



Education, Health and Care Plans

FAMILIES EXPERIENCE



Somerset Parent Carer Forum
CIC Ltd



SUMMARY

This independent report has been prepared to provide a snapshot of the Education, Health and Care plan (EHCP) experience of families in Somerset.

The information in this report forms part of a presentation coproduced with SENDIAS and "The Unstoppables" which is available on our website.

The report evidences the experiences of families in particular, regarding:

- involvement of children, young people and their families
- the reviewing of the plan
- the child being reflected in the plan

Reflecting upon these recent experiences, we can see that all parts of the system need to make further improvements, to ensure all children with a plan have a positive experience.

"We do not learn from experience... We learn from reflecting on experience"

John Dewey





KEY FINDINGS

1. EHCP does not equal provision being made.
2. Children with EHCP's are sometimes on reduced hours, not attending an education setting or have been suspended.
3. Delays in the annual reviews of plans.
4. Plans not being updated following annual review when it was felt there was significant changes.
5. There are children with an EHCP who have no provision or are unable to move to a suitable provision (refusal by setting to accept).
6. Poor communication between parents and the SEND statutory team.
7. Parents purchasing private assessments due to access issues.





BACKGROUND



Somerset Parent Carer Forum CIC is an independent not for profit organisation led by parent carers. The forum has 2880 members which are families of children and young people with Special Educational Needs and/or Disabilities (SEND) aged 0-25.

The forum is recognised as the strategic partner for parent carer participation in Somerset by the Department for Education.

In December 2022 OFSTED and CQC revisited the local area and acknowledged that there has been progress in the provision of EHCP'S. Inspectors found that in some case having a plan did not equal provision being made.

The forum has heard from a lot of parents about their experience of the SEND system in Somerset and this report focuses on the Education Health and Care plan (EHCP) process.



METHODOLOGY

Our work with "The Unstoppables" and SENDIAS has identified that the experience in Somerset indicated that the EHC plan does not always reflect the current needs of the child or young person.

During the period of 24th April to 1st May we ran a poll to capture an up to date snap shot of local experiences. This was added to the experiences we have heard between January and April 2023 through groups, emails and calls.

- 69 people completed the poll
- 27 parent experiences were heard
- 25 hours spent discussing the topic
- Additionally we have heard lots of experiences via social media.

*All experiences have been anonymised to protect the identity of the families.





QUESTIONS

The following questions were asked as part of the poll.

1. Were you involved in the creation of the plan?
2. Were you involved in the review of the plan?
3. Has your plan been reviewed in the last 12 months?
4. Do you feel the plan reflects your child's current needs?

There was also an open ended text box for parents to share any relevant information. (Please see Appendix)





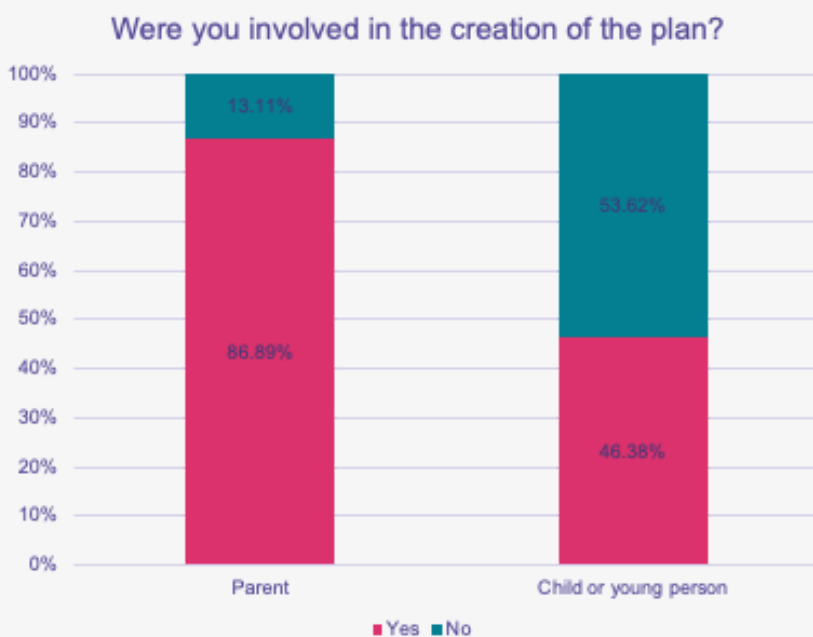
FINDINGS

Were you involved in the creation of the plan?

Legal Context

"Where a local authority is required to secure that an EHC plan is prepared for a child or young person, it must consult the child's parent or the young person about the content of the plan during the preparation of a draft of the plan."

Children and Families Act 2014 (38.1)



While it is encouraging to see a large percentage of parents (87%) reporting being involved in the creation of the plan, the quality of this involvement varied. Parents reported feeling ignored and a couple of parents reported meetings taking place despite them not being able to attend.

Several parents reported they were involved only once they had a solicitor involved or sourced independent reports.

"We were 'involved' only to be told that was what was going in the plan. All amendments were ignored. Facts that were inaccurate have been included in it and information from another child's EHCP were cut and paste where we told the case worker who failed to reply. We were sadly ignored and the draft went live with all the mistakes and gaps".

Parent Carer April 2023

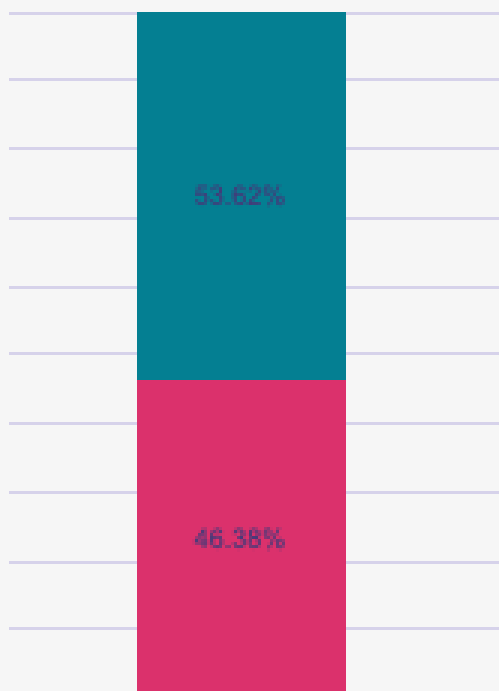


FINDINGS CONT...

Were you involved in the creation of the plan?

Legal Context

"Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously". UNCRC article 12



Child or young person

Less than 47% of children and young people were involved in the creation of their plan.

Feedback from "The Unstoppables" highlighted they are not consistently involved and they aren't always informed of the process:

- "I didn't know about it until we went to tribunal"
- "I didn't know about it until I moved into work life"

"In order to get an EHCP that reflected my child's needs, we had to go through appeal and nearly tribunal. The process was very detrimental to my child's mental health because of the way the LA handled it".



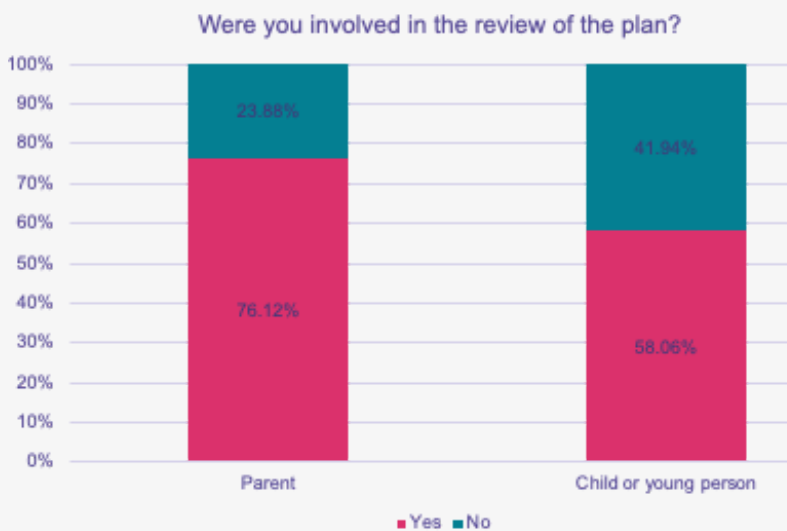
FINDINGS CONT...

Were you involved in the review of the plan?

Legal Context

"During a review or re-assessment, a local authority must consult the parent of the child, or the young person, for whom it maintains the EHC plan".

Children and Families Act 2014 (44.6)



Less parents reported being involved in the review of the plan (76%). More children/young people were involved (58%) compared to the original plan but this is still unacceptably low.

Parents reported spending time at reviews but feeling it was a pointless process, as plans were not updated.

Several comments were made regarding the lack of attendance by the statutory SEND team and felt this role had become an admin role.

"We did our review in July last year my son desperately needs to go to a sen school as current school cant meet his needs. We still haven't had the amendments done and it's now 9months later and its ridiculous."



FINDINGS CONT...

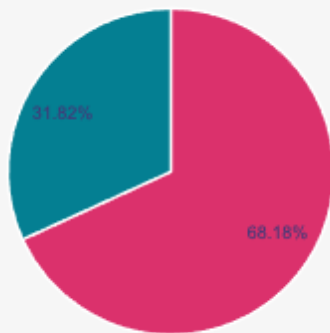
Has your plan been reviewed in the last 12 months?

Legal Context

"A local authority must review an EHC plan that it maintains—
(a) in the period of 12 months starting with the date on which the plan was first made, and
(b) in each subsequent period of 12 months starting with the date on which the plan was last reviewed under this section."

Children and Families Act 2014 (44.1)

Has your plan been reviewed in the last 12 months? Plans are not always being reviewed in line with the legal requirement of 12 monthly reviews (6 months under 5).



■ Yes ■ No

"AR was 5 weeks ago we still haven't received the annual review report plus all of us, including professionals, we're only given 3 working day's notice to write our reports which is totally unlawful as they must be shared 2 weeks in advance of the meeting".

Reviews that are taking place are not always following the statutory process and timescales are not being followed. There is a lack of awareness that the process is not just the meeting but involves various stages. Full timeline available at <https://councilfordisabledchildren.org.uk/about-us-0/networks/information-advice-and-support-programme/useful-resources-publications/what-0>

Lack of contact from the SEND team is a reoccurring theme, with parents reporting they do not know what is happening and feel they are left in limbo.



FINDINGS CONT...

Do you feel the plan reflects your child's current needs?

Guidance on implementing SEND legislation.

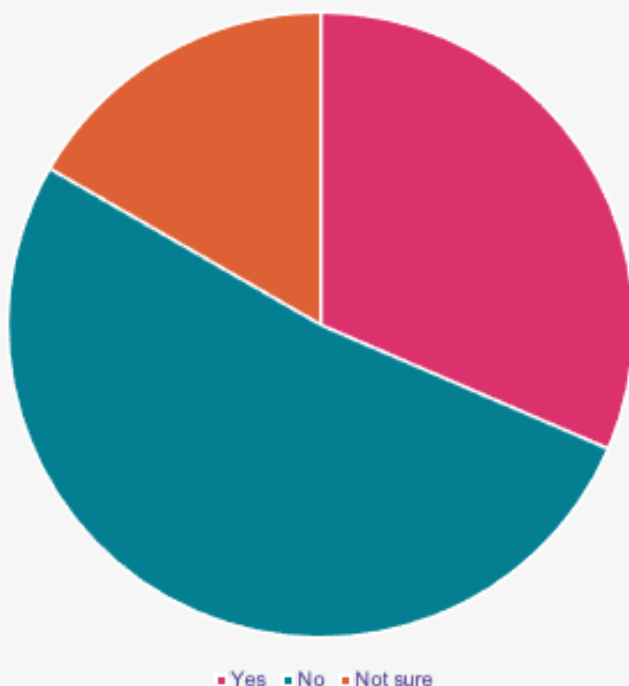
"This section applies to amendments to an existing EHC plan following a review, or at any other time a local authority proposes to amend an EHC plan other than as part of a re-assessment.

EHC plans are not expected to be amended on a very frequent basis. However, an EHC plan may need to be amended at other times where, for example, there are changes in health or social care provision resulting from minor or specific changes in the child or young person's circumstances, but where a full review or re-assessment is not necessary"

9.193

Relevant legislation: Sections 37 and 44 of the Children and Families Act 2014 and Regulations 22 and 28 of the SEND Regulations 2014

Do you feel the plan reflects your child's current needs?



Only 31% of parents felt sure that the plan reflects their child's needs.

Parents expressed significant concerns that plans were only updated at phase transfers and often relied on/included very outdated information.

Parents and young people reported reports as far back as primary being used to inform plans for college transitions.



FINDINGS CONT...

Do you feel the plan reflects your child's current needs?
cont..

"Moreover, for some children and young people who have an EHC plan, parents and carers continue to experience difficulty in securing the appropriate provision to meet needs. Consequently, there are still too many children and young people who do not receive the provision set out in their EHC plans."

Ofsted and CQC SEND Local area Inspection December 2022

Parents reflection on the impact of having an out of date plan

"We had our annual review and it was pointless as the LA have decided to amend nothing on my child's plan. His needs have dramatically changed and despite having professional reports from consultants, physio, SALT, OT, dieticians, continence team they still feel they know best and are working on a plan that doesn't reflect my child's needs."

"My child has been out of school on medical grounds since November 2022 and even though I have requested alternative provision it has been ignored and I have also requested a change of placement as my sons needs are too much for a mainstream school. Again this has been ignored."

"So this week I have mediation to request my sons ehcp get looked at again to add all the relevant changes into his plan such as his tube feeding which is very important, his physio requirements and his diagnosis. Then I have to go to tribunal to go through change of placement. It shouldn't be this difficult when the evidence is right in front of them. I have so much evidence explaining my child's needs. The review was done in October and it took them to the end of February just to tell me no changes were being made. By the time I get this sorted we will be on another annual review and more needs will be refused to be met."



MAIN THEMES

1. Having an EHCP does not equal provision being made.
2. Children with EHCP's are sometimes on reduced hours, not attending an education setting or have been suspended.
3. Delays in the annual reviews of plans.
4. Plans not being updated following annual review when it was felt there was significant changes.
5. There are children with an EHCP who have no provision or are unable to move to a suitable provision (refusal by setting to accept).
6. Poor communication between parents and the SEND statutory team.
7. Parents purchasing private assessments due to access issues.



CONCLUSION

We welcome the progress that has been made in some areas, for example more parents now reporting being involved in the EHCP process, but some areas still need further improvement.

For a plan to be effective it needs to reflect the child or young person, both their strengths and needs. This will never be achieved effectively without their involvement, so work needs to be done to ensure they are included in the review meetings held by education settings.

We need a system wide response to the heart breaking stories we heard of parents and children feeling settings have rejected them. This is impacting negatively on the mental health of the whole family.

While there are some signs of green shoots of hope for many families the experience is still poor. Therefore we have the following recommendations to help those green shoots grow.

RECOMMENDATIONS

1. Conversations need to start from a position of 'what can be done' to support a child or young person accessing an education setting rather than focusing on barriers.
2. Communication needs to be clearer around the EHCP process in particular:
 - what the annual review process involves
 - when would a member of the statutory SEND team attend a review
 - what do we mean by a significant change in circumstances which would require a change to the plan (COP 9.193)
 - how to manage circumstances when minor changes may be required to a plan
 - what a family should do if provision is not being made in a plan
3. A plan is put into place to look at older plans to ensure they accurately reflect the child's needs
4. To improve communication, implement a system of dedicated time each week when calls can happen, so parents know when they can talk to someone rather than waiting on call backs.



APPENDIX

The following comments were collected during the poll from parent carers in Somerset. These have not be altered with the exception of removing information which could identify the child.

- Not received final plan yet, draft given 2/02/23 this has been going on for 27 weeks now
- The process is arduous and requires careful preparation planning and thought. It seems unfair to families who may not have the same time and resources.
- Been waiting since 10th Feb for annual review son only gets 1hr tutor an 2 hrs REACH provision a week and is in yr10 with no prospect of sitting any exams having not been in school for 3.5 years
- Statutory deadlines not met by LA, leaving children without the support they need. My son's latest review was nearly a year ago and still do not have a final EHCP in place. To get correct services funded, parents often need to go through expensive tribunal processes. Professional reports ignored. No appreciation that early intervention saves money in the long run. Children not put at the heart of the process. The SEND team at the LA is chronically understaffed, under resourced and underfunded. This seems to be the underlying cause of the difficulties outlined and faced. Vulnerable children are being let down: not receiving the support they need in a timely manner (or at all) impacting their ability to learn, impacting their life chances, impacting social mobility.
- He needs more one to one school is not fulfilling the echp at all
- Plan amended due to transition but all parts weren't updated. Medical side is deemed unimportant as its for education. (La told me this) provision sentences were removed weren't explained why and were not replaced with equal specific information. (On questioning LA I was told its no longer in plans and its not specific enough and said reading the plan it suggests what's needed so it's fine!)
- Only a year into our plan. All ok so far.



- The school are not following the plan, xxx school are meant to be involved for six weeks it's not happening. The plan was in draft for months, la names school even though they said they couldn't meet needs to me and that my son needed specialist provision. Communication was terrible throughout the whole process.
- Send continue to act illegally and out of time scales. The La reports break professional codes and are written for the benefit of the LA and not the child. The plans are illegals with words that don't mean anything and make it impossible for the child to get the provision they need. The stress involved to parents is intolerable. The COMS process is illegal It's a s*** show
- Once again, the LA failed to meet the timeline set by law. We are now in the position that we have to pay for a solicitor to chase them for our son's EHCP review amendment. Our son is transitioning to college in September, and we don't know if our and his preferred placement will be named, or we will have to go to tribunal again. LA doesn't care about the mental health toll and the work disruption, the impact on our lives and the challenges we have to face every day. They just act unlawfully repeatedly, and they do not get any consequences for it.
- We have not received the plan although by law it was due on 31st March 2023. The LA are completely and utterly useless and have broken the law as regards the time scale. The LA needs to get their act together as the young person or child is left stressed, anxious and without knowing where their placement will be. The parents are also affected and have high levels of stress and anxiety. It is difficult enough to raise a child/young person with SEN without having to deal with the utter incompetence of the LA.
- I cannot understand how the LA can name a placement in a legally binding contract when that placement hasn't agreed to even take them. If this isn't amended ASAP then it will have a detrimental effect on my son, and I envisage school /college refusal again after years and years of building up his confidence to be able to attend a school setting.



- The EHCP is not fit for purpose. This is largely due to the LA not agreeing to my requests for assessments - not diagnoses, as they fed back to me (I didn't need those as I had them already!). As a result, the EHCP only mentioned my child's ASD diagnosis despite the Paediatrician also diagnosing Sensory Processing Differences, a Demand Avoidant Profile (PDA), and severe anxiety. The Ed Psych wasn't allowed to mention the SPD nor PDA, even though it had been mentioned in health reports because the ARO wouldn't allow her to (she was a Trainee!). In addition, the Consults to schools took 3 rounds over the course of 8 weeks, I suppose because they kept hoping for a change of response ... they didn't get one - each school, primary, secondary (our child is in Yr6 - was in Yr5 when this started), specialist, and mainstream with an ASD base all were unable to meet our child's needs for varying reasons! However, the LA clearly know best and subsequently had a Section F call with the SENCO of the secondary school who immediately changed their response to a one-liner if 'we can meet needs'! Needless to say, we are appealing the content and placement of the EHCP. Our hearing is very soon. My evidence is over 800 pages, compared to less than 50 from the LA. The evidence proves from professionals what I've been saying for years. Besides the above we now have further diagnoses including dyspraxia, dysgraphia, severe anxiety and is socially isolated and now school refusing
- The whole system is a failure to our children
- AR was 5 weeks ago we still haven't received the annual review report plus all of us, including professionals, we're only given 3 working days' notice to write our reports which is totally unlawful as they must be shared 2 weeks in advance of the meeting. There is a significant & severe lack of training in the SEN team...this happened last year too, I formally complained, they apologised & then did exactly the same this year...our SEN children with severe learning difficulties learn & remember more than the SEN team do!!!!
- Getting the plan was an outright nightmare and has caused PTSD - fighting the LA tooth and nail for support should not be on the child's or parental to-do list!!



- We were 'involved' only to be told that was what was going in the plan. All amendments were ignored. Facts that were inaccurate have been included in it and information from another child's EHCP were cut and paste where we told the case worker who failed to reply. We were sadly ignored, and the draft went live with all the mistakes and gaps. The EHCP set my child up to fail which then happened where he has gone from School to School and now is at home with no support. We have not had an EHCP review for well over 2 years.
- Everything about the SEND department is catastrophically impacting all disabled and SEN children in Somerset. FULL STOP. You do not meet deadlines, you deny need, you ask for unlawful criteria to be met, you ghost parents, there is no excuse for the gaslighting and deception that occurs. You have had plenty of surveys, stop asking and start doing something about the appalling situation, TODAY. You are destroying children and parents and families. It is not acceptable on any level. The department needs a complete overhaul if you want things to change, too many bad apples employed. Ask yourselves why parents always win at tribunal or the few days before when you cave, it is because the parents were right in the first place. Every time. Stop hiding behind funding issues, start asking central government for more money. People lose their lives because of your priorities being completely misplaced. Please, as a mother who nearly lost her children, please start doing it well. It is simply vile how you exploit people and do not support the most vulnerable in your community. If the councillors do not understand the system, stop being hoodwinked into believing the staff, they are lying to you. Start opening your eyes and ears and start listening to parents.
- Annual review overdue by 6 months both times. After meeting eventually held in December, no contact or updates since! (4 weeks statutory time scale!!)



- I have had to drive everything and feel exhausted by it. I found colleges and applied to them, I chased and chased and demanded a caseworker, I diarised aftr annual review and chased, and chasd and chased. I demanded meetings with caseworkrs to have post 18 college application processes explained to me. I was promised someone at annual review. Nobody came from LA. I have almost fortnightly followed up and it is only because of this my daughter is likely to have a college place. I feel very lucky but so scared for so many families and young people as the annual review process seems totally broken but is absolutely critical for youngsters with really complex needs getting support from multiple different social, health, therapies and educational agencies. The SEND caseworker role seems to have been reduced to basic admin so they are just typing things in boxes, with no knowledge of the young people, the provisions, needs, or anything, so it feels as if you are held up for interminable amounts of time because of a lack of admin . There still is not enough gathering of health and social information - no details of direct payment and respite packages included on ehcp even though we are in receipt of them - not until I pushed and said it had to go on.
- I'm having a great experience because my child goes to an amazing specialist school. The LA have been useless throughout. It took nearly 2 years to get the EHCP and I had to pay for real professionals to do the LAs job for them. The LA have never shown up for a review meeting. Not once.
- In order to get an EHCP that reflected my child's needs, we had to go through appeal and nearly tribunal. The process was very detrimental to my child's mental health because of the way the LA handled it.
- Our last review was December and we still don't have a finalised plan, 5 months later, so not able to answer above questions. Consulting with schools it's been 25 days since consults went out and me and my son are asking for continuation of EOTAS provision. All statutory guidelines for timescales are being ignored, my son is in transition year, and we've had 4 case workers in the last 5 months! All whilst annual review process happening, and we are still in draft!



- We did our review in July last year my son desperately needs to go to a SEN school as current school can't meet his needs. We still haven't had the amendments done and it's now 9 months later and it's ridiculous.
- Content being removed to try and get student to fit the requirements of a mainstream FE setting. Transport refused. No final plan yet.. deadline end of March has passed. Student needed tutors all last year. School and parents ignored. Horrendous trial to get anyone to respond in less than two weeks as time ticks towards exams and the breakdown of another SEN student. Much needs to be addressed with the system.
- Would be nice if I had been given help to do a plan
- Plan got finalised without my consent, whilst I was on the phone to the caseworker one of her colleagues finalised it as a "favour" plan is not specific or quantified enough according to my son's next placement.
- My son's plan was very out of date when he transitioned to college, and I had to pay for a private EP to do a review. They wanted to keep documents from primary school in the plan when no longer relevant. His plan has only ever been updated when he transferred placement making it very difficult for settings to know what should be provided.
- Still waiting for updates but waste of time as needs have never been met
- Somerset LA don't accept any changes between key stages which, to me, makes no sense. Any agency getting involved with our son for the first time. Annoy rely on his EHCP for accurate up to date information about him, his needs, what he likes doing which - surely - was the point of this document. The review is a literal tick box exercise which is a waste of everyone's time.
- Our EHCP only reflects my child's needs after spending thousands of pounds on private experts to assess my child thoroughly over a few days. Plus using and paying for solicitors and advocate charities to help us keep the LA within the law and keep the EHCP focused on the child's needs not cost cutting.



- Plans state child's needs can be met in a mainstream school, they did not include the OT or physio reports as child is now home educated, not given any information or option for eotas or advice regarding applying for personal budgets.
- Had an AR May 2022 still have not received updated finalised plan. Letter received today apologising for delay and should have an allocated worker by June 2023. School have just completed another review. Question how long this will take to be finalised. This is a constant saga. My child has had a statement/EHCP for many years and feel the process and support has become more and more lacking. "My child can only complete this journey once. It's a very important journey. Getting it wrong can have a very long-term negative affect." The difficulties around the constant failures of the LA to implement, support and follow the EHCP Process and the support the needs of my child have had a big impact of my health and mental wellbeing.
- Common sense requires a professional report which is frankly ridiculous imo especially since educational psychologists are as available as rocking horse poo. My son needs a specialist placement asap, but the LA are happy for a vague & useless plan to be used for consultation which fails my son and does not show schools what needs he has in full. As ever, disappointed and a rather pissed off with this excuse for a SEN hub and LA.
- Really torturous process for both children (both have EHCPs), hard to describe in short but Local Government Ombudsman ruling against Somerset for both boys with significant compensation spanning 3 years. Failure to meet any legal timelines, failure to act on annual review when mainstream school said they couldn't meet need in Year 10. One child with no education at all for 3 years, the other during GCSES with no education for 14 months. Still fighting now. Whole system is combative and unsupportive. Have to fight them on every single decision they make. Currently going to tribunal for one and have a formal complaint in for discrimination under the Equalities Act. Shambolic.



- The school have been excellent, sadly Somerset Council's SEND services are horrendous and not fit for purpose. To hear that in the recent reshuffle no one was relieved of their duties in this department, simply sums up Somerset.
- My son has been denied an assessment of needs. Despite the threshold for both parts being 'may have/may need' and having clear evidence of SEN and school saying they cannot meet his needs in mediation. The LA still refuse to do the assessment. Parents win at tribunal 94% of the time according to Sendias. So clearly the panel are making the wrong decisions 94% of the time. This doesn't fill me with confidence for the rest of the process. I also have an 11-year-old who isn't able to attend school. Is not getting any AP and no formal mental health support despite having EBSA for 5 years and trying to end his life in Dec 22. The whole system is shocking!!!
- County completely disregard timescales and mandatory regulations. They're full of excuses.
- When early annual reviews are called due to a change of needs, there is often no support from county or the SEND team. Parents are left having the same conversations with schools who are already struggling and have no further suggestions or feel that they are already meeting the requirements of the existing EHCP and are unwilling or unable to do more and as such there is no progress.
- Children left with no education or alternative provision for months. Timescales not being kept. Not returning phone calls.
- I think that having a ehcp means nothing tbh my child nearly had one for a whole year and out of school for 4 years and still not in school no support



- We had our annual review, and it was pointless as the LA have decided to amend nothing on my child's plan. His needs have dramatically changed and despite having professional reports from consultants, physio, SALT, OT, dieticians, continence team they still feel they know best and are working on a plan that doesn't reflect my child's needs. My child has been out of school on medical grounds since November 2022 and even though I have requested alternative provision it has been ignored and I have also requested a change of placement as my sons' needs are too much for a mainstream school. Again, this has been ignored. So, this week I have mediation to request my sons ehcp get looked at again to add all the relevant changes into his plan such as his tube feeding which is very important, his physio requirements and his diagnosis. Then I have to go to tribunal to go through change of placement. It shouldn't be this difficult when the evidence is right in front of them. I have so much evidence explaining my child's needs. The review was done in October and it took them to the end of February just to tell me no changes were being made. By the time I get this sorted we will be on another annual review and more needs will be refused to be met
- The application process is an absolute disgrace. Refusals to assess when the school are clearly stating the child needs extra support. Not even contacting the parent or school in the case of my child! Not carrying out necessary assessments including involving SALT or OT even though current reports indicate these assessments are needed for the child. And EP reports are not complete and lawful not including outcomes and provision in full. The standard of ehcp produced from the process is incredibly poor and set to fail the child. With an 80% + appeal success rate for parents the LA need to look at what a poor job they are doing to end up with so many lost tribunals. Also, the complete lack of provision for children out of school during this process is a disgrace! SEND parents should not have to fight this hard to get their child the education they are legally entitled to. The child is not at the centre of this process!

.



Somerset Parent Carer Forum C.I.C

May 2023
