

## **Question 1 on notice: Where are the unhelpful institutional personal responses to ADHD? In schools, workplaces and families? How do we unpack trying to redirect people to the right evidence base?**

People with ADHD receiving unhelpful responses, although improving:

- Tends to be the norm rather than the exception.
- Occurs in all areas of life - from the parent-child attachment relationship and home environment, to healthcare, school, social environments.
- Results from ADHD-related challenges being incorrectly viewed as behaviours one should be able to learn to control, rather than symptoms of a neurodevelopmental condition one needs to learn to scaffold and adapt to.

These unhelpful responses leave children and adults with ADHD feeling misunderstood, inadequate, embarrassed and incompetent, and increase the risk they will find themselves on the receiving end of constant correction, redirection, punishment and social isolation. They also likely contribute to the following research findings:

- Children and adults with ADHD often experience difficulties with identity formation, feel like they do not belong (Ringer, 2020) and believe there is something innately wrong with them (Kendall et al., 2004).
- Children with ADHD tend to view their most problematic behaviour as being uncontrollable, embarrassing and bothersome to others (Wiener et al., 2012). They also feel the stigma associated with their condition (Wiener et al., 2012).
- Children suffer emotionally due to their ADHD. Thirty-four per cent of parents who participated in a European study conducted by Sikirica et al. (2015), reported that their child experienced low self-esteem and a lack of confidence, while seventy-five per cent of the adolescents who participated in the same study reported feeling embarrassed, ashamed and annoyed about having ADHD. Parents who participated in an Australian study reported that their children expressed self-loathing and two out of 13 caregivers mentioned that their child with ADHD wanted to die (Leitch et al., 2019).
- Fifty per cent of Australian parents who participated in the 2019 Parents for ADHD Advocacy Australia study [Parents and carer experiences of ADHD in Australian Schools: Critical gaps](#) reported difficulty obtaining appropriate ADHD support for their children at school. Furthermore, ninety-five per cent of parents believed teachers and school staff need specific ADHD training, thirty per cent of children with ADHD have been subject to informal exclusions, and twenty-four per cent of children with ADHD have been suspended. This particularly concerning as research indicates there is a [direct pipeline between school suspension and incarceration](#).
- People with ADHD and parents of children with ADHD report receiving inappropriate care and a number of unmet needs as outlined in the following 2023 paper, [Practitioner Review: It's time to bridge the gap—understanding the unmet needs of consumers with attention-deficit/hyperactivity disorder—a systematic review and recommendations](#) (paper provided).
- ADHD continues to be a highly stigmatised condition as per the following 2022 paper, [Recent Attitudes toward ADHD in the Broader Community: A Systematic Review](#)

There are likely to be multiple reasons why this occurs.

Firstly, appropriate education and information on ADHD tends to be lacking, and the quality of what is available, varies greatly. I have not come across any books or education programs that I feel meet the needs of people with ADHD and their families, or education programs for parents, teachers and clinicians that I would recommend, which makes it hard to direct people to appropriate resources. Instead, often the content:

- Is overly clinical or superficial.
- Rarely provides any real insight into ADHD.
- Contains theories, models and assumptions presented as facts or grand statements that cannot be backed up by the research data.

- Suggests home and school interventions based on operant conditioning, which is inappropriate as per the confidential document I provided when I appeared in front of the Senate enquiry, ***Examination of parent management programs currently recommended when children have ADHD – An integrated review.***
- Ignores the fact children and adults with ADHD have agency as well as different needs and wants, and that there's not, and never will be, 'one size fits all' strategies that work for everyone with ADHD. Furthermore, teaching strategies to people with ADHD, rather than using motivation interviewing techniques as a means of helping people with ADHD developed their own personalised strategies in a collaborative manner, is disempowering. It robs them of the opportunity to develop self-awareness and personal empowerment, and can result in them:
  - Feeling infantilised and like their challenges are not valid or understood.
  - Becoming more anxious about making mistakes, especially if they interpreted the strategies as being mandatory instructions rather than ideas they can experiment with.
  - Experiencing overwhelm due to the sheer volume of suggestions offered to them or the number of steps involved, which can trigger procrastination or make them want to give up altogether.
  - Excitedly trying a *recommended* strategy only to discover that it didn't work for them, or that the strategy had a use-by date due to the role interest plays stimulating dopamine availability and therefore self-regulation capacity. These experience can leave people with ADHD feeling like a failure and fuel any deep-seated negative self-beliefs.

From a personal perspective, the delivery of education is often stigmatising. It can feel judgemental and leave you wondering if the people providing education on ADHD really understand the condition, or like people with ADHD.

Getting education on ADHD right is vital as the explanation a person attributes to a child or adult's challenging traits greatly influences how they will perceive and respond to them. These explanations also influence how a person with ADHD will perceive and respond to themselves. Furthermore, you cannot effectively scaffold and support a child or adult with ADHD or learn to scaffold and support yourself, if you do not know and understand the developmental and cognitive difference associated with ADHD.

To address the unmet need for appropriate education on ADHD for parents, as part of my PhD I am developing, and about to pilot, an ADHD education program for parents that aims to empower them to commence the process of fostering the development of their children as independent, healthy, functioning adults with ADHD in their prepubescent years. To my knowledge, this will be the first ADHD parenting program (1) informed by a purposeful integrated review of the ADHD literature and convergent research findings, (2) grounded in biopsychosocial theory, (3) encompassing acceptance of disability, recovery and shared management principles, and (4) developed using non-judgemental language like that outlined in [AADPA's Talking about ADHD guide](#). It will also be the first ADHD parent education program that provides insight into the neurotypical baseline and the divergent neurodevelopmental and cognitive differences associated with ADHD in order to better facilitate parental understanding of ADHD and the impact the condition has on children. For it is only with this information, that parents can respond to children with ADHD in a competent, attuned manner and protect the parent-child attachment relationship, as well as foster in them the protect traits they will require to successfully navigate the challenges they will inevitably face, and live full and rewarding lives with ADHD. Please see additional submission titled, ***About the narrative and integrated review conducted to inform the development of an ADHD parent education program.*** This integrative review of the literature was designed so that it could also be used to develop other evidence-based education programs on ADHD.

To address the need for teacher education on ADHD I also wrote [ADHD in Primary School: A guide to understanding and supporting students with ADHD in the classroom](#), and a four-hour workshop for teachers that I have run in Perth, Melbourne and Sydney. I have updated and [recently ran the teachers workshop](#) since completing my integrative literature review, and am now working to update

the teacher's guide. Like the ADHD parent education program, the teachers workshop (and soon the teacher's guide):

- Is grounded in biopsychosocial theory.
- Encompass acceptance of disability, recovery and shared management principles.
- Was developed using non-judgemental language like that outlined in [AADPA's Talking about ADHD guide](#).
- Provides insight into the neurotypical baseline and the divergent neurodevelopmental and cognitive differences associated with ADHD to assist teachers to respond to students with ADHD in a competent, attuned manner.

Secondly, ADHD was first viewed as a behaviour disorder that children grew out of, and children with ADHD were thought to be naughty, lazy, stupid, bad, etc. Unfortunately, thus far the education provided on ADHD has not been able to irradicate these misconceptions. This is despite:

- There being overwhelming and irrefutable evidence that shows:
  - the symptomatic behaviour displayed by kids with ADHD stems from genetic differences that result in alterations in brain development, structure, connectivity and function, and is beyond their own making and ability to control, and
  - the condition tends to affect people throughout the life course.
- ADHD being reclassified as a neurodevelopmental disorder in the 5th edition of the DSM (American Psychiatric Association, 2015).

It is hoped that incorporating insight into the neurotypical baseline and the divergent neurodevelopmental and cognitive differences associated with ADHD into ADHD education programs will assist people to adjust the framework through which they view and interpret people with ADHD, and thus irradicate these misconceptions.

Thirdly, children and adults with ADHD are expected to fit into a neurotypical world that was not created for them. Most treatment and support interventions were also created using a neurotypical framework (i.e., parent training interventions, emotional regulation and social skills training, time management and organisational skill development courses), and rarely take into consideration a child's delay in cognitive development and subsequent lagging cognitive skills, or an adults ongoing ADHD cognitive differences. This is highly problematic as support interventions developed using a neurotypical framework, set people with ADHD up to fail, and this failure further impacts upon their self-perception and poor self-esteem. It also increases the risk they will go on to receive further criticism due to the misconception that 'now they have been taught how to do something, they should be able to do it.' However, this presumption reflects a poor understanding of ADHD and the impact interest and dopamine availability has on a person self-regulation capacity. I have a saying, "You can teach someone with ADHD to use a diary, but that doesn't mean they can. If you do not understand this, you do not understand ADHD."

There are other copious historical factors that also contribute to the unhelpful institutional personal responses people with ADHD receive. These include:

- The stigma and misunderstanding that surrounds ADHD, which was once insurmountable, and the rife fear mongering around ADHD medication. While we have made marked headway here, these problems still exist.
- Research into ADHD not being conducted using participatory research practices (meaning people with ADHD were not involved in research conceptualisation, development, and implementation). This has improved but needs to be mandated to ensure it becomes the norm rather than the exception.
- The use of research tools that were developed prior to ADHD being conceptualised as a neurodevelopmental condition. Many of these tools continue to be used despite the inferences and language contained within them being stigmatising and inappropriate. *(Please see section **A word on problematic research tools**, below).*
- The use of operant conditioning and behavioural practices at home and at school as a means of controlling children with ADHD, which are unfortunately still in use. Hence, parents and teachers have been taught, and are continuing to be taught, to respond to children with

ADHD in an unattuned and harmful manner. A manner that severs the parent-child and teacher-student attachment relationships, and increases the risk children with ADHD will develop poor self-concept and self-esteem, and other risk factors associated with ADHD.

To combat these historical problems, moving forward:

- All research on ADHD should be conducted in a participatory manner. This will help to bridge the gap between research and lived experience, and ensure research findings are of high validity, utility and relevance.
- All educational and informational resources on ADHD should:
  - Be based on the best available research evidence and reflect convergent research findings (rather than the results of one or two studies).
  - Aim to help people really understand the underlying neurological and cognitive differences associated with ADHD.
- All ADHD research findings and education resources should be delivered using non-judgmental and non-stigmatising language (Please see section below, **Why words matter**).
- The use of operant conditioning and behavioural practices, at home and at school, should cease.

## A word on problematic research tools

Many research tools used in ADHD research were developed prior to ADHD being classified as a neurodevelopmental condition. For this reason, I believe many are no longer appropriate for use. For example, the classification terminology and language contained in some tools is deficit based and can feed into negative narratives and stereotypes as well as cause psychological harm to people living with ADHD. As an example, various tools:

- Classify individuals as 'abnormal' (Derogatory term, infers less than).
- Label a tool subscale with the term 'problem' i.e., emotion problems or peer problems (Deficit based, infers a predetermined judgement, subconsciously influences assessor perception).

Many studies also use terms like behavioural, behaviour problems or problematic behaviour. However, ADHD is not a behaviour disorder. These terms automatically elicit thoughts like 'behaviour is a choice', 'naughty', 'child needs punishing'. Furthermore, the scoring systems employed by ADHD studies often does not allow for differentiation between a child or adult's medicated verses unmedicated presentation.

Two examples of research scales that I believe require reviewing and updating prior to further use in ADHD research include the:

- The Strengths and Difficulties Questionnaire.
- Parent Cognition Scale.

### The Strengths and Difficulties Questionnaire (1997)

The Strengths and Difficulties Questionnaire was developed to screen for emotional and behavioural problems in children. It was developed prior to ADHD being classified as a neurodevelopmental disorder. The questionnaire consists of one strengths subscale and four difficulty subscales. These being:

- Prosocial Behaviour
- Emotion Problems
- Conduct Problems
- Hyperactivity
- Peer Problems.

These subscales are summarised by the higher-order Internalising Scale (Emotion Problems and Peer Problems), Externalising Scale (Conduct Problems and Hyperactivity), and Total Difficulties Score (all scales except for the Prosocial scale). The attributed scores are typically interpreted in relation to cut-off scores that delineate between “normal”, “borderline” and “abnormal” results.

The use of deficit-based language is harmful. Use of the word problem infers a predetermined judgment, which likely subconsciously influences the user’s perception of the study participant. It would be better if the subscale used less judgemental language i.e.:

- Emotional Regulation Capacity
- Social Conduct
- Peer Relationships.

The use of the word ‘abnormal’ also needs to be abolished and replaced with a neutral term such as ‘atypical’ or ‘indicative of ADHD or a neurodevelopmental condition’, and the Total Difficult Score should be given a neutral name i.e., Total Symptom Score.

### Parent Cognition Scale (2009)

The Parent Cognition Scale was developed to examine disruptive behaviour prior to ADHD being classified as a neurodevelopmental condition. The scale does not provide parents with the opportunity to choose any ADHD informed response options (i.e., responses that align with the likely reasons underlying their child with ADHD’s presentation), nor does the scale enable parents to provide feedback on the use of appropriate parenting responses. Instead, all response options infer that the:

- Child in question is wilfully non-compliant and their symptoms are character flaws.
- Parent is failing to gain compliance and control over their child and need to be stricter/firmer.

As a result, when used in ADHD research the scale inadvertently feeds into the stigma surrounding ADHD it can negatively influence parent’s perception of their child with ADHD, which in turn can compromise their ability to respond to their child in a competent, attuned manner and damage the quality of the parent-child attachment relationship.

Examples of inappropriate response options:

- ‘My child won’t listen.’ This response option implies a child’s symptoms are character traits. It would be more appropriate to state ‘my child cannot listen’ (as they are struggling to be present due to internal distractions or can’t sit still).
- ‘My child wants what he wants when he/she wants it.’ This response option implies a child is wilfully trying to manipulate a situation rather than struggling to delay gratification and self-soothe.
- ‘I handle my child’, ‘I can’t control my child’, ‘My child won’t do what I think they should do.’ These response options imply that effectively parenting children with ADHD is all about gaining control and compliance, rather than listening with empathy, connection, validation, keeping them safe by scaffolding their developmental delay, and providing emotional support and gentle guidance, etc. These terms also infer the child in question is bad, naughty, defiant, etc.

## **Why words matter**

When talking or writing about ADHD, many people, even those with the best intentions, often unwittingly use language (words/rhetoric) that elicits negative narratives and feeds into the stigma surrounding ADHD. Language that although unintentional, can also cause psychological harm.

When a person hears a word, no matter who they are, the word elicits an immediate and automatic production of other words (in the form of thoughts that pop into their mind). These thoughts impact

the person's perception as well as their future thoughts, words and actions.

For example, on hearing the word *behaviour*, words such as good, bad, well behaved or naughty pop into the mind of most people. When used during a discussion or media segment involving ADHD, however, the word *behaviour* often elicits negative narratives (or broad beliefs that have become established in the public consciousness that are difficult to budge), such as 'children with ADHD are just naughty,' ADHD is an excuse for bad behaviour,' or 'adults with ADHD are lazy and rude.' Each time this negative narrative is elicited, the association between the word *behaviour*, ADHD and the negative narrative is strengthened and further embedded into public perception. The only way we can break this association is to cease using the word *behaviour* when talking about ADHD, and instead describe the symptoms and traits associated with the condition i.e., hyperactivity, restlessness, impulsivity, inability to inhibit oneself, distractibility, problems with self-regulation, etc.

The word *manage* is another example of a problematic word. Use of the term:

- *Manage a child* frames children with ADHD as a 'problem' that needs to be fixed or controlled rather than as little humans that need to be nurtured and scaffolded while growing up.
- *Manage behaviour* frames ADHD symptoms and impairments as intentional behaviours rather than as symptoms of a neurodevelopmental disability. This perception places children with ADHD at risk of (1) negative feedback due to their neuropsychological impairment and (2) *behavioural* interventions that seek to control them (which adults with autism and ADHD continue to report cause psychological harm).
- *Manage ADHD* frames ADHD as a burden that a person has to control to survive rather than as a condition that a person can adapt to and thrive with.

In contrast, the term *learn to live with* aligns with the recover paradigm, leaves room for compassion and empathy, fosters hope and optimism, and the belief that:

- Children with ADHD can grow up to live full and rewarding lives if they are provided with understanding, empathy and ADHD appropriate scaffolding, guidance and support in childhood.
- With treatment and support, adults with ADHD can adapt to their condition by developing the understanding, tools and strategies they require to live successfully with their condition and thrive.

For further guidance on the language, please see [Talking about ADHD Guide](#).

**Please note:** Language used during educational presentations and in academic papers, government documents, and other literature also matters as it:

- Influences how clinicians view people with ADHD.
- Seeps into the conversations between clinicians and people with ADHD and their family members, and often ends up in the media.
- Influences how the person with ADHD perceives and treats themselves or how a parent perceives and treats their child with ADHD.

### **Why refer to ADHD as a disability:**

- ADHD meets the definition of disability under the 1992 Disability Discrimination Act.
- The word disability should not hold negative connotations.
- The disabled community has, with only a few exceptions, chosen to use the terms 'disability' and 'disabled' to describe and identify themselves.
- There are fabulous examples of people thriving with a disability (i.e., Dylan Alcott), that help to combat the risk of learned helplessness and instead role model that people with a disability can live full and rewarding lives.
- Acceptance of disability is empowering and aligns with the recovery paradigm. For example, promoting acceptance of disability helps parents come to terms with the need to support and

scaffold their children while at the same time fostering in them the self-awareness, self-acceptance, self-compassion and the knowledge and skills required to live successfully with the condition. For adults, acceptance of disability has been shown to correlate with better adjustment as it facilitates non-judgemental self-awareness and critical problem-solving.

- The term 'ADHD can be disabling' may leave room for judgment from self and others, and invite comparison and criticism.
- From a policy perspective 'ADHD is a disability' infers children and adults with ADHD are entitled to accommodations and support.