With the support of whanau we bring you these taonga – stories which are life affirming and positive. They show people, young and old, fulfilling valued roles within their whānau, their hapu, their iwi.

As women support Maori people with disabilities, we spent a long time considering what we should record for this book. We spoke to several people before choosing these stories. They are celebrations of life.

The first story is of Akitai Williams. He was born with multiple disabilities and the doctors’ prognosis was very poor. Akitai went to a pre-school for children with special needs but subsequently has been mainstreamed into an ordinary primary school and is no longer thought of as ‘disabled’. The second story is about Tepiko[[1]](#footnote-1). He fits the image of ‘disabled’ as viewed by Tauiwi culture, and yet is also a valued and contributing person in his community.

As Polytechnic tutors, we facilitate learning for people supporting Maori people with disabilities. Where Tauiwi (non-Māori – the other tribes) are the learner, the depth of cultural differences are often little understood, and we constantly grapple with what needs to be known to ensure Māori people with disabilities have their culture affirmed wherever they may live.

We hope these stories help Māori hold fast to their heritage, and help Tauiwi come to terms with cultural difference and work out their place in ensuring valued roles for all Māori with disabilities. We hope these stories enlighten and inform and touch the hearts of Māori and Tauiwi alike.

Tauiwi reading these stories must take a leap sideways, for this reality is not their reality.

**Note:** There is a glossary of Maori words at the end of the chapter.

**Akitai Williams’ story, as told by his parents, Tom and Molly Williams**

**The Land and the Tribe**

*Tom:*  Our tribe is Ngatiawa; our hapu is Taiwhakaea, our old people originated from up north. My great grandfather, Akitai, that is his name, that’s where he originated from. On our great, great grandfather’s side is from up North. Our great, great, grandmother, she was Ngatiawa.

This land, it’s all part of Ngatiawa confiscated land, but Akitai married Matihura Te Puni from the East Coast. She had heaps of money so her father, Harawira, he came down from the coast and bought this 100 acres. I suppose you can say that this part of the Ngatiawa block is one of the first that ever came back to the Ngatiawa people, although it had to be bought back by our family. It’s been with us ever since.

Our place had been leased out 21 years when the old people died, the old man and my auntie. Māori Affairs took it over and they leased it for 21 years. Of course I tried to buy it back but I never had the money, but the lessee let us go back there to build or do what we want. That’s how we came back to Wainui. I thought, well, we’re not going to let the land go again. We just left our work and came back here.

It was round those times that Akitai was born. I don’t really understand why we moved from town to the country, but when we did make them move a lot of good things started happening. We came to the church and the wairuas of our old people were showing themselves at different times. We had to find out why they were doing that, and well Akitai was more or less brought up in that environment. He’s one child that knows all about the taha wairua.

**Akitai’s Birth and Leaving work**

Akiati is our youngest child. He is seven now. When he was born, he was born a cripple, with his legs folded underneath him. There was a lot of other things that were wrong with him. His diaphragm inside his stomach was split and his stomach went all up into his chest. It was pushing up against his lungs, he couldn’t breathe. Molly had to take him to Auckland for that one – she stayed up there three months, and all the time church was going, asking God to help Akitai through this crisis.

Ourselves, we just had to stay home. I had to finish work because we needed a car 24 hours a day, because he also had asthma at the same time, and eczema. We had four sicknesses with Akitai all in the one go, right from the beginning.

I look back now on when I was working, well both of us working, earning something like $ 1000 a week. Yeah, and I look back now and think for what, for nothing really. Going nowhere in particular. It wasn’t until he was born and things started happening, changing, changing. Gave everyone a shake up. We just stayed home and did the best we could for Akitai. I think we found more enjoyment in having church and watching Akitai get better than going out and enjoying doing whatever we wanted to do.

I say I’m glad there is no job and no money. We’ve tried that. We’ve made money our God you know. As long as I can remember I was earning big money, huge money, but where was it going to? Take our marae, Taiwhakaea. When there was a lot of money we never bothered to go back there. Now there is nothing, everyone is going home and they are looking for something. I feel that is what it is, they are looking for God.

I think it’s been good for Akitai to be brought up in this environment. There’s no TV, no anything like that. He doesn’t worry about it unless we go down town and he watches TV, but one day away and he wants to come home. Well I look at it, there’s not much to come home to, but he wants to come home. I think it was a move on our part, or a move on our old people’s part. I think more and more of our old people, they really brought us back up.

**His Sickness and Healing**

When the operation on his diaphragm was complete it was a success but he was still as crippled as ever. We took him to a doctor. They put a brace between his legs, a steel brace, and put bandages on to keep his legs apart. But through all the two or three days he had them on, he was suffering. So, I said to my wife that I think these things should come off. They weren’t helping the child in any way at all.

I said to Molly, ‘We’ll go with our korouas down to the Ringatu marae, Te Kanohi o Te Motu and have church’, and that’s actually where our koroua had church for Akitai, for his legs were still folded up. First church at night, and in the morning they had come apart. We stayed with it, with the old people there at the marae. I didn’t know. I thought I was just going to help them cook their kai and wash up, but then I found out, no it wasn’t for that at all, I had to take the church, so oh well, it’s good. It’s a new way of life to what I’ve been used to. We went to Kanohi o Te Motu marae until the old fellow died, and we started taking church back here.

Today you wouldn’t know Akitai was a cripple when he was born.

*Molly:* Dr M got a bit startled. You know he said he was going to be deaf and dumb, and not able to walk. And every time he was told to walk (by the doctor), he wouldn’t, but when we are at home it’s no trouble. He was scared of people with white clothes on.

I couldn’t stay with him at the hospital because I am asthmatic too, so I had to go home to my daughters. He used to cry at night time, no matter what time of the night. The nurses were real good, they were good. They would ring up, and we had to come back.

When we came here to stay, he was asthmatic all the time and we’ve got no power here. He had an asthmatic machine donated to him and we used to run it off our generator. When it was raining too much we had to go over to Ruth’s place to put him on the power, and it was hard to get up her driveway in the pouring rain. The next day we would go to one of my sons so we could have the power. But now he very seldom uses it, just the odd time, otherwise he is as good as gold.

He goes to school and he has two jerseys on, one thick and one thin one. When the teacher tells him to take one off, he says ‘Oh I’ll get cold’ – that’s his asthma. If he gets cold in the chest he gets sick, and if he keeps them on he is hot and doesn’t get sick. We used to have these nebulisers at school, and oh they think he can do it by himself. But he’s got awkward fingers and he can’t do it, so when one of them said to help himself and he unplugged the tubes, it broke. We had to go and buy him some more parts for it and I told them that we don’t really let him do it, and his hands are not good enough. Otherwise he is good.

He’s seven this year. His Nanny Awhi says ‘How old are you Akitai?’ and he says ‘I’ll be seven soon’, and she says ‘We’ll have to have a birthday for you’. He likes to drive our tractor, ride the motorbike, chase the cows. He’s got some nieces and nephews older than him and he’s more advanced than our mokopunas. He corrects them – it’s too much.

*Tom:* But he does all sorts, all sorts. We were down the bottom in the corner and there was a short block of wood just round the corner, ‘cause we didn’t see him and he must have got up there and then he rolled it down the blinking hill, we were down the bottom. You know he could have rolled it the other way out onto the road and hit the blimming cars and, oh, you know he’s just an ordinary kid really.

He likes playing with machinery but if he had a choice between staying on the tractor and going to the marae, he’s gone. He loves his kuias, immaterial of what they do. Whether they growl him or whether they do anything, it doesn’t worry him. Me and Molly can be talking about one of his kuias and he’ll turn around and say ‘No, she’s not like that’. So I said to Molly, ‘It looks like you and I will have to change our ideas’, of going by scripture and that, you have to love your neighbour and all that, and that’s what it’s all about, that’s what he’s all about.

**Akitai’s taha wairua**

He likes everything Māori, everything to do with the marae – tangihanga, anything to do with the marae, he’s there. If he can get hold of a walking stick, he’s waving it around on the pae. Crikey, for a person his age he shouldn’t even be worried about that. And he goes to waiata with the women and then he goes to sit by the tupapaku and sits there for half an hour or so. I know what he’s doing, he’s trying to take all the things that have happened to that particular person and even to take his wairua, take it with him and take it home, bring it home, so I can see there is something wrong. I have church to clear whatever he’s got and he knows exactly what’s going to happen to the wairua once I’ve had church, it goes straight up. This is all the things he does. It’s terrible at times. He gets that sick at times. It is severe, very severe.
What I will say about Akitai’s sickness is that he takes the anger of people within himself, he gets it and puts it in himself. When he gets home I know there is something there so I have church to clear Akitai of what he picked up.

It keeps me on my toes, otherwise I might say ‘Never mind the church tonight, let’s have a good sleep’. I think too it’s probably a learning for me as well. You’ve got to find the problem, you’ve got to find out what is wrong. Sometimes I ‘m sitting on my chair at night and having a prayer, asking for something to be shown.

He understands that it was the church that helped him, and when other mokopunas get a bit sick, he actually goes to them. He talks in his own way. What he’s saying I’m not sure but I believe he is also trying to have church for them, he’s trying to help them whatever their sickness is. When he comes back home here, he says to me, so and so is sick, and he just looks at me as if to say, ‘Well go on’. This is his understanding. I suppose there was that much church done that he knows exactly what it is and where it is coming from.

You know he understands the church very well – the himene, the panuis and the waiatas of the Ringatu Church, it’s no problem for him to learn it.

We had a big healing session in the weekend and nothing at all happened to him, and yet between the brothers there was a lot of friction and I was waiting for him to go down but he didn’t. He kept singing a song and the only word I could hear was rangimarie, rangimarie, you know. That in itself tells a story, doesn’t it, you know he is telling the boys to go on the light side. One of them called the hui and I agreed and they all came. One, only one was a bit reluctant to talk because he couldn’t understand how you tell a person just what you think he is, how you tell him straight to his face. What he was doing was throwing everything around and not actually getting to the thing inside himself and that’s when the kid started singing ‘rangimarie’. By the time all the family walked away from that hui on Sunday, after the church and all that, there was some of them reckoned they walked this high off the ground.

We can have a church meeting and he’ll never ask a question about why was that done, why did you do that? Never. But if I have to go to town for some reason, he’ll want to know every detail of where I’ve been, what I’ve done, where to the next place…..

I’m not saying that because it’s church he doesn’t want to know. I have the feeling he does know, he knows what Jesus Christ is about. But how does he, a young person like that, go round and start telling people well this is how you’re supposed to do it? Even myself and Molly, we’ve learnt a lot from him just through being with him.

You know all our kids there, all the boys even, they humble themselves to him, even George. As wild as they are, as big as they are, they humble themselves, you can see it, although they may not agree with what I am saying, you can see the humbleness in their eyes, the love for the child, all that sort of things.

Yeah, I suppose he is a leader in his own way, his own fashion. But he has lots of hurdles to get over, personal ones for himself.

**School**

*Molly:* He understands Māori and English. He can talk in Māori. In the school there’s not as much Māori. I’d like him to have more.

*Tom:*  School is something he goes to because we tell him he’s got to go. Otherwise he just wouldn’t be bothered. No doubt he has learned a lot from school but he still can’t understand what people are all about yet. But he is very quick to learn. I ask him a (telephone) number. He keeps it all in his head, and here I am and not having my glasses on, ‘Which one are you looking for. Oh, so and so’.

He’s very clever, this is right. You tell him the name of a person and he’ll remember the name, and we may not go back there for six or seven months and he’ll look for that person and tell you there’s so and so. He sees too many things and he gets confused and they tell him this and he’s not up with it. School is something he doesn’t care for, but anything Māori, well… . Anything at all, to do with the marae, he loves it. All the old people on our pae, if Akitai is there, they’ll give him the walking stick. They know what he is looking for and they just give it to him and he does his thing, you know.

**Akitai Prefers the Pa to School**

Sometimes we may go to the marae, but we may go to George’s for a while before we go up, and when I look around for him when I go to the marae he is already there, inside the wharenui. Probably done his thing, whatever he’s been doing, and what I feel is that he is making it safe for people, you know, that’s what he is doing. He’s asking God in his own way to clear everything from inside the wharenui so that the people can walk in and out no problem, nothing to interfere, you know. These are all the things he does.

I tell you what, our old people were very tapu in those days, the olden days, but this kid here has taught me how to lift it, to lift those tapus up, not as if to throw it away but just leave it on the side so that people won’t get hurt. This is some of the things he’s told me, not verbally, but through his sicknesses.

But I just don’t know how to approach different places to help kids like that because I know a lot of the parents would never agree to that. Because in the beginning the Pākehā people actually said that the Ringatu was talking Satan, was a church of Satan, of witchcraft. I’m afraid they’re very wrong, but the thing is it’s still in the minds of people today, the feeling of, oh gee what’s those fellows going to do? Little do they know that I myself do nothing, it’s God that does it all. The other thing is the church itself is all in Māori and they can’t begin to understand. Little do they know that all we do is ask, just like any other church does, but in a different tongue, that’s all.

I just have a feeling it is time for it to come. You wouldn’t have got me on this thing twelve months ago. I would have said no way, no way. But then I have seen children, Akitai and kids that have never had the help, and their legs are deformed and hands are deformed whereas if they had had the help, they could have been all right today. The Ringatu people are never allowed to ask people, although they know what is happening, they know all the churches can cure it.

And I think to be able to go back to where your old people lived and had church and do what they did in those days, I think is very important. The ones who have sold their land and lost it, then they have lost almost everything. And I think it is said somewhere, our old people have always said it from way back down through the generations, that once you sell your land you’ve got nothing at all.

What they are saying I suppose is that money is not as important as the land your people are on. When I came back I did not know what I was coming back for, but then our mokopunas started seeing our kuia and koroua walking around there, smiling, crying, then I thought, what the hang is going on here? That was something new for me. I was not into that sort of thing before. But when they come and tell me I have to think about it, think what was going on – yes, I think there is something in the land of the old people. See they have church on the land and they leave something there and it holds the land together, and when you come back, when you get onto it, it holds you together. Those things are still there. Of course when you sell it, then you’re selling your tipunas. That’s the way I feel about it. A lot of people would disagree with me.

I feel the belief in the land of the people. Very important. And when you have sold it, there is not much you can do. A lot of the lands were taken. We can say that. Both sides were doing wrong in those days. Fighting was something that shouldn’t have been, but there you are. We can’t correct it, we can’t judge them either, all we can do is try to help this generation.

It’s been that bad people just don’t worry about one another. I remember when I came from Gisborne, and I came back here. I remember my father standing on the side of the hill there and singing down to the people on the road walking along, to come up for a kai, you know. Today, gee, you’re in such a hurry to get nowhere that you don’t worry about those things and you get in your car and you’re off here and off there.

A lot of our mokopunas come home to Wainui, the ones who get up on the streets a bit. Their parents send them up here. And when they go home from here they feel a lot better in themselves, they’re more mature.

I think that we have a chance now that our young people have no work and are coming back to the marae and looking for something. Now we’ve got to do something about it, for our kids, young people, and people like Akitai.

**Tepiko’s story, as told by his uncle**

The kettle’s been boiling ever since you walked in, I think, and he’s been waiting for somebody to tell him to make the tea for the visitors. That’s what he said to me this morning. ‘Pākehā’. I didn’t tell him we were having visitors but he knew straight away when I lit the fire and I got these things out of the cabinet, and he knew straight away we were going to get visitors, so he put the kettle on. Those were Mum’s teachings, you always feed your visitors, how to manaaki, those were Mum’s teachings, and that’s what he was doing as he saw me get these things out of the cabinet. ‘Pākehā’ – if that was just for you, Hine, we would give you a chipped mug!

**Tepiko’s Early Years**

Tepiko was born with the handicap he has now, 41 years ago. We are Tuhoe.

He was brought up by his Mum, my sister, and his Dad for the first two years of his life, then they parted. So another grandmother and grandfather from further up the road brought him up. I think he was about seven when they passed on, so my Mum, his other grandmother, took him over. She taught him everything he knows, right up to the present day.

My father was a hard-working man. He had more or less no time for people like Tepiko, but Mum, she spent all her time with the kids as well as with Tepiko. I wasn’t around then. I had gone to work. My younger brothers and sisters, they were Tepiko’s whanau, plus all the mokopunas. They knew Tepiko, they knew who he was and what he was. They always treated him as a normal person. They grew up with him and looked after him. And Tepiko looked after them. Tepiko helped bring them up from when they were babies. Mum had been educating Tepiko on how to do all these things, how to nurse them, how to look after them, so Tepiko had more or less a hand in seeing my younger brothers and mokopunas grow up.

So as he was growing up there was always that thing between his whanau and his extended family, they were always there. The first whanau he grew up with, they never forget Tepiko even today. They ask ‘How’s Tepiko?’, or if they are up this way they pop in to see him.

I can remember though, when, for Tepiko’s education, they tried to take him to one of those institutions, when he was about nine years old. They took him for two or three months but Mum couldn’t stand the thought of him being away so she went and picked him up and brought him back home. He was thin, very small, underfed. She picked him up because she missed him and she sensed that there was something wrong. Mum took him to the doctor because of the condition he was in. The doctor told her not to send him back, she could do better than the institution by looking after him and educating him. She took the doctor’s advice, so that was the start of Tepiko’s education with Mum and the family. He never went to school and he never went back to any institutions either.

Mum was a good teacher. Even myself, I always came to her and just sat and talked to her because she’s from the old school at Waikaremoana. She was 14 when she moved back there. Mum was brought up in the old school. How to look after people in the old way, that aroha way, was very strong. That whanau thing was very strong with the old people. That’s what kept the family together, and Tepiko.

To me that old system of bringing children up, whanau, that was the old Māori way of doing things. There is always the extended whanau that knows so and so is my so and so. As long as they know who you are, where you are from, and who your pakekes are, they immediately know you are one of the family.

She was brought up by the Ringatu, the kuias and korouas. She was baptised in the Church of England but she was strong in the Ringatu. That was when she was a young girl. They went to the twelfths. They went to the closer ones, to the coast and to local maraes, they didn’t go far. And Mum had her karakia by herself in her house. They had their karakia, her and Tepiko.

Oh he knows about his church, always comes over and says ‘karakia’, puts his hand up. So we sit down and have church, if and when I remember. But he remembers, he doesn’t forget. I’m Ringatu myself. I listened to Mum’s teachings and her ways of looking at things and I always thought to myself, sure, why not?

**The Gardens and the Animals**

Tepiko knows and loves the garden and gardening. I didn’t teach him any of these garden things but we’ve always had gardens ever since Mum and Dad were home on the farm. All of us started gardening and so did Tepiko. Tepiko wasn’t left out of anything. I think Mum had a very strong influence on Tepiko.

I’ve always had a garden in for me and Tepiko. We plough the back up, plough the front up and he knows straight away what is happening. He helps plan potatoes, cabbages, silverbeet, and all the kai you can grow in the garden. He enjoys it because he knows he has something to do. He likes to be busy and he weeds his garden.

Sometimes it is in the one place but that’s okay. It’s better than what I can say about those mokopunas, but you tell him to move along and as soon as he knows that he’s got to do then he goes and does the whole row. And he gets his silverbeet when his silverbeet is ready, gets all his kai, digs up his own potatoes, he goes over to his sister’s house, Pare’s house. I growl the mokopunas over there because they are not doing anything, and Tepiko is in the garden weeding. He knows when the kamokamo is ready, and goes and gets all the kamokamo. I growl him don’t bring too much, as they sit in his fridge and go all yellow. He cooks his kamokamo and he’s got a pot full of kai over there and I growl him, ‘E hoa, don’t cook too much’ – he has chicken and sausages and potatoes and watercress all in one pot – a big boil up.

Another thing that used to surprise me about Tepiko is animals. I can remember one time after we were coming back from my town and around. There was a great big sow at home. Nobody would go near it because she had some young ones. Even Dad couldn’t get near it so they wanted me to go, so I went up with a gun. If it turned on me I would shoot it. Mum yelled at me to leave the gun alone so I went up to this damn pig. This bloody thing took after me and I took off and Tepiko was there watching.

The whole family was trying to get this damn pig to come back to the pen. So Tepiko walked up and we all stopped and stared. He walked up to this great big sow and about 20 little ones and he started driving them back and they followed Tepiko back to the pigpen. Everybody was swearing at these pigs and Tepiko was just walking along. He was always good with animals, any kind of animals. There’s a pony out there and he always talks to it and the darn thing won’t come near me. If I want to catch the pony I get Tepiko to walk up to it because it will come closer to Tepiko than it will to anyone. Mum knew that Tepiko was capable of doing these things.

He speaks only Māori but you can understand him by his actions, if you look closely and watch what he is doing. But I think Tepiko has his own way of communicating to be exact. I don’t think he likes us to talk about him. He gets around, Tepiko. He knows where he’d rather be. He knows what is happening down the road, whether there is a party going on. He’ll tell you exactly who has been with who. I love to hear the stories he can tell. He comes back and tells us so and so went with so and so. He tells you everything. He has a voice.

**Tepiko’s Walkabouts**

Years ago he went on what we call his walkabouts, before Mum died. The first time he ever did that, everybody was around looking for Tepiko and my brothers were going to half kill him. Everybody was ready to throttle Tepiko, but he came back all right. Then he used to go again, for up to a week

We didn’t know, we really didn’t know what it was, but all we knew is when he was gone, he was gone. He went down to the river or down the valley, and most of the time he went to his maraes.

Some of the old kuias there used to see him, and a couple of them rang my mother up and said she was cruel and all those sorts of things, but we all knew where Tepiko was and what was happening so we never took any notice of them. There was always the people that said ‘Oh, he’s all right’. Mostly a majority of the people understood him. The people around here got used to it.

In a Pākehā setting he would not be allowed to roam. They would have put him away. They would have found something in the rules, course they would. We would have been put away for letting him roam, you know, for not caring for him properly! They would have come up with something, jacked a rule up somewhere, said “Right oh, cart these people away’. Yet there were people all around to look after him. Everybody knows what is happening – mind you I’m the last one to know what’s going on, unless Tepiko tells me!

So that was his walkabout and sometimes on his walkabout he sees these things. One time there, the old fellow Heemi got up very early in the morning to get his cows, just across the road. There used to be hives full of honey. Heemi was walking down by the cemetery and he saw this person standing up behind the hives. Heemi reckons his hair just stood straight up and then he turned around, he didn’t run, and whistled and walked slowly back, and then he took off. It was Tepiko.

I think he was inclined to have a partner. He was inclined that way and I don’t blame him. It’s normal. And in his walkabouts he must have met someone, yeah. I just forget who the girl was but he was quite rapt in her, and he kept going back that way. We had a bit of a talk with Mum – maybe he was inclined to want a woman. We didn’t know what to bloody do, but we thought to ourselves, well why not, nothing wrong with that. So he kept going back to this girl down the road, girl or woman, and there must have been a bit of communication down there. We knew there was a thing going on, but we never interfered with it, we let it take its place. Then all of a sudden it stopped. It didn’t do any harm to Tepiko, he just carried on with life as it is.

Tepiko was taking walkabouts right up to the time when Mum died. Since then to now, Tepiko has never gone on his walkabouts. I think it is the responsibility that he has taken on. He knows that Mum’s died. Well he has responsibility to his house, to himself, and to life itself I suppose, whereas before it was Mum.

**Tepiko’s Parents**

I think he would have been about 30 when his father came back here. I suppose he was genuine in his own way about Tepiko so he came back home. He had a bit of a yarn with Mum, and my sister who was back here then, Karen. She had a bit of a soft heart and he wanted to take Tepiko back with him. Karen being Karen said ‘No, no, no’. Somehow he got Mum to agree so he took Tepiko for a holiday.

He was there I think a couple of weeks and Mum found out Tepiko wasn’t coming back. His father had gone to the courts to legalise keeping him, so there was a bit of a war going on. Mum and Karen went and got Tepiko back and you could see how upset he was, how it affected him.

So his father was sorry for what he’d done, because he could see how it affected Tepiko, just yanking him away suddenly. After all the man had only been back a month and he wanted to change the whole world for Tepiko, you know. Still, he was his father. Anyway Mum got Tepiko back and life carried on normally.

Then I found out where his Mum was, had a hell of a job looking for that one. I found her and abused the shit out of her. That was Pare’s Mum too, and I told her about so and so, and why the hell doesn’t she come and visit Tepiko. So anyway she did, but she never did interfere with what Mum was doing with Tepiko. Her thing was Mum brought him up, you people brought him up, he is better off there with you all. I’ll come and visit him sometimes. Tepiko knows his mother, knows her well, but she won’t try and disrupt what the family is doing. So that was good.

Tepiko found out that he had another family, that was on his Mum’s side, her second marriage, and then those kids found out who Tepiko was, that they had a brother older than them. I can remember one brother, Peter, he was down in Napier, and he came back and he found out who Tepiko was. Mum never told them that there was a Tepiko around. He hugged Tepiko and he wanted to take him for a holiday, so that was the introduction.

Of course Tepiko was happy with his other extended family. Every time his sisters and brothers came back they stay with Tepiko, they ring him up when they’re coming and Tepiko knows them. It’s good that they come.

**His Kuia Dies**

When Mum passed away he was very upset. The first time I’ve ever seen him crying tears. Tears were actually coming out of his eyes. He knew she was gone. He’s got an amusing way of saying someone has died. He gestures a finger across his throat and a go-away wave.

So when Mum passed away, well I just took over from Mum with all my sisters. Course Pare coming back to stay here, that’s good, it’s a bit of a load off my problems. Yeah, good to have her around.

The whānau decided Tepiko should stay in the house. It was just sort of a natural thing to leave Tepiko there because we knew he could look after himself and of course I was there to look after him as well. Everyone agreed. The house was there, the house was Tepiko’s and he can look after himself. He’s got all of Mum’s teachings and he could look after himself better than any other person that we knew of could look after themselves. I’ve seen kids, 16, 17 year olds, 20, 21 year olds, that can’t even look after themselves, don’t know how to look after themselves. They’re frightened of all sorts of things. I don’t know what they’re frightened of, but Tepiko is not like that. Tepiko can do all these things, make his bed, vacuum his house, cook, like for instance when he boiled a cup of tea for us.

Shave himself – that’s the only thing he can’t do. So I do that for him, give him a shave. My brother gives him a haircut. Just given him a haircut because we’re going down the line next week, myself, Tepiko and Mum, we going down to this Koromako thing. They’ve got it in Hastings and carry on to my sister’s place, Karen. Tepiko wants to see her.

I shave him once a week, and give him a bath, good soak in the bath. He’s got a skin disorder and I rub him down with ointment, his face and his body. Funny sort of skin disorder, it goes away but if you don’t keep at it, it comes back again and it’s blotchy. I don’t know what it is.

I’ve been so many times to his doctor, John. He knows Tepiko well. He gets his high blood-pressure checked every time he is there. Those are the sort of things I just watch out for every day, well sometimes I forget. John is a Pākehā but he speaks Māori. He speaks Māori to Tepiko all the time, knows Tepiko well.

**Tepiko’s Operation**

A couple of years back I took him to Rotorua, to the Rotorua Hospital, for an eye operation for his cataract. And of course I had to sign everything for him. He knew what was happening and kept pointing to his eye, moving his fingers around for the operation. And of course, being Tepiko, no one there understood hm. I had to stay there for the night and all the people there were running around looking at this big Māori who can only speak Māori to this person, you know. Everybody was coming around peeking in the doorway. There was a couple of old Pākehā, koroua Pākehās, and they couldn’t get over it, a person like me communicating with Tepiko and everything I said Tepiko understood. They just couldn’t get over it and they kept asking me questions and I said, ‘Well, you know this is our way, how we look after our people’. ‘Does he understand everything you say?’ and I said ‘yes, but in Maori. If you people speak Māori you can do the same thing’. And I said he lives by himself and they couldn’t get over it.

We stayed there you know, and the next day I had to be there to talk to the doctors for Tepiko. With his high blood pressure they couldn’t put him to sleep for his operation – no general anaesthetic. So I had to go into the theatre with the nurse and those people who cut you up. I had to go to the theatre and they put me into these gowns and couldn’t fit me, so they had to run around. We got into the theatre, got everything all ready, all these clean looking sheets and gloves. Tepiko was lying there on the table, eyes staring up, wide open. He was still awake, just a local anaesthetic.

I am right next to the surgeon and I’m doing the talking, trying to comfort Tepiko, to keep his eyes open, not to roll his eyes around and all that. The surgeon had to go in and cut the film off Tepiko’s eyes.

That’s the first time I believe it’s been done in the hospital with someone like me coming in for support right through the whole operation. He could handle it, he felt safe, because I was there with him, he could hear my voice, to comfort him, to talk to him. That was an experience for the staff of the hospital, to realise that they couldn’t do anything without me being there, without whānau.

Quite a few of the whānau help. Even the first whanau that Tepiko lived with have always communicated with our family about how he is doing, or they come and pick Tepiko up to take him to visit their whānau. They all communicate about Tepiko so there is no chance of him going around without anybody knowing who he is and watching out for his welfare.

**Tepiko’s Other Whānau**

Tepiko was brought up with Mere – that’s Mum’s mokopuna. She’s always had the welfare of Tepiko at heart. One time there she came up here for a holiday. She always comes back home for holidays. Tepiko gets hoha with them sometimes. Yeah, he gets hoha with my sisters, he gets hoha with Mere. I think he’s grown up, he doesn’t want to be treated like somebody that has to be looked after. He’s very independent, so he says ‘Hoha, hoha’.

But Mere insisted on taking him for a holiday, you see, and I said to her he won’t last long. He’ll come straight back home. ‘No, he’ll be all right with us.’ And I said, ‘Take him’. So they flew down and I knew he wouldn’t last. He went on the plane, away they went, and the next day I got a phone call from Mere, ‘This you-know-what wants to come home’, and I said ‘I told you, and no, I won’t send you any money, you pay for it’. It’s Tepiko’s own money, you see. He pays his own way all right. He was upset, he wanted to come straight back, and that was it.

He wants to be treated like an adult. I growl him, you know. I don’t try to teach him like how Mum does, I just carry on like Mum has left him. I growl him like an adult, tell him off like an adult and make him do things like an adult.

Tepiko is his own person. He used to travel with Mum before. Now he goes to visit his whānau. His cousin meets him, puts him back on the plane. I just load him up on the plane. They’re quite good, those people, there’s somebody at the other end to pick him up to meet him, no problems, at the airport. I can remember one time he was talking to an air hostess. Tepiko speaks and understands Māori and tries to communicate, and she knows he was trying to say something to her but she couldn’t understand it. She apologised, ‘Oh look, I’m sorry, I couldn’t understand. He’s such a lovely person’.

He flies down to Palmerston North too. I can remember this day we took him down to my sisters, took him in the car that time. We left him there while we came out to see out kids. In the meantime, Tepiko stayed with the auntie. She was doing some concreting and Tepiko helped in his own time and at his own pace. The sister rung me up and said he’d had a bit of an accident, the wheelbarrow took off balance. Instead of letting go he hung on top of it, and he slowly tipped over with it. There was a bit of a bruise but he was all right.

But that was Christmas, and just last week he had done something wrong out there and I growled him. Immediately he lifted his shirt up and showed me but there was nothing there, and I said, ‘What’s the matter?’, and he was saying ‘wheelbarrow’ in Māori. He was trying to cover up for what he had done wrong. Every time I growl him he talks about somebody else – but it doesn’t take him long, and in the end he’ll tell you the truth because he can’t keep it up. He has a good sense of humour. We have our arguments. We argue. Then he tried to cover it up by telling me something.

But sometimes he gets really upset. You can tell by his actions. He starts shaking his head, his mouth wide open, sounds coming out everywhere.

Tepiko finds his own watercress, and the amusing part is that I send my mokopunas to get it and they come down on their horses and come back saying, ‘Koro, there is nothing’. I say ‘Go over to Tepiko and he’ll take you down to get the watercress’. and I come over here and there’s Tepiko with a big bunch of watercress and he goes like this (handing it over) and I say ‘This for me, Tepiko?’ and he says ‘Yes’, and I take his watercress off him and leave him on his own. That’s how independent he is. He knows where everything grows.

We take him to town to shop. And the girls come over. They’re always coming over, to pick him up and take him to a party. He loves parties, he loves his beer. That’s another thing. He tells me all about these parties and he tells me all what happens.

He goes over to the pa, sweeps the floor, and if there’s anything going on he gives you the sign to leave him there, so what can you do? He’s all right, there’s always people, somebody there to look after him. They’ll put him to bed in the morning.

There was a whānau wedding the other day. It was a good night for Tepiko. He’s got a niece there, Serena. They got up to dance and Tepiko thoroughly enjoyed himself. His mouth was hanging open and he was bent over and doing all sorts and drinking at the same time, so he was really enjoying it, with his best new clothes on. So we all came back and left him with Richard and Tame. Richard said, ‘Leave him behind, we’ll bring him back’. They never got around to bringing him back, so we went to pick up Tepiko the next day and he was a bit worse for wear but he enjoyed himself.

I had Tepiko for tea last night. I rang him, ‘Eh Tepiko’, in Māori, ‘come up for tea’. I make him walk and I say, ‘Leave your dog behind’, so he walks up. I used to growl at people for picking him up, because every time he comes up they know straight away he’s coming up to me. I say ‘Leave him along, let him walk up, have his exercise, it’s getting warmer now’. He loves it. Sometimes I ring up and there’s a definite ‘No’ on the phone, so I just leave him. I think he must have his kai all ready.

He’s had visitors from Auckland, my nephews, street kids. They always get used to Tepiko and they always make sure he’s fed, and if they come back the second time to the pa they always ask ‘Oh, where’s Tepiko?’ I’m the one who forgets, and they ask ‘Uncle, where’s Tepiko?’ ‘Oh shit, he’s at home.’ So they get on the phone and ring him up. He answers the phone, gives a couple of grunts and I tell him ‘Walk over’, so he comes.

**Whanaungatanga**

For me it’s matemateanga, I mean when people in the extended families look after each other and love each other. If they see anything wrong, there’s always somebody from that extended family that looks after them, or if they see anything happening, they say, ‘Oh, give me that moko, I’ll look after him’. It’s a natural thing. Those were the things that were very natural. I used to remember that quite well with koroua, kuia used to look after their mokopunas, no matter whose mokopunas it is, and they call it the matemateao.

They grew up together years ago, and they say, ‘We’ll go and get that mokopuna’. When Mum took Tepiko over it was the same. There was a kuia before Mum and she passed on. There is always someone to take over. Maybe that’s what it is. For some others it is no longer the same. They’re so scattered and the aroha, that matemateao, is not there any more.

Where all the old people have passed on, it’s the young people now. They have to be got together to come as a whānau again and talk to them about these things. They have to come back together again. Quite a few of the young people now are looking at their roots, coming back to the land where their tipunas were originally from, and it becomes strong again.

Every time Tepiko goes back to bed at night, he turns the photos down. He just lies them flat on the mantelpiece. When he goes to bed, so do the photos of his kuia, his koro, his cousins, his aunties, Just a thing to him I suppose. It’s night time, time to go to sleep, so people everywhere are going to sleep, even the ones in the photos.

At first I wondered why this fellow is doing this, then I thought he’s gone to bed so other people go to sleep too. We thought it a bit of a joke, but we realise that he is quite serious because he does it all the time, you know. Sometimes he forgets to stand the photos up, to wake them up, so I tell him, ‘What’s the matter? Don’t they wake up today?’, but he just gives me a bit of a stare, then I go and stand them up, wake them up, put them back in their places. The people are very important to him because they are part of his whānau that he grew up with, and he knows they’ve passed on and he knows that some of them are still alive but he still puts them all to sleep in any case.

The land is important too, but it’s the human factor, whanaungatanga, the people coming back together. These gangs – people, families are torn apart because they don’t realise what they are doing by going to these gangs. Their whanaungatanga, their aroha, is lost, is lost. People here are starting to move back to the land. People I don’t know, I’ve never dreamed of, but until I know the background, oh you’re so and so’s kid and I immediately related myself through the people who have passed on, then I come back and I gradually work myself down to these people and bring them over to me, I’ll look after them. ‘Leave him alone, he’s so and so’s kid’.

The land is important to Tepiko. Especially that house itself where the land is. Just recently I asked Tepiko would he like to come up here to stay with me, to live with me, and he shook his head and he started pointing to the land, and he shook his head. ‘No’. And that’s it, that’s all right. I stopped.

I’ve had this in my mind for a long time, you know. I get this aroha thing, but he’s all right. It’s me that’s got the problem. I’ve got the problem, not Tepiko. He’s quite happy! There is a lot of influence of his tipunas. He knows who he is, he knows where he’s from, where his tipunas are. He knew why he was there, he knew what he wanted to do. And he pointed to the land.

**Choosing the Stories**

We chose these stories for this book because they are life affirming, joyous and grounded in Māori culture. But, sadly, we must also acknowledge that such stories are exceptional. Their reality is not the reality for many Māori people with disabilities. Not all lead values lives, not all are mebraced by their whānau, or even aware of wairua.

What conclusions can we draw from these stories that will help us, Māori and Tauiwi, learn just how we can best support Māori people with disabilities?

These stories show Māori culture and traditions remaining strong with three important dimensions – whānau, whenua and wairua – intact. And significantly, we believe, te reo – the language – is strong. This is the basis of culture, for language brings a way of viewing the world, of describing reality.

For many Māori families this is no longer their reality. The reasons lie in the history and present day policies which have affected the whole of Māoridom. The dishonouring of the Treaty, the loss of land and economic base, the loss of language, the move to the cities; all these have put enormous difficulties in the way of retaining the culture.

In spite of the history, and present day policies, there is now a resurgence of language and cultural practices, a new vitality evident in every tribe. This needs to flow on to services for Māori people with disabilities which have in the past removed them from whānau to institutions far from home.

Yet today, even services close to home rarely acknowledge Māori culture. The influence of wairua and the importance of te reo are denied, and links with whānau allowed to lapse. The choice for many families is to opt into Pākehā-style services or to do without.

We hope that these stories have revealed the depth of cultural difference to readers. We cannot expect Tauiwi to learn all that is necessary to affirm whānau and wairua, to work in a positive way with Māori people with disabilities. Yet Tauiwi can support Māori by developing positive attitudes, recognising cultural needs, ensuring Māori values are given recognition. These are the attitudes and values that enhance cultural safety, a concept developed in the field of nursing, but one that applies equally to work with Māori people with disabilities.

Cultural safety means the right to have your culture validated, cultural practices, beliefs, values and priorities respected, adhered to and taken into account when decisions are made. Cultural safety is based on attitude change. If safe attitudes are held by Tauiwi in the field of disability, they will be able to work with the continuum of Māori people, from traditional practitioners of the culture to those who have been denied any information about their Māoritanga.

We remain convinced that, wherever possible, and wherever Māori people with disabilities and their whānau wish it, Māori should work with Māori people with disabilities. Yet the reality is otherwise, and until new services are developed, Tauiwi will support Māori people with disabilities for a long time to come. It is vital that these Tauiwi are culturally safe in their attitudes and practices.

Ultimately we believe that for major improvements to the lives of people with disabilities, two things need to happen:

* Māori need to be enabled to develop their own services. This is tino rangatiratanga. There are now a few residential homes run by Māori for Māori and this is encouraging. Māori people are developing their own ways of doing things for their own people. Tauiwi can help this happen, by ensuring the resources are made available to such groups.
* The honouring of the Treaty throughout Aotearoa is ultimately the most important move for Māori people with disabilities, as for all Māori. Through that, whānau, whenua and wairua can remain strong or regain their strength.
* Māori people as a whole are working to retain their language and land, to strengthen whānau, and to develop an economic base. We hope and pray that these moves will ensure that there are more life-affirming and joyous stories to be written in the decades ahead.

**Glossary**

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| --- | --- | --- | --- | --- |
| aroha | love |  | matemateao | signs of great affection, expressions of great aroha |
| himene | hymn |  | mokopuna | grandchild |
| hoa | friend |  | pakeke | older person, older generation |
| hoha | bored |  | panui | notice |
| hui | meeting |  | rangimarie | peace |
| kai | food |  | Ringatu | a faith founded by the prophet Te Kooti |
| karakia | the prayers addressed to God; they affirm the sacredness of a person |  | Taha Wairua | the spiritual aspect |
| kuia | elderly woman |  | tangihanga | funeral, ceremony of mourning the dead |
| koroua | elderly man |  | tapu | sacred |
| manaaki | to care for, hospitality |  | tipuna | ancestor |
| marae | traditional meeting place |  | twelfths | religious occasions of the Ringatu church |
| matemateanga | a succession of deaths, times of great sorrow |  | whānauwhanaungatanga | the extended family or group that supports the individual through crisis or anything else of consequence. A basic belief of the Māori is to expose a child to his or her kinship groups as soon as possible and through the whole of his or her lifetime. |

1. In this second story all the names have been changed to protect the privacy of people involved. [↑](#footnote-ref-1)