133 Molesworth Street
PO Box 5013
Wellington 6140
New Zealand
T+64 4 496 2000

4 April 2023

[redacted]

[redacted] [redacted]
Ref: H2023020115

Tēnā koe [redacted]

Response to your request for official information

Thank you for your request under the Official Information Act 1982 (the Act) to Manatū Hauora (the Ministry of Health) on 13 February 2023, for information regarding attention deficit hyperactivity disorder (ADHD). Please find a response to each part of your request below.

> *…The release goes on to identify the six actions as:*
> 1. *Improving access to ADHD medicine*
> 2. *Increasing the understanding of ADHD*
> 3. *Building a consistent model of service*
> 4. *Adopting new medical practice guidelines*
> 5. *Establishing an ADHD reference group*
> 6. *Delivering quality ADHD training.*
>
> *All documents describing the commitments made by the Ministry in each of these six areas and the current or planned work resulting from the commitments*
> *All planning and project management documents showing the timelines for the current or planned work, from commencement through to completion, along with all documents showing the progress of this work to date.*

Manatū Hauora has identified six documents within scope of your request about activities planned and underway to support the improved outcomes of people with ADHD. All documents are itemised in Appendix 1 and copies of the documents are enclosed.

Please note, a further two documents were also identified to be within scope of this part of your request. However, these documents are withheld in full under section 9(2)(ba)(i) of the Act to protect information that is subject to an obligation of confidence and making it available would likely prejudice the supply of similar information, or information from the same source.

Where information is withheld under section 9 of the Act, I have considered the countervailing public interest in release in making this decision and consider that it does not outweigh the need to withhold at this time.

Manatū Hauora has no project management documents regarding ADHD. Therefore, this part your request is refused under section 18(e) of the Act, as the information requested does not exist.

Under section 28(3) of the Act, you have the right to ask the Ombudsman to review any decisions made under this request. The Ombudsman may be contacted by email at: info@ombudsman.parliament.nz or by calling 0800 802 602.

Please note that this response, with your personal details removed, may be published on the Manatū Hauora website at: www.health.govt.nz/about-ministry/information-releases/responses-official-information-act-requests.

Nāku noa, nā

Kiri Richards
Associate Deputy Director-General
Mental Health and Addiction
System Performance and Monitoring | Te Pou Mahi Pūnaha

Appendix 1: List of documents for release

#	Date	Document details	Decision on release
1	2022	Arorereti ni Programme: Reference Group	Released in full.
2	27 September 2022	Aide-Memoire: Priorities to improve ADHD assessment and treatment (HR20221447)	Some information withheld under the following sections of the Act: • Section 9(2)(a) – to protect the privacy of natural persons; and • Section 9(2)(b)(ii) – where its release would likely unreasonably prejudice the commercial position of the person who supplied the information
3	21 October 2022	Select Committee Submission: Response to 2020/281 Laura Williams (HR20221501)	Some information withheld under section 9(2)(a) of the Act.
4	13 December 2022	Aide-Memoire: Meeting with Chloe Swarbrick on ADHD (HR2022018242)	Some information withheld under the following sections of the Act: • Section 9(2)(a); • Section 9(2)(b)(ii); and • Section 9(2)(f)(iv) – to maintain the constitutional conventions that protect the confidentiality of advice tendered by Ministers and officials
5	3 February 2023	Letter from Professor Dave Coghill and CEO ADHD New Zealand Suzanne Cookson to the Minister of Health	Released in full.
6	13 February 2023	Background and talking points regarding Laura Williams's petition and oral hearing on 15 February 2023	

Document 1

ARORERETINI PROGRAMME: REFERENCE GROUP

Terms of reference

This document sets out the terms of reference for The Aroreretini Programme *Reference Group* set up to support the delivery of a group of initiatives agreed at the ADHD hui on 22 August 2022.

The Māori word for ADHD is aroreretini, which is interpreted to mean 'attention goes to many things'.

Context

The ADHD hui was hosted by ADHD New Zealand (ADHD NZ) with support from Green MP Chlöe Swarbrick to address issues the ADHD community and their whānau face gaining access to diagnosis and support.

The hui was attended by representatives from the Ministry of Health, NZ Police, Pharmac, Te Whatu Ora New Zealand, the medical colleges for GPs, psychologists and psychiatrists, and health care practitioners including psychologists, psychiatrists, GPs, paediatricians, and mental health nurses. ADHD NZ represented the lived community. The Health Minister Hon Andrew Little attended at the end of the hui to hear what initiatives the group had identified to better support the ADHD community. The following six initiatives were agreed:

1. Improving access to ADHD medicine by addressing issues with special authority renewal and considering new medicines not currently available in NZ.
   Resulting outcomes/actions:
   - Pharmac and the Ministry of Health have agreed to look at changes to special authority rules.
   - Pharmac, with input from RANZCP, will investigate access to new medicines.
2. Increasing the understanding of ADHD in Aotearoa through better data and research at both a macro and micro level.
3. Building a consistent model of service for supporting those with ADHD across Aotearoa as part of the health sector reforms.
   Resulting outcomes/actions
   - Te Whatu Ora has agreed to collaborate with providers to develop a consistent and quality model of service for assessment and support for ADHD as part of the health sector reforms.
4. Adopting new medical practice guidelines for ADHD.
   Resulting outcomes/actions
   - The RNZCGP, NZCCP and RANZCP will investigate endorsing the Australian ADHD Professionals Association (AADPA) guidelines in the interim with a view to tailoring for our local context – especially in terms of Te Tiriti recognition. Australia's guidelines were developed in consultation with RANZCP and ADHD NZ believes these guidelines are world leading.
5. Establishing an ADHD reference group with representation from government agencies, medical professionals and ADHD NZ to improve collaboration and information sharing and support the implementation of this programme of improvements.
   Resulting outcomes/actions
   - ADHD NZ has taken responsibility for this action point. Without this central point of collaboration there is a risk that the proposed actions will lose momentum and will

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

fail to achieve the intended outcomes. Also it is important that all of these actions are connected and developed within the context of a wider health system.

6. Delivering quality ADHD training for healthcare practitioners Including GPs, clinical psychologists, paediatricians and psychiatrists to ensure their understanding of ADHD remains up to date.

   Resulting outcomes/actions

   - Each of the colleges will begin upskilling their workforces with ADHD specific training – possibly drawing on AADPA training. This will be consistent across all colleges.

Status

The reference group is a collaborative network group to support the delivery of the initiatives and outcomes/actions listed above. The group does not make decisions or provide governance but will provide guidance and connection with the ADHD community.

Purpose

The purpose of the reference group is to support the delivery of the initiatives identified at the ADHD hui by:

1. Facilitating collaboration and a 'whole system' approach so the initiatives are not delivered in silos, leading to better outcomes
2. Ensuring the principles of Te Tiriti o Waitangi and equity are foundational to supporting the initiatives
3. Giving visibility across sectors to the progress being made on the delivery of the initiatives
4. Enabling collective problem solving where there are barriers to implementation
5. Acting as a clearing house for sharing information across the system
6. Providing expert advice where there are options to choose between
7. Being champions of change, advocating for these initiatives and communicating the benefits
8. Identifying opportunities to build on the six initiatives from the hui with complementary actions.
9. Provide an opportunity for the ADHD community and their whānau to have input.

Role of participants

Participants will be asked to:

- Represent the views of the organisation/sector they belong to in discussions
- Share knowledge and expertise to support the delivery of the initiatives (i.e. identifying options, risks, opportunities)
- Take a strategic and whole of system view – while being grounded in the realities of delivering a programme of work
- Communicate the work of the Arorereteni programme

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Participants

The reference group aims to enable a system wide view of the implementation of the initiatives. Participants are asked to join as representatives of a part of the system, based on their status as a sector leader with expert knowledge and experience.

Organisation	Representative
ADHD NZ	Darrin Bull - Chair Suzanne Cookson - CEO Dr Sarah Watson - Board member
Department of Corrections	TBC
NZCCP	Dr Paul Skirrow - Executive Advisor
NZNO, Mental Health Nurses section	Anna Elder, NP Rubashnee Naidoo, NP
NZ Police	TBC
NZ Society of Paediatricians / Clinical Paediatrician	Dr Garth Smith, Paediatric Society of New Zealand, and the Child development and disability clinical network.
Pharmac	Dr David Hughes - Chief Medical Officer
Ministry of Education	TBC
Ministry of Health	John Zonnevylle – Acting Chief Clinical Advisor, Mental Health and Addictions
Ministry of Social Development	TBC
Oranga Tamariki	TBC
RNZCGPs	Dr Bryan Betty – Medical Director Maureen Gillon - Manager - Policy, Advocacy & Insights
RANZCP	Jane Renwick - Manager, NZ National Office
Te Aka Whai Ora	Aroha Metcalf, General Manager for Mental Health and Addictions
Te Whatu Ora	Anne Brebner - Acting Group Manager- Mental Health Specialist Services

Convenor

The group will be convened by Darrin Bull who will be responsible for leading the discussion through the agenda.

Non-disclosure of information

The reference group will be most effective when it is able to have free and frank discussions and visibility of draft or confidential information. The discussions and any materials are not to be disclosed beyond the group, including with media, without prior agreement from the reference group.

Meeting length and frequency

The reference group will meet monthly for one hour online. The frequency and duration of meetings will be adjusted as needed to support the implementation of initiatives.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Out of pocket expenses

Participants will be responsible for their own out of pocket expenses – hence the meetings will be held online.

Service of meetings

ADHD NZ will act as the secretariat for the meetings and will provide the agenda (after consultation with participants) and any reading materials at least five days prior to meetings. Documents will also be available on a sharepoint site. The contact point for reference group participants is via the email suzanne@adhd.org.nz

Working groups associated with the reference group

Working groups may be established to support the delivery of the initiatives. For example, a working group may be established to support the data collection and research initiative. Working groups would report on their progress to the reference group and may seek reference group input into their work.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Document 2

Aide-Mémoire

Priorities to improve ADHD assessment and treatment

Date due to MO:	27 September 2022	**Action required by:**	At your convenience
Security level:	IN CONFIDENCE	**Health Report number:**	HR 20221447
To:	Hon Andrew Little, Minister of Health		
Consulted:	Health New Zealand: ☒ Māori Health Authority: ☐		

Contact for telephone discussion

Name	Position	Telephone
Robyn Shearer	Deputy Chief Executive and Deputy Director-General, System Performance and Monitoring	S9(2)(a) [redacted]
Arran Culver	Acting Associate Deputy Director-General, Mental Health and Addiction	

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Document 2

Aide-Mémoire

Priorities to improve ADHD assessment and treatment

Date due:	27 September 2022		
To:	Hon Andrew Little, Minister of Health		
Security level:	IN CONFIDENCE	**Health Report number:**	HR 20221447

Purpose of proposal:

Chlöe Swarbrick, MP for Auckland Central, has written to you to propose that work be undertaken to better support people with Attention Deficit Hyperactivity Disorder (ADHD). This aide memoire:

- responds to priority actions identified at the hui you attended on 22 August 2022 organised by ADHD New Zealand
- discusses support for ADHD New Zealand to organise an ADHD reference group
- encloses a draft response to Ms Swarbrick.

This aide-mémoire discloses all relevant information.

Comment:

- ADHD is a neurodevelopmental disorder. People with ADHD have differences to other people in the parts of the brain that control the ability to plan, organise and focus.
- Our previous briefings HR 20221324 and HR 202208246 outlined a range of issues related to ADHD assessment and treatment.

Context

- ADHD medications are classified under the Misuse of Drugs Regulations 1977 as Class B, due to the potential for abuse.
- Pharmac's 'special authority' rules require that, to gain access to medication, an assessment must be made by a paediatrician or psychiatrist, with a re-assessment every two years.
- Assessment and treatment of childhood ADHD occurs in a number of settings.
- Young people with ADHD, who have transitioned from Infant Child and Adolescent Services at around 18 or 19 years of age, may have difficulty securing ongoing medication.
- Adult mental health services are stretched and only funded to support people with ADHD if they also have other mental health conditions.
- This means adults typically need to see private psychiatrists, who are costly and hard to access.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

- The impact of restricted access to assessment and treatment is likely to fall inequitably on Māori, Pacific and disadvantaged communities.

Priorities identified at the ADHD New Zealand hui

The hui discussed issues facing the ADHD community and possible solutions. The following areas for action were determined and are reiterated in Ms Swarbrick's letter:

- Improve access to ADHD medicine
- Increase the understanding of ADHD
- Build a consistent model of service
- Adopt new medical practice guidelines for ADHD
- Establish an ADHD reference group
- Deliver quality ADHD training

ADHD NZ indicates the group of initiatives would be called the "Aroretini programme". Aroretini is a te reo term meaning "attention on many things".

Roles of respective health agencies

The respective roles of health agencies in relation to ADHD are:

- Manatū Hauora has a stewardship role including providing regulatory policy and clinical advice
- Te Whatu Ora, working with Te Aka Whai Ora, has a commissioning and funding role and is lead across operational practice matters.

Medsafe, within Manatū Hauora, is responsible for the regulation of therapeutic products in New Zealand. Pharmac, a Crown entity, is responsible for deciding which medicines and pharmaceutical products are subsidised for use in the community and public hospitals.

These agencies hold expertise on ADHD and some actions are already in train, as indicated in the action table discussed below.

Action plan

Appendix A outlines the action areas identified at the hui, and details of potential opportunities, state of play and next steps.

Health agencies do not currently have specific resourcing to support a work programme around ADHD of the large scale and nature discussed at the ADHD NZ hui. For instance, some actions do not have identified sources of resourcing, including work proposed for Te Whatu Ora to develop a new model of service for assessment and support for ADHD.

However, there is valuable work already underway in some key areas:

- Cabinet has agreed to an amendment to the Misuse of Drugs Act 1975 to allow Class B controlled drugs (which includes ADHD medication) to

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

be prescribed for up to three months, rather than just one month, and regulation changes are in train
- Pharmac has committed to make better known the waiver that enables continued prescriptions after the authorisation period elapses, for reasons such as wait times to access a psychiatrist
- Work is underway to introduce an additional medication, lisdexamfetamine, which is better tolerated by some patients and less open to abuse for recreational purposes
- The Royal Australian and New Zealand College of Psychiatrists (RANZCP) has agreed to endorse, for the New Zealand context, new and comprehensive Australian medical practice guidelines for managing ADHD
- RANZCP is also developing a Policy Statement that presents system level principles for improvements in care for people with ADHD, including a commitment to improved training for psychiatrists.

There are opportunities across health agencies to undertake more substantive work. For instance, a significant area of opportunity relates to the requirement for two yearly re-assessments by a psychiatrist to enable ongoing provision of medication. As noted above, psychiatrists can be hard to access, and costs disproportionately impact disadvantaged populations. Manatū Hauora will continue discussions with Pharmac and Medsafe about options, with the most readily achievable being the potential to change re-assessment frequency, for instance from two years to five years.

Further details can be provided in due course on what would be required to consider progressing more substantive work if desired.

Reference group

ADHD NZ is seeking to establish a reference group in the next six weeks to support delivery of the priorities identified at the hui. It would have an advisory function only, providing guidance for decision-makers.

ADHD NZ suggests the group would include representatives of Pharmac; Manatū Hauora; Te Whatu Ora; NZ Police; the professional associations for general practitioners, psychiatrists, psychologists, paediatricians and nurses; and iwi/Māori. It would meet for 12-18 months, with potential for an extended but less intensive role thereafter.

S9(2)(b)(ii) [redacted]

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

A reference group could be valuable in bringing together the key relevant organisations, and in providing advice and support to agencies with relevant responsibilities. At this stage a funding source has not been identified within Manatū Hauora or Te Whatu Ora and the funding request cannot be met. Further consideration is required as to potential funding for the secretariat component only, and its representation, scope and time span, balanced with other priorities.

Some work could still be progressed by groups within both Manatū Hauora and Te Whatu Ora, in liaison with ADHD NZ without a formalised reference group. Manatū Hauora can contribute some policy coordination and overview across various actions in train and report to you on progress.

Risks/mitigations

A full risk assessment, in terms of patient safety, would need to be undertaken if any change is pursued to the requirement for two yearly re-assessments by a psychiatrist.

In relation to the reference group, not funding the proposal may reduce the ability to achieve coordinated action across agencies. This is mitigated by the goodwill already evident, and commitment from Manatū Hauora to maintain an overview and pursue progress in collaboration with ADHD NZ and other key stakeholders. If a group is established, risks would need to be managed such as increased expectations about the pace of action possible. Given the advocacy role of ADHD NZ, and independent chair could be desirable.

Response to Chlöe Swarbrick MP

A draft letter back to Chlöe Swarbrick is attached for your consideration.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Robyn Shearer
Deputy Chief Executive and Deputy Director-General
System Performance and Monitoring
Date: 27/9/22

Document 2

Appendix A: Priority action areas for ADHD

Key to acronyms
NZCCP: NZ College of Clinical Psychologists
RNZCGP: Royal New Zealand College of General Practitioners
RANZCP: Royal Australian and New Zealand College of Psychiatrists

Action area	Context/issue	Current/potential responses	Who	Next steps
Improve access to ADHD medicine	Patients have to seek a new prescription each month, which is costly and requires organisational skills that may be challenging for people who experience ADHD.	Cabinet has recently agreed an amendment to the Misuse of Drugs Act 1975 to allow Class B controlled drugs to be prescribed for up to three months, rather than just one month. Changes need to be made to the appropriate regulations.	Lead: Manatū Hauora	Aiming for regulation changes by the end of 2022.
	Currently, a psychiatrist must make the initial authorisation of medication for adult ADHD with two yearly re-assessments. Psychiatrists can be hard to access and costly.	Pharmac determines how long it will subsidise a prescription, which affects how often re-assessments of a patient must be made. One option is to change re-assessment frequency, eg from two years to five years.	Lead: Pharmac Involve: Medsafe, Manatū Hauora, Regulatory Authorities, professional associations	Pharmac and Manatū Hauora have had an initial discussion around options. Pharmac's timeline is dependent on its capacity following an external review, with priority needed for funding new investments.
		Under regulation 22 of the Misuse of Drugs Regulations, Medsafe issues Gazette notices about who can prescribe and supply certain drugs. An option is to determine other health professionals (eg, psychologists, general practitioners and other relevant primary care clinicians) to provide the re-assessments, which could then be reviewed and endorsed by a paediatrician or psychiatrist.	Lead: Medsafe Involve: Pharmac, Manatū Hauora, Regulatory Authorities, Professional associations	Any change to authorisation levels would require significant discussion. Manatū Hauora will continue discussions with Medsafe and other key stakeholders on options in this area.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

	Few people are aware of a waiver that enables continued prescriptions after the authorisation period elapses, for reasons such as wait times to access a psychiatrist.	Pharmac undertook at the Parliament hui to do more to raise awareness of this option to prescribers and others.	Lead: Pharmac Involve: ADHD NZ	Pharmac to follow up with ADHD NZ and RNZCGP to discuss how best to share information on the waiver process by October 2022
	There are medications not currently in use in New Zealand which are long-acting and better tolerated by some people, and less open to misuse.	Lisdexamfetamine is a drug that is used overseas and is not currently available in New Zealand.	Lead: Pharmac	The new drug has been approved and its classification will be confirmed in 2022. Pharmac health economists will undertake further analysis in line with the cost neutral recommendation of its expert clinical advisers.
Increase the understanding of ADHD	Medical practitioners and others (eg in schools, criminal justice system) do not understand the impact that ADHD has on affected people.	Better data, research and information provision is needed. A broad range of organisations could have potential roles. S9(2)(b)(ii) [redacted]	Lead: ADHD NZ Involve: Universities, Te Whatu Ora, Whaikaha, workforce development centres	S9(2)(b)(ii) [redacted]
Build a consistent model of service for supporting those with ADHD	There is no clear national pathway for adults with ADHD to receive consistent care.	A consistent and quality model of service for assessment and support for ADHD could be developed, including through changes to Health Pathways (online manual used by clinicians to help make assessment and management decisions)	Involve: Te Whatu Ora, service user stakeholders (eg ADHD NZ), Pharmac, key professional groups	Development of a model of service is not currently resourced within Te Whatu Ora's work programme.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Document 2

Adopt new medical practice guidelines for ADHD	Currently, RANZCP endorses United Kingdom and Canadian guidelines. Australian guidelines will shortly be released and New Zealand reviewers believe these to be the most comprehensive and up-to-date.	RANZCP has agreed to endorse the Australian guidelines for New Zealand. A version or addendum could be developed for our local context, particularly to provide cultural context.	Lead: RANZCP Involve: RNZCGP, NZCCP	ADHD NZ is arranging for Australian leads to present to NZ medical colleges in December 2022. Further development for the NZ context could be investigated by RANZCP but is currently not resourced.
Establish an ADHD reference group	Currently there is no collaborative or strategic forum to pursue improvements to assessment and treatment barriers.	Establishing a reference group would aim to ensure knowledge is pooled and momentum on key actions is maintained. S9(2)(b)(ii) [redacted]	Lead: ADHD NZ	S9(2)(b)(ii) [redacted]
Deliver quality ADHD training for healthcare practitioners	Professionals including clinical psychologists, paediatricians and psychiatrists need to ensure their understanding of ADHD remains up to date.	Professional colleges Including GPs, clinical psychologists, paediatricians and psychiatrists need to upskill their workforces with ADHD specific training – possibly drawing on Australian training.	Involve: Professional associations, Te Whatu Ora, workforce development centres	RANZCP is developing Position Statement principles, to be published 2022, that include commitments to enhancing ADHD training of psychiatrists. ADHD NZ is having discussions with the colleges for GPs and psychologists.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Select Committee Submission

Response to 2020/281: Laura Williams

Date due to MO:	21 October 2022	**Due to Committee by:**	28 October 2022
Security level:	IN CONFIDENCE	**Health Report number:**	20221501
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Dr Arran Culver	Associate Deputy Director-General, Mental Health and Addiction, Te Pou Mahi Pūnaha (System Performance and Monitoring)	S9(2)(a) [redacted]

Action for Private Secretaries

Confirm noting by 28 October 2022 **Date dispatched to MO:**

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Response to 2020/281: Laura Williams

Purpose of report

This briefing is to inform you that Manatū Hauora (the Ministry of Health) has drafted a response to the petition of Laura Williams on increasing funding for, and access to, adult Attention Deficit Hyperactivity Disorder (ADHD) screening and diagnosis. The Manatū Hauora response will be sent to the Petitions Committee by 28 October 2022.

Key Points

- A petition was presented to the House of Representatives on 10 August 2022 by Laura Williams and 2,890 others. It urges the House to increase funding for and access to adult ADHD screening and diagnosis.
- The Health Committee has asked Manatū Hauora to prepare a written submission on the petition by 28 October 2022. Our submission is enclosed.
- Laura's petition highlights the need for adults to have access to screening, diagnosis, and treatment for ADHD. This includes early intervention and subsidised diagnosis through the public health system. The petition also requests investigation into access barriers and increased funding so that services are available to New Zealanders who need them.
- The Manatū Hauora response acknowledges that while understanding of ADHD has improved significantly, there are gaps in the health system that could be addressed to better support people who may experience ADHD. Current work and future opportunities include:
    - Cabinet has agreed amendments to the Misuse of Drugs Act 1975 which will allow Class B controlled drugs to be prescribed for up to three months rather than just one month
    - Manatū Hauora (including Medsafe) and Pharmac have had initial discussions for updating the approach to obtaining a 'Special Authority' for medication
    - collaboration with partners to create more consistent pathways for access to screening, diagnosis, and treatment for ADHD, which are a focus of the new health system reforms
    - additional training for health professionals in assessing and supporting people with ADHD.
- Manatū Hauora will continue to work with relevant agencies including Te Whatu Ora (Health New Zealand), Pharmac, Whaikaha (Ministry of Disabled People), relevant health professional bodies, and ADHD New Zealand to address barriers and improve outcomes for people with ADHD and their whānau.

John Hazeldine
Acting Deputy Director-General
Te Pou Mahi Pūnaha (System Performance and Monitoring)

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Document 3

133 Molesworth Street
PO Box 5013
Wellington 6140
New Zealand
Phone (04) 496 2000
www.health.govt.nz

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Hon Jacqui Dean
Chairperson
Petitions Committee

By email: petitions@parliament.govt.nz

Tēnā koe Hon Jacqui Dean

Re: Petition 2020/281 of Laura Williams and 2890 others

Thank you for the opportunity to provide a written submission on the petition of Laura Williams, requesting that:

> *"the House of Representatives acknowledge that adult ADHD is a worthy concern, acknowledge that, for many, it is financially inaccessible to get a diagnosis for, and increase funding for it."*

Manatū Hauora (the Ministry of Health) has considered Laura's submission and the information provided in support.

Manatū Hauora response to Laura William's petition

I thank Laura for her advocacy and acknowledge the issues raised in her petition regarding better access to screening, diagnosis, and treatment for adults with Attention Deficit Hyperactivity Disorder (ADHD). I would like to assure Laura that Manatū Hauora is supportive of making changes across the health system to improve outcomes for people with ADHD and their whānau.

Laura notes in her petition that she would like Parliament to prioritise early intervention for people affected by ADHD and to make access to diagnosis subsidised through publicly funded health services for anyone who wishes to access it.

Many issues relating to the assessment and treatment of ADHD and a range of options for addressing them were discussed at a recent hui organised by ADHD New Zealand and hosted at Parliament. At the hui key partners, including Manatū Hauora, discussed ways to make it easier for adults with ADHD to access assessment, diagnosis, and treatment and there was commitment from partners to investigate

options for alleviating the barriers that people with ADHD and their whānau experience with a view to improving treatment pathways.

The following response prepared by Manatū Hauora and in consultation with other relevant agencies provides contextual information on ADHD in New Zealand, an overview of the issues, as well as the actions underway and future opportunities to be explored for addressing barriers for people with ADHD and their whānau.

Prevalence and assessment of ADHD in New Zealand

ADHD is classified as a neurodevelopmental disorder which is commonly diagnosed in children and often continues into adulthood with many people successfully managing the associated challenges. Prevalence data from the New Zealand Health Survey shows that children and young people aged 2 to 14 years diagnosed with ADHD fluctuates between 1.5 percent and 2.7 percent yearly. Australian epidemiological data collected in 2015 suggests a 12-month ADHD prevalence of 7.4 percent in children and young people aged 4 to 17 years.[1] International data on the prevalence of adult ADHD is mixed, but a meta-analysis of epidemiological studies conducted in 2021 suggests that persistent ADHD affects between 4 percent and 5 percent of the adult population worldwide.[2]

ADHD can significantly impact someone's functioning (socially, and educational attainment, ability to hold employment or increase their likelihood of coming into contact with the criminal justice system), and people may experience insomnia, concentration difficulties, restlessness, rapid shifts in emotions, and may have trouble making decisions. These may negatively impact future attainment and relationships for those with ADHD, both diagnosed and undiagnosed. These symptoms can be features of other common mental health conditions and thorough assessment is required to ensure people get the right diagnosis and treatment. Assessment of ADHD involves examining the impacts of these symptoms across a range of settings in the person's life and considering the potential for co-existing neurodevelopmental and mental health conditions as well as ruling out other potential causes. Assessment can therefore be time-consuming and complex and is often best managed by a specialist multi-disciplinary approach.

Health professionals providing assessment and treatment for ADHD in New Zealand draw on guidelines such as those produced by the Canadian ADHD Resource Alliance or the National Institute for Health and Clinical Excellence (NICE) in the UK. The Royal Australian and New Zealand College of Psychiatrists (RANZCP) recommends the use of both of these guidelines. Both emphasise the importance of thorough and multi-modal assessment to ensure the wide range of possible other diagnoses are excluded. They also recommend that treatment of ADHD is not simply the supply of stimulant medications, and that professionals providing such services should be appropriately trained regarding ADHD and provide access to other treatment such as

[1] Lawrence D, Johnson S, Hafekost J, Boterhoven De Haan K, Sawyer M, Ainley J, Zubrick SR (2015) The Mental Health of Children and Adolescents. Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing. Department of Health, Canberra.

[2] Song P, Zha M, Yang Q, Zhang Y, Li X, Rudan I. The prevalence of adult attention-deficit hyperactivity disorder: A global systematic review and meta-analysis. J Glob Health. 2021 Feb 11;11:04009. doi: 10.7189/jogh.11.04009. PMID: 33692893; PMCID: PMC7916320.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

cognitive behavioural therapy, psychological, social, occupational, and educational supports.

Current processes for diagnosing and treating ADHD in children and adults

Assessment and diagnosis of childhood ADHD occurs in a number of settings, including paediatric outpatient and child development centre services and Infant, Child and Adolescent Mental Health Services (ICAMHS). Children with ADHD presenting with higher complexity symptoms are likely to be assessed and diagnosed in ICAMHS. We are aware that there is an issue for young people with ADHD, who have transitioned from Infant Child and Adolescent Services at around 18 or 19 years of age, and experience difficulties in accessing a psychiatrist to secure ongoing support and medication.

Adults seeking a diagnosis of ADHD may be referred to specialist Adult Mental Health Services, however we acknowledge these services are under significant pressure, and the availability of a specialist workforce with the skills and knowledge for diagnosing and treating ADHD is limited. Adult mental health and addiction services are funded to support people with the highest mental health and addiction needs, and often people experiencing ADHD do not meet the high threshold for access. Adults who do not meet the criteria for these services can seek a private psychiatrist, but this can be costly, and the availability of private psychiatrists is constrained. These costs have a higher impact on those people with fewer resources, which disproportionately includes Māori and Pacific communities. There is work underway to grow the mental health and addiction workforce as well as work by professional bodies to upskill the existing workforce.

The online Health Pathways platform, which is used by health professionals such as general practitioners and some of the specialist workforce, supports consistent practice for ADHD diagnosis, treatment, and referral pathways, however Manatū Hauora recognises Health Pathways are not available in all districts and there is an opportunity to ensure more consistent care across the country to meet the needs of people experiencing ADHD. Ensuring consistent pathways is a key aim of the health and disability reforms which took effect on 1 July 2022 and are still in the early stages of implementation.

Access to pharmaceutical treatments for ADHD

ADHD medications (such as methylphenidate and dexamphetamine) are more tightly controlled than most other medications used for mental health-related conditions. ADHD medications are scheduled in the Misuse of Drugs Act 1975 as Class B controlled drugs due to concerns about the potential for abuse. As part of this classification there are restrictions under regulation 22 of the Misuse of Drugs Regulations 1977 as to who can prescribe these medicines.

Only paediatricians or psychiatrists can make an initial diagnosis of ADHD and initiate pharmaceutical treatment, additionally neurologists and clinical psychologists are also able to diagnose ADHD, but they are not able to prescribe. The original prescriber can apply for Special Authority which allows a general practitioner or nurse practitioner with appropriate scope to prescribe the medication for up to two years. However, once the Special Authority expires, the person needs to be seen by a specialist again to

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

renew the Special Authority, creating further demand on the paediatric and psychiatrist workforce and barriers for people seeking ongoing treatment.

ADHD medications are also restricted in the amounts that can be prescribed at one time and can currently only be obtained as a one-month prescription. Families and whānau must renew a prescription monthly, adding a further barrier to accessing medication, although work is underway to increase the prescription length from one to three months.

Present actions and future opportunities to support people with ADHD

There are key role players in the health system who are responsible for the regulation of, and settings for, ADHD medication and prescriptions. Medsafe within Manatū Hauora is responsible for the regulation of therapeutic products in New Zealand, and determines which professions can prescribe certain drugs, including those for ADHD. Pharmac, a Crown entity, determines which medicines are subsidised for use in the public health system including determining how often specialist re-assessments of a patient are required for ongoing provision of ADHD medication.

Ongoing collaboration is important, including exploring future work with health entities including Manatū Hauora, Medsafe, Pharmac, and Te Whatu Ora, and with other key stakeholders such as ADHD New Zealand, and with Whaikaha - Ministry of Disabled People who for example, can provide information on how Disability Support Services are able to provide treatment for people experiencing disability because of neurodevelopmental disorders such as ADHD.

Developing a consistent national pathway for assessment and treatment of ADHD

Initial discussions have taken place on how a nationally consistent pathway could be developed between key agencies such as Manatū Hauora, Te Whatu Ora and Pharmac, and key professional groups (such as psychiatrists and general practitioners). Creating better national consistency for health services is a key focus of the health and disability reforms and this will be explored further as changes to the health system are implemented.

Improving access to diagnosis and pharmaceutical treatment for ADHD

Cabinet has recently agreed an amendment to the Misuse of Drugs Act 1975 which will allow Class B controlled drugs to be electronically prescribed for up to 3 months, rather than just one month [SWC-22-MIN-0146 refers]. This will remove a barrier to people with ADHD and reduce the cost of prescriptions. This regulation change is expected by the end of 2022.

The petitioner asks that access to ADHD diagnosis be subsidised through the public health system for anyone who wishes to access it. A key limitation in the specialist health system is the availability of clinical psychologists and psychiatrists. A multi-faceted work programme is underway to increase and diversify the workforce but this will take time.

Manatū Hauora (including Medsafe) has had initial conversations with Pharmac around the current requirement for a Special Authority to be obtained from a paediatrician or psychiatrist every two years in order for medication to be continued.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Pharmac has committed to make the waiver that enables continued prescriptions after Special Authority period has lapsed for reasons such as wait times to access a psychiatrist better known. Work is also underway to introduce an additional pharmaceutical, lisdexamfetamine, which are longer-acting ADHD medications better tolerated by some patients and less open to abuse for recreational purposes.

Supporting the workforce with guidelines and training

Manatū Hauora understands that the Royal Australian and New Zealand College of Psychiatrists (RANZCP) has agreed to endorse, for the New Zealand context, new and comprehensive Australian medical practice guidelines for managing ADHD, which have been published this year by the Australian Association of ADHD Professionals. RANZCP is also developing a Policy Statement that presents system level principles for improvements in care for people with ADHD, including a commitment to improved training for psychiatrists.

Discussions will continue across relevant agencies, professional colleges and ADHD New Zealand about upskilling the health workforce with ADHD specific training, possibly drawing on Australian training.

Concluding remarks

I would again like to thank Laura for her petition, and I hope the information we have provided in our response assures her and the Committee that Manatū Hauora and agencies are committed to removing barriers for people to access support and continuing to explore ways to improve outcomes for people with ADHD and their whānau.

Ngā mihi nui

John Hazeldine
Acting Deputy Director-General
Te Pou Mahi Pūnaha
Manatū Hauora

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Document 4

Aide-Mémoire

Meeting with Chlöe Swarbrick on ADHD

Date due to MO:	13 December 2022	**Action required by:**	N/A
Security level:	IN CONFIDENCE	**Health Report number:**	H2022018242
To:	Hon Andrew Little, Minister of Health		
Consulted:	Health New Zealand: ☒ Māori Health Authority: ☐		

Contact for telephone discussion

Name	Position	Telephone
Dr Arran Culver	Associate Deputy Director-General, Mental Health and Addiction, System Performance and Monitoring	S9(2)(a) [redacted]
John Zonnevylle	Chief Clinical Advisor, Mental Health and Addiction, System Performance and Monitoring	

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Document 4

Aide-Mémoire

Meeting with Chlöe Swarbrick on ADHD

Date due: 13 December 2022

To: Hon Andrew Little, Minister of Health

Security level: IN CONFIDENCE **Health Report number:** H2022018242

Details of meeting: You are meeting with Chlöe Swarbrick, MP for Auckland Central, at 17:00 – 17:30 on Wednesday 14 December 2022. Eliza Prestige Oldfield (Political Director) and Sarah Saunders (Researcher) from her staff will also attend.

Purpose of meeting/ proposal: Chlöe Swarbrick has indicated that she wishes to discuss Attention Deficit Hyperactivity Disorder (ADHD) and specifically:

- progress on ADHD priority actions identified at the Parliamentary hui you attended on 22 August 2022
- funding opportunities for peer support services.

Talking points are provided in **Appendix A**. You will be supported by John Zonnevylle, Chief Clinical Advisor from Manatū Hauora, at the meeting.

Comment: **Roles of respective health entities**

- Improving support for people with ADHD and removing barriers to treatment requires activity across a number of health agencies including:
    - Manatū Hauora which has regulatory policy and clinical advice roles in relation to treatment for ADHD
    - Medsafe, within Manatū Hauora, which is responsible for the regulation of therapeutic products in New Zealand
    - Pharmac, a Crown entity, which is responsible for deciding which medicines and pharmaceutical products are subsidised for use in the community and public hospitals
    - Te Whatu Ora, in collaboration with Te Aka Whai Ora, which has a commissioning and funding role and leads operational practice matters
    - relevant professional bodies (eg, Royal Australian and New Zealand College of Psychiatrists, New Zealand College of Clinical Psychologists, and Royal New Zealand College of General Practitioners) who have a key role in supporting guidelines and training for health professionals on ADHD.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Update on ADHD activity

- Our previous briefings [HR20221324 and HR202208246] outlined a range of issues related to ADHD assessment and treatment. These issues were discussed at the August 2022 Parliamentary hui, which was organised by ADHD New Zealand (ADHD NZ) and hosted by Chlöe Swarbrick. The hui proposed a broad work programme ranging from regulatory to operational matters including:
    - improving access to ADHD medicine
    - increasing the understanding of ADHD
    - building a consistent model of service
    - adopting new medical practice guidelines for ADHD
    - establishing an ADHD reference group
    - delivering quality ADHD training.
- An overview of the priority action areas for ADHD including current and proposed future work is provided in **Appendix B**. While health agencies do not currently have specific resourcing to support an ADHD work programme of the scale and nature discussed at the Parliamentary hui, there is valuable work underway in key areas.
    - The Misuse of Drugs Act 1975 has been amended to allow Class B controlled drugs (which includes ADHD medication) to be electronically prescribed for up to 3 months, rather than just one month, and this will come into force on 22 December 2022.
    - Pharmac is looking at the potential to review the current requirement for a Special Authority to be obtained from a paediatrician or psychiatrist every 2 years (in order for medication to be continued), while balancing this work against its other priorities.
    - Pharmac has committed to improve awareness of the waiver that enables continued prescriptions after the authorisation period elapses in circumstances where there are long wait times to access a psychiatrist.
    - Medsafe is progressing work on aligning the regulatory requirements for lisdexamfetamine for the treatment of ADHD with other commonly used ADHD medications, once it is scheduled as a controlled drug. Pharmac will also be considering funding for lisdexamfetamine in 2023.
    - The Royal Australian and New Zealand College of Psychiatrists (RANZCP) has agreed to endorse, for the New Zealand context, new and comprehensive Australian medical practice guidelines for managing ADHD (published this year by the Australian ADHD Professionals Association).

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

- RANZCP is also developing a Policy Statement that presents system-level principles for improvements in care for people with ADHD, including a commitment to improved training for psychiatrists.

Funding opportunities for peer support services

- Te Whatu Ora, as health sector commissioning lead, does not currently have funding for additional peer support services targeted specifically for ADHD. However, efforts are underway to support the peer workforce more broadly, and there are opportunities through the health system reforms for localities to develop pathways and services to better support people with ADHD in their local communities.
- What is available for local communities will be guided by the development of the Oranga Hinengaro System and Service Framework by Manatū Hauora, in collaboration with Te Whatu Ora and Te Aka Whai Ora. The framework sets the direction for mental health and addiction service configuration over the next ten years. It outlines the type of services that should be available to different groups of people, and supports for neurodevelopmental needs (eg, ADHD) are included. S9(2)(f)(iv) [redacted]
- Work to support the mental health and addiction workforce is a high priority area for health agencies. Budget 2019 invested approximately $77 million over 4 years in mental health and addiction workforce development. Budget 2022 investment in specialist services ($100 million over 4 years) also included workforce development funding of $10 million. This investment will help ease some immediate pressure, but this funding builds and it will take time to see the effects.
- Part of this workforce development investment includes efforts to diversify the workforce (eg, through greater use of peer, cultural and support workers). Te Pou, one of the 4 national the mental health and addiction workforce development centres, has developed a Consumer, Peer Support and Lived Experience Workforce Development action plan which is relevant for growing ADHD peer support.
- Te Whatu Ora are currently running a procurement process for Peer Leadership Training, and ADHD peers will be able and welcome to access this training once it is up and running.

Other information that may be raised at the meeting

- S9(2)(b)(ii) [redacted]

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

- ADHD NZ has, however, progressed establishment of a 'collaborative network group' of professional associations and government agencies. Manatū Hauora, Te Whatu Ora and Pharmac were represented at the initial meeting on 8 November 2022 and will continue to participate. We consider this will be a valuable mechanism for progressing further work.
- Pharmac recently met with Chlöe Swarbrick in November 2022 to discuss their work programme priorities and updates on their actions included in this aide-mémoire for the treatment of ADHD.
- The President and Vice President of the Australian ADHD Professionals Association (AADPA) plan to visit New Zealand on 28-30 March 2023 and wish to meet with you (as well as the Ministers of Education and Corrections) to discuss common issues and solutions to support treatment of ADHD. We understand your office will receive a meeting request from ADHD NZ on behalf of AADPA.
- We are aware that the work of AADPA has strong support from Australian leaders including Hon Mark Butler MP, Minister for Health and Aged Care.
- This aide-mémoire discloses all relevant information.

Kiri Richards

Acting Associate Deputy Director-General, Mental Health and Addiction

System Performance and Monitoring

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Appendix A: Talking points for ADHD meeting

- Thank you for organising this meeting to talk about support for people with ADHD. It is important to me that we support people experiencing ADHD to improve their social, education, and work lives by providing better access to treatment.
- I acknowledge your leadership in this area, and in particular, for supporting the recent hui at Parliament alongside ADHD NZ, and also for sharing your own personal experiences. The hui was successful in bringing together all relevant stakeholders, including health agencies, to discuss a range of actions for improving outcomes for people with ADHD.
- The scale of the work programme discussed at the recent hui is significant and will have resource implications. While health agencies do not currently have specific resourcing to support all areas of an ADHD work programme of the scale discussed, there is work under way, and health agencies are keen to explore opportunities for undertaking further work in the future.
- ADHD NZ is a key leader in this area and has progressed establishment of a 'collaborative network group' of professional associations and government agencies. Manatū Hauora, Te Whatu Ora and Pharmac were represented at the initial meeting and will continue to participate.
- There is valuable work happening in some key areas to improve treatment for ADHD, which will bring significant benefits for people.
    - The Misuse of Drugs Act 1975 has been amended to allow Class B controlled drugs (which includes ADHD medication) to be electronically prescribed for up to 3 months, rather than just one month.
    - Pharmac is looking at the potential to review the current requirement for a Special Authority to be obtained from a paediatrician or psychiatrist every 2 years for medication to be continued.
    - Medsafe is progressing work on aligning the regulatory requirements for lisdexamfetamine for the treatment of ADHD with other commonly used ADHD medications, once it is scheduled as a controlled drug. Pharmac is also planning to assess a funding proposal for lisdexamfetamine next year.
    - The Royal Australian and New Zealand College of Psychiatrists has agreed to endorse, for the New Zealand context, new and comprehensive Australian medical practice guidelines for managing ADHD.
- Following the health reforms, Te Whatu Ora and Te Aka Whai Ora are responsible for commissioning and delivering health services within new localities across the country. There are opportunities for new localities to provide health services based on the needs of their local populations which includes services to improve support for people with ADHD.
- Manatū Hauora is also developing the Oranga Hinengaro System and Service Framework which will set the direction for mental health and addiction services over the next 10 years. This framework will provide guidance on the types of services that should be available to people regionally and nationally, including for neurodevelopmental needs like ADHD.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

- Addressing a stretched mental health and addiction workforce is a high priority area for health agencies. Alongside a broad workforce development programme to grow and upskill workforces, there are also efforts to diversify the workforce, for example, through greater use of peer, cultural and support workers.
- For example, one of the national mental health and addiction workforce development centres Te Pou is leading actions to increase the peer support workforce through a new strategy and action plan. Te Whatu Ora is also in the process of procuring Peer Leadership Training, which will be available for peers with ADHD.
- I have asked to be kept updated on activities to improve support for people experiencing ADHD and look forward to hearing about further work and discussions with the collaborative network group.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Appendix B: Priority action areas for ADHD

Key to acronyms

NZCCP: New Zealand College of Clinical Psychologists RNZCGP: Royal New Zealand College of General Practitioners
RANZCP: Royal Australian and New Zealand College of Psychiatrists

Action area	Context/issue	Current/potential responses	Who	Next steps
Improve access to ADHD medicine	Tāngata whaiora have to seek a new prescription each month, which is costly and requires organisational skills that may be challenging for people who experience ADHD.	The Misuse of Drugs Act 1975 has been amended to allow Class B controlled drugs (which includes ADHD medication) to be electronically prescribed for up to 3 months, rather than just one month. (SWC-22-MIN-0146).	Lead: Manatū Hauora	New regulations will come into force on 22 December 2022.
	Under Misuse of Drugs Regulations, a paediatrician or psychiatrist must make the initial authorisation of medication for ADHD. Pharmac's Special Authority rules require 2 yearly re-assessments by a paediatrician or psychiatrist. Adult mental health services are stretched, and many people with ADHD do not meet criteria for specialist services, therefore adults typically need to see private psychiatrists, who can be costly and hard to access. This experience can be similar for children and young people.	Pharmac determines how long it will subsidise a prescription, which affects how often re-assessments of a patient must be made. One option is for Pharmac to change re-assessment frequency (eg, from 2 years to 5 years). Pharmac could also consider whether other health professionals (eg, psychologists, nurse practitioners, general practitioners and other relevant primary care clinicians) could provide the re-assessments, potentially to then be reviewed and endorsed by a paediatrician or psychiatrist.	Lead: Pharmac Involve: Medsafe, Manatū Hauora, Regulatory Authorities, professional associations	Pharmac has indicated commitment to reviewing its Special Authority requirements but the timeline for this is dependent on its capacity and other pressing priorities. It will require a legal, clinical, financial and health economics assessment, and initial consideration by its mental health advisory committee which next meets in the third quarter of the 2023 calendar year. Broad engagement would be required to ensure any changes are well supported across medical professions.
	Few people are aware of a waiver that enables continued prescriptions after the authorisation	Pharmac undertook (at the Parliament hui August 2022) to do more to raise awareness of this option to prescribers and others.	Lead: Pharmac Involve: ADHD NZ	Pharmac will follow up with ADHD NZ and RNZCGP to discuss how best to share information on the waiver process.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

	period elapses, for reasons such as wait times to access a psychiatrist.			
	There are medications that will be available for use in New Zealand which are long-acting, better tolerated by some people, and less open to misuse.	Lisdexamfetamine is approved for use in New Zealand for treatment of ADHD in adults, adolescents, and children aged 6 years and older. Lisdexamfetamine has been assessed by the Expert Advisory Committee on Drugs and Cabinet has agreed to schedule lisdexamfetamine as a Class B2 controlled drug under the Misuse of Drugs Act 1975 from 15 December 2022.	Lead: Medsafe, Pharmac	Medsafe is investigating a 'blanket' ministerial approval for the prescribing, supply and administration of lisdexamfetamine which would align it with regulatory requirements for other stimulant medications (dexamphetamine and methylphenidate) once lisdexamfetamine is scheduled as a controlled drug. A proposal for funding of Lisdexamfetamine is under assessment by Pharmac and is likely to be completed towards the end of 2023.
Increase the understanding of ADHD	Medical practitioners and others (eg, in schools and the criminal justice system) require upskilling to understand the impact that ADHD has on affected people.	Better data, research and information provision is needed. A broad range of organisations could have potential roles. S9(2)(b)(ii) [redacted]	Lead: ADHD NZ Involve: Universities, Te Whatu Ora, Whaikaha, workforce development centres	Te Whatu Ora, as health sector commissioning lead, does not currently have a source of funding for ADHD NZ for this work. However, health entities will continue to explore opportunities to support this objective within current work programmes and in collaboration with the workforce development centres.
Build a consistent model of service for	There is no clear national pathway for adults with ADHD to receive consistent care.	A consistent and quality model of service for assessment and support for ADHD could be developed, including through changes to Health Pathways (online manual used by	Involve: Te Whatu Ora, ADHD NZ, Pharmac, key	Development of a model of service is not currently resourced within Te Whatu Ora's work programme.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

adults with ADHD		clinicians to help make assessment and management decisions).	professional groups	
Adopt new medical practice guidelines for ADHD	Currently, RANZCP endorses United Kingdom and Canadian guidelines. New Australian guidelines have recently been released, and New Zealand reviewers believe these to be the most comprehensive and up-to-date.	RANZCP has agreed to endorse the Australian guidelines for New Zealand. NZCCP intends to review the guidelines. A version or addendum could be developed for our local context, particularly to provide cultural context.	Lead: RANZCP Involve: RNZCGP, NZCCP	Leads from the Australian ADHD Professionals Association plan to visit New Zealand on 28-30 March 2023 to promote the guidelines and enhancement of ADHD treatment. Further development for the New Zealand context could be investigated by RANZCP but is currently not resourced.
Establish an ADHD reference group	There was a gap for a collaborative or strategic forum to pursue improvements to assessment and treatment barriers.	ADHD NZ have established a collaborative network group which has had its first meeting. Manatū Hauora, Te Whatu Ora and Pharmac are participants in the group alongside professional associations and other agencies.	Lead: ADHD NZ	The next hui is planned for early 2023.
Deliver quality ADHD training for healthcare practitioners	Professionals including clinical psychologists, paediatricians and psychiatrists need to ensure their understanding of ADHD remains up to date.	Professional colleges including GPs, clinical psychologists, paediatricians and psychiatrists need to upskill their workforces with ADHD specific training – possibly drawing on Australian training. There is existing training through workforce development centres (eg, e-learning on ADHD and neurodevelopmental disorders for child and youth developmental workforce, and mental health and addiction).	Involve: Professional associations, Te Whatu Ora, workforce development centres	RANZCP is developing Position Statement principles, to be published by the end of 2022, that include commitments to enhancing ADHD training of psychiatrists. The GPs college has revamped the registrar training to include ADHD as part of the mental health element of the programme.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Document 5

3 February 2023

Hon Dr Ayesha Verrall
Health Minister
Via email: a.verrall@ministers.govt.nz
Cc: j.tinetti@ministers.govt.nz; k.davis@ministers.govt.nz; john.zonnyville@health.govt.nz; anne.brebner@health.govt.nz; david.hughes@pharmac.govt.nz

Kia ora Minister Verrall

Congratulations on your appointment as Health Minister. With your medical background and knowledge of the health system it must be very rewarding to be responsible for this portfolio.

By way of introduction, ADHD New Zealand is an organisation that supports and advocates for the estimated 280,000 people in Aotearoa with ADHD. The Australian ADHD Professionals Association (AADPA) is a member organisation for healthcare professionals with a special interest in ADHD and last October AADPA launched the new Australian evidence-based clinical practice guideline for ADHD.

ADHD hui – six priority actions
You may be aware that the previous Health Minister attended an 'ADHD hui' at parliament last August along with Chloë Swarbrick, officials from the Ministry of Health, Te Whatu Ora, Pharmac, Police and delegates from the Royal Australia-New Zealand College of Psychiatry, the NZ College of Clinical Psychologists, the Royal College of GPS, Nurse Practitioners NZ, as well as clinicians from each of these groups and a paediatrician. We discussed some of the issues facing people with ADHD and agreed the following six priorities for action.

1. Improving access to ADHD medicine by i)addressing issues with the special authority renewal; and ii) considering new medicines not currently available in NZ.
2. Increasing the understanding of ADHD in Aotearoa through better data and research at both a macro and micro level.
3. Building a consistent model of service for supporting those with ADHD across NZ as part of the health sector reforms.
4. Adopting new medical practice guidelines for ADHD (and consideration of adopting/adapting the AADPA guideline for New Zealand).
5. Establishing an ADHD Collaborative Network Group with representation from government agencies, medical professionals and ADHD NZ to improve collaboration and information sharing and support the implementation of this programme of improvements.
6. Delivering quality ADHD training for healthcare practitioners Including GPs, clinical psychologists, paediatricians and psychiatrists to ensure their understanding of ADHD remains up to date.

Visit to New Zealand by leaders of the Australian ADHD Professionals Association (AADPA)
In December, we wrote to the previous Health Minister, Hon Andrew Little, asking if he would meet with the president and immediate former president of AADPA – Professors David Coghill and Mark Bellgrove. We haven't received a response, but as the new Health Minister we would like to extend this request to you. We will be in Wellington on Tuesday 28 and Wednesday 29 March.

New Zealand and Australia face many of the same challenges in supporting people with ADHD: medical workforce shortages, lack of professionals with a specialisation in ADHD, an education system that is challenging for neurodiverse students, a criminal justice system with a high proportion of youth offenders and prisoners with ADHD, links between those with ADHD and substance use disorder, much higher incidence of suicide for those with ADHD, and a lack of local data and research about ADHD. Research commissioned by AADPA found the social and economic cost of ADHD in Australia to be $20 billion annually.

Australia took a big step forward in addressing these issues when the AADPA ADHD clinical practice guideline was launched in October by Hon Mark Butler, Minister for Health and Aged Care. These evidence-based

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

guidelines are regarded by many as the best in the world and have been endorsed in Australia by every major professional Association and College including the Royal Australia-New Zealand College of Psychiatry and the Royal Australasian College of Physicians. AADPA leadership were heavily involved over the six years it took to complete them. Of course guidelines are only a starting point, and AADPA has also been involved in discussions with Australian federal and state government ministers and officials to identify changes at a system level that will improve outcomes for people with ADHD.

We think there is much to gain from Australia and New Zealand collaborating on these issues. We hope you are able to find time to meet with us to start this dialogue. We are also writing to your ministerial colleagues Hon Kelvin Davis, Corrections Minister and Hon Jan Tinetti, Education Minister, as there may be interest in a joint meeting given the system level challenges.

We also plan to bring together the agency officials and representatives of the medical colleges who attended the ADHD hui for a workshop with the AADPA delegation. You would be welcome to attend some or all of this as well – it is on Tuesday 28 March, 9-1pm.

We look forward to hearing from you. If you have a preference for a particular meeting time on 28 or 29 March, please let us know.

Ngā mihi

Professor Dave Coghill
President, AADPA

Suzanne Cookson
CEO, ADHD New Zealand
suzanne@adhd.org.nz

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Background and talking points regarding Laura William's petition and oral hearing on 15 February 2023

Context

- You will be appearing in person at the Health Committee on **Wednesday 15 February 2023** at **10.35am** to make a ten minute oral submission in response to Laura William's petition on Attention Deficit Hyperactivity Disorder (ADHD).
- These talking points provide a summary of the petition and the Ministry's response.

Overview of Laura William's petition and our response

- Laura William's petition urges the Government to consider adult ADHD a worthy concern, and recognise that, for many, it is financially inaccessible to get a diagnosis.
- Laura proposes the Government:
  - investigate barriers to access to ADHD diagnosis and treatment
  - increase funding to enable better access for adults to screening, diagnosis, and treatment for ADHD.
- Our written response acknowledges that while understanding of ADHD has improved significantly, there are gaps in the health system that could be addressed to better support people who may experience ADHD.
- Many of the barriers to diagnosis and treatment of ADHD were discussed at an August 2022 Parliamentary hui, which was organised by ADHD New Zealand (ADHD NZ) and hosted by Chlöe Swarbrick MP. Relevant health agencies and professional bodies attended and agreed to continue to work together to improve treatment for ADHD in New Zealand.
- There is significant work underway to increase support for ADHD which includes the following.
  - The Misuse of Drugs Act 1975 has been amended to allow Class B controlled drugs (which includes ADHD medication) to be electronically prescribed for up to 3 months, rather than just one month.
  - Pharmac is looking at the potential to review the current requirement for a renewal of the Special Authority to be obtained from a paediatrician or psychiatrist every 2 years for medication to be continued.
  - Medsafe is progressing regulatory work towards scheduling lisdexamfetamine as a controlled drug alongside other ADHD medication. Pharmac is also planning to assess a funding proposal for lisdexamfetamine this year.
  - The Royal Australian and New Zealand College of Psychiatrists has agreed to endorse, for the New Zealand context, new and comprehensive Australian clinical practice guidelines for managing ADHD.
  - ongoing collaboration with partners to create more consistent pathways for access to screening, diagnosis, and treatment for ADHD, in keeping with increased focus on consistency through the health system reforms.

Background on Laura Williams and the petition

- Laura Williams is an advocate for better access to screening and diagnosis for adults with ADHD in Aotearoa New Zealand.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

- Laura's petition includes a survey of 116 people who are part of the ADHD Adults in New Zealand Facebook group. Around 44% of survey respondents reported costs of over $600 for an ADHD diagnosis, and a majority of 70% reported that the greatest barriers to treatment and diagnosis for ADHD are costs and waiting lists.

Talking points

- Firstly, I would like to thank Laura for submitting the petition, and her work to advocate for better access to diagnosis and treatment for adults with ADHD.
- We know that ADHD can significantly impact on a person's functioning in many areas of their life, and like many conditions, people can experience a wide range of seriousness and associated degree of impacts. There is evidence that there is unmet need, particularly for adults who may be experiencing ADHD in New Zealand.
- ADHD is treatable with a variety of options including with the prescription of stimulant medications and with a range of options aimed at helping individuals to manage their symptoms such as Cognitive Behavioural Therapy, and lifestyle management.
- We are keen to make sure that people have access to appropriate assessment and treatment for their mental health needs, including for ADHD.
- Adult ADHD is an emerging area and ADHD has previously been mainly considered a childhood neurodevelopment condition.
- It is important that ADHD diagnosis is done thoroughly and appropriately which includes assessing how symptoms affect the person across a range of settings. Assessment is often best managed by a specialist multi-disciplinary approach.
- This is to ensure the right diagnosis is made as there are many potential causes of reduced attention, including other neurodevelopmental, mental health or medical conditions that could be driving the persons symptoms.
- Adults seeking a diagnosis of ADHD may be referred to specialist Adult Mental Health Services, however, these services are under significant pressure, and the availability of a specialist workforce with the skills and knowledge for diagnosing and treating ADHD is limited.
- Specialist mental health and addiction services are funded to support people with the highest mental health and addiction needs, and many people experiencing ADHD do not meet this threshold for access.
- Adults who do not meet the criteria for these services can seek a private psychiatrist, but this can be costly, and the availability of private psychiatrists is limited.
- There are a range of other supports available for people who experience ADHD, but we acknowledge these supports may not lead to a formal diagnosis of ADHD nor to the prescription of medications for ADHD. This includes GP practices and the primary mental health practitioners that now sit in over 422 practices around the country. People are also able to seek support through a range of online and telehealth options such as the 1737 helpline and the free Groov App.
- These concerns were discussed at a Parliamentary hui last year organised by ADHD NZ, and hosted by MP Chlöe Swarbrick, which considered current and future actions for improving outcomes for people with ADHD.
- The scale of the work programme discussed at the hui was significant and while health agencies do not currently have specific resourcing to support every single area discussed, there is considerable work underway, which will help address of the barriers outlined by Laura's petition.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

- I can provide an update on the key areas that will bring significant benefits for people with ADHD.
    - The Misuse of Drugs Act 1975 has been amended to allow Class B controlled drugs (which includes ADHD medication) to be electronically prescribed for up to 3 months, rather than just one month. This will reduce the frequency people need to see their GP for a script and associated costs.
    - Pharmac is looking at the potential to review the current requirement for a renewal every 2 years of the Special Authority that is required to endorse the prescription of ADHD medications by a paediatrician or psychiatrist
    - Medsafe is progressing work on scheduling lisdexamfetamine as a new controlled drug for the treatment of ADHD, and Pharmac is planning to assess a funding proposal for lisdexamfetamine this year.
    - The Royal Australian and New Zealand College of Psychiatrists has agreed to endorse, for the New Zealand context, new and comprehensive Australian clinical practice guidelines for managing ADHD.
- Ongoing collaboration is important, as well as exploring future work with health entities including Manatū Hauora, Te Whatu Ora, Te Aka Whai Ora, Medsafe, Pharmac, and with other key stakeholders such as ADHD New Zealand, and with Whaikaha - Ministry of Disabled People.
- ADHD NZ has established a 'collaborative network group' of professional associations and government agencies. Manatū Hauora, Te Whatu Ora and Pharmac were represented at the initial meeting and will continue to participate.
- To summarise, I would again like to thank Laura for her petition and assure the committee that there is considerable work underway by health agencies to improve access to treatment for ADHD.
- We are happy to take any questions from the committee.

Potential Q&A

1. Do health entities consider it positive the amount of ADHD medications distributed has increased so significantly?

Recent research has indicated dispensing of ADHD medication to children and young people is increasing over time in Aotearoa New Zealand (98% increase in prescriptions of ADHD medication to all age groups between 2018 to 2022).

However, dispensing of ADHD medication in New Zealand remains lower than the worldwide prevalence of the disorder indicating that ADHD medication is probably not over-dispensed.

Recent mental health specific campaigns have made it easier for people to recognise that they may need to access mental health support. This is no different for children and young people who may present with symptoms of ADHD.

Increased access to healthcare and medication, greater awareness and changes to clinical practice may have resulted in an increase in people seeking intervention and treatment, which would lead to better health outcomes.

2. Would health entities consider ADHD an under diagnosed condition in Aotearoa?

Prevalence data from the New Zealand Health Survey shows that children and young people aged 2 to 14 years diagnosed with ADHD fluctuates between 1.5% and 2.7% yearly. According to AADPA (Australian ADHD Professionals Association), the prevalence of ADHD in children and adolescents internationally is 5–8% and in Australia is between 6% and 10%. This may indicate that some ADHD may be undiagnosed in Aotearoa New Zealand compared with similar countries .

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Currently, there is no central source of information on how many New Zealanders have been diagnosed with ADHD or how they're being treated so this is unknown. It is likely that there will be some people who are undiagnosed. Further, there is growing awareness that ADHD may have not been recognised earlier or may continue into adulthood, so more people are likely to be coming forward seeking diagnosis and treatment as a result of recent mental health campaigns and public discussion.

There is also a need to be mindful that young children in particular can present with symptoms of ADHD which on further exploration and assessment can be either attachment or anxiety based or indicative of some other learning need or physical health problem such as hearing loss which may impact a child's learning. ADHD symptoms can be features of other common mental health conditions and considering the potential for co-existing neurodevelopmental and mental health conditions is an important part of ensuring children and young people receive the most appropriate support.

3. Are health entities aware of the challenges those with ADHD are describing when trying to access medication?

Yes, there is awareness of the current challenges. In August last year, a Parliamentary hui including health entities discussed a range of issues and potential actions. Following this, the Ministry is participating in a collaborative group of stakeholders on further joint discussion and action. There is valuable work happening in some key areas to improve treatment and medication access for those with ADHD for example:

- the Misuse of Drugs Act 1975 has been amended to allow Class B controlled drugs (which includes ADHD medication) to be electronically prescribed for up to 3 months, rather than just one month. The new regulations came into force on 22 December 2022
- commitment from health entities to continue collaboration and update consistent pathways for access to screening, diagnosis, and treatment for ADHD, in keeping with opportunities through the health system reforms
- the RNZCGP (Royal Australian and New Zealand College of Psychiatrists) has agreed to endorse the Australian ADHD Professionals Association guidelines in the interim with a view to tailoring for the local Aotearoa New Zealand context – especially in terms of Te Tiriti o Waitangi compliance.

4. Do you consider it timely to improve access to a diagnosis of ADHD and access to medications?

Diagnosis of ADHD by a specialist is important to ensure any other potential causes of symptoms are taken into account and other potential neurodevelopmental and mental health conditions are considered.

However, there may be alternatives that can be considered to the current Special Authority requirement for a paediatrician or psychiatrist to undertake a reassessment every two years in order for medication to be continued.

For example, by decreasing the frequency of needing a reassessment or increasing the workforces who can provide Special Authority.

5. Why is there now three month e-prescribing of ADHD medication, but people can only get subsidies for the first month?

A recent amendment to the Misuse of Drugs Regulations 1977 means that prescribers are now allowed to prescribe Class B controlled drugs for three months instead of just 1 month. However, changes are also needed to subsidy regulations (Pharmac) to ensure all three months of medication are subsidised to avoid the patient needing to pay the full cost of medication dispensed in the 2nd and third month.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982