

“I'm always up against a brick wall with them”: Parents' experiences of accessing support for their child with a newly recognised developmental disorder

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## Abstract

Three of the most prevalent developmental disorders (DDs) include autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD) and fetal alcohol spectrum disorder (FASD). As part of a study screening for DDs in Greater Manchester, UK, a unique opportunity was taken to explore parents' experiences of receiving reports about their child's previously unrecognised DD. Six parents out of a possible 16 took part in interviews, which were analysed thematically. Findings revealed a number of barriers to accessing support for their child's additional needs, including resistance from school especially for quiet, well-behaved girls, and difficulty accessing assessment or referrals. There needs to be greater awareness of additional needs in children without externalising behaviours; the presence of gender-specific differences in presentation of DDs; and FASD as a commonly occurring DD. Ultimately, better support for these children would reduce the burden of unmet needs for the children, their families and wider services.

## Introduction

Developmental disorder (DD) is a term used to cover a wide range of conditions all characterised by impairment or delay in the central nervous system (WHO, 2013). Three of the most common DDs are autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD) and fetal alcohol spectrum disorder (FASD). ASD conditions are characterised by deficits in social communication skills, unusual fixations and repetitive behaviours, and can be associated with intellectual disability (DSM-V, 2013). ADHD conditions are characterised by reduced attention span, increased impulsivity and often hyperactive behaviour (DSM V, 2013). FASD is the name given to a range of conditions which can be caused by prenatal alcohol exposure (BMA, 2016). The neurological deficits seen in FASD can impact on attentional and social communication pathways, and in severe cases, can lead to both ASD and ADHD as outcomes (Mukherjee, Wray, Curfs, & Hollins, 2015).

Of the three conditions ADHD is thought to be the most common, with an estimated global prevalence of 2-7% (Sayal, Prasad, Daley, Ford, & Coghill, 2018), and affecting between 1.4 and 8.8% of children in the UK (Polanczyk, De Lima, Horta, Biederman, & Rohde, 2007; Russell, Rodgers, Ukoumunne, & Ford, 2014). ASD has an estimated global prevalence of 0.7% (Baxter et al., 2015) and is thought to affect 1.7% of children in the UK (Baxter et al., 2015; Brugha et al., 2016). Historically more males than females have been diagnosed with ASD and ADHD, at a rate of around 2.5:1 male to female (Whitlock, Fulton, Lai, Pellicano, & Mandy 2020; Zwaigenbaum et al., 2012), and there has been much debate about whether this is a true distribution or due to lack of understanding of the how these conditions present in girls and women (Allely et al., 2019). FASD is thought to affect 0.77% of children globally and 2% in Europe. Estimates for the UK are at 3.24% (Lange et al., 2017), while the first study to directly assess for FASD in a small sample suggests a conservative estimate of 1.8% (Authors name et al., 2021). However, globally, only a small fraction of cases of FASD are diagnosed, and FASDs have been described as an under-recognised area of special educational needs (Blackburn & Carpenter & Edgerton, 2012; Carpenter, Blackburn & Egerton, 2013). FASD training is needed across different professional groups including teachers and other education professionals (Blackburn, Carpenter, & Egerton, 2012) The relatively low levels of training in the UK are reflected in significant knowledge gaps, and low levels of awareness and confidence of professionals (Schölin et al., 2021; Mukherjee et al., 2015).

The Assessing the Prevalence of Developmental Disorders in Greater Manchester Children Study (ADD-GM) (Authors name et al., 2021) was an active case ascertainment study that aimed to estimate the prevalence FASD and other DD's in mainstream schools in England. ADD-GM was the first study of its kind in the UK and was part of the Greater Manchester Health and Social Care Partnership's wider programme to prevent alcohol exposed pregnancies (Reynolds et al., 2021). In ADD-GM, all children in year group 4 (aged 8 or 9 years) had been first pre-screened and had been invited for full assessment if they were either: on the school's special needs register; small for their age (and/or with a small head circumference), in the care of the local authority (or previously in care), or if parents or teachers were concerned about the child's development or behaviour. Screen positive children had been invited for neurodevelopmental assessments, including two hours' of tests with children and two hours' medical history interview with mothers. Parents were sent a comprehensive report indicating likely diagnoses of a neurodevelopmental condition, and suggestions for actions they could take to support their child including onwards referral. Assessments for ADD-GM had been completed just prior to the UK's first national COVID-19-related lockdown (March 2020), which involved widespread disruption, including closing schools to most children and a move to online learning. This

formed a significant backdrop to parents' receiving the individualised report for their child. This study described here was carried out alongside ADD-GM, with the aim of exploring the experience of the parents of children who had a disorder identified by the screening study. As well as exploring feelings and opinions on the process and outcome, the study aimed to find out whether this had been impacted by COVID-19 related lockdowns.

## Methods

### Details of participants

Parents of children in two participant schools who had recently taken part in the wider ADD-GM study were invited to take part. After excluding one parent who had not yet received their child's report, 16 invitations were sent. Contact was made via email or SMS text message (the parents' preferred method of communication) to ask if they would be willing to give feedback on their experience of taking part in the ADD-GM study. Nine responded and received a participant information sheet and consent form, of which, six returned consent forms and agreed to take part in the interviews.

All participants ( $n = 6$ ) were female, identified as White British ethnicity, spoke English at home, were born in the UK and aged between 25-43 years (mean 34 years). Three of the participants were the child's birth mother, one was an adoptive mother, one a legal guardian and one was a foster parent. Four parents had achieved higher level education. The remaining two had achieved fewer than four GCSEs (or equivalent). The GCSE (General Certificate of Secondary Education) is an academic qualification taken in England at the age of 16 years. Since most people sit nine or more GCSE examinations, achieving four or fewer is considered a low attainment.

Two of the parents had opted their child into the study because of concerns over the child's development ('parent opt in'), one child had been invited due to being small for age, two children had been invited due to being under the care of the local authority (LA), and one previously under the care of the local authority (Prev LA). Three of the parents had received reports stating that their child may have FASD, two as ASD and one received a report suggesting ADHD (Table 1). All parents had received their child's final report on the assessment at least 30 days previously to ensure parents had adequate time to read and digest the results.

Further information about participants and their child is given in Table 1. Children are here by referred to using pseudonyms.

## **INSERT TABLE ONE**

### Design

A qualitative method was used in line with other studies examining parents' experiences of having a child with a DD (Mohamed, Carlisle, Livesey, & Mukherjee, 2020; Myers, Mackintosh, & Goin-Kochel, 2009; Salmon, 2008),

The interview guide comprised questions that probed the experience of taking part in the study. Parents were asked to describe their feelings, thoughts and experience of having a child identified as having a DD, identified during the course of the ADD-GM study. Interviewees were asked if their child had been seen by a specialist, about the support their child had received from school before and after taking part in ADD-GM. For the experience of taking part, we asked questions such as 'how did you feel when your child was invited?' 'What did you make of the results?' The support received after receiving the report was probed with questions such as 'have you accessed any of the support services mentioned in your report?' 'Has your child been seen by a specialist?' 'What impact has the report had on your child's school?'. We also asked whether COVID and the associated national lockdown had an impact (e.g. 'what impact has receiving this report had on your experience of lockdown?' 'How has lockdown impacted on your ability to access support?' 'What impact has lockdown had on your child's behaviour?'). Questions were developed by XXX and XXX and based on existing literature and on the research questions.

Digital recordings were made of each interview, with a mean duration of 28:00 minutes (range: 14:00 - 37:00) and the interviews were transcribed verbatim by researcher XXX.

### Analysis

Data analysis was informed by processes of thematic analysis – an inductive approach designed to identify, represent, and report thematic patterns that occur within the data (Braun & Clarke, 2006).

As the research questions guided the study, the first level of qualitative data analysis for interviews transcripts and observation data, was a priori. It allowed analysis to organise, condense and categorise data. This was followed at the second level by an inductive process that allowed initial codes or sub-categories that described participants' experiences to emerge. After initial codes had been identified in the first transcripts, subsequent codes could be compared and contrasted for similarities and differences in categories. Categories stayed close to the original expressions or records. Some were changed through abstraction and through combining of sub-categories during the analytical process (Charmaz, 2000). To increase validity, the transcriptions

and thematic analysis that had been conducted by the lead author were checked and coded independently by a second researcher (XX). The findings were then compared and reviewed by a third researcher (XX).

### Ethics

Informed consent, right to anonymity, right to withdraw at all stages of the research was established and re-confirmed prior to starting the recording. Ethical approval was granted by the **(host institution removed)** for the ADD-GM project (HSR1819-100 May 2019) and for this sub-study (HSR1819-100, May 2020).

## Findings

Analysis of the data revealed three main themes. One of the themes related to participation in a research study, and is not reported here as it is less relevant to education. Table 2 gives the themes and sub-themes reported in this paper. The first theme was “barriers to support”. This was a strong theme since none of the children had not previously received a neurodevelopmental diagnosis and therefore their needs had not been met at school. The second theme was “lockdown” and was related to the unprecedented circumstances of the first UK national lockdown as a result of the COVID-19 pandemic. It was prompted by our specific questions about lockdown.

### **INSERT TABLE TWO**

#### Barriers to Support

Universally, parents described obstacles to obtaining appropriate diagnosis, intervention, understanding or compassion for their child’s additional needs. This included failure to recognise and acknowledge the presence of additional needs, especially in school. Parents described resistance from school when communicating their concerns about their child's development, and/or actively advocating for formal assessment or support. This appeared to be a particularly significant issue where the children were described as quiet, well-behaved girls. There was overlap here with the theme of lockdown when parents described current barriers to diagnosis and support rather than those they had experienced in the past.

#### ***“Brick Walls” Accessing Support from School***

Several parents had experienced resistance when communicating with school and felt their concerns about their child’s development had been dismissed. In the wider ADD-GM study,

being on the school's register for special educational needs was one of the screening criteria for full assessment. However, none of the six parents who came forward for this study had their child listed by the school as having special educational needs. The reason that their children had been assessed was because they were opted in because of parent concerns or had been invited due to being currently or previously in the care of the local authority, or because they were small for age. When talking critically of the response from their child's school, parents spoke in a manner which suggested they were choosing their words carefully and were cautious with the tone they used. Despite this, parents described significant resistance from school when they raised their concerns.

*'I spoke to the teachers at parents evening first and I'd expressed our concerns to them ... and both the teachers were there, and they said, "Err yeah but well we don't see that little girl", and that had been the same response I'd had previously from the teacher last year' (Emily's mother)*

Alexander's mother reported that home-schooling during lockdown had made it possible to see more of Alexander's and other children's work. This parent felt there was an obvious difference, enough to suggest her child was significantly behind his peers and this was at odds with communication from school, which had placed the child as achieving age-appropriate levels:

*'So yeah, as a result of home schooling I think I've got a better idea of where Alexander is because they (school) say he's doing ok but, well school are telling me he's where he should be and ...I'm not criticising them, .... but I think he's quite behind. So, it's quite an eye opener and you shouldn't compare, but I see the other work that the other kids are doing, assuming the parents aren't doing it, he's quite far behind that' (Alexander's mother)*

Lucy's mother reported struggling to access support from school for her child for two years. She described how school argued against her request for assessment for her daughter, denying her concerns, and how she was left feeling patronised and belittled. This parent also used the metaphor of a brick wall for trying to get school to acknowledge that Lucy was struggling:

*'...yeah, about two years I'd asked for help. I'd asked to have her assessed and they'd been like there's no problem there's no problem and ... clearly there is. Yeah. I'm always up against a brick wall with them because they just look at me like I'm stupid I'm not stupid...' (Lucy's mother)*

Lucy's mother also explained she felt school were reluctant to acknowledge an issue and pursue assessment if they felt they were unlikely to get extra financial support for the child in the form of an Education and Health Care Plan (EHCP):

*'I'm not gonna lie I'll even say it to the school's face, unless they know that child's gonna get the extra funding they don't put anything through'* (Lucy's mother)

And for the same child, while school staff were reluctant to refer, they were also reluctant to allow adaptations without a diagnosis, and Lucy's mother described with frustration the process of trying to get support for her daughter as circular:

*'I've mentioned can she take ear defenders in, but they say no cos she's not diagnosed with anything.... it's a circle'* (Lucy's mother)

Another parent found that school staff now having awareness of her child's additional needs has been hugely beneficial to her daughter's experience at school. This is despite the changes only being slight, such as letting the child eat lunch in a quiet room and encouraging the use of sensory toys in the classroom.

*'they've put lots of little, just sort of little tweaks in place... the teacher will kind of say "change your pen" and direct her to the pen that's got the chewy buddy on'* (Emily's mother)

### ***"Little girls are getting missed" Quiet well-behaved girls***

A strong sentiment through interviews with the parents of girls, was the idea that their child's extra needs had gone undetected or unacknowledged by school as they were quiet and well-behaved. Gender was not mentioned by the parents of boys. By comparison, the parents of girls described having more contact with school. They were more likely to have initiated contact with school themselves and expressed more frustration with the process than the parents of boys.

*"I think a lot of little girls are getting missed because they do try, and they are more aware of what's socially expected of them even if they don't always enjoy it."* (Emily's Mother)

*'They say "yeah (mother's name) she is quiet in class; she is a bit behind her peers". Well DING DONG! Why is that bell not being rang? ... but it tends to be the child who is being very disruptive in class they will go for that child first rather than thinking Lucy is very quiet and wondering why'* (Lucy's mother)

Emily's mother felt having the support of other girls in Emily's circle of friends was masking some of Emily's symptoms. This parent implied that this would not have happened with a circle of friends who were boys and that this could have been one explanation as to why school had not acknowledged her daughter's additional needs earlier.

*'one of the things that has been picked up on while we're having the meetings is that sometimes they (Peers) can step in and kind of tell Emily what she needs to do to. Y'know that rather than letting her experience it, they say "Emily you don't like this, you need to do this, or you need to do that"' (Emily's mother)*

### ***"Not enough evidence" Accessing Further Support***

Parents were asked what had happened since receiving the diagnostic findings and suggestions from their child's participation in the wider ADD-GM study to identify DD, and their responses highlighted further barriers to accessing support. This included struggling to arrange referral and diagnosis and their feelings about accessing parent support groups and advocacy services.

Barriers ranged from resistance from school and medical professionals to local variations in referral pathways and their own readiness to ask for a referral. Some parents had been referred but none had received a confirmation letter or appointment date. One parent described being sent back and forth between school and the family doctor. The way Lucy's mother recounted the scenario communicated feelings of frustration, disbelief, and injustice:

*'I've been to doctor, they said school need to refer to CAMHs and basically went back to school, told school doctors need school to refer, they say we don't have enough evidence, I said well she been in your school since nursery. You must have something on her and basically and went back to the doctors and said "Look, one of yous is going to refer her!'" (Lucy's mother)*

One parent described how her family doctor had asked for a written list of symptoms as well as the study report findings before making any referral for a child who had been identified by the ADD-GM study as having FASD.

*'She (the family doctor) said to write some notes of my experiences, y'know symptoms that I'd noticed at home and send in a copy of your report with my notes. But I haven't written up my notes yet, but she thought without that, like some notes from me as well that she wouldn't... was unlikely she'd get a referral for ...anywhere really' (Charlotte's mother)*

Most parents talked about referral as an option or possibility rather than the immediate or obvious next step. They talked with reticence and often sounded unsure and vague when discussing it. George's mother, who was a foster-carer described:

*'it was brought up at the LAC [looked after child] review and they're not sure what they're gonna do about it at the moment whether we pursue it with him being assessed for this condition that he might have. So, we just talking about that at the moment'* (George's mother)

Kyle's mother described trying to access mental health services for her child and expressed her annoyance at reaching out for help for her child only to be offered parent courses:

*'the community mental health team said they don't work with children under the age of eleven...so, face to face anyway it's more erm doing courses for the parents or carers... and we've done all the courses!'* (Kyle's Mother)

All parents were sent information leaflets with their child's results, including details of local support groups but none reported having contacted the support organisations listed on them. Lucy's mother described why she felt a support group was not helpful for her as most of her child's issues were school-related. This same parent did indeed report improvement in her daughter's symptoms as a result of being home schooled during lockdown:

*'there is some good support groups local up here that you can connect to but .... because going to support groups doesn't help in school. when I'm trying to help Lucy in one way, she's in school nine to three [9am-3pm] it's all irrelevant, because school are gonna do what they're gonna do'* (Lucy's Mother)

### Lockdown

Government mandated lockdown restrictions related to Covid-19 between March and June 2020 were in force during the time in which the interviews were conducted, and this was a prominent theme in parents' responses. Although schools were not open to all students during this time, some of the children in this study were still attending school either because, as per the UK government rules at the time, they were under the care of the local authority, or because their parents were 'critical workers' (e.g. those working in health and social care, and key public services).

### ***“Losing Routines and bringing families closer together”*: Child’s Experience**

Participants, overall, reported lockdown had been a positive experience for their child and few reported increased anxiety or sleep or eating disturbances.

For children identified by the study as having ASD, parents reported their children liked the increased time at home and reduced travel and social expectations, such as for food shopping or visiting relatives. Parents expressed some surprise and relief at this:

*‘She’s quite enjoyed lockdown, because Emily doesn’t like going to crowded places, she doesn’t like going supermarket, going shopping so... and she doesn’t particularly like going visiting family members’* (Emily’s mother)

Parents of children identified as having FASD all reported a change in behaviour under lockdown that, although it had not been immediately obvious, as time went on their child had struggled more with the loss of routine and social interaction. This included issues with behaviour and emotion regulation, impulse control, and feelings of shame. One parent referred to their child's lying (which can be a symptom of poor memory function in those with FASD, which is more accurately described as ‘confabulation’). Some of these changes in behaviour are exemplified by the following comments:

*‘We’re struggling with him; his attention span isn’t great, he gets very frustrated, he gets angry constantly’* (George's mother)

*‘She handled it really well at first. For the first four weeks, y’know she was handling it really well with doing her schoolwork but once the novelty has worn off at home her behaviour’s kinda come back again’* (Charlotte’s mother)

*‘I think from a behaviour perspective yeah we’ve had a lot of tears, a lot of tantrums and he’s quite down on himself (...) we’re getting a lot of “I’m a terrible child” and I tell you what else has increased, the lying’* (Alexander’s mother)

Several of the children had continued to attend school through lockdown and parents spoke about this positively. They felt this was helpful to their child’s wellbeing. Some parents reported that still being able to attend school kept in place the structure that school provides both for day to day in terms of dictating a fixed time to get up and regular mealtime but also by preserving the structure of a working five-day week with a two-day weekend.

*‘he’s still been attending school so; he has been kept in the same routine which I think helps’* (Kyle’s mother)

No parents reported increased anxiety or fears in their children specifically related to Covid-19.

*'With regards to the news she doesn't know that much, she knows that it's a virus and it's out there, there and that's the reason mummy and daddy don't go to the supermarket together anymore and the reason we don't see family members'* (Emily's mother)

Several parents reported extra time together as a family unit as a positive aspect of lockdown and talked about the benefits of extra time at home. Some of these benefits included learning life skills that they would not have had the opportunity to learn about at school, for example about baby care:

*'It's really nice. They've been with us more... er... I think as a unit... and they've been helping out with the baby a lot, read to him and help with bathing and things like that so they're learning a lot. Yeah, in that respect I think it's brought us closer together'* (Kyle's mother)

Only one parent reported concerns that their child's education had been set back by lockdown; others reported that their child was missing friends and extracurricular activities:

*'She's gonna be a year behind as she missed so much school and I know she's gonna struggle because she's definitely going to need extra help when she goes back'* (Lucy's mother)

*'... he's saying he's missing his activities, his football cricket and swimming, but we all are missing the things we can't do. We'll probably all appreciate it more when we get back and do those things'* (Kyle's mother)

### ***"Waiting 'til we come out of lockdown" Finding support during lockdown***

Many participants referred to services not being available or further delayed during lockdown, and there was a sense stoicism and acceptance that nothing would be done until lockdown finished. This was in contrast to the frustration that was felt by those who had perceived that schools had failed to detect a potential problem.

*'...so we've had a referral to the mental health team for her so at the moment it doesn't seem that... but they're not working with families at the moment and its more parent and carers doing courses, well we've been on courses! So, there's not really a lot at the moment that can be done til we come out of lockdown'* (Kyle's mother)

In the case of Lucy's mother, the end of lockdown and return of 'normality' was going to be the point at which she would vigorously pursue avenues of support for her daughter:

*'When this corona goes, if it goes and life goes back to some kind of normality. I'm not even gonna lie, I'm gonna be on the phone, I'm gonna be badgering them all'* (Lucy's mother)

The waiting time for referrals had also delayed school-level support, as one parent felt they needed to wait for a referral before sharing their child's report with the school. Other parents mentioned that they had not accessed support groups due to lockdown. However, in contrast to the previous distress and frustration caused by resistance from school or general practitioners prior to lockdown, the lack of progress due to lockdown seemed to be accepted. There was a sense of being in stasis at this unique moment in time.

*'I was waiting to get referred erm and get a bit more information before I sort of jumped in and started talking to school...'* (Alexander's mother)

*'Obviously I haven't accessed that (support groups) as all the children are off school and I'm home schooling'* (George's mother)

## Discussion

This study reports on parents' experiences of school support for children with a previously undiagnosed developmental disorder (DD) whose difficulties had previously been unrecognised by the school. Although parents of children on the special educational needs and disability (SEND) register had also been invited to take part, the children of those parents who volunteered to be interviewed were not on the schools' register. All the children whose parents took part had had difficulties with engaging with learning at a level that could reasonably be expected to have been detected by a mainstream school in children of this age. Not surprisingly therefore, a major theme was frustration that the school had not detected and supported their children.

### Failure to Detect and Support

Parents reported many barriers to accessing the correct support for their child, expressing frustration and distress. Schools failing to detect that a child may need assessment or extra support increases the risk that individuals will present to services later with complex secondary mental and physical health issues that may have been preventable (DSM V, 2013; Streissguth et al., 2004). Long term lack of support can lead to increased risk of interaction with the criminal justice service, children's services, and hospital admissions (Bradshaw, Steiner, Gengoux, & Koegel, 2015; Streissguth et al., 2004). Therefore, failing to detect and support DDs is likely to have significant multi-service cost implications in the long term. In two cases, parents described having had their concerns dismissed by school for some time. The child we have called Lucy

was found to have a Full Scale IQ score of 66. While not a complete picture of a child's abilities, it does indicate a strong possibility that a learning disability is present. This had not been detected by the school despite Lucy's parent asking for assessment and additional support for two years. The issue was raised particularly for children who were described as 'quiet, well behaved girls', and this came out as a subtheme in our analysis. As observed by Lucy's mother, children who may be perceived by school as disruptive are more likely to be assessed than well-behaved children, and this is reflected in the findings of previous research (Van Bergen, Graham, Sweller, & Dodd, 2015). Similarly, Emily's mother described raising concerns over a year prior to taking part. Emily's mother attributed the failure to detect additional needs in girls to masking of symptoms. This is consistent with the findings of previous studies which have explored ASD in females (Allely, 2019; Hull, Petrides, & Mandy, 2020). An increasing number of studies have found that ASD is underdiagnosed or unrecognised in females (Russell, Steer, & Golding, 2011; Whitlock, Fulton, Lai, Pellicano, & Mandy, 2020). One of the potential explanations for this is camouflaging where females with ASD will compensate for and mask their autistic characteristics (Dean, Harwood, & Kasari, 2017; Hull, Lai, Baron-Cohen, Allison, Smith, Petrides, & Mandy, 2020; Halsall, Clarke, & Crane, 2021; for review see: Tubío-Fungueiriño, Cruz, Sampaio, Carracedo, & Fernández-Prieto, 2021). Camouflaging strategies are diverse. Some can be very simple (e.g., when someone develops rules to use eye contact in a conventional manner) and others can be complex. An example of a complex camouflaging strategy would be a teenage autistic girl who purposefully studies the behaviour of a non-autistic girl at school, and then, over time, adopts her attitudes, dress, gestures and facial expressions – essentially imitating the behaviour of the non-autistic girl. By doing this, the individual develops a persona in order to enable them to navigate social situations (Mandy, 2019). Given the well-established finding of camouflaging in many females with ASD, teachers and other professionals should receive training and have an awareness and understanding of how some girls with ASD may engage in camouflaging behaviours.

In the UK, the updated Special Educational Needs Code of Practice (Ponsford et al.; DfE/DOH, 2015) introduced the new Education, Health and Care Plan for children with SEND. The intention of these reforms was to ensure integration between educational provision and training provision, and health and social care provision, where this would promote wellbeing and improve the quality of provision for disabled children and young people and those with SEND. The most recent data for England show that although 12.8% of primary school children have acknowledged special educational needs, fewer than a third have been awarded with plans, suggesting issues in accessing the new Education, Health and Care plans except for children with the most complex SEND. Boys are more likely to be classed as having SEND (64.6%) and even

more likely to be awarded an Education, Health and Care Plan (ONS, 2020; Ward & McLoughlin, 2020).

The account of Charlotte's mother, who took their report to the family doctor only to be asked to make notes about Charlotte's symptoms before a referral could be made, illustrates a significant barrier to accessing support, which has the potential to increase health inequalities and echoes the findings of other research (Petrenko, Tahir, Mahoney, & Chin, 2014). This child was suspected of having FASD, and this barrier might have arisen because there is currently no official diagnostic pathway for FASD (although this is in development in England: NICE, 2021). This highlights the importance of increasing awareness of FASD and suggests there is a need to improve training offered to professionals. Relative to other conditions, FASD is associated with higher levels of shame and stigma (Mukherjee et al., 2015; Salmon, 2008). This could mean parents are less likely to pursue diagnosis and support. Indeed, Charlotte's mother came across as feeling defeated by the system and was yet to write up notes on her daughter's symptoms for their family doctor. By comparison, in this study, parents of children identified with ASD and ADHD were more comfortable naming and discussing these conditions, which are more widely known and understood in recent years. This suggests drawing from the success of campaigns to increase awareness of ASD and ADHD, similar campaigns could bring about similar progress for FASD and other DDs.

The study was carried out at a particular moment in time when the UK had gone into the first national government-mandated COVID-19 restrictions. There was an acceptance that there was going to be a longer wait for services, and a reluctance to push for a referral. This may have been because participants were aware of the general pressure on the health care system, and that waiting lists were longer for care for many different conditions. The feeling that everyone is having to wait seemed to be linked to a degree of stoicism and acceptance.

### Lockdown

The wider study to identify DDs in schools, the ADD-GM study, was in the process of completion by the time the first UK national lockdown (between March and June 2020) was implemented. One research aim was to investigate how this unprecedented situation had interacted with the experience of receiving the report that stated that their child had a previously unrecognised DD. While schools were closed for the majority of pupils, some of the children in this study were still attending school either because they were deemed 'vulnerable' (due to being in the care of the local authority) or because their parents were 'critical workers' (e.g., health care or key public service workers).

Overall, the parents reported little negative impact of lockdown on their child, whether children were still attending school or not. Parents of the children identified as having FASD were more likely to describe lockdown-related changes in behaviour, which could indicate increased levels of stress or distress in these children. Parents of children identified as ASD felt their children benefited from reduced social interactions and travel. There is little research to date relating to children's experiences of the first lockdown. Further research is needed to identify if these positive stories are generalisable for parents of children with ASD or DDs or the general population, and whether the negative stories are generalisable to children with FASD.

Data collected by the Children's Commissioner in England suggest in general, children's levels of anxiety have increased as a result of COVID-19 (Children's Commissioner, 2020). However, no parents in our study reported increased anxiety in their children related awareness of COVID-19 or media coverage of the pandemic. This is an interesting finding as anxiety is a symptom associated with all three conditions. It also contrasts with symptoms of anxiety that parents described in their children relating to attending school, travel and social interactions.

### Strengths and limitations

Although over a third of the eligible parents took part in the study (6 out of 16), the sample size was nevertheless small, making it difficult to extract findings specific to factors such as the specific DD, the gender, or parents' socioeconomic status. The sample size is adequate according to recommendations for thematic method of analysis (Braun & Clarke, 2013). The findings of this study may be affected by the bias of the individual parent, or the interviewer. Transcriptions and analysis were repeated independently by another researcher and reviewed by a third in an attempt to improve the validity of the findings. The fact that parents of children already on the SEND register chose not to take part suggests that this sample may have been more reflective of those who were grateful to receive our report on their child's DD. As with much qualitative research of this nature it is possible that individuals with strong feelings were more likely to take part. These are limitations inherent to qualitative research and mean the results may not be generalisable to the wider population. Nevertheless, studies to investigate the prevalence of DDs in school settings are rare, and this study capitalised on an opportunity to explore parents' experiences of taking part, thus making a novel contribution to the literature.

### Conclusion

A wider study into the prevalence of DD, the ADD-GM study, provided a unique opportunity to examine the experiences of parents of previously undiagnosed children. The findings of this research revealed significant barriers for parents when accessing support for children with the three most common DDs. The mainstream schools who took part in ADD-GM had previously

failed to detect and support significant additional needs in this particular group of children. A lack of recognition was perhaps unsurprising for FASD, which although common, is widely unrecognised. However, similar issues were raised by parents of children with ASD. Parents' reluctance to discuss FASD may indicate the shame and stigma associated with FASD is another barrier specific to detection of the FASD, and this is likely to be another barrier to accessing support. Another barrier was experienced for parents of girls: for children described as 'quiet, well-behaved girls', parents' concerns had been dismissed by school for some time prior to their participation in the study. Parents felt that children with externalising behaviours were more likely to be assessed and supported, and that camouflaging of ASD symptoms in girls may be another factor affecting detection in mainstream schools.

The disruption caused by the COVID-19 pandemic was another barrier to accessing services. The national lockdown was a strong theme in itself, with experiences being markedly different between participants, from those whose children were still attending school, to those who were not, and those whose behaviour improved during lockdown (typically for ASD) to those where it got worse (typically FASD).

Further research is needed to measure the extent of undetected and unsupported additional needs in primary schools in England.

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## Tables

*Table 1 descriptive data on participants' children.*

<b>Pseudonym of child</b>	<b>Gender</b>	<b>Reason for invite</b>	<b>Identified disorder</b>
Alexander	Male	Prev LA	FASD
Charlotte	Female	Parent Opt in	FASD
Emily	Female	Parent Opt in	ASD
George	Male	LA	FASD
Kyle	Male	LA	ADHD
Lucy	Female	Small for age	ASD

Prev LA previously under local authority care

LA under local authority care

FASD fetal alcohol spectrum disorder

ADHD attention-deficit/hyperactivity disorder

ASD autism spectrum disorder

*Table 2 Themes identified using framework analysis*

<b>Theme</b>	<b>Sub-theme</b>
Barriers to support	Accessing support from school
	Well behaved girls
	Accessing further support
Lockdown	Child's experience
	Accessing support during lockdown
Participation in a research study (not included in this article)	Reaction to invitation
	Parent and child experience of data collection
	Receiving the report
	Impact
	Shame and stigma as a barrier to participation