



Association for  
Children with a  
Disability

# Association for Children with Disability

## Submission: Assessment and support services for people with ADHD

May 2023

ACD is the leading advocacy service for children with disability and their families in Victoria. We are a not-for-profit organisation led by, and for, families of children with disability.

For more than 40 years we have been advocating to improve the lives of children with disability and their families.

Our vision is that children with disability and their families have the same rights and opportunities as all children and families.

### **For more information contact**

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## Executive summary

ACD welcomes the opportunity to provide feedback to the Senate Community Affairs Reference Committee's inquiry into Assessment and support services for people with ADHD.

ACD receives calls from hundreds of families of children with ADHD. Education is the number one issue raised by families. Too often, children with ADHD are not getting the support they need in school to thrive. This can result in poor mental health, suspension or expulsion.

Families supporting children with ADHD who do not have a dual diagnosis are in a particularly difficult position. Their access to community health services can be limited, and many families can't afford high out of pocket costs for private allied health services.

More needs to be done to ensure the education and health systems are equipped to support children with ADHD. This includes more training and professional development for teachers about ADHD, greater accountability around Student Support Group meetings, and greater access to affordable allied health services for children and families.

## Recommendations

1. Increase access to essential allied health services so children and families can access support without long wait times.
  2. Address gaps in pre-service teaching and professional development opportunities to ensure teachers understand and can support students with ADHD.
  3. Increase consultation with students and families through Student Support Group meetings and improve consistency and quality of reasonable adjustments.
  4. Increase accountability and oversight of informal suspensions and reduced hours at school for students with ADHD.
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## The adequacy of access to supports after an ADHD assessment

Families tell us the supports available for children with ADHD are limited, particularly for children whose primary disability is ADHD, and who are older than seven. When children can't access timely support, it can impact their engagement with school down the track.

For many families, getting an ADHD diagnosis doesn't happen until after their child starts school because that's when the signs of ADHD become more visible. This is also when access to early childhood intervention under the NDIS drops off. Many families will understand their child is showing signs of delay or signs their child is struggling in environments like school, but have no formal diagnosis.

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*More than 800 calls made to ACD's support line since 2019 related to a child with ADHD*

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For children and families engaged in early childhood intervention and who age out, the need for supports is still there but access to services becomes difficult. For children and families without a dual diagnosis, their only affordable avenue of mainstream support is from community health services.

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*Of the calls made to ACD about a child with ADHD, 10 per cent of those children's primary diagnosis was ADHD*

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The scarcity of resources allocated to tier 2 services, such as community health, means children face long wait times and families often feel their child isn't getting access to *enough* support. Families will try to piece together supports from community health and private therapists, creating inconsistency for children, and emotional and financial hardship for families.

While some community health services in Victoria are available for children 0-12, others note children must be 0-6. In at least one instance the community health provider advises families to talk to their child's school for concerns about children 6-18 years.

Families are often referred to the NDIS for children with ADHD. Because there is no clear pathway to access the appropriate supports, families can be bounced between services. This created confusion and stress for families who are left to navigate complex systems on their own.

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## Case study – Alex

Alex is seven years old. When Alex started school at five, Alex's family, pediatrician and school teachers noticed Alex might be showing signs of ADHD. Alex was able to access early childhood intervention services not long after starting school.

However, Alex's family was still compiling evidence and information and did not have a diagnosis when Alex turned seven. When Alex did receive an ADHD diagnosis, Alex's family were told to seek support from community health services. While they progressed on the waiting list, Alex's behaviour started to escalate at school because they didn't have access to timely supports. The school teachers didn't have access to the right professional development to understand ADHD and how to support Alex. Alex didn't meet the threshold for additional support at school.

When Alex reached the top of the community health waiting list and received funding for a therapist, Alex was shy and took some time to feel comfortable. Alex's family felt relieved when they could see Alex begin to make progress again under professional guidance. Just as Alex started making strides, Alex's access to community health ran out. Alex's family felt overwhelmed and were not confident they could put the right strategies in place. There had been little or no contact between Alex's therapist and the school.

Alex's engagement and behaviour at school began to decline. As Alex's struggles with school work increased, Alex's mental health declined. Alex started refusing to go to school. Alex didn't meet the threshold for community mental health support.

Meanwhile, Alex's family went back on the waiting list for community health services. Alex's family had fortunately been told they could access some subsidised services through Medicare. However, Alex's family couldn't afford the gap fee for an Occupational Therapist under a mental health plan.

When Alex did attend school, Alex began exhibiting challenging behaviours. The school began calling Alex's family telling them to pick Alex up from school. As this was not considered a formal suspension even though Alex was not permitted to remain at school, it was not recorded and not reported to the Department of Education.

Alex's family were at risk of losing employment because they often had to leave work to pick Alex up early, or care for Alex when they refused to attend school. Alex's family are feeling emotionally and financially strained.

Without intervention and the right supports Alex's future is uncertain. Alex's family call ACD's support line because Alex has fallen through the cracks and they're not sure what to do.

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

Too many children with ADHD are not being supported by the education system. Pre-service teaching hasn't equipped teachers to understand, identify and support students with ADHD. Students with ADHD who don't present with hyperactivity are more likely to fly under the radar as too little is known about other signs of ADHD such as difficulties focusing on a task.

Students with ADHD may not receive additional loading under the Schooling Resource Standard, which creates additional pressure for government schools who don't currently receive 100 per cent of the base level of funding required to meet the educational needs of students.

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*56 per cent of calls made to ACD's Support Line about children with ADHD related to issues with education*

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Many students with ADHD have a dual diagnosis. While awareness and understanding of other disabilities has improved over time, such as autism, more work is needed to understand students holistically, including the impact of ADHD. The resources and professional development available for teachers in supporting students with ADHD is limited. This can impact the student's support at school and create challenges in getting a diagnosis.

Teachers play an important role in early identification, and can be an important source of knowledge and information for therapists doing a diagnosis. If teachers don't have the skills to identify and understand possible issues, children can fall through the gaps.

When support isn't provided proactively, schools are likely to see an increase in challenging behaviours and poor student mental health.

Student Support Group meetings are a key part of ensuring students are placed at the centre and proactively supported by the right team of people, including the child's family. However, ACD hears from families that these meetings aren't always run consistently or properly. When this happens, proactive supports are often missing, particularly if the student doesn't attract individualised funding. This can lead to higher risks of school refusal, informal suspensions, formal suspensions, or expulsion. Many families also report schools will not organise a Student Support Group meeting if the student doesn't attract individualised funding.

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Families contact ACD about school refusal for children with ADHD who are experiencing poor mental health. School refusal for these students can occur because the student's difficulty focusing on a task has flown under the radar and there's been a decline in their mental health when they fall behind. Other students may have trouble coping in the school environment.

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*More than 30 per cent of calls made to ACD's Support Line since April 2022 about reduced school attendance, suspension, or expulsion related to a child with ADHD*

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### **Case study – Sam**

Sam is seven years old and has a diagnosis for autism. Sam's therapists also see early signs that Sam may have ADHD. Sam accessed early childhood intervention via the NDIS and transitioned to the full NDIS at seven based on the autism diagnosis.

As Sam gets older, Sam receives a diagnosis for ADHD.

While ADHD is not considered an eligible disability to access NDIS support, Sam's therapists provide holistic support and work with Sam and Sam's family to meet goals relating to autism, *and* address issues that relate to ADHD.

Sam receives individualised funding at school due to the autism diagnosis and related needs. Student Support Group meetings are not being run as intended, and sometimes they don't happen each term. Sam is not always being proactively supported by teachers, who also have limited understanding of Sam's ADHD diagnosis.

Sam's family begin to receive calls to pick Sam up from school early. When Sam becomes overwhelmed and can't cope, teachers don't have the training and support to work with Sam deescalate or prevent challenging behaviours. Sam is put on reduced school attendance. Sam is not formally suspended and it is not reported to the Department of Education.

Sam begins to feel isolated from friends at school and misses out on important school events. Sam's family are distressed and facing pressure in meeting their paid employment obligations due to Sam's restricted access to school.

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## The social and economic cost of failing to provide adequate and appropriate ADHD services

When families can't find the right support for their child, it causes significant emotional and financial hardship. When children with ADHD can't get the right support, they risk social exclusion and poor educational outcomes from reduced school attendance.

Women in particular face the brunt of the emotional and financial load through their primary caring responsibilities. When schools reduce children's attendance at school, it is overwhelmingly female family members who are pulled from work to pick up their child and navigate the education and health systems in an attempt to get subsequent support. ACD has heard from mothers who haven't been able to sustain paid employment because their child's school calls multiple times a week to pick their child up early, or because their child has been placed on restricted attendance.

Families want their child to access high-quality education to set them up for success in the future. When families see schools focusing on deficits and excluding their child, the emotional toll is significant. Families shouldn't have to spend time fighting for their child's rights. This means significant gaps need to be addressed to meet the needs of children with ADHD.