SBS INSIGHT

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DOSE OF REALITY

There are now more people being treated for attention deficit hyperactivity disorder than ever before. In 10 years the number of Australians taking medication for ADHD has doubled. Recently the biggest increase has been in adults and girls. Some are worried the condition is being over diagnosed and that the medication is potentially harmful. But for many it has really helped.

JENNY BROCKIE: Here's Sashka Koloff.

SHY'S STORY:

REPORTER: Sashka Koloff

ALISON TULLY: You're doing really well.

You know from the time they're born and you can't mistake it, you really can't. There's a very big difference between a normal child and a child with ADHD.

Alison Tully could see the affects of ADHD in her son Shy when he was just a baby.

ALISON TULLY: As an 8-month-old baby, you know, you could get babies to smile or giggle or anything like that. Shy wouldn't and couldn't. He was very aggressive even as a baby - arms swinging around and everything like that.

Shy was born with a host of medical problems - torticollis, a condition which affected the muscles in his neck, and a severe middle ear infection commonly known as glue ear. When Shy was two, doctors suggested he might have ADHD as well.

ALISON TULLY: Shy went to a few childcare centres because I was trying to work at the time he was little, and a lot of the childcare centres were saying, "Look, we haven't seen a child like this, we cannot control him, we can't have him." So that actually led me to finishing all work and just taking Shy totally. That's when he said "OK, he's got the ADHD. We don't know because it's in such a line on what degree that he has it or anything."

At two, Alison thought Shy was too young to medicate. She tried adjusting his diet instead but it didn't work.

ALISON TULLY: He would be sitting there and he would just start screaming and screaming and these screams would last for five to six hours. You just couldn't stop them, you couldn't sidetrack him to anything else, he'd just be so angry. His little fists would be clenched like that, his face would be so angry like this, you know. Ready, go.

As Shy grew up, his behaviour became even more extreme. Again,

Alison sought the help of doctors.

ALISON TULLY: I was quite distraught at the time and I told them that I didn't feel that I was qualified to look after him and I didn't know why. And, um... Sorry. The thing was a lot of the doctors want you to go into their offices for like five seconds or whatever, a couple of minutes, and if your child's got this, the child's ripping the office apart, they're looking at you like, you know, "Control your child," and it's not me, there was something wrong with my child.

SHY TULLY: They want me to show them my karate shirt.

ALISON TULLY: WellWHERE is it?

When Alison took Shy to be assessed by Perth paediatrician and ADHD specialist Dr Trevor Parry stimulant medication was suggested.

ALISON TULLY: Giving your child dexamphetamine is very scary to do. He didn't adjust well the first day. We sat out here and cried.

What happened?

ALISON TULLY: Shy ripped the house apart. He was uncontrollable. He was just looking at things going, "I'm going to break it, I'm going to smash it!" And then he'd look another way - "I hate that too!" - and he'd just pick up a chair and fling it and he would just lose it. In the morning when he goes to school he'll have the quarter, I'll just place it straight in his mouth and he will just have it, he doesn't even need water.

Alison persisted with the medication and although things got better, the side effects worried her.

ALISON TULLY: His loss of appetite as well is very extreme because on the tablets it puts a shade on him that he won't even try other foods or anything, you know.

OK, Shy, get your little purse out so I can put your medicine in for school.

Shy takes breaks from his medication during school holidays and on weekends. But during the week he takes a quarter of a dexamphetamine tablet twice a day. After trying everything, Alison says medication was her only option.

ALISON TULLY: I actually had to put my child on medication at the age of four for him to be able to function. And that's the only reason Shy takes these tablets, is so that he can function and have a life. Prior to that he couldn't, I didn't know what I could do.

JENNY BROCKIE: Well, welcome, everybody. Thanks very much for joining this discussion tonight. And special welcome to you, Alison. And to you Shy, hello. Thanks for coming in too. Alison, how different is Shy when he's on the dexamphetamine to when he isn't?

ALISON TULLY: Oh, there's a big difference. Like.. Shy's sitting here right now all happy and very calm. Without the medication he can't take things in and process them. It's just bang, bang, bang, bang, bang and he doesn't stop. But on the medication, you know, he's still a little boy, he still runs around and goes wild and everything but there's that controlling, that he

can actually intake things.

JENNY BROCKIE: Do you feel different, Shy, when you take that tablet to when you don't take it?

SHY TULLY: Um, yes.

JENNY BROCKIE: When you don't have your medicine how do you feel?

SHY TULLY: Um, silly.

JENNY BROCKIE: Silly. OK, Jessica, you're Shy's sister. How is it impacted on you, this whole situation?

JESSICA TULLY: I find it really hard to talk to Mum just about anything, basically. Like "How's school?" I'm like "Oh, yeah, school was good." But then she's too sidetracked with Shy. Just anything - I can't really talk to Mum because she's always so sidetracked with him.

JENNY BROCKIE: Have you noticed a difference since he's been on the meditation?

JESSICA TULLY: The medication's good, yeah. You can tell when he's not on it.

JENNY BROCKIE: Deborah, you're a single mum with three kids. And your son Jake, who's with you tonight as well, was diagnosed with ADHD when he was six, is that right?

DEBORAH FAYERS: Yes.

JENNY BROCKIE: What's it been like for you?

DEBORAH FAYERS: Very hard, very difficult. I mean, as a single parent with three children the other two find it very hard to cope. I've had them both come to me and ask if Jake could leave home to make it easier on them, to make it easier on us as a family. So it's been a long, hard road.

JENNY BROCKIE: What kind of things did Jake do when he was diagnosed? What sort of behaviour?

DEBORAH FAYERS: Well, he was in Grade 1 and he wouldn't stay in the classroom. The main reason that I got him diagnosed was because I was virtually told he was either put on medication or he would be expelled from school.

JENNY BROCKIE: Who told you that?

DEBORAH FAYERS: The principal.

JENNY BROCKIE: The principal told you that?

DEBORAH FAYERS: Yes.

JENNY BROCKIE: And what would he do at home?

DEBORAH FAYERS: He'd just go from happy to angry like this and he'd

just make everyone's life hell at home.

JENNY BROCKIE: Jake, you're 11 now. We're talking a lot about you here. Do you remember what it was like then, when you were younger? Do you remember how you felt?

JAKE WITHERS: Angry mostly.

JENNY BROCKIE: Angry mostly?

JAKE WITHERS: At school at least.

JENNY BROCKIE: And now?

JAKE WITHERS: Happy, sometimes.

JENNY BROCKIE: And he's on medication, Deborah, yes?

DEBORAH FAYERS: Yes, he is.

JENNY BROCKIE: What is he taking at the moment?

DEBORAH FAYERS: He's taking Concerta. We've dried dexamphetamine and Ritalin to no avail but Concerta is certainly working very well.

JENNY BROCKIE: What was the reaction like on Ritalin? He took Ritalin and dex for a while.

DEBORAH FAYERS: We started off on dexamphetamine and that was for a few years. Now, with Ritalin he was very angry. And it was the school as well as myself that noticed that it just wasn't working. So with We saw a paediatrician at the Royal Children's Hospital in Brisbane and she suggested Concerta. Now, that was at the time the most expensive one to be on but when it's your child you'll pay anything if it works, and it certainly has worked.

JENNY BROCKIE: Jake, I'm interested in exploring with you a little bit more how you feel now you're on that, you're taking that drug?

JAKE WITHERS: I'm not that angry any more.

JENNY BROCKIE: You don't feel that angry any more. How do you feel now?

JAKE WITHERS: A lot better since I've been taking the new tablets.

JENNY BROCKIE: And what about friends?

JAKE WITHERS: I've got a lot more now.

JENNY BROCKIE: And your siblings, your brothers and sisters?

JAKE WITHERS: Sometimes happy with them.

JENNY BROCKIE: Sometimes happy, that's pretty normal. OK. Michael, I'd like to ask you about your diagnosis because you were diagnosed with ADHD 10 years ago?

MICHAEL SIEMIANOWSKI: Roughly, yes.

JENNY BROCKIE: Is that right, when you were 66? Now, what were your symptoms?

MICHAEL SIEMIANOWSKI: The same symptoms that my son had - distractibility. I've got a terrible short-term memory.

JENNY BROCKIE: How long have you had the bad memory?

MICHAEL SIEMIANOWSKI: All my life.

JENNY BROCKIE: And what made you think you might it might be ADHD that you had, though?

MICHAEL SIEMIANOWSKI: Well, I'd never heard of ADHD but my son did poorly in school and he blew his HSC monumentally. And I learned about the ADD support group here in Sydney, got in touch and they guided me to a psychiatrist who diagnosed Paul, put him on dexamphetamine, and shortly thereafter when I learned it was hereditary, I was diagnosed as well so I've been on dex all that time too.

JENNY BROCKIE: So you did you go You actually went to this support group thinking you had it so by the time you went to the psychiatrist were you suggesting that's what it was?

MICHAEL SIEMIANOWSKI: I was classic, for sure.

JENNY BROCKIE: You were sure that's what you had. Are you taking medication now?

MICHAEL SIEMIANOWSKI: Yes.

JENNY BROCKIE: The dex, dexamphetamine again?

MICHAEL SIEMIANOWSKI: It helps a lot.

JENNY BROCKIE: Patrick, you're a paediatrician and an ADHD specialist. The characteristics here are quite different. We're talking about hyperactivity, bad short-term memory. What is ADHD?

DR PATRICK CONCANNON, PAEDIATRICIAN: Well, it's highly inherited, as has been mentioned, and it's lifelong - I think the gentleman up the back is an example of that. It's a disorder of the brain where And it occurs in about 3% to 5% of the population. And that's studies right around the world are showing thatWHEREver they do it, so it's not peculiar to one country. Males are affected more often than females. And I think the three major features that you look for are that difficulty paying attention, the trouble with that excessive level of activity and the impulsive, sort of often unpredictable behaviour.

JENNY BROCKIE: But also there's talk about dreaminess and absentmindedness as being a condition as well. How can that be, as well, a symptom?

DR PATRICK CONCANNON: Well, there are different subtypes. And I think the classic ones that we see are the hyperactive preschooler, the young child who's uncontrollable, the boy in the classroom who runs out of classroom, who's disruptive, distractible. But there's also quite a large

percentage of people with ADHD that only have this sort of daydreaminess, this inattention. And they're often the ones who don't present until later because often they can cope, they don't stand out as a bad learning problem, they don't have behaviour problems.

JENNY BROCKIE: But there can be a lot of reasons for dreaminess, can't there?

DR PATRICK CONCANNON: I'm not saying that dreaminess means ADHD but that's one of the symptoms, that daydreaminess, that lack of being able to keep your focus on a task.

JENNY BROCKIE: And explain for all of us how taking stimulants can make you less hyperactive because I think a lot of people find that a very confusing idea.

DR PATRICK CONCANNON: That's right. It sort of seems a paradox. The brain uses molecules which we call neurotransmitters to move messages from one nerve to another and we need that to be operating efficiently. The trouble in the ADHD person is that that message, that neurotransmitter is not working very effectively. The stimulants work by actually making that connection better, making the neurotransmitters work better and so the information's going from one part of the brain to the other and this results in the person making a bit more structured decisions. And that can be a child who decides he's not going to race out of the classroom, the child who says, "I will stay and pay attention to this book. rather than just do a page and run away."

JENNY BROCKIE: David, you're 49 and you were diagnosed with this condition at 40.

DAVID LEWIS: Correct.

JENNY BROCKIE: How long you think that you'd had it?

DAVID LEWIS: Without any doubt all my life. I just wish I could have had the medication as a child. It would have made an enormous difference to me had I been able to do that. I can look back and see the way that I behaved as a child - and in accordance with this dreaminess, which is my form of ADD, if I could have had the medication as a child, it would have dramatically changed the way I lived.

JENNY BROCKIE: And both of your daughters have also been diagnosed?

DAVID LEWIS: That's correct.

JENNY BROCKIE: Michelle, you run a support group for people with ADHD in Western Australia where there's a high rate of diagnosis, higher than the national average - quite a lot are, I think, nearly twice as many people diagnosed. How often are parents and their children being diagnosed now with this condition?

MICHELLE TONER, 'LADS', WA: Well, more and more, I think. We know that ADHD is as heritable as height. And very often when children are diagnosed a parent is diagnosed as a result of that. When parents hear from teachers that, "For some reason your child's doing really well at

school today, lately. What has happened in the last month at home that may have contributed to his, you know, his better focus at school and the fact that he seems like a much happier child?" and that often coincides with one of the adults in the family being diagnosed with ADHD.

JENNY BROCKIE: George, you're a child psychiatrist in Melbourne. do you think it's genetic?

DR GEORGE HALASZ, CHILD PSYCHIATRIST: I'd have to say that in terms of individual stories, especially here in the audience, it's a very sensitive question to negate what their doctors or carers have said. So I'd like to say a general comment that I have not actually heard any scientific evidence that it's the ADHD symptoms - which is not an illness, it's a set of symptoms - is like height, I have never seen that in a scientific paper, the link between a gene that causes ADHD as closely as genes for height in families. I've not heard the experience that has been mentioned that it's so clear-cut as an illness, as our colleagues have said. And indeed there is a huge global controversy on this subject. So to hear this medical model on genetics, I'm actually quite surprised.

JENNY BROCKIE: Patrick?

DR PATRICK CONCANNON: I think there's been twin studies done in Australia, large big study by Flo Levy, which showed again that high inheritability. There's been three or four others that have replicated that - not in Australia, overseas - where they've showed that the risk If you've got identical twins separated at birth, never seen each other, one has ADHD, if you go and find the other one, probably the chance of that person having it will be 75% to 80%. Fairly strong links, I would suggest.

DR GEORGE HALASZ: Ah, exactly, there are fairly strong links. I don't want to get technical but there are things like temperament that are inherited and certainly there are certain qualities of children with certain temperaments who are more easily irritated, more sensitive to their surroundings, more sensitive to the attachments they have with caregivers. So the association I agree with but certainly I know of no study that is clear-cut on causation. That's the implication.

JENNY BROCKIE: We'll get back to some of this controversy about diagnosis in a moment. And we are in a moment going to meet a family where a father and three of his children have been diagnosed with ADHD. The number of Australians being diagnosed with it is rising. In some cases multiple members of the same family are being medicated to deal with it. Here's Sashka Koloff.

THE BRANDTMANS:

REPORTER: Sashka Koloff

12 years ago Patrick Brandtman was the class clown. He was always getting into trouble at school.

PATRICK BRANDTMAN: Something I do remember distinctly was the class reward system, when you're in that young grade, was just a pyramid that you climbed. They had your little name at the front of class and they'd climb you up as you, you know, if you did something good or you helped out and whatnot, and I could never get off the bottom, I was always doing

something silly, very silly.

REPORTER: Like what would do you?

PATRICK BRANDTMAN: When the teacher left the room I'd run up the front and pretend to conduct and just talking, not playing attention, a lot of mucking around, distracting other students - you name it I was doing it and having a great time at the expense of others I'm afraid.

When he was nine he was diagnosed with ADHD. As part of his treatment, he was prescribed Ritalin.

REPORTER: Tell me do you remember what difference that made to you?

PATRICK BRANDTMAN: Yeah, I went up the pyramid, that's about it. That's all I remember.

A couple of years after Patrick was diagnosed, his father, Mark, and mother, Toni, suspected their second child, Jack, might also have ADHD.

MARK BRANDTMAN: Jack was a good boy at school. He won the Christian living award every year because he was a good boy and looked after everybody and was quiet in the class, but he was off with the pixies.

REPORTER: How did you know then that he had…

MARK BRANDTMAN: The school said to us when he was in Year 3 that they were very concerned about his learning because he wasn't getting his work done, you know, and he wasn't demonstrating an ability, so they felt we should consider repeating Jack. So we were quite shocked by that and we had him assessed by a psychologist who told us that Jack had a superior IQ, and then when we realised that for poor Jack, you know, he wasn't accessing this ability, you know, he was really disadvantaged.

JACK BRANDTMAN: I remember like when I took the medication and went to class I'd come in and I could focus constantly, like I could always do the task and I found that I did the task a lot quicker. If we had a writing task or something I could do it. And it was really good, like I noticed at the end of the day I came home and I was like wow, you know, I did all this work and I can do my homework. And it was just great because I just found it was so much easier.

After both of his sons were diagnosed with ADHD, Mark suspected he had it too.

MARK BRANDTMAN: I don't think my story's any different for any other adult ADHD. Generally adults find out that they're ADHD through their children. A diagnosis is made of their child, they start reading the material, it makes a whole lot of sense to them that, you know, being a genetic disorder that some parent may have this condition and generally one parent will identify very closely with the symptoms at a child level.

At that time little was known about adult ADHD. Mark found it hard to get the diagnosis.

REPORTER: How many times did you get knocked back by..

MARK BRANDTMAN: Twice. Well, by the same fellow a couple of times. I said, “But look,” you know, when Jack was diagnosed I went in after Patrick was diagnosed and I said, "Well, if it's hereditary clearly it's me." And he said "No, no." And then when Jack was diagnosed I said, "Well, look, this is two, you know, This is not by mistake," you know.

REPORTER: If the doctor told you twice that you were not ADHD, why didn't you believe him?

MARK BRANDTMAN: Because I grew up with this, I knew, you know, I knew I couldn't concentrate. Even when he was talking to me I was distracted.

Mark has been taking Ritalin every day for the past nine years. For him the medication has been a revelation.

MARK BRANDTMAN: I think that what it did do was allow me to be really focused and not waste time and to do what I did prior to the medication with half the effort.

Making good use of his time is critical to Mark. Seven years ago he started a business educating people with ADHD about how to manage it. He now sees 60 clients a week. Keeping up his own treatment is vital. Although his psychiatrist, Dr Kneebone, didn't make the original diagnosis, he's been treating Mark for over four years.

DR MARK KNEEBONE: With Mark, being an attention deficit hyperactivity disorder specialist having expertise in it, he knew about his symptoms and he knew about the condition and knew about its evolution, and I was just ticking the boxes as he was talking.

A few years after Mark's own diagnosis he again thought he could see symptoms of ADHD in a member of his family, this time in his 9-year-old daughter, Marta, whom he didn't want to appear in this program.

MARK BRANDTMAN: Girls can do something that boys can't do - they can appear to be concentrating, they can look you in the eye but they're off with the pixies.

REPORTER: You sort of suspected that if the other two boys and you had it, she might too?

MARK BRANDTMAN: It's the most hereditary condition we know of.

REPORTER: So you got a diagnosis for her too?

MARK BRANDTMAN: Yes.

Although Mark and all three of his children have been diagnosed with ADHD, he doesn't see it as an ailment.

MARK BRANDTMAN: I believe ADHD is an asset. In fact I feel sorry for people who don't have it. But the proviso is as long as it's managed. I think a lot of people are undiagnosed out there.

JENNY BROCKIE: Mark, that seems like an extraordinary thing to say

- that you feel sorry for people who don't have ADHD. Why?

MARK BRANDTMAN: Well, I think being ADHD, when managed and when diagnosed properly and having the insight to your behaviours, you gain a lot of control and the quality of enjoyment out of life you get is enormous. I think it can be a real positive in life.

JENNY BROCKIE: Now, when you said it's the most hereditary condition we know of, I mean, that's clearly being disputed here tonight.

MARK BRANDTMAN: In fact it's the most hereditary condition we know of outside childhood autism. But some people focus on the behavioural which is unfortunate because that goes with the diagnostic statistical manual. There are some errors, well, not so much errors, but the way people look at those things you know, as in terms of behaviour when this is a neurological condition.

JENNY BROCKIE: Jon Juredini, I'd like you to comment on this. You're head of psychological medicine at the Women's and Children's Hospital in Adelaide. What's your response to what you've just heard?

DR JON JUREDINI, CHILD PSYCHIATRIST: I think it's easy for people to confuse the fact that something is heritable with the fact that it's a disorder. There's lots of evidence that the qualities of impulsivity and overactivity and inattentiveness run strongly in families but the comparison's been made as it often is to height, and we don't think of height as a disorder even though that's very strongly inherited. So you need more than just a strong pattern of inheritance to make something a disorder.

JENNY BROCKIE: So your concern is that it's being turned into this condition that's being treated with drugs when in fact it might be, what, behavioural?

DR JON JUREDINI: I think that, you know, almost every case that's presented to me as a case of ADHD, with careful evaluation I can come up with a better explanation for what's going on.

JENNY BROCKIE: Can you treat it effectively or help people get through whatever it is?

DR JON JUREDINI: Sometimes you can, sometimes you can't. But, you know, what we're looking.. What all of the medication experiences that people are describing are non-specific responses. This drug has the same effect on any member of the population. It's a non-specific performance enhancing drug and there may be a place for it as long as we're honest about what we're using and why we're using it. We're not using a specific drug to treat a specific disorder. We're just sharpening up people's alertness and attention in the short term, and there is as yet no evidence that long-term learning outcomes are improved by the drug.

JENNY BROCKIE: Mark, do you think the numbers that are being diagnosed now reflect how many people actually have the condition?

MARK BRANDTMAN: Well, if the number of the population worldwide is consistent, which is between 3% and 5% of the population, and Western Australia has the highest population diagnostic rate of 1.8%, clearly we're

under-diagnosing this condition.

JENNY BROCKIE: You think we're under-diagnosing it?

MARK BRANDTMAN: Absolutely.

JENNY BROCKIE: Paul, you're the head of child development at the Westmead Hospital in Sydney. Do you think that misdiagnosis is a problem in this area? Jon's been raising this issue.

DR PAUL HUTCHINS, PAEDIATRICIAN, WESTMEAD HOSPITAL: Jon had a very strong point of view that he can undiagnose and choose better diagnoses. 'Better' means he has a point of view that something is better than ADHD - that's an opinion. We're talking about, and everybody's talked about a range of behaviours that in certain settings, under certain demand are a disability. That's what we're talking about. Society does determine the demand, human difference determines how vulnerable you are. Jon said height is never an illness. If you want to be a jockey and you're 5'8", you may not make it. If you want to be a basketball player, you're extremely disabled.

JENNY BROCKIE: But you're not diagnosed as ill as a result of that.

DR PAUL HUTCHINS: Well, the simple fact is a test of function, a test of how difficult it is and that is why all of us take a lot of information from children, adolescents, parents, we take a lot of information from the people who are the child's world. We put that together. And in terms of the studies of populations, the diagnostic checklists, the decision is - is this an impairment? That's a very complex decision and medication is only one way of improving how the brain organises its response to that.

JENNY BROCKIE: George, a reaction from you.

DR GEORGE HALASZ: Yes, because I think West Australia has been brought up and a number of us see West Australia as a case study where the concern of the difference in prescribing in that State - the higher prescribing compared to other States - resulted in a parliamentary inquiry in that State. And it was handed down in 2004 and the findings were that there were major flaws in the prescribing process in that State. Now, around that time a new monitoring system was introduced to combat this over-prescribing compared to the rest of the State. Now, the parliamentary report had all the available scientific evidence available for it, unless it was claimed to be a biased parliamentary report.

JENNY BROCKIE: So is misdiagnosis a problem, do you think?

DR GEORGE HALASZ: I mean, it's in the literature that it is a problem, yes.

JENNY BROCKIE: Patrick, as a paediatrician, how can you be sure that you're getting it right?

DR PATRICK CONCANNON: In terms of diagnosis?

JENNY BROCKIE: In terms of diagnosis, yeah. It seems as though a lot of the symptoms here - and I'm not trying to downplay at all the seriousness of the condition when people clearly are benefiting from these drugs - but it does seem that a lot of the conditions are things

that could easily be something else?

DR PATRICK CONCANNON: Well, I think that's part of the assessment and I don't think it's a 5-minute assessment. I think it does need a lot of time like that mother indicated, and even then you don't always quite get it right. And I think it's a case of trying to take a good history, listen to the voice of the teachers, the preschool teachers, the people who are looking after the child and try and put it together. But what you also need to do is to try and exclude those other things that can mimic ADHD and part of that is having the experience and the time to be able to try and tease out what are the things that can be masquerading. And when you're left with no diagnosis except ADHD, that's really what it is.

JENNY BROCKIE: Julie, your son Ethan is 13 and he's here too. Hi. He was first treated for ADHD when he was six, is that correct?

JULIE GREATBATCH: Not first diagnosed but first given medication, yes.

JENNY BROCKIE: First treated. And he was prescribed medication. What was he prescribed?

JULIE GREATBATCH: He was prescribed dexamphetamine.

JENNY BROCKIE: And..

JULIE GREATBATCH: And when that didn't work they'd decided that they'd give him an antidepressant. And when 10 dex a day weren't working and a whole Zoloft wasn't working, they then decided that they'd give him Respiratol.

JENNY BROCKIE: And did he have ADHD?

JULIE GREATBATCH: No. My son has Irlen. My son has Irlen, light sensitivity.

JENNY BROCKIE: Light sensitivity.

JULIE GREATBATCH: He had glue ear from birth to seven, severe glue ear, so he only ever heard intermittently. We found out last year he had Irlen, which is not really accepted amongst a lot of the medical profession here in Australia. But he has very, very deep purple lenses in his glasses and he can now see.

JENNY BROCKIE: So how long was he being treated for ADHD before you realised this?

JULIE GREATBATCH: So he would have been six when he was first medicated. And when he was nine-and-a-half we ended up getting into the Families at Work program in Perth which is run through Bentley Hospital.

JENNY BROCKIE: He's nudging you. Speak up, Ethan. Come on.

JULIE GREATBATCH: Sorry, he's trying to tell me he was eight.

JENNY BROCKIE: You were eight, OK. You just pipe up whenever you feel like it.

JULIE GREATBATCH: Interrupt me, feel free. So we went into Families at

Work and Ethan had to spend they run a 10-week program, Ethan had to do 20 weeks in there because his anxiety levels were so high and they found it so hard to put him back into school. From that point he's not been medicated again, OK.

JENNY BROCKIE: And how are things now?

JULIE GREATBATCH: Brilliant. Once he was given the glasses and we put him into an agricultural college, OK. Because he started high school this year so we put him into an agricultural college. Once we started that he's never looked back.

JENNY BROCKIE: Who first suggested he might have ADHD?

JULIE GREATBATCH: Initially it was the first school that we were in. The principal, let me put it this way, she didn't come straight out and tell me but the inference was definitely there if I didn't get him medicated, that she would expel him.

JENNY BROCKIE: Linda, you studied the links between schools and ADHD diagnosis. What have you found?

LINDA GRAHAM, CHILD AND YOUTH STUDIES, SYDNEY UNIVERSITY: I mean, it can be so innocuous as a teacher suggesting to the school counsellor that there are problems with the child, and sometimes the teacher is not aware how loaded the language that they're using is.

JENNY BROCKIE: And what's wrong with that, though? What's wrong with a teacher suggesting to a counsellor there's a problem with the child?

LINDA GRAHAM: Despite what we've heard earlier tonight, there are numerous reasons for a child displaying behavioural symptoms. Learning difficulties can be one, poverty, hunger can be others, autistic spectrum disorder - all of these so-called diagnoses have very, very similar profiles.

JENNY BROCKIE: But are you finding there's more of a prevalence to move to the ADHD suggestion than anything else in the research you're doing?

LINDA GRAHAM: Well, the way it works is - and this is pretty much the situation in every single State. But in order for a teacher to get support to help children in her class learn, she...they need to get support funding. The way that that is tied, it's tied to disability category criteria.

JENNY BROCKIE: This is a pretty serious suggestion you're making, that teachers are actually - and I don't want to paint a sinister picture of teachers here because I have a lot of respect for teachers - but clearly your concern from the research you're doing that people are looking too quickly to this as a possible answer for why there's inappropriate behaviour.

LINDA GRAHAM: I think the most important thing that needs to be understood is that first of all ADHD has the behaviours of children have become highly medicalised. We have a kind of public vernacular that uses words like 'hyperactivity', 'impulsivity' and 'attentional difficulties' to describe things that, you know, 20 years ago we would have said 'scatterbrain'

instead. But also teachers are pretty much caught in a vice between increased responsibilities upon schools and decreasing resources.

JENNY BROCKIE: Alright, Cheryl, I'd like to get a comment from you about this because you're a primary school principal. You're also president of the NSW Public School Principal Forum. Is there a tendency to see this? I mean, is it... has it become a part of vernacular in a sense and is it something upper most or prominent in teacher's minds?

CHERYL MCBRIDE,PUBLIC SCHOOLS PRINCIPALS FORUM: Certainly it's become something that we're aware of. I have to say I'm extremely disappointed with what Linda is saying because I just don't believe that to be true. We go through a process, if a child is displaying continuous, outstandingly different types of behaviours that are significantly impacting on their learning, on their social interaction with other children if there hasn't been some major trauma in the family. So you know, we'd always make sure we'd try and eliminate anything unusual such as the poverty issue and abuse issue, change of diet, etcetera. And I think teachers have never been better at assisting parents and assisting the medicos to give information, give good and relevant information about what is wrong with a child.

JENNY BROCKIE: Jon, what did you want to say?

DR JON JUREDINI: That's what worries me a little bit - the idea that the role of a teacher is to pick up mental problems in schools. I mean, what we need to be supporting teachers in schools to do is to provide a good educational and pastoral care environment.

JENNY BROCKIE: Deborah, you might want to comment on this.

DEBORAH FAYERS: Well, in my personal experience with Jake, at a school level, once your child is diagnosed with ADHD, it's like there's a black mark against their name.

JENNY BROCKIE: Diagnosed is a weird word to use because a school can't diagnose anything.

DEBORAH FAYERS: But having a principal come to you and say that, "I really think that your child should be medicated or he's going to be expelled," was very, very dramatic.

MARK BRANDTMAN: Jenny, but what the teachers do, they're looking for things that are impairing this child's ability to learn. Teachers are particularly... they are experts at age stage. They know where they're supposed to be.

JENNY BROCKIE: But they're not doctors.

MARK BRANDTMAN: No, they're not. And that's the other point. They don't make a diagnosis. They are looking for impairment in this child's learning - what could it be? They go through an extensive process and then they refer them to a doctor. He makes the diagnosis, not the teacher.

JENNY BROCKIE: Patrick, I'm just interested whether a school has ever suggested a case of ADHD when you've contacted them about a

patient, or whether you've had a school come to you and say, "We think this child has ADHD."

DR PATRICK CONCANNON: No, but sometimes the parents will come along saying the school are concerned about the child in some ways - paying attention, being disruptive - and they feel the child needs some more assessment. I mean, when the mother's saying that I think I've had once where, you know, the mother came along and said, "The school said he's got to be on medication." That's once in 25 years. You need to have information from people who are living with the kids.

JENNY BROCKIE: Alright, Jake wants to say something. Jake?

JAKE WITHERS: Every time I get in a fight in my school I get in trouble. I'm always the one that gets blamed for it, not the other people. Like the teachers just take it out on me.

JENNY BROCKIE: They take it out to you. Why do you think that is?

JAKE WITHERS: There's always two sides to it but I never even win, like I always get into trouble.

DEBORAH FAYERS: They don't ever listen to what Jake has to say.

JENNY BROCKIE: You feel like people don't want to listen to you. Ethan, what do you want to say?

ETHAN GREATBATCH: At my old school when I was... when I was younger, I always used to get into fights the same as Jake, and they never ever wanted to hear my side of the story. It was always the kids that weren't naughty that got...never got suspended, never.

JENNY BROCKIE: Julie, what do you want to say?

JULIE GREATBATCH: I want to say that - and I'm only speaking for Western Australia and my experience, OK - I find that the education system in general is ready to use these children as scapegoats for the inappropriate decisions grown-ups make in schools. I really wish I had a principal like this lady over here, I would have loved it, I would have absolutely loved it that there was someone there to actually support me. No-one was ever interested in why Ethan behaved the way he did - why did he run away from class, why was he noisy, why was he.. No-one was ever interested in the why. All they cared about was the behaviour. They weren't interested in the why. They didn't want to know about the why. It was too hard to know about the why.

JENNY BROCKIE: The number of Australians taking medication for it is rising. And Brett Mason, I'd like to bring you in at this point. You're the Federal Parliamentary Secretary for Health. You've been listening to this discussion tonight. Your Government is reviewing the national guidelines for diagnosis and treatment of ADHD. Why are you doing that review?

BRETT MASON, PARL. SEC. DEPT OF HEALTH: Well, there's been a lot of public concern about misdiagnosis or over-diagnosis or over-prescription of drugs. Secondly, of course, because the guidelines are updated every few years in any case. So it's a matter of getting the evidence in and then

by about the end of this year or early next year there will be a new practice guidelines.

JENNY BROCKIE: Now, recently the chair of that review committee, Daryl Efron, stood down after he acknowledged that he was working in an advisory role for two of the pharmaceutical companies making ADHD medication - Novartis and Eli Lilly. Do you think that was a conflict of interest that he had in being on that review committee?

BRETT MASON: Well, the physicians as well as the National Health and Medical Research Council have rules regarding conflicts of interest and it did seem to be in conflict with that.

JENNY BROCKIE: I'm interested in that conflict of interest question. Patrick, you chair the NSW Stimulants Committee which advises the State Health Department, is that correct, on prescribing. Now, do you work in an advisory role for any of these companies, the drug companies?

DR PATRICK CONCANNON: Yes, I went to an advisory meeting for one of the companies last year. I mean, the college has guidelines and I think that hopefully... I feel I fit within those. I mean, I think what I'm happy to do is to talk to a drug company, a behavioural company, anybody who's got something that potentially can offer some help to these kids. That doesn't mean to say that I'm, you know, sort of doing something at their bequest. I'm really interested in trying to get the best treatments that we can for these kids. And it's not just medication.

JENNY BROCKIE: But you are advising the State Health Department on prescribing drugs, aren't you? I mean, that's one of your functions on the stimulants committee is to give advice.

DR PATRICK CONCANNON: On the monitoring of the use of stimulant medication, yes.

JENNY BROCKIE: Paul, what about you, from Westmead Hospital? Have you ever worked in an advisory role for any of the pharmaceutical companies?

DR PAUL HUTCHINS: I have been on advisory boards for each of the manufacturers. I was also one of the writers of the old NHMRC guidelines and Talk Time Team Work. The college statement in support of Daryl Efron is absolutely contrary to Brett Mason's statement that he thought there was a conflict of interest. The college has come out very clearly supporting Daryl's ethics.

JENNY BROCKIE: So you think it's appropriate to have that relationship, those relationships?

DR PAUL HUTCHINS: And the college ethical guidelines state of course it's appropriate to have expertise shared with a range of interested people. The college guidelines state that and - as we all do - to declare those interests.

JENNY BROCKIE: So do you think Daryl Efron should have stood down or been moved from the committee?

DR PAUL HUTCHINS: Well, that's a political point of view. The college professional point of view has very strongly supported him.

JENNY BROCKIE: Yes, you've made that point.

DR PAUL HUTCHINS: I've made that point clear.

JENNY BROCKIE: Jon?

DR JON JUREDINI: I think sadly there's no such thing as safe sex with the pharmaceutical industry, that abstinence is what we doctors need to practice.

JENNY BROCKIE: But how many doctors do that? Haven't you ever taken a pen or a notepad from a drug company?

DR JON JUREDINI: Not in the last 10 years, no. It is possible not to enter into that kind of relationship with the pharmaceutical industry. And, you know, when drug companies ask doctors to be consultants for their firms, really the evidence suggests that what they're asking us doctors to do is to help them with the marketing process. They've got plenty of scientific expertise within their own organisations from which they can get all the information they need in order to make their scientific decisions. We doctors are used and abused by the pharmaceutical industry in order to promote their marketing ends.

JENNY BROCKIE: David, you wanted to say something.

DAVID LEWIS: Jenny, look, we're on a witch-hunt here and I fail to understand why we're in this situation. People with ADD.

JENNY BROCKIE: Hang on, hang on. What do you mean a witch-hunt? We're having a debate.

DAVID LEWIS: I know. I'd like to make my point. The people with ADD are being vilified consistently. Are we arguing the condition doesn't exist? I live this every day, I know what it's like. Other people who live with it every day. These misdiagnoses are tragic and they're errors of judgment of professionals. To argue that there are poor teachers out there who are misusing the system to rort it so that they get better funding is a fallacious argument and I find highly offensive. At the same time, to argue that to say that there aren't doctors who make misdiagnoses would also be absurd. But why are we going through this process of examining whether stimulant medication is good or bad?

JENNY BROCKIE: Because we have evidence that we have one particular State in Australia that has almost twice the level per head of population that all the rest of the States do. Because we have evidence that the numbers of people being diagnosed are going up. And we're asking the question whether that is happening because there are more cases or whether there might be an issue of misdiagnosis.

DAVID LEWIS: Why aren't we doing this with Ventolin? Ventolin is prescribed to many children. There are side effects with Ventolin. I'm quite certain that there are people who are diagnosed with asthma who don't have asthma who are prescribed Ventolin. So where is this drive against

really the stimulant medication and a line of argument or questions to doctors which said "Are you in effect doing something inappropriate by having a relationship with a drug company?"? I'm sure there are people that do the wrong thing in a whole range of different industries but to go through a process where we're arguing against a form of medication, which I can tell you has an enormous benefit to me and others, is unsatisfactory.

JENNY BROCKIE: I'm going to give Linda a chance to answer.

LINDA GRAHAM: I'd really like to respond to the kind of embellishment of what I've said because I am not saying that teachers are out there doing something bad. What I'm saying is that the structural arrangements of the system encourage schools and teachers to look for other reasons for, you know, disruptive behaviour in schools. The medical construct of ADHD actually operates as an escape clause because then schools and teachers don't actually have to look at their own practice if kids are bored in school, if kids don't understand what's going on. And the fact of the matter is that ADHD is not supported as, you know, a disability or a learning disability.

CHERYL MCBRIDE: I think your observations show a sad lack of what really happens in most schools most days. And I think perhaps you're going down the line of the infinitesimal. And I feel sorry and I express disappointment and sorrow for those parents who have had difficulty. We don't get additional funding for ADHD children.

LINDA GRAHAM: I just said that.

JENNY BROCKIE: Nicola Roxon, you're calling for a national inquiry into this. Why? Into the whole issue of ADHD?

NICOLA ROXON, SHADOW HEALTH MINISTER: Well, I'm concerned that the Government's review is going to be a very restricted one. Now, I've been told by some of the other participants that they are confident that this review will look at some of the broader issues that have been raised today, like whether we need to provide more support to our teachers, whether we need to make sure there's more support for allied health professionals, whether some of these other alternative options that should be looked at before a final diagnosis is made, will form part of that review. But there's nothing that's publicly available that shows that something is being looked at that widely.

JENNY BROCKIE: But are you concerned about the situation now?

NICOLA ROXON: I am concerned. I have said publicly and I am concerned that there is a risk of over-diagnosis. I'm concerned, to be honest, not with just ADHD. I think that we can over-medicalise a range of things. And I think when you've got young children yourself, you become very acutely aware of whether you would want your child to be on medication unless you were clear it was the right thing. And I don't dispute that for many of the stories that have been told today for those children it obviously has been the right thing.

JENNY BROCKIE: Brett Mason, do you agree with those sentiments that Nicola Roxon has raised?

BRETT MASON: I agree with Nicola that it's a broad issue and a difficult problem but one of the reasons why we're looking at it across education,

diet, parenting and other issues is to ensure that we cover all those issues in the review, and the assessment is, as I say, based on world's best practice.

JENNY BROCKIE: The long-acting ADHD medication Strattera will be on the PBS from 1 July, I understand. Now, it includes a warning for anyone prescribing the drug for children to balance the risk - what it says, and I'll quote here - "The risk of suicidal thoughts or behaviours" against the clinical need for the drug. Are you concerned about that drug being made more widely available, especially given some of the concerns we've heard tonight?

BRETT MASON: Jenny, I'm always concerned about all drugs and all drugs have potential side effects, you're quite right. It's a matter of balancing on the one hand the benefits of a drug and on the other hand, of course, the potential side effects it might have. but that's really a job better left for clinicians and the Therapeutics Goods Administration and other experts, not to politicians.

JENNY BROCKIE: OK, Patrick, how do you respond to this call for an inquiry?

DR PATRICK CONCANNON: I think it's great to have an inquiry, provided it's broad and it looks at all the aspects. We've talked tonight a lot about medication and medication is an important thing in the treatment of ADHD but there is a lot of issues, a lot of other interventions that need do be addressed. And I think it's good for the NSW and the federal inquiry and the review of that to look broadly.

JENNY BROCKIE: George, what would you like to see?

DR GEROGE HALASZ: Look, I think I'd like a little bit of rationality, because in a learned setting with colleagues saying that there's a genetic cause - I appreciate the refinement of association, at least that gives us a little bit of breathing room - we are perpetuating myths. Now, ADHD actually stands for the words "attention deficit and hyperactivity disorder". It was created by a committee of psychiatrists in America. I don't know of asthma, for example, being created by a committee. I don't know appendicitis being created by a committee. This is a construct of the American Psychiatric Association. I would also point out the fact that it was given almost as gospel that the statistics throughout the world are the same. They're not. Those countries that use the ICD, the International Classification of Diseases, have a different rate of ADHD equivalents, there are different rates over different years. So I think to have misinformation is a disservice to our community.

JENNY BROCKIE: I'm going to get a couple of final comments from our guests we started with. Alison, I'd like just to final comment from you about what you've heard tonight.

ALISON TULLY: I think it's out there but I know that I'm doing the right thing for my son. I can see it in him, everyone can see it in him. He's doing really well now we've taken the right levels and everything like that.

JENNY BROCKIE: Julie, final comment from you. What would you like to see?

JULIE GREATBATCH: What would I like to see? All children have proper eye examinations, all children have comprehensive hearing examinations, right, at pre-primary, at kindy, all children and all children be Irlen tested. Scandinavia does it, why can't Australia, why can't Western Australia? Really check these children out before you decide to give them a drug that no doctor - and I went to three doctors in Western Australia, not one of them told me that taking Ritalin or dex could cause heart attack, could cause stroke, cause nausea, cause depression, caused a whole range of other I was never told that. So how about you start telling the mums what we're actually giving our children.

JENNY BROCKIE: OK.

ALISON TULLY: It's up to us to actually go in deeper and look at that.

JULIE GREATBATCH: I strongly disagree.

ALISON TULLY: A doctor can say this drug and that, no way.

JULIE GREATBATCH: It's a medical... it's a doctor's... As far as I'm concerned it's a doctor's obligation.

ALISON TULLY: And yourself to do it as well.

JULIE GREATBATCH: Then you inform a parent, you let a parent know exactly what the consequences of using that medication are.

ALISON TULLY: Absolutely. They ran through all the side effects on his drugs.

JULIE GREATBATCH: I'm happy for you, I'm really glad it's all worked out really well for you and I really hope that that's You know, I'm really happy for you, I sincerely mean that. But our experience has never been as positive as yours, and I have four other friends.

JENNY BROCKIE: We are going to have to leave it there. And we're leaving it there with two very different experiences, which I think is probably an appropriate way to leave it. I would like to thank you all very much for joining Insight tonight.