

# Growing up kāpo Māori: Whānau, identity, cultural well-being and health

This research project was about how kāpo (blindness and visual impairment) affects Māori. It explored how health and education services impact on the identity, cultural well-being and health of kāpo Māori and their whānau. Māori and Pakehā researchers, and kāpo Māori and their whānau, worked together through a Research Management Committee from Ngāti Kāpo O Aotearoa Inc. to investigate the experiences and stories of ten such whānau. The aim of this study was to contribute to the knowledge about kāpo Māori so that services for kāpo Māori will better address the cultural well-being and the health of kāpo Māori and their whānau.

This study, funded by the HRC, was a nationwide study and ran for two years (2007 - 2009). It was conducted by researchers from the Donald Beasley Institute, Ngāti Kāpo o Aotearoa and Victoria University of Wellington, and led by principal investigator, Dr Nancy Higgins.

The research team interviewed 78 people, who were kāpo Māori, whānau members or worked with kāpo Māori, about their experiences of, and thoughts about, being kāpo Māori. The four overall and common themes that were identified in the data included cultural location and dislocation, cultural consonance and dissonance, visibility and invisibility, and transformation and change.

Whānau was central to the kāpo Māori interviewed for this study, with all the participating kāpo Māori being strongly and culturally located in whānau. However, not all participants were connected into hapu and iwi networks. For some this connection

was not a priority, for others whakapapa was a dominant factor in their identity. Many of the participants were emphatic that they were first and foremost Māori who happened to be blind or vision impaired.

Access to appropriate services was a key theme for kāpo Māori and their whānau. Analysis of the interview data indicated that access to and uptake of ophthalmological services were issues and that some participants believed that being kāpo was either their 'lot in life', or was just natural, and may not have accessed services because of these beliefs. The majority of health and education services are monocultural and participants saw these as 'not Māori', foreign, and therefore inaccessible. Few fulfilled kāpo Māori aspirations for services that were culturally relevant and appropriate.

The researchers also found that the Royal New Zealand Foundation of the Blind had no record of an identifiable diagnosis of the cause of vision impairment for 42 per cent of kāpo Māori children on their roll, and the Blind and Low Vision Education Network had no overall national information about kāpo Māori children's eye conditions. This lack of knowledge may have a considerable impact on the learning and health services being developed, which kāpo Māori children may be able to receive.

The research team was successful in gaining further HRC funding in the 2009 annual contestable funding round to investigate these issues with their project, *Growing up kāpo Māori: Accessing paediatric ophthalmology services*.



Dr Nancy Higgins

#### Key words:

- Māori, kāpo, blindness, visual impairment, cultural well-being, health, whānau

#### Aims of this research:

- The aim of this study was to contribute to the knowledge about kāpo (blind and visually impaired) Māori, so that services for kāpo Māori will better address the cultural well-being and the health of them and their whānau

Despite the lack of appropriate support services the researchers found that the kāpo Māori and their whānau who participated in this research were highly resilient and resourceful in their everyday lives, expressing in a variety of ways their desire and rights to be self-determining. That is, 'to be Māori who happen to be kāpo'.

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