

Questions on notice: What is the best practice approach for all stages of the ADHD assessment and treatment process—from initial assessment and diagnosis, through to medication (as required) and other treatment, as well as ongoing support and treatment plans.

Multidisciplinary diagnosis and treatment pathways, care provision models and ADHD education program development – things to consider

When it comes to the development of multidisciplinary pathways for diagnosing and treating people with ADHD and care provision models, it feels like everyone wants a piece of the pie. That every specialist feels like they know what's best or should be solely responsible for screening people for ADHD. Or that everyone who has developed a multidisciplinary treatment pathway or care provision model feels theirs is the best. The same goes with ADHD education for clinicians, teachers, etc.. It makes me feel very uncomfortable, and I can't help but wonder if anyone asked people with ADHD that do not have a vested interest for their input during the development process (i.e., people with ADHD who do not work in a profession or role that supports people with ADHD)? Or made sure that the lived experience voice was not overshadowed by the voices of others during the development process? And how do we ensure their voices are heard and considered moving forward?

People with ADHD should be involved in developing all ADHD research, interventions and education. In fact, the use of participatory research practices in the neurodevelopmental space is now viewed as being a [moral obligation and a practical imperative](#). [The integration of lived experience into research](#) ensures research is patient centred and enhances methodological sensitivity, data accuracy, validity of results, and the overall relevance to service users. [In the autism space](#), it has been shown to:

- improve the quality of research methods and place findings within a real-world context, thus facilitating the translation of findings into practice
- ensure that research yields relevant and meaningful benefits for the autism community
- enhance involvement, collaboration and trust between researchers and autistic people and their allies.

While I acknowledge all input into the development of ADHD research, interventions and education is invaluable, it is important to understand that, in general, there is a big difference between the views and input of academics or clinicians with ADHD that sit firmly in the research or clinical space, versus a person with research, clinical and lived experience that remains solely seated in the lived experience/advocacy space at all times. There is also a big difference between someone who gives their personal lived experience opinion (which is important and valid) versus an advocate who tries to listen to, understand and represent the voices of all people and groups of people with ADHD, while also consulting the research before providing input.

The presentation, experiences and needs of people with ADHD and autistic individuals with ADHD can also be very different, and needs to be taken into consideration. For example, autistic adults with ADHD generally prefer the use of identity first language i.e., 'I'm autistic ADHD'. From observing copious conversations online and in person on this matter, I am aware that most people with ADHD do not. They prefer using person first language i.e., 'I have ADHD.' Many people with ADHD are also concerned their feelings about this matter are not being heard or are being overridden by louder voices. It is likely people with ADHD feel this way because calling someone ADHD is calling them a deficit and a disorder. If people with ADHD had a term like 'autistic' they could use, it is possible this would change.

Diagnostic process – things to consider

As per the Australian Evidence-Based Clinical Practice Guidelines for ADHD, assessment for ADHD should involve:

- A full clinical and psychosocial assessment, including a discussion about the person's symptoms and strengths, and how they present
- A full developmental, mental health and healthy history
- Observer reports and assessments of the person's symptoms and mental state

- A medical assessment to exclude other causes of symptoms and identify any associated disorders that also require investigation, intervention and support. Medical investigations should be performed if clinically indicated.

My understanding is that developmental paediatricians, psychiatrists and some GP's are the only specialists that can (legally and due to training and experience) currently perform all components of the above ADHD assessment process and prescribe ADHD medication (the recommended treatment intervention for anyone with ADHD over the age of 6). Due to their previous training, experience and credentialing, GP's and Mental Health Nurse Practitioners are the only other clinical groups that would also have the ability to perform all components of the ADHD assessment process and prescribe ADHD medication if they were provided with appropriate training and support.

Of further consideration is that:

- The more clinicians a patient has to see during the diagnostic process, the more confusing and expensive the diagnostic process will be.
- Diagnostic pathways and care provision should always be tailored to each individual's presentation, needs, and goals and not be guided by a strict one size fits all pathway.
- Some professions are more prone to pathologising people with ADHD than others, and to forgetting they have agency. Clinical pathways if not implemented mindfully, can also contribute to the pathologising of people with ADHD (and to over servicing).
- Children undergoing screening for ADHD should also be screened for [autism](#) as well as other conditions such as learning disorders.
- If the clinician undertaking an ADHD assessment identifies that a child is at high risk of autism, formal assessment should not be delayed. However, if the clinician undertaking an ADHD assessment identifies that the child is at high risk of one or more learning, formal assessment does not have to be completed straight away. The decision as to when this assessment will occur should be made in consultation with the child's parents. The reason being that while some parents may be happy if their child undergoes assessment for ADHD and one or more learning disorders at the same time, another parent may feel overwhelmed by the ADHD assessment process and subsequent diagnosis, and prefer to address one of their child's challenges at a time. There will also be parents who can afford to pay for their child to be screened for ADHD and one or more learning disorders at the same time, and others who will need to save money between assessments.
- An assessment for one or more learning disorders is not required in order to diagnose a person with ADHD, and should only occur if a:
 - Child displays a number of traits that indicate they are at risk for a particular learning disorder.
 - Adults displays a number of traits that indicate they are at risk for a particular learning disorder and they feel that receiving a diagnosis and treatment would be beneficial.
- When a child with a diagnosis of ADHD is going to attend a clinic to be screened for one or more learning disorders, their parents are asked to give their child their ADHD medication prior to their assessment. I believe this is to avoid their ADHD traits being confused with the traits associated with a learning disorder. Hence, ADHD can be diagnosed and treated first (and it may be beneficial if it is).
- People with ADHD and their families should be provided with information related to their assessment options (i.e., via paediatrician, psychiatrist or psychologist) and the costs involved, so that they can make an informed decision regarding the diagnostic route they take. I have witnessed copious adults with ADHD complain every year that the person assessing them for ADHD did not tell them they couldn't prescribe ADHD medication until after their assessment was finalised. As a result, they had to go and see another specialist and doing so was going to cost them more money. Many also report it would have been cheaper if they were diagnosed by the clinician who could prescribe medication in the first place.
- The use of computer-based tools when screening for ADHD likely increases the cost of the diagnostic process and the patient/families out of pocket expenses. Therefore prior to their use,

consideration should be given as to whether these tools are more efficacious than standard rating scales when assessing for ADHD (Neither should be used in isolation).

- Current measurement-based assessment tools for ADHD only assess for ADHD symptoms. I would argue that when it comes to assessing medication efficacy, the assessment tools used should also assess for psychological measures such as improvements in being able to stay present, self-awareness, self-esteem, ability to get more done, etc. Furthermore, no tool should be used in isolation. The treating clinician should also ask the patient for their input i.e., Do you think the medication has made a difference? What have you noticed (the good and the bad)? Has it helped you to get more things done in a day? Do you feel more or less stressed?
- While the Guideline recommends that all patients/parents receive psychoeducation on ADHD, currently there are no Australian standards for training health professionals and teachers on ADHD and no consensus on what psychoeducation on ADHD should include.
- If a patient/parent decides they would like to work with an ADHD coach, they should be provided with information on how to determine whether a coach has undertaken ADHD specific coach via an accredited coach training organisation. Although ADHD coaches should be a member of the International Coaching Federation or be working towards or hold accreditation, there are people offering ADHD coaching in Australia without the appropriate training to do so. This website contains a list of Australia ADHD coaches who have undergone appropriate training.
<https://www.adhdcoachesaustraliaonline/>
- Should speciality clinics be set up, it would be more beneficial if they were neurodevelopmental (for children) and mental health (for adults) clinics not solely ADHD clinics as people with ADHD often present with one or more co-occurring conditions.

Philosophy underpinning all ADHD treatment and support

As per my previous submission, best practice approaches to all stages of ADHD assessment and treatment should be:

- evidence-based
- holistic
- protective
- collaborative
- person-centred
- recovery-orientated
- trauma informed
- adaption focused.

All care provided should be adapted to each individual patient and aim to foster:

- self-awareness
- acceptance of disability
- self-compassion
- informed decision-making
- co-production of a person's individualised treatment plan
- personal empowerment, independence and self-determination.

This care paradigm needs to start in childhood, as symptom control and behaviour management are not the end goal. The end goal is for children with ADHD to grow into self-aware, well-adjusted individuals who understand their condition and accept themselves fully—individuals who have learned to harness their strengths and scaffold their challenges to the best of their ability so they can competently navigate societal expectations and the challenges they will inevitably face, and live full and rewarding lives.

Holistic care provision can be defined as care that:

- takes into account a person's individual biological, psychological, educational, social, spiritual and cultural background, and needs and wants
- includes all aspects of a person's functioning, activities, participation, abilities and disabilities and the context in which they occur.

Recovery in the mental health arena, is conceptualised as being:

- a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles (Anthony, 1993, p. 527)
- important for living a life where one feels hopeful, satisfied and able to contribute to society irrespective of any limitations resulting from illness or disability (Anthony, 1993; Green, 2004; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011).

Conceptualised as an alternative to the medical model, recovery-focused care fosters hope, self-understanding of one's abilities and limitations, self-determination, independence, self-determination and self-advocacy skills. It also emphasises the right to a life that is inclusive, meaningful, of one's own choosing, and free of discrimination (Anthony, 1993; Green, 2004). More information on Recovery Focused Care can be found [here](#).

Trauma-informed care is based on the understanding that:

- a significant number of people living with mental health conditions have experienced trauma in their lives (including people with ADHD)
- trauma may be a factor for people in distress
- the impact of trauma may be lifelong
- trauma can impact the person, their emotions and relationships with others.

Trauma informed care providers view trauma survivors as 'unique individuals who have experienced extremely abnormal situations and have managed the best they could' (Dr Cathy Kezelm). They avoid re-traumatising or blaming victims for their efforts to manage their traumatic reactions and instead promote healing and foster hope, optimism and the belief that recovery is possible.

The core principles underlying trauma informed care include:

- Safety (both emotional and physical)
- Trust
- Choice
- Collaboration
- Empowerment
- Respect for Diversity (Fallot and Harris, 2001).

More information about trauma informed care can be found [here](#).

Acceptance of disability acknowledges that a person's health and well-being are not exclusively determined by the characteristics of their disability or illness and that people can be happy and healthy despite their disability (Schultz et al., 2002). Positive acceptance of disability enables people with a disability to accept their reality, recognise their own values and strengths, and to move towards adaption and recovery.

Co-production refers to clinicians and people with ADHD working together to develop a individualised treatment and support plan with people with ADHD and their families being at the centre of all decision-making.