

# **EDUCATION AND HEALTH STANDING COMMITTEE**

## **INQUIRY INTO ATTENTION DEFICIT DISORDER AND ATTENTION DEFICIT HYPERACTIVITY DISORDER IN WESTERN AUSTRALIA**

**TRANSCRIPT OF EVIDENCE TAKEN  
AT PERTH  
ON WEDNESDAY, 26 NOVEMBER 2003**

### **SESSION 2**

#### **Members**

**Mrs C.A. Martin (Chairman)**  
**Mr M.F. Board (Deputy Chairman)**  
**Mr R.A. Ainsworth**  
**Mr P.W. Andrews**  
**Mr S.R. Hill**

**Co-opted Member**  
**Mr M.P. Whitely**

[10.50 am]

**TONER, MRS MICHELE EVA**

**Executive Officer,**

**Learning and Attentional Disorders Society of WA,  
examined;**

**The DEPUTY CHAIRMAN (Mr M.F. Board):** Good morning. You were here when I made my introductory comments earlier, were you not?

**Mrs Toner:** Yes.

**The DEPUTY CHAIRMAN:** You heard what I had to say about our inquiry.

**Mrs Toner:** Yes.

**The DEPUTY CHAIRMAN:** This is a hearing of the Parliament and therefore needs to be treated with the same respect as the Parliament. Any deliberate misleading of the committee may be regarded as contempt. Have you completed the "Details of Witness" form?

**Mrs Toner:** Yes, I have.

**The DEPUTY CHAIRMAN:** Have you read the information for witnesses?

**Mrs Toner:** Yes.

**The DEPUTY CHAIRMAN:** You were obviously here when we were talking earlier. I have a number of questions. I would like to explore various aspects of LADS. You were privy to some comments made earlier in which it was asked why it is that LADS is consulted. I want to ask about the information you have gathered, the sorts of people you have brought together and what you see as the role of LADS? Has it now got an official status of some kind; if not, do you think it should have?

**Mrs Toner:** I have a short statement I would like to make about LADS - uninterrupted, if possible - just stating for the record what LADS does and what we are.

**The DEPUTY CHAIRMAN:** We would be more than happy with that.

**Mrs Toner:** First, I would like to start by thanking the committee for giving me the opportunity to appear again, because I did feel at my last appearance that I was not given a fair hearing. I would like to thank the committee for the opportunity to come back.

For the record, I will not be answering questions about a video that I made a year ago, which is really not relevant to this hearing at all. Just for the record, in reply to questions that were made last time, the professional advisory board has confirmed that there was nothing that I said on that video that was incorrect or outside my area of qualification, and that any future queries about that video should be directed to them. Once again for the record, it was a video about adults with ADHD and at no time was any advice given to parents on how to treat their children with ADHD.

About the two submissions I made to this committee, the first submission I made was my master's dissertation. This was a qualitative study of adults with ADHD who were undiagnosed as children, and is the study that Steve was referring to a minute ago. The University of Western Australia appears to have regarded it as a study of some worth because I was awarded my masters with honours at UWA. I also won its prize for best research in special education in that year - I think it was 2001 - and I was valedictorian at my graduation. I hope my study will give the committee

some sense of what it feels like to grow up with undiagnosed ADHD and the sense of grief that adults feel over the years lost to the undiagnoses and the chaos that has ensued in their lives as a result of their lost years through undiagnoses. Also, it is very important for the committee to hear and understand the frustrations experienced by adults with ADHD because of the total lack of treatment for adult ADHD in the public health system. It is very expensive to try to access treatment for adult ADHD.

I would like to talk mainly though about my second submission, which was made as part-time executive officer at LADS. I would like to talk a little about LADS because statements have been made about LADS on the public record, in the media and in Parliament that have been incorrect. I would like to correct those now, so that next time they are made in Parliament under parliamentary privilege, perhaps you will all know the truth and will be able to correct them.

LADS was established 10 years ago as a support group for adults and children with ADHD. LADS is an evidence-based support group, which means that we only recommend ADHD treatments that have been proven effective in scientific studies - and I mean scientific studies, not surveys done in someone's waiting room. We do not recommend, and have never recommended, the use of medication alone for the treatment of ADHD. Clearly, research shows that the multimodal treatment of ADHD is the best way to treat it, and that is what we advocate. This may include speech therapy, occupational therapy, behaviour management, counselling for adults, individuals, children and families, tuition and medication, if appropriate and if tolerated by the individuals.

It is important to know that LADS is advised by a professional advisory board consisting of educators, paediatricians, psychiatrists, clinical psychologists, a speech therapist, an occupational therapist and a dietitian/nutritionist.

[11.00 am]

LADS is held in high esteem by many government departments. In our recent strategic business plan, for example, both the Department of Education and Training and the Office of Mental Health were quoted as saying that they regarded LADS highly, particularly because of our evidence-based approach. LADS is managed by a management committee which consists of a minimum of four professional members. At present we have a teacher, a nurse, a counsellor and an educational consultant. LADS is an active member of the Neurological Council of WA, the WA Association for Mental Health and the Genetic Support Council WA. We work very actively in those organisations. LADS is the only effective scientific group for ADHD in WA. Furthermore, LADS is the leading support group for ADHD in Australia and advises ADHD groups in other States. At the moment I am assisting South Australia and New South Wales to set up professional advisory boards for their support groups. I am the only paid staff member of LADS. LADS runs on a shoestring budget. For the public record, the part-time executive officer of LADS earns \$400 a week. A highly qualified and trained group of volunteers assists in the running of our office. These include one PhD, three masters in special education, a librarian, a pharmacist, two nurses and three students.

It is very important for the committee to know that government departments such as DCD and the State Child Development Centre refer people to LADS on a regular basis. In the past two weeks we have had two children come to LADS for treatment for depression, which is complicating their ADHD. The two children have been sent to our counsellor, who is working with them in conjunction with the State Child Development Centre because there is a dire shortage of those services in the state system. Furthermore, child and adolescent mental health services refer people to us, and in writing. The Department of Education and Training, the Department of Justice, juvenile justice and the Office of Mental Health give out our number regularly. Despite this, LADS does not receive recurrent funding from the Government and struggles for survival. Why do you suppose we get these referrals? We offer excellent services at very reduced rates in order to assist people in accessing the multimodal treatment of ADHD. These services include regular individual

and family counselling and nutritional consultations, monthly support group meetings for parents and for adults with ADHD, and a quarterly newsletter. In addition, in the past year we have run two behaviour management workshops for parents, two effective nutritional workshops, three workshops for teenagers with ADHD and have featured guest speakers on depression, anxiety, the latest research - for example, Stephen Houghton - coaching, mentoring and psychotherapy for ADHD. One of our volunteers has conducted two respite weekends for mothers of children with ADHD. One of those weekends was partly funded by Carers WA. We also run professional development sessions for teachers, TAFE lecturers and GPs through our professional advisory board. Community groups such as Riding for the Disabled Association of Australia, Probus and the Kidlink early intervention program have been supplied with speakers from LADS. Students from TAFE and universities have made extensive use of our library for their assignments. We have collaborated with several universities on scientific research. We have a web site under development, which was funded by the Telstra Foundation and which will support people in remote areas.

Finally, and very importantly, it is important to note that LADS does not promote, but rather condemns, the plethora of so-called drug-free ADHD treatments, which are unproven and unscientific. These include cranial manipulation, neuro feedback, megavitamin therapy, sugar-free diets, more exercise, more fresh air and, my particular favourite, essence of tarantula spider. These fanciful cures come at a very high price. We are very concerned about the thousands of dollars that are spent by vulnerable members of the public on these unscientific snake oils that do not achieve positive results. Thank you.

**The DEPUTY CHAIRMAN:** Thank you, Michèle. The work of LADS is obviously extensive. You mentioned that you do not receive any recurrent government funding. Where does your funding come from? What are the different sources?

**Mrs Toner:** We have in the past received two lots of emergency funding from the Office of Mental Health when we have been very close to closing our doors. We received \$10 000 this year and \$5 000 the year before. We really get our money through fundraising and memberships. We charge a membership of \$33 or \$16.50. We try to fundraise. Our resources are limited anyway. We are trying to get a web site up. Fundraising takes up a lot of our time.

**The DEPUTY CHAIRMAN:** How many members do you have?

**Mrs Toner:** At the moment we have between 600 and 700 members.

**The DEPUTY CHAIRMAN:** How many other people would you touch?

**Mrs Toner:** A lot. People obviously do not have to be members to access our help line, which runs Mondays to Fridays between 9.00 am and 1.00 pm. They do not have to be members to come to support group meetings. We ask people to become members before they can access counselling, the library or the majority of our workshops. That brings our membership up.

**The DEPUTY CHAIRMAN:** Are most of the people who come to you or who join looking for a support mechanism to share their experiences and work out a way in which to deal with their children? Do you have adult members who suffer from ADHD?

**Mrs Toner:** Yes, we run an adult support group.

**The DEPUTY CHAIRMAN:** What would be the percentage of those people compared with those who are there for their children?

**Mrs Toner:** In the past we predominantly received phone calls from parents, but at the moment we probably get an equal amount of calls for adults and children.

**The DEPUTY CHAIRMAN:** Have any corporate bodies or bodies outside of government used you in terms of providing advice for in-house activities?

**Mrs Toner:** For their staff?

**The DEPUTY CHAIRMAN:** Yes.

**Mrs Toner:** Certainly. We were approached this year by a mining company. Our professional advisory board received a letter from a mining company to get some feedback on ADHD in the workplace and on the mines. We have advocated on behalf of adults with ADHD in one or two workplace situations in the past. However, there has not been a lot of input from corporations. We would certainly welcome it and would like ADHD to be better catered for in the workplace.

**The DEPUTY CHAIRMAN:** Before I open up to general questions, it was mentioned earlier that LADS is not consulted. What sort of relationship do you think you should have with government agencies, particularly the Department of Education and Training and maybe the Department of Health, in terms of the advice and assistance you may be able to give.

**Mrs Toner:** I think that we would be a very valuable resource, because we are in touch with the public; we are in touch with their client base and the people whose tax dollars are funding those departments. We get about 3 000 phone calls a year. In fact, I got a phone call from someone in Mr Hill's constituency. She wrote you an e-mail because we had had the discussion in the committee and I thought it was important for you to hear from an adult with ADHD. I believe that we have valuable information to pass on to government departments about the kinds of things that taxpayers are experiencing.

**The DEPUTY CHAIRMAN:** Okay. Do you think that you should have formal recognition as an agency?

**Mrs Toner:** I think so. I think we certainly have informal recognition across the country. It would be nice to get formal recognition as an agency, along with some funding.

**Mr P.W. ANDREWS:** I do not have any questions about the video. However, why do you not want to answer questions about the video?

**Mrs Toner:** Because it is not relevant, Mr Andrews.

**Mr S.R. HILL:** I have just a quick one. We heard earlier from Stephen that older people in the community are now coming to the point at which a lot of them are participating in community activities. For example, a group of seniors may get together and may want to volunteer for a lot of things. Does LADS have involvement with that? Do you get a lot of calls from older members of the community who now want some knowledge of why life has turned out for them as such?

**Mrs Toner:** We certainly do. We get calls. One of our volunteers is well into her 70s. She was diagnosed with ADHD in her 70s. She has found that that has made a big difference in her life. We get calls from older people but we find that people in their 70s and 80s are reluctant to go down the ADHD route because it is such an unknown entity in that age group. We certainly get queries from that age group.

**Mr S.R. HILL:** Sandy mentioned it earlier. As an elected member, I tend to get a lot of people who come to my office and want to volunteer to help with the Riding for the Disabled Association, for example - we have a school in Geraldton. I just wanted some information about people of that age making contact with LADS.

[11.10 am]

**Mrs Toner:** It is quite common for people to be diagnosed in their 60s. I had one gentleman in my study who was diagnosed very late in life, and had gone back to university to finally enter the profession he had always wanted to pursue. There are people who find in their 70s and 80s that they have the condition, and do not know what to do. Because there has been no research in that area that I know of, it is very difficult to advise them, except to give them the name of a psychiatrist and a psychologist and ask them if they would like to take part in some of LADS' activities. However, if a retired person suddenly must find \$250 for a psychiatrist's consultation, it is almost impossible for that person if he or she cannot access the service through the public health system.

**The DEPUTY CHAIRMAN:** One of the points that was raised, and one of the reasons for this inquiry, is the fact that many parents have been singled out and criticised because their children are on medication. Quite a number of letters have come into my office from people who have been attacked by the P and C association in their school. Has your organisation been asked to represent parents in any way? Does it play a mediation or education role in that sense? What role does LADS play in those instances?

**Mrs Toner:** I will preface my answer by saying that LADS is of the opinion that the media in Western Australia, which have taken a bit of a bashing here this morning, have been very understanding of late about the scientific background of ADHD. There has been a lot less sensationalist reporting and a lot more responsible scientific reporting about ADHD. There is a stigma attached to ADHD. One of the things we do on a regular basis is give talks to the school drug education project. Because there is so much hysteria about dexamphetamine in the playground - it is something that always comes up in drug education in schools - one of the things we do is give talks to school communities, parents and teachers about the appropriate use of dexamphetamine and the reasons people use it, and say in no uncertain terms that people with ADHD have a legitimate diagnosis and have every right to take medication for their ADHD. We do that fairly regularly for people.

**Mr M.P. WHITELEY:** I have just one question, but you may not be able to answer it. You made reference to some 70-year-olds being diagnosed with ADHD.

**Mrs Toner:** I referred to one such person, yes.

**Mr M.P. WHITELEY:** The diagnostic criteria say that some hyperactive, impulsive or inattentive symptoms that caused impairment were present before the age of seven years. How does anybody go back, retrospectively, 63 years to assess whether those symptoms were present?

**Mrs Toner:** The answer to that question, and all the questions you have raised about the diagnostic criteria is the reason the diagnosis of ADHD is entrusted to specialists like paediatricians, psychiatrists and neurologists. As you so cleverly pointed out, ADHD, anxiety and depression all have very similar symptoms. Psychiatrists spend years and years training in the art of the clinical interview, so that they can differentiate between anxiety and depression. The lady who was diagnosed in her 70s with ADHD has a mind like a steel trap, and she can remember exactly what happened to her when she was a child.

**The DEPUTY CHAIRMAN:** A lot of statistics have been thrown around already, and we have read various things about what has happened in other States. We heard just a little while ago that 29 per cent of people in India suffered the syndrome, although I am not sure how those figures would be arrived at. Do you have a feel for this, considering your experience and the representation you give to parents of the extent of ADHD and other symptoms that accompany it? Are we talking about 10 per cent of the population with ADHD?

**Mrs Toner:** I do not know; I cannot answer that from personal experience. All I can say is that there are huge epidemiological studies that identify prevalence rates. Internationally, according to DSM-IV, the figure is between three and seven per cent. At last count, 4.2 per cent of children were diagnosed with ADHD. In terms of the co-morbid conditions, it is very rare for us at LADS to find someone with pure ADHD, possibly because those are the easiest cases to treat. Ken Whiting, who is the chairman of our PAB, always says that your co-morbidity determines your outcome. When people do not treat all of the disorders - the ADHD, the anxiety, the depression and whatever else is in there - the outcomes are poorest. However, as we know, they require expensive treatment, and many people cannot afford them.

**The DEPUTY CHAIRMAN:** What did you hope would come out of this inquiry? What is missing from the equation from a government policy point of view? What had you hoped we could resolve in terms of clarity and certainty in this issue?

**Mrs Toner:** I would like the Government to assist in educating the public to establish ADHD as a legitimate disorder, and not just an easy hand-out of pills by parents who are too lazy to discipline their children. It would be excellent if there were some education of the public about what ADHD is and how difficult it is for families affected by the syndrome. It is essential for the Government to start making the treatment of ADHD in adults accessible in the public health system, and to educate psychiatrists in the treatment and diagnosis of ADHD. A handful of psychiatrists are willing and trained to do that, but they are very expensive. It would be a lot easier to access multimodal treatment, and there would be less medication if other treatments were available.

**The DEPUTY CHAIRMAN:** Is cost a factor?

**Mrs Toner:** Cost is a huge factor. If you can afford it, you can get state-of-the-art treatment for ADHD in Western Australia.

**The DEPUTY CHAIRMAN:** What sort of costs are you talking about? I am sorry to do this, but it is important to get it on the record, because that might be one of the reasons people are not seeking support. Can you take us through a normal situation in terms of costs?

**Mrs Toner:** I will just think of a typical family. Bear in mind that in many families there is more than one child with ADHD, and also perhaps an adult with ADHD. They have to see a paediatrician, psychiatrist or neurologist every six months. That would cost perhaps \$130 to \$140 a visit. Some of that is rebatable through Medicare. If there were motor coordination problems, which there often are, you would then have to see an occupational therapist. I am not sure what they charge these days - at least \$50 a session. Very often a speech therapist is involved because there is a language disorder. So we have speech therapy, occupational therapy and a paediatrician to pay for. Then there is medication, and in order to access the best medication options people really should be going for the slow-release medication, and that is not on the pharmaceutical benefits scheme, so that is another \$50 a month. Then there is counselling if there is a bit of anxiety, and cognitive behavioural therapy for anxiety costs \$120 a session. Except for the paediatrician, whose charge is partly covered by Medicare, none of the other services are covered unless you qualify to access them through the public health system, and only a very small proportion of people qualify for that. If you do qualify, you are very often on a waiting list.

**Mr P.W. ANDREWS:** Right on that point, do you find that many parents you come into contact with are trying to treat their children themselves?

**Mrs Toner:** In what way?

**Mr P.W. ANDREWS:** You have just talked about the sheer cost of going through this exhaustive process. Do you find that many parents try to come up with other means, using tutors or that sort of thing?

**Mrs Toner:** Absolutely. There are people who home-school their children, for example. There are children who just get medication because their families cannot afford anything else.

**Mr P.W. ANDREWS:** Do you think there is pressure on them to medicate because they cannot get any treatment other than the medication?

**Mrs Toner:** The other treatments do not necessarily replace the medications. All they are getting is one part of the treatment, which is not ideal. They might be getting one part of the multimodal treatment, which is not fulfilling their requirements. If they cannot afford tutoring for example, and they are three years behind in their school work, but they are getting their medication, they are able to concentrate in class, but because they have not caught up on the years they have missed, medication is not actually doing the trick it should be doing. It is not fulfilling its potential. Once again, if they are getting medication but no occupational therapy, they will not correct their gross or fine motor problems. Another thing is social skills training. A lot of parents are paying for social skills training, because the social skills of children and adults with ADHD are often lacking, and they find themselves socially isolated. So parents pay for social skills training as well.

**Mr P.W. ANDREWS:** Would you say parents feel pressure to put their children on ADHD medication?

**Mrs Toner:** I did not say that at all. I said that parents are under pressure because they cannot afford the treatment of ADHD. Some children only get one part of the treatment, and that would be medication with dexamphetamine or Ritalin, because they cannot afford the rest.

**The DEPUTY CHAIRMAN:** We had a group of parents in here some weeks ago. You talk about the social problems these people had. It nearly made us cry to find that some of these young people right through their primary school years had never been invited to another child's birthday party. These families have not gone out for years as a family, because of the social difficulties of taking their children. They were socially isolated. The impacts of those things often are not understood or are overlooked. How do you deal with those things? Obviously, that is why people come to LADS, to try to get that sort of support. What do you do with them?

**Mrs Toner:** LADS is a safe place because people can come and not be judged. At our coffee mornings, which are held once a month for parents, they are just able to come and talk about everything, and know that no-one is raising their eyebrows at them. Our coffee mornings are also run by a clinical psychologist, so she is able to give them some pointers on things they might be able to do. There are tricks around if you cannot afford social skills training. There are some tricks that you can give parents, and things that parents are always doing to try to get their children socially accepted. Also in the adult group, when the adults with ADHD come, they just feel so relieved because they are in a group where everyone understands what they have been through, and they cannot believe that there are other people who have the same experience as they do. In a sense, LADS is a safe haven where there is no judgment and no blame, and that is very comforting for people. When people phone sometimes and they tell you things, and you understand because you have heard it 20 times, people are reduced to tears, because you are not sending them to a positive parenting course, which will not make a blind bit of difference, because it is not tailored to children with special behavioural needs. Certainly we will then offer our behavioural management courses, and tricks for parents to help them socialise their children better. One of the most tragic things is - I have one member who phones me in particular because her mother is so condemning of the fact that her child is on medication, and that she has had a child diagnosed with ADHD. She finds that very often there is no support within the immediate family, so they are condemned. At family barbecues, Uncle Bill is saying "Send me this kid for a day and I will sort him out". Everyone thinks they know about ADHD and how to fix it, because they watch *Today Tonight*, when in fact people have no idea of the complexity and the problems families go through.

**The DEPUTY CHAIRMAN:** Thank you for re-attending. I apologise that I was not here at the last meeting. Thank you for the information you have given us today; it has been most valuable.

**Committee adjourned at 11.25 am**