THE HOUSE OF ASSEMBLY GOVERNMENT ADMINISTRATION COMMITTEE B MET IN COMMITTEE ROOM 1, PARLIAMENT HOUSE, HOBART ON FRIDAY, 21 FEBRUARY 2025

INQUIRY INTO THE ASSESSMENT AND TREATMENT OF ADHD AND SUPPORT SERVICES

The Committee met at 10.02 a.m.

CHAIR (Ms Haddad) - Good morning. Welcome to today's hearing of the parliamentary committee into ADHD. Thank you for the written submission that you've provided and for agreeing to appear before us today in person and to give us your time. Could I ask you, first, just to state your name and the capacity in which you're appearing before the committee?

Ms MacDONALD - My name's Ellen MacDonald. I am here in the capacity of CEO of Health Consumers Tasmania.

CHAIR - Can I confirm that you have received and read the guide sent to you by our committee secretary?

Ms MacDONALD - Yes.

CHAIR - Thank you. In the guide you would have read, but I'll just reiterate, that you're covered today by what's called parliamentary privilege. This means you are free to speak to us in any way that you want, share any information with us that you want to, without any fear of being sued or questioned in any court or other place outside of parliament. The only exception to that is that protection isn't accorded to any statements that you might make that could be considered defamatory, if you then refer to them outside of these parliamentary proceedings.

It's a public hearing. We haven't any members in the public gallery right now, but members of the public may attend throughout the day or be watching the broadcast online. Likewise, media may attend or be watching the broadcast online.

I've introduced all of the committee members. You've got all parts of the state and all political parties and independents represented on this committee. We're really keen to learn from the experience of your organisation and from yourself personally to provide the best recommendations we can to government in our report.

Ms ELLEN MARY MacDONALD, CHIEF EXECUTIVE OFFICER, HEALTH CONSUMERS TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Thank you. We've also agreed, as a committee, to make a short sensitive content statement at the beginning of each session, for anybody watching or accessing the transcript or recording of this afterwards. I'll just quickly do that now.

As a committee, we recognise that during these hearings we may discuss highly sensitive matters and themes that have deeply impacted the lives of Tasmanians. This may be a trigger or distressing for individuals listening to or participating in these proceedings.

As a committee we encourage anybody impacted in that way to contact services such as Lifeline on 13 11 14 or 1800 984 434, ADHD Foundation Helpline on 1300 39 39 19, or Kids Helpline on 1800 55 1800.

Additionally, for today's in-person hearings, we do have another breakout space next door that is available if you wish to make use of it. If we need to take a break at any point during today's hearings, that's fine.

One other thing I forgot to say is if you do, some time through our conversation, wish to give us information in private, you can make that request of us as a committee. There's a short process we do to move into what's called an in-camera session. We can then hear evidence in private, if that's more comfortable for you. That's all the formalities done. I'd really love to invite you to start with an opening statement, if you'd like to do that.

Ms MacDONALD - I guess I didn't reflect on who I'm representing here today in terms of my organisation and what we've heard from consumers across the state in relation to ADHD diagnosis and support, but also my own lived experience, which I did briefly talk about in our submission. I believe that's important, and I'm really glad there's the opportunity for people with lived experienced to talk today. We're the statewide peak for health consumers, so all people wanting to access health services. We know that the influence of people with lived experience is what helps to inform really good decision-making.

We pulled together what we could in terms of the submission, based on the data that we have just from broad consultations. I've talked at other inquiries before about the way that we undertake consultation with community. We've talked in reasonable depth to more than 800 Tasmanians, and this is just what's come from really broad questions around health and wellbeing. ADHD does come up. Also through conversation with consumers generally and what we understand to be their experience.

It's more prominent in my mind as well, because of my own experience and the difficulties that I've come up against. I have the privilege to have money to pay for assessments and go through all these processes, which a lot of other people don't have. The additional barriers in a lot of ways that some other people in the community might experience, including young people, it's quite difficult.

You've had amazing submissions, which is incredible. I did want to highlight a few things from what we've heard, which is pretty consistent with what you've already heard. Talking from personal experience, right now going through a really difficult process with trying to change psychiatry practices, where there are immense barriers occurring. There's also really interesting public dialogue around ADHD and how it's perceived and experienced, which has the potential to create even more barriers for people to diagnosis. The income disparity, and all of those things, is a big one.

Accessing medication and the ongoing access is really problematic. If I refer to my current experience - the two-year prescribing window. Needing review is up for me, so I needed to be referred. That experience has been so layered and problematic. The psychiatrist that I was seeing moved practice. I'm trying to go to a different practice, and they're telling me that I need to have a whole new assessment. They won't let you book an assessment without paying almost $1100. Then you need to wait for the appointment until you can get anything back from Medicare.

CHAIR - What could that potentially mean - sorry to cut you off - for your medication regime, if you're waiting a long wait time to see a new psychiatrist?

Ms MacDONALD - Yes, I think that I feel reasonably lucky. Look, I feel backed into a corner right now because the practice manager that I had spoken to on the phone said, 'Oh, there's 50 other practices you could choose from'. I'm sort of like, I don't have time to get into somewhere else.

Mr BEHRAKIS - This is the psych?

Ms MacDONALD - Yes, the representative from the practice who I assume is the practice manager.

Mr BEHRAKIS - There's not 50 other practices.

Ms MacDONALD - Maybe nationwide.

CHAIR - I wish there were 50 practices for Tasmanians to access.

Mr BEHRAKIS - I think there is like four that work with ADHD.

Ms MacDONALD - I think what I'm seeing at the moment, in terms of how practices are operating in this model, like this is the pathway for ADHD, and I think that it's good that it's being talked about and people are trying to make it more accessible, but I also think it's a marketing model that also sets people up to have to follow this pathway, which is what I'm experiencing now. They're saying no matter what, you have to go down this path. It doesn't matter if it's this full assessment or this initial appointment, this is the rate that we will charge, no matter what. But, when you look at the rates for initial appointments, they're sort of $500 to $700, usually. The kicker of it all for me is that the psychiatrist that I want to see has moved to this practice. I have all of my assessments -

CHAIR - So, it's the same practitioner that you're trying to see.

Ms MacDONALD - That's the one that I'm trying to see, and they've said it doesn't matter. So, I think -

CHAIR - Sounds very bureaucratic.

Mr BEHRAKIS - Sorry, so the psychiatrist who did your initial assessment has moved to another practice. You want to move to that practice and that practice won't accept the assessment from the same psychiatrist because it was from when they're in a different practice.

Ms MacDONALD - Yes, they're saying any new patient to the practice needs to have - and look, everyone does need to have an initial assessment, but I also argue, is this science if you're not saying - do you know what I mean? I'm not questioning, you know, that at all. I understand the need to review what has happened before to look at the criteria and all of the documentation.

CHAIR - You should be able to do that with your care provider who happens to have moved administratively to another practice, but is your still your treating practitioner. It's a huge barrier.

Ms MacDONALD - Yes, it's massive. And that's for someone who has the ability to pay the $1100 and sit on it, let alone anyone else who might not be able to. I think it's just so unnecessary. For me, it's creating this model where you're not being referred for an initial appointment like you would with any other type of practitioner to sort of look at what is the picture here and going down this pathway. There's a lot of talk about over-diagnosis, which I don't want to buy into that conversation at all.

I think we want to talk about the risks of misdiagnosis, but there's still quite a large level of under diagnosis, particularly with certain portions of the community. I thought the timing is just unbelievable really, but I'm still trying to have that conversation with them and I would like to think that, hopefully, when I eventually see the practitioner that something might be different. But, you have to pay the money and you have to jump through the hoops.

CHAIR - That message might not even be getting through to the doctor.

Ms MacDONALD - I would say not.

Mr BEHRAKIS - It's a very convoluted and admin-heavy, and a bureaucratically heavy process for someone trying to seek treatment for something that specifically disadvantages them in navigating bureaucracy and processes and systems. I know people that have had other conditions or injuries, or what have you, and there's, it's almost a bit of handheld, like, 'This is what you do here, and this is where you go. We'll organise this for you. We'll make a referral. You just go there on this day and it'll all be fine'. And I've heard this from a few people and it was my experience as well, it's sort of a 'figure it out', but there's a very, very distinct process you have to go through. You don't know what it is. If you get it wrong, you'll be stuck for six months in limbo. 'Good luck'. It seems to be what it's like.

CHAIR - The system is set up to be as difficult as possible for a cohort of people who would benefit from it not being so complex.

Ms MacDONALD - It's an interesting point. If you do really want to understand what is happening and why, then I'm already feeling like I'm the problem patient. You get concerned about making a complaint. I talk about complaints a lot and whether or not that's going to impact your access. I think, for me, being able to access medication and understanding ADHD and how my brain works has been life-changing. I absolutely wouldn't be in the job that I am now. I would have struggled. I think it's really important that it's understood better and more accessible to people.

I think that the medication issue is another one that impacts me, but also people who - when we talk about systems and how they're set up and how they impact people - people who have utilised self-medication with non-prescribed medications - drugs - and how restrictive it is for them to access a prescription. Because, I just think, for me, it's not actually about the safety of the patient or the wellbeing of that patient to say, 'You have this history, so you can't have the medication'. You're essentially saying to someone, 'Just continue to use and not be cared for and be monitored?' I think that that's something that really needs to change. It needs to be seeing the patient for the patient.

Mr BEHRAKIS - It seems like there's a risk aversion when it comes to prescribing - and there is some risk, for sure, but it's not measuring against the cost of not providing that care. It's just measuring against the risk of that particular drug, which is, whatever above zero, but the risk of not - and the issues that come from continuing to go untreated and the issues of trying to seek other solutions to what might be better treated through evidence-proven medication. Is this something that a lot of people who have come through your organisation or have come to your organisation have faced?

Ms MacDONALD - I've heard about it from a number of people. People haven't talked about it in our focus-group-type consultations. It's probably more in one-on-one conversations that we have heard about it, but it's also something that people don't talk about.

Mr BEHRAKIS - Because they're scared too.

Ms MacDONALD - Yes, yes, they are scared too and people are also scared to disclose their full history in fear of whether or not they're going to be able to access treatment, which creates more problems.

CHAIR - I'd love to get your insights. First of all, thank you for sharing not only your own personal experience, but for the work that Health Consumers Tas has done in collecting such meaningful experiences of Tasmanian health consumers. The committee has heard from multiple hearings about the restrictions around prescribing. We will be hearing later at a different hearing from the Health department around some of those issues, but there aren't the same restrictions around other drugs of addiction as there are around the stimulant medications that treat ADHD, so we're hearing a lot about those barriers. I wondered if you had one or two pertinent messages that you would want the system, for want of a better word, to hear around the experience of consumers navigating that pathway with their healthcare providers, what that might be?

Ms MacDONALD - Look, there's a lot of people who don't know how it works, including health practitioners. I think that that's a big part of the problem. From our perspective as an organisation, and myself personally, consumers don't want to risk safety. They want access, but they're not interested in risking safety either. So, I think for us, it's the capacity of and the knowledge of primary care providers in understanding how this works because the barriers in what is now, for most people, a co-prescribing model, are immense. I hear from people all the time, and my own experience was my very trusted GP did not feel comfortable in this space at all.

So, I think there's a lot of opportunity there, but I also think that the very restrictive way in which you can get the medication dispensed is really problematic. Particularly if you have a patient - there's so many different circumstances that we could use as an example, but yes, the daily prescribing, there's all sorts of problems, but even in the regular schedule, like for myself, going every 29 days, I'm not always there, and my prescription has to stay with the same pharmacy. To be able to actually be in Launceston at that pharmacy -

CHAIR - You're in a busy job, too, that requires travel, like a lot of people would be. It's almost like there is an expectation of drug diversion or misuse with those restrictive prescribing situations.

Ms MacDONALD - I believe that if there was, I don't know if it's a function of the prescribing system. Even if there was flexibility around not picking up too many prescriptions in your time period, you have your scripts for six months, but to be able to go five days before and not have to go through - you have to try to talk to the same pharmacist. There's a lot of nervousness even in that space, when you say, I need to come two days earlier because I'll be somewhere else.

Mr BEHRAKIS - The automatic tendency is to assume that you're trying to get a double prescription.

CHAIR - It's an unfair misassumption.

Ms MacDONALD - Yes. I just want to check my emails, you know what I mean? There's nothing dodgy happening here.

Mr BEHRAKIS - Also get to committee meetings on time.

CHAIR - That's right. I mean, you are in Hobart today. What if today was day 29 and you could not be at the pharmacy in Launceston? It means you're not able to access what you need when you need it.

Ms MacDONALD - Yes, and some pharmacies are closed on Sundays, and I know that many pharmacists, I'm sure, will be very much across this and have these sorts of flexible arrangements. You're having to go down these paths and continuously ask for that and justify your life and what you are doing.

CHAIR - Like I said, the committee is aware of the necessity for some restrictions around drugs of addiction, but those same restrictions don't exist around a whole lot of other drugs of addiction, including the pick-up schedules, the co-prescribing rules. It is a frustration that we're hearing from a lot of people who are sharing their stories with the committee.

Mr BEHRAKIS - The fact that it's one of those drugs of addiction, people that need them sit through the day wondering if they remembered to take them.

Ms JOHNSTON - Thank you very much for the submission and the powerful inclusion of lived experience for us. It's something that we've heard a lot, particularly when you touched on, in the beginning, assessment and the difficulty and your experience as someone who has quite a lot of privilege, great health literacy, that kind of thing.

We are hearing a lot, particularly from families trying to access assessment for children, the long wait list for accessing a paediatrician in Tasmania. You highlighted that with a quote from one of the consumers from Hobart of a three-year wait to access a paediatrician. Can you talk to us a bit more about what that means for parents who might not have the same level of privilege or health literacy or access to services? What it means for them and their child, particularly in their early years where early diagnosis is so important to have the best chance of success at school and entry into school, and what you're hearing from consumers about their frustrations? Are people giving up?

Ms MacDONALD - People are incredibly resilient in a lot of ways, but it is understandable when some will. It has wide-ranging impacts on families. I probably can't speak to it as well as some others might be able to, but from our knowledge, access to diagnosis for kids is the most difficult for people. I have heard that, for some, access has been a little bit easier more recently than what it has been in the past, but I don't know if that's a certain situation with certain families. A lot of the time, I guess, some people can be quite anti-diagnosis, but I think having a diagnosis is just so important for kids and families to be able to access the support that they actually need, because often you can't get it unless you have the piece of paper. I believe it's incredibly problematic.

The other thing is, more broadly if we're looking at diagnosis and what's happening for me, it's ADHD, but it's also, more broadly, that child might not have ADHD. There could be something completely different going on, but I guess that child and that family's whole wellbeing and health, the fact that kids aren't able to obtain an assessment from a specialist around whatever that could be is really concerning.

Mr BEHRAKIS - I have questions for days, but I don't want to dominate. On accessing GPs and accessing specialists, and for some people there is an aversion to paediatricians, GPs, some psychs. There are very few that do, and then there are a lot that very specifically don't want to go near it. You mentioned there are some preconceptions in the community about ADHD which can make it harder. That's in the public, but it exists in the medical sector as well.

I don't know if I'd be necessarily talking about forcing medical practitioners to provide models of care they might not be comfortable with, but would it benefit people like yourself, people who come to your organisation, even if there was a website that said, 'These are the GPs who you can go to, these are the psychs who you can go to'. An ADHD-friendly sort of GP, so you know that this GP is comfortable- you know if you go there, they're not going to turn you away because of whatever aversion they have to dealing with it. You don't want to be turned away, and at the same time, GPs or other medical practitioners might have this fear of accidentally diagnosing someone who shouldn't have been diagnosed and then they're in trouble with the PSB, or what have you. Maybe that's why they're not wanting to go near it.

Is there perhaps a benefit in having somewhere where someone who thinks they have ADHD might go, 'Where do I go? Who do I talk to?' Go to anyone on that list and you'll be looked after.

Ms MacDONALD - Yes. Firstly, I believe that all GPs really should be across this. If you give them the opportunity to have the capacity to be across what's happening in the space, as with any other health condition, that could be really useful. I also think there's immense capacity even within the community themselves, lots of community members are having these conversations amongst ourselves. That could be really useful, in a similar way to how that happened with queer-friendly specialists and doctors.

CHAIR - Yes, that's what came to my mind as well.

Ms MacDONALD - I believe that could be a really positive thing. As well, consumers love it when we go to a health practitioner that we know has a lived experience. Opening the door - which is probably a bit beyond the work of this committee - in terms of health practitioners, being safer for them to disclose different health conditions or disability is really important. It's often not something that happens, due to discrimination that exists in those spaces. That is something that's really important. It is a bit of a different experience when you see a health practitioner who understands what it's like.

The GP that I saw, who I adore, just didn't really have a very good understanding. They said some things, for example, 'Medication isn't the be-all and end-all', comments like that, where I thought, I'd been seeing a psychologist for a couple of years about this and had seen a psychiatrist, and there was a recommendation there. That ability to build knowledge and have an understanding, and even if you have a personal perspective on it, to keep it on the inside.

CHAIR - One of the things that we've heard from people who've presented to the committee is - territorialism is not the right word - but one of the frustrations that we've heard, particularly from psychologists, is obviously they can make the initial assessment but not the diagnosis. Someone needs to then go to a paediatrician or a psychiatrist for the diagnosis, and sometimes there's some pushback. My daughter's in that exact situation right now. Equally, at the GP end, there could be a disconnect between three medical professionals who, for want of a better word, need to agree, for the benefit of patient wellbeing. Do you have any insights from the members who have shared stories with you about that?

Because it also feeds into the cost barrier, the access barrier, when we know that, right now, you need that appointment with a psychiatrist or paediatrician to confirm diagnosis and if they disagree with what the psychologist says, then it exacerbates the problem for those patients and families. Do you have any insights into those communications between different layers of medical professionals?

Ms MacDONALD - I really strongly believe that actually listening to patients is probably the best way. I think that there's different vested interests from the different professions and different opinions, but I think at the end of the day, if that clinician is actually focused on that patient and what they're telling them and what they need, then everything is a bit easier.

CHAIR - We're in a bit of a rush, sorry. I want to ask one more that really has come to mind after what you just said. From a Health Consumers Tas organisational perspective, what would you like the committee to hear about, one, the importance of consumer voices being heard in system improvements in the healthcare system, but two, how best to embed those consumer voices in a way that's meaningful and does actually inform systemic change from a consumer experience perspective?

Ms MacDONALD - Now, I could be the one that will go on all day. Look, I think that there's just immense opportunity in really embedding consumer perspectives across all levels of health, including in areas where people don't really think that it is necessary. And, I think that the issues around different vested interests from different practitioners, the consumer perspective is the one that's focused on what patients want and need and is really important.

In terms of this work in particular, there's a lot of opportunity to include people with lived experience and consumers in looking at what the recommendations are. I think there's the review of the *Poisons Act* this year. I think that having consumer voices in there will be essential because we can listen to people, we can consult, and come away with what we think the solutions are. Sometimes they're quite different from what we've sort of assumed and, even if we have a fair idea, having consumers involved at every point means that it's collaborative and that it's going to hit the mark. Because, sometimes it's quite easy to get stuck in very clinical places, which don't recognise, I guess, that the consumer perspective might be quite different and doing that together means that you have both perspectives working together to get the best outcome.

Mr BEHRAKIS - Sometimes the consumer might have perspectives but not have information that medical professionals may have as to why things are the way that they are. But, at the same time, the flip side is often true, where people can look at it from a very bureaucratic or very, like you said, clinical perspective and lose that connection to the actual outcomes on the ground that people are dealing with.

Ms MacDONALD - Yes, and I guess often what we find is that sometimes things are how they are because that's how they've always been. There's not been the opportunity to open the box and say, 'How could this be different?' Sometimes the barriers aren't real ones. I think sometimes you can get really stuck in a system and in the way things are. So, yes, sometimes even just asking a question makes a big difference in how something ends up forming. So, yes, and, when consumers are doing work with health services in consumer representation roles, they understand that there is that clinical knowledge and perspective that comes into things and then there's their expertise as a consumer, which is quite different.

Ms ROSOL - Thank you for your submission. I'm looking at the last point you raised, which is access barriers to health services more broadly than just for ADHD diagnosis and treatment. That hasn't come up much in other submissions and from other people we've heard from. I'm wondering if you can expand on that because that seems to be a fairly significant part of the stigma that people with ADHD live with. Is there more that you can share on that?

Ms MacDONALD - For sure. We did hear from a few people talking about - and I guess what we were talking about before about the complexity of the system that's meant to support us, that is not made for our brains often - but yes, there are a lot of layers to that. There's a lot of misunderstanding in terms of the need to be - look, honestly, it's just seeing people for people rather than making assumptions about why things are how they are, or even things like the judgment around losing your blood's form. I'm like, can I just not get that on my phone? And there is judgment experience going to different health practitioners. And you have people who need the blood's form, but don't want to go back because they know that they're going to get the eye roll. This is important and we know it's important, it's not recognising that there's executive dysfunction happening. It's not on purpose. It's not because someone's lazy.

Mr BEHRAKIS - It's the reason why you’re here asking for help in the first place.

Ms MacDONALD - Exactly. Yes. And I think that that can be quite difficult. But yes, the judgment about - I think there's one example around dental.

CHAIR - That was a shocking quote. That's a really heartbreaking story.

Ms MacDONALD - I think that experiencing that stigma becomes the barrier to accessing health services when you are just anticipating that and don't want to experience it again.

Ms ROSOL - You talked earlier about how ideally all health professionals would have some knowledge about ADHD, and that's what we're talking about here, isn't it? That need for that broad knowledge of the impacts.

Ms MacDONALD - Yes, and to not come from a place of judgment about why someone might do something or not do something, or have capacity for something or not.

Mr BEHRAKIS - It's one of those things where, if you're talking about very, very niche conditions, you might forgive medical practitioners for not being fully up to date on it, but we're talking about something - last I checked it is one in 20 people. It's a lot of people. It's not exactly a niche rare condition that you forgive someone for not knowing at least a little bit about it.

You mentioned earlier the issue about you might have multiple contact points of medical professional, GPs, psychologists, and the patient really needing them to all be on the same side for them to actually get any progress. Is that something - especially when you have different medical practitioners with varying levels of understanding about it - something like what AADPA (Australasian ADHD Professionals Association) has suggested as far as having a clinical model for assessment and treatment like an algorithm that everyone can say is a Tasmanian, or preferably the Australian, procedure? It's clear, people can look it up and there is some understanding that if five people go through the process they're going to have the same experience, rather than it really depending on the characters you're engaging with and having very, very different experiences.

Ms MacDONALD - Yes. I think having a defined pathway is really useful and dealing with some of the cross-jurisdictional issues is also important, particularly in this space. I think, however that looks though, it is important to have - I think in my experience, and it's not the same as everyone else's, but the psychologist that I've seen has been the person that knows me best around this and has been the support around managing things and my source of trust, I guess. And the psychiatrist is the person who has to tick the box and go through the assessment and all that sort of thing.

But, I think having a really good robust system around it is important because there is risk around misdiagnosis, if those parameters aren't at play. I would be really interested in some of the different models that are being talked about at the moment, and how - I guess just looking at the risk and patient safety and balancing access. I guess it's that information access about what the pathway is and understanding that, for sure.

I feel like some of the psychiatrists' clinics are trying to create that through what I talked about at the beginning around these different pathways and things, but yes, the support side of it is important to talk about.

Mr BEHRAKIS - I think we all know that misdiagnosis, whether it's diagnosing people who have something else or not diagnosing people who should be, is not a good outcome. Is part of - and maybe I'm asking the wrong person - but, part of the reluctance from a lot of medical professionals to even be willing to engage in that space is a fear of getting it wrong and being seen as having done a wrong thing in the eyes of whichever regulatory authority, like if you diagnose and prescribe someone who turned out not to need it, then you have assisted in drug-seeking behaviour and what have you. Is there a danger in putting medical professionals in a situation where they're scared to potentially be wrong, so they just take the least risky option?

Ms MacDONALD - Look, I think in the context that we're currently working in, I don't believe that that's a problem because the psychiatrists are the only ones who can do the diagnosing and the initial prescribing. In my experience, and the experience of other people who I've talked to, the reluctance comes from a lack of confidence that GPs may or may not have, in that they're doing the right thing in terms of medications. So, I don't think there's - yes, there is a bit of stigma and a bit of misunderstanding, but yes, I think it's actually having the confidence to know that if they are adjusting the dose, they feel confident in what they're doing and that they aren't going to do the wrong thing, and that they're doing what's best for the patient.

Mr BEHRAKIS - So, it's not so much a fear of the regulatory system, it's just a fear of the doctors wanting to do the right thing for the patient?

Ms MacDONALD - Yes, and maybe a misunderstanding of the system and what they can do and what they can't do.

CHAIR - A friend of mine whose teenage child has ADHD and is well treated - they live in another state though - described it to me like tuning a radio, in terms of getting the meds right. I thought that was such an illustrative description because it could be the right medication, wrong dose, it could be the wrong medication. And one of the barriers that we've heard from consumers who have presented to the committee is that stigma around why - if a doctor prescribed you the wrong amount or wrong kind of antidepressants or heart medications, it's very easy to adjust that dose and prescribe something different that might work better for that patient. But, one of the barriers that we've heard from patients accessing stimulant medication is going back to get reapproved to adjust medications sometimes ends up, potentially, leading to the misconception that there's something amiss here, there's something going wrong, this is an attempt to do the wrong thing, rather than seeing it from that medical perspective of the practitioner trying to get the medication right for their patient. Have you had any experience of that through the organisation or others you've heard from who have had that experience in trying to get meds adjusted?

Ms MacDONALD - Not necessarily. I guess there's that reluctance, even sometimes when there's the letter that says, 'You can go up to this dose,' from the psychiatrist to the GP in making the adjustments. I probably haven't heard that necessarily, but yes, I can imagine it exists for sure.

CHAIR - Miriam, I don't want you to miss out online. I don't want to skip over you. Do you have anything you'd like to raise?

Mrs BESWICK - Thank you, Chair. No, I've been enjoying the conversation. Thank you so much for coming in. I have just had a bit of patchiness in terms of the internet dropping in and out. It has been really interesting and thank you for your time today.

Ms MacDONALD - Thanks.

CHAIR - We've really just gone to time. I feel like all of us could talk to you all morning.

Mr BEHRAKIS - I have another two hours worth of questions.

CHAIR - On that note, please don't hesitate to stay in touch with the committee. If you leave today and think, 'Oh, there was so much more I wanted to raise,' please get back in touch with us individually or through our secretary, Michael. We would be very keen and eager to hear further from you or if individual people involved with Health Consumers Tas want to share information with us, we are open to that as well. Thank you for attending.

Mr BEHRAKIS - Thanks so much for coming and speaking to us.

THE WITNESS WITHDREW.

The Committee suspended from 10.44 a.m. to 11.02 a.m.

CHAIR - Good morning and welcome to today's hearing of the Parliamentary Inquiry into the Assessment and Treatment of ADHD and Support Services in Tasmania. Thank you very much for giving us your time to appear today before the committee, but also thank you for taking the time to provide such a detailed written submission, which we've all received and have read. Could I ask for you first just to state your name, please, and the capacity in which you are appearing before the committee?

Mr ANDERSON - My name is Chris Anderson. I'm just a citizen who was diagnosed with adult ADHD last year at age 39 and we've also been pursuing a diagnosis for our daughter and potentially for our son, as well, just with some of the struggles that we've had with that.

CHAIR - Yes, we're looking forward to hearing more - well, that's not the right word, but we're keen to hear more about those struggles. Can I confirm that you've received and read the guide sent to you by the committee secretary?

Mr ANDERSON - Yes.

CHAIR - Thank you. I'll just remind you that the hearing is covered by what's called parliamentary privilege. What that means is that you're free to speak to us in any way you wish, you can share any information with us that you want the committee to hear without fear of being sued or questioned in any court or place outside of parliament. The only exception to that is the protection doesn't accord to statements you might make that could be considered defamatory if you repeat them outside of these parliamentary proceedings.

The hearing is a public hearing. There's no members of the public in the gallery right now, but it is a public session and there could be members of the public or media that attend today and, indeed, be watching the broadcast online. I'll just introduce the committee to you. My name is Ella Haddad, I'm a member for Clark and the Chair of the committee; across the table from me, we have Simon Behrakis, who is also a member for Clark; next to him is Cecily Rosol, who is member for Bass; next to me is Kristie Johnston, who is a fellow member for Clark, so you have three Clark members here; and online you can see there, Miriam Beswick, who's one of your local members in Braddon, so you have all political parties and all parts of the state represented on this committee. So, it's very much apolitical and we're keen just to hear from people's experiences.

Mr CHRIS ANDERSON WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - We have also agreed just to read a short sensitive content statement into the record at the beginning of each session for people who might be watching online, for people participating, or for people accessing the transcript later. As a committee, we recognise that during these hearings we may discuss highly sensitive matters and themes that have deeply impacted the lives of Tasmanians, which could be a trigger or distressing for individuals listening to or participating in these proceedings and the committee encourages anybody impacted in that way to contact organisations including Lifeline on 1800 984 434 or 131 114, ADHD Foundation Helpline on 1300 393 919 or Kids Helpline on 1800 551 800.

That is all of the formalities dealt with. We would love to invite you, if you would like to, start with an opening statement and then we can move into more of a conversation.

Mr ANDERSON - Good morning, everyone. Thank you for the opportunity to be able to present to you and to give you some further understanding based on my written submission, but also a few updates on just how our lives have been impacted knowingly and unknowingly by all of this.

As I mentioned previously, apologies for my voice, I've been a little bit unwell this week, but hopefully will make it through.

I would like to specifically thank Mr Behrakis for his diagnosis and his willingness to open up about it and to be able to push for this inquiry to find how big a problem it is across Tasmania, and to look at ways that we can improve all of these things. That is something I did not know I needed until last year, but the timing has been incredibly helpful and fortuitous. I hope you have been able to get a deeper understanding of everything and to also be able to process the wide range of emotions that a diagnosis can bring. As I have been living through that, I know there are a lot of emotions that get brought up with it. Thank you for the opportunity.

CHAIR - Thank you very much. I might start with an opening question before opening it up to the rest of the committee. You have referred in your written submission a couple of times to the positive impact of being able to access services and receive that diagnosis. I really loved your statement that said, when describing your diagnosis to people, you have likened it to being 'stuck in a library all my life, but finally found the section that you need for all my answers'. I know we will get into the barriers to receiving treatment and diagnosis, but I just wondered if you would like to reflect on what sounds like a profound beneficial change for you since you have been able to access treatment and diagnosis.

Mr ANDERSON - I have always felt different and I could never figure out why. I struggled making friends in school and all sorts of things, and it would just seem to be so many different conflictions in my mind. I would like to think I was of reasonable intelligence, but I felt like I was pretty dumb because I couldn't do basic things. Having this and just being able to search for things based from an ADHD perspective, I found things just made so much more sense to me. And, it has enabled me to find what my limitations are, find areas in my life that I need to work on, and it's not just because I'm dumb, it's because there's a medical reason that I can't organise myself or things like that.

It has helped me to be able to forgive myself a lot more for things and to be able to research and feel a lot better in my life and a lot more comfortable, knowing that there are a lot more people out there. I've been able to self-diagnose some friends and they've been able to get diagnosed and they report the same things now. I really want to be able to help people to be able to get through that.

Mr BEHRAKIS - I have a couple questions on the same sort of topic. Thank you for agreeing and for contributing. It is very helpful for all of this and to help make that case. I think it is important to get it out there and on the record, so people know. As far as - and a lot of this I can relate to - what it was like before, in the sense of before you even knew that you may have ADHD and going through a life like that, and before you were treated, how did it feel just knowing what it was, rather than thinking, like you said, 'Am I dumb?' What effect did it have just knowing?

Mr ANDERSON - It helped me feel a lot more in control of things. My diagnosis came as AuDHD, which is autistic and ADHD, which, up until about 10 years ago it wasn't even known that the two could coexist. It explained a lot of the conflicting things in my mind. My mind's just always been hyperactive, overactive, all the time, always thinking, can never rest, can never take a break. Up until last year, I thought that was normal. I felt different, but I also felt like I was completely normal to everybody else. Finding out that there's certain traits of mine that are from the autistic side, then others that are the ADHD side, and then others from other bits and pieces that are associated with it.

One example that I've seen is autistic Chris: he needs routine, he loves structure, he needs routine, he needs everything to be right because if things are out of place, then there are problems in his mind and it's just going to go bad. ADHD Chris cannot for the life of him create a routine or a structure that he's proud of and he's happy with. Those two conflict -

CHAIR - That's such a great description.

Mr ANDERSON - Then we throw in another one - which I haven't had proper diagnosis with, but reading up with things it makes perfect sense - which is oppositional defiant disorder, reading up about that one. It's one that I've actually turned into something that I can work with, well, work is a quiz, toast, and things. It's a tough one. That one is where someone will make a helpful suggestion and say something like, 'Well, why don't you try it this way?' and, the way that I should take that advice is, 'Hey that's really great advice, I'll try to put it into practice'. Whereas, in my mind it actually goes, 'Well, I don't want to do it that way now. I wanted to, but I'm not going to because you suggested it'.

Mr BEHRAKIS - Yes, I was going to do it that way and now you told me to, I'm not going to do it.

Mr ANDERSON - Yes. Finding out there are all those at play, having awareness of that means you can work towards it, work towards overcoming it.

Mr BEHRAKIS - I'll pass on after this because I'll go onto other topics after, but two questions. One, and I think Ella asked about it as well, is what it felt like when you did finally get that treatment, and how that's changed your life. I had a reaction to one of the paragraphs you have in here about:

> The way I would describe to people the way I was living would be by every day trying to give 100% to work, 100% to my wife, 100% to my kids and 100% to myself and I would still always feel like I was drowning or not doing enough and beating myself up constantly

That paragraph there, and talking about people - and you mentioned your brain being hyperactive all the time. I think one of the misconceptions that people have with ADHD is that it's that kid bouncing off the walls in the classroom. Hyperactivity isn't necessarily that. It can be being exhausted because you can't switch your brain off. It can present in ways that are not intuitive for someone who's not going through that. Can you speak a little bit about that and then how that's changed after you've been able to get treatment?

Mr ANDERSON - It hasn't changed enough, as much as I'd like. But again, there's awareness of it. I think there are a lot of things. One of the things that happened as a kid that

I just wanted to get away from, because I wasn't interested in doing a lot of things, like when Mum and Dad wanted to go out and do stuff in the garden, we had to go and do those. I wasn't interested and I couldn't even fake interest, just couldn't do anything. There was a perception of being lazy. Different things like that, always being a nuisance, being annoying, upsetting people.

Then, later on in life, as I've grown up, I've turned into a people pleaser and I'm just way too far with that. So, I will give absolutely everything to try to make everyone happy. I'll be constantly trying to work out people's emotions, to work out if they're upset with me, or what I can do to try to help them to make their day better, taking on all their problems because – I don't know, I've still got some free brain capacity with my own, so, why not take theirs on as well? And there was just never any respite from that.

It probably didn't really become an issue until after we got kids. Our oldest is 10 years old. That was a bit of a struggle before that. We went through IVF with all of that as well. So, just years and years and years of increased brain capacity and so much going on. Eventually, it just all came to a head and it got to the point that I could function enough to go to work every day. I could do my job and do the things I have to do, but for every other time, I'd just be on the couch, I just had nothing, couldn't do anything around the house - I just had nothing left. When I'm trying to help out my wife and help with the kids, and do all that sort of thing, it was just hard and really heartbreaking. Then, when you have kids who are hyperactive, and they needed help as much me, it broke me.

It was really hard being in that position. We did find ways through. We found that watching sport on TV actually worked. For my son, that worked for him because he could watch the numbers, he could do his maths and he could work things out and he did research about all the different teams and different things around. But, for my daughter, it actually calmed her brain down. Both of us would sit on the couch and we could watch things and actually feel like a real family because we could enjoy stuff without everyone being aggro at each other. It's been a tough few years.

CHAIR - Yes, I'm sorry and thank you for sharing such deeply personal information with the committee. Like I said, we acknowledge that it is hard to share such personal information and it really is to the benefit of Tasmanians and this committee's work that you're able to do that. Thank you, very much.

Miriam on the screen, do you have any comments or questions?

Mrs BESWICK - Chris and I talk regularly. What brought it to head, Chris? How did you go about finding out this diagnosis and what were the barriers along the way?

Mr ANDERSON - My main role is as an IT technician - working with computers. Again, it was something that I never worked out what I wanted to do when I grew up. I loved computers, and I just ended up in computers because until I figure out what I want to do when I grow up because I couldn't make a decision. Now it's been over 20 years, I think I'm stuck here. One of my other roles is I do trivia nights, so I do pub trivia nights and that's been really great for me because I love the social side and I found out that it's actually really beneficial as an ADHD person. That's actually one of the real strengths is having the ADHD with it, but I also meet some great people.

One of the people one night I was talking to her and she'd just been diagnosed and I was explaining about how exhausted I was and everything else that was going on. She put me in touch with where she just had a diagnosis, and I thought, 'Well, ADHD, hyperactivity, I'm talking about how tired I am all the time, like, how wrong can you be?' But once I started reading, then it all made sense. Then the impulsivity kicked in as well, where right within one night I've already decided right, 'This is it, I've got to have it. I want it straightaway.' I pursued the diagnosis there and everything just started to make sense.

Mrs BESWICK - Did you go through someone in Tasmania?

Mr ANDERSON - No, I went for this place that was in Sydney. I didn't really look too hard around Tasmania, I'll admit that, because again, impulsivity. However, I do think that it is harder in Tasmania. We went for a doctor in Sydney, who was really great.

The practice themselves was understanding. They emailed and said, 'Yes, we know that people suffering from ADHD struggle with paperwork.' They were quite understanding with all that sort of thing. I had to get my parents to fill out forms as well, just to show that I had indications of it as a child. Then I had a meeting - it was about a year ago a week ago. I had a meeting and I was very nervous because I was expecting I was going to be hammered with questions and didn't think I was going to be believed and all this sort of stuff. However, the guy was really great, really helpful, straight away. That was a really good experience. Then, unfortunately, it's just been much harder with children, with a child. That's probably the most important one.

CHAIR - Do you want to expand a little bit about that barrier to access for your kids?

Mr ANDERSON - Yes. I'll talk about our son first, because we haven't really pursued much with him. We've gone a couple of times for checking out whether he's ASD, so the autism side of things, because he's very gifted, very intelligent with different things, but also struggles a lot with emotions and anxiety. Even just toileting, he's 10 years old now, and for years we had problems where he would not go to the toilet unless it was a white toilet and a white toilet seat. Until you encounter situations like that as a parent, you never know how hard it is to find those sorts of things. Just having to control his emotions and regulations and hyper focused topics and everything.

He's doing really well now, but it's our daughter who's been the biggest challenge. We've been looking for about 18 months now for a diagnosis for her. We've been suspecting things for years, but it's been tough. We've looked around Tasmania several times, and we've had to go to Sydney. Last year, we went to Sydney in April and did some testing and obtained a provisional diagnosis of ADHD. That came through about June, from memory. We thought, great, that's the hard work done. Then we went looking for paediatricians here in Tasmania, and we haven't been able to find them. We've looked publicly and we've searched privately several times and no-one's taking on new people at the moment. That's been hard because the behaviour keeps getting worse and worse as the days go on.

We had an appointment late last year with a guy in Brisbane and, unfortunately, that one set us back even further. We had an appointment with him and it was really frustrating. It was Telehealth. I went in, my wife was nervous about it. She thought that it was going to be like, I was going to defend it or we have to explain it, the way I was feeling about my meeting, whereas I thought no, this will be fine. We've done all the hard stuff, it'll be fine. Unfortunately, I was wrong and she was right. The doctor dismissed a lot of the things that I said and my experiences. He didn't believe it about her and, of course, she was really well behaved for the appointment. That would be great normally, but really tough with that one. He just spent the time yawning through the appointment and, in the end, he just suggested melatonin to help her sleep and we should do parenting classes.

CHAIR - Was that a paediatrician, Chris?

Mr ANDERSON - Yes, I believe it was. That was just really hard. We stuck with it for a bit, and then we were due to have an appointment just after Christmas last year and he stuffed us around with appointments there.

We just had to make the decision that it was not working out. We begged our GP, and our daughter's been seeing a child psychologist here in Devonport as well. We have an appointment with the place where we had the testing done. It's a paediatrician appointment in Sydney at the beginning of March, so about a week away. We will be heading up to Sydney for that one, where hopefully we'll be able to get some answers. They prefer not to do it that way, because of the restrictions across the state borders with all the different medications and everything, but they understand that we're struggling and how hard things are.

Cost wise, that's another $1500 that it's costing us. While we are in a position that my wife is really good with money, we're not rich. We are stable, which is good, so we can afford to do these sorts of things. Whereas if I was - well, I've already been sacked from the finances because of my splurge spending. We probably wouldn't have been able to do it otherwise.

There was another point I was going to have with it as well.

CHAIR - That's coming up for two years that you've been trying to access that treatment for your daughter?

Mr ANDERSON - Yes, it would be coming close to two years.

Mr BEHRAKIS - You haven't reached the end of that road yet?

Mr ANDERSON - No. When we rang up about Christmas time, we were told that it was going to be years in the public system. That is hard, because - I detailed a lot of her behaviour in my submission - but even then, it's become worse in the last week. Every night that my wife has picked up our kids from school, she's had a complete meltdown. She's fine at school, but then she gets in the car and she starts throwing things, biting, having a tantrum. If you're not paying her enough attention - she called my wife an 'effing B' yesterday afternoon. We don't do that language around here, and it's heartbreaking when you get told that she hates you and things like that, when you know that it's not her talking, it's the brain talking, or she's just trying to get attention and things like that.

CHAIR - She is probably exhausted, too, from the day at school.

Mr ANDERSON - Yes, and it's just because she's been masking all day. Then she is also absolutely terrified. Yesterday, my wife pulled her over and said, 'Right, there's your teacher. I'm going to tell her what you just called me'. She immediately stopped and she was scared. She sat straight, because she is scared of the teachers. She is scared of school and getting in trouble there. I do understand that, because that related very well to my experience as a child. I was scared of getting in trouble at school and everywhere else, but at home it was okay and in Sunday school, at church, there were no consequences. I would get told off, but there I could go on and be a bit badly behaved.

Ms ROSOL - Hi, Chris. Thank you for sharing and for your submission. I was reading in there some of your journey regarding medication and some of your experience with that. I was wondering if you had anything that you wanted to expand on there about your experience with accessing medication and what that's been like.

Mr ANDERSON - For me, accessing the medication's been good, but there are challenges with it and I understand why there are challenges with it. It was good in terms of, I got the diagnosis from up in Sydney, then he passed it back to my GP in Latrobe, and my GP was able to then, applied to be able to dispense the medication to me with the government. He organised to make sure that I had all the appropriate tests, because it can cause heart issues and things like that. He made sure that my body was going to handle it all. He has been really great with all that side of things. It is a bit different than going to your shop and getting paracetamol, regarding the restrictions, but I understand why they're there. The pharmacy that we go to, they keep the prescription and they also make sure that they're on top of when I get it.

The other week, I was running low on the medication and trying to be organised. My wife was going out and I said, 'Can you go and pick up the next script?' It was about three or four days early, and they said, 'No, it's too early, we can't give it to you yet.' I believe there's about a two-day period. That's good that they're onto all that sort of thing. I do know there are stories around of reasons why it needs to be kept that way. Some people do sell the medication on the streets and things like that. I don't know what can be done to ease that process but also keep things secure and keep it from getting in the wrong hands.

Ms ROSOL - I was reading that you said that after a while, the effects started to be less noticeable for you. I wondered if there had been any changes to your script and if there had been a process around that at all?

Mr ANDERSON - I did initial ramping up with my scripts. I think I could potentially ramp up more. Also, there are days where I do start to question and go, 'Is it still working?' Then as soon as it runs out, the brain just gets filled more and it's just more chaos, and everything seems like it's too big, and the anxiety comes back and I go, 'Okay, obviously it is working'. I had a day last week where, mid-afternoon, around 3.00 p.m., all of a sudden I was really tired and really struggling with everything. I was just talking to someone, and it's just been a really busy period, working in a school and back to school time and everything. Then I realised my medication had run out about four hours ago. I went and had another dose and sure enough, I was fine for the last 20 minutes of the day. So, I do recognise that it is still working and having a great effect.

One thing I noticed, though - I'm on antidepressants as well - they help with the depression and the anxiety, then this other stuff with the ADHD. I feel like when I start the day now, I'm on par with other people. Before, I would be stressed and anxious and I could bite someone's head off just because they said good morning to me. I felt always at that elevated level of stress where anything would break me. Now, I feel like, 'Okay, I can actually achieve things today, I can take things on, I can plan a bit.' I'm not ready to lose it at nothing. Having that level of control and emotional regulation is a huge win for each day.

Ms ROSOL - Thank you for sharing.

Mr ANDERSON - Thank you.

Mr BEHRAKIS - Thank you. You mentioned earlier, talking about your daughter, you said that was another $1500. Like you said, you're not at the end of that road yet. How much has it cost to date? With your daughter, just for the one person so far.

Mr ANDERSON - I'm not sure exactly, but we'd probably be looking at about $5000 for everything all up so far, over a couple of years. It's reasonably significant.

Mr BEHRAKIS - I was similar - it wasn't $5000 for me but, as you said, you're in a position where you're able to pay for those costs. It's still a lot of money. For a lot of people that can be the difference between, do I pay for mine or my kids' medical expenses to get treated or do we pay the rent?

Mr ANDERSON - Yes. I'm not sure whether we've had things that have been covered by private health insurance, because we do have private health insurance. There is Medicare for some things. I know that a lot of the time Medicare covers a lot of our psychologist appointments and things like that, which is great, but things are expensive, especially when you're in regional Tasmania.

So, our airport, Devonport Airport, only has flights to Melbourne and they're quite expensive compared to the other airports, so we have to go to Launceston. So, you're adding on a tank of petrol, flights, accommodation for things and it can all add up. I do know of a family down here now where they're struggling with similar things and we've been helping them through with getting appointments and stuff for their children. But the dad is recognising that he needs help as well with things, but they simply can't afford to pursue a diagnosis for him. That's really hard because I know that things would benefit him greatly and his mental health and everything but he's got to put his children first, before him, and it's a tough decision.

Mr BEHRAKIS - And how much harder is it being in a regional area?

Mr ANDERSON - It kind of is a lot of the time for all sorts of things, like, you get used to 'Oh, I've got appointments,' so you go to Launceston or Hobart and things. I mean, Devonport or Burnie aren't too bad for things, but I can imagine that for people down the west coast - Queenstown, those sort of areas - things will be hard. And then, when you do have to go to the mainland for different things, we don't have the cheap airfares that Hobart gets and the big sales and things like that. So, you do have to pay a premium at times.

Mr BEHRAKIS - There's a lot in here where it almost sounds like you're telling my story, in some of these parts, but one thing - and we heard from a lot of people that, as you said, there are people who just have ADHD, which as far as I understand, is me, and there are a lot of people who have comorbidities - and autism and ADHD is a very common one. We've heard that. Can you talk about how that extra thing, what that experience is like, having that comorbidity and how it interacts with your ADHD? How it affects the treatment and everything else?

Mr ANDERSON - Effectively, it means that, often, nothing gets done because you got one side of the brain that wants to do this and the other side that just counteracts it. It's just this ongoing struggle and you're just like, yeah. It's crippling and you just go, 'Let me know what you want me to do when you sort yourselves out,' and you just sit on the couch and don't get anything done.

So, it's really having that awareness, again, that that exists and that's not normal that helps you to be able to go through things. I've just finished reading a book, which is actually a really big thing for me too, because, I don't know whether you can relate to this, but for me, reading a book was one of the hardest things to do because it was either not stimulating enough, so it would put me to sleep, or it was too frustrating because if I was reading, my mind would be wandering constantly and I have to keep rereading different pieces and I just give up because I just end up too frustrated.

Mr BEHRAKIS - I either had that or I had a hyperfocus to read the whole thing in one night. That was my experience.

Mr ANDERSON - Yes. That's how I wrote essays in college and everything.

Mr BEHRAKIS - The night before it was due.

Mr ANDERSON - Yes, that's the best time. Seeing in this book, just how much it can affect things. So, I think it's with the autism side of things that, often comorbidities are things like dyslexia, dyscalculia, dysgraphia and dyspraxia, all those sorts of things, there are all those learning difficulties for kids there. Then on the ADHD side, you have the oppositional defiance disorder, the rejection sensitivity, depression and anxiety, increased risk of suicide, all sorts of different types of dysregulation, so emotional. I've got temperature dysregulation, executive dysfunction issue - so many different things all fighting and conflicting. And then finding out there's a whole bunch of other things like addictions, eating disorders, impulsivity, splurge spending, all these things that I thought they're just not good things that I've got, but actually did find that they all related back to this central thing.

One of the things I think is really hard is for people trying to pursue a diagnosis. These are the people who might not have the money because they just don't have good financial literacy. But also, they have poor executive functioning, so they struggle with filling out forms and we're wanting them to do all these things and to actually keep on top of pursuing these appointments, making appointments. They've probably got anxiety with ringing up on the phone to book appointments. They don't want to upset people by appearing to be needy, all these sorts of things. So, all these things going against people that they're just not going to be able to for sure diagnosis because it's too hard and why should I bother and all that sort of stuff.

So, it's really tough because there's so much that goes against people and our brains can be our own worst enemy for us because of all this conflicting stuff. I don't want to be seen as a difficult person. I was seen as annoying, I was seen as lazy, I was seen as all these other things as a kid and I don't want to do that anymore, so I don't want to draw attention to it. Then, I'll just go to a government committee and put myself completely out.

CHAIR - Chris, one of the things that we've heard as a theme through this committee from medical professionals is how common it is for there to be multiple conditions co-diagnosed with ADHD, as you've just described really clearly. In your experience with medical professionals, do you feel like there's been a good understanding of that complexity and the very common likelihood of there being multiple diagnoses for different conditions alongside ADHD?

Mr ANDERSON - I think it's getting better. Things are getting pretty good, but again, a lot of things have just changed in the last 10 years. It's just a matter of people getting up to speed with things. But, out in the general community, you've got that perception that, 'Oh it's just the naughty kid at school or the kid bouncing off the walls.' Whereas it seems that girls are highly affected by ADHD, but they're just not found out because they manage to mask it better and then it just becomes internalised, which is where you just get all the struggles inside the head.

Also, at the moment you hear from some people, 'Every man and their dog is getting diagnosed with ADHD these days. It's just the new cool thing to do' and, 'We don't need labels,' and things like that. It's just really hard with those because you're saying, 'Well, no, it's just because we understand now, what it is.' So, it's a matter of playing catch up and trying to diagnose all these people. And I can see where people are coming from with the 'We don't need labels,' I'd like to think they're all the same.

Mr BEHRAKIS - You need the label if you're going to get the pharmacy to give you the medication that's going to help you. I couldn't care less about the label. I just need the treatment.

Mr ANDERSON - Yes, exactly. My wife could send me to the pantry and say, 'Look, get out the white powdery stuff from the pantry,' and that could be flour, which could be plain flour, or corn flour, it could be sugar, icing sugar - there's so many different white powdery things that are in there. I need labels to know which one she needs. There's lots of different things.

One thing that is really good these days is the schools. I feel like the schools have really improved with things. With the school that my children go to, I've got a teacher there who's a wellbeing teacher and she is absolutely brilliant. I would not be able to talk her up higher. She loves the kids, she looks after them, she pushes them, she works with their anxieties, and she just really gets the best out of them and understands them, and that's so good to see.

I remember back when I was at school, I remember about grade four or grade five, I was sick every morning. I was feeling really sick every morning, and it was just seen as me wanting to get out of school, it was me faking it and things like that. I remember getting laughed at because it was called 'Chris's morning sickness' sort of thing. It was really hard because I didn't want to miss school, but also I felt really sick. If I said that to anybody today, it would be simple to say, 'Oh, that was just anxiety'. But even 30 years ago, that wasn't really known about back then. There was nothing that could really be done. It was, 'Have some of this Rescue Remedy stuff,' or something like that. Now, there's a recognition of all those sorts of things. I know with my kids' school, my son was showing me the other day that there's a special chair in his classroom that kids can sit in if they need to and it blocks out a lot of the sound and sensory stuff in there. So, if you need a moment to realign yourselves and calm down. That's great.

People are understanding what sensory overwhelm is now. A lot of the schools have a special room where kids can go to now if they do need a bit of time out, if they need a bit of a chill space. They're not just getting sent to the principal because they're naughty and disruptive. That's good. Now working at a secondary school, working with learning enhancement, learning support teams there, I've seen the different learning plans that kids get these days. It's really great seeing all that stuff now that is being done for people. I think awareness would be a really great thing to get out there in the community for people.

CHAIR - Chris, I feel like we could keep asking you questions all morning, but we've reached the end of our time together.

Mr ANDERSON - I know, I just looked at the time, too.

CHAIR - Please stay in touch with us, though, either individually or through our secretary of the committee, Michael, who you've heard from. You might come out of today's session and think, 'There was this other thing I wanted to say,' that's very common, so please do stay in touch with the committee. We're really grateful for the information you've been able to provide to us, and we're happy to hear more from you as the committee continues its work, if you would like that.

Mr ANDERSON - Yes, I might actually send through my notes that I had for this.

Mr BEHRAKIS - Please do.

Mr ANDERSON - I'm sure there's plenty in there that I missed.

CHAIR - Thanks, Chris, it's been great to meet you and we're really grateful for your insights and experience. Thank you.

Mr ANDERSON - Thank you very much. Thank you for the opportunity. I hope it goes well with the rest of it and the report and everything, so we can see some change.

CHAIR - Thank you, Chris.

THE WITNESS WITHDREW.

The Committee suspended from 11.48 a.m. to 12.01 p.m.

CHAIR - Hello and welcome. Thank you for attending today's hearing of the Parliamentary Inquiry into the Assessment and Treatment of ADHD and Support Services in Tasmania. We're really grateful for you giving your time, your experience, and your expertise to the committee today.

Could I first ask you to state your name and the capacity in which you are appearing today?

Mr WYNANDS - Capacity in which I'm appearing?

CHAIR - Member of the public, I suppose. However you'd like to describe.

Mr WYNANDS - My name is Scott John Wynands, and I'm a member of the public with ADHD, or ADD - I prefer that.

CHAIR - That's fine. Could I confirm that you have received and read the guide sent to you by the committee secretary?

Mr WYNANDS - I have, yes.

CHAIR - I'll just remind you, you would have seen in the guide that in this hearing you are protected by what's called parliamentary privilege, which means you can speak freely. You can tell us whatever you want us to hear in whatever way you want us to hear it without fear of being sued or questioned in a court or any place outside of parliament. The only exception to that is if you make statements that could be considered defamatory and then refer to them outside of these proceedings, then that parliamentary privilege doesn't apply to you in that instance.

It is a public hearing. There's no members of the public here right now, but there might be people, including media, come in and out and, indeed, watching the webcast online.

I'll quickly introduce the committee; my name is Ella, I'm a member for Clark here in the south; Cecily is a member for Bass in Launceston, in the north; Simon is a member for Clark; Kristie is a member for Clark. You've got three members for Clark. Miriam Beswick is on screen, she's a member for Braddon in the north-west, and we have a couple of members away today - another member for Bass and a member for Franklin. You have all political parties and independents represented here, and every part of the state as well.

Mr SCOTT JOHN WYNANDS WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Thank you very much. We've also agreed, as a committee, to make a short sensitive content statement at the beginning of each session, since people are jumping in and offline and who might not have heard this support information until now. I'll quickly do that.

As a committee, we recognise that during these hearings we may discuss highly sensitive matters and themes that have deeply affected the lives of Tasmanians, which may be a trigger or be distressing for individuals listening to or participating in these proceedings. The committee encourages anyone impacted in this way to contact Lifeline on 13 11 14 or

1800 984 434, ADHD Foundation Helpline on 1300 39 39 19, or Kids Helpline on 1800 55 1800.

Additionally, we also have a breakout room next door that's available for you if you need it, if we want to take a break at any point or after today's hearing.

I should also have said at the outset that if, at some point during the evidence that you give to us today, you would prefer to give your information to us in private, that's an option available to you. Just make that request of the committee at the time. We have a short procedural thing that we need to do to agree to go into what's called an *in camera* hearing. At that time, you can provide us any information that you would like to in public, just recognising that people are sharing deeply personal information with the committee, and we're very grateful and acutely aware of that as a committee, that we're here to learn from your experience, but only in the way that is most comfortable for you to share that with us.

With those formalities completed, would you like to start with a general opening statement, or anything in particular that you'd like us to hear first up?

Mr WYNANDS - I was only diagnosed about four years ago, roughly. I didn't even really believe in it, to be honest. I didn't even think it was a thing. I grew up in the generation of 'kids just needed a good smack' or that kind of thing. It was very challenging, especially seeing as my father still doesn't believe in it. That's okay, that's his problem. Now, I want to help as many people as I can. That's my aim, to make people more aware and get more support out there.

CHAIR - What you've described is probably the experience of lots of people - that kind of historical cynicism or disbelief in ADHD being a true condition. You've come full circle now, to the point of diagnosis. Can you talk us through what that experience was like? How you came to be from probably ADHD - denial might not be the right word, but right through to actually recognising traits in yourself moving forward with diagnosis?

Mr WYNANDS - Certainly. As a child, I had a lot of childhood trauma. I have actually been seeing professionals since I was probably about five years old. No-one managed to pick up on it because I was a highly intelligent child and I was combination presenting. So, I was hyperactive at one stage, but then I'd be internalising and hyperfocusing on something and just leaving everyone alone.

I was diagnosed with depression and anxiety and - I know it's not an official thing - but C-PTSD (complex post-traumatic stress disorder). 'PTSD' will make it easier. I then worked through my trauma, and I was still suffering bad depression and anxiety, so I was a clinical diagnosed depression. I had meds, but they didn't really help or do anything. I saw a provisional psychologist, who asked me a very interesting question that I'd never even thought of. That was only in a four-year span, someone new that I was seeing. She said to me, 'I know this is a weird question, but have you ever tried speed before?' I had, once, in my 20s. I worked a very long shift, possibly illegally, with the back-to-backs I had. I wanted to stay awake and a friend offered me something to perk me up. I realised afterwards what it was. She goes, 'And what happened?' I said, 'I had a really productive day and I went to bed and slept like a log.'

CHAIR - You certainly weren't high.

Mr WYNANDS - Yes. I was actually really focused. It didn't do what I've seen it do to people in my youth and that started us going down doing a DIVA-5 and thinking it could be possibly ADHD, ADD. Then it was hard to get psychiatrists, especially in this state. I did manage to find one. I went through my story and my school reports and had to go through a lot of history and bring in family members who knew me and things like that. I was known as a hyperactive kid, but I wasn't really full-on, and yes, I got my diagnosis.

It was a bit of a shock. I was also diagnosed with borderline personality disorder, but that was due to the trauma. When you take away the trauma, I'm left with only ADHD symptoms. I had my therapy focused on that for years, when it was incorrect.

CHAIR - How transformative has it been for you in your life since you've had that change in approach from your psychologist and now your diagnosis?

Mr WYNANDS - It has been really interesting. I have managed to get things done that I was uninterested in before. It is funny sometimes like a hyperfocus for someone else can make them money and make them successful or it can be really detrimental to the person itself and mine mixes and matches. I have totally forgotten where I was going with this and I'm already medicated.

CHAIR - It was about basically the change that you've experienced since diagnosis.

Mr WYNANDS - Yes, thank you. It has been really good. I can normally hold my train of thought quite well and focus on things that were menial before. I am even thinking of going back to study to finish off. On a different train of thought on studying, I wanted to study psychology and help others who are in a similar boat to me. I think I can actually achieve it now, whereas before I could not.

CHAIR - We've heard from others how important it is to have medical professionals who do have lived experience across the board, so I think that's great to hear that you are thinking of doing that.

Mr WYNANDS - I actually had a lot of trouble with my first GP who I had seen since I was a 15-year-old. Even though I moved to Sydney, lived there for a while and moved back, I still had the same GP, but it almost felt like he did not even believe in ADHD.

Mr BEHRAKIS - That is an experience a few people have had. My first trip to the GP they were trying to convince me that I may have an iron deficiency instead.

CHAIR - That's so bizarre.

Mr BEHRAKIS - I suppose from when you initially identified that that might be something to look into, to when you sat in front of someone who formally diagnosed you and gave you a prescription, can you outline what that experience was like and how long are we talking, from the beginning of that process to when you actually got where you need to be?

Mr WYNANDS - Well, that was my first conversation with my psychologist over the phone, but before my actual appointment with her. As I said, she was provisional but she was amazing and she also had ADHD herself. That really helped with a lot. I went through the DIVA-5. It was hard because it was actually through my work agency that I was going through because I was searching for work at the time. It was about three weeks between, sometimes even four, between appointments, which was really difficult, but I could not afford to see a psychologist otherwise, so that was actually quite helpful. Then that process went through, but trying to get the psychiatrist, that took a while because I also needed to find the funding to see the psychiatrist.

Mr BEHRAKIS - How much were we talking?

Mr WYNANDS - It was about $1200 for the initial assessment and it would be lower with follow-up appointments, but I can't actually afford the follow-up appointments. I am concerned in the next, well, year now, when I need to reapply for my medication, will I be able to access it because I cannot afford to see a psychiatrist?

Mr BEHRAKIS - You can't afford it, but then you can't afford not to either.

Mr WYNANDS - That's right.

Mr BEHRAKIS - So, you're in a position you can't afford either way.

Mr WYNANDS - Sort of in limbo at the moment. It took a long time for that. I was actually quite lucky I had a six-month turnaround from managing to find a psychiatrist to be able to organise an appointment. I was looking at over a year and a half and I was seen within six months.

Mr BEHRAKIS - How much have they - because we've heard a lot of people who have talked about either the delays but also, and it was in my experience as well, just having to figure out on the fly where you need to go and going to the wrong place and waiting then having to bounce around before you get to where you need to go. How much of a difference did having someone who knew the system, because they were supportive and also had the lived experience - just having someone who could say, 'Go there, talk to this person,' how much did that help?

Mr WYNANDS - That helped immensely because, as I said, my GP at the time, was a bit sceptical. I found out he didn't believe in it really, later on. But, it was so good to have someone who understood what I was going through and being able to get that support and also ADHD coaching from her to be able to support my life was amazing as well. It was life changing. I can't put it in any other words but, it was life changing. It really helped.

Mr BEHRAKIS - I can ask another thousand things, but I will spread the love.

Ms JOHNSTON - You talked about that provisional psychologist with the lived experience being so supportive during that time. What kind of practical things were they able to put in place for you until you received your official diagnosis? Were they able to give you some tools to help manage daily life? What kind of things were useful for you?

Mr WYNANDS - I had a couple of books that she recommended I read. One of them was *ADHD 2.0*, and that was a really amazing book. That really helped me. And, because I was interested in what was wrong with me, I read it. Otherwise, I probably wouldn't have. Also cognitive behavioural therapy, CBT, and lots of other life experiences, because it was relatable, things that may have helped her, she thought, 'I'll see if they will help you.' Everyone presents differently, so you can never really tell, but with a bit of an idea, you can work around it and then branch off and go in different ways, 'Okay, that seems to be working and more focused on this, so we'll go this way, or we'll go the other way.' Lots of different methods. Also, I have rejection sensitivity dysphoria. I have a hard time task switching, and she was helping me learn how to task switch without making myself anxious or uncomfortable.

Ms JOHNSTON - That's sounds like great support that she was able to offer you. Are you able to reflect on, if you hadn't had that support and those tools and guidance during that time, how much harder it would have been waiting for that diagnosis? We've heard from other people with lived experience of that, the frustration of feeling like you're this close to a diagnosis but you're not quite there, and you haven't got the tools yet to do it. You're in limbo, it's like a limbo.

Mr WYNANDS - You are. It does feel like that. That is the best way to describe it, feeling like you're in limbo. That was long enough for me. I can't imagine what it would be like for other people. I was very lucky, my psychologist managed to get my job network to actually pay for my psychiatrist appointment.

CHAIR - Oh, fantastic. That's the first time I've heard that.

Mr WYNANDS - Otherwise I wouldn't have been diagnosed and I wouldn't be where I am now - thinking of going back to studying.

Ms JOHNSTON - You'd still be in that limbo, where you've kind of got an idea of what's going on but you haven't got that answer.

Mr WYNANDS - Yes. You're stuck. It's a horrible, horrible feeling. Another thing, too, is I want to be productive and I want to do things, and I have been in my life, but then something will happen, or I have a disagreement with my boss, and it's just not good.

Ms ROSOL - Hi, Scott. You mentioned medication in passing, I'm just wondering if you could talk about what your experience has been like around medication and accessing a prescription, and obtaining it.

Mr WYNANDS - It's been a nightmare. I had to wait two years for my medication.

CHAIR - Two years?

Mr BEHRAKIS - Two years?

CHAIR - Oh my goodness.

Mr WYNANDS - Yes. Because my doctor - I don't know whether he didn't put the paperwork in, or he didn't follow it up, it took him ages to even get in contact with my psychiatrist, even though she had emailed him. I found that out from the staff there. He then sent off, apparently, I don't know what the form's called, but -

Mr BEHRAKIS - The authorisation, yes.

CHAIR - 59E, is that what it's called?

Mr WYNANDS - The authorisation, thank you. I heard nothing back. He said, 'Call back in two weeks,' I did, another two weeks passed, I did, another two weeks, 'Oh, they may have lost it, I'm not sure, I'll give them a call, call me back in two weeks,' and I got that for a year. Then I was getting really sick of it, and I booked an appointment and said, 'What is going on?' and he says, 'You've been rejected.'

CHAIR - But they hadn't told you that?

Mr WYNANDS - I went, 'Right,' I said, 'Can I see this rejection letter, or the reason why, can I get some input into it?' And, 'No, no you can't see it. But, we can give you alternative methods.' So, I changed my doctor.

Mr BEHRAKIS - Is this the same doctor that was not on board with the idea of -

Mr WYNANDS - Yes.

Mr BEHRAKIS - Yes, okay.

Mr WYNANDS - So I changed my doctor. That took a little bit of a time because the people who overlook the thing lost my paperwork twice. Then he followed it up, and I finally got medicated. I wasn't rejected at all. There was no reason why I shouldn't have had my medication.

Mr BEHRAKIS - So, the doctor never filed it?

Mr WYNANDS - No.

CHAIR - Oh, gosh. What a nightmare.

Mr WYNANDS - Knowing that practitioners are out there like that and people seeking help, doesn't fill me with a lot of faith.

Mr BEHRAKIS - What was the process - they're two very separate and serious things - when you went to the other doctor and he actually did the things he was supposed to do, what was the engagement with the authorisation body like there?

Mr WYNANDS - It was brilliant. I actually found out from someone else, who had ADHD them themselves, that this doctor understands what it's like and that's how I found the doctor that I saw that helped me through. So, he was like, 'No, what we need to do is this.' He walked me through the whole process, showed me everything, was completely transparent.

Mr BEHRAKIS - And then the regulatory body, that was no dramas at all?

Mr WYNANDS - Not really. As I said, they did lose my paperwork, but then, when he followed it up, it got sorted out and it wasn't long afterwards, about three weeks after that, but all up, that process took me two years.

Mr BEHRAKIS - I think you said earlier, you're on the same things that I'm on, are you on any restrictions, any conditions?

Mr WYNANDS - No, no.

Mr BEHRAKIS - I'd love to know if there's any - surely a doctor doing that sort of stuff, they'd -

CHAIR - It'd be grounds for some kind of complaint at the very minimum.

Mr BEHRAKIS - Yes, that sounds very, very serious. Because we've had people face delays for numerous reasons, whether it's waiting to get to the psych, waiting for the prescriptions to be authorised or whatever have you, that period of a year, what was that like?

Mr WYNANDS - Hell, because I knew that I needed it and when I thought back, because it's weird - I don't have a photographic memory, but I can remember a lot of things from youth to now and how I felt at particular times in big events and I felt lost. I felt alone. I felt like I couldn't move forward. It was a hard period of my life, too, because I'd just gotten over caring for my mother. I got diagnosed with a blood condition, almost lost my hands, then I got diagnosed with ADHD, and then I had to figure out what I'm going to do for a career now because the career I did do, I was in retail management, I couldn't do anymore and it was tough because I was dealing with all those facets as well.

Mr BEHRAKIS - And then you're in limbo, waiting for something.

Mr WYNANDS - That's it, yes, and I'm running out of time. I'm in my forties, I can't waste any more time.

CHAIR - Forties is the new thirties.

Mr WYNANDS - I've got to get into it!

CHAIR - Miriam, did you have any questions? I don't want you to miss out, being joining us remotely.

Mrs BESWICK - Thank you. Obviously, it's been pretty rough. I think we had a really nice chat with Chris earlier, but, now that you are in help, how has your life been different? What sort of improvements have you seen in your capacity?

Mr WYNANDS - Well, I started to ease myself into study. So, I'm studying a Mental Health Cert IV and I'm actually completing the work, whereas I'd get side-tracked, or it will be a boring part and I'll ignore it until it's too late and I'll rush it out, get it done, or I'll just completely ignore it and then stress about not doing it. Now, I don't have that. It's bliss to be honest. I actually feel normal now, whereas before I never did. I always felt sort of out of place or I didn't quite fit in. Yes, it's really good. Hard to explain. I feel whole.

CHAIR - That's beautiful.

Mr WYNANDS - There isn't broken pieces scattered everywhere and I have to try to rebuild them, constantly trying to push a square peg into a round hole.

Mr BEHRAKIS - Please feel free to not answer because I know it might be a sensitive thing, but can you can you speak to how your experiences with ADHD, before being diagnosed and then being diagnosed, in the context of you mentioned a lot of the trauma and depression and stuff like that, and like I said, feel free to not answer certain parts of that, but-

Mr WYNANDS - I can detail everything, but I will say that if -

Mr BEHRAKIS - How that interacts, how all that's interacted with each other?

Mr WYNANDS - Certainly, certainly. So, I was a victim of child sexual abuse growing up. So, my trauma was I was a very angry kid growing up. That took a lot to deal with, hence why they gave me the borderline personality disorder, because my emotional regulation was really, really bad. It took me years to work through that trauma, which I can openly talk about now, no trigger, no nothing. Calm, and I'm glad I'm able to because, as hard as it is, it also gives a full picture to anyone so they can understand what it was like. Then I also had separation growing up, and then I moved to a different state - I moved to Tasmania.

I was always sort of an active child, but I'd have weird hyperfocuses. I took on swimming - inter-high swimming team straight away, no qualms. Loved it, did it. State volleyball champions.

I didn't like school. I had a teacher when I was younger who didn't like me very much and I spent almost an entire year writing lines. I went from gifted child who was absolutely genius to 'oh, he is stupid'.

CHAIR - Primary school age or high school age?

Mr WYNANDS - Primary school. I gave up on studying, then. I literally instantly rejected it. I had a maths tutor once. He was really cool, explained it in a really amazing way, then I was, like, in grade 8 Australian maths competition. Got a credit. I only really tried for a week. I rebuilt a VHS player when I was four years old. If I'm focused on it, I can do it, but this is the thing - I didn't even realise what I was doing at the time. Then having all these people saying, 'oh, it's just depression, it's just anxiety', because I suffered from anxiety and depression my whole life.

Work life, same thing. I had one job that was really, really good. My boss - I don't know whether he had an understanding of what I was like or anything, but with his help I managed to, on my own, triple business profit across the country - because he made it interesting and fun. Then when I had other jobs where it was, like, 'Oh, Scott, you forgot this. How could you forget that? That's so simple.' I'd be like, right, okay. I'd forget something else and I'd get ridiculed for it. I'd leave and find something else. Back and forth, back and forth, back and forth. It's very hard, when you don't understand the demon you're battling, to be able to focus on healing or getting anywhere.

All the way building up and then being told I had borderline personality disorder, but I was never manic. Hyperfocused, but never manic. I thought in myself, in my limited knowledge, that's odd, and questioned it.

As soon as I worked through my trauma, I was only left with the ADHD symptoms, as I said before. Well, working through these is just changing everything.

Mr BEHRAKIS - Yes. Knowing - not so much the treatment, because that's another thing, obviously, and how life-changing that was - but just going from when you were in school and you were a smart kid and clearly very capable. Then you have those symptoms, that sort of focusing on the wrong things. Just knowing what it was, how much has that changed your life? From before it being a moral choice - he's lazy or he doesn't care, or whatever - how much has that changed things, just knowing yourself what it was?

Mr WYNANDS - It's brilliant, because I can prepare myself not to fail. Having that awareness, I won't put myself in a situation that is too overwhelming, or I'll see a situation where - it's good to have that foresight. I've done a lot of reading on ADHD and I sort of hyperfocused on it for a while once I was diagnosed, and tried to learn as much as I can, so I can effectively avoid situations. I have impulse control problems. It was funny, because I'd have, like, addictions through my life, but they weren't - when I was a teenager, I smoked more marijuana than most people, and most people thought I was a junkie. I had a son born. I gave up in the flick of a switch and became a model parent. I was a bartender at an RSL club. All the flashy lights, all the dopamine hits - I developed a gambling problem. As soon as I left that environment, I didn't have a gambling problem. I could have been treated for addictions that I didn't really have, but it was searching for the dopamine.

Mr BEHRAKIS - You were addicted to the dopamine.

Mr WYNANDS - Yes, that's right. Exactly.

CHAIR - Can I ask you a question, and I don't know if I'm going to phrase it quite right, so just bear with me. Just a personal observation of my friends and family who have been diagnosed with ADHD, either as young people or several adult diagnoses as well, it's actually so misunderstood and treated as a disadvantage or a disability. In actual fact, there are so many positives about the way that neurodiverse brains think, work, approach problems, solve problems.

Mr WYNANDS - There really is. Not all of us are Richard Bransons.

CHAIR - I suppose it came to mind when you were talking about your experience in the workforce. You had one boss who obviously benefited greatly from your ADHD brain and saw profits increase as a result, whereas you had others who ridiculed you and arguably missed out on that benefit that they could've had by taking advantage of an ADHD brain in their workplace. I wondered if you'd like to reflect on, not really a question, but just an observation.

Mr WYNANDS - Yes, that's fine. I mean, with the right support and understanding, you can do amazing things, and I think that's where a lot of people go wrong. I mean, they're constantly told that they're lazy or they're useless. You tend to believe that after a while.

A lot of people will say, 'I'm a Jack of all trades'. You probably have ADHD, not really a Jack of all trades. I have a lot of different skills in a lot of different areas, and it's all due to hyperfocus. If you can make something fun - like, I've even thought of getting myself a coloured keyboard so that every time I type a button, the colour, like, waves on the keyboard, to keep me at my computer desk when I study.

CHAIR - You should invent that. Patent it.

Mr WYNANDS - Yes. There's actually one available. Understanding that, I wouldn't have even thought of that before. I didn't know my brain needed dopamine. Now I'm doing the mental health course, and it is very interesting, and I want to help other people. That started off basically because of the lack of support after my full-time carer job; there was no support after my mother died. It was like, 'Why don't you get into a job doing aged care?' I was a businessman. I didn't want to get into aged care. I did it for my mother and I saved thousands of dollars in carers' fees and things like that. So, depending on where your hyperfocus is, you can do so much. With the right support and the right people around you, the sky is the limit - with anyone. I believe that's what makes the biggest difference, is the people around you and how you're treated.

Mr BEHRAKIS - Getting to a point where you can manage it so you can direct it into productive places, rather than letting it, sort of, manage you.

Mr WYNANDS - Exactly.

Mr BEHRAKIS - We've heard from a few people, and one of the common themes is how uncommon everybody's experiences are. Not uncommon, but a hundred people and they've all had very different experiences in navigating from day one to getting treated. From the sounds of it, you were very lucky in that you found someone who was appreciative of what you were going through and supportive. Then you had some not-great experiences with the GP.

One of the things that we've been given in submissions, and also the Senate inquiry into ADHD recommended, was adopting a set of guidelines - I think AADPA has a set of guidelines, whichever - a set of guidelines to standardise the process for 'if you think this person' or 'if you have ADHD, this is the bouncing ball for you to follow so you know where to go and who to talk to' and whatnot - rather than try to figure it out and make it up on your own.

How much help do you think that would've given you if you were going through this process on day one? Rather than luck of the draw, am I going to get a psychologist or a psychiatrist that's going to be really good? Am I going to get one that's sort of cynical and doesn't believe in it? Having some sort of standardisation so you're not necessarily reliant on being lucky enough to get one of the good ones.

Mr WYNANDS - I've given it a lot of thought, actually. I believe that a streamlined method is great. I mean, everyone presents differently. A streamlined method through diagnosis would be so helpful, so you don't have to wonder who you are going to get and is it going to work.

Mr BEHRAKIS - Have I called the right place?

Mr WYNANDS - Yes, that's right. A lot of people are in the dark with it as well. I've thought that even having a specialised centre would be a beneficial thing - where people are purely focused on the study and also diagnosis and help of an ADHD area. I mean, any mental health illness could benefit from something like that.

It would have made so much difference for me. At the moment I have three children who are struggling at school. I can't afford to get them diagnosed, and I just try to teach them as best I can. Luckily, they don't have too many emotional regulation problems. They're good children; they treat people with respect and have a good outlook - but I can see their struggles.

I also have autism in my family line. I'm not a psychiatrist but I swear my middle daughter has autism and it makes it hard to drag her away from anything she is really focused on. If I had more support in that sense, with the right health professionals, I'd be able to get them the right help and not say, 'Okay, well, we're not eating for a year because we have to pay for this to happen.'

Mr BEHRAKIS - That affordability is a big thing for a lot of people.

Mr WYNANDS - It really is.

Mr BEHRAKIS - Some people are lucky enough - it still sucks when you have to pay those big bills, but for a lot of people, it's: do you get yourself or your kid the support that they need or do you pay for food or rent this week? That's a really tough place to put people into.

From your perspective, what supports exist outside of having private health insurance?

Mr WYNANDS - Not many, really. You get the Medicare rebate, but a lot of people - and I've seen it and I live in a low socioeconomic area - I've seen some struggles. Also the family support. There's so many different dynamics because normally family members who have it as well, but don't realise it with the kids, then they make bad lifestyle choices, whatever you want to call it. I don't want to insult anyone, but they do, and then they suffer, and then they suffer, and then they suffer. Then you have this chain reaction of unnecessary suffering, when they could have been amazing, functional people in society. All because they were overlooked. It's so simple.

Mr BEHRAKIS - Like you mentioned, as far as having a one-stop shop clinic, you get a lot of people - myself - you go to the GP and you have to twist their arm to even get them to help send you to a psychologist. Psychologist says, 'Look, we can give you therapy but we can't diagnose or prescribe you so I don't know why they sent you to me.' Then you go back and you go back.

Mr WYNANDS - Actually, I have a really big thing I have to say. Psychologists. I think it is so unfair that psychologists are claiming they can diagnose ADHD, charging the rates of a psychiatrist and then they have to go see a psychiatrist for the exact same price anyway. I understand that they may need to do a DIVA-5 or something like that. I've seen it more common now, charging for an ADHD diagnosis that is invalid.

Mr BEHRAKIS - Which isn't an ADHD diagnosis.

Mr WYNANDS - It's not.

Mr BEHRAKIS - Once again, that comes down to, like, when I went, the psychologist was great. She said, 'I can give you therapy, but I can't diagnose you. You need to go to a psychiatrist.' Once again, it depends on the fact that you have to rely on getting someone that's going to do it in the right way because there's no standardised process.

Mr WYNANDS - If you're unsure and you don't know where you're going to look for help, you're already financially struggling, and you think, 'Oh yes, this will help me.'

Mr BEHRAKIS - We're talking about a condition that, when untreated, is almost defined by being disadvantaged in navigating all that bureaucracy. Having a one-stop shop - you have GPs, psychologists, psychiatrists, in the one place, you go in. There's no 'oh, this is the psychologist's job'. Just walk into that room. You don't have to run through the gauntlet of trying to figure out who you have to talk to and it's the wrong person, and this GP or psychiatrist doesn't look at ADHD - try to get another booking and wait six months for that - that ordeal. Having something like that would be very helpful.

Mr WYNANDS - It would be absolutely beneficial. You've even got psychiatrists who don't believe in ADHD themselves. That's a personal choice and their opinion. However, there's been so much study and results in medication helping others that - well, it's changed my life and now I'm going to be back to being functional again.

Mr BEHRAKIS - Yes, I was saying to you before we started, I've heard stories of people who - it's wrong and we can't condone it - have taken a partner's ADHD medications and had quite the experience. I take that same medication and it levels me out and I'm sure the same thing would be to you, so there is subjectively something there. I don't know what the right reaction is, as far as telling psychiatrists or psychologists or medical professionals that they have to engage in things that might provide models of care that they don't believe in. Like, I get that, I can disagree with them as far as making rules there, but do you think even having something as simple as some sort of list online or some sticker that a doctor can put on the website or on the front of their practice, that someone, when they're looking up GPs, this is an ADHD-friendly -

Mr WYNANDS - ADHD-friendly, yes.

Mr BEHRAKIS - Yes, so that you know, and you go, 'Okay, at least I know if I look up GPs or psychiatrists that treat ADHD, it's one of these ones, even if it's a wait, I'm not going to wait for six months just to get told I have to go to somebody else.'

Mr WYNANDS - That's right, a lot of people go in and talk to their GP about it and they say, 'Oh, I'm sorry, I don't believe in it, you need to see someone else', and then they have to change doctors. It's hard enough to get a doctor to begin, let alone see a doctor within a two-week span.

CHAIR - Having that kind of system would allow them to refer you to someone else.

Mr BEHRAKIS - At least you're not unnecessarily waiting.

Mr WYNANDS - Yes, that's right. Exactly. It's pretty full-on.

CHAIR - Is there anything else that hasn't come up in our conversation that you were hoping to share with us?

Mr WYNANDS - I did have something like two seconds ago.

CHAIR - It's okay, take your time.

Mr WYNANDS - Okay, now I remember what I was going to say. So, I had a really great way to help people who didn't believe in ADHD have a bit of an understanding on it. It happened when I was at the dentist and one of the dental nurses was talking about how many cups of coffee her friend had. I said, 'Have you ever thought of going getting her diagnosed?', because that's enough coffee to kill a small animal. I can drink 20 coffees a day and not even feel a buzz, well, before the Vyvanse of course, because you shouldn't drink coffee on Vyvanse, but I used to be able to - I lived it.

CHAIR - Did you know that?

Mr WYNANDS - You're not supposed to drink too much coffee.

Mr BEHRAKIS - I didn't know that.

Mr WYNANDS - Too much coffee. I mean, I still drink coffee, I couldn't live without coffee. It's a staple of me, but when I was younger, and even now, caffeine drinks, even just look at the youth cruising around with Monster cans, for instance, you know? They're drinking 12 of those a day.

Mr BEHRAKIS - Just to get through the day.

CHAIR - They're full of so many other awful things.

Mr WYNANDS - And they could go to sleep.

CHAIR - Yes, I get the point. You're right.

Mr BEHRAKIS - He was like I can take 10 coffees and go to sleep, it's like, 'Well, do I have something to tell you.'

Mr WYNANDS - That's right. Exactly.

CHAIR - My dad would wake up at night, drink a short black to go back to sleep.

Thank you, Scott, very much for sharing your personal experience with us. As I said at the outset, it's really meaningful for us as a committee to hear lived experiences like yours and it's really generous of you to give the time to actually share that with a parliamentary committee like this. We'll keep you up to date with the report writing that we will ultimately do. We'll be providing a report to the parliament, but if you leave here today and there's something else that you think, 'Oh, I wish I'd said that,' please get back in touch with us.

Mr WYNANDS - There will always be something.

CHAIR - Yes, personally or through our secretary, Michael, we're easy to find and, yes, we'd be more than happy to keep hearing from you through the next stages of our work.

Mr WYNANDS - Excellent and if you need me again for any purpose or any reason to help lend a hand or anything at all, please reach out.

CHAIR - Will do, thank you.

The witness withdrew.

The Committee suspended from 12.44 p.m. to 1.39 p.m.

CHAIR - Good afternoon. Hello and welcome to today's hearing of the Parliamentary Committee into an Inquiry into the Assessment and Treatment of ADHD and Support Services in Tasmania. Thank you for making your time available to us today and being generous enough to share your personal experience with the committee. Can I ask you first just to state your name for the record?

Mr SPOHN - My name is Nicholas Joseph Spohn.

CHAIR - Can I confirm that you have received and read the guide sent to you by the committee secretary?

Mr SPOHN - I have, yes.

CHAIR - I'll just remind you as you would have read in the guide that in this hearing you are covered by what's called parliamentary privilege, which allows you to speak freely with us without any fear of being sued or questioned in any court or place outside of parliament. You're free to tell us anything you want to say in any way that you want to. The only exception to that is the protection isn't accorded to statements you make that could be considered defamatory and you then repeat them outside of these parliamentary proceedings.

It's a public hearing. There's no members of the public in the gallery right now, but it's not impossible that some could wander in. Equally, people might be watching online, members of the public or the media.

I'll introduce the committee. My name's Ella Haddad, I'm a member for Clark. You've got two other members for Clark at the table here, Kristie Johnston and Simon Behrakis. Also, Miriam Beswick is a member for Braddon, who's joining us remotely. There are a few apologies today, a Greens member for Bass, a Liberal member for Bass, and a Liberal member for Franklin. The committee comprises all political parties and independents. We're here not for politicking, but for hearing a rich evidence base from the Tasmanian community and making good recommendations.

Mr NICHOLAS JOSEPH SPOHN, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Thank you. We've also agreed to the committee to make a short sensitive content statement at the beginning of each session, just in case people didn't hear it earlier, if they weren't watching online. I'll read that short statement now.

As a committee, we recognise that during these hearings we may discuss highly sensitive matters and themes that have deeply impacted the lives of Tasmanians, which may be a trigger for individuals listening to or participating in these proceedings. We encourage anyone affected in that way to contact Lifeline, ADHD Foundation Helpline, or Kids Helpline.

That's the formalities out of the way. We'd invite you, if you would like, to start with any kind of opening statement that you'd like us to hear.

Mr SPOHN - Sure. Stop me if this starts going in a direction that is not going to be relevant. I am concerned that I might have overstepped some of the stuff that I was writing to your questions. The long and short of it is, I wrote a statement and I'll just read it out.

I believe ADHD needs a rebrand. It's come a long way from being called a moral deficiency. It was identified as such. It still has a ways to go though, and it's not as simple as being unable to avoid becoming distracted mid 'squirrel'. Again, I have a way of explaining it to kind of justify myself to people as I'm introducing myself to them sometimes.

A better way to understand it is it's lacking agency in what our attention fixes on and when it does that. This document I'm reading is a good example. I was writing it last night before talking about it today, and actually some part this morning, because I finished at one in the morning. Should I have written this weeks ago? Obviously. Would I have lost track of where I had saved it? Absolutely. Welcome to the struggles of time blindness and object permanence. We can add those to the list of the things that this can cause.

I was undiagnosed until 33. What that looked like was from about year 11 and onwards I had various bouts of bad anxiety and depressive episodes. They, obviously, negatively impacted my life, in some small ways, but other times in more significant ways. I have struggled to find a job I could stick to. My pattern usually went: get hired, do my best, enjoy some time actually excelling at the job, begin to falter, completely flame out, quit, and repeat. That was the cycle. I just assumed, 'Okay, I've just got a chemical imbalance in my brain. I just have anxiety and depressive issues that I need to,' - you know - so I would medicate for those.

The last time this cycle went through, and I was reaching the flame-out stage, I worked for a time as a sign designer for a local business in Launceston. I entered the phase where I began making more and more careless mistakes. The way that the art-to-print pipeline works, by the time a mistake from the art room was identified, be it a colour had been used wrong, in the wrong sort of RGB, CMYK colour spectrum - you don't need to know about that, never mind - but by the time those sorts of problems were coming up on the print bed or even affixing to the building, the cost could be many thousands of dollars to the business and, yes, the embarrassment gets thrown in for free.

So, as these things were sort of sneaking through and I'm trying to hold it together, more and more of checks were put into place, so more things I had to sort of put my name next to and tick yes, I've done this. So, more of these things were coming in, I put more and more pressure on myself to not screw up, and that was actively starting to ruin me. The whole time it seemed like my subconscious was actively trying to screw me over as well, so I'd somehow make errors that no-one could have anticipated. Always stress-testing the checks that had been put in place with some new and exciting way to screw up in the periphery of those things.

So, at this stage, I often required - I was prescribed antidepressants and while they made living in my head tolerable, I found it dulled my thoughts and made the creativity I relied on to do my job next to impossible - sorry I'm wobbling the table. Finally, after a foul-up that, honestly, kind of haunts me to this day, I decided I couldn't, in good conscience, continue working for this company because they were trying, and they never forced me out the door, but I was just like racked with guilt. It was not - I don't want to, in any way, be disparaging to this business. I have no ill will towards them or feel like I was forced out. It was in here. I just wanted to be very careful to say that, privilege aside.

CHAIR - Yes, that's totally fine. It sounds really tough.

Mr SPOHN - So, yes, I resigned and, basically, had completed another lap of this. So, my resume at this stage just looks very eclectic, it's very, 'I've done this, I've done this, I was here for this long,' so it was compounding.

It was becoming harder to find employment in this and then COVID hit, so that was just amazing. Because I tried to start my own business in that time and that went great. We actually - I ended up making headbands and like visors for pharmacies and things during that because I was able to find a group of other people with 3D printers and we all made these face shields and things for that. So, we were able to sort of help a shortfall of the supply there, which, retrospects. You know, filling a need in a very short amount of time, I think that's a very ADHD thing.

So, anyway, after finishing that part of the cycle, that's the rock and the hard place I found myself in between, I'm openly wondering, it's like, 'What the F is wrong with me?' So, one theory I ironically remember worrying about was, 'Am I suffering from early onset dementia?' because that kind of like, 'Why can't I hold this in my head?' Like, I know this. I know what the sequence has to be, but it's always like wrestling control away from like a really aggressive autopilot, if that makes sense. Like, if you've ever like driven from Launceston to Hobart in one day and you're going, 'Did I pass Epping Forest? I'm in Kempton - what? I don't get it.' So, yes, it's something like that.

CHAIR - It sounds very familiar to all of us.

Mr SPOHN - Yes, it's good to make it local. So, ironically around now, the sequence of events gets a bit hazy.

At the time, my eldest daughter had begun experiencing difficulties with emotional regulation in kindergarten through prep and, again, this is not me personally, but this is my experience of going through what she was at the time. So she could be very intense to be around and she would be screaming with excitement one second, howling in disappointment the next, and it was at the point where the other kids in her peer group were actively ostracising her, which is painfully understandable, but heartbreaking. We'd be waiving some of this off as, 'That's just normal, I was like that as a kid,' so watch out for that, but at that time, I believe she was on the track to being diagnosed as ADHD for when she was in grade 1, and it still hadn't clicked for me somehow that this is something I should probably be looking at myself.

One of the things that's really come out in the wash after all this is just realising the genetic traits; how strongly the genetic lineage of this really goes. I will circle around back to that.

For me, it really came about to, 'oh, this is what's going on with me', when I was listening to a friend talking to a group of us, at a wedding, I think. He was freshly diagnosed and he was sharing his story. It resonated in me at a level I'd not really felt in any way before. The memory issues, the mistakes, the eternal burnout, everything. You know how you can google symptoms related to having, like, a runny nose and you conclude you're dying of cancer by the end of the browsing? I was wondering, is this just that? However, I felt this in my bones, that this was probably what was going on with me, and I could get out of this, like, constantly treating the depression and the anxiety that underlying cause was presenting as. So, I began to seek diagnosis.

This is my memory of it and things may have changed since then. So, I believe this is maybe 2021. At the time, my pathway was presented as: you go to a GP, the GP refers you to a psychologist, the psychologist will then refer you to a psychiatrist. It's a bit of a leapfrogging thing. I'm not sure if that's what it's like now, but that's what it was to be at the time. It wasn't that helpful. Then I think in the wake of 2020 and TikTok hitting the scene, it was trendy to be starting to think, 'oh, everyone's ADHD' and stuff. There was a bit of a barrier, I guess, trepidation, from health care practitioners to just let you through that. Like I said, I'm sort of second-guessing myself as well thinking, is this what it actually is? I was pretty fixated on it at this point, so I persevered.

One example is, I do remember talking to my GP, saying 'I think this is what might be going on.' They asked me how I did in school. Instinctively, I said, 'Pretty well', and I'm very zeroing-in on - I did quite well in year 10. I was dux of the school in that year. I said words to that effect and they said, 'Well, it's probably not that.' That was it, as far as that conversation went.

CHAIR - It shows a very limited understanding of neurodiversity.

Mr SPOHN - Absolutely. Again, I don't want to necessarily be disparaging to the doctor because, at the time, I wasn't 100 per cent certain myself. It was this balance. Again, I return back to this, but there is a certain point. It's like, what is personality, and when does that tip over into disorder? That's one of the things I juggle, I guess, in that way.

After having that conversation with the doctor and really thinking about it, I started to think, 'Well, no, I did all right in year 10' - year 10's a culmination of a lot of things. Primary school, though, I had a teacher's aide on my shoulder all the time because I was really behind in writing, I was really behind in reading. In years 11 and 12, I really fell off the rails because that was far more, like, you have to direct your own research, direct your own learning and that sort of thing. It wasn't structured - the bell goes off now, you're in this room now and you're doing this until - the structure had evaporated, in that context, as well.

Once I wound my scope to that, I was able to - fortunately, my mum's very sentimental, so she still had all my primary school reports. I was able to dig those out and then find so many pages of, like, prep, grade 1: 'If only he could apply himself', 'If only he could pay attention', 'If only he'd sit still'. All of those little moments of - 'a kid being a kid' is suddenly gold to me, because I'm looking at these and going, 'thank you'. I was able to take those to the doctor and they go, 'Okay, there's something here.' I count that as lucky, honestly, because that then finally started pushing that up the flagpole.

Then came getting a psychiatrist appointment that, at the time, was something north of $600 for the appointment, and it was a six-month wait. Again, I get it - it was kind of a tough time. There was a spike in people having a similar realisation to me. I guess the pathway is kind of obstructive in and of itself because you really need to drive yourself, you need to be fixated to actually see it through. That will automatically cancel out people who just can't be bothered, but again, that can be more of a problem. I had to wait on a list for six months, just hanging on, thinking, 'I just want to sort this out.' I was able to get in in three months in the end because he had a cancellation.

Then actually going through the appointment itself, that was quite nerve-wracking. I was certain that this is what had been screwing up my life and now I needed to prove it, not just to my doctor, but to myself. For most of the appointment, I felt really - the way he conducted it - and I am sure this is a part of the diagnosis - but I felt really off kilter, like I was tripping over myself. I was missing the points I'd wanted to say, points I had actually rehearsed, because I was like, I want to get this down, I want to actually say that there is a certain concern of needing to make sure he sees what I am, and not miscommunicate anything. At one point, he said something and I just sort of riffed on the comment and he pointed out, 'That, that's a brain fart. You had no control over whether you could say that or not.' I had never felt so exposed.

He finally said, 'Yes, this is what it is, and we are going to start getting you medicated.' I cannot stress enough the relief that moment had for me. It wasn't even being right. All my life I'd been accumulating these tiny little grains through my life: moments of guilt, shame, cringe, whatever you want to call it. I would hold on to them and scrutinise them. 'Why did I say that? Why did I do that? Why am I like this?' Over and over again.

Over time, if you collect enough grains, you end up with a mesa. That's basically depression and anxiety, because you're constantly like, 'No, I can't do this. I can't be this'. The relief came in finally understanding all those 'whys'.

Mr BEHRAKIS - Like a validation.

Mr SPOHN - Exactly. Yes. I could finally just release it. It's the *Good Will Hunting* moment. It's not my fault, I'm just wired like that. It was just such a - I've not had - I still get anxious, I still get sad, but it's not chronically debilitating where you can't go outside, can't get out of bed sort of depression and anxiety anymore. Just that validation moment was a really, really big moment. I'm still feeling the relief from that, to be honest.

That is the part where the name ADHD gets it right. It's a disorder. That's how it presents, that's how it ruins you. That's how it changes the course of what your life could have been otherwise.

I do want to be careful in my final words on that point, though. I am not saying that everyone with these traits is doomed to suffer. There are cases where people who exhibit these traits absolutely thrive. If you ever get the time to, watch a show on Disney+ called *Light & Magic*. It charts the special effects house that started with *Star Wars*. I am no psychologist, I am no psychiatrist, but those are my people. They're very chaotic - in how it all started. Just having that lateral thinking - that's the sort of thing that this condition can allow for if given the right environment.

Many people can have their brain sitting in this low-dopamine environment and never struggle or spiral or have the doubt they might-. The likely reason I flew under the radar for so long is probably because the way my brain works often was also to my advantage. I'm a creative thinker, I'm a fast learner, a problem solver, I'm calm under pressure. I'm pressured under calm, but that's another thing. I can hyperfocus on finding solutions or completing urgent tasks - occasionally. It can be quite a very useful tool, on occasion.

Thriving is not off the table with any of these neurodiverse traits. I do believe, however, that luck currently has a lot more to do with the trajectory of people with this than it has any right to. The stigma around it, I did it performatively at the start, but it's often just reduced down to, you know, 'squirrel.’ It's a lot more nuanced than that and I think that stigma is what kept me away from thinking that this is what it could be for so long. You have a concept of, 'That was the ADHD kid - they're the ones who used to swear at the teacher, who used to be removed from the classroom, then it goes away when you're not in school anymore.' That was definitely not the case.

That was my prepared stuff.

CHAIR - Thank you. It was great, though, and it was very - what's the word - we're grateful for you being able to share that global perspective of start to finish. It was really insightful and really useful for the committee.

I wanted to ask a quick question before opening it up to the whole group, because I know we will all have lots to ask of you. You described your work pattern really well, of that rinse-and-repeat kind of process. Post-diagnosis and treatment, what kind of changes have you seen in your work life?

Mr SPOHN - Currently, I am a meter reader for TasNetworks. For a start, one of the things I started looking for - not even looking for, in work - I got picked up through Hays Recruitment, because I was sort of in a spiral after the whole COVID thing and tanked the prospect of trying to get my business up and running. I got picked up by Hays, so I was working as a temp at a few different places, and the meter reading position came up at TasNetworks. It fits a few requirements that I had for what my next period of time at work was going to be. When it started, there was so much walking. I think I was regularly walking 80 to 100 kilometres in a week.

CHAIR - Oh, wow.

Mr SPOHN - It was very good for my health - mental and physical. That was very serendipitous timing, as far as that was concerned. I've been able to stick with that job longer - I've been able to sit in that position without necessarily feeling like I'm starting to 'flame out.' There was a point where I had a bit of a bad time of bogging the car a couple of times, going out to some of these more regional areas, but I was able to actually come out of that spiral. It was the first time I feel like I actually broke that cycle - which was really nice.

Mr BEHRAKIS - Getting treatment hasn't stopped it from happening, but it's let you catch yourself as it's happening?

Mr SPOHN - Yes, it's more that I understand what's going on now. A part of it is, there's the initial excitement or honeymoon period of starting a new job. You go at it for a while, you pick up things, you start to improvise little things that make your life a little bit better, make the job a little easier, make you a bit more impressive, sometimes, in doing it. Then the brain one day goes, 'I'm bored'. That's it. You lose your hyperfocus, you end up with that autopilot rearing up again, and it makes you make some questionable decisions sometimes. Well, it doesn't make you, but you become prone to making poor decisions. Then that can start to compound, and that's where the spiralling can come from. However, it's like, no, I know what's going on now. I've been able to mitigate that boredom setting in, rather than having to succumb to it, if that makes sense.

Mr BEHRAKIS - From when you decided that you wanted to look into whether or not you had ADHD to when you got to the point of being formally diagnosed and treated - you would say it was a number of months - how easy or difficult was it for you to figure out the steps: you need to go to the GP, need to go here, and navigating that on your own? How much support did you get in doing that, and how easy or hard of a time did you have in navigating that?

Mr SPOHN - That's a good question. For me, there were a lot of steps, it felt. It was mostly informed by talking to my friend who had been diagnosed himself, and he outlined the steps to get there. As far as support was concerned, it was basically: I make the appointments, I show up to the appointments, I take the actionable steps, all of that. There wasn't really a framework to follow so much as just the advice of a friend who'd gone before me.

Mr BEHRAKIS - When you were in that waiting period, you knew what was going on?

Mr SPOHN - Yes.

Mr BEHRAKIS - Were you getting any other support while you were waiting to see the psychiatrist? What was it like when you were in that period of waiting to sit down with the person who was going to formally diagnose you? You kind of know what's going on inside your head - but what was that like?

Mr SPOHN - Oh it's basically like being on hold for all eternity. You're dealing with a few feelings. You're feeling excited - you know, finally I'm getting to the bottom of this. You're feeling like terrified: like, what if I'm wrong? This has been an awful lot of effort and an awful lot of money if I'm wrong.

Yes, it's a bit of a tangle, again, around that period. I'm trying to remember it in a linear sense, but I do think I had a mental health plan in place at the time as well. I was seeing a psychologist at the time to sort of 'therapy me back' out of the pits of bad anxiety that I'd been having. There was definitely, like, mental health help going on, but not specifically to help an ADHD brain with anxiety and depression so much as just like, 'This is the anxiety and depression medication we - ' - well, not medication, but the therapy we give to everyone.

CHAIR - Oh, sorry, Nick. Keep going.

Mr SPOHN - No, I was honestly trying to trail off the sentence without sounding like it was going nowhere.

Ms JOHNSTON - That's okay. It was really powerful when you talked beforehand about that moment when you did get that diagnosis and that overwhelming sense of relief, that you had an explanation for the way you are, and a validation. I think Simon used the word 'validation'. The steps immediately after that - you have the diagnosis, now stepping into treatment. Did you find that challenging? Was it a good process for you or were there some barriers to getting treatment?

Mr SPOHN - I had a pretty easy time of it. I think at the time, it was basically my psychiatrist in particular was able to get clearance for me to be able to get the medication the same day.

CHAIR - Wow.

Mr SPOHN - Yes, it was a ridiculously fast turnaround, especially after some of the stories.

CHAIR - You're a unicorn.

Mr SPOHN - I know. I believe I can speak his name in this. I don't think it's a problem. My doctor's a guy up here called Lev Fridgant. Whatever he's doing to be able to get that clearance that quickly, that really needs to be standard, I believe. Again, this could have just been for me. I'm not certain of the universal experience of diagnosing people or giving them their medication or whatever. Yes, it was a pretty fast turnaround for me.

The thing that I found a little bit strange, in a way, was how different it was for my wife. Similarly, at the same time as me, she began seeking a diagnosis herself. Again, the same reasons I had. It was more a case of, at the time, my anxiety/depression issues were really bad. On the scale of things, I was more of a priority. Some of the difficulties for Tracy at the time were - she couldn't go and see the same psychiatrist I had. Out of the two psychiatrists in northern Tasmania that were taking patients, that's one of them already out.

She ended up getting an online appointment with someone out of the state or someone in Hobart, over the internet. Her getting clearance for her medication took a lot longer. I'm not sure if that's because she wasn't necessarily able to attend in person, discussions with a psychiatrist, or if there were just more considerations because I was already getting medication and because my daughter was already getting medication. How it played out, there was a bit of a discrepancy there.

Mr BEHRAKIS - What are we talking about by longer? How long are you talking?

Mr SPOHN - Sorry, time blindness - I believe it felt like, maybe, three to six months. It seemed to drag on a really long time. The other thing was, because she started with 'this' amount of medication, but then go on up to 'this' amount of medication, each time requires so many more moving parts to get there. I was keen to have her getting the help that I had been able to receive. It was a frustrating time for her, because I was keenly on her back about it as well, I suppose.

This is actually, like, a jump forward a little bit in recommendations from my experience of it. I believe part of the idea of this needs to be coming through the lens of, this is a very family ordeal. We do tend to find each other, as a community. We do tend to gravitate to each other. Whether that informs our relationships, it certainly informs the type or types of children we're going to end up having. That sort of consideration to accommodate for, you know, if the kid has it, it's likely the parent has it. Are they suffering from anxiety/depression? Are they ticking these boxes? Yes, maybe look into this.

Obviously, diagnosis and seeking one is quite a personal experience, so I don't necessarily know how you thread that needle, but it's something that needs to be looked at, because this isn't a thing that happens in isolation. It really gets woven into you. Where I said as well about the genetic aspect of it, and about the disorder being a disorder, I can look up my family tree as well and look at my mum - absolutely has ADHD. Her life has just panned out in a way that she's not explicitly suffered from it in a similar way to me.

That's where I say, that line between - where is it personality and where is it disorder? That's where it's tough. It's a bit like, these days as well, I had this fantastic knack of finding careers and literally just going away. My first main job, I guess, was working at the newspaper here, *The Examiner,* creating advertising in the ad blocks and stuff. That, obviously, newsprint, that was definitely one to last. Sorry, digressing.

Ms JOHNSTON - That's alright. You're highlighting what we've heard is a common theme, it's an issue facing families. There are often multiple people in the one family group who are seeking diagnosis or going through treatment. What we're hearing a lot is the disparity in experiences between family members. Certainly, we've recognised there's a cost barrier to some people seeking diagnosis, even though they strongly suspect - but they're choosing, 'I'd rather get my child diagnosed than myself diagnosed with the cost implications'.

Can you perhaps speak to, and maybe elaborate a bit more on, what that means for your family dynamics? Even if you've all been or are going through the process of diagnosis or treatment, about the different approaches between yourself and your wife, and how that plays out. We'd hope that everyone gets fair and equitable access to health care, yet in the one family you have really different experiences. That must be really hard in your day-to-day family dynamics of relationships.

Mr SPOHN - Yes, it did come down to the priority of who would go first.

Ms JOHNSTON - We hear that a lot.

Mr SPOHN - I believe Amy, my eldest daughter, she was probably the first because she was - for us as parents, as well, you don't want to see your kid struggle. How primary school was shaping up for her at the time was really tough to witness because kids do not have a filter. They do not mince words, 'Go away, I don't want to be your friend,' yes. And, like I say, my mental health went 'ehhh,' so that was the next - that was the adult in the room that had to go first. I understand why - well, I understand that certain safeguards do have to be in place. I'm sure there's an issue about the same psychiatrist treating both sides of a married couple, or even same family members. Whether there can be a way to pass out, 'It's very likely that this group has these things'. There's a certain degree of common sense that surely can come over the top of that. Like I say, the luck for me was - my earnings have been quite in flux since 2020 at least, well they were at the time, but I was lucky that my parents were quite well off. I was never at a point where I was like, 'I just cannot afford to go to this'. I have a number of friends, some of whom are in government housing, and they can't. They just can't. They've got their son diagnosed. He's got autism as well, which is a compounding factor, or ADHD is a compounding factor. Sorry, digressing.

CHAIR - That's okay.

Mr SPOHN - In terms of, yes - it's just you have to be pragmatic about it. It's not that we have a smorgasbord of psychiatrists to choose from and the ones that we do have, they might not be taking patients. We might just have to wait.

CHAIR - That's what we're hearing.

Mr SPOHN - So, that bottleneck, yes. It's a similar story, I think. I remember the story about the Stonewall riots in America and how that led to gay rights being marched in the street and stuff. What came of that was the visibility of, 'Oh, these people are like me,' and together you form a movement and that sort of thing. That's essentially what the whole 'fad' of catching ADHD off TikTok has been, I think. It's been highlighting that visibility to everyone who has either gone through life to a certain point and is struggling in one way or another like this, like, 'Why am I failing at being normal,' right? There is that similar thing of everyone waking up to it, and the resources available aren't necessarily forthcoming to be able to deal with it.

CHAIR - There's more knowledge and understanding.

Mr SPOHN - The way they deal with it as well is quite cumbersome.

Mr BEHRAKIS - Just on that and - people are waking up to it a bit and that's come with some pressures and whatnot, but more awareness in this space is obviously better. You spoke about how being treated and being aware of it has changed your life and that feeling of validation when you found out about it. If we were in a world where the processes were such that people could access that in a reasonable time and there was more understanding of it in the medical space that people could get identified at an earlier age, whether at school or as a younger adult. If you were able to get picked up for ADHD and treated earlier, how different do you think - what effect would that have had? I know we have heard from a number - and I'm rambling now. We have heard from a few people and seeing where people have talked about experiencing grief after finding out they have ADHD because you think about all the things that could have been. How life changing is accessing that and how different would it have been if you accessed it earlier?

Mr SPOHN - It is an interesting thing because I can see in my eldest, certainly, the pathway that could have been mine, had the services or the knowledge been around when I was her age. There is a certain amount of grief of what could have been. Certainly, I would have probably not job-hopped nearly as much. I would have probably, earlier on, decided to maybe try to stick into a career that would have been more - or stick to studies that were far more leaning towards my interest and things. I went through college and I was doing methods, maths and what else, like English, communication - things that I felt that I probably should do because I was good at them in high school, but have not really come into play at all.

Just as an aside, the exam process, having to cram knowledge into your own head to spew out on a paper in a certain amount of time. Not saying it can't be done, but that is not how the world is these days. We literally have all human knowledge condensed into our pocket these days.

It is not that your memory is the most important thing to life these days. We have a network that goes beyond that. I look at how I would probably have stuck more with certain work. I would have probably pursued a different career; I'd probably have been able to earn more. I would love to be able to take my kids on holidays interstate and stuff. I am just a casual at this temp agency and have been for a number of years. It's not that I am struggling with money, but it's tight and there is not necessarily the latitude that my parents had to take us on holidays, for example. I think there are certainly missed opportunities and currently I'm like, 'Well, you know what, I haven't gone bald yet. I am still doing all right. It is not over yet'.

CHAIR - Nick, I feel like we could keep chatting to you all afternoon, but our time together has rapidly come to a close. Sorry, we went a bit over. I wanted to make up the time that we missed at the beginning with our technical difficulties, but we have learned a lot from you. Thank you very much for giving us your time and being so generous with your time to present to the committee.

Mr SPOHN - I appreciate it. If I can have one last thought before I go. A friend of mine, she was diagnosed as an adult and for some reason she is charged a different amount for her medication than I am. I don't think that should happen. It is not something you just catch when you are an adult. If you want something submitted from her?

The second thing just to state, my wife's experience is the way it's medicated: the medication does not take into consideration the female monthly cycle. That is probably something that needs to be scrutinised as far as the treatment is concerned because when you're treated on this day, you might be very different to this day.

CHAIR - That's a great point and I would give an unsolicited support of that comment, in saying that most medical research doesn't consider the bodies of women. So, this is another example of medical research that needs more input from the effects on women's bodies.

Mr SPOHN - Certainly, and yes, it was just more of the rigmarole to actually get the medication is just so convoluted anyway, so that's just something that probably should be - maybe UTAS can get onto that? I don't know.

CHAIR - Yes, more research. Thanks, Nick.

Mr SPOHN - Thank you so much for having me and thank you so much for accommodating me to actually appear here, so thank you very much.

CHAIR - We're really grateful that you could give us your time.

THE WITNESS WITHDREW.

The committee adjourned at 2.26 p.m.