

**Foetal Anti-Convulsant Syndrome NZ
(FACSNZ)
written submission to
Governance and Administration Committee
on Plain Language Bill**

29 March 2022

Firstly, we would like to commend the intent behind the Plain Language Bill and would state that it is necessary.

Fetal Anticonvulsant Syndrome (FACS) is an umbrella term relating to a range of conditions whereby an unborn foetus is negatively impacted by the child-bearing person taking anti-seizure medicines while pregnant.

While mainly taken to prevent seizure disorders, anti-seizure medicines are also prescribed for mental health conditions, migraines and pain management.

Currently in New Zealand a lot of childbearing people who are pregnant and taking an anti-seizure medicine are doing so without informed consent.

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

Our FACS tamariki are exactly the sort of people who are going to benefit from this Plain Language Bill.

Part 2

Plain language requirements

6 Relevant documents to use plain language

(2) **Subsection (1)** applies only to relevant documents issued or revised after this Act comes into force.

We would like to state that all of the websites that are specified under Subsection (1) should be updated. Ideally all current Bills/Acts/legislation etc would be updated, however this probably is not realistic, so whenever Bills/Acts/legislations are being reviewed/amended the old Bill/Act should be updated into plain language at the same time, allowing submitters to understand what the old Bill/Act said. Also, when there are disabled people known to be trying to interpret legislation not in plain language that is to be put into plain language. The perfect example of this would be the Loss of Potential Earnings legislation that directly relates to our FACS tamariki who are eligible under ACC.

7 Plain language guidelines may be issued

There needs to be the removal of the word “may”. Words open themselves up for interpretation and the use of the word “may” is a great example of this. Instead the word “will” should be used.

(2) We would like to ensure that one of the people being consulted with is disabled people, and those who will benefit most from this Bill.

10 Compliance reports

(1) The use of guidelines is problematic as they are not enforceable. A perfect example of when good guidelines go wrong, is the “guidelines” around sodium valproate (Epilim) use in pregnancy. If a medical profession is not following the guidelines they do not have any enforceable repercussions.

We recommend that there is an enforceable element to the Bill, so that agencies cannot opt out of doing the “guidelines”, or just get away with doing the bare minimum.

An additional comment here is that currently agencies, such as the Ministry of Health (Manatū Hauora), have 60 working days to respond to Recommendations put forward to The House from a petition committee, however there is no repercussions for an agency that does not comply to this timeframe. An example is that we are still awaiting a response to the Health Committee’s recommendations that went to The House in August 2019, from the Ministry of Health. This is why there needs to be an enforceable element to the Bill.

11 Other enactments not affected

We would like Te Reo and New Zealand Sign Language part of this Bill. This is not saying that it would replace any other Acts listed under **11**, it is just saying that there are people within the Māori and the deaf and hard of hearing communities, that would hugely benefit from having accessible, plain language, in their first language. Based on this we would recommend that there is access in English, Māori, and New Zealand Sign Language.

If there is an opportunity for an oral submission we would like to present.