



April 2018



www.scottishadhdcoalition.org

The Scottish ADHD Coalition is a charity registered in Scotland number SC047630

Introduction	2
What is ADHD, and why do services for children with ADHD matter so much?	2
Previous work on ADHD in Scotland	3
Our Survey	3
Findings from the survey	4
1. Time taken to get an ADHD diagnosis	4
2. Child and adolescent mental health services (CAMHS)	5
2.1 Prescribed medication for ADHD	5
2.2 Provision of parent training and information about ADHD	6
2.3 Provision of other therapies besides medication	9
2.4 Ongoing follow up by the specialist team after diagnosis	10
2.5 Joined up neurodevelopmental assessment	11
2.6 Liaison between CAMHS and education	11
2.7 CAMHS approaches valued by parents	12
3. Education services for children with ADHD	13
3.1 Implementation of additional support plans at school	14
3.2 Teacher training on ADHD	15
3.3 Communication between school staff	15
3.4 Specialist provision when needed	16
3.5 ADHD and exclusion from school	16
4. The value to parents of peer support	17
Conclusions and recommendations	19
For Health Services	19
For Education Services	20
Appendix - Survey Methodology and Respondents	21
How was the survey carried out?	21
Who responded to the survey?	21
References	22

The Scottish ADHD Coalition was launched in 2017 to bring together the voluntary organisations providing support to families and adults affected by ADHD across Scotland. One of our aims is to shine a light on the provision of treatment and support for people with ADHD by public services in Scotland and to represent the voices of people affected by ADHD about where these could improve.

Between November 2017 and January 2018 we ran a survey of parents of children with a confirmed diagnosis of ADHD, living in Scotland, to find out their views about health and education services. 217 responses to the survey were analysed, representing parents from every mainland Health Board in Scotland (for more details see Appendix). This report summarises the results.

What is ADHD, and why do services for children with ADHD matter so much?

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental condition with three core symptoms: persistent and age-inappropriate inattention (difficulties with focus and memory), impulsivity (acting without regard to the consequences) and hyperactivity (a need to move or fidget). A complex mix of factors including genes, environment and early childhood experiences have been implicated in causing ADHD but, of these, genes have been shown to play the largest role and it is considered a strongly heritable condition¹. The symptoms are apparent in early childhood and, for most people with ADHD, continue into adulthood².

ADHD is relatively common. Approximately 5% of school age children have ADHD, more boys than girls². The prevalence of more severe ADHD (hyperkinetic disorder) is widely accepted as approximately 1.5% of school-aged children in the UK^{2,3}. Within Scotland, around 9,000 school age children were being treated for ADHD in 2016/17⁴. This represents only 1% of school age children, suggesting that ADHD remains under-diagnosed in many areas.

ADHD rarely exists on its own; it is associated with other neurodevelopmental conditions including autistic spectrum disorder (ASD), dyslexia, dyspraxia (coordination problems), sensory processing disorders and tic disorder. ADHD is also associated with long term mental health conditions such as anxiety and depression, which are particularly likely to take hold if the ADHD is not recognised, diagnosed and well managed.

ADHD can lead to multiple problems over the course of life such as poor academic achievement, unemployment, criminal behaviour and drug and alcohol dependency. ADHD also impacts on many aspects of family and school life around children who are affected by it. However, studies have also shown that prompt diagnosis and treatment can significantly improve the lives of people with ADHD and reduce the chances of these difficulties occurring⁵.

Previous work on ADHD in Scotland

From 2006 – 2012, Health Improvement Scotland carried out a three-stage project, [ADHD Services over Scotland](#). The final report³, published in 2012, found that mental health services for children with ADHD in Scotland were generally good, with children being diagnosed, monitored and followed up appropriately. There had been improvements in many areas over the course of the project, for example in raising awareness of ADHD and implementing shared care arrangements for young people moving on to adult services. However, the report found improvement was still needed in many areas, including:

- **Prompt recognition and diagnosis:** The number of children diagnosed with ADHD in Scotland still fell far short of what would be expected, at 0.7% overall – with wide variation between health boards.
- **Sufficient specialist staff:** It was noted that CAMHS services were over-stretched, and that further increases in the number of children diagnosed with ADHD, without more resources or new ways of working, would put services under unacceptable strain. (The number of children in Scotland being treated for ADHD has in fact increased by 43% since the report was published)⁴.
- **Behaviour training programmes for parents:** Not all NHS board areas were providing these consistently and it was noted that they are an important aspect of a multi-modal package of care for children and young people with ADHD.

Our Survey

The purpose of our survey was to assess parents' perceptions of these issues, six years on from the original SOS report, as well as to find out their thoughts about education services.

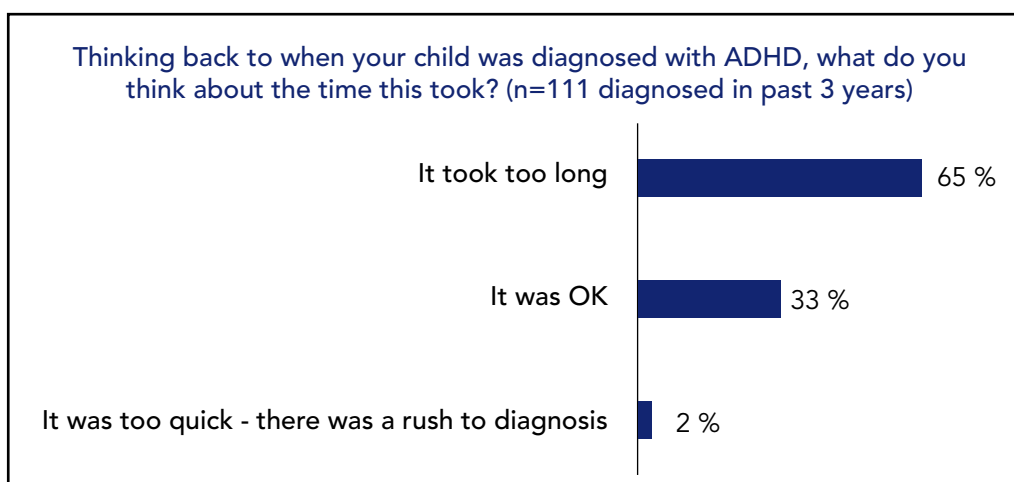
The results presented in the following sections are related to the [Scottish Intercollegiate Guidelines Network \(SIGN\) Guideline on ADHD⁶](#). A new [NICE Guideline on ADHD⁷](#), which applies in England, was published in March 2018 and provides a more up to date review of the evidence about best practice in diagnosis and treatment.

Each chart presented shows 'n', the number of respondents who responded to that particular question or whose responses have been included in the analysis. Where respondents were asked for free text comments, a selection of these has been included to represent the themes and overall weight of responses received. Positive comments, highlighting good practice, are shown in **green**, and comments about things which could improve are shown in **red**. Recommendations are given at the end.

1. Time taken to get an ADHD diagnosis

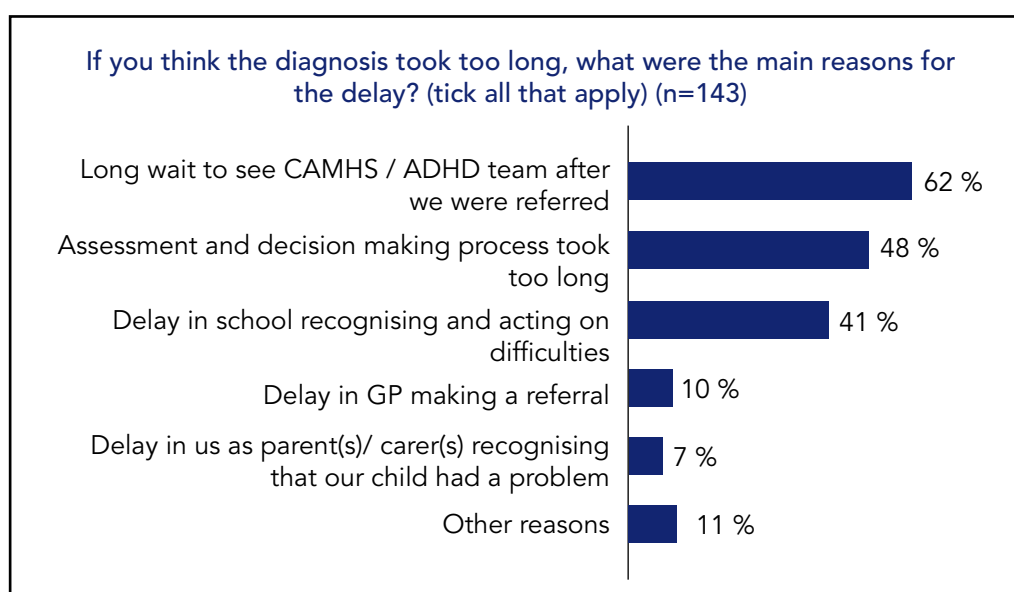
- 82% of respondents to our survey said their child had been diagnosed by an NHS CAMHS team, with 13% saying it had been an NHS paediatrician and the rest a private healthcare provider.
- Of those whose child had been diagnosed in the past 3 years, nearly two thirds said they thought the process had taken too long (figure 1).

Figure 1



- The most common reasons cited by respondents for delays in diagnosis were long waiting times to be seen at CAMHS, but delays in school acting on difficulties were also cited by 2 in 5 who thought it took too long.

Figure 2



“Once referred to the CAMHS service the waiting time for an appointment is so long. Then once you receive a diagnosis the wait for titration of medication is another lengthy wait. It’s such a long process and I think most families are overwhelmed at this point and desperate for their child/children to be treated.”

Other reasons for delay included problems with CAMHS staffing and rejected referrals:

“I first took my daughter to CAMHS when she was 7. I was told to do the Positive Parenting Programme. I explained I already did the training as I was in early years. I was basically left in limbo.”

“The referral was rejected by CAMHS after 2 days when they couldn’t have done any assessment. We were re-referred and all agreed that son was ADHD. This shows that we were just pushed out of system automatically at first try even with school educational psychologist and GP behind our decision.”

“Staff changes caused assessments to be delayed or needing to be repeated.”

Overall, therefore, there is room for improvement in timely recognition and diagnosis of ADHD – with both schools and CAMHS teams having a part to play.

2. CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS)

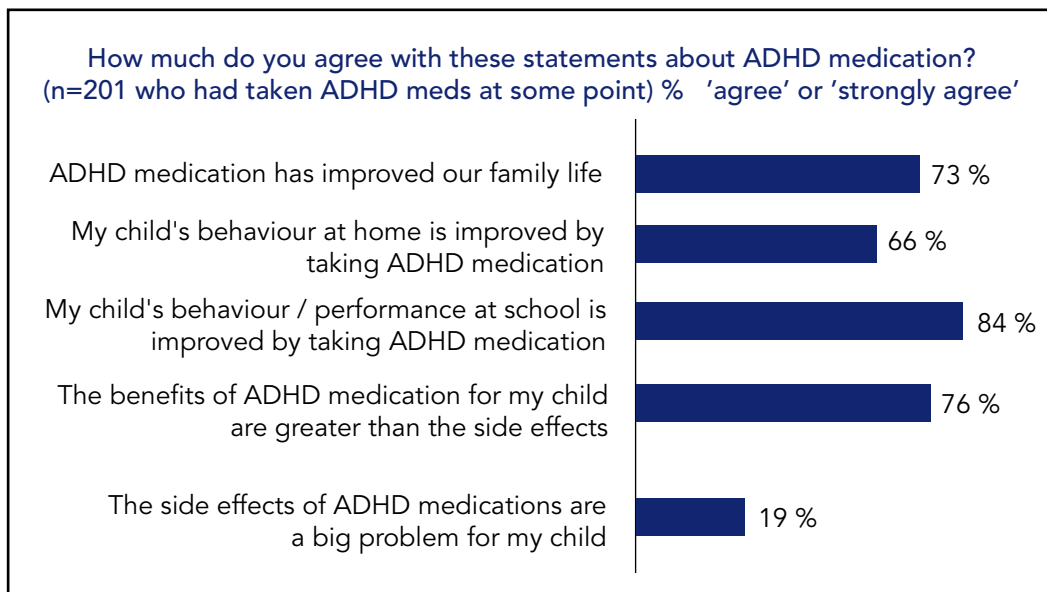
2.1 PRESCRIBED MEDICATION FOR ADHD



The SIGN guideline⁶ states that medication should be offered to all school age children with moderate to severe ADHD.

- 93% of respondents reported that their child had taken ADHD medication at some point.
- 88% said their child still takes ADHD medication now.
- Of those who said their child had never taken ADHD medication, in most cases this was down to parental choice. Others said they were waiting to start medication or there was a medical reason why their child couldn’t have it.
- 86% of respondents whose children are on ADHD medication reported that they are taking just a stimulant medication. Only 13% are taking a non-stimulant form of ADHD medication. These proportions are close to the national picture reported by ISD Scotland⁴.
- The vast majority of respondents whose children had ever taken ADHD medication felt that it had been beneficial, although 1 in 5 said that the side effects were a big problem for their child (figure 3).

Figure 3



Overall, therefore, the survey suggests that medication is being offered as per SIGN guidelines.

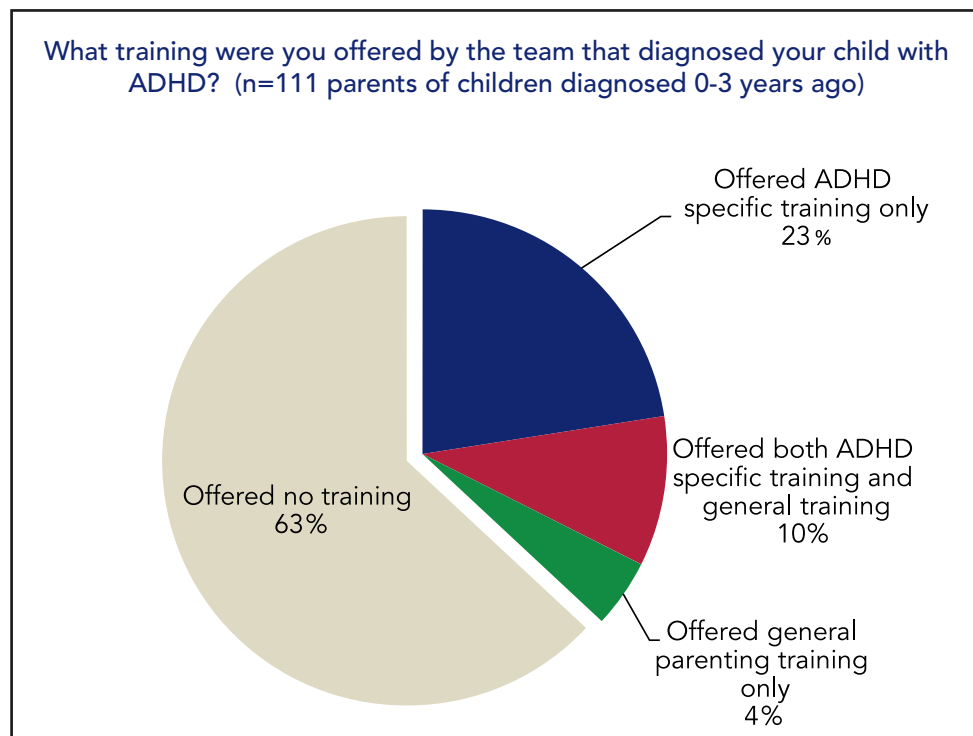
2.2 PROVISION OF PARENT TRAINING AND INFORMATION ABOUT ADHD



The SIGN guideline⁶ recommends behavioural parent training for parents of all pre-school children with ADHD symptoms, and for parents of pre-adolescent children with ADHD who also have other difficulties such as oppositional behaviour or anxiety. The SOS project found that 84% of children with ADHD displayed behavioural problems³ and also noted that ADHD-specific training was found to be much more helpful by parents than generic parent training.

- 63% of respondents whose children were diagnosed in the past three years were offered no parent training to help them manage their child's ADHD related behaviour (figure 4). Less than a quarter were offered an ADHD specific training programme, such as the Parents In Control (Pinc)© programme for parents of primary school children or Young People In Control (YPinc)© for parents of adolescents. Both courses were developed by NHS staff in Scotland and are available wherever local CAMHS staff have been trained to deliver them.

Figure 4



"You are left to read up on things by yourself and only see doctor once every 6 months. [We need] specialist groups for parents/ children to attend where advice could be sought. Training courses where both parents could attend and at a time more suitable than during the day, when most parents are working."

"They need more groups so parents can get together and talk and exchange ideas. As a parent you feel you're all alone and no one understands and it is only you that has a child with ADHD."

"We had a gap between diagnosis and starting medication and during this time were not seen. When things got worse we then went back to CAMHS. Medication was the only option offered to us. I would like to see an improvement in behavioural/ emotional support for both my child and us (parents). "



The SIGN guideline⁶ recommends that parents/carers of children with ADHD, and older children with ADHD, should be given information about ADHD and about possible interventions, including their potential risks and benefits.

Of our survey respondents whose child had been diagnosed within the last 3 years (111):

- Only 59% said they had been offered written information about ADHD aimed at parents and carers. 41% had not.
- Only 45% said they had been offered information on where to find out more about ADHD, such as a list of useful books or websites. 55% had not.
- Only 35% said they had been offered written information about ADHD aimed at their child. 65% had not. Even amongst parents of older children aged 10+ at diagnosis, only 36% had been offered information about ADHD designed for their child.

“We need support and guidance on how to manage ADHD, not just left to look on the internet.”

“[We needed] more information and support both for my son and for me as his parent. It was ‘here’s a label now take meds and go away.’”

“I would like more information to be given, as I was left confused and blaming myself.”

“[We need] more information for my son as all the information is written for adults and it’s him that is living and trying to understand ADHD.”

“[We need] more information in a child friendly format to help [our children] understand why they are different from some of their friends.”

However, many respondents wrote positively about the time and trouble taken by CAMHS staff to communicate well verbally with both parents and children directly, and to answer questions.

“[They] explained ADHD to us very well and how they came to their conclusion and why not a different diagnosis such as autism.”

“The staff at CAHMS were at all times very good and could answer all our lists of questions. The medication was tweaked several times until we were getting the best result and phone calls were returned promptly with any concerns we encountered.”

“[The best thing has been CAMHS] listening and believing us as a family and now at age 11 speaking to our child directly about condition.”

“[I like] the importance and attention paid in personally knowing my child at each appointment, showing him he is known and valued there and feels important when he is asked questions which the health team remember about his likes etc.”

“We have valued having a fantastic doctor who took time with our child to discuss his needs and worries with him. The previous professionals we have seen didn’t want our child in the sessions as they wanted to concentrate on our strengths and weaknesses as parents... The difference this doctor has made in a short period of time had been fantastic. We now have a happier child who understands why he feels the way he does at times, and a much happier family life.”

Overall, therefore, there is a need to improve the availability of ADHD-specific parent training. Good two-way communication between CAMHS teams and parents is vital, and is often provided but in addition, there is a need for better written information aimed both at parents and children themselves

2.3 PROVISION OF OTHER THERAPIES BESIDES MEDICATION

Whilst the SIGN guideline makes no recommendations on psychological therapies for ADHD apart from parent training, the new NICE guideline⁷ recommends that cognitive behavioural therapy (CBT) should be considered for children who still struggle significantly with symptoms despite ADHD medication. Furthermore, the wide range of comorbidities and other mental health problems which often accompany ADHD (see Appendix) means that for many children, medication alone is unlikely to be enough.

- Only 15% of respondents to our survey had been offered any psychology input, counselling, CBT or other therapy input for their child. 85% had not. Many respondents said they felt their child would have benefited from other input besides medication, including psychology, occupational therapy, speech and language therapy and dietetics.

"Medication should be accompanied by face to face, one to one "talking therapy" and coping strategies for my child and for us as a family."

"My daughter has real anxieties and other difficulties but I don't feel that she is getting help with this. No self help strategies. I feel the support we have had as a family has been very poor and actually has detrimentally affected my daughter's mental health."

"We need a more rounded approach, not just given medication and a review every so often, access to other therapies would be so beneficial."

There needs to be more support for family on dealing with challenges... more support for child. After diagnosis we've been on our own except for medication. There has been no psychology support which we had at early intervention stage."

Where other therapy input had been offered, parents commented:

"The support the psychologist has given to myself and my son was amazing she worked with and around my family to allow us the best use of the service."

"Clinical psychologist brilliant. Very supportive. Taught good coping strategies."

"Referral to family therapy in a time of crisis and ongoing has been a lifeline."

"The child psychologist was the person we found most understanding and helpful. He listened and appeared to understand took time to help us cope and try and understand and give coping strategies."

"The input from CAMHS has been invaluable. My child has also been referred to other professionals within the CAMHS team to help with difficulties he currently has."

"Occupational Therapy are by far the most useful providers who seem to 'see' difficulties that others don't. OT provide many recommendations of supports to schools and provide it too if needed."

Overall, our survey suggests that there is an over-emphasis on medication as the only treatment approach to ADHD, when many children would benefit from more input from the multi-disciplinary team to address the complex range of difficulties they face.

2.4 ONGOING FOLLOW UP BY THE SPECIALIST TEAM AFTER DIAGNOSIS



The SIGN guideline⁶ states that the initiation of pharmacological treatment for children with ADHD should only be undertaken by a specialist, in either child and adolescent psychiatry or paediatrics, who has training in the use and monitoring of psychotropic medications. Thereafter, a shared care protocol between specialist and primary care should be used.

- The vast majority of respondents (89%) said that their child was still regularly seeing a specialist health professional about their ADHD.
- 2% said they were no longer being followed up through their own choice. 5% said they had been discharged because their child was not on medication:

"They offered no support unless we chose to medicate her. We were told we could ask to come back at any time if we would medicate her but otherwise there were no other supports to offer. Unbelievable!"

"As soon as we said we didn't want to medicate, CAMHS just wanted to discharge us immediately."

- A further 5% said they were not being followed up due to staffing issues:

"We do not have regular reviews even though I try to get them. My daughter's nurse specialist left and it's been a nightmare since."

"We have only had 1 review since he was 3 (he is now 7) because the paediatrician left, wasn't replaced and we have had to fight to get another."

"We were told tier 2 CAMHS no longer exists. We may be sent an appointment in a year."

Whilst the vast majority of respondents' children were still being followed up, there was a view from many that CAMHS teams were overstretched and review appointments too brief and medication-focused.

"There need to be more staff at CAMHS. They are inundated with patients and I feel that I don't get enough time with staff to discuss concerns. This is so even in a crisis situation."

"I think CAMHS departments are over-stretched. There is nothing offered to my child, other than her 6 monthly appointment with the psychiatrist. Children need support, other than medication."

Overall, our survey suggests that most children with ADHD are being followed up by the specialist team. However, where families are reluctant to try medication it appears that some CAMHS teams are quick to discharge them, making it harder for them to offer further support down the line.

2.5 JOINED UP NEURODEVELOPMENTAL ASSESSMENT

Given that ADHD is so often accompanied by related conditions, there were many comments that boxing it into a pathway on its own makes no sense for children, and a more holistic approach to assessment and management is needed.

“I don’t believe that the Asperger’s and ADHD should have been diagnosed separately, or at the very least [the paediatrician] should have referred us to CAMHS team. Professionals should be there when needed and parents not passed from pillar to post.”

“There should be better multi diagnosis. One label fits all is damaging for the child and family. [Our service] rushed to diagnose ADHD and offload the case so that other behaviours outside this umbrella were not addressed.”

“Professionals need to identify other disorders which have an impact on children’s lives at the same time as ADHD diagnosis and to better explain the implications of diagnosis to the education system and how this must cater to the child’s needs.”

2.6 LIAISON BETWEEN CAMHS AND EDUCATION



The SIGN guideline⁶ recommends that there should be regular communication between health and education services to promote understanding of the difficulties of ADHD/hyperkinetic disorder, to ensure a consistent approach to the individual across settings and to monitor the effectiveness of intervention(s).

Of our survey respondents whose child had been diagnosed within the last 3 years:

- Only 69 % said that their CAMHS team had offered to communicate the diagnosis to their child’s school so that they were aware of it. 31% said this had not been offered.

The lack of communication from CAMHS to schools was cited by several respondents as an area for improvement:

“We would like not just to be left. School were hoping to liaise with CAMHS, yet all that was given was confirmation of diagnosis.”

“[There needs to be] better communication... Health services need to provide support in school e.g. speech and language therapy assess but then do nothing, CAMHS say they can only provide medication but can't get involved with support in school.”

“[CAMHS need to be] liaising with schools so that teachers fully understand how ADHD affects the child in school.”

Overall, there is a need for more proactive outreach from CAMHS teams towards children's schools to ensure that they understand the diagnosis and what they need to put in place to support the child at school. Schools also have a key part to play, as discussed in section 3.

2.7 CAMHS APPROACHES VALUED BY PARENTS

Many respondents provided positive comments about CAMHS services. Most often, this was because the attitude shown by team members was particularly supportive and they actively listened to parents:

“Their friendly and understanding manner. They always made our whole family feel welcome and calm.”

“The team I work with for my child really understands our circumstances and they are able to provide practical advice.”

“I love that the paediatrician listened to me! She took my thoughts and concerns on board and explained what was caused by ADHD and what was dyspraxia.”

“We have built a good trusting bond with the ADHD specialist nurse. She is very good with my child.”

“I value the ADHD nurse at CAMHS that we see regularly. She listens, actually cares and is always available if I have questions.”

3. EDUCATION SERVICES FOR CHILDREN WITH ADHD

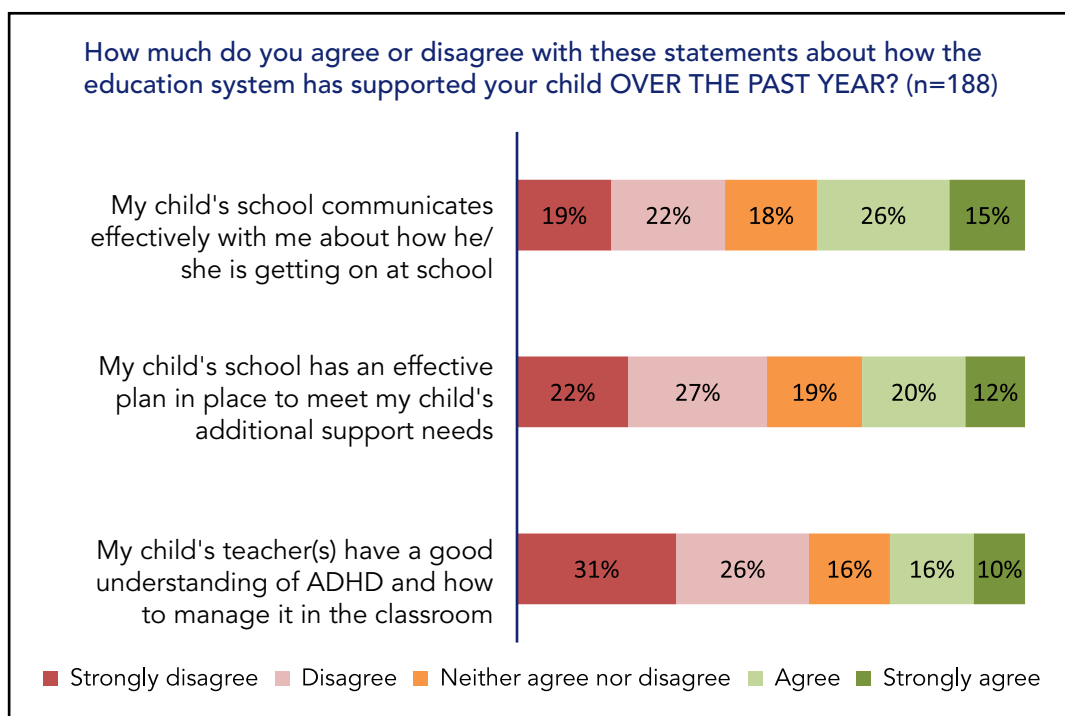


The SIGN guideline⁶ recommends that there should be regular communication between health and education services to promote understanding of the difficulties of ADHD/hyperkinetic disorder, to ensure a consistent approach to the individual across settings and to monitor the effectiveness of intervention(s).

Respondents' views on how well their children were supported at school were mixed (figure 5).

- Only 41% of respondents felt their child's school communicated effectively with them about how their child was doing
- Only 32% of respondents felt that an effective plan was in place at school to meet their child's needs
- Only 26% of respondents felt that their child's teacher(s) had a good understanding of ADHD and how to manage it in the classroom.

Figure 5



When asked what could most improve educational provision, a number of themes came up over and over again.

3. 1 IMPLEMENTATION OF ADDITIONAL SUPPORT PLANS AT SCHOOL

The Education (Additional Support for Learning) (Scotland) Act 2004 mandates education authorities to make adequate provision so that children with additional support needs, including ADHD, can access the curriculum and thrive at school.

Our survey responses highlighted that appropriate plans were not always made, to the knowledge of parents. Even when they were, they frequently didn't translate into day to day reality. In particular, there was a perception that access to Personal Support Assistants (PSAs) and support for learning staff to assist classroom teachers was jeopardised by staff and funding shortfalls.

"Unfortunately the shortage of Support for Learning Assistants within school has had a negative effect on the support given to our child and others. This needs to be reviewed."

"The promise of additional needs assistants for as long as my child needs them...at the moment it is all down to funding if he will get support each school year."

"[My child needs] more one on one PSA support."

"Schools need to be implementing additional support that the child is legally entitled to and understanding the social isolation experienced by families and supporting them, not making their job harder by forcing parents to fight for support to which they should be getting anyway. There should be access to records and assessments of children. Even after a subject access request, I have no chronology or information regarding my child's educational attainment. Schools must understand that continuously punishing ADHD behaviours won't fix the problem. This will only hurt the child's self esteem. ADHD kids need space to run, bounce, and de-stress. This does not mean locking the child in a room for half an hour."

"[There should be] much better understanding and support e.g. around organisation. Better use of technology so we know what homework and assignments he has. Quicker meetings, actions happening more quickly e.g. getting a mentor in place for him. Frankly, we can't wait until he has made it through the school system. It's been terrible."

Many respondents gave examples of where schools had offered tailored high quality, support for children, showing how it can be done with the right resources, knowledge and leadership. However, there were many comments that the support was inconsistent and depended on particular, interested staff.

"My child's school have embraced his problems and work hard to ensure he gets the education he deserves. His 1:1 support is fantastic."

"They have set out a child plan and took the time to discuss with me the issues at school."

"The teachers, including the Head that we have had over the years have been excellent with our son. Support has been in place since P1 and is ongoing."

“When my child moved school, his new school provided so much support. At his old school, the understanding of ADHD and his needs were overlooked and he was punished for bad behaviour. Without the individual support, the relationship and trust between his support teacher (at his new school), I do not know where my son would be in the education system. His schooling is catered to his needs, enabling him to engage in a class but also being able to retreat to his own space with his support teacher, make friends, share his reward time with friends and because of all this his school work has improved significantly so much so he has moved up 6 groups.”

“The introduction of a fantastic new Head Mistress dramatically changed the course of my son’s school experience. She introduced many strategies for my son to achieve to improve his behaviour before diagnosis and after diagnosis. They have Support for Learning staff and Intervention and Prevention staff which has been key in my son’s learning.”

“The ONLY good thing has been the support of the Head of Support for Learning at our school. Our son went on the 1st day of P7 never to return that year. She worked tirelessly with him to gain his trust & has supported him all through each school year. This is more LUCK than anything to do with the education department or even the school itself.”

3. 2 TEACHER TRAINING ON ADHD

This was the suggested improvement needed in education services most often mentioned by respondents.

“[There needs to be] better understanding of ADHD and also making it a standard process for all student teachers to do a course on ADHD so it’s not a shock to them, when faced by difficult challenges.”

“Teachers [need to be] taught more about ADHD. I had a parent of another child approach me as the teacher spent most of her day shouting at my boys, which in turn made them worse.”

“Schools need regular study days on ADHD, to eradicate the view that ADHD is ‘bad behaviour’.”

“[What would improve things is if] teachers are given proper training and strategies on how to support children with ADHD and realise that each child with the condition is completely different.”

3. 3 COMMUNICATION BETWEEN SCHOOL STAFF

A number of respondents commented that staff were not always aware of their child’s issues, especially at secondary school level where more teachers are involved.

“[We need] better communication, emails etc. and teacher understanding. At a recent parents’ evening all her teachers were not aware she has an Individual Education Plan (IEP).”

“When my son was in first year his pupil support teacher was fantastic and made teachers aware and he got support. However he got a lot of new teachers and a new support teacher in 2nd year and he is getting no help whatsoever. I was advised by a guidance teacher that “teachers don’t have the time to read everyone’s reports”. They called me to complain about my son’s fidgeting! And still are. They throw him out the class every day. One exception is one teacher who has taken the time to understand my son and what he needs, which is slow precise instructions which are repeated. Doing this, he keeps my sons attention and he doesn’t forget. But every other teacher has complained that they “need to keep repeating themselves” and that “he has no understanding”.”

“I would like more inclusion for my child and more communications from the schools we have been to in relation to concerns they have or how they may be able to support parenting.”

3. 4 SPECIALIST PROVISION WHEN NEEDED

For a minority of parents, they felt that mainstream education was simply not working for their child.

“[We need] more schools / units for kids with ADHD / ASD or other needs. Its ok saying put the kids all in same class but a lot of kids are suffering as they can not cope with the large class numbers and not enough staff to meet their needs.”

“Presumed mainstream is entirely wrong for some children. This causes unnecessary anguish for all involved especially as most decisions and refusals are on monetary terms.”

“We need transparency and honesty. Less focus on mainstream inclusion when it is not realistic. Sitting a child in a corner with ear defenders on behind a privacy screen so they can be seen as inclusive is counter productive. The child would be more included in a SEN classroom that better meets his sensory requirements. ”

3. 5 ADHD AND EXCLUSION FROM SCHOOL

Our survey asked respondents to say whether their child had ever been excluded from school, and how often. There was evidence that ADHD is associated with a high level of school exclusion – both formal and informal. This reflects the findings of the Scottish school census⁸ which showed that in 2017, children with additional support needs were five times more likely to be excluded from school than those without.

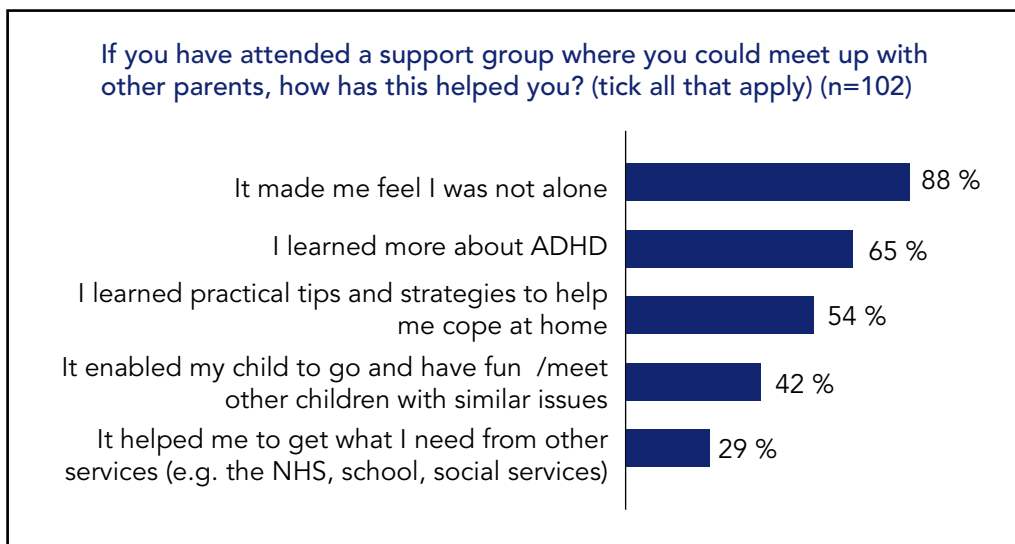
- 5% of respondents said that their child had been permanently excluded from a school.
- 33% of respondents said that their child had been temporarily excluded from a school at least once. On average, this had happened six times to each of these respondents.
- 21% of respondents said that their child had been put on limited hours at school at least once. On average, this had happened on 96 days to each of these respondents.
- 16% of respondents said that they had been asked by their child’s school to come into school to supervise their own child at least once. On average, this had happened on 35 days to each of these respondents.

These exclusions not only harm children's education, sometimes irreparably, but place an enormous strain on parents, both emotionally and financially. Our assessment would be that more continuing professional development and resources for teachers about ADHD, together with well developed and communicated individual education plans which are consistently implemented, would reduce this damaging outcome.

4. THE VALUE TO PARENTS OF PEER SUPPORT

71% of survey respondents said that they were part of a parent support group (an unsurprisingly high proportion, given that survey respondents were mainly recruited via support groups). Those who had been part of a support group cited real benefits (figure 6)

Figure 6



Comments from those who didn't enjoy support groups were:

"I'm not sure about attending... I felt that ADHD took over our life. I wanted to look at my child as a person not a diagnosis. I struggle because I do think I need the support of other parents but don't want it to define my family - my child is more than ADHD."

"I hated it as felt the other people attending were too focused on the negatives. It wasn't for me."

But the vast majority of comments about groups highlighted how valuable they were for parents:

“I am very impressed with Perth ADHD. They attend school meetings with me and support me fantastic.”
(Parent in Perth and Kinross ADHD+)

“It has given me some much needed adult/parent company where I finally feel I belong, it has also taught me a lot about not only ADHD but associated conditions.” (Parent in Perth and Kinross ADHD+)

“Just hearing from others that they are going through the same things, as even family think it's down to bad parenting and can't understand why they don't fall asleep for hours, or won't answer.”
(Parent in ADHD Parental Support Caithness)

“Good for difficult times and for information and to realise others are experiencing the same issues/frustrations with and lack of services.” (Parent in Dundee and Angus group)

“Having other parents/carers to chat to makes a huge difference as they get it. Parents with non ADHD children just don't understand the challenges we face daily.” (Parent in Dundee and Angus group)

“Great to talk to other parents. Before this group we thought we were the only family dealing with some of our son's issues.” (Parent in Signpost West Lothian Lego group)

“They help you to stay positive and you've always got someone to talk to if you're having a bad day.”
(Parent in West Glasgow Group)

“It's good to have someone to talk to who understands the challenges parenting a child with ADHD.”
(Parent in Edinburgh group)

Where children's provision was on offer, this was also highly appreciated by parents:

“Brighter Days has been good for us all. Everyone is lovely and welcoming and my son enjoys being himself and not getting bullied. It's the only place I can go and people know how I feel and can relate.”
(Parent in Brighter Days Lothian)

“My child's confidence grew attending the group and he now volunteers with the group they have been a great support system to myself and son throughout the past few years.”
(Parent in Dundee and Angus group)

Our findings give cause for hope. Despite a significant increase in the number of children diagnosed with ADHD over the past five years, many parents report that they are receiving sensitively delivered, high quality care from CAMHS teams. ADHD nurse specialists, often forming close partnerships with families, enable them to manage often difficult situations more effectively than they otherwise could. Others said that school staff had gone the extra mile to put in place tailored support for their children at school. There is evidence that systems for prescribing and monitoring ADHD medication are working well, and many children are seeing real benefits from this.

However, this high quality support is patchy and inconsistent, and far too many respondents feel let down by health and education services. Our recommended priorities for improvement based on this snapshot of parents across Scotland are as follows.

For Health Services:

- 1 Waiting times for CAMHS teams are unacceptably long in some areas and this is a barrier to timely assessment and review of children with ADHD. They need to be reduced.
- 2 Parent training tailored to the needs of parents of children with ADHD should be offered to all families at diagnosis. Programmes such as Pinc© for parents of primary school children and Young People In Control (YPinc)©, which recognises the changing needs of adolescents, should be available for all families.
- 3 The availability of written information offered to parents and children about ADHD needs to be improved. Children need information tailored to their age group. As children mature and reach adolescence, it is particularly important that they are supported to find out about ADHD for themselves and begin to take responsibility for managing their own condition.
- 4 Current treatment for ADHD is very medication-focused. Whilst our survey could not assess unmet need, there is a case for greater multi-disciplinary team support, involving not only ADHD nurses and psychiatrists but also psychologists, occupational therapists, speech and language therapists and dieticians for children with more complex needs. Families who do not at first accept the offer of medication should not be discharged from the service if they still have needs.
- 5 ADHD cannot be seen in isolation. There is a need for more joined-up neuro-developmental care pathways where children can be assessed for related difficulties such as ASD and sensory issues alongside ADHD, and holistic treatment plans can be put in place.
- 6 CAMHS teams need to be more proactive in reaching out to education services, and not only as part of the assessment process. After diagnosis, CAMHS should be working with schools to ensure they understand the diagnosis and make and implement appropriate plans, and jointly to monitor the effectiveness of both health and educational interventions.

For Education Services:

- 7 Additional support plans for children with ADHD need to be made and, crucially, consistently implemented by schools. This includes clear communication between teaching staff and between schools and parents.
- 8 Teachers need more training about ADHD, both in order to recognise signs and symptoms and refer children for assessment and also to manage children with ADHD in the classroom. There should be a systematic programme of continuing professional development about ADHD and related disorders, as well as online resources available as needed to support teachers.
- 9 Mainstream education may be an unrealistic goal for some children with ADHD and more complex needs. Where needed and appropriate, specialist provision should be available.

How was the Survey carried out?

The survey was carried out online. The survey was drafted by the Scottish ADHD Coalition leadership group and tested by leaders of groups within the Coalition.

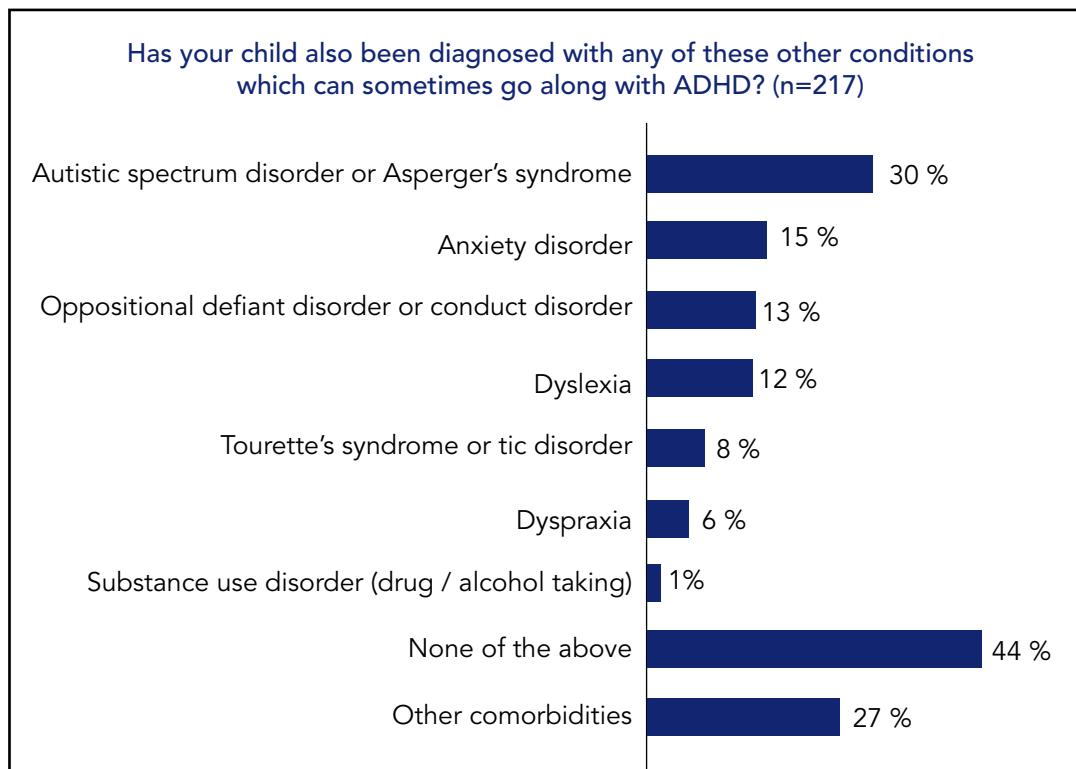
Coalition members invited their members to take part using email and via their Facebook groups. The link was also publicised on the Scottish ADHD Coalition website and Facebook page, and via the Facebook groups 'ADHD/ASD UK Community Support', 'Borders Additional Needs Group', 'SPOKAN Edinburgh' and 'SPOKAN Glasgow'. The survey instructions made clear that responses were sought from parents or carers of children with a confirmed diagnosis of ADHD, aged 18 or under and living in Scotland.

The survey was open from 24 Nov 2017 to 24 Jan 2018. Results were downloaded and analysed using Excel.

Who responded to the survey?

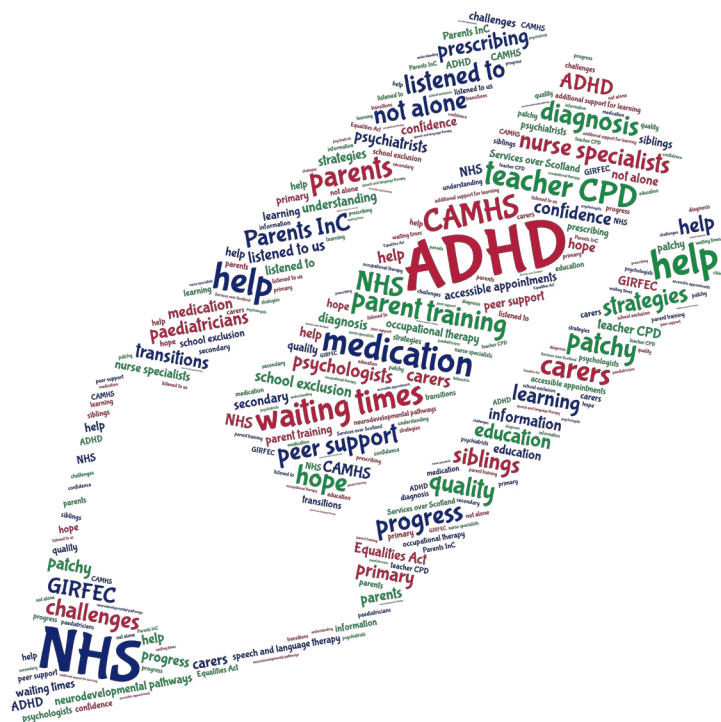
- 236 responses were received from unique IP addresses. 19 were excluded from analysis as the respondents had dropped out at an early stage in the survey, leaving 217.
- Respondents came from every mainland Health Board of Scotland. Tayside was somewhat over-represented, reflecting the very active parent support groups in this area.
- 93% of respondents said they were mothers, 2% were fathers and 5% were other carers (such as foster carers or kinship carers)
- The average age of respondents' children with ADHD was 11.3 years (range 6 to 18 years). The average age when they were diagnosed with ADHD was 7.7 years (range 3 to 17 years).
- More than half of respondents' children had been formally diagnosed with another neuro-developmental or mental health condition alongside ADHD (see figure 7). 30% had a diagnosis of Autistic spectrum disorder (ASD) or Asperger's Syndrome, and in a further 4% of cases a comment was made that an ASD diagnosis is currently underway. It should be noted that many children with ADHD may also have related conditions which have not had a formal diagnosis.

Figure 7



References

- 1 Faraone SV, Perlis RH, Doyle AE, Smoller JW, Goralnick JJ, Holmgren MA, et al. Molecular genetics of attention-deficit/hyperactivity disorder. *Biological psychiatry*. 23-1313:(11)57;2005.
- 2 Attention deficit hyperactivity disorder: diagnosis and management (Clinical Guideline CG72). National Institute for Health and Care Excellence (NICE), 2008, updated 2016
- 3 Attention Deficit and Hyperkinetic Disorders: Services Over Scotland (final report). Health Improvement Scotland 2012.
- 4 Medicines used in Mental Health 17/2016 - 5/2004. NHS Scotland Information Services Division (ISD), 2017 October 2017.
- 5 Shaw M, Hodgkins P, Caci H, Young S, Kahle J, Woods AG, et al. A systematic review and analysis of long-term outcomes in attention deficit hyperactivity disorder: effects of treatment and non-treatment. *BMC Med*. 10:99;2012.
- 6 Management of Attention Deficit and Hyperkinetic Disorders in Children and Young People (Clinical Guideline 112). Scottish Intercollegiate Guidelines Network (SIGN), 2009.
- 7 Attention deficit hyperactivity disorder: diagnosis and management (Clinical Guideline NG87). National Institute for Health and Care Excellence (NICE), 2018.
- 8 Summary Statistics for Schools in Scotland, No. 2017 :8 Edition. Scottish Government.



We would like to thank the many parents of children with ADHD who took part in our survey, and the leaders of support groups who helped to publicise it. Thanks are also due to the Trustees of the Coalition for their input and comments. Data analysis and report authoring was carried out by Geraldine Mynors.

www.scottishadhdcoalition.org