

INA ORA TE WAHINE, KA ORA TE WHĀNAU, KA ORA TE HAPŪ, KA ORA TE IWI E!

(When women are in good health, the Whānau, Hapū and Iwi will flourish)

# Women's Health Action Trust Health and Disability System Review

Dear Review Panel,

It is with great pleasure that we write to you to share our perspectives on the changes needed to ensure we have a 21st century health care system in Aotearoa New Zealand that is sustainable, optimises technological advances, and promotes equity of outcomes. As a national organisation that has worked to improve the health and well-being of women, their families and whānau for over 30 years we believe we hold a wealth of knowledge that we are keen to share with you. In addition to Women's Health Action, this submission is supported by, and represents the views of some of our Sister organisations including: MAMA Maternity, Federation of Women's Health Council, Maternity Consumer Engagement Services, and Health Promotion in Partnership.

We have also included the thoughts and feelings of some of our stakeholders and wider networks, their voices are captured throughout this document as quotes.

### Background

Women's Health Action (WHA) is a charitable trust in its 34th year of operation. Formerly Fertility Action, WHA was founded in 1984 by women's health activists Phillida Bunkle and Sandra Coney. Fertility Action had its beginnings in reproductive health and rights and came to national prominence with our key role in exposing the 'Unfortunate Experiment' at National Women's Hospital which resulted in the landmark Cartwright Inquiry and subsequent 'Cartwright Report' in 1987/1988.

Our team work with consumers (service users), whānau, hapū, iwi, health professionals and other agencies/providers (including Ministries and DHBs) across the health, social development, education, and justice systems/sectors. We aim to reduce inequalities, draw attention to the social determinants of health and take an assets-based approach to health promotion and disease prevention. We have special interests in maternal and child health (including breastfeeding); body image (including weight and size-based discrimination); sexual and reproductive justice; and screening. We approach health within a holistic framework of the whole of women's lives recognising Taha tinana, Taha wairua, Taha whānau, Taha hinengaro.

Below are our responses to the review questions including quotes from our stakeholders gathered in an on-line survey in preparation for this submission:

#### 1. What are the most important values for our future public health and disability system?

- A. We need a commitment to longer term funding agreements, that support investment in infrastructure and other assets required to develop a more flexible primary and community sector. Current short-term contract/funding arrangements restrict innovation, inhibit long-term thinking, create workforce uncertainty and instability, reduce community trust and buy in, and make it difficult to demonstrate long-term, cross-sectoral benefits from investment (Dr Murray Horn -Commissioned by the Director General of Health, 2015; Minister of Health, 2016; Cox, 2013).
- B. A system that supports service users to become part of an open, consumer-driven ecosystem will enable a culture of health (Hagel III, Keith, Brown, Samoylova, & Hoversten, 2014). The health and disability system must include authentic co-design of pathways through which service users and community organisations can contribute to the strategic and operational direction of health services at all levels of service design, delivery and funding.
- C. Whānau Rangatiratanga A non-judgemental space of determination and ownership of one's own health outcomes, values built on relationships and accountability. Community-buy in for community designed engagement. Understanding and acknowledging Te Reo me ona Tikanga as the foundations of Mātauranga Māori used as engagement tools for all New Zealanders.

- **D.** The Government and Ministry of Health prioritise, value and protect pregnant people and babies via meaningful investment in safe and quality maternity services. This **must** include sufficient funding to allow our midwifery workforce to deliver services in a manner that is sustainable, responsive and flexible. We also need to see greater investment in, and support for:
  - Connecting newly pregnant people and whānau with maternity providers
  - Primary birthing, including greater access to primary birthing facilities and the option of birthing at home
  - Diverse, culturally appropriate and accessible pregnancy and parenting education
  - Breastfeeding support services and Tamariki Ora Well Child Services
  - A more culturally diverse maternity workforce including specifically more Māori and Pacific midwives
  - Maternal mental health services at primary, secondary, and tertiary level

"I had full confidence in my midwife, which allowed me to cope very well with what she thought was a very traumatic emergency delivery. She was also proactive about referring me for physio for my subsequent prolapse. My midwife was overloaded or overworked during my postnatal care. There were times when she was more exhausted and frazzled than me (& I was a wreck). After the first week, I opted to drive into the clinic rather than her drive to my rural home, because I was concerned for her safety" (WHA Maternity consumer experience survey, 2018)

"In 2018 - this pregnancy (#4) by far has been the most difficult to get a midwife and that's a worry for me. I have had to go through Christchurch women's Core midwife s outpatient and obs. The care is amazing I have a great midwife at present, but it's always a worry that I don't have a midwife in call as I would usually. I just wish she was going to be there when I have my baby." (WHA Maternity consumer experience survey, 2018)

"Greater inclusion and diversity in the workforce, a more accessible country, more education for teachers regarding special needs and far more lateral thinking

regarding inclusion generally" (WHA Maternity consumer experience survey, 2018)

"I have lost total trust in NZ's healthcare system. Several doctors and specialists have ruined my life both physically and mentally and to add insult to injury - they don't even pretend to care" (WHA Health and Disability Review Survey – 2019)

- 2. Think about how the best health and disability system for New Zealand might look in 2030. How would that be different from the system we use today?
  - **A.** Government departments, Ministries and District Health Boards are required to include service users and community providers at all levels of health and social service design, implementation, delivery and evaluation.
  - **B.** Whānau Māori are actively engaging and accessing health care that is aligned to their cultural needs and aspirations, and achieve equity of outcomes. This is first and foremost to be achieved by embedding a strengths based approach into our health and disability systems rather than working from a deficit base. We know from experience that fear based programs are not successful when it comes to interaction with whānau. Therefore, a wellness approach encompassing not just health and physical activity, but one that incudes waiata, art, music, refuge, safety, te reo, childcare assistance from 0-5, and living wage for stay at home parents. This can be supported by workforce training and technology development which supports accurate information and advances to help bridge gaps between whanau and services.
  - **C.** The health and disability workforce and its decision-makers are culturally competent and confident, and value the partnership relationship between tangata whenua and tangata tiriti in the design, development and delivery of all health services and initiatives.
  - **D.** Equitable access and safe services including culturally competent health services for specific populations including Māori, Pasifika, older people, young people, disabled

people, rural people, and Lesbian, Gay, Bisexual, Transgender, Takatapuhi and Intersex people.

**E.** The drivers of health across all government sectors and policies are addressed through the World Health Organisation's (2014) Health in All Policies country framework in order to support people and communities to be well and thrive.

"Less arrogance and more transparency from DHB's and better care taken by doctors. A whole lot more honesty wouldn't go astray either" (WHA Health and Disability Review Survey – 2019)

## 3. What changes could make our health and disability system fairer and more equal for everyone?

- **A.** Address issues with funding arrangements that contribute to disparities between groups in their access to services, and widen the gap in unmet need (Dr Murray Horn Commissioned by the Director General of Health, 2015)
- **B.** Work with service users and community groups to acknowledge and address the drivers of inequalities in access to primary health care, in particular addressing gender and ethnic differences in access (Ministry of Health, 2019). For example, in the Ministry:
  - Women (33%) had higher rates of unmet need for primary health care than men
     (23%).
  - Women (21%) were more likely to have been unable to get an appointment within 24 hours than men (15%).
  - Women were more likely than men to not visit a GP due to cost, after adjusting for age differences (the unadjusted rates were 18% and 11% respectively).
  - More women (8.3%) than men (4.7%) had not visited an after-hours centre due to cost.
  - Women were almost two times more likely than men not to have collected a
    prescription due to cost at some point in the past 12 months, after adjusting for
    age differences (the unadjusted rates were 9% and 5% respectively).

- C. About one in four New Zealand women will terminate a pregnancy at some point in their reproductive lives, making abortion one of the most common gynaecological procedures. Yet despite this, abortion remains stigmatized in our society and governed by restrictive and out of date legislation. WHA urges the government to progress with Option A in the Law Commission's' Report 'Alternative approaches to abortion', completely removing the governing legislation surrounding abortion and placing the decision making about abortion in the hands of pregnant people and their doctors. We believe this is important to ensuring the timeliness, accessibility and de-stigmatisation of abortion care. We believe that the following principle should underpin sexual and reproductive health care in New Zealand: Every person in New Zealand has equal opportunity to access, without cost or restriction, any sexual and reproductive healthcare service they choose, be it contraception, abortion, sterilisation, or prenatal care, without the approval of any doctor but their own, if needed.
- D. Lesbian, Gay, Bi-sexual, Transgender, Intersex, and queer people experience stigma and discrimination in health care in the form of homophobia, biphobia, transphobia, heteronormativity and cisnormativity (Stevens, 2013). This compounds the health inequalities experienced by rainbow communities across a range of indicators and reduces access to care (Mental Health Foundation of New Zealand, 2017). We urge the development of a Rainbow Health strategy and investment in cultural competency training for all health care providers. We welcome the investment in gender affirmative healthcare announced in the Wellbeing Budget 2019 and would like to see this investment continue to grow.
- E. There is growing evidence that when academic researchers collaborate with non-academic partners, they address authentic problems that challenge the research team to produce more effective solutions (Shneiderman, 2018). We would like to see Investment and support in innovative collaborative research between academics, iwi and community providers to explore the experiential, aspirational social, economic and cultural influences that contribute to the health and wellbeing of people living in Aotearoa New Zealand.
- F. Address the social determinants of health through collaboration between government departments. Whānau can't look after their own health when they are having to deal with "what's on top", i.e., poverty and justice.

"Free doctors' visits mean mothers don't delay seeking advice and elderly receive regular care without concern for cost. Easy access to health professionals that seek to empower rather than prescribe and have great knowledge about diet and lifestyle"

"There's so much information about where to seek help. But actually, accessing these services can be difficult"

(WHA Health and Disability Review Survey respondents – 2019)

## 4. What changes could most improve health for Māori?

- **A.** Services designed by Māori for Māori, i.e. responsive to needs. For example, services can be modelled on successful programmes such as Hapū Wānanga to have continuity of care across and into other sectors, i.e. the delivery rooms onto the Well Child provider, giving whanau raising whanau opportunities.
- **B.** The health and disability workforce and its decision-makers are bi-culturally competent and confident, and value the partnership relationship between tangata whenua and tangata tiriti in the design, development and delivery of all health services and initiatives.
- C. All health providers are responsible for ensuring all their decision makers and health workers are actively strengthening their bicultural competence and confidence through participation and engagement in professional development opportunities or community activities that support the development of bicultural competence and confidence of services to whānau.
- D. Removing barriers to services such as initial screening appointments being made by Māori for Māori; transport to appointments; childcare during appointments; appropriate communication and representation during appointments, i.e. staying with whānau during an appointment to be sure that they understand what the medical professional is saying.

**E.** Group health opportunities. Iron Maori registrations sell out in minutes, whānau of all ages and sizes enthusiastically train together in preparation of an awesome event because it is not targeting one person about their own health issues.

"Hau ora approach where whanau support is provided. Adopt current successful programmes incorporating Non-judgment, empathy and tikanga"

"Stop targeting [us] as more vulnerable and treat me with the same care and compassion as everybody else. Ethnicity should not result in different treatment"

"More use of cultural friendly programmes that are whānau inclusive"

(WHA Health and Disability Review Survey Respondents— 2019)

- 5. What changes could most improve health for Pacific peoples?
  - A. More Pacific health providers and workers.
  - **B.** Services designed by Pacific for Pacific peoples.

"Include those most impacted in decision making i.e. teens, men aged 30-40 – support and encourage them to talk. Inspire Pacific youth rather than knocking them down"

"Having information in each pacific languages in regards to financial support and where and how we can obtain this"

(WHA Health and Disability Review Survey respondents – 2019)

6. What changes could make sure that disabled people have equal opportunities to achieve their goals and the life they want?

"Longer appointment times and easy access to comprehensive, unbiased and preferably independently researched information online as well as access to a wider range of health options including "alternative" treatments"

"Listen to individual experiences. Understand that one person's experience of a health issue or disability is not the same as the next persons. Stop comparing people. Treat the individual, not the condition as a whole"

"Investment from local government eg. Awareness disabled friendly facilities"

"Adequate funding for requisite equipment and support.

"Again, good community care. Give people financial freedom/better pay so that it is affordable to provide help within the community to support disabled people and their families"

"Employment of persons with empathy and enough of them. Looking at the whole person holistically with a follow through navigator to ensure they are receiving everything possible"

"Hospitals would be far more accessible. Health care would improve vastly for those with intellectual and physical disabilities once they turn 18"

(WHA Health and Disability Review Survey respondents – 2019)

- 7. What existing or previous actions have worked well in New Zealand or overseas? Why did they work, and how might they make things even better in the future?
  - **A.** Establishment of the Code of Health and Disability Services Consumers' Rights in July 1996. It grants several rights to all consumers of health and disability services in New

Zealand, and places corresponding obligations on providers of those services. There has been some great work done to provide this information in audio formats and many languages.

- **B.** Enactment of The Health Practitioners Competence Assurance Act 2003 (the Act) providing a framework for the regulation of health practitioners to protect the public where there is a risk of harm from professional practice.
- **C.** The Health Quality and Safety Commission has contributed to a greater focus on quality and safety; continuous quality improvement; transparency/open disclosure around reporting and learning from serious adverse events.
- D. We were encouraged by the requirement that District Health Boards include consumer involvement within their Maternity Quality and Safety Programmes (MQSP) to help ensure service users and their families/whānau were not overlooked/dismissed and are incorporated into service design. However, the evaluation of the MQSP programme (Allen + Clarke Commissioned by The Ministry of Health, 2015 ) found there was plenty of room for improvement in this area. This includes improving ways the DHBs recruited, supported and engaged with consumers who are less likely to have the skills to effectively engage yet represent those consumer populations who experience poorer health outcomes. We would like to see a National MQSP consumer committee formed with support from the Ministry of Health.
- **E.** Patient access to their clinical information Patient Portals enable online access to summary information (some practices enable patient access to clinical notes)
- **F.** Hapū Wānanga, Weaving Wānanga, work well to engage whānau in culturally sensitive ways. Community designed programmes have buy-in from the community to continue whether they are run by outside organisations or not.

- 8. What are the most important changes that would make the biggest difference to New Zealanders?
  - A. A joined up, cross-government commitment to improve the health and well-being of all New Zealanders by addressing the social determinants of health and incorporating health considerations into all policies. This will enable our health and disability sector to be sustainable and meet the technological demands of the 21<sup>st</sup> century by helping to keep people well. Pressing issues that are impacting on whānau and community health include: housing affordability and quality, energy insecurity, food insecurity, zero hour contracts, living wage, unliveable benefit levels, paid parental leave entitlement well below the minimum wage, and unaffordable child care, climate change and ecological degradation.
  - **B.** Women's Health Action believes it is essential that Aotearoa New Zealand develop a specific women's health strategy (led by consumers and NGOs and supported by the Ministry of Health) to guide health services. Such a strategy would help achieve:
    - A health system that is responsive to the needs of all women and actively promotes participation of women in health care
    - Planning and delivery of health services and health research that includes all
       women and will prioritise the needs of those with the highest risk of poor health
    - Health equity between women, and with men
    - Gender analysis in health care policy and research, and greater understanding of gender as a key determinant of health
    - Greater understanding of how women's health needs differ with life stages
    - Equitable access and safe services including culturally diverse health services for specific populations including Māori, Pasifika, older, teen, disabled, rural and Lesbian, Bisexual, Transgender and Intersex people
    - The strategy should be consistent with the principles of the Treaty of Waitangi
      and other relevant Aotearoa New Zealand legislation such as the Human Rights
      Act and the international human rights conventions to which we are signatories
  - **C.** An inquiry into the oral health care of New Zealanders including a specific focus on inequities in oral health, with the view of dental health care reform and increased investment in publicly funded dental health care.

- D. Investment and service provision to improve the mental health of New Zealanders. Evidence is clear that the mental health of New Zealanders is under strain with specific and detrimental impacts on women and their children. For example, maternal suicide is the leading 'single' cause of death in pregnant women; rates of anxiety and depression are high in comparison to other OECD countries and are significantly higher amongst women than men. WHA welcomes the findings of the He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction and the associated extra investment in mental health care in the Wellbeing Budget 2019. We urge the government to continue to prioritise mental health care reform and investment, including increased investment in maternal and infant mental health services.
- **E.** Whānau Māori the biggest difference would be a change in attitude, to not treat a person like their illness. Specific interventions include:
  - To have kuia and kaumatua representation on health boards (paid positions)
  - Development and training for creation of resources, i.e., more trained weavers to weave waikawa/wahakura
  - Research and use of mātauranga Māori to create By Māori for Māori systems
     with awhi wrap around continuity in the community
  - Maori responsiveness policies through every organisation
  - Communication between the Ministry departments to aid organisations to be able to accurately refer to each other

"Make doctors' visits free and teach doctors about diet and holistic approaches to illness/wellness as well as the option to refer to alternative practitioners. Turn the system around so that it acts preventatively and empowers the patient, rather than being reactionary and picking up the pieces"

"Addressing public health issues like poverty, housing, education Taxing appropriately so we can afford a health system in 20 yrs"

"More accessible on every level. Encourage more Māori youth to go into medicine, nursing and allied health professions. More advocacy roles to support Māori and Pacific island families navigate the system. More top-level management awareness of the importance of valuing their workforce"

#### 9. Is there anything else you wish to add?

A. WHA believe that technological advances in data collection will pose some ethical challenges for the health and disability sector in the 21<sup>st</sup> century. Although the use of algorithms and predictive risk modelling may be seen to improve efficiency in services dealing with large amounts of data, we hold concerns that decision making based on trend and behaviour based algorithms may inadvertently reflect historical bias against vulnerable populations thereby promoting further bias, leading to inequality in health care (Wood, 2018). For this reason, we also need to exercise caution when amassing and sharing data, especially cross-sectorally.

Thank you for the opportunity to contribute our perspectives to the Health and Disability Systems Review. We greatly look forward to hearing the outcome of this important and timely process.

Ngā manaakitanga

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## References

- Abel, S., Finau, S., Tipene-Leach, D., & Lennan, M. (2003). *Infant care practices amongst Maori, Pacificans, and Pakeha: Implications for maternity and well child services in New Zealand.*IPHR and SPHPC Working Paper No 5 . Suva: Institute of Pacific Health Research, Fiji School of Medicine. .
- Allen + Clarke Commissioned by The Ministry of Health. (2015 ). *Evaluation of the Maternity Quality and Safety Programme*. Wellington .
- Best Practice Journal. (2010). BPJ Special Edition Antenatal & Postnatal Depression. *Best Practice Journal*, 5-11.
- Cheng, D. (2018, February 12). Homeless crisis: 80 per cent to 90 per cent of homeless people turned away from emergency housing. Retrieved from nzherald.co.nz: https://www.nzherald.co.nz/nz/news/article.cfm?c\_id=1&objectid=11992371
- Cornwall, J., & Davey, J. (2004). Impact of population ageing in New Zealand on the demand for health and disability support services, and workforce implications. Wellington: Ministry of Health.
- Cox, S. (2013). Overcoming Short-termism within British Business: The key to sustained economic growth: An independent review by Sir George Cox commissioned by the Labour Party. The Labour Party.
- Dr Murray Horn -Commissioned by the Director General of Health. (2015). From Cost to Sustainable Value An Independent Review of Health Funding in New Zealand. Wellington: The Ministry of Health.
- Dwyer, S. (2009). *Childbirth education: antenatal education and transitions of maternity care in New Zealand.* Wellington: Families Commission.
- Hagel III , J., Keith, J., Brown , J. S., Samoylova, T., & Hoversten, S. (2014). *A consumer-driven culture of health. The path to sustainability and growth .* Deloitte University Press .
- Health Services Consumer Research. (2008). Maternity services consumer satisfaction. Auckland.
- Levine, C. F. (2010). Civic Engagement and the Transition to Adulthood. *The Future of Children*, 159-179.
- Mental Health Foundation of New Zealand. (2017). Suicide prevention and the rainbow population. A submission on: A Strategy to Prevent Suicide in New Zealand 2017: Draft for public consultation. Retrieved from Mental Health Foundation:

  <a href="https://www.mentalhealth.org.nz/assets/Our-Work/policy-advocacy/Suicideprevention-and-the-rainbow-population-submission-to-the-draft-NZSPS-26062017.pdf">https://www.mentalhealth.org.nz/assets/Our-Work/policy-advocacy/Suicideprevention-and-the-rainbow-population-submission-to-the-draft-NZSPS-26062017.pdf</a>
- Minister of Health. (2016). *New Zealand Health Strategy: Future direction.* Wellington: Ministry of Health.
- Ministry of Health. (2011). *Healthy Beginnings: Developing perinatal and infant mental health services in New Zealand.* Wellington: Ministry of Health.

- Ministry of Health. (2019). Annual Data Explorer 2017/18: New Zealand Health Survey [Data File]. Wellington. Retrieved from https://minhealthnz.shinyapps.io/nz-health-survey-2017-18-annual-data-explorer
- New Zealand Government. (2018). *Benefit Fact Sheets: September 2018 Quarter*. Wellington: Ministry of Social Development.
- Ratima, K., Ratima, M., Durie, M., & Potaka, U. (1994). A comprehensive maternity service for Māori women: a pilot study of Māori women in the Palmerston North region. Palmerston North: Te Pūmanawa Hauora, Department of Māori Studies, Massey University.
- Report of The Health Committee. (2013). *Inquiry into improving child health outcomes and preventing child abuse*. Wellington: New Zealand House of Representatives.
- Research New Zealand. (2015). Maternity Consumer Survey 2014.
- Shneiderman, B. (2018). Twin-Win Model: A human-centered approach to research success. *PNAS*, 115(50), 12590-12594.
- Stevens, M. W. (2013) Rainbow Health: The Public Health Needs of LGBTTI Communities in Aotearoa New Zealand with Policy Recommendations. Auckland: Affinity Services.
- The Ministry of Health . (2002). *Breastfeeding: A Guide to Action.* Wellington : The Ministry of Health.
- The National Health Committee. (1999). *Review of Maternity Services in New Zealand*. The National Health Committee , September 1999.
- Wilson, D. (2004). *Nga Kairaranga Oranga: The Weavers of Health and Wellbeing. A grounded theory study.* . Doctoral thesis, Massey University. .
- Women's Health Action . (2018, July). Consumer views on Maternity Care and Services in Aotearoa New Zealand. Auckland, New Zealand.
- Wood, M. (2018). How algorithms can create inequality in health care, and how to fix it -, University of Chicago. Retrieved from https://medicalxpress.com/news/2018-12-algorithms-inequality-health.html
- World Health Organization . (2003). *Global Strategy for Infant and Young Child Feeding. Infant and young child feeding* . Geneva : World Health Organization .