

PaCC Emotionally-Based School Avoidance (EBSA) Report – November 2023

Drawing upon parent carer experiences to create better support for families during their EBSA journey.

INTRODUCTION

PaCC is a parent-led carer forum which represents parents and carers of children and young people, up to 25, with additional needs and disabilities who live in Brighton & Hove.

Across the country, many children and young people have experienced or may experience EBSA. In Brighton & Hove, we currently recognise the term EBSA to encompass a wide range of individual circumstances. The *emotions* displayed might include anger, sadness, fear or anxiety. *Avoidance* might include anything from disengaging or truanting from lessons, to completely withdrawing from school for a sustained period of time (Thambirajah et al, 2008). The onset of EBSA can occur suddenly or develop gradually over time and may be linked with a range of other things (e.g., separation anxiety, social anxiety, autistic burn out, unmet or undiagnosed learning needs, family circumstances, school culture, mental health conditions, medical conditions).

EBSA may present as:

- Dysregulation and distress before and after school – feeling sick, crying, clinging to a parent, arguing, shouting and physically resisting entering the school building.
- Difficulties with sleep as a result of worry linked to attending school.
- Complaints of feeling ill without obvious cause – physical symptoms of stress, anxiety and fear (e.g., sickness, chest pain, breathing difficulties, headache, blurred vision).
- Seeming to 'burn out' part way through the school week and appear completely exhausted.
- Needing to be in constant contact with a parent (e.g., calling and texting from school).
- Withdrawal from normal daily activities and reluctance to leave home.
- Dysregulation, disengagement and oppositional behaviour.
- Truanting from lessons and regularly leaving the school site.

PaCC has been working in co-production with Brighton and Hove's Hidden Children's Officer and representatives from the Local Authority, health, schools and the voluntary and community sector to produce an EBSA Toolkit. This will consist of a website with 2 pages; firstly, a landing page, and then a second page which will be a portal with 3 areas with information for

- 1) Children and Young People
- 2) Families
- 3) Schools

The website will be a living document, an electronic resource that changes over time with information amended and added to as needed.

The term Brighton & Hove are currently using to recognise EBSA may change as the toolkit develops.

To contribute to the creation of the EBSA toolkit, PaCC gathered feedback from parent carers at our termly education workshop in October, as well as through a survey that was sent out to members. PaCC identified 4 questions we wanted to collect feedback on and these form the basis of this report.

- 1) What helps / doesn't help your child feel safe in school?
- 2) What impact does your child's attendance have on you?
- 3) What were the early warning signs of your child experiencing EBSA?
- 4) What would help or would've helped with your child's experience of EBSA?

FINDINGS

1) What helps / doesn't help your child feel safe in school?

Relationships

Parent carers highlighted that relationships with staff and children in school were an extremely important factor in how safe their child felt in school. Their child having friends in school was a popular response on our survey when asked what helps them feel safe in school, and as expected experiencing **"social isolation"** and feeling **"informally excluded"** were terms parent carers gave as to what makes their child feel unsafe. The relationships their child had with teachers and staff members were also of great importance. Parent carers said that their child felt safe when there was a **"safe adult"** or **"key adult"** that their child could go to. **"Known familiar adults who listen to him and give him space."** This

;was particularly crucial at the start of the school day, one parent carer stated, ***“My child needs to feel safe going into school, but any TA support, needs to be the same person each day”***. Parent carers mentioned that any change to or withdrawal of support, was likely to cause their child to feel unsafe again and that a child appearing to cope after support is put in place is not a signal for support to be withdrawn, quite the contrary, it was often evidencing the support is needed. Staff members not acknowledging a child’s difficulties, not empathising with them or offering adaptations was a risk factor identified by several parent carers. One stated ***“Staff being annoyed about how long it takes to get through the door, unexpected changes, lack of support and understanding”*** doesn’t help their child feel safe. Other parent carers said similarly that ***“Teachers not understanding autism”*** ***“Telling them ‘They’ll be fine’ when they are extremely anxious and afraid”*** and ***“Physically dragging them from parents screaming”*** all contributed to their child feeling unsafe in school.

Communication

Parent carers highlighted that good communication between home and school really helped their child feel safe, seen, heard, and understood. Conversely, a lack of communication made their child feel disregarded and that their needs were being overlooked. This also applied when parental input and expertise was ignored. One parent carer stated, ***“Schools don’t listen to parents when parents have suggestions, schools often don’t work with parent carers.”*** Another parent carer said ***“There is a battle to be believed, parents feel doubted, and say ‘mum is a bit anxious, mum is worried’. The school lack understanding of masking. When my child is home, he is not fine.”***

Communication between teachers within school was also considered to be of paramount importance; once a reasonable adjustment has been agreed, this must be communicated between teachers. One parent described how the school had agreed her daughter didn’t need to wear a skirt, but this message was not passed on, resulting in their child being pulled out of assembly and forced to wear a skirt from lost property. Then, because their child did as she was told and wore the skirt that day, there was an assumption there was no issue and they could wear the skirt every day. The parent stated, ***“They think if she keeps being pushed, she won’t be autistic anymore”***. Similarly, another parent carer mentioned ***“supply teachers who don’t know him well”*** makes their child feel unsafe. These issues are particularly accentuated within secondary schools with more teachers needing to get to know the child and also apply when there is a job share in primary schools, where a message at the start of the week doesn’t get passed on to the teacher who takes over in the middle of the week. A one-page profile detailing how best to help and support a child would

be of great benefit in schools and would prevent these occurrences. When a one-page profile has been shared with teaching staff, parent carers don't always feel that it has been read or taken into account.

Environment

Parent carers highlighted that the school environment had a significant impact on how safe their child felt at school. Noise, crowds, busy classrooms, changing staff, long hours of learning, unpredictability, and lots of demands were all reported by parent carers as making their children feeling sensorily overwhelmed, vulnerable, and unsafe. Parent carers said it was frustrating when this wasn't acknowledged by the school. One parent carer stated

“Schools are not equipped to know what they are looking for when it comes to dysregulation. There is an assumption that the teacher and SENCO know best and if they don't see a problem then it isn't there. I am trying to advocate for my child but I'm coming up against a brick wall.” The schoolwork required and the way in which it is taught is another risk factor identified by parent carers. One parent carer said of their child

“She struggles with the work, gets very emotional and removes herself from class.”

Another parent carer suggested ***“A curriculum tailored to their needs would be what is required, i.e., one that appreciates the monotropic nature of the autistic mind.”*** Parent carers need to be listened to because children might be masking in school to go 'under the radar' and not draw attention to themselves or their difficulties, and masking comes at a cost. Parent carers may be seeing a very different child at home, who has held everything in all day. EBSA where a child is described as 'fine in school' may be evidence that masking is no longer sustainable, and they have reached breaking point.

2) What impact does your child's attendance have on you?

Mental Health

Unsurprisingly, parent carers highlighted that their child's experience of EBSA had a profound negative impact on their mental health, due to the stress the situation caused, particularly worrying about the future. One parent carer said their child's attendance had ***“a negative effect on my mental health as I need the separation to work and have space. I find myself worrying about the future.”*** Another parent echoed this, stating ***“I worry so much about her mental wellbeing, her lost learning time and what her future in secondary school will be.”*** Alongside these feelings of stress and anxiety, parent carers

also identified feelings of ***“sadness”, “failure”*** and ***“shame”*** in relation to their child's attendance, as though it were their fault, this is exacerbated by Section 444(1) Education Act

1996 and the subsequent issuing of fines. One parent carer stated, ***“The huge stress has come from the parent blaming and threatening letters.”*** Unfortunately, these effects of EBSA were far-reaching for the whole family. One parent carer stated, ***“His distress impacts the whole family and prevents others from doing things they need to do or enjoy.”***

Another factor which impacts the mental health of parent carers is the increased practical tasks that have to be completed when you have a child experiencing EBSA. There is a greater administrative workload and emotional labour stress which needs to be acknowledged. One parent carer stated, ***“I am suddenly care worker, therapeutic support, advocate and educator for my child.”*** and another referred to the ***“Constant stress and the emotional and administrative load, the pressure of juggling work and never feeling able to plan.”***

Economic Concerns

Parent carers highlighted that having a child experiencing EBSA created additional and unpredictable childcare responsibilities, compromising their ability to remain in paid work. One parent carer stated, ***“I have had to leave my paid work”***, and another said they ***“Can’t always work”***. Many children experiencing EBSA are placed on a part-time timetable, and whilst this may offer a temporary solution, it doesn’t help the parent who then must reduce their hours or leave their job. One parent carer said ***“A part-time timetable doesn’t always solve the EBSA, and what is the long-term plan? It feels like the part-time timetable only benefits the school. I’m the one asking for meetings and to make plans.”*** The struggle / inability to remain in remunerative work understandably has a negative economic impact, creating further stress for families experiencing EBSA, which is intensified for single-parent families. One parent carer highlighted the impact of all of this on their wellbeing, reporting they were ***“Unable to do my job. Severely disrupted sleep. Live day to day. Prioritising my child’s mental health has had a profound experience on my life.”***

3) What were the early warning signs of your child experiencing EBSA?

Physical and Mental Health Symptoms

Parent carers said their children started reporting a variety of physical symptoms of sickness at the beginning of their EBSA journey. These included ***“Tummy aches and headaches”***. One parent stated, ***“My child would start saying they are poorly and have to stay at home”***. Parent carers highlighted these physical signs of distress would often start the night

before with their child getting worried about school in the morning and **“not sleeping”**, and then this would continue in the morning. Parent carers noted a deterioration in their child’s emotional wellbeing. One parent reported **“My son was so full of happiness, curiosity, and loved writing, drawing and workbooks. That all stopped when he started school”**. High sensitivity with children crying easily was reported several times as an early warning sign, both in the morning and after school, along with **“being unable to calm down”** and **“very clingy”**. Children also experienced **“more meltdowns / shutdowns in school”**, **“shutdown before / after school”** **“blanking out”** and **“depression”**.

Avoidance Behaviour

Several parent carers also noticed their children started to display avoidance behaviour once inside school. One parent carer **stated “She avoids when she is in school, often going to the toilet, filling her water bottle repeatedly or using an out-of-class pass, and is missing huge chunks of her learning.”** These avoidance behaviours, although helping the child to be physically in school, clearly have a knock-on effect on their learning. One parent carer raised the point that **“The attendance figures are not always reflective of what is going on. What about when a child is in school but not learning, or in school but not coping?”** Parent carers also highlighted their children started to struggle with schoolwork which then extended into a dislike of schoolwork and complete refusal to engage. One parent carer said **“My child is in school on a part-time timetable and never goes into class. I think to myself how long can this go on for? He is regressing with other things too and doesn’t want to participate.”**

4) What would help or would’ve helped with your child’s experience of EBSA?

Quicker Intervention

One of the main things parent carers identified they needed was to be trusted and listened to as the expert when it came to their child. One parent carer stated, **“I have always been exact in my predictions but it was always ‘let’s wait and see’ or ‘try this’ which is part of what has caused trauma.”** Another parent carer said **“I contacted them straight away and explained what I thought might be behind it and advocating for my child’s needs in the words they had shared. They listened and acted very quickly.”** Quicker intervention was mentioned by several parent carers and for this there needs to be widespread understanding of masking within school and an awareness that appearances can be deceiving. One parent carer stated they needed **“Staff not to tell us that she’s ok when you leave. For school to listen and act quickly.”**

Adjustments and Approaches

Parent carers would like to see an end to sanctions and punishments for their children, including forcing children into lessons. Instead, parent carers would like a gentler, low demand and positive approach, with a designated adult their child could trust and safe space areas within the school building. All these elements come down to better training for school staff, greater flexibility within the learning environment and improved communication between all school staff. One parent carer reported about their child ***“She needs constant reassurance and praise. She really needs much smaller classes or group work.”*** Another parent carer stated ***“There needs to be more alternative provisions for our children that’s not something we have to battle for. Ultimately there needs to be acceptance that many children with EBSA are not suited to a mainstream environment.”***

SUMMARY

- Relationships that children have with others within their school, communication about a child’s needs between teachers and staff within a school and communication between home and school, are significant determinants of whether a child will experience EBSA.
- The school environment has a significant impact on a child’s ability to cope within school and therefore affects their chance of developing EBSA.
- EBSA negatively affects the whole family, causing increased stress not only to the children involved, but also hugely impacts those who care for them. Parent carers reported deteriorating physical and mental health due to EBSA, as well as economic consequences.
- Parent carers noticed their children displayed symptoms of deteriorating physical and mental health, avoidance behaviours and difficult transitions into school as the earliest warning signs of EBSA.
- Parent carers highlighted the need for quick and effective intervention for children experiencing EBSA, including better training for staff around masking in school, flexibility in terms of adaptations of the school environment, a designated keyperson, and a gentler, more positive approach for their children.