



Dudley Parent Carer Forum

Annual Survey 2021

Results report –April 2022

Dudley Parent Carer Forum are recognised by the Department for Education as the official Parent Carer Forum for Dudley.

Dudley Parent Carer Forum wanted to produce a survey which would gather a wide range of views from parents within the borough regarding many aspects of support for children and young people with Special Educational Needs and Disabilities (SEND). The survey was launched on 1st September 2021 and closed on 3rd November 2021. It is our aim to repeat this survey annually.

Who responded to our survey?

The survey received 151 responses from parent carers. We received responses from both male, female and non-binary parent carers across the age ranges of under 18 to 65 plus years. The vast majority (78%) were females aged 35-54 years.

Of the respondents 18% of parent carers considered themselves to have a disability. We received 7% of responses from Black, Asian and Minority Ethnic communities.

We were very pleased to have gained responses from parent carers of children and young people across the whole age range of 0-25 years. From the responses, 29% of parent carers had two or more children with SEND.

When asked about the main areas of need for their child or young person we received responses from parent carers to each need listed, however the most commonly identified needs were Autistic Spectrum Disorder (68%), Speech, Language and Communication Needs (54%) and Social, Emotional and Mental Health Difficulties (44%).

The education placement or situation of the respondents children or young people was varied: 28% were attending a local special needs school, 26% were attending a local mainstream school and 7% of children/young people attending independent specialist schools. The remaining 39% of responses were split between a range of placements for example specialist or mainstream colleges, Elective and non-elective home education, EOTAS (Education other than at school, Specialist Early Years settings and NEET (Not in Education Employment or Training).

In terms of the type of support the children and young people were receiving, 76% had an Education Health and Care Plan (EHCP) and 11% were receiving SEND support. Just 1% were receiving DSA (Disabled Students Allowance) at Higher Education Level. The remaining respondents reported that their child or young person was either not accessing any additional support or that they did not know if they were accessing anything. In addition to this, 6% of children and young people were eligible for Pupil Premium and a further 3% eligible for Pupil Premium Plus funding.

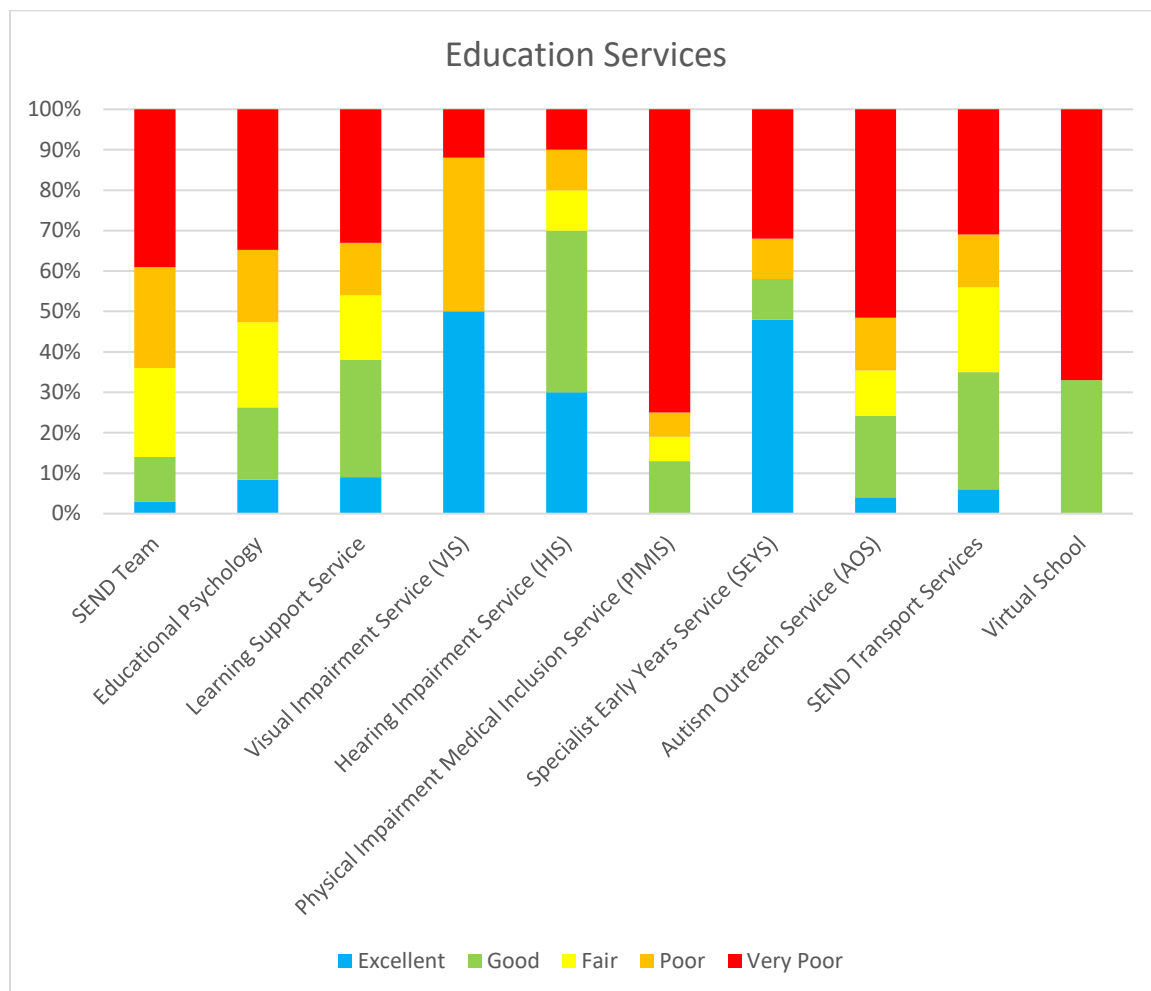
Key finding

When asked how long it had taken them to receive a diagnosis for their child or young person after first raising concerns 75% of parent carers said it had taken them longer than one year to get this. These results are broken down as follows: 21% waited 1-2 years, 16% waited 2-3 years and 38% waited 3 years or more. These results highlight that over 50% of children or young people waited for over two years of their childhood to received their diagnosis, from first concerns being raised.

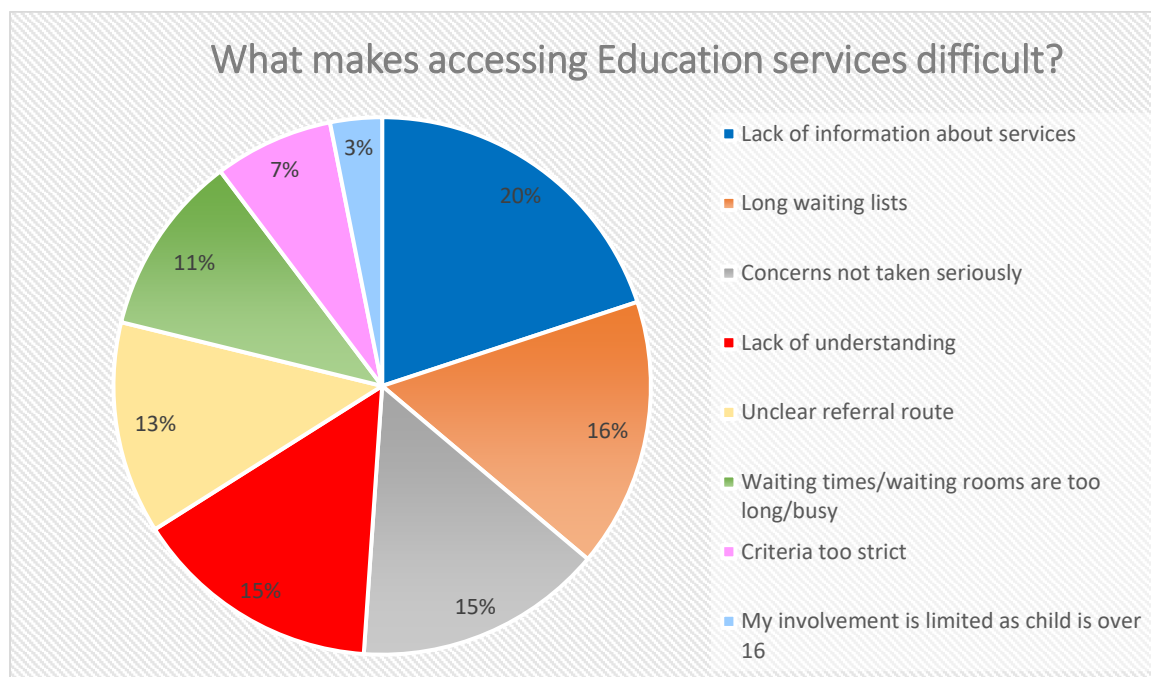


Education

Participants of the survey were asked to rate the overall quality of services and support from Educational Services that they have accessed over the last two years. Of the respondents that had accessed the services and answered this question the results are as follows:

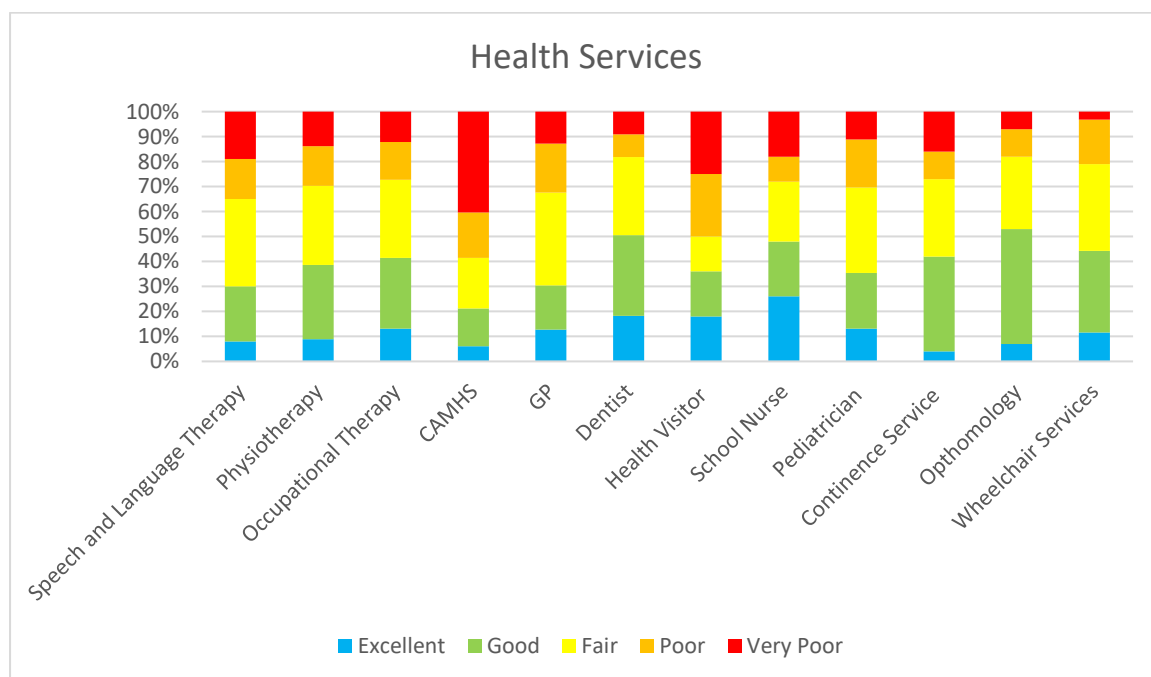


Following this, we asked what, if anything, made it difficult to access the educational services listed. The results showed the following:

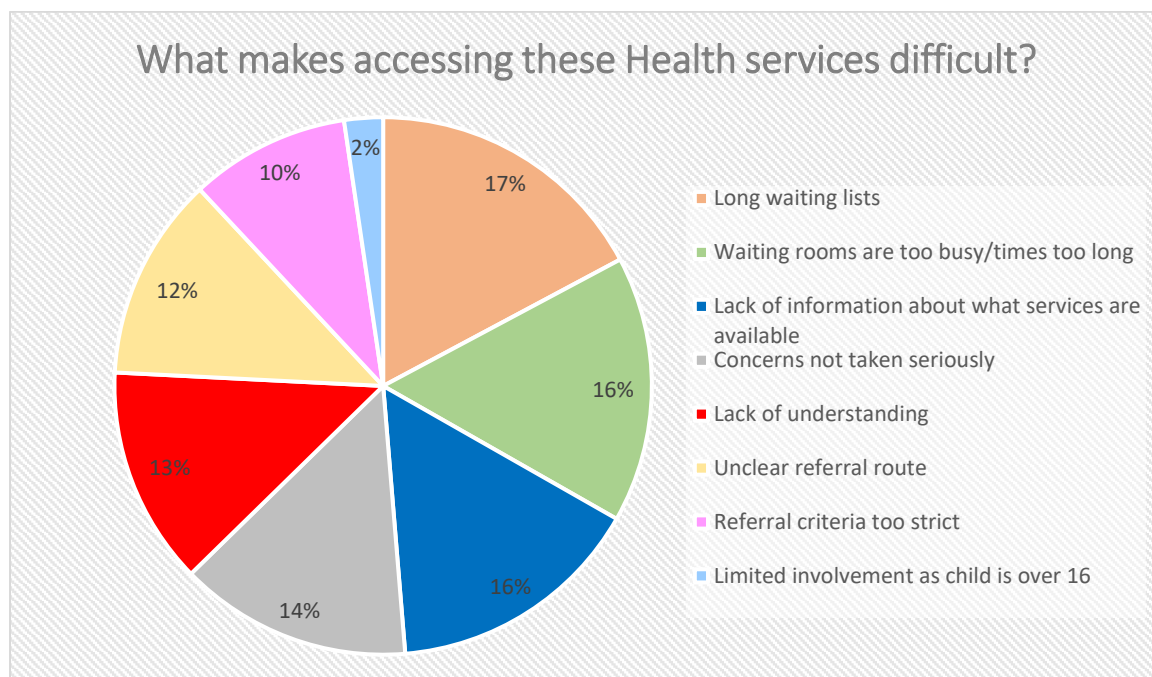


Health

Participants of the survey were asked to rate the overall quality of services and support from Health Services that they have accessed over the last two years. Of the respondents that had accessed the services and answered this question the results are as follows:

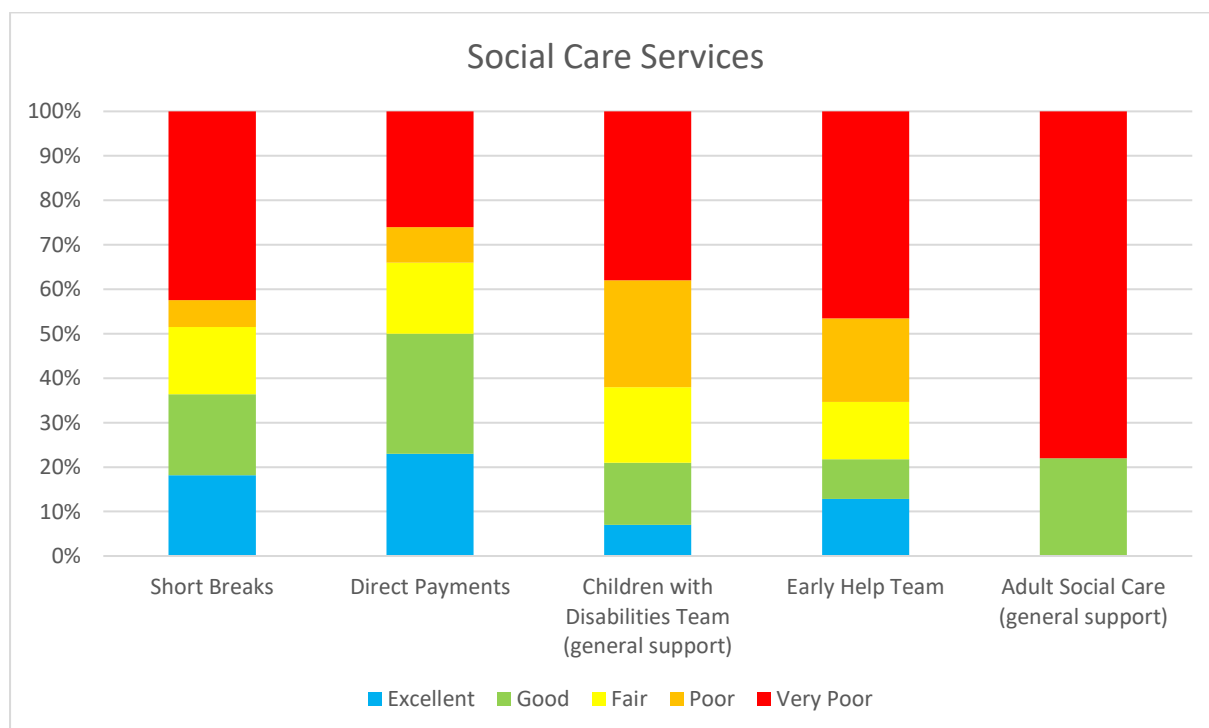


Following this, we asked what, if anything, made it difficult to access the Health services listed. The results showed the following:

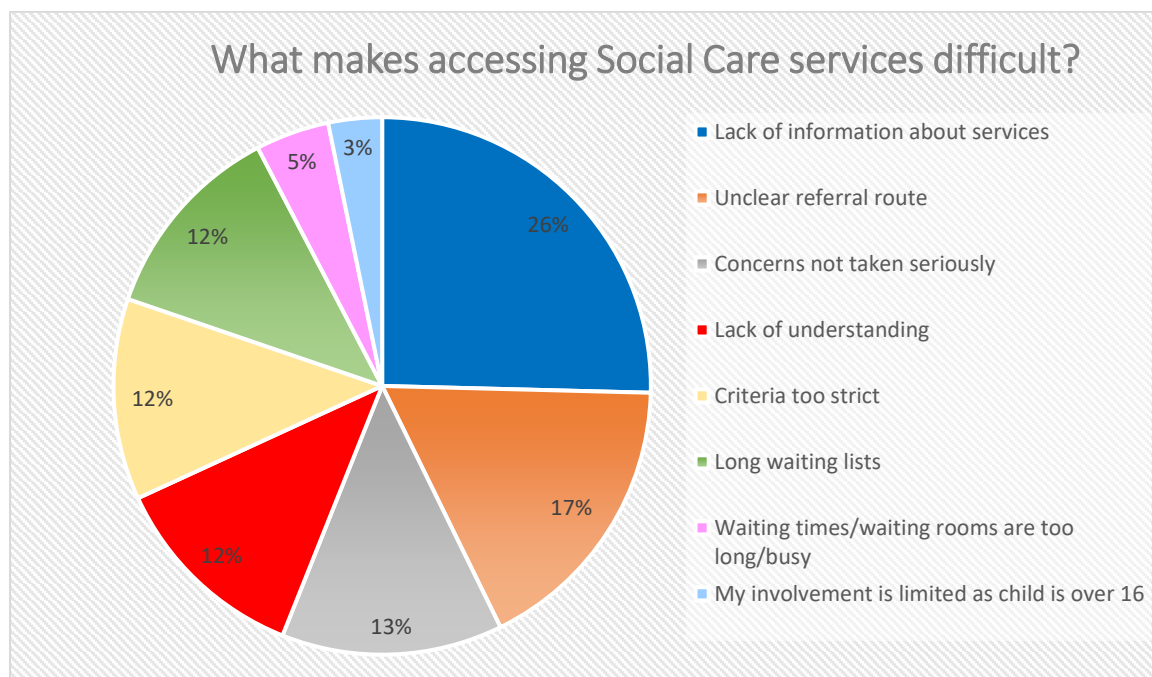


Social Care

Participants of the survey were asked to rate the Social Care Services that they have accessed over the last two years. Of the respondents that had accessed the services and answered this question the results are as follows:



Following this, we asked what, if anything, made it difficult to access the Social Care services listed. The results showed the following:



Focus area's

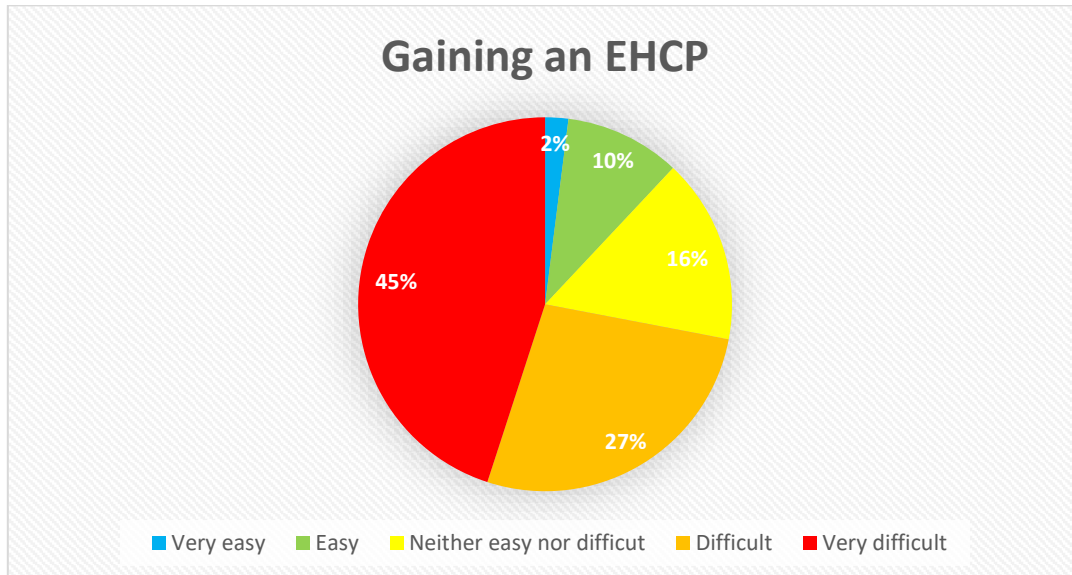
For each of our annual surveys we will have focus area's to gain views regarding specific area's that may not be covered elsewhere. This year our three focus areas were:

- Education Health and Care Plans
- Preparing for Adulthood
- The experiences and impact of caring for a child or young person with SEND

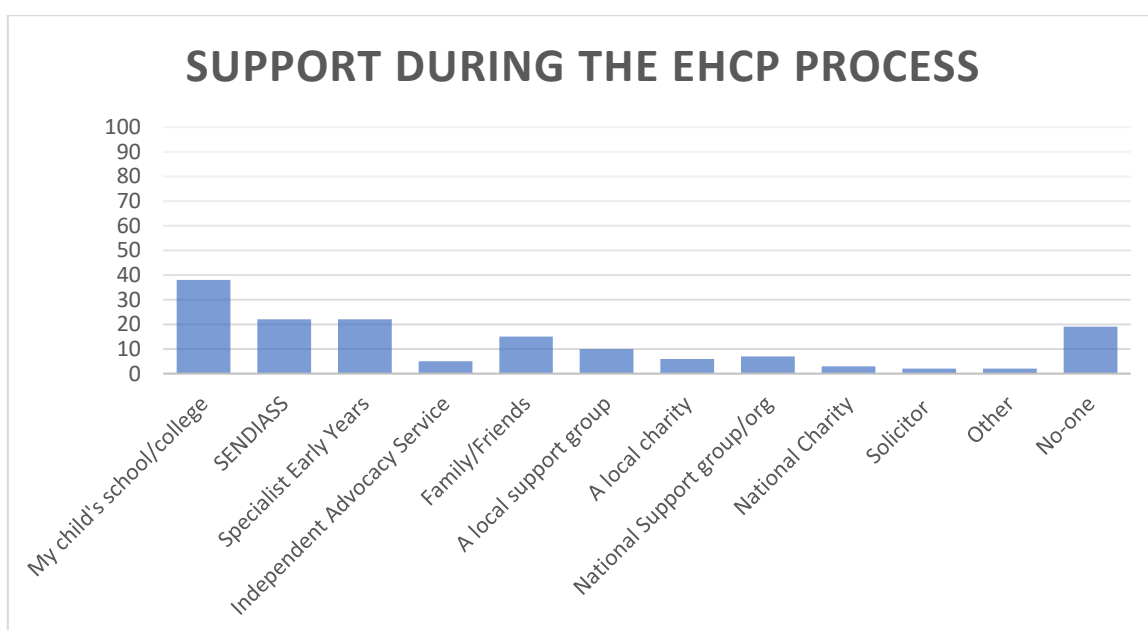


Education Health and Care Plans

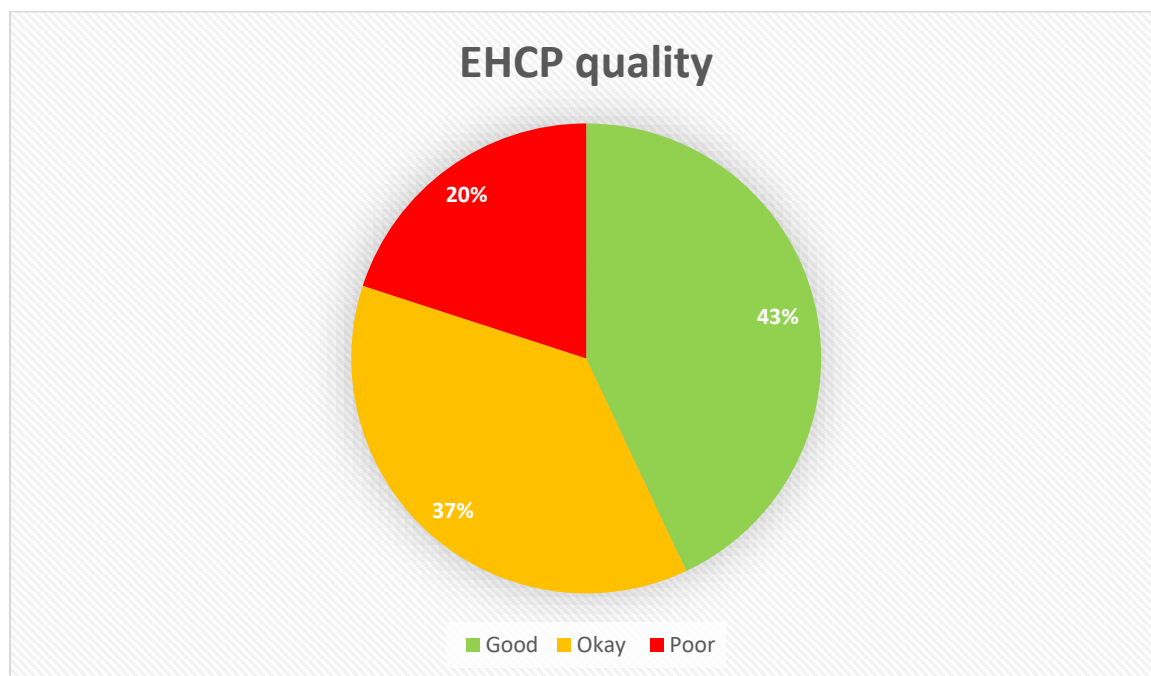
Respondents were asked about their experiences of gaining an EHCP and how they found this process. As the results below show, **72% of parents found the process either difficult or very difficult**:



When asked who had supported them with the process of gaining an EHCP, 38% of parent carers stated that their child/young person's school or college had supported them. The local IASS service (SENDIASS) had provided support to 22% of parent carers, with local charities or support groups supporting 16% respondents. Responses identified that 15% of parent carers had gained support from family and friends, and 19% had received no support at all. It was not clear from responses if this was down to personal choice or whether the parent carers did not know where to access support. The full breakdown of responses were as follows:



Parent carers were asked to rate the current quality of their child/young person’s EHCP. Just 50% of respondents thought the quality of their child/young person’s EHCP was of ‘good’ or ‘okay’ quality straight away or after some tweaks were made. There were 30% of parent carers who felt the EHCP was ‘good’ or ‘okay’ only after extensive changes were made or after a tribunal hearing. The remaining **20% of parent carers felt their child/young person’s EHCP quality was poor regardless of the amount of effort put into improving it.**



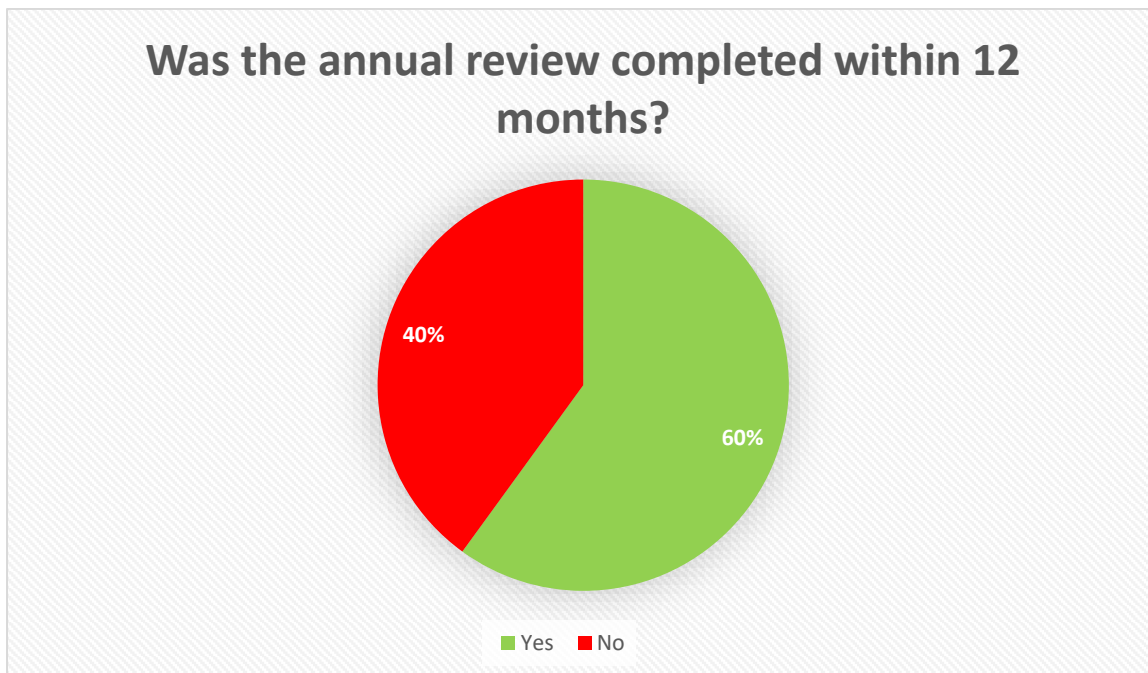
A full breakdown of these responses are as follows:

Good (straight away)	10%
Good (after some tweaks were made)	16%
Good (only after extensive changes made)	8%
Good (only after tribunal ordered changes)	9%
Okay (straight away)	11%
Okay (after some tweaks were made)	13%
Okay (only after extensive changes made)	11%
Okay (only after tribunal ordered changes)	2%
Poor (straight away)	11%
Poor (even after some tweaks were made)	4%
Poor (even after extensive changes made)	4%
Poor (even after tribunal ordered changes)	1%

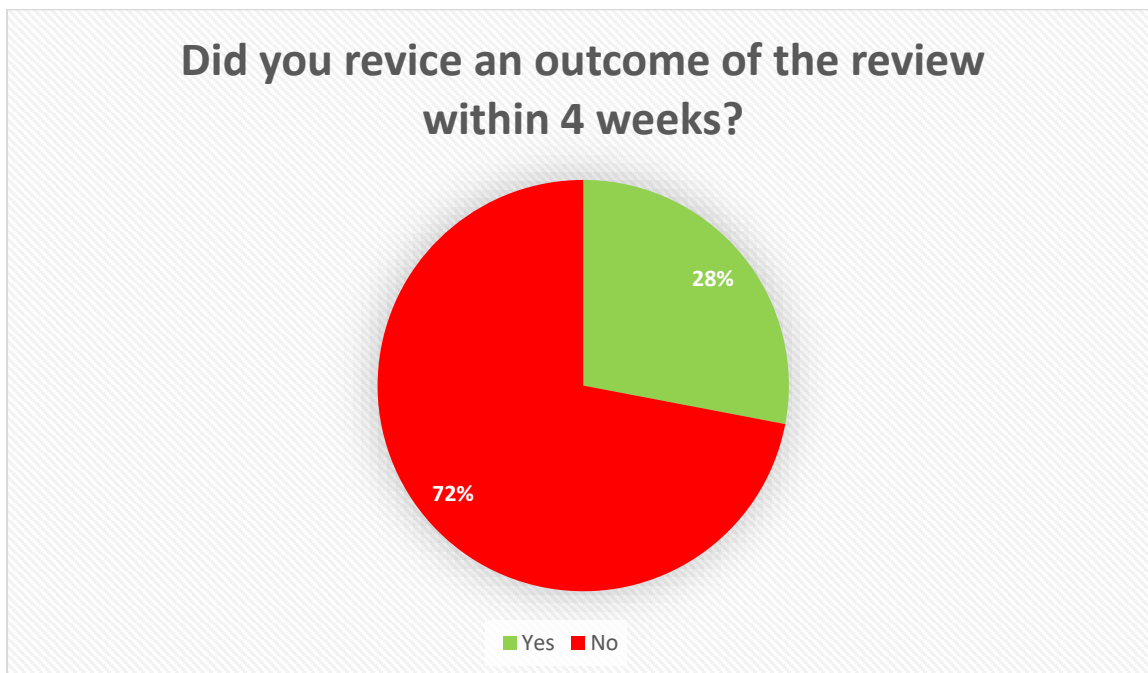


“My child’s Annual Review was in November and the draft came back the following September after many emails”

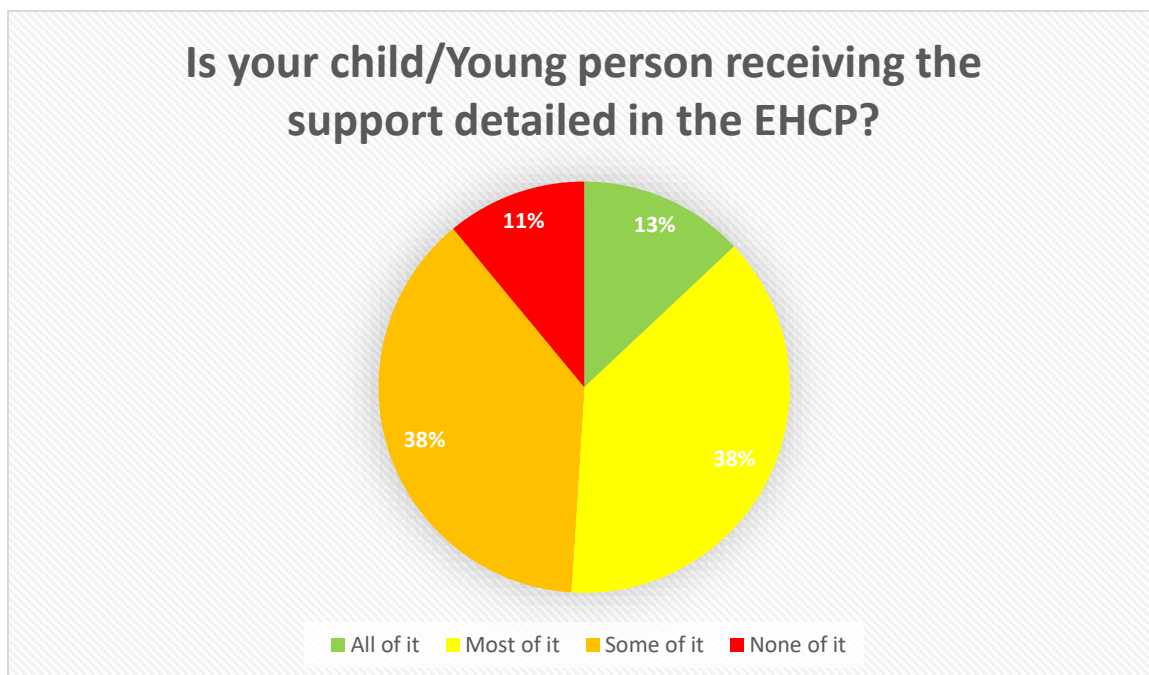
We asked parent carers that in cases where their child or young person had had an EHCP in place for over 12 months, had their annual review been completed within 12 months of the final plan or previous review. The responses were as follows:



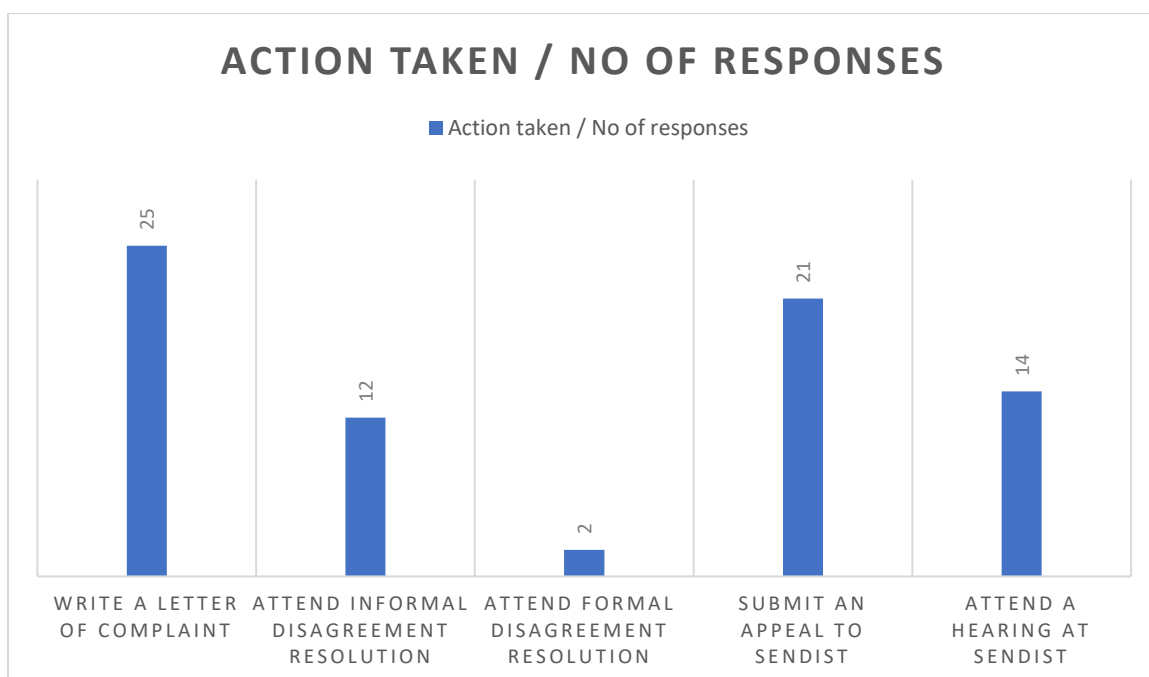
We then asked that following an annual review did the parent carers receive an outcome, such as a notification within 4 weeks stating the LA's intention to maintain, amend or cease the EHCP. The responses were as follows:



We asked parent carers of children/young people who had an EHCP, if they were receiving all of the support detailed within this. The responses highlighted that **just 13% of children/young people with EHCP's were receiving all of the support as detailed in their plan.**

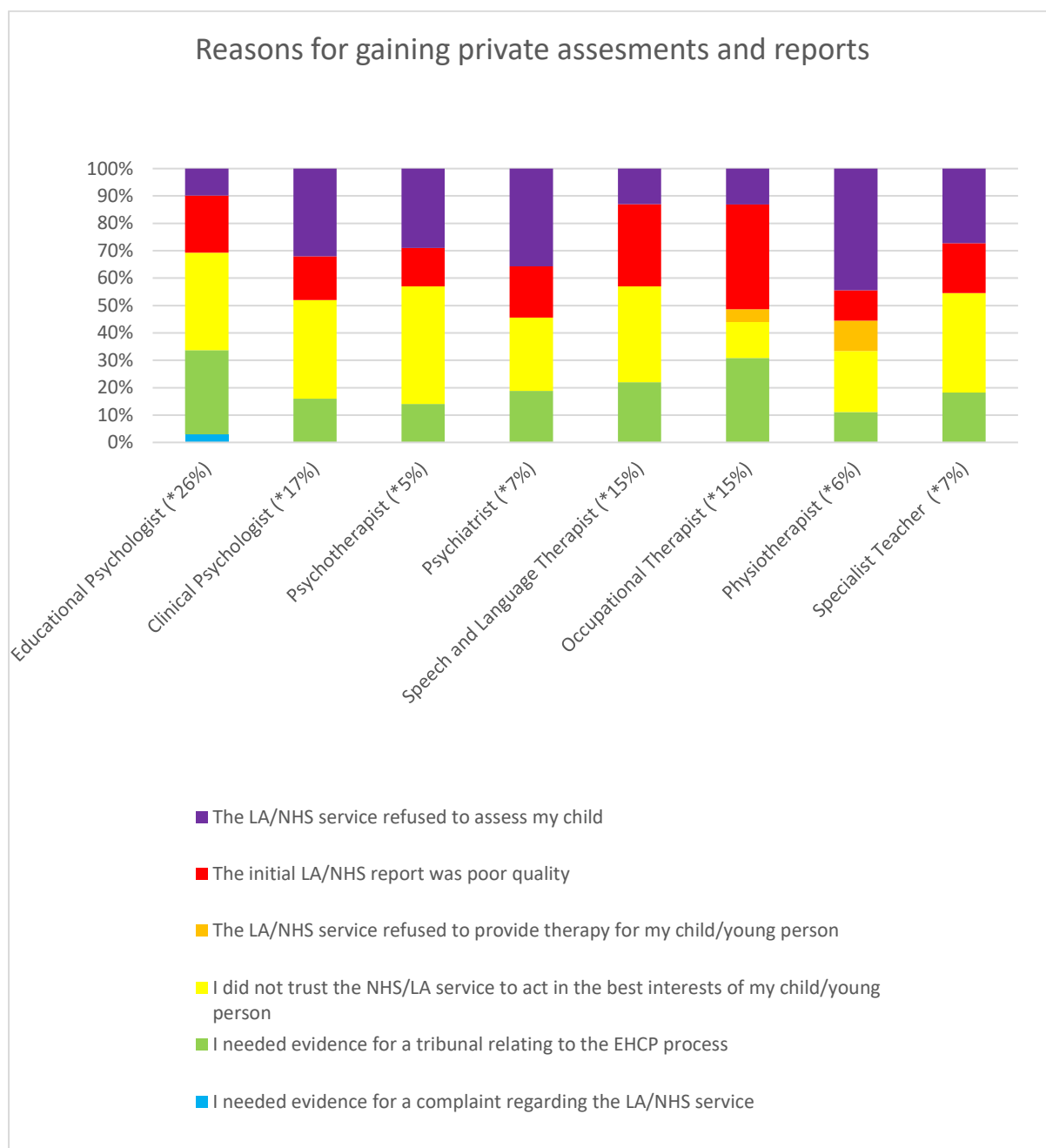


Out of the 114 parent carers who replied saying that their child currently had an EHCP, over 40% had to take some form of further action to gain an appropriate EHCP for their child/young person, this included with **nearly a quarter having to write a letter of complaint and nearly 20% having to submit an appeal to tribunal** with 12% of EHCP holders having to go to a full hearing.



We wanted to gain an understanding into how many parent carers had paid for a private assessment or report with regards to their child’s difficulties and what the reason was for doing this. **We were pleased to find that the majority of parent carers have not had to gain private reports or assessments.**

The area which resulted in the highest number of private assessments of private reports being sought by parent carers was Educational Psychology, which was 26% of our total survey respondents. The results are as follows:

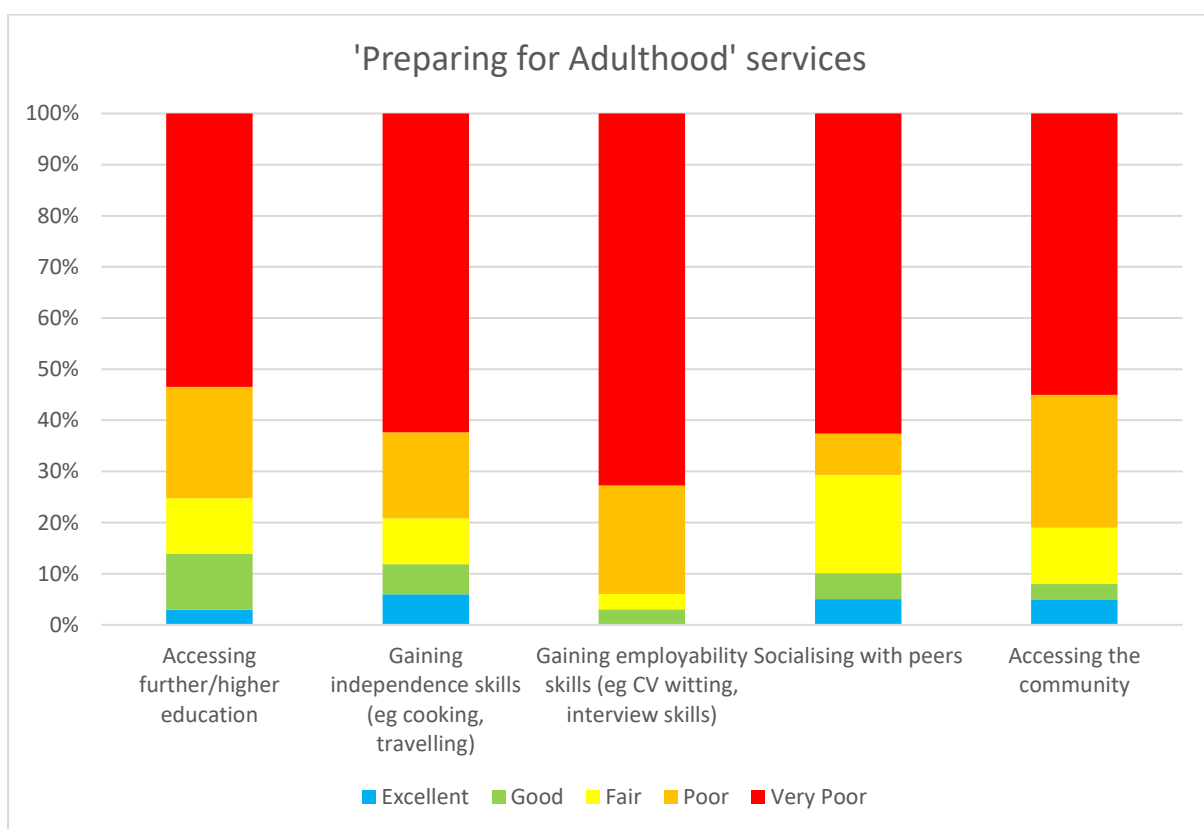


*Percentage of total survey respondents to have gained a private assessment/report in this area

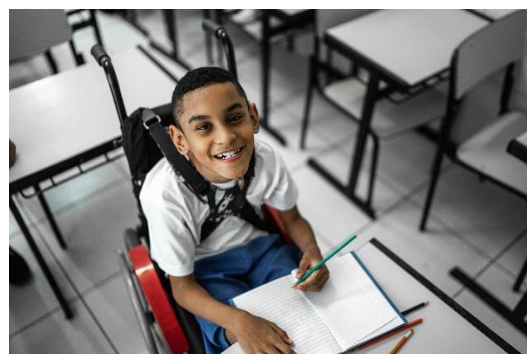
Preparing for Adulthood

Although we have limited data within this field due to the slightly lower number of respondents with young people in this age group, we still feel it is important to highlight the current views of this area.

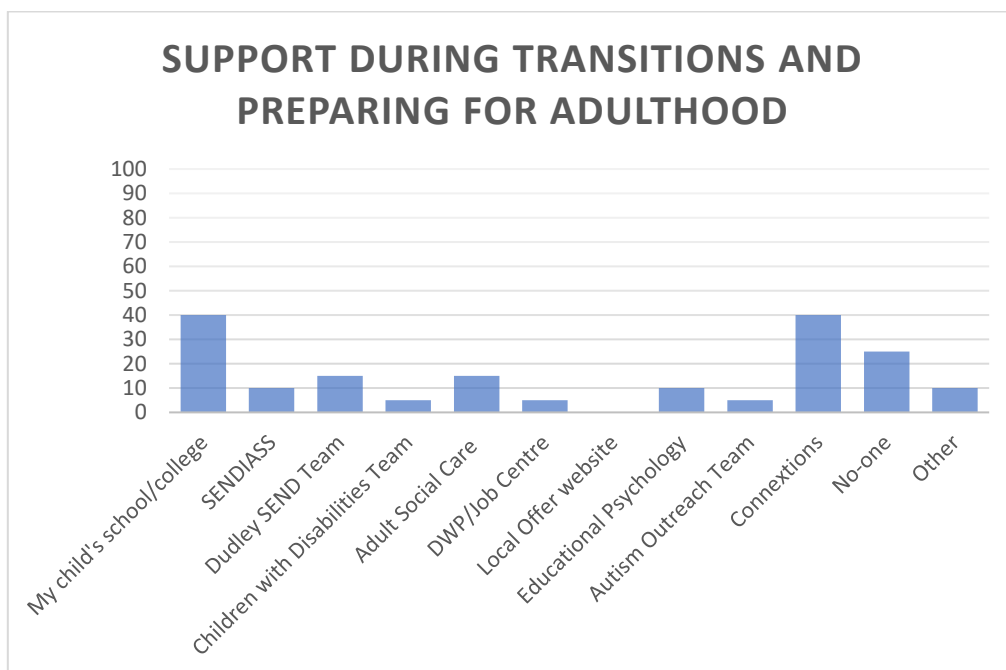
We asked respondents with young people over the age of 14 to rate the support received towards a range of outcomes. We found these results to be particularly worrying, for example with **96% of parent carers stating their young person had received poor or very poor support towards gaining employability skills**. In addition 81% said they had received poor or very poor support in accessing the community. The full results are as follows:



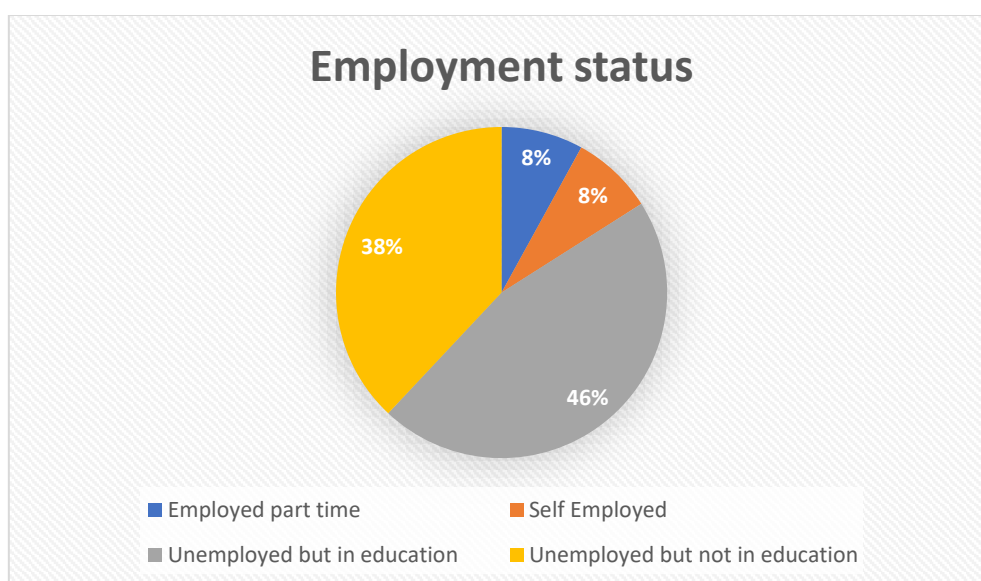
“After age 16 you are left to fend for yourself. I’ve tried to get help but get told there’s no funding or their service is not suited to my child”



We asked parent carers who had provided support to their child/young person from age 14 onwards with regards to transitions and preparing for adulthood. We were pleased to see that 40% of young people were receiving support from their school/college and/or the local Connexions service. However this also raises a question of whether the remaining 60% of young people are also being supported in some way from other agencies. A significant percentage, 25%, of young people were not given any support in this area which is concerning.



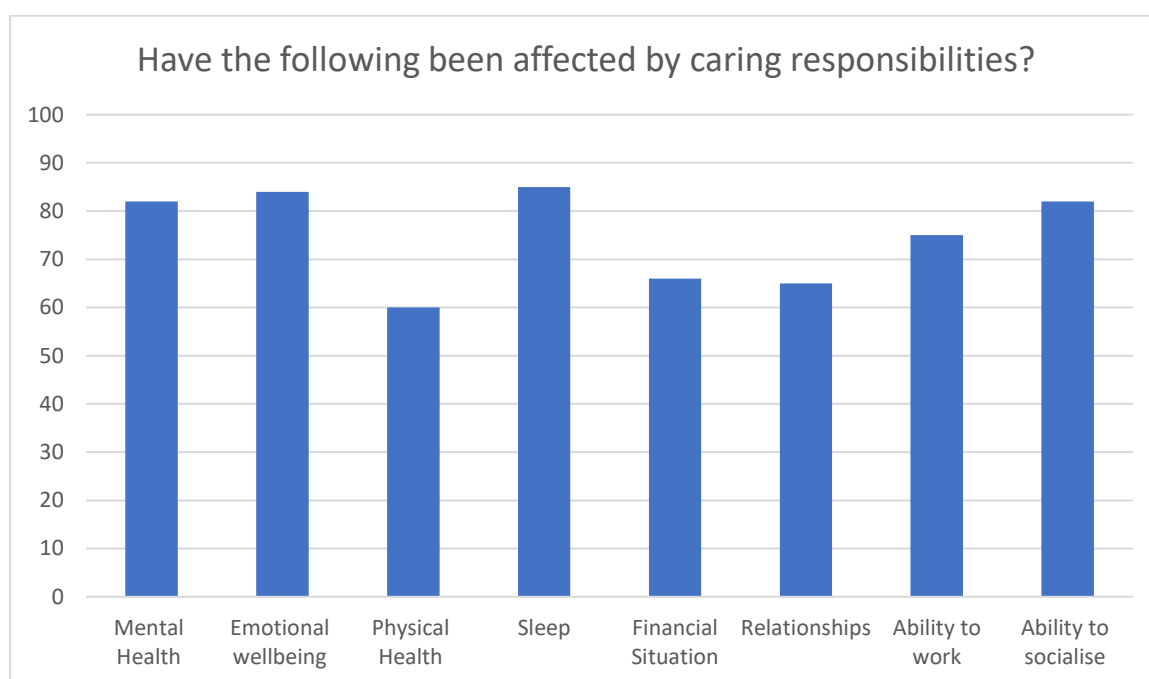
We asked those parent carers of young people over the age of 18 what their current employment status was. The results highlight that whereas 62% of young people were either in employment or remain in education, **a significant percentage – 38% are unemployed and not in education**. We received no responses from people whose young people were in full time employment or who were accessing an apprenticeship.



Experiences of being a carer

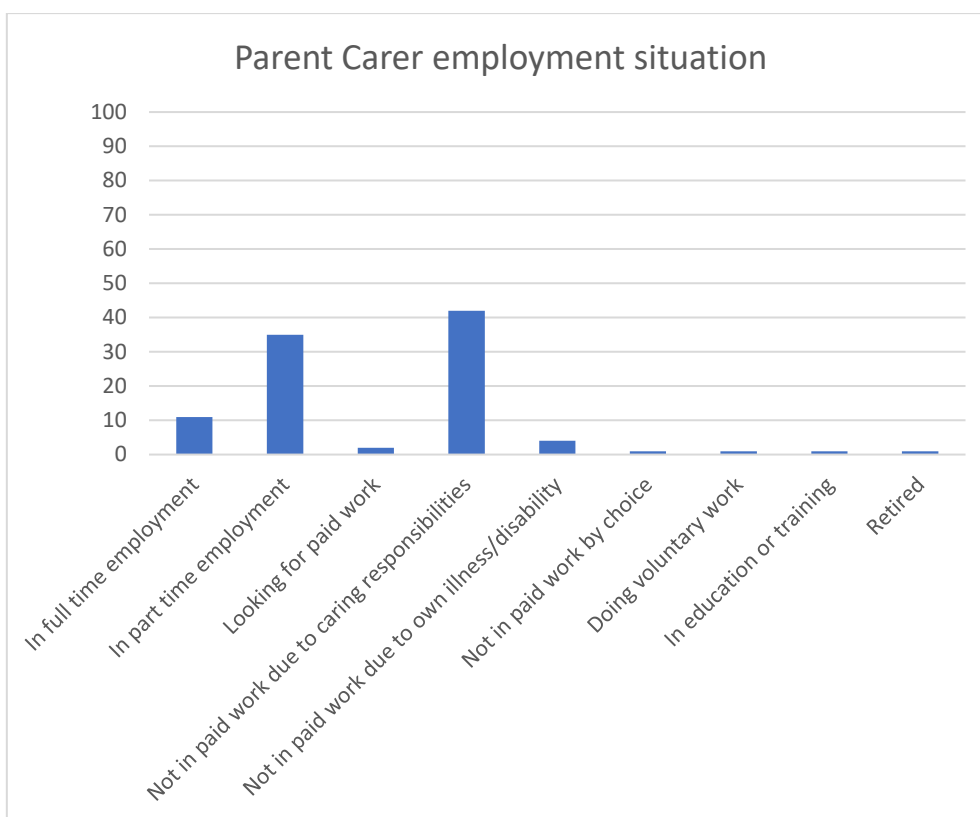
As part of this focus area we asked parent carers to answer a number of questions about how their caring responsibilities affected their day to day life.

Firstly we asked respondents to identify which, if any, areas of their life that had been affected by. The results identified that a **85% of parent carers felt their sleep had been affected by their caring responsibilities**, 84% felt their emotional wellbeing had been affected, 82% felt their mental health had been affected and 82% felt their ability to socialise had been compromised. These results along with the other affected areas detailed below identify the significant strain that is being placed on parent carers within the borough. These results clearly show that further work is needed to provide better support to carers.

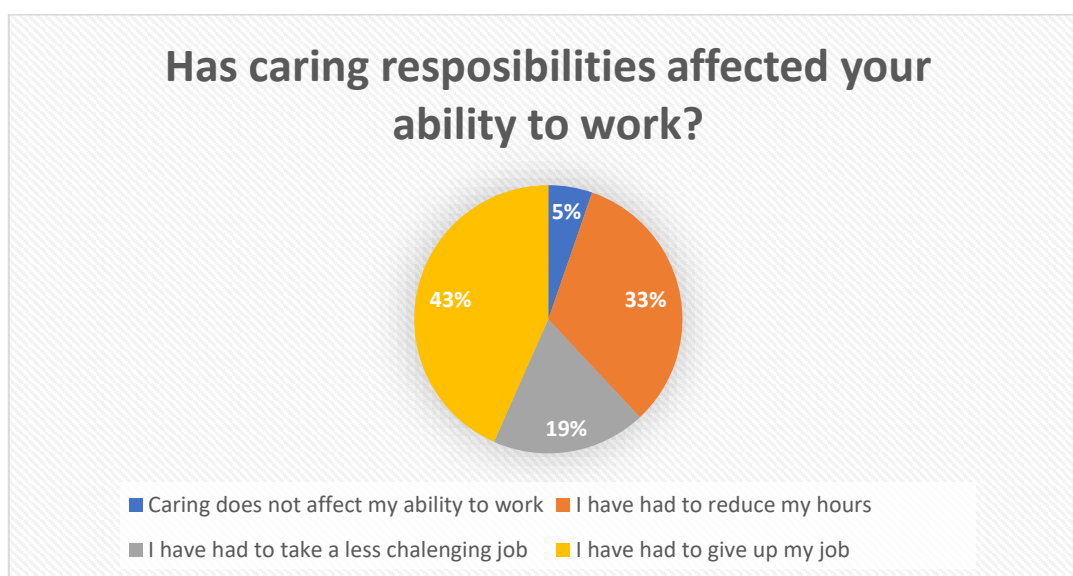


“Why do parent carers have to reach crisis point before any kind of home help is offered?”

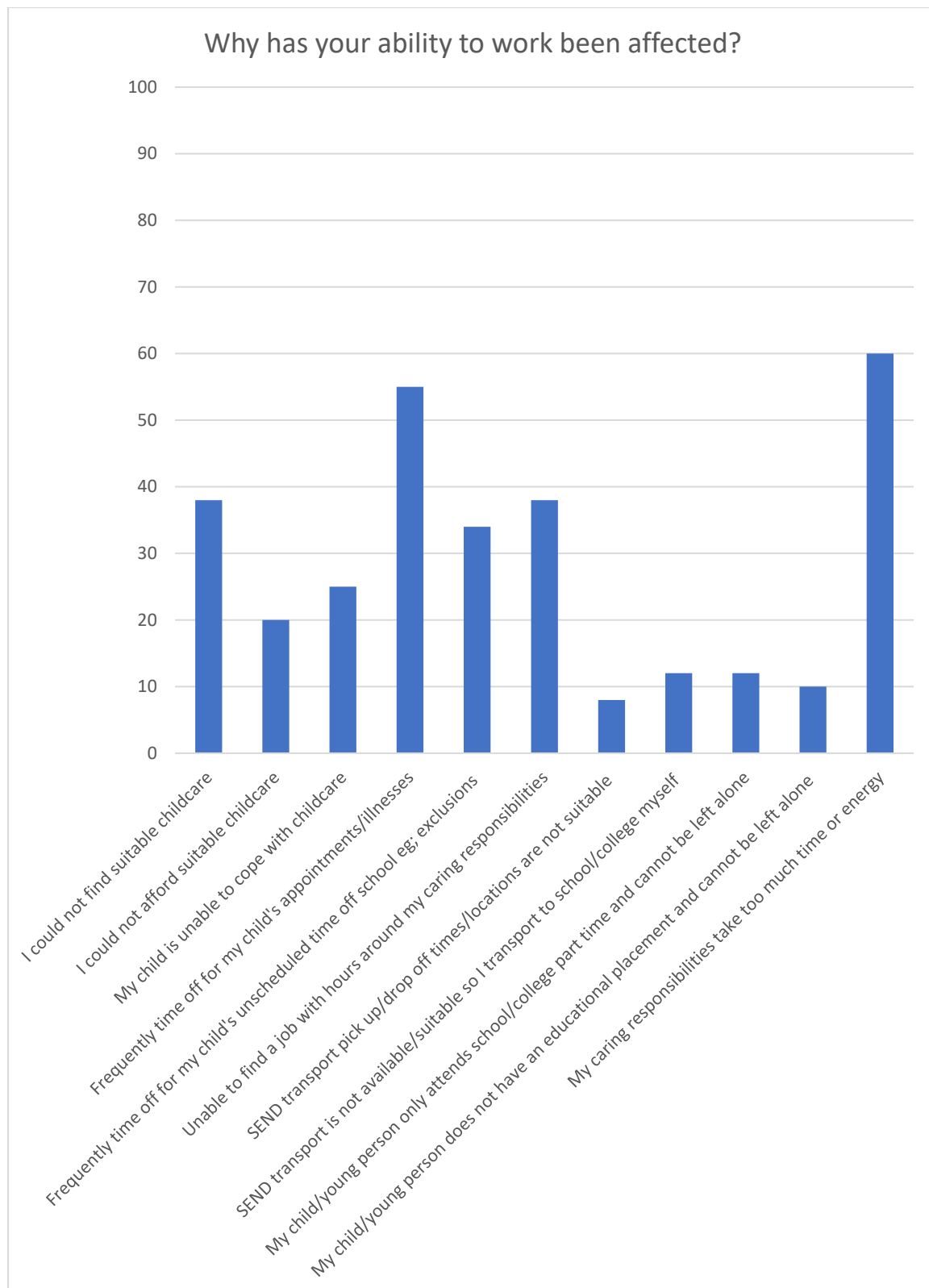
We asked parent carers what their current employment situation was. The results identified that around 47% of respondents were in either full or part time employment. However a significant number of parent carers, **42%**, were **not in paid work due to their caring responsibilities**. The full results are detailed below:



We then asked parent carer whether their caring responsibilities had affected their ability to work. A significantly high number of respondents, 49%, stated that they had needed to give up work in order to fulfil their caring responsibilities with a further 21% needing to reduce their working hours.

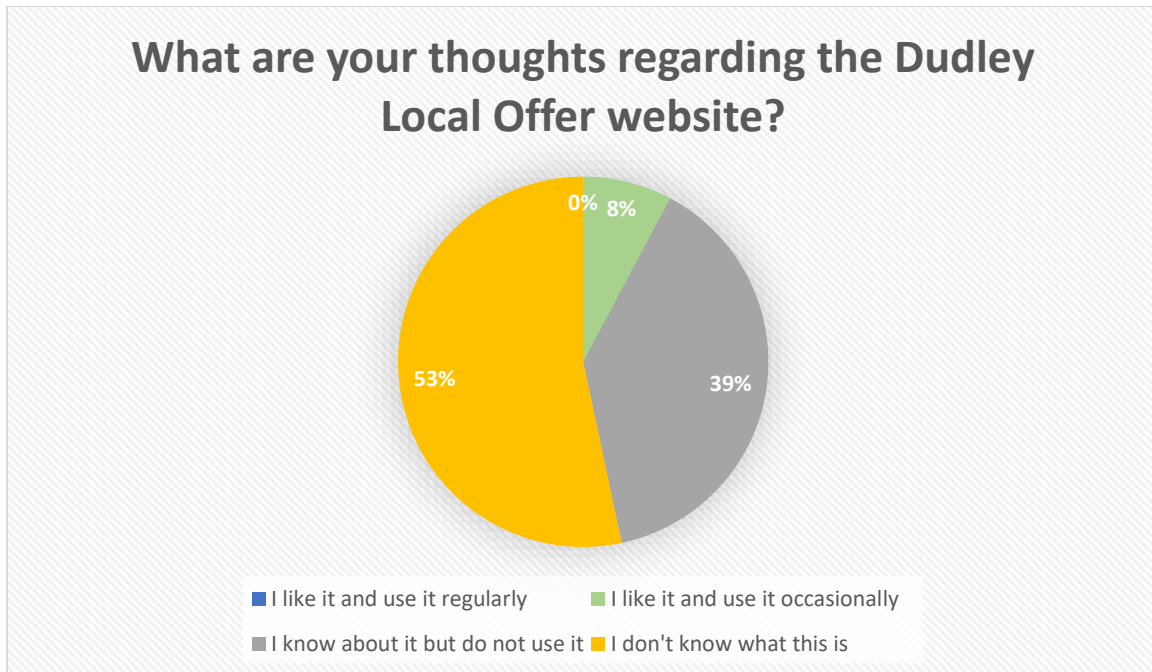


We then asked parent carers to detail the reasons that their employment situation had been affected. The results showed that 60% of parent carers felt they had no time or energy to work due to their caring responsibilities. This fact is unsurprising given the impact of caring on parent carers identified in our survey and discussed previously in this report.



Additional Survey questions

The Local Offer is regarded as a key factor in providing support to parent carers and their children/young people, as well as making information on these services easily available. Therefore we asked parent carer views on the Local Offer website, the results of which showed that **53% of parent carers are still unaware of the Local Offer website**, and 39% who knew about it but did not use it. There were no parent carers who stated they knew about this and used it regularly, whilst just 8% used it occasionally.



Parent Carer Forum priorities

In order to continue being the voice of parent carers within the borough we asked our respondents to identify what needed to improve and where we should focus our efforts over the next 12 months. From a list of 26 options respondents were able to choose the 3 areas most important to them. We received responses to all 26 options available, however the 10 most frequently chosen options are shown below, in rank order.

1 st	EHCP journey and quality
2 nd	SEND Team communication, understanding and training
3 rd	Child and Adolescent Mental Health Services (CAMHS)
4 th	Reducing the need for complaints or tribunals relating to SEND Team
5 th	Special School provision
6 th	Speech and Language Therapy Service (Children)
7 th	Mainstream School provision
8 th	Educational Psychology
9 th	Post 19 provision
10 th	Post 14 transitions/preparing for adulthood

Therefore for the following 12 months we will focus our efforts on EHCP journey and quality, SEND team communication, understanding and training, and CAMHS.

However we would like to reassure parent carers that whereas these will be our priority areas it will not stop us working on a variety of other projects, workstreams or issues. As an example we have a current and ongoing workstream looking at 'Preparing for Adulthood' which is a very problematic area for parent carers in the borough. We will continue with this work due to significant impact the issues are having on the lives of young people in the borough. We appreciate that the landscape can change very quickly and therefore will remain flexible to ensure we are always working for parent carers on what matters most to them.

Overall rating

Finally, we asked respondents to think about Dudley SEND services relating to Education, Social Care and Health, as a whole and give them a star rating of between 1 - 5. The results were varied, but the **overall rating was 2.0**. We feel this shows very clearly that parent carers are still very dissatisfied with the SEND services, across all agencies within Dudley.

Overall start rating of the combined SEND services in Dudley



Dudley Parent Carer Forum key recommendations

As a Parent Carer Forum we will continue working with colleagues across the CCG and LA to try and resolve some of the issues highlighted in this survey and work towards brighter futures for the children and young people of Dudley.

The parent carer forum would like to see the following actions in response to this survey report:

- A review of the diagnostic pathway by all stakeholders to ensure that children and young people are receiving their diagnosis in a timely and seamless manner. We would also like to see an increase in recognition from practitioners around the importance of diagnosis for children/young people and their families in terms of gaining support, understanding and access to services.
- We would like to see an urgent review of all services that received 50% or more of 'poor' or 'very poor' rated feedback by parent carers.
 - For the Local Authority these are: The SEND Team, Autism Outreach Services, PIMIS, The Educational Psychology Service and the Virtual School for looked-after children.
 - For health services these are currently CAMHS and the Health Visiting Service.
 - For Social Care Services these are currently The Children with Disabilities Team, Early Help and Adult Social Care.
- The LA, health services and social care services should look at ways to make accessing their services easier. Based on feedback we would like to see much clearer information shared about services, what they offer and how they can be accessed. A review of criteria to access services and a reduction in waiting list times is also needed. In addition we would like stakeholders to work with parent carers and young people to review waiting room environments to make these more SEND friendly and also review the involvement of parent carers in appointments for young people over the age of 16. Finally, we would like to see an increase in staff training to ensure a higher level of collaboration between parent carers and practitioners to ensure concerns are heard and that the child/young person and their family feel understood.
- The LA should urgently review the EHCP process to ensure that parent carers find this process clearer, easier and that they feel supported during this time.
- The quality of EHCPs needs to be urgently addressed to ensure that all plans are of good quality and are legally sound.
- The LA should look to improve its annual review process and ensure that they are completed on time, and that parent carers receive a decision following this review within 4 weeks.
- A comprehensive plan of action, led by the LA SEND team to develop a process of ensuring continued and consistent accountability with regards to the delivery of provision stated within EHCPs This should include children and young people within educational settings as well as receiving other forms of education such as EOTAS. The law around delivery of provision should be followed and parent carer concerns over this must be taken seriously.

- A thorough review to unpick the underlying reasons for the substantial amount of complaints, appeals and tribunals currently taking place. We would like to see a vastly different approach moving forward that focusses on simple good customer service principles. It is vital that good relationships are established between parent carers and case officers at the earliest possible stage to enable emerging issues and concerns to be addressed without the need for escalation.
- Improved understanding is needed about the legalities of the SEND provision process and clearly documented decision making such as you would expect in any other crucial decision making process in a child's life. All decisions should be clearly recorded in official records, including the person or persons responsible for making the decision and the reasons for this. It is important that decisions are shared with parent carers at the earliest possible opportunity with full explanations for this decision. Where this is decision was made by a panel, there should be full minutes available upon request with the names of all decision makers to allow for full transparency.
- In areas where parent carers felt the need to obtain private assessments or reports, we would like to see the relevant LA and health services looking at the reasons for this with a view to improving services, increasing trust and reducing the need for this action by parent carers.
- The area of 'Preparing for adulthood' is of particular significant given the severity of poor feedback received. All areas require scrutiny and immediate action to address the gaps in this area to ensure that the young people of Dudley with SEND are significantly better supported for this crucial stage of their transition to adulthood.
- We would like to see an active programme of work to understand the reasons why young people are classified as NEET (Not in Education, Employment or Training). Where this due to a lack of support or provision this should be addressed without delay.
- The reality of the parent carer experience should be considered across all agencies. It is vital that services understand how issues such as sleep deprivation, financial difficulties, feelings of isolation and poor physical/emotional health impacts on a parent carers daily life. An upcoming training event on Parent Carer experiences is being developed by Dudley Parent Carer Forum and should be accessed by all agencies
- Consideration should be given to this surveys output with regard to the impact of the caring role on parent carers when developing short breaks criteria, process and availability

Overall, we would wish to see an improvement in all poor or very poor ratings by the time our next survey is developed and the results published in early 2023. We would also like to see an improvement in the overall star rating.



Right to reply

This report was shared with representatives from the Local Authority and Black Country and West Birmingham Clinical Commissioning Group two weeks prior to its publication in order to gain a response on our findings. The responses are shared below:

“We have noted the findings within the PCF Survey and recognise that a number of the areas highlighted are already represented within our current workplan that we have been, and are currently working on. In light of the recent review of the Memorandum of Understanding (MOU) with the Parent Carer Forum, and with the release of the new Green Paper this week, those priorities that have been outlined in the PCF survey will align with the broader themes in the Green Paper.

As a Local Area, we will continue to work on improving the lived experiences of Dudley SEND children, young people and their parents/carers as we associate the actions of the workplan to outcomes and impacts that will chime with the wider SEND changes that have been identified within the Green paper.

We look forward to the continued working relationship between the PCF and the Local Area, using the monthly meetings to address any specific areas that requires a localised solution.”

Dudley Local Authority
Black Country and West Birmingham Clinical Commissioning Group

