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Educational experiences of young people with ADHD in the UK: Secondary analysis of qualitative data from the CATCh-uS mixed-methods study

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Abstract

Background: Attention deficit/hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterized by inattention, hyperactivity and/or impulsivity. Young people with ADHD have poorer educational and social outcomes than their peers. We aimed to better understand educational experiences of young people with ADHD in the UK, and make actionable recommendations for schools.

Methods: In this secondary analysis of qualitative data, we used Thematic Analysis to analyse information relating to experiences of education from 64 young people with ADHD and 28 parents who participated in the Children and adolescents with ADHD in Transition between Children's services and adult Services (CATCh-uS) study. Emerging patterns within and across codes led to organization of the data into themes and subthemes through an iterative process.

Results: Two main themes were generated. The first described young people's early experiences of education, often within a mainstream setting; we labelled this *the problematic provision loop*, as this was a negative cycle that was repeated several times for some participants. The second theme described young people's more positive progression through education once they progressed out of the problematic loop.

Conclusions: Educational experiences for young people with ADHD are often negative and fraught with complication. Young people with ADHD often found themselves on a more positive trajectory after they were placed in an alternative form of education provision (mainstream or otherwise),

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or where they were able to study topics that interest them and play to their strengths. We make recommendations that commissioners, local authorities and schools could consider in order to better support those with ADHD.

KEYWORDS

ADHD, education, qualitative, school, thematic analysis

INTRODUCTION

The worldwide prevalence of attention deficit/hyperactivity disorder (ADHD) in children and young people is approximately 5% (National Collaborating Centre for Mental Health (UK), 2009), although estimates vary. A recent population-based study in the UK reported a prevalence of 1.6% in 5–19 year olds (NHS Digital, 2018). ADHD is an early-onset neurodevelopmental disorder characterized by inattention, hyperactivity and impulsivity present across multiple settings (Del Barrio, 2016). These core symptoms are dimensional traits that are univocal across the population: ADHD is diagnosed where these are severe, persistent and impairing across settings (Thapar & Rutter, 2015). Understanding and intervention for ADHD is important because it is associated with poor long-term outcomes that persist into adulthood, including low academic attainment, antisocial behaviour, involvement in the criminal justice system, low self-esteem, poor physical health, poor occupational outcomes, increased risk of accidents and impaired social functioning. Although interventions for ADHD can improve these outcomes, children with ADHD often remain impaired or developmentally delayed relative to their peers (Shaw et al., 2012).

The influences of a young person's environment during their development can be conceptualized using Bronfenbrenner's Ecological Systems Theory (EST). EST recognizes the importance of interactions between influences from different areas of a developing child's or young person's life and what effect these may have on the child, meaning that the theoretical framework can be utilized to consider particular developmental challenges for a child or adolescent with ADHD. EST offers a child-centric theory of development in which influencing factors and the context of the child's development are nested within one of five systems: microsystem, mesosystem, exosystem, macrosystem and chronosystem (Bronfenbrenner, 1979, 1986). We provide an example of how these systems interact in the case of ADHD in the Data S1.

Ecological systems theory can be used to explain the influence of external outcomes on the development of an individual child, for example students with ADHD are more vulnerable to many risk factors of low school attendance, including bullying (*microsystem*), low academic attainment (*macrosystem*), and social isolation (*mesosystem*) (Elliott & Place, 2019), which can go some way to explaining why rates of school absences in 5–19 year olds with ADHD are higher than for students without the disorder (Melvin et al., 2019). School absence may also be due to temporary or fixed-term exclusions, which are utilized by schools as a disciplinary method to discourage harmful or disruptive behaviour from students (despite evidence that this is an ineffective punitive measure) (Finning et al., 2018). Young people with ADHD and related disorders may also be formally recognized as having Special Educational Needs and Disabilities (SEND), which will place greater demands on the school. ADHD falls under “social and emotional mental health” in the SEND code of practice (Tutt & Williams, 2015), and children and young people with ADHD may need an Education, Health, and Care Plan in place in order to access appropriate resources to support their learning and experiences of school.

While young people with ADHD often demonstrate an understanding of the expectations set by their teachers, and that there is room for improvement in their schoolwork, they often have difficulty achieving this due to varied and interacting reasons, including self-reported difficulties setting goals and staying organized (Wiener & Daniels, 2016). Many young people with ADHD disclose negative

experiences of education, and report bullying or isolation from peers from a young age through to higher education (Kwon et al., 2018; Wiener & Daniels, 2016). One study reported that the presence of even one close friend within the child's class can be a protective factor; it gives the child access to an important contact within the microsystem who has more positive learning experiences, and therefore improves their well-being (Feder et al., 2017). Evidence suggests that young people experience variability in ADHD behaviours across different learning environments and contexts (Wheeler et al., 2009). This indicates the need for a wider range of methods that can be implemented to support and educate young people, which would require: i) better recognition from teachers that behaviours vary with context, ii) more time within the classroom or with a teaching assistant (TA, supplied by senior staff) and iii) easily accessible interventions.

Research has shown that educational practitioners' views of ADHD influence the support offered to young people with ADHD (Russell et al., 2016). Teachers and teaching assistants can blame parents or young people for ADHD if they have a lack of understanding regarding its neurobiological basis, which may lead to victimization or stigma. Some teachers report a lack of understanding about ADHD, its management in the classroom and that they would like more training in this area (Arcia et al., 2000; Moore et al., 2017; Russell et al., 2016). A lack of understanding can act as a barrier to offering appropriate support (Greenway & Edwards, 2021; Sibley & Yeguez, 2018). As modelled in EST, parent-teacher interactions can also affect how the child is supported: a recent study indicated that parent-teacher conversations can present a barrier to accessing the right support for young people, and that socioeconomic factors can also affect the relationships and support offered. For example one qualitative study showed that teachers believed parents from advantaged backgrounds had more knowledge about ADHD (and mental health literacy), greater cultural capital and similarity to the teacher, leading to a streamlined process of recognition, assessment and diagnosis. This delay in recognition and diagnosis could further disadvantage families experiencing adversity who may be struggling to manage a child with ADHD (Simoni, 2021).

Better understanding the educational experiences of young people with ADHD who have recent experience of the UK education system will allow researchers and commissioners to understand what changes could be made to our educational environments and systems to the benefit of children and young people with ADHD. The current study provides qualitative insights from the experiences of young people, who are often overlooked in the research literature. Much qualitative research on ADHD focusses on the reflections of adults on children's experiences and so this study addresses this gap by predominantly including interviews from young people with ADHD. Findings from our study will allow services and education systems to better respond to the challenges experienced by young people with ADHD. The Children and adolescents with ADHD in Transition between Children's services and adult Services (CATCh-uS) study, from which the data in this study originates, was a National Institute of Health and Care Research– funded study that employed mixed methods to better understand the transition of people with ADHD from child to adult mental health services in the UK (Janssens et al., 2020). Semi-structured interviews produced a qualitative data stream which was analysed using Framework analysis to explore the views of different stakeholder groups on the transition between services. An important theme in the dataset regarding young people's experiences of education arose but was not explored further at the time as it was not part of the objectives of the original project. The data relating to education covered two topics: transition from child to adult mental health services (Benham-Clarke et al., 2021), and experiences of progressing through the education system. The current study expands on the educational progression data to add to a currently limited knowledge base, and previous studies have shown the importance of retrospective perspectives of education (Bartlett et al., 2010). Whilst teacher and parent views of ADHD in relation to education have previously been documented, the views and experiences of young people with ADHD are often overlooked. Using this subset of data from the CATCh-uS study, the current study aimed to:

1. Better understand educational experiences of young people with ADHD.

2. Make actionable recommendations in the form of best-practice guidance for government, schools and families.

METHODS

The CATCh-uS qualitative stream sampled groups of key informants via participating National Health Service Trusts. Health professionals (clinicians working at child health services and adult health services, and general practitioners [GPs]), young people with ADHD and parents of children with ADHD were recruited for the original study. The current analysis utilizes data from the 64 young people with ADHD (20 female, 44 male) who participated in CATCh-uS, and the separate sample of 28 parents of children or young people with ADHD (25 mothers, 3 fathers).

Participants were recruited for the original study using purposive sampling. The sampling strategy was tailored for each group to ensure inclusion of the widest possible breadth of experiences, based on their stage in the process of transitioning from child to adult mental health services. The groups relevant to the current study were young people with ADHD (1) pre transition (21 young people mean age 15 years [*SD* .92]), (2) post transition (22 young people mean age 18 [*SD* .96]), (3) who did not transition but returned to adult services (21 young people mean age 23 [*SD* 3.11]), and (4) parents of children with ADHD. Only patients seen in services at the time of recruitment were invited.

Semi-structured interviews were conducted, following a topic-guide, to cover themes including current and future medication use, contact with services, experiences of transition and views on optimal transition for young people and parents. The topic guides were informed by the patient and public involvement group, NICE guidelines, and existing research. Data collection took place in two phases (April–November 2016 and March–May 2017) using the constant-comparison method to inform both topic guides and recruitment methods for subsequent phases. While there were few direct questions relating to education included in the interviews, they provided a view of the strong association between the management of ADHD and the educational setting.

The University of Exeter Medical School Research Ethics Committee and National Research Ethics Service (NRES) Committee Yorkshire and the Humber-South Yorkshire granted ethical approval for the subset of data used in the present study. Informed consent was sought from all participants, with parents of participants aged under 15 consenting to the participation of their child with assent sought from the young person.

Analysis

The dataset for this secondary qualitative analysis of the data collected in the CATCh-uS study was generated by running queries across anonymised transcripts of participant interviews for any terms, extracts and discussion relating to education, that were then read to identify data relevant to the study aims. Data extracts about education that focussed on transition, medication, or clinical services were excluded as these are the subject of separate analyses and publications (Janssens et al., 2020; Benham-Clarke et al., 2021).

Thematic Analysis was used to analyse the data, and NVivo software was used to organize the data (Braun & Clarke, 2021; Decrop, 2004). An inductive coding scheme was developed after initial reading and re-reading of the dataset by AR. Codes were discussed with SBC and refined, and all data coded accordingly. The information within and across codes was then examined for common meanings and to ensure consistency across codes; additional codes were implemented as necessary. Initial content and organization of the codes were reviewed by all authors, and their validity and pervasiveness within the wider CATCh-uS dataset were discussed.

A reflexive Thematic Analysis approach (Braun & Clarke, 2019, 2021) was adopted based on an experiential qualitative framework. The research team comprised the lead author, who had not collected

data or been previously involved in the wider project, and co-authors who were involved in the additional data collection and other analyses. The lead author has a background conducting research on ADHD in education settings, including qualitative studies with staff but not with young people around education, therefore they had some preconceived notions of what the data may contain. The wider team had detailed insight into the broad dataset but had not specifically focussed on the content or meaning of the education data, except for in relation to medication management. Data were coded inductively. These descriptive codes were reviewed to form an initial coding framework. At this point an element of a deductive approach was introduced, where initial coding was discussed with the original study team, who had insight into the entire dataset and perceptions about the relevance of some of the codes developed through the inductive approach. Codes were a mixture of semantic (e.g. 'symptom manifestation' containing descriptions of core ADHD symptoms expressed in school) and latent (e.g. 'schools being unsupportive' whereby data that described experiences of school that were perceived by the research team as being unsupportive of a young person with ADHD were coded), and these were synthesized together in order to generate themes.

Following the iterative coding of data, a model was devised from commonalities of participants' educational experiences, refined with the input of all authors with knowledge of the wider context of the dataset, as well as the education-focussed data. Further discussion of emerging patterns within and across the established codes led to organization of the data into themes and subthemes through an iterative process. Attention was paid to situating the analysis within Bronfenbrenner's EST and potential interactions between different individuals within the mesosystem: parents, teachers, SENCos, educational psychologists, Child and Adolescent Mental Health Services (CAMHS), other parents, peers and GPs. This led to generation of two themes, each with several subthemes, enabling us to answer the first study aim (to better understand the educational experiences for young people with ADHD); the themes are presented and interpreted in the results. The second aim, to make practical and actionable recommendations for schools and families, is answered by considering the implications of the themes and subthemes resulting from the analysis and compiling a series of best-practice guidance points, presented in the discussion.

RESULTS

Two main themes were generated. The first theme described young people's early experiences of education, often within a mainstream setting. We have labelled this *the problematic provision loop*, as this was a negative cycle that was repeated several times for some participants. This theme also covers how young people and parents first noticed that the young person was different to others. Remaining within mainstream provision was not universal for the young people in this study, and the interaction of students' ADHD-related functioning and the demands of the mainstream school context was felt to have caused negative impacts on their learning and relationships. Based on young people and parents' experiences, we have created a cartoon infographic that captures common experiences of the problematic provision loop (Figure S1).

The second theme describes young people's progression through education once they progressed out of the problematic loop. This was usually initiated following a change in school. Positive aspects of progression out of the loop were characterized by learning that engaged the young person, often related to the young person's interests, hobbies, and strengths; modes of learning where they were able to engage with the teacher and classmates appropriately, and flexibility around difficulties related to their ADHD. Chronological progression through the education system, with fewer mandatory subjects as young people got older, played increasingly to young people's interests and desires to pursue subjects that engaged them.

Theme one: The problematic provision loop

- Subthemes
 1. Noticing difference
 2. Mismatch between young person's needs and mainstream provision
 3. Impacts on the young person due to their ADHD within the school context

Theme two: progression out of the problematic provision loop.

- Subthemes
 1. Change of school
 2. Fit between new provision and young person with ADHD
 3. The impact of time on improving educational experiences
 4. Leveraging strengths and interests

Theme one: The problematic provision loop

Noticing difference

Young people with ADHD explained how they initially noticed they were different to others in primary or early secondary school in terms of their ability to engage in learning in the classroom, expression of inattentiveness, hyperactivity or impulsivity, or their ability to produce work of similar volume or standard to their peers. This was conveyed through comments from teachers to the child, or their parents: “Then the school picked it up first” (*parent*); “The teachers were saying I wasn't concentrating and that kind of thing” (*young person*). Where schools recognized a potential diagnosable problem, they would suggest that families take the child to the GP or CAMHS to seek assessment and diagnosis.

At this point, young people generally reported realizing that they were different to other children:

My parents not knowing what was wrong with me, and why I was different to other children.

(young person)

Parents reflecting on this reported that school staff did not necessarily understand their child. Because mainstream primary teachers see many children of the same chronological age, problems were often first noticed at school in comparison to the behaviour of a child's peers. One parent recalled a teacher saying:

‘Look, this is what he produced this year’ and I thought, ‘well it's not much but it's, you know’, and then she showed me what someone else had produced which was massive and I thought ‘yes, something is not right’.

(parent)

Many individuals were involved in this process of noticing and reinforcing a sense of difference. Diagnostic processes or assessments were reported to result in diagnostic confusion for some young people: “I thought he was on the autistic spectrum, that's what I got told...that was by his paediatrician” (*parent*), and others had experiences of being bounced between school and medical services. Generally, there was very little communication between health and education from the perspectives of young people and their parents “There's no connection between CAMHS and school, no” (*parent*), although in isolated instances participants reported taking information from school to the clinician, or CAMHS suggesting strategies to a school.

Some families reported that they noticed the young person was different prior to the school or teachers raising the issue. One parent reported noticing her child's behaviour in class as being completely inattentive and disengaged, however the staff had not noticed:

Because she hasn't got hyperactivity she's not bouncing off the walls so it's almost unnoticeable unless you are actually looking at her.

(parent)

Mismatch between young person's needs and mainstream provision

I think the reason I've seen ADHD as being a problem is because you have to go through the education system the way it's laid out and I think if you didn't, it wouldn't have felt like a problem. Because my day-to-day life doesn't feel like a problem, it just feels a little bit different.

(young person)

As a result of the differences in the young person's behaviour and development, attributable to ADHD, participants reported that they were not able to adapt successfully to their original school: “[my child] was having lots and lots of problems at the school and that was reflecting a lot on his behaviour” (*parent*). It seemed common that participants began their education in a mainstream setting (although at least one began in a SEND school). Many then experienced multiple school placements as mainstream schools were reported to have difficulties supporting them. ADHD symptoms at an impairing level result in difficulties at school, but equally, as delineated in the EST, the system of schooling in the UK presents difficulties for those with ADHD, especially at later Primary and early to mid-Secondary stages of education when the system may become less flexible to a child's or young person's needs.

Experiences of punitive measures that further aggravated children's ADHD and associated impairments were reported, such as not being allowed outside: “At playtime he was permanently kept indoors” (*parent*), being victimized by others “Serious physical, mental abuse over quite a long period of time” (*parent*) or perceived negative experiences with teachers. From the accounts of participants, it appeared that teachers were generally unaware that young people with ADHD did not have full volitional control of their behaviour, reactions to others and to their surroundings, which they linked to a lack of understanding of ADHD. One young person reflected:

Looking back at it, [my mental health problems] were caused by having ADHD... I used to get told off at school and I used to get so much shit thrown at me from such a young age... I thought it was because I was being badly behaved.

(young person)

In cases such as this where participants felt that teachers had lacked understanding of the conditions of the students they taught, participants reflected that opportunities may have been missed to help the student and make a difference to their learning. Participants reported experiences of some helpful strategies, such as extra time in exams and movement breaks, but also less helpful strategies that were reportedly offered as the only options to integrate flexibility or accommodations: “He's allowed more time...not at the beginning of the exam, it will be during, which he's grateful for any help, but it wasn't quite the help that he was after” (*parent*). ADHD impairments also meant that academic learning was very challenging for these young people, and long periods of sitting still and listening attentively were described as “torture” (*parent*) for someone who could not concentrate easily, and hours of focus demanded for essay writing, or assessments on computers were also considered burdensome.

In many cases, mainstream schools were unable to adapt sufficiently to the young person, or the young person was unable to adapt to the particular school. Where schools could adapt, medication was often relied on to manage symptoms “I don't get support from the school, no, but that's...partly down to the medication being able to help me cope in daily work” (*young person*).

Impacts on the child due to the mismatch with school context

The core symptoms and impairments attributable to a diagnosis of ADHD, and the underlying difference in neurodevelopment from most peers of a similar chronological age, means that a child's ADHD has various negative and positive impacts that were visible and operated within the school context. Participants felt that school staff had misinterpreted their behaviour and needs “You'd be classed as a naughty child” (*young person*), but also reported positive experiences of support in various education contacts “I would get a printout from the teachers...and the pastoral [team] was just amazing, they really did know how to treat him” (*parent*).

One example of a school misinterpreting a child's behaviour, was when they reported to the parent that they considered it inappropriate that the child liked to interact with the younger peer group within the school. Other participants reported that inattentive symptoms of ADHD were ignored or unrecognized (a mismatch between symptoms and understanding or diagnosis). These impairments could result in children being labelled as lazy or naughty prior to a diagnosis or explanation of ADHD, or that parents were blamed for their behaviour “And they said basically it was bad parenting...so I was quite insulted by that” (*parent*). Aspects of the school context, such as having assessment deadlines of midnight, were considered to be unhelpful: “They are going to work up to midnight if they need to” (*parent*).

There were examples of where well-placed support had helped young people in education, which included medication, allowing more time in exams or breaks, having support to learn and apply self-regulation strategies, having a scribe to help take notes, and support from a teaching assistant. Others reported the benefits of smaller class sizes, having the same teacher for several years in a row, and CAMHS discussing strategies with the school. On the whole, these types of support were mentioned in relation to later in a young person's school career, once their needs had been recognized and understood.

The process of diagnosis and accurately identifying ADHD led to the most substantive and positive changes in young people's educational experiences. This included the ability to transfer out of mainstream provision or access additional support for learning. Parents still felt that young people did not reach their educational potential in secondary school, particularly if they were struggling to get a diagnosis:

He left primary with level 4s and secondary... looking like he's hardly going to get any GCSEs. Now level 4 is an average child, so she should be getting at least about 5 Cs.
(parent)

Diagnosis and labelling of ADHD, as well as being “different”, sometimes meant that there were negative impacts for young people and families, including one young person reporting that their ADHD was recognized because they were aggressive towards others in primary school. They reported “not wanting to go into school and not really liking it at all” (*young person*) which may have been either the reason for- or alternately- due to reactions to, their aggressive behaviour. Participants reported negative experiences, including that children's difficulties were at times directly attributed to bad parenting, as well as misdiagnoses and peer victimization.

The mismatch in mainstream school meant that young people often experienced exclusion and expulsion in their education:

I kept being sent to Centre...six weeks of exclusion;
(young person)

Year 5...shocking horrendous year...two days of expulsion.

(parent)

In other cases, the process of diagnosis and assessment led families to pursue less conventional mainstream provisions, such as moving their child to a school with larger classes when they were in an extremely small school, or smaller classes from a large school. Participants reported that class sizes of nine or 10, or learning on their own were manageable for them:

Well I ended up going to a small school, because the first one I went to...it was a really big school, the teachers didn't have time to sit and understand.

(young person)

That both smaller and larger schools worked as alternatives to the original school size shows that individual difference contributes to a child's experiences of school and this must be taken into account when trying to accommodate for a young person with ADHD; the same environment will not be suitable for every child.

Theme two: Progression out of the loop

Change of school

Changing schools was common for families, as one parent said: "Yes we had to change Primary schools", which was the parents' choice in cases where young people were not expelled from school: "We pulled him out the school because we'd had enough at that point" (*parent*). When young people described their recent educational experiences in their interviews, they often described their current school as some form of move out of mainstream school "I'm doing an online kind of home school" (*young person*). Some of them were articulate about these being special schools or schools specifically to cater for pupils who were expelled from mainstream "It's like a pupil referral unit for children that have been excluded or [are] not managing for whatever reason" (*parent*), whereas others described settings that are considered alternative provision, although this was not explicitly acknowledged or recognized as such by participants.

Some young people reported feeling apprehensive or actively negative towards new school placements whereas others found the new placement positive and exciting: "And he spent the morning there, absolutely loved it" (*parent*). Generally, young people reported that their new placements were a better fit than mainstream school once they had started there:

It's nice there.

(young person)

I'm fine moving school.

(young person)

Fit between new provision and young person with ADHD

Participants reported enjoying their experiences in schools attached to hospitals, one-to-one tutoring, online learning with a distant tutor or teacher, boarding school, or schools that adapted to their needs (such as not being able to sit still or pay attention for long periods of time). When the 'right' school or method of provision was found, be that because they could meet individual needs of participants or because they had a more inclusive culture, participants reported positive experiences:

He's at a different school now and it's a lot smaller and his confidence has just shot up, it's amazing.

(parent)

Being here, where you get help and support, is actually really good. I've been here since... Year 7...I'm now in Year 11.

(young person)

The characteristics of these provisions often meant that the young person felt they had some agency over how and what they were learning, and provisions were able to respond flexibly to the young person's needs:

You go to this place and they give you all different positions to choose from.

(young person)

Provisions were also understanding and supportive of behavioural difficulties and the need to learn to self-regulate:

Without sport I can't cope with the ADHD...because I need this outlet otherwise I don't know what to do with this amount of energy I have.

(young person)

Where ADHD was well managed, or supported by being surrounded by the right contextual factors, young people stayed on a different, more positive path which contrasted with the original negative feedback loop of mainstream provision; one participant describes her aspirations for her GCSE results: "So hopefully I get what I want for college". The contextual factors that supported young people varied, including being able to engage with subjects that interested them, in a manner that was not overly-demanding of sustained attention, having agency and choice over what they studied or how they engaged with school, having the ability and permission to exert physical energy, and flexibility, understanding and support from staff members. If their ADHD was poorly supported in a new type of provision however, they may have ended up in the same loop in a different setting, further reinforcing their negative self-perceptions instilled from their initial school experience, as happened for this young person who did not receive an accurate diagnosis until late in his education:

And then it was getting close to GCSE period and I was still really, really struggling.

(young person)

The impact of time in improving education experiences

It was clear from the data that as participants progressed through their education, their feelings towards education and school changed. This was often in relation to the journey of labelling and understanding their difficulties (and strengths), the changing structure of the curriculum which gives you more subject choice, and of greater awareness of the impact of their ADHD on themselves and those around them. One parent describes this progression and the positive impact it had on their daughter:

When she went to do her GCSEs it improved slightly because then you are getting rid of some subjects that you don't particularly want to do...and that improved slightly. I think once she goes to college, because it's a course she wants to do, I'm hoping it will improve again...She won't be forced to do subjects that she found torturous...to sit in a lesson...

and copying them [things on the board] down is just torturous for someone who can't concentrate.

(parent)

Time could also improve experiences through moves to new placements that were better suited to young people. Others reported improvements in education related to their ADHD medication, which was available only after navigating the journey to get an accurate diagnosis, which could take years to achieve. An extreme example was this young person's experience:

I had a teacher notice that I was a little bit different right down in Primary school...year 1 or year 2...[describes assessments and misdiagnosis and continuing difficulties]...so I came here for my ADHD diagnosis, so I got here when I was 15 [years old].

(young person)

Leveraging strengths and interests

As young people progressed through school and grew older, they reported being able to spend more time doing subjects that engaged and interested them, and were able to play to their strengths such as creativity or logical thinking to “use my ADHD and channel it into something productive” (*young person*). Their experiences of school in the context of their personal interests and strengths was much more positive as a result:

He goes to a specialist engineering college...which he absolutely adores.

(parent)

I'm actually a sports scholar.

(young person)

Similarly, young people reported positive attributes about themselves, their identities and their responsibilities: “I'm a prefect” (*young person*). The mismatch experienced and move out of mainstream education did not appear to hold back or temper young people's aspirations. Several young people talked about their future plans for higher education “I like the idea of going to college” or future careers, taking into consideration their ADHD:

I would want a job that is both active and routine but not constant...so there's still variety in your daily life and at the same time something that will allow me to move about in the middle of the day.

(young person)

DISCUSSION

The themes and subthemes developed in this analysis described how children with ADHD risk being stuck in a problematic provision loop, where their school context does not fit their needs, but also how impactful adaptations could be. In the former, negative interpersonal experiences and a cycle of increasing frustration and disruption, often centred on school, seemed to arise from the combination of other adults' lack of understanding of ADHD and the lack of appreciation of the support needed to alleviate a child's difficulties. In the second theme, we described how educational trajectories improved when children found themselves in a placement that could adapt to support their needs. A variety of

provisions were mentioned, indicating the importance of tailoring adaptations to individual's profiles of strengths and weaknesses: there is no "one size fits all" provision that suits every child with ADHD. There is little empirical evidence about what strengths children with ADHD have, however evidence suggests that individuals with ADHD may be able to 'hyper-focus' on things that engage their interest, bring energy and fun to group settings, be creative and think outside the box (Groen et al., 2020; Hupfeld et al., 2019).

It is clear from the data and from the findings that there were a wide range of opportunities where support for the child or flexibility of the school context could interrupt the negative reinforcing cycle of the problematic provision loop, and enhance young people's experiences of education.

Based on these findings, we suggest that the following points represent best-practice guidance for supporting children with ADHD through their education, however many of these guidance points are relevant to every child with neurodevelopmental differences:

For policy-makers, commissioners and local authorities resourcing schools to provide better support for children:

- 1. Resource and deliver neurodevelopmental and mental health training for educational practitioners.** There is a need for school staff to better understand ADHD and other neurodevelopmental conditions from a biopsychosocial perspective, including how these present in young people, that ADHD is caused by neurodevelopmental differences and not by family context, and importantly understanding that children with ADHD do not always have full conscious volitional control over their behaviour. SEND professional development around neurodevelopmental disorders, combined with mental health professionals sharing their knowledge and experience with teaching staff will help to address this need. Key areas of focus include underlying deficits in information processing relating to ADHD (e.g. executive functioning, delay aversion), sensory processing and perception differences, as well as the overlap between ADHD and other neurodevelopmental traits.
- 2. Provide sufficient resources for schools to implement support for children with ADHD.** Mainstream schools need to be resourced so that they can adapt to the needs of children with ADHD, for example providing equipment, adapting the classroom or school physical environment, or additional teaching assistant support. Many of the costs of ADHD fall on education and schools (Telford et al., 2013), and funding levels that match the needs of young people at this stage may mitigate progression of these young people into the justice system, where costs are much higher and young people's problems more entrenched. There are many levels where the needs of children with ADHD are mismatched with school expectations, and schools could address the negative consequences of labelling, address inclusivity and challenge the performative agenda that they currently face. There is an extensive evidence-base showing that school-based interventions can improve the functioning of many children with ADHD and reduce impairments (Moore et al., 2019). Many of these interventions involve supporting the child to recognize their emotions, to support the child to regulate their emotions and behaviours, and to build positive relationships with peers and trusted adults, which will require an investment of time by at least one adult. Strategies that leverage and support the increased use of young people's strengths and interests could promote positive school experiences for young people and increase engagement with school, as well as boosting self-esteem.
- 3. Refine and speed up processes for the assessment and diagnosis of neurodevelopmental disorders, and provision of Education Health and Care Plans (EHCPs)** that are needed in order to access specialist education provision, providing more capacity and a faster process. The length of the current process and reliance on a clinical diagnosis frequently results in extremely poor early education for children with ADHD as mainstream schools may not have sufficient resources or expertise to adequately support children to access learning, and children not realizing their academic potential. If difficulties are recognized and support is available for the child when they are still in early primary school, it would facilitate finding the right provision to suit the child, and help build a positive cycle of learning experiences. Schools are often involved in initial

requests for EHCPs, however the Local Authority is the body that carries out assessments and issues EHCPs. Addressing recommendation one would improve the ability of schools to identify children in need of an EHCP and to respond to the accommodations that are made in an EHCP once issued.

4. **Provide resources for schools supporting children awaiting a formal diagnosis** (see guidance point 7 below). ADHD does not begin the day it is diagnosed, and although SEND support may be given through a school-managed budget, often economic resources are only accessible to schools and families from the point of diagnosis. Schools need additional resourcing to provide individualized and easy-to-access support for the needs of children who are waiting for assessment or who may have impairments that do not meet diagnostic thresholds.
5. **Provide a range of suitable education provisions for children with ADHD and other SEND.** Traditional classroom learning, where there are many pupils in a class, few staff, and children are expected to sit still and be attentive for long periods of time often do not suit children with ADHD and children with other SENDs. A range of other provisions and options however can suit these children: finding what works for each individual is important for their attainment, socio-emotional development and health. Sharing best practice from alternative provision and SEND specialist schools may support children with ADHD and other SEND to remain in mainstream school contexts.
6. **Allow schools to offer a more flexible curriculum.** If children with ADHD are allowed to specialize in fewer subjects at an earlier stage of their school education, it appears that this may improve their experience of school. The broad range of subjects the children are expected to learn when they are young does not play to the strengths of young people with ADHD, and many of their more positive experiences later in education were linked to the fact that they could choose subjects that interested them. However, it should also be recognized that too narrow a focus early in education may limit children's options later in their education and potentially widen academic and social inequalities.

For school senior leadership teams and staff:

1. **Promote inclusion and celebration of individual difference.** Young people with ADHD are negatively affected by their initial understanding that they are different from the majority of their peers. A school culture that promotes inclusion, and celebrates individual differences, could help to remedy some of these negative impacts, reduce victimization, and improve young people's experiences of education. Young people with ADHD are aware that they are different from their peers from an early age and are sensitive to being treated differently. School staff should make efforts to support the child but also not to single them out in front of their peers, working collaboratively with the child and their family to understand as much as possible about their strengths and needs. Children are likely to be resistant to interventions that make them feel further distanced from their peers. Including classroom-wide adaptations may be appropriate, and individual adaptations need to be implemented sensitively, noting the child's reaction as well as that of their peers.
2. **Offer genuine individual accommodations and tailor learning to interests and needs.** Flexibility offered to a child with ADHD should not simply be a predetermined list of potential adaptations. Instead, young people should be consulted on what they think is most likely to help them and where possible this should be implemented, in combination with using observational and other assessment methods to understand their strengths and difficulties. It may well be that nobody knows what will help, and a range of potential adaptations could be discussed with parents and trialled with the young person. Children with ADHD reported that they really enjoyed learning when subjects tapped into their interests. Teachers who take time to know the child and understand what engages them can benefit the young person's educational outcomes and promote social inclusion through peers identifying mutual interests. Boosting young people's existing strengths and tailoring activities to their interests may be more positively experienced by young people than focussing solely on their challenges. Learning how to best use individual strengths

may also have longer term benefits for the young person beyond education, although a combination of both overcoming current difficulties and supporting use of individual strengths is likely to be most supportive in the school environment.

3. **Support children and families awaiting a formal diagnosis.** Children with ADHD and their families may be bounced back and forth between different healthcare services while going through the process of assessment and diagnosis, yet the problems that impair a child with ADHD are already happening. This process can take years, and schools need to be aware that this is a stressful time for families as they are attempting to seek support for their child, and may be in limbo without a formal label or explanation. School staff could talk to parents about this process, and ask how the school can support the child or during the process of assessment.
4. **Be aware of stressful periods for the child and family.** There are particular periods that are more problematic for children with ADHD and their families. The gap between recognition of problems and getting support, and transition from primary school to secondary school are some of the most problematic times for young people with ADHD. Providing an understanding and supportive environment at school, and facilitating development of peer and teacher-student relationships (Rushton et al., 2020), is important during these stages.
5. **Minimize or eliminate use of exclusion and suspension for children with ADHD, and avoid isolating children.** It is very common for young people with ADHD to experience multiple suspensions, exclusions and permanent expulsion from school (Guevara et al., 2013; John et al., 2021; Parker et al., 2019). These kinds of incidents are extremely negative for young people, and schools that make every effort not to exclude young people, but rather work with them to resolve issues, results in the young person being less likely to become trapped in the problematic provision loop.
6. **Working on trusted relationships with a new student with ADHD.** Schools should bear in mind that if they have a young person with ADHD in attendance, they may already have a history of attending other schools, and experiencing exclusion. They may also have a history of negative relationships and interactions with teaching staff, and new schools will need to work hard to develop trusting relationships between staff and the child in question.

The findings from this study echo existing literature in the field, which finds that teachers have a poor knowledge of ADHD, and that children with ADHD are more likely to be absent, suspended, or expelled from school than their peers (Guevara et al., 2013; Parker et al., 2019). They also provide evidence that the reason for these exclusions relate to the conflict between a mainstream school context where the child is expected to fit in, and a child with ADHD finding it challenging to regulate or change their behaviours to meet these expectations.

This negative experience, as well as being labelled as naughty or challenging, impacts on the self-identity of young people with ADHD, their educational career and attainment. The impact of a negative school experience also influences peer relationships, and relationships with other relevant adults and teachers. When children become stuck in a problematic provision cycle, they may fail to complete mandatory education or obtain qualifications; these are risk factors for increased probability of involvement with the criminal justice system due to antisocial and criminal behaviours (Dowse et al., 2014; Merrill et al., 2020; Young & Thome, 2011). If we could provide young people with ADHD a better start in their education, it could have positive knock-on effects that influence the entire lifespan. It should also be noted that there may be inter-generational influences present due to ADHD being highly heritable (Faraone et al., 2005): cycles of negative school experiences of people with ADHD may ripple across generations, increasing expectations for negative experiences for the child of a person with ADHD. There may also be resistance to involvement with education on the part of the parent as well as the child, or the parent may disengage with school, or feel actively negative towards school staff due to their own experiences of education.

Strengths and limitations

This study was a secondary analysis of qualitative data that were originally collected in order to explore young people's experiences of transition from child to adult mental health services in the context of ADHD. Education was not something that was explicitly included in the interview topic guide, however participants mentioned education frequently in their interviews and as such we conducted this analysis with the aims of better understanding their experiences of education. We have qualitative data from a large sample of young people and their parents, all of whom have confirmed ADHD: studies using qualitative methods with this population are rare, and much of what we know on this topic comes from parent or school staff perspectives (Gwernan-Jones et al., 2016). However, as the initial interviews did not ask directly about education, this analysis is based on opportunistic data where people with ADHD or their parents believed that their education experiences were relevant to the wider topic of transition being discussed in their interview. Further themes may have been developed had participants been asked a series of questions about their experiences of education. The data on education were present across interviews, indicating that experiences of education described were common across participants with ADHD, and considered to be of importance to them.

A strength of this study is that we hear directly from young people with ADHD who were either still progressing through school or had left education within the past decade. A limitation of the study is that the original recruitment focused on three specific groups of young people with ADHD, who are not representative of all young people with ADHD. Those recruited to take part in CATCH-uS were either in CAMHS, had recently transitioned to adult mental health services, or had re-entered adult mental health services after being discharged from CAMHS at the time of recruitment. All participants were registered with CAMHS or an adult mental health service at the time of recruitment and were in the NHS system. Therefore, young people with ADHD who had dropped out but not returned to mental health services, or those with undiagnosed ADHD, were not included. Because of the recruitment and sampling strategy, we will not have captured the most disengaged or detrimentally-impacted young people with ADHD, and our findings are potentially more positive than the educational experiences of a representative sample of young people with ADHD. Also, many of the individuals were taking medication for their ADHD during at least some of the education experiences described (Benham-Clarke et al., 2021). Many young people with ADHD however choose not to take medication and are therefore more likely to be discharged from mental health services, or indeed not receive a diagnosis of ADHD to begin with. This group is not represented in this analysis. Further studies could explore whether the findings of this qualitative work apply to a larger population of young people with ADHD in the UK through survey methods, and to conduct additional in-depth qualitative research with teachers to understand more of their perceptions and understanding of ADHD to further inform our 'policy recommendation one'. Studying those who have ADHD and report positive experiences of early education may also be valuable in understanding what facilitates this. Interventions where schools actively aim to improve their flexibility for catering to individual needs, and that provide support for young people with ADHD as well as appropriate training for staff should be evaluated to assess how best to improve the education experiences for people with ADHD in the UK.

CONCLUSION

In conclusion, this qualitative study found that early educational experiences for young people with ADHD are often negative and fraught with complication. Suspension and exclusion are common, and young people with ADHD often find themselves on a more positive trajectory after they are placed in an alternative form of education provision, or where they are increasingly able to study topics that interest them and play to their strengths. Engagement with education is associated with long-term positive outcomes, so finding methods to better support young people with ADHD in school is critical (Allison et al., 2019). There are many factors that commissioners, local authorities and mainstream schools could

consider in order to better support these young people. These include better resourcing of schools to support pupils with additional needs, training education practitioners on ADHD and related impairments, supporting families and young people going through the process of assessment and diagnosis, and developing school policies that allow for flexibility around individual need. More active liaison between education, health and other services around the child and family should also be supported and resourced to allow for improved communication and a more integrated understanding of needs and areas of strength. Ultimately, such changes are likely to benefit a wide range of children and families and develop an improved educational environment for all.

AUTHOR CONTRIBUTIONS

Abigail Emma Russell: Formal analysis; methodology; software; writing – original draft; writing – review and editing. **Simon Benham-Clarke:** Formal analysis; writing – review and editing. **Tamsin Ford:** Conceptualization; formal analysis; funding acquisition; methodology; writing – review and editing. **Helen Eke:** Data curation; formal analysis; methodology; project administration; writing – review and editing. **Anna Price:** Data curation; formal analysis; methodology; project administration; writing – review and editing. **Siobhan Mitchell:** Data curation; investigation; methodology; writing – review and editing. **Tamsin Newlove-Delgado:** Investigation; methodology; supervision; writing – review and editing. **Darren Moore:** Methodology; supervision; writing – review and editing. **Astrid Janssens:** Conceptualization; data curation; formal analysis; funding acquisition; investigation; methodology; supervision; writing – review and editing.

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CONFLICT OF INTEREST STATEMENT

Tamsin Ford received an honorarium for presenting the results of the CATCh-uS study to the Nurses Training forum funded by Takeda in March 2019. The authors declare there are no other known conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

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