



# **Emotionally Based School Avoidance in Hackney: a survey of local parents**

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Hackney Independent Parents (HiP)



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### **About the author:**

Tim Linehan has worked in the charity sector, specialising in children and mental health. A former journalist, he has created campaigns for charities including The Children's Society, where he developed the framework for The Good Childhood Inquiry, Barnardo's and Action for Children. Most recently he worked as Head of Communications at the Anna Freud Centre where his work included promoting whole school approaches to mental health in schools.

**Important note:** This work has been carried by volunteers without any budget. It has not been possible to design the final report. This means that some of the questions in the graphs appear incomplete. Where this has happened, the complete questions are listed in a reference at the bottom of the relevant page.

## 1. Introduction

The idea for this survey emerged in response to the development of a document produced by The London Borough of Hackney, *Emotionally Based School Avoidance: Guidance for schools and support services*. This guidance was developed following concerns about school absence and an emerging concern that, throughout the country, some children were not attending school because it caused them significant distress. Although what has been known as 'school phobia' has been around for a decades, it appears that the numbers of children suffering Emotionally Based School Avoidance (EBSA) is rising and the awareness of the need to support children and families who experience it is growing.

Successive governments have promoted increasingly ambitious attendance targets for schools in order to improve outcomes for pupils. There is a well-established evidence base which supports the view that school attainment is linked to attendance.

Government attendance targets can be enforced by powers for local authorities and schools to fine or prosecute parents who fail to ensure the child's attendance at school. This punitive approach is based on a historical belief that sees a child's absence from school as 'skiving', or truancy; deviant behaviour often aided and abetted by irresponsible parents who do not value education and are complicit in their child's absence from school.

The question this survey asks, is what is the best approach schools and families can take to ensure that children who are unable to attend school have the education which is their right. The purpose of this survey is to bring the voices of families to this debate, and to collate their experiences of their child's absence and the impact on them and their children.

Evidence is now emerging about the degree of distress some children feel when they go into school and the damage that forcing them into school can cause them. Children talk about self-harm and suicide; parents about the stress it causes to their relationships with their partners, the fear of prosecution and the impact on their jobs and income and their children's life chances. There is growing acceptance that many long-term absences are not due to children 'choosing' not to go to school, but because they find school to be debilitatingly anxiety inducing.

EBSA is increasingly linked with neurodivergence, particularly autism. As research in the field progresses, so does our understanding of what children and their families are going through when they experience the acute anxiety that can make school a terrifying place to them. Understanding these experiences offers a humane and supportive way of helping children reconcile themselves to school or to finding alternative ways of being educated, opening up the opportunities that learning and qualifications offer everyone.

EBSA, or school distress, remains an under-researched field. While Hackney Independent Parents were consulted on the Hackney Guidance for schools and support services, it felt that the parents' voice had largely been missed. This survey is our attempt to add our voice to the debate to help inform local policy by including a wide range of perspectives to the discussion on school absence. We have made these voices available to the local authority to help staff in their pursuit of an inclusive education that meets the needs of all children.

HiP would like to thank Hackney Council for its partnership and support in developing and disseminating this survey. In particular we would like to thank Yvonne Wade, Principal Educational Psychologist at Hackney Council. Others who lent their time and support, at no cost other than to themselves, were HiP members Anita Cassidy, Jo Macleod, Sophie Theunissen, all of whom are parents affected by EBSA and who, along with Yvonne Wade gave their time to develop the questions and to oversee the editing process. Vanessa Linehan from HiP offered generous advice and support and helped promote the survey. Other members of the HiP EBSA group who supported the work were Carys Miller, Andrea Jones, Kim Dee and Kirstin Sherman. Lastly, and most importantly, we would like to thank all those parents who took the time to share their experiences.

HiP and its members would like to continue to offer support to the council by providing input to future materials on EBSA and to contribute to any training programmes on EBSA that the council may choose to run.

## **2. Hackney's approach to mental health and wellbeing in schools**

The London Borough of Hackney is committed to supporting children's mental health and wellbeing. In September 2018 Hackney set up The Wellbeing and Mental Health in Schools (WAMHS) project as a pilot to improve mental health and wellbeing support for children and young people in schools, colleges, specialist and alternative provision education settings in City & Hackney. Schools were reporting higher numbers of students experiencing difficulties managing their emotions, making the most of their learning and life opportunities at school and coping with the stresses of life both in and out of school. Following an evaluation, WAMHS was extended and now runs in almost all Hackney schools.

In September 2019 Hackney became a Trailblazer site for a new Government initiative, Mental Health Support Teams (MHST). As part of this initiative, Educational Mental Health Practitioners (EMHPs) are trained to offer support to young people and their families in the school setting. The Mental Health Support Teams (MHST) support whole-school approaches to mental health by providing workshops about mental health related issues for children, young people and parents/carers, to help to reduce stigma and increase mental health awareness. They offer focused evidence-based support to young people and their parents/carers when young people are experiencing mild-moderate difficulties with their emotional wellbeing that might best be managed within a school setting. They deliver the interventions to groups of young people and to their parents/carers alone or with their children.

The WAMHS Project supports schools to nurture an environment where children and young people can learn about all areas of life. WAMHS focuses on building academic, social and emotional resilience and coping skills in students and helping them to identify and access additional support if needed. The project is also based on further developing knowledge and skills in education staff so that they are more confident and feel more able to support students, and their families, who may be experiencing mental health difficulties.

City & Hackney have also published a number of guidance documents to support children with SEND in schools. These include *Hackney Education's Approach To Working With Autistic Children And Young People*; *Graduated Response* which outlines, the educational provision that the Local Authority expects to be available to children and young people with special educational needs and/or disabilities in Hackney; *The Graduated Approach and Team around the School Model*; and *Emotionally Based School Avoidance: Guidance for schools and support services*. All documents are available from Hackney Education. This survey aims to support Hackney's WAMHS initiative to help children with EBSA. By seeking out the lived experiences of families whose children have experienced EBSA, it is hoped that these findings can provide important data to support Hackney's commitment to children who are unable to attend school and their families and to support them.

### **3. Methodology and approach**

The survey questions were developed by the author, Tim Linehan, in consultation with the HiP EBSA group, Vanessa Linehan and Yvonne Wade. The questions were reviewed by two academic experts, Larissa Pople PhD, Research Fellow (Survey Manager) at UCL and a child wellbeing expert, and Beth Bodycote PhD, founder of Not Fine in School and a leading expert in EBSA.

It was decided to take a quantitative approach to the survey and to enrich the findings by including some opportunity for qualitative responses. The main reason for choosing this approach was to get the best quality data in the time available given that the survey was being conducted by volunteers.

While HiP is pleased that the target of 50 responses was exceeded, we acknowledge that the numbers are not sufficient for scientific validity. Nevertheless, given the lack of evidence on EBSA in general, and that hitherto no data on EBSA in Hackney is available, the findings will offer insight into the issues at a time when school attendance is likely to come under increasing scrutiny as more stringent Government guidelines on absence come into force in September 2023. Later on in this report, findings from research have been quoted to provide context to the findings from this survey.

The survey was sent out through the HiP networks of parents and shared with all Hackney SENCOs who were asked to encourage parents and carers affected by EBSA to contribute to the survey. The survey was also promoted on social media and the London Borough of Hackney's Local Offer web page and ran from June 21 – July 14.

Responses to questions are given in percentages. This is because not all questions were answered by everyone so percentages offered a consistent approach. Percentages have been rounded to the nearest number. Further details of methodology are available on request.

The term 'parents' is used throughout to cover all respondents, whether birth, adoptive parents, or carers, corporate or individual, who have responsibility for a child.

## 4. Findings

### I. Who responded?

We received 58 responses. These included one duplicate submission. Two submissions were blank leaving 55 responses in total. One respondent filled in the form for two of her children, both of whom had experienced EBSA. Both submissions have been included.

54 of the 55 responses were from female parents and one from a male. There were no responses from trans or non-binary parents or carers. Of those who responded, 24 (44%) identified as White British and six (13%) as White Other. Six (11%) identified as mixed race, four (7%) as Black Caribbean, three (6%) as Black African. One person (2%) each identified as Turkish and Chinese. The remainder classified themselves as 'other' (13%) or preferred not to disclose their ethnicity (2%). This compares to the census findings in the London Borough of Hackney in which 53.1% of the population identified as White and in which Black people were the largest minority group, accounting for 21.1% of the population, Asian and Asian British 10.4% mixed or multiple ethnic groups 6.7% and other ethnic groups 8.7%.

47% of respondents were in receipt of free school meals. In 2022-3, 42% of all secondary school pupils in Hackney were eligible for free school meals.<sup>1</sup>

Thirteen respondents (6%) had one child, 25 (37%) had two, 9 (17%) had three, six had four and one had five or more. Most respondents (61%) had one child affected by EBSA. 16 (30%) had two children affected, four (8%) had three and one respondent had four children affected by EBSA.<sup>2</sup>

A slight majority (55%) had children who were at primary school when they first experienced EBSA and 23 (43%) were at secondary. One was at a special school. The most common age for children to experience EBSA was between 5-8 followed by 12-16.

8. At what age did your child start to experience difficulties attending school? (0 point)

[More Details](#)

● 5-8	24
● 9-11	13
● 12-15	16
● 16+	1



<sup>1</sup> Data from [Local Government Association](#)

<sup>2</sup> For the purposes of the survey, where parents had more than one child who had experienced EBSA, they were asked to respond based on their experiences of their most recent child. This is because it felt unrealistic to ask parents to fill in more than one form. However, one parent did complete the form for both children.

## II. Who had a diagnosis?

Most parents (87%) said they had noticed that their child was unhappy at school before they stopped going in. 83% said their children were diagnosed with a special educational need. 11% said they were looking into a diagnosis at the time of responding to the survey and the three remaining respondents said their child had not been diagnosed.

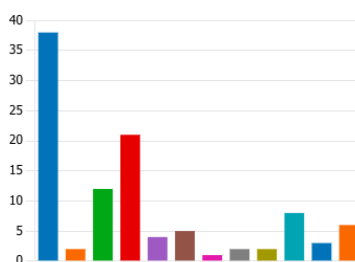
A significant number of children were diagnosed as a result of their school non-attendance. Of those parents whose children were diagnosed, 65% said their child was diagnosed before they stopped going to school, the remaining 35% were diagnosed afterwards. These numbers should also take into consideration the proportion of children who were in the process of being assessed for diagnosis.

We asked respondents to tell us about the diagnosis of their child. Parents<sup>3</sup> were invited to give as many responses as applicable to their child. The most common diagnosis by far was autism (83%), followed by anxiety (46%) and ADHD (26%).<sup>4</sup> A significant proportion (17%) also cited sensory processing disorder.<sup>5</sup>

12. If your child is diagnosed, what have they been diagnosed with? (you can tick as many as apply) (0 point)

[More Details](#)

Autism	38
PDA (Pathological demand avoi...	2
ADHD	12
Anxiety	21
Dyslexia	4
Dyspraxia	5
Dyscalculia	1
OCD (Obsessive compulsive dis...	2
Eating disorder	2
Sensory processing disorder	8
Learning disability	3
Other	6



Of the children who had been diagnosed, 33% were diagnosed with one condition and 66% were diagnosed with more than one condition. Of these:

- 22% had two diagnoses
- 24% had three diagnoses
- 11% had four diagnoses
- 7% had five diagnoses
- One child had six diagnoses.

<sup>3</sup> 46 people responded to this question.

<sup>4</sup> It is often argued that not being able to attend school is a symptom of anxiety. However, this question asked whether they were *diagnosed* with anxiety.

<sup>5</sup> The second option on the graph reads PDA (Pathological demand avoidance). OCD is obsessive compulsive disorder

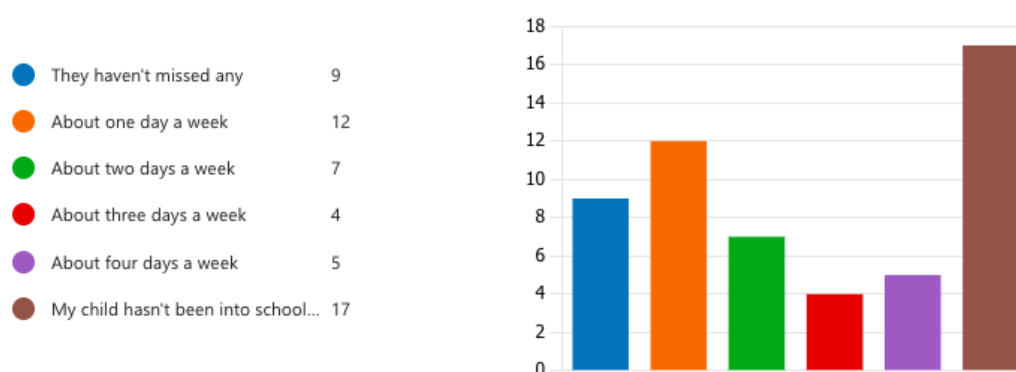
With the exception of one, the children with multiple diagnoses were all diagnosed with autism. Breaking this down, 29% children diagnosed with autism had a single diagnosis while 71% had multiple diagnoses. From this survey, it is clear that many children who are unable to attend school have multiple needs.

### III. Attending school

We asked parents how much school their child had missed over the last month. 83% said that their child had missed school over this period. The most common response, from 31% of respondents, was that they hadn't been in at all. The second most common response, from 22% was that they missed one day a week. The third most common response, from 17%, said that they hadn't missed any school in the previous month.<sup>6</sup>

13. How much school has your child missed over the last month? (0 point)

[More Details](#)



53% of respondents said that their child had not been able to attend school full time for over a year, including 18% who said that their child had not been able to do so for three years or more.<sup>7</sup>

Respondents were also asked if their child did eventually return to school. Out of 51 responses, 35% said they returned full time, 37% said they didn't return to school at all and the remaining 28% returned part time.<sup>8</sup>

Responses to this question suggest that children with EBSA are at a high risk of having their education permanently curtailed.

### IV. What support was offered?

The next section explored the support that families said they had experienced from the school their child attended.

<sup>6</sup> The last option on the graph reads: My child hasn't been into school at all.

<sup>7</sup> We should note that the finding about the length of time a child hasn't been able to attend school will be conservative as children's non-attendance is likely to be ongoing.

<sup>8</sup> Please note, there is an apparent anomaly in this answer given that in the answer to the previous question only 17% claimed to have not missed any school in the previous month, yet 35% said they returned full time.



## EBSA in Hackney: a survey of local parents

We asked respondents whose child had returned to school, whether they'd received the support needed. They were asked to rate their responses from 1 (1= no, they didn't get anything) to 5 (= they got everything they needed). The average rating was 2.94 out of 5.

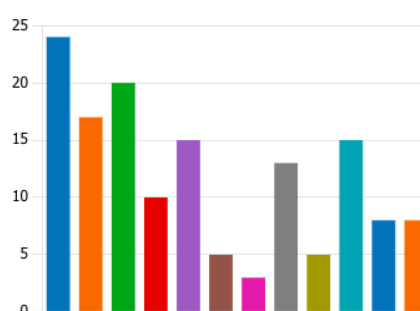
18% said their child didn't get any support and 11% said they got everything they needed.

Parents were then asked about the adjustments their child was offered by the school. Respondents could include as many responses as were relevant.<sup>9</sup>

17. At school, was your child offered any of the following to help them? (0 point)

[More Details](#)

● A time out pass (to allow a child...	24
● Access to a quiet area	17
● A part-time timetable	20
● School work to complete at home	10
● Permission to change seating	15
● Permission to move around the ...	5
● A buddying or mentor scheme ...	3
● A buddying or mentor scheme ...	13
● Free resources about metal heal...	5
● Reference to a support service o...	15
● Other	8
● No they weren't offered anything	8



There were a wide range of responses, with some parents being offered seven separate adjustments, while eight said they were offered nothing. On average, respondents were offered around 2.5 separate adjustments.

### V. What would parents have liked?

Parents were then asked what additional support their child would have benefited from. Several identified early interventions and earlier diagnosis:

If my child's needs were picked up and she was offered help earlier, some of the strategies may have worked.

One parent described how the support was only offered once their child stopped going to school. Another parent said that promises for adjustments were made but not kept:

I approached the school in January about my concerns, and though they said they would put in place a whole range of measures – buddies, help at playtime, school-counselling – they didn't actually supply anything and all she got was some ear defenders and a CAMHS referral.

<sup>9</sup> The **first option** reads: A time out pass (to allow a child to leave a classroom if they are stressed); the sixth: permission to move around the classroom; **the seventh**: A buddying or mentor scheme with a student; **the eighth**: A buddying of mentor scheme with a member of staff; **the ninth**: Free resources about mental health (eg information about ADHD or Autism)

Others called for more teacher training for SEND, particularly around autism, including the need to break down tasks and understanding the learning processes of neurodivergent children. One called for more support for her son's teacher:

My son has a caring and loving teacher, however I believe her lack of deep knowledge of autism makes the situation really hard both for my son but also herself. I would like to see more support for his teacher in the classroom from an autism and SEND professional. So that the teacher is able to learn more and understand more.

Other support that would have been valued included working in smaller classes, and providing a personalised curriculum with fewer subjects and a more flexible approach to meet their child's needs.

...a kinder, more flexible and inclusive culture. We asked for a reduction in the number of subjects studied, so that he could build self-esteem by doing well in some subjects (a private Spanish tutor at home has helped with that subject) rather than badly in all of them.

Sometimes adjustments or support available to some were not accessible to others, for example mentoring or buddying schemes. Some parents requested quiet areas for their child, an option that was offered to a significant number of other parents. Other times interventions were put in place, such as time out cards, but the teachers were unaware of them, requiring children repeatedly having to explain themselves.

Parents described delays in accessing support, including EHC plans not being completed within the 20 week statutory timeline. One parent described the lack of support in terms of a series of systemic delays and inflexible offers that failed to offer the support that was needed:

My child has situational mutism on top of developmental trauma and dyspraxia. These needs were never picked up by schools despite my being concerned even in primary. My child self-harmed in school loos and then finally slowly an (private) assessment (costing ££) was done which unlocked understanding of needs. By that point EBSA (66%). I had to apply for EHCP. Extra support helped me get her to her GCSEs (driving her in everyday as Hackney will only help travel IF 95% attendance – impossible for my daughter and I believe this to be disability discrimination. I have had the SLT [speech language and communication disorder] diagnosis and report of situational mutism for almost a year and STILL not on EHCP and STILL no SLT help in school. Now child will be going to college and concerned yet again that SENCO not ENGAGING and my child's anxiety over talking in lessons will severely affect her enthusiasm to follow what she believes to be her vocation: health and social care. The system is too slow, unwieldy.

Some parents identified bullying as an issue which they felt had not been addressed at school.

## EBSA in Hackney: a survey of local parents

Two parents said that they had either accessed a specialist school or wondered whether mainstream school was the right place for their child.

Parents were also asked which services had supported them and how they were accessed. Only 44% respondents said they had accessed other services, with home tuition being the most commonly identified.

19. Have you had support from any of the following services? (0 point)

[More Details](#)

<span style="color: blue;">●</span> A re-engagement unit (this is a ...	3
<span style="color: orange;">●</span> A home tuition service	10
<span style="color: green;">●</span> Online schooling	2
<span style="color: red;">●</span> Other	9



People accessed additional support through the school (31%), the local authority (17%) through their own endeavours (31%) and through social care or CAMHs (21%).

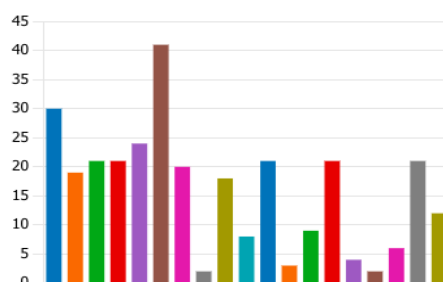
15% of parents were offered alternative provision outside school organised by the school or the local authority. When asked how long it took for this provision to start, one person said it took less than a month; two between one and two months; three between 2 and 3 months and four between six months and a year.

## VI. What stopped children from going to school?

Parents were also asked which events or difficulties contributed to their child not being able to attend school (they could choose as many as applied to them).<sup>10</sup>

### More Details

● Struggling with school work	30
● Conflict with teachers	19
● Worry about breaktimes or lunc...	21
● Worry about a specific lesson or...	21
● Strict behaviour policies	24
● Sensorial difficulties related to t...	41
● Academic pressure,for example, ...	20
● Sexual harassment or unwanted...	2
● Transition from primary to seco...	18
● Separation anxiety	8
● Verbal bullying such as insults a...	21
● Online or text bullying	3
● Physical bullying	9
● Relational bullying (being left o...	21
● A traumatic family event (for ex...	4
● A problem at home such as fam...	2
● An illness	6
● Sleep problem and difficulties g...	21
● Something else	12



On average, respondents identified 5.6 different events that contributed to their child's absence. For the purposes of this paper, I have grouped them into the following categories:

1. The school environment
2. Bullying
3. Academic pressure
4. Conflict with the school
5. Child development and change
6. Domestic issues and family events

However, it should be noted that further research might be required to get more detail about these experiences. For example, in some cases 'struggling with school work' may be academic pressure, in other cases it may be related to a learning difficulty, dyslexia or other cognitive difficulties.

<sup>10</sup> Option **three reads**: Worry about breaktimes or lunchtimes; **Option four**: Worries about a specific lesson or subject; **Option six**: Sensorial difficulties related to the school environment (eg noise, crowds, odours, lighting); **seven**, Sexual harassment or unwanted attention; **eight**: Transition from primary to secondary school; **eleven**: Verbal bullying such as insults and name calling; **fourteen**: Relational bullying (being left out or being talked about in a hurtful way); **fifteen** A traumatic family event (for example, an illness or death in the family or a separation); and **sixteen**: A problem at home such as family relationships or having to carry out caring responsibilities; **eighteen**: Sleep problem and difficulties getting up in the morning

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The total number of mentions in each category are not the same as the number of children. For example, the same child may have experienced verbal bullying, physical bullying and text bullying.

<b>1. The school environment</b>	<b>Number of mentions</b>
Sensorial difficulties relating to the school environment	41
Worry about lunchtimes or breaktimes was mentioned	21
<b>Total mentions</b>	<b>62</b>

<b>2. Bullying</b>	<b>Number of mentions</b>
Relational bullying (being left out/talked about in a hurtful way)	21
Verbal bullying	21
Physical bullying	9
Text bullying	3
Sexual harassment or unwanted attention	2
<b>Total mentions</b>	<b>56</b>

<b>3. Academic pressure</b>	<b>Number of mentions</b>
Struggling with school work	30
Academic pressure eg, expectation to achieve or pass exams	20
<b>Total mentions</b>	<b>50</b>

<b>4. Conflict with the school</b>	<b>Number of mentions</b>
Strict behaviour policies	24
Conflict with teachers	19
<b>Total mentions</b>	<b>43</b>

<b>5. Child development and change events</b>	<b>Number of mentions</b>
Transition from primary and secondary school	18
Separation anxiety	8
<b>Total mentions</b>	<b>26</b>

<b>6. Domestic and family events</b>	<b>Number of mentions</b>
An illness	6
A traumatic family event (for example, an illness or death in the family, or a separation)	4
A problem at home, such as family relationships or having to carry out caring responsibilities	2
<b>Total mentions</b>	<b>10</b>

Three other events which parents said contributed to their child not being able to attend school were not included in the above categories. These are:

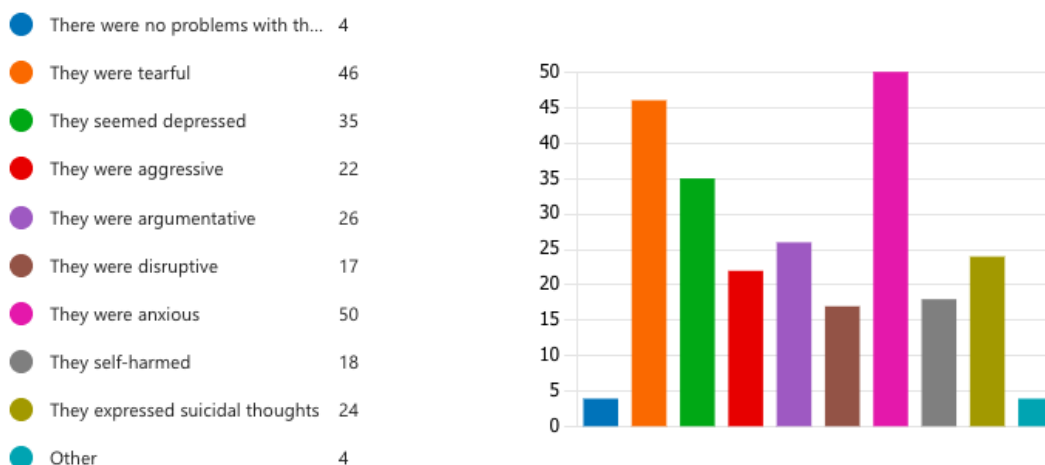
- **Worry about a specific lesson or subject: 21 mentions**  
This is an important finding because of its specificity. However, it is not categorised in any of the groups above because it's unclear whether this is due to the class environmental reasons (eg bright lights); conflict, perhaps, with a teacher or academic pressure.
- **Sleep problems and getting up in the morning: 21 mentions**  
Again, this is an important finding, but perhaps it is too general to draw any conclusion from it. For example, it is unclear whether sleep problems and getting up are a symptom of anxiety, or the cause of non-attendance. There is [evidence](#) that children with autism and ADHD are more likely to have sleeping problems. However, findings from this survey do not indicate that sleeping problems are the source of EBSA.
- **Something else: 12 mentions**  
No further information was collected for this category

## VII. Did children behave differently at home and at school?

The following two questions focused on the perception of a child’s happiness or otherwise as parents understood it from their perspective and how they interpreted the school’s response.<sup>11</sup>

23. When your child was unhappy about going to school, how was their behaviour at home? (0 point)

[More Details](#)



The survey uncovered disturbing levels of distress among children not attending school. Only four respondents said that there were no problems with behaviour at home. Parents were asked to respond to as many questions as relevant and identified on average 4.4 symptoms of unhappiness per child.

### Parents’ home experiences of children who not attending school:

- 98% of parents who said their child was unhappy at home said their child was anxious
- 89% said their child was either aggressive or argumentative at home
- 64% said their child seemed depressed
- 44% said that their expressed suicidal thoughts
- 33% said their child self-harmed
- Only 7% said that there were no problems with their child’s behaviour at home.

We asked parents to provide additional information about their child’s behaviour at home. We received 35 responses in which parents illustrated the levels of distress their children felt in relation to their school, and the impact this had on family home life. Many said their children experienced low moods and depression and isolated themselves, staying alone their room or house and becoming inert.

<sup>11</sup> Option one reads: There were no problems with their behaviour.

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My child refused to leave the house, go to school, drink and eat, wear clothes .... Refused to leave the house and to school for 5 months, then for another two months refused to go to school until I managed to bridge her back. Her anxiety was really alarming.

Our daughter spent hours in a darkened room and experienced very low moods

My child was very depressed and hopeless. She felt she had failed already because she couldn't catch up with her peers.

A number of parents talked about how their children managed their anxiety at school by 'masking' their distress at school and releasing their anxiety on their return home.

My child is very quiet and mostly well behaved at school and meltdowns violently at home.

Our daughter masks. While she seemed ok at school, she fell apart at home. She only managed to mask at school for two-three weeks before her mental health took a serious downturn and we had to take her out of school (eg; three emergency reviews in 12 months).

Child withdrawn, hides in bed all day or becomes aggressive verbally/physically to herself and family.

Some said that the pressure to attend school increased the levels of stress their children felt

My son has been too scared about getting in trouble at school later to take time off when very anxious and stressed. This has made him more traumatised and having never been aggressive or violent now often has violent outbursts at home. He is now accepting the need to not go in some times.

His behaviour can get overwhelming like kicking me and banging things, and he attempts to run off from the house. He keeps saying, he wants to do home schooled. He hates his school.

Many parents spoke about how their children's distress was specifically related to school:

My daughter reverted back to not speaking due to her autism. She stopped eating entirely at school, she would cry and beg not to go to school every single day and would come home and cry. She has been severely affected by this and now believes every school is the same and she will be physically hurt and not listened to. She felt/feels unsafe at school.

He didn't even want to look at the uniform. He would get so despondent as soon as it's Sunday, off his food, walking up and down the corridors, he had such high anxiety and a lot of apathy.



Crying the night before school about specific subjects, expressing 'hating school' extremely sensitive in the mornings, blowing up at the slightest thing. Saying the work is too hard. Mornings before school, stress is through the roof, cannot regulate emotions. She would be happy...on returning home but as the evening progressed, became tearful again about the next day.

Unable to carry out morning routine – wash/dress/brush teeth. Reports tummy aches, can't walk, feels sick. Outright 'no mummy, don't take me to school'... My son is five years old.

My child was ok with me at home when I wasn't making them go to school. Since I was told I had to make them go our relationship really suffered and they lost trust in me. This was very hard as my daughter has preverbal developmental trauma (adopted) and anxious attachment. It could have broken our relationship entirely... I lived in state of nerves over her self-harm and suicidal thoughts.

Other parents talked about their child's depression, self-harming and suicidal thoughts:

Wished that she was dead, low self-esteem and feeling worthless about herself. Became argumentative with siblings, frequent meltdowns. Just very sad. Writes 'I am sad' on her body.

Significant self-harm and suicidal thoughts that we received no help due to waiting lists.

He is very tired and irritable. He has problems with going to sleep at night, having anxious thoughts about school and teachers ... My son feels depressed and disheartened. He often says "why do I live in this world, if I am always sad and tired, and have to suffer?"

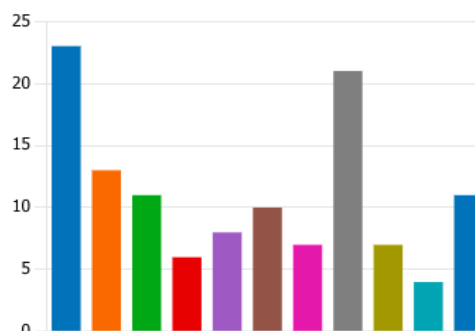
## EBSA in Hackney: a survey of local parents

Parents were then asked how the school described their child's emotions or behaviour.<sup>12</sup>

25. When your child was unhappy at school, but still going in, how did the school describe their emotions or behaviour? (0 point)

[More Details](#)

● They said that there were no pr...	23
● They were tearful	13
● They seemed depressed	11
● They were aggressive	6
● They were argumentative	8
● They were disruptive	10
● They were angry	7
● They were anxious	21
● They self-harmed	7
● They expressed suicidal thoughts	4
● Other	11



In answer to this question, parents said that the school identified 1.8 symptoms per child at school, compared to 4.4 they identified themselves at home, almost two and a half times as many. The most common observation from school was that there were no problems, which was also the least commonly observed symptoms by parents. The experiences of parents at home and the experiences at school, as identified by parents, are compared below.

Observed symptom	Home	School
They said there were no problems <sup>13</sup>	4	23
They were tearful	46	13
They seemed depressed	35	11
They were aggressive	22	6
They were argumentative	26	8
They were disruptive	17	10
They were angry <sup>14</sup>	n/a	7
They were anxious	50	21
They self-harmed	18	7
They expressed suicidal thoughts	24	4
Other	4	11
<b>Total number of symptoms (not including 'there were no problems')</b>	<b>242</b>	<b>98</b>

<sup>12</sup> The first option reads: They said that there were no problems with their behaviour.

<sup>13</sup> This question was asked differently: In the first question, parents were asked 'When your child was unhappy about going to school, how was their behaviour at home?' In the second, parents were asked 'When your child was unhappy at school, but still going in, how did the school describe their emotions or behaviour?'

<sup>14</sup> This question was only asked about school

## EBSA in Hackney: a survey of local parents

*Comparison of answers to: 'when your child was unhappy at school, how was their behaviour at home?' with 'when your child was unhappy at school, but still going in, how did the school describe their behaviour.'*

There is a significant contrast in the answers to these two questions which suggests that either schools underestimated the level of distress children experienced or that children's symptoms may have worsened when they spent more time at home. This survey is unable to provide a definitive answer as to which of these theories is more accurate. However, many parents have told us that their child masked their behaviour at school, some that they behaved better at home when they were not being 'forced' into school and that some schools did not recognise the anxiety of their child, suggesting that schools may have underestimated the distress of children or that the children hid their distress from school. The greatest differential was in expressing suicidal thoughts which was six times more likely to be observed at home than at school.

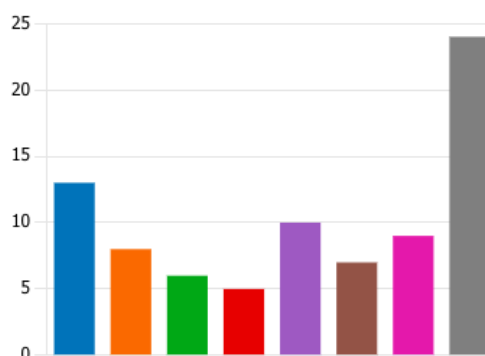
### VIII. Managing behaviour at school

Parents were asked about the school's approach to behaviour management. Parents could give more than one response.<sup>15</sup>

26. Did the school use any of the following behaviour management methods in response to your child's behaviour? (0 point)

[More Details](#)

● Detention	13
● Behaviour points	8
● Isolation rooms	6
● Attendance rewards	5
● Exclusion	10
● Suggesting or organising a man...	7
● Other	9
● They didn't use any behaviour ...	24



The most common approach was to not use any behavioural management methods, mentioned by 48% of respondents. Of the 52% who said that the school used a behavioural management method 50% said their child had been given a detention; 38% said their child had been excluded; 30% said they had been given behaviour points; 27% said schools suggested or organised a managed move and 23% said that the schools had used isolation rooms.

<sup>15</sup> Option **six** reads: Suggesting or organising a managed move; **Option eight** reads: They didn't use any behaviour management methods

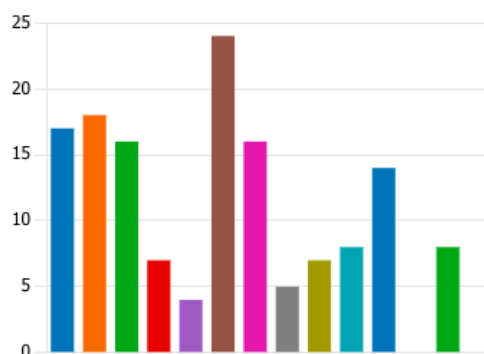
### How did the school help children?

Parents were then asked how the school responded to their child’s non-attendance. They were allowed more than one option.<sup>16</sup>

27. How did your school respond when your child wasn't attending? (0 point)

[More Details](#)

- They called me to a meeting wit... 17
- They put together a joint plan w... 18
- They gave me advice 16
- They placed my child on the SE... 7
- They arranged alternative educa... 4
- They pressured me to force my ... 24
- They referred me to other supp... 16
- They punished my child for not ... 5
- They told my child we would be ... 7
- They pressured my child by sayi... 8
- They threatened me with a fine 14
- They fined me 0
- They threatened me with prosec... 8
- They prosecuted me 0



On average parents identified 3.3 responses per child. The most common was that the school pressured them to force their child to school, which was identified by 55% of parents. This was followed by putting together a joint plan (41%); calling a meeting with other professionals (39%); and being referred to other support services (36%). The same number said the school gave advice. Almost one in three parents (31%) said they had been threatened with a fine. 18% said that they were threatened with prosecution while 16% said that their child was told that their parents would be fined or sent to prison. However, no parents were fined or prosecuted.

Parents were then asked what schools did that was helpful. Four parents said that their school’s approach in general, was very helpful. For example:

School been trying to find the way to help me, been very understanding.

They listened. They put no pressure on. They reassured us they wanted her to return to school. They reassured us they wouldn’t fine us. They came to do home visits and were respectful and polite and kept within her requested responsible adjustments.

<sup>16</sup> **Option one:** They called me to a meeting with other professionals; **option two:** They put together a joint plan with me; **option four:** They placed my child on the SEND support register; **option five:** They arranged alternative education for my child; **option six:** They pressured me to force my child to attend; **option seven:** They referred me to other support services, such as CAMHS social care, early help, youth services; **option eight:** They punished my child for not attending; **option nine:** They told my child we would be fined or sent to prison; **option ten:** They pressured my child by saying that their life would be negatively impacted by their absence from school; **option thirteen:** They threatened me with prosecution.

## EBSA in Hackney: a survey of local parents

They were encouraging. They stood by us when we were battling with support services to try to get help.

A number of parents talked about how their school accommodated their child's needs by making adjustments, providing school visits, providing simple incentives to come and being flexible and imaginative in their approach.

Reduced school time table. My child did not need to go in, when there was no lesson, eg self-study time. That meant he could go to school late, or leave early. The school teachers had regular meetings with me and suggested ways to support me and my child.

His teacher allowed him to play Lego 5 minutes before the class if he was on time in class.

Two parents contrasted approaches by different schools and praised less punitive approaches. One said:

They were quick to identify SEND issues that were overlooked in primary school. The school has supported our EHC plan application, and has worked with CAMHS and other external services we have engaged. They stopped giving my son detention for unfinished or missing work when EP[educational psychologist] suggested reducing mental load.

A number of parents praised good communications with parents. For example:

Good communication with the SENCO on a daily basis. School also organised a weekly session with a staff member that our daughter likes and feels comfortable with. This has really helped with the transition.

Others identified acts of kindness, such as meeting the parent and child at the school gate and encouraging the child to join clubs.

Some parents highlighted the lack of punitive or unhelpful practice as a positive contribution which may perhaps reflect low expectations of support:

They didn't prosecute me and they mark his absence as authorised. The tutoring has been helpful. They're keen to get him off roll so they've been quite helpful with his EHCP.

The school [x] was very helpful in that they paid for an Educational Assessment and helped me write form for me to apply for an EHCP - but it was too late. Neither [x nor y school] ever noticed the needs when I think they should have. My child masks and is compliant and never a problem – until she started coming to them with bleeding wrists at break...But the school itself tried hard with pastoral care: report cards, head of year emails and didn't shame me or child for the lack of attendance – though I did get a letter saying it was high.

Seven parents (17%) said that the school did nothing that was helpful:

They helped themselves by suspending.

Absolutely nothing.

Some parents said that the school had tried their best but did not have the resources to respond in the way that they would have liked to. For example:

Our school has been extremely supportive and want to help my son feel less anxious, however due to lack of funding and not enough adults, they struggle to put everything in place they want to.

#### **IX. What did the school do that was unhelpful?**

Parents were then asked what the school did that was unhelpful. Several said they didn't receive enough support and that it was offered too late, despite appeals by parents:

They intervened too little, too late. The SENCO wasn't helpful and all but advised us to drag her in to school. We also only saw her once in the whole time anyway.

Parents said that they felt blamed or threatened which added to their stress:

Old school put pressure and blame on us and said without a formal diagnosis they couldn't do anything.

It unhelpful to talk about patents will get fine! It made me stress.

Whenever I managed to get him in, they punished him for truancy, underachieving and defiance. Which in turn makes him not want to go in, it was a vicious cycle.

Others said that the school was inconsistent and pushed their child too hard

It has been unhelpful that every time things get a little bit better they push her more into more challenging situations, back into mainstream, as if the problem is solved, then things get worse again and school avoidance starts again. I wish the school would keep support in place and not constantly try to take support away again.

Putting additional pressure. Forcing child to attend and not giving them to reintegrate. Not taking notice of their emotions. Parent blaming and saying I was encouraging the behaviour.

Some said their school failed to meet their child's need by being inflexible:

Refused to reduce the number of subject but offered a 'part time timetable' by removing his prep and non-exam classes. The prep sessions were actually useful

## EBSA in Hackney: a survey of local parents

because x finds it easier to do homework there than at school. Did not offer any alternative provision or schooling when we asked for their help on that.

Parents said that their child's absences were mis-recorded as unauthorised and had no experience or understanding of EBSA.

Outwardly seemed sympathetic but actually don't really understand EBSA (eg: said things like "why don't you pretend you have to work in the office she doesn't have a choice to stay at home?")

Told us we were the only people they'd ever come across in this situation so it took ages for us to understand what was going on. Judged it round attendance - he had a complete mental breakdown- but it wasn't helpful to base any recovery on getting back to school as quickly as possible. Left us alone. In the end this was good, but for the first couple of terms it was terrifying.

They said that school staff didn't understand 'masking' behaviour or their child's distress, even when the school was sympathetic.

Some TAs blamed her 'behaviour' when she was in fight or flight. Not all staff would let her come home when she became upset. We have a long relationship with school and having a MH crisis with an older child so they were understanding rather than confrontational.

Others said that parents were simply not listened to.

Failed to listen to my own observations and opinions and keep in good communication, failed to make reasonable adjustments. used punitive measures for behaviour relating to my child's special needs/difficulties.

Others talked about punishments for what they saw as minor infringements and of not protecting their child against bullying:

Detentions. Every day our daughter attends is a huge achievement. Punishing for not completing homework works counterproductive. Especially when she has tried to do the homework but it's not clear to her what's expected. She would never ask in class.

Put her in isolation rooms. Forcefully removed her out of class when she shut down.

Punish her for being late when she got lost.

Threats, exclusions, detentions, bullying my child, threatening my child, allowing my child to be assaulted on school site, protecting the bullies.

There was a complete lack of understanding from the school about EBSA. Instead of getting support they tried to force her in, it was a punitive approach and left her traumatised. For example, they banned her from the after-school club she loved and told her she couldn't take part in the school show as her attendance was so low.



Pressuring rather than having an understanding.

Some parents were confused by the inconsistency of the school's response, for example trying to persuade them to encourage their child to go in one day and on the next day threatening them with court action.

Three parents answered that 'everything' the school did was unhelpful while others talked about the help and support they received from the school. Two parents said that EBSA was interpreted as a safeguarding issue. This impacted on their child's mental health leading them to self-harm, in the parent's view.

### **XI. Relationships between parents and their school**

Parents were then asked to rate how the school responded to their concerns on a scale of 1 (not at all) to 5 (very good). Taking a 'poor' response as a score of 1-2 and a 'good' response as a score of 4-5, parents responded as follows:

<b>Statement</b>	<b>Poor</b>	<b>Good</b>
The school listened to my concerns	55%	30%
The school listened to my child's concerns	56%	30%
The school supported me	59%	27%
I felt my input was valued	59%	25%
The school made reasonable adjustments for my child	56%	23%

The areas where parents scored the school responses lowest were 'the school listened to my child's concerns' where 38% answered 'not at all' and 'I felt my input was valued' to which 37% of parents responded 'not at all'. Parents gave the school the highest rating in response to the statement 'the school listened to my concerns' with 25% of them giving the school a top mark of 5.

Parents were then asked to rate how they felt about their relationship with the school. (Low = score of 1-2; high = score of 3-4)

<b>How did you feel about your relationship with the school?</b>	<b>Low</b>	<b>High</b>
Empowered	54%	28%
Blamed (low score = felt blamed)	59%	21%
Judged (low score = felt judged)	62%	25%
An equal partner	55%	37%
Listened to	47%	32%
Ignored	60%	20%

## EBSA in Hackney: a survey of local parents

Far more parents felt they had a negative relationship with the school than a positive one. As with the previous question, parents had very different experiences. In all the negative responses, parents giving the lowest score (1) easily outweighed those scoring two.

- 48% of parents gave the lowest score (1) for blame
- 47% of parents gave the lowest score (1) for being judged
- 41% of parents gave the lowest score (1) for being empowered.

By contrast, the highest scores were:

- 21% gave full marks for being listened to
- 21% gave full marks for being treated as an equal partner
- 20% gave full marks for being respected

The responses to this question clearly suggest a breakdown in relationships between school and many parents at a time of crisis, a development likely to lead to conflict between parent and school and damage the chance of a successful reintegration into school.

## XII EHC Plans and referrals to other services.

60% of parents had an EHC plan. Of those who had a plan, only 18% said that it met their child's needs with 82% saying it didn't.

Parents were asked, if their child was referred to other support services, which ones they were referred to and what was the outcome:

34. If your child was referred to other support services, which ones were they referred to? (0 point)

[More Details](#)

● CAMHS	39
● Youth services	7
● School counsellor	8
● Early help service	5
● Other (please name) (text requir...	7



Families whose child was referred to another service were then asked about the outcome of the referral.

The most common outcome was 'being put on a waiting list' (42%), followed by 'people now have a better understanding of the difficulties my child has experienced' (25%). 15% said they received support with the situation and 12% said they received support 'which made things more difficult'. Only one said that their child could now attend school without difficulty.

### **XIII What else did parents have to say?**

Finally, parents were invited 'to add anything about your experience' and 39 parents contributed their input.

#### *Early intervention and delays in support:*

Many parents described how, in their view, earlier interventions could have prevented their child's crisis, particularly where there were signs of unhappiness at school. Some parents said that better staff understanding of EBSA and other mental health or neurological conditions would have also helped. The frustration at the delays in action were not always aimed at schools. Delays in accessing CAMHS support was a major source of frustration. One person reported waiting five years for a diagnostic assessment.

An earlier diagnosis could have helped avoid things getting to the point we're at now as there were some signs in primary school. When starting secondary school, staff having more knowledge on ASC [Autism Spectrum Condition] and EBSA would certainly have made a big difference, I feel. I most likely wouldn't have had suggestions like, 'don't make home enjoyable'! Now that I'm in the process of moving my child, the school's input is barely there!

Some parents described the impact of delays on their child's wellbeing:

They [the school] were quick to identify the SEND issues (although not as quick as my son who'd already referred himself via GP) but did not follow up with effective support, leaving him suicidal after his first year.

It took many months for us to actually get support from CAMHS and by the time we did my child had experienced such damaging and traumatising experiences that it will take years to unpick.

One parent was particularly frustrated at the delays given that their child had been in the looked-after system and had a social worker.

No urgency among education, health services or children services. No-one seems to think it is a problem...No professionals in education, health or children's services seems to have any strategies or solutions, just "tell child to come to school" and "we'll take you to court". They seem bemused and flummoxed like they have never dealt with a child who refuses to go to school. And this is a child who is previously looked after and has a social worker so I would expect professionals to find it concerning they have not attended school (or had any tutoring or even work sent home) for a year.

#### *Punitive responses*

Some parents said that they were met with punitive responses from school, either aimed at them or their child. Parents resented being 'reminded' or 'threatened' with fines for their child's absence and wanted their absence to be recorded as 'authorised' to reflect their child's poor mental health.

I'd appreciate not being constantly reminded that I could end up being fined, and I feel her days off ought to be classed authorised, not unauthorised – mental health is as important as physical health.

In my experience the school's first step was to threaten with a fine for poor attendance despite me raising my concerns consistently about my child's school avoidance being emotionally based....She was often punished and put into the headteachers office with no careful consideration as to the difficulties she was experiencing.

One parent described how incentivising a child to return to school but refusing to provide resources to study at home had the opposite effect:

CAMHS also now appear to be about to disengage as they don't know how to support her. But the damage was done when her school resolutely refused to supply her with resources to catch up. This was requested in the early autumn term of year 10 last year. Their rationale was to try and force her to return to school. Now after 10 months of no school at all she is too overwhelmed by the amount she's missed to be able to return. As it stands, I don't expect her to return to school nor achieve any GCSEs. Her school don't seem to have the capacity to help.

Another described how their child, who wasn't attending school, was refused permission to attend an after-school club which she enjoyed, until her attendance improved. She also described how the child's absent mindedness (forgetting pens and books) resulted in detentions in her first week of secondary school which was followed, shortly after, by her first experience of non-attendance which then continued throughout her school and college career.

#### *Importance of stability and friendships*

Some parents noted how their child's well-being at school could be undone by change, for example, the annual changes in classes which could have an impact on friendships and relationships with trusted teachers:

He is happy to attend school now because he has made a friend. Next year he will be with different teacher and class peers, so I don't know how he will handle this. If he is with his friend in class he will be ok (I think), if not, I am scared that we go backwards again.

My child accepts to go to school because he made a friend in class but I am not sure if this child will be in my child's class from September. So, I don't know if he will accept to go to school then or not. As my child has ups and downs through the academic year.

Another highlighted the pain of a friendless child:

Having no friends and being frozen out by the class is now the worse problem. She would frequently hide under the desks and scream when overwhelmed. Everyone

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thinks she is weird. She wants to learn and is academically able - so not being able to attend is very distressing - she just wants friends:

### *The school environment and flexibility*

Problems caused by the school environment were raised by several parents. For example, some children had difficulty following screens or felt that lessons were explained too quickly. Others wanted quiet spaces where their children could go to recover from being overstimulated.

I do strongly feel that a quiet area (decompression room) is much needed in this very busy overcrowded school. My daughter hides in the library at breaks and lunch times (and thus often doesn't eat).

Some wrote about the transition between primary and secondary school being a shock to their child, with both the size of the school and the new responsibilities on pupils becoming overwhelming.

She had always been happy at primary school but secondary school was completely different, it was noisy, busy and completely overwhelming for her. She struggled with organisation and got detentions for forgetting things and being late. In a matter of weeks, before our eyes, she completely fell apart. She went from being a content, confident child to one who spent her days in a darkened room saying she wanted to kill herself....Schools aren't set up for children like her, she is bright, creative and talented, but she couldn't cope with a rigid education system where she was made to feel as if she had failed. More recognition of the causes of EBSA and how to support children with it is needed so that children like her are not left traumatised by their experiences of school

A small number of parents said that they felt that their child was not able to cope in mainstream education as it currently is. Others that significant changes were needed to make mainstream education possible for their child.

It's too rigid, too crowded and someone like my daughter who is academically very capable completely disappears in the system. She would never speak up, ask questions if she's not sure (which often happens as she reads demands like home work differently) and she just hides and is the quiet girl in the class room. Meanwhile internally it is a massive volcano building up with tension that then erupts at home. We have serious concerns that as she gets older and the demands of exams, more pressure etc. become bigger she will not cope.

Please work with the council in saving and creating one form environments for SEND children. It is a crime to deny education to children that have special needs. These needs can be met better in one form entry schools. Additionally it is easier for SEND kids to attend one form entry schools. Creating APR units in one form entry schools would greatly help SEND kids in Hackney.

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She has been pressured to perform as most of her neurotypical peers. Schools should have more flexibility to support children's needs attendance policies need to be changed to accommodate children who have anxiety/emotionally based school avoidance. Flexi schooling should be an option in mainstream schools. There should be less emphasis on following a system and more focus on the diversity & wellbeing of children and families.

### *Listening to parents and children*

Parents felt frustrated and angry that their expertise in understanding their child wasn't acknowledged:

Parents voices are extremely important and when a knowledgeable parent offers information to a school to support their child then they should be taken seriously.

One mother, who had two children with EBSA, and who recognised difficulties with her second child at an early stage as a result said the school ignored her experience leading to further delays in support for her second child:

Because of my experience with my elder child, I am better informed about EBSA and SEN processes. And when I saw the signs in my younger child, I knew what was happening and I tried to get school to do something about it. But they didn't. I feel really angry that despite all the talk of early intervention, there isn't really any early intervention. It seems like the child has to actually fall out/ break down of school before they take it seriously.

Another said that the school would have responded better to their child's needs if they had listened to them:

If they valued our opinion and useful suggestions, based on our child voicing his troubles, and put that into practice, instead of presuming that they know better. They effectively silenced our young son by failing to listen to him and take notice.

The theme of masking was raised by several and how children behave differently at home, suggesting that without listening to parents they would be unable to get a full picture of their child's experiences.

He did masking in school that he is ok. Instead, he showed emotional stress at home and it was difficult to calm him down.... Even after we have a meeting with the school's SENCO, she said my son is very good in school but my son still refused to go to school because of his stress

### *Conflict between professionals*

Sometimes parents said that they had to devise strategies to support their children in response to what they felt were the delays in accessing support. Some parents acknowledged that schools were doing what they could in the face of under-resourcing and under-funding. Sometimes conflict between professionals led to difficulties for parents.

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The school did not do the referral to CAMHS, I did. They did not value the expertise as CAMHS didn't agree with the way the school was handling the situation. They referred me to a specialist autism support person, but once again, he didn't agree with the school's using a rigid behaviour policy to deal with the situation. Despite the fact that they did the referral, they simply stopped engaging with the service!!

Sometimes the conflict existed within the same school:

I think the school and especially the SENCO tries very hard to accommodate for her within the space and time they have. I can read between the lines that this is not always easy. The SENCO knows what's needed but the headteacher doesn't always agree.

### *Parent support*

One parent acknowledged the difficulty in getting help quickly, but said that it would have been helpful to be put in touch with other parents with similar experiences.

I think it's hard for schools but they should help parents identify what's happening quickly and point them to the right places for help - even if it's just other parent groups for help. Because it's so scary and isolating when it starts.

### *Training*

Several parents raised the issue of teachers not being trained in SEND and called for more training, particularly for young teachers.

Teachers and Substitute teachers need to have Autism training and should be familiar with the individual needs of each child...they should not bully Autistic kids...and they should support Autistic kids who are being bullied by their peers

### *Anger and frustration*

There was a great deal of anger from some respondents who said that the experience of schooling had resulted in long-term harm to their children:

I personally feel that the academic achievements are extremely valued more than the children needs. I feel children are being tortured psychologically and emotionally and beyond. Schools are not prepared to support children with needs, they should declare so rather than pretending to be inclusive rather than telling parents that they are a mainstream school which I personally find it offensive. Also school should provide video evidence of children reporting to parents on how bad they are treated by certain members of staff. Children know where there are cameras to prove how bad they have been treated by adults. I feel very humiliated when the school refuses to provide CCTV evidence. Also some members of staff can signal their concerns but are not bold enough to expose their colleagues. They themselves are already under immense pressures either leave or deal with it. This is very hard because you cannot expose them left alone be assured that they are willing to witness against their colleagues. This is very daunting for me as a parent and across the entire household.

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The experience caused long lasting damage. They are still experiencing trauma from this now and struggling to process what happened.

Several parents expressed their anger with CAMHS. Sometimes this was about waiting times, sometimes about professional conflict:

CAMHS have utterly failed my child. She has multiple diagnosis' and CAMHS are the only service who can support her outside of inpatient services. They have messed us around, we have been mistreated, they have behaved badly, she has had more care coordinators than I can remember. She needed consistent high-level care not the mixed up mess we have been subjected to. It's very sad. We really needed help and the named service couldn't offer it.

### *Disability*

One respondent highlighted their child's physical disability:

My child has cerebral palsy and is a wheelchair user, the school completely lacked equality and inclusivity. My child really suffered due to that.

### *Bullying*

Bullying was a constant theme. Some parents suggested that their teachers had bullied their child, but most comments were about bullying by peers:

My daughter was physically and verbally bullied for a long period of time. I made the school aware of everything and not one thing was done to either support my daughter or to punish the two boys at school.



## 5. Analysis

### *Context of research*

This survey represents a small sample of 55 parents in an under-researched field. It focuses purely on the perspectives of parents whose children have experienced EBSA. However, its findings resonate with other research in the field and it is hoped that this survey, based on the views of parents in the London Borough of Hackney, will encourage the council to reflect on the views of parents and help pave the way to practices that will support children who experience EBSA and their families.

It is clear from our findings that EBSA is an indication of mental distress in a child. Almost all children had a diagnosis or were awaiting one. Levels of anxiety were disturbingly high and punitive approaches alienated parents and caused them distress. In order to test the findings of this survey, in this section we have cross-referenced some of our findings with larger scale research studies.

For the purposes of this survey, no definition of EBSA was offered. The acronym makes it clear that the survey was aimed at parents whose children's absence from school was a result of distress and it was felt that parents were best placed to assess their child's emotional status.

The survey has been carried out at a time of political debate around growing absenteeism in school. This Autumn [new guidelines on attendance](#) are due to come into force, although this may now be delayed. Under the proposed guidelines school staff will be under a legal duty to refer children who are 'persistently absent' without the head teacher's permission, to the local council. The council will be required to issue penalty notices and if parents don't pay a £60 fine within 28 days. Those that don't will face criminal prosecution and possible imprisonment. Hackney has stated that fines or prosecution will only be used as a last resort and in this survey it is welcome that although some parents were threatened with fines, no fines nor prosecutions were issued by Hackney. Nevertheless, some parents told us that their child's absence due to EBSA was unauthorised, leaving them at risk of fines under these new guidelines.

It's estimated that around 28% of children will experience difficulties attending school and that 1-2% of children will experience EBSA. We know that children with mental health problems or those who have a neurodevelopmental disorder<sup>17</sup> are more likely to be absent from school.<sup>18</sup> We know that poor school attendance due to absence (authorised or unauthorised) leads to immediate and long-term socioeconomic disadvantages. It is associated with:

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<sup>17</sup> We might need to define these. Neurodevelopment disorders include ASD ADHD etc and are sometimes described as 'organic' mental health problems. Anxiety, depression and eating disorders are usually described as mental health problems

<sup>18</sup> Several small-scale studies in the UK, USA, and Australia, with sample sizes ranging from less than 100 to 13000, suggest that absence from school is more common in children with a mental disorder, specifically depression, anxiety, and disruptive behaviour disorders, through school refusal, truancy, or the condition itself <https://pubmed.ncbi.nlm.nih.gov/30989389/>

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- poor educational attainment
- unemployment
- poverty

We also know that [school absenteeism is associated with self-harm and suicidal ideation](#), findings replicated in this survey. The research above calls for strategies to support young peoples' engagement with school to prevent absenteeism and it is the purpose of this survey to help identify some of them. The case for ensuring that children have an education, whether in school or outside it, is compelling and should be a cornerstone policy for anyone interested in equality, inclusion and fairness.

Parents are very clear as to the distressed state of mind their children are in when they are unable to attend school. They talk about how at home, self-harm, suicidal ideation and high levels of anxiety which sometimes manifests itself in aggression or violence. Importantly, they also talk about 'masking', or how children who appear to be well behaved and demonstrate calmness at school, reveal the true state of their anxiety at home. This is most apparent in the finding below:

Observed symptom	Home	School
They said there were no problems <sup>19</sup>	4	23
They were tearful	46	13
They seemed depressed	35	11
They were aggressive	22	6
They were argumentative	26	8
They were disruptive	17	10
They were angry <sup>20</sup>	n/a	7
They were anxious	50	21
They self-harmed	18	7
They expressed suicidal thoughts	24	4
Other	4	11
<b>Total number of symptoms (not including 'there were no problems')</b>	<b>242</b>	<b>98</b>

*Comparison of answers to: 'when your child was unhappy at school, how was their behaviour at home?' with 'when your child was unhappy at school, but still going in, how did the school describe their behaviour.'*

These findings illustrate a theme of this survey, which is supported by research elsewhere, namely that schools seriously under-estimate the distress experienced by children with

<sup>19</sup> This question was asked differently: In the first question, parents were asked 'When your child was unhappy about going to school, how was their behaviour at home?' In the second, parents were asked 'When your child was unhappy at school, but still going in, how did the school describe their emotions or behaviour?'

<sup>20</sup> This question was only asked about school

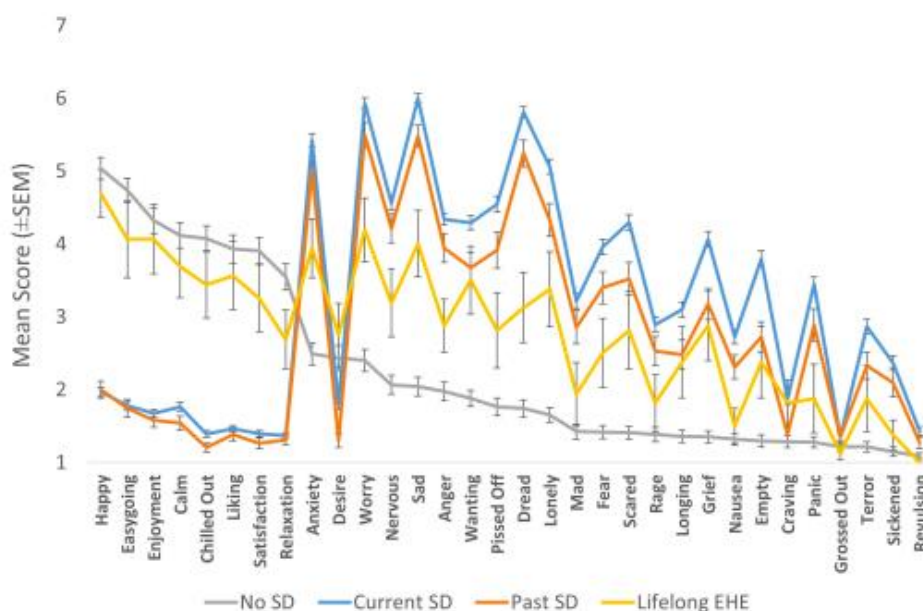
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EBSA. This is associated with a scepticism about the child's level of anxiety, which is sometimes dismissed as a result of over-sensitive parenting. Similarly, research which talks about the 'push and pull factors' of a child staying at home rather than going into school suggesting that children stay at home because they like it, is dismantled by the findings in this small survey. It's clear from these parents that children feel under a huge amount of pressure to attend, and that this pressure is communicated to the child, increasing already high levels of anxiety.

This finding is supported by [research to be published shortly](#) which shows the 'devastating' impact of 'school distress' (SD, or the author's terminology for EBSA) on parents. In this research, in which the views of 738 parents with 'school distress' were surveyed, they scored far higher on negative emotions than other groups of parents.

### To what extent do you experience these emotions?

1 = Not at all ... 7 = an extreme amount



(No SD = no school distress; Current SD = current school distress; Past DS = past school distress; Lifelong EHE = Lifelong Elective Home Education)

In the same research, parents were asked to rate the stressful impact of SD/EBSA compared to other traumatic life events. Parents with children experiencing current SD/EBSA were asked to rate twenty stressful life events in order. The top ten were:

1.	Death of a first degree relative including child or spouse
2.	<b>Child school refusing</b>
3.	Serious illness or injury to self
4.	Serious illness or injury to close relative
5.	Death of close family friend or second degree relative

6.	Major financial crisis
7.	Separation due to marital difficulties
8.	Problems with policy/court appearance
9.	Sacked from job
10.	Serious problems with close friend neighbour or relative

In the research parents were also asked to identify five tones of communications used most frequently by professionals with parents of children with SD/EBSA. They found as follows:

Position	Current SD/EBSA
1 <sup>st</sup>	Dismissive
2 <sup>nd</sup>	Critical/Unsupportive
3 <sup>rd</sup>	Uninformed
4 <sup>th</sup>	Calm
5 <sup>th</sup>	Caring

The purpose of quoting other research findings is to provide context in which the responses of Hackney parents can be interpreted. The research findings mirror our own in many respects. The research concludes:

Findings revealed that parenting and supporting a child with SD is an overwhelmingly negative experience for parents, with parental blame and hostile and punitive treatment from the professionals surrounding the family compounding this experience. The responses in this study also revealed that those experiencing SD from the perspective of a parent perceive this experience as being one of the most threatening possible life events, superseding even a serious illness or injury to themselves. Moreover, this study documents for the first time the extent of the deleterious impact that parenting a child with SD has on all aspects of parents' lives, not least on the parents' own mental and physical health, their careers, their financial situation, and their wider family (including their other children). Urgent recognition of the most common antecedent of SD (i.e. unmet need at school often stemming from complex neurodevelopmental profiles (1)), alongside recognition of the daily stressors and serious threats facing these parents, is urgently required by educational, health and social care professionals, so that supportive and non-threatening relationships can be fostered with the parents of CYP experiencing SD.

Both this research and our own survey identifies a need for better relationships based on mutual respect, listening and working together to achieve the best needs of a child, rather than an approach based on sanctions, in other words, a move from a behavioural approach to a relational one.

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[This is supported by a survey](#) carried out by the Not Fine in School Facebook page which confirms our findings, namely that many parents were told to force their child to attend school with disastrous results. 44% of parents said this did not help and 53% said this made things much worse.

The same survey found that 63% of respondent said their parenting was blamed and 69% said that their child's attitude was criticised.

## **6. What does this mean for Hackney?**

This document has already outlined the commitment Hackney has made to improving the mental health and wellbeing of children in schools through its WAMHS initiative. This survey aims to build on this work by providing evidence of the lived-experience of families whose children have experienced EBSA.

Our findings show that autistic children are the single most highly represented group among children with EBSA. 29% children diagnosed with autism had a single diagnosis while 71% had multiple diagnoses.

From this survey, children's EBSA peaks at 5-8 years old and 12-15 years old, although it is hard to draw any conclusion from this finding.

The survey is too small to uncover any useful information about the ethnicity of children. No respondents mentioned racism or discrimination in any of their answers. However, no specific question on race was included in the survey.

Most parents (87%) were aware that their child had problems at schools before they felt unable to attend school, although some said that refusal came with no prior signs of unhappiness at all.

Almost all the parents who responded to this survey said their child was diagnosed with a neurodivergent condition. The prevalence of autism was very high. It is clear from this survey that long-term school absences should be considered as a SEND issue rather than an attendance problem.

EBSA can have long-term impact: 53% of respondent said their child had not been able to attend full time school for at least a year. 18% said their child had not been able to attend full time school for three years or more.

Sensorial difficulties and the school environment were the most commonly identified reasons for their child not being able to attend school, followed by bullying. Text bullying was rare.

Worry about a specific lesson or class scored highly (mentioned 21 times) and could be relatively easy to resolve, if that were the sole cause of school absence.

Children who don't attend school don't stay at home because they like it. They are also extremely unhappy at home, registering on average 4.4 symptoms, but feel safer than they do at school:

- 98% of parents who said their child was unhappy at home said their child was anxious
- 89% said their child was either aggressive or argumentative at home
- 64% said their child seemed depressed
- 44% said that their expressed suicidal thoughts
- 33% said their child self-harmed
- Only 7% said that there were no problems with their child's behaviour at home.

These levels of distress that children experience challenges the behavioural approaches of incentivising children to attend or making their home life less welcoming. They also suggest that the pressures put on families are felt by children, causing additional and often acute distress.

This survey purposely avoided identifying individual schools. However, from the evidence it appears that there is a significant difference in the approaches taken by individual schools. For example, some parents said that their school used no behaviour management methods in response to their child's behaviour (although some children did not 'misbehave' in school) while others responded with detention, isolation rooms and exclusions. Sharing of best practice with regard to EBSA between schools may help develop a more uniform and family centric approach.

In addition, although a large majority of parents expressed great frustration with school, a minority spoke very highly of the responses from their child's school. It is worth repeating a quote from a parent who was highly appreciative of the school's response:

They listened. They put no pressure on. They reassured us they wanted her to return to school. They reassured us they wouldn't fine us. They came to do home visits and were respectful and polite and kept within her requested reasonable adjustments. They were encouraging. They stood by us when we were battling with support services to try to get help.

55% of parents said that they were pressured to force their children to school. Many parents felt this to be destructive. No-one said that it resulted in a positive outcome.

82% of parents said that the EHC plan didn't help. This is an alarming figure for what is often a time-consuming and fraught process, both for schools and parents and suggests a breakdown of a process that it is in need of review.

Once a child stops going to school, relationships between the school appear to breakdown. Over half the parents questioned said the school did not listen to their concerns, did not listen to their child's concern, did not support them, did not value their input and did not make reasonable adjustments for their child.

Between 47% and 60% of parents said they did not feel empowered, they felt blamed, they felt judged they didn't feel like an equal partner, did not feel listened to and felt ignored.

These are deeply concerning figures and suggest that families in crisis are being marginalised, their skills and expertise ignored and are poorly advised and badly treated. In children's educational prospects are being significantly damaged.

## 7. Conclusion

Parents whose children have experienced EBSA are predominantly negative about how schools respond to their child's anxiety. Hackney is not unique in this, indeed, the absence of fines and prosecutions, as well as some of the positive reflections from some parents demonstrate areas of what parents see as good practice in the borough. Nevertheless, the experiences of families of children with EBSA are predominantly negative.

However, this survey has been carried out to define the problem and to help both parents and schools work together develop an inclusive education. It is also acknowledged that schools and school staff are under a great deal of pressure. Many school staff do not receive sufficient training on mental health and how to accommodate neurodivergent children as part of their PGCE training or. Hackney's Wellbeing and Mental Health project in School ([WAMHS](#)) has aims to improve mental health and wellbeing support for children and young people in schools, colleges, specialist and alternative provision education settings in City & Hackney and perhaps involving parents of children with EBSA to share their lived-experience in this initiative may further improve understanding of mental health in schools.

It may also be worth reflecting on the cultural change that schools have been expected to embark on since the Government's 2017 White Paper [Transforming Children and Young People's Mental Health Provision](#) first outlined their expectations to support children's wellbeing and mental health. Although Hackney has invested significantly in improving mental health support in its schools, this limited survey suggests that the cultural changes, of working with children and their families when they need support, has some way to go when it comes to children with EBSA. The most significant and urgent finding from our survey is that while schools need to work with families to support them and some do successfully, most families of children with EBSA have overwhelmingly felt alienated from school.



## 8. Recommendations

### 1. Recognise EBSA as a mental health and wellbeing issue

It is clear from this survey that children and their families were experiencing extremely high levels of mental distress as a result of EBSA. It is also clear that most children were diagnosed with a neurodivergent condition, most commonly autism. It's clear that the processes for encouraging a return to school in most cases, exacerbated that distress. Recognising EBSA as a SEND issue, rather than an attendance problem would provide a more child-centred and supportive approach.

### 2. Embed training

It is welcomed that Hackney is carrying out and developing borough-wide training for schools on autism and EBSA. This should be continued and rolled out with the involvement of parents.

### 3. Work with children and parents

We suggest that there should be a particular focus on working in partnership with parents and children, respecting and trusting them and learning from their views and listening to families whose children are finding it difficult to attend school. There are several examples in this research where helpful information from parents was ignored (for example, a parent who had previous experience of a child with EBSA identifying early signs of EBSA in her second child). Schools should, wherever possible, take a strength-based approach with parents to identify how they can best support their child. Parents should be seen as equal partners whose skills and experience can enhance support for their child. Even families in complex situations have strengths that can be used. Conflict between parents and school is likely to escalate the problem of non-attendance. Other areas for further exploration are:

- To set up a support group for parents with EBSA.
- To encourage a school dialogue on policy on EBSA which includes parents and children
- To listen to, accept and respect parents lived experience of EBSA

### 4. Be flexible

Parents were critical of inflexible, or 'one-size fits all' approaches to their child. Many children with EBSA suffer high levels of anxiety. In such circumstances it is unlikely that punitive responses are going to help resolve EBSA. Children with high levels of anxiety may benefit from flexibility around school rules. Examples suggested by parents in this survey include:

- Flexibility over minor infringements such as not completing homework, forgetting school equipment (eg calculators); inability to wear school uniform (eg because the texture is uncomfortable)
- Part time timetables
- Personalised curriculum
- Flexibility over punishments for behaviour that could be explained by anxiety

As one parent put it, 'There should be less emphasis on following a system and more focus on the diversity & wellbeing of children and families.'

Some parents felt that their child would not be able to cope with the school environment, and that a more flexible environment was needed with smaller classrooms for children who need it, or special education facilities.

**5. Place education above school attendance**

Some parents said that the emphasis should be on prioritising their child's mental health and finding the best environment for them to be educated rather than returning them to school. Being present in school is no solution if it is causing a child trauma or upset.

**6. Promote relational approaches**

Good relations between school and families are most likely to help children. Seeing children and families as exaggerating their difficulties and interpreting EBSA as a symptom of a child or family whose behaviour does not meet school expectations caused anger and resentment. Low levels of trust between parents of children with EBSA and the school are likely to reduce the chances of enabling a child to continue their education. We recommend prioritising relational approaches over behavioural approaches based on sanctions and incentives.

**7. Review the EHC plan process**

We welcome the fact that Hackney has been reviewing the EHC plan process by introducing a Graduated Response plan in Sept 21 and the Team Around the School model in Sept 22. The benefits of these initiatives have not had time to filter through the system in time for this survey. However, it is noteworthy that an alarming 82% of parents said that the EHC plan didn't help their child. We suggest that Hackney take note of this finding, and continue to review and monitor the process of EHC plans, taking into account the views of families and their children.

**8. Avoid threats, make punishments appropriate**

It was very welcome that no parents were prosecuted or fined in this survey. However, parents resented being threatened with them. Punishments for distressed children may be more likely to discourage school attendance.

**9. Review the environmental conditions in school**

Environmental conditions were raised by many as a source of anxiety for children. Moreover, some schools provided safe spaces where others didn't. It may be worth considering (i) asking schools to have an environmental audit to support neurodivergent children (ii) asking schools to share best practice (iii) involving parents and children in this process.

**10. Adopt borough wide standards and guidance**

This survey deliberately did not ask parents to identify schools. However, it seems that there is a wide range of practices in schools in Hackney. Sharing best practice, involving children and their families may help provide more support for children with EBSA. Policies on authorised and unauthorised absences, for example, should be adhered to, and absence coding must be accurate.

**11. Collect better data**

There appears to be little data on EBSA in Hackney, or for that matter elsewhere. It is recommended that Hackney identifies what data is needed to better understand EBSA and support the children who experience it.

**12. Adopt whole school approaches to mental health**

There are several models of this and it may be that many schools have adopted whole-school approaches. However, the evidence from this survey is that few schools are embedding it with regard to EBSA.

**Tim Linehan 30-08-23**