Inquiry into Respite Care Services in the ACT

Terms of Reference

To inquire into and report on government and non-government respite care services in the ACT, with particular reference to:

- the Auditor General’s Report, No 3 of 2009, Management of Respite Services in the ACT
  
  Not applicable – we have no access to this service

- the needs of care recipients (including children, teenagers and adults with a disability, elderly people, people with mental health issues and people from culturally and linguistically diverse backgrounds) and their carers
  
  Not applicable – we have no access to this service

- the needs of staff who provide respite care, including working conditions and training
  
  Not applicable – we have no access to this service

- the range, availability and suitability of respite care services, including any unmet need
  
  The Canberra & Queanbeyan ADD Support Group Inc have observed that their members have found it very difficult to access respite care, even for a few hours. They have been told in the past that there is at least a two year waiting list which gives our members little hope of accessing this service.

  The Canberra & Queanbeyan ADD Support Group Inc had approached Carers ACT to access their assistance in holding educational sessions to assist our members in their caring role. This was refused because ADHD is not considered to be a profound or severe disability under the HAAC program. We strongly dispute this policy. ADHD can be, and is in some circumstances, extremely profound and disabling. ADHD is also largely genetic, if a child is having problems with ADHD, then a parent usually is too.

  Attention Deficit Hyperactivity Disorder (ADHD) in children can be worsened because of the lack of understanding and services for this disability. Children with ADHD can have the following comorbidities either separately or a combination of one or more which add to disability. They include Anxiety, Depression, Oppositional Defiant Disorder, Conduct Disorder, Obsessive Compulsive Disorder, Tourette Syndrome, Epilepsy, Migraines, Allergies, Aspergers Syndrome, Asthma, learning disabilities, auditory and vision processing problems and night terrors, lack of social skills, sensory processing and
pervasive development delay. Very little assistance is given to ADHD children in the school system and this can strongly impact on families and cause stress not only for the ADHD child, but parents/carers and siblings. Low self esteem associated with untreated ADHD can eventually lead to anti-social behaviour, self harm, risk taking behaviours such as alcohol and substance abuse and eventually, juvenile justice issues. See Attachment 2.

Now there is the added stress for ADHD students and their families as the students are required to stay at school until they are 17 years of age. As there is no additional assistance provided for the child’s learning problems, the impact on families is even greater. A significant number of families with children with ADHD have a single parent coping with these problems by themselves. They are stressed out and feel that no-one cares or understands their problems.

Our group members would like to receive recognition as carers, to be able to have a couple of hours away from caring so that they can do such things as attend a medical appointment by themselves, a legal appointment or even sort out why their child has been suspended from school (increasingly important now as School Principals have greater powers to suspend). A night or weekend respite for their ADHD child so that the siblings can have quality time with the parents/carers is an under-recognised need, as is a weekend away from family to de-stress or to attend seminars so as to better educate themselves on ADHD.

Dr Michael Sawyer, one of the authors of Mental Health of Young Australians (2000) mentioned in his talk to our group in 2006 that the parents/carers were more stressed than any other parent/s with child with a physical disability. This can happen because the child has no friends at school or home, is not achieving in the education system and is dropping behind academically. Now with the added stress that an ADHD child can be suspended for three weeks at a time without an excuse being given i.e. School Refusal will just add to their problems. Other children, their parents, magistrates, journalists etc., criticise the child and their parents while lacking the understanding of the complex nature of ADHD and its interactions. Basically ADHD families feel isolated. Siblings of the ADHD child are not receiving adequate time with their parents because the focus is on the ADHD child. Sleep disorders are common in ADHD (not a cause of ADHD but a function of hyperacusis and hypervigilance). An ADHD child may not get the necessary amount of REM sleep until the early hours of the morning and then find it difficult to get up and go to school on time. More stress for parents/carers and the child itself.

Other states and territories recognize the need and are able to provide parents/carers of ADHD children with respite care so why can’t the ACT? Other ADHD support groups have accessed a weekend away for their parents/carers so that they can relax and even learn more about ADHD, parenting programs and just general share what they have to cope with.

Another issue is Care and Protection – see out attached submission from ACT Budget 2008 – See Attachment 1.
• **the interaction between government and non-government providers of respite care**

  Not Applicable – we have no access to this service

• **the experience of service users who utilise government and non-government providers of respite care**

  No applicable – we have no access to this service

• **any other related matter.**

  See unmet need above. Ideally we would like to see someone come to the home to look after the child/ren that is educated in ADHD behaviour management. ADHD children do not like to be co-located with other physically disabled children as they do not see themselves in that same way. They may be very empathetic (often overly so) with the physically disabled children but it could also cause problems. Most of ADHD children are called “psycho” at school and this does not help their self esteem.
Attachment 1 – dated 28 September 2007

Forensic Health in Adult and Juvenile Offenders

Introduction

We are combining adult and juvenile forensic health in the one submission partly for convenience and partly because,

the most serious and persistent adult offenders had been detained as a juvenile … . In terms of crime reduction, interventions that focus on reducing the likelihood of juveniles escalating to adult offenders will have significant benefits for the whole of the Australian community.¹

Canberra and Queanbeyan ADD Support Group supports the new Alexander Maconochie Centre. We are particularly impressed by the ACT Government’s stated goal of providing real rehabilitation.

Since research shows that ADHD is highly prevalent in prisons and predicts substance abuse and recidivism, then screening for and treating ADHD offers an effective pathway towards achieving those rehabilitation goals.

Yet ADHD is seriously under-diagnosed and under-treated in NSW prisons. This is a disturbing breach of human rights.

Research on ADHD and Prisoners

ADHD is a common factor associated with delinquency, adult criminal behaviour in men and women and recidivism. Court records data indicate that people with ADHD are more likely to be arrested, and often have a history of multiple arrests and convictions. Using screening questionnaires, studies from various countries report 22-71% as possibly having a childhood diagnosis of ADHD, depending on the assessment tools and cutoffs applied. In adulthood, some 30-50% are screened as possibly being fully symptomatic, with a high

The proportion of inmates (15-50%) screened as being in partial remission of their symptoms. (references omitted)²

45% of young male prisoners had DSM IV ADHD, according to a study of prisoners from a prison taking all young people sentenced in Saarland, a German state. Ages were 19.5±2 years. The combined prevalence of ICD-10 Disturbance of Activity and Attention (DAA) and ICD-10 Hyperkinetic Conduct Disorder (HCD) was 21.7%. 89% of DAA/HCD cases had DSM IV alcoholism and substance use disorder. The difference in ADHD and DAA/HCD prevalence was attributed to the DSM IV hyperactive and impulsive subtype which has no equivalent in ICD-10.³

A US prison doctor wrote that, “Other studies and our own experience have led us to believe that upwards of 40% of our residents in a medium security prison have the findings along the Tourette/ADD spectrum”.⁴

A study of 451 South Australian offenders aged 11 to 19 showed that ADHD signs measured on the Secure Care Psychosocial Screening V.4 (SECAPS) (developed by the author) strongly predicted recidivism. The author, who is Chief Clinical Psychologist for Youth and Juvenile Justice in South Australia, recommended that offenders be screened for ADHD and those with high ADHD scores be assessed and treated in order to reduce recidivism.⁵

A related study of 900 South Australian offenders aged 11 to 20 showed that ADHD symptoms measured on SECAPS predicted later substance abuse independently of conduct disorder symptoms.⁶ The author recommended that substance users with

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⁶ Aldis Putniņš, ‘Substance Use Among Young Offenders: Thrills, Bad Feelings or Bad Behaviour?’ (2006) 41 Substance Use & Misuse 1, 4.
ADHD receive ADHD treatment including, in some cases, stimulant medications.\textsuperscript{7} He noted that treatment with stimulants during childhood and adolescence is associated with reduced substance use later.\textsuperscript{8} Slow release formulas have less abuse potential.\textsuperscript{9} Alternatives to stimulants include strattera and bupropion.\textsuperscript{10} The latter is not available for long-term use in Australia, but it is an effective second line treatment for ADHD.

**ADHD in the NSW Prison System**

NSW does not appear to have ever screened its prisoners for ADHD, although it was recommended in 2003 that a more comprehensive survey of prisoners’ mental health including disorders such as ADHD be funded.\textsuperscript{11} The 2001 NSW Inmate Health Survey did give figures for prisoners with a prior diagnosis of ADHD.\textsuperscript{12} The percentages in the report are clearly wrong, so they have been recalculated (the report’s figures are in brackets). The highest prevalence was 6.6\% (2\%) among men younger than 25. The next highest prevalence was 5.6\% (1.8\%) among men aged 25-40. The prevalence for all women was 1.9\% (0.4\%). The prevalence for all prisoners was 3.9\% (4.3\%).\textsuperscript{13} This is well below the level of ADHD found in gaols where it is screened for.

The percentage of all prisoners taking psychostimulants was only 0.8\% (0.8\%).\textsuperscript{14} This is a very low treatment figure. One prisoner in the survey complained he was unable to keep taking dexamphetamine in gaol due to lack of prescribers. As a result he was a lot more violent.\textsuperscript{15}

Current low levels of diagnosis and treatment are seriously discriminatory. Treatment can allow an offender to participate in education and training and other rehabilitation

\begin{footnotes}
\item[7] Ibid.
\item[9] Nutt et al above, n 24, 14, 19.
\item[10] Ibid, .
\item[13] Ibid.
\item[14] Ibid.
\item[15] Ibid, 206.
\end{footnotes}
activities. Treatment can also improve behaviour which in turn affects parole and therefore actual sentence length. So the failure to provide treatment locks offenders with ADHD out of rehabilitation and probably lengthens their time in gaol. It also leaves their drug problems untreated.

One NSW prison psychiatrist said one barrier to treatment was the frequent movement of prisoners, as they did not know where to send prescriptions. This at least should not be a problem in the AMC.

Another NSW prison psychiatrist said another barrier to ADHD diagnosis and treatment is that there are not enough psychiatrists to provide it, given the other mental health needs of prisoners. This is totally inconsistent with human rights. It also makes no economic sense. The economic, social and human capital returns to investing in rehabilitation and reduced substance abuse are substantial.

Since the Draft Adult Corrections Health Services Plan 2007-2010 is based on health needs identified in the The 2001 NSW Inmate Health Survey then there has been no, or inadequate, planning for the needs of prisoners with ADHD. Consequently, it will be necessary to provide more hours of forensic psychiatry and forensic psychology.

**Recommendations**

**ACT Health should fund:**

- Education in ADHD for all forensic health clinicians and social workers;
- An additional part-time (two days per week) forensic psychiatrist with experience in ADHD and addiction; and
- An additional full-time forensic psychologist with experience in ADHD and addiction.

**The Department of Disability, Housing and Community Services should fund:**

- Education in ADHD for all clinicians providing treatment to juvenile offenders; and
- A trial of the SECAPS screening tool and risk tool in juvenile justice.
2008 Budget Submission to ACT Health and Department of Disability, Housing and Community Services

by Janet Hutchison

Care and Protection of Children

ADHD and Children in Care

The Centre for Parenting & Research reports that foster children are diagnosed with attention deficit hyperactivity disorder (ADHD) and conduct disorder (CD) at higher levels than other children. A study of 326 children and adolescents (aged 6–17 years) residing in home-based foster care in the Adelaide metropolitan region between August 2004 and January 2006 revealed far higher levels of attention problems among this group (44.0%) compared with Australian children and adolescents generally (6.4%).

Child protection professionals commonly attribute the high prevalence of ADHD to child abuse as a causal factor for ADHD. It is far more likely, however, since ADHD is predominantly genetic, that many of these ADHD children have ADHD parents. In other words, parents with ADHD are more vulnerable to child removal than the general population.

The failure to acknowledge ADHD among parents involved with child protection agencies is a breach of human rights. However, since ADHD is treatable, acknowledging ADHD provides a tremendous opportunity to bring about positive changes in a significant number of families.

Of course, most parents who have ADHD are good parents. Also, most individuals who have ADHD do not use illegal substances or engage in criminal behaviour. There are many positive aspects to ADHD.

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ADHD and Genetics

ADHD is directly inherited and is not due to poor parenting. Twin, family, and adoption studies have consistently demonstrated this. Genetic factors account for around 80% of variance among individuals. Environmental factors shared by family members account for less than 5% of variance and unshared environmental factors, which may be biological, account for around 15 – 20% of variance.

Prevalence and Diagnostic Incidence

The NSW Department of Health estimated conservatively that 2% of adults have ADHD. Other researchers claim that between 1 and 6% of adults have ADHD.

Diagnostic incidence can be estimated based on the rate of stimulant medication usage, although actual diagnostic incidence is higher. At June 2003, under 0.1% of NSW adults were taking stimulant medication to treat ADHD. In NSW in 2002 about half the adults treated with stimulant medication for the first time were women and 60% were 30 years or older.

The NSW Department of Health said:

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23 Salmelainen, above n 6, 3.

24 Ibid, 23.

Comprehensive and judicious assessment procedures are essential for ensuring that patients with ADHD are properly identified and receive the most appropriate treatment.26

**ADHD and Substance Abuse**

Substance use disorders are common with ADHD, although most adults with ADHD do not abuse substances.27 One researcher found that 30% of poly-substance abusers had ADHD.28 The only other Australian study of ADHD among drug users showed that both childhood (36%) and adult (46%) ADHD were over-represented among male adults using illicit drugs or alcohol, not necessarily regularly, and involved with drug use agencies.29 Regular or problematic substance use or abuse was present amongst 13.3% of adults treated with stimulants for the first time in NSW in 2002.30

Substances used included cannabis, alcohol, ecstasy, amphetamines, cocaine, heroin, LSD, and therapeutic narcotics. Often doctors described this behaviour as self-medicating.31 Most abusable substances will treat ADHD symptoms of one kind or another. Research shows that stimulants have some differential effects in individuals with ADHD.32 Treatment for ADHD usually extinguishes interest in abusing.33

Despite this, ADHD seems to be under-diagnosed in drug programs. The fact that parents who abuse drugs are also over represented among child support agency clients34 suggests a link between substance abuse and ADHD for some of these parents.

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26 Salmelainen, above n 6, 4.
28 John Anderson, interviewed by Tony Delroy, ABC Radio 2002. He is now deceased and his research remains unpublished.
29 Kaye, above n 7, 2.
30 Salmelainen, above n 6, 23.
34 Cousins, above n 3.
Falkov claimed that ‘underlying PD associated with intermittent depression & self harm, complicated by substance abuse in a parent carries a particularly poor prognosis for dependent children’.\(^{35}\) There is anecdotal evidence that clinicians working in the field of substance abuse prefer to diagnose personality disorders and fail to diagnose ADHD even when there are significant symptoms. Of course, the two conditions can co-occur. Women with ADHD can be misdiagnosed as having personality disorders.\(^{36}\)

**ADHD and Teen Pregnancy**

ADHD is a risk factor for teen pregnancy and early intervention programs need to recognize that link. One study found that 38% of a sample of ADHD teens were involved in a teen pregnancy.\(^{37}\)

**ADHD and Antisocial Behaviour**

Adults with ADHD are more prone to antisocial behaviour than adults without ADHD.\(^{38}\) Children with ADHD are more prone to oppositional defiant disorder (ODD) and CD. CD may develop into APD in adults. Girls with ADHD are much less prone to ODD and CD than boys.\(^{39}\)

There are significant genetic factors in ODD (estimates ranging from 14% to 65%), CD (27% to 78%) and APD.\(^{40}\) Clearly, environment is very important to the development of these conditions. It is therefore critical to provide evidence based preventive interventions.


\(^{37}\) Russell A Barkley, above n 4, 95.

\(^{38}\) Salmelainen, above n 6, 9; Kaye, above n 7, 2.


\(^{40}\) Baker, Bezdjian and Raine, above n 5.
Recommendations

The Department of Disability, Housing and Community Services should fund:

- education on ADHD in children, adolescents and adults for Care and Protection staff;
- development of ADHD friendly social interventions for parents with ADHD;
- reporting and review of interventions by qualified researchers; and
- co-operation with other agencies to develop best practice in prevention of crime and substance abuse among young people with ADHD and comorbid ODD/CD so as to reduce the risks for subsequent generations.

ACT Health should fund:

- education on ADHD in children, adolescents and adults for all staff providing mental health care, drug and alcohol treatment and child, adolescent and young persons care and early intervention to mothers at risk; and
- An ADHD public health education campaign.
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42 DJ Nutt, K Fone, P Asherson, D Bramble, P Hill, K Matthews, KA Morris, P Santosh, E Sonuga-Barke, E Taylor, M Weiss and S Young, Evidence-based guidelines for management of attention deficit/hyperactivity disorder in adolescents in transition to adult services and adults: recommendations from the British Association for
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