

## Just Say Forum’s SEND Survey Results and Report.

The Just Say steering group have set up their own online survey about SEND services in Barking and Dagenham. The survey link was posted via Facebook, our website and WhatsApp groups that steering group members were part of on 24<sup>th</sup> May 2024. We had a deadline date of 7<sup>th</sup> June 2024 and we have received 23 responses.

The results can also be viewed via this link:

[JSF SEND Survey](#)

I will report below key points in each section of the survey (and will abbreviate children and young people to CYP). Comments left by carers will also be included:

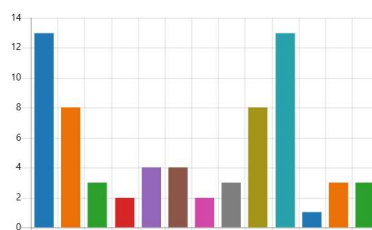
### Questions 1-7 “About you and your child(ren)/young person(s)”:

Less than half of the carers had disability themselves (39%) and for the same amount English wasn’t their first language (45%). We suspect a higher percentage due to people who do to not have English as their first language due to the difficulty in getting help in understanding and filling in the form. 60% of respondents described themselves of white ethnicity, 24% Asian and 8% as black.

The majority of our respondents had one child with SEND (78%) and under half of the children (44%) were aged 0-4 years old. The highest areas of needs were ‘autistic spectrum disorder’ (19%) and ‘speech, language and communication needs’ (19%), ‘social emotional and mental health’ (11%) and ‘hearing impairment (11%)’.

6. What are your child(ren)/young persons' areas of need/difficulty?

Autism spectrum disorder	13
Hearing Impairment	8
Visual Impairment	3
Multi sensory impairment (visi...	2
Moderate learning disability	4
Physical disability	4
Profound and multiple learnin...	2
Severe learning disability	3
Social, Emotional and Mental ...	8
Speech, Language and Comm...	13
Specific Learning Difficulty eg...	1
Unsure/awaiting assessment	3
Other	3



The best ways of communicating with them were quite varied, with the top three being ‘gestures/reaching’ (23%), ‘communication books’ (20%) and ‘PECS’ (16%).

## “About your child(ren)'s/young persons' education, health and social care”

### Question 8-14 “Education”

Most of the CYPs attend an educational provider in Barking and Dagenham (73%) and most are attending mainstream settings (primary 18%, secondary 14% nursery 7%) or an ARP within a mainstream school (18%). 7% are attending a specialist/special needs setting. None are attending a mainstream college.

Just over half (56%) of the respondents felt that their child was in the best educational setting to meet their needs. 37% of the CYPs had EHCPs, 20% had SEND support and 10% were eligible for free school meals.

On asking about the overall quality of educational services accessed within the 12 months most services were rated excellent. Where physical impairments were accessed, half rated it as ‘very poor’ and half rated it ‘excellent’. 62.5% of respondents felt services from the SEND Team was ‘poor’ or ‘very poor’.

12. If your child/young person is currently accessing any of the educational services listed below, or has accessed them within the last 12 months, please rate the overall quality of this provision, thinking about things like communication, practitioner knowledge, range and level of service:



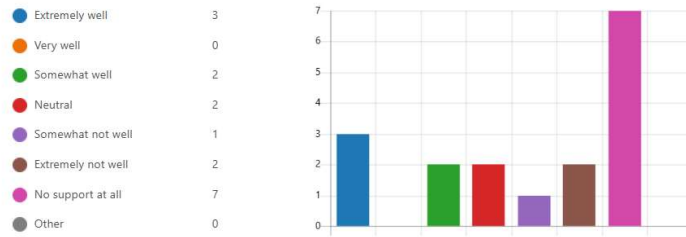
Parent/Carer’s Comment:

*“I had been fighting for a ehcp for my child for the last 4 years, the school and La haven't bothered. This year when I chased it yet again, I was told that the Sen department would be laughed at sending in for a ehcp plan in March and it wouldn't be done anyway”*

### Q15 – 20 “Health”

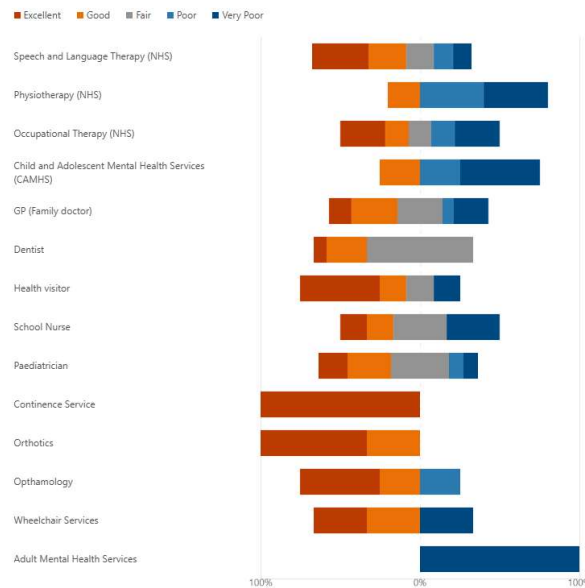
Over half (57%) of the respondents have recently received a diagnosis for their CYP. Almost half of them (41%) stated they’ve had ‘no support at all’ after diagnosis. Where they’ve had support most (33%) have stated ‘other’ as sources of support and 28% have received support from their CYPs’ school/other educational provision.

16. If yes, how supported do you feel after their diagnosis?



On asking about the overall quality of health services accessed within the 12 months the results were very mixed. The ‘continence service’ has come out top with all who used it rating it ‘excellent’. ‘Orthotics’, ‘ophthalmology’ and ‘wheelchair services’ have had more than half of very good and excellent ratings. On the other hand, ‘adult mental services’ was rated 100% ‘very poor’. This is followed by ‘physiotherapy’ ‘CAHMS’ and ‘occupational therapy’ respectively with high ratings of ‘poor’ or ‘very poor’.

18. If your child/young person is currently accessing any of the health services listed below, or has accessed them in the last 12 months, please rate the overall quality of this provision, thinking about things like communication, practitioner knowledge, range and level of service:



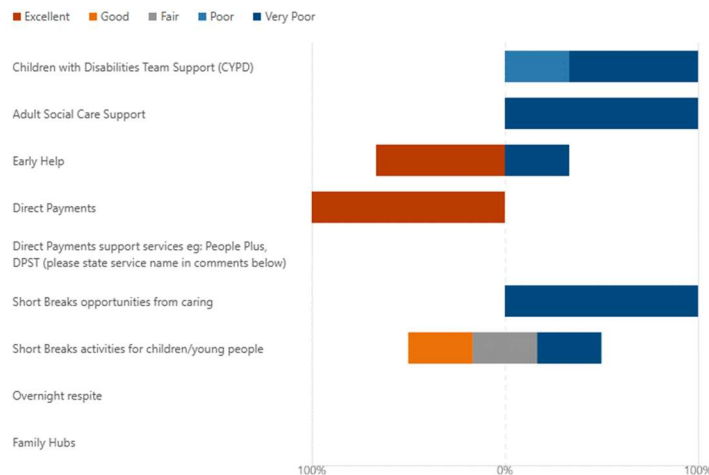
Parent/Carer’s comments:

*"Many times we get told, referrals will be made but to only find out no referrals have been made at all. Therefore months have gone past and your thinking your on a wait list when your actually not, so having to start again and wait more longer. When refferals are made you need, the waiting list times are ridiculous! 3 years for ASD assessments and Diagnosis, 3 Months for reports! No follow ups! You get told your child has Autism, there you go, you figure out the rest! Sycamore Trust have been a life saver! The new early help team have been the best support I have had!"*

## Q21-24 “Social Care”

Most people (72%) didn’t know what Family Hubs are or don’t know how to access them – we have 11 in the borough including the CYPD Hub. For social care services accessed within the last 12 months, ‘direct payments’ was rated ‘excellent’ by 100%, and ‘early help’ was rated excellent by (66.7%) of users. ‘Adult social care support’, ‘short breaks opportunities from caring’ and the ‘Children with Disabilities Team Support (CYPD hub)’ all had 100% poor to very poor ratings.

22. If your child/young person is currently accessing any of the Social Care support/services listed below, or has accessed them within the last 12 months, please rate the overall quality of this provision, thinking about things like communication, practitioner knowledge, range and level of service:



## How to make education, health and social care services easier to access

To make it easier to access the services mentioned above in education, health and social care, ‘shorter waiting lists’, ‘better information provided about the services available’, ‘a clearer or more flexible referral/assessment/support criteria’ and ‘better understanding from staff and practitioners of my child/young person’s difficulties’ were highly rated being needed.

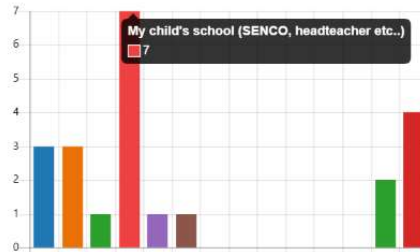
## Q25 – 36 EHCPs and its process

Of those who have had their CYPs EHCPs issued in the last 12 months, about a third (31%) have found going through the process ‘neither easy nor difficult’, slightly more than a third rated it (37%) as ‘difficult’ or ‘very difficult’ and the other under a third have rated it ‘easy’ or ‘very easy’.

Most have had support from their child’s school (31%). Almost a fifth (18%) stated ‘other’ as their source of support and about an eighth (13%) have said they ‘did not know how to get support’. Where concerns were raised on the EHCP process most (70%) did so by writing a letter/email of complaint.

26. Did anyone support you in the process of an EHCP assessment, or in the ongoing management of EHCPs such as annual reviews?

- No one - I did not require this 3
- No one - I did not know how t... 3
- SEND Case Officer 1
- My child's school (SENCO, hea... 7
- Carers of Barking and Dagenh... 1
- Specialist Early Years Service (... 1
- A solicitor 0
- An independent advocacy ser... 0
- A local charity 0
- A national charity 0
- A local support group 0
- A national support group/org... 0
- Family/friends 2
- Other 4



**Parent/Carer's Comments:**

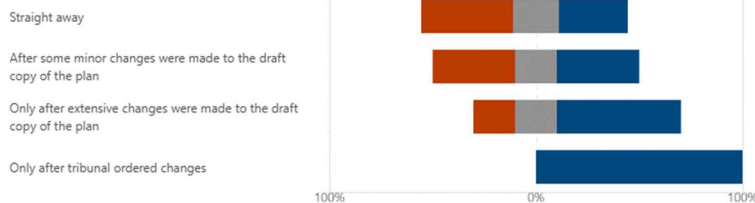
*"EHCP co ordinator do not reply! Still waiting for an updated EHCP from emergency review in November 2023. Shocking system. Last year complaint was made to ombudsman who upheld that the council EHCP team had failed my child. "*

*"The complaints process was not even worth it! Your complaints are never answered in direct words. Always going round about way. They never accept what they have done wrong."*

Regarding the quality of their CYP's EHCPs, many respondents have felt it's poor and this is despite 'after tribunal ordered changes' (100%). It appears that those who were satisfied with it, were so 'straight away' (44%) or 'after minor changes were made' (40%).

29. Overall how would you rate the quality of your child/young persons final EHCP (eg do you feel that it accurately captures their wishes, their needs, agreed outcomes and provision)?

- Good
- Okay
- Poor



**Parent/Carer's Comments:**

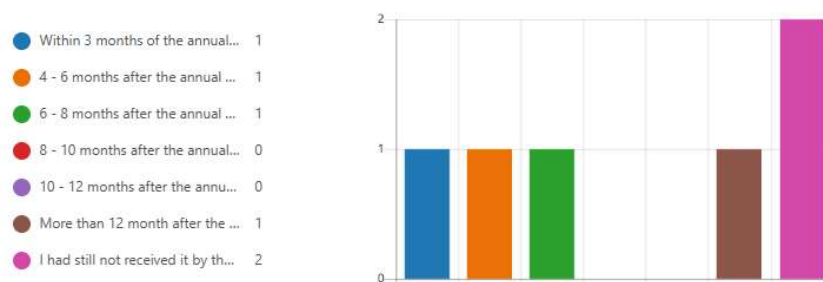
*"I am still in the process of beginning the process with support."*

*"I never got any of the reports prior to the EHCP, I have to make many changes, some things I did not understand! I asked but they were never clarified and was told its the way it should be. "*

Over the last 12 months more than half (56%) were ‘not sure’ if their CYPs last annual review was completed on time and over a fifth (22%) said ‘no’. Following the annual review 91% stated that LA did not notify them within 4 weeks of the decision to amend, cease or maintain the EHCP.

Where there was a decision to amend the EHCP only 16% received it within 3 months of the annual review. With the rest receiving it in a longer time than this and a third (33%) of them not receiving it by the next annual review.

33. Following the annual review, if there was a decision made to amend the EHCP, how long did it take to receive the amended final EHCP?



Parent/Carer’s Comment:

*"I’m still waiting it’s been 6 months since review"*

*"The school SENCO completed the annual review but I received nothing from the local authority. No acknowledgement, no updated plan "*

No respondents felt their CYPs are getting none of the support identified in the EHCP, with more than half (60%) saying some of it and the rest (40%) saying most or ‘all of it’.

Parent/Carer’s Comments:

*"My child is not receiving the speech therapy services outlined in the EHC plan "*

*"We have had a number of meetings where my child’s 121 has been sent else where and my child has been left alone or sent home because 121 isn’t available "*

### **Q37-46 “Children Out of School or on Reduced Timetables”**

A very small amount of our respondents had their CYPs in this category which amounted to 10%.

Parent/Carer’s Comment:

*"This wasn’t easy camhs suggested it school refused it and then referred us to ewo by this time school decided they couldn’t cope and sent child home "*

They (66%) stated ‘other’ reasons not listed in the survey for them not being in school full time. The same amount of them stated that there was no plan in place to work back to full time hours in school, and the same amount feel that their CYPs could be in school full time with the right support or in the right environment.

40. Was there a plan or is there a plan in place with school to work back to full time school hours?



41. Did you/do you feel your child could be in school full time with the right support, or in the right environment?



The majority (83%) of CYPs have not spent more than 15 consecutive days. But we do have one each stating more than 12 months, 4-8 months and 15-30 days. One stated ‘no school place available’ and another stated ‘other’ as reasons for them not being in school. They have also stated that they were given no support during this time. They were either still out of school or back to school in the same or different setting.

Parent/Carer’s Comments:

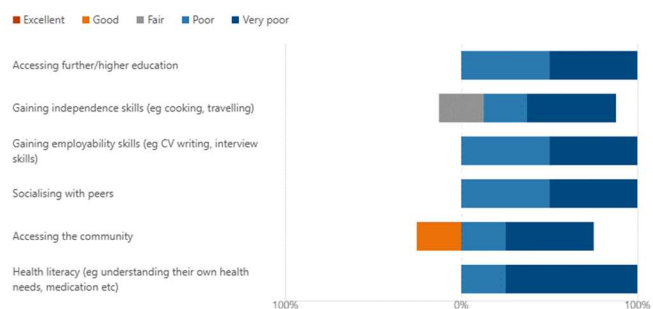
*"Child was excluded from main stream and no alternative education was offered. Has to fight to get support. Fails from the local authority was upheld by the ombusman"*

*"School made this more difficult than it needed to be They didn’t follow the guidelines played out by camhs "*

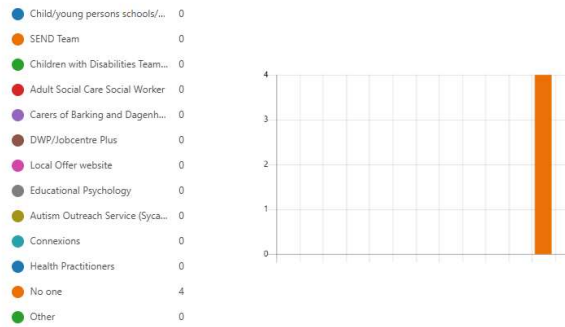
### Q47-50 “Preparing for Adulthood”

There was hardly any positive feedback here with all the support listed in the survey having ‘poor’ or ‘very poor’. Also, all respondents this applied to have said no one has provided advice or support during transitions. One person said that their CYP is not in education training or employment.

47. If your child is over the age of 14, how would you rate the support they have received for their preparation for adulthood?



48. If your child/young person is over the age of 14 years, who has provided advice or support during transitions?



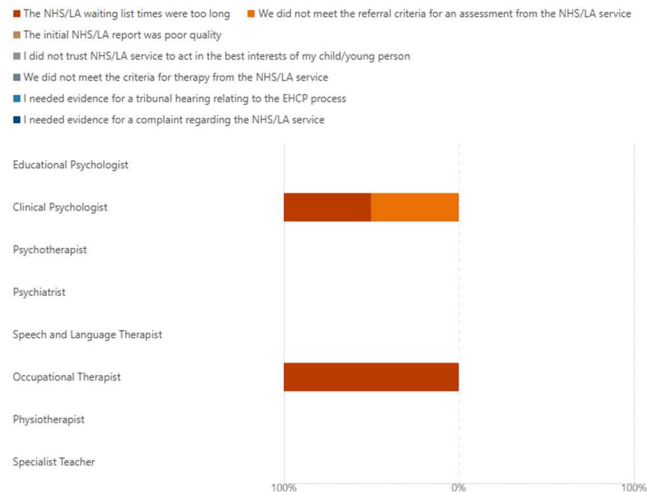
Parent/Carer's Comment:

*"The left hand doesn't know what the right hand is doing camhs don't talk to paediatrics school ignores advise "*

### Q51 -56 Other questions

Paid for private assessments - A paid for assessment/diagnostic report was sought from a private occupational therapists and clinical psychologists within the last 12 months and the reasons for it and 'NHS/LA waiting lists times were too long' was marked as the main reason. Also 'not meeting the referral criteria for an assessment from the NHS/LA service' was also marked as a reason for seeking a private clinical psychologist report.

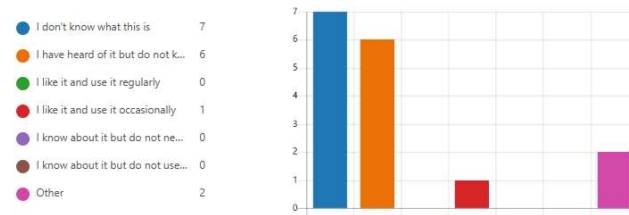
51. If you have paid for an assessment/diagnostic report from a private practitioner within the last 12 months please tell us the main reason for doing this?



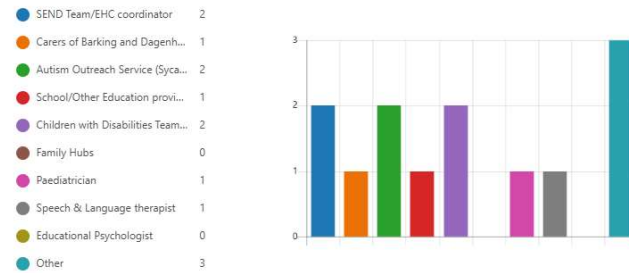
Local Offer – 80% of respondents either do not know what this is or have heard of it but do not know how to use it. Those who have heard of it, have so from various sources almost equally, and most of them access it through using their website.



52. What are your thoughts regarding the Local Offer?



53. Where did you learn of the Local Offer from?



Thoughts and experiences either positive or negative – below are personal comments respondents have left:

*"For every thing you wait for months, you don't react in time. We have a physiotherapist we see her twice a year and seeing her doesn't help us at all. It doesn't show us anything for my daughter to progress."*

*"I think the education services provided are extremely poor. Camhs doesn't provide any assistance or appointments whatsoever. The school and the La are not bothered about my sen child. Absolutely disgraceful!"*

*"The Sycamore Trust, have been the only ones who actually are therefore you, who actually care and who actually support you. The processes for EHCP are horrendous! Over deadlines, never explained anything properly, rush you through and they do not even have the knowledge of the SEND CODE OF PRACTICE AND THE CHILDRENS FAMILIES ACT 2014. The EHCP process has been the most mentally draining, depressing, lonely thing I have ever fine through. Deadlines were never met, you can not get through to the EHCP coordinators, telephones where never answered and on top there was foul play by them. They did not adhere to the regulations and when complained about, our complaints and questions were never answered. The CYPD hub are not very friendly, and there is not much information about I feel as though there is not much support for families with SEND children. Health visitors are non existant. Basically, people working within this sector within the council, do not have the knowledge of that area."*

*"There is no complex needs speech therapist. My child is not seen often enough or provided any therapy sessions by a speech therapist "*

*"It's been a poor experience for 3 young people between the ages of 25, 19 and 15 all with different needs but the same poor outcome agency's not talking to each other and the time frame is ridiculous a young person didn't meet the camhs remit until they did and they professionals ask why they weren't seen before ? "*

The overall rating for the borough averaged at 2.5\*(1\* being lowest and 5\* being highest). 33% rated it 1\*, 28% rated it 3\* and 4\* each the remaining 11% rated it 2\*.

56. Finally, when thinking about all of the Education, Social Care and Health services for children and young people with SEND in Barking and Dagenham as a whole, how many stars would you give this as a rating (with 1 being the lowest and 5 being the highest)?

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[Insights](#)

2.50  
Average Rating

