



COMMONWEALTH OF AUSTRALIA

# Official Committee Hansard

## SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

**Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD**

Public

MONDAY, 24 JULY 2023

PERTH

BY AUTHORITY OF THE SENATE

## COMMUNITY AFFAIRS REFERENCES COMMITTEE

**Monday, 24 July 2023**

**Members in attendance:** Senators Kovacic [by audio link], Liddle [by audio link], Pratt, Rice [by audio link] and Steele-john

### **Terms of Reference for the Inquiry:**

Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD, with particular reference to:

- a. adequacy of access to ADHD diagnosis;
- b. adequacy of access to supports after an ADHD assessment;
- c. the availability, training and attitudes of treating practitioners, including workforce development options for increasing access to ADHD assessment and support services;
- d. impact of gender bias in ADHD assessment, support services and research;
- e. access to and cost of ADHD medication, including Medicare and Pharmaceutical Benefits Scheme coverage and options to improve access to ADHD medications;
- f. the role of the National Disability Insurance Scheme (NDIS) in supporting people with ADHD, with particular emphasis on the scheme's responsibility to recognise ADHD as a primary disability;
- g. the adequacy of, and interaction between, Commonwealth, state and local government services to meet the needs of people with ADHD at all life stages;
- h. the adequacy of Commonwealth funding allocated to ADHD research;
- i. the social and economic cost of failing to provide adequate and appropriate ADHD services;
- j. the viability of recommendations from the Australian ADHD Professionals Association's Australian evidence-based clinical practice guideline for ADHD;
- k. international best practice for ADHD diagnosis, support services, practitioner education and cost; and
- l. any other related matters.

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**LEAHY, Dr Tim, Member, RACGP WA ADHD Committee, Royal Australian College of General Practitioners**

**LEECH, Dr Andrew, Member, RACGP WA ADHD Committee, Royal Australian College of General Practitioners**

**SEGRE, Ms Antonella, Chief Executive Officer, ADHD Western Australia**

**TONER, Dr Michele, OAM, Chair, Board of Management, ADHD Western Australia**

**Committee met at 09:07**

**CHAIR (Senator Rice):** I declare open this hearing of the Senate Community Affairs References Committee's inquiry into barriers to consistent, timely and best-practice assessment of attention deficit hyperactivity disorder—ADHD—and support services for people with ADHD. I'll begin by acknowledging the traditional custodians of the many lands we're meeting on today. I am in Naarm/Melbourne, on Wurundjeri country. The hearing is taking place on the lands of the Whadjuk Noongar people. I pay my respects to their elders, past and present, and extend that respect to all Aboriginal and Torres Strait Islander people, including the people who are joining us here today.

These are public proceedings being audio streamed live via the parliament's website, and a Hansard transcript is being made. I remind all witnesses that, in giving evidence to the committee, they are protected by parliamentary privilege. It's unlawful for anyone to threaten or disadvantage a witness on account of evidence given to a committee, and such action may be treated by the Senate as a contempt. It's also a contempt to give false or misleading evidence. Witnesses also have a right to request to be heard in camera. I now welcome representatives from the RACGP WA ADHD working group, including representatives from the RACGP and ADHD WA. I understand that information on parliamentary privilege and the protection of witnesses giving evidence to Senate committees has been provided to you. I now invite each organisation to make a short opening statement. At the conclusion of any remarks, members of the committee will ask you some questions.

**Ms Segre:** I thank the committee for providing the opportunity to give evidence today. ADHD WA is a specialised peak that has been operating in WA for the last 30 years as an unfunded, not-for-profit organisation within a social enterprise model advocating for the early intervention and treatment of ADHD that would contribute to positive long-term outcomes for children, adults, their families and carers. The organisation has a unique approach to ADHD, having developed a person centred, holistic model, integrating clinical service and education programs for parents, teachers, employees and employers and valuing the role that the peer support group plays across pre- and post-diagnosis. It is a member based organisation with over 2,000 members. That equates to over 4,000 individuals, families and carers. We take a collaborative and co-design approach across all our service delivery areas. All of our training is developed and delivered in collaboration with a professional advisory body and with input from its two lived experience advisory bodies, adults and carers, and youth. We are operating at the coalface. We average 200 calls per month and 30 emails per day, with over 70 per cent requesting support and information. We remain their first touchpoint and hold the experience and knowledge to support the ADHD community. Our submission represents the collective voice of 606 of our members. I hope that you have taken the time to listen to their stories and the recommendations, which are solution based.

**Dr Toner:** In writing the submission, we felt it important to add three recommendations under term of reference (1). Our first recommendation is that patients attending emergency departments as a result of suicide attempts be assessed for ADHD and treated accordingly. This is informed by the pilot conducted at Perth Children's Hospital, described in our submission, which found ADHD in 79 per cent of that group and found that meaningful intervention showed a significant reduction in future suicide attempts, particularly in girls. Unfortunately, it's not as effective in those who are non-binary. There is a great deal of work to be done there. A second recommendation regards the education system, which is so often a hostile place for students with ADHD despite teachers' best efforts. That is outlined in our submission. Our third recommendation is to fund ADHD WA in order to make our service accessible to all socioeconomic groups, Aboriginal and Torres Strait Islander people, and cultural, linguistic and gender diverse individuals and families.

I have one final comment. When I started this work some 30 years ago, I had to learn two skills. The first was to compartmentalise the tragic stories that we hear on a daily basis, and the second was to leave my emotions at the door. However, at present I find myself unable to do either of those, as the current situation for people with ADHD is worse than it's ever been in the 30 years that we've been here. We've had nothing but lip service from successive state and federal governments for 30 years. So we thank you for undertaking this important work and we look to this committee holding the government to account through this process. Thank you very much.

**Dr Leahy:** Thank you and good morning. I'm speaking on behalf of Dr Andrew Leech, who's next to me today and our colleague Dr Sean Stevens, who couldn't be here today. I'm also speaking as part of the WA GP ADHD collaboration. We're fortunate to have the great support of the RACGP, ADHD WA, the WA Primary Health Alliance and specialist paediatric and psychiatrist supporters. Dr Leech, Dr Stevens and I have clinical and lived experience of ADHD in our families. We daily face the realities of the unmet needs of our patients. We have researched the models available in Australia and we appreciate the assistance we've had from their authors.

The problem: there is an enormous cost to ADHD in Australia, personally and in economic costs. This is increasingly being appreciated. What also needs to be appreciated is this: there will never be enough paediatricians and specialists to address the unmet need. There is a real cost too, in GPs not being used to their full scope. A significant number of GPs want to do more. One thousand college GPs recently attended an upskilling on ADHD—not the usual 40 or 50 but 1,000.

The future: GPs should be providing the majority of care to the 50 per cent plus of patients that are relatively straightforward. How are we going to get there? We need federal and state policy and funding to achieve this goal. GPs need to be upskilled. The upskilling needs to be easily available and not onerous for a lot of GPs. The training will follow the national guidelines, the evidence-based guidelines and the about to be released prescribing guidelines, both from the AADPA. GPs need better funding for longer consults, not less pay per minute as the consult gets longer. We should not get paid less for assisting patients with ADHD. GPs need to be funded to have brief discussions with specialists. This needs to be an MBS item. We need funding for communities of practice, with groups of GPs and specialists having monthly meetings to discuss patients and upskill. We need to be able to get timely assistance from specialists, psychologists and ADHD coaches and education and employment support for our patients—the sorts of supports highlighted in the ADHD WA submission. Dr Leech, my colleague, is already doing this in his practice with the support of Dr Desiree Silva, who you will hear from later today. The results are impressive.

Redesigning the system to support GPs in this more central role needs funding. Collaboration with peak bodies, colleges, primary health organisations and others is ongoing work and needs financial support. The funding for all of this is urgent. The emphasis should be on early detection and appropriate treatment, with GPs playing a central continuing role with appropriate support from specialists, other providers, organisations and government. Our approach does address almost all of the terms of reference for the inquiry. I just want to make one small point, which possibly we left out of our submission. Point D talks to the impact of gender bias in ADHD assessment, support services and research. More than 50 per cent of GPs are female. I would challenge you to find a more diverse group in the community that represents the Australian population and is tuned into the needs of its patients. Thank you.

**CHAIR:** Thanks very much.

**Senator STEELE-JOHN:** Thank you both so much for your opening statements and for the effort that's gone into putting together comprehensive submissions. I want to first go to ADHD WA, but if others have thoughts on these same topics, please jump in. You've stated in your submission that access to diagnosis in WA is inadequate. I wondered if you could give the committee some examples of what that inadequacy looks like.

**Dr Toner:** Currently, people are waiting over a year to see someone in the public sector. They would be children with ADHD. They're having great difficulty getting hold of multidisciplinary treatment within the public sector. Child paediatric services is just unable to cope. So we have some members who are actually working two jobs to try to get their children private treatment with OTs and speech therapists wherever necessary. What that's also doing is putting great pressure on private paediatricians, who are being really badgered by parents who just are desperate to get their children to see a doctor and have a diagnosis of ADHD. Then, of course, in the adult sector, there is little or no treatment for ADHD and has never been. So they have to wait to see a private psychiatrist. That can often take up to a year as well. Many private psychiatrists and paediatricians are retiring, and there just aren't enough doctors to take over from them. It's also important to note that CAMHS—Child and Adolescent Mental Health Services—will not treat people with ADHD or with autism. So people are really desperate and have nowhere to go.

**Ms Segre:** Can I share some of the comments from our members?

**Senator STEELE-JOHN:** Absolutely.

**Ms Segre:** One reads:

Our kids are suffering from not having diagnoses available. From not having any additional funding to help support them—unless you include all the teachers that try desperately to make school more manageable for them, out of their own pocket or with amazing Principals (very rare).

One from an adult:

Being adult-diagnosed, it was incredibly liberating to start receiving appropriate care—however as a child. I experienced immense struggles in my schooling and socialising, that consistently felt as if I was at the back of the pack. It wasn't until I was in my 20s that a psych student asked me about my problems.

So the impact is absolutely considerable.

**Senator STEELE-JOHN:** Absolutely—considerable. And if you are needing to wait up to two years in the public system for a child diagnosis and if there's no pathway for public diagnosis for an adult, which is something the WA Department of Health has confirmed, your only option is the private sector, which also has long wait times but also significant costs. We heard in our previous hearing that individuals are paying massive amounts of money. Can you share with us examples that your members have shared with you of the kinds of cost barriers that they are experiencing when seeking that diagnosis in the private system?

**Dr Toner:** Yes. As I said, we have one member who has her normal Monday to Friday job, and then on Saturdays and Sundays she's cleaning houses to earn enough money to pay for her child's speech therapy privately. We also have children who are being excluded from schools because their ADHD isn't being addressed. It's not unusual for a child to be excluded from a school for a year while they are waiting. So they're falling behind on their education and they're not socialising because their parents either can't afford to go privately or can't actually find someone in the private sector to treat them. People talk about the ADHD tax. It's a very expensive condition to treat, and they're being discriminated against, really.

**Senator STEELE-JOHN:** Absolutely. Dr Leech?

**Dr Leech:** In response to your question, the last letter I have received from the Child Development Service indicated a wait time of in excess of 29 months to see a paediatrician for assessment of ADHD. So the patients are getting that response at the moment on our referral. Even if we write 'urgent' for the private paediatricians, we've basically got to the point where there is no access. We've got to capacity. I've got most of the patients I've referred returning quite frustrated, emotional and overwhelmed by the response that they're getting from the referrals that I've sent—very good referrals. They've explained to me that the phones just ring out when they call up to try and make a booking, or they're told to send an email and they'll be put onto a waitlist.

**Senator STEELE-JOHN:** Doctor, in your experience, when you are working with a family that is having to endure that kind of 29-month wait time, what impact does that have on them, their health and their mental health?

**Dr Leech:** A significant impact. The impact is also not only on the patient but also on us as GPs as they return with increasing problems related to their ADHD—particularly in mental health, school attendance, the learning difficulties that develop out of untreated ADHD, the exponential problems that arise from not having adequate care and not having adequate access, and my limitation of not being able to diagnose, because we are taught not to diagnose; we're taught just to manage their symptoms. So we're then limited in what we can do other than try to involve some allied health providers, which also are now building up in their capacity.

**Senator STEELE-JOHN:** In terms of your view on what we should be looking to achieve in terms of tackling, first of all, the cost question, it seems to me that one of the priorities needs to be to make assessment and diagnosis more affordable for people, potentially even to make it free.

**Ms Segre:** Yes, I wanted to share the cost—the question around the costings. We're looking at families that are looking beyond \$20,000. We need to address that. Research clearly indicates it is a genetic condition and therefore there will be multiple members of that family that will have the condition. As such, they're having to make decisions on which member of the family will have the treatment. We have stories of parents, when they've been able to access the medication, having to share the medication, which obviously is not best practice, between the family members. So, yes, absolutely. We're really advocating for subsidising of treatments and looking at how we can—ADHD WA has been looking at how we can access a form of Medicare rebate. Looking at that, the assessment itself, the first hour can be seen as therapy and then the feedback can be seen as therapy. That could save members of the community between \$180 and \$200. But, when we look at the overall, as you said, average of the cost of just an assessment within the private sector, ADHD WA is coming in at the lowest possible cost, which is still \$1,275. So we are not being able to support the community; we're really just being able to support those that financially can. I really do need to have it noted that we need to look at what's happening in the regions. It's even more dire. I think that Dr Leech and Dr Leahy will confirm that.

**Senator STEELE-JOHN:** In terms of the assessment and diagnosis pathway, it sounds to me that, from your perspective, there would be great benefit in bringing it into line with the assessment and diagnosis pathway for other conditions, where there are publicly funded pathways for both children and adults that are free under Medicare.

**Dr Toner:** Absolutely. If you look at the NDSS website for people with diabetes, just to have the information available and therapy that they can access online—it's just accepted that, when someone is diagnosed with diabetes, they get all the support they need. It would be wonderful to have a world where ADHD is treated in the same way.

**Senator STEELE-JOHN:** Absolutely. And, from the practitioner perspective, you're very much of the view that you should be able to work to the top of your scope, including diagnosis and prescribing of medication and, critically, that you are given the funding support through the rebate for your consult times that enables you to spend the time with the patient that is needed and to coordinate that multidisciplinary team—correct?

**Dr Leech:** That is correct, yes. We believe that, with adequate training and adequate upskilling for the GPs with a special interest—this won't appeal to all GPs, but we certainly have shown that we have a lot of interest from GPs—we would be able to do this sort of work and would be happy to do this sort of work, as we do with many other chronic conditions.

**Senator STEELE-JOHN:** Absolutely. I have one last question before I pass to Senator Pratt. Post-diagnosis, what supports exist currently for folks that are diagnosed and for families in that period after diagnosis in terms of support, guidance and advice?

**Dr Toner:** Aside from ADHD WA, very little, really. People get a prescription and hopefully their doctor refers them to a multidisciplinary team, but what they really need is support and a safe place to go where they can speak to other people, which is what ADHD WA offers. But essentially they are mainly given a script and put on a waiting list to perhaps get some other treatments available. We know that pills don't teach skills, so people have to upskill themselves in managing, learn specialised parenting skills and learn skills in managing their ADHD, because the medication doesn't do it all.

**Senator STEELE-JOHN:** Yes.

**Dr Leahy:** Could I just add that, as a GP with a partner and two children with ADHD, I'm very familiar with the journey. As a GP making the diagnosis and discussing with patients, there are many aspects. Following the guidelines, there's a significant process of psychoeducation required. Part of it is dealing with the grief of the diagnosis—the life that could have been lived if children had not been constantly told that they were naughty or that they were lazy and if they hadn't had to revert to being the class clown to get a bit of attention and support—and then later to wonder about the drug career and all sorts of self-medication approaches and then to think, 'Well, how do I adjust to this in my current work and in my family?'

Pointing towards parent training, supports and groups at ADHD WA, helping a person to make practical decisions and get accommodations and support in the classroom, and writing support letters—these are things that I'm doing on a daily basis as a GP. It's not one consultation; it's repeated consultations over a time, because to adjust to the diagnosis of ADHD is a process of years. It's not a single session.

I think you need people who are sympathetic to the needs and are educated not just in the prescribing of stimulants but in the whole process of psychoeducation and the various processes. There are two examples. Executive function is a major issue, and people need supports: they need ADHD coaching and other supports. Emotion dysregulation is another major issue. For example, the modules on the CCI here in WA are very good around helping with tolerating big feelings, but emotion dysregulation is a key part of the whole picture and needs to be addressed as part of the psychoeducation.

**Senator STEELE-JOHN:** Absolutely.

**Senator PRATT:** Thank you. It wouldn't surprise you to know, for example, that someone like me wasn't diagnosed with ADHD until my early 40s or that we contacted 12 different paediatricians and I think it took us about a year to find one and get our son on their books. None of that's surprising to you.

Can I ask about what needs to change? You've got a pilot. I've seen the political debates historically that have said ADHD is overdiagnosed, and I was wondering if you think that's played a role in the diagnosis and prescribing practices being so limited and locked down, if you like, to paediatricians and psychiatrists. Who has to make the decision to unlock that? It's my understanding that there has been coalescence between that political pressure on governments and the control of the different medical professions and their turf. So who needs to change that, and how, to introduce a model like the one you've outlined more holistically?

**Dr Toner:** I'd like to speak to the overdiagnosis and then pass to others. That has been a total myth. There was a very strong anti-ADHD movement within the parliament of WA. In WA, we're famous for our de-identified databases. We spend a lot of money and time counting pills. At the last count, there were 0.6 per cent of the adult population being treated with stimulant medication for ADHD, out of a potential four per cent. So the



overdiagnosis debate is a nothing. It's a myth. That was perpetrated by the media and really, I think, caused a lot of damage. As to what needs to be unlocked, I'll leave that to my colleagues.

**Dr Leahy:** Could I say, Senator Pratt, knowing a close family member who was seen by 10 psychiatrists before she was diagnosed, and having seen this frequently, I want to say sorry, on behalf of the health system, for your experience. 'Sorry' is one of the first things I say to many, many patients about what they're experiencing at the hands of the health system. What people have experienced—the pain and suffering that their families and they themselves have experienced—is not a trivial matter.

Going to your point about the forces, I think we do need to recognise commercialisation—the influence of drug companies and the push for more prescribing. These are real forces in society. But, when you see a person in front of you and you go through their criteria, their experiences and all the rest of it, you should be able to make a free decision as a clinician and as a patient about whether or not you'll access an evidence based treatment, free of all sorts of scaremongering and free of crazy limitations. I can prescribe all sorts of drugs, narcotics, hep C treatments—you name it. I can treat cardiac failure and diabetes. I can treat any complex chronic condition. But, when it comes to treatment of a person with a clear diagnosis of ADHD, for some reason, even with evidence based prescribing guidelines available, I'm restricted. It doesn't make sense.

**Dr Leech:** We also don't dispute the fact that ADHD rarely exists alone. It often co-exists with other conditions and can become complicated. But we're also perfectly positioned as general practitioners who often have a view of the family over a lifetime and have a really special bond and knowledge of how that family interacts and that child's life journey. So I think the ability to see and look out for complications that might occur along the way and to screen for other comorbid conditions is something that we actually would be quite well placed to do.

**Senator PRATT:** If someone has been screened for anxiety or depression, to what extent will you automatically also screen for ADHD?

**Dr Leech:** We would, and we should.

**Dr Leahy:** We do.

**Dr Leech:** We do. The other fact is that it's not necessarily a simple process, to screen for ADHD, and we're not advocating for a rushed, simple, 15-minute consultation. We believe this requires a significant amount of time and effort to make a diagnosis. That time and effort is not well remunerated and takes multiple consultations. But we do think we have that ability and we have already got the opportunity to have multiple consultations with our patients, as we do in general practice.

**Senator PRATT:** Are the royal Australian colleges of psychiatry and paediatrics supportive of releasing this diagnostic and prescribing power to general practitioners, or is that in dispute?

**Dr Leahy:** I think we would say that we have very supportive colleagues—both paediatricians and psychiatrists—who want to be part of our model. We haven't done a ballot of all psychiatrists and all paediatricians. What we do hear from all doctors in every state is that every doctor has had a very poor experience of ADHD training in their own undergraduate experience. Their postgraduate experience has been generally very poor and tokenistic. One day—

**Senator PRATT:** So you wouldn't necessarily want them doing that prescribing or diagnosis until they had it properly within their scope of practice?

**Dr Leahy:** I think the evidence based guidelines point to the need for proper upskilling, and it's silent on the issue of who it absolutely has to be. There is no justification for saying it should be absolutely this person and absolutely not that person. It should come down to competence—medical competence.

**Senator PRATT:** In order for someone to gain a prescribing right—for example, nurse practitioners gain a prescribing right for sexual health or for diabetes—if you're going to say general practitioners are going to get a prescribing right for this, what is the training and what are the criteria for reaching that milestone in your view?

**Dr Leahy:** We addressed that in our submission to WA Health. We're drawing on the professional development that's available in Australia—in other jurisdictions, such as New South Wales—and online training. We hope to draw on the expertise that's here in WA, through ADHD WA, to develop appropriate packages and a range of packages that are available in the regions, face-to-face and online, for GPs who do need a range of options.

**Senator PRATT:** I think this is your model here—

**Dr Leech:** This is the model that I put forward, yes.

**Senator PRATT:** It still has a paediatrician consult in it.

**Dr Leech:** We've based this model on the current rules around prescribing and the current rules around a paediatrician being required to make a diagnosis. We've basically gone forward and put to the test the collaborative approach to diagnosis of ADHD in children. We've run this through with a number of patients now, with excellent feedback. We've managed to see approximately 10 patients over about a four- to six-week period, with the consultation and a lot of the legwork being done by the general practitioner with the collaboration with the paediatrician via telehealth and then some ongoing interactions with the paediatrician as required to continue to make changes to medications or whatever is required within the legislation around prescribing.

We just wanted to show a proof of concept because we believe that collaboration is really important still. Whether it's collaboration through allied health psychologists, paediatricians or psychiatrists, we still benefit from their input and expertise to help us with managing patients, especially those that are more complex. But we wanted to show here that we can do these over a number of consultations using the right screening tools under the umbrella of good education.

**Senator PRATT:** What can you tell me about comorbidities in terms of patients who might have underlying ADHD but are actually presenting with addiction, anxiety or depression and are struggling, for example, to work out whether ADHD is something they should be treated for because their drug use is more predominant? How common is that?

**Dr Leahy:** Yes, I saw a young guy recently who was about to go back to prison, probably. He's got hep C, warts on his foot and, probably, ADHD. He wants them all dealt with. I've organised hep C treatment for him, and he's probably going to go back to prison hopefully continuing that, but I won't be able to organise the ADHD diagnosis and treatment in a timely way, because of lack of access. It really is a patient centred approach that we take. We want to see the top priorities of the person. Sometimes their depression is the first thing that needs to be treated, and we come back to ADHD. Often these days it's the ADHD that really needs to be dealt with, because all of these other issues have been identified but the rate-limiting step is the ADHD. It's an executive function disorder. It's a difference between capacity and carry through. This person can do it. They've got these diagnoses—drug, mental health or whatever—but to actually action to get to seeing that therapist or doing that plan or changing, they need help with their ADHD. So it's often the issue.

**Ms Segre:** I want to take a different approach, if I may. We know that it's going to take time to look at the model. As you know, ADHD WA has been part of the submission with Dr Tim Leahy and Andrew Leech. What we can see that can be an immediate impact on the community is that, whilst adults and children are waiting for their diagnosis, there is the opportunity to access group therapy that would hold them in the interim. Let's look at a child with a teacher who articulates the need for the six-year-old to be able to be assessed for ADHD. During that period of time, if we're looking at this two-year wait within the public system and looking from a socioeconomic point of view, we have the opportunity to expose them to programs that would hold them and enable them to thrive and not lose two years of education and/or we look at an adult not being able to stay engaged in employment. We're looking at 40 per cent of adults with ADHD which are not employed on an ongoing basis. I heard this morning the whole conversation around what casual work is. I do wonder and question how many are in this 'casual work' due to their ADHD. So there are some immediate solutions that could be placed.

What we hear from our members and from the community is that even at the point of diagnosis they're not provided with sufficient information of where to go from here. This is something that ADHD WA is also working on. The programs that have been developed, which we'd love to see subsidised by government, will support the child, the parent, the partner and the adult through their life span, keeping them engaged in community. Therefore, let's look at the costs that currently lie for government. You mentioned it; there are comorbidities—depression, anxiety. That is impacting on the mental health system. As Dr Toner mentioned in her opening, we're looking at a high suicide distress rate. We know that at the moment there's research that's been funded through the mental health commission by the telephon institute around looking at what is the after-care. That is another issue. I just wanted to bring in that there are solutions that can be actioned with immediate effect.

**Dr Leech:** Just a personal example with a patient, in response to your question, Senator Pratt: a 20-year-old female I've been seeing for a number of years who had obvious ADHD was unable to access public services. I had referred her to a number of private psychiatrists—probably in excess of seven or eight—and had rung each of those psychiatrists but had rebound letters saying, 'This girl is too complicated', for various reasons. This girl was accessing Telegram, an app, to access ADHD stimulant medication, but was led down another pathway with that app and was led to other medications, and, sadly, overdosed last week and died. As an example of what we're talking about, with suicide, we're talking about death and very serious examples of patients who are unfortunately suffering from prolonged wait times.

**Senator PRATT:** We really need to divert people from self-medicating in order to prevent that.

**Ms Segre:** I think we really need to look at the cost, which was your initial question. We have a terrible story of a woman who was diagnosed at 46 years of age and was no longer able, due to financial reasons, to access her psychiatrist and no longer had her medication. She was finally on a waiting list, and she died of an overdose on depressants and alcohol just two weeks away from being on that cancellation list. These are stories that need to sit with the Senate. Her name was Joanna.

**Senator KOVACIC:** Thank you for your submission. Dr Toner's submission indicates there is an ADHD prevalence internationally of about five to eight per cent, but it's six to 10 per cent in Australia. Almost all submissions, and indeed the evidence today, suggest a backlog in diagnosis. But Australians seem to be diagnosed at a greater rate than our international counterparts. I'd like to understand whether you have any information or insights into that. Additionally, the federal department of health's submission to this inquiry points out that WA has the highest rate of ADHD medicine prescriptions for adults in the country, at about 9.35 per 1,000 people. Do we know why it's so prevalent in WA compared to the other states, and nationally compared to globally, and what could be causing this and the pressure on the WA health system as a result and on medical practitioners and their patients?

**Dr Toner:** The first point to make is there is no overdiagnosis of ADHD; there is still underdiagnosis of ADHD. I'd encourage you to speak to Professor Desiree Silva, when she appears later today, about worldwide prevalence and where Australia sits in that diagnosis. There is no evidence to show that ADHD has been overdiagnosed in our country.

Going back to WA: I would say the reason adults are more often diagnosed in WA than other states is we have an excellent team of people and excellent ADHD awareness, including ADHD WA. As I mentioned earlier, in the WA health department's most recent report into stimulant prescription, 0.6 per cent of the adult population was receiving stimulant medication from ADHD WA—so that is still an underdiagnosis.

**Senator KOVACIC:** Thank you. I wasn't suggesting overdiagnosis; I was trying to get an understanding of why our rates here are higher than what is reported, in the submissions to this inquiry, to be the global rate. I'm curious as to that, if you guys have insights into that.

**Dr Toner:** I can only speak to WA. I would say our rates are higher because many of the pioneers of ADHD treatment started in WA—Trevor Parry, Ken Whiting, Roger Paterson. A lot of things were pioneered here. As to globally, it is my understanding that we are in line with ADHD diagnosis globally, but I don't know whether my GP colleagues have any further information on that.

**Dr Leahy:** I don't have more information. Perhaps we're global leaders in watching TikTok! I don't know. There are very big forces at play. Social media has played a very big part in recent trends. There are big forces at play in each state and lots of local issues, too. I think we've got a lot in common with other states. I don't think we should be seen as outliers, because the more I talk to my colleagues in other states, the more I hear we are all dealing with similar issues.

**Senator STEELE-JOHN:** I think it's important to note there that social media has helped people identify that they have ADHD and connected them to other people experiencing the same thing. They've had the collective lightbulb moment.

**Senator PRATT:** Yes—even if they do spend too much time scrolling on TikTok!

**Senator KOVACIC:** Thank you. That probably leads into my next question. In that, do you see that there are difficulties, and if so what are those difficulties, in terms of inconsistent regulations across the Commonwealth and states? What kinds of issues do they create for your members, your GPs and your patients in that regard?

**Dr Toner:** For our members—I remember having this discussion at the parliamentary inquiry in the 2000s—I think one of the biggest problems is the lack of prescription criteria across the country, so that each state is responsible for it. Dr Paterson, who's coming later, will be able to give you a lot more information on that. He's a bit of a full bottle on prescribing regulations in each state. The first problem is that there is inconsistency around prescription regulations across the states. I think around diagnosis and treatment it's consistent now with the AADPA guidelines, but I think it would be a really good idea to have consistent prescription regulations around the country, because it causes terrible problems for our members when they move states and they can't access their scripts in other areas.

**Dr Leech:** I've certainly had patients travel from Western Australia to Victoria or Sydney to try and seek a diagnosis and treatment only to return here and be unable to continue that treatment, due to the differences in the legislation. There are significant differences. Also, in each state, I believe, different practitioners can diagnose ADHD. I've got colleagues in Sydney, GPs, who are able to diagnose and manage ADHD. We know that in

Melbourne general paediatricians can manage and diagnose ADHD; in WA it's encouraged that only developmental paediatricians diagnose and manage ADHD. So there are differences and nuances across all states, which makes it very complicated.

**Dr Leahy:** Could I add: a patient of mine who attends an inner-city public mental health service here has been told by a couple of clinicians, 'You should get your ADHD treatment.' It's previously been diagnosed. He's got bipolar and a whole range of other things. He's a disability pensioner. But he's also been told, 'If you're going to get that diagnosis, you must go to a private psychiatrist, and if you do you'll be discharged from our clinic and you will not get your medications at a cheaper rate through the hospital anymore.' So he's being told by the same clinic, 'You should go and get your treatment, but we'll discharge you, and you'll have to go privately.' This is for a guy whose medications they are already subsidising because he's got economic hardship. So I would point not just to discrepancies between jurisdictions but also to discrepancies between institutional systems within the same state. Another example would be two patients who have recently come out of prison with clear diagnoses of ADHD, who can't get the diagnosis within the Department of Justice health system and who are now outside. At least one of them is already going back to prison; another one is at high risk of going back to prison without proper help. I'd point to the discrepancies within our own systems, within state budgets, that are also an issue.

**Senator STEELE-JOHN:** Absolutely. Senator Liddle, did you have any questions before we conclude?

**CHAIR:** Senator Liddle didn't indicate that she had questions, so I think we should wrap up now. Thank you, everyone, for your very moving evidence today.

**Senator STEELE-JOHN:** I just have one final question, sorry. Could I slip it in before we finish?

**CHAIR:** One very quick question.

**Senator STEELE-JOHN:** Yes. Very quickly, on the question of the barriers to stimulant prescription: in WA, and in a couple of other jurisdictions as well, if you are found or suspected to be a user of certain illicit substances, you're barred from taking stimulant medication. My understanding and the evidence we've heard as a committee is that often, either because of the barrier to diagnosis or because of the cost of the medication, people are not able to get the medication that they need and so they self-medicate with other substances. Do you think we need to update some of these rules and restrictions so that people can access the actual medications that they need regardless of whether they've previously used illicit substances?

**Dr Leech:** I think everyone deserves an opportunity to access care and diagnosis.

**Senator PRATT:** What is that preclusion based on? I've certainly seen the same in some people with ADHD. If they're known, for example, as a marijuana user, even if it's prescribed, psychiatrists won't prescribe them both.

**Dr Leahy:** There's a legitimate concern about diversion and poly-substance-use. We're talking about people some of whom have impulse problems and a history of poor decision-making in various contexts. At the same time, untreated ADHD is a driver for many of these problems. Frequently, I hear people say, 'It's only when I'm on speed that I can watch a full movie, clean up my room, feel normal.' So there is self-medication in the absence of proper health systems. I think we just need to be real about it. We need to acknowledge that many people have more than one problem—there's complexity—and we have to acknowledge that some people have a history of substance abuse and it's related to their ADHD. With many of the patients I see, I say, 'Look, you're going to have to have clean urine at the time of your psychiatry appointment.' You really need to be upfront about it: 'You won't be able to continue to use when you're in treatment,' et cetera. Many patients, when they see the havoc that ADHD has had on their lives, are prepared to make that step and move on. But we do need to be more real about it, for sure.

**Senator STEELE-JOHN:** Thank you.

**CHAIR:** Thanks very much for your evidence today. I don't think there were any questions that were taken on notice, but if you do want to add anything extra to the committee's information, if you could get that to us by Monday 14 August, that would be appreciated.

**DOWDEN, Ms Stephanie, Director, Children's Nurse Practitioner, NursePrac Australia, Just Kids Health Clinic**

[10:04]

**CHAIR:** Welcome. Thanks for appearing before the committee today. I now invite you to make a brief opening statement, if you'd like to do so, and after that the committee members will ask you some questions.

**Ms Dowden:** I run a clinic in the southern suburbs of Perth. It is unique in Australia. There's no other service like this that we're aware of. We see children aged from zero to 18, and their parents, and we focus on ongoing health issues for children. One of the outcomes or flow-on impacts of COVID in particular and the increased pressure on child development and paediatric services in Western Australia has been an inability to access services, and we're finding a huge flow-on to our clinic for children of families who are unable to access public and private systems, particularly around child development and child behavioural concerns.

In addition to that, we have a very strong partnership with one of the Perth family support networks, who support parents who are having challenges in their lives. We receive a lot of referrals from the Fremantle-Rockingham Family Support Network for children, usually of primary school age but of all ages, when parents are finding that their children's behaviour is out of control and the school is unhappy with what's happening at school, and they're wanting some sort of assessment of what's going on. What we find with many of those children is a huge—I don't even know the word for it—soup of complexity. There are developmental concerns, there's trauma at home, there's poverty, there's adversity, and very commonly there are intergenerational neurodiversity and neurodevelopmental concerns. So, we're seeing many families with things like ADHD that has been through multiple generations, and we're seeing the consequences. We're seeing parents who've had school failure themselves, educational failure and work failure and who have been in and out of the justice system, and now we're seeing the next generation.

It's been really concerning to us, probably in the last year particularly, that the flow-on has grown at a very alarming rate. As the flow-on into the public and private systems has become untenable for those systems, we're getting more and more. Every single day that I'm in clinic I would have at least two and sometimes up to four or five children or families presenting with these concerns. So, I really welcomed the opportunity to share some of our thoughts with you.

We have four nurse practitioners, and we're all very focused on children's wellbeing and children's outcomes. We feel that there are opportunities for not only children's nurse practitioners but also adults' nurse practitioners to be much louder and more visible in this space, because we can all work together to help resolve some of these concerns.

**Senator PRATT:** What can you tell me about how nurse practitioners bring ADHD and other children's development issues into their scope of practice? And what does that allow you to do?

**Ms Dowden:** At the moment the main barrier is around the prescribing limitations in Western Australia, although that is being addressed at the moment with the poisons act and changes to the poisons act that are coming.

**Senator PRATT:** Can you unpack that? Does that mean it will be within the scope of practice for GPs and nurse practitioners to prescribe ADHD medication?

**Ms Dowden:** I spoke to the chief pharmacist about this just recently. It's not entirely clear what final decision will be made. It sounds like it will probably be at least co-prescribing rights. So, if the medications were prescribed by a developmental paediatrician or a psychiatrist, the GP or the nurse practitioner could be a co-prescriber if they were nominated. There seems to be some indication that GPs might have full prescribing if they've got the appropriate training. I'm not sure whether that's been quite decided.

**Senator PRATT:** What is appropriate training from a nurse practitioner point of view? And in order for me to get my head around the sustainability of services like Just Kids Health, what's your business model? For example, the government has recently made some changes to the MBS item numbers and the payments for nurse practitioners. Are they relevant to your practice? Or are you entirely privately funded with out-of-pocket costs? What does it look like to create access?

**Ms Dowden:** It is a very interesting question. Thank you for asking that one. We have a very strong social conscious—or I do, as the director—and we currently bulk-bill all families with healthcare cards or on pensions. I can assure you that that's barely sustainable, because between 40 and 50 per cent of our client base are in the cohort. As you may or may not be aware, the Medicare billing for nurse practitioners, from the point of view of the reimbursements, is very low. Even with the proposed 30 per cent increase, it's still not going to be sustainable.

Unfortunately, we've just been informed—a few weeks ago—that that increase probably won't happen until July next year, which is really gutting, because services like mine were really hoping that this would actually start to make a difference for us.

We have a mixed billing model. Families that can afford it are charged a private fee and they get the Medicare rebate. We still seriously undercharge compared to any other services around neurodevelopment, neurodisability and child development assessments. We're very clear with families that we do assessments and we make recommendations and we can refer on, because there's a lot of ambiguity around who can and can't diagnose and assess. As the previous group mentioned, it varies state by state. There are rules and regulations that have been put in place. They aren't necessarily based on anything in particular except perhaps tradition and maybe outdated ideas around what should be done, rather than on looking at what the need is and how we can help the clients that need this service the most.

**Senator PRATT:** What can you tell us about a series of appointments with a nurse practitioner?

**Ms Dowden:** What we currently do?

**Senator PRATT:** Yes.

**Ms Dowden:** I've got a mother who contacted me yesterday afternoon in an email to my business to say: 'I've got a three-year-old and a five-year-old. Help. I think they might have ADHD.' So I've offered her an appointment. I said we will do a general assessment. We'll do a child development assessment, particularly for the three-year-old. If we think ADHD might be on the list, we'll certainly be looking at some of the ADHD screening tools. We'll look at mental health and wellbeing, because there's a very large overlap between childhood anxiety and neurodiversity and neurodisability. We'll be looking at family trauma. We'll be looking at child adversity—ACE scores. Because we have such experience in our clinic with children with family violence in their homes and parents with drug and alcohol problems, we are not at all reluctant to ask those questions and really explain to parents that, if you live in an environment with a lot of fear and adversity and disadvantage and unsettledness, that has a huge impact on behaviour, and that, if we can, we will somehow address some of those things. Or if the family environment has shifted—for example, if the mother has moved away, out of that difficult relationship, and is living separately—we do a huge amount of work to see how can we support that parent to parent differently and more safely and to help these children with their attachment and their feeling of safety so they can then be much less reactive, because a lot of what we see that gets a label of ADHD, often from the school, is a child who's just reacting to all the difficulties in their life and just needs help to calm down, to be less worried and to feel safe.

**Senator PRATT:** How often is there an ADHD diagnosis with that?

**Ms Dowden:** Often. The problem is that they're so intermeshed. I get really concerned when I meet families whose children have been started on stimulants with very little exploration of what else is going on at home. I would say that even single day it's: 'We just need you to get us to the person to write the script.' And I'll say: 'No. No. No. It's much bigger than that, because a script isn't going to fix everything. A script will only help you with perhaps the inattention or the educational failure. It's not going to help with all the other stuff.'

**Senator PRATT:** So once you've passed that point and a child's been diagnosed, what does a series of support appointments look like?

**Ms Dowden:** We do a lot of work with parents. We do a lot of parent coaching, and we do child coaching as well, around: 'Can we set some goals around behaviour? Can we set some goals around what's going on at home? You would probably benefit from getting anxiety addressed. You would benefit from this support group. You would benefit from maybe going to the student clinic at Curtin University, for example, which has a special interest in anxiety,' because we know these are low-cost, affordable services where parents can get help. We work really closely with other parent support agencies in our network. Again, we can cross-refer to those services.

**Senator PRATT:** Once all of those things are addressed, a child with ADHD, even when they're medicated, is not always going to sit still and pay attention at school. What are the kinds of interventions that you look to at home and at school to assist a child to get the most out of their day?

**Ms Dowden:** Assisting them to know how to regulate, to know how to calm down, to have good sleep routines, to have good activity routines and to not spend too many hours on their screens. That means getting exercise, going outside and doing things as a family. A lot of it is really basic. It's also helping parents to try and move away from the reactive parenting to calm parenting. Often these are very reactive children. They're very busy. They're always on the go. They get told off a lot. It's getting parents to flip their parenting around the other way so that they notice when their children are doing things they want them to do and when they're managing to self-manage their anxiety or their over-reactive behaviour so we can help them actually be their best selves.

**Senator PRATT:** Thank you. Jordan?

**Senator STEELE-JOHN:** Thank you so much for your submission, for your opening statement and for taking the time out of what is a very busy job to be here with us this morning. In your submission you make the statement that, in addition to the cost barriers and the capacity barriers that exist between a person with ADHD and getting the mental health supports that they might need, there exists another barrier in the form of reluctance on behalf of mental health services in WA to take the referral of an individual who has ADHD. Can you give the committee some examples of what that reluctance looks like?

**Ms Dowden:** It's partly because, if there is a named diagnosis that seems separate, then—and I don't understand why—there seems to be the idea that this can't be a mental health problem. I find it really concerning how limited the view is amongst quite a few mental health clinicians that co-diagnosis exists. The most common co-diagnosis for someone with ADHD entering adulthood is anxiety and often bipolar disorder. We know these are coexisting diagnoses. We see them evolving in the children who come and see us. We see mood swings, severe anxiety and social anxiety, but often we also see the aggressive behaviour because often anxiety leads to aggression, particularly in boys, because it's much more socially acceptable to be aggressive than it is to say, 'I'm scared. I'm worried.' Or you internalise. You get the group of children who internalise, and then they self-harm or withdraw, and then you get the ones that externalise, and it tends to be naughty behaviour and aggressive behaviour. Really, when you look at what's behind it all, it's often severe anxiety that hasn't been addressed at all.

**Senator PRATT:** And they're delightful kids.

**Ms Dowden:** They're wonderful. I've got a couple of complete ratbags at the moment, who are angels with me, and I know they completely destroy their school. It's a really challenging thing for their school to manage and for their families to manage, but I know they have capacity because I know they can do it with us in a one-on-one environment. It's helping them to try to learn that they can do this all the time and they can somehow harness their power in a different way.

**Senator STEELE-JOHN:** So the reluctance in practice often looks like an unwillingness to take that referral. What impact does that then have on the person who is seeking the mental health service?

**Ms Dowden:** It's devastating. I have a little boy at the moment who desperately needs some very intensive mental health support that I don't think he's going to get. We have managed to get him some equine therapy, which his family are pretty well funding, even though they have very low income and they're struggling to afford it. But that's the one thing that helps him regulate. He's a tiny little kid, and he's telling me how cool it is to get on this really big horse. He has to be calm to be on a horse, so he has to regulate to enjoy that experience at the same time as learning how to do that. But he can't attract NDIS funding and he can't attract mental health support. Mind you, his equine therapist has a mental health background, so he's getting it kind of through a sideways system.

**Senator STEELE-JOHN:** Equine therapy is a great example of the support which any other disabled kid would be able to access through the NDIS.

**Ms Dowden:** It's ironic, right?

**Senator STEELE-JOHN:** But with an ADHD diagnosis it's very, very difficult to access that. Would you support the committee recommending that the NDIS make it easier for folks with ADHD to get support?

**Ms Dowden:** I think so. There are a number of ways you might do it. I know there's a lot of anxiety about, 'Oh my god, we can't open the floodgates for NDIS,' but I think we must look at the long-term cost to the community of people having unmanaged and unsupported ADHD.

I had a mother the other day who brought her five-year-old to see me. We started talking about family history, and she went, 'I wonder if his dad's got ADHD.' I said, 'What makes you say that?' and she said, 'Well, he failed at school. He was having educational challenges, and the school wanted him to have additional support, but his parents didn't agree, so he never got supported. He still has trouble reading and writing. He won't fill in any forms. He's a truck driver, and I have to do all our family finances and anything that involves writing because he feels so shamed about it.' I can pretty much guarantee he's got undiagnosed ADHD and educational challenges, probably dyslexia or something, that went with it, but he never had any support. He's never had a diagnosis, and it has impacted his entire life.

**Senator STEELE-JOHN:** The witnesses previous to you made it very clear that, in their experience, ADHD is deeply misunderstood and that, even those who currently have exclusive prescribing rights or play a significant role in diagnosis—psychologists, psychiatrists, paediatricians—receive very limited amounts of training in relation to ADHD before they begin practice. We've also heard, both today and in previous hearings, about discrimination that is experienced by people with ADHD in relation to medical practitioners but also other people.

It's a topic that you focused on in your submission as well. Would you be able to share with the committee some examples of, tangibly, what that discrimination looks like, what that lack of understanding looks like?

**Ms Dowden:** It looks like blaming and shaming parents. It looks like blaming adults. It looks like people being accused of drug-seeking behaviour. It looks like, 'Oh, you're just following trends on TikTok,' rather than people looking at these videos and going, 'Oh my God, this is me; I've been struggling with this all my life; I need help with this,' and then trying to seek help and finding that it might cost them \$3,000, and they might get a cursory video assessment that says, 'Oh yes, here you go, here's a script, goodbye,' rather than helping that person unpack what they can do and what would help them. Children are still blamed a lot for their behaviour at school. I presented a case of one of our clients, and her child was labelled as a 'naughty kid' from kindy.

**Senator STEELE-JOHN:** What does it do to somebody when they're labelled that way?

**Ms Dowden:** Try being labelled that way for five years. That family found out recently that he'd been banned from birthday parties, and they didn't know. They only found out accidentally. He'd been banned from all class birthday parties for the last five years. They were devastated. They were like: 'This isn't his fault, and he's not that naughty.' But he'd been given this label, and so people weren't inviting him. He already has difficulties with social connections with other children. Because he was the naughty one, it was like: 'We don't want our children near him; there's a contamination effect; we will avoid him,' even when he has got support, got on medication and learnt to write his name—in grade 3, because he could finally concentrate. There was a very tragically prolonged wait to get services. That was a family who fought very, very hard and saved up money so they could achieve that through the private system, because they weren't getting their needs met.

**Senator STEELE-JOHN:** In that case, you were referring to somebody who is a little boy. We know—and you addressed it in your submission, and others have addressed it in theirs—that there is a deep gender disparity and gender bias when it comes to ADHD assessment and diagnosis services. Can you give us some examples of what that looks like?

**Ms Dowden:** It looks like girls with autism being diagnosed with inattentive ADHD, not autism, or both. There's a real lack of understanding that neurodiversity and neurodevelopmental conditions have a massive overlap. At the moment, you would think it's maybe 90 per cent boys who have ADHD and only 10 per cent girls. I suspect it's probably equal. But it presents differently. Children are socialised differently. Girls are less allowed to be naughty and act out, so it's not so obvious. They internalise more. Boys are allowed to act out, so it becomes very obvious. I think it's as simple as that. Desiree Silva, who is here this afternoon, did her PhD on ADHD, and I know one of her papers said that 70 per cent of it is heritable. My opinion would be—it's completely off the cuff—if it's 70 per cent, it's probably 100 per cent. But we know there are environmental factors that increase your risk. It's around attachment, those first few years of life, how calm you are and how connected you are to your primary caregiver. We know all of those things have a very big impact on child development.

**Senator STEELE-JOHN:** Absolutely. Based on your understanding, would you support the federal government increasing its funding—and indeed providing funding in the first place—for specific training to be made available to mental health practitioners, general practitioners and the healthcare workforce more broadly and also specific supports being put in place for those who are already qualified and working in the workforce so that they can get training at the same time as new folks coming through are getting in-house experience in their postgraduate and pregraduate experience?

**Ms Dowden:** I think we can't afford not to. I have learned, literally, by immersion over six years. I have a 30-year background in paediatrics, I've worked in tertiary children's hospitals and I've worked in the community. And this has been immersion in a really complex problem, and the more I've worked in it the more I've learnt, and the more I've realised how few people who work in this area actually have a deep understanding of it. So I can't agree more that that's a good idea.

The other option might be to do—like they did for early autism diagnosis, where you had maybe 20 Medicare items that you could use over a few years, with a mixture of paediatricians and allied health. That might be seen, perhaps, as a more palatable framework to fund it, rather than the scary, 'Give everyone to NDIS,' which I know is freaking people out at the moment. Personally, I think either option would probably be as beneficial, as long as you get good providers who know what they're doing and actually make a difference.

**Senator STEELE-JOHN:** Thank you. I'll give the call back to the Chair in case any other senator wants to ask a question.

**CHAIR:** Thanks very much, Senator Steele-John. I don't think we've got any other questions from the other senators that are online. Thank you so much for your evidence today. It's been very useful to the committee, Ms



Dowden. I don't think you took any questions on notice, but if there was anything more that you wanted to add to what you've shared with us, if you could get it to us by 14 August that would be terrific.

**Ms Dowden:** Thank you.

**MAGLADRY, Dr Mad, Senior Policy and Research Officer, Consumers of Mental Health WA**

[10:26]

**CHAIR:** I now welcome the representative from Consumers of Mental Health WA. Thank you for appearing before the committee today. I will hand over to the senators that are in the room, who can manage this much more easily than I can via the phone. If you would like to make an opening statement, the committee will then ask you some questions.

**Dr Magladry:** Thank you. I am here today representing Consumers of Mental Health. We conducted a survey of our members. We attracted about 63 responses, and this is an issue that is extremely important to our members. We can see this not only through the responses to the survey but through ongoing consultation, feedback and reporting through our service arms, including our individual advocacy program and our service navigation program. Through those services, not only are we hearing about the barriers to accessing appropriate person centred holistic recovery oriented supports for ADHD; through our individual advocacy program we're also seeing what the true impacts of those barriers are: what happens when the supports aren't there or when they are suddenly taken away. So it is really important today that I am here speaking on behalf of consumers. I am a consumer myself. I would like to thank you for the opportunity to give evidence today.

**CHAIR:** Thank you. Senator Steele-John?

**Senator STEELE-JOHN:** Thanks so much, Chair. In your submission—and it was touched on in other submissions as well—was the issue of the barrier to accessing medication due to cost, particularly for young people on a certain type of medication subsidised by the PBS who are not able to access that medication anymore when they become adults. Can you give us some examples of what impact it has on consumers, if medication is something that they need, not to be able to access the medication that's right for them?

**Dr Magladry:** Yes, absolutely. First off, I should say that a lot of our consumers talk about ADHD as a mental health issue, and some of them don't. That's just to be clear. For example, one of the significant impacts is that, when someone is not allowed their medication, their other mental health conditions will get much worse. The impact of that is that people's mental health will get worse in other areas, from the feelings of being dismissed. If someone tells you that your medication isn't necessary, you end up feeling like your condition isn't real or your feelings aren't valid. Through that, why would anyone want to continue seeking help when they feel like that? So that can be a huge barrier to anyone seeking help in the future and to trusting doctors more broadly—maybe wanting to move outside of the clinical system or the medical model. That would be a huge impact.

**Senator STEELE-JOHN:** So you would support the expansion of the PBS to cover all approved medications for ADHD?

**Dr Magladry:** Yes, I would.

**Senator STEELE-JOHN:** Regardless of whether you're a child or an adult?

**Dr Magladry:** Yes.

**Senator STEELE-JOHN:** In terms of the barriers that consumers experience when accessing diagnosis in—to begin with—adulthood, we've heard, and it's mentioned in your submission, about the barriers of cost and the wait time for diagnosis and assessment. Can you share with the committee a little bit of what impact that has on consumers—both the financial impact and other flow-on impacts from not being able to get the diagnosis or the assessment?

**Dr Magladry:** Yes. There are a couple of things. Firstly, obviously, as I said before, feeling rejected by that system is going to push people outside of that system. It's no accident that, in a system with very long wait times and inaccessible practitioners, there is also a popping up of unregulated sources of information. The previous witness mentioned TikTok, for example. There's a reason that that's popular, and it's not just because it's out there or because it's necessarily right; it's because it's information where there is very little information to be found. It's support, even, because those influencers offer some degree of social support or understanding that you cannot access from the doctor because you cannot see the doctor.

Again, this would definitely exacerbate people's existing mental health conditions, and it also encourages people to look for supports—things like peer support, which is excellent. People should be able to seek that. But, because what people are trying to access through a doctor is not just understanding and validation but concrete evidence based strategies to help their ADHD or to access medication, which you can't do through other channels, that is a profound impact.

**Senator STEELE-JOHN:** Absolutely. In terms of what the committee might consider recommending, would you be supportive of, basically, the federal government intervening in such a way as to make it more affordable to access that diagnosis and assessment process, including making it free under Medicare?

**Dr Magladry:** Yes, I think it should be free. In addition to that, it's not just the cost but the number of people who have authority to make diagnoses or prescribe. If we're talking about whether we should make accessing psychiatrists, for example, free then there need to be other things in place to mean that that system doesn't bottleneck.

**Senator STEELE-JOHN:** Indeed. One of the suggestions was that GPs, subsequent to some specific training and upskilling, should be able to make that diagnosis and have those prescribing rights. Is that something you would support?

**Dr Magladry:** Yes; that would definitely reduce the barriers.

**Senator STEELE-JOHN:** This will be my last medical question; there is more that needs to be addressed here than just a medical lens. This issue of the different ways in which stimulant medication is regulated state by state seems, to me, from the evidence we've heard, to be a significant barrier to consumers' ability to travel interstate or internationally. Can you tell me a little bit about the barriers that people have shared with you that are created by the different regulatory systems, and whether you support a nationalised standardisation of those regulations.

**Dr Magladry:** A nationalised standardised system would definitely go a long way towards reducing the gaps people experience in being able to access their medication. We hear a lot from consumers who have moved interstate about having been diagnosed and receiving prescriptions there, and then moving here or, as you say, internationally and not being able to access their medication. I know someone who flies back to France to renew their prescription and then returns. That is more accessible to them than having to go to a psychiatrist for \$900 and get a new prescription and a diagnosis that's recognised in WA.

**Senator STEELE-JOHN:** It's a hell of a symbol of a broken system when it's easier and cheaper to fly back to France than it is to get something here! Beyond the medical frame: in terms of the discrimination people with ADHD experience in the workforce and in the education system, what have members shared with you about what those forms of discrimination look like, and are there any suggestions for changes that need to be made to the employment and education system to support people?

**Dr Magladry:** One of the key things we've been told is there is a simultaneous depathologisation where ADHD is dismissed as, 'Oh, everyone has it.' It's simultaneously depathologised as 'everyone has it' and dismissed—'Oh, you don't have that; that's not real'—which people really struggle with in having any of their needs met. When that process happens, when someone depathologises something in a way that's very dismissive, they're refusing to acknowledge the person has any kind of need. As the previous witness mentioned, we've heard a lot from consumers who have claimed that, at their job, school or uni, they will internalise a lot of feelings of being lazy, and have that projected onto them as well.

**Senator STEELE-JOHN:** Thank you.

**Senator PRATT:** What does best practice look like for people with ADHD in terms of the health institutions and other institutions they interact with?

**Dr Magladry:** It almost depends on the person. We've discussed some recommendations for standardisation, but we've heard from consumers that it is quite different to each person. Universally we want to recognise that we have individual needs, that we have individual lives, that our mental health issues affect all aspects of our lives and that we need to be viewed as a whole person.

**Senator PRATT:** That makes sense, but how do we embed that in the things that need to be standardised? When you're looking to public subsidy or to people working out what they're prepared to pay for or cross-subsidise themselves, how do we help navigate that so they land as quickly as they can with the kinds of things that suit them?

**Dr Magladry:** Offering support—for example, service navigation is something we have identified as incredibly important for people with ADHD. That's one of the programs Consumers of Mental Health WA offers, and not just for people with ADHD. Giving people support to make their own decisions and giving people information to access the supports they might need is something that is very useful. Further to your point earlier: training and promoting a deep granular understanding of ADHD as it presents in all kinds of people is really important. I don't have a lot of clear ideas or nitty-gritty ideas beyond offering support.

**Senator PRATT:** I wonder if you might give a personal comment on the fact that we see in the data an overlap between people who identify as gender diverse and ADHD.

**Dr Magladry:** Thank you for asking that question. A lot of this is to do with both communities having an understanding of identity as something that is socially constructed. Once you get into one or the other, either the neurodiversity—

**Senator PRATT:** If you're struggling to conform, that's going to play itself out.

**Dr Magladry:** Those communities are very accepting of figuring out ways to understand yourself that aren't about placing blame or an inherent lack on the person, and saying, 'You're not lazy; you have ADHD, you're neurodiverse,' or, 'There's nothing wrong with you; you're gender diverse.' Those are accepting, validating languages to explain human experience.

**Senator PRATT:** Thank you. That's really insightful.

**Senator KOVACIC:** Thank you so much for your time today. I want to get an understanding of whether, in your view, mental health diagnosis and follow-up treatment is too siloed. Do we have too much specialisation in relation to depression, anxiety and ADHD, and does that provide difficulty in providing adequate care? Or is that a necessity and part of what we need to navigate in order to have adequate care? Where do you feel the federal government needs to step in to streamline the diagnosis and treatment, if you do feel siloed?

**Dr Magladry:** That's a really good question. I have definitely heard from consumers that they've felt misunderstood both in their mental health conditions and in their ADHD, if they view those as separate things. People have been told, 'You can't really get help for your ADHD until you have your mental health sorted out,' or vice versa. I think specialist treatment has a time and a place and can be appropriate, but I think the solution to attitudes like that is more holistic training for everyone who has to come into contact with consumers about the intersections of mental health and neurodiversity. Does that answer your question?

**Senator KOVACIC:** Yes, thank you.

**Senator PRATT:** In terms of the recommendations that you've got in here, have you got a sense of who should be doing this work? When we say government should develop strategies for educating employers, government's not necessarily best placed to do that, but government needs to mandate that someone do it, with the right expertise and the right people at the table to do that.

**Dr Magladry:** Yes.

**Senator PRATT:** So I'm interested in asking you about that, from the point of view of health consumers. If you bring health consumers and practitioners to the table, what is the right ecosystem of people to work with to create change?

**Dr Magladry:** We definitely need to involve, obviously, clinicians and practitioners. But, being a representative of consumers, I'm going to say that consumers need to be at the centre of any decisions made and that any consumers involved in co-design and co-production of systems like these need to have their capacity built to be able to contribute fully.

**Senator PRATT:** Feel free to take this on notice, because it's been a long and evolving debate: to what extent, from the health consumer's point of view, have turf wars about the scope of practice between different practitioners, or campaigns that say ADHD might be overdiagnosed, contributed to a lack of service access for consumers?

**Dr Magladry:** It should be acknowledged, and I think we all acknowledge, that the consumer voice is not just one voice and that there is dissent among those voices. Just as many of the respondents to our survey embraced the medical model, there were many who disavowed that model and wanted non-clinical alternatives. Just as many of them said how great influencers on TikTok have been for helping them feel recognised and supported, a lot of them have also complained about them. I think the trick to that is ensuring a diversity of consumer voices rather than trying to push one above another.

**Senator PRATT:** Thanks.

**Senator STEELE-JOHN:** Doctor, I just want to give you an opportunity at the end and ask you whether there are any other topics that were shared in the survey that you haven't had the opportunity to raise.

**Dr Magladry:** That's a great point. I don't think there's anything that I haven't already raised in the submission or in this hearing. No, I think that's it.

**Senator STEELE-JOHN:** Thank you so much for your evidence.

**Dr Magladry:** Thank you very much.

**CHAIR:** Thanks very much, Dr Magladry. I'm not sure whether you took a question on notice from Senator Pratt or not, but if you would like to add further evidence then, if you could get it to us by Monday 14 August, that would be really appreciated.

**Proceedings suspended from 10:48 to 11:01**

**SCHONELL, Mr Stuart, Chief Executive Officer, Advocacy WA**

**CHAIR:** Welcome. Thank you for appearing before the committee today. Do you have any comment to make on the capacity in which you appear?

**Mr Schonell:** Advocacy WA is a regional advocacy provider for disability.

**CHAIR:** Thanks very much. I now invite you to make a brief opening statement if you'd like to do so, and then the committee members will ask you some questions.

**Mr Schonell:** Thank you for having me appear today. First up, from the perspective of Advocacy WA, I note that we are not clinicians or academics. We do employ psychologists and people with social work degrees, but not practising registered psychologists.

We're often the last resort for people. Regardless of the disability, including ADHD, when people have found that they've got nowhere else to turn, they will often be referred to us or they'll be searching online for someone in the regional areas that can assist them, and they'll come across us and they'll contact us. So our experience of this is completely at the coalface. The people who are desperate and have nowhere else to turn come and see us. I've included one of our case studies in the notes that I've provided to this committee.

There are just a couple of things that I'd like to put on record. No. 1 would be the disability sector's complete reliance now on the NDIS. It's changed the landscape. For a lot of people it's changed the landscape for the better, but for some people it actually hasn't. Those people that can't get on the NDIS seem to be struggling more than ever. From our perspective, this is creating a new form of discrimination. I would ask this committee to consider what's happening in the future with legislation, rather than going back and looking at what's happened in the past, and particularly to pay attention to the Disability Services and Inclusion Bill, which does not actually define disability—or currently, in the versions that we're looking at, it hasn't defined it. It doesn't limit support to people with permanent disabilities, and it states that, whatever the origin, nature, type or degree of disability, all people with disability should have the same human rights as other members of society.

Finally, the last thing I'd like to draw everyone's attention to is the fact that we are a signatory to the UNCRPD, and the new bill specifically mentions this and mentions that Australia will be following the UNCRPD. According to the UNCRPD, disability is a social concept. It's not viewed anymore as a medical-deficit concept, and it results from interaction between an impairment and attitudinal or environmental barriers that hinder full and effective participation in society, and this is exactly where ADHD falls. Thank you.

**CHAIR:** Thanks very much.

**Senator PRATT:** Can you give us an overview, as a regional organisation doing advocacy, of the particular barriers that people confront in terms of access to services, health care and community and social networks?

**Mr Schonell:** The more remote the region, the more difficult it is to access any sort of service, particularly around getting a diagnosis. People in small towns really struggle, and often financially, and we often find that people with disabilities will move to a small town, because rents are so much cheaper and it's so much cheaper to live day to day. However, on the flipside, it's more difficult to access services. I think that's one of the big issues.

The next thing is how expensive it is to get a proper diagnosis for ADHD and the fact that getting a proper diagnosis isn't covered by Medicare. For families who are already struggling, who have moved into the regions because of the difficulty of paying bills in capital cities, to ask them to fork out \$1,200 just to get an assessment for ADHD for a child—that's a significant bit of money.

**Senator PRATT:** What does make a difference? Have you started to see virtual and online types of services or peer support playing a beneficial role? What are the steps you take to advocate and support someone?

**Mr Schonell:** It's tough, because we get to see people when they're ready to give up. People who already have adequate supports are probably not going to come to us. We're seeing the ones who are ready to give up who have been trying probably for a couple of years to get some sort of government support, who've been trying to have someone recognise that what they have is a disability that means that they can't participate properly in society. So I guess for us it's a little bit different. We also, of course, see parents of children who come and see us who have been trying, who have been pushed, often by schools, to get their child diagnosed because the child has some sort of a behavioural difficulty. The schools will say to the parent: 'This child is disrupting the class. You need to get them diagnosed. We think they've got ADHD. If you don't get them diagnosed they'll have to leave the class.'

**Senator PRATT:** And that's a very real phenomenon.

**Mr Schonell:** That's very real, yes.

**Senator PRATT:** And if someone's living in a regional area, there's not necessarily another school.

**Mr Schonell:** That's right. And it's really tough, because, from the school's perspective, the school will actually get support. ADHD is classified as a disability for a school, and once that child's been diagnosed the school then can put in for direct funding. So, they—

**Senator PRATT:** But it's my understanding that you don't necessarily require a diagnosis for that. Do you suggest that schools apply for that funding, or are they being really prescriptive in terms of requiring a diagnosis?

**Mr Schonell:** The parents that we speak to have been pushed by the school to have their kids diagnosed. That's what the school has demanded.

**Senator PRATT:** My understanding is that there are a couple of tiers of school funding attached to ADHD and autism, depending on their severity. One is just a general allocation for supporting the teacher and their training. Then the other high level might require a more specific plan for a child.

**Mr Schonell:** Yes.

**Senator PRATT:** I can follow up perhaps with the Council of State School Organisations later, but how do you go about advocating? Do you advocate to schools as an advocacy organisation? What approach do you take to that?

**Mr Schonell:** We're completely client led, so it depends on what the client wants. For us, often the support people want is with government departments and services and how we access it. We've just come across barrier after barrier after barrier, so—

**Senator PRATT:** Could you outline what some of those barriers are?

**Mr Schonell:** For parents, it's a lack of understanding from different government departments. They're looking for some sort of support for their child—some sort of funding that they might be able to access to enable them to get a proper diagnosis, to enable them to get some sort of educational interventions and those sorts of things. That's what we get from that perspective. Very occasionally we'll have a client come to us because they want to talk about discrimination in the school. That doesn't happen as often for us. I know we did have a case—it wasn't to do with ADHD—where we were asked to go and intervene in the school and look at school policy, and we do do that, but generally speaking people come to see us because they're at their wit's end regarding finances and they're just looking to see if we can crack that barrier within different government departments.

**Senator PRATT:** How often are you able to fix it?

**Mr Schonell:** We're pretty good, actually. We can often find something. Our advocates really know their stuff. They know exactly who to talk to, whether it's someone in the NDIS or in the health department, or local hospitals or local psychologists. More often than not we can help people. That may not necessarily be financial; however, our service is free, so we can engage lawyers for them and we can do all sorts of things that are at no cost to them.

**Senator PRATT:** Where do you source that funding from? You must be dealing with a whole diversity of different issues on behalf of families.

**Mr Schonell:** We do. Our funding is both state and federal. I think we've currently got about seven different funding sources that cover pretty much every type of disability.

**Senator PRATT:** How often would someone eventually end up on the NDIS versus just needing extra? They might not qualify for that threshold.

**Mr Schonell:** From our experience, you don't get on the NDIS till you've been diagnosed with maybe a form of autism. We've got clients who will just keep going to see different specialists until someone can eventually give them a diagnosis of autism, and that's the case that I actually put in the notes that I submitted to the committee. There's a client who was diagnosed with ADHD at age 22, could get no supports and was unable to work. It wasn't until nearly seven years later that they were finally able to get a diagnosis also for autism—it was basically a co-morbid diagnosis—and that enabled them to get supports such as a disability support pension and get on the NDIS.

**Senator PRATT:** Has that improved their participation, or has it institutionalised them as having a disability outside—

**Mr Schonell:** I guess I'd go back to that social view of disability. It comes down to that person. That person is unable and has been since childhood to effectively contribute to society, and for many, many years she didn't know why. Now we know that these sorts of neurodevelopmental disabilities build over time. From our perspective, if she could have had a diagnosis when she was four or five years old, that would have completely changed her whole life. But she couldn't do that—she couldn't get that. She was just a troubled child. Then, at age 22, when she's having difficulty concentrating and is unable to work and forgetful, she finally gets a diagnosis of ADHD and gets some form of medication but is still unable to really contribute, because that person has now had

22 years of this build-up of issues. Then she still can't get the full supports. Nearly seven years go by before she gets herself in a position where, okay, now the supports are happening. But I think it's too late.

**Senator PRATT:** Do you do advocacy to employment organisations? I imagine that you might at times. How responsive are they to saying, 'Here's a range of—for example—'self-regulation skills or pre-employment skills that have that ADHD management perspective embedded in them'?

**Mr Schonell:** We do quite a bit of work on the employment side, trying to help people with disabilities to get jobs. It's really difficult. Often, jobs only last for as long as government funding lasts for that particular person. An organisation might get around about \$10,000 for six months to employ someone, and once that runs out, so does the job. That's what we normally find. We run our own programs for people to support them, and we've been reasonably successful. I feel for employers as well, because a lot of small businesses and regional towns are doing it really tough, so it's hard for them as well to have someone on the books who has a disability and can't concentrate as much, is forgetful or can't interact as well as others. At some stage, for a small business, if it becomes too much of a liability when their budgets are really tight, that person is moved on, unfortunately.

**Senator PRATT:** What kinds of opportunities and employment do work, in the communities that you are active in?

**Mr Schonell:** One of the things that we're really trying to push at the moment is volunteering. We see volunteering as a great way for people to actually get that experience and to build self-confidence over a period of time. So I think that works. Also, it's pretty much pressure free. You're not looking at particular time lines and budgets. Those pressures are gone in volunteering, so it's an easy way into that sort of world of work. So I think that's really successful. We'd like to see more funding for entrepreneurship in disability, particularly for people with neurodevelopmental and psychosocial disabilities, to enable them to even work part time, to have some sort of funding there that assists them to set up some sort of microbusiness. I'm not talking about a business that's putting beads on a piece of string or something; I'm talking about things that are tech related, things that you can do at home within your own safe environment. We'd actually like to see more of that sort of stuff.

**Senator PRATT:** I'd be really interested in hearing some examples of that working, because clearly, when people with ADHD are truly invested in something, they're able to concentrate and pay attention to it quite effectively.

**Mr Schonell:** Yes.

**Senator PRATT:** Are the usual places you would go to learn those skills for running a small business viable?

**Mr Schonell:** No.

**Senator PRATT:** How would they need to change to support this cohort of people?

**Mr Schonell:** I think what we need—I'm pushing our own barrow!—is funding for advocacy-type agencies and the agencies that can put support personnel with that person to get them through the first 12 months, to help them with the set-up, to turn up to meetings, to prompt them to get to that end stage of: 'I've got my concept.' The one we're currently trying to get funding for is around technology—things like software development, app development. Businesses are really excited about it. We've had a number of big businesses in the south-west say that they'd come on board not only with funding but also with trying to contract those people to work with them, because there is a shortage of personnel in those areas—so targeting skill shortage areas and also thinking about the nature of the disability. As you said, if someone with ADHD can be focused on something that they're passionate about, they're more likely to be successful.

**Senator PRATT:** Who is best placed to do that career development side?

**Mr Schonell:** I think it's a combination. We've been looking at trying to partner with Edith Cowan University, using their business students, using their tech students, partnering with their Creative Tech Village in Bunbury, using our own advocates, our social workers, who can be part of that process, employing someone with small-business experience who can be a mentor, looking for mentors within some of those bigger organisations that can also support. It's got to be multipronged.

**Senator PRATT:** In that context, there would clearly be people with ADHD who are already students in business and technology and in other places where they're able to hire and mentor others.

**Mr Schonell:** That's true.

**Senator STEELE-JOHN:** I have some quick contextualising questions. How many people with ADHD does Advocacy WA support?

**Mr Schonell:** Over the last two years, we've had 34 people we've supported. That's children and adults.



**Senator STEELE-JOHN:** In terms of the kinds of issues with which they come to you looking for support to resolve, what kinds of issues bring them to your door?

**Mr Schonell:** From the children's perspective, it's the parents whose children have got behavioural issues. Many of them have been pushed by the schools: 'You have to do something about it.' So they'll come to us to see what sort of support is available. Then, from the adults' side, it's normally people who are looking for some form of funding support and support workers—people who can help them in daily tasks.

**Senator STEELE-JOHN:** Are there any particular daily tasks that are re-occurring in people's requests?

**Mr Schonell:** It's the inability to concentrate, forgetfulness and those sorts of issues. One of the issues that people have, particularly around ADHD, is the lack of interconnection between state and federal governments and local governments, the lack of interconnection between different departments. This is particularly true of people who have any sort of neurodevelopmental disorders, as well as other people with disabilities. It's the fact that, every time you get bumped to another department, you've got to begin that whole story again. When you're forgetful, when you have problems with concentrating, it's really, really tough to be told, 'That's not our area; you need to talk to the Office of Disability,' and then you give them your story, and it's, 'That's not our area; you need to talk to the Department of Health,' and then it's, 'Oh no, that's not our area; you need to talk to the Department of Social Services.' Imagine how difficult it is for someone who can't concentrate properly and is forgetful. 'What was I supposed to do? Where was I supposed to go next?' Eventually they just give up. That's why they come and see us.

**Senator STEELE-JOHN:** For everybody, that is frustrating. For somebody with ADHD, that is inaccessible.

**Mr Schonell:** That's correct.

**Senator STEELE-JOHN:** That's the key differential. It sounds to me like, between ADHD coaching and those kinds of activities of daily living that you might be supported for if you were, say, a disabled person under the NDIS with any other condition—you'd be able to get funding and support to do some of that—

**Mr Schonell:** That's correct.

**Senator STEELE-JOHN:** But if you've got ADHD you can't.

**Mr Schonell:** That's correct.

**Senator STEELE-JOHN:** If ADHD were listed as a category A or category B condition, people would be able to get those supports under the NDIS, potentially. Would that be something that you as an organisation would support?

**Mr Schonell:** Absolutely. That's exactly what's needed. In our view, it should be looked at in the same way as autism spectrum disorder is looked at, with different categories. I think it begins with proper diagnosis. That's where we have to start.

**Senator STEELE-JOHN:** We're experiencing nationally a housing crisis in Australia, broadly. Are there any particular cases that come to mind for you where you've supported people with ADHD who have been at the same time struggling with those inaccessibility barriers in the housing system?

**Mr Schonell:** Off the top of my head, no, I can't think of anything in housing.

**Senator STEELE-JOHN:** Anything in financial management?

**Mr Schonell:** Definitely in financial management. People with ADHD often struggle with their finances, and we'll put them in touch with financial counsellors. As an organisation, we don't define disability. If anyone comes to us and says, 'I have a disability,' we accept that. We're funded to support them, so, regardless of what the next issue is, we will be there to support them, whether that is because of a housing issue or not—and we see housing issues with a lot of other disabilities. We will be supportive. It's difficult.

**Senator STEELE-JOHN:** Even though you don't need a diagnosis for people to engage with you, are people in need of a formal diagnosis when they come to you?

**Mr Schonell:** They don't need a formal diagnosis to come to us, but they will need a formal diagnosis to get particular services.

**Senator STEELE-JOHN:** Yes, absolutely.

**Mr Schonell:** So we will then support them to get the diagnosis. We can't pay for a diagnosis—we can't afford that with our funding—but we do know where people can go. We can make phone calls and organise appointments. We can go with people to particular appointments. We work in the justice system a lot, so our advocates will visit prisons and support people with prisons. We know that there is a high rate of prisoners with ADHD.

**Senator STEELE-JOHN:** Yes, of course.

**Mr Schonell:** For us, that is also a major issue, around: this is a disorder.

**Senator STEELE-JOHN:** So self-diagnosis gets you through your door, but, then when you try to support them—

**Mr Schonell:** It doesn't get you through others.

**Senator STEELE-JOHN:** Not through other organisations' doors. In terms of bringing that cost barrier down, would you support federal government funding to make diagnosis and assessment free?

**Mr Schonell:** Absolutely. For us, No. 1 has got to be that we've got to look after children. We've got to start somewhere, and we should be starting with children, and we should be funding parents to enable them to get their child properly diagnosed. That's got to be the first thing that happens. After that, at least they can start looking at what sorts of behavioural supports need to be put in place for that child and whether or not it's a category that enables that child to get some sort of NDIS support. But No. 1 is that we've got to have proper diagnosis.

**Senator KOVACIC:** Thank you for your evidence. I have a question for you. Most of the evidence today has talked about all the different challenges and complexities and the processes involved in diagnosis. From your perspective as advocates, what do you see as key low-hanging opportunities to cut red tape and make these processes simpler? Is part of the issue that we have siloed diagnoses? You spoke about autism, depression and anxiety and then into ADHD. Is there any easy way that you've seen, through your advocacy, to make this a lot simpler?

**Mr Schonell:** No. 1, we need better integration or interconnection between government departments. That's got to be the first thing that'll help support people.

**Senator KOVACIC:** Are you talking about state departments or federal or a cross-section of both?

**Mr Schonell:** I think local, state and federal. No-one seems to talk to each other, particularly in this disability sector, so that's got to be No. 1. If we had better interconnection, I think the processes for people would be much quicker.

We all know the issues around getting medical professionals into regional areas. That's got to be No. 2. We need more specialists. We need more medical professionals in the regional towns to support people with ADHD. I completely understand why state governments have been looking really closely at the way different stimulants are prescribed. I know Western Australia's become a lot stricter in the way that stimulants are prescribed. But on the flip side of that is the fact that if fewer people can prescribe them then, when you live in a regional area, you've got a far lower chance of actually being able to get a proper diagnosis, and it could take you several years.

**Senator STEELE-JOHN:** It's not exactly overflowing with psychiatrists in regional Australia.

**Mr Schonell:** That's right.

**Senator KOVACIC:** Thank you.

**Mr Schonell:** In some states GPs can still do it, but in Western Australia they can't.

**Senator STEELE-JOHN:** So you'd support the expansion of that prescribing ability to GPs?

**Mr Schonell:** I don't know if I would, because then the GP's got to be properly trained.

**Senator STEELE-JOHN:** Yes, but if they had proper training?

**Mr Schonell:** If they were properly trained. But I also think we could take a leaf out of the American book, with the DSM-5. If we could put together a proper diagnosis kit that GPs could use then, yes, I'd be fully supportive of that.

**CHAIR:** Senator Kovacic, have you got any further questions?

**Senator KOVACIC:** No other questions from me, thank you.

**CHAIR:** Thank you very much, Mr Schonell, for your evidence today. It's been really valuable to the committee.

**Mr Schonell:** No problem.

**CHAIR:** I am now going to hand over chairing to Senator Pratt. I've got to leave for the next half an hour. Over to you, Senator Pratt.

**ACTING CHAIR (Senator Pratt):** Thank you, and thank you, Mr Schonell.

**BROWN, Ms Louise, Private capacity**

[11:34]

**ACTING CHAIR:** Good morning, Ms Brown, and thank you for joining us as a witness today. I believe you've been given all the right documentation et cetera. Do you have anything to say about the capacity in which you appear today?

**Ms Brown:** Please call me Lou. I have ADHD, and so does my son. I am the Lived Experience Director on the AADPA board. I wrote the consumer companion to the *Australian Evidence-Based Clinical Practice Guideline for ADHD*, and I co-wrote AADPA's *Talking About ADHD* guide. I've been involved in advocacy ever since I was diagnosed, to the point that I'm doing a PhD, which is one big advocacy project that's focused on developing an ADHD parenting program that aims to empower parents to foster the development of their pubescent children with ADHD into independent, healthy, functioning adults with ADHD.

**ACTING CHAIR:** Thank you, Ms Brown, and thank you for your ongoing advocacy and your work supporting people with ADHD. It's very valuable work, of which I have been the beneficiary. I want to ask for your key advice to our committee, based on the challenges that you see children and families experiencing in Australia and in Western Australia.

**Ms Brown:** I have some information here that may be a good place to start, and then you can ask me about that.

**ACTING CHAIR:** Great. That's terrific.

**Ms Brown:** There are a few things that I really want to bring to your attention. I am very grateful that you invited me to be a witness. Firstly, ADHD tends to be a lifelong disability. While ADHD medication effectively reduces ADHD symptoms and is invaluable and often lifesaving, it does not take all your ADHD symptoms away. It doesn't rectify a lag in brain and cognitive development or make a person with ADHD neurotypical. Therefore, we need to ensure that care and support provided to people with ADHD is holistic, protective and adaptation focused. Medication should only form one part of a person's treatment plan that aims to foster acceptance of disability, hope, self-determination and personal empowerment.

This care paradigm needs to start in childhood, as symptom control and behaviour management are not the end goal. The end goal is for children with ADHD to grow into self-aware, well-adjusted individuals who understand their condition and accept themselves fully—individuals who have learnt to harness their strengths and scaffold their challenges to the best of their ability so they can competently navigate societal expectations and the challenges they will inevitably face, and live full and rewarding lives.

For this to happen, the use of currently promoted operant conditioning practices at home and at school really needs to stop. Using rewards and punishment as a means of trying to control a child with ADHD and ensure they're compliant is absolutely inappropriate and harmful. These practices are only successful when the behaviour displayed by a child is a choice. The inattentive, hyperactive, impulsive behaviour displayed by children with ADHD is a manifestation of their neurodevelopmental condition. It is not a choice or in their ability to control. There are generations of adults with ADHD that can contest to the devastating effect these practices had on their long-term mental health and wellbeing. You cannot punish the ADHD out of a child, and offering them a reward in the hope that you can get them to do something they have not yet developed the ability to do basically sets them up to fail.

These practices also cause immense psychological damage and increase the chance that they will go on to develop significant mental health issues. Suicide is an extremely large risk in the ADHD population, especially in women. While it may appear that some children with ADHD are more compliant in the short term, they are ill-prepared for any type of independence and are often highly anxious and full of shame, so they rebel and give up.

What children with ADHD need is care and support at home and in the classroom that validates their feelings and experiences, scaffolds their developmental delay and lag in cognitive skills and fosters in them, in a collaborative manner—not in an 'I'm going to teach you how to do this' manner but getting them to work out and learn via this process, and develop self-awareness and self-empowerment in the process—the personal insight, knowledge and skills they require to develop in a healthy manner, reach their full potential and thrive. I've brought that document with me today. It has more information about that.

Secondly, while there's a huge need to ensure that all healthcare providers, teachers and people with ADHD receive high-quality education on the condition, the way this education is provided needs to change. Currently the quality of education in all arenas varies greatly. Often the content is either overly clinical or superficial and contains theories, models and assumptions presented as facts or grand statements that cannot necessarily be

qualified in the research data. Sometimes, from a personal perspective, I think the delivery is stigmatising. It feels judgemental, and it really feels like people don't understand that there's this massive gap between lived experience and what's in the research and clinical practice.

What we need is for education to be based on the best available evidence and to reflect convergent research findings. It should help people really understand the neurological and cognitive differences associated with ADHD and be provided using non-judgemental and non-stigmatising language, like that outlined in AADPA's *Talking About ADHD* guide. To address this need, the integrative review of the ADHD literature that I completed as part of my PhD was actually designed to ensure it could be used to develop any ADHD programs that are required. A well-planned education strategy aimed at delivering staged ADHD education across health and education at both university and practitioner level does not have to be costly.

Thirdly, all research into ADHD treatment intervention design and service design needs to be participatory in nature. I'm witness to a lot of paternalism, a lot of invalidation of people's experiences and a lot of pathologising of people with ADHD. We are people in our own right who have our own strengths and abilities. We just need assistance learning how to scaffold ourselves and to use our strengths. Unfortunately for many of us, without medication, you can teach us anything in the world, but we won't be able to do it anyway. That's all I had to say. There are a few things that you asked before that I could answer.

**ACTING CHAIR:** Yes.

**Ms Brown:** You asked about school funding when a child has ADHD. I can tell you that the school can apply for funding, but that funding is generalised. It goes into the school, not to the child, and it can be used by the school in any way that it wants.

**ACTING CHAIR:** How would we know if a school had or had not applied for funding?

**Ms Brown:** My brain is not very good at giving me information in the moment, so I'll get it to you.

**ACTING CHAIR:** That's fine.

**Ms Brown:** There is a database that collects data that they have to fill in. There's a computer system that they go to. They fill in the child's details, and that's how the funding is distributed. It's only if you get a diagnosis for something like autism that you get child-specific funding that can be used specifically for that child. So teachers will still say, 'Yes, the child's got ADHD and the school might have got funding, but I don't have the funding in my classroom or additional support in my classroom to scaffold this child.'

The other thing that you asked about was who's best to support people into the workforce. It's usually ADHD coaches because a lot of them have ADHD. There's a lot of care, and the way that people are spoken to is provided from a neurotypical perspective rather than an ADHD or neurodiversity perspective, whereas ADHD coaches have been taught to understand that. I was witness to a conversation the other day. Someone was upset. Someone in a different profession would say they're much more qualified and there's no place for ADHD coaches, but I think that what people find is that they don't feel pathologised by ADHD coaches. They feel like they get them, they understand them and they know how to help them be their best self.

When you've got ADHD—and I know, Louise, that you alluded to this before—if you don't have an interest in what you're doing, you don't have the dopamine to do it. You just can't do it. You can teach someone to use a diary. You can teach them all these skills. I have a saying that you can teach someone with ADHD how to use a diary, but that doesn't mean they can. If you don't understand that, you really don't understand ADHD. You need that care and connection that goes to the heart of helping somebody to really understand who they are, to develop a connection with their deep-seated values and interests to help them drive their decisions and find that motivation.

For a lot of people with ADHD, if you grow up and you haven't been medicated so you can't control your focus, you struggle to go inside and get to know yourself. You struggle to figure out who you are and what you're good at. You can't pay attention, so you don't learn, not just in the classroom but in social situations and all these things. Then you're really, really lost. People that look at kids with ADHD and go, 'We have to teach them to do this, and they should do that and they should do this'—these kids are just having all these negative messages constantly thrown at them.

If you had someone in a work environment, and the boss came in and said, 'From now on, we're all doing this,' you don't get very much compliance or much buy-in or agreement. It's only through collaborating and talking with people with ADHD and kids with ADHD and saying, 'What's going wrong, what's happening with you, what do you need right now, what might be ahead for you?' that you help to build that self-awareness, you help to build the knowledge and skills for them to work it out. They have the best insight into what will help them, better than anyone else can. I'll stop now.

**ACTING CHAIR:** That's very insightful. If people want an ADHD coach, do they pay for that privately?

**Ms Brown:** It's privately, and I'll just declare that I am not coaching any more. I didn't say that because I used to be a coach. I'm really trying to stay in my advocacy role, trying to provide my opinion, which is based on all the things I've seen to offer greater oversight of the big picture. I'm in a very privileged place where I get to see that when most people don't.

**ACTING CHAIR:** In terms of the evidence basis that you are talking about where there are unhelpful institutional personal responses to ADHD in the schools, workplaces or families, how do we unpack trying to redirect people to the right evidence base?

**Ms Brown:** What's really hard is that with ADHD research, although there is a lots of research, it's been very hard to unpack it. It's being conducted by so many different areas using many different methodologies, and so it's really hard to pull the findings together. That's why I did the integrated review of the literature to try to look at that from a different perspective. What's happening for someone who is neurotypical? How does their brain work? There are theories, so what is the theory when someone manages their emotions? What skills do they use? What happens to them before a stimulus and after the stimulus? What things do they do? You need to compare that to what is likely to be happening to somebody with ADHD because they usually try to do some things we can't do.

That kind of information is necessary because you cannot scaffold yourself if you don't understand where the differences lie. If you know that you're likely to go from here to catastrophe in 2.5 seconds when you're triggered and you don't have medication on board, whereas if you have medication on board you respond differently, you can make sure that you are medicated if you're likely to go into such situations. You can also decide not to get into such a situation. We always think that we have to do everything and we have to achieve all this stuff, but we are allowed to protect ourselves and make decisions not to get into such situations. People will self-soothe, if it is something that people with ADHD really struggle with, and we need to know that.

People know these things innately, and we just don't. We might nut down on those things and try to help people to develop self-awareness. We don't want people to need care for the rest of their lives. We want to empower them to become self-determined and to understand and accept themselves.

**ACTING CHAIR:** In your experience, what are the best ways to help people, especially children, with ADHD to discover and reinforce their strengths and to use their strengths as part of this scaffolding?

**Ms Brown:** I think is a really hard question to answer in a compact way. It's different for children and for adults. I'll focus on children to start with. Some people don't even tell their kids they've got ADHD because they're so worried about the stigma around it. But basically that message is stigmatising because it's giving the child the message that ADHD is stigmatised. The language that they use can make a child not understand or really get to know about ADHD. It's about listening and validating. It's also about going gently. It's easier when you're a parent. I used to go to my son and think I'd need to write down anything he has asked me to remind him about because I can never remember anything. I'd say, 'It's a really good idea to write a post-it note, so let's write one and put it on the fridge.' One day I was washing the dishes when he asked me to remember something, and I said, 'How about you write the post-it note this time and put it on the fridge?' He's written post-it notes ever since, and he's learned that without being told off or told he has to do it. He's worked out for himself that it works for him without feeling bad. If you're told off as a kid and you need to write things down on post-it notes, you don't have that buy-in, connection or understanding for yourself. Basically, most kids hear only the message that there's something wrong with them.

**ACTING CHAIR:** There's a lot of information overload for everybody, whether it's bureaucracy, tax, getting to work on time, assemblies or showing up at the right place at the right time. What are they told and where do you advise people to go for support and advice?

**Ms Brown:** It depends on what exactly they need. Unfortunately, I wouldn't even have one book that I would say is the best book to go to. I find some of the information very generalised or superficial. That's why I'm doing my PhD and why I've done the integrated review and things: I don't think we have nailed that yet. If we keep doing what we used to do and keep rolling out the same thing, we're still going to have the same results.

**ACTING CHAIR:** Can the government help set a direction to get the long-term research support right in the long term?

**Ms Brown:** I think that developing programs that can be rolled out—my desire would be, say, for my parenting program to be free and accessible to every single parent with ADHD. It's been designed in a way that you attend a workshop to make sure information isn't lost in translation and the person has been trained to do it. There are videos as well. There's information that you want to explain about ADHD that you know doesn't transfer across unless it comes from the lived experience. Video content can help people really get it. The aim is

to train up people who are psychologists or coaches so they understand the same type of framework and have received education. Then the person can have ongoing care and support with that person. We're all working off the same page.

**ACTING CHAIR:** In your experience, if you're trying to overlay meeting the needs of families, individuals and children with ADHD when they're being referred to more generalised parenting workshops, which can be important because they help with self-regulation and can help de-escalate but lack the support for the fact that people's executive functioning just means they're not going to pay attention in the same way, what advice do you have for government when we decide which kind of parenting programs to support?

**Ms Brown:** The research I've handed you is part of my integrated view about some of the parenting programs. When you ask the research question, which I haven't got in front of me—do you want to read the research question? It's at the top of the first page.

**ACTING CHAIR:** 'The examination of parent management programs currently recommended when children have ADHD from a child development perspective. Research question: what does the evidence tell us about the aim, usefulness and effectiveness of the current parent management training programs recommended to parents who have children with ADHD, including their ability to enhance the quality of the parent-child attachment relationship; empower parents to respond to their prepubescent child in a complete manner; bolster their development as independent, healthy, functioning adults; and improve long-term outcomes of children with ADHD?'

**Ms Brown:** Basically, the answer is that there's no evidence that the current paradigms that underly all the parenting programs out there do any of that. Most of them are based on operant conditioning. They involve rewarding and sometimes removal of privileges et cetera in order to gain compliance and get the kids to do what they want them to do. That's what they've been developed for, but that's really not helpful when you're a child with ADHD, because they you end up punished for something that you haven't got the ability to do or are told, 'We'll reward you, and you can get this if you can do this.' Then, if you can't do that, you get punished by not getting that reward. So I think we need to go back to the drawing board, and we actually need to design these parenting programs based on what kids with ADHD need, the type of support they need, that actually helps them to develop in a positive way. Punishment and reward severs the parent-child attachment relationship so quickly. It might look like kids are compliant when they're really young, but, by the time they're teenagers, they have no ability to have independence in a successful manner and are pretty much over it.

**ACTING CHAIR:** Where do such programs with an evidence base exist, and who should be developing them?

**Ms Brown:** They don't exist. I'm doing my PhD—I think about retiring all the time—because it doesn't exist and it needs to change. It has to change.

**Senator STEELE-JOHN:** Thank you so much for the evidence that you've given us and the submission that you've made. When you were describing the system that we should have and the way in which it should support people to access the supports they need to live a good life as determined by them, I was struck by how closely that basically aligns with what the NDIS should be and what it was created to provide to people. It strikes me that you've given one of the most compelling pieces of evidence so far for the inclusion of ADHD within the NDIS. Is that a reform that you would support?

**Ms Brown:** Absolutely.

**Senator STEELE-JOHN:** Would your hope be that, under the NDIS, people with ADHD, if they so choose, would be able to access ADHD coaching and the other human rights based effective supports?

**Ms Brown:** Yes. The one thing I would say is that there are a lot of treatment and support options out there that are available, but from my perspective—I was a registered nurse; I worked as a coach; I have ADHD; I'm doing research; I participate in research in other universities—sometimes care might be provided and it's available, but I don't think it's actually been developed from a neurodiverse perspective or based on that framework. You'll get someone going to an OT and being taught emotional regulation techniques—fantastic—but then there's this presumption that they've been taught and can use those skills. That is really unfair and that sets a child up to feel like, 'Now I can't use them, there's something even more wrong with me, and now I'm going to get punished because I can't use them, even though I've been taught them.' You've got to come from a perspective where you say, 'We're going to teach you this, but you might not get it right all the time. That's okay.' We need to foster self-compassion in these kids, not make them highly anxious, and then help them practise slowly and get them to work out why they want to do that.

We can't do things naturally without dopamine. If you just tell us to do something, that doesn't go anywhere. You have to help us find the value in what we're doing so we get the dopamine to be able to do it, and we need to practise. You need to change the expectations on people, especially on children, between when they're medicated and when they're not. When they're medicated, yes, that's one thing. If they don't have very complex histories and just have the challenges of ADHD without any other condition, and they haven't been to hell and back in their life journey—I absolutely fell apart when my son and I were diagnosed—medication, support, coaching or counselling might be things that they need. But sometimes people don't need much. Their diagnosis, the medication and two conversations with the coach or one with a psychologist are what they need to be off and running. Not everyone's like that. We need to make sure that the people who are struggling the most get the other interventions and things that they need, and we need to make sure those things are provided from a neurodiverse framework.

**Senator STEELE-JOHN:** In the absence of public funding to support people to access ADHD coaching or to access really good professionals, many neurodiverse people are left with the option of nothing or find what they can themselves through social media.

**Ms Brown:** And there are some brilliant clinicians out there in all the areas, but there are some really terrible ones as well.

**Senator STEELE-JOHN:** Absolutely.

**Ms Brown:** It's not a one—

**Senator STEELE-JOHN:** Yes, it's not a one-size-fits-all process. What would your view be on the pros and the cons, if you like, of a system that seems to leave you with nothing or simply to find your way through social media?

**Ms Brown:** That's not appropriate. That's why I do what I do. It's got to change. It doesn't have to be that hard. I have a concern about overservicing as well. I do feel sometimes that people with ADHD in some situations, especially children, are expected to have a range of tests that aren't necessary to diagnose them with ADHD. Yes, that might be beneficial for them, but, if the parents can't afford that right now or aren't ready for that and just need psychologically to take one step at a time, the best thing you can do out of all them is address the ADHD. That will support all the others. And then, when the person or the parent is ready, we can go, 'Okay, how about we have this assessment or that assessment?' This one-stop shop where you get assessed and to have part of that assessment you've got to have this done and this done and this done is going to end up with overservicing. So we need to find that balance. There could be a way where you go: 'We do this if there's this. If you notice this, then we do this. Otherwise, you don't do that.'

**Senator KOVACIC:** Thank you so much for your evidence, Ms Brown. I'm thinking through a couple of the comments that you've made, particularly around how things shouldn't be so hard, and potentially around inadequate servicing in some elements and then overservicing in others. Do you have any insights as to how we could actually make it simpler in terms of the red tape that people need to go through to access services but in doing so ensure that we don't have duplication so that these precious resources and time aren't wasted on repeating the same thing when the actual deeper information that needs to be extracted or processes that need to be followed don't then get the time that they should have?

**Ms Brown:** I'd like to be able to give you some information on notice about that, because there's a lot in that question. I don't even know where to start, actually.

**Senator KOVACIC:** Sure.

**Ms Brown:** So many things just pop into my mind, and then I've lost them and can't figure out where I am.

**Senator KOVACIC:** No, that's completely fine. It's interesting because it's almost like we're trying to fix one problem, but when we fix that problem it overflows and creates another one over here. So I'd be really interested in your insights. On notice is fine.

**Ms Brown:** Yes, because there are definitely ways of doing that. As a nurse, we had clinical pathways in the hospital if somebody was diagnosed or came into the hospital and had a hip replacement or something. It wouldn't be exactly like that, but it could be that, when you're determining whether someone has ADHD and stuff, if there are signs of these certain things, then this referral is needed. But you're going to find that, amongst the clinical practitioners out there, everybody has a different opinion. I might be shot down for saying this, but everybody, whatever clinical seats they sit in—whether they're a psychologist or a psychiatrist et cetera—thinks their way is the best and most important and most appropriate and does the best service, so it's very hard to work out what actually is best. I think that, with consideration and finding the right team to help you, not necessarily always the

people that talk the loudest—although I am very loud—I feel like I have a really good idea of how that could be done, how you could achieve that.

**ACTING CHAIR:** Feel free to get back in touch with the committee, either with a verbal statement that you've recorded or with something in writing. That would be terrific.

**Ms Brown:** There are so many things in this that don't have to be so hard. There are actually quite simple solutions to most of them. It does come at a cost, but it doesn't have to be a blowout cost, either.

**Senator KOVACIC:** That's great. I would say that I'm happy for you to provide any information down the track that you feel would be useful to us, because I'd very much like to get your insights, particularly given your broad lived experience in this space, on how we could make it simpler. Simpler usually equals faster as well, which is very clearly important here.

**Ms Brown:** Sure.

**ACTING CHAIR:** Unfortunately, we have run out of time because we are due to have a Senate committee meeting now, but I want to wish you all the best for your research, Ms Brown, and for your advocacy. Feel free to forward any further views or opinions to the committee.

**Ms Brown:** Thank you very much.

**Proceedings suspended from 12:05 to 13:31**



**Edward, Private capacity**

**Henry, Private capacity**

**Lexy, Private capacity**

**Mary, Private capacity**

**CHAIR:** Let's kick off. I remind witnesses that this hearing is being audio broadcast. Just be aware that what you're saying is going live. If you've got any concerns, please let us know, and we can suspend the broadcast. I now welcome people with lived experience of ADHD from the Perth community. Thank you very much for appearing before the committee today. I remind you not to divulge any confidential or identifying information when you speak. For us as a committee, primarily these sessions are a listening experience, so we may or may not want to ask you questions. If you don't want to be asked any questions, that's absolutely fine. I'll now call each of you one by one to make a statement to the committee. Please try and keep your statement to under 10 minutes. I'll give you a warning at eight minutes, when you're towards the end of your time. I now welcome Lexy to share their experience with us.

**Lexy:** Thanks so much for inviting me to give evidence today. I'm really hopeful that this inquiry will lead to meaningful changes that improve the lives of people with ADHD. I am a researcher, writer and artist. In 2020, the year I turned 30, I was diagnosed with ADHD. Like many millennials, I first learned about adult ADHD on TikTok. I know that that's not really a reliable source, but it did show me that ADHD isn't just the stereotype that we're all familiar with. It's not just six-year-old boys who throw things in class. This was the first time that I was exposed to the idea that ADHD might be what's wrong with me. I use the words 'what's wrong with me' because that's how I've always felt. Throughout my life, I've always felt that there is something wrong. I've always struggled with depression, anxiety, inconsistent motivation and impulsiveness, and my brain is constantly whirring with the hum of a hundred simultaneous thoughts. With a hundred thoughts, come a hundred ideas—ideas for research projects, new hobbies, a different way to arrange the kitchen, dismantling my shed to make an outdoor oasis.

But the thrill of a new idea is fleeting, so I had stacks of unfinished papers, a craft room bursting with unused supplies and the skeleton of a shed in my yard—a daily reminder that I just can't seem to finish anything and that there is something wrong with me. I went for 30 years believing that the things that I struggled with were a result of a bad attitude or weak character. I didn't have a neurodevelopmental disorder; I had a lack of discipline and self-control. I've lived through long periods of depression, self-harm, drinking problems and suicidality, never knowing that I was also living with an untreated and unsupported disability.

I try not to think too much about what might be different if I'd been diagnosed as a child. But I can confidently say that I could have avoided many, many painful, dangerous and harmful experiences. What I find quite frustrating about my experience is that, when I was 10 and my sister was eight, my sister was diagnosed with ADHD. Why wasn't I screened? Why wasn't my brother screened? So something we can change is that, any time an individual is diagnosed, their siblings and their parents are also recommended for assessment, and GPs are trained and supported to conduct these assessments.

Nineteen years after my sister was diagnosed, I seriously started to consider that maybe I also have ADHD, and then I spent many hours of ADHD hyperfocus on ADHD. I really wanted to understand how it manifested in my life as an adult and, of course, what I could do about it. Surprisingly, I couldn't find any answers. I didn't find much useful information. Most information was for parents and teachers of children with ADHD. And I really struggled to find evidence based information that was directly relevant to my experience and experiences of adults with ADHD. So I had to rely on TikTok, Reddit and Twitter to make sense of my experiences and to find strategies and advice that might help me manage my ADHD and to cope with the mental health problems that it had caused along the way.

When it came to pursuing my diagnosis, I was overwhelmed by the lack of guidance and transparency in the process. Every internet search turned up different recommendations, my GP was unsure, and all the people I spoke to had different experiences. Eventually I found the adult ADHD clinic. Several appointments and hundreds of dollars later, the psychologist said that I probably have ADHD and referred me to a psychiatrist who did another round of diagnostics and seemed more interested in whether I was a drug seeker than in how ADHD actually impacted me. Again, after many hours and many hundreds of dollars, he sent me off with a script for Ritalin, an appointment for three months time, and a recommendation to 'read up' about ADHD—which I had already been trying to do. So I didn't get any formal resources, suggestions for psychosocial support or strategies beyond medication adherence.

Lots of people describe their first day of ADHD medication as life-changing. I was a bit sceptical of that. How could Ritalin fix the plethora of challenges that characterise my daily life? And I found that it can't. It helped me to get up in the morning. It helped me to focus and to be more attentive, but it didn't fix my time blindness, my impulsivity and my distractibility. My daily life was still chaos—and it still is. When I tried to explain this to the psychiatrist, he went on a bit of a rant about dopamine pathways and then called Medicare. I changed psychiatrists soon after that, and, while my new psychiatrist is more compassionate about my experience, I still don't have any practical supports to help me manage my life. I'm stabilised on medication, but my daily life feels anything but stable.

The approach and process of assessment, diagnosis and treatment for ADHD in adults is horribly inefficient. It's convoluted and demeaning and fails to achieve its primary purpose: to connect us with services that have a positive and meaningful impact on our functioning and wellbeing. Yes, the medication helps, but we need accessible and affordable psychosocial supports that are tailored to our individual needs and preferences, and these services just aren't available. They either have long waitlists, require a psychiatrist-given diagnosis, are informal or group based or are completely inaccessibly expensive.

What I wish for is comprehensive, multifaceted support that helps me and other adults with ADHD manage their symptoms in all areas of our lives—personalised support that offers practical and effective strategies that are tried and tested by adults with ADHD. There is a need for research, funders and service providers to recognise that ADHD is hugely impactful on the lives of individuals, families and communities. It is time that ADHD receives the attention and the funding that is proportionate to its impact.

Adults with ADHD are underrepresented in research and undersupported in communities. They are disadvantaged by their disability and deprived of the opportunity to thrive. Thriving shouldn't be a privilege. It shouldn't be a luxury. The chance to thrive should be everyone's right no matter their neurotype.

**CHAIR:** Thank you very much for sharing that with us today. I'd now like to ask Mary to share their story.

**Mary:** I'm here to talk to you about our family's experience in handling diagnosis and the complicated support system around managing ADHD. My son is 11, nearly 12, and has been diagnosed with ADHD. He also has dysgraphia and generalised anxiety disorder. I have a number of recommendations that I'll run through that my husband and I feel very strongly about, and I'll explain why I've come to these conclusions with a few examples that we've lived through in the last few years. From listening to Lexy just now, I feel that the points that I'm about to raise, although relevant to ourselves and our family and from the perspective of having a child with ADHD, are relevant to everybody. They're relevant to adults as well.

First on my list—there are a few things—is more affordable and better access to paediatricians and child psychiatrists. They need to be government funded. There need to be access and options available from both the private sector and the government to support people with or presenting with signs of ADHD. There needs to be a holistic approach. We need a holistic approach for the management of ADHD in both diagnosis and prescription, not just medication but inclusive of behavioural therapies, counselling, parent support, lifestyle adjustment and educational support. Through trial and error and through having a solid team around us, we have come to the conclusion that we need a lot of these things ourselves. By 'a solid team' I mean my husband and me. Thank goodness we work together through this; so many people don't have that who are single parents on low incomes.

We have two sets of parents, so four grandparents, who are all supportive, and they're amazing. We use every resource available to us. I have a friend who is a mental health nurse who previously worked at PCH and other friends who I seek. I see parents at the school struggling, and lo and behold they have a child with some sort of neurodiversity. We help each other, but it is not straightforward by any means.

We need waiting times to see paediatricians, psychiatrists and health practitioners to be reduced to a mere couple of months and, in doing so, we need more incentives for people to enter into mental health services and to study mental health, including ADHD, for degrees to be affordable and accessible and not to have to do long practical components without any financial support. There have to be incentives to assist people with studying this field.

Children's hospitals need to be equipped to assist someone who is diagnosed with ADHD when presenting at emergency for help. We have presented and we have received no help despite being there for eight hours. At a push, we were referred to CAMHS to then speak to CAMHS in an online session a couple of weeks later. They were amazing people in their field but could not help, because the support processes were not there. What we really needed was just an adjustment and a review of our son's medication. This couldn't happen, so it was back to us to make the lifestyle adjustments that we made. A child or an adult could have their details under Medicare

accessed by other practitioners and not just have complete reliance on one private practitioner, who may be on leave, leaving you stuck.

Teaching degrees need to include thorough training on ADHD, its complexities and how it presents differently for different people. It needs to include executive functioning lists. It's important for there to be understanding of the differences in the brain between a neurodiverse and a non-neurodiverse person. I'm aware that, in at least two universities in Australia, for a full teaching degree, which I believe is four years, there is one unit in the whole degree for differentiation and diversity, and, in that, one week is allocated to ADHD, what it is and what its symptoms are. It doesn't cover teaching methods for teaching neurodiverse brains. You can't become a specialist for teaching and caring for children and adults with this lack of knowledge. To me it just seems ludicrous. It's the luck of the draw whether you have a teacher who gets it, who cares enough and who has the EQ for it.

Caregivers also need to understand that ADHD presents very differently for different people. It isn't one size fits all. Emotional intelligence here is also vital, and it is viewed that you cannot teach emotional intelligence, but you actually can. I say that because I've done some studies in it myself. Schools simply need the funding to be able to support EAs having a school psychologist who is available to parents and to children. We have a school of 580 students. There is one psychologist there who is available two days a week, and you can't get through to her. She wants to help, but she simply can't.

There needs to be early intervention. Early identification and intervention can make a world of difference, and having screening programs in schools and communities through community nurses can make a world of difference. I know that my husband and I knew there was something going on with my son at three years old. It was always put down as, 'Oh, he's just a child,' but we knew.

Lastly, there needs to be a process that private practitioners need to go through to close their practice so their patients are not left stranded if they suddenly close their practice, as has happened with us. Private records need to be accessible, at least in emergency situations. GPs need to be given authority to prescribe. There need to be enough practitioners available to provide backup if and when this occurs. Not doing so can have severe and dangerous consequences, and the effects of this were detrimental to our family and community. That was my short list of recommendations which I think are vital to improving the situation.

As I mentioned, we used every single resource available to us to assist us in the last few years. At the end of 2018, we returned from living overseas. Our son at that stage was seven years old. We questioned a lot of different neurodiversities that we had researched ourselves, but we didn't really know what was going on with him and for him. In the first 12 months after we started this process, we went through—and I say 'went through' because these all have costs involved, and remember that, for every single appointment here, there's a little seven-to eight-year-old who has to be dragged along and go through this, which is horrendous for a child that young and doesn't do anything for their mental health. We saw two paediatricians—two because the first one just wasn't the right fit and simply didn't have the knowledge. They were giving me knowledge that I had researched years prior. A physio assessment, an ongoing psychologist, a mental health OT, the second paediatrician, which we continued with, and a psychiatrist—the costs for this are enormous, and thank goodness we were in a position where we could make this work. I find it absolutely heartbreaking that others simply cannot afford this and so are left in the lurch. This is detrimental not just to the child or to the adult involved but to society as a whole. It has a roll-on effect, and that cannot be ignored.

Overall, we found the best assistance as parents was through a well-experienced psychologist who was referred to us from our fief, who is a mental health nurse. She provided support for us not only for us personally but also to navigate the difficult health system. 'Try this. Try this. Don't do this. This won't be the right fit for you. This isn't what you need to do. No, that's not right. I don't know why you got that advice. Try this.' Everything she told us was spot on. She also got us onto a mental health occupational therapist, who we—and I say 'we' because she's practically a part of our family—have been seeing regularly for five years. She has been a godsend. She is accessible; we see her once a month. She has our son's and our trust and his heart. She has been a constant in our lives, and this leads me to the holistic approach that's needed. We needed her input for a diagnosis, and it needed to happen much sooner than it did.

**CHAIR:** One more minute, Mary.

**Mary:** When we eventually got through to a paediatrician, it took 12 months before we got a diagnosis and we really had to push for it and to try medication. Very briefly, we tried one type of medication which had horrendous effects on my son. We were in a position where he was nine years old and he took off in the night, at 9.30 at night. I ran after him, lost him in the dark—no shoes, no phone—and it was terrifying. And this was simply because the medication wasn't the right fit for him. Thankfully, he came home 20 minutes later. That's just one example.

At the end of 2021 our paediatrician closed her practice. We had no one to go to for 12 months. During this time, our son was assigned to a class teacher who we had asked he not have. In the first six months of being in this class our son's wellbeing went downhill dramatically. We were dealing with suicidal ideation. As a parent, having to tell your 10-year-old, 'Don't do that. No, no, don't do that. That's not okay,' is horrendous, and no parent should have to do this. We couldn't go to the hospital for help, which we did. We couldn't go to anyone. We did everything ourselves and with the help of our OT and psychologist. Now, eventually, we have a psychiatrist. All he had to do was a mere tweak of his medication, and it made the world of difference. Our son now has a teacher who sees him as a person. He's not seeing that he has a problem; he is just a person. Yes, he has his quirks, but he also knows his strengths and his amazing ability to be the person that he is.

When I told my son that I was coming here today, all he said was: 'Oh, can I talk? But I'm the one with ADHD.' And then he said, 'Well, can you get an autograph from the senators for me?' And when I said, 'Why?' He said, 'Well, I want to show my class. They're senators.' And then he went on to say, 'They're part of the government, so they're pretty good.' He thinks the government's pretty good, so I hope the government makes changes here. Thank you.

**CHAIR:** Thank you very much, Mary. I'm sorry I'm not in the room to give you a signature for your son. Thank you for that evidence that you've provided to us today. I'd now like to call Henry to share his story with us.

**Henry:** Thank you for the opportunity of coming along to present a lived experience today. Thanks, Lexy and Mary for your presentations. They were wonderful. I could sum up my lived experience with one word, and that is 'no'. It's not an articulated 'no'. It's a 'no' as in: 'You don't quite fit. You didn't do that quite properly.' Those things are constantly being brought to one's attention.

As the first two presentations were taking place a phrase came to mind, that where I find myself now is that I've retreated in the face of capability. I know what I can do. I know that I can achieve certain things, but I don't. And it's incredibly disheartening.

I was a very easygoing child who was very compliant, and, unfortunately, I was also inattentive. My school reports talked about, 'When will he reach his potential? What is holding him back?' et cetera. I felt on the periphery of everything, aimless and directionless. After school I got a job in a bank for a very brief period of time and then was fortunate to get a job in an academic library where I worked for about 10 years. And then about 20 years ago I became a public servant. After marrying, we moved to Canberra where we lived, and my wife gave birth to our first child.

My wife was driving along the road one day, and she was listening to Radio National. There was an interview on *Life Matters*, or something, with Professor Brown from Harvard University, a psychiatrist. He was in Sydney for a medical conference. He's a noted ADHD specialist, and he ran through the presentation list of adult ADHD. After my wife recovered and didn't drive off the road—she thought she was going to—she told me that night about what she'd heard.

I tracked down the conference, found out the name of the recommended hotel, then phoned around and eventually was put through to Professor Brown in his hotel room. He said: 'I've only got a couple of minutes to speak. I'm too busy.' After three-quarters of an hour of a wonderful conversation, he gave me the names of two psychiatrists in Sydney that he could recommend as being across adult ADHD.

I travelled from Canberra to Sydney to see one, who made a positive diagnosis. On my second visit to him he prescribed dexamphetamine. I was euphoric to get the diagnosis and to have some clarity that this amorphous life that I feel could be slotted into some sort of scaffolding framework and, potentially, treatment. Very soon after, I realised the medication was having barely any effect. It was a stimulant and I felt slightly activated and, over time, became psychologically dependent upon it, so when I missed whatever medication I started to feel increased self-doubt et cetera.

We moved back to Perth, expecting our second child. I saw a psychiatrist who was recommended as being across ADHD. That consultation, with my wife present, consisted of him reading out the 19 questions from DSM-IV, and warning me not to lie in order to get stimulant medication. It sounds ludicrous but that was the standard of consultation with a particular psychiatrist. I didn't go back and I sought further assistance. I saw another psychiatrist and was able to get medication.

I was suffering from depression and my GP referred me to a psychologist, who referred me to another psychiatrist for tweaking of the medication. That psychiatrist claimed not to be across ADHD, as such, but continued to treat me for 10-plus years. Over that time I was referred to other psychiatrists for second opinions to confirm the diagnosis, underwent a PET scan in conjunction with a Stroop test, which is the presentation of congruent and incongruent stimuli to observe executive functioning under particular imaging, which in their eyes

confirmed the diagnosis again. Each second opinion I went to I was holding out that perhaps this might be the professional who could assist and help. Each time it didn't eventuate.

Eventually I moved on from that psychiatrist. I sent him a letter withdrawing my permission for him to consider me a patient discussed with other people, and also a letter of referral to my GP outlining my treatment over those 10 years. It consisted of three very brief paragraphs with absolutely no reference to medication, so none of that medication history was captured and transferred on. About a quarter of an hour after dropping off the letter to his practice I got a phone call in which he asked if anything was wrong. I kind of just wanted to move on, and he then espoused something about how sessions in psychiatry can get very emotionally charged, as if that was my reason for moving on.

The reason why I moved on was more to do with transparency and the exchange of information amongst medical practitioners. I had a workplace anxiety issue for which I was referred to a medical officer for a fitness-for-work assessment—a psychiatrist, who I treated as a doctor. When I was asked questions, I answered fully, absolutely fully. The report that came back to my workplace was like a verbatim recording of what I'd said. It was not a consideration of what I'd said—for example, 'Here is my professional opinion.' So my family dynamics and family medical history, everything, were in the report, which was retained by my employer. I was just plainly naive. In the report, he referred to having spoken with my psychiatrist by name, and when I asked my psychiatrist about that, he said: 'No. I did not discuss you with that other psychiatrist.' So I'm not sure who was speaking truthfully in that situation.

I moved on to another psychiatrist that I had identified who had particular specialities in pharmacology, because there were other medications I was keen to try like modafinil, which is sometimes used overseas. That psychiatrist practice received my referral, and I was triaged to another colleague without discussion. It was just, 'This is who you will see.' That psychiatrist had moved from public to private practice. Their biography on their website had absolutely no reference to ADHD, which was the reason I was referred to them, because the psychiatrist I had identified had no experience with ADHD. I then went to another psychiatrist, who, in two consultations with me, referred me to an app on how to organise appointments and to do lists et cetera—the rage I felt! Then there were 30 sessions of transcranial magnetic stimulation therapy, which caused discomfort, which wasn't resolved until the 27th or the 28th consultation. I'm getting off the topic.

**CHAIR:** Just one more minute, if you could, please.

**Henry:** Great; perfect timing. The other thing with psychiatry is that a friend told me about a psychiatrist who was meant to be excellent for ADHD. I phoned and made an appointment. They told me the initial consultation would be \$830, and I hung up the phone at that point. I don't know who's worth \$830 an hour. People make that in the world—I understand that—but my time isn't worth that. Their time isn't worth that, regardless of the amount of training they have. The person who referred me to that person said that they actually asked them why they charged that, and they said, 'It's a way of filtering out those who are after stimulant medication only.' I'm upset—as you can hear by my voice—and that's partly emotion caused by the disappointment of where I find myself as a 60-year-old who was diagnosed 20 years ago. But a very good part of it is also rage, absolute rage. Thank you. Thanks for your time.

**CHAIR:** Thank you, Henry. Thank you for that very moving contribution to our committee of your experience. I can understand why you feel that rage. I'd now like to invite Edward to share their experience with us.

**Edward:** Hello all. Forgive me, I have struggled to construct this presentation and haven't even read through it because of all the usual symptomology, so forgive me if I pause every now and then. I was diagnosed in September 2020. I was first medicated in December of that year. I was diagnosed at the age of 45. I think I'm 47 now. I'm so grateful and in debt to you all for this; it means a lot.

The trade books recommended by all the ADHD organisations when I was first diagnosed outlined best-practice options for late-diagnosed adults based on the trade literature that often accompanies the diagnosis and is referred to by these organisations. The predominant recommendation for a late-diagnosed adult principally is medication, coaching for organisation and employment and usually, as a result of the late diagnosis being brought about by either mental health issues but mainly relationship fallout, counselling for relationships. I have struggled getting treatment and medication, being without medication for one to 1½ years and so rationing my medication, which has also recently been identified as inadequate. Searching for relationship counselling ironically ended my relationship in combination with being medicated for the first time and not being informed about hyperfocus. It sent a tornado of misfortune into my life, which is still reverberating today.

I complained about the lack of services to my psychiatrist at that time, knowing that I had SUD issues, as 50 per cent of adults with ADHD do. He tried to make me retreat from my protests through a threat to have a drug test in order for me to have the ability to get my medication. Given that the substance used has a long half-life, it's essentially holding you to ransom for treating your own trauma based on the government's inability to treat you in the first place. I found this very offensive. I refused to go back to the psychiatrist and didn't know that I would be unable to get another treating psychiatrist for another 1½ years. As a result I was without a prescription from December 2021 to Christmas Eve December 2022.

In between those dates my symptoms worsened and my quality of life worsened and my challenges increased. I was taken to Joondalup hospital under the mental healthcare act on 29 February 2022 after my ex-partner issued me with the separation FVRO. It was in hospital that Joy Toll, a beautiful, caring and supportive advocate with an Order of Australia attached to her name for being an advocate for ADHD support and awareness and a director of the ADHD Foundation, told me via the hotline that ADHD was not addressed in the public health system. I found this out in a bed in the mental healthcare ward within the emergency department of the hospital after being taken there by ambulance for the sole reason that it might help me get some medication.

I signed myself out of that hospital, and, when asked to declare that I was signing myself out, I asked them to sign a form to say that they weren't treating me for the condition that I said needed treatment. This is a violation of public healthcare principles. My lack of medication and the trauma of my experience resulted in this VRO and another VRO—all incidental; please don't be intimidated by that—six months off work with a disciplinary issue, or actually two, and my licence being reduced to one point. I've lost all of my finances in the separation through a form of gaslighting that's not unusual for people with this condition. I lost my children for six months, which essentially made my executive function unworkable in the separation process and resulted in that loss of finance. It's removed my aspirations to a better life, and my situation wanting to benefit my children has been on pause indefinitely.

When I finally got a medicating psychiatrist, I was told to get a drug screen, as it was procedure. I was not told that the compulsory drug screen was going to be accompanied by a lady observing me urinate. With my high anxiety after these last four years, and a lifetime of anxiety, I found it hard to urinate with a lady one foot away from me in a closed toilet. I tried to urinate. I tried this for three days at three different clinics, all the day before Christmas, just to get medication to help me be. Eventually, the last lady just insisted that I do it unsupervised. This was accepted because I rang my psychiatrist every time this happened and protested. This is how I spent Christmas Eve.

I thought I'd be treated and embraced by a holistic healthcare plan in December 2020. Three years later, my life is a wreck. I'm still undermedicated, causing significant emotional and functional issues. I finally have a chance to get this fixed with my psychiatrist tomorrow, on account of a fitness-for-work assessment by the bloke who broke the guidelines, who also works as a forensic psychiatrist, who stated that I was undermedicated. Even with the symptomology, it feels like it's worse than prior to when I was diagnosed. I've cried every single day since 27 February 2021, when I lost my family. I'm not ashamed to say that.

Very recently I've been given an indication of CPTSD, complex trauma and also, potentially, autism. I have booked in to start this process. Finally treating my condition of trauma feels like the therapy that always should have been given for this condition. This said, the most often misdiagnosed and similar condition, being autism, can't be diagnosed by the same psychiatrist who's treating me for ADHD. Given that these are the two biggest neurodevelopmental issues that have such a huge range of comorbidities attached to them, you would think that this is a starting point and compulsory for any psychiatrist. I'll be going to another specialist, incidentally. This defies logic. CPTSD is also not included in the public health system. I acknowledge that it's not yet included in the DSM-5 or DSM-IV, but it's part of the ICD-11. The Fiona Stanley Hospital has a gaming addiction centre that could only be accepted if ICD-11 was also used within the public health system, so it is.

I think governments needs to acknowledge that people on social media are filling the research hole that is not filled by government policy. I believe our current issues are simply a result of a lack of proactivity and failure of public health policy to actively apply science to policy as would be expected. I could have been screened and medicated, including adjustment, and treated for this condition within two months. This is what should have happened, and that has cost me so much.

A brief summary of what I see as the core issues: firstly, diagnosis, screening and treatment in the first line is inadequate. Diagnosis for this condition occurs through people finally breaking after decades of not responding to the wrong treatment, at the expense of their lives and the lives of people around them. I believe asking 16 questions might be a more efficient approach. ADHD screening and detection is reactive. Diagnosis is often referred to as a diagnostic odyssey. This is another way of saying that the psychiatric profession identifies people

through the methodology of watching them slowly break down. The lack of training and inclusion in the health system has, of course, resulted in the crisis of availability and quality of service. Undermedication and overmedication arising from this lack of availability also affects patients just as negatively, to the extent that it's the same or worse as the untreated condition itself. By the time this is identified with the current constraints, trauma is well and truly a given. The public health system doesn't seem to listen.

I've read the submissions of the ADHD advocate organisations to various federal and state inquiries going back 20 years. These submissions have offered all the valid evidence and best practice treatments arriving from this evidence that we are still referring to today, decades later. The results of these submissions have amounted to nothing, as they have been systematically ignored by every state government in every state for over 20 years. I'd like to know why. I can only deduce that there are other motivations for not validating medical science other than fulfilling the public need that these inquiries are established to address. This is not an old or under-reported condition.

In reference to the culture within psychiatry, people diagnosed with ADHD as an adult are very interested in the condition that has coloured their lives. We become very well read very quickly and expect the services and assessment of comorbidities. We are sick of struggling, and we want it done now. Our very condition makes this natural. The very nature of ADHD means that the effects of this condition are shaped by the person's character and environment specific to them themselves. In order for the psychiatrist to do a good job treating people with ADHD, they need education, good communication, empathy and genuine curiosity. Additionally, they also have to be a good educator. The personal skills of many good psychiatrists aside, I do not believe there is an emphasis on this systemically, and the lack of availability of psychiatrists doesn't help.

I understand that these issues extend to child services, which appear to be hugely under pressure. I'm halfway through waiting for my boy to be diagnosed—a 2½ year wait, even though I asked the school department to diagnose him—proving that his diagnosis of dyslexia and poor working memory and my diagnosis were all major markers for ADHD. They chose not to. They didn't see the markers. I know that this is not the sphere, so perhaps—sorry, I will start again—

**CHAIR:** If you are able to finish up, too, please.

**Edward:** Okay. The patient psychiatrist relationship is affected by public health. I've got major issues with the government mandating things such as drug testing to restrict availability of something that, as best practice says, will reduce those issues. This is not as per medical evidence. The lack of acknowledgement of public health systems extends to other arms of the government. Commissions and inquiries such as the federal disability discrimination commission provide counselling for complex trauma. This is not acknowledged or treated in any state system. Additionally, the federal department for disability use a group of lawyers for those requiring pro bono representation specific to the challenges described in the commissions. The same law firm represented me during a VRO and did not address my invocation of the use of the discrimination act, nor did the state magistrate. It has caused me a lot of trauma.

I'd like to list what I'd like to see happen. We need inclusion in the NDIS. At the very least, we need much more inclusion for those who really need it. Neurodevelopmental issues need to be core to assessing mental health issues, as the very first step in the process, with mandated proactive screening to better diagnose but also to facilitate better industry knowledge based on the results of such screening. Following on from this needs to be an extensive assessment of associated comorbidities—and don't stop until the patient says so; make this compulsory.

We need to proactively adopt all best practice methodologies as asked for by lived experience. No-one else is going to raise the issue that you need to treat oppositional defiance disorder before the age of four to effectively treat your child, as stated by Russell Barkley, more than people who actually care that this is the case. We need to end the mixed messages of state and federal governments in their representation of public health. State governments need to include ADHD and also treat the trauma it causes by acknowledging complex trauma. We should have one unified and united public health policy and, I believe, function. I don't care who pays for it, but I want to ensure that disenfranchised populations are not fragmented into smaller populations, reducing their voice in local areas.

We should have education and streamlining of psychiatric and psychological services to ensure the net of comorbidities are addressed, with emphasis on neurodevelopment comorbidities as a natural first assessment stage. Please fund the facilitation of a lived experience community-run resource or organisation for and by the people and also fund an associated peak body designed to facilitate and manage the delivery of services and funding and to represent the lived experience service providers for the good of its community. This needs to be separate from the health industry and psychiatry representations.

Fund the ADHD national helpline and acknowledge the crisis generated by historical lack of treatment causing intergenerational trauma. I second the suggestions in the submissions I've seen from ACT ADD and other organisations regarding acknowledging the discrimination in the sentencing and treatment of prisoners who are still not diagnosed, along with the establishment of a discrimination watchdog organisation. As a sweeping statement, please accept all the basic recommendations by our advocate organisations—AADPA, the ADHD Foundation, ADHD Australia, ADHD WA, ADHD ACT, the Royal Australian College of General Practitioners and the Royal Australian and New Zealand College of Psychiatrists. Thank you, all.

**CHAIR:** Thank you very much, Edward, for that very moving submission to us today. We've a bit of time for questions if people are willing to answer some questions and if people have got questions. I might hand over to Lou and Jordon in the room to judge that.

**Senator STEELE-JOHN:** I've got just a couple. Are you okay to answer questions? I know it wasn't necessary flagged with you. Is that okay? Henry, you listed a number of psychiatrists that you've engaged with through your journey. Do you have a record of actually how many you've engaged with from the beginning of your journey to now?

**Henry:** It's funny that when I consulted a new psychiatrist and talked about my journey there it felt like I hadn't seen any. This is, hopefully, the one that's going to work. I've just looked through shop windows up until now. Writing notes in preparation for today I realise that there's a gap. I can't remember who I've seen in that period of time after moving back to Perth. Did you want a specific number?

**Senator STEELE-JOHN:** Just a ballpark number.

**Henry:** I would say six easily. There's a cost and a real cost to Medicare with that as well.

**Senator STEELE-JOHN:** And a cost to you in those appointments.

**Henry:** Yes, which is a given. With comorbidities and things you often reach the safety net quite quickly. When you're on the safety net your scheduled fee is covered plus 75 or 85 per cent of the difference between the scheduled fee and what the doctor chooses to charge. So, if a doctor is choosing to charge \$830 for a consultation, that's a massive amount of money coming out of the public purse to fund that doctor's practice. We're not talking about radiology, surgery or things that require hardware. We're talking about people who use their mind, pencil and paper. It's a long answer.

**Senator STEELE-JOHN:** No. Mary, I have a question for you in terms of the journey alongside your child through the education system. We heard earlier today a couple of examples of parents being told that, if they didn't get a diagnosis or weren't able to get medication for their child, their child would no longer be welcome at the school that they were hoping to attend. Has anybody on the panel had the experience of being told that they wouldn't be able to attend an education institution if they weren't able to get a diagnosis or medication?

**Mary:** No. I've never heard of that before.

**Senator STEELE-JOHN:** That's good. I hope not to hear too much of it. It's the second time we've heard it.

**Mary:** I'm surprised to hear it. Did it sound like that's what I said?

**Senator STEELE-JOHN:** No, no. I just needed to check. Thank you.

**Senator PRATT:** I want to thank you all for your visibility today. I had an adult diagnosis of ADHD in my early 40s; I'm now 50. In our family, we're now working with our son to make sure he also gets the support that he needs. I very much related to parts of all of the stories that you've given us today. I want to commend you on your resilience. Have you ever found your ADHD or your child's ADHD to be beneficial? We do need to look at our positive attributes, not just see our deficits. In Western Australia in particular there's a big ADHD community. You've highlighted very strongly some of the challenges in getting access to care. What have you retrofitted that with in terms of trying to find your own ways of self-care or support services to bridge that gap?

**Mary:** Sorry—you had two parts to the question, and I've forgotten the first.

**Senator PRATT:** Where is ADHD your, or your child's, superpower? When we're not getting the support we need elsewhere—your family highlighted the personal support networks of a nurse, but what else has worked?

**Mary:** I would have spoken about my son's superpower if there was more time. He has an amazing teacher this year, as I mentioned—it's his final year of primary school, so it couldn't be better timed; hopefully, it's lifted his confidence to go into high school. My son is very articulate. He's highly verbal. He could stand here and speak eloquently about it, but if he was asked to write about it he would say, 'I can't write,' because he also has dysgraphia, which is a comorbidity. If you saw his writing, it would be difficult to read, but he can verbalise it and he can express it. The amazing thing about his teacher is that he hasn't spoken about the negatives but he has very quickly seen the strengths and who my son is as a person.



So I would say: he's articulate, and his general knowledge is incredible. I joke that I don't say, 'Look it up'—or 'Call your mum or your dad,' as it used to be—I just say, 'Let's ask my son,' for any question under the sun that my two younger kids will ask. I have a joke now: 'Let's just ask him. He'll know.' He loves reading. He has hyperfocus, but he has a broad general knowledge. He is learning to use his humour and his energy in a positive way, realising that he doesn't have to be the class clown. He's learning how to use that in a really positive way. That's just a few, but I agree that the positives need to be there and they need to be looked at. As I said, his teacher seeing him as a person—as opposed to: 'This is what he has'—is amazing because it naturally lifts him. I think that's what everyone needs.

In terms of other supports, I've just mentioned the people around us. While I've thought, 'This has been really tough for us,' you've made me realise: my goodness, you've been doing this for so much longer! Weirdly, for the first time, I've thought, 'Maybe we're one of the lucky ones!'

**Senator PRATT:** For people born in the seventies and eighties—probably not much chance!

**Edward:** At the same time, [inaudible] a young child having a meltdown, and my thoughts went exactly the opposite way.

**Mary:** Yes. In terms of support, in addition to the people around us that we've used to the nth degree, and they have been amazing—I say 'used', but it's with love that they've come forward. When we went through this incredibly hard time, we came up last year, when he had suicidal ideation. We were going to just go away for a few days, but we extended it and went away for two weeks. We had a break from everything and spent that time together as a family. We were talking about moving house anyway, but we were chopping and changing how we were going to do it. A big driver—from my perspective, anyway—was: 'Let's move to this place. It's a smaller house, and everything in the house is smaller, but there's a big backyard with a tree; it'll give the kids space.' When we had a follow-up appointment with CAMHS, they pointed out all those changes. We fought the school—or that's what it felt like—for him to change classes, changing his environment. It was all of those things, not just the medication. It's the holistic approach, not just the medication.

**Senator PRATT:** Do you happen to be aware of what you child has been assigned—whether they have had that extra loading attached to them? It's not applied to them as an individual. It doesn't get extra resources, but it's supposed to be there for teacher training and support.

**Mary:** Yes, I'm aware of funding, if that's what you mean. Are you talking about through the school?

**Senator PRATT:** The funding should be through the school, but it's really there for the classroom and the teacher. But it's very hard to tell whether a school has proactively sought to apply that—to find all the eligible kids in the school, apply that loading and then do something with it.

**Mary:** I certainly wasn't aware of it just from the school perspective. I'm aware of it because the psychiatrist said, 'I can release those funds through the school.' He used the word 'release' in his letter to the school. That's how it was applied, through the school, and then the school could release the funds. I don't know if the school—

**Senator PRATT:** It should really be the other way around—schools being proactive about it.

**Mary:** If the school could've been proactive about it, that makes my blood boil. I've had numerous meetings. I know that the classes he was in had an EA, but it was always worded as, 'We've got funding because there are X many children in this class who have it.' I've spoken to other parents about it, and it's all about whether the funding has been there. It's come via a specialist—unless, perhaps, the school has really reached its quota; I'm not sure.

**Senator PRATT:** I'd be interested in other people's response to my questions, too.

**Edward:** I have one answer, which is 'everything together'. I saw a BBC interview with a journalist who'd been diagnosed about two years ago, and he described a strength of the condition as relentlessness. With the challenges that came—the unmasking, the lack of treatment, and my need to get treatment but also advocate—everything became one thing, and I found myself advocating and sourcing treatment through the same people, such as for complex trauma. I was trying to understand the idea of the bidirectional effect of ADHD with trauma, which is meant to magnify each way. Why aren't people talking about that in terms of the basic symptoms of the condition? I asked Lou, who I think will be speaking, or has spoken, about this.

**Senator PRATT:** Yes.

**Edward:** I've asked others about this, and that's where I think the CPTSD—the lady spoke to me for half an hour and recounted my last four years, and it was amazing. It was just as enlightening as my ADHD diagnosis and made more sense in that context. That's where I've gotten my supports. There's a good and bad part to that relentlessness. In light of not being able to get adequate medication, the only chance I have to function is to lean

into what I already know. My lifelong anxiety is gone; it's only anger now that drives my brain, with the lack of dopamine. I have some medication that exacerbates it. This is not a healthy approach, but it's the way I have driven myself forward, advocating. Two nights ago, I watched a video for the first time in four years. I have been working and trying to organise, with a depleting executive dysfunction, till 12.30 on most nights of those four years. I'm exhausted, and the relentlessness has driven me on. But I've only just come to terms with the true value, as you said, of rest and recuperation and being given a chance to pause. I feel that all of these issues, essentially, are making sure that we're not able to have a rest unless we give up.

**Senator PRATT:** It certainly seems that way.

**Edward:** And that's a really tight place to be in.

**Senator PRATT:** Thank you.

**Edward:** No worries.

**Henry:** For myself, I claim packing the car before travelling as a superpower!

**Senator PRATT:** My wife won't let me do that, because of my ADHD!

**Henry:** I don't know what it is. It could be due to the pressure to conform, when your inclination is not to conform, that you become very good at making things around you conform to you. Genealogy—I'm a whiz at that! I'm almost obsessive about the past and what has led me here because of the disquiet I feel in the present. But most of the positives come with negatives. I think, from what people tell me, that I'm articulate. I remember at high school in English virtually leading the class discussion but getting 38 per cent in my final exam in the written component. I remember passing because of the combination of the two elements. I find committing to paper extremely difficult, but I'm quite good at talking through an idea and generating a rapport with people on first encounter. On second encounter, not at all. It's like I've spent it, and I don't know what to say. That's an extreme.

**Senator PRATT:** That's terrific. There's a very viable career for you in politics because they're all character attributes that I have in spades!

**Henry:** ADHD is as heritable as height. I'm absolutely positive my father had it and my mother did not, but both of them were absolute born salespeople. They could generate incredible rapport—genuine, sincere rapport—with people. In terms of support, I would have to say it is personal relationships. I'm just fortunate beyond belief to have encountered my wife when I did and maintained a relationship for as long as we have. Probably unfairly to her, I describe her as linear all the way, very applied; I'm lateral. We had an encounter that bubbled to a conversation the other day where we finally realised that my coming out with ideas all the time she finds incredibly burdensome because they are things she has got to plan for. I would be thinking, 'That's my contribution—the ideas!'

**Senator PRATT:** That's very insightful.

**Henry:** It's the personal relationship with my wife and others that sustains me.

**Senator PRATT:** Thank you. Lexy?

**Lexy:** I'll start with the benefits. I'm extremely creative, as I mentioned. I constantly have 100 million thoughts and ideas, always happening, all the time. I'm really creative, and I think that allows me to think outside the box when it comes to problem solving. I often can come up with solutions for things that other people haven't thought about. And then—this is impulsivity coming in—I have a real can-do attitude. People will tell me I can't do something, and I'm like, 'That's ludicrous,' such as creating an oasis out of my shed I still believe that that will happen! I'll update you next time. But that impulsivity, I think, also makes me really good in emergencies. I'm good in a crisis because I can just act. I don't get bogged down in the thinking, because I'm too impulsive. Because of all of those things, I'm sort of a jack-of-all-trades. I can do lots of random things.

**Senator PRATT:** You'd be good in politics too!

**Lexy:** You're just recruiting people! I think those are probably the key things that stand out for me in terms of what I think ADHD brings in terms of benefits.

In terms of bridging the gap of support, that's been really difficult for me because I don't have a family structure to rely on. I don't have a relationship with my mother or, really, my father. My siblings are somewhat estranged as well. So I really have to rely on friends, my found family, and thankfully I have the most patient partner in the world. If it wasn't for him, I don't know where I'd be right now. So it's friends, my partner and—I know I shouldn't keep mentioning TikTok, but, like you said before, that gap in knowledge is filled by social media people. It's relatable. It makes you feel like you belong and that you're part of a community and that people understand you. Sometimes I feel the most validated after spending 10 minutes looking at memes about ADHD.

**Senator STEELE-JOHN:** Is it 10 minutes or a bit longer than 10 minutes!

**Lexy:** I don't know. I've got time blindness!

**Senator STEELE-JOHN:** I just know for myself it's never 10 minutes!

**CHAIR:** We are at time, so I think we'd better wrap. It's been a wonderful session hearing from the four of you and then the interaction, those questions, in the last 20 minutes.

**Senator KOVACIC:** I would just like to say thank you to each of the witnesses here today. I don't have any questions, but I was very compelled by your evidence. Thank you.

**Senator STEELE-JOHN:** Thank you to every one of you.

**CHAIR:** Yes. We're going to take all of your experience and your recommendations to heart in the findings of this inquiry. It's been incredibly powerful and important evidence for us to hear. Thank you.

**PATERSON, Dr Roger, Vice President, Australian ADHD Professionals Association**

[14:45]

**CHAIR:** Welcome, Dr Paterson. Thank you for appearing before the committee today. I invite you to make a brief opening statement—I'm presuming you wish to do so—and after that, the committee members will ask you some questions.

**Dr Paterson:** My statement is as per the document which I tabled. I think you have a copy of it. My name's Roger Paterson. I have over 30 years consultant psychiatrist experience with ADHD, running a busy private practice. My secretary told me today that I'm treating about 3,000 patients: children and adults aged from six to 90. So you can see it's an across-the-lifespan condition. I've been involved, over those 30 years, in research, professional bodies—currently vice president of AADPA—and community support group, ADHD WA. I think you heard from them this morning. I'm also the chair of a combined psychiatrist and paediatrician peer review group which has about 80 members. We meet bimonthly to further our experience. I thank the committee for the opportunity to give evidence today, and I'm going to bring up several issues that I believe are increasing the barriers for diagnosis and treatment of ADHD.

To provide some context over those 30 years, when I started, ADHD was very much a medical fringe issue. It has now moved to mainstream. It's a highly topical mainstreaming of a neurodevelopmental condition, increasing awareness of both the disabling symptoms and their treatability—and I emphasise 'treatability'. In some ways, we're feeling the effects of the mainstreaming with a disjuncture between demand and supply of treatment. That treatment often involves stimulant medication, which has had its own issues over the years but even now is becoming less stigmatised and more accepted by the general population. Because it is somewhat controversial medication, it's restricted to specialist paediatricians and psychiatrists in the initial stages, for the most part—although GPs do get involved with some co-prescribing after the initial diagnosis.

People are coming forward. They're genuinely seeking ADHD treatment, and the evidence is that ADHD is not being overdiagnosed. I have to emphasise that because we hear that a lot—that it's everywhere, that every second person is on stimulant medication and that it's being overdiagnosed. It is not. We're finding that clinicians are not inappropriately overprescribing. If anything, they're underprescribing. That's why we're here today. There are definitely barriers to that prescribing, which, in some ways, is why we are underprescribing. I'll mention the barriers by name and go into some detail if you prefer. They are: one, a lack of ADHD treatment in the public sector; two, insufficiently trained health professionals; three, restrictive prescribing regulations; and four, there's a general lack of funding for the implementation of what would be considered best practice in various guidelines and also a lack of funding for community ADHD bodies.

**CHAIR:** Thanks very much, Dr Paterson. Over to Senator Steele-John.

**Senator STEELE-JOHN:** Thank you, Dr Paterson. A lot of the issues you've given to us in your statement echo what we have heard as a committee throughout the day. I particularly would start with this issue around restrictive prescribing regimes, which you've got at dot point 3 in your statement. Can you tell me, from your experience, what the impact of those restrictive practices currently are upon patients?

**Dr Paterson:** In Western Australia specialists have been encouraged to coprescribe with GPs so that we do the initial assessment and then we stabilise on medication. As we've heard, if we don't get the medication right, the patients are not appreciative. In some ways, ADHD has been described as easy to treat, but hard to treat well. So the specialists spend a lot of time in those first three to six months fine-tuning and optimising the medication. I had a patient this morning who was on a long-acting dexamphetamine preparation called Vyvanse. She said to me, '50 milligrams is terrible, but when I take 40 milligrams it's fantastic.' So it's as fine-tuned as that. If we don't get it right, then the patient's not getting their money's worth, as we've heard.

So specialists initially, but then what does the specialist do once things are stabilised? The condition remains reasonably stable. Most of my patients I see six-monthly or even 12-monthly. Things are very stable. They can be handed back to GPs for prescribing. However, in WA the current rule is that they can go back to the GP once, and they then have to come back to me very year for a review. When they go to the GP, the GP can't change anything; they can't change any medication dose or type. I tried it for many years, and it just wasn't working. My secretaries were being driven crazy by the admin involved in making sure my patients return every year as was prescribed by the health department.

To their credit, the health department is now going to introduce new regulations next year which will free up that coprescribing so that patients can go and see their GPs for up to three years before a review is necessary. Even then, I suspect, some of them will not come back for those three years, but if they're stable, no harm done. And the GPs can change things, so they can manage, as they properly should—

**Senator PRATT:** Will that enable you to open up your books more?

**Dr Paterson:** Exactly. So I'm not full of the stable follow-ups; I can do more assessments. That is gradually happening around Australia, from my experience. GPs are getting more and more involved. Not every GP will want to get involved in that coprescribing; some GPs don't like stimulant medications for various reasons, and they will say, 'No, I'm not getting involved.' But that will free things up.

Now there are moves afoot for GPs to get involved at the outset, even doing the original diagnosis and stabilisation, and then doing their own coprescribing, as it were. There are various problems with that. Basically, training is required. I think you heard this morning from a group of GPs who are doing some excellent training. That's the future, I think. The current WA regulations that are going to come in the next year or so say that they will allow GPs to do that initial prescribing, and they'll be authorised on a case-by-case assessment, to quote them. That is, if they've had adequate training by, I suspect, the Royal Australian College of GPs, they'll be stamped and endorsed and told, 'Right, you're safe to do it.' That is happening in New South Wales, and it's happening with some GPs in Queensland. That will probably happen as time goes by.

The problem has been that in many ways we're playing catch-up with the skills of the specialists at the moment, because it was not mainstreamed. It was not taught to junior doctors coming through paediatric and psychiatric training programs. Specialists have gone out into practice, patients are presenting with ADHD, and they've had no training in it. They're now quickly rapidly upskilling as best they can, hence a number of them belong to either the Australian ADHD Professionals Association or a specialist network within the College of Psychiatrists, attending grand rounds, talking to colleagues, going to conferences. There's a conference this weekend in Melbourne where we're going to be addressing these sorts of issues. We're trying to upskill the specialists, and now the GPs are saying, 'Well, what about upskilling us?' Well, which one are we going to do first?

**Senator STEELE-JOHN:** We've heard compelling evidence that upskilling both is quite urgently needed.

**Dr Paterson:** Ideal.

**Senator STEELE-JOHN:** We heard some powerful evidence—you may have been in the room when it was given—around the real-life impact of having to do things like urine testing in order to be prescribed. We heard of somebody who literally couldn't because of anxiety around going to the bathroom in front of somebody—completely understandable. Have you had patients share with you the barriers that urine testing creates? There are many other jurisdictions that don't require it.

**Dr Paterson:** WA has been particularly keen on the idea, although it's not compulsory. It's only regulated as a 'should' criterion, not a 'must'. There's clinical discretion as to whether you proceed or not. If I'm not suspicious, it's a routine situation. They don't do supervised urine drug screens. It's very easily done; it's not a big test. I have some patients who have what's called pee shy syndrome, and I find other ways to assess the veracity of what they're telling me—usually by involving third parties, as to whether their spouse is involved in alcohol and drug issues.

**Senator STEELE-JOHN:** We've also heard today that people, in the absence of being able to access the stimulant they need, seek other forms of stimulant. Sometimes that is an illicit form of stimulant. One of the things we're considering as a committee is: should there be a role at all for use of an illicit substance as a blocker to accessing these medications?

**Dr Paterson:** Generally speaking, no. There's a recognition that the two go together quite commonly. Most experienced psychiatrists will cross-titrate the medication: 'Please come off the illicit while you're going onto the licit.' A period of a few months whereby the patient can be encouraged to—as long as it's not extreme substance abuse, in which case they need a special clinic. If it's moderate level alcohol or marijuana, we can say, 'Okay, let's encourage to come off while encouraging to come onto medication.' Once you're on stimulant medication, you don't need the illicit.

**Senator STEELE-JOHN:** So you would support us recommending that that be a reform that's taken up?

**Dr Paterson:** Absolutely. I think the substance-use clinics are now realising that about a third of their population have ADHD, and it's well worth addressing because it improves the outcome measurably.

**Senator STEELE-JOHN:** Going to the stimulant medication available under the Pharmaceutical Benefits Scheme: you've noted there are a number of stimulant medications not covered by the PBS when used for adults. What impact does the exclusion of these medications from the PBS have on the people you work with?

**Dr Paterson:** To be fair to the PBAC, they're getting better. But that has required a lot of input from clinicians—often, we've felt, to deaf ears. Recently, one of the long-acting methylphenidates has been authorised

as of 1 May—so we now have a long-acting methylphenidate that we've never had before. There are only two brands: Ritalin LA and Concerta. Ritalin LA is now on the PBS for newly diagnosed adults. It would be nice if Concerta was available because not everyone likes Ritalin LA; they prefer Concerta. This is sometimes what the PBAC don't recognise. They say, 'You've got Ritalin; one will do.' No, no—patients require trials of all medications available to find the one that suits them, at the right dose.

**Senator STEELE-JOHN:** As we've heard, it's not just 'suits them'; if it's the wrong type of medication or if they have a bad reaction to it, it can have some quite adverse—

**Dr Paterson:** Make things a lot worse. There's Concerta for adults now; we'd like that to come on before the PBAC. Unfortunately, because it's been around a while, the drug company that makes it is not likely to push it, and, from experience, unless the pharmaceutical company makes an application, it ain't gonna happen.

**Senator PRATT:** Do you know what its underlying costs are compared to—

**Dr Paterson:** It's a few hundred thousand dollars.

**Senator PRATT:** Per patient?

**Dr Paterson:** No, for the application.

**Senator PRATT:** I'm asking about the per patient cost, because dexamphetamine is probably quite cheap.

**Dr Paterson:** On a private script, it's about \$60 to \$70 a month.

**Senator PRATT:** So it's not uncomparable with the taxpayer subsidy that might go to—

**Dr Paterson:** It's not astronomical. It's double the PBS, if you like.

**Senator STEELE-JOHN:** The other strange regulatory piece that we've discovered as a committee is that, in the different state regulations, there are different amounts that you are able to prescribe and different durations that you're able to prescribe them for, meaning that, when a patient travels interstate or moves interstate, there can be issues around filling the prescription from the pharmacist or the regulatory body. So again, would there be value in a nationally consistent approach to these rules?

**Dr Paterson:** There certainly would be because now, especially with telehealth coming in, a lot of psychiatrists are seeing patients who are quite remote from where they are. They think: 'Right, I'm in Perth, and I'm seeing someone in Sydney. I'm free. I've got appointments, and you can see me. I'll see some Sydney people who can't get into a Sydney psychiatrist. Come and see me in WA.' Great. But then when I try and prescribe, I'm blocked from prescribing to them. I have to apply for special authority, which I can get, but it's a barrier, and it puts some doctors off. Again, AADPA has certainly written to the various health departments around Australia to say, 'Can we get together and have a national strategy day and try and work out some of these things?' A minority of the health departments responded to the letter saying, 'We've received your mail,' without even coming up with a solution. So they're very deaf to our entreaties to try and move things forward.

That said, one of my roles within AADPA is to try and understand the national guidelines. Gradually there's a movement towards freeing things up, so it's going in the right direction. It would be nice if that were increased because, at the moment, we have ridiculous situations. If I see a patient in Victoria and I prescribe to them, I have virtually unlimited maxima; however, if they go a few hundred kilometres north into New South Wales, suddenly not only is it limited to what would be reasonable, it's actually half the dose of what's usual. For some reason New South Wales is particularly restrictive. In WA we're allowed to prescribe 12 tablets a day of Ritalin or dexamphetamine; in New South Wales, they're allowed to prescribe six. So you have the ridiculous situation where you have a large 17-year-old child who is virtually unrestricted—the regulations are based on milligrams per kilogram—but, when they turn 18 and have to see an adult psychiatrist, suddenly they might have to halve the dose that they were previously on just by virtue of changing from a paediatrician to a psychiatrist. It's quite farcical.

**Senator STEELE-JOHN:** Quite farcical. I'll pass the call to Senator Pratt.

**Senator PRATT:** In this context, in terms of the overlay of state and Commonwealth regulation, when a psychiatrist makes the call to get permission to dispense something in Western Australia, is that call to a state or Commonwealth authority?

**Dr Paterson:** In terms of prescribing, what I can prescribe and how much I can prescribe is governed by state and territory regulations, as it is for a number of S8 medications—

**Senator PRATT:** That's regulations, but the phone bank that they call to do that—

**Dr Paterson:** The call is to Medicare. That's a Commonwealth call—

**Senator PRATT:** And are they implementing a variety of different state regulations that they will know?

**Dr Paterson:** No, that's just purely a funding model: 'I'm ringing to get permission for this to be on the PBS.' It's purely: 'Does this qualify for the government to subsidise it on the PBS?'

**Senator PRATT:** And they will make that call every time a script is—

**Dr Paterson:** So, if I'm trying to prescribe too much, they'll say, 'No, Doctor, you're only allowed eight tablets, not 10 tablets.'

**Senator PRATT:** Yes, I've seen it happen; that's right

**Dr Paterson:** And, if I tried to prescribe Concerta for an adult, they'd say, 'No, we don't allow Concerta for newly diagnosed adults.' It's those sorts of thing. So the money call to Medicare is federal, but what restricts us in our daily practice is state regulations, and all the states and territories vary quite a lot.

**Senator PRATT:** In that context, if you were to get rid of all the state legislation and just have that federal system and get all the states to refer into one set of regulation, what would that regulation need to look like to overlay over the top?

**Dr Paterson:** I think the states can still have a say. I mean—

**Senator PRATT:** Of course. Well, they have the power—

**Dr Paterson:** I doubt the states would give up their power, but if they could just all be roughly uniform with each other, that would be very useful. Of course, one of my worries is if they all decided to be uniform with New South Wales and we'd all suddenly be handcuffed in trying to do the right thing for our patients.

**Senator PRATT:** Can you give us an overview of ADHD medications—their application, their variability and their accessibility, for both adults and children?

**Dr Paterson:** The two main medications are dexamphetamine and methylphenidate, which is known by its trade name, Ritalin. Dexamphetamine has been around since 1940, and it was selling very well. In 1950 they invented Ritalin. It was called methylphenidate and was invented by an Italian chemist whose wife was called Marguerite; he called her Rita. She tried it, she liked it and he named it after her: Ritalin, Rita's tablet. So, for many years—the 1940s, the 1950s—we had those two tablets, and they were great. But they didn't last all day; they lasted only half a day or a third of a day and had to be taken two or three times a day. In those 20 years they've invented long-acting dexamphetamine, and there are two types. One is Vyvanse, or compounded dexamphetamine, and the other is long-acting Ritalin—Concerta and Ritalin LA. But still the two main medications are dexamphetamine and Ritalin in shorter long-acting versions. They're beautiful medications, because they're what we call very clean medications: they're very effective, with hardly any side effects.

When I first started, 30 years ago, I was told that one in four patients would go paranoid—psychotic—and they'd all be addicted. I wish they were addicted! My patients ask me, 'Am I going to be addicted?' and I say, 'I wish you would be, so you'd remember to take them!' They are not addictive medications. Patients wake up craving their coffee; they don't wake up craving their dexamphetamine or Ritalin. And, as I said, the medications have been around awhile—the 1940s, the 1950s. So, if they were going to be dangerous, nasty drugs, we'd know about it.

**Senator PRATT:** Can you tell us about side effects? One of the things in supporting families and children with ADHD is—well, I don't know: I've got to get my son to eat his lunch when I'm not there to supervise him. How do we, in terms of wholistic care, make sure we're supporting a child and a family with ADHD but not letting their other health needs fall behind?

**Dr Paterson:** There are rarely any severe side effects, but there are some pesky side effects, particularly in children: appetite, and hence weight and height can be affected; sleep is the other problem. There are ways around it. By fine-tuning the medication we can maximise benefit and minimise side effects. I spend my life optimising medication.

**Senator PRATT:** What's ideal to you? I guess I'm trying to find a public policy metaphor to say, 'Okay: this is your perception as an expert of how often you might need to see someone'—in general terms, because on one hand we want to try to make better access more universal and more standard, but, equally, we don't want people to drop out because that standardisation didn't suit them. Over what period do you tweak someone's medication? And does it change at different life stages?

**Dr Paterson:** I'm very active in that initial three to six months—what we call the titration period—and I start off seeing them two-weekly until the patient has some confidence in trialling different doses themselves, because it's very much a trial-and-error process. So: two-weekly, three-weekly, four-weekly, six-weekly. Usually by the end of three to six months we've got a pretty good idea of what medication is required. Sometimes it will be longer, in paediatrics. But that length of time is about right. And once they're stable I don't see them very often,

and this is where I say to my colleagues in the public sector who are afraid they're going to be overwhelmed with ADHD patients and clogged up with repeat scripts, 'I've got 3,000 patients, and I'm just one person.' How do I do it? Because I'm active, initially, and then very inactive later on, because I can be—and if I do co-prescribing I'll be even more inactive with my follow-ups.

**Senator PRATT:** Of course, medication is not a panacea, although it's super helpful. What other supports do you refer people to?

**Dr Paterson:** Can I just concentrate on the medication. The medication is very good for the core symptoms. It's calming, it's focusing, and people are much less impulsive and much more productive. So that's the core symptoms, but all that we've heard about in terms of the associated symptoms—learning problems, social problems and mood disorders—tends to involve psychologists, coaches, schools and those sorts of people. So I say to every patient that I see, 'I'm going to talk about medication, but that's not the whole story,' and I give them a referral to a coach or a psychologist or a counsellor or a speechie for someone to do some of that. I especially refer quite commonly to ADHD WA, which has now set up some therapy programs, to their credit.

**Senator PRATT:** Is there an evidence base to show that if someone is treated and medicated early they will avoid those other psychological impacts? How is that evidence base emerging and could you point us to that academically?

**Dr Paterson:** I was very selective in my references. I've referenced the international consensus statement and the AADPA guideline. There's evidence, as you would expect, that if you can treat ADHD early, they're less likely to go down the path of suicidality, criminality, drug abuse, educational difficulties et cetera. That's the beauty of it, because my colleagues in the public sector say, 'We only treat the severe end. There's only limited supply. We have to choose one end, so we choose the severe end.' And I say, 'Well, why wait until they're severe? Why don't we get in early?' ADHD is very treatable. That's why I specialised in the area. I used to be a general psychiatrist across the lifespan, and I gradually focused more and more on ADHD because that's where I made the most difference.

**Senator PRATT:** ADHD is a normal part of neurodiversity, and you've clearly now got a good understanding of that. Tell us what's good about having ADHD. How do you get people to keep the things they like about themselves?

**Dr Paterson:** For all of us, neurodiverse or not, it's best if we play to our strengths and minimise our weaknesses, and certainly in ADHD there are strengths. There's energy. There's amiability. There's lateral thinking. There's excellence in a crisis. Often they drift into work that involves drama and they do very well. Creativity is probably the No. 1 factor which shows up on research as being more enhanced by ADHD. My creative patients say, 'Doc, the medication dampens that down a bit,' and I say, 'Okay. Well, what if you just take it on certain days when you need it and on other days, when you want to be creative, you don't take it,' and that seems to work out pretty well. It's a beautiful medication group because you can take it or leave it. You can be on it all the time or just now and again. There are no major withdrawals or problems.

It's fair to say they can be abused, and that's why they were kept to the specialists initially, and it's why, if we open it up to GPs *holus-bolus*, we're going to see more misuse and abuse. They are stimulants. People, mostly students around exam time but also in pubs and clubs when they're a bit drunk or stoned, do take them for that—for energy and to stay awake. So there is a bit of misuse and abuse. There's a bit of street traffic. There is a value on the streets, so we've got to be careful about that and not be blind to that side of things. But generally speaking they're pretty useful medications.

**CHAIR:** Thanks, Dr Paterson. Thanks, Senator Pratt. I have just one question that I'd like to finish off with, Dr Paterson. Are there other countries in the world that you could point to that you think are doing about as well as we could be doing it in Australia, in terms of the management of ADHD?

**Dr Paterson:** It's a good question. I've just been to the world ADHD conference in Amsterdam, talking to colleagues about their style of practice and what happens, and I've got to say that if I had ADHD I think I'd be happy being in Australia—and even happier if I was in Perth, Western Australia—having treatment. Our standard of care is very good. Comparable treatments? Canada, I would say, is probably up there. Then you start looking around. The UK has caught up very, very well. They used to be way behind 10 or 15 years ago. They've caught up. But in terms of the variety of medications, the variety of treatment disciplines, the support groups and the accessibility of the medication, I think Australia does very well, but we can always do better.

**Senator STEELE-JOHN:** Are there any countries that you have seen that have brought down those cost barriers to diagnosis, assessment and medication further than we have?



**Dr Paterson:** Yes. Canada allows more family practitioners to get involved. In saying that, not all want to get involved. They're allowed to, but not many do, only those who have actually upskilled. That's one way. But, as I say to my patients, perhaps trying to justify my private practice fees, 'It's money well spent.' It is expensive upfront, but I guarantee that I will save them money. By getting them to be much more efficient and focused, they'll have success at work, they'll have success in relationships, they'll do their tax returns they haven't done for 10 years, they'll answer those 40,000 emails—and I'm not exaggerating. So it is expensive, but it is money well spent, if you like. It's usually an upfront fee and then an annual fee. But, that said, I've been an advocate for many years for public sector treatment, because not everyone can afford private practice.

**CHAIR:** Yes. We've certainly heard plenty of evidence to this inquiry and others of people who aren't yet able to access the private services that you obviously do so well. Thank you very much, Dr Paterson, for your evidence today. I don't think you took any questions on notice, but if there's anything more that you would like to provide us with, could you get it to us by the close of business on 14 August. That would be really appreciated. We're now going to take a break.

**Proceedings suspended from 15:17 to 15:30**

**BROOKS, Mrs Julie, Senior Vice President, Western Australian Council of State School Organisations [by audio link]**

**CHAIR:** Welcome. I invite you to make a brief opening statement, if you'd like to do so, and after that I'll invite the committee members to ask you some questions.

**Mrs Brooks:** As the peak voice of WA parents in public education, WACSSO's submission is based on the collective parents' voices from across WA. Often, parents contact us seeking assistance in how to navigate the school system to ensure their child has access to the best educational opportunities. Parents are often overlooked due to the opinion of experts, but no-one is better placed to provide experience regarding their children.

Parents want you to know the following regarding access to diagnosis services and support for their children with ADHD. Parents are concerned that access to diagnosis and treatment for ADHD is underserved, underfunded and often not accessible, especially for those families in regional and remote areas and those who experience financial and cultural barriers.

The school experience for students with ADHD is often fraught with problems. Students often have problems with peer interactions, concentrating and completing tasks. They are often labelled as 'lazy', 'unorganised' or 'class clowns', just to name a few, which is further detrimental to a child's mental health. Students who misbehave in class are often labelled as 'disengaged' when, in many cases, they are struggling with inattention, and with adjustments could better engage with their education.

Parents are often given labels such as 'bad parenting'. Families experience feelings of isolation and sometimes guilt through the process of a diagnosis and the decisions regarding whether to medicate their child. Parents want the best for their children, and the current system is often not providing support that these children need to thrive and be productive members of our community.

ADHD is a lifelong condition, and it doesn't end once a child enters adulthood. Management and intervention need to be in place for as long as each individual requires. WACSSO believes that all our children in public schools deserve a world-leading education. For this to occur, our students with ADHD require better access to diagnosis and intervention, and better resources are required in school settings to allow children to reach their full potential.

**CHAIR:** Thank you, Mrs Brooks. I'll kick off with an opening question. You talked about the need for adjustments in school settings. Could you expand on what sort of adjustments work, in the experience of your organisation? In terms of those adjustments, is the school working with parents to create the best environment for students to thrive?

**Mrs Brooks:** Often we are hearing from parents that they are not able to have communication regarding IEPs—individual education plans. Quite often we hear that they are put in place by the school and parents are signing off on them at the end, as opposed to having open communication. The types of supports in place can be anything from behaviour management through to specific individual goals for the individual children. Obviously, that's quite varied. In the current system parents are telling us that ADHD alone doesn't allow for an allocation of the education assistants' time. Quite often you have children in the class that are being managed in groups, where another student in that class has an allocation of time.

**CHAIR:** Have you got any examples of where the adjustment to school has worked really well for particular students?

**Mrs Brooks:** We were vast and varied examples. I don't have any specific examples on me at the moment, but I can take that on notice and definitely send them through.

**CHAIR:** Thank you. I'll hand the call over to Senator Pratt.

**Senator PRATT:** Do you have an overview of how the school resourcing standard is applied or not applied to children with ADHD?

**Mrs Brooks:** Obviously, we are not experts in this, and I don't necessarily know all the ins and outs around that. From a parent's perspective, we are currently being told that funding is not just allocated. His children are in classrooms and are being labelled. As I said before, there is no specific funding allocated to these children, which means that they are not able to have education support time. The resources put in place do not include the necessary expertise for teachers. Teachers love their jobs, and schools are doing absolutely wonderful jobs. Schools are really well placed to assist these children, but they need education specific to ADHD for their teachers' and educators' training.

**Senator PRATT:** It's my understanding that ADHD is not eligible for individual supports, but within the school resourcing standard, once the diagnosis is made, that is counted for the school to conduct teacher training

and extra professional development. It's really unclear to me how you would go about holding a school to account to know whether that had been applied or what was being put in place for consolidating opportunities for smaller schools to make training and support available to teachers. Perhaps you can help us to work out how to ask the right questions of professionals in that regard.

**Mrs Brooks:** Currently, schools are given an allocation of money, and, as you said, the accountability is not always there. I think accountability is quite tricky because it is a bundle of money. Often students have individual education plans, and the schools are accountable for meeting the goals set in those plans. There could be strategies and interventions put in place in those plans.

**Senator PRATT:** How do we know how many children with ADHD do have a plan and the numbers of children who have ADHD who don't have a plan? How do we empower parents? This is relevant to the Commonwealth in the sense that the Commonwealth has set this resourcing standard and has asked state public and private schools to adhere to it. There's a trend that shows non-government schools are now more active in registering for those top-up payments not only for disability support, where there are more resources for the classroom in terms of individual support, but also for more generalised support. But there's some evidence to say that state schools are no longer keeping up with that. In part, I can understand that because the state government then needs to pay for it. I'm interested in how we empower school communities and parents individually to hold schools to account for making sure that those resources are sought and that they're used appropriately for the children that they're relevant to.

**Mrs Brooks:** I think that's tricky as a parent because, obviously, we're not there on the ground. We can't see what's happening. A big part of that is the individualised education plans, which are a collaboration with the school and the parents, and specialists in many cases. Sometimes there's that gap missing where students often have intervention, and there are already some really good strategies being used and then implementing them. The schools put in place the EA and these strategies for students with ADHD, which can be tracked through the outcomes of the educational plan.

**Senator PRATT:** Is that a formal written plan? How does a parent know whether their conversation with the teacher, when these things are written down or communicated, is real?

**Mrs Brooks:** They're tangible. When they're set in collaboration, there's an outcome. So, along with your normal report, there is a report to that plan as well.

**Senator PRATT:** Very good. What kind of support and advice do you provide to parents when they come to you with these issues?

**Mrs Brooks:** They usually come to us in crisis. Obviously, there are P&Cs. Sometimes individual parents will come to us, and sometimes a collective school might come to us as a group. We're obviously not experts, so we can't give the advice that experts give, but we're always very big on communicating with schools and with teachers and keeping those lines of communication open so that everyone's working from the same page. We're all there for the same reason. As parents, we want what's best for our kids, and we know that schools want the same as well.

**Senator PRATT:** How many parents would be aware that their child might be eligible for an individual education plan and that their child doesn't have one?

**Mrs Brooks:** That's a really good question. I don't know whether anybody would have the answer. I certainly don't.

**Senator PRATT:** That's really helpful. The fact that you don't know the answer is helpful in and of itself.

**CHAIR:** I'll give the call to Senator Kovacic.

**Senator KOVACIC:** Thank you for your evidence. It's much appreciated, Mrs Brooks. My question is in relation to how ADHD is not considered a funded disability within the WA Department of Education. Could you give me some background on this? What, if any, steps are currently in play in having ADHD considered a funded disability? If the state governments were to do that, what impacts would that have on the classroom learning environment for children with ADHD?

**Mrs Brooks:** I can only speak from a parent's perspective. I'm obviously not part of the department. I can tell you what parents are telling us. We quite often have parents with children in classrooms that are labelled as 'misbehaving'. Like I said earlier, they are distracting from other children in the class, and quite often these children are diagnosed and may even be undiagnosed ADHD. I believe it is a system which is quite complicated to navigate, through the department. Obviously I do not know the ins and outs of that. For students to have a dedicated EA would mean that we could have training for education assistants and teachers which could put the

same skills and strategies in place for students as they need them. They could have education assistant time and funding to learn skills to be able to navigate education. If they're able to learn and interact with their teachers and their peers and engage in education, they're going to have much better outcomes and be able to access and be in society and function at a much greater capacity for everybody.

**Senator KOVACIC:** I have one other question, again from a parent's perspective. Do many parents talk about the different challenges with the complexity of the system and the red tape they have to navigate for these processes? In that, do they say, 'If we did this or this or this, it would be simpler'? Are there any simple, basic solutions that you guys see that perhaps at a state or federal level could be implemented to make things easier for families and children?

**Mrs Brooks:** Parents, particularly, are always talking about navigating and the minefield it is to navigate the system sometimes. Schools are really well placed. There's already a system. Schools are there to educate. We understand they're there to educate our children, and they do a fantastic job, but they already have psychologists and things like that in place. If the students could have access to some of those services, that expertise, if there were targeted intervention strategies, if there was knowledge within the system itself, and that peer mentoring, which is really important for students, and for students to understand that these children are struggling; they're not naughty—quite often these students are being expelled or suspended from school for their behaviour—if we got back to putting strategies and interventions in place, these students could excel in their education and be vital community members.

**Senator STEELE-JOHN:** Just following on from that last piece of evidence you gave us: on the question of expulsion and suspension, are you able to give us any statistics or any further examples of the way in which this myth that ADHD kids are naughty—rather than just having different accessing support needs—is actually impacting on kids in terms of expulsion or suspension rates?

**Mrs Brooks:** Again, I don't have access to that information, sorry.

**Senator STEELE-JOHN:** We've heard from other witnesses examples of parents being told that, unless their child is diagnosed and medicated, the child will no longer be welcome at the school. Have your members given you those kinds of examples too?

**Mrs Brooks:** It quite often happens. We also have instances where parents have decided not to medicate their children and have chosen to take other avenues. At schools, quite often, we have teachers and administration coming to parents, almost giving them ultimatums and saying, 'Your child needs to be on medication.' There is an impact on families and parents in making that decision to medicate a child. We're talking about medications that are very strong. The parents feel isolated and really struggle. Again, with WACSSO we really push the vital communication between schools and parents.

**Senator STEELE-JOHN:** We've heard throughout the course of the day, in the previous public hearings and in the many submissions that have come to us as a committee, time and time again, that there is an incredibly significant financial barrier to getting diagnosis and that, without diagnosis, you can't access medication. Whether or not you want to take that step, you're unable to. We've heard in WA that the waiting time for the Child Development Services assessment team is between 24 and 29 months. Basically, what you're telling us is that parents are being given ultimatums around the future of their children's position at an educational institution that is, in fact, based on their ability to pay for an assessment that can stretch into the thousands if not tens of thousands of dollars and take two years or more.

**Mrs Brooks:** Yes, but we've also got to realise that we've got teachers in a classroom that are trying to teach X amount of children with very few resources. I'm sure, if they had the resources and training in place, they would do all that they could. It's really about getting those resources into the schools so that everybody can cope and these kids can come out well educated.

**Senator STEELE-JOHN:** Absolutely. Can you talk about what those resources and supports are and what they look like in a tangible sense? Senator Pratt has already mentioned the issue of what funding might be provided to the child to fund additional supports. There's also the other side of the equation, which is training and support that can be given to teachers to enable them to teach to every child in their classroom—the Universal Design in Learning principles and those kinds of things. Are there any recommendations that you'd have for us as a committee as to basic, across-the-board, graduate-level and postgraduate-level training that you think would be helpful for teachers to enable them to teach students that are neurodiverse and have ADHD?

**Mrs Brooks:** It's evidence based. As I said, we're not experts, but it's evidence based.

**Senator PRATT:** I wanted to ask if you could shed some light on NAPLAN from the point-of-view of the Council of State School Organisations. I had noted that the NAPLAN results might highlight when a child needs

additional support in order to reach expected educational milestones. Those national reports don't actually highlight what those additional supports are or where you would go to get them. I wondered if you might comment on that.

**Mrs Brooks:** All I can tell you is that it's set through ACARA, the school reporting authority.

**Senator PRATT:** Okay, but do you think it's a problem that, if you're getting an official NAPLAN report—and I know NAPLAN has its issues—that's consistent with a child's school report and that says a child is not yet meeting developing milestones and requires extra support and assistance, but you're not being told as a family where you would get that support and assistance? What should we be asking for to rectify that?

**Mrs Brooks:** I think the understanding from our parents was that schools actually spoke with parents around accommodations that could be made with NAPLAN. That's on an individual basis, I believe.

**Senator PRATT:** Yes, but I think that's to make reasonable adjustments—

**Mrs Brooks:** Sorry, I must be missing your point!

**Senator PRATT:** I think the point is that you can make reasonable adjustments so that you can do the test, but if you're still underperforming in the milestones and you need extra support to meet your educational milestones and you don't qualify for the disability standard, there's no guidance as to what extra supports you could seek.

**Mrs Brooks:** No, there definitely isn't. WACSSO has always advocated for all-children education. Be that funding or resources, we want all children to be able to come out of public education with a world-leading education, with the best education possible.

**CHAIR:** Thanks very much, Mrs Brooks, for your evidence today. It's been very helpful to the committee. I think you took a question on notice from me about best-practice and good examples of interventions within schools. If you were able to get any more information back to us, that would be great. If that could be provided by the close of business on Monday 14 August, that would be really helpful.

**ELLIOTT, Professor Catherine, Director of Research and Deputy Executive Director, Telethon Kids Institute**

**SILVA, Dr Desiree, Professor of Paediatrics, Telethon Kids Institute**

**WEATHERILL, the Hon. Jay, Director, Thrive by Five, Minderoo Foundation**

[15:55]

**CHAIR:** I now welcome representatives from the Telethon Kids Institute and Thrive by Five. Thank you for appearing before the committee today. Do you have any comments to make on the capacity in which you appear today?

**Mr Weatherill:** I'm also the director of public affairs at the Minderoo Foundation.

**Dr Silva:** I'm the professor of paediatrics at the University of Western Australia and Joondalup Health Campus and the director of research at Joondalup Health Campus.

**CHAIR:** I now invite each of the organisations to make a brief opening statement, if you'd like to do so, and then the committee members will ask you some questions.

**Prof. Elliott:** Good afternoon, committee members. Thank you for the opportunity to appear today. I'm speaking from the lands of the Whadjuk Noongar people in Western Australia. I acknowledge their ownership of this land and pay my respects to elders past, present and emerging. Today I am here in my capacity at Telethon Kids Institute, and I'm here with Professor Desiree Silva. Professor Silva is co-director for the ORIGINS Project and a professor of paediatrics at the University of WA and Joondalup Health Campus. She qualified as a doctor in the United Kingdom and completed her paediatric specialist training in Western Australia and the Northern Territory. Professor Silva has a strong interest in neurodevelopmental disorders, with over 20 years experience in managing children diagnosed with ADHD, autism, anxiety and developmental disorders. She is currently involved in the GP pilot program to co-manage ADHD in a private setting.

I will now turn to make some preliminary comments in relation to this inquiry. I start by emphasising that notable features of my career and that of Professor Silva's have been working at the intersection between clinical services and research and the translation of research into improvements in clinical practice. I'm firmly of the view that parents and families must be placed at the centre of child development and wellbeing. Our approach at the institute is to bring a sound evidence base to the importance of early assessment, intervention and treatment to support child development. We recognise the value of building support around parents, the family unit and communities. The evidence is overwhelming that the years from zero to five are vital in a child's development. What that essentially means is that the earlier we can assess and provide support to children who are developing differently the better it is. Intervention as early as 10 weeks has been shown to make a real difference in the trajectory of a child's health and wellbeing.

We also know that services cannot keep up with demand, with needs growing faster than services can respond to them. And the equitable access to child development services is an enormous challenge. We know that many families, particularly vulnerable Aboriginal families and children living in remote and regional locations, are waiting for the services that we know will not only improve their child's life but also greatly reduce the demand both financially and socially on long-term services. We also know the staff who work in child development services and paediatric care are incredibly dedicated and work hard to deliver services. The problem lies not in the people but in the system. We believe we need to think differently about how to deliver child development services. It won't be easy; it will take enormous changes at the system level, and any change must put families and communities at the centre.

In a 2015 study by the institute, led by Professor Silva and published in the *Journal of Attention Disorders*, we found that children with ADHD have significantly worse school outcomes than children without the disorder. The study found that children with ADHD need more educational support and are at risk of going on to struggle in adult life. It reported that more research is needed to ensure that children with ADHD receive the best evidence-based practice to improve their educational outcomes. As a paediatric research institution, Telethon Kids continues to have a strongly held view that more research is needed to better understand why the rate of diagnosis and the severity of diagnoses of ADHD in children and young people is increasing. Thank you for the opportunity to provide this opening statement, and we're happy to take questions from the committee.

**CHAIR:** Thanks, Professor Elliott. Mr Weatherill.

**Mr Weatherill:** Thank you, senators. The first thing I should do is explain the capacity in which I'm appearing here. As I said before, I'm the director of public affairs at the Minderoo Foundation, but my role includes running a campaign called Thrive by Five. That campaign's goal is a universal, high-quality early learning system for

Australia, but that campaign goal itself is really an arrowhead for a broader policy agenda, which is to create an early childhood development system for this country. It focuses its attention on, if you like, what we used to call child care—early education and care; early learning—as, in a sense, the backbone to provide a framework for a broader early childhood development system. That's the principal reason I'm here.

It's probably worth saying what I'm not. I'm not an expert; I listen to experts. If I have an expertise, it's probably more in the dark arts of politics, rather than in anything to do with the development of children, although I've been Minister for Early Childhood Development, minister for disability, Minister for Education, minister for aboriginal affairs and, of course, Premier, over 16 years. What it culminated in, of course, was the creation of the NDIS. I was responsible for the South Australian launch of the NDIS. I want to confine my remarks to the systemic issues rather than the—I know you were exploring some of the detail—diagnoses and issues, which I'm not qualified to talk about.

I want to touch on this notion of a system of early childhood development and the importance of that for not just ADHD but a whole range of developmental disorders, autism in particular, and many other things that might be put in the category of challenges for children in terms of their development. Some of the things that might manifest themselves as challenges and differences—or however you might describe them—may not necessarily reach the threshold of disability, depending on the nature of the support and intervention that can occur. What we might be grappling with in some respects is the end point of the absence of a system that's able to actually meet the needs of children.

Having said that, like many things within the disability area, there are obviously profound disabilities which manifest themselves in real and significant needs, but at another end there are things on the edge of the threshold of diagnosis which, if they had a different systemic response in the first five years of life, might lead to very different outcomes for the child and fewer struggles later in life. Without wanting to really engage in a debate about diagnosis and certainly not suggesting that people who are not neurotypical somehow need to be fixed or changed in any way, certainly the trajectory for their life and their ability to engage with fewer struggles is profoundly affected by the level of support that occurs in the first five years of life.

What we don't have at the moment is essentially a system that is easy to navigate, is accessible, is of high enough quality and is certainly affordable enough for everybody to get what they need in the first five years. Given what we know about how children's brains develop in the first years of life and how profound that is for their life trajectory, you imagine it should receive as much, if not more, attention as things that occur later, but so much of the discourse is what happens at school, what happens at high school and what happens at university. Yet there's some powerful evidence to suggest that the trajectory is very substantially affected by what occurs in the first five years.

What we have in this country at the moment is really a mishmash of responsibilities and service systems that don't speak effectively to one another in the first five years of life, so you have infant maternal health, child care, preschool, child protection, disability services and allied health—and that's before you look at all of the services that support parents and the particular challenges they might have: drug and alcohol abuse, adult mental health, domestic violence and parenting support. So the number of people and services involved in the lives of very young children in the context of their family is enormous, yet the connections between those things and the gaps that exist for many of those children are really quite profound.

Our campaign is all about trying to create an accessible, high-quality offering at the level of the neighbourhood where people can access these services—ideally before a child is born. The first manifestation might be to go to a place as a pregnant mother and receive support. There would be a trusted relationship at the level of the neighbourhood where all of these services and supports can be provided.

Some say that these things don't exist. They do exist in some places. Interestingly, the models that occur in some Aboriginal communities are actually quite good models because they tend to look at the child in the context. They don't separate them out into various silos. They tend to have Aboriginal-controlled organisations where trusted relationships are formed and the various supports et cetera are brought in rather than people having to get on the end of a large number of queues to try to find their support. There does seem to be something quite counterintuitive about having to queue on a long waiting list to then get a diagnosis that would then lead you to get some reference to finally get some help. The truth is that, in the gap between the time when that can actually happen and the time you get support, the developmental window may have profoundly closed.

There are two models that work in our minds here. One is a medical model, which is a referral, a diagnosis, a waiting list and a cure—and I'm oversimplifying to make a point. The other has very low barriers to access. It's something with very low barriers to entry that exists at the neighbourhood level. Everyone is in—there's universal access—and the people who are trained to identify challenges or difficulties are able to organise those things to be

available in a really easy and accessible fashion and the person doing that navigation has a trusted relationship with that family so that those connections can be made.

So I suppose we see this as a systemic thing. What doesn't exist at the moment is an early childhood development system. To some degree this and the various challenges we're now seeing in the NDIS really is the evidence of the lack of a system of early childhood development. You've heard the phrase 'the oasis in the desert'. In a sense the NDIS is used to catch all those things that aren't caught in the developmental system. The extent of all our mainstream systems fails children. They've now found a place to go, which is the NDIS—which, in a way, is a good thing, because it's made manifest the failings in the existing developmental systems.

Before the NDIS, these would be children who simply didn't exist, were not visible to the system. Now they've become a massive challenge to public policymakers because they're now showing up. And while they're probably not showing up in the best possible way, because they're showing up late and they're showing up in not necessarily the model we would prefer, we've got to get busy building this system that doesn't exist at the moment. The building blocks exist, and the government is now talking about a universal childcare system, which, if it were to be built out, could I think be the backbone for such a system. But it doesn't yet exist, and I think that's how we would frame this question, as opposed to just seeing it through the prism of the diagnosis of ADHD.

**Senator PRATT:** That's why we invited you here today. That's very good. I don't think the school resourcing standard kicks in until primary school. Is that correct? I'm pretty sure it is. Otherwise, I think, given your 'thrive by five', you would know. In terms of the longitudinal studies that Telethon has done, what can you tell us about this cohort of children with ADHD and where and how their needs are being met or not met? When do they need distinct interventions that are about their ADHD? And where is that more-universal model just as relevant?

**Dr Silva:** I might answer that one. Thanks a lot for the opportunity. There's a linked dataset in Western Australia, which is unique, which links up to all children who are born here—hospitalisation, schooling results like the NAPLAN-Warner testing, justice outcomes and all those things. So, it's using linked data, plus there's linked data on the children who have been diagnosed and treated for ADHD—the stimulant medication. That's one aspect of research. But obviously there's a flaw there, because it's very much dependent on what can be linked to determine what is actually happening.

I was very interested in the development of ADHD—what's causing it, the causal pathways to this condition. We have a study neatly embedded with Telethon Kids Institute, and we did this with Joondalup Health Campus, called the ORIGINS, study. We got 10,000 pregnant mums, and we're following up their children, and with 4,000 of them we're doing very deep sampling—lots of questions, plus lots of actual samples like urine, hair and lots of different things. There's an opportunity, using ORIGINS, which is absolutely unique internationally, that could look at the causal pathways of not just ADHD but also some of the neurodevelopmental conditions, and we're very interested in that.

So now our kids are just turning five, and I'll mention what's happening here. We've got a thousand children that we've examined at three years of age and we have found that a third of these children have got some level of anxiety above the average level of anxiety that one would consider. For half of them, the parents report them as being emotionally labile, where 15 per cent of them are—

**Senator STEELE-JOHN:** Emotionally?

**Dr Silva:** Emotionally labile. That means their emotions go up and down; it's difficult to control their emotions. And 15 per cent of them are very severe. We've got 22 per cent, nearly a quarter, with symptoms of inattention and hyperactivity—now, there's no way you'd diagnose ADHD at three years of age, but these are emerging symptoms—where seven per cent have very elevated scores. And we've got lots of sleep issues; about a third of them have problems with their sleep.

We've only done about 150 five-year-old checks. The situation is not getting better. It's either staying the same or getting worse. So the point is that we need to understand what's actually happening in those early years, as Jay just mentioned, because ADHD is very much a genetic condition but there's an environmental component there. As researchers, what we're interested in is this epigenetic effect. That means that you find that an environmental hit will switch a gene on. So what are these environmental hits? When do they occur? Why are those genes getting switched on? These questions need to be addressed in order that we can substantially make a difference in this area. I feel that we've got the capacity. Obviously, we need the funding, but we've got the capacity to do some really groundbreaking work in this area.

**Senator PRATT:** I'll ask you all this question: as far as reform goes, what would you apply now, with the existing resources that we have, and what would you apply with better resources?



**Dr Silva:** On the existing resources, let's say that the train full of kids with ADHD is stuck in the tunnel and we've got to try and get them out. At the moment, there are loads of children on the waiting list, so the existing system is broken; it's not working. We really need to look at some novel ways of making a change. We cannot get a sudden increase in our workforce—it's just not going to happen that we're going to get an incredible increase. So we've got to use some innovative ways to have these children assessed, diagnosed appropriately and correctly—I think that's really important—and managed correctly with evidence based treatment.

I feel that we probably need to, first of all, look at ways of using artificial intelligence as well—AI systems—in investigating the severity of these conditions and determining which ones do need to be managed, because there are a lot of worried well on the waitlist. So let's try and work out which ones really do need to be managed. And then, if there's a workforce issue, we need to be looking at who else in the workforce can help with this condition. So I think general practitioners, who are particularly interested in this field of ADHD, need to be educated about it because they know the families; they're with the families and see them. I'm running a pilot program to look at how this works, and I've found that from having my books closed completely I've opened my books up because I can see new patients and then help the GP work with that.

The other area that I think really needs to be looked at is adult ADHD management because there's nothing in the public sector. So these kids are in the public sector and there's nowhere to send them—absolutely nowhere. They have to go and find the money to go into the private sector, and you know that these children have got problems. They struggle with their education, and they generally don't have a job. They can't afford the treatment. And I think it's just so unfair. I certainly feel, as a paediatrician, we look after these children—we really look after them—and we love them. We get to know the whole family, and then they just drop off the cliff, which is just so wrong.

**Mr Weatherill:** In terms of existing resources, we already have a system of child care, early education and care that has a workforce that is the touchpoint for many families—not as many as there could and should be but, nevertheless, they do see a lot of children—just lifting their general level of capability. Also, the parents are a massive resource.

Not everything is amenable to a solution which just involves taking children to a place and 'fixing them'. It's about the ecosystem that exists around the child. It's more about what happens at home with their parents than some sort of hour or two of magic therapy. So it's about realising that there already are a lot of professionals who have probably built up over a significant period of time a body of knowledge because they have seen a lot of children but who with an additional degree of support could actually be an important part of the workforce.

We have all these labels. We have divided the children up into a whole lot of different professional things. But the truth is that it's just one child and it's about their health and development. I think anybody who is involved in the lives of children needs to be given the information necessary to assist them to play a role in advancing the healthy development of the children and then imparting that knowledge to the parents. Some parents are not familiar with it. They might be interpreting things a certain way. I heard the earlier conversation about 'naughty children'. It may be that the way in which the parents are given to understand the behaviours of their children could have a profound impact on their child's development.

There are a whole bunch of kids who are invisible in the system. If we had more money, once again, I wouldn't try to build a whole new system for just kids with ADHD. I would see this as part of a healthy early childhood development system. That means a whole range of challenges could be understood and needs met. I suppose to the extent that the Commonwealth is seeing a justification for what is going to have to be a very large increase in expenditure to build out this early education and early learning system these are some of the costs that are being brought into account. These are costs that are now being experienced by the NDIS. What's visited against us sometimes when we ask for these reforms are, 'It's very expensive.' My response to that is, 'We are already paying the bill.' You are already having to pick up the costs of failed early intervention or late intervention because there hasn't been an earlier response. That would be how I would look at those two questions and respond.

**Senator PRATT:** Very good. If you have any health economic references that we can—

**Mr Weatherill:** We are doing a bit of research on that at the moment in the context of autism. But we are seeking to update a piece of work that we did back in 2019 on the costs of intervention which back then estimated not intervening to be costing the economy \$15.2 billion per annum, which was quite a conservative number. We are now in the process of seeking to update those numbers, which we expect will be dramatically higher, especially given what we now understand about NDIS. It's not the principal reason you should be investing early. The principal reason is to ensure that children develop well. But a really important secondary consequence to this is that it actually avoids a whole lot of costs.

**Dr Silva:** I think it's about supporting the kids that require it rather than constantly pushing a diagnosis. I think the pushing of a diagnosis is a factor with NDIS and a whole range of things. It's clearly about looking at the child at the time. If they are not functioning and have needs, that's where the money needs to be spent. I think it makes a huge difference further down the track.

**Senator PRATT:** Can you give us a bit of an overview. In the course of this inquiry in talking to people giving evidence they've said, 'We've got the diagnosis, but we still don't know what supports and interventions we should be looking to.' In terms of the kinds of supports, adjusting a child's routine or, over time, working out what's going to work at home and at school, have you got any evidence to show where something might be ADHD specific? Those interventions have a lot in common with broader child development frameworks. Yes, it is true that children with ADHD might struggle to sit still or might interrupt the class, but how many other children will benefit from the kinds of interventions that better manage those things in an early childhood context?

**Dr Silva:** That is a really good question. The interesting thing is that there isn't that level of research. If you think about it, you see that a lot of the time the teachers can't cope with a particular child. We know that medication has the best evidence in terms of treating that child, but, as we all know, pills don't teach you skills, so you do need the skills there to work with. I think that piece of work that you're talking about—the impact it has on the whole class and the whole environment—probably hasn't been pieced together adequately. There have been a lot of studies looking at evidence of psychology, mediation or a combination of it. Generally, the international research has shown that medication does work the best, but I think you need that combination, a lot of education and identifying kids that have certain issues earlier so that we can change their trajectory. I genuinely believe that trajectory can change.

I wrote this vignette when I was doing my PhD. Kids with ADHD can be very difficult to manage. They're often incredibly talented and are never boring. They're really fabulous kids, so I don't think all of them need medication, and we know that from the percentage of kids that are in treatment. If you can get kids functioning who have ADHD and have the school system and a home environment where they're allowed to learn a different way, I think you'll find that they'll thrive. They probably won't have the problems that we're seeing today.

**Senator PRATT:** That is interesting and helpful. When it comes to neurodiversity in very early childhood and we're really looking to that ecosystem and what supports are in place, what's working well, and at which point might children need to be triaged for a bit of extra support or specialist intervention where they're not actually getting that? Are there kids in the system who aren't picked up and triaged out, or are they just not in the system at all? I don't mean triaged out of the system; I mean having their needs identified.

**Dr Silva:** With the origin study, we can see so clearly what's going on with the parents, because we get them to fill out questionnaires at set times, give them feedback and provide them with support. Paediatricians will review those sets of validated questionnaires, give them a ring and have a chat to them to direct them to services. There are a number of them that probably wouldn't be in the system, and picking them up early and helping them—we get the most beautiful thankyou notes from families because we've actually supported them early without them having to enter a crisis. So I think there are a lot of children out there.

**Mr Weatherill:** There is a clinic running a program about neurodiverse children working with babies six to 18 months old and supports social interaction and communication. The thing I found interesting about that is that there are different ways in which some children communicate their needs, and this is not immediately understandable by their parents. It's part of the process. It's as much about educating the parents. It only stands to reason; of course they're going to be spending the overwhelming majority of their life with their parents at that stage, so the home environment and the subtle cues that are given by children are not developing typically will then lead to different behaviours by the parents, which then lead to very different interactions that do switch on the positive genetic development. This is not my area, but it does seem that that Inklings program that's being trialled by a clinic is being rolled out across the country. It seems to be powerful example.

**Prof. Elliott:** It's really about supporting the whole family unit and really empowering parents so that they can provide the support to their children really early, before they get to that crisis point. That study identifies babies who might be at risk of not having good communication skills. Parents know very early that their child is not developing like their other children, and it's really about wrapping the support around the whole family.

**Senator STEELE-JOHN:** Dr Silva, I'm so glad you're able to join us today. Professor Stanley recommended you very highly, so it's great that you've been able to join us this afternoon. With your long history and background in paediatrics, I wanted to put a question to you that's come to us through evidence today and also at the previous hearing. It is the question of capacity within the system to perform the assessment. Particularly with children, obviously, that is a role that is kept with paediatricians and specially trained child psychologists, but

we've heard again and again today that the waitlists are so long that kids are phasing out of eligibility for some services before they are accessing them. Would you support an expansion of the ability to perform the assessment or the diagnosis? We've heard conversations about prescription and the role that GPs might play in diagnosis and prescription for adults as well.

**Dr Silva:** I would absolutely support expanding the system, because it's not working at the moment. We've really got to look at other ways. There's always a worry that we're not doing platinum-standard treatment, but I reckon gold-standard treatment is good.

**Senator STEELE-JOHN:** Any treatment would be ideal.

**Dr Silva:** Let's support these kids who have genuine issues. Let's not keep them on a waitlist for so long, because these issues get so much worse. I think people genuinely want to be educated in this area, so let's educate them. Now the system is so much easier with fabulous podcasts, videos and training programs, but develop them so people genuinely know how to deal with this. I'm very keen for GPs, if it is GPs, to be associated with paediatricians, because the trouble is that, if a GP goes out, diagnoses a child with ADHD and starts them on medication, and things don't go according to plan, which often is the case with the very young age group of kids—because you don't just have ADHD. You usually have a whole range of other conditions with ADHD. So they're going to struggle then. What do they do? Do they put the child on a two-year waitlist to see a paediatrician? You've got to get them working together. The paediatricians then are looking more at the really complicated, complex kids, but the kids that are much more settled on stimulant medication and are going okay without too much change should be handed back to the GP to provide some of that support. When things go wrong, they obviously come back. So I think about that system, and I've found that I've started doing that in my practice, so the spots have opened up. I see them once a year rather than every three or six months, because I know someone is looking after them.

**Senator STEELE-JOHN:** In WA we are an outlier. You probably know that every state and territory regulates stimulant use differently. We are the only jurisdiction to both explicitly recommend testing and recommended it for people over the age of 13, so we do have people in the young area to the adolescent area that are required to take those steps. Is that the kind of thing that we need to require people to do to get medication to help them?

**Dr Silva:** We certainly will test them if there's an indication, and in the adult population they get tested. But we don't routinely test the younger kids necessarily with that.

**Senator STEELE-JOHN:** The guidelines say over the age of 13 that can be brought in. But, again, no other state or territory does that. South Australia has a provision for it, as you probably know, but doesn't require it, which is a unique halfway house as part of the process.

**Dr Silva:** You've got to make it an easier process rather than a more complicated one.

**Senator STEELE-JOHN:** Yes. Finally, on the question of affordability, we've heard emphatically throughout the day and at previous hearings that the financial barrier to assessment and diagnosis in the private system is impossible to climb over for many people. Would you support the expansion of federal government funding to provide for free or more affordable forms of access to diagnosis and assessment?

**Dr Silva:** Absolutely. We're in the child development service, which is a public service that has provided what I would say is platinum standard care, and they need more support within that service so that they can then move them on. Kids are coming to the service and then they don't leave, so essentially you have to have a way to continue to treat them. If you have an appendectomy, you see the surgeon and then that's it as the next person comes in. But they're actually in the service for as long as they can be, and there needs to be a way to have them find other services within the community to support them well so that there is the throughput. Otherwise, the systems stalls, which is what is happening at the moment.

**Senator STEELE-JOHN:** It has completely stalled. Former Premier Wetherill is part of the Thrive by Five initiative. If you're in the child development service, you can be in it for 2½ years, so half of that window is gone even if you've begun it at the age of zero, which is unlikely. It's clearly a system that isn't working. Do you know of any initiative within the WA government—and we'll speak to them in a bit—that's actually trying to solve this problem?

**Dr Silva:** I'm absolutely sure, because everyone is a specialist, that it worries them.

**Senator STEELE-JOHN:** It worries me.

**Dr Silva:** You can't keep a system going like this, so I would think that they absolutely are looking at lots of different ways to solve the problem. I'll wait for you to talk to them about that because about five years ago I said

that this was what was happening. I could see that there was this wave happening, and I know that the kids' and the parents' mental health is enormously challenging these days. The anxiety levels and depression amongst parents are very high, and they're particularly high for parents with children with these conditions.

**Senator STEELE-JOHN:** Thank you. Back to you, Chair.

**CHAIR:** Yes, with the lack of affordability and lack of access you can only imagine the anxiety levels that families are facing. Thank you very much for your evidence today; it's been really useful. I don't think you took any questions on notice, but, if you did want to add any extra information, please get it to us by close of business Monday 14 August. That would be really appreciated. Thank you.

**Dr Silva:** Thank you.

**JONGELING, Dr Bradley, Medical Head of Department, Child Development Service, Child and Adolescent Health Service, Department of Health, Western Australia**

**TOWLER, Dr Simon, Chief Medical Officer, Department of Health, Western Australia**

[16:40]

**CHAIR:** Thank you for appearing before the committee today. The Senate has resolved that an officer of a department of the Commonwealth or of a state shall not be asked to give opinions on matters of policy and shall be given reasonable opportunity to refer questions asked of the officer to superior officers or to a minister. This resolution does not preclude questions asking for explanations of policies or factual questions about when and how policies were adopted. If a witness objects to answering a question, they should state the ground upon which the objection is made, and the committee will determine whether it will insist on an answer, having regard to the ground which is claimed. If the committee determines to insist on an answer, a witness may request that the answer be given in camera.

Now I invite you to make a brief opening statement, should you wish to do so. After that, I will invite committee members to ask questions.

**Dr Towler:** My office is at the moment involved in work around ADHD. We are currently doing some work with private providers and with Child and Adolescent Health Service looking at opportunities of service. I do have an opening statement, so I'll move to that.

Firstly, I'd like to thank the committee for inviting representatives of WA Health to participate and give evidence today. Whilst I'm here, I wish to acknowledge the traditional owners of the land on which we meet, the Whadjuk people of the Noongar nation, and pay respects to elders past and present. I profoundly acknowledge the contribution of emerging leadership whom I believe have presented to you today. For those of you visiting Western Australia, we believe we are privileged to be living in Noongar country, where their custodianship of many years has preserved this land.

I'd like to acknowledge the work of this committee. I'm sure from the previous information you've been given, you have an understanding that in fact before the committee was announced Western Australia was engaging in some work. We have a child development services inquiry being currently conducted through the WA parliament to look very much at the issues that you raised a minute ago. Access to timely ADHD care is of enormous significance in Western Australia. As the minister's officer I've been required to respond to a range of ministerials seeking to understand why we can't improve service.

Specialties in paediatric and psychiatry are particularly vulnerable in Western Australia. Because of the circumstances you outlined, I think that's understandable. We have a problem with the paediatric and psychiatric workforce, both in the public health system and, because of that, also in the community. These workforce vulnerabilities, as you've understood, impact heavily on ADHD care and the management of children and adults in both the metropolitan and rural areas of Western Australia. In WA the rural areas are worth significant consideration.

Apart from these workforce challenges for Western Australia, this inquiry is timely for several reasons. The WA Legislative Council select committee inquiring into child development services is currently in progress. Dr Jongeling and I have both presented twice to the hearings, and we're expecting a report from that committee by 31 December 2023. A consultation process by the Department of Health is in progress with respect to amendments to the Medicines and Poisons Regulations 2016, including the Schedule 8 Medicines Prescribing Code, which has already been mentioned. The Western Australian Metropolitan Child Development Service, MCDS, under the Child and Adolescent Health Service, is working towards a shared care model using clinical and other specialists to support paediatricians. I'm sure Dr Jongeling will have something more to say about it.

The Department of Health has also received a proposal from the Royal Australian College of General Practitioners working group, comprising ADHD WA and the primary healthcare alliance—who gave evidence, I understand, earlier today—to support a pilot project to fill an unmet need for timely, efficient and accessible assessment, diagnosis and treatment of ADHD. The proposal seeks access to private specialists in the face of workforce shortages and aims to simultaneously upskill GPs to manage ADHD.

I note from some recent public committee hearings in Canberra that there's been a call for harmonisation of stimulant regulatory schemes and support for shared care using a range of health professionals. We would certainly consider this as an appropriate need.

Historically in WA, the Western Australia Stimulant Regulatory Scheme was established following what were concerns some years ago in the community. Currently in WA, as you know, only specialists can prescribe

stimulants for patients with ADHD. GPs and other professionals can, though, be nominated as co-prescribers. Looking to enhancement of this model is part of what we're considering currently.

WA's stimulant prescribing pattern is currently different to some other states, with significantly higher levels of prescribing for adults. Queensland, New South Wales, Tasmania and ACT rates are higher than WA's for children. Its focus to date has been consideration of necessary public protections and balancing issues of access to treatments against individual and community safety. Amendments to the code might well be less restrictive, as real-time monitoring systems, as you may be aware—particularly ScriptCheck—might mitigate risks to safety that had been identified a number of years ago.

WA is experiencing long waitlists for ADHD assessment, diagnosis and treatment for children, and there are no public services for adults with ADHD at this time. For youth transitioning to adulthood, ADHD management is a challenge from both a cost and continuity perspective. Shared care models can potentially offer support for improved management and care as an alternative to current models that are highly reliant on the specialist workforce.

As alluded to earlier, and in our submission, in WA there has been exploration of a shared care model using clinical nurse specialists within the metropolitan Child Development Service. However, with limited resourcing, it is yet to be scaled up, and the community's needs remain, unfortunately, largely unmet. More recently there has been a call to action by the community, represented by peak bodies preparing a joint proposal, as we said, with the Royal Australian College of General Practitioners to pilot a new model of care using GPs alongside private specialists to support improved access to ADHD assessment, diagnosis and treatment. While WA Health is supportive of examining a variety of shared care models and supportive of improved access to ADHD assessments, diagnoses and treatments, any financial support to the RACGP WA GP ADHD care working group to pilot a concept will require the WA government to come to an arrangement with the Commonwealth. WA Health is acutely aware this is in a Commonwealth space and welcomes urgent Commonwealth support for the proposal.

Furthermore, in the context of GP shared care, changes to the Medicare Benefits Schedule to allow co-consults, as I think you heard from Desiree just before, will improve the viability of specialists in the private sector to work with GPs in the community to meet the needs of people with ADHD. Given the demand for assessment, diagnosis and care, and the necessity for new models of care to allow greater access to support, there is an acute need for better education, training and professional development of a range of relevant health professionals. WA is aware that other states are developing training packages for GPs. WA would welcome Commonwealth support to work with the specialist college and professional bodies to endorse accredited training packages and to support the development and evolution of shared care models for ADHD for use locally and nationally.

Finally, WA is supportive of better integration between state and Commonwealth departments to better meet the needs of people with this condition and to support their families, and looks forward to working together to facilitate improvements in this area.

**Senator PRATT:** Dr Jongeling, do you have any remarks?

**Dr Jongeling:** I do. Sorry for my voice today. It's partly because I've been lecturing for 2½ hours to the medical students on normal development, autism, ADHD and other developmental issues. I've been working in this service for 23 years. I'm the current head of department of the Child Development Service, which I've been in for the last 10 years. I'm also a member of the Royal Australasian College of Physicians committee on advanced training in community child health, an inaugural member of the Neurodevelopmental and Behavioural Paediatric Society as well as a general paediatrician in my own right. I also work privately. So I have a broad breadth of understanding. I've also been before inquiries in the past, including the ADHD implementation inquiry in WA back in the mid-2000s. I've also participated in NHMRC-funded research with the childhood attention project which was led by Professor Emma Sciberras, Daryl Efron and Vicki Anderson in Melbourne, which was a long-term follow-up of a community sample group of children with ADHD, a very well phenotyped group. That showed really good evidence about the complexities, the comorbidities and the maintenance of ADHD diagnosis over time. It was not funded beyond the first three to four years. I've also published in paediatrics myself, on ADHD, including a publication in 2016 on current paediatric practice and parent perspective.

Today I represent the metropolitan Child Development Service in Western Australia, which is part of the Child and Adolescent Health Service. Our service provides the majority, if not all, of the public assessments of ADHD and ongoing treatment of children with ADHD. Unlike some states, we're quite aware of the increase in referrals for neurodevelopmental issues in the last three to five years, because we have a centralised intake process across the metropolitan area fed into by child health and school health nurses and by referrals from outside. Our own service has seen an increase in referrals of more than 150 per cent more generally around developmental issues

over the last three to five years. Specifically around attention, 21 per cent of referrals in 2021 had attention concerns versus previously 11 per cent of referrals. Average wait times have increased significantly, and we are acutely aware of that and the needs of those families who are waiting, with an average wait time of 17 months, but at some sites moving up to beyond two years. To give you an idea of the size of our service: currently we have about 3½ thousand patients, or 35 per cent of our active paediatric case load, that have a diagnosis of ADHD and more than 6½ thousand that might have some additional concerns around attention or have been diagnosed with ADHD. In addition, we have a total paediatric case load of developmental issues of over 10,000 children within the metropolitan area and a number in the thousands, of course, waiting on our wait lists.

It's important to note that the children have often been through our service prior to paediatric assessment, so, while many of the children wait for an ADHD assessment, more than 35 per cent of children—in fact, 70 per cent of children that we see—have already been previously active for occupational therapy or speech pathology. I listened to the previous talk by Jay Weatherill about the importance of a community of practice and a community leading to those children developing, and I would agree that one of the advantages of a service like ours is the engagement of child health and school health nursing and early developmental support.

I'd like to note that currently, as far as training for paediatrics goes, and particularly community paediatrics and diagnosis of ADHD, it is a fairly intensive training program of six years, including, for general paediatricians, at least six months of training in psychosocial paediatrics in a service like ours. For those who do community child health training, the majority of people in my role, it would be at least six months of child population training, six months of training in a service such as ours, three months of child protection training, three months of social paediatric training and attending a 12-month course on community child health education, with a tutorial series, as well as learning about the normal developmental milestones and developmental behaviours. I highlight this because ADHD is a complex neurodevelopmental disorder. It involves children with complex presentations that are not always easily observable as necessarily ADHD or, if they are, they may also indicate underlying issues such as autism spectrum disorder, trauma, parenting related challenges, issues around fetal alcohol spectrum disorder et cetera that require some knowledge of assessment prior to diagnosis.

Finally, I note that I agree entirely about the importance of early intervention, putting around a community of practice and support for families earlier on. It's worth noting James Heckman's work around what great gains are to be made by investing in the early years of child development and the idea of spending a dollar here and gaining \$7 in terms of prevention costs. Indeed, there is James Fraser Mustard's work, 'From Neuron to Neighbourhoods', which confirmed the old adage that it takes a village to raise a child. Supports around child access to family and educational supports, early access to early childhood supports, child health and school health medicine, play groups and et cetera are extremely important. We are dealing with a significant increase in neurodevelopmental concerns, and prevention and upstream factors need to be considered as much as assessment.

**Senator STEELE-JOHN:** Fantastic, thank you. I'll take you first to the WA Department of Health Schedule 8 Medicines Prescribing Code of 2018 pages 30 to 32. That takes us to the relevant section that I want to begin with, where WA Health recommends:

A urine drug screen...should be undertaken by all patients 13 years and older before treatment with a stimulant is commenced. Further testing is recommended annually and as indicated.

Additional requirements are required for the treatment of people with a history of drug dependency, including authorisation for treatment. We've requested, as a committee, for a bit of research to be done to look at what the other states and territories do. WA is the only jurisdiction that has that recommendation.

**Dr Towler:** It is, and that's a factual statement.

**Senator STEELE-JOHN:** My question to you is: upon what evidence is that recommendation based?

**Dr Towler:** I've been the chief medical officer for nine months. Meeghan Clay is our chief pharmacist. There is a robust background to the establishment of this code. To give you the information you need, I would have to take that question on notice.

**Senator STEELE-JOHN:** Please do, because we'll—

**Dr Jongeling:** I might be able to help.

**Senator STEELE-JOHN:** Okay, thank you.

**Dr Jongeling:** My understanding is that the proposed stimulant guidelines are to change, potentially, to children 16 and over. In addition, we've done some research in our own department on the percentage of children who have had a drug urine screen for children older than 13. Am I able to share that? One of our paediatricians, Dr Dharmapuri, did a study on this which showed that, even in our own service, we were probably only assessing

about two per cent of the children who presented with ADHD for drug urine screens. That was because it's recommended; it's not mandated.

**Senator STEELE-JOHN:** I do understand that, but—

**Senator PRATT:** But it puts people off going.

**Dr Jongeling:** I think it's important to note also that we would agree that it's a challenge from a clinical perspective, because you may well have a test now that is negative, but when do you test again? Substance misuse may happen later or earlier. We are supportive of the health department's suggestion about moving it to 16. I think they've changed the terminology also in that regard.

**Senator STEELE-JOHN:** But, again, my question would be: when you have no other state or territory making such a recommendation, upon what evidence is WA basing this on, whether it's 16 or 13? Why would it exist in WA when it wouldn't in Victoria? What evidence do we have?

**Dr Jongeling:** I think we would need to go and have a chat with the decision-makers in that regard, other than to note that stimulant medications can be associated with the development of psychoses when used with a substance of misuse. I suspect it's in order to try and prevent that. On what research there is, I would have to take that on notice.

**Senator STEELE-JOHN:** Thank you. If you go also to the question of the various other differences in the way that we regulate stimulant treatments, in WA there is currently a requirement to seek a reauthorisation for the prescription after a six-month period. As part of the reviews into the regulation, is it envisaged that that duration will increase or be removed?

**Dr Towler:** That view is continuing, and it has been informed by clinical expertise in the sector. My understanding is that that is one of the issues under consideration. Certainly, from the point of view of looking for some flexibility around a co-prescriber model, that would seem to be sensible. The outcome of that work is not finalised at the moment, but my understanding from speaking previously with the Chief Pharmacist is that that process is ongoing and opportunities to change the code are being considered. ADHD WA is involved in that work.

**Senator STEELE-JOHN:** Do we have date for the finalisation of that work?

**Dr Towler:** I don't have it with me, but I can certainly provide it for you.

**Senator STEELE-JOHN:** Could you take that on notice and also the publication date. They're two distinct things—finalising and publishing. It would be great if you could take that on notice for us. Going to the waiting list for the Child Development Service, you cited an average of 17 months. Your submission references 24 months. We heard earlier today that it can be as long as 29 months. This really is an unacceptably long time for families to be waiting to access supports. I understand that you shared that there is a review underway. To put it in a tangible way, I know there's been a change recently in positions, but when was the last time that the minister sought a briefing on the wait times within the service?

**Dr Towler:** I don't know the answer to that. It would come through the Child and Adolescent Health Service.

**Senator STEELE-JOHN:** Would you be able to—

**Dr Jongeling:** I have certainly not met with the minister myself, but we've certainly met with the minister's representatives around our nurse-led ADHD clinic proposal and had discussions about those things. I understand the inquiry is still in process. In fact, I'm meeting with them tomorrow, and I suspect that funding arrangements will be partly informed by that process.

**Senator STEELE-JOHN:** Yes, but you said they are reporting on 31 December.

**Dr Jongeling:** I believe it is December now, yes.

**Dr Towler:** They've just sought a three-month extension because of the quantum of the work being done.

**Senator STEELE-JOHN:** But that means they won't make tangible recommendations until parliament reconvenes in March next year.

**Dr Towler:** That would be usual.

**Senator STEELE-JOHN:** So we have people who have been on the waiting list for years who will be waiting for the recommendations to come down. I'd like to know when the minister last requested a briefing as to the wait times and what can be done between now and when those recommendations—

**Dr Jongeling:** Certainly, they are very aware of the wait times in parliament. I think it's been reported many times what our current wait times are. We certainly provide KPIs to the Child and Adolescent Health board which I presume are put further. It's worth noting that even within the Child Development Service, within the Child and



Adolescent Health Service, we've had some extra funding to deal with things like emergency medication waiting lists—where private practitioners or services have closed down or are not prescribing—so that we can manage that. We had a little bit of funding to be able to do that. A couple of years ago, we managed to get some funding within CAHS to increase the number of our registrar trainees and paediatricians to also provide an improved service.

**Dr Towler:** I think you need to understand that, at the moment, the minister's office is being briefed regularly through the process of the GP project that we've just spoken about in the presentation. That work has largely been managed through the parliamentary secretary the Hon. Simon Millman. The minister's advisers are being updated on that work basically every few weeks at the moment. We're finalising that proposal for her consideration. I think you need to understand that the minister is well aware of this issue and is being—

**Senator STEELE-JOHN:** I'm sure her team is, but I want to know when was the last time that the minister was briefed directly about the time frame and what's being done to bring it down, precisely because while the community waits for recommendations and reviews people are still waiting on those lists. You've agreed to take that on notice; good. I'll pass now to Senator Pratt.

**CHAIR:** Actually, we've got a question from Senator Kovacic, so I might go to her first.

**Senator KOVACIC:** Thank you; I appreciate that. We've heard a lot of evidence today about all the things that we need. We need more psychologists, psychiatrists and paediatricians. The waiting lists are far too long. I'm really confused, because we have a state government with a \$3 billion surplus and yet we have the Department of Health calling out for extra funding. So I'm a little confused as to what is driving these shortages—whether it is funding, whether it's a lack of resourcing or whether it's a combination of both—but what I'd also like to understand is whether there have been any discussions with the department and the minister and with the Department of Education as to why ADHD is not considered a funded disability within the WA Department of Education. Has that had any attention or discussion, or is it on the agenda for it to be discussed?

**Dr Towler:** Brad, do you have any views on the education department?

**Dr Jongeling:** I can't speak for the education department, being clearly the health department, but we certainly have been in—

**Senator KOVACIC:** I mean in conjunction—have there been discussions between the two in relation to this?

**Dr Jongeling:** We certainly meet regularly with the education department to discuss areas of agreement and challenge in providing appropriate support services for children with neurodevelopmental disabilities. One of the challenges of these children with complex issues for their families and in diagnosis is that there is no clear test that we can use. Services and supports that are diagnostically driven can impact upon diagnostic rates, and we've seen that already within the autism spectrum diagnosis area and NDIS funding. That's why—certainly as far as the College of Physicians goes—we are very much in favour of accessing support services that are based on functional needs. So the question as to the education department having ADHD as a disability issue should be looked at in terms of the functional impairment of the child. There are certainly children with ADHD and other diagnoses who fall outside of, say, autism spectrum disorder or intellectual disability who probably deserve extra support and attention within the education department. Traditionally, that support is seen as assistance from an educational assistant within class, but the education department, and I'm aware of this, has other funds that it can provide to support children in learning within their own system that may not be specifically an EA. The question is whether an EA is actually the most appropriate support, and you would have to direct that to them.

**Senator KOVACIC:** Thank you.

**Senator PRATT:** I have a supplementary question to that. How would we go about working out the extent to which the cohort of children that you've got within CAMHS have a student resource standard attached to them for either a disability or for the supplementary educational adjustment allocation? I understand that's not spent on an individual child, but it is there to support those strategies within a school and that a parent might also work with a teacher on an individual education plan. How would we go about working out the number of children that you've got within CAMHS who have had that educational adjustment applied to their place?

**Dr Jongeling:** I should just correct you. It's not CAMHS. CAMHS stands for Child and Adolescent Mental Health Service. We're the Child Development Service, a part of the Child and Adolescent Health Service. We also work well with CAMHS—

**Senator PRATT:** No, I do understand the difference. It was just a slip up on my part.

**Dr Jongeling:** CAMHS is also responsible for the complex ADHD team. We can certainly have a look and potentially provide some data about the number of children within our service who have an NDIS related

disability diagnosis, such as autism or ADHD, who may be able to access services, but we could not tell you how many of the children who don't reach that threshold who might have ADHD, plus many other comorbidities, are accessing individual education plans. That would be a question, really, for the education department to answer.

**Senator PRATT:** From my perspective as a parent in the state school system, I've never been asked by the school, or I wouldn't know whether they had audited their school population, either by asking parents whether their child has a diagnosis or whether they've worked with the school psychologist to audit their school population to bring in extra resources. Do you have data by region or a smaller microcosm, so we can start to compare the data between what CAHS has and the state education system has?

**Dr Jongeling:** I don't think I can speak to what the education department has.

**Senator PRATT:** No.

**Dr Jongeling:** I understand that. Certainly as practising paediatricians, we always recommend to our children with ADHD that the letters we produce that are part of their assessment process are shared with the parents and with the school. More than 50 per cent of children with ADHD have a comorbid learning disability, and those children really do need engagement with support, either an IEP, an individual behaviour plan or educational supports. We would encourage that to be discussed with school, but we would not necessarily have a record of that in an easily accessible manner. We would often ask for copies of any of their case conference meetings that parents and children have with the education department psychologists and schoolteachers.

**Senator PRATT:** In that context, when you say that a child could be referred for extra supports, what are they here in WA to maintain that development of adjusting a child or a teen or the interventions?

**Dr Jongeling:** Are you talking about something from our submission or from what I've just said?

**Senator PRATT:** I'm happy to go and reflect on the other materials.

**Dr Jongeling:** What I was trying to convey at the beginning was that children with neurodevelopmental disorders—as Dr Silva said earlier on, ADHD is very rarely a standalone diagnosis. It's associated with complex comorbidities, with 30 per cent of them potentially having autism spectrum disorder, 50 per cent having a learning disability, a large proportion with a language impairment, particularly higher level functions, and risk of anxiety and depression. So it partly depends on what that comorbidity is, essentially. If it's a learning issue, we would encourage discussion with the school and access to educational supports in the school, which should be funded at the school level. It may be engagement with a school psychologist. Sometimes it will be a suggestion that more formalised psychometric and learning assessments are considered to look at whether there are specific reading disabilities or specific learning issues related to reading, writing or spelling—what we used to know as dyslexia, dysgraphia and dyscalculia. They need to be supported at an educational level. We can make those recommendations, but we certainly don't have educational clinicians with us.

We have more recently been doing a pilot program with the School of Special Educational Needs: Medical and Mental Health within the education department to try and have a bit of a back-and-forth discussion around the kids that we manage. That hasn't fully been funded, but it is an area we'd like to do a little more work in, because we do see that need for a clear agreement and engagement between education and health on children that we both have responsibility for.

**Senator PRATT:** That's helpful. Finally, what can the Commonwealth do to unlock the workforce challenges? You've outlined what they are and that there's stuff going on. I know federally we've announced an increase in the rebates for nurse practitioners. I'm interested in what you think the Commonwealth's role in meeting that workforce shortage is.

**Dr Jongeling:** I think that's a real challenge. One of the key questions here is the state and federal funding divide, and the issue between public systems such as what we provide at the state level and federally funded positions, which end up mostly being within the private sector. Equity of access is a key and important thing for a service like ours. We provide a free service that any family or child can access, with free assessments and ongoing support from zero through to 18 years of age. From an equity perspective, it's the best model. It carries a waitlist, of course. Having said that, there are clear waitlists also in the private service.

I also want to ensure that there's quality of assessment. The Royal Australasian College of Physicians has been fairly clear that as far as ADHD diagnosis goes, it should rest with a very experienced paediatrician or someone with clear evidence of training. That shouldn't be just a few hours, because these things are complex, and labelling or diagnosing appropriately is something we have to do carefully, and there are risks with doing that inappropriately. I think I would say that, from our perspective of a service, we're very supportive of shared care models and coprescribing, providing there are appropriate supports and access to a consulting paediatrician for discussions. I think integrated models of care and integrated model hubs are very important. I note what Jay

Weatherill said regarding some of that aspect. I would have to say that a service like ours, which is a child development service, does actually have some of that with child health and school health nursing already, with multi-allied health services involved. The issue is having the sufficient funding to provide that across service.

I think other things that would be valuable—and I would agree with the general practice on this—would include funding longer consultation sessions with patients from a Medicare perspective, and the case conferencing, which Simon has clearly identified. The other area, which is part of that integrated model of care, is the planned community hubs. Certainly in the case of WA community hubs—and we have a number planned for hopefully Midland and for Murdoch—those that have been funded at state level are really good ideas for having child health nursing, child development services and mental health services. Potentially I would encourage other models, and maybe there's a role for federal funding for those kinds of things that bring in general practice as well—and this is me speaking, not the health department—to have the community of practice exposed to assessment and treatment options, learn about ADHD, be able to work in their own practices like that, and have that supervisory model that we already give to our registrars, which is why we train them for a minimum of six months, because it's not necessarily a simple area to step into.

**Dr Towler:** A colleague who spoke earlier talked about the difference between hospital based care and community based care. But Commonwealth initiatives at the moment around integrated care pathways are relevant to this. Regarding ADHD, you heard from Dr Jongeling about the shared responsibility around the patient for developing a treatment, particularly for those on medication, and at the moment if two clinicians are involved only one receives a fee. The time involved here is significant. The nurse practitioner model that's been developed at CAHS in relation to doing the extensive amount of information collection—finding the background school information and history, understanding the family dynamics—can be applied on a broader basis. But the real story here is how we develop in a partnership, which was emphasised in the submission, for the care of children, many but not all of whom need ongoing integrated care between the two environments. One thing I would say is that we have not had one mention today of the WA Country Health Service. There are colleagues in the delivery of these services to people who don't live in the metropolitan area. They've been extensively involved in the child development inquiry, and the issues are even more challenging for them further away from the metropolitan environment. There's a lot of interest in the telelink model of support, and we're seeing a few examples in disciplines not like this one but things like immunology care to build the partnership between the hospital system and community based care for people with ongoing needs. We think that's really important.

**Dr Jongeling:** And I think it's worth highlighting that nurse led clinic model, which is something that we're very in favour of within our service—having nurses take that responsibility by using online systems for collection of information and ways of also trying to improve throughput.

**Dr Towler:** Dr Jongeling is being very modest about that. That pathway has been researched and has been shown to be beneficial.

**Senator PRATT:** I look forward to looking it up. Thank you very much.

**CHAIR:** Thank you very much. You're obviously a fount of knowledge, and if there is more that you want to share with us, please feel free to do so. You did take some questions on notice. If they could be provided to the secretariat by the close of business on Monday 14 August, that would be really appreciated. Thank you.

**Dr Jongeling:** Perhaps I could make just one more comment, and that is that in this whole area I think one of the things that is important is that developmental concern—and Jay Weatherill said something in this regard—that children are not referred with ADHD, or ADHD only. They're referred with developmental and behavioural concerns or socialisation challenges. It's the role of the clinician to tease that out and decide, with the family, what the disorder is. So, setting up pathways that deal only with a specific problem is fraught with danger and are complicated, because they end up driving towards a diagnosis rather than considering what the multitudinal factors are here. That diagnosis may be ADHD, but it may also be autism or comorbid learning, and you need to consider all those things when you're making a decision about the services you provide—which is why a service that has that multidimensional review is helpful.

**Senator PRATT:** I do like the way the state parliament framed their inquiry, so that's good.

**CHAIR:** Thank you. It's an awful lot of information. Thank you for your willingness and your patience about sharing that information with the committee. That concludes today's hearing. Thank you to all the witnesses who appeared and to Hansard and broadcasting for their assistance, and the secretariat for their ongoing wonderful work. I will note again that we've agreed that responses to questions on notice should be provided by Monday 14 August.

**Committee adjourned at 17:20**