

2023

Key Performance Indicator Baseline

Taken from the Parent Carer and Children
and Young People Surveys

May 2023

Parent Carer Responses **372**

Young People Responses **58**



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Introduction

Parent Carer Forum Devon (PCFD) – our role

We are all parents and carers of children and young people with Special Educational Needs and Disabilities (SEND) within Devon local authority. We are independent and proactive, working in a solution focused approach to influence policies, decisions, and services. Our aim is to make sure that services provided by education, health and care meet the needs of children with SEND and their families.

Parent Carer Forum Devon is part of the [National Network of Parent Carer Forums](#). This means that the voices of parent carers in Devon reach decision-makers in national government.

Background to this survey

In May 2022, Ofsted and the Care Quality Commission revisited the area of Devon to decide whether sufficient progress had been made in addressing each of the areas of significant weakness identified in their December 2018 inspection. Their [report](#) concluded that the area had not made enough progress in addressing any of the significant weaknesses. In September 2022 an [Improvement Notice](#) directed the local area to produce a [Devon Local Area SEND Improvement Plan](#). Actions included in the plan should be delivered by February 2024 or sooner.

PCFD carried out a previous very wide-ranging survey in December 2021. The [results](#) are available on our website and were shared with inspectors before the May 2022 revisit. The current local focus is on the Improvement Plan and the four areas of significant weakness. Hearing from families is crucial in order to understand the baseline experience and monitor any progress against the Key Performance Indicators in the Improvement Plan. It is very important for families to have the opportunity to share their experiences with us as an independent and separate organisation rather than with the local area directly. Particularly if the lived experience of the system is negative, parent carers may fear consequences of sharing their opinions with those who make decisions about their families.

Surveying parent carers and young people allows us to monitor changes in family experience of the four areas of significant weakness, and to measure any improvements. Repeat surveys are planned into 2024. We will share our findings on our [website](#), on [social media](#), with strategic partners across the local area and with Department for Education & NHS England advisers.

Baseline Key Performance Indicator Survey

The surveys were completed during May 2023

As the Baseline KPI requirement was based on a limited number of questions, further questions were also asked to be able to provide a more complete picture. For example, rather than just asking about a parent's confidence in the Education, Health and Care Plan (EHCP) process, we wanted to ask questions such as the benefit the EHCP had made to the Child or Young Person (CYP).

All the questions were asked as statements, so that the respondents could rank from very poor through to very good.

In addition to these baseline & ranking style questions, the respondents were given the opportunity to write further detail about their experiences. They could also provide reasons why they gave the ranking or opinion that they did, as well as "what one thing would you change".

All of the responses were then read & understood, a list of broad answers were formulated, and a matrix of these completed. These answers were then put into groups where they have a similarity, creating overarching macro themes.

For example, when respondents were asked "if you could change one aspect of the EHCP process, what would it be?" Many people referred to improved communication, being able to talk face to face, and for staff to be more transparent. These are three individual answers, however together they create one macro theme of improved communication.

Within the CYP survey, which was created in partnership with the Youth Participation Team at Devon County Council, not all the Baseline Key Performance Indicators (KPIs) were covered exactly. Young people felt that some of the terminology used was not CYP centric, nor were the KPIs facts that could have been effectively obtained from the survey.

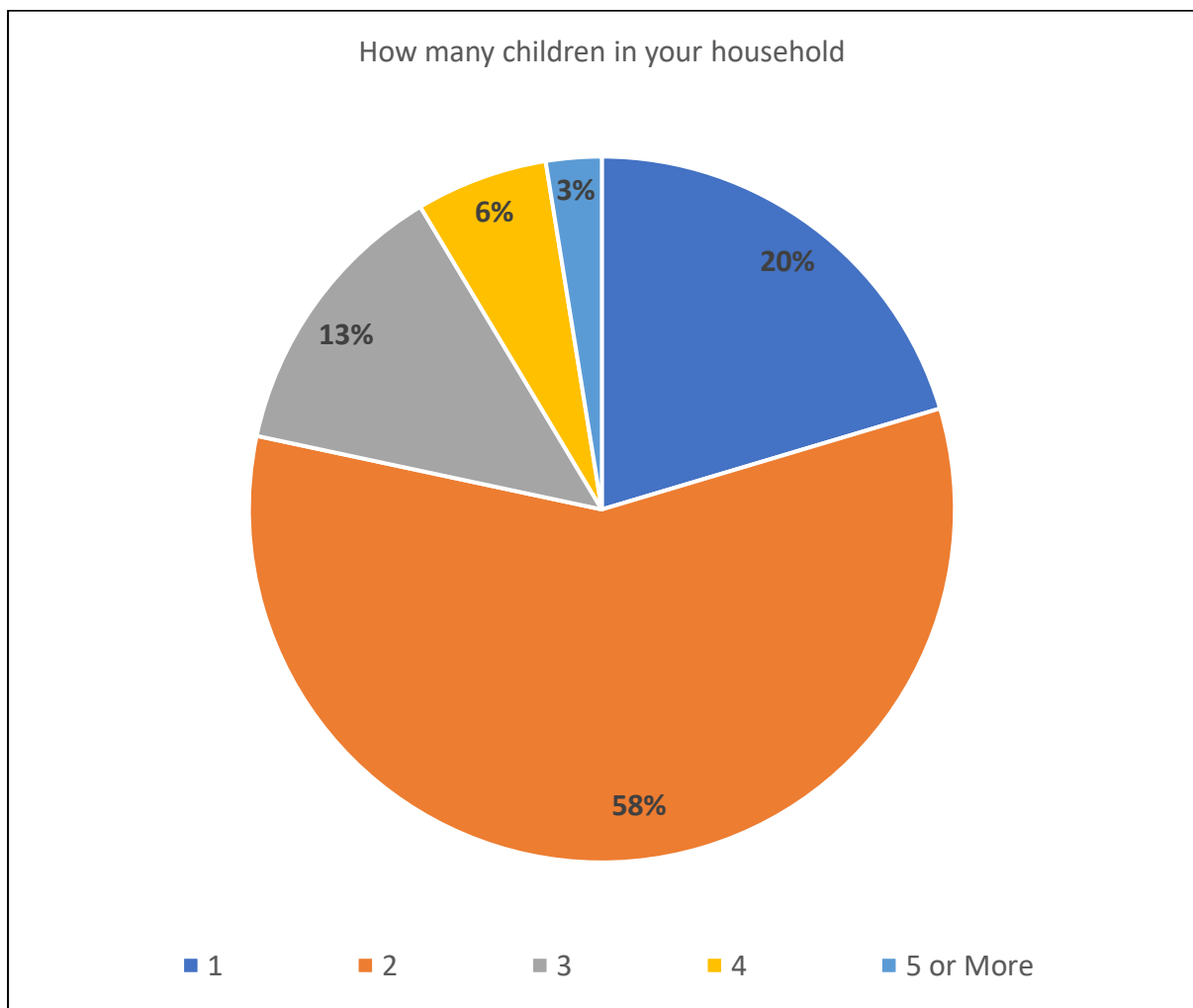
The numbers that make up these baseline KPIs, whilst essential to be able to gauge a sense of improvement in the future, are really only half of the story. Many parents, carers and young people have added a lot of information to explain the reason for their views, and more importantly have given suggestions and views as to what, in their eyes would improve the various services that they interact with. All these views, both critical and complementary, are summarised within this report. They provide a true reflection of the lived experience currently felt by parents, carers, children and young people in Devon. We have included many direct quotes from parent carers, children and young people.

Respondent Demographics

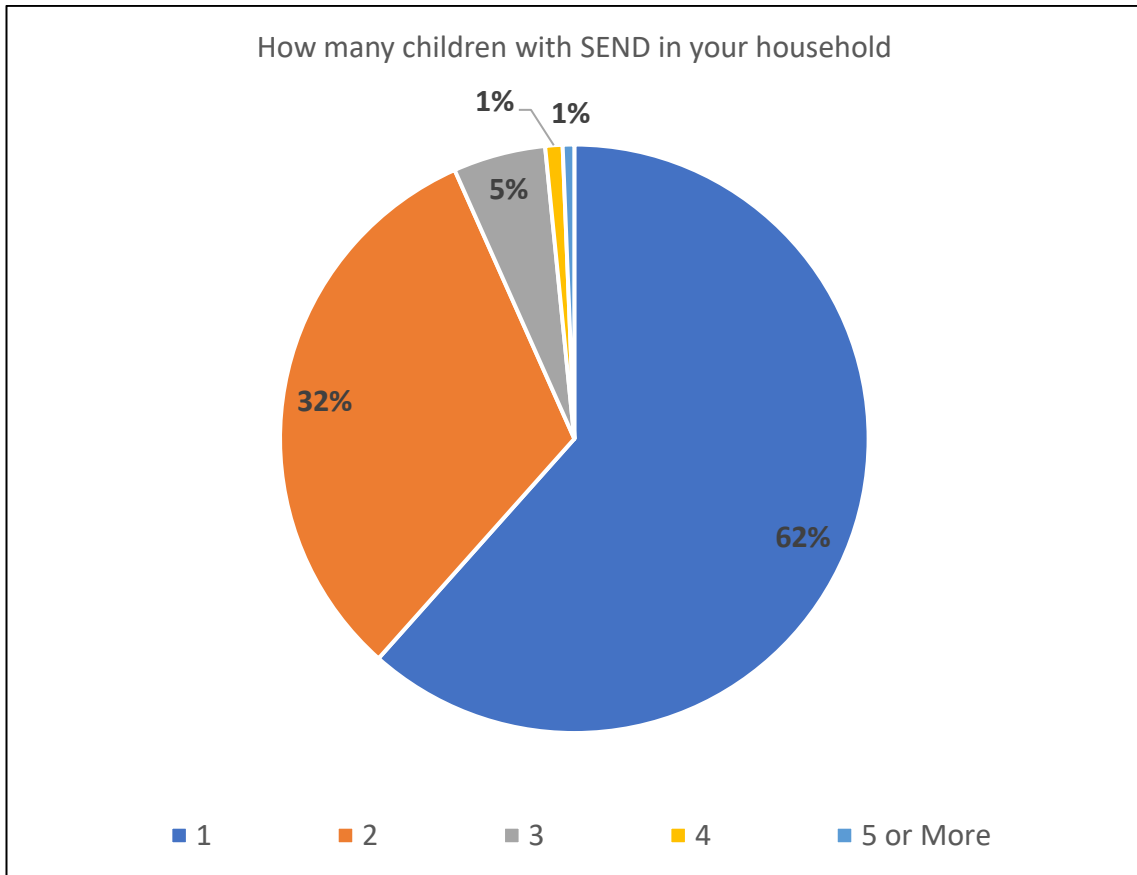
372 parent carers and 58 children & young people completed the survey. We asked for additional details about how many children in the household, age, gender, needs and educational settings.

The following charts illustrate a wide representation across demographics.

Household information

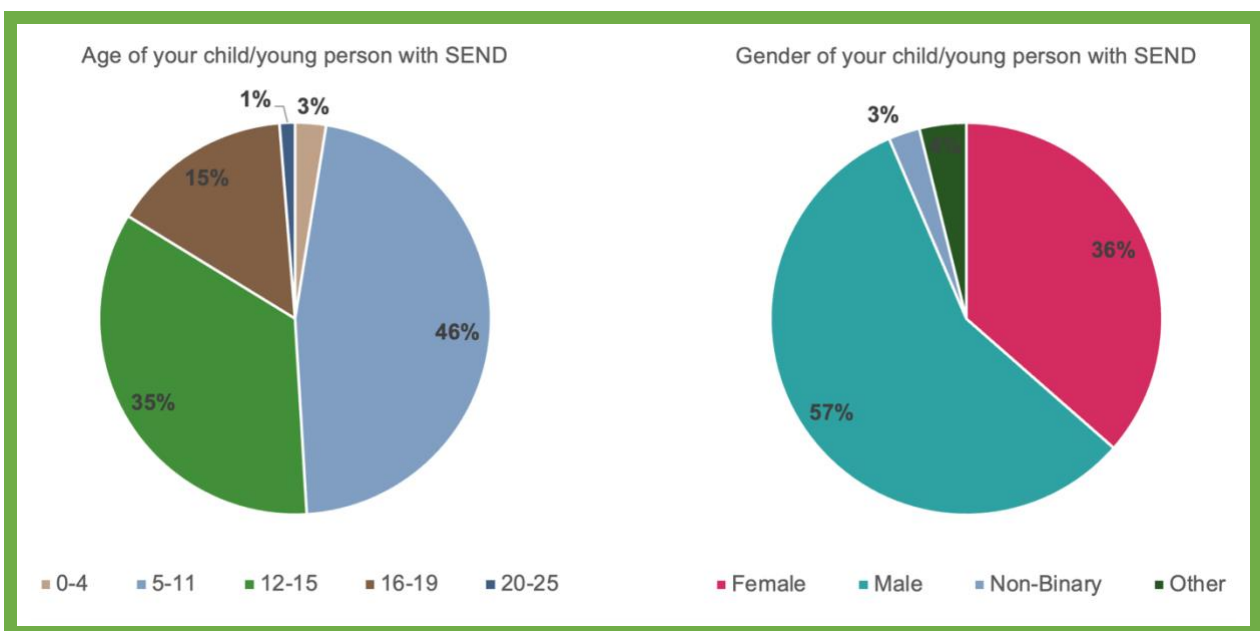


Most families had one or two children. Less than a quarter of respondents had three or more children in the household.



Only one in ten households had three or more children with SEND. Almost two thirds of respondents had just one child with SEND in the household.

Age and Gender



Respondents showed a range of ages, with slightly more males than females.

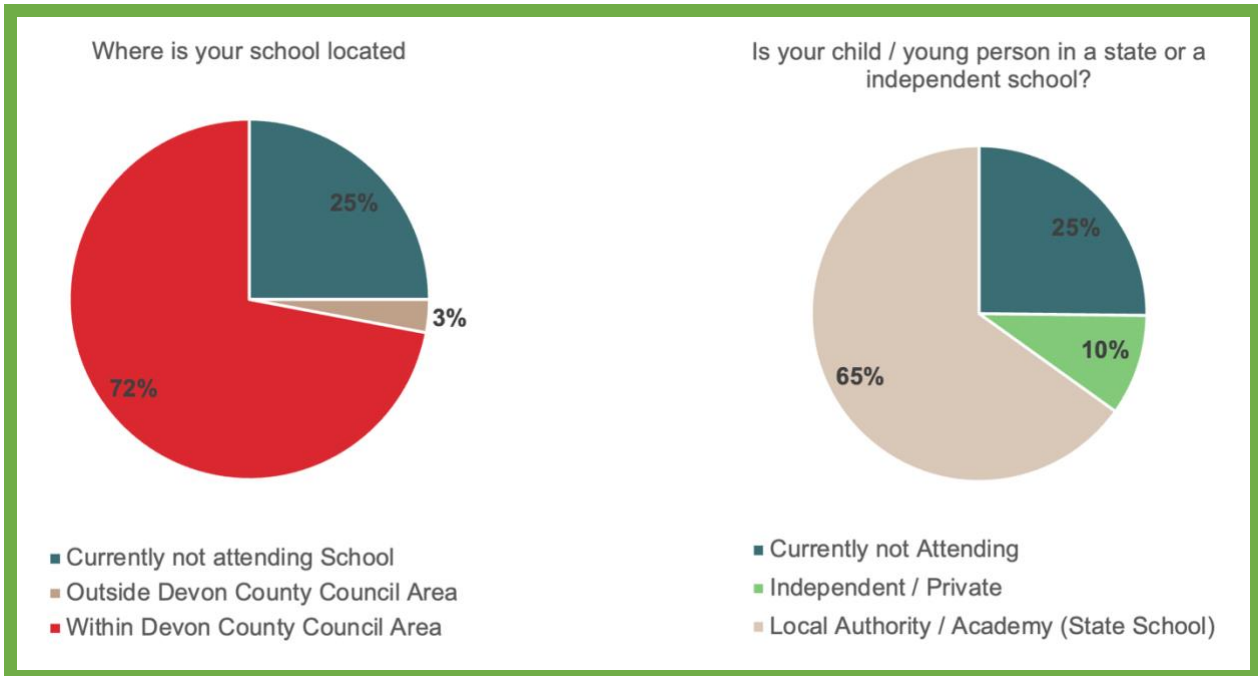
SEND Needs

We asked families to tell us more about their child or young person's needs or diagnoses.

64%	Autism
39%	Speech, Language and Communication Needs
38%	Emotional or mental health needs
38%	Sensory Processing Disorder
25%	Specific Learning Difficulty
22%	Other
22%	ADHD or ADD
14%	Medical or Complex Health Needs
14%	Moderate Learning Difficulties
13%	Global Developmental Delay
11%	No diagnosis
10%	Physical Disability
9%	Visual Impairment
9%	Severe Learning Difficulties
5%	Hearing Impairment

There was a wide range of needs among the families who completed the survey. Autism was the most represented need.

About Educational Settings



We asked families to tell us about their child or young person’s educational setting. Most children and young people attend local authority or academy settings within the local area. A quarter of children and young people are currently not attending an educational setting. These figures are very concerning.

We also asked about the type of educational setting and again had a wide range of responses. The majority had an EHCP and were attending mainstream primary and secondary schools, or special schools. More than 1 in 10 were home educated.

Section A- Strategy

Section A of the Devon Local Area SEND Improvement Plan addresses strategic shortcomings. The local area is working towards “clear and understood strategic plan and SEND arrangements”.

8% of parent carers rated their lived experience of Local Area SEND services as ‘good’ or ‘better’.

The Baseline KPI in the Devon Local Area SEND Improvement Plan of

“Young people rate their lived experience of Local Area SEND services as ‘good’ or ‘better’, identifying improvement in relation to joint working and communication”

was not specifically asked.

For Children & Young People, to gauge these views, we will need to ask more specific questions for a variety of services and then aggregate the answer. On reflection it is unlikely that joint working and communication would be specifically referenced by most Children and Young people. How children and young people prefer to be communicated with is presented later on in this report.

“A conversation with a member of the 0-25 team who had a clear understanding of the whole system and was able to answer lots of different questions in one conversation”

“This whole process was a nightmare from start to finish”

“The whole system is a joke and are failing our children on a daily basis”

Section B - Communication

Section B of the Devon Local Area SEND Improvement Plan focuses on communication. The local area is working to improve “communication with key stakeholders, particularly with parents and families”.

Key Results

The following boxes summarise the findings about communication and information for both parent carers as well as for children and young people.

6% of parent carers rated their confidence as ‘good’ or ‘better’ regarding information provided for SEND pathways within the local SEND system

Percentage of young people’s confidence regarding information provided for SEND pathways within the local SEND system, was rephrased;

16% of children & young people rated their experience of how local SEND services had communicated to them as ‘good’ or ‘better’

16% of parent carers rated their understanding of the arrangements to support children and young people with SEND as ‘good’ or ‘better’

14% of parent carers rated that communication in relation to EHC needs assessment and drafting of plans as ‘good’ or ‘better’

17% of parent carers rated that communication in relation to EHC drafting of plans as ‘good’ or ‘better’

9% of parent carers rated communication in relation to the neurodiversity pathway as ‘good’ or ‘better’

0% of young people rated communication in relation to the neurodiversity pathway as ‘good’ or ‘better’

For Children and Young People, the following baseline KPIs described in the Devon Local Area SEND Improvement Plan:

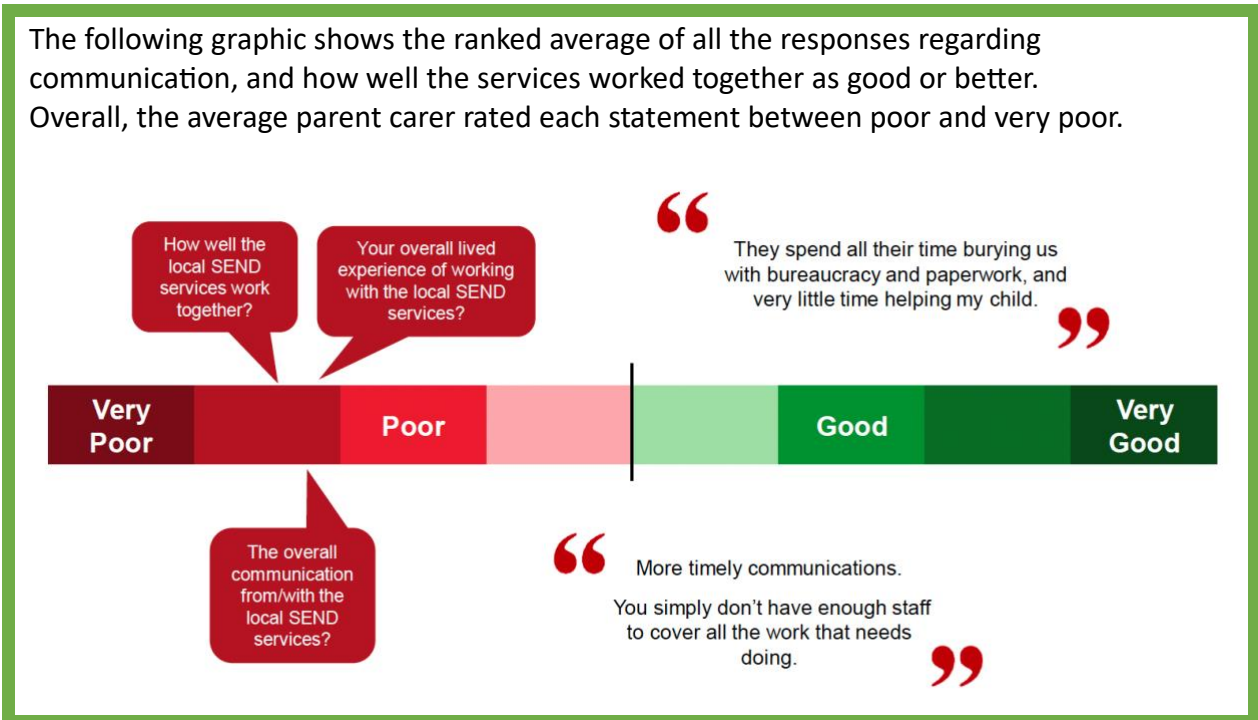
- “Percentage of young people who rate their understanding of the arrangements to support young people with SEND as ‘good’ or ‘better’”*
- &
- “Percentage of young people who rate that communication in relation to EHC needs assessment and drafting of plans as ‘good’ or ‘better’”*

Were **not** specifically asked. Instead, led by feedback from young people, various, person centred agreement questions were asked. These provided responses such as:



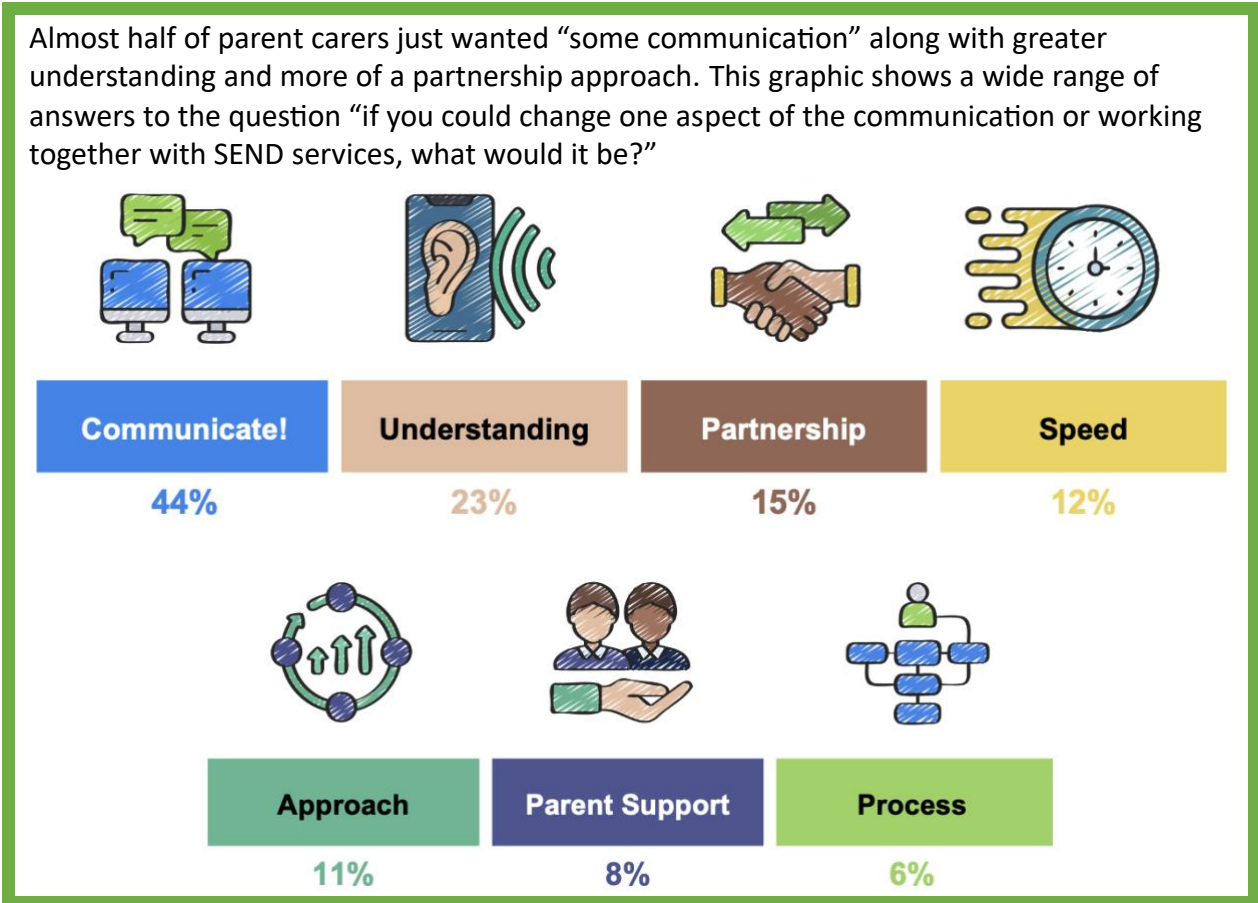
These provide a good understanding of the CYP’s views.

Parent Carers rate communication and how well services work together



Parent Carers suggest changes to improve communication and working together

Almost half of parent carers just wanted “some communication” along with greater understanding and more of a partnership approach. This graphic shows a wide range of answers to the question “if you could change one aspect of the communication or working together with SEND services, what would it be?”



Quotes from Parent Carers about improving communication

What could change to make things better with communication and working together with SEND services.

- “Be empathetic to children’s needs and act in a child centred way”
- “It is continually up to parents to follow up”
- “More transparency. What exactly is discussed at panels and how decisions are made”
- “Keep me informed in language I understand”
- “Better staffing levels leading to faster responses and progress”
- “Some contact would be great”
- “Find the hub difficult to navigate and egress doesn’t keep the thread of emails”

Headlines from Children & Young People - communication

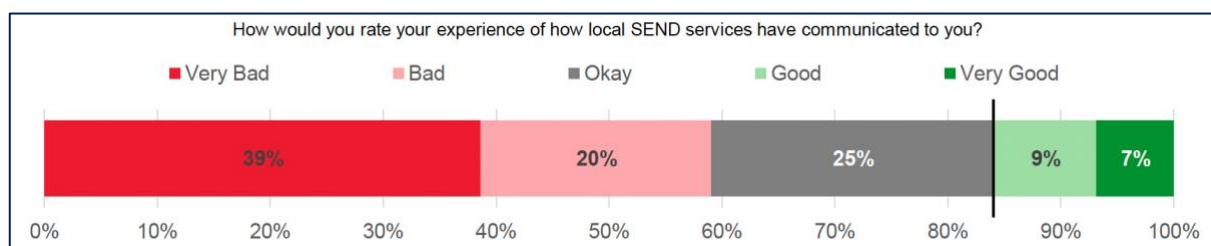
These are some headline figures about what children and young people told us about communication:

88%	of children or young people had not been communicated with directly by SEND services
43%	of children or young people would NOT like to be communicated with directly by SEND services
65%	of children or young people would not know where to find information about local SEND services – of the third that did, they would use their school, go online, or ask their carers or parents
10%	knew what the Local offer website was, however two thirds would use a website for information and advice about local SEND services and opportunities designed just for young people
92%	wanted to be communicated to in person, either by their parents or face to face through workers

It's clear that children and young people want to be involved and communicated with. These basic principles are crucial in starting to improve the lived experience of SEND services.

Children & Young People rate communication with SEND services

16% of children and young people rated their level of communication with SEND services good or better

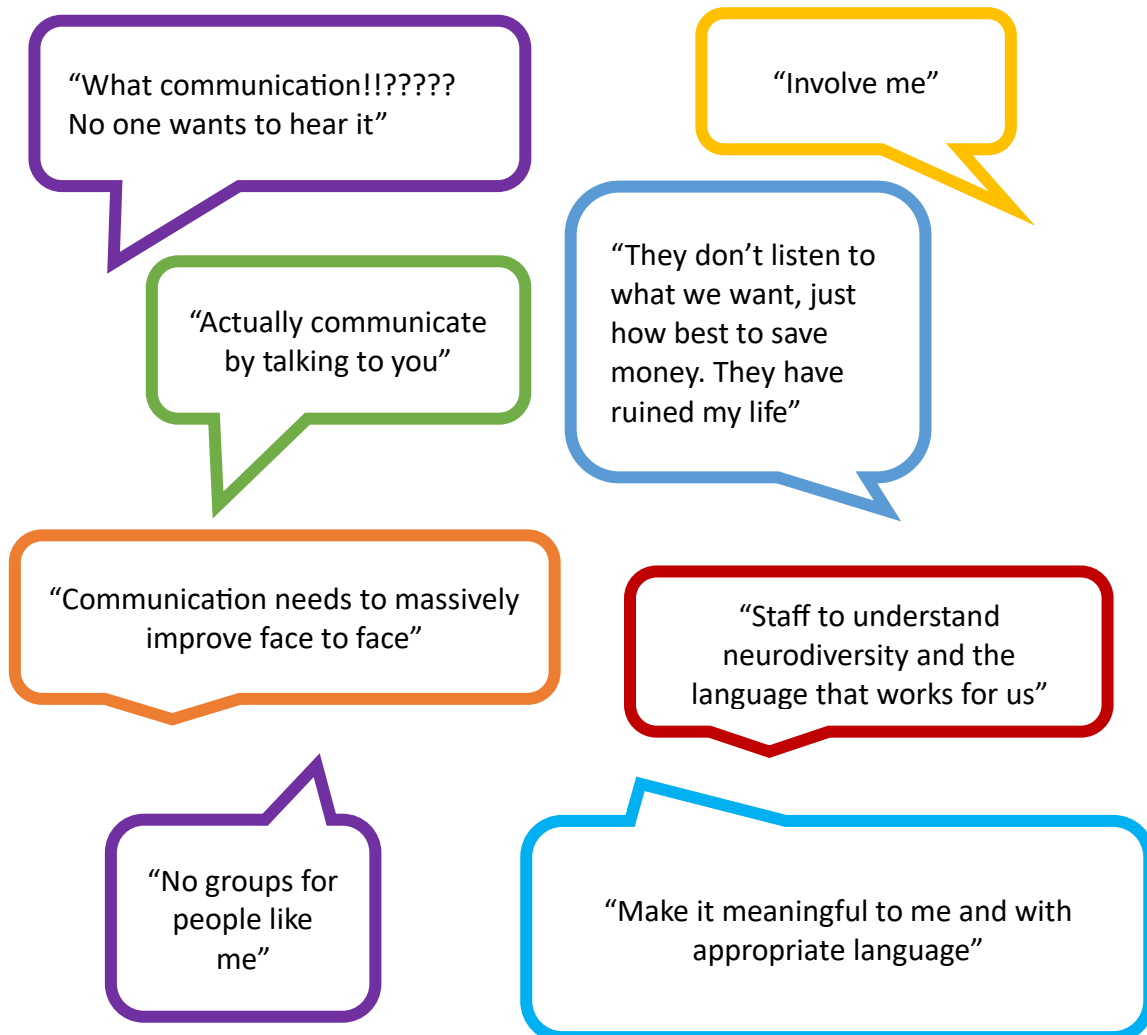


Children and young people have a poor experience of communication with SEND Services. It is difficult to work out why this is the case without finding out more.

Quotes from Children & Young People about communication

Young people would like increased relevant communication, including face to face and using appropriate language.

Here are some things children and young people said when we asked them to tell us about the one thing they would change about the way services communicate with them.



Parent Carers rate different aspects of communication & information

Among parent carers, there is a clear dissatisfaction with the level of communication either regarding SEND pathways, or the EHC process. Just under half of respondents rated the communication regarding SEND pathways, or during the EHC process as very poor.

15%	Of parent carers rated their knowledge of the arrangements that support children and young people with SEND as good or better
6%	Of parent carers rated the information provided and communication received regarding the SEND pathways within the local SEND system
14%	Of parent carers rated communication during the EHC needs assessment after May 2022 as good or better
17%	of parent carers rated the communication during the ECH drafting of plans after May 2022 as good or better
9%	of parent carers rated communication in relation to the neurodiversity pathway after May 2022 as good or better

Overall, there are very low levels of satisfaction among parent carers about the quality of information, communication and collaboration within the local SEND system. There is much room for improvement in these areas to better meet the needs of families and individuals with SEND.

Quotes from parent carers about communication

“Some services ghost you and do not reply, they will not provide you any information on your child”

“The replies leave you going round in circles not actually achieving anything, you are signposted on to someone else who signposts you back and you don’t get anywhere”

“Quality of communication is often questionable and doesn’t address those questions asked”

“Appalling lack of communication”

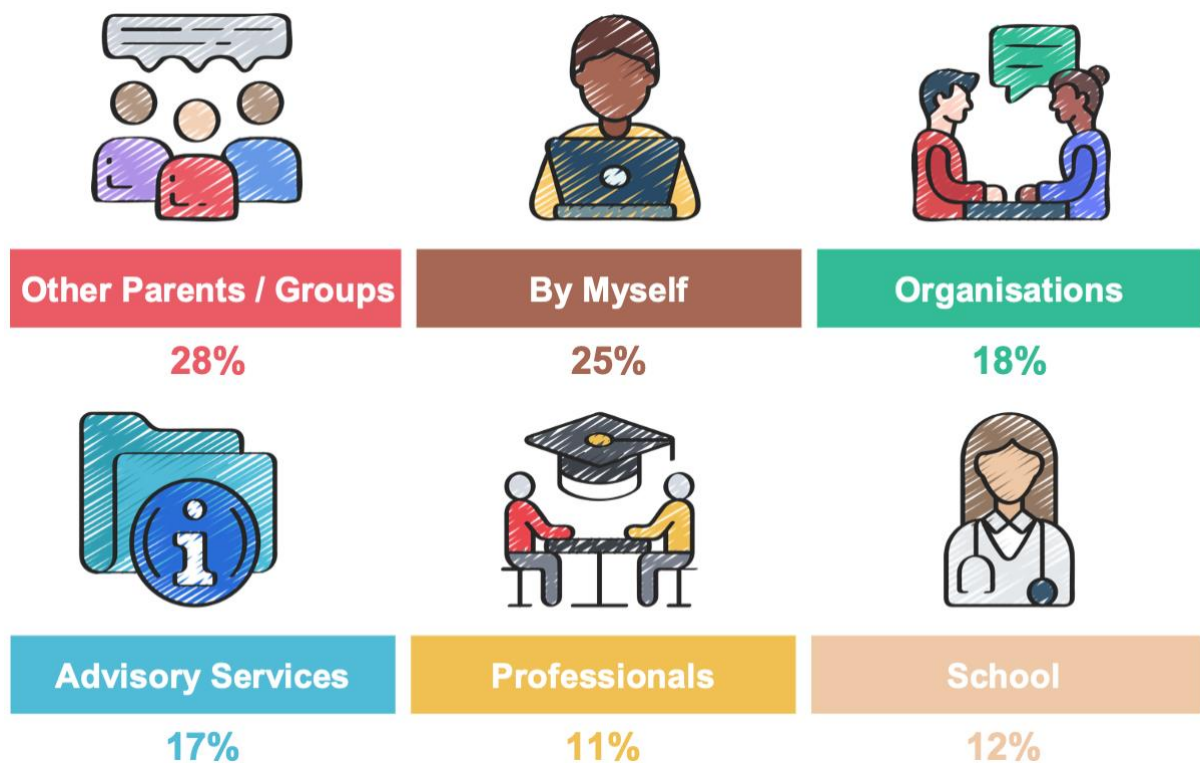
Parent carer forum

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Valuable communication and information for parent carers

We asked parent carers to tell us about the most beneficial piece of communication they received about the SEND pathways or that helped improve their knowledge of arrangements to support young people with SEND. Over 40% of parent carers had not received any information at all about the local SEND pathways. The main sources of information for parent carers were from other parents or their own research.



“We had lots of useful advice from our preschool”

“Having a lead professional who was incredibly knowledgeable”

DIAS have been helpful

“A conversation with a member of the 0-25 team who had a clear understanding of the whole system and was able to answer lots of different questions in one conversation”

“I’ve had to look up everything myself – no help anywhere”

“Talking to other parents at support groups or events”

Section C - EHCPs

Section C of the Devon Local Area SEND Improvement Plan focuses on the EHCP process. The local area is working towards improving the “timeliness and quality of EHC plans”.

Key results

39% of parent carers surveyed had made an **EHCP application**, or had one made on their behalf **since May 2022**

Half of those who completed the young person survey had an **EHCP**
51% Have had a **EHCP review** since **May 2022**

10% of parent carers rated their confidence in the EHC process as **‘good’** or **‘better’**

20% of parent carers rated the benefit of an EHCP to their child or young person as **‘good’** or **‘better’**

15% of parent carers rated amending the EHC plans following annual review as **‘good’** or **‘better’**

Within the Devon Local Area SEND Improvement Plan, the Baseline KPI:

“Percentage of young people rate the annual review process as ‘good’ or ‘better’ in amending existing EHC Plans and provision”

Was NOT specifically asked, as Children & Young People may not be aware of the review process, or its significance – so to understand their views, young person-centred agreement questions were asked. These provided responses such as:

“I was happy with my overall EHCP experience”

“The EHCP has been beneficial to me”

“The outcomes of my EHCP were relevant to me”

Parent carers discuss the EHC assessment process

Whilst there is not a lot of confidence from parent carers in the process, significantly more felt the EHCP benefited their child or young person.

“It really help get her the right school placement and the right help”

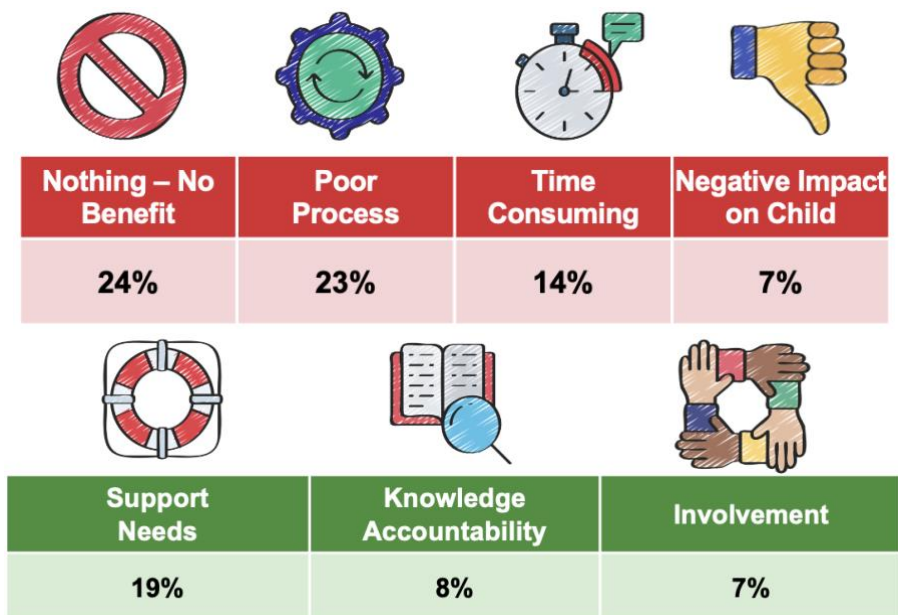
“It is absolutely hopeless. We have been fighting for an EHCP for years, despite a clear need.”

“My child has not benefitted from the process but has in face been negatively impacted”

“He is a lot happier and is now started to learn”

Positive aspects of EHC assessment for parent carers

We asked parent carers to tell us about the aspect of the EHCP process that made the most difference. Despite asking for positive difference, half of respondents focused on negative aspects of little change or benefit, or the poor process itself. The key benefits of the EHCP were getting needs met through support in school, with greater accountability and involvement.



Parent carers suggest improvements in the EHC assessment

Focusing on the EHCP process, we asked parent carers to tell us what they would like to change. Speed, communication and making decisions based on needs by listening to the parents or child are key suggestions.

“Not to have to reach crisis point before support at an appropriate level is provided”

“Length of time, it took 51 weeks from start to finish, not the 20 weeks it’s supposed to take”

“Honest face to face communication with families and children”

“Communication and involving parents more in the decision of our children’s future”

“It’s very ‘professional’ driven and not parent friendly at all”

Children and young people suggest improvements in the EHC assessment

Young people also told us what they would like to change about the EHCP process. They would like to see a quicker process, with greater understanding and an output that was both more relevant, and helpful to them.

“I want to spend time with my family, but they have to fight to get an education for me that I can do. I don’t care about your money. I’d just like to feel supported”

“Make it quicker I’ve needed help for way too many years”

“Not having lots of appointments with different people”

“It’s too slow and complicated”

“Focus on me and my hopes not what school or Devon council expect me to do”

“That is doesn’t take so long”

“I have no idea how it works”

Children and young people rate various aspects of EHCPs

From the young person’s perspective, whilst the EHCP has brought benefits, there is scope to improve the structure and process.

35%	Of children and young people were happy with the overall EHCP experience
60%	Of children and young people said their EHCP was beneficial
50%	Of children and young people had a say in their EHCP
37%	Of children and young people told us their EHCP captured their hopes and aspirations
59%	Of children and young people said the outcomes of their EHCP were relevant to them
28%	Of children and young people said that the layout of their EHCP was easy to follow

Parent carers rate EHCP reviews

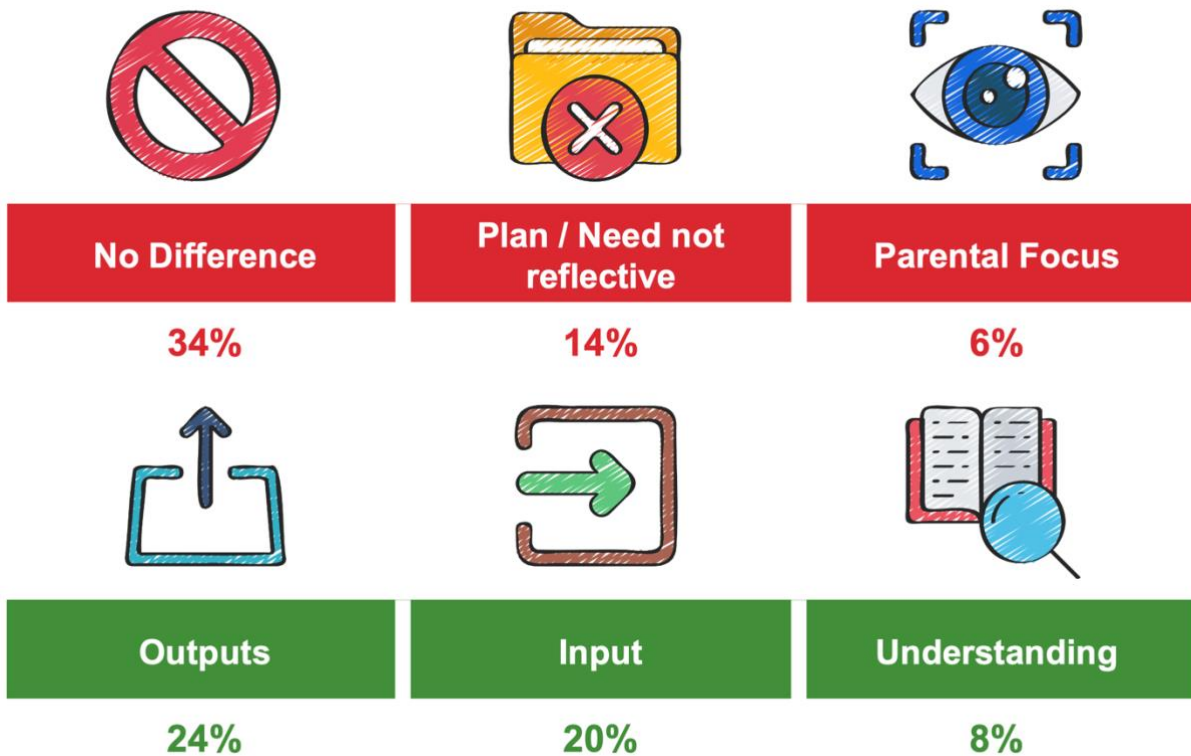
51% of respondents had an EHCP review since May 2022

Across the board, between a third and half of respondents rated aspects of the EHCP review as very poor.

15%	Of parent carers rated their overall confidence in the EHCP review process as good or better
19%	Of parent carers rated amending the EHCP following annual reviews as good or better
21%	Of parent carers rated the benefit to their child/young person following the amendment of the EHCP as good or better
22%	Of parent carers rated the overall annual review process as good or better

Value of ECHP reviews for parent carers

We asked parent carers to tell us about the one aspect of the EHCP review that made the most difference to their child or young person. Despite asking for positive differences, almost half of respondents focused on negative aspects of little change or the poor process. The main positives of an EHCP review were outputs and amends, the ability to contribute, and the increase in parent carer’s understanding.



“It was a negative difference – hours of wasted time and frustration. Draft EHCP issued before the review and not changed at all after the review. What’s the point?”

“To be honest my only conclusion is that I have to do everything myself”

“None whole process is a shambles”

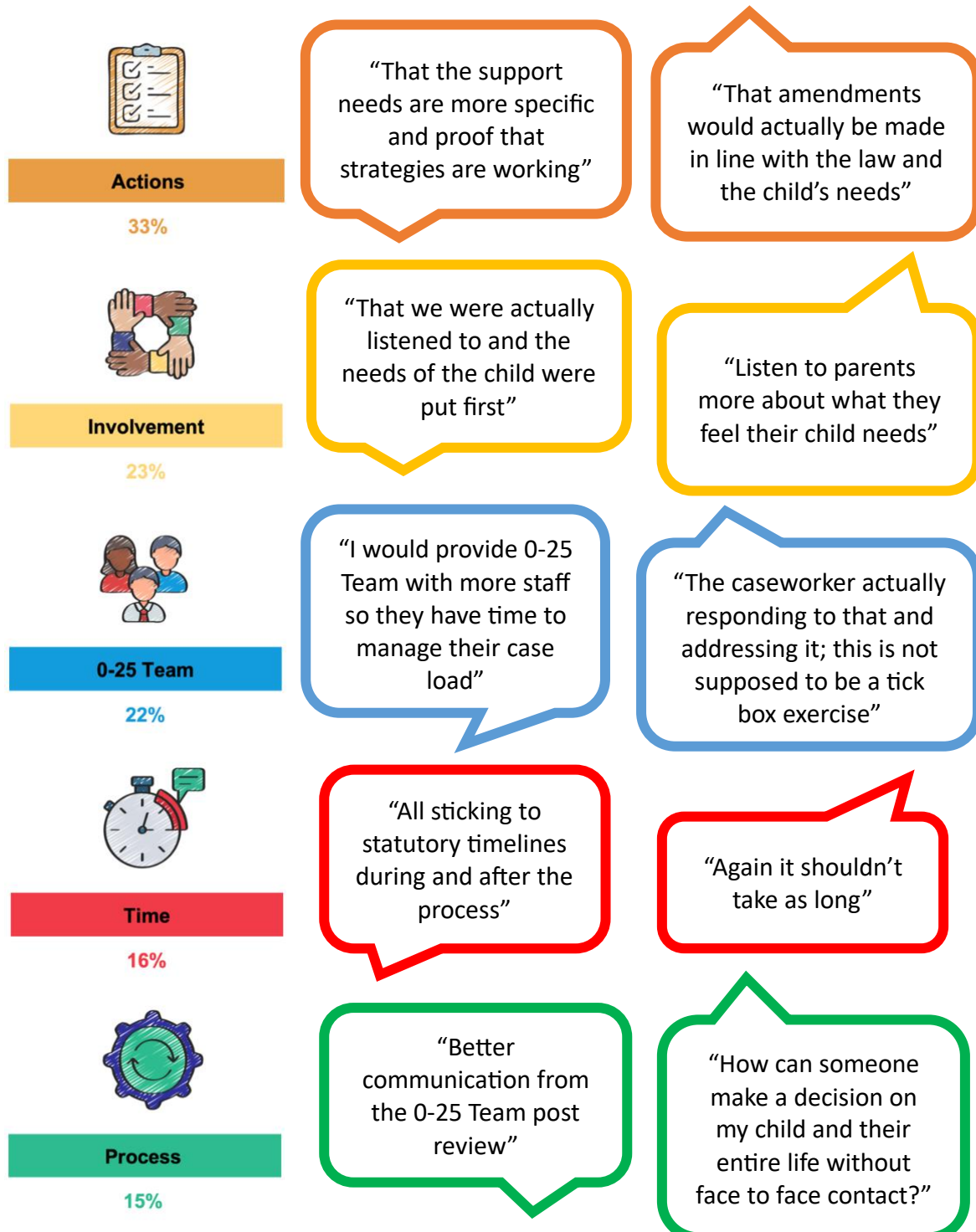
“Support with speech, reading and writing”

“The fact that his placement have a very thorough understanding of his needs and made good quality evidenced submissions

“Getting to know more about how my child is doing at school”

Parent carers suggest improvements to EHCP reviews

We asked parent carers if they could change one aspect of the EHCP review, what would it be? They told us they would like to see a quality, child centred, timely review, with 0-25 Team involvement and clear amendments.



Section D - Autism

Section D of Devon’s Local Area SEND Improvement plan focuses on improving “weaknesses in the identification, assessment, diagnosis and support of those children and young people with autism spectrum disorder”.

Key results

53% of parent carers had a child or young person on the Autism pathway

40% of young people surveyed were on the Autism pathway

7% of Families with girls who are neurodiverse say that support is targeted to meet specific needs of their daughter / girls

5% of Children and young people report that their experience of the support available while waiting for a diagnosis is ‘good’ or ‘better’

5% of parent carers that report their experience of the support available while waiting for diagnosis is ‘good’ or ‘better’

Parent carers rate autism pathway support and communication

Less than 10% of parent carers rated the support or communication while on the autism pathway as good or better.

5%	Of parent carers rated the support available while waiting for a diagnosis as good or better
8%	Of parent carers rated the level of support received to meet their child or young person’s neurodiversity needs as good or better
8%	Of parent carers rated the communication about the autism pathway as good or better

“There is no support during or after diagnoses so I really wonder the point of getting diagnosed at all?”

Useful support or information for parent carers - autism pathway

We asked parent carers to tell us about the most beneficial information or support they received while waiting for an autism assessment. Almost half of people did not receive any information or support during their wait for a diagnosis.

48%	Did not receive anything
14%	Were supported by professionals
13%	Did their own research
8%	Found support on social media
6%	Completed specific courses
6%	Used books or online resources
5%	Received information from school
4%	Were supported by other parents
4%	Used DiAS information and advice

Quotes from parent carers about useful autism support or information

“We have received nothing beneficial”

“My GP has been excellent”

“To do your own research and not rely on the system”

“I’ve only been supported in social media groups”

“What was the old cygnet course for parents”

“Information and book recommendations”

Children and young people rate the autism pathway

There is little satisfaction from children and young people regarding the autism pathway. They told us they would like a quicker pathway as well as improved, frequent and clear, sometimes face to face communication.

6%	Of children and young people rated their overall experience of the pathway as good or very good
0%	Of children and young people rated communication with them while on the pathway (for example update about place on the list) as good or very good
5%	Of children and young people rated the support they received while on the pathway as good or very good

Quotes from children and young people about the pathway

“What support. No-one wanted to help me only school and my mum and dad”

“Diagnosis makes no difference as schools and wider professionals don’t understand”

“More communication, laid out more easily, sticking to set appointments”

“More clear, concise and regular communication”

“Speed it up ... Faster”

“To get some support other than my carers”

Overall recommendations from families

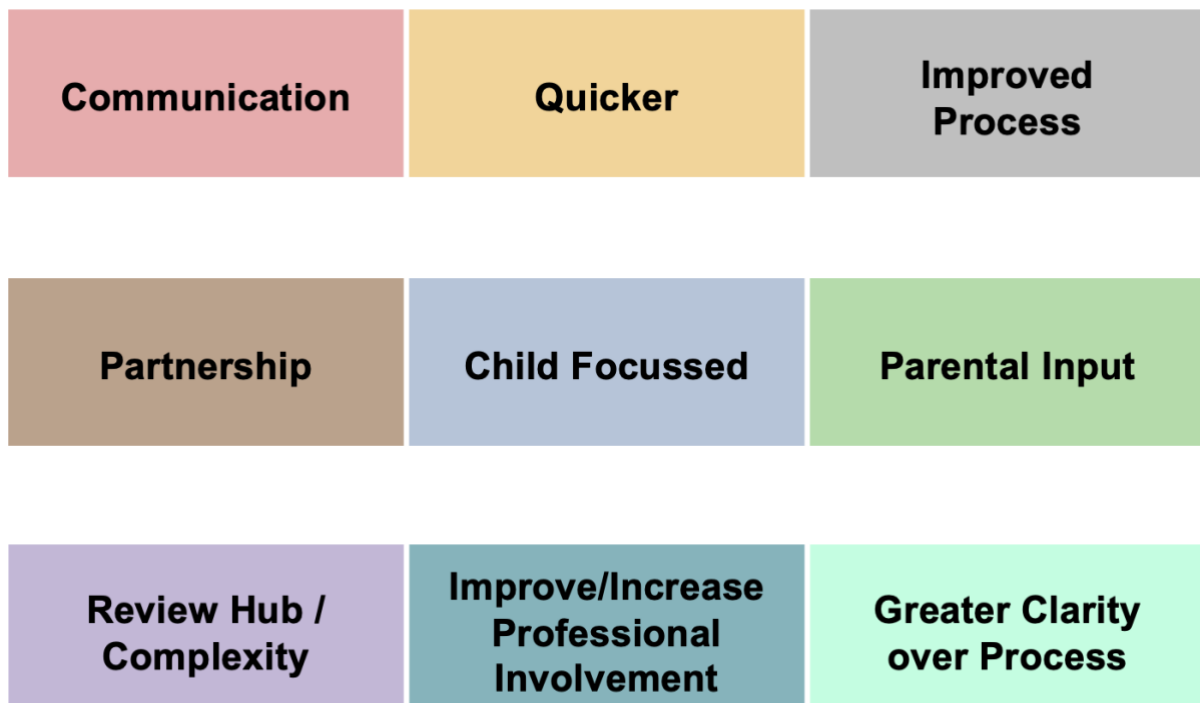
The responses to three key questions in the survey can be broadly classified into nine areas for improvement.

We asked parent carers to tell us about one aspect they would change of: communicating and working with SEND Services, the EHC needs assessment, and EHCP reviews.

Respondents could write as much or as little as they wanted, and were not constrained by any pre-selected answers. These responses can be broadly classified into nine areas for improvement.

Nine areas for improvement

Summarising all the feedback received, parent carers are seeking more communication and a quicker, improved process which is more of a partnership with greater involvement. We've drawn together what families have told us about changes they would like to see and have summarised these into nine areas for improvement. These have been colour coded for ease of understanding.



SEND Services

We asked:

If you could change one aspect of the communicating & working with SEND services what would it be?

Parent carers would like to see:

Improved communication, along with greater understanding or involvement and more of a partnership approach – done quicker

Communicate with parents / Reply to E-mails	24%
Just Want some Communication	13%
Cross Communication Different Teams	7%
Listen to Parents	7%
Have 1 Person / Know who to contact	6%
Communication not Always Parent Led	6%
Regular Updates	6%
Work Together / Collaborative Working	5%
Child Centred - Need Focus	5%
Review Hub	5%

EHC needs assessments

We asked:

If you could change one aspect of the EHC needs assessment, what would it be?

Parent carers would like to see:

An improved quicker process, with greater communication and parental involvement

Meet Legal Deadlines / Quicker	34%
Improved Communication	20%
Make Decisions based on needs	15%
Listen to Parents / Child	15%
Clearer accountability during & after the process	8%
Less "hub"	7%
Professionals Involved	7%
Train to Write Effective EHCP's	6%
Face to Face Communication	6%
Reduced Complexity	6%

EHCP reviews

We asked:

If you could change one aspect of the EHCP review, what would it be?

Parent carers would like to see:

A quality, action centred review, with increased involvement from the parent, child and the 0-25 team completed quicker

More 0-25 Involvement	18%
Quality Review / Review Outcomes	17%
Ensure Amends are Made	16%
Time / Timing	16%
Child Centred	15%
Parents Involvement	12%
Professional Input	12%
Improved Communication	8%
Improved Hub	5%
Clarity over Process	5%

Executive Summary

Parents and carers were asked about how and where they like to receive information about SEND improvement work in Devon. Parents and carers are using a wide-ranging source of information, with 75% using 2 or more sources, and 25% using 5 or more. DIAS & word of mouth were the two most popular, with the next most popular collection of resources being, online groups, their child's school, SEND e-mail and the Parent Carer Forum. Choosing which method people prefer is based on convenience, and ease of getting the information.

When asked about communication, almost half of parent carers just wanted "some communication", with a quarter specifically just asking for their e-mails to be replied to. Parents and carers wanted a greater understanding, be that a feeling of being listened to more, through to having a more child centred, and more of a partnership approach – all happening quicker.

Whilst the majority of CYP have not been communicated to directly, just under half would not like to be communicated to. Of those who did, 92% wanted to be communicated to in person, either by their parents or face to face through workers.

There was a clear dissatisfaction with the level of communication either regarding SEND pathways, or the EHC process. In fact, over 40% of respondents had not received any information at all regarding the SEND pathways. The main sources of information for parents and carers were from other parents or doing their own research.

On the topic of EHCPs - whilst there is not a lot of confidence in the process, significantly more did feel that there was a benefit to the child following the EHC plan. There was a large differential between the confidence in the process and the benefit following implementation.

Despite asking for positive differences the EHCP had made, half of respondents focused on negative aspects of little change or benefit, or the poor process itself. That said, the key benefits of the EHCP were getting their child's needs met through support in school, with greater accountability and involvement. Speed, communication and making decisions based on needs, by listening to the parents or child are the key aspects of the EHC process that people would change. In essence, a quicker, more child focussed approach with improved communication and accountability is what parent carers would like to see.

From the young person's perspective, whilst the EHCP has brought benefits, there is scope to improve the structure & process, by making it quicker, with greater understanding and an output that was more both relevant, and helpful to them.

When asked about the EHC review, across the board between a third, and a half rated aspects of the EHC review as very poor. Similarly to the EHC process, despite asking for positive differences, almost half of respondents focused on negative aspects of; little change or the poor process. The main positives of EHC review were the outputs and amends to the plan, the ability to input into the review, and the increase in parents understanding.

Moving forward, ensuring a quality, child-centred timely review, with 0-25 team involvement and clear amendments is the ask of parent carers.

The average parent carer rated the Autism pathway between poor & very poor, with less than 10% of respondents rating the support or communication as good or above. Almost half of people did not receive any information or support during their wait for a diagnosis. Furthermore, there is also little satisfaction from children and young people regarding the Autism pathway.

Within the questionnaire, the respondents were asked what would be the one aspect they would change in relation to communicating and working with SEND services and the EHCP process and review. From the almost 600 individual responses, if there was such as thing as an “average parent carer” then they would, in summary be seeking more communication to a quicker, improved process which is more of a partnership approach with greater involvement;

What families would like to see

Communicating & working with SEND services

Improved communication, along with greater understanding or involvement and more of a partnership approach – done quicker

EHC Needs Assessment

An improved quicker process, with greater communication and parental involvement

EHCP Review

A quality action centred review, with increased involvement from the parent, child & the 0-25 team completed more quickly

Thank you!

Thank you to each and every one of you lovely 372 parent carers and 58 young people who completed this survey! You were so generous with your time and effort, sharing your thoughts and experiences of the SEND system in Devon. Your insights and inputs are so important to build a clear picture of what it's like for our SEND families.

We are parent carers ourselves, and we know all too well how busy life is as well as the extra challenges of navigating the SEND system. Sharing your experiences says a lot about your dedication, not only to your own families, but also to the broader SEND community.

Your responses and recommendations are a vital foundation in our efforts to ensure that services provided by education, health and care meet the needs of children and young people with SEND and their families. Thanks to your contributions, we have been able to produce this report which we hope will help to drive positive change, help to produce quality information resources and improve support for families in Devon.

Thank you again for being a part of this. Your voice matters, and we are committed to using it to make a difference to all SEND families in Devon.

