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REVIEW

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What do we know about the intersection of being blind and being Māori in Aotearoa New Zealand? Taking an applied community psychology approach to a systematic review of the published literature

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Abstract

Self-determination and dignity are guaranteed rights for disabled persons under the United Nations Convention on the Rights of Persons with Disabilities. However, such rights have been slow to eventuate for Māori (Indigenous people of Aotearoa New Zealand). This paper brings together systematic fashion publications that currently exist regarding blindness and Māori, centring throughout Māori understandings of disability and blindness. We employed a structured approach alongside PRISMA protocols and reflexive dialogue. Included publications were quantitative data reviews, surveys, qualitative studies, literature reviews and works of fiction. For our analysis, we formulated a matrix that drew from Kaupapa Māori, applied community psychology and disability rights literature. This meant we made explicit where research practices included—and excluded—self-determination, democratic participation and inclusion of both disabled and Māori. Our review highlights inconsistency across disciplines regarding self-determination and democratic participation by both Māori and disabled key stakeholders. Our approach can be utilised across disciplines as a tool for considering the ways in which researchers uphold Indigenous self-determination, disability rights and data sovereignty. Please refer to the Supplementary Material section to find this article's Community and Social Impact Statement.

KEYWORDS
disability, indigenous health, low vision, tāngata kāpō

1 | INTRODUCTION

For tāngata kāpō and their whānau[1] in Aotearoa New Zealand (NZ), health service provisions 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 Māori in particular, there is a shortage of low vision services and significant unmet need, as noted by Duckworth "People in need of low vision services who identify as Māori …and/or who live in provincial and rural areas are not receiving adequate services currently" (2015, p. 6).

The 2019 Māori Health Disability Statistical Report, which was submitted as part of the Waitangi Tribunal Claim #2575, found delays, absent data, baselines lacking and issues with rounding[2] when attempting to locate robust, comparable data for Māori disabled (Himona, Talamaivao, Yeh, & Paterson, 2019). Smaller population groups (such as kāpō Māori) are more easily identifiable, even within de-identified data. This has implications for ethical data use and makes it difficult to source statistically robust information. Despite challenges in sourcing accurate data, Himona et al. (2019) found that non-Māori children were attending ophthalmology appointments at twice the rate of Māori children. While Māori have increasing access to health services, these improvements are not reflected in attendance at appointments for ophthalmology or paediatric services at local publicly funded hospitals (King, 2019).

The experiences of tāngata kāpō reflect wider experiences by Māori within the publicly funded health system (Graham & Masters-Awatere, 2020). There are clear findings regarding inequitable outcomes for Māori within NZ's public health system (Reid, Cormack, & Paine, 2019; Talamaivao, Harris, Cormack, Paine, & King, 2020). This includes greater likelihood of adverse outcomes such as permanent disability and death for Māori patients in hospital (Blakely, Ajwani, Robson, Tobias, & Bonné, 2015; Davis et al., 2006), increased likelihood of inappropriate care and reduced likelihood of appropriate follow-up by medical professionals (Anderson et al., 2019), and delays in receiving appropriate care and referrals for specialist consults (Jansen, 2006). Vicariously experiencing negative treatment by caregivers also negatively impacts health outcomes (Paine & Stanley, 2020). Alongside this, current healthcare systems create barriers for Māori health professionals and patients to give and receive culturally appropriate care (Masters-Awatere, Cormack, Graham, & Brown, 2020).

There have been and remain ongoing calls for disabled persons worldwide to have self-determination with regard to decision-making (Charlton, 1998; Wong, 2020). The phrase "nothing about us without us" reflects this clear call from the disability community. Self-determination is a core orientation for critical disability studies, which utilises the socio-political construction of disability in arguing for the full social inclusion of disabled persons (Meekosha & Shuttleworth, 2017). However, while the discipline emphasises the need for social change to challenge systemic inequalities and social exclusion, understandings of disability are from a predominantly Western worldview (Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019; Smith & Routel, 2010). In contrast, a Māori-centred approach privileges Indigenous worldviews and takes a culturally specific orientation to disability (Nikora, Karapu, Hickey, & te Awekotuku, 2007). In NZ there are ongoing calls for tāngata whaikaha[3] to have rangatiratanga (self-determination) and to be treated in dignified and respectful ways (Nikora et al., 2007; Watene, Mirfin-Veitch, & Asaka, 2021).

Both self-determination and dignity are guaranteed rights for disabled persons under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Yet these gains have been slow to eventuate for the Māori disabled (Watene et al., 2021). Hickey (2020) and Ferdinand et al. (2021) argue that a contributing factor is the UNCRPD not fully recognising Indigenous approaches to disability.

Self-determination includes the right to decide what data is collected, held and how it is interpreted (data sovereignty). Indigenous scholars have strongly advocated for data sovereignty as a right to self-determination under Article 3 of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (Lovett et al., 2019). This right includes the right for Indigenous peoples to have their data and information collected either by themselves or in collaboration with them (Kukutai & Taylor, 2016). In a NZ context, this means Māori determine either alone or jointly what data is collected, how it is stored, how it is interpreted and how it is disseminated (Kukutai & Cormack, 2020). With regard to health data and disability, there remains a need for Māori rights to health data to be recognised, including the application of the principles of data sovereignty (Cormack, Reid, & Kukutai, 2019).

This review focuses on the existing literature on blindness as one aspect of disability in order to provide a more comprehensive and targeted analysis than would occur from a generalised review. This focus allows for a more nuanced understanding of blindness that includes a te Ao Māori[4] perspective. Additionally, blindness as a physical disability in NZ represents a specific set of access challenges that differ from those faced by individuals with other disabilities (La Grow & Daye, 2005), and as such represents a case study for examining how assumptions and inequities are perpetuated (Flyvbjerg, 2011). Furthermore, a systematic literature review that focuses on one aspect of disability can avoid making homogenised assumptions about the experiences of all Māori disabled.

Initial findings from our 2021 scoping project *"Seeing" Kāpō Māori* noted that everyday life has many barriers to participation for kāpō Māori and that disability supports and services are not consistently or readily provided (Masters-Awatere, Graham, & Cowan, 2021). During the initial COVID-19 response, blind persons experienced barriers with regard to accessing information, being able to independently travel, and finding services inaccessible (Graham, Masters-Awatere, Cowan, Stevens, & Wilkinson, 2021). Despite these findings, disability providers are still not necessarily able to meet vision-related needs in a culturally appropriate and supportive way. Tāngata kāpō who participated commented that some providers were "task-focused" rather than interested in ongoing supportive and reciprocal relationships (Masters-Awatere et al., 2021). This resulted in a sense that social services and/or health providers were "ticking the box" for funders, rather than intentionally seeking to meet the individual needs of tāngata kāpō and whānau. Expressed throughout was a clear desire to access available services and supports, information and documents in a way that was self-determining and dignifying.

This paper is an attempt to bring together, in a systematic fashion, the data and publications that currently exist with regard to blindness and Māori. In doing so, we seek to bring Māori understandings of disability and blindness into conversation with health-related publications detailing blindness and low vision as it occurs within Māori. In considering our positionality as a research team, we are Māori (BMA, CC) and Pākehā[5] (RG). Both RG and BMA are grounded in a community psychology orientation that values health equity, social justice and community well-being in research practice. Two authors (RG, CC) work within kāpō communities but are not disabled or blind themselves. We intentionally engaged in reciprocal relationships with tāngata kāpō as subject matter experts (SME) at each level of our work (direction, findings, discussion, dissemination) to ensure our paper appropriately reflected key kāpō concerns. Specifically, we met with SME throughout to engage in iterative discussion. Engaging in this process kept our analytical and academic work centred on matters of value and importance to tāngata kāpō. This was important to the authors in order to avoid replicating the research practice of non-disabled and/or non-Māori persons publishing work about disabled and/or Māori without engagement, consultation, or partnership. Our main research question was: What published literature already exists regarding blindness, low vision and vision loss in Māori? Our secondary research question was: Are the published findings interpreted from within a Māori framework of understanding? We deliberately cast our net wide in order to capture health and non-health-related studies, as even those studies published outside of health may have relevant information for our study.

2 | METHODS

We employed a structured approach alongside PRISMA protocols (Page et al., 2021) and reflexive dialogue (Graham & Masters-Awatere, 2020). The review process involved a systematic literature search, screening articles for relevance to the research question, selection and appraisal of studies, analysis and synthesis of findings.

2.1 | Systematic literature search and screening process

We utilised systematic procedures to search within three key database collections: ProQuest, PubMed and the University of Waikato's library. The ProQuest databases searched: Coronavirus Research Database, Medical Database, MEDLINE®, Psychology Database, PTSDpubs, Publicly Available Content Database, Social Science Premium Collection, Criminology Collection, Education Collection, International Bibliography of the Social Sciences (IBSS), Library & Information Science Collection, Linguistics Collection, Politics Collection, Social Science Database and Sociology Collection. ProQuest was selected as it includes both social science and medical databases. PubMed had a wider medical-related study search than the other two databases. At the time of the search, the University of Waikato Library had access to 271 databases. Due to our focus on Māori, we also specifically searched AlterNative: An International Journal of Indigenous Peoples for relevant articles. Utilising search terms across all four gave us confidence that our systematic search was sufficiently broad to include adequate published literature at the intersection of blindness, low vision, visual impairments and Māori.

The systematic search was organised around two core categories: Māori and visual impairments (Table 1). Search terms were challenging in that "vision", "visual" and "blind" have multiple meanings and are utilised in academia to refer to items such as "double-blind trial" and "future vision". The search terms "vision loss" and "sight loss" produced minimal results. We did not search for specific diagnoses due to the large range and diversity of eye conditions that result in vision loss. We identified the terms "low vision" and "blindness" as terms that specifically referred to sight loss and which produced sufficient articles across social science and medical databases when utilised in the described manner. We found no difference in search items from using macrons or without that is, kapo/kāpō and Māori/Maori produced the same results from database searches. Using the double macron as per Waikato-Tainui[6] dialectical practice (e.g., Maaori) produced no results. All searches were conducted on 6 April 2022 and included articles published in English and in te reo Māori.[7]

Inclusion criteria were: (1) Publication discusses blindness/visual impairments, (2) study participants were clearly identified as Māori and/or publication centred te Ao Māori and (3) publication was in English. Exclusion criteria were: (1) Publications unrelated to visual impairment; (2) lists of abstracts, indexes and presentations where no further content was available and (3) Māori participants not clearly defined or no Māori participants in the study. We intentionally included all items and all dates due to the paucity of published material on the topic of blindness and Māori.

2.2 | Study selection and appraisal

The ProQuest search yielded 334 potential publications. PubMed databases resulted in 163 potential studies. The University of Waikato's database listed 101 potential articles. There were no publications in AlterNative. Lists of abstracts and presentations ($n = 12$) were excluded, as were articles not in English or Māori ($n = 2$). Removing duplicates ($n = 32$) left 552 articles which were read by title and abstract. This screening process excluded publications on topics other than blindness and visual impairments ($n = 243$) and publications that did not have Māori participants ($n = 271$). The remaining 41 items were subject to a full-text assessment and appraisal process and 8 publications identified as not meeting the inclusion criteria were excluded. One additional article was identified for inclusion. Altogether 34 published items fully met our inclusion criteria (Figure 1).

TABLE 1 Search terms and results.

Database and search	Search terms	Items (*n*)
ProQuest		
Search 1	Kapo Maori	18
Search 2	"Low vision Maori"	2
Search 3	"Low vision" + "Maori"	32
Search 4	"Low vision" + indigenous	242
Search 5	Su("BLINDNESS") AND ("Maori")	37
Search 6	Su(blindness) and su(Maori)	3
PubMed		
Search 1	(Kapo) and (Maori)	0
Search 2	(Kapo)	80
Search 3	(low vision) AND (Maori)	33
Search 4	(low vision) AND (indigenous)	50
University of Waikato		
Search 1	Any field contains kapo* AND any field contains Maori	70
Search 2	TI contains low vision AND any field contains Maori	4
Search 3	TI contains low vision AND any field contains indigenous	21
Search 4	SU is exact blindness AND SU contains Maori	6
Alternative		
Search 1	Kapo Maori	0
Search 2	Kapo	0
Search 3	Low vision Maori	0
Search 4	Blindness	0
	Total	598

Included publications were quantitative data reviews, surveys, qualitative studies, literature reviews and works of fiction. The rationale for including the latter is that these works are relevant to te Ao Māori and provide a wider context within which to situate understandings of disability and blindness. These publications were assessed (see below) for their contribution to insight and understanding of te Ao Māori with regards to being kāpō (a central focus of the review).

A checklist for appraising qualitative research for "rigour" and "research quality" (such as the Critical Appraisal Skills Programme or CASP) is typically utilised in systematic reviews. These checklists focus on procedural aspects pertaining to positivist research paradigms. Kaupapa Māori[8] perspectives and/or contributions to te Ao Māori are absent from these assessment processes. As noted by Rolleston et al. (2020), Graham and Masters-Awatere (2020) and Wilson, Moloney, Parr, Aspinall, and Slark (2021), criteria grounded in positivist paradigms are inadequate for assessing Kaupapa Māori-oriented research work. Therefore, we did not use the CASP appraisal process to exclude qualitative studies, as even so-called "low-quality" qualitative studies can contribute highly relevant and useful information (Mbuzi, Fulbrook, & Jessup, 2017). Instead, we drew on Sandelowski and Barroso's (2007) typology of qualitative appraisal, which involved several readings of each article to become acquainted with the content. This "reflexive dialogue" (Graham & Masters-Awatere, 2020; Ludvigsen et al., 2016) approach is congruent with our stated Kaupapa Māori orientation.

We undertook a full-text assessment and applied our reflexive dialogue appraisal to all 39 papers. During this process, we were guided by the following questions:

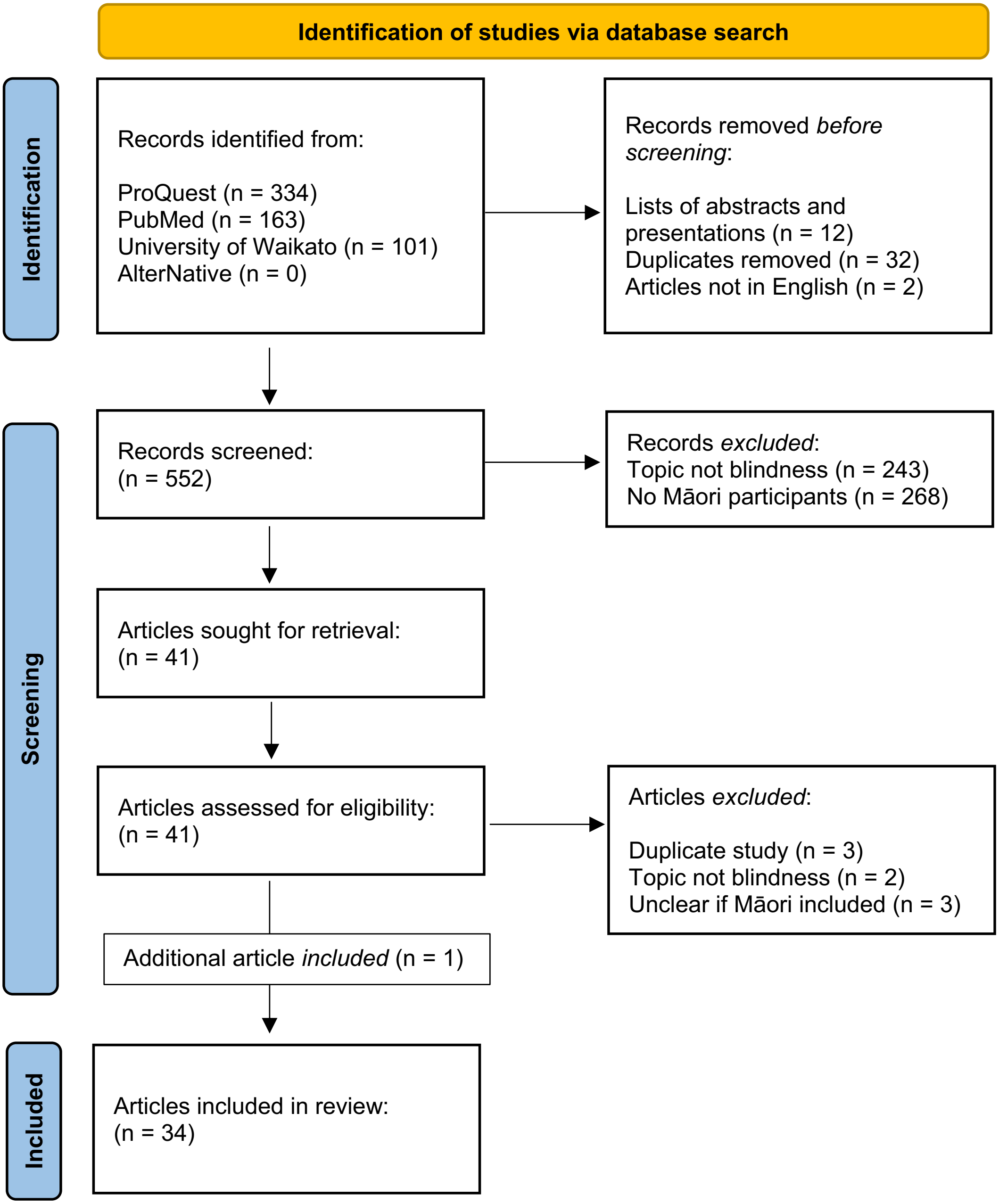

FIGURE 1 Flowchart of the study selection process (Page et al., 2021).

1. Does this publication contribute knowledge regarding blindness, deafblindness, low vision or vision loss in Māori?
2. Do the research papers clearly state the number of Māori participants?

Subsequent to our appraisal process we excluded a further 7 papers. One excluded study referred to the "multi-ethnic" heritage of participants, and to "African and Asian ancestry" but it was unclear if this included Māori. Another study stated that the study cohort was "culturally diverse (reflecting national averages)", implying Māori were included but the actual numbers of Māori participants were not explicitly stated within the study. Another drew on previously published work teaching Māori students Braille but did not include Māori students. These three (3) studies were excluded due to a lack of clarity regarding the inclusion of Māori participants. Additional studies were excluded due to discussing wider disability issues (but not blindness) ($n = 2$), and duplicate studies ($n = 3$). Duplicates were an illustrated edition of a previously published work ($n = 1$), an Introduction to a Special Issue which introduced an already-included publication ($n = 1$), and a protocol for an already-included review ($n = 1$).

During the appraisal process, one review included two (2) papers from NZ. Both of these publications included Māori participants with a vision-related diagnosis (diabetic retinopathy). One study was already included (Reda et al., 2003), but the other was not (Jagadish & Dalziel, 2017). A decision was made to include this second study due to its relevance to the topic and meeting the inclusion criteria (visual impairment, inclusion of Māori participants, publication in English).

2.3 | Analysis

Our iterative process involved a thorough reading of all included studies by the first author who undertook the initial analysis and noted core themes. This was followed by a robust, collaborative discussion with all authors and further conversation with key stakeholder groups (tāngata kāpō). Following this we grouped publications into three core areas: (1) te Ao Māori understandings of blindness; (2) experiences of tāngata kāpō; and (3) medical studies. It was clear when reading as a research corpus that, while (1) and (2) drew on each other, (3) was often disconnected from (1) and (2). We were curious as to why health and medical studies were so disconnected from the experiences of tāngata kāpō and te Ao Māori.

In considering how the published studies related more generally to a disability, we took an applied community psychology approach. This involved centring self-determination of disabled persons (Prilleltensky, 2001), democratic participation in research (Gokani & Walsh, 2017) and disability activism (Balcazar & Suarez-Balcazar, 2016). In particular, we were interested in how each study promoted wellness and welfare and supported/challenged the social order with regard to advancing the self-determination of disabled persons (Prilleltensky, 2012). These community psychological values are applicable to disability-related research and are useful in arguing the need for research to be undertaken *with*, not *on* tāngata kāpō. Our research approach aligns with the disability slogan "nothing about us without us", which has long been utilised by the disability community to argue for self-determination and inclusion (Charlton, 1998). We were interested to see if this community psychology and disability-centric values of autonomy and self-determination were consistently applied across research areas. Taking a critical community psychology orientation to a disability, and more specifically to vision-related disabilities, broadened the focus of our review beyond individual diagnoses and experiences of institutions to the wider social context.

Subsequently, we asked the following questions of each article:

- How does this research incorporate and/or apply to Ao Māori to their methods and/or analysis and/or discussion?
- What does this work contribute to knowledge about tāngata kāpō? Does the study method and/or findings support self-determination for tāngata kāpō?
- Is there democratic participation by Māori? Did key stakeholder input by tāngata kāpō occur? Was this clearly documented in the research process? Are the authors Māori and/or tāngata kāpō and is this clearly identified?
- Does the study promote the wellness and welfare of disabled persons? Does the study challenge the social order and/or advance the self-determination of disabled persons?

These questions and findings for each paper were entered into a matrix and colour coded according to the answers (yes = green, somewhat = yellow, not at all = red). This matrix is available via Data S1.

2.3.1 | Limitations of our approach

Reports and other grey literature are not necessarily searchable or findable within academic databases. Māori-centred health research is often found outside of academic databases (Rolleston et al., 2020). For example, there is a lengthy research report on the experiences of growing up kāpō Māori by Higgins, Phillips, Cowan, Wakefield, and Tikao (2010). This report is available online but is not included in academic databases. This is a limitation for systematic reviews in general, and our paper is no exception. We have included grey literature in the introduction and discussion to ensure the review does not exclude this material. Another limitation of our paper is that in focussing on Māori we risk excluding the experiences of disabled persons and/or suggesting that the disabled are a "separate" category. There is room for more research that incorporates disability and Māori perspectives and which does not perpetuate a false dichotomy of having to choose between groups.

3 | RESULTS

Our systematic processes reduced 598 identified publications to 34 (Figure 1). Included studies (Table 2) have publication dates from 1966 to 2022 and all contributed information regarding visual impairment and Māori.

Part of our analytical process involved placing publications in chronological order. Doing so highlighted the paucity of research on the topic; between 1966 and 2008 there were only 4 publications that met our inclusion criteria. Chronological reading highlighted that several publications were connected to specific researchers and/or a particular (funded) project (e.g., Bevan-Brown $n = 3$; Higgins $n = 3$, BLENNZ data sets $n = 5$, Graham $n = 2$). Reading the publications in chronological order also made visible the ways in which Kaupapa Māori research practice has (or has not) been included over six decades. Early European writings by Grosvenor (1966) and, later, Nagel (1998) refer to "Maoris", a grammatically incorrect anglicised pluralism that has since been discarded. The first publication by a Māori author on the topic of blindness was in 2008, with Ivan te Momo's thesis. His approach centred on Māori experiences and carefully documented the way in which tāngata kāpō historically experienced erasure and cultural violence with regard to language, education and inclusion in society. Subsequent qualitative work consistently included Māori authorship and explicitly drew on Kaupapa Māori theories and methodologies, a clear shift in research practice from 2008. This was most obvious in education-related publications that evidenced a clear conceptual shift from Nagel in 1997 to McFarlane et al., in 2021. The quantitative examination of medical datasets has not evidenced the same shift.

Unusually for a systematic review, we included works of fiction and literary writings. The rationale for this was that (a) these publications communicate valuable knowledge regarding Māori perspectives, and (b) as a group, these writings (Table 3) provide a framework within which to view and analyse subsequent published work on the topic of blindness. Tikao et al., (2009) documented oral histories and oral stories (such as Hyland's) and collectively analyses how these stories communicate te Ao Māori conceptualisations of blindness and disability. The literary analysis by Barker (2013) of *Baby No-Eyes* links blindness and disability to the wider context of whānau well-being. Central to *Baby No-Eyes* is the link between Māori health and the land (and how experiences of colonialisation have disrupted this). Both Tikao et al., (2009) and Barker (2013) draw on oral histories and cultural practices to communicate the value of whānau members that extends beyond physical impairments. Tapping's short story is located within childhood experiences of kura (school), tangihanga (funerary practices) and whānau (family). Tapping incorporates dialectical nuance which is assumed as background knowledge. The te reo Māori educational resources by McMillan (2012), Kaa (1998) and Mataira (1991) embed and draw on the understanding of te Ao Māori as naturally occurring in everyday life. All three communicate family, friendship and connection, where disability (blindness) is an ordinary part of childhood experience.

Across Table 3, blindness, disability and even death are treated as ordinary parts of the rhythms of life. Disability and care are constructed as occurring within the context of wider familial and friendship connections, with an

TABLE 2 Summarised list of included studies in the systematic review.

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
Bevan-Brown, Walker, 2013	Taking culture into account: A Māori perspective on visual impairment.	10 kāpō (8 men, 2 women, ages youth to 76) and whānau from 5 kāpō (numbers not stated).	Purposive sampling from a list of Ngāti Kāpō members.	In-depth, face-to-face interviews, questionnaires and KM approach implied. Thematic analysis.	Discusses barriers to cultural participation.
Bevan-Brown, Walker, 2015.	Working with Māori children with special education needs: he mahi whakahirahira.	10 kāpō (8 men, 2 women, ages youth to 76) and whānau from 5 kāpō (numbers not stated).	Purposive sampling from a list of Ngāti Kāpō members in the Wellington, Horowhenua and Manawatu regions.	In-depth, face-to-face interviews, questionnaires and intentional KM. Thematic analysis.	Book chapter—Goes more in-depth than the journal article regarding the research process.
Bevan-Brown, 2013	Including people with disabilities: An indigenous perspective.	10 kāpō (8 men, 2 women, ages youth to 76) and whānau from 5 kāpō (numbers not stated).	Utilised previous data set.	Re-analysed previous data set, this time with an intentional KM lens. Inclusion lens applied to thematic analysis.	Reviews 3 research studies investigating Māori perspectives of intellectual disability, blindness, vision impairment and autism examined for evidence of inclusive and exclusive attitudes and practices. Findings show that people with intellectual disabilities, ASD, blindness and vision impairment were generally valued family members and many examples of inclusive attitudes and practices were shared.

(Continues)

TABLE 2 (Continued)

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
Boyd, Kvishinadze, Kho, Wilson, Wilson, 2020	Cataract surgery for falls prevention and improving vision: Modelling the health gain, health system costs and cost-effectiveness in a high-income country.	Not explicitly described.	Literature review, PubMed, Cochrane and DARE databases, NZMJ, NZ blind foundation website, NZ Ministry of Health national data collections.	Data modelling and QALY (quality-adjusted life year) to determine risk reduction based on first eye surgery.	Expedited cataract surgery is cost-effective. Routine cataract surgery is very cost-effective as it prevents falls. No difference in findings for Māori c.f. non-Māori. The younger the person is, the more cost-effective the surgery.
Burn et al., 2021	Eye care delivery models to improve access to eye care for indigenous peoples in high-income countries: a scoping review.	Included 2 studies from NZ with Māori participants.	Systematic review of published literature. PRISMA protocols followed. Included studies had to have at least 50% of participants as indigenous (in NZ, Māori) participants.	Thematic analysis. Descriptive statistics. Levesque model of access dimensions. Data read for indigenous engagement and cultural sensitivity.	Barriers to eye care that exist in NZ for Māori are similar across other high-income countries. Connects kāpō experiences to wider indigenous challenges. Lack of literature on Māori (and indigenous) experiences and eye care more generally. Eye care studies rarely follow basic protocols for working with Indig groups, including Māori.
Chilibeck, Mathan, ng, McKelvie, 2020	Cataract surgery in New Zealand: Access to surgery, surgical intervention rates and visual acuity.	5,460 Māori referred for cataract surgery Nov 2014–Mar 2019.	National prioritisation data for cataract surgery from NZ Ministry of Health NPWS database. NZ census data.	Retrospective cohort study of all patients referred for cataract surgery in NZ public healthcare system from Nov 2014 to March 2019. Statistical analysis.	Ethnicity of patients referred reflects NZ ethnicity data. Māori is likely to be referred to younger and with worse cataracts. By the time Māori patients are referred with

TABLE 2 (Continued)

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
					prioritisation their eyesight is significantly worse than for Europeans. Māori develop more advanced cataracts at a younger age than Europeans. Access to cataract surgery is inconsistent across DHBs. Study notes inequities for Māori consistent with other health disparities in the NZ health system. Study recommends improving access for Māori to cataract surgery.
Chong, Dai, 2013	Cross-sectional study on prevalence, causes and avoidable causes of visual impairment in Māori children.	106 blind and 64 low vision Māori students (under 16 years).	Retrospective data collection of BLENNZ students under the age of 16.	Retrospective review. Statistical analysis.	Main cause of blindness in Māori children is CVI. Prevalence and causes of blindness comparable to other ethnic groups, except for avoidable causes of blindness, which are NAI (24.5%), neonatal trauma (15.1%) and neonatal infections (9.4%). Avoidable causes of low vision in Māori children are aphkia (18.2%), corneal scarring (18.2%) and trauma/ asphyxia (13.6%).

(Continues)

TABLE 2 (Continued)

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
Chong, McGhee, Dai, 2019	Causes of childhood low vision and blindness in New Zealand.	143 blind Māori children. 125 low vision Māori children.	Retrospective data collection from records of students registered with BLENNZ. NZ Census 2013 dataset.	Retrospective audit. Descriptive statistics. Statistical analysis. No separate statistical analysis conducted for Māori children.	Disproportionately high proportion of Māori children with visual impairment (30.7% c.f. 23.1%). No reason given for this finding.
Chong, et al., 2018	Predictors of long-term neurological outcomes in non-accidental head injury.	27 Māori children diagnosed with NAI May 2005–May 2010.	BLENNZ data. Local children's hospital medical records. NZ Census 2006 data. Children diagnosed with NAI (non-accidental injury) May 2005–May 2010.	Ordinal logistic regression with explanatory variables. Statistical analysis using SPSS.	Two-fold prevalence of NAI in Māori children when compared to other ethnic groups in NZ. No other separate statistical analysis for Māori children in the study.
De Kok et al., 2017	What is the relationship between visual impairment and cognitive function in octogenarians?	421 Māori from the LILACS study over the age of 80, of which 210 Māori over the age of 80 participated in the study.	LILACS NZ study data.	Interviewer administered the questionnaire, physical assessment ad medical records. Descriptive statistics. Māori and non-Māori results analysed separately.	No association found between visual impairment levels and cognitive function in octogenarian Māori. Predictors of poorer cognitive function in Māori were male gender and more depressive symptoms. Post-secondary educational levels are associated with better cognition.
Ferguson, sung, McKelvie, 2019	New Zealand childhood ocular trauma study: Analysis of 75,601 cases of ocular injury from 2007 to 2016.	12,807 Māori 0–17 years from the national dataset. 3,172 Māori 0–17 years from Auckland region. 327 Māori 0–17 years from	ACC dataset. NZ Census 2013 data. Auckland Hospital medical records.	Retrospective analysis of all ocular and adnexal traumatic injuries in children aged 0–17 years from 1 Jan	Overall incidence of ocular injury is no different for Māori and non-Māori aged 0–17 years, but Māori 60% more likely to have permanent

TABLE 2 (Continued)

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
		Auckland hospital records.		2007 to 31 Dec 2016 in NZ. Statistical analysis.	vision loss from ocular trauma. No separate analysis for Māori. No discussion on ethnic disparities. Use of protective eyewear for Māori recommended.
Goh, Andrew, McGhee, Dai, 2014	Clinical and demographic associations with optic nerve hypoplasia in New Zealand.	33 Māori children enrolled at BLENNZ under the age of 16 with optic nerve hypoplasia.	Retrospective review of medical records of BLENNZ students under the age of 16, 2010–2012.	Retrospective review. Descriptive statistics. Statistical analysis via SPSS. Analysis of maternal age.	Māori children with optic nerve hypoplasia are overrepresented (40%) compared with other ethnic populations in NZ (14.6%). Median maternal age for Māori mothers (19.0 years) is younger than for other ethnic groups. Authors postulate maternal age as a causation/risk factor.
Graham, et al., 2021	COVID-19 and blind spaces: Responding to digital (in)accessibility and social isolation during lockdown for blind, deafblind, low vision and vision impaired persons in Aotearoa New Zealand.	Analysis by authors of observed experiences. 2 authors are Māori and 1 author is deafblind.	Critical examination of lived experience of consumer group members.	Iterative discussion with literature and lived experience	Documents challenges faced by people who are blind, deafblind, low vision and vision impaired (BLV) during the COVID-19 lockdown of NZ. Details ways in which people who are kāpō and Māori managed to care for each other and uphold ways of being Māori despite government actions.

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TABLE 2 (Continued)

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
Grosvenor, 1966	Causes of blindness in New Zealand's Māori and European children.	39 Māori children enrolled at the blind school.	RNZFB data.	Descriptive statistics.	Māori children are disproportionately blind, affected by infectious diseases (rubella), lower survival rate than prem babies. Māori whānau are more likely to care for children at home.
Higgins, Phillips, Cowan, Tikao, 2009	Identity, cultural well-being and growing up kāpō Māori.	6 rangatahi kāpō 13–20 years (3 male, 3 female), 9 whānau members of 5 kāpō tamariki (under 12 years).	Does not explicitly state but is implied that participants are from Ngāti Kāpō.	Unstructured open-ended interviews, intentionally KM. Thematic analysis.	Explores how education services impact the identity and cultural well-being of kāpō Māori.
Higgins, Phillips, Cowan, 2013	Eighty years of growing up kāpō (blind) Māori: What can we learn about inclusive education in New Zealand?	39 whānau members and 8 kāpō Māori of various ages.	Recruitment not stated.	Unstructured open-ended interviews, intentionally KM, created 10 case studies. Case study approach, thematic analysis	Covers 80 years of the history of kapo and the experiences of different age groups.
Hyland, 1997	Te Kāpō the Taniwha, from Paki waitara: Myths & legends of the Māori.	Stories from te Ao Māori.	Re-tells the story of Te Kāpō the Taniwha.	Fiction	The story of a south island taniwha who carved the hills and valleys, but who was tricked by the gods who took his sight.
Jagadish & Dalziel, 2017	Discharge outcomes of patients referred to specialist eye clinic from diabetic retinopathy screening in Northland (2014–15).	57.1% of 98 patients were referred by DRS to a specialist eye clinic at Whāngarei Hospital over 12 months period (56 Māori patients).	Retrospective audit of 2014–2015 data from optimise database which stores the diabetic retinal screening photographs.	Descriptive statistics. Pathways for Māori not analysed separately. Non-attendance rates mentioned. Unclear how many Māori attended specialist	90% of patients who did not attend their specialist appointment were Māori. Barriers to access for Māori were sought through a patient

TABLE 2 (Continued)

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
			Database records demographics, disease data and digital retinal photographs.	appointments after the referral process is unclear. Analysis glosses over this part.	satisfaction survey and addressed via flexibility in changing appointments, new referral forms and telephone confirmation of attendance. Non-attendance rates at specialist eye clinics are being researched via patient surveys and focus groups.
Kaa, 1998	He kāpō ahau.	Blind child describing a cat.	Children's junior reader in te reo Māori.	Fiction. Te reo Māori learning resource for children.	A child is using her hands and fingers and describing what she feels as she is petting a cat.
Macfarlane, Macfarlane & Mataiti, 2020	Cultural and sociocultural influences and learners with special needs.	Book chapter considering sociocultural learning needs of Māori students.	Literature review and synthesis.	Literature analysed using Kaupapa Māori approach/framework.	Draws on literature included in this review regarding kāpō Māori. Extends this to disability and education in general.
Masters-Awatere, Graham, Cowan; 2021	Technical report. “Seeing” Kāpō Māori: Making visible the experiences of Kāpō Māori during and after COVID-19.	Seven (7) kāpō Māori from the Waikato region.	Recruitment not stated.	Two (2) wānanga (group interviews). Utilised He Korowai Oranga framework from the Ministry of Health.	Kāpō participants discussed barriers and facilitators to support during COVID-related lockdowns.

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TABLE 2 (Continued)

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
Mataira, 1991	Te kuia kapo me tana mokopuna.	Blind grandmother and her grandchild at the zoo.	Children's play in te reo Māori.	Fiction. Te reo Māori learning resource for children.	A blind grandmother and her grandchild visit the zoo. The grandchild describes various animals, ending in a humorous encounter with an elephant.
McGhee, Zhang, Patel, 2020	A perspective of contemporary cataract surgery: The most common surgical procedure in the world.	Included studies with Māori participants.	Review of previously published cataract studies.	Descriptive statistics. Core themes across published studies.	Biometry characteristics in Māori and Pacific populations. Disparities in health care (more advanced cataract at an earlier age, greater risk of intra-operative complications, yet disproportionally less access to cataract services) for Māori.
McMillan, 2012	Colour the stars/Taea Nga Whetu.	Bilingual children's book on the topic of blindness.	Author's observations and knowledge.	Fiction picture book.	Book written in English and translated into te reo Māori. Uses fiction to communicate knowledge on blindness, friendship and disability.
Nagel, 1998	Towards access and equity: The education of students with visual impairment in New Zealand.	Not specifically stated for students. Mentions the 500 members of the RNZFB who identified as Māori in 1990.	Ministry of Education data on visually impaired learners in 1998. 1996 survey data. Relevant Ministry of Education policies. Historical RNZFB report data.	Synthesises data sets into a summary of currently available supports and current needs.	Summarises the history of the emergence of culturally appropriate support for Māori in the early 1990s and recognition by RNZFB of the need to provide whānau workers for Māori who were blind or

TABLE 2 (Continued)

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
					had low vision. Recognises the need for culturally relevant educational and health support for Māori.
Pandita, Merriman, 2012	Ocular trauma epidemiology: 10-year retrospective study.	287 Māori patients presenting at Waikato Hospital with ocular trauma.	Waikato DHB case study review notes from Jan 1999 to Dec 2008.	Statistical analysis (chi-squared, ANOVA) on causes of ocular trauma. Data on Māori not analysed separately.	Includes Māori in the results section but results are only discussed with regard to gender not ethnicity.
Papali'i-Curtin, Cox, Ma, Woods, Covello, Hall, 2019	Keratoconus prevalence among high school students in New Zealand.	267 Māori high school students in year 9 and year 11 in the Wellington region.	49 high schools in the Wellington region, year 9 and year 11 students. NZ Census 2013 dataset.	Population-based prospective cross-sectional cohort study. Screening by an ophthalmic technician. Statistical analysis.	Māori high school students are more likely to have keratoconus (1 in 45 Māori c.f. 1 in 191 non-Māori). Keratoconus diagnosis associated with lower deciles.
Reda et al., 2003	Screening for diabetic retinopathy using the mobile retinal camera: The Waikato experience.	1731 Māori (880 female, 851 male).	Retrospective audit of the diabetic retinal photo-screening programme at Waikato DHB 1993–2001.	Descriptive statistics.	Did not attend (DNA) rates for Māori 32.2%. Māori have a higher prevalence of vision-threatening retinopathy (VTR) due to diabetes. "Despite significant efforts to improve physical access to photo-screening, the failure-to-attend rates in all ethnic groups other than Europeans are disappointingly high".

(Continues)

TABLE 2 (Continued)

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
Barker, 2013	"The ancestors within" genetics, biocolonialism and medical ethics in Patricia Grace's Baby No-eyes.	Fictional character, Baby No Eyes.	From the book, Baby No Eyes, by Patricia Grace.	Author interpretation of Grace's work.	Gives insight into the construction of blindness within te Ao Māori.
Tan, Chong, Darlow, Dai, 2015	Visual impairment due to retinopathy of prematurity (ROP) in New Zealand: a 22-year review.	18 Māori children with ROP (retinopathy of prematurity).	Retrospective review of children under the age of 21 with ROP registered with BLENNZ 1991–2012.	Retrospective review. Independent sample *t*-test, fishers test. Statistical analysis.	Prevalence of ROP is consistent across ethnic groups that is, not more for Māori children than in other ethnic groups. Data for Māori not analysed separately.
Tapping, 2015	Kata and Kāpō	Fiction short story in Huia short stories 11: Contemporary fiction.	Two girls (nicknamed Kata and Kāpō).	Chapter assumes knowledge and understanding of the Māori language and practice.	Deals with death and dying and children's friendships. Visual impairment and death framed as ordinary parts of life that just "are".
Te Momo, 2008	From Darkness to Dawn? A Forum for Kāpō Māori.	8 kāpō of various ages.	Known to author, author contacted directly.	Face-to-face unstructured interviews, intentionally KM. Thematic analysis.	History of te reo Māori, Ngāti Kāpō, RNZFB. Discusses te reo Māori, Māori identity and blindness. Identifies that blind sector has a history of being unresponsive to Māori cultural needs. Documents oral histories from participants and the challenges they face in this regard.

TABLE 2 (Continued)

Author, date	Title	No. Māori participants	Recruitment process/ data set	Methods & Analysis	Key findings relevant for kāpō
Tikao, Higgins, Phillips, 2009	Kāpo (blind) Māori in the ancient world.	Written studies, stories and oral histories.	Literature review	Analysis of oral histories and written texts that examine how blind people were viewed and treated pre-colonisation.	Provides clear themes regarding the role of kāpō within traditional Māori society.
Turner, 1991	Te kuia kapo me tana mokopuna.	Short play for children is part of a collection of short plays for children in te reo Māori.	Blind grandmother (kuia kapo) and her grandchild (mokopuna).	Te reo Māori teaching resource for children.	Grandmother and grandchild are visiting the zoo, grandchild is describing the animals to the blind grandmother as they walk around the zoo grounds.
Warman et al., 2011	Circadian-related sleep disorders and sleep medication use in the New Zealand blind population: An observational prevalence survey.	42 adult Māori, 24 of which were blind, 12 with light perception and 6 sighted.	RNZFB member database.	30-min telephone survey. Statistical analysis via SPSS matched for domicile deprivation rating.	High rate of participation by Māori (5% of RNZFB database, 11% participation rate in study). Circadian-related sleep disorders are slightly worse for Māori (increased rate of drifting sleep).

TABLE 3 Included works of fiction and literary writings.

Author & title	Short synopsis & relevance
Hyland (1997). Kāpo the Taniwha.	Children's storybook, which includes the story of a south island taniwha (Kāpo) who carved up the hills and valleys, and who lost his eyesight as a result of losing a bet with the gods. In this story, blindness was an affliction that befell a taniwha who made a foolish bet with the gods and slept on the job.
Tikao, Higgins, & Phillips (2009). Kāpō (blind) Māori in the ancient world.	Analysis of Oral histories and written texts that examine how blind people were viewed and treated pre-colonisation. Brings together multiple stories and oral histories into one publication. Oral histories and stories talk of strong and capable (kāpō) ancestors. Blindness is viewed as a gift, as a part of life, as a sign and blind people are viewed as no more or less valuable than fully sighted peers.
Barker (2013). "The Ancestors Within". Genetics, Biocolonialism and Medical Ethics in Patricia Grace's Baby No-Eyes	Literary analysis of Patricia Grace's book, Baby No-eyes. Grace's book is utilised as a conceptual foundation to decolonize genetic science. Article considers indigenous approaches to bioethics, health policy and international law. Article provides insight into the construction of disability and blindness within te Ao Māori. Discusses whānau relationships, the sacredness of the body and historical ways medical professionals have been dismissive of Māori.
Tapping (2015). Kata and Kāpō.	Short story written from a child's perspective of her classmate and friend dying. Visual impairment, disability and death framed as ordinary parts of life that just "are".
McMillan (2012). Colour the Stars/ Taea Ngā Whetu	Bilingual children's book (English/Māori) and teaching resource. Tells the story of a blind child and a sighted child discussing how each "sees" colour. De-constructs the idea of blindness as dependence. Friendship demonstrated as occurring across abilities.
Kaa (1998). He kāpō ahau	Learning resource. A child is describing what they feel with their hands and fingers as they pet a cat. Rich use of language (te reo Māori), strengths-based (focuses on what the child can do/feel/sense) and normalises disability.
Mataira (1991). Te kuia kapo me tana mokopuna	Play in te reo Māori. A blind grandmother and her grandchild visit the zoo. The grandchild describes various animals, ending in a humorous encounter with an elephant.
Turner (1991). Te kuia kapo me tana mokopuna	Learning resource. Short play written for children in te reo Māori. Showcases the warmth between a blind grandmother and her sighted grandchild. The story also acts as a teaching resource on how to audio-describe an event for a blind person. Strengths-based (focuses on the trip to the zoo and what the blind grandmother can do), relational and normalises blindness as an ordinary part of life.

emphasis on the relationships that people have with each other. This is particularly the case in *Kata and Kāpō*, which deals with the death of a child yet the focus of the story is on the friendship of the named characters. The nature of the disability of each person in each fictional work is described from a strengths-based perspective. For example, in the teaching resources, the blind protagonists describe their world in a rich and evocative manner and interact with friends and family in a warm and humorous manner. Oral histories and stories such as these carry Indigenous practices and ways of interacting that are intrinsic to dignity and well-being when receiving medical care.

As a group, therefore, these publications provide a valuable perspective from which to view and analyse disability research. The information in these works is a form of data in and of itself. Research regarding Māori typically attempts to "fit" research findings into non-Māori and non-Indigenous frameworks rather than utilising Indigenous frames (Oetzel et al., 2017). We understand the incongruity of writing about Indigenous oral storytelling histories and of doing so within a framework such as a systematic literature review. Yet, to discard these works would perpetuate the dominance of non-Indigenous conceptualisations of blindness and disability. Including them is a form of decolonisation praxis within already existing structures. Hence, we include fictional and literary works as they contribute nuance, extend the perspective of the review beyond individual notions of health and provide a framework from which to engage in our analysis.

Considering the remaining 27 research papers and the colour-coded analysis matrix (Data S1), our method of carefully applying disability-centric values and Kaupapa Māori research practice highlighted areas where approaches to tāngata kāpō included and involved tāngata kāpō aspirations and values—and where it did not. Publications ($n = 10$) within the social sciences had high levels of working alongside Māori and tāngata kāpō. The fields of study were Education ($n = 5$, authors = Bevan-Brown, Macfarlane, Nagel), Psychology ($n = 2$, authors = Graham, Masters-Awatere), and Māori and Indigenous Studies ($n = 3$, authors = te Momo, Higgins). Publications were either qualitative in approach or reflective pieces drawing on previous publications. The remaining 17 studies were located within the field of medical health.

Of these 17 publications, only two generated new data (c.f. retrospective audits and pre-collected data). Warman et al., (2011) undertook a telephone survey and generated new data on the topic of blindness, which noted a "disproportionately high" number of Māori participants (that is, Māori were more likely to talk on the phone than non-Māori). Similarly, De Kok et al., (2017) utilised face-to-face interviews and physical assessment to generate new data and worked in conjunction with a local Māori health provider to collect this information. Burns et al., (2021) reviewed Indigenous engagement and inclusion in vision-related studies in OECD nations. There was a clear attempt by the research team to engage with Māori and disabled groups and to consider the wider implications of their research. Each of the three mentioned studies engaged with Māori stakeholders. The remaining 14 studies included data about Māori in their data sets, but these papers were published by non-Māori authors without clear key stakeholder input from either Māori or disabled persons.

4 | DISCUSSION

Looking across the research corpus, there remains a dearth of published studies at the intersection of disability, blindness and te Ao Māori. Qualitative publications have detailed the experiences of tāngata kāpō. However, these have drawn from only four data sets; te Momo's thesis (8 participants), Higgin's Donald Beasley Institute-funded study (14 participants, 48 family members), Bevan-Brown (10 participants, 5 family members) and Masters-Awatere (7 participants). It is unclear what degree of crossover between participants has occurred. Nevertheless, it is clear that, in comparison to the numbers of Māori patients included in the quantitative studies, the experiences of tāngata kāpō remain under-researched. Published medical studies drawing on pre-existing data sets with Māori patients have not consistently connected their findings to existing literature with regards to Māori, disability, or tāngata kāpō. More recent studies where the research teams worked with key stakeholders (e.g., de Kok et al., who worked with Ropu Kaitiaki) and/or members of the research team were Māori (e.g., Burns et al) contributed new health knowledge in a manner that enhanced self-determination, democratic participation and agency for both Māori and disabled persons. Despite this, it is over 50 years since Grosvenor's 1966 paper and very little has changed with regard to ensuring that the experiences, aspirations and priorities of Māori, disabled, and, more specifically, tāngata kāpō are included, let alone aligned with those undertaking medical research.

The fictional literature included in this review presents an excellent starting point for researchers who may be unfamiliar with te Ao Māori cosmologies and conceptualisations. The use of stories (pūrākau) counter-acts positivist approaches that strip people and data from their wider cultural contexts (Seed-Pihama, 2019). Additionally, this literature connects experiences of being kāpō and understandings of disability to wider cultural concepts, such as care for family members, inclusion, and the healthy expression of emotion. *Baby No-Eyes* in particular links the impacts of colonisation (loss of land and wealth alongside erasure of important cultural practices) to negative health impacts for Māori in a way that is memorable and challenging. The stories of strong and knowledgeable ancestors who were blind as presented by Tikao et al. provide a strengths-based alternative to the paternalism endemic to research on disabled persons. This is particularly important given the tendency of health and disability research to subsume Indigenous experiences and values into individualistic, colonial narratives (Graham & Masters-Awatere, 2020; Smith, 2021). Taking a pūrākau-based approach to learn through reading fictional literature such as that included here can work to counteract the dominant narratives regarding health and contribute as one mechanism towards decolonising health research practice.

Strongly contrasting with the included pūrākau, the medical health studies included in our review rarely took a Māori-centred or disability-centric approach when collecting and/or analysing data. In particular, research that drew on retrospective audits of pre-collected data consistently failed to consider the wider implications and contextual factors for Māori or for disabled persons. Contextual awareness is crucial to high-quality research with Māori data (Cormack et al., 2019). Researchers utilising retrospective data analysis need to consider the racialised context of data within the existing social environment (Lovett et al., 2019; Reid, Cormack, & Crowe, 2016). As yet, there are no ethical consequences or holding to account for researchers who utilise or contribute to deficit models when engaging with Māori people or data (Reid et al., 2019). More thought needs to be given to the way in which non-Māori use decontextualised health data, and the ways in which findings can cause harm or utilised to denigrate Māori (Cormack et al., 2019). Where specialists are oblivious to the wider context for Māori they utilise data on its "face value" and cause harm (e.g., Chong et al., 2018, 2019). Ignorant reporting on "risk factors" for eye conditions (e.g., diabetic retinopathy, non-accidental injury) can result in state justification for increased surveillance of Māori patients. This contributes to the risk of harm for Indigenous and disabled persons. Greater care must be taken by health researchers so that their work does not contribute to further harm for marginalised groups.

There was an inherent epistemic authority that researchers in retrospective studies gave to data. It was assumed across studies working with existing datasets (e.g., hospital records, Ministry of Health NPWS database, BLENNZ, ACC) that the data was robust, unproblematic and accurate. Studies that had more data sources and more highly linked data (e.g., ACC datasets, NZ Census 2013 data and Auckland hospital medical records) assumed this meant that the data was of higher quality and more robust. One example of how this data is not as robust as may be assumed can be seen in Grosvenor's 1966 research, which determined whether or not someone was Māori based on the judgement of the admissions nurse. Thirty years later, in 1996, there was a formal alignment between health services and Statistics New Zealand, which resulted in self-selected ethnicity data becoming standardised practice (Bartholomew, Sharpe, Cormack, Hancock, & Phimmavanh, 2017). Despite this, health personnel continued to use their judgement to record missing patient ethnicity data (Cormack & McLeod, 2010; McLeod et al., 2000). If the health datasets drawn from do not accurately identify Māori, then Māori remain either absent or incorrectly documented in both data and the research that draws on it (c.f. Silwal et al., 2022). Where health researchers draw from the same medical data sets (which poorly collect information), the findings will not necessarily reflect Māori health needs.

Additionally, the absence of explicit consent by Māori for their medical data to be shared and analysed by non-Māori is problematic. The same applies to disabled having their medical data shared and analysed by non-disabled researchers. Accessing de-identified data for retrospective analysis is a common practice in the field of medical health research. Such papers do not need to gain additional ethical consent, due to the data being anonymised and de-identified prior to access. Continuing to use de-identified health data, which is typically information that has not been collected by or for Māori (or by and for disabled persons), means perpetuating research on rather than with groups. There is a need for health-related data which is collected by institutions about Māori patients (including tāngata kāpō) to have stronger Māori-led governance to protect the interests of Māori. Ensuring Māori-led and disability-led governance over health data would also be congruent with the rights as stated in the UNCRPD and UNDRIP. When taken together these two documents clearly state that disabled and Indigenous persons have the right to self-determination and to be treated in dignified and respectful ways. Considering the NZ context, self-determination over health data and related research (data sovereignty) would mean that Māori determine (alone or jointly) what data is collected, analysed and reported on regarding Māori. It is clear from our review that research in the area of vision and health is not meeting these rights.

There is room for future research that engages iteratively with tāngata kāpō Māori regarding the specifics of kāpōtanga and engaging respectfully with tāngata kāpō, tāngata whaikaha and Māori in the health and disability space. There is some emerging material on this topic (for example, see Ingham et al., 2022). Nonetheless, providing additional concreteness for researchers and practitioners on shifting their practice to being inclusive, collaborative and self-determining for the Māori disabled is needed. This includes providing specific examples of how to incorporate oral histories, shifting paternalistic discourses around disability and centring Indigenous worldviews in disability research.

5 | CONCLUSIONS

We began this review with an outline of inadequate service provision and patchy data for Māori with vision-related disabilities. What we found was published literature regarding Māori conceptualisations of blindness (which were strength-based, holistic and grounded within familial relationships), literature on the experiences of tāngata kāpō, and studies that stripped Māori participants from their wider sociocultural context. Our introduction highlighted that the key health-related issues facing Māori disabled in NZ are poor quality care, culturally inappropriate care and lack of access to publicly funded specialist services. As our review has noted, non-Māori-led research has been entirely inadequate in addressing these issues for tāngata kāpō. Not only that, but research practices by non-Māori and non-disabled medical specialists utilising de-identified data have been extractive, undermined data sovereignty and have contributed to deficit views of Māori and paternalistic assumptions regarding disabled persons. Health research ought not to be enacted 'on' either disabled or Māori persons nor should it strip their data from the wider context of their lives. Our review highlights inconsistency across disciplines regarding self-determination and democratic participation by both Māori and disabled as key stakeholders.

Our innovative approach of drawing from research practice across Kaupapa Māori applied community psychology, and disability rights and creating an analytical matrix meant that we were able to make explicit where research practices included—and excluded—self-determination, democratic participation and inclusion of both disabled and Māori. Where researchers made attempts to involve key stakeholders in some form, this had a positive flow-on impact on the inclusion of disability rights and considerations of wider social contexts. Our approach can be utilised across disciplines as a tool for considering the ways in which researchers uphold Indigenous self-determination, disability rights and data sovereignty.

The aspirations of disabled and Indigenous persons must be central to all studies utilising their data, whether qualitative, quantitative, or mixed methods. Studies (both medical and non-medical) cannot solely rely on previously collected statistical data. There is a need for researchers across health to engage in culturally appropriate data collection methods and to work with both Indigenous and disabled stakeholders when utilising their medical data. Our review highlighted the absence of such an approach. However, there was a handful of vision-related studies where the research team worked alongside Māori as research partners. This indicates that there may be an emerging shift in research practice. Nevertheless, there is a need for this slight improvement to rapidly increase and for researchers to consistently enact core values of self-determination, data sovereignty and inclusion when working with data from Indigenous and disabled persons.

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The authors declare that there is no conflict of interest

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ENDNOTES

[1] Tāngata kāpō in this paper refers to Māori who are blind, deafblind, low vision or visually impaired. We use kāpō as an inclusive term that includes all types and levels of visual impairment. Whānau refers to family members who are involved with care and support. Māori are the Indigenous people of Aotearoa New Zealand.

[2] Results for Māori disabled had large variances because of low numbers. When working in the Integrated Data Infrastructure (IDI) working with low numbers and the rounding technique used by Statistics NZ to maintain confidentiality means sourcing accurate results is difficult.

[3] Tāngata whaikaha is a broad term that includes all Māori disabled

[4] Te Ao Māori denotes the Māori world, which includes Māori ideas, values, worldviews, and practices

[5] European/non-Māori citizen of NZ

[6] One of the regional tribal areas

[7] The Māori language

[8] An approach that incorporates the knowledge, skills, attitudes, and values of Māori society

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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