



Spotlight on SEND

Experiences of special educational needs and disability (SEND) reforms and service provision in Newcastle upon Tyne

About Healthwatch Newcastle

Healthwatch Newcastle is one of 152 local Healthwatch organisations established throughout England on 1 April 2013 under the provisions of the Health and Social Care Act 2012. We have a dual role to champion the rights of users of publicly funded health and social care services for both adults and children, and to hold the system to account for how well it engages with the public.

We collect feedback on services from people of all ages and from all communities. We do this through our network of voluntary and community sector organisations; during events, drop-in sessions and listening events at a range of venues across the city; online through the feedback centre on our website; via social media; and from callers to our 'Just ask' helpline. As part of the remit to gather views, we also have the power to 'enter and view' services and conduct announced and unannounced visits.

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Executive summary

Introduction

Special educational needs and disability, often called 'SEN' or 'SEND', is a term for children and young people who need extra support during their education due to one or more of the following: communication and interaction problems; cognition and learning; social, emotional and mental health difficulties; and sensory and/or physical needs. Not every child or young person who has one of the above conditions has a SEND; it is only if they cannot succeed without special educational provision that they have a SEND.

There are many children and young people that have special educational needs. In England, one in seven pupils (1,228,785 children and young people or 14.4%) at school have a special educational need¹. In Newcastle the proportion is slightly higher than the national figure at 15.2% (6,651 of the 43,707 pupils).

National SEND reforms were introduced in England in September 2014, as a result of the Children and Families Act 2014. These reforms set out comprehensive changes to how support is provided to children and young people with SEND. They have the potential to transform the support they receive and the outcomes they achieve. The reforms are based on the following principles that local authorities, health and social care services must:

- Work with parents/carers and young people to improve services
- Make sure that young people and their parents/carers get the right information and support to take part in decisions which affect them
- Offer support in a way that enables children and young people to achieve the best possible educational progress and helps them do what they want in their lives as they grow up
- Must work more closely with schools and colleges when they are deciding on the support available for children and young people

The reforms have also set out ambitious changes for those who require high levels of SEND services, often from several education, health and social care providers. This includes the introduction of a new planning tool called the Education, health and care (EHC) plan, which replaces the previous tool known as a Statement. In England, 236,805 children and young people at school have an EHC plan or Statement (2.8% of all school pupils).²

Healthwatch Newcastle carried out this research into SEND because it was prioritised for in-depth research by members of the public and attendees at our 2016 annual conference. We focused this research on the views of young people and their parents/carers who have EHC plans or Statements because:

1. They are a very vulnerable group, requiring high levels of support across multiple publicly-funded providers
2. Certain support services are under severe operational strain
3. Our engagement with parents and carers of children with SEND highlighted a number of issues, with the EHC plan being the most common
4. The SEND reforms were introduced two years prior to this research and this was deemed to be a sensible timescale for review

^{1,2} Data from 'Special educational needs in England: January 2016' (2016) Department for Education
<http://tinyurl.com/hsmkrr6>

This research aims to better understand service users' experiences of SEND services in Newcastle upon Tyne, with a focus on the new EHC plans. It is the first time that their views have been systematically gathered since the EHC plans have been implemented. Potentially transformative reforms are still in the early stages of implementation. We want our work to provide useful evidence of the views of young people and parents/carers, which can be fed back to providers and commissioners to support the continuous improvement of SEND services.

Approach

During a ten week period from September to November 2016 we ran two questionnaires: one for young people between 16–25 years with EHC plans or Statements, and another for parents and carers of children and young people between 0–25 years with EHC plans or Statements, in Newcastle. The questionnaires were a mix of closed and open questions.

We achieved a good response, with 201 valid questionnaires from parents/carers and 51 from young people. The response rates of 14% and 13% respectively enabled us to achieve a representative sample of service users in Newcastle who have EHC plans or Statements.

What we found

Parents, carers and young people said that they were generally satisfied with most health and social care services and were positive about the introduction of EHC plans. The most common positive views of the EHC plan from parents and carers were that the plan helped their child get the required support, attend the right school, and gave them a sense of direction for the future. These comments align well with the aims of the SEND reforms.

Almost every parent and carer rated the introduction of an EHC plan as the same as, or an improvement on, their Statement. The most common words people used to describe their EHC plan/Statement were 'helpful', 'good', 'supportive' and 'informative'.

This research also brought up a number of issues about specific services or aspects of the EHC plan process. The main issues raised were:

- The most important improvement parents and carers wanted was better communication between providers and themselves, and also among providers
- Parents and carers wanted better attendance of providers at EHC planning meetings
- Some parents and carers felt they were not being listened to enough by professionals
- Some parents and carers had little knowledge about the SEND reforms and their important role in them
- Many parents and carers did not understand 'who does what', and where to go for specific information or support
- Many parents and carers did not have good communication with their SEN Case Worker during the EHC plan development
- Half of parents and carers had not been informed about Independent support workers
- Parents and carers were very concerned about their child becoming an adult and didn't feel that EHC plans sufficiently addressed these concerns; young people were less concerned, and most interested in finding work and making their own decisions
- Young people, parents and carers wanted more training for life skills and more support to gain employment
- A quarter of parents and carers said that not all services were being provided according to what had been agreed in their EHC plans or Statements
- Nearly half of young people said they needed extra support than they were receiving
- Waiting times for certain services were too long for some parents and carers

- Parents and carers wanted more access to speech and language therapy (SALT)
- Parents and carers raised concerns about the accessibility and quality of the Children and Young People's Services (CYPS) for mental health support
- Parents and carers raised issues with access to the 'Get Connected' activities service

Recommendations

In response to our findings we have made twelve recommendations to address the issues faced by service users. They are categorized into the four main reform principles:

Service users to participate as fully as possible in decision-making

- 1 Service users need a single point of contact**
A single point of contact (as the SEND code of practice advises) could significantly help the communication issues raised and improve service user's participation
- 2 All relevant stakeholders must attend EHC meetings/review meetings, including providers and parents/carers**
To introduce a register of EHC meeting attendance to improve attendance
- 3 Give equal value to the views of parents and carers**

Providing information and support to service users to enable them to participate in decision-making

- 4 The principles and aims of the reforms need to be better promoted to parents/carers and young people**
- 5 Increase awareness of 'who does what' and specific EHC processes**
To support service users to better understand the roles and responsibilities of certain SEND support roles, and better inform service users on parts of the EHC process

Preparing effectively for adulthood



- 6 Improve the preparation for adulthood**
We recommend that this is made a priority area for improvement, including more specific medium and long-term goal setting
- 7 Teach more life skills at school**
To investigate what skills are needed, and see how new initiatives can be established at schools to address this need



High quality provision to meet the needs of children and young people with SEND



- 8 To investigate why a quarter of parents and carers said that what was agreed in their EHC plan or Statement had not been provided**
- 9 To reduce waiting times for services**
- 10 The findings in this report should be considered as part of the existing improvement plan of the mental health services for children and young people**
- 11 The findings in this report should be considered as part of the existing improvement plan for speech and language therapy services**
- 12 Clarify and publicise for whom the Get Connected service is most suited to, and incorporate a performance indicator to routinely gather service user feedback**



Quotes from key SEND stakeholders on this report



 We are keen to listen to the views of our families and to learn and act on the feedback that the survey has produced...
Dean Jackson, Newcastle City Council 



 There is much for local services to celebrate, but clear challenges too, and the recommendations contained in this report should serve as a reminder that there is still much to be done, and that the needs of children and young people with SEND should remain an absolute priority for commissioners and providers of services in the local area – Healthwatch Newcastle has produced an excellent report!
Dr David W Jones, Newcastle Gateshead Clinical Commissioning Group 

 ...The Trust welcomes this review... We will continue to work actively as members of the SEND Board to review the report and respond to these findings.
Jane Melvin, Newcastle upon Tyne Hospitals NHS Foundation Trust 

 The findings of this report will form part of the discussions with Newcastle and Gateshead CCG and the SEND programme board to ensure that the service delivered by the trust provides a quality service for children and young people with SEND.
Rebecca Campbell, Northumberland, Tyne and Wear NHS Foundation Trust 

 Contact a Family North East Office support the recommendations within this report... The recommendations give a clear steer as to how Newcastle can build on the work already done and continue to develop services and processes...
Jacqui Adams, Contact a Family North East 

 Northeast Special Needs Network is pleased to endorse this important work from Healthwatch Newcastle, which focuses on the experiences of children and young people with SEND. The research is timely and is the first opportunity that parents, carers and children and young people with SEND have had to provide feedback on the effectiveness of the new Education Health and Care Plans.
Siobhan O'Neil, Northeast Special Needs Network 

 We at Pass It On Parents really welcome the Healthwatch Newcastle SEND report as we feel it reflects what we are hearing to be families' experience of the EHCP process in Newcastle and highlights some very important issues.
Jillian Allan, Pass It On Parents 

1 Introduction

1.1 What are special educational needs and disability?

Special educational needs and disabilities are often referred to as 'SEN' or 'SEND', which is a term for children and young people who need extra support during their education.

The SEND code of practice³ states that 'A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her.' Disability is defined as when someone has 'a physical or mental impairment which has a long-term and substantial adverse effect on their ability to carry out normal day-to-day activities'.

There are many different kinds of SEN and disability, which fall into one of four main groups:

1. Communication and interaction
2. Cognition and learning
3. Social, emotional and mental health difficulties
4. Sensory and/or physical needs

Not everyone who has one of the above conditions has a SEND. For example, you can have a level of autism or visual impairment but be the highest performer in your school. It is only when children and young people cannot succeed without special educational provision that they are said to have a SEND.

In England, 1,228,785 children and young people at school are registered as having a SEND, which is more than one in seven pupils (14.4%)⁴. There are 236,805 children and young people with complex SEND, which is 2.8% of all children and young people at school, and around one fifth of children with SEND. These children and young people with high levels of SEND, who often require substantial support from education, health and social care services, are provided with a Statement or an Educational, health and care plan (EHC), which is further explained in section 1.3.

The Children and Families Act 2014 did not change the definition of SEND, but it did widen the eligibility to include young people up to 25 years who are still in education or training.

1.2 What are the SEND reforms?

The SEND reforms have come as a result of the Children and Families Act 2014. The reforms aim to improve the support system for children and young people with SEND by giving more importance to the views, wishes and feelings of children and young people and their families.

It represents a comprehensive change in how support is provided to children and young people with SEND, and has the potential to transform the support they receive and the outcomes achieved. The reforms are based on the following principles:

³ SEND code of practice: 0 to 25 years (2014) Department for Education and Department of Health <http://tinyurl.com/omv3tpc> Statutory guidance for organisations that work with and support children and young people who have SEND: tells local authorities, schools and others how they must carry out their duties under the Children and Families Act 2014.

⁴ Data from 'Special educational needs in England: January 2016' (2016) Department for Education <http://tinyurl.com/hsmkrr6>

Participation – local authorities and health partners must work with parents, carers and young people to improve services in their area.

Outcomes – local authorities must offer support in a way that enables children and young people with SEND to achieve the best possible educational progress, and helps them do what they want in their lives as they grow up.

Joint decisions – local authorities must make sure that young people and their families get the right information and support to take part in decisions which affect them.

Joint working – education, health and social care services must work closer together when they are deciding on the support available for children and young people with SEND in their area.

In practice these reforms aim to:

- Give children and young people and their parents/carers more say about the help they get
- Make sure children, young people and families know what help they can get when a child or young person has SEND
- Make sure that different organisations work together to help children and young people with SEND
- Have one overall assessment process to look at what special help a child or young person needs with their education, health and social care needs
- Get education, health and social care services working together
- Give a child or young person one plan to meet their education, health and social care needs, which if necessary can run from birth to 25 years
- Make sure children, young people and their parents/carers can choose some of the help they need

1.3 Education, health and care plans (EHC)

An important part of the SEND reforms is a new planning tool called the Education, health and care plan (EHC) for children and young people with more complex SEND.

The EHC plan replaces the Learning Difficulty Assessment and Statements and can continue up to 25 years of age if a young person still needs the extra support to complete his or her education or training.

EHC plans have been implemented to help achieve many of the aims of the SEND reforms. They aim to:

- Better include the views of the young person and parents/carers in decisions-making
- Bring together in one place the support required across education, health and social care
- Be aspirational and to develop robust long-term planning to achieve these aspirations

The EHC plan document is significantly different to the previous Statements. EHC plans have sections to describe:

- The views and future goals of the child or young person
- The outcomes the child or young person is expected to achieve
- Health needs linked to special educational needs of the child or young person
- The health provision needed by the child or young person because of their SEND; if health provision is included in a plan there is a legal duty to provide it
- Social care needs and provision linked to the child or young person's SEND; there is a separate law covering social care assessments and provision, but details must be included in the EHC plan

1.4 SEND in Newcastle

The Department for Education's January 2016 report stated there were 6,651 children and young people with SEND in Newcastle. This is 15.2% of all school pupils⁵ (slightly more than the national average of 14.4%) and 1,054 of these had a Statement or EHC plan. This equates to 2.4% of all pupils in Newcastle, which is below the national average of 2.8%⁶. As of 1st December 2016 there were 1,431 children and young people up to 25 years old on EHC plans or Statement in Newcastle upon Tyne⁷.

The city has experienced significant reductions in the local authority budget. Within this very challenging context, Newcastle City Council has protected its SEND budget, avoiding any cuts.

An important local organisation which provides support to children and young people with SEND, the Northeast Special Needs Network, is under financial strain and is reducing services from early 2017.

The Newcastle upon Tyne Hospitals NHS Foundation Trust was rated as outstanding by the Care Quality Commission in 2016.

In Newcastle a new multi-agency body called the SEND programme board has been established to implement the SEND reforms. The board coordinates and has oversight of how these wide-ranging changes are being implemented. As of 1 December 2016, 1,166 children and young people had EHC plans (71%)⁸, with most of the remaining 265 planned to be complete by June 2017. The deadline for all transfers to be complete is April 2018. The number of SEN Case Workers has increased to accommodate this additional work.

Newcastle has higher than the national average of special schools, with 759 pupils (1.7% of all children) attending special schools. Nationally, the average attendance at special schools is 1.2%. This is a particularly high number when taking into account that the proportion of children and young people who have an EHC plan or Statement in Newcastle is 14% lower than the national average. Even so, special schools are at full capacity and demand is very high, providing a challenge for the local authority.

^{5,6} Data from 'Special educational needs in England: January 2016' (2016) Department for Education <http://tinyurl.com/hsmkrr6>

⁷ Data provided by Newcastle City Council, January 2017

⁸ 789 under 16s and 377 over 16s on EHC plans. For the 2016–17 academic year there were 259 under 16, and six over 16 to transfer from Statements to EHC plans (data provided by Newcastle City Council, January 2017)

Newcastle City Council wants to increase social inclusion for children and young people with SEND. There were a series of events with service users, providers and support organisations during 2016, seeking ways for children and young people to be more included in society across all aspects of their lives. This campaign was driven by the ambitions of both the local authority and service users.

1.5 Why spotlight on SEND?

Healthwatch Newcastle's remit is to gather service user views on publicly-funded health and social care services from all groups within the community. Each year we select a number of topics, services or issues for more targeted research, in response to local views.

We chose SEND for the following reasons:

- Young people with EHC plans or Statements are a very vulnerable group, requiring high levels of support across multiple publicly-funded providers
- Certain support services are under operational strain
- Engagement with parents and carers of children with SEND highlighted a number of issues, with the EHC plan being the most common
- Two years after the SEND reforms were implemented, it seemed an opportune time to gather the experiences of service users
- We had little knowledge of SEND services in Newcastle

Our aim is to provide useful evidence, which can be fed back to providers and commissioners to support continuous improvement of the implementation of these important SEND reforms.

1.6 The scope of the SEND research

This SEND research aimed to gather views of local health, social care and education provision, and experiences of an EHC plan or Statement in Newcastle from two groups:

- Young people between 16–25 years with an EHC plan or Statement
- Parents and carers of children and young people between 0–25 years with an EHC plan or Statement

While our area of activity covers all publicly-funded health and social care, education is outside of our remit. However, due to the interdependence of education, health and care support for children and young people with complex SEND (and in the spirit of the SEND reforms) we have included education in this research. It should be noted however, that the main focus is on health and social care services.

This research did not look at the following:

- Children and young people with SEND who did not qualify for an EHC plan or Statement. After engagement carried out prior to this research we made the decision to focus on those with more complex needs (with EHC plans or Statements); we recognise the opportunity cost of excluding the broader group of children and young people with SEND – they have their own set of issues and account for the vast majority of children and young people with SEND
- Those that have had an EHC assessment but who did not meet the necessary eligibility criteria for an EHC plan; therefore issues relating to selection criteria and communication related to eligibility are outside the scope of this research
- Personal budgets
- Complaints procedures

2 Our approach

We phased this research into three distinct stages:

2.1 Literature review stage

To get a clearer idea of key issues or trends in the area of children and young people with SEND, we conducted a literature review. This review highlighted some national and local issues which helped us prepare for the listening stage.

2.2 Listening stage

We carried out three main activities in this stage:

1. Conducted an online one-question poll

In July 2016 we asked SEND service users to tell us their top three issues around receiving SEND support. The poll was available online and publicised through social media; and promoted by SEND voluntary and community organisations, the SEND Parent Carer Forum and Newcastle Council for Voluntary Service. We received 57 responses. The top five issues the respondents had were:

1. Waiting times for services (by far the most common issue)
2. Not being listened to by professionals
3. A lack of coordination between the services
4. A lack of availability of knowledge, advice and support
5. The need for services to be better adapted for children and young people with autism

The answers from the poll are represented in the word cloud below, where the more commonly mentioned themes are in a larger font size:



2. Focus groups

From May to July 2016 we conducted three focus groups with parents and carers who had a child with SEND. A total of 19 parents and carers attended the focus groups held in Newcastle city centre, Hadrian School and Thomas Bewick School. A fourth focus group was held with case workers from the Northeast Special Needs Network.

The principle themes which emerged from these focus groups were:

- Waiting times
- A lack of communication between providers and parents/carers
- A lack of coordination between services
- Parents not being sufficiently listened to
- A lack of knowledge about the SEND reforms
- The challenges of including children with complex needs in the usual recreational activities of children
- Certain services, especially health providers, not attending EHC planning meetings
- A lack of appropriate facilities for, and knowledge of, how to run services for autistic children

3. Interviews with stakeholders

From May to August 2016 we conducted interviews with many SEND stakeholders in Newcastle. This included Newcastle City Council, Newcastle and Gateshead Clinical Commissioning Group (CCG), various special schools and schools with Additional Resource Centres (ARCs), various voluntary and community organisations and the Newcastle SEND Parent Carer Forum. For the complete list of interviews conducted please see the 'Spotlight on SEND appendix' at <http://tinyurl.com/SENDappendix>

2.3 Questionnaire stage

We carried out two questionnaires: one for young people between 16–25 who have an EHC plan or Statement, and a more in-depth one for parents and carers of children and young people between 0–25 years with an EHC plan or Statement.

The questionnaires were designed using the information gathered during the literature review and listening stages. Both questionnaire templates can be found in the 'Spotlight on SEND appendix' at <http://tinyurl.com/SENDappendix>

The questionnaires were shared with several key stakeholder organisations during development, including Newcastle SEND Parent Carer Forum, Newcastle City Council, Northeast Special Needs Network, Skills for People, Pass It On Parents, SEND Information, Advice and Support Service (SENDIASS) and Contact a Family.

This was to ensure we asked the most appropriate and pertinent questions, provided appropriate answer options for closed questions, used appropriate language and terms, and that the questions were impartial.

The two questionnaires were launched on the 23 September 2016. A paper copy of the parent/carer questionnaire was posted to every parent and carer of a child or young person in Newcastle with an EHC plan or Statement.



A paper copy of the young people's questionnaire was sent to every 16–25 year old in Newcastle with an EHC plan or Statement. The questionnaires were also available to complete online.

To maximise the number of responses the questionnaires were publicised via:

- SEND support organisations from the voluntary and community sector including, Northeast Special Needs Network, Skills for People, Pass It On Parents, Contact A Family and the SEND Parent Carer Forum, which also organised events to complete questionnaires
- A lead article on the Newcastle City Council Local Offer webpage
- Special schools and mainstream schools with Additional Resource Centres (ARC) included information in school newsletters and put leaflets in school bags
- Newcastle and Gateshead CCG, which publicised the questionnaires in health-related institutions and communication channels, including GP practices
- Surestart Centres displayed posters in their premises
- A SENCo Coordinator distributed information to all SENCos⁹ in Newcastle
- Newcastle Council for Voluntary Service promoted the questionnaires through its newsletters and social media
- Newcastle City Council social workers promoted the questionnaires with service users

Data entry and quality assurance test

All paper questionnaire responses were entered into the online questionnaire by a staff member. To check the accuracy of data entry, a 10% sample for each questionnaire type was randomly selected and checked by another staff member and found to have a high level of accuracy.

Questionnaire response

We received a good response to the two questionnaires, with a total of 252 respondents. This included 201 valid responses from parents/carers, and 51 from young people. This equates to 14% of the full cohort of parents/carers in Newcastle, and 13% of young people. We were pleased to have gained a large enough sample size to have representative samples.

⁹ SENCo (SEN Coordinator) is a role performed in mainstream schools, with responsibility to ensure all children with a SEND are identified and provided with the support needed to succeed in school.

3 Findings

3.1 Questionnaire for parents and carers

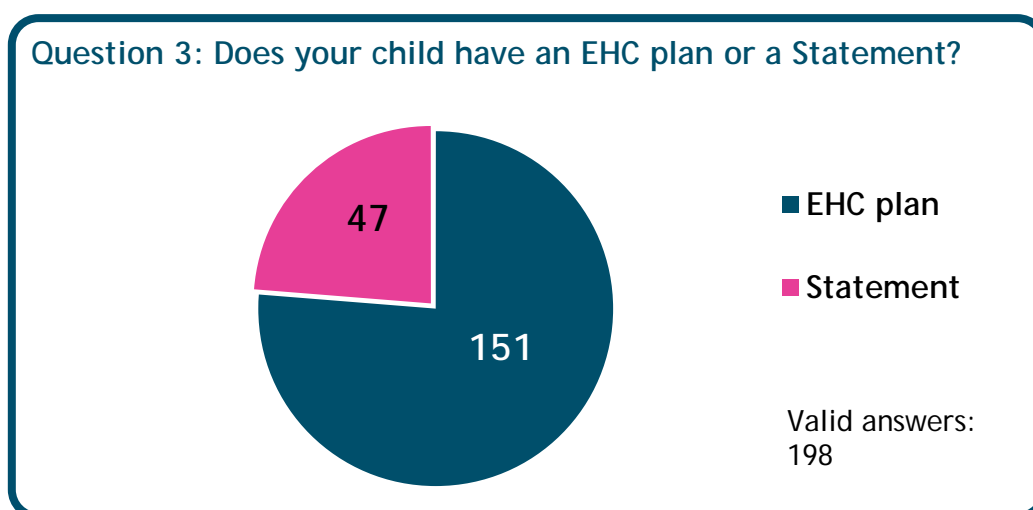
3.1.1 Section 1: general information

We received a total of 201 valid responses for the parents and carers questionnaire, with the age distribution shown below in figure 1. You can see in figure 2 that just over three quarters of respondents had a child on an EHC plan, with the remainder on a Statement.

Figure 1: Child’s age from the parent/carer questionnaire, compared with the total Newcastle population of children with an EHC plan or Statement

Age in Sep 2016 (yrs.)	Number of children and young people	Proportion by age groups from survey group	All Newcastle children and young people with an EHC plan or Statement
0–4	19	9.5%	3.8%
5–11	80	39.8%	36.7%
12–16	69	34.3%	44.0%
17–19	28	13.9%	7.3%
20–25	5	2.5%	8.2%

Figure 2: Proportion of children with EHC plans or Statements from respondents of the parent/carer questionnaire



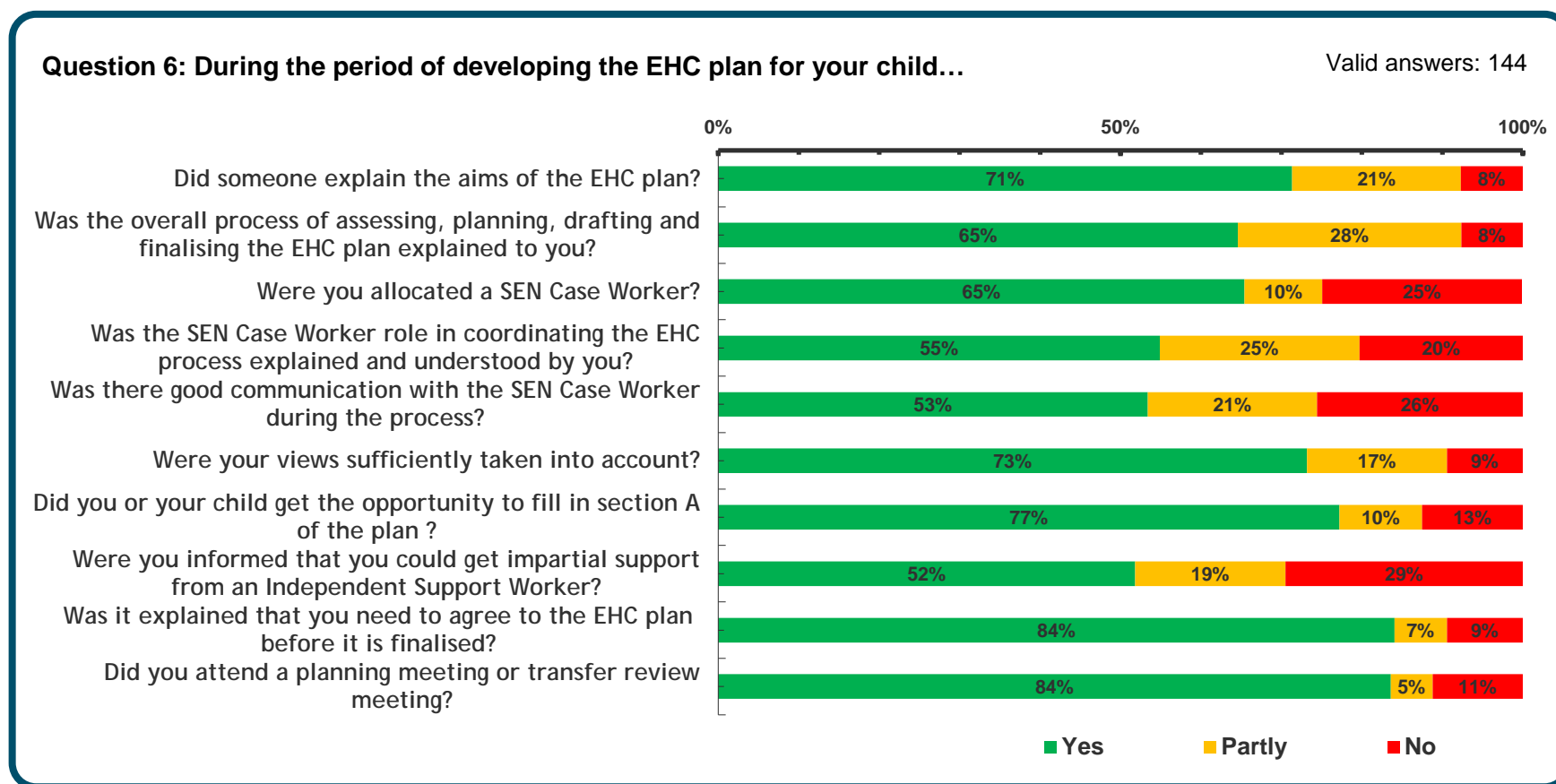
A good representative sample from all children and young people with an EHC plan or Statement in Newcastle

We compared the age, ethnicity and where people lived (first half of the postcode) of our 201 respondents with all the children and young people in Newcastle with an EHC plan or Statement, to see how well our sample reflects the full group in Newcastle. With age, as you can see in figure 1 above, the 14% sample corresponds well with the spread of age groups for children and young people with EHC plans or Statements in Newcastle overall. In terms of ethnicity there was a similar sample of the full group; 78.1% of our respondents were white British and 21.9% BME, compared to 73.4% and 24.6% respectively across Newcastle. Comparing postcodes, these correlated well providing a good representation across the city.

3.1.2 Section 2: experiences of producing and moving to the EHC plan

When asked about their experiences of moving to an EHC plan, you can see in figure 3 below that there were a range of answers. 55% of respondents said the role of the SEN Case Worker was explained to them, and 53% said they had good communication with them during the process. The answer with the lowest positive response was to the question about whether or not the role of the Independent Support Workers was explained (52%). The two most positively answered questions (84%) were: if people had been informed they had to agree to the EHC plan, and if they had attended an EHC plan meeting. Although this is over 4/5's of the respondents, it is a concern that 16% didn't respond positively to questions relating to such important aspects of the plan.

Figure 3: Parent/carer responses to the EHC plan development phase



We asked parents and carers to suggest improvements to the process of producing the EHC plans. The answers were collated into themes (figure 4 below). The most common answers were about better written and oral communication with parents and carers. The second most common suggestion was for receiving more information about the EHC process and plan. Parents and carers commented that they particularly wanted more information about the process from either the schools or SEN case workers, as well as updates during the process.

Suggestions relating to EHC meetings were mostly about ensuring that all professionals attended meetings, followed by being informed in advance about how the meetings are run. A number of parents and carers also said that SEN Case Workers did not communicate well, or that they provided incorrect information. Below is a sample of the comments from these popular themes:

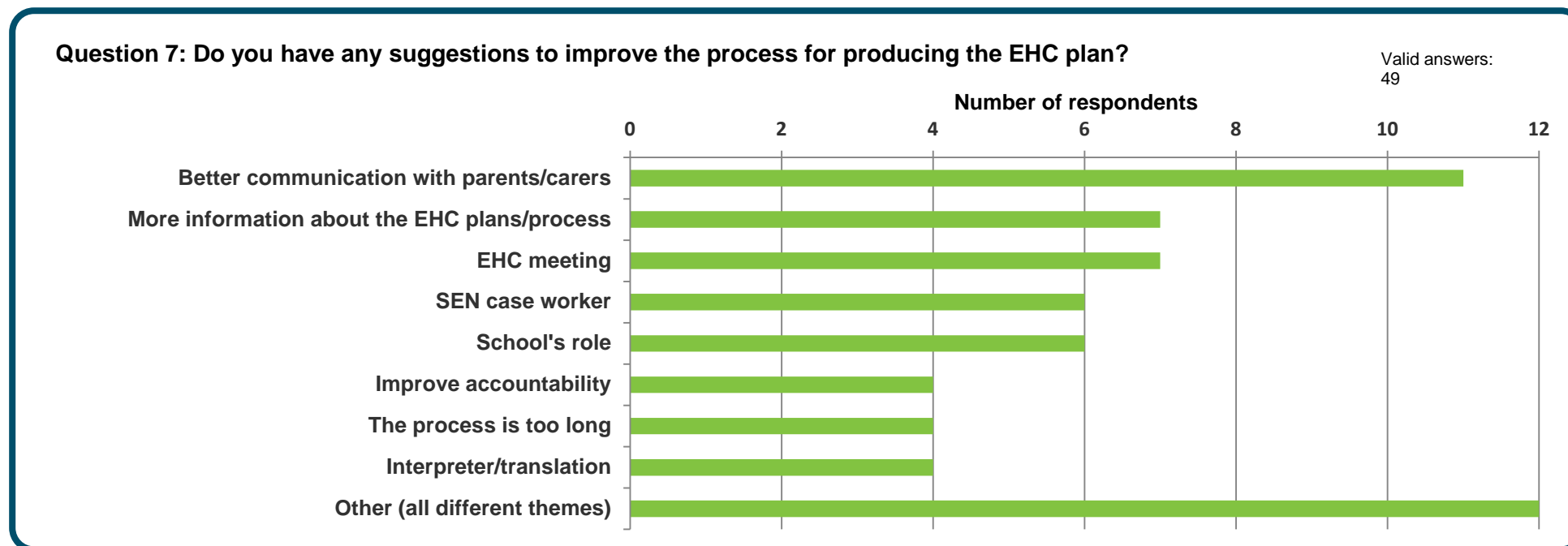
“Some better written communication”

“If the process could be informed promptly what we are expecting next would be more helpful”

“Our case worker was very bad at communicating with us”

“Ensure all team members attend meetings”

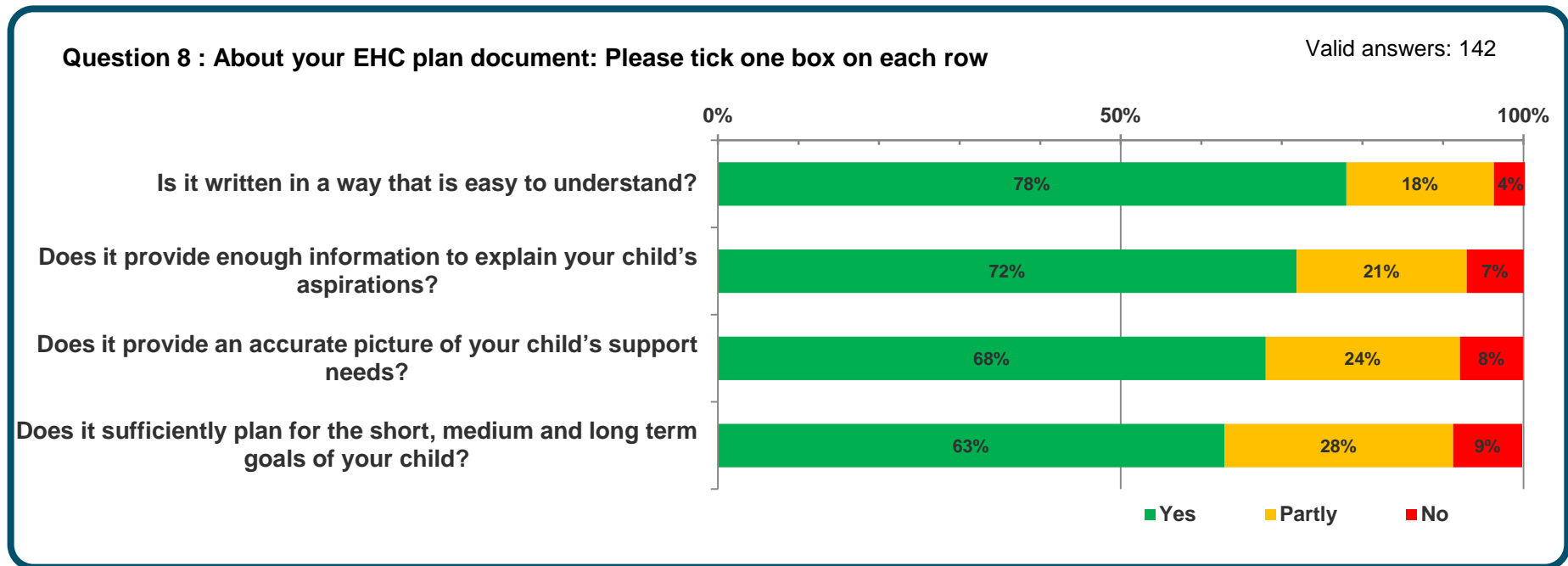
Figure 4: Parent/carer suggestions to improve the process of producing the EHC plan



3.1.3 Section 3: views on the EHC plan documentation

From figure 5 below you can see that parents and carers were quite satisfied overall with EHC plan documentation. All four questions asked received a 'yes' or 'partly' answer from over 90% of respondents, with most saying that they found the EHC plan easy to understand. The lowest scoring question (63%) related to whether the plan provided sufficient planning for their child.

Figure 5: Parent/carer views on the EHC document





If respondents answered 'no' to any of the questions about the EHC plan document, we asked them for further comments.

There were a low number of comments to this question because very few respondents had answered 'no' (see figure 6 below).

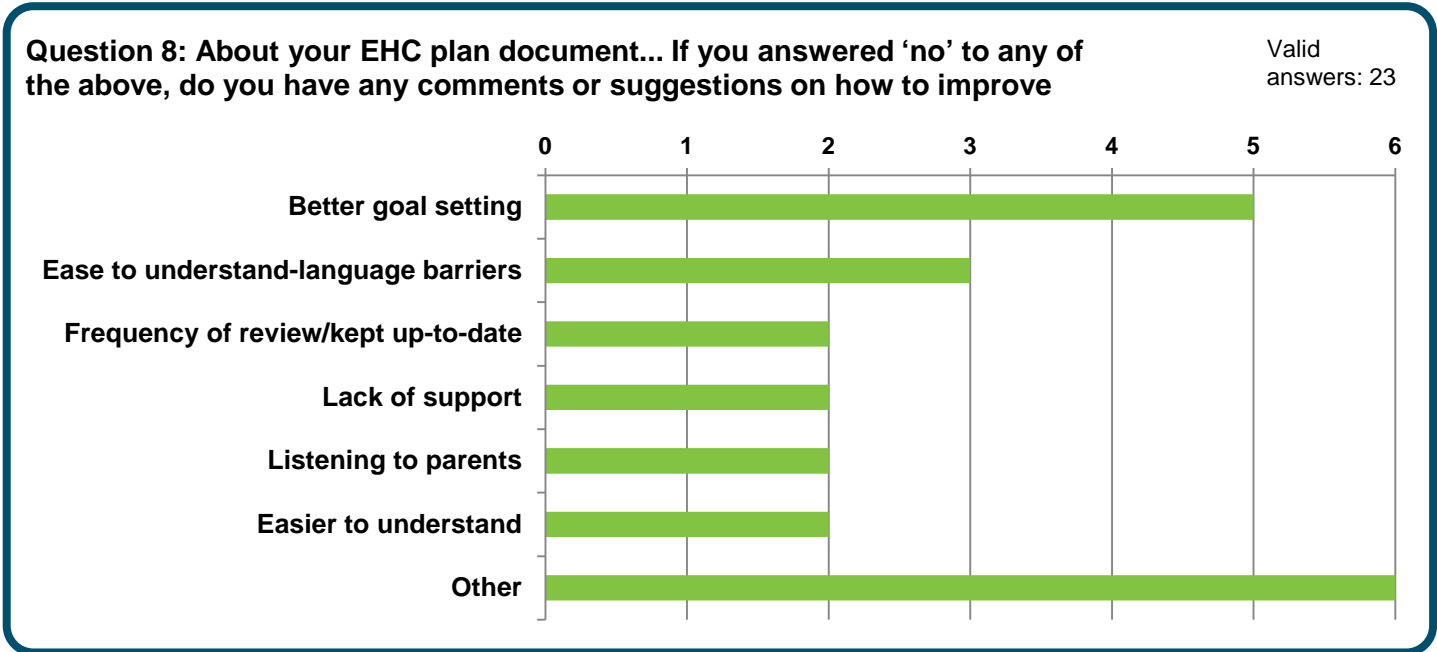
However, the most common theme related to improving goal-setting.

Comments were mostly about setting clear and concise goals and better planning for transition. Several comments were made about vague goals which were open to interpretation, and not specific enough to hold people to account.

"Aims and provisions need to be better throughout and correlated to give a more concise plan with clearer support inputs and desired outcomes"

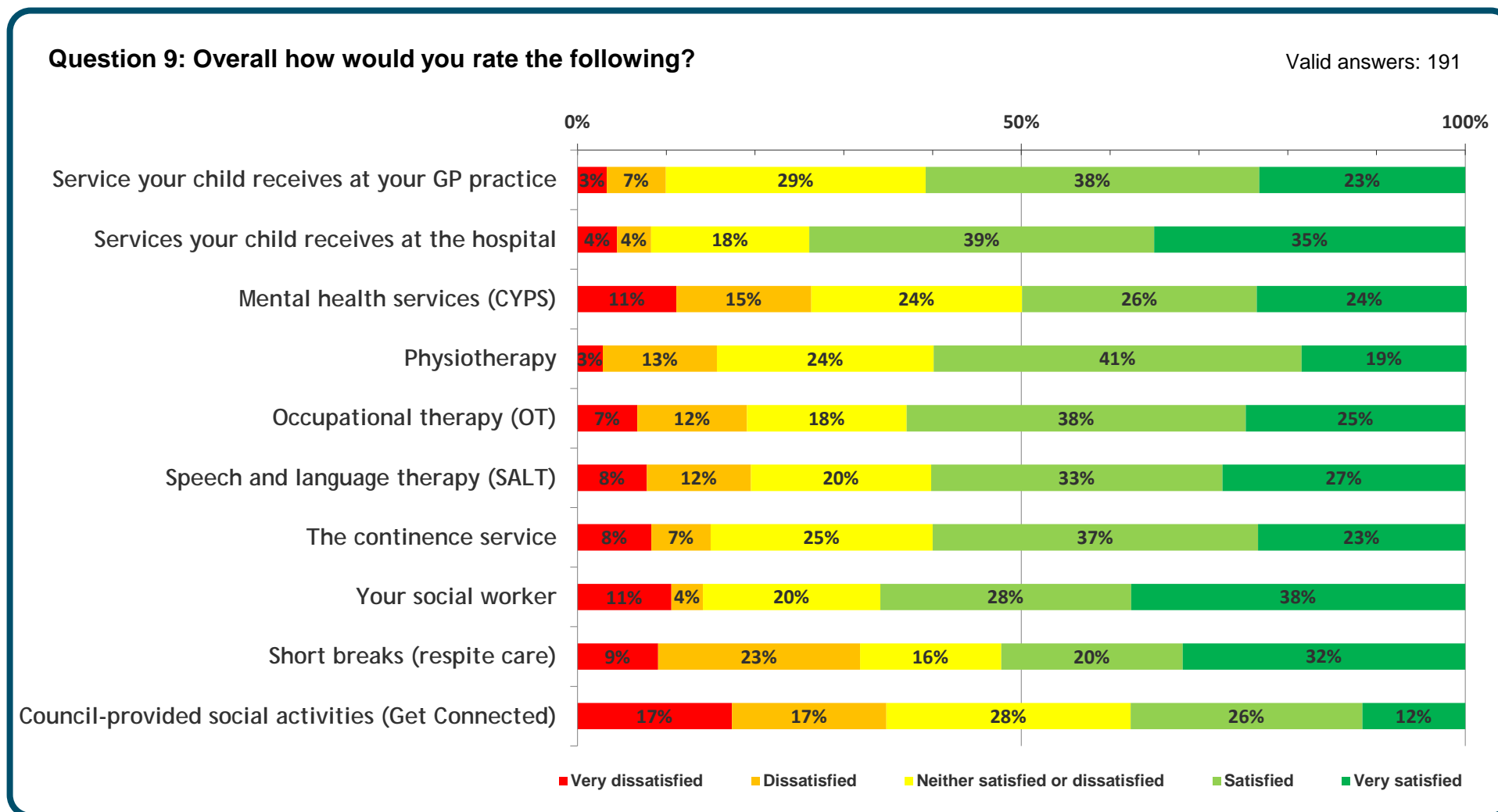
"We were approaching transition – and the EHC process didn't consider it at all"

Figure 6: Parent/carer suggestions to improve the EHC plan document



3.1.4 Section 4: Views of the health and social care services received

Figure 7: Parent/carer satisfaction with specific health and social care services



Figures 7 and 8 show that parents and carers are more satisfied with hospital services than any other health and social care service; this was followed by social workers and General Practice (GP) services.

The three services with the lowest satisfaction scores were child mental health services (CYPS), respite/short break services and Get Connected activities services. Both Get Connected (34%) and respite/short break services (32%) had around one third of respondents being dissatisfied or very dissatisfied with the service, with 17% of respondents very dissatisfied with the Get Connected service.

Figure 8: Parent/carer mean satisfaction scores by health and social care service

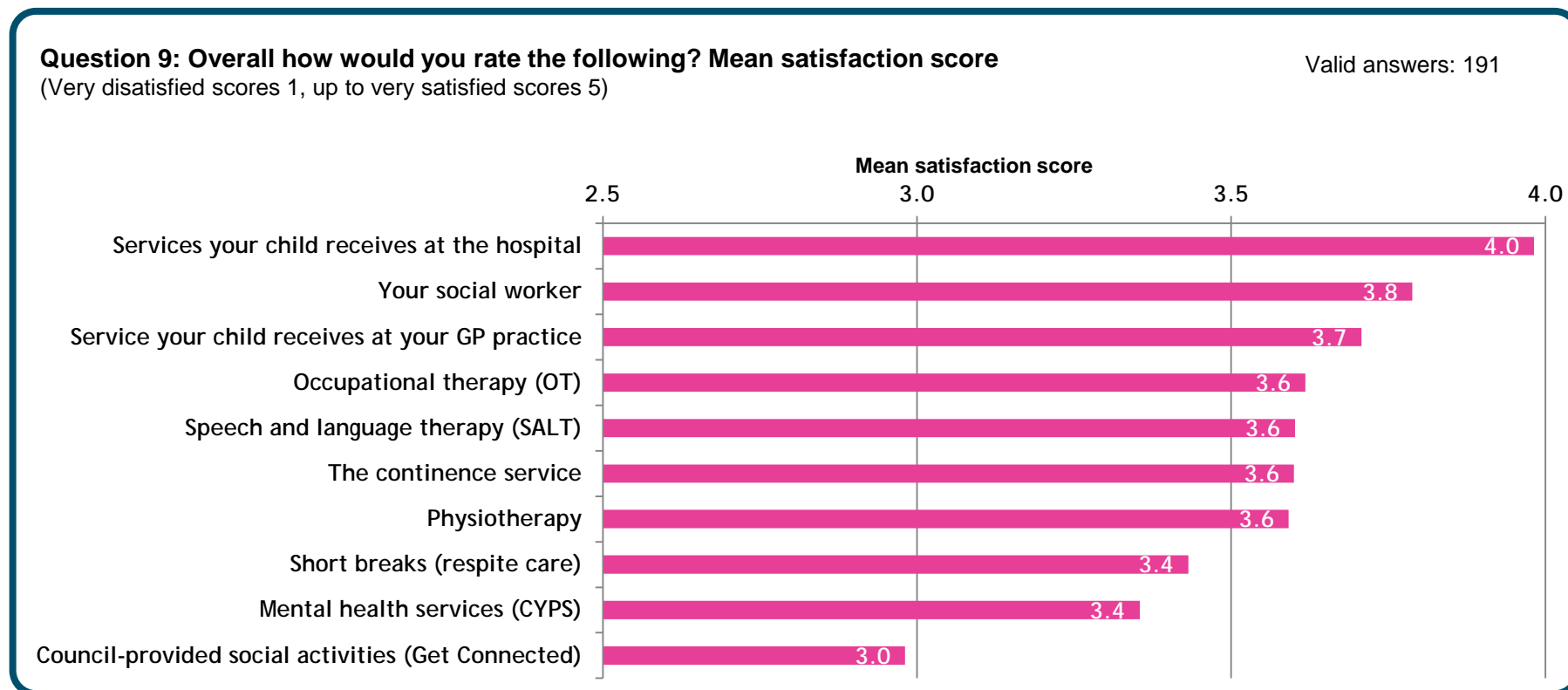


Figure 9 below shows the comments by theme that parents and carers made about health and social care services. The most common theme was about speech and language therapy services (SALT). Respondents highlighted how valued the service is, but also raised the following two issues:

1. **Amount of service offered** – either the service being discontinued when parents and carers wanted it to continue, or that they were allocated less time than parents and carers wanted.

“SALT is now ended but it was very effective and was a great service to engage with.”

“SALT says they cannot help any further which is very disappointing.”

2. **Lack of SALT offered at mainstream schools** – examples were given where children couldn't access SALT in mainstream schools, but were able to when they moved to special schools.

“It's too difficult to ask the speech and language therapy service when a child is in mainstream school. But when he transferred to an ARC he started to benefit from speech and language therapy. But we already missed the golden time of an intervention to improve his understanding that's really really irreversible and regretting it.”

“SALT- satisfied since our son started Percy Hedley School. No provision prior to this move despite Statement.”

The second most common theme was that children and young people were not receiving the requested support. Many comments did not specify which services. However, occupational therapy, physiotherapy, education psychologist and SALT were mentioned.

“No help from outside services even though requested.”

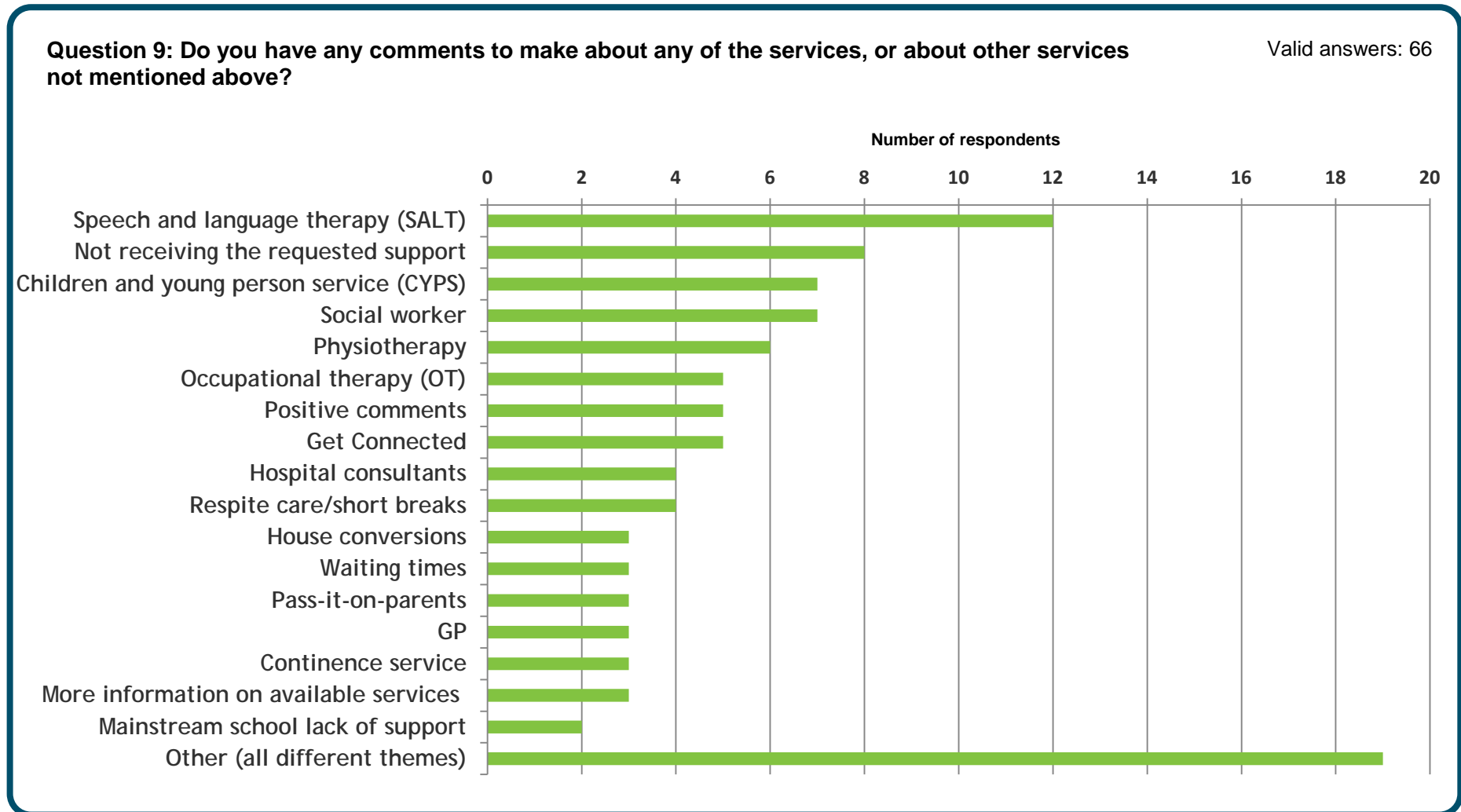
“Educational Physiologist refused to engage in terms of attending meetings or explaining report.”

The third most common theme related to children and young people's mental health services (CYPS). With one exception, all the comments about CYPS were very negative, making this the most negatively responded area in our research. Issues raised included long waiting times, unhelpful communication, disorganised provision and providers' non-attendance at EHC plan or review meetings.

“CYPS are terrible. I'm still waiting for an appointment after telling them my son started to self-harm! They never attend meetings either or support even when your crying begging for support.”

“CYPS - we have had very bad experience with them so far. Long waiting list, not wanting to consider my son, same questionnaires sent to me few times (I send them back) and they kept no records of my questionnaires. Very disorganised. Terrible.”

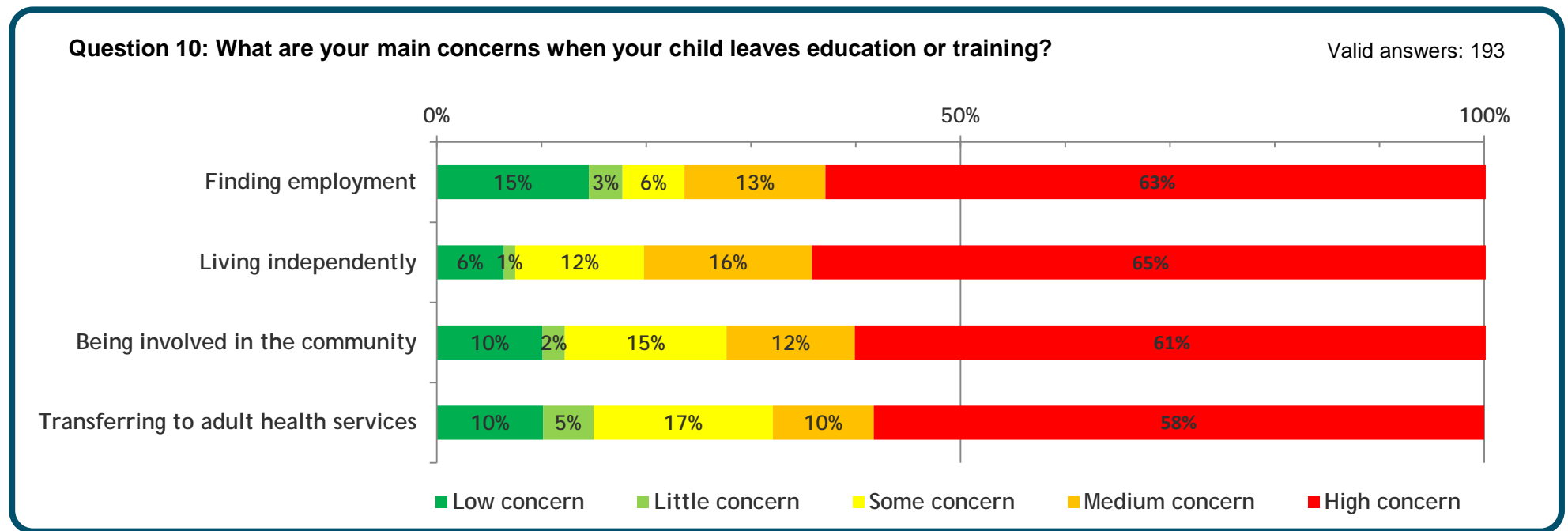
Figure 9: Parent/carers themed comments related to health and social care services



3.1.5 Section 5: Views on preparing for adulthood

Figure 10 below shows that parents and carers were also very concerned about all four of the stated aspects of adulthood: finding employment; living independently; being involved in the community; and transferring to adult health services. This was the only closed question in the survey that had an answer where the majority were in the most extreme category. When this data was examined by age group (0–11 years, 12–16 years, and 17–25 years), the parents and carers of the 12–16 age group were the ones with the greatest concern about preparing for adulthood. However, the trend was similar for all groups (see the ‘Spotlight on SEND appendix’ at <http://tinyurl.com/SENDappendix> for more details).

Figure 10: Parent/carers level of concern for their child as they reach adulthood

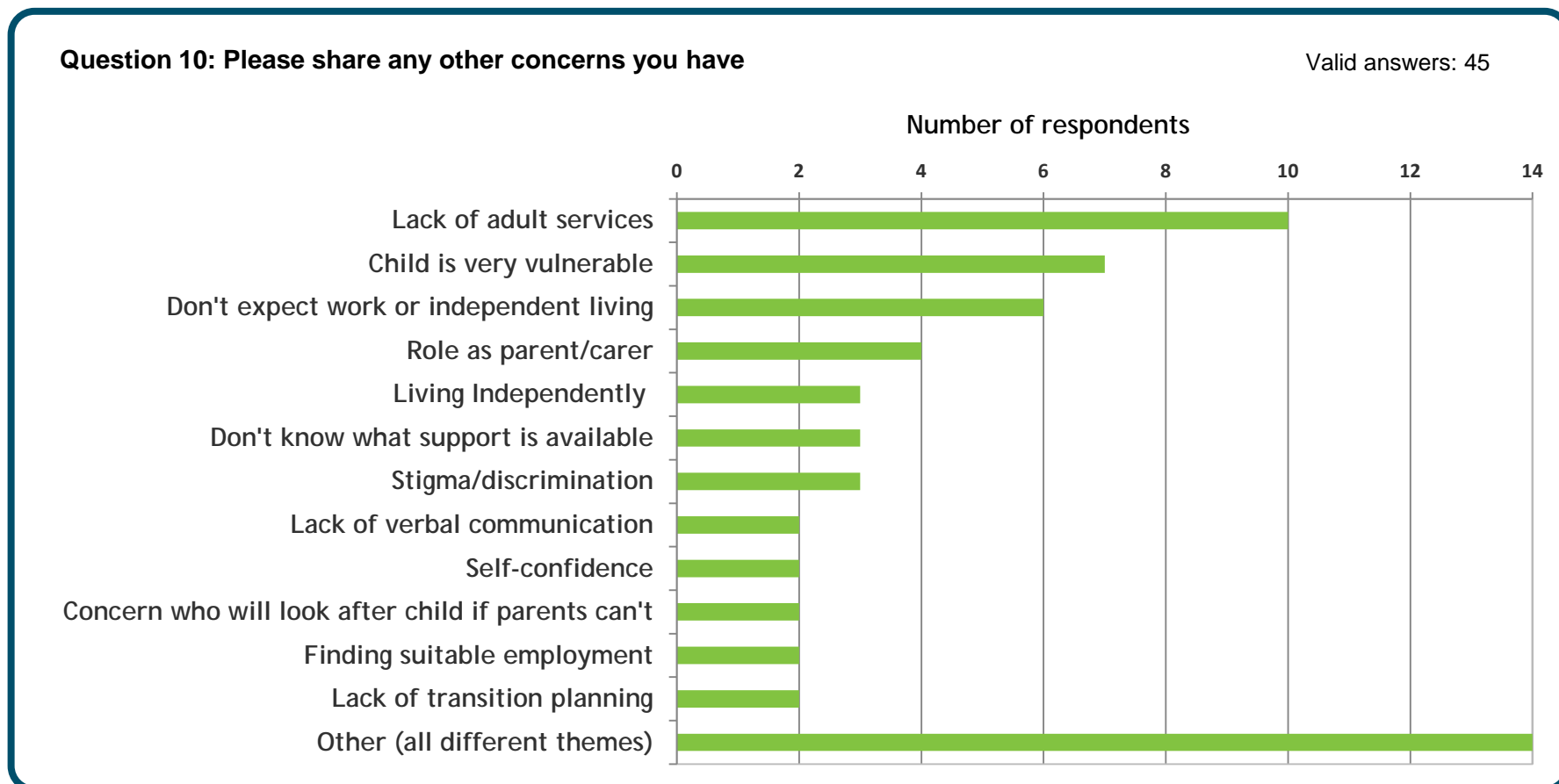


As figure 11 shows, the most frequent comment made about the above concerns was the lack of adult services. Focus group participants used the concept of 'falling off the cliff' when transitioning to adult services and respondents said:

“Major concerns regarding the transfer to adult services as hear negative things e.g. lack of provision.”

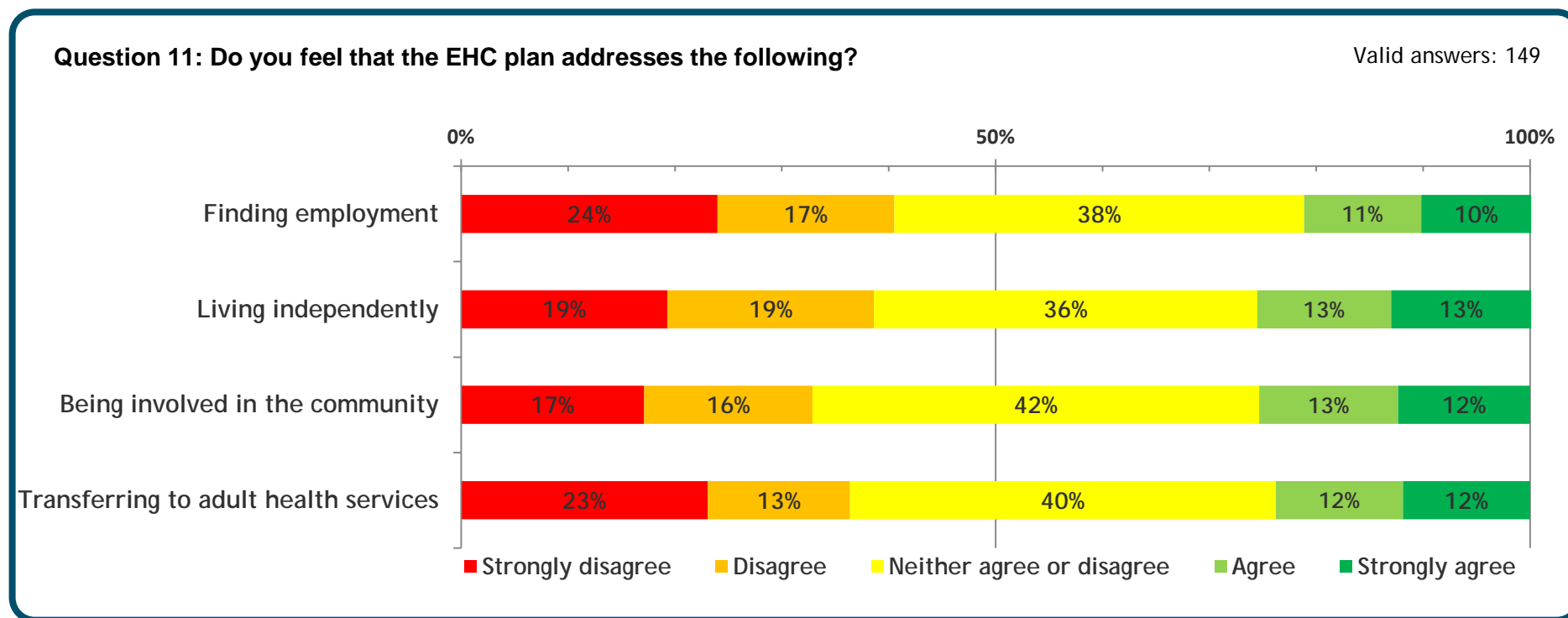
“My daughter transferred from Children's Services to Adult Services without any transition. Had I not been involved as I was with her care/education/health etc. she would have disappeared in the system. I felt extremely let down by the system.”

Figure 11: Parent/carer themed comments related to concerns for their child as they prepare for adulthood



Respondents also indicated (see figure 12 below) that they did not feel that the EHC plan addressed their concerns about preparing for adult life. There were more negative responses than positive; 41% of respondents disagreed or strongly disagreed that the EHC plan addressed their concerns about finding employment, with almost a quarter (24%) strongly disagreeing. When this data was examined by different age groups (0–11 years, 12–16 years and 17–25 years) the trend was similar, with the 12–16 group slightly more positive about the EHC plan. See the 'Spotlight on SEND appendix' at <http://tinyurl.com/SENDappendix> for more details.

Figure 12: Parent/carer views about if the EHC plan addresses their concerns for preparing for adulthood



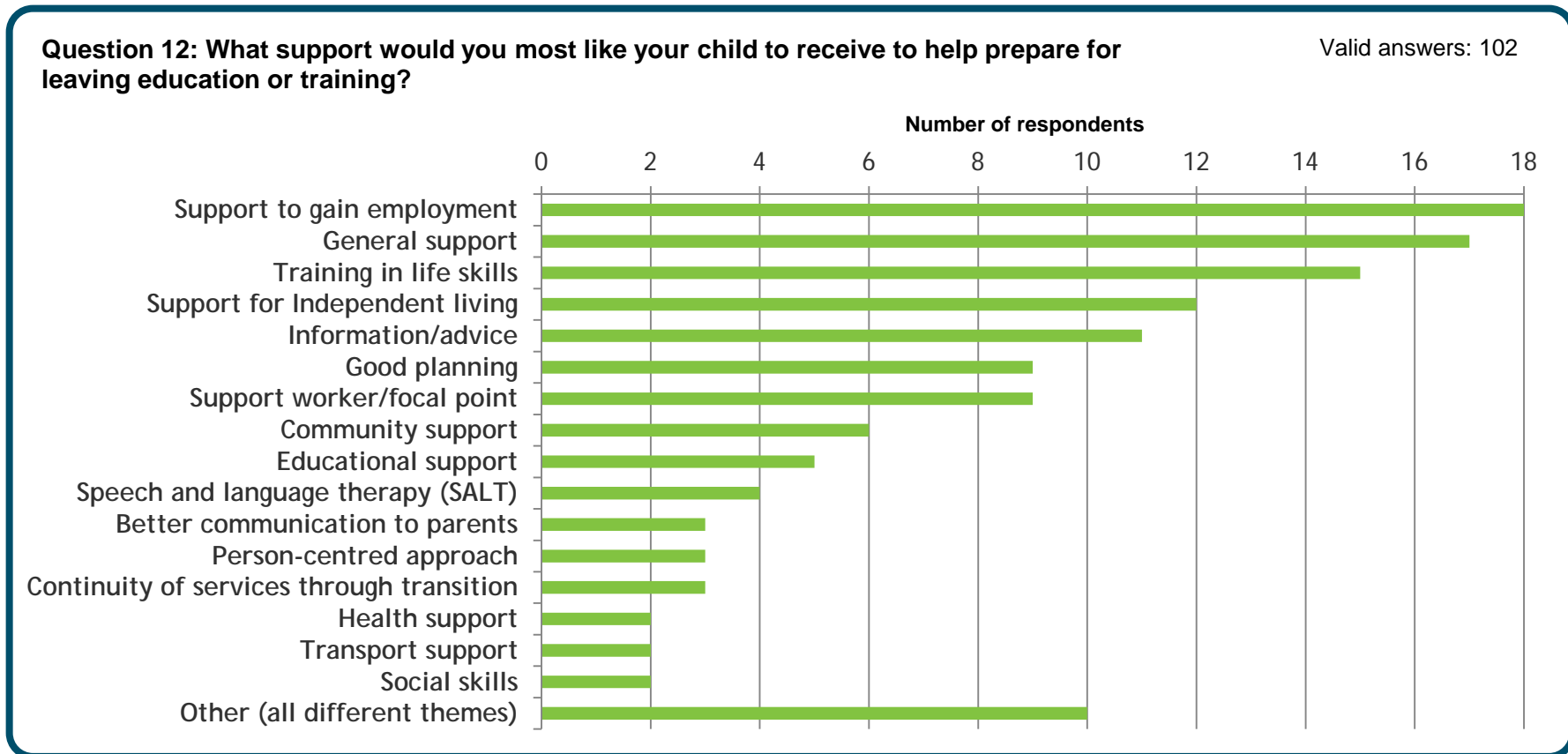
We asked parents and carers what support they would most like for their child to prepare for adulthood. The most common answer was support to find employment (figure 13).

“Developing the skills that he has to maximise employment opportunities.”

“Help with how to deal with everyday stresses in the workplace such as dealing with authority, personalities of other workers and general expectations of being employed.”

“Appropriate support to access appropriate sustainable employment.”

Figure 13: Parent/carer themed comments related to the support they would like their child to receive to prepare for leaving education or training



However, as figure 15 shows below, a quarter (25%) of parents and carers said their child was not receiving the support that had been outlined in the EHC plan or Statement. Figure 16 shows which services parents and carers said had not been provided. Certain aspects of school support and SALT were the most commonly stated services.

Figure 15: Parent/carer responses to the proportion of support provided

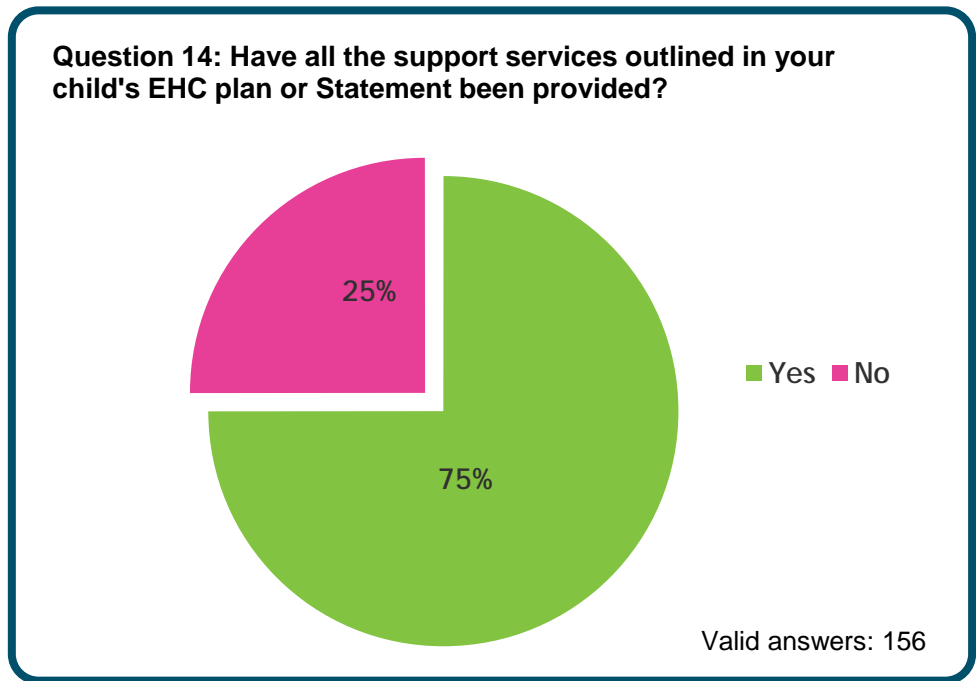
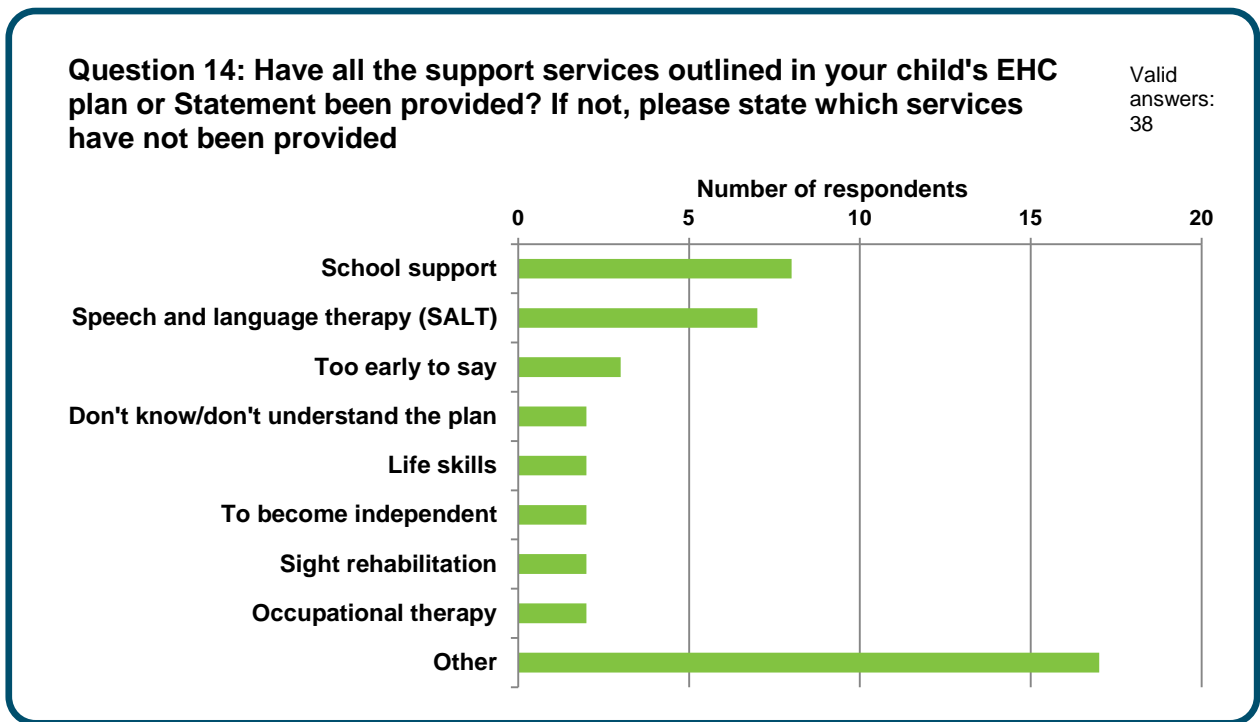


Figure 16: Parent/carers responses to which agreed services had not been provided



We asked parents and carers about the upsides (figure 17) and downsides (figure 18) of their EHC plan or Statement. More than three quarters of the responses were from parents and carers of children and young people on EHC plans.



When talking about the upsides, the three most common themes were that the EHC plan or Statement enabled their child to receive the support they needed, to get into the right school, and to have a sense of direction for their child.

“My child has received the required amount of support needed to reach her potential in mainstream school.”

“Since getting his EHCP he is now in a special school which is able to meet all his needs.”

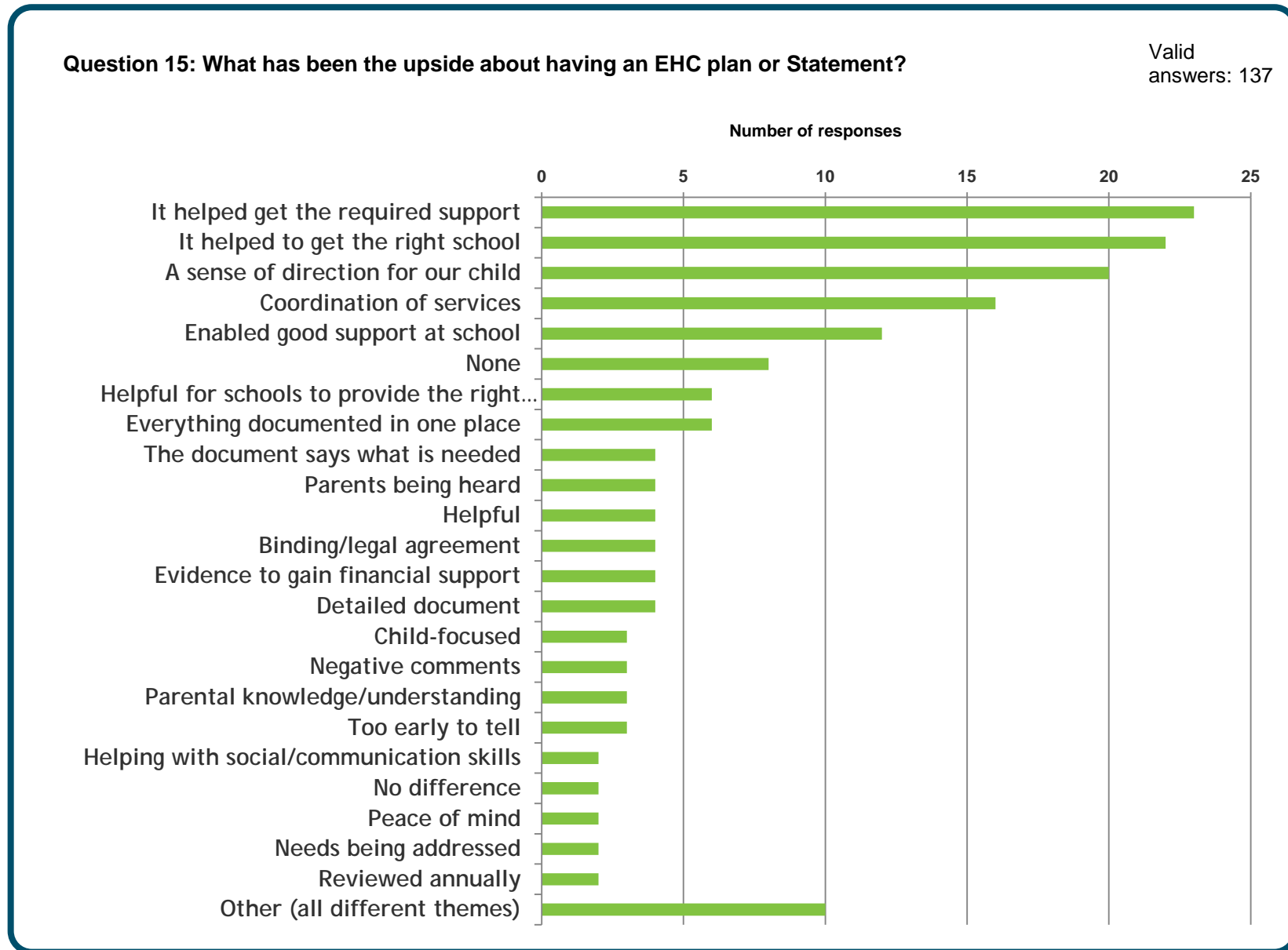
“It explains my son without us having to panic to get everything out and covered for needs.”

“Our son gets the right support in the right environment.”

“Principles are valid and stimulate questions and planning.”

“I think it seems a lot clearer of what needs to be done and when and how.”

Figure 17: Parent/carer themed comments about the upsides of the EHC plan or Statement





When talking about the downside of an EHC plan or Statement the most commonly stated answer was 'none', from a quarter of all respondents. The second most common theme was about the delays and the length of time the EHC process took. The third most common theme was a lack of action from service providers once the plan was completed:

"We haven't seen any downside."

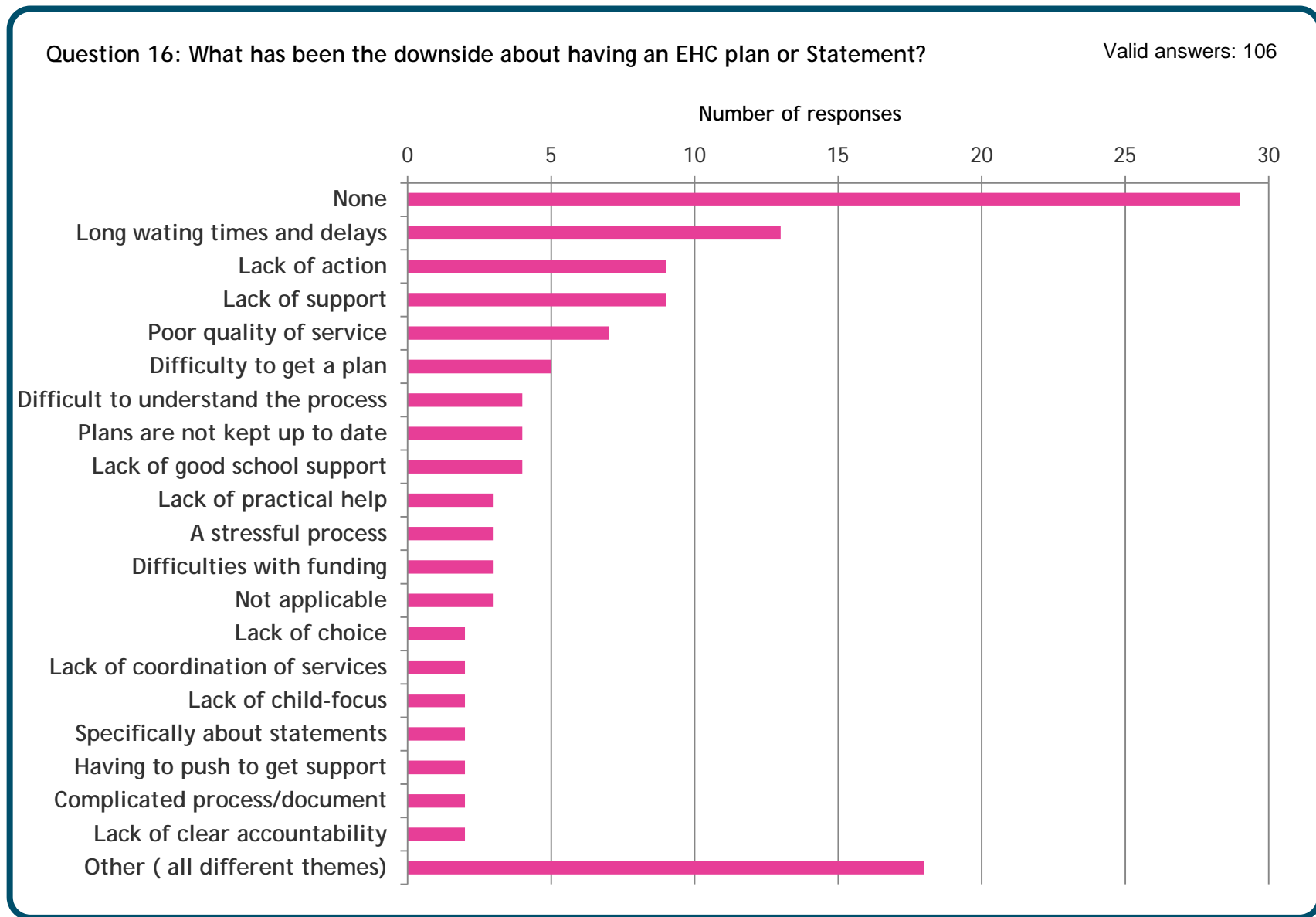
"It was time-consuming to actually go through the process. I felt this was time cost when my daughter could have been benefiting in a special school earlier."

"It takes a long time to get an EHC plan. The waiting was very long and arduous."

"Once it has been completed it feels like it's pushed to the side and no longer relevant."

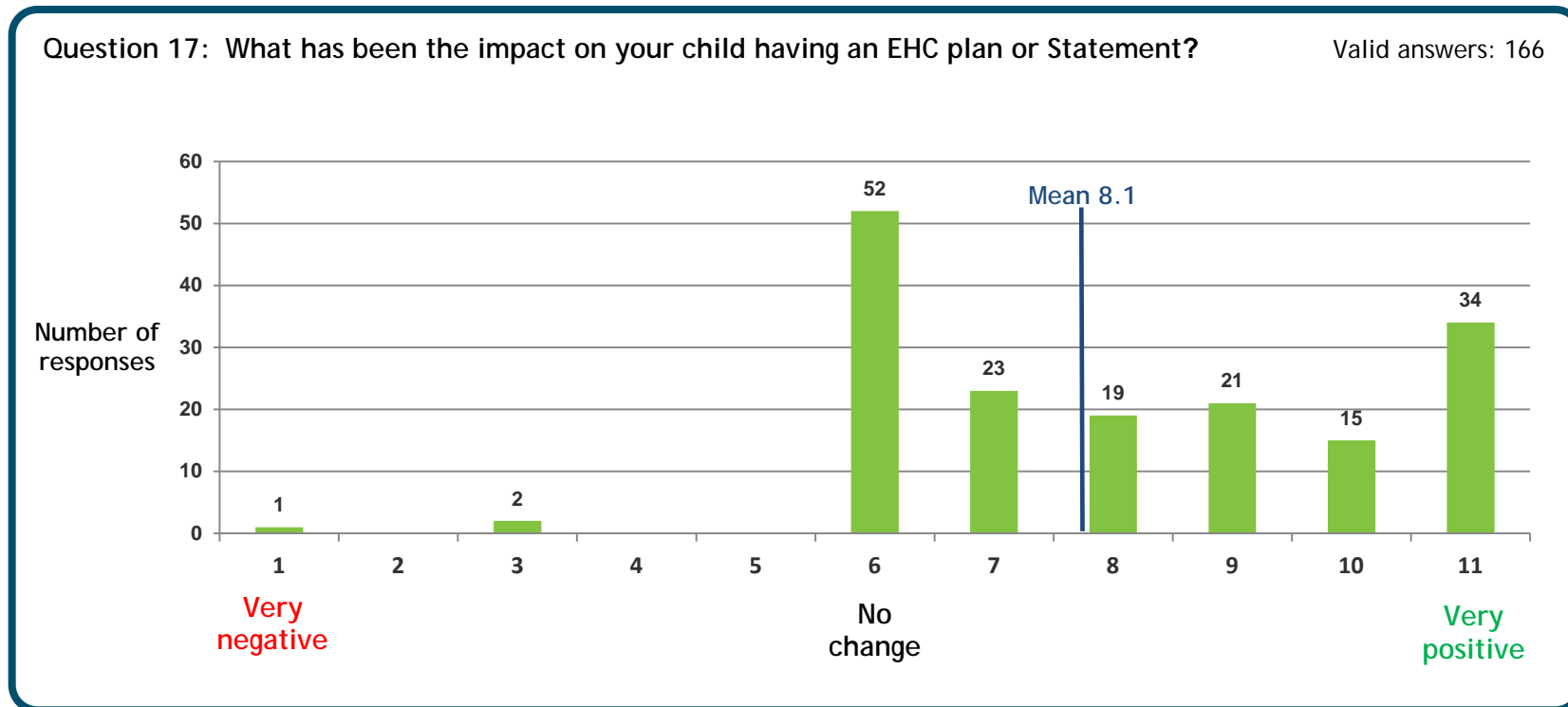
"Too much on paper but no actual working plan."

Figure 17: Parent/carer themed comments about the downsides of the EHC plans or Statements



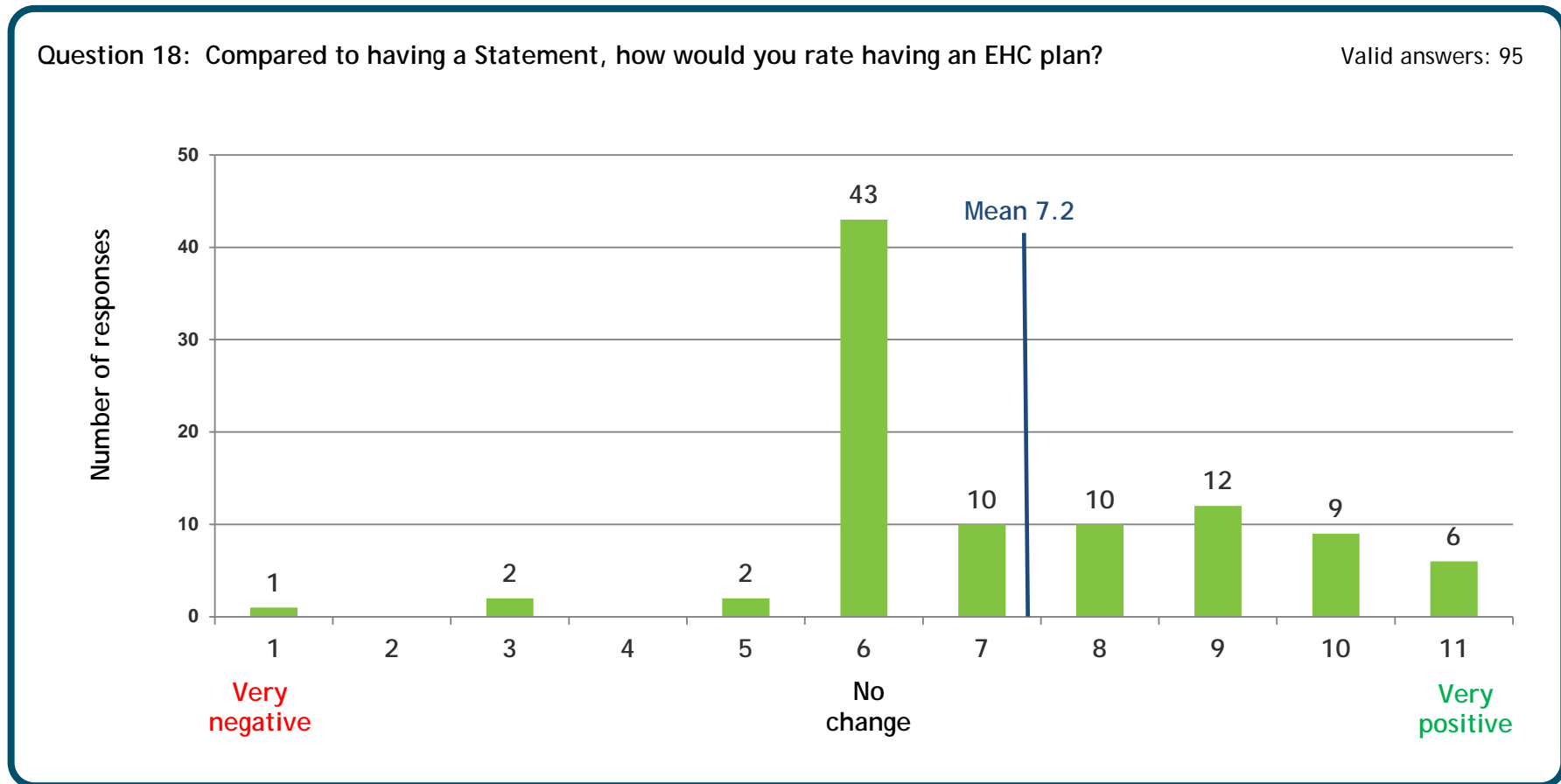
We asked people to rate the impact that an EHC plan or Statement has had for their child (figure 18 below). Two thirds said their EHC plan or Statement had a positive impact (7–11 on the scale), and only three respondents stated that the EHC plans or Statements had a negative impact on their child. Nearly a third of respondents (52 out of 166) said that they had seen no difference in their child since having the EHC plan or Statement.

Figure 18: Parent/carer rating of the impact on their child of an EHC plan or Statement



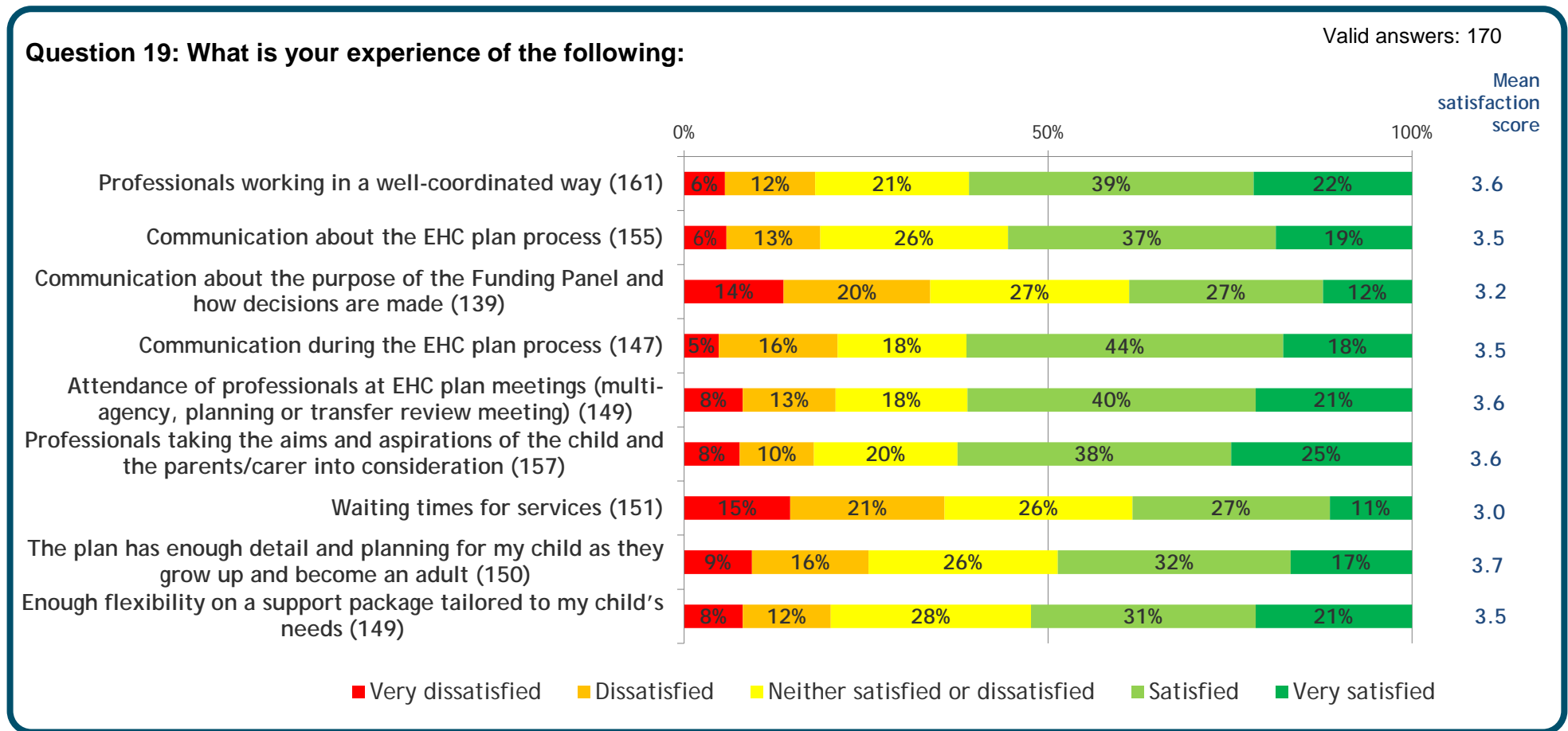
Almost half of respondents (47 out of 95) said they viewed an EHC plan more positively than a Statement (7–11 on the scale), with 43 out of 95 seeing no change between their EHC plan and previous Statement (figure 19). Five respondents view their EHC plans less favourably than their Statements.

Figure 19: Parent/carer rating of having an EHC plan, compared to a Statement



Our focus groups allowed us to identify some themes relating to the EHC plans which we then asked about in this question. Figure 20 below shows a wide distribution of satisfaction, with parents and carers overall more satisfied than dissatisfied. From the mean satisfaction scores in blue (1 refers to very dissatisfied, up to 5 being very satisfied) the areas that parents/carers were most satisfied with are the planning in the EHC plan, professionals taking their child’s aspirations into account, attendance of professionals at meetings and the coordination of services. The two lowest satisfaction figures are waiting times, and communication about the funding panel and how decisions are made.

Figure 20: Parent/carer satisfaction scores by specific area of the EHC plan process



We asked parents/carers what service improvements they felt would help their child. As you can see in figure 21 their responses were collated into 24 themes, where at least two respondents shared a similar answer. The category 'other' represents comments with different themes which could not be grouped. The third most common theme was about how pleased people were with the service. If we exclude this answer, the top five improvements parents and carers wanted to see were:

- 1. Better communication between parents/carers and providers, and among providers**
Comments were most commonly about better communication between parents/carers and providers, then better communication between providers, followed by more transparency from providers to parents/carers:

"Just more communication between parent and services."

"It was stressful to have to be constantly chasing and bothering people."

"Much more transparency from professionals/departments involved in the whole process."

"There's always this communications through departments which is a problem. Reception staff do not provide appropriate advice/ignore your call e.g. do not pass on information. This delays things."

"It would be good to have one person to contact who would oversee the implementation of the EHCP."

- 2. Better coordination of EHC and review meetings**
Most of the suggestions here were about better attendance at EHC planning meetings:

"Ensure staff attend meetings."

"Council professionals to attend review meetings at school to ensure Statement criteria is being met by the school."

- 3. Listen more to the views of parents and carers**

"More input from parental views."

"Parents views to be taken seriously and considered appropriately and not be swayed by the views of one individual professional."

- 4. Better information sharing of what services are available**

Most of these comments were general in nature, with half being more specific regarding information related to support for preparing for adulthood:

"No ideas about what services are available."

"Parents need to be informed about other help and support available for them, such as financial, social and psychological support from other providers."

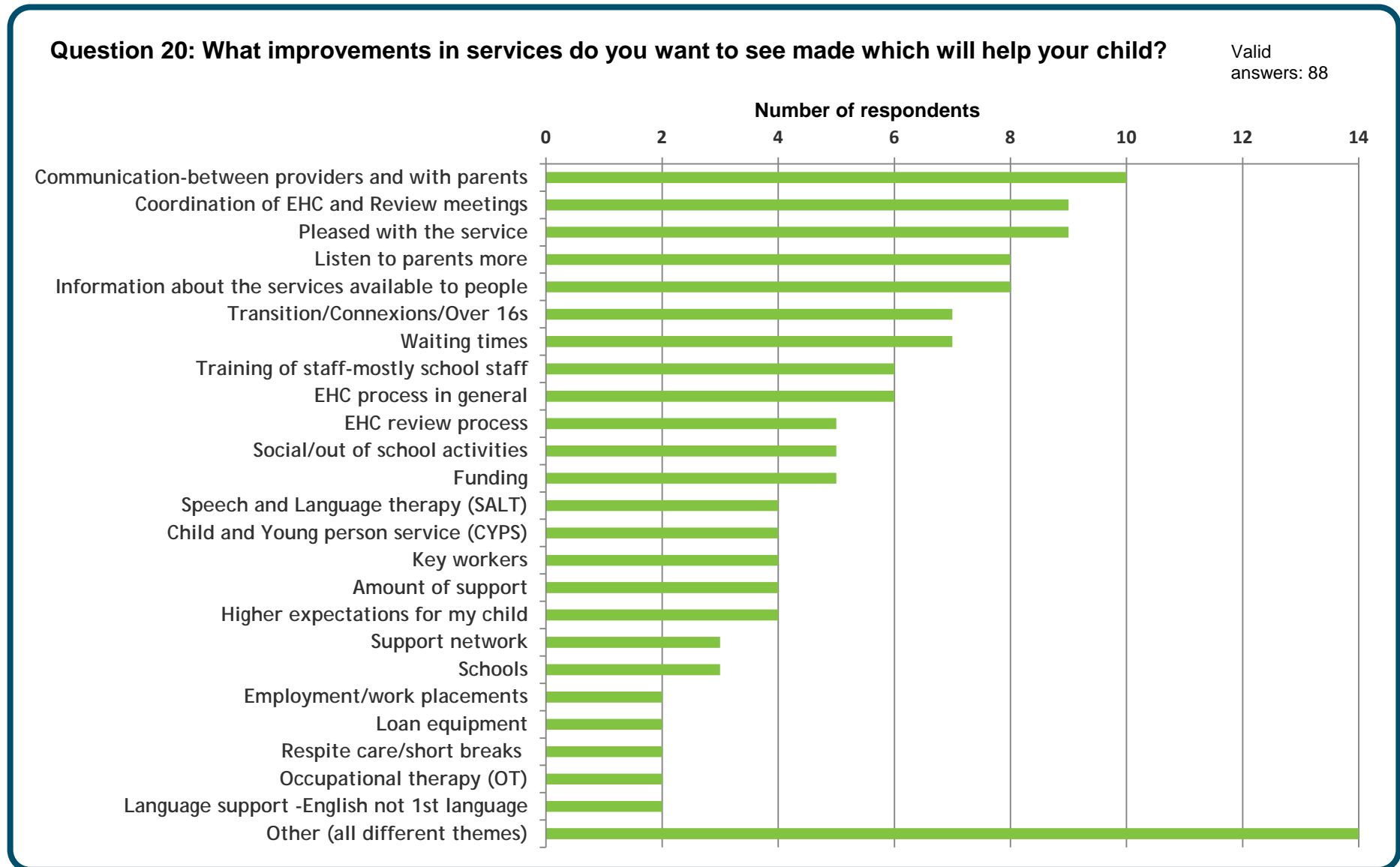
- 5. Improvements for preparing for adulthood**

The suggestions here were about earlier and better planning for preparing for adulthood, as well as the continuity of services through this transition:

"Transitions should be better catered for."

"Focus on real transition planning – with adult services being involved before the age of 18."

Figure 21: Parent/carer themed comments about improvements they want to see



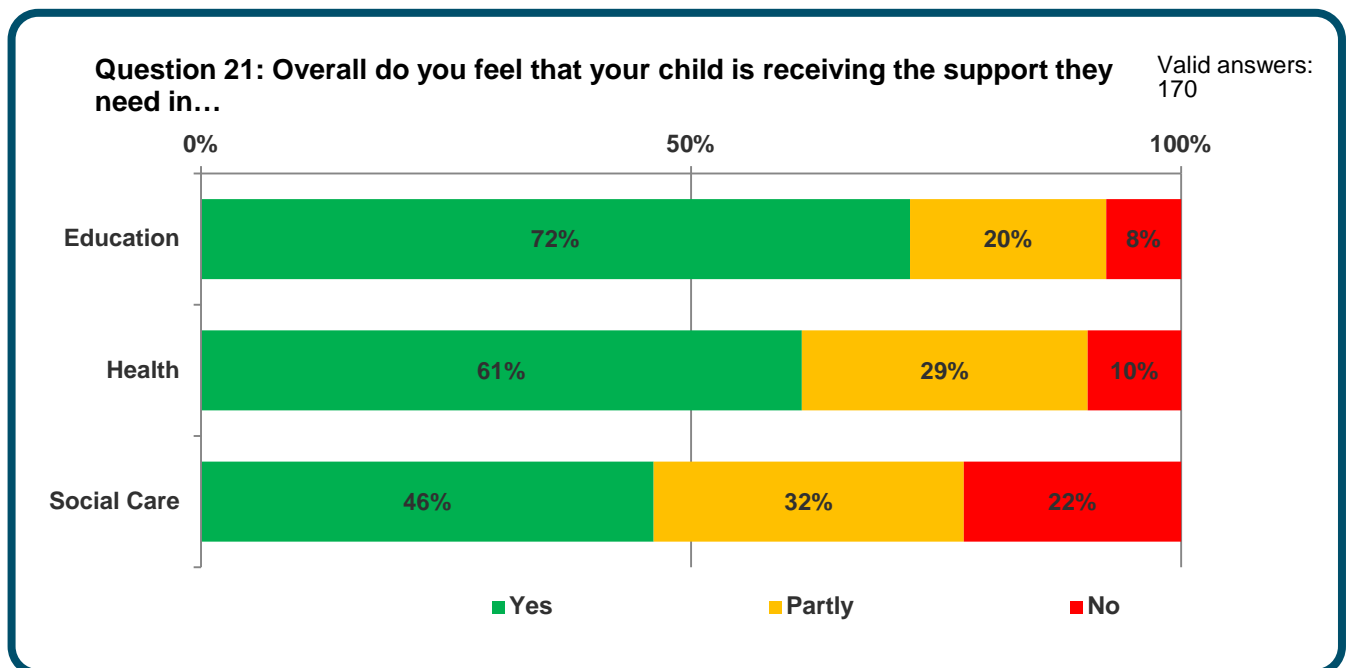
We asked parents and carers if their child was receiving the support they needed in education, health and social care overall.

As you can see in figure 22, parents and carers are most positive about education, followed by health and then social care.

Most parents and carers said 'yes' or partly' to education and health (90% or more), which reduced to 78% for social care. Less than half of respondents answered 'yes' for social care.



Figure 22: Parent/carer overall satisfaction with education, health and social care services



3.2 Questionnaire for 16–25 year olds

3.2.1 General information

We received 51 valid responses to the young people’s questionnaire, which equates to 13% of the 383 young people with Statements or EHC plans in Newcastle. We received more responses from 16–18 year olds than 19–25 year olds (figure 23). Over four fifths of respondents had an EHC plan (figure 24), and so our sample had an over-representation of young people on Statements, as over 90% had EHC plans at the time the survey took place.

Figure 23: Young people’s ages

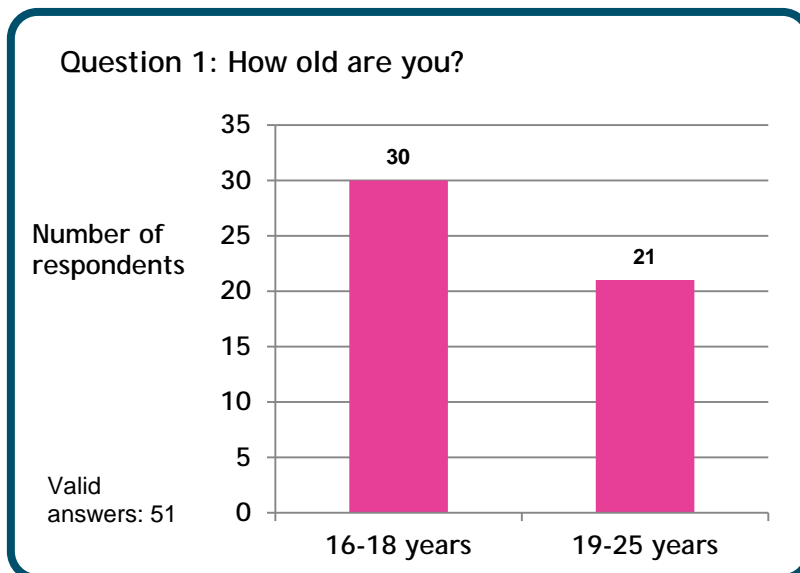
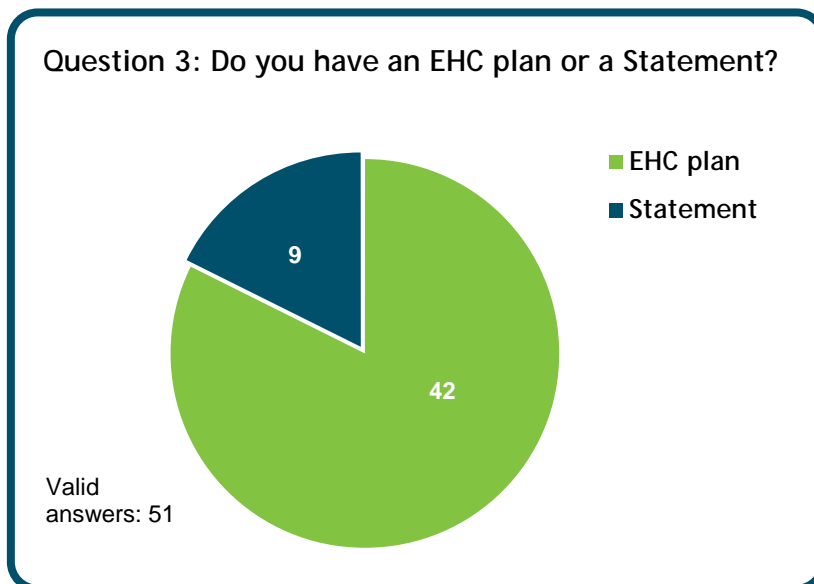


Figure 24: Proportion of young people with an EHC plan



3.2.2 EHC plan preparation

Figure 25 shows that almost three quarters of young people said they were involved in putting their EHC plan or Statement together. In Figure 26 you can see that the majority of respondents agreed or strongly agreed that they were listened to when they made their Statement or EHC plan.

Figure 25: Young people’s involvement in their EHC plan or Statement

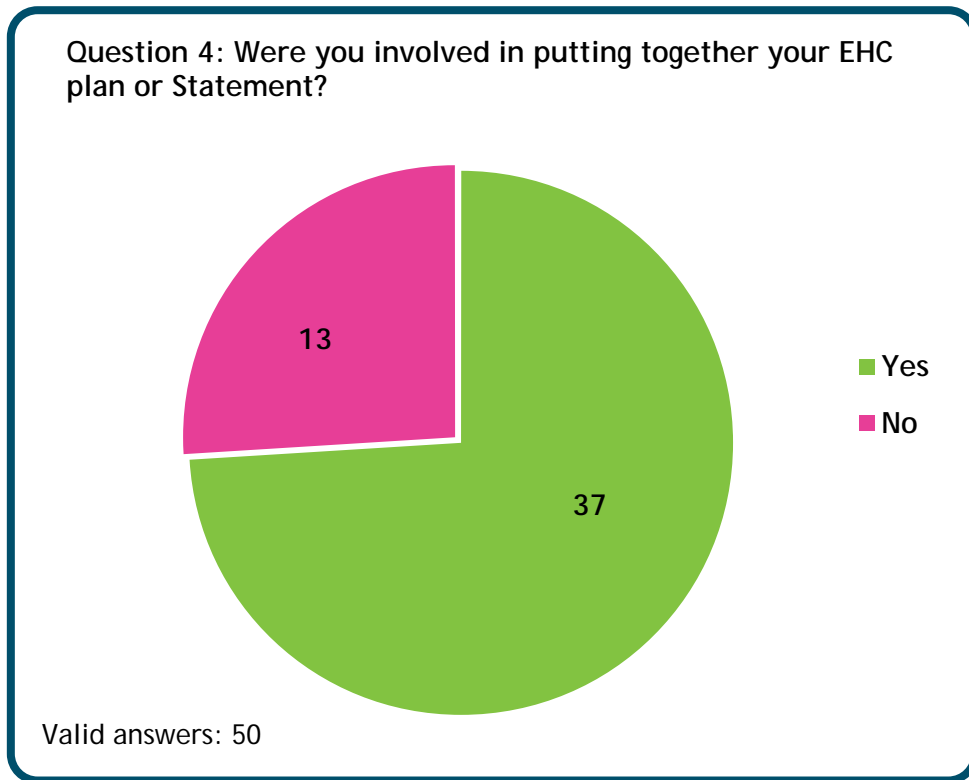
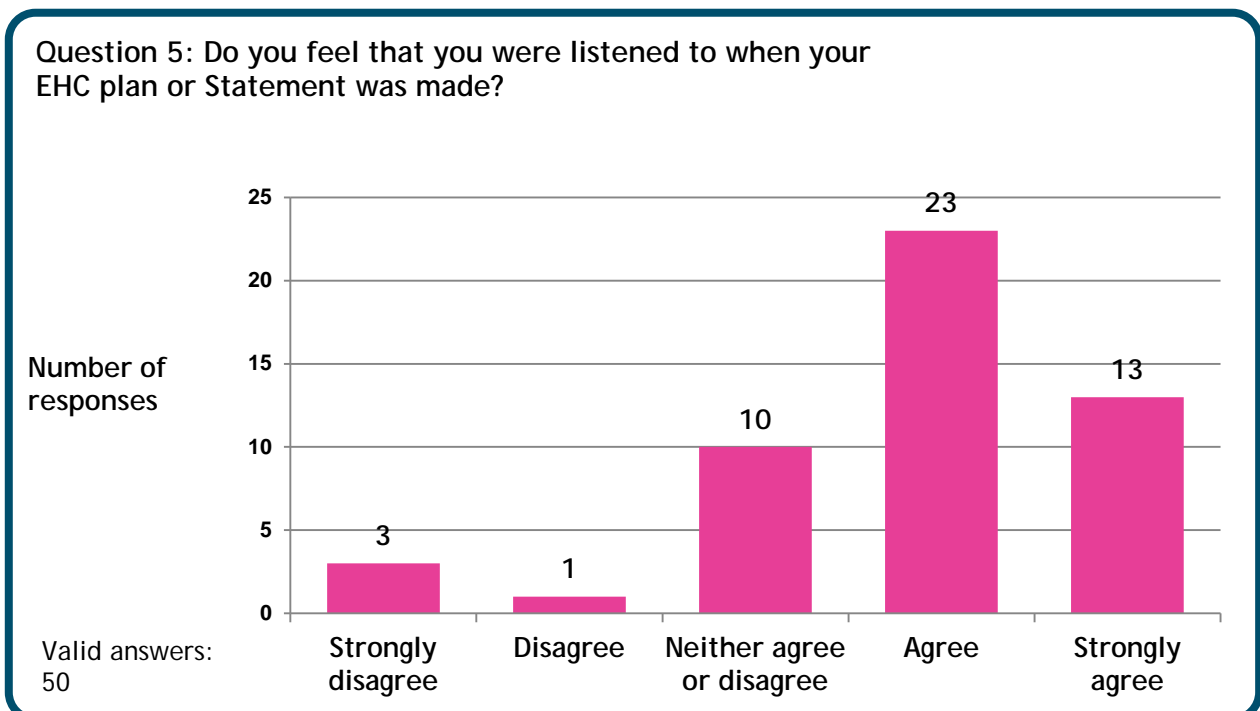


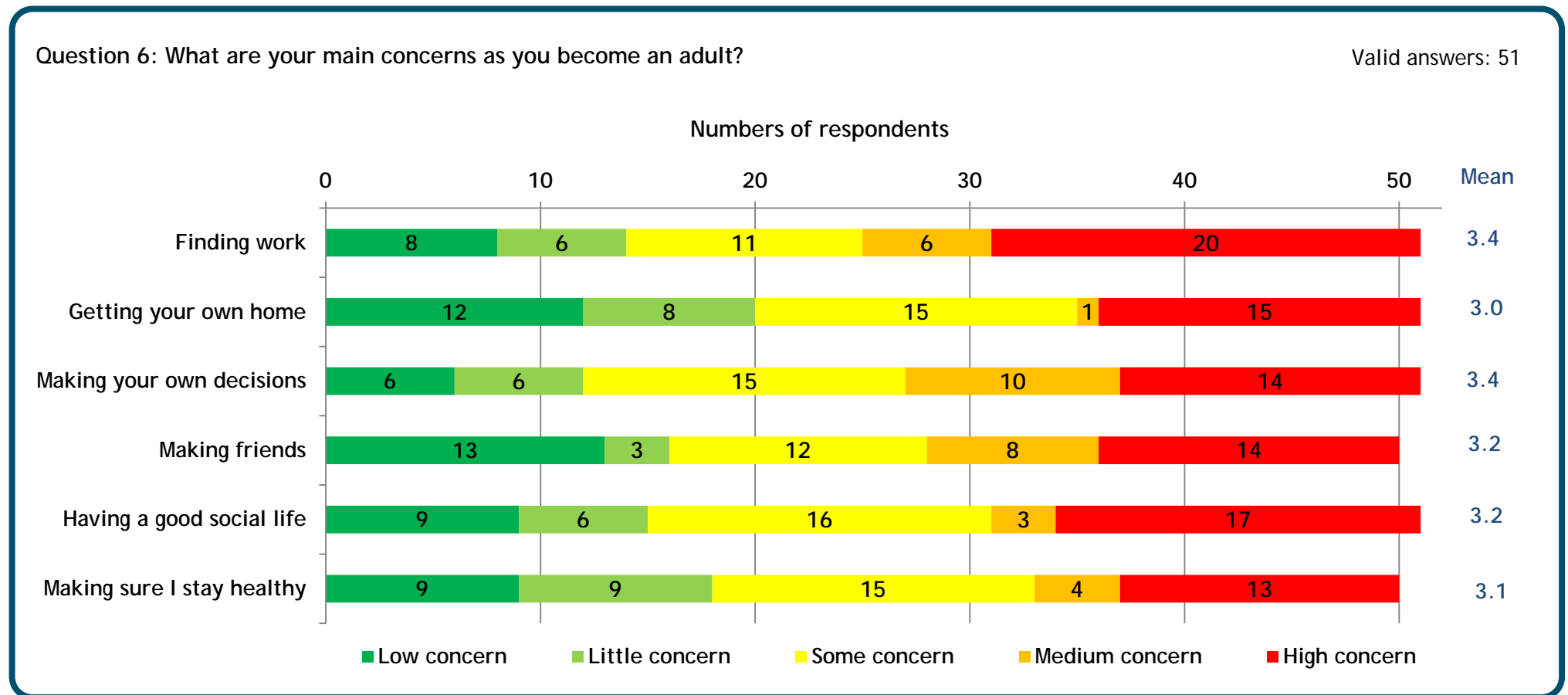
Figure 26: Young people’s views on whether they were listened to



3.2.3 Preparing for adulthood

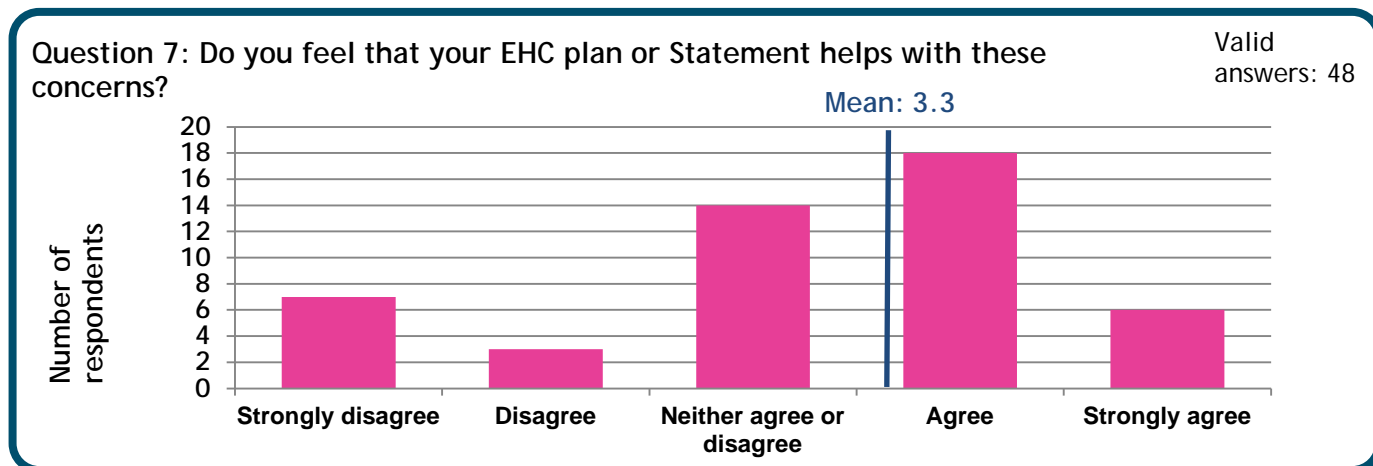
There were a range of concerns from young people about preparing for adulthood. As figure 27 below shows, the two issues which respondents were noticeably more concerned about were finding employment and making their own decisions. Getting their own home was their least concern. On the right of the graph below, the mean satisfaction scores are shown in blue (with 1 being low concern, up to 5 being high concern).

Figure 27: Young people's main concerns as they become an adult



We asked if young people felt that their EHC plan or Statement helped to address their concerns in becoming an adult (Figure 28). Half (24 out of 48) of respondents agreed or strongly agreed their EHC plan or Statement helped with their concerns. This is a much more positive response compared with parents and carers.

Figure 28: Young people’s views on whether the EHC plan or Statement is helping with their concerns in figure 27



3.2.4 Support needs

Almost half of respondents (23 out of 50) said they needed extra help (figure 29). We asked an open question to find out what extra support people would like (figure 30). The most common answer was learning more life skills. A range of specific skills were mentioned including: social skills; money management; running a house; cooking; personal hygiene; and workplace skills.

“Would like to have more support at work with communication; example being telephone calls, emails, verbal communication.”

“I need independent skills when it comes to travelling and some money skills because I have some problems when it comes to maths.”

The second most requested area of support was at school, followed by support with finding work. The comments made were general in nature and did not make specific suggestions for school or work:

“More support to find a job.”

“Help with getting good grades.”

“I write down ‘no’ and that is correct but one thing that has to be said I think the system the length of time people wait to get the help they really need is very slow, I myself waited about seven months from when I was released from hospital until a place was found for me at college. Now that I am in it, it is the best thing in my life. I love the place and all the staff are superb. But I waited too long to get in there.”

Figure 29: Young people's need for extra help

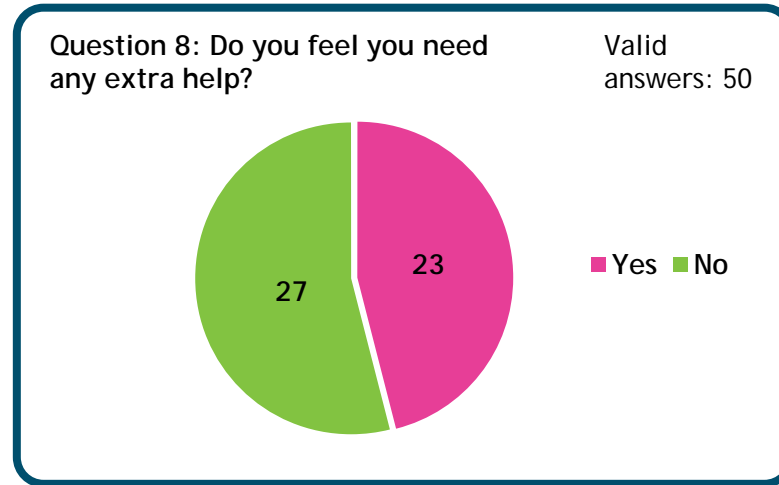


Figure 30: Young people's themed comments about what extra support they want

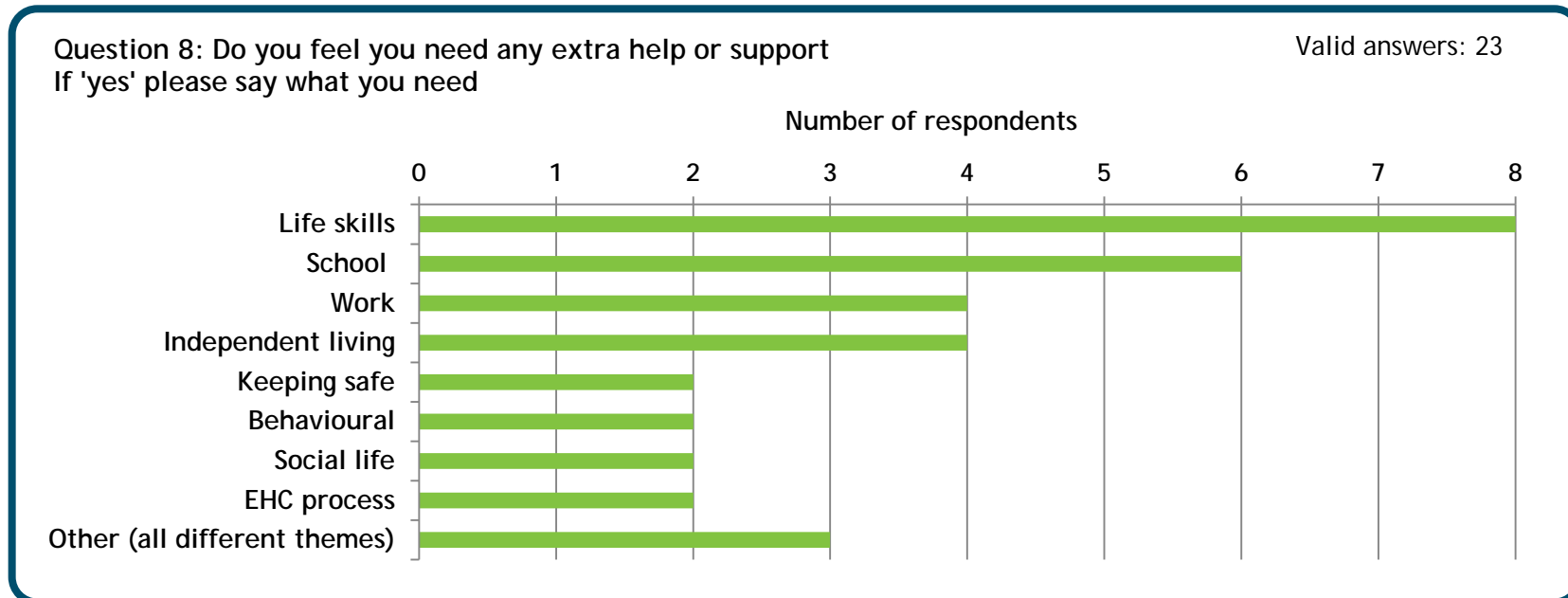
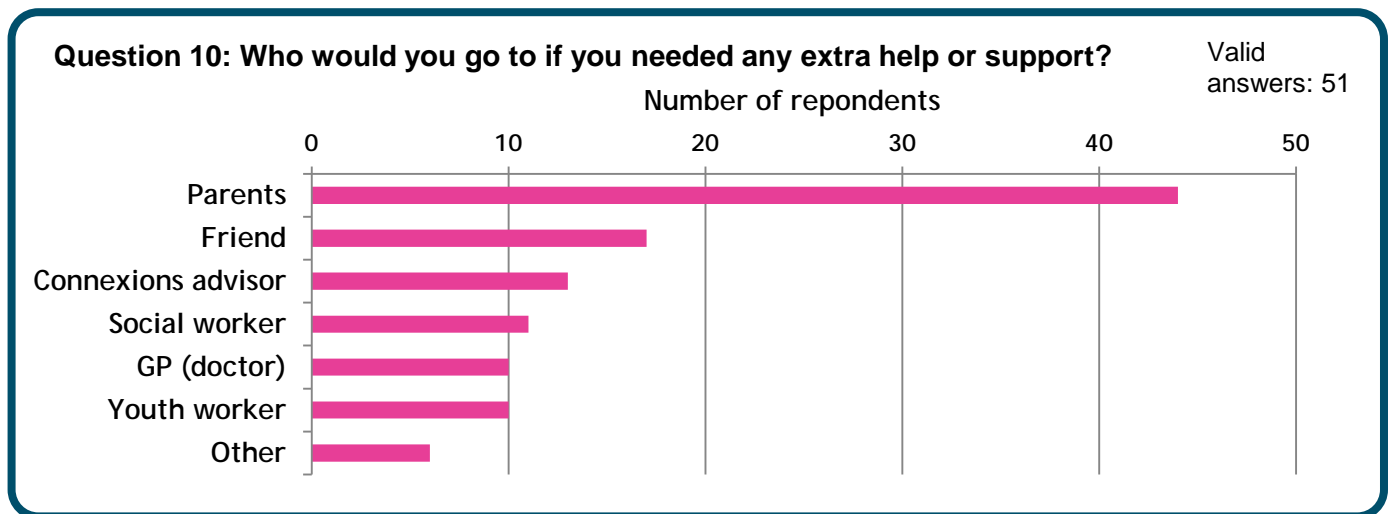


Figure 31 below shows that nearly all young people would go to their parents if they need extra help, with friends being their second choice and the Connexions advisor third.

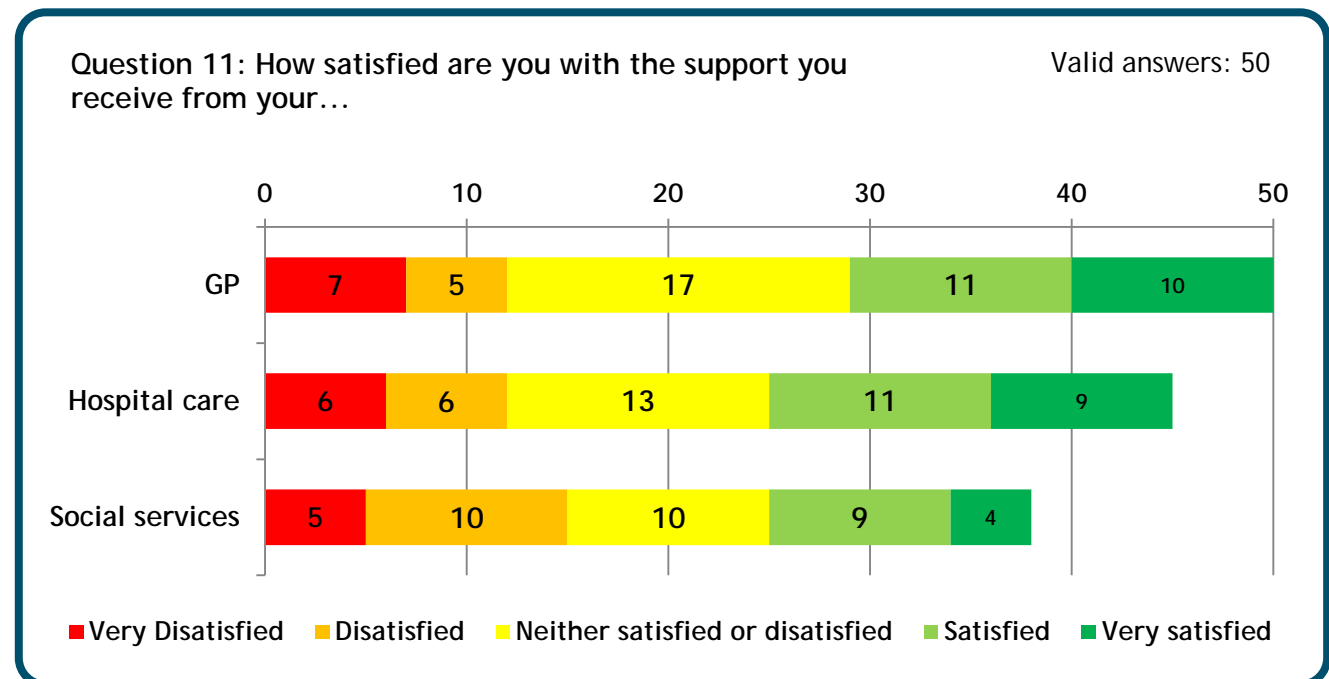
Figure 31: Where young people go if they require additional support



3.2.5 Satisfaction of services

We asked a general question to find out how satisfied young people were with their GP, hospital care and social care services. GP and hospital care services scored higher, with social care receiving a lower score (figure 32). Health services being rated above social care services corresponds with the responses of parents and carers to a similar question.

Figure 32: Young people’s satisfaction of GP, hospital and social care



4 The key themes

From what parents, carers and young people have said in our survey, some clear themes have emerged about their EHC plan and Statements, as well as about specific health and social care services provided in Newcastle.

4.1 Some parents and carers have little knowledge of the SEND reforms

An unexpected finding was the number of parents and carers who had limited knowledge of what the SEND reforms are and what this means for them. A number of parents and carers could not complete the questionnaire, or required support, because they did not know if their child had an EHC plan or Statement. This was a stark illustration of a gap in knowledge about the SEND reforms and missed opportunities for some to be more involved in their child's support and future planning.

4.2 EHC plans are appreciated and an improvement on Statements

EHC plans were appreciated by parents and carers, with positive responses overall.

- When parents and carers were asked for three key words to describe their general experience of the EHC plan or Statement the most common responses were 'good', 'helpful', 'supportive' and 'informative'
- When parents and carers were asked about the downsides of their EHC plan the most common response by a significant margin was 'none'
- 90 out of 95 parents and carers rated the EHC plan as 'the same or more positively' compared to their experiences of a Statement; 47 out of 90 said it was more positive than a Statement, but nearly half (43 out of 90) rated them the same
- Parents and carers stated that the positive aspects of an EHC plan or Statement were: their child received the right support; attending the right school; there was a sense of direction for their development; and that services were well-coordinated

4.3 Producing and moving to an EHC plan has been a positive experience, but communication is an issue

The process of producing an EHC plan, either transferring from a Statement or developing a new EHC plan was a mostly a positive experience for parents and carers; 87–92% of parents/carers said 'yes' or 'partly' to the following areas:

- The aims of the EHC plan were explained
- The process of assessing, planning, drafting and finalising the EHC plan was explained
- Their views were taken into account
- Their child had the opportunity to fill in section A of the EHC plan
- They were informed that they needed to agree the plan before it was finalised
- They attended a review or transfer meeting

Nearly three quarters of the young people said they were involved in preparing their EHC plan, with very positive satisfaction scores about being listened to during the process.

However, many parents and carers did not understand the role of the SEN Case Worker nor had good communication with them. Moreover, parents and carers said that improvements in communication with SEN Case Workers and providers, and more information about the EHC plan process, were the most important areas to improve in preparing the EHC plan. Almost half (48%) of respondents had not been explained the role of the Independent Support Worker.

4.4 The EHC plan document is liked, but goal-setting can be improved

Overall, the format and content of the EHC plan document was well-supported by parents and carers; 78% of respondents said they found the plan easy to understand, rising to 96% when including those who said 'partly'. Over 90% of respondents said 'yes' or 'partly' to the EHC plan providing: enough detail about their child's aspirations, an accurate picture of their support needs and sufficient planning for the child's short, medium and long-term goals.

However goal-setting was the least supported area, with fewer than two thirds (63%) saying 'yes' and 28% of respondents answering 'partly' to sufficient planning of short, medium and long-term goals. Parents and carers comments were most commonly about the need for improvements in goal-setting, in particular about setting specific long-term goals to help prepare for adulthood.

4.5 Satisfaction scores were overall positive but certain health and social care services need improvement

Over half of respondents were 'satisfied' or 'very satisfied' with almost all SEND-related services. Parents and carers rated school services the highest, with 72% saying they received all the support they needed, rising to 92% when including those who answered 'partly'. Next highest rated were health services, and social care services came last with less than half (46%) saying 'yes' to the same question. For young people, social care services were similarly rated behind healthcare services. When parents and carers were asked about specific health and social care services, health services generally scored higher, with hospital services coming top, Social Work second and GP services third.

The three lowest performing services were the 'Get Connected' service, the respite/short break services provided by Newcastle City Council, and the children and young people's services for mental health (CYPS) provided by Northumberland, Tyne and Wear NHS Foundation Trust.

The service which received the most comments from parents and carers was the speech and language therapy service (SALT). The SALT satisfaction score was average and judging by the comments appeared to be a highly valued service by parents and carers. However, parents and carers wanted more SALT services for their child, either as more intensive support (more therapy each month) or for a longer duration than had been offered. Two respondents said they could not access SALT services while their child was at a mainstream school, but were able to when their child was transferred to a special school. Although this was only mentioned by two people it deserves further investigation.

4.6 People are very concerned about adulthood, and don't feel the EHC plan prepares them enough, wanting support to find employment and learn life skills

Parents and carers were very concerned for their children as they become adults, with 58–65% choosing the highest category of concern for questions about their child finding employment, living independently, being involved in the community and transferring to adult services. It is the only question in the survey where the majority of answers were in the most extreme category available. The mean levels of concern for each of the four categories were similar (between 4.0–4.3). Interestingly, for young people the mean level of concern was significantly lower (between 2.9–3.4). For young people, finding work and making their own decisions were their biggest concerns.

Parents and carers said that overall the EHC plan did not sufficiently address these concerns, with more people disagreeing than agreeing, when asked if the EHC plan was addressing their concerns for adulthood. Only 22–26% said they 'agree' or 'strongly agree'

that the EHC plan addressed those same four areas of concern. Young people were more positive about the EHC addressing their concerns, with the mean figure being 3.1 out of 5. Nearly half of young people (23 out of 50) said they wanted extra support or help.

Parents, carers and young people mostly wanted support to gain employment and training in life skills, both being in their top three answers. It is clear from many open questions, as well as the focus group discussions, that for many finding employment is their main aspiration, as it enables many other aspirations to be achieved. Young people requested life skills training more than any other. Parents, carers and young people identified a range of life skills that they wanted help with.

4.7 A quarter of parents and carers say that not everything in their EHC plan or Statement has been provided

A quarter of parents and carers (25%) said that not all the support service agreed in their EHC plan or Statement had been provided. Whilst a small proportion of the EHC plans will be new and therefore not all the services will have been arranged, this is still a high figure. This could be a result of a number of factors, including a gap in service provision, possibly due to long wait times, or a disconnect between the provision and knowledge or expectations of parents and carers. Waiting times and 'lack of action' were the second and third most common themes when asked about the downside of EHC plans or Statements.

4.8 Parents/carers want to see all the relevant providers at the EHC plan/review meeting, and more parents/carers need to attend too

Some parents and carers reported that certain professionals did not attend their EHC plan or review meetings. EHC plan meetings attendance was the second most suggested improvement to help their child. This issue was raised strongly in focus group meetings. Although 84% of parents and carers said they attended their EHC plan meeting, this means a significant number of parents and carers are not attending these important meetings.

4.9 Some parents and carers don't feel sufficiently listened to

Some parents and carers made comments in the questionnaire, as well as in focus groups, that they felt their views were not being sufficiently taken into consideration by professionals in developing the plans. Less than three quarters of parents and carers (73%) said they felt their views had been sufficiently taken into consideration when preparing the EHC plan. 'Listening to parents more' was the fourth most popular suggestion to improve the service. Numerous parents expressed that although they were not 'experts' in a specific condition or therapy, they were the 'experts' when it came to their child – and some felt their expertise was not sufficiently listened to and utilised in meetings. It was raised that a child's behaviour outside of the structured environment of school can be very different, and should form part of the planning process.

4.10 Some parents and carers feel they are waiting too long for services

For some parents and carers, there was frustration with the waiting time to access certain services (only 38% were satisfied or very satisfied with waiting times). Waiting times received the lowest satisfaction score when people were asked about EHC known challenges (question 19). Waiting times was the second most common answer when parents and carers were asked about the downsides to an EHC plan or Statement (the top answer was 'none').

5 Recommendations

To respond to the issues raised during this research, we make the following recommendations, categorised in relation to the four main SEND reform principles:

Service users to participate as fully as possible in decision-making

Recommendation 1: Service users need a single point of contact

A. Two of the key principles underpinning the SEND code of practice¹⁰ are that:

1) parents/carers and young people's views must be heard so they can participate as fully as possible in decisions affecting them 2) they are given the information and support to enable that participation in decision-making. To achieve these principles, parents/carers and young people must have effective communication with providers and know who to contact for information and support. The communication challenges expressed in this survey, and the potential benefit it will offer service users, make a strong argument for Newcastle City Council to implement a single point of contact model for parents, carers and young people in accordance with 2.21 of the SEND code of practice 2014:

2.21: Local authorities should adopt a key working approach, which provides children, young people and parents with a single point of contact to help ensure the holistic provision and co-ordination of services and support.

A single point of contact will bring many benefits including:

- Rapport-building between parents/carers and providers
- Better exchange of information between parents/carers and providers
- Simplification for parents/carers within a complex system which many parents/carers simply don't understand
- A better understanding of what services are available to parents/carers
- Better alignment of expectations between providers and parents/carers
- Potentially less stress and anxiety for parents/carers
- More parent/carer views being heard
- A better adapted plan which will ultimately lead to better outcomes

A number of positions could potentially act as the single point of contact: SEN Case Worker/EHC Plan Coordinator, the school SENCo, SEND Information Advice and Support Service (SENDIASS) or Independent Support Workers. This single point of contact can conduct their usual role and signpost people to the right service when it is outside their scope of work. Whichever position is allocated the single point of contact role, they will need to be well informed about who provides what, and will need sufficient time and resources to enable appropriate communication with parents/carers and young people.

B. That providers continue to seek ways to reduce the requirement for parents/carers to repeat information, in accordance with the 'tell us once' approach of the SEND code of practice:

9.33: As far as possible, there should be a 'tell us once' approach to sharing information during the assessment and planning process so that families and young people do not have to repeat the same information to different agencies, or different practitioners and services within each agency.

¹⁰ SEND code of practice: 0 to 25 years (2014) Department for Education and Department of Health
<http://tinyurl.com/omv3tpc>

Recommendation 2: All relevant stakeholders (including parents and carers) must attend EHC meetings/review meetings

Multi-agency coordination meetings with parents and carers are a fundamental aspect of the SEND reforms and of vital importance for the child's development.

- A. That every effort is made to find ways to improve attendance at EHC plan and review meetings.
- B. That an attendance record is taken at EHC plan or review meetings, and reported to the SEND programme board, so that evidence is available to help hold professionals and providers to account.
- C. That if attendance in person isn't possible, to mitigate this we recommend that new ways are found to ensure that their service is represented in the EHC meetings by someone, and the latest information and reports are available to that representative.
- D. That a SEN support role (ideally the single point of contact) encourages and supports parental attendance by removing barriers to attendance where possible, and makes every effort to reschedule a date for the meeting if parents and carers cannot attend the proposed date.

Recommendation 3: Give equal value to the views of service users

To ensure that the views of parents/carers and young people are heard in accordance with principle 1.1 of the SEND code of practice. Every effort should be made to ensure the views and suggestions of parents, carers and young people are sufficiently heard in the process of planning and reviewing support plans for young people with SEND. This is following 9.24 of the SEND code of practice which states:

9.24: Local authorities should support and encourage the involvement of children, young people and parents or carers by:

- providing them with access to the relevant information in accessible formats
- giving them time to prepare for discussions and meetings, and
- dedicating time in discussions and meetings to hear their views

We recognise that this empowerment of parents/carers and young people is a continuous process and a cultural shift from the previous system. This could be addressed in a number of ways including: more opportunity for parents/carers to write their views and suggestions in the EHC plan document, to ensure attendees of EHC/review meetings are reminded to make the meeting accessible to parents/carers and the importance of their views being heard, to improve communication and information through implementing a single point of contact model as per the first recommendation.

Providing information and support to service users to enable them to participate in decision-making

Recommendation 4: The principles and aims of the reforms need to be better promoted to parents/carers and young people

- A. To put more local resources into promoting the principles and aims of SEND reforms in order to address the present gap in knowledge. We are aware of the national work provided by Contact A Family. We are also aware that information, advice and support available to disabled families or parents, carers and disabled children/young people in Newcastle will reduce in 2017 due to resource constraints at the Northeast Special Needs Network.

- B. Ensure that when the EHC plan process is initiated, that someone (the SEN Case Worker, EHC Plan Coordinator, SENCo or other) is allocated the role to have a face-to-face discussion with parents/carers and young people about the aims of the reforms and EHC plan process, and the importance of their views within it.
- C. To provide more comprehensive and accessible information on the Local Offer website. Newcastle City Council should consider a range of ways to communicate such as using video etc. This information should explain the reforms' aims, and the main principles underpinning the reforms relating to the services users' voice and their role in decision-making.
- D. To utilise social media as a valuable tool to improve access to information.

It should be noted that Contact A Family, as well as many other local and national providers, have tools already prepared that can be utilised to help with this information sharing, and are willing to share them.

Recommendation 5: To increase awareness of 'who does what' and certain EHC processes

- A. All opportunities are taken to clarify and promote the roles and responsibilities of SEN case workers, EHCP coordinator, Independent Support Workers at Skills for People, SENDIASS and school SENCos (or the equivalent at special schools) so that parents, carers and young people are clear and empowered about who is responsible for which aspect of their support. Better information-sharing relating to these services not only benefits young people with EHC plans, but also the service providers involved in their support and care.
- B. In addition to recommendation 4C, to improve the information available on the Local Offer website, related to roles and responsibilities and including infographics to help direct parents and carers in their most common needs. This work could be carried out by the SEND Information, Advice and Support Network. Clear information on the scope of services will be of assistance to providers and service users alike.

The SEND code of practice 4.59 states:

4.59: The Local Offer **must** provide information for children, parents and young people about where to get information and advice.

- C. That every parent and carer who begins the EHC plan process is advised of the impartial support they can receive from an Independent Support Worker from principally Skills for People or SENDIASS. This is in accordance with 9.29 of the SEND code of practice which states:

9.29: Local authorities **must** provide all parents, children and young people with impartial information, advice and support in relation to SEN to enable them to take part effectively in the assessment and planning process. This will include the EHC needs assessment process, EHC plans and Personal Budgets (including the take-up and ongoing management of direct payments). This should include information on key working and independent supporters as appropriate.

- D. That parents and carers are better informed about the EHC process, the funding panel and how decisions are made, as part of the initial briefing related to the EHC plan process. This is in accordance with SEND code of practice 9.29 above.

Preparing effectively for adulthood

Recommendation 6: Improve the preparation for adulthood

We recognise that the Connexions team and others are already working to improve the preparation for adulthood offer. This work includes the innovative piloting of a new EHC plan format specifically designed to help plan for adulthood, among other initiatives. However, the preparation for adulthood is one of the three fundamental principles of the SEND reforms and one that service users must have full confidence in. SEND code of practice, 1.1, states:

1.1: the need to support the child or young person, and the child's parents, in order to facilitate the development of the child or young person and to help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood

- A. That the preparation for adulthood is selected as a priority improvement theme.
- B. That providers work with parents and carers to develop the best possible long-term planning, which is aspirational and uses SMART outcome goals, in accordance with 9.61 of the SEND code of practice:

9.61: EHC plans **must** specify the outcomes sought for the child or young person. Outcomes in EHC plans should be SMART (specific, measurable, achievable, realistic, and time-bound).

SMARTer goals will better deliver better outcomes, and address the concerns of parents and carers about vague goals which are open to interpretation and hinder holding specific providers to account.

- C. Recognition that the four categories for preparing for adulthood (finding employment, living independently, being involved in the community and transferring to adult health services) are all similarly concerning for parents and carers. However, employment is seen as the biggest aspiration for many, as finding work also fulfils other aspirations about independence, community involvement and a sense of worth.

Recommendation 7: Teach more life skills at school

- A. Newcastle City Council to engage with parents/carers and young people on what life skills they would like included at school, with the aim of incorporating with any common themes which may arise more routinely in schools. In a special school setting these could result in a more structured adaptation or supplementation of the curriculum. This investigation recognises that the aspirations of young people (which for many is to gain employment) is the driver for this work, in line with article 8.37 of the SEND code of practice:

8.37: Education and training should include help for students who need it to develop skills which will prepare them for work, such as communication and social skills, using assistive technology, and independent travel training. It can also include support for students who may want to be self-employed, such as setting up a micro-enterprise.

High quality provision to meet the needs of children and young people with SEND

Recommendation 8: To investigate why a quarter of parents and carers said that what was agreed in their EHC plan or Statement had not been provided

- A. For the SEND programme board to take action to investigate this finding to better understand how much this relates to genuine gaps in service provision or about parent/carer perceptions and expectations.
- B. To take action on these findings once they are better understood.

Recommendation 9: Reduce waiting times for services

We recognise that many services are under strain in the present climate and some waits are unavoidable. However, this survey has given examples of excessive waiting times which are not in accordance with 9.35 of the SEND code of practice, which states:

9.35: Where particular services are assessed as being needed, such as those resulting from statutory social care assessments under the Children Act 1989 or adult social care legislation, their provision should be delivered in line with the relevant statutory guidance and should not be delayed until the EHC plan is complete. For social care, help and support should be given to the child and family as soon as a need is identified and not wait until the completion of an EHC needs assessment.

- A. That every effort is made to ensure that provision is delivered in line with the statutory guidance to initiate services, in order to minimise the negative impact these delays cause to children's development.
- B. To provide 'SMART'¹¹ objectives in the EHC plan with clear and realistic timeframes for service initiation to support clearer expectation-setting for everyone concerned.

Recommendation 10: The findings in this report should be considered as part of the existing improvement plan for mental health services for children and young people services (CYPS)

- A. That Northumberland, Tyne and Wear NHS Foundation Trust (NTW - which runs the CYPS service) and Newcastle and Gateshead CCG (which commissions the service) acknowledge the findings of this survey and feed them into the present service review, to improve the service they offer to SEND service users as a matter of urgency.
- B. That Newcastle and Gateshead CCG and the SEND programme board closely monitor the service delivered by the trust to ensure it provides a quality service for children and young people with SEND. That the SEND programme board provides feedback to NTW and Newcastle and Gateshead CCG regularly to ensure improvements are made.

Recommendation 11: The findings in this report should be considered as part of the existing improvement plan for speech and language therapy services (SALT)

- A. To ensure that children with SEND in mainstream schools have an equitable access to SALT as those at special schools, in line with the Equality Act 2010 and 6.9 of the SEND code of practice:

¹¹ This is a project management acronym to ensure good goals or objective setting. SMART strands for: Specific, Measureable, Agreed upon, Realistic, Time bound

6.9: All schools have duties under the Equality Act 2010 towards individual disabled children and young people. They **must** make reasonable adjustments, including the provision of auxiliary aids and services for disabled children, to prevent them being put at a substantial disadvantage. These duties are anticipatory – they require thought to be given in advance to what disabled children and young people might require and what adjustments might need to be made to prevent that disadvantage. Schools also have wider duties to prevent discrimination, to promote equality of opportunity and to foster good relations.

We recommend further investigation into what potential barriers may exist at mainstream schools that could hinder access to SALT services, or any other support services for children and young people with SEND.

- B. As parents and carers highly value SALT service, we recommend that all possible resources be allocated to SEND children to maximise their potential for effective communication, and the enormous life-benefits this has for them.
- C. That the 2016 Newcastle and Gateshead CCG and Newcastle City Council review of SALT service is published and implemented, and that these recommendations related to children and young people with SEND are incorporated into the improvement plan, if not already included in it.
- D. That the recommendations from the recent survey report of the Royal College of Speech and Language Therapists related to the SEND reforms are considered alongside the local feedback from service users in this research.

Recommendation 12: Clarify and publicise for whom the Get Connected service is most suited to, and incorporate a performance indicator to routinely gather service user feedback

We recognise the challenges of providing social activities to satisfy everyone's individual needs and interests. We also recognise the huge efforts Newcastle City Council is making to improve social inclusion of young people with SEND and the changes it is making in 2017 to improve service provision.

- A. That the council acknowledges these findings, and seeks solutions on how to improve the level of service user satisfaction with the Get Connected service.
- B. To publicise their services more and to clarify with service users and support organisations, who the services are best suited to, whilst recognising the importance of being inclusive.
- C. To introduce a new performance indicator to routinely incorporate service user feedback to help with ongoing monitoring, evaluation and improvement of the service (procurement in spring 2017).

We are confident that with the strong and representative response from parents, carers and young people that these recommendations reflect the improvements that service users want to see with SEND services in Newcastle. We sincerely hope that providers and commissioners profit from these valuable findings and adopt, where possible, these recommendations.

6 Acknowledgements

This research was only made possible by the close collaborative working and commitment of many organisations. We would like to take this opportunity to profoundly thank the following individuals and organisations for their support to enable us to conduct this research:

Parents, carers and young people

Who gave their precious time to fill in the questionnaire and to attend focus groups.

Voluntary and community organisations

Contact a Family – Jacqui Adams, North East & Cumbria Manager; Sarah Lewis, Regional Information Officer; Helen Bailey, North East Parent SEND Advisor
Newcastle SEND Parent Carer Forum – especially Sharon Hand, Parent Development Officer
Northeast Special Needs Network – Siobhan O’Neil, Chief Executive plus case worker team
Pass It On Parents – Lucy Liu; Shelagh Middleton; Jilian Allan
Skills for People – Nick Ball, Deputy Chief Executive; Kathy Steele, Independent Support

Newcastle City Council

Alison Priestley, Service Manager, Early Help and Family Support
Ann Banks, Project Manager
Ann Graham, Connexions LLDD Coordinator
Dean Jackson, Lead Assistant Director, Education and Skills and Chair of the SEND programme board
Lara Lillico, Educational Psychology Service Manager
Jill Tough, SEN consultant
Judith Lane, SEND Information Advice and Support Service
Luke Connor, Admissions and Information Specialist
Martin Donkin, Social Work Senior Practitioner (Personalisation Children with Disabilities)
Paul Connelly, Transitional Worker
Philip Morris, Acting Head of SEN Assessment, Provision and Review Service
Sheila Kingsland, SENCo Coordinator
Sophie Stallworthy, Business Improvement Project Manager

Newcastle and Gateshead Clinical Commissioning Group

Alison Thompson, Patient Experience Lead
David Jones, Clinical Director
Julie Young, Joint Commissioning Manager (Children’s)
Sharon Simpson, Joint Commissioning Manager (Children’s) – predecessor to Julie Young

Newcastle Upon Tyne Hospitals NHS Foundation Trust (NUTH)

Paula Drummond, Consultant Community Paediatrician

Northumberland, Tyne and Wear NHS Foundation Trust (NTW)

Rebecca Campbell, Head of Child Services

NHS

Dominic Slowie, National Learning Difficulties Director

Schools

Benfield School – Maria Irving, Deputy Head teacher
Hadrian School – Chris Rollings, Head Teacher; Marian Stokle, Deputy Head Teacher
Kenton School – Andy Clark, Vice Principal; Alyson Barrett, Assistant Principal
Sir Charles Parsons School – Karen Hamilton, Head Teacher
Thomas Bewick School – Diane Scott, Head Teacher

Others

Roots and Wings – Alan Ramsay
Sportworks – Neil Cameron
Ifte Khan

7 Statements about this report from key SEND stakeholders

Dean Jackson
Lead Assistant Director, Education and Skills
Newcastle City Council



Newcastle City Council is fully committed to the principles of collaborative working and co-production of services with our parents/carers, children and young people. We are keen to listen to the views of our families and to learn and act on the feedback that the survey has produced.

I was delighted when Healthwatch Newcastle announced they were planning this survey and it was sent out with my full support. I was very pleased with the overall conclusion that most of our families are satisfied with the way we have introduced EHC plans. We do accept, however, that there are areas in which we need to improve and, in particular, in how we communicate with our families.

The March meeting of our SEND Management Board, (which includes representatives from parent/carer groups, the voluntary sector and our schools) is devoted to agreeing the improvements we need to make to address the concerns raised by families. Our action plan will be published on our Local Offer and we would welcome any further comments.

Judith Lane
Lead Specialist Newcastle SEND Information, Advice and Support
Service (SENDIASS)
Newcastle City Council



Newcastle Special Educational Needs and Disabilities Information, Advice and Support Service welcomes the Healthwatch survey. This is a valuable piece of work portraying, as it does, the views of so many parents and young people who have gone through statutory processes.

Alongside the acknowledgment that these processes support children and young people in having their needs met, the survey has given an insight into how going through those processes can feel, what parents and young people want to know about the process and the support that is available to them.

I am delighted that the survey has been well received by the SEND Management Board, I know that they will be keen to respond to the concerns that families have raised.

Dr David W Jones
Designated Clinical Officer for SEND
Newcastle Gateshead Clinical Commissioning Group



Just over 2 years since the introduction of the SEND reforms in September 2014 this report is a very timely evaluation of how well the ambitious changes set out in the Children and Families Act have been implemented locally from the perspective of young people, and their parents and carers, with Education Health and Care plans. There is much for local services to celebrate, but clear challenges too, and the recommendations contained in this report should serve as a reminder that there is still much to be done, and that the needs of children and young people with SEND should remain an absolute priority for commissioners and providers of services in the local area - Healthwatch Newcastle have produced an excellent report!

Thank you for sending the 'Spotlight on SEND' draft report for review.

The Trust welcome this review and are pleased to see that overall the SEND reforms appear to have made a positive impact on children, young people and families. The Trust are members of the SEND Board and welcome the opportunity to work with partners to further improve the process.

There is just one point to raise in relation to Trust services.

- 1) Access to SALT. SALT in special schools is provided by NTW. Any child in Newcastle requiring SALT outside of special school provision can be referred to Trust services. SALT resource is limited and we welcome your recommendation 11.
 - o That all possible resources are allocated to SALT.
 - o That children who require SALT have access.
 - o That the 2016 review is published.

We look forward to working with the NGCCG on this specific point.

We will continue to work actively as members of the SEND Board to review the report and respond to these findings.

Rebecca Campbell
Service Manager, Children & Young People Community Services
Northumberland, Tyne and Wear NHS Foundation Trust (NTW)

Northumberland, Tyne and Wear 
NHS Foundation Trust

Thank you for sending me the above report which is a very full and comprehensive report and for asking for comments in relation to the findings and recommendations. Please see below comments from NTW

NTW acknowledge that Children & Young People can currently experience a long wait to receive a service and are working very closely with the CCG and other providers to improve this.

NTW Community CYPS have also recently been undergoing a period of transformation and re modelling to address waiting times which will support the services in moving towards all referrals seen and in treatment within 18 weeks from receipt of the referral in line with National waiting times.

The Service is dedicated to improving the experience and outcomes of all the Children, Young People and Families that we work with and support the introduction of a Single Point of access and are committed to working with other agencies to improve the communication and involvement of the YP and families when discussing and agreeing EHC Plans.

NTW have been working closely with the Local Authority and other stakeholders to agree systems and processes to ensure that there is involvement in the EHC Planning when appropriate and to make sure that all transitions from Children to Adult services are planned and co-ordinated in a timely way to meet the needs of the YP and their families.

The findings of this report will be form part of the discussions with Newcastle and Gateshead CCG and the SEND programme board to ensure that the service delivered by the trust provides a quality service for children and young people with SEND.

Andy Clark
Vice Principal, Kenton School

We are delighted that such a comprehensive report has been carried out in an area that is so important for the young people of our city. Whilst we are disappointed at the relatively low number of responses to the questionnaires submitted, we feel that the views expressed mirror the thoughts that we hear on a day to day basis. We are unsurprised that respondents state waiting time and (lack of) co-ordination of services as frustrations, as we feel exactly the same. We would also question the role and effectiveness of the SEN case worker, as they appear to have very little impact on the process, especially when compared to other professionals involved. We would also like to see an increased emphasis on ensuring that supply meets demand in matching the services needed to support young people with identified needs.

Jacqui Adams
Regional North East & Cumbria Manager
Contact a Family North East



Contact a Family North East Office support the recommendations within this report. The report provides a comprehensive picture of parent carer perceptions of how Newcastle City Council are implementing the Special Educational Needs and Disabilities (SEND) reforms and embedding these into current practice. The recommendations within this report give a clear steer as to how Newcastle can build on the work already done and continue to develop services and processes with regards to SEND ensuring that this process is delivered in coproduction with local parent carers, statutory agencies and voluntary organisations.

Siobhan O'Neil
Chief Executive
Northeast Special Needs Network



Northeast Special Needs Network is pleased to endorse this important work from Healthwatch Newcastle which focuses on the experiences of children and young people with SEND. The research is timely and is the first opportunity that parents, carers and children and young people with SEND have had to provide feedback on the effectiveness of the new Education Health and Care Plans. The good response rate reflects the work that went into publicising and supporting as many families as possible to complete the questionnaire. It is also reflective of a strong partnership approach with statutory and community voluntary sector agencies working together to support the research and welcoming the findings. The research provides valuable information and a list of recommendations which can be used by decision makers and commissioners to improve the delivery of services and for individual organisations to improve their practice. This has already started with the SEND Information, Advice and Support Network using the research to further improve the Local Offer through the development of a 'Who's Who' guide and 'Frequently Asked Questions'. This demonstrates the way in which partner organisations are working together to use the feedback from the research to improve service for Disabled families.

Jilian Allan
Family Support Worker,
Pass it On Parents



We at Pass It On Parents really welcome the Healthwatch Newcastle SEND report as we feel it reflects what we are hearing to be families' experience of the EHCP process in Newcastle and highlights some very important issues.

We particularly welcome the recommendations which focus on informing and empowering parents/carers regarding the SEND reforms and the EHCP process. Some families are

confused about the process and their role within it and this can limit their involvement. We feel that schools can play an important role in providing this information, in collaboration with others such as the SENDIASS service and ourselves.

As recommended in the report, a single point of contact for families would be ideal. This would improve communication and allow for individualized support to help families be fully involved and develop an EHCP that best reflects their child's aspirations and needs. We are aware that at present, parents/carers have to initiate contact with the Independent Support Service and wonder if a more proactive process with Independent Support contacting families would be more supportive.

The report highlights that a quarter of parents/carers feel that not everything in their child's EHCP or statement has been provided. We feel this is very significant and certainly reflects the concerns about support that we are hearing from families. We agree that goal setting is key and could be improved. The use of SMART outcomes provides a greater level of transparency and allows families to fully understand what their child should be receiving. This empowers parents/carers as they can then ensure that providers are accountable.

Kathy Steele and Clare Penn-Evans
Independent Support Co-ordinators
Skills for People



We at Independent Support are pleased to give the following comments in response to the Healthwatch Newcastle 'Spotlight on SEND' report. The report highlights significant issues about how parents and carers are informed and empowered throughout the ECHP process. As our Independent Support role is to ensure parents and carers get good information and are at the heart of the process, we very much welcome the recommendations that the report makes.

In particular our experience and feedback received from parents and carers suggests an apparent lack of clear information at the beginning (and throughout the process) about what will happen, what they can expect and who can help. These points are highlighted in the Healthwatch Report. Many parents have reported to us that the information provided by letters and in written format is often confusing, and it is often difficult to pull out the salient information they need.

We continue to believe that SENCO's and schools are the best people to inform parents and carers at an early stage about the SEND Reforms and EHC process. We also recognize the value added role and contribution we could potentially make by offering support and training to SENCO's about good practices when engaging parents/carers in these discussions. In particular we want to engage better with SENCOs and offer workshops, advice and guidance as appropriate. This is something that is also of interest to Contact a Family and we are currently in discussions with them about how we could facilitate this jointly together. We would be happy to pursue discussions with Newcastle Local Authority and Contact a Family to take this forward.

We also agree with the recommendation of the Healthwatch report that there needs to be a single point of contact throughout the process and we would welcome the opportunity to take on this role should parents and carers wish this. It is clear that the coordinating role of SEN Case Workers and pressures they experience doesn't allow for this, but it could well be something we could undertake. Feedback we receive highlights that parents and carers really value the integral role we often fulfill in acting as a named contact person throughout the assessment and planning process. We believe we could also fulfill a valuable

role of liaising across a range of agencies and maintaining a link with the parent or young person throughout the process. We would be keen to pursue further discussion with Newcastle Local Authority about how this could be realized.

On a final note, we want to comment on the significance of the Healthwatch 'Spotlight on SEND Report' and its findings. We believe it to be a good and well written report which reflects the considerable attention and detail that has been given to the process of engaging families through this much needed survey.

We have very much appreciated having the opportunity to be involved and to make a contribution.

Contact details



Healthwatch Newcastle, Broadacre House,
Market Street, Newcastle upon Tyne, NE1 6HQ



0191 338 5720



07551 052 751



info@healthwatchnewcastle.org.uk



www.healthwatchnewcastle.org.uk



@HWNewcastle



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