



SUPPORT

CANBERRA + QUEANBEYAN

23 April 2009

Committee Secretary
Senate Standing Committee on Community Affairs
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Dear Sir/Madam

***Inquiry into Social Security Legislation Amendment (Improved Support for Carers) Bill 2009
[provisions]***

Please find enclosed is our submission. If you require references we can provide them asap.

The submission has been authorised by the Committee of Canberra & Queanbeyan ADD Support Group Inc and is to be seen as the Canberra & Queanbeyan ADD Support Group Inc's submission.

The Contact is Beryl Gover, Secretary/Treasurer, PO Box 717, MAWSON ACT 2607. Telephone contact is 6287 4608.

Yours faithfully

Beryl Gover
Secretary/Treasurer
encl

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Introduction

There are two critical issues for families and individuals affected by ADHD in this Bill. The first is that the Disability Care Load Assessment (Child) Determination take into account the actual impact of ADHD and comorbid conditions. The second is that the disability of the carer be taken into account in assessing the overall care load.

About the Support Group

The Canberra & Queanbeyan ADD Support Group Inc (ADDACT) is a non-profit organisation staffed by volunteers. ADDACT is GST registered and Tax Invoices are issued. We hold the status as registered charity and donations of \$2 or more are Tax Deductible.

Our group commenced in 1991 and incorporated in 1993. We have been offering the community our services since then. We are one of a few ADHD support groups in Australia which have lasted over the years. The membership includes professionals including paediatricians, psychologists, teachers, occupational therapists as well as parents/carers and adults with ADHD.

Individuals with ADHD form a significant proportion of the population but their needs are not being recognized. Unfortunately, our organizations lack the resources to educate government and the community effectively about the myriad of issues relevant to ADHD.

ADHD

ADHD is a neurobiological condition associated with an imbalance of the brain's neurotransmitters (substances used to convey messages between nerve cells) and differences in brain anatomy. There is a common perception that ADHD is a childhood condition. In reality, ADHD is a condition that affects all ages: children, adolescents and adults. Adult ADHD affects around 5% of Australia's population (based on US population surveys) of adults and with young people 11% (Mental Health of Young Australians 2000 by Department of Health & Family Services).

Under the Carers allowance with Centrelink, unless an ADHD child has another disability or that there are two children with ADHD in a family, parents/carers cannot access this allowance.

Many parents of children with ADHD suffer serious and constant stress from explosive anger and violence or impulsive dangerous behaviour. Some children with ADHD need constant supervision and careful attention to things like procedural fairness in a family in order to prevent such behaviour. Parents are also distressed at seeing their child miss out on friendships or full educational participation. In around 25% of families parents also have ADHD and are overstretched by the intense needs of their child, despite their greater understanding and empathy for her or his situation.

Disability Care Load Assessment (Child) Determination

The Minister should ensure that the developers of this assessment tool consult with ADHD consumer organizations including Canberra and Queanbeyan ADD Support Group such that the tool fully measures:

- ⇒ The real impact of ADHD;
- ⇒ The multiplier effects when more than one child or one or more parents have ADHD;
- ⇒ All the comorbid conditions that a child or children have including trauma;
- ⇒ The adjustment phase for a family where one or more members have just been diagnosed;

197D

It is critical for families with ADHD that the parent's or parents' disabilities be taken into account as ADHD is a genetic condition. Because recognition of ADHD has been slow, many families still experience a double or triple whammy of children and parents being diagnosed at the same time. For a parent there may be an adjustment phase as they work out what is needed for both themselves and individual children. Sometimes parents are significantly affected by anger and grief about their own late diagnosis and this must be worked through before their treatment for ADHD is effective. In addition parents may have comorbid conditions that also need treatment and increase their care load. All of these factors must be considered in assessing care load and the disability status of the adult.

Thus s 197D should make it clear that the adult with a disability may actually be the carer. In addition the Adult Disability Assessment Tool or whatever tool is used for assessing an adult's disability under this section must adequately assess

the full impact of adult ADHD and comorbid conditions and the challenge of raising children with ADHD.

Additional Comments re Carers Inquiry

Unfortunately we were not aware of the original inquiry into Carers last year and wish to make the following comments.

We were unable to get statistics from Carers ACT with regard to families with ADHD refused respite care. Next year their database will have that information. Unfortunately our members have been told by Carers both in the ACT and NSW that under Home & Community Care program, ADHD is not seen profound or severe and therefore these parents/carers are unable to access respite care. We totally disagree. According to Professor Michael Sawyer speaking at our Seminar in Canberra in September 2005, based on the parents that he and his colleagues saw, ADHD parents/carers were more stressed than parents of a physically disabled child. Other anecdotal information is that some of our parents are being physically abused by their ADHD adolescents. Other siblings and of course the parents/carers do not lead a normal family life even for a break which they desperately need. Some instances I will elaborate later in the submission as well as other evidence to back our claims. As most ADHD children are impulsive, parents/carers even siblings are on edge as they never know what is going to happen next. I am sure that this type of existence for these family members is very detrimental to their health and could impact on Australia's health system now and in the future.

Not only do parents/carers of ADHD children and adolescents need respite but the young children need the respite as well. The children need to have a break and benefit from contact with another less stressed adult or where appropriate in a specific program.

Another issue is that there would be a good percentage of ADHD children that have parents who are ADHD. Surely the load that this family is carrying should be assisted by the carers program in HACC.

Years ago our members were able to access help with the family ie for parent to attend a medical appointment or even doing the shopping without the ADHD child but this is not possible now.

When a parent takes their child to the supermarket which invariably is in a large shopping centre, the bright lights, movement, noise, colour, smells from chemicals in the laundry aisle can contribute to them having a tantrum and making it impossible for the parent to finish the shopping. Invariably other shoppers make comments like ““what a bad parent” that person is. This leads to the parent/s being isolated and feeling very much alone.

A great percentage of families with adhd children are single parents, therefore the load is not always shared.

As the state/territories education system does not support ADHD children and the teaching universities do not teach teachers to teach ADHD children, this contributes to more stress on the child and in turn on the family. Fifty per cent of ADHD children have learning disabilities and these can include both vision and auditory processing problems, dyspraxia, developmental delay, fine and gross motor skills etc.

Other co-morbidities of ADHD children include anxiety and/or depression, epilepsy, obsessive compulsive disorder, oppositional defiant disorder and conduct disorder. Children may also be traumatized by negative reactions to their behaviour by others.

If an ADHD child does grow up with low self esteem, because s/he has not achieved their educational outcomes, does not have friends, cannot see the future improving (especially now that it has been mooted by several states and territories that the leaving age for school will shift from 15 yrs to 17 yrs) they often turn to drugs and alcohol to cope with this failure.