Commissioning for Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder in adults
ASD AND ADHD IN ADULTS

INTRODUCTION

Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) are common lifespan conditions that have a significant impact on spending in the NHS.

This handbook is aimed at clinical commissioners to aid understanding of the issues faced by adults with these conditions and shed light on treatment options.

It is a collaboration between South London and Maudsley NHS Foundation Trust, home to the National Autism Unit and national ASD and ADHD Clinics, and The Commissioning Review.

The National Autism Unit is for male adults with autism spectrum disorder, additional mental health difficulties, such as ADHD, and offending or challenging behaviour. The adult ASD and ADHD clinics offer out-patient assessment and management options for both males and females.

With 20 years experience the service offers in-depth assessments, and effective, evidence-based, patient centred treatments.
The facts

Why commissioners need to know about autism and ADHD in adults

Autism spectrum disorders (ASD) and attention deficit hyperactivity disorder (ADHD) are common lifespan conditions that cost society more than cancer, diabetes and heart disease combined. It is now clear that effective assessment and intervention leads to increased patient and carer wellbeing and to decreased long-term social and health care costs. This has led to:

1 Clinical guidance issued by the National Institute for Health and Care Excellence (NICE).
2 The Autism Act 2009 – the first disability-specific legislation passed in the UK;
3 The Strategy for Adults with Autism in England (Fulfilling and Rewarding Lives; Department of Health, 2010). Critically, this states that local authorities have a responsibility to provide:
   - increased availability of diagnosis
   - a more accessible service for adults
   - improved access to services and support.

This handbook describes how a range of national and local services have been developed to support commissioners to meet their responsibilities for those with ASD and/or ADHD.

What commissioners need to know about ASD in adults

Autism spectrum disorders (including Asperger’s syndrome) are lifelong conditions in which there are:

- Abnormalities in social and communication skills
- Restricted interests and repetitive behaviour
- Difficulty tolerating change is common, and many people with ASD are exquisitely sensitive to some environmental stimuli. ASDs are very common, occurring in about 1% of the population.

Typical scenarios leading to an ASD assessment include:

- A person has always felt ‘different’ and performs a positive screening test on-line or in their local health centre;
- A GP notices unusual social interaction during a routine consultation;
- A teacher notices a university student struggling with friendships;
- A family is worried about a person’s social abilities and isolation;
- An intellectual disability service observes repetitive behaviours.

Even when very subtle, ASD may profoundly affect a person’s financial, relationship and employment prospects, so detecting ASD is very important.

In adults the diagnosis is based on triangulating all available information – including patient experience, carer reports and special interview schedules – to find out if characteristic behaviour was present during early childhood and has continued to adulthood.

People with autism are at about 70% risk of suffering from at least one other mental health difficulty. Such ‘comorbid’ problems may include learning disability, ADHD, tic disorders, anxiety disorders and mood problems.

Comorbid mental health problems may be obscured by autism or may obscure the autism itself. This means that special expertise is often required not only to diagnose autism, but also to diagnose comorbid mental health problems.
There are no ‘treatments’ for core autistic problems, but comorbid difficulties are usually reversible. This means that making the diagnosis is an important first step to improved mental health, decreased carer burden, and cost savings.

**What commissioners need to know about ADHD in adults**

ADHD includes problems from childhood with attention, hyperactivity, and impulsive behaviour that cause serious difficulties coping with life’s everyday problems. ADHD is the UK’s most common behavioural disorder and is estimated to affect between 2.5 and 4.3% of people.\(^2\)

ADHD during childhood often continues into adulthood. At age 25:

- 15% of people still have a full range of symptoms;
- 65% of people still have symptoms which affect their daily lives.\(^3\)

Of course, much ADHD was not recognised during childhood, so there are many adults with the disorder who have never had a diagnosis. The diagnosis of ADHD in adults can be complicated and is made using patient reports, school reports and special interview schedules.

Unfortunately ADHD during adulthood greatly increases the risk of one or more ‘comorbid’ mental health problems, including anxiety/mood disorders, personality disorders, autism and substance misuse. Comorbid difficulties may mask underlying ADHD, so special expertise is often required to disentangle the effects of ADHD and comorbidity.

ADHD in adults often improves dramatically with medication – which may include stimulant or non-stimulant drugs. Effective treatment hugely benefits a patient’s relationships with others, work-related performance and quality of life. Society benefits...
from increased productivity, decreased health and social care costs, and decreased criminal behaviour.

**Are specially adapted psychological treatments important?**
Pills do not build skills! People often need further help to develop and apply helpful coping strategies, even when they have benefitted from medication. It is also important to consider the needs of people who are unable to take or do not wish to take medication.

People with ADHD and/or ASD grow up with difficulties that affect their family life, schooling and social relationships. In adulthood, they may suffer the ‘hangover’ effect of this, leading to worsening occupational, relationship, mental health and behavioural problems. Left untreated the consequences can be far-reaching for the individual, families and wider society.

**ASD**
Comorbid mental health difficulties are very common in people with ASDs.

NICE guidelines state that specially adapted psychological treatments should be available for people with autism.

Examples of appropriate adaptations include:

- An ‘autism aware’ communication style;
- A focus on emotion recognition work;
- Motivational interviewing techniques particularly around ideas of change, with concrete examples;
- Use of handouts and visual information
- A ‘hands on’ approach.

Currently, adapted treatment is only rarely available within primary or generic secondary care mental health teams.

**ADHD**
NICE recommends a holistic approach to treating ADHD in adults. NICE says that cognitive behavioural therapy (CBT) should be available for people who:

- Choose not to have drug treatment;
- Have difficulty adhering to drug treatment;
- Have residual/remitting ADHD symptoms.

Adapted CBT for ADHD is important to address the core symptoms of ADHD as well as associated features such as low mood, anxiety, emotional regulation difficulties, relationship difficulties, and sleep problems.

**What about transition from childhood?**
Becoming an adult involves the need to negotiate difficult personal and social challenges for everyone. People with ASD and/or ADHD are likely to find this transition much more difficult. Unfortunately, they have to do this at the same time as they move from child services (who know them well) to adult services (which may not exist).

Happily, both ASD and ADHD are increasingly
recognised and treated during childhood. On the other hand, there are few services for affected adults, so those entering adulthood commonly experience a sudden withdrawal of treatment and support at a time of maximum vulnerability. This leads to:

- Poor educational/employment outcomes
- Poor social outcomes
- Increased carer burden, including depression and anxiety
- Increased use of A&E services
- Problems with the police and offending.

The personal and societal costs of failed transition are why the NICE ADHD guidelines (2008) recommend planned transition to adult services and a full adult assessment after transition. Likewise, the NICE guidelines for ASD in both children (2011) and adults (2012) emphasise the importance of smooth transition to adult services.

It is unlikely to be news to the reader that differences in the structure and funding of child and adult services serve to make the development of clinical pathways from childhood to adulthood extremely difficult. We have found that by working together, clinicians and commissioners can develop imaginative, needs-led solutions for the benefit to patients, carers and the local health economy.

Do inpatients with ASD need a specialist environment?

People with ASDs are much more likely than the general population to experience mental illness including anxiety disorders (such as obsessive compulsive disorder) and mood disorders. Occasionally, these may be very severe indeed. When severe mental health difficulties – whether due to autism or not - have been unresponsive to the best community treatments available, or are associated with unacceptable risk to self or others (including suicidal or criminal behaviour), inpatient treatment is necessary.

Acute inpatient mental health units are often highly unsettled and disturbed places. By definition, someone with an ASD has social and communication difficulties, is very likely to have difficulty tolerating change, and may be very sensitive to noise. As a result, their ability to cope is likely to be overwhelmed if they are admitted to a unit that is not able to take their autism into account. This means that admission to a unit that is not ‘autism-friendly’ runs the risk of making a person’s difficulties worse.

Another key advantage of an ‘autism-friendly’ unit is the specialist expertise that goes with it. Such expertise includes understanding how autism modifies mental illness and vice-versa, and how medical, psychological and social treatments should be adapted for people with autism. Knowledge of what community resources can be co-opted to help maintain the person in the community on discharge is also essential.

Sometimes people with ASD make social errors that get them into trouble, including with the police and with the courts (such as internet offending or stalking). If sufficiently serious to require admission to hospital, specialist expertise is likely to be required to understand the reasons for the behaviour, design appropriate treatments, assess the risk of future offending, and advise on the intensity of future supervision.

Reference
3 Faraone SV et al. Psychol Med 2006;36:159-65
4 Young S, Murphy CM, Coghill D. Avoiding the ‘twilight zone’: Recommendations for the transition of services from adolescence to adulthood for young people with ADHD. BMC Psychiatry. 2011 Nov 3;11:174.
Introduction
The South London and Maudsley NHS Foundation Trust dates back to the building of the Bethlem Royal Hospital in 1247. We are the oldest psychiatric institution in the world. We have over 20 years of experience in the development and delivery of evidence-based diagnostic and treatment interventions for adults with ASD and ADHD.

Our internationally renowned multidisciplinary team includes psychiatrists, geneticists, psychologists and nurses. We hold the world’s biggest grants for research into autism. We are proud that we won the NHS Innovation of the Year Award for a new brain imaging autism diagnostic technique.

We use evidence-based approaches to diagnosis and treatment, and person-centred approaches to treatment. This means that resources go where they should, and that we help patients to improve their coping skills and daily living abilities according to individual need. We are determined to work closely with families and local teams to support patients in their local communities.

We have found the models of ADHD and/or ASD service provision described below effective in meeting the needs of both adults and those in transition to adult services.

1 National Services
These services for adults with ADHD and/or ASD cater for:
a) People from areas in which there is no bespoke service provision, and
b) People with complex conditions or a significant risk history.

Recently, communications technology has become advanced enough to allow secure assessments and psychiatric or psychological consultations by ‘telemedicine’ (this is like ‘Skype’). This is particularly useful for people who live in remote areas, though it is likely to be used increasingly by those who have difficulty with or prefer not to travel.

2 Local Services
These services for adults with ADHD and/or ASD are easily accessible to local populations and include those provided to our neighbouring boroughs (Lambeth, Southwark, Lewisham and Croydon) and further afield (for example, in Kent). In addition, we have recently begun to provide neurodevelopmental services to local specialist populations (for example, Wandsworth Prison).

In addition, we provide clinical and service-related training opportunities via our collaboration with the Department of Forensic and Neurodevelopmental Science at the Institute of Psychiatry.

1 National services
National Autism Unit
The National Autism Unit (NAU) provides specialist inpatient and daycare assessment and treatment for men with ASD and:
- Severe treatment-resistant mental illness
- Behaviour that severely restricts social integration
- Forensic behaviour (including internet crime and serious sexual and physical assault).

The NAU is an autism-aware and autism-friendly environment designed to:
- Provide an ideal recovery environment
- Make the most of a person’s own coping abilities
Provide national and international expertise in the management of ASD and comorbidity.

The NAU provides evidenced-based treatments including a range of skill-building packages to develop life skills, promote independence and allow maximum function in the community. This includes:

- 24 hour psychologically informed care from CBT-trained nurses
- Autism-adapted CBT treatments for mental health difficulties
- World-leading psychopharmacological management
- Improving physical health
- An 'autism-friendly’ environment
- An insistence on maximum autonomy and community integration.

**Adult ADHD Clinic**

Since the inception of SLaM’s adult ADHD Clinic in the early 1990s, we have developed a specialist service providing diagnostic ADHD assessment and treatment for over 3000 people across the UK. The clinic undertakes over 50 assessments each month, with a follow-up and medication management caseload of between 350 and 400 patients. This allows us to provide a unique, accomplished service in an area where there is currently little clinical experience or service provision in the NHS.

We have developed innovative and effective psychoeducation workshops and individual CBT specifically adapted for people with ADHD and contributed to published guidelines about ADHD and transition to adult services. Pilot data from our service shows that CBT can reduce both ADHD symptoms and associated impairment (see figures 1 and 2). We are carrying out the UK’s first randomised controlled trial of our most recent CBT intervention and the results will be published soon.  

**Autism Assessment and Behavioural Genetics Clinic**

This truly pioneering service started in the 1990s and offers a one-stop appointment which
includes specialist diagnostic assessment and feedback on the day.

Our evidence-based services provide assessment and treatment for people with:
- Suspected or diagnosed ASD
- ASD and additional mental health problems, including obsessive compulsive disorder, psychosis, depression and anxiety
- Suspected chromosomal abnormalities or single gene disorders, including 22q deletion and fragile X syndrome.

Our expertise includes assessment and management of ASD in women who may have subtle differences in presentation compared to men. The clinics also provide follow up and medication management advice and clinical genetics reviews.

Our autism-adapted evidence-based psychological treatment programme includes education, CBT, social skills training, and anger management techniques to help patients improve their coping skills and daily living abilities. Our research has shown that adapted CBT is effective for people with ASD and anxiety including obsessive compulsive behaviour.

Critically, we work closely with families and local teams to support patients in their local communities. We have changed our referral pathway to ease access for patients and professionals, including on-line referral forms for GPs and local consultant.

2 Local services
Both ADHD and ASD are common conditions,
so services for people affected by them should be delivered locally. In addition, local people should benefit from national and international expertise. We provide medical, nursing and psychological services to:

The London boroughs of Lambeth, Southwark, Lewisham and Croydon

Increasing recognition of local need has appropriately seen greater emphasis on the provision of diagnostic and treatment services for people with ASD and ADHD, and we are now in a position to provide efficient high quality services to our local boroughs.

There is ready access to our services by primary care physicians – and this yields huge benefits in efficiency and the prevention of unnecessary health and social care costs. This model of service provision benefits patients, carers, the general population (for example, by reducing recidivism in people with ADHD) and the local health and social economy.

East & Coastal Kent

We also provide local assessment and treatment services for adults in East Kent. We work from a local health centre to deliver:

a) Adult ADHD diagnostic assessment,
b) Follow-up services, and
c) Screening for associated co-morbidity.

The service is accessed from primary care and is available to adults who are

• Presenting for the first time for ADHD assessment, or who were
• Diagnosed with ADHD as children or young adults but who are no longer under the care of children’s’ services.

In addition, we provide a transition service for young adults diagnosed and treated for ADHD in childhood. These young adults may be

• Stable on medication and require monitoring
• Stable on medication but have comorbid problems that require additional drug and/or psychological treatments
• Unstable on their current treatment and needing assessment.

We have worked hard to keep prescribing local – and include a local GP who has a special interest in neurodevelopmental disorder in our team.

This model has proven popular with patients, clinicians and commissioners, so we are keen to expand it into other areas.

Her Majesty’s Prison, Wandsworth

ADHD is associated with impulsivity and offending behaviour, so it is no surprise that it is very common in prisoners. Ironically, this means that a prison is the ideal place to detect people who may benefit from assessment and treatment for ADHD. If successful, such treatment is likely to decrease rates of offending behaviour in a very high-risk group, as well as improve the offender’s life chances. We are developing other prison services and hope that this will give rise to important benefits for both society and the individual.

References

2 Young S, Murphy CM, Coghill D. Avoiding the ‘twilight zone’: Recommendations for the transition of services from adolescence to adulthood for young people with ADHD. BMC Psychiatry. 2011 Nov 3;11:174.
Training and teaching

Training and Education
We are part of King’s Health Partners Academic Health Science Centre. As such, we have a responsibility to bring together clinical excellence, translational research and high-quality training. We collaborate closely with a number of international partners to ensure that we deliver the best care possible.

We provide a range of high-level postgraduate programmes that include diplomas, masters’ programmes and PhDs in various aspects of neurodevelopmental (including ADHD and ASD) and forensic subject-matter. These are accredited via King’s College, London.

We provide bespoke clinical supervision for psychologists from other trusts and training opportunities to visiting doctors and mental health professionals.

Via the Department of Forensic and Neurodevelopmental Sciences, the Estia Centre and Maudsley International we have a long history of providing tailored evidence-based training and development programmes across a wide range of social, health and educational settings.

Research
Our research programme is tightly integrated with clinical practise. Our aims are to:
I Develop new diagnostic and treatment response prediction techniques
II Develop new methods of early intervention and prevention
III Discover and test new psychological and pharmacological treatments.

Our successes include a number of landmark developments and discoveries. Examples include:
1 Developing MR brain imaging to assist diagnosis of ASD. This is now in trial in our clinic.
2 Using MRI to show that reducing brain serotonin restores more typical patterns of brain activity in people with ASD. Brain serotonin is modified by antidepressant drugs like SSRIs, so we are investigating how SSRIs can be used to improve the treatment of people with ASD and anxiety/depression.
3 Using brain imaging to show that the balance between two brain chemicals (excitatory glutamate and inhibitory GABA) may be abnormal in people with ASD. We are now investigating the use of existing drugs which act on this system to see if symptoms can be treated.
4 Careful genetic screening of patients has led to the discovery of genes potentially linked to ASD. This has allowed us to establish the UK’s first Psychiatric Genetics Clinic. This service provides a comprehensive medical genetics assessment to people with ASD caused by genetic alterations.

Other than the above, our team is involved in researching:
• Other aspects of brain development and ageing
• The impact of ASD on society
• Sex differences in developmental disorders
• Genetics in neurodevelopmental
disorders (such as chromosomal deletions and insertions)
• Service development including pathways from children’s to adult services
• The development of evidence-based psychological treatments for ASD and ADHD
• Medical education, including distance learning.

Research that benefits patient and their families is a cornerstone of our service. The synthesis of clinical delivery and research makes sure that our patients are always the first to benefit.

Our Clinical Team
Our team includes national and international experts specialises in adult, child, neurodevelopmental and forensic psychiatry and psychology. We are:
• **Dr Sarah Blainey** Clinical Psychologist
• **Dr Michael Craig** Senior Lecturer, Institute of Psychiatry, Consultant Psychiatrist
• **Dr Quinton Deeley** Senior Lecturer, Institute of Psychiatry, Consultant Psychiatrist
• **Dr Antonia Dittner** Senior Clinical Psychologist
• **Thembani Dube** Clinical Nurse Specialist
• **Dr Neil Hammond** Consultant Clinical Psychologist
• **Christine Hutchings** Clinical Nurse Specialist
• **Dr Grainne McAlonan** Senior Lecturer, Institute of Psychiatry, Clinical Academic Group Head of Research, and Honorary Psychiatrist
• **Dr Stefanos Maltezos** Consultant Psychiatrist and Honorary Senior Lecturer
• **Dr Clodagh Murphy** Consultant Psychiatrist and Honorary Senior Lecturer
• **Professor Declan Murphy** Head of the Department of Forensic and Neurodevelopmental Sciences at the Institute of Psychiatry, King’s College London, Honorary Consultant Psychiatrist
• **Dr Chris Ohlsen** Staff Grade Psychiatrist
• **Mark Pitts** Clinical Nurse Specialist
• **Dr Dene Robertson** Honorary Senior Lecturer, Consultant Psychiatrist and Clinical Lead for Neurodevelopmental Disorders

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**The CBT I’ve had has really helped me... understand a bit about what’s happening and also taught me tools to deal with the thoughts**

*Patient*

• Dr Susie Whitwell Consultant Psychiatrist, Honorary Senior Lecturer and Head of Education and Training.

**Patient stories from the ADHD Clinic**

**Male aged 40:**
As an adult with a late diagnosis of ADHD I came to understand I had developed a range of...negative views of myself and my capabilities. By committing to the individual course of CBT offered and personably delivered by [my clinical psychologist], I learnt to understand where the roots of my [problems] lay...and...we were able to collaborate in developing strategies to meet my individual issues. The programme of therapy...exceeded my expectations. It has altered the pattern of my thinking and provided a blueprint for change and the skills to manage this challenging condition.

**Male aged 65**
After some initial doubts about the workshop I found it to be an exceptionally enlightening experience. The workshop was professionally run, and from the first session the team running it outlined what was going to happen in a clear easy to understand way. The CBT sessions have helped me with my planning and organisational skills, and strategies to cope with the negative sides of ADHD, and to realise the positive side...
The workshop and CBT sessions has given me a clear understanding of my ADHD related problems of the past, and more importantly workable strategies to use in the present, and help plan for my future.

**Male in his 60s**

The process is smooth and sophisticated.

At the Sittingbourne clinic, I had to pass a battery of tests to assess whether I was ADHD... Having ‘passed’, I worked with a specialist GP to try pills of widely various dosages and periods. It was truly fascinating to feel and report the changes – I felt as if I was in a partnership.

Finally I settled into a routine, my main long lasting pills (8-12 hours) transform my day and shorter lasting ones I take for an event in the evening for which taking pills would be worthwhile. The daytime pills have no side effects for me: only massive benefits that bring me pleasure and enjoyable achievement where there used to be stress, but evening pills can cause sleep problems for me so I use them sparingly.
### List of high impact publications in order of publication date

<table>
<thead>
<tr>
<th>Publication</th>
<th>Journal</th>
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<tbody>
<tr>
<td>Christakou A et al. (2012). Disorder-specific functional abnormalities during sustained attention in youth with Attention Deficit Hyperactivity Disorder (ADHD) and with Autism</td>
<td>Molecular Psychiatry</td>
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<tr>
<td>Sarkar S, Craig MC, Catani M, Dell’ Acqua F, Fahy T, Deeley Q, Murphy DGM (Feb 2013). Front temporal white-matter microstructural abnormalities in adolescents with conduct disorder: a diffusion tensor imaging study.</td>
<td>Psychological Medicine</td>
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### Books
Pavilion Publishers
We offer over 20 years of experience in the management of adults with complex autism spectrum disorders, co-morbid mental health difficulties and offending or challenging behaviour. We provide in-depth assessments and effective, evidence-based, patient centred treatments.

Our team includes highly skilled, multi-professional senior clinicians and internationally renowned academics, working together to translate cutting edge research into best clinical practice.

We are committed to facilitating rapid recovery, and assist our patients in the transition towards less restrictive community settings.

**Referrals**
We welcome referrals from consultant psychiatrists based across the UK. If you would like further information about our service, please contact us on 020 3228 4183 or email naureferrals@slam.nhs.uk

**Referrals can be made to:**
Dr Michael Craig  
Dr Quinton Deeley  
Haddy Quist (Team Leader)

**National Autism Unit**  
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