

Ref: AF23/10023 31 May 2023

Committee Secretary Senate Standing Committee on Community Affairs PO Box 6100 Parliament House, Canberra, ACT 2600

Re: Inquiry into the assessment and support services for people with ADHD - NSW Carers Advisory Council submission

Dear Committee Secretary,

The NSW Carers Advisory Council (the Council) writes to you regarding the terms of reference for the inquiry by the Senate Standing Committee on Community Affairs into the barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD.

The Council provides advice to the NSW Government on legislation, policy and other matters relating to carers. For more information, about the Council and our members, the majority of whom are carers, please visit our website at www.facs.nsw.gov.au/inclusion/advisory-councils/carers.

Following are the Council's responses to the terms of reference.

Term of Reference		Council comments
a)	adequacy of access to ADHD diagnosis;	It is often diagnosed at schools for boys who have behaviour issues and executive functioning slower than peers. Girls and Regional/ Remote Students and older people miss out due to lack of funding for diagnosis.
b)	adequacy of access to supports after an ADHD assessment;	This is often hard and parents resort to doctors, paediatricians and medications rather than other treatments to support their child if it is the only thing on offer.
c)	the availability, training and attitudes of treating practitioners, including workforce development options for increasing access to	It is important to improve public comprehension so the person with ADHD or ADD is not just seen as a difficult child with behavioural concerns in classrooms, leading to school disengagement and lower school completion.

Term of Reference		Council comments
	ADHD assessment and support services;	Later this impacts employment opportunities which can result in the person with ADHD having a lower social capacity and limited economic participation across their lifetime.
d)	impact of gender bias in ADHD assessment, support services and research;	Currently there is a significant gender bias in ADHD and ADD diagnoses favouring boys as they are less able to mask ADHD symptoms, similarly to ASD. Girls are often ADD and so are thought of as daydreaming, rather than the normal responses to ADHD.
e)	access to and cost of ADHD medication, including Medicare and Pharmaceutical Benefits Scheme coverage and options to improve access to ADHD medications;	All medications should be on PBS as they have efficacy and can be used long term to support the person with ADHD/ADD. Once the person has a diagnosis they should be able to get repeat scripts from a GP with minimal supervision from psychiatrists or paediatricians. Reissue of prescriptions should then be managed when a check-up is required to reduce the cost to families and freeing up specialist services.
f)	the role of the National Disability Insurance Scheme in supporting people with ADHD, with particular emphasis on the scheme's responsibility to recognise ADHD as a primary disability;	The NDIS considers how your diagnosis affects your functional capacity so if it is significant it should be allowed to be the primary diagnosis. Council is aware of 'doctor shopping' to get an autism diagnosis to allow access to the NDIS. This is dishonest; skews the prevalence data for both ADHD and ADD. If a person's functional capacity is impaired enough due to ADHD then they should warrant NDIS support including early intervention.
g)	the adequacy of, and interaction between, Commonwealth, state and local government services to meet the needs of people with ADHD at all life stages;	This is a prime area where state, federal and local government should work together to support, particularly young children with ADHD. There are many services that are labelled early intervention that benefit young children - community preschools and health nurses, federal funded NDIS, allied health such as OT, speech and play therapy, and schools with teachers, specialist teachers, counselling etc.
h)	the adequacy of Commonwealth funding allocated to ADHD research;	Council is not aware of current funding so cannot comment on the adequacy of this or not. It would be beneficial to consider innovative research methods that maximise funding and research outcomes.
i)	the social and economic cost of failing to provide adequate and appropriate ADHD services;	Council considers the social and economic costs to be substantial if those with ADHD are not adequately supported and provided with access to appropriate services. This has impacts on lifelong learning; workforce participation; and caring, both paid and unpaid care workers.

Term of Reference		Council comments
j)	the viability of recommendations from the Australian ADHD Professionals Association's Australian evidence-based clinical practice guideline for ADHD;	Published on their website and cited for others that use it.
k)	international best practice for ADHD diagnosis, support services, practitioner education and cost; and	
l)	any other related matters.	

On behalf of the Council and carers across NSW, I ask that you review our feedback taking into consideration needs and the role of carers. We also give permission for our submission to be published.

If you wish to discuss this further, please contact me on 0408 020 904 or at NSWCarersAdvisoryCouncilSecretariat@facs.nsw.gov.au.

Sincerely,

Prue Warrilow

Chair - NSW Carers Advisory Council