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Attention deficit hyperactivity disorder (ADHD) in adults with intellectual disability

Rohit Shankar *Peninsula Medical School*

Bhathika Perera *North East London NHS Foundation Trust*

Laura Korb *Barnet, Enfield and Haringey Mental Health NHS Trust*

Ken Courtenay *Barnet, Enfield and Haringey Mental Health NHS Trust*

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Shankar, Rohit; Perera, Bathika; Korb, Laura; Courtenay, Ken

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CR230

Attention deficit hyperactivity disorder (ADHD) in adults with intellectual disability

February 2021

COLLEGE REPORT

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Working group

Chair and editor

Bhathika Perera

Consultant Psychiatrist, Barnet, Enfield and Haringey Mental Health NHS Trust London UK;
Chair of the ADHD in Intellectual Disability Peer Group, Royal College of Psychiatrists UK

Deputy editors

Laura Korb

Consultant Psychiatrist, Barnet, Enfield and Haringey Mental Health NHS Trust London UK;
Secretary of the ADHD in Intellectual Disability Peer Group, Royal College of Psychiatrists UK

Ken Courtenay

Consultant Psychiatrist, Barnet, Enfield and Haringey Mental Health NHS Trust London UK;
Chair of the Faculty of Psychiatry of Intellectual Disability, Royal College of Psychiatrists UK

Members of the working group

Rohit Shankar

Consultant Psychiatrist, Cornwall Partnership NHS Foundation Trust, Cornwall UK;
Honorary Associate Clinical Professor, Exeter Medical School UK

George Collins

Specialty Registrar in Cardiology; Wellcome Trust Clinical PhD Fellow, University College London, London UK

Charles Knight

Consultant Interventional Cardiologist; Professor, Queen Mary University of London, London UK;
Chief Executive, Saint Bartholomew's Hospital, London UK

David O'Regan

Consultant in Psychiatry and Sleep Medicine, Sleep Disorder Centre, Guy's Hospital, London UK

Shoumitro (Shoumi) Deb

Visiting Professor of Neuropsychiatry, Imperial College, London UK

Meera Roy

Honorary Consultant Psychiatrist, Worcestershire Care and Health NHS Trust, Worcestershire UK

Swapnil Palod

Consultant Psychiatrist in Intellectual Disability, Your Healthcare CIC, Surrey UK

Jane McCarthy

Consultant Psychiatrist, Sussex Partnership NHS Foundation Trust, Sussex UK; Honorary Associate Professor in Psychological Medicine, University of Auckland, New Zealand; Visiting Senior Lecturer, Institute of Psychiatry, Psychology & Neuroscience, London UK

Eddie Chaplin

Professor of Mental Health in Neurodevelopmental Disorders, London South Bank University, London UK

Sam Tromans

Specialty Registrar in Psychiatry of Intellectual Disability; Honorary Academic Clinical Lecturer, University of Leicester, Leicestershire UK

Verity Chester

Research Associate and RADiANT Research Consortium Network Manager, Hertfordshire Partnership University NHS Foundation Trust, Hertfordshire UK

Hassan Mahmood

Consultant Psychiatrist, Birmingham Community Healthcare NHS Foundation Trust, Birmingham UK

Raja Mukherjee

Consultant Psychiatrist and Clinical Lead Adult Neurodevelopmental and Foetal Alcohol Spectrum Disorder Service, Surrey and Borders Partnership NHS Foundation Trust, Surrey UK

Aleksandr Sapunov

Core Trainee in Psychiatry, London UK

Anusha Wijeratne

Consultant Psychiatrist, Central and North West London NHS Foundation Trust, London UK

Natalia Perez-Achiaga

Consultant Psychiatrist, Central and North West London NHS Foundation Trust, London UK

Nicole Eady

Consultant Psychiatrist, East London Foundation Trust, London UK; Joint Training Programme Director Psychiatry of Intellectual Disability, London UK

Boyd Mason and Angela Zuppa

Service user and carer, London UK

Feroz Nainar

Consultant Psychiatrist, Birmingham Community Healthcare NHS Foundation Trust, Birmingham UK

Sonya Rudra

Specialty Registrar in Psychiatry of Intellectual Disability, London UK

Paul Shanahan

Behaviour Analyst, Neurodevelopmental Service, Your Healthcare CIC, Surrey UK

Asit Biswas

Consultant Psychiatrist, Leicestershire Partnership NHS Trust, Leicestershire UK;
Vice-Chair of the Faculty of Psychiatry of Intellectual Disability, Royal College of
Psychiatrists UK; Honorary Associate Professor, University of Leicester, Leicestershire UK

Eileen McNamara

Consultant Psychiatrist, Barnet, Enfield and Haringey Mental Health NHS Trust, London
UK; Joint Training Programme Director Psychiatry of Intellectual Disability, London UK

Foreword

The field of neurodevelopmental disorders is an exciting one in clinical practice. People with intellectual disability are more likely to have associated neurodevelopmental disorders such as autism and attention hyperactivity disorder (ADHD). The current practice of diagnosis and management of ADHD in people with intellectual disability is based on findings from assessment and treatments in the general population. People with intellectual disability often have additional comorbid disorders that may conceal or exacerbate the signs of ADHD and, for this reason, treatments applicable in the general population may not always be appropriate in treating a person with intellectual disability.

To fill this gap in knowledge and practice, this College Report on *ADHD in adults with intellectual disability* is very welcome and timely when so much more is understood about ADHD in general. The challenge for clinicians in supporting people with intellectual disability and ADHD is to deliver the best care based on good evidence on the effectiveness of assessment processes and treatments. This report brings together the current evidence as applied in people with intellectual disabilities and it benefits from the expertise and knowledge of clinicians, built over years of experience working with people with intellectual disabilities. The evidence base will grow from more original research on ADHD in intellectual disability to understand how the disorder manifests in people with intellectual disability. The report will prove to be a valuable resource to clinicians and services in applying evidence to support and treat ADHD in people with intellectual disability.

Ken Courtenay

Chair, Faculty of Psychiatry of Intellectual Disability
Royal College of Psychiatrists UK

Scope of the report

Psychiatrists working with people with intellectual disabilities (ID) require knowledge and skills in assessing and managing neurodevelopmental disorders such as attention deficit hyperactive disorder (ADHD) and autism spectrum disorder (ASD). The presence of one or more neurodevelopmental disorder in people with ID can lead to a complex presentation of behavioural and/or mental symptoms and diagnostic and management challenges. ADHD in people with ID is often misdiagnosed, under-recognised and inadequately managed, despite ADHD-specific treatment strategies that can be highly effective. There is limited good quality research in ADHD specific to people with ID compared with that for ADHD in the general adult population. With the growing evidence base on ADHD in ID, there is an increased awareness of diagnosis and treatment of ADHD in ID but an absence of specific guidance on the disorder.

This report aims to provide an up-to-date review of the current evidence base, clarify the diagnostic process and summarise the management of ADHD in the ID population. It aims to guide psychiatrists working with people with ID to identify and treat comorbid ADHD. The report discusses factors that need to be considered and the value of screening and diagnosing ADHD alongside the pitfalls of not recognising it. It then goes further and extrapolates from the evidence available in people with ADHD without an ID.

Both pharmacological and non-pharmacological management strategies are described. As the evidence for pharmacological interventions is limited, case vignettes have been used to highlight good practice. Due to the limited evidence available, some recommendations are derived from expert consensus. This is a pragmatic report aiming to give guidance using the best available practice from research and expert opinion. The report recognises its limitations and acknowledges that future research might refine the evidence further.

We hope this helps to support clinicians in their area of practice and, most importantly, confers real-life benefits to patients and their families.

Executive summary

Intellectual disability (ID) is a lifelong condition of impaired intellectual functioning associated with deficits in adaptive functioning. Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterised by symptoms of inattention, hyperactivity and impulsivity. ADHD, in common with other common medical and psychiatric disorders, is influenced by multiple genes, non-inherited factors and their interplay. The correct diagnosis of ADHD helps to utilise evidence-based treatments, both pharmacological and non-pharmacological, that can improve clinical and social outcomes for people with ID.

Comorbid psychiatric, neuropsychiatric and neurodevelopmental disorders are commonly seen in people with ID and ADHD. Clinical expertise is important to recognise comorbid mental disorders and decide which conditions need to be treated first. In people with ID, especially where communication and language are limited, differentiating phenomenological presentations such as autism spectrum disorder (ASD) and ADHD can be particularly challenging. ADHD and epilepsy have also been reported to co-occur. Therefore, it is important that all comorbidities are considered when supporting people with ID and ADHD.

Diagnosing ADHD in people with ID can be challenging. The strict application of diagnostic criteria, such as from the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), can limit the diagnosis as some of the criteria may not be applicable, especially for people with more severe levels of ID. Therefore, overall, clinical judgment and seeking collateral reports on the presence of inattention and/or hyperactivity and impulsivity symptoms is important when considering the diagnosis of ADHD in people with ID.

The evidence base for ADHD medications in adults with ID remains limited to evidence used in the treatment of ADHD in the general population being extrapolated to the ID population. There are two main groups of ADHD medications, stimulants and non-stimulants. The National Institute for Health and Care Excellence (NICE) guidance, published in 2018, recommends using either lisdexamfetamine or methylphenidate as the first-line pharmacological treatment for adults with ADHD. The choice of ADHD medication in adults with ID can be influenced by factors such as the duration of symptom control needed, the side effect profile and available preparations. Atomoxetine is often used in adults with ADHD and ID because of its longer half-life compared with stimulants and therefore its ease of administration.

It can be a challenge to assess cardiovascular risk and cardiac disease in people with ADHD and ID due to the difficulty in collecting both subjective and objective data. In addition, there is little to no robust evidence in the scientific literature to guide clinical practice. To assist clinicians in arriving at balanced judgements under these difficult circumstances, this report provides scientific data on ADHD medications, a summary of the latest guidance, some tailored additions to the guidance and the information an assessing cardiologist may request.

Non-pharmacological strategies can be defined as any intervention that does not include the use of medications. Although non-pharmacological strategies lack a robust evidence base, it is best practice for care plans to include non-pharmacological interventions using personalised approaches based on cognitive and behavioural principles. Psychoeducation is fundamental in helping people with ID, and their carers, to understand the symptoms of ADHD. Cognitive Behavioural Therapy (CBT) has been shown in some studies to reduce the core symptoms of ADHD, associated symptoms and associated functional impairments. Adaptations may be needed for people with ID when delivering psychological interventions.

Sleep problems are reported in up to 50% of people with ADHD and are likely to be more frequent in individuals with a comorbid ID. In people with ADHD and ID, comorbid sleep disorders can result in significant functional impairments that affect mood, behaviour, health, quality of life and carer burden.

ID and ADHD combined confer an increased risk of entering the Criminal Justice System. Prisoners with ID have complex needs with significant problems including inattention, hyperactivity, impulsivity or social communication combined with their cognitive impairments. Comorbidities are complex in this group and the overlap also extends to ASD. The presentation of ADHD in people with ID could increase the risk of offending behaviours, so it is important to identify ADHD early in those with ID and implement appropriate evidence-based treatments.

Given the challenges in diagnosis and treatment, psychiatrists and other clinicians working with people with ADHD and/or ID should be encouraged to access case discussions, peer group and reflection meetings regularly and gain skills by attending suitable training sessions. In addition to using available evidence as highlighted by the current report, there is an urgent need to improve awareness of the significant comorbidity of ADHD and ID along with further research to the person-centred outcomes of ADHD in people with ID.

It is essential that health and social care commissioners are aware and sensitive to the current report and its findings. Incorporating the findings of the report could be part of the Commissioning for Quality and Innovation (CQUIN) contracts for provider organisations. Equally, thought needs to be given to creating a national register at a primary care level to identify those diagnosed with ADHD and ID, to allow for evaluation and research on outcomes going forward. This would directly and positively influence the current national aspirations of reducing polypharmacy, particularly psychotropic medication and be a step towards parity of care.

Objectives and methodology

Objectives

- To provide guidance to psychiatrists to improve awareness and recognition of ADHD in people with ID.
- To provide guidance on the diagnosis and management in line with national standards and contemporary practice to improve outcomes for people with ID and ADHD.
- To improve care and outcomes for patients and their families.

Methodology

This report attempts to combine up-to-date published research with the everyday practice of experts in the field of ADHD in ID. The development of this analysis was carried out as follows:

- A working group of experts was created through the network of ADHD in ID peer group of the Neurodevelopmental Disorders Special Interest Group in the Royal College of Psychiatrists. The group involved clinical and academic psychiatrists whose primary job role is in ID services and who have expertise in ADHD. Advisors to support the core committee were identified from cardiology, forensic psychiatry and sleep medicine. A service-user and his carer were also involved. A preliminary meeting established the objectives and framework.
- The editors conducted a focused literature review of publications on ADHD in ID and a review of the best practice documents and current models of care. The findings were collated, areas identified, discussed and considered, regarding their suitability for inclusion in the College Report.
- The College Report was circulated to all working group members for comments and feedback. The feedback received was reviewed by the editors and incorporated into the report.

Chapter 1: Introduction

1.1 Intellectual disability

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines intellectual disability (ID) as a developmental disorder that affects both intellectual and adaptive functioning in conceptual, practical and social domains (American Psychiatric Association, 2013). ID affects approximately 2% of the population (Maulik et al, 2011). It is classified into mild, moderate, severe and profound, based on life skills, the need for support and the results of IQ testing (American Psychiatric Association, 2013). People with ID are at higher risk of comorbid mental disorders and neurodevelopmental disorders compared to people without an ID (Cooper et al, 2007; Hughes-McCormack et al, 2017; Perera et al, 2019b). Such disorders can make the diagnostic process more challenging in people with ID.

1.2 Attention deficit hyperactivity disorder

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterised by symptoms of inattention and/or hyperactivity and impulsivity (American Psychiatric Association, 2013). Signs of ADHD are evident during the developmental period, causing functional impairment in different domains of life. The three main criteria for the diagnosis of ADHD in adults are:

- 1 the presence of five or more symptoms from inattention and/or hyperactivity and impulsivity domains
- 2 several of these symptoms must present before the age of 12 years
- 3 signs of functional impairment in two or more settings.

Depending on the presence of inattentive or hyperactivity/impulsivity symptoms, ADHD can be further categorised into three types: combined, predominantly inattentive and predominantly hyperactive/impulsive types.

1.3 Why does diagnosing ADHD matter?

ADHD causes significant functional impairments varying from increased comorbid mental illnesses, substance misuse, accidental injury and unemployment to many other domains of life (Gjervan et al, 2012). A recent register-based study showed increased premature death in people with ADHD further increased with increasing psychiatric comorbidity (Sun et al, 2019). In people with ID, functional impairment can also present as challenging behaviour (Perera, 2017; Korb, 2019). This, amongst many other restrictions, can significantly reduce an individual's ability to access leisure and occupational activities. The under-recognition of ADHD in people with ID is also likely to contribute to the overuse of non-ADHD psychotropic medication in people with ID and challenging behaviour (Korb et al, 2019). Therefore, the diagnosis of ADHD is equally important in people with ID as much as in people without ID.

People with ADHD and ID have a ‘double deficit’ in cognitive functioning secondary to both ADHD and ID. This may also predispose them to a ‘floor effect’ and diagnostic overshadowing. Thus, early consideration of ADHD in this patient group, with a view to providing treatment and support necessary to improve outcomes, is important.

There is a strong evidence base that supports the fact that treatment of ADHD can significantly reduce functional impairments (Chang et al, 2019; Harpin et al, 2016). Al-Khudairi et al (2019) showed that people with ID and ADHD on ADHD medications are less likely to use antipsychotic medications compared to people with ID and ADHD not on ADHD treatment. Therefore, it is important that the diagnosis of ADHD is considered in people with ID and assessed appropriately.

1.4 Aetiology and epidemiology of ADHD in people with ID

1.4.1 Prevalence

Determining the prevalence of ADHD in people with ID can be challenging for several reasons. Fundamentally, there is a lack of awareness about ADHD and the absence of established protocols on diagnosis in this population. Differences in methodology, diagnostic criteria and intellectual functioning across study samples compound the reliability of prevalent estimates. The current evidence suggests that individuals with ID are at an increased risk of ADHD compared to those without ID. Rates range from 0.4% (Cooper et al, 2007) to 19.6% (La Malfa et al, 2008), whereas the prevalence of ADHD in the general population is estimated to be approximately 2.5% (Simon et al, 2009).

1.4.2 Aetiological factors

ADHD is influenced by multiple genes, non-inherited factors and their interplay. There is no known single cause for ADHD. Known associations include having a biological relative with ADHD, copy number variants, gene variants, extreme early adversity, pre/postnatal exposure to lead, low birth rate and prematurity (Thapar et al, 2012). Individuals with foetal alcohol syndrome are increasingly recognised as having a high prevalence of ADHD of up to 75% (Young et al, 2016).

Certain genetic syndromes are associated with ADHD (Table 1) but most people with ID and ADHD do not have a specific genetic syndrome. Given the possibility of underlying genetic syndromes, it is worth considering genetic testing of people with ID and ADHD on a case-by-case basis.

Table 1: Genetic disorders associated with ADHD

Behavioural Phenotypes	Chromosome	Rate of comorbidity
Down syndrome	Trisomy 21	43%
Fragile X syndrome (Predominantly inattentive type)	Xq27.3	>55%
Klinefelter syndrome	XXYY	>60%
Neurofibromatosis	17q11.2, 2p22-21	>38%
Smith-Magenis syndrome	17p11.2	ADHD-like symptoms present
Tuberous sclerosis (Predominantly inattentive type)	16p 13.3, 12q14, 9q34	64.7%
Turner syndrome (Predominantly inattentive type)	XO	24%
Velo-cardio-facial/Di George Syndrome	22q11 deletion	>40%
William's syndrome	7q11.2	30–60%

Table adapted from Turk, 2009

Prevalence rates taken from Ekstein et al, 2011; Leyfer et al, 2006; Lo-Castro et al, 2011; Zelenova et al, 2018

Chapter 2: Comorbidities in adults with ADHD and intellectual disability

2.1 Introduction

Comorbid psychiatric, neuropsychiatric and neurodevelopmental disorders are commonly seen in people with ADHD (Beiderman, 1993; Kooij et al, 2012; Reale et al, 2017) and in people with ID (Copper et al, 2007). The presence of ID and ADHD should therefore prompt an assessment to rule out other comorbid disorders. This is important as specific comorbid disorders have bespoke treatments. Further care and consideration should be given to these disorders and how treatments can influence the course of ADHD and its management. The task of separating mental disorders from ADHD and ID can be challenging. Diagnostic overshadowing can often cause under-diagnosis of various comorbidities. This chapter considers common comorbid psychiatric, neuropsychiatric and neurodevelopmental disorders in people with ADHD and ID and provides evidence to distinguish them from ADHD.

2.2 Bipolar affective disorder

There is an overlap between symptoms of ADHD and bipolar affective disorder (BPAD), that can often lead to difficulties in distinguishing one condition from another. The overlap of the elated mood evident in manic episodes and ADHD may lead to under-diagnosis of either of these conditions (Biswas and Thomas, 2018). In people with ID, it can prove a challenge to diagnose elated mood, as mood disorders may present as behavioural problems more commonly in people with severe and profound levels of ID. There are similarities in the presentation of manic/hypomanic episodes and ADHD such as symptoms of racing thoughts, emotional dysregulation, distractibility, impulsivity, disturbance in attention or concentration and disturbed sleep. The episodic nature of bipolar affective disorder helps to differentiate it from ADHD. Signs of BPAD may appear in late adolescence or the early twenties, compared with ADHD symptoms which are present from childhood, emphasising the importance of a full developmental history. Psychotic symptoms, e.g. grandiose delusions, if present, could help in differentiating BPAD from ADHD. Adults with ADHD generally have a better understanding or insight into their symptomatology compared to a person experiencing a manic episode.

2.3 Depressive disorder

Depressive disorder is a mental disorder with signs and symptoms of persistent low mood (American Psychiatric Association, 2013). There is a considerable overlap between symptoms of ADHD and depressive disorder. Symptoms intrinsic to ADHD, such as inattention, sleep disturbance, irritability and emotional dysregulation, may be present during a depressive episode. Low mood, thoughts of worthlessness, regression, self-harm, suicidal ideas, reduced appetite and sleep disturbances often have a clear onset in a depressive disorder.

2.4 Anxiety disorders

Anxiety may present with a range of signs and symptoms similar to those of ADHD, for example, internal restlessness, racing thoughts and tachycardia. A clinician needs to take a thorough history in order to differentiate the two conditions. Anxiety disorders often have a clear onset compared to ADHD which originates in childhood. The history should focus on the cause of the person's anxiety and whether ADHD is a predisposing factor if it is comorbid. The severity of anxiety symptoms is also important to assess. These will help to decide whether anxiety should be treated first or whether treatment of ADHD may improve a person's anxiety symptoms.

Similarly, impulsivity related to obsessive compulsive disorder and related conditions may be misattributed to ADHD and vice versa.

2.5 Emotionally unstable personality disorder

Emotionally unstable personality disorder (EUPD) is characterised by thoughts, feelings and behaviours that cause distress (American Psychiatric Association, 2013). Impulsivity is a symptom associated with both ADHD and EUPD. In EUPD, impulsivity is primarily driven by interpersonal factors as compared with ADHD where deficits in attention and cognitive processing account for impulsivity (Matthies and Philipsen, 2014).

Emotional dysregulation is a core feature of EUPD. Emotional dysregulation has three important components including temper control, affective lability and emotional over-reactivity. Although it is not a diagnostic criterion for ADHD (American Psychiatric Association, 2013), it is being increasingly considered as an important symptom of adult ADHD (Shaw et al, 2014). The pervasive patterns of unstable relationships and knowing that both disorders are trait presentations, as opposed to episodic in nature, further adds to the diagnostic complexity (Marchant, 2013; Moukhtarian, 2018).

2.6 Autism spectrum disorder

Autism spectrum disorder (ASD) is a social communication disorder that affects how people relate to others and in understanding their thoughts and feelings (American Psychiatric Association, 2013). ASD is considered a dimensional disorder that manifests to varying degrees. The prevalence of ASD in ID is approximately 18% compared to approximately 1% in the general population (Tonnsen et al, 2016). The prevalence of ASD was over 75% in a cohort of adults with ID and ADHD (Al-Khudairi et al, 2019). It may be challenging to differentiate ADHD from ASD. When assessing people with ID, especially where communication and language is limited, differentiating phenomenological presentations can be particularly challenging. A person with ADHD may present with symptoms of hyperactivity such as 'not being able to sit in one place for long' and presenting as 'always on the go'. Symptoms of hyperactivity, while not included in the diagnostic criteria for ASD (American Psychiatric Association, 2013), can present if an autistic person is not engaged in their stereotypic interest. A differentiating feature between the two conditions is that a person with ADHD will present with pervasive hyperactivity, often with difficulties in regulating attention irrespective of their preferred activity. A person with ASD and ID may appear transiently hyperactive due to loss of

structure or self-identified sensory stimulation. Hypervigilance (being always aroused) and hyper-focus (being able to concentrate for prolonged periods on tasks) are significant challenges to differentiate in people with ID, ADHD and ASD.

2.7 Epilepsy

ID with comorbid ADHD is associated with more complex epilepsy presentations (Holdsworth et al, 1974), a higher symptom burden (Reilly et al, 2017) and higher psychiatric comorbidity (Ettinger et al, 2015). Antiepileptic drugs (AEDs) are also associated in several ways with ADHD. Valproate use in pregnancy is associated with inattentiveness and hyperactivity in offspring (Auvin et al, 2018). In the past, AEDs were considered to increase activity levels, irritability and attentional deficits in a person with epilepsy but most studies suggest that AEDs have little effect on cognitive functions such as attention (Tan et al, 2005).

Practical considerations

- ADHD symptoms may complicate the diagnosis of epilepsy as they may be mistaken for seizures.
- Treating seizures first should be the priority. If seizures can be controlled, some symptoms of ADHD may improve.
- Treating ADHD in a person with ID and epilepsy may lessen stress and improve the person's ability to manage his or her medication and life challenges.
- A full and thorough risk assessment of epilepsy is essential. Consider using the [SUDEP and seizure safety checklist](#) (Shankar et al, 2019).
- There may be concerns about worsening of seizures when starting ADHD medication in a person with epilepsy. The current evidence suggests that although people with ADHD are more likely to suffer from seizures, the rates are lower in individuals taking ADHD medication. Close monitoring of seizures is advised but epilepsy is not a contraindication to starting ADHD medication (Wiggs et al, 2018).
- For further recommendations for epilepsy in ID: RCPsych College Report CR203 and CR206.

Chapter 3: Assessment of ADHD in adults with intellectual disability

3.1 Introduction

Assessing ADHD in adults with ID often includes taking a history from the patient and a collateral history from support workers, carers or family members. Reports from settings where the person with ID spends a lot of time, including schools, day services or work, is invaluable. In addition, information from videos of the person can be helpful.

ADHD diagnostic assessment includes:

- 1 psychiatric assessment including a detailed developmental history
- 2 an assessment of ADHD symptoms as per DSM-5 or ICD-10 criteria.

A complete psychiatric history is important to assess for comorbid psychiatric, neuropsychiatric and neurodevelopmental disorders.

3.2 Assessment of ADHD symptoms as per DSM-5 criteria (American Psychiatric Association, 2013)

Clinicians need to explore the history of ADHD symptoms using objective diagnostic criteria. This can be done using a structured diagnostic tool or a clinical history focusing on ADHD symptoms. There are several ADHD screening and assessment tools available, however, only one, to date, is specific for ADHD in people with ID and can be used across a range of settings. The Diagnostic Interview for ADHD in Adults with ID (DIVA-5-ID) (McCarthy et al, 2017) is based on the DSM-5 criteria for ADHD and provides a list of examples from clinical practice for both current and childhood behaviour in people with ID for each of the 18 symptom criteria for ADHD. There are four main diagnostic criteria of ADHD in adults as per DSM-5:

- the presence of five or more inattentive symptoms and/or five or more hyperactivity and impulsivity symptoms in adulthood, that are inconsistent with developmental age
- several symptoms of inattentive and/or hyperactivity/impulsivity symptoms prior to the age of 12 years
- symptoms to be present in two or more different settings
- functional impairment secondary to the symptoms.

Criterion 1

The presence of five or more inattentive symptoms and/or five or more hyperactivity and impulsivity symptoms in adulthood which are inappropriate for developmental age.

Assessment of inattention and hyperactivity/impulsivity symptoms can be challenging in people with ID. ADHD symptoms may present differently in people with ID. People with ID are often absent from settings commonly referred to in a standard diagnostic criterion, e.g. the workplace. As such, we have detailed how standard DSM-5 criteria may present in people with ID in Table 2.

Table 2: DSM-5 criteria in an adult with ADHD and ID (McCarthy et al, 2017)	
DSM-5 criteria (American Psychiatric Association, 2013)	How they manifest in people with ID (Developed from clinicians' experience)
A1. Often fails to give close attention to details or makes careless mistakes in schoolwork, at work or with other activities	Struggles to pay attention at work, home, day centre, college, during occupational therapy (OT) activities, drawing, etc.
A2. Often has trouble holding attention on tasks or play activities	Difficulty sustaining attention at work, home, during OT activities, drawing, etc.
A3. Often does not seem to listen when spoken to directly	Appears not to listen to the conversation, asks for information again, cannot remember parts of the conversation
A4. Often does not follow through on instructions and fails to finish schoolwork, chores or duties in the workplace, e.g. loses focus, side-tracked	Starts an activity but does not complete the task. Needs a lot of support and prompting to complete tasks
A5. Often has trouble organising tasks and activities	This is often not relevant in the ID population as they are usually not given the responsibility of organising tasks or activities, however, it can be manifested in their ability to plan simple tasks
A6. Often avoids, dislikes or is reluctant to do tasks that require mental effort over a long period of time (such as schoolwork or homework)	Struggles to complete a task or activity that take a long period of time or involves concentration
A7. Often loses things necessary for tasks and activities, e.g. school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones	Will leave belongings behind even when aware of what is needed for the day. Will not know where something is if it has not been put in its usual place
A8. Is often easily distracted	Gets distracted by every little noise. Moves from one task to another quickly. Will struggle to get back into an activity where they were previously engaged
A9. Is often forgetful in daily activities	Will forget where they have put objects such as phone or keys. This is difficult to assess in a person with a more severe ID who is fully supported with their daily activities or may not be in possession of a phone or keys
H1. Often fidgets, taps hands or feet or squirms in seat	Often cannot be still; always moving around

Table 2: DSM-5 criteria in an adult with ADHD and ID (McCarthy et al, 2017)

DSM-5 criteria (American Psychiatric Association, 2013)	How they manifest in people with ID (Developed from clinicians' experience)
H2. Often leaves seat in situations when remaining seated is expected	Often moves around, finds it hard to sit in one place for long durations. Finds it hard to sit and have their meals or stay seated on the lavatory
H3. Often runs about or climbs in situations where it is not appropriate (adolescents or adults may be limited to feeling restless)	Moving around most of the time, internal restlessness can lead to agitated appearance. Runs/moves around in the waiting room of an outpatient clinic
H4. Often unable to play or take part quietly in leisure activities	Speaks loudly, finds it hard to do activities quietly (for people with verbal communication)
H5. Is often 'on the go' acting as if 'driven by a motor'	Excessive energy, often moving around, not able to sit in one place for long, likes to be outdoors most of the time engaging in activities
H6. Often talks excessively	Talks a lot without taking turns (for people with verbal communication)
H7. Often blurts out answers before a question has been completed	Will blurt out answer to any question asked (for people with verbal communication)
H8. Often has trouble waiting his/her turn	Becomes agitated or aggressive when asked to wait for any length of time. Not able to queue for activities, finds it hard to wait if their needs are not met immediately
H9. Often interrupts or intrudes on others	May not have a sense of personal space, interrupts other people's conversations

Criterion 2

Several symptoms of inattentive and/or hyperactivity/impulsivity symptoms prior to the age of 12 years.

The current consensus is for three or more ADHD symptoms to be present before the age of 12 years (McCarthy et al, 2017). Trying to establish whether symptoms were present before the age of 12 years, especially in older people with ID, can be challenging. People with ID often have memory difficulties and may not be able to recall details from their childhood and this is compounded if relatives are not available to provide information to meet this criterion. It is therefore recommended that more weight is given to clinical opinion and that a pragmatic approach is taken when applying this criterion in cases where a collateral history is not available.

Criterion 3

Symptoms to be present in two or more different settings.

The presence of symptoms in two or more settings such as home, school, day service or work is important to assess the pervasiveness of symptoms. However, it is acknowledged that people with ID often lead lives which are restricted in nature and are

under-represented in many areas of public life, e.g. education, work or social settings. As such, the careful consideration of the individual's personal context is advised when assessing ADHD in people with ID.

Criterion 4

Functional impairment secondary to symptoms.

ADHD can restrict a person's life as they cannot engage in social activities because of their behaviour. Functional impairment secondary to ADHD can be seen in different domains of life that include activities of daily living; personal life/social life; work; school; or attendance at a day service. ADHD symptoms may limit the ability of a person with ID to achieve their potential, by causing significant functional impairment, as it may often present as challenging behaviour (Korb et al, 2019).

This criterion therefore requires further consideration when assessing a person with ID since it could be explained by the ID alone or another comorbidity such as anxiety. In such circumstances, it may be useful to seek the perspective of professionals involved with the person and who are experienced in supporting people with ID. They may be able to elucidate whether the severity of functional impairment is more pronounced in the individual being assessed compared to others on their case-load.

3.3 Limits of DSM-5 criteria

Applying DSM-5 criteria in people with ID can be limited, especially in people with severe ID and with limited communication skills. A2, A8, H2 and H5 are commonly seen among people with ID and ADHD (Perera et al, 2019a). People with ID may be supported by carers in activities of daily living to varying degrees. This may limit the relevance of A5, A6, A7, A9 domains. People with limited communication skills may not meet A3, H6, H7 as these criteria are based on the person's ability to communicate verbally.

Strict application of the requirement to have five or more DSM-5 criteria may limit the diagnostic process. In such situations, the overall clinical picture and clinician's opinion is considered to have more validity than the strict application of DSM-5 criteria when diagnosing ADHD in people with ID (Perera et al, 2019a).

3.4 Overcoming challenges

When assessing symptoms in a person with ID, a clinical judgement needs to be made on whether the person's level of inattention, hyperactivity or impulsivity correlates with what is expected at the person's level of developmental age. Even though this can be challenging, a careful history from different sources can be helpful. For example, school reports and information from a day centre, college, school or from care home staff who have experience of supporting people with similar levels of intellectual abilities may be helpful. Often a person with ADHD and ID is well known for being hyperactive or for being more distractible or needing more support to stay focused on a task compared to their peers with a similar level of ID.

Chapter 4: Pharmacological management of ADHD in people with intellectual disabilities

4.1 Medication in ADHD and intellectual disability

The literature on ADHD medications in adults with ID remains limited with evidence in the general population extrapolated to the ID population. Furthermore, much of the research has focused on children (Aman et al, 1993; Agarwal et al, 2001; Aman et al, 2003; Fernandez-Jaen et al, 2010; Aman et al, 2014) with no studies in adults. A recent systematic review by Tarrent et al (2018) on the effectiveness of methylphenidate in the management of ADHD in children with ID revealed 13 RCTs, one of which used a parallel design and the rest were crossover trials. On average, 40–50% responded to methylphenidate in the ID group compared to a response rate of 70–80% reported among the non-ID children (Courtenay and Elsner, 2016). The reasons for a lower response are not clear.

A Cochrane Review by Thomson et al (2009) on the use of amphetamines in ADHD in ID found one eligible study with a follow-up period of one week. The drawbacks include a small sample size ($n = 15$) and a short follow-up period. Despite this, the study highlighted some promising results with the type and rate of adverse effects among children with ID being similar to those in children without an ID (average 12–24%).

Studies report various adverse effects with ADHD medications in people with ID (Molina-Ruiz et al, 2017) that include: sleep difficulties; poor appetite with weight loss; irritability; social withdrawal; and increased motor activities including tics (Tarrant et al, 2018). Furthermore, pre-existing movement disorders may be exacerbated by ADHD medication, although a Cochrane Review by Osland et al (2018) found that stimulants do not cause a worsening in tics in most people with tic disorders.

Previous concerns regarding the use of methylphenidate in people with ASD has not been substantiated in recent studies that have shown positive effects of methylphenidate on some core symptoms of ASD. Therefore, ASD could not be considered as a contraindication to prescribing methylphenidate. Its epileptogenic effect is not clear therefore a pragmatic approach to prescribing on a case-by-case basis should be adopted (Tarrent et al, 2018). A review by Miller et al (2020) highlights the benefits in the cognitive and behavioural domains for ADHD medications in people with ID and suggests that higher doses may be needed.

4.2 Guidelines on the management of ADHD

The key national and international guidelines on the pharmacological treatment of ADHD in the general population who do not have ID include: NICE Guidelines on Attention Deficit Hyperactivity Disorder: Diagnosis and Management (NG87) (National Institute for Health and Care Excellence 2018); Updated European Consensus Statement on Diagnosis and Management of Adult ADHD (Kooij et al, 2019); and the

British Association for Psychopharmacology Guidelines on Pharmacological Management of ADHD (Bolea-Alamañac et al, 2014). The guidelines were used in the preparation of this report.

4.3 Pre-treatment assessment

Before prescribing medication to treat ADHD, the clinician should conduct a thorough assessment of the person.

- assess for underlying cardiac diseases including a history of congenital cardiac diseases, current cardiac symptoms such as shortness of breath, chest pain and a family history of sudden death in a first-degree relative aged less than 40 years that may suggest cardiac disease.

Please refer to section 4.9 on ‘ADHD and cardiac disease’ for advice about treatment when there are concerns about cardiac disease **

- conduct a physical examination to include measurement of weight, blood pressure and heart rate. People with ID and untreated ADHD may not cooperate with such examinations and therefore adopting a pragmatic approach to decisions on treatment that may benefit the person is recommended. National Institute for Clinical Excellence (NICE) guidelines recommend a cardiovascular examination including auscultation. An electrocardiogram (ECG) is not needed before starting ADHD medications unless specific concerns have arisen from the physical history and examination.

4.4 Medication

There are two main groups of ADHD medications: stimulants and non-stimulants (Table 3, 4 and 5). Stimulants act by blocking the reuptake of noradrenaline and dopamine. In addition, dexamfetamine directly stimulates dopamine release (Stahl, 2010). Atomoxetine more selectively targets the noradrenaline transporter but, as the noradrenaline transporter clears both noradrenaline and dopamine in the prefrontal cortex, atomoxetine increases both dopamine and noradrenaline (Bymaster et al, 2002; Kratochvil et al, 2003). Clonidine and guanfacine act as alpha 2 agonists on the pre-synaptic receptors, modulating the release of noreadrenaline and dopamine.

Table 3: Stimulant and non-stimulant ADHD medication

Stimulants	Non-stimulants
Methylphenidate Dexamfetamine	Atomoxetine Clonidine Guanfacine

Table 4: Stimulant medications for ADHD in adults with ID in the UK

Drug	Preparation	Trade name	Formulation	Dose range	Other information
Methylphenidate	Methylphenidate Immediate release (IR)	Methylphenidate immediate release	5mg, 10mg, 20mg tablets	5mg–100mg	Various trade names available
	Methylphenidate modified release (MR)	Concerta XL	18mg, 27mg, 36mg, 54mg tablets	18mg–108mg	Do not crush or chew, swallow whole
		Medikinet XL	5mg, 10mg, 20mg, 30mg, 40mg, 50mg, 60mg capsules	10mg–100mg	Can be opened and mixed with food, have with food
		Equasym XL	10mg, 20mg, 30mg capsules	10mg–100mg	
Dexamfetamine	Dexamfetamine IR	Dexamfetamine oral solution	Oral solution 5mg/5ml	5mg– 60mg	
		Dexamfetamine tablets	5mg, 10mg, 20mg	5mg–60mg	
	Lisdexamfetamine	Elvanse	20mg, 30mg, 40mg, 50mg, 60mg, 70mg capsules	20mg–70mg	Capsules can be opened and mixed with food

Information from the BNF (Joint Formulary Committee 2020)

Table 5: Non-stimulant medications for ADHD in adults with ID in the UK

Drug	Preparation	Trade name	Formulation	Dose range	Other information
Atomoxetine	Atomoxetine capsule		10mg, 18mg, 25mg, 40mg, 60mg, 80mg, 100mg	40mg–120mg	Can be given once or twice a day
	Atomoxetine liquid		Oral solution 4mg/1ml	40mg–120mg	
Clonidine	Clonidine tablet		25 micrograms (mcg), 100mcg	50mcg-1.2g (Maximum dose based on the indication for hypertension)	
	Clonidine oral solution		Oral solution 50mcg/5ml		
Guanfacine	Tablet	Intuniv	1mg, 2mg, 3mg, 4mg	1mg–7mg	

Information from the BNF (Joint Formulary Committee 2020)

4.5 Medication choice for adults with ID

NICE guidelines (2018) recommend using either methylphenidate or lisdexamfetamine as the first-line pharmacological treatment for adults with ADHD.

- Consider switching to lisdexamfetamine for adults who have had a six-week trial of methylphenidate at an adequate dose but have not derived enough benefit in reduced ADHD symptoms and associated impairment.
- Consider dexamfetamine for adults whose ADHD symptoms are responding to lisdexamfetamine but who cannot tolerate the longer effect profile.
- Offer atomoxetine to adults if they cannot tolerate lisdexamfetamine or methylphenidate or their symptoms have not responded to two separate six-week trials of lisdexamfetamine and methylphenidate, having considered alternative preparations at adequate doses.

The choice of ADHD medication can be influenced by factors such as the duration of symptom control needed, side-effect profile, existing comorbidity and available preparations. Al-Khudairi et al (2019) showed that atomoxetine is often used in adults with ADHD and ID because of its longer half-life compared with stimulants and therefore its ease of administration.

4.6 Dose titration in adults with ID

Titration of the dose of medication helps to achieve the most effective dose with the minimal adverse effects.

- ADHD symptoms and functional impairments should be recorded at baseline and at each dose change during the dose titration period
- Start with a lower dose and titrate slowly
- Increase the dose to higher doses before ruling it out as not being effective
- Titrate the dose against symptoms and adverse effects in line with the British National Formulary (Joint Formulary Committee, 2019) until dose optimisation is achieved with reduced symptoms, positive behaviour changes and improvements in functional impairment with tolerable adverse effects
- Ensure that dose titration is slower and monitoring more frequent if any of the following are present in people with ADHD:
 - other neurodevelopmental disorders such as ASD or tic disorders
 - mental illness such as anxiety disorders, obsessive-compulsive disorder, schizophrenia, bipolar affective disorder, depression, personality disorder, eating disorder, post-traumatic stress disorder or substance misuse
 - physical health conditions, for example, cardiac disease, epilepsy or acquired brain injury.

4.7 Practical considerations when prescribing ADHD medication in people with intellectual disability

The following factors should be considered when prescribing in clinical practice:

- Functional impairment – does it present as challenging behaviour throughout the day, needing longer duration of symptom control?
- Convenience and adherence – can the person take medication as prescribed, especially if it needs to be taken more than once a day? What extra support is available to the person to take medications as prescribed?
- What facilities are available in which to store and administer controlled medications at home, day centre or college?
- Pharmacokinetic and pharmacodynamic profiles – does the person metabolise medication slower or faster than expected?
- Not responding to one stimulant medication does not mean that the person may not respond to another stimulant medication from the same group.
- When prescribing stimulants for ADHD, be aware that effect size, duration of effect and adverse effects vary from person to person.
- Consider combining in the drug regimen immediate and modified-release preparations of stimulants to optimise effect, for example, a modified-release preparation of methylphenidate in the morning and an immediate-release preparation of methylphenidate at another time of the day to extend the duration of effect.
- Prescribers should be familiar with the requirements of controlled drug legislation governing the prescription and supply of stimulants. (See NICE's guideline on controlled drugs.)

4.8 Caution

Consider treating a comorbid anxiety disorder (if relevant) prior to starting ADHD medication in people with ID and ADHD because there is a risk of increased anxiety and worsening of behaviour. Treat anxiety first or use medications/strategies to reduce anxiety when starting ADHD medications. If there is worsening of anxiety and behaviour, stop ADHD medications and restart when the person's level of anxiety has been treated.

4.9 Combining ADHD medications

There is no published literature on combining ADHD medications but using a combination of ADHD medications is seen in clinical practice when one ADHD medication does not fully control symptoms of ADHD. Advice from a specialist in ADHD in ID can be sought in such instances.

4.10 ADHD medication and the cardiovascular system

NICE 2018 recommendations on the assessment, management and monitoring of cardiac disease and cardiovascular risk in people with ADHD also applies to people with ID. However, given that people with both ADHD and ID present specific challenges, we have tailored our advice accordingly. In this section pragmatic advice is provided based on experience, available evidence and published guidance to help clinicians exercise their clinical judgement on a case-by-case basis and to escalate, where appropriate, in what can be challenging circumstances largely unsupported by scientific evidence or published guidance.

The adverse cardiac effects of ADHD medications, such as hypertension and tachycardia, result from their adrenergic and dopaminergic activity. QTc prolongation also occurs through unknown mechanisms. Because data on cardiovascular safety in adults with ADHD and ID is absent, these recommendations are extrapolated from studies in healthy people and younger people with ADHD but without ID.

Reports of sudden death in adults treated for ADHD have raised concerns about an increased risk of sudden cardiac death but observational studies have not consistently shown this to be the case (Fay et al, 2019).

Before starting ADHD treatment, it is important to exercise caution in people who are at increased risk of decompensation caused by increases in heart rate, blood pressure and QTc interval that may occur. These include people with known or suspected heart failure, valve disease, arrhythmia, coronary artery disease, hypertension and complex congenital heart disease. Therefore, before starting treatment, all patients should have a stratified cardiovascular assessment to explore for such conditions that should include:

- **a cardiovascular history (from person or carer):**
personal history of cardiac symptoms, drug history, family history of cardiac disease and sudden death
- **a cardiovascular examination:**
signs of heart failure or murmurs
- **basic cardiovascular investigations:**
height, weight, blood pressure and heart rate.

*A pragmatic approach is needed when a person with ID and ADHD needs treatment; a cardiovascular examination may not be possible due to their behaviour. Inability to perform a cardiovascular examination should not prevent them receiving ADHD treatment in the absence of evidence of a possible cardiovascular condition.

4.10.1 Blood pressure

Normal blood pressure in people with ADHD who are not on treatment should be in the range 100–120/60–70mmHg, the same as in healthy adults. ADHD drug treatment increases the average blood pressure by 3–8mmHg (systolic) and 2–14mmHg (diastolic) (Fay et al, 2019). These changes are small, for example the average blood pressure would need to rise consistently by 20mmHg (systolic) or 10mmHg (diastolic) for ten years to increase the incidence of cardiovascular death from 1% to 2% per decade

(Prospective studies collaboration, 2002). For this reason, NICE (2019) do not recommend diagnosing and treating hypertension until the average home blood pressure readings are above 135/85mmHg.

People with ADHD and ID are unlikely to experience significant increases in blood pressure or cardiovascular risk due to ADHD medications that would justify withholding treatment. Indeed, guanfacine can cause hypotension. Where clinic blood pressure measurement is not possible, basic measures such as reassurance, de-escalation, watchful waiting and home blood pressure monitoring are reasonable first steps. In home blood pressure monitoring, blood pressure is recorded twice in the morning and twice in the evening, one minute apart, for four to seven consecutive days. Values from day one are discarded and the remaining values are averaged. This is useful in people with ADHD and ID because it can be performed at home, at rest, by carers and away from the clinic.

Blood pressure should ideally be measured at baseline before drug treatment, before and after dose changes and at six-monthly intervals. Clinic readings consistently in the following ranges should trigger the appropriate actions:

Table 6: Actions to take depending on blood pressure (BP) values	
Value	Action
Systolic below 140mmHg or diastolic below 90mmHg	Continue ADHD medications and up-titrate if required
Systolic above 140mmHg or diastolic above 90mmHg	<ul style="list-style-type: none"> • Continue ADHD medications at the current dose • Perform home BP monitoring and re-review • Refer to cardiology if home BP readings remain above 135/85mmHg
Systolic above 180mmHg or diastolic above 120mmHg	<ul style="list-style-type: none"> • Reduce or hold dose of ADHD medications • Perform a cardiac history, examination, fundoscopy, urine dipstick, blood test (HbA1c, U+Es, lipids) and urine sample (ACR), where feasible • Perform home BP monitoring. Refer to cardiology if home BP readings remain above 135/85mmHg • Arrange for a GP review within seven days • If evidence of acute end-organ dysfunction e.g. chest pain, new confusion, heart failure, proteinuria, haematuria or retinal damage, or it is difficult to exclude, then arrange for same day medical assessment. At a minimum, seek telephone advice, e.g. medical registrar on call or ambulatory care unit
Orthostatic hypotension due to fainting using guanfacine	Down titrate dose or change to alternative

4.10.2 Heart rate

The normal heart rate is 60–100bpm in sinus rhythm. On initiating of ADHD drug treatment, the heart rate increases by 3–10bpm on average (Fay et al, 2019). This is a small rise not likely to be associated with adverse events or to justify withholding ADHD treatment. The risks due to sinus tachycardia in patients with ADHD, where alternative causes have been excluded, are extremely low. As with blood pressure, the heart rate should ideally be measured before and after changes in dose, and every six months, unless there are other indications.

ECG examination is not necessary in the absence of other specific clinical indications or if any of the ‘high-risk’ features listed below apply. It is recognised that taking objective measurements in this population can be challenging. The heart rate may be recorded more easily by pulse oximetry, smartphone devices, smart watches or at home, perhaps in combination with home blood pressure monitoring. Heart rates consistently in the following ranges should trigger the following appropriate actions:

Value	Action
60–100bpm	Continue ADHD medication and up-titrate if required
100–120bpm	<ul style="list-style-type: none">• Continue ADHD medication at the current dose• Look for causes including agitation, pain, concomitant medications, dehydration, infection, anaemia and hyperthyroidism• If there are concerns about more worrying causes such as sepsis, pulmonary embolism, cardiac ischaemia or acute heart failure, discuss with ambulatory care or arrange same day hospital assessment
120bpm or above or sustained arrhythmia	<ul style="list-style-type: none">• Reduce or hold the dose of ADHD medication• Consider and exclude alternative causes of sinus tachycardia listed above• Perform an ECG, arrange a routine 24-hour HR monitor and refer to cardiology• Discuss with ambulatory care or arrange same day hospital assessment

4.10.3 QTc interval

The QTc interval is the time between ventricular depolarisation and repolarisation. People with ADHD but not using drug therapy to treat this disorder have QTc intervals similar to healthy populations: average 420ms, upper limit of normal 440ms for men and 470ms for women, 99th centile 470ms for men and 480ms for women. The limited evidence suggests that cardiac risk increases exponentially above normal limits and stronger evidence links QTc values over 500ms to a clearly increased risk of arrhythmia (Jenkins et al, 2016). The QTc changes that occur when starting ADHD therapy are modest, ranging from minor decreases in QTc, to increases of 7ms or less (Fay et al, 2019). As a result, an ECG is not required before starting treatment unless there are other indications or any of the ‘high-risk’ features below apply. The challenges of recording an ECG in the setting of ADHD and ID are recognised and therefore using simple smartphone

devices may be useful in overcoming such difficulties (Parks et al, 2017). When an ECG is performed, consistent QTc measurements in the following ranges should trigger the following appropriate actions:

Table 8: Actions to take depending on QTc values	
QTc Value	Action
Under 470ms (men) or 480ms (women)	Continue ADHD medication and up-titrate if required
Between these values and 500ms	<ul style="list-style-type: none"> • Continue ADHD medication at the current dose • Review drug history for other QTc-prolonging medications • Assess and correct electrolyte abnormalities (Mg²⁺, Ca²⁺, K⁺) • Perform annual ECG monitoring • Refer to cardiology
Above 500ms	<ul style="list-style-type: none"> • As above but reduce or hold the dose of ADHD medication • Discuss with ambulatory care or arrange same day medical assessment

4.10.4 Cardiovascular risk

As for the general population, cardiovascular risk should be assessed, using the QRISK3 score, at least every five years (qrisk.org/three). ‘Severe mental illness’ and ‘use of atypical antipsychotics’ were recently added to this score as they are associated with incremental increases in cardiovascular risk (Hippisley-Cox et al, 2017). Although every effort should be made to complete the score comprehensively, it is accepted that some criteria are challenging to fulfil in the mental health setting and in people with ID. An estimation of cardiovascular risk can be provided despite incomplete information. The following score should be accompanied by the following appropriate actions.

Table 9: Actions to take depending on QRISK3 score	
QRISK3 score	Action
<10%	<ul style="list-style-type: none"> • Offer lifestyle advice including smoking cessation, weight loss (if overweight), alcohol reduction, dietary modification and regular physical activity • Request that the GP optimises the management of cardiovascular risk factors including atrial fibrillation, chronic kidney disease, diabetes mellitus, dyslipidaemia, hypertension, physical inactivity and obesity
>10%	As for <10%, but also request that, after the GP has excluded hypercholesterolaemia, familial dyslipidaemia and secondary causes of hyperlipidaemia, atorvastatin 20mg should be offered for the primary prevention of cardiovascular disease, unless contraindicated

4.10.5 Cardiology referral

A cardiology opinion is warranted if any of the following 'high-risk' features are present:

- symptoms such as cardiac syncope, angina, breathlessness, ankle swelling or rapid and regular palpitations that start and stop suddenly
- known cardiac disease, hypertension, aortic dilatation or previous cardiac surgery
- a family history of sudden death in a first-degree relative
- a cardiac murmur on examination
- resting tachycardia above 120bpm
- QTc previously >470ms for men and 480ms for women.

Cardiology referrals should include details of the cardiac history, examination and investigations to date, blood pressure, heart rate and ECG findings. If deemed appropriate, it is also reasonable to request further investigations whilst awaiting a cardiology review such as an echocardiogram, e.g. suspected structural or congenital heart disease or 24-hour cardiac monitor, e.g. tachycardia or suspected arrhythmia. If, following referral there is agreement between cardiology and psychiatry that ADHD treatment is safe, then people with ADHD and cardiac disease require slower dosing and more frequent monitoring. Importantly, the following cardiac diagnoses are not contraindications to ADHD therapy:

- mild and asymptomatic cardiac valvular stenosis or regurgitation
- asymptomatic mitral valve prolapse
- asymptomatic valve replacement or repair
- successfully repaired atrial or ventricular septal defect
- unrepaired but asymptomatic patent foramen ovale, atrial septal defect or ventricular septal defect.

Chapter 5: Non-pharmacological management of ADHD in intellectual disability

5.1 Introduction

Non-pharmacological strategies can be broadly defined as any interventions that do not include the use of medications. This is an umbrella term which covers a wide range of activities. Currently, there are limited evidence-based non-pharmacological treatments for ADHD in general. The existing evidence is considered to be of low quality with imprecise results and multiple biases. The evidence base for non-pharmacological management of ADHD in people with ID is further limited (Knouse et al, 2008; Safren, 2006)

Despite the absence of evidence, ADHD requires a comprehensive, collaborative and multimodal treatment approach tailored to meet the unique needs of the person with ID and ADHD chosen from a range of non-pharmacological strategies. These strategies can be considered as follows:

- supporting an individual to manage the core symptoms of ADHD
- supporting the associated symptoms of ADHD, such as mood fluctuations, anger, emotional dysregulation, anxiety and mental illness
- reducing functional impairment, such as challenging behaviour.

Despite the paucity of evidence for non-pharmacological interventions in people with ID and ADHD, evidence extrapolated from studies undertaken in the general population and the strength of underlying theoretical principles may be helpful when supporting people with ADHD and ID.

Non-pharmacological interventions using personalised approaches based on cognitive and behavioural principles are recommended. The choice of intervention depends on factors such as the severity of ID, severity and nature of challenging behaviour, risks, motivation of the individual to engage in interventions and the availability of resources:

- psychoeducation to person with ID and/or carers
- cognitive behavioural therapy (CBT)
- organisational skills/school or workplace targeted interventions
- exercise/outdoor activities.

5.2 Psychoeducation to person with ID and/or carers

Psychoeducation can be delivered on an individual basis and/or in a group. It can help people with ID and their carers to understand the symptoms of ADHD and how it is related to behaviours and different functional impairments. It also supports the psychological formulation of a person's behavioural difficulties and mental health issues which can contribute valuable information to the positive behaviour support plans (PBS).

Psychoeducation helps to reduce isolation and stigma by sharing experiences and knowledge with others. It is an opportunity to involve family members, close friends or caregivers in a person's care.

The key concepts of psychoeducation in ADHD were outlined by Van Lammeren and Bruggeman (2011) as the following:

- recognition of the symptoms attributed to ADHD for each person
- recognition of the positive aspects of ADHD for each person
- becoming aware of the functional disabilities due to ADHD
- the consequences of ADHD on different areas of life, e.g. work, social life, relationships, parenting
- learning how to find reliable information on ADHD
- learning to think in a constructive way about the problems related to ADHD.

5.3 Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) has been shown in some studies to reduce the core symptoms of ADHD, associated symptoms such as emotion dysregulation, anxiety and depression, and functional impairments across different areas of daily living in adults. Certain adaptations may be needed for people with ID when delivering CBT depending on the person's intellectual functioning (Vereenoghea and Langdon, 2013). Young and Bramham (2012) suggest therapists should rely more on behavioural techniques when delivering CBT to individuals who have both ADHD and ID and to be mindful of an individual's difficulties with impulsivity if implementing a reward-based behavioural programme.

5.4 Organisational skills/school or workplace targeted interventions

The following strategies can be implemented with carers and other support networks depending on the severity of the ID, the degree of functional impairment and the settings where ADHD symptoms can cause problems.

Box 1: Examples of different strategies (Young and Bramham, 2012)

Reduce auditory distractions by supporting the person with ID and ADHD in a quieter place using low level music, noise cancelling headphones, earplugs if the person tolerates them

Reduce visual distraction by appropriate positioning in the room

Use bright colours or cue cards to attract attention to the task

Use rewards, such as tea breaks or short walks

Introduce a competitive element

Set achievable goals

Break up activities into smaller manageable tasks/goals

5.5 Outdoor activities

Even though there is no strong evidence to support exercise, regular exercise is beneficial for people with ADHD. In addition to physical health benefits, it may reduce behavioural challenges associated with ADHD if the person has adequate space to remain active (Den Heijer et al, 2017). This is likely to be equally applicable to those with ID and ADHD. Therefore, people with ADHD and ID should have access to regular outdoor activities.

Chapter 6: Case vignettes

6.1 Introduction

The following case vignettes illustrate the various challenges that clinicians face when assessing and managing ADHD in people with ID.

Case vignette 1 – Missed diagnosis

Sarah is a 21-year-old woman with a mild ID. She presented with thoughts of self-harm when distressed, getting into arguments/fights, being impulsive and not getting on with her family. Previous diagnoses include drug-induced psychosis, antisocial personality disorder and emotionally unstable personality disorder. She was unable to keep a job despite having the ability. She was diagnosed with ADHD and was started on a stimulant medication. There was a marked improvement in her symptoms that had been attributed to personality disorder in the past. Her aggression reduced significantly and she was able to take up employment in a supermarket.

Case vignette 2 – Challenging behaviour

George is a 19-year-old man with severe ID, ASD and ‘challenging behaviour’. He was known to Child and Adolescent Mental Health Services (CAMHS) and treated with low dose risperidone. His aggression escalated resulting in him being detained in hospital under the Mental Health Act. During his long admission to hospital he spent most of his days running around the vast grounds. On discharge to an urban environment, he damaged property, ran into the road and was aggressive. He commenced a short-acting stimulant which possibly made his behaviour worse. Atomoxetine was introduced following which he was able to access the community and engage in meaningful activities. In addition, the damage to property and aggression reduced, leading to less need for a required medication. Attempts to withdraw risperidone were not successful.

Case Vignette 3 – Non-responder

John is a 36-year-old man diagnosed with severe ID, ASD and ADHD. He presents with aggression, hyperactivity, restlessness, self-injurious behaviour and poor sleep patterns. He was given a trial of different stimulants and non-stimulant medications without any clear benefits.

Case Vignette 4 – Side effects

Nadia is a 19-year-old woman with moderate ID, autism and challenging behaviour. She was ‘always on the go’ and found it hard to sit in one place. Due to the nature of her behavioural difficulties, along with hyperactivity, she was accompanied by support staff when in the community. A diagnosis of ADHD was made and she started atomoxetine. Within a day of starting ADHD medication, she became extremely agitated and needed to be restrained several times a day. This was a clear worsening of her existing challenging behaviour. The non-stimulant medication was stopped and within days the aggression and agitation subsided but she continued to present with challenging behaviour.

Case vignette 5 – Genetic syndrome – Smith-Magenis Syndrome

Adam is a 19-year-old man with a diagnosis of Smith-Magenis syndrome, severe ID, ASD and a long history of challenging behaviour. He has struggled with his sleep all his life. He was 'always on the go', often labile in mood and exhibited physical and verbal aggression. He was prescribed antipsychotic medication and anti-anxiety medication with mild improvements. He continued to present with increasing behavioural difficulties as he got older and it was difficult to implement behavioural and psychological strategies. Due to the higher prevalence of ADHD in Smith-Magenis Syndrome, ADHD was considered and diagnosed. ADHD medication was started with a clear improvement in his hyperactivity and agitation within a few weeks. Carers were able to implement positive behaviour support plans with the improvement in his behaviour which further enhanced his quality of life. His sleep pattern improved significantly.

Chapter 7: Special groups

7.1 Introduction

There are certain groups of patients who require specific consideration when treating ADHD, including individuals with sleep disorders and offenders.

7.2 Sleep disorders in adults with ADHD and ID

Sleep problems are reported in up to 50% of people with ADHD (Wajszilber et al, 2018) and are likely to be more frequent in individuals with a comorbid ID. Despite this, primary sleep disorders (Table 10) are often not assessed and therefore untreated. In people with ADHD and ID, comorbid sleep disorders can result in significant functional impairments that affect mood, behaviour, health, quality of life and carer burden.

Given that both ADHD and primary sleep disorders commonly co-exist and have a negative interactive effect (Table 10), it is important to conduct a baseline sleep evaluation during the initial assessment of ADHD in an individual with ID, as well as regular screening for sleep problems as part of ongoing ADHD management. This is of particular importance given that untreated sleep disorders are likely to reduce the efficacy of ADHD interventions (Stein et al, 2012).

Table 10: Common primary sleep disorders in ADHD and ID

Sleep disorder	When to suspect it	Relationship between sleep disorder and ADHD	Management
Obstructive sleep apnoea (OSA)	<ul style="list-style-type: none"> • Snoring • Pauses in nocturnal breathing • Excessive daytime sleepiness 	<ul style="list-style-type: none"> • Repeated nocturnal hypoxia increases the symptoms of ADHD 	<ul style="list-style-type: none"> • Optimise weight management • Refer to a sleep disorder centre for assessment/management
Restless legs syndrome (RLS)	<ul style="list-style-type: none"> • The individual may report uncomfortable sensations in the legs which they have to move in order to attain relief • This will be most noticeable in the evening and at rest • In individuals with communication difficulties, increased restlessness/agitation in the evening may be observed • Insomnia may ensue from uncomfortable leg sensations and the need to move around • Increased daytime fatigue 	<ul style="list-style-type: none"> • RLS may be present in up to 44% of individuals with ADHD • Dopamine dysregulation and iron deficiency link RLS and ADHD • Sleep disruption from RLS worsens ADHD • RLS symptoms e.g. restlessness may mimic ADHD 	<ul style="list-style-type: none"> • Iron supplementation in individuals with a ferritin < 75mcg/l • Review potentially causative medications, e.g. SSRIs, SNRIs especially mirtazapine, β-blockers, antihistamines, antiemetics, e.g. metoclopramide • Reduce caffeine intake and nicotine • Refer to a sleep disorder centre for assessment/management

Table 10: Common primary sleep disorders in ADHD and ID

Sleep disorder	When to suspect it	Relationship between sleep disorder and ADHD	Management
Delayed sleep-wake phase disorder (DSWPD)	<ul style="list-style-type: none"> The person regularly goes to sleep and wakes up >2 hours later than is considered normal Enforcing 'regular' sleep/wake times results in insomnia and/or excessive daytime sleepiness When left to sleep/wake via the individual's own rhythms there are no sleep-related difficulties 	<ul style="list-style-type: none"> DSPD is very common in ADHD (up to 70%) Individuals with ADHD have a myriad of changes in the biological clock, e.g. changes in the pineal gland and 'clock' genes There are also behavioural associations, e.g. impulsivity at night impedes settling down to sleep, leading to bedtime resistance and delays sleep onset 	<ul style="list-style-type: none"> Optimise control of ADHD Refer to a sleep disorder centre for assessment/management
Insomnia	<ul style="list-style-type: none"> Difficulty falling asleep or staying asleep despite adequate sleep opportunity Increased daytime dysfunction, e.g. irritability, low mood, anergia 	<ul style="list-style-type: none"> Insomnia is very common in ADHD (up to 66%) Unhealthy sleep practices, poor routines and bedtime resistance are more common in ADHD 	<ul style="list-style-type: none"> NICE (2015) and the British Association of Psychopharmacology (Wilson et al, 2019) recommend use of melatonin in adults with ID Gunning and Espie recommend: <ol style="list-style-type: none"> Optimise sleep hygiene Optimise sleep/wake schedule. This is best initiated by setting a fixed rising time that is maintained 7 days a week. Napping should be discouraged Stimulus control, i.e. only use the bedroom for sleep, sex and getting dressed Varying structured daytime activity Refer to sleep disorder centre for assessment/management

In addition to an awareness of primary sleep disorders in people with ADHD and ID, it is important to consider the effect of ADHD medications on sleep. Stimulants can exacerbate sleep problems and therefore timing of medication administration and the preparation used must be carefully considered to avoid worsening or causing sleep problems in this population.

7.3 Offenders with ADHD

ADHD is a risk factor for entering the Criminal Justice System (CJS). In the UK, it is estimated that, in detention settings, about 25% of prisoners have ADHD (Young et al, 2015). In addition, people with ID are overrepresented in prisons, with prevalence rates of 7% for those with an IQ less than 70 and nearer to 23% for those with borderline intellectual functioning (Jones and Talbot, 2010). However, little is known about how ADHD presents among offenders with ID in terms of their risk of entering the CJS. Prisoners with ID have complex needs with significant problems including inattention, hyperactivity, impulsivity or social communication combined with their cognitive impairments, thus increasing their risk of entering forensic settings (Chaplin et al, 2017).

The limited evidence available reflects high comorbidity between ID and ADHD for those in contact with the CJS. In a study of 240 male prisoners screened for neurodevelopmental disorders, 18 (7.5%) were identified using the Learning Disability Screening Questionnaire (LDSQ) as likely to have ID (Chaplin et al, 2017). Prisoners who screened positive on the LDSQ were highly likely to also screen positive for ADHD at a rate of 67%. This rate compares to studies in non-offender populations, such as La Malfa et al (2008), using the Conner's Adult ADHD rating scale in 46 adults with ID, which found a prevalence of 'ADHD-positive' of 19.6%.

Studies across clinical settings have explored the interaction between ADHD and ID with equivocal findings. In a longitudinal study of former Norwegian child psychiatric in-patients ($n = 541$) who were matched to the National Register of Criminality, conduct disorder and hyperkinetic conduct disorder ($RR = 2.7$, $95\% CI = 1.6-4.4$) were reported as significant predictors of future criminality whereas ID was a protector against future offending (Modre et al, 2011). In a UK study of 477 adults with ID in specialist forensic ID services (non-ADHD group $n = 73$ v ADHD group $n = 404$) those in the ADHD group showed higher rates of physical aggression, substance use and histories of aggression, sexual offences, property offences, birth problems and abuse in childhood. It was also noted that impulsivity related to ADHD was not a universal explanation for offending as this may have been a trait in the non-ADHD sample (Lindsay et al, 2013).

7.3.1 Implications for practice

Screening for both ID and ADHD across the Criminal Justice System has been highlighted in key national documents such as the Bradley report (2009) and should be introduced as routine practice across the System. However, these recommendations have been in place for several years, with limited uptake within forensic settings.

The presentation of ADHD in people with ID may be an indicator of an increased risk for offending type behaviours. It is therefore important to identify ADHD early in those with ID and implement appropriate evidence-based treatments. An ADHD diagnosis is also relevant within rehabilitative programmes because, if the diagnosis is not recognised, it is likely that an individual's ability to benefit from treatment will be negatively affected.

Chapter 8: Personal story

An interview with a person with ID and ADHD and their mother.

What was your life like before starting medication for ADHD?

I was anxious. My anxiety level was very high. I was struggling with sleep. I was angry with the whole world. I used to break things, hit walls. Once I damaged a door, I could see right through it. I used to bang my head on the doors. I could not go on the bus or be in places where there were too many people. This stopped me going to shops and other places. Someone always had to be with me. I found it hard to manage my anger and temper. I used to pick my skin a lot when I was restless and angry

What was your son like before starting medication for ADHD and what difference has medication made?

He used to follow me everywhere. I had to talk to him for days if we were planning to go out on a bus or train. He would get very anxious, very irritable and agitated leading to behavioural problems. He would push people out of his way when he was outside. He did not like people blocking his way. He would shout at them. He was angry with everyone and he was aggressive.

Since he was started on treatment there has been a clear improvement. His mood is a lot more stable. He is calm. He is relaxed. He can engage in a conversation. His sleep is so much better. This is somebody who always struggled with his sleep all his life. He used to wake up in the middle of the night and disturb everyone else in the house. He was always moving around and could not sit in one place but now he can sit and enjoy various things. He now has got two jobs. He works in a bakery and in a cleaning job. He takes a bus to get to work which he could not do in the past. He does not get angry as much as he used to. Since he started his job, he is very proud of himself. He bought a TV, shelves and blinds for his bedroom. His bedroom looks a lot nicer compared to how it was, as in the past he used to damage and destroy some of his personal belongings.

He can now go to the shops on his own and buy things for himself which he could never do in the past. He is more independent and I do not need to support him as much I used to. I am so pleased with the progress he has made.

Appendix

How to write a stimulant (controlled drug) prescription

All stimulants come under controlled drug regulations in the UK. There are specific requirements that the clinician must adhere to when writing a prescription. The dose and the total number of tablets or capsules needs to be written in numbers and letters.

Box 2: Examples of stimulant prescriptions

Prescription for lisdexamfetamine 50mg OD for 28 days:

Lisdexamfetamine 50mg capsules. Take one capsule at 8am.
Supply 28 (twenty-eight) capsules of lisdexamfetamine 50mg (fifty) capsules

Prescription for methylphenidate immediate release 15mg three times a day for 28 days:

Methylphenidate immediate release 5mg tablets. Take one tablet three times a day
Methylphenidate immediate release 10mg tablets. Take one tablet three times a day
Supply 84 (eighty-four) tablets of methylphenidate 5mg (five) tablets
Supply 84 (eighty-four) tablets of methylphenidate 10mg (ten) tablets

Prescription for Concerta XL 63mg OD for 28 days:

Concerta XL 36mg tablets. Take one tablet at 8am.
Concerta XL 27mg tablets. Take one tablet at 8am
Supply 28 (twenty-eight) tablets of Concerta XL 36mg (thirty-six) tablets
Supply 28 (twenty-eight) tablets of Concerta XL 27mg (twenty-seven) tablets

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