

Assessing and managing attention-deficit hyperactivity disorder in people with intellectual disability

ARTICLE

Bhathika Perera , Jane McCarthy & Ken Courtenay

SUMMARY

Attention-deficit hyperactivity disorder (ADHD) is a common neurodevelopmental disorder with a higher prevalence rate in people with intellectual disability compared with their peers without such disability. The classic presentation is that of inattention and/or hyperactivity and impulsivity, but these symptoms can manifest differently in people with intellectual disability. Despite a higher prevalence, the rate of diagnosis and treatment of ADHD in intellectual disability remains low. This article discusses the clinical presentation of ADHD in people with intellectual disability and the relationship between ADHD and other comorbid conditions, such as autism and bipolar disorder. Pharmacological and non-pharmacological interventions are discussed from a practical and a clinical point of view.

LEARNING OBJECTIVES

After reading this article you will be able to:

- understand the clinical presentation of ADHD in people with intellectual disability
- distinguish common comorbid psychiatric disorders that make the diagnosis of ADHD complex in people with intellectual disability
- understand the principles of pharmacological and non-pharmacological management of ADHD in intellectual disability.

KEYWORDS

ADHD; intellectual disability; hyperactivity; methylphenidate; challenging behaviour.

Attention-deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder that affects children, adults and older people. It has been widely researched and has strong evidence-based interventions. Even though recognition of ADHD in clinical practice is relatively recent, it was first described in the literature as a disorder of attention by Melchior Weikard in Germany in the 18th century (Barkley 2012). In 1798, Alexander Crichton described ADHD-like symptoms in a medical textbook as a disorder of distractibility and lack of concentration

(Palmer 2001). Over the years, it has undergone several name changes, along with the rise of pharmacological treatments. The validity of ADHD as a diagnosis and the widespread use of stimulants, especially in children, have been criticised by various groups (Kazda 2021); however, the evidence for treating ADHD in adults has become more established in the past decade (Faraone 2021). Advances in research have helped to shape the diagnostic criteria, focusing on specific symptoms and leading to more accurate diagnosis and the development of new medications offering a broad range of treatment options.

The prevalence rate of ADHD in people with intellectual disability is approximately 20% in clinical samples, although estimates vary widely across different studies (La Malfa 2008; Reilly 2011). Owing to the limited number of studies on ADHD in this group, the evidence for diagnosis and treatment is extrapolated mainly from studies involving people without intellectual disability. Those have shown that diagnosis and treatment is associated with significant improvements in quality of life. Even though there are no large studies evaluating the benefits of treatment in people with intellectual disability, evidence overwhelmingly supports it (Perera 2018, 2021; Faraone 2021).

A recent report by the Royal College of Psychiatrists on ADHD in people with intellectual disability highlights the need among psychiatrists for improving skills in diagnosis and treatment (Royal College of Psychiatrists 2021). A good understanding of the symptoms and different manifestations of ADHD is important in carrying out a diagnostic assessment in a person with intellectual disability. Similarly, an understanding of the various pharmacological and non-pharmacological options available is important to provide personalised intervention.

Diagnosing ADHD in people with intellectual disability

Diagnostic criteria

DSM-5 (American Psychiatric Association 2013) or ICD-11 (World Health Organization 2019) criteria

Bhathika Perera is a consultant psychiatrist in intellectual disability services with Barnet, Enfield and Haringey Mental Health Trust, London, UK. **Jane McCarthy** is a consultant psychiatrist in intellectual disability services with Sussex Partnership NHS Trust, Brighton, UK. **Ken Courtenay** is a consultant psychiatrist in intellectual disability services with Barnet, Enfield and Haringey Mental Health Trust, London, UK.
Correspondence Dr Bhathika Perera. Email: bhathika.perera@nhs.net

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are used to diagnose ADHD. Although the two sets of criteria are broadly similar (Box 1), there are some clear differences. DSM-5 requires that six out of the nine criteria (or five if the person is aged 17 or older) in inattention and/or hyperactivity and impulsivity are met, whereas ICD-11 requires ‘several symptoms to be present in at least one of the symptom groups’ (First 2021). The latter may help with the diagnosis of ADHD in people with intellectual disability as the precise symptom count required by DSM-5 may not be possible for many reasons. The most common reason is that some of the criteria are not applicable to people with more severe intellectual disability owing to verbal communication difficulties and different day-to-day demands of life (Perera 2020). ICD-11 has added an extra symptom under impulsivity which is not in DSM-5, described as ‘a tendency to act in response to immediate stimuli without deliberation or consideration of risks and consequences (e.g., engaging in behaviours with potential for physical injury; impulsive decisions; reckless driving)’ (World Health Organization 2019). It could be argued that this addition may help to assess impulsivity better in people with intellectual disability, compared with symptoms such as the inability to wait for one’s turn in a conversation, which may not apply to an individual who is non-verbal.

Clinical features of ADHD in people with intellectual disability

The presenting symptoms of a person with ADHD and intellectual disability could be due to signs of ADHD or manifestation of its functional impairment. The main symptoms of ADHD are inattention, i.e.:

- difficulty sustaining attention on tasks that do not provide a high level of stimulation or reward,

BOX 1 Broad criteria for attention-deficit hyperactivity disorder in ICD-11 and DSM-5

- There is a persistent pattern of inattention and/or hyperactivity/impulsivity that interferes with functioning or development and sits outside the limits of normal variation expected for age and level of intellectual development
- Symptoms were present prior to the age of 12 years
- Symptoms are manifested across multiple settings
- Symptoms have a direct impact on social, occupational and/or academic functioning

(World Health Organization 2019; American Psychiatric Association 2013)

- lacking attention to detail and making careless mistakes
- easily distractible, daydreaming or mind ‘elsewhere’
- often does not seem to listen when spoken to
- loses things and is easily forgetful, has difficulty planning

and hyperactivity, i.e.:

- excess motor activity, not able to sit in one place or often ‘on the go’
- fidgetiness
- difficult to engage in tasks quietly or talks a lot
- blurts out answers before a question is completed, difficulty waiting their turn, impatient
- tendency to act impulsively without considering consequences (included in ICD-11 but not DSM-5).

These criteria are primarily developed for people without intellectual disability. Therefore, careful analysis of each symptom and how it can present differently in people with intellectual disability is important.

All ADHD symptoms are dimensional traits even though the final diagnosis is categorical. Assessment for ADHD symptoms aims to identify the extreme end of these dimensional traits. This is a big challenge in people with intellectual disability as the added task is to determine whether the symptoms sit outside what is expected for the individual’s level of intellectual development. This is a subjective judgement by a clinician as there are no objective tools to measure what level of inattention, hyperactivity or impulsivity is ‘normal’ for a person’s level of intellectual disability.

The next challenge is to adapt the criteria to be relevant for someone with intellectual disability, particularly the symptoms of inattention. Adults with intellectual disability are often supported by family or carers to meet the day-to-day demands of life. Therefore, when carrying out an interview to assess for ADHD, questions need to be adjusted depending on the individual’s level of developmental ability, skills and the support they receive. Criteria based on communication skills will not be relevant to a person with severe intellectual disability and poor communication. If most day-to-day tasks are carried out by carers or family members, criteria such as ‘ability to organise tasks and activities’, ‘often loses things necessary for tasks or activities’ or ‘often forgetful in daily activities’ need to be considered carefully (and may be meaningless).

Impaired control of attention is a core feature of ADHD. An inability to sustain attention, being easily distractible, moving from one task to another quickly and having difficulty staying focused on a conversation are common symptoms

of inattention. People with intellectual disability are not likely to complain about such symptoms and this might explain why ADHD as a diagnosis is not often considered in people with intellectual disability.

The hyperactivity and impulsivity symptoms of ADHD are easier to assess in people with intellectual disability as these symptoms can manifest in behaviour. Behavioural disinhibitions, hyperactivity and impulsivity are often viewed as the hallmark signs of ADHD, rather than the inattention symptoms, which are also seen in a broad range of clinical conditions (Barkley 2018). Therefore, analysis of hyperactivity and impulsivity symptoms is important when diagnosing ADHD in people with intellectual disability. People with ADHD often respond quickly and find it hard to wait. They react without considering the negative consequences of their actions. These are symptoms often described by carers of people with intellectual disability and ADHD. Carers also often describe an inability to defer gratification, which may lead to acting impulsively without consideration for consequences (Nigg 2001). These behaviours can be challenging and may become more difficult to manage.

Carers often describe how hard it is for a person with intellectual disability and ADHD to remain seated. Descriptions include the person pacing the room even in the middle of the night and difficulties settling to sleep. Carers describe them as 'on the go'. People with intellectual disability and ADHD often prefer outdoor activities that allow them to move around. Carers often add that the person has 'lots of energy' and that they find it hard to keep up with the person's pace all the time. Hyperactivity and restlessness may be more obvious in low-stimulus environments such as returning home from highly stimulating activities to more restful and less energetic conditions. It has been proposed that heightened activity in low-stimulus situations is due to the stimulation-seeking nature of ADHD (Antrop 2000). This needs to be considered when developing interventions for people with intellectual disability and ADHD. Day centres and colleges may report that someone requires extra support to keep them seated in one place: the task for the clinician is to determine whether such hyperactivity and restlessness in a person with intellectual disability is developmentally appropriate or a symptom of comorbid ADHD.

Functional impairment

The most common presentation of a person with intellectual disability and ADHD in a mental health clinic is related to functional impairment. Therefore, it is important to distinguish

ADHD symptoms from functional impairment when making the diagnosis and planning specific treatments.

Functional impairment related to ADHD varies in different settings. For example, hyperactivity may be appropriate if the individual is engaging in outdoor activities such as running around in a park. Most observers would not see the person's high level of activity as a problem in such a situation. If the person continues to exhibit the same high level of activity when they return home, it might lead to behavioural challenges.

Functional impairment can affect academic, social or occupational domains but the most common functional impairment in people with intellectual disability is challenging behaviour affecting many domains of life. A recent study of adults with intellectual disability and ADHD reported that almost 70% presented with challenging behaviour (Perera 2021). Therefore, a careful analysis of functional impairment is important to explore underlying ADHD symptoms. Behavioural difficulties described as 'challenging behaviour' may be driven by the components of ADHD (Perera 2017; Korb 2019). The requirement for functional impairment in making the diagnosis of ADHD is crucial, particularly in people with intellectual disability. Specific interventions in people with intellectual disability and ADHD need to be focused on the functional impairments more than the core symptoms of ADHD. However, an understanding of the domains of functional impairment in people with intellectual disability and ADHD is limited.

ADHD symptoms in multiple situations

People with intellectual disability may behave differently in different situations. Those with behavioural problems who do not have ADHD may show these difficulties only in a particular setting, owing to specific environmental factors. Similarly, symptoms of ADHD may not be evident in certain situations, for example if the individual is engaged in activities that provide intense stimulation and frequent rewards. The requirement that ADHD symptoms need to be present in two or more settings ensures that people with intellectual disability and behavioural problems are not misdiagnosed as having ADHD. However, the clinical reality is far from simple where an individual with intellectual disability and ADHD also has behavioural difficulties due to specific environmental factors.

Assessing ADHD in people with intellectual disability

Objective diagnostic assessment for ADHD is essential in confirming the diagnosis. Some believe that

ADHD is underdiagnosed, whereas others consider it overdiagnosed (Kazda 2021). The accurate diagnosis of ADHD (or ruling it out) in people with intellectual disability is important to avoid delaying potentially effective treatments for underlying conditions. There are no assessment tools validated in larger populations to screen for ADHD in people with intellectual disability. A recent study in a small group showed that the following three questions have high positive and negative predictive values, sensitivity and specificity (Sawhney 2021):

- Does the person find it hard to sit in one place for long?
- Does the person pace up and down most of the time?
- Is the person easily distractible by busy environments?

These three questions can be helpful in helping to decide whether to progress to a full diagnostic assessment.

A diagnostic interview should include a psychiatric and developmental history, followed by an ADHD-focused interview (Box 2). In the clinical interview focusing on symptoms of ADHD, the evidence for ADHD can be elicited using structured diagnostic tools such as the Diagnostic Interview for ADHD in Adults with Intellectual Disability (DIVA-5-ID; DIVA Foundation 2019), which adheres to DSM-5 criteria. As highlighted above, ADHD criteria must be adapted for people with

intellectual disability. Similar challenges are also encountered when ADHD criteria are applied to adults, as current criteria have been established for children aged 4–17 years and not tested for adults (McGough 2004). For these reasons the strict use of DSM-5 criteria has been shown to lead to missed diagnoses of ADHD. Overall, in people with intellectual disability clinical impression of the presence of inattention and/or hyperactivity/impulsivity appears to have high sensitivity and specificity in contrast to using DSM-5 criteria (Perera 2020).

Difficulties in obtaining a childhood history can be a challenge in older people with intellectual disability. A pragmatic approach is recommended in such situations, as the diagnosis of ADHD should not be ruled out simply because a childhood history is not available.

Comorbid psychiatric disorders

Autism spectrum disorder

Studies have shown that nearly 70% of people with intellectual disability and ADHD also meet diagnostic criteria for autism spectrum disorder (ASD) (Perera 2021). Recent evidence points in the direction of genetic links between ADHD and the wider group of neurodevelopmental disorders (Rietz 2020). ASD and ADHD share aetiological factors and create greater morbidity and clinical challenges when they co-occur (Leitner 2014). The two conditions are viewed as two distinct clinical disorders with different diagnostic criteria but with close overlaps of their core symptoms. Therefore, when assessing each ADHD symptom, it is worth considering how it is exaggerated or masked by the person's ASD. For example, a person with symptoms of inattention associated with ADHD may not lose items because of their rigid routines related to keeping their belongings. Similarly, a person may over-focus on tasks that they are interested, making it difficult to assess the severity of inattention. Sensory stimulation and repetitive behaviours may cause a person to appear hyperactive. Therefore, the challenge is to understand whether ADHD and ASD coexist and avoid focusing on one condition and ignoring the other.

Bipolar disorder

The evidence for the higher comorbidity of bipolar disorder and ADHD is very strong. A recent systematic review showed that 1 in 13 adults with ADHD also had a diagnosis of bipolar disorder, and nearly 1 in 6 adults with bipolar disorder had ADHD (Schiweck 2021). Even though there are no epidemiological data on the prevalence rate of bipolar disorder in people with ADHD and

BOX 2 Assessment of attention-deficit hyperactivity disorder (ADHD)

- Psychiatric history:
 - current and historical information on presentation
 - developmental history
 - psychiatric history
 - diagnosed neurodevelopmental disorders – autism, tics, etc.
 - medical history – specific questions on history of cardiovascular diseases or symptoms
 - medication history
 - forensic history
 - illicit drug use
 - family history of neurodevelopmental disorders, sudden deaths from cardiac conditions
- Interview focusing on inattention, hyperactivity and impulsivity symptoms of ADHD and the functional impairment caused by those symptoms
- Mental state examination
- Physical observations – blood pressure, heart rate, weight (height in children)

intellectual disability, findings in non-intellectual disability populations suggest that the possibility of bipolar disorder in people with intellectual disability and ADHD should be considered. To the clinician, the challenge is that ADHD and bipolar disorder share a similar set of symptoms, including mood lability, increased motor activity, distractibility, disturbed sleep and excessive talking (Barkley 2018). The episodic nature of bipolar disorder helps to distinguish it from ADHD, as does a decreased need for sleep (rather than difficulty falling/maintaining sleep). Symptoms of grandiosity, pressured speech, flight of ideas, disinhibition and psychosis are also good markers for bipolar disorder rather than ADHD.

Managing ADHD in people with intellectual disability

The management of ADHD in a person with intellectual disability involves a very personalised approach. It is important to agree on the functional impairment caused by ADHD and to direct interventions at reducing it. Given that standard scales to monitor response to ADHD treatments are not often suitable for people with intellectual disability, we suggest agreeing on specific goals of treatment with the person and their carers/support networks. This will help to assess the effectiveness of treatments as well as providing a holistic approach to care.

Managing ADHD in people with intellectual disability can be divided into three main areas:

- psychoeducation
- pharmacological treatment
- behavioural and psychological interventions.

Psychoeducation

After diagnosing ADHD in a person with intellectual disability, it is useful to spend time discussing the diagnosis and how symptoms of ADHD cause the functional impairment. Understanding the diagnosis itself can help carers in developing practical strategies to manage some of the challenges, particularly behavioural difficulties associated with ADHD.

Pharmacological management

Pharmacological treatments are effective in people with intellectual disability and moderate to severe ADHD. However, very few studies have looked at the effectiveness of ADHD medications in people with intellectual disability and most of these were undertaken in children (Courtenay 2016; Miller 2020). The two main classes of ADHD medication are stimulants and non-stimulants (Box 3). Studies have mainly focused on methylphenidate and atomoxetine. A UK national audit showed that all

types of ADHD medication are used in people with intellectual disability, with methylphenidate and atomoxetine been the most commonly prescribed preparations (Perera 2021). When prescribing ADHD medication, it is important to understand the different preparations available.

NICE guidelines recommend methylphenidate or dexamfetamine preparations as the first line and atomoxetine as second line (National Institute for Health and Care Excellence 2018). Choosing ADHD medication depends on the functional impairment and the duration of symptom control needed. Methylphenidate and dexamfetamine have short acting lasting up to 4 h and longer acting lasting up to 14 h of symptom control. Non-stimulants such as atomoxetine are useful when 24 h control of symptoms is needed. A national audit of medication use for ADHD in adults with intellectual disability in the UK has shown that methylphenidate was the most used (54% of patients), followed by atomoxetine (39%) (Perera 2021). The Royal College of Psychiatrists (2021) College report on ADHD in intellectual disability gives an overview of a number of medications for ADHD in adults with intellectual disability.

Other medications trialled in the treatment of ADHD include bupropion, modafinil and venlafaxine. A Cochrane review has shown low-quality evidence for possible benefits of bupropion for ADHD in adults (Verbeeck 2017). It was suggested that extended-release preparations of bupropion may be an alternative for people who cannot take stimulants. In people with intellectual disability, risk of seizures needs to be considered carefully, given increased risk with bupropion. Modafinil, which is licensed for treatment of narcolepsy, has also been used in ADHD, but a recent meta-analysis

BOX 3 Medications for attention-deficit hyperactivity disorder (ADHD) licensed in the UK

Stimulants

- Methylphenidate preparations:
 - methylphenidate immediate release
 - methylphenidate modified release
- Dexamfetamine preparations:
 - dexamfetamine immediate release
 - lisdexamfetamine

Non-stimulants

- Atomoxetine
- Guanfacine
- Clonidine

comparing it with stimulants showed no efficacy of modafinil (Stuhec 2019). Possible serious skin reactions have also limited its use. Very limited evidence on venlafaxine in ADHD suggests possible benefits, but the evidence base is not strong enough to recommend its use in ADHD treatment (Ghanizadeh 2013).

A good understanding of ADHD medication that includes the duration of action and expected benefits and side-effects is important to optimise treatment response and adherence and to minimise side-effects. It is important for the person with intellectual disability and their carers to understand that symptoms of ADHD and functional impairment may re-emerge when a stimulant medication wears off. For example, family carers may not notice an improvement with some stimulants as the person is out of the family home when the ADHD medication is effective.

In clinical practice, doses of ADHD medications prescribed for people with intellectual disability are reported to be low (Miller 2020). This may not lead to full control of ADHD symptoms, and therefore gradual titration of doses while monitoring for side-effects is important to optimise treatment.

Blood pressure, heart rate and weight (and height in children) are measured before starting ADHD medications in people with ADHD (National Institute for Health and Care Excellence 2018). This may be difficult in individuals with intellectual disability because of behavioural challenges. If there is no evidence for underlying cardiac disease, it is worth considering medication for ADHD. Anecdotal evidence shows that people with intellectual disability and ADHD are more compliant with blood pressure monitoring and other medical interventions if ADHD symptoms are well controlled and when they feel relaxed and calm.

In the UK, initiation of ADHD medications is carried out by specialists. Once the person is stable on the medication, prescribing is handed over to the general practitioner through an agreement called a shared-care protocol. Clinicians should familiarise themselves with local agreements, as prescribing responsibilities can vary from one country to another.

Behavioural and psychological management

Behavioural and psychological strategies can be developed focusing on the individual's functional impairments and the symptoms of ADHD driving them. Where hyperactivity is a prominent symptom, physical activity needs to be considered as part of the person's day-to-day activities to help them remain engaged. Such strategies may include regular physical activity in schools, modifications to the

learning environment and adjusting the length of teaching activities. When impulsivity is a problem, strategies that enable the person to wait for a certain task, such as keeping the person with intellectual disability engaged or effective communication strategies, can reduce behavioural problems. These strategies need to be part of a positive behavioural support plan and will involve other members of the multidisciplinary team, including behavioural practitioners, speech and language therapists, occupational therapist and psychologists.

Management of comorbid psychiatric disorders

Treatment of underlying mental illnesses such as psychotic or bipolar disorder should take priority. Treatment of mental illness will also give a better understanding of underlying ADHD and functional impairment. Even though first-line ADHD medications remain the same despite underlying comorbid conditions, clinicians might choose different ADHD medications depending on underlying comorbidities. For an example, medications such as clonidine and guanfacine can be considered for ADHD in people with tic disorders.

Conclusions

ADHD is a well-recognised neurodevelopmental disorder commonly seen in people with intellectual disability. DSM-5 or ICD-11 diagnostic criteria used to diagnose ADHD in the general population are applicable in people with intellectual disability, but various adaptations are needed. ADHD in people with intellectual disability is manifested in different ways, with challenging behaviour as one of the most common presentations. It is important to separate the symptoms and functional impairment caused by ADHD from those due to intellectual disability. Assessment of ADHD in people with intellectual disability involves a psychiatric assessment followed by specific questions on the core symptoms of ADHD. Identifying whether ADHD symptoms are beyond what is expected for the person's level of development is important. Information from various sources and informants can be helpful when making the diagnosis.

Pharmacological and non-pharmacological treatments are used to reduce the functional impairment associated with ADHD and improve quality of life. Various preparations of stimulant and non-stimulant medication offer flexibility in targeting of symptoms and duration of symptom control. All interventions, including psychoeducation, behavioural and pharmacological treatment, need to be personalised to achieve the best outcomes for the individual.

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MCQ answers

1 c 2 e 3 a 4 b 5 a

MCQs

Select the single best option for each question stem

1 Essential criteria for diagnosis of ADHD in a person with intellectual disability do not include:

- a presence of ADHD symptoms during childhood
- b presence of inattentive and/or hyperactivity/impulsivity symptoms
- c presence of mood fluctuations
- d presence of impairment secondary to ADHD symptoms
- e presence of symptoms in more than one situation.

2 Which of the following symptoms is present in ICD-11 diagnostic classification for ADHD, but not in DSM-5?

- a difficulty sustaining attention
- b difficulty waiting for turn
- c easy distractibility
- d often loses items
- e tendency to act in response to immediate stimuli.

3 24 h control of ADHD symptoms can be achieved using:

- a atomoxetine
- b dexamfetamine
- c lisdexamfetamine
- d methylphenidate immediate-release preparation
- e methylphenidate modified-release preparation.

4 Before starting ADHD medication in a healthy person with intellectual disability and ADHD it is not necessary to measure:

- a blood pressure
- b brain activity (by electroencephalogram)
- c heart rate
- d height (in a child)
- e weight.

5 Of the following, the condition with the highest prevalence rate in people with intellectual disability and ADHD is:

- a autism spectrum disorder
- b bipolar disorder
- c depressive disorder
- d schizophrenia
- e tic disorder.