



**Parent & carer
experiences of ADHD in
Australian schools: **Critical gaps****

Parents for ADHD Advocacy Australia





ADHD is a common developmental disorder. Whilst classification of ADHD is based on behavioural criteria, the disorder is biologically based, with strong genetic transmission. ADHD results in genuine disability, acknowledged by the educational, legal and medical communities.

School is the place where the most damage can be done, but also where the greatest difference can be made. With sufficient government recognition and support, funding, diagnosis, medical care, parent and teacher education, cultural and attitudinal change in schools, a focus on inclusion, and specific adjustments, we can change the trajectory that children with ADHD face and achieve better life outcomes for those with ADHD and their families.

On behalf of all stakeholders in the ADHD community, ADHD Australia supports PAAA's findings and recommendations, and will continue to advocate for positive change in our education system for children with ADHD.

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Foreword

Attention Deficit Hyperactivity Disorder (ADHD) is the most prevalent mental health disorder in school-aged children¹.

Stigma and lack of understanding of ADHD in the community has meant that the impact of ADHD on individuals and families is often unrecognised. Many perceive ADHD to be a behavioural disorder, however, in reality it is a neurobiological disorder. People with ADHD have brains that function differently from those who do not. ADHD may also be accompanied by one or more comorbidities, such as learning disorders, anxiety, *oppositional defiant disorder* and *conduct disorder* which can add complexity in the areas of mental health, learning ability, social skills and emotional regulation.

The symptoms of ADHD such as impulsivity, inattention, *emotional dysregulation* and poor *executive function* can make navigating school a difficult and stressful experience for individuals. Research in Australia has shown that students with ADHD can fall behind academically in comparison to their peers^{1,2}. The self-esteem and emotional wellbeing of students with ADHD can also be greatly impacted by how they are treated at school by others. As a result, school can be major source of stress and worry to children with ADHD as well as their parents, many of whom lack the confidence needed to advocate for their child and feel alienated by the school system.

The prevalence of ADHD means that within each classroom at least one to two students will need additional assistance or an altered teaching and supportive approach³. Under the *Disability Discrimination Act (DDA)* and *Disability Standards for Education (DSE)*, students with ADHD have a right to an inclusive education, which allows them to access education ‘on the same basis as their peers’.

But are schools providing adequate support to students with ADHD or are they often treated as if they do not belong?

This question was a key driver for Parents for ADHD Advocacy Australia (PAAA) to undertake a survey about the experiences of students with ADHD in Australian schools, based on the perspectives of their parents and carers. The survey explored themes such as: parent investment, school support, communication, discipline and procedural fairness.

This report presents compelling ‘real world’ data outlining critical gaps and inconsistencies in the capacity of schools to support the learning, social and emotional needs of many students with ADHD.

This report also outlines the distressing impact that these gaps can have on the lives of individuals and families. Finally, the report provides evidence that indicates the education system is failing to provide an inclusive education to students with ADHD.

We urgently call for a multi-agency effort involving governments, education departments, principals, teachers, medical professionals, parents and carers of children with ADHD and other allied stakeholders. The shared goal must be recognition of the challenges faced by students with ADHD, working together to ensure that young people with ADHD have a successful school experience which allows them to achieve their potential.

*Doris Hopkins, Louise Kuchel and Rimmelle Freedman –
Parents for ADHD Advocacy Australia*



Purpose of this document

This document reports the results and conclusions of a survey of parents and carers of children with Attention Deficit Hyperactivity Disorder (ADHD) in Australian schools. Drawing on the experiences and needs identified in the survey, it makes recommendations to improve educational, social and emotional outcomes of students with ADHD.

For ease of reading, 'parent' will be used to describe 'parents and carers' throughout this document.

“Many respondents shared personal commentary to further highlight key issues, which we have included as direct verbatim quotes throughout the report.”

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In short

What we did

Parents for ADHD Advocacy (PAAA) conducted an online survey of parents of school-aged children with ADHD over three months in 2018.

The survey was the first in Australia to gather information about what it is like to have a child with ADHD in the *Australian school system*.

The survey attracted 1,184 respondents and achieved a proportionate spread of respondents from across Australia. Eighty percent of the students with ADHD were male, with three quarters of the students attending primary school. Close to half (49%) of the students with ADHD represented in the survey attended a primary school in the public setting.

The results suggest there are critical gaps in the capacity of schools to include and support students with ADHD.

The critical gaps we found

Skills, knowledge and resources

Parents reported a large gap in ADHD-specific knowledge among school staff and educators with many students missing out on appropriate resources and adjustments to help them learn.

Punitive and exclusionary practises

Parents reported high rates of detentions, exclusions and suspensions among their children with ADHD resulting in reduced time in education and a negative impact on mental health.

Negative impact on students' wellbeing

Parents reported high levels of bullying and social isolation experienced by their children, which was often not adequately addressed by schools and caused distress for children and their families.

Lack of ADHD funding

An absence of ADHD-specific funding for learning support resulted in parents being pressed by some schools to gain alternative or escalated diagnosis for their children and/or give their children medication or adjust their medication dose.

Procedural fairness

Parents expressed a limited capacity to redress their child's access to education, with suspension and appeal policies not well understood and a perception that their child's ADHD was not adequately taken into account when schools applied punitive measures.

Meanwhile, parents of students with ADHD carry a large financial and emotional burden including paying for health expertise, undertaking ADHD training and reducing work hours or giving up employment to support their children.

What needs to be done

From a collective parent and carer perspective, there are critical gaps in how students with ADHD access and receive support in Australian schools, which is at odds with schools' obligations to DDA and DSE disability legislation. Students with ADHD are experiencing poor learning, social and emotional outcomes and families experience a high financial and emotional burden. Given the 7% prevalence of ADHD in children⁴ and the lifelong impact of inadequate school support for these students, these gaps warrant urgent review.

There is an urgent need for ADHD to be recognised by the Australian Government and education departments as a legitimate disability and for the current gaps in the education of students with ADHD to be addressed.

Governments, departments of education, principals, teachers, medical professionals, parents of children with ADHD and other allied stakeholders all have a role in improving the school experience for children with ADHD. Only by working together to address these gaps can we create school environments that are equipped to adequately support children with ADHD and allow them to achieve their potential.

How we did this survey

Members of the PAAA Survey Working Group developed questions for an online survey based on gaps they had noticed in the published literature (such as research papers and education department reports) as well as online discussions on Australian ADHD social media networks.

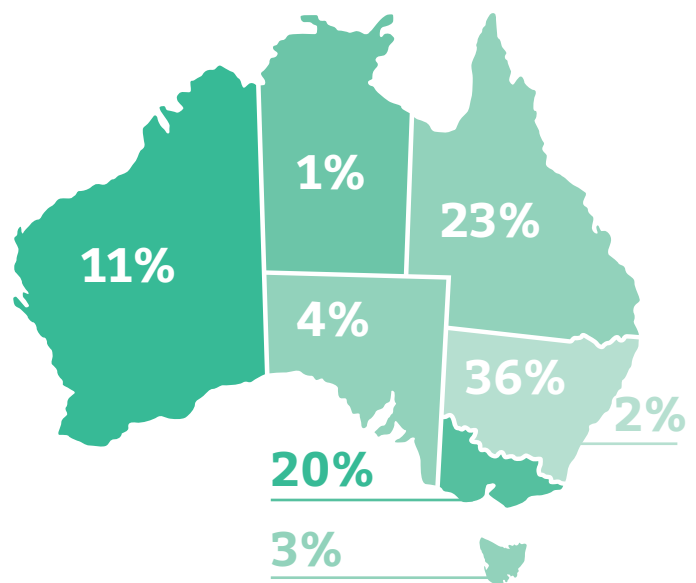
The survey ran from July to September 2018 and was shared and promoted in Australia using Facebook and other social media to target ADHD support and community groups. It was also promoted at an ADHD community morning and on ADHD Australia's website.

The survey instructions stipulated that it was to be completed by parents and carers of children with ADHD aged 5–18 years old who had attended or were attending Australian schools.

The data was organised, assembled and compiled using Microsoft excel to provide insightful data interpretation. Considerable time was spent analysing one particular subset of respondents, namely those who had been suspended from

school, comparing various measures of this data with the total sample and using p-values, where relevant, as a measure of the statistical significance of the findings.

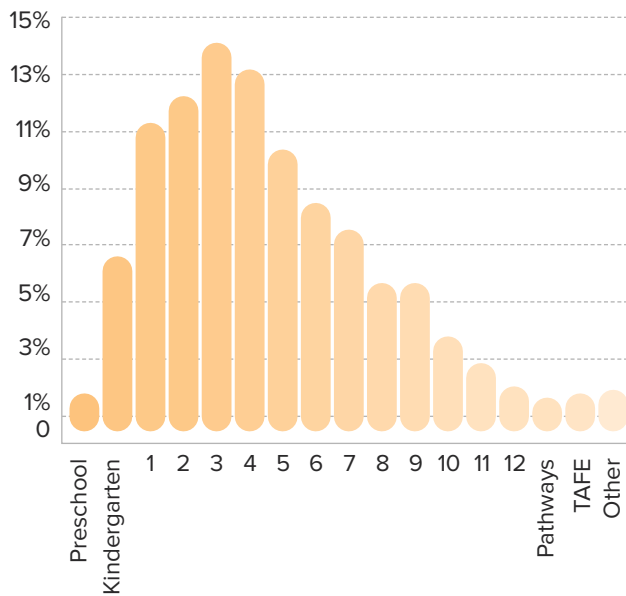
Where are respondents from?



Who took part

The survey resulted in 1,184 people taking part, with 97% of respondents identifying as female. All Australian states and mainland territories were represented. New South Wales had the most responses (36%) which roughly reflects Australia's population distribution. Participants came from capital city and rural locations.

School year



While some parents had up to four children with ADHD, most indicated they had one child with ADHD (80%). Seventeen percent of respondents had two children with ADHD. The respondents reflected the prevalence of ADHD with more being parents to boys with ADHD (79%) than girls with ADHD (21%). More than half (52%) indicated that they were parents to a child with *combined type ADHD*, but respondents also had children with *inattentive ADHD* (21%) and *hyperactive ADHD* (17%). One in ten of the parents were not sure of the type of ADHD their child or children had or preferred not to say.

Gender of children with ADHD

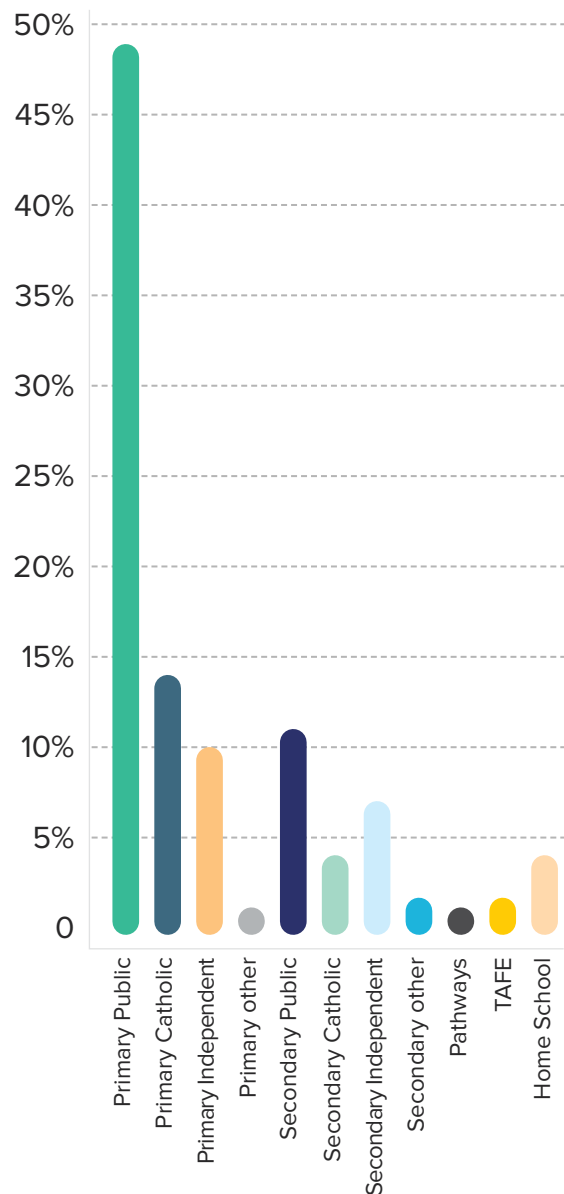
Total Number of survey respondents n=1184



The parents identified 14 additional disorders or conditions (known as *comorbidities*) experienced by their children that are known to often also occur in children with ADHD. Anxiety (58%), sensory issues (42%) and emotional/behavioural dysregulation (34%) were the top three identified.

Most people taking part in the survey had children in primary school (73%), and most (60%) of the students were in public (or state) schools. A small number (2%) had not informed their child's school of the ADHD diagnosis.

Type of school



What we found

Skills, knowledge and resources

Parents perceived a lack of knowledge, skills and resources to support students with ADHD in schools. One in three (34%) parents rated their schools' strategies for supporting students with ADHD as poor/non-existent or inadequate. However, an equal proportion described them as good or excellent. This variation points to a lack of consistency across schools in support for students with ADHD.

Thirty percent of parents had changed their child's school due to ADHD-related issues.

Some parents reported making multiple moves to find a school with effective support. Others indicated they had not moved school but were considering it.

Five percent had left formal schooling for home-schooling, PATHWAYS, apprenticeships, vocational courses or work.

30% changed schools due to ADHD-related issues

"His ADHD was treated like bad behaviour that could be punished out of him. We left for a year of home-schooling."

"Four different high schools couldn't support him."

"Lack of support and belief in my child's diagnosis, resulting in chronic anxiety which left him housebound and violent if we tried to force school."

"We moved our daughter into a private independent school this year as the level of support we were receiving in the public system was insufficient. One of our previous teachers went as far as to deny that our daughter has ADHD as the outwards symptoms she has do not match the typical male ADHD. This needs to be made more of – that ADHD looks different in different children."

School support options for students with ADHD

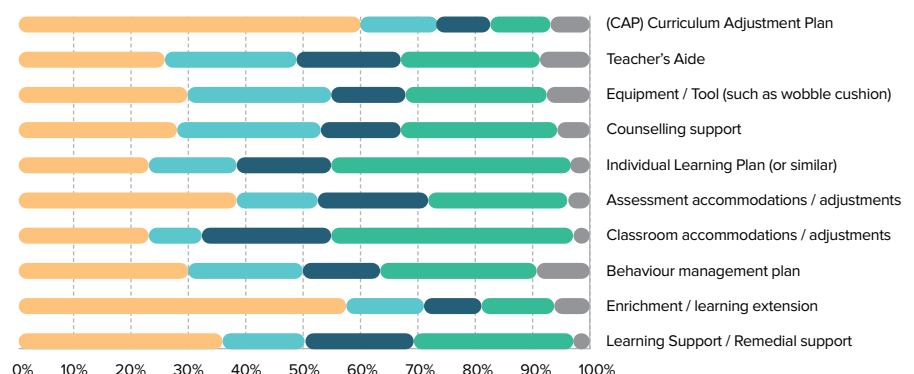
Many parents were unaware of or had not sought access to a range of support options that schools are legally obliged to provide for students with ADHD. Parents were asked to rate their familiarity with and access to a range of school support options. At least a fifth of parents were not aware of all the support options listed in the survey and around a quarter were not aware of key supports such as *individual learning plans* (ILPs) (24%), *classroom accommodations* (23%) and *learning support* (35%). Parents were also often unaware of *assessment accommodations* (40%) and more than half (55%) did not know about *learning extension* or *enrichment supports*. Where students with ADHD were accessing a support such as ILPs (33%) or classroom accommodations (39%), at least 50% of parents reported difficulty in accessing these supports for their child.

>50% of parents reported difficulty obtaining the ADHD support for their child

Many parents are unaware of resources available to them or have not sought access to them

To what extent are you familiar with the following?

- Not heard of this at all
- Aware, have not sought to access
- Aware/requested, not sure if in place
- Aware/requested, in place
- N/A



Access to adjustments

More than a third of parents (36%) reported that there had been no adjustment in teaching, classroom tasks and assessments processes, while one in five were unsure if these adjustments had been made.

The most common adjustment was for the student to sit away from distractions, followed by the teacher using signals to redirect the student's focus. Adjustments also included adjusted time for tests, sitting alone at their desk and being given a view to a clock or a clock on their desk. When adjustments had been put in place almost half of the parents were either unsure if they were adequate (27%) or did not consider them adequate (22%).

Adjustments were usually designed by the teacher (42%) or through collaboration between parent/carer, teacher and health professional (38%), and sometimes designed by the parents (9%) or health professionals (3%).

My child with ADHD would do better if schools ...

- Offered ADHD training and professional development for staff
- Stopped punishing children for their ADHD and thinking of them as 'naughty'
- Allowed for more movement, interaction and breaks as part of the day
- Offered access to support, one on one attention, adjustments and resources as needed
- Fostered wider understanding of ADHD in the community, e.g. information in newsletters
- Improved communication
- Demonstrated zero tolerance to bullying of children, including those with disabilities
- Worked with ADHD specialists to develop strategies, including supporting the cost of specialists such as occupational therapists visiting the schools

Adjustments are not used, used inconsistently or not reviewed

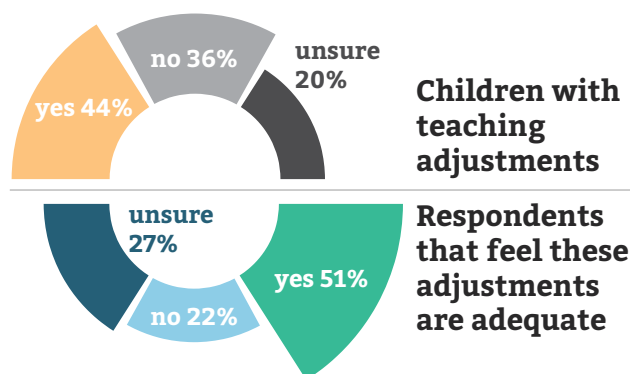
"They're either not consistently used or not reviewed for effectiveness. School would rather 'set and forget' than monitor, review and change."

"We don't feel that removing him from the room is always the best adjustment as he misses out on peer interaction and isn't learning regulation in a class environment."

"All teachers should receive training on how to make adjustments for ADHD students. A lot of teachers still don't understand the symptoms or the condition itself."

"Supporting kids with ADHD in schools is a frustrating, stressful and very upsetting experience. There seems to be a lack of understanding about the condition and how best to deal with it. I have been shocked by the lack of access to support services, even with a diagnosis. It feels like the school presents a lot of problems without being part of the solution, and it is disappointing to see so many lost learning opportunities and your child stigmatised and treated as an unusual outsider, rather than embracing the positives."

"We have found the overall process very confusing and frustrating. Schools seem to know nothing about ADHD and despite our child showing symptoms from reception, nobody said anything until we brought up concerns. It was very difficult to navigate how to get him assessed. Now we are in term 3 and still trying to figure out how to support him in class. His teacher this year has been great, but this is not the norm for us."



What we found

“I have been blown away by the support my child has received at the Christian school she attends. The education support staff were crucial in helping guide us through the process of diagnosis and informing us of what benefits/supports we were entitled to apply for. The ed support teacher attended a session with the diagnosing psychologist to help instruct the individualised education plan. They suggested many strategies for overcoming the issues my child experiences at school and the issues she was concerned about. They constantly seek feedback from my child and us as her parents. I couldn’t have asked for better support.”

“I have been very lucky our school has had training from an occupational therapist in the things that help these kids. They provide wiggle items and are very accommodating in providing a good school experience. We moved schools 2 years ago and our old school wasn’t so accommodating or upfront with what was going on.”

Communication and parent/school interface

For more than half the parents (53%) the classroom teacher was their main contact. Others identified the special education teacher (12%), the principal (19%) or the deputy or assistant principal (12%). Communication appears to be based around need and varying from daily to once a term or only in an emergency.

Three quarters of parents preferred to communicate via email and many (57%) had the contact details to do so, although 5% indicated that the school did not allow direct contact in this form. Most schools were willing to communicate by email, with just 2% of parents reporting their school was unwilling to do so.

Most parents were happy with the relationship they had with their schools, although 17% reported they felt unsupported by the school. Additionally, the majority of parents felt the quality of communication was satisfactory or

better, with 32% describing it as good and 19% reporting it was excellent. When parents described it as poor or very poor (about a quarter of parents), they attributed this to a lack of interest or understanding in their children’s ADHD or a lack of time. Some parents were unable to email teachers directly and others wanted more specific information and follow-up. Additionally, some parents sought information on what their children had done well, rather than just negative information.

Parents’ suggestions to improve parent/school interface

- Better education about ADHD for parents and teachers
- Clear lines of communication including email access to child’s teachers, meetings to discuss needs and plans and follow-up communication
- Culture of less blame, more empathy
- Conflict resolution through third party mediators (someone from outside the education department)

ADHD knowledge among school staff

Parents overwhelmingly (95%) thought teachers and key staff needed professional development and training to better understand and support students with ADHD.

95%

of parents believed teachers and school staff need specific ADHD training

Those taking part in the survey lacked confidence in teachers’, school counsellors’ and principals’ knowledge of ADHD and effective support strategies. Less than half (42%) thought classroom teachers had good or excellent knowledge in this area. The figures were even lower for principals (27%) and school counsellors (25%).

“My experience is that there is no real understanding of ADHD and its impact on a child, academically, socially and emotionally. Expectations are the same as a ‘normal’ child. This creates situations where a child struggling to control their emotions isn’t helped. In most instances the situation is exacerbated by those trying to manage the child. In my experience the teachers lack understanding and don’t see a child struggling to manage a situation or themselves – they just see a child being disruptive on purpose.”

“Medication really helps my child, but more teacher education would go a long way too. There are so many symptoms of ADHD and more knowledge and understanding of how to treat the symptoms would benefit the child, rather than make them stand out when they are struggling and appearing uncooperative.”

Behaviour management plans

A behaviour management plan is a formal support document that is individualised for the student. It outlines specific behaviours where support or correction is required and the processes and consequences that follow non-compliance with the plan.

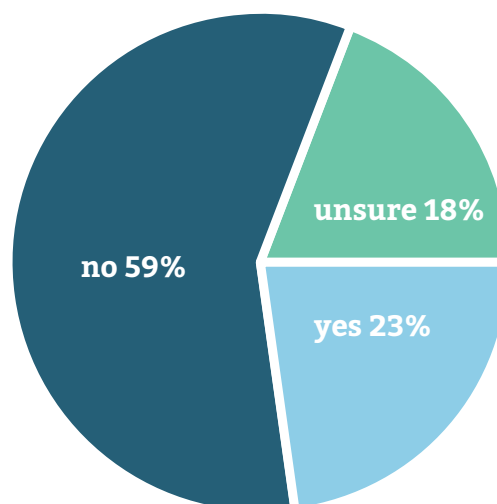
When asked if their child’s school had developed a formal behavioural management plan 23% of respondents reported that one had been developed. More than half (59%) indicated their children did not have a management plan and 18% were not sure. These plans were usually communicated in a face-to-face meeting, although a small number were communicated by email or over the phone. Some parents indicated the plans had not been communicated with them. Of those who had plans for their children, most (72%) were consulted as part of forming the plan, however more than a quarter (27%) were not. Schools usually did not consult with children’s medical and support practitioners regarding these plans. Only one in four parents indicated that these professionals had been included when forming their child’s plan.

When plans were in place, many parents reported that schools were fully following the plans (42%) or partially following them (40%). Half of the parents believed that using a behaviour management plan had prevented suspensions, however this may not have been an aim when forming the plan.

When parents had sought to have their children’s healthcare providers visit the school to provide advice on support strategies and needs, more than a third found the school very receptive or quite receptive (35%). Almost one in five (19%) found the school somewhat unreceptive or totally unreceptive.

Forty-six percent of parents thought teachers and key staff used praise and positive reinforcement frequently as a technique. This may have taken the form of class awards, points, verbal praise, phone calls or letters to parents, sticker charts and rewards such as time on a tablet. However, approximately one in four (26%) thought teachers’ understanding of the effectiveness of praise for children with ADHD could be improved.

Children with formal behavioural management plans



What we found

Wellbeing

Bullying

Most (83%) parents reported that their children had been subjected to bullying at school because of their ADHD, with 31% describing it as frequent or very frequent. Most (60%) were not confident or unsure if school anti-bullying rules protected their children, with 26% indicating these rules did not offer protection.

Parents often (53%) believed that this bullying had resulted in their child being punished for responding to it, while more than a third (37%) indicated that their child has been accused of or engaged in bullying.

83% report their child had been subject to bullying at school due to ADHD

“He retaliated and got into trouble, but the bullies don’t get the same punishment even though they started it.”

“Previous school stated he needed to learn to deal with it when kids bullied him, but if my kid did anything wrong he was sent home.”

“They don’t believe him.”



Children with ADHD subject to bullying
31% report frequent bullying

Social isolation

Sixty-eight percent of parents believed their children had difficulty with friendships and feeling included by other children at school. Eighty-one percent of these parents reported that this sense of exclusion resulted in distress for their child. One in three (32%) thought the school tried to assist their child with social skills, friendships and social inclusion. Where assistance had been given, some felt it had made a difference.



Find it difficult to make friends

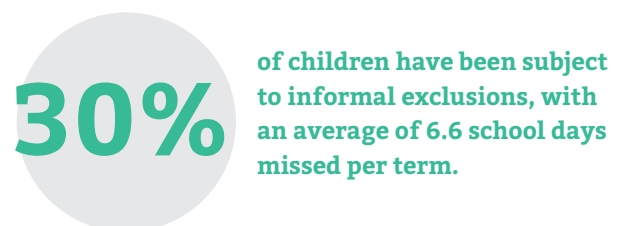
Parents value social skills training and friendship support provided by schools. Examples included:

- Supporting access to different playground areas, allowing friendships to be made from lower levels
- Clubs that support child’s interests
- Facilitating a friendship or social skills group
- Lunchtime structured program
- Encouragement from teachers for other students to include child in activities and understand his/her differences
- Frequent role playing to enhance friendships between students
- Class discussions about relationships and being a good friend
- Teacher keeping an eye on the situation
- Wellbeing, sensory or time out room

Discipline

Exclusions

Some parents reported that their child had been prevented from taking part in school excursions (17%), school camp (10%) and school run activities such as sport and band (20%). Some (18%) parents had been required to accompany their children as a condition of their participation in these activities.



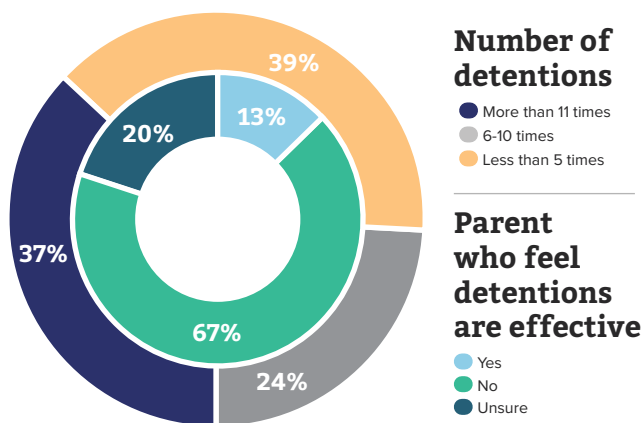
Almost a third (30%) of children had experienced informal exclusions, for example, being sent home from school early during the school day or under an enforced partial attendance pattern.

These informal exclusions resulted in an average of 6.6 school days missed per term with a high proportion (35%) missing more than 10 days per term. Almost three quarters of these parents (73%) felt that informal exclusions were not useful in addressing the behaviours of children with ADHD.

“Public schools need to help these kids, not victimise them. They punish these kids instead of helping them and then blame the parents, saying they are bad parents. The schools never admit that their procedures are hurting the kids who just need love and support.”

Detentions

More than half of parents (56%) reported that their children had been given a detention for behaviour associated with their ADHD. Those who had received detentions, had often received a high number of detentions. Of the 583 people who answered this question, 37% stated their child had received 11 or more detentions, 24% indicated they had received 6 to 10 detentions and 39% stated it was less than five.



The most common reason detention was given was due to the child’s behaviour towards other students (29%). Less often it was given for outbursts or excessive restlessness in class (24%), incomplete classwork (10%), behaviour towards the teacher (10%), incomplete or not handed in homework (7%), uniform code (2%), lost items (1%) or other unspecified reasons (16%). More than two thirds of parents (67%) felt that detentions did not address the behaviour of concern; a fifth were not sure they were effective.

More than half had children who had been given detentions for ADHD-associated behaviour

“Fleeing the classroom because of perceived injustice.”

“Forgetting or losing sports uniform.”

“For talking or being over excited! Had to stay still and 10 minutes were added every time he moved!”

“The transgression is not deliberate. There is no voluntary control. Being held inside is completely inappropriate and exacerbates the problem.”

“Not sure if my child really understands why he is punished for having trouble regulating himself.”

“Not sure putting them in a room alone does anything.”

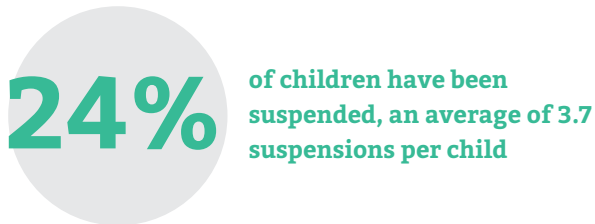
“Would a child in a wheelchair be detained for not climbing the stairs within a given amount of time, with no support? My daughter shouldn’t be made to stay in during her free time, because her teachers’ expectations of her were unrealistic. This does nothing but make her feel punished for something she has very little to no control over.”

“It’s just more punishment for something they often can’t help. Schools approach should come from a teaching/education perspective – make the child do something to make up for their behaviour and have a conversation with them based on cognitive behavioural therapy type things that help emotional regulation – not a hard framework to use.”

What we found

Suspensions and expulsions

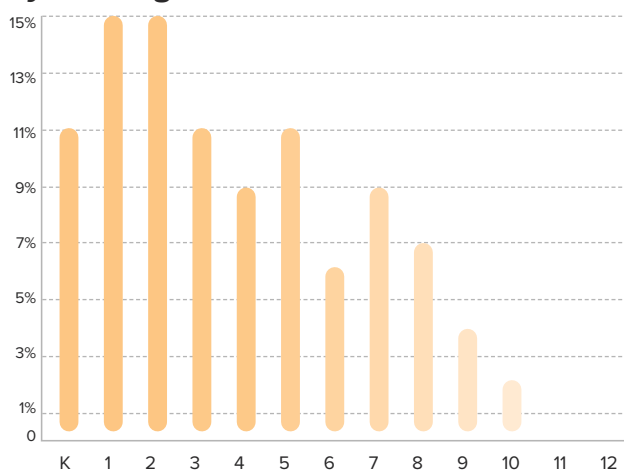
Almost a quarter (24%) of parents had children who had been suspended, with a total of 902 suspensions reported by parents, and an average of 3.7 suspensions per child. The time frame was unclear, including if some were pre-diagnosis with ADHD, however 41% of suspended students were in Kindergarten/Prep to Year 2.



Males were more likely than females to have been suspended (accounting for 79% of children represented in the survey, and 89% of the suspensions). Children with *combined type ADHD* (52% of survey, 56% of suspensions) were more likely to be suspended than those with *inattentive ADHD* (22% of survey, 8% of suspensions) or *hyperactive ADHD* (17% of survey, 22% of suspensions). Of those being suspended, the majority (68%) also suffered anxiety, while half had ODD (50%) and/or emotional/behaviour dysregulation (47%). Others had ASD (30%) and/or depression (17%).

These suspensions had an impact on the working life of parents who may have had to take time off work (44%), seek assistance from other family members (9%) or leave a child at home alone (4%).

Percentage of total suspensions by school grade



Parents reported that suspensions had a severe negative impact on the wellbeing of the child (48%), parents (63%) and siblings (23%). Eighty-four percent of parents felt that suspensions were not effective in helping to address the behaviour of concern.

A quarter of parents had appealed the suspension. Reasons for not appealing included being unaware that appeals could be made, finding the process discouraging or not understanding it, time, and fear of ramifications.

Two percent of children had previously been expelled from school.

“The suspensions achieved nothing. They just meant my child felt really bad about himself – he didn’t really understand what he’d done wrong. His behaviour was an outcome of the impulsive side of ADHD.”

84% of parents felt that suspensions were not effective

“Doesn’t address the issue causing the problems.”

“It’s a day off school which he hated going to anyway.”

“Child suspended for standing up for themselves against bullies that the school refused to acknowledge, despite evidence of physical injury to child.”

“They miss school when already behind academically and reward them by letting them stay home.”

“The behaviour might change for a short period and then another incident would occur because the underlying issues were still not being addressed. For example, anxiety, poor social skills, poor emotional regulation or bullying.”

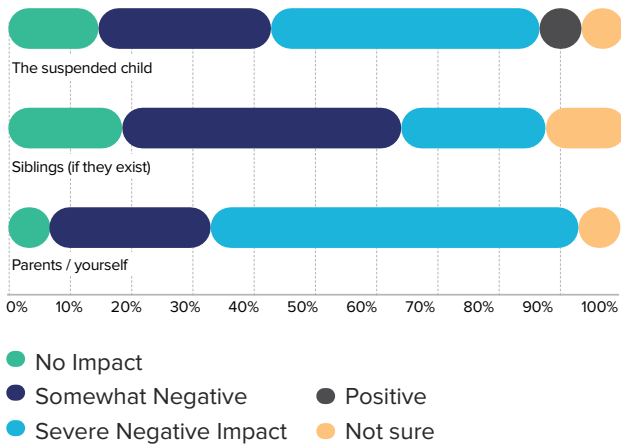
“We have felt really let down by the education system. We feel we have been in constant battle to advocate for our daughter over the years. Her exclusion has sent a strong message to us that she is not part of their community and they don’t want her. She lacks trust in people and making friends and has little self-esteem. She has not been at

a mainstream setting since year seven and her mental health continues to deteriorate, and she has also used drugs to cope. We have constantly needed to take time off due to suspensions, needing to attend meetings including post suspension meetings, excursions and camps and part time attendance.”

“Life is hard for a child suffering with ADHD. There is no social awareness, no obvious physical difference, so quickly they become ‘that naughty kid’. The stigma never leaves, so the anxiety grows. There is a promise that all children have the right to an education, but my son isn’t getting one. He does not receive the support he needs to be successful in the classroom. He gets punished every day for just being himself. He’s 6 now and engaging in dangerous self-harm. What do I do when he’s a teen and feeling this way? Help us, before my son kills himself.”

Suspensions of children from school have a negative impact on well-being of all family members:

When a suspension is issued to your child, how would you describe its impact on the wellbeing of:



A closer look at suspensions

One in ten respondents reported that they were told suspensions helped the school get funding support. A higher proportion of parents of suspended children had undertaken parent training for ADHD (37%) versus the total sample (32%), but the difference is not statistically significant. The survey also found no statistical difference in the number of medical appointments each year for those suspended

and those not suspended and found their expenditure on appointments to be similar. Parents of children who had been suspended were more likely to have moved their child to a new school (49%) compared to the total sample (30%). More suspended children had a behaviour management plan in place (46%) compared with the overall sample (23%). More than half of the parents indicated that either these were not effective in preventing suspensions (49%) or they were not sure of their effectiveness (17%). Parents of children who had been suspended experienced similar levels of difficulty gaining support as those with children who had not been suspended.

Children who have been suspended appear to receive more funding support (24% versus 17% of total sample). However, this may be the result of having other conditions, such as autism spectrum disorder. Funding was usually put towards a teacher’s aide, but parents were often unclear about how the funding was used. There was little difference in the proportion of children receiving adjustments for ADHD, between those who had been suspended (47%) and those who had not been suspended (44%).

The parents of children who had been suspended were more likely (30% compared to 21%) to report being pressed by the school to gain a different, additional or escalated diagnosis for their child to gain funding support. They were also more likely to have felt pushed to give their child medication or adjust the amount of medicine they gave their child (49% compared to 31%).

Children who had been suspended were also more likely to be excluded from activities outside the classroom including school-run activities such as sport and band (47%), excursions (45%) and camp (30%). More than a third of parents (38%) had been asked to accompany their child on these activities. Children who had been suspended were much more likely to be subject to informal exclusions with suspended children missing an average of 7.6 days each term compared with 6.6 for other children in the survey.

Parents of children in the suspended group were more likely to report that their child had been bullied as a result of their ADHD with 48% reporting that it was very frequent or frequent.

What we found

Additionally, 45% of the parents with children who had been suspended felt their child was not adequately protected by the school anti-bullying rules (compared with 26% in the total sample). The suspended children were much more likely to have been accused of or taken part in bullying behaviour themselves (64% compared with 37%).

“ADHD kids are punished for symptoms of their learning disability – so unfair. We all need better skilled teachers and mentors to help these kids be successful, both academically and socially. Suspensions lead to disengagement from learning. This sets them on a downward trajectory. ADHD kids usually grow into ADHD adults – who are over represented in the prison system. Constant negative messages and ‘over-punishment’ creates negative internal messaging. They give up trying to do the right thing! Many of these kids are really smart and have unique ways of looking at the world and at problem solving. Many of our top entrepreneurs have ADHD. We should be seeking and nurturing their strengths not punishing them because they don’t fit into our rigid school systems.”

“Suspension traumatises and humiliates children who are vulnerable. It compounds their problems and does not help them. No research suggests that out of school suspensions or exclusions are beneficial to students with behaviour support needs, yet departments persists against expert evidence to the contrary. Our child has suffered depression and anxiety as a result of repeated suspensions. It is not OK.”

One in 15 parents reported that their child was refused a school enrolment due to their ADHD

Enrolment offers

A small proportion (5%) indicated that their child had been subjected to a trial period at school to determine if an enrolment offer would be made. This increased slightly to 10% if their child had previously been suspended. However, one in 15 parents reported that their child was refused a

school enrolment due to their ADHD (7%) and this was more likely if they had been suspended previously (13%).

These enrolment refusals were found across school sectors and were usually communicated verbally in person (37%) and over the phone (33%) rather than in writing (27%).

Procedural fairness

Many parents (56%) did not know their school’s policies for suspension and exclusion. Those who were aware of the policies had varied responses as to their fairness, with 47% feeling they were fair, and 53% feeling they were unfair.

Discrimination complaints against schools were rare among those who took part in this survey with just 2% indicating they had lodged a discrimination in education complaint against a school on behalf of their child through the Australian Human Rights Commission or the state-based anti-discrimination boards or commissions. Complaints were slightly more common (3%) among those who had had a child suspended. More than a third (38%) of these complaints were resolved to the parents’ satisfaction. None of the respondents had ever commenced legal proceedings against a school through the court system.

Most (64%) were unsure of the balance of power between parents and school authorities in the mediation and legal system. While many (30%) thought schools had more power, a few parents (5%) thought it was balanced and fair, and a small number (1%) thought parents had more power. However, parents of children who had been suspended were more likely to feel that the school held the balance of power (52%). Forty-four percent remained unsure, 3% felt it is balanced and fair and <1% felt parents have more power.

Most respondents (61%) were uncertain about the strength of disability discrimination laws in education. While 24% considered them to be weak, 4% considered them to be strong. Those whose children had been suspended were slightly more likely to consider the disability discrimination laws in education to be weak (32%), however 53% were unsure and only 4% considered them to be strong.

Just 2% of respondents had lodged a discrimination in education complaint

“I was too stressed to keep going.”

“The school did not approach the process with a desire to mediate, but rather to deny all complaints and feel out their legal case.”

“Complaints are useless as education department does not follow them up. There is no accountability by schools or teachers who are breaking disability discrimination law.”

“From what I hear it’s a very stressful process that often doesn’t work.”

“Generally, parents have poor knowledge to know what their child’s rights are.”

“Cost!! Schools know they will get away with behaviour.”

“Case law is very weak on disability discrimination laws in Australia. This is due to the loophole around ‘unjustifiable hardship’ and the various legal precedents around that issue. School education departments have unlimited legal defence budgets while most families cannot afford to commence proceedings. There is a huge power imbalance which means that taking matters to court is risking the financial wellbeing of a family and may well put them in debt for life. It is an unacceptable risk for most. This means there is no means to balance power and therefore no real access to justice.”

Funding

An absence of ADHD-specific funding for targeted learning support may result in parents being pressed by some schools to gain alternative or escalated diagnosis for their children and/or give their children medication or adjust their medication dose. When funding is made available, it is usually invested in teacher aide hours, but most parents (48%) were not sure if the teacher’s aide had ADHD-specific training and only one in five indicated that teacher’s aide did have this training.

Less than one in five (17%) parents reported that their child received funding support from the school to assist with their needs. Almost half (47%) did not know where the funding came from, although some identified allocation from shared general school funding, such as Every Student Every School, and dedicated funding, such as Integration Funding Support.

1 in 5

respondents report being pressed by staff for a change in diagnosis to secure funding

One in five (21%) reported feeling pressed by a school to gain a different, additional or escalated diagnosis as a means to gain funding, including discussions on autism spectrum disorder and anxiety.

“Learning support and inadequate funding have meant a fight each step of the way for support. My daughter is not adequately supported, and it is difficult to advocate as I am not fully aware of her legal rights.”

“From our experience there is little or no funding available for ADHD kids in schools which means they get little in the way of assistance or accommodations. We have received neither.”

“This is my first child in school and we are begging for help from any support and no one seems to be able to help. School apparently has no funding and claim to be doing all they can.”

“We were continually told they didn’t have the funding to deal with our son and were pressured to get a diagnosis or try to fast track a diagnosis. The school even offered to help pay to go privately for a diagnosis to speed up the process.”

“Are you sure he’s not autistic? An autism diagnosis attracts funding.”

What we found

Financial and emotional burden on parents

Parents of students with ADHD reported a large financial burden including paying for health expertise, undertaking training, reducing working hours or giving up employment. This was required to meet the demands of appointments, suspensions, informal exclusions, reduced school hours or home-schooling. They may also bear a large emotional burden, feeling their child with ADHD is seen as 'too naughty' or 'too hard' to be included in the school community, rather than understood as having a neurodevelopmental condition that can be managed with support.

Half of parents who responded (52%) had changed their working hours due to their child's ADHD. Thirty-four percent reported having to reduce their working hours or move to part time work and 18% quit work all together. Just 27% reported no change in working hours. Patterns did not vary greatly between those raising children with different types of ADHD.

More than three quarters of families reported spending more than \$1,000 each year on ADHD-related therapies; 5% of families reported spending more than \$10,000 a year. The mean yearly investment by parents in ADHD-related therapies was \$2,382 per child.

\$2,382
per child

Average yearly cost of ADHD-related therapy

Nine out of ten parents reported that they did not receive any support from the National Disability Insurance Scheme (NDIS). Despite this, more than a third (38%) of parents indicated they had attended more than 20 ADHD-related medical appointments within a year, with the mean being 12 appointments per child each year.

90%

of parents receive NO funding from the NDIS

Parents reported investing in expert assistance from paediatricians (86%), psychologists (68%), and occupational therapists (45%). They also paid for speech therapists, psychiatrists, counsellors/behavioural therapists, naturopaths/alternative therapists, remedial tutors, dieticians/nutritionists and other unspecified professionals.

32%

of parents have had ADHD specific training to support their children

Almost a third (32%) of parents reported taking part in training to assist their children with ADHD, including Triple P, 123 Magic, Circle of Security, behavioural therapy, ADHD coaching and positive parenting.

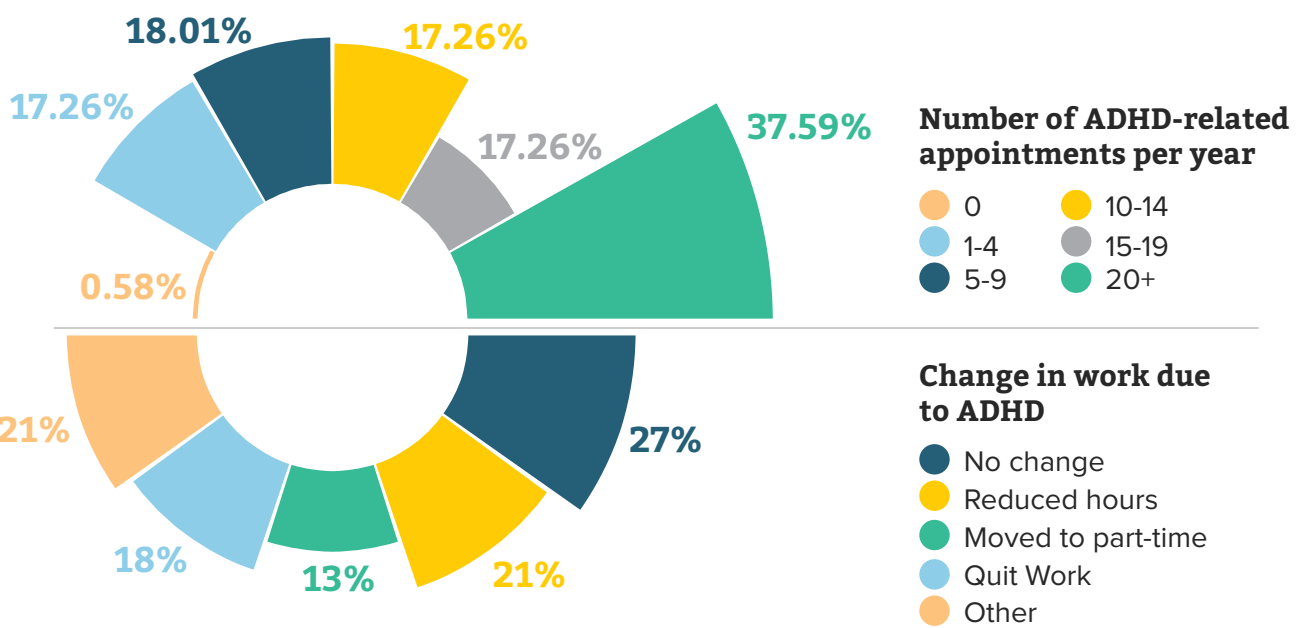
More than half of parents had changed their working hours due to their child's ADHD

"Resigned from full time work as ... I needed flexibility for my son and appointments"

"On call while he's at school so just can't work."

"Can't work due to my child getting into too much trouble at school and needing to be picked up."

"Classroom teachers need more education in this area, they need more support, they need more funding. We, at home, are spending hours and hours, and thousands of dollars getting as much help as we can but if the school doesn't follow through with suggestions made by the professionals we pay thousands to, the child will not be helped. The circle of care and support cannot be broken. We need to work together for our kids not fight against each other because they don't want to allocate funding to help our kids."



Case studies

The following profiles were taken from the survey and depict the struggles of young people with ADHD in schools



Tom*

Tom is only in Year 3 at his public primary school, but soon he hopes to start in his second school. Before he was diagnosed with ADHD (*combined type*), he was suspended 13 times in just six months. He also has *emotional/behavioural dysregulation*, anxiety and auditory processing issues.

His parents spend up to \$2,000 each year on appointments with specialists, but one has had to give up work because of Tom's ADHD and all the time Tom has missed school due to suspensions.

The first school used a behavioural management plan, but it didn't work, and the school seemed to give up.

Tom has been bullied at school, but the school had Tom earmarked as the aggressor in the bullying even when he was only trying to defend himself and broke his arm.

Tom's parents are hoping to re-introduce him back into the education system soon and have also changed his medication in the hope that this will help.

**Names have been changed to protect confidentiality*



Lachie*

Lachie is in Year 7 at a public secondary school. He has ADHD (*combined type*) as well as autism spectrum disorder, *oppositional defiant disorder*, *emotional/behavioural dysregulation*, *anxiety*, depression, general learning difficulties and auditory processing issues. His mum has reduced her working hours so that she can pick him up when he is sent home, be there when he comes out of school and take him to more than 20 appointments each year in an attempt to get him help. The appointments cost the family more than \$2,000 each year.

Lachie has changed schools several times, often due to bullying by classmates, but also due to expulsions. He is anxious. His confidence is low because he knows that the teachers don't like him, don't listen to him and don't believe him when he tells them about the bullies. The bullies have punched and kicked him. They tell him they will stab him.

His mum struggles to get support from school. She describes them as 'hostile'. School said "this is not a mental health facility". She thinks the school does not want her son there. He has been suspended at least 10 times for 15 or more days each time – including one suspension for threatening to squirt a water bottle, which was for 20 days.

Lachie is now severely behind with his schooling.

He is about to move schools again.

What these results mean

This survey was designed to collect data on experiences of parents as to how effectively the Australian education system is meeting the learning, social and emotional needs of students with ADHD.

This survey found a number of critical gaps in the capacity of schools to support students with ADHD and meet their legal obligations to provide an inclusive education under disability legislation.

Children with ADHD at risk in the education system

ADHD is the most common neurodevelopmental disorder in children and yet the findings of the survey suggest that many children with ADHD in Australia attend schools where ADHD is poorly understood. As a result, children and their parents feel unsupported in the school environment as students with ADHD struggle to meet academic and social expectations while being punished and excluded due to their disability.

They may experience further disruption and distress as their parents move them to new schools in the hope of locating educators with the capacity to support their children's education.

A picture emerges of families financially and emotionally stressed and at odds with Australian schools due to a lack of understanding about ADHD and resources to effectively support the education of children with ADHD.

Inequitable access to education for students with ADHD

This survey has depicted inconsistency and inequity for students with ADHD in the education system when accessing *accommodations* and education resources for their medical disability.

This may be attributed to a number of causes, including gaps in schools' and educators':

- knowledge about ADHD and how it impacts learning
- provision of ADHD resources and adjustments
- collaboration and communication with parents of students with ADHD
- commitment to the wellbeing of students with ADHD
- overuse of punitive and exclusionary methods of behaviour management
- lack of funding to support students with ADHD



Collectively, these gaps reflect the lack of recognition of ADHD as a serious impairment to learning within the Australian education system which is at odds with obligations under the Disability Discrimination Act 1992 (DDA) and the Disability Standards for Education 2015 (DSE), whose purpose is to ensure students with disability can access education on the same basis as their peers.

What needs to happen now

We need to improve access to quality, inclusive education for students with ADHD.

It's time to recognise the profoundly negative and lasting impact ADHD has on children's education, social skills and outcomes in adult life, as well as on their families.

There is an urgent need for ADHD to be recognised by the Australian Government and education departments as a legitimate disability and for the current gaps in the education of students with ADHD to be addressed.

Without knowledge and understanding of the true impact of ADHD on students' ability to learn by the Australian Government and associated education departments, it is unlikely that schools will receive the funding they need to ensure there is adequate support for children with ADHD.

It is also important to recognise that parents play a pivotal role in supporting their child with ADHD in partnership with educators – the success of this relies on collaborative, open and transparent communication and shared understanding of the rights of the child, an approach which needs to be supported by education stakeholders and parents alike.

Systemic reform in the education system is needed to ensure the rights of children with ADHD are upheld.

Parents for ADHD Advocacy Australia (PAAA) urgently calls for a multi-agency effort in the recognition of the challenges of students with ADHD in schools. Government, departments of education, principals, teachers, medical professionals, parents of children with ADHD and other allied stakeholders need to work together to address the gaps and create school environments which allow children with ADHD to thrive, as well as meet obligations to DDA and DSE.





Government

Recognise ADHD as a disability with serious risk to learning and self-regulation in education policy and funding.

Provide and mandate professional development on ADHD, DDA and DSE for educators

- Provide educators access to quality, evidence-based professional development modules on ADHD as well as classroom adjustments by qualified service-providers
- Mandate that teachers and key staff, including principals, complete professional development on ADHD, teaching strategies and adjustments, as well as the DDA and DSE legislation

Address lack of disability funding for ADHD

- Review criteria for targeted funding to improve support and reduce requests for escalated diagnosis
- Ensure that schools' understanding and use of Nationally Consistent Collection of Data on School Students with Disability (NCCD) adequately captures the use of adjustments for students with ADHD, to ensure funding to schools is reflective of the true incidence of ADHD within the education system



Schools

Communication with parents

- Build collaborative, open and transparent relationships with parents where clear channels of communication are maintained

Improve accessibility and implementation of adjustments to students with ADHD

- More students with ADHD should receive quality adjustments that are easily accessible and reviewed in collaboration with parents and healthcare professionals

Reduce use of punitive and exclusionary practices

- Ensure schools review, reduce and report the use of punitive and exclusionary practices such as detentions, partial exclusions and suspensions for students with ADHD
- Implement supportive behavioural management strategies for children with ADHD, especially for younger students in K–Year 2.

Deliver targeted psychosocial support to improve student wellbeing

- Deliver targeted, evidence-based psychosocial support strategies to support those at risk of bullying and social isolation
- Build whole-school understanding of neurodevelopmental diversity through awareness programs



Parents

Communication with schools

- Build collaborative, open and transparent relationships with schools where clear channels of communication are maintained
- Increase awareness of their child's rights under DDA and DSE legislation, and the adjustments and resources schools can provide

“There is insufficient focus on ADHD in teacher-training, and insufficient professional development activity to redress the misconceptions that many teachers seem to hold. None of this is the fault of teachers – the problems are much higher up and are driven by funding choices. These problems don't get solved because discussion always winds up pitting parents against teachers in a blame game. Teachers and parents need to work together to bring about change at a higher level. A more helpful culture amongst teachers responding to ADHD will follow from there.”

Resources and references

1. Young Minds Matter: Child and Adolescent Mental Health and Educational Outcomes report (December 2017). <https://youngmindsmatter.telethonkids.org.au/our-research/>
2. ADHD and academic performance: why does ADHD impact on academic performance and what can be done to support ADHD children in the classroom? (D. Daley and J. Birchwood, 2010). <https://pdfs.semanticscholar.org/c0ef/bfe63368b0f0ce2b62616a44b4e91c029b54.pdf>
3. Designing out barriers to student access and participation in secondary school assessment. (Linda J Graham, 2018) <https://eprints.qut.edu.au/117748/1/10.1007%252Fs13384-018-0266-y.pdf>
4. Lawrence, D., Hafekost, J., Johnson, S. E., Saw, S., Buckingham, W. J., Sawyer, M. G., et al. (2016). Key findings from the second Australian child and adolescent survey of mental health and wellbeing. <https://pdfs.semanticscholar.org/>



Glossary

Accommodations	Tools and procedures that provide equal access to instruction and assessment for students with disabilities.
Australian school system	In this report this term includes state-funded, church/state-funded and independent-state fund schools.
Combined type ADHD	A form of ADHD characterised by both inattention and hyperactivity-impulsivity behavioural traits.
Comorbidities	A medical term for two or more medical disorders that occur at the same time.
Conduct disorder	A mental disorder found in children and young adults which results in serious behaviour problems such as being aggressive or violent towards people and animals, stealing and or breaking other rules of society.
Emotional dysregulation	Inability to modulate one's emotional experience and expression, which results in an excessive emotional response considered inappropriate for the developmental age of the individual and the social setting in which it occurs.
Enrichment support	Strategies, resources and practices to enable students with learning difficulties to achieve their full potential.
Executive function	A set of mental skills required to organise, begin and complete a task.
Hyperactive ADHD	A form of ADHD characterised by impulsive and hyperactive behaviour.
Inattentive ADHD	A form of ADHD characterised by problems regulating attention.
Individual learning plan (ILP)	A working document, designed by teachers in collaboration with stakeholders, which informs the planning, delivery and evaluation of an educational program to deliver appropriate learning outcomes for identified students with specific needs.
Learning extension	Extension opportunities for students who can perform above their expected grade level.
n=	Number of people who answered the question.
Oppositional defiant disorder	A behaviour disorder found in children who are constantly hostile and disobedient.

How and why we did this work

Who are PAAA?

Parents for ADHD Advocacy Australia (PAAA) is a national advocacy group comprised of over 1000 parents of children with ADHD who are passionate about advocating for better outcomes for children with ADHD. Formed in January 2018 through social media networks, our discussions of the shared personal and environmental challenges of supporting children with ADHD led to the formation of key goals for our group. Our goals are:

- To increase public awareness and reduce stigma surrounding ADHD
- To ensure families are informed and empowered to help their child with ADHD successfully navigate life and reach their full potential
- To increase the capacity of schools to manage ADHD and comorbid conditions in students proactively and in an evidence-based manner.

Limitations to this work

We have taken care to report the findings of our survey accurately, however, this study was designed and undertaken by parents of children with ADHD working in a volunteer capacity.

The survey questions were not tested outside of PAAA for meaning and clarity, hence may have been misinterpreted by some people taking part. The initial survey release inadvertently allowed those taking part to select multiple answers and skip questions. This was fixed part way through the live period to ensure all questions were answered. However, it has resulted in variations in the number of people who answered each of the questions (n=). Data from complete and incomplete survey responses were compared and no major variances in the pattern of responses were found. All data, survey questions and sample sizes are available on request.

As participants were recruited online via ADHD support groups, the sample may not be representative of the total population.

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