



# **SNAP PARENT CARER FORUM**

CENTRAL BEDFORDSHIRE

## Summer 2024 Test the Temperature Survey Report



**August 2024**

## **Introduction**

### **SNAP PCF – our role.**

SNAP (Special Needs Action Panel) is a proactive, independent forum of parent carers who all have children and young people with Special Educational Needs and/or Disabilities (SEND). As members of the National Network of Parent Carer Forums (NNPCF), we support the development of parent carer participation, a process in which parents work together with education, health, and social care professionals to improve local services.

SNAP Parent Carer Forum (PCF) is a conduit for various local professionals in our work with children and young people with SEND. Our purpose is to improve the services provided for children and young people aged from 0-25 years. We have a support and challenge role and are critical friends to Central Bedfordshire Council Children Services and local health services, including the BMLK ICB. Please see our [Partnership Agreement](#) for further information about how we coproduce our work.

### **Test the Temperature – Spring and Autumn Term 2023 survey.**

The aim of our 'Test the Temperature' survey is to monitor how parent carer experience of the Education Health and Care Plan (EHCP) process has changed from collecting data in our surveys in November 2020, March 2022, June 2023, December 2023, and August 2024 and to measure any progress with Annual Reviews to EHC plans between June – August 2024. We also checked parental satisfaction with education, health, and social care services.

This report reflects the voices of 297 parent carers who live within Central Bedfordshire; we added an additional question to the survey asking parents to confirm they live in Central Bedfordshire, and 100% confirmed they did. The Parent Carers told us about their experiences with the EHCP process during 2024, particularly focusing on satisfaction levels with their child's EHCP Annual Review and their experience communicating with the EHC Team. Responses to our 'Test the Temperature' survey were collected from the 12th of June 2024 to the 4th of August 2024.

This 2024 survey now provides us with four years of data and feedback. This is important because Central Bedfordshire Council (CBC) and the Bedfordshire, Luton, Milton Keynes Integrated Care Board (BLMK - ICB) implemented an Accelerated Progress Plan after the revisit of OFSTED and the Care Quality Commission (CQC) in July 2022.

During this revisit, inspectors determined although there had been improvements in all six areas of significant weakness identified in the 2019 full SEND Inspection, that there had not been sufficient improvement made regarding their Written Statement of Action (WSOA) in the following three areas:

- Ensuring that the needs of children and young people are identified and met in their EHCPs.
- Improving the quality of new EHCPs
- Delivering good outcomes for children and young people with SEND

Further information can be found on the [Local Offer Website](#).

### **Executive summary**

The SNAP PCF Steering Group has reviewed the survey data collected in June/August 2024 and compared it to previous 'Test the Temperature' surveys. It is disappointing that the data indicates an overall and continuing decline in the satisfaction levels of parent carers with the Education Health Care Plan (EHCP) process and in their communication with the EHC Team over these four years.

We have continually raised that the need to increase EHCPs to be finalised by 20 weeks as part of the Accelerated Progress Plan is impacting the quality of the plans and parental satisfaction, as

parents tell us that their plans are finalised even if the parent would like additional time to get it right.

## Overall satisfaction of the EHCP process and communication with the EHC Team

To test parent's overall satisfaction of the EHCP process and communication with the SEND Team, we asked the following questions:

*How would you describe your overall experience of the EHCP Process?*

Overall satisfaction rate: 27% July 2024

Overall satisfaction rate: 24% November 2023

*How well have the Central Bedfordshire Council EHC Team communicated with you and kept you up to date with your Child's/Young Person's EHCP?*

Overall satisfaction rate: 29% July 2024

Overall satisfaction rate: 26% November 2023

*To what extent have you felt listened to by the Central Bedfordshire Council EHC Team?*

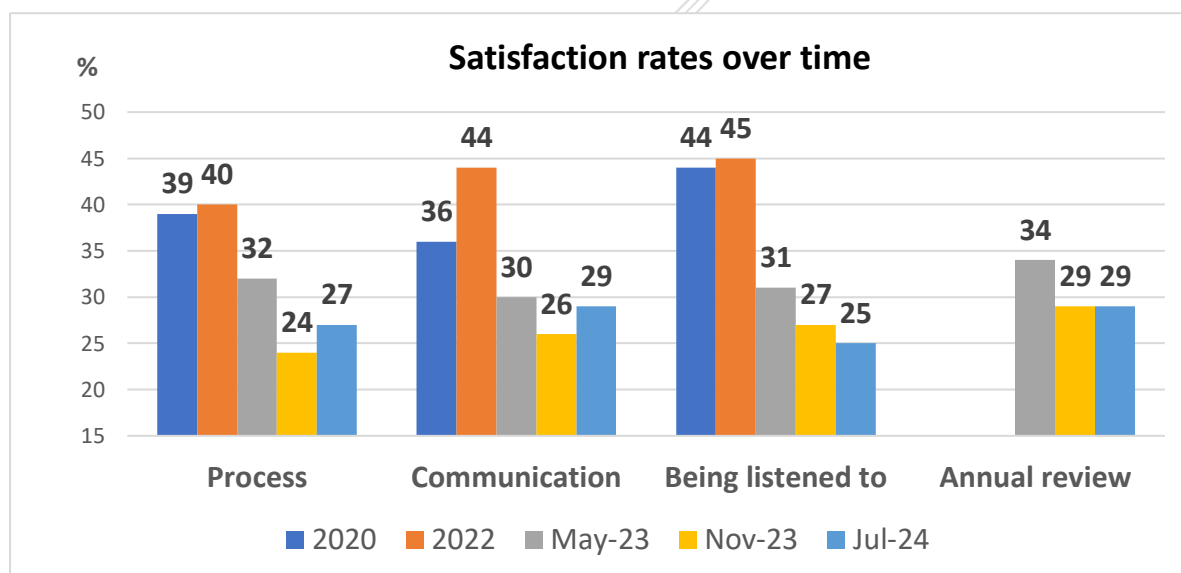
Overall satisfaction rate: 25% July 2024

Overall satisfaction rate: 27% November 2023

*Were you satisfied with the Annual Review process when this was last completed?*

Overall satisfaction rate: 29% July 2024

Overall satisfaction rate: 29% November 2023



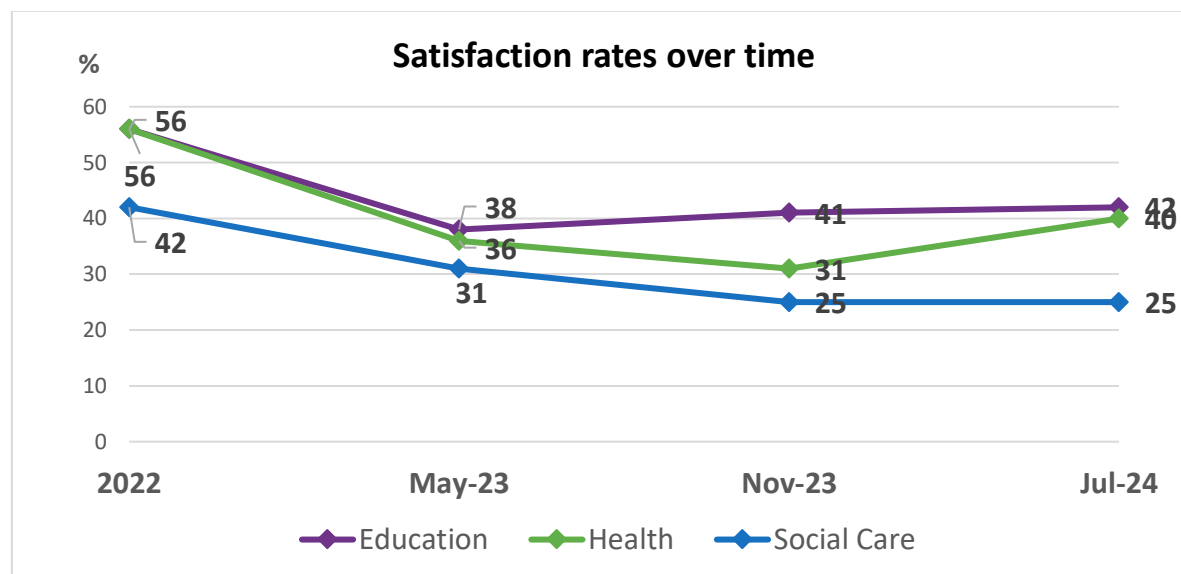
Base: 2020 n=636; 2022 n=498; May 2023 n=537; Nov 2023 n=225; July 2024 n=297

A minority of parents we surveyed told us they are satisfied with the EHCP process and EHC team communication. This summer's satisfaction scores are similar to those from the previous two surveys (going back to May 2003) from the perspective of parent carers responding to this survey, the indication being that satisfaction hasn't tangibly improved over the past year.

## Satisfaction with Education, Health, and Social Care services

We also tested parent's overall satisfaction with Education, Health, and Social Care services for their child by asking the following question (This question has been included since November 2022):

*How do you feel the 3 main areas of Health, Education and Social Care are currently supporting your child/young person with Special Educational Needs in Central Bedfordshire?*



Base: 2022 n=498; May 2023 n=537; Nov 2023 n=225; July 2024 n=297

Satisfaction with Social Care continues to be low. It is difficult to conclude why this is and whether the survey feedback is about Early Help or the Children with Disability (CWD) Team. We know many parents want a CWD social worker but do not meet the criteria, which causes further upset to parent carers, we discuss this more later in the report. Satisfaction for education and health is better but needs to be higher. The improved satisfaction for health services since Autumn 2023 is noteworthy and may be due to the work we have done together with Bedfordshire Community Health Services discussed further in this report.

## Test the Temperature, July 2024 – Main Report

This report sets out the experiences of the parent carers who completed our Summer 'Test the Temperature' survey.

In Autumn 2023, we changed the way we analysed this survey data by 'coding' the open-text responses into themes. For this report, we have analysed the data in the same way. This has allowed us to quantify the thoughts and feelings expressed by parent carers, creating an as objective analysis of the issues as possible.

As part of our analysis, we also looked at the data by the age of child or young person. We didn't find any statistically significant differences in satisfaction levels by age of the child or young person, although this would always be difficult with the sample sizes we are working with. Statistical tests aside, the indication is that satisfaction levels across the EHCP process do drop off with the age of child or young person. This could be due to the options and specific needs of the children becoming more complex with age but could also be due to parent carers becoming more aware over time of what the level of service should be.

We have also included our Steering Groups reflections and recommendations for Central Bedfordshire Council and our health services to consider.

Here are a few quotes from parent carers that capture the main findings from the Autumn temperature check:

"Phase transfer overlooked. No sense of urgency to rectify this"

"I have always been very lucky with annual reviews; this year has been very poor"

"Failed to complete, failed to process, failed to get it right"

"Still waiting for amendments to be done which was agreed in October, phone up and email and nobody is interested"

## What parents told us

"The fight to get the EHCP in the first place was stressful and exhausting. It's not so bad now that the contents were rewritten following a tribunal hearing"

"What's the point of time scales. Why are the reports still not quantified and require chasing?"

"I applied as a parent and had no problems"

"I feel isolated and alone in a battlefield I never chose to be in."

## Detailed Analysis

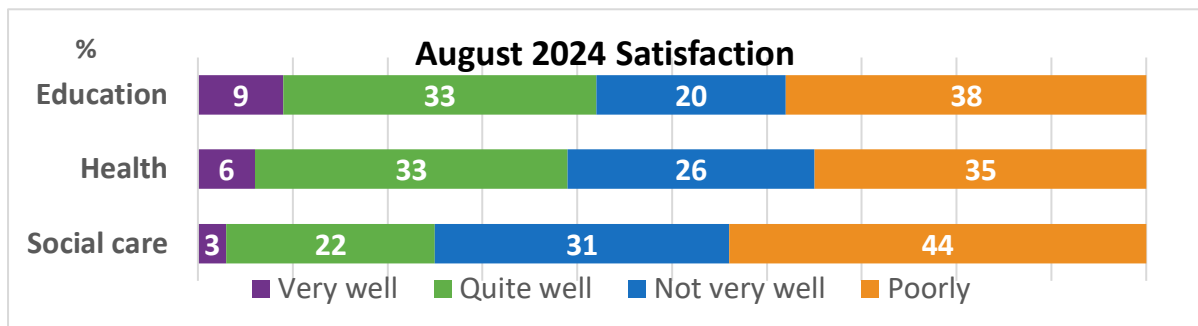
### Response Breakdown

Of the 297 parent carers who responded to the survey, 295 shared the age of their young person(s): 17 0–4-year-olds; 120 4–10-year-olds; 162 11–17-year-olds and 25 18–25-year-olds.

Of the 297 responses 133 came via SNAP PCF; 56 from links on social media and 56 from other sources (52 respondents didn't answer this question).

## Satisfaction with broader service provision for children & young people with SEND

How do you feel the 3 main areas of education, health and social care are currently supporting your child/young person with Special Educational Needs in Central Bedfordshire?

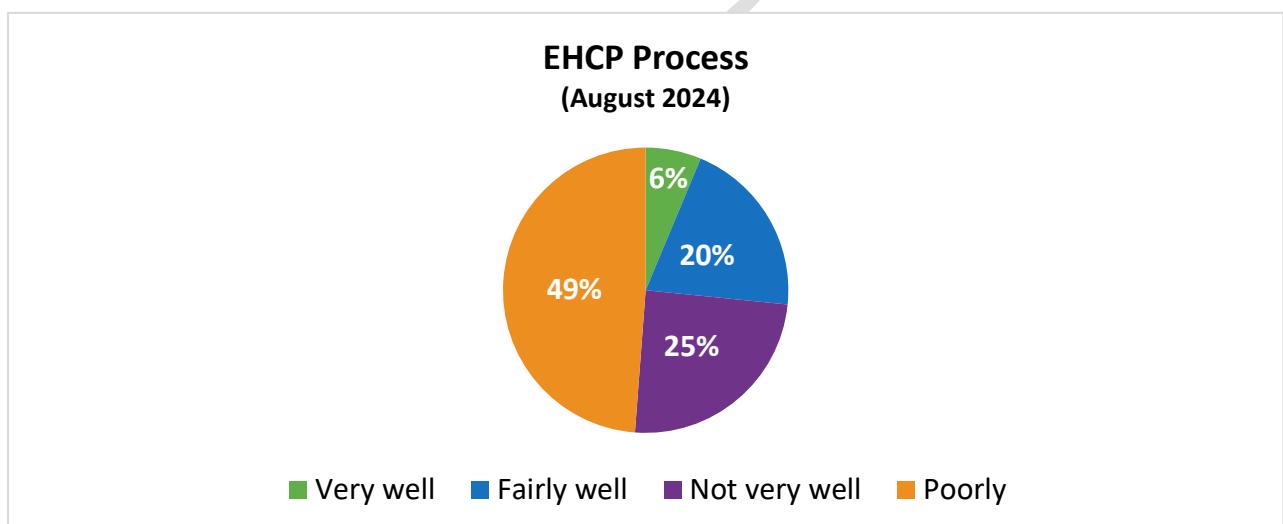


Base: Education n=292; Health n=278; Social Care n=202

Significant proportions of parent carers rated all three services as poor with Social Care coming off worst.

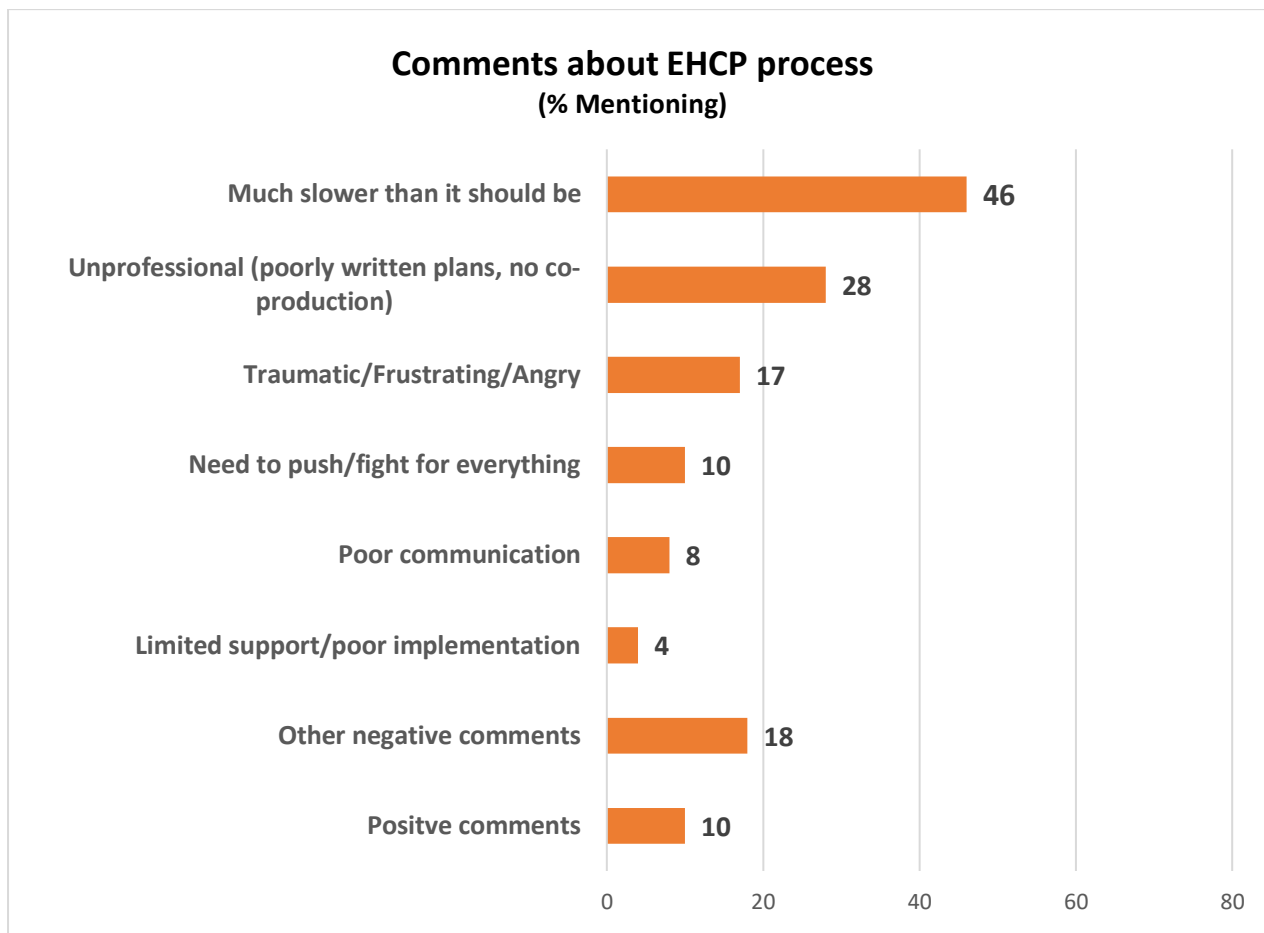
## Satisfaction with the EHCP Process

How would you describe your overall experience of the Education, Health & Care Plan Process?



Base: n=256

74% rated their **experience of the EHCP process** as 'not very well' or 'poorly'.  
Reasons for poor satisfaction with the **EHCP process** are shown in the chart below.



Base: N=145 comments

As we found last autumn, the key issue raised is around the speed of the process and this is with respect to the initial assessment, the creation of the plan itself and subsequent reviews. A handful of parent carers feel the process is deliberately complex and designed to be slow.

*"Still waiting for an EHCP review from February to be done and still waiting for a final copy of a renewed EHCP that got accepted Nov 23!"*

*"It has been long winded for no reason, unnecessary push back from the LA. I've been passed around different team members with long response waiting periods. Which has caused my son to miss nearly all of year 2."*

*"Shrouded in mystery!! Seems complex with intention of confusing parents/carers."*

*"Took a long time to get it initially then review was completed in time, but not finalised for 6 months. I wasn't aware of the processes that should have happened and trusted the process. I have now equipped myself and am fully prepared for the next review."*

In Autumn 2023 the second biggest issue was around the feeling that you must push and fight for everything. This issue was mentioned less this summer and this time there were many more comments about Central Bedfordshire Council being unprofessional in the way they deliver the service. This included issues around poorly written plans, incorrect or missing information and inconsistencies between staff members.

*"6 weeks to advise me they couldn't open the file type of an attachment. On my initial email with consent to share info attached after acceptance. 6 weeks!!!"*

*"So many mistakes six months on from annual review."*

*"The fight to get the EHCP in the first place was stressful and exhausting. It's not so bad now that the contents were rewritten following a tribunal hearing."*

**Poor communication around the process is also evident in many of the comments. This is with regards to a lack of communication from the EHC team and the EHC team not responding to queries. More on this in the next section on Communication.**

*"Lots of chasing on our part and very little response/slow communication from CBC."*

*"Slow moving, lack of communication, dictatorial approach to parents."*

*"I think it was ok and then other parents say did they do that and where was that bit and did you know etc and then I feel I've let my child down as I've not asked the right questions or known the right thing and I feel fobbed off. If you don't know what they should be doing, I feel they take advantage of that. So, I thought they had communicated well with me and now I realise they didn't."*

*"It feels like a two-tier system, those parents they can get things by as they don't know all the law and are happy, they got an EHCP and those that do get a better service. Comparing my child's EHCP with more experienced parents' ones I feel so let down, they haven't listened to my child's needs or what I was saying to them, they have given us the bare minimum and it doesn't meet their needs at all, and I feel I have failed them, why Didn't I know what the EP should have been doing? Why do I have to become an expert on the law to get my child what they are entitled to? They should be listening to me and doing their job not me having to do learn it and do it for them."*

**We have been also seeing more evidence of the negative emotional impact of the process on parent carers, with talk of frustration and anger.**

*"Frustrating."*

*"Horrendous."*

*"Shocking."*

*"I feel isolated and alone in a battlefield I never chose to be in."*

*"The fight to get the EHCP in the first place was stressful and exhausting."*

**There were some positive comments though.**

*"We are very lucky that my son's school are really on the ball with supporting parents and children through the process."*

*"Process was more straightforward than I expected."*

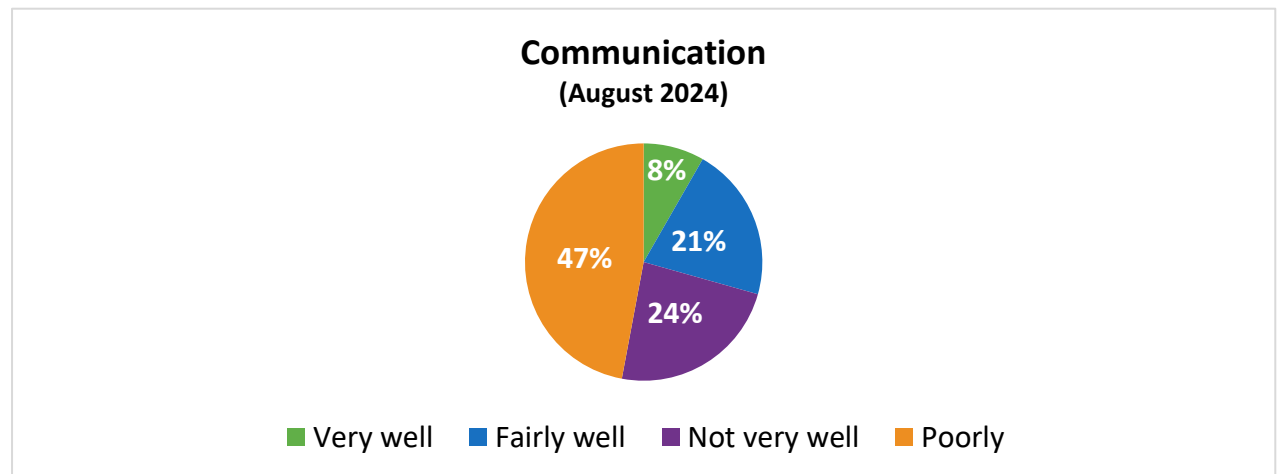
*"It feels like such a pressurised process. However, the team seems to be running to proper deadlines at the moment."*

*"Family partners within the children with disabilities team have been great."*

*"Family partner has been very helpful, adult services officer has also been helpful"*

## Satisfaction with Communication

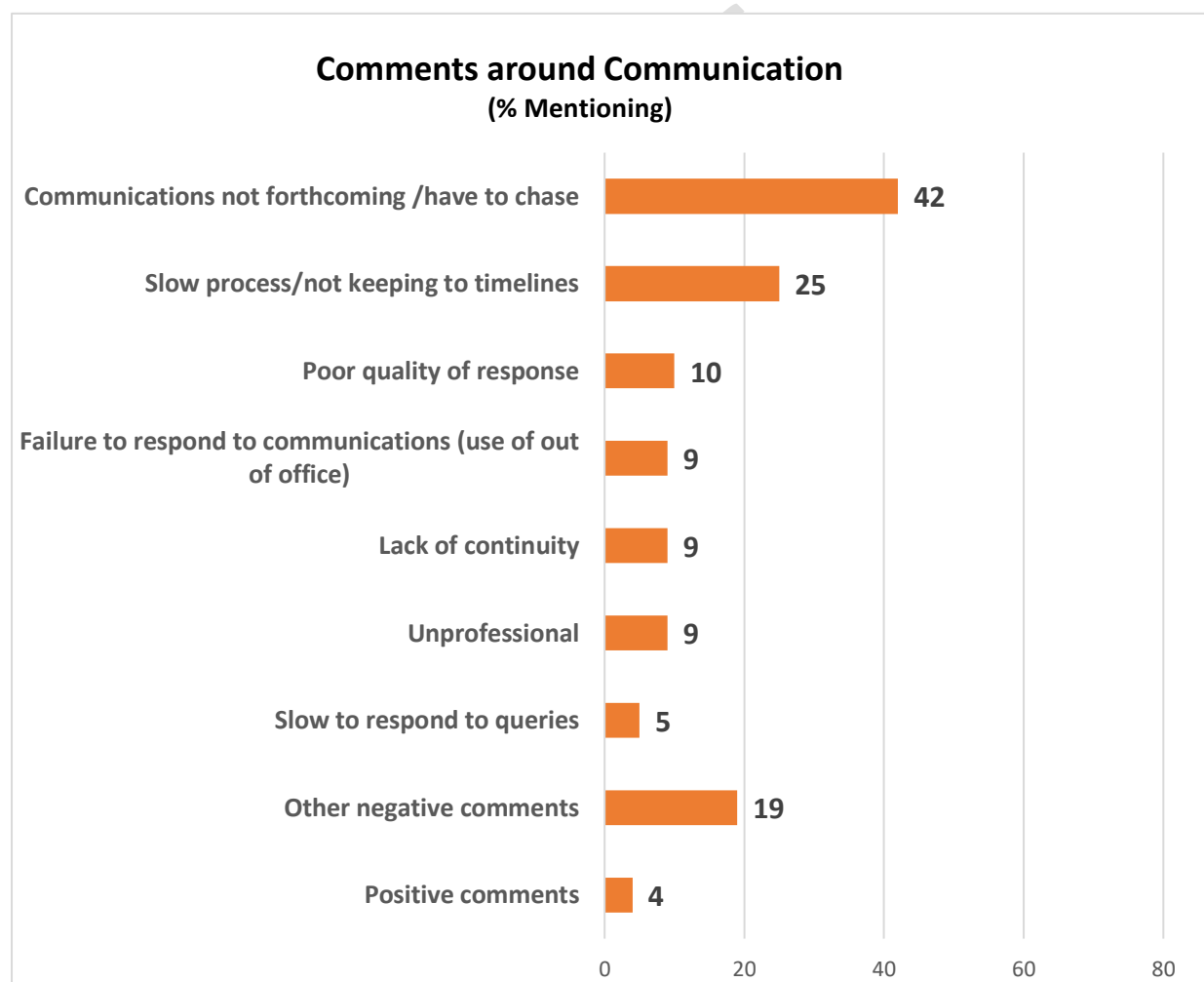
How well have Central Bedfordshire Council Education, Health & Care Plan Team communicated with you and kept you up to date with your child's/young person's Education, Health & Care Plan?



Base: n=242

71% rated **Communication** as 'not very well' or 'poorly'.

Reasons for this poor satisfaction with **communication** are shown in the chart below.



Base: N=111 comments

The key issue around communication continues to be 'a lack of it'. Almost half parent carers commenting on communication talked about it not being forthcoming and having to chase to find out what was happening with their 'case'. There is a sense from the comments that if you don't chase then you will hear nothing. As we mentioned in the Autumn report, there is clearly an expectation from parent carers that there should be updates on what's happening with their 'case', even if nothing substantial is happening.

*"Very one sided with us doing the chasing."*

*"We have to chase and chase. They never answer the phone. When they do reply they send an email which never answers the questions being asked."*

*"No communication at all. Ever!!!"*

*"Had to chase final EHCP several times during a school transition period as it wasn't sent to new school. Only to be told your key worker is on leave she will deal with when she returns in 2 weeks!"*

*"Constantly having to chase. The team probably mean well but there is not enough of them, or they don't prioritise well, or it's managed badly as it's a battle to get anything done."*

**Not keeping to timelines (and general slowness of process) comes through as a big issue this time, more so than in Autumn 2023. This just serves to frustrate parent carers and underpins a lack of faith in the process/service overall.**

*"Annual review has not been chased by the SEND team! 15 months overdue!"*

*"Constantly missing deadlines. It's almost a full-time job chasing CBC staff to reply."*

*"Can take a long time to receive communication. Not always in the time frame given."*

*"Do not commit to dates or manage expectations."*

*"Months behind statutory deadlines Unanswered emails Weeks of no communication Multiple staff changes and no information and because so many staff changes, they are constantly on annual leave (or feels like it) No contact updates from senior management even just an acknowledgment Lack of information Lack of personability."*

**Poor quality of responses, slow responses to queries or just failing to respond, also get significant mentions.**

*"To be fair to our send officer she does always respond to queries. They aren't always helpful answers though!"*

*"I have had to repeatedly chase. Answers are not given to my direct questions."*

*"Incorrect advice, send officers covering for each other, refusing to answer basic questions like if a child is in y5 when should the transfer review be done."*

**As found in Autumn 2023, lack of continuity is raised as an issue. There were mentions of poor communication around staff changes, who the main point of contact should be and failure to handover cases properly.**

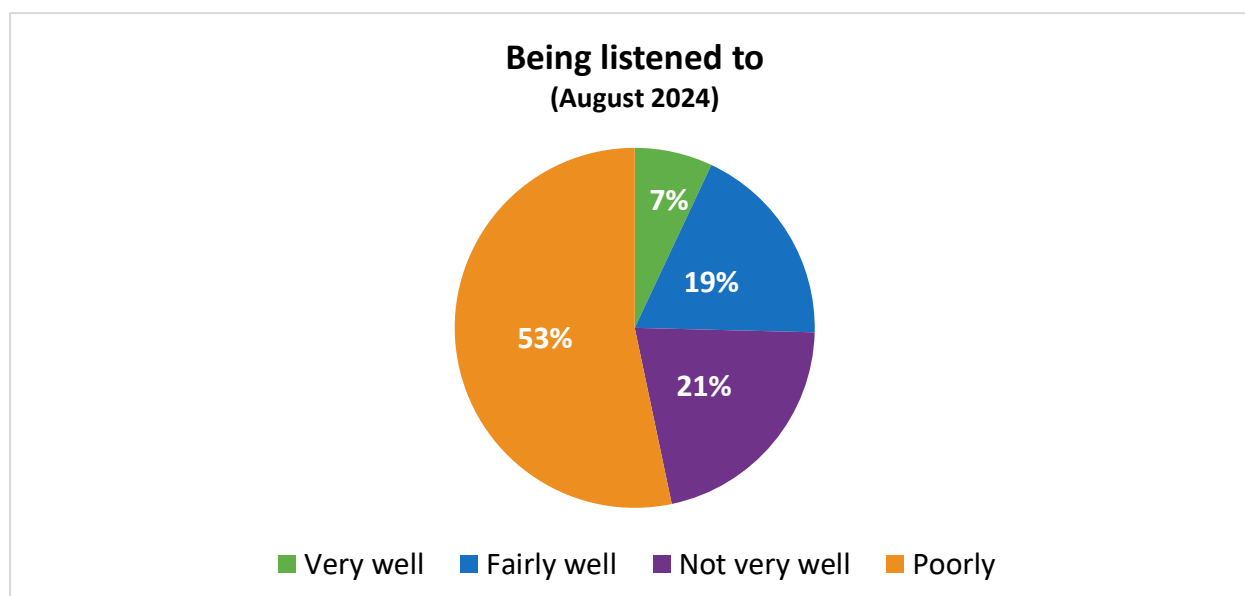
*"Complete lack of communication. Misinformation. Pleasant team but fed up with being passed from one person to another."*

*"The staff kept leaving. We had poor communication."*

*"It takes a long time to get a response, officers always seem to be away on holiday/sick and frequently change without notice."*

## Satisfaction with Feeling listened to

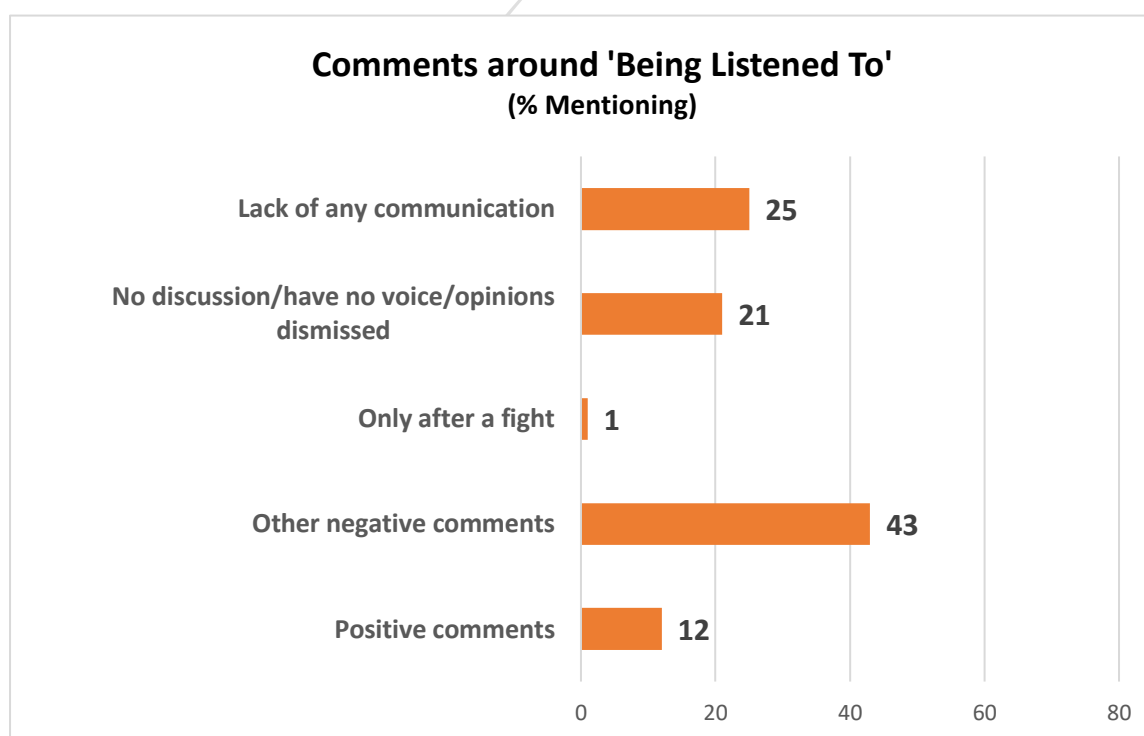
To what extent have you felt listened to by the Central Bedfordshire Council Education, Health & Care Plan Team?



Base: n=244

74% rated **'feeling listened to'** as 'not very well' or 'poorly'.

Reasons for this poor satisfaction around **feeling listened to** are shown in the chart below.



Base: N=91 comments

**As we found in Autumn 2023, the main negative themes are around a complete lack of communication and a complete lack of regard for the views and opinions of parent carers.**

*"Difficult to be listening when you don't communicate."*

*"Communication has been very poor. Emailed for months with no response. Same applies to school (emailed for support with no response)."*

*"No actual contact other than e mails but not listened to just batted away."*

*"They never reply to emails. They even got the nature of my complaint wrong so didn't even listen to that properly either."*

*"Don't feel listened to at all, don't get to know you or your child to know who they are making life changing decisions about. Ignored and unheard."*

**There were also a significant amount of other negative comments covering a broad range of issues.**

*"Why would they listen, children might actually get support that way and that costs money."*

*"They say one thing, do another and neither support our daughter."*

*"When you finally get a reply or a meeting. It is rushed and they just say how overworked and unsupported they are. It is not the fault of the staff. The council need to increase its resources."*

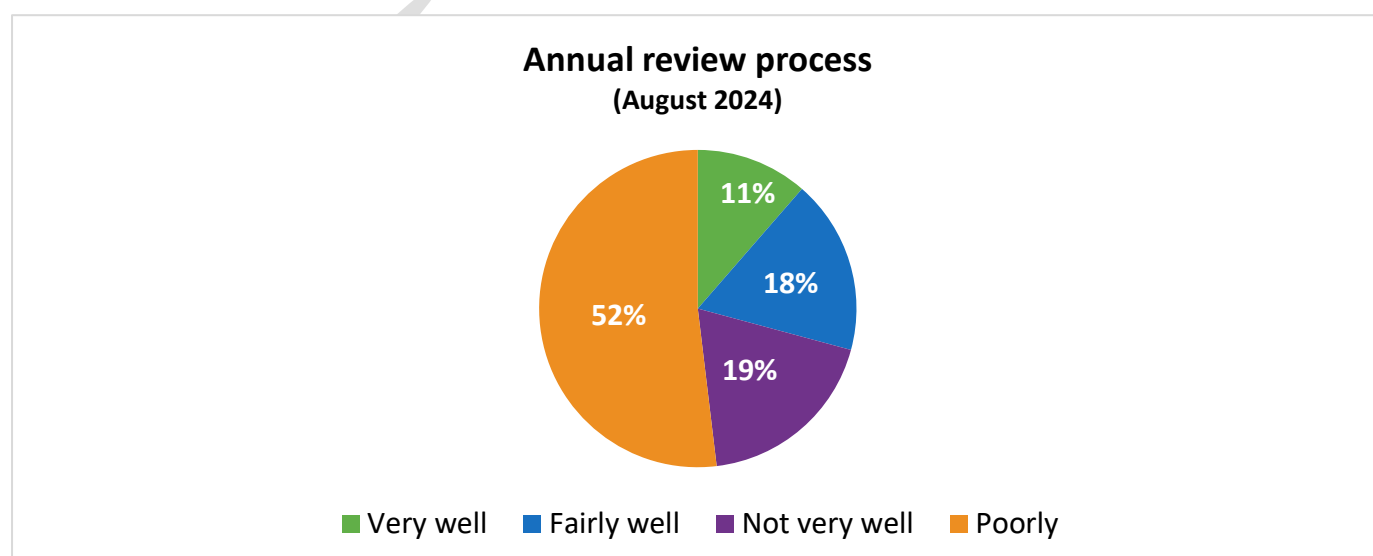
**There were positive comments made too, although not quite to the same extent as Autumn 2023.**

*"Again, this is a more recent change for our experience. Our son has had an EHCP since he was 5 (he is now 15). In the last 18 months we have seen a big improvement for our particular case."*

*"I've felt they understand the support needed and taken on board my suggestions on provision when I've sent them on."*

## **Satisfaction with Annual Review**

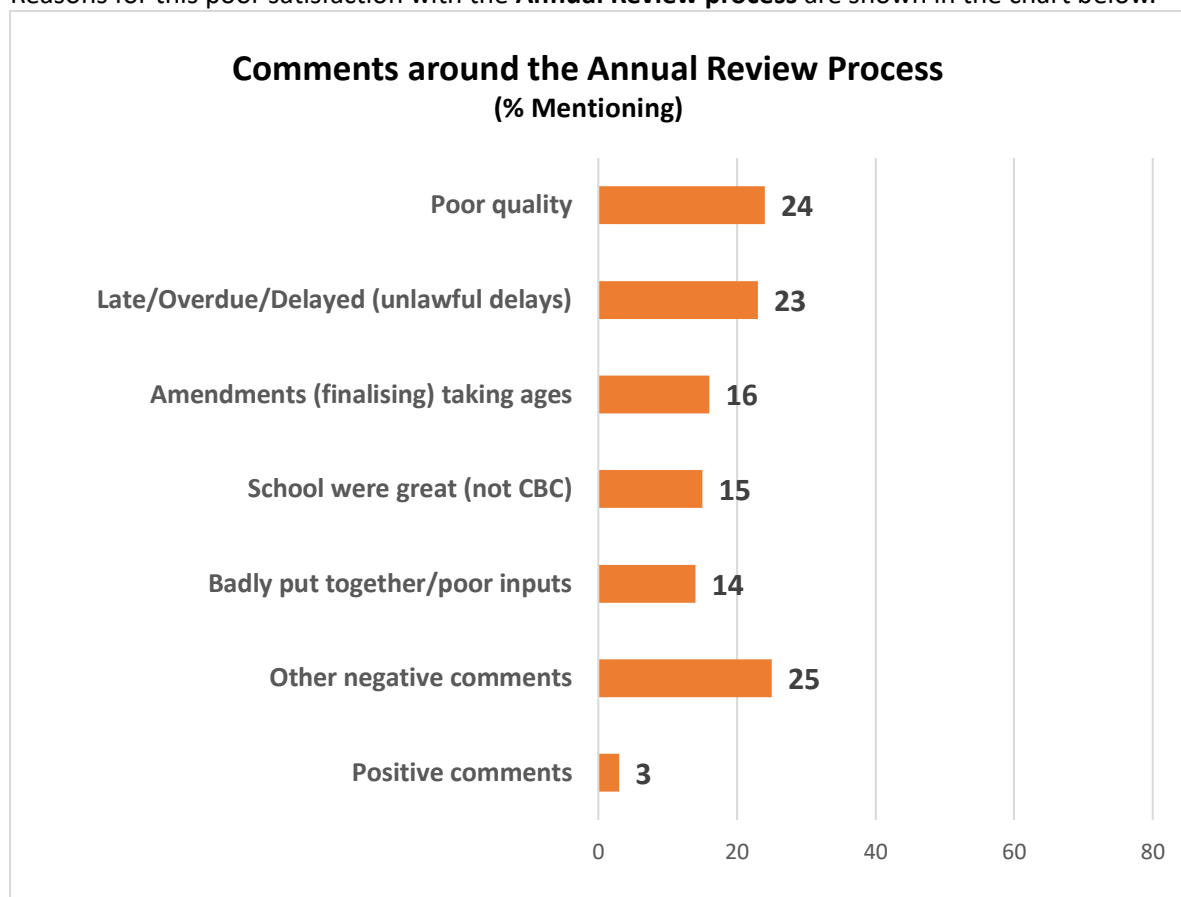
Were you satisfied with the Annual Review process when this was last completed?



**Base: n=185**

71% rated **the Annual Review process** 'not very well' or 'poorly'. There are no notable differences in experience by age of young person.

Reasons for this poor satisfaction with the **Annual Review process** are shown in the chart below.



Base: N=80 comments

The poor quality of the Annual Review process came through more strongly in the comments this time, compared to Autumn 2023. In addition, there were a lot of references to it being badly put together with poor or missing inputs.

*"No, it was a joke. The process wasn't followed properly, the SEND team sent out paperwork giving 15 days for amendments over the Christmas period, case worker was on leave for 2 weeks (14 days) and schools were closed yet when this was pointed out to them that I need to speak to someone regarding the document they sent before I could make amendments, I was basically told tough. Very unfair to issue a document for review and then to have most of the SEND team on leave over Xmas, new person couldn't help with my query despite being a line manager and schools shut, how is that fair that I have to keep to 15-day deadline when they have failed to meet statutory deadline?"*

*"No, it was rushed. The school failed to include all the reports. CBC don't listen, faceless panels make decisions, and you are just told to take us to court (like it's a game). Coproduction is a joke."*

*"Last review It took them 4 months to finalise. CBC didn't issue the amends at 4 weeks just a notice to amend. Professionals were given 1 day to read the documents. I wasn't told who was coming. I was given 1 day to amend after CBCs changes. They proceeded to send 4 different finalised versions on the day they finalised. Current AR that is pending. The wrong contacts were invited. The wrong documents were sent. Files were missed out. I wasn't able to access the files. Professionals and I were only given one date for the meeting. I suspect I will not receive the amends at 4 weeks, and it will be the same disaster as last year."*

*"Phases transfer paperwork was completed on time and notification of changes was received in timely manner, but draft and final copy contained another child hopes and aims for the future!"*

*"Completed in May, but plan from May 2023 finalised 2 weeks before AR and so professionals did not have a current plan to look at and provide advice from. Is this a performance issue or does this team require reviewing re capacity?"*

*"As usual I had to chase-LA did not keep to statutory timelines. I think it's laughable in the recent SEND bulletin from CBC they have patted themselves on the back for achieving 33% of plans within timelines."*

*"But only because school do it - however there still seems to be no additional support offered via it."*

*"The process was not followed correctly as legally set out. BUT school have been brilliant! Can't praise them enough- total confidence in them as they impact, they have made has been incredible."*

*"School were excellent, but CBC staff made typo errors and were never available on the phone."*

What one or two words would you use, to sum up how you currently feel about support and/or services for your child or young person with Special Educational Needs in Central Bedfordshire?

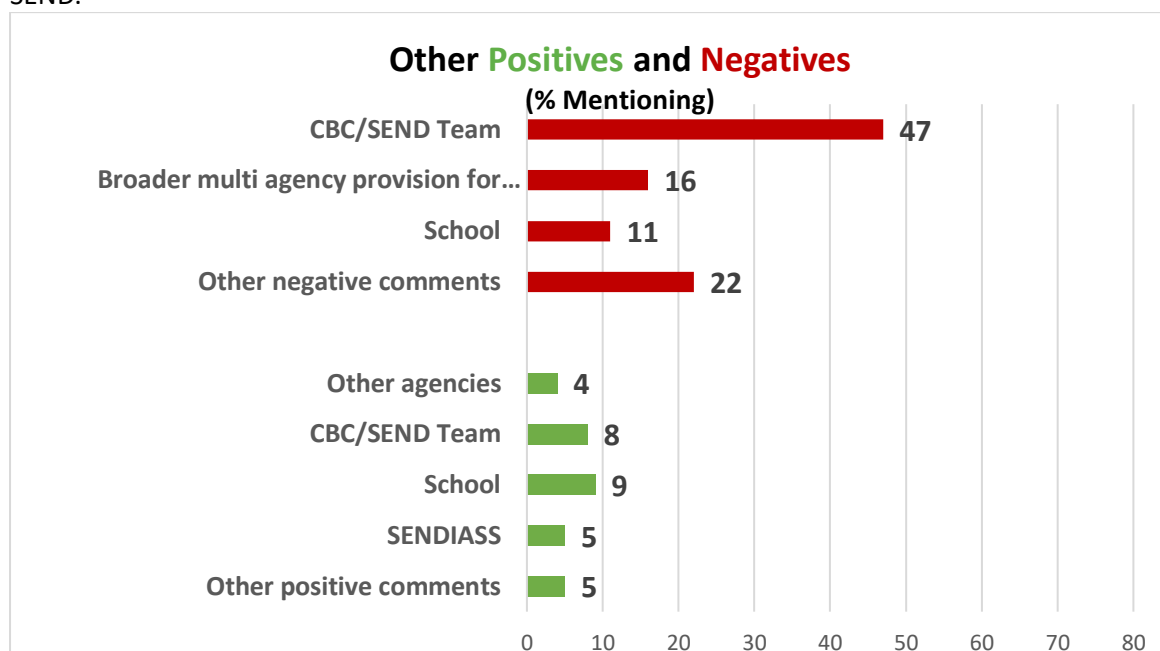
The word cloud below is a visual representation of the word data collected, with the increasing frequency of each word being represented by a larger font.

**The language used by parent carers highlights their feelings.**



## Other positive/negative experiences with local SEND services

Is there anything else, positive, or negative, that you'd like to tell us about? For example, your experience of the services and support available to you as a family of a Child/Young person with SEND.



**Base: N=185 comments**

The additional negative comments from parent carers focus primarily on the CBC EHCP team and associated processes and these have already been covered in previous sections of the report.

**A significant number of parent carers did take issue with the overall provision for children and young people with SEND in the area, with a lack of cohesion between different agencies and departments.**

*"The process seems so flawed. Early intervention isn't available. Takes so long to get anything in place. Repeatedly having to give the same information history to different agencies. Surely this could be resolved by a digital passport/history which follows the child."*

*"The reality is that the whole system is completely broken. All organisations point you to another, yet no help is actually given. Training in PDA is crucial and collaboration between all organisations, local authorities, schools and parents is so incredibly important however until such time PDA is recognised and understood by professionals' things cannot improve."*

*"This probably sounds crazy, but I feel that I (and other families) were allocated a 'key worker' who is there to support the family and guide the family to help make the right decisions for their child. At the minute, I feel isolated and there is little coming together of county, school and the family itself."*

**Other parent carers have had negative experiences from schools with schools failing to meet their children's needs and deliver to their EHCP plan.**

*"I think the problem is a huge gap between different support received from SENDCo's in different schools. We had to move my older son from school where SENDCo was terrible (my child had all symptoms of trauma caused by that person) and there was almost no support. On the other hand, our current school is absolutely amazing and has lots of SEND provision and great support. The difference is striking. That makes me worry about other parents who are not as lucky as we are."*

*"Sick of being brushed off by school (because they have no funds and therefore no staff to run interventions) and being fobbed off by LA despite my child having a diagnosis and clear need of social help at school."*

*“Complete lack of appropriate school support. Attitudes and approaches outdated! Prejudgments made, excuses and no accountability.”*

**There are positive comments about the work of the EHC team which underline that they also provide a good service to some parent carers.**

*“Our experience has seen a big improvement in the understanding of our son's needs, and we have felt very supported by CBC. I do now support other families and the key to removing those barriers is of course communication and transparency - even when the message is not ideal. I have seen very recently great examples of a case worker demonstrating excellent support for a family - it is of course easier to achieve this with advocacy but nonetheless, it was heartening to see.”*

*“My SEND officer has been really good and went above and beyond to make sure we got the right school place.”*

*“The process of finding the support needed has been long, uncertain and stressful, though I did feel the send team, ourselves and school were all on the same page and we got there in the end.”*

**Schools and their SENCOs also get praise from a small number of parent carers.**

*“To be honest we only really get support from school.”*

*“I feel for the SEND staff in school who have to 'fight for' basics such as a desk in a classroom that can be reached from a wheelchair or a working lift. Is such a basic requirement. SEND staff are brilliant but these needs rolling out to all staff who do not all see that pupils with SEND deserve equal access.”*

#### **Central Bedfordshire SEND data as of August 2024**

| Measure                                                                                                                     | Previous Year<br>Jan-Dec<br>2023 | Previous Year to date<br>Jan-June<br>2023 | Current Year to date<br>Jan-June<br>2024 | Direction<br>of travel | Q3<br>2023<br>July-Sep | Q4<br>2023<br>Oct-Dec | Q1<br>2024<br>Jan-Mar | Q2<br>2024<br>Apr-Jun |
|-----------------------------------------------------------------------------------------------------------------------------|----------------------------------|-------------------------------------------|------------------------------------------|------------------------|------------------------|-----------------------|-----------------------|-----------------------|
| No of Tribunals                                                                                                             | 99                               | 43                                        | 78                                       | ↑                      | 26                     | 29                    | 36                    | 42                    |
| % EHCPs issued within statutory timescales (20 weeks) excluding exceptions                                                  | 33.4%                            | 28.3%                                     | 43.6%                                    | ↑                      | 41.9%                  | 22.9%                 | 53.0%                 | 37.1%                 |
| % EHCPs issued within statutory timescales (20 weeks) including exceptions                                                  | 27.5%                            | 21.8%                                     | 34.6%                                    | ↑                      | 39.2%                  | 19.0%                 | 33.9%                 | 35.4%                 |
| % making a decision (and notifying parents) on whether to amend or cease a plan within 4 weeks of the Annual Review meeting | 42.1%                            | 46.5%                                     | 59.2%                                    | ↑                      | 36.6%                  | 30.1%                 | 54.5%                 | 63.9%                 |

The EHCP team has worked hard to improve the timescales of completing an EHCP within the statutory 20-week time scale. Their cumulative figure from January to the end of July 2024 is 46.2%. This figure continues to improve; in 2021, it was 9%. This is one of the targets the Department for Education set, and they have succeeded. SNAP PCF has previously raised concerns at the SEND Executive Board that the focus on improving the 20-week statutory time scales is the reason parental satisfaction has significantly decreased as the quality of plans and the satisfaction levels are being measured separately to the Department for Education requirement as part of the Accelerated Progress Plan to reduce the statutory timescales to ensure they are within the 20-week timescales.

#### **On page three the satisfaction rates over time graph shows**

- From their highest score in 2022 there has been a **32.5% decrease** in satisfaction levels of the EHCP process.
- From the highest score in 2022 there has been a **34% decrease** in satisfaction levels of being communicated with by the EHC team.
- From the highest scores in 2022 there has been a **44% decrease** in satisfaction levels of parent carers saying they felt listened to by the EHC team.
- From the highest score in May 2023 (this is the first time we measured Annual Review satisfaction scores) there has been a **14.7% decrease** in the satisfaction levels.

When we also look at the Tribunal data, 99 tribunals were lodged in the whole of 2023, whereas 78 Tribunals had already been lodged in the first six months of 2024.

## **Quality Assurance of EHCPs**

### **An update about the EHCP Audits**

SNAP PCF has collaborated with Central Bedfordshire Council (CBC) since 2020 to establish an effective EHCP Audit process aimed at improving outcomes for individual children and increasing overall trust in the EHCP process among families. Although the creation of the EHCP Audit Tool took longer than anticipated, in March 2023, we finalised a comprehensive, co-produced tool aligned with the SEND Code of Practice.

We supported moving from a spreadsheet to a digital version for round two, but Central Bedfordshire Council encountered technical issues that affected the data, this was not clearly communicated to us. SNAP PCF could have completed a trial run of the online audit tool when moving the information to an online platform. However, this work was done independently of us, we were not given the opportunity to support this work.

From the start, SNAP PCF raised concerns about the need for a transparent audit process, especially regarding mediation, post-audit action plans, and Central Bedfordshire Council's failure to contact families whose EHC plans were inadequate.

Central Bedfordshire Council agreed to address the issues we raised; however, we removed ourselves from the process as we were informed that due to time constraints, they were going ahead with round three without us as there was no time to work with us before round three needed to start. The absence of our involvement for some parents may undermine parent carers' trust in the audit process.

We encountered further difficulties when we were presented with a draft of a new audit tool just two hours before a meeting, which bore no resemblance to the co-produced tool from round one. The new tool, which had not been co-produced with SNAP PCF, lacked detailed guidance and appeared more focused on general case reviews and on the principles contained within the Ofsted

Area Inspection Framework rather than a systematic audit of EHCPs as required by the SEND Code of Practice.

We expressed concerns that this shift in focus diluted the audit process's validity and effectiveness. SNAP PCF believes that a broader Case Review should be separate from a detailed EHCP Audit to ensure the integrity of the process. Furthermore, the proposed new tool came to SNAP PCF with no accompanying guidance notes to explain how each section would need to be completed by the auditor to ensure a collective understanding and consistency of approach to auditing across different agencies and auditors, preventing us from even commenting on how this new tool might work in practice.

SNAP PCF acknowledges the need to look at the wider child, parent, and even professional experience of the EHCP process. However, this constitutes a related, but very different, exercise than an EHCP Audit and changes the purpose and nature of the task being undertaken. The new proposed 'Audit Tool' had lost its granular and systematic focus on each section and element of the EHCP, which in our view, is required to ensure that any judgement about the quality of the contents can be legitimately justified and can reveal in detail the reasons for the EHCP's strengths and weaknesses so that these can be addressed and translated into learning and positive change for the future.

Despite three audit rounds, SNAP PCF's ongoing concerns about the absence of any visible impact for children and family's needs to be resolved. We have seen no evidence that a single child or young person EHCP has been improved due to three rounds of the EHCP Audits.

For SNAP PCF's continued involvement, we recommended the following:

- Returning to the original co-produced EHCP Audit tool with iterative improvements.
- Ensuring all auditors pre-read EHCPs and supporting documents before multi-agency meetings.
- Allocating 45 minutes per EHCP during audits to ensure thorough consideration.
- Distributing EHCP documents at least three weeks in advance to all auditors.
- Establishing a clear post-audit action plan with thresholds for notifying parents of necessary EHCP improvements.
- Collating and sharing audit data, actions, and outcomes with SNAP PCF for broader dissemination.
- Reaffirming the importance of coproduction as per our Partnership Agreement.
- Creating a flowchart outlining the entire audit cycle, from EHCP selection to resulting actions.
- Using audit results to develop a long-term plan for embedding EHCPs within school practices.

Following a meeting with Central Bedfordshire Council, they have agreed to our recommendations and committed to sharing round three audit data and ensuring all staff are familiar with our Partnership Agreement and the values of coproduction.

## **Quality Assurance – Review of recent audits**

We have been assured that new EHCPs are quality-assured before being sent to parents, which, is positive news. To verify this, we reviewed three new plans and one annual review plan shared by our members.

Using the original co-produced Audit Tool, we assessed these plans without relying on its final scoring system. We are unsure how Central Bedfordshire Council calculates scores, especially when social care input is missing. Instead, we rated each section from 'Inadequate' to 'Outstanding' and concluded that all the plans reviewed overall 'Require Improvement' since they all had several sections needing improvement. We accept that our findings have limited validity because we didn't

review the supporting advice, and our assessment is based solely on SNAP PCF's data without external moderation. Nevertheless, according to the original tool, these EHCPs require improvement in multiple areas. However, without the supporting advices, we cannot determine whether this is due to poor advice, EHC officers, or both.

In our November 2020 survey, we expected that by November 2021, families would see improvements in EHCP quality, communication, trust in Central Bedfordshire Council and BMLK ICB professionals, and a culture change within these organisations. Unfortunately, as of August 2024, despite our efforts, parent carers continue to report issues with EHCP quality, deteriorating trust, and no noticeable culture change. While some EHCP officers are commendably child-centred, some parents are still telling us of their frustrations around communication and feeling listened to.

## **Waiting Time for our local Health Services**

For this report we wanted to include the waiting times for some of the vital local health services children and young people with SEND use. As you will see below children and young people will wait for more than a year to have an appointment to see a paediatrician and waiting times for a young person to have a full autism assessment is around 20 months. Some parents still report to us that their school will not support the child or young person's needs before a diagnosis is made, this is wrong as the focus must be on being 'needs led' and not diagnosis led' we have added this to the [FAQ document](#) on the Local Offer website. We know that an assessment of an EHCP has increased, one of the reasons for this may be due to waiting times and needs not being met without a diagnosis in schools.

## **Bedfordshire Community Health Services waiting times information**

### **Community Paediatrics**

Bedfordshire Community Health Services regularly meets with the three Bedfordshire parent carer forums, including the SNAP Parent Carer Forum, to discuss the key themes and issues the Parent Carer Forums collate from our members. The forums have consistently raised concerns about the length of the waiting times for a first appointment and progress to the relevant clinical pathway that meets a child/young person's presenting needs. We have worked together to find solutions to ensure parents are being supported whilst they are waiting and that schools are communicated with to ensure they are putting support in place for the child and not waiting for a clinical outcome before doing so. This feedback and positive ways of working together to find solutions may help to explain the increase in parental satisfaction for health in the 'Satisfaction Rate Over Time' graph on page four.

Bedfordshire Community Health Services measure the waiting time for a child or young person to start their care with the service. This could be a nurse led intervention, early intervention contact or support from a Speech and Language Therapist. Children and young people may wait more than a year for an appointment with a paediatrician, so it is important there are opportunities for support during this waiting period.

### **Speech and Language Therapy**

77% of children and young people on the waiting list have been waiting less than 18 weeks for an appointment. On average, Children and Young People wait 20 weeks to receive support from the service, though we know most children under five years of age are seen sooner than this, and some school-aged children are waiting much longer.

Following investment from Central Bedfordshire Council, the Speech and Language Therapy Service has started allocating Speech and Language Practitioner time to schools. Over the next six months, all mainstream schools in Central Bedfordshire will have a named link Speech and Language

Practitioner to support the school in meeting the needs of children with speech, language, and communication needs.

### **Occupational Therapy**

100% of children and young people on the waiting list have been waiting less than 18 weeks for an appointment. On average, Children and Young People wait seven weeks to receive support from the service.

## **Bedfordshire and Luton Child and Adolescent Mental Health Services (CAMHS) – waiting times for an autism assessment.**

The waiting time for first contact from CAMHS following the first referral is that 97-99% of referrals are contacted within 12 weeks of a referral. This includes contact with the Neurodevelopmental Team (NDT), which completes the assessments to determine if a young person is autistic. Waiting times for a full autism assessment to commence is about 20 months. CAMHS is advising that the waiting times can be around 20 months. In July 2023, waiting times averaged 12 months, so these have almost doubled in a year.

In April 2024, there were 496 young people aged 13 plus waiting for an assessment to commence, and 36 assessments for autism were being assessed. Autism assessments can be complex. The assessments must be accurate as it is a lifelong diagnosis. A full autism assessment can take around 15 hours of clinical time, which includes assessment, observation, review of scores from family and educational settings, and multidisciplinary discussion. The process time taken to complete a full autism assessment can vary; on average it can take two to three months. CAMHS waits until they have all the information required to give an assured diagnosis before providing feedback to the young person and their family.

The Neurodevelopmental Team's caseload is becoming more demanding due to the increased number and complexity of cases. This means staff have less time to carry out assessments, write reports, and give feedback. The waiting times are causing considerable distress to families.

### **Test the Temperature Workshop**

Following our previous Test the Temperature report, we were invited to hold a workshop for senior managers across Central Bedfordshire Council, the BMLK ICB, and local health providers to discuss our concerns and how we thought things could be improved. The focus of the workshop was how they could improve their communication and build positive and sustainable relationships with parent carers.

The professionals' workshop was successful in identifying what is working and where improvements can be made, how these can be made, and how barriers can be removed to lead to improved and sustainable relationships with parent carers. A comprehensive list of themes and what is needed to make improvements for each of the six areas, Care, Communication, Consistency and Co-production, Clarity, and Commitment was developed after the workshop.

We have asked that each service area review the 6C's value-based framework and create a page on the Local Offer website that describes how their service will incorporate these as a pledge to parent carers. SNAP PCF aims to create a short survey on our website where we can ask specific questions to parent carers to measure any impact of the implementation of this approach.



## Improving SEND services through shared values and culture change

Following SNAP PCF Test the Temperature Workshop with Central Bedfordshire Council, the BMLK ICB and our local Health providers SNAP PCF have asked that the following 6C's be adopted as a new way of working together.



## SNAP PCF recommendations from previous reports

Red background awaiting to start/complete.

Amber background work has either started, or we are waiting to see impact.

Green background complete

| SNAP TEST THE TEMPERATURE PARENTAL SURVEYS - RECOMMENDATIONS                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                     |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 2022                                                                                                                                                                                                                                                                                                                  | 2023                                                                                                                                                                                                                                                                                                                |
| SNAP PCF would like to see increased funding and capacity for SENDIASS                                                                                                                                                                                                                                                | An up-to-date Quality Assurance process in place and monitored using SMART objectives. Include SNAP PCF in reviewing complaints and case studies to triangulate the data.                                                                                                                                           |
| SNAP PCF believe that a Preparing for Adulthood Steering Group needs to be established to map out the current offer; to develop better ways to clearly communicate this to families                                                                                                                                   | Customer service training for the EHC Team. (This has been delivered however, our report shows lack of impact)                                                                                                                                                                                                      |
| An Early Intervention offer for schools that is linked with the Early Help Offer, and which is co-produced with all key partners including SNAP PCF.                                                                                                                                                                  | A review of all waiting times, including any our commissioned local charities and review the support families are receiving whilst they are waiting                                                                                                                                                                 |
| Additional resources are needed to deliver on the improvements to the Early Help offer and Parent Carer Needs Assessment. (Work is starting on the PCNA)                                                                                                                                                              | A training package for parents running across the year, like Hertfordshire's model using Families in Focus. (This work started but has not progressed)                                                                                                                                                              |
| An operational Group to include SNAP PCF to review the data dashboard. (Agreement to meet to discuss the DD with SNAP PCF agreed September 2024 so needs to be embedded)                                                                                                                                              | Ensure better publicity and awareness of service developments and improvements amongst families, coupled with meaningful and timely communication with individual families by all services. (There are more updates about services developments, however the individual communication still needs to be progressed) |
| Improved training for all professionals to better understand neurodiversity and Pathological Demand Avoidance.                                                                                                                                                                                                        | A review of the current offer of Occupational Therapy (OT) – The focus is for Sensory OT, which is not commissioned by the BMLK ICB however, there is a need that we reported in our previous survey report.                                                                                                        |
| A training package for parents running across the year, like Hertfordshire's model using Families in Focus. (This work started but has not progressed)                                                                                                                                                                | Welcome booklets for Education Health Care Needs Assessment (EHCNA), phased transfer, and Annual Review. This would also include Early Help, Children with Disabilities Team and SEND Transport.                                                                                                                    |
| Co-produce an Audit tool for the EHCP Audit, using the advice from the SNAP PCF report so families can trust and have confidence in results which are detailed, robust, and transparent                                                                                                                               | An action plan coproduced from the previous two EHCP audits. (The information provided in this report explains why this is amber)                                                                                                                                                                                   |
| Embed the Co-production Charter within all departments and provide a workshop for senior managers at CBC to ensure a clear and collective understanding of what the principles of coproduction is, so that they can then disseminate this to all staff. (Individual coproduction practices still need to be embedded) | Create an Education Other Than at School (EOTAS) Policy. (This work is progressing)                                                                                                                                                                                                                                 |

|                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                            |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Ensure better publicity and awareness of service developments and improvements amongst families, coupled with meaningful and timely communication with individual families by all services. (CBC have moved away from the original template however, parents are not telling us this feels parent friendly)                                                                                                                          | A review of CBC Customer Services (Relations) processes to become more personalised and move away from using a prescribed template. The process to become parent friendly. (CBC have moved away from the original template however, parents are not telling us this feels parent friendly) |
| Create a dedicated section on the Local Offer that maps out all support available to children and young people with their mental health and wellbeing.                                                                                                                                                                                                                                                                               | Create a problem-solving task and finish group to review, the survey feedback and find solutions such as how to improve the communication of the EHC Team, for example the use of out of office and a set process of when and how to communicate following a panel decision.               |
| The Local Offer needs to be accessible as more than just a website. SNAP PCF would like to see an information booklet being produced with a printed copy being placed in all schools, children centres, libraries, and health settings etc. We would also recommend having regular drop-in sessions where parents can receive an online tour of the Local Offer and be assisted to navigate and access the information they require. | Information about the criteria, referral process and waiting times for CAMH and Paediatrician referrals.                                                                                                                                                                                   |
| A review of all waiting times across education, health, and social care services; with a commitment to commission additional services to support families Post 16 whilst they are waiting to access these services                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                            |
| A detailed CBC plan for school places, which communicates a clear strategy and vision for additional special school places so that wherever possible children can attend school within their local area.                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                            |

### Additional Recommendations from this report

While the SEND Partnership across Central Bedfordshire Council, the BMLK ICB, and local health services continue to work on our recommendations from 2022 and 2023, we do have the following recommendations for consideration.

We use case studies from complaints to inform practice development in a similar way that we have worked with social care teams by developing and presenting workshops to gain insight into the impact negative experiences have on parents and work together to improve practice.

To review the Key Performance Indicators (KPIs) for the EHCP team, there is a strong focus on ensuring EHCPs are completed within the statutory 20 weeks. We believe there is a case to be made that focusing on this measure is impacting the quality of the plans and the communication with parent carers.

For any new staff interviews, there is a focus on employing people who are child-centred and can be empathetic with parent carers. The importance of having the right technical knowledge is also stressed. If the 6C's were part of the interview process, this could help to support this.

If only one recommendation from our previous report could be prioritised, it would be to create a problem-solving task and finish a group to review the survey feedback to find solutions and implement them. Hopefully, this would work towards an increase in parental satisfaction.

## **Reflections from SNAP PCF Steering Group**

For this and the previous reports, we commissioned a data analyst to review the survey answers and group the parent carer responses into themes. We hope the themes have helped explain the reasons why parent satisfaction levels continue to decline.

Some parent carers copy [admin@snappcf.org.uk](mailto:admin@snappcf.org.uk) into their complaints and correspondence with Central Bedfordshire Council, parents understand that although we cannot get involved with individual cases as this is the role of [SENDIASS](#), it does allow us to see the realities of parent carer experiences trying to navigate receiving the support their child or young person needs. We continue to see complaints where a provision is included in Section F (which makes the provision legally enforceable) to find at the following Annual Review provision is removed without any reports/evidence to do so, even when the previous plan was directed at a Tribunal, this causes parent carers distress as they fight with the council to keep the provision in place. The timeliness of receiving the EHCP after the Annual Review also creates distress for parent carers; parents need a timescale for when to expect to receive the EHCP.

We continue to see parents having to chase officers for a response; we previously recommended to Central Bedfordshire Council that they change their out-of-office notification from three working days to five working days as they were unable to reply within three but felt five working days was achievable, we asked that on day five even if there was no update and email was sent to inform the parents of that and when they could expect to receive an update, we are hearing from parent carers that this is not happening. We understand that there continues to be an increase in EHCPs. Are the caseloads for officers too high?

We noticed that the 'Satisfaction Over Time' chart on page four of our report shows there is a further decline in social care; when reviewing the parental feedback, the main issue appears to be that parents want access to the service and are not meeting thresholds, which is causing further distress. Previously, there was a Head of the Children with Disability Team (CWD), and this post was removed several years ago. This role has now been reinstated which is positive, and we are working with the head of the service on workshops with parents who have had a complaint upheld on lessons learned with the social care teams; the first one was positive, and we held a second workshop in September, which was as equally positive. The team is open to listening and learning from complaints; it is refreshing to see this in action; it would be a positive step if this approach could be replicated within the EHCP team. We will soon be working together to review the Parent Carer Needs Assessment and the Children with Disability criteria.

We appreciate the role of the [Special Advisory Team](#). Since this role has been developed and expanded, they have been able to support schools in improving their SEND offer and, at times, act as a conduit between the school and parents.

The flexible ways in which Central Bedfordshire Council has tried to create opportunities to recruit Educational Psychologists (EP) is also to be welcomed; without enough Educational Psychologists, this impacts on the timescales for an EHCP, following a conversation at the SEND Overview and Scrutiny Sub Committee, we would like to see the Educational Psychologist being offered the [Soulbury Scale](#) to further reduce barriers to EP's wanting to work for Central Bedfordshire Council.

SNAP PCF has received additional funding from the BMLK ICB to localise a [‘Supporting your Neurodiverse Child Young/Person’ book](#), which originated from Essex. We have worked tremendously hard to ensure the book adds all the local information. We had a very successful book launch with guest speakers and stallholders providing information across education, health, and social care. The feedback we received was so positive about the book and the launch; parents are telling us they want access to information in a supportive and informal way, and they trust SNAP PCF to deliver this for them. We have also received additional funding to enable us to support parents wellbeing by delivering the [Healthy Parent Carer Programme](#), the first sessions started in September.

We applied for an additional grant for an Engagement Officer to create SEND Roadshows and to promote our Supporting your Neurodiverse Child/Young Person book; we were successful in gaining half of the funding we requested, this has enabled us to employ an Engagement Representative for twelve months, we hope that Central Bedfordshire Council will see the benefit of this additional role and continue to fund this moving forward.

During the Summer term, OFSTED held Thematic Reviews on Preparing for Adulthood; SNAP PCF conducted a survey and is currently writing a report about this, which we will publish. Although Central Bedfordshire was not one of the areas where the Thematic Review was conducted, there is an appetite across the SEND partnership to work together to improve the transition into adult services and try to reduce the cliff edge. SNAP PCF is also creating a Padlet written by parents who have gone through the process to provide other parents with the information they may need to navigate a complex pathway. We will publish the report and tablet later in September.

The issues faced in our area are not dissimilar to many local authority areas; as members of the NNPCF, we are able to work across our Eastern Region and nationally to understand the wide-ranging issues encountered by parent carers. After 11-plus years of austerity with councils having brutal cuts to their funding, we can see waiting lists for health services have increased exponentially. Councils start to gatekeep resources to ensure they go to those in the greatest need. At the same time, parent carers who understand the Children and Family Act 2014 and know what their child/young person is entitled to, begin the fight to get the right support at the right time for their child/young person, parental mental health breaks, and children are left without the support they need and deserve, however, the culture of poor communication and how some parents are left feeling after communicating with Central Bedfordshire Council and at times health services is about the culture, not funding. We hope if the 6C’s are implemented this will support progress in this area. SNAP PCF has provided recommendations in previous reports over the past few years, and as you can see from the information provided in this report, many recommendations we have made were agreed but still have not been acted upon or are yet to be embedded.

SNAP PCF has been operating for over ten years; in that time, we have worked successfully with Central Bedfordshire Council and our local health services to make positive improvements; the recent [SEND newsletter](#) during coproduction week provides some examples; we are particularly proud of the work we did to get Therapeutic Thinking brought into Central Bedfordshire. However, we do reflect that the quality of EHC Plans is not improving consistently; the EHCP Audits have not made a difference yet; we hope that the additional steps, including at the end of the audit meeting next steps and actions are agreed, monitored and acted upon as well as any inadequate plans will be amended either at the following annual review or an interim review taking place (depending on timings) and the updated plan being part of another round of audits to check the quality will help to make the EHCP Audits effective in creating a meaningful change.

As always, we would like to remind the professionals reading this report that the parent carers who have taken the time to complete yet another survey have done so in isolation of each other; they are not discussing their concerns on a Facebook page or in a coffee morning, they have independently taken the time, probably at the end of a busy and stressful day, to tell us how things feel for them; we ask, if you do nothing else, to go back and read the comments on the word cloud and to look again at

the Satisfaction Rates over time to see the significant decline in parental satisfaction over the past two years.

**The question once again from the SNAP PCF Steering Group is when we can expect to see parent carers reporting consistently and positively to the four main questions:**

1. *How would you rate your overall experience of the Education Health Care Plan process?*
2. *How well have the Central Bedfordshire Council Education, Health & Care Plan Team communicated with you and kept you up to date with your Child's/Young Person's EHCP?*
3. *To what extent have you felt listened to by the Central Bedfordshire Council Education, Health & Care Plan Team?*
4. *Were you satisfied with the Annual Review process?*

## **Thank you**

We would like to thank the parent carers who took the time to complete our survey and thank them for all the support that they give our Parent Carer Forum. We are only as strong as the parents who wrap around us, champion us, and share with us their lived experiences. We will continue to listen to them, raise their concerns about local SEND services, and work with Central Bedfordshire Council, the Integrated Care Board, and our local health providers to find solutions.

## **Case Studies**

We wanted to bring to life parent carers lived experiences by providing two case studies.

### **SNAP PCF Sharing Real-Life Experiences and Outcomes**

#### **Acknowledgement**

SNAP PCF would like to sincerely thank the family who participated in this case study for their generous contribution of time and input. Your experiences and insights are invaluable in understanding and addressing the challenges families face navigating the EHCP process and obtaining a suitable and timely educational place.

#### **Disclaimer**

This case study reflects the personal experiences and perspectives of the family involved. To maintain confidentiality, the young person's name, her mother's name and any other confidential information has been changed.

#### **Background**

"Aisha" is a young person who will enter Year 7 in September 2024. Aisha has been diagnosed with autism, which includes traits of demand avoidance, though these traits are not considered severe. Academically, Aisha is capable, demonstrating her potential to succeed in a supportive environment. Aisha's Mother is referred to as Lisa in this case study.

However, Aisha experiences significant challenges in emotional regulation. When overwhelmed, she can become nonverbal, struggling to communicate her needs effectively. During these times, Aisha requires access to a safe space where she can regulate and recover. Throughout Year 6, Aisha did not attend school on a full-time basis; her attendance was around 50%. This partial attendance reflects the difficulties Aisha faces in a typical mainstream school setting, particularly in environments that are not adapted to accommodate her autism, sensory and emotional needs.

The experiences shared by Aisha's family shed light on the complexities and struggles involved in securing appropriate educational support through the EHCNA and EHCP processes. These challenges underscore the importance of timely, transparent, and collaborative approaches that genuinely consider the unique needs of each child.

*This account highlights the challenges Lisa has faced in navigating the Education, Health, and Care Needs Assessment (EHCNA) and Education, Health, and Care Plan (EHCP) processes for her daughter.*

**Below is a summary and the key points of concern:**

**Delayed EHCNA for Aisha:**

While Aisha's sibling's EHCN assessment met statutory timescales, Aisha's assessment did not. Despite being given a 12-week timescale with a deadline of Boxing Day, there was a lack of communication from both the Educational Psychology (EP) service and Child and Adolescent Mental Health Services (CAMHS). This led Lisa to repeatedly chase the EHC coordinator to engage the relevant professionals. The CAMHS professionals involved did not directly consult with Aisha, resulting in an incomplete assessment based primarily on the Lisa's input- although vital this is not sufficient. Aisha was not included in CAMHS assessments/discussions. She was seen by the EP at school, in an appointment made at the last minute in the week before Christmas.

**Part-Time Timetable and School's Reactive Approach:**

Due to difficulties in managing Aisha's triggers (noise and people), it was agreed (after Lisa had consistently expressed concerns and Aisha had struggled to attend for nearly a whole term) that she would move to a part-time timetable. The school acknowledged its limitations in supporting Aisha in a mainstream setting. The EP supported the part-time timetable, hoping to gradually build upon it.

**Issues with the EHCP Process and Quality:**

The draft EHCP provided to Lisa was unsatisfactory. She had to make significant amendments and return it under severe time pressure. During the coproduction meeting, the EHCP Coordinator admitted not having read the mother's amendments. This led to confusion and questioning of the validity of the meeting. Despite the issues, a final EHCP was issued without a proper coproduction meeting. Lisa having raised a complaint then felt dismissed and not listened to in subsequent discussions with another EHCP Team Official. She felt 'gaslighted' and that her concerns were not taken seriously. The interactions were described by Lisa as, "adversarial and confrontational." The final EHCP is still deemed as "not fit for purpose" (as stated by Lisa).

**Concerns Over Suggested School Placement:**

A placement panel recommended that Aisha attend a special provision school, W Academy. This is a middle school and so would involve a traumatic transition into Year 7, only to have to do another one at the end of Year 8. With support from Aisha's social worker, Lisa challenged this, and the LA panel revisited their discussion, then deciding to name X Academy (a secondary school), which was agreed upon without consulting Aisha or her mother. Concerns were raised by Lisa that X Academy did not meet Aisha's needs, and no prior meeting took place with Aisha or Lisa. The X Academy staff did not meet Aisha or discuss Aisha with her family. The provision is not open yet so the place will not be available until January at the earliest.

Lisa preferred a specialist out-of-county school where Aisha's sibling had a positive and transformative experience. This school offered an immediate start and a tailored transition process and supportive environment which would enable Aisha to flourish and thrive, but the parental choice request for this school was declined. Instead, an Additionally Resourced Provision (ARP) was recommended, which Lisa strongly believes will not meet her daughter's needs.

In the meantime, the LA have issued a final EHCP naming W Academy without Lisa's consent.

**Current Situation and Next Steps:**

Aisha has returned to school in September, continuing in her mainstream provision on a part time timetable – aiming to be there 75% of the time. The LA expect her to change schools in January to X Academy, where she will be expected to spend 80% of her time in a mainstream setting and 20% in the ARP, contrasting with her current arrangement of 75% attendance and 25% home-based support. The ARP cannot provide Aisha with the environment to regulate and recover. This has led Lisa to feel that unrealistic expectations are being placed on Aisha and that she is being set up to fail. The move to Year seven involves significant changes for Aisha from a primary environment to that of a secondary approach with frequent changes of rooms, staff and peers, none of which Aisha can manage.

In her current provision, Aisha will need to come home for periods of the day most days, as she is rarely able to manage whole days at school (and frequently needs a day off if she has done more than one full day in a week). This is incredibly demanding for her mother to manage as she works. The preferred specialist school that can fully meet needs and which is attended by her sibling, is willing to hold a place for Aisha for six months. Due to the specialist setting Aisha would be able to attend full time and not on a reduced timetable, enabling Lisa to remain at work. In pursuit of suitable education, Lisa is seeking legal support through a SEN Solicitor and is preparing for a tribunal, set for 2025. Due to the long wait time, she is also having to fund a private EP to ensure that Aisha's needs are accurately represented in current documentation.

**Summary of Concerns:**

The need to chase the EHCP Coordinator to meet statutory timescales and the lack of direct engagement with Aisha during the EHC assessment process. The poor quality of the EHCP and the mishandling of the coproduction process. The choice of school placement, which appears not to consider Aisha's individual needs, and the lack of consultation in making these decisions.

The adversarial and dismissive communication style experienced by Lisa in meetings with officials. Financial strain on the family due to the need to engage legal support and private assessments to advocate for appropriate educational provision for Aisha.

The impact on the family of having a child on a reduced timetable that requires frequent disruption to the mother's working day to manage.

*Lisa is actively seeking a solution that will meet her daughter's educational needs full time and provide the support required for Aisha to thrive, highlighting the importance of proper consultation, understanding, and individualised planning in the EHCP process and school placements that are reflective of and meet the needs of individuals.*

**Case study two**

This case study highlights Henry and his family's numerous challenges in navigating the complex SEND system of obtaining educational and social support for a child with Special Educational Needs and Disabilities (SEND). The case involves Henry, who has significant SEND, including SEMH (Social, Emotional, and Mental Health needs) mild hypermobility in his hands, which were not initially recognised due to inconsistent assessments and a lack of collaboration between professionals.

**Acknowledgements:**

A special thanks to Henry's family for sharing their experiences to improve the system for others facing similar challenges. Their perseverance and advocacy are invaluable in highlighting the gaps in the current processes and paving the way for necessary improvements.

## **Disclaimer**

This case study reflects the personal experiences and perspectives of the family involved. To maintain confidentiality, the young person's name, his mother's name, and any other confidential information have been changed.

## **Key Issues:**

### **Inadequate EHCP Assessment:**

Henry's Education, Health, and Care Plan (EHCP) was initially incomplete and inaccurately reflected his primary needs. His transition from mainstream to ASD provision and later to SEMH provision was fraught with miscommunications, delays, and inadequate planning, impacting Henry's emotional well-being and increasing to behavioural challenges.

His initial EHCP was not clear that Henry's primary need was not ASD but SEMH. Despite saying their needs could not be met, he was placed in an ASD provision. However, this was not a smooth transition as a teaching assistant needed to be in place, and transport was not arranged in time for him to start in September. Following two years at an ASD provision where it became apparent that his primary need was not ASD but SEMH, his EHCP was amended to reflect this so a place could be sought at a SEMH School. Initially, this was declined as it was again stated that due to ASD, he could not attend; however, after further discussions, a place was offered to start Year 6 at the SEMH Specialist School. Henry's needs not being met in the ASD provision led to a significant number of restraints being used, which had a significant detrimental impact on Henry's image of himself; he viewed himself as 'bad.' COVID also meant that Henry was placed in bubbles, so he was not prepared for his transition to the SEMH school to be with larger numbers of children and was overwhelmed, unprepared, and dysregulated.

### **Miscommunication and Lack of Proper Review:**

During a crucial Annual Review in 2023, the local authority (LA) and SEN services failed, only 45 minutes were allocated for the review. It had been made clear at the beginning of the meeting, that a re-assessment was going to be requested. The Senior Officer was argumentative and informed that Henry did not require a reassessment. The EHCP had first been issued five years previously and there was unmistakable evidence to support the requirement for a full reassessment.

During the review the Senior Officer advised the school they could write new outcomes (which is not the correct procedure). Lucy requested a reassessment in November 2023, which was submitted with the Annual Review paperwork. Lucy raised repeatedly that Henry needed updated Educational Psychologist and Speech and Language advice, the significance of his needs is apparent from the fact Henry was placed under Speech and Language care aged seven months. Following this request, Lucy received an email stating that the request for reassessment was declined without providing rights to appeal. The EHCP amendment notice was issued in December with no suggested amendments. When Lucy finally received the draft with the amendments, she found that most of Section B SEN had been crossed out, without any supporting evidence. Lucy asked for a meeting with the EHC Team, which was granted. Lucy raised the concern regarding the amendments being crossed out and was informed that this was due to temporary staff being used. Lucy requested that Henry's teacher be involved with providing evidence for Section B SEMH, these requested amendments were sent to the EHC Team, but never used in the EHCP.

Lucy chased again the decision letter for refusal to assess, but when it was received it had another child name in it, Lucy raised concerns and was informed it was just a 'typo.' The letter was dated December but was not received until February. Lucy received the corrected letter after informing the LA's solicitor that the letter had incorrect details on it.

**Speech and Language Support:**

Central Bedfordshire Council conceded and agreed to reassess Henry's EHCP, despite having no further evidence submitted to support the change of decision. As part of the EHCNA, Lucy made it clear that Henry required further assessment / advice from the speech and language service. This was then further supported following the Education Psychologists assessment further compounded his difficulties in communication, social interactions, and self-esteem. Lucy has been told that for Henry to be reassessed by the speech and language service, he needs to have changed his profile and presentation, which is evidenced by the advice given by the Educational Psychologist report and previous Specialist Advisory teacher report.

Health partners must be legally compliant when contacted with a request for advice via an education health and care needs assessment to assess and recognise any unmet needs, they must be of high quality, consistent and safe. They must be children and young person centred. Blanket responses are not practical nor appropriate; the speech and language service declined to provide updated advice for the purpose of the EHCNA and gave the last report which was of poor quality and did not meet the standards required to obtain a full understanding of Henry's SLC needs.

*These are Lucy's comments after reading Henry's EP report which clearly set out Henry's needs, this was used to dispute a discharge letter from SALT services to evidence the ongoing issues and needs that must continue to be supported by SALT.*

- The Educational Psychologist report shows the requirement for Henry to have an assessment for Phonological Disorder – this is a speech sound disorder that affects the ability to use speech sounds correctly for the age group.
- Henry is reported as “still having significant delays in both receptive and expressive language.”
- The impact of not having his needs fully investigated and subsequent therapy is Henry being misunderstood and difficulties with social aspects of life that require speech, for further information please see the link from the RCSLT.

Guiding the LA on how to apply section 21(5) CFA 2014, paragraph 9.74 of the Special Educational Needs and Disability Code of Practice 2015 states:

“Since communication is so fundamental in education, addressing speech and language impairment should normally be recorded as special educational provision unless there are exceptional reasons for not doing so.”

The response from the Speech and Language service was unacceptable. The LA has a duty to ensure that all educational needs are identified. If it is unable to do so through commissioned services, then it is not unreasonable to request independent services. This was raised in Lucy's complaint and has been responded to by copy and pasting a paragraph of the SEND Code of Practice.

**Lack of Social Care Assessment:**

Henry's mother, Lucy, has twice requested a Section 17 Child in Need assessment (CiN) and requested updated Parent Carer Needs Assessment (PCNA), which were either delayed or inadequately addressed. Lucy has also raised concerns that a section 17 Child in Need assessment should occur. Lucy believes that staff sent to undertake the first assessment have a miss-held view that children with complex and severe physical/social disabilities can get support and was informed they were undertaking a Section 47 safeguarding assessment. Again, Lucy raised concerns about the report.

Lucy was informed by the social worker, from the second request, that “the Children with Disabilities Team, who had advised that the referral does not meet the threshold for an S17 CWD assessment, has advised if you could apply for a Parent Carer Needs Assessment. From there, CWD will contact you and explore further support.”

Lucy had a significant family event that needed her full attention during this time. As a result, Lucy did not have the time, energy, or strength to continue fighting for Henry's social support. A subsequent report stated that Lucy was not engaging, with no acknowledgment of the severe family incident.

Lucy's complaint regarding a lack of Section 17 Child in Needs Assessment was submitted, and this was not acknowledged or responded to. Following the request for a Section 17 Child in Need assessment, Lucy resubmitted this and the extra details as part of her subsequent complaint. As a result, despite repeated requests for a satisfactory Parent Carer Needs Assessment to take place, this still needs to occur.

There has been a constant push by social care for Lucy/Henry to receive universally available support, which Lucy says does not meet Henry's needs. An example of how information has been misinterpreted is that the social care report provided for the EHCNA states, "Mum is teaching Henry to cook." The incident this refers to is when Mum was upstairs, and Henry tried to reheat a cookie in the microwave on a plate that melted. This was a total misinterpretation and was an example of why Mum requested a S17 Assessment. The last time PCNA had been used was March 2020, despite had having meetings with Access and Referral and trying to chase what was happening. In Lucy's view, the push towards accessing universal services is inappropriate. Henry has a primary need for SEMH, and the local universal services cannot provide this. As Lucy highlights, "There is no youth club provision, holiday provision for a child with Henry's needs. There is for autism but not for his ADHD / SEMH needs." Despite this, Lucy is still no closer to Henry having a full Section 17 assessment.

#### **Legal and Procedural Failures:**

Lucy states there were multiple breaches of law and procedural guidelines, including:

- Failure to amend the EHCP in a timely and accurate manner.
- Lack of proper health and social care advice, as required under the SEND Code of Practice and the Children and Families Act 2014.
- Mismanagement by SEN health and social care services leading to emotional and financial strain on the family.
- Inappropriate responses to complaints, including failure to adhere to legal timelines and standards.

#### **Positive Outcomes:**

Despite the significant challenges, Henry eventually made notable progress, particularly after being placed in the correct educational setting for his SEMH needs. With a supportive teacher and key worker in Year 7 who validated and understood Henry, Henry's behavioural incidents dropped significantly, highlighting the importance of proper support and validation. This success can be measured in that Henry went from having three to four significant incidents a week to just two in the whole year. In addition, when the two incidents were reviewed, it was clear that the body language of staff had been a contributing factor escalation of the incidents.

Lucy and Henry saw a new manager for the Occupational Therapy service, this appointment was positive, the manager was clear and concise and treated Henry as an individual she was child centred. Lucy said she felt that coproduction was positive as she felt listened to.

#### **Conclusion:**

This case exemplifies the systemic issues faced by families dealing with complex SEN, where a lack of collaboration, rushed decisions, and inadequate professional support lead to a detrimental impact on the child's development and well-being. Henry's case underlines the necessity for a more joined-up approach in delivering education, health, and social care services and the importance of giving families the time, attention, and respect they deserve to ensure their children's needs are fully understood and met.

*The impact on the family is significant and ongoing. Lucy is a single parent who works and is neurodivergent. Henry has a sibling who also has additional needs. The impact on the family has also been detrimental, and the 'fight and battles' continue for them.*

### Word cloud of parent carers views of SNAP PCF



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