EPIC Parent Carer Panel: Survey Results 2024

Survey completed by EPIC PCF with support from Healthwatch Luton 2023-2024

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Personal Quotes

> "Significant delays in receiving the EHCP draft meant it was obsolete by the time it was received"

SUMMARY

EPIC (Empowering Parents Influencing Change), Luton's Parent Care Forum (PCF) worked with Healthwatch Luton (HWL) in 2023 to devise a survey to ask for baseline review on people's experiences of the SEN offer, and the process for parents with their children who have with Special Educational Needs Disability (SEND).

EPIC asked parents and carers living in Luton about their lived experiences, and 38 parents in Luton responded. At the time of the survey being conducted, the EPIC PCF had 170 registered members, and 27% of the 38 people who took part in the survey were EPIC members.

Each Local Authority in England is funded via the Department of Education to support the creation of a Parent Carer Panel or Forum[1] to ensure parent and carer experiences are used in line with the delivery planning and commissioning of SEND (Special Educational Needs Disability) services in their local area.[2]

The National Network of Parent Carer Forums[3] have been closely engaged in the development of the new framework with CQC and Ofsted to produce a handbook for local area inspections on SEND services; to which the Local PCF should be involved, engaged and supporting.

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[1] Establishing your parent and carer panel - GOV.UK (www.gov.uk)

[2] Area SEND: framework and handbook - GOV.UK (www.gov.uk)

[3] DfE guidance – National Network of Parent Carer Forums C.I.C (nnpcf.org.uk)

EPIC Parent Carer Panel: Survey Results

Luton's EPIC PCF was created and is supported by over 170 registered parents and carers of families who have children with SEND or Learning Difficulties or Disabilities (LD)

This survey was created to ensure the newly formed PCF understood the leading needs of the population it is serving and supporting. This initial survey has raised various priorities to consider with the PCF and Local Authority for 2024 and this report highlights recommendations from the parents. /carers experiences.

Healthwatch Luton (HWL) supported this survey by providing an independent forum and analysis of the findings, and promotion of the report findings.

EPIC PCF would like to thank all those who took part in the survey and to the parents and carers who took time to complete the survey.

SURVEY DEMOGRAPHICS

The majority of the survey participants have caring responsibilities for a child with SEND and are under the age of 11 years, with 65.79% are aged between 5 and 11 years, and 21.05% are under the age of 4 years. The remaining 13.15% of the participants based their views on looking after children or young people over the age of 12 years.

75% of the respondents resided in LU2 or LU3, and 68% had male children, and most of the respondents had children aged 5-11 (65%)

The majority of respondents were White British (44%) with 18% being Asian or Asian British Pakistani, 10% were Bangladeshi.

55.26% of all children and young people attend mainstream schools, with the remaining 44.74% attending special schools, (28.95%), preschool or nursery (13.16%) or education other than at schools (2.6%). Most of the parents outlined their children were in mainstream primary school (50%), and the majority who responded had children with Autism (64%) or Speech and Language difficulties (56%)

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59% of respondents had a Educational Health and Care Plan (EHCP) in place already, and 48% were current seeking SEN support, or going through the assessment process.

Most of the respondents were not PCF current members (67%)

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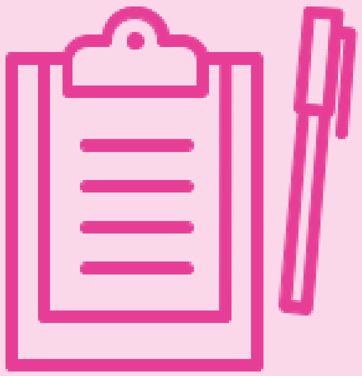
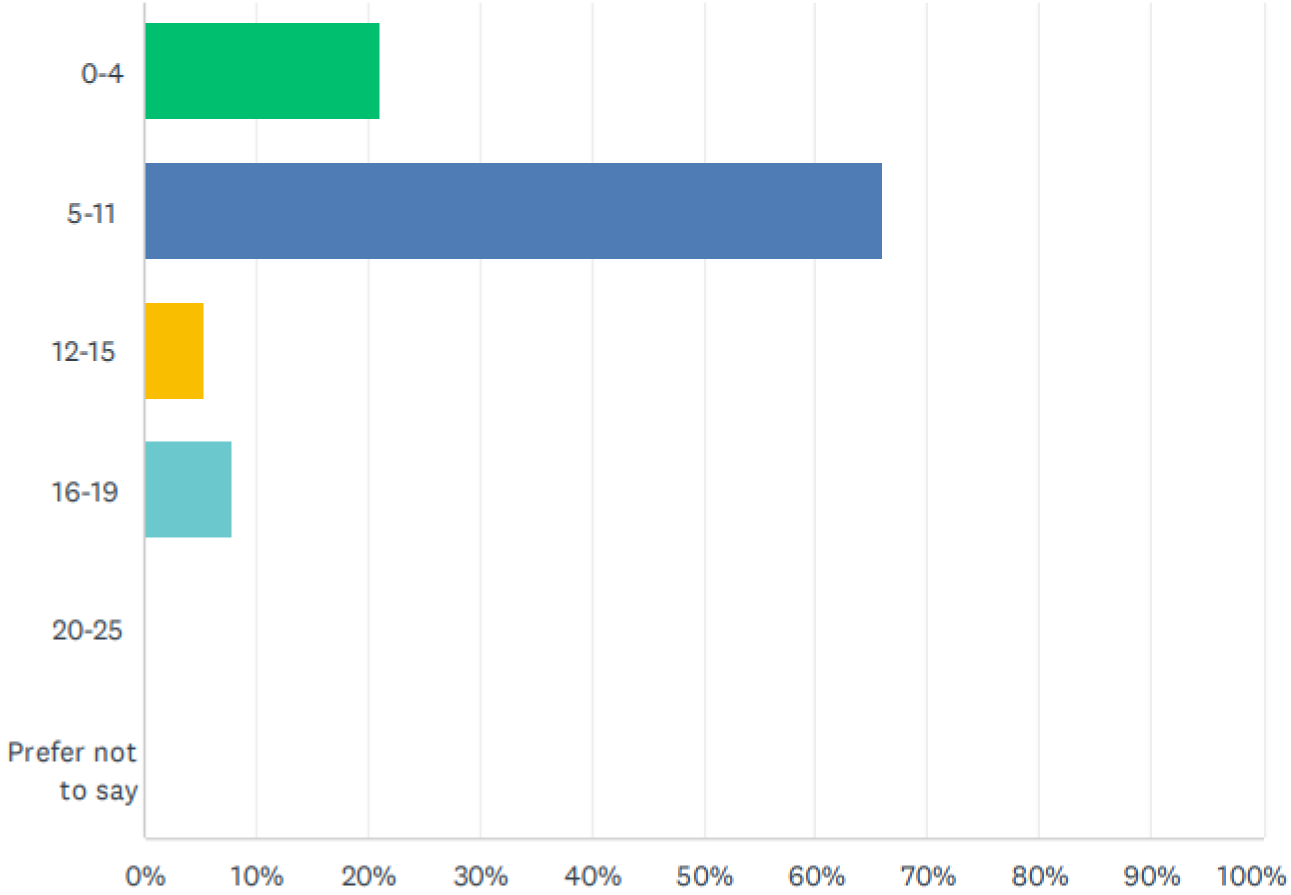


38 Parents took part in the survey



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Individual needs of children

ADHD/ADD	16.22%	6
Autism Spectrum	64.86%	24
Specific Learning Disability	5.41%	2
Emotional/Mental Health Needs	21.62%	8
Global Development Delay	16.22%	6
Hearing Impairment	0.00%	0
Visual Impairment	0.00%	0
Medical Needs/ Complex needs	8.11%	3
Physical Disability	18.92%	7
Moderate Learning Disability/Difficulty	10.81%	4
Severe Learning Disability/Difficulty	10.81%	4
Sensory Processing Difficulties	16.22%	6
Speech and Language Difficulties	56.76%	21
Profound and Multiple Learning Disabilities (PMLD)	5.41%	2
Dyslexia/Dyscalculia	2.70%	1
Don't Know	5.41%	2
Other	5.41%	2
Prefer not to Say	0.00%	0

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Overall Summary of Report Findings

31 of the 38participants described their overall experience of the EHCP process, 45.16% were satisfied, very satisfied or moderately satisfied. 32.25% were dissatisfied, moderately dissatisfied or very dissatisfied. While 22% were neither satisfied or dissatisfied. The main reasons for dissatisfaction included;

- delays in starting the EHCP process, diagnosis, receiving EHCP
- lack of staff, trained staff conducting EHCP
- complicated procedures

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- the most dissatisfied part is that most of the professionals who need to set important objectives do not attend meetings and that most objectives not followed in class.
- Moderate dissatisfied, 'was declined assessment, when evidence was clear, (child has numerous diagnoses and now has EHCP and attends a special school.

Among those who had given a moderate response of neither satisfied nor dissatisfied feedback was negative.

- *Annual reviews very slow process had to complain before something was actioned from a year ago.*
- *They are behind schedule*
- *I had an appointment with paediatrician back in April 2023 and they said they would send me a report and send my son for blood and genetic testing but after 6 months I'm still waiting for their response – SEN support stage parent states their at this stage EHCP Process not even started due to not receiving a diagnosis report which they have been waiting for*
- Sometimes better than others. Updates are rarely made in a timely fashion, and sometimes not made before the next year's review.

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- **Q9** How well have the Senat (Special Education Needs Assessment Team) communicated with you and kept you up to date with your Child's/Young Person's EHCP?

32 of the 38 parents and carers shared their experiences of how SENAT had communicated with them as well as keeping them up to date about their child's EHCP. Of these, 53.12% did not have a positive experience and 46.88% responded positively stating it was fairly well or extremely well.
Other than one participant who explained the *School SEN team have been very helpful,* participants did not expand upon their reasoning for positive responses. However, some of those who do not feel SENAT communicates well have explained this is due to:

- ***The length of time it took them to respond '8 months.***
- ***When my son was in primary school, got frequent updates. Since gone to high school, no updates. Chasing people but no response.***
- ***We meet each year with school and never any outside agencies.***
- ***Senat has never spoken to me***
- ***Always late***
- ***I didn't hear from them I had to chase it up regularly***
- ***Not very well If this is the EHCP co-ordinator, have only heard from her at the time the plan was drafted, sent emails after that but had generic response, not from same person.***

- ***Very hard to get hold of them and most importantly to get any meaningful answers.***
- ***Had to chase to communicate.***

Q10. How well did services identify and assess your child/young person's needs, including the support they are providing?

- Schools most likely to identify and assess child or young person
- GP/ other professional likely to get support

Education e.g. school, college	***Health services e.g. GP, Hospital specialist, wheelchair services, SALT, OT, Continence services, CAMHS***	***Social Care e.g. Early Help, short breaks, respite services, residential and supported living***
31 responses	*27*	*24*
Quite well	*Neither*	*Neither*
Poor	*Poor*	*n/a*
Not all his need's have been addressed	Health services diagnosed his needs fairly early and put support in place i.e. speech and language	Support is quite poor applied for respite lost carer because could not access funds. Placed a freeze on account for unrelated matter and

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		have been unreachable to resolve
Supportive	Very long process for diagnosis and still no written report	
My Son’s nursery, Pastures way was very good and quick in identifying his needs and moved on to get the support needed right away	Well	*Not at the moment*
Poor	*Poor*	*Great*
School identified	*none*	
beech hill were quite good but nothing official in place until got diagnosis confirmed from health services	Massive delays and appointments being cancelled. Referral took too long	
They have been very helpful and informative. 1 to 1 is very good.		
Nursery		
Pre school she attended helped to apply for the EHCP and were very supportive	Not much from SALT. Continence team currently helping us.	Not had any support in terms of short breaks or respite
Excellent	*Good*	*Good*
Very well		
Yes	*Yes*	*Yes*
School is and has been amazing.	After an assessment it pretty much stops.	Be more told about the them. I know nothing about social care or what they can offer
Poorly they do not support her well	Gp really well she is treated as a human	*n/a*

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Preschool		
Beach Hill Primary School	Kingsway Health Centre Luton	
Beech Hill primary		
Very well	*Very well*	*n/a*
Good	*None*	*None*
Well	*Well*	*Not heard from but not necessarily needed*
Very well	Not had much (if any) contact at all	Not had much (if any) contact at all
Weatherfield Academy has been excellent in every way they can.	Poor to moderate. Now needs SALT, but that's not available. GP surgery can be difficult to contact, slow to respond, and is inflexible due to the total reliance on technology. and hospital specialists Allergy clinic was very inconsistent. My son no longer has access to professional allergy support, even though we were advised his allergies will be lifelong.	No support has been forthcoming at all. We were told that due to my husband getting support for his disabilities, our son was not entitled.
Even though my son attends a special school he often come home with injuries and the school staff do not know how he sustained the injuries! I'm always worried about what bruises he will come home with. Our concerns are not dealt with adequately	GP services are very poor and do not understand the suffering that children with SEND have. My son has suffered numerous times from various health conditions which is worsened because he doesn't take the oral medication. However, dispute my pleas for help the	Respite services has failed us very badly!

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	GP surgery not alter their standard processes to help.	
Helped after a push	*GP was rubbish*	*n/a*
Good	*Good*	*n/a*
Appallingly, let down by the mainstream primary school	Waiting list ridiculously long but CAMHS have done ok	Social worker the most effective
Ayla's nursery has been very supportive in identifying her triggers and behaviours and supporting us in getting an EHCP for Ayla.		
	Generalised for children with more complex needs, mostly discharged. Feeling those with higher needs do not need provisions , those with better cognitive abilities offered more direct support. Very sad	What is this ? Do they ever offer help, follow their policy not the LAW
They noticed	*Long waiting list but support given*	*n/a*
Awful	Neurologist consultant was a great help	Early help were good for support in 2019

Very little to no involvement from Social Care, there seems o be a lack of awareness of how they would feed into meeting a CYPs SEND needs would be beneficial to do a piece of work to promote this. When considering working in a multidisciplinary way consider closer working with social care not just health and education.

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Long delays with delays with Health Services, General dissatisfaction with wait time for diagnosis, lack of follow up.
Education, credited as the main way CYPs SEND needs are identified and supported, May be beneficial to explore what is working well and whether it can be implemented at an earlier stage via health, i.e. Diagnosis, assessments with a particular focus on education as well as Social Cares involvement in a meaningful way to education i.e. Respite ,activities that teach life skills, social skills making education more accessible.

Q11 What could services have done differently to support/ meet your child/ young person's SEND needs.
Areas for improvement include better communication and more involvement of carers. More staff training.

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1 participant stated ' Nothing. They are amazing Support her more rather than treat her as a 'naughty child'.

Another participant stated 'Since attending Weatherfield Academy, I am very happy with the support there. The school fits his needs 100%.'

Education e.g. school, college	***Health services e.g. GP, Hospital specialist, wheelchair services, SALT, OT, Continence services, CAMHS***	***Social Care e.g. Early Help, short breaks, respite services, residential and supported living***
More communication	*Regular updates*	*n/a*
Support an EHCP	Don't delay referrals eg OH	*n/a*
Listened more, provide more tailored support	Have a clearer communication route	
	Quicker diagnosis and support	
More support with training and pointers to access or support for family members	More face to face	A few work shops and training face to face
Listened	Listened	
School is failing to meet the needs of my daughter. No quiet/ sensory room. No changing room as she is in nappies- currently changing her in an office. Keep changing her 1-1 staff so she is unsettled.		
	Please reduce the assessment period	

Nothing. They are amazing Support her more rather than treat her as a 'naughty child'	Offer more appointments and checking rather than signing off.	Be more informed I know nothing about social care or what they can offer
Having the staff and training	Speech language non existent	Everyday care
Help with his learning		
More options available at a younger age to help reading and writing	Although telling me she needs an EHCP and telling me to chase, they could have written a letter to support the application	*n/a*
Now my child has moved schools she is in a better place	Continue continence	None
Nothing needed yet but only been there 5 weeks	Earlier intervention, should have followed up on CP investigation after birth	N/a
	Long waiting lists	
	Contact me & explain support available	Contact me & explain support available
Since attending Weatherfield Academy, I am very happy with the support there. The school fits his needs 100%.	GP needs to be more easily accessible, and more flexible. Allergy support/regular allergy checks need to be made available. Speech and Language Therapists need to be available - if my son had intervention as soon as his problem developed, it would not become established.	Social services have a limited budget. In my experience their assessments are more to do with saving them money than with actually helping people.

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Listened to us and the difficulties we have at home. Kept a better eye on my son in the playground.	Find an alternative medicine for my son because he cannot take the oral medication due to his ARFID diagnosis.	They are so busy that they cannot help everyone which leaves a lot of SEND children and their families suffering
Have his teacher believe my concerns	GP needed to be more knowledgeable and have up to date understanding on autism not outdated beliefs	N/A
Communicated in a timelier manner	Better handover to school before being discharged	N/a
Educate SENCO manger held her accountable for the failure of our son's education. Educate staff on mental health and ASD how to spot it and support a child with these needs and to work with parents not against them	To have more time for it child. More CAMHS workers to support more children on a regular basis. Also have workers to support parents too.	To help parents not feel threatened by there presence to help parents not judge them.
If the nursery had had more resources and staff for her needs.		Offering parents more support and options of having respite care in the home.
Options of independent schools and colleges on local offer and given to child	Stop discharging those with complex needs, tailored support	Give help to parents carers and families
They did report before EHCP draft	They gave support after long wait	They did report before EHCP draft
Listen. Sign post me to support like the parent carers	Let me know that ASD was a higher likelihood since his	Advocate for me and my son. Sign post to benefits

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forum. Offer support like an invite to the coffee morning held in the school family room.	epileptic seizures. Let me know sleep issues were more likely and common then I would have reached out for help with them sooner	available. Help or sign post to help to apply for example to Luton a money Advice Centre. Someone suggest carers allowance and DLA

For education, main ask for parents and carers is support would have been in place sooner if they were actively listened to and concerns were taken seriously. May also be useful to explore what those educational settings with positive feedback are doing differently to meet the CYPs needs more effectively.
Training : Maybe useful to do Coffee sessions, focus groups etc to identify what type of training families feel is needed – also if they mean training for professionals or parent/carer.
Health: not treat CYP as a diagnosis, tailor support to them and ensure interventions with SEND families are done in a more meaningful way, giving them strategies to support CYP from an earlier age. Promote pre-diagnostic support (make it more accessible)
Social care: Better open communication channels with family, create opportunities to promote what they do and address concerns from families about getting them involved

Q12 What can SEND services do/ provide to help you as parent/carers to support your child/young person's Education, Health and Social Care needs?

Education e.g. school, college	***Health services e.g. GP, Hospital specialist, wheelchair***

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	services, SALT, OT, Continence services, CAMHS
Advise rather than signpost	Regular updates on appointments
Support an EHCP	Timely referrals
Reduce wait times on getting EHCP draft	Na
Support with EHCP	More communication
More support with training and pointers to access or support for family members	More face to face
Listened	*Listened*
Providing more resources to be able to provide one2one support for the child. Also regular updates to the parents	Quicker times to get diagnosed and also more resources to help parents getting a diagnosis
I think my son can't fit into mainstream school and needs to be sent to special school. He doesn't speak or join with any learning	
Education	
Help to speak to school, where are they using the funds they received for my daughter?	
None	*None*
Next steps very limited with options to suit child’s needs.	Stop doing wrong operations and to do what needs to be done so quality of life is given.

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Bring in more resources for my child's needs	Instead of discharging work with these children
Help with his work	
School is helpful and supportive - more aware of working parents who can't attend meetings due to work	More aware of working parents
Continue with coffee mornings and info sharing	Be consistent and clear
	Mor support whilst awaiting diagnosis
	Contact me & explain support available
Communication is key	
Listen to parents. Weatherfield Academy does this very well.	More accessible. Register young people as having LD, so when they turn 16 medical help is not refused when requested by parent/carer based solely on the young person's birth date. We have had to ask our son to speak to medical people several times to give his consent, which he finds confusing
They need more staff to know the specific needs of the child so that they can support their specific needs	More trained staff who have the understanding of how to best treat children with SEND
Clear communication, better time keeping	Better explanation/handover before discharging to school

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Communicate, not judge, or parent blame, to educate themselves so parents don't feel they are fighting against those who think they know better.	More support for parents as well as child. More communication more services groups etc
Offer classes or courses to help have a better understanding of children with autism	Needs more priority when booking tests and appointments
Advocate independent to come to meetings (not subdues)	Advocate from health
Suggested options to support	More speech therapy
Monitor what schools are doing. Especially look at cases and how unsupportive the school were. Support the mental health of all family members.	Support the mental health of all family members

For all three services better, open communication, keep them better informed even if there are likely to be delays.
Education – upskill train parents will help with wrap around support for the CYP. Regular coffee sessions
Health- improve communication, offer more face to face intervention, more services, shorter wait times, May be useful to

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explore ways of upskilling families in use of pre and post diagnostic support, ensuring it has an focus on education
Social Care: Clarity on how they can support SEND families, make support more accessible, improve communication methods.

Q13 How do you feel the plan of care provided by services reflects your child/young person's needs?

A real positive is that 71.05% of participants expressed. how they felt the plan of care provided by services reflected their child or young person's needs. Feedback around the plan generally was very good, with participants stating it was good and excellent.

- Well -break the needs down and set targets specific to them
- Below expectations
- Address almost all his needs
- Not very well
- Not adaptive enough as the child grows up. Support to be provided accordingly and also to take parents feedback on board, instead of being dismissive

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- Have had to compromise on his academic ability to meet his other needs as no moderate learning school and special school do not accommodate full
- Currently my daughters needs are not being met
- Excellent
- Good
- Not completely as there is no MLD school nearby and would've have to moved away from family and my support network to get my child the proper support tat catered to her needs.
- I am unsure on the plan
- Limited speech
- Good
- Good
- They seem to be good until on the list for an operation and then all gets put on hold.
- Very good
- Well so far
- The school have done a great job. The nursrey was not on the ball.
- Good

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- School's plan of care is excellent. Weatherfield Academy is exactly the right place for our son. Health and social services are poor and do not provide appropriate support.
- The plan is never met! We put the needs of our child in the EHCP but it simply isn't followed in school.
- Expectation from health that school will pick up all aspects is not appropriate
- There has not been even enough contact or updates, Ayla has been on a waiting list for Edwin Lobo too long
- Not accurate and needs not met , child suffering but no help or support
- It provides a gradual impact
- It's basic
-

Recommend work is done so follow up is done to ensure plan of support is actually being put into practice, is actually meeting CYPS needs by making a positive difference, regular interventions, not just annual reviews, or one off diagnosis, plot the SEND journey with impact of support/ intervention

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Q14, Do you feel this plan is monitored frequently and/or appropriately?
Confidence in monitoring the EHCP Frequently enough or approximately is low. less than a third of the parents and carers feel that the EHCP is monitored frequently enough and/or appropriately. The remaining 69.44% either believe required actions are not happening or are simply unsure on the matter.
EPIC Luton PCF recommend that further investigation is done on this matter.

Q15 As a parent/carer how involved are you in decision making about setting your child/young person's targets and outcomes?

A real positive response from 82.86% of the parents and carers have stated that they are either quite involved or very involved in the decision making about setting their child or young person's targets and outcomes. However, feedback shows that there is more that can be done to enable them to actively participate.

Q16 Parents and carers have asked for:

- Regular meeting with parents
- Discuss support/ provision in place as well as reasoning for it

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- I think it’s more about educating the parent.
- Listen
- Regular meeting with the child and see what support can be provided to help achieve the targets. Also providing guidance to parents, in helping reach these goals. Also service to be provided in other languages
- Be in touch directly with the school to ensure they are following the EHCP and not misusing the funds. 5 weeks in to the term and no changes made.
- If there is such things as, support with holiday, trips out. I’m a single full time employed mother of 3. It cost me more to send my child to a special school than it did with my other two. I don’t get that when there is funding. When it comes to social skills it should be funding by the EHC. It shouldn’t cost me more cause she has extra needs. The holidays and trips support really gets to me. As all my children have missed out of those things due to not being informed.
- More communication rather than pushed aside
- Bring back all the help that parents need and someone to talk to when needed instead of brushing problems aside m,

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a mainstream school that wants to be inclusive needs all the help and support to help our children thrive not be left behind
- Like a sensory slot for parents to see there child do things
- Inform of progress
- We are very involved in the EHCP meeting and in setting targets but they are not achieving or monitoring throughout the year.
- Communication
- Nothing I can think of at the minute as ayla's receives a lot of support at home with her parents and at nursery
- What does the child need to achieve best possible outcome, then give them that and then we can see what the child can really achieve
- Stick to IEPs
- Show examples of what they could be

Q17 How well do you think the professionals from Education, Health and Social Care work together to support your child/young person?

55.55% of parents and carers believe different professionals from Education, Health and Social Care sometimes communicate and work together or rarely, if at all, when it comes to supporting their children or young people. They state:

- 'Due to this, they have to draw all services together and tell person A what person B has said and so fourth'
- Some professionals haven't really been in touch with me and I don't know if they been in touch with GP or anyone else
- No-one works together, checks notes, discuss, every appointment you spend most of it filling them in on what and when they have had anything. That's a waste of time when you have 40-1hr appointments everything is timed to bring everyone up to speed. Waste of time
- There is Lack of communication/ handover between services - expectation that school will do it all
- Tick box approach where you feel they have come together in some aspects but you really do not feel there's a plan or support that works but ' everyone's hands are tied'.
- Poor working together all separate. Feel like all the onus is on me

Further work is needed for education, health and social care to not only work collaboratively with their inner sub teams/ services but for

all three collectively as one rather than fragmented education or health or social care support.
18 Do you think there are enough leisure activities for SEND children or young people to access in Luton?

62.86% of parents and carers, do not feel there are enough leisure activities in Luton for SEND children or young people to access. A further 5.72% (other, don't know). while not actively looking for any feel these activities are lacking. Parents and carers feel:

- 'children's parks need to be more adapted to children with visible and invisible disabilities'.
- 'Not enough for children and young adults without additional needs let alone children with needs'
- Cannot get my child into a gymnastics group tried to no avail as of yet sports clubs seem to be a no for our children , my son loves basketball ball but nothing to help him live his dream
- No, I'm not aware of any
- No, I have looked and even signed up to autism Bedfordshire and not enough activities for school infant children and families.
- No, Nothing within 30 mins drive, yet we have one of the biggest/newest sports villages (Inspire) on our doorstep

- No, There aren't enough sen sessions for activities in Luton
- No, Limited/one of session as opposed to regular session s
- No, Child too complex and nothing offered , those more able gave full choice
- No, Unless your child is diagnosed with autism I find there is not a lot of services available
- No, Definitely not

Review of leisure activities that are accessible especially for those with complex SEND needs CYP – piece of work primarily with social care, however may be beneficial to involve health and education as there is some overlap

Q19. Have you heard of the Luton Local Offer SEND Information Hub? Prior to completing this survey 50% of the parents and carers had heard of the Luton Local Offer SEND Information Hub. Q20 After using the Hub 24 of the participants shared how well they found what they were looking for :

While 8.33% found what they were looking for easily and quickly, 58.33% struggled with varying degrees to find what were looking for however 33.33% never found what they needed. this resources intended purpose is to make it ***easier for children and young people with special educational needs or disabilities, and their families, to find information about what support services are available in their local area in one place, as such further work is required to make it more user friendly, create more awareness about it, we would recommend this done collaboratively with end users at various stages of their send journey to make it more fit for purpose.***

Q 21. Do you feel your child/young person has the help they need to achieve their best possible outcomes?

- No, more services and activities need to be SEN centred and inclusive.
- Maybe, some teachers have no clue and find the behaviours disruptive rather than there could be more.
- No, not enough information. With my child's need I couldn't even think of sending to college even though that is what she wants, as she will be emotionally or physically abused, no support.

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She doesn’t even know what she would want to do maths and English is all she says. She has done terms where she has visited them. What does that say in it self. Internships which is the way to go for my child. Again no information and not many options.

- No, I don’t feel my child is supported much at school
- Maybe, Always room for help and support.
- Maybe, School have been great so far.
- No, Apart from at school we don't get any other support
- Maybe, While he is at Weatherfield Academy, I have confidence that he is receiving the most suitable support for him as a person. It's what happens after he leaves that makes my answer a maybe.
- No, We are very concerned that our son isn’t getting the help he needs which will be a detriment to his later life
- No, Discharged from health too easily with the expectation that school will pick up all support - still need health input
- No, His school let him down for so many years it may be beyond repair. There's nothing being offered to help him get past that, therapy etc they need more fun things to do with mentor support to try to trust adults in education again. And it's not

being offered. Everything takes too long and or needs a prolonged application and then accept to see if your child is worthy of such help. This is not helping a child thrive and be there best.

- No, Lack of personalised support detrimental to child leading to poor education, mental health issues and a need to come out of settings soon
- *More ownership of each interventions, signposting with explanation why, Review ensure follow up is done, avoid labels/stereotyping, tailor support to child treat as an individual not a diagnosis, active listening, address family concerns*

Themes

A common theme identified was the waiting time for an EHCP and the annual review of an EHCP. Respondents identified the EHCP process was slow and annual reviews were behind schedule. However, in relation to how well educational needs were met, the majority of schools are meeting children's / young peoples' individual needs, with positive feedback including, professionals identifying triggers and behaviours and being very supportive to meeting needs. A minority of

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responses identified their child's needs were not being met within the school.

The majority of respondents felt their needs were being met and did not need to improve. The majority of parents/ carers felt they were involved in the care plan. When asked how service provider could improve, communication and meetings were highlighted. One respondent asked about provision outside school, for social development.

Another common theme is around poor communication, across education, health and social care services, and meetings should include including a range of professionals attending the meetings to set objectives and these being followed through in class. Respondents identified good communication is the key for SEND provision to work well. Listening to the carer and supporting the whole family. Proving enough resources within schools and special provision where it is needed. Providing specialist nursing care where needed.

Most respondents 63% thought there was not enough leisure activities for SEND children and young people, one respondent identified how

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much more expensive it was for SEND children and young people to participate in activities.

50% of respondents had heard of the local SEND hub. Those respondents who have used the SEND hub 50% found what they were looking for after a bit of a search.

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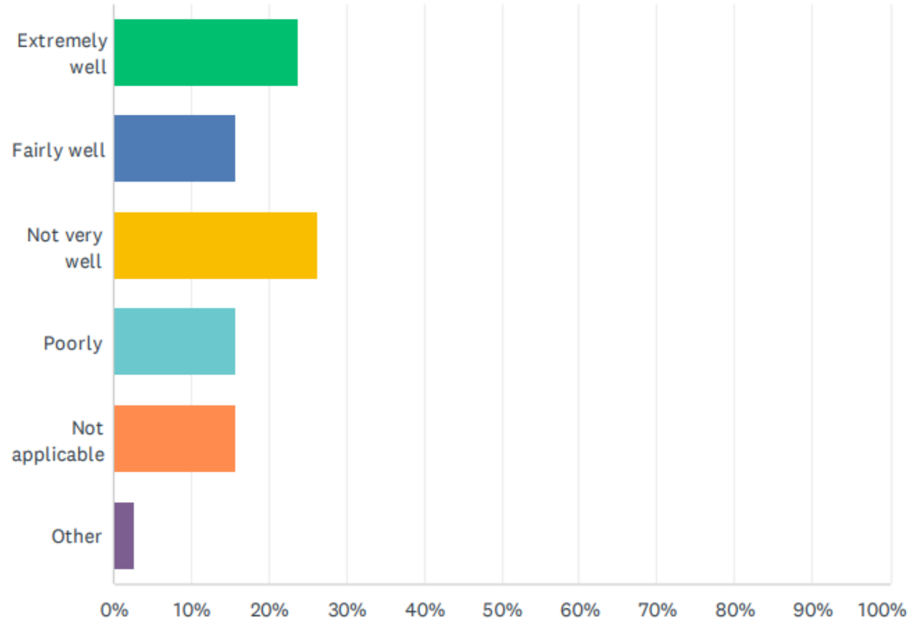
Q9 How well have the Senat (Special Education Needs Assessment Team) communicated with you and kept you up to date with your Child's/Young Person's EHCP?

Answered: 38 Skipped: 0



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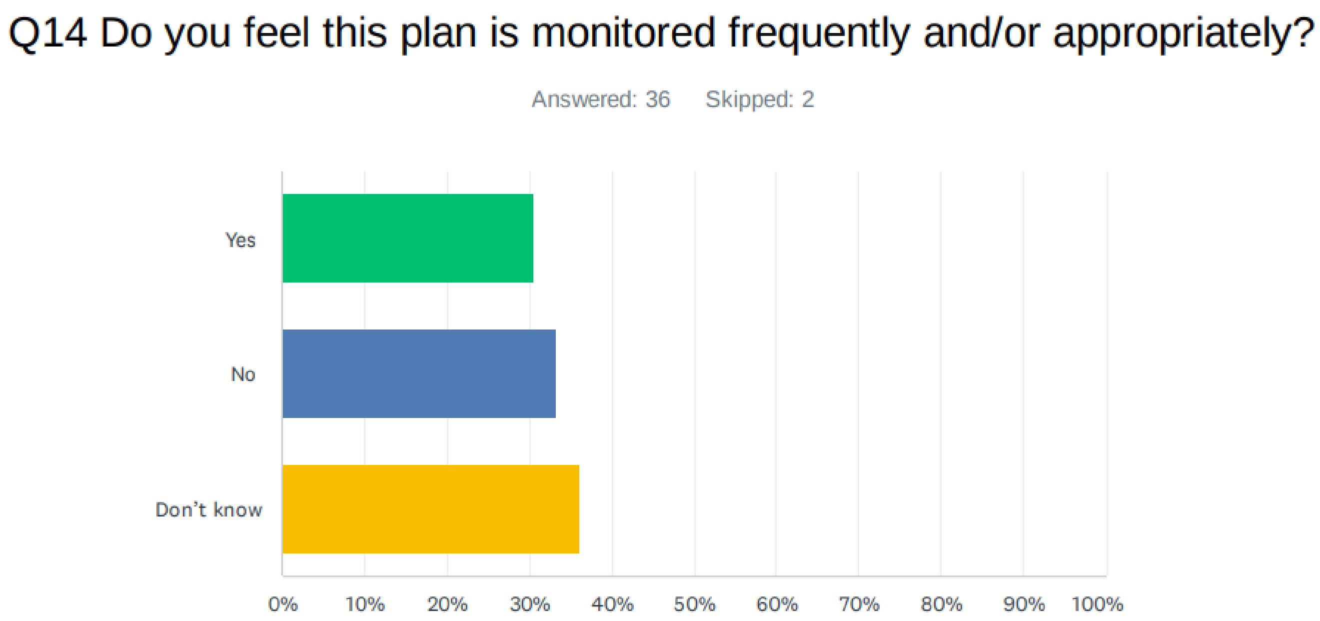

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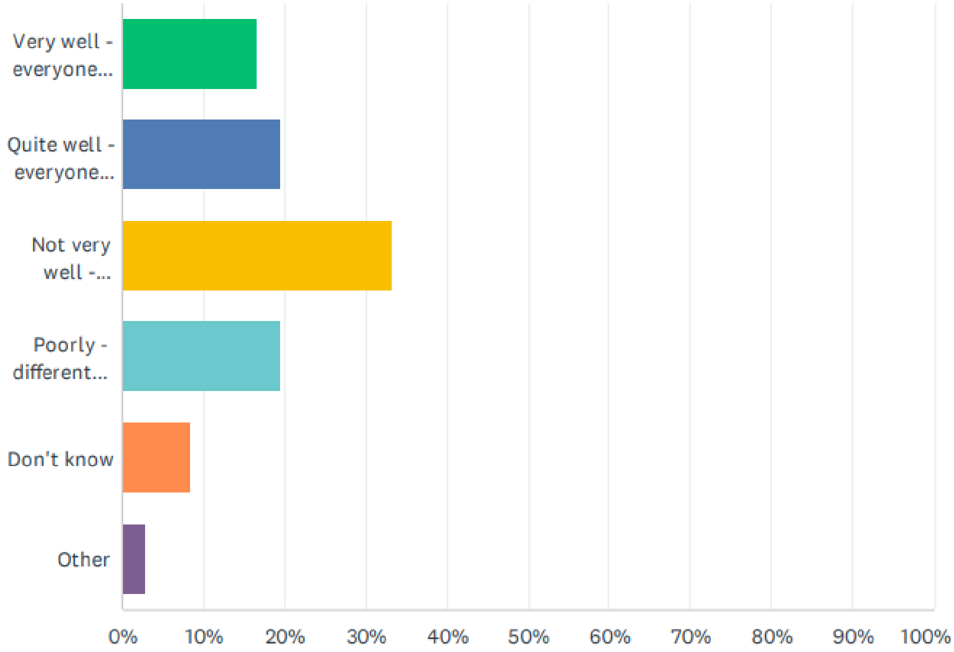
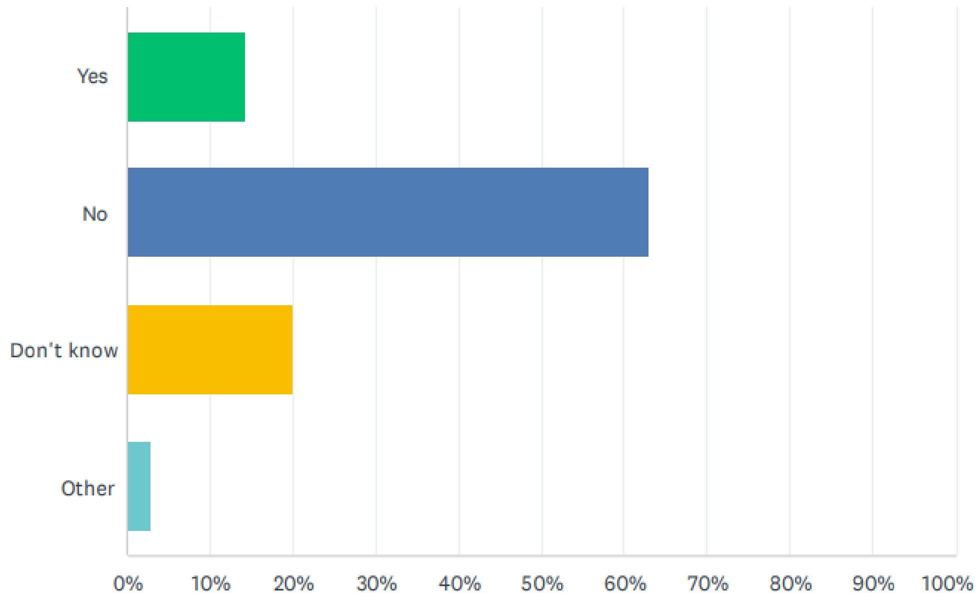
Q17 How well do you think the professionals from Education, Health and Social Care work together to support your child/young person?

Answered: 36 Skipped: 2



Q18 Do you think there are enough leisure activities for SEND children or young people to access in Luton?

Answered: 35 Skipped: 3



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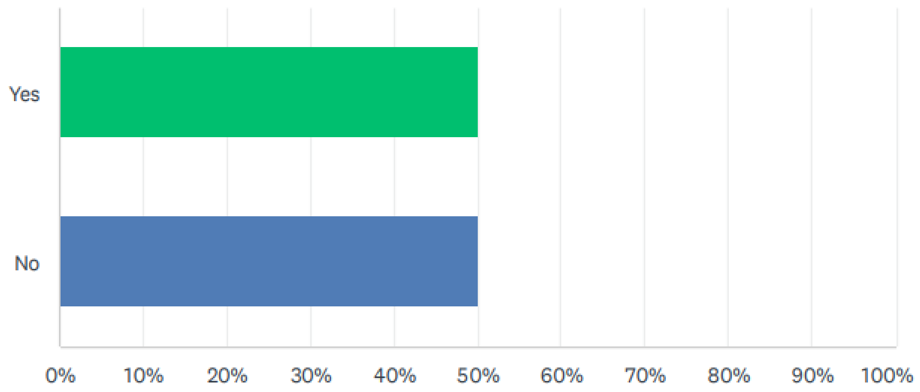

Q19 Have you heard of the Luton Local Offer SEND Information Hub?

Answered: 36 Skipped: 2

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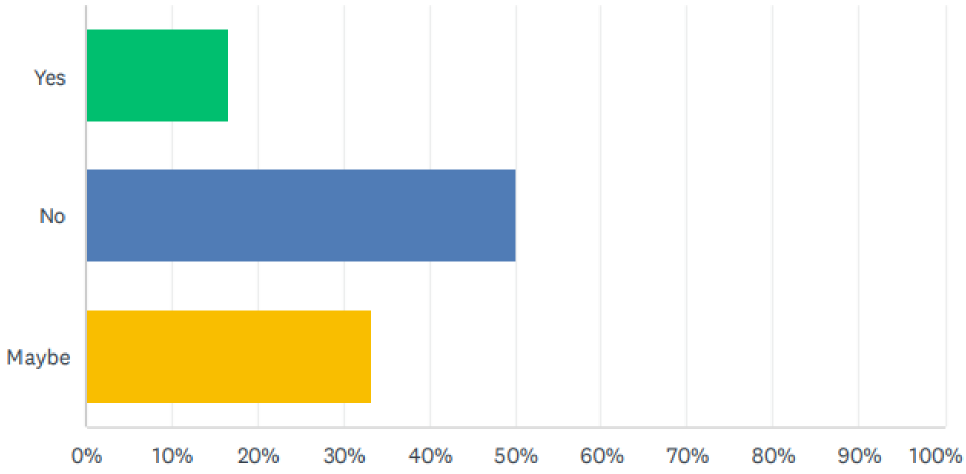
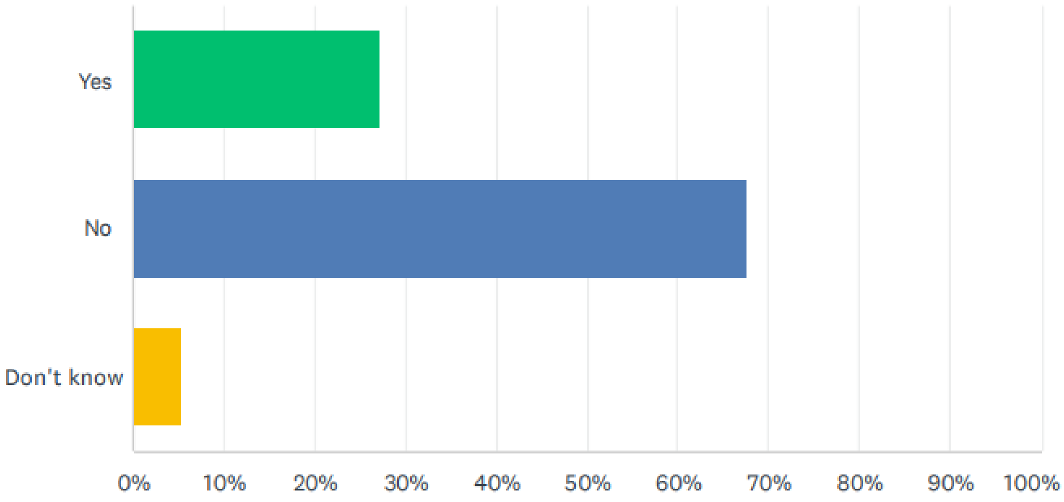
Q21 Do you feel your child/young person has the help they need to achieve their best possible outcomes?

Answered: 36 Skipped: 2



Q22 Are you a member of EPIC Luton Parent Carer Forum?

Answered: 37 Skipped: 1



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Recommendations for improvement.

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Healthwatch Luton would recommend referral times for initial EHCP to be reduced, enabling intervention and support in schools earlier. Annual reviews of EHCP to be more timely and multi-disciplinary team involved in setting targets. EHCP should be shared with professionals and carers quickly.

Healthwatch Luton recommends communication between education, health and social care professionals is vital. Communication between professionals and carers needs to improve and have a clear route of communication, which will involve regular meetings, to discuss progress in meeting the EHCP. Carers/ family voice is important.

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