Submission to the
the Senate Select Committee Inquiry on Mental Health

by

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on behalf of **LADS'**
Professional Advisory Board,
Management Committee and
Members

"The totality of deficits associated with AD/HD serve to
cleave thought from action,
knowledge from performance,
past and future from the moment, and
the dimension of time from
the rest of the three-dimensional world"
-Professor Russell Barkley-

LADS would welcome the opportunity to appear before the Committee to present our case. Any of the following persons may be called upon to appear before the Committee:

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Background

AD/HD in Western Australia

Attention Deficit/Hyperactivity Disorder (AD/HD) has been declared the responsibility of the Division of Mental Health (DMH) in WA, (formerly the Office of Mental Health, OMH), and is governed by a policy developed by that office in 2002[1]**.** Unfortunately, due to a lack of funding and resources, the multi-modal treatment stipulated in this policy is seldom accessible to families with AD/HD. Furthermore, the policy does not address the issue of AD/HD in adults, many of whom are primary caregivers of children with AD/HD, due to the heritability of the disorder. AD/HD. There appears to be an unofficial policy in the public health sector that that AD/HD adult presentations are not managed at mental health services. Clinicians may see people with AD/HD as not being unwell enough to make them a priority and therefore may allocate their resources elsewhere.

The Education and Health Standing Committee of the WA Parliament conducted a parliamentary inquiry into AD/HD in 2004. **The following are some of LADS concerns relating to the 2004 inquiry** :

- The report stated that WA doctors are prescribing four times as much stimulant medication than doctors in other states[1a.] However, the report **failed to differentiate between prescriptions written for children and adults**. Attempts by **LADS** to obtain copies of the provisional figures provided by the chief pharmacist to the committee in order to clarify this issue were unsuccessful. However, Senator Chrissy Sharp asked the question of the Health Minister in parliament and his response was that **1.8% of children (under 18) in WA are being prescribed stimulant medication for the treatment of AD/HD (Hansard, 25/11/04). This figure is in line with the national average, and the committee had misinformed the public via media conference. Previous incorrect estimates by the govt were that 4.2% of WA children were prescribed stimulants**[1]. The Health Minister also informed Dr Sharp and the parliament that 0.4% of adults in WA are being prescribed stimulant medication for AD/HD. This figure is **four times the amount currently prescribed for adults in NSW**, which is 0.1%[1b]
- The report neglected to address the issue of adults with AD/HD, which is alarming in light of the above figures, and the fact that treatment is not provided for adults with AD/HD in the public health system. Also, although the DMH

policy of 2002 makes provision for paediatric facilities to treat people with AD/HD until they turn 25[1], this does not always happen in public health clinics. **LADS** constantly receives phone calls from 18 year olds who have been given our number by the state clinic and told to 'find a psychiatrist who bulk bills'.

- The relationship between AD/HD and substance abuse was not addressed, with no recommendations relating to this serious issue, although it was one of the terms of reference for the parliamentary inquiry.
- AD/HD was stigmatised in the media as members of the committee made sensational, and exaggerated claims in a press conference called by the committee. Despite **LADS** successful challenge of the committee's figures, they have made no attempt to modify their claims.

The Learning and Attentional Disorders Society of WA (LADS)

LADS is a support, information and advocacy agency, founded in 1993 for people with AD/HD, their parents and families and others affected by AD/HD and associated conditions. The agency recognises the effect of AD/HD and attentional and behavioural disorders across the lifespan. It believes in the value of diverse views and approaches to AD/HD, its causes, effects and treatment and advocates on behalf of its stakeholders, working in partnership with others to ensure appropriate services become available. **LADS** encourages and supports evidence based professional practice and approaches to AD/HD that respect each client and family's rights and needs.

LADS is the leading non-government agency in Western Australia for parents and families affected by AD/HD and associated conditions and is recognised for its commitment to evidence based practice:

"**LADS** is perceived as a credible agency" (Health Dept Feedback, **LADS** Business Plan p33).

"**LADS** is viewed as a well respected and valued agency" (State Child Development Centre Feedback, **LADS** Business Plan p33)

The participation of **LADS** is sought by organisations in national and international professional arenas associated with this disorder. Nationally, the President attends advocacy workshops, and participates in a national "e-group" with organisations from other states. In May 2004 **LADS'** President was invited to Tasmania to speak at the launch of their AD/HD support group. She

attended a workshop for the establishment of a Global Advocacy Network of AD/HD support groups held in Amsterdam in June 2003. She also attended a Global Advocacy Advisory Board Meeting in Paris in June 2004, where she was invited to present on Australian advocacy initiatives.

The participation of **LADS** is also sought in State Govt initiatives, despite the fact that the govt does not fund **LADS**, and has refused numerous requests for funding. In 2004/2005, the president and vice-president of **LADS** participated in an AD/HD working group with representation by several govt depts, which was formed to report to the DMH Clinical Advisory Group (CAG). Currently, **LADS** is also represented on a committee which has been formed by the DMH to oversee the implementation of recommendations made by the recent Education and Health Committee's parliamentary inquiry into AD/HD.

LADS receives no recurrent government funding, despite the fact that it has made many attempts to attract ongoing funding from the Health Department. Its continued existence is constantly in doubt due to its precarious financial position.

The Society is run by a Management Committee of 10 elected voluntary members consisting of a minimum of three professionals, the complement comprising of parents and adults with AD/HD. It is supported by a 20-member Professional Advisory Board, comprising specialists from education, health and allied health services. There is one part time paid position of Executive Officer.

LADS' Interest in the Inquiry of the Senate Select Committee

LADS was officially opened in September 1993 following a one-year government sponsored research program, which clearly demonstrated that services for those diagnosed with AD/HD were inadequate, poorly coordinated and unable to cope with the demands placed upon them. It also highlighted the very poor levels of support and information that were available to individuals and families. **LADS** considers that a great deal of work remains to be done to improve support and services for families and individuals affected by AD/HD.

During the 2003 / 04 financial year, some 220 families received counselling at the **LADS** offices, with over half of these referred to professionals. 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.

LADS thus has a very active interest in addressing the issues under investigation by this Senate Committee. Of particular concern to us is the shortage of services such as behaviour management, family support, remedial tutoring, speech therapy and social skills training, within the public health sector. These services, along with medication when appropriate, form part of the multi-modal treatment of AD/HD which is recognised as best practice by evidenced based research and also recommended by the Western Australian Department of Health's policy document on the diagnosis and management of AD/HD and associated disorders in children.[1] In fact **LADS** supplies many of the recommended services at very reasonable prices.

International Research into AD/HD, and the state of current treatment in WA.

This submission will not address each of the terms of reference outlined for the current Inquiry, due resource restraints. Instead, current scientific research is presented, along with concerns about the level of treatment currently available in WA. It is hoped that this information will address many of the terms of reference.

AD/HD is the most common childhood mental health disorder. Using DSM IV criteria, the prevalence of AD/HD is estimated to be between 8% and 10% of the childhood population. The child and adolescent component of the Australian National Mental Health Survey (2000) established a prevalence of 11.2% in a community-based sample. This study ignored impairment and therefore represents a distorted figure. Postgraduate doctoral research at UWA established a prevalence rate for AD/HD of 7.5% in metropolitan areas and 11.4% in rural areas of Western Australia.[3]

The International Classification of Diseases and Related Health Problems, Version 10, (ICD 10) specifies criteria for the diagnosis of Hyperkinetic Disorder of Childhood. This diagnosis is comparable to only the most severe forms of AD/HD Combined Subtype (as defined using DSM IV criteria). The use of ICD 10 criteria as a diagnostic tool results therefore in a lower AD/HD prevalence rate. Although, ICD 10 mentions AD/HD Predominantly Inattentive Subtype it does not provide criteria for its diagnosis. Furthermore, according to its system of diagnosis the existence of any anxiety disorder or mood disorder, eg depression, dominates over a diagnosis of AD/HD and must be regarded as the primary condition. In effect ICD 10

precludes AD/HD Predominantly Inattentive Subtype as well as AD/HD with comorbid mood disorders.

The WA Mental Health Office policy on AD/HD diagnosis and treatment[1] states that 4.2% of Western Australian children are being prescribed stimulant medication, mostly for AD/HD. However, as previously stated that figure has been shown as inaccurate, and the current figure is 1.8% (Hansard, Legislative Council, WA parliament, 25/11/05). **LADS** is of the opinion that many people with AD/HD remain undiagnosed.

The divergence of public opinion on issues surrounding AD/HD appears to be media driven. Inaccurate stories rendering AD/HD a benign condition leave the public with a general sense that this disorder is not valid or real, or consists of a rather trivial affliction[25]. In the absence of a government policy (until recently), governing the diagnosis and treatment of AD/HD, the media has been allowed to focus on sensationalising the condition. The public needs to be informed of evidence-based practices within the treatment of AD/HD, which would reduce the level of ignorance within the community and dispel the myths surrounding AD/HD.

There is consensus within the international scientific community about the diagnosis and treatment of AD/HD. This is reflected in the International Consensus Statement on AD/HD (2002), which was issued by an independent consortium of leading scientists concerning the status of the disorder. “Among scientists who have devoted years, if not entire careers, to the study of this disorder, there is no controversy regarding AD/HD”[25]

There appears to be much undiagnosed AD/HD in the indigenous population. **LADS** was recently invited to speak to a group of Aboriginal women who reported that the needs of their children and grandchildren with learning and attentional problems were not being met. Currently Dr Tracy Westerman, an NHMRC Health Professional Research Fellow is conducting research in this area.

The most effective treatment for AD/HD is a **multimodal** approach, involving both pharmacological and non-pharmacological interventions[7,8,9,5]. Such treatment should include "simultaneous medication use, behaviour management, family counselling and support, educational management, and specific developmental issues"[9].

Stimulant *medication* (dexamphetamine or methylphenidate) has been prescribed for children with AD/HD symptoms since 1937 when Bradley's study of hyperactive children on amphetamines, showed them to become calmer and more goal-directed than before[36]. The efficacy of stimulant medication in the treatment of AD/HD has been demonstrated in a large body of research. For example, the National Health and Medical Research Council of Australia, reported improvement in AD/HD symptoms in 70-80% of patients on stimulant medication[9]. These included improved working memory, increased work output, on-task behaviour, accuracy and neatness at school, improved social interaction, communication and responsiveness, with aggression restored to within the normal range, and reduced sibling conflict and enhanced parental warmth[11] . The National Institute of Mental Health Multimodal Treatment of AD/HD (MTA) Study[5] noted improvements in core AD/HD symptoms, teacher-rated student aggression and parent-rated social skills in children treated with stimulant medication over a 14 month period. **LADS** members report increased self-esteem in their children who are able to attend in class with the help of stimulant medication. Adults find as a consequence of treatment with stimulant medication that they are able to focus their attention on tasks, a skill which had previously eluded them. Dexamphetamine and methylphenidate are short-acting medications which necessitates several doses throughout the day. Two forms of Sustained Release stimulant methylphenidate are now available in Australia, but are not listed on the Pharmaceutical Benefits Scheme (PBS).

A new, non-stimulant medication (atomoxetine) has been developed for the treatment of AD/HD. Studies have shown that it reduces the core AD/HD symptoms of inattention, hyperactivity and impulsivity, and improves family and social functioning. Symptom reduction lasts into the evening on one daily dose without causing insomnia. Atomoxetine is not listed on the PBS.

Presently, there is only one medication (dexamphetamine) available on the Pharmaceutical Benefits Scheme (PBS) for the treatment of AD/HD symptoms. This means that people with AD/HD are not able to afford the sustained release medications, which are often more effective in the control of their symptoms. Furthermore, the inclusion of sustained release medications

on the PBS would remove the 'black-market' trade in dexamphetamine. It would also make it easier for schools who have the added responsibility of administering midday doses of schedule 8 medications to their students.

Behaviour modification, when used alone has a modest effect on the management of AD/HD[5,9]. However, when combined with medication it becomes the most effective method of reducing the core symptoms of AD/HD[5]. *Social skills training* can also be undertaken to help children understand the impact of their behaviours on others, and to teach them acceptable social practices[12]. In addition, c*ounselling* that involves the whole family has the potential to motivate children with AD/HD, and improve their social skills[13]. Family counselling is beneficial in reducing the parenting and family stresses associated with AD/HD[14], while individual counselling alleviates secondary symptoms such as poor self-esteem[15]. Many **LADS** members who have been treated with stimulant medication alone make notable gains when their treatment is supplemented with counselling at **LADS** or social skills training to which we refer them.

LADS is concerned that the aims of the DMH policy[1], including the provision of multimodal treatment of AD/HD will not be achieved in the current health economic climate. The current weaknesses with regard to the management of AD/HD lie in the lack of provision of expensive behaviour management services specific to AD/HD. The absence of these services within the public health sector is often forgotten and overshadowed by the more emotive debate about prescribing medication for children with AD/HD. Generic behaviour management programmes, such as the Triple P programme serve little purpose, other than to further harm the self esteem of parents whose children have AD/HD, as they are often not effective when applied with children who have problems with inattention, distractibility or inattention. It is important to note that **LADS** offers parenting courses specifically targeting AD/HD behaviours, at a nominal rate for its members.

Counselling, or the services of clinical psychologists are very difficult to access in the public health system. **LADS** members currently report a waiting list of up to six months to see a clinical psychologist or counsellor. **LADS** offers counselling at a reduced rate for individuals and families affected by AD/HD. Clinical psychologists on our Professional Advisory Board also offer group consultations to families in areas where CAMS does not operate.

Comorbidity is the simultaneous occurrence of two or more disorders. Between 50% and 80% of children diagnosed with AD/HD also meet criteria for at least one other disorder[11]. DSM-IV acknowledges the substantial comorbidity of oppositional defiant disorder and conduct disorder, and describes higher prevalence rates of mood disorders, anxiety disorders, learning disorders, communication disorders, and Tourette syndrome co-occurring with AD/HD in children. Tannock[11] cited the following figures for comorbid conditions: Between 40% and 90% of children with AD/HD also display comorbid oppositional defiant disorder, while anxiety disorders and learning disorders occur in 25%, and in 20% of children with AD/HD, respectively. Research by Biederman and colleagues also identified bipolar disorder in 23% of children with AD/HD[20].

It is not uncommon therefore for a child diagnosed with AD/HD to have more than one comorbid disorder. Langsford[3] established that AD/HD is the most comorbid of the school-age disorders referred to school psychologists, giving rise to serious implications for both assessment and management. For example, the diagnosis of AD/HD with comorbid conditions often results in the various conditions interacting to produce deficits and outcomes, which are worse than those associated either with the AD/HD or the comorbid condition[11]. Diagnoses are also complicated by the fact that AD/HD and comorbid disorders have overlapping symptoms. Contrary to this, however, Millberger and colleagues demonstrated that the symptoms of AD/HD can be separated from the symptoms of comorbid depression, bipolar disorder and general anxiety disorder in adults. Finally, there is evidence that stimulant medication is less effective in controlling symptoms of AD/HD when anxiety comorbidities are present[7]. Consequently, the presence of these associated or comorbid conditions has a significant impact on the treatment of AD/HD, and additional medication is often required.

Children with AD/HD and co-morbid conditions are often diagnosed with AD/HD only, while the co-morbid condition goes undiagnosed and untreated. Paediatricians in WA are doing the work of psychiatrists. The *Journal of Paediatrics and Child Health* last year highlighted the lack of facilities for children with mental health problems in Australia: while 18 year olds form almost 30% of the population, no states direct more than 10% of their total mental health funding to this age group. NO states fund systematic crisis assessment teams for children and adolescents. Children presenting to paediatric emergency with aggression and self harm currently receive limited follow-up, although they are at risk of further self-harming and have increased mortality rates. These young children are at risk of mental health problems and substance abuse in adulthood. The child and adolescent component of the Australian National

Mental Health Survey (2000) found that the commonest cause of death in young people was suicide. They also reported the damning finding that 1 in 4 Australian children with a mental health problem was receiving treatment.

Little information is circulated about adult AD/HD. The majority of adults diagnosed with AD/HD are self-referred. Studies show adults with AD/HD displaying high levels of psychiatric comorbidity, consistent with those seen in children and adolescents. Up to 97 % have a comorbid disorder, with 56% displaying four or more, 18% three, 12% two, and 11% one comorbid psychiatric disorder. The most common comorbidities are mood and anxiety disorders (43% to 52%). There is also evidence of oppositional (30%), conduct (20%), and antisocial personality disorders (10%), as well as dependencies on alcohol (27%) and illegal drugs (18%)[21]. Bipolar disorder, Tourette Syndrome[22], obsessive compulsive disorder[23], panic disorder[24], and learning disorders[21] also coexist with AD/HD in adults.

General practitioners need to be informed about AD/HD in adults: this would promote the dissemination of accurate information within the community and decrease the incidence of undiagnosed AD/HD in the adult population

There appears to be no funding and no treatment for adult AD/HD in the public health sector. Many adults cannot afford the fees charged by private psychiatrists to have their AD/HD treated. Many children with AD/HD are cut adrift from the public health system when they turn 18, despite provision in the HDWA policy for paediatricians to continue seeing people with AD/HD up to the age of 25. Also due to the lack of policy addressing the diagnosis and treatment of adults with AD/HD, members of **LADS** report a substantially inconsistent approach to the diagnosis of AD/HD by adult psychiatrists and the absence of multimodal treatment for their condition. Adults are unable to request accommodations in the workplace or tertiary institutions for a disorder which is treated by society with scepticism. **LADS** regularly advocates on behalf of adults with AD/HD in the workplace and educational institutions.

Research has shown that young people and adults with AD/HD are more likely than their non-AD/HD peers to develop substance abuse problems. For those with undiagnosed/ untreated AD/HD, the risk is even greater. However, despite the well-documented efficacy and safety of stimulants for the treatment of AD/HD, an unfounded belief persists among the general public that it creates risks for subsequent substance abuse Two new studies independently concluded

that treatment of AD/HD with stimulants does not lead to substance abuse disorders; rather it actually produces a "protective effect" from subsequent drug and alcohol abuse.

The first study, led by Russell A. Barkley, Ph.D., followed 147 children with AD/HD for approximately 13 years[31]. Barkley's study found that stimulant-treated children had no greater risk of ever trying drugs by adolescence or any significantly greater frequency of drug use by young adulthood. Indeed, stimulant treatment for one year or more may contribute to a protective effect concerning the risk of hallucinogen abuse disorders in adults.

The second study, led by Timothy E. Wilens, M.D., of Massachusetts General Hospital, examined over the course of from 4-15 years, more than 1,000 youths with AD/HD who had participated in one of six long-term studies designed to determine if stimulant therapy for AD/HD can lead to substance abuse disorders[32.] Wilens' study found that stimulant treatment in youths reduced the risk for substance abuse by half. Of similar interest, untreated adults with AD/HD have twice the risk of developing substance abuse disorders, while it appears that treatment reduces the risk to the same as that observed in young adults without AD/HD.

There is no funding for the treatment of those with AD/HD and co-morbid substance abuse, simply because there is no funding for adult AD/HD. Regulations governing the use of stimulant medications for patients with substance abuse issues make it difficult for psychiatrists in private practice to rehabilitate these patients.

Consequences of Untreated AD/HD

The deficits associated with AD/HD come at a great cost to society. Long-term studies have reported considerably poorer academic outcomes for children with AD/HD than for controls. In an eight-year follow-up study of 158 children with AD/HD Barkley et al[28] found that almost 10% had dropped out of school, and 30% had repeated a year. The number of suspensions and expulsions was significantly higher than that of controls, and the levels of academic achievement on standard tests were significantly lower in maths, reading and spelling.

Children with AD/HD encounter problems on the educational and social fronts, and their behaviour is a major cause of disruption in families. They are often rejected by their peers despite their best efforts to socialise. This sometimes results in a significantly lower rate of extracurricular and community activities amongst youths with AD/HD, as they curb their social contact to avoid unpleasant consequences[27].

Follow-up studies of adults with AD/HD report significantly lower educational attainment, occupational rank, and socio-economic status[29,30]. Adults with AD/HD choose jobs with flexible hours and frequent breaks, thereby allowing them to work with some autonomy. They seek employment in areas of high personal interest and avoid careers that highlight their weaknesses[33]. Perhaps this is why many are self-employed[29]. Adults with AD/HD frequently quit or lose their jobs[26].

Parenting stress in families of children with AD/HD is high, and this is receiving increased attention in the research literature. Parents of children with AD/HD report higher levels of depression than the control groups in both mothers and fathers[34,14,35]. 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 than control families[14].

It is important to note that **LADS** already provides many of the services referred to in the Policy with regard to "ensuring parents or primary caregivers have access to a range of support services, including parenting programs, respite care and behaviour management workshops"[1]. Examples of workshops offered by **LADS** include:

- Effective Nutrition for AD/HD (Facilitator – Nutritionist/Dietitian)
- Parent as Coach (Facilitator – Teacher/Life Coach)
- Aussie Optimism – Optimistic Thinking for 12 to 16 year olds (Facilitators – Curtin University Masters Students under supervision)
- How to Manage your AD/HD Child (Facilitator – Clinical Psychologist)
- Strategies for Parents of Students with AD/HD. (Facilitator – Educational Consultant)
- Organisational Strategies for AD/HD (Facilitator – Clinical Psychologist)
- AD/HD and Depression (Facilitator – Psychiatrist)

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APPENDIX

EXTRACT FROM LADS BUSINESS PLAN 2003-2007

PART A: LADS STRATEGIC BUSINESS PLAN

Agency Identity (How LADS sees/defines itself as an agency)

Founded in 1993, **LADS** is a support, information and advocacy agency for people with AD/HD, their parents and families and others affected by AD/HD and associated conditions.
LADS aspires to be the leading non- government agency in Western Australia for parents and families affected by AD/HD and associated conditions and to be recognised for its commitment to evidence based practice.

Vision (The future LADS wants to achieve for individuals, families, society and the agency)

LADS's vision is that by 2007:

- **LADS** will be recognised as the leading non-government agency for AD/HD and associated conditions.
- The suffering of people with AD/HD, families and others affected by AD/HD and associated conditions will be recognised and acknowledged.
- The negative impact of AD/HD will be reduced.
- AD/HD will be recognised as a condition by professional groups and the society at large, resulting in reduced stigma.
- Multi modal treatment as well as related services will be available and affordable to children, youth and adults with AD/HD throughout the lifecycle, and to people affected by AD/HD.
- **LADS** will be financially secure with recurrent funding.

Purpose (The need or problem that LADS is trying to address/Why LADS exists)

The Purpose of **LADS** is to improve the lives of people affected by AD/HD, attentional and learning disorders and related conditions.

Mission (What LADS does)

The Mission of **LADS** is to provide support, advocacy and accurate information to members, parents and families and people affected by learning and attentional disorders, to advocate on their behalf and to work in partnership with others to ensure appropriate services are available.

Values/Principles (The things LADS believes that underlie everything it does)

LADS is committed to the following Values and Principles:
Voice: LADS will provide a voice for people whose lives are affected by AD/HD and associated conditions.
LADS acknowledges and values the significant experience and expertise of people with AD/HD, their families and those affected by the condition and recognises them as a critical and legitimate source of knowledge.
Advocacy: LADS will ensure that the concerns and views of people with and affected by AD/HD are accurately presented to the media, clinicians, service providers, politicians, policy makers and services.
Lifespan: LADS recognises the effect of AD/HD and attentional and behavioural disorders across the lifespan.
Recognition/Understanding: **LADS** believes that greater understanding about AD/HD will benefit people with and affected by AD/HD, as well as the community as a whole. **LADS** will promote more informed understanding of AD/HD in the community.
Diverse Approaches and Evidence Based Practice: LADS believes in the value of diverse views and approaches to AD/HD, its causes, effects and treatment. **LADS** encourages and supports evidence based professional practice and approaches to AD/HD that respect each client and family's rights and needs.
Involvement/Participation: People affected by AD/HD will be involved in establishing the direction of the agency, its management and its operations.
Balanced Debate: LADS encourages and promotes balanced and informed debate on AD/HD. **LADS** believes in presenting views and positions supported by evidence, rather than ideology and populist rhetoric about AD/HD.

Affordable and Accessible Services: LADS believes that all people affected by AD/HD have a right to appropriate services. **LADS** works towards making those services accessible and affordable to those who need them.
Reduce Suffering and Harm: LADS believes in reducing the harm and suffering that result from AD/HD and associated conditions.
Partnerships: LADS will work in partnership with agencies, groups and services concerned about and interested in AD/HD.
Accountability: LADS will demonstrate accountability and integrity in meeting its responsibilities and commitments.

Target Groups (Who LADS exists to serve)

LADS target groups include its members, children and adults with AD/HD, parents and family members of people with AD/HD and others affected by attentional, learning and behavioural disorders and associated conditions.

Key Strategic Issues for LADS

Strategic Issues are "big picture" issues that affect the future and the viability of **LADS** and shape where it is going and how it should respond.
The following issues were identified during the Planning process and the Strategic Business Plan has been developed in response to these issues.

EXTERNAL ISSUES

Relationships with Government Departments and NGO's:

- Responsibility for addressing AD/HD rests with many government agencies and private providers. No one government agency is responsible for responding to AD/HD with the result that responsibility is shifted around.
- **LADS** needs to establish productive relationships with a number of Government agencies including the Education Department, Department of Justice, Department of Health (Office of Mental Health), Department of Community Development and Disability Services Commission.
- **LADS** is currently not listed on the Health Department's preferred providers list and this needs to be redressed.

Services:

- Existing Government services look at AD/HD from their own perspective and there is a need to promote a much broader perspective on AD/HD.
- There is a lack of affordable services for people affected by AD/HD.
- Mainstream services tend to put up barriers to people.
- Few services exist for Children & Families and where they do exist they are unaffordable for some people. There is considerable unmet need and the demand for service is growing.
- There is a growing need for services for Adult AD/HD. Once people turn 18 the only services available are from private providers which are too expensive for some people.
- Few service providers are trained in multi modal approaches.
- More specialist services are needed such as Occupational therapy, Speech therapy, support, counselling and parenting skills.
- There are few services outside Perth.
- People's ability to access service is determined by their capacity to pay.

Policy:

- The new State Government policy on AD/HD represents an important opportunity for **LADS**.
- **LADS** needs to have more influence over policy and resource allocations for AD/HD.
- There has been a shifting of responsibility for responding to people affected by AD/HD from the public and private system to an unfunded volunteer agency.
- AD/HD is not formally recognized as a disability with the result that people cannot access disability services and funding.

Diagnosis and Treatment Issues;

- The number of people diagnosed with AD/HD is increasing.
- 70% of people with AD/HD have a co- morbid condition.

Effects on and Costs for Families:

- AD/HD has a significant negative impact on families. **LADS** could document and highlight the real costs to families and develop a pilot family project to support and strengthen families.

Issues in the wider community:

- There exist negative perceptions and a lack of understanding about AD/HD in the wider community.
- The over-focus on medication distracts from balanced discussion and debate.
- There is considerable misinformation and stigma attached to AD/HD.
- Different ideologies, values, philosophies and assumptions exist about AD/HD in the community and among service providers.
- Greater awareness and understanding are needed to address stereotypes about people with AD/HD in the workplace.

Profile, Influence and Legitimacy:

- **LADS** needs to have a higher profile and greater influence. Professional legitimacy is also important.

INTERNAL CHALLENGES

Financial Viability:

- Agency viability is a constant struggle which could be resolved with secure funding. **LADS** needs to secure recurrent funding.
- **LADS** also needs to secure multiple funding streams and not be reliant on one stream or funding from one government department.

Membership:

- **LADS** is a membership driven agency and needs to remain responsive to its members' needs. It also needs to maximize use of its member's expertise.

Demand for Services:

- There is increasing demand for the agency's services, but due to its limited financial resources **LADS** has limited capacity to respond.

Mandate:

- The mandate of the agency is broader than AD/HD as people with AD/HD often have other co-existing problems.

Volunteers:

- The agency is heavily dependent on volunteers. Getting enough skilled volunteers to do the work will continue to be a challenge. Volunteer development and training therefore has to be a priority.

Conflicting Ideologies and Views:

- Very different and conflicting views and ideologies exist about AD/HD. **LADS** has to reconcile these shifting and conflicting views, professional assumptions and ideas about AD/HD and provide the best response.

Administrative Systems:

- **LADS** needs to participate in the management and development of The Niche.
- **LADS** needs to improve its protocols and procedures including:
- Clarification of roles and responsibilities;
- Preparation of Executive Officer job description;
- Annual review and updating of **LADS**'s procedures manual for all **LADS** operations and activities.

Agency Strategic Ends and Goals

Strategic Ends are "big picture" outcomes that **LADS** wants to achieve. These will address the strategic issues facing the agency, provide direction to the Board/Management Committee, EO and volunteers, and provide the basis for monitoring **LADS** performance. The Strategic Ends form the basis of the Agency's Strategic Business Plan.

Over the next three to five years **LADS** will work to achieve the following four Strategic Ends and fourteen Goals:

1. To be a financially viable and effective agency recognised for its expertise and experience.

Goal 1: Ensure financial stability
Goal 2: Develop membership and volunteer base
*Goal 3: Increase the profile and visibility of **LADS***
Goal 4: Ensure agency legitimacy and quality control

2. To enable children and adults with AD/HD and associated conditions, and those affected, to access information, support and services appropriate to their needs.

Goal 1: Provide support, advocacy and counselling services to people with AD/HD, parents and family members.
Goal 2: Link people to services and information appropriate to their needs.
Goal 3; Identify services required and advocate and lobby for those services.
Goal 4: Develop and disseminate information and resources.
Goal 5: Identify and develop innovative projects in response to needs.

3. To engage agencies and service providers including health, medical and education professions working with and for people affected by AD/HD and associated conditions.

*Goal 1: Enhance **LADS** influence on relevant policies and programs*
Goal 2: Develop partnerships with key Government Departments and agencies
Goal 3: Promote Evidence based practice
Goal 4: Develop early intervention capacity.

4. To contribute to social and community understanding and acceptance of AD/HD and associated conditions.

Goal 1: Increase public understanding of and reduce the stigma and misinformation associated with AD/HD and associated conditions