre of the research. Whanau have indicated that this process worked well for them and the stories show that where due regard for the Treaty and the principles is in evidence, whanau can access and appreciate the resources and services to support them with their special needs children.

One of the major trends showing in all of the stories was the difficulty whanau face trying to find and access help and support, including specialist services and appropriate specialist or mainstreamed schooling. Whanau often lack information. Those living away from their home area without the help of extended whanau also face a much steeper challenge to respond to the needs of their own children. Whanau with tangata whenua status in a given area found it easier to access support networks and services than whanau who were from another area originally. This suggests that the strength of the whanau lies not only in emotional support, but also in information-sharing, encouragement, and practical help.

The special needs of children and their whanau in isolated rural communities are exacerbated when the whanau feels isolated from their community even where they are tangata whenua because they have a special child who is “not normal”. Matauranga Motuhake shows the importance for children and whanau of their acceptance by the schools and community where they are not the butt of pity or embarrassment, but are fully accepted and honoured as unique individuals who have much to offer to those around them.

When whanau have access to services and support that enable their children to experience education on a par with other children, an equitable solution has been reached.

Solutions to the problems of special educational needs for Maori whanau are often hard to come by. But the positive stories presented here of whanau who have met some of their needs with the help of services, schools, and support agencies suggest that there *are* solutions for whanau with special children.

The themes emerging from the research show aspects of kaupapa Maori in the strength of whanau, the importance of whakawhanaungatanga and respect, the frustration of whanau who have neither, the support of manaakitanga, and the spiritual values that can strengthen persistence in the face of ongoing challenges.

Recommendations from Whanau

All whanau were faced with the questions of what to do, where to go, and how to get help. It was generally felt that it would be useful to have information on available support and resources more readily available, local doctors were more often than not the first point of call for help and advice. However, it appears anecdotally that some whanau were not aware that doctors' visits for children up to 6 years of age are free. This information could make a positive difference for whanau.

While most of the whanau in the study were not actively involved in their local marae, most with tangata whenua status were linked loosely to marae through their extended whanau. Information available at marae about the existence of national 0800 numbers that give access to information on special needs or about the range of early childhood intervention and education services would be useful and likely to reach whanau through their extended whanau.

Several whanau thought that services should link Maori whanau, particularly those who have moved into an area, with other local whanau experiencing the same or similar special needs. In this way their concerns could be shared, and advice sought from those with a greater knowledge or awareness.

Whanau suggested that a section in the local telephone directory listing services generically, e.g. physical disabilities support, health services, or help with behaviour and learning problems, would be helpful, especially those with Maori-specific services which follow Maori kaupapa and tikanga. At present, services have a range of names, not always known to whanau, and Maori titled services are spread throughout the directories. Many whanau said that once they knew the name of a service, it was easier for them to access it.

The need for services to be informed of the nature of Maori whanau and tikanga was a common thread through the case studies, and where services and schools have this awareness and/or use Maori staff to deliver support, whanau were unanimously positive and appreciative.

All whanau, schools and services were willing to be involved in the hope that their stories would reach other Maori whanau and schools with special needs children and let them know that they are not alone and that the sharing of these stories is both a support and a challenge.

ABBREVIATIONS

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
CCS	formerly Crippled Children's Society, now CCS (New Zealand) Inc.
CYFS	Children, Youth and Family Services
CYPFS	Children, Young People and Family Services
ECE	Early Childhood Education
ECS	Early Childhood Service of The Correspondence School
IEP	Individual Education Plans
KDEC	Kelston Deaf Education Centre
KKM	Kura Kaupapa Maori
MOE	Ministry of Education
NICU	Neonatal Intensive Care Unit
NZCER	New Zealand Council for Educational Research
NZEI	New Zealand Educational Institute
ORS	Ongoing Resourcing Scheme (name changed in 2000 to OTRS)
OTRS	Ongoing and Transitional Resourcing Scheme
RTL	Resource Teacher: Learning and Behaviour
SBI	Severe Behaviour Initiative
SCBU	Special Care Baby Unit
SE2000	Special Education 2000
SES	Specialist Education Services
SLI	Speech Language Initiative
TCS	The Correspondence School
TPK	Te Puni Kokiri
WINZ	Work and Income New Zealand

LIST OF MAORI WORDS AND PHRASES

aroha	personal regard and respect, love
arohanui	intense love and concern
awhi	support/special care
awhitanga	The provision of support/special care
haka	a set chant and actions usually signifying preparation for conflict
hapu	sub-tribe
harakeke	New Zealand flax
hariru	shake hands
hauora	health
hoha	impatient or wearied
hongiri	greeting by pressing noses
hui	meeting, gathering
iwi	tribe
kai	food
kaiako	teacher
kaiarahi i te reo	Māori language assistant
kaiawhina	assistant to the teacher
kaiawhina matua	first assistant teacher
kairangahau	researcher
kairangahau awhina	research assistant
kaitiaki	trustee, guardian
kaiwhakahaere	organiser, coordinator
kanohi ki te kanohi	face to face, eye to eye
kapahaka	posture dance and music
karakia	prayer
kaumatua	elder
kaupapa	agenda, philosophy
kawa	protocol
kia ora	(greeting) hello
kina	sea egg
koha	gift, contribution, donation
kohanga reo	language nest (Kaupapa Maori pre-school)

kohere	cake
korero	talk
koro	grandfather
kotahitanga	life, unity, movement
kaumatua	elder
kuia	female elder
kura	school
kura kaupapa	schools based on Maori kaupapa
kura matua	parents of the school children
mahi	works, acts
mana	personal prestige or self-worth
manaaki	show respect or kindness or entertain
manaakitanga	caring and giving, hospitality
manuhiri	visitor, guest
marae	meeting place, space in front of wharenui
matakite	seer or vision
matauranga	knowledge, education
matua	parent
mihi	speech, tribute
mihimihi	frequentative of mihi
mokopuna	grandchild(ren)
motuhake	special, distinct
Pakeha	European New Zealander
pakeke	adult, grown up often used as advisor
piupiu	grass skirt like garment worn at the
waist	
pohara	poor
poi	ball on short string used in dance
poutama	tukutuku panel illustrating life stages of learning
powhiri	welcome
pukenga	someone skilled in; repository of knowledge
puku	stomach
putiputi	flower
rangahau	seek or search out, also research
reo	language
runanga	council
taha Maori	Maori side

taiaha	actions involving the use of a wooden fighting staff
Tanemahuta	Atua(god). of the forest
tangata whenua	people of the land
taonga	treasure
tauwiwi	people from elsewhere
tautoko	support
teina	younger sibling
te taha tinana	the physical domain of person
te taha wairua	the spiritual domain of person
te taha whanau	the family domain of person
te taha hinengaro	the mental domain of person
tiakitanga	watching or guarding
tikanga	ethics, belief, custom, law
tino rangitiratanga	power, chieftainship, authority
tipuna	ancestor
tohunga	priest
tuakana	older sibling or teacher
tukutuku	woven panel in wharenui
turangawaewae	a place to stand, land
waiata	song
wairua	spirit
waka	canoe, also indicating ancestry
wananga	school, learning
whaea	aunty
whakama	ashamed or embarrassed
whakamaramatanga	to make light or clear
whakapakehatanga	Pakeha/English version
whakapapa	ancestry, lineage
whakatauki	proverb, saying
whakatika	put right
whakawhanaungatanga	causing connectedness, interactive relationships
whanau	family (extended)
whanaungatanga	relationships, kinship
whangai	adopted out
whare kura	school house
whare wananga	school/house of learning
wharenui	meeting house
whenua	land

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APPENDIX 1



Matauranga Motuhake

“Tena koutou katoa nga whanau whanui o te motu, no te Taitokerau tai atu ki Rakiura. Haere atu ra nga aitua kua hingahinga i runga i nga marae, me nga hapu o ia rohe o ia rohe haere atu ra ki nga kainga tuturu o nga matua tupuna kua whetu rangitia haere atu ra ki tua o te arai takoto mai ra koutou i waenganui i te kopu o te whenua. Na reira e nga mana e nga reo e nga karangatangamaha o te motu tena koutou tena koutou tena koutou katoa.”

*Nau i whatu te kakahu he taniko taku
The cloak is woven before the ornamental border is added*

Greetings, this letter has been given to you to give you information about a research project called Matauranga Motuhake. The project is looking at a series of case studies from all around New Zealand that tell the story of Maori children with special needs from the point of view of their whanau. The stories will be published in a report that tells how Maori whanau, some with the help of special services, are looking after their own children in a positive way.

All of the case studies will be confidential or anonymous, with changes to the story including the name of the child/children and the whanau so that readers can not identify the child or the whanau.

You have been given this letter because the story of your whanau and your child / children would be of much interest to many people. If you were interested to be a part of our research it would involve an interview either at your home or somewhere nearby. You could look at the questions before the interview when we talk about your whanau and your child or children and any support you have. This would take up to 2 hours and you would be sent a draft of the story or case study to read over and make changes as you see fit.

I have enclosed information about the research project case studies and a form that shows you are interested to offer your story for the research.

Margaret A Wilkie
KAIRANGAHAU/RESEARCHER

**APPENDIX 2
CONSENT FORM**



MATAURANGA MOTUHAKE CONSENT FORM

Name: _____

Postal Address: _____

Contact Phone: _____

Child name: _____ **Age:** _____

Name to use in the published story: _____

Kairangahau for the story: _____

Case Study featuring: _____

I understand this consent form is my agreement to tell our story for the Special Education for Maori research project. I agree for this story to be used in publications from the research.

I understand that our personal information is 100% private and that at any time I can withdraw from this research.

Signed: _____ **Dated:** _____

APPENDIX 3

Questions for Whanau



- 1.** A general question – what do you know or how do you see special needs for Maori?
- 2.** How were the special needs for your child first recognised?
- 3.** Where does the child fit in the whanau? (Who has looked after or is now looking after the child?)
- 4.** Who lives with the child (story of who is in the house usually)?
- 5.** Are there other special needs in the whanau ? If yes please tell me.
- 6.** Can you share the story of the child and whanau (about the special need)? How did the child get to the place or situation they are in now ?
- 7.** What services are or were available to your child or whanau?
- 8.** Can you tell us about the support (tautoko) for the child from people, services, or schools. Please tell us about the past and the present negative and/or positive experiences)
- 9.** Did the support or service help you feel comfortable or safe, in good hands (manaaki)?
- 10.** Was it easy to find and get into the support and services for your child and whanau? Did anyone help you – if yes please name.
- 11.** Where do you live (describe- rural, urban or city)? Tangata whenua or tauiwi?)
- 12.** Do you (whanau or child) korero in te reo Maori?
- 13.** Is the hapu of the child/whanau known? If yes name.
- 14.** What iwi does the child or whanau belong to?
- 15.** Is there anything else you would like to say?
- 16.** What are the names we can use for the child and whanau in the story for other people to read?

Thank you for sharing your story and thoughts with us.

Appendix 4

Matauranga Motuhake Wharenui Framework



The logo was created for Matauranga Motuhake by 30 year old Steve. It represents graphically the kaupapa of the research process. Steve has special educational needs and this year was classified as dyslexic. Spending most of his life illiterate, Steve's problem solving skills are well developed and he enthusiastically offered his solution to the need for a project logo.

Each person is invited to consider their own response to and interpretation of the logo which aims to show the child of Maori and other bloodlines protected within the shelter of a range of kaupapa Maori supports represented by the wharenui. The roof of the wharenui is not entirely complete just as structures in support of Maori children and their whanau are not complete. The rising sun offers new hope in a Maori response to the issues of special educational needs.

The Wharenui Model of the research

Koruru: Kaupapa Maori is the centre of the Matauranga Motuhake framework, and as such heads the project. It is traditionally offering a warning and a challenge for all that see it. Descending from the head are the two arms which are the frames whanau, hapu and iwi and of the statistical data available from government and research literature.

Amo Amo: The two standing amo amo show importance and significance to the wharenui, as frames for the research. On one side the Treaty of Waitangi and the other side the government policies and funding for special educational needs.

Paepae: Under the shelter of the wharenui is the paepae, an important place for tangata whenua to be part of whaikorero. The research questions and process of korero with whanau have a protected place of safety within a clear structure.

The wananga held for the purpose of analysing the Matauranga Motuhake research data was conducted e noho marae, with participants sleeping within the protection of a wharenui.

Matauranga Motuhake offers protection to all participants, the child, and the whanau, the schools and service providers, the rangahau and kairangahau and advisors within the shelter of Kaupapa Maori tikanga.