From: s 9(2)(a) <s 9(2)(a)>
Sent: Monday, 28 November 2022 12:28 pm
To: Consult
Subject: Fwd: Pharmac consultation: proposal to amend Pharmaceutical Schedule Rules on prescribing and dispensing of Class B controlled drugs

You don't often get email from s 9(2)(a) Learn why this is important

Hi,

I'd like to add, as someone who's prescribed methylphenidate, that shifting to 3 monthly scripts with monthly dispensing will save a lot of money for many patients.

Some GP's I've been charged between $10-$40 per month to have the script created/repeated, so having this shit to 1 script per 3 months will reduce my GP fees by two thirds.

Cheers,
s 9(2)(a)

---------- Forwarded message ---------
From: **Te Pātaka Whaioranga - Pharmac** <consult@pharmac.govt.nz>
Date: Mon, 28 Nov 2022 at 08:59
Subject: Pharmac consultation: proposal to amend Pharmaceutical Schedule Rules on prescribing and dispensing of Class B controlled drugs
To: <s 9(2)(a)>

View this email in your browser

Pharmac consultation: proposal to amend Pharmaceutical Schedule Rules on prescribing and dispensing of Class B controlled drugs

Kia ora

Please follow this link to the Pharmac Consultation regarding proposed changes to the Pharmaceutical Schedule Rules on prescribing and dispensing of Class B

controlled drugs.

Pharmac welcomes feedback on this proposal.

To provide feedback, please email consult@pharmac.govt.nz by **5pm on Friday 9 December 2022**.

Please circulate this email to others who may be interested.

Ngā mihi,

Belinda Ray-Johnson | Schedule Development Manager

Pharmac | Te Pātaka Whaioranga | PO Box 10 254 | Level 9, 40 Mercer Street, Wellington | P: 0800 660 050 | www.pharmac.govt.nz

From: s 9(2)(a)
Sent: Thursday, 1 December 2022 5:55 pm
To: Consult
Subject: Proposal to amend Pharmaceutical Schedule Rules on prescribing and dispensing of Class B controlled drugs - Response

s 9(2)(a)

get email from s 9(2)(a) Learn why this is important

Dear Pharmac

I am writing in support of your proposal to amend the PSR rules on the prescribing and dispensing of Class B controlled drugs.

In this instance, I am writing, not as a service provider to Pharmac, but has as a consumer representative.

I am/have been the main care giver of s 9(2)(a) s 9(2)(a) s 9(2)(a) s 9(2)(a).

s 9(2)(a) been on other unit-dose packaged medicines prescribed in three monthly lots, and sent to us monthly. This works beautifully. Requires little intervention by myself, the pharmacy and the doctor.

Managing the morphine however is time-consuming and difficult. The pharmacy needs to constantly ring me and ask me to ring the doctors and get another morphine script, I have diarised the days I need to ring and get supplies for the Xmas shut period.
As an former pharmaceutical wholesaler and s 9(2)(a), I need to be on my game to make sure it all works smoothly! I really fear for families who do not have my experience in this area.
The extra work for me, the pharmacy, the practice nurse and the GP is just staggering.

Reconcile it! Lets get the morphine delivered with everything else – please.

s 9(2)(a) is totally reliant on this morphine to control the misery of end-stage heart failure and the resultant shortness of breath. He worries that the morphine delivery will be late or will not come. It is an added stress he does not need.
I don't need another thing on my to-do list 😉

Many thanks for your consideration.

s 9(2)(a)
s 9(2)(a)
P s 9(2)(a)
E s 9(2)(a)
A s 9(2)(a)
s 9(2)(a)

From: Kent Duston <[redacted]>
Sent: Monday, 12 December 2022 4:38 pm
To: Consult
Subject: Submission on the proposal to amend Pharmaceutical Schedule Rules on prescribing and dispensing of Class B controlled drugs
Attachments: Aroreretini Aotearoa - Submission on changes to Schedule rules on Class B drugs.pdf

You don't often get email from [redacted] Learn why this is important

Kia ora,

Our submission on the proposal to amend Pharmaceutical Schedule Rules on prescribing and dispensing of Class B controlled drugs is attached.

Ngā mihi,

Kent Duston
Co-convener

e: [redacted]
m: [redacted]
w: www.aroreretini.nz

Aroreretini | Aotearoa

The adult ADHD advocacy organisation

Arorereti ni | Aotearoa

The adult ADHD advocacy organisation

This is the submission of Arorereti ni Aotearoa on the Proposal to amend Pharmaceutical Schedule Rules on prescribing and dispensing of Class B controlled drugs

This submission is made on behalf of Arorereti ni Aotearoa. We are a voluntary policy advocacy organisation working on behalf of adults with ADHD in Aotearoa.

Context

According to overseas research and evidence from the Dunedin Longitudinal Health Study, ADHD is a condition that affects 5%-7% of the adult population. It is characterised by different brain chemistry and topology, brought about by lower than median levels of dopamine. Adults with ADHD face a variety of challenges in a neurotypical world and bring a unique set of skills and capabilities to society. While many adults with ADHD struggle with focus and task completion, we also bring innovation, creativity and energy to the many roles we fill in Aotearoa.

ADHD is identified in DSM V as a disorder; as a community, we prefer the Te Reo term Arorereti ni, which means, mind on many things. We see ourselves as neurodiverse rather than "disordered", and take exception to being stigmatized by far too many in the Health sector by the use of the "disorder" label.

Our community routinely suffers from a lack of understanding and a lack of compassion from people who do not have the requisite knowledge of ADHD. We are told that ADHD is the result of too much sugar, or too many video games, or of poor diet or inadequate parenting; we are told ADHD isn't actually a thing, or that it is merely a quest for attention, or represents a lack of willpower or perhaps a deep-seated flaw in our characters.

None of these things are true. If we take a person with ADHD and put them in an MRI machine, there are structural differences in brain structure and blood flow compared to neurotypical people. The Mātai Medical Research Institute in Tairāwhiti under Professor Justin Fernandez is conducting research using state-of-the-art imaging systems and software that identify exactly how ADHD brains respond differently to neurotypical brains – and those changes are visible on the screen, in real time. These differences are apparent in the real world, not merely in our imaginations.

Our interactions with the Health sector

Unfortunately, the Health sector in Aotearoa has an exceptionally poor record of interaction with neurodiverse communities. The sector:

- Routinely talks *about* us instead of *to* us, and engages in policy initiatives without the input of ADHD New Zealand, ourselves, or any of the plethora of advocacy groups
- Fails to have any neurodiversity requirements within its staffing, which is particularly acute in policy and operational policy areas, resulting in systemic organisational and legislative biases against neurodiversity
- Has failed to follow the international leads on the diagnosis, treatment and support for the ADHD community, particularly new policy directions from Australia and the UK
- Does not have a joined-up approach to diagnosis or treatment pathways, few if any work plans for addressing the systemic challenges, and a track record of inaction.

The experience of the Health sector by many in the Arorereti ni community is highly negative. We have struggled to get referrals for assessment, are regularly and repeatedly refused diagnosis by DHBs, are forced into private diagnosis pathways strewn with high costs and access issues, and then forced to observe a

prescription and dispensing process which is intentionally punitive and not fit for purpose – all because we are neurodiverse. To us, too many of the current processes aimed at the Aroreretini community by the Health sector smack of bigotry.

The impact of the Class B classification on the Aroreretini community

As Pharmac is aware, the front-line medications for ADHD are all Class B drugs. There is no objective reason for this classification, as is widely acknowledged – the Class B classification was simply the result of a moral panic in the 1990s, which the Ministry of Health has failed to rectify for 25 years.

However, the Ministry's unwillingness to address this systemic failure places a very substantial financial and logistical burden on the Aroreretini community. In fact, our community pays the greatest price and suffers the greatest administrative overhead from the current classification and prescribing arrangements – based on the Ministry's Pharmaceutical Data Web Tool, more than 40,000 people are forced to get monthly prescriptions from their GPs and have them dispensed on a monthly basis. This archaic and bureaucratic system costs the country more than $100 million per annum in direct and indirect costs.

This is a ridiculous state of affairs. As was noted by Police at the recent trial of Dr Tony Hanne, methylphenidate is not the subject of any law enforcement interest, and in the words of the Police witness is "not on their radar". Neither the Ministry of Health nor anyone else has ever presented evidence that methylphenidate is the subject of widespread abuse in Aotearoa.

The number of people in the Aroreretini community accessing methylphenidate vastly outweighs all other patients receiving Class B drugs put together. On the basis of equity alone, the impact of the proposed changes to the Pharmaceutical Schedule Rules on prescribing and dispensing of Class B controlled drugs on the Aroreretini community should therefore be paramount to all other concerns.

We wish to make the following recommendations

From the perspective of decreasing the costs and complexities of obtaining access to methylphenidate, the changes proposed by Pharmac are welcome and bring the Rules into line with the Regulations. This represents a small but useful reduction in the excessive bureaucratic overhead associated with being neurodiverse in Aotearoa.

However, we are very concerned about the slowness of implementation. The unnecessary delay between the Regulations coming into effect on 22 December and the Pharmac Rules coming into effect on 1 February will:

1. Cause more than 40,000 additional methylphenidate prescriptions to be written, due to the need to meet the current one month restriction before the revised Rule comes into effect
2. Cause an additional cost and productivity burden on the Aroreretini community and the primary health sector, without any countervailing benefit
3. Cause some in the Aroreretini community to lose access to their medication over the January period, due to smaller GPs being closed or unavailable during the holiday period and unable to provide a prescription, with consequential impacts on health and wellbeing.

The reasons Pharmac offers for the delay do not justify the impacts on the Aroreretini community.

Pharmac provides no evidence to back its assertions that there will be insufficient stocks of methylphenidate on hand, or that pharmacies will need to review their stock holdings. Given the 40,000 monthly prescriptions dispensed across the country on a monthly basis, it is clear on a *prima fac*ie basis that there are no supply chain or logistical constraints on aligning the Rules with the Regulations.

The only remaining obstacle is the apparent requirement for Pharmac to allow "sufficient time for technical and system changes to occur". Whatever these are, they are clearly not sufficient justification in themselves to negatively impact the lives of 40,000 New Zealanders. Pharmac was presumably consulted on the changes to

the Regulations at the time they were being developed by the Ministry of Health, so by any reasonable standard has had adequate time to make the required “technical and system changes”.

Accordingly, our recommendation is that the Rules are aligned with the Regulations, and that the changes come into effect on 22 December 2022.

Kent Duston
Co-Convener
Arorereti ni Aotearoa
e: s 9(2)(a)

From: Lucy King <s 9(2)(a)>
Sent: Wednesday, 21 December 2022 1:46 pm
To: Consult
Cc: Trevor Simpson
Subject: Pharmac Consultation on Controlled meds closes 5pm 21st Dec 2022
Attachments: Consultation.pdf

You don't often get email from s 9(2)(a) Learn why this is important

Dear Pharmac

Please find attached the submission from ADD Information Service on Controlled medicines on three monthly scripts as per the November 2022 legislation change finally ending paid monthly scripts for stimulant medication.

We are asking for people to be treated the same consideration and support as others are re meds pick ups.

SIncerely

Lucy King
Research Assistant
With
Robin Wynne-Williams
www.addinfo.org.nz

PS CC to Trevor Simpson to hear about some related Māori initiatives from as long ago as 2003.

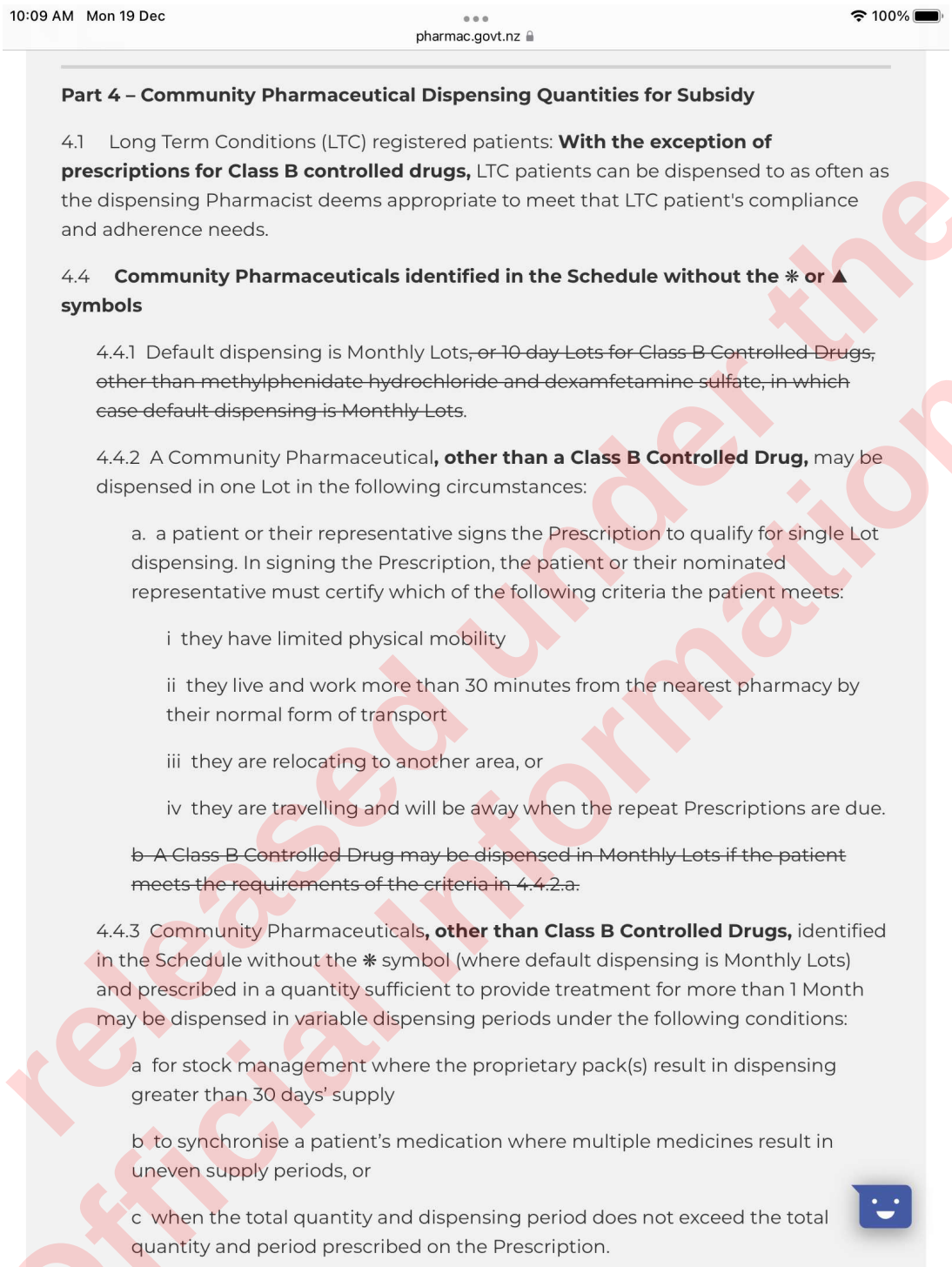
ADD Information Service
www.addinfo.org.nz/history
Research assistant Lucy King
B Forestry Sc Hons, Dip Ag Sc, Grad Dip ECT
s 9(2)(a)

Pharmac Consultation
WELLINGTON

To Whom it May Concern

Re this consultation
https://pharmac.govt.nz/news-and-resources/consultations-and-decisions/2022-11-28-proposal-to-amend-pharmaceutical-schedule-rules-on-prescribing-and-dispensing-of-class-b-controlled-drugs/

The salient point is the edits proposed as below that we oppose.



Reason is people needing controlled meds are already at a disadvantage and this acts to undo some of what parliament has tried to do in improving their dignity in their communities. Making people stand

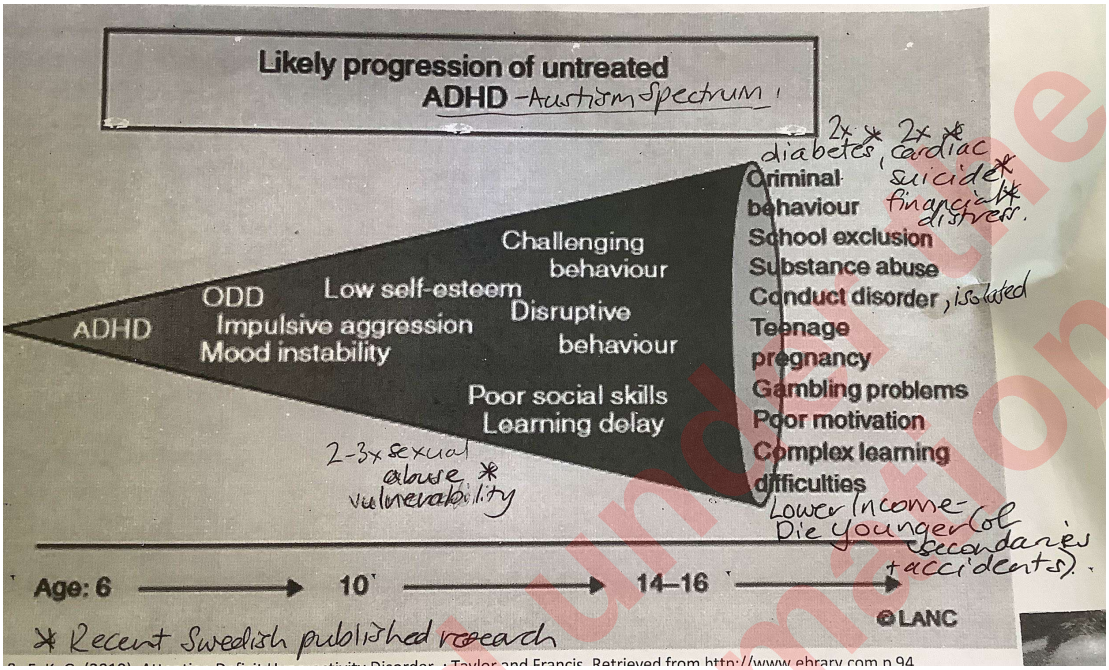
out like this is out of line with overseas and unsympathetic and makes no one safer eg even from burglary if their workmates know they need time off to get to the pharmacy. Pharmacists can decide as for any other med in Canada about pickups respecting personal circumstances. GP/NP scripts are annual not even three monthly (pers comm www.caddra.ca) with a wider range of meds and far fewer barriers, because state govts have decided they want to treat ADHD eg GPs have Vyvanse/lisdexamfetamine slow release (FDA approved for binge eating) (1).

Other mahi for Pharmac/Medsafe is to review why outdated DSM4 is still on chem forms like SA1965 that restricts quality Concerta (with alza pump) severely AND EXCLUDES autism specifically?(2).
Autistic/ADHD/Takiwātanga can be reasonably be seen as one person rather than a series of DSM boxes in te ao Maōri so using DSM4 is offensive (3,4).

Māori already have tipuna who know how to really include people with autism/ADHD/takiwātanga. Meng Foon notices “Māori are speedy and effective when responding to an emergency.”
https://www.hrc.co.nz/news/recognising-maori-resilience/
He iti he pounamu.
Takiwātanga is part of everyone’s whānau whānui, shared traits passed down (2). Tipuna knew about it we know from the Māui stories that come to us from tangata moana (Pasifika) before the kōrero came here (see Gavin Bishop’s (Ngāti Mahuta ō Tainui, Ngāti Pūkeko ngā hapū) book called ‘Atua’ about Māui).

So undignified rigid rules for real people, on controlled meds, might be harmful.
What parliament has passed as law (Nov 2022) should not be undermined by any Pharmac/Medsafe policy additions that do not really save any money even for Pharmac anyway. We have enough problem with the two yearly renewals, that appears to be just Medsafe Pharmac policy not law already, making people lose effective meds and be unable to restart them as adults. (See PS at end).

Below is a simple summary of what people are going through in education now, see the detail in the big research consensus statements on ADHD (alone without including the autism) that includes one titled "Live fast, die young" (5-10).



If Medsafe/Pharmac really does not WANT to allow ongoing stimulants for teens and adults then cut the whole diagnosing industry and just allow both non stimulants atomoxetine AND ALSO GENERIC GUANFACINE XR be funded at the GP/NP, better than nothing. Stop the diagnosing. See www.caddra.ca meds chart to compare here with there and the doses given out here are too low.

Right now ADHD is confined to 'mental health' though MOH admits it is neurodevelopmental difference, but law states neurologists cannot initiate the meds. This supports the idea autism/ADHD is illness. Patients are meant to hide to mask and to 'grow out of it' as evidenced by the lack of adult services in the whole South Island. But Robin Wynne-Williams nurse says "I haven't seen too many grow out of ADHD and autism."

"It is entirely due to evolution."

"My patients like it when I say "Your brain isn't wrong."

It's just the environment doesn't suit it. It's like a square peg in a round hole.
ADHD Meds rub the corners off the square peg a bit and make it a bit more round."

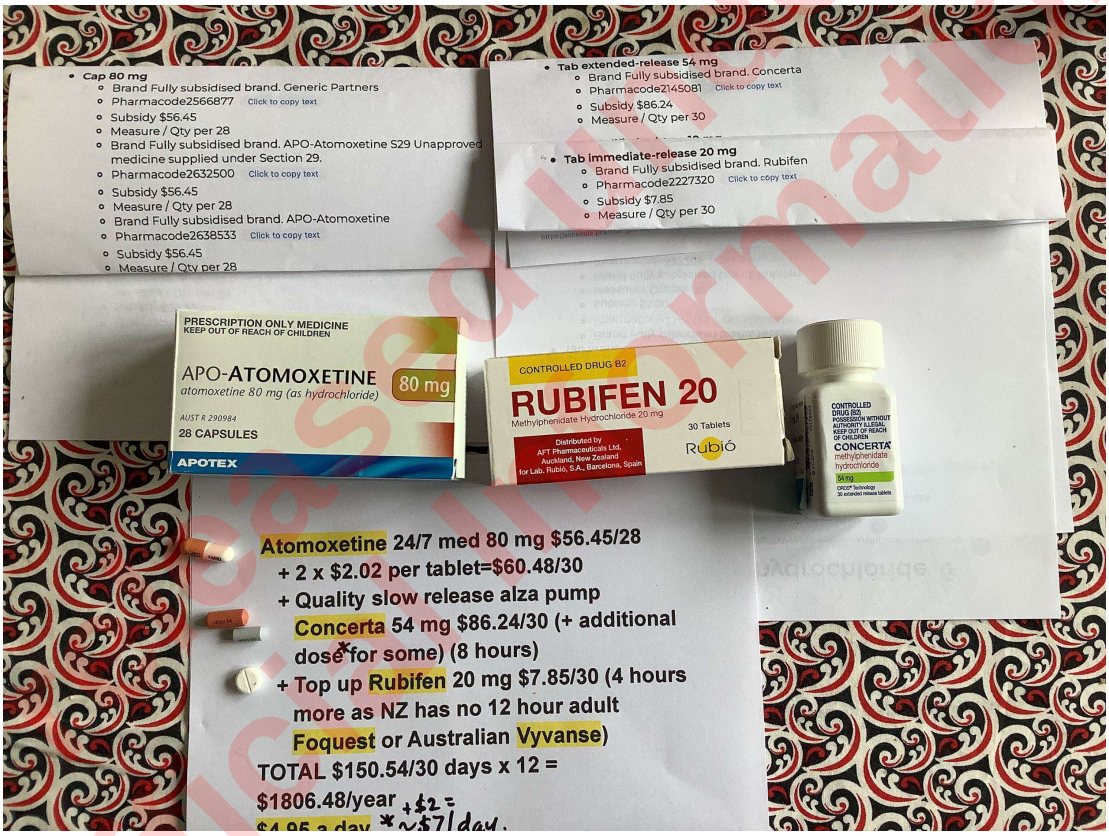
Pharmac/Medsafe staff, Trevor Simpson especially, might consider Te Tiriti and existing Māori initiatives, with nurse Robin, started in 2003 by the late Dr Leo Buchanan, (Te Atiawa, Taranaki), paediatrician and founder of the Māori section of the specialists, chair of his Parihaka iwi tenths trust at his death (see "Kō Taranaki te Maunga" BWB books authored by his daughter Dr Rachel Buchanan, and here . https://www.rnz.co.nz/national/programmes/teahikaa/audio/2018669518/dr-rachel-buchanan-the-shame-of-parihaka-is-so-great-it-can-never-end The Māori initiative of a whānau community clinic with nurse preassessment (Robin) ended in 2014 and is described here www.addinfo.org.nz/history.

An attempt to continue the Māori initiative of whānau was made by NZNO in 2018 asking for prescribing rights (rejected, see Pharmac MH Minutes online) https://pharmac.govt.nz/assets/ptac-mental-health-subcommittee-minutes-2018-06.pdf.

Now in 2021 NZNO, before the parliamentary hui, produced a local aspirational policy one pager (11). It shows the steps to restart community care for Māori and other whānau for ADHD and autism eg it could be alongside rongoā Māori and mirimiri eg at Kahukura in Christchurch.

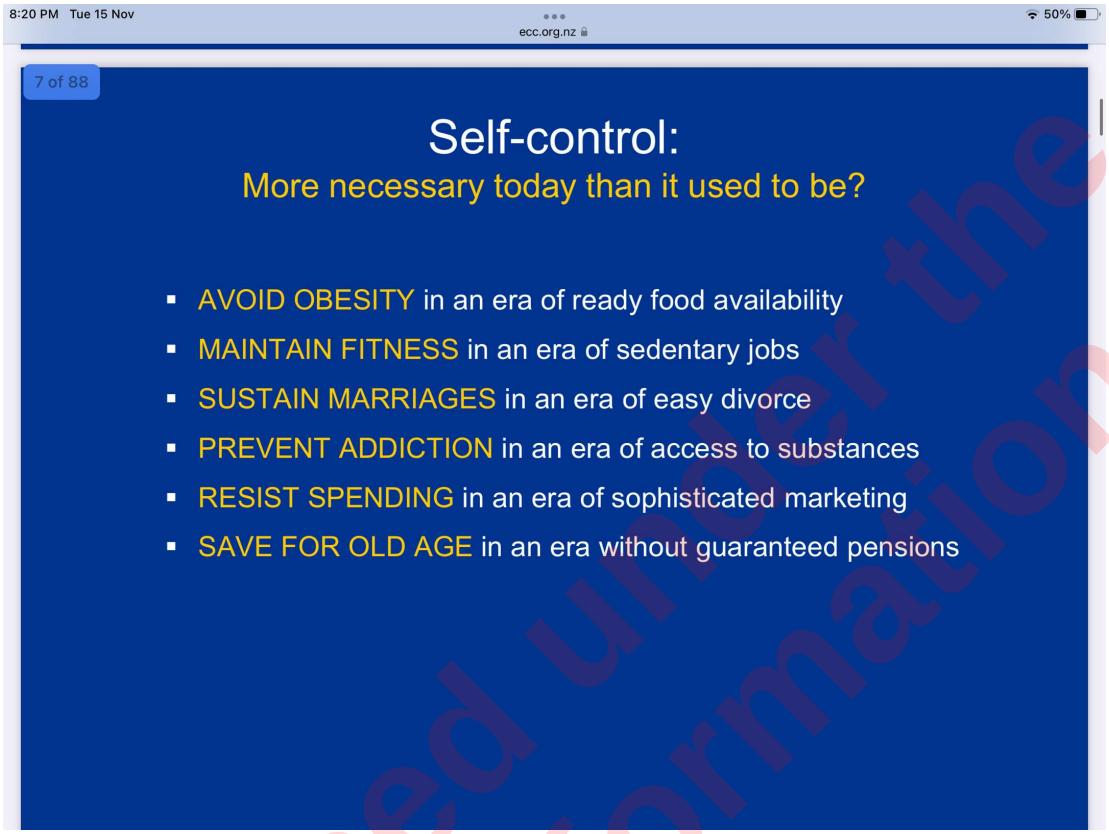
The Māori view is always holistic. "Māori don't put people in boxes." Kaumatua. It also happens to harmonise with the science, that autism/ADHD is heritable, is not 'preventable', is necessary, and highly variable, passed down so you are like your tipuna. It is NOT the result of 'gut health', computers, maternal behaviours like smoking etc etc (endless minor PhD's muddling cause and effect).

Optimised meds remain a tried and true safe highly effective accommodation to help people with this brain wiring really flourish in modern day life (12-14). No wonder big pharma doesn't want them accessible, they can sell more for more $. No wonder USA drug sellers don't want them, they can sell more for more $. No wonder CBT don't want them, they can sell other services and products for more $. Follow the money to know why meds are not accessed in good quality and price except if the people get organised. And so it is debated whether stimulant meds should still be controlled meds or whether that does more harm. Adequate meds combinations (seldom obtained in NZ, cost about $7/day) are much more effective than the other nonpharmacological treatments (14). For example this is possible but rare in Aotearoa for a successful rangatahi Māori of 75kg, 18 years.



We recommend the evaluating staff read the big consensus statements not just be swayed by experts if they have vested interests. Note epigenetics for ADHD and autism is not proven and if proven ever the effect size is tiny, in the 72 country consensus (6). Also read the whole pdf of the Dunedin study that linked low self control to ADHD to

executive function to health, wealth crime etc. As the Dunedin study's Prof Richie Poulton explains self control is more necessary than ever right now there is no longer a tiger around the corner (15).



"What the experts know and what the people at the bottom know are two different things." (K. Kahika).

What is true should come up many times in many places across time and ring true at the grass roots too. (Dr Russell Barkley sic, google who he is.)

NZ cannot afford not to go on treating ADHD adequately any more than other countries can (14). (Even poor countries like Spain treat more than here.) Significant epigenetics and effectiveness of CBT for ADHD is a NZ myth (see the 72 country consensus statement on epigenetics (10).

We oppose the added red tape and inflexibility of part 4 in this consultation on the basis of human rights and Māori rights, tino rangatiratanga.

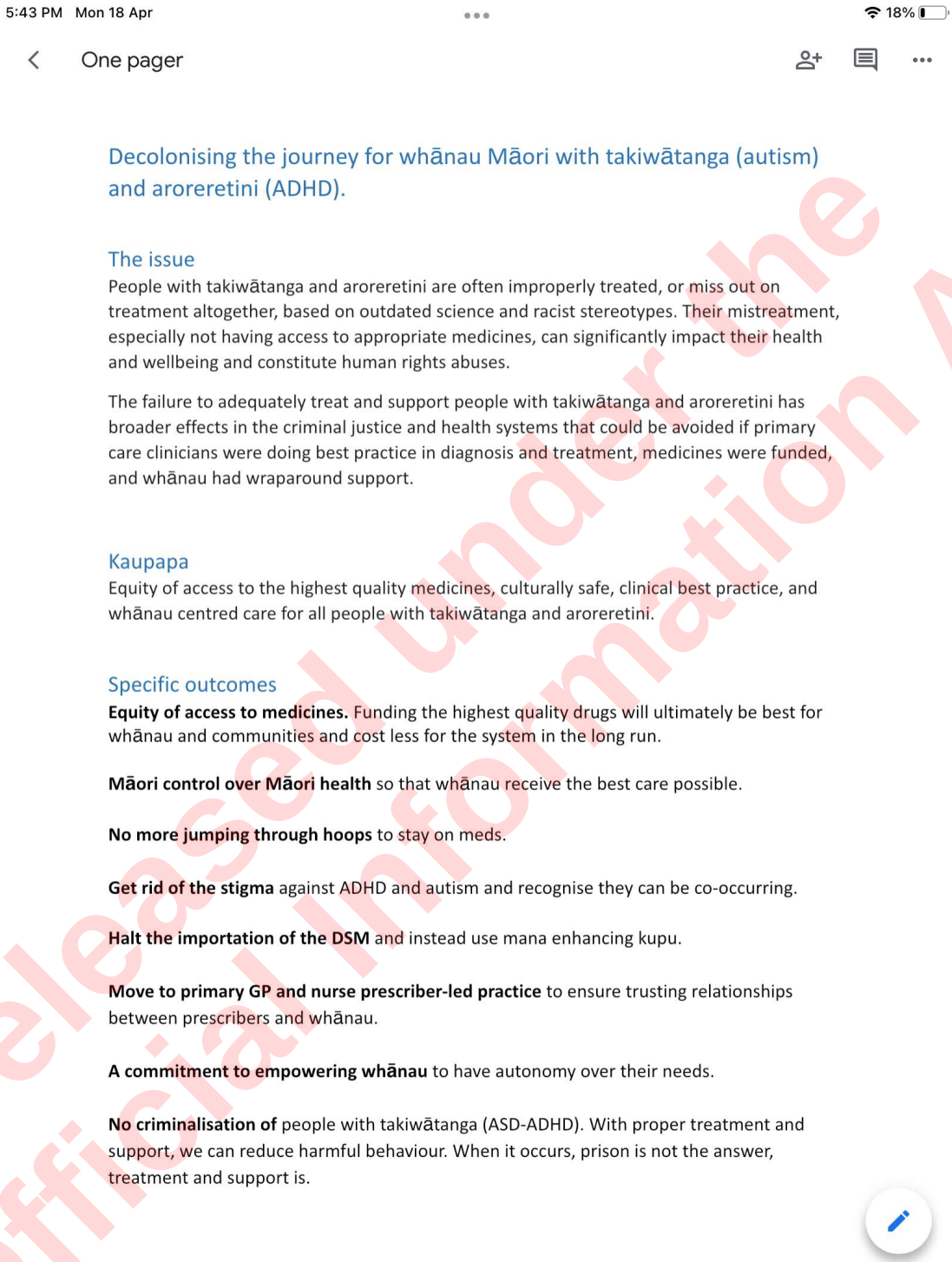
Ngā mihi nā

Lucy King
B Forestry Sc Hons, Dip Ag Sc, Grad Dip ECT
[redacted]
Research Assistant
With
Robin Wynne-Williams QSM
BSc Health Sc, RN/Obs, PG Dip Nursing, Tertiary Teachers Certificate.
ADD Information Service
www.addinfo.org.nz
Robin was working as nurse on the Māori initiative, a whānau community clinic, of paediatrician and founder of Māori specialists group, the late Dr Leo Buchanan (Te Atiawa, Taranaki), and of the late Dr Paul Taylor QSM, paediatrician, autism expert, author and parole board member you can see here https://youtu.be/YDmgSuKyk0w

FURTHER READING LINKS:

1. https://www.caddra.ca/provincial-and-federal-public-formulary-overview/ USA https://adhdrollercoaster.org/tools-and-strategies/home-delivery-stimulant-medications/
2. Concerta form https://schedule.pharmac.govt.nz/2023/01/01/SA1965.pdf
3. https://www.autismspectrum.org.au/about-autism/fact-sheets
4. Keri Ōpai pers comm. In time takiwātanga will cover much more. www.tereohapai.nz
5. https://pubmed.ncbi.nlm.nih.gov/30195575/ Live fast die young.
6. https://www.sciencedirect.com/science/article/pii/S0924933818301962 Updated 72 country consensus statement on adult ADHD.
7. https://www.sciencedirect.com/science/article/pii/S014976342100049X
8. https://pubmed.ncbi.nlm.nih.gov/29510390/
9. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3949159/
10. https://www2.deloitte.com/au/en/pages/economics/articles/social-economic-costs-adhd-Australia.html

11. Source: NZNO Māori policy unit. Contact: Kerri Nuku



5:43 PM Mon 18 Apr 18%

One pager

Decolonising the journey for whānau Māori with takiwātanga (autism) and arororeretini (ADHD).

The issue

People with takiwātanga and arororeretini are often improperly treated, or miss out on treatment altogether, based on outdated science and racist stereotypes. Their mistreatment, especially not having access to appropriate medicines, can significantly impact their health and wellbeing and constitute human rights abuses.

The failure to adequately treat and support people with takiwātanga and arororeretini has broader effects in the criminal justice and health systems that could be avoided if primary care clinicians were doing best practice in diagnosis and treatment, medicines were funded, and whānau had wraparound support.

Kaupapa

Equity of access to the highest quality medicines, culturally safe, clinical best practice, and whānau centred care for all people with takiwātanga and arororeretini.

Specific outcomes

Equity of access to medicines. Funding the highest quality drugs will ultimately be best for whānau and communities and cost less for the system in the long run.

Māori control over Māori health so that whānau receive the best care possible.

No more jumping through hoops to stay on meds.

Get rid of the stigma against ADHD and autism and recognise they can be co-occurring.

Halt the importation of the DSM and instead use mana enhancing kupu.

Move to primary GP and nurse prescriber-led practice to ensure trusting relationships between prescribers and whānau.

A commitment to empowering whānau to have autonomy over their needs.

No criminalisation of people with takiwātanga (ASD-ADHD). With proper treatment and support, we can reduce harmful behaviour. When it occurs, prison is not the answer, treatment and support is.

12. https://chadd.org/advocacy-blog/chadds-position-on-patient-access-to-adhd-medications/

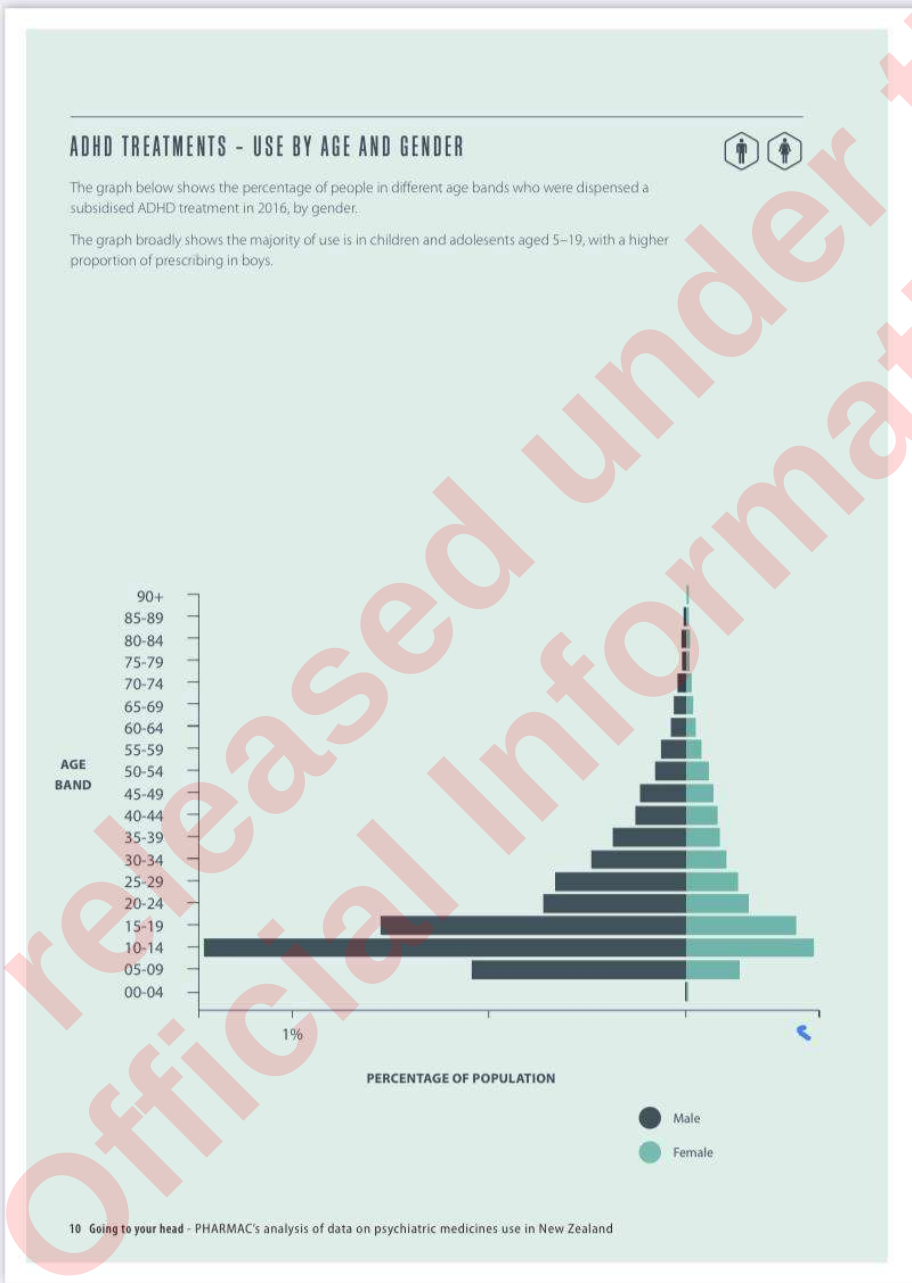
13. https://www.jneuropsychiatry.org/peer-review/addressing-common-misconceptions-about-attention-deficit-hyperactivity-disorder-in-adults-neuropsychiatry.pdf
14. https://apsard.org/are-nonpharmacologic-treatments-for-adhd-useful/
15. https://www.ecc.org.nz/Folder?Action=View%20File&Folder_id=349&File=KEYNOTE4Richie_Poulten.pdf
16. https://chadd.org/attention-article/adhd-and-life-expectancy-treatment-matters-more-than-you-might-think
17. https://www.additudemag.com/adhd-type-2-diabetes-health-link/
18. https://chadd.org/advocacy-blog/chadds-statement-at-the-public-meeting-on-patient-focused-drug-development-for-stimulant-use-disorder/

THE DIFFERENCE BETWEEN POLICY AND LAW:

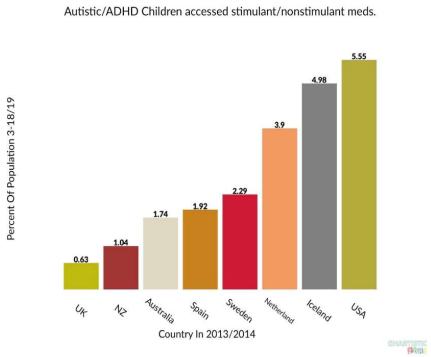
The two yearly renewals that appear to be entirely Medsafe/Pharmac policy not law have led to a LOT of people losing meds and being unable to restart them (see OIA 2022 Dec Medsafe reply. 2015 legislation specifies who can initiate most of the stimulant medicines (what happened 1999-2015 we asked). That is all. So it is Pharmac/Medsafe policy adding in two yearly psychiatrist/paediatrician renewals excluding the palliative specialists that would have allowed market forces to operate instead of a closed shop (and neurologists who asked for meds for brain injuries and the sleep specialists who asked Pharmac too as recorded in the minutes).

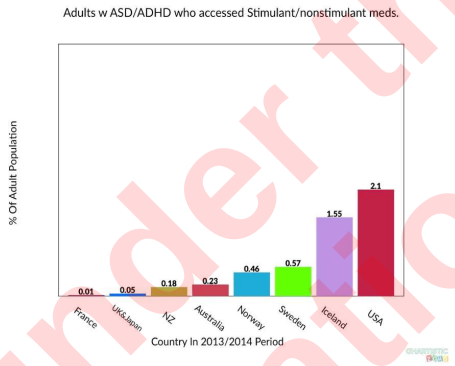
THE PERFORMANCE OF THE CURRENT SYSTEM $12M MEDS SPEND (2021).

The performance of the current system costing just $12M in medicines is terrible internationally, with few staying on adequate doses of meds for long it appears.



BEHIND NEARLY EVERYWHERE, FOLLOWING BRITAIN.





Sources: Pharmac and NZ Stats infoshare (population), Raman et al (Lancet Psychiatry Oct 2018),

Update to 2020 Pharmac data, the percent of population below is still low, compared to overseas even back in 2014.

Most recent data.	Children	Adults
France 2014	0.39	0.02
UK 2014	0.64	0.05
Japan 2014	0.65	0.05
Finland 2012	1.01	0.12
NZ 2014 3-19, 20+	1.05	0.18
NZ 2020 3-19, 20+	**1.61**	**0.36**
Hong Kong 2014	1.25	0.01
Denmark 2013	1.52	0.52
Taiwan 2010	1.54	
Australia 2014	1.74	0.23
Norway 2013	1.77	0.47
Spain 2014	1.93	0.11
Germany 2012	2.20	
Sweden 2013	2.30	0.58
Netherlands 2012	3.90	
Iceland 2013	4.99	1.56
USA 2014	5.56	2.11

What we need is more people continuing meds because no country can afford NOT to treat ADHD medically in this 5-6% with the most of it. Mostly new diagnoses get 'treated' with low dose monotherapy covering only a few hours, that are simply not kept up over time. Patient numbers don't look cumulative, as below, and yet like insulin if meds are stopped the benefit stops. Was the main benefit actually to the diagnoser receiving a few thousand tax dollars per person so why treat whānau together, it is too efficient.

Table: Number of Special Authority approvals for ADHD medicines

	2019		2020		2021	
Age	Initial	Renewal	Initial	Renewal	Initial	Renewal
0-4 years	42	1	38	1	33	
5-9 years	3,000	807	3,143	864	3,316	900
10-14 years	2,328	2,894	2,432	3,102	2,958	3,348
15-19 years	1,271	1,739	1,575	1,820	2,350	2,057
20+ years	4,109	3,845	4,950	4,359	7,695	5,188

The current system is clearly already too difficult to negotiate and NZ needs to show aroha to these patients and support three monthly scripts with the same rights for care as others get.

ADDITIONAL FOOD FOR THOUGHT:

Big pharma could be happy when old cheap ADHD meds are effectively locked up in a meds monopoly (turned down for neurologists, sleep specialists and nurses as seen in Pharmac minutes leaving only psychiatrists and paediatricians but ADHD is out of their league as it affects the whole body with complications, general medicine). MUCH MORE EXPENSIVE MEDICINE and devices like libre sensors $$$
The gangs could be happy as no stimulant medication means a big P industry $$$, Nicotine $$$ Caffeine $$$ Medicinal Cannabis is showing promise for overlapping autism and epilepsy see google scholar. But Self medication is unsafe.
Social sciences can expand and give employment in this robot age -$$$ Many helping jobs and graduate jobs and research lecturing and policy jobs are created from disadvantaged people.

But is using people right? Relationships matter not just life expectancy that is the main focus of research, and those at the bottom know ADHD/autism treatments help relationships and reduce violence and misunderstandings.

Note slow release stimulant lisdexamfetamine (Vyvanse) FDA approved to treat the associated binge eating for dopamine, (also used in UK prisons) was to reach a range of doctors like gastroenterologists, breaking up any psychiatry meds monopoly, but it will instead fall into mental health alone, if it is controlled at Medsafe (?at Pharmac request after discussion after these minutes which presumed it was already controlled…https://pharmac.govt.nz/assets/2021-09-Mental-Health-Subcommittee-record.pdf see last item lisdexamfetamine). It was actually released after 5 years' consideration to the full range of specialists as a prescription med by Medsafe 01/04/2021 to Pharmac yet someone sent it to Mental Health but not also the committee on diabetes.
This loss to general medicine will cost and cost. MH advisors should not advise that Vyvanse and methylphenidate are interchangeable as for 20% of patients they are not.

People are born with this genetics and now live in a modern (and indoor) environment that demands individual 'self control', less exercise, not as much iwi/tribe control. It's difficult sitting at school, and in adulthood 'coping mechanisms' start including substances/binge eating/risk-taking/arguing in place, worse with autism possible meltdowns depending on the stressors.

Whānau still face prejudice/judgement/intergenerational child removal rather than adequate ongoing medicine and accommodations with mana. While Māori children get medicated often (and are often in foster care) we see that is not the case if these fostered children try to return to meds as adults. 501 returnees/ram raiders are possibly missed or ceased ADHD care. Who asks this? https://link.springer.com/article/10.1007/s12111-016-9325-5 (The USA black school to prison pipeline).

Whānau experience risk of child removal from cultural misunderstanding in mental health, and judgement of family size, engagement with 'education' and resources, as it is not sympathetic unlike the experience of by Māori and for Māori and others kaupapa Māori services the Dr Leo Buchanan whānau model would allow.

Society is the beneficiary of the different ways of thinking ADHD/autistic people have, even if it does have its down side for education, income, and health. I feel your advisors should be pointing you to the huge consensus papers like this and others https://www.sciencedirect.com/science/article/pii/S0924933818301962 where you will see epigenetics for ADHD is not proven and of small effect size.

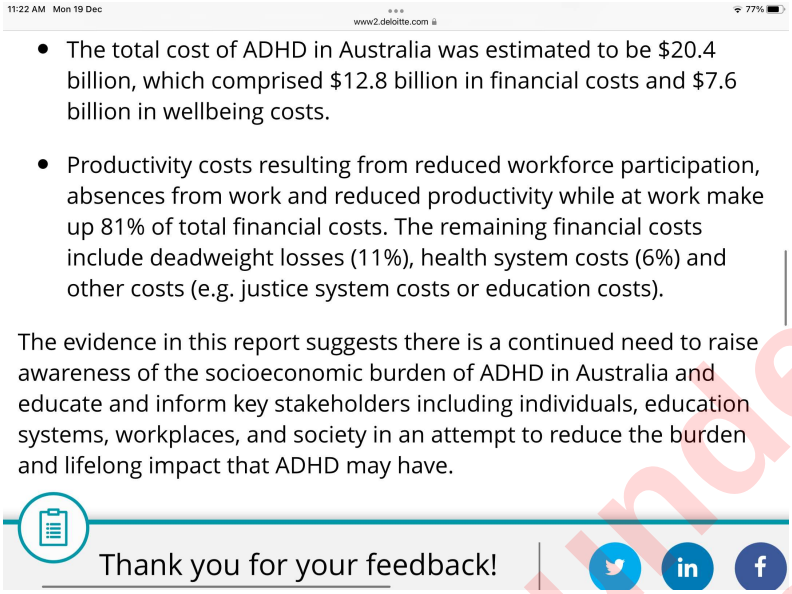
No one gets to choose whether they, of their siblings, are born more or less autistic/ADHD and actually need meds to function better in the current environment. Without meds it is hard to focus to reorganise restarting meds so strictly limiting monthly pickups and not helping people synchronise all their meds is wrong.

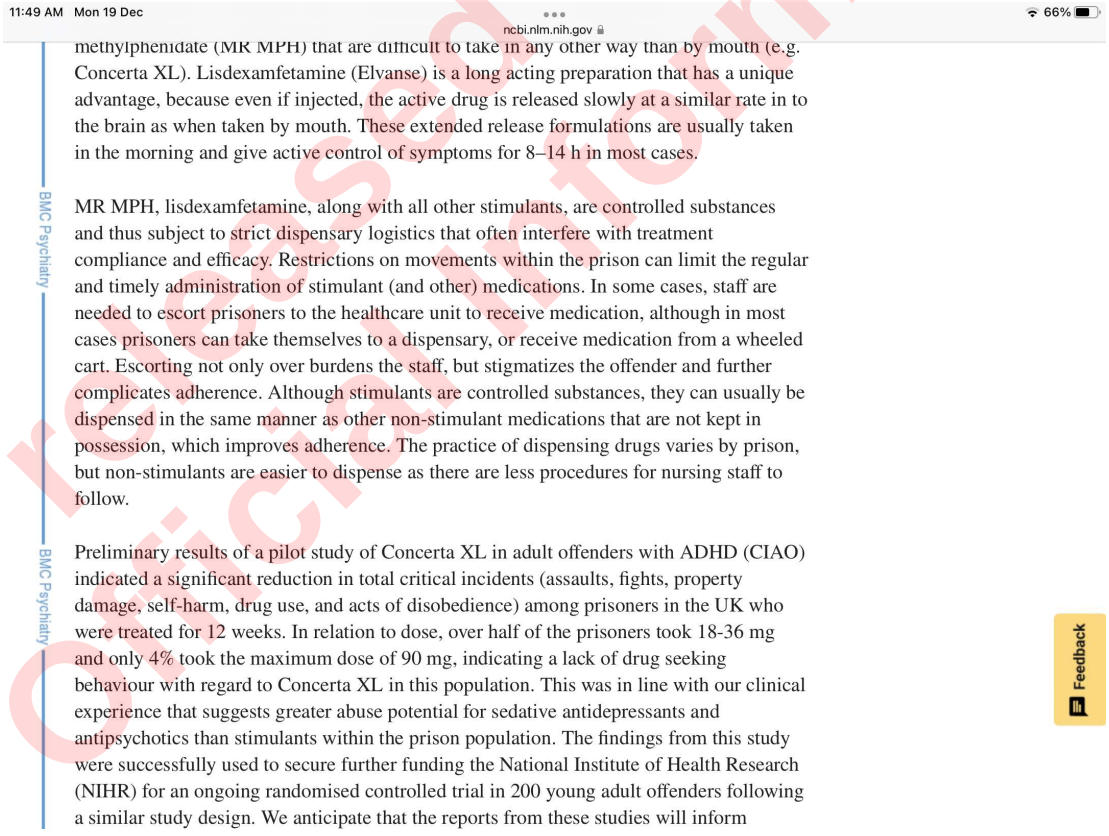
Basically improving relationships is what ADHD and autism controlled and uncontrolled meds combinations do if they cover enough hours for home. Research shows it. Whānau with a brain oriented towards survival NOW don't think long term, neurons connect differently, but they will challenge terrorist, stop a gunman, who is best then? Who gives the internet and updates it? These controlled meds increase the pause button and make people more able to live in nuclear family life we have now we are not often in tribes.

22,000/31,000 are on low quality stimulants. Number on typical adult doses shown in yellow. About 2500 adults. Cost $12M. This is the performance of the system we have now. No wonder it is rumoured in Aotearoa that ADHD meds don't work long term. No one much has them optimised nor is able to continue on them into adult years where they make the MOST difference. It is never too late to have a better life and a better family.

"ADHD"	2021	NZ		Pharmac	
Rongoā/Medicine	Dose	Price	People*	Cost	
			Medsafe	annual	/person
1. Concerta			*=monthly scripts/12		x12
Even release 8 hrs	18mg	$58/30	1291		$700
alza pump technology	27mg	$65	1373		$780
SA limits access	36mg	$72	2230		$860
hard to abuse	**54mg***	**$86**	**1997**		$1000+
stimulant			**6891 people***	**$6.46M**	
2. Atomoxetine			*=script/4		
High Quality	10-40mg	$18-29/28	1821		$300
nonstimulant	**60mg**	**$46**	**212**		$550
Generic 24/7	**80mg**	**$56**	**188**		$670
complementary med	**100mg**	**$58**	**95**		$700
open access (2020)			**2316 people***	**$1.1M**	
nonabusable					
3. Low Quality					
multidose	dex 5mg	$21/100	1462		$240
uneven release	Teva 18-54mg	$8-22/30	520		$100-260
old technology	Other 5-54 mg	$3-25/month	20 491		$40-300
abusable			**22 473 people***	**$3.85M**	
stimulants					
TOTAL*			**31 680 people***	**$12.43M**	
*people approx	(31428 in 2020)				
Note NZ has only 1 out of the 4 adult quality even release meds below. Canada has all in primary care.					
Foquest, and nonabusable lisdexamfetamine, guanfacine XR, are not here yet.					
ADULT DOSES are about 1 mg/kg Source: www.caddra.ca meds chart. Scripts annual picked up monthly.					
Source: Pharmac OIA 20221/2022 script numbers. Website: prices.					

A Deloitte Australian ADHD study says employers cop most of the bill for untreated ADHD, not schools or the government.





individual doses are missed. They are particularly useful for patients who have a rapid return of severe ADHD symptoms once stimulant effects wear off during the day. Additionally, non-stimulants are the medication of choice for patients with a previous history of stimulant abuse.

Pharmacological treatments for offenders with co-morbid conditions

In the presence of co-morbid anxiety, autism spectrum disorder (ASD), aggressive behaviour, or mild affective symptoms, ADHD should usually be treated first, followed by a careful evaluation of the medication's effect on the co-morbid symptoms. While adults with ADHD are reported to misuse drugs [50, 51], detoxification is provided by prison mental health services, and despite reports in the media about drug abuse in prison, there is no longer regular access to major drugs of abuse. Substance abuse is stabilised and under control in most cases in prison settings, so that diagnostic assessments and treatment for ADHD can proceed.

Symptoms commonly shared between ADHD and co-morbid disorders may be better managed with pharmacological treatments for ADHD rather than with pharmacological treatments for the co-morbid disorders themselves. For example, irritability and low mood symptoms secondary to ADHD are alleviated more effectively by ADHD medication than with antidepressants or antipsychotics. Similarly, we have observed that conditions such as post-traumatic stress disorder and borderline personality disorder sometimes improve following treatment of concurrent ADHD. Subsequent treatments for co-morbid disorders may be required and can be added one at a time to discriminate their effects. Conversely, in the presence of psychosis, bipolar disorder, and/or a clear depressive episode, ADHD should not be treated first. Care should be taken, however, to avoid mistaking the ADHD symptoms of emotional instability for the episodic mood changes of bipolar disorder or the chronic symptoms of a personality disorder.

In the case of co-morbid anxiety disorder, pharmacological treatment for the anxiety can

Top picture credit Gavin Bishop, Te Atua.
Script reads (Māui) “He had many names. Sometimes he was called Māui-Atami because he was brainy. And because he did some great things for humankind, he was also called Māui-mohio because his trickster ways made some people suspicious of him and they named him Māui-Tinihanga.
He could be charming and witty or very serious, and at other times a trickster, a clown, a flibbertigibbert. He rarely sat still because his head was so full of new schemes.
He may have been the first in the world with ADHD.”

WHAT MAKE SPECIAL WHĀNAU STAND OUT?
NOT BEING INCLUDED OR VALUED.

From: Paul Collinson <s 9(2)(a)>
Sent: Thursday, 8 December 2022 3:54 pm
To: Consult
Cc: Miles Roper
Subject: Submission -Proposal to amend Pharmaceutical Schedule Rules on prescribing and dispensing of Class B controlled drugs

You don't often get email from s 9(2)(a) Learn why this is important

Hi

The change to what and how controlled drugs are prescribed implies Patient Administration Systems need to be updated. I do not have an issue with this. The timing of the change is of concern. Many organisations enforce an IT change freeze over the Christmas holidays for good reason; maintaining system stability over a period when staff numbers are low. Ours change freeze is from 15th December to 15th January. As Te Tai o Poutini West Coast owns and manages 4 general practices, the change freeze also impacts them. To roll this change out at this time creates risk to system stability. Would you please consider moving the change to later in January?

Regards

Paul Collinson
ISG Programme Manager
Te Tai o Poutini West Coast

waea pūkoro: s 9(2)(a) | **īmēra:** s 9(2)(a)
71 Water Walk Road, Greymouth | PO Box 387, Greymouth 7840

Te Whatu Ora
Health New Zealand

Te Whatu Ora – Health New Zealand
TeWhatuOra.govt.nz

From: Craig MacKenzie <[redacted]>
Sent: Wednesday, 14 December 2022 5:06 pm
To: Consult
Subject: Response to Proposal to amend Pharmaceutical Schedule Rules on prescribing and dispensing of Class B controlled drugs

Hello
I am sending this in my hospital role and as a pharmacist. I don't usually provide feedback on Pharmac consultations but I feel strongly about this potential change.

I am concerned the current proposal would allow for increased supply of Controlled Drugs. The proposal states "*While the change from ten day dispensing to monthly dispensing would increase the amount of a Class B controlled drug able to be given to a person per visit, the total amount being dispensed would not change.* "

I think this statement is naïve and lacks an understanding of the clinical context. Each dispensing will in effect result in a third more controlled drug being supplied to patients. Potential harms may result for some patients as a result of having access to greater quantities of controlled drugs.
These harms could include amongst the following

- abuse/dependence,
- accidental or intentional overdose
- reduced opportunity for monitoring of efficacy and side-effects
- increased risk to household members including children, due to higher quantities of medicines being present in the home at any one time
- increased risk to the community through diversion, amongst other risks.

From a hospital perspective, we know we have challenges with getting prescribers to prescribe an appropriate quantity on prescription. Hierarchy's of control promoting forcing functions rather than education/policy are the most effective method for promoting safety. The current 10 day supply rule provides a forcing function/limit on supply.

Allowing a month to be dispensed at one time could exacerbate the risks outlined above. For example, there could be a cohort of patients who may end up dependant because they have more medicines at home than is needed (e.g. a patient is currently dispensed a 10 day supply and then think they don't need any more so not pick up repeats – but if they get a month, they continue to take it which may result in an unintended harm).

This also seems contrary to the HQSC approach in regards to the atlas of healthcare variation. Opiates are a particular focus within the Atlas and the purpose of the Atlas is to prompt debate and raise questions about health service use and provision amongst clinicians, users and providers of health services about why any differences exist, and to stimulate improvement through this debate.

The opiate Atlas has been used by regions to reduce opiate use given the inherent challenges inappropriate prescribing, dispensing and use of opiates can result in.

I have discussed with one of our Specialist Addiction Service Clinicians who shares similar views.

Kind regards
Craig

Craig MacKenzie

District Pharmacy Manager & Professional Lead
Pharmacy Services / Te Wai ounamu / Southern
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