6 June 2023

Attachment A: Submission by Central and Eastern Sydney PHN: Senate inquiry into assessment and support services for people with attention deficit hyperactivity disorder (ADHD)

The Central and Eastern Sydney Primary Health Network (CESPHN) supports primary health care providers involved in the assessment and ongoing support of children and adults with ADHD. This submission summarises the experience of primary care clinicians, specialists, and health care consumers in our region and identifies how primary health care networks could support further initiatives addressing ADHD. We believe that that people with ADHD and their families have many unmet needs and there is an urgent need for policy and service reform.

Access to ADHD diagnosis:

In the CESPHN region, as seen nationally, clinicians are noting a significant increase in the number of people seeking support for ADHD diagnostic assessments. Access to these assessments and ongoing support is being severely constrained by workforce availability, cost and is often dependent on an individual's socioeconomic status and their understanding of the health system. For these reasons we are hearing that many people and their families in our region our missing out on care or receiving delayed care regards ADHD.

Early diagnosis is critical with the benefits well understood however access to ADHD assessments and diagnosis remains a prohibitive undertaking for both children and adults. General practitioners (GPs) and specialists in our region are noting a lack of services or delayed care for patients to access assessments and ongoing support. Within our region waiting periods of up to 12 months for public or low-cost assessments by paediatric, psychiatry, or psychologist services are common. Access to private psychiatry or developmental paediatricians can be extremely costly and inconsistent, with some services not accepting new referrals and the emphasis being on individuals and/or their GPs to search for a suitable alternate.

Long waiting periods for specialised diagnostic assessments from medical and allied health providers are incompatible with evidence supporting the need for early intervention. Delays in accessing appropriate supports can further entrench developmental disadvantage and place significant stress on patients, their families and carers, and health professionals and in the case of children compromise their learning outcomes. We have also heard that schools struggle to support children suspected of having ADHD and then adjusting their educational offerings to a child and their family when a diagnosis is confirmed leading to missed opportunities for early intervention and then ongoing support.

We specifically acknowledge the high comorbidity of mental health disorders in young people with ADHD. Services in the CESPHN region note the common occurrence of young people presenting with mental health disorders who are identified as having ADHD, with this not having been assessed or treated earlier in childhood. The delay in accessing assessment and treatment for ADHD is often a contributing factor to their mental health condition. This leads to a more complex mental health presentation and compounds the challenges they have experienced

participating in education, and their capacity to participate and benefit from treatment for their mental health condition. Mental health clinicians are finding that once ADHD is effectively treated, the young person can make substantial gains in their mental health treatment further emphasising the need for consistent and early access to assessments and treatment for ADHD.

Access to ongoing supports after an ADHD assessment:

In our view accessing ongoing support after an ADHD diagnosis is as prohibitive as gaining a diagnosis itself. Acknowledging that ADHD commonly occurs alongside other co-morbidities, accessing coordinated care from a multidisciplinary team is challenging to obtain. Within the CESPHN region, a number of factors limit access including lack of consumer health literacy and awareness of available services and supports, limited service capacity of publicly funded paediatricians, psychiatrists and psychologists, and financial constraints limiting access to private services. The costs of medications alone are a significant barrier for some consumers in our region.

The Australian Evidence-Based Clinical Practice Guideline for ADHD (2022) highlights the growing body of evidence recommending multimodal treatment alongside pharmacological interventions for people with ADHD. Individuals should receive support with sleep, diet and physical activity, parent and carer training, and cognitive behavioural interventions. These best practice guidelines need to be embedded in training for GPs and mental health clinicians, supported by regional referral pathways and include guidance on how to support access to this care via chronic disease management plans, team care arrangements and subsidised integrated models of care.

In addition to challenges accessing clinical interventions, our stakeholders in the CESPHN region report inadequate access to coordinated supports across the health, disability, and education systems. There appears to be significant disconnects between the education, health, and disability systems and clearly there is an urgent need for an upskilling of workforce skills to better support children and adults regards ADHD.

A continuation of the current care pathways will only contribute to a large and growing cohort of people and their families with ADHD missing out on care or receiving care and educational supports that are clearly sub optimal. CESPHN strongly believes that there is a need for a national plan that addresses all the elements of ongoing support for this complex population cohort and that actions have the support of States and Territories and are reflected in cross jurisdictional funding agreements.

Workforce development options:

In the CESPHN region, we note a strong willingness from clinicians to develop skills and expertise in assessing and supporting people with ADHD. There is an opportunity to build the capabilities of primary care clinicians to take on more care to ensure improved access while increasing the capacity of specialist services. Training needs to incorporate a person-centred approach for the individual being diagnosed, as well as wrap around support for carers and family members.

Paediatricians in our region specifically note delayed diagnosis in children as the result of long waiting lists and GPs not having the confidence to conduct preliminary screening assessments to

streamline diagnosis. Anecdotal reports from paediatricians in our region indicate only half of referrals include adequate information and results from preliminary assessments that could be completed by GPs or primary care nurses. General practitioners report frustration at the large cost their patients are experiencing from having to access private specialists who have extremely long waiting lists. A stronger authorising environment for GPs would enable primary care providers to deliver care that promotes earlier intervention and reduces waiting lists.

PHNs are in a unique position to build the capacity of the primary care workforce (both medical and allied health) regards ADHD to reduce knowledge gaps and increase confidence to complete preliminary assessments. Noting the high comorbidity of mental health disorders in young people with ADHD, there is an opportunity to specifically equip mental health services to support the assessment and treatment for ADHD as part of a comprehensive assessment of a young person's needs.

There are opportunities to facilitate greater cross-sectoral approaches when developing a model for best-practice support for children with an ADHD diagnosis, and the education sector needs to be included in this. Capacity building for teachers is necessary to ensure wrap around support can be provided to children diagnosed with ADHD ensuring they do not fall behind their peers in the classroom – anecdotally we are hearing that schools are struggling to support children and their families with ADHD.

In May 2023, a training workshop targeting primary school educators was facilitated by CESPHN and paediatricians from the Sydney Children's Hospital. The voluntary session focused on supporting children with learning difficulties and behaviours of concern and was attended by over 70 teachers from four schools. Such training is unique for our educators, and the strong uptake indicates a willingness of teachers to be upskilled but there is clearly a need for much greater support in this sector. A national standard of training for educators would ensure continuity in support for children moving between education settings, with benefits for children, their families, and teachers.

Access to ADHD medication:

There is distressingly limited access to bulk-billing clinicians who prescribe stimulants and provide ongoing monitoring for people with ADHD within the CESPHN region. This is of particular concern to young people and their families with limited funds. Psychiatrists within the public sector have noted their concern that the responsibility then falls on GPs with limited expertise to provide ongoing monitoring. There appears to be a somewhat artificial barrier that has resulted in psychiatrists not being allowed to prescribe for older adolescents aged 14 years and over. These adolescents may present with anxiety, depression and substance use for which psychiatrists can prescribe but not prescribe for ADHD which may also be present.

We have also heard that GPs feel that their scope of practice could be extended regards supporting the medication needs of people with ADHD – currently GPs ability to prescribe in this area is very limited.

CESPHN strongly supports a review of the prescribing and monitoring processes for people with ADHD accessing medication and increasing training opportunities for primary care clinicians and specialists. Expanding the healthcare workforce who have capacity and expertise to prescribe ADHD medication will reduce costs for consumers and facilitate timely access to qualified support.

CESPHN supports national consistency in prescribing guidelines, ensuring safety and effectiveness based on evidence and best-practice guidelines. We specifically note however, that supporting improved access to ADHD medication is not in lieu of increasing access to non-pharmacological supports outlined above.

The role of the National Disability Insurance Scheme (NDIS)

The NDIS has a leadership role to play in delivering cross-sectoral support to this population group as many of those eligible for NDIS also have ADHD. This leadership role should focus on building sector and workforce capacity and enabling localised delivery of educational support strategies to health, educational and community support workers. ADHD can be present in isolation and have a significant impact on an individual's functioning and on their quality of life.

Access to multidisciplinary supports should be guided by function and need, not solely by a diagnosis, and access to NDIS funded supports has the potential to greatly improve the outcomes for people with ADHD and reducing stress of family and carers.

Adequacy of, and interaction between, Commonwealth, state and local government services to meet the needs of people with ADHD at all life stages.

The issue of ADHD strongly highlights how the interfaces between health, disability and education are misaligned – designed, funded, lacking coherence and inconsistent. The lack of policy coherence across these areas ultimately contributes to service fragmentation and suboptimal user experience for children, adults and their families experiencing ADHD.

There is a lack of intersectionality between heath, education and disability that must be addressed to ensure that the needs of those with ADHD are met. The service fragmentation is real and widely acknowledged and efforts at resolution must be revitalised as a matter of priority. Incentives that reward collaborative efforts at helping bridge the silos between health, disability, and education should be provided. Given that the Commonwealth is a major policy maker and funder of these services it has a key role to play.

CESPHN believes that any proposed interventions must be evidence based to work out where service fragmentation has resulted in service gaps. Consideration should be given to joint commissioning of projects that go across education, disability, and health.

PHNs are themselves at the interface of education, disability, and health and increasingly we are taking the initiative and addressing gaps through our work in intellectual disability, and our work in schools. Our efforts, while a start, are small in relation to the large numbers of children, adults and their families impacted by ADHD.

Summary

In summary, CESPHN strongly supports:

- Development of a national plan specific for ADHD that would address all the major elements required to support children, adults, and their families with ADHD. This plan and accompanying targets must be reflected in cross jurisdictional funding agreements in heath, disability, and education.
- A workforce development strategy which includes comprehensive training for primary care clinicals and specialists on ADHD assessments, and ongoing pharmacological and non-pharmacological management in line with national guidelines.
- Improved mechanisms for all people with ADHD to access medications and ongoing monitoring and support and this would include reviewing and improving the capacity of GPs to prescribe ADHD medication.
- Improved system integration between health, disability, and education sectors to ensure the long-term needs of this population group are met.

Primary Health Networks (PHNs) are in a unique position to support these objectives and build the capacity of the primary care workforce to improve access to assessments and support for people with ADHD. There are opportunities to align activities in this area with existing Commonwealth funded initiatives such as the Primary Care Enhancement Program, aimed at upskilling the primary care workforce to deliver care for people with intellectual disability.

PHNs can leverage off existing relationships with primary care clinicians and embed ADHD awareness, training, and support within successful project models. PHNs are also able to tailor support to priority population groups within their regions, including Aboriginal and Torres Strait Islander Peoples and people from multicultural backgrounds.