



Not Fine in School

SCHOOL ATTENDANCE DIFFICULTIES: PARENT SURVEY RESULTS

May 2018

'Not Fine in School' was established in 2017 by parents who are working in partnership to offer support and guidance to other parents and professionals. In addition, we also campaign and raise awareness of school attendance difficulties.

Our group was created in reaction to the growing number of children who are struggling to attend mainstream school, and the difficulties parents experience in finding understanding and support for their children. Whether their struggle is related to anxiety, unmet Special Educational Needs, physical illness, bullying or academic pressure, many children are experiencing increasing difficulties within education systems in the UK, and in other countries around the world.

We have a Facebook parent support group with 1,767 members on the day we published this report (approximately 50 new members join each week). Our Facebook public page and Twitter page allow us to share stories and articles of interest with a wider audience.

In March 2018 we launched our website where we publish our resources, articles and member's personal stories.

The Survey

In May 2018 we devised a simple survey to gather data from parents in our Facebook group, and in other parent support groups on Facebook. Our aim was to create a snapshot of the current situation and illustrate the difficulties parents are experiencing.

The survey was shared on social media for one week and received 1,661 responses during that time.

This report provides details of the findings. We have included a large number of comments made by parents in the survey as they all have a valid voice that needs to be heard. We also felt that collectively, the comments and descriptions illustrate the situation much more vividly than any other data source.

SUMMARY OF FINDINGS [1,661 responses]

Attendance: 25.6% of parents have children who are attending school with anxiety and mental health difficulties. A further **18.4%** have children who are attending with SEND difficulties, and **19.3%** have children not receiving any educational provision at all.

Onset: 74.6% of parents have children who started to experience difficulties before secondary school age (**43%** at primary school and **31.6%** at nursery age). This reflects the WHO (2013) observation that half of all mental health conditions first occur by the age of 14.

SEND: 92% of parents think that school attendance difficulties are related to SEND that are inadequately supported or unrecognised in school. **64.1%** of parents report that their child has a SEND diagnosis and a further **26.6%** of parents suspect a diagnosis is needed.

Influences: Inadequate support for SEND (**73.7%**), along with Cognitive Difficulties (**60.9%**) and Pre-existing Anxiety Disorders (**51.8%**) are considered to be highly influential. Social Anxiety and Friendship Difficulties are also a concern according to **70.2%** of parents. Other influences that are considered most significant are the School Environment (**73.7%**), School Culture (**62.3%**), Academic Pressure (**62.4%**), and Bullying (child or adult) (**44.3%**).

Support: Those services and professionals we automatically turn to when school attendance becomes an issue do not score highly for their levels of support. Considering the definition of their role, EWOs were only found to be supportive by **5.4%** of parents. Local Authorities (**13.7%**) and Social Workers (**10.2%**) do not rate highly for support. Neither do school based staff - School Nurses were positively rated by (**7.5%**); School Counsellors/Therapists (**12.7%**); School SENCO's (**33.1%**) and School Teachers (**33.3%**). The most supportive source is peer related with social media support groups rated by **66.7%** of parents, and online websites found supportive by **46.5%** of parents.

EHCP: The most striking aspect of the feedback here is that although **24.6%** of parents have been successful in getting an EHCP in place, another **20.4%** have been told by schools or CAMHS not to bother applying, or that they will not get an EHCP. In addition, a further **20%** of parents do not know what an EHCP is, suggesting that professionals are not providing them with relevant information about the options for their children in getting the right support. Parent's comments also reveal that their applications are being obstructed, or they are being misinformed about the relevance and process of applying for EHCP's.

Educational Provision: School adaptations such a reduced timetable or changes to the environment have been tried by **67.9%** of parents and schools. **34.7%** of parents report that they have been provided with homework by their school. Alternative provision has been provided in some cases – via home tuition (**11.6%**); hospital school (**4.1%**); PRU (**4.7%**); SEN school or unit (**12.2%**) and funded online school (**4%**). **6.4%** of parents are funding online school themselves, while **22.3%** are home educating. **17.8%** of parents have children who are not currently receiving any educational provision, and **12.4%** have children currently too unwell to take part in any education.

'School Refusal': Considering that the term we hear used most frequently in practice and debate is 'school refusal', we were surprised to see that a diagnosis of 'school anxiety' was reported by more parents in the survey (**5.1%** compared to **14.6%** respectively). **74.8%** of parents stated that an attendance related diagnosis had not been given at all, which suggests that there is a lack of acknowledgement of many children's difficulties.

Blame: The results illustrate the tendency to blame school attendance difficulties on poor parenting (55.5%) and/or children's negative attitudes towards school (60.8%).

Penalties & Prosecution: While 26.3% of parents reported that they have been threatened with a fine as a penalty for unauthorised attendance, a smaller figure of 2.5% have actually been fined. We were surprised to find the number of parents who report being prosecuted for non-attendance is low at 1.3%, however, that does equate to 20 families who were unfairly put through a distressing and costly experience.

Almost a quarter of parents (24.9%) report that they have been referred to Social Services because their child has a difficulty with school attendance.

FII: Almost a fifth of parents (18.4%) report that they have been accused of Fabricating or Inducing Illness (FII) in relation to their child's difficulty with school attendance.

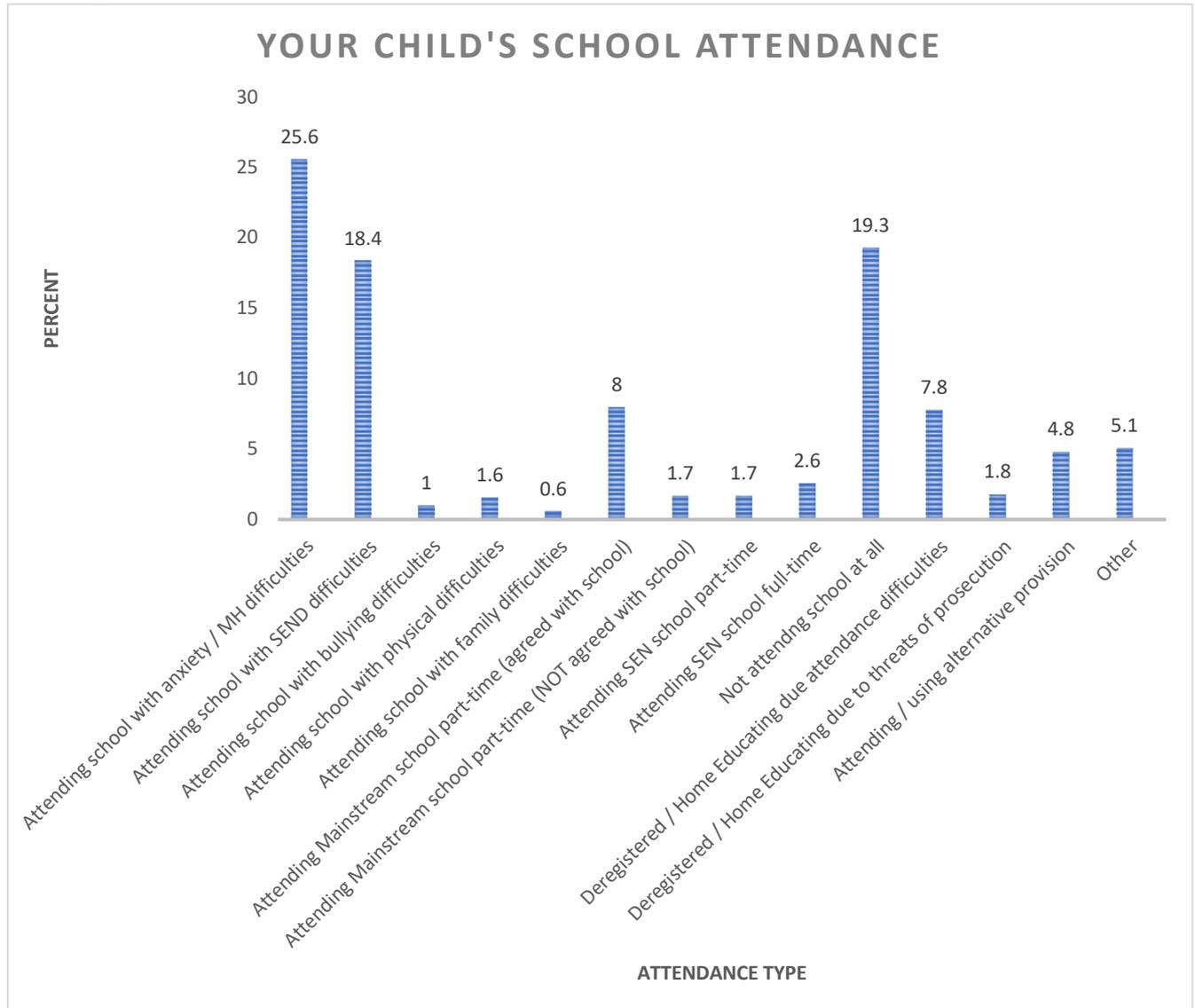
Forced Attendance: Almost half (45.5%) of parents in the survey state that they have forced their child to attend school, as they felt under pressure to do so; in addition, 21.2% felt under this pressure but have refused to force attendance.

When asked if they use of force was helpful in resolving their child's anxiety, 36% said no, and 59.1% said it has made things much worse. Only 0.4% of parents thought force did help and 4.5% thought it might have helped.

SURVEY RESULTS

School Attendance

Which option best describes your child's attendance currently?



[1,661 responses]

It was difficult to define and measure the options for this question because there is a wide variation in approach and options provided when a child struggles to attend school. Many people wanted to tick more than one option, which must surely reflect the chaos that is created by the lack of recognition of the problem and the lack of guidance for schools on how to resolve it.

The most significant things to note are the number of children who are not receiving any educational provision (19.3%), and the number of children struggling to attend with mental health difficulties (25.6%).

A SAMPLE OF PARENT'S DESCRIPTIONS OF THEIR CURRENT SITUATION

Home educating because school was so horrific he was suicidal

Deregistered due to ASD, mental health problems. Informed LA that cannot HE any longer in March, nothing in place at present. Will be EOTAS from September.

Home educating because of complex needs meaning unable to cope in school

Deregistered because she couldn't cope with school

Attending with a reduced timetable due to anxiety, send needs and bullying.

SEND - Autism, plus severe anxiety and OCD - Still in school, just.

Home Educating due to bullying by staff, due to a lack of specialist school places. Which lead to reluctance to attend, and threats of prosecution from educational social workers

Now in college, but previously in mainstream, then at home, in the PRU then in independent specialist provision

Deregistered and home educating as mainstream became unattainable because child is on the 'Highly Sensitive' framework and couldn't cope with noise and crowds.

Deregistered and internet schooled following mistake in school and threat of expulsion.

Been permanently kicked out of mainstream and now seeking alternative education

Deregistered/home educating because our non-verbal child was unhappy - didn't realise until later that he had been attempting to tell us how much he didn't want to go to school/refuse school.

Has EHCP and is in independent school. Diagnosed ASD at 13 and only just full time after 1 year of school refusal.

1 hour a day at Pupil Referral unit. My son has ASD and high anxiety

Trying to be allowed to attend school but constantly excluded as school can't meet SEN

My son 17 I can't get him into a college, so still has no education.

Enrolled, not attending, receiving one-to-one tuition outside the school, 4 hours per week

Attending a PRU for children with anxiety and school refusal, after refusing to go to school due to anxiety and bullying.

My son refuses to attend school when he deems he can achieve his study aims more effectively at home.

Attending special school full time and being excluded for PDA behaviours.

Deregistered/Home Educating due to bullying issues and the school being unable to safely and properly put in place steps to support my ASD son.

In specialist school with mental health problems

She has type 1 diabetes as well as clinical depression and anxiety

MH, SEMH, SEND & physical difficulties due to genetic condition led us to part-time timetable at therapeutic school

My child is on role at a school but has not attended full time for 18 months, he is currently signed off as medically unfit after 8 months of trying a reduced timetable. He receives 2 hours of home tuition a week, this is all he can currently manage.

Back attending full-time after cause of anxiety was finally addressed after missing four months

Daughter is ASD with GAD and OCD and phobias

Attends mainstream as and when able to, marked as ill when not attending.
Asperger's, with anxiety. EHCP in place.

Medical provision outsourced to an internet provision

The school staff bullied my SEN son to a breakdown

Online school while registered at mainstream

Whilst on pathway awaiting diagnosis the length of time is causing additional anxiety

School now pay for 'Interhigh' as daughter can't access school

Twin is suspected ASD / PDA and refuses school

Attending, arriving late, anxiety and ASD

Alternative part time specialist provision with anxiety due to mental health and has EHCP.

Home educating due to reasons outlined above and because no school exists in the area to help those children who are too academic for special school and too autistic for mainstream school

Just managing 3 brief sessions per week with SENCO having been off completely for 6 months

Also inadequate SEN support and bullying tactics by the SENCO

Threatened prosecution but still refuse to home educate as not in best interest for my daughter or myself
Very high anxiety, rarely attends. Also attending vocational training place. Again rarely attends.

In a reintegration programme

Goes to expected secondary school with tutor 4 hrs a week 1 to 1

Although my son goes to school 4 afternoons a week he does not access classroom or learning environment, he remains within residential unit and is supported by residential staff

Currently refusing to attend special needs school.

Stopped attending due to significant anxiety and has not gone onto further education – 17

Attending with anxiety and high sensory needs. Main carer has recently had to leave part time job to meet these needs to enable attendance (and general wellbeing) at school.

Has autism, very high anxiety because of school will probably have to home school eventually because of this as he's not coping at all in yr5 and will not cope at all with high school.

Deregistered because of fears for my child's health. We were threatened with prosecution also but not the main reason for deregistering. My son breaking down was.

Has additional learning and medical needs which are not been met

My child is allowed to go in late without any repercussions, also learns at home when needed

Attends one hour per fortnight 1-2-1 maths lesson. Private English tutor. Mixed anxiety/depression, ASD traits, bullying

Attending mainstream school with medical needs - spends a lot of time off unwell and in hospital

Nurture group also attended 3 mornings a week

Home educating due to SEND /mental ill health which caused non attendance

Still registered at mainstream but studying with 'Interhigh' at home.

Also separation anxiety after his mummy died

Attending very sporadically on an ad hoc basis owing to MH difficulties, undiagnosed despite 15 months in the CAMHS system.

Nurture provision for 2 days per week, no education other 3 days as School say cannot meet need & we refuse to home educate. LA aware. 14 weeks education missed so far. Still on role at previous mainstream primary.

Taking unofficial leave, revising for GCSEs, authorised by school

My son is attending school but sporadically.

On the brink of de-registering

My daughter isn't attending school due to mental health and bullying

Attending p/t and moving on to home education from next week.

My son has Type 1 Diabetes which affects him physically but also mentally. It is a very difficult condition to manage and stress and illness can make it even more challenging.

Attending school part time agreed with school but not EWO with ANXIETY ISSUES

Remained in primary for year 7 doing a slow transition to high school

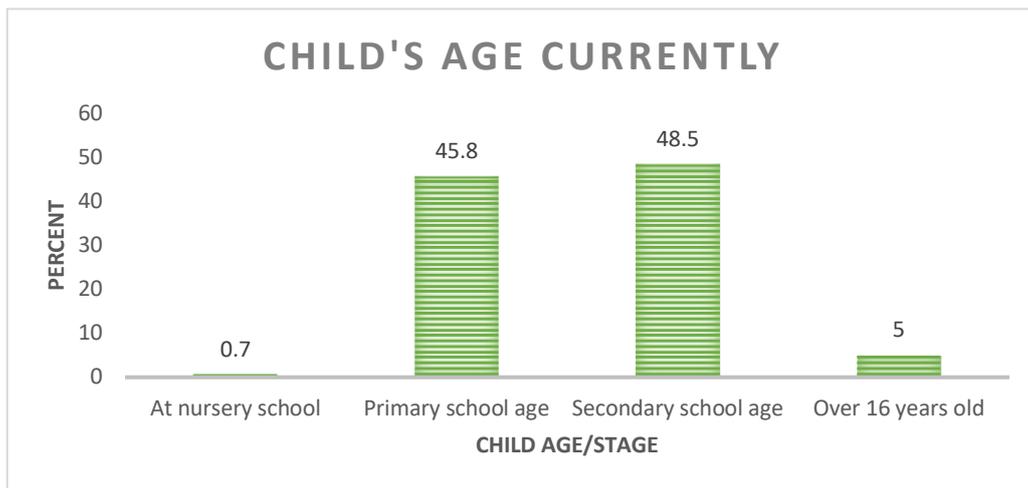
Trying to get anxiety and mental health better and using BBC Bitesize for subjects he can manage.

School provide tutors for maths and English

Separation anxiety and sensory difficulties, school refusal some days but happy to go in other days

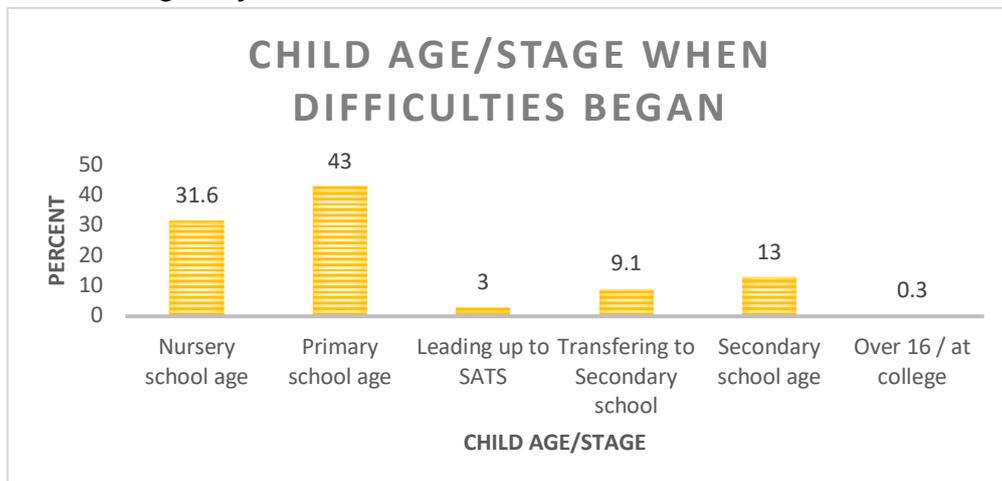
Child has been permanently excluded due to the school's inability to deal with their SEN

Your Child



[1,661 responses]

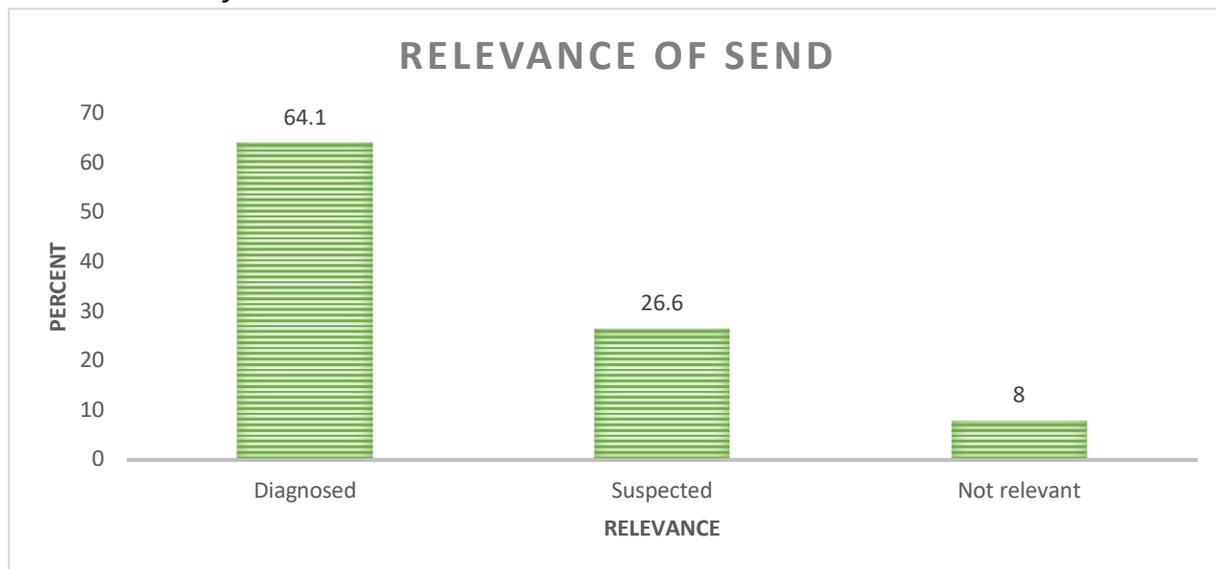
When the difficulties began my child was:



[1,661 responses]

Special Educational Needs or Disability

Does your child have a diagnosis or do you think they should have a diagnosis of a Special Educational Need or Disability?



[1,661 Responses]

What diagnosis has been given?

The lack of appropriate support for children with special educational needs or disabilities is clearly a factor in school attendance difficulties. We gave parents the option of stating what diagnosis their child had received and for approximately 650 – 700 parents their response involved Autism, ASD, ASC, HFA, Asperger's Syndrome or Tourette's Syndrome.

A diagnosis of other types of SEN were repeatedly mentioned such as Dyslexia, Dyspraxia, ADHD, ADD, Sensory Processing Disorder, Somatic Pragmatic Disorder, Pervasive Demand Avoidance, ODD, Learning Disorder, GDD, OCD, Irlen Syndrome, Down Syndrome, Ehlers Danlos, EDS, POTs, Foetal Alcohol Spectrum Disorder, HEDS, Working Memory and Cognitive Processing Speeds.

Also frequently mentioned were –

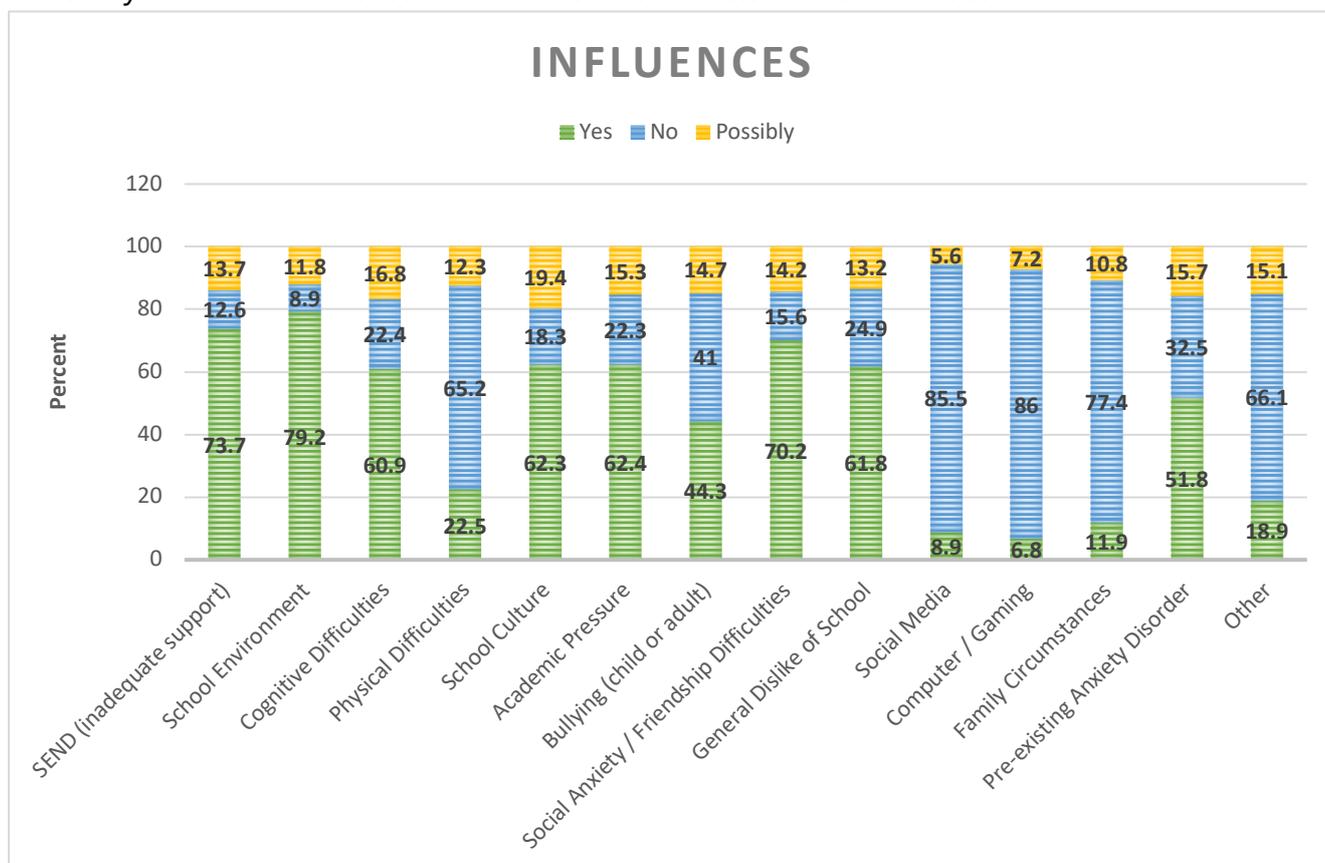
Anxiety disorders such as: Generalised Anxiety Disorder, Separation Anxiety, Social Anxiety Disorder, and Selective Mutism.

Mental health difficulties such as: Depression, Anorexia, Low Self-Esteem, Suicidal Ideation or Tendencies, Attachment Disorder, Trauma, PTSD and Emetophobia.

Physical Illnesses and Difficulties including: Hypermobility, Epilepsy, Asthma, Chronic Pain, Motor Coordination Disorder, Fine Motor Difficulties, ME, Chronic Fatigue Syndrome, Chronic Constipation, Encopresis, Ulcerative Colitis, IBS, Migraines, Diabetes, Hyperacusis, and Hypotonia.

Influences

What do you think has influenced or caused the school attendance difficulties?



Inadequate support for SEND (73.7%), along with Cognitive Difficulties (60.9%) and Pre-existing Anxiety Disorders (51.8%) are considered to be highly influential. Social Anxiety and Friendship Difficulties are also a concern according to 70.2% of parents. Other influences that parents consider are of most significance in relation to attendance difficulties are the School Environment (73.7%); School Culture (62.3%); Academic Pressure (62.4%) and Bullying (child or adult) (44.3%).

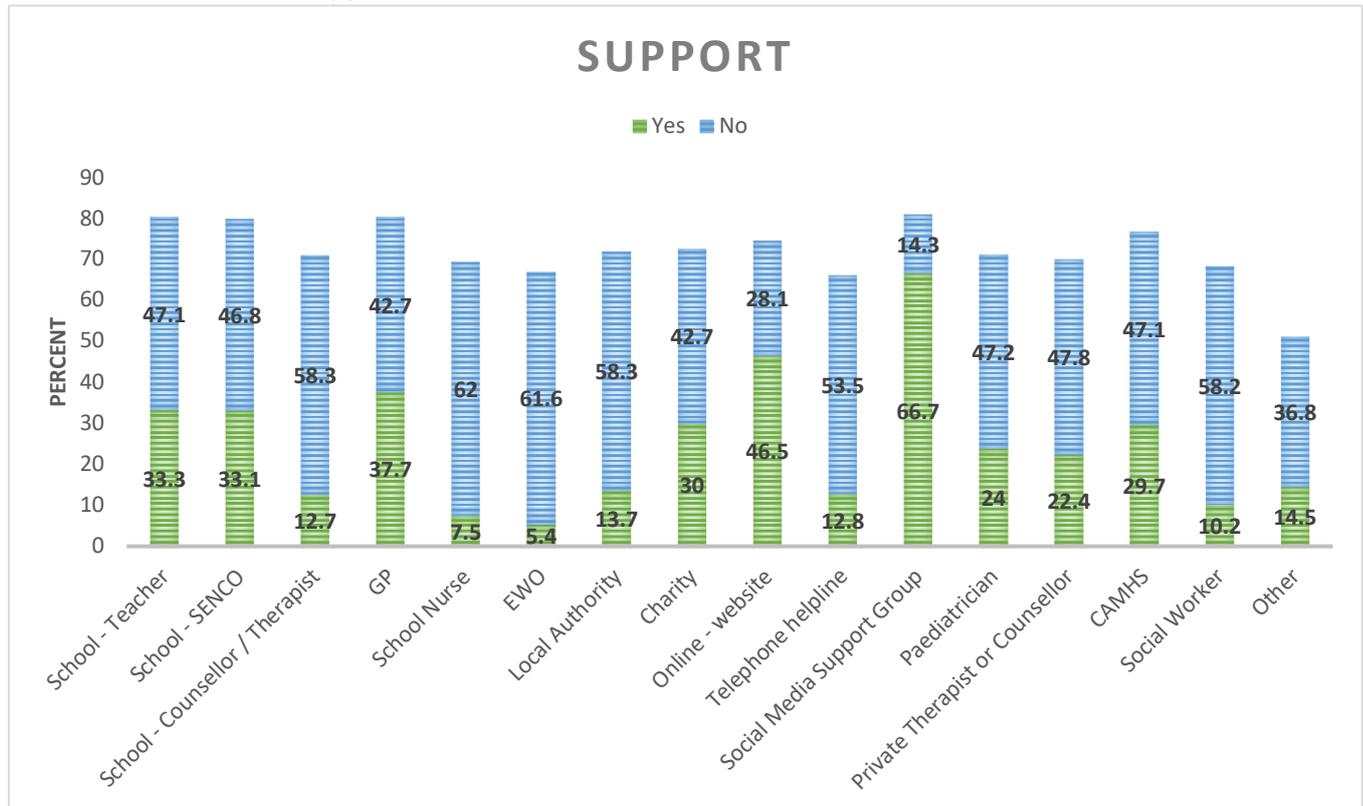
We seem to hear many reports in the media expressing concern over the effects of social media (8.9%), computers and gaming (6.8%), yet parents who completed the survey do not seem to share these concerns. They do not consider these are a major factor in school attendance difficulties. It could be argued that this reflects what the Children's Commissioner referred to as the "two sides of social media" in the *Life in Likes* report – observing that social media influences can be positive and negative.

A child's general dislike of school is acknowledged by 61.8% of parents. A dislike of school could be linked to any, or a combination of the factors related to school attendance.

Existing research and literature has tended to lay the blame for school refusal on family circumstances, yet only 11.9% of parents agree with this opinion.

Support

Where have you found support?



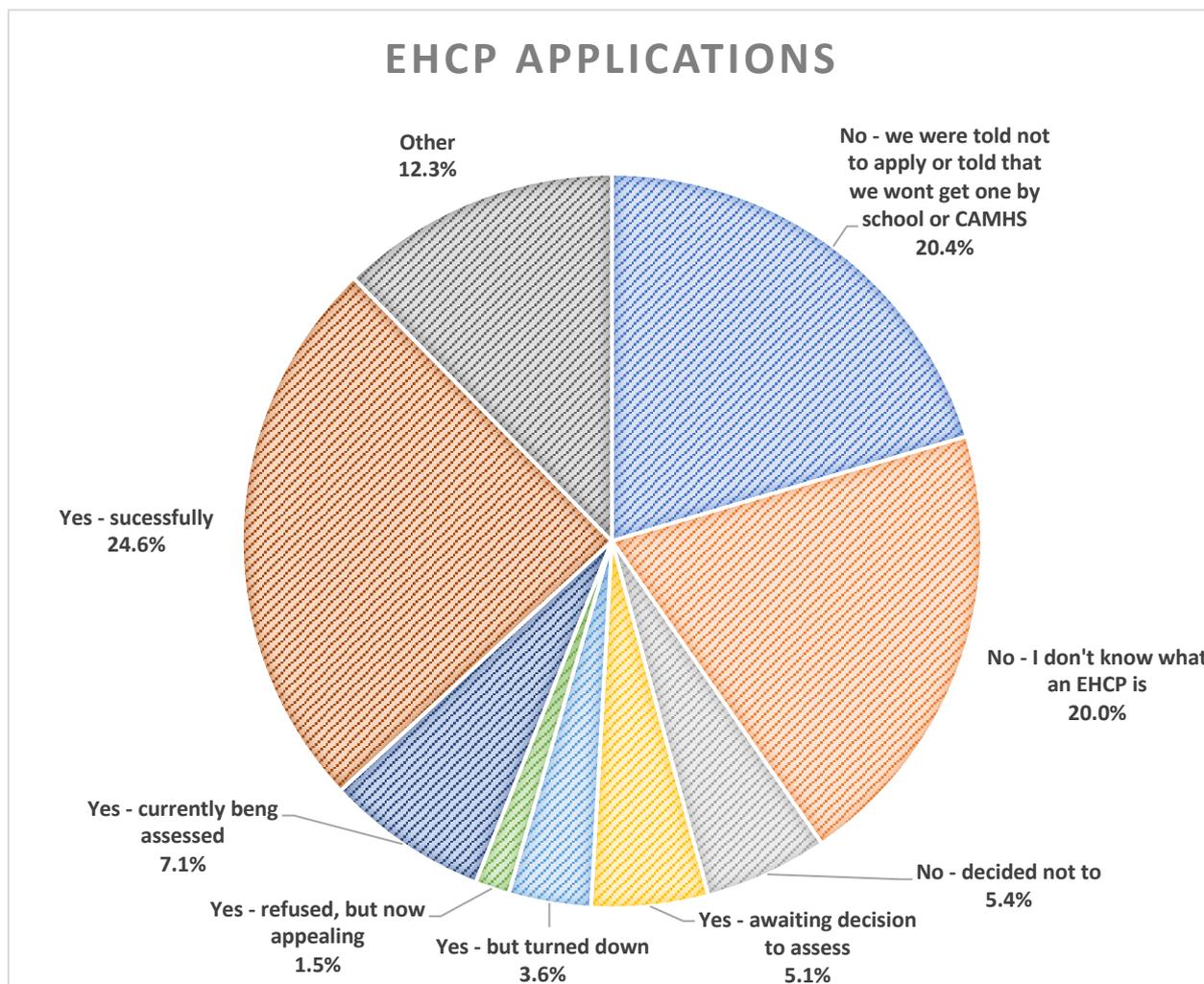
Those services and professionals that we automatically turn to when school attendance becomes an issue did not score highly for support in the survey - Educational Welfare Officers were only found to be supportive by 5.4% of parents yet their original role is deemed to be one of support and problem resolution. Some argue that funding cuts and political demands have now changed their role to one purely of monitoring and enforcing penalties.

Local Authorities (13.7%) and Social Workers (10.2%) do not rate highly for support, and neither do school based staff - School Nurses (7.5%); School Counsellors/Therapists (12.7%); School SENCO's (33.1%) and School Teachers (33.3%). There are various reasons why support from those professionals (who are expected to know how to help children) is not rated highly. One of the biggest difficulties appears to be the difference in priorities of parents and professionals that has been created by the demands of data collection, accountability and funding cuts.

The most supportive source is peer related with social media support groups (66.7%) and online websites (46.5%) offering the most highly rated levels of support. Members of support groups often observe that they feel great relief in finding other people who understand how they feel, and can offer advice about the problems they are struggling with.

Education Health & Care Plans

Have you applied for an EHCP?



The most striking aspect of the feedback here is that although 24.6% of parents have been successful in getting an EHCP in place, another 20.4% have been told by schools or CAMHS not to bother applying, or that they will not get an EHCP. In addition, a further 20% of parents do not know what an EHCP is, suggesting that professionals are not providing them with relevant information about the options for their child.

A SAMPLE OF THE 'OTHER' COMMENTS ABOUT EHCP APPLICATIONS

Not appropriate. He just needed to be out of the school environment causing the anxiety.

We will apply if his ADOS indicates ASD or if he can't overcome anxiety

My son is at a medical needs school but on roll at a 14-16 college provision. The school believe he should have an EHCP but the college he is on roll at have done nothing to support this. They haven't even turned up for the last two EHP meetings! And their head is the EHP lead!

No – we are in Scotland / Australia / Ireland / Wales / Jersey (where EHCP's do not apply)

Assessment agreed and undertaken. 2.5 yrs later, still without an issued Plan that meets need and is properly quantified, specified and funded. Stage 2 complaint going through at Council. Exceptional Circumstances Funding 2 years application at CCG.

Yes but it took 53 weeks to finalise causing SEMH issues for my child

Not considered yet due to no diagnosis

The school have not yet been ready to apply for one until my son has a medical diagnosis to support the need to have one

Given but not completed as no school can be found

School told us in a meeting in Nov 17 that they would apply early for an Education Psychologist report (apparently school usually have to observe students for two terms to assess a need for an EHCP) in order to start the ball rolling quickly. In a meeting at school in April 18 (6 months later) they now tell me that when they rang (Nov 17) to get an Ed Psychology appointment they were told that because there was a backlog of assessments that no appointments would be given, and to ring back in April 18 to be given an assessment date. School have now rang (April 18) back as advised, and are still unable to get a date for an assessment. School are also NOW telling me that they will sort out the paperwork for the EHCP and send it in WITHOUT an ED PSYCHOLOGIST REPORT. Time is ticking and my daughters education is suffering because the process of obtaining an EHCP is NOT fit for purpose.

Refused, successfully appealed, but by then too ill to attend

Would now like to apply but as daughter is 15, told it's too late

Yes, but doesn't meet needs

Yes now (2nd time round) 1st time refused due to school saying he had no SEND. 2nd time AFTER applying (being refused due to school), then complained to governors, school reported to SS, SS threatened child protection unless we stopped asking the school to put him on SEN register / support - specialist family support workers sent into school to investigate our 'child abuse' - suddenly dropped without a word and the local authority issued an EHCP (no mention of social care needs !!!!)

Turned down, failed at appeal insufficient evidence - CAMHS let us down

Applied twice, both applications 'lost'

About to begin - but told to expect to be turned down.

Currently collecting evidence towards EHCP

Applied for statement went to tribunal for part 4 lost the tribunal they named a school that it was impossible for him to attend and he has been out of school. He's not attended for 3 years.

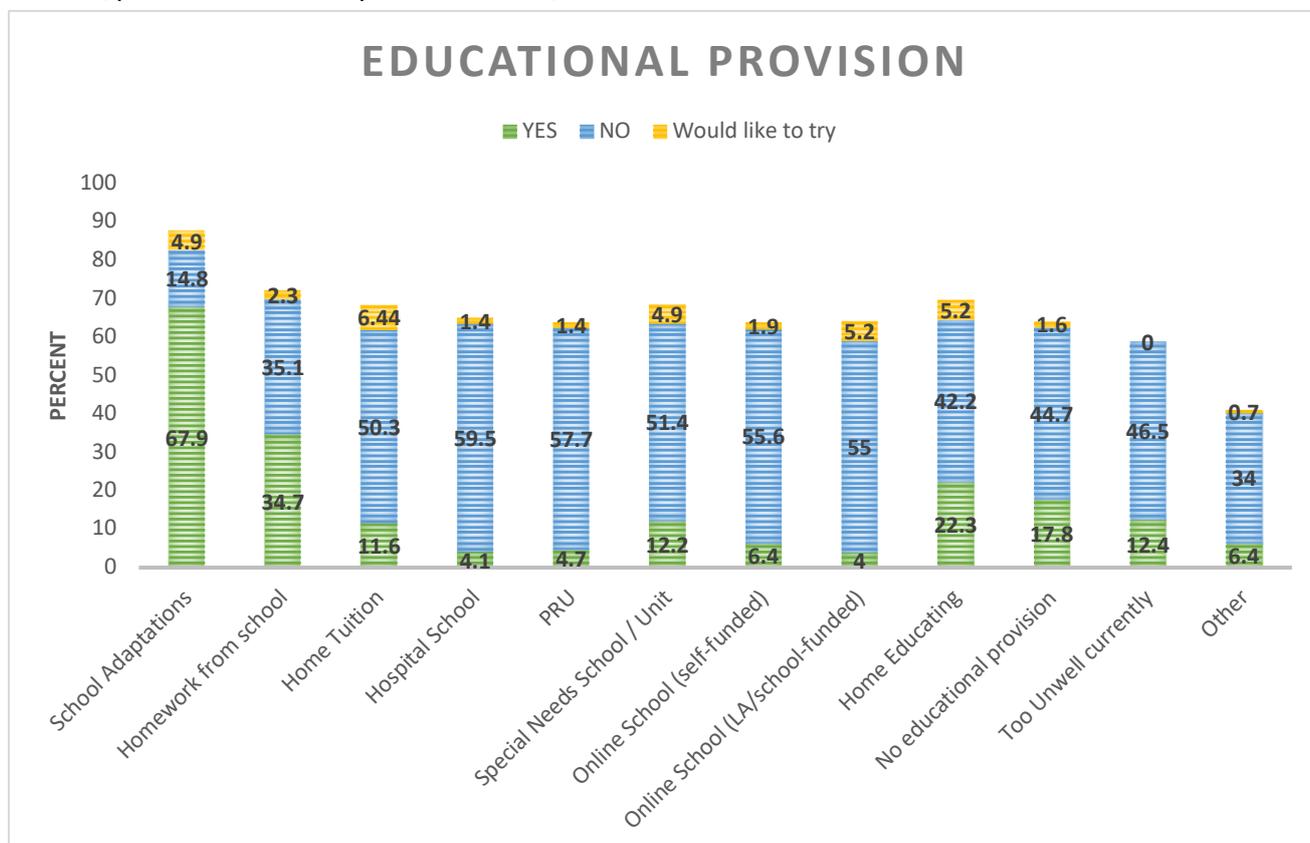
Yes after being told not to bother, being refused to assess then granted.

Issues arose too late. As very able and compliant until total school refusal, they did not recognise his SEN.

Please note: These comments reveal that many EHCP applications are being obstructed, or parents are being misinformed about the relevance and process of applying for EHCP's.

Educational Provision

Which types of educational provision have you tried?



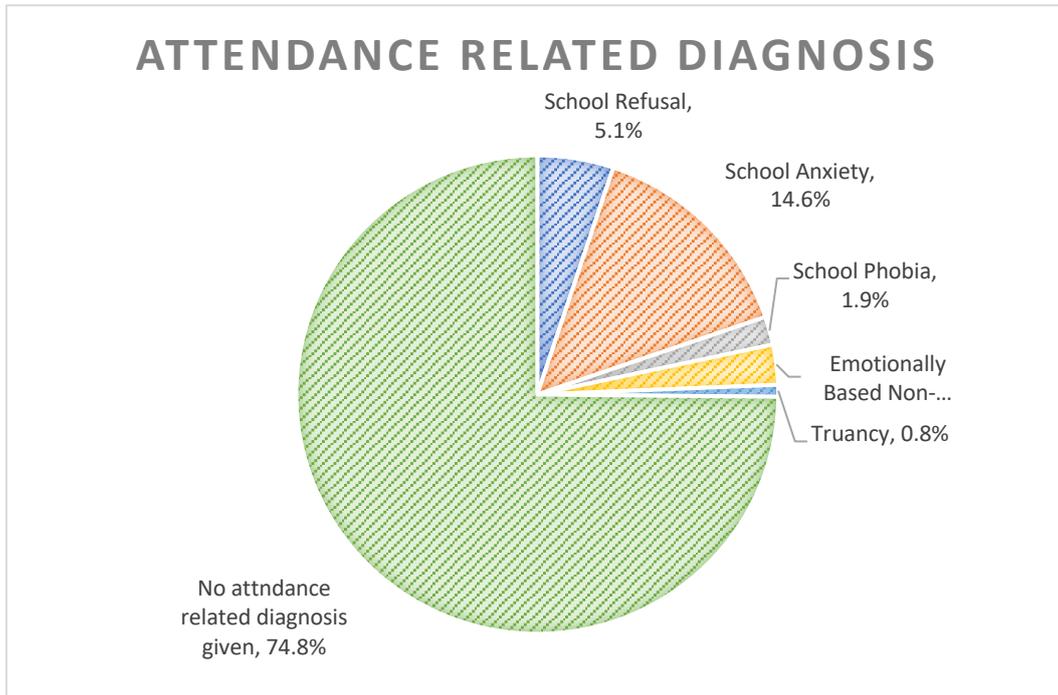
School adaptations such as a reduced timetable or changes to the environment have been tried by 67.9% of parents and schools. 34.7% of parents report that they have been provided with homework by their school.

Alternative provision has been provided in some cases – via home tuition (11.6%); hospital school (4.1%); PRU (4.7%); SEN school or unit (12.2%) and funded online school (4%). 6.4% of parents are funding online school themselves, while 22.3% are home educating.

17.8% of parents have children who are not receiving any educational provision and 12.4% have children who are currently too unwell to take part in any education.

'School Refusal'

Have you been given a diagnosis of:



Understanding the meanings attached to the label of 'school refuser', and the influence of these meanings is an important consideration. It is suggested that the label a pupil is given has significance as it influences perceptions of the child and the subsequent management of a situation. It can be argued that the lack of an agreed standard term or definition restricts the identification of children requiring support, and in this case, causes misunderstandings about the reasons for school absence.

The lack of clarity in understanding reasons for non-attendance begins with the differentiation between truancy and school refusal. A child who truants is usually absent without their parents knowledge, is generally unmotivated in regard to their education and the absence does not have an emotional basis. Alternatively, a child who is school refusing does so with the awareness of their parents, has previously been achieving well academically and is concerned about their education, but is negatively affected by emotional (or other) difficulties.

In 1932 Broadwin first noted a type of school truancy that was specified as 'absence from school due to excessive anxiety'. Then in 1941 the term 'school phobia' was first used by Johnson to refer to 'a type of emotional disturbance in children associated with great anxiety that leads to serious absence from school'. Since then it has been identified under a variety of labels that reflect differing attributed reasons for the difficulties, these include: 'home-bound school absence' (Waller & Eisenberg, 1980); 'school refusal' (Berg et al, 1969) and 'emotionally-based-school-non-attendance' (West Sussex Educational Psychology Service, 2004/2018).

There is a lot of confusion, debate and protest about the terms 'school phobia', 'school refusal'

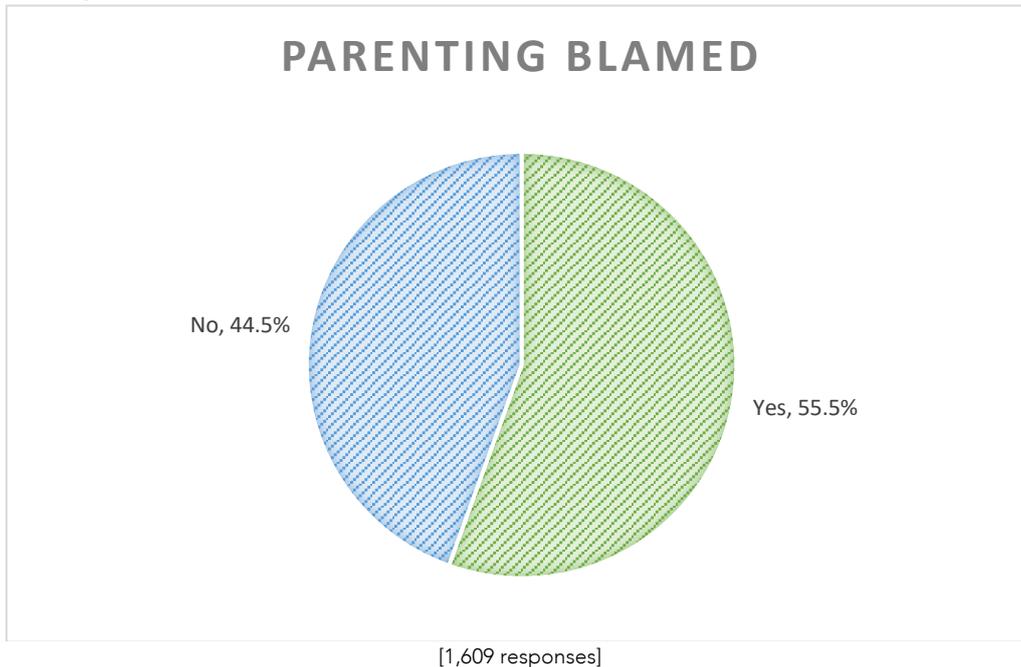
and 'truancy', which highlights the tensions that exist in defining the problem and apportioning cause or blame. Pellegrini (2007) suggested the variation in terms happens because the problem has been 'conceptualised by different agencies' and so has tended to reflect the related clinical, medical or educational focus. In response, he suggested the term 'extended school non-attendance' would be preferable as a more neutral and less judgmental option to describe the problem.

The range of terminology creates obstacles for families in locating the correct support because the focus on 'within-child' explanations, prevents additional consideration of alternative factors such as the school environment and academic pressure. This is significant as Kearney and Silverman (1990) highlighted, the crucial issue in resolving school refusal is to identify the function and need behind the behaviour. Therefore the terminology used to describe the difficulty could deflect attention from the correct causal areas in assessments and consequent treatments.

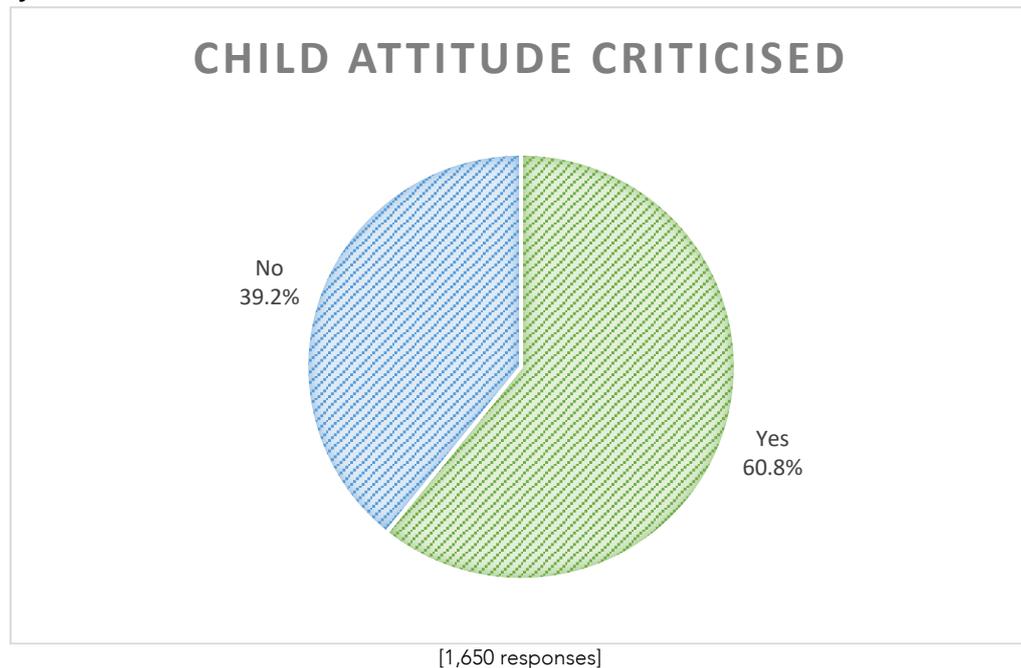
Considering that the term we hear used most frequently in practice and debate is 'school refusal', we were surprised to see that the use of 'school anxiety' was reported by more parents in the survey (5.1% compared to 14.6% respectively). 74.8% of parents stated that no attendance related diagnosis had been given and that suggests that there is a widespread lack of acknowledgement of many children's difficulties.

The 'Blame Game'

Has your parenting been blamed for the difficulties?



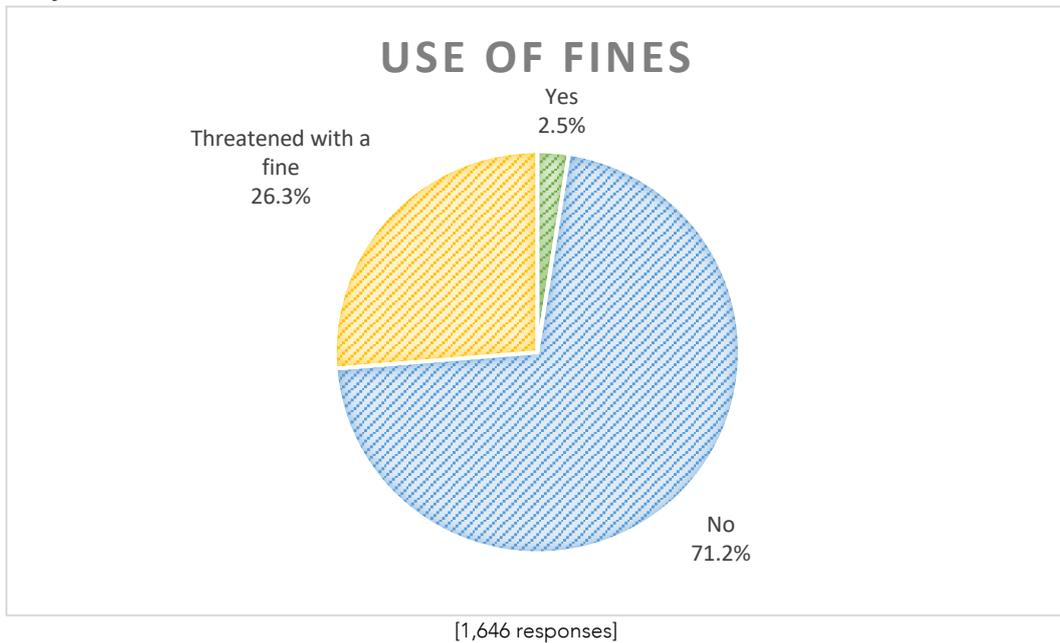
Has your child's attitude to school been criticised?



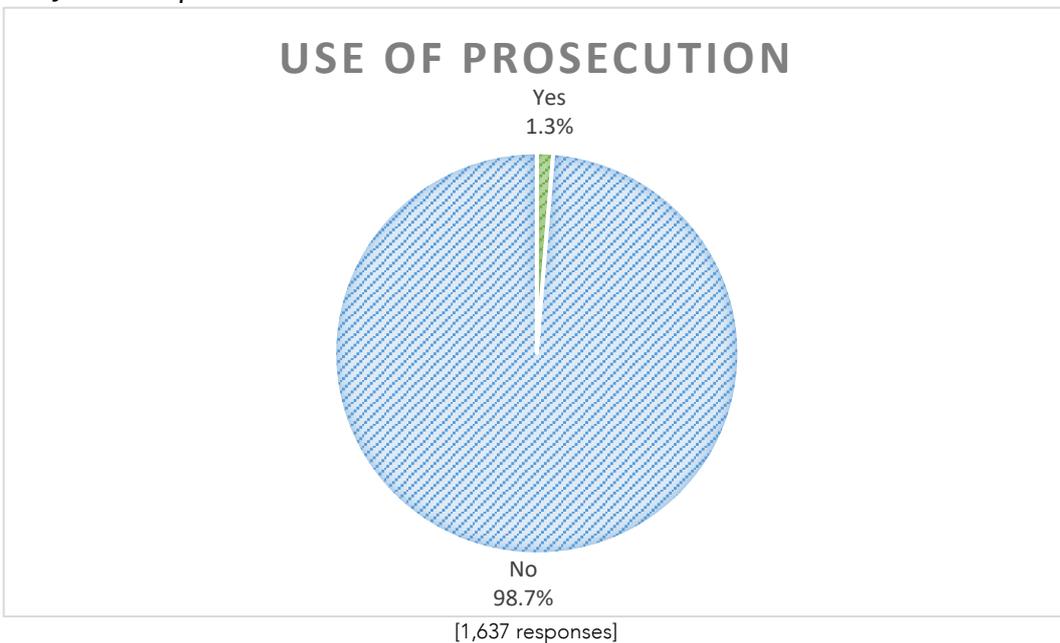
These results illustrate the tendency to blame poor parenting (55.5%) and/or children's negative attitudes towards school (60.8%). This is a frustrating thing to experience when parents are generally doing all they can to resolve the situation. Children and young people are often desperate to continue their education and be 'normal' but they find they are overwhelmed with anxiety and rather than not being bothered about school, they are simply unable to go.

Penalties & Prosecution

Have you been fined?



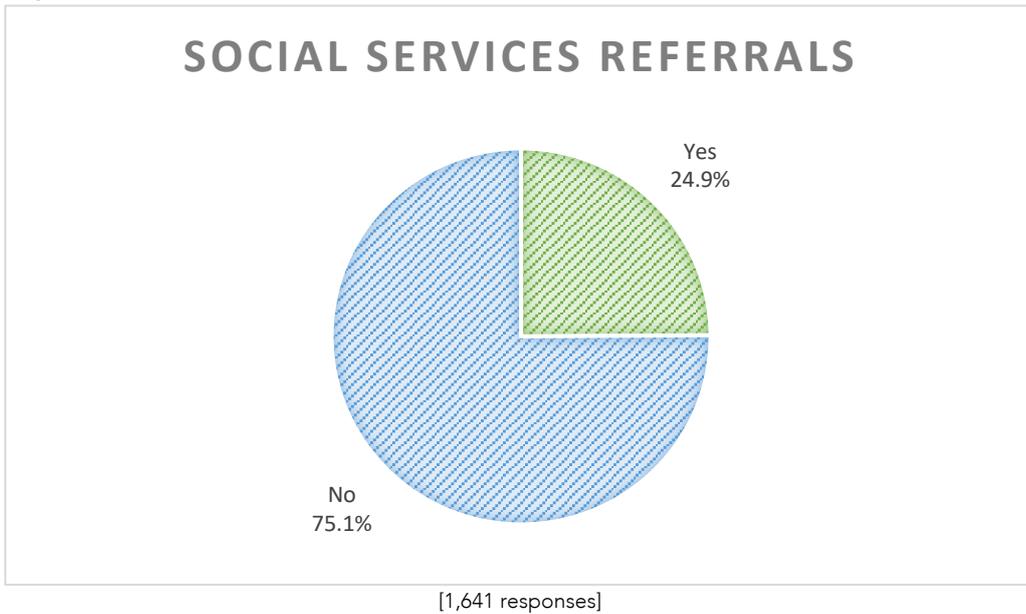
Have you been prosecuted?



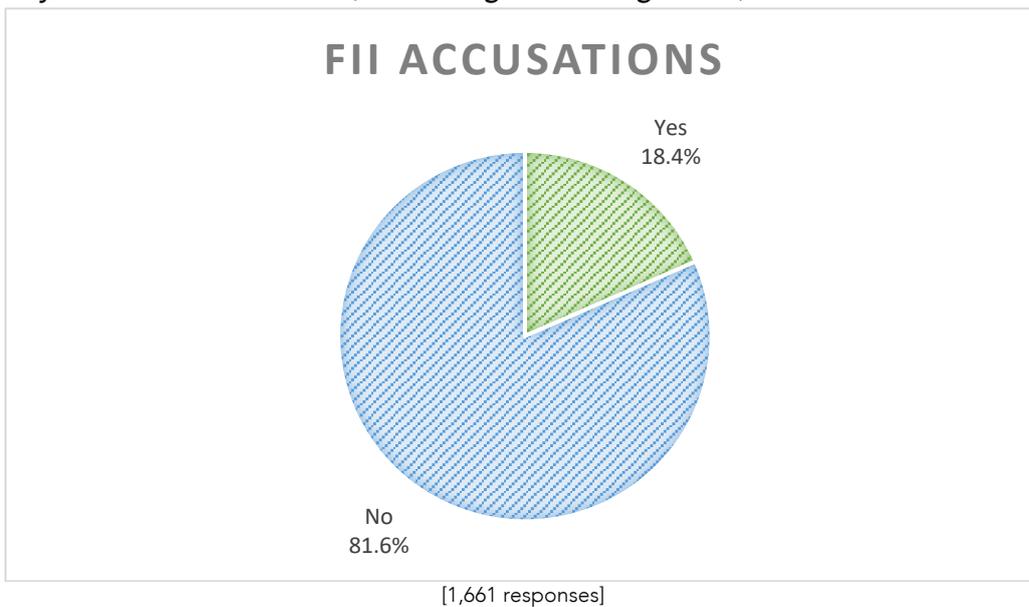
While 26.3% of parents reported that they have been threatened with a fine as a penalty for unauthorised attendance, a lower number of 2.5% have actually been fined.

We were surprised to find the number of parents who have been prosecuted for non-attendance is low at 1.3%, however, this equates to 20 families who were unfairly put through a distressing and costly experience.

Have you been referred to social services?



Have you been accused of FII (Fabricating or Inducing Illness)?

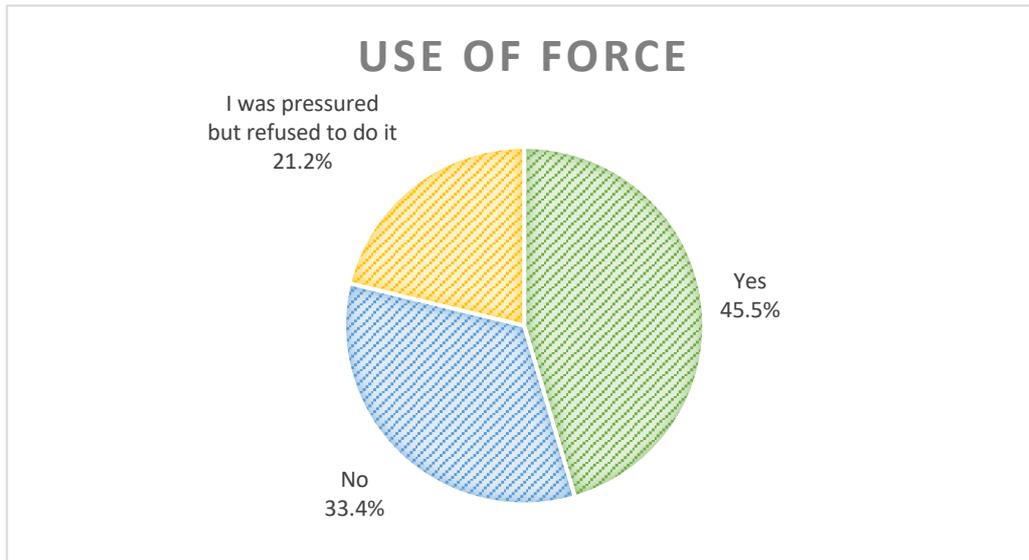


Almost a quarter of parents (24.9%) report that they have been referred to Social Services because their child has a difficulty with school attendance.

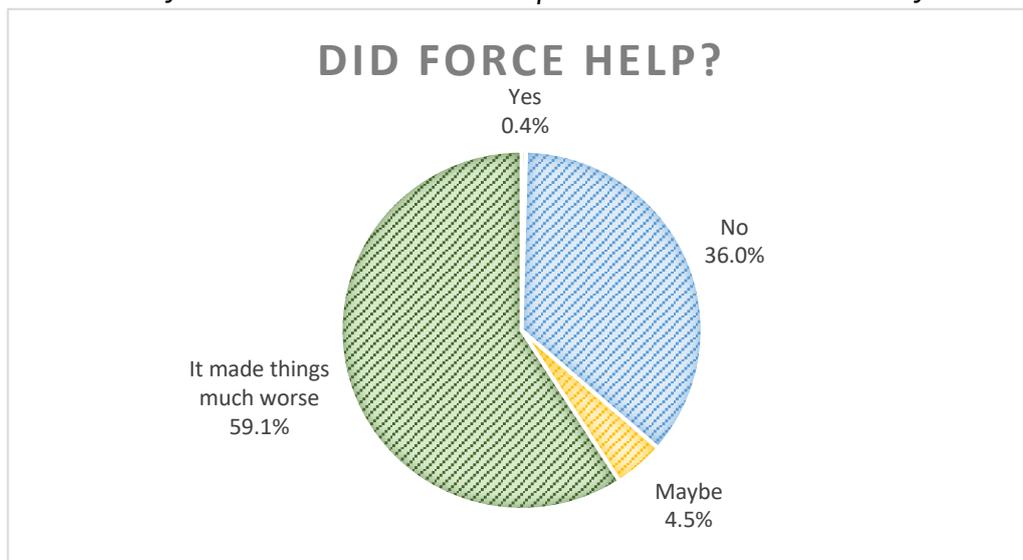
Almost a fifth of parents (18.4%) report that they have been accused of Fabricating or Inducing Illness in relation to their child's difficulty with school attendance.

Forced Attendance

Have you been made to force your child into school?



If you did force your child to attend did it help them to resolve their anxiety?



We hear many parents say that they have been put under pressure to force their child to attend school, no matter what effect it has or how difficult it is. Some parents have been told to 'drag their child in no matter what, even if they are in their pyjamas'. Almost half (45.5%) of parents in the survey state that they have forced attendance as they felt under pressure to do so, and 21.2% of parents have felt this pressure, but have refused to force attendance.

When parents were asked if the use of force was helpful in resolving their child's anxiety, 36% said no, and 59.1% said it had made things much worse. Only 0.4% of parents thought it did help, and 4.5% thought it might have helped.

APPENDIX

Parents were invited to submit a comment at the end of the survey and many people took this opportunity to express their feelings, and describe the difficulties they are experiencing. We decided to include all of the submissions in this appendix as we feel all parents have a valid 'voice' that deserves to be included. We also felt that collectively, the comments and descriptions illustrate the situation much more vividly than any other data source.

My son was diagnosed with ASD after 2 failed school placements. the 3rd school knew he was under assessments but still failed to support him maintaining he was fine in school. School refusal due to unmet needs and anxiety around school. successful with getting EHCP but another mainstream named so appealing for specialist provision

Our child suffers from ongoing anxiety but masks well- she does well when support is in place - she collapses when HTs take that support away cos she seems fine to them - we are a rollercoaster of educating school staff into keeping the support in place. We currently have good support but had terrible year 6. It is a constant spiral due to lack of understanding.

The months (& education) are slipping away and my child is not being helped. I've only just realised that my daughter has been refusing school because of extreme anxiety.

School has great difficulty in believing the child's problems are education related, rather they believe it is as a result of weak parenting

The forcing into school only happened twice but that was two times too many. Didn't happen again. In a previous question about support SENCO tried to help but school attitude made it difficult. GP offered to write school a letter regarding the anxiety. LEA offered to investigate and audit the school because they were being paid to supply an LSA but weren't for weeks.

SEN provision within statement not provided by school. Should have had full time 1:1 support but found out too late this was shared out between other children. By the time we realised the root of the problem school anxiety was beyond reconciliation. Totally traumatised & unable to return. It hurts!!

We thought all would be well once we got him to indi SS and it was for 1 year. Then management and staff change and there was a huge failing by school and I had to pull him out. We have been left hanging with no support. After safeguarding complaint to LA we were managed out (L.A. all over them now). Currently putting together stage 2 complaint for failure to provide education stipulated in section F of the plan. All my 10 year old son's trust in school, teachers and most adults is now broken.

Can't cope 😞

Support has been severely lacking, and the current timetable was something I fought for months to get in terms of support. Now we have it, progress is slow but steady and consistent! However prosecution has been threatened because progress isn't fast enough - despite part time timetable being instigated with permission, and in the presence of the EWO.

Absences and lateness have also been recorded incorrectly, without consideration of anxiety being a health issue.

Our daughter will never be able to return to her current school, despite being predicted A's and B's at GCSE in all subjects - neither will she reach her full potential if she is only ever going to receive 5 hours Home Tuition a week 😞 That said we will NEVER again force her into a school - her mental and physical health is far more important than any education!

If my son's primary school has listened to me when I first brought up my concerns in year 2 I don't feel he would ever have got into his current situation. He was diagnosed in year 9 but by that time he hated school, had terrible anxiety & felt all teachers were against him & had severe self-esteem issues. Now dealing with mental health issues and slowly trying to rebuild a relationship with school with only 1 year left before he leaves.

In some ways I am lucky because I have worked in education. We have had money to pay for extra help, this gives the impression we are proactive parents. Talking to other parents I have been shocked at how they have been treated. I always tell people, dyslexia was only described as a phenomenon, when every other possible parent blaming explanation had been ruled out. This is why dyslexia was perceived as a middle-class class issue, because all the working class dyslexic children had bad parents!

Awful terrible bad attitude and lack of services. Suspicion on family.

The pressure on attendance at all costs is so detrimental! The 'one size fits all' education system is so unfair on children.

As much As the SENCO is making noises I don't think that she is actually doing anything. This could be because my son is yr6 and about to leave there anyway...

We had years of no help from schools and they blamed us for not taking her to school. It was only when we got a new CAMHS key worker and there was a new SENCO at senior school(who was a friend and knew how much we were struggling as a family) that we began getting help. If my friend had not got the job she did we would be in a totally different situation. We are still trying to get more help but there's not a lot out there. It's a constant fight which is draining.

In the last week we reached near crisis point and for the first time in two years of increasing school refusal we are being listened to and the school are pulling their fingers out to get some help and support in place. We will see what happens. I don't know where we would be without the understanding and support of the social media groups I am a member of.

CAMH services are the worst people ever I would never trust them ever again. They almost caused our family to split up.

My child would be ok in school now that the timetable had changed to part time and all lessons would be 121. However he cannot get himself to school - he has no resilience and desperately wants to get back to school. This is where support for mental health is lacking. Medical needs team have refused to do an assessment because he has an EHCP so the school feel they have no option than to try home-schooling him with the learning support teachers that he already knows! This will only be for 6 weeks so he gets some sort of education. Without this we would just be left to get in with it!

My child needs a diagnosis very strongly believe it is dyslexia, has very hard time reading etc. School refuse to get him the test and say nothing will change but say they are doing all they can. They are NOT. My son needs to know why he finds it hard to understand and school is not doing all they can! I buy more school provisions than them!!!!

Parents are made to feel like they are to blame & keeping the child away from school. Letting the child down.

School's lack of understanding of emotional and psychological trauma caused by medical issues has compounded problems.

We have meeting with EWO in few days: their attitude so far does not suggest that they will be supportive.

No help from school as I am able to get child to attend school, late most days, if unable to get child to attend will be marked as unauthorised with no explanation from school !

Lack of places in specialist schools. I've had to fight to get a move but no place until August meanwhile we are left adrift. Why is specialist provision the last resort instead of a proactive choice for parents.

Daughter has prosopagnosia which we have only recently discovered.

For six months we were in a strange position where they acknowledged her diagnosis of chronic anxiety by a consultant psychiatrist so agreed to a reduced timetable yet simultaneously marked all absences as unauthorised. The result was that this prevented her being referred to the LA for the support she needed and as her attendance worsened we found ourselves threatened with legal action. After a year of problems and complete non-attendance in year 11 they finally referred to the LA after the intervention of our psychiatrist. The LA were amazingly quick and within 3 weeks she had a home tutor. She is flourishing now. What saddens and angers us is that she should have received that help months earlier and it was only schools obsession with registers/attendance that stopped this. How can that be allowed?

Even though signed off as unfit for school for last year, we have had very little official support with education: nothing for first 6 months, then 1 hr per week for 5 months, only just increased to 2 hours per week.

Withdrew daughter in y1, school claimed I taught her to be autistic. Home Ed for 18 months, then moved to new school who have been amazing, they fought for her dx of Autism and full believe she has PDA too. She's now doing 2 hours a day in a PRU and loves it. Increasing to 3 hrs this month.

Teachers don't believe us when we have expressed concerns about our son having anxiety regarding son and meltdowns at home even though we have video evidence of these. All they see is a child that doesn't misbehave at school but is academically 3 years behind his classmates.

My child has migraines as well as dyslexia. Leading up to a migraine will become very agitated and will school refuse had no support in primary now in secondary and we have a health plan and is believed so is less stressed as is able to manage this more easily.

My child also epilepsy and is on several medications which effect their cognition. On the dyspraxia levels but won't diagnose cause of neurological condition

The lack of support and being told to force her into school made things worse and had a detrimental effect on the whole family. It's so hard when you constantly ask for help but keep getting told it's your fault and your child is being naughty and that they are "fine once they are in school." She is quite clearly not.

I am disgusted with having to fight for 8 years for the support my child deserves. We have received a lot of support from a Pastoral Support Officer based in school There seems to be a lack of understanding at that school refusal could only be part of the issue kids mask especially girls and teachers need training on ASD in girls x

CAMHS have been useless. They diagnosed separation anxiety but said I just need to be firm but kind.

School staff need to listen to and believe parents because they know their children best. This is the most traumatic time of my life so far.

Although not accused of FII it's been hinted at. My child was told in front of me by the head of first school that mum and dad will get in trouble if she doesn't come in to school. When seeking help paediatrician told me to force her in - that was the advice (child being assessed for ASD at the time. No help available anywhere only threats and blame. Very traumatic and inflicted long term damage.

We feel very lucky that our sons school did not blame us for his non-attendance but that is partly because we had a very collaborative and honest relationship with the SEN at his school. They recognised that he had autism and that was the root of his difficulties way before he was diagnosed. We still had issues in terms of the lack of reasonable adaptations made to support him which ultimately led to his school refusal but blame was never directed at us.

He has been seen by CAMH on 3 separate occasions and discharged as he just has bad behaviour. After a huge emotional meltdown he is now being seen by a psychologist at CAMH but we have yet to receive a formal diagnosis but we have been told he has attachment disorder, anxiety and he is to be tested for Asperger's. We are waiting for it to be put in writing.

Referred to social services for a SEND SC assessment, not safeguarding section. So far this has been a supportive experience.

He also has type 1 diabetes so gets a lot of support from psychologist attached to his unit. School have to date been fantastic facilitating getting him in without pressuring him.

My son was out of education for 8 months between mainstream and special and unsupported by la. He moved to specialist and was the worst thing I've ever done. He's on roll but out of school physically since Dec 17. LA possibly looking at personal budgets for education, health and social care until clinical psychology/tac team assess for a clearer pathway

Just deregistered child today through lack of support from school & professionals (autism Outreach) & concerns about increasing mental & physical health.

Only that he desperately requires specialist provision but unable to obtain due to high functioning needs

Social worker not due to school issues.

I have been judged by the school and had to find the reason why my son has been struggling since year 3. There was no problem before this.

Child get shoved from one waiting list to the next. No consistency, have to fight for every tiny little thing.

How a 7 year old can be so mentally unwell due to the 'system' and the lack of understanding for a small, terrified child I do not know. We are self-funding therapy for the whole family, at huge expense. If only someone had listened at the start of our journey or we had been brave enough to take him out of the system earlier I really believe we would be in a happier place.

I was a bit confused by the questionnaire- my child is now attending school but still has anxiety and is occasionally ill and refuses to attend school if not feeling 100% as worries about being told off for not performing. So I felt that my replies to the later questions weren't really relevant.

Our son's situation was caused by a very badly planned and unexpected class transition. He ended up in a situation he couldn't cope with and the school refused to make any changes and allowed his situation to escalate. GP very helpful but couldn't do anything. School ignored medical advice including letter signing our son off. Local authority did eventually step in after insisting we complete the school's very painful complaints process. Our year 6 son worked at home independently wearing school uniform and following the school timetable for four months. Luckily his friends and their families were very supportive and his attendance has been 100% since returning. If a child refuses to attend school why assume there's a problem with the child ... Two GPs and a private educational psychologist were very clear that the problem was with the school and our son's reaction was normal in adverse circumstances. He is somewhat anxious and has sensory issues but does cope well in school when he's not isolated from his friends. (And thank you for looking into this topic.)

Unfortunately school attendance officers only care about percentages and ticking a box. My child's mental health absences have been unauthorised absences from school. Why is mental health treated differently to physical health.

Initially school were not at all supportive as they had no previous experience of this issue. 2+ years down the line they are very supportive. The problem isn't school itself, but that my son struggles to leave the house frequently. Obviously school is the most frequently affected place.

Mainstream is not an inclusion it's a death sentence for kids who are not academic...

School were unsupportive. Head treated us like the lowest of the low. They eventually put stuff in place but too little and too late. And inconsistent. And made it clear they didn't really want to. Kept telling us she was fine. There is no mental health support. Early help next to useless and also not early. EWO basically told us to drag her in without using those words. We were scared of having her taken away when they threatened us with prosecution. Now we are out on our own. Daughter is traumatised and not in the right state of mind to learn and we have no support.

This child (already answered for eldest) has DLA due to his eczema and anxiety. It would be possibly interesting to know how many NFIS kids get DLA and EHCP or just one. Our youngest doesn't need an EHCP but both our older children. One NFIS one who loves school and has had support since year 1. PTSD from undiagnosed ASC then lack of SEND support following transition to high school. Changed school but child too traumatised to go back. Interim measure to do a dual placement failed. Needing urgent EHCP review and specialist placement. 18months + missed of secondary education. Should be starting GCSE /ks4 in sept but very risky to MH.

So much to say! My son stopped attending his mainstream secondary midway through October 2016. He has yet to return and no signs of it being likely any time soon. 34 weeks into EHCP process but LA only prepared to draft the Plan with school based outcomes despite his non-attendance.

CAMHS have signed my son off with anxiety but no formal assessment has ever taken place to help him overcome this.

This evidence from CAMHS initially gave just 2 hours of medical tuition PER WEEK 7 months after refusal started. This is not an education for a child that should have started his GCSE subjects! Medical provision finally (after 8 months) outsourced the provision to InterHigh. This is just 7 hours a week (Math, English, Science & computer studies but still not at GCSE level).

Social worker claims that mental illness is not classed as a disability! Social Worker is clear that my son is to return to the same mainstream school although the consensus from other professionals (inc. CAMHS) is that this is unlikely for some time if at all.

No one listens to the child. No one listens to the parents. No one listen to those that have day-to-day knowledge of the child and their needs/difficulties.

No one listens!

I would like to see a lot more support for children with mental health illnesses.

I want to change schools but he will struggle with the big change. The school do not understand my son.

The only support we have been given has been fought for. There have been five schools involved and none have been of any solid help.

I feel lucky that we have chosen a very supportive school. The guidance teacher is very understanding and accommodating and very supportive when daughter is in school and has made many adaptations for her. There are a few of her teachers that are less understanding, but fortunately they are in the minority. Even though her attendance is about 60% they have not threatened us at all. We are in Scotland so fortunately no fines are issued.

Unfortunately CAMHS have not been as supportive, and it has been a constant battle to get help even when she was suicidal.

My child is now in a Special social emotional behavioural and mental health School and attendance is where it should be. But it was an emotional rollercoaster and battle with all the professionals over numerous years of getting him there.

School were completely unsupportive & unhelpful.

Inadequate support from 4yrs old...now 13. Primary had an Ed psych in yr 6. I had requested it in yr 1! School failed to inform me that he had learning difficulties and also failed to inform secondary, and also didn't follow recommendations made by Ed psych for easier transition to secondary. We have been to fair access panel twice to try and get him in a PRU but was turned down and order to go to the school he refusing to go to.

Not the right support given when my son's dad passed away suddenly in Feb 2017 all the school cared about was attendance figures.

My grandsons case is a very complex one, one that can't be explained fully by this survey.

The only reason why my son is stuck in the position he is in is because the school and the local authority broke the law. My son has lost a year of education because the council refused to have a proper transition from primary to secondary which meant he had none of the support in place that he had in junior school with the reason given that it encourages independence, it took 5 months to get anyone to listen to me and even though they know that they did not provide any of his provision the school still blamed my son's behaviour instead of helping his mental health and the local authority ignored me and now I'm breaking the law to keep my son's mental health safe as it takes 7 months to get a lead appointment as there is only 2 for the area. The whole system let my son down and still blamed him and when that didn't work they just went budget cuts as a justification for breaking the law.

There is no in-between provision for children like mine, mainstream is too inflexible.

He doesn't refuse to go but hates school. He hates the bullying and teasing and feels life isn't worth living

The education system at primary and secondary level is outdated

Mental health services are inadequate. Took a huge battle to get a referral accepted and now he's been seen we have a year's wait to access any support.

I wish there was more help we are drowning

Despite my sons anxiety caused by the School setting, I have managed to get him to school so far (except for a handful of days) but it has been to the detriment to his mental health, we are now on wait list for counselling. We are awaiting assessments for autism/Asperger's/add and general processing skills. He is coping currently but for how long? The curriculum and School setting does not fit all. The waitlists for our children are unacceptable.

Been fighting 7 years for a diagnosis been passed from pillar to post everyone passes the buck and the ones who can help are too busy even a crisis of a suicide attempt takes CAMHS 9 weeks to do an assessment and 6 weeks for a worker.

No support what so ever.

Left in total distress only threatened by school to make your child perform resulting in broken children.

School was rigid and unwilling to make accommodation, coming in at 9.30am was the only thing consistently offered.

My son has been out of school over 3 years because his needs were not met in the early stages of being bullied, he has never received support for this and has been utterly failed by the education system. Now there is no appropriate provision to meet his needs. 15 years old and unable to access education or leave our home due to severe anxiety. What hope is there....

My daughter has joint pain (diagnosed) but each time she has a flare up the school bully us into returning and refuse a home tutor, she is owed 3 months of schooling this year so far. I've have ongoing complaints for refusal of a tutor!

I begged all profs involved Inc L.A. to help me keep her in school. Not one replied.

Too much pressure on children academically in school. Not enough understanding of autism and anxiety or enough support for teaching staff or children.

We're lucky the school has been really supportive and it's really helped

Medical issues don't seem to be understood or acknowledged by the authority's...but school has been very supportive

Let down by CAMHS constantly, takes 1 member of staff to destroy a good school , child's view comes last when should be first...treated horrendously by social care

School believe attendance is the most important and the education can be worked out
Specialist Schools have been recommended headmaster and SENDCO at short term school has recommended the same. However the LC has refused.

My daughters primary school have ruined her school life. We are fortunate she now has a supportive high school.

I am appalled by the ignorance of teachers towards children with difficulties. My poor son has been put through hell his 1st 3 years at school as not one of his teachers knew how to deal with a child with anxiety (caused by bullying in p1!) & also possibly on the autism spectrum. It's taken until an absolute angel of a teacher took over in p4 & eventually getting classroom support for him that his school life had improved beyond belief. We now have no more sick days or refusal to go to school or exclusions. He's top of his class at most subjects & his reading is 3 years in advance to the rest of his class.

Only the Attendance Officer who's a Mum in an Admin job in the School has been supportive as has an Autistic niece.. rest of School a waste of time from Head, Senco, Student support.. talk the talk don't walk the walk..

For my child it isn't so much his refusal as school unable to support the needs and nowhere else available. Currently battling the local authority.

Thank you for doing this. It's a desperate time for many parents who quite frankly fighting everyone to get the basic of education for their children.

At my sons first school they even refused to believe his diagnosis and threatened me with fine. His next school have been much more supportive. However are pressuring me to deregister him as he isn't in school however I've said no until we find alternative provisions or EOTAS

I have consulted the Equality Advisory Support Service (EASS) which has twice confirmed that it is unlawful to discriminate against a child who has time off school due to matters arising from their disability and also to suggest the parents are to blame. I am taking legal advice this week about suing the school for breach of the Equality Act 2010, which I complained about a year ago. The EASS has also confirmed that sending me poor attendance letters is victimisation and harassment under the terms of the Act.

School have been supportive but exams will be difficult if at all as not adapted for physically disabled children to take, 3 hours of writing far to long for a child who can barely hold a pen or type but who is very bright

Feel let down by the system

Teachers and support staff need more training to recognise learning difficulties and anxiety in children and how to deal with these children. It is clear most teachers just see children with anxiety as having a bad attitude and do not make any effort to help the child through the situation which then leads to further anxiety and depression and school refusal.

I may as well bang my head against a brick wall than expect help from the LA or Social Services. CAMHS are a total waste of time

No help offered whilst in school from L.A. and since I have started home ed. Disgusted at the whole school system.

My daughter has been disliking school since the age of five, she is now 11 and although we have had problems in her coming to school in the past it is only now that I am unable to get her in because she has got so big.

Mainstream primary school was increasingly difficult and eventually I home-schooled until my son reached secondary school age. At this point he was offered a place in an Area Resource Base where I feel his needs are finally being recognised and an attempt made to meet them. I just want to emphasise that I am quite a resilient person (I'm counsellor and have had plenty of personal counselling over the years!) but my experience of supporting my son through mainstream primary school (there are no special schools for children like my son in Cornwall, ie academically-able but with severe sensory/behavioural/ relationship issues) brought me close to an emotional breakdown. Eventually home-schooling felt like the only option.

The school doesn't understand home issues, mum having cancer, son being autistic. They refuse to believe the issues we have at home, refused the EHCP request, we had to do it ourselves. Told our son he's not autistic, he's disruptive. Home education has been a very big part in thinking of his future to ensure he feels safe and learns as the school are failing him.

I do manage to get my child into school, eventually, following a few hours of meltdowns and refusal. I feel the class teacher believes it is a home issue, but thankfully the SENCO is amazing and knows my child well (taught my child for 2 yrs)

Not enough is done to help these children. I have considered home ed so many times.

Very little or no support is available. Sick of hearing she is "fine in school". Um why has she now developed school phobia then ?! There are other conditions too, however, for six years I've been telling school she has difficulties, but we weren't listened to. Early intervention is crucial ! A little empathy from school staff would be appreciated too . A great survey by the way, hopefully everyone will complete it.

In process of ASD/PDA diagnosis

I am the foster parent of a LAC. His mother's neglect of him is to blame for his difficulties which began well before he came to me therefore no one has blamed me or threatened me with fines and prosecution.

Have experienced a massive lack of understanding of child's condition from lots of professionals and even refused to accept the diagnosis given by specialist consultant.

There is not good enough support for children at schools Don't get listened to No support for children with certain difficulties

No one knows how to help my daughter we have just been left to get on with it

Education settings have further traumatised my adopted child by forcing him to fit them. He has been treated as a naughty child isolated excluded and expelled. Only in last 6 months out of 12years have I found a school that will listen to me and make adjustments although not all staff agree but it's working he's in school but late most days but in and learning. Ignore the negative behaviour and reward the positive most schools won't do this because they have zero tolerance behaviour policies.

Current school supportive. Difficulties caused by previous school which resulted in PTSD

Anxiety brought on by school exam pressure, bully and the upcoming transfer to senior school. Been told I need to toughen up and force him into school. But I won't as I know my child is not faking it, he's increasingly anxious. Disappointed with school attitude.

School won't believe diagnosis given by 2 separate consultant psychiatrist because they don't "see" it. Child restrained and secluded on daily basis or sent home by 10 am, yet told no SEN. Now so unwell - unable to attend school, go out, or do anything that involves expectations. Heavily medicated as a result.

Our adopted daughter age 12 school refuses 2 - 3 x per week. We usually manage to get her in but every other week she just can't cope and needs a day or completely refuses to go to school so stays off.

Mental health nurses needed in school!!! Teachers have little education on children that need different scope of work and outlook on schooling! There's not enough done.

I've told them their measures against her lateness are increasing her anxiety and I fear this will push her over the edge into outright refusal. I was met with blank disbelief. Senior school leadership have decreed the punishment must continue.

Mainstream schooling have failed my son. They didn't want him from point of application but local authority made them. They couldn't meet his needs and continually excluded a child who was made to

feel more shame in enforcing that decision. More funding for higher level teaching assistants in schools needed. And all teacher should be trained on mental health and non-violent resistance strategies(and follow thru with using it) my child and many others act appallingly due to anxiety/stress and they don't want to act this way, yet they are pushed aside and treated like they don't matter to save school reputation

Help is so limited so sad to see my son deteriorate before my eyes and get no help

My child has been accused of fabricating illness and I have to be in court on the 5th of July for non-payment of fine

From starting nursery to now yr 6 my child has struggled in many ways at school but became worse, a lot worse the older he got and expectation of him got greater along with the comply and conform of school culture was too much for him. The support has not always been forthcoming and everything has been a battle with school while all the time my son's emotional wellbeing and mental health has suffered, not to mention the emotional drain on myself . My son went from a fun loving, loves life carefree young child to getting to about yr 3 to not coping in school and hating everything about school. This has caused not wanting to go to school, anxiety and emotional breakdowns. My hope and prayers are that he gets better support in his next school. Currently in therapy to help with all things including transition to secondary and therapists also meeting with SENCO at new school. The demands of school has truly taken its toll on my child and has almost broken him.

Heartbreaking.

The school have been horrendous - supposedly Ofsted outstanding - they have been anything but to us. Unwilling to engage other than to insist on 100% attendance. G.P. poor too, zero help other than special support group on Facebook.

Thank you for doing this, I have also had to put my career on hold and it has ruined my reputation as a mental health professional and led to me losing complete faith in services. I can cope with my child needing a different approach to others, it's the blame and judgement from agencies that has nearly broken me

My 4yo never went into School refusal but she was clearly not coping so we pulled her out of the school putting pressure on us to increase her hours beyond what she was capable of and put her in one that agreed to a significantly reduced time table. I'm sure if we had continued with the first school she would have eventually gone into refusal.

Another reason I Home Ed is because the EHCP process is too stacked against the parents and after an ordeal dealing with the school I don't have the personal resource to fight the LA. There is also no school in my county that is right for child or worthy of a fight to get him in there. All inadequate.

All services have been at a loss as to what to do.

There is very little understanding or provisions made at secondary school for anxiety. Focus is on attendance, marks, OFSTED. The mental health of children is placed at the bottom of the pile. Until children's mental health is treated with seriousness it deserves, the education sector and the government are seriously and detrimentally failing our children. Shame on them.

My child is in school full time. But gets no help and support at all. Nothing. He is actually neglected at school and we are considering legal action.

Main problem which led to issues were teachers' lack of understanding and lack of support. An unwillingness to follow my advice even though I am the parent and know best. I am also a SENCo and tried to suggest ways SENCo could get support from external agencies. All this was ignored. School were trying to save money and just saw behaviour issues. They could not see that they were the cause and making things worse. They were quick to exclude, yet whenever I suggested my daughter stayed home for her own wellbeing, they would not have it.

Time table for school needs to be made flexible over a 7 day week

I don't know if my parenting is blamed as teachers wouldn't tell me. He goes to a YMCA place where he has help but it's just a way of getting rid of him. Head of year asked me to send him to another school. I said no. Not in year 11 and it's moving his problems around. Said he would receive counselling at school never did.

One teacher says it might be wise to be checked for ADD. GP said only extreme cases are sent to CAMHS.

He's misbehaving at exam time and I'm worried he's not going to get on course he's accepted on or display bad behaviour and be kicked off. He's horrible at home so don't want him here all day.

I'm just so worried and think there's something not right with his mind and behaviour. Or is it just teenage stuff. He's not eligible for SEN plan so left feeling hopeless

It took an overdose for anyone to really listen to us and to stop blaming poor parenting

I requested withdrawal from SATS but have been refused. School refuses to have her in school if she doesn't do SATS, and then the unauthorised absence will trigger a fine due to previous poor attendance. I have 3 other children with additional needs and have been open about the issues we face at home. They have not given any support or acknowledgement of how difficult this is for my youngest daughter.

We are fortunate that we had a place in Independent special school before difficulties with attendance arose, there is no pressure to attend and no issue made about attendance, currently around 40%, recently had 10 weeks of non-attendance! Although he is willing to go to school he refuses any attempt to introduce academic learning, he spends time in residential unit and out in community with key worker.

Although I was eventually granted EHCP, my child was out of school for a year and initially turned down for EHCP. The system is skewed against the parents as budgets are fiercely protected. Only reason I wasn't prosecuted was a 100% attendance twin proving I wasn't the reason for his continued absence. Very little support was offered at school, suspected ASD was dismissed by them until CAMHS appt took place with school.

Son has amazing alternative provision by a charity Breakthrough Transformation Trust. Very supportive and happy to take things slowly. Son very resistant but glimmer of hope appearing. I go with him, but

Breakthrough are ok with this and I'm not put under constant pressure to have an " exit strategy" like another one I've tried. The problem is it a charity not a school so he is still registered at mainstream and the provision isn't named at all in his EHCP, so I worry about funding being withdrawn.

There is not enough formal support for young children with anxiety in Primary School. Paediatricians do not listen to parents and when the anxiety gets to the stage it is then overwhelming and they do refer for the child for therapy CAMHS advise that the child does not fit their criteria! Leaving the child and parent without the support that is desperately needed.

I have felt disregarded as a concerned parent, judged and at times belittled as I did go through a dv relationship and it's always been put on that even though there were signs of difficulties before that relationship and now his difficulties are worse 7 years down the line! Only after self-referral to CAMHS and 100th plead to go and son school refusing and seeing for them self's how I can't physically make him get dressed are professionals listening

Teachers and support staff need more training to recognise learning difficulties and anxiety in children and how to deal with these children. It is clear most teachers just see children with anxiety as having a bad attitude and do not make any effort to help the child through the situation which then leads to further anxiety and depression and school refusal.

Wouldn't it be nice when the government would provide more help regarding education teacher with special children ?

Wouldn't it be nice to get a faster and helpful diagnosis that would help a parent to deal with their special children ?

The whole system needs to change. The new SEN reforms aren't working and professionals aren't listening to the views, wishes and feelings of the parent/child/young person contravening the section 19 principles of the cfa2014

We are from Australia, but I have found the questions here relevant to our situation.

We feel absolutely stuck - facing being fined, but have told EWO that I can't guarantee my son will be in every day as he can't cope with the school environment. We do all we can to get him to go to school, but we also have his mental health to consider. Education providers really need to make more provision for cases such as ours.

After discovering her dad is not nice and refusing to see him (effect was the same as a parent dying and she needed time to grieve) , my daughter had severe anxiety, depression and panic attacks and was unable to get out of bed. School's only support was to threaten prosecution. CAMHS response was to suggest home educating and to contact Kooth (somehow deal with it ourselves!). Daughter was previously "fussy" with food as it was the only control she had in life. 3 years later, after patiently trying to support her myself, little learning occurring and having an eating disorder, daughter has gone to GP who has been great. She has referred her back to CAMHS and is seeing her monthly. Still waiting for CAMHS! On reflection, daughter thinks school should have done more to support her and she could have stayed in school to take her GCSEs this year.

i am now at point that I'm sick of relying on the system to help as just a vicious circle from nursery age nothing really changed even though we are very lucky as our boy has had an enormous amount of help especially in early stages but sadly last couple years has dwindled away for all different reasons mainly

money funding related. our boy's struggling massively now in yr5 I'm dreading yr6 let alone high school but we've as a family decided if he deteriorates more than he is now we will go down the road of home schooling as tried before for a little while and was very successful and much calmer n happier boy. my eldest son who's Asperger's n mental health issues was sectioned at 17yrs because system let him down and we have sworn that we are not going to let the same happen again to our youngest boy. my daughter in yr4 can barely read n write but because of funding issues has not been properly diagnosed as yet. there is a lot more but sadly cannot fit all on here . bottom line is he will probably end up being home schooled because he cannot cope with pressures of school at all and we have to pick up the pieces 24/7 which at times is heart breaking to watch him go through all this at such a young age at least my other son was a lot older before his mental breakdown because of not coping with college environment. the system is completely broken and it is our youngens that are suffering for it.

Have had good support from school and CAMHS's

It is a hard place to be

I recently realised son has attachment disorder.

Problems started in year 6 primary school - on reflection son had anxiety and depression due to realising his dad is not a nice man, as well as attachment issues that caused a lot of anger in my son. School was supportive (teacher came to house to take him to school) . Transition to secondary school was difficult. Secondary school had a few days in summer holidays to support this. During years 7 and 8, son became progressively worse - refusing to get out of bed to attend school. School referred to school nursing team who suggested parenting classes. Situation didn't improve and pressure from school added to anxiety for my son and myself which made situation worse! Threatened with prosecution, so took son out of school. Went to GP (son has insomnia too) and GP suggested getting in a good night time routine and suggested we contact Kooth for support. Problems still ongoing and worsening which affects daughter who has anxiety, depression and an eating disorder (waiting for referral for CAMHS for her). Son wants to go back to school but due to insomnia, his attendance will not always be good so not sure who to turn to for help.

Sometimes kids have social problems and is hard to get them in school , I know education is very important but child's happiness And anxiety is more important And if people can take their kids out of school and home school why can't they do it when kids refuse especially when they have disabilities

School system needs an overhaul

After suffering with joint pains in KS1 primary school and told by GP it was growing pains, daughter was finally referred to hospital in year 6. Diagnosed with joint hypermobility syndrome. In summer of year 9, she tore her meniscus and destroyed her anterior cruciate ligament of left knee. She had to have 2 operations so missed most of the first term of year 10. School pressured us to get her back to school (she couldn't walk!) and finally engaged tutors (English, maths and science only) . Daughter had depression caused by the situation and tutors only came once a week so she started her GCSEs a term behind. On returning to school in the spring term, she was under constant pressure to catch up. She still suffered painful joints and some days she couldn't move so couldn't attend school. Again I was pressed to get her into school because of her low attendance. She completed school and gained 9 GCSEs. She is now in first year of A-levels at a local college. She has now been diagnosed with dyslexia (not even considered at secondary or primary schools because she is bright) and another joint issue (bilateral hip impingement). This causes her more pain and difficulty walking. She has missed days of college and,

although her attendance is low, the college have been very supportive. However, her problems are mainly physical with MRI scans and hospital consultant letters to "prove" her main problem for missing college. They are also supportive of her anxiety and depression and dyslexia. If only her younger brother and sister could have the same support in their secondary schools for their mental illnesses (anxiety and depression for daughter and anxiety and attachment issues for son).

More pressure from Social Services and EWO to get my son into school 'by any means necessary' has caused my son to totally school refuse now! Absolutely appalling the way our children are forced to go to school when there is real genuine anxiety around doing so x

I wasn't sure what the question about who we got support from meant. I have answered no to many of the people not because I didn't seek their help (I did for all) but because they were not helpful. Was also threatens with foster care by the true school despite calms labelling me as an exceptional parent with an excellent relationship with my child. We also tried 3 different schools. My child wanted to go to school but was hampered by late diagnoses and lack of appropriate support.

Horrendous support from SENCO at our academy had to call in early intervention team myself daughter want in school for 5 months she's 13yr old. Daughter only just in a specialist provision 4 lessons a week. School admitted massive failings and mistakes and in the process of formal complaint now we had provision place. CAMHS not much better help with them 5 years in end sent to Manchester children's hospital to social development clinic and given diagnosis after a full day assessment!

An excellent survey. Can't wait for the results!

More help needed to education and support my son

My sons school is a constant battle to get what little support he needs. He can't read or write at 8years and the school deny any kind of social, emotional, mental health or learning need, he self-harms and sensory seeks constantly.....

School offered no support at all, behaviour of the Head worsened the situation. It took a year to fix the damage done

My child acts like everything is ok an explodes at home. He will not tell school anything that is wrong

In a mainstream school I find they try and support but only to a certain extent and based on their knowledge which is very little. Most teachers don't have training in ASD....there is too much pressure on attendance figures and not the child's mental health. When my daughter was in infants they sent reported U.S. to the EWO who was not even aware my daughter has autism and had issues going to school. CAMHS are useless my daughter is now having panic attacks and being sick due to anxiety and I have just been told by primary CAMHS that secondary don't feel my daughter has anxiety!! The GP is kind of supportive but has to refer to CAMHS and they don't help. The only help I have got has been through Barnardos and other charities. I have home schooled which would be ideal as she got a lot better but I have a 1 year old and 3 year old and found this very difficult. The whole system is wrong and I find it all unbelievable.

Only support offered was if child went into school to receive it - no help available for transition from home to school, child's difficulty due to fear of bullying etc.

So far gentle and persistent encouragement is working. Next two years will be harder with the move up to secondary school

My two children are adopted, school and authorities are not meeting their needs!! The constant fight and stress is relentless.

Behaviour policy just makes him worse - shames him
We are 'working' with school to get an amended policy for children like him

Adopted/trauma

There isn't enough support and understanding. It's taken 6 years for a diagnosis and I've felt my child has been judged and misunderstood throughout. Very few teachers have an understanding of mental health problems. Misunderstanding at school has made her worse. We've had a lot of negative judgement and there is NO HELP! We've only now got help by seeing a private psychologist which has cost £1000 to date and we've a long way to go.

Too much pressure on young children for doing well in SATS in middle school age 10. School spent the whole year before on a countdown to the SATS exam. My son is a complete nervous wreck panic attacks etc stress anxiety worries. And also has grey hairs on his head. He is 12 now. All I can do is a mother is stress that school and exams are not the be all and end all of life !! Seriously considering Home schooling

The conveyor belt of secondary education has been my child's undoing. She loved her early years/primary but secondary she hates it. She gets in trouble for moving and talking ADHD/DCD and because she masks they don't see it. Look at her work or lack off there's the proof. I am not giving in

I was not pressured but it would have come to that if I didn't decide to home educate

School are completely out of their depth. CAMHS are useless and try to downplay the problem even when agreeing my 10yo is a suicide risk. We are finally getting support and professionals are acknowledging this is not down to poor parenting but it has taken 18 months of school refusal to get to here and it might not have been so bad if they had helped when he was first in crisis

We are considering EHCP but school really don't need to do much to make her feel okay, they just don't see the need or importance.

My child has trauma due to child abuse by his birth parents. We adopted him five years ago. Trying to get school to understand his difficulties is impossible as they happen at transition times, ie at home. We are totally exhausted by it all and fighting in school for him unnecessarily adds extra pressure, uses more spare time we don't have and leaves our birth child depleted of time with us. When will the government realise it needs to do more to support vulnerable families

Have abandoned school. Very bright child will leave with nothing. Due to illness since 12 has had barely and school for 4 years. Excellent Support worker now in place trying to plan with her for picking things up at college in sept. Sees her around 3x1 hour per week.

Successfully applied for EHCP and got a therapeutic placement which is nothing like school, starts in 2 weeks

There is no suitable school provision in our county

It's extremely stressful experience for parents, schools have limited understanding and can make you feel so inadequate!

Behaviour policy just makes him worse - shames him

We are 'working' with school to get an amended policy for children like him

Adopted/trauma

When my child returned to school after a period of School refusal, they spent the next 8 months only 10% in class on timetable. The rest of the time was spent colouring or playing; not learning! The one to one was used elsewhere because my child refused to engage in learning. My child lost even more confidence self-esteem & learning.

There needs to be more mental health awareness & understanding within schools/communities. 'They MUST attend' is a ridiculous answer to extreme anxiety in children.

The SENCO told us "your son clearly has additional needs that we are failing to address here in main stream school. He needs a place in a specialist school, but you won't get one as there aren't many. An he's special, but not special enough!"

That from a SENCO. I knew from that one statement, I was my sons only hope!

SEN child now missed almost a school year of education from 'outstanding' mainstream primary.

Medically fit to attend. LA aware of aware of school marking as 'educated off site' for 3 days per week despite no education in place. Utterly failed.

Shocking lack of support in Leicestershire from social services, Paediatricians and CAHMS. Been trying to get a diagnosis for 9 months since exclusion for violent and distributive behaviour

My son has loads of health issues and the school have been supportive so far

I have been fined once and have another court case next Friday, my son has managed to attend school 3 full days this week, such an achievement for him. Wish they spent more funding on diagnosis than wasting time playing the blame game on parents .

It has taken 4 months of forcing my child to school every day for him to break down and snap for anyone including the school to listen and help. I refuse to force him now and he hardly attends.

My child has been bullied we are currently being forced into a multi Academy trust the new head is bullying the teachers and kids, also we are unable to take a holiday this year due to the fact that we work in tourism

My son is consistently being punished and given sanctions for struggling in school. I've had meeting after meeting but appears they are more interested in complying with their own policies than adapting to my son's needs.

There are a lot of children having these issues yet schools and professionals seem to just want you to force your child into an emotionally distressing situation which can lead to further issues with mental health.

Daughter started with separation anxiety and couldn't leave the house after becoming ill with a bad throat infection a few weeks after SATs. Once she was told she was better and could go back to school after about 3 weeks of illness she kept saying she felt sick couldn't cope with seeing friends or family spent most of her time in bed. Wouldn't go out anywhere. Her Dad died when she was 8. I took her in each day but she didn't make it into the building spent up to an hour with ELSA in the playground if she was able to get out of the car. Saw CAMHS for initial assessment which I had to force her in and out of car to get to was told to buy a self-help book which I bought and phoned back said I think that needs more help they put her on a waiting list but was informed it would be months of waiting. Because of bereavement managed to get appointment with clinical child psychologist at the hospice who cared for my husband. Who she has seen for the past 18 months. There was no support with transition to secondary school. For the first term she got in everyday but to the detriment to her mental health. She wasn't seeing anyone or able to do much at weekends or evenings. After another sore throat and flu and school holidays it became almost impossible to get her to school again. I had to ask for someone to help from the school and I met the SENCO and Elsa who helped with getting her in gradually from just sitting in a room in learning support to attending some lessons to now where she attends 5 lessons and arrives at school slightly late around 9.15 most days but always under pressure to increase the time and being told that they haven't the funding to help as it has been a year. The psychologist kept insisting on baby steps. She feels sick every day and is scared of being sick she feels trapped and says no one understands at school if she says she feels sick they say it's just your anxiety. After forming a relationship with the ELSA so was told she was no longer able to see her as this would be going backwards. A new SENCO started after Christmas and she was very unhelpful and unapproachable compared to how much the other one had helped. I was accused of not providing medical evidence when they hadn't asked for any. They said they would have to fine me if they didn't have it. They had had email contact with the psychologist and she had attended a meeting at the school. She did a report and I got a letter from GP and they said as long as her attendance continues to increase they won't find me now they have a report. They keep asking for time scales of how long it will take for her to be better. The pressure coming from the head of house that she had to cope with a full day and all lessons without help or maybe I should take her out of school even though she had come such a long way. A complete lack of understanding of mental health and bereavement in children and being told she should be 'over it by now'. and she is 'fine when in school'. They started giving her detentions for being late when she was later than the agreed time more than 3 times a week even if it was only a few minutes late and she had overcome so much anxiety to get there. After one detention I told them she would not be attending the next one as I didn't agree with punishments for mental health problems. The assistant head of house said it was a consequence to her behaviour that she had to learn! My parenting was judged and the assistant head of house was insisting I do a parenting course. I work from home and I was told if I had a proper job then it wouldn't have happened because I would have had to get her in on time! I am doing a course at the moment it is interesting but isn't going to help much with anxiety. Quite a few class teachers have been very understanding and have put her at ease in their lessons. She is able to sit by the door and has an exit card. The head of house who was her geography teacher questioned her when she used it in her class which caused huge increase in anxiety and made the day she had her lesson really hard to get in. We are almost 2 years on and at the moment she is progressing well. They still don't understand that the anxiety isn't going to go away she is having to find coping strategies and even when we get to the point of being in at normal time and full time lessons there will be times that she could still need support. It is always harder after a school holiday and I

expect after the summer it will be tough with new teachers to start to trust. Sorry for the long message but that is our story so far.

The questionnaire doesn't really give enough scope to reveal the horrors and full ugliness of the practices school's engage in but it does allow us to cover some disgraceful things. School gave unauthorised bogus medical assessments in an attempt to disprove any difficulties, cheated and provided false academic screening results and failed to provide the academic government directed intervention that my child should have had, misused Thrive as a child interrogation tool (purely mother witch hunt) and provided nothing other than an inquisition - no support related questions whatsoever, blocked the private in school observation by a clinical psychologist that was the final part of a diagnosis process with a written response stating that my attempt to diagnose was a safeguarding matter and damaging my child's self-esteem, stalked my child in the playground and took photographs which they erroneously thought could be used to disprove autism, repeatedly used ad hominem attacks on me instead of addressing whether my child may be experiencing difficulties I described and they withdrew THRIVE after two sessions with the suggestion that it was just poor parenting (my child told them I gave him sweets for meltdowns which isn't true but must have seemed a good answer to repeated answers of a highly loaded what does your mother do to you) intimidating and threatening me to halt diagnosis with a vague implied threat of police action, repeatedly ambushed me to attend urgent and immediate meetings which they knew my husband couldn't attend and they directed their attacks at 'mother' even though dad was as much behind the need to diagnose. It doesn't feel like we as a society have moved very far from the idea of a refrigerator mother, we're certainly still mother bashing. Only the most resourceful, resilient, determined and process-sleuthing seem likely to make it to the end of a diagnostic process. For us I think the ugliness of the battle arises from the conflict that the school who are the providers and financers of support are also the key to diagnosing difficulties. To diagnose difficulties which would lead to them paying for intervention is not in their best interests and it's those interests that they are working in. I suspect if my child wasn't also dyslexic and if we hadn't started from a position of asking for help to teach him to read we might have found our path smoother.

A lot of SENCO staff try and hide and overlook lots of problems that these children experience. This is to justify them not requesting an EHCP

School has made my child ill, they have no idea how to deal with anxiety, they say my child's fine once in school but they're not - the signs are there, have tried mainstream and special needs can't cope with either now looking into home schooling but don't know how it will work as school doesn't come into the home, would like to try online schooling as I think it would be the answer but it is too expensive and we simply can't afford it.

Starting school at compulsory school age in reception alleviated a lot of difficulties and now only occasional problems with dropping off at school. Compared to serious anxiety about nursery.

On the question what help have I had I wanted to answer none and it's wasn't an option. Although people have been involved I don't feel as if they helped at all.

We are at the beginning if this very tricky and hard process

Our son is fostered but School makes no concessions or give extra support for the ordeal he suffered in his first 5 years of life. Only two teachers in the last 5 years (he is now 10) have tried to understand his difficulties and try and understand his behaviour as we do - which isn't easy.

Lack of school support and awareness of child's condition is very stressful. Daughter not very supported by teachers in school. Not knowing where to ask for support or help. GP very dismissive.

All the signs of ASD were very clear from the start and my child was at a school with a specialist resource base but still it took 4 years, a change of school, an FII accusation and my daughter to have a breakdown to get diagnosis and start the fight for support. Everything that has been put in place to help is only there because I fought for it, against threats and accusations. She is not in school, it is very damaging to her health and wellbeing. The MS school's comprehension of ASD was dangerous, ableist and ridiculous.

My child is a foster child and the 'system' of social workers, virtual school and school fail to agree making life so difficult!

Our child had to start school just 11 weeks after moving to our family – far, far, too soon for him to feel safe and secure at home with us, let alone in a busy scary school environment. While we'd rather he had been allowed to defer, the school (who did not make the deferral decision) has been very supportive, working with us to build a phased transition into school, starting with half an hour a day and building up to our current 4 day week. I take him in late every day (agree with school) and we are not marked absent for that. He doesn't have specialist support but the class TA does 121 with him for a period each day to help him catch up with what he's missed during and before school. We also have monthly meetings to discuss the support plan in place. There's no funding for more formal support, but other than that I feel lucky with how the school has put his well-being over curriculum requirements. For him the greatest challenge is the social aspect of school, particularly playtime which is busy and scary for him. With this approach we manage to get him o school in an ok frame of mind almost all the time. In a more rigid environment we would definitely have had absences. We are in Scotland.

No one seems to care or understand his dyspraxia has caused problems and bullying but school didn't deal with it made me out a liar over his anxiety refused the need for EHCP

School have tried to help, but during long absences due to physical disability we have not received any work home for him, which has seriously affected his achievement and working levels. Effectively he has missed massive chunks of his education since year 7.

It has affected our mental health too. Academies are a mistake that is how schools are causing this they are virtually untouchable. It has been a horrendous journey. It is about time the Government looked at how schools are acting unlawfully re attendance. Nobody is accountable for this mess and we are running out of fight about 3 yr battle and no school for my Son to attend.

School have been very helpful and kind, though they did put too much exam pressure on in first place.

Child in need

School was supportive for a few days and then they became very threatening saying they would come and drag him in. He has 100% attendance before this and totally out of character. They said I would be fined. It gradually has got better but I'm worried it will start again.

It's because of the school not taking any notice of my child's diagnosis that my child ended up with so much time off of school. Because my child doesn't have a disability that the school gets funding for they couldn't care about my child's disability. They ignored hospital letters and caused my child to have 6 months off school, we had constant attendance meetings which were a joke as it was the schools failings. My child is due to leave school soon and I cannot wait. Some teachers are severe bullies and shouldn't be in the job.

This year my son's attendance was not great. He has been in hospital twice with abdominal pain, which we now believe was stress related and has missed days here and there due to being unwell with his diabetes or a virus. Over the years I have built a good relationship with school but have to put a lot of effort in by constantly sending emails, explaining the situation, copying our Specialist nurse in and providing medical evidence to make sure all his absences were authorised. We definitely feel the pressure and it would be just nice if school understood that it is almost impossible for a child with an underlying health condition to achieve a 100%, especially since everyone is sending their children into school when they are sick, because it doesn't seem to be acceptable no more to fall ill. School life is so stressful! We have to be careful that we don't wear them out and a sick child does not belong in school but should be allowed to recover at home!

Actually the school thus far have been amazing but pressure applied by children's services and paediatrician to increase school hours
Families are under immense pressure enough as it is.

The gap between C and his peers got wider as he got older. We always knew it would but it happened earlier than we expected. Except for one child persistently and relentlessly bullying C (which was never dealt with effectively) most of the children were kind & helpful although that wore off as they got older. Also the school told the lovely girls who 'looked after' him & helped him with lots of things (their own decision) not to do it. So they stopped and unless he asked for help he was largely ignored by the other children to the extent of extreme isolation. It wasn't malicious ignoring, he just wasn't on their radar. The staff seemed to treat him like another pupil there who is autistic and who (apparently) avoided interaction with peers. So the pupils did the same. His mental health got worse, at 10 he had planned how to kill himself and we refused to send him back as school just kept saying there were no problems. They even tried to block the hospital education service working with him. (They didn't succeed!) His SALT was the most support, she arranged to visit us at home for 1.5 hours each week for a whole term while he was out of school and did a load of work with him which school had to pay for. She made huge progress with his speech in that time and started to rebuild his self-esteem and confidence. I'm not sure who the 'school refuser' was - he said he wouldn't go once and I went to school at 8AM to talk to staff as he was suicidal. They were so awful that I refused to send him back. They threatened me with the EWO so I went home and rang them and they said as I had asked for an emergency review they would take no action! School rang my GP instead (without telling me) to prevent him from signing C off. I changed GP and he got signed off!

Frankly that was irrelevant to me, I wasn't sending him back, what their paperwork said was their problem, not mine! I just knew it would be helpful to have GP support. We were supported by his TA, SALT, OT, EP & CAMHS (who didn't even meet him, they just met me and agreed with what I said) in our insistence that he needed to move to specialist provision. Thankfully despite the headteacher, class teacher & SENCO school looking very, very stupid at the final emergency review meeting, we won. But it's taken over 3 years in an amazing special school to undo the harm done and get him really settled, able to trust staff and have real friendships.

Good luck with your with this work, I've since discovered that while it was horrendous for us at the time

and it significantly impacted my mental health, especially that final meeting, we appear to have had it easy compared to many other families.

Too much focus on results rather than learning in schools. A happy child learns better than a stressed, anxious child who is frightened of doing something wrong all the time.

I hope I have helped by doing the survey.

More help is needed with our children's mental health and schools

My grandson who is 12 has complex needs and finds school very overwhelming school have tried with him but his anxiety and stress levels are causing insomnia and he is not well enough to attend getting help from CAHMS but it's early days hasn't attended school for 6 weeks

CAMHS no help at all. Now he's 17 the LA and everyone else haven't bothered with him, so he's home and doing nothing :(

We needed help earlier in Secondary and asked for it since 1st year but nothing done till everything fell apart in 3rd year it has upset every member of extended family as everyone felt helpless and so let down by school

No one seems to really care about the lack of education our son has received this year. He is at high risk of being lost to a system that does not work for him. Alternative provision is supposed to be being sorted but 20 school days on since a 10 day exclusion and it still isn't!

So much needs to change

13yo son has HEDS gets lots of pain and is always very tired. During school holidays he sleeps 12-16 hours every day (actually asleep). He is often physically exhausted, despite trying to get a good balance between activity and sleep. He almost certainly has SPD and probably ASD but due to my own ill health I haven't been able to pursue it. Was thwarted at primary school as headteacher was also the SENCO. Although some support from class teachers.

My child has a history of school refusing (in primary) he ended up in a PRU and is now in mainstream high school (back to refusing) He was referred to CAMHS (primary age) but not diagnosed with anything. I was blamed for his behaviour but after my own research I believe he has PDA (he is now in high school) but this is not recognised by this area (SUFFOLK) so I will have to find a private diagnosis. My son could have had much earlier support had other conditions been considered at the time - eg he was only considered for Asperger's, Autism and Anxiety but because he didn't full fit any of those he was deemed 'normal'

For months I corresponded with teacher and ELSA it wasn't until school refusal took hold then everyone on board with loads of support.

My son was excluded from mainstream at six years old , just before his appointment for diagnoses came through, school were not supportive I had to fight the whole way to get to that point they tried to blame me and said was chosen behaviour, 1 month after excluded he was diagnosed with as I thought ASD, SPD, Dyspraxic as I suspected but also ADHD which I wasn't expecting.

Given EHCP after a fight for that placement in an independent SEN school, use of restraint and seclusion rooms, staff not qualified left him with bruising and mentally traumatised , fought to get him out school with backing of CAMHS, now currently at home with L/A tutor application for personal

budget to provide comprehensive home schooling package turned down, they are now looking for other placements, but I know now it's too late

I am sure professionals think my daughter manipulates me and exaggerates her condition. The school blame her for friendship problems and don't give much support to help sort them out. We have had no input from wellbeing officers at school despite being out of school for 2 years. We feel completely lost and stuck. We don't know what is causing the difficulties for our son, and we are at a loss as to how to help him.

Child is in year 10 and has experienced anxiety all through secondary school, her school counsellor, she saw him for 18mths has told the headmistress that he doesn't believe dd has anxiety. We now have to get a doctors letter! She was with CAMHS until 2 years ago.

Recently discharged from all services, CAMHS originally diagnosed anxiety and agoraphobia with possible ASD (screening completed awaiting results). CAMHS totally back tracked on the original diagnosis at a school meeting and decided my child was manipulative and controlling because she recently managed to go to a quite local cafe (no other customers there). I am concerned that too many children are being failed and written off in this way and parents being blamed for what is obviously a child struggling to cope in mainstream school because the setting is not conducive to learning for children with anxiety and/or noise sensitivity.

More help and less wait times for the little people

No real pressure from school, but also feel they don't understand or are not bothered if she goes or not. Adaptations only made when child has not been into school for a few days and anxiety is very high, very difficult to get anything changed. Very poor communication between staff.

Currently have a LA funded home tutor that doesn't understand my daughter, no support for my daughter or family.

I think my daughter should be allowed to flexi school but the school have refused. So, while they are fine for the time being with her only attending three days a week they are marking her absences as unauthorised. The only way we can get her a part time timetable is if a consultant signs her off but we have heard diagnosis in five year old girls is quite rare. My daughter also masks and complies at school. We would home educate were it not for the fact that she enjoys school and wants to be there after she has her days off.

My child began having difficulties in p7. Her teacher told me to drag her in kicking & screaming if necessary, or that if I felt I couldn't, he would. The whole attitude from him & the EWO was that she was just naughty & slacking. It was all about just getting her over the door, no understanding of trying to understand & help her be comfortable in school again, as she had always been previously. I honestly thought it was the P7 teacher she had the problem with, as when it came time to change to big school she was excited, but after just a few weeks she began refusing again. The new school were very patient & did try to help, although they would not send any work home, so she fell behind very quickly which added to her stress, but EWO just kept forcing the issue of getting her over the door & basically telling us if she didn't go I'd be prosecuted & I always "had the option to de-register". I pushed & struggled to get her help, (including paying for private counselling & even hypnosis, which I really couldn't afford) & back to school for two years, but eventually had no option but to de-register or they would have prosecuted me. I just felt there was little understanding or care for my child; it was just all about attendance figures & bums on seats. Disgraceful.

I was told by junior school to get in whatever but eventually I refused as could see the trauma it was causing. My secondary school have asked me to say he has a headache/sick or other rather than anxiety so it doesn't affect his attendance! Shocking!! Anxiety is medical 🤒

School is a massive distress for a kid that really struggles

My son spent a whole year out of school due to not being listened to school not acting on advice by other agencies they broke my boy which I'm still trying to get my old boy back now, he is in a specialist school. It's not the right school but it was the only school that could take him he needs an ASD specific school but he was turned away by them as he was too academic, no Peres and his sensory issues would cause conflict in the class.

He has had 4 failed mainstream primary's no one is ever held accountable for failing children.

Don't get me wrong the school now tries and changes things for him but it's the behaviour of other students that affects him and he is slowly making progress but for his marks to drop from 6s to 3s and 4s in under a year is saying something but this term they have slightly risen

On our case he has a lot of hospital appointments but I do not think these should effect attendance as he has to attend when he is told to.

My son finds school very difficult due to his Attachment Disorder. It has been two years now that I have been fighting to get an EHCP and any other help for my son's specific needs. Lack of funding is a huge problem and also finding a school that can cater for his needs is proving difficult also.

The think because my child appears high functioning, that he doesn't require as many supports, they are always on the aids side and didn't read his cognitive report.

If we hadn't committed to one parent leaving work we would have been unable to support our daughter fully in being able to attend school. This is not financially viable for some families. Incredibly poor support from LA particularly around the recognition and validation of bullying of our daughter, poor access to psychological therapy. Overall the attitude of the LA has been of blame and criticism for our ability to manage the situation at home. If we had not been fortunate enough to have had a wonderful mainstream primary school who got an EHC and a place at SEN secondary school we doubt she would be attending mainstream high school. Her needs have not been recognised due to multiple moves and social workers and a diabolical lack of continuity and structure in reviewing her case and supporting her needs.

We moved area and school this helped short term

Pol did not manage preschool due to social and separation anxiety related to her autism (at that point undiagnosed) We home educated and then tried her part time at school at 14 which was unsuccessful and caused a worsening of her mental health. We tried again at 16 and she has now got 60% attendance at a small FE college who support her reasonably well.

More wide spread awareness about Ehler Danlos syndrome, to schools, education authorities, Drs and the general public .

School don't see the home explosion. Homework is even worse. Often says she wishes she was dead. Doesn't want to be home-schooled as doesn't want to lose friends at school.

My child is a looked after child with layers of grief, loss and attachment problems as well as anxiety and depression. I have had to fight for changes to be made and for it to be recognised he has an illness. There is a long way to go in making sure his needs are being met...

My child has self-harmed in an attempt to avoid school but all I am told is he has to attend. He often talks about killing himself rather than going to school and this is a real fear for me.

I feel really let down by all the services that are supposed to support families and children.

More help needed to education and support my son

A relevant understanding of these difficulties

Our school is under-funded & under staffed. Children with all different needs are put together ie ADHA, ASD, DS, violent behaviour, mental health

The school is useless, they find it easier to put a DVD on for the children to watch.

We have been under CAMHS for nearly 3 yrs & are still

No further on, we are awaiting a screening 4 an ASD diagnoses but the wait is forever. As have been accused of lying & all sorts of things & the lack of belief is unreal fr CAMHS. The service has let us but more importantly our son down. He has had NO education since Dec 17 & has rescued since Y7. The school Didn't want to know until it started to affect their Ofsted figures. I feel we r fighting a losing battle & don't get me started on Social Services. Just because we own our own house & work doesn't mean we need any less help than those on Social Benefits. We live daily with a violent child for the past 9 yrs with no help what so ever as no one believes us as he can mask so well.

I'm in touch with the school attendance officer and our GP due to my daughters illness flailing up, resulting in time off school each month and trying to get help from the NHS.

The pressure in year 1 from reception started this.. loved school till then. I have heard the same frequently and work with send kids. the nature of school and hideous curriculum and testing is damaging kids mental health from age 6 at least. I have to force or cajole a distressed bright confident child who is surviving the system at best. I am considering home school as are many others in Bristol. The difference a good teacher made was very important but they have no control now over what they have to do.

Action and support was needed straight away. The longer time passed worse it got and he never went back in last 18 months. School did not listen to us about potential problems re his adoption. By then too late as mental health became very poor and could not return.

SENA try and keep your child in mainstream school, even when every professional says not mainstream because all to do with money for them, not health of child.

I am not sending him anymore until I know he is well enough to attend. Now under CAMHS but so slow but at least we have this access. Wanting to kill himself was the last straw. School were a disgrace new the difficulties he was facing but said they could not refer to CAMHS for low mood/depression. Previous junior school said did not have any issues in school but then Head wrote and told me he was concerned about my son's emotional and mental wellbeing. Very stressful.

Thank you for running this survey, make sure you send the results to the media!

Schools are shameful. Nowhere near the help given to kids that so desperately need it. My son has anxiety brought on solely by not being able to do work set and the school denying he has any problems. Private assessment says otherwise

Test Anxiety started because of SATS and got progressively worse with transition to secondary ending in school refusal, self-harm, OCD and talk of suicide. The school was not equipped to deal with this and implied problems were stemming from home. Since deregistering my daughter is healthier, happier and enjoying learning through Interhigh. 12 months on and she is the happy child that she deserves to be!

My son does attend each day but asks not to go and hates most of his time there. Schools are shameful. Nowhere near the help given to kids that so desperately need it. My son has anxiety brought on solely by not being able to do work set and the school denying he has any problems. Private assessment says otherwise

Schools are shameful. Nowhere near the help given to kids that so desperately need it. My son has anxiety brought on solely by not being able to do work set and the school denying he has any problems. Private assessment says otherwise

My child is now attending a small nurturing private school, living it and attending full time . Mainstream secondary school refused to use any known anxiety related interventions for him, e.g. gradual desensitisation with his peers. The SENCO was negligent and outwardly hostile towards me and inappropriate with my son (eg calling him fat). He was in a separate room in the learning support department, teaching himself and a learning mentor (who was lovely and caring) popped in every half hour or so. He often did not see anyone else during the 3 hours he attended each day for 4 months. His tutor (main pastoral system) visited only on 3 occasions each time after I complained. I'm an educational Psychologist and I even couldn't get the system to work for my son! His school place is currently being funded by his grandmother; it felt like his previous school was leaving him to die.

Current counsellor thinks my student has PTSD from treatment from bricks & mortar school. Cyber school gives us more flexibility and my student has a greater sense of control, with much better support from teachers.

I have never had any help from the school with the bullying, they wanted to move my child to another tutor group and different classes when she was the victim (2 children in the tutor group were bullying her from Primary school until I removed her from school the first year of Secondary school). I have also had to fund the online school she is currently attending even though I am a carer for my mother and do not have much of an income. No help given.

Anxiety at an early age needs to be taken seriously

My child crashed in year 8 of very difficult time for whole family. We were told just to drag him to school. Even when he was having panic attacks. Child still very difficult to leave house. Very bright with low prospects due to severe anxiety and no support.

None

Girl diagnosed with Asperger's. School will not accept diagnosis. CAMHS discharged when diagnosed as will not support. Child has very high anxiety wakes up crying as it's too hard. School will not put things in place as she is fine when in. Before goes in has nightmares can't eat can't sleep. Cry's upon waking saying it's too hard can't face it. No support.

Not directly accused of being bad parents but feels like unspoken. GP. OT and specialist teacher at complex communications needs team all recommended I self-refer to children's services. Even though

I'm the one subjected to violence from my daughter, due to her extreme need to control because of her anxiety associated with ASD I feel I'm under threat by children's services when they're not trained or equipped to deal with these issues. (just like I wasn't some years ago when I trained! Since left the profession and retrained.)

school has gone out of their way to blame us as parents and ignore all medical evidence they do not agree with. consequently my child is suffering emotionally physically and educationally . they also refuse all attempts to work together with us as a team . our child need not be behind but she is and its negligence. if the system pushes parents to force ill kids into school to then not support them and if they don't attend they fine the parents or threaten court what rights does the child and family have ? our children are not fine in school they deserve an education and have rights to one within their limitations to reach their full potential but they are being let down daily .

My child because she had no other serious issues meant we were both called liars, to our faces. She had problems from nursery to 6th form, leading to a complete breakdown

Can't seem to get any help anywhere

Little help from school. Husband and I very proactive forcing others to be involved. No understanding of children's anxiety at school.

We are awaiting online school. My daughter is very intelligent but getting no education at the moment I kept my son home illegally for over 3 years and reported myself to school welfare more than once to force the issue, still nothing.

We are awaiting online school. My daughter is very intelligent but getting no education at the moment

It's not easy when violence from child due to anxiety

My son only return to full time for first time in 2 years next week

My child is academically capable but is in constant pain and often exhausted. Her school know us well and have been as helpful as possible with lift pass, corridor pass, uniform adaptation but they can't seem to see the problem with attendance which is caused partly by needing so many healthcare appointments and partly be her susceptibility to injuries.

Very poor support from head teacher of school. wasn't interested in control measures just wanted known issue removed from school. many hidden issues in the same school not dealt with.

School suggested to home school now after a year no school my daughter at her dads and Birmingham council no support at all mixing all information no communication with them and workers that are there to help

A massive amount of work needs to take place for children who mask at school alongside those that are academically high achieving but suffer while achieving those results.

My daughter has spent years struggling in school but 'looking fine' while every attempt I have made to engage professionals has been met with a parenting course or the notion of 'she's doing it for your attention'

We are lucky to have a fantastic school at present who work really well with us and for us, and an autism champion who sees past my daughters masking but this is seldom the case, and I'm fearful that secondary education in September will be even less able to do this and nurture her.

In my opinion also the minute a child has school difficulties, before it ever gets to school refusal there should be a culture of reflection and assessment of how that school is meeting that child's need, rather

than the current culture of just blame the parent and use fines, attendance figures and EWO's to force that child to conform to something that is obviously not working for them.

If schools were allowed to be more fluid and child centred rather than government, curriculum and league table confined in its methods then I feel there would be a lot more happy children in schools and a lot less school refusal.

The school has made both my child and myself ill with worry, zero support for my child, picking even stupid things and sending her to referral- like the colour of her socks, her shoe lace not being tied. She was in the top group of everything, worked hard, homework always completed. Just hated school and started self-harming. My daughter's mental health is worth more than any of the things they find important.

My son was diagnosed with type 1 diabetes when he was 11. A month later he wasn't attending at all. He has anxiety and depression brought on by his diagnosis.

He is now 14 and is attending two lessons a week in the library and two in school.

His diabetes control isn't perfect but he's feeling a bit better about his life now thankfully

Schools simply don't care about students wellbeing they only care about their attendance/performance

My daughter is very intelligent but struggles socially and emotionally due to the effects of her ASD. We only received her diagnosis weeks before starting Secondary School and as such were ill prepared for the catastrophic effects that the environment there would have on her. It is clear to everyone involved that the best setting for her to learn would be at a specialist school, of which there are few. My only fear is that she is caught in this system for years whilst everyone has to jump through hoops, getting nowhere SLOWLY!!!!!!!

Complete lack of understanding from school as she is a girl and was deemed "naughty" and "manipulative"

My poor 8 year old doesn't have any support in school, they keep telling me she is fine. Why does she miss weeks at a time, and no one even contacts me to find out what is going on. We are in Scotland so we wouldn't be fined as far as I'm aware.

SATs should be scrapped as place a lot of unnecessary pressure on the children and are worthless... stats purposes only. Children worry about them from years 3-4 and in year 6 education is wasted as they are just taught how to pass the tests by doing past papers. Not good for mental health.

I had very little help from school. GP referred us to CAMHS but they offered only 1 counselling session as my daughter couldn't engage, surely they should be trained to deal with anxiously teenagers!!! She failed most of her GCSE's and won't do any further education - no one has contacted us except careers advice service.

My son has separation anxiety and many difficulties and there is no support for his anxiety yet, been 18 months since diagnosis and is just starting to see CAMHS but not starting well, so not optimistic

Schools HAVE to change. We are failing our kids. Teachers attitudes that the child and parents are at fault and have to fit in or we will be threatened is absurd.

Currently my daughter (15) is at her worst she has ever been. CAMHS wrongly discharged her and we are now not receiving any help. My daughter can't take life anymore and no one in the country is willing to help

My child because she had no other serious issues meant we were both called liars, to our faces. She had problems from nursery to 6th form, leading to a complete breakdown

Basically I struggle 5 days a week to get my child on the transport bus as I have a child who don't want learn go to school but it's the law so I'm constantly battling to get him to school always threaten with my child being suspended on transport as his behaviour because he don't want go school only at primary

School refusal (apart from the last week) wasn't an issue although she did go in crying every morning. School had a one size fits all policy and allowed a few strategies (time out card, wearing earphones to go into building) but still insisted she should be in lessons and shouldn't be crying as she was in year 8!

My daughter had a diagnosis and EHCP from yr 2, school just didn't put enough reasonable adjustments in place

My son as never liked school, life will be much better when he as finished with education .

We have been marked as unauthorised absences at every occasion, despite our GP acknowledging anxiety and mental health as being the issue.

My daughter hates school due to her difficulties and I don't think she is supported enough in school due to cuts in funding for schools and because of the focus being on tests and tests results rather than the wellbeing of children. My daughter is dyslexic and struggles with spelling and other areas she works and tries really hard every single day and knows she is behind. She struggles with relationships and friendships with other children and I don't feel she is helped or supported in school for this. She hates going to school. She is happiest and the child I know and love when she is at home and around family when she is at school she is down , upset and negative i fear how this will impact on the rest of her time in school especially when she goes into secondary. School is not enjoyable for kids anymore and i personally wouldn't blame some for not wanting to be in that environment where kids are pressurized to perform or where they are surrounded by horrible children and made to feel the way they do.

My son is now 19 in college but primary didn't believe the diagnosis of ASD when he was given it, and he got no support, then couldn't cope with transition to secondary school, started to self-harm and tried to strangle himself on school premises. Poor response from CAMS was referred and discharged 3 times. Now settled in college at age 19 and doing A levels but still has anxieties around change and exams

Severe anxiety led to ever increasing school refusal and in January I decided the trauma was too much and causing my daughter's mental health to massively decline. She has been waiting for CAMHS and Neurodevelopmental assessment/support for a long time. The best support and advice has been from you and other groups. Don't think we could have coped otherwise.

Waiting for an EHCP and have found some lovely specialist schools close by. So who knows what the future will hold.

School refusal is primarily passed back to the parent. I was told if I didn't let him play games at home he wouldn't want to be at home all the time. I was told he had separation anxieties and worried about leaving me.

I was told that he showed no signs of attendance issues in Y7 (in fact I had been written to in the Jan concerning his attendance percentage).

I was told he would not be passed to SEN unless he had a diagnosis ergo he would have to continue the Pastoral path that had been decided for him.

I was told by the Head of SEN/Pastoral that he showed clear signs of ASD/ASC but a diagnosis would trigger the right support for him.

After I blew up at the handling of Pastoral (putting him in a trigger lesson after I asked them not to and gave reasons) who did not discuss with me their investigation into and subsequent decision to put him back in. Within a week he was in SEN and within a few weeks all involved staff noted a 180 turn in his character. He still shows clear signs of ASD but is keen to start at a new school. He will not return to his old school, even to sit in the safe place and see his friends. We do not yet know whether his attendance will affect school application and/or if/how he will settle into a new school.

I've had a truancy officer

My child was under CSA whilst there

Trying to get my child back into school is incredibly difficult because schools simply do not want her despite her having no behavioural difficulties and very, very, high academic ability. They see the EHCP and run a mile.

My child attends a rural school which due to lack of funding is only in session 4 days per week. Due to strict state laws the school says it is "forced" to enforce attendance and all day attendance is even required of kindergarteners at this school. The school is structurally compromised, does not have fully functioning heaters due to disrepair. The school does not take measures to prevent communicable diseases and many, far too many children are sick. Since moving to this new area, and attending this school, my children's illnesses have *tripled*. I cannot possibly send them to school with active flu, strep throat, chicken pox, pink eye, staph, or any of the other illnesses children at this school have been getting and passing along because parents are forced to send them in sick. My child has anxiety about getting sick, and despite all our efforts through nutrition, vaccination, and hygiene, illness still occur. I actually see that this is the school's problem.

My son is now at a specialist school with full EHCP and is attending with no difficulty. He is now 10. However his school refusal began when he was 7 and went on until almost 9 when he was eventually signed off school by CAMHS after attempting suicide as he couldn't bear the thought of going back to school.

Never forced, but small indie school where full and total support given. But most professionals told us it was not a good idea to remove from school. We resisted that and did what we thought was right. Using a commercial online school which we have to fund ourselves and due to lack of resources, CAMHS no help that we couldn't do online ourselves.

Extra transition to secondary school was not provided despite parental request and diagnosis. Failings to make reasonable adjustments until too late. Morning only timetable offered after child too unwell to attend at all.

My child has diabetes

The school has cuts

And not enough staff to look after 7 yr old

Junior school very frustrating as didn't want to acknowledge any problem despite fact she spent most day wandering or in medical room

There is a real lack of provision for children who can't cope in mainstream with big classes / unmanageable expectations. I feel that my son is heading down the road of having to be home educated because his anxieties are too high in the environment he is in which is preventing him from learning.

I feel that lack of support and understanding by school and me pushing him into school environment has now led to complete refusal to go due to anxiety overload but if support had been put in place earlier it may not have happened

Despite asking for help, Ed Psychologist, CAMHS the only help I found was Early Help who tried but lack of information. Schools SENCO did not believe in MY daughter's issues she just wanted her in classes. However physically and mentally my daughter was getting iller every day. So I took only option I could see deregister and pay for her to be schooled online where she's flourishing.

My child is a Foster child and has been with us for 10 months. She has been seen twice by CAMHS but has a 20 week wait to be seen.

When your child has IEP, you're informed your child will receive help in school, but only for certain lessons. However, school had 14weeks of exams every year (out of 39wk school year) & your child has to lose that help when the exams are on. School budgets mean send kids have to forfeit their support, so the staff can be used for the whole school.. I believe it's a case of misappropriation of funding, and it shouldn't be allowed.

Only on day 3 of school refusal. Have not spoken to the school yet.
Maternal anxiety blamed for symptoms which have since had a medical diagnosis

School is unsupportive and non-inclusive. The system doesn't work and the support surrounding mental health and all other 'invisible illnesses' is terrible.

Dislike how the school keeps reporting 'he's fine in school', when he is not. He 'masks' so much to try and be like the others.

The pressure placed on our child created pressure on us as parents and therefore had a knock effect to our entire family of 5. We weren't helped or believed for 6yrs but once the diagnosis was given finally we were listened to.

I was never offered a reduced timetable when my son was at school despite him struggling more & more each day. The school only cared about their attendance record. My son was told to 'man up' by his head of year! I am now paying for all his learning. It's a strain but his mental health is now back on track. When are we as a society going to care more about mental health and therefore a healthy society than figures and materialistic wealth!

School said we (parents) had created an anxiety disorder. They actively blocked a diagnosis. Had to go out of area and private assessment diagnosed him. We are going to complain to the school governors

My youngest is caught up in so much stress and upset surrounding her autistic sister it's had a knock on effect to her mental health and anxiety levels

The fight to get people to understand that she's struggling not naughty is exhausting

My 8 year old sons mental health was damaged by continuous exclusions from mainstream school. The school lacked training & didn't allocate my sons EHCP funding adequately. I refused to allow him to go back after they refused to take him on a school residential. We're facing a 4 month wait for placement in a special school.

We are at an early stage of school refusal. I envisage if I was to do this questionnaire again in 6-12 months my responses are going to be very different

We had a bad experience with the process of getting help from CAMHS.

The GP referred our daughter to CAMHS but because the school had an arrangement with Relateen, CAMHS said they would not help unless Relateen referred her. Unfortunately, there was a long waiting list at the school for Relateen and the school insisted that my daughter would have to have weekly 'counselling' sessions with a member of the teaching staff before seeing Relateen. This went on for some time. The teacher was not qualified to help, she did not know what she was doing and she was out of her depth, she had no understanding or knowledge about my daughter's situation, the process made my daughter very upset. It was a huge setback and a painful time for my child, I had to give up my job just to get her to school. After some months she eventually got her appointment with Relateen. After just a couple of sessions, the Relateen counsellor actually said to my daughter 'I can't help you, I'm not a psychiatrist.' After hearing about this, I deregistered my child from school and took her back to the GP, this time CAMHS accepted the referral. On her second appointment with a psychologist, CAMHS said that my daughter had severe anxiety, possibly autism but they could not diagnose because it was hard to see through the anxiety. A psychiatrist that attended the second appointment offered a prescription of Sertraline which my daughter refused to take. CAMHS made it clear that they could not help if she did not take the medication. My daughter now learns with an online school and is enjoying learning again. Being out of school has help my daughter enormously. She is now managing her anxiety very well and is beginning to enjoy life once more.

breakdown in Y7, autism discovered, too ill, separates school and home, no education

Worse I've winter, from year 5 to year 8 . Now year 10 , going into school now, but struggling with anxiety and concentration. CAMHS 2nd appointment next week, but I feel they don't believe her..

I answered these questions based on my boys old school. Now he is in a SEN school he is happy and doing very well, he has stopped self-harming and actually talks to people now

My child is registered with a private school at this time otherwise I'm sure I would be facing penalty fines etc. There does not seem to be any sense of urgency from school or CAMHS to formulate a support plan and try to resolve bullying issues. My child has refused to go to school for four weeks now. She has refused to attend previous schools at times mainly due to bullying and anxiety. Lack of action has built up mistrust. We have been researching and providing study materials independently to ensure she does not fall behind. No work sent from school although we have requested it.

Our son was signed off by a GP (suggesting class change), supported by a second GP and Ed Psych but the school marked unauthorised, threatened penalty notices and refused class change. When they eventually changed his class - no cost or problem to them - his attendance immediately reverted to 100% attendance as it had been before they made the change that led to our son's anxiety. CAMHS & SS after 3 counsellors. Didn't offer anything after assessments. Said our son had to choose how to behave. 12-16 terrible. Still unresolved issues affected & not diagnosed - but no faith in professionals now. He agreed to get help before.

my granddaughter desperately wants to learn and attend college after 16 there is no help and support they hope you will go away. Local Authority don't do enough assessments of the child before recommending suitable schools. Not enough help for ASD children.

The first question everyone asks about her non-attendance is whether she's been bullied, but the bullying - of her and of me - only began when she ceased to attend. It was always about attendance, about how they were 'trying' to keep the EWO off my back and stop me being prosecuted (implied threat). It took six weeks for anyone to ask after her welfare (and only then when I pointed out that no one had). I was told she needed to learn resilience. In the two years since then, a late diagnosis of Asperger's has made it clear just how resilient she has been through 12 years of schooling; the schools continue to expect her to do all the adapting.

Only attending 1 hour per day. No work set for home, does 15 mins of English or maths during her hour at school. I get her to do work of all subjects with books that I have brought for her.

I am made to feel if I say he is off because he is having a meltdown that it's my fault. So I have to lie and say he is ill... I hate doing it but I don't get any intervention other than when they maim about his behaviour and then lie at how well he is doing.. He's seven soon and can't even write yet but apparently that's normal.

started with nursery and he used to throw uniform in bin, ok in infants, better in juniors and they did lots of work with him after diagnosis, lots of mentoring as he was starting to show signs of anxiety, started to deteriorate after just two weeks at senior school, stuck it for a year making him go then in October this called it a day when anxiety was back and having a negative knock on effect on whole family.

School has been supportive and excellent disability social worker but the environment isn't right for him. The difference between him and peers is getting more obvious as he's getting older.

Poor teacher made attendance more difficult, this improved when teacher changed.

Very lucky to have extremely supportive Head teacher. It's relentless and extremely stressful.

I found staff wanted to help but didn't have the resources or knowledge.

This is our 3rd child, things are worse now than ever before in schools. My job is a SENDIASS officer so I have an insight into the situation across many schools and what I'm facing, others are also. My child has autism and struggles with anxiety as well as trying to conceal his tics related to Tourette's Syndrome... Being told to bring him in for school to decide was not helpful at all. Previous class teacher totally

clueless as to his needs and accused us of making it all up! He's also struggling with understanding bereavement his grandad died 6 months ago. He doesn't understand what this means. He's terrified of the upcoming SATS and transfer to high school. He's terrified of the upcoming school trip, end of year concert and leavers assembly. He wants to stay at home as the change is stressful. Every day is torture getting him to school and I dread high school.

As a parent you have to fight for everything, support, homework, EHCP etc. CAMHs are woefully under resourced and poorly managed. I have all but given up hope of my child ever getting the support required to enable them to achieve the means to make a meaningful life for himself. I am frightened of what the future holds for him.

My child has said he wants to go to school but just cant

My daughter 9 year old has gone through 2 primary schools. She was bullied by children and staff at both. She has threatened to take her life on more than one occasion. Since she has been homed schooled (8 weeks) I have seen a complete turnaround in her mental health.

I must say that I do not think it's fair that parents of children with SEND a having to result in home schooling in order keep their children safe and sometimes alive.

Staff need better educating with SEND children

I had to push my daughter's School into listening to me , I recorded her meltdowns when she was struggling and too anxious to go into school and sent detailed daily emails of what she was going through. It was only when we got a private assessment that they began to listen and only after they received the report when I pushed again to ensure that they put supports in place that the Dr said our daughter needed. We pushed again to start the EHCP application which they were reluctant to do. My feeling is that they aren't going to bother with supporting our daughter as she is in Year 6 and leaving in July. One teacher told us in Year 2 that if our daughter was a boy, she'd think ADHD. We followed this up with the head but it was all played down and we thought they knew best. They didn't and we should have pursued an assessment then and saved our daughter from a breakdown in November of last year and many, many, anxiety attacks and self-injurious behaviour since. She is coping better now that she finally has some support in place and her anxiety levels are down.. but we have secondary school and puberty looming and that feels daunting. More education on spotting girls on the spectrum and early diagnosis for girls is crucial.

We were 1hr a wk mainstream for 3 1/2 yrs he also attended a farm for between 2-4 mornings 9-12. Other than this he stated at home No tutor etc from Education dept in all that time. We only recently obtained a diagnosis before that it was parenting, SEB difficulties etc 7 1/2 yrs for a diagnosis. He currently now attends 12 hrs a wk but that was after an Education solicitor became involved and I still have to battle for extra hrs. He should be going to secondary school next year but he has not been in school full time since half way through P2

Clearly the fabricated illness report by previous school was unsubstantiated as I only found out by reading her hospital notes. She was subsequently given several diagnosis but I have not received an apology and the report is still on the file of both of my daughter's in their subsequent school, even though it was 2 years ago and I wouldn't know if I hadn't got a copy of medical records.

Mainstream is not suitable but no-where else to go.

Had more support from the home education community than I ever did from school or local authority. Support groups online have been invaluable, made online friends who I have met locally. Thanks to all my online support.

The school have just got a new SENCO so we are being supported now. The SENCO before was terrible.

My daughter is a different child since beginning home education. We are able to socialise more and she is confident to go out and give things a go. Social services couldn't believe that we had been referred to them or accused of fabricating her illness. Very sad situation.

My 11 year old has been out of school for 18 months. School have too much power in diagnosis and no training in autism or mental health. We were failed by 2 L.A.'s due to cross border school issues - neither L.A. would take responsibility - Derbyshire and Notts. Help was completely wrong due to a failure of understanding of the differences in autism in girls. CAMHS discharged us without notice and when we needed them refused access. We had a delay of 4 months before we managed to complain enough to get back into the service. Nobody would take this seriously enough until we were in crisis. Our girl is now on medication for anxiety and depression.

This is a great thing you're are done no, thank you

My sons difficulties in getting to school have been slowly progressing over a few years. During this time everyone has refused to help because he masked his anxiety so well, so everyone we spoke to just kept fobbing us off onto someone else and we were just going around in circles. They are only just beginning to take notice now because he has refused to go into school for the last 5 months. We are still however under referral stage, currently awaiting a TaMHS appointment and still have no help as yet(except the school sending homework). I wonder if we had help earlier if it would have avoided school refusal? No way to prove/disprove this of course but this is my gut feeling.

The current education system does not suit all of the children in today's society. Too much pressure is put on children to do well at school when they are not academically able to cope with the class room environment. The system needs to change not the children.

I have so many! Had the head been aware of anxiety as an illness/issue or able to control the few bullies that targeted my little girl I sincerely believed that she would still be in school today.

I feel I haven't had as much support from the school even though they know my personal circumstances

My child attends private school reluctantly but it is way better than local secondary!

The local authority tried to prosecute me for my son's low attendance. They spent money on lawyers and court fees. My son was ill but the LA tried to prosecute me rather than find ways to keep him in education. I deregistered him to stop prosecution and also because there was no support for him in the school. Children's mental health needs to be a priority with proper funding in schools and in the NHS. All children have a right to an education and to receive support in school if they need it.

I would like to make further comments, but I'm so exhausted and demoralised at dealing with the failed education system and its traumatising effects on my son, that I simply don't have the energy. I'm sorry. I've spent the last 15 years explaining my son's (fairly basic and human) needs to various professionals, in the hope that they would at least try to meet them. Sadly, this hasn't happened. My son is now 18 and his self-esteem is so low due to his experiences of school and college that he has attempted

suicide 4 times already this year. I really wish I had had the courage and money to home educate and to pull him away from all the trauma he's had to put up with over the years. There's nothing else to say really. The system has destroyed him, and that's that. There's no recourse or redress. We just have to live with the consequences and do the best we can for him now. The treatment of SEND pupils in mainstream settings is a shocking disgrace.

School would not apply for an EHCP because 'they could not justify it as they didn't give enough support to warrant it'. We did a parent application and whilst it is not finalised it has been agreed she has been awarded the highest banding funding in the city. All too late as now the years of fighting the system and warning professionals has led directly to her being admitted into a CAMHS inpatient unit.

School been threatening to take us to court for 3 years finally they had us in court 2 months before my daughter leaves. No fine or family support given before this. Prosecutor failed to disclose all our medical evidence but we did. Because we went guilty (can't afford a bigger fine) if went not guilty it would probably got thrown out. It's been hell school refused to get some things to help my daughter with migraines and refused to communicate with us. Refused to help us all work together and support my daughter. I feel they have ruined her education. She was outgoing, nothing would bother her and able to stand up for herself when she started. Now she is depressed no motivation, can't be bothered. Gets really anxious when leaving the house which makes her IBS worse.

Lost 2 years sixth form having to go to college now in September 6 high schools no one cared no GCSE courses studied so far behind now completely failed by system

Education authority and teachers are too quick to judge home environment parenting and influences outside of education before asking about any concerns or problems within school. My son was subject to a vile torrade of cyber bullying via social media outside of school and in school hours had a gang of 20+ teenagers name calling and pushing him, the school rather than deal with the group of bullies wanted to place my son in isolation. From here his problems with anxiety, low self-esteem just got worse.

Accused of FII in 2013 by previous school. LA backed us after we passed parenting assessment and proved we were telling truth but even they were ignored. Stigma of fii sticks.

If I am unable to get my child into school due to anxiety related illness I will keep them off school. Fortunately it is usually for short spells currently.

Forcing my child in to school massively increased her anxiety and ruined her relationship with her dad. She was out of school for 2.5 terms before starting another mainstream but smaller setting. Only lasted 1/2 a term. Then out for another almost 2 terms before county agreed to a tutor. Has taken a year to get EHCP sorted. Hopefully getting an offer of special school place next week. She is in y10. Whole family affected by this.

Staff tends to view reports of challenges and difficulties as tied to lack of motivation, lying, etc. by any and all students they work with who are struggling with mood. Therefore, when my daughter told her counsellor and case manager that her mother was seriously ill, and also that my daughter was experiencing increased physical pains, etc. from joint issues, they brushed it off.

We're at the early stages of non School attendance it's only been a week but things have broken down over several weeks GP appointment tomorrow

Thank you for undertaking this survey.

My autistic daughter masks and endures immense anxiety and overwhelming sensory difficulties once heightened. She is also highly motivated and determined to 'fit in' at all costs. There is no work avoidance on refusal days, she now independently contacts classmates to get homework and despite also being dyslexic achieves highly. She has taught us so much. The key has been listening to her needs and celebrating her courage to try rather than actual attendance. Accepting the situation has reduced so much of the tension that we, as parents, added. There is still regular refusal but without the trauma. Also once the issue has passed she returns to her normal school routine.

We did have some parental CAMHS support eventually, but by that time my daughter was peopled out, as she was dragged through assessments with what felt to her like countless 'random professional strangers'. She refuses direct support. I feel we worked this out ourselves and the professionals are still playing catch-up as they tick boxes.

Apologies for the long comments. I am just so grateful to be heard.

We've been very lucky with an extremely supportive mainstream school. He's on roll but learning at home while waiting for his specialist school placement to start in September. His school have stayed in contact and support us with work and resources. We also had input from a helpful CAMHS buddy. But I've had to be very pushy for input from OT, LA SEN Team and other services. The NHS is stretched so thin we've had to pay for private child psychology sessions.

School don't return my calls when I phone them to say she has refused to go

I am lucky in that the SENCO was very supportive but unfortunately this support didn't cascade well to individual teachers, some were on board some weren't and the ones that weren't broke him.

The pastoral team who are the ones who are supposed to provide the emotional support were dreadful and seemed determined to make him serve every detention, even tho the SENCO had agreed that detentions shouldn't be given where they were as a result of his difficulties.

He's leaving school to hopefully start UTC in September for science/engineering GCSE's which will play to his strengths.

Teachers need education on the needs of children with attachment disorder and related issues

My son does attend school, I insist upon this but although compliance is better he has had major meltdowns over going to school in past to a point I've had to dress him and carry him there. He now will get angry when he realises it's a school day and sometimes takes a long time to get ready with me reminding him what to do next. He will go to school but he is not happy about it.

I was told there was nothing more the school could do for my child 3 months before his GCSE's and that unless I removed him from school they would prosecute me for non-attendance. He therefore leaves school with no qualifications, despite being registered as gifted and talented in primary school. School have actually been very helpful overall. In the first instances though it was a really tough time with school giving advice and making comments that accused us of bad parenting and bad behaviour on his part, this made things extremely difficult for all of us. After diagnosis school have been very helpful but there just isn't enough resources to manage issues well for all involved and relies heavily on being directed by the parent. I feel this causes issues as there isn't enough parental support so it's like fumbling around in the dark !!

We knew this year was going to be difficult for our son and told the school but they didn't listen. He started refusing to go once every couple of weeks, then it got worse, then from November, (6 months ago,) he hasn't left the house at all. School was very little help, got threatened with fines, they turned up and tried to force him onto the school bus which resulted in him totally shutting down and banging his head on our gardens concrete steps. It was an absolute nightmare trying to get him help, we went to the GP, contacted his paediatrician, and self-referred to "early help"! We self-applied for CAHMS but had to wait 5 months. Finally got an assessment and they said his anxiety was so severe that they couldn't even work with him until they prescribed him medication to bring down his anxiety and they informed the school that we can't even think about getting him back to education until he is ready to do so. Getting help is a long process with many hurdles, if our son got help when we first asked for it, his issues wouldn't be half as bad as what they are today.

I feel like schools have very limited knowledge of school anxiety or anxiety based conditions in general and how to manage these in a school environment.

We are currently waiting for a specialist school to accept my son. Total lack of support from school until diagnosis made by which time my daughter was out of school for over a year after a total breakdown - became more co-operative once diagnosis made but at all times have shown a lack of understanding/knowledge of her condition

We don't know what to do.

It's difficult as schools are not prepared for medical and mental health problems and her school often send her home due to her distress levels and big rise when stressed then the EWO threatens to fine.

There is not enough help for children having difficulties in the school environment especially school refusers.

There is a lack of knowledge and understanding surrounding school refusal. I would be happy to provide further information regarding my son to develop understanding and appropriate help. Awaiting specialist provision but all full. Going through tribunal.

We've had my son's autism blamed on us being bad parents, suggested he might be being abused, we should be shouting more/not shouting. We've been told he can't be in school because he's not emotionally healthy. Staff changed this new head and SENCO, a brilliant teacher and he's had no exclusions, been attentive in school and is making amazing progress. Last year he had 32 fixed term exclusions. He is year 3.

School were supportive by suggesting Flexi schooling which we did for a year and a half, but the L.A. banned such arrangements and I was told he had to go back full time or it would be unauthorised absences.

We want to help my child not to become a school refuser. Their anxiety is getting in the way of learning.

My child manages to keep a lid on their emotions during the school day but on arriving home is overwhelmed and has sensory meltdowns which can include verbal and physically aggressive behaviour. My child is constantly worried about school - he is in a hyper-vigilant state and constantly looking for evidence to corroborate his feeling that he can't do something/anything or will be told off.

Sport has been and continues to be his saviour although he puts an enormous amount of pressure /expectation and fear of failure on himself and as soon as there are more competitive events he can

freeze or is unable to attend.

We are looking now to get a more formal diagnosis as we think perhaps there are additional learning difficulties that he is experiencing ADHD/OCD ...we want to ensure that we get the tight help ASAP.

The best support provided will never "make" my son like school or willingly go to school. Every day is a fight

This is my youngest child. I am much better at dealing with schools after three SEND children. Your survey should provide for more than one child! He is getting some support but Wiltshire does not appear to recognise dyslexia so I have had to pay for that diagnosis myself. I have Ehlers Danlos Syndrome it is pretty likely my three have that but hard to diagnose at this age as it is a progressive condition. I was diagnosed at 42. Fingers crossed he does not have it. Epilepsy mainly behind us. The school failed to notice bullying and missed lots of signs of female autism because our daughter is 'bright' and was a star pupil. We have so many emails highlighting our concerns and they failed to take appropriate action or listen to her.

My child's problems started as soon as he started secondary school. He couldn't cope in that environment. It took over two months for the SENCO to actually see us, this is after keep asking. He was put on a part time timetable which didn't help. I applied for a EHCP and the SENCO wasn't happy and told me he wouldn't get one. It was refused first time but the school did get an EP involved because they needed evidence and she could see my son's problem. After 6 months and my son completely refusing to go in I got our local MP involved. After this the school especially the SENCO was very helpful. The local authority were slow and saying he still didn't need a EHCP but the SENCO fought them. After a year not having an education my son was sent to a very small special school. It took him 15 months to settle because of the trauma he had been put through but he now attends full time for the last 5 months. CAHMS wouldn't help him till he was in education even though he needed help then. He has had CBT privately as CAHMS were not very good. When we were having problems at school we did have an early helper who was brilliant.

Some children love school, some children don't like school but go anyway.

Some children like my son hate everything about school and cannot cope with all the challenges it brings. My son at the age of 9 tried to throw himself out of an upstairs window, because he would rather be dead than be forced to go to school. He said his brain is on fire when in school. From that day I never forced or coaxed him into school. I don't care what the LA say or do, my son's health is my main concern

There are plenty of kids who're unhappy in school that do not refuse to go. The rigidity of routine and process that my autistic son has, means he can't get his head round NOT going to school, but isn't happy while he's there. He's trapped therefore, knowing he doesn't want to be there, but not being able to NOT go.

Secondary aged child - father and all uncles both sides very dyslexic. Have had to pay for assessment ourselves as Wiltshire will not. Significant physical disability probably has Ehlers Danlos Syndrome like his mum - progressive condition can't diagnose yet. Almost died of bronchiolitis aged 3 weeks, hip infection wheelchair bound aged 7, poor immune system, cluster migraines, joint hypermobility syndrome affects writing

Anxiety always been present. Hit a head at SATS level. I have been fighting for 4 years to get child assessed as I am sure there is SEND and in the end self-referred after doctors thought it was my anxiety presenting itself in my child. I have contacted CAMHS...OT...speech and language myself and have finally got them to agree to testing. He is also visiting a paediatrician next month to have stomach

issues looked at (I am sure its pressure and anxiety making him ill) although all of this is happening he is still fine in school (apparently, i know otherwise) and i am being threatened with a fine for his absence. Daughter diagnosed with Autism aged 7 and joint hypermobility syndrome. I had to pay for dyslexia diagnosis as Wiltshire will not. Very high functioning gifted child prone to bullying. Had to move her to the private sector to get adequate provision. This is completely against my principles but as the only course of action available. About to do A-levels.

We moved child to different school with a more welcoming, inclusive environment where there is a willingness and ability to deal with issues in a satisfactory manner. Child's attendance no longer a problem.

My daughter is a rule follower, this helps get her to school, but at huge cost to her mental health and well-being. Every single school morning she says she feels ill. I try to gauge how bad the feeling ill is (anxiety and exhaustion). When I feel she is at breaking point I give her a few days off. Whilst my child's anxiety has been exacerbated by death of a grandparent, schools inability to address his problems, led him to being labelled lazy, rude, and being told he was lazy, which has knocked his confidence, so had the constant detention for not finishing work and being disruptive.

Parents and Guardians are ridiculed for their advocacy regularly when it comes to schools and absences. I was threatened by school that they would call CPS for anymore unexcused absences.

My daughter's attendance problems have been intermittent and the specific reasons have always been medical rather than related to the dyslexia. She was part time from nursery to the middle of year one and has been full time since then when possible, and she's not gone back to an agreed part time timetable. We have been very well supported by the primary and secondary schools and have worked in partnership with them to get the balance we need between the importance of education and recognising when it's not possible for her to attend. The SENCO at her secondary school has made all the necessary provisions for her for physical and educational support, and the communication between the SENCO, year head, form tutor and other teachers has been very good.

We have run the gamut : complaining parents to collaborative parents. We are articulate, highly knowledgeable on ASD. What we were never regarded as however were experts. Kept extensive written records. It was by not listening to us that the most damage was done. Our daughter will not have an adequate education as it stands. We are on second EHCP application but to be honest I have no faith in the outcome.

Hope this survey will help schools/LA/government to understand.
Education dept nor children's services in Norfolk are child centred
Awaiting paed's assessment and on CAMHS waiting list for counselling. School expects constant attendance in the interim and keeps withdrawing environmental support eg lunch passes.

Our main problem was the schools attitude. Everything they were doing was the right way and anxiety and stress does not exist in children who are at junior school, even when an education psychologist diagnosis was anxiety

We are not home educating yet but we will be in the next few weeks due to her anxiety and PTSD.

We are not yet home educating but will be in next few weeks due to schools failing support and lying in reports from meetings

Schools need more education specific person that has good knowledge of Autism, stress, Anxiety etc. Once again it's all down to money.

We had horrendous time 5 years ago with other daughter, long story. Got took to court, thrown out by judge should never of got that far. Very upsetting time.

It has been the hardest 3 years of our lives, affected the whole family. After EHCP and a term trying a new school, we are now trying g a new route at home, trying to get L.A. support and tutoring.

Everything takes so long to sort out.

Son became suicidal in mainstream age 8. CAMHS states it was entirely due to school. Now in ASD school and got 100% attendance on first term. Had to go through solicitor for ECHP to name our choice of school.

Our daughter was shouted at by a teacher and her work held up and the class told not to not do it like this. She is a good sensitive child this traumatized her after that she started weeing at night with nerves and getting distressed about school the school dragged her off me to go in that hurt both of us. They blamed separation anxiety. We took her doctor who referred social services to check because anxiety. They never came .went to CAMHS they said just growing anxiety. We changed schools this school is only 50 pupils they encourage not push they listen to us and adapt they have helped so much and although she doesn't like school she isn't as distressed now and copes and she is becoming confident she can now do some talking singing acting in front of people. This school understands us

Amazing support.

We are lucky enough to have an EHCP with 30 hrs of 1:1 support in place for my son. Because of this, his school are understanding and have agreed to part time timetabling when his anxieties are at their worst, but this is mainly to make life easier for them. When he's highly anxious, his behaviour becomes extremely violent and disruptive and they simply do not have the resources to deal with this. As a consequence to this, we have both had to take on part time roles to allow for one of us to be available at any time during the school week, taking a massive cut in income and the stress that this brings. The irony of receiving an email from the LA SEND team saying they would not consider him for a special school, followed by a phone call from school asking you to go in and support your child because they cannot cope.... Too mainstream for special school, too special for mainstream - we are now looking at home ed options before too much psychological damage is done.

School head not interested. Only bothered about attendance figures. Went for meeting and she had a go at my daughter about her lateness and attendance before we'd even started the meeting.

Taken 5 years of persistence to get any help. CAMHS refuses to even see her.

Feel forcing child to school does not help anxiety and pressure from social work when your told you will be sent to children's reporter has caused anxiety for myself and they make you feel like a bad parent no other help is offered

My dtr missed 3 yrs of school. It was a constant struggle to be listened to, get referrals, get help, find suitable provision, navigate the whole system & finally to get a placement authorised. Dtr now in year 11 & so much key time gone...😞

Leading up to SATS the anxiety/meltdowns have increased.

Not missed a day yet but anxiety every morning and often late. School say she's fine, she says she's not. Her expectations are high, she's a perfectionist and it's hard to convince her to lower expectations!! Lack of understanding of the complexities of a school refusal situation by education and health staff has made our situation so much more unbearable.

I have based my answers on our experience at two schools. I changed my child's school in year 2 and her anxiety etc improved greatly. She no longer has the level of refusal she had since nursery due to kinder approach and support which was non-existent at previous school. The schools are within walking distance of each other yet have different approaches concerning children's emotional wellbeing etc. SENCOs should be trained to a much higher level, with relevant specialist experience, not seen as a rung on the promotion ladder as I have witnessed.

I have lied on many occasions to take my son out of school for mental health days, having to say it was physical illness. School will give me an argument and say its unauthorised absence otherwise.

my son has a no interest in school and has an attendance rate of around 80%. he was on a part time timetable in primary school. he has an EHCP but I don't feel that his current secondary school pays any attention to it. the SENCO goes through the motions of annual reviews. the school don't seem to pressure him with homework (he never does any). he hates the pressure in lessons and his teachers say he lacks motivation etc. so frustrating has he has ASD and they have no clue what this means for him. he will not do well in GCSE's so I am very concerned for him after year 11. although his attendance is 80% they have never talked to me about it, just mentioned it on reports. they seem to be ignoring him as much as possible.

We asked for help and support, all school had to was listen to the parents, one of which is a health professional. Due to the failure of school to act of CAMHS recommendations and the attendance getting less and less, a CAF meeting that adopted flooding techniques that failed. Threats of fines and many suggestions to off roll etc. No support when we applied for EHCP and were granted and no support for hospital School again we were granted. Words fail me for the lack of support and help, if we as a family had not found NFIS as support I dread to think where we would be. Thank you My son has continued to attend school but this has been difficult for him. School has offered no support and refused to recognise problems. There is very little real support available and it has taken years to see CAMHS which has helped him. I have no idea how he will cope with the transition from primary to secondary school

My daughter has only missed 4 days off college which she has caught up the work. However, these were due to meltdowns with her anxiety. We have spoken to college to try and help her reduce her anxiety level whilst at school

The whole system stinks it truly does.

I am told my child has support staff that are trained on autism but not enough. Not good enough.

My child became a LAC child in March 2017. This is has had massive negative impact on his school attendance, school have tried to be supportive but refuse to assess whether it is the right setting for my child which I believe it is not especially when he is struggling with anxiety, depression or melt downs.

The EWO, la ,school and social services always blame the parents and never see school as the problem. This needs to change as so many kids with ASD are put on child protection it's not right.

CAMHS say that my son's anxiety about school is due to trauma caused by teachers at school and the way they have treated him.

Junior school a disaster, secondary is much better.

diagnosis of PTSD from interpersonal stress at school. With good social functioning when well.

More understanding and support needed from CAMHS in particular, but also school funding for extra support

My son used to like going to his special needs school - however, since 2015 my son has had PHP's put in place (without my knowledge or consent) and he was shut in 'Quiet Room' to deal with his 'challenging behaviour'. Things have changed at this School now but it's too little too late for my son: he has been traumatised and he has regressed in some areas because of this.

I give up with all the services. My child functions much better this way because I have more energy +much less stress.

My child has asked me to be homeschooled.

My child was forced to attend breakfast club so he would be at school on time instead of being late every day.

I was surprised that I was threatened with court action for just looking after my child. She's functioning ok now But I've had to more or less work out what was wrong myself, explain it to CAMHS. And go against the psychiatrists recommendation and take her out of school to attend Interhigh. It's the best thing I could have done. She's not in the environment which caused her so much difficulty any more. So she's doing really well.

My son attends a progress centre for a couple of hours a day but does not go to lessons. He is not getting any 121 support and effectively no education at the moment. The system for EHAT EHCP take too long and it is impossible to get the help they need due to funding cuts.

My son doesn't struggle because he is in the right place, however I've seen children who are not in the right place who clearly struggle with school attendance and this could easily be me. He did not do well in his first nursery and didn't last longer than 20 minutes in his settling period which made me take him out. I was anxious sending him to school when it came to reception year however we had a brilliant SENCO in the second Nursery who have helped him get an EHCP in time and that got him in the right school where he is thriving.

We changed our son's secondary school because they were inflexible and put pressure on him and us regarding attendance. Current school much more sympathetic but not geared up to offer specific medical support or ongoing educational support when son misses classes.

My daughter is 8, and I can physically force her in to school but it hurts and has aggravated my back problem. The school has failed in the duty of care - physically and emotionally. Social services are useless; inexperienced and time-poor.

I find it extremely difficult to engage with anything to do with my son's education prior to home education because I'm still so angry, bitter, demoralised & disgusted how my son & myself were treated by the school. Thank you for listening.

I am new to the whole SEN process and in very early stages. We have only just started having attendance issues

At every point we have had to get to CRISIS point to get the help and support for my child. They are now in a supportive and understanding specialist school and love school what a difference the right environment makes.

More support is needed for family's having attendance difficulties regarding many circumstances. There's a lack of empathy and care within many organisations at the moment including schools and local authorities.

Despite know needs since year 1 secondary school failed to provide any support or adaption till last term of year 11 after complaints

There's so much lack of school support for both my children with additional needs and it's also impacted on me

My boy is just child for whom school is not proving to be his natural habitat. He has vs and so the modern classroom is problematic. he struggles to pay attention in the ways schools want. He has no cognitive difficulties but by school standards is 18mths behind. He opens his eyes most mornings and says I don't want to go. He (and now the whole family) counts down to the weekends. Every. Single. Week. I suspect dyslexia.

The pressure to keep sending my son to school was immense, making me doubt my gut instincts, but he was being traumatised by the experience so I went ahead with deregistration, much to every professional's disapproval.

Schools understanding of Autism in girls and mental health is severely lacking. Teachers need better training throughout their careers to ensure that it is not just a SENCO with adequate knowledge.

I really feel that something needs to change with how we teach children in this country

Due to pressures from LEA and LA my child is in care. The expert psychologist is trained in forensic and criminal psychology. LA have no interest in his ASD diagnosis - his behaviour is seen as reflecting my own. I have had a breakdown (burnout) in the process and although I am waiting for ASD testing myself the same psychologist believes I have severe mental health problems - again, she does not understand autism. I am accused of abuse because I went to work and left my son in the family home with his dad - seriously! I have 36 hrs until court, where I hope this judge knows more about autism than the experts.

At my wit's end, sick and tired of the bullying by the education system towards bright children with SEN requirements.

Mainstream school staff including SENCO have little if no understanding of autism. Thankfully a magistrate understood and my son is in the independent school I chose. LA clearly put cost before my child's needs. As a parent I needed support and understanding not a tribunal to meet my highly intelligent child's (recognised as gifted and talented) needs. At 10 years old he came to court with me and fought for an appropriate education. How is this right? Thank you for this survey, it means our voices are heard.

We didn't have a difficulty with attending school, but it became clear when my son needed a different approach because of his dyspraxia. We have managed to make a positive transition to flexi-schooling for P6 and P7. We will home educate full time from S1.

We had to fund thousands for private support to get our child into an independent specialist needs specific school. Parents should not have to do this, many cannot. Thankfully things are now getting better as our child's needs are understood and the environment is conducive to meeting them.

School made Jake go part time from day 1 as they wanted to slowly integrate over a few months against our wishes

SENCO won't help or apply for financial help in anyway and School don't want children with disabilities in there school and put a whole load of blame and guilt on me as parent / carer (grandmother and grandfather bringing one of our granddaughters up as one of our own) .

We pay a qualified primary SENDCO to tutor at home from his DLA. The head did not understand sensory processing and thought forcing Young Voices (thousands of children singing in front of tens of thousands watching at the National Arena) would help him overcome his autism. The paediatrician asked me if the head would remove wheelchairs to help children walk, too. It's impossible to negotiate with that depth of ignorance, even when classroom staff are trying.

It is such a sad thing. So many parents who are law abiding citizens are not being supported. Being punished. We are lucky, school are trying to help us but the NHS is not supporting us at all. CAMHs is a black hole of obstacles which prevent the other agencies from Making progress. Kids are dying in the process from self-harm and suicide. Someone HAS to change something.

There needs to be more awareness of PDA of what it is and how it affects the pupil and their families Schools special schools especially need to recognise that a PDA child's social and emotional wellbeing is key and keeping their anxiety low. Authoritarian approaches and punishment exclusions are not the answer.

Strategies are a must as accurate EHCPs which state such strategies and how they must be followed to keep anxiety low.

Schools need to make reasonable adjustments not excuses to exclude as PDA children will still be PDA children after the exclusion.

INCLUSION IS KEY AS IS APPROPRIATE TRAINING FOR TEACHERS FOR PDA AND IT'S MANAGEMENT.

There still needs to be more understanding of the effects of mental and physical illness in young people and how it affects their school attendance and other things. Often the child is seen as controlling/disobedient and the parent seen as neglectful or not strict enough. As a parent with a child experiencing health problems, my experience has been tough even though I engage with everyone. Mental illness is often referred inappropriately to social services and parents are accused of failing. It is so wrong and unhelpful.

We are awaiting further support as none is forthcoming from school, particularly we suspect, as our child is due to change to junior school soon

The full on thing around school more worried about bums on seats than children's welfare. just over 3 years and it took my boy to have a break down for the school to listen

My child is in a unit of 4 kids within main school and feels isolated lonely and very unhappy. I am very cross too

I really feel that something needs to change with how we teach children in this country

The school have been trying to get to the root of my son's behaviours but I find they are very quick at sending him home when he does have a meltdown or lashes out. They evacuated the classroom once as he went down on the floor and went a dead weight. I found this way over the top and I feel they need more understanding in the classroom on how to deal with it

My child is in an ASD base at mainstream and they try to get him to perform to a non ASD child

Although high anxiety throughout primary school, support was overlooked saying just quiet. Took for a breakdown at secondary to get diagnosis after referral to paediatrics, who couldn't believe school had not referred sooner

Son had to change school in year ten due to no support and bullying which led to extreme anxiety. Late diagnosis at 13 due to A* student,

Thank goodness for Facebook groups. The school system is outdated and children with SEN are left and I had to go private due to CAMHS waiting list. Everything is a battle and this needs to change!! I'm sure if school etc listened to me earlier my son would not have got to this point where he is medicated to just live each day. X

Absolutely disgusting, lack of understanding from primary school, they didn't see a problem, made me feel like a liar

The system is broken and nearly pushed my 11 year old to kill himself

Grateful to have found out about school refusal online and that it's likely to be anxiety. Complementary therapies and CBT in hand

Parental application for EHCP after been told he would never get one, been told by headteacher all my son's problems were years of learnt behaviour before permanent exclusion

We had to get a second opinion at CAMHS as we kept being blamed for son's behaviour, we were not listened to and "poo poed" at everything we had researched ourselves. Second Dr at CAMHS, listened, took on board what we said and is now prescribing the medication we mentioned to the first dr. Social Services were also utterly useless, again, it was all our fault he was like he is!!

Our daughter 7, is ASD with suspected PDA. We have had 40/120 unauthorised absences noted on her school record where we have struggled to get her to school on time. This can range from a few minutes to a whole morning. Her behaviour has become less violent, but she is walking out of class a few times a week due to not wanting to be there, anxiety and sensory issues. She often needs individualised support/alternative work from her support worker. Class teacher and SENCO are very supportive, and try to integrate her into the normal school day. They understand the problems we have in getting her to school and pre warn us of issues they can envisage - e.g when class teacher is going to be away on a school trip etc.

The school and CAHMS have been very supportive

As a parent I have felt helpless to help my child but have felt blamed by all professionals involved. No-one seems to "get" how my child thinks or perceives school and I have doubted myself frequently, I know she is not refusing to be "naughty" or "lazy" her refusal began on transition to high school where she was very "disappointed that it was not what she had imagined and it has gone from bad to worse. The only thing school have been able to do effectively is to threaten me with prosecution, I have had to fight for involvement of all others currently involved by myself, without guidance from school.

Have been told despite the fact my son has a lot of support (which I have battled for) after he wanted to die rather than go to school last year (aged 7!) that it's not even worth applying for an EHCP as he won't get one unless he is failing and unless we want a special school for him.

He won't cope in Secondary school without significant support, and I don't want to see him fail just to meet their criteria (he is very bright, but has significant sensory / emotional & other issues) if he hates school any more than he does now I fear he will just completely disengage! It feels like he doesn't fit anywhere in the education system but is just squeezed into a system that doesn't suit him and gives him a huge amount of stress/unhappiness, he comes out of school exhausted and frequently just sobs.

Mainstream school made my son physically unwell through stress & anxiety, the teachers were as bad as the bullies. I pulled him out of school and he remained at home for nearly a year (at year6) until I was lucky enough to get an EHCP (on our third attempt) and he now attends a special ASD school. It has changed our lives.

Not sure this survey applies very well in Scotland. Special needs support very good here but diagnoses required before it can be applied. Also abbreviations should be written in full at least once!

Greater awareness needed in educational staff of mental health issues.

Internet school has been the solution and should be made available by the state for kids in similar situations. No "physical" school can modify its physical environment enough for kids with autism etc.

With small adjustments to the day my child could still be in school. As it has happened we now enjoy Home Education but for those who can't or won't then what happens to those children that find school totally overwhelming.

SENCO not qualified to be a SENCO , school had no idea what to do .

My son has only recently (yr 5) started non-attendance for anxiety . We are trying to get support etc as we can see his anxiety escalating and want to put support in before it becomes more of an issue and he starts secondary (which he is already getting anxious about)

We have been consistent with him on the need to attend. Now we are in the situation that he does attend but does not do work while there. At least he is learning by being present in class, but he will not cope in high school. When they try and press him to do work he responds in violent outbursts and has been excluded several times which is a nightmare when you are trying to hold down a job. He is excluded today as I write this.

Just about to go back to tribunal for 2nd time , LEA consistently name an inappropriate school that does not meet the child's needs and does not take his opinion into consideration. He has stated that he will harm himself and others if he is made to attend the school.

My son is adopted and we have support from our LA post adoption. He has been in trouble with the police and has 2 accusations against him Social services are involved because of this. . Thus has not

helped. His current friendship group has non-attenders which reinforces his non-attendance. School have been very supportive but this has been going on properly since Christmas.

This was about my grandson who lives with us. He is also our foster child. He had a diagnosis of ASD and PDA. We were threatened with prosecution for non-attendance at school and his removal from our care. We were given 14 days notice of his removal from our care to be put into a residential home with multiple carers who would teach him to behave like a 13 year old. We went to court and he remains in our care after a long and difficult fight.

In general our school were supportive and tried hard I think the problem is the whole education system which is getting more and more restrictive and teach to test based. Far too much formal education and testing to early putting huge stress on the kids and indeed teachers, most of whom would teach in a more inclusive, varied way to suit their kids if they were allowed to in my experience.

Attachment and trauma strategies are not understood or treated appropriately in schools. It's all about behaviour management tests and exam results

More understanding of behaviours and adoption related issues would benefit my child as well as more specialist provisions within mainstream settings

More support for children struggling in high school without EHCP is definitely needed

Got a family support worker involved school refused to interact with me had a tad meeting but nothing in place to help no point of contact at school at all no feedback they even lost my child when I did get him in school didn't inform me don't know anything about diagnosis or how to go about it right at beginning of journey

Our current arrangements will not work long term for my daughter, particularly when she moves into secondary school

We as parents are made to feel like bad parents or are lying when we fight for our children's rights to have the best education possible when mainstream schooling is no longer working for them.

My son age ten had the mental ability of an eighteen month old. I hate that he has to go to school. It should be ability not age. He will be home educated and will not be going to special secondary school

Schools are not set up to provide for the needs of children with ASD. However they need to adapt as children with SEN can't adapt to fit in. Late or no diagnosis means children cannot get the help they need in school and/or an EHCP. P was first seen by CAMHS at 12 but not diagnosed until 17. I had to fight the system for 6 years to get any support from school, a diagnosis from CAMHS then EHCP for my daughter who is probably now too damaged to be able to take up the support now on offer for September. This has badly affected all our family relationships, my ability to work and nearly led to relationship breakdown.

I have had no support from school so now home educate

As he's getting older, he's 9, things are improving. This may be because he's maturing but I think it has more to do with ASD being suggested last summer by the GP and the approach, by both school and myself, to dealing with his reluctance/ refusal has changed.

The school has also implemented a variety of strategies to support him in dealing with different situations that he struggles with (play/lunch time being a biggie) which have help his self-esteem and I think this has made things less stressful for him.

So hard to get them to do anything when they sit down and so "no".

I won't use bribery but almost anything else goes: waiting him out, gentle cajoling, talking to work out what the issue is and how we can deal with it, cuddles, taking things down a notch and going 1 step at a time and threats including, as a last resort, "we need to go in 5 minutes. If you're not dressed you'll go as you are, even if you're naked!" He's not gone naked yet; I put that down to him knowing I would follow though if he didn't get dressed!

My daughter was repeatedly ill with viral induced wheeze and hospitalised for this on several occasions. Our GP said that stress from bullying at school would have made this illness much worse. A new head teacher was obsessed with high attendance figures and school was not viable because of this. Since home educating her health so far has been much better and she is so much happier.

We've had a mixed response from various professionals, some supportive (particularly SENCO and inclusions manager), some not at all (including head teacher and GP)

Absolute shambles system is broken

My daughter suffers every day and every day I feel like a failure as a parent.

Anxiety, school refusal, overwhelming sensory overload, square peg in a round hole, is different but also made to feel different, cannot cope, feels the need to be someone they are not, trying so hard to be the perfect student & still doesn't feel good enough by the measure of teacher comments or standards, not able to filter out background noises makes it difficult to hear or follow all of the teachers instructions which makes student appear not as talented as they may potentially be (given the right set of circumstances), anxiety over many areas of school life, generally finds it difficult to fit in.. religious grounds & personality of being a tomboy.

We changed school at they are much more helpful but his first school were utterly unhelpful, blamed us and labelled child as difficult, naughty, disruptive

The problems were at the end of primary. Since getting specialist support attendance has been fine at secondary (32.5 hrs 1:1 and knowledge of PDA).

always our fault. EWO / FSW threatened due to Lateness (he struggles to leave house) - will not tell school staff issues. they know how to deal with our child better than us. EHCP - plan do review - NOT done (coming up to 1 year review) - Trouble really starting to ramp up !!! I want to move house / school but don't have the money, nor is there a school nearby. despite the LA being well aware of the issues in the school & are going in again, they state the local school meets his SEND needs (LA SEND local inspection not come out the best). I have given up work & now volunteering to manage the situation / hubby has cut hours down. No support whatsoever from school - we are scared of saying or doing anything.

My son is 19 and has no future pathway planned. He has had no successful education or training since 16, despite an EHCP, trying several different courses, A levels at a 6th form and 2 different colleges.

I blame myself, feel a failure as a parent

My son is chronically ill but yet to see a consultant. Have appointment in 2 weeks when i asked for referral 6 months ago. I did not know SS still accused parents of FII. Thought that went the way of Roy meadows career, he's disgraced but his theory is alive and well. Currently school are in process of prosecuting me and I will probably have to home educate.

My son is chronically unwell physically and mentally. All they do is threaten with prosecution and removing my child from me and accuse me of FII. At the same time claim to be helping me and acting in the interests of my son. And everyone believes the SS who themselves are subservient to the doctors. The unspoken assumption is that doctors are infallible and are 100% right 100% of the time. To question or disagree is heresy. This is an extremely dangerous state of affairs and will lead to terrible miscarriages of justice. Doctors have limits to their knowledge as we all do, they get things wrong. To dogmatically rely on their often flawed opinions is foolish

Every day was a challenge to motivate my child to go to school, and every evening at 4pm they would have a complete melt down. I decided to home educate and for their mental wellbeing it has been the best thing. However as a parent I constantly question if I'm good enough to educate them with very little funding/help from the government and L.A. to make sure that they have a successful career and future.

My son is late for school most days and had a letter from the council
EWO is used as a threat to improve attendance rather than as a positive involvement

Whole thing has been a nightmare in process of complaint

We have had an awful experience. Our son refused to attend his school because he was struggling and has been out of school for over a year. The local authority have done nothing to help us and it has led to the breakdown of our previously happy family. We are having to take them to tribunal.

The quiet children get ignored by school.

Very lucky to have an incredibly supportive head teacher