



Read our CEO **Jonny Wilkinson's** regular column in The Northern Advocate

"A Different Light"

A Different Light - 8 May 2021 "Let's be kind – and that includes you Pharmac"

Unintended consequences can occur when one tries to make a single change within a complex system, thereby instigating an outcome one didn't expect or necessarily want.

This can range from the trivial and domestic, such as trying to make bacon crispy by frying it on a high heat and then charring the whole lot into an inedible burnt offering, (thinking of a personal recent misadventure), to a historical event such as when the English colonial rule in India offered financial rewards for people who killed and turned in cobra snakes. The locals, reacting to the incentives, began breeding the snakes, in order to cash in on the scheme. Once the reward program was scrapped, the population of cobras in India rose as people released the ones they had raised.

So when Fiona Tolich, a Patient Advocate, took a case to the Human Rights Commission, she unfortunately encountered a negative unintended outcome. Tolich who has Spinal Muscular Atrophy (SMA), has made it her mission to make Spinraza, (a drug that is highly effective on the treatment of that condition) freely available in New Zealand, as it is in Australia and 56 other countries. She thought she had found an inconsistency in Pharmac's funding regime that would give her some leverage, some comparison in which she could argue her case. She realised that there was a Pharmac policy that stated "hospitals may give and will be eligible to receive a subsidy for, any pharmaceutical for use within a paediatric oncology/haematology service for the treatment of cancer." She thought she was onto a winner. She thought she had the grounds to go the Human Rights Commission and argue that Government was discriminating against children with SMA by not funding the drug. This however was not the outcome.

To Tolich's horror, Pharmac's response was not to raise the eligibility of drug funding to include children with SMA but to review the blanket funding of kid's cancer drugs and to potentially decrease access to new cancer drugs for children.

Tolich who has been campaigning for Pharmac to fund it for three years, felt her plea for SMA children to be granted access to life saving medicine was being met with a threat to take treatment away from children with cancer.

Pharmac says it has long viewed the special exemption for child cancer drugs as “inconsistent” but that it was jolted into finally addressing the issue in response to the discrimination claim taken under the Human Rights Act. It said no final decisions had been made but the most likely outcome of its review would be that it would bring child cancer drugs into the normal Pharmac process. They stressed that no current medicine used by child cancer patients would be taken away. However, the inference is that blanket funding for drugs for children with cancer may be scrapped in the future. This is a shockingly inhumane response to restoring equality of treatment, an unwanted and unintended consequence of the worst type. It is the type of consequence that acts as a veiled threat for activists and advocates seeking fairness of treatment and services.

The Disability community has for some time been pointing out the inequality between services people get from ACC if their disability is caused by an accident or injury when compared with the support services they get from the Ministry of Health if their disability is genetic or as a result of a medical condition. This is a stark contrast. It's like day and night, with ACC providing timely, gold-plated services and equipment while those dependent on the Ministry of Health for disability supports face waiting lists and limited options. It makes me wonder- if this issue is pushed harder or indeed makes its way to the Human Rights Commission, whether ACC Disability Supports would simply decrease to be in line with the Ministry of Health. A level playing field is all well and good so long as elevation is used as the leveller and not a downhill slippery slide into the abyss.

Advocates should not be placed in this unenviable position of potentially seeing services and options diminished as a result of their mahi. Let's hold our health services to a higher standard rather than bringing things down to the lowest possible denominator. In other words, as we have been repeatedly told-let's 'Be Kind'-and that includes you, Pharmac!

Jonny Wilkinson is the CEO of Tiaho Trust - Disability A Matter of Perception, a Whangarei based disability advocacy organisation.