

Mental Health in Intellectual Disabilities

A complete introduction to assessment,
intervention, care and support

Fifth edition

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Chapter 9: Attention deficit hyperactive disorder (ADHD)

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Summary

This chapter describes the presentation and treatment of attention deficit hyperactive disorder (ADHD) in adults with intellectual disabilities (ID). ADHD is a common condition in children with ID but often goes unrecognised in adults. The presentation of ADHD in adults with ID is often complicated by the presence of other conditions such as autism. In addition, ADHD impacts on a person's achievements and on their social functioning, so hindering their personal relationships. To date there has been no diagnostic tool available to diagnose ADHD in adults with ID, although an assessment tool specifically developed for the purpose is in development. The approach to the treatment of ADHD in adults with ID is same as in the general population, using a combination of both pharmacological and non-pharmacological interventions. This is why it is important to raise the awareness and understanding of ADHD in adults with ID as good treatments are available.

Introduction

ADHD is a common childhood disorder that can persist into adulthood. It affects 3% to 4% of children and 1% of adults. It is a neurodevelopmental disorder as is ID and autism spectrum disorder (ASD), all of which are lifelong conditions affecting several domains of functioning. The age of onset for ADHD within DSM-V (American Psychiatric Association, 2013) is before the age of 12 years. In adults, ADHD commonly occurs with other conditions including ID, anxiety, depression, drug and alcohol use and antisocial behaviour. For children with ADHD, common co-morbid conditions include oppositional defiant and conduct disorders, anxiety and mood disorders, tics or Tourette's syndrome and autism.

A third of children with ADHD go on to have the diagnosis as adults, whereas two thirds show a persistence of symptoms that impacts on their functioning as adults. ADHD can impact on the social, academic and occupational functioning of a person, therefore not just on what they may achieve at school but on their personal relationships as children and adults.

ADHD is three times more common in individuals with ID than in the general population with some studies indicating that up to a third of children with ID are affected by symptoms of ADHD. For those with ASD, up to 50% may be affected with symptoms of ADHD. The prevalence of ADHD is equal in boys and girls for those with ID, which compares to the findings in the general population in which five boys are identified to every one girl. This gender difference may in part be due to less awareness of ADHD occurring in girls.

Studies indicate there is a significant genetic component that influences the risk for developing ADHD. The risk for first degree relatives is four to 10 times the population rate and the prevalence of ADHD among first degree relatives is in the range 20 to 50%. In addition, there are environmental factors associated with ADHD. These include exposure of the foetus to alcohol, nicotine, drugs, high blood pressure, maternal stress during pregnancy, being born preterm and low birth weight. However, these environmental factors (which are associations and not shown to be direct causes) may be modified by genetic factors.

ADHD and ID

ADHD is common in people with ID, with those less able at more risk of showing symptoms. Traditionally, there has not been a focus on ADHD in adults with ID despite it being one of the most common disorders in childhood.

There is increasing evidence to support the diagnosis of ADHD in adults with ID and that this group of the population is at increased risk for the condition (Xenitidis *et al*, 2014). Until recently, the research focused on children with mild ID, confirming an increase of ADHD symptoms in this group (Simonoff *et al*, 2007). The challenge has been to establish how best to apply the diagnostic criteria in people with ID, and others have questioned if ADHD can be diagnosed in children with low IQ. A further complication is that the inattention and associated deficits of executive function in ADHD may result in lower IQ scores, but this will not necessarily indicate ID as defined by the international diagnostic systems (Ek *et al*, 2011). In adults with ADHD, the severity of symptoms has a negative correlation with IQ scores. One study examining symptoms of ADHD in adults with ID found that there was greater severity of (adult and childhood) symptoms compared to people with ADHD with no ID. It was also the case that

the latter group could expect a greater improvement of symptoms in adulthood than those with ID (Xenitidis *et al*, 2014).

Currently there are no specific rating scales designed to assess ADHD in adults with ID that work with the ICD-10 and DSM-V diagnostic systems. La Malfa *et al* (2008) reported on the use of the Conner's Adult ADHD rating scale in 46 adults with ID, finding an 'ADHD-positive' prevalence of 19.6%. There is also an increasing recognition of the need to screen for the neurodevelopmental disorders as defined by DSM-V to identify when ADHD and ID occur together, especially in at-risk populations such as those in the criminal justice system (McCarthy *et al*, 2015). The key area for future research, therefore, is to develop a validated tool to diagnose ADHD in adults with ID that will lead to the development of studies looking at response to treatment, and so increase understanding of the long-term outcomes in adults with ID and comorbid ADHD.

Diagnosing ADHD

Central to the diagnostic criteria for ADHD in children in DSM-V is a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development as characterised by:

1. Inattention: six or more symptoms (which have been present for at least six months) that are inconsistent with developmental level and that negatively impact directly on social and academic/occupational activities. The individual may: overlook details; have difficulties remaining focused on conversations; seem like their mind is elsewhere; fail to finish tasks; fail to meet deadlines; have problems completing forms; lose items such as keys or phones; be easily distracted and often forgetful in daily activities such as keeping appointment and paying bills.
2. Hyperactivity and impulsivity – at least six symptoms: often fidgets; restless; often 'on the go'; talking excessively; unable to wait turns in a conversation; intrusion into or taking over what others are doing.

For older adolescents and adults (age 17 and above) at least five symptoms are required.

DSM-V notes that although motor symptoms of hyperactivity become less obvious in adolescence and adulthood, difficulties persist with restlessness, inattention, poor planning and impulsivity. DSM-V also stipulates that symptoms are excessive and maladaptive for developmental level, which is a very important issue to consider when making a diagnosis in a person with mild ID compared to a person with severe ID.

The current severity of ADHD is also specified in DSM-V as below:

- Mild – few if any symptoms in excess of those required to make the diagnosis are present, and symptoms result in no more than minor impairments in social or occupational functioning.
- Moderate – symptoms or functional impairment between ‘mild’ and ‘severe’ are present.
- Severe – many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe are present, or the symptoms result in marked impairment in social or occupational functioning.

DSM-V states that ADHD can be diagnosed with known genetic syndromes such as fragile X syndrome, velo-cardiofacial syndrome and Down’s syndrome.

Assessment of ADHD

There are a number of screening tools available, but it is important to remember that symptoms of ADHD start in childhood, are chronic, and do not fluctuate overtime. The hyperactive and impulsive symptoms do modify more than the attentional symptoms.

Diagnosis is based on a careful assessment, including developmental history and a detailed psychiatric history. The use of informants is helpful specifically in recognising the level of impairment on functioning. There are screening instruments available for identifying adults with ADHD such as the six item World Health Adult Self Report Scale (ASRS). For diagnosis, there are number tools such as the Conners’ Adult ADHD Rating scale and Diagnostic Interview for ADHD in adults (DIVA), which is available free on line at www.divacenter.eu. The DIVA has now been developed into a version for use with adults with ID known as DIVA-ID and will soon be available for wider use.

Other symptoms that are commonly associated with ADHD but not necessarily a requirement of the diagnostic systems include procrastination, low tolerance of frustration so seeming on a ‘short fuse’, and mood lability. Mood lability is very common, with mood changes occurring a number times a day, and low self-esteem is also very common due to earlier experiences of failure and rejection. Adults with ADHD do not settle with age and are often underachievers but will change and/or lose jobs and relationships through being fired or being bored. The clinical picture of ADHD is commonly complicated by frequent comorbid conditions that may occur, making a complex picture of conditions to unravel and treat (Hellings *et al*, 2016).

Parents and carers may report the person with ID to be moody, aggressive or anxious so there may be a response to prescribe medication such as antipsychotics or mood stabilisers. However, this would result in the person not receiving the most appropriate treatment for their ADHD, and therefore missing the opportunity to have much better control of their ADHD symptoms.

Types of ADHD

How ADHD presents will differ by individual. There are three main ways it can present:

1. ADHD where the person is predominantly hyperactive and or impulsive. The person with this will feel the need to move constantly. They may also struggle with making good choices as they become impatient as their impulse control can be affected. Although there may be some issues with inattention, this is not seen as a problem.
2. ADHD where the person is predominantly inattentive and has difficulty paying attention. The person is easily distracted but not usually impulsive or hyperactive. This can often be missed as the person is not seen as disruptive and can even be seen as shy, whereas those in the first group are often seen as disruptive.
3. ADHD, combined presentation. This is the most common type of ADHD, where the person experiences symptoms in both types 1 and 2.

ADHD and other mental disorders

Diagnosing ADHD in people with ID can be challenging as it can be mistaken for a behavioural issue or a mental illness where there is an increase in activity such as hypomania, or where there is a lack of attention paid due to poor concentration, such as depression. However, it is equally important to ensure that symptoms are not better explained by an underlying mental health problem. Some of the ways to distinguish between ADHD and other mental health problems is to look at the presentation in context e.g. chronicity of symptoms, recent stressful life events, severity of symptoms or other medical conditions such as infection.

In addition, ADHD shares some of the symptoms of borderline personality disorder such as impulsivity, mood instability and feelings of boredom.

Treatment

Symptoms of ADHD can be treated effectively in both children and adults. The effects of both stimulant medication and atomoxetine on the core symptoms of ADHD are well established.

Treatment can be broken into pharmacological and non-pharmacological interventions. The focus of treatment should focus on improving symptoms and functioning. Traditionally, those with ID have been excluded from studies of ADHD in the general population as it was felt the symptoms were part of the ID – diagnostic overshadowing. Current clinical practice in treating adults with ID presenting with ADHD is therefore to apply the current evidence available for the non-ID population as described in NICE guidelines for adults with ADHD (NICE, 2008).

Table 9.1 summarises the key treatments for ADHD. The evidence indicates that children with ID and ADHD may not have the same response to psychostimulant medication, such as methylphenidate, as other children.

Table 9.1: Treatments for ADHD

| Pharmacological | Non-pharmacological |
|--|---|
| <p>There are five types of medication licensed for the treatment of ADHD:</p> <ul style="list-style-type: none"> ■ Methylphenidate. ■ Dexamfetamine. ■ Lisdexamfetamine. ■ Atomoxetine. ■ Guanfacine. | <ul style="list-style-type: none"> ■ CBT. ■ Lifestyle and diet. ■ Behavioural interventions. ■ Psychoeducation. ■ Social skills. ■ Parent education programmes. |
| <p>(For more information, see NHS Choices: http://www.nhs.uk/Conditions/Attention-deficit-hyperactivity-disorder/Pages/Treatment.aspx (accessed December 2017))</p> | |

Pharmacological

Medicines are not intended to be a cure for ADHD but are designed to help with symptoms, for example to make the person more able to concentrate, be less impulsive, feel calmer, and take part in things they would not have been able to before, such as learning. In the UK, all of these medications are licensed for use in children and teenagers and are commonly prescribed as extended release preparations, which have a duration of action of many hours, possibly allowing a one-a-day dose. Atomoxetine is also licensed for use in adults who had symptoms of ADHD.

It is reported that children with ADHD may be more at risk of the side effects from the stimulants as described below. Stimulants may worsen self-injury behaviour so use of non-stimulant ADHD medication may be more suitable.

What side effects can stimulants cause?

Side effects often happen early in treatment and for most people are mild and short-term. Common side effects can include:

- Decreased appetite/weight loss.
- Sleep problems.
- Social withdrawal.
- Rebound effect (increased activity or a bad mood as the medication wears off).
- Tics.
- Stomach aches.
- Mood swings.
- Dizziness.
- Increase in blood pressure or heart rate.
- Bizarre behaviour.
- Growth delay in children.

There are a number of ways side effects can be helped including:

- Changing the dose or time of medicines.
- Trying a different type of medication, for example trying a different stimulant or trying a non-stimulant medicine.

Non-pharmacological

In terms of non-pharmacological treatment, education (psychoeducation) of individuals, carers and parents is often used. In terms of adult treatments, psychological intervention such as cognitive behaviour therapy (CBT) is often used, which helps the person to change the way they think and behave by looking at how they interpret the relationship between their thoughts and behaviours. Some interventions are used both for adults and children such as social skills training, which can incorporate roleplay situations, to show how the person's behaviour affects others.

Another issue often overlooked is diet, as some types of food may worsen ADHD symptoms, for example sugar, food additives and caffeine. There are also some food supplements that may reduce symptoms such as omega-3 and omega-6 fatty acids, although there is currently little evidence as to whether this is effective or not.

Case study: Paul

This is a case example of a failure to recognise ADHD in both childhood and in adult life leading to the diagnosis of a personality disorder in adult life and misuse of alcohol with a devastating impact on the well-being of Paul.

Paul is a 30-year-old man with mild learning disabilities and a diagnosis of emotionally unstable personality disorder. He has had a history of behavioural problems since childhood, including disruptive behaviour, fidgeting, struggling at school and having severe temper tantrums. As a result he has presented as impulsive, disorganised and chaotic throughout his adult life, which has led to multiple presentations to hospital with overdoses and self-harming behaviour, along with a long history of alcohol misuse and accompanying mood instability. Failure to recognise Paul's presentation because of a lack of awareness of ADHD has led to a diagnosis of personality disorder.

Case study: Mark

This case example is an example of making an early diagnosis and providing appropriate treatment.

Mark is 14-year-old boy with moderate to severe ID. He presented with many behavioural difficulties along with restlessness and hyperactivity, which was initially put down to his ID. These behaviours and his presentation caused major difficulties at his special school in terms of engaging and supporting him. On further assessment it was recognised that his hyperactivity and restlessness were much more than expected for his developmental level. Following psychiatric assessment, Mark was diagnosed with ADHD, started on a stimulant and provided with social skills training. Following the initial phase of treatment there was significant improvement in his behaviour and he is no longer being oppositional, is able to participate in family events and to go out to play with his friends.

Case study: David

This is a case example of a person being recognised as having ADHD in childhood but where there was no follow up into adult services to ensure he continued with appropriate treatment. This lack of appropriate treatment is probably contributing to his current presentation.

David is 22-year-old man with mild ID, diagnosed with personality disorder and recognised as having had ADHD in childhood. He has recently been in prison for threats to his ex-partner. In prison, David self-harmed and, due to his continuing vulnerability on release and an increase in his threatening behaviour, he is admitted to an intensive care mental health ward under Section 3 of the Mental Health Act. On the ward he is assaulting staff, damaging property and self-harming by cutting himself with broken objects. He is diagnosed with adult ADHD and commenced on stimulant treatment. On leaving children's services at the age of 18 years, David's ADHD had not been seen as a problem and had not previously been picked up as an adult.

Key learning points

- ADHD is a common condition in people with ID and can persist throughout adult life.
- ADHD can be misdiagnosed as personality disorder or mood disorder as they share some traits.
- There is a need to improve recognition and diagnosis of ADHD in people with ID to improve outcomes in both childhood and adult life.
- ADHD can have a significant impact on the functioning of a person with ID, including on their personal relationships.
- There is a good response to treatment so it is important to recognise and diagnose ADHD in a person with ID.

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Website resource

UKAAN is the UK Adult ADHD Network and host an annual congress, provides training and has a number of free resources on the website including assessment tools and publications: www.ukaan.org