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The gifts of kāpō: Systemic failures that impact the lives of kāpō who are Māori

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Abstract

This paper describes our approach to identifying and clearly describing ways in which individuals, groups, organisations, agencies, and governing bodies can approach and engage with an Indigenous-led group and their representatives. Our research began immediately after New Zealand's COVID-19 restrictions were introduced and has continued over the last 4 years. As a process of engagement, we draw out challenges experienced by Indigenous blind persons (tāngata kāpō Māori). We highlight the systemic failures that continue to impact the lives of kāpō who are Māori. Our approach describes how we aspire to uphold the self-determination (tino rangatiratanga), governance (kāwanatanga), and equity (ōritetanga) of tāngata kāpō Māori in Aotearoa New Zealand in the hopes that other psychologists working will learn from the experiences we share and think about how these may apply when working with Māori in other contexts (whether kāpō, disabled or not).

Keywords: blind, low vision, kāpō Māori, ethics, Te Tiriti, research, disability

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Introduction

Understandings of ethical research and professional practice are ever evolving. In Aotearoa New Zealand, the Cartwright Inquiry (1987 – 1988) marked a significant shift in the understanding of ethical practice by health professionals, leading to major reforms in patient legal rights, and establishing an external system of accountability. The results of the Inquiry shifted previously entrenched thinking regarding ethical practice. Another shift occurred in the development of the *2002 Code of Ethics for Psychologists Working in Aotearoa/New Zealand* (Seymour & Nairn, 2012). Movement away from a rules-based model to an aspirational one, offered guidance for ethical decision-making that related to a set of core principles and values. The then new Code reflected a wider sociocultural shift towards a more bicultural model, which explicitly stated and included views of Māori (Indigenous people of Aotearoa New Zealand). This included a growing understanding of the role of community and culture in people's lives (Seymour & Nairn, 2012). Heath research funders progressed alongside with the introduction of *Te Ara Tika: Guidelines for Māori Research Ethics – A framework* to assist researchers when applying for research funding (Atatoa-Carr et al., 2012; Hudson et al., 2010). This framework draws on tikanga Māori (Māori protocols and practices) as part of formal ethical decision-making processes and articulates ways of undertaking research in ethically and culturally appropriate ways. Nonetheless, research ethics processes continue to struggle to adequately address and acknowledge tikanga Māori (Pihama et al., 2015; Robson & Reid, 2001; Smith, 2021).

The 2002 Code of Ethics for Psychologists Working in Aotearoa/New Zealand is currently under revision. Representatives from He Paiaka Tōtara, the New Zealand College of Clinical Psychologists, the New Zealand Psychological Society, the New Zealand Psychologists Board, and Pasifikology comprise a working group tasked with the review. The revised ethical framework for psychologists in Aotearoa New Zealand will encompass a Code of Conduct and a Code of Ethics. The *Code of Conduct* will outline the behaviours that are mandated as part of professional work and that form base-line expectations of behaviour and practice. It specifies those things that the psychologist must or must not do. The *Code of Ethics* will cover the core ethical values and principles that guide psychologists' practice and behaviour. Many decisions that psychologists need to make are not directly covered in the Code of Conduct, so psychologists are encouraged to use the principles in the Code of Ethics to assist with determining the most ethical course of action. The proposed revisions to the Code of Ethics align more closely with the articles of Te Tiriti o Waitangi (The Treaty of Waitangi). Subsequently we thought it timely to present this paper that captures our reflections of our psychological research in alignment with both the incoming Code of Ethics and the articles of Te Tiriti o Waitangi.

Within Aotearoa New Zealand, the key documents that uphold the rights of Māori, as Indigenous persons, to self-determination, partnership, and full participation in all aspects of life, are He Whakaputanga o te Rangatiratanga o Niu Tireni (the Declaration of Independence of the United Tribes of New Zealand) initially signed in 1835, and Te Tiriti o Waitangi, initially signed on 6th February 1840. Te Tiriti o Waitangi in particular established a formal relationship between immigrants (predominantly European - Pākehā - at that time) and Māori providing guidance for a standard of conduct and an ethical duty to act in good faith. Subsequently, Māori rightly have an expectation that the psychology received and participated in is a psychology in which Māori recognise themselves (Masters-Awatere et al., 2022). This aligns with the epistemological underpinnings of Indigenous psychologies and provides an opportunity to develop a psychology that is not imposed or imported from elsewhere (Nikora, 2006). Indigenous psychologies consider the multiple contexts in which people live, develop knowledge within and alongside cultures using a variety of methods, and produce appropriate locally relevant psychological knowledge (Ciofalo et al., 2022; Pe-Pua and Protacio-Marcelino, 2000; Waitoki & Levy, 2018).

Internationally, Aotearoa New Zealand is signatory to several United Nations conventions and declarations that set out expectations for the ethical upholding of human rights, including two of direct relevance to this paper - the United Nations Declaration on the Rights of Indigenous Persons (UNDRIP) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The latter sets out expectations for disabled people to self-determination and full participation in all aspects of life. The ratification of the UNCRPD in Aotearoa New Zealand has resulted in the New Zealand Disability Strategy (Office of Disability Issues, 2016), leading to shifts over time in public attitudes and policy approaches towards a more disability inclusive and disabled-led approach to wellbeing (Social Wellbeing Committee, 2021). However,

progress remains glacial (Hickey, 2020). A core limitation of the UNCRPD is that it does not adequately understand collective rights or approaches and is heavily individualistic (Colchester, 2021), resulting in the inclusion of disabled persons being reliant on an individual's capacity to self-advocate (Ingham et al., 2022). Disability approaches by Crown-based agencies and their partners remain stubbornly individualistic, deficit-based and Pākehā-oriented (Wiley, 2009). Psychology is no exception. As a discipline, psychology remains distrusted within the wider disability community for being individualistic, dominated by non-disabled, and unethical (Goodley & Lawthom, 2006). Health professional training programmes, including psychology, provide limited recognition of models of disability and associated systemic biases faced by disabled people (Ravichandran et al., 2022).

Psychology has also struggled to adequately provide services and supports for Māori. Recent and ongoing Waitangi Tribunal Claims document successive failures by the Crown in this regard (see, for example, *Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry (Waitangi Tribunal, 2023)*). Relevant to this paper, is Waitangi Tribunal Claim 2109 #1.1.1(a), which addresses systemic failures by the Crown to ensure adequate roles for Māori disabled in the design, establishment, management, and implementation of policies and services; the lack of health research and data; poorly designed health, disability and other welfare policies; and inadequate services for Māori (Tibble, 2019). Regarding the profession of psychology, Waitangi Tribunal Claim 2725 #1.1.1 provides evidence that Māori are both over-represented as consumers of psychological services and encounter active resistance to their presence when training in the profession of psychology (Levy, 2018). There is ongoing need to ensure psychologists are culturally competent, to increase the Māori psychologist workforce, and to develop an Indigenous Māori psychological profession that meet the needs and aspirations of Māori.

The intersections of ethical approaches, psychological practice, and disability have compounding impacts for Māori. Most Māori disabled identify as Māori first (Hickey & Wilson, 2017). Māori cultural identity encompasses te reo (language), whakapapa (genealogy), kawa (cultural principles), tikanga (cultural practices), and linkages to te taiao (environment), all of which are paramount to everyday life (Mead, 2003). However, the predominance of biomedical approaches to disability and Pākehā-oriented systems in health and psychology combine to create structural barriers that actively exclude Māori from participating as Māori and from receiving culturally appropriate services (Hickey, 2020; Reid et al., 2017). This is despite the prevalence of disability within Aotearoa being disproportionately borne by Māori (P. T. King, 2019).

Māori have higher proportions of disability across all age groups (Ministry of Health, 2015), are more likely to experience disability after an injury (McCarty et al., 2018), and are more likely to experience multiple impairments across their life course (Office for Disability Issues & Statistics New Zealand, 2010). There is greater likelihood of adverse outcomes (permanent disability and death) for Māori patients (Blakely et al., 2015; Davis et al., 2006), increased likelihood of inappropriate care by medical professionals (Anderson et al., 2019), and Māori are more likely to experience delays in receiving appropriate care and specialist referrals(Jansen, 2006). Māori are more likely to have both ongoing issues with accessing healthcare services (McCarty et al., 2018) and to experience discrimination and face structural barriers to services (P. T. King, 2019). These are clear findings of inequitable outcomes for Māori (Reid et al., 2019; Talamaivao et al., 2020), driven in large part by healthcare system barriers (Masters-Awatere et al., 2020). The disability and social service landscape within Aotearoa New Zealand is separated into individual specialist areas. For end-users, this requires engaging with multiple providers and layers of bureaucracy, much of which is physically and culturally inaccessible. The process forces disabled people to engage with multiple persons to access services; persons who may or may not be appropriately equipped to manage disability and who may or may not have an understanding of Māori specific cultural needs.

The prevalence of disability within Māori communities' mirrors disproportionate representation in socioeconomic factors such as lower income, higher unemployment, and reduced access to education (Statistics New Zealand, 2015). Together, these compound and intensify negative impacts, resulting in Māori disabled being less likely to receive needed services and supports, let alone Māori-centred ones. The prevalence of disability also contrasts with accounts from the 18th Century when the British navigator James Cook arrived (Kukutai & Pool, 2014; Pool, 2015). Accounts from this time refer to Māori as a well-built, muscular, and healthy people (c.f. M. King, 2003). One hundred years after Cook's arrival, poor health conditions were widely

evident among Māori communities(M. King, 2003; Pool, 2015). The ongoing impacts of colonisation (Mikaere, 2015), including the introduction of foreign diseases (Moewaka Barnes & McCreanor, 2019), theft of land (Durie, 1994), state removal of children (Savage et al., 2021), and punitive state actions (Hodgetts et al., 2013) have all severely impacted on the physical and psychological health of Māori. The disparities in psychological and physical health continue today. Yet, these disparities are a reflection of the imposed systems that actively alienate Māori and Indigenous persons denying them access to wellbeing across the social, emotional and psychological spheres.

Case study: Tāngata Kāpō Māori

In considering the intersectionalities of ethical, disability rights, and Te Tiriti o Waitangi obligations, we draw on our work with tāngata kāpō Māori (Māori who are blind or low vision). This provides a case study through which we can exemplify the challenges experienced by Māori, systemic failures, and the need for researchers and practitioners alike to (re)consider their ethical obligations in research and practice. The experiences of tāngata kāpō Māori reflect wider experiences by Māori (Graham et al., 2023). Service provision can be patchy, inadequate, hard-to-access, and have multiple administrative hoops and bureaucratic barriers (King, 2019). There is no standard or comprehensive package of services for citizens with low vision and services vary depending on the person's age and where they live (Duckworth, 2015). For tāngata kāpō Māori, there is a shortage of low vision services and significant unmet need (Duckworth, 2015), with disability supports and services inconsistently provided (Himona et al., 2019; Ratima & Ratima, 2007). In short, participation in everyday life has multiple barriers, many of which remain invisible to fully sighted persons.

Case study: Methods

We collaboratively designed our research approach, bringing together academics, psychologists, and Māori. Together we drew on the combined lived experience of our respective networks and grounded the research design within Kaupapa Māori practice (Curtis, 2016). From the outset we prioritised relationships, engaged in specific processes of relationship building, and embedded appropriate tikanga Māori practices into research engagements (Cram et al., 2006). We did this by explicitly combining Kaupapa Māori methods (Smith, 2021) with kāpōtanga (social practices and ways of being that are specific to kāpō). Our collaborative process took time; we spent six to eight months in a period of relationship building. During this process we also mapped a three-year research programme plan that would enable each author to take a leadership role and access a fund tailored to that researcher's organisational interests. We also established clarity about the nature of the work and the obligations each team member held and could contribute. This all occurred prior to the first research funding application.

Across the research programme, wānanga were held in three major cities (Auckland, Hamilton, Christchurch) and online via video conference. Depending on the number of attendees, the duration of wānanga was between 2-5 hours. Altogether, six research wānanga were held; four with tāngata kāpō Māori and whānau (n=10, n=8, n=6, n=7), and two with industry professionals (n=2, n=3). Wānanga participants ranged in age from young adult (18 years) to elderly (over 80 years). Vision ability of participants ranged from none to some, with a variety of vision conditions represented. Some participants met the criteria for legally blind while others were whānau members of a blind child. Ethical approval from the University of Waikato Human Research Ethics Health Committee was obtained for each tranche of wānanga (reference: HREC(Health)2021#3; HREC(Health)2022#17).

Wānanga are distinct from Pākehā-style meetings, in that there is a particular set of meeting protocols that support an understanding of the process of learning (Mead, 2003). These protocols include (but are not restricted to) use of te reo Māori throughout speeches and karakia, ensuring appropriate time to engage in whakawhanaungatanga, answering the questions of attendees, and provision of manaakitanga. Intertwined with these are ways of engaging that are specific to Māori (Mahuika & Mahuika, 2020). Through this process of culturally appropriate relational engagement, that invited lengthy open and honest discussion, tāngata kāpō Māori and whānau were provided opportunities to share, confirm interpretation(s), and affirm research findings. The process of building a relationship took time; by the time a participant arrived at the research wānanga they had already had multiple interactions with members of the research team (introductory phone call, follow up phone call, reminder text, emailing of information sheet, emailing consent forms, transportation arrangement and confirmation). This support is particularly necessary for participants who regularly find events physically inaccessible, hard to navigate, and/or have had poor prior experiences. Interactions with participants across the entire

research process had to be inclusive, accessible, and of value for tāngata kāpō Māori. Such an approach was essential for creating the high level of trust necessary for the level of openness and sharing that occurred.

Case study: Key findings

When considering our research interactions across the four years, we present seven research activities that made visible the inadequacies of institutional research ethics when working with tāngata kāpō Māori. These components of research (informed consent, koha, wellbeing check, transport costs and dissemination) fall within 'standard' ethical considerations when undertaking research and includes considerations of people with a disability (such as carer support and accessibility requirements). Our observations of these activities are presented as learning opportunities for psychology researchers and practitioners working alongside people with lived experience of disability across the life course.

Informed consent

The Cartwright Inquiry highlighted the crucial importance of informed consent. Subsequently, a standard component of research practice is to gain informed consent via written consent forms, provision of information sheets, and to outline the procedures for doing so in applications to ethics committees. Signed consent forms are preferred, in part as this protects the institution and researcher from the risk of claims of non-consent. However, for some communities (e.g., participants with no or limited vision), written consent can be impractical, impossible, or unethical. Most research materials (e.g., recruitment posters, information sheets, consent forms) are not routinely provided in alternate forms such as Braille, New Zealand Sign Language, or Easy Read format[1]. Institutional ethics applications do not routinely require information to be available in alternate formats, nor do they recommend alternate formats be offered as an option. Consequently, research participation is difficult and inaccessible for disabled communities who use these languages.

As part of our negotiated relationship with tāngata kāpō Māori, we found that a Tiriti-based consent process would allow for the negotiation of consent to be achieved via different forms (e.g., written, oral, collective, individual). Taking a partnership approach considers the ways in which people access information, explicitly provides options for the provision of research materials in alternate formats and builds in adequate time to answer questions and discussions prior to beginning formal interviews. Similar to the experiences of Hodgetts et al. (2022) with homeless participants, producing written material for consent purposes can be associated with negative experiences and therefore harmful. Taking a purposefully decolonial approach to research embodies ōrite (equality) aspirations as described in Te Tiriti o Waitangi (Rua et al., 2021).

Our experience when working with tāngata kāpō Māori was that participants appreciated the offer of alternate formats such as Braille, or software readable information as pdf and word documents in large print. Explicitly stating that these were available signalled to participants that we understood a range of access requirements and would be prepared to meet them. Our participants found the following practices sufficient for enabling access: provision of materials ahead of time in electronic format, using a sans serif text (arial) and large font sizing (18pt), provision of printed materials on arrival at the wānanga, ensuring documents were high contrast (black text on white paper), and ensuring documents were not cluttered/without overly complicated background graphics. We also ensured that someone was available to read the text to participants, both prior to attending and on the day of the wānanga. All participants, despite their level of vision, wanted to personally sign the written consent form as an expression of self-determination and inclusion.

At the beginning of the very first wānanga in 2021, a matua (adult male) in attendance interrogated the research team in front of the wider group. Emboldened by the matua, participants asked questions beyond what was contained in the information sheets and consent forms. These questions included what the research team would do to materially improve the lives of participants and for tāngata kāpō Māori more generally. There was strong interest in how participating and sharing their experiences would result in actionable changes. It was only after we had satisfactorily answered these questions that the matua agreed to formally participate and the others present also. As a form of collective consent, whereby a more senior person takes on the role of undertaking due diligence before agreeing to proceed, and which signals to the others

[1] A type of presenting information developed to support people with learning (intellectual) disability. For more see https://www.odi.govt.nz/assets/Guidance-and-Resources-files/guide-to-writing-easy-read-information-people-first-2014.pdf

in attendance that the research is deemed satisfactorily appropriate, this not necessarily understood within Western frameworks that only recognise individual consent.

Koha

Koha, as a practice of maintaining social relationships and carries connotations of reciprocity, has evolved over time and is present in various forms. In the context of research, koha involves recognition of the time, expertise, and generosity of participants. For researchers, the lived experience of participants is appreciated for its expertise that brings valuable insight to the research topic. Reciprocal in nature, koha is not necessarily monetary. Reciprocity incorporates components such as providing transportation, adequate food and refreshments, and a sense of being valued (Masters-Awatere et al., 2021). Institutional ethics committees can misunderstand koha as a form of coercion, and, because of definitions provided by the Inland Revenue Department for tax purposes, mischaracterise koha as income. Subsequently, there is an added layer of interrogation by institutional committees on koha as part of routine research practice.

A Tiriti-based ethical approach recognises the diverse contexts within which people live, and that there is a need to be responsive to this diversity within the lives of participants. Being Tiriti-based in practice means recognising and valuing reciprocity in relationships. It is based on an understanding that reciprocity between researcher and participant leads to a greater depth of insight and sharing within the research relationship (Cornish et al., 2023). Providing freedom of choice with regards to koha is an offer of kāwanatanga (authority) and tino rangatiranga (self-determination) for participants.

Within our research, just as participants appreciated us being explicit about materials being available in alternate formats, participants also appreciated that we were explicit about what we would provide (transportation, food, vouchers access to any publications). However, as a form of reciprocity, it was that tangible items were provided within the context of value and care that was of more importance than the material act (of offering). Generous provision of food and refreshments during the wānanga contributed to a sense of feeling valued for their contributions and that this was a reciprocal (not an extractive) endeavour. Transport we discuss in detail in the next section. Providing vouchers at the end of the wānanga and offering access to any publications produced was a material act that concluded our formal interactions.

Transport

Transportation organisation and costs incurred travelling to and from research interviews is typically considered to be primarily the responsibility of participants. There may be some allowance for a petrol voucher or for public transportation costs, whichever is the lesser of the two. However, this framing fails to consider the increased financial cost and logistical implications faced by disabled persons. Tāngata kāpō cannot drive a vehicle, for obvious reasons. This leaves participants reliant on whānau, waiting on public transport (somewhat unreliable), or needing to book a taxi. A key feature from the outset was ensuring that each person had; forewarning of pickup and drop-off times, adequate transportation and were not out-of-pocket due to transport costs. We arranged prepaid taxis or drivers for participants and their support person. Mindful of anxiety caused by getting into a car with a stranger, we provided as many details as possible ahead of time (eg. Taxi company name, driver name, vehicle make, model, colour and registration). Arranging transport with the mindset of lessening anxiety for blind/low vision persons was quite an administrative task requiring considerable planning and effort.

Through taking on the task of organising transportation, we conveyed care for participants and that we valued their time. And despite our best efforts, this was not always possible. An example from our research was with a participant who expressed interest in attending the wānanga who lived 55mins from the wānanga venue. We discovered that arranging transportation suitable for an electronic wheelchair is financially prohibitive and logistically challenging. The cost of a mobility taxi vehicle with the required hoists, ramps, and weight grading to safely transport that participant was close to NZ$500, which was equivalent to the total cost for 7 other participants. There is no suitable public transport that can take an electronic wheelchair. We learned that simply asking "Do you need assistance?" is not enough; research needs to be financed appropriately to meet the additional transportation needs disclosed by potential participants. This example highlights the difficulties faced by disabled people in attending research interviews, the poor state of accessible transport, and the high cost of transport funding often borne by the participant rather than the researcher. In this case, our entire research travel budget would have been used in meeting the costs of one person.

Mobility challenges impact on people's lives in diverse ways. Standardised approaches to meeting transport needs can unintentionally act to exclude disabled persons and a more nuanced approach to resourcing participants to attend is required. The inconsistency of disability supports and services noted earlier by Himona et al (2019) and Duckworth (2015) are further compounded by institutional frameworks that fail to take into account that mobility can be varied amongst those with disability (eg. tāngata kāpō Māori and in a wheelchair). In respecting mana motuhake for tāngata kāpō (self-determination and control over one's own destiny) psychologists and researchers need to be mindful that assistance may be varied and as such ensure they have delegated sufficient resources.

Carer support

Sometimes a disabled person may require the assistance of a paid worker or family carer to attend a research interview. Research interviews and associated ethics applications often fail to include costs for support persons or acknowledge the ethical implications of having non-disabled caregivers of participants present. Our work with tāngata kāpō Māori revealed that for some participants, attendance is only possible due to the assistance of a paid carer or whānau member. This meant our wānanga needed to be able to cater for additional persons in terms of meeting space, transport costs, and food provisions. In terms of inclusion of non-disabled in our research, our position, after careful thought and discussion as a team, was those carers and whānau had valuable information to offer our research. We understood that the presence and support of a known and trusted person enabled the disabled person to attend the research wānanga and to contribute. Therefore, we welcomed both paid and whānau carers, including everyone, and treating carers and support persons with respect and dignity. We checked with the disabled person if they would like their carer and/or whānau member(s) to stay with them; if they said yes, we provided the carer/whānau member with an information sheet, obtained formal informed consent to participate, and included their perspectives. Tino rangatiratanga for participants was maintained throughout. When it came to analysis, we privileged the voice(s) of the disabled person; that means, the perspectives of tāngata kāpō Māori were front and centre, with the voices and perspectives of carers and whānau valued in support. This practice enabled us to uphold the intent of our research, support participants to attend and participate fully, and ensure that the voices of non-disabled were not spoken over or for.

Wellbeing check

Typically, research interviews take a 'hands off' approach to participants. Wellbeing checks tend to only be offered if the participant is perceived to be in distress or becomes visibly upset during the interview. Ethics applications to committees require consideration of potential areas of distress or harm, and for researchers to detail how they will manage this. Checking the wellbeing of any participant is a valuable and important process. For our participants who were being picked up by an un-known driver, taken to a setting to be with people they did not know, there was an added layer of apprehension that required 'checking in' ahead of time. Being kāpō enhanced the layers of concern that required managing. Participants had multiple questions regarding transportation, venue accessibility, and of the research team. Previous experiences attending events at inaccessible environments, past encounters with dismissive professionals, and memories of finding it difficult to arrange transport left participants reluctant to expose themselves to further harm. Having a designated person 'checking in' with participants across the entirety of the research assisted with alleviating concerns and provided a welcoming mechanism for participants to raise questions. In practice, we were able to support mana motuhake for participants through regular phone calls ahead of the wānanga, checking availability, sending a reminder to participants, and ensuring accessible transport. It also required follow-up phone calls to check participants felt comfortable and cared for throughout.

Accessibility requirements

Accessibility requirements are not necessarily considered when recruiting participants, nor are accessibility needs routinely considered in institutional ethics processes. The onus of responsibility to raise any access requirements predominantly lies with the participant, who is expected to disclose and request their access needs to the researcher. Accessibility requirements differ from person to person; central to the provision of accessibility is being able to ask, listen, and provide the supports needed for a person to attend and participate. As we identified under the heading Informed Consent, where a researcher identifies that alternate formats are available, specifies the accessibility of a chosen location, and/or acknowledges the need for low sensory environments, this communicates to potential participants that the researcher (a) has considered accessibility, and (b) is open to discuss and meet their specific access requirements. The absence of

communication regarding accessibility also communicates a message – that the researcher has not considered accessibility and may not be sympathetic to such requests. This has impacts regarding participation and disclosure of need.

Accessibility requires time, thought, and resourcing. Much information regarding access needs and how to meet them can be located online, but it does require intentional seeking out of such information. For example, venues for in person interviews will often provide accessibility information – if they are asked directly. A recent University of Waikato PhD project designed and made freely available Easy Read formats for consent forms and information sheets (Newcombe, 2024). Other access needs such as Braille and NZSL will require specialist translators and resourcing. Researchers demonstrate value towards ōritetanga when they are open to providing resources in whichever formats are desired or required by participants.

Dissemination

Psychology and academic institutions privilege publications in international, high impact, peer-reviewed, academic journals over presentations at conferences. While criticisms of the inequity of access and privileging of certain forms of knowledge are debated elsewhere, our reason for including dissemination here is because there is an ethical responsiveness required to present findings across different formats to ensure effective communication with participant groups and key stakeholders. Access to peer review journals behind pay walls that make them only accessible through membership often denies access to the very people who contributed to the knowledge (L. W. Nikora et al., 2017), invisibilising their perspective in the deluge of other 'research' (L. W. Nikora et al., 2016) and silencing their voices (Groot et al., 2012).

When considering various mechanisms for disseminating our research, we were mindful of the diverse audiences we wanted to interact with (politicians, health providers, psychologists and researchers), and our intention to prioritise the voices of tāngata kāpō Māori when making our arguments. While we were speaking to audiences who were not kāpō, we made sure to seek confirmation from tāngata kāpō beforehand. Presentations at conferences hosted by Kāpō Māori Aotearoa (KMA) and Parents of Vision Impaired New Zealand (PVI) to their membership ensured feedback and guidance on our thinking before producing written work for wider dissemination. Advice from Ngā Rōpū o Manaaki Tāngata Kotahitanga (M.T.K.), along with several newsletters, social media tiles, illustrations, and in person conversations provided feedback loops. In the context of our research, we found that dissemination in these alternate formats (c.f., peer reviewed journals) was preferred by disability communities. For the community we were working with, the dissemination of findings is connected to relationship maintenance and is therefore essential and ongoing.

The seven research activities are presented in summary format below (Table 1). In the left-hand column are a brief description of the above-mentioned standards we as researchers were expected to follow to obtain ethical approval and maintain ethical standards for our research. In the middle column are descriptions of the adaptive strategies we both used and considered important to delivering a Tiriti-informed ethics approach to our research. In the right-hand column are lessons we learned and in some instances the resource implications we noted when enacting our Tiriti-informed research activities.

Discussion

Previous Crown-led shifts to disability support services, such as the implementation of Whānau Ora (Taskforce on Whānau-Centred Initiatives, 2010; Te Puni Kokiri, 2016) and Enabling Good Lives (Social Wellbeing Committee, 2021), indicated numerous possibilities for creating Māori and whānau centric approaches, with emerging successful results (Were, 2017). However, more recent changes by the current National-led government to disability support services (Office of the Minister for Disability Issues, 2024) indicate that barriers to full participation and partnership for both disabled and Māori will remain, and that the Crown will continue to fail in its obligations to both. This has implications for the physical and psychological wellbeing of Māori disabled and their families. The politics of ethics, health and disability, and inclusion are intricately tied to ideas about human rights and Te Tiriti of Waitangi. Psychology as a discipline is enmeshed in the systems outlined in this introduction and requires a critical analysis of how structures and systems perpetuate inequitable outcomes and exclusion. The ongoing inequities for disabled people and for Māori reflect societal framings, inaccessible services, and chronic underfunding for both.

Key observations made over the course of our research programme have been presented in this paper to highlight the ways in which systems created by people without disability-centred knowledge unwittingly perpetuate inequity in ongoing ways.

Table 1. Research activity and relevant ethical approaches

Research Activity	Institutional research ethics	Tiriti informed research ethics	Resourcing lessons we learned
Informed consent	Preferably written format that produces a signed consent form	Can be received in different forms (eg. written, oral, collective, individual)	Information presented and stored in different formats, and languages costs
Koha	Definition is determined by taxation (IRD) and cannot equate to income	Recognises the diverse contexts people live; can vary between participants	Renumerate lived experience as a form of expertise that brings valuable insights
Transport	Standard contribution to cost of public transport (with exceptions) - for participant only	Mobility can impact people's lives in different ways, resourcing is required	Asking "do you need assistance?" is not enough. Dedicate resources to provide ongoing support
Carer support	Not included	Must be included	Requires resourcing
Wellbeing check	Is only required if harm or distress is identified	Essential throughout the entire process	Needs a designated person throughout the entire project
Accessibility requirements	Onus of responsibility on the participant	Onus of responsibility on the researcher	Requires time, commitment, and resources
Dissemination	Written formats (high impact journals) prioritised	Present across different formats to ensure effective communication	Connected to relationship maintenance and is essential and ongoing

Through presenting a sample of research activities engaged over the course of our research programme we are able to list institutional ethics expectations and consider how research activities may be expressed and/or experienced differently when reviewed within a Tiriti-informed lens/framework. The resource implications presented by the research team are offered as lessons learned and gifted to psychologists working with disabled peoples- whether as a client, service provider, teacher, supervisor or researcher. A common feature of research activities that follow institutional ethics processes derived from a WEIRD psychology lens is the way in which researchers place the onus of responsibility on participants. Experiential examples shared in the findings highlight how institutions value a researchers' time and energy (as a commodity) while simultaneously failing to recognise the expertise or demands being placed on research participants. This is most clearly evident in transportation requirements to the interview venue and in the provision (or lack thereof) of research materials in alternate formats.

The current arrangement of research funding encourages a transactional process between researchers and participants. These processes facilitate extractive interactions, whereby a researcher extracts examples from participants and compensates their inconvenience by offering a small token of appreciation. In contrast, 'expert advisors' to the research project can be paid high-level consultancy rates for their time. This has the unexpected result of keeping consultancy exchanges comparatively short (to save on research budget costs). In contrast, research participants are expected

to pay for and organise their own transportation to interviews, make themselves available during the workday and/or evenings, and to share intimate details of their lives. This means that there is a higher likelihood that the length of interaction is longer. Given that researchers would be unable to produce their report, publication(s), or frameworks without participants, there is a risk of voyeuristic and extractive research activities. Within the research exemplar shared in is paper, we intentionally share our purposeful approach to highlight how a partnership relationship built on a Te Tiriti understanding could work. This avoids the tendency towards voyeuristic or extractive approaches and creates a value-based, relational approach.

Māori never ceded their sovereignty. Rather, through Te Triti, Māori entered into a relationship with settlers that respected the self-determination (tino rangatiratanga), governance (kāwanatanga), and equity (ōritetanga) of both settlers and Indigenous persons. Despite this hope, ongoing processes of colonisation has seen experiences of marginalisation, invisibility, and 'othering' become the norm for Māori, and even more so for Māori disabled. The announcement of Whaikaha – the Ministry for Disabled People presented an opportunity to acknowledge chronic underfunding of Māori health service provisions. However, this opportunity has not been realised, with the current National-led government moving swiftly to curtail any such hopes.

The Waitangi Tribunal claim (WAI2575.2) lodged by Dr Michelle Levy (2018) challenges psychology for its role as a settler-colonial tool. WAI2575.2 describes the multiple ways that the employment, training and regulation of psychologists in Aotearoa maintains the poor outcomes experienced by Māori. These outcomes are intertwined with sociopolitical climates and actions in Aotearoa New Zealand. For example, the current National-led government is removing guaranteed Te Tiriti provisions in legislation and policies. This has the effect of keeping psychologists busy responding to these distractions. It also means that psychologist allies have less energy to consider systemic influences and how they impact on psychological research. The psychology profession is in a transitional state with the forthcoming review of the Health Practitioner Competence Assurance Act, review of ethics, and potential implementation of assistant/associate psychologist pathway. There is much potential here to shift approaches for the betterment of all.

Closing statement

Our research aimed to center kāpō Māori lifeworlds through documenting the experiences of tāngata kāpō Māori and their whānau. This paper presents descriptions of our research approach with Māori and disabled persons in the hopes that other psychologists and researchers can learn from our shared observations and experiences. We feel that the current work on proposed changes to the Code of Ethics, to align with Te Tiriti o Waitangi, are taking psychological practice and research in Aotearoa in the right direction. Our reflections provide insight to how psychologists can make better connections of national and international frameworks for disabled persons.

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