

NEWSLETTER

February-March • 2023

a voice for women's health





Auckland Women's Health Council

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Annual General Meeting

The Auckland's Women's Health Council AGM will be held at **1.30 am** on **Friday the 5**th **of May 2023** via Zoom.

If you are interested in attending the AGM please RSVP by email to receive further details and a Zoom link.

awhc@womenshealthcouncil.org.nz



In this edition of the Newsletter, we have a guest contributor, Anja Morris, the founder of Active and POP. Anja talks about something that affects many women — pelvic organ prolapse — but that few talk about openly. We support women to contribute to the newsletter on topics that are important to you or requests for us to cover particular topics in women's health: —Editor.

Active and POP

You might tell a friend over a cup of coffee that you've got a sore back, but "Guess what happened, my bladder/uterus/rectum slipped."?

Or "I can't lift my child because... I've got an issue down below."?

Not likely!

Pelvic organ prolapse (POP) affects approximately 50 percent of women and 30 percent of female athletes, some of whom haven't even given birth. Maybe your mother, sister, wife, partner, daughter. It affects our family, work and social life; it restricts our sporting activities.

POP is common, yet most of us get caught by surprise

when it happens, because we have never heard of it before. Due to its location in the body, an intimate area, it is not often talked about.

I love the outdoors: I'm a keen tramper; I enjoy standup paddle boarding and kiteboarding. I feel fit and active, yet my pelvis went POP. Why me?

That was the question I asked myself when, in July 2019, my uterus unexpectedly slipped lower than it should be.

So, what actually is a pelvic organ prolapse?

As explained by pelvic floor physiotherapist, Michelle Kenway, "A prolapse is another word for a hernia. Hernias occur in different parts of the body when our elastic tissues overstretch; just like overstretching a piece of elastic which no longer recoils back into position having been stretched."

In a pelvic organ prolapse, the bladder, uterus or rectum move out of their usual position and drop down into the vagina.

Why me? It turns out that having given birth, age, genetics and simply being a woman was enough to have made me a POP candidate. I was told active life would 'never be the same again'. It was all about



create a resource where women could share their experiences, find support, encouragement and reassurance that they weren't alone with this.

To find answers to my questions, I started the 'POP goes my pelvis' project. The aim was to

Trying to get information out there about the project was a reality check it — revealed some of the reasons why POP was not talked about. Out of thirty New Zealand newspaper editors I contacted, only one replied. She commented that most editors were male and that POP 'was not exactly a sexy topic!'

public information, little cona continuing silence.

There is a vicious cycle: lack of fidence to talk about it, and thus

A year of collecting stories from active women around New Zealand who have experienced a prolapse, and gaining feedback from a range of pelvic health physiotherapists, resulted in the Active and POP website. Women in their thirties to seventies share their experiences and offer advice on something they thought would never happen to them.

Together, we talk about POP to raise awareness and remove the stigma. We provide links to helpful resources. Most importantly, we want women to know that they are not alone and that they can live an active life again!

If you have experienced a prolapse and would like to share your story to support other women (totally anonymously!) feel free to contact us via the website, or for information, stories, articles and advice please visit us at Active and POP.

I felt lost, alone, disappointed in my body for letting me down, desperate for answers. It wasn't a good place to be and one where I definitely didn't want to stay!

So, my POP experience started me on a new journey. I had so many questions: if POP was such a common condition, why was it not talked about? Why was there such a stigma associated with pelvic organ prolapse?

Think of a man with a hernia — they drop their pants to show you the scar whether you want to see it or not!

I started talking about POP. I told my female friends and found out that two of them had had a prolapse as well. I thought if POP affects so many of us, there must be lots of other active women out there in the same situation. Surfers, trampers, cyclists, joggers, yogis...

How did they deal with the restrictions that POP imposed on their daily lives and their sporting activities? The physical and especially the mental impacts!

Will the Therapeutic Products Legislation Protect Consumers?

By Sue Claridge

The AWHC is generally in support of the Therapeutic Products Bill (TPB)*. The existing Medicines Act 1981 is well past its 'use-by-date', and it was enacted before many critical developments in medical practice and therapeutic products. It significantly predates many technological developments outside medicine (such as the internet), that have had a major impact on the way in which consumers and health services providers interact and practice, and how information is disseminated.

The current regulatory system, particularly for implantable medical devices, is not working. We support the regulation of therapeutic products across their lifecycle; this is important for implantable medical devices and medicines that, despite short term safety studies and follow-up, may, and often do, cause harm many years after implantation or prescribing.

Regulation should support choice of, and equity of access to, therapeutic products. This principle is not only important in addressing existing inequities and disparities in healthcare and health outcomes in New Zealand, but also because there is no such thing as "one size fits all". There are many medicines that are effective or safe for a limited number of people and alternatives must be available. No therapeutic product works all the time for all people, and choice, and informed decision making about therapeutic products is a critical principle that must be applied.

We look forward to having a regulator that will both authorise therapeutic products and have compliance and enforcement powers. Stringent regulation of implantable medical devices has been catastrophically lacking in our regulatory regime for a long time. It is vital that this is corrected. Our hopes for the new Therapeutic Products Regulator are balanced against significant concerns about whether this new Regulator will fulfil the promises made in the TPB or not.

A Health System for the People!

A health system for the people is what we were promised by then Health Minister Andrew Little at the beginning of the health system overhaul, and that is what it should be — without the people, the

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^{*} For our full written and oral submissions see our website.

health consumers, we would have no need for the health system!

There are significant indications that despite the stated purpose of the TPB being "to protect, promote, and improve the health of all New Zealanders" this Bill is focussed on giving pharmaceutical companies, manufacturers and suppliers, and any other profit driven entity access to consumers. It is clear that the Bill is market-focussed, favouring corporates within the medico-pharmaceutical industrial complex, rather than being truly focussed on benefit to the health consumer.

We strongly believe that *ALL* consumers have an inalienable right to be involved at *ALL* levels of the health system. We argue that the new Therapeutic Products Regulator must be a signatory to the Code of Expectations for health entities' engagement with consumers and whānau and act in accordance with the that code. The Code of Expectations was required under the Pae Ora (Healthy Futures) Act 2022 (Section 59 and Section 60).¹

We are disappointed that this is not explicitly set out in the Therapeutic Products Bill.

We understand that engaging with consumers takes a lot of time, it makes things messy for advisors, policy makers and legislators who like things nice and tidy, dispassionate, impersonal and nailed

down. The reality is that people are messy and difficult and take time. But people are also experts by experience; we know more about what we need from our health system than the legislators do. We know that if consumers don't have a say about issues that affect them it makes for very poor outcomes.

Aotearoa New Zealand has been a democracy for a long time. We pride ourselves on having been the first in the world to give women the right to vote. Not giving consumers a

seat at the table is not anything to be proud of. Paying lip service to consumer engagement and consultation is not anything to be proud of.

In the Bill there are clauses that rely on the Regulator determining who will be affected by any regulations rather than taking the standpoint that ALL New Zealanders may be affected and are entitled to be consulted.

Consumers should be involved in development of secondary legislation, in reviews, and at every stage be invited to provide feedback. After all we were promised a people-centred health system; nothing less will do.

Patient Safety

Patient or consumer safety is of paramount importance in any legislation or regulatory regime that controls therapeutic products. No New Zealander should be worse off for the use of a therapeutic product. The needs and wants of health practitioners, sponsors, suppliers, the pharmaceutical industry and manufacturers must all be secondary to the health and well-being, and safety of health consumers.

However, we simply don't take medical harm and treatment injury seriously enough in this country.

In the US, preventable medical error is the third biggest killer behind heart disease and cancer. A 2016 study by Johns Hopkins University calculated that more than 250,000 deaths per year in the US are due to medical error.² In a New Zealand study published in 2006, Auckland University School of Population health lecturers Mary Seddon and Alan Merry found more than 1500 people were killed or permanently disabled annually in this country through preventable medical error.³ They wrote:



"The evidence is incontrovertible—we are inadvertently harming an unacceptable number of our patients by the very healthcare intended to help them."

An earlier New Zealand study⁴ found that "up to 30% of public hospital expenditure goes toward treating an adverse event", and that does not consider the cost to individuals in both direct and indirect costs, loss of quality of life etc., and to the

community in loss of productivity and participation. Brown *et al.* found in 2002 that "adverse events are estimated to cost the medical system \$NZ870 million, of which \$NZ590 million went toward treating **preventable** adverse events." [our emphasis]

Given the harm caused by surgical mesh alone in the last decade or more, that cost has only gone up. ACC payments for surgical mesh injuries alone have increased from \$500,000 in 2017 to \$5.1 million in 2021.⁵

Modern medicine is littered with examples of the serious harm inflicted on people — often

disproportionately impacting women — by inadequately tested and inadequately regulated drugs, medicines and procedures. Primodos. Thalidomide. Diethylstilbestrol. Contraceptive coils. Vioxx. Fenfluramine-Phentermine (Fen-phen). Essure contraceptive device. Breast

implants. Lung sealant. Pacemakers. Deep brain stimulators. Endometrial ablation. Surgical mesh.

As a nation, we are performing abysmally in patient safety. In late February, Denise Astill, Founder, Trustee and Executive Officer of FACSNZ* attended the 5th Global Ministers Summit on Patient Safety in Switzerland as a consumer advocate, yet there was no New Zealand ministerial or government representative there!

"Confronted with worldwide evidence of substantial public health harm due to inadequate patient safety, the World Health Assembly (WHA) in 2002 adopted a resolution (WHA55.18) urging countries to strengthen the safety of health care and monitoring systems."

We are signatories to resolution WHA55.18,⁷ which recognises the need to promote patient safety as a fundamental principle of all health systems. It urges Member States to pay the closest possible attention to the problem of patient safety; and to establish and strengthen science-based systems, necessary for improving patients' safety and the quality of health care, including the monitoring of drugs, medical equipment and technology.

The Therapeutic Products Bill does not give sufficient attention to the problem of patient safety or establish and strengthen science-based systems, necessary for improving patients' safety and the quality of health care, including the monitoring of drugs, medical equipment and technology.

We argued, on behalf of all New Zealanders who have been harmed in the health system, and all those who will be in future if our legislation does not adequately address patient harm, that the proposed Bill be amended to place a priority on keeping people safe. We asked that the precautionary approach be embedded in the Bill, that the legislation be shored up with a robust and effective harm notification system that really works, one that is nimble, responsive and above all recognises harm early and ensures that it stops.

In the TPB, there is repeated use of the phrase "likely benefits should outweigh the likely risks". This is a critical principle and how benefit and risk is balanced is crucial to whether or not the Bill protects consumers. However, a simple calculation that "benefits outweigh risks" is a low threshold and risks permitting products that are not harmful 51% of the time.

A simple calculation that "benefits outweigh risks" is a low threshold and risks permitting products that are not harmful 51% of the time. Using such an inadequate measure results in situations such the surgical mesh issue, where a therapeutic product could cause catastrophic harm for thousands of people, yet still be evaluated as having benefits in that it does not harm a slender majority of consumers.

The term "proportionate" is also frequently used in the proposed legislation, with no definition provided. That is because "proportionate" is a highly subject measure, and one person's idea of proportionate will be entirely different from another's based on experience and perspective.

The subjective concept of having "regard for the likely benefits and risks" permits the sponsor of a therapeutic product and/or the Regulator to ignore or dismiss harm that has not been thought likely or has not been considered at all; absence of evidence is **NOT** evidence of absence.

The Regulation of Implantable Medical Devices... which the TPB does not address appropriately

The regulation of implantable medical devices is one of the most critical issues in patient safety. It is widely recognised that, internationally, regulation of implantable devices is grossly inadequate. Catastrophic levels of harm have been inflicted upon health consumers in New Zealand because,

^{*} Foetal Anti-Convulsant Syndrome NZ

we too, have had years of gross under-regulation of implantable medical devices.

In 2018, *The British Medical Journal's* Editor in Chief, Fiona Godlee, asked "Why aren't medical devices regulated like drugs?"⁸ A major international investigation, involving 59 organisations and including *The BMJ*, found device regulation unfit to protect patients from harm."⁸

The major investigation of medical devices — the *Implant Files*⁹ — found that "sources of harm to patients include a lung sealant that leaked, breast implants that went rancid, implanted pacemakers that stopped working, and deep brain stimulators that had to be removed."

The website <u>Implant Files</u> is devoted to the first-ever global examination of the medical device industry, which has found that health authorities across the globe have failed to protect millions of patients from poorly tested implants.

The investigation found that when flaws are found in medical devices, and safety alerts and recalls are triggered, all too often these warnings fail to reach doctors and patients. Recalls, withdrawals and bans on devices are not uniformly applied from country to country, causing confusion and raising risks to patients where insufficient action is taken.

The *Implant Files* state that "Doctors and manufacturers often fail to report adverse events, and when they do the information can be unverified and incomplete. And over large swaths of the planet, health authorities refuse to disclose information about harm to the public — or just never collect it in the first place."

New Zealand was one of the countries specifically mentioned. There is no escape from the fall out — our national regulators facilitated significant harm to New Zealanders because they failed to do their jobs properly!

The TPB is the opportunity to not only protect New Zealanders, but to lead the world in implantable device regulation.

So, what are we going to do?

Because of the Transitional provisions, we will wait another six and a half years before our regulatory authorities hold sponsors of implantable medical devices accountable for the lack of safety of their products.

The transitional provisions may well be acceptable

for medicines that have always been subject to better and more robust regulation. However, it is unconscionable that New Zealanders have to wait this long to have any sort of confidence that our therapeutic products regulators are going to take our safety and protection from harm from implantable medical devices seriously.

The transitional provisions in the TPB effectively give health practitioners *carte blanche* to continue using harmful devices, such as surgical mesh, because such implantable devices will automatically be given a temporary market authorisation. This Bill may not come into force until as late as the 1st of September 2026. Therefore, the temporary market authorisation for a medical device will have up to three years after that date before that it expires — entirely likely to be not until September 2029. We conceivably have to wait until late 2029 to see implantable medical devices sufficiently regulated to give some assurance of safety.

Meanwhile, New Zealanders will continue to be exposed to devastating harm from virtually unregulated implantable devices.

The Health Select Committee must amend the Bill, go back to the drawing board if necessary, but stand up for those who will be harmed over the next six or more years and demand better from both the legislation and from the suppliers of medical devices.

- 1 Pae Ora (Healthy Futures) Act 2022
- 2 Makary MA and Daniel M, 2016: Medical error the third leading cause of death in the US, *British Medical Journal*, May 3; 353: i2139.
- 3 Merry A and Seddon M, 2006: Quality improvement in healthcare in New Zealand. Part 2: are our patients safe and what are we doing about it? *New Zealand Medical Journal*, 2006 Jul 21; 119(1238): U2086.
- 4 Brown P et al., 2002: Cost of medical injury in New Zealand: a retrospective cohort study. *Journal of Health Services Research and Policy*, 2002 Jul; 7 Suppl 1: S29-34.
- 5 Russell E, 2022: <u>In Her Head: Women's health Surgical mesh investigation</u>, claims surgeons harmed women, New Zealand Herald, 30 June 2022.
- 6 WHO, 2009: WHO Guidelines for Safe Surgery 2009: Safe Surgery Saves Lives, World Health Organization: Geneva, 2009.
- 7 WHA, 2002: *Quality of care: patient safety, Resolution* WHA55.18, Fifty-Fifth World Health Assembly, 18 May 2002.
- 8 Godlee F, 2018: Why aren't medical devices regulated like drugs? *The BMJ* 2018;363:k5032.
- 9 ICIJ, 2018: Medical Devices Harm Patients Worldwide As
 Governments Fail On Safety, The Implant Files, International
 Consortium of Investigative Journalists.



Will Our Women's Health Strategy Be What We Need it to Be?

By Sue Claridge

Calls for a women's health strategy for Aotearoa New Zealand began at least as early as 2014, with the Women's Health Action discussion paper, A Case for a National Women's Health Strategy in Aotearoa New Zealand.¹ They wrote:

A women's health strategy recognises that sex and gender are basic determinants of health, which give rise to different health outcomes and different health care needs for women and men.¹

Over the last few years, Auckland Women's Health Council has added our voice² to the increasingly loud calls for inequities and disparities in women's health to be addressed. In our submission on the Pae Ora (Healthy Futures) Bill³ we argued strongly for a women's health strategy to be added to the health strategies to be developed under the new legislation. Those calls were answered, and the inclusion of a women's health strategy was announced in April 2022.⁴

At the end of 2022, Manatū Hauora | Ministry of Health called for written submissions on the women's health strategy and we recently lodged our submission.⁵

Many women in this country do not have accessible, affordable, available, and culturally appropriate and acceptable health care. Beyond this, an unacceptable number of women are harmed in some way — often extremely seriously — by their experiences of health care, and many more have their basic health care rights breached. The women's health strategy must address the inequities and disparities, and harm/injury experienced by women in health care.

There are many things we need the women's health

strategy to be. It MUST focus on more than sexual and reproductive health. It MUST focus on the leading causes of loss of quality of life, disability and death for women. The strategy must:

- take a life course approach that addresses health needs in different stages in a woman's life;
- focus on achieving and maintaining health not just treating illhealth;
- acknowledge the factors that influence women's lives and health such as ethnicity, disability, sexual identity and background;
- address the social determinants of health: gender is a social determinant of health, interacting with other factors such as income and poverty, education, occupation, housing, and domestic violence;
- include a national health needs assessment for women and provide for gender analysis in any assessment of population health needs; a gendered approach to the collection and utilisation of health data;
- examine the pathways and quality of care for women within the health system; identify evidence-based strategies that could be implemented to ensure women receive the best available care;
- consistently recognise, promote and allocate resources to address a broader, integrated women's health agenda;
- address the barriers to women seeking early care (including time, responsibilities, care of other family members, childcare, jobs and transport, as well as

financial considerations), and develop and implement strategies to improve timely access to care;

- require that all medical and health research in Aotearoa New Zealand is appropriately designed to facilitate the inclusion of gendered analyses, and that appropriate and representative numbers of women are included in clinical trials;
- involve consumers in monitoring and reviewing the progress of the women's health strategy, and assessing how the health system has performed against the strategy.

What we also need the women's health strategy to be is informed. It must be informed by the lived experience of wāhine/women in Aotearoa New Zealand. The only way that the women's health strategy can possibly address the inequities and disparities, the barriers and discrimination that women face in health care and health outcomes, is for the women's health strategy team tasked with developing the strategy is to talk to women from all over the country and hear about their experiences and their needs. They need to hear all the ways in which the health system is failing women.

We believe that the Manatū Hauora | Ministry of Health women's health strategy team probably want to do this. The constraint is time. The Pae Ora (Healthy Futures) Act 2022⁶ requires that the various health strategies including the women's health strategy, take effect 12 months after the enactment of the legislation — that is, in June 2023.

This is insufficient time to adequately seek and collect women's stories; their experiences and their needs. In December 2022 Manatū Hauora | Ministry of Health set up an online platform - Tātou - for people to contribute their ideas for improvements to the health system including for the health strategies.

"This is a bizarre way of getting feedback and I am confused about who it is targeting. Certainly not the most vulnerable users of the health system."

 A contributor on the Transforming the Health System Discussion

When it was launched they said "in order to develop [the health] strategies, we want to hear from and speak with a wide range of people and organisations. This will help to ensure the strategies meet needs of those they're meant to serve. One way we want to hear from you is our Tātou online platform, which is now LIVE!" As of the 29th of March 2023, only 80 ideas had been contributed to

the "Achieving pae ora (healthy futures)" discussion, from a population of five million!

There is now only just over two months before the anniversary of the enacting of the Pae Ora (Healthy Futures) legislation; just over two months until the women's health strategy must take effect. Just over two months to seek out the views of women/wāhine who most need to be heard: the women who have unmet health need; those who are isolated; those who don't have internet access; the hard to reach like the elderly, the disabled, the disenfranchised, those for whom English is a second language; those so badly harmed by their experiences that they no longer trust the health system.

We can't see how the women's health strategy is going to be properly informed by the women who most need this strategy to address their health needs and remove barriers to both health care and better health outcomes. The women/wāhine who need a health system that will fix the myriad types of harm that has already been done to them and prevent it happening again. Past failures of the health system to address the needs of women are in part owing to a failure to engage and listen to women. In effect the Pae Ora (Healthy Futures) Act has set up those developing the women's health strategy to ensure that the health system will fail again.

In all likelihood there is no way to stop the women's health strategy coming into effect in June. All we can demand now is that it is an interim strategy; that Manatū Hauora takes another two years to undertake a thorough and complete lived experience survey of women/wāhine, including the hardest to reach and most inadequately served women, undertake a complete gendered analysis of women's health, and produce the women's health strategy version 2.

- 1 WHA: <u>A Case for a National Women's Health Strategy in</u>
 Aotearoa New Zealand, Women's Health Action.
- 2 AWHC Newsletters <u>June-July 2021</u> and <u>October-November 2021</u>
- 3 Claridge S, 2021: <u>Submission of the Auckland Women's Health</u>
 <u>Council on the Pae Ora (Healthy Futures) Bill</u>, Auckland
 Women's Health Council, 9 December 2021.
- 4 Russell E, 2022: <u>Govt commits to including a women's health</u> <u>strategy in new Pae Ora legislation</u>, *New Zealand Herald*, 13 April 2022.
- 5 Claridge S, 2023: <u>Submission of the Auckland Women's Health Council on the Women's Health Strategy</u>, Auckland Women's Health Council, 24 March 2023.
- 6 Pae Ora (Healthy Futures) Act 2022

A Consumer-Centred, Co-Designed Health System

The Consumer Advocacy Alliance's Five 'I's Framework for women's health

The women's health strategy is an opportunity to rethink the way that we deliver health services, to create a truly consumer-centred, co-designed health system. To achieve a health system that does not disadvantage women, and that addresses women's often complex health needs, we must address gender bias by considering all aspects of health care through a gendered lens.

So, what does a consumer-centred, co-designed health system look like?

The Consumer Advocacy Alliance (CAA), of which the Auckland Women's Health Council is a member, believes that the ideal provision of health care services to women, especially those that live with complex health needs and multiple and often interrelated conditions, is through women's health clinics that provide "wrap-around" and interdisciplinary health services.

THe CAA envisages a new vocational group — women's health physicians. Inspired by the development of the breast physician vocational group in the late 1990s and early 2000s in the UK, Australia and Aotearoa New Zealand, a typical women's health physician would be a female GP who has undertaken further, more specialised training in a range of women's health disciplines. Women's health clinics would employ a range of different practitioners (this may depend on size and demographics of the population it was serving), and as well as the women's health physician/s include physiotherapists, midwives, nutritionists, acupuncturists and/or pain specialists, endocrinologists or hormonal/menopause specialists, etc.

Women's health clinics would adopt the Five 'I's Framework (see below), an holistic and integrated approach to health care with ethics at its heart. The

The Five 'I's Framework

an holistic and integrated approach to health care with ethics at its heart.

Interdisciplinary

Medical professionals from a range of disciplines working together with the aim of organising and co-ordinating health treatments and care services. Providing an environment that supports co-operation, respect and collaboration between colleagues and health practitioners to provide seamless, continuous care.

Integrated

A healthcare approach that takes account of the whole person, including the social determinants of health, their past, present and future. Holistic practice that considers the interconnectedness and interrelationship of the different parts of the body as well as mental, spiritual and physical wellbeing, while utilising all appropriate therapies.

Interrelated

Building and fostering relationships with team members. Valuing and validating personal and individual strengths to achieve desirable patient outcomes, effective communication and provision of quality care. Information sharing across the team and with consumers/patients.



Intergenerational

Actively promoting, valuing, fostering and encouraging intergenerational communication with patients/consumers and whānau. Understanding the impact of intergenerational trauma, adopting a trauma informed approach to health care.

Inclusive

Validating identity, diversity and culture.

Being aware of unconscious bias.

Ensuring accessibility for all to a range of community services that support mental health and wellbeing. Meeting the needs of individual consumers/ patients and whānau, providing patient centered care.

Charlotte Korte, Kat Gibbons, Denise Astill and Sue Claridge: "The Five 'I's Framework", Consumer Advocacy Alliance, Copyright © 2022



women's health physician would refer women to specialists as required, and the women's health clinic might co-ordinate health treatment and care services to ensure an interdisciplinary approach.

Over the past five years, a diverse range of health advocates have presented more than 40 petitions to parliament, calling for changes or improvements to aspects of women's health. These advocates often have lived experience of harm.

The Interdisciplinary Approach

The evidence is clear that "interdisciplinary care", in which all clinicians work together in a synthesised and harmonised manner, is much better than "multidisciplinary care" in which many clinicians are dealing with their own small bit of the "elephant" (see illustration below).

Many women present with complex health needs, sometimes with both systemic and localised symptoms. They are often pushed from one practitioner or specialist to another, repeatedly having to tell their 'story' and finding no answers and no resolution to the health conditions that can dramatically reduce their quality of life.

An interdisciplinary approach, in which health professionals work together to organise and coordinate health treatments and care services, offers women with complex needs faster diagnosis and treatment, better outcomes and significantly improved quality of life.

The <u>Consumer Advocacy Alliance</u> is an independent consumer alliance that ensures scrutiny of the health system at all levels — including all government, public and private health entities — for the benefit of all New Zealanders, to protect people from harm and to ensure quality consumer-focused health care and services.

Being independent allows us to be intentionally consumerfocused; independence enables us to evaluate health issues objectively and work constructively with the sector to find solutions.

We are a collective of experienced health care advocates who share a common passion for creating positive, effective and lasting change. Our founders have a common standpoint; that health care, as it is now, is not working; that the experience of New Zealanders in the health system is not what it should be. By working together and pooling our experience we identify areas and opportunities where we can facilitate change within the health system and ensure that our voice, the consumer voice, is heard.

Vision A people-centred health system in which health consumers/patients work in true partnership with health care providers for health and well-being, and in which health consumer/patient rights and safety are paramount.

Goal To contribute to creating a patient-centred health system that encourages transparency and shared decision making; to ensure that the consumer voice is not only heard but that co-design with lived experience consumers is at the heart of all legislation/regulation, policy, development, design, implementation, research and service provision within the health system.





In our women's health strategy submission, we wrote of the need to focus on achieving and maintaining health, not just treating ill-health. While women in Aotearoa New Zealand live longer on average than men, they live more of their life with disability or poor health. In 2013, wāhine/women had a life expectancy of 83.2 years, yet their health expectancy was only 65.2 years, meaning that on average they spend 18 years in poor health!

Addressing health and well-being — or the lack of — in women/wāhine is not just about having a well-resourced, highly functional health system that delivers best practice, evidence-based medicine. To attain health, well-being and healthy longevity necessitates addressing social and commercial determinants of health and focusing on prevention of disease, particularly non-communicable and degenerative diseases, which significantly take away from productive healthy lives and contribute to disability-adjusted life years.

The Health and Disability System Review – Final Report – Pūrongo Whakamutunga 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."²

It is imperative that the social and commercial determinants of health are given a high priority in the women's health strategy. Gender is a social determinant of health, and there is a complex interplay between gender and other factors, such as income and poverty; education; occupation; housing; tobacco, alcohol and drug use; and domestic violence.

While many of the social determinants of health lie outside of the health system — income and poverty; education; occupation; housing and homelessness; tobacco, alcohol and drug use; and domestic violence — health policy, including the women's health strategy, must take account of these and the myriad other factors that influence a woman's health.

In our submission, we chose to focus on one factor: poverty... specifically poverty in childhood. Poverty and material hardship has been a major policy focus of the current Labour Government. However, the Covid pandemic, recent weather events and the cost-of-living crisis have only served to place more pressure on families living with the highest levels of deprivation in Aotearoa New Zealand.

Despite Government commitments to reducing the number of children living in poverty in this country, not only has there been no improvement, but it has gotten worse.

In 2019, 235,400 children (21.0%) lived in a low-income household.* In addition, in 2018/2019:³

- children living in the most disadvantaged communities were more than twice as likely to end up in hospital as those from the most advantaged communities;
- one in five children lived in households without access to enough food or healthy food; severe-to-moderate food insecurity was experienced in 42.8% of households with children with income at or below \$50,000 per annum.
- 282,228 children lived in damp housing and 237,543 in housing with mould;
- 77,976 under-18 year olds lived in homes without access to one or more basic household amenities such as safe tap water, cooking and washing up facilities, a bath or shower, a toilet, a refrigerator or a supply of electricity.

A 2021 report 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 had been fully implemented.⁴ 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."³

The report goes on to express concern that "it could take decades to implement welfare reform as envisioned by WEAG"3, thus ensuring that the children who currently live in poverty may be consigned to lifetime of health inequity and poor health outcomes. As I write, it has been revealed that scant progress has been made in reducing child poverty in the four years since this country began measuring and reporting on material hardship. After a 2.3 per cent decline in material hardship between 2018-21, no further gains were made in 2022. The newly released figures only go to June 2022, before the advent of the current cost of living crisis; next year's figures may tell a more devastating story.⁵

One out of every five girls in Aotearoa New Zealand live their lives in poverty, and the impact that this will have on the health of those girls later in life cannot



be underestimated. A recent study of 10,784 adults in the US found that "severe indicators of childhood poverty are associated with general and chronic health problems as well as adult depression." 6

Data from the Dunedin Multidisciplinary Health and Development Study found that, compared with those from high socioeconomic status backgrounds, children who grew up in low socioeconomic status families had poorer health at the age of 26 across all health measures (except systolic blood pressure), irrespective of health in infancy or adult socioeconomic status. The study concluded that subsequent higher socioeconomic status "did not mitigate or reverse the adverse effects of low childhood socioeconomic status on adult health."

A subsequent analysis of data from the Dunedin Study, that followed the cohort to the age 32, confirmed that "low childhood [socioeconomic status] was associated with an increased risk of substance dependence and poor physical health in adulthood." The authors found that adults who had "experienced childhood disadvantage were especially likely to experience multiple health problems by the time they reached adulthood" compared with those from high childhood socioeconomic status group.⁸

This study also found that there was an intergenerational impact on health: low socioeconomic status children were more likely than high socioeconomic status children to carry a familial predisposition to poor health.⁸

^{*} A low income household is defined as one with equivalised disposable income below 50% median income after housing costs. Housing costs are regarded as non-discretionary, as households cannot simply decide not to incur them.³



Reliance on food banks has increased since the start of the Covid-19 pandemic, and people who have never previously found themselves unable to cope are now waiting for food banks to open to be able to feed themselves. Auckland, the city mission had consistently provided 2000 food parcels a week for months.

Canadian studies confirmed the Dunedin Study results. Raphael found that "children who live in poverty are more likely as adults than their peers to develop and die earlier from a range of diseases. These effects are especially strong for cardiovascular disease and type II diabetes." Subsequent improved life circumstances only had a modest ameliorative effect.

Rita Paul-Sen Gupta and colleagues from Toronto Public Health found that "in addition to experiencing higher rates of adult mortality between the ages of 26 and 54, children from economically disadvantaged backgrounds have poorer adult health in a number of areas, including physical disability, clinical depression and premature death." ¹⁰

There appears to be little research that focuses specifically on the impacts of childhood poverty on women's health. However, women experience higher levels of intergenerational poverty.¹¹

There appears to be a complex interplay between childhood poverty, adult health and intergenerational poverty leading to poorer health outcomes in subsequent generations of children.

For the health of our wāhine/women and their children, we must address poverty in Aoteroa New Zealand. This means addressing the financial barriers to health, not just the barriers to accessing health care.

- 1 MSD, 2016: *The Social Report 2016 | Te pūrongo oranga tangata*, Ministry of Social Development, June 2016, Wellington: NZ.
- 2 Health and Disability System Review, 2020: <u>Health</u> and <u>Disability System Review Final Report Pūrongo Whakamutunga</u>. Wellington: HDSR.
- 3 Duncanson M, et al., 2020: Child Poverty Monitor 2020 Technical Report, NZ Child and Youth Epidemiology Service, University of Otago, Dunedin.
- 4 Neuwelt-Kearns C, et al. 2021: <u>Children can't live on promises:</u> <u>A 2021 stocktake of implementation of the Welfare Expert</u> <u>Advisory Group's 2019 recommendations</u>, Child Poverty Action Group, December 2021.
- 5 Grant M and Prickett K, 2023: <u>Child poverty in NZ: The plateau</u> is a signal for change, *New Zealand Herald*, 23 March 2023.
- 6 Lee H, et al., 2021: Childhood Poverty, Adverse Childhood Experiences, and Adult Health Outcomes, Health Soc Work; Aug 5;46(3):159-170.
- 7 Poulton R, et al., 2002: Association between children's experience of socioeconomic disadvantage and adult health: a life-course study, *Lancet*; Nov 23;360(9346):1640-5.
- 8 Melchior M, et al., 2007: Why do children from socioeconomically disadvantaged families suffer from poor health when they reach adulthood? A life-course study, Am J Epidemiol; Oct 15;166(8):966-74.
- 9 Raphael D, 2011: Poverty in childhood and adverse health outcomes in adulthood, *Maturitas*; May;69(1):22-6.
- 10 Gupta RP, 2007: The impact of poverty on the current and future health status of children, *Paediatr Child Health*; Oct;12(8):667-72.
- 11 Mandle J, 2019: Intergenerational Poverty, Women's and Children's Health, *The Utah Women's Health Review*, May 2019.



Women's Health in an Uncertain Future

how women's health is disproportionately impacted by pandemics and climate change

By Sue Claridge

When people talk about women's health there is a strong focus on their sexual and reproductive health; for example at medical school "women's health" is really obstetrics and gynaecology. This focus is at the expense of the biggest causes of morbidity and mortality, non-communicable diseases.

Bonita and Beaglehole write that the global discourse on health largely views women in terms of their reproductive capacity, a persisting myth reflecting gender bias that shifts the focus away from non-communicable diseases, violence, and other injuries.¹

Today, women also face two other growing threats to their health. Severe global or national events, such as pandemics and weather/environmental events caused by climate change, disproportionately affect women in ways that can significantly negatively impact on their health.

While an increasing volume of research has investigated the impacts on women's health in low and middle-income countries, there is a dearth of quality research on the impact of pandemics and climate change on women's health in Aotearoa New Zealand. Kim van Daalen and colleagues write that "Despite obvious disparities between genders, gender-disaggregated health data are often either under-represented or non-existent as a variable when assessing the health effects of climate change in medical research, environmental research, and strategic planning of mitigation and adaptation policies. This disregard for gender differences is

particularly concerning as climate change is predicted to worsen existing social and economic inequalities between and within countries."²

These issues must be addressed, as the evidence is clear that such events will increase in frequency. There must be a change in our culture to ensure that women do not suffer a greater loss in health as the result of pandemics and weather events. We argued in our submission on the women's health strategy that the strategy must incorporate a blue-print for bringing about that change.

Pandemics expose and exacerbate the existing dynamics of a society — good and bad

Dr Lieberman Lawry, an Associate Professor in Preventive Medicine and Biostatistics, and colleagues found that "despite decades of understanding that sex and gender impact health, public health and disease, these impacts are routinely overlooked during pandemics." Pandemics exacerbate existing gender inequalities and Lieberman Lawry *et al.* say that "inclusive gender assessment that covers sex and all genders is necessary at baseline, early recovery, and post-disaster phases" so that policy, programmes and interventions properly respond to different needs of people.³

We have written previously in the Newsletter⁴ about the gendered impacts of Covid-19 on women's health: The changes in the way we lived because of the Covid-19 pandemic, and the restrictions imposed, disproportionately impacted on women's health and wellbeing. As Chloe Cooney noted: "Pandemics expose and exacerbate the existing dynamics of a society — good and bad."⁵

The pandemic response and lockdowns involved a radical revision of "home" as an intense site of practically everything. Many government responses assumed home as a safe space to retreat to. We know that home is a privileged location for some, and for others a place of dispossession, disconnection, violence and loss. Our homes were invested with enhanced capacity where governments and employers assumed free and amenable space (and time) for work, leisure, sustenance, care, childcare and education.⁶

We are facing a 'care crisis',⁷ which could lead to profound and long-lasting shifts in women's work and life outside the home. Rates of anxiety and stress among women are reactions to their position as frontline workers and care providers, and to the impossible choices they can face regarding childcare, education, and their economic and personal security.

Ongoing research, both here and internationally, continues to paint a very poor picture for women's health through the Covid-19 pandemic.

Ann Keeling, senior fellow at Women in Global Health and lead author of the report *The State of Women and Leadership in Global Health* says "It's not surprising now that what we see is massive exhaustion amongst the women who've been on the frontline for three years. They're burnt out. But it's

also to do with this concept of moral injury."8

'Moral injury' is what happens when health workers can't treat patients in a way that aligns with their values or professional training because the situation doesn't allow it. We see this in Aotearoa New Zealand in our nurses and midwives. When they take strike action, for example, it is not just about pay, it is about their working conditions and the safety of their patients. They face working in situations where there is not enough nursing staff to provide safe care, and they have unreasonable workloads are forced to work excessive overtime.

Keeling goes on to say that during the pandemic more women were on the front lines, they were more exposed to the virus and more likely to get sick, leading to death or disability from long COVID — a condition that early research shows tends to affect women more than men.⁸

"All of this means health care is now seeing a 'great resignation' from women across the field. And women may begin looking for better-paying jobs in other countries, creating staff shortages in the places they're leaving."

Unfortunately, this is a situation that is all too familiar in Aotearoa New Zealand, with chronic shortages of nursing staff in both hospitals and aged-care facilities.

However, despite women being at the frontline of the health response during Covid-19, they were typically "excluded from decision-making at country level during the pandemic: a WGH study in 2020 found 85% of 115 national COVID-19 task forces had majority male membership."

While Aotearoa New Zealand fared better than many countries, with women comprising 36% of our Epidemic Response Select Committee, we still fell well below gender parity and did not do as well as a number of other countries, such as Argentina, Chile and Ireland, Canada, South Africa, Finland, the latter three of which reached 50% women or just above.⁹

So, while in Aotearoa New Zealand women have had a diminished role in Covid-19 decision making, women have likely suffered a greater direct and indirect impact on their health.



New findings linking 'long COVID' symptoms to women's reproductive capacity suggest that COVID infection may have an ongoing impact on women's health, quality of life and ability to carry out the paid and unpaid work that is expected of them. For example, women seem to experience less severe symptoms short-term but suffer worse long-term COVID complications, including depression, reduced physical activity, and deteriorating lifestyle habits. 10, 11, 12 In addition, differences in women's innate immunity lead to women consistently reporting more adverse reactions than males in response to vaccines including COVID-19.3

Gender inequality is an ongoing social, economic, political and *health crisis*, which has been exacerbated by the pandemic.¹² [our emphasis]

One of the biggest impacts on women as a result of the pandemic and measures to control it, is increased domestic violence, ¹³ with an increase in frequency and severity of violence against women and children. ¹⁴ So pronounced has that increase been that it has been labelled the 'shadow pandemic'. ¹⁵ "Increases in intimate partner violence were described as rising in parallel with the lock-down, with the police and Women's Refuge reporting surges in family harm related calls." ¹⁶

Research in Aotearoa New Zealand has found intimate domestic violence/intimate partner violence (IPV) is significantly associated with current health effects, including: self-perceived poor health, physical health problems (e.g. pain), and mental health problems (e.g. suicide attempts).¹⁷ In an Aotearoa New Zealand 2023 study of 1431 women "closely comparable with New Zealand's ethnic and area deprivation composition", exposure to "any IPV and specific IPV types was significantly associated with increased likelihood of reporting adverse health outcomes."¹⁸

Additionally, "people with disabilities report experiencing a significantly higher lifetime prevalence of intimate partner violence compared with people without disabilities." ¹⁹

In 2020, our Government received advice from the Ministry for Women that support and recovery measures to date had not been designed with gender equity in mind, and ran the risk of exacerbating Covid-19 impacts, particularly for Māori and Pāsifika women.²⁰ It advised government to develop a cross-government gender-Covid response, including meaningful specific actions to mitigate the disproportionate effects on women in Aotearoa New Zealand.

It is absolutely vital that a gendered response to future pandemics is developed before we face the next one.

Climate Change and Extreme Weather Events

It is clear that as climate changes, and accepting that even addressing this now will take decades to see effective and positive change, we must consider human health in all our environmental and climate change decisions.

Women and girls often face disproportionately high health risks from the impacts of climate change when compared to men and boys. Globally women are more affected by health impacts associated with climate change than men, and are more likely to die or suffer injury from extreme weather particularly cyclones and heatwaves; experience food insecurity; and suffer poor mental health and partner violence.²¹ Pregnant people are particularly vulnerable:²² "climate change might also affect women's ability to seek reproductive and maternity health services, and pregnancy-related outcomes can be affected by changes in infectious diseases, temperature, and nutritional status."²

While many of the worst effects of climate change will have the greatest impact on under-developed and impoverished nations, and therefore have the greatest gendered impact on women and girls of such nations, Aotearoa New Zealand is far from immune to the disproportionate impact on women's health.

As with the Covid-19 pandemic, the severe weather events that devastated parts of New Zealand in February 2023, particularly cyclone Gabrielle, resulted in an increase in reports of domestic violence.²³ This is not a new phenomenon; the 2004 Manawatu floods also resulted in increases in domestic violence.^{24, 25}

Food security is a world-wide issue, one that many New Zealanders might consider to be the least of our country's climate change problems. Again, however, the devastation of cyclone Gabrielle has had a significant impact on the availability and cost of fruit and vegetables²⁶ adding to the already soaring cost of food over the last year.²⁷ With the destruction of orchards and farms in the Hawkes Bay, we can expect fruit costs, at least, to remain high for several years while these horticultural areas are re-established.

Reductions in global food availability, and fruit and vegetable consumption in particular, are estimated to result in 500,000 climate-related deaths worldwide

by 2050.²⁸ In Aotearoa New Zealand reduced availability and high cost may not result in direct deaths, but in significantly reduced health measures and an increase in diet-related conditions, such as cardiovascular disease, diabetes and cancer. With the existing cost of living crisis already putting pressure on those living in areas of higher deprivation, reduced availability of healthy food will disproportionately affect those with lower incomes and living in poverty.

In their report *Human Health Impacts of Climate Change for New Zealand*, the Royal Society Te Apārangi state that "the effects of climate change will not be spread evenly across the population, exacerbating existing socioeconomic and ethnic health inequalities," but that the "adaptability and resilience of health and welfare systems are important factors in minimising the effects of climate change on human health."²⁸

- 1 Bonita R and Beaglehole R, 2014: Women and NCDs: overcoming the neglect, *Glob Health Action*; May 5;7:23742.
- 2 van Daalen K, et al., 2020: Climate change and gender-based health disparities, Lancet Planet Health, Feb;4(2):e44-e45.
- 3 Lieberman Lawry L, et al., 2023: Overlooked sex and gender aspects of emerging infectious disease outbreaks: Lessons learned from COVID-19 to move towards health equity in pandemic response, Front Glob Womens Health; 2023 Feb 20;4:1141064.
- 4 Palmer de Preez K, 2021: <u>COVID and women's wellbeing:</u>
 <u>New feminist analyses</u>, *AWHC Newsletter*, October-November 2021.
- 5 Cooney C, 2020: <u>The Parents Are Not All Right</u>. GEN, 6 April 2020.
- 6 Jenkins F, 2020: <u>Did our employers just requisition our homes?</u> *Canberra Times*, 4 April 2020.
- 7 Smith J., et al., 2021: More than a public health crisis: a feminist political economic analysis of COVID-19. *Global Public Health*, Aug-Sep;16(8-9):1364-1380.
- 8 WGH, 2023: Policy Brief: The State of Women and Leadership in Global Health: The XX Paradox, Women in Global Health.
- 9 van Daalen KR, et al., 2020: Symptoms of a broken system: the gender gaps in COVID-19 decision-making. BMJ Glob Health; 5(10): e003549.
- 10 Bucciarelli, V., et al., Depression pandemic and cardiovascular risk in the COVID-19 era and long COVID syndrome: gender makes a difference. *Trends in Cardiovascular Medicine*, Jan;32(1):12-17.
- 11 Torjesen, I., 2021: Covid-19: Middle aged women face greater risk of debilitating long term symptoms. *BMJ*, Mar 25;372:n829.

- 12 PAHO, 2021: Gendered Health Analysis Covid-19 in the Americas, Pan American Health Organization, Washington DC: US.
- 13 Bettinger-Lopez C, and Bro A, 2020: A Double Pandemic: Domestic Violence in the Age of COVID-19, *Domestic Violence Report*, Vol 25, No. 05, June/July 2020, pp.85-86(2). Civic Research Institute.
- 14 Koziol-McLain J, et al., 2023: Impact of COVID-19 on the Health Response to Family Violence in Aotearoa New Zealand: A Qualitative Study. *Inquiry*. 2023 Jan-Dec;60:469580221146832.
- 15 Sri AS, 2021: COVID-19 and the violence against women and girls: 'The shadow pandemic', *Int J Soc Psychiatry*, Dec;67(8):971-973.
- 16 Every-Palmer S, et al., 2020: Psychological distress, anxiety, family violence, suicidality, and wellbeing in New Zealand during the COVID-19 lockdown: A cross-sectional study, *PLoS One*, Nov 4;15(11):e0241658.
- 17 Fanslow J and Robinson E, 2004: Violence against women in New Zealand: prevalence and health consequences, *NZ Med J*; Nov 26;117(1206):U1173.
- 18 Mellar BM, et al., 2023: Association Between Women's Exposure to Intimate Partner Violence and Self-reported Health Outcomes in New Zealand, JAMA Netw Open; Mar 1;6(3):e231311.
- 19 Fanslow JL, et al., 2021:Lifetime Prevalence of Intimate Partner Violence and Disability: Results From a Population-Based Study in New Zealand, Am J Prev Med, Sep;61(3):320-328.
- 20 Ministry for Women. <u>COVID-19 Advice to Minister</u>. 2020.
- 21 Sellars S, 2016: *Gender and Climate Change: A Closer Look at Existing Evidence*, Global Gender and Climate Alliance, November 2016.
- 22 Pandipati S and Abel DE, 2023: Anticipated impacts of climate change on women's health: A background primer, Int J Gynaecol Obstet; Feb;160(2):394-399.
- 23 Iasona S, 2023: <u>Hawke's Bay family violence support</u> service hears from whānau 'we've never heard of before', *NewsHub*, 21 February 2023.
- 24 Houghton R, 2009: 'Everything Became a Struggle, Absolute Struggle': Post-Flood in Women, Gender and Disaster: Global Issues and Initiatives (Eds. Enarson E, & Chakrabarti PGD), Chpt 8, SAGE Publications: India.
- 25 Houghton R, 2010: "We had to cope with what we had": Agency perspectives on domestic violence and disasters in New Zealand. Victoria University of Wellington, Wellington.
- 26 Kitchin T, 2023: Cyclone Gabrielle's impact on New Zealand's 'fruit bowl', Radio New Zealand, 9 March 2023.
- 27 Prasad A, 2023: <u>Cyclone Gabrielle: Fresh produce prices likely to rise, experts say, New Zealand Herald</u>, 16 February 2023.
- 28 Royal Society Te Apārangi, 2017: Human Health Impacts of Climate Change for New Zealand, Evidence Summary, Royal Society Te Apārangi, October 2017, Wellington: NZ.