The ADHD Experience

Chapter summary

In this chapter we look more closely at what children, their parents and teachers have to say about the experience of having ADHD or living and or working with a child who has the condition.

- Personal perspectives of AD/HD for children parents and teachers
  - Case studies explored
- Different perspectives
- AD/HD and medication
  - Case studies explored
- Limitations of medication
- Key points to remember

An individual’s experience

This understanding is important for a number of reasons, the chief of which is our need to understand the realities of ADHD as they are experienced by those who live and work with the condition. Whether or not you, the reader, contest or accept the objective reality of ADHD, it is likely that you are concerned about the effects of ADHD on those who bear the label. Exploring the way the social environment impacts on the child with ADHD, helps to clarify the thought process governing behaviour and the consequences this has on the way people think and respond.

A second important reason for caring about the perceptions of those who experience ADHD is that they have a right to be heard. All human beings have the inalienable right to have their voices heard. This is fundamental to a democratic society. Furthermore, the voices of the potentially or actually marginalized are a vital element in societies that aspire to social justice.

A third reason for listening to these voices is a technical one that relates closely to the two already mentioned. The DSM IV diagnostic criteria (APA, 1994) indicate that the information needed to make a clinical diagnosis, in part, relies upon data gathered from the first-hand
accounts of children, their parents and their teachers. In addition, the *DSM IV* recommends gathering data from direct observation of the child. Behaviour rating scales, situation questionnaires, psycho-educational testing and medical evaluation are also used (McMullen et al., 1994).

**Parents’, teachers’ and children’s perspectives on ADHD**

The cases that follow are taken from interviews with children diagnosed with ADHD, their parents and their teacher, and highlight some of the behavioural difficulties that arise in both the home and the school setting. (For more details at the data source, see Hughes, 2004.) The extracts suggest that in failing to consider ADHD as a bio-psychosocial condition, children’s behavioural difficulties are exacerbated.

### Case study

Padraig’s mother explains that his school work has deteriorated due to bullying in school and that as a result he is a very unhappy child. However, although she believes that Padraig’s condition has a biological origin she also believes that he is responsible for the way he behaves.

*Parent:* I get the impression that he can’t be bothered. It’s a lot of laziness. I think a lot of laziness. It’s, all, ‘I don’t want to do it. I can’t be bothered with it’.

Padraig’s mother interprets his lack of concentration as being laziness, but his teacher explains that in her view Padraig is preoccupied about what others think of him.

*Teacher:* The only reason he stands out from the others in the class is because he worries so much about what other people think of him.

The teacher suggests that he creates his own anxiety. She believes he has a negative perception of himself, and that this is reinforcing his negative view of others. She does not make the link between the bullying behaviour of Padraig’s peers and his anxiety and low self-esteem. Padraig on the other hand is concerned as to why others view his behaviour as being ‘silly’, and is puzzled by their hostility towards him.

*Padraig:* Some people beat me up. It’s been happening in school. A couple of days ago, every time I went outside all these boys jumped on me and started beating me up and said ‘We’ll be back to beat you up later’, and then they pretend to go, but they’re hiding behind the wall and I think, they’re gone, so I go outside and then they jump on me. I cry, sometimes on my own. My mum says that I sometimes act stupid and that’s why they tease me, but to me I’m not acting stupid, I don’t think it’s stupid.

In Padraig’s case his teacher and parent believe that Padraig is responsible for his own difficulties, no consideration is given to the influence environmental factors might have on his behaviour. Teacher and parent have perspectives on Padraig’s situation that conflict with his own, leaving Padraig isolated and confused, and, in the absence of effective self-management skills, all the more vulnerable to bullies.
This case highlights the importance of understanding behaviour and support being available in the child’s school and home environment. It highlights the negative consequences of failing to consider the circumstances surrounding the problem behaviour and failure to change them.

Case study

Amy’s mother is concerned that, in school, Amy is blamed for problems that are outside her control and, as a result, she has become a scapegoat for the bad behaviour of others.

**Parent:** She’s very sharp and this causes problems. For instance at school there was something in the playground that was wrong, it was started by another child, but Amy was the one that got caught and punished, that would make her react. She’s not particularly naughty, it’s because she reacts to things that normal children would ignore or pass by, she reacts to situations and makes it into a problem.

Amy’s mother believes that her daughter is very sensitive, and as a consequence, this aspect of her psychological make-up leads to her overreacting to situations. Her teacher, however, takes a slightly more benign view, describing Amy as an ‘astute’ child who strives for perfection. The teacher suggests that in school her behaviour only deteriorates when she comes into conflict with people who do not know her, and are less tolerant of her individualism.

**Teacher:** There was an incident in the classroom, with another teacher, she [Amy] threw a book and went over and scribbled all over the board. She would never do that with me. She would never get to the point where she would feel she had to do that. The only problems I have with her are her calling out and being a pest sometimes.

This is a remarkably forgiving position for a teacher to take in relation to what most people would see as an extremely disruptive episode. For this teacher, Amy’s disruptive behaviour in the classroom is not the result of malice, but is often the product of this highly intelligent girl’s need for a high level of mental stimulation. In the case of the aggressive outbursts, these, she believes, are due to the way others respond to her when they do not understand this intense need.

In this case, Amy’s teacher concedes that ADHD has a biological component, that makes certain aspects of her social and academic engagement difficult for her to regulate, but she is also considering the contribution social factors may have on her difficulties. For her, getting to know Amy’s idiosyncratic ways, and finding a positive way of framing some of the things that make her potentially challenging to work with are key to preventing her frustration escalating into seriously disruptive behaviour.

Amy struggles to describe her own behaviour other than to say she was ‘bad’. She referred to an outburst in school where she had sworn in the hearing of a lunchtime supervisor, who had mistakenly (according to Amy) thought she had sworn at her. By her [Amy’s] account the supervisor had reprimanded her and she [Amy] had struck her. Amy’s reasoning was that she had not sworn at her but at someone else, and that she was being blamed unnecessarily. She regretted hitting her but equally thought that she was ‘getting her into trouble’.
In some ways, Amy’s is an unusual case. First, on the basis of the teacher’s account, it would seem that Amy’s class teacher is remarkably tolerant of her aggressive behaviour, especially towards staff. The teacher’s framing of these behaviours as the consequence of ‘perfectionism’, indicates a real effort to understand Amy’s difficulties from an educational perspective. To some extent, this belies the mother’s claim that the school adopts a blaming approach towards Amy. Her class teacher clearly is not culpable here, though other staff and Amy’s peers may be. A second, unusual feature of Amy’s case is her highly reasoned account of her behavioural outbursts. Both examples given here are justified by Amy in terms of a response by her to injustice. The book-throwing incident is even described in terms that indicate it to have been a planned act, carefully executed to avoid undesirable consequences: I threw a book once, but I had asked Kate to move out of way first so I didn’t hit her. I wasn’t aiming to hit anyone I was just aiming to wreck the classroom because we had a point taken off us for talking in general knowledge quiz. But everybody else was talking, and nobody else got a point taken off them. It wasn’t fair, ‘cos everybody else was two and a half points ahead.

Amy claims her anger is a justifiable response to what she perceives as injustice. She attributes her aggression to the way others treat her, and she states that in a situation where she is wrongly accused she will retaliate to defend her self.

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Before we jump to the conclusion that Amy’s apparent thought processes render her disruptive behaviour as being not sympabuatic of ADHD, we must bear in mind, on the basis of both the mother’s and the teacher’s accounts, that Amy is a ‘sharp’ and ‘astute’ child. These qualities make her extremely capable of providing justifications for her behaviour. As a ‘perfectionist’ she may well have a vested interest in explaining her ‘bad’ behaviour in terms that protect her self-image, even if this means inventing reasons for her behaviour after the event. The fact that she repeatedly finds herself ‘in trouble’ suggests that she is not as in control of her behaviour as appears to claim. Her way of resolving the dissonance between her aspirations for perfection and her ‘badness’, may be to invoke the injustice argument. Her argument is that she is forced to be ‘bad’, because she is intolerant of injustice, of which she is repeatedly a victim.

Amy’s case contrasts with Padraig’s in two ways. First, Padraig appears bewildered, and acknowledges that he has difficulty in regulating his behaviour. Second, whilst Padraig is clearly a victim of the aggression of others, Amy is, even by her own account, aggressive towards others. Amy’s tendency to portray her own behaviour in rational terms that indicate a degree of self-control, whilst this may not be as clear-cut as she claims, does offer opportunities for intervention that may not be as readily available in Padraig’s case. In so far as Amy is able to self-regulate, her motivation to employ self-regulation is not aided by her current pattern of highly rational self-justification. Her reasoning ability has the potential to be exploited by adults (especially
parents and teachers) to challenge the self-justification. A successful challenge may produce one of two outcomes. The first might be to undermine her current justification, and thus replace her distorted rationale with one which renders her misbehaviour irrational, and, therefore, cause her to modify it. On the other hand, if she is unable to exert an adequate degree of control over her behaviour, as her parent and teacher assume, then this will emerge as the appropriate rational explanation. If the latter were to happen, the way would be paved to support Amy with educational accommodations (for example, reducing the opportunities for her to become over stimulated) and cognitive interventions (for example, the teaching of cognitive-behavioural self-management techniques). See Chapter 5 for more details of these interventions.

In summary, this case is similar to the previous one in that the child’s behaviour is subject to a range of different interpretations. In both cases the child is cast in the role of victim, though in the second case, there is a much greater sense of the child’s receptiveness to rational explanations for her behaviour. In both cases there is evidence that there has been little active communication between the key stakeholders, which could have the effect of producing a coherent account of the situation in which the children find themselves. Without this, it is difficult to see how effective intervention in the school and home settings can be achieved.

Case study

Abu’s mother believes that people misunderstand her son, and that their negative attitude towards him can lead to him becoming frustrated and aggressive. She finds this misunderstanding reflected at home, as she and her husband do not share the same understanding of what they both see as Abu’s difficult behaviour.

**Parent:** My husband will not accept that he’s not just a naughty child and we have terrible weekends, because he believes he just needs a good smack, and Abu immediately picks up on this and reacts … His outbursts can last two hours, we have to restrain him, and when it’s over he slumps and he’ll say, ‘I’m sorry Mummy’, and he’ll put his arms round me, and he’ll sob; he’ll sob his heart out.

This suggests that Abu’s parents’ different views about the cause and course of his behaviour are reflected in the different approach they adopt for managing his outbursts.

Abu’s teacher suggests that a lot of Abu’s behavioural difficulties are due to his home environment and that Abu has learnt that unacceptable behaviour is tolerated.

**Teacher:** You know, it was very much [as if Abu says], ‘I have moods, and tough: you’ve got to put up with me!’ I believe there is some element of reinforcement from home, that such things are accepted. Obviously at school you try and encourage the children to become part of the ‘norm’ system, and to produce behaviour which is acceptable, rather than accepting unacceptable behaviour. Abu knows exactly what he is doing: he wants attention.

Because Abu’s problems are seen by his teacher as being due to his ‘attention-seeking’ tendencies, she will not tolerate this behaviour within the class, and in order to discourage it she ignores him. A key feature of this perspective is the apportioning of blame. ‘Abu knows exactly what he is doing’, and manipulates situations in order to get people’s attention.
Whilst Abu believes that medication plays an important role in reducing his outbursts, this is not supported by his parents or teacher. With no consensus about the cause of his difficulties, Abu is on the receiving end of inconsistent attempts to manage his behaviour. Furthermore, the triangular conflict involving him, his father and mother can only serve to undermine his sense of emotional security. And although his mother appears to be sympathetic towards him, she also appears unable to convince other key players (her husband and the teacher) to share her sympathetic view.

In summary, this case identifies different perspectives about ADHD. The inconsistencies within the home and between parents and teachers exacerbate the child’s difficulties, leaving the child to believe that medication is the only form of effective support, even though the other stakeholders appear to see little significant evidence of this effectiveness.

Looking at ADHD from different perspectives

These cases highlight how professionals and parents can each approach the child with the ADHD diagnosis from different and, sometimes, conflicting perspectives. There is often only a consensus in relation to the view that the child presents with disturbing behaviour. The explanations for the behaviours tend to reflect debates in the literature, with different views being expressed as to the extent to which the behaviours are within the control of the child, or are the product of biological or social influences. These differences in opinion tend to lead to different approaches to handling the child or, in some cases, to an abdication of responsibility. The lack of coherence between the views held by the different stakeholders results, in each case, in a failure to achieve a consistent and effective approach to intervention, which is a fundamental barrier to positive change. One of the most glaring issues that is repeatedly neglected is the way in which the failure to establish a shared view of the problems faced by the child contributes to an environment which exacerbates the problems. Even the more sympathetic responses tend to translate into patterns of blame, rather than positive intervention strategies. The children themselves tend to respond to these confusing circumstances with either a sense of helplessness or a tendency to blame others. In each of the three cases, there is a sense of an impaired self-image: the children feel helpless, ‘bad’ or guilty.

These brief cases suggest that almost regardless of the actual nature of ADHD, in terms of the origins of its core characteristics of inattentiveness, impulsivity and/or hyperactivity, the social
context in which it is manifested is of enormous importance. In all three cases, the conflicting views surrounding the child are a source of distress and confusion, and as such they are barriers to improving the child’s situation. If we add to this the assumption that, by virtue of each child being the bearer of the ADHD diagnosis, each child exhibits severe problems with two or more of the three core features of ADHD, then we can see how these difficulties are likely to be compounded by the failure of the adult stakeholders to engage in a constructive dialogue with one another and the child.

ADHD and medication: what do children, parents and teachers think?

We now move on to another important aspect of the experience of ADHD, which affects many children of who bear the diagnosis. The following case studies taken from interviews with children diagnosed with ADHD, and their parents and teachers, highlight their views of the effects that psycho-stimulant medication has on both behaviour and learning outcomes. We also consider the impact of the ways in which they construe their experiences on opportunities for positive intervention. The cases illustrate how ideas about what medication is able to achieve has consequences for the options that teachers, parents and children believe they have for alleviating difficulties.

**Case study**

Rajiv seems unequivocal in his belief as to the effectiveness of medication for ADHD:

*Rajiv:* I will be very, very good then [when I have taken medication], sitting quietly, sitting sensibly. I’m naughty, only when me tablets have wore off. I need me tablets to stop me from being naughty.

Not only does he believe medication to be responsible for enabling him to sit ‘quietly’, which is probably an accurate behavioural observation, he also attributes more qualitative effects to the medication. This is reflected in his use of the words ‘good’ and ‘sensibly’. It is medication, or its absence, that determines whether or not Rajiv is ‘naughty’. This indicates a belief in the power of medication to control his behaviour directly, rather than its power to influence his ability to control his behaviour. The idea that he may have a role to play, in terms of his ability to make behavioural choices does not appear to figure in his account, indicating little or no appreciation of the role of human agency and motivation in the process behavioural self-regulation.

Rajiv’s mother offers a different perspective to her son’s school experience, and indicates to us that the medication has not always had the effects Rajiv describes:

*Parent:* He wasn’t getting an education because every other day I was being phoned up telling me that he was too bad and I had to come and get him, the Ritalin and school just didn’t seem to go together.

As a result, the mother has moved Rajiv to a different school.

From Rajiv’s teacher’s perspective, medication has had only a limited effect on his behaviour, and she believes that his difficulties are the product of neurological dysfunctions that are beyond remedy.
This case illustrates the way in which unrealistic expectations about what medication can achieve may restrict the range of options for intervention that might be considered. This theme will emerge repeatedly in the following examples.

**Case study**

Daley’s mother suggests that medication has improved some aspects of his behaviour but there are problems due to the side effects of the medication, and she is worried about the long-term implications.

**Parent:** I worried when he first took them. He has had chest pains last month, [and] the doctor gave him a scan. Now they didn’t think it was related to tablets, but he has pins and needles in his feet and that’s a problem, and he’s lost weight. Since he lost weight he’s got paranoid about his bones, I mean his bones seem to be like sticking out but you know if he knocks his-self, and he’s very sensitive.

Daley’s mother attributes both physical and psychological problems to his medication, despite reassurance from the doctor.

Having said this, Daley’s mother also tries to convince Daley of the need to continue with the medication.

**Parent:** I’ve explained and I’ve said that ‘these tablets will make you lose weight but they are to make you good, do you want to be good?’ and he said ‘Yeah’.

This well-intentioned effort has the potential to exacerbate the psychological difficulties she believes Daley to have. On the one hand, he is experiencing anxieties regarding the side effects of the medication, and yet his mother is attempting to persuade him to take the medication. His refusal to take the medication is likely to be interpreted as a lack of desire to ‘be good’. The benefit of ‘being good’ is his mother’s approval, but the cost is deep concern about the physical effects of the medication. This is a classic ‘double bind’ situation, which is likely to increase Daley’s negative feelings. Furthermore, the mother is, unwittingly, encouraging Daley to see himself as both dependent on the medication and, therefore, powerless in relation to his condition.
The view, that medication alone has the power to transform the child’s behaviour and academic performance, that is evident in this case, places a sensitive child in a highly problematic situation. For Daley medication is associated with two conflicting beliefs. The first is that medication has the power to correct the difficulties that distress his mother and himself: he can become the child both he and his mother want (and the student he and his teacher want) only through the taking of medication. On the other hand, medication is, in his eyes, associated with serious physical side effects that threaten his health and emotional stress, which is caused by the way in which it is managed in school. This complex of negative factors suggests that the benefits that may be associated with the medication, in this case, are offset and probably outweighed by the associated emotional toll.

Daley’s difficulties are further compounded, according to his mother, by what she sees as his teacher’s insensitivity towards him, particularly in relation to the way that medication is managed in the classroom situation:

**Parent:** He doesn’t like to be embarrassed. That does affect him if you embarrass him. And this is what is happening at school, when his teacher was calling him out to take his medication, that would make him angry, the embarrassment.

The public way in which Daley’s medication is handled by the teacher is not only a source of embarrassment to Daley, but the embarrassment, in turn, leads to angry outbursts. This suggests that factors around the ways in which medication is portrayed and managed, both in the home and at school, actually exacerbate the very problems that the medication is intended to alleviate.

Daley’s own attitude towards medication reveals a child who feels himself to be at the mercy of his medication, in relation to both his behaviour and his educational performance:

**Daley:** Sometimes the tablets work because sometimes they make me be good, but when they’re not working I don’t do any work.

Whatever sense of personal agency he may have had is eroded by parental perceptions that place unrealistic expectations on the medication.

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**Case study**

Ivan’s teacher suggests that, despite the medication generally having a calming effect on Ivan’s behaviour, it does not stop some violent outbursts.

**Teacher:** He just started to go, just the odd time and his language was appalling and then this year, we’ve had various instants.

The teacher goes on to explain that it is not only those around Ivan who are disturbed by these outbursts, Ivan too is distressed by them:
As in Daley’s case, Ivan is sensitive to his mother’s anxieties about his behaviour, and aware of the importance that she attaches to medication as a means of controlling this behaviour. Daley’s and Ivan’s concern about taking medication is echoed in the next case study.

**Case study**

Luca, like Daley and Ivan, feels unhappy about taking medication. Like Daley, Luca dislikes the physical side effects of medication, which in his case involve his sense of vitality:

*Luca:* I don’t like medication, because, I mean, I want my energy, ‘cos I won’t have enough energy to do anything – enough energy to go out and play football.

Furthermore, unlike Daley and Ivan, Luca does not believe that medication is effective in helping to manage his behavioural and attention problems:

*Luca:* I’m still naughty, even when I do take my tablets my room is a mess, and I forgot to tidy it. I keep trashing stuff because I get angry. I feel angry because my mum’s going, ‘Clean your room, clean your room’ and then I go upstairs and don’t do it.

The contrasting feature of Luca’s case with those of Daley and Ivan, is the sense that his active distaste for medication carries through into a reluctance to taking it. Furthermore, this resistance can be seen as reflecting a genuine sense of self agency, which is reflected in his active efforts to self-manage some of the difficulties he believes himself to have:

*Luca:* I don’t want to play with other children, people keep annoying me. I have friends, but I don’t want to play with them, because I want to be on me own.

We may think of Luca’s preference for solitude as a means of staying out of trouble potentially problematic in relation to his social and emotional development, however, we can also interpret this independence of thought and action as a positive quality that might be exploited to enable him to learn more pro-social self-management strategies.
No matter how we look at this case, Luca comes across as a child who has a sense of his own agency. He is not disempowered by the beliefs he has about ADHD, though he is concerned that he has difficulties managing his anger and sustaining attention to classroom tasks:

Luca: I get into trouble for not listening to the teacher. I get a time out sheet at least 20 times. But I do listen but then I forget because I’m doing something else. I was doing the tables and someone said stuff, and then I forgot what to do next, and then Miss sent me for a time out sheet.

Although we can see positive possibilities in Luca’s orientation to ADHD, we have to acknowledge that these do not (according to his account) appear to be being exploited to positive effect in the classroom. Furthermore, there is an implication that his view of ADHD and how it should be handled is not shared by either his mother or teacher. This situation may add to the self-imposed isolation that is Luca’s preferred approach to managing the difficulties he experiences.

The limitations of medication

As we have shown, many of the children and parents interviewed in this study expressed a very strong belief in the almost magical power of medication to improve behaviour. Even when this is the case, however, many adults also express concern about what they see as unwelcome aspects of medication.

Luca’s mother believes medication has caused him to become sensitive and emotional; behaviour which makes him susceptible to emotional outbursts: ‘This is the downside of the medication. He is already emotional but once he has had that medication, the emotions increase. So if someone antagonizes him he’ll start crying, uncontrollably.’

Abu’s teacher perceives that although medication has improved his behaviour, he believes that Abu’s personality has been adversely affected.

Teacher: ‘The one negative side is that he’s lost his sparkle. He’s quite a character and verbally he’s got a lot to say. I think he knows a lot as well, he’s got a good knowledge.’

Padraig’s mother believes her son has become dependent on the effect of medication in the management of his behaviour. She would rather he developed ways of coping without medication.

Parent: I think he’s got this impression that if he doesn’t have his tablets, he can’t do anything. I said, ‘Well, Padraig, you are going to have to try without thinking about, “I’ve got to take tablets or I can’t do it”. You’ve got to help yourself and not to rely on these tablets.’

The following example demonstrates the concern of one mother that medication is being used as a prop. She believes that the problems underlying her child’s behavioural difficulties are not being addressed. She believes that ultimately it is the child who has to learn how to manage his behaviour.

Parent: I’m so concerned about his anger management, him doing something about himself. I don’t want him just to rely on the medication. He just forgets things and he’s kind of in a world of his own, he can’t remember where he puts things, he doesn’t know what day it is, he doesn’t know what happened five minutes ago.
Yet another parent is concerned that her son is now seeking medication to avoid being told off: ‘He might say something, say you’re telling him off, “Well why don’t you give me a tablet?”’

These extracts demonstrate that whilst medication is often seen as having the effect of controlling some of the surface features of ADHD, some adults express concerns over the limited effectiveness of medication in dealing with the underlying causes of the ADHD behaviours.

It would make life so much easier for all concerned if it were possible to create simple definitions for the things in our world, unanimous definitions that everyone could agree on. From the voices represented in this book we are already beginning to see the problems differences of opinion can course. Whilst there is an acceptance among many, though not all, of those interviewed that ADHD provides a valid account of the difficulties being experienced by the children in question, there are divergent views as how the condition should be understood. There are those who opt for a straightforward biological explanation for the condition, and then there are those who adopt more social and psychological explanations. Similarly, where medication is part of the ADHD experience, whilst there is support for the belief that medication is a powerful and reliable intervention for ADHD, there are differing views about its wider effects on the children. There are concerns, for example, about the overreliance that some children may develop on the medication, and its assumed effects.

As we have seen, adults often play a leading role in shaping the beliefs that children develop about the nature of ADHD, and the power of medication. They do this in direct ways, by virtue of what they tell their children about these things. They also influence their children in more indirect ways. When children are exposed to adults’ sometimes conflicting perspectives and opinions, they tend to experience confusion and anxiety. This leads them to take sometimes desperate measures in order to ‘be good’, and to thereby cease being a source of trouble to their parents or teachers. Unfortunately, among these cases, confusion and conflict seem to be common denominators. In these circumstances, as we have seen, because of difficulties in achieving a consensus among stakeholders, there is a repeated failure to identify and implement constructive and coherent intervention strategies. In place of appropriate intervention we find confusion, anxiety, blame, guilt and an overreliance on medication.

Key points to remember

- Children’s perspectives need to be heard, and understood by teachers and parents.
- Combined support is required in home and school settings.
- Greater communication is needed between all parties and shared views.
- Understand the strengths and limitations of medication.
- Consider the wider environmental factors influencing behaviour.