

RESEARCH

`Korero I wish I could've had with the Well Child nurse'

BY CHRISTINA SEVERINSEN, FELICITY WARE, MARY BREHENY AND SARAH AITKEN December 20, 2022

Wāhi Kōrero is a unique research project where patients share their stories of care that did not meet their needs, via an online story-sharing platform. In the first part of this project, young mothers share challenging accounts of their experiences with Well Child nurses.



'Our previous research with young mothers highlighted how surveillance by health services undermined their confidence and limited their autonomy as mothers.' PHOTO: ADOBE STOCK

Introduction

Timely access to and effective use of health care leads to better health outcomes. Unmet need for health care is a key indicator of health system performance and is a significant driver of persistent health inequities.1,2

Unmet need is typically explored in terms of practical barriers to accessing services. 1,3 However, barriers to health-care access are complex; they include difficulties in making appointments, transport barriers, cost, as well as perceptions of unfair treatment. 4 Dissatisfaction with health services can lead to low rates of engagement.

There have been numerous government initiatives to reduce barriers to care, with little change to rates of unmet need. 2,4 Health-system reviews tend to focus on difficulties in navigating the system to reduce rates of unmet need. This view of access overlooks how interactions within health services are shaped by macro-economic, political, social and cultural structures. Taking a broader perspective of health service access will increase understanding of how people experience health care.

Barriers to health care access are complex; they include difficulties in making appointments, transport barriers, cost, as well as perceptions of unfair treatment.

Certain groups are particularly poorly served in health interactions, such as young mothers, whānau on welfare, and Māori parents.5,6,7

While surveillance — the systematic collection of personal data by government agencies — may be an important part of monitoring health systems in some circumstances, there are links between surveillance and stigma.

Collection of information about women's lives, personalities and behaviours puts their private lives under scrutiny, which can lead to a sense of being controlled and stigmatised, and feelings of fear and anxiety. Surveillance is experienced as particularly intrusive by marginalised populations, such as poor families and Māori whānau.

This can lead to non-disclosure — ie patients not disclosing personal health information or practices — and their disengagement from health services.

Our previous research with young mothers highlighted how surveillance by health services undermined their confidence and limited their autonomy as mothers.6,7 Understanding these

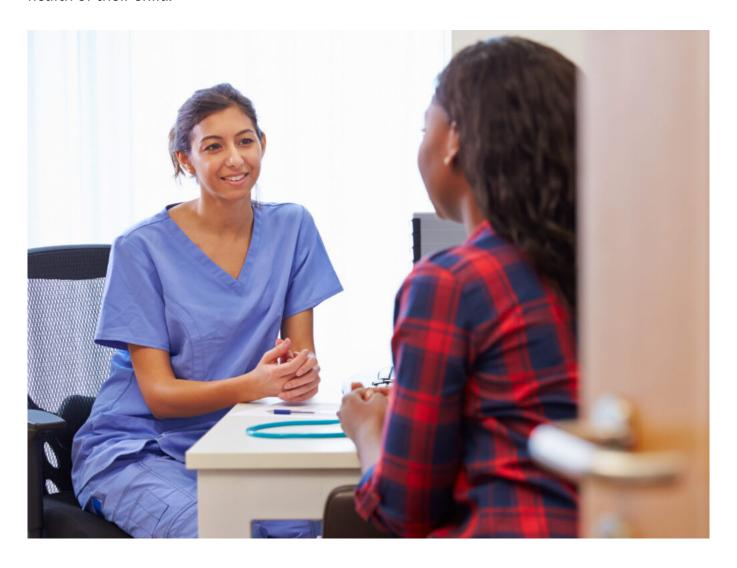
complex relationships between patients and health services can improve health-care provision, leading to more effective service engagement and better outcomes.

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Unmet need is not due simply to the characteristics of patients or the actions of health professionals. It is located within the social system that produces the health interaction.8

Understood in this way, addressing unmet need is about identifying issues that shape the health system, rather than pointing to deficits of particular patients or health professionals. Identifying the social setting that produces these health interactions has profound implications for addressing unmet need.

Nurses can play a pivotal role in engaging patients, families and whānau. The relationships established by nurses providing the Well Child service can support mothers to maintain the health of their child.





Nurses can play a pivotal role in engaging patients, families and whānau. PHOTO: ADOBE STOCK

This article identifies barriers experienced by participants in their relationship with their Well Child nurse. It provides recommendations to better address these unmet needs at a training and practice level, service provision and organisational culture level, and contracting and funding level.

The Wāhi Korero project

Addressing unmet need requires that we listen to challenging accounts of service provision. In our research programme, we aim to understand the drivers of unmet need by seeking and listening to accounts of health experiences where people feel that they have not received the care they needed.

To achieve this, we developed our novel online story-sharing platform <u>Wāhi Kōrero</u> (http://www.wahikorero.co.nz). This platform enables people to anonymously share their stories of unmet need, including challenges in accessing care, missing care, and suitability of care.

Importantly, we hear about situations where care was not sought. This information is often absent from health surveys and consumer experience surveys. $\underline{1}$

In 2021, we launched the first Wāhi Kōrero project with the storyline prompt, "Kōrero I wish I could've had with the Well Child nurse." This prompt invited people to share their stories of nondisclosure to their Well Child nurse.

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We focused on the relationship with the Well Child nurse as one of the key health supports available for children under five years of age. Understanding why people might not tell health services the full story helps to improve how health services are delivered.

In this article, we present initial findings from this project, and discuss the implications for person-centred and whānau-led primary health care in Aotearoa New Zealand.

The project received ethics approval from the Massey University Human Ethics Committee, and was launched on August 29, 2021, remaining open for nine weeks. Through our social media campaign, word of mouth and emails sent out as part of our partnership with community campaigning organisation Action Station, we received 420 stories.

Most stories were submitted by women and the average age of those submitting stories was 34 years. Of those who indicated ethnicity (61 per cent), 19 per cent indicated Māori, 3 per cent Pacific, 81 per cent NZ European Pākehā, and 6 per cent other.



Many participants felt judged about their babies' sleeping and feeding. PHOTO: ADOBE STOCK

Wāhi Kōrero was monitored and moderated to ensure safety, anonymity and proper use. The identities of participants posting stories and of other people and organisations mentioned in the stories were protected through the removal of identifying information.

All the stories submitted as part of the project can be viewed on our website (https://wahikorero.co.nz/projects/korero-i-wish-i-couldve-had-with-the-wellchild-nurse/). We approached the kaupapa from a

Māori perspective and sought to make visible Māori experiences.

Many participants had questions they would have liked to ask and things they felt they couldn't share. Several topics were commonly referred to in the stories: sleep, feeding, mental health, and relationships with the Well Child nurse.

Sometimes participants talked in the same way about different topics. For example, many felt judged about their baby's sleeping and feeding.

To go beyond a topic-based approach, we conducted a thematic analysis of *how* people talked about the services they received. We identified the following six themes that we see as representing both tensions in the way the service is provided and possibilities for change.

Excitement

The participants spoke of anticipation and eagerness to engage in the Well Child programme, and of high expectations of the service. Participants saw Well Child services as a key part of their parenting journey in acknowledging and supporting the growth and development of their child.

"When I got to see my Well Child nurse, I was always super excited & had so many milestones to share. One day when I went into the office I was left alone with my daughter in the room. My file was on the desk and I peeped over to see what lovely things were written about my gorgeous little girl... The nurse has said I talk too fast & excessively and was possibly on DRUGS!?! What the actual? I wish I had of been brave enough in myself to say something. I didn't & I just went home and cried my heart out. I couldn't believe being a young enthusiastic first time mum could be perceived so wrong. Really put a damper on the whole system for me and shut me down from ever wanting to open up at any other appointments."

Engaging with families and whānau

Participants organised their households for their Well Child visits, which felt futile when appointments were cancelled. Often the visits did not meet their expectations. Participants felt that the nurses were not always well-prepared for their visits.

Relationships with the nurses were often hampered by a lack of whanaungatanga and failure to build reciprocal relationships with patients.

They wished for a continuum of care or handover from their midwives, in which the Well Child nurse received information before meeting with them. Relationships with the nurses were often hampered by a lack of whanaungatanga and failure to build reciprocal relationships with patients.

Although the participants acknowledged the difficulties of funding and staff resources within the Well Child programme, they felt that the service as provided did not support mothers:

"My son is nearly 2, and I've only seen Plunket 3 (maybe 4) times, each for maybe 15 mins. One appointment was double-booked and I had to come back another time.

Another appointment they asked to push out a few months as they couldn't keep up with the workload in the region. While I'm sympathetic to these lovely people, they would be the last people I go to for any concerns regarding my child, especially one that I feel society may judge or shame me for. While I have no doubt they do their best with 15 mins every few months, it's simply not enough time for someone in the vulnerable position of being a new mother – as well as any other challenges people face like race, socio economic factors etc."

Centring family and whānau understandings and priorities

Many participants referred to the "tick box" approach of visits. Assessment approaches from

initial visits through to the B4 School Check were experienced as superficial questioning, based on a physiological framework, and in some cases irrelevant.

There was little recognition of what is normal for their families and whānau. Many of the concerns participants did express were dismissed or overlooked. Participants wanted services that recognised their experiences and perspectives and upheld their own ways of knowing. They felt that the service was designed to meet institutional needs, as opposed to improving the wellbeing of their family.

"It was after her second visit I realised something wasn't right. She was asking questions and replying with answers that were totally unrelated to what I had just said. She was on her mission to tick the boxes in the Well Child book. And boxes she ticked. All of them!! Even the ones that didn't apply to my son."

Partnering for hauora

Participants desired a relationship where they could work together to find a set of solutions that would work for their families and whānau. Often they spoke of advice provided that was generic, narrow or misguided. They felt they could not talk openly, particularly about safe sleeping, feeding and the mother's mental health.

Participants also questioned the advice given by Well Child nurses. They spoke of knowing their child best, and how they wished the Well Child nurses would acknowledge this expertise. They wanted to develop ways forward with Well Child nurses in whānau-led relationships.

"An anxious new Mum that had severe PND but my WellChild provider kept telling me I was 'fine' and 'having a baby is hard'. She literally wrote in my Plunket book 'does not enjoy motherhood' — THEN HELP ME!"

"It was too difficult to have a real conversation about these things so I felt left on my own with getting information and making decisions. I felt that if I did not follow the standard advice and pathways to the letter, I would be judged as a bad parent or overanxious or something else negative and dismissive. What I really needed was a real conversation about the needs and my concerns and the possible benefits and risks."

Feeling fear and judgment

Interactions with their Well Child nurse led some participants feeling judged, shamed and angered. Where they experienced a sense of surveillance, they felt fearful and compelled to withhold information from the Well Child nurse.

"My daughter's Plunket nurse was extremely judgmental and I was always left feeling like a failure as a parent after one of her visits. My house was not warm enough. I HAD

to make it warmer for the baby. My next two power bills added up to \$1100."

"I had developed a fear of her coming back and taking my baby. As she had written falls risk all over our Well Child book with no explaining as to what it meant. I kept wondering what I had done wrong. What did it mean??"

Disengagement

Ultimately, the lack of relationship and feelings of shame led to non-disclosure of parenting practices and in some cases disengagement from Well Child services. Participants spoke of actively deciding to withdraw from the service when their needs were not being met. Their experiences lowered their expectations and trust in health-care relationships.

"I told my Plunket nurse we were struggling with sleep. She referred me on to their 'sleep expert' who advocated for stopping overnight feeding and sleep training. When I said I wasn't prepared to let him cry and what else could I do, she literally had no advice. I felt let down and cried. After that, I never told my nurse we started bed sharing. I never got the safe bed sharing advice I needed. I never used their crap service with my second child."

"Despite following up numerous times, we heard nothing until the B4 School check for our eldest. When the nurse asked her to count to 10, and she replied in Māori to be told "No, in English". My heart melted and we walked out, never to return. I wish I could tell them how my heart broke for the pepi of whānau who don't have the courage to walk out, who fear their babies will be taken from them if they don't comply. I wish I could tell them they need to change, because right now, they do far more harm than help."

Discussion

Hearing these stories can be challenging for Well Child nurses, but they help us to understand how current services are provided and how to create services that better respond to the needs of families and whānau.

Treating these accounts as legitimate and worthy of serious consideration is the first step in acknowledging the ways that health professionals and their patients can differ in their experiences of health services.



These specific and personal experiences arise out of the wider context of service provision. They help us to understand the limitations of current strategies to improve the health-care system.9



Hearing these stories can be challenging for Well Child nurses. PHOTO: ADOBE STOCK

Improving patients' experiences with the health service requires an understanding that health-service access is shaped by the processes and practices of unequal distribution of privilege, resources and power that is deeply embedded within society.

These processes and practices play out within health and social services, and can produce harmful power relations within these settings. An important step in improving equity is for health professionals

to use a relational approach to the service they provide, ie building relationships with patients and whānau based on respect, empathy, kindness and cultural responsiveness. 10 Without this we cannot hope to improve unmet need.

At the interpersonal level, nurses have a key role in partnering with and advocating for families. They are well-placed to develop effective relationships through their provision of face-to-face Well Child services in homes.

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Our research shows that family and whānau priorities, ways of being and knowing, and preferences, were often unheard in their relationships with Well Child nurses. These experiences highlight power imbalances between health professionals and patients in these health interactions.

Using person-centred care, nurses can build partnerships through collaborative decision-making, respectful communication, and compassionate and culturally responsive care to empower and uphold the self-determination of those they are working with. 11,12 Whānau-centred care makes whānau active negotiators of their health information and relationships.

At the organisational level, our findings question whether Well Child services prioritise the needs and aspirations of families and whānau. Models of practice and service schedules across the early years of a child's life need to enable information-sharing, continuity of care

and partnership.

In Aotearoa New Zealand, practice models must consider both culture and clinical aspects and be evidence-based. Te Puni Kōkiri<u>13</u> states that it is essential that health-care practice adopts an holistic approach to supporting whānau aspirations and needs.

Creating better experiences for families and whānau will lead to more meaningful engagement and care, and improved outcomes.

The stories also challenge the wider health system, highlighting concern with surveillance and data collection. This suggests that contracting and reporting structures, funding, resources, training, and workloads have not been designed to centre family and whānau needs and aspirations.

Narrow biomedical understandings of health and child development fail to account for the child in their family/whānau context, which can negatively affect the experiences of those receiving Well Child services.

Conclusion

The stories shared on the Wāhi Kōrero platform demonstrate the subtleties of unmet need and what drives patients to disengage from health services. Lack of connection meant that some needs were unmet. Feelings of distrust — and sometimes shame — lead to non-disclosure to Well Child nurses about parenting practices and health behaviours.

These stories provoke us to reflect on the primary health care provision environment and how current health system reform can advance us further towards an understanding of the importance of relational care. This approach is key to prevent patients distancing and withholding information, and to promote the wellbeing of all.

Instead of increasing surveillance to improve health outcomes, health services can enact culturally responsive, relationship-based, mana-enhancing solutions to unmet need. Creating better experiences for families and whānau will lead to more meaningful engagement and care, and improved outcomes.

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