

## Improving educational services for kāpo Māori: What does our research suggest.

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## The beginnings of our research story

- Hine: Someone must have come down to have a talk with my parents. . . They decided to put me in (Sunrise Home). I was two.
- *I think (my mother) felt left out . . . she would have liked to have been involved.*
- *I think because I grew apart from (my brothers and sisters) I'm still apart from them. . . .*
- *She said she felt homeless, and "I really enjoy being with my own. I feel aware when I'm with my own, both as a Maori person and a blind person."*

Higgins, N. (2001). *Blind people: A social constructivist analysis of New Zealand education policy and practice*. Unpublished Doctoral Thesis, University of Otago, Dunedin, New Zealand.

## The projects (2)

- 1<sup>st</sup> projects of their kind
- Kaupapa Māori Driven
- Collaboration with and accountability to kāpo Māori through **Ngāti Kāpo o Aotearoa, Inc.**
- Research Management Committee
  - support the research team to *plan, interpret, and disseminate* the results of this research
- Kāpo Māori Researcher
- Pan tribal
- Whanaucentric
- Multi disciplinary and inter professional

## 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?

## Mixed Method

**Quantitative data: demographic and vision questionnaire** from 150 whānau of kāpo tamariki (children) and rangatahi (youth) developed through research team hui and with Research Management Team

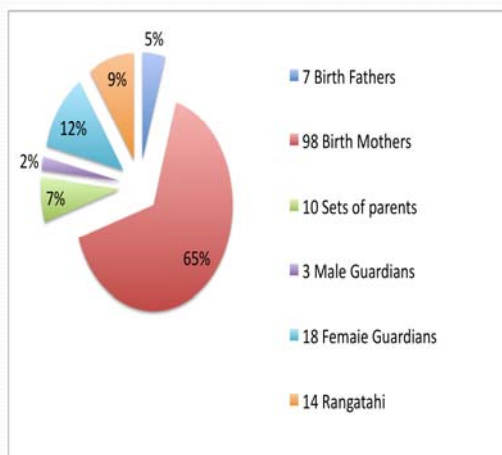
(73% response rate from potential participants, who were able to be contacted for informed consent through the BLENNZ roll)

### Qualitative Data

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

## Participants

**Quantitative Data**  
150 Demographic and Vision Questionnaires

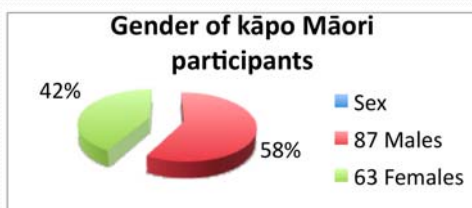


**Qualitative Data**  
37 Interviews

- 3 Birth fathers
- 16 Birth mothers
- 1 Birth parents
- 9 Whānau interviews (parents, siblings, kāpo child)
- 4 Whangai aunties/grandmothers
- 4 Rangatahi

## Some basic demographics

150 Questionnaires



37 Qualitative Interviews

(3 whānau with 2 kāpo children)

Gender –53% (n=21) males  
48% (n=19) females

84% - North Island

16%- South Island

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

87% (n=32) –North Island

13% (n=5) South Island

## Household Numbers

### Research

4.7 people

Average number of people in participant's household

(n=149) (median=4)

Ranged from 2 to 12 people

### 2006 NZ Census

2.6 people

NZ average number in household

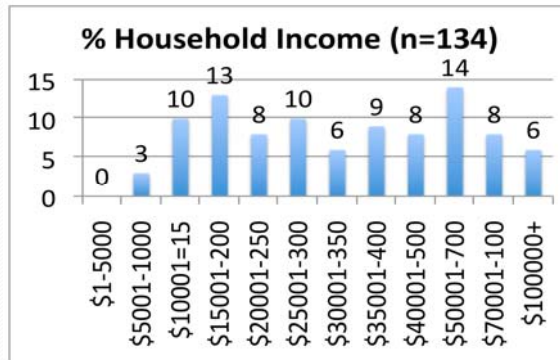


## Household Income

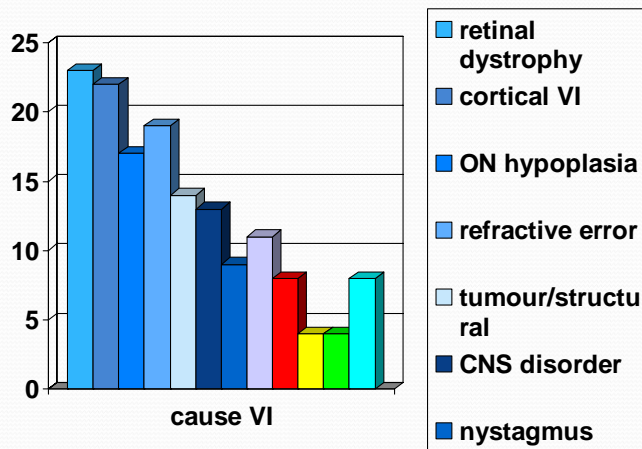
**Approximated**

\$40, 690 Respondent's Average\* (\*midrange of scales, 110,000 estimated for top income earners) (32,500 median)

**\$79, 300** NZ 2010 Household Income Average



## Causes of vision impairment



Best VISUAL ACUITY OF PARTICIPANTS	
Not recorded	0% (N=0)
6/6-6/18	21% (N=32)
6/18- 6/60	26% (N=39)
6/60-3/60	14% (N=21)
3/60-1/60	5% (N=8)
1/60-NLP	22% (N=33)
NLP	10% (N=15)
Cannot be tested	1% (N=1)
Believed Blind	1% (N=1)

10% had field losses  
But in general there were low rates of field testing

## Participants' identification of diagnosis and specialist

% of Participants identifying a diagnosis	
No diagnosis yet	.7% (n=1)
Not told diagnosis	3% (n=4)
Don't remember	9% (n=13)
Don't know	10% (n=15)
Blank	.7% (n=1)
<b>TOTAL</b>	<b>23.4%</b>

- 5% said they had no eye specialist, 1% didn't know if they had an eye specialist, and 21% didn't know their eye specialist's name.

## Additional Health Conditions or Impairments

### Additional Health Conditions or Additional Disabilities

(n=150)

No; 19%

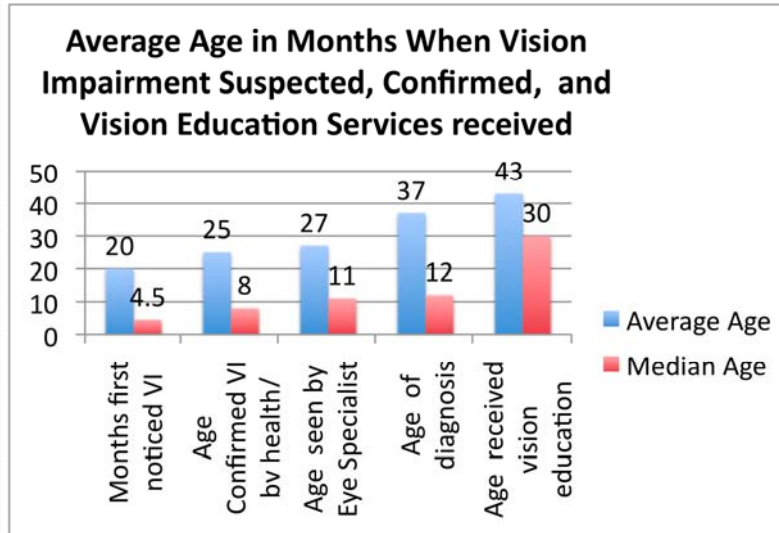


Yes; 81%

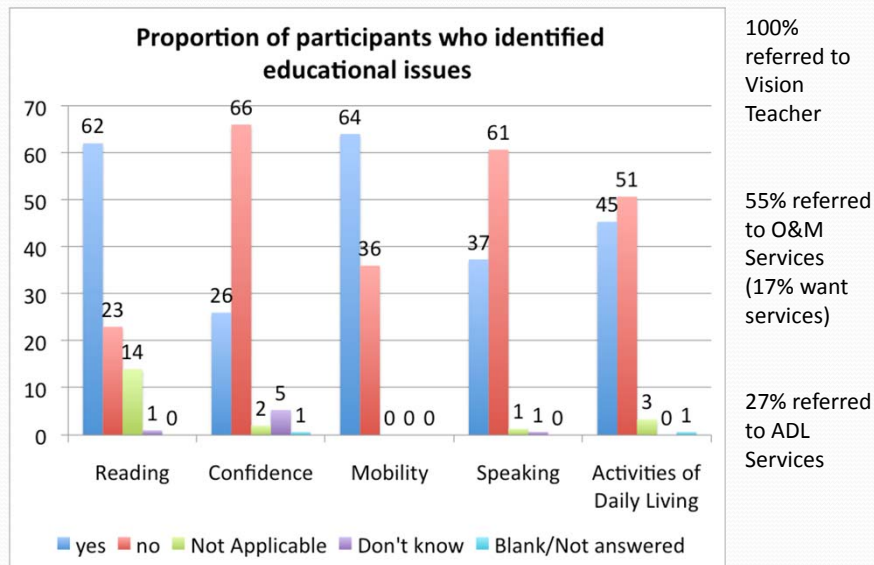
## % of Impairment type (n=132)

- 55% Developmental Delay
- 45% Speech Impairment
- 42% Physical Disability
- 40% Intellectual Disability
- 29% Epilepsy
- 26% Cerebral Palsy

## Health Services



## Educational Issues

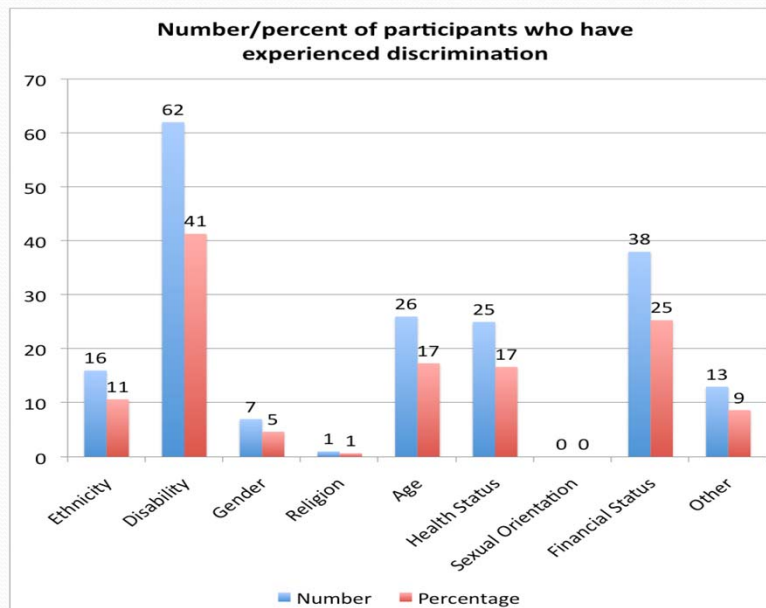




## Services received and services wanted

% of all participants (n=150) receiving or want referrals for service					
	Receiving/Received/Will receive	Didn't know about service/s	If Not: Yes, Want Services:	If Not: No, don't want services	If Not, Don't know if want services
BLENNZ	90%	.7%	1%	2%	1%
RNZFB	74%	3%	8%	11%	1%
<b>Ngāti Kāpo O Aotearoa, Inc</b>	<b>22%</b>	<b>35%</b>	<b>60%</b>	<b>14%</b>	<b>5%</b>
<b>Māori Health Services</b>	25%	9%	<b>45%</b>	27%	1%

## Discrimination



## Whānau narratives

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
- 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 & deficit lenses*
- *'Professional' knowledge and practice*
- *Stereotyping*
- *Inflexible interactions, and healthcare policies and practices*

## Theme 2:

### Barriers to accessing services

- *Ophthalmological and other medical services*
- *Professional overload*
- *Lack of communication between services*
- *Delays to services*
- *Appropriate services not available*

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## Theme 2:

### Barriers to accessing services

- *Cost of accessing services*
- *Hospital appointments and waiting rooms*
- *Prioritising one impairment over another*
- *Accessing appropriate and consistent education and learning services*

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## Theme 3:

### Focusing on whānau and people: Holistic service provision

- *Whānau ora*
- *Friendly and responsive doctors and specialists*
- *Coordinated services*
- *Age appropriate services*
- *Vision education services*

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## Theme 4: Looking to the future - Recommendations

The recommendations come from whānau narratives are organised in four sections:

Whānau  
Ophthalmology services  
Health services  
Educational services

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## Whānau

- Kia kaha
- Find doctors that works for you
- Don't be shy about speaking up and asking questions,
- Research your questions on the internet as well.
- Find out about services - are they effective.
- Don't' accept mediocre services
- Try and maintain relationships and connections ,
- Take all opportunities to network.
- Be prepared to act as a mediator and advocate
- Be organized and keep track of appointments.
- Get hooked into BLENNZ straight away, even if your baby is very young.
- Work towards continuity of care
- Find out what support there is out there for whānau.
- Ask about individualised funding

## Ophthalmology services

- Professional development for specialists
- Home placement as apart of training.
- Build positive relationships
- Information in every-day language.
  - Use pictures and other media.
- Appointment times – set and longer
- Improve processes for relaying diagnosis to whānau.
- Take more time in your first meetings with whānau.
- Work towards continuity of care.
- Ensure the eye clinic is baby, child and youth friendly

## Health services

- Whanau navigator positions
- Streamline forms (passport system)
- Work as a team
- Provide more information (packs and online)
- Increase/establish integrated service approaches
- Develop 'jargon free and simple language' file
- Work towards continuity of care.
- Ensure the clinic or organization's environment is tamariki and rangatahi friendly
- Transition of rangatahi, paediatric to adult health care
- Increase nursing/nurse aide staff levels in hospital.
- Provide greater choice in health and support services for whānau, including services that are culturally relevant and have alternative therapies.
- Employ more Māori staff, training them if necessary.

## Educational service

- Establish advocacy support services
- Transition phases
- Training for teacher aides
- Flexibility/creativity in allocation of teacher and aide time
- Class teachers work with tamariki / rangitahi
- Employ social worker support
- Jargon free files

## Thoughts - based on quantitative

- Ophthalmic diagnosis known in >95%
  - Causes of vision impairment similar to other western countries
  - Many cases preventable
- **The 2 year gap between noticing the vision impairment (aged 20 months) and vision education services (43 months) is too long.**
- Access to Māori Services an issue
- **Better relationships and communication between professionals, and between professionals and whānau**

## Messages for BLENNZ

### What was valued:

- responsive
- accessible
- effective communication with whānau
- comprehensive assessment
- expert knowledge
- worked with whānau
- secured ORRs funding



## BLENNZ: strengthening the mat



## Whānau will always be there

Nui:

*He's got to go and explore . . . and test the water. And [we will] always be there to love and support [him] when things don't go [right].*



## Bibliography (1)

- Bevan-Brown, J. (1989). *Intellectual disability: A Māori perspective*. Unpublished Masters Thesis, Massey University, Palmerston North, New Zealand
- Bevan-Brown, J. (2003). *The cultural self-review: Providing culturally effective, inclusive, education for Māori learners*. Wellington: New Zealand Council of Education Research.
- Bevan-Brown, J. (2004). *Māori perspectives of Autism Spectrum Disorder*. Wellington: Ministry of Education.
- Bishop, R. (1996) *Collaborative Research Stories: Whakawhanaungatanga*. Palmerston North: Dunmore Press.
- Collins, A., & Hickey, H. (2006). *The role of whānau in the lives of Māori with physical disabilities. Blueskies Report no 12/06*. Wellington: Families Commission.
- Cresswell, J. W. & Miller, D. L. (2000) "Determining validity in qualitative inquiry." *Theory into Practice*, 39, 124-128.
- Durie, M. (1997). Whānau, whanaungatanga and healthy Māori. In P. Te Whāiti & M. McCarthy & A. Durie (Eds.), *Mai i rangiātea: Māori well-being and development*. Auckland: Auckland University Press with Bridget Williams Books.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage
- Health Research Council of New Zealand (2004) *Ngā Pou Ranghau kia Whakapipi Ake Te Hauora Māori: The Health Strategy to Improve Māori Health and Wellbeing 2004-2008*. Wellington: Health Research Council of New Zealand. Downloaded from [www.hrc.govt.nz](http://www.hrc.govt.nz).
- 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. Available from: [http://www.google.co.nz/#hl=en&client=psy-ab&q=final+report+growing+up+kapo+maori&pbx=1&oq=final+report+growing+up+kapo+maori&aq=f&aqj=&aql=&gs\\_sm=s&gs\\_upl=339141357431136990131121010101014051391412-4.7.111210&bav=on.2,or\\_r\\_gc\\_r\\_pw\\_r\\_qf,cf.osb&fp=c691fb3b4cf314fc&biw=1137&bih=644](http://www.google.co.nz/#hl=en&client=psy-ab&q=final+report+growing+up+kapo+maori&pbx=1&oq=final+report+growing+up+kapo+maori&aq=f&aqj=&aql=&gs_sm=s&gs_upl=339141357431136990131121010101014051391412-4.7.111210&bav=on.2,or_r_gc_r_pw_r_qf,cf.osb&fp=c691fb3b4cf314fc&biw=1137&bih=644)

## Bibliography (2)

- Kingi, J., & Bray, A. (2000). *Māori concepts of disability*. Dunedin: Donald Beasley Institute.
- Macfarlane, A. (2003). *Culturally inclusive pedagogy for Māori students experiencing learning and behaviour difficulties*. Unpublished Ph.D., University of Waikato, Hamilton.
- Nikora, L. W., Karapu, R., Hickey, H., & Te Awakotuku, N. (2004). *Disabled Māori and disability support options: A report prepared for the Ministry of Health, Hamilton Office*. Ministry of Health: Hamilton.
- Pipi, K., Cram, F., Hawke, R., Hawke, S., Huriwai, T. M., Matakī, T., et al (2004). A research ethic for studying Maori and Iwi provider success (Electronic Version). *Social Policy Journal of New Zealand*, 23, 141-153. Retrieved October 20, 2007, from <http://www.msd.govt.nz/publications/journals/23-december-2004/index.html>.
- Smiler, K., & McKee, R. L. (2006). *Perceptions of Māori Deaf identity in New Zealand*. *Journal of Deaf Studies and Deaf Education*. Retrieved on October 12, 2006, from <http://jdsde.oxfordjournals.org/cgi/content/abstract/en1023v1>.
- Smith, L. (1999) *Decolonising Methodologies: Research and Indigenous Peoples*. London: Zed Books & University of Otago Bookshop.
- Statistics New Zealand (2006). New Zealand Census. Retrieved from [www.statisticsnz.govt.nz](http://www.statisticsnz.govt.nz).
- Statistics New Zealand (2010). Subnational family and household projections 2006 (base)-2031 update. Retrieved from [www.statisticsnz.govt.nz](http://www.statisticsnz.govt.nz).
- Wilkie, M., Berryman, M., Himona, T., & Paul, T. (2001). *Matauranga motuhake*. Wellington: New Zealand Council for Educational Research.

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Our participants

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- Associate Professor Joanne Baxter, University of Otago