SUBMISSION TO THE SOCIAL DEVELOPMENT STANDING COMMITTEE, SOUTH AUSTRALIAN PARLIAMENT
AUGUST 2001

NAPP SUBMISSION ON ATTENTION DEFICIT HYPERACTIVITY DISORDER

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THE PROBLEM

The core of the problem is rising prescription rates of amphetamines. This is a problem because it appears at times to be the only treatment being made available to ADHD diagnosed children. That in turn is a problem because:

1. The internationally recognized treatment[1] would appear to be inaccessible to many patients; and
2. The status of ADHD as a discrete diagnostic entity is controversial.

The result is that other conditions are being misdiagnosed as ADHD and that children are unnecessarily being given powerful drugs which can substantially affect their emotional development. The influence of the major drug companies in marketing strategies using professional publications is heavily underestimated.

Other important aspects of the problem are that:

1. Psychotherapeutic expertise is not available in the public health system and this leaves a hole in public education strategies. In the private system these strategies are difficult to access because of restrictive Commonwealth financial arrangements. This is part of a larger social justice issue; and
2. The fact that about 90% diagnosed ADHD children are male. This suggests that there may be an inappropriate cultural and/or educational element in diagnosis or misdiagnosis.

SUGGESTED SOLUTIONS

- Child psychotherapeutic expertise should be reinstated into a core component of assessment and possible treatment of alleged ADHD children and made more accessible, if needed, to those correctly diagnosed and, in addition, other allied conditions currently diagnosed as ADHD;
- To this end, a transparent career path for child psychotherapeutic professionals should be created within the State Department of Human Services;
- The Department for Human Services should create a multi-disciplinary framework dedicated to the management and treatment of childhood disorders including but not limited to those within the education system and headed by professionals with multi-disciplinary specialist training. Those are likely to be child psychotherapeutic professionals because of their education and training;
- The Education Department should keep accurate statistics on the number of children required to attend focus rooms and whether or not these children are medicated with amphetamines.

A NOTE OF CAUTION

Amendment of the State *Equal Opportunity Act* to include ADHD diagnosed individuals may be counterproductive. Experience from overseas, where this has been done shows that the effect may well be to encourage inappropriate diagnosis of ADHD because of perverse financial incentives.

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[1] The question of the exact nature of the internationally recognized treatment will be discussed in the body of our submission.

Preamble

The National Association of Practising Psychiatrists (NAPP) is of the view that this enquiry by the Social Development Committee is to be commended in seeking to address issues that are vital to the welfare of our children. To quote from the Mental Health Statement of Rights and Responsibilities , "supporting the community in improving the mental health of its members is a major investment in all aspects of community life.." (p vii).

In seeking to address the Social Development Committee on the issue of Attention Deficit Hyperactivity Disorder (ADHD), we would respectfully ask that the Committee bear in mind that our organisation (NAPP) is comprised of *practising* psychiatrists. We speak from the position of *clinicians* who hold the interests of the patient to be paramount. We maintain that ADHD is a complex clinical, scientific and societal problem. We also hold, perhaps more importantly, that resolution of the issue of increasing rates of prescribing practice for ADHD will depend on an appreciation of the political and economic forces that are brought to bear on patients, their families, and service providers.

NAPP is aware that investigation into the complexities surrounding ADHD has already been reduced, in some quarters, to an overly simplistic notion of "doctors overprescribing". We feel it would be unfortunate if that were to become the "5 minute news grab" from this enquiry, as the truth is rather more complicated; scapegoating a profession for what is in essence a policy issue will not help families already in distress.

Healthy emotional development of children is the bedrock of our society and the requisites for this have been, and will remain, unchangeable. These are times of accelerated change and this is likely to increase, as are economic and political forces that threaten the notion of the importance of the individual. If we are to be advocates for children into the future, as we were in the past when we spoke for their needs in regard to separations in hospitals, child care and the family court, then it is imperative that the emotional needs of children are not forgotten.

In a society plagued with problems such as youth suicide and drug abuse, depression and antisocial behaviour, it is our responsibility to not forget what we already know - that children who have stable and secure relationships with their parents (Bowlby), and who can play, and thereby develop a strong sense of self and purpose, tend not to run into these problems.

A recent study of 12,000 adolescents from 80 high schools across the United States, has found that young people who indicated a strong sense of bonding, closeness and attachment to family, regardless of the nature of that family - single parent, dual parent, adoptive family, (and this was corrected for class and income), have lower levels of smoking, drinking, drug use, suicidal thinking and behaviour, risky sexual behaviour and exposure to violence. These adolescents also felt more closely connected with school and teachers (Resnick MD, Klein JD).

It follows then, that an appreciation of the importance of family attachments (what strengthens them and what weakens them, irrespective of the nature of the "family") and a thorough knowledge of the stages of normal development must underpin any assessment of children with any disorder - be it physical, emotional, behavioural or learning disorders.

Prior to addressing the Terms of Reference in order, we will detail an actual (de-identified) case study that illustrates the issues we face as clinicians - these necessarily inform the approach in our submission.

Case History - A Second Opinion.

Justin aged 11 sat calmly, withdrawn, during the first assessment meeting with his parents doing most of the talking. His parents reported that he had been an 'impulsive' and at times 'aggressive' child both at home and school. They told me that he was diagnosed with ADHD aged 6. His developmental paediatrician prescribed Ritalin, two tablets in the morning and half tablet at midday. After starting medication, Justin's behaviour had improved dramatically. Both parents, as well as Justin, were relieved.

Regular medical follow-up was arranged along with speech pathologist, paediatrician, occupational therapist, and optometrist. At school, special educational support was started.

After five years on medication, his aggression persisted, although he was less disruptive, but the parents were concerned with his struggle with school's educational demands and his relationships with siblings and parents. The parents reported that Justin did not want to do his homework because he was 'unmotivated', and that he was easily provoked to rage by siblings. A second opinion was then sought.

Second opinion

During the lengthy four session assessment, Justin's developmental history elicited the following relevant facts whose significance had been previously ignored. Justin was in fact not unmotivated, but he was clearly a stubborn, opinionated and defiant youngster. During the meetings it emerged that neither parent, based on their own traumatic and inhibited patterns of family relationships, had the capacity to recognize ordinary defiance, let alone have the psychological resources to respond appropriately to Justin's testing manner. The reasons for the parental sense of lack of confidence were complex, but the transgenerational history helped me understand and to explain to them the relevance of how they responded to Justin's immediate behavior.

First, mother was diagnosed and treated with psychotic depression after Justin's birth. Second, to support mother during her depressive illness, Justin had three live-in caretakers, each for a period of about 2-3 months. Third, aged 3 and starting kindergarten, Justin was noted to have speech delay. Fourth, the birth of a sibling around this time resulted in Justin becoming a 'bully'.

During my assessment sessions, I could see the stresses that Justin's parents lived under, stresses that were exacerbated by mother's depression. Although one could understand the need for her to obtain additional help to assist with parenting her baby, the family were never helped to lessen the impact <u>on child development</u> of both maternal depression and the legacy of early, multiple care-takers.

The parents were genuinely surprised when I pointed out how these experiences can affect their child's later capacity to develop secure relationships, in particular his risk to develop attachment disorders characterized by anxiety, or more serious disorganization and disruption. Dr Isla Lonie, past president of the Australian Association of Infant Mental Health observed how many professionals also either are unaware or tend to ignore this link between early attachments and later psychological symptoms

At this point, a skeptic could misrepresent my second opinion as highlighting that with time, most families could disclose disruptive events in their children's early childhood that could be construed later to need psychiatric intervention. That would be a distortion of the clinical facts - facts which demonstrate the fundamental need to assess children with ADHD 'symptoms' in a family and developmental context.

Justin's history highlighted a series of experiences of deprivation of stable care. That deprivation resulted from the well-intentioned replacement of the unavailable maternal care (due to maternal depression) with a series of substitute transient carers. Those episodes of making and breaking of substitute attachments in infancy can result in later attachment disorders, whose symptoms of impulsivity, aggression and lack of focus and concentration may mimmick ADHD. In short, the symptoms can be seen as the child's protest at disruptions to his / her attachment bonds, and an attempt to reinstate stability.

The later symptoms of chronic disruptions in early phases of attachment (0-3 month is the phase of undiscriminating social responsiveness; 3-7 months, the phase of discriminating social responsiveness; 7 months to 3 years is the phase of active initiative in seeking proximity and contact) may result in the child's later difficulty in regulating his behaviour, mood and relationships, which the Hon. M J Elliott noted in his speech.'The pressures faced by families affected by ADHD, sometimes over successive generations, can threaten family affection, cohesion and survival.'

We are not of the opinion that such transfer of symptoms across the generations must be thought to occur <u>only</u> in the form of genetic transmission. Current studies that explore the 'infants' display of particular attachment patterns has deepened our understanding of the intergenerational transmission of attachment.' (Lyons-Ruth et al)

These views support the Hon. Mr Elliott's concern that pressures can, if left unattended or misdiagnosed by the professionals, be passed on from generation to generation. The reliance on medication in ADHD, as Justin's case highlights, in the short term may reduce problematic behaviours, but in the long term, initial misdiagnosis, overmedication or inappropriate medication may result in the pressures being compounded for the child and the family.

Justin's parents benefited greatly from discussions that facilitated increased empathic listening skills and patience - these discussions were <u>*only*</u> *possible because they were able to be based on an understanding of why each parent had difficulties in this area, and this understanding was then able to be put to Justin's parents in a non-threatening way.*

The end result was a marked decrease in Justin's aggressive outbursts.

We now turn to the Terms of Reference in this enquiry.

1. Recent stimulant medication prescription practices and trends.

The ADHD controversy is centered on the clinical, scientific and social phenomenon that has resulted in increasing numbers of younger children, some under the age of five years, being prescribed powerful mind-altering (psycho-stimulant) drugs. National figures reveal the dispensing of Ritalin (methylphenidate) throughout community pharmacies in the calendar years 1990-1998 (public hospital drug use figures are not included) rose from 24,335 to 345,868, while dexamphetamine jumped from 9,937 to 248,286**, a twenty-four-fold** increase . Prescribing rates differ from state to state, and within each state, from area to area. It seems that there is an over-representation of ADHD prescriptions in the northern and southern suburbs of Adelaide. The number of children being medicated for treatment of ADHD within South Australia is understood to be in the order of 5500.

Dexamphetamine PBS prescriptions, state by state. Methylphenidate is not on PBS

<u>State</u>	NSW	Vic	Qld	**SA**	WA	Tas	ACT	NT
1992-93	6253	1590	2555	**2250**	3450	191	190	80
1999-00	69312	35761	32290	**22446**	71510	8226	2891	960

The South Australian figures show a nearly tenfold increase from 1992/3-1999/2000.

2. Appropriate diagnosis and treatment protocols

Do these prescription rates represent a genuine increase in ADHD? What other explanations may account for the increase? And what exactly is ADHD? These important questions are addressed by an overview below that outlines areas of contention in this debate, and this is divided into *issues in diagnosis* and *issues in treatment.*

Issues in Diagnosis
Although ADHD is the most diagnosed childhood condition in the US, the prevalence of ADHD in Australian children is reported to be between 2.3 -6% (NH&MRC).

The impact of medication on symptoms is to reduce behavioural problems following medication with Ritalin or dexamphetamine. Yet major debate centres on the 'scientific' status of ADHD. The symptoms of ADHD include **inattention, impulsivity** and **hyperactivity** to a level that impairs social, academic and occupational function. But as Jureidini has noted "this symptom cluster can be reliably identified…but reliability of identification does not entail validity *as disease"* (italic ours). He adds further, that "there are no neuropathological correlates of ADHD" and that therefore, the diagnosis of ADHD must be a diagnosis of exclusion (given that there are many reasons why a child might be overactive, varying from the understandable and transient, to the entrenched and pathological).

ADHD is a disorder of unknown aetiology, with a number of theories as to the possible underlying pathology coming out of increased understanding of neurobiology.

The key principle of developmental neurobiology is that the brain develops and organises itself as a reflection of developmental experiences, organising in response to the pattern, intensity and nature of emotional, sensory and perceptual experience. The quality of the attachment bond (*see illustrated case)* between the primary caregiver and infant determines the maturation of the infant's brain, specifically the maturation of the structural connections within the areas that come to mediate both the interpersonal and intra psychic aspects of all the child's future social and emotional functioning (Shore). Perry of Baylor College of Medicine in Houston says: "experience is the chief architect of the brain", and it is via the experiences of the individual that genes exert their effect. His group found that children who don't play much or are rarely touched develop brains that are 20% to 30% smaller than normal for their age.

The experience of the traumatised child is fear, unpredictability, frustration and the traumatised child's template for brain organisation is the stress response. In the developing brain neurotransmitters play an important role in basic developmental processes. Young children, victimised by trauma are at risk for developing permanent vulnerabilities - changes in brain organisation- and these alterations in brain development have an impact on all aspects of emotional, cognitive and behavioural functioning (Perry)

There is overwhelming evidence suggesting sensitive, if not critical, periods for brain development and function associated with mental health - including attachment, modulation of feelings, anxiety regulation and behavioural impulsivity. The brain's greatest period of growth spurt draws to a close around the age of 10 years. This is critical in planning early intervention and preventative programs, for there is also compelling evidence that the brain is plastic and capable of great changes, under the influence of experience (*hence the imperative for appropriate treatment resources).*

One opinion of causation then, is that ADHD is caused by developmental delay in the regions of the brain that control self- regulation. Work in the United States by Rapaport and Yelich has confirmed that ADHD may be caused by developmental delay but has *dismissed the popular opinion that response to medication is proof* of the existence of ADHD. In fact, they found that *all children* respond to stimulant medication with increased self-control and attention. So, response to psychostimulants is not proof of a biological cause of ADHD.

The Committee will understand, therefore, that in NAPP's opinion the cause of ADHD is a complex interaction between the environment (family, peers, school etc), and the individual child's genetic vulnerability, temperament and so on. We take issue with views expressed in some quarters that seek to portray ADHD as a *purely physical* disorder; it is no more a purely physical disorder than say, depression. This view takes from the complexity of the issue, and protocols can only be developed from an understanding of this complexity.

It is for this reason that the Australian National Health and Medical Research Council's Attention Deficit Hyperactivity Disorder Report recommend a range of tests and treatments for ADHD, *and not the prescription of medication alone*. These tests centre on a checklist of behaviours [detailed in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)] which must be exhibited in both the home and school environment. Due to the similarity of behaviours resulting from other disorders, there have been cases of misdiagnosis.

To underscore the difficulty in diagnosis, 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 mimick or coexist (comorbid) with ADHD. Behavioural changes can include disruptive or erratic, unfocused behaviour. From a simplistic perspective, such behaviours fulfill DSM IV criteria for ADHD. A number of psychological conditions in childhood share the symptoms of 'attention deficit' and 'hyperactivity'. Children's attention can be compromised in a number of settings in medical/psychological conditions such as 'minimal brain dysfunction' (a term used in the past to describe an immature state of the central nervous system); intense grief reactions; moderate or severe depression; post traumatic stress as occurs after physical or emotional abuse; and times of family crisis or chronic family dysfunction.

It is worthwhile reminding ourselves that DSM, in all its versions, was only ever intended to be a tool to enhance communication amongst researchers and clinicians. Yet, it has assumed a status where some professionals assume that its operational criteria define conditions as 'proven'. However this trend has been strongly challenged in the US. For example, the US National Institute of Health's ADHD consensus statement concludes that: the '*unproven*' status of the disorder (ADHD) *'should give pause to both researchers and clinicians who may have reified ADHD as a 'true entity'* (rather than a *working hypothesis* that serves scientific, communication, and clinical decision-making

purposes) - (Jensen). The 'scientific' status of ADHD therefore seems to be 'on hold'. Yet, recent books and reviews persistently refer to ADHD as if it was 'proven'.

The current trend to diagnose a child by his behavior, *rather than the meaning of that behavior,* is a complicated issue that perhaps has its roots in a wish for simple explanations or perhaps has a basis in the understandable wish of parents / society to seek a "biological" explanation rather than a more comprehensive assessment of emotional development that would include a compassionate self-assessment of one's parenting style.

NAPP feels therefore, that diagnosis of ADHD must be by exclusion; must be accompanied by appropriate investigation to rule out other similar conditions; and must never be made by the "tick-a-box" method where there is no regard for developmental issues. Neither do we feel that ADHD is to be diagnosed by a "trial of medication" - improvement does not equate to diagnosis.

Issues in Treatment
In discussing treatment issues, we reiterate our clinical position that treatment must be based on sound fundamental knowledge of emotional development *(see case illustration).*

As we are living in times when the quick, cheap cure is increasingly becoming imbued with moral meaning, and there is ever more sophisticated pharmacology, we can not afford to forget that children and adults are different not merely in degree *but in kind*. This knowledge is a necessary precondition to treating children. Children, and many adolescents, cannot communicate complicated feelings directly, they cannot conceptualise complex or abstract ideas and express feelings at a verbal level. Children are brought to us most often because their behaviour is disruptive to an adult, sometimes they are brought because they have learning problems, and only rarely because someone thinks they are unhappy or unduly anxious. Disturbed behaviour or aggression, arousing alarm or anger in other people, restlessness, difficulty concentrating , may be the first indication that a child is struggling with an emotional disorder - to upsetting life experiences past or present and to emotional turmoil.

When patients are ill, and especially so when they have psychological illness or emotional pain, feeling understood is often a precondition for the amelioration of symptoms, *even in those situations where medications are indicated*.

The current system - DSM- is a medical model based on the organic <u>disease</u> analogy for considering behavioural and emotional disturbance. This system fails to grasp the developmental significance of the attachment history, the role of experience is relatively neglected, as is early adaptation or processes of change in childhood. The repertoire of the developing child to express psychic pain and distress is limited - behavioural and emotional disturbance reflects a succession of adaptations that evolve over time, in the same way that occurs with normal development (Sroufe).

Research of Sroufe et al showed that changing support for caregivers and changing the relationship status of these children with caregivers were the most consistent predictors of

change in child behaviour problems. As the primary caregiver's relationship stabilised or destabilised, the child's manifestation of attentional and hyperactivity problems changed.

On the other hand, NAPP is of the view that stimulants are not specific in their effect - indeed, Jureidini notes that research indicates that "the response of normal boys and men (to stimulants) did not differ importantly from those with ADHD". He further goes on to add that a marked behavioural rebound effect (on cessation of stimulants) is often confused with a re-emergence of symptoms thus leading to an escalating cycle of prescribing. Jureidini is quite clear that "a child with ADHD should never be treated with stimulants until there is an explanation for overactivity, or at least until all major pathology has been excluded" (p 202). NAPP holds then, that the prescription of stimulants should be a last resort, to be used in exceptional circumstance, though we acknowledge that there might be a role for judicious use as a "circuit breaker" in the context of other interventions.

So what are these "other" interventions, and on what are they based ?

There are many things we do know, and they have been known by many people for a long time: children grow up and develop, *and develop problems*, in the context of their significant relationships - parents initially, siblings, teachers and peers. If we want to help children with problems, we need to know what's going on in their lives at present, and their past history - what has contributed to their development, their personality and their symptoms. We need to know what's worrying them, and we won't often be told directly, we need to be able to interpret them. Treatment of disturbance, like development, becomes meaningful in the context of a relationship based on rapport and understanding and the experience of being understood makes the patient more accessible to whatever interventions we feel are appropriate or possible.

There's no doubt that powerful psychotropic drugs will influence a child's (and adult's) behaviour, and sometimes their mood. This neither confirms a diagnosis nor in many instances justifies their use. A child's brain, their mind and personality, is evolving and modifiable in structure and function, by experience for a long time.

If we can modify their environment, their relationships, and offer an opportunity for growth of the personality so they can think about problems that arise rather than just react to them, be helped to tolerate unpleasant affects and to develop a capacity to symbolise conflicts in words and play, they will be better prepared to face life in the future as adults.

As Jureidini states,"there is no stronger influence on children than the quality of their parenting". While he, and NAPP, acknowledge that there is a lot to be gained by reducing the burden on parents of unacceptable or overdeveloped guilt feelings in relation to parenting, nevertheless we must as clinicians understand that families are pivotal to a child and their emotions, just as schools are, or peer relations. To do otherwise is to delude ourselves and thereby betray the welfare of our children.

Treatment issues then, if they are to be truly effective and are to work in the interests of the child, need to include a broad range of options. Now this is not necessarily, in NAPP's opinion, what is referred to as "multi-modal treatment". If one looks closely, we find that "multi-modal treatment" has become something of a catch-cry, but what is defined as "multi-modal" is in reality an arguably constricted range of initiatives. According to the NH&MRC protocols, management is based on the following:

4 Medication

- 4.1 Rationale for use of medication
- 4.2 Stimulant medication
- 4.3 Non-stimulant medications
- 4.4 Medication compared to and combined with other treatments
- 4.5 Medication for ADHD in special populations and with other disorders
- 4.6 Monitoring of medication prescribing

5 Educational management

- 5.1 Educational problems encountered by ADHD children
- 5.2 Overcoming learning difficulties
- 5.3 Education policy issues

6 Behaviour management

- 6.1 Behaviour modification
- 6.2 Cognitive behaviour therapies
- 6.3 Anger management training
- 6.4 Family intervention

When we look more carefully at "Behavior Management" (6.1 - 6.4), NAPP finds very little intervention based on the developmental underpinnings as detailed in our submission. No mention is made of the invaluable role of child psychotherapeutic approaches, and this is unfortunately reflected in policy statements more generally.

NAPP openly acknowledges the value and effectiveness of behavioural and cognitive techniques in management. However they have arguably become an "all - or - nothing" approach, their appeal perhaps lying in a perception that they are quick or easy to introduce into most settings. NAPP however is mindful that entrenched problems in children and their families can often require individual and / or family therapy. The NH&MRC protocol for family intervention amounts to little more than providing information and more behavioural training.

NAPP cannot state too strongly, in regard to treatment protocols, that not only must we re-establish understanding children as the cornerstone of treatment, but that policies must encourage an expansion of psychotherapeutically informed strategy. **To divorce behavior from its meaning in children is to be "penny wise but pound foolish".**

Stimulant use has been around for long enough that we are seeing some of these treated patients in their early twenties. They are then being diagnosed as borderline, anxious, etc. Having been untreated (psychotherapeutically) for so long, it then becomes necessary for this new generation of patients to provide longer term intensive treatments at greater cost to the community at large and to the individual in particular.

A fundamental issue in providing what NAPP calls true "multi-disciplinary treatment" is that there should be, in policy and in effect, explicit respect for differing expertise in differing fields. NAPP feels very strongly that current policy is more about encouraging competitiveness, increased economies, and undermining the development of expertise. Competition policy has no place in medical practice, and the desirability of economic downsizing of the health sector is a matter for the community to debate in an informed manner.

True multi-disciplinary assessment of all children, with or without ADHD, should include protocols that facilitate discussion of the issues of individual patients between all the service providers (such as psychiatrists, paediatricians, psychologists, speech pathologists, teachers, occupational therapists, nurses, etc). Given NAPP's continuous emphasis on context and meaning in a child's life, on understanding and working through problems in the family or the child, we feel it is imperative that the devaluing of psychotherapeutic expertise in our child psychiatry training be reversed forthwith, and that this be supported in policy.

In practice, the provision of these services might range from having such experts train and work in our public hospital settings (eg consultant positions for child psychoanalysts might be seen as a necessary repository of expertise) or private settings, to their educating teachers and health professionals, right through to informing the various approaches and parenting assistance programmes that were once available through our child welfare agencies. To quote from the Mental Health Statement of Rights and Responsibilities , "the consumer has the right to expect that educators…and other non-health professionals will receive sufficient education to enable them to recognise and refer…".

We reiterate our position that behavior therapy is not all that should be available, and that expertise in other areas should be immediately reestablished as imperative in management strategies.

3. Accessibility of Multi-Modal Treatment

As noted above, NAPP feels that the issue of access to treatment omits the important point of *what* treatment is required by each individual child. We reiterate our view that "internationally recognised multi-modal treatment" is different to what clinicians at the coal-face think of as appropriate intervention.

Access to a range of treatment options that are informed by developmental understanding would seem to be self-evidently desirable - eg a clinician might well feel that many

children and their families referred for "ADHD" might benefit from parenting support programmes of the kind that were <u>once</u> available, rather than opt for the prescription pad as a first option.

In essence, the definitions of "multi-modal treatment" seem to be talking about something that used to be called a "multi-disciplinary approach" which all professionals agreed with. This point is not a semantic one since, if one examines the operational views of the "multi-modal" approach one sees that there is a very heavy reliance on behavioural and cognitive strategies to the exclusion of understanding what is going on in the family and in the child. Many child psychiatrists in Adelaide feel, we believe, that there is an overemphasis on behavioural management and "information" - or that, pressed by desperate families in need of help, and knowing that alternatives are limited, they feel they must do something.

This might particularly affect paediatricians as a group, who might feel that the chronic lack of psychiatric services leads them into having to prescribe stimulants in order to feel they have helped in some way (Jureidini). NAPP does however acknowledge that cognitive / behavioural methods do have a rightful place in treatment as part of a range of possible strategies.

In short, and in regard to child psychotherapy, there is little or no access to this (recognised) form of treatment if a child (eg from financially disadvantaged families) requires it due to restrictive Commonwealth funding, and unclear career paths for such specialists which in turn discourages training in this vital area.

The importance of this point is made by the Hon M J Elliott in his address to the House in April 2000 when, in arguing for an enquiry, he stated that when one child is affected by ADHD then there are also "collateral" patients in the form of parents, siblings, peers etc. Providing access to all forms of treatment, indeed maintaining expertise, is vital if one is to reduce the overall reliance on medication. The Mental Health Statement of Rights and Responsibilities document states that "the consumer has the right to a co-ordinated and ongoing range of adequately resourced …treatment" and further that "the consumer has the right to be treated in the most facilitative environment with the least intrusive treatment "(p7). Medicating the minds of young children is nothing if not intrusive.

As the Hon M J Elliott noted in his address, public service delivery in this area has meant children have to wait in the order of one year for effective public intervention - unless the family can pay for private services. Not only has expertise in one particular field (therapy) been unavailable for selected cases, but those behavioural interventions sanctioned by policy makers are in effect unavailable - a year is a long time in a child's life, and for their distressed parents, and a year is long enough to cement maladaptive patterns of behavior that might otherwise have been modified.

Again, to quote from The Mental Health Statement of Rights and Responsibilities document "the consumer has the right to obtain treatment at an early stage of their illness…" (p7). The Hon M J Elliott opines "the common theme of government responses

has been reassurance to the public that all necessary services are available and reaching those in need. That simply is not the case."   NAPP agrees completely.

Another factor limiting access to timely treatment, we believe, is what the Hon M J Elliott refers to in his speech on the matter as an "issue that does not settle anywhere and does not have any *ownership" (*italic ours). This confusion of ownership is reflected in the profusion of policy statement by the educational sector, who look to the health sector for guidance but find any input to be ad hoc, and poorly resourced.

NAPP would advocate that multi-disciplinary treatment, involving all relevant professionals under the auspices of those whose training is indeed multi-disciplinary in approach, might be a more useful long term strategy for definitive treatment. This would, we feel, place ownership of the problem in the child psychiatry sector (where we believe this would work best), would allow expertise to be developed and maintained in conjunction with paediatricians, and this in turn would allow the wider dissemination of educational and liaison strategies to reach areas most in contact with these children - eg teachers, welfare sector providers etc. Of necessity this demands a greater policy commitment to properly fund and resource this approach.

4 Any other related matters

Whilst NAPP is cognisant of not wanting to burden the committee with too much broad information, we do believe that ADHD presents a complex array of problems that span several disciplines, and cut across several Parliamentary portfolios.

For example, NAPP understands that consideration is being given to the proposal that amending the Equal Opportunity Act, by making it more inclusive and less restrictive, might then enhance access to treatment for children diagnosed with ADHD.

Whilst NAPP can see that this might be potentially useful if it were to lead to proper definitive treatment as described above, we are also cautious in that this might inadvertently *increase* the rate of diagnosis and therefore *increase* stimulant prescription rates. NAPP bases this on experience in the US where Perrin et al observed that when children receive income as part of a program of disability benefit for ADHD, the diagnosis can ‘reflect bias because providers tend to code conditions and procedures that are likely to be reimbursed. Thus, the diagnoses on claims may not accurately reflect the conditions that children have.’ This raises critical questions: could the culture of ‘cash benefits to a maximum of approximately $6000.00 per year per beneficiary’ under the Supplemental Security Income in the US be a contributing factor that *promotes the increase* in the rate of prescriptions for drugs used to treat ADHD?

That non-ADHD psychological and social factors may bias the prescribing habits of the medical profession to diagnose children with ADHD for eligibility to claim up to $6000 in disability payment (in the US) should at least be considered a part of the ‘wider forces’ that might influence the complexities of the condition.

NAPP is also mindful that professional information in regard to drug management is disseminated via articles in professional journals. There is increasing concern that these same articles that purport to set objective standards are indeed caught up in conflicts of interest, occasioned by the fact that drug companies often heavily influence the reported findings.

This was recently stated thus :
" NIMH effectiveness research clearly is the result of several forces that emerged in the early- to mid-1990s," said Michael Thase, M.D., of University of Pittsburgh, who co-chaired the symposium with Gary Sachs, M.D. "First, in the area of psychiatric therapeutics, it became abundantly clear that there was a large disconnect between what we knew from randomized clinical trials and what was done by practitioners on an everyday basis…. Secondly, it became clear that we were entirely dependent, in terms of our knowledge of new treatments and their relative merits, on the information funded by…the very companies that would serve to benefit from the information about the new treatments."(Kaplan).

Further, we also need to consider the wider political forces that impinge on this problem. NAPP will now table a book (*She Still Won't Be Right, Mate)* written by the Psychiatrists Working Group in 1999. We would like to draw the attention of the Committee to three chapters that we deem to be relevant to the issue of ADHD and its management :

- *Fact and fiction about unmet need for mental health services - D Grant & G Anaf*
- *"Voltaire's bastards" and the rights of the child: the manufacture of epidemics - George Halasz*
- *Managerialism, psychiatric reform and the community - Gil Anaf*

Fact & Fiction - In this chapter the authors argue that the notion of "unmet need" so often reported in policy documents in Australia is in fact an exaggeration of the truth. The development of this notion is traced back to flawed documents that have as their agenda the purpose of cost cutting and downsizing the health sector, in line with the American models of health care.

We quote from this chapter "In short, the talk is about financial policies that in one way or another can be referred to as managed care strategies. These same policies have been imported from the US where they have led to devastating reductions in the availability of adequate care for large sections of their community…" (p50)

NAPP believes it is not a coincidence that as our health system is "Americanised", so too will our diagnostic patterns closely follow US trends, as is the case with ADHD and the increasing lack of access to definitive treatment.

Voltaire's bastards - "As we enter the 21st Century, the paradigm shift in administrative practice called "managerialism" and the marketisation of health care is daily eroding

valued aspects of the Australian health care delivery system and the values of ethical health care, including the right of the child to be heard" (p186).

In this chapter the author puts the view that market forces, and our reliance on them, erode what can be done to help children in need particularly since these same forces encourage stimulant use, thereby creating "the manufactured epidemic of ADHD". The author quotes from research into ADHD where particular comment is made on the lack of importance placed on psycho-social factors (the child's environment, parenting, schooling) as primary or secondary contributors to the emergence of ADHD.

<u>Managerialism, psychiatric reform and the community</u> - Lastly, this chapter puts four key issues that beset our health policies that in turn rebound onto vulnerable members of our community eg children. First, the author describes the complexities of policy changes that drive health care further away from the notion of concern for the underprivileged - and closer to a competitive, exploitative system. Second, the view is put that to turn social services into defacto businesses only leads to ethical dilemmas we can ill afford - eg do we only treat ADHD with pills ? Third, we see how managerialist theory now underpins policy, so that the longer term interests of the community no longer become paramount. Finally, the author argues that the nett effect of the above has negative implications for the whole of medical practice and hence the community at large, such as increased alienation of families, social fragmentation and rising medical costs with less access (p69). The problem of ADHD is a timely example. The author concludes with the view that governments must not abandon their social obligations - this would extend to ensuring comprehensive treatments remain available, and that all interventions are to be made potentially available for those in need.

Lest the Committee feel that the issues addressed in the chapters noted above might be far removed from the local scene, and that US problems "can't / won't happen here", NAPP would like to draw the Committee's attention to the existence of Item 319 Legislation in the Medicare Benefit Schedules.

This legislation has been in force since 1997. Its explicit intent and effect is to *reduce* the number of outpatient visits in any one calendar year for a particularly vulnerable group of mental health patients who require long term intensive treatment. The rationale for its introduction was the saving of money, and to increase access to psychiatrists more generally - a bit like a surgeon giving a patient half an operation so that another patient might also have half an operation.

Some (little) money has been saved, but access has decreased rather than the reverse. The emotional cost on individual patients and their families of being deprived of *proper* treatment has been tragic and severe in some cases.

NAPP feels very strongly that this has been the direct result of policies based on the issues we describe above, and that the issue of ADHD is likely to fall into the same category. Further, one can easily imagine that if a distressed parent needed *their own* treatment in order to ameliorate the effect of a child with ADHD, how easily this might

become problematic for no other reason than Commonwealth funding arrangements. An escalating cycle of illness within a family will then have been created, which might easily have been avoided.

5 Recommendations

5.1 Child psychotherapeutic expertise should be reinstated into a core component of assessment and treatment of alleged ADHD children and made more accessible to those correctly diagnosed and, in addition, other allied conditions currently diagnosed as ADHD;

5.2 To this end, a transparent career path for child psychotherapeutic professionals should be created within the State Department of Human Services;

5.3 The Department for Human Services should create a multi-disciplinary framework dedicated to the management and treatment of childhood disorders including but not limited to those within the education system and headed by professionals with multi-disciplinary specialist training. Those are likely to be child psychotherapeutic professionals because of their education and training;

5.4 The Education Department should keep accurate statistics on the number of children required to attend focus rooms and whether or not these children are medicated with amphetamines or have a history of diagnosis of ADHD;

5.5 The standard of broader professional expertise for the diagnosis/management of ADHD can be increased by providing increased training at the level of school councilors and general practitioners, and at welfare agencies, - that is to the professionals who usually have first contact with the child displaying behavioural problems.

5.6 Where overprescribing is suspected, the Health Insurance Commission and Pharmaceutical Benefit Scheme already have processes for review based on patterns of prescription, (as occurs with pethidine) which would allow the under-usage of the multi-disciplinary approach to be more closely evaluated.

5.7 Lastly, given the critical role of adequate resourcing and funding of our stated initiatives and being cognisant of the need for reasonable accountability, NAPP would urge that a review of such funding be undertaken through the Estimates Committee to ensure that all reasonable funds are made available, so as to reduce the over-reliance on medication by increasing effective and timely interventions.

In conclusion, NAPP would respectfully urge that the issues detailed in this submission, which present an overview of the complex issue of ADHD and its management, be given serious consideration. We believe that if the overarching principles for assessment and

treatment outlined in this document were fully adopted, then South Australia would once more have taken the lead in an important national area involving health and social justice issues for the vulnerable in our community and their children.

NAPP wishes to gratefully acknowledge the valuable contribution made by Dr R Falk, in preparing this submission.

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