Māori and autism: A scoping review

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Abstract

Cultural groups may vary considerably in their understandings of autism spectrum disorder and approaches to supporting autistic individuals. However, approaches to researching, identifying and managing autism are largely dominated by Western perspectives. This review provides an overview of the literature related to autism and Māori, the indigenous people of Aotearoa/New Zealand. A search of the peer-reviewed and grey literature identified 273 potentially relevant publications, and 13 of these met inclusion criteria. The included publications addressed questions related to Māori understandings of autism, Māori prevalence rates and diagnostic and support services for Māori. Findings suggest broad differences in Māori and Western understandings of autism and slightly higher autism prevalence rates for Māori than for non-Māori New Zealanders. The need for diagnostic and support services that are both effective and culturally appropriate for Māori was also highlighted. These findings are discussed in relation to implications for future research and the provision of services for autistic Māori.

Lay abstract

Most current approaches to identifying, researching and managing autism are based on Western views and understandings. However, different cultural groups may understand and approach autism differently. We searched a wide range of websites, academic journals and other sources for published information related to autism and Māori, the indigenous people of Aotearoa/New Zealand. Our search identified 13 publications that addressed questions related to Māori understandings of autism, Māori prevalence rates and diagnostic and support services for Māori. Overall, we found broad differences in Māori and Western understandings of autism and slightly higher autism prevalence rates for Māori than for non-Māori New Zealanders. Findings also highlighted a need for diagnostic and support services that are both effective and culturally appropriate for Māori. We discuss what these findings might mean for future research and the provision of services for Māori with autism.

Introduction

Rationale

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder that is defined by difficulties in social communication and the presence of restricted or repetitive behaviours, interests or activities (American Psychiatric Association, 2013). Current clinical and scientific understandings of autism draw heavily on the Western medical perspective (O'Dell et al., 2016), and diagnostic criteria and tools are largely based on Western populations (Masi et al., 2017). Autism research has also traditionally been conducted with samples lacking in cultural and ethnic diversity (Freeth et al., 2014; T. Smith & Iadarola, 2015).

However, definitions and understandings of autism can vary widely across different cultural groups (Bernier et al., 2010; Freeth et al., 2014). Indeed, 'culture is integral to the way in which autism is experienced, defined and managed' (Freeth et al., 2014, p. 1010).

Attitudes towards the inclusion and treatment of autistic individuals also appear to vary across cultures

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(Ravindran & Myers, 2012; Welterlin & LaRue, 2007). For example, cultural context can impact on the extent to which families seek intervention or support (Freeth et al., 2014) and the intervention outcomes that they value and prioritise (Tincani et al., 2009). Thus, Westernised intervention approaches may not necessarily be appropriate for use with non-Western populations (Boston et al., 2015; Freeth et al., 2014; Masi et al., 2017; Norbury & Sparks, 2013; Ravindran & Myers, 2012). There is also evidence to suggest that autistic individuals from minority groups are less likely to access evidence-based treatments (Baumann et al., 2015; Smith et al., 2020). This may be especially true for indigenous populations who have a well documented history of health disparities across a broad range of outcomes, including access to healthcare (Rolleston et al., 2020). Furthermore, some families may look to support systems within their wider families or communities, rather than seeking an interventionist treatment approach. Within this response, child development may be considered with a differing set of cultural measures which may not align as readily to an established set of measurements within the medical discourse around autism and disability.

Māori are the tangata whenua (indigenous people) of Aotearoa/New Zealand and make up approximately 16.5% of New Zealand's total population (Statistics New Zealand, 2020). Māori are a diverse group with differing beliefs, values, tribal affiliations and economic and social circumstances (Bevan-Brown, 2004; Houkamau & Sibley, 2018). As a group, Māori experience significant disparities across a wide range of outcomes, including health and well-being (Reid et al., 2014), employment (Marriott & Sim, 2015) and education (Bishop et al., 2009). These disparities must be understood in the context of New Zealand's colonial history (Keown et al., 2018) which has had profound negative effects for Māori and caused significant historical trauma (Moewaka Barnes & McCreanor, 2019). It is also important to acknowledge that institutional racism and economic disadvantage continue to create and sustain disparities for Māori (Masters-Awatere & Nikora, 2017; Savage et al., 2020). Disparities experienced by Māori also extend into the area of disability where, compared to non-Māori, Māori are significantly more likely to experience disability and significantly less likely to receive support (Ratima & Ratima, 2007). It is therefore possible that Māori with disabilities, such as autism, are at risk of poorer outcomes than non-Māori.

Given the significant impact of culture on the understanding and management of autism, and the existing health disparities experienced by Māori, it seems important to explore the literature on Māori and autism. We opted to use a scoping review approach because of the paucity of existing literature on this topic. Our review is loosely modelled on the scoping review by Bailey and Arciuli (2020) which summarised the literature related to Indigenous Australians and autism.

Objectives

The aim of this review was to provide an overview of existing literature related to Māori and autism. We were interested in publications focussed on Māori perspectives of autism, the prevalence of autism in the Māori population and the provision of diagnostic and support services for Māori, including the experiences and perspectives of the individuals using and providing these services. Specifically, we sought to answer the following questions:

1. What is known about Māori understandings of autism?
2. What is known about the prevalence of autism in the Māori population?
3. What is known about diagnostic and support services for autistic Māori (including how they are provided and how autistic individuals and their families access and experience them)?

Method

This scoping review is based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension guidelines (PRISMA-ScR; Tricco et al., 2018). We have included the 20 essential reporting items outlined in the PRISMA-ScR guidelines but have not included the two optional items because they involve critiquing the quality of included articles which is beyond the scope of the present review.

Eligibility criteria

Given the paucity of literature focussed on Māori and autism, broad eligibility criteria were used for the present review. Publications of any type, date and language were eligible for inclusion, provided that they met the inclusion criteria detailed below. A further reason for the use of broad eligibility criteria was to ensure that Māori research and perspectives were included as these may have been more likely to be included in dissertations or grey literature. No restrictions were placed on publication type, date or language.

Inclusion criteria. To be included in the review, publications needed to discuss both autism and Māori. Publications that not only focussed on Māori and disability but also made specific reference to autism (e.g. one or more participants were autistic) were also included.

Exclusion criteria. Articles that did not discuss both autism and Māori were excluded, as were articles where results for Māori could not be separated out from results for non-Māori. Articles that focussed on Māori and disability but did not make specific reference to autism and articles

where results for autistic participants could not be separated out from results for participants with other disabilities were also excluded. Finally, publications that provided a summary of findings from already included articles, without adding any new information related to Māori and autism, were also excluded.

Information sources and search strategy

Electronic database searches were carried out by the first author, in consultation with a Māori studies subject librarian, in June 2020 using the A+ Education, CINAHL complete, Cochrane library, PubMed, Proquest, ERIC and Psychinfo databases. For all databases, the following search terms were used: (*Autis*, ASD, Asperger*, takiwātanga* OR *developmental*) AND *Māori.* No date, publication type or language limits were applied. These initial electronic searches returned 119 articles.

Next, in July 2020, the first author conducted a search of the grey literature. This involved manually searching the following websites: Ministry of Social Development, Ministry of Health, Ministry of Education, Poutama Pounamu (education research and development centre at Waikato University), Māramatanga (New Zealand's Centre of Māori research excellence), the Office for Disability Issues, Autism NZ, Te Puni Kōkiri (Ministry of Māori Development) and Whānau Ora (government-funded, whānau-centred health and social service initiatives). In addition, hand searches were conducted for the NZ Medical Journal, Altogether Autism, E-Tangata and AlterNative, using the same keywords that were used during the database searches. Finally, author and reference list searches were conducted for articles identified during the database and grey literature searches. The grey literature, author and reference list searches returned a further 154 articles.

Selection of sources of evidence

The process used to select the sources of evidence is illustrated in Figure 1. First, the titles of the 273 publications identified during the initial searches were screened to check for their potential eligibility for inclusion. After excluding 226 publications, the abstracts for the remaining 47 publications were screened. At this stage, 30 publications appeared to be eligible for inclusion and consequently, the full text of each of these publications was reviewed to ensure that each met all the inclusion criteria. In total, 13 publications met the inclusion criteria. The search and screening processes were carried out by the first author (J.T.). The third author (H.W.) reviewed the 17 studies that were excluded at full-text stage to check that they were not eligible for inclusion, and the second author (S.C.) reviewed the final 13 publications to confirm that they met the inclusion criteria. Thus, 13 publications were included in the final review.

Data items and charting process

The first and second authors (J.T. and S.C.) agreed upon the categories for data extraction and developed a data extraction chart (see Table 1). The first author then used this chart to extract data from the included publications. The second author independently extracted data for 38% ($n=5$) of the included publications. Any disagreements were resolved through discussion.

Community involvement statement

Two of the authors from the current review (D.T.-S. and J.T.) are Māori and three of the authors (A.G., D.T.-S. and H.W.) have family members who are on the autism spectrum. Four authors (S.C., D.T.-S., J.T. and H.W.) are also involved in the delivery of community-based services for individuals on the autism spectrum and/or their whānau.

Results

Table 1 summarises the publication type, aims and population/sample for the 13 included publications. Of the included publications, six (46%) were peer-reviewed research reports, three (23%) were governmental reports/surveys, two (15%) were reports from non-governmental organisations and one (8%) was a narrative account which was published in a peer-reviewed journal. The earliest publication was from 2004 and almost 70% were published in the last 5 years (since 2015). Almost half (46%) of the publications included the perspectives of parents and/or whānau. Whānau is an important concept for Māori; it has been described as the foundation of Māori society (Tibble & Ussher, 2012) and a vital part of individual and collective well-being (Durie, 1994). The term can be roughly translated to mean extended family. However, whānau is a diverse concept that can mean different things to different people (Tibble & Ussher, 2012) and may include blood relatives (e.g. children, parents, grandparents, aunties, uncles) and/or individuals who are not blood relatives but share common interests, goals or so on (Lawson-Te Aho, 2010). Where the term whānau has been used in included publications, we have also used this term in reporting and discussing findings.

Table 2 summarises the key findings for each research question from the 13 included studies.

RQ1: what is known about Māori understandings of autism?

Five (38%) of the included publications reported on Māori understandings of autism (Bevan-Brown, 2004; Birkin et al., 2008; Ministries of Health and Education, 2008; Te Pou o te Whakaaro Nui, 2019; Wastney et al., 2007). There was a general consensus across publications that Māori understandings of autism may differ from the dominant
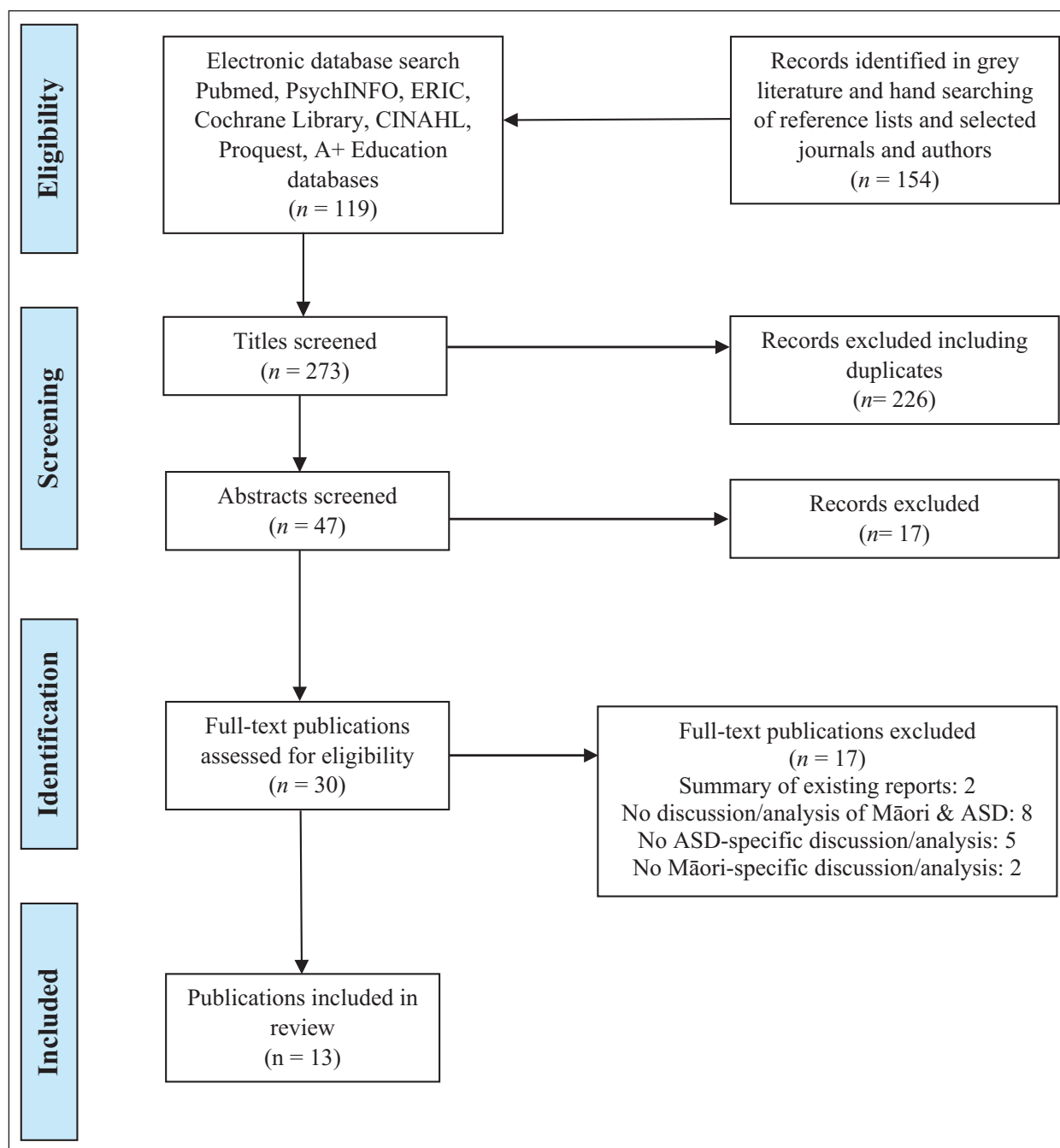
Figure 1. Flow chart of search strategy based on PRISMA flow diagram.

Western understanding. However, no one universal 'Māori view of autism' was reported, which is to be expected given the diversity of the Māori population. The Māori parents, whānau and professionals who were interviewed for the Ministry of Health and Education's governmental report suggested that Māori understandings of autism are often influenced by Māori world views and models of health and disability. They went on to suggest that Māori models of health tend to be holistic, include a focus on spiritual and emotional development and often contrast with Western models and views of health.

Differences/disabilities (including autism) were described in different ways by Māori participants from across the included publications. For example, they were described as something to be nurtured (Birkin et al., 2008), a normal part of life and a gift to be embraced (Ministries of Health and Education, 2008), and bringing both strengths and challenges (Wastney et al., 2007). Participants from Birkin et al.'s (2008) peer-reviewed research report suggested that for some Māori, autism may be considered a consequence or punishment for previous behaviour in the family.

Table 1. Summary of publication type, aims and population/sample for included publications.

Author(s) and publication date	Publication type (design)	Aim(s)	Population/sample
1. Bevan-Brown (2004)	Government report	To investigate Māori perspectives of ASD and experiences with health, education and care services.	Parents and whānau of 19 Māori children with ASD or ASD tendencies (*n* = 32)
2. *Birkin et al. (2008)	Research report (two interlinked qualitative studies)	To examine parents' access (including barriers to access) to the EarlyBird early intervention programme.	Study 1: Caregivers of children with ASD aged up to 6 years (*n* = 77); 6% Māori. Study 2: Caregivers and professionals working with children with ASD (*n* = 12); 33% Māori.
3. *Drysdale & van der Meer (2020)	Research report (quantitative)	To examine the rate of ASD diagnosis among 0–19 years living in Lower Hutt between 2012 and 2016.	Individuals aged 0–19 years, living in Lower Hutt, who received an ASD diagnosis between 2012 and 2016 (*n* = 228; 23.6% Māori.
4. *Eggleston et al. (2019)	Research report (quantitative)	To explore New Zealand parents' experiences of obtaining an ASD diagnosis for their child and to identify factors that predicted parent satisfaction.	Parents/primary caregivers of children with a diagnosis of ASD (*n* = 516); 8.7% Māori.
5. *McAnelly & Gaffney (2017)	Research report (qualitative)	To explore how one early childhood community was able to support the active participation of a young Māori child with ASD.	5-year old Māori boy with a diagnosis of ASD (*n* = 1).
6. Ministry of Health (2019)	Government survey	To present data from the 2018–2019 NZ Health Survey related to the prevalence of ASD in children aged 2–14 years.	Children aged 0–14 years (*n* = 4503); 35% Māori.
7. Ministries of Health and Education (2008)	Government report	To establish evidence-based guidelines to assist health professionals, educators and others in their work with individuals with ASD.	n/a
8. *Searing et al. (2015)	Research report (mixed)	To examine the caregivers' perceptions of the availability and helpfulness of supports for their child with ASD.	Caregivers (*n* = 92) of children aged 3–14 years with ASD; 12% Māori.
9. Simpson et al. (2012)	Government report	To summarise available data related to the health of Māori children with chronic conditions and disabilities.	n/a
10. Te Pou o te Whakaaro Nui (2015)	Non-governmental organisation report	To describe the professional development opportunities provided to the workforce supporting individuals with ASD through Ministry of Health funding.	n/a
11. Te Pou o te Whakaaro Nui (2019)	Non-governmental organisation report	To present a framework of competencies required by professionals working with individuals with ASD.	n/a
12. *Thabrew & Eggleston (2018)	Research report (mixed)	To compare the current status of assessment and intervention for children with ASD with recommendations provided in the NZ ASD Guideline (2008)	Professionals working with children with ASD (*n* = 32)
13. *Wastney et al. (2007).	Narrative account (qualitative)	To describe a session that one Māori mother ran with her son's primary school class to teach them about ASD and encourage the inclusion of her son.	n/a

ASD: autism spectrum disorder.
*Published in a peer-reviewed journal.

Table 2. Summary of key findings for included publications.

Author(s) and publication date	Key findings		
	RQ1: Māori understandings of ASD	RQ2: Māori ASD prevalence rates	RQ3: diagnostic and support services for Māori with ASD
Bevan-Brown (2004)	• Most participants had a good understanding of ASD based on the 'triad of impairments' medical model. • Six participants were described as 'ASD experts' by the author. • Most participants identified the internet as playing a role in informing their perceptions of ASD. • Most participants wanted their whānau to have a better understanding of ASD.	n/a	• Satisfaction with diagnostic and support services varied across participants. • ASD can adversely impact on an individual's ability to participate in culturally valued activities. • Participants varied in the extent that they desired cultural content to be included in ASD services. • Support services should align with families' cultural expectations. • Māori services need to develop greater ASD-specific knowledge and skill and ASD specialists need to develop greater knowledge of Māori language and cultural customs. • ASD assessment materials and support programmes that are culturally appropriate for Māori should be developed. • Some Māori parents would appreciate having access to ASD support groups specifically for Māori parents. • The extent to which participants received support from whānau varied widely. • Māori parents experienced many of the same barriers to accessing ASD support services as have been identified by non-Māori. • Detrimental attitudes from professionals and the general public were also described as barriers for Māori parents. • Traditional Māori values support the care and protection of children with ASD. • Services for Māori with ASD need to be physically, spiritually and culturally safe.
Birkin et al. (2008)	• Māori in general may have a low awareness of developmental disorders, such as ASD. • Within Māori culture, children who are different are usually nurtured, not pathologised. • Some Māori may consider a child who is different to be a consequence or punishment for past behaviour in the family.	n/a	• Māori parents were less likely to access the EarlyBird programme than European parents, this may suggest barriers to access for Māori. • Relationships between service providers and whānau Māori are fundamentally important. • Māori professionals may find it easier to build relationships with whānau than non-Māori professionals. • Support providers need to ensure that their expectations of families and pedagogical approach are culturally appropriate. • Culture-specific networks should be used to advertise programmes, such as EarlyBird. • Children from Māori families have a later age for diagnosis and often remain undiagnosed until they start school.

Table 2. (Continued)

Author(s) and publication date	Key findings		
	RQ1: Māori understandings of ASD	RQ2: Māori ASD prevalence rates	RQ3: diagnostic and support services for Māori with ASD
Drysdale & van der Meer (2020)	n/a	The rate of ASD diagnosis for Māori was higher than the proportion of Māori in the general population.	Māori living in the Hutt Valley appear to have good access to ASD assessment.
Eggleston et al. (2019)	n/a	n/a	Māori parents' rates of satisfaction with the ASD diagnostic process were not significantly different from the ratings of non-Māori parents.
McAnelly & Gaffney (2017)	n/a	n/a	• Active participation in the preschool setting is encouraged when teaching staff view all children as valuable, capable learners. • The learning environment should be changed to meet the needs of the child with ASD, rather than the child having to change to meet the requirements of the learning environment. • Responsive and reciprocal relationships between children, teachers and whānau are important.
Ministry of Health (2019)	n/a	Prevalence rates for Māori were higher than for any other ethnic group.	n/a
Ministries of Health and Education (2008)	• Māori world views and models of health and disability impact on their understandings and definitions of ASD. • Some respondents wanted ASD-related labelling to be eliminated. • Māori children with ASD are seen as a gift and are embraced by their whānau. • Autism is viewed as a normal part of life.	n/a	• Information about ASD needs to be made more accessible for Māori. • Kaiarahi (cultural guides) may be useful in supporting Māori with ASD and their families. • Service providers should not make assumptions regarding an individual's cultural background or needs. • There are a number of barriers to Māori accessing ASD diagnostic and support services. These may be similar to those faced by non-Māori. • Māori may be more likely to face barriers to diagnostic and support services because they are more likely to experience geographical isolation, lower socioeconomic status, mistrust of the system and reluctance/delay in seeking treatment. • Māori cultural protocols, values and world views should be incorporated into ASD diagnostic and support processes. • Māori organisations should be provided with funding to deliver services to Māori with ASD.

(Continued)

Table 2. (Continued)

Author(s) and publication date	Key findings		
	RQ1: Māori understandings of ASD	RQ2: Māori ASD prevalence rates	RQ3: diagnostic and support services for Māori with ASD
			• Support for parents and family members should include counselling and education services and different agencies (e.g. health, education and social welfare) should work together and share information. • There is a shortage of Māori who have specialised ASD training. • The use of home-based or marae-based settings for service delivery may be culturally appropriate. • All professionals who work with individuals with ASD should receive cultural training. • There are issues regarding the provision of culturally appropriate respite care for Māori with ASD. • Traditional Māori rules and protocols can be used to support individuals with ASD and their whānau.
Searing et al. (2015)	n/a	n/a	• Non-Māori caregivers perceived significantly more supports to be available to them than Māori caregivers. • Māori and non-Māori caregivers perceived similar availability of formal supports, but Māori caregivers perceived significantly fewer informal supports than non-Māori caregivers. • Supports were rated as more helpful by Māori caregivers than non-Māori caregivers.
Simpson et al. (2012)	n/a	There is no definitive data regarding the ASD prevalence rate for Māori.	• From 2005 to 2009, 187 Māori children/young people with ASD were admitted to hospital. • The average rate of hospital admissions for Māori children/young people with ASD was 0.36 admissions per year. • The proportional rate of admissions for children/young people with ASD was significantly lower for Māori than non-Māori.
Te Pou o te Whakaaro Nui (2015)	n/a	n/a	• 26.3% of training providers reported that their programmes were suitable for training professionals working with Māori with ASD.
Te Pou o te Whakaaro Nui (2019)	The term 'Takiwātanga' can be used as a Māori interpretation of ASD. It can be translated to mean 'in his or her own time and space'.	n/a	• Cultural competency is a prerequisite skill for any professional working with Māori with ASD.
Thabrew & Eggleston (2018)	n/a	n/a	• Training in Māori cultural issues was reported to be routinely available by 77.3% of respondents. • 22% of DHBs reported having a kaiarahi available to work with Māori children and their whānau. • 22.7% were aware of information about ASD in Te Reo
Wastney et al. (2007).	All individuals with ASD are different. ASD brings both strengths and challenges.	n/a	• Increasing understanding of ASD among peers can encourage acceptance for a child with ASD in an inclusive school environment. • Māori parents may have specific cultural concerns regarding the education of their child with ASD.

ASD: autism spectrum disorder.

In Bevan-Brown's (2004) governmental report, interviews with Māori parents and whānau (extended family) revealed that most participants' understanding of autism was based around the medical 'triad of impairments model' and largely shaped by information found on the Internet. Six (19%) of the participants were described by Bevan-Brown as having an 'expert-level' understanding of autism, developed through having to advocate for their children. However, some of Bevan-Brown's participants also described a lack of awareness and understanding among their wider whānau. Participants from Birkin et al.'s (2008) study also suggested that Māori may have a low overall awareness of developmental disorders, such as autism.

Some of the Māori parents, whānau and professionals who contributed to the governmental report by the Ministries of Health and Education (2008) suggested that autistic individuals should not be labelled because, for Māori, autism was considered to be a normal part of life. Indeed, until fairly recently, there does not appear to have been any specific Māori term for autism. In 2019, Keri Opai proposed the term 'Takiwātanga' as a way of encapsulating a Māori view of autism (Te Pou o te Whakaaro Nui, 2019). The word is derived from 'tōku/tōna anō takiwā' which means my/his/her own time and space. Takiwātanga draws on a whakataukī (Māori proverb) about the tītoki tree which is highly valued but does not fruit regularly. In line with this, the term Takiwātanga alludes to accepting and celebrating people with autism for who they are and allowing them to bloom in their own time and space (Te Pou o te Whakaaro Nui, 2019).

RQ2: what is known about the prevalence of autism in the Māori population?

Three (23%) of the included publications discussed the prevalence of autism in the Māori population (Drysdale & van der Meer, 2020; Ministry of Health, 2019; Simpson et al., 2012). In their peer-reviewed research report, Drysdale and van der Meer (2020) retrospectively analysed the rate of ASD diagnosis for individuals aged 0–19 years residing in the Hutt Valley region from 2012 to 2016 and found that 54 (23.6%) of those diagnosed identified as Māori. This was higher than the proportion of Māori in the general Hutt Valley population at the time (17.4%). Dyrsdale and van der Meer's findings were based on data from referrals made after a clinical diagnosis of ASD, rather than from the actual rate of diagnosis because the District Health Board in charge of overseeing healthcare for the Hutt Valley region did not have a system for collecting data on ASD diagnoses. The governmental report by Simpson et al. (2012) analysed hospital admission rates for Māori children and young people with autism across New Zealand and also highlighted an absence of definitive data regarding autism prevalence for Māori. Finally, the Ministry of Health (2019) analysed data from

the 2018–2019 New Zealand Health Survey, a self-report governmental survey that included a sample of 4503 children aged 0–14 years (35% Māori). As part of the survey, parents of participating children were asked to report on whether their child had a diagnosis of ASD. Results from this survey suggest that the autism prevalence rate for Māori children (2.7%) may be higher than the rate for the general child population (2%).

RQ3: what is known about diagnostic and support services for autistic Māori?

Twelve of the included publications discussed some aspect of diagnostic or support services for autistic Māori (Bevan-Brown, 2004; Birkin et al., 2008; Drysdale & van der Meer, 2020; Eggleston et al., 2019; McAnelly & Gaffney, 2017; Ministries of Health and Education, 2008; Searing et al., 2015; Simpson et al., 2012; Te Pou o te Whakaaro Nui, 2015, 2019; Thabrew & Eggleston, 2018; Wastney et al., 2007). Four key themes emerged from these publications: (a) access and barriers to accessing diagnostic and support services, (b) cultural values and needs and the provision of culturally appropriate services, (c) parent and whānau satisfaction with diagnostic and support services and (d) relationships and inclusion. In the following section, findings are discussed in relation to of these themes.

Access and barriers to accessing diagnostic and support services. Six publications discussed access and/or barriers to accessing autism diagnostic and support services for Māori (Bevan-Brown, 2004; Birkin et al., 2008; Drysdale & van der Meer, 2020; Ministry of Health and Education, 2008; Searing et al., 2015; Simpson et al., 2012). Drysdale and van der Meer reported that, based on their analysis of rates of ASD diagnosis from 2012 to 2016, Māori living in the Hutt Valley appeared to have good access to assessment and diagnostic services. However, Māori parents and professionals from Birkin et al.'s study reported anecdotal evidence that Māori children tended to receive an ASD diagnosis later than non-Māori children.

In terms of support services, a peer-reviewed research report by Searing et al. (2015) found that, compared to non-Māori caregivers, Māori caregivers reported significantly fewer available supports. The authors also examined caregivers' perceptions regarding the availability of formal supports (e.g. from professional agencies or the child's school/preschool) versus informal supports (e.g. from friends or family). They found that Māori and non-Māori caregivers' perceptions regarding the availability of formal supports were similar, but Māori caregivers perceived significantly fewer available informal supports. Bevan-Brown (2004) found that the informal support that participants received from their whānau varied widely and some participants reported feeling well supported by whānau while others reported that they received very little

support. Simpson et al. (2012) retrospectively examined hospital admission rates from 2005 to 2009 for Māori children/young people with autism and found that the admission rate for Māori was significantly lower than the rate for non-Māori, non-Pacific children/young people. In their first study, Birkin et al. (2008) also found that Māori parents were less likely than European parents to participate in the EarlyBird programme for parents of young children with autism. The authors suggested that this may be due to Māori parents experiencing additional barriers.

Māori parents, whānau and professionals from two of the included publications (Birkin et al., 2008; Ministries of Health and Education, 2008) reported a need for better access to information about ASD and services for Māori. Participants from Birkin et al. suggested that culturally specific communication networks (e.g. Māori health organisations and community groups) should be used to advertise support programmes to encourage awareness among the Māori community. Parents, whānau and professionals from Ministries of Health and Education suggested that the different agencies involved in providing services should work together to provide more streamlined information and support for whānau. They also suggested that these supports should include counselling and education services for parents.

Potential barriers to Māori access to autism diagnostic and/or support services were also discussed in three of the included publications (Bevan-Brown, 2004; Birkin et al., 2008; Ministries of Health and Education, 2008). Participants from the Ministries of Health and Education reported a number of barriers faced by Māori when accessing autism diagnostic and support services. These included poor access to services for those living in rural locations, funding and resource constraints, a lack of information and reluctance to seek treatment. Many of these barriers were described as being similar to those experienced by non-Māori. However, some participants felt that access was more challenging for Māori because they were at an increased risk of geographic isolation, lower socioeconomic status and mistrust of the system and were more likely to be reluctant to seek treatment or to delay seeking treatment. Parents and whānau who participated in Bevan-Brown's study also suggested that many of the barriers faced by Māori when accessing support services were the same as those faced by non-Māori. However, some participants also reported that negative attitudes towards Māori from professionals and the general public created an additional barrier. One participant from Birkin et al.'s (2008) study suggested that a lack of trust in professionals could act as a barrier to accessing services for some Māori parents.

Cultural values and needs and the provision of culturally appropriate services. Seven publications discussed Māori cultural values and needs and the provision of culturally appropriate diagnostic and support services for autistic Māori (Bevan-Brown, 2004; Birkin et al., 2008; Ministries of Health and Education, 2008; Te Pou o te Whakaaro Nui, 2015, 2019; Thabrew & Eggleston, 2018; Wastney et al., 2007). The Māori parents and whānau who were interviewed by Bevan-Brown described Māori cultural world views, values and customs as promoting the care and protection of autistic individuals. They also suggested that services should be delivered in a way that is physically, spiritually and culturally safe for Māori children. However, these participants also reported a range of views regarding the inclusion of cultural content in autism services (e.g. education). Specifically, two participants did not want any cultural input while the remaining 30 participants desired some degree of cultural input. Generally, participants whose children attended kōhanga reo (Māori medium preschools) or kura kaupapa Māori (Māori medium schools) were most likely to want a high level of cultural content included in services for their child. The inclusion of Māori values in diagnostic and support services for Māori was also widely supported by the parents, whānau and professionals from the Ministries of Health and Education's report.

Bevan-Brown's (2004) participants also highlighted the impact that autism can have on an individual's ability to take part in culturally valued activities and processes, such as learning te Reo (Māori language), noho marae (staying overnight at a cultural meeting ground/place) and kapa haka (Māori cultural performing arts). This led some of the parents who were interviewed by Bevan-Brown to describe children with autism as 'culturally disadvantaged'. In their narrative account, published in a peer-reviewed journal, Wastney et al. suggested that Māori parents may have specific cultural concerns related to the education of their child with autism. They suggested a list of cultural considerations that Māori parents may wish to explore when choosing an education provider for their child. Examples of considerations on the list included the extent to which the child will have access to Māori cultural activities and the availability of Māori teaching and support staff. Bevan-Brown's participants also suggested that support services should align with the cultural expectations of Māori parents and whānau. However, participants from Ministries of Health and Education (2008) cautioned that there is no 'one size fits all' for Māori. They suggested that service providers should not make assumptions regarding the cultural backgrounds, needs and expectations of autistic Māori.

Three publications highlighted the need for more culturally appropriate autism services for Māori (Bevan-Brown, 2004; Birkin et al., 2008; Ministries of Health and Education, 2008). Specific reference was made to the need for culturally appropriate respite care (Ministries of Health and Education), parent education programmes (Birkin et al., 2008), assessment materials and support programmes

(Bevan-Brown, 2004). Birkin et al.'s participants also emphasised the importance of ensuring that providers' expectations of the families that they serve are culturally appropriate. Specific suggestions regarding culturally appropriate services included parent support groups specifically for Māori (Bevan-Brown, 2004), delivering services in marae (cultural meeting ground/place), kohanga (Māori language immersion preschools) or home-based settings, and the use of kaiarahi (cultural guides) to support Māori families (Ministries of Health and Education, 2008). Thabrew and Eggleston's (2018) peer-reviewed research study found that four (22%) of New Zealand's District Health Boards reported having a kaiarahi available to work with Māori children and their whānau. They also reported that seven (22.7%) of the professionals that they surveyed were aware of information about autism in te reo Māori.

Several publications referred to the importance of organisations and providers/staff having adequate knowledge of Māori language and culture (Bevan-Brown, 2004; Ministries of Health and Education, 2008; Te Pou o te Whakaaro Nui, 2019). Indeed, cultural competency was described as a prerequisite skill for all professionals working with autistic Māori (Te Pou o te Whakaaro Nui, 2019) and it was suggested that all non-Māori professionals working with Māori should receive cultural competency training (Bevan-Brown, 2004; Ministries of Health and Education, 2008). In their non-governmental organisation report, Te Pou o te Whakaaro Nui (2015) shared findings from a survey of organisations providing training for professionals supporting autistic individuals. They found that five (26.3%) of the training providers described their programmes as suitable for training professionals who worked with autistic Māori. In contrast, 25 (77.3%) of the participants from Thabrew and Eggleston's study, who were professionals working with autistic individuals from across 20 of New Zealand's district health boards, reported that training in Māori cultural issues was routinely available to them. However, the authors of this study did not report the number of professionals who had attended the available training sessions as this appeared to be beyond the scope of their study.

A shortage of Māori professionals with specialised knowledge in autism was also reported by participants from Bevan-Brown (2004) and Ministries of Health and Education (2008). Some participants suggested that targeted funding for Māori health organisations and/or the provision of scholarships to train Māori in autism-related disciplines may help to address this shortage.

Parent and whānau satisfaction with diagnostic and support services. Three publications included discussion of parent and whānau satisfaction with diagnostic and support services (Bevan-Brown, 2004; Eggleston et al., 2019; Searing et al.,

2015). The parents and whānau who were interviewed by Bevan-Brown varied in the extent to which they were satisfied with the diagnostic and support services that they had received. For example, some participants reported receiving no information and support during the diagnostic process while others reported feeling well informed and well supported. In their peer-reviewed research study, Eggleston et al. reported on a survey which found that Māori parents' ratings of their satisfaction with the ASD diagnostic process were not significantly different from the ratings provided by non-Maori parents. In a survey of caregivers of children with autism, Searing et al. found that, Māori caregivers' ratings of the helpfulness of autism supports ($M=3.27$ out of 5) were higher than the ratings provided by non-Māori caregivers ($M=2.82$ out of 5).

Relationships and inclusion. Four publications included discussion of relationships and/or inclusion (Birkin et al., 2008; McAnelly & Gaffney, 2017; Ministries of Health and Education, 2008; Wastney et al., 2007). Māori parents and professionals who were interviewed by Birkin et al. described the relationship between service providers and Māori parents and whānau as fundamentally important. In their peer-reviewed research report, McAnelly and Gaffney also noted the value of responsive and reciprocal relationships between teachers and whānau in their case study of the inclusion of a young boy with autism into a mainstream preschool. It was also suggested that relationships should be built upon trust and confidentiality (Ministries of Health and Education, 2008) and that Māori professionals may find it easier than non-Māori professionals to make connections and build relationships with whānau (Birkin et al., 2008).

McAnelly and Gaffney (2017) also described the features of the preschool that enabled successful inclusion of the participating child into the preschool environment. These included teachers viewing all children as valuable, capable learners and shaping the learning environment to meet the needs of the child, rather than expecting the child to meet the demands of the environment. In Wastney et al.'s (2007) narrative account of encouraging the inclusion of a Māori child with autism into a mainstream school environment, the authors described how increasing peers' understanding of autism can facilitate acceptance and inclusion.

Discussion

We set out to identify and describe the published literature related to autism and Māori. We conducted searches of the peer-reviewed and grey literature to address questions related to Māori understandings of autism, Māori autism prevalence rates, and autism diagnostic and support services for Māori. In total, 13 publications were included in the review. Almost half of these were peer-reviewed

research reports, with the other half primarily made up of governmental reports/surveys and reports from non-governmental organisations. Most of the included publications were published since 2015, perhaps indicating a recent increase in focus on this topic. Five of the included publications reported information related to Māori perceptions of autism and three publications reported on Māori autism prevalence rates. However, 12 publications discussed some aspect of autism diagnostic or support services for Māori. Four key themes emerged from the findings related to autism services for Māori. These were (a) access and barriers to accessing services, (b) cultural needs, values and the provision of culturally appropriate services, (c) parent and whānau satisfaction and (d) relationships and inclusion.

There was evidence of broad differences between Western and Māori understandings of autism (Bevan-Brown, 2004; Birkin et al., 2008; Ministries of Health and Education, 2008; Te Pou o te Whakaaro Nui, 2019). These differences appear to stem from contrasts between Māori and Western views of health and disability more generally (Ministries of Health and Education, 2008) and have also been observed among other indigenous groups (Bailey & Arciuli, 2020). However, there was also evidence of heterogeneity in Māori understandings of autism across included publications and participants, and even within whānau (e.g. Bevan-Brown 2004), which is to be expected given the heterogeneity of the Māori population (Houkamau & Sibley, 2018). In general, traditional Māori values appear to encourage the acceptance and support of individuals with differences/disabilities and a number of the included publications reflected this view (e.g. Bevan-Brown, 2004; Ministries of Health and Education, 2008; Wastney et al., 2007).

Findings also suggest that the autism prevalence rate for Māori may be higher than for non-Māori. However, this finding should be interpreted with caution as there is a need for more definitive prevalence data (Drysdale & van der Meer, 2020; Simpson et al., 2012). This appears to be the case for autism prevalence data for the general New Zealand population (Eggleston et al., 2019) and for some other countries too (Bernier et al., 2010). Prevalence data have important research, policy and funding implications, such as informing research recruitment strategies, determining the scale of support services needed and assessing equity of access to services for different groups. Thus, the systematic collection of New Zealand autism prevalence data, including Māori prevalence rates, may contribute to ensuring that future autism research, policy and services align with the populations that they are designed to serve (Drysdale & van der Meer, 2020).

Access to and satisfaction with autism services for Māori appears to vary greatly across individuals and families. In general, Māori may have poorer access to autism diagnostic and support services than non-Māori. This appears to align with findings regarding access to autism services for minority ethnic groups in other countries. For example, a recent review of the literature (Smith et al., 2020) found that ethnic minority groups in the United States had poorer overall access to autism services. Barriers to accessing services are likely to be similar for Māori and non-Māori; however, Māori may be more susceptible to barriers related to socioeconomic status, mistrust of the health system and geographical isolation. The two studies (Eggleston et al., 2019; Searing et al., 2015) that directly compared the rates of satisfaction with services for Māori parents and caregivers with those of non-Māori parents and caregivers, found similar (Eggleston et al., 2019) or better (Searing et al., 2015) rates of satisfaction/helpfulness across Māori and non-Māori. However, parents from another publication (Bevan-Brown, 2004) reported feeling that they were forced to choose between autism expertise and cultural competence when selecting services for their child with autism. The need for Māori to have access to services that are both effective and culturally appropriate was emphasised across the included publications. This appears to align with recommendations for Māori public health services more generally (Savage et al., 2020). Several publications also highlighted a need for training for services and staff to enable them to deliver effective, culturally appropriate autism services.

Implications for future research

Several implications for future research can be drawn from the findings of this review. First, there is a clear need for more research focussed on Māori and autism, particularly research that is conducted by, or in partnership with Māori. This Māori-centred approach to research is important in ensuring that Māori perspectives are privileged, and that research agendas and approaches align with the needs and values of Māori communities. In line with this, future research should also include the perspectives and voices of autistic Māori. Although the perspectives of parents, whānau and professionals were well represented across the included publications, the voices of autistic Māori were largely absent.

This review also highlights a need for research to directly examine Māori autism prevalence rates. This may require the development of a rigorous system for collecting ASD diagnostic data from the Ministry of Health and/or District Health Boards (Drysdale & van der Meer, 2020). In line with this, future research evaluating the cultural appropriateness of current diagnostic tools for Māori may also be of value because current diagnostic tools may not be appropriate for use with non-Western populations (Masi et al., 2017). Similarly, it may be valuable for future studies to evaluate the cultural appropriateness of specific autism services or programmes for Māori. Finally, it may be valuable for future research to directly compare Māori

and non-Māori across variables, such as autism prevalence rate, age at diagnosis and access to and satisfaction with services. This type of research may be valuable for identifying and measuring disparities across these two groups.

Limitations

Several issues may limit the interpretation and use of these findings. First, while the breadth of our search enabled us to identify and include a wide range of literature, it also makes the integration and interpretation of findings challenging. Thus, readers should view this review as a map of the available literature rather than a synthesis from which firm conclusions can be drawn. Similarly, our decision, not to include the optional quality critique items from the PRISMA-ScR framework, means that review findings should be interpreted with caution. Furthermore, we have summarised the key findings for each of the included studies; however, our summaries are not exhaustive. Readers are therefore encouraged to read the full texts of included publications to gain a deeper understanding of each publication.

Also, it is possible that there is relevant unpublished information that is not included in this review. Māori have a long history of self-determination and finding solutions for their own communities (Pipi et al., 2003) and a complicated history with Western research (Rolleston et al., 2020). It is therefore possible that there is knowledge held within Māori communities that has not been captured in the published literature. Indeed, this review serves to highlight a paucity of Māori-centred research and a lack of input from autistic Māori. Community-led initiatives also appear to be largely absent from the published literature. This highlights the need for more research to be conducted by, or in partnership with, Māori communities in a space where Māori voice and culturally aligned research methodologies and theoretical paradigms are embedded and privileged. Indeed, one of the authors of this review, D.T.-S., lives in Tairāwhiti, a region on the east coast of New Zealand's North Island where approximately half of the population identify as Māori. Tairāwhiti is somewhat isolated from other major towns and cities and has therefore developed a strong community spirit and learnt to be largely self-reliant and innovative. This extends to supporting Taonga Takiwātanga (individuals with autism) and their whānau. D.T.-S. recently set up Taonga Takiwātanga Charitable Trust, which aims to address the growing need from Tairāwhiti whānau for an effective kaupapa Māori-based disability support service. The trust works within a Māori cultural framework to provide a range of supports and initiatives for individuals living with Takiwātanga, their whānau and the wider Tairāwhiti community. The focus of the trust is to educate the local community about Takiwātanga through marae-based and community wananga (educational workshops), thus raising awareness of the disparities between Te Ao Māori and Te Ao Pākeha.

Conclusion

Taken collectively, these findings suggest that there may be broad differences between Māori and Western understandings of autism which may have important implications for the way that autism is defined and assessed and the provision of services for autistic Māori and their whānau. The findings also highlight the importance of ensuring that autism diagnostic and support services are both effective and culturally appropriate for Māori. Finally, although valuable foundational research has been conducted (e.g. Bevan-Brown, 2004; Ministries of Health and Education, 2008), this review reveals significant gaps in the literature. There is a pressing need for more research, particularly research that is driven from within Māori and autism communities.

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