Attention Deficit and Hyperkinetic Disorders

Services Over Scotland

Final Report

November 2012
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Acknowledgements

In 2006, Healthcare Improvement Scotland (then NHS Quality Improvement Scotland) embarked on the Attention Deficit and Hyperkinetic Disorders – Services Over Scotland (ADHD-SOS) project, a programme of work to look at services for children and young people with ADHD. During the following 6 years, children and young people with ADHD, parents/carers, and service providers from across Scotland have helped us to understand:

• how many children and young people in Scotland are diagnosed with ADHD
• what services are in place for them
• how those services are organised and delivered
• where service development is required, and
• perhaps, most importantly, what it is like to use services, and what might improve the experience for children and young people, and their parents/carers.

We gratefully acknowledge the time and effort that have been invested by everyone involved with the various stages of this project. These stages have culminated in this report, the fourth in a series. Publication of this report concludes our current programme of scrutiny and assurance work on ADHD.

We are particularly grateful to Dr Fiona Forbes who chaired the ADHD-SOS steering groups and who, since September 2008, has also been Child and Adolescent Mental Health Clinical Advisor to Healthcare Improvement Scotland. We would also like to record our gratitude to all those who contributed to the steering groups which included parents/carers, young people, health professionals, and colleagues from social services, education, Her Majesty’s Inspectorate of Education (now Education Scotland) and the Scottish Government.

Similarly invaluable, was the input of Fiona Thomson and Ruth Thomson – joint chairs of the user and parent/carer sub-group – and Grace Mitchell, a young woman with ADHD who sat on this group. They made sure that we involved and captured the voices of children, young people and their parents/carers.

John Duffy, the independent statistician who advised on, and supported, the statistical analysis of the 2007–2008 implementation review data was a key part of the team. We extend our thanks to John.

Finally, we would like to thank all the staff from NHSScotland and partner agencies, who provided us with information, and met with us to help us understand ADHD services better.
Executive summary

The challenge

Healthcare Improvement Scotland has produced over 200 publications that provide evidence-based advice and guidelines on a wide range of health conditions. These publications summarise and present the evidence of best practice in a way that supports implementation and informs the development of local and national services. In the past, we have relied on NHS boards and partner organisations to implement guidelines locally in order to improve services. We have carried out selective reviews to test the effectiveness of this. We know now that publishing guidance does not guarantee successful implementation, in part or in full. The challenge is to develop approaches that combine evidence, implementation support and assurance.

One of our very early programmes of work, where we started to use such an approach, was child and adolescent mental health. We used ADHD as a tracer condition. We decided to look at ADHD because:

- it is a common reason why children and young people seek help from health services, and
- there had been a lot of publicity about prescribing practice related to the condition.

Variation in access to, and the quality of services for children, young people and their families living with ADHD had also been highlighted. We set out to determine whether the care and treatment for this group of children and young people was being delivered in line with evidence-based best practice.

What is ADHD?

ADHD is one of the most commonly diagnosed neurodevelopmental disorders in children and young people. The core features are persistent (at least 6 months’ duration) and developmentally inappropriate levels of inattention and hyperactivity, often with impulsive behaviour, with onset before the age of 6 years. These symptoms can present either individually, or in combination.

Children with ADHD are at increased risk of low self-esteem, academic underachievement, poor peer relationships, disrupted family relationships, accidents and anti-social behaviour. They may also be at increased risk of later substance misuse. ADHD is associated with an increased risk of other disorders including depression and anxiety. Sleep problems are also common.

ADHD is a long term condition and early diagnosis and appropriate intervention, with the development and implementation of a long term management plan, is crucial.
How common is it?
Studies indicate that worldwide prevalence rates for ADHD are about 5% of school age children. In Scotland, this means around 37,000 children and young people may be affected and need access to support and services. Prevalence of the most severe form of ADHD, hyperkinetic disorder, is about 1.5% which equates to about 11,000 children in Scotland. There is also an emerging awareness of the continuation of ADHD difficulties into adulthood. It is estimated that up to two thirds of children and young people affected by hyperactivity will continue to experience problems.

We know from our previous work that there are an estimated 4,539 Scottish children and young people with a diagnosis of ADHD in contact with specialist services: child and adolescent mental health services (CAMHS) and paediatric services. These data, when compared with epidemiological estimates, suggest that ADHD is under-recognised in the Scottish school-aged population.

What does the evidence say is effective?
Scottish Intercollegiate Guidelines Network (SIGN) Guideline 112 – Management of Attention Deficit and Hyperkinetic Disorders in Children and Young People recommends the following.

- Comprehensive specialist assessment to inform diagnosis. This should include information from the child or young person, their family and their school.
- Implementation of an appropriate package of care, which commonly includes:
  - behavioural parent training for parents of pre-school children with symptoms of ADHD
  - a combination of medication, and behavioural treatments for school-aged children with comorbid behavioural and/or generalised anxiety disorders, and
  - medication for school-aged children with hyperkinetic disorder (severe ADHD).
- Routine follow-up and monitoring.

What we did
We delivered our ADHD-SOS project in three stages.

Stage 1 – Service profiling (2006–2007):
a review of information about the configuration and delivery of services for children and young people with ADHD. This included visits to every NHS board area and meetings with people involved with ADHD services.

data collection based on the recommendations in SIGN Guideline 52, validated by randomised case note review. The views of service users and their parents/carers was a critical element of this stage of our work. We carried out the first Scotland-wide online survey to find out what children and young people with ADHD and their parents/carers thought about the care and treatment they receive.

Stage 3 – Follow-up review (2011–2012):
we revisited every NHS board to review progress against the recommendations made in our implementation review report (2008). NHS boards completed a self-assessment and we organised regional feedback and discussion events to allow networking and sharing of information, current research and good practice.

We explain these stages in more detail on pages 8 and 9.

This was a unique programme of work carried out over a 6-year period. All of our work was supported by a project team, which included our CAMHS clinical advisor. The successful involvement of children, young people and their families and strong clinical and partner agency engagement in our work was fundamental to the success of this programme, and the quality of the information collected and reported. The programme also evolved over time in response to our findings. As we built up a picture of services across Scotland, and identified some of the challenges faced by those using and providing services, we set up three complementary and supportive projects:

- SIGN Guideline 52 selective update
- development of Standards for Integrated Care Pathways for Child and Adolescent Mental Health Services, and
- the ACHIEVE pathway modelling project.

Based on General Register Office for Scotland (GROS) mid 2011 population estimates for children and young people in Scotland aged 4-16.

SIGN Guideline 52 - Management of Attention Deficit and Hyperkinetic Disorders in Children and Young People has since been selectively updated and was republished as SIGN Guideline 112 in 2009.
What we found

In summary, at each stage of the project we found that:

• the diagnostic rate for ADHD in school-aged children in Scotland falls far short of what we would expect
• once referred, most children and young people are being assessed, treated, monitored and followed up appropriately
• the care and treatment provided by specialist services is good; the children, young people, and parents/carers whom we spoke with agreed that this was the case, and
• services in all NHS boards are already stretched to meet current demand, and would be further stretched if there is a significant increase in the number of children and young people diagnosed with ADHD.

Impact

This is a complex area of healthcare involving many services; this makes it difficult to assess the direct impact our work may have had. Reflecting on where we are now, compared with 2006, when we started this work, we are confident that all NHS boards:

• are raising awareness of ADHD and are identifying more children and young people with ADHD and referring them to specialist services
• are developing their services to make sure they provide a more more equitable and evidence-based service
• are working more effectively on integrating services; in particular they are forging stronger links with education, and
• have transition arrangements in place for young people moving on to adult services.

The map on page 30 highlights the innovative practice reported to us by NHS boards in Scotland.

Opportunities

There is no doubt that the ADHD landscape in Scotland is changing for the better, but there is still some way to go to make sure that all children, young people and adults with ADHD can easily access the support and services that they need. Our work forms a strong basis for going forward and for further improvement of ADHD services. In particular, consideration must be given to:

• improving systems for data collection to make sure that future service planning is based on accurate and complete information
• alternative methods of service delivery to meet increasing demand
• implementation of CAMHS integrated care pathways (ICPs)
• making sure that children and young people experiencing problems are referred early to specialist services, and
• developing capacity and capability within adult services.

As outlined more fully in our key messages and conclusions section, there is currently a strong national focus on child and adolescent mental health and NHSScotland is already working on a number of these priorities. The Scottish Government’s newly published Mental Health Strategy for Scotland 2012–2015 underpins this.
Background

In 2004, NHS Quality Improvement Scotland published the *Health Indicators Report – A Focus on Children*. This report detailed a marked increase in the prescribing of psychostimulant medications for children and young people with ADHD. Specifically, prescriptions dispensed for methylphenidate had increased from 69 prescriptions per 10,000 population to 603 per 10,000 population over a 7-year period (1996–2003). The report also showed variation in prescribing rates between NHS boards. This upward prescribing trend appears to have continued, with recent data from Information Services Division (ISD) showing that prescribing of drugs indicated for ADHD grew by 7.1% between 2010–2011 and 2011–2012. These latter data include the non-stimulant medication atomoxetine. Prescriptions dispensed to people over the age of 18 are also included in these statistics.

There were limitations to the 2004 health indicators report data. The number of individuals prescribed methylphenidate could not be identified because it was difficult to assign a defined daily dose. While it was also clear that the number of prescriptions was increasing, compared to epidemiological estimates of ADHD prevalence, in reality, the prescribing rate was lower than expected.

We initially set out to investigate:

- how ADHD services in Scotland are configured and delivered
- how many children and young people have a diagnosis of ADHD, and
- whether their care and treatment is delivered in line with the evidence-based national SIGN Guideline 52.

What we did in the ADHD–SOS project

Stage 1 – Service profiling 2006–2007

We developed a service profiling questionnaire and piloted it in two NHS board areas before sending it to all NHS board areas to complete. The questionnaire asked for information about how services for children and young people with ADHD are configured and delivered. Following the analysis of the returned information, small teams of stakeholders met with representatives from each NHS board area to talk about the responses and seek clarification on any gaps. The report of this work was published in March 2007.


We developed a data collection tool, based on the recommendations in SIGN Guideline 52. We then asked NHS boards to collate and submit an anonymised list of all active ADHD case files. We employed an independent statistician to advise NHS boards about randomisation and size of sample required.

We provided funding to each NHS board area to help them recruit an appropriate member of staff to undertake the case file review and data collection. The case file reviewers were also provided with comprehensive support to do this. All NHS boards input their anonymised case file data into a specially designed web-based data capture tool. These data were subsequently analysed by our independent statistician.

We shared a summary report of their returned data with each NHS board. Following this, small teams of stakeholders met with representatives from each NHS board area to talk about the data and seek clarification on any gaps. Each NHS board area received a local report of the implementation review findings, and we also published an overview report.
ADHD-project user and parent/carer subgroup (ADHD-PUPS): we knew that reviewing implementation of SIGN Guideline 52 would only give us part of the picture. It was important to find out what service users thought about their treatment and involvement with services. With this aim, we set up a steering group which was chaired by two parents and included young people with ADHD.

We developed an online questionnaire and promotional posters and flyers. We asked service providers, all primary and secondary schools in Scotland, third sector organisations and local ADHD support groups to display posters and flyers in relevant locations. We also asked clinicians to include a promotional flyer in their clinic appointment letters for the duration of the project.

To supplement the information from the questionnaires, we held a one-day conference in November 2007. Children and young people with ADHD and parents/carers from across Scotland gave us their views in facilitated focus group sessions. In 2008, we published the full report of this work.

Stage 3 – Follow-up review (2011–2012)

The implementation review exercise report included a number of recommendations. We committed to revisit each NHS board area and report our findings by the end of 2012. This was primarily to follow up on the recommendations, but also to revisit the national diagnostic rate (see page 12). We wanted to determine to what extent our recommendations have been implemented, and if they have improved services in Scotland for children and young people with ADHD. We were also keen to learn about local innovations (see page 30) and any challenges to service delivery and development.

Again, we gave NHS boards a data capture tool. This time, it was based on the recommendations made in the 2008 implementation review report. NHS boards completed and returned the data capture tool, and the data were analysed.

We used a different approach to meeting NHS boards. Rather than hold individual meetings, representatives were invited to attend one of three regional sessions in Glasgow, Aberdeen or Edinburgh or to participate by videoconference. We hoped that this would allow networking and sharing of successes and challenges with peers. Part of each regional session was dedicated to individual facilitated group discussions, with each NHS board area, about their returned data. At these sessions, we also shared information with NHS boards about:

- the ACHIEVE ADHD pathway modelling that we had commissioned (see other related work below for detail), and
- the current Scottish and international ADHD landscape.

We produced short local reports for each NHS board area. This final report draws together the Scottish picture and our detailed findings are outlined in the next chapter.

All the reports mentioned above can be downloaded from the ADHD section on our website (www.healthcareimprovementscotland.org/programmes/mental_health.aspx).
Other related work

A number of other child and adolescent mental health and ADHD-specific projects have been completed or are under way. These all complement the ADHD-SOS work programme.

SIGN guideline selective update (October 2009): SIGN set up a multidisciplinary group of practising service providers and parents/carers to review the treatment section of SIGN Guideline 52 and update as required. The selectively updated SIGN Guideline 112 was published in October 2009. This updated guideline reflects the most recent evidence on psychological and pharmacological interventions, as well as introducing sections on nutrition and complementary and alternative therapies. The guideline is available on the SIGN website (www.sign.ac.uk).

Standards for Integrated Care Pathways for Child and Adolescent Mental Health Services (June 2011): we published Standards for Integrated Care Pathways for Child and Adolescent Mental Health Services, and an associated online toolkit in June 2011. The standards have a strong quality improvement and person-centred focus. Delivery of care through ICPs contributes to continuous quality improvement, and will help NHS boards and partner agencies to consistently deliver care that is ‘person-centred, clinically effective and safe, for every person, all the time’. The ICP standards and toolkit are available on our website (www.healthcareimprovementscotland.org/programmes/mental_health.aspx).

The ACHIEVE pathway modelling project (October 2011): we commissioned Queen Margaret University, Edinburgh to lead on this work which captured the views and experiences of frontline staff, managers and parents/carers to inform:

- the review of existing ADHD pathways in a defined NHS board area, and
- development of new pathway models that would be easily transferable to other NHS board areas.

The ACHIEVE project was delivered using a partnership approach. The partnership included experts in child and family research, health professionals and management scientists. This work completed in October 2011 and was shared with delegates at our regional sessions. The associated pathways and resources are available on our ICP toolkit website (www.icptoolkit.org).

Proposal for an adult ADHD SIGN guideline: a proposal to develop a SIGN guideline for ADHD in adults was submitted to Healthcare Improvement Scotland in early 2012. The proposal is currently progressing through the Healthcare Improvement Scotland/SIGN topic selection process. This process appraises proposed topics for inclusion in the core work programme on the basis of:

- burden of disease
- the existence of variation in practice, and
- the potential to improve outcome.
Follow-up review findings

Diagnostic rate

The prevalence of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form (equivalent to hyperkinetic disorder) is approximately 1.5%\(^1\). At the time of the last review, we reported an administrative prevalence rate of approximately 0.6% of the school-aged population. The administrative prevalence reported previously was calculated using estimated ‘eligible’ data. We were able to estimate eligible cases as each NHS board had undertaken a sampling exercise. The data provided by NHS boards for the follow-up review represent total ‘reported’ cases. This time, we did not have sufficiently detailed data to allow the number of eligible cases to be estimated. To allow us to compare like with like, we have used reported data from the previous review. Based on this, the reported national diagnostic rate appears to have increased by 0.1%; this equates to an increase of approximately 750 children.

In 2012, for the first time, ISD has made ADHD prescribing data\(^9\) available by number of patients, age range and gender. These data indicate that 0.6% of the under-18 population in Scotland is being prescribed medication for ADHD. There will be additional children and young people accessing health services who are not receiving medication as part of their treatment plan.

Furthermore, the ISD data show that 1,338 people over the age of 18 were prescribed medications indicated for ADHD during 2011–2012. A proportion of these may be people who have been prescribed dexamfetamine sulphate which is licensed for the treatment of narcolepsy in the elderly. Approximately one tenth of these identified adults are aged over 65 years.

It is recognised that more boys than girls have ADHD. A recent systematic review and metaregression analysis\(^1\), found the worldwide male to female ratio to be just over 2:1. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1. Although most NHS boards reported an increase in the number of girls diagnosed with ADHD, our data suggest that the overall ratio has not changed since 2007–2008. The 2011–2012 ISD data\(^9\) indicate a male to female ratio of 4:1. However, these data only relate to children and young people who are receiving pharmacological treatment and are not reflective of the total population with a diagnosis of ADHD.

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\(^1\) Eligible cases were deemed as those with a diagnosis of ADHD in active contact with services. Ineligible cases included closed cases, for example families that had moved away from the NHS board area, and cases where a diagnosis had not yet been agreed.

\(^9\) Reported cases are the total number of active ADHD case files declared by each NHS board.
Figure 1 below shows that most NHS boards reported an increase in the number of children receiving treatment for ADHD since the previous data collection exercise in 2007. At the time of the follow-up review, the reported diagnostic rate ranged from 0.21–1.17%. However, it is still lower than we would expect to see.

Figure 1: Reported diagnostic rate (%) of ADHD in the under-18 population by NHS board and year

Findings against the key recommendations

The implementation review report\(^3\) published in 2008 identified a number of key recommendations. The following pages summarise what we found during the implementation review exercise in 2007–2008, and what we found during the follow-up review in 2011–2012. The recommendations are arranged under five headings:

- awareness raising and recognition
- non-pharmacological interventions
- outcomes
- transition, and
- systems, processes and skills.
1. Awareness raising and recognition

1.1 Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child/young person's difficulties.

Implementation review

This exercise identified the diagnostic rate of ADHD in school-aged children in Scotland to be approximately 0.6%. This is just over one tenth of the total children and young people with any form of ADHD, and less than half of that expected when compared with UK epidemiological prevalence estimates for hyperkinetic disorder, the most severe form of ADHD. This suggested that there are significant numbers of Scottish children living with ADHD, and the difficulties associated with it, who are not being recognised and referred for appropriate support and intervention.

Follow-up review

All NHS boards provided evidence of work to raise awareness and recognition of ADHD within health and education. This included providing training to colleagues in paediatrics, community child health, CAMHS and adult mental health services. There were also some joint training initiatives for colleagues in partner agencies, particularly in education. A number of NHS boards have also developed information for referrers.

NHS boards were also able to demonstrate increased interaction with social services through the development and implementation of their integrated children's services plans. However, NHS boards working with two or more local authorities reported that this could be a barrier to implementation, due to their differences in professional approach and service organisation. In general, NHS boards were less likely to have worked with third sector colleagues, although there were areas of good practice, particularly in the island NHS boards.

Despite this work, most NHS boards did not report a significant increase in the numbers of children and young people with a diagnosis of ADHD. Within NHSScotland, there was no reported increase in the ratio of girls diagnosed with ADHD when compared with boys.
1.2 Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

**Implementation review**

Children and young people with ADHD often underachieve academically. School-based behavioural and academic interventions are recommended. This review exercise showed us that not all children and young people with ADHD had both of these interventions in place, and some had neither.

**Follow-up review**

All NHS boards provided evidence of stronger links with colleagues in education at both local and strategic levels. In a few NHS boards, there are either nominated link workers in schools or ADHD liaison co-ordinators. *Getting it right for every child* (GIRFEC) processes have been widely adopted, but the benefits of this have not yet been demonstrated. NHS boards are working closely with children’s services and education to ensure that additional support for learning is in place where required.

1.3 Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

**Implementation review**

The review identified that there is a wide range of ADHD information packs used by NHS boards. These varied in terms of what information was included.

**Follow-up review**

Ten NHS boards had standard information packs that contained all the required information. A few NHS boards also provide information specifically for children and young people with ADHD. This information is usually available in hard copy, but some NHS boards provide links to local or national websites. Translations and easy read formats are available on request.

In some areas, the information packs have been developed locally. Others provide externally produced information, or a mixture of the two. Externally produced information used includes SIGN and National Institute for Health and Clinical Excellence (NICE) parent/carer leaflets and information from the Royal College of Psychiatrists, the Mental Health Foundation and the National Institute of Mental Health.

Only two NHS boards reported the involvement of children or young people in developing the information packs, while seven reported involving parents/carers.
2. Non-pharmacological interventions

2.1 Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

Implementation review

We reported that the majority (84%) of children and young people in Scotland with an ADHD diagnosis also had other behavioural difficulties. The SIGN guideline\(^5\) for ADHD recommends a multi-modal approach to ongoing management, which may include behavioural parent training. We noted that 76% of cases were receiving other interventions in addition to medication. However, often the behavioural parent training programmes available were generic in nature. Anecdotal evidence suggests that parenting programmes specifically for parents/carers of children with ADHD are more beneficial, as they allow parents/carers to benefit from peer support and focus on behaviour problems in the context of an ADHD diagnosis. We also found that, for a range of reasons, parents sometimes found it difficult to engage with the programmes.

Follow-up review

In five NHS boards, the group parenting programmes that are available are for parents of children with behavioural problems who may or may not also have ADHD. Due to the remote and rural nature of many NHS boards, ADHD parenting programmes may not be available in all areas, or there may be access issues due to programmes being held in centralised locations. For this reason, some NHS boards may offer one-to-one sessions as required. Programmes are delivered by a range of trained professionals including those in health, social work, education, youth justice and the third sector.

SIGN Guideline 112\(^4\) recommends behavioural parent training for parents of:

- pre-school children with symptoms of ADHD, and
- pre-adolescent children with symptoms of ADHD and comorbid conditions such as anxiety, oppositional defiant disorder and/or aggressive behaviour.

Again, anecdotal evidence suggests that parents of children with ADHD and other behavioural problems, prefer attending parenting groups with parents of children with a similar range of problems, including ADHD.

Most NHS boards reported:

- capacity issues, as programmes are time and resource intensive, and
- a lack of suitable venues.

A number of NHS boards also reported difficulties in establishing meaningful parental engagement.

We also asked NHS boards about their awareness of, and engagement with, local parent support groups. A few NHS boards reported engagement with local groups. NHS Fife staff told us that a social media site and network account, set up by a parent, has proved popular with parents/carers.
A professionally rated, validated tool is used to measure outcomes.
3. Outcomes

3.1 Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

**Implementation review**

This review indicated that the vast majority of children and young people receiving treatment for ADHD were being monitored and followed up appropriately. However, NHS boards rarely carried out systematic outcome evaluation.

**Follow-up review**

All NHS boards described how outcomes for children and young people are clinically assessed. In 10 NHS boards, outcomes are evaluated at least every 6 months, while in two NHS boards they are evaluated at least every year. However, less than half reported the routine and systematic evaluation of outcomes for children and young people. The reasons for this included a lack of resources (financial, staff, time and appropriate IT systems). Three NHS boards plan to audit outcome results during the course of the year, while another three will include routine evaluation when the care pathway is fully implemented.

The majority of NHS boards also described the local systems that are in place for more complex cases that do not respond to standard treatment options.
4. Transition

4.1 In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

**Implementation review**

We know that at least two thirds of children will continue to have ADHD symptoms through adolescence. For many, symptoms and functional impairment will persist into adulthood. The implementation review exercise indicated that 12% (560 cases) of the total number of children and young people receiving treatment for ADHD at that time were aged 15 years or over. We recognised the importance of robust systems to ensure a smooth transition from CAMHS or paediatric services to adult mental health services for those young people who continue to need support and treatment.

**Follow-up review**

At the time of this follow-up review, not all NHS boards had a formal transition protocol in place. Six NHS boards reported that a generic CAMHS transition protocol was either in place or was in development, and a few of these made specific reference to transition arrangements for young people with ADHD.

The NHS Borders protocol is a generic paediatric document that includes references to mental health services. No other NHS boards provided evidence of transition from paediatric to adult services. The protocols in use in Orkney, Shetland and the Western Isles reflect a multi-agency approach to transition. NHS Fife provides a weekly clinic for young people to help them prepare for transition, while in NHS Dumfries & Galloway, there is a dedicated transition worker. Two NHS boards provide a leaflet for young people moving onto adult mental health services. Two others reported specific transition protocols for young people with learning disabilities who may or may not have a comorbid diagnosis of ADHD.

In a few areas, individual clinicians may continue to provide care for patients after the formally agreed transition age and sometimes into the patient’s early twenties.
The workforce around the child or young person takes a consistent and structured approach to transitions and involves children, young people and their parents/carers, where appropriate, in planning at key transition points.
4.2 In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

Implementation review

It is now widely accepted that ADHD is not solely a disorder of childhood; rather, that a proportion of adults will continue to experience symptoms and will be functionally impaired. Recent epidemiological estimates give the average point prevalence of ADHD in the adult population as 3.5%\(^6\). The implementation review exercise recognised the potential impact and burden of these rates on adult services. This was both in terms of providing continuing care for young people with an existing diagnosis and service provision for previously undiagnosed cases.

Follow-up review

At the time of this review, all NHS boards were providing continuing care services for young people making the transition to adult mental health services. However, most service provision is dependent on general adult psychiatrists with a special interest in ADHD. There were no established dedicated adult ADHD services. Some NHS boards reported that shared care protocols are being developed with GPs for the prescribing of ADHD medications for adults. Seven NHS boards reported awareness of NICE Guideline 72\(^6\) that includes the diagnosis and management of ADHD in adults, and are referring to this as required. In NHS Greater Glasgow and Clyde, clinicians refer to the British Association for Psychopharmacology guidelines\(^7\). Two NHS boards reported using SIGN Guideline 112\(^4\) as the basis of their continuing care.

A few NHS boards reported regular training sessions on ADHD for colleagues in adult mental health. From April 2012, NHS Lothian will fund some multidisciplinary specialist sessions to provide consultation and training and to manage the most complex cases. NHS Lanarkshire has established a board-wide multidisciplinary ADHD steering group for child, adolescent and adult services.

The three island NHS boards reported no plans to introduce ADHD care pathways for adults. This was due to:

- the small numbers involved
- their awareness of the ongoing needs of the young people on their caseload who are approaching adulthood, and
- multi-agency involvement and support at the transition stage.

During the regional sessions, staff reported concerns that colleagues in adult mental health services may not recognise previously undiagnosed ADHD in adults. This could be due to a lack of knowledge around the condition, or a lack of belief that the condition persists into adulthood. Training and capacity issues within the adult mental health service workforce were identified as barriers to successful transition from CAMHS or paediatric services.
CAMHS ICP Standard statement 6

In each NHS board area, systems are in place to record and analyse the category of diagnostic or assessment information.
5. **Systems, processes and skills**

5.1 **Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.**

**Implementation review**

This review exercise gave us an estimate of the numbers of children and young people with a diagnosis of ADHD in Scotland. However, few NHS boards had robust, up-to-date systems in place to easily provide these data. It is fundamental to accurate future service planning that NHS boards can easily access data about the diagnosis of children and young people actively in contact with services.

**Follow-up review**

During the follow-up review, we found that few NHS boards had electronic systems that could easily and accurately provide this information. Some have electronic systems, but may lack the administrative resource to make sure that data are kept up to date.

Three NHS boards were unable to provide a complete breakdown by gender for all the children and young people on their caseload. This was due to a lack of administrative resource or a recent change in service organisation. Eight were unable to provide data for the number of children and young people with a comorbid diagnosis of learning disability.

NHS Highland was unable to provide us with complete data for the period under review.
5.2 **Implement a standardised proforma for assessment to improve clinical record-keeping, and**

5.3 **NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.**

**Implementation review**

We found that there was variation in the recording of assessment information in clinical notes. For example, it was not always apparent, in the case files reviewed, that the child/young person had been engaged in, and interviewed as part of the assessment process. NHS boards told us that this was probably due to this information not being recorded during the assessment process, rather than the child/young person actually not being involved.

All of the clinical staff that we met during the implementation review exercise reiterated that an assessment would never be undertaken without the child/young person being present and fully involved in the process. We recommended that a standardised proforma be implemented to:

- supplement the more detailed assessment information in the notes,
- and
- provide clarity that the key components of the assessment, as outlined in SIGN Guideline 52\(^1\), are covered for every child/young person, every time.

**Follow-up review**

Five NHS boards reported the use of a single standardised proforma to improve clinical record-keeping, while six others provided evidence of the protocols or operating guidelines that specify the information that should be routinely captured and recorded. Three NHS boards reported plans to introduce standard forms during 2012.

NHS boards described the variety of ways in which the child/young person’s engagement in the assessment process is captured. This could be through the use of a standardised proforma, GIRFEC\(^14\) processes, self-developed care plans, or as specified in the local care pathway or operating guidelines. However, only a few provided evidence of regular audit to make sure that key information is routinely captured.

A few NHS boards run assessment clinics with two clinicians to make sure the child/young person (and parent/carer) can be seen on their own for part of the appointment as appropriate.
CAMHS ICP standard statement 14

There is a record that children, young people and their parents/carers have been actively involved in the planning of their care.
5.4 **Ensure that there is a consistent approach to screening for psychiatric comorbidities and that all staff who undertake ADHD assessments have the necessary skills to do this.**

**Implementation review**

The findings showed us that when a child and adolescent psychiatrist was involved in the assessment process, it was more likely that screening for other psychiatric comorbidities was undertaken. We know that some children and young people are assessed and followed up by paediatric services only, and it is important that they receive the same screening as those in contact with CAMHS.

**Follow-up review**

In response to this recommendation, NHS boards referred mainly to their systems for continuing professional development and appraisal. The five NHS boards using a standard proforma for clinical assessment do include screening for psychiatric or non-psychiatric comorbidities. Others provided evidence of the protocols or operating guidelines that describe the approach to be taken.

5.5 **Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.**

**Implementation review**

In the implementation review exercise, NHS boards told us that information on the child/young person’s level of attainment in basic skill areas such as reading, spelling and number work would always be sought from their school as part of the assessment process. We noted variation between and within NHS boards as to the extent to which this information was returned to the assessing clinician.

**Follow-up review**

NHS boards reported a variety of ways in which this information is gathered. Most NHS boards use standard documents, including teacher questionnaires, to request this information. A few NHS boards reported routine classroom observations and/or face-to-face teacher interviews as part of the assessment process. Others may contact schools by phone. NHS boards did not report difficulties in obtaining this information from schools.
5.6 Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

**Implementation review**

We found that in nearly all (96%) of the cases reviewed, where psychostimulant medication was being used, it was initiated in an appropriate specialist setting. Similarly, starting dose, titration regimes and frequency of monitoring during the titration phase was appropriate for the majority. We recommended that NHS boards developed a formalised and agreed written initiation and titration protocol to support this.

**Follow-up review**

Nine NHS boards reported following national guidelines for the initiation and titration of medication. These include SIGN\(^4\), NICE\(^\text{16}\) and British National Formulary (BNF)\(^{18}\) guidelines.

At the time of this review, only NHS Tayside had implemented a board-wide written protocol. However, a number of NHS boards provided evidence of draft protocols or pathways that were due to be introduced during 2012–2013. NHS boards confirmed that the child or young person’s medication, blood pressure, pulse, height and weight are routinely monitored during clinical appointments. Most use a standard appointment document to check and record this information.

A few NHS boards provided evidence of the protocols in place for nurse prescribers. Others reported plans to introduce more nurse-led clinics, following recent changes to prescribing regulations.
Local innovative practice

During the self-assessment process we asked all NHS boards to tell us about examples of innovative practices that are making a difference to local services. The list below highlights some of these.

/01 Nurses in NHS Ayrshire & Arran are being trained in the physical care and monitoring of children with ADHD.

/02 NHS Borders has implemented a board-wide neurodevelopmental pathway.

/03 NHS Dumfries & Galloway’s primary mental health worker service provides training and support to colleagues in health, education, social work and the third sector, as well as supporting children and young people.

/04 NHS Fife provides regular Parents INC, behavioural parent training, and holds weekly ADHD evening clinics for adolescents.

/05 NHS Forth Valley’s primary mental health team has adopted an early access role to advise parents and referrers about ADHD.

/06 NHS Grampian has a multi-agency ADHD strategy group and created a nurse prescriber post.

/07 NHS Greater Glasgow and Clyde has developed a board-wide ADHD pathway.

/08 NHS Highland and Highland Council are developing a joint commissioning approach to children and young people’s services.

/09 NHS Lanarkshire has a multidisciplinary ADHD steering group for child, adolescent and adult services.

/10 NHS Lothian has implemented a board-wide ADHD pathway that is promoting closer links with schools.

/11 NHS Orkney has good support systems for individual children, particularly in schools.

/12 NHS Shetland is developing a multi-agency integrated care pathway in consultation with parents and children.

/13 NHS Tayside has nurse-led clinics and introduced a range of standard documents to aid clinical practice.

/14 NHS Western Isles works closely with partner agencies to provide ‘wrap around’ services for children and young people.
Key messages and conclusions

Key messages
The follow-up review findings section of this report summarises what we found in 2011–2012. Throughout all of our ADHD-SOS work we have identified:

- areas that are working well
- areas where improvements could be made, and
- ongoing or planned initiatives that could support and inform future service developments.

The following tables highlight a number of these areas and link the areas for improvement to supportive and complementary national work.

<table>
<thead>
<tr>
<th>Transition</th>
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<tr>
<td><strong>What's working well</strong></td>
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<tr>
<td>All NHS boards have transition arrangements in place and are providing continuing care services for young people making the transition to general adult mental health services. There is also an increased awareness of the persistence of ADHD into adulthood, and an emerging expertise within general adult psychiatry in the assessment and management of ADHD in adults who were not involved with ADHD services as children.</td>
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<tr>
<th>Areas for improvement</th>
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<tr>
<td>Only one NHS board area has a longer-term strategy for developing adult ADHD services.</td>
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<tr>
<th>Supportive national work</th>
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<tr>
<td>As previously mentioned, the Mental Health Strategy addresses capability and awareness raising in respect of neurodevelopmental disorders. This commitment covers the adult and child and adolescent population in Scotland.</td>
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Service provision

What's working well

All NHS boards know the evidence-based standard of care (SIGN 112), that should be provided for children and young people with ADHD in Scotland. Children and young people in contact with specialist services are being assessed, treated and followed up appropriately.

NHS boards have clearly demonstrated their commitment to improve local ADHD services including forging stronger links with colleagues in education services. Service co-ordination has evidently improved since we began this work.

All NHS boards have shared care protocols with general practices for the prescribing of ADHD medications for children and young people.

Areas for improvement

The current data systems in place across NHS Scotland cannot easily provide up-to-date information on current numbers of children and young people diagnosed with ADHD. This information is essential to allow NHS boards and partner agencies to make informed decisions about service planning to make sure that provision is based on demand and needs.

We know that ADHD is still under-recognised in Scottish school-aged children. Those children and young people not identified and referred, in their early years, to appropriate specialist services, are likely to experience poorer life outcomes.

Not all NHS board areas are providing regular, accessible behavioural parenting programmes. Such programmes are recognised as an important aspect of a multi-modal package of care for children and young people with ADHD.

Discussions with general practices about the ongoing treatment and management of adults with ADHD have not started or are in the very early stages in the majority of NHS boards.

Supportive national work

The standards for ICPs for Child and Adolescent Mental Health Services highlight the importance of systems for:

- bringing together anonymised data to identify the total number of children and young people with a particular diagnosis or presenting problem, and
- sharing that information appropriately with other services involved in care delivery.

The Mental Health Strategy for Scotland 2012-2015 (Commitment 33) commits to: …undertake work to develop appropriate specialist capability in respect of developmental disorders as well as improving awareness in general settings. Commitments 15 and 17 promote closer working with GPs and better management of long term conditions.

The National Parenting Strategy (2012) recognises that: ‘Valuing and supporting Scotland’s parents is one of the single biggest ways of giving the nation’s children the best start in life.’ In line with Commitment 7 in the Mental Health Strategy, the Parenting Strategy outlines a commitment to roll out provision of parenting programmes for parents of 3–4 year olds with particularly difficult behaviour. Thereafter, the Early Years Taskforce will ‘…explore the potential for a national rollout of evidence-based parenting programmes on a population basis.’
## Networking and partner engagement

### What’s working well

A key strength of our programme of work has been the opportunity for partnership working between NHSScotland, other relevant agencies, children and young people with ADHD and their parents/carers. All of these groups have a shared interest in improving the quality of ADHD services.

### Areas for improvement

Stakeholders who met with us during our ADHD-SOS work expressed a desire for a formalised national ‘ADHD hub’ to sustain the opportunities for networking with peers, sharing ideas, innovative solutions, service improvement approaches and evidence-based practice.

The ADHD-SOS work, and the current situation in Scotland, provides a unique research opportunity, specifically, the development of a national ADHD database.

### Supportive national work

There are a number of national mental health special interest groups (for example the Scottish Mental Health Nursing Forum, the National Forensic Network and the Scottish Perinatal Mental Health Forum). The models used by these groups could be used as a basis for an ADHD hub.

The models used by other research communities (for example, the Scottish Mental Health Research Network and Scottish Pain Research Community – SPARC) could inform the establishment of a national ADHD research community.
Conclusions

As highlighted throughout this report, ADHD services in Scotland are continuing to improve and there have been developments within all NHS boards since we started this programme of work. However, there is still work to do. The data that we have collected on diagnostic rates show us that services are still being accessed by only a minority of the children and young people who have ADHD. NHS boards have told us that services are already stretched when assessing and managing current numbers, and would struggle if demand increased. The requirement for services for adults is also growing. Our work has shown that while all NHS boards provide some form of continuing care for those diagnosed with ADHD in childhood, most have not yet developed a strategy to manage the demand for ADHD assessment and treatment in adults with no previous diagnosis.

However, we are not starting from scratch. We already know how many children and young people are accessing services in Scotland, and from epidemiological data, how many more might need to. Better ways to identify those children, young people and families that are ‘suffering in silence’ and provide a service for them need to be addressed. Similarly, adult services will need to develop capacity and capability to meet new demands for assessment and continuing care.

There is currently a strong national focus on child and adolescent mental health and NHSScotland is already working on a number of priority areas. The Mental Health Strategy covers neurodevelopmental disorders, across the age spectrum, and addresses ADHD specifically. The strategy commits to develop appropriate specialist capability and improve awareness in general health settings. We have evidence-based standards for ICPs for mental health services. These cover the whole age spectrum. The Mental Health Strategy outlines how improvement work will be supported. It references ICPs as one of the key programmes of work that will make sure that processes are designed to deliver effective, evidence-based interventions. We are currently working on a new national implementation and support plan for mental health ICPs. These initiatives are by no means an exhaustive list and there are many other linked pieces of work under way or planned.

The successful involvement of key stakeholders in our work was fundamental to the success of this programme, and the quality of the information collected and reported. The commitment and enthusiasm already demonstrated – by professionals, parents/carers and people with ADHD – can hopefully be built on. This will be a crucial next step in the process of continuing to improve ADHD services and the lives – now and in the longer term – of many children, young people and adults in Scotland.
References


### Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>atomoxetine</td>
<td>A non-stimulant drug commonly used in the treatment of ADHD.</td>
</tr>
<tr>
<td>attention deficit and hyperkinetic disorders (ADHD)</td>
<td>Attention deficit and hyperkinetic disorders are among the most commonly diagnosed behavioural disorders in children and young people. The core features of ADHD are persistent (at least 6 months’ duration) and developmentally inappropriate levels of inattention, hyperactivity and/or impulsive behaviour. These symptoms can be present either individually or in combination.</td>
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| British National Formulary (BNF) | This is the reference book that provides UK health professionals with up-to-date information on:  
  - selecting  
  - prescribing  
  - administering, and  
  - managing the use of medicines. |
| child and adolescent mental health services (CAMHS) | A range of services available within local communities which provide help and treatment to children and young people who are experiencing emotional or behavioural difficulties, and/or mental health problems. |
| comorbid | The presence of two or more disorders at the same time. For example, a person with ADHD may also have depression or anxiety. |
| dexamfetamine sulphate | Dexamfetamine sulphate is a stimulant drug primarily used in the treatment of ADHD. |
| epidemiological estimates | These are based on the calculations of the causes and effects of health and disease in defined populations. They are often used in public health studies and clinical research. |
| getting it right for every child (GIRFEC) | The Scottish Government’s multi-agency initiative to improve life outcomes for children and young people. |
| guidelines | Systematically developed statements which help in deciding how to treat particular conditions. |
| hyperkinetic disorder (HKD) | Persistent impaired attention and hyperactivity, evident in more than one setting (for example home, school, social situations), with onset before the age of 6 years. |
| impulsive behaviour | Suddenly doing things without thinking, little sense of danger. |
| inattention | Difficulty in concentrating. |
| integrated care pathway (ICP) | An explicit agreement made by a local group, both multidisciplinary and multi-agency, of staff and workers to provide a comprehensive service to a clinical or care group on the basis of current views of good practice and any available evidence or guideline. It is important that the group agrees on communication, recordkeeping and audit. There should be a mechanism to identify when a patient has not received any care input specified by the pathway so that the omission can be remedied. |
### Learning Disabilities
A person with learning disabilities is often less able to understand new or complex information or to learn new skills, and to cope on their own.

### Methylphenidate
A prescription psychostimulant drug commonly used to treat ADHD in children and young people. Brand names of drugs that contain methylphenidate include Ritalin® and Concerta®.

### Multi-modal
Multi-modal treatment or therapy is a combination of both medication and behavioural therapies.

### Narcolepsy
Narcolepsy is a sleep disorder. The symptoms can range from mild to severe and may include:
- falling asleep suddenly, without warning
- excessive daytime sleepiness, and
- cataplexy which is temporary muscle weakness in response to emotions such as laughter and anger.

### National Institute for Health and Clinical Excellence (NICE)
The organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. NICE produces guidance on health technologies and on clinical practice for the NHS in England and Wales.

### Prevalence
The overall proportion of the population with a particular condition.

### Psychostimulants
A group of drugs with differing structures and common actions such as increased motor activity and lessening of sleep necessity. They can be used to treat a range of disorders including ADHD.

### Scottish Intercollegiate Guidelines Network (SIGN)
To help improve the quality of healthcare in Scotland, SIGN develops national clinical guidelines aimed at reducing variations in clinical practice and in outcomes for patients. Founded in 1993 by the Academy of Royal Colleges and Faculties in Scotland, SIGN is part of Healthcare Improvement Scotland. Further information relating to SIGN guidelines or the methodology by which SIGN guidelines are developed can be found on their website (www.sign.ac.uk).

### Stakeholder
An individual or group with an interest in the success of an organisation in delivering results and maintaining the quality of the organisation’s products and services.

### Third Sector
The term used to describe the range of organisations that are neither public sector nor private sector. It includes voluntary and community organisations such as registered charities, self-help and community groups, social enterprises, and co-operatives.

### Transition
Moving from one service to another, for example from CAMHS to adult mental health services.
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