REPORT OF THE

STANDING COMMITTEE ON CONSTITUTIONAL AFFAIRS

IN RELATION TO

A PETITION REGARDING ATTENTION DEFICIT HYPERACTIVITY DISORDER

Presented by the Hon Murray Nixon JP MLC (Chairman)

Report 47

STANDING COMMITTEE ON CONSTITUTIONAL AFFAIRS

Date first appointed:
21 December 1989

Terms of Reference:

1. The functions of the committee are to inquire into and report on:

   (a) the constitutional law, customs and usages of Western Australia;
   (b) the constitutional or legal relationships between Western Australia and the Commonwealth, the States and Territories,

   and any related matter or issue;

   (c) a bill to which SO 230 (c) applies but subject to SO 230 (d);
   (d) any petition.

2. A petition stands referred after presentation. The committee may refer a petition to another standing committee where the subject matter of the petition is within the terms of reference of that standing committee. A standing committee to which a petition is referred shall report to the House as it thinks fit.

Members as at the date of this report:

Hon Murray Nixon JP MLC (Chairman)
Hon Ray Halligan MLC
Hon Tom Helm MLC (resigned from the Committee November 9 1999)
Hon Kenneth Travers MLC [1](appointed to the Committee November 10 1999)

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[1] See Appendix A.

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REPORT OF THE LEGISLATIVE COUNCIL STANDING COMMITTEE ON CONSTITUTIONAL AFFAIRS

IN RELATION TO A PETITION REGARDING ATTENTION DEFICIT HYPERACTIVITY DISORDER

1 INTRODUCTION

1.1 THE PETITION

1.1.1 On April 29 1998, Hon Ray Halligan MLC tabled a petition *(Tabled Paper # 1561)* concerning Attention Deficit Hyperactivity Disorder ("ADHD"). The petition requested the Legislative Council to:

> "1. In line with the World Health Organisation, National Health and Medical Research Councils and Commonwealth Government Policies, acknowledge the existence of Attention Deficit Hyperactivity Disorder (including ADD and Associated Learning Disabilities) as affecting an unknown but significant number of children, youth and adults in Western Australia.
>
> 2. Ascertain the services and facilities available to those disadvantaged in this way within the Ministries of Health, Education, Disabilities, Youth, Children and Family Services, Justice and Employment and Training.
>
> 3. Encourage a program of public and professional education and awareness to allow the facilitation of early identification and appropriate remediation for sufferers of this neurobiological disorder.
>
> 4. Encourage the establishment of a professional advisory board to advise Government of the appropriate remediation and protocols within Government agencies."

1.1.2 The petition was retabled by Hon Ray Halligan MLC on September 8 1998 *(Tabled Paper # 140)* and again on September 7 1999 *(Tabled Paper # 135)* again requesting that the Legislative Council consider the matters raised in the petition.

1.2 ADD/ADHD

1.2.1 In this report the term Attention Deficit Disorder is abbreviated to ADD and the term Attention Deficit Hyperactivity Disorder is abbreviated to ADHD.

1.2.2 At the Committee hearing conducted on October 21 1998 (referred to in detail in paragraph 9 of this report) one of the witnesses, Professor Landau, advised the Committee that the three core behaviours of both disorders are inattentiveness, impulsiveness and over-activity. It is the extent of the third category that determines whether the disorder is labelled ADD or ADHD.

2 THE PETITIONER'S SUBMISSIONS

2.1 The Committee received a letter from the principal petitioner dated May 13 1998 as part of her submission to the Committee. In that letter the principal petitioner stated that:

- ADHD is "described as a neurological development disability, frequently characterised by developmentally inappropriate degrees of inattention or overactivity and impulsivity";

- ADHD and ADD came within the World Health Organisation's definition of a disability and ADHD is classified as a disability under the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders;

- "there are little or no services for ADHD sufferers in any Government Services. Children with ADHD are only treated at Western Australia's sole children's hospital if they have a co-existing medical problem which requires attention. A diagnosis of ADHD does not allow services to be made available. Some children are seen at the Child Development Centre (Rheola Street) but the majority of children are serviced through the private sector, scattered scant regional facilities and the Attention Deficit Society in Mosman Park which is a benevolent society with little or no government funding";

- "parents who have ADHD children and who have the financial means will have access to appropriate medical assistance. There is [sic] absolutely no facilities at all for Aboriginal children, many of whom suffer from ADD/ADHD";

- "there exists no Government education or direction in the wider community to protect these vulnerable children and their families from the prejudice generated by a misinformed media"; and

- "a professional body of appropriately credentialed personnel with a substantial degree of clinical practice could assist Government policies in being more targeted and as a rule more effective in remediating such tragedies in our community."

2.2 In a subsequent letter to the Committee dated July 23 1998 the principal petitioner stated that "one of the tragedies of our Mental Health System is that ADHD/ADD clients are being diagnosed with an exotic array of psychiatric disorders and are subsequently being "warehoused" at facilities like Graylands Hospital".

3 THE MINISTER FOR EDUCATION'S SUBMISSION

3.1 The Committee received a letter from the Minister for Education dated July 6 1998 advising the Committee that the Education Department recognised that ADHD was a disorder which may affect a percentage of children in Western Australian schools. The Department was aware that there were no reliable tests for ADHD and was concerned that some children may be labelled inappropriately.

3.2 The Minister advised that the Education Department did not treat ADHD as a separate learning and behaviour category but as one of many disorders which may place a child at educational risk. The Minister advised the Committee that the Education Department had developed a comprehensive and coordinated strategy for students at educational risk titled *Making the Difference.* The strategy included *Policies and Guidelines for Students at Educational Risk*, a *Framework for Successful Practice for Students at Educational Risk* and teacher resources. The strategy focused on prevention, early identification and intervention to address the needs of the diverse group of students at educational risk, which included students with ADHD.

3.3 The Minister advised that all schools had access to support for teachers, students and parents from the Student Services personnel based in each district education office. These included School Psychologists and Aboriginal Liaison Officers, and may also include School Social Workers and School Welfare Officers.

3.4 The Committee was advised that the Education Department agreed, in principle, to a program of public and professional education, provided it did not cut across its existing policies and guidelines. The Education Department did not support the establishment of a professional advisory board, but did support the effective utilisation of existing support agencies such as the Learning and Attentional Disorders Society of Western Australia.

Administration of medication to students by school staff

3.5 The Committee made further inquiries with the Education Department concerning its policies and procedures for the administration of medication to students by school staff.

3.6 In response to its request, the Education Department provided the Committee with a copy of its policy document entitled "Administration of Medication Policy and Procedures" dated 1997 ("the Education Department policy"). The Education Department policy may be used for all students who attend Government schools and facilities up to the age of 18.

3.7 The Education Department policy states that school staff are required to comply with reasonable requests for assistance for the administration of medication while the child is under the authority of the school. Assistance for students who require administration of medication will depend on:

- the ability of the school staff to meet the particular needs of the student; and
- the contribution toward care which may be provided by the student (as in self-administration), parents, teachers and other staff, school community nurses, community pharmacists and other community organisations.

3.8 The Education Department recognises that:

- some students have a need to access medication on a regular basis for medical conditions;
- the presence of quantities of drugs in the school can be a problem and needs to be monitored;
- the extent to which assistance can be offered will be governed by available school and staff resources; and
- a student self-care concept (where the student is capable of self-administering medication) is preferable if this is a viable option.

3.9 The Education Department policy for prescribed medication states that if a student is required to carry and self-administer prescribed medicine while at school, the parent/guardian/carer must advise the principal of all relevant details such as what form the medication takes, the correct dose and the symptoms associated with misuse, overuse,

or under use as indicated by the treating doctor. Only the quantity of medication for the school day can be brought onto the school premises by the student.

3.10 The Education Department policy also states that school staff are not expected to administer prescribed medication or treatments which require specialist training, such as giving injections.

3.11 According to the Education Department policy, if the student is determined to be incapable of self-administering prescribed medication and school staff are to administer medication to the student, the following protocol applies:

- the parent/guardian/carer must provide written authority for the school staff accepting responsibility to administer the prescribed medication;
- the parent/guardian/carer is responsible for the submission in writing of any requirements of the student for medication, including details from the medical practitioner, and of the circumstances for the appropriate use and application of the medication;
- the parent/guardian/carer must provide the medication in a properly labelled container noting the name of the student, the name of the medication and the dose to be taken. Minimal quantities only should be sent to school unless there is a need for larger amounts to be sent, by agreement with the school;
- school staff should only administer prescribed medication in accordance with instructions or the advice of a medical authority;
- principals must ensure the medical information for the student is available to all staff who have the student under their care; and
- the choice of a prescribed medication is the treating doctor's responsibility. It is not the responsibility of school staff to comment on prescribed medication for students.

3.12 The Education Department policy requires that all records of medication administered by staff members to a student be retained for the period up to that student's 25th birthday. These records are deemed to be confidential and their collection, storage and security are the responsibility of the school principal.

4 THE MINISTER FOR HEALTH'S SUBMISSION

4.1 In a letter to the Committee dated July 13 1998 the then Minister for Health, Hon Kevin Prince MLA, stated that there is a considerable body of research evidence regarding ADHD, which is a recognised condition with defined criteria. He also advised the Committee that all mental health services, including outpatient psychiatric clinics and inpatient units, are required to provide a comprehensive range of services to all client groups, including those with ADHD.

4.2 The then Minister also advised that in order to understand this condition and its impact in Western Australia, he had requested Professor George Lipton, General Manager of the Health Department's Mental Health Division, to establish a small panel of internationally recognised psychiatric experts to address the issues associated with persons suffering from ADHD in Western Australia. The eminent experts would visit Perth in August/September 1998 and undertake consultative forums to discuss the local prevalence, diagnosis and treatment of ADHD. They would then spend another 2 days analysing the information gained from the forums and the Western Australian and Australian literature. Based on this evidence they would prepare their report which would come to the Minister and the Cabinet Sub-Committee on ADHD for consideration. The report would provide advice on sound modern clinical practice in the diagnosis, treatment and care of people with ADHD.

4.3 The Committee subsequently requested further information from the Minister for Health concerning the manner in which ADHD is dealt with by the Health Department. The Committee was advised by Hon John Day MLA, the current Minister for Health, that the Mental Health Division within the Health Department of Western Australia is currently in the process of developing a Government policy on the diagnosis and treatment of ADHD.

4.4 The Minister advised that there are many issues surrounding the diagnosis and treatment of ADHD that do not lead to simple resolution. The issues are complex and there are divergent views within the community and between professionals.

4.5 The Minister stated that the policy will provide guidelines about those aspects of ADHD diagnosis and treatment that can be best addressed by Government. The Minister anticipated that a draft of the policy would be available for public consideration in the New Year.

5 MINISTER FOR FAMILY AND CHILDREN'S SERVICES SUBMISSION

5.1 The Committee made inquiries with the Minister for Family and Children's Services concerning programs that have been and are being developed by the Department of Family and Children's Services to assist families with children with ADHD.

5.2 In response to its inquiry, the Committee received a facsimile letter from the Department dated October 29 1999 which informed the Committee that the department provides a range of services which are not specifically targeted at children with ADHD and their families. The department will assess all the needs of a child and family and provide services in cooperation with other agencies and with reference to medical practitioners where relevant.

5.3 The Department of Family and Children's Services advised the Committee that the department does not provide specific services for families with children who have been diagnosed with ADD or ADHD. However, families with these children will have a range of needs which may result in them being referred to the department for assistance.

5.4 Family and Children's Services develops programs that enhance the functioning of families, particularly those with complex needs. Where families or carers have a child medicated for ADD or ADHD, additional methods of management are essential. The family will require information, support and strategies relating to parenting and behaviour management issues. The Department's workers will assess all the needs of the family and children and provide appropriate services to meet those needs.

5.5 The Committee was also advised that the Department employs a number of specialists who work with families with complex needs, including education officers and psychologists. Management strategies are developed with families to manage the child's behaviour and the Department will work in cooperation with other agencies and service providers, including medical practitioners, to assist the family.

6 REPORT OF THE INTERNATIONAL PANEL ON ATTENTION DEFICIT HYPERACTIVITY DISORDER

6.1 Following their visit to Perth towards the end of 1998 the panel of international experts referred to at paragraph 4.2 of this report prepared a report entitled *Attention Deficit Hyperactivity Disorder in Western Australia - Report of the International Panel on the Diagnosis and Treatment of ADHD* ("the International Panel Report") which was presented to the Mental Health Division of the Health Department of Western Australia.

6.2 The report arose from concerns within the Health Department of Western Australia that some children might be being treated inappropriately with stimulant drugs, either because of misdiagnosis or because of mismanagement.

6.3 The terms of reference for the International Panel were:

- to participate in a Consultative Forum in Perth to discuss the local prevalence, diagnosis and treatment of ADHD;
- to examine reports referring to ADHD treatment;
- to examine documented prescribing patterns in Western Australia and Australia in relation to ADHD;
- to examine documented drug availability, regulations, the Pharmaceutical Benefits Scheme and Western Australian Government Policy in relation to ADHD; and
- to provide a report on the diagnosis and treatment of ADHD from a psychiatric perspective, incorporating current knowledge as well as information gained in the consultative forum and documentation provided.

6.4 The International Panel comprised the following members:

- A/Professor Brain Barnett, School of Psychiatry, University of New South Wales;
- Dr Brian Greenfield, Associate Professor of Psychiatry, Magill University School of Medicine, Montreal Children's Hospital, Quebec;
- Professor Laurence Greenhill, Professor of Clinical Psychiatry, Division of Child and Adolescent Psychiatry, New York State Psychiatric Institute, New York;
- A/Professor Florence Levy, School of Psychiatry, University of New South Wales;
- Professor Robert McKelvey, Professor and Director, Division of Child and Adolescent Psychiatry, Oregon Health Sciences University, Oregon, USA; and

- Professor Barry Nurcombe, School of Psychiatry, University of Queensland.

6.5 The International Panel Report includes:

- advice on sound modern clinical practice in the diagnosis, treatment and models of care in ADHD in children, adolescents and youth;
- recommendations on the roles and responsibilities of core professionals in their contribution to the multidisciplinary team offering diagnosis and treatment of ADHD;
- advice as to the conditions falling within the diagnostic parameters of ADHD; and
- advice on local issues influencing needs for further research.

6.6 The International Panel Report states that stimulant medications are clearly recognised as effective and helpful in the treatment of properly diagnosed and managed ADHD. Nevertheless, the rapid increase in prescribing of such medication for children both in Australia and internationally has led to growing concern. The International Panel Report notes that many people in the lay and professional communities are questioning whether all those children who are being medicated have been correctly diagnosed and whether alternative or adjunctive treatments have been duly considered.

6.7 The International Panel Report recommended that an epidemiological case-finding study of ADHD in Western Australia be carried out and that a multidisciplinary oversight committee be established to facilitate and oversee that study. The International Panel Report proposed that the committee be called the Treatment of ADHD Standards Committee ("TASC").

6.8 The International Panel Report recommended that membership of TASC should consist of recognised national and international experts on ADHD, psychiatric epidemiology and health care delivery systems. TASC's responsibilities would include review of the proposed research design, the implementation and execution of the study and the interpretation of the results.

6.9 The International Panel Report stated that it is essential that TASC be seen as a truly independent scientific monitoring and advisory body, neither dependent upon, nor involved directly with, the funding body or the study's researchers.

6.10 The Committee notes the advice from the Minister for Health that the recommendations in the International Panel Report, including the recommendation that a multidisciplinary oversight committee be established, will be addressed in the process of developing the Government policy on ADHD, discussed at paragraph 4.3 of this report.

7 REPORT OF THE TECHNICAL WORKING PARTY ON ATTENTION DEFICIT DISORDER

7.1 In 1996, a Technical Working Party on ADD was constituted by a Cabinet Sub Committee of the Western Australian Government. Its terms of reference were to inquire into and report to Government of the incidence of ADHD in Western Australia and to seek expert opinion on the appropriate diagnosis and treatment for this condition.

7.2 The Technical Working Party was chaired by Professor Lou Landau of the University Department of Pediatrics, Princess Margaret Hospital and consisted of representatives from the Health Department of Western Australia, the Education Department, Family and Children's Services, Disability Services, and the Director, State Child Development Service.

7.3 The Cabinet Sub Committee comprised the following members:

- Hon Colin Barnett MLA, Minister for Education;
- Hon Cheryl Edwardes MLA, the then Minister for Family and Children's Services;
- Hon Kevin Minson MLA, the then Minister for Disability Services; and
- Hon Kevin Prince MLA, the then Minister for Health.

7.4 During its inquiries the Committee obtained a copy of the Technical Working Party's report on Attention Deficit Disorder to the Cabinet Sub Committee dated April 1997 ("the Technical Report").

Introduction

7.5 The introduction to the Technical Report states that in Western Australia, ADHD is thought to affect 2.3 - 6% of children[2] and is characterised by three core behaviours: inattentiveness, impulsiveness and overactivity which are at a level inappropriate for the child's expected developmental level.

7.6 A child with inattentiveness quickly loses the focus of his or her attention resulting in boredom, distraction and flitting from task to task without achieving to capacity. Schoolwork often suffers as work takes a long time to complete or never gets finished. With impulsivity, the child often speaks and acts without thinking and has a quick temper. Overactivity is characterised by restlessness, fidgety behaviour and hyperactivity.[3]

7.7 Some conditions which commonly have symptoms similar to those of ADHD include:

- hearing impairment;
- intellectual disability;
- specific learning disability;
- autism;
- brain injury;
- epilepsy;
- childhood depression and other emotional problems;
- family dysfunction; and
- the normal active preschooler.

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2 Glow, RA (1990), 'A validation of Connor's TQ and a cross-cultural comparison of prevalence of hyperactivity in children' in Burrows, G and Werry, J (eds), *Advances in Human Psychopharmacology,* Conneticut, JAI Press, pp. 303-320 as noted at p. 4 of the Report of the Technical Working Party on Attention Deficit Disorder to the Cabinet Sub Committee dated April 1997 ("the Technical Report").

3 Green, Dr C and Chee, Dr K (1994), *Understanding ADHD*, Doubleday, Australia and New Zealand as noted at p. 4 of the Technical Report.

7.8 The Technical Report states that overlap with conduct disturbance, learning difficulties, emotional disorders, family dysfunction and disorders such as Tourette's Syndrome may lead to problems in diagnosis although in many cases there will be comorbidity.[4]

7.9 The Australian Bureau of Statistics defines comorbidity as "The occurrence of more than one disorder at the same time." The term is not limited to mental health diagnosis. For example, it can be used to describe a person who has co-occurrence of mental health, health or disability disorders.

7.10 The introduction also states that although there is no completely reliable test for ADHD, the methods currently available to professionals bring some objectivity into a very subjective area. Such methods are not foolproof, but can act as pointers towards a probable diagnosis of ADHD. The diagnostic criteria commonly used in Western Australia are outlined in the *Diagnostic and Statistical Manual of Mental Disorders (DSM - IV)*, American Psychiatric Association (1994), Washington DC ("the DSM - IV criteria").

ADHD in Western Australia - A Comparison with Australia

7.11 The Technical Report notes that in Western Australia, prescriptions for Dexamphetamine have increased from an annual consumption of 38 per 100 five to fourteen year olds in 1990 to 7780 in 1993 and for Methylphenidate, from 2205 to 5080 over the same period. It is estimated that approximately 1.6% of male children and 0.15% of female children in Western Australia are on stimulant medication.[5]

7.12 The Technical Report also notes that the ratio of males to females prescribed with stimulant medication in Western Australia in 1993 was 5.6:1.[6] Therefore males are almost six times more likely to be diagnosed with ADHD than females.

7.13 Compared with other States and Territories, Western Australia has a disproportionately higher usage of both Dexamphetamine and Methylphenidate. This may indicate that

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[4] Biederman, J, Newcorn, J and Sprich, S (1991), *Comorbidity of Attention Deficit Hyperactivity Disorder with conduct, depressive, anxiety and other disorders*, American Journal of Psychology, pp. 148, 564-77 as noted at p. 4 of the Technical Report.

[5] Valentine, J, Zubrick, S and Sly, P (1996), 'National trends in the use of stimulant medication for Attention Deficit Disorder', *Journal of Paediatrics and Child Health*, Vol 32, No 3, June, pp. 223-227 as noted at p. 6 of the Technical Report.

[6] *Ibid*.

either Western Australia is mis-diagnosing and/or over-prescribing stimulant medication or that the other States and Territories are yet to 'catch up'.

Diagnosis and Management

7.14 The Technical Report notes that the inaccurate and inappropriate diagnosis of ADHD is counterproductive to attempts to provide adequate resources in this area. Over diagnosis places a drain on scarce resources which should be targeted to those children most in need. Inaccurate diagnosis may direct resources inappropriately and deprive some children and families of resources which they would receive if an accurate diagnosis were made. Under diagnosis leads to inequality of access to quality care.

Diagnostic Criteria

7.15 It is stated that the diagnosis of ADHD is a clinical judgement based on many factors both positive and exclusive. It is dependent on behavioural and functional aspects with the exclusion of conditions which may have similar symptomatology. The Technical Report notes that there is a concern when the parent is the sole provider of information as this can lead to subjectivity.

7.16 The Technical Working Party recommends that the DSM - IV criteria be widely adopted by professionals involved in the diagnosis of ADHD in children. There are five broad diagnostic criteria:

- *Criterion A.* The essential feature of ADHD is a persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequent and severe than is typically observed in individuals at a comparable level of development.

- *Criterion B.* Some hyperactive-impulsive or inattentive symptoms that cause impairment must have been present before age seven years.

- *Criterion C.* Some impairment from the symptoms must be present in at least two settings (for example; at home, school or work).

- *Criterion D.* There must be evidence of interference with the developmentally appropriate social, academic, or occupational functioning.

- *Criterion E.* The disturbance does not occur exclusively during the course of a pervasive development disorder, schizophrenia, or other psychotic disorder, anxiety disorder, dissociative disorder, or personality disorder.

7.17 The Technical Report states that if the DSM - IV criteria are to be followed and accurate diagnosis made on the basis of the criteria, the following principles must be adhered to:

- Diagnostic criteria are collated from at least two settings which, in most cases, would include the school and the home.

- Diagnostic information is objective. Behaviour rating scales may assist in providing objective information but should, where possible, reference the symptoms to population norms for the behaviour of concern.

- In diagnosing ADHD, issues of differential diagnosis need to be carefully considered. There is a need to determine whether symptoms are:

    - appropriate behaviour for active children of that age;

    - excessive for the child's mental age (symptoms of inattention are common with children with low intelligence quotients);

    - arising from the child being placed in settings inappropriate to his or her intellectual ability;

    - those of oppositional or conduct disorders; or

    - arising out of a pervasive developmental or psychotic disorder.

- As well as utilising the information provided by parents, the accurate diagnosis of ADHD requires a multi-disciplinary input. The information required for accurate diagnosis draws on the specialised skills of a variety of professions including paediatrics, psychiatry, clinical psychology, speech pathology, educational psychology, teaching and social work.

7.18 The Technical Working Party expressed its belief that professional development of those involved in the diagnosis and treatment of children with ADHD is integral to ensuring a best practice standard for attending to attentional disorders. It also stated that consideration should be given to the establishment of an institute for applied child

development and learning which would provide a best practice standard for assessment of and intervention with attentional disorders.

Management

7.19 The Technical Report states that ADHD is one of the most frequent reasons for referral of children to the various Child Development Centres in Western Australia. ADHD is essentially a community concern and needs to involve the skills and cooperation of a number of community agencies.

7.20 The Technical Working Party identified a six stage program for the management of children with ADHD as follows:

- Early identification of children with ADHD.

  Children with behavioural, language and other developmental delay may well have associated ADHD. These children can be identified early by community nurses, general practitioners, child carers, pre-primary teachers and a range of health professionals involved with developmental issues of childhood.

- Appropriate and comprehensive assessment.

  This would usually involve medical and educational evaluation with considerations of social and emotional issues, speech and language development, behavioural adaptation, and possibly fine and gross motor control[7].

- Appropriate management of ADHD.

This applies at the school and at home, and includes other therapies (such as speech therapy, occupational therapy and physiotherapy), counselling and medical management. The Technical Report states that stimulant medications are known to be effective in 80% of children with carefully diagnosed ADHD.[8] Methylphenidate (short acting) and

[7] Kelly, D, Forney, J, Parker-Fisher, S and Jones, M (1993), 'Evaluating and managing Attention Deficit Disorder in children who are deaf or hard of hearing', *American Annals of the Deaf*, 138, pp. 349-357.

Urk, RR (1995), 'A diagnosis of attention deficit disorder: What does it mean for school counselors?', *School Counselor*, 42, pp. 292-299 as noted at p. 12 of the Technical Report.

[8] Greenhill, LL (1992), 'Pharmacotherapy Stimulants', *Child and Adolescent Psychiatric Clinics of North America*, October 1(2) as noted at p. 16 of the Technical Report.

Dexamphetamine (long acting) are generally considered to be safe, effective and non-addictive with minimum side effects when used as recommended for the treatment of ADHD.[9] The Technical Report places a caveat on this, however, by stating that stimulant medications should only be used following a careful assessment and a definitive diagnosis. Once the diagnosis is established and medication commenced, it is most likely that the major difficulty with medication will be appropriate dosage.

- <u>Appropriate coordination and advocacy.</u>

Once diagnosed, the child normally requires interventions over a range of different activities and settings. Severe behaviour problems in children involve the family, the school, medical and therapy staff, psychologists and others. The Technical Report states that coordination of a management program requires a clearly designated case manager. Case management must be collaborative, involving all parties including the family and the child.

- <u>Community and professional development.</u>

The Technical Report states that there is a persisting mythology in the community concerning ADHD together with a range of prejudices which mitigate against the best interests of the child. Professionals/centres involved in the multimodal management of ADHD have a responsibility to assist in community and professional development by personal contact, arranging seminars, lectures, media information and professional scientific updates.

- <u>Access to care.</u>

The Technical Report notes that children with ADHD and co-morbid conditions may be seen by private physicians and health professionals in child development centres or in child and adolescent psychiatric clinics. Such clinics are not often used due to long waiting lists and the stigma perceived to be associated with the use of the name ‘psychiatric clinic’.

<u>Treatment - Stimulant Medication</u>

7.21 The Technical Report states that short term responses to stimulants in children with ADHD is well documented with improvements in tasks requiring sustained attention, as well as improvement in self-esteem, maternal-child relationships and peer relationships.

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[9] *Ibid*.

It also notes, however, that improvement in academic performance and prevention of anti-social behaviour over the long term has not been documented.

7.22 The Technical Report states that potential adverse effects of stimulant medication appear to be uncommon. In spite of use over 50 years, however, concerns regarding the long term effects of stimulant medication have not been allayed and surveillance and monitoring should continue.

7.23 Appetite suppression and initial insomnia are common side effects of stimulant medication and that headaches and gastrointestinal symptoms may occur. There is also evidence to suggest that associated tics and the lowering of seizure thresholds may occur and that depression, psychosis, drug abuse and the effects of being labelled ADHD are possible concerns.[10]

7.24 The American Academy of Pediatrics and the Australian College of Paediatrics have both indicated that treatment of ADHD is multidisciplinary and that medication should never be used as the single first treatment.[11]

7.25 The Technical Report notes that the Health Department of Western Australia has established a Stimulants Committee which has developed Guidelines for the use of Dexamphetamine and Methylphenidate. Those guidelines suggest that Dexamphetamine is a much cheaper drug than Methylphenidate and, in most children, equally effective. Therefore, in all children over eight years of age, Dexamphetamine should be tried first. If it is not effective or is causing side effects, a trial of Methylphenidate may be undertaken.

7.26 The Technical Report also points out that the US Food and Drug Administration has instructed the manufacturers of Methylphenidate to amend the labelling of the drug to include new information about a potential risk of liver cancer found in a recent rodent study, even though they consider the evidence to be only a weak signal of carcinogenic potential.[12]

<u>Guidelines to Cease Medication</u>

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[10] Hazell, P (1995), ‘Stimulant treatment for attention deficit hyperactivity disorder’, *Australian Prescriber*, pp. 18, 60-63 as noted at p. 19 of the Technical Report.

[11] American Academy of Pediatrics; Australian College of Paediatics as noted at p. 19 of the Technical Report.

[12] US FDA, Scrip No 2097, 26 January 1996, p. 21 as noted at p. 19 of the Technical Report.

7.27 The Technical Report states that children with ADHD usually require stimulant medication in their primary school years and that the majority of children will probably require continued use of medication in early high school.

7.28 The Technical Report also states that consideration should be given to short trial periods off medication with the gathering of school, home and other relevant information to determine whether the ongoing use of medication is required. If this is done, it is expected that by the end of high school the majority of children with ADHD may not require medication.

7.29 There is a growing awareness of the possibility of a continuing problem for some adults with ADHD and that the extent of this should be the subject of further research. At present, the prescribing of stimulant medication for those over 18 years of age requires assessment by a psychiatrist.

Monitoring

Monitoring of Individual Cases of ADHD

7.30 The Technical Report states that there is a substantial body of knowledge in the world literature regarding the use of stimulant medication. While safety and the lack of significant adverse effects of stimulant medication in the short term are well documented, the long term efficacy and outcomes are not clear. The Technical Report states that an Australasian survey to this effect is required.

7.31 The Technical Report states that the use of stimulants should be monitored as to efficacy as well as acceptability for the child and family with careful review of weight, height, blood pressure, side effects and the possible emergence of comorbidities. The child should be seen at least within the first six to eight weeks of the commencement of medication and thereafter once during each school term. Once the situation has stabilised, it may be acceptable for the child to be seen only twice a year by a consultant. Negative drug reactions should be recorded centrally.

Monitoring of Prescription of Stimulants

7.32 At present in Western Australia, stimulant medication can not be prescribed without an authority under the *Poisons Act (WA) 1964* ("the Poisons Act"). This authority is provided by the Commissioner of Health who has delegated this authority to the Principal Medical Officer. Part of the role of the Stimulants Committee is to advise the Commissioner and to monitor the prescribing of stimulants.

7.33 The Technical Report notes that the Stimulant Guidelines published by the Health Department of Western Australia provide that initial authorisations under the Poisons Act are granted only to paediatricians, developmental paediatricians, paediatric neurologists or psychiatrists. Such specialists who have become familiar with the Stimulant Guidelines for prescribing stimulants have been issued with an *en bloc* authorisation and do not have to apply for authorisation for individual patients provided treatment is in line with the appropriate diagnostic and dosage criteria and the patient's age and weight are written on any prescriptions for stimulants. Where the specialist feels that prescribing by the patient's general practitioner is appropriate then a joint general practitioner/specialist authorisation can be issued at the specialist's request. Renewals of such authorisations will require that the general practitioner provide evidence of continued supervision of the management of the child by the specialist. [13]

7.34 The Technical Report notes that the Stimulants Committee does not currently have criteria for stimulant usage that are uniformly accepted as good practice by a wide range of health professionals and that it has little power to monitor usage. It states that strict diagnostic criteria need to be accepted and that the Stimulants Committee should be resourced sufficiently to enable it to monitor the authorisation of stimulants. Further, the Stimulants Committee should be authorised to carry out random audits into the use of *en bloc* authorisations and that paediatricians and psychiatrists found to be failing to abide by appropriate criteria should have their block authorisation capacity removed.

Financial Costs of Treating ADHD

7.35 The Technical Report notes that the main financial issue in treating ADHD is the high cost of Methylphenidate. Dexamphetamine is a much cheaper drug than Methylphenidate and the Technical Report states that there are no convincing general differences between the two drugs for the treatment of ADHD, although individual patients may respond better to one than the other. It also notes that Dexamphetamine is longer acting and that this has social benefits for children in the school setting.

7.36 The Technical Report states that, in general, Dexamphetamine should be the medication of first choice. In the meantime it should be determined whether Methylphenidate will be covered federally through the Pharmaceutical Benefits Scheme or at State level by the provision through hospital pharmacies with adequate resourcing.

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[13] *Stimulant Treatment Guidelines (February 1998),* Health Department of Western Australia.

Community Support and Public Education

7.37 The Technical Report notes that there is a range of support groups such as the Learning Attentional Disorders Society and that these groups can provide valuable information, advocacy and support to families and children with behavioural disorders. It warns, however, that support groups must be careful not to advocate unvalidated interventions.

7.38 The Technical Report also notes that public education about ADHD is important as the community is confused by statements from extreme protagonists or antagonists of stimulant usage. Resources are required to provide the community with advice on where to seek information regarding the condition, its treatment and medication, how to address the issues with teachers, and access to care in the public and private sectors.

Further Key Actions

7.39 The Technical Report highlights the need for professionals and the community to be informed about ADHD, for continuing research into ADHD to be conducted, and for ongoing evaluation to be carried out.

Strategic Directions For Western Australia

7.40 The Technical Report states that addressing the needs of children with ADHD and their families will require a commitment to intersectoral coordination and cooperation between key government departments and service providers. This will require a commitment by Government for additional funding to relevant departments. Funding should be based on epidemiological data and models of best practice.

7.41 Community groups play an important role in raising awareness and providing opportunities for practical support for families with children with ADHD. The Technical Report states that the role of community groups should be recognised and enhanced with appropriate resourcing.

7.42 The Technical Report states that the Health Department of Western Australia should take the lead role in the development of multidisciplinary treatment services for children with ADHD. The Health Department is also responsible for the areas of assessment, diagnosis and treatment, education and training for health care professionals, monitoring standards and quality of care, and best practice research.

7.43 The Technical Report notes that the Education Department develops programs to address the educational needs of children with learning and behavioural difficulties (including ADHD) and allows these children to remain within mainstream services.

7.44 The Technical Report also notes that Family and Children's Services develops programs that enhance the functioning of families of children with ADHD. It is important that close links with the Health and Education Departments are maintained.

7.45 Research into the assessment and treatment of ADHD will need to underpin the strategies referred to above. A proposed institute for applied child development and learning could play a key role in education and the dissemination of information to professionals and the wider community.

Key Actions

7.46 The Technical Report lists 21 proposed key actions to assist in the diagnosis, treatment and management of ADHD. Those key actions are attached as Appendix B.

8 NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL REPORT - DECEMBER 1996

8.1 During the course of its inquiries the Committee obtained a copy of the National Health and Medical Research Council Report on Attention Deficit Hyperactivity Disorder December 1996 ("the NHMRC Report").

8.2 The NHMRC Report was prepared by a working party chaired by Professor Allan Carmichael, Professor of Paediatrics and Child Health at the University of Tasmania. The other members of the working party consisted of paediatricians, psychiatrists, an educational psychologist, a general practitioner and a consumer representative.

8.3 The terms of reference for the working party are broad and as a result the NHMRC Report is comprehensive in its discussion of the issues involving ADHD. The NHMRC Report considers issues such as the diagnosis and assessment of ADHD and the management of ADHD through medication, education, behaviour management and other forms of management such as diet and alternative therapies. It also considers ADHD in society, with specific discussions on issues for preschoolers, adolescents and adults with ADHD. The report also lists ADHD support groups throughout Australia.

8.4 The Committee notes the issues raised in the NHMRC Report however due to its length and the range of complex specialist issues involved, the Committee has resolved to highlight only those areas of the NHMRC Report it considers relevant to the petition. For a more detailed discussion of these issues, the Committee refers interested readers to the NHMRC Report in its entirety.

8.5 The NHMRC Report states that ADHD is a behavioural syndrome in which symptoms of hyperactivity and/or inattention cause impairment in social, academic or occupational functioning.

8.6 Over recent years concern has been expressed in Australia about an apparent increase in the diagnosis of ADHD and the associated increasing rate of stimulant drug prescription for this condition. The NHMRC Report notes that these observations, combined with evidence of widely differing rates of drug utilisation between and within States and Territories[14] have prompted health authorities and practitioners to approach professional bodies such as the National Health and Medical Research Council for advice on the assessment and management of ADHD with particular reference to guidelines for the use of stimulant medication.

8.7 The NHMRC Report acknowledges that the topic of ADHD has aroused much controversy and emotive debate amongst professionals and in the community in general. The apparently increasing prevalence of ADHD occurs in the context of raised awareness amongst parents, educators and health professionals of the adverse effects of learning and behavioural problems in children. These affect the current performance and self-esteem of children, with cumulative effects extending into adulthood.

8.8 It is also noted that there has been an increasing understanding of factors influencing child behaviour and development, together with the importance of early identification and intervention in the management of developmental problems.

8.9 The NHMRC Report indicates that the main diagnostic systems used to classify mental and emotional disorders, including ADHD, are the DSM-IV criteria and the *International Classification of Diseases,* 10th edition (ICD-10), Classification of Mental and Behavioural Disorders (WHO 1993). These systems both group symptoms and signs into diagnostic categories according to descriptive criteria. The NHMRC Report recommends that the criteria set down in the DSM - IV criteria should be met before a diagnosis of ADHD is made.

8.10 The NHMRC Report states that for children who have behavioural and learning problems that are thought to be due to ADHD, a comprehensive assessment, including medical, developmental and educational evaluation is required. It is essential that the assessment utilises multiple sources of information, preferably from multiple settings. Such an assessment process will enable alternative diagnoses to be excluded, co-

[14] Zubrick, Silburn, Garton et al 1995; Valentine, Zubrick and Sly 1996 as noted at p. 1 of the National Health and Medical Research Council Report on Attention Deficit Hyperactivity Disorder dated December 1996.

morbidities with other mental and emotional disorders and learning disabilities to be determined, and management plans to be developed.

8.11 The use of either categorical or trait approach to the classification of symptoms and signs results in different prevalence rates and, consequently, widely differing prevalence rates of ADHD have been reported, depending on the methodology used, ranging from 1.7 per cent to 6 per cent. The NHMRC Report also notes that Australian studies have found prevalence rates of ADHD between 2.3 per cent and 6 per cent. Most studies have found a higher incidence of ADHD in boys than girls, with boys scoring higher particularly on measures of hyperactivity and disruptive behaviour scales.

8.12 It is acknowledged in the NHMRC Report that the cause of ADHD is essentially unknown. Evidence suggests that many factors, including genetic, neurophysiologic, cognitive, familial and environmental factors are involved. It is likely that a combination of these factors contribute to the symptoms of ADHD. Co-morbidity of ADHD with Oppositional Defiant Disorder, Conduct Disorder and learning disability have been found to be common in both clinical and community samples.

8.13 The NHMRC Report notes that the disruptive symptoms of ADHD, together with the associated learning, behavioural and emotional problems as well as family stress and the continuation of the condition into adolescence and adulthood, combine to produce considerable pressure to treat ADHD. It also notes, however, that multiple causes, changes over time and the range of possible treatments make management complex. While different treatments are not equally validated, the NHMRC Report acknowledges that there is a general professional consensus that multimodal therapy is necessary. The simultaneous use of medication, behaviour management, family counselling and support, educational management, and management of specific developmental issues should be considered.

8.14 With respect to stimulant medication, the NHMRC Report notes that in the short term stimulant medication has been shown to be effective in modifying disruptive behaviour and improving performance both in children and adolescents with ADHD. It notes that there is extensive research evidence to support the efficacy and safety of medication and little evidence of stimulant abuse in the treatment of ADHD.

8.15 Also considered in the NHMRC Report are other treatments for ADHD such as remedial education, behaviour management and family support. The NHMRC Report states that these should be considered in specific and individualised management plans formulated for each child and family. It is acknowledged, however, that support services are limited and waiting lists are long.

8.16 The NHMRC Report states that educational management of ADHD focuses on maximising attention and concentration, reducing impulsive behaviour, improving self-esteem and socialisation, assisting in overcoming learning difficulties and improving communication between school and home. Management methods involve teacher assessment and observation as well as skills training and role plays. Behaviour management typically incorporates systematic problem solving, open and effective communication and anger management/conflict resolution.

8.17 It is accepted in the NHMRC Report that these non-medication treatments will form part of the intervention package for each child and be essential for the individual who does not require or respond to medication.

8.18 It is noted that some studies have demonstrated that dietary components influence some behavioural symptoms, including some found in ADHD. Presently available evidence does not, however, support routine dietary manipulation. Therapies such as megavitamins, patterning, kinaesthiology and others, such as optometric training or tinted lenses, which have been proposed for treating learning disorders, are not supported by scientific evidence for the management of ADHD.

8.19 ADHD in preschoolers, adolescents and adults presents additional challenges as diagnosis and management is complicated and relevant literature is sparse. Preschool children show a variable and wide range of behaviour due to the rapid developmental changes that are normal in this age group, while co-morbidity frequently complicates ADHD in adolescents. Consequently, for these groups more care is required in monitoring and evaluation. While diagnosis of ADHD in adults uses similar techniques and criteria to those used in children and adolescence, behaviours and dysfuntions may alter over time with fewer hyperactive symptoms. The NHMRC Report recommends further research into the assessment and management of ADHD in each of these age groups.

8.20 The NHMRC Report sets out 26 Recommendations which are attached as Appendix C.

9 HEALTH DEPARTMENT OF WESTERN AUSTRALIA STIMULANT TREATMENT GUIDELINES - FEBRUARY 1998

9.1 In February 1998 the Health Department of Western Australia published revised Stimulant Treatment Guidelines for Criteria for Issue of Authority Under the Poisons Act to Prescribe Dexamphetamine or Methylphenidate for Children or Adolescents ("the Guidelines").

9.2 The Criteria for Routine Granting of Authority to prescribe Dexamphetamine or Methylphenidate includes diagnostic criteria, age criteria, a caution if the child has certain conditions, a guide as to dosage levels and a prohibition against the routine granting of authorisation if there is a history of substance abuse.

9.3 The diagnostic criteria guidelines requires that symptoms must be of at least six months' duration, manifest before seven years of age and significantly affect the child's behaviour and performance at school and/or home. Other causes of inattention such as emotional, physical or sexual abuse and intellectual, visual, auditory or other medical impairments must have been considered. The diagnostic criteria also states that supportive evidence such as reports by education psychologists, teachers' reports on the behaviour of the child or behaviour checklists are helpful.

9.4 The age criteria guidelines provide that children younger than four years of age are not to commence therapy with stimulants and that adults beyond their 18th birthday are not to commence or continue therapy with stimulants. Authority for children younger than four years of age will be approved only on the recommendation of the Stimulants Committee. Patients who are 18 years of age or older should be referred at the earliest opportunity to a psychiatrist for assessment for adult attention deficit disorder. The guidelines call for caution to be exercised if any of the following are present: tics[15], dyskinesia[16], history of Tourette's disorder[17] or autism[18].

9.5 The dosage criteria guidelines state that, in general, the dose should always be the lowest possible and should be given only as many times per day as is necessary to achieve

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15 A habitual, irresistible, repetitious, stereotyped movement or complex of movements, of which the patient is aware but feels compelled to make in order to relieve tension. *Blakiston's Gould Medical Dictionary, Fourth Edition,* 1935, p. 1377.

16 Any abnormal or disordered movement, particularly those seen in disorders affecting the extrapyramidal system. Impairment of the power of voluntary motion, resulting in partial movements. *Blakiston's Gould Medical Dictionary, Fourth Edition,* 1935, p. 418.

17 A severe form of habit spasm, beginning in late childhood and adolescence and characterised by multiple tics associated with obscene utterances, echolalia (the purposeless, often seemingly involuntary repetition of words spoken by another person) and other compulsive acts. *Blakiston's Gould Medical Dictionary, Fourth Edition,* 1935, pp. 557 and 423.

18 A tendency in one's thinking where all material, including objective reality, is given meaning unduly influenced by personal desires or needs; an interest in daydreaming and fantasy; a form of behaviour and thinking observed in young children, in which the child seems to concentrate upon himself or herself without regard for reality; often appears as excessive shyness, fearfulness or aloofness and later as withdrawl and introspection. Intellect is not impaired. It may be an early manifestation or part of the childhood type of schizophrenia. *Blakiston's Gould Medical Dictionary, Fourth Edition,* 1935, p. 138.

adequate management. Patients should be commenced on a low dose which is titrated according to response. Dosage exceeding the recommended levels will only be considered with details of specific effects at different doses which demonstrate the inadequacy of the lower dose.

10 HEALTH DEPARTMENT OF WESTERN AUSTRALIA AND TVW TELETHON INSTITUTE FOR CHILD HEALTH REPORTS

10.1 The Health Department of Western Australia in conjunction with the Institute for Child Health Research has recently developed two reports on child and adolescent health in Western Australia:

- Child and Adolescent Health in Western Australia - An Overview ("the Overview Report"); and

- Specific Child and Adolescent Health Problems in Western Australia[19] ("the Specific Report").

10.2 The Overview Report was developed to provide an overview of child health in Western Australia and identifies important issues that need addressing. The Specific Report examines some of the priority issues in child health and provides a more specific epidemiological overview, basic models of care in order to predict service needs, strategies for consideration and research opportunities.

10.3 The Specific Report states that ADHD and learning problems were the most common condition documented by rural visiting paediatricians over the past six years. The Overview Report also notes that of the children diagnosed with behaviour/ADHD/learning problems by the Rural Paediatric Service, 34% and 19% were seen in the Pilbara and Goldfields areas respectively.

10.4 Both reports note that the percentage of children diagnosed with behaviour/ADHD/learning problems appears to be a major problem in rural mining towns around Western Australia. Twenty eight percent of the total number of children seen in Paraburdoo, 18% in Newman and 18% in Tom Price in 1996 were seen for behaviour/ADHD related problems.

10.5 The Specific Report states that a multidisciplinary approach is lacking in most rural areas with a scarcity of allied health professionals and family support systems. It goes on to

[19] *Ibid.*

state that ADHD is essentially a community concern and needs to involve the skills and cooperation of a number of community resources.

10.6 The Specific Report also states that the treatment and management (including the need for continuing medication) of ADHD should be reviewed by a case manager (usually the paediatrician) every three to six months. At least once a year a review should be made using the same parameters as for the initial diagnosis. Such a review should collect information from multiple sources and consider the need for continuing medication.

11 COMMITTEE HEARING

11.1 On Wednesday, October 21 1998 the Committee conducted a hearing into the matters raised in the petition. The witnesses who attended the hearing were:

- Professor George Lipton, Chief Psychiatrist and General Manager, Mental Health Division, Health Department of Western Australia;
- Dr Hugh Cook, Psychiatrist, Department of Psychiatry, Princess Margaret Hospital for Children;
- Professor Louis Landau, Executive Dean, Faculty of Medicine and Dentistry, University of Western Australia;
- Dr Stephen Houghton, Associate Professor/Psychologist;
- Dr Kenneth Whiting, Paediatrician; and
- Mrs Sandy Moran, mother and nurse and the principal petitioner.

11.2 The Committee heard a substantial amount of evidence from the witnesses concerning a range of issues relating to ADHD/ADD.

11.3 In her address to the Committee Mrs Moran stated that "there is no formal recognition of the existence of the ADD population in Western Australia, and yet epidemiologically we know this group of people is a significant percentage of our community who have gross difficulties in everyday activities. ADD is a serious public health issue."

11.4 Mrs Moran also stated that there are no services for Aboriginal children with ADD. Further, access to services at Princess Margaret Hospital for Children is available to ADD children only if they have a co-existing medical condition, and that while some

children are serviced through the child development centre, there are few services available in regional hospitals.

11.5 Mrs Moran expressed concern that "ADD is not on the diagnostic agenda. There are no systematic identification programs that I am aware of in juvenile justice, the prison system, domestic violence units, the alcohol and drug authority or Family and Children's Services."

11.6 Mrs Moran also expressed her concern that her experience demonstrates that "most teachers, nurses and doctors have a scant understanding of the consequences of unremidiated ADD in children, youth and adults." Mrs Moran claimed that this ignorance is aided and abetted by a media mentality that constantly distorts the image of ADD.

11.7 Mrs Moran concluded by stating that:

- appropriate services must be made available to assist ADD families;
- the Attention Deficit Society of Western Australia must be given financial assistance to continue its valuable community service;
- professional development must be a priority; and
- public education is a serious issue in breaking down the prejudice that exists in our community towards people who have special needs.

Mrs Moran also expressed her opinion that Government policies must change to accommodate the needs of the ADD community.

The Education System

11.8 Dr Cook addressed the issues of ADD in the context of education and expressed his belief that Western Australia does not have the range of educational facilities to cope with children with ADD.

11.9 Dr Cook also noted the concern about a range of attitudes towards ADD. Dr Cook told the Committee that "Certainly, the education system does have a range of attitudes. Some schools frown on children taking medication at school that may help them get through the afternoon. It helps many children if they can take medication at lunch time. It is very difficult in some schools, but others are very co-operative. The range of recognition in the education system is as great as that in the medical profession."

11.10 Professor Landau expressed his view that "we need a good education program to ensure teachers have the experience, knowledge and support to help to make an appropriate diagnosis, use a treatment where appropriate, accept that there is treatment where appropriate and recognise where educational support is a more appropriate treatment than drug treatment for individuals."

11.11 Professor Landau also stated that there needs to be much better interdisciplinary collaboration between the groups involved to ensure that appropriate government and private support is provided for children and families with ADD and ADHD.

11.12 Dr Whiting expressed the view that ADHD is the single most common condition which can lead to learning and behavioural difficulties in the classroom.

Stimulant Medication

11.13 Dr Cook expressed the opinion that because the understanding of ADD has evolved very rapidly and because, in his view, there is a built-in conservatism in most medical practices, people become anxious about prescribing stimulant medication. Dr Cook stated that although evidence suggests that in the long term there are no apparent serious side effects from stimulant medication, "Nevertheless, one cannot help but be concerned about that, particularly with the children who have co-morbidity, such as conduct disturbance, and who are extremely difficult to manage, both at home and at school. Many of those children may eventually take very large doses of medication."

11.14 Dr Cook stated that as more and more of these children who are taking medication grow into adulthood, we are faced with the dilemma of how many of them will need to take medication for the rest of their lives, and at what personal and medical cost. However Dr Cook also stated that there is a group of children who need help and who can be substantially helped, not only by medication but also by a range of multi-modal services, such as educational and behavioural management.

11.15 Dr Cook also raised the issue of the stigma perceived to be attached to taking medication, and spoke of the children he saw in his practice who do not want other children to see them taking their medication because they want to be seen as ‘normal’. Dr Cook advised the Committee that these children are very concerned that they are being labelled as someone who has ADD.

11.16 Professor Landau agreed that ADD and ADHD "are recognisable conditions and that treatment is available that should be provided in one form or another." Professor Landau

stated that the difficulty is that within the community there is a range of attitudes about the prevalence of the condition and how those suffering from it should be treated; that

is, whether they should receive educational support or behavioural therapy or whether they should receive drugs. Professor Landau stated this is where most of the disagreement arises.

11.17 Professor Landau advised the Committee that co-morbidity is another complication with prescribing medication to treat children with ADD or ADHD. Professor Landau advised the Committee that children who have other conditions are treated the same way as those who do not, but often they do not respond. Their doses are therefore increased and they are put on more drugs. Professor Landau expressed concern that in the end they are taking a large number of very active drugs, which is potentially dangerous.

11.18 The Technical Report considers this issue of stimulant medications being prescribed for ADHD in situations where ADHD coexists with other disorders. The Technical Report notes that different single medications may have different benefits for behaviour, mood and learning. Children with the most severe, complex or intractable problems may be treated with multiple drugs and sometimes by more than one doctor at the same time. The Technical Report states that with multiple medications, the potential side effects, pharmacological interactions and effects on symptoms are more worrying and need even closer collaboration.

11.19 The Technical Report also states that combined medications should be used with great caution as little scientific evidence exists regarding toxicity and long-term side effects. Prescribers should be well acquainted with recent literature and current expert clinical advice.

Financial Considerations

11.20 Professor Lipton expressed his opinion that although the mental health services of the Health Department of Western Australia have received additional funding in the last two years and have been reorganising services which are now somewhat better, they are still not as they should be. Professor Lipton expressed the view that the child and adolescent mental health aspect of the Health Department is still way behind what should be provided and that the services for ADHD are still not adequate.

12 CONCLUSIONS

12.1 The Committee concludes that ADHD and ADD are recognisable conditions which affect a significant number of children, youth and adults in Western Australia. The Committee notes the figures published in the Technical Report which indicate that ADHD affects 2.3-6% of children in Western Australia, however it accepts that these figures are only an estimate. The Committee also notes that ADHD appears to affect substantially more males than females.

12.2 The Committee also concludes that there is a range of attitudes within the community about the prevalence of ADHD and how those suffering from it should be treated. There is particular community concern about school students taking prescribed medication for the condition and considerable disagreement as to whether those students should be treated by way of educational support, behavioural therapy, with drugs, or whether they should receive a combination of all these treatments.

12.3 The Committee concludes that the Health Department of Western Australia recognises that ADHD is a medical condition with defined criteria. Although constrained by limited funding, the Health Department does provide some services to people with ADHD through its mental health services.

12.4 The Committee believes that a significant contribution to community concerns about ADHD and a barrier to the effective treatment of ADHD in children and adolescents in Western Australia lies with the Education Department treating ADHD as one of many disorders which may place a child at educational risk rather than as a separate learning and behaviour category. The Committee believes that children and adolescents with ADHD should be treated for that condition rather than being treated with a diverse group of children considered to be at educational risk, regardless of the cause of that risk.

12.5 The Committee agrees with the petitioners that there should be a program of public and professional education and awareness to assist in the early identification of the condition and to facilitate the remediation of people affected by ADHD. The Committee believes that the professional development of those involved in the diagnosis and treatment of people with ADHD is integral to ensuring a best practice standard for treating the condition.

12.6 The Committee is aware of anecdotal evidence that suggests that many of the problems associated with crime, in all sectors of our community, could in some way be attributable to ADHD. Should further research confirm this anecdotal evidence, early intervention could provide considerable long term financial savings and benefits to those suffering from ADHD, their families, and the community in general.

12.7 To undertake research in relation to ADHD in Western Australia the Committee concludes that a Professional Advisory Body should be established. The Professional Advisory Body should comprise members from the following areas:

- Aboriginal Health;
- the University of Western Australia Graduate School of Education;
- Psychiatry (both adult and child);
- Paediatrics;
- Juvenile Health;
- Princess Margaret Hospital for Children; and
- Community Nursing.

12.8 The Committee suggests that the Professional Advisory Body:

- obtain an acknowledgement from appropriate government agencies that ADHD is an existing condition and ascertain the policies and regimes in place (if any) to assist people suffering from this condition;
- identify whether Ministerial co-operation could be enhanced to assist in the diagnosis and treatment of people suffering from ADHD;
- propose potential policies and guidelines to the Government to overcome apparent existing deficiencies in the diagnosis and treatment of people suffering from ADHD; and
- assist with the co-ordination of information dissemination between government agencies.

12.9 The Committee concludes that more research into the diagnosis, management and treatment of ADHD should be conducted and the results reported to Cabinet.

13 RECOMMENDATIONS

Recommendation 1: That more research into the diagnosis, management and treatment of ADHD be conducted and the results reported to Cabinet.

Recommendation 2: That a Professional Advisory Body be established to formulate guidelines and policies for the diagnosis, management and treatment of ADHD. Such an advisory body should comprise members from the following areas:

- Aboriginal Health;
- the University of Western Australia Graduate School of Education;
- Psychiatry (both adult and child);
- Paediatrics;
- Juvenile Health;
- Princess Margaret Hospital for Children; and
- Community Nursing.

Recommendation 3: That the Professional Advisory Body propose potential policies and guidelines to the Government to overcome apparent existing deficiencies in the diagnosis, management and treatment of people suffering from ADHD and to assist with the co-ordination of information dissemination between government agencies.

Recommendation 4: That a program of public and professional education and awareness be established to assist in the early identification of ADHD and to facilitate the treatment of people affected by the condition.

Hon Murray Nixon JP MLC

Date:

APPENDIX A

APPENDIX A

LETTER FROM HON KEN TRAVERS MLC TO HON MURRAY NIXON JP MLC, CHAIRMAN OF THE COMMITTEE DATED DECEMBER 1 1999.

KEN TRAVERS MLC
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Hon Murray Nixon JP MLC
Chairman
Standing Committee on Constitutional Affairs
Parliament House
PERTH WA 6000

Dear Murray

Further to our discussion, I wish to confirm that it is my intention to exclude myself from Report Number 47 of the Standing Committee on Constitutional Affairs.

Due to my recent appointment to the Committee, I did not participate in the hearings and deliberations and have not had the opportunity to fully and properly apprise myself of the draft reports at this time. I understand it is the intention of the Committee to finalise the Reports in the near future and I therefore believe it would be inappropriate to associate myself with the final Reports.

Yours sincerely

Hon Ken Travers MLC
Member for North Metropolitan Region

1 December 1999

APPENDIX B

Appendix B
The 21 proposed key actions listed in the Technical Report.

Key Actions

1. *That the diagnostic criteria as outlined in DSM-IV be widely adopted by professionals involved in the diagnosis of ADHD. The diagnostic phase should be a collaborative effort between specialist medical and allied medical professionals and data required by paediatricians or psychiatrists to make a medical diagnosis should be acquired.*

2. *That State child health services be resourced further to establish multi-disciplinary teams for the assessment and treatment of children with attentional disorders. Such teams can provide an integrated approach to case management and on-going monitoring not currently available in Western Australia.*

3. *That the multi-disciplinary teams referred to in Key Action 2 provide services based on best practice standards for the diagnosis and treatment of attentional disorders based on the principles listed herein.*

4. *That encouragement is given to private practitioners to establish and utilise multi-disciplinary networks within the private and public sectors for the diagnosis and treatment of attentional disorders.*

5. *That an institute for applied child development and learning be established for professional development of those involved with children with attentional and developmental disorders;*

   That the institute provide a best practice standard for attending to children diagnosed with attentional disorders and to have the following roles:

   - *the development and coordination of training for professionals;*
   - *policy development; and*
   - *research.*

6. *That Western Australian guidelines for practice in the identification and assessment of ADHD and medical, psychological and educational management of those diagnosed with ADHD be written collaboratively between the Health and Education Departments for professional and parental use.*

7. *That information from schools be provided, at the request of, and to the parent or guardian.*

8. *That resources for professional development of teachers in dealing with students with ADHD be provided by the Education Department.*

9. *That issues of confidentiality in the provision of information on students be addressed by the Education Department.*

10. *That guidelines for the educational management of ADHD be developed by the Education Department as part of its policy for students with educational risk.*

11. *That specific programs designed to assist families to deal with children with attentional disorders and associated behaviour problems be trialed and evaluated by the Health Department in collaboration with the Education Department and Family and Children's Services.*

12. *That case management for children diagnosed with ADHD be adopted;*

    That case management models which take into account the range of severity of ADHD be developed collaboratively between the Departments for Health and Education and offered to relevant professionals;

    That training in this model to include implications for the Ministry of Justice, Family and Children's Services and the Disability Services Commission, and rural and Aboriginal communities.

13. *That medical practitioners follow the guidelines for stimulant prescribing as developed by the Stimulants Committee of the Health Department of Western Australia.*

14. *That the incidence of ADHD in persons above the age of 18 years in Western Australia be the subject of further research.*

15. *That the Stimulants Committee of the Health Department be authorised to carry out random audits into the use of block authorisations; and that paediatricians and psychiatrists found to be failing to abide to the appropriate criteria have their block authorisation capacity removed.*

16. *That resources be provided to the Stimulants Committee to monitor authorisation of stimulants.*

17. *That stimulant medication should be continued only if evidence of efficacy and lack of adverse effects is available.*

18. *That treatment and management (including the need for continuing medication) of ADHD be reviewed by the case manager every three to six months. At least once every year a review should be made using the same parameters as for the initial diagnosis. Such a review should collect information from multiple sources and consider the need for continuing medication.*

19. *That the Federal Minister for Health and Family Services be urged to make Methylphenidate available on NHS standard listing (restricted). In the meantime the Health Department of Western Australia fund hospitals to provide Methylphenidate to children diagnosed with ADHD who require medication, irrespective of means.*

20. *That the role of groups such as LADS in providing a support network for families with children with ADHD be supported.*

21. *That an interdepartmental committee be established to develop and coordinate services as detailed in this report.*

APPENDIX C

APPENDIX C
The 26 recommendations listed in the NHMRC Report.

Recommendations

Criteria for diagnosis

Recommendation 1

As a minimum, the criteria set down in DSM-IV should be fulfilled before a diagnosis of ADHD is made.

Assessment

Recommendation 2

A comprehensive assessment of a child with suspected ADHD should include the following elements:

- **History**: Family, past and current medical, psychosocial;
- **Medical**: Physical and neurological examination and any appropriate investigations;
- **Developmental**: To exclude significant specific and/or global problems, hearing and vision difficulties, and further referral as appropriate;
- **Behavioural**: Description of behaviour in various settings, especially home and school; and
- **Educational**: A review of classroom observations and prior testing, including estimates of intellectual capabilities (incorporating intellectual/cognitive assessment), strengths and weaknesses and measure of academic achievement, including language development.

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Recommendation 3

Multiple sources of information should be utilised during assessment eg parents, care givers and relevant professionals, especially teachers.

Rating scales

Recommendation 4

Appropriate rating scales should be used as part of the assessment for obtaining systematic information from different settings and to gauge treatment response.

Brain imaging and neurological tests

Recommendation 5

Further investigations such as brain imaging and neurophysiological tests are not recommended as part of the routine assessment of ADHD.

Overall management

Recommendation 6

A specific and individualised management plan should be formulated for each child with ADHD and their family.

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Recommendation 7

Associated problems such as learning difficulties, peer relationships, low self-esteem, family dysfunction and co-morbid conditions should be specifically addressed in the individualised management plan.

Recommendation 8

Treatment should be multimodal and involve consideration of simultaneous medication use, behaviour management, family counselling and support, educational management, and specific developmental issues.

Recommendation 9

Treatment and management of ADHD should be reviewed regularly. At least once every year a review should be made using the same parameters as for the initial diagnosis. Such a review should collect information from multiple sources and specifically evaluate any deterioration following significant interruptions to the medication regimen.

Recommendation 10

Further research should objectively evaluate methods of assessment and management of ADHD.

Recommendation 11

Further research, including comparative studies, should be undertaken to establish the cost-effectiveness of the various components of management of ADHD.

Recommendation 12

Appropriate, relevant and up-to-date information on ADHD should be available and accessible for children, families, and professionals.

Use of stimulant medication

Recommendation 13

The use of stimulant medication should be considered as part of the management plan for most children with ADHD. The efficacy and safety of stimulant medication has been established for short-term use.

Recommendation 14

While the response of most children is similar for both methylphenidate and dexamphetamine, the efficacy and side-effects are not identical. Some children may respond better to one than the other. Therefore, children should have equal access to whichever drug is necessary for their optimal treatment. Further research is required to determine the comparative effectiveness and cost-effectiveness of the two medications, and to determine criteria which will predict the optimal therapeutic option for individuals.

Recommendation 15

The routine use of placebo to assess individual response to treatment is not recommended.

Recommendation 16

Further research should examine the efficacy and safety of medications, particularly psychotropic medications, and prolonged or continuous use of stimulant medication.

Recommendation 17

Co-morbid conditions frequently coexist with ADHD and need to be addressed in management. Where drugs other than stimulants and/or multiple drugs are considered, expert opinion should be sought.

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Prescription of psychostimulants

Recommendation 18

Where State/Territory authority is a requirement for prescription of pyschostimulants, authorising bodies should use criteria which are consistent with the recommendations in this report. Uniform data collection at State/Territory level is recommended to assist monitoring and research.

Diet

Recommendation 19

While some studies have suggested that food and food additives influence some behaviours in some children, dietary manipulation is not recommended in the routine management of ADHD. If a special diet is instituted, it should be under the careful supervision of a qualified dietitian, preferably with experience in this area.

Other therapies

Recommendation 20

Other therapies such as optometric training, tinted lenses, megavitamins, and patterning are sometimes considered in the management of learning difficulties. There is no scientific evidence to support their use in the management of ADHD.

Management in preschoolers

Recommendation 21

The diagnosis of ADHD in toddlers and preschoolers is complicated by normal developmental changes and environmental factors. Behaviour management and parent guidance is essential, and medication should be used with caution.

Management in adolescence

Recommendation 22

The diagnosis of ADHD in adolescents is often complicated by co-morbid conditions, and the sequelae of long-standing dysfunction or other significant developmental changes. Therefore medication use should be carefully considered.

Management in adults

Recommendation 23

Research should be undertaken into lifestyle issues of ADHD such as participation in sport, employment, and eligibility for insurance.

Recommendation 24

Further research should be carried out on the management of adult ADHD

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Interagency collaboration

Recommendation 25

Doctors, educators, other relevant professionals and parents should collaborate to ensure the optimum management of ADHD.

Recommendation 26

Further research is required regarding the impact of ADHD in the education, health, welfare and justice systems.

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