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ORIGINAL ARTICLE

Prioritized strategies to improve diagnosis and early management of cerebral palsy for both Māori and non-Māori families

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Abstract

Aim: To identify prioritized strategies to support improvements in early health service delivery around the diagnosis and management of cerebral palsy (CP) for both Māori and non-Māori individuals.

Method: Using a participatory approach, health care professionals and the parents of children with CP attended co-design workshops on the topic of early diagnosis and management of CP. Health design researchers facilitated two 'discovery' (sharing experiences and ideas) and two 'prototyping' (solution-focused) workshops in Aotearoa, New Zealand. A Māori health service worker co-facilitated workshops for Māori families.

Results: Between 7 and 13 participants (14 health care professionals, 12 parents of children with CP across all functional levels) attended each workshop. The discovery workshops revealed powerful stories about early experiences and needs within clinician–family communication and service provision. The prototyping workshops revealed priorities around communication, and when, what, and how information is provided to families; recommendations were co-created around what should be prioritized within a resource to aid health care navigation.

Interpretation: There is a critical need for improved communication, support, and guidance, as well as education, for families navigating their child with CP through the health care system. Further input from families and health care professionals partnering together will continue to guide strategies to improve health care service delivery using experiences as a mechanism for change.

Worldwide, cerebral palsy (CP) is the most common paediatric-onset physical disability, with a prevalence of 1.6 cases per 1000 live births in high-income countries, such as Australia, and across Europe.[1] The associated comorbidities attributed to neurological impairment in the developing fetal or infant brain[2] are complex, vary in severity, and can have a lifelong impact on the functioning, health, and well-being of both the child and their family. In Aotearoa, New Zealand, the exact incidence of CP is not known but the types of CP, levels of severity, associated impairments, and reported causation are similar to Australia, based on data from the 2022 New Zealand Cerebral Palsy Register report.[3]

Receiving a CP diagnosis is a significant moment for many families that can be central in shaping parental roles.[4] The first years of life for a child with CP often include multiple appointments with different health care professionals, and commonly a 'wait and see' period before a diagnosis is provided to the family. In many reports, the process of obtaining a diagnosis itself is delayed (perceived to be by families),[5–8] and has been linked to parental dissatisfaction,[6] parental depression,[6] increased stress,[9] and developing mistrust for health care professionals.[10] Some children will receive early therapy (although only half of children with CP will receive this before 12 months[8]), advice, and targeted

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surveillance for emerging impairments. However, for many, the gates to access and receipt (and funding) of intervention(s) only begins after a diagnosis. Varying use of key diagnostic tools, unclear referral pathways, and limited access or availability of therapy services[10] all present roadblocks and detours along early detection and management pathways for children and their families. With growing access and awareness of evidence-based assessment tools[11] and early intervention,[12] there are continued opportunities for improvement in health care service delivery.

In Aotearoa, New Zealand, families of children with CP tell us that there are delays in diagnoses and that obtaining health care for their child is challenging, with a 'high number of appointments, a large health care team and multiple services involved'.[5] An 'overwhelming administrative component in navigating the health system for a child with a complex diagnosis' is also reported, with a lack of support or guidance through the process.[5] There is also emergng evidence of poorer respiratory and hip health outcomes for Māori (the Indigenous people of New Zealand; Table 1) children with CP,[11] which is consistent with the known and unjust inequitable health outcomes and experiences for Indigenous Māori across Aotearoa, New Zealand.[12,13] To explore these findings further, we chose to use co-design,[14] a health design method that values a consumer-driven participatory approach, where patients, families, and health care staff work together in partnership to co-design better health services and importantly can ensure that the views of the Indigenous population are captured in health care system design.[15,16] This participatory framework supports an interdisciplinary design process to ensure that outcomes reflect real, rather than assumed, needs,[17] and can also offer innovative strategies to assist in the resolution of complex problems.[18] This method relies on patient experiences as the mechanism for change,[17,19] and has been effective when improving services, while helping to change practitioner attitudes and behaviours.[17,20]

Therefore, the overall aim of this study was to explore further the need(s) for change and co-create prioritized strategies using co-design methods, with a goal to support improvements in early health care service delivery around the diagnosis and early management of CP in Aotearoa, New Zealand. Approximately 26% of all children with CP on the New Zealand Cerebral Palsy Register identify as Māori,[3] reflective of the paediatric Māori general population distribution in Aotearoa, New Zealand. Therefore, a series of co-design workshops, incorporating culturally appropriate (Te Ao Māori, the Māori world/worldview) practices were offered to families identifying as Māori and with children with hōkai nukurangi (the Te Reo Māori term for CP[21]).

TABLE 1 Glossary of Māori terms.

Hōkai nukurangi	The Māori term for CP, to achieve what is important to you.
Kaitiaki	a Māori person recognised as a guardian by the tangata whenua, the tribal group with authority in a particular area.
Karakia	Māori incantations and prayer used to invoke spiritual guidance and protection.
Kaupapa Māori	'The Māori way', Māori strategy, approaches, philosophy.
Māori	The indigenous people of New Zealand.
Mihimihi	Introductions, sharing who you are, where you are from and your connections.
Taha hinengaro	Mental and emotional wellbeing.
Taha tinana	Physical wellbeing.
Taha wairua	Spiritual wellbeing.
Taha whānau	Social wellbeing.
Te Ao Māori	The Māori world/worldview.
Te Whare Tapa Whā	A model for Māori health.
Whānau	Extended family, family group.
Whare	A Māori hut or house.

What this paper adds

- Information about a diagnosis or suspected diagnosis of cerebral palsy should be honest and tailored to the needs of the family.
- An ideal child disability service should incorporate working together and nurturing spiritual, mental, and emotional well-being, while providing equitable access.
- Key actions should include an educational toolkit for parents, and improved appointment and service management systems.
- Key actions should also include regional early detection and management hubs, and pastoral support.

METHOD

Two co-design workshop series, facilitated by a health design team and led by one of the authors (INK), were held with families of children with CP, and health care professionals working with children under the age of 5 years with (or who may be at risk of) CP in Aotearoa, New Zealand. The two series of workshops were held across two cities in the North Island of Aotearoa, New Zealand (approximately 120 km apart), the first in October 2020 and the second in March 2021. The March workshop series was held with all Māori whānau (family) participants (and participating mixed ethnicity health care professionals). This workshop followed a co-governance model, being co-led with a local kaitiaki health support worker (a Māori person recognized as a guardian by the tangata whenua, the tribal group with authority in a particular area) and according to culturally appropriate protocols and following Kaupapa Māori (the

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'Māori way'). The study was approved by the Health and Disability Ethics Committee (ref. no. 18/NTB/169).

Participants

Families were eligible for inclusion if they had a child in their family with CP and were able to attend the face-to-face workshops. Participants were excluded if their child had not received health care within Aotearoa, New Zealand in their first 5 years of life. Family participants were recruited via social media channels through the Cerebral Palsy Society of Aotearoa, New Zealand (a member-based organization for people with CP and their families), and with the assistance of a local kaitiaki (a Māori person recognized as a guardian by the tangata whenua, the tribal group with authority in a particular area) through community consumer groups and targeted invitations through regional clinical services (for our Māori participants). All family participants were offered koha (a gift, remuneration for childcare, and fuel expenses). Health care professionals were recruited via promotion through professional networks and health services associated with the local hospitals; they were eligible to participate if they were currently working with children under the age of 5 years with (or who may be at risk of) CP. Participants were invited to attend either one or both workshops within the series, with care taken to balance the ratio of health care professionals to family participants to minimize the potential for power imbalance.

Co-design workshop series

Each series included two workshops (approximately 2 hours per workshop), that is, a 'discovery' and a 'prototyping' workshop. Design, creative, and cultural practices (for example, the use of Karakia [Māori incantations and prayer used to invoke spiritual guidance and protection], mihimihi [introductions, sharing who you are, where you are from, and your connections]), and activities using Te Whare Tapa Whā model[22] (a model for Māori health) were used throughout the co-design process to generate data and inform knowledge mobilization activities.[23] Creative participatory methods helped to overcome power imbalances between researchers and participants,[24] to enhance the safety of participants articulating their unique experiences through creative processes,[25] and to create a shared understanding and relatedness between participants.[26] Brief descriptions of the workshop goals and activities are outlined in the following sections.

Discovery

The 'discovery' workshop focused on sharing experiences, opinions, needs, and ideas about the diagnosis and early management of CP. The goals of the sessions were to understand fears, concerns, barriers, and gaps associated with health service delivery to identify priorities for change.

The first activities used 'thinking through objects' (i.e. using objects as a medium for participant discussion and storytelling),[27] which became a tool for participants to express their thoughts, and helped facilitate discussion and acted as prompts to scaffold the conversation.[28] Examples include introducing themselves through creating shapes with playdough (thinking through making), and selecting an intentionally ambiguous object[26] that reminded them of something about themselves, or a meaningful moment from their child's life they saw in their professional practice and talking through it with the group. A scenario-based activity was then used, whereby a hypothetical CP diagnosis scenario (inspired by common narratives from previous research[5,29]) was presented to the group to stimulate open discussion (Appendix S1). This then led the group through 'empathy mapping' of common feelings, thoughts, and needs, and what worked well and not so well under the current health systems.

Prototype

Summaries of discussion points from the 'discovery' workshops were brought as inputs into the 'prototyping' workshops, which aimed to explore 'solutions' to improve health care service delivery that would be useful, appropriate, and timely for families and health care professionals.

For the first series of workshops, participants engaged in a card sorting exercise to explore the types of information and topics to cover in an educational resource. The main themes from the 'discovery' workshop were used as high-level information topics for the resource (displayed on individual cards), which were then sorted into groupings of 'must have', 'nice to have', or 'not needed' topics in a resource. Additional subtopics were added by participants through this process, unpacking what was most important for people to know.

In the second series of workshops with Māori whānau (extended family, family group), the focus was on collectively exploring how health service(s) of the future could meet the hauora (a holistic view of health and well-being) needs of the whānau. Using the contemporary Te Whare Tapa Whā model for Māori health,[22] which considers health holistically as a whare (a Māori hut or house), encompassing physical well-being (Taha tinana), social well-being (Taha whānau), mental and emotional well-being (Taha hinengaro), and spiritual well-being (Taha wairua) (Figure 1), participants engaged in a making activity using arts and crafts to 'dream big' and create their ideal whare (house) to represent what an ideal service should look like.

Collation and analysis

All workshops were audio-recorded and group discussions were transcribed by a researcher in the team (INK);

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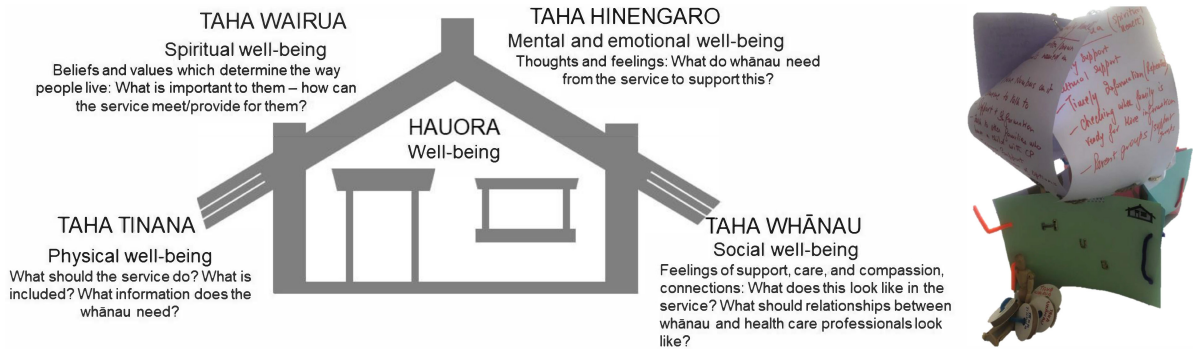

FIGURE 1 The Te Whare Tapa Whā model for Māori health and considerations discussed within the workshop series for Māori whānau (families),[22] with an example of a model developed within a workshop.

photographs of participants' creations, empathy maps, and card sorts were also used for the analysis. Data were summarized and analysed using the general inductive approach for the analysis of qualitative evaluation data described by Thomas[30] and previously used by Cunningham and Reay[31] and Nakarada-Kordic et al.[32] Members of the research team (INK, SAW) analysed the data thematically by first grouping the responses to all questions into small groups of similar ideas, which were then collated to construct key themes representing participants' thoughts, ideas, needs, and experiences. The research team subsequently came together to reflect on the outputs of the workshops to ensure that a collective understanding was created. For the workshops with Māori whānau (family) specifically, data were reviewed and validated by the local kaitiaki health support worker to ensure that the themes represented the key collective findings from each activity and discussion. Data themes and summaries are presented under 'experiences and needs' and 'proposed solutions'.

TABLE 2 Summary of participant characteristics of the co-design workshop series.

	Characteristics of family participants ($n = 12$)	
Ethnicity	Child ethnicity Māori: 6 Non-Māori: 5	Parent ethnicity Māori: 7 Non-Māori: 5
Age of the child	Median 9 years 6 months (range 5–20 years)	
Year born	2000–2015	
Age at CP diagnosis	8–36 months	
GMFCS level	I and II: 5 III: 2 IV and V: 3 Not reported: 1	
	Characteristics of participating health care professionals ($n = 14$)	
Ethnicity	Non-Māori: 13 Not reported: 1	
Profession	Paediatric doctor: 8 Therapist: 5 Neuropsychologist: 1	
Usual role	Provide diagnosis: 7 Complete screening and assessments that may contribute to diagnosis: 9 Provide follow-up monitoring, intervention, support: 12	
Years' experience working with CP	3 years: 1 More than 10 years: 13	

Data are *n* unless otherwise stated. Abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

RESULTS

Participants

Six mothers and nine health care professionals (eight females) participated in the first series of workshops, with five mothers and six health care professionals attending both workshops (Table 2). Five mothers and one father (of five children with CP) and five health care professionals (all female) took part in the second series of workshops. Four parents and two health care professionals attended both workshops (Table 2).

Discovery (experiences and needs)

Parents described the period within their child's journey receiving a diagnosis of CP as characterized by feelings of fear, shock, feeling alone, unsupported, betrayed, excluded, and isolated, and a need to adjust to the new normal and 'simply trying to cope' (Figure 2). For families, this was a time of uncertainty, made difficult by the lack of information regarding the diagnosis and the severity of the condition, and not knowing what to expect next. Three primary themes were generated from the data, outlined as experiences and (related) needs within: (1) clinician–family communication; (2) service provision; and (3) information provision. Both Māori-specific and other sessions identified similar themes.

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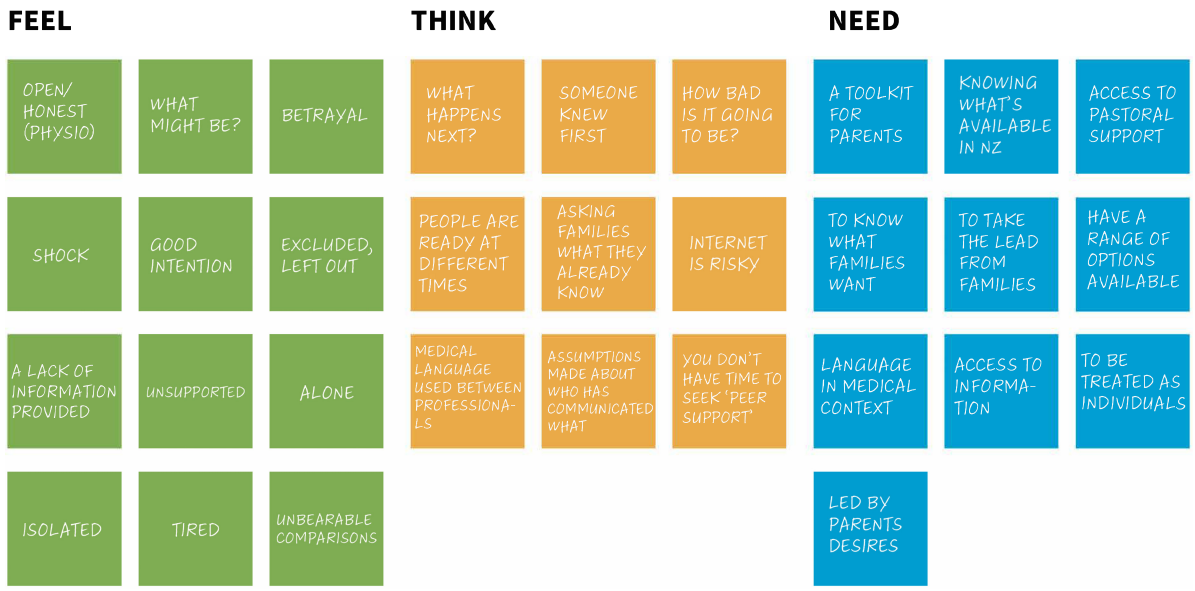

FIGURE 2 Empathy mapping of the feelings, thoughts, and needs identified by participants about the process or diagnosis and early management of cerebral palsy in New Zealand.

Theme 1 (clinician–family communication)

Both families and health care professionals shared their experiences with miscommunication and information not always being communicated or conveyed to the family, including the reluctance of health care professionals to verbalize to carers the possibility of a CP diagnosis:

> I have parents who have had their child at NICU. But no one had ever mentioned your child might have CP. So I'm thinking, why did no one tell them?
>
> (Health care professional)

Consequently, parents reported finding out about the diagnosis by accident, for example, through written correspondence between health care professionals or when their child was being seen for a (seemingly) unrelated health issue:

> I was in [xxx] and my girl got a bit crook with a chest infection, and I took her down to [xxx] hospital. And this old doctor comes to me, he took one look at her and he goes 'How long has your daughter had CP?', and I was 'ay?! That's a new one on me, mate! They never told me that in [xxx]! She was still pretty young then.
>
> (Parent)

It was described that assumptions were often made about who communicated what, resulting in parents having to speak up and constantly feeling the need to advocate for their child. Table 3 summarizes key needs for communication that were collectively agreed on by participants.

Theme 2 (service provision)

Families and health care professionals talked at length about system complexity. Families found the services overwhelmingly complex, disconnected, and inefficient. Participants discussed how families often had to juggle multiple appointments and it was difficult for them to understand who was involved in the care of their child, what roles they had, what support was available and how to access it, and make sense of the medical jargon used in written and spoken communication. Some of these concerns were echoed by health care professionals:

> It is complicated, isn't it? And sometimes, I think, there's confusion amongst therapists—who's going to be taking which responsibility.
>
> (Health care professional)

Both health care professionals and parents voiced their concerns about primary care practitioners (general practitioners [GPs]) lacking the knowledge to manage a child with CP:

> I would want the information from my paediatrician; my GP wouldn't know anything about it. He looked … puzzled. So do I wait a whole year to be seen?
>
> (Parent)

> I think they find it complex. Maybe we have not empowered GPs enough. For most of the children with complexities and CP, GPs would just call us or send them to the hospital system. GP should be the one who should be developing that relationship, but I can see that

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TABLE 3 Overarching principles and key needs for an ideal child disability service for the diagnosis and early management of cerebral palsy (CP), as co-designed by parents and health care professionals.

Overarching principles		
Working together Being able to have a foundation to build a relationship with family from which their holistic well-being needs can then be met. It is important for the health care providers to have a holistic picture of the family's circumstances that may impact on how health care is delivered, for example, housing situation, social support, and whānau relationships.		
Nurturing taha wairua/spiritual well-being and taha hinengaro/mental and emotional well-being Allowing space and time for health care professionals and families to be able to reflect on things together, learn from each other, and help others (e.g. a forum, such as the co-design workshops themselves).		
Equitable access Equitable access to the service and information sharing through different modes of communication and information sharing. This could include better access and use of technology (e.g. telehealth), in-person assistance (e.g. through a health navigator as a mediator), and physical information (e.g. paper booklet/folder).		
Key needs		
Clinician–family communication	**Service provision**	**Information provision**
• Honest, open communication between families and health care professionals. • Communication on 'suspected' or 'under surveillance' for CP to be given early. • A tailored approach to information delivery: ask families what they already know, what their needs are, and take the lead from families. • Plain language. Wording is important. Saying 'at risk of CP', 'monitoring for CP', 'suspecting CP', rather than 'wait and see'. • Not placing a ceiling to what the child might achieve; every child is unique. • Be aware of the wider family context (e.g. multiple health issues). • Acknowledge and value the family lived experience. • Parents to be told to bring a support person to the appointment when a diagnosis is suspected • Cognitive issues to be talked about early; currently, priority is given to motor development. • Willingness among health care professionals to engage in discussions about alternative treatments.	• A clear service map (laying out the types of services available and teams, and their roles). • A case manager or health navigator early on to help families navigate the complexities of health care. • Equitable access to services, accommodating for different cultures and geographical locations. • Having group (interdisciplinary team) consultations. • Parents to be able to initiate appointments. • Better 'access' to specialists for advice and asking simple questions. • Pastoral support and grief counselling (for both families and staff).	• The breadth of local expertise available to them, that is, who, when, why, and how you get there. • That there may be things down the track where families might need help and to know who is involved (not just regarding health care, but also the child's education). • 'Go-to' websites with trusted information. • Cognitive development, behavioural, emotional, and sensory issues that may arise. • Current research, complementary therapies, alternative treatment options.

> you go there, and they see your child and they don't understand the condition.
>
> (Health care professional)

Lack of diagnosis counselling and continuity of care were also described as a common issue, with families describing 'falling through the cracks' by getting discharged from paediatric services if the child was diagnosed as mildly impaired. While support services existed, they were fragmented and hard to navigate. Participants commented that although there were ways to access funding, it took a lot of time and paperwork to organize. For example, to get government-supported child disability allowance, an application needed to be signed by a doctor and resubmitted every 1, 2, or 5 years, although the child will have CP for life. A summary of agreed on needs to improve service provision is outlined in Table 3.

Theme 3 (information provision)

Despite a distinct need for information on the disorder and the services available, families and health care professionals were not aware of there being any locally available educational resources for families of children with CP:

> Because you literally don't get given anything. I don't have an encyclopedia book to use.
>
> (Parent)

> I don't know [if there are any resources] for the parent. Actually, there is nothing for clinicians as well.
>
> (Health care professional)

Participants commented that digital information on CP was perceived as overwhelming, country-specific (i.e. not always relevant for Aotearoa, New Zealand), and not always trustworthy. Table 3 provides a summary of key areas where participants felt that more education was needed.

Prototype (proposed solutions)

Prototyping sessions resulted in families and health care professionals working together to prioritize areas that

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TABLE 4 Tangible and prioritized action solutions for improved detection processes and early management of cerebral palsy.

Action solutions	
An educational toolkit for parents An information resource to support families in the early management of their child and guide them through their child's developmental journey. These could be in the form of accessible information packs gradually introduced for different ages and stages, including information on different options for treatment to be made available to families at the suspected diagnosis (with information that focuses on the functional aspects of presentation, cultural support, well-being, grief, hospital care and support services, and navigating the system). The pack could also feature personal stories. These would enable self-directed learning for families to access at their own pace ('when your headspace allows'), with the links to further trusted resources to access at later stages and with more detailed information. The resource should also enable patients to document their journey and experiences over time, and serve as a tool that allows families to share and discuss their disorder with others.	**Regional early detection and management hubs** A clearly mapped out 'one-stop' regional integrated service was proposed, where: (1) families can self-refer; or (2) a child gets referred to as soon as there are 'red flags'; or (3) a child goes to straight from a neonatal intensive care unit or special care baby unit. Such a service would also allow for: • coordinated service appointments all in one place, on the same day; • interdisciplinary team consultation (with therapists, doctors, teachers); • organization according to the child's age (0–2, 2–5, 5–10, 10 years and above); • one coordinated and clear care plan, relevant to the stage; • clear care pathways from the neonatal intensive care unit to paediatrics, and from paediatrics to adult services; and • cultural support, spiritual support and pastoral care, and mental health support and family support groups that can be accessed easily.
Appointment and service navigation management system To give parents more control over managing appointments and accessing services, a digital app or system could be implemented or access to a CP health navigator, where families could: • access the information on their child's health care team (including their roles and contact details); • communicate their needs in real time; • manage and make their own appointments; • be sent reminders (e.g. in 6 months' time); and • availability of an online forum to connect with other parents and health care professionals, ask questions, and share experiences.	**Pastoral support** Following on from the insights regarding the experiences surrounding the timing of the diagnosis, workshop participants proposed some practical steps for how families could be better supported through this traumatizing and emotionally charged period. These included: • empowering families by offering them the educational toolkit (described above); • being strength-based (conveying information that also covers strengths, and not only deficits); • inviting the family to bring a support person at the initial appointments (when something is first suspected) worded carefully to separate this from any other generic appointment letter (e.g. 'This is your first appointment. Bring someone with you'); • providing the family with a follow-up appointment after the initial 'diagnosis' appointment, allowing them time to process and come back with questions to ask.

needed improvement and co-design specific solutions to address these. The overarching aspirations for the ideal service voiced to a degree by all participants, Māori and non-Māori, were well articulated in the workshop with Māori whānau. Three overarching principles for successful service delivery were identified: (1) working together; (2) nurturing taha wairua (spiritual well-being) and taha hinengaro (mental and emotional well-being); and (3) equitable access (see Table 3 for further details). Based on the needs identified in the 'discovery' workshops (Table 3), four tangible and prioritized solutions were proposed in the prototyping workshops to improve communication, service provision (including navigation and access to services and support), and information provision. These included: (1) an educational toolkit for families; (2) an appointment and service navigation management system; (3) regional CP detection and early management hubs; and (4) pastoral support (particularly for initial appointments). Table 4 outlines further explanations.

Reflection on the methodology

Several participating health care professionals expressed concern before the workshops that family participants would not feel comfortable to engage in workshops shared with health care professionals, although this was not the case, potentially because of the planning and facilitation of the workshops. One family member stated that they felt empowered after the discovery workshop, while another asked if their partner could attend the second workshop to also experience the session. Multiple participants from both family and health care professional groups inquired when the research team would be holding future workshops for other related topics.

DISCUSSION

With support of experienced co-design facilitators, co-design was a valuable methodological approach for the intent of this study. The co-design workshops revealed powerful stories relating to early experiences around the diagnosis and early management of CP in Aotearoa, New Zealand and highlighted key needs relating to clinician–family communication, service provision, and information provision. From these workshops four tangible action areas were identified for improving service delivery: (1) an educational toolkit for families; (2) regional early detection and management hubs; (3) appointment and service navigation management systems; and (4) the provision of pastoral

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support. Furthermore, three overarching principles were identified to guide future approaches to health service delivery related to the detection and early management of CP: (1) working together; (2) nurturing spiritual and emotional well-being; and (3) equitable access. While the findings of this work have been co-designed by health care professionals and families in Aotearoa, New Zealand to improve the diagnosis and early management of CP within Aotearoa, New Zealand, the findings from this study are not specific and could be similarly applied to other groups, taking into account cultural and ethnic settings.

Improving service delivery and enabling earlier detection of CP is a priority globally; for example, work from Australia and the USA has been informing and trialling new models of care.[33–35] The identification of the need for additional educational resources and pastoral support in this study is also consistent with international practice.[36,37] However, both actions require the addition of local and culturally specific information, to ensure that they are transferable to individual countries and health settings. Our participants desired greater use of regional early detection and management hubs and improved appointment and service navigation management systems to maximize the value of hospital outpatient appointments, while (hopefully) reducing the number of appointments per year. Internationally, children with CP attend outpatient clinics frequently,[38] with both resource and financial implications. Coordinated care for children with complex disorders has been identified as important to improve the quality of health care[39] and can reduce the secondary consequences for those with CP, such as hip dislocation.[40] However, the need to better use virtual or telehealth reviews to reduce the physical burden on families of frequent in-person reviews has been highlighted, as face-to-face reviews can act as a source of inequity, placing a greater burden on those who live rurally or at a great distance from the hospital.[41]

Inequities in health outcomes specific for Māori children with CP, such as admission rates for respiratory-related illnesses,[11] highlighted the critical need to plan health service delivery using approaches that ensure health equity for Indigenous populations. To respect the value in hearing Māori views in health care planning and delivery,[42] this study specifically sought to identify needs and solutions prioritized by and for Māori. In recognition of the imperative for addressing persistent Māori health inequity, Māori-specific workshop outcomes were planned to be prioritized within the developed solutions. However, the experiences and solutions were similar for both Māori and non-Māori families. Further to this, experiences around the diagnosis of CP and desire for improvements relating to communication, the provision of social support, and navigation within the health care system are echoed from previous research also conducted in Aotearoa, New Zealand,[5] and similar to findings related to health care delivery identified by families of children with CP in Australia,[43] giving confidence to the validity of the findings and clear direction for enacting change.

With that in mind, it is important to acknowledge that the findings of this study may be in part only reflective of the experiences of those involved. Indigenous Māori continue to be significantly underrepresented in the Aotearoa, New Zealand health workforce,[44] and none of our participating health care professionals were Māori, revealing a potentially critical gap in perspective. The study researchers were non-Māori; however, the study methodology aimed for a high level of inclusion and cultural integrity, with oversight of research processes and outcomes for Māori by the Māori kaitiaki health support worker. Different experiences and priorities may have been identified by further co-design sessions across groups with regional and cultural variation. Future research in Aotearoa, New Zealand could consider co-design to include a wider demographic, for example, Pasifika or refugees or asylum seekers.

Conclusion

Outcomes from this study highlight key needs and clear action strategies to improve health service delivery for the detection and early management of CP. While some needs and strategies could be enabled quickly and with minimal disruption (for example, the development of local information and resources for improved communication for families and health care professionals about CP), others may require more significant input to enact, such as additional or redirection of funding and resources, or the implementation of regional 'one-stop shop' hubs. We encourage health services to review the 'key needs' that were co-developed by the health care professionals and families in this study to reflect on their own services. This work highlights the need to empower families with open communication and access to self-directed and culturally appropriate information and support.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

The following additional material may be found online:
Appendix S1: Hypothetical scenario provided to participants for the scenario activity.

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