

Growing up kāpo (blind/vision impaired) Māori: Whānau narratives of their encounters with health and education services.

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Impetus for current study

Higgins, N., Phillips, H., Cowan, C., Tikao, K., & Wakefield, B. (2010). *Growing up kāpo Māori: Whānau, identity, cultural well-being and health: Final Report*. Dunedin: Donald Beasley Institute & Hastings: Ngāti Kāpo o Aotearoa, Inc.

- Historically, RNZFB and BLENNZ service provision has revolved around the individual and the individual's impairment, rather than considering kāpo Māori in a holistic manner or as being culturally situated as part of whānau, hapū and iwi.
- Some kāpo Māori in this study did not have easy access to a visual diagnosis and assessment
- Blind and Low Vision Education Network NZ (BLENNZ) did not have complete overall information about, including the causes of vision impairment, Māori children on its roll.

Our Research Questions

1. What are the barriers to accessing ophthalmological services and a visual diagnosis for kāpo Maori children and their whānau?
2. What are the general demographics of kāpo Māori children?
3. What are the causes of vision impairment in kāpo Māori children?

Other Relevant Research

There are only a few studies that examine the experiences of disabled Māori and the impact of their interactions and 'non-interactions' with health and education services (Bevan & Brown, 1989, 2003, 2004; Collins & Hickey, 2006; Smiler, 2006;).

Kingi and Bray (2000) attempted to identify appropriate support and services to disabled Māori and their whānau but found that most of their participants were mistrustful and cynical of the health system, and that accessing services was difficult.

They found that the whānau was integral to the provision of health services as other scholars have also written.

(Durie, 1997; Macfarlane, 2003; Nikora et al, 2004; 2004; Wilkie et al, 2001)

Methodology

Two year project funded by the Health Research Council

Maori ways of knowing and doing were privileged in this project.

Māori and Pakeha researchers from multiple perspectives will work together, through a research management committee from Ngāti Kāpo o Aotearoa, to plan, interpret, and disseminate the results of this research.

Positioned as a Māori development project.

Cresswell and Miller's (2000) (Bishop, R., 1996; Cresswell & Miller, 2000; Health Research Council, 2004; Pipi et al, 2004; Smith, 1999)

Mixed Method

Quantitative data: demographic and vision questionnaire for whanau of kāpo tamariki (children) and rangatahi (youth) developed through research team hui and with Research Management Team

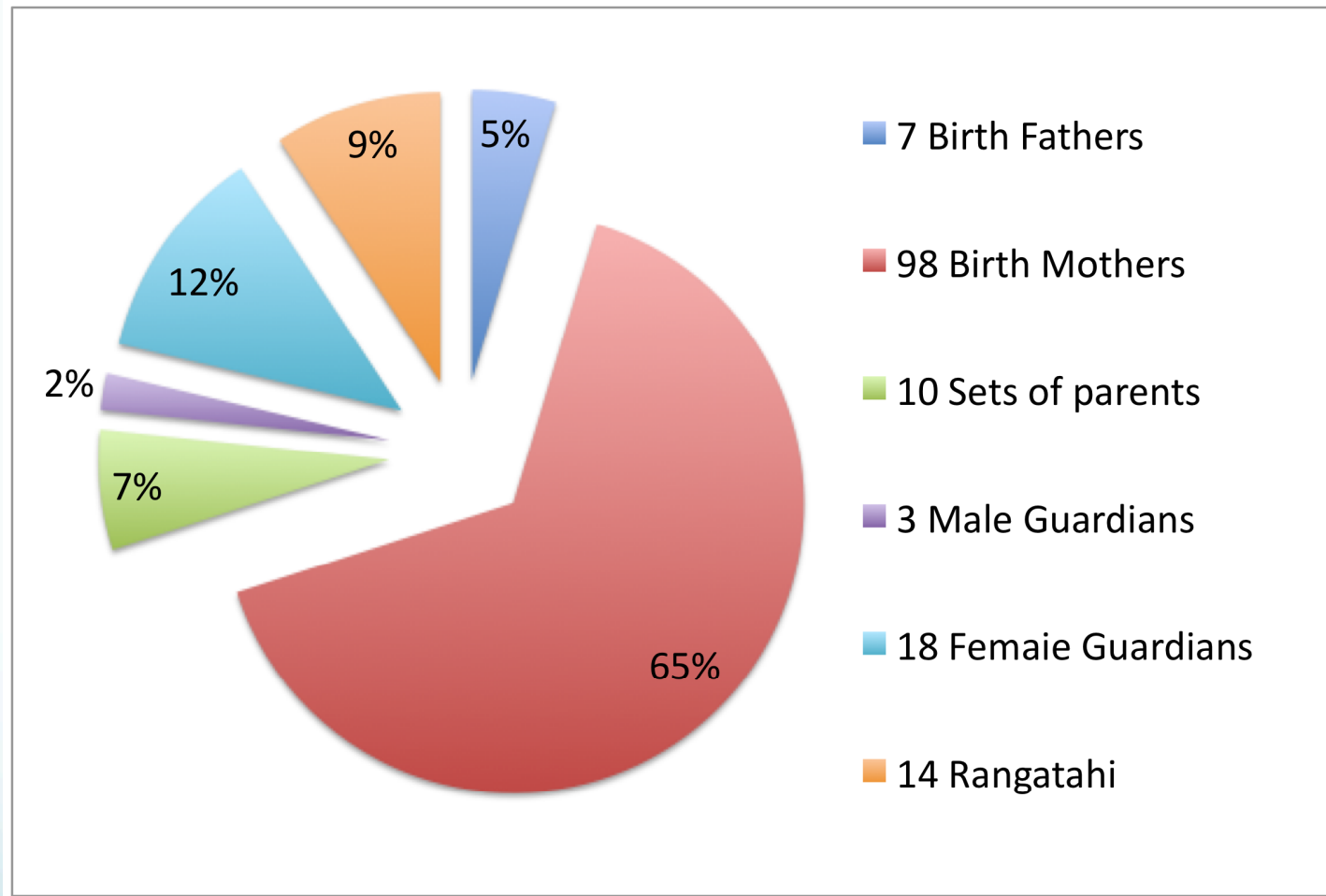
- **OUTCOME:** National Paediatric Database being established under BLENNZ day to day management, with Ngāti Kāpo O Aotearoa being kaitiaki of the database. *The database can inform ophthalmological services, health strategies, and health and education service provision.*

Qualitative Data

- Field notes gathered during 150 whānau hui and questionnaires
- 38 Whānau narratives through in-depth qualitative interviews

This paper presents initial results from 13 narratives and field notes with a bit of demographic information

Participants



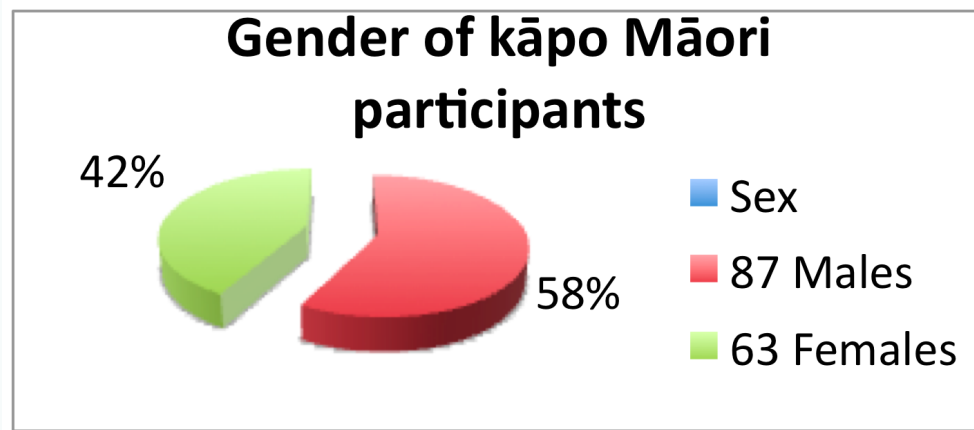
**Qualitative
Data**

**13
Interviews**

**2 fathers
11 mothers
(1
interviewed
with son)**

Demographic and Vision Questionnaires

Some basic demographics



150 Participants were associated with a range of iwi across the country with 53 Iwi being mentioned

**About 84% - North Island
About 16%- South Island**

Range of ages (around about 5% in each age group)

Interviews

**9 males (64%)
5 females (35%)**

**About 80%-
North Island
About 20%-
South Island**

**Aged 2-20 (4
kāpo participants
aged 18 or over)**

Additional Health Conditions or Impairments

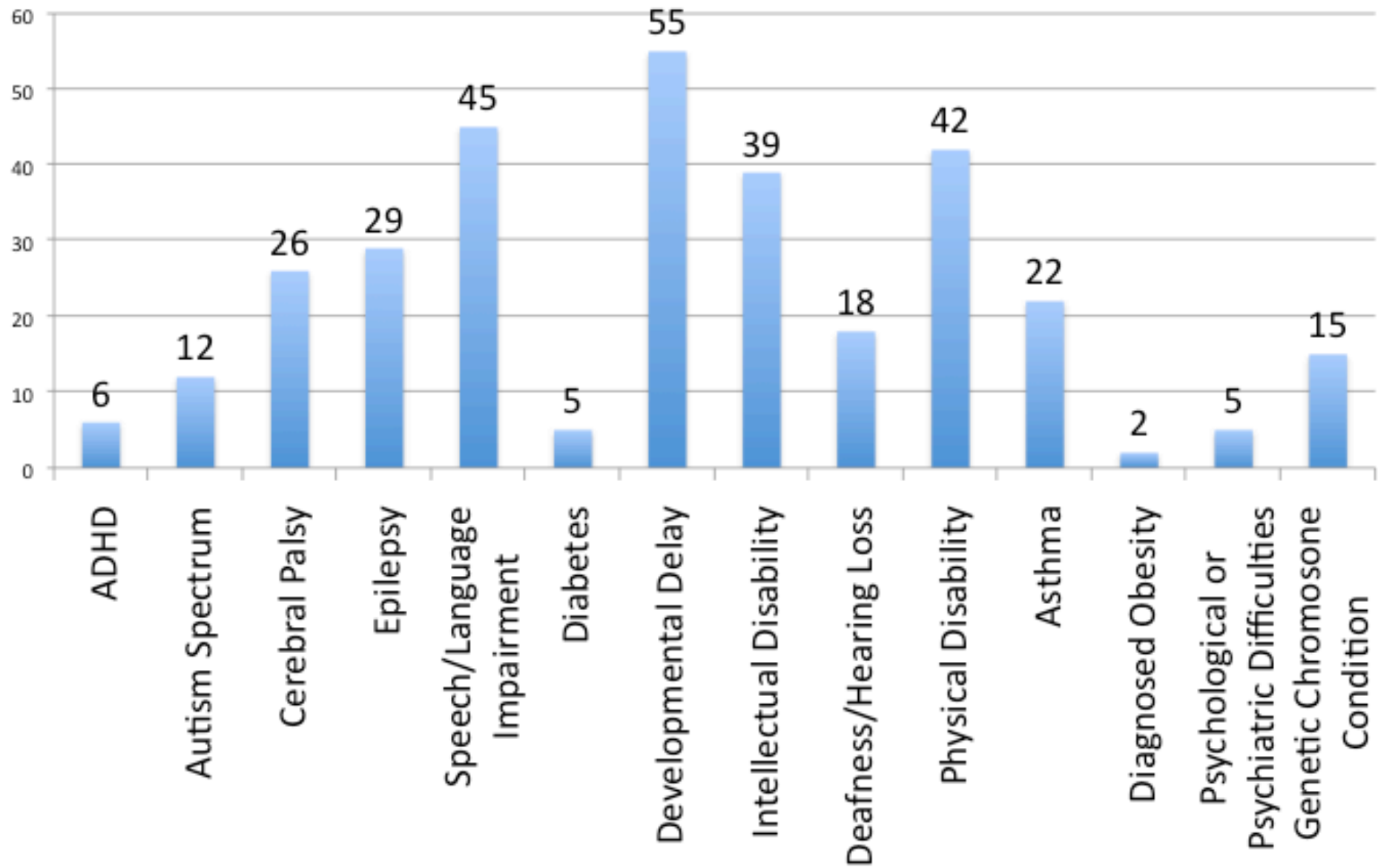
Additional Health Conditions or Additional Disabilities (*n=150*)

No; 19%



Yes; 81%

Proportion of participants' specified additional Health Conditions/ Disabilities (n=132)



Whānau narratives: how we have read their stories

- Grounded in the stories we were told – from notes taken when undertaking questionnaires and the qualitative interviews

Four themes from narratives

- Focusing on the body: Exclusionary discourse and practice
- Barriers to accessing services
- Holistic service provision
- Looking to the future

Theme 1: Focusing on the body: Exclusionary discourse and practice

- Exclusion through medical discourse & medical model
 - Deficit lenses
 - ‘Professional’ knowledge
 - Stereotyping
- Inflexible interactions, and healthcare policies and practices

Focusing on the body: Exclusion through medical discourse

"I tell you what really got up my nose was the geneticists - yeah it was kind of 'your daughter's fingers are too long, her ears are too big, her toes are too long'...I know what they were doing, they were trying to find specific areas of her body that might have been related through to some sort of genetic... I couldn't take that"

Focusing on the body: Deficit lenses

“And then the Social Worker from the Hospital . . . said not to expect Caleb to achieve anything, he’s not going to reach normal milestones like a normal child, and we had to prepare ourselves for the worst, is what she told us. . . . Yeah, on the day he was born . . . (My partner) and I were just flabbergasted, and we haven’t liked her since. . . . I mean being told not to expect your child to achieve anything, horrible, when you’ve just been told his condition”

Focusing on the body: 'Professional knowledge'

“They use jargon and I can't understand it”

“There's nobody there to clarify things, they couldn't clarify my worries”

“I've become a right little Google master at things.”

Focusing on the body: Exclusion based on stereotyping

“the difference between what John got and what [my friend’s] twins got was quite obvious. She got better treatment ... So we weren’t offered as many things as she was offered.... In the hospital she’d sort of go, ‘Hey I got this. Why can’t John have that? . . . There was a bit of discrimination going on...I feel there was also me being a single parent... Maybe it was just her personality and me just not asking questions”

Focusing on the body: Inflexible interactions, and health care policies and practices

Interactions:

“ ... We went up to (the hospital) and we waited for (the neurologist), ...we went in and put her nose into David's paper work and never actually talked to us. She was reading the stuff and talking about David at us but never to us. And she goes, 'oh that's all I need to know, ok so you can go now'. There was a ten minute meeting and she didn't even check him...It was Christmas time and it was actually hard to get the money together to be able to do this.

Focusing on the body: Inflexible interactions, and health care policies and practices“

Policy and Practice

“Well we had to spend hours there and he would scream. He’d go to the nurses first, then you’d see the registrar, then you had to go over there and wait for the visual assessment and then you had to go back and wait to get back to the surgeon again. It was a very long process. Being there for hours is really hard”

Focusing on the body: Inflexible interactions, and health care policies and practices

Transition Services

“When he was under paediatric service I never felt alone...Under adult services I’ve nowhere to go. I feel like I’m medically isolated. It’s horrible. I’ve even got a letter stating that the general physicians up here won’t take him on...It’s too complex for them and it’s a horrible feeling”.

Theme 2: Barriers to accessing services

- Delays due to not being taken seriously
- Delays due to lack of 'professional' knowledge leading to parent blame
 - No identifiable ophthalmologist
 - Cost of accessing services
 - Appropriate services not available
- Communication, referrals and information
 - 'Professional' overload
 - The broader social economic context

Barriers to access: Delays due to not being taken seriously

- Many whānau experienced delays between the identification of a vision impairment and diagnosis, especially if their child had multiple disabilities.
- Many also experienced delays between diagnosis and referrals to vision education services.
- Whānau described their early experiences as ‘stressful’, ‘scary’, ‘angry’, ‘upsetting’, ‘feeling guilty’, ‘maddening’, ‘anxious’, ‘my heart was broken’, and ‘overwhelming’.

Barriers to access: Delays because not being taken seriously

Young mother

“My mum, most of the time she’s right. She knew something was wrong, but I was just so happy. I’d just had a baby, I just wanted to enjoy my baby. I was more concerned about the gunky eyes... so we went to the doctor. We went four times still the same thing came home with eye drops. It was full on for about six months with his eyes. It wasn’t until my aunty came – its kind of like Plunket but it is a Māori one. She came round ...She referred me again. . . . That’s when he called in someone else. It would have been nice if he’d called in someone earlier. If my aunty hadn’t of stepped in we probably would have gone back to him again and nothing. It was kind of annoying that he had not brought in anyone else.

Barriers to access: Delays because lack of professional knowledge, and parental blame

Parent Blame:

“Why I am such a bad parent? Why are they, make me under scrutiny as a bad parent? Why make me under scrutiny and asking questions and under the microscope all the time, that really affected me.”

Barriers to access: No identifiable ophthalmologist

5% of kapo Maori had no specialist or 20% didn't remember their name:

“They'll send you an (eye) appointment and you roll along and you see whoever. So we went from Alex XX, and then Felicity XX, and the next thing we see whoever.”

Barriers to access: Costs of accessing services

Kāpo Māori whānau household income was \$40, 690

NZ household average income is \$79, 300 (Statistics NZ, 2010)

4.7 average number in kāpo Māori whanau household

2.6 average number in NZ households

“We’ve noticed if we know some people that have money that they were getting services, it seemed like (the hospital) paid them more attention. There were times when I couldn’t make it up to the hospital and they would come down here. But, they were like, ‘oh this is costing the hospital money’. And it was like, ‘Well I can’t get up there (because) it costs too much.’ Now we have to get dropped off because we’ve got to pay for parking.”

Barriers to access: Appropriate services not available

One parent talked about the fragility of respite care for her and her child with complex and multiple needs. She talked about the increasing frustration of finding appropriately trained carers to look after her son.

“It only takes one of that domino thing to fall over and that’s it, my break is gone. If a service provider rings me up at 8 o’clock in the morning and says their worker called in sick I have had to cancel a whole morning because they can’t send anybody who is not trained to care for him. They’ll say, ‘I will send so and so’, and I will say, ‘don’t bother they don’t know him.’”

Barriers to access: Communication, referrals and information

“One of the things I wish had been better was the doctors didn’t communicate to BLENNZ and the Foundation for the Blind. They should have sent a letter at the very beginning when the eye doctor saw us. If one doctor had taken five minutes to write a letter to the Foundation we would have been linked into that resource when we needed to be. By the time we met the counselor we had gone through all the trauma.”

Barriers to access: Professional overload

One whānau talked about the ‘breaking point’ when they had too many learning support professionals ‘pushing in their own direction at a group meeting’. They felt that the focus became on the specific disabilities that their son had rather than the fact that he is a child.

Another whanau recounted that they have had ‘five or six people come in a day one after another’ and that it got ‘a bit too much.’

Barriers to access: The broader social economic context

Several whānau indicated that in the NZ environment of a shrinking health dollar there is no wonder that the public health system is struggling to meet health needs

“I think they could always treat you better but I think you just have to appreciate the restrictions that they have. You know funding and the availability of space, whatever, ...”

“I think it is a real tough time across the board not just here (where I live).

Theme 3: Focusing on whānau and people: Holistic service provision

- Whanau involvement is critical
- Tikanga, faith, & whānaucentricity
 - Other whānau
 - Giving back
- Doctors and specialists who were friendly, responsive, took them seriously, involved them, honest, trustworthy, & provided continuity of care
- Hospital staff coordinated services, made making and keeping appointments easy, & arranged travel/accommodation for whānau that needed to travel
 - Age appropriate services
- Specialist worked together, referred them on to other services, and coordinated their care
 - Vision education services (BLENNZ) was user friendly

Holistic service provision: Positive relationships

Just as there are many instances of whānau having negative experiences, whānau also talked about positive experiences that supported both their and their child's health, well being and learning needs.

The overarching theme of their positive experiences was about them and their children being known, understood and treated holistically.

At the heart of their korero was the importance of developing and maintaining positive relationships:

- within whānau

- with specialists, doctors & hospitals

- with support services, and

- with education services

Whānau involvement is critical

“We have always been involved, especially his care through his specialists, his upcoming teachers, his school. There are some basics we try to keep going, like a working telephone, having a monthly planner on the wall. Yeah that keeps us informed. We are involved in our extended families.”

Tikanga (culture), faith, and 'whānaucentricity'

Whānau also call on tikanga and their faith to guide them in their care of their children.

“We have faith in Te Atua so what we do as a family is approach it from our Māori world view. We ponder, we pray and we talk to each others about it with our family.”

Other whānau and ‘giving back’

Many whānau recognised that support from other whānau who have children with disabilities is important.

“You get so involved with the medical and the doctors and everything that sometimes you just need another parent with a child with a disability, to even just sit in the same room but don’t have to speak, just understand which is really good. I’ve got a nice little support team of mates.”

Other whānau and ‘giving back

“I was the . . . Whānau Worker on and off, I’d get called in to fill in, for three months, . . . , and then you know the staff keep leaving, so I’d just fill (in). (My predecessor) was my social worker. I ended up you replacing her, Yeah, um, I’ve got a certificate in Social Work. . . . So I ended up being at some stage my own social worker, which was really confusing”

Holistic and Coordinated Services; Good doctors, specialists and hospitals

Whānau noted that good experiences were with doctors and specialists :

who were friendly and who took time to engage with them,
who listened to their concerns and took them seriously
that they could trust, and
that were honest with them.
provided continuity of care

One whānau talked about how their eye specialist ‘knows the whole family’ and that that ‘makes a huge difference’ to the services that they receive.

“They know how we feel about her and how important she is to us and they work with us to help her along.”

Positive experiences include:

- Professional responsiveness to whānau concerns about their son's or daughter's eyes and vision that lead to quick referrals
- Being able to make decisions with their doctors about their tamariki
- Having open access to specialists and doctors, often giving whānau their cell phone numbers
- Valuing the expert knowledge of doctors even though their bedside manner might not be the best
- Doctors who take the time to explain things well
- Providing half hour long appointment times
- Doctors taking the time to connect whānau to other services
- Paediatricians were mentioned a lot for their knowledge of and expertise in caring for children, the way they explained things to and gave options to whānau, and the way they are able to talk to whānau
- It also helps if professionals have children with disabilities of their own

Holistic and Coordinated Services; Good doctors, specialists and hospitals

Whānau were quick to point out instances where they got good support from hospital staff.

They made making and keeping appointments easier,

They arranged travel and accommodation for whānau who had to go to travel,

Holistic and Coordinated Services; Good doctors, specialists and hospitals

“I know one of the nurses that’s there all the time now and she always puts (my daughter’s) file at the top of the pile.”

Holistic and Coordinated Services; Good doctors, specialists and hospitals

“We were waiting for the cataracts clinic we were grouped with a lot of elderly people. There was nothing for children...They brought in this woman that dealt with children . . . There was some promise there for a brief moment, somebody who seemed to have more experience with children. She had little toys and things .. She had all the gear.”

Holistic and coordinated services

- Specialists from different areas working together to provide appropriate services for whānau
- Doctors supporting whānau in accessing services not directly associated with health or education services
- Integrated/coordinated health care

“Just to have all the professionals in the same place at the same time and have different doctors looking at her and assess her, and gather all that information up at the same time was amazing.”

A big tick for Vision Education Services

Whānau liked the:

- prompt response from BLENNZ when referrals were made
- easy accessibility to learning support and staff
- relationships that they had with BLENNZ staff
- comprehensive assessment that gives ‘hope’ to whānau
- information that helped whānau understand their child’s vision impairment, learning, and behaviour
- expert knowledge that helped to intellectually, visually and physically extend their children
- way Vision Resource Teachers worked with whānau, and shared ‘tips’ to help extend their child at home even if no-one knew the extent of the learning ability of the child
- way BLENNZ helps to secure ORRs funding

Theme 4: Looking to the future: Recommendations that have come from the narratives of whānau

Whānau narratives: Recommendations

The recommendations are organised in four sections:

Whānau

Ophthalmology services

Health services

Educational services

Whānau recommendations for whānau

- Find doctors that will listen to you and your concerns, that are respectful and non-judgmental
- If your doctor or paediatrician is not working for you change them, ask for another one
- Don't be shy about speaking up and asking questions.
- It is not just important to find out what services are out there it is also important to know which services are effective
- Don't' accept mediocre services, plug for the best
- Talk with other whānau in similar situations
- Find out what support there is out there for whānau
- Get hooked into BLENNZ straight away, even if your baby is very young
- Work towards continuity of care, maintaining familiarity of people and places in health and education services
- Ask for individualised funding which enables access to support outside of 9-4pm workdays.

Whānau recommendations for ophthalmology services

- Professional development for working with people with multiple disabilities and with babies and young children
- As part of their training place ophthalmologists (and other specialists working with children) should have a home placement for a week
- Put technical terms and descriptions of eye conditions into everyday language
- Explain eye conditions using pictures and other media
- Set specific and increase appointment times for children and their whānau
- Set in place appropriate processes for relaying diagnosis to whānau – schedule more time for whānau to take in and ask questions, ensure meeting takes place in an appropriate and private space, encourage whānau to have support people with them, take a more considered approach

Whānau recommendations for health services

- Establish whānau navigator positions – support people who have experiences to support and guide whānau
- Develop and implement a ‘passport’ system so that whānau only have to fill in one form which gets handed to all services
- Increase/establish integrated service approaches to cut down on the number of specialist appointments for whānau to attend
- Reconsider transitioning of rangatahi 18-21 years of age from paediatric to adult health care.
- Increase nursing/nurse aide staff levels so that people with disabilities are better cared for in hospital
- To provide greater choice in health and support services for whānau, including services that are culturally relevant and have alternative therapies
- Increase the option for individualised funding to whānau.
- Develop internet information portals for whānau to access information

Whānau recommendations for education services

- Establish advocacy support service for whānau, run by whānau
- Organise and manage transition phases for disabled students– preschool, high school and tertiary - early
- Provide and require training for teacher aides
- Be more flexible/creative in the allocation of specialist teachers and teacher aide hours to better meet the needs of learners

Conclusion

This project took an in-depth look at the experiences of whānau, when accessing health and education services for their child. It is clear from the narratives of whānau that services could be improved to ensure social inclusion and access to appropriate services and information, so that kāpo Māori can experience well-being.

Its findings fits with other studies about health and education service access for Māori, who face exclusion and barriers to full participation in a ‘society who does not take account of their culture and needs’.

Despite the barriers whānau face, they are overwhelmingly optimistic about their children and their futures.

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