# Auckland Women’s Health Council Newsletter

# December 2021

# Pae Ora: A Healthy Future for All New Zealanders?

By Sue Claridge

Our health system is broken.

The health of New Zealanders is beset by inequities and disparities, and the quality and accessibility of health care is often determined by where one lives. There is entrenched racism in parts of our health system, delays in diagnosis and treatment, and our health workforce, particularly nursing and midwifery (strikingly, a sector that is largely staffed by women), is underpaid, under-resourced and under-staffed.

So what’s new? All our readers will be well aware of the dysfunctions and inadequacies of the current health system, and numerous reports, most notably the Health and Disability System Review interim and final reports, have set out problems faced by our health system and those who rely on it for their health and well-being.

Readers will also be well aware of the plans to overhaul the health system.

Health Minister, Andrew Little, announced in March this year that the Government was to set about delivering healthcare that is equitable and sustainable so more New Zealanders get the health services they need.

He said “Our guiding vision is for a health system delivering pae ora/healthy futures for all New Zealanders, where people live longer in good health and have an improved quality of life.”

He went on to set out five outcomes needed to realise the vision:

**Equity** for all New Zealanders – so everyone can achieve the same outcomes, and have the same access to services and support, regardless of who they are or where they live.

**Partnership** – through embedding the voice of Māori and other consumers of care into how the system plans and makes decisions, ensuring that Te Tiriti o Waitangi principles are meaningfully upheld.

**Excellence** – ensuring consistent, high-quality care is available when people need it, and harnessing leadership, innovation and new technologies to the benefit of the whole population.

**Sustainability** – focusing the health system on prevention and not just treating people when they are unwell – ‘wellness not illness’ – and ensuring that we use resources to achieve the best value for money.

**Person and whānau-centred care** – by aiming to empower people to manage their own health and wellbeing and put them in control of the support they receive.”

On the 9th of November, the Government published the Pae Ora (Healthy Futures) Bill, the draft legislation that will provide the legislative structure for the new health system. When enacted, this legislation will replace the New Zealand Public Health and Disability Act 2000 in its entirety. The Explanatory note to the Bill sets out the inadequacies of the existing health system and says that the Bill addresses “these issues and provides for a new structure and new accountability arrangements. The purpose of the reforms is to:

* protect, promote, and improve the health of all New Zealanders; and
* achieve equity by reducing health disparities among New Zealand’s population groups, in particular for Māori; and
* build towards pae ora (healthy futures) for all New Zealanders.”

In releasing the Pae Ora (Healthy Futures) Bill, the Pae Ora Legislation Committee sought public submissions on the Bill, which closed at midnight on the 9th of December.

The Auckland Women’s Health Council are entirely supportive of the need for the health system to be overhauled and rebuilt. We have published articles on this on a regular basis, including reviews of the two Health and Disability System Review reports, and several further articles since the overhaul was first mooted in March.

We undertook a review of the Pae Ora (Healthy Futures) Bill in order to make a submission. The Bill is substantial – 102 pages – and we concentrated on the issues that we felt were of greatest significance and importance to our “constituency”. Our focus was on: women’s health; advocating for a truly consumer/ patient/whānau centred health system with consumer representation at all levels of the system, including at the design and build stage of the new health system; addressing inequities and disparities in health and health outcomes; and our belief that the articles of Te Tiriti should shape the Bill.

While broadly supportive of the Bill – in as much as it provides the structure for the new health system – we have some significant concerns about the detail of the proposed legislation and some significant omissions in the legislation.

It is not the intention of this Newsletter to reproduce the [AWHC submission](https://www.womenshealthcouncil.org.nz/site/aklwhc/Auckland%20Women's%20Health%20Council%20submission%20on%20the%20Pae%20Ora%20Healthy%20Futures%20Bill%209-12-21.pdf), but to present our main responses and concerns, and discuss issues that must be addressed in developing the new health system, but that are not the sort of detail that is the purpose of the legislation to deal with.

The first of our concerns was the consultation process itself!

# The Consultation Process and Submission Timeline

Our immediate response was one of great concern that submissions on the Pae Ora (Healthy Futures) Bill (the Bill) were only open for one month. With a long history of making submissions on a wide variety of issues, including previous Bills before Parliament, we are all too familiar with what it takes to research and write a considered and thoughtful submission.

It is very disappointing that the Government appears to believe that this extraordinarily important legislation, that will change the way in which our entire public health system operates and functions, including a complete change to the administering bodies (i.e. replacing DHBs with Health NZ and the Māori Health Authority), was only worthy of only one month of consideration by the 5.1 million people who will be affected by these changes, some of whom will be affected for the rest of their lives.

While we acknowledge that the Parliamentary process, including multiple readings and debates in the House, as well as public consultation, is part of a lengthy process that must be undertaken and that there is an intention to enact the new legislation in the middle of 2022, we believe this is far too important and consequential a piece of law to rush.

With release of the Bill document on the 9th of November, and while more than one fifth of the country’s population were still working under considerable Covid-19 restrictions, and in the lead up to Christmas, it seems that the with this process the Government was paying lip service to the concept of true consumer consultation – not a good start for a health system that the Minister of health claims is to be person/whānau centred.

Notwithstanding the short submission period, we note that the Pae Ora (Healthy Futures) Act 2021 is to come into force on 1 July 2022. This appears to be insufficient time to properly consider stakeholder/public feedback on such a significant piece of legislation and genuinely incorporate that feedback into revisions of the Bill, before it proceeds through the subsequent readings and debates in Parliament.

# Te Tiriti O Waitangi

The AWHC is not a tangata whenua organisation and cannot speak for or on behalf of Māori. However, we support the establishment of a Māori Health Authority (MHA).

For decades, Māori have suffered the impacts of inequities and disparities in health that manifest as greater incidence of ill-health, poorer access to health and disability services, and significantly poorer health outcomes. For example, the **Health and Disability System Review - Interim Report, Hauora Manaaki ki Aotearoa Whānui – Pūrongo mō Tēnei Wā***2* found that:

* On average, Māori die seven years earlier than non-Māori and are 2.5 times more likely to die from diseases that can be addressed through health care.
* One-third of Māori preschool children receive no oral care, and more than half of 5-year-old Māori children have dental caries (33% higher than for non-Māori children).
* Young Māori have poorer general physical and mental health, are more overweight, have greater substance use, and higher exposure to violence.
* Hospital admissions for self-harm are higher and suicide rates double among Māori aged 15–24 compared to non-Māori.
* Māori develop diabetes up to 10 years younger and progress earlier to more serious disease, yet are less likely to receive appropriate monitoring and testing.
* Despite being significantly more likely to report multiple disabilities, Māori aged 65 and over are much more likely to have unmet need for a disability aid than non-Māori.

Even where “Māori are accessing health services, they do not always receive optimal quality of care, and this negatively affects outcomes for Māori. Lower quality of care includes suboptimal prescribing and over-prescribing to Māori, poor communication between professionals and Māori patients, delays in treatment and surgical interventions, and longer hospital bed stays after acute admissions.”

Entrenched racism in the health system has been acknowledged both by the Government and in various reports including the Health and Disability System review reports. Submitters to the health and disability system review panel “noted that there is evidence of implicit bias by professionals in the health system, which perpetuates and maintains power imbalances in the system, and impacts on the quality of care Māori receive.”

It is imperative that the new health system addresses these inequities and disparities and ensures that not only are inequities and disparities removed, but that this be achieved by Māori for Māori throughout all entities of the new health system, not just the Māori Health Authority; that our obligations to Te Tiriti o Waitangi be embedded in all aspects of Health New Zealand and associated health entities.

It was with huge disappointment, and not a little despair, when randomly reviewing a number of other submissions on the Bill, that it became apparent that some New Zealanders believe that addressing a long-standing history of inequities, disparities and discrimination that seriously impact the ability of Māori to enjoy the same level of health and well-being as other New Zealanders, is itself racist.

We do not wish to give credence to the comments in some of the submissions opposing the establishment of a Māori Health Authority by publishing those views here, save to say that these submissions claim that a Māori Health Authority and recognition of our obligations under Te Tiriti is divisive and racist and we should all be treated as one people.

“One people” is aspirational and a great idea in theory, except that Māori have not benefitted from a “one people” policy, and health entities have for decades very firmly operated through a Pākehā lens. As we have amply illustrated in previous Newsletters, Māori have been the victims of racist policies and a fundamentally racist system.

It is not just in our health system that there is a problem; institutionalised racism across all our social systems that impact upon health must also be addressed. In his foreword to **A Window on the Quality of Aotearoa New Zealand’s Health Care 2019 – a view on Māori health equity**, Professor Sir Mason Durie says “It would be misleading to conclude that failures in the health system are the reason for all the disparities. Sub-standard housing, poor education, unemployment, low incomes, cultural alienation, alienation from land, and frank discrimination have all contributed to the problem. In that respect, a whole-of-society remedy must be sought.”

In the **New Zealand Medical Journal**(2019), Came et al*.* write that “Compelling evidence suggests racism against Māori, in all its forms, has become a normalised part of New Zealand society”, and that racist policies and practices have “resulted in many Māori living in conditions that put their health at risk and has entrenched preventable health disparities.”

For a very long time we have had a health system that was supposedly for all New Zealanders, yet the health and well-being of Māori continues to be well below that of their non-Māori peers. A “one people” system is clearly not working, and it is time that we tried something different.

Te Tiriti o Waitangi “was based on the fundamental exchange of kāwanatanga, the right of the Crown to govern and make laws for the country, in exchange for the right of Māori to exercise tino rangatiratanga over their land, resources, and people.”Te Tiriti “promised ōritetanga (equity) with British subjects.”

One hundred and eighty-one years after the signing of Te Tiriti o Waitangi, it is long past time the Government of Aotearoa New Zealand honoured its obligations. This Bill gives Māori tino rangatiratanga over the health and well-being of the tangata whenua.

# Significant Omissions

## Where is the Code of Health and Disability Services Consumers' Rights?

In short, it doesn’t even rate a mention in the Bill!

The Code of Health and Disability Services Consumers' Rights (Code of Rights) became law on the 1st of July 1996. It grants a number of rights to all people using health and disability services in Aotearoa New Zealand, and places corresponding obligations on providers of those services.

The Code of Rights, prescribed by regulations made under the Health and Disability Commissioner Act 1994, was a direct response to the recommendations of the Cartwright Inquiry. Dame Silvia Cartwright recommended that the Human Rights Commission Act 1977 should be amended to provide for a statement of patients’ rights and the appointment of a Health Commissioner.

The purpose of the Health and Disability Commissioner Act 1994 is to promote and protect the rights of health consumers and disability services consumers.

It is hard to imagine how any health system, or any legislation that governs it, with a stated purpose to “protect, promote, and improve the health of all New Zealanders” – as stated in the purpose of the Pae Ora (Healthy Futures) Bill – could fail to include any mention of, or reference to, the Code of Rights.

It is of enormous concern to the AWHC that the Code of Rights is not mentioned in the Bill and this must be rectified. The new health system cannot lay claim to being person, whānau or consumer centred without recognition of the Code of Rights in the governing legislation.

## Where are the ‘Other’ Health Strategies?

The Pae Ora Bill provides for the development of a number of health strategies:

* New Zealand Health Strategy
* Hauora Māori Strategy
* Pacific Health Strategy
* Disability Health Strategy

The AWHC is pleased to see that there will be specific health strategies developed for Māori, Pāsifika and New Zealanders with disabilities, and entirely supports the development of these strategies. But where are the women’s health, mental health, LGBTQI+ and rural health strategies?

While Māori, Pāsifika and people with disabilities may experience the greatest inequities and disparities, and certainly the most publicised and researched, there are other groups of New Zealanders who face considerable barriers to health and well-being and experience unmet need, in particular, women, those who live with poor mental health, those who live in rural areas of the country and members of the LGBTQI+ community.

Of these, only rural New Zealanders may have their specific needs addressed through the locality plans, which will assess health needs at the local level and set out the priority outcomes and services for the locality.

All New Zealanders must have easy access to equitable, affordable, accessible and available as well as culturally appropriate and acceptable health care when and where they need it. Addressing inequities and disparities in the provision of health and disability services must be the highest priority for the new health system. No-one should receive a poorer level of care or have poorer outcomes based on gender, sexual orientation, ethnicity, culture, disability, level of deprivation or location of residence.

The specific needs of women, people with poor mental health, and the LGBTQI+ community cannot be met through the provisions for locality plans.

## The Need for a Women’s Health Strategy

We have written extensively on women’s health issues, in particular in the Newsletters of June 2019, March 2020 and October/November 2021 and the need for a national women’s health strategy or plan.

As pointed out by the Gender Justice Collective in their Parliamentary petition, “Currently, the quality of health care that many women, wāhine, intersex, trans women and non-binary people can access depends on where they live, how much money they have and what colour they are. Racism, poverty, prejudice, discrimination, ignorance, lack of appropriate training, and a failure to listen and engage with the community are just some of the reasons for this. So, too is a lack of political will.”

In Aotearoa New Zealand women suffer under an inadequately resourced and regulated health system. For example:

* Women are disproportionately affected by the harms caused by surgical mesh; 76% of ACC claims for mesh injury between 2005/06 and 2017/18 were from women.
* Aotearoa New Zealand has a tragically high rate of maternal suicide, with 30 maternal deaths by suicide reported by the PMMRC between 2006 and 2018. “Wāhine Māori have statistically significant higher rates of maternal mortality than New Zealand European women... [suicide] remains the single largest cause of maternal death in Aotearoa/New Zealand, with suicide accounting for 44 percent of direct causes of maternal death since 2006.”
* Access to contraceptive advice and contraception is “often guided by morality rather than evidence and informed consent.”
* A number of small provincial birthing units have closed forcing women to have to travel long distances – sometimes for two hours or more – to have their babies. According to the Ministry of Health 2017 report on maternity, 11 primary birthing facilities have closed around the country. Since this report was written a further unit, Lumsden, has been downgraded to a “hub” forcing local women to travel to Southland or Dunedin hospitals.
* In a review of severe maternal morbidity (SMM) in New Zealand in 2018, researchers found that “severe maternal morbidity was 6.2 per 1000 deliveries with higher rates for Pacific, Indian and other Asian racial groups.” The research found that “that over a third of cases were potentially preventable, being due to substandard provider care with increased preventability rates for racial/ethnic minority women.” Provider factors such as inappropriate diagnosis, delay or failure to recognise high risk were the most common factors associated with potential preventability of SMM. Pāsifika women had over twice the rate of preventable morbidity.
* Prof Jackie Cumming (Professor of Health Policy and Management, Victoria University of Wellington) has said that there are “alarmingly high rates of unmet need due to cost, particularly for Māori and Pacific women and women in the areas of lower socio-economic status.”
* There is significant -inequity of access to quality pelvic floor health care, rehabilitation services and education on prevention (pre and post birth).

It simply is not good enough for women in Aotearoa New Zealand to be receiving such grossly inadequate care, or for the quality of care to be so clearly tied to their ethnicity. According to Stats NZ, at 31 March 2020, females made up 51% of our population, and that 51% of the population experiences significant barriers and unmet need, including for many a lack of accessible, affordable, available, and culturally appropriate and best practice health care.

## Mental Health

In late 2017, the then new Labour government said that mental health and addiction services were a high priority and there would be a review of mental health services. At a Health and Disability Conference in November of that year, several delegates questioned whether or not yet another review was what was needed; that many people in this sector already knew what the issues were and what needed to be done, that now was the time to just get on with doing it.

Chris Walsh from the HQSC asked whether or not we needed a ministerial inquiry or a ministerial implementation plan? In response, Shaun Robinson, Chief Executive of the Mental Health Foundation said that there was a blame culture and when people ask for an “inquiry” what they are really asking for is “change”. He said that there is widespread belief in a “cover-up” and that we don’t need an 18-month inquiry just to conclude what we already know.

Four years on from the Governmental promises and three years since the release of the **He Ara Oranga Report of the Government Inquiry into Mental Health and Addiction** and there has been regular criticism from those in the mental health sector about the lack of progress.

We would like to see clear commitment to implementing the findings of He Ara Orangain health service design and commissioning, and engagement in prevention and health promotion work. As written, the Bill does not make the lines of accountability for appropriate and responsive mental health and addictions service design and delivery, prevention and public health measures clear. As the main service commissioning bodies, Health New Zealand and the Māori Health Authority should be required to implement action plans developed by the Mental Health Commission and Ministry in response to sector and consumer concerns.

Addressing mental health and addiction is not just important for the sake of improving mental health in New Zealanders.

Gibb and Cunningham (2018) found that research shows that people in contact with mental health services experience poorer health and excess mortality (from causes other than self-harm) compared with the general population.

Their report found that:

* mental distress increases as deprivation increases;
* use of secondary mental health services follows a similar pattern to distress, increasing as deprivation increases;
* people with severe mental illness have higher rates of many physical health conditions and shorter life expectancy, and this gap has increased over time;
* the gap in physical health status between those with and without mental illness is greater for women;
* Māori with severe mental illness experience disparities in physical health compared to non-Māori with severe mental illness;
* high mortality from physical health conditions is due to both a higher risk of developing a condition, and also to worse outcomes once a condition has developed.

Clearly there is a complex inter-relationship between mental and physical health and well-being, and that social determinants of health, especially deprivation, have a significant impact on both physical and mental health. Additionally, the disparities in physical health status relative to mental illness are greatest for Māori and women. This supports the need for both mental health and women’s health strategies alongside the Hauroa Māori Strategy, and the need for a holistic approach and strong links between all the health strategies.

## A Health Strategy for LGBTQI+

Which leads into the unmet mental and physical health needs of LGBTQI+ New Zealanders. The LGBTQI+ community face inequities and disparities in access to health services and outcomes from health care yet are neglected by policy makers. Despite advances in the rights and legal status of LGBTQI+ New Zealanders, social prejudice and bias that extends deep into our health system negatively impacts on members of the LGBTQI+ community.

A 2013 report found that “Rainbow communities, especially those of diverse gender identity (transgender) and diverse biological sex (intersex) have a troubled history of interaction with the health system. This can lead to health problems becoming more complex and expensive to manage as people delay engaging with the health system out of fear.”

Health issues include, but are not limited to, greater levels of suicide, depression and substance abuse, as well as higher levels of obesity, and certain forms of cancer.In addition, the “lack of targeted research means the health needs of the Rainbow community are hidden from and thus excluded from current public health policy.”

**Counting Ourselves**, a 2019 report on the health and wellbeing of trans and non-binary people in Aotearoa New Zealand found that transgender and non-binary New Zealanders had particularly negative interactions with the health system and suffered significant barriers to adequate and culturally appropriate health care. The report found:

* high numbers of transgender and non-binary New Zealanders wanting but not being able to access gender-affirming health care;
* in the 12 months prior to the report, 13% of participants were asked unnecessary or invasive questions about being trans or non-binary, that were unrelated to their health visit, when they were trying to access health care;
* 17% reported they had experienced conversion therapy: that is, a professional had tried to stop them from being trans or non-binary;
* 36% of participants had avoided seeing a doctor because they were worried about disrespect or mistreatment as a trans or non-binary person;
* 71% aged 15 and older reported high or very high psychological distress, compared with only 8% of the general population in Aotearoa New Zealand;
* 56% had seriously thought about attempting suicide in the last 12 months; 37% had attempted suicide at some point and 12% had made an attempt in the last 12 months.

The Government Inquiry into Mental Health and Addiction found that there are unmet mental health needs for LGBTQI+ New Zealanders, while the Health and Disability System Review report found that “patterns of use for both inpatient and community mental health specialist services show higher rates for people who identify as LGBTQIA+ (among other minority groups).

A 2018 Masters of Health Sciences dissertation on LGBT community mental health needs, found:

“that the LGBT community are exposed to unique social stressors that have a direct impact on their mental wellbeing… the LGBT community have specific needs when accessing and engaging mental health services for these needs. The community is exposed to essentially a heterosexist international health system, and is frequently pathologised by health professionals because of the cultural differences, in particular when engaging with mental health services. The LGBT communities are generalised as a whole community, and not as individual cohorts, which creates additional barriers for specific needs, in particular those of the transgender community.”

Samuel Rees recommended that health care systems review their role in improving the health disparities of this minority population, and reduce the stigma and discrimination currently experienced by improving health policy and education development.

Although recent figures released by Statistics New Zealand found that only one in 20 New Zealanders identify as LGBTQI+ (0.8 percent identified as transgender or another gender/non-binary and 3.7 percent reported being gay, lesbian, bisexual or another sexual identity), that still means that the LGBTQI+ community totals some 175,870 New Zealanders. This is a significant group of New Zealanders who face barriers to health care and unmet health needs.

“This represents a significant segment of the wider population whose health needs are generally invisible or ignored by the health system.”

It is not good enough to expect that the inequities and disparities faced by LGBTQI+ New Zealanders can be addressed through the health documents proposed in the Pae Ora (Healthy Futures) Bill.

# Focus on Achieving and Maintaining Health

The Pae Ora (Healthy Futures) Bill does not place enough emphasis on achieving and maintaining health and well-being, rather focusing on treating ill-health. While, obviously, it is vital that we have a health system and supporting legislation that ensures that all New Zealanders receive best practice, evidenced based health care, the new health system must have prevention of ill-health and the promotion of lasting good health, well-being and longevity for all New Zealanders as its primary aim.

Addressing health and well-being – or lack of them – in Aotearoa New Zealand is not just about having a well-resourced, highly functioning health system that achieves excellence. To a considerable extent, our public health system is the ambulance at the bottom of the cliff, dealing with the impacts on health and the causation of disease contributed to by underlying factors. To attain health, well-being and healthy longevity for all our citizens requires us to address the social and commercial determinants of health:

* education,
* occupation/employment and income,
* poverty and deprivation,
* culture and ethnicity particularly as they pertain to underlying socioeconomic status,
* homelessness, and inadequate and poor-quality housing,
* unhealthy diet and the availability and affordability of mass-produced unhealthy food,
* domestic violence,
* tobacco, gambling, alcohol and other drug related harm.

Poverty and deprivation are particularly important factors when so many of our children live in poverty. Poverty is a huge driver of poor health and children living in poverty seem destined to a lifetime of poorer health than their contemporaries who live in households with an adequate standard of living and income.

A new report, dated the 8th of December 2021, has found that none of the Government-convened Welfare Expert Advisory Group’s (WEAG) 42 key recommendations on a programme of ‘overhaul’ for the welfare system have been fully implemented. The report’s authors say that “The number of children living in benefit-receiving households has risen by over 15% in the last two years to 208,000 children, roughly one in every five in Aotearoa. Yet the social security system still provides inadequate income and other support for these families, who are among the most likely to live in entrenched poverty.”

The report goes on to express concern that “it could take decades to implement welfare reform as envisioned by WEAG”, thus ensuring that the children who currently live in poverty may be consigned to lifetime of health inequity and poor health outcomes.

The Health and Disability System Review concluded that “The health and disability system is not the main factor in determining health outcomes. If New Zealand does not significantly reduce intergenerational poverty and act on the social determinants of health, little that happens in the health and disability system would have a lasting impact.”

The report went on to say: “Improving the health and wellbeing of the population would not come from the efforts of any single organisation nor should it be driven primarily from within traditional health services. The health and disability system and its institutions would need to partner across government and with other sectors to address inequity and improve outcomes”.

It is imperative that the social and commercial determinants of health are given a high priority in the new health system, and the key documents address these major influences on health, and that the various health entities have the capacity to influence the issues outside the health system.

In addition, a significant focus on prevention needs to be built into the new health system. Two of the three purposes of the Bill are:

* to protect, promote, and improve the health of all New Zealanders; and
* to build towards pae ora (healthy futures) for all New Zealanders.

Yet ‘prevention’ of disease, in particular the non-communicable diseases and conditions that are the most prevalent causes of mortality and morbidity, is not mentioned once in the proposed legislation that will govern our new health system. How can it be possible to protect, promote and improve the health of all New Zealanders if specific provisions to prevent the major causes of preventable morbidity and mortality are not explicitly included in the legislation?

The top ten risk factors that drive the most death and disability are all preventable metabolic, environmental/occupational or behavioural risks,including tobacco and alcohol consumption, high body-mass index and dietary risks, and high blood pressure, among others.

# Patient Safety

Patient safety is another significant concern for the AWHC.

The enormous harm done by surgical mesh in this country, as so clearly demonstrated in the Restorative Justice report, makes clear how deficient our patient safety and protection regulations and agencies are. The entirely inadequate response to the surgical mesh crisis undermines any confidence that consumers might have that their health and well-being will be protected from flawed medical devices, and dangerous pharmaceuticals and medical procedures in future.

We discussed this in an article on medical devices in the February 2019 edition of the newsletter and have also discussed at length the deficiencies of the only agency that New Zealanders can go to when they suffer harm in the provision of health services, the Health and Disability Commissioner.

The reality is that the existing legislation and regulations governing pharmaceutical drugs and medical devices do not safeguard New Zealanders and are inadequate to prevent substantial harm to patients and consumers.

In December 2018, the MoH released a consultation document on the Therapeutic Products Regulatory Scheme. A Therapeutic Products Bill was being developed to replace the outdated Medicines Act 1981 (and its associated regulations) and establish a new regulatory scheme for therapeutic products. Attempts to reform regulations governing pharmaceutical drugs and medical devices began in the late 1980s and early 1990s, and the proposed Therapeutic Products Bill, among other things, would have changed the way in which medical devices are regulated.

AWHC made a substantial submission on the consultation document in early 2019 and despite initial hopes that this Bill would make medical devices safer for New Zealanders, the Bill appears to have sunk without a trace. The most recent mention on the MoH website refers to the 2018 consultation document and the fact that consultation closed in April 2019. There is no mention of the Bill at all on the Parliamentary website.

To ensure patient safety in the future, the regulation of therapeutic products must be updated and, in particular, the regulation of medical devices completely overhauled. In addition, AWHC recommends that the Minister of Health’s role be expanded to include patient safety as a specific responsibility. On a practical level, this responsibility could be delegated to the Director General of Health, but with Ministerial oversight. However, in addition an independent Patient Safety or Patient Advocate role, with a strong consumer voice, must be established.

Additionally, patient safety must be a priority in the New Zealand Health Charter and New Zealand Health Strategy.

# We Must have a Consumer/Patient-Centred Health System

The new health system must have the patient, the consumer of health and disability services, firmly at its centre. Health is about the person, the patient, the New Zealander. Long gone are the days when it was acceptable for patients to be expected to passively accept the word of their doctor or health practitioner and just “do as they were told”.

The person seeking health and disability services is the person for whom any health advice, treatment or procedure has the greatest impact, and thus any interaction between the person and the health system, any interaction between the person and the provider of health or disabilities services, must be, at the very least, a partnership for the health and well-being of that person.

In March 2021, Health Minister Andrew Little said that two of the five of outcomes needed to achieve the vision for the new health system were:

* Partnership – through embedding the voice of Māori and other consumers of care into how the system plans and makes decisions, ensuring that Te Tiriti o Waitangi principles are meaningfully upheld; and
* Person and whānau-centred care – by aiming to empower people to manage their own health and wellbeing and put them in control of the support they receive.

In Andrew Little’s **Health and Disability System Review – proposals for reform** cabinet papers (April 2021) he says the health system reform proposals are for a health system “that embeds partnership with the people it serves, that promotes person and whānau-centred care”.

Health Quality and Safety Commission chief executive, Dr Janice Wilson, says about the consultation on the Bill, “This is a great opportunity for people to have a say in how the new health system is built. We need to make the most of this time, as the Pae Ora (Healthy Futures) Bill is being considered, to put consumers at the centre of their health care.”

The HQSC states that the aim of the Partners in Care work programme is to “foster and promote, at both the individual, population and system level, te mahi tahime te kaiārahitangangātahi (partnership and shared leadership) between consumers and whānau, and health and disability service providers,” and that this is founded on an evidence-base that involving consumers and whanau in true partnership at **all levels** [our emphasis] leads to overall improvements in the quality and safety of the system.”

The HQSC says ‘All levels’ means direct care, policy and governance.

However, AWHC has substantial concerns about how genuine are the assurances that this new health system is to be a truly consumer-centred partnership for the health and well-being of New Zealanders. In reading the proposed legislation, the sense we gain of a consumer-centred partnership for the health and well-being is more about paying lip-service to the consumer voice and consumer representation rather than a commitment to genuinely engaging with consumers at all levels of the health system, including in building and implementing the new health system over the next few years.

We, the consumers, the patients, the ordinary New Zealanders must be front and centre at **ALL LEVELS** of designing, building, implementing, governing and regulating this new health system. If we are not, it will fail to deliver on the promises. We must not just be held out to be front and centre but there must be genuine consultation; consultation that is thorough, consistent, continuous and, importantly, heeded.

To borrow from the disabled community and disability rights movement:

Nothing about us without us!

If the Government genuinely puts New Zealanders at the centre of our new health system, then maybe we will have a genuine chance of achieving a world class health system that represents excellence in practice and care, health and well-being; a system that really will deliver pae ora/healthy futures for all New Zealanders.

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