

Setting up Adult ADHD Service in the United Kingdom

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Abstract

A high proportion of children with ADHD, around 70-80%, continue to have this condition into adulthood and the rate of comorbidity is high. The NICE (2008) guideline on attention deficit hyperactivity disorder (ADHD) recommends the development of services and/or clinics specialised in the treatment of adults with ADHD. This is a challenging endeavour in times of austerity measures. We illustrate how existing and recently started adult ADHD clinics/services can be used as models for new service development projects in the United Kingdom.

Introduction

Adult ADHD is a significant and relatively common psychiatric disorder with prevalence rates of 2-4% (1). It carries high social and economic costs for the individual and the society.

ADHD was originally thought to be a developmental disorder that resolved by late adolescence/early adulthood. However, studies, some dating back to 1960s, have consistently shown that up to 70-80%

of those diagnosed with ADHD as children continue to present with symptoms of ADHD into their adulthood (2) (also see paper by Kooij in this issue).

As is common in children with ADHD, up to 80% of adults with ADHD have psychiatric co-morbidity. Personality disorder, depression and anxiety disorder, alcohol and drug misuse are some of the common co-morbidities. Additionally, they have difficulties with poor self-esteem, anger outbursts, poor organisation and time management, mood dysregulation and sleep (3).

Untreated ADHD has serious consequences in the form of poor academic and work related outcomes, family and relationship problems and increased involvement with the criminal justice system (2,4).

Adult ADHD is still under-recognised and a number of factors have contributed towards this, including stigma in the general population and among professionals due to negative propaganda and misperception about the diagnostic validity and its treatment. Lack of awareness and training often leads to ADHD being mistaken for other common mental health problems (2).

The NICE (2008) (5) guideline was a major step forward in giving adult ADHD the recognition it deserves and set out clear standards regarding the need for services for adults with ADHD and how to set up such services. Despite this guideline, there are only a few established services available in the country. On a positive note, there is much activity taking place in many areas to develop new services.

Adults with ADHD fall into three broad groups: First, those who can be described as transition patients, i.e. being transferred from children's services (CAMHS and Community Paediatric Services). Second, those who were known to childhood services but dropped out of follow up, either due to lack of transition/adult services or non-compliance with treatment (6). These patients are now returning to adult mental health services via primary care or other agencies. Third, there are patients who are presenting for the first time for an ADHD assessment (7).

Because of a variety of factors, adults with ADHD continue to experience difficulties in accessing appropriate services in most parts of the country. This situation persists despite NICE recommendations suggesting that if there were services developed they should be able to provide, as a minimum, a diagnostic service, psychological support and a drug monitoring service (8).

The NICE guideline makes clear recommendations for assessment and management of ADHD in all age groups, from children to adults. The guideline recommends two service models: a generic service model in which general adult psychiatrists diagnose and manage patients (within secondary care) and a specialist neurodevelopmental model, described as tertiary care model which delivers care to adults with ADHD.

Current state of adult ADHD services in UK

Despite NICE recommendations, there appears to be great variation in the availability of treatment and services for adults with ADHD throughout the UK.

A limited number of adult ADHD services have been established and they operate with different arrangements for funding and with different service models. Information on the following representative services was obtained from lead clinicians, published and internet sources.

The South London and Maudsley (SLAM) National Adult ADHD Service (tertiary service) was the first adult ADHD clinic in the UK and has been operating for more than 15 years. This clinic is an internationally recognised research and training centre. The National Adult ADHD Service provides comprehensive multidisciplinary assessment for ADHD in adults. Referrals are received from various sources, locally and nationally, from within the NHS and externally. After confirmation of the diagnosis, treatment recommendations are made to the referring organisation and supervision of treatment initiation and monitoring can be provided but needs to be funded by the referring team. The Avon and Wiltshire Mental Health Partnership NHS Trust adult ADHD service (tertiary service)

was established in 2007 and covers all Bristol areas. Referrals are accepted from other areas on a spot purchase basis. It provides follow up for a period of six months or maximum one year.

The South West Yorkshire Mental Health NHS Trust (tertiary service) established a specialist adult ADHD service in April 2009, which provides a comprehensive service with a well-staffed multidisciplinary team led by a consultant psychiatrist. This service also receives referrals for funded patients from the Midlands.

The Sheffield Adult ADHD service (generic/secondary care service) is one of the first adult ADHD clinics integrated into general adult mental health services. There is an exemplary shared-care protocol, where medication is initiated in secondary care and GPs continue the prescribing once the patient's condition is stable (8).

The Leicester Adult ADHD service offers a combined model (secondary and tertiary service). This service has been operating since 2002, initially as a special interest clinic and since January 2009 as a commissioned service. The model is based on joint work between a specialist ADHD clinic and generic general adult psychiatry team. The generic psychiatry team carries out the initial screening assessment, and all care needs including CMHT support and co-morbidities are assessed and treated by the generic psychiatry team. The adult ADHD clinic carries out the ADHD assessment and, when necessary, initiates and stabilises the treatment. Stabilized patients are gradually transferred back to their generic psychiatry teams. At a later stage, when the patients have been stable for a period, and have no unmet needs, they are discharged back to the primary care with the provision of yearly review as per the NICE guideline. Once the treatment has been stabilised, prescribing is taken over by primary care in keeping with the agreed shared-care protocol. The aim of the service model is that once appropriate training has been completed, all general adult psychiatrists will be able to carry out initial assessments and initiate and monitor treatment. The ADHD clinic will then function as a second opinion service to deal with complex cases.

The Adult ADHD Research Clinic (tertiary service) in Cambridge was funded in 2000 and has a strong academic background. This clinic is a joint venture between the Department of Psychiatry, University of Cambridge, and the regional mental health trust, Cambridgeshire & Peterborough NHS Foundation Trust (CPFT). The clinic has provided diagnostic assessments and treatment recommendations for more than 500 patients from Cambridgeshire and the rest of East Anglia. A number of senior trainees and consultants who were supervised in this clinic have opened new adult ADHD clinics in the region. Future NHS-funding of the service provided by the Adult ADHD Research Clinic in Cambridge is being negotiated.

The Lothian Adult ADHD service based at Royal Edinburgh hospital is Scotland's first service that provides diagnostic assessments and treatments for adults with ADHD. Individuals are usually referred by their GPs or their psychiatrists and although referrals from outside Lothian area are considered, the service is primarily aimed for those in the Lothian regions.

A number of mental health trusts throughout the UK are either in the process of or are planning to establish services for adults with ADHD, including in Bedford, South Essex Partnership University NHS Foundation Trust (SEPT), through the effort of lead author (RZ).

Why do we need specialist adult ADHD services?

ADHD is one of the most common psychiatric disorders in children. As already stated, in the majority of cases the condition does not disappear on reaching adulthood and continues to cause impairment. It is important to recognise that the manifestation of many classical symptoms of childhood ADHD is altered by biological, emotional, cognitive and social changes of adulthood. In adults with ADHD, there appears to be a more prominent deficit in executive functions and self-regulation of affect, but less obvious impulsivity and hyperactivity, although the latter can be often experienced as internal restlessness.

Although the number of symptoms and their severity often reduces with age, the overall impact on psychosocial functioning can be greater due to a different set of demands faced by adults. Individuals with ADHD often face educational and occupational failures. They are more likely to misuse alcohol and suffer from substance use disorders, display antisocial and criminal behaviour and indeed face emotional and relationship difficulties. Adults with ADHD often have comorbid conditions, which include, anxiety, depression, bipolar disorder, personality disorders and other neurodevelopmental disorders, as well as, generalized and specific learning disabilities (9,2).

The current state of knowledge suggests that adult ADHD is a common psychiatric disorder with significant morbidity and co-morbidity. There are large unmet needs that are currently not being addressed by primary care and secondary mental health services. This unsatisfactory situation is improving only slowly in the current financial climate. The UK Adult ADHD Network (www.ADHD.org) has made significant contributions towards awareness, training and support of the development of services.

Effective management of adult ADHD not only requires specialised pharmacological treatment, but also non-pharmacological treatments, which include, CBT, psycho-education, counselling and other psychosocial interventions (10) (see table 1).

Table 1. Psychosocial interventions in adults with ADHD address

- Low self esteem
- Poor anger management
- Poor social and communication skills
- Time management
- Organising, or planning activities
- Relationship difficulties
- Work/vocational difficulties

Setting up a service for adults with ADHD

Setting up a dedicated service for adults with ADHD within the NHS has many challenges. There are a number of factors that would need to be considered when planning to develop a new service (see table 2).

Table 2. Preconditions for local / regional adult ADHD service development project in the UK:

- Willingness on part of health authority, Primary Care Trusts/Care Commissioning Groups, NHS mental health trusts and clinicians to recognise this unmet need/gap in service delivery and be willing to address it.

Essential decisions and requirements:

- Diversion of existing or identification of new funds
- Agreement on service model that meets local/regional needs
- Training of clinicians (psychiatrists, GPs, nurses, pharmacists etc.)

Key requirements:

- Development of care pathways
- Transition agreements
- Shared care agreement with general psychiatry and other sub-specialities
- Shared care protocols with primary care
- Peer supervision arrangements
- Clinical governance

What would be the benefits of establishing a local, NHS-funded, adult ADHD service?

As discussed above, adults with ADHD often present with co-morbid psychiatric conditions. A local NHS-funded service would be best geared to address the needs of these patients. Close links with a variety of regional agencies and stakeholders within the NHS and externally are essential. At times, patients with complex needs, during transition from children services to adult mental health services, require joint working which will be more easily achieved within a local pathway. Additionally, a local service with robust transition arrangements will help reduce the likelihood of poor transition outcomes, which remain a concern (11). New patients and their families (who provide valuable information on developmental history) will find it easier to access local services. Additionally, local services will have better access to and liaison with other local NHS services, law-enforcement agencies, prison services and voluntary agencies. It will be easier for local services to negotiate shared care arrangements with all agencies/departments involved.

Overall, a local and NHS funded Adult ADHD service is likely to play a more effective role in better diagnosis and management of adults with ADHD. It will allow continuity of care during transition (from childhood to adulthood and from secondary to primary care) and aid quicker recovery, improve morbidity; it is likely to reduce the social and economic burden on individuals and local populations that it aims to serve.

GP Comment.

What Have I learned from this paper?

1. The NICE ADHD guideline recommends service for adults with ADHD but the availability of such services in the UK is currently very patchy.

2. A well-organised adult ADHD service could greatly facilitate the coordinated care of patients.
3. Because 70-80% of children with ADHD continue to have this condition into adulthood, with a high rate of psychiatric comorbidity, the provision of adult ADHD services is an important issue.
4. Reading this paper raised several issues for me as a GP, including the following.
 - How many cases of adult ADHD go unrecognised?
 - What training is needed in primary care to enable us to recognise and assist such patients?
 - Where should we refer such patients for secondary care?
 - What would be the best model for a locality service – should each district have a separate centre or should there be a “hub-and-spoke” model with links to a centre of excellence?
 - What would be the best way of coordinating the adult services with the child and adolescent services for ADHD and how should education/probation and prison services be involved?

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