Draft Joint Submission to the Productivity Commission re the proposed National Disability Insurance Scheme [NDIS] for support organizations for Attention Deficit Hyperactivity Disorder [ADHD].

Submitting organizations:
The ADHD Coalition of Victoria Inc.
The Canberra & Queanbeyan ADD Support Group Inc.
The Attention Deficit Association of South Australia Inc. ADASA.
ADDults with ADHD (NSW) Inc.

The above-named Australian support associations for Attention Deficit Hyperactivity Disorder [ADHD] welcome the proposal for a National Disability Insurance Scheme. We applaud the aim of exploring alternative approaches to funding and delivering disability services, and we particularly welcome the focus on early intervention. We are extremely encouraged by the other roles envisaged for the NDIS in "mustering community resources, providing information to people, quality assurance, diffusion of best practice among providers, and breaking down stereotypes."[i]

ADHD: a disabling condition

We hope that the eligibility criteria for disability to be adopted by the NDIS will include ADHD. It is recognized as a disability under the 1992 Disability Discrimination Act.

Incidence in Children and Adolescents

In Australia, the National Survey of Mental Health and Wellbeing reported that 11% of children and adolescents fulfilled the criteria for ADHD.[ii] On a national basis, 0.5% of 4–17 year olds were prescribed stimulant medications to treat the condition between June 2006 and May 2007.

The proportion of children prescribed stimulants varied between states (e.g. in NSW, 1.5% of 4–17 year olds were prescribed stimulants in the period). Similar to other countries, the vast majority of diagnosed ADHD cases in Australia are boys. In the 2006–07 period, 15,466 males were prescribed stimulant medication, compared to 3872 females, a ratio of about 4:1.

There has been an increase in the reported number of children with ADHD in the past decade, and the prescription of stimulant medication to treat the condition has also increased. For example, in Australia from 1984 to 2000, the number of scripts issued for stimulant medications to treat ADHD increased by an average of 31% per year. However the proportion of children prescribed stimulant medication remains below the proportion of children with ADHD and this apparent increase in the rate of reported cases of ADHD is due to increased awareness amongst health professionals and the public on the condition.

Incidence in Adults

4 % of adult ADHD in Australia, converting into about 360,000 adults between the ages of 18 and 44 (ABS stats).[iii]

The ADHD organizations above strongly support the submission of the Australian Human Rights Commission in recommending to the Productivity Commission that any consideration of an NDIS or similar mechanisms should commence from the basis that the scope of the scheme should facilitate full and equal enjoyment of the full range of human rights for people with disability.

> *Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.*[iv]

In addition, we endorse the argument of the Australian Human Rights Commission that, in the devising the National Disability Insurance Scheme, the Productivity Commission

- *base its work on a social model of disability;*
- *take into account the effect of disabling environments in considering appropriate eligibility criteria and levels of benefits or entitlements;*
- *in particular take into account the particular impacts in this respect of disadvantage affecting Indigenous people in Australia; and*
- *consider roles for institutions administering an NDIS or similar scheme in achieving reduction in or removal of social and environmental barriers which result in disability for people with impairments.*[v]

The Handicap of ADHD

ADHD has been called "The Hidden Handicap" because individuals with ADHD are often [but not always] able-bodied, and free from obvious physical, intellectual, motor or sensory impairments. However, in order to warrant a diagnosis, the main characteristics associated with a diagnosis of ADHD: inattention, impulsiveness and hyperactivity, must be present to such a degree as to constitute evidence of "moderate to severe impairment across settings, including home and school".[vi] This impairment is an essential part of the diagnosis. When the condition is not treated appropriately, these ADHD characteristics often produce a range of adverse outcomes that constitute a significant handicap for those with ADHD. These outcomes include under-achieving at school, poor work performance, poor self-esteem, problems in relationships, cognitive deficits, learning difficulties and social adaptive difficulties, and the development of other mental and physical health-related adverse conditions.

Early Intervention

ADHD is a significant disability for individuals with the condition, their families and carers, and incurs significant costs for society. The total burden of the condition is greater than for other mental disabilities or illnesses. Largely, however, ADHD is easily treatable. The earlier that it is correctly diagnosed and appropriately treated, the greater benefits there will be for the individual, and his or her family and society at large. Many individuals with ADHD who receive appropriate help, manage their symptoms well, and can have creative, productive and fulfilling lives.

Barriers to diagnosis and treatment of ADHD

Among the most common reasons for individuals with ADHD not being appropriately diagnosed and treated from an early age are the following:

- Lack of awareness and understanding of ADHD, its diagnosis and treatment by primary care providers.
- Unwillingness to seek out or accept a diagnosis of ADHD. [stigma and lack of unbiased information].
- High cost of diagnostic tests, especially objective testing.
- High cost of development and implementation of an individualized treatment plan. Such plans are typically multi-modal in nature, and usually include counseling, remedial education and medication.
- Shortage of clinicians with expertise in the internationally acknowledged "best practice" methods of ADHD diagnosis and treatment. This is particularly acute in the public health sector.

Costs of treatment

Diagnostic tests by qualified psychologists usually amount to several hundred dollars, and in some complex cases, may amount to more than a thousand dollars. Yet such tests are an important precursor to the development of an appropriate treatment plan. For children with ADHD, there are often costs associated with tutoring and remedial help, with counselling and medication. Travel costs are an additional burden for those families in remote locations.

For adults, the Pharmaceutical Benefits Scheme subsidy does not apply to the non-stimulant medicine Strattera, unless the individual was diagnosed with ADHD in childhood. However, the difficulty of getting such a diagnosis in the past has meant that few of those who should be eligible are in fact eligible. These adults are thus double disadvantaged.

Adults who attend a mental health unit within a public hospital report that they rarely get appropriate diagnosis and effective treatment. This leaves adults with no option other than private psychiatrists, who in NSW charge anywhere between $250 and $550 per visit. Whilst Medicare does refund around $200, this is still leaves a lot out of the pocket of those on pensions etc.

Respite

ADHD is a very exhausting condition for families, carers and spouses. Unlike other conditions that are episodic in nature, ADHD is chronic, and places great demands on the immediate family. Respite is a need that is always reported, but seldom met, so that families are frequently placed under continuous, unremitting pressure.

NDIS –Secondary Functions

We are encouraged to read in the Overview and Recommendations the following:

> *Beyond that main function (and the biggest source of its costs), the NDIS would have several other important roles, including mustering community resources, providing information to people, quality assurance, diffusion of best practice among providers, and breaking down stereotypes.*

ADHD has for some decades been the subject of sensationalised media treatments that have promoted misinformation and negative stereotypes, and thereby created a

particularly strong stigma around the condition. This stigma is an additional burden for those with ADHD. Partly for this reason, it has been difficult to make headway with the education of the community, and with the dissemination of the conclusions of the vast scientific literature about ADHD among the health and education practitioners. We would appreciate the NDIS having a role in the capacities listed above. Many of these issues are very important to those who are living with ADHD, and we applaud their inclusion in the aims of the NDIS.

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[i] *Disability Care and Support. Productivity Commission Overview. Draft Report. Key Points p.2.*

[ii] *The Mental Health of Young People in Australia: Child and Adolescent Component of the National Mental Health Survey, 2000.*

[iii] *www.virtualmedicalcentre.com.au*

[iv] *http://www.un.org/disabilities/convention/conventionfull.shtml*

[v] *http://www.un.org/disabilities/convention/conventionfull.shtml*

[vi] *NHMRC Australian Guidelines On Attention Deficit Hyperactivity Disorder –Draft p X1.*