EHCP Pathways

The perspective of parents and carers in Barking and Dagenham

August 2023

healthwatch
Barking and Dagenham

About us

Your health and social care champion

Healthwatch Barking and Dagenham are an independent champion for people using local health and social care services. We listen to what people like about services and what could be improved. We share their views with those with the power to make change happen. We also share them with Healthwatch England, the national body, to help improve the quality of services across the country. People can also speak to us to find information about health and social care services available locally. Our sole purpose is to help make care better for people.

In summary - Local Healthwatch is here to:

- help people find out about local health and social care services.
- listen to what people think of services.
- help improve the quality of services by letting those running services and the government know what people want from care.
- encourage people running services to involve people in changes to care.

Everything that Healthwatch Barking & Dagenham does will bring the voice and influence of local people to the development and delivery of local services, putting local people at the heart of decision-making processes.

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Summary

Over the past few years, both in Barking and Dagenham as well as nationally, the number of students with special education needs and disabilities (SEND) has increased along with the demand for EHC plans.[1] SEND encompass a wide range of difficulties that affect a child or young person's capacity to learn, resulting in the need for extra support, such as assistance in taking part in usual class activities or help communicating with others, and help with physical and personal care.

This complex care is specified in an Education, Health and Care Plan for a child or a young person up to the age of 25, to enable them to achieve what they want in their life.[2] It is important to note, that educational achievement is firmly correlated with health outcomes. However, Barking and Dagenham still has too many children and young people achieving low educational performance.[3]

This report will reflect the variation of responses received by parents, for example:

- 83% of respondents indicated that their child had either fully or partly been supported to achieve their best educational outcomes
- 57% of respondents indicated that they and their child allowed to participate as fully as possible in decisions, and provided with the information and support necessary to do so
- 68% of parents/carers indicated that their child was offered careers advice, apprenticeship or work experience opportunities

However, respondents' experiences varied, indicating that not everyone in need has equal access to the process and support. It became clear that some families go through the procedure without a SEN caseworker being involved, and that the process and follow-ups are lacking coordination from one. Along with speeding up access to services that are anticipated to operate more cooperatively, more has to be done to involve parents and carers in the discussion and support them in understanding the EHCP.

EHCP content sometimes differs from what is offered in the real world, however, discrepancies in support received is not an issue confined to LBBD; many areas

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[1] SEND Provision Report (lbbd.gov.uk)

[2] BHRJSNA2022_LBBD_Final_internal version.pdf

[3] LBBD-Corporate-Plan-2020-2022_0.pdf

are under resourced, and this is an issue for multi-agency partners rather than sitting with one organisation.

At the start of 2023, Healthwatch Barking and Dagenham conducted a research project to look at the effectiveness of EHC plans and to understand what the barriers are in getting and following through an EHCP. Healthwatch Barking and Dagenham also investigated the areas of EHCP that are working well.

Additional areas that Healthwatch Barking and Dagenham explored were the EHCP process and SEN Case Worker`s role[1], family involvement, quality of EHCP, annual reviews, quality of education, support with transition into work-like activities and quality of support received from health, social care, and other support services. Families that didn`t have an EHCP also were given an opportunity to share feedback on relevant subjects.

Healthwatch Barking and Dagenham attended 9 schools and 1 local support group to gather responses to a survey and gather qualitative data through focus groups. Despite the greatest efforts to promote attendance, no responders were present at 2 schools. The survey was distributed via social media on Twitter and Facebook and also shared in Healthwatch and other stakeholder newsletters. Healthwatch Barking and Dagenham received assistance from several support organisations in disseminating the survey to parents and carers. In total, 79 respondents who participated in a survey or focus group discussed their experiences.

Overall, parents want their children and young people to be treated holistically and to have their opinions heard. Promotion and incorporation of excellent practice examples are required, based on feedback from participants, such as the SEN Caseworker being fully involved to reduce the burden of this complex process, and providing good communication on updates.

Introduction

As recovery from the pandemic begins, it is evident that children and young people with SEND are now even more vulnerable than they were before. The importance of good-quality universal services for children and young people with SEND across education needs to be ensured, as it has been identified that

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[1]

about 1 in 10 children are born with or develop substantial and lasting difficulties thus requiring support from health, social care, and education professionals.[1]

This study was carried out by Healthwatch Barking and Dagenham to examine the efficacy of EHC plans and identify any obstacles to obtaining and implementing one. In addition, we are interested in learning about the areas that are working well. More significantly, this study captures the perspectives of Barking and Dagenham's most vulnerable service users.

This report was requested by the SEND partnership which includes the council and health services as part of a self-reflected improvement plan. Additionally, past feedback from residents showed that the EHCP procedure has gaps, which made this study necessary.

Furthermore, children with social, emotional, and mental health needs identified as a primary need on their EHCP, as a percentage of all school-age children, is higher in London Borough of Barking & Dagenham (LBBD) (2.7%) than the national average (2.4%), and rates in London Borough of Havering (LBH) (1.2%) and London Borough of Redbridge (LBR) (1.9%) are significantly lower, according to Barking & Dagenham, Havering, and Redbridge Joint Strategic Needs Assessment Profiles. Furthermore, reported rates of children and young people with SEND in LBBD (14.5%) are higher than England's average (14.4%), LBH (11.0%) and LBR (11.8%).

In response to this, and due to an unprecedented surge in demand for services, LBBD have invested additional funding in recent years to increase the capacity of its EHCP team, and the NHS have invested in building upon their ASD diagnostic pathway.

It is important to note that Healthwatch has not conducted this kind of research before in North East London.

Methodology

The research was carried out using focus groups and a survey. Most conversations have been face-to-face because this is more effective in obtaining high-quality feedback. Parents and carers recognised that we refer to official case workers as SEN caseworkers throughout all of our engagement work.

Over the course of two months, focus groups were held at 9 schools and one location where a parent support group meets.

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[1] BHRJSNA2022_LBBD_Final_internal version.pdf

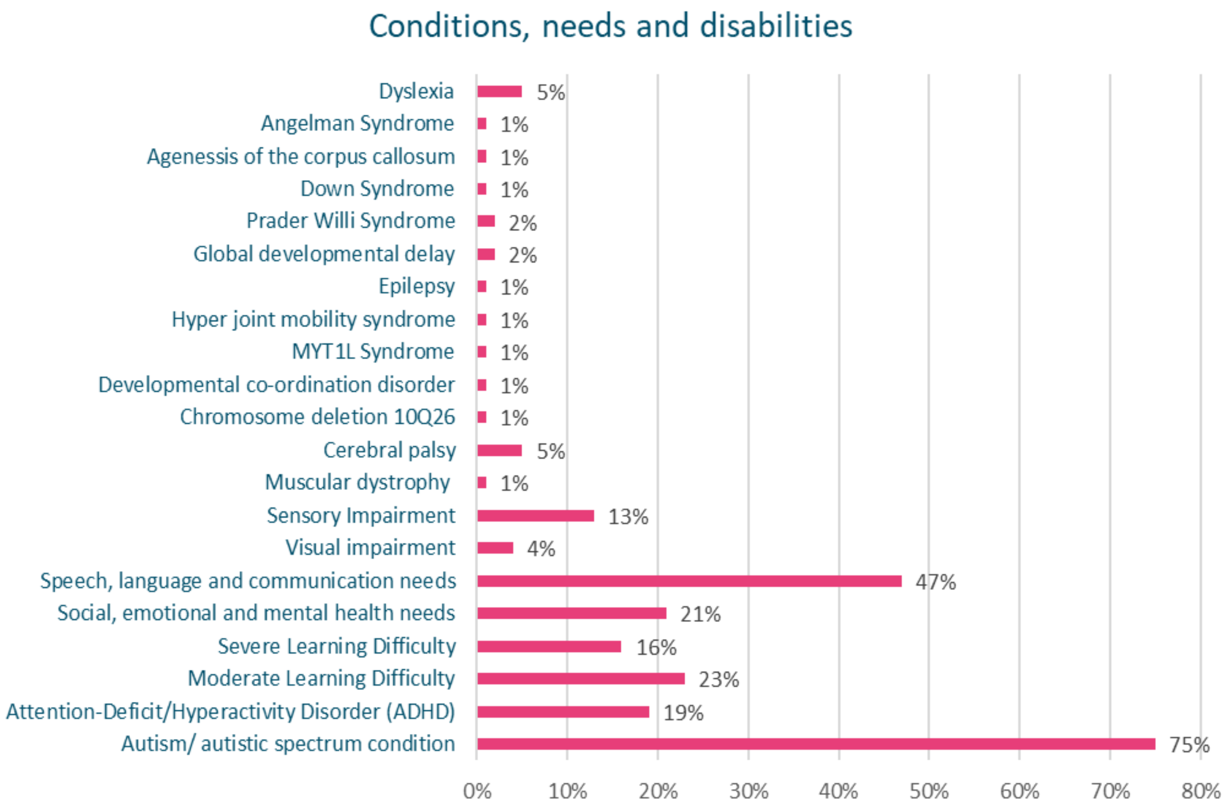
The survey has been disseminated through social media, including Twitter and Facebook, as well as newsletters from Healthwatch and other stakeholders. This study included 79 respondents.

Before launching the project, the Just Say forum and the Carer's Centre were visited. Residents who expressed interest in participating in the project were then given the survey. A printed and online survey was distributed among current contacts with the assistance of the Ab Phab Youth Club.

Child/young person`s demographic information

Conditions, needs and disabilities.

The graph below shows the conditions, needs and disabilities that respondents` children or young people had.



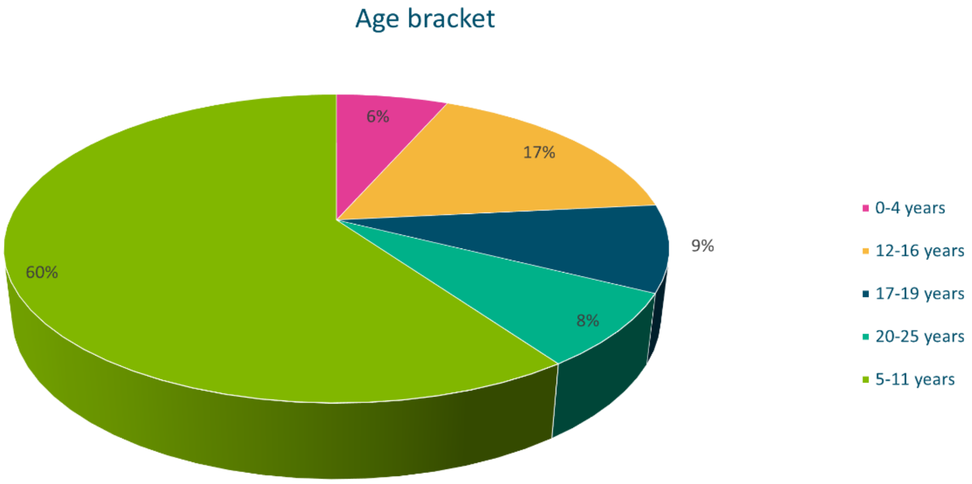
75% of children or young people have autism, and 47% have speech, language, and communication needs. These findings are consistent with Barking and

Dagenham Joint Strategic Needs Assessment 2022, where Autistic Spectrum Disorder is listed as the most common primary need identified in EHCPs, followed by speech, language, and communication needs.

The fact that nearly a quarter (24%) of children and young people have four or more conditions, needs, or disabilities suggests the necessity for effective multiple-service participation to assist with those.

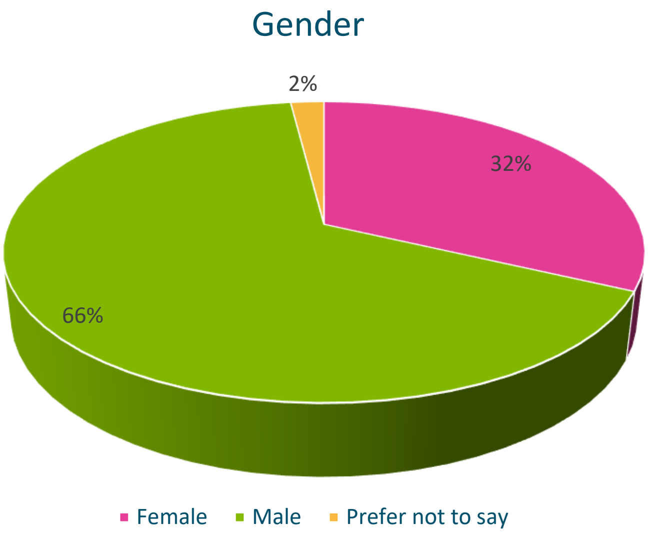
Age

At the time of undertaking this project, the majority of children (60%) were 5-11 years old, 17% were 12-16 years old, 9% were 17-19 years old, and 8% were 20–25 years old. The smallest proportion was 0-4 years old (6%).



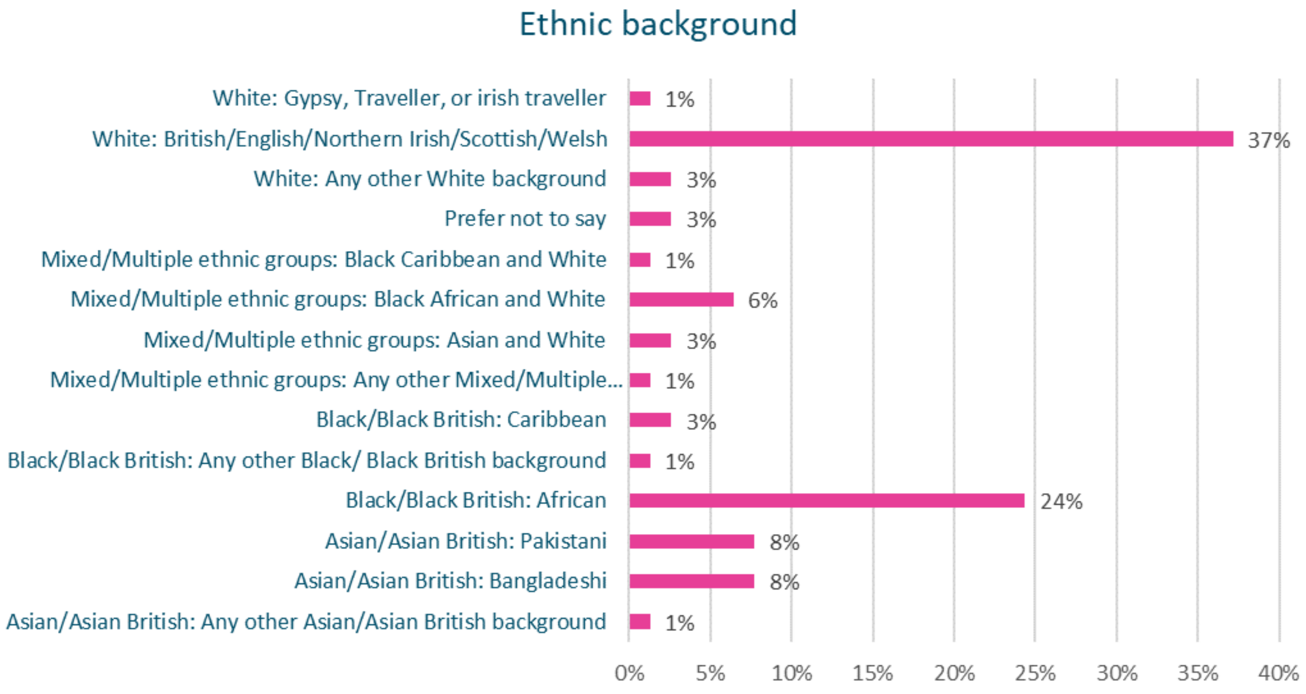
Gender/gender identity

66% of children or young people were male, 32% were female, and 2% preferred not to disclose their gender.



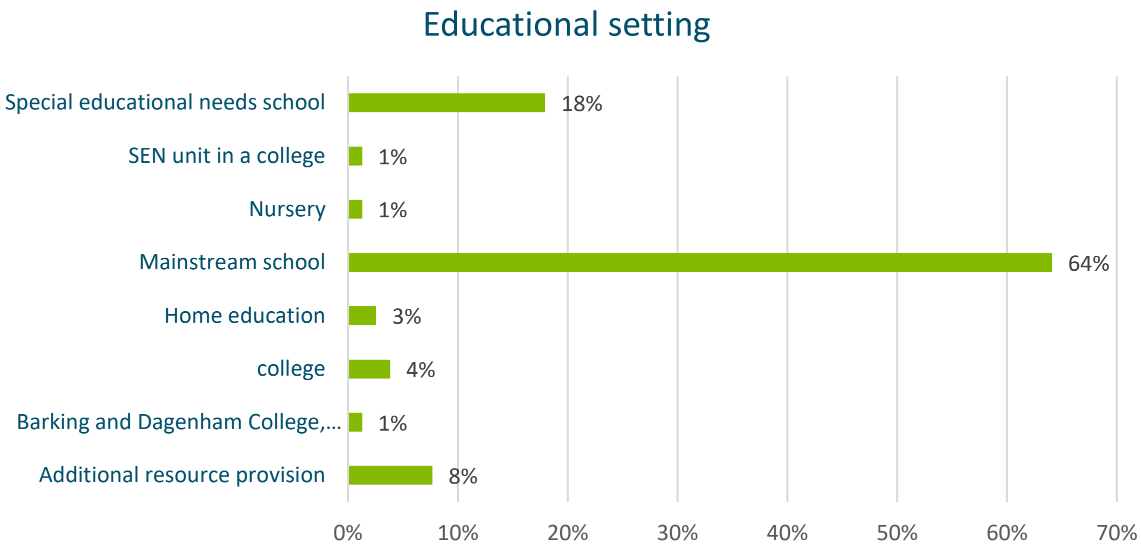
Ethnic background

More than half (56%) of children or young people were from black, Asian and minority ethnic communities.



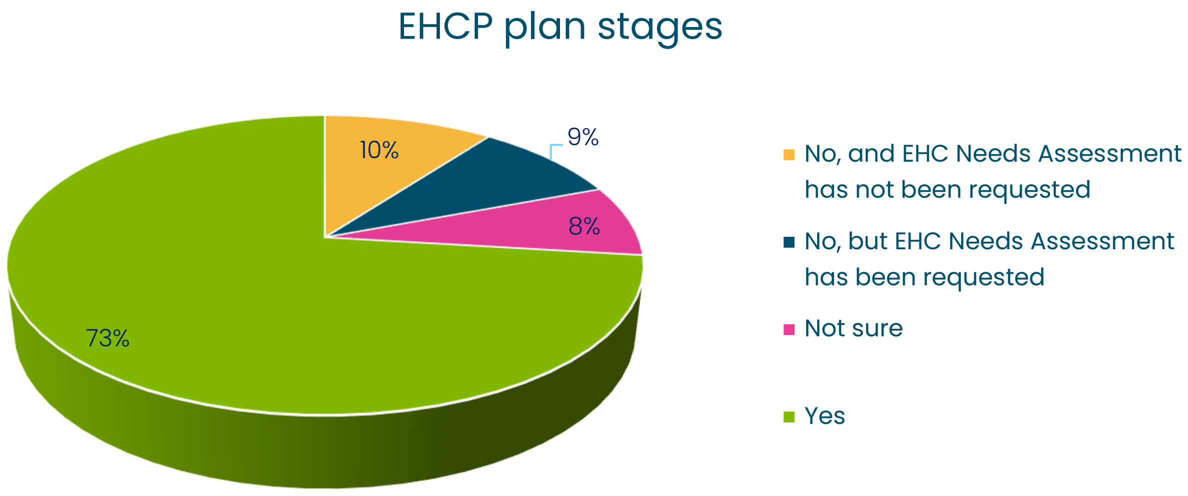
Educational setting

During the time our team undertook this research, 64% of children attended a mainstream school, 18% were attending a special educational needs school, and around 6% were in college. 3% were home-educated.



Does this child or young person have an EHCP?

At the time of speaking to parents, 73% of children of the respondents had EHCP in place and 10% didn`t. For 8% of children an EHCP was requested, and 8% were not sure about the status of EHCP.



Findings

1. EHCP Process

1.1 SEN worker role and EHCP implementation process

EHCPs aim to meet the special educational needs of children and young people, improve outcomes across education, health, and social care, preparing them for adulthood.[1] The process of obtaining and implementing an EHCP can be overwhelming and confusing for many due to numerous barriers and communication challenges between parents, schools, and local authorities. [2]

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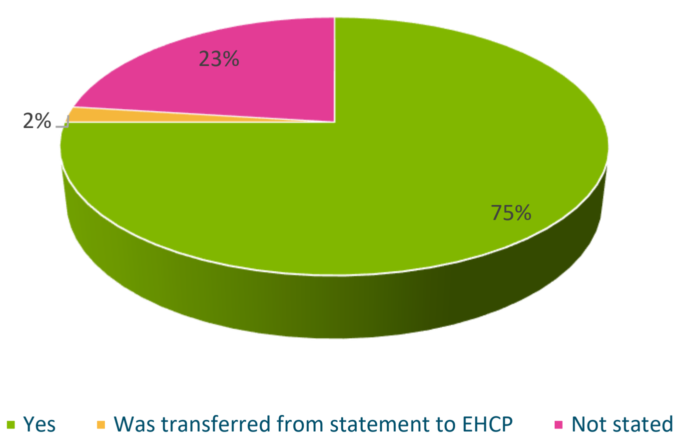
[1] Special Educational Needs - childlawadvice.org.uk

[2] The remark is cited; it does not suggest that this is unique to Barking and Dagenham. However, the lack of resources accessible to families with children who have SEND is highlighted in our report. According to what we've said before, Healthwatch serves to represent the opinions and experiences of the community. As such, your suggestion for more financing ought to be included in a formal response, as the experiences of the research participants did not align with its advantages.

Were you explained the purpose of EHCP?



We wanted to find out if parents and carers were explained the purpose of EHCP. The majority of respondents (75%) expressed that they were explained the purpose of EHCP. It appears that parents often recognise their children's need for an EHCP early in their childhood. As a result, these parents and caregivers are typically well-informed about the purpose and importance of an EHCP.

Many parents and caregivers struggle with the process of coordinating the EHCP process. This often leads to the process breaking down early on. This experience was reported by several respondents in our research study. It has also been found that there is a lack of understanding regarding the responsibilities of the SEN Case Worker. [1] This individual is responsible for writing the plan, which includes specific goals for the child or young person. They will also liaise with individuals in regards to the process.

When asked if they were allocated a SEN Case Worker to coordinate the process, 56% of respondents confirmed that they have been allocated one, and 44% said they weren`t. This suggests that caseworkers need to explain their role right at the start of the process, to ensure that parents and carers are aware of their role.

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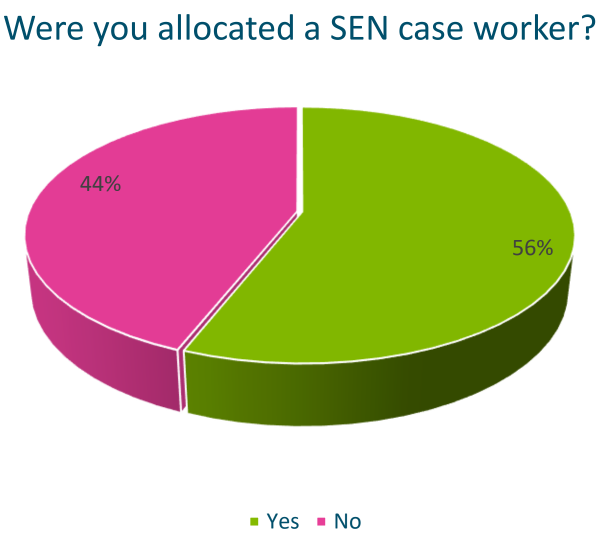
[1] We ask you to provide this information in the official response. As previously mentioned, these families were provided with little to no support in the process regardless of how this role is named, therefore it does not change their experiences.



Some of the respondents who had a SEN caseworker[1] expressed their disappointment because they felt that the worker had not been involved enough and had provided very little support:

> *"No caseworker in the process of attaining EHCP. After getting a plan EHCP coordinator only turns up to an annual review when requested, otherwise no real contact/support."*
>
> *"Initially when my daughter was younger but unsure who this is now."*
>
> *"Only available when renewing EHCP. No other support. Also, staff turnover, no contact made when changed."*

These are the comments provided by respondents who did not have a SEN case worker. It seems that the experiences have been influenced by a lack of knowledge regarding the role and its significance:

> *"I have no idea unless the head of the year who does help then yes, I do."*
>
> *"Didn't know we could have one.".*
>
> *"I've never been informed I have one, or who they are."*

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[1]

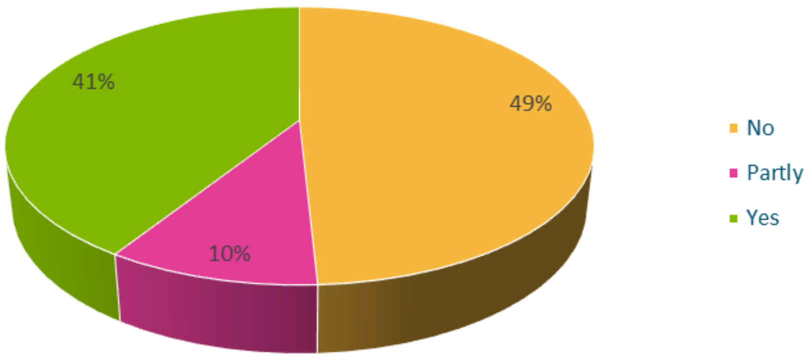
“Only found out about a caseworker when trying to make a complaint!”

“Not sure what an SEN case worker is or does, every meeting I’ve had regarding the EHC plan has been with the school, and no input from the local authority or the EHC team.”

Additionally, based on the feedback received from the focus groups, it was found that a few parents and caregivers were introduced to the role of a SEN caseworker for the first time while responding to the survey questions for this research.
[1]

Following on from that, nearly half of the participants (49%) reported that they were not properly informed about the responsibilities of the SEN case worker in facilitating the EHCP process, leading to a lack of understanding on their part. 41% of respondents stated that the SEN case worker's role was explained to them, while only 10% reported a partial explanation.

Was the SEN Case Worker role in coordinating the EHCP process explained and understood by you?

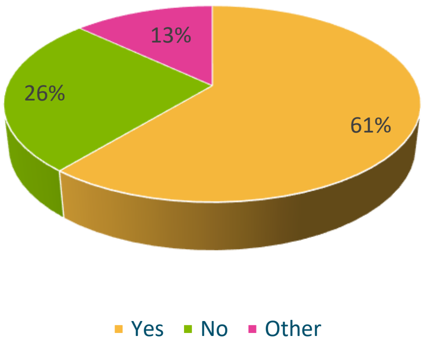


Respondents who claim to have a comprehensive understanding of the SEN Case Worker's responsibilities have shared some positive aspects of their role during the EHCP journey:

- SEN caseworker explained everything and communicated productively.
- Having only one person to go to with questions and concerns was very helpful.
- SEN caseworker explained the next steps so that the parent or carer knew what to expect.
- SEN case worker explained what support will be given to the child.
- Active involvement in annual reviews.

Research findings indicate that having an involved SEN caseworker eases the burden of responsibility during a complex process and offers clear guidance on both the process and the desired outcome. On the other hand, individuals who were not informed about the duties of the SEN case worker reported their lack of understanding was because they were not provided with any information about the role or because the SEN caseworker's involvement was minimal, lacking communication and presence.

Was the overall process of assessing, planning, drafting, and finalising the EHC plan explained to you?



Next, respondents were asked if they were explained the process of assessing, planning, drafting, and finalising the EHCP. 61% of respondents said that the overall process of assessing, planning, drafting, and finalising the EHCP plan was explained to them and 26% said it was not. 13 % had neither positive nor negative experiences. Here are some selected quotes that reflect respondents` experiences:

“Have no idea of the best things or availability of things/resources for my daughter. “

“It was a very long process having the EHCP agreed.”

“It was explained but I don`t know everything.”

“It was extremely difficult to get put in place. It took way too long.”

“It's time-consuming and depends on too many people as my son`s was driven by his college and I had to keep on top of them.”

“LBBD failed to have adequate staff.”

“No one tells you anything, you must obtain information by yourself.”

“This was processed and explained by the school.”

“We had to struggle a lot to get the EHCP. I did my own research which helped but I feel it was still complicated with no real explanation given. “

I was explained the process of assessment but not the rest.

“Some bits were explained by the school - no input from LBBD.”

“Somewhat, however, I did a lot of my own research.”

Based on these experiences, it appears that parents and caregivers must conduct their own research to effectively participate in the EHCP process. Evidence suggests that respondents would welcome a reliable source of information and contact with a qualified professional to assist them in the decision-making process. Additionally, the extended duration of the EHCP process, along with the parental application and external pressures to complete it, contribute to a sense of dissatisfaction with the process. Feedback collected from focus groups indicated that meeting with parents or caregivers who have experienced or are experiencing the process can offer significant support, particularly in situations where statutory services are lacking.

Below are additional comments about assessing, planning, drafting, and finalising the EHC plan:

Personal experiences:

“I did not find out it was a working document until I went to tribunal.”

“I felt under pressure to finalise.”

“I have to work hard to go through the process as it was a parental request, and the school was not happy to provide EHCP.”

> “It took us almost 2 years to finalise EHC and still my daughter is still not receiving complete support in school”.
>
> “It's time-consuming and depends on too many people.”
>
> “LA has never explained how to form a good EHCP. It was training provided by the Just Say forum.”

When respondents were asked about their experience with their SEN Case Worker during the process, only 42% reported good communication while an equal percentage (42%) did not. According to the survey, 16% of participants experienced fluctuations in communication, which resulted in delays in completing or making changes to their EHCP.

This is what respondents who did not experience good communication had to say:

“Once contact was made with my case worker at the end of the process, he was good at communicating. However, my new case worker has not communicated well with me at all resulting in a year’s delay in finalising amendments following my child's first annual review.”

“She was good when it came to putting the EHCP together but didn't receive much communication after EHCP renewal was drafted.”

“A presence needs to be felt and a contact number that works needs to be given.”

“Parents need a cooperative and communicative case worker who follows the case through properly and cohesively.”

“The whole understanding of what can be achieved with an EHCP, face-to-face communication with someone that can provide this, more

knowledge as a parent from a professional that has a clue and is willing to share. "

According to the survey respondents, communicating with the SEN case worker was hindered by high staff turnover, limited involvement in certain aspects of the process, failure to follow through on commitments, difficulty reaching officials through existing contact methods, and insufficient information sharing with parents and caregivers. On the other hand, individuals who had a positive experience communicating with their SEN caseworker found that being allowed to participate in plan editing, receiving frequent updates, having gaps in their knowledge filled, and being connected with other support services all had a positive impact on their satisfaction with the process. Below are selected comments from respondents:

"Had multiple changes implemented before submitting EHCP."

"Once the process was passed to her, she kept me updated on where the case was."

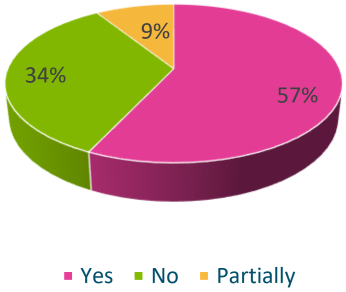
"She explained to me the steps in the process and answered all the questions I had."

"So far, we exchanged one email (which was very useful)."

"Was very good and had found more resources and help."

Of the respondents, 57% reported being given many opportunities to fully participate in decisions with the necessary information and support, while 34% stated they were not afforded the same level of involvement and participation.

Were you and your child allowed to participate as fully as possible in decisions, and provided with the information and support necessary to do so?



Out of all those who responded, 9% claimed to have some involvement in the decision-making process, albeit not entirely, as their feedback suggests:

"In as far as going through sections with school/college."

"I was given some support. It could've been improved by working more in-depth about identifying my son's needs and agreeing with me on the best way to meet them."

"Yes, by the school but more can be explained if someone from the actual team was present."

Parents and caregivers were asked to provide real-life examples of good practices to gain insight into the importance of decision-making involvement:

"After stating my child's needs the school meets with me to discuss his progress and what he will still need in the education section to support him."

"Amended/challenged some decisions based on the progress of the child."

"As I appealed, we had meetings with everyone supporting us as parents."

"Caseworker visited home a few times."

“I had to complete the questionnaire and give permission for my child to be interviewed by a psychologist.”

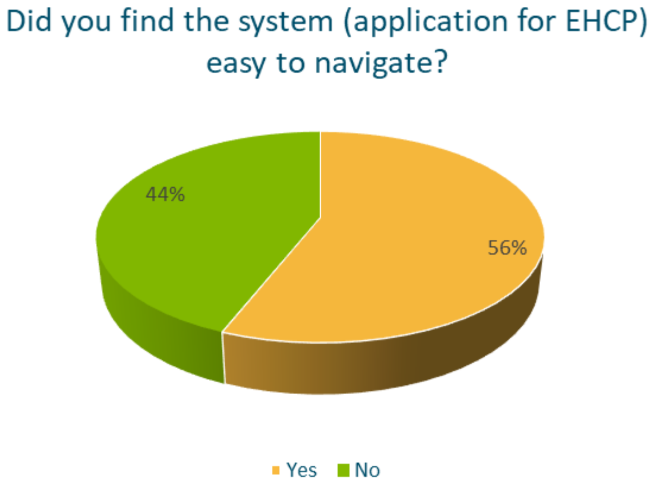
“I was invited to meetings where my views were sought.”

“She asked if I have specific requirements regarding my son`s condition or other help.”

In summary, parents and caregivers feel more confident in participating in decisions when educational settings take the initiative in identifying the most effective approaches to support a child or young person. It's also helpful when there's an option to challenge decisions and provide feedback to improve the report, all with the best interest of the child or young person in mind. Additionally, visiting the family at home adds a personal touch to the experience. Respondents' experiences have highlighted some important considerations to encourage informed family involvement in decision-making:

- Parents can make informed decisions about the functionality of the EHCP by receiving regular updates from the school regarding their child or young person's progress.
- Parents expressed preferences should be considered.
- Ensure LA officials’ attendance at annual reviews to increase the family`s opportunity to fully participate in the decisions.
- Make sure to have a comprehensive plan that includes speech and language, occupational therapy, and dietary input before finalizing it.

Next, respondents were asked if the application for EHCP was easy for them to navigate. Out of the total respondents, 56% found it easy to navigate the EHCP system while the remaining 44% did not.



Participants shared various strategies that proved useful in navigating the process. These included the school taking a proactive approach, seeking assistance from the community, asking straightforward questions about the child's requirements and needs, and accessing resources and information from the educational environment.

The process of obtaining an EHCP can be challenging due to various barriers, such as not knowing where to begin or who to speak to, assessments causing distress for the child, having to apply for an EHCP without the school's support, inadequate information and contact details on the LBBD website, a complex rejection and appeals process, involving a large number of assessments and professionals, and the potential impact on the mental wellbeing of parents or carers. Below there is a summary of what respondents deemed helpful and unhelpful:

Barriers that are making the process difficult to navigate	Aspect that help navigate the process:
Discussing distressing experiences and answering difficult questions	School application (some respondents referred to it as an "automatic application", thus suggesting there was little to no extra effort required to receive an EHCP.)
Premature discharge from support or health service.	Being linked with a service that supports the process.
Not knowing where to start and who to talk to.	Sufficient information and guidance.
School refusing to support with the process/Parental application.	Receiving support from Portage and Nursery, which provides home based early intervention and support.
The language barrier and reliance on translating services or family support.	SENCO`s support.
Parent`s mental health.	
Length of the process	
Absence of clear contact details (phone and email) on LA`s website.	

1.2 Suggestions to make the EHCP process more effective.

According to respondents, certain changes need to be made to improve the EHCP process and the experience of those accessing it accordingly. Below are selected comments from respondents:

Next steps

- "Most parents do not understand what needs to be done in the education sector and the support their child could get, therefore clear information needs to be provided."

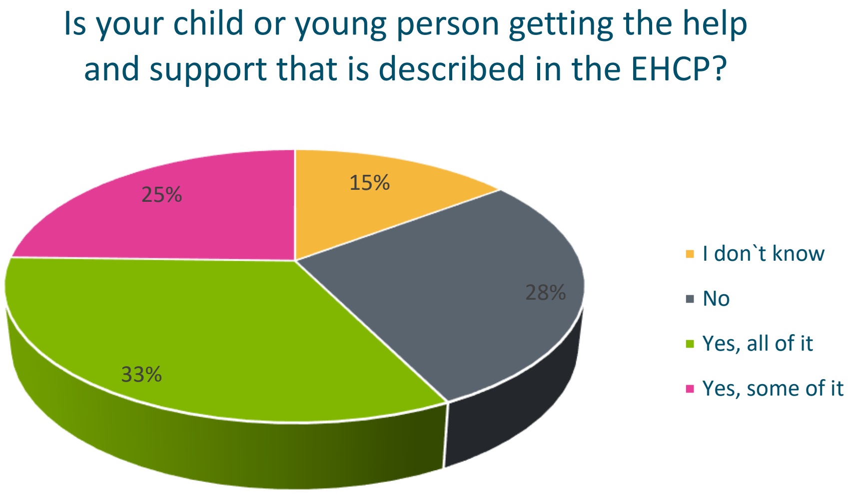
- “An actual coordinator and or case worker to turn up to one of the reviews as never met them.”
- “A better and fairer look at each case is necessary to avoid appealing a refusal.”
- “I think good communication and expectations should be highlighted to parents, carers early on in the process.”
- “Assessments to be completed promptly, less delays for the child.”
- “By making communication and feedback available. Being able to communicate with caseworkers would make it easier.”
- “Caseworker to be more involved with parents.”
- “Clear and transparent communication and information, plus contact numbers for relevant professionals. Only parents and carers of SEN children/young people truly understand the daily challenges that we face. They do not get back to you when you call, and their phone does not get picked up.”
- “EHCP should be reviewed more often and referrals to the right places done. More coffee mornings to meet other parents. Staff should receive more training about conditions and learn about behaviours.”
- “Ensure that LBBD has sufficient staff in place and that they work with families and the child. The current system is broken, and the backlog is not being processed, it is failing the child on a government law.”
- “I'm due to update my daughter`s EHCP for this year but have only just received the final copy of the previous EHCP. I think it should be processed faster.”
- “Make people accountable, it took me from his 6th birthday till his 17th to get it put in place. Schools passed the buck and unless I chased the college, I would still be waiting for it. Everybody who met him said that they were surprised he didn't have an EHCP in place, but nobody wanted to get involved.”
- “Needs to be easier to update when medical information changes.”
- “Schools should identify children`s needs on time and provide inclusive education. They should include parents in decisions.”
- “There needs to be a family liaison officer who supports parents.”

- “There should be more physical involvement with the parent/child rather than having all assumptions on paperwork which might not be detailed thereby under allocating.”
- “They told me to sign the EHC papers during the Christmas holidays for my daughter to receive her support without any further delays. As soon I signed the papers they disappeared and she’s in school without any support. It is heartbreaking for a parent to see their child without support.”

In summary, those surveyed expressed a desire for an increased understanding of how an EHCP pertains to education and a designated individual to oversee and streamline the process. Feedback suggests that a comprehensive and rational evaluation of applications could reduce avoidable rejections, and managing parental expectations, and ensuring sufficient staffing for essential services would enhance transparency in the EHCP procedure. One of the suggestions included an exploration of an online platform where parents and caregivers could keep track of the progress, which would address a current issue of lack of information and updates and difficulties contacting professionals. Moreover, timely delivery of an updated EHCP is required, quicker delivery of assessments and EHCP plans to ensure appropriate support for the child and young person.

1.3 Quality and Functionality of the EHCP

Next, respondents were asked if their children or young people are getting the help and support that is described in it, based on their knowledge or experience. Once an EHCP is finalised, this places a legal obligation on the statutory services involved in the process, including the local authority and North East London ICB, to deliver the provision.



A third of respondents (33%) said their child or young person is getting all support, and 25% reported they were getting some of what is detailed in the EHC plan. 28% said their children did not get the support that was provided in the plan and 15% did not have the knowledge or updates from school to be able to make that judgement.

Issues that are contributing to those discrepancies, according to respondents, are:

- EHCP being out of date.
- Expert interventions being unavailable.
- Limited specialist school staff availability.
- Miscommunication between different support organisations.
- Lack of access to specific information.
- Disagreements between support services regarding responsibility for the provision of service.
- Support goals not being specific, measurable, achievable, relevant, and time bound.

If the proposed concerns were resolved, children and young people with SEND would benefit by having an effective EHCP plan, and it is crucial that this plan is carried out successfully. Here are some real-life examples from respondents, whose children or young people are not getting the support that is listed on the EHCP:

“EHCP very out of date - most items not relevant.”

“Information used for the ECH plan was from when the child was a baby. So, using old information for someone who is an adult is misleading. If it were not for me sitting down when I had time, I would have never found out. “

“EHCP says one-to-one support, but my child does not get one-to-one.”

“I realised that old information was used in the EHCP about him, and the secondary school place was refused based on that. The primary school updated the plan and sent it to the council; however, the council did not update it from their end. I still do not know if my son will get an education, it is very unsettling. I have even contacted an MP.”

“Help is only written on the EHCP but it’s not active. My child doesn’t receive the support she needs face to face.”

“My child is non-verbal, incontinent & has epilepsy but has NOTHING included in Section G (health care provision section) of her EHCP. There are no quantified therapies, so I feel it’s really hard to truly measure & account for progress (or lack of it). My child originally had a Statement of Special Educational Needs (which was used before EHCPs were introduced). There was no meeting with parents to discuss the conversion, the child’s EHCP was created simply by cutting & pasting from the Statement. The info used was 6 years out of date in this case.”

“Hours were allocated but not used as described.“

“I am unhappy as although my child has been granted 32.5 hours support, his TA is being used as a whole class TA and supports other children in class regularly who do not have an EHCP.”

“If the EHC plan is not finalised, then no action is taken. The different teams at times push responsibility to each other resulting in the young person being left with no support.”

“My son is non-verbal so I wouldn’t know how well he is learning or meeting his targets.”

“Not quantified or specified. No real provision. Rejected by other schools who can`t meet needs. “

“My 18-year-old son`s EHCP says he was still in nappies because the plan was not updated.”

“EHCP reads well (although needs updating) yet I feel the school choose to interpret this in a way that suits them and not what is best for my child.”

“Overnight Respite isn’t being provided which is stated in EHCP and care package.”

“The LBBD representative said it was not worth revising the EHCP last week as she will be leaving education. Not sure this is classified as supportive?”

2. Annual review

The annual review looks at how a child or young person is progressing and ensures that the plan is kept up to date. The purpose of the review is to make sure that everyone involved checks that the plan is still effective. The annual review should focus on what the pupil has achieved, as well as any difficulties they have had. It is a chance for everyone to say how they think the plan is working and whether it needs any changes.

- 73% of respondents had their child`s EHCP reviewed in the past 12 months.
- 53% received relevant reports at least 2 weeks before the review meeting.
- 49% received a letter about an outcome of the review within 4 weeks after the meeting.

Our results indicate that more needs to be done to guarantee that every child or young person gets their EHCP evaluated annually and that families receive relevant reports at least two weeks in advance. Within four weeks of the meeting, it must be guaranteed that everyone is informed of the review's findings.

Following are the respondents' opinions on how the annual review process was handled:

“Due a renewal in 3 weeks but only just received last year`s EHCP.”

“I need to update EHCP but don't know how.”

“I was due a review in May, still have not got a date. I did not receive any reports before the meeting. The meeting itself was rushed, we didn't go through the whole thing (this was my first time and I now realise it wasn't conducted properly). The school did send me a summary, but I had to chase the council for his amended EHCP and only received this in May this year - a whole year later! I had no idea who his case worker was when I did find out she was on long-term sick, but nothing had been communicated with me. It is an endless battle and struggles on top of the struggles I already face parenting a child with additional needs.”

“I was expected to review as if I know what was available, I’m a parent not an educator or disability expert in my daughter’s field, never received any helpful or knowledgeable reports, can’t honestly remember if I received an outcome of the review and not had any meetings just a letter to say if I don’t respond to agree with the new plan that the EHCP will be removed or words to that effect.”

“LBBD having the staff in place and learning to communicate.”

“LBBD to be part of the process.”

“Local authority did not act on the recommendations at the end of the review.”

“The panel didn`t take place until 5 months after the request. After I threatened to go to court.”

“The process should allow EHCP to update the needs of a child within the plan not adding attachments.”

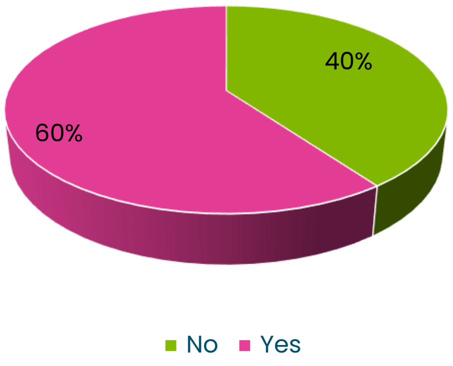
“There were changes in my child`s behaviour and I wanted to meet to discuss, but I have not received any correspondence.”

“We had a review of her 2021 EHCP in early 2022. We have not had a revised copy of this, plus have just had the 2023 review and they do not even bother going through the EHCP as they said it was not worth

amending, as she was leaving education this year. So, she leaves education with her un-amended 2021 plan."

To summarise, to improve the effectiveness of the annual review, it needs to be ensured that an updated document is received shortly after a review, and to ensure that agreed updates and changes are documented in the EHCP. More importantly, a review needs to happen on time to ensure that concerns can be voiced and proposed amendments and ask questions. In general, respondents said they wanted LBBD representatives to be more involved in the editing process of the EHCP and better manage EHCP amendments.

If you had requested changes to the EHCP, were these made?



60% of respondents said that the changes they requested for the EHCP were made, whereas 40% said they weren`t made. Following on from that, respondents were asked to provide the reasons, why requested changes were not made, and this was their feedback, which confirms earlier criticisms about how the annual review is handled:

"College said they do not update the EHCP, and the borough had not updated it due to the original SEN leaving. "

"Changes were done, but the plan was not updated."

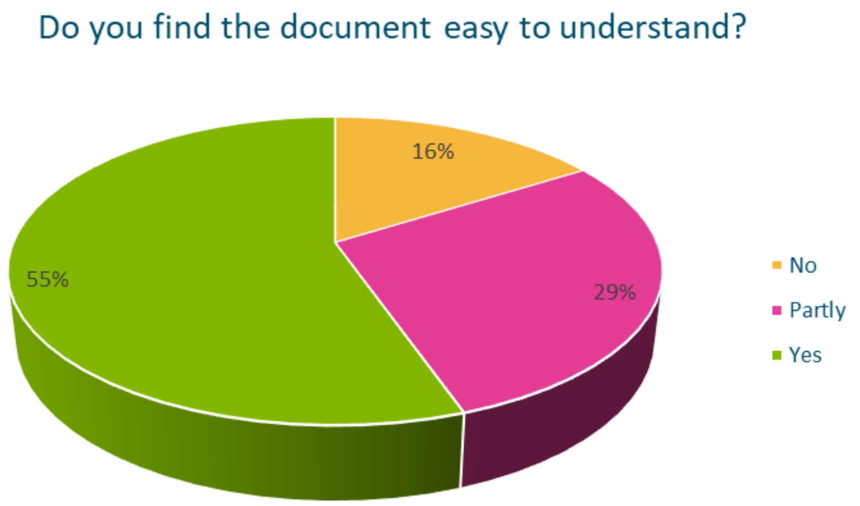
"I have not heard from SEN Team although amendments were agreed last year."

"It took 4 months to get a change made."

"Waiting on a decision and a caseworker, the previous two failed and left."

To summarise, employee turnover and a lack of follow-up have a detrimental impact on the annual review process. A delay in updating the EHCP also appears to exist, as several respondents reported that an updated EHCP only showed up when it was time for a new yearly review.

Next, respondents were asked if the EHCP document was easy to understand. Over half (55%) of respondents found the document easy to understand, 29% of respondents admitted to just partially understanding the EHCP document, 16% did not find it easy to understand. .



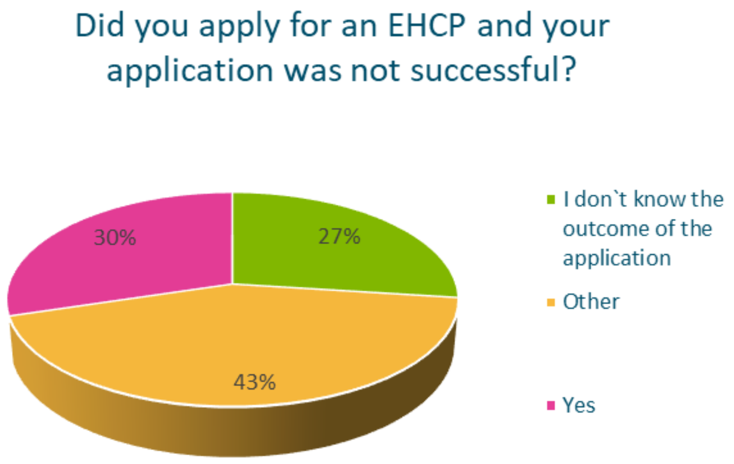
People that selected that they did not feel the document easy to understand, or only felt they partly understood the EHCP document felt that the following internal and external factors make it difficult to understand the EHCP document. Feedback included

- The document's terminology and language is not understood by some parents, making it difficult for parents to determine whether the document's content is appropriate to their child's needs. Parents and carers would benefit from additional booklets or informational materials to assist them in better grasping the information contained in the EHCP.
- Parents with learning disabilities and mental health challenges have trouble reading words accurately and fluently.
- The document's length makes it harder to grasp.

- It must be made clear which information belongs in which part. Parents must be aware of the ramifications of missing information in sections requiring a duty to support.
- The listed support must be quantified and specified.

3. Experiences of families without the EHCP

EHCP was absent for certain families for several reasons. Among the respondents, 30% had their applications rejected, while 27% were unaware of the decision.



Those, whose applications were turned down, offered their comments:

“Declined twice despite college helping.”

“My son was not given an ECH Plan because he was academically intelligent even though he had other disabilities.”

“Educational Psychologist said that school meets his needs.”

“Our application was rejected, did not say why, only this time we decided we would not grant EHCP. Getting your child diagnosed and appealing the EHCP decision prolongs the process even more. It would be very helpful for parents to know the reason for rejection.”

"Very long process, EHCP was refused, and I then appealed it, I had the stress that I did not need. No reasons for rejection so you are left even more confused. I did not know where to go. My daughter masks her symptoms well, and therefore we were not believed. She is so much happier now that she is on EHCP."

"Poor attendance was the reason given."

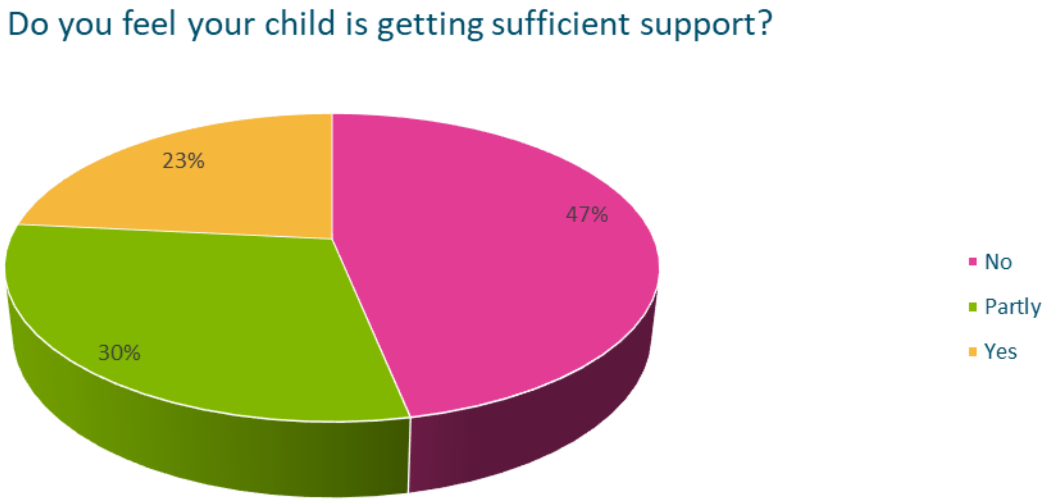
"They point blank refused to assess my child, which was heartbreaking."

"Son was in and out of school to the point his ECH plan expired and was never renewed. Son was then determined to go back to school but there was no support in place because of no ECH. If the ECH had a longer renewal time, it would have helped with trying to get back into school."

Feedback suggests that respondents would welcome more information on reasons why EHCP had been rejected. In the worst-case scenarios, families are left with little choice since their child refuses to attend school, possibly as a result of a lack of assistance, which then prevents them from applying for an EHCP due to poor school attendance.

43% of respondents stated that they did not have an EHCP because their child was assessed as not academically failing despite having additional physical, emotional, sensory, and behavioural problems. A more holistic approach should be employed when evaluating children and young people with SEND, according to some reports that EHCP was denied for children who were masking their symptoms at school.

Investigating the assistance available to children and young people without an EHCP was a goal of Healthwatch Barking and Dagenham. According to 47% of respondents whose children or young people did not have an EHCP in place, their child was not receiving enough help. While 23% believed that there was adequate assistance, 30% thought that there was only partial support.



Respondents described how their children and young people were affected by a lack of support:

“Always neglected in school when he cannot express himself, he is also stammering.”

“My child is currently not attending school due to the school not meeting his current needs.”

“My daughter has been under assessment for over 10 years for autism and ADHD. was told she is 'normal' but may have sensory issues. The school never really helped with anything.”

“Not all staff at the school are aware of her challenges, so she isn’t treated consistently.”

“She gets no support; she gets to school but won't go to class. She only sits outside her class. Goes into nursery in AM to play.”

“She needs more assistance in the form of observation to keep her safe.”

“She would love to return to college education but without support, she cannot do so.”

“The nursery takes care of him, but they don`t have 30 hours of space, which would make a massive difference.”

“Unable to process information and pass this issue at home.”

“The school refuses to help without an EHCP plan. The child is home-schooled even though it is still the same struggles as it was in school. I find it frustrating because my child may be academically intelligent but physically it is a challenge.”

“I was told to homeschool my child, but no resources were given to me.”

Respondents were invited to relate their experiences to determine what lack of support looked like in the absence of an EHCP. Children missed school in the worst-case scenarios because their needs weren't satisfied. Parents and carers were also concerned that their children or young people weren't provided with the communication tools they required. A diagnosis was referred to be a "golden ticket" to support by those who found it challenging to obtain one. Others struggled with loneliness and isolation in addition to being unable to continue with further education.

Despite this, several encouraging examples were recounted, indicating that steps can be taken to support children and young people even in the absence of an EHCP. Here are some instances and examples of good practice where appropriate help has been given without an EHCP:

“He is in a smaller group now with an amazing teacher who is nurturing and helping him with his development.”

“My child`s teacher is not trained in SEND but is very helpful. He was not talking before but is now talking because of that teacher. These children need fun teachers. Strict teachers made my child upset and she regressed in her education.”

Respondents also discussed the effects of a lack of interventions to support children and young people with SEND to further emphasise the significance of proper support even in the absence of an EHCP:

“Doesn't want to go to school and deteriorating.”

“Having an out-of-date EHC has confused and has stopped interventions and assistance.”

“He was often in trouble-suicidal in senior school.”

“He struggles in social situations, that he does not know and understand other children/ person body language, which causes him distress, and causes him to act out and sometimes become aggressive.”

“I have concerns that in mainstream reception class, there are not enough teachers. He improved because 3 nursery teachers are looking after 7 kids.”

“My child becomes anxious when not given enough time, looks sad and occasionally has a meltdown.”

“My child is missing out on his education and interaction with his peers, which is affecting his mental well-being.”

“My daughter`s condition got worse because she didn’t receive the right support at the right time. Her sensory issues got worse. She has severe teeth grinding now which she did not have last year. Lack of support affected her and us. As a parent seeing her in pain is the most difficult thing in life. Still, she’s in school with incomplete EHC and still waiting for LA to provide support for her needs. I don’t how many more days we have to wait.”

“My son has autism with speech delay and with difficulty getting his attention. He is sometimes aggressive when he doesn`t have things his way. He cannot be in the main class with so many kids.”

“My son has refused to go to school and is now home-schooled. He cut himself and tried to take an overdose.”

“My son's diet is not adhered to strictly in school because I cannot update the ECHP.”

“She cannot attend college. She cannot get support to join in at many clubs she would like. We had to remove her from college as they couldn't fund support without the EHCP.”

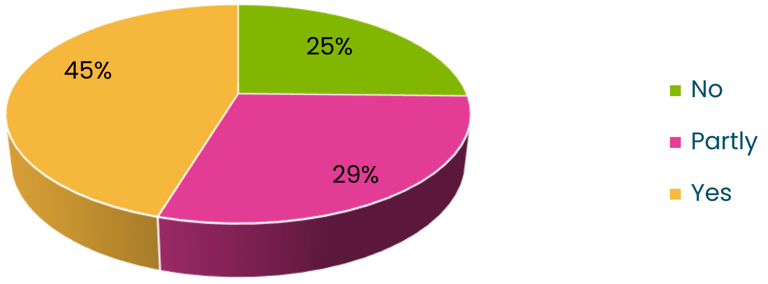
“Teachers aren’t aware of her challenges or how to help her thrive. “

“My child was suspended and excluded from school several times.”

4. Education

45% of respondents agreed that teachers have specialised teaching abilities to address the requirements of children and young people with SEND, while 29% thought that the teachers' skills were only partially developed.

Does your child`s teacher have specialist teaching skills to meet the needs of children and young people with SEND?



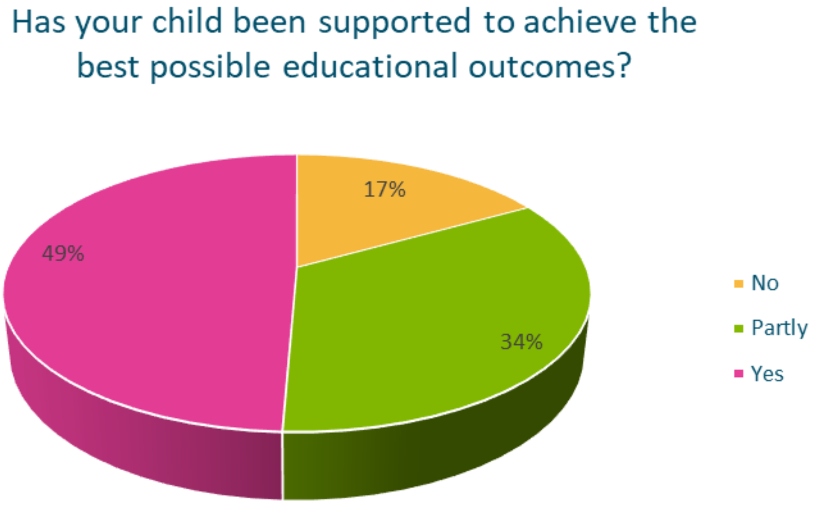
When asked to give examples of good practice, respondents pointed out that having a caring attitude, trying to get to know children and young people with SEND, providing one-on-one support, being patient and giving time, using techniques to reduce overwhelm, using visual aids, and teaching in small groups have all had a significant positive impact on their children and young people's academic outcomes.

According to 25% of respondents, teachers lacked the specialised knowledge necessary to satisfy the requirements of children and young people with SEND. Most respondents cited the need for increased teacher training on how to serve children and young people with varying needs and disabilities. Other feedback included:

> *"Teachers didn't seem aware of how ADHD presents in girls."*
>
> *"I don`t think there are always adequate resources. The college has been cancelled for the week on a couple of occasions this past year due to staff sickness."*

“Needs more understanding of children`s needs and skills from the teacher and more stability from staffing point (there is a lot of agency staff that keep changing).”

Following on from that, respondents were prompted to state whether their children or young people had received support to obtain the best educational outcomes. Nearly half (49%) of those surveyed believe that their child or young person has received support to obtain the highest academic results.34% felt that their child had been partly supported.



When asked to give examples of good practice, respondents provided the following feedback:

“He is happy and has come out more confident.”

“My son was allowed to not take tests to avoid stress.”

“My child has gained a lot of confidence since joining his ARP but still has issues due to anxiety.”

Some respondents reported that their child or young person's mood or behaviour had improved as a result of receiving support. Others have identified practical factors that include reduced class sizes, differentiated assignments, engagement and participation in daily school life, a regular schedule, and the opportunity to consider various possibilities.

According to respondents, every child has distinct needs and abilities, even those with the same condition or disability, hence the key to getting the best educational outcomes is for school staff to be supportive in working around individual needs and abilities.

17% of those interviewed said that school was not doing enough to help children or young people get the best possible education results. What they considered to be deficient and/or in need of improvement is as follows:

“For the last 2 years still waiting for the support she needs.”

“He is in ARP with an experienced teacher but no speech therapy or OT support.”

“Lack of support staff at times.”

“Not enough resources and staff to keep it consistent.”

” Sometimes giving inappropriate activities not suited to their age and ability.”

“Still non-verbal and his behaviour is getting worse.”

“Teacher has implemented some strategies without getting to understand my child first.”

“Would be nice to have 30 hours, and the question is if he is ready for reception.”

“The recent teacher strikes they did not plan for children with EHCP when other local schools did. My child really struggled to understand why he wasn't at school and his brother was.”

This implies that for an EHCP to support a child or young person, they must make sure that all components are operating and offering support. Also, the problem of not having enough workers in educational settings continues to exist.

Healthwatch Barking and Dagenham also sought to learn more about how school environments support and nurture SEND students. This is what respondents expressed:

“Good with communication.”

“Groups and interventions. Specialists, for example, speech therapist, visits. Special seating arrangements. Visual timetables - all sorts of things to help her feel comfortable coming to school. Flexibility with the uniform.”

“He has teachers that are aware of his needs.”

“Initial stage he was unable to talk clearly, seen him grow his confidence.”

“My daughter has a teaching assistant for the majority of the day.”

“My son gets more time to complete tasks and the tasks are broken down, so they aren’t too difficult.”

“My son is very active, he loves to run and get rid of energy, which he can do at school.”

“The sensory room was in place to calm him when he is having a bad day and work his around the house compound to calm him and he enjoys it.”

“Setting out tasks/activities for my son. Recognising his anxieties and having the sensory room available for him. Managing his behaviour when he gets unsettled.”

“She works in a small group on a personalised set curriculum.”

“Try to regulate his behaviour when he is having a meltdown.”

“They created a small classroom specifically for my child.”

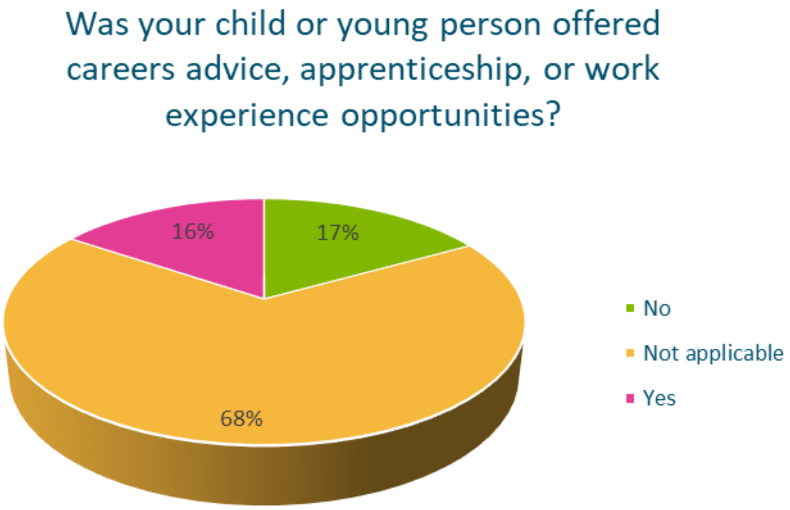
“My son could not manage the changeover at school, so they allowed him to leave earlier to prevent him from having a meltdown.”

According to research, children, and young people with SEND benefit from adequate staffing levels, recognising their needs, and tailoring interventions to meet those needs, whereas inconsistent interventions, inadequate staffing levels, and a lack of staff experience led to poorer educational outcomes.

It is important to note that, in spite of difficulties facing the SEND system nationally, schools LBBD, are doing well at ensuring that pupils receive the care and attention they need, which boosts their self-esteem and emotional health, as highlighted in comments above, and that there is some really good practice that can be learned from.

5. Transition to further education and adulthood

16% of respondents received career guidance, possibilities for apprenticeships, or job experience, whereas 17% did not.



Due to the lack of local educational settings, respondents were concerned about the future and chances for their children, illustrated by the comments below:

> *"If I cannot find the right setting, my child will lose his EHCP after 16. I have been told he cannot make progress in further education. These children are disregarded. Life skills education is as important."*
>
> *"She questions the definition of "Learning" for those over 18; their capacity for progress is different & should not stop them from accessing education (e.g., life skills, self-help not just GCSEs). There*

> *needs to be more Learning Centres in the Borough to reflect the needs of the area."*
>
> *"A lot of provisions do not accept post-19 with EHCP."*
>
> *"Covid paused a lot, and he was transitioning but never had a transition meeting with anyone."*

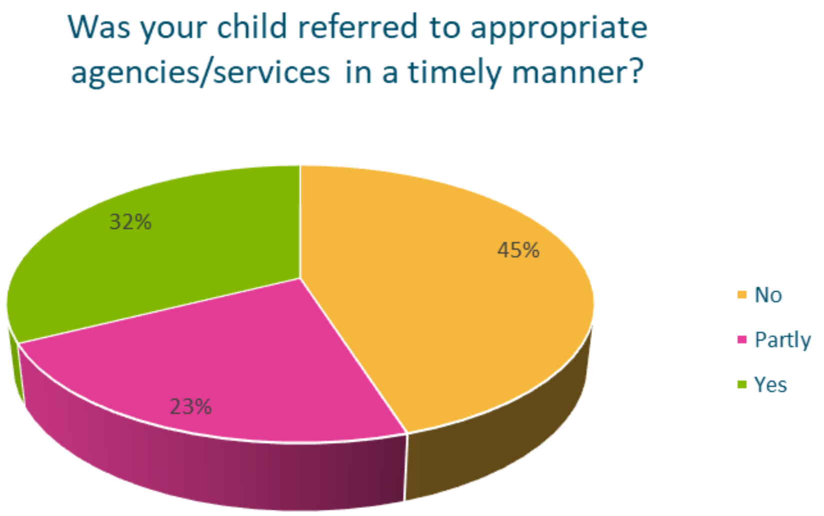
It seems that greater support for families is required when it comes to transition planning between educational settings for children with SEN and disabilities. This should take the form of giving young people a better selection of opportunities to learn life skills when they enter adulthood. It is important to emphasise that, receiving the right transitional help favourably impacts a young person with SEND's well-being, as this comment demonstrates:

> *"Once he went to college, he absolutely loved it. He felt free and felt like an adult. He even mentors other children because of how much college was able to help him."*

6. Health, social care and support services

6.1 Access to support services

Nearly half (45%) of respondents didn't get a prompt referral to the right services. 33% stated they were promptly referred to the proper agencies, while 23% said this was only partially true.



Those that reported having positive experiences about getting appropriate referrals to support services gave the following insight:

"Although the waiting time was long, we were seen in time."

"It ensured he had the support in place before starting school."

"Thanks to the speedy process now my child receives support at school until I know if he will be put on the EHCP."

"They recognised my son was going through a bit of crisis and made referrals very promptly."

"I was quite lucky to get the diagnosis for my child within 4-5 months."

In response to feedback, prompt referrals to support services aid in ensuring that the needs of vulnerable children and young people with SEND are promptly met. The difficulties that children and young people with SEND experience will have a direct impact on how well they can learn from their peers and the academic curriculum. Students may struggle to advance academically and may not learn how to deal with their problems or how to overcome them if support is not provided to help with these concerns.[1]

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[1] The Importance of Supporting Children With SEN (senploy.co.uk)

Those who only partially agreed that their child was promptly referred to support services provided these comments:

"I had to push for it all."

"I haven`t always known the services he requires."

"Some delays when staff changed (SENCO) or delays on GP`s end."

"There was some confusion while transferring from another Borough."

"When younger, but once she reached age 11, support seems to have stopped."

Feedback from respondents suggests that referrals are an area that requires effort to make sure they are timely and supportive. Staff turnover, coordination issues among the services, transfers outside of the borough, and services ceasing support for unknown reasons are all factors that impede the process. According to respondents, the effects of receiving support too late can be detrimental to children's and families' well-being:

"Having to have an operation on her toe and also failure to spot issues with her back."

"Everything is so slow some said they couldn't help. We are still waiting for a diagnostic report from CAHMS."

"He had his diagnosis recently, but it took 1,5 years - it should not have been this long."

"He has never had external support until last year when we got a family support worker assigned."

"I have to push for a professional assessment to be done."

"It took long, she was 2 when we approached services and got diagnosed at the age of 5."

"Mum has to advocate and apply for EHCP as the previous SEND teacher was not interested."

“My son is 6.5 years old but struggling to get enough support. He is still in the queue for speech therapy and OT. They always promise us to do so but no luck.”

“Overdose”

“We had to pay for a private diagnosis, and still haven’t managed to transition to NHS care.”

“We could not go forward with the application without the Educational Psychologist`s input. That should not be the case. There are not enough of them in the borough. My son started regressing from the age of 3, he only got his diagnosis by the age of 10.”

“You need to push them to get what you want. My son is 6.5 years old and still has no ST/OT.”

In conclusion, families with SEND frequently struggle with service accessibility issues, lack of inclusion, and a shortage of specialists to handle demands. Additional criticism about the use of and access to social, health, and care support services indicates that not all components are functioning well to provide support and that parents' voices are not being heard and believed, which is also adding to the problem. Some families don't have a good understanding of the resources they can use. Families also observed a shift in the pattern of discontinued support when their children started to enter adulthood. According to this research, service access delays are still a problem. Those, who had positive experiences, highlighted the professional helping link in with other services and diagnose quickly. Peer support groups were found to be an excellent resource for families with SEND. Here are some selected comments about accessing and using social, health, and care support services:

“Absolutely shocking, care package in place but not getting anywhere with regards to accessing the services.”

“Feels like the support groups help because not all people understand the different issues we face on day-to-day bases.”

“After getting support from a family support worker I have received information on other services. “

“As soon as she turned 16 it was like they couldn’t get her off their books fast enough.”

“Delays in their responding. CAHMS said my son’s behaviour was a progression of his autism so cannot do any more about it. The social worker made visits, but I felt wasn’t hearing me out well. It was in the child-in-need meeting when the teacher backed up what I was saying - that was when she made more appropriate referrals.”

“Generally, a good experience, my child was being assessed for autism rather fast.”

“Found it very difficult to get the ball rolling and to be heard. My son desperately needed support, but he was first refused an EHCP, and I had to fight that decision.”

“I'd be lost without Sycamore’s trust with always available for support. I wish there were daily coffee meetings in Dagenham. I've started my parent-support coffee afternoons at the school where they have supported me in doing this. “

“The health visitor was very active and helped me in understanding his diagnosis and explained the process that will take place.”

“It was very difficult emotionally and my son was ignored for the whole term without involving any SEN or professional assessment. “

“Waited and still waiting 4 years for Educational Psychology assessment.”

“CAHMS - I think waiting until my son is at a suicidal point for them to help is delaying it too far.”

“Long delays in having appointments, there is a lot of support on offer, but you may not always know what is available.”

“Long waiting lists, speech therapists are great when you meet them in person, but difficult to access them.”

“LA doesn’t always accept diagnoses from private medical professionals or their recommendations for therapy/ support.”

“Only just entering this phase - awaiting the borough`s support. I have been emailing services that I have found online myself.”

“Parents need to advocate for their children as they understand better than the EP and teachers who do not face the difficulty of parents and children’s needs.”

“Rubbish everybody says they are busy, and you have to find out about them yourself no one tells you more than they have to.”

“Rubbish, it has taken me 4 years to get a social worker even then when I have asked for help, they are short-staffed or pass me on to another department, who then pass me back to social services as they say they are not the right department to help my son.”

“Some of the agencies that have my son listed did not contact us for over 2 years but did when they needed to complete their documents and the excuses were on and on when I pointed this out.”

“Very challenging. Assessment procedure should be made easier as parents are already facing a lot of difficulties coming to terms with their children`s challenges.”

“We asked for our child to be referred for an ADHD assessment in 2019, it took 2 years to get an appointment and then we were discharged with a referral to the school for speech therapy. The speech therapy referral was refused - it wasn’t needed anyway as that wasn’t one of our daughter’s issues.”

“We were accused of fabricating illness and had a long court battle to prove my child was genuinely facing the issues she has. This led to the decline of the first EHCP at the end of year 6. We decided to home-ed as she could not have survived with zero support. When we joined college, they were amazing but cannot do anything other than support us in attempting to gain EHCP.”

6.2 How effective multi-agency working was/is?

Since many children and young people have several needs or disabilities that affect their daily lives, as was already covered in this report, effective multi-agency service coordination is necessary. Positive feedback regarding multi-agency working has been heard, and it suggests that improving information exchange between services offers a quicker, more coordinated response.

However, respondents` feedback also indicates that adjustments are required to guarantee accountable and stable multi-agency working.

“Does not seem effective at all, always say it’s about the money when to me it’s about helping my child have as normal a life as possible.”

“I felt that they were not communicating well with each other.”

It would help to have at least one consistent person who was to tell us what is happening.”

“I have had no issues with this, there is a good team around my child, and he is happy.”

“It is good, I think they are working well together, but again it is the speed and waiting.”

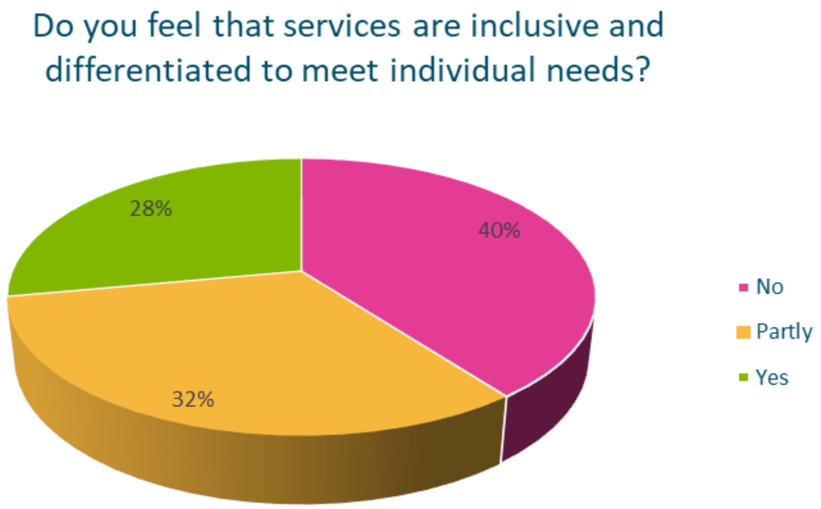
“I have also been open and keen to share all information with all agencies to ensure the best care for my child, yet no other agencies attend meetings or seem to have any communication with each other."

“It’s hard to keep on top of everybody… Contacting each person for a different area of need.”

“Never saw the same person twice.”

“When you meet them, they are professional and caring.”

Only 28% of respondents felt that services were inclusive and appropriate for every person's requirements, while 40% disagreed. 32% thought that services were only partially inclusive and differentiated.



The comments below outline the respondents' positive views on inclusive and unique services:

> *"They are trying their best to help my child."*
>
> *"The experts are experienced in what they are doing."*
>
> *"They assessed my son and made the right referrals so that he could get all the help he needs."*
>
> *"You are referred to services that are most appropriate to your needs."*

Following the use of the services, respondents expressed satisfaction with them, as indicated by feedback. However, respondents have pointed out several areas that require improvement to enhance inclusivity and differentiation:

“80%, they start but not finish.”

“Always have to explain the reason you need help as they fail to read notes on the child.”

“As a council a lot of being missed out and there is not a joint approach. Things should be looked at the first point of contact not fobbed off and given numbers to be contacted without even knowing if those numbers work.”

“General hospitals should have better provision for people with additional needs.”

“Help as much as possible without EHCP.”

“I think a lot of people that weren’t strong-minded would give up on the process as it takes forever.”

“Problems with Barking and Dagenham Adult learning towards people with disabilities.”

“Services are too limited and either overpriced or not based locally.”

“Some don’t cater very well for families where more than one child has a disability - they don’t provide staff to help you, so you end up not accessing these things.”

“Paediatrician is not very helpful as no knowledge of what to do about the diagnosis. She is not my biological child and came to me when she was 2. I was told there is a grey matter in her brain. Doctors do not have more info on that and therefore cannot advise me on how to support her.”

“Some help was given promptly but other times the prescribed medicine was the answer.”

7. Parental wellbeing

An arising theme is that having trouble acquiring an EHCP and having an EHCP that isn't functioning effectively has a detrimental influence on parents' well-being and their capacity to handle day-to-day challenges of raising children with SEND. Even though the survey did not include questions about parents' well-being their responses indicate this:

"Eventually I will not be stronger than him...he smacks me in the face and used physical violence. You are judged all the time. I wish services and schools were more understanding, I feel so judged, I tried dragging my son to school, taking all his pleasures away, but that did not work."

"My daughter was assigned Trinity, and then taken off from it. My complaints were not answered, and my children got taken away for more than a year, only for them to find out that everything I was saying about my daughter`s needs was true. Even more, the damage was done to my children. My daughter`s hair was cut without my permission."

"Some parents don't have the capacity to understand all that is in the Plan or the ability/knowledge to fight for what their child needs. "

"It is very difficult to be at home during holidays, they cannot enjoy themselves. I wish we could get a discount to attend a soft play or a swimming pool."

"I have an 8-year son with a range of learning & physical needs as well as a 3-year-old daughter who has recently been diagnosed with ASD. I am concerned about my own mental health & the toll that having 2 children with SEND has taken on me & my husband."

"I tried dragging him and putting him in a car (to attend school). The school promised to put things in place but that did not happen."

As has been already covered in this report, having significant difficulties and lacking support in the EHCP process negatively impacts parents' or carer`s well-being and relationships. The well-being of parents and carers is hoped to be supported by the suggested changes within this report, and the expansion of currently effective practices.

8. Independent perspective from SENCO

We spoke to a SENCO as part of this project, to get an independent professional perspective about the process. Below is an account of how SENCO felt about the EHCP process.

Personal experience:

From my experience, SENCO`s role is remarkably busy, constantly referring and chasing appointments and reports. I would like to highlight to parents and carers that not attending appointments might mean less support for their child from external services and it may make the process longer. It is important to note that discharge from speech therapy would occur straight away if an appointment were not attended; there is a big demand for this service, and they can only support those who are actively engaging. I would encourage parents to keep bringing reports to school every time they get one. In my experience, more rejections come from parent applications. Parent applications require skills. However, support is provided in school even if there is no EHCP. This is called the SEN Support stage, as per the SEN Code of Practice. Local Authority always asks the school if they agree with the EHCP application and will ask for evidence of the support the child is already receiving in school.

Speech therapy is difficult to access, assessments are often online, and constant staff turnover. Staff are overworked and underpaid. Retention of staff is an issue. OT services have the same problem. Educational psychologists must prioritise those already with EHCP, so those waiting for an initial assessment often have to wait a long time.

The whole EHCP process should be about the child. Everyone involved in the process needs to be held accountable. The school arranges annual reviews and documents them in a timely manner but there are often hold-ups in social services. The quality of EHCP increases if schools can engage parents. However, home life is a grey area, where professional support is often not provided, only in most needy cases. Therefore, parents need to be empowered to be able to best support these children at home.

> I think that there should be more opportunities for parents to get together and talk and more support post-diagnosis. Parents often go through a mourning period after the diagnosis, their mental health gets impacted. Parents need support and sometimes therapy; they need help to have a life.
>
> To all parents, I would say "We are working together to get the best for your child."

Conclusions

According to the government's Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan[1], the SEND system is experiencing systemic problems across the country, and the challenges highlighted in this report are not unique to LBBD.

Our report highlights that families struggle with the numerous services and assessments making it challenging to manage, especially for the families of children and young people with the most complex needs. Some families feel that support is only given to families after they reach a crisis point due to the challenges involved in negotiating children's social care assessments and the lack of consistency in the offer within the local authority.

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[1] Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan (publishing.service.gov.uk)

Word cloud from words that respondents used to describe EHCP process.

Recommendations

After thorough evaluation of all the data gathered for this study, we would like to offer the following recommendations to the SEND Board in Barking and Dagenham:

Recommendations for the process of EHCP

1. Ensure that each parent or carer is well-informed about the process for evaluating, planning, developing, and concluding the EHCP plan. For example, providing parents with a flowchart/process map of the EHCP. It is recommended that parents are involved in co-production of previously mentioned material to ensure it is user friendly. Healthwatch Barking and Dagenham are happy to facilitate this meeting.

2. Ensure that as many families as possible are adequately included and well-informed in the consultation and decision-making throughout the EHCP process and annual reviews. This includes informing them on how long a certain process will take and about potential completion dates.

Recommendations based on SEN case workers

3. Make sure that each family is aware of the SEN caseworker that has been assigned to them and that they have easy access to contact information, for example ensure that contact information has been provided to parents and carers including email and telephone numbers.

4. Ensure all SEN caseworkers take the central role in coordinating the EHCP process.

5. Ensure that SEN caseworkers respond back to parents and carers in a timely manner.

Recommendations for time frame of EHCPS

6. Ensure EHCPs are up-to-date and contain specific, measurable, achievable, relevant, and time-bound goals and outcomes.

7. Ensure that EHCP reflect what was discussed and agreed in an annual review and an updated EHCP plan is shared with all parties including parents in a timely manner.

8. Ensure that annual reviews happen face-to-face and that there is a case worker present in the meeting.

Education and transition recommendations

9. Ensure the provision of additional training opportunities for teachers working with SEND students.

10. Make sure that children and young people without EHCP have an equal chance to succeed in learning and in work-like activities by providing support tailored to their needs.

11. Ensure better systems for providing support to people entering adulthood. For example: better opportunities for those who need development and support in daily living skills rather than only academic progress.

12. Make sure that children and young people receive therapies (such as occupational therapy and speech therapy) if they are indicated in the EHCP, and that it has been made clear to the parents and carers how often sessions/support will take place.

13. Make sure that families are supported after a diagnosis by giving them a brochure or information pack with the resources and contact information of services and support available in the borough. Make sure that booklets in other languages are available for those whose English is limited. It would also be advisable for an easy read version to be available. We recommended that parents/carers are involved in producing these.

Healthwatch Barking and Dagenham would be happy to support facilitation and development of these as part of this project.

14. Ensure that after a visit to a community service (speech, occupational or physiotherapy and paediatricians) reports are sent to parents and carers in a timely manner. This is to ensure that parents and carers are clear on the diagnosis, progress, and plan of action. For example, if the physiotherapist has given advice on exercises that need to work on at home, a report of the this would guide the parent. Some reports are also helpful for schools and applying for blue badges etc.

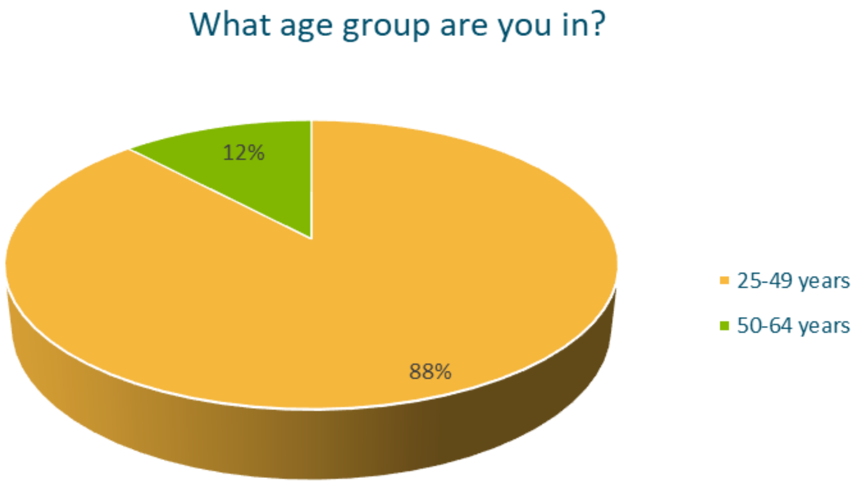
Acknowledgements

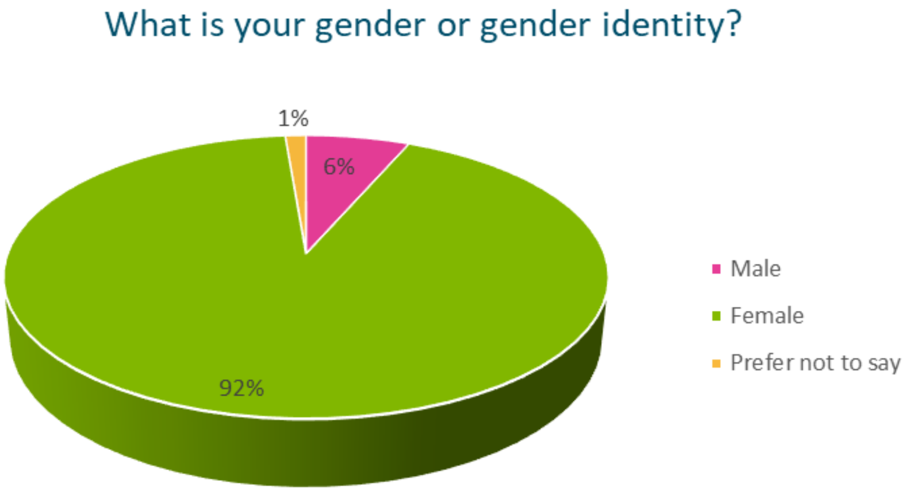
All the schools and their SENCOs who invited parents and carers to and hosted our focus groups deserve the warmest thanks from Healthwatch Barking and Dagenham. We also want to thank Nicolle Rowson, Lead Professional for SEND Quality and Achievement, for introducing Healthwatch Barking and Dagenham to those schools.

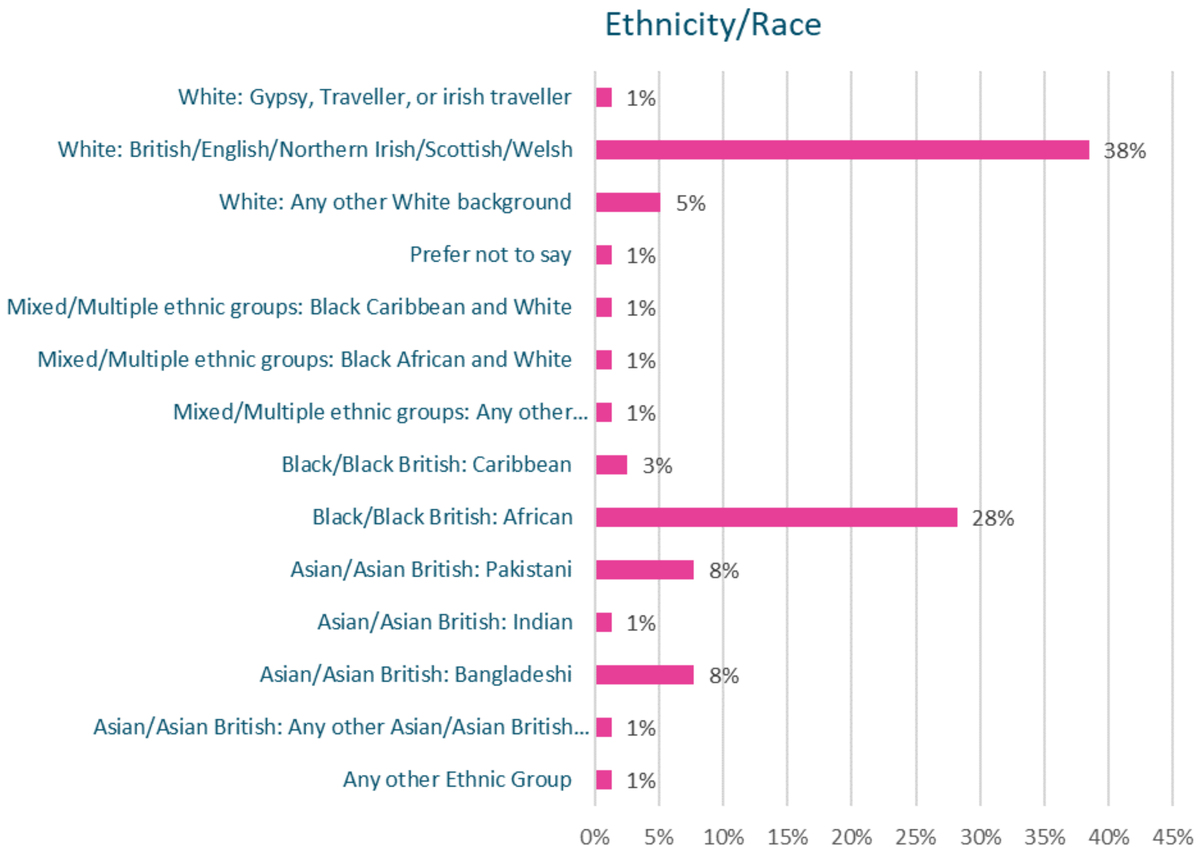
Thank you to our volunteers for generously volunteering their time. Your support allows us to continue to fulfil our mission and represent people in our community.

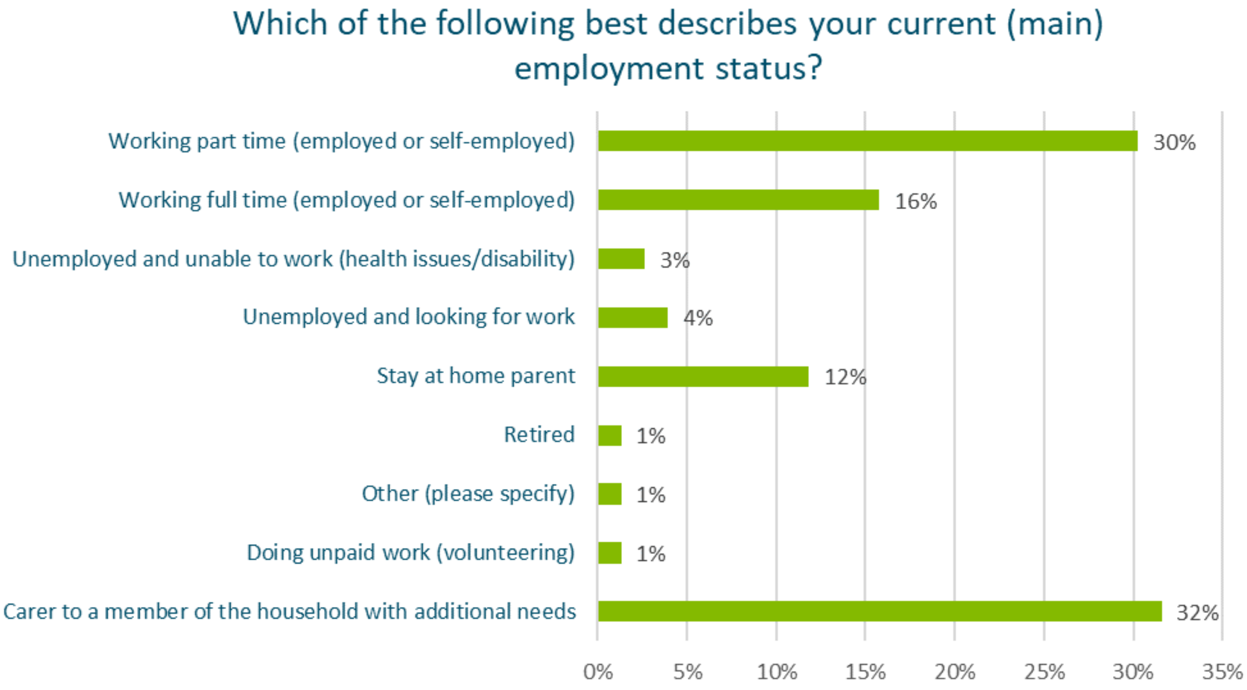
We are grateful to all the parents and carers, and a Special Educational Needs Co-ordinator who participated in this study. Additionally, we want to thank Carers of Barking & Dagenham, Just Say Forum, Ab Phab Youth Club, and Sycamore Trust for helping to distribute our surveys and facilitate focus groups.

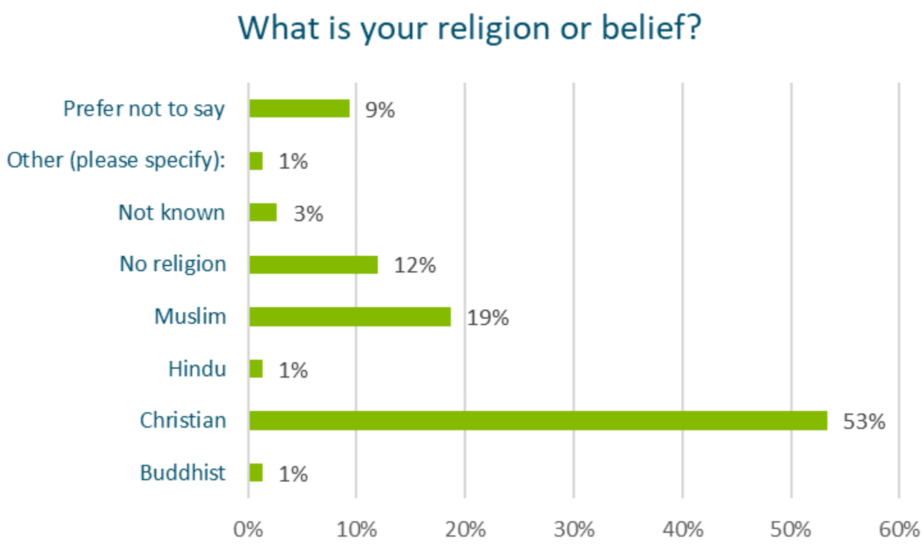
Appendix 1 – Parent and carer background

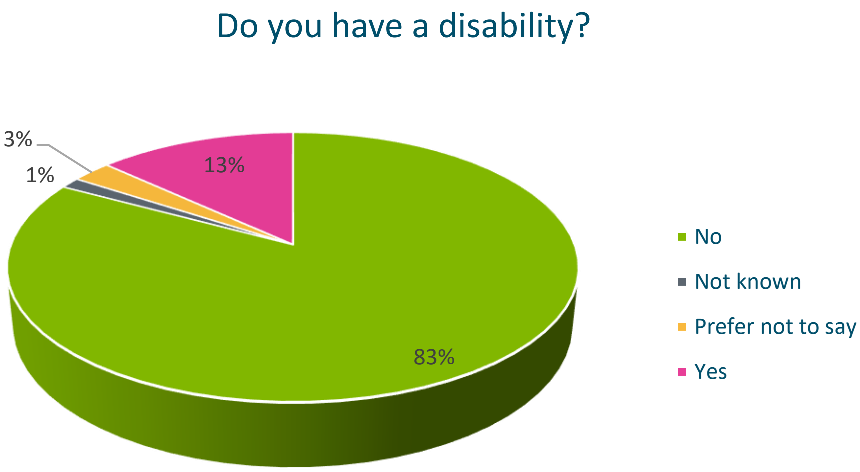


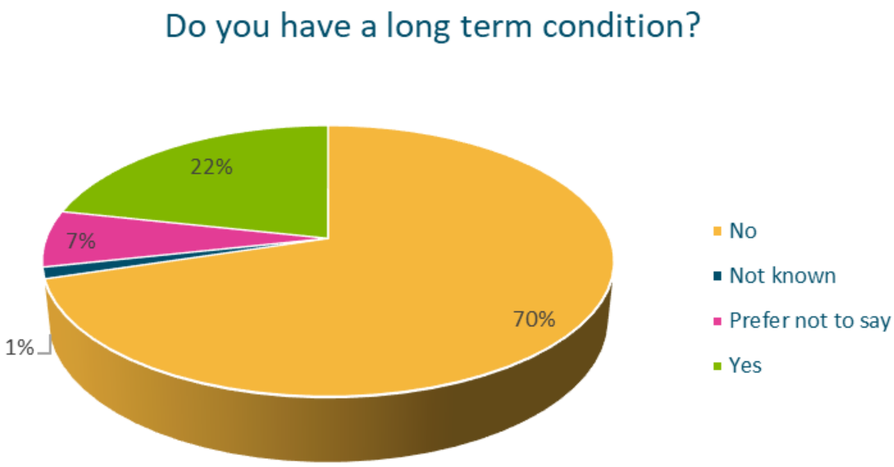


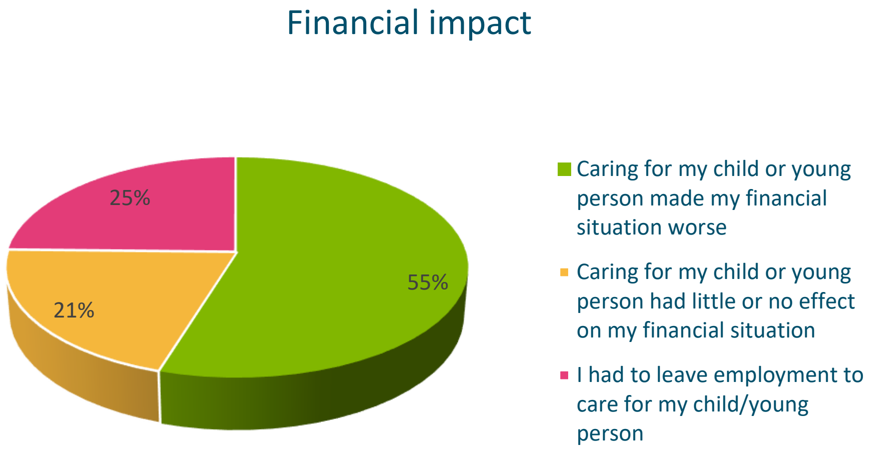

Ethnicity/Race
White: Gypsy, Traveller, or irish traveller 1%
White: British/English/Northern Irish/Scottish/Welsh 38%
White: Any other White background 5%
Prefer not to say 1%
Mixed/Multiple ethnic groups: Black Caribbean and White 1%
Mixed/Multiple ethnic groups: Black African and White 1%
Mixed/Multiple ethnic groups: Any other... 1%
Black/Black British: Caribbean 3%
Black/Black British: African 28%
Asian/Asian British: Pakistani 8%
Asian/Asian British: Indian 1%
Asian/Asian British: Bangladeshi 8%
Asian/Asian British: Any other Asian/Asian British... 1%
Any other Ethnic Group 1%
0% 5% 10% 15% 20% 25% 30% 35% 40% 45%


Which of the following best describes your current (main) employment status?
Working part time (employed or self-employed) 30%
Working full time (employed or self-employed) 16%
Unemployed and unable to work (health issues/disability) 3%
Unemployed and looking for work 4%
Stay at home parent 12%
Retired 1%
Other (please specify) 1%
Doing unpaid work (volunteering) 1%
Carer to a member of the household with additional needs 32%
0% 5% 10% 15% 20% 25% 30% 35%


What is your religion or belief?
Prefer not to say
9%
Other (please specify):
1%
Not known
3%
No religion
12%
Muslim
19%
Hindu
1%
Christian
53%
Buddhist
1%
0%
10%
20%
30%
40%
50%
60%


Do you have a disability?
3%
1%
13%
83%
No
Not known
Prefer not to say
Yes


Do you have a long term condition?
22%
7%
1%
70%
No
Not known
Prefer not to say
Yes


Financial impact
25%
21%
55%
Caring for my child or young person made my financial situation worse
Caring for my child or young person had little or no effect on my financial situation
I had to leave employment to care for my child/young person

Appendix 2 – Case study

You should not have to fight for what your child deserves

The Covid-19 pandemic and lockdowns drastically y exacerbated flaws in the system that many children with SEND and their parents were experiencing. This is a story of a mum of three children with SEND living in Barking and Dagenham, who requested the EHCP for her son during the Covid-19 pandemic. She described the process as lengthy and exhausting and burdened with additional challenges, such as not being able to attend appointments face to face, her son missing school and being suspended twice, and support services generally being hard to reach. It is noteworthy, that for children with SEND; being excluded, absent or missing from school much more frequently than other pupils nationally is a persisting weakness.[1]

She also told us that the process to complete an EHC plan can take up to 40 weeks – a length of time that she found inconceivable considering how much her son struggled at school, even though he had some support in place prior to obtaining an EHCP. She emphasised that every parent who sees their child struggling would want to get help faster. Subsequently, the process becomes even harder when the school officials are not so forthcoming with support.

"MY SON WAS SUSPENDED FROM SCHOOL TWICE DUE TO HIS BEHAVIOUR, OR SHALL I SAY THE SCHOOL WAS UNABLE TO MEET HIS NEEDS BECAUSE THEY WEREN`T RECOGNIZED."

Quite often she felt frustrated taking on a 'coordinating role' trying to connect all professionals (school, social services and 2 support workers, which were privately paid through social services). This can be a huge challenge, due to the parent lacking the capacity to keep up the momentum.

She cannot recall being ever included in the discussion, which was quite fragmented; she wishes that all parties involved could represent themselves equally. This highlights a very important aspect that children and their families should play a much more central part in making decisions about how needs could best be met.

"I FEEL SAD THAT THEY NEED TO SEE SIGNED DOCUMENTATION TO ACKNOWLEDGE MY SON`S NEEDS".

Her son already had a speech and language therapist as he was born with a tongue tie, which delayed his speech. However, she expressed difficulties communicating with a paediatrician - she has asked for support with her son`s rage issues and was told to make sure he is fed and taken out regularly to use his energy. She has also been made

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[1] SEND: old issues, new issues, next steps - GOV.UK (www.gov.uk)

to feel like she was doing some kind of damage by allowing her son some limited screen time. When she asked further questions, the doctor replied that she has got other people to call. However, contact with an educational psychologist was a breakthrough, as he provided her with very useful information, noticed her son`s struggles and gave a push forward in the process which sped up the process. It shows that greater coordination of services and clearer responsibility for all support services, all leading to more effective multi-agency working, are key.

Relief and reassurance followed soon after her son`s EHCP was completed and official – she explains this meant a lot to her because his support needs were officially acknowledged and clearly listed. “I feel sad that they need to see signed documentation to acknowledge my son`s needs”, she added. “Fortunately, the school has gone above and beyond to help my son since EHCP was awarded. My son has not been suspended since he has got EHCP. I think that what is on the EHCP and what is done practically somewhat match. When you see your child happy and smiling, then you know that it is working.”

One sentence that she would say to sum up the process as a whole: “It is stressful; you must fight for what they deserve and experience a lot of mum guilt”.

To summarise, getting an EHC plan provides children with additional support and allows them equal opportunities to succeed, and having a more holistic approach to the child’s well-being reflects on the whole family.

Response from the service provider

Partnership Response to Healthwatch published report.

The SEND Partnership Board thanks Healthwatch Barking and Dagenham and all those who participated in this report.

The Partnership Board always welcomes the views of parents and carers and work very closely with the Just Say Parents' Forum.

While this work with parents significantly influences our priorities, actions and improvement plans, we commissioned Healthwatch Barking and Dagenham to seek the views of parents and carers who may not otherwise come forward and share their views.

Their report gives us hugely valuable feedback which will help us make further improvements.

We would also like to encourage everyone who took part to join the Just Say Parents' Forum, where they will be able to share their views and also access the support network it provides.

The broader context is that requests for Education Health Care Plans (EHCPs) doubled in 2022 in Barking and Dagenham – four times the national increase, and we continue to see approximately 500 applications per year, a much higher rate than before Covid. Despite challenges of workforce availability and financial constraints, the Council has employed additional staff to manage this increased volume of work.

We look forward to using the parent and carer voices captured in this report to improve our support for children and young people with SEND.

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