

Parent Carers Experiences of Children with Emotionally Based School Avoidance (EBSA)



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About Healthwatch Bath and North East Somerset

Healthwatch Bath and North East Somerset are the county's independent champion. For people who use health and social care services. We're here to make sure that those running services, put people at the heart of care.

As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care.

We are here to listen and understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

We focus on ensuring that people's worries and concerns about current services are addressed. We are totally independent and can provide you with impartial and independent signposting advice

We are part of a network of 150 local Healthwatch across England and cover the whole of Bath and North East Somerset.

About B&NES Parent Carer Forum

B&NES Parent Carer Forum (PCF) are parents of children or young people with a variety of disabilities, who bring their experiences and knowledge together to provide a voice to advocate for change. [BanesPCF – Banes Parent Carer Forum](#)

Parent Carers are the experts on their children and, as such, they should have a say in what happens in the local area when it comes to strategy, commissioning of services and support.

The PCF's role is to work closely with parent carers through our website, information sessions, social media and events.

PCF then works in partnership with the Local Authority and other strategic groups to ensure that they listen and hear what it is really like for families, children and young people. Highlighting what change is needed to ensure that there really is an inclusive offer.

Background to research

Healthwatch has been engaging with B&NES Parent Carer Forum since September 2022, when we first attended a parent carer cafe to hear from parent carers about their experiences. Following on from these regular engagements the Parent Carer Forum approached Healthwatch in Spring 2023 to undertake joint research around EBSA (Emotionally Based School Avoidance) to explore levels of understanding and support from GPs and schools in relation to this issue.

The Parent Carer Forum raised this issue, due to the feedback they were hearing from parent carers including:

- the variable way in which EBSA is dealt with by GPs and schools
- new guidance given to schools around attendance, which is impacting especially on those children with EBSA, but where any other diagnosis is absent
- that EBSA has become more common since COVID but was present beforehand

They had received feedback that:

If a child has an EHCP then the needs of children are much better met, but anxiety can be a standalone issue without any diagnosis, or there could be delays in EHCP.

Some GPs are charging to provide an 'authorised absence' certificate which can then be given to the school, whilst others do not.

Some schools accept that anxiety is an issue and will work around that – with part time school days and being able to call parent to collect their child.

Others experiencing children being told that 'Mummy will go to prison if you don't come to school'.

Some primary schools physically wrenching child off parent to get into school.

Some schools have a 'resource base' for autism, which is positive, but the same space may be trying to meet needs of children with widely different needs.

The Parent Carer Forum are part of an EBSA steering group involving schools, Educational Psychologists, Sendias and the Local Authority, but with limited health input.

The Parent Carer Forum provide EBSA workshops for parent carers, and have recently started providing these for school teachers, with input from Educational Psychologists and support from Sendias.

This is also a current issue in the media with recent reports of 20% of schoolchildren regularly missing days at school, at least in part due to issues around anxiety. Nationally there were over 770,000 children absent in 2018/2019 due to EBSA, (source: Square Peg) and anecdotally this would be a higher number if those de-registered from school for this reason, were included.

Interaction between Health and Education

Parent carers would like to see schools and GPs planning and working together better for the best outcomes for children, including developing and sharing best practice for dealing with EBSA.

Based on initial feedback one of the aims of the research was to find out if there was an observable difference in responses from parents of children with a diagnosis and those without, to test the assumption that children's (and parent carers') experiences at school would be easier if they had a diagnosis.

What we did

Healthwatch and the Parent Carer Forum jointly devised an online survey which was shared via their membership and also via Healthwatch social media channels and monthly newsletter.

The survey was open for 4 weeks and parent carers had additional opportunities to feed into the survey via EBSA workshops and parent carer cafes.

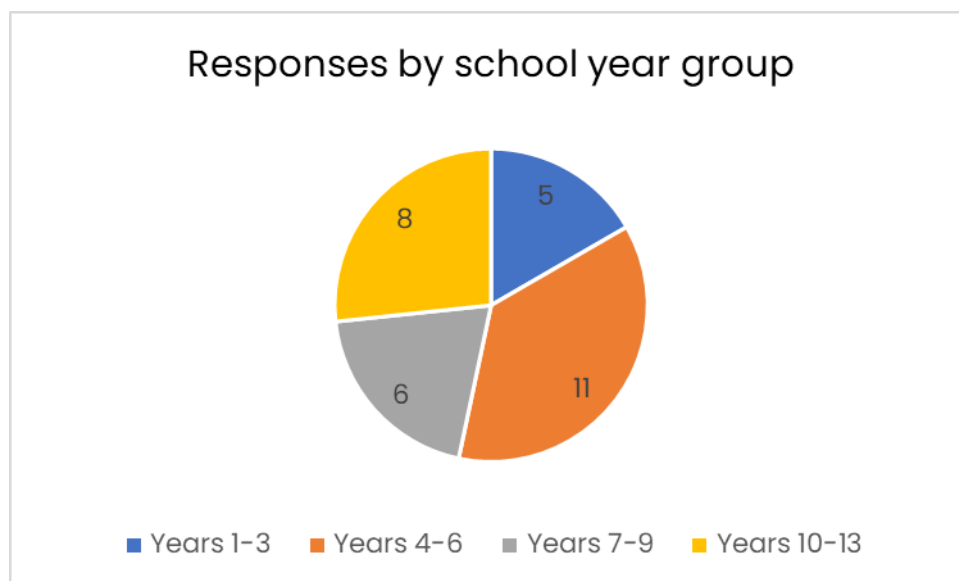
The survey is attached at Appendix 1.

Who replied?

30 responses were received in this time frame both from existing members of the Parent Carer Forum and in response to the online and newsletter invitation.

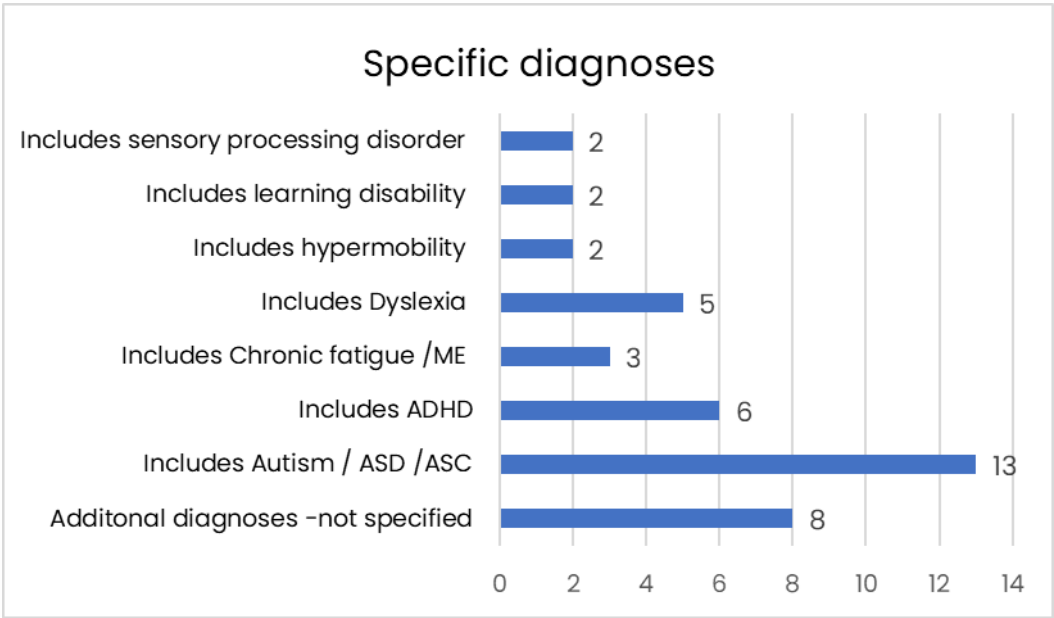
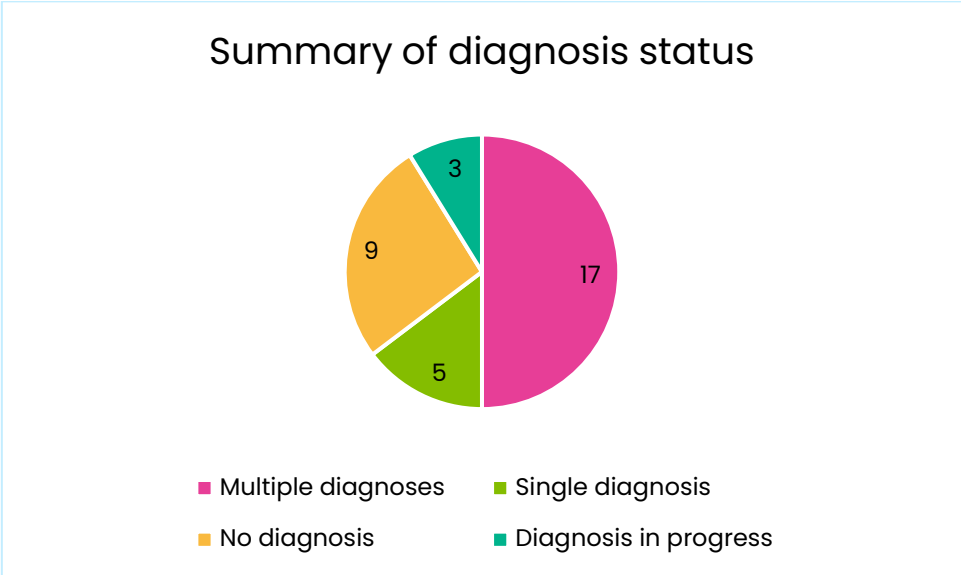
All those responding had or cared for a child or children with special or additional needs.

Responses were received in roughly equal numbers in relation to primary and secondary school pupils.



It can also be seen that there was a mix of responses with regard to whether a diagnosis had been received, was in progress, or where there was no diagnosis. Where there was a diagnosis only 5 respondents noted a single diagnosis, where 4 of these were related to Autism or Autistic Spectrum Disorder or Condition, and 1 to Dyslexia.

It is clear that many parent carers and children were managing complex and multiple conditions, including physical conditions.

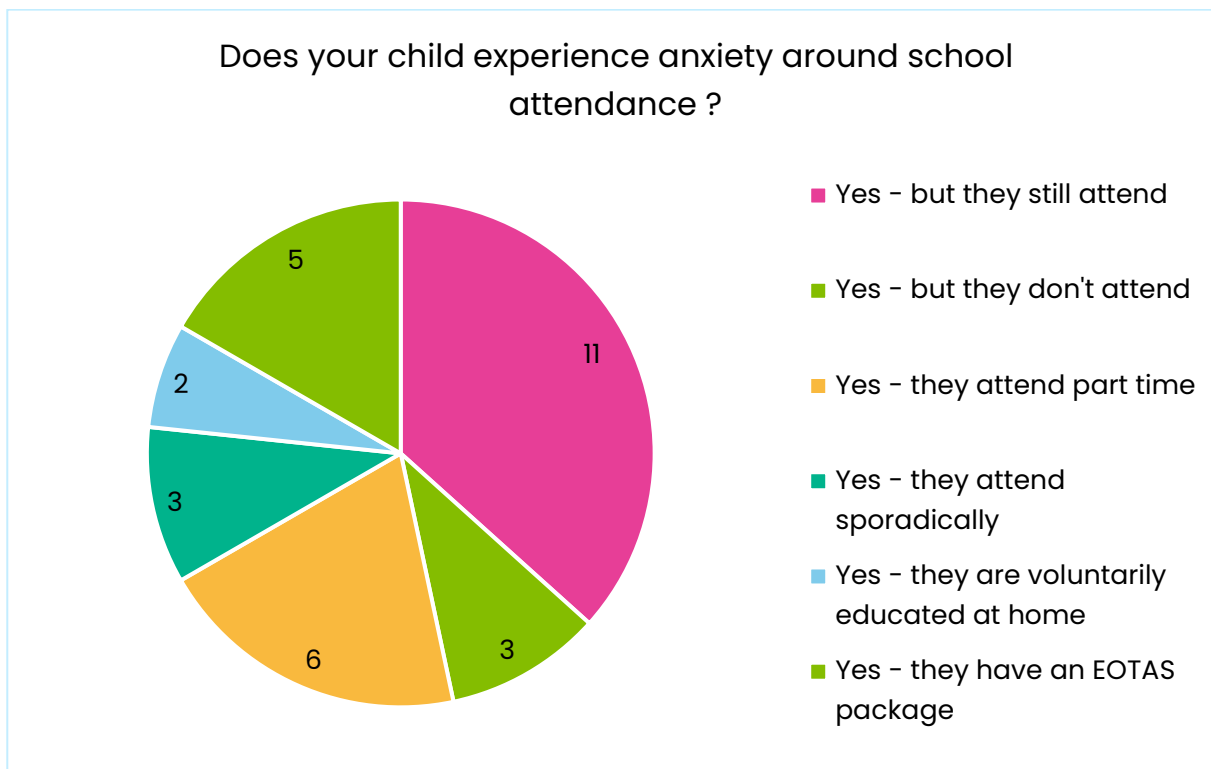


The additional specific diagnoses were:

- Anxiety
- Dyscalculia
- Perinatal stroke
- Hypotonia
- Selective mutism
- Chronic constipation with encopresis
- Global Development Delay (GDD)
- Pathological Demand Avoidance (PDA)
- Developmental Coordination Disorder (DCD)

Anxiety around school attendance

All those responding to the survey had, or looked after, a child or children, who experienced anxiety around school attendance. Just over a third said their children still attended and 10% that they were not attending. 30% were attending either part-time or sporadically. The remainder were educated either at home or through an EOTAS (Educated Other Than At School) package.



Support and advice from GPs

The survey asked a number of questions about parent carers' contact with their GP and whether they received helpful support and advice. The results show that nearly three quarters of respondents had either visited or spoken with their GP about this issue but also that a similar proportion remained unsure whether or not their GP recognised EBSA as a condition.

A little under half of respondents (45.8%) were offered advice by their GP and only 18.2% found the advice helpful, with a further 23% being unsure, with the remainder saying the advice was not helpful.

Examples of Advice Given

"Speak to SENCO"

"Wait and see"

"Really sorry we can't help, call an ambulance. In fairness to GP staff they wanted to help but there is no community offer it would appear due to lack of time and funding."

"At the time she was in mainstream and it was suggested that specialist (school) might be better"

"Make home a safe and peaceful place, let go of expectations of GCSE results or completion"

"Try CAMHS, but they have a two-year waitlist so you will be triaged"

"To contact CAMHS - GP said they had no power to help. Couldn't issue a sick note or back up anxiety diagnosis. GP said CAMHS are the only health professionals who hold any power for young people with mental health concerns."

“Refer to CAMHS re Anxiety. GP has focused on physical symptoms.”

“To get my child back into mainstream school as soon as possible”
(Added comment: The GP had no understanding of school anxiety and would not write a letter to the school. I had to change GP's to eventually get a letter of support and also change GP surgery.)

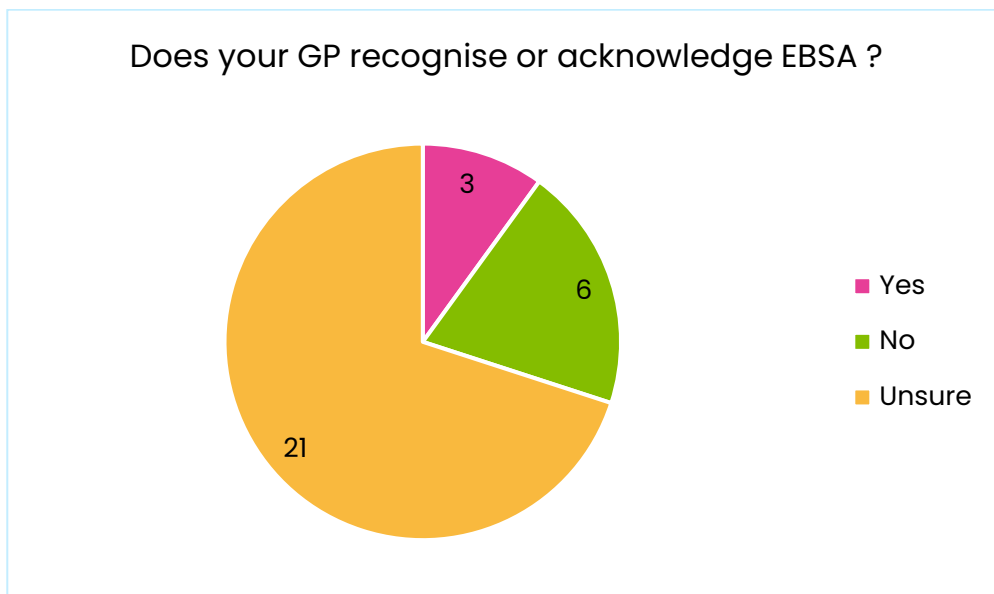
“I asked the GP to write a letter for me to give to the school to say my child has school anxiety and is unable to attend school.”

Parents were also asked if their child had been ‘signed off’ school due to EBSA. Of the 27 respondents to this question 11 (40%) hadn’t asked for their child to be signed off, whilst 8 were signed off and another 8 were not. It is not clear whether this was due to their GP being unwilling to do this or another reason.

2 respondents had been asked to pay for a certificate to support their child’s non attendance at school.

Three respondents mentioned they had a paediatrician and access support this way, and one respondent’s child was with CAHMS.

Charts showing responses for specific questions are set out below.



Respondents' overall experiences of support from their GP varied greatly as illustrated by the examples given below:

GP is kind and supportive but not able to offer any mental health/ anxiety support as nothing available. Focused on physical issues. CAMHS is only option. She completed referral for HERS but HERS never got back to us."

"The GP has written several letters supporting my daughter's EBSA and has been very helpful.

CAMHS was discussed but she was already receiving therapy elsewhere so we did not pursue it."

"No"

"Non-existent"

"Unhelpful"

Who else did parent carers consult ?

The survey asked who else parent carers had consulted about their children's anxiety around school or experience of EBSA.

A majority (80%) had consulted the school teacher, and 43% had contacted the school manager or administrative staff and 30% the school nurse.

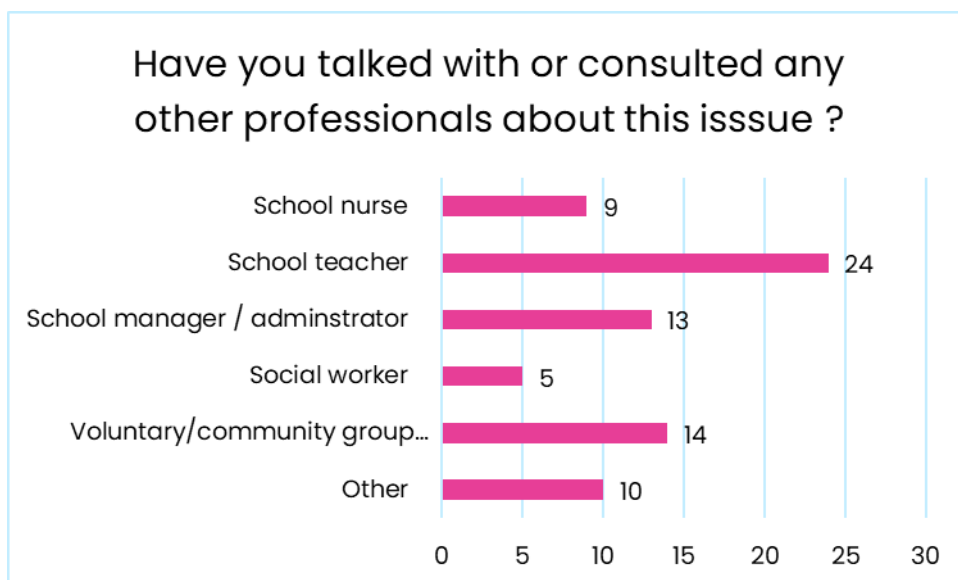
Nearly half of respondents (46.7%) had consulted a voluntary or community support organisation.

From the wide range of other organisations involved it appears clear that parent carers are working very hard to get the support needed for their children, engaging across education, health and the voluntary and community sector. Finding support in itself is time consuming flagged in the comment below:

“It would be so lovely if GP's, CAMHS and other agencies could sign post to up-to-date support nationally and locally. Parents are left to discover all this for themselves and made to feel as if they are alone. They should be able to signpost towards NFISUK and Square Peg”

Other organisations parent has been in contact with included:

- Sendias
- SEN team
- SASS (Specialist Autism Support Service)
- School behaviour manager / attendance and behaviour panel
- Student support officer
- Family Liaison Officer, Education Welfare Officer
- Community/hospital paediatrician
- CAMHS
- Chronic fatigue clinic
- OT at RUH
- PDA society (Pathological Demand Avoidance society)
- National Autistic Society
- Southside
- TRC (Trauma Recovery Centre)
- Youth Connect
- Connecting Families
- Educational Psychologist
- Parent Partnership



See Appendix 2 for further details of organisations.

In terms of helpfulness and advice 70% had been offered advice. As with GP responses there was a really wide range of responses in terms of how helpful parents found the advice offered, as illustrated by the examples below.

Parent carers' responses:

"The school nurse was very supportive in my daughter's transition from Primary to Secondary, organising 1:1 trips for my daughter to visit the school on several occasions."

"The staff at my daughter's secondary have been amazing in meeting her every day for the first two years, endlessly patience and working in co - production with myself as a parent."

"We trialled half days for a few weeks which seemed to help (specialist school so much easier it be flexible)"

"Yes, as they have a better understanding of school anxiety and the causes of this than the outdated view of schools and the NHS."

“Parent Partnership gave me good advice on what steps to take. Local authority would not accept a request for an EHCP”

“Attendance office demands until I had a GP letter for medical condition. (Chronic fatigue not EBSA though !) School going silent when child stopped attending. How can she go back to school that have cut all ties. HERs bothering to get back to referral requests”

“No, SASS told to keep a routine”

“School teacher comments of "can't the other parent bring them as they are fine for them"

“Senco refused to apply for EHCP even with an attendance of 61%, but did try to put some support in places, TA to greet each morning, 1 to 1 time to decompress before joining class this was all unsuccessful”

“No, they just gaslighted me and blamed me for my child's anxiety.”

“All I got was "she must attend school or I go to court'.”

What else has helped?

The questionnaire asked parent carers about what else had helped in managing their on-going concerns around their children's anxiety / EBSA. Eighteen responses were received.

Specific organisations found to be helpful included Mentoring Plus and Banes Parent Carer Forum, including the EBSA workshops.

Finding support through other parents was important for at least 7 respondents, and 1 person mentioned self-help through finding the work of particular authors on the subject

Other helpful steps mentioned included keeping in positive communication with the school, but also changing schools.

Some other examples are included below:

“Bath Parent Carer Forum has been a real support. The only place EBSA is really discussed and I learnt what it was!”

“He has been seeing a counsellor through school but paid for by us which has really helped him to communicate his worries to us”

“Realising the child needs an education not a school”

“Talking to someone helps but the underlying problem remains for lots of people.”

“Time, being outside, horse therapy, a period of home school, tutoring, the dog, love and the connections of family and friends.”

What has been unhelpful?

Respondents were also asked what else had been unhelpful. Again, eighteen responses were received. The responses primarily focused on the school responses to their child’s needs, a lack of good communication, and the pressure this places on them as parent carers.

A number of comments flagged up ‘attendance pressures’ including threats to prosecute and that they (the teacher) might ‘lose their job’ as it was their responsibility.

Good communication was an issue, with examples of both a lack of communication or too much.

“School going silent when child stopped attending. How can she go back to school that have cut all ties ?”

“Continuing to say that the school needs to check up and phone me every week when they already know my child has alternative provision.”

CAMHS was also mentioned with regard to a parent feeling they were “fobbed off” to CAMHS, which is “totally underfunded” and “not fit for purpose”

Social care staff were also found to be “very unhelpful” by another parent.

Some parent carers also responded that the lack of awareness and understanding, and ‘uninformed comments’ amongst friends or people in general was also difficult.

More quotes:

“My daughter goes into GCSE next year, we are at present trying to up the band funding for her EHCP's however this cannot be done without a updated Ed Psych report. The Ed Psych team in B&NES are so short staffed/overwhelmed with cases that they are currently closed to referrals for pupils who already have EHCP's. The impact of this is that funding will now not be in place as she starts GCSE and we are three months into a review upon increasing the BP budget money for tutoring which is now a shortfall of £5000.”

“The previous school didn't even try to understand and just said she had to go. Some staff even resorted to telling her they might lose their jobs if she didn't go in as they were responsible for her.”

“Head of SEN at (secondary) school telling daughter to 'leave her mental health issues at home'”

“Trying to get me to deregister my child and home educate her so it's no longer the school's responsibility and they don't have to report this as non attendance. Also the school trying to mark the attendance as unauthorised despite having a GP letter and a Consultant Community Paediatrician letter stating anxiety as reason for long term absence.”

“Nothing has helped during this time it all caused more trauma which is why we took daughter out of school”

“For schools to have more empathy and a better understanding of children who are undiagnosed and have school anxiety. Better understanding of autism and masking. School should stop treating absence like it's all the same and stop threatening parents with fines and this just piles in more stress for the family.”

What is the impact of the lack of support?

A number of parent carers expressed their frustration at the impact of time lost due to delays in accessing the right support.

“After being out of school for six months in 2018 my daughter was referred to the HERS at Broadlands. Had this support been more timely in intervention the co-issues that have grown up around EBSA would have been less extensive. By the time of one hour a week support I had already resigned my job as a deputy head teacher of 15 years in order to support my daughter. I know of many BANES parents who have done the same due to EBSA.”

“My child has been unable to attend school for over a year now. Gaining an EHCP seems to be the gateway to support but almost too late. We have a specialist school with a start date for April next year, my child is currently receiving Alternative provision since Feb. If my child was dealt with differently in the beginning I think things would have been different. For years it was just labelled as separation anxiety, we were repeatedly told he would grow out of it and he was fine once I had left. There needs to be more education to schools.”

Did a diagnosis make any difference ?

In terms of one of our original aims, to find out if there was a correlation between the advice and support given to children according to whether or not they had a diagnosis, we found no correlation.

Only 4 respondents to the survey had not talked with anyone at school; these were all from parents of children *with* a diagnosis.

Of parent carers of children *with* a diagnosis 8 said they hadn't been offered advice by the other organisations they contacted (schools plus others) compared to 13 who had been offered advice.

Of those *without* a diagnosis only 1 person said they had not been offered any advice: however, where helpful advice had been received this was generally from organisations other than the school.

When looking at parent carers of children *with a diagnosis* there were more 'not helpful' responses than 'yes, helpful'. As mentioned above, when looking at parent carers of *undiagnosed* children there were more positive responses, although these tended to be from organisations other than the school.

In terms of advice and how helpful or unhelpful it was, it was therefore difficult to draw any conclusions about whether having a diagnosis made any difference.

What changes do parent carers want to see ?

Parent carers were asked what they would like to see happen to make things easier. Responses were given by 21 parent carers and these are provided in full below.

Whilst these recommendations and requests from parent carers primarily relate to schools and the education system, the interconnectedness with healthcare is of course paramount to issues around EBSA.

This includes issues around diagnosis, training and awareness for teachers and school staff about anxiety and EBSA, the availability of mental health support for children and teenagers, and the impact on the well-being and health of the whole family due to the current shortfalls in responses to EBSA.

Regardless of whether children had a diagnosis or not there were many responses about wanting to see more awareness, understanding and support – from schools, GPs and also, with one response, from friends.

This included at the 'system level', for example, 'a better updated education system' and 'schools staffed and equipped to help' and at the 'front line' level of the individual school for example 'more practical support for child before they reached the stage of being too scared to attend' and for schools to be more flexible in their responses.

There were some specific comments about the need for support during the process of awaiting a diagnosis and that being left in 'limbo for 2+ years' was really difficult.

Parent carer responses are given below:

"More awareness and understanding and access to support. LA speed up with decisions!

GPs understanding that EBSA is real!"

"I would have liked some practical support to support my child to get to school before it got to the stage she was too scared to attend."

"Help for children who can't attend school without a diagnosis or at least during the process of gaining one as 2+ years in limbo without support is not good enough at all and creates more trauma for the children and families"

"As a member of the B&NES PCF I am part of the LA EBSA steering group. We provide EBSA workshops for parents. I would like to see this developed for staff in Schools who are at the front line of wanting to work with our young people."

"Schools to address the difficulties children have"

"I would like school to help with anxiety and general mental health"

"Mental health support for teenagers. CAMHS is so overwhelmed that unless your child is trying to kill themselves there is no support"

"For my daughter to feel like school has her back"

"Better understanding of how to support children with this issue"

"More support with schools who are very resistant in supporting your child; knowing what to do when the schools tries to off roll your child."

"A better updated education system that works for everyone. More respect and less fear of fines etc"

"More understanding from school and more support"

"Schools need to be staffed and equipped to help. My daughter desperately wants to be in school and wants to make friends but her anxiety and panic attacks stop her. There is no help available to reintegrate her slowly and effectively. She has been going in for an hour but is put in a room by herself and given a workbook. No set work or help to get her caught up with it."

"Absence to be recognised as authorised as it is for a genuine reason."

"Increase awareness at school More flexibility to ease anxiety Allowing reasonable adjustments"

"EBSA be a recognised issue and better intervention/support for child and parents before child falls out of school. Once child out of school, better HERS or other provision so child not just abandoned by education system"

"I'm not sure - I think it's about the school environment (who are being super helpful) but it's causing stress and anxiety"

"Educate all the healthcare professionals including school nurses, bladder and bowel nurses, Paediatricians and teachers about EBSA and burnout and ensure that they do not parent blame and try and force kids back into school as this is often the worst advice. My child needed time out to recover from school burnout and trauma. Empathy and compassion from them would have been helpful and assisting me with the sign off of my child rather than saying we cant do that."

"For schools to have more empathy and a better understanding of children who are undiagnosed and have school anxiety. Better understanding of autism and masking. School should stop treating

absence like it's all the same and stop threatening parents with fines and this just piles in more stress for the family.”

“More education to professionals about the effect it has on the whole family unit. Education to all staff that physically restraining children to stay at school actually causes more trauma. Maybe an specific advocate in banes that specialises in EBSA that can be activated early on to help access support for both child and parents. Remove the threat of fines, training to GPs on EBSA and how they can help support to access alternative provision. Also trying to access services like school nurse difficult when ur child attends a somerset school and you have an address in BANES as they were both unsure of who was responsible”

“Acceptance into CAHMS”

Next Steps

Healthwatch

- To distribute and present report to the Health and Well-being Board and appropriate forum of the Integrated Care Board.
- To publish the report on our website, and highlight in our social media channels

The Parent Carer Forum

- To distribute and present to the appropriate forum /board of the Integrated Care Board.
- To publish on the Parent Carer Forum website
- To share the report with the EBSA steering group for B&NES.

Joint action

We will jointly repeat the research in 18 months to see if parent carers are experiencing any improvements or changes.

Recommendations

1. All schools in BANES to take up the available EBSA training e.g. Horizons training & Parent Carer Forum training. This should include all staff and the level of take up be reported to the EBSA steering group.
2. Health professionals (GPs, school nurses, Health Visitors, specialist nurses, paediatricians) should access EBSA awareness training, and be aware of strategies to help.
3. At the transition between key stages schools should share information which specifically identifies EBSA, where this is relevant rather than sharing only low attendance. Linked to this it is recommended that all secondary schools ask the same question on this issue for ease of completion of forms by primary schools.
4. Clarity should be provided to parent carers whose children are educated 'out of county' about which local authority or agency they should communicate with for help and support around EBSA.
5. Schools should be aware of the support available to parent carers and signpost them appropriately to this support.
6. GPs should be aware of the support available to parent carers and signpost them appropriately to this support
7. Education and health providers should find ways to share examples of good practice so schools and GPs can learn from each other
8. More mental health support should be provided for teenagers especially, both in and outside school
9. More support should be available for children to help build their confidence and resilience for example, mentoring support, whether they are in alternative provision, or struggling to maintain attendance in school.

Appendices: Online Survey

Does your child struggle to attend school due to anxiety or mental health issues ?

A short survey by the Parent Carer Forum supported by Healthwatch Bath & NES to find out about the experiences of children with EBSA (Emotionally Based School Avoidance)

The survey is for parents of children with EBSA who are aged from 4 to 18 years.

If you have more than 1 child experiencing this please complete a separate survey for each child.

Healthwatch Bath & NES will help analyse the responses but no personal details will be shared with any other organisations.

The PCF and Healthwatch B&NES will write a report using the results of this survey to ensure that health services are aware of the issues raised and to ask that health services work with schools raise their awareness of EBSA and how absence from school is recorded in registers.

We intend to share the report with the EBSA working group, Health and Well-being Board, Children & Young People's Network and the Bath, Swindon and Wiltshire Integrated Care Board.

Thank you

Does your child struggle to attend school due to anxiety or mental health issues ?

1. Do you consider your child has special or additional needs ?

Yes

No

2. If 'yes' has your child had a diagnosis ?

Yes

No

3. If you are happy to share this diagnosis please add details below:

Your answer

4. How old is your child and which year group is your child currently in ?

Your answer

5. Does your child experience anxiety around school attendance ?

Yes - but they still attend

Yes - but they don't attend

Yes - they attend part time

Yes - they attend sporadically

Yes - they are voluntarily educated at home

Yes - they have an EOTAS package (Educated Other Than At School)

Unsure

6. Have you visited or spoken to your GP about this issue ?

Yes

No

7. Does your GP recognise or acknowledge EBSA as a condition ?

Yes

No

Unsure

8. If you did speak to your GP were you offered any advice ?

Yes

No

9. What was the advice you were given ?

Your answer

10. Was this advice helpful ?

Yes

No

Unsure

11. Was or has your child been signed off school due to this condition ?

Yes

No
I was not asking for them to be signed off school

12. Were you asked to pay for a certificate (to support your child's non- attendance at school) to be provided by the GP ?

Yes
No

13. Do you have any further comments about support from your GP for your child ?

Your answer

14. Have you talked with or consulted any other professional(s) about your child's anxiety around school attendance / EBSA ? Please tick all that apply.

- School nurse
- School teacher
- School manager or administrative staff
- Social worker
- Voluntary / community organisation support worker
- Other (please state below)

15. Please give details of any other professional organisations / people you have spoken with below

Your answer

16. Have they offered you any advice ?

Yes
No

What was this advice ?

Was it helpful ?

Your answer

18. Is there anything else you would like to see happen to make things easier ?

Your answer



19. Please let us know about anything else that has helped with your continued / on-going concerns ?

Your answer



20. Please let us know anything else that has not helped with continued /on-going concerns ?

Your answer



21. Would you be willing to join a face to face focus group or to answer some additional questions with a member of the PCF or Healthwatch to explore this further ?

Yes

No

Not sure

22. Please give either a telephone / mobile number or email address if you would like to have any further contact about this issue and/ or your or your child's experiences:

Thank you

Organisations to contact for help and advice

BANES Parent Carer Forum

[BanesPCF – Banes Parent Carer Forum](#)

www.banespcf.co.uk

Sendias

[Supporting children and young people with special educational needs and disabilities \(SEND\) | sendbathnes.gov.uk \(sendiasbathnes.org.uk\)](#)

www.sendiasbathnes.org.uk

SASS (Specialist Autism Support Service)

[Specialist Autism Support Service | Fosse Way School](#)

www.fossewayschool.co.uk/specialist-autism-support-service-2/

PDA society

[PDA Society – Pathological Demand Avoidance](#)

www.pdasociety.org.uk

National Autistic Society

[National Autistic Society \(autism.org.uk\)](http://autism.org.uk)

www.autism.org.uk

Southside

[Home page - Southside \(south-side.org.uk\)](http://south-side.org.uk)

www.south-side.org.uk

Youth Connect South West

[Youth Services | Youth Connect South West | Bath and North East Somerset](#)

www.youthconnectsouthwest.org.uk

TRC (Trauma Recovery Centre)

[Home | Trauma Recovery UK \(trc-uk.org\)](http://trc-uk.org)

www.trc-uk.org

Connecting Families

[Request early help or support for families with multiple needs | Bath and North East Somerset Council \(bathnes.gov.uk\)](#)

Square Peg / Not Fine in School

[not fine in school | squarepeg \(teamsquarepeg.org\)](#)

See also LiveWell site for additional resources and information, including Parent Partnership

[Livewell in Bath & North East Somerset \(bathnes.gov.uk\)](#)

www.livewell.bathnes.gov.uk



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