

## “Seeing” Kāpō Māori: Making visible the experiences of Kāpō Māori during and after COVID-19

**Bridgette Masters-Awatere, Chrissie Cowan, Rebekah Graham**



Associate Professor Bridgette Masters-Awatere (Te Rarawa, Tūwharetoa ki Kawerau) is the Director of the Community Psychology Programme and the Māori & Psychology Research Unit (MPRU) at the School of Psychology, University of Waikato. Her research interests are in Indigenous evaluation, Kaupapa Māori methodologies, narrative inquiry, and service programmes that contribute to Māori health and development. Bridgette lives with her husband Shaun (Ngati Porou) and their two children in Hamilton. As a Community Psychologist Bridgette’s approach is seek to understand experiences in a broader context and to find pathways for those impacted the most by power and resource differences. Email: [bridgette.masters-awatere@waikato.ac.nz](mailto:bridgette.masters-awatere@waikato.ac.nz)



Chrissie Cowan (Ngāti Kahungunu, Ngāti Kahungunu ki Rangitane, Ngāti Porou) is the Chief Executive for Kāpō Māori Aotearoa New Zealand Inc., a national Indigenous organisation founded by blind, low vision, vision impaired and deaf blind Māori and their whānau. We are guided by Māori values, principles and practices, and support tāngata whaikaha (disabled people) and their whānau to attain whānau ora (wellbeing), be strong self-advocates and leaders in their whānau and communities and contributes to educating Aotearoa society about Indigenous disability. Email: [chrissie.cowan@kapomaori.com](mailto:chrissie.cowan@kapomaori.com)



Dr Rebekah Graham (Pākehā) lives in Kirikiriroa (Hamilton) with her husband (Joe, Ngati Ranginui) and three of their four children. Dr Graham is the National Executive Director for Parents of Vision Impaired NZ, a blind consumer group with Blind Low Vision NZ. In this role, Rebekah advocates strongly and consistently for inclusion, accessibility and support for all, with a focus on parents/whānau of a vision impaired child. A registered community psychologist, Rebekah has research interests in the area of food insecurity, disability, health, and community resilience. Email: [rgraham@pvi.org.nz](mailto:rgraham@pvi.org.nz)

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## Introduction

This piece reflects on our research process when undertaking face-to-face interviews with tāngata kāpō (Māori people who are blind, deafblind, low vision or vision impaired). Particular attention is given to the access requirements of tāngata kāpō and the intersections of Māori and disability. These experiences are shared as learning opportunities for others who are undertaking research in ways that are mindful of Tiriti and disability obligations, and in the current COVID-19 environment.

Our collective decision to undertake this externally funded project emerged after a positive collaboration experience on a previous piece of writing (see Graham, Masters-Awatere, Cowan, Stevens & Wilkinson, 2021). While discussing the digital exclusion experiences of blind, deafblind, and low vision citizens during Aotearoa New Zealand’s first experience of lockdown in March-May 2020, the absence of Māori perspectives highlighted an area that warranted further investigation. In July 2020 Ngā Pae o te Māramatanga advertised a call for small-scale collaborative projects that brought to the fore descriptions of Māori experiences during and after the COVID-19 lockdown. The timing, nature, and size were a perfect fit for our investigative team of 3 women in senior positions within our respective organisations.

Over Zoom we three discussed the design for a scoping project that would be focused on the intersection of Māori and disability within the context of a pandemic response

(COVID-19). Collectively, we were interested in the experiences of tāngata kāpō during and post the first COVID-19 lockdown in early 2020. We intentionally centred the needs of tāngata kāpō in a culturally responsive manner and on their health-related aspirations for themselves and their whānau. This also involved identifying facilitators and barriers that tāngata kāpō and their whānau face.

Initially we planned for our project to begin late December 2020 with an immediate start. We were mindful of the potential risk posed by COVID-19 lockdowns and regional variations. Unfortunately, we had not anticipated the University ethics committee taking a recess for 2 months (December-January). The first sitting of the University ethics committee did not occur until February 2021. Neither did we anticipate an 8-week wait for the University ethics committee to process our application through to approval. Receiving official ethical approval in March 2021 meant a 4-month delay to our project and necessitated two design tweaks:

1. The area for participant recruitment reduced from the Central North Island to strictly Hamilton City and surrounding areas; and,
2. Rather than recruiting participants to two separate wānanga, with a final hui to disseminate, we invited participants to two wānanga; one to collect narratives, and the second to discuss our analysis and potential plans for dissemination.

We calculated the inclusion of

no more than sixty minutes one-way travel to the wānanga. This circumference enabled the inclusion of participants from Te Kauwhata and Paeroa (in the North), Otorohanga and Putāruru (to the South), Te Aroha, Matamata (to the East) and Whāingaroa (to the West). Travel to the wānanga for any participant from these townships meant their participation involved eight hours of their time (essentially a day’s disruption to work, health, or social activities). That is a long time to ask of anyone, let alone people with a disability who may require assistance, medication, or support.

To recognise and appreciate the contribution of each participant, we incorporated into the project budget a \$100 koha for each participant. While this amount may sound generous, when you calculate the per hour amount the result is \$12.50 per hour. This is less than minimum wage (\$20/hour as of 1 April 2021). We believed that this nominal amount would not be considered as income. Nonetheless, the application for \$100 gift vouchers was declined by the Research Office on the basis that this amount could be construed as income (and therefore subject to taxation). Instead, an amount of \$60 per participant (maximum) was recommended and subsequently approved by the Chief Financial Officer. This amount equated to \$7.50 per hour. Despite our protests, when acknowledging participant contributions, it seems that there is little consideration given to participants outside of policy assumptions of “normal” i.e. young, fit, healthy, privileged, and white. Assumptions embedded into current

systems of ‘reimbursement’ typically do not factor in persons whose lives require more support, such as those who are tāngata kōpō.

To help make up for lost time, Kōpō Māori Aotearoa (KMA) administration staff distributed recruitment information in the appropriate alternate formats to their members in the Waikato region. KMA staff are familiar voices. Feedback during the wānanga clarified that having a familiar voice on the phone, who listened to their questions and answered their questions, ensured that participants felt appreciated and fully informed. These actions made a big difference for tāngata kōpō who attended the wānanga. The number of calls and follow up inquiries by KMA was another cost that was not factored into the budget. The research team recognised this additional work through a koha to Kōpō Māori Aotearoa.

Subsequent to KMA’s follow-up phone calls with participants, the research team realised there was a need to implement a clear process for transporting participants to and from the venue. While some costings for this was included in the original budget, there was an assumption that participants would be able to access disability support services and/or a driver service. It soon became clear that we had underestimated the level of independence afforded to participants from these services. In reality, driver services were expensive, taxi services unreliable, and participants were understandably reluctant to impose on friends and family for transportation to and from each wānanga.

Before the first wānanga the research team had not fully comprehended the conditions that might co-exist for tāngata kōpō, or the impact this might have in determining appropriate vehicle requirements. While we had asked if there were specific needs that we should factor into transport, below are specific examples we encountered closer to the date:

- **Accessibility.** This meant an appropriate van with a hydraulic lift for a tāngata kōpō who needed transport along with their wheelchair safely secured in the vehicle. Transporting a participant who lived 55mins drive from Hamilton via this means was \$500 per day.
- **Equipment.** Walking frames are personal items that can provide a sense of familiarity and security. For one kōpō participant their walking frame did not collapse for ease of transport. This meant the driver and vehicle could only transport one participant, with the walking frame directly impacting the size of vehicle required. We did not know, or think to ask,

this detail when arranging transport.

- **Mobility.** For some participants physical assistance was required. We provided instructions to drivers beforehand on the appropriate way to approach and assist tāngata kōpō. Even though our drivers did offer to assist, sometimes the offer (from a stranger) made participants feel uncomfortable and ‘lesser’ than – which was not our intention.

The day of the wānanga made aspects of transport and the need to have specific supports in place highly visible. For example, one participant was an elderly wāhine Māori with multiple health conditions who lived in a self-contained flat. A nurse visited her place of residence every second morning to administer necessary morning medications. Consequently, she was unable to depart from her home to attend the wānanga until after this regular routine had concluded. There was a need to adjust “on-the-fly” and be flexible in our approach – such as delaying the wānanga start by 30minutes and reorganising the programme to allow for this.

For tāngata kōpō their accessibility, equipment, and mobility needs are part of their everyday life. Even though the research team had asked if there were specific needs, their “no” response reflected their sense of autonomy and independence. As researchers whose members are psychologists and Māori, and who are not tāngata kōpō, we had a duty to ensure that we, through our actions or in-actions, did not diminish their sense of autonomy or independence (Code of ethics, 2012).

**Overall, participants dreamed of accessible supports and culturally appropriate services readily provided when required.**

The two wānanga were hosted (April, May) at the Blind Low Vision NZ recreational centre in Liverpool St, Hamilton. Eleven participants initially consented to participate and drivers arranged to transport each to the wānanga. However, for different reasons, not all were able to attend on the day of the wānanga. Seven adult participants who reside within the Waikato area came to the wānanga and shared their experiences of the 2020 lockdown. Participants also shared their aspirations for the future. The specific findings of our research are being prepared for another publication. However, we share some of the experiences by participants briefly below. From our research conversations with tāngata kōpō Māori, we heard a clear call for everyday life to be accessible, with few barriers to ordinary activities. For

example, being able to interact with Work and Income staff on the telephone instead of being directed to the MyMSD website (which participants experienced as being inaccessible). One participant noted that it was 'on file' that she was blind, yet every interaction she had with Work and Income staff required explaining her disability and the barriers to utilising the website. Another participant described the challenges they faced when queuing at the bank and not being able to physically see (a) when the queue moved and (b) when the bank teller beckoned them forward. This occurred frequently, despite this particular participant wearing dark glasses and utilising a white cane, both of which are clear visual indicators of a vision impairment.

**In contrast, we present our reflection piece in order to highlight the under-considered complexities of research processes, particularly when working with marginalised and excluded groups, such as disabled people.**

Another participant spoke of the challenges they faced when seeking to enrol at a local tertiary organisation due to their inaccessible website. They were concerned that if it was this hard to overcome multiple access barriers just to enrol, that the courses themselves would offer little to no accessibility supports.

Overall, participants dreamed of accessible supports and culturally appropriate services readily provided when required. This dream was reiterated across both wānanga. Essentially, for those we talked with, barrier-free, high quality, available and accessible services with professional staff who consistently

treated kāpō Māori with dignity and respect was viewed as both the gold standard and as an unachievable dream.

It was clear to us as we listened that disability and service providers across all areas of life need to do better to fulfil their Tiriti obligations to tāngata kāpō (as outlined in the Wai2575 Claim <https://www.health.govt.nz/our-work/populations/maori-health/wai-2575-health-services-and-outcomes-kaupapa-inquiry>). The government, in conjunction with the Access Alliance, is currently progressing Accessibility Legislation (<https://www.accessalliance.org.nz/the-accessibility-act>). This legislation will go some way towards ensuring tāngata kāpō have healthy, secure, and accessible futures for themselves and their whānau. However, creating accessible health services requires all of us to consider our own practices and the ways in which our assumptions create access barriers for disabled persons.

### Conclusion

This reflection piece has been prepared with the intention of describing some of the learnings the researchers gained from this project as one of the 12 funded research grants administered by Ngā Pae o te Māramatanga (the Māori CoRE) as part of its COVID-19 Tautoko Grant Programme (Jan-June 2021). Academic articles can convey a picture of research as though every aspect was planned for and executed perfectly. In contrast, we present our reflection piece in order to highlight the under-considered complexities of research processes, particularly when working with marginalised and excluded groups, such as disabled people. Additionally, this piece provides a forum to examine the ways in which research institutions embed assumptions

into policies and make decisions that unwittingly diminish the independence of disabled persons and de-value their expert knowledge, while simultaneously perpetuating stereotypes of whose knowledge is 'valuable'.

While we worked hard to ensure our research approach was strengths-based, ethically sound, and culturally appropriate, there were missteps along the way. These provided valuable learnings that continue. We have ongoing obligations as researchers who have disseminated our findings to the Minister for Disability Issues (Masters-Awatere, Graham & Cowan, 2021). We intend to present our findings at the national Kāpō Māori Aotearoa conference 2021 (which has currently been delayed because of the resurgence of COVID-19 in the form of the Delta variant).

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