

A report based on research amongst children and parents illustrating the impact of ADHD on the school day





1 Want Someone to Hear Me!

It is well known that children living with ADHD can struggle to achieve and be happy at school, but the views of the children themselves, currently going through the school system, as well as those of their parents, are less well explored.

'School Report: Perspectives on ADHD' - A New Source of Information

The 'School Report' has been designed to provide a resource of information about the impact of ADHD. In 2004, more than 50 children with ADHD and 90 parents were surveyed about their experiences of living with ADHD and its impact at school, the largest survey of its kind in the UK. Alongside this significant quantitative research, focus groups of parents and children were co-ordinated. The 'School Report' presents the results of the survey alongside personal testimonies from parents and children who joined the focus groups and recounted their experiences. We have also presented some basic facts and figures about ADHD and its impact. The 'School Report' is intended to be helpful to anyone with an interest in this condition, by providing insight into the feelings, concerns and fears of parents living with children with ADHD, and also of the children who are dealing with the ups and downs of getting through school with this extra burden.



We all accept that our childhood prepares us for adulthood and is important in shaping who we are and how much we believe in and like ourselves. Children with ADHD have a right to a happy and successful school life in the same way that other children do, but face an absolute battle trying to fit in and adapt to the classroom and playground, to get on with learning and to make friends.

We should never underestimate the importance of our school days in getting the right start in life, and perhaps we should accept that it is in the school environment where ADHD has the most profound and lasting impact.



Andrea Bilbow, Founder and Chief Executive, ADDISS (The National Attention Deficit Disorder Information and Support Service)



Myths and Truths

The media in the UK has contributed to some negative and false perceptions about ADHD becoming popular opinion.

It is a MYTH that ADHD does not exist

"Why have we created a medical condition to excuse our spoilt brats?"

"Not ill just naughty"

The Spectator 26 February 2005

Daily Express 2 March 2005

"There is no evidence that ADHD exists"

The Mail on Sunday 27 February 2005

The TRUTH is rather different.

We cannot overemphasize the point that, as a matter of science, the notion that ADHD does not exist is simply wrong. All of the major medical associations and government health agencies recognize ADHD as a genuine disorder because the scientific evidence indicating it is so overwhelming. And there is no doubt that ADHD leads to impairments in major life activities, including social relations, education, family functioning, occupational functioning, self-sufficiency, and adherence to social rules, norms, and laws.

Clinical Child and Family Psychology Review, Vol. 5, No. 2, June 2002 International Consensus Statement on ADHD January 2002¹

It is a MYTH that ADHD is over-diagnosed

"An indication of the growing popularity of the ADHD diagnosis can be gleaned from the fact that in 2003-4, 329,300 methylphenidate prescriptions were dished out, compared with just 2,000 in the early Nineties"

Daily Express 2 March 2005

The TRUTH has been well-stated by credible sources.

The National Institute for Clinical Excellence, using a conservative approach to decision making on treatment, reported that in England and Wales only 30% of patients with hyperkinetic disorder, the most severe form of ADHD, were receiving stimulants. Evidence suggests a similar situation in the rest of the UK. Thus the increase seen in the prescription of psychostimulants over recent years represent less of a worrying explosion than a move towards better recognition and

treatment of a serious childhood disorder

David Coghill BMJ 16 October 2004²

Not all children who meet the diagnostic criteria for ADHD are diagnosed. NICE technology appraisal guidance No. 13. 2000³

Facts and Figures

ADHD is estimated to affect 5% of school-aged children in the UK.3

ADHD impacts on academic performance in many ways:4

- Poor concentration
- Inability to reflect
- Carelessness
- Working memory impairment
- Lack of confidence in ability
- Poor group work
- Auditory processing impairment
- Handwriting difficulties
- Poor organisational skills
- Spelling difficulties

In addition, children with ADHD may be hampered in making and keeping friendships because of certain characteristics:4

- Socially 'blind'
- Lack of inhibition
- Over-talkativeness
- Lack of responsiveness
- Insatiability

- Difficulties reading facial expression
- Lack of judgement
- Poor understanding of group dynamics
- Lack of awareness of image

ADHD may be associated with long-term adverse outcomes. Children can develop poor self-esteem and emotional and social problems.3

ADHD leads to impairment in major life activities:1

- 32-40% more likely to drop out of school
- 50-70% more likely to have few or no friends
- 70-80% more likely to under perform at work
- 40-50% more likely to engage in antisocial activities
- 40% more likely to experience teen pregnancy
- 16% more likely to contract sexually transmitted infections
- 20-30% more likely to experience depression
- 18-25% more likely to develop personality disorders



School Report: Perspectives on ADHD

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ADHD Matters: to Me

"Teachers don't say
ADHD very much. Maybe
they just think it's crazy
disorder."

Mark, age 11



Attention deficit/hyperactivity disorder (ADHD) affects 5% of children in the UK.3 The symptoms of this neurobiological condition vary from child to child, but most children with ADHD have a combination of problems with inattention, hyperactivity, and impulsivity.3 Unsurprisingly, living with ADHD can cause real problems for children at school.3,5

While ADHD develops in early childhood it is not usually detected in children before they start school and begin to demonstrate problems with learning.^{5,6} For many children with ADHD, their first difficulties when they start at school at the age of four or five will mark the beginning of a long struggle through the education system that makes each school day hard and can have long-term consequences that last into adulthood.3

Could do Better, Must try Harder

"We do things we don't mean to do, like fiddling around and like fidgeting and it makes fidgeting and it makes you stick out."

Tobias, age 14





Children with ADHD face a number of problems at school that put them at a disadvantage to their classmates. Academic work is harder as the symptoms of ADHD make a traditional learning structure problematic. 5,6

Schools require children to adopt certain behaviour patterns, for example being a good listener, being able to sit and focus for extended periods of time, and by having good reading and oral language skills. A child with ADHD may frequently appear not to be listening when they are spoken to, may find it difficult to concentrate on what the teacher is saying or writing on the board, and will be easily distracted by things happening around them. They may often interrupt their teacher or classmates by shouting out answers and yet they find it difficult to finish schoolwork projects, and may put off anything that requires substantial mental effort. 5,6

"I get picked on every day. I got picked on today. I got picked on yesterday. Every single day. They make names up and they always do it when there aren't any teachers around. Even if they knew they wouldn't be able to do anything about it. I just get treated weird. Like an alien."

Children with ADHD also have problems forming and keeping friendships with their peers. Because they behave in an uninhibited way their actions are often seen as inappropriate, and they can be perceived as a nuisance by other children. In the same way that a child with ADHD is unable to control the impulse to blurt things out in class, interrupting the teacher and not waiting their turn, they often cannot help intruding on other children's conversations and games which can quickly make them unpopular.5

Growing Pains

"I'd never want to tell a girlfriend that I had ADHD!"

Adrian, age 12



While childhood ADHD has a major impact at school, adolescent ADHD may be even more difficult to cope with. In secondary schools there is more demand for independent work, with less structure and more pressure on students to multi-task, taking on a variety of subjects and subject teachers. If symptoms persist, teenagers with ADHD may fall behind in their work and continue to find social relationships stressful, leading to academic underachievement, social isolation and low self-esteem.^{3,5}

Back to the Future

The importance of treating ADHD effectively in childhood and adolescence is now generally recognised because the cumulative effect of poor social and academic functioning can result in people with ADHD entering adulthood with low self-esteem, resulting in poor employment prospects.3,5

The majority of children with ADHD have to live with the condition longterm, with an estimated 65% still displaying the symptoms as adults.7 Early recognition, assessment and management of ADHD can re-direct the educational and psychosocial development of most children with ADHD.8

Survey Results: The Children

42% of the children surveyed are sent out of the classroom at least once a week and more than a third (36%) are sent to see another teacher at least once a week. Children were asked how these punishments made them feel – over two thirds (77%) said 'angry' and almost two thirds (62%) said 'fed-up'.



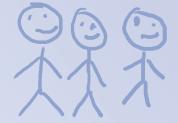
"If teachers know you are ADHD as soon as someone does something they will blame you instantly."

John, age 13

Two thirds (66%) of the children surveyed said ADHD has some effect on their ability to get to school in the morning.

"I buy a pen and lose it on the day I buy it and sometimes I forget my books." Ben, age 13

59% of the children surveyed said they wished they didn't have to take medication all of the time. 10% of children feel they get picked on for taking medication at school.



"I hate taking tablets at lunchtime. It's really annoying, I have to go up three flights of stairs to get to the room where I go to take it."

"I've got my name in the register and it says — on Ritalin. Every day children get picked to take the register down and I've seen them looking at it. So now they know I'm on Ritalin. They don't know what it's for but they know I'm on it."

Dean, age 12

According to the children surveyed the most difficult things about living with ADHD at school are not being able to concentrate (77%), with 69% of children getting into trouble with teachers and 63% not being able to finish their work.

"I quite often go into daydreams because of my ADHD, I might drift off for a few minutes and then when I come back round I realise everyone else is two pages ahead of me. I can't turn round and say that I'm behind though as it would just get me into more trouble."

Mark, age 13

"Everything distracts you at school. If someone drops a pen on the floor you know about it. Actually if someone drops a pen on the floor in a different school, you'd probably still know about it."

Joe, age 11

Half of the children surveyed said that ADHD causes them problems making or keeping friends at school.

"With ADHD sometimes you can make friends easier, but you can't keep them — you lose them the next day. You can't concentrate and people don't want to be friends with people who can't remember anything. You get too hyper and they like you for that, but the next day they think its lame. They think you're weird."

Richard, age 11

More of the children surveyed said they feel they need medication all of the time at school (44%) than feel they need it all of the time at home (17%) or in their social life (19%). However, school is also the place where the children feel most uncomfortable taking their medication. 16% of children stay away from school because of their ADHD once a week or more.

Survey Results: The Parents

83% of the parents surveyed said it was very important for their child to have control of their ADHD symptoms during the day. 48% thought it was very important for their child to have control of their ADHD symptoms at home.

"I think medication is important at school but not at home. He doesn't need it at home but he definitely needs it in school. In school he is like a kettle ready to boil."

Mary, mother of Anthony, age 14

A quarter of the parents surveyed said they feel that they rarely get to see their child 'as they really are' when they are on medication.



"I love him as he is without the medication and while he needs it in school he is old enough to make the choice with us about whether or not to take it when he is out of school."

Donna, mother of Gavin, age 8

70% of the parents surveyed describe the impact of ADHD on their child's education as 'huge', while 90% are concerned about the impact of the condition on their child's future. The impact on teacher/student relationships and on making and keeping friends worry almost a quarter of parents (23%) more than academic performance.



"In some ways the problem of school is harder than the actual problem of ADHD because of socialising and making friends. My son is always straight out of school and doesn't want to hang around."

Sally, mother of Connor, age 14

"Joe has no friends. If you ask him he will name individuals, but he never gets invited to friends' houses, and never gets invited to parties. It breaks my heart."

Christine, mother of Joe, age 14

"My son gets very worked up over school, it's easier to give him the odd day off here and there".

Angie, mother of Jackson, age 12

"They tease him terribly sometimes which hurts him terribly and devastates us. One kid said to him the other day that if he carried on the same way he'd never make any friends at secondary school. He was in floods about it, he's counting on the new school as a new opportunity."

"School is incapable of giving my son his medication at lunchtime.

They know when he is supposed to take it but don't want to chase him."

Tracy, mother of Jordan, age 8

"Her impulsiveness means that she often makes 'smart' comments which for most of us, thinking for a second, would remain as just thoughts. Some teachers understand that these comments are a misjudgement because of her impulsiveness and brush them aside, but others take them at face value and impose disciplinary measures'. She does not understand what she has done wrong and feels angry at the punishment and being misunderstood."

Helen, mother of Laura, age 15

Over half of the parents surveyed said they feel they are not currently in control of their child's health and well-being and would like to have more control over their medication.

And

58% of the parents surveyed either have some reservations or are uncomfortable about their child taking medication and over a third (37%) say they feel guilty about agreeing to their child having medication.



These stories were taken from interviews with a boy living with ADHD and his mother as part of the focus group research.

About Me by Jack

"My name is Jack and I'm eleven years old. I live with my Mum and Dad, my little sister and my cat. I'm going to secondary school in September. I've had ADHD for a long time and I knew something was wrong before I got told it was ADHD. I thought there was something wrong with my head, like something inside it. Not that I knew because I couldn't see inside other people's heads to see what was going

on in there – but I just felt like I was different. After I saw a doctor and got diagnosed I knew it was ADHD and now I am on tablets. The hardest thing about having ADHD is being at school. Because of my ADHD I find a lot of things more difficult than a lot of other children like writing stories and remembering things that people say to me. I would like more friends but I don't have any really at the minute."

About Jack by his Mum

"Jack was always a handful as a baby, but he was our first child so to be honest we didn't really know if the way he was behaving was normal or not. He was a very loving baby and young child, the whole family adored him. It was only really when he went to nursery that we found out for definite that something was wrong. The first report we got from nursery said that he was asking inappropriate questions - for attention. That comment has appeared in every single report we've had since. When he reached key stage 1 and was doing his SATS his teacher said to us that she thought he might have ADHD. We had sort of thought about it before then but were basically in denial I think, and we were

wary of pigeon-holing him too. He eventually began treatment after a terrible two years when we were constantly tearing our hair out. He was a terribly naughty boy, always in trouble, with very few friends. We had mixed feelings about medication. We wanted to do the right thing for him but we saw it as an absolute last resort. Now we have no doubts about how much he needs it at school. If there is ever a day when he doesn't take it and we don't tell his teacher - they tell us they can tell instantly if he isn't on his medication. But he doesn't have it in the holidays or at weekends – his main need for it is in school and it is good for him to have times when he is not relying on it."

Please note that all names in this report have been changed for purposes of anonymity.



35 years ago people said dyslexia was a middle class disorder but parents of dyslexic children refused to accept this and fought for the rights of their loved ones. ADHD today is too often still classified as an issue of poor parenting/teaching when so often this is just not the case. The findings in this report provide us with an opportunity to stand on the roof tops and yell that ADHD damages people's lives, particularly at school. A failure to deal with this reality is a failure of this society to both its children and to its children's children.



Fintan O'Regan, Education Director of ADDISS



Educational underachievement is one of the most substantial findings revealed when children with ADHD are followed up into adult life. With this in mind, the perspectives of affected children and their parents, on school life and learning are enormously important. This study goes beyond dry findings and illuminates the real world of school through the eyes of children and their families.



Professor Peter Hill, Honorary Consultant in Child & Adolescent Psychiatry ADDISS Professional Board



It is amazing to hear what these children have to say about the impact of ADHD at school. It is so important to give kids with ADHD the chance to talk, to express themselves, and to feel comfortable talking about their condition. If ADHD is hidden from people the children think they have a contagious disease and that is such a shame for them and so isolating. To hear directly from them gives us a real opportunity to think about what they are telling us.



Sheila Kelly, Founder ADD+UP, Hornchurch, Kent ADD+UP co-ordinated the children's focus group session used in the 'School Report' research.

Conclusion

The research findings in this report reveal the devastating impact of ADHD at school.

Parents know only too well that ADHD is often perceived by others as purely a behavioural problem rather than a learning disorder. This cruel denial must constantly be challenged and overturned if our children are to be properly helped.

Life at school is the biggest single worry for parents and children, and it is vital that we listen to their fears and concerns, so that we can find ways to help them.

What all parents want for their children is to see them safely through the school system, eventually to leave as happy, well educated and confident young adults. All too often for parents of children with ADHD this modest desire seems an impossibility. They worry constantly not just about daily problems, but about the long-term damage caused by poor academic performance and inadequate social skills.

Our school years shape the rest of our lives - negatively so for children whose ADHD is unrecognised and/or ignored. But paradoxically - although school is the place where the most damage is done - it is also the place where we can make the most difference to these children's lives with the right interventions. This means that the doctor treating the child, the medication the child receives, the school they are at, their parents, and the child - must all work together with the shared goal of making those school days a success and allowing the child to go on to have the chance of a happy and successful life.

Every child matters.

Andrea Bilbow, Founder and Chief Executive, ADDISS (The National Attention Deficit Disorder Information and Support Service) Registered Charity 1070827



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