

Organisation: Foetal Anti-Convulsant Syndrome New Zealand

Submission to: Manatū Hauora, Ministry of Health

Subject: Women's Health Strategy

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Your imagination, our reality:

Imagine being a woman, a woman who was born only just a few generations ago, who would get institutionalised, for having “funny turns”. Never having a future or the opportunity to live a fulfilling life. Imagine finding out if these “funny turns” were actually epilepsy. Imagine living in this world where the clinical trials for the medicine you needed for your epilepsy was only clinically trialled on men. Imagine if that medicine was tested on pregnant animals and known to be teratogenic, the Department of Health was advised, but you as a disabled woman were never told. Imagine if you got pregnant and your baby died, or was permanently harmed because of this medicine, but you were never told that. Imagine you as a disabled woman, taking your disabled child to the doctor's or specialists, and told nothing was wrong, or it was down to your parenting style. Now imagine as a woman trying to have faith in the health system or the health care professionals who you are meant to trust with your life. Our disabled women come into the health system with a heavy weight on them, and for our Fetal Anticonvulsant Syndrome community we do not need to imagine, this is our reality!

This submission has been written by Denise Astill, Founder, Executive Officer, and Trustee of Foetal Anti-Convulsant Syndrome New Zealand, a charitable organisation that provides support, education, awareness, and prevention of Fetal Anticonvulsant Syndromes (FACS).

FACS is an umbrella term relating to a range of conditions whereby an unborn foetus is negatively impacted when a childbearing person took anti-seizure medicines while pregnant (often without receiving full informed consent or informed choice). While mainly taken to prevent seizure disorders, anti-seizure medicines are also prescribed for mental health conditions, migraines and pain management.

Some of the ways the person exposed to the medicine could be affected include: dysmorphic facial features, congenital malformations, developmental delay, neurodevelopmental difficulties, attention and memory difficulties, lower IQ, Autism Spectrum Disorder, speech and language difficulties, gross and fine motor difficulties, low muscle tone, or even death.

There are approximately 20 anti-seizure medicines available in New Zealand, with each of these anti-seizure medicines having different impacts on a developing foetus, or some just not known for the effects.

The anti-seizure medicine sodium valproate, carries the highest risk of up to 40% of babies exposed during pregnancy having developmental delays.

Approximately 338 babies would have been harmed due to sodium valproate exposure during pregnancy between 2007-2019, of which over a third would have been Māori. This does not include those babies that would have died during this time period. Sodium valproate has been available in New Zealand since 1975.

As at 17 June 2023, ACC had spent over \$17.5 million supporting babies, children, and adults affected by exposure to sodium valproate or carbamazepine during pregnancy. Of the 42 claims accepted only 4 were Māori, and 6 were of Pacific, Asian, or Other ethnicity.

Systemic failures have lead us to the place we are today with individuals, and whānau being harmed by exposure to anti-seizure medicine(s) during pregnancy.

With this in mind whilst FACSNZ is primarily focussing on our FACS community, we will be addressing other areas as well. Additionally please refer to our *Addressing the past, present, and future for people of childbearing potential on anti-seizure medicines*, February 2023, document for more information.

The 5 I's Framework

Charlotte Korte, Kat Gibbons, Denise Astill, and Sue Claridge; The Five I's Framework. Consumer Advocacy Alliance is absolutely endorsed by Foetal Anti-Convulsant Syndrome New Zealand for the Women's Health Strategy. In fact, we would like to pull out the Intergenerational aspect and elaborate more.

The harm caused by exposure to anti-seizure medicines in pregnancy has caused intergenerational harm, on more than one level. If we address it from the fact that the childbearing person hasn't been fully informed about their medicine and the affects it could have on an unborn baby, just imagine the guilt that that childbearing person has. This is a guilt that is sometimes outwardly visible, or internally dormant, but it is always there. Often, they blame themselves for what has happened to their child. Then put on top of this that the professionals might blame the parenting style. The person loses all trust in the system, the system that they must work with. This is then echoed into the individual with FACS. So now you not only have compounded harm to the childbearing person, but you also have intergenerational harm occurring. How will we break this cycle? Have a look at the 5 I's to see how we can start to address it.

On a side note, there is research just in its infancy indicating that the person that has been affected by the exposure to the anti-seizure medicine(s) in pregnancy could then pass some of the difficulties onto their own biological child. Imagine if you are the childbearing person, what a legacy to leave that you are now affecting the grandchildren, by not being given informed consent or informed choice.

Future:

For the future of a women's health strategy there needs to be a whole life cycle approach. Currently there seems to be almost a shame of talking about perimenopause and menopause, yet people quite happily talk about Viagra! Perimenopause and menopause are just an example of what needs to be in a whole life cycle approach. A lot of our community is on lifelong medicines, so we need to be having expert advice around perimenopause and menopause and what to expect, yet when a person in our community raised with a (male) neurologist about this topic, he simply dismissed it and said you don't need to worry about that. That person got catapulted back to the trauma she experienced when she asked about if her medicine would be safe in pregnancy, and the lack of informed consent and everything that occurred after that point.

There needs to be a restorative approach designed for not only the individual cases, but for group situations, such as what happened with mesh, and FACS. There are going to be more future group situations and the design needs to happen now. It is causing more and more trauma for those already traumatised, by not having this option available.

The consumers with lived experience or experts by experience need to be around every table, co-designing, and officials adhering to the World Health Organization's "Global Patient Safety Action Plan 2021-2030", and the Code of expectations for health entities' engagement with consumers and whānau.

FACSNZ would love to one of the organisations around the table, co-designing and providing an oral submission to Manatū Hauora.

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

