

EDUCATION AND HEALTH STANDING COMMITTEE

ATTENTION DEFICIT HYPERACTIVITY DISORDER IN WESTERN AUSTRALIA

Report No. 8

2004

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Education and Health Standing Committee

Inquiry into Attention Deficit Hyperactivity Disorder in Western Australia

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ATTENTION DEFICIT HYPERACTIVITY DISORDER IN WESTERN AUSTRALIA

Report No. 8

Presented to: **The Clerk of the Legislative Assembly** and deemed tabled on Friday, 29 October 2004

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COMMITTEE'S FUNCTIONS AND POWERS

The functions of the Committee are to review and report to the Assembly on:

- (a) the outcomes and administration of the departments within the Committee's portfolio responsibilities;
- (b) annual reports of government departments laid on the Table of the House;
- (c) the adequacy of legislation and regulations within its jurisdiction; and
- (d) any matters referred to it by the assembly including a bill, motion, petition, vote or expenditure, other financial matter, report or paper.

At the commencement of each Parliament and as often thereafter as the Speaker considers necessary, the Speaker will determine and table a schedule showing the portfolio responsibilities for each committee. Annual report of government departments and authorities tabled in the Assembly will stand referred to the relevant committee for any inquiry the committee may make.

Whenever a committee receives or determines for itself fresh or amended terms of reference, the committee will forward them to each standing and select committee of the Assembly and Joint Committee of the Assembly and Council. The Speaker will announce them to the Assembly at the next opportunity and arrange for them to be placed on the notice boards of the Assembly.

INQUIRY TERMS OF REFERENCE

On referral from the Legislative Assembly, the Education and Health Standing Committee will examine and report on:

- 1. the extent of the incidence, diagnosis and use of stimulant medication for the treatment of Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) in Western Australia, taking into account all previous reports and inquiries;
- 2. an analysis of those figures compared to other States of Australia and other countries;
- 3. the analysis of emerging medical opinion and varying medical and behavioural approaches for the treatment of ADD and ADHD;
- 4. the divergence of public opinion and the need for a more defined State Policy;
- 5. the relationship, if any, between those diagnosed with and/or medicated for, ADD or ADHD and drug addiction; and
- 6. the relationship, if any, between ADD or ADHD and the educational, economic and social wellbeing of individuals.

CHAIR'S FOREWORD

I am pleased to present for tabling the eighth report of the Education and Health Standing Committee, which was first appointed on 30 May 2001. The Education and Health Standing Committee (the Committee) is one of three portfolio-related standing committees appointed by the Legislative Assembly at the commencement of every Parliament.

The issue of Attention Deficit Hyperactivity Disorder (ADHD) and, in particular, the use of psychostimulant medication as a mode of treatment is contentious for a number of reasons. The main reason for contention is that in most cases, it is young children who are being diagnosed and subsequently treated with an amphetamine based medication. Furthermore, the rate at which this medication is dispensed in Western Australia (WA) is disproportionately high when compared to other Australian states. This report does not attempt to end this debate, and in some instances raises more questions that will require consideration in the future.

From the outset, the Committee agreed that the rights of individuals, particularly children and their parents, to make informed choices regarding treatment options would be a key driver behind its deliberations. In this respect, the Committee has sought answers as to why so many young Western Australians are being placed on medication for ADHD, and whether other options are available and accessible to the broader community.

The Committee was mindful of the pressures that are placed on those who have children, partners and students diagnosed with ADHD and of the pressure that is placed on the medical specialists who are currently treating these people. The shortage of health professionals, misinformation about the condition and associated stigma, the economic burden and potential for educational risk are just a few of the many external pressures that those living with ADHD face. For these reasons, among others, the Committee has not attempted to make a determination on the legitimacy of ADHD and does not endorse one theory over another. Rather, the Committee notes the divisions amongst the many medical professionals, researchers, support groups and parents who gave evidence or presented submissions to the inquiry.

It is the Committee's view that the disproportionately high use of stimulant medication in WA is likely to have resulted in part from the shortage of multidisciplinary health services available within this state. The Committee is concerned that WA is significantly out of step with the national average and believes that a precautionary approach is warranted, particularly in the absence of studies into the long-term effects of stimulant use. There was broad agreement among Committee members that medication should not be the first line of treatment. However, the current arrangements in terms of state services lean toward the medication first model, largely due to difficulty of access to appropriate multidisciplinary treatment. It is hoped that this report will provide the impetus for the establishment of multidisciplinary assessment and treatment teams within the context of the current health system. WA has the blueprint for such an arrangement and the depth of talent within the state's health and education sector will provide the necessary expertise in this endeavour.

I would like to thank my fellow Committee members for their individual and collective contributions to this report, including the Member for Roleystone, Martin Whitely, who was co-opted for the duration of this inquiry. I thank the staff of the Committee for their dedication and support, in particular the Principal Research Officers, Karen Hall and later Liz Kerr, and the Research Officer, Peter Frantom. I commend this report to the House.

MRS C.A. MARTIN, MLA CHAIR

ABBREVIATIONS AND ACRONYMS

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
CAMHS	Child and Adolescent Mental Health Services
CARD	Centre for Attention and Related Disorders
CCHR	Citizens Committee on Human Rights
CA	Carer Allowance (child)
СР	Carer Payment (profoundly disabled child)
DoH	Department of Health
DSM-IV	Diagnostic and Statistical Manual of the American Psychiatric Association 4th Edition
HIC	Health Insurance Commission
ICD-10	Classification of Mental and Behavioural Disorders, World Health Organisation
LADS	Learning and Attentional Disorders Society of WA Inc.
MTA Study	The Multi Modal Treatment Study of Children with Attention-Deficit/Hyperactivity Disorder Cooperative Group
NHMRC	National Health and Medical Research Council
ODD	Oppositional Defiant Disorder
PBS	Pharmaceutical Benefits Scheme
SNR	Stimulant Notification Regime
SPN	Stimulant Prescriber Number
The Committee	Education and Health Standing Committee
UK	United Kingdom
US	United States

Aetiology The study of factors of causation or those associated with the causation of disease or abnormal body states. Comorbidity The presence of coexisting or additional diseases with reference to an initial diagnosis, or in this case, the presence of more than one mental disorder. Epidemiology The study of disease in populations. Usually concerned with identifying or measuring the effects of risk factors or exposures. The common types of analytic study are case-control studies, cohort studies, and cross-sectional studies. Psychostimulant and/or stimulant medication Within this report, the term 'psychostimulant medication' refers to either the drug methylphenidate (Ritalin) dexamphetamine sulphate or (dexamphetamine).

GLOSSARY

EXECUTIVE SUMMARY

The issue of ADHD in Western Australia (WA), in particular its treatment with stimulant medication is significant. It is well established that the use of stimulant medication is disproportionately higher in this state when compared to other states of Australia. There is community debate about whether the difference represents best or worst practice by WA, and is largely the reason ADHD remains a key issue. This inquiry canvassed the various opinions, issues and concerns within the Western Australian community with regard to its diagnosis and treatment. In line with its Terms of Reference, the Committee examined the level of consumption of stimulant medication in Western Australia, the range of available diagnostic and treatment options and the policy framework that includes ADHD.

Chapter Two summarises a number of issues that emerged within both written and oral submissions. A consistent theme was that non-medication therapies are expensive and in short supply. Where a family is on a limited income, often the only real option available is stimulant medication, due to its availability on the Pharmaceutical Benefits Scheme (PBS). All parental submissions noted the difficulty children have at school and day care, with contrasting accounts of the support available to them. Many submissions expressed frustration that previous inquiries and reports have consistently recommended an increase in multidisciplinary services, however, it appears little has been done to address the shortage of publicly available facilities of this type.

The Committee's principal focus in Chapter Three is how WA compares with other jurisdictions in terms of the incidence of diagnosis of ADHD, and the application of stimulant medication in its treatment. Further, whether there is any correlation between the diagnostic tools used to identify ADHD and prevalence rates within various localities. The relevant data infer that variations in the rates of diagnosis occur internationally, depending on the methodology used. Available data indicates significant differences in the use of stimulant medication in treatment approaches occur in WA compared to other Australian states and territories. The Committee examined some of the reasons given for the variations and was advised that many paediatricians have not been adequately informed throughout their training to recognise alternative diagnoses that appear similar to ADHD. By virtue of their training and workload it is likely that paediatricians are more prone to use drug therapy in the first instance than the other therapies recommended for the management of ADHD.

Chapter Four explores varying perspectives on the treatment of ADHD, particularly, but not limited to, those within the medical and allied health sector. It is clear there are divergent views within the medical, research and wider community in this regard and medical opinion remains divided, despite extensive research and analysis. Submissions received from the majority of health and education professionals recognised ADHD as a legitimate medical condition, with broad, at times qualified, support for the use of stimulant medication as part of a range of treatment options.

Those taking this view believe stimulant medication addresses a neurological/chemical discrepancy enabling a reduction in the symptoms or behaviours that impair the patient's life.

There is an opposing view that the causes of dysfunctional inattentiveness and/or impulsiveness and hyperactivity in children are many and varied and cannot be easily determined. Those of this view caution that without a definitive biological test to prove a chemical imbalance, dysfunctional behavioural traits may instead be attributable to a variety of underlying causes. In this view, underlying problems are not easily diagnosed using the standard check list diagnosis, and the use of stimulant medication may address symptoms, rather than cause. The Committee found that the absence of a definitive test to identify it is one of the reasons for the divergent views on the existence of ADHD as a clinical entity.

There is the potential for misdiagnosis as many people diagnosed with ADHD are affected by a number of comorbidities, or coexisting conditions that may be characterised by similar behavioural symptoms. With the level of resourcing required to ensure adequate assessment and an indication that many people cannot afford such an assessment, concern arises that many patients are not receiving a thorough, careful diagnosis. In this respect, there may be many children receiving simulant medication when it is not necessary or warranted. The Committee is therefore of the view that prior to the use of medication, a child must be afforded access to a thorough diagnosis, and recognises that the current model of private sector treatment, where cost is borne largely by families, is inadequate.

Chapter Five examines multidisciplinary assessment in both Victoria and WA, then turns to the ADHD policy to determine whether the stated policy objectives are sufficiently resourced to be effective. The Committee found that the disproportionately high use of stimulant medication in the treatment of ADHD in WA is likely to be due to the shortage of multidisciplinary and/or supplementary treatment options available in the public health system. The lack of publicly funded services means there is a tendency for diagnosis and treatment to be undertaken primarily by private sector paediatricians. While most reports and inquiries in this area have recommended a multidisciplinary approach, it appears there remain limitations on the capacity of the WA public and private sectors to provide such services.

The Committee found that the framework outlined in the Western Australian policy document *Attentional Problems in Children: Diagnosis and Management of Attention Deficit Disorder and Associated Disorders* is progressive. However, a critical lack of resources, including a shortage of qualified health professionals in both the private and public sector, prevent its implementation. It is within this chapter that the Committee makes its prime recommendation that the State Government urgently develops and adequately funds a primary model of multidisciplinary assessment and diagnosis for ADHD and other behavioural syndromes based on the existing tertiary service provided at the Bentley Health Centre. The Committee believes these services must be available for children undergoing initial assessment and diagnosis and to those already diagnosed.

Chapter Six questions whether the treatment of children and youths with psychostimulant medication for ADHD may result in an increased risk of drug addiction. Many health professionals concur with research that children who are diagnosed and treated with stimulant medication for ADHD are less likely to become substance misusers later in life. Undiagnosed children are generally considered to be at greater risk, with at least one submission focussing on the connection between serious substance abuse and undiagnosed ADHD. Whilst some submissions asserted a connection between undiagnosed ADHD and later substance misuse, no science-based evidence was provided to the Committee of a causal link between the two.

A significant number of submissions raised the issue of misuse of stimulant medication, with a particular concern being the selling of medication for recreational or study purposes. While evidence of misuse is largely anecdotal, the frequency with which the issue was raised in submissions, and some emerging qualitative data, indicate this as a growing problem. It was suggested that the necessity for children to take medication to school, because of its short therapeutic effect, presents an opportunity for the medication to be diverted from its intended purpose. Furthermore, the Committee heard evidence to suggest that patients are able to fill repeat prescriptions well within the recommended time frame, which raised the issue of the adequacy of current regulations governing the dispensing of prescription medication.

The relationship between ADHD and the educational, economic and social well being of individuals was addressed in Chapter Seven. It is clear that, not only the individual with the diagnosis, but also the immediate family and those within the school setting experience the impacts of behaviours associated with ADHD. The Committee found a common belief amongst parents that children diagnosed with ADHD are not adequately catered for in the school system. In terms of education support, families cannot easily access services for children diagnosed with ADHD unless the child is also identified as having one of the major categories of disability. Provision is not specifically provided for a single diagnosis of ADHD.

The shortage of resources for the public education system again proved to be a key issue. The roles and responsibilities of the Department of Education and Training and the Department of Health with respect to ADHD are not clearly defined and there is considerable confusion amongst health and education professionals as to what is expected from those involved. There is a level of dissatisfaction within the education system as to what is expected of teachers in relation to ADHD and the adequacy of the professional assistance and advice provided.

The Committee learned that many children that exhibit ADHD behaviours experience social isolation, both within and outside of the education system. A number of submissions detailed the negative effect of social exclusion on self-esteem and the ability to develop and maintain relationships. Some parents and/or carers of children suspected to have ADHD experience pressure to have their child formally diagnosed and medicated before that child is included in academic and social activities. Whilst there is evidence of a correlation between the diagnosis of ADHD and family social

and economic dysfunction, whether ADHD is the cause of the dysfunction or ADHD behaviours are the result of the dysfunction is not clear. Families have reported experiencing financial difficulties as a result of attending to the special needs of children diagnosed with ADHD. Economic constraints often inhibit the use of treatment options other than medication.

It is evident that the variances in opinion on diagnosis and management of ADHD have been debated in some detail in various reports and forums. Although acknowledging the contribution of the latter to the formulation of initiatives for improved medical, social and educational outcomes of those effected, the Committee remains concerned about inadequate provision of resources and the high use of stimulant medication in this state. In particular, the absence of sufficient public health services for treatment and diagnosis and reliance on individual schools for provision of support services and professional development.

It is the Committee's view that the disproportionately high use of stimulant medication in WA is likely to have resulted in part from the lack of available multidisciplinary services, and the tendency for diagnosis to be undertaken primarily by paediatricians. The Committee is concerned that WA is significantly out of step with the national average and believes that a precautionary approach is warranted, particularly in the absence of studies into the long-term effects of stimulant use. There was agreement among Committee members that medication should not be the first line of treatment. However, the current arrangements in terms of state services lean toward the medication first model due to a cost factor and difficulty of access to appropriate multidisciplinary treatment.

Central to the Committee's argument for reform is the progressive implementation of multidisciplinary diagnostic and treatment teams. It views that many of the factors seen as contributing to levels of stimulant medication in this state would at some level be contained within this structure. Evidently the broader issue of the shortage of health professionals would need to be appropriately planned and managed. The recommendation for multidisciplinary teams is not new. The state health policy provides a framework for standardised, quality clinical practice in the assessment, treatment and management of ADHD. However, evidence to this inquiry supports the notion of a lack of resource commitment to ensure the efficacy of the policy.

FINDINGS

Page 14

Finding 1

The use of different diagnostic tools may explain the variation in ADHD prevalence rates between Australia (DSM-IV) and the United Kingdom (ICD-10).

Page 14

Finding 2

Broadening the diagnostic criteria in the DSM-IV to include 2 subtypes, ADHD Hyperactive-Impulsive Type and ADHD Inattentive Type, is likely to have contributed to the growth in diagnosis of ADHD in Australia.

Page 19

Finding 3

The consumption of dexampletamine in Western Australia is disproportionately high in comparison with other Australian and international jurisdictions. Prescriptions for dexampletamine were almost four times the national average in the period 1999 to 2003.

Page 24

Finding 4

During their training, paediatricians have not been adequately informed about the extent of alternative diagnoses and treatment methods, and are therefore more likely to use drug therapy in the first instance in the management of ADHD.

Page 25

Finding 5

The provision of dexamphetamine on the Commonwealth Pharmaceutical Benefits Scheme, combined with the reliance on paediatricians to provide the majority of assessment and care of children with behavioural and learning difficulties, is likely to have contributed to the growth in its use in the treatment of ADHD in Western Australia.

Finding 6

Figures obtained from the new Stimulant Notification Regime indicate that approximately 98 per cent of prescribed psychostimulants in Western Australia are dispensed for the treatment of ADHD.

Page 29

Finding 7

Data obtained from the new Stimulant Notification Regime demonstrate that the majority of stimulant prescriptions in Western Australia for ADHD in the period 1 August 2003 to 25 August 2004 were for males between the ages of 5 and 25 years.

Page 31

Finding 8

Overall, paediatricians were responsible for 57 per cent of ADHD notifications in the period 1 August 2003 to 25 August 2004. Child and adolescent psychiatrists were responsible for 25 per cent and adult psychiatrists 17 per cent. Of the 59 registered paediatricians, five of those accounted for 26 per cent of all ADHD notifications in the reporting period (or 3,708 of 13,194).

Page 31

Finding 9

The Stimulant Regulatory Scheme introduced in August 2003 will enable basic data on the use of stimulant medication in Western Australia to be collected and compared with other published data.

Page 39

Finding 10

The behavioural symptoms underlying the diagnosis of ADHD are a key factor in the controversy surrounding the condition as many are within the range of 'normal' childhood behaviour.

Finding 11

The clinical diagnosis of ADHD is most often based on reported behavioural observations made by parents and/or teachers. There are no tests that identify the existence of ADHD in a biological sense. This is one of the reasons for the divergent views on the existence of ADHD as a clinical entity.

Page 39

Finding 12

Comorbidities or coexisting conditions may be misdiagnosed as ADHD due to the similarity in behavioural symptoms.

Page 42

Finding 13

There is a paucity of evidence on the long-term effects of psychostimulant medication on children.

Page 46

Finding 14

Individuals who are prescribed psychostimulant medication may also be prescribed other medications to alleviate side effects.

Page 46

Finding 15

There have been cases in Western Australia of prescribed stimulant medication levels exceeding the recommended dosage, which have resulted in some children requiring hospital admission for detoxification and reported episodes of psychotic behaviour.

Page 53

Finding 16

There is widespread recognition of the need for a multidisciplinary approach in diagnosis and treatment of ADHD.

Finding 17

The disproportionately high use of dexampletamine in the treatment of ADHD in Western Australia is to a large extent due to the shortage of multidisciplinary assessment and treatment options available in the public health system and the prohibitive cost of private sector treatment options.

Page 57

Finding 18

The multidisciplinary framework outlined in the current Western Australian ADHD policy document is sound. However, critical shortages of resources in both the private and public sector prevent its implementation.

Page 57

Finding 19

There are limited services available for diagnosis and treatment of behavioural and learning problems in metropolitan areas. Services are further limited in most of regional Western Australia.

Page 57

Finding 20

There is a shortage of clinicians specialising in the child and adolescent mental health area, particularly child and adolescent psychiatrists, clinical psychologists and mental health nurses in Western Australia.

Page 60

Finding 21

The greater use of dexampletamine in Western Australia for the treatment of ADHD is inconsistent with practice in all other Australian States and Territories.

Finding 22

The services offered at the Bentley Clinic are widely recognised as providing the most comprehensive and appropriate assessment and treatment options for Western Australian children with ADHD. These services are currently only available to a small number of children who have been diagnosed and generally medicated for extended periods of time.

Page 64

Finding 23

There are divergent opinions in relation to a connection between ADHD, stimulant medication and later substance misuse. The Committee found that there have been no conclusive results from the studies undertaken on the connection between ADHD, stimulant medication and later substance abuse. Further, no science-based evidence was provided to the Committee of a causal link between undiagnosed ADHD and illicit substance misuse.

Page 66

Finding 24

There is a growing body of evidence to suggest that stimulant medication is sometimes diverted for illicit use.

Page 69

Finding 25

Western Australian pharmacists do not have access to patients' prescription and dispensing histories. This affects their ability to monitor the appropriateness of dispensing stimulant and other Schedule 8 medication.

Page 70

Finding 26

There is evidence that repeat prescriptions for stimulant medication are on occasions dispensed too frequently in Western Australia, creating the opportunity for abuse. Currently there are no restrictions on dispensing repeat prescriptions of Schedule 8 medication in Western Australia.

Finding 27

There is a common belief amongst parents that children diagnosed with ADHD are not adequately catered for in the school system.

Page 78

Finding 28

The practices and attitudes of individual teachers and schools may influence the rate at which students are diagnosed and possibly medicated for ADHD.

Page 79

Finding 29

There is a level of dissatisfaction within the education system as to what is expected of teachers in relation to ADHD and the adequacy of the professional assistance and advice provided.

Page 79

Finding 30

The roles and responsibilities of the Department of Education and Training and the Department of Health with respect to ADHD are not clearly defined and there is considerable confusion amongst health and education professionals as to what is expected from those involved.

Page 84

Finding 31

There are individual cooperative programs endeavouring to move towards a multidisciplinary model for the diagnosis and treatment of ADHD. Whilst many of these programs are effective, they are developing on an ad hoc basis and do not receive adequate government support.

Page 86

Finding 32

There is disparity between the level of support teachers are expected to provide for students diagnosed with ADHD and the level of support proffered to teachers through the Education Department.

Finding 33

Although additional resources are provided for children with disabilities, there is inadequate classroom support for children with behavioural and learning difficulties.

Page 87

Finding 34

Many children that exhibit ADHD behaviours experience social isolation, both within and outside of the education system. Submissions detailed the negative effect of social exclusion on self-esteem and the ability to develop and maintain relationships.

Page 88

Finding 35

Some parents and/or carers of children suspected to have ADHD experience pressure to have their child formally diagnosed and medicated before that child is included in academic and social activities.

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Finding 36

The effects of ADHD behaviours often encompass the immediate family. Many parents believe they are 'blamed' for their child's behaviour and are labelled irresponsible for putting their children on medication.

Page 89

Finding 37

Whilst there is evidence of a correlation between the diagnosis of ADHD and family social and economic dysfunction, whether ADHD is the cause of the dysfunction or ADHD behaviours are the result of the dysfunction is not clear.

Page 93

Finding 38

Families report suffering economically as a result of attending to the special needs of children diagnosed with ADHD. Economic constraints often inhibit the use of treatment options other than medication.

RECOMMENDATIONS

Page 25

Recommendation 1

The Committee recommends that the Commonwealth Government ensure that the disproportionate use of dexampletamine on the Pharmaceutical Benefits Scheme between Australian states is not only measured but also investigated and addressed at a national level.

Page 42

Recommendation 2

The Committee recommends that the State Government encourages and/or facilitates research into the safety and efficacy of the long-term use of psychostimulant medication.

Page 46

Recommendation 3

The Committee recommends that prior to the use of psychostimulant medication, a child must receive a thorough diagnosis, incorporating an analysis of the child's medical, social and familial circumstances to minimise the potential for misdiagnosis and the potential for unnecessary treatment with medication.

Page 47

Recommendation 4

The Committee recommends that in order to provide the opportunity for informed consent, the clinicians that carry out the diagnosis of ADHD and subsequent treatment with psychostimulant medication, be required to provide comprehensive information to parents regarding:

- the full range of potential side effects of medication; and
- the manner in which the diagnosis is made.

Recommendation 5

The Committee strongly recommends that the State Government prioritise the development of comprehensive strategies to address workforce shortages in the child and adolescent mental health area, particularly child and adolescent psychiatrists, clinical psychologists and mental health nurses in Western Australia.

Page 60

Recommendation 6

The Committee recommends that the Department of Health, in conjunction with the relevant medical professional bodies, develop protocols to ensure a consistent approach to the diagnosis and treatment of behavioural and learning difficulties, including ADHD.

Page 60

Recommendation 7

It is the prime recommendation of the Committee that the State Government urgently develops and adequately funds a primary model of multidisciplinary assessment and diagnosis for ADHD and other behavioural syndromes based on the existing tertiary service provided at the Bentley Health Centre. These services must be available for children undergoing initial assessment and diagnosis and to those already diagnosed.

Page 70

Recommendation 8

The Committee recommends that the State Government and Commonwealth Government facilitate better access for pharmacists to patient databases.

Page 70

Recommendation 9

The Committee recommends that Western Australian legislation be amended in line with New South Wales, to restrict the frequency with which repeat Schedule 8 medication prescriptions may be dispensed.

Recommendation 10

The Committee recommends that the Department of Education and Training place greater emphasis on providing training and resources for teachers dealing with students with behavioural and learning difficulties.

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Recommendation 11

The Committee recommends that the Department of Education and Training ensure that teachers are made explicitly aware that the information they provide about students behaviour may be used in the diagnosis of ADHD.

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Recommendation 12

The Committee recommends that the State Government liaises with the Commonwealth Government to ensure the full range of treatment options for ADHD are provided at a public level.

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Recommendation 13

The Committee recommends that the Ministers for Health and Education in Western Australia establish a multidisciplinary body to oversee the implementation of the recommendations contained within this report.
MINISTERIAL RESPONSE

In accordance with Standing Order 277(1) of the Standing Orders of the Legislative Assembly, the Education and Health Standing Committee directs that the Minister for Health and the Minister for Education report to the Assembly as to the action, if any, proposed to be taken by the Government with respect to the recommendations of the Committee.

CHAPTER 1 INTRODUCTION

1.1 Background to the inquiry

There has been considerable community debate in recent years associated with the diagnosis and treatment of Attention Deficit Hyperactivity Disorder (ADHD), one of the most commonly diagnosed behavioural disorders among Australian children. ADHD behaviours have the potential to impact upon the individual, the family and the community in terms of explicit and implicit financial costs, family stress and disruption in schools and workplaces.

The issue of ADHD in Western Australia (WA) is significant as it is well established that the use of stimulant medication in its treatment is disproportionately higher in this state when compared to other states of Australia. The treatment of children with an amphetamine-based medication is contentious, and the degree of difference between the Australian states and territories in the use of stimulants to treat ADHD raises questions for parents, policymakers and service providers alike. The debate about whether the difference represents best or worst practice by WA continues, and is largely the reason ADHD remains a key issue.

There is confusion in the broader community, particularly among parents, who are concerned about whether they are doing the right thing by their children. Some have indicated they are being singled out because they are administering stimulant medication to their children. Further, many children demonstrating ADHD and other behavioural problems are stigmatised, which may further compound learning difficulties and lead to social isolation.

There have been numerous inquiries over the past decade as ADHD has gained prominence on the public agenda. The issue has also been the subject of significant debate in both Houses of the WA Parliament. On Wednesday, 16 April 2003, in accordance with Standing Order 287(2), the Legislative Assembly referred the following Terms of Reference to the Education and Health Standing Committee (the Committee), for investigation.

(a) Terms of Reference

On referral from the Legislative Assembly, the Education and Health Standing Committee will examine and report on:

1. the extent of the incidence, diagnosis and use of stimulant medication for the treatment of Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) in Western Australia, taking into account all previous reports and inquiries;

- 2. an analysis of those figures compared to other States of Australia and other countries;
- 3. the analysis of emerging medical opinion and varying medical and behavioural approaches for the treatment of ADD and ADHD;
- 4. the divergence of public opinion and the need for a more defined State Policy;
- 5. the relationship, if any, between those diagnosed with and/or medicated for, ADD or ADHD and drug addiction; and
- 6. the relationship, if any, between ADD or ADHD and the educational, economic and social wellbeing of individuals.

1.2 Core issues

This report canvassed the various opinions, issues and concerns within the Western Australian community with regard to the diagnosis and treatment of ADHD.

In line with its Terms of Reference, the Committee examined the level of consumption of stimulant medication in Western Australia, through comparison with other jurisdictions. The scope of the inquiry was therefore broad and included, but was not limited to, examination of the following points of interest:

- The use of stimulant medication in the treatment of ADHD;
- The range of diagnostic and treatment options, including access to those options; and
- The policy framework that includes ADHD, specifically, but not limited to Western Australia.

1.3 Co-opted Member

The Member for Roleystone, Mr Martin Whitely, MLA, who is not a member of this Committee, has had a longstanding interest in the use of stimulant medication for the treatment of ADHD. Standing Order 249 (4) states that:

The Assembly may on motion co-opt any member of the Assembly, not being a Minister, to participate for a specified inquiry, in meetings of a portfoliorelated committee or the Public Accounts Committee in relation to portfolio matters allocated to it. That member is not a member of the committee and may not vote, move any motion or be counted for the purpose of a quorum, but in relation to that inquiry may ask questions of witnesses and participate in a deliberative meeting. Following consideration of Mr Whitely's interest and further to the above-mentioned resolution of 16 April 2003, the Legislative Assembly agreed to a motion -

That in accordance with Standing Order 249 (4) Mr M.P Whitely be co-opted to participate in the Education and Health Standing Committee's investigation into Attention Deficit Disorder and Attention Deficit Hyperactivity Disorder in Western Australia.¹

1.4 Conduct of the Inquiry

An advertisement calling for public submissions was placed in the *West Australian* newspaper on Saturday, 17 May 2003. Submissions were directly invited from 192 organisations, including a range of health professionals, community organisations and identified support groups. The Committee received 83 submissions, which provided a comprehensive account of the key issues pertaining to ADHD and most addressed the Terms of Reference for this inquiry (see Appendix One).

The Committee held 11 public hearings and heard evidence from 23 people (see Appendix Two), and undertook investigative travel to Adelaide and Melbourne as part of the inquiry process. The individuals and organisations the Committee met with are listed in Appendix Three.

This report draws on evidence presented to the Committee, as well as current literature and research in the field. The Committee acknowledges the quality of that research and of the submissions lodged. Many included invaluable links to relevant material that assisted the Committee's inquiry process. Every attempt has been made to incorporate the evidence presented, however the range and depth of the latter inevitably means that certain elements may be excluded from the current discourse.

1.5 Terminology

The primary diagnostic tool used in Australia is the Diagnostic and Statistical Manual of the American Psychiatric Association 4th Edition (DSM-IV). Within the DSM-IV, ADHD is the term currently used to encompass the three subtypes:

- ADHD Predominantly Inattentive Type ;
- ADHD Predominantly Hyperactive-Impulsive Type; and
- ADHD Combined Type.

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Parliamentary Debates, Western Australian Legislative Assembly, Wednesday 16 April 2003, p.6848.

For the purpose of this report, the term ADHD will be used to encompass both ADD and ADHD, with distinctions made where it is considered necessary. The following background information is provided for context.

(a) What is ADHD?

2

ADHD is the term used to define a collection of behaviours that are considered to cause impairment in social, academic or occupational performance. Hyperactive, restless, inattentive and sometimes destructive behaviour impedes on a person's ability to function in the home, at school and the wider society in general. The diagnosis occurs in a clinical setting, and is largely based on the two leading psychiatric manuals, the above mentioned DSM-IV and the Classification of Mental and Behavioural Disorders (ICD-10), published by the World Health Organisation.

Historically, the behaviours that make up the ADHD diagnoses have been clinically noted and treated to varying degrees for over 100 years.² ADHD is more commonly diagnosed in males (three to one) and it is believed that up to two thirds of children diagnosed with ADHD maintain the diagnosis into adulthood.

While treatment may involve a number of behavioural and therapeutic interventions, the primary medication used to treat ADHD are the central nervous system psychostimulants. The use of psychostimulant medication in the treatment of 'behaviourally disturbed' children began as early as 1937, however, it did not become widespread in Australia (and the US) until the 1980s. The most commonly used drugs are dexamphetamine and methylphenidate (generally marketed as Ritalin). The term 'stimulant' may be used herein to refer to the psychostimulants used in the treatment of ADHD.

George Still, 1902, 'Some abnormal physical conditions in children', Lancet i p.1009, in Submission from Krievs, W. (1998) *Living with Attention Deficit Hyperactivity Disorder: Family Members Perspectives*, Honours Thesis, School of Social Work, Curtin University of Technology, Western Australia, p.3.

CHAPTER 2 OVERVIEW OF SUBMISSIONS

2.1 Key Issues

The Committee received 83 submissions from a range of stakeholders, representing a cross section of the WA community, including parents and/or carers of children diagnosed with ADHD, health and education professionals, non-government support groups, government service providers and academics.

A consistent theme was that non-medication therapies are expensive and in short supply. All parents noted the difficulty children have at school and day care, with contrasting accounts of the support available to them. Many expressed frustration that previous inquiries and reports have consistently recommended an increase in multidisciplinary services, however, it appears little has been done to address the shortage of publicly available facilities of this type.

In many of the case studies presented to the Committee, parents and (families) have experienced several years of the condition before seeking diagnosis and treatment and most indicated that life has become relatively 'normal' with the use of stimulant medication. Nonetheless, a number remain reluctant to medicate for various reasons, including uncertainty about long-term effects, known side effects and the associated stigma.

The submissions reflected a range of views (some diametrically opposed) on the cause and existence of ADHD. There was considerable support for the theory that ADHD results from a chemical imbalance in the brain, while others believe the 'normal' behaviour of children has been 'medicalised' to the benefit of the medical profession and pharmaceutical companies.

This chapter summarises a number of issues that emerged within both written and oral submissions to the Committee, many of which are expanded upon in later chapters. Parents' comments have been de-identified for reasons of sensitivity.

2.2 Adequacy of diagnostic tools

Many submissions raised the question of the adequacy of the diagnostic tools used to detect ADHD in children. A number indicated concern that the criteria used to assess children may reflect 'normal' childhood behaviour, or the behaviours may represent underlying anxiety or stress due to undetected causes.

Many people diagnosed with ADHD are also affected by a number of comorbidities (or coexisting conditions) that present with similar symptoms (see section 4.4 (a)). It is recognised, however, that in many cases individuals do not receive a thorough

diagnosis, possibly due to the increasing pressure on a limited number of specialists to treat a growing number of patients.

2.3 Treatment options

There was broad agreement that the public health sector does not have the capacity to deliver the required treatment options. Treatment options other than medication alone were indicated as the preferred choice in most submissions. Concern was raised that medication is sometimes used as the primary and only method of treatment, largely because the full range of recommended treatment options are not available in the public sector. One submission made the following observation:

There is precious little support in the public health system for our ADHD children in this state. Private counselling is expensive (\$130 per session).

This view was echoed in a number of submissions and in evidence taken throughout the inquiry. For families without the capacity to access private options, medication, in particular dexampletamine, is considered the most accessible therapy due to its availability on the PBS (see section 3.4 (c)).

(a) Stigma

3

The stigma associated with ADHD was a key issue raised in the submissions received from parents and support organisations. There is a level of pressure applied to affected children, their parents and the family unit in this regard.

The Committee heard of children not being included in school excursions and birthday parties, as a direct result of them exhibiting ADHD behaviours. Some parents indicated they have experienced pressure to have their child formally diagnosed and medicated prior to inclusion in activities, and a significant number noted the social isolation experienced by affected children and youth, and the negative effect this has on self-esteem and the ability to develop and maintain relationships.

The Committee was advised that:

Observation of reporting trends in the bulk of senior high schools indicates that parents of students with ADD or ADHD are unwilling to identify their children as requiring support or advocacy by a school nurse. They do not want the students labelled as different...much like the parents of epileptics or diabetics did in the past.³

Such pressure has been attributed to negative media representation of ADHD and to a general misunderstanding within the education system and the broader society about the condition. Some parents expressed the view that both health and education

The East Metropolitan Health Service, Population Health Unit, Submission, 4 July 2003, p.1.

professionals had not taken them seriously in seeking treatment for their child, while others felt they were being 'blamed' as poor parents or that people thought their child was simply undisciplined or unruly.

There is a sense of self-reproach evident in some submissions, and it is clear that medicating children has been a decision that has caused a great deal of angst. The following extracts illustrate the level of frustration experienced by many parents and carers:

The media coverage of the issues relating to this disorder in WA has made it extremely difficult for many parents to feel competent and comfortable in making decisions;

The media likes to demonise the use of medication, suggesting that parents who put their children on medication simply want to put them under control;

The frustration that descends on the parents can be overwhelming. Siblings fight and argue and families breakdown under the strain;

I have encountered some very hostile opinions from people, when they find out that my child is on medication;

Media reports and the ignorant misinformed comments of people that vilify parents who put their children on stimulant medication only add to the stress and trauma that is experienced with these ongoing disorders;

There is little or no support for those that choose not to medicate.⁴

In most of the case studies presented, the use of stimulant medication has meant that ADHD sufferers and their families have been able to achieve some 'normality' in their lives, and medication has improved quality of life in general for the individual and the whole family. However, in spite of achieving a sense of normality, a number of submissions indicated concern about the medication of children, in terms of the associated known and unknown consequences.

(i) Side -effects

Stimulant medication causes known side effects in some patients, including sleeplessness, loss of appetite and mood swings (see section 4.5 (a)). There is a concern that these are then treated with more medication (polypharmacy - see section 4.5 (b)). Some believe, however, that long-term problems stemming from the use of stimulant medication are unlikely, or at least not overtly apparent at this stage, and therefore the application of medication is warranted.

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The identities of the people referred to here have been omitted for reasons of sensitivity.

A number of submissions raised the issue that while stimulant medication improves a sufferer's ability to participate in classroom and social activities, an associated problem arises whereby the personality or true character of the sufferer is suppressed and is replaced with a docile, subdued demeanour.

The physiological effect stimulant medication may have, in particular on the developing brains of children, was also raised as a concern. Some submissions call for a cautious approach, particularly given the lack of studies into the long-term consequences of stimulant use in young children.

(b) Shortage of qualified health professionals

The shortage of qualified health professionals who are approved to diagnose ADHD and to then administer stimulant medication was a common theme in submissions. This view was particularly evident in non-metropolitan submissions, where the shortage was thought to impact on the ability to gain a second opinion and to access the full range of treatment options. Often in regional areas, medication is seen as the only option for treatment. One family was compelled to move to Perth due to the lack of treatment options to try as an alternative to stimulants alone. The pressure on the limited number of specialists to treat patients in a manner in which they can afford was noted, and it was considered likely that this pressure would lend itself to specialists prescribing the most cost-effective method for patients.

There were mixed views as to the appropriateness of paediatricians being the primary point for diagnosis. A significant number of submissions indicated satisfaction with their involvement although there was concern that paediatricians may not be adequately trained to detect underlying, psychosocial comorbidities that are common in sufferers (see section 3.4).

2.4 Education Concerns

Learning difficulties were overwhelmingly represented within submissions as a key concern for all stakeholders. Although many children diagnosed with ADHD are considered to be of above average intelligence, they are often at risk of developing poor numeracy and literacy skills, and have different educational requirements to most students. These relate to the child's apparent inability to concentrate and focus in the traditional classroom setting.

Students currently fall under the umbrella of the 'students at educational risk' policy and individual schools are left to develop programs that fit within the broader policy (see section 7.2 (a)). Early intervention and correct diagnosis were found to be key areas for the effective management of ADHD students. However, the shortage of resources for the public education system is an issue. For one parent, a one-on-one teaching situation proved successful, however the provision of such services depends largely on individual school policies, unlike specific programs for other children with disabilities.

Concern was raised about the inappropriateness of disciplinary measures for dealing with children diagnosed with ADHD. Parents made the following comments:

There is ignorance within the education system, particularly, but not only, among older teachers. ADHD children may be sat apart from other children so as not to disturb them. Teachers want me to do something...but are unwilling to help - it is too hard, or they are too busy; and

So much damage was done by the school's rigid and punishing approach to the problem. The school refused to look at any management strategy other than punishment. It would have been so easy to implement a reward program along with training.⁵

Education professionals noted the need for resources in the form of professional development and stress management for teachers. The lack of a uniform approach to ADHD management was also raised in this context, with various levels of success discussed at different schools.

2.5 Substance Misuse

5

Relatively few of the submissions indicate concern about a connection between the use of stimulant medication and later substance abuse by ADHD sufferers. Many health professionals concur with recent research that children who are diagnosed and treated with stimulant medication for ADHD are less likely to become substance misusers later in life. It is the undiagnosed children who are considered to be at greater risk and substance abusers are thought to be (unwittingly) self-medicating with illicit narcotics (see section 6.2 (a)).

A significant number of submissions raised the issue of misuse of stimulant medication, with a particular concern being the selling of medication for recreational or study purposes. While evidence of misuse is largely anecdotal, the frequency with which the issue was raised within submissions, and some emerging qualitative data indicate this as a growing concern (see section 6.3 (a)).

The following chapters address the Committee's Terms of Reference and expand on many of the key issues highlighted in this chapter.

The identities of the people referred to here have been omitted for reasons of sensitivity.

CHAPTER 3 THE EXTENT OF THE INCIDENCE, DIAGNOSIS AND USE OF STIMULANT MEDICATION FOR THE TREATMENT OF ADHD IN WESTERN AUSTRALIA

3.1 Introduction

The Committee's principal focus in this chapter, is how WA compares with other jurisdictions in terms of the incidence of diagnosis of ADHD, and the application of stimulant medication in its treatment. Further, whether there is any correlation between the diagnostic tools used to identify ADHD and prevalence rates within various localities.

The relevant data infer that variations in the rates of diagnosis occur internationally, depending on the methodology used. Available data indicate significant differences in the use of stimulant medication in treatment approaches occur in WA compared to other Australian states and territories.

Prevalence rates on ADHD are an estimate of the proportion of individuals in a given population exhibiting behaviours classified as such in the two most widely used diagnostic manuals, the DSM-IV and the World Health Organisation International Classification of Diseases (ICD-10) (see 3.2 (b)). Prevalence rates do not equate to diagnostic rates, as they are drawn from surveys and questionnaires rather than actual clinical figures. In this respect, the Committee questions their accuracy, however, recognises they provide a useful indicator on how the use of different assessment methods can affect the diagnostic process.

3.2 Variation in prevalence rates of ADHD between jurisdictions

The School of Paediatrics and Child Health, University of Western Australia, advised the Committee that the incidence of ADHD varies dramatically, depending upon the method of measurement and the way in which a society views the behaviours that constitute ADHD.⁶ Prevalence rates in the United States (US) are greater than in Australia, however both Australia and the US differ from the United Kingdom (UK), where prevalence rates are significantly lower.

⁶

School of Paediatrics and Child Health, University of Western Australia, Submission, 24 June 2003, p.1.

(i) Australia

Australian studies have shown prevalence rates ranging between 2.3 per cent and 6 per cent, which reflects the diagnostic criteria used, the population sampled and whether ADHD without hyperactivity is included.⁷ Recent survey data from the WA Health and Wellbeing Surveillance System (collected in 2001 and 2002) suggested that the prevalence of doctor diagnosed ADHD in WA was 4.4 per cent.⁸

(ii) United States and the United Kingdom

Prevalence rates of between 1.4 - 13.3 per cent have been reported in children and adolescents in the US⁹, while a 1998 study estimated a 6.8 per cent prevalence rate among US school aged children.¹⁰ Conversely, in the UK prevalence rates have been estimated at between 1 and 2 per cent of school aged children, with recent data suggesting the prevalence of Hyper Kinetic Disorder (HKD), which is similar to a diagnosis of combined type ADHD, to be 1% of that same group.¹¹

(b) Differences in diagnostic tools

The identification of ADHD involves a clinical diagnosis based on descriptive classification systems, notably the DSM-IV and the ICD-10. Australia and the US largely rely on the DSM-IV, whereas the ICD-10 is the primary tool used in the UK.¹²

As discussed, using the ICD-10, a diagnosis of HKD is broadly similar to the DSM-IV combined ADHD. Whilst the list of behavioural diagnostic criteria in the ICD-10 are almost identical to DSM-IV, HKD differs in that it requires all three core signs (inattention, hyperactivity and impulsiveness) to be present before a diagnosis is made.

⁷ National Health and Medical Research Council, 1997, *Attention Deficit Hyperactivity Disorder*, p.12.

⁸ Reported by mothers of children aged 0-15 years and by young adults aged 16-24 years, WA Department of Health, Submission June 2003, p.3.

⁹ Barkley, RA, 1998, *ADHD: A handbook for diagnosis and treatment* (2nd edition), New York: Guildford Press, Chapters 8-10.

¹⁰ Wolraich, ML. Hannah, JN. Baumgaertal, Feurer, ID, 1998, Examination of DSM-IV criteria for ADHD in a country wide sample, in *Journal of Developmental and Behavioural Paediatrics*, 1998; 19: pp.162-168.

¹¹ National Health and Medical Research Council, 1997, *Attention Deficit Hyperactivity Disorder*, p.12, and National Institute for Clinical Excellence, Technology Appraisal Guidance - No. 13, *Guidance on the use of methylphenidate (Ritalin, Equasym) for Attention Deficit/Hyperactivity Disorder (ADHD) in childhood,* October 2000, <u>www.nice.org.uk</u>, accessed January 2004, p.3.

¹² Refer to Appendix Four and Appendix Five for a full representation of the DSM-IV and ICD-10 diagnostic criteria respectively.

The predecessor to the DSM-IV required an individual to display at least 6 or more inattentive and 6 or more hyperactive-impulsive behaviours prior to diagnosis. The DSM-IV effectively broadened the criteria for diagnosis by including the 2 subtypes, ADHD Hyperactive-Impulsive Type and ADHD Inattentive Type (often referred to as passive ADD). In fact, the DSM-IV notes that:

*The prevalence of Attention-Deficit/Hyperactivity Disorder as defined in DSM-IV may be somewhat greater than the prevalence of the disorder based on DSM-III-R criteria because of the inclusion of the Predominantly Hyperactive-Impulsive and Predominantly-Inattentive types.*¹³

In addition, both DSM-III and DSM-IV contain another category, *Attention Deficit/Hyperactivity Disorder - Not otherwise specified*, which further broadens the criteria to include "individuals whose symptom pattern does not meet the full criteria for the disorder but have a behavioural pattern marked by sluggishness, daydreaming and hypoactivity."¹⁴ The ICD-10 on the other hand recognises that problems of inattention constitute a central feature of hyperkinetic syndromes and caution that:

In recent years the use of the diagnostic term 'attention deficit disorder' for these syndromes has been promoted. It has not been used here because it implies a knowledge of psychological processes that is not yet available, and it suggests the inclusion of anxious, preoccupied or 'dreamy' apathetic children whose problems are probably different.¹⁵

Both the DSM-IV and ICD-10 involve assessments using observational methods (including teachers rating scales and parent observations), however the multiple diagnoses possible in DSM-IV in the presence of comorbid conditions may explain the variation in prevalence rates. Comorbid conditions are separate, but often coexisting disorders which may result in similar behavioural symptoms (see section 4.4 (a)).

The Social Development Committee of the South Australian Parliament highlighted this when it noted:

The DSM-IV allows for multiple diagnosis with comorbid conditions such as conduct disorder, while ICD-10 does not. Under the latter diagnostic system, children presenting with ADHD plus conduct disorder will not be classified as ADHD but as Hyperkinetic Conduct Disorder. As a result, prevalence studies

¹³ DSM-IV, p.90.

¹⁴ DSM-IV, p.93.

¹⁵ World Health Organisation (1993) International Classification of Diseases (ICD-10) The Classification of Mental and Behavioural Disorders, Diagnostic Criteria for Research, Geneva, pp.262-263.

from other countries using the ICD-10 (eg. UK) indicate much lower ADHD rates than those from Australia and the USA.¹⁶

Results from a 1998 study into the use of medication by young people with ADHD inferred that overall, 1.8 per cent of Australian children (6-17 years) received stimulant medication with 23 per cent of that group not meeting the DSM-IV diagnostic criteria for ADHD. In the same study, the diagnostic criteria was narrowed to reflect the DSM-III and ICD-10, which then showed the proportion of children that did not meet the criteria that received stimulants increased to 57 per cent.¹⁷ This study demonstrates that variations in diagnosis and treatment options can occur, depending on the diagnostic criteria used.

The Committee believes that the use of different diagnostic tools has contributed to the variance in prevalence rates between Australia and the US when compared to the UK. However, as discussed earlier, the examination of prevalence rates does not necessarily equate to an accurate representation of rates of diagnosis. Studies on prevalence rates usually rely on parent questionnaires on the behavioural characteristics of their children, rather than actual number of diagnoses carried out by clinicians. Similarly, consumption rates of stimulant medication are not a completely reliable indicator of rates of diagnosis, as a diagnosis of ADHD does not necessarily result in treatment with medication. Further, stimulants are used in the treatment of some other, unrelated conditions. Nevertheless, a comparison of stimulant use between jurisdictions reveals contrasting approaches to the treatment of ADHD.

Finding 1

The use of different diagnostic tools may explain the variation in ADHD prevalence rates between Australia (DSM-IV) and the United Kingdom (ICD-10).

Finding 2

Broadening the diagnostic criteria in the DSM-IV to include 2 subtypes, ADHD Hyperactive-Impulsive Type and ADHD Inattentive Type, is likely to have contributed to the growth in diagnosis of ADHD in Australia.

¹⁶ Social Development Committee, South Australian Parliament, *Inquiry into Attention Deficit Hyperactivity Disorder*, 2002, pp.2-4.

¹⁷ Sawyer, M.G. Rey, J.M. Graetz, B.W Clark, J.J. and Baghurst, P.A, (2002) Use of medication by young people with attention-deficit/hyperactivity disorder, *Medical Journal of Australia*, Vol 177, 1 July 2002, pp.21-25.

3.3 Use of psychostimulant stimulant medication

(a) Recent national and international data

Using data compiled by the International Narcotics Control Board, Berbatis, Sunderland and Bulsara (2002) compared the rate of Australia's total licit consumption of psychostimulant medication with nine other developed countries, then compared the rate of consumption between all Australian jurisdictions. It was found that Australia's rate was high in international terms, and that the rate in WA alone was comparable to both the US and Canada. Figure 3.1 below represents the rate ratios of total legal consumption of psychostimulant medication between 1994 - 2000 in ten countries. With Australia represented by a rate ratio of 1.0, Canada and the US were the only countries found to consume significantly more psychostimulant medication. The rate of consumption for the UK was lower than Australia, at 0.5.

Figure 3.1

Rate ratios of licit psychostimulant consumption - international.¹⁸



¹⁸ Figure 3.1 drawn directly from Berbatis C.G, Sunderland V.B and Bulsara, M. (2002) Licit Psychostimulant consumption in Australia, 1984-2000: International and jurisdictional comparison, *Medical Journal of Australia*, 177 (10) p.540. © Copyright 2002. *The Medical Journal of Australia* - reproduced with permission.

The above table demonstrates Australia's position internationally in relation to consumption of psychostimulants. However, Berbatis, Sunderland and Bulsara (2002) have demonstrated that while Australian per capita consumption rates of stimulant medication are lower than US and Canadian rates, between 1994 and 2000 the per capita rates for the use of psychostimulants in WA were similar in the US and Canada.¹⁹

(b) Consumption of psychostimulant medication in Australian jurisdictions

Whilst noting that the consumption of psychostimulant medication in Australia was high by international standards, it was also found to vary considerably between Australian states and territories. The data indicated that between 1984 and 2000, licit psychostimulant consumption increased in Australia as a whole by 26 per cent per annum. There was an 8.46 fold increase in the national consumption, with WA ranked first, almost double the second ranked NSW.²⁰

The School of Paediatrics and Child Health, UWA, advised the Committee that whilst the rates of prescription of stimulant medication in the treatment of ADHD appear to have stabilised in several parts of Australia after increasing progressively in the 1990s, this has not been the case in WA.²¹ The increase in the use of stimulants within WA over the past decade is significant. In 1989, 880 people were prescribed stimulant medication, a figure that rose to approximately 20,000 by the year 2000.²² To put this into context, WA had 64,000 prescriptions in 2001 compared to 61,000 in NSW,²³ despite the fact that NSW has a considerably higher population.

Figure 3.2 overleaf demonstrates that WA (as at 2000) led all other Australian jurisdictions by a rate ratio of approximately six to one in the use of dexamphetamine (measured using a defined daily dose per 1000 population). The rate increased steadily from 1994. The data indicate that consumption rates for dexamphetamine in Western Australia have skewed the figures for total licit consumption of psychostimulants in this state.

¹⁹ Berbatis C.G, Sunderland V.B and Bulsara, M. (2002) Licit Psychostimulant consumption in Australia, 1984-2000: International and jurisdictional comparison, *Medical Journal of Australia*, 177 (10) p.541.

²⁰ i*bid*, pp.539-543.

²¹ School of Paediatrics and Child Health, University of Western Australia, Submission 24 June 2003, p.2.

²² WA Department of Health (2002) Office of Mental Health, *Attentional Problems in Children: Diagnosis and Management of Attention Deficit Hyperactivity Disorder (ADHD) and Associated Disorders*, Government of Western Australia, p.21.

²³ Cited in Western Australian Department of Health, Drug and Alcohol Office Submission, 20 June 2003, p.ii.

Figure 3.2

Standardised total licit consumption of psychostimulants in Australia.²⁴



Berbatis, Sunderland and Bulsara (2002) concluded that:

The consumption of psychostimulants in Australia is high internationally and varies significantly between States and Territories. The results imply varied jurisdictional prescribing determinants and supply processes throughout Australia, which may require new national prescribing standards and access to online patient data for prescribers and dispensers.²⁵

Data that represent total licit consumption rates of psychostimulants, unless specified, contain dexamphetamine figures. The data presented above infer that while psychostimulants are disproportionately high in WA, the rate of consumption of dexamphetamine was highest. The Committee notes with interest that WA was comparable to other states in the consumption of methylphenidate, which is not subsidised on the Commonwealth Pharmaceutical Benefits Scheme (PBS).

²⁴ Figure 3.2 drawn from Berbatis C.G, Sunderland V.B and Bulsara, M. (2002) Licit Psychostimulant consumption in Australia, 1984-2000: International and jurisdictional comparison, *Medical Journal of Australia*, 177 (10) p.540. © Copyright 2002. *The Medical Journal of Australia* - reproduced with permission.

²⁵ *ibid*, p.539.

(c) Consumption of dexamphetamine in Australian jurisdictions

Figure 3.3 below represents dexampletamine prescriptions provided via the PBS from the period January 1992 to December 2003, Australia wide. These figures confirm that WA is the leading consumer (and prescriber) of dexampletamine in Australia, at a rate that is steadily increasing, where other jurisdictions appear to be stabilising.

Figure 3.3

Number of prescriptions for dexamphetamine supplied through the Pharmaceutical Benefits Scheme.²⁶



Recent studies by the Commonwealth Department of the Parliamentary Library (herein referred to as the Commonwealth reports), examined the disparity in the number of prescriptions dispensed for dexampletamine in different parts of Australia and reinforced the finding that comparatively, WA figures were disproportionately higher.²⁷ The studies categorised Commonwealth Department of Health and Aged Care data by postcodes of the pharmacy dispensing the medication and converted it into Federal Electorates. An analysis of PBS data for the years 1999-2003 (as represented in Table 3.1 below) indicate that the number of prescriptions dispensed

²⁶ Data obtained from Health Insurance Commission 'Statistical Information' <u>http://www.hic.gov.au/providers/health_statistics/statistical_reporting.htm</u> accessed 30 April 2004.

²⁷ Commonwealth Department of the Parliamentary Library, *Medication for the Treatment of ADHD: an Analysis by Federal Electorate*, Current Issues Brief, No.11 2000-01 & 2004-05 (Draft copy).

per 1000 population for dexampletamine was significantly higher in WA. As Table 3.1 demonstrates, prescriptions for dexampletamine per 1000 population were almost 4 times the national average in 1999-2003.

Table 3.1

Number of prescription	s for dexamphetamine per	r 1000 population ²	1999-2000. ²⁸
------------------------	--------------------------	--------------------------------	--------------------------

State/Territory	1999/2000	2003
New South Wales	9.5	9.1
Victoria	6.7	6.1
Queensland	8.2	9.5
Western Australia	43.2	44.2
South Australia	10.2	12.8
Tasmania	16.3	18.3
Northern Territory	4.6	3.6
Australian Capital Territory	8.5	9.9
AUSTRALIA	11.3	12.5

Finding 3

The consumption of dexampletamine in Western Australia is disproportionately high in comparison with other Australian and international jurisdictions. Prescriptions for dexampletamine were almost four times the national average in the period 1999 to 2003.

3.4 Reasons for variations

There is no simple explanation for the differences in prescription rates between Australian states. The Commonwealth reports note that at this stage there is still insufficient evidence available to mount a credible explanation of the main causes for

²⁸ Table 3.1 drawn from Commonwealth Department of the Parliamentary Library, Medication for the Treatment of ADHD: an Analysis by Federal Electorate, *Current Issues Brief, No.11* 2000-01 & 2004-05 (Draft copy).

those differences.²⁹ Table 3.2 overleaf indicates the variations between electorates and also demonstrates the increase in each of the WA electorates (apart from O'Connor and Moore) over the past 3 years. The table shows all 15 WA electorates and includes the two highest non-WA electorates for the purpose of demonstrating the variation between states. In 2000, the top ten federal electorates were in this state, and by 2003, this had increased to the top fourteen.³⁰ The Committee recognises that the data is drawn from pharmacies in various electorates dispensing the medication. As such, consideration must be given to variables such as the number of pharmacies within electorates. Nevertheless, the pattern of dispensing dexamphetamine appears inconsistent across WA.

Consideration was given to whether the differences in rates between WA electorates may be attributable to differences in the proportion of school aged children within them. However, the electorates with the lowest number of prescriptions in WA have only slightly lower proportions of children aged 5-14 years and persons attending school than those with the highest number of prescriptions. For example in first ranked Canning, the proportion of school aged children aged 5 - 14 years within the electorate was 17.3 per cent, while in thirtieth ranked Kalgoorlie the rate was 14.9 per cent.³¹ Drawing on demographic data from the 1996 and 2001 census, the Commonwealth reports concluded that:

- Socioeconomic data alone does not explain why such wide differences exist between electorates in the number of prescriptions dispensed for dexamphetamine sulphate;
- Higher unemployment rates and lower levels of family income appear to be significant in some jurisdictions, but this is not consistent across all States;
- Outer metropolitan electorates have the highest or second highest numbers of prescriptions in each State except Victoria and Tasmania; and
- The mix of electorates with high and low numbers of prescriptions indicates that location of prescriber does not consistently explain variations evident in the data.³²

²⁹ Commonwealth Department of the Parliamentary Library, Medication for the treatment of ADHD: an Analysis by Federal Electorate (2001-03), *Current Issues Brief, 2004-05*, Parliamentary Library, Canberra, 2004 (Draft Copy) p.7.

³⁰ *ibid*, p.11.

³¹ *ibid*, p.17.

³² *ibid*, pp.15-16.

Table 3.2

Variation in the number of prescriptions for dexamphetamine sulphate between Western Australian Electorates including national ranking.³³

Current ranking	Electorate	2003 number	2002 number and ranking	2001 number and ranking
1 st	Canning	8573	8303 (1)	7986 (1)
2 nd	Brand	7641	7323 (2)	7117 (2)
3 rd	Curtin	7498	6473 (4)	5516 (4)
4 th	Perth	7109	6104 (5)	4906 (7)
5 th	Swan	6913	6017 (6)	4590 (10)
6 th	Hasluck	6697	6720 (3)	6404 (3)
7 th	Fremantle	5758	4963 (9)	4615 (9)
8 th	Tangney	5673	5429 (7)	5001 (5)
9 th	Cowan	5419	5300 (8)	4923 (6)
10 th	Stirling	5274	4676 (12)	4342 (13)
11 th	Pearce	4934	4739 (11)	4466 (11)
12 th	O'Connor	4618	4911 (10)	4888 (8)
13 th	Moore	4492	4617 (13)	4436 (12)
14 th	Forrest	4338	4153 (14)	3769 (14)
15 th	Oxley (QLD)	3380	3283 (16)	3108 (18)
16 th	Wakefield (SA)	3356	3275 (17)	3453 (15)
30 th	Kalgoorlie	2166	2005 (33)	1972 (35)

(a) Variations in clinical perspective

Variations such as those presented in this report raise questions regarding whether the differences represent appropriate clinical practice. As far back as 1997, it was established that WA had a disproportionately high usage of stimulant medication in

³³ Data drawn from Commonwealth Department of the Parliamentary Library, Medication for the Treatment of ADHD: an Analysis by Federal Electorate (2001-03), *Current Issues Brief, 2004-05*, Parliamentary Library, Canberra, 2004 (Draft Copy)

relation to other Australian jurisdictions. The National Health and Medical Research Council (NHMRC) stated at the time that:

Overall prescribing rates in Australia are less than one per cent of school aged children (lower than the 2-5 per cent incidence of ADHD). Prescribing rates are highest in Western Australiapresumably this is due to variation in clinical perspective rather than significant differences in child population or in support services, the availability of which may diminish or enhance the relative benefits of medication.³⁴

The Committee was interested to learn whether a small number of clinicians may be responsible for most of the prescribing in WA, as was the case in Adelaide in the 1990s, when (as noted in the Commonwealth reports discussed above) five prescribers accounted for sixty-one per cent of patients. Anecdotal evidence provided to the Committee indicated that this has been the case in WA. Associate Professor Trevor Parry, Developmental Paediatrician, School of Paediatrics and Child Health, University of Western Australia, noted that:

there was a time in Western Australian history - now fortunately concluded in which one or two prescribers were following a pattern of prescribing that came out of New South Wales and that was not the gold standard model which most of us believed in and which certainly did not have the endorsement of the college of either paediatrics or psychiatry. That caused a skewing of overprescribing within certain locations in the metropolitan area...... There was a professional glitch in the system, I guess, that we believe has now fortunately been addressed.³⁵

Dr Parry proposed that a training program for paediatricians operating over the past 30 years in Western Australia had impacted on "professional awareness of the diagnostic procedures of the condition".³⁶ Although principally referring to the incidence of ADHD, Dr Parry attributed low figures in Victoria, including the application of stimulants, to training of practitioners until approximately a decade ago.

It was suggested that, until recently, "there was a whole cohort of [Victorian paediatricians and other] professionals trained in that environment who were not equipped to do an appraisal of the problem."³⁷ Discussions the Committee held in Victoria reflected disagreement with this view. Factors such as access to comprehensive child and adolescent mental health services were considered to better

³⁴ National Health and Medical Research Council, 1997, *Attention Deficit Hyperactivity Disorder*, p.69.

³⁵ Transcript of Evidence, 20 August 2004, p.2.

³⁶ Transcript of Evidence, 20 August 2004, p.2.

³⁷ Dr Trevor Parry Developmental Paediatrician, School of Paediatrics and Child Health, University of Western Australia, Transcript of Evidence, 20 August 2004, p.2.

explain the variations, rather than simply a difference in training approaches in the fields of paediatrics and paediatric neurology.

(b) Training variances between therapeutic disciplines

The Committee was advised that paediatricians in general might not have received adequate training to recognise and manage the comorbidities associated with ADHD,³⁸ and questioned whether training variations between disciplines might also be a factor in approaches to treatment. Professor David Hay of the School of Psychology, Curtin University, advised the Committee that:

It is more than that. My concern is that these kids may be presenting with what appears to be ADHD for many other reasons....we need to be able to make a really good diagnosis. I argue that it is much more the profession of the child psychiatrist than the paediatrician....paediatricians may well be involved...however we need a broader perspective of what is going on. Unfortunately, that costs money.³⁹

Dr Susan Prescott of the School of Paediatrics and Child Health, University of Western Australia, noted that seeing a paediatrician, as opposed to a mental health professional, has been identified as a 'risk factor' in the use of stimulant medication:

By virtue of their training and workload it is also possible that paediatricians may be more prone to use drug therapy than the other therapies recommended for the management of ADHD.⁴⁰

Dr Prescott's evidence suggests it is likely that paediatricians are the principal prescribers of stimulant medication in the treatment of ADHD because of the pressure to support people with problems that require alternative specialist care. Dr Prescott notes that:

The shortage of child and adolescent mental health personnel and services in our community has been offset by paediatricians becoming involved in the care of children and adolescents with ADHD. While this arrangement now supports the system, it has shortcomings. Paediatricians have in general not received adequate training to recognise and manage the co-morbidities associated with ADHD. Nor are they, in general adequately trained to recognise alternative diagnoses that appear similar to ADHD, such as anxiety, depression, phobic disorders and post-traumatic stress disorder....The combined shortages of child psychiatrists and the availability

³⁸ School of Paediatrics and Child Health, University of Western Australia, Submission, 24 June 2003, p.3.

³⁹ Transcript of Evidence, 23 June 2004, p.5.

⁴⁰ School of Paediatrics and Child Health, UWA, Submission, 24 June 2003, p.3.

of paediatricians may be factors contributing to the continued increase of prescriptions for stimulants in Western Australia.⁴¹

It appears that the reliance on paediatricians to provide the majority of assessment and care of children with ADHD is an important factor in the high rate of prescription of stimulant medication in WA. The Committee does not question the commitment or professionalism of Western Australia's paediatric specialists. Rather it recognises that in many cases, paediatricians are in the difficult position of dealing with an increasing demand to treat a range of complex conditions in the face of personnel shortages in the child and adolescent mental health sector. These issues are discussed in greater detail in Chapter Four.

Finding 4

During their training, paediatricians have not been adequately informed about the extent of alternative diagnoses and treatment methods, and are therefore more likely to use drug therapy in the first instance in the management of ADHD.

(c) Pharmaceutical Benefits Scheme

Western Australia's higher rate of consumption of dexamphetamine has an impact at a national level. The main support mechanism provided by the Commonwealth for people diagnosed with ADHD is in the form of subsidised dexamphetamine under the Pharmaceutical Benefits Scheme (PBS). Current provisions governing the operations of the PBS are embodied in Part VII of the *National Health Act 1953* together with the *National Health (Pharmaceutical Benefits) Regulations 1960* made under the Act. The PBS is a Commonwealth program that is administered by the Health Insurance Commission (HIC) and as such is beyond the jurisdiction of the state government. Of the stimulant medication available for the treatment of ADHD only dexamphetamine is subsidised under the PBS. An alternative medication, methylphenidate (Ritalin) is not covered under the scheme.

Dexamphetamine currently accounts for more than 95 per cent of prescriptions dispensed for the treatment of ADHD⁴² and is therefore the most commonly dispensed medication for ADHD in this country. Prior to January 1997, public hospitals in WA could provide Ritalin to child patients with ADHD free of charge, at a cost to the state. An interim policy, dated January 1997, confirmed that no new cases of ADHD were to

⁴¹ School of Paediatrics and Child Health, UWA, Submission, 24 June 2003, p.3.

⁴² Commonwealth Department of the Parliamentary Library, Medication for the Treatment of ADHD: an Analysis by Federal Electorate, Current Issues Brief, No.11 2000-2001, p.14.

be funded through the public hospital system (apart from Princess Margaret Hospital) due to the significant growth in demand and costs for supply of Ritalin free of charge to the Community.⁴³

It is the Committee's view that the availability of dexamphetamine on the PBS combined with the shortage of child psychiatrists and publicly available multidisciplinary services (discussed further at Chapter Five) have contributed to the tendency for stimulant medication to be used as the first line of treatment for suspected ADHD.

Further, the Committee queries the level of responsibility of the Commonwealth to ensure that inequitable consumption of stimulant medication on the PBS between Australian states are not only measured but also investigated and addressed at a national level.

Finding 5

The provision of dexampletamine on the Commonwealth Pharmaceutical Benefits Scheme, combined with the reliance on paediatricians to provide the majority of assessment and care of children with behavioural and learning difficulties, is likely to have contributed to the growth in its use in the treatment of ADHD in Western Australia.

Recommendation 1

The Committee recommends that the Commonwealth Government ensure that the disproportionate use of dexampletamine on the Pharmaceutical Benefits Scheme between Australian states is not only measured but also investigated and addressed at a national level.

3.5 Monitoring stimulant usage

The DoH has implemented an approach to address the concerns about WA stimulant prescription rates. It is expected the new Stimulants Notification Regime (SNR) (see section 3.6) will provide evidence of anomalies, and enable further examination of those practitioners who appear to be prescribing at a higher rate than others.

⁴³

Hon. John Day, then Minister for Health, Legislative Assembly Parliamentary Debates, Tuesday 13 October 1998, p.1977.

WA is the second Australian jurisdiction to have introduced a notification system to monitor the use of stimulant medication. The NSW Department of Health has been monitoring trends in the prescribing of stimulant medication for the treatment of ADHD for a number of years, which will enable a useful comparison between these jurisdictions in future.

(a) Prescription guidelines in New South Wales and Western Australia

The prescribing of dexampletamine and methylphenidate in NSW is subject to the *Poisons and Therapeutic Goods Act 1966* and its regulations. A medical practitioner requires approval from the NSW Department of Health. In NSW, a number of requirements are imposed on clinicians to ensure that prescribing of stimulant medication for very young children with ADHD is appropriate. These include requirements to submit written applications supported by clinical reports, to provide written progress reports, and, in cases where the child is aged two years, requirements to obtain a second opinion on the appropriateness of stimulant medication for treatment.

Doctors other than paediatricians and child psychiatrists may apply to prescribe stimulant medication to children with ADHD on an individual patient basis. These doctors are generally adult psychiatrists, advanced trainees in paediatrics or child psychiatry, general practitioners with paediatric training that work in rural or remote areas or general practitioners working in a paediatrically-orientated practice. Approval must be sought for each patient and is restricted to those that meet routine prescribing criteria.⁴⁴

The WA *Poisons Regulations 1965* require a medical practitioner to have the prior authorisation of the Commissioner of Health before prescribing oral methylphenidate and dexamphetamine.⁴⁵ While the diagnosis of ADHD may involve a General Practitioner and relies on information obtained from the school setting, state regulations stipulate that only certain specialists may prescribe stimulant therapy. Authorised prescribers are able to prescribe stimulants within the regulatory guidelines, which place restrictions on the age, dose and co-morbidities in much the same manner as the NSW guidelines outlined above. Prescription of stimulants for a patient that falls outside of the guidelines requires an authorisation issued by the Commissioner of Health following an assessment by the Stimulants Assessment Panel,

⁴⁴ NSW Department of Health (2002) Trends in the Prescribing of Stimulant Medication for the Treatment of Attention Deficit Hyperactivity Disorder in Children and Adolescents in NSW, *NSW Public Health Bulletin Supplement*, Vol 13 No. S-1, January 2002, pp.17-18.

⁴⁵ Except for therapeutic trials of up to 30 days when initiated by a paediatrician, paediatric neurologist or paediatric psychiatrist, WA Department of Health Western Australia, Submission, 3 July 2003, p.9.

which replaces the Stimulants Committee.⁴⁶ These restrictions are reflected in Section 51GAD of the regulations.

3.6 New Stimulant Notification Regime

The WA Department of Health (DoH) has given consideration to the possibility that the higher prescription rates in WA may be attributable to the practices of a small number of specialists. The new Stimulants Notification Regime (SNR) was, in part, developed to address these concerns. It was developed in collaboration with paediatricians and psychiatrists through workshops and a written consultation process. Dr Rowan Davidson, Chief Psychiatrist with the DoH, advised the Committee that:

The work of the stimulants panel...is very much directed at trying to provide a degree of control and support for issues such as accuracy of diagnosis and monitoring, so that we monitor not just the overall patterns but also individual clinician prescribing patterns, and can then ask an individual clinician for appropriate explanations about prescribing patterns.⁴⁷

The Committee notes that until recently (late 2003), the majority of data available on the incidence, diagnosis and use of medication for the treatment of ADHD in WA has been limited largely to figures on overall consumption rates. Prior to 1 August 2003, authorised specialist medical practitioners were able to prescribe stimulants *en bloc.*⁴⁸ That is, a practitioner was able to apply to the DoH and be granted blanket approval to treat any number of patients with stimulant medication, without further notifying of changes to individual patient details or dosage.

From August 2003, a practitioner must apply to the DoH and obtain a unique Stimulant Prescriber Number (SPN) to initiate stimulant treatment in any patient. The partitioner must provide individual patient details, including age, gender and dose required, thus enabling the collection of data for future analysis of stimulant use in WA. The Committee understands that the data provided from the first twelve months of the new system relate to the numbers of notifications that have been sent to the DoH. This reflects the diligence of the prescriber in informing the DoH as much as being representative of the number of patients being prescribed stimulants. A Notification form is sent to the DoH at the commencement of treatment, or during the transition period for the introduction of the new scheme when existing patients visit

⁴⁶ The role of the Stimulants Assessment Panel is to oversee the use of stimulants in the treatment of ADHD where the indications for treatment, the clinical parameters or the planned treatment regime fall outside the regulatory guidelines.

⁴⁷ Transcript of Evidence, Wednesday 15 September 2004, p.11.

⁴⁸ Specialist Medical Practitioners in this case being paediatricians, developmental paediatricians, paediatric neurologists, neurologists, thoracic medicine physicians, rehabilitation physicians or child and adult psychiatrists.

their consultant. The DoH does not require further information unless there has been a change in the patient's details, drug or dose.

(a) Preliminary analysis of Stimulant Notification Regime

Data obtained from the first twelve months of the new system provide the following preliminary results. The 12-month transition period ended on 31 July 2004. However, because a large number of notification forms were received by the DoH in the first few days of August 2004, the catchment dates for reporting were set at 1 August 2003 to 25 August 2004.⁴⁹ During the reporting period there were 14,204 patient notifications, and a further 3,221 patients obtaining stimulants through pharmacies for which it is not clear whether notifications have been submitted. The DoH is in the process of clarifying whether or not these patients' details have been collected and as such they are not included in the following data.

Table 3.3 below represents the number of patients notified and the diagnosis for which stimulant medication has been prescribed. This indicates that approximately 98 per cent of notifications were for a diagnosis of ADHD.

Diagnosis	Number of patients	Percentage of patients
ADHD	13,914	97.96
Depression	131	0.93
Narcolepsy	127	0.89
Brain damage	26	0.18
Other conditions	6	0.04
Total:	14,204	100.00

Table 3.3

Use of stimulant medication by diagnosis 1 August 2003 to 25 August 2004.⁵⁰

Finding 6

Figures obtained from the new Stimulant Notification Regime indicate that approximately 98 per cent of prescribed psychostimulants in Western Australia are dispensed for the treatment of ADHD.

⁴⁹ Information provided by the Minister for Health, Hon. Jim McGinty, MLA, 26 October 2004.

⁵⁰ Data provided by the Minister for Health, Hon. Jim McGinty, MLA, 26 October 2004.

Figure 3.4 below represents the age and gender distribution for ADHD notifications for the first year of the SNR. This data demonstrates that most notifications were for males between the ages of 5 and 25 years and corresponds with reported views that approximately 3 out of 4 ADHD diagnoses are for boys and adolescent males.

Figure 3.4





Finding 7

Data obtained from the new Stimulant Notification Regime demonstrate that the majority of stimulant prescriptions in Western Australia for ADHD in the period 1 August 2003 to 25 August 2004 were for males between the ages of 5 and 25 years.

(b) **Prescribers by profession**

At 25 August 2004 there were 180 registered specialists who notified the DoH that they had prescribed stimulant medication for the treatment of ADHD. Table 3.4 overleaf represents that group by profession, the number of notifications within that group, and the number and percentage of patients treated by the top five prescribers in each profession.

Table 3.4 demonstrates that overall, paediatricians were responsible for 57 per cent of ADHD notifications, child and adolescent psychiatrists 25 per cent and adult psychiatrists 17 per cent. Of the 59 registered paediatricians, five of those accounted

for 26 per cent of all ADHD notifications (or 3,708 of 13,194) in the period 1 August 2003 to 25 August 2004.

Table 3.4

ADHD notifications by profession and the number and percentage of notifications submitted by the top five prescribers by profession.⁵¹

Profession	Number of registered prescribers	Number of notifications	Total number of notifications submitted by top five prescribers within each profession	Percentage of notifications submitted by top five prescribers within each profession
Adult Neurologist	12	1	1	100
Adult psychiatrist	67	2,381	1,711	72
Child and adolescent psychiatrist	24	3,450	2,471	72
Paediatric neurologist	7	127	126	99
Paediatrician	59	7,955	3,708	47
Respiratory and sleep physician	11	0	0	0
Total:	180	13,914	8,017	

The data appears to confirm the view that paediatricians are the highest prescribers of stimulants for the treatment of ADHD in WA, and that a small number of those are prescribing at a rate that is disproportionate to others within their profession. The same may be said for child and adolescent psychiatrists and adult psychiatrists.

51

Data provided by the Minister for Health, Hon. Jim McGinty, MLA, 26 October 2004.

Finding 8

Overall, paediatricians were responsible for 57 per cent of ADHD notifications in the period 1 August 2003 to 25 August 2004. Child and adolescent psychiatrists were responsible for 25 per cent and adult psychiatrists 17 per cent. Of the 59 registered paediatricians, five of those accounted for 26 per cent of all ADHD notifications in the reporting period (or 3,708 of 13,194).

The Committee notes that since the introduction of the new regime in 2003, there appears to be a decline in the number of individuals being prescribed stimulant medication. For example, in 2000 the DoH estimated there were 20,648 individuals prescribed stimulant medication.⁵² In the first 12 months of the SNR, there were 14,204 notifications and, as discussed at section 3.6 (a), a further 3,221 patients that are not included in the above mentioned figures.

The DoH is in the process of clarifying if the further 3,221 are patients for whom prescribers have previously sent in a Notification form, or whether they are patients without a Notification form. If all of the 3,221 patients' details had not been provided then there would have been 17,425 patients being prescribed stimulant medication. This is a reduction from the 2000 estimate but care is necessary in interpreting this preliminary data, as there may have been a significant number of patients being recorded more than once in the 2000 estimate.

Finding 9

52

The Stimulant Regulatory Scheme introduced in August 2003 will enable basic data on the use of stimulant medication in Western Australia to be collected and compared with other published data.

WA Department of Health (2002) Office of Mental Health, *Attentional Problems in Children: Diagnosis and Management of Attention Deficit Hyperactivity Disorder (ADHD) and Associated Disorders,* Government of Western Australia, p.21.

CHAPTER 4 VARYING MEDICAL AND BEHAVIOURAL APPROACHES TO THE TREATMENT OF ADHD

4.1 Introduction

There are divergent views within the medical, research and wider community with regard to the treatment of ADHD. Medical opinion remains divided, despite extensive research and analysis. One of the most contested questions in the debate on ADHD relates to its cause, or aetiology. The 1997 report of the NHMRC acknowledged that the cause of ADHD is essentially unknown, however, available evidence suggests numerous factors, including cognitive, familial, neurophysiologic and environmental factors may be involved.

The Committee does not wish to enter into a debate on cause and definition in this report. Rather, it acknowledges the expertise within the fields of medicine, genetics, psychology, psychiatry and neurology, where opinions (some diametrically opposed) converge and diverge on various theories. However, the Committee did find agreement among the research community that the condition is clinically heterogeneous, or results from a diverse range of factors. This chapter explores varying perspectives on the treatment of ADHD, particularly, but not limited to, those within the medical and allied health sector.

4.2 Legitimacy of ADHD and the use of stimulant medication

The majority of submissions received from health and education professionals recognised ADHD as a legitimate medical condition, with broad, at times qualified, support for the use of stimulant medication as part of a range of treatment options. Those taking this view believe stimulant medication addresses a neurological/chemical discrepancy enabling a reduction in the symptoms or behaviours that impair the individual's life. The clear change in sufferers' behaviour is considered a positive outcome, in that life for the individual, the family and peers becomes easier.

The Royal Australian and New Zealand College of Psychiatrists (WA) Branch stated that:

ADHD is a legitimate psychiatric entity and does affect both children and adults. Stimulant pharmacotherapy is a legitimate treatment modality.... [However], less severe cases of the disorder may be adequately managed by psychological treatments alone. In more severe cases, the ideal treatment is a combination of both psychotherapy and medication. ⁵³

⁵³ The Royal Australian and New Zealand College of Psychiatrists (WA) Branch, Submission, 23 June 2003, pp.1-2.

There is an opposing view that the causes of dysfunctional inattentiveness and/or impulsiveness and hyperactivity in children are many and varied and cannot be easily determined. Those of this view caution that without a definitive biological test to prove a chemical imbalance, dysfunctional behavioural traits may instead be attributable to underlying causes. In this view, underlying problems are not easily detected using the standard check list diagnosis, and the use of stimulant medication may address symptoms, rather than cause. Dr Lois Achimovich, Consultant Psychiatrist, advised the Committee that:

from being a peripheral 'syndrome', the concept of ADHD has virtually hijacked child psychiatry. Almost any behaviour disorder of childhood can be made to fit the diagnosis and thus allow the quick fix of stimulant medications.⁵⁴

(a) Informed consent

The Citizens Committee on Human Rights (CCHR) is clear in its rejection of ADHD as an actual disease, and urged the Committee to attempt to find scientific proof of its existence or legitimacy before validating it as such. For the CCHR, the bottom line is that the child and/or parent's rights to give informed consent in relation to the diagnosis and treatment of ADHD are being violated.⁵⁵ Dr Fred Baughman, Paediatric Neurologist, advised the Committee that:

All physicians have this duty of diagnosis of determining whether there is a disease or not. They then have a duty of informed consent, which is to tell parents and patients all the facts about their condition and about the drugs that might be used in their treatment. I submit that, in saying ADHD is a disease, they totally abrogate informed consent with that one statement alone. If they go on to categorise these drugs as non-addictive or hardly addictive, they defeat informed consent on yet another score.⁵⁶

It is clear that the debate on the legitimacy of ADHD remains active. The views represented above are a small sample of those the Committee encountered throughout the inquiry process and represent opposing positions on the issue. There are also views that fall between those mentioned above. However, there is agreement that the absence of a test that can pinpoint the disorder as a biological manifestation, is one of the reasons for the prevailing scepticism.

⁵⁴ Dr Lois Achimovich, Submission 4 July 2003, p.1.

⁵⁵ Citizens Committee on Human Rights, Submission July 2003, p.16.

⁵⁶ Transcript, of Evidence, 2 June 2004, p.2.
4.3 Treatment options

Treatment options for ADHD include a range of social, psychological and behavioural interventions, which may focus on the child, parents and/or teachers. These vary from the provision of information and advice, through to formal psychotherapeutic interventions.⁵⁷ Stimulant medication is only one of a range of treatment options available, however, as stated in section 2.3, treatment options other than medication alone are indicated as the preferred choice in most submissions and within the medical, educational and research communities.

(a) Multi modal treatment

There is broad scientific and medical agreement that multi modal approaches to treatment offer the best chance of alleviating the symptoms associated with ADHD in children.⁵⁸ Multi modal treatment involves the use of a variety of therapeutic methods including: parenting-skills training and home help, pharmacotherapy (stimulants), teacher counselling about ADHD and classroom management strategies and educational programs for learning disabilities. It is the approach stated in the WA Government policy *Attentional Problems in Children: Diagnosis and Management of Attention Deficit Disorder and Associated Disorders,* (ADHD Policy), released in November 2002. The greater number of reports and inquiries over recent years have endorsed multi modal therapy as a valid approach, and most endorse stimulant medication as a safe and effective part of that treatment.

(i) The role of non-government organisations

Community-based, non-government voluntary organisations provide a number of multi modal services that are not currently available within the public sector. The principal community-based organisation that has received some support from the DoH is the Learning and Attentional Disorders Society of WA Inc (LADS).⁵⁹ LADS is a support, information and advocacy organisation that provides assistance to people affected by ADHD. It is acknowledged by the DoH as a group that offer a range of services for both families and individuals who have ADHD and provides, among other things, seminars, workshops and counselling services including information and advice for teachers. One particular parent advised the Committee that:

⁵⁷ National Institute for Clinical Excellence, Technology Appraisal Guidance - No. 13, *Guidance* on the use of methylphenidate (*Ritalin, Equasym*) for Attention Deficit/Hyperactivity Disorder (ADHD) in childhood, October 2000, www.nice.org.uk, accessed January 2004, p.3.

⁵⁸ Zubrick, S.R. Silburn, S.R. Gurrin, L. Teoh, H. Shepherd, C. Carlton, J. and Lawrence, D. (1997) Western Australian Child Health Survey: Education and Health Competence, Perth, WA: Australia Bureau of Statistics and the TVW Telethon Institute for Child Health Research, p.36.

⁵⁹ Dr Rowan Davidson, Chief Psychiatrist, Department of Health, Transcript of Evidence, 15 September 2004, p.3.

*I have been fortunate enough to have been introduced to the support group LADS. The wonderful people there offer great support and services to people like myself.*⁶⁰

LADS does not receive ongoing government funding, rather it relies on membership fees, some private sponsorship and volunteers to provide its services.⁶¹ The Committee was advised LADS has received some emergency funding through the DoH to enable it to continue its range of services in 2003/2004.⁶²

4.4 Varying opinions on diagnosis

As indicated, current diagnostic tools are primarily based on behavioural observation. A number of submissions noted concerns about the adequacy of the diagnostic tools used to detect ADHD, particularly in the absence of a test to definitively identify its existence. Associate Professor David Leach, Clinical Convenor, School of Psychology and Douglas Brewer, PhD candidate at Murdoch University are not convinced that current diagnostic procedures are sufficiently precise and accurate to trust the incidence figures that are reported. It is their experience that diagnoses are too frequently being made without rigorous investigation and application of valid, objective assessment protocols.⁶³

For many, the diagnostic problem is to determine at which point a child's behaviour is seen as 'normal' and at which point it is seen as disordered and/or dysfunctional. Mr Neil Darby, Director of Schools in the Albany Education District observed the absence of medical, neurological, psycho-educational or laboratory tests, which can make a definitive and reliable diagnosis of ADHD.⁶⁴ The DSM-IV notes that:

There are no laboratory tests, neurological assessments, or attentional assessments that have been established as diagnostic in the clinical assessment of Attention-Deficit/Hyperactivity Disorder.⁶⁵

For the Committee, the symptoms that make up the ADHD diagnosis in many ways resemble ordinary behaviour. The symptoms as stated in DSM-IV are listed in full in Appendix Four of this report and include:

Inattention

⁶¹ Ms Michelle Toner, LADS, Transcript of Evidence, Monday, 27 October 2003, pp.4-5.

⁶⁰ W Killick, Submission, 23 June 2003, p.2.

⁶² Dr Rowan Davidson, Chief Psychiatrist, Department of Health, Transcript of Evidence, 15 September 2004, p.4.

⁶³ Associate Professor David Leach and Douglas Brewer, Murdoch University, Submission, June 2003, p.2.

⁶⁴ Albany Education District, Submission, 16 June 2003, p.1.

⁶⁵ DSM-IV, 2000, p.88.

- Often fails to give close attention to details or makes careless mistakes in school-work, work or other activities;
- Often has difficulty sustaining attention in tasks or play activities; and
- Often has difficulty organising tasks and activities.

Hyperactivity

- Often fidgets with hands or feet or squirms in seat;
- Often leaves seat in classroom or in other situations in which remaining seated is expected; and
- Often talks excessively.

Impulsivity

- Often blurts out answers before questions have been completed;
- Often has difficulty awaiting turn; and
- Often interrupts or intrudes on others.⁶⁶

The Committee is concerned that to the untrained and inexperienced observer, in particular teachers (see section 7.3) the symptoms and behavioural traits underpinning the diagnosis are difficult to distinguish from 'normal' childhood behaviour. Of further concern to the Committee is that the diagnosis is largely based on third party reports of a child's behaviour. The DSM-IV states that:

Signs of the disorder may be minimal or absent when the person is receiving frequent rewards for appropriate behaviour, is under close supervision, is in a novel setting, is engaged in especially interesting activities, or is in a one-to-one situation (e.g., the clinician's office). The symptoms are more likely to occur in group situations (e.g., in playgroups, classrooms, or work environments). The clinician should therefore gather information from multiple sources (e.g., parents, teachers) and inquire about the individual's behaviour in a variety of situations within each setting (e.g., doing homework, having meals).⁶⁷

It is the Committee's view that the reliance on third party reports increases the likelihood of misdiagnosis. As discussed, the clinician carrying out the diagnosis does not often see the patient out of the clinical setting.

⁶⁶ DSM-IV, 2000, p.92.

⁶⁷ DSM-IV, 2000, pp.86-87.

(a) Potential for misdiagnosis

The Committee recognises that many people diagnosed with ADHD are affected by a number of comorbidities, or coexisting conditions and that some of these may be characterised by similar symptoms. These include, among others, oppositional defiant disorder, conduct disorder, anxiety and depression. The Committee was advised that:

due to the similarity of behaviours with other disorders, there have been cases of misdiagnosis.⁶⁸

A field officer for the Department for Community Development in Cannington further noted:

Children are often misdiagnosed or given medication as a 'quick-fix' solution.⁶⁹

Most health professionals agreed that it is preferable to conduct an extensive diagnosis and trial of alternative behavioural neuro/psycho treatment options prior to medication. The ADHD assessment team at the Bentley Family Clinic (Bentley Clinic) viewed ADHD as being over diagnosed in WA, with a high incidence of misdiagnosis. The team stated that:

Many of the children who have been referred to [the Bentley Clinic] with a previous diagnosis of ADHD do not in fact have ADHD. Our statistics show that following thorough multidisciplinary family assessment only 20-25% of children are given a confirmed ADHD diagnosis. In our experience, many of the children misdiagnosed with ADHD in fact are assessed to be suffering from significant developmental and learning disorders; attachment problems; anxiety or depression.⁷⁰

The Committee was advised that between 50 and 80 per cent of children diagnosed with ADHD meet the criteria for at least one other disorder, and that it is not uncommon for a child to have more than one comorbid disorder.⁷¹ Professor David Hay, of the School of Psychology at Curtin University, advised the Committee that:

The current estimate is that at least 80% of children with ADHD have another (and usually well recognised) problem. These include those related to speech, reading, motor control and internalising problems such as anxiety and depression.⁷²

⁶⁸ Dr Gil Anaf, Submission, June 2003, p.10.

⁶⁹ Department for Community Development, Cannington Branch, Submission, 25 June 2003, p.2.

⁷⁰ Bentley Health Service, Submission, 24 June 2003, p.2.

⁷¹ Learning and Attentional Disorders Society of Western Australia, Submission, 9 July 2003, p.9.

⁷² Professor David Hay, School of Psychology, Curtin University, Submission, 23 June 2003, p.4.

It is understood that ADHD does not cause these other conditions to be present, however they are often found to coexist in people diagnosed with the disorder.⁷³

Dr Gil Anaf, President of the National Association of Practicing Psychiatrists noted the difficulty in making an accurate diagnosis when:

young children often display behavioural changes before they develop adequate language to communicate states of distress that accompanies anxiety, panic, terror or abuse and trauma, conditions which may mimic or coexist with ADHD.⁷⁴

While the symptoms for some of these other conditions may resemble those that present in ADHD, the treatment options may differ markedly.

Finding 10

The behavioural symptoms underlying the diagnosis of ADHD are a key factor in the controversy surrounding the condition as many are within the range of 'normal' childhood behaviour.

Finding 11

The clinical diagnosis of ADHD is most often based on reported behavioural observations made by parents and/or teachers. There are no tests that identify the existence of ADHD in a biological sense. This is one of the reasons for the divergent views on the existence of ADHD as a clinical entity.

Finding 12

Comorbidities or coexisting conditions may be misdiagnosed as ADHD due to the similarity in behavioural symptoms.

⁷³ Green & Chee, (2001) *Understanding ADHD*, p.50.

⁷⁴ Dr Gil Anaf, Submission, June 2003, p.10.

4.5 Varying opinions on the use of stimulant medication

Treatment with stimulant medication assumes a biochemical imbalance in individuals diagnosed with ADHD and is thought to address a neurological/chemical discrepancy in the brain of sufferers. Many parents, health and education professionals indicated that a child's increased ability to focus and concentrate had a significant positive educational impact, although an improvement in social or familial relationships was less apparent. It is important to note that a favourable response does not necessarily confirm or refute a diagnosis of ADHD. Studies have found that the effects produced by stimulants also improve behaviour and attention in children who do not display symptoms of ADHD.⁷⁵

On-going studies, (notably the MTA study⁷⁶) maintain that in children with carefully diagnosed ADHD, the most consistently effective treatment for positive change was the combination of stimulants plus therapy.⁷⁷ Dr Kenneth Whiting, a Consultant Paediatrician, advised the Committee that:

Results from the MTA study provide the clearest picture of current thinking regarding the role of behavioural therapy and medication in the management of ADHD.....The study found that pharmacotherapy and multi modal treatments were both clinically and statistically superior to behavioural therapy alone.⁷⁸

While the MTA study is considered by many to be the defining study on the efficacy of stimulant medication in the treatment of ADHD, the Committee heard evidence to suggest the study contained methodological flaws. For example, it has been noted in a submission provided by Dr Lois Achimovich that:

The MTA study failed to adhere to basic scientific standards for clinical trials of medication efficacy....It was not placebo controlled and lacked a nontreatment control group. It was not double blind. Teachers and parents provided the ratings relied upon by the study, but both groups knew whether or not the children were taking medications. The MTA study was 'open label' and would not have qualified, for example as a study for the FDA Approval

⁷⁵ Rapoport, J.L. *et al*, (1980) Dextroamphetamine: Its cognitive and behavioural effects in normal and hyperactive boys and normal men, *Arch Gen Psychiatry* 1980; 37: 933-943, cited in NSW Department of Health, (2002) Trends in the prescribing of stimulant medication for the treatment of Attention Deficit Hyperactivity Disorder in children and adolescents in NSW, *Public Health Bulletin Supplement*, Vol 13, Number S-1 January, 2002, p.14.

⁷⁶ The Multi Modal Treatment Study of Children with Attention-Deficit/Hyperactivity Disorder Cooperative Group - a 14 month randomised clinical trial of treatment strategies for ADHD.

⁷⁷ Dr Trevor Parry, Head of Department, Department of Community and Developmental Paediatrics, Women's and Children's Health Services, & Clinical Associate Professor, School of Paediatrics, UWA, Submission, 30 June 2003, p.2.

⁷⁸ Dr Kenneth Whiting, Submission, 30 June 2003, pp.5-6.

process. As research purporting to demonstrate the effectiveness of stimulant drugs it is scientifically unsound.⁷⁹

The NHMRC have previously recommended that further research is required to establish the efficacy and safety of stimulant medication in the long-term⁸⁰, while the DoH makes reference to concerns that:

children under 4 years are being prescribed stimulant medication with little knowledge about how this will impact on the early or later years of development.⁸¹

Nevertheless, Dr Trevor Parry, advised the Committee that:

In general scientific terms, the efficacy and safety of stimulants is no longer a point of controversy. A recent report has indicated that more than 1000 studies have demonstrated stimulants to be safe and effective in the vast majority of <u>properly diagnosed</u> patients.⁸²

The Committee agrees with Dr Parry's observation that patients must be properly diagnosed prior to receiving stimulant medication. This issue goes to the heart of the concerns the Committee has with respect to ADHD and is reflected within a great number of submissions. With the level of resourcing required to ensure adequate assessment and an indication that many people cannot afford such an assessment, concern arises that many patients are not receiving a thorough, careful diagnosis. In this respect, there may be many children receiving simulant medication when it is not necessary or warranted. When questioned about the lack of long-term studies into the effects of stimulant, Dr Parry advised the Committee that:

Some say that the studies have not been done and therefore stimulants are potentially harmful; I do not know that that necessarily logically follows. They have not been done. We have not got to where we are now - the stimulants have been used since about 1937 - by randomised control studies, but we have got a lot. I mean, the literature is full of things that we do know. We know that stimulants are non-addictive in carefully prescribed doses; they do not affect the cardiovascular system or the liver; they do not delay puberty; and a whole heap of things. That is balanced by the fact that we have a lot of

⁷⁹ Breggin, P (MD), <u>www.breggin.com/mta.html</u> provided by Dr Lois Achimovich, Supplementary Submission, 6 September 2004, pp.19-20.

⁸⁰ National Health and Medical Research Council, 1997, *Attention Deficit Hyperactivity Disorder*, p.55.

⁸¹ WA Department of Health (2002) Office of Mental Health, *Attentional Problems in Children: Diagnosis and Management of Attention Deficit Hyperactivity Disorder (ADHD) and Associated Disorders*, Government of Western Australia, p.22.

⁸² Dr Trevor Parry, Head of Department, Department of Community and Developmental Paediatrics, Women's and Children's Health Services, & Clinical Associate Professor, School of Paediatrics, UWA, Submission, 30 June 2003, p.3 (emphasis added).

growing evidence of damage to children who have not had medication but should have. I am not arguing that to say that all children should be put on it; that is not my point. My point is that I think we need to be very careful to use the argument that we do not have long-term studies, as though that says this is something that is problematical, evil, suspicious....We do not have long-term studies to show that the use of ventolin in children with asthma is beneficial. We just do not have it. That does not mean that long-term use of ventolin is non-beneficial or harmful.⁸³

However, the Committee remains troubled by the absence of long-term studies into the effect of stimulants on the individual, in particular young children who may begin taking the medication at a very early age, and continue to do so throughout their formative years. The following section focuses on the potential side effects associated with stimulant medication, which the Committee believes is further cause for a cautious approach.

Finding 13

There is a paucity of evidence on the long-term effects of psychostimulant medication on children.

Recommendation 2

The Committee recommends that the State Government encourages and/or facilitates research into the safety and efficacy of the long-term use of psychostimulant medication.

(a) Side effects of stimulant medication

Stimulant medication is known to cause short-term side effects in some patients. The manufacturers of dexamphetamine and Ritalin have detailed a list of common effects associated with the medication. These include:

- Nausea, vomiting or abdominal pain;
- Headache;
- Dizziness;

⁸³ Transcript of Evidence, 20 August 2004, p.7.

- Tremor or palpitations;
- Restlessness, nervousness or insomnia;
- Loss of appetite, which can lead to weight loss or slower growth in children;
- Blurred vision or problems focussing your eyes;
- Muscle cramps; and
- Hair loss.⁸⁴

The pharmaceutical company leaflet advises that the above side effects are usually mild and mostly occur within the first few days and may disappear as the body adjusts to the treatment. Other side effects thought to occur less often include stomach pain or other stomach problems that will not go away, dry mouth, metallic taste, uncontrolled movements, impotence, skin rash or itchiness. The more serious side effects include fits (seizures), changes in personality, hallucinations and some heart and circulatory problems.⁸⁵

The manufacturers of Ritalin also note that some people may have other side effects that are not yet known or mentioned in the product information leaflet. ⁸⁶ Some of the listed potential side effects of Ritalin that differ from dexampletamine include:

- Mood changes such as depression;
- Sudden increase in body temperature, sweating, fast heartbeat, muscle stiffness and fluctuating body pressure, which may lead to coma;
- Unusual bleeding or bruising;
- Unusual tiredness;
- Tightness in chest;
- Fast or irregular heartbeat; and
- Severe or persistent headache.⁸⁷

⁸⁴ Sigma Pharmaceuticals (1997), Consumer Medicine Information, Dexamphetamine - CMI Novartis Pharmaceuticals Australia Pty Ltd (2003), Consumer Medicine Information, Ritalin 10-CMI.

⁸⁵ Sigma Pharmaceuticals (1997), Consumer Medicine Information, Dexamphetamine - CMI Novartis Pharmaceuticals Australia Pty Ltd (2003), Consumer Medicine Information, Ritalin 10-CMI.

⁸⁶ Novartis Pharmaceuticals Australia Pty Ltd (2003), Consumer Medicine Information, Ritalin 10-CMI.

The Committee was alarmed to learn that in some cases, the side effects associated with the use of stimulants might be treated with other controlled drugs to alleviate these effects.

(b) **Polypharmacy**

Polypharmacy is the term used to describe the use of multiple pharmacological interventions, or a variety of medicines. Submissions and evidence to the Committee raised concerns about the incidence of polypharmacy in the treatment of ADHD.

Mr John Ferguson, a school psychologist for 30 years across a range of school settings and year groups submitted that:

Prescribing a cocktail of mood and behaviour altering drugs is particularly invasive...these practices are well ahead of any research into the efficacy of polypharmacy. Danger signs start to flash when some of the cocktail are used to counter balance the side effects of other drugs in the mix.⁸⁸

(c) Concern with stimulant medication dosage

The Committee received a submission from a parent of a thirty-four year old person, who was prescribed dexamphetamine following a diagnosis of adult ADHD. The diagnosis occurred following symptoms of episodic schizophrenia, a condition considered to be related to the person's long-term cannabis use.⁸⁹ After two months on dexamphetamine, the person suffered a psychotic episode that resulted in an involuntary stay at a mental health unit. Blood tests indicated the person had overdosed with dexamphetamine. Following a six-week stay at a mental health unit, the person was released and six months later the person's doctors authorised the resumption of dexamphetamine treatment. Within two months a second psychotic episode occurred. The conclusion drawn by the person's parent was that:

people with substance abuse problems being treated with dexamphetamine are being inadequately supervised.⁹⁰

The Bentley Clinic ADHD team cited concerns about toxicity levels in children as a result of stimulant dosage:

⁸⁷ Novartis Pharmaceuticals Australia Pty Ltd (2003), Consumer Medicine Information, Ritalin 10-CMI.

⁸⁸ John Ferguson, School Psychologist, Submission, 24 June 2003, p.1.

⁸⁹ The identities of the people referred to here have been omitted for reasons of sensitivity. For a discussion on the association between substance misuse and ADHD refer to Chapter Six.

⁹⁰ Submission to the Committee, identities withheld.

Even when medical intervention is justified for children with ADHD, we have seen alarming levels of stimulant dosage and use of polypharmacy, which has reached significant levels of toxicity. It has certainly not been unusual for the ADHD team...to assess children who are on more than 10 stimulant tablets a day in addition to antidepressant and anti-psychotic medications. Much of the Consultant Psychiatrist's role in the team is to reduce these toxic levels of stimulants, regularly by more than 80%.⁹¹

The Committee was advised that stimulant medication levels exceeding the recommended dosage in children presenting at the Bentley Clinic have regularly resulted in hospital admissions for detoxification.⁹² A further concern is the number of children referred to the clinic who have been exposed to progressively increasing levels of medication with no apparent alleviation of symptoms. An increase in medication has in some cases lead to an increase in violent behaviour, which in turn has led to parents returning to their treating doctors, who have then increased medication levels further in an effort to address the problem.⁹³

Data collected at the Bentley Clinic also suggests there are a number of children who are treated with stimulant medication unnecessarily. Table 4.1 below demonstrates that the percentage of children on stimulant medication prior to treatment at the Bentley Clinic has increased between 1999 and 2000.

Table 4.1

Children on stimulant medication prior to and following assessment by Bentley Health Service ADHD team.⁹⁴

Children on Stimulant medication	1999	2003
Prior to assessment at Bentley	65 per cent	82 per cent
Following assessment at Bentley	25 per cent	38 per cent

The Committee recognises that these cases represent a relatively small proportion of the cases of children on stimulant medication in Western Australia, yet believes that the indication that a significant number need not have been medicated further highlights the need for a thorough assessment.

⁹¹ Bentley Health Service, Submission, 24 June 2003, p.3.

⁹² Bentley Health Service, Submission, 24 June 2003, p.3.

⁹³ Bentley Health Service, Submission, 24 June 2003, p.3.

⁹⁴ The 1999 figures were based upon approximately 24 children and the 2003 figures were based upon 39 children.

Based on evidence submitted, the Committee is concerned that as the criteria for assessment of children with suspected ADHD may reflect 'normal' childhood behaviour, or a range of underlying problems, there is the potential for misdiagnosis, and a great possibility for the unnecessary use of stimulant medication. While side effects may usually be mild, there have been reported incidences of unsafe effects associated with its use. All members of the Committee agreed that the unnecessary use of any medication is highly undesirable, especially in the case of very young children. The Committee is therefore of the view that prior to the use of medication, a child must be afforded access to a thorough diagnosis, and recognises that the current model of private sector treatment, where cost is borne largely by families, is inadequate.

Finding 14

Individuals who are prescribed psychostimulant medication may also be prescribed other medications to alleviate side effects.

Finding 15

There have been cases in Western Australia of prescribed stimulant medication levels exceeding the recommended dosage, which have resulted in some children requiring hospital admission for detoxification and reported episodes of psychotic behaviour.

Recommendation 3

The Committee recommends that prior to the use of psychostimulant medication, a child must receive a thorough diagnosis, incorporating an analysis of the child's medical, social and familial circumstances to minimise the potential for misdiagnosis and the potential for unnecessary treatment with medication.

Recommendation 4

The Committee recommends that in order to provide the opportunity for informed consent, the clinicians that carry out the diagnosis of ADHD and subsequent treatment with psychostimulant medication, be required to provide comprehensive information to parents regarding:

- the full range of potential side effects of medication; and
- the manner in which the diagnosis is made.

CHAPTER 5 THE NEED FOR A MORE DEFINED STATE POLICY

5.1 Introduction

The key state policy on ADHD, is *Attentional Problems in Children: Diagnosis and Management of Attention Deficit Disorder and Associated Disorders'*, (ADHD Policy), released by the DoH in November 2002. The ADHD Policy aims to enhance the system of care for children diagnosed with ADHD and associated disorders within the context of the current child and adolescent health, mental health and education services. The policy acknowledges that diagnosis and treatment should only occur after a comprehensive assessment process.

While most reports and inquiries in this area have recommended a multidisciplinary approach, it appears there are limitations on the capacity of the WA public and private sectors to provide such services. This chapter begins with an examination of multidisciplinary assessment, then turns to the ADHD policy to determine whether the stated policy objectives are sufficiently resourced to be effective in this respect.

5.2 Multidisciplinary assessment and diagnosis

The Committee is aware of a growing concern that the term 'multi modal treatment' represents a constricted range of initiatives rather than the comprehensive range of treatment options offered by a multidisciplinary approach.⁹⁵ This combines various fields of health management, including, but not limited to, psychiatric, psychological and medical approaches.

As discussed in Chapter Three, the Committee believes the likelihood of diagnosis being made by a paediatrician and the absence of multi modal and multidisciplinary options in WA are a contributing factor in the disproportionately high use of stimulant medication for the treatment of ADHD in this state.

(a) Multidisciplinary assessment in other jurisdictions

Each Australian State recognises ADHD as a legitimate clinical entity. The level of each jurisdiction's commitment to provision of services depends on a number of factors, including budget allocation, policy development, availability of health professionals, and standards of professional development.

As part of its inquiry, the Committee visited representatives from some interstate organisations responsible for assessment, diagnosis and monitoring treatment of

⁹⁵ Dr Gil Anaf and Dr George Halasz, National Association of Practicing Psychiatrists, interstate meetings, July 2004.

ADHD in the public sector, in particular South Australia and Victoria. The use of stimulant medication is considerably lower in those states than in WA (see figure 3.3).

(i) South Australia

In South Australia, a paediatrician, psychiatrist or neurologist must make the initial ADHD diagnosis. However, once stable, the treatment may be managed by a GP. It is estimated that in South Australia, paediatricians do 80% of the prescribing of stimulant medication. Most diagnosis and treatment occurs in the private sector. The role of the Drugs of Dependence Unit and Pharmaceutical Services includes oversight of dispensing practices relating to S8 drugs of dependence (including stimulant medication). In South Australia, there are some 27,000 S8 scripts dispensed per month. The department receives approximately 120 letters per month regarding non-compliance with regulations. The dispensing pharmacist must be satisfied that it is appropriate to dispense medication and is answerable to the government agency, through the Board. The relevant Act and regulations provide the power to take away a pharmacist's right to prescribe certain medication if the Board considers inappropriate practices are occurring.⁹⁶

On balance it was found that South Australia resembles WA most, in terms of availability of public services and the reliance on private sector services in the treatment of ADHD. However, Victoria differs from both in that a primary multidisciplinary assessment service is accessible within the public sector.

(ii) Victoria

In Victoria, for the medical condition 'childhood ADHD' dexampletamine or methylphenidate, a paediatrician or psychiatric specialist may simply notify the Department of Human Services (DHS)⁹⁷ that they are prescribing for a patient younger than 18 years, and must review them at least annually. Otherwise a GP must hold a permit prior to prescribing.

Thirteen public Child and Adolescent Mental Health Service (CAMHS) clinics across Victoria assess and treat children and young people aged less than 18 years with serious emotional disturbances or mental illness. Services provided by multidisciplinary teams include:

 Community based case management that co-ordinate assessment and treatment. Treatment may include individual, group and/or family therapy, parental counselling, specialist intervention clinics, medication and consultation with schools and other key agencies;

⁹⁶ Information provided by representatives of the South Australian Department of Human Services, interstate meeting July 2004.

⁹⁷ Which administers the *Drugs, Poisons and Controlled Substances Act 1981*, and *Drugs, Poisons and Controlled Substances Regulations 1995*.

- A mobile 24 hour crisis and acute assessment and treatment response;
- Intensive Mobile Youth Outreach Services; and
- Outreach services to complement community-based clinics.⁹⁸

Generally, a team of specialists will thoroughly assess a patient before a diagnosis is made. CAMHS staff is drawn from a variety of backgrounds, for example psychiatrists, doctors training in psychiatry or paediatrics, psychologists, social workers and speech pathologists. A typical metropolitan CAMHS unit has 2 inpatient components of 12 beds each, 3 outpatient teams of approximately 8 equivalent full time staff each and a number of other services. An associated school program is funded separately through the Victorian Education Department. Cases are usually seen by an experienced clinician, sometimes with a more junior colleague who is undertaking training. All staff receive supervision and can call on the senior medical staff for expert opinion regarding medication or clarification of diagnosis.

There are 7 rural CAMHS in Victoria that also have some smaller satellite clinics. The rural CAMHS generally do not have permanent psychiatrists and tele-psychiatry (for example videoconference) is used extensively. This technology is employed to supervise some rural CAMHS.

Currently no referral is required, however, individuals are often referred through schools, general practitioners, external counselling services, and child protection agencies. There is, however, approximately a six-month waiting period for treatment at CAMHS clinics.

(b) **Previous reports and inquiries**

The Committee examined a number of reports pertaining to ADHD, with a particular focus on, although not limited to Western Australia. The majority of reports and inquiries over the past decade have indicated that the type of multidisciplinary assessment outlined above is an essential criterion for appropriate diagnosis and treatment. Many of these reports have guided state policymakers in the development of the 2002 ADHD policy discussed at section 5.3 overleaf.⁹⁹

(i) The NHMRC Report - Attention Deficit Hyperactivity Disorder

The 1996 NHMRC report entitled *Attention Deficit Hyperactivity Disorder* is largely viewed as the defining report on ADHD in Australia. The final report recommended that the criteria set down in the DSM-IV should be met before a diagnosis of ADHD is

⁹⁸ Victorian Department of Human Services, Submission, 23 July 2003, pp.2-3.

⁹⁹ WA Department of Health (2002) Office of Mental Health, *Attentional Problems in Children: Diagnosis and Management of Attention Deficit Hyperactivity Disorder (ADHD) and Associated Disorders*, Government of Western Australia, p.6.

made. The report found that there is a general consensus amongst professionals that a multimodal form of therapy is necessary and that the simultaneous use of medication, behaviour management, family counselling and support, educational management should be considered. However, the NHMRC stressed that for children with behavioural problems, a comprehensive assessment, including medical, developmental and educational evaluation is required.¹⁰⁰

(ii) WA Child Health Survey

The earlier 1995 WA Child Health Survey report *Developing Health and Well-Being in the Nineties* noted that:

*limited resources, including appropriately trained staff, [mean] it is unlikely that existing mental health out-patient clinics and other specialised mental health facilities will ever keep pace with service demand through the direct provision of treatment on a case by case basis.*¹⁰¹

The report highlighted the need for:

- Improved targeting and coordination of mental health treatment and support services;
- Development of new or improved models of service delivery in existing services;
- Improved training and accreditation arrangements to extend the availability of suitably skilled mental health professionals; and
- Inter-sectoral collaboration to develop preventative policies and programs (targeted at both whole populations and individuals).¹⁰²

(iii) Report of the Technical Working Party on Attentional Deficit Disorder

One of the Key Actions recommended in the 1997 *Report of the Technical Working Party on Attentional Deficit Disorder to the Cabinet Sub Committee* noted that:

State child health services [should] be resourced further to establish multidisciplinary teams for the assessment and treatment of children with attentional disorders. Such teams can provide an integrated approach to case

¹⁰⁰ National Health and Medical Research Council, 1997, *Attention Deficit Hyperactivity Disorder*, pp.1-39.

¹⁰¹ Zubrick *et al*, Western Australian Child Health Survey: Developing Health and Well-being in the Nineties, 1995, p.52.

¹⁰² Zubrick *et al*, Western Australian Child Health Survey: Developing Health and Well-being in the Nineties, 1995, pp.51-52.

management and on-going monitoring not currently available in Western Australia.¹⁰³

The report made the important point that inaccurate or inappropriate diagnosis places a drain on scarce resources and may in fact lead to inequality of access to quality care.¹⁰⁴

(iv) Report of the Standing Committee on Constitutional Affairs in relation to A Petition Regarding Attention Deficit Hyperactivity Disorder

The 1999 Report of the Standing Committee on Constitutional Affairs in relation to A *Petition Regarding Attention Deficit Hyperactivity Disorder* indicated that both the American Academy of Paediatrics and the Australian College of Paediatrics recommend a multidisciplinary approach and that medication should never be used as the single first treatment.¹⁰⁵

Clearly there is a well-established recognition of the need for a multidisciplinary approach in diagnosis and treatment of ADHD. This is reflected in the current state ADHD policy. The following section includes an overview of the key principles within that document and discusses some apparent limitations on the effectiveness of the current arrangements.

Finding 16

There is widespread recognition of the need for a multidisciplinary approach in diagnosis and treatment of ADHD.

5.3 Current Health policy

The types of services provided in the Victorian public sector as discussed in section 5.2 are, in many respects, in keeping with the stated aims of the WA ADHD policy. The ADHD policy encourages early identification of children with symptoms of ADHD, timely and comprehensive assessment, appropriate multi modal treatment options and integrated management of treatment. For those children who have

¹⁰³ Report of the Technical Working Party on Attentional Deficit Disorder to the Cabinet Sub Committee, 1997, Government of Western Australia, p.11.

¹⁰⁴ *ibid*, p.9.

¹⁰⁵ Report of the Standing Committee on Constitutional Affairs in relation to a Petition Regarding Attention Deficit Hyperactivity Disorder, 1999, Legislative Council, Western Australian Parliament, p.17.

persistent and severe problems, services should provide appropriate and accessible assessment, treatment and ongoing support.

Key principles include enhancing the system of care through:

- Developing health promotion and illness prevention responses;
- Negotiating the roles and responsibilities of services central to the care of children with ADHD and associated disorders to ensure services are working compatibly and without duplication;
- Developing a comprehensive range of services, preferably located at the regional level;
- Ensuring services are accessible; and
- Developing inter-agency mechanisms to provide seamless service delivery.¹⁰⁶

Throughout the course of the inquiry, the Committee heard evidence to suggest that the types of services supported in the policy document are not filtering through to the broader community. For example, the policy document states that:

The diagnosis and treatment of ADHD should only occur after a comprehensive assessment has been undertaken. Service providers including paediatricians, child psychiatrists and psychologists in the private or public sectors can assess the majority of children. If the case is more complex, a more comprehensive psychosocial assessment may be required from specialist multidisciplinary services. This type of assessment will require the input of a range of professionals working as a team to evaluate various functional areas where problems may be occurring.¹⁰⁷

While the ADHD Policy infers that both the private and public sectors can handle the majority of cases, evidence to the Committee indicates otherwise. The following comments highlight some of the issues experienced within the WA community and indicate the current system is not adequately resourced to be effective:

• Our overstressed mental health facilities can't or won't cope with these patients. The waiting time for private psychiatric consultants and their charges rule out many deserving cases who fall through the mesh;¹⁰⁸

¹⁰⁶ Department of Health, Submission, 3 July 2003, p.6.

¹⁰⁷ WA Department of Health (2002) Office of Mental Health, *Attentional Problems in Children: Diagnosis and Management of Attention Deficit Hyperactivity Disorder (ADHD) and Associated Disorders*, Government of Western Australia, p.20.

¹⁰⁸ Dr Pat Cranley, Submission, 16 June 2003, p.2.

- I endorse the current stated policy and I believe priority should be given to the resource implications for both the Education and Health Departments. [However], the capacity of public health services to provide comprehensive and timely assessment is limited;¹⁰⁹
- Time and resourcing constraints appear to result in some children being diagnosed inappropriately with ADHD. It appears a lack of resources (in terms of public access to multidisciplinary diagnostic teams) and long-term support services is leading to an overuse of stimulant medication to control such difficulties;¹¹⁰
- Volunteers at LADS received approximately 3,000 calls from parents and adults most of whom were experiencing difficulty accessing services from the Public Health Sector;¹¹¹
- Access to Child and Adolescent Mental Health Services has been markedly hampered because of the under-resourcing of informed child psychiatrists, clinical psychologists and social workers;¹¹²and
- Despite recommendations, there has been little improvement in resources for health, mental health and education sectors to adequately tackle the population issue of ADHD.¹¹³

The Committee recognises that WA is the only state that has developed a sound policy specific to ADHD and commends the DoH on its work in this respect. However, it appears the policy is not adequately resourced to provide the key services it recommends. Critical shortages of resources in both the private and public sector prevent its full implementation.

5.4 Shortage of qualified health professionals

The DoH has noted the concern regarding the capacity of the current system to respond effectively to the escalating number of children requiring assessment and treatment.¹¹⁴ The Committee raised the question of why the WA public health sector

¹¹⁴ WA Department of Health, Submission, 3 July 2003, p.3.

¹⁰⁹ Dr Amanda Wilkins-Shurmer, Community Paediatrician, Armadale Health Service, Submission, 24 June 2003, p.5.

¹¹⁰ Child Study Centre, School of Psychology, University of Western Australia, Submission, June 2003, p.2.

¹¹¹ Learning and Attentional Disorders Society of Western Australia (Inc), Submission, 9 July 2003, p.4.

¹¹² Dr Trevor Parry, Clinical Associate Professor, School of Paediatrics, University of Western Australia, Submission, 30 June 2003, p.4.

¹¹³ Dr John Wray, Developmental Paediatrician, Submission, 11 June 2003, p.1.

is unable to provide primary multidisciplinary services similar to the tertiary services provided at the Bentley Clinic and the services provided at LADS (see section 4.3). It was advised that the lack of budgetary resources is only part of the problem. Dr Rowan Davidson, Chief Psychiatrist with the DoH stated that:

It is also the availability of the clinicians, particularly child and adolescent psychiatrists, but also the full range, for instance, of clinical psychologists who specialise in the child and adolescent mental health area and also the mental health nurses....we have huge problems in terms of staff resources.¹¹⁵

Dr Davidson expressed concern that if the state were to provide multidisciplinary services in a direct service role, it would be quickly overwhelmed and would become ineffective in supplying the tertiary service the state currently provides.¹¹⁶ The shortage of qualified health professionals is not simply a problem in the public sector but is also apparent in the private sector.

The situation has further implications for families in rural and regional areas of WA. The Committee heard details of the difficulty involved in obtaining GP services in rural and regional areas, let alone specialist medical services for children. The WA Department for Community Development submitted that many country settings have limited options in terms of availability of paediatric specialist services and/or General Practitioner services. This generates difficulties in obtaining a second opinion on ADHD diagnosis and treatment.¹¹⁷

The WA Country Health Service in the Great Southern Health Region reinforced this view, submitting that there are no established multi modal assessment and treatment services available in rural WA.¹¹⁸ Therefore, medication is seen as the most accessible and straightforward option for treatment.

Finding 17

The disproportionately high use of dexampletamine in the treatment of ADHD in Western Australia is to a large extent due to the shortage of multidisciplinary assessment and treatment options available in the public health system and the prohibitive cost of private sector treatment options.

¹¹⁵ Transcript of Evidence, 15 September 2004, p.9.

¹¹⁶ Transcript of Evidence, 15 September 2004, p.8.

¹¹⁷ Department for Community Development, Submission, 20 June 2003, p.1.

¹¹⁸ The WA Country Health Service in the Great Southern Health Region, Submission, 1 July 2003, p.1.

Finding 18

The multidisciplinary framework outlined in the current Western Australian ADHD policy document is sound. However, critical shortages of resources in both the private and public sector prevent its implementation.

Finding 19

There are limited services available for diagnosis and treatment of behavioural and learning problems in metropolitan areas. Services are further limited in most of regional Western Australia.

Finding 20

There is a shortage of clinicians specialising in the child and adolescent mental health area, particularly child and adolescent psychiatrists, clinical psychologists and mental health nurses in Western Australia.

Recommendation 5

The Committee strongly recommends that the State Government prioritise the development of comprehensive strategies to address workforce shortages in the child and adolescent mental health area, particularly child and adolescent psychiatrists, clinical psychologists and mental health nurses in Western Australia.

(a) Training of health professionals

The shortage of health professionals in WA is a subject this Committee has covered in previous reports and inquiries¹¹⁹ and clearly remains an issue of concern. The inadequacies of the current system in terms of communication and cooperation between the Commonwealth, States/Territories, education sector and professional

¹¹⁹ see Education and Health Standing Committee Adequacy and Availability of Dental Services in Regional, Rural and Remote Western Australia (Report Number 1 2002) and the Role and Interaction of Health Professionals in the Western Australian Public Health System (Report Number 6 2004).

bodies to address health workforce planning have been previously highlighted.¹²⁰ The Commonwealth Health Reform Committee, and subsequently this Committee, recommended the establishment of a national Inter-Agency Commission to address workforce shortages, which the Committee notes to date, has not occurred.

The Committee is of the view that the current patient care model adopted in WA with respect to ADHD tends toward a medical management model, whereby stimulant use is often the first line of treatment. As discussed in section 3.4, many paediatricians have not received adequate training to recognise alternative diagnoses that appear similar to ADHD. Discussions with practitioners in WA and Victoria indicate that this issue needs to be addressed at the curriculum level within the medical universities. The Committee was advised that Victorian medical universities are moving toward a more integrated method of training, with students being exposed to a broader range of treatment options incorporating multidisciplinary approaches.

5.5 A Western Australian model for consistency in assessment and treatment

The numbers of children prescribed stimulants in WA, especially when compared to other jurisdictions, is cause for concern. Further, the variations in the numbers of prescriptions in WA electorates (discussed at Chapter Three) indicate an inconsistent approach to the application of stimulants in the treatment of ADHD.

The diagnosis of ADHD is problematic because a number of behavioural problems present with similar characteristics. Paediatricians may not posses the necessary skills to determine whether behaviours being exhibited by an individual are reflective of ADHD or are the result of more intrinsic problems. The Committee believes that in order to get a more consistent diagnosis, an individual experiencing behavioural and learning difficulties must first go through a process of eliminating other possible causes for the behaviour.

The chronic shortage of multidisciplinary services at in the public sector has meant that children presenting with abnormal behaviour are likely to be seen by a paediatrician at the beginning of diagnostic process rather than at the end. The Committee is of the opinion that there needs to be a structured process in determining ADHD. Access to a multidisciplinary ADHD assessment team, encompassing a child psychiatrist, a senior social worker, a senior speech pathologist, a senior occupational therapist, a psychologist and a psychiatric registrar would allow systemic, developmental and medical analysis prior to an official diagnosis. Figures supplied by the Bentley Health Clinic (table 4.1) indicate that this form of assessment would significantly reduce the number of individuals being misdiagnosed with ADHD.

¹²⁰ Finance and Information Group, Western Australian Department of Health for the Health Reform Committee, *Commonwealth/State Relations*, October 2003, p16.

Western Australia currently has a blueprint from which to develop a primary system of multidisciplinary assessment and diagnosis. The Bentley Clinic is one of nine state-operated child and adolescent mental health services in the Perth metropolitan area. However, it is the only clinic in the state that operates a multidisciplinary ADHD assessment and treatment team, comprising of a consultant child psychiatrist, a senior social worker, a senior speech pathologist, a senior occupational therapist, a psychologist and a psychiatric registrar.

The team's purpose is to offer a multi-faceted approach encompassing systemic, developmental and medical paradigms in an endeavour to assist children and their families. The clinic is a tertiary referral service and provides services for individuals and families with severe problems. This means that patients have been through diagnosis and treatment prior to admission to the clinic. Currently, this service is not available as a primary option in WA.

The Committee is of the view that the types of services offered at the Bentley Clinic provide a useful starting point from which to develop further multidisciplinary teams. It is recommended that the establishment of a number of teams, dedicated to the assessment and treatment of childhood behavioural and learning disorders be implemented by child health professionals, with multidisciplinary specialist training.

The key principles of the ADHD policy provide an adequate framework from which to develop appropriate strategies. This will require a level of resourcing that is not currently available and will include strategies to address the shortfall in health professionals specifically related to these areas of expertise.

The stated ADHD policy recognises the need for standardised, quality clinical practice to reduce the current variance in practice and to ensure better outcomes for individuals and families.¹²¹ The Committee agrees and believes a cautious approach is warranted when advocating the use of potentially harmful medication in children, particularly in the absence of reliable long-term studies, and is of the view that prescription of stimulants should be a last resort, rather than the first line of treatment. It is acknowledged, however, that there is support for the judicious use of stimulants in the context of other interventions.

The Committee strongly recommends that the DoH, in conjunction with the relevant medical professional bodies (for example the Australian Medical Association and the Divisions of General Practice) develop protocols to ensure consistency in the diagnosis and treatment of behavioural and learning difficulties. This, combined with the ability to refer patients to state multidisciplinary assessment teams would assist paediatricians in determining the appropriate diagnosis for children presenting with behavioural and learning difficulties.

¹²¹ WA Department of Health (2002) Office of Mental Health, *Attentional Problems in Children: Diagnosis and Management of Attention Deficit Hyperactivity Disorder (ADHD) and Associated Disorders*, Government of Western Australia, p.18.

Finding 21

The greater use of dexampletamine in Western Australia for the treatment of ADHD is inconsistent with practice in all other Australian States and Territories.

Recommendation 6

The Committee recommends that the Department of Health, in conjunction with the relevant medical professional bodies, develop protocols to ensure a consistent approach to the diagnosis and treatment of behavioural and learning difficulties, including ADHD.

Finding 22

The services offered at the Bentley Clinic are widely recognised as providing the most comprehensive and appropriate assessment and treatment options for Western Australian children with ADHD. These services are currently only available to a small number of children who have been diagnosed and generally medicated for extended periods of time.

Recommendation 7

It is the prime recommendation of the Committee that the State Government urgently develops and adequately funds a primary model of multidisciplinary assessment and diagnosis for ADHD and other behavioural syndromes based on the existing tertiary service provided at the Bentley Health Centre. These services must be available for children undergoing initial assessment and diagnosis and to those already diagnosed.

CHAPTER 6 THE RELATIONSHIP, IF ANY BETWEEN THOSE DIAGNOSED WITH AND/OR MEDICATED FOR ADHD AND DRUG ADDICTION

6.1 Introduction

The Committee's fifth Term of Reference questions whether the treatment of children and youths with psychostimulant medication for ADHD may result in an increased risk of drug addiction. Many health professionals concur with recent research that children who are diagnosed and treated with stimulant medication for ADHD are less likely to become substance misusers later in life. These health professionals consider undiagnosed children to be at greater risk, with at least one submission focussing on the connection between serious substance abuse and undiagnosed ADHD.

A significant number of submissions raised the issue of misuse of stimulant medication, with a particular concern being the selling of medication for recreational or study purposes. While evidence of misuse is largely anecdotal, the frequency with which the issue was raised in submissions, and some emerging qualitative data, indicate this as a growing problem. It was suggested that the necessity for children to take medication to school, because of its short therapeutic effect, presents an opportunity for the medication to be diverted from its intended purpose. Furthermore, the Committee heard evidence to suggest that patients are able to fill repeat prescriptions well within the recommended time frame, which raises the issue of the adequacy of current regulations governing the dispensing of prescription medication.

6.2 ADHD and later substance misuse

A number of submissions to the Committee indicated that diagnosis and subsequent treatment reduced the probability of an individual with ADHD becoming involved in substance misuse and/or abuse. These submissions indicated that a person with undiagnosed and untreated ADHD was at 'increased risk' and had a much higher probability of being involved in later substance misuse and/or abuse. Some submissions inferred that there was no connection. The Child and Adolescent Mental Health Service of Victoria indicated that there had been few studies to date on the link between stimulant medication and hard drug abuse. They advised that the findings from these studies were somewhat mixed, with one showing no propensity to use drugs; another a marked increase in risk; and one finding no propensity either way.¹²²

¹²² Child and Adolescent Mental Health Service, Monash Medical Centre, Victoria, Submission, 26 June 2003, p.7.

The Drug and Alcohol Office (DAO) of WA advised that children diagnosed with ADHD, and subsequently treated with stimulant medication, would experience less alcohol and other drug misuse, including tobacco, than children diagnosed with ADHD but not treated with stimulant medication.¹²³

There is some support for a connection between comorbid conduct disorders and substance misuse. The Committee was advised that:

increased problems with attention and impulsivity are risk factors for illicit drug and alcohol abuse and use of cigarettes especially where other externalising behaviours are present.¹²⁴

The DAO also support this connection. In their submission, they suggest that conduct disorders, rather than ADHD, appear to be predictors of alcohol and other drug misuse.¹²⁵ Evidence suggests that ADHD alone is no more likely to put a person at a higher risk of substance misuse than a person without ADHD. A meta-analytic review of the literature available on the subject of stimulant therapy and possible later substance abuse found that stimulant medication may, in actual fact, act as a preventative measure for later alcohol and drug use.¹²⁶ However, the presence of comorbidities, in particular those with a psychosocial bias, is thought to increase the potential for substance abuse in later years.

Professor David Hay informed the Committee that over the last decade, researchers at Harvard Medical School in the US have been looking at the use and non-use of stimulant medication and found:

... that [the] use of such stimulant medication is very important as a preventative measure as those using stimulants were six times less likely to become substance abusers.¹²⁷

Dr Amanda Wilkins-Shurmer, Community Paediatrician with the Armadale Health Service¹²⁸ also referred the Committee to research that suggests the medical treatment

¹²³ Drug and Alcohol Office, Government of Western Australia, Submission, 26 June 2003, p.6.

 ¹²⁴ Child and Adolescent Mental Health Service, Monash Medical Centre, Victoria, Submission, 26 June 2003, p.7.

¹²⁵ Drug and Alcohol Office, Government of Western Australia, Submission, 26 June 2003, p.6.

¹²⁶ Wilens T.E., Faraone S.V., Biederman J., and Gunawardene S., Does stimulant therapy of attention deficit hyperactivity disorder beget later substance abuse?, A meta-analytic review of the literature, Paediatrics; Volume 111(1), January 2003, pp179-185.

¹²⁷ Professor David Hay, School of Psychology, Curtin University of Technology, Submission, 26 June 2004, p.4.

¹²⁸ Dr Amanda Wilkins-Shurmer, Community Paediatrician, Armadale Health Service, Department of Health, Government of Western Australia, Submission, 27 June 2003, p.4.

of ADHD (with stimulant medication) may be a protective factor for future substance abuse.¹²⁹

Dr Lois Achimovich, Consultant Psychiatrist, advised the Committee of a different perspective on this issue. When questioned as to whether there is any evidence to show that the use by young people of dexamphetamine or stimulant medication generally may lead to long-term drug dependency or even illicit drug use, Dr Achimovich stated:

Yes. I believe that is teaching kids that a drug is the answer....My other hat is that I am a consultant at Next Step, which deals with youth, drugs and alcohol. We have a huge number of kids who have been given amphetamines as children...They now want to use another drug. What would be interesting is to see - because it should not be hard to find out - what is the incidence of amphetamine used early in the children's lives compared with a more ordinary comparative population. I think you will find it is higher.¹³⁰

As discussed above, there are conflicting views on the connection between stimulant use in the treatment of ADHD and later substance misuse. A related issue is the purported connection between undiagnosed or untreated ADHD and later substance misuse.

(a) Undiagnosed ADHD and substance misuse

The Committee received a submission from the Chemical Health Centre, which supported the theory that undiagnosed, and untreated ADHD sufferers are prone to substance misuse as a form of self-medication. According to this theory, the unusual brain chemistry and brain electricity of ADHD sufferers causes them to feel very uncomfortable and their inattention and other disturbances cause them to function and perform poorly. To feel and perform better, it is suggested that sufferers use excessive caffeine, tobacco and alcohol, or a friend's dexamphetamine, in childhood or in their early teens.¹³¹

Dr Geoff Dixon, Dr Wendy Reid and Professor Roderic Underwood of the Cambridge Private Hospital advised the Committee that, as part of their research into ADHD, they have found a significant proportion of the people undergoing treatment for substance abuse at a Perth detoxification centre were subsequently diagnosed with ADHD.¹³² It

¹²⁹ Geidd, J., (2003) ADHD and Substance Abuse in *Medscape Psychiatry and Mental Health,* Volume 8 No. 1, 2003, accessed on 24 September 2004 http://www.medscape.com/view/456199>

¹³⁰ Transcript of Evidence, 25 August 2004, p.5.

¹³¹ Chemical Health Centre, Submission, June 2003, p.16.

¹³² Dr Geoff Dixon, Dr Wendy Reid and Professor Roderic Underwood, Cambridge Private Hospital, Submission, 3 July 2003, p.4.

was suggested that substance abuse is often an attempt by people with underlying ADHD to unknowingly self-medicate.¹³³

The Committee found that while there are theories on a connection between ADHD, stimulant medication and later substance misuse, there have been no conclusive results from the studies undertaken thus far.

Finding 23

There are divergent opinions in relation to a connection between ADHD, stimulant medication and later substance misuse. The Committee found that there have been no conclusive results from the studies undertaken on the connection between ADHD, stimulant medication and later substance abuse. Further, no science-based evidence was provided to the Committee of a causal link between undiagnosed ADHD and illicit substance misuse.

6.3 Diversion of stimulant medication

The diversion of stimulant medication for illicit consumption is a growing concern in Western Australia. The Committee obtained evidence of shortcomings within the regulatory framework covering the control of Schedule 8 (S8) medication in Western Australia and subsequently met with representatives from the Pharmaceutical Council of WA and the School of Pharmacy at Curtin University, who highlighted a number of key issues in relation to control over dispensing S8 (controlled) drugs. A 2004 review of the *Poisons Act 1964* stated:

*Historically, prescribers, law makers and the public have had concerns about the addiction potential of schedule 8 substances and the potential for diversion or abuse to occur.*¹³⁴

There is considerable anecdotal evidence that stimulant medication is being diverted for illicit use, yet hard data is deficient in many respects. The Committee received a paper that surveyed the non-prescribed use of dexamphetamine and methylphenidate among students in Perth high schools, which found that:

• From a survey of 227 students' ages 13 to 18 years, 7.8% of participants used prescribed stimulant medication for which they did not have a prescription;

¹³³ Dr Geoff Dixon, Dr Wendy Reid and Professor Roderic Underwood, Cambridge Private Hospital, Submission, 3 July 2003, p.4.

¹³⁴ WA Department of Health, Review of the *Poisons Act 1964*, Discussion Paper 2, April 2004, p.19.

- More females than males and more year 12 than year nine students self-reported using non-prescribed stimulant medication;
- The medications were used mainly at parties and to stay awake for study; and
- Users reported stimulants were cheap and easy to obtain through friends and peers for up to \$1 each.¹³⁵

The WA Drug and Alcohol Office *Indicators of Drug Use: Western Australia* show a marked increase in the number of seizures of a number of drug groups, including dexamphetamine, which increased by 247 per cent in the period 1998-2002.¹³⁶ The annual number of referrals to Community Drug Service Teams for amphetamine use increased over the same period from 7.9 to 21.7 per cent.¹³⁷ From mid 1997 there has been a marked growth in the number of illicit psychostimulant related calls to the Alcohol and Drug Information Service (ADIS). Calls increased from 186 in the June quarter 1997 to a peak of 835 calls in the March quarter of 2001, an increase of 349 per cent.¹³⁸ The Committee notes with concern that illicit use of amphetamines in general by students between the ages of 12 and 17 years are twice the national average in WA.¹³⁹ The above data strongly suggests that stimulant medication is being diverted for illicit use in WA.

(a) Alternative forms of medication

The issue of short acting medication was raised as a problem as at least one dose is required while the child is at school. Some suggested this is a contributor to the problem of the illicit trade in dexampletamine.

The New Zealand equivalent to the PBS is the Pharmaceutical Management Agency (PHARMAC). Since November 2000, PHARMAC has fully funded the slow-release form of methylphenidate (Ritalin) in addition to dexamphetamine. The potential benefits of slow-release medication are:

Relieving schools of the responsibility of giving lunchtime doses;

¹³⁵ Margaret Vikingur, (2001) A dissertation submitted in partial fulfilment of the requirements for the degree of Master of Special Education, *The non-prescribed use of Dextroamphetamine Sulphate and Methylphenidate Hydrochloride among students in Perth High Schools*, Undertaken in 2001 in the Graduate School of Education at the University of Western Australia, Submission, July 2003., pp.78-87.

¹³⁶ WA Department of Health (2003) Indicators of Drug Use: Western Australia, Drug and Alcohol Office, June 2003, p.3.

¹³⁷ *ibid*, p.4.

¹³⁸ *ibid*, p.11. **Note**: it is not clear what the specific nature of the calls was, therefore it cannot be assumed that all related to use of psychostimulants.

¹³⁹ WA Department of Health (2003) Indicators of Drug Use: Western Australia, Drug and Alcohol Office, June 2003, p.9.

- Greater confidentiality;
- Increased compliance;
- Simplicity of regimen;
- Reducing stigma and the risk of intimidation and/or misuse of medication outside the home; and
- Steady response rather than peaks and troughs.¹⁴⁰

Associate Professor Heather Jenkins, Curtin University of Technology advised the Committee that:

The high rate of student medication with psychostimulant dexamphetamine, particularly in WA (Berbatis et al, 2002), and the requirement that it is administered three times daily, has created significant problems for schools in managing its administration and policing students to prevent the selling of drugs in the playground...The investigation of an alternative nonpsychostimulant medication that is administered once daily at home is of considerable interest to school if its educational benefits can be demonstrated.¹⁴¹

Associate Professor Jenkins advised the Committee of her current research project that is investigating the effects of a nonpsychostimulant medication on education, social and mental health outcomes over the next three years. The Committee anticipates there will be great interest in the results of the study.

Finding 24

There is a growing body of evidence to suggest that stimulant medication is sometimes diverted for illicit use.

(b) Doctor and pharmacy shopping

The issue of 'doctor shopping' and 'pharmacy shopping' has been raised in relation to the provision of stimulant medication. Doctor shopping refers to the practice of attending various doctors for the same problem and receiving a number of prescriptions for medication. Similarly, pharmacy shopping refers to the practice of attending various pharmacies for provision of medication. The Committee did not

¹⁴⁰ New Zealand Guidelines for the Assessment and Treatment of ADHD, Ministry of Health 2001, pp.22-23.

¹⁴¹ Associate Professor Heather Jenkins, Department of Education, Curtin University, Submission, July 2003, pp.3-4.

receive direct evidence of doctor shopping. However, there is evidence to suggest pharmacy shopping is occurring in WA.

The Committee heard evidence to suggest that patients are able to fill repeat prescriptions well within the recommended time frame. Commonwealth Health Insurance Commission (HIC) data confirm this with a series of Western Australian case studies in which pharmacists have dispensed large numbers of dexampletamine tablets within unreasonably short periods of time.¹⁴² Table 5.1 represents a case study of a 17-year-old male patient who has been able to fill repeat prescriptions for medication that should last approximately 175 days within 13 days.

(c) Western Australian case studies of repeat prescriptions for dexamphetamine

Table 5.1

Supply	Date	Approval
Original	06/11/00	А
1 st repeat	08/11/00	В
2 nd repeat	11/11/00	С
3 rd repeat	13/11/00	D
4 th repeat	14/11/00	С
5 th repeat	17/11/00	E
6 th repeat	19/11/00	В

Table 5.2 overleaf represents a case study of a 40-year-old male patient who has been able to fill repeat prescriptions for medication that should last approximately 125 days within 45 days.

¹⁴² Data drawn from figures represented in *Pharmacy Guild Bulletin*, Issue 873, 18 May 2001, p.3.

Table #	5.2
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40 year old male. 100 tablets per prescription, dose = 4 x 5 milligram tablets per day.

Supply	Date	Approval
Original	17/05/00	В
1 st repeat	20/05/00	F
2 nd repeat	07/06/00	F
3 rd repeat	12/06/00	G
4 th repeat	17/06/00	н
5 th repeat	30/06/00	G

The approval column in both tables represents the pharmacy approval number, indicating that the patients have been to various pharmacies within the time period discussed.

Concern was raised regarding the limited control pharmacists have over dispensing S8 drugs, including the stimulant medication used to treat ADHD. Professor Bruce Sunderland of the School of Pharmacy, Curtin University of Technology advised the Committee that the way in which S8 medications are currently controlled has not changed in the past 40 years. Professor Sunderland stated that:

When I qualified as a pharmacist 40 years ago...Schedule 8 medications were used only occasionally, and entries in most pharmacies into what was called the DD register - the drug and addiction register - at that time probably occurred only once or twice a week. We now see from information in the document from the Department of Health...that it is getting close to 500 000 schedule 8 items that are dispensed a year in Western Australia alone.¹⁴³

Currently pharmacists cannot access databanks to determine whether it is appropriate to dispense medication, particularly when it comes to repeat prescriptions. While it is acknowledged that a pharmacist may be able to determine from a prescription whether it is too soon for a repeat to be issued, it is not possible to determine whether the patient has been 'doctor shopping' and has obtained a number of prescriptions from different doctors. Mr Con Berbatis of the School of Pharmacy, Curtin University of Technology advised the Committee that:

Pharmacists who dispense these drugs have increased knowledge and skills... but they do not have online access to the data in other databanks. HIC records which are already retrieved by many doctors who prescribe for

¹⁴³ Transcript of Evidence, Wednesday, 16 June 2004, p.4.

patients, and the big bank of state health department data ... are two different groups of data that could be made available online.¹⁴⁴

The Committee was advised that in NSW, regulations pertaining to S8 drugs of addiction restrict the number of times those drugs can be dispensed. Section 86 (1) (c) of the *NSW Poisons and Therapeutic Goods Regulations 2002* requires that:

a pharmacist must not supply a drug of addiction on prescription if the interval of time that has elapsed since the drug was last supplied on the prescription is less than that indicated by the prescription as the minimum interval that must elapse between successive supplies of the drug.

Section 89 (1) of the *NSW Poisons and Therapeutic Goods Regulations 2002* further states that:

A pharmacist who supplies a drug of addiction on prescription must keep the prescription, whether or not the prescription authorises more than one supply of the drug.

Currently in WA there are no restrictions similar to those in the NSW regulations. Hilary Le Page, of the South Metropolitan Child and Adolescent Mental Health Service advised the Committee that:

With all the anxiety about amphetamines going astray.....I am not able to cancel repeats on a prescription once issued.¹⁴⁵

The Committee is of the view that tightening regulations pertaining to the dispensing of S8 drugs may go some way to reducing the availability of these drugs for illicit use. This may be achieved by facilitating pharmacist's access to databases currently only accessible to doctors. The Committee acknowledges that this will require a commitment to change at both the Commonwealth and state level and in this respect recommends the issue be raised at the next available opportunity.

Finding 25

Western Australian pharmacists do not have access to patients' prescription and dispensing histories. This affects their ability to monitor the appropriateness of dispensing stimulant and other Schedule 8 medication.

¹⁴⁴ Transcript of Evidence, Wednesday, 16 June 2004, p.2.

¹⁴⁵ South Metropolitan Child and Adolescent Mental Health Service, Submission, 30 June 2003, p.1.

Recommendation 8

The Committee recommends that the State Government and Commonwealth Government facilitate better access for pharmacists to patient databases.

Finding 26

There is evidence that repeat prescriptions for stimulant medication are on occasions dispensed too frequently in Western Australia, creating the opportunity for abuse. Currently there are no restrictions on dispensing repeat prescriptions of Schedule 8 medication in Western Australia.

Recommendation 9

The Committee recommends that Western Australian legislation be amended in line with New South Wales, to restrict the frequency with which repeat Schedule 8 medication prescriptions may be dispensed.
CHAPTER 7 THE RELATIONSHIP BETWEEN ADHD AND THE EDUCATIONAL, ECONOMIC AND SOCIAL WELL-BEING OF INDIVIDUALS

7.1 Introduction

The relationship between ADHD and the educational, economic and social well-being of individuals was addressed in many submissions. It is clear that in this respect, not only the individual with the diagnosis, but also the immediate family and those within the school setting experience the impact of ADHD. Learning difficulties and the lack of supportive resources and professional development for teachers were common themes within submissions. Early intervention and correct diagnosis were found to be key areas for the effective management of ADHD students. However, the shortage of resources for the public education system again proved to be a key topic of discussion in the submissions.

In terms of education support, families cannot access services for ADHD children unless the child is also identified as having one of the major categories of disability, a comorbid learning difficulty or behaviour problems. Provision is not specifically provided for a single diagnosis of ADHD. The Committee was interested in whether the WA education system is adequately resourced to deal with the increasing incidence of ADHD within the school system, and whether teachers are supported in their role in relation to the diagnostic process. This chapter examines the current approach relating to ADHD within the education system and issues that relate to the educational, economic and social well-being of individuals.

7.2 Current State education policy

The provision of assistance to students diagnosed with ADHD or other learning difficulties is primarily the responsibility of individual state governments. As with other Australian jurisdictions, WA does not have a specific education policy relating to ADHD. Generally, students diagnosed with ADHD fall into the category of students with learning difficulties.

The WA Department of Education introduced its Students at Educational Risk program in 1998, and continues to operate this policy today. The program aims to address the major educational risks identified in the WA Child Health Survey of 1995,

notably low intellectual ability, speech and language disorders, and mental health problems.¹⁴⁶

(a) Students at Educational Risk

The Education Department recognises that schools are responsible for the provision of appropriate educational programs for all students, including those diagnosed with ADHD. Under the policy *Students at Educational Risk - Making the Difference* the Education Department provides on-line information on ADHD and outlines support strategies to assist individual schools, teachers, parents and students to develop management strategies.

Ms Margaret Banks, Acting Deputy Director General, Schools, informed the Committee that because of the diverse range of 'points of view', the Education Department has had to create a holistic rather than a specific policy to deal with students diagnosed with ADHD. The outlook is health based and allows the Education Department to use their 'student health policy' as the medium through which to deal with ADHD. Ms Banks stated that:

Using the advice of the medical professionals and the advice from parents, the school is expected, under this policy, to work collaboratively in the interests of achieving the optimum health outcomes for the student. Then it is the role of the school to make whatever adjustments to the curriculum and the learning program in order to support the education outcomes for the student.¹⁴⁷

The teacher is expected to establish strategies that will provide a structured classroom environment; minimise the potential for distraction; institute a collaboratively developed behavioural plan (between the home and the school); develop consistent routines; teach required behaviour; and break work into smaller, more manageable units.¹⁴⁸

Although the Education Department has designed guidelines pertaining to the creation of strategies to deal with school children diagnosed with ADHD, there is disagreement as to how these are to be enacted. Evidence put to the Committee indicates that:

Teachers would like to think there was some assistance available to the children in the classroom environment; at the moment there is none. Those

¹⁴⁶ Silva, D.T. Palandri, G.A. Bower, C. Gill, L. Codde, J.P. Gee, V. and Stanley, F.J (1999a) Child and Adolescent Health in Western Australia - An Overview, Health Department of WA and TVW Telethon Institute for Child Health Research, p.19.

¹⁴⁷ Transcript of Evidence, 29 October 2003, p.1.

¹⁴⁸ Western Australian Department of Education and Training, Students at Educational Risk, Information for Teachers, Government of Western Australia, http://www.eddept.wa.edu.au/SAER/policy/supatt.htm, accessed 29 July 2004.

children are in many cases creating difficulties not only for themselves but also for their peers. In the absence of assistance, a class that might have two or three of these children can be very difficult to manage.¹⁴⁹

The actual extent of school support may involve the creation of partnerships between the school, the parents, medical and allied health personnel. Collaboration between the various parties provides a medium through which strategies can be implemented to assist in the development of a 'management plan'.

(b) Management plans

Management plans are designed to facilitate responsible and appropriate behaviour in and out of the classroom.¹⁵⁰ The Committee was informed that in reality, collaboration between the school, parent and student in the development of a management plan involving medical and allied health professionals rarely occurred. Evidence from a group of parents indicated many experienced difficulties in having their child's needs addressed in the classroom setting. It became apparent that each school operates differently, depending on the level of expertise of individual teachers within the school.

One parent reported that her son had struggled in his first years of school until year 4, when he encountered a class teacher trained in special needs. Many parents indicated that they felt they were not being taken seriously by the school and that in some cases, the school was reluctant to offer support unless the child was medicated. The difficulty in receiving the support theoretically available to these children is evident in the following comments:

On advice from my district education office I knew that I was entitled to a student-at-risk program, I was entitled to an individual education plan, and I was entitled to expect teachers and principals to be informed about the needs of ADHD children, non-medicated or medicated. Our school would not provide any of these, so it was time for us to leave and find another school that would. The next hurdle was: was there a state school that catered for [my child's] needs? I contacted numerous schools in my local area...we were not offered a place at any of these schools, as they felt they did not have the resources to assist us.¹⁵¹

Teachers who have students diagnosed with ADHD are advised by the Education Department to seek advice and support from colleagues to assist in the management of

¹⁴⁹ Mr Philip Mort, Principal, Atwell Primary School, Transcript of Evidence, 27 October 2003, p.2.

¹⁵⁰ Western Australian Department of Education and Training, Students at Educational Risk, Information for Teachers, Government of Western Australia, <http://www.eddept.wa.edu.au/SAER/policy/supatt.htm, accessed 29 July 2004.

¹⁵¹ Evidence taken in closed session

these school children.¹⁵² It appears the amount of support depends largely on available resources and skills of individuals within particular schools.

Finding 27

There is a common belief amongst parents that children diagnosed with ADHD are not adequately catered for in the school system.

7.3 The role of teachers in diagnosis

Apart from strategies to assist within the classroom, the school setting is one of the key areas through which information is gathered to enable a diagnosis of ADHD to be made. Under the 'Students at Educational Risk Policy and Guidelines', the Department of Education and Training developed a series of initiatives aimed at increasing teacher knowledge and raising public awareness of ADHD. These initiatives are based on the understanding "that the diagnosis and treatment of ADHD is made by medical practitioners and falls beyond the expertise of teachers"¹⁵³.

The Department currently recognises ADHD as a medical condition and defines the condition as characterised by three core behaviours: inattentiveness, impulsiveness and over-activity which are at a level inappropriate for the child's expected developmental level. The teacher or other observer trying to determine whether a child's behaviour in the classroom is normal or not, is inextricably linked into the diagnostic process.

Mr Neil Darby, Director of Schools in the Albany Education District, highlighted the concerns that many within the education system face, when he stated:

... there is no clear cut-off point between those [students] who have a normally active, impulsive and inattentive temperament the ("spirited" preschooler), and those who are considered to have AD/HD.¹⁵⁴

A series of comments made by teachers about the process involved in the detection of learning difficulties, in particular ADHD, highlights some concerns:

¹⁵² Department of Education and Training, Government of Western Australia, Students at Educational Risk, Information for Teachers, 29 July 2004, http://www.eddept.wa.edu.au/SAER/policy/supatt.htm

¹⁵³ Mr John Brigg, Manager, Inclusive Education, Department of Education and Training, Submission, 14 July 2004, p.4.

¹⁵⁴ Mr Neil Darby, Director, Schools, Albany Education District, Department of Education, Government of Western Australia, Submission, 27 June 2003, p.1.

- There are many different forms and checklists used to document and report observations to support the medical diagnosis and management of ADHD;
- There may be professional bias towards a predetermined or preferred diagnosis;
- Teacher values, perceptions and professional knowledge about ADHD influences reporting;
- Checklists alone do not provide a comprehensive picture of what has been observed and the many factors [that] may be contributing to behaviour. Nor does a checklist reflect on what strategies have been successfully used by the teacher;
- Students experiencing stress, trauma and some psychiatric disorders may present behaviours that 'look' like ADHD to classroom teachers; and
- Mechanisms are needed for allied professionals to share professional observations and expertise to inform appropriate diagnosis, treatment and management. This is particularly important as classroom teachers and families are often dealing with many other conditions associated with ADHD, such as learning difficulties and depression, which all impact on each other.¹⁵⁵

ADHD presents a dilemma for those in both the medical and education professions and the parents and/or carers of children wanting to do the 'best' for their children. Differing views and opinions on what ADHD is, active debate on how it can be diagnosed and the increasing demand on teachers to recognise and categorise 'abnormal behaviour' has left those dealing with children at educational risk in an invidious position.

Attempting to determine whether a student has ADHD based on classroom observations is difficult. Ongoing professional development to enable a teacher to engage in a range of educational styles to meet the learning needs of identified students is considered essential.¹⁵⁶

The DoH ADHD policy refers to the role of schools in identifying students who may be at educational risk. The policy points out that it is not "the role of education professionals to determine a medical diagnosis of, or treatment for ADHD, but to be

¹⁵⁵ Comments provided by teachers to Mr John Brigg, Manager Inclusive Education, Department of Education and Training, Submission, 14 July 2003, pp.5-6.

¹⁵⁶ Ms Jan Little, Director Schools and Services, Joondalup Education District, Department of Education and Training, Submission, 2 July 2003, p.1.

aware of developmental problems and share information about a child's behaviour and development".¹⁵⁷

The practices and attitudes of individual teachers and schools may influence the rate at which students are diagnosed and possibly medicated for ADHD. The Committee is aware that in some cases, schools actively identify and categorise students with problems believed by teachers to require attention, referring these on to school psychologists for further assessment. Mr Philip Mort, School Principal, advised the Committee that:

If a child had been presenting with difficulties, his or her records would be in a red file that the teacher would immediately pick out of the class set. Those red files identify the children who need additional attention. There would be records on behavioural issues, academic progress and parental interview. If we believed that it was a condition that needed to be pursued at any greater length, we would engage our school psychologist, who would administer rating inventories to the teacher and family. We would be able to use that to supplement anecdotal records and observations. The process we go through is thorough and professional. We do not ever draw the conclusion that a child does or does not have ADHD; we would say that there were sufficient indicators for us to recommend that the family pursue it with a paediatrician. We would then make that information available to the paediatrician.¹⁵⁸

Information collated through observation can be a key factor in having a child identified as exhibiting ADHD behaviour and being at educational risk. The Committee is of the view that it is particularly important that teachers in this position have sufficient training that will allow them to make accurate observations.

Mr John Brigg, Department of Education and Training believes that the DoH ADHD policy infers that teachers are qualified to make a determination on whether a child has ADHD or some other developmental problem. Mr Brigg stated:

While classroom teachers are qualified to observe and report on attentional behaviour difficulties, the Policy incorrectly implies that school personnel are qualified to distinguish ADHD from other developmental concerns.¹⁵⁹

(a) Adequacy of professional development

The Health Department ADHD policy recommends that schools provide resources for the professional development of their staff to ensure a co-ordinated and informed

¹⁵⁷ WA Department of Health (2002) Office of Mental Health, *Attentional Problems in Children: Diagnosis and Management of Attention Deficit Hyperactivity Disorder (ADHD) and Associated Disorders*, Government of Western Australia, p.13.

¹⁵⁸ Transcript of Evidence, 27 October 2003, p.5.

¹⁵⁹ Mr John Brigg, Manager Inclusive Education, Department of Education and Training, Submission, 14 July 2003, p.12.

approach to students diagnosed with ADHD. Teachers do not always feel adequately trained or supported in this area. Mr Philip Mort noted that:

teachers would like...to consult with a paediatrician as they deal with the issues that the children are presenting. At the moment this is not available through the education system. Sometimes we will have group access to the child's paediatrician that they are dealing with through their family, but as a general rule it is the exception rather than common practice for us to have the depth of understanding that our teachers would seek as we go through and assist these children.¹⁶⁰

The Committee notes the inconsistency between what the stated policy advocates and what the respective departments involved can deliver and was informed that one of the enduring problems with the education system is that so little is known about ADHD:

The most prominent source of information is the media and whilst my observations are that it has gradually become more balanced and responsible, it does not constitute a suitable base for professional development. It would be pretty safe to say that ADD has an impact in most classes, and that most teachers have had no formal professional development on the subject.¹⁶¹

When asked about what sort of in service work has been done in providing additional professional development for teachers to assist them in identifying students at educational risk, in particular students who may have ADHD, Mr Philip Mort advised the Committee:

At a system level, there is precious little......Most teachers will have exposure to these children most years. The opportunities for professional level information to be available to them are very slim. For most it has been current affairs programs. That is a real indictment of the system.¹⁶²

The Committee understands the Centre for Attention and Related Disorders (CARD) at the University of Western Australia provides a number of professional development opportunities for educators, school psychologists and other professionals with an interest in ADHD and related disorders. The overall aim of the CARD is to provide a local, national and international focus for multidisciplinary research in childhood and adolescent ADHD and comorbid disorders. The specific aims include to:

 Promote University inter departmental, cross departmental, and cross agency (for example the Health Department) research into Attention Deficit and Related Disorders;

¹⁶⁰ Transcript of Evidence, 27 October 2003, p.2.

¹⁶¹ Mr Philip Mort, School Principal Atwell Primary School, Submission, 27 June 2003, p.2.

¹⁶² Transcript of Evidence, 27 October 2003, p.5.

- Develop within the Centre an Internship programme as an integral component for Graduate Diploma in Education School Psychology students;
- Extend and strengthen existing links with the teaching, psychology, and health professions through the dissemination of research findings and collaborative ventures in both research and professional development;
- Extend existing links with the local community, schools, professional agencies, and support groups through the formalised development and maintenance of a referral and assessment clinic; and
- Extend and strengthen existing links with parents of children and adolescents with Attention and Related Disorders through the continued development and organisation of parent seminars.¹⁶³

In this sense it appears WA has the foundation for the form of professional development that many teachers and health professionals have requested throughout the inquiry. Professor Stephen Houghton, Psychologist and Director of the CARD, advised the Committee that:

[there is] a centre of excellence on your doorstep,...the Department of Education and Training... gets us to come along and do talks. It produces the at-risk programs and booklets, but it has never once referred to us...... Is it any wonder that recent research into the myths and beliefs of teachers about attention deficit disorder found that teachers have the lowest level of understanding about this condition?¹⁶⁴

The Committee believes the absence of clear directives has compounded the problem of providing adequate strategies, with adequate support, to deal with children who are exhibiting behavioural problems in the school environment. The information required is simply not flowing through to those who require the knowledge, guidance and support. The Committee is of the view that the policies relating to ADHD are perhaps too generic to be effective. There is doubt about which department has ownership and there is evidence to suggest that there is insufficient intersectoral partnership. The roles and responsibilities of the Department of Education and Training and the DoH are not clear and there is considerable confusion as to what is expected from those involved.

Finding 28

The practices and attitudes of individual teachers and schools may influence the rate at which students are diagnosed and possibly medicated for ADHD.

¹⁶³ <u>http://card.gse.uwa.edu.au/_</u>accessed November 2003.

¹⁶⁴ Transcript of Evidence, 26 November 2003, p.6.

Finding 29

There is a level of dissatisfaction within the education system as to what is expected of teachers in relation to ADHD and the adequacy of the professional assistance and advice provided.

Finding 30

The roles and responsibilities of the Department of Education and Training and the Department of Health with respect to ADHD are not clearly defined and there is considerable confusion amongst health and education professionals as to what is expected from those involved.

It is clear that programs to address this problem must be incorporated into the existing policy framework in relation to learning and other specific disabilities. The challenge for government is to develop a collaborative strategy, between the various policy areas, primarily health and education, not only in terms of coal face professional development, but also at the academic level, whereby the teachers and medical professionals are better trained to deal with the range of behavioural problems. This would facilitate greater understanding of the possibility of alternative diagnosis.

7.4 Approaches to management in Western Australia

The Committee received submissions from a number of organisations within the WA education and health sectors that have developed collaborative, inter-agency approaches to the increasing problems of behavioural and learning difficulties. There are a number of pilot projects and initiatives under way, which have been developed within the existing policy framework and provide a valuable knowledge base for future policy directions. The Committee commends the initiatives taken within the various organisations, a number of which are outlined in the following sections.

(a) Wrap Around Project (WRAP)

In 2002, the ADD/ADHD Wrap Around Project (WRAP), a joint initiative between the North Metropolitan Health Services, in particular the Joondalup Child Development Centre, and the Department of Education and Training was instigated.

The Education Department's strategies on 'Student's at Educational Risk' focuses on prevention through early identification and intervention to address the needs of students who exhibit behaviour that could be interpreted as ADHD. As the majority of children with ADHD come to professional attention in their first few years at school as a result of behavioural and/or academic concerns it was logical that pilot programs targeting early intervention would focus on the Kindergarten to Year Three strand.

The WRAP project was implemented in 12 government schools across the Joondalup Education District with the aim of using an early intervention model to focus on children with ADHD at developmental and educational risk. Utilising this model would provide a plan of management for children diagnosed with ADHD, enabling an early diagnosis as a result of the children being fast tracked through a number of different specialists.

The project was continued through 2003, with the focus remaining on the development of a team approach to manage targeted students. In their joint submission to the Committee, the Joondalup Child Development Centre, North Metropolitan Health Service, West Coast Education Office and the Department of Education and Training indicated that cooperation and collaboration were the key issues:

The WRAP 'team' comprising paediatrician, speech and occupational therapist, school psychologist, school administrator, class teacher and family members would meet on school site to discuss assessments, define outcomes, plan intervention, allocate tasks, monitor achievement and make provision for the needs of students with attentional difficulties to ensure improved learning outcomes and citizenship¹⁶⁵.

The School of Psychology at Edith Cowan University conducted a review of the WRAP project midway through its operation in December 2002. The review identified a number of strengths and highlighted areas that needed further development. The review also put forward a series of recommendations aimed at improving the capabilities of the project, the more important of these were:

- The WRAP should be developed further and implemented in schools as an early intervention;
- Any attempt to include more children in the project relies on significant funding increases and substantial increase in workload of the professionals involved;
- At present, limited support is available to students identified at risk in the school setting (limited teacher and student time). Extra resourcing would certainly assist in more effectively addressing individual students and school needs;

¹⁶⁵ Joondalup Child Development Centre, North Metropolitan Health Service and the West Coast Education Office, Department of Education Office and Department of Education and Training, Submission, 4 July 2003, p.2.

- Additionally, a coordinator for the program would need to be factored into an expansion of the program to ensure smooth and effective management of the caseload, continuing effective communication across and between stakeholders, so that issues on a wider level are addressed;
- Expanding the project to include students in year 4 will need to be considered in the future; and
- A mental health professional (ideally a clinical psychologist) should be part of the WRAP team to participate in the assessment as well as management of students with attentional difficulties. Our vision is a collaborative Joondalup WRAP around model involving current stakeholders, the Child and Adolescent Health Team and the Department of Community Development (Family and Children's Services).¹⁶⁶

The WRAP project has since failed to attract further funding and the Committee was informed that in July 2004, the project and follow up service was terminated.

(b) West Coast Education District Individual Behavioural Plan

In the West Coast Education District, primary school behaviour management is supported by the North West Socio Psychological Education Resource (SPER) Centre. The Committee was informed that 60 per cent of the referrals to the Centre are students diagnosed as having ADHD.

The West Coast District Service Centre advised the Committee that the needs of students diagnosed with ADHD vary, and the necessary learning and teaching adjustments most often relate to behavioural management. The Individual Behaviour Plan (IBP) was designed in response to ADHD students' inattention, hyperactivity and impulsivity affecting their ability to access the curriculum effectively.¹⁶⁷ The IBP encourages a partnership between parent, child and teacher to not only work on the difficulties a student with ADHD will have with various aspects of the curriculum but to also promote and develop the individual's strengths and competencies.

As with many initiatives under the students at educational risk policy umbrella, partnerships with parents are promoted to ensure that behaviour management plans are jointly formulated and most importantly, jointly implemented.

Strategies are developed using consultative processes and included within an Individual Behavioural Plan. The IBP is designed to accommodate the

¹⁶⁶ Joondalup Child Development Centre, North Metropolitan Health Service and the West Coast Education Office, Department of Education Office and Department of Education and Training, Submission, 4 July 2003, p.4.

¹⁶⁷ West Coast Education District Service Centre, Department of Education and Training, Submission, 2 July 2003, p.2.

specific needs of the individual child and other approaches to deal with managing difficult behaviours.¹⁶⁸

The West Coast District Service Centre advised the Committee that the future of IBPs was dependent upon adequate resources being made available to those at the front line, in particular the schools and the teachers.¹⁶⁹

(c) The Albany Model - A collaborative model of intervention and management

The Albany Model was developed in accordance with the National Health and Medical Research Council on Attention Deficit Hyperactivity Disorder standards and guidelines from the need to have increased collaboration between professionals working with children diagnosed with ADHD. The need to appropriately identify children and young people at risk and then plan and monitor them in schools, became a common goal of the Visiting Paediatrician and the Manager of Student Services. Out of this common need arose *the Albany Model - a Collaborative Model of Intervention and Management; A Practical Process.*

The Committee met with Professor Harry Dumbell, Visiting Paediatrician to the Lower Great Southern Health Child Developmental Services, and Ms Josey Hurley, Manager, Student Services, Albany District Education Department to discuss the initiative currently underway in that region.

Professor Dumbell and Ms Hurley noted that interventions for children with differential diagnoses or behavioural issues were being delayed. There was no collaborative approach available and it seemed there were professionals working in isolation in the area without communicating with each other. Further, the request for stimulant medication was increasing and there was no clear way of succinctly bringing together information from a number of sources that were working with the same children and their families. These concerns, along with the introduction of NHMRC Best Practice Guidelines, led to the beginning of a joint approach and increased cooperation in the development of improved processes and protocols.

The Albany Education District School Psychology team is an integral element in enabling the multi modal, multidisciplinary approach to happen. They act as a conduit of information between key players and are closely linked to the Paediatrician in gathering information from teachers in schools prior to the Visiting Paediatrician's regular visits. The expansion of their role to interface with GPs has enhanced and increased mutual understanding of roles and facilitated more open communication between GPs, School Psychologists and families. The model allows for an accurate

¹⁶⁸ *ibid*, p.1.

¹⁶⁹ *ibid*, p.2.

differential diagnosis and helps identify and evaluate comorbidities/coexisting conditions, a prerequisite to providing a reliable diagnosis and effective treatment.

(d) The GP Plus Team Program

The Perth Hills Division of General Practice (PHDGP), in conjunction with Swan Education District and local schools, have implemented a multidisciplinary case conference initiative, the GP Plus Team Program. The GP Plus case conference team includes a medical practitioner, the parent or carer, and at least two other members (may be a school psychologist, teacher, school nurse, or social worker). Key stakeholders are identified as being the:

- Child and their family;
- Schools;
- GP Plus GPs; and
- Allied health professionals.

The GP Plus program combines the Education Department of Western Australia's case management in schools initiative and the Commonwealth government's Medicare Benefit Schedule, which permits GPs to be involved in and organise a multidisciplinary case conference. GP Plus does not solely assist with those with ADHD but with all chronic conditions. Cases have included severe injury resulting from road accidents, Tourette's syndrome, sleep disorder and conduct disorder. The aim of the program is to improve the educational and social outcomes for children with chronic conditions. The team outlined some of the drivers behind the initiative, including:

- GPs are at the forefront of health care in the community [and] are therefore well versed in the needs of children and their families relating to disorders such as ADHD; and
- A lack of communication between schools, allied health professionals and GPs, coupled with the GPs traditional lack of experience of working in a team has been one of the major barriers to improving the health, educational, and social outcomes for children with ADHD.

The original schools have now moved to run the program themselves with their teams and the PHDGP is overseeing 3 new schools joining the program - 2 primary and 1 secondary. Following an evaluation of the program in January 2004, the following findings were made:

- Major benefits reported by GPs included the opportunity to extend their knowledge and to build relationships with schools and other health professionals;
- Allied health professionals appreciated the opportunity to assist teachers and offer coping strategy suggestions;
- The response from schools ranged from 'hugely valuable' to 'essentially a good idea'. Schools mainly saw the GP Plus program as a 'last resort' to be accessed when school resources had been exhausted; and
- The GP Plus program was successful in that it gave parents strategies to manage behaviour and was very informative.

Overall, GPs, Schools and Allied Health Members were generally very positive about the program, finding it valuable in terms of community liaison and of benefit to family and schools. The main concerns were about how the program would be resourced, particularly if the GPDWA were to withdraw.¹⁷⁰

Finding 31

There are individual cooperative programs endeavouring to move towards a multidisciplinary model for the diagnosis and treatment of ADHD. Whilst many of these programs are effective, they are developing on an ad hoc basis and do not receive adequate government support.

7.5 Resource allocation for education

School resources are provided to support students with disabilities, the provision of such resources allows these children to attend and participate in a classroom environment. Additional resources can range from the allocation of a teacher's aide, trained to handle a specific disability, through to the simple provision of advice from peers. Although ADHD is recognised by the Department of Education as a medical condition, it is not recognised as a disability.

With respect to how we define attention deficit hyperactivity disorder, our policy for students with disabilities embraces about three and a half to four

¹⁷⁰ GP Plus Evaluation January 2004 (an overview), Department of Education and Training, Swan Education District Office.

percent of our student population and ADHD and attention deficit disorder are not defined as a disability.¹⁷¹

The Committee was told that although additional resources are provided for children with disabilities, there is little or no support for children diagnosed with ADHD.

If a teacher were to ask for assistance to help these children, it would have to be provided through the school's resources, and typically these would not be sufficient. If a child has autism or cerebral palsy, it is a different circumstance altogether - the support is available. If the children are on an inclusion program in a mainstream school and have an IQ below 70, they will have some support made available to them. However, if the child's disability is attentional, no support is available.¹⁷²

The Committee was advised that three and a half to four per cent of students have a disability and that another 14 per cent of students have particular learning difficulties that require special support. In essence, 18 per cent of students have some form of disability or impairment that without support will increase the likelihood of these children not reaching their full educational potential.

The Department of Education categorises these students as at educational risk. Depending on which category a student is placed in, resources and support are available to assist them at school.

...whilst we categorise four per cent of students with disabilities and the 14 per cent are not given additional support, the whole range of 14 per cent do everything in their power to be categorised as part of the four percent. Our longer-term plans and needs are to provide better for that whole range of students. However, it is a resource-intense approach and our whole thinking and way of supporting the four per cent of students has been built on a deficit model in which we give students a label and they get a package of supports that go with it. If students are not categorised in that way, they get nothing¹⁷³.

The Committee is of the view that clear direction, combined with adequate resources is required to address this and other issues raised in the above sections.

¹⁷¹ Ms Margaret Banks, Acting Deputy Director General, Schools, Department of Education and Training, Transcript of Evidence, 29 October 2003, p.2.

¹⁷² Mr Philip Mort, School Principal, Atwell Primary School, Transcript of Evidence, 27 October 2003, p.7.

¹⁷³ Ms Margaret Banks, Acting Deputy Director General, Schools, Department of Education and Training, Transcript of Evidence, 29 October 2003, p.2.

Finding 32

There is disparity between the level of support teachers are expected to provide for students diagnosed with ADHD and the level of support proffered to teachers through the Education Department.

Finding 33

Although additional resources are provided for children with disabilities, there is inadequate classroom support for children with behavioural and learning difficulties.

Recommendation 10

The Committee recommends that the Department of Education and Training place greater emphasis on providing training and resources for teachers dealing with students with behavioural and learning difficulties.

Recommendation 11

The Committee recommends that the Department of Education and Training ensure that teachers are made explicitly aware that the information they provide about students behaviour may be used in the diagnosis of ADHD.

7.6 ADHD and social well being

Evidence presented to the Committee suggests that ADHD has some impact on the social development of individuals categorised with the disorder, however, the extent of the impact is undetermined. It is important to note that social wellbeing and economic wellbeing are often co-dependent.

There is substantial variation in opinion on this subject. Some indicate that an early diagnosis and proper management allows the child to grow into adulthood with the same outcomes as a child without ADHD.¹⁷⁴ Some who subscribe to this view do

¹⁷⁴ Drug and Alcohol Office, Government of Western Australia, Submission, 26 June 2004, p.25.

suggest, however, that the outlook is far more sombre for the individual who reaches adulthood with undiagnosed and untreated ADHD.

Studies that have reported on low employment status for adult ADHD cases frequently relate to cases where diagnosis has occurred in adulthood. These cases have not received treatment through childhood and adolescence. It is very probable that this has significantly influenced lifetime outcomes, including employment status.¹⁷⁵

The Drug and Alcohol Office informed the Committee that "poor educational and other life outcomes have been associated with children with ADHD who remain undiagnosed and untreated".¹⁷⁶ The General Practices Division of Western Australia, though not differentiating between treated or untreated ADHD, suggested that people with ADHD will experience more social problems than people without.

ADHD has the potential to cause devastating problems for patients and their families. Studies have shown that sufferers are more likely to drop out of school, have few or no friends, under-perform at work, engage in anti-social activities, and use tobacco or illicit substances. Children growing up with ADHD are more likely to experience teen pregnancy, sexually transmitted diseases, to speed excessively and have multiple car accidents and to experience depression and personality disorders as adults¹⁷⁷.

In many submissions and in formal evidence before the Committee, parents and/or carers detailed experiences of social isolation, such as their child not being included in activities both within and outside of the school setting, as a direct result of them being labelled with ADHD. Many detailed the negative effect of social exclusion on self-esteem and the ability to develop and maintain relationships. Further, a number of parents indicated they have experienced pressure to have their child formally diagnosed and medicated before being included in such activities.

Finding 34

Many children that exhibit ADHD behaviours experience social isolation, both within and outside of the education system. Submissions detailed the negative effect of social exclusion on self-esteem and the ability to develop and maintain relationships.

¹⁷⁵ *ibid*.

¹⁷⁶ *ibid*.

¹⁷⁷ General Practices Division of Western Australia, Submission, 9 July 2003, p.5.

Finding 35

Some parents and/or carers of children suspected to have ADHD experience pressure to have their child formally diagnosed and medicated before that child is included in academic and social activities.

(a) Impact on families

The effects of ADHD behaviours often encompass the immediate family. Parents of children diagnosed with ADHD report greater parenting stress than do parents of children with other special needs. In particular, mothers of ADHD patients are considered more likely to be depressed, and to experience marital difficulties.¹⁷⁸ Difficulties experienced by these parents often include "a less supportive and more stressful family environment, lower levels of interpersonal relationships, and more divorces and separations".¹⁷⁹

Parenting skills and a possible connection to ADHD was also an area of concern raised in some of the submissions. While there is no scientific evidence to support bad parenting as a cause, many parents felt as though they were being blamed for their child's behaviour and were being labelled as irresponsible for putting their children on medication. These issues were a cause of great distress.¹⁸⁰

Finding 36

The effects of ADHD behaviours often encompass the immediate family. Many parents believe they are 'blamed' for their child's behaviour and are labelled irresponsible for putting their children on medication.

¹⁷⁸ Closed Submission, 27 June 2003, p.6.

¹⁷⁹ Michele Toner, Executive Officer, Learning and Attentional Disorders Society of Western Australia Inc., Submission, 9 July 2003, p.13.

¹⁸⁰ Child Study Centre Clinic, School of Psychology, The University of Western Australia, Submission, 27 June 2003, p.3.

Finding 37

Whilst there is evidence of a correlation between the diagnosis of ADHD and family social and economic dysfunction, whether ADHD is the cause of the dysfunction or ADHD behaviours are the result of the dysfunction is not clear.

7.7 ADHD and economic wellbeing

The effects of ADHD, from an economic perspective, can be categorised into two areas. The first is the economic effect that ADHD has on the individual and whether it restricts or limits employment options. The second area is the financial impact ADHD has, particularly if children are involved, on the immediate family or those responsible for the child.

For a child diagnosed with ADHD there is evidence to suggest that a phenomenon known as 'social drift' may occur whereby the child grows up with less education than their peers and then drifts into a level of employment that is indicative of poor academic performance.¹⁸¹ A study by Barkley *et al* (1990) examining children with ADHD over an eight-year period, found that:

- 30% had been retained in a grade at least once, with many retained more than once;
- 46% had been suspended on more than one occasion;
- 11% had been expelled from school; and
- 10% had simply dropped out of the education system.¹⁸²

In their submission, the Albany Education District Office advised the Committee that longer-term follow up studies on the work conducted by Barkley *et al* showed that:

- over 50% of students with ADHD were retained in a grade at least once;
- 35% never completed high school; and

¹⁸¹ Barkley, R.A., *ADHD and the Nature of Self Control,* The Guildford Press, 1997, cited in South Australian Department of Human Services (2002) Response to Recommendations by the Sixteenth Report of the South Australian Parliament Social Development Committee, 'Inquiry into Attention Deficit Hyperactivity Disorder', Government of South Australia, December 2002, pp.4-5.

¹⁸² Barkley, R. Fischer, M. Edelbrock, C. & Smallish, L. (1990) The adolescent outcome of hyperactive children diagnosed by research criteria: I. An 8 year prospective follow-up study, *Journal of the American Academy of Child and Adolescent Psychiatry*, 29, pp.546-577.

• only 5% completed tertiary education.¹⁸³

The majority of children with behavioural and learning problems are vulnerable in terms of academic development. The Committee was informed that children with ADHD who do not receive specialist teaching and appropriate learning programs are at risk of:

...academic failure which may lead to behavioural/emotional dysfunction, possible school drop out and subsequent economic difficulties in their adult life.¹⁸⁴

The inability to achieve scholastically may restrict employment opportunities in adult life, which may in turn affect an individuals economic potential. Developmental paediatrician Dr John Wray advised the Committee that "there is no doubt that ADHD symptoms are associated with poorer educational, health, economic and social outcomes"¹⁸⁵ and that these outcomes are made worse if there is a co-morbid condition present. A student diagnosed with ADHD is considered less likely to have a positive learning experience at school and this is reflected in many underachieving and consequently failing to reach their individual potential.¹⁸⁶

The Committee was advised that children who are "poorly managed in their early school years lose their drive to succeed and the will to learn"¹⁸⁷ and these children have a greater "chance of entering their adult life poorly educated, socially inept and lacking in confidence".¹⁸⁸ It was suggested though that children with ADHD who do make a successful transition into adult life often "channel their immense drive, determination and single mindedness to be outstanding in business or public life".¹⁸⁹

(a) Financial burden for families

There is an obvious economic impact on the families of children who have been diagnosed with ADHD. The Committee received a number of submissions highlighting this fact. For example:

¹⁸⁶ *ibid*.

¹⁸³ Albany District Education Office, Department of Education, Government of Western Australia, Submission, 27 June 2003, p.4.

¹⁸⁴ Child Study Centre Clinic, School of Psychology, The University of Western Australia, Submission, 27 June 2003, p.3.

¹⁸⁵ Dr John Wray, Developmental Paediatrician, Submission, 30 June 2003, p.3.

¹⁸⁷ Albany District Education Office, Department of Education, Government of Western Australia, Submission, 27 June 2003, p.4.

¹⁸⁸ Albany District Education Office, Department of Education, Government of Western Australia, Submission, 27 June 2003, p.4.

¹⁸⁹ *ibid*.

ADHD as a disorder has been a long term financial burden for our family, in terms of travel and accommodation to seek professional help, prescriptions, psychological services etc. Many parents don't bother quantifying this because their main goals are to keep their family and ADHD child alive and well and able to function in the outside world — and it's hard to put a price on that. You just do it.¹⁹⁰

Further expenses are incurred where a parent or carer does not work in order to care for their child. Dr Kenneth Whiting, Paediatrician, informed the Committee:

*Families can suffer an economic impact resulting from parents missing work or having to give up work in order to meet the unique demands and special needs of a child with ADHD.*¹⁹¹

The General Practices Division of Western Australia presented a similar point of view suggesting that families suffer economically as a result of attending to the 'special' needs of their children.¹⁹² While the Committee has noted a clear shortage in the provision of state services, it was interested to learn of the level of Commonwealth financial support in this area, which may assist families in accessing private sector therapies.

(i) Financial assistance available to carers

The Committee heard anecdotal evidence to suggest that carers of children with ADHD are eligible for financial assistance through the Commonwealth government. The Committee wrote to the Department of Family and Community Services and ascertained the following information:

There are two forms of Commonwealth financial assistance available to carers of children under 16 years of age with a disability or chronic medical condition: Carer Allowance (CA) (child) and Carer Payment (CP) (profoundly disabled child). Eligibility for these payments is not linked to medication use.

The CA is an income supplement paid in recognition of the impact of caring. Care and attention must be made on a daily basis and the receiver of care is required to undergo a medical assessment. There are two stages in assessing for the CA:

• The child is assessed against the Lists of Recognised Disabilities. If the child has a disability or medical condition on the lists their parent or carer will receive the allowance without need for further medical assessment. ADHD is not listed as a recognised disability for the purposes of CA (child) assessment;

¹⁹⁰ Ms Ginny Dadd, Submission, 23 June 2003, p.3.

¹⁹¹ Dr Kenneth Whiting, Consultant Paediatrician, Submission, 30 June 2003, p.8.

¹⁹² General Practices Division of Western Australia, Submission, 9 July 2003, p.5.

Where a child's medical condition or disability is not on the lists, they will be assessed using the Child Disability Assessment Tool (CDAT). The CDAT is comprised of a Treating Doctors Report (TDR) completed by a medical practitioner and a questionnaire completed by the customer. The responses from the TDR and questionnaire are then used to calculate a score that determines eligibility for CA.

The CDAT measures the severity of disability by assessing whether the child functions according to standards (in terms of language skills, self-care skills, social and community skills and motor skills) appropriate to his or her age. The CDAT is not aimed at specific disabilities, medical conditions or particular age groups.

Where a carer is eligible for the CA (child), a Health Care Card will be provided in respect of the child. If a carer is not qualified for the CA based on the level of the child's functional disability, the carer may still qualify for a Health Care Card if the child requires at least 14 hours per week of additional care and attention.

The CP, on the other hand, provides income support to people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation. Children who meet the medical eligibility criteria for the CP (profoundly disabled child) would typically require institutionalisation if the care was not provided at home.¹⁹³

(b) Collaboration between the State and Commonwealth

The Commonwealth support outlined above does not specifically relate to support for the behavioural and learning problems associated with a diagnosis of ADHD. The Committee has acknowledged that the State Government must provide more resources to address shortages in WA, particularly in the form of multidisciplinary assessment and diagnosis, and in the provision of support in the area of education. However, it is the Committee's view that the Commonwealth Government also has a role to play in the provision of support for families affected by learning and behavioural problems.

Further to the discussion of the impact of the provision of dexampletamine on the PBS in Chapter Three, the Committee believes the State Government must work collaboratively with the Commonwealth Government to ensure the full range of treatment options, other than medication, are provided at a public level.

¹⁹³

Information in this section provided by Commonwealth Department of Family and Community Services, Correspondence to the Committee, 27 April 2004.

Finding 38

Families report suffering economically as a result of attending to the special needs of children diagnosed with ADHD. Economic constraints often inhibit the use of treatment options other than medication.

Recommendation 12

The Committee recommends that the State Government liaises with the Commonwealth Government to ensure the full range of treatment options for ADHD are provided at a public level.

CHAPTER 8 CONCLUSIONS

8.1 Future directions

It is evident that ADHD, particularly the variances in opinion on diagnosis and management, has been debated in much detail in various reports and forums. Although acknowledging the contribution of the debate to the formulation of initiatives for improved medical, social and educational outcomes of those affected, the Committee remains concerned about inadequate provision of resources and the high use of stimulant medication in this state. The Committee believes this inquiry has provided a timely reminder that these are, after all, young children that are being medicated and as such a cautious approach is warranted. Medication should not be the first line of treatment.

It is clear that WA has adopted a medication first model of treatment for ADHD and that the rate of stimulant use is alarmingly out of step with the national average. The absence of sufficient public health services for treatment and diagnosis and reliance on individual schools for provision of support services and professional development are contributing factors to this situation.

Evidence tendered to the Committee about the application of stimulant medication in WA indicates concern about a number of issues. Those that the Committee considered most troubling included:

- the potential for incorrect diagnosis;
- side effects of stimulant medication and polypharmacy;
- the diversion of licit medication for illicit use; and
- the absence of conclusive longitudinal studies on the impact of long term use of medication.

The rate at which WA leads other jurisdictions in the use of stimulants to treat ADHD was attributed to a range of factors including:

- limited comprehensive assessment and treatment options;
- the affordability of certain stimulant medication;
- adequacy of diagnostic tools; and
- workload pressures on, and prescribing practices and qualifications of, practitioners.

Central to the Committee's argument for reform is the progressive implementation of multidisciplinary diagnostic and treatment teams. It views that many of the factors seen as contributing to levels of stimulant medication use in this state would at some level be contained within this structure. Evidently the broader issue of the shortage of health professionals would need to be appropriately planned and managed. Further recommendations include the development of stronger protocols for clinicians to improve the understanding of and subsequent diagnosis and management of behavioural and learning difficulties.

The Committee is concerned about the diversion of stimulant medication for illicit use, and has recommended stronger dispensing controls. While evidence of misuse is largely anecdotal, the frequency with which the issue was raised in submissions, and some emerging data, indicate this as a growing problem. It is hoped the recommended changes to the existing regulatory framework may go some way in addressing this issue.

The recommendation for multidisciplinary teams is not new. The state health policy provides a sound framework for standardised, quality clinical practice in the assessment, treatment and management of ADHD and the Committee commends the DoH in this regard. However, evidence to this inquiry supports the notion of a lack of resource commitment to ensure the efficacy of the policy. This requires commitment at both the State and Commonwealth level to ensure adequate service delivery.

A similar concern is reflected within the educational domain. ADHD falls within a generic educational policy pertaining to learning difficulties, *Students at Educational Risk.* Both this policy and that of the DoH place responsibility for provision of resources for students and professional development of staff on individual schools. The perception is that teachers are required to develop strategies and are inextricably linked in to the diagnostic process through behavioural observation, without adequate assistance or training. A lack of consistency is apparent in the approach to management of these children because it is largely reliant on what schools can provide and their level of expertise.

Teachers are expected to develop management plans for children with a diagnosis of ADHD, however it was reported that this often does not eventuate. These plans are dependent on collaborative arrangements between a number of professionals, including medical and allied health. The Committee did note, however, that a number of initiatives aimed at coordinating health and education approaches have been developed, albeit in isolation. The Committee would perceive that an absence of multidisciplinary teams able to offer multi modal management approaches would impact on this approach. In effect, in education we are seeing a replication of what is occurring within the medical domain, that is, a lack of resources leading to a request for a "quick fix".

In light of the intersectoral issues and the controversy surrounding the diagnosis and treatment of ADHD in WA, the Committee believes a coordinated multidisciplinary

approach is required to oversee the implementation of the recommendations of this report. The Committee believes that the underlying cause(s) (be they familial, biological, environmental, medical, dietary, psychological and/or social) of a child's behavioural problems must be accurately identified. The Committee unanimously agreed that it is essential that treatments match the cause.

Recommendation 13

The Committee recommends that the Ministers for Health and Education in Western Australia establish a multidisciplinary body to oversee the implementation of the recommendations contained within this report.

APPENDIX ONE

SUBMISSIONS RECEIVED

List of Submissions received for the inquiry.

Submission	Name	Position	Organisation
1	Mrs Gloria Rowe		
2	Dr Pat Cranley		
3	Dr Darryl Lacey	General Practitioner	
4	Dr Kim Pedlow	General Practitioner	
5	Ms Ginny Dadd		
6	Professor Louis Landau	Executive Dean, Faculty of Medicine and Dentistry	University of Western Australia
7	Ms Jane Brazier	Director General	Department of Community Development
8	Ms Michele Kosky	Executive Director	Health Consumers' Council
9	Mr Phillip Lipple		
10	Ms Andrea Nixon	Manager, Cannington Office	Department of Community Development
11	Mr John Ferguson	School Psychologist	
12	Associate Professor Susan Prescott	Head of School, Faculty of Medicine and Dentistry	University of Western Australia
13	Mr Keith Evans	Director, Drug Programs and Populations Strategies Branch	Department of Human Services
14	Mr A.J. and Mrs M.D. Hartley		
15	Ms Winnie Killick		

Submission	Name	Position	Organisation
16	Dr John Penman	Chairman	The Royal Australian and New Zealand College of Psychiatrists
17	Dr Ruth Shean	Director General	Disability Services Commission
18	Mr Alan Plumb	Manager, Student Services	Bunbury District Education Office
19	Dr Peter Binns	Consultant Psychiatrist, Morley Adult Mental Health Centre	Swan Health Service
20	Ms Vicki Rundle	Director, Children and Families	Department of Health and Human Services
21	Ms Christine England		
22	Professor David Hay	Professor of Psychology	Curtin University of Technology
23	Dr Paul Lee	Child Psychiatrist, Child and Adolescent Mental Health Service	Monash Medical Centre
24	Dr Denzil McCotter	Acting Executive Director	Drug and Alcohol Office
25	Dr Neil Beck		The Chemical Health Centre
26	Ms Wendy O'Connor	Clinical Psychologist	
27	Mrs Carol Eaves		
28	Ms Jeanette Cole	Social Worker	Murchison Health Service
29	Associate Professor David Leach	Clinical Convenor, School of Psychology	Murdoch University
	Mr Douglas Brewer	PhD Candidate	
30	Mr Neil Darby	Director, Albany Education District	Department of Education and Training

Submission	Name	Position	Organisation
31	Dr Donald Coid	Director of Medical Services	Armadale Health Service
	Dr Richard Christie	Paediatrician	Armadale Kelmscott Health Service
	Dr Amanda Wilkins- Shurmer	Community Paediatrician	Armadale Health Service
32	Dr Gil Anaf	President	National Association of Practising Psychiatrists
33	Ms Sandy Moran		
34	Mr Philip Mort	Principal	Atwell Primary School
35	Ms Susan Moore	Clinical Nurse Manager	Peel and Rockingham Kwinana Health Service
	Dr Neil Banham	Director, Emergency Department	
36	Closed Submission		
37	Ms Margaret Jones	Senior Clinical Psychologist Co- ordinator, North Metropolitan Health Service	Department of Health
38	Ms Janet Fletcher		Child Study Centre Clinic, School of Psychology, University of
	Ms Robin Harvey		western Australia
	Mr Steve Heath		
39	Ms Margaret Jones		
40	Closed Submission		
41	Ms Helen Gryzb	Director	Helen Gryzb and Associates
42	Dr Trevor Parry	Clinical Associate Professor, School of Paediatrics and Child Health	University of Western Australia
43	Ms Michele Toner		

Submission	Name	Position	Organisation
44	Dr Kenneth Whiting	Consultant Paediatrician	
45	Dr John Wray	Developmental Paediatrician	
46	Mr Eamon Ryan	Director, Office of Health Review	Health and Disability Complaints
47	Ms Jan Battley	Executive Director	Holyoake
	Haylee Clark	Co-ordinator/counsellor	
	Georgia Sallis	Co-ordinator/counsellor	
48	Dr Michele Larose	Consultant Child and Adolescent Psychiatrist	Bentley Health Service
	Ms Helen Stevens	Senior Social Worker	
	Ms Therese Faulkner	Clinical Psychologist	
	Ms Gemma Vincent	Senior Occupational Therapist	
	Ms Amanda Styles	Senior Speech Pathologist	
49	Closed Submission		
50	Ms Hilary Le Page	Child and Adolescent Psychiatrist	South Metropolitan Child and Adolescent Mental Health Service
51	Dr Georgia Carragher	Programme Co-ordinator, GP Plus Team	Perth and Hills Division of General Practice
52	Mr Siyavash Doostkhah	Director	Youth Affairs Network of
	Dr Bob Jacobs	Psychologist	Queensiand
53	Ms Sandy Moran		
54	Ms Mary Keeley	School Nurse	Kensington High School
55	Ms Jan Little	Director, Schools and Services, Joondalup Education District	Department of Education and Training

Submission	Name	Position	Organisation
56	Dr Geoff Dixon		Cambridge Private
	Dr Wendy Reid	General Practitioner	Hospital
	Professor Roderic Underwood	Psychologist	
57	Professor M.J. Garlepp	Head, School of Pharmacy	Curtin University of Technology
	Mr K.T. McNuff	President	Pharmaceutical Council of Western Australia
	Mr H. Zafer	President, Western Australian Branch	Pharmacy Guild of Australia
58	Mrs Elizabeth Spencer- Fawell		
59	Mr Keith Symes	Regional Director, Great Southern Health Region	WA Country Health Service
60	Dr Annakathrin Franzmann	Community Paediatrician	Joondalup Child Development Centre
	Ms Robyn Oliver	Student Services Area Manager	West Coast Education District
61	Dr Brad Jongeling	Community Paediatrician	Joondalup Child Development Centre
62	Ms Margaret Vikingur		
63	Dr Gervase Chaney	Chairman	Royal Australian College of Physicians
64	Dr Lois Achimovich	Consultant Psychiatrist	
65	Ms Cobie Rudd	Chief Executive	General Practice Divisions of Western Australia Ltd.
66	Ms Michele Toner	Executive Officer	Learning and Attentional Disorders Society of Western Australia Inc.
67	Ms Nancy Da Costa	Acting Nurse Co- ordinator, School/Adult/Youth Program	East Metropolitan Health Service

Submission	Name	Position	Organisation
68	Associate Professor Heather Jenkins	Head, Department of Education	Curtin University of Technology
69	Mr Richard Madden	Director	Australian Institute of Health and Welfare
70	Mr Mike Daube	Director General	Department of Health
71	Ms Glyn Palmer	Area Chief Executive	East Metropolitan Health Service
72	Mr Frank Rockett	Director General	Disability Services Queensland
73	Mr John Brigg	Manager, Inclusive Education	Department of Education and Training
74	Mr Ron Carlisle	President	Citizens Committee on
	Ms Shelley Wilkins	Director	Human Rights Inc.
75	Dr Kim Pedlow		
76	Ms Paula McLennan		
77	Ms Pam White	Executive Director, Community Care Division	Department of Human Services
78	Ms Jill Forslind		
79	Ms Jan Eastgate	President	Citizens Commission on Human Rights International
80	Mrs Annemarie Leask		
81	Ms Robin Barrington		
82	Dr Fred Baughman	Neurologist	
83	Ms Dawn Allen	Teacher	

APPENDIX TWO

PUBLIC HEARINGS

Date	Witness	Position	Organisation
27-Oct-03	Mrs Michele Toner	Executive Officer	Learning and Attentional Disorders Society of Western Australia (Inc.)
	Mr Philip Mort	Principal, Atwell Primary School	Department of Education and Training
	Dr Annkathrin Franzmann	Paediatrician	North Metropolitan Health Service
	Dr Bradley Jongeling	Consultant, Community Paediatrician	
	Ms Robyn Oliver	Student Services Area Manager, West Coast Education District	Department of Education and Training
29-Oct-03	Mr Paul Albert	Director General	Department of Education and
	Ms Margaret Banks	Acting Deputy Director General Schools	Training
26-Nov-03	Mrs Sandy Moran	Research Nurse	
	Professor Stephen Houghton	Psychologist/University Professor	University of Western Australia
	Mrs Michele Toner	Executive Officer	Learning and Attentional Disorders Society of Western Australia (Inc.)
3-Dec-03	Dr Michele Larose	Child Psychiatrist/ Consultant	Bentley Health Service
	Ms Amanda Styles	Senior Speech Pathologist	
2-June-04	Dr Fred Baughman	Paediatric Neurologist/ Author	
	Mr Ron Carlisle	Chairman	Citizens Committee on Human Rights

Date	Witness	Position	Organisation
16-June-04	Mr Constantine Berbatis	Lecturer	Curtin University of Technology
	Ms Zoe Mullen	Pharmacist	Pharmaceutical Council of Western Australia
	Professor Bruce Sunderland	Professor of Pharmacy	Curtin University of Technology
	Associate Professor Heather Jenkins	Academic	Curtin University of Technology
23-June-04	Professor David Hay	Professor of Psychology	Curtin University of Technology
30-June-04	Dr Kenneth Whiting	Paediatrician	
20-Aug-04	Associate Professor Trevor Parry	Clinical Associate Professor, School of Paediatrics and Child Health	University of Western Australia
25-Aug-04	Mr Murray Patterson	Chief Pharmacist	Department of Health
	Dr Lois Achimovich	Consultant Child and Adult Psychiatrist	
15-Sept-04	Dr Rowan Davidson	Chief Psychiatrist	Department of Health
APPENDIX THREE

BRIEFINGS

Date	Name	Position	Organisation
07-July-04	Mr Geoff Anderson	Manager, Drugs of Dependence Unit, Drug Programs and Populations Strategies Branch	Department of Human Services, South Australia
	Mr Bill Dollman	Principal Advisor, Pharmaceutical Services, Drug Programs and Populations Strategies Branch	
	Dr Gil Anaf	President	National Association of Practising Psychiatrists
08-July-04	Professor Richard Silberstein		Swinburne Brain Sciences Institute, Victoria
	Mr Jacques Duff	Psychologist	
	Mr Daniel Andrews, MP	Parliamentary Secretary for Health	Victorian Parliament
	Mr William MacDonald	Project Manager, Mental Health Branch	Department of Human Services, Victoria
	Mr Tass Mousaferiadis	Senior Adviser	Office of the Victorian Minister for Health
09-July-04	Ms Sue Lancaster	Project Officer, Early Intervention, Family and Community Support	Department of Human Services, Victoria
	Dr Neil Coventry	Director of Psychiatry	Austin Hospital
	Dr George Halasz	Child and Adolescent Psychiatrist	
22-Sept-04	Ms Josey Hurley	Manager of Student Services	Albany District Education Office
	Dr Harry Dumbell	Visiting Paediatrician	

APPENDIX FOUR

DIAGNOSTIC CRITERIA FOR ATTENTION-DEFICIT/HYPERACTIVITY DISORDER¹⁹⁴

A. Either (1) or (2):

(1) six (or more) of the following symptoms of **inattention** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Inattention

- a) often fails to give close attention to details or makes careless mistakes in schoolwork, work or other activities
- b) often has difficulty sustaining attention in tasks or play activities
- c) often does not seem to listen when spoken to directly
- d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behaviour or failure to understand instructions)
- e) often has difficulty organizing tasks and activities
- f) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)
- g) often loses things necessary for tasks or activities (eg., toys, school assignments, pencils, books, or tools)
- h) is often easily distracted by extraneous stimuli
- i) is often forgetful in daily activities

(2) six (or more) of the following symptoms of **hyperactivity-impulsivity** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity

- a) often fidgets with hands or feet or squirms in seat
- b) often leaves seat in classroom or in other situations in which remaining seated is expected
- c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- d) often has difficulty playing or engaging in leisure activities quietly
- e) is often "on the go" or often acts as if "driven by a motor"
- f) often talks excessively

Impulsivity

- a) often blurts out answers before questions have been completed
- b) often has difficulty awaiting turn

¹⁹⁴ American Psychiatric Association, DSM-IV, 2000, pp.92-93.

c) often interrupts or intrudes on others (e.g., butts into conversations or games)B. Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before age 7 years.

C. Some impairment from the symptoms is present in two or more settings (e.g., at school [or work] and at home).

D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder and are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a personality Disorder).

Code based on type:

314.01 Attention-Deficit/Hyperactivity Disorder, Combined Type:
if both criteria A1 and A2 are met for the past 6 months
314.00 Attention-Deficit/Hyperactivity Disorder, Predominantly
Inattentive Type: if Criterion A1 is met but Criterion A2 is not met for the past 6 months
314.01 Attention-Deficit/Hyperactivity Disorder, Predominantly
Hyperactive-Impulsive Type: if Criterion A2 is met but Criterion A1 is not

met for the past 6 months

Coding note: For individuals (especially adolescents and adults) who currently have symptoms that no longer meet full criteria, "In Partial Remission" should be specified.

314.9 ATTENTION-DEFICIT HYPERACTIVITY DISORDER NOT OTHERWISE SPECIFIED

This category is for disorder with prominent symptoms of inattention or hyperactivityimpulsivity that do not meet the criteria for Attention-Deficit/Hyperactivity Disorder. Examples include:

1. Individuals whose symptoms and impairment meet the criteria for Attention-Deficit/Hyperactivity Disorder, Predominantly Inattentive Type but whose age at onset is 7 years or after

Individuals with clinically significant impairment who present with inattention whose symptom pattern does not meet the full criteria for the disorder but have a behavioural pattern marked by sluggishness, daydreaming, and hypoactivity

APPENDIX FIVE

DIAGNOSTIC CRITERIA FOR HYPERKINETIC DISORDERS - ICD-10

The research diagnosis of hyperkinetic disorder requires the definite presence of abnormal levels of inattention, hyperactivity and impulsivity that are pervasive across situations and persistent over time, and which are not caused by other disorders such as autism or affective disorders.

- **G1** *Inattention* At least six of the following symptoms of inattention have persisted for at least 6 months, to a degree that is maladaptive and inconsistent with the developmental level of the child:
- 1) often fails to give close attention to details, or makes careless errors in school work, work or other activities;
- 2) often fails to sustain attention in tasks or play activities;
- 3) often appears not to listen to what is being said to him or her;
- 4) often fails to follow through on instructions or to finish school work, chores or duties in the workplace (not because of oppositional behaviour or failure to understand instructions);
- 5) is often impaired in organising tasks and activities;
- 6) often avoids or strongly dislikes tasks, such as homework that require sustained mental effort;
- 7) often loses things necessary for certain tasks or activities, such as school assignments, pencils, books, toys or tools;
- 8) is often easily distracted by external stimuli;
- 9) is often forgetful in the course of daily activities.
- **G2** *Hyperactivity* At least three of the following symptoms of hyperactivity have persisted for at least 6 months, to a degree that is maladaptive and inconsistent with the developmental level of the child:
- 1) often fidgets with hands or feet or squirms on seat;
- 2) leaves seat in classroom or in other situations in which remaining seated is expected;

- 3) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, only feelings of restlessness may be present);
- 4) is often unduly noisy in playing, or has difficulty in engaging quietly in leisure activities;
- 5) exhibits a persistent pattern of excessive motor activity that is not substantially modified by social context or demands;
- **G3** *Impulsivity* At least one of the following symptoms of impulsivity has persisted for at least 6 months, to a degree that is maladaptive and inconsistent with the developmental level of the child:
- 1) often blurts out answers before questions have been completed;
- 2) often fails to wait in lines or await turns in games or group situations;
- 3) often interrupts or intrudes on others (eg butts into others' conversations or games);
- 4) often talks excessively without appropriate response to social constraints;
- G4 Onset of the disorder is no later than the age of 7 years;
- **G5** *Pervasiveness* The criteria should be met for more than a single situation, eg the combination of inattention and hyperactivity should be present both at home and at school, or at both school and another setting where children are observed, such as a clinic (evidence for cross situationality will ordinarily require information from more than one source; parental reports about classroom behaviour for instance, are unlikely to be sufficient).
- **G6** The symptoms in G I & G3 cause clinically significant distress or impairment in social, academic or occupational functioning.
- **G7** The disorder does not meet the criteria for pervasive developmental disorders (F84,-) manic episode (F30,-), depressive episode (F32,-) or anxiety disorders (F41,-).

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