

# The Parent / Carer Engagement Report

North East and Cumbria



Researched and written by Skills for People April 2019

# The Parent/ Carer Engagement Report

## Introduction

This report this report was commissioned as part of the Children's and young people's Accelerator Site project. Transforming care, North Cumbria and North East. The aim was to support organisational development across the system. The remit given to Skills for People was to carry out a mapping exercise of the views of parents / carers in respect of community support to identify issues and areas that need improvement

We hope to provide a picture of the views and experiences of the parent / carers of children and young adults with a learning disability, Autism or both, covering topics like diagnosis, the school years, social activities, the strength of the parent / carer voice and a range of related issues such as parent / carer support and training.

Running alongside the primary work with parent / carers has been the work to find out the views of professionals covering similar ground as well as more specific questions around long stay hospitals.

We have had:

- 237 parent / carer questionnaires returned
- 65 professional questionnaires returned

It is believed that the analysis of these 302 questionnaires will provide the commissioners and providers of services with ideas of where gaps in services might be and possible areas to explore further and consider for future commissioning priorities.

## Methodology

Two separate questionnaires were developed using Survey Monkey, one for parents / carers and one for professionals.

A film was made explaining the project. The film was shared together with the questionnaires via Facebook, Twitter, and both general and regionally specific email distribution lists.

Alongside the distribution of the questionnaires via social media, a dedicated Project Worker also visited many regional parent / carer groups and forums to carry out consultations. Where needed our Project Worker signposted people to services.

The targeted area for the questionnaires was the North East and Cumbria. It was hoped a wide range of returns would allow for meaningful regional comparisons.

Whilst 302 questionnaires were returned, the numbers have varied considerably across the region with some areas producing far higher rates of return than others. When regional comparisons have been made, the disparities in returns have been noted and explained.

## Summary

Please note that this summary is the headline reports of a very large amount of data. The full breakdown of the data, with charts and regional comparisons is included in the appendix.

### Diagnosis

A significant proportion of parent / carers and professionals describe the experience of getting a diagnosis as poor. The process was described as taking 'far too long', 'is too complicated to navigate' and is not completed in a 'timely manner'.

The minority who described the process as 'very good' talked in terms of the speed of diagnosis; in many cases that their child was diagnosed at birth.

Regional variations on this issue indicate that Gateshead, Stockton and Northumberland have the highest percentage of people dissatisfied with the experience of having a diagnosis.

Nevertheless it is overwhelmingly clear that the majority of parents / carers and professionals place a high value in having a diagnosis.

- It opens doors to services and personal plans
- It helps with a wider understanding of the child's needs
- It removes the stigma of blame from the parent / carers

(See recommendation 1)

### Education

Of the responses received over half of children and young people have Education, Health and Care Plans (EHCP). Northumberland, with a significant return, has the highest percentage of people with an EHCP.

A large majority of the professionals in this research have involvement in an EHCP. Only 10% of professionals said an EHCP made no difference. The rest of professionals were evenly split between those who said the plans made a difference and those who said they sometimes made a difference.

The main reasons given by professionals for the success or failure of an EHCP is the lack of commitment from mainstream schools, the skills of the workers involved and people's level of understanding of the complex issues.

About one in five parent / carers said they were very happy with their child's education. There were significantly higher positive comments for specialist education compared to mainstream education. The primary critical comments of mainstream schools centred around:

- Lack of understanding of their child's needs
- An inability to provide specialist support and resources such as Speech and Language Therapy

Despite parent / carers reservations, they did report that the large majority of the children were actually happy to attend school. Durham and Sunderland, with moderate returns, slightly buck this trend with only 50% of children being reported as happy to attend school.

(see recommendation 3)

### Activities in the community

Over half of children and young adults attend activities in the community. There is some regional variation with North Tyneside having a higher percentage of people attending community activities.

A large percentage of parents / carers feel there are not enough opportunities in the community. The highest levels of concern are from Durham, Northumberland and Stockton.

Examples of barriers that mitigate against greater community activity include:

- Transport
- 'Behavioural' issues
- Noisy, crowded and unsuitable environments
- Peoples high levels of anxiety and stress
- Being able to employ suitable support, particularly recruiting suitable Personal Assistants
- Lack of awareness and support from the staff employed in mainstream leisure venues

Parent /carers obtained information on activities from a variety of sources but primarily social media (mostly Facebook), other parents / carers and parent / carer support groups.

Only 4 people mentioned using the Local Offer specifically.

### The local offer

There is a high rate of awareness from both parent / carers and professionals about the Local Offer. A large percentage of professionals said that they signpost people to the Local Offer.

Despite this high level of awareness only a handful of carers in the survey mention using the Local Offer in any way.

Parent / carer sources of information on a range of subjects came primarily from social media, mostly Facebook from other parents and carers and friends and specifically from parent support groups, teachers at school and service providers.

(see recommendation 2)

### **Support for parent / carers**

The majority of parents/carers belong to a parent / carer group. Often this is via Facebook, seen as a practical option for people with busy and complicated lives.

Many parents / carers struggle to find advice and guidance particularly for housing and financial issues.

In regard to finding advice and guidance there is a strong regional variation. Newcastle had the fewest people struggling to find the right advice and guidance whilst Northumberland had the highest rate of people struggling to find the right advice and guidance.

(see Recommendation 4 & 5)

### **Emotional support**

The issue of emotional support, carer anxiety and stress was mentioned on many occasions. However, 81% of parents / carers state they receive no emotional support.

(See Recommendation 5 & 6)

### **Training that would help parents / carers in the role**

Parent / carers identified their most pressing training need as training in stress and anxiety, closely followed by training that supported them to deal with 'challenging behaviour'.

This this was followed by training in sensory issues, communication and sleep.

(see recommendation 7)

### **Experience of professional support and services**

People had a range of professional support. What is clear is that the quality of staff is crucial to parent / carers and is a theme that is returned to regularly.

About 1 in 5 people gave their experience of services a very low mark. Most people gave marks in the middle range and about 1 in 10 a high mark.

Half of parent / carers thought they had been listened to in terms of their child's support plan, half did not. The most cited views were:

- Staff didn't understand the child's needs
- Having to 'fight' to be listened to
- Mainstream Schools not listening

People who gave comments on critical services did not show up distinct patterns across the localities. Most commented upon areas were long waiting times, issues with bureaucracy and poor communication.

Parent / carers gave the following examples of the services they would like more of:

- More leisure and social groups
- More availability of Speech and Language Therapy
- More counselling services
- Sensory needs training

Beyond specific training and services several people valued having more parent support groups, carers assessments and general advice work-shops.

The professionals described the most effective services **in their own region** at supporting parent /carers as 'the third sector', parent / carer support groups, the community learning disability teams and the SENCO service.

The professionals said the services **not in their own region** that would support parent / carers would be autism support groups and emotional counselling and support groups for parent / carers after diagnosis.

### **The parent / carer role in the development of services**

About 4 in 10 parent carers are part of a group, forum, or network designed to give parent / carers a voice.

There is quite a disparity across the region with Durham, Gateshead and Newcastle having the highest involvement numbers and North Tyneside, Sunderland and then Northumberland having the lowest.

The overwhelming majority of parents / carers do not think services either listen to them or use their voice and opinions in the future planning of services. Words like Austerity, Tokenism and a box ticking exercise were frequently used.

Professionals however overwhelmingly believe there is an active parent / carer engagement strategy with meaningful involvement. Many examples of how this engagement occurs were given, such as feedback surveys, information sharing days and forums. Concrete examples of changes as a result of the parent / carer voice were also given (see appendix).

(see recommendation 8)

## The professional views of Long Stay Hospitals

Just over half of professionals had heard of Transforming Care and just under half had heard of Care and Treatment Reviews.

Nearly all of the professionals were aware of Positive Behavioural Support training.

Of the 30 professionals involved at some level in the treatment of people in long stay hospitals, it was evenly split between those who believed other approaches could have reduced admission and those who didn't.

The most popular idea is to reduce admission was more crisis support and more short breaks.

## Recommendations

### 1

Clearer pathway for parents on the process of getting a diagnosis and greater communication with parents throughout the timeline so they understand where they are and why it may be taking longer than anticipated. Introduction of strategies to help parents cope with behaviour / sensory issues whilst awaiting a diagnosis.

Look at what more can be done to support children and young adults, especially those with higher support needs, to more successfully access mainstream community activities. Look at working with mainstream staff around:

- Disability awareness training with the emphasis upon making reasonable adjustments

Understand the importance of voluntary sector organisations that support community participation such as Friends Action North East

### 2

Research why the Local Offer appears to have such a small impact upon parent / carers.

Look at:

- Regional variation in the Local Offer
- Quality of services advertised by the Local Offer
- Accessibility of the Local Offer
- The apparent disparity between awareness of the Local Offer and its use by parent / carers

### 3

What more can be done to support children and young adults, especially those with higher support needs, to more successfully access mainstream community activities. Look at working with mainstream staff around:

- Disability awareness training with the emphasis upon making reasonable adjustments
- Understand the importance of voluntary sector organisations that support community participation such as Friends Action North East

### 4

What can be done to further support mainstream schools to understand the needs of people with a learning disability and / or autism? Training for all school staff to raise awareness of the needs of children / young people with a learning disability and or autism



## 5

How advice and guidance services are advertised to parent / carers. Ensure there are enough avenues for advice for all the areas indicated in this report. What impact has austerity had on access to advice and support services across the region?

## 6

Understand that the emotional needs of parent / carers are an area of significant concern. Research what support services are available to people including:

- Parent/ carer support groups, including those that can provide post-diagnosis support
- Wider post diagnosis support such as professional counselling
- Research if mainstream counselling services such as Access to Psychological Therapies understand the needs of parent / carers

## 7

Understand that parent / carers and professionals have been clear that parent / carer support groups and the voluntary sector are seen as crucial to people's lives. Ensure commissioning priorities take this into account.

Look at the parent / carer priority for training. In particular look at:

- Availability of Positive Behavioural Support
- Managing stress and resilience training

## 8

Research how to increase the participation of parent / carers in the development of services as there is a disparity in views between parent / carers and professionals over how effective the parent / carer voice has been in service development. In particular:

- Share regional examples of good practice that make a real difference
- Analyse further any regional variations in the effectiveness of the parent / carer voice. Ensure an effective remedial strategy for any area where there is not meaningful engagement
- Ensure there is practical support for meaningful engagement

## Conclusion

There was an excellent response to the questionnaires, although regional disparities in returns should not be ignored. It is clear that parent / carers experience, overall, is one of great stress. Having to 'fight for it', 'not being listened to' and 'feeling blamed' were words that stuck out from parents' comments. This should not mean we ignore all the good stories and the 'good staff' that were mentioned. It is also clear that both professionals and parent / carers highly value the work of the voluntary sector and in particular parent / support groups. Support and friendship from peers with lived experience cannot be underestimated in terms of importance.

The overall returns from the questionnaires should give us some pause for thought – there is still a great deal of work to be done.

## Acknowledgement

We would like to thank all the parent / carers and the professionals who took the time to fill in the questionnaires.

## Appendix

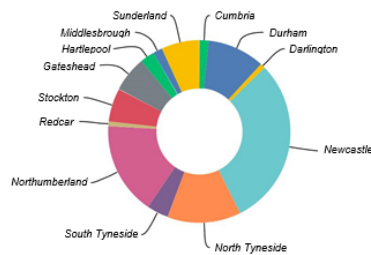
This appendix is a detailed analysis of the 237 questionnaires returned from family carers and the 65 questionnaires returned from professionals.

The greatest responses came from Newcastle, Northumberland, North Tyneside and Durham. Stockton, Gateshead and Sunderland all returned around 15 questionnaires; South Tyneside was close behind. Other areas such as Darlington, Cumbria, Redcar and Middlesbrough returned far fewer questionnaires. This imbalance between returns from around the region is reflected in the analysis below.

### Background information for Parent / Carers

Q1 Where do you live?

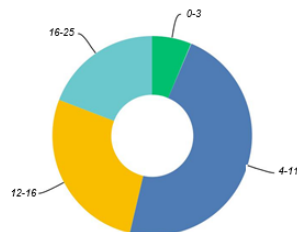
Answered: 237 Skipped: 0



ANSWER CHOICES	RESPONSES	
Cumbria	1.69%	4
Durham	10.13%	24
Darlington	0.84%	2
Newcastle	29.96%	71
North Tyneside	13.08%	31
South Tyneside	3.80%	9
Northumberland	16.46%	39
Redcar	0.84%	2
Stockton	5.91%	14
Gateshead	6.33%	15
Hartlepool	2.53%	6
Middlesbrough	1.69%	4
Sunderland	6.75%	16
TOTAL		237

Q2 What is the age of your child?

Answered: 235 Skipped: 2



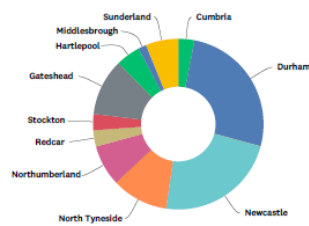
ANSWER CHOICES	RESPONSES	
0-3	6.38%	15
4-11	47.23%	111
12-16	27.23%	64
16-25	19.15%	45
TOTAL		235

With over 47% of people aged between 4 and 11 and 74% overall under the age of 16, the survey results present an up-to-date picture of people's experiences, in the generality, from around the region.

## Background information for the professionals

Q1 What region do you work in?

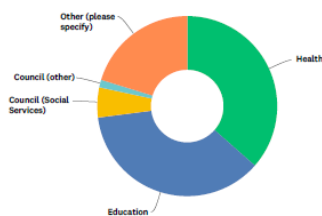
Answered: 65 Skipped: 0



ANSWER CHOICES	RESPONSES	
Cumbria	3.08%	2
Durham	26.15%	17
Darlington	0.00%	0
Newcastle	23.08%	15
North Tyneside	10.77%	7
South Tyneside	0.00%	0
Northumberland	7.69%	5
Redcar	3.08%	2
Stockton	3.08%	2
Gateshead	10.77%	7
Hartlepool	4.62%	3
Middlesbrough	1.54%	1
Sunderland	6.15%	4
TOTAL		65

Q2 What field do you work in?

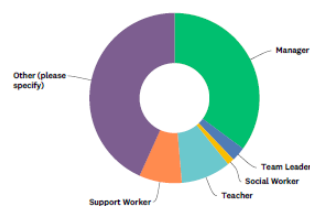
Answered: 74 Skipped: 0



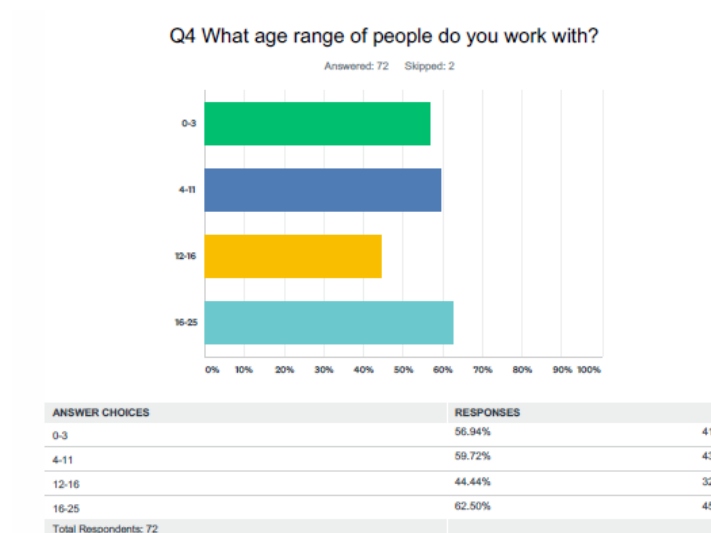
ANSWER CHOICES	RESPONSES	
Health	36.49%	27
Education	36.49%	27
Council (Social Services)	5.41%	4
Council (other)	1.35%	1
Other (please specify)	20.27%	15
TOTAL		74

Q3 What type of role do you have?

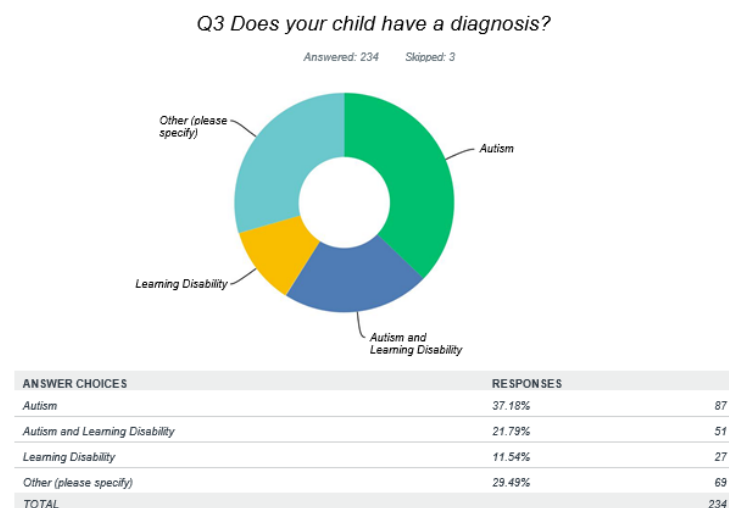
Answered: 74 Skipped: 0



ANSWER CHOICES	RESPONSES	
Manager	35.14%	26
Team Leader	2.70%	2
Social Worker	1.35%	1
Teacher	9.46%	7
Support Worker	8.11%	6
Other (please specify)	43.24%	32
TOTAL		74



## Diagnosis



It is striking that 59% of people had autism, sometimes alongside having a learning disability.

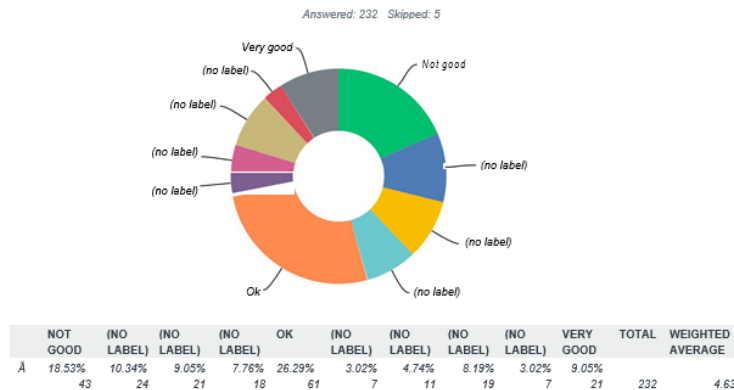
In the comments section, parent / carers gave many other examples of their child's disability.

- Attention Deficit Hyper-Active Disorder = 12 people
- Cerebral Palsy= 7 people
- Sensory processing = 6
- Social phobia = 5
- Reactive Attachment Disorder = 5
- Hearing related issues = 5

There were also around 15 people who mentioned individual and unique conditions that do not fit into any of the above.

## Experience of getting a diagnosis

Q4 What is your experience of getting a diagnosis?



Areas of note from the above chart, Q4:

- The 3 more critical boxes represent 38 % of the total
- The 3 more positive boxes make up 20 % of the total
- The largest individual segment, however, is the okay box, at 26 %.

Most of the written comments tended to be on the more critical side, not necessarily reflecting the breakdown of experiences represented by the Q4 Chart.

## Written reason given for a poor experience of diagnosis

- 39 people said the process of getting a diagnosis took too long
- 7 people said they felt their views were ignored
- 7 people criticise what they saw as the bureaucratic system failings e.g. 'lost files,' 'not joined up', 'lack of continuity'
- 5 people commented on the quality of staff

**For those who described their experience as okay the main comments were:**

- 13 people were positive about the experience of getting a diagnosis once it had started but still said the waiting was too long
- 8 people describe getting a diagnosis as fast

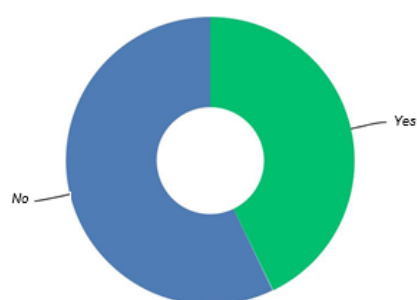
## Written reasons given for a good experience of diagnosis

- 6 people describe having a fast diagnosis
- 12 people talked about their child's disability being diagnosed at birth or in-utero. 4 people mentioned the children being born with down syndrome

## Experience of navigating the diagnosis's process

Q5 Did you find the process straightforward and easy to navigate?

Answered: 231 Skipped: 6



ANSWER CHOICES	RESPONSES	
Yes	42.86%	99
No	57.14%	132
TOTAL		231

From graph Q5, it is quite stark that 57% out of 231 returns found the process of getting a diagnosis complicated.

Regional differences in responses to the questions 'did you find the process straightforward and easy to navigate'			
Town / City / Area	Numbers who replied	Yes	No
Cumbria	4	3	1
Darlington	2	1	1
Durham	14	14	10
Gateshead	15	3	12
Hartlepool	6	3	3
Middlesbrough	4	3	1
Newcastle	67	30	37
North Tyneside	31	13	18
Northumberland	39	13	26
Redcar	2	0	2
South Tyneside	9	3	6
Stockton	12	2	10
Sunderland	16	11	5

### Regional differences of note:

- Gateshead had 80 % of people say 'no' out of 15 people and Stockton had 83 % say no based on 12 people. The number of returns is on the low side but, perhaps, enough, to raise questions.
- Northumberland had 67 % say no based on a reasonable return of 39 people.

### Written comments from people who found the process easy to navigate included:

- Having excellent school staff
- That the process of diagnosis was quick
- That people had a clear route to 'talking to the right people'

### Written comments from people who found the process hard to navigate included:

- Having to push to get appropriate help and advice
- People not being believed
- Not having enough support after diagnosis
- Poor communication
- Inadequately trained staff
- Too much waiting
- Conflicting advice
- Too many appointments and too much repeating of the same information

### The speed of the diagnosis

Q6 Was the diagnosis in a timely manner?

Answered: 227 Skipped: 10



ANSWER CHOICES	RESPONSES	
Yes	42.73%	97
No	57.27%	130
TOTAL		227



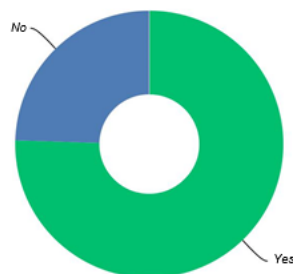
The following numbers came from the written comments from parent / carers								
9 months	18 months	2 years	3 years	4 years	5 years	6 years	8 years	Diagnosed much later
2 people	3 people	7 people	1 person	1 person	4 people	2 people	1 person	1 person said 10 years

Regional differences in responses to the questions 'was the diagnosis in a timely manner'			
Town / City / Area	Numbers who replied	Yes	No
Cumbria	4	1	3
Darlington	2	1	1
Durham	23	10	13
Gateshead	15	6	9
Hartlepool	6	1	5
Middlesbrough	4	2	2
Newcastle	69	36	33
North Tyneside	28	10	18
Northumberland	38	15	23
Redcar	2	0	2
South Tyneside	9	3	6
Stockton	11	4	7
Sunderland	16	8	8

## Does having a diagnosis make any difference to people's lives?

Q7 Did having a diagnosis make a difference?

Answered: 216 Skipped: 21



ANSWER CHOICES	RESPONSES	
Yes	75.46%	163
No	24.54%	53
TOTAL		216

It is clear, that whatever people's frustrations with things like waiting times, process and bureaucracy, 75% of people clearly think having a diagnosis makes a difference.

Regional differences in responses to the questions 'Does having a diagnosis make any difference to people's lives?'			
Town / City / Area	Numbers who replied	Yes	No
Cumbria	4	4	0
Darlington	2	0	2
Durham	22	13	9
Gateshead	14	10	4
Hartlepool	5	4	1
Middlesbrough	4	4	0
Newcastle	67	51	16
North Tyneside	30	25	5
Northumberland	31	27	4
Redcar	2	2	0
South Tyneside	9	6	3
Stockton	11	7	4
Sunderland	16	10	6

**Comments from people who thought diagnosis made a difference:**

- 52 people thought a diagnosis opened the door for both services and their children getting a plan
- 12 people said it helped them and the wider family to understand the child and to be able to offer explanations to other people
- 13 said having a diagnosis helped them with their own sense of well-being. They no longer felt 'to blame' and felt 'the stigma' for bad parenting was reduced. People often thought they were being judged or blamed for doing something wrong
- 6 people said a diagnosis gave access to benefits
- 5 people believed a diagnosis helped them to become better at supporting their own children
- 4 people said the diagnosis led to reasonable adjustments being made
- 4 people mentioned increased peer support
- 3 mentioned more understanding from professionals

**Comments from people who thought having a diagnosis made little difference:**

For the 14 people who commented that the diagnosis made no real difference, the 2 main reasons that were given were lack of follow-up support (3) or simply because support was already good (4).

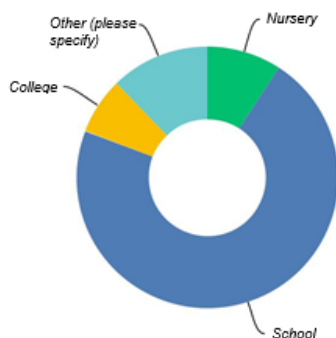
## The views of the professionals regarding diagnosis

Professional views of the experience of getting a diagnosis			
	Not good combined with next lowest score on the chart	okay	Very good combined with next lowest score on the chart
Parent / Carers	29%	26%	12%
Professionals	21%	22%	5%
Views on how straightforward the process of getting a diagnosis is to navigate			
	yes	No	Varies (please note carers were not given this option- so comparisons to this question need caution)
Parent / Carers	43	57	
Professionals	7	34	59
Was the diagnosis given in a timely manner?			
	Yes	No	
Parent / Carers	43	57	
Professionals	39	61	

## Experience at school or nursery

Q8 Is your child/young person currently attending Nursery, School, College or other?

Answered: 229 Skipped: 8

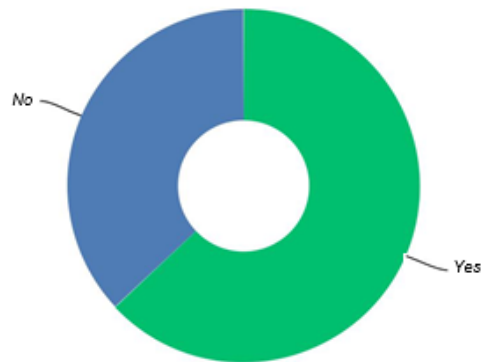


ANSWER CHOICES	RESPONSES	
Nursery	9.17%	21
School	71.62%	164
College	6.99%	16
Other (please specify)	12.23%	28
TOTAL		229

The main point to note from Q8 is that this report is primarily about people attending school.

### Q9 Do they have an Education, Health and Care plan?

Answered: 227 Skipped: 10

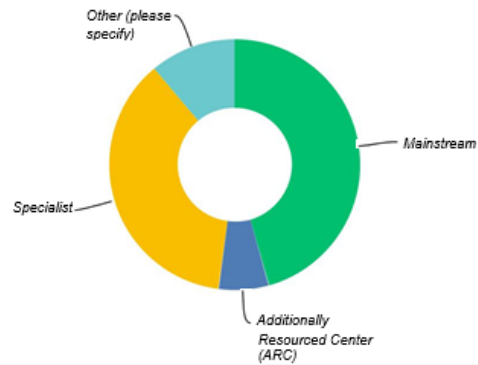


ANSWER CHOICES	RESPONSES	
Yes	63.00%	143
No	37.00%	84
<b>TOTAL</b>		<b>227</b>

Regional differences in responses to the questions 'Do they have an Education, Health and Care Plan?'			
Town / City / Area	Numbers who replied	Yes	No
Cumbria	4	3	1
Darlington	2	0	2
Durham	23	13	10
Gateshead	13	10	3
Hartlepool	6	3	3
Middlesbrough	1	1	0
Newcastle	68	44	24
North Tyneside	31	20	11
Northumberland	26	22	4
Redcar	2	2	0
South Tyneside	8	7	1
Stockton	14	7	7
Sunderland	16	7	8

Q10 If in school/college, what type?

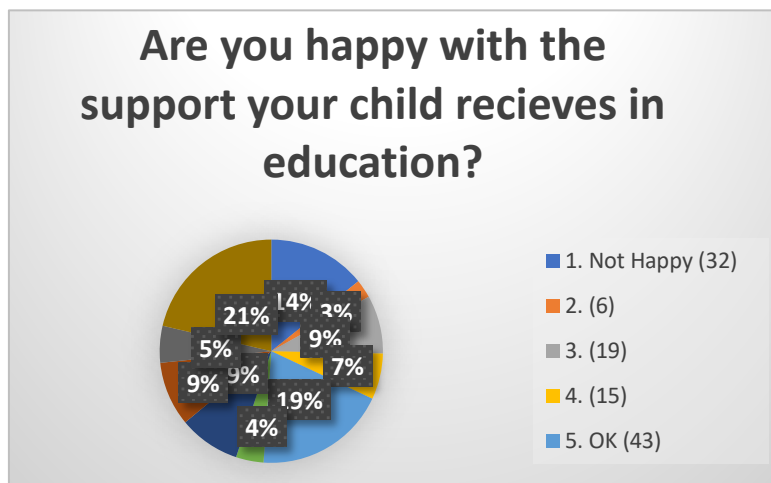
Answered: 217 Skipped: 20



ANSWER CHOICES	RESPONSES	
Mainstream	45.62%	99
Additionally Resourced Center (ARC)	6.45%	14
Specialist	36.87%	80
Other (please specify)	11.06%	24
TOTAL		217

Regional differences in responses to the question 'if in school / college what type?'					
Town / City / Area	Numbers who replied	Mainstream	Specialist	ARC	Other
Cumbria	4	1	2	1	
Darlington	2	1			1
Durham	23	14	5		4
Gateshead	14	3	8	1	2
Hartlepool	5	3	1	1	
Middlesbrough	1		1		
Newcastle	63	10	12	3	2
North Tyneside	27	10	12	3	2
Northumberland	25	20	13		2
Redcar	2		2		
South Tyneside	8	3	3	1	1
Stockton	12	5	5		2
Sunderland	15	8	1	1	5

Q11



### Analysis of the written comments for Q11

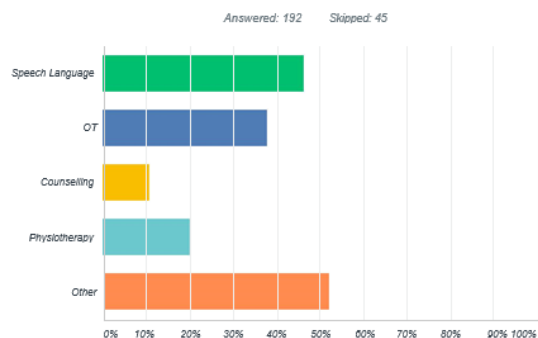
#### Written comments for those who are happy with the support their child receives

- 17 People were especially positive about the **specialist school experience**
- 9 People were especially positive about the **mainstream school experience**
- 7 people described **mainstream school as 'okay'** – and elaborated that it was still a struggle
- 6 people were positive about Additionally Resourced Centres
- 5 were happy but concerned about future sustainability in terms of finances
- 4 People talked about having good support staff
- 3 people noted some improvements and adjustments made for child

#### Written comments for those who are not happy with the support their child receives

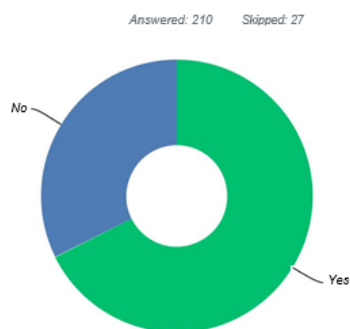
- 17 people were critical of mainstream schools' lack of understanding of their child and 'inability to provide specialist support'
- 4 people felt resources were too stretched
- 4 people talk about the 'struggle' to get the resources and support they needed
- 3 people said there was not enough additional specialist support, especially Speech and Language Therapy
- 2 people are now home schooled
- 2 people were unequivocal in their criticism of the experience of specialist school
- 1 person mentioned poor transition

Q12 Does your child access other services within school?



ANSWER CHOICES	RESPONSES	
Speech Language	46.35%	89
OT	38.02%	73
Counselling	10.94%	21
Physiotherapy	20.31%	39
Other	52.08%	100
Total Respondents: 192		

Q13 Is your child happy to attend school?



ANSWER CHOICES	RESPONSES	
Yes	67.62%	142
No	32.38%	68
TOTAL		210

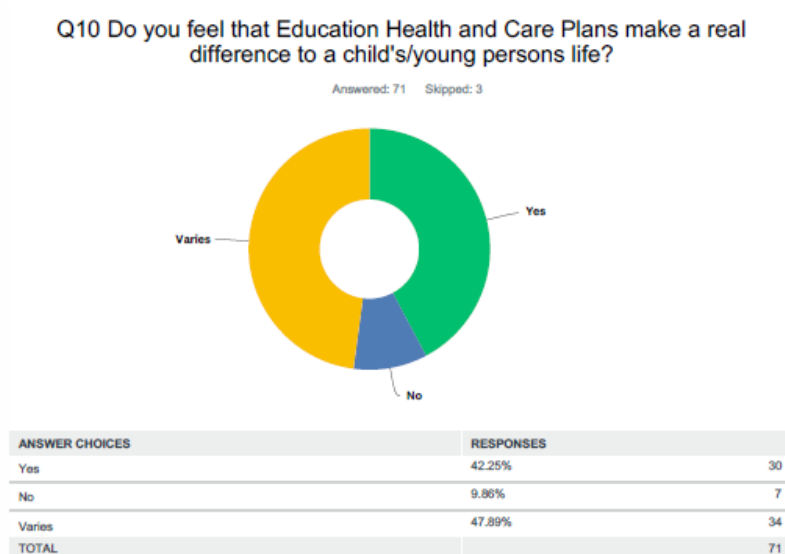
Regional differences in responses to the questions 'Is your child happy to attend school'			
Town / City / Area	Numbers who replied	Yes	No
Cumbria	4	3	1
Darlington	2		2
Durham	22	11	11
Gateshead	13	9	4
Hartlepool	6	2	4
Middlesbrough	1	1	
Newcastle	65	51	14
North Tyneside	27	20	7
Northumberland	24	18	5
Redcar	2	2	
South Tyneside	8	5	3
Stockton	12	9	3
Sunderland	14	7	7

## Analysis of the written comments for Q13

### Written comments for those who believe their child is happy to attend school:

- 8 people said their child was happy at a specialist school
- 5 people said their child was happy at a mainstream school
- 2 people said their child was happy at a Additionally Resourced Centre
- 2 people said their child was mostly happy at their mainstream school

### The perspective of the professionals on the use of Education, Health and Care Plans (EHCP)



74% of professionals have been involved in people's Education, Health and Care Plans at different levels. 42% have been involved in Annual Reviews and carrying out the actions of the plan.

42% see the plans as definitely making a difference and 48% say success varies between the plans. 10% of professionals answered they made no real difference.

### Written comments from the professionals said ***that success depended upon:***

- 6 people cited access to specialist provision and support
- 3 people cited partnership working
- 3 people cited people having an understanding of the issues

### Written comments from the professionals said that ***lack of success depended upon:***

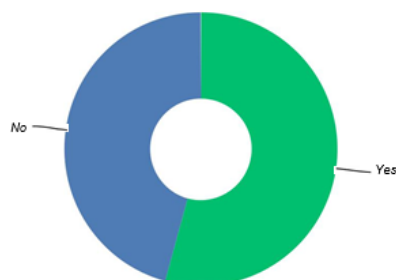
- 4 people cited poor commitment from mainstream schools
- 3 people cited workers' skills
- 3 people cited the quality of the plan
- 3 people cited the child / young person moving onto another school



## Activities

Q14 Does your child attend any activities in the community?

Answered: 225 Skipped: 12



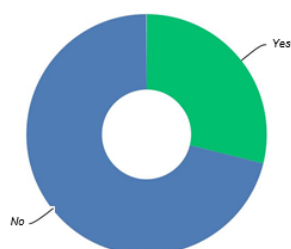
ANSWER CHOICES	RESPONSES	
Yes	54.22%	122
No	45.78%	103
TOTAL		225

### Regional differences in responses to the questions 'Does your child attend any activities in the community?'

Town / City / Area	Numbers who replied	Yes	No
Cumbria	4	3	1
Darlington	2	2	
Durham	24	9	15
Gateshead	14	4	10
Hartlepool	7	6	1
Middlesbrough	1		1
Newcastle	66	35	31
North Tyneside	28	19	9
Northumberland	37	20	17
Redcar	2	1	1
South Tyneside	8	5	3
Stockton	14	8	6
Sunderland	14	7	8

Q15 Do you feel there are sufficient activities for your child to attend?

Answered: 218 Skipped: 19



ANSWER CHOICES	RESPONSES	
Yes	28.90%	63
No	71.10%	155
TOTAL		218

Regional differences in responses to the questions 'Do you feel there are sufficient activities for your child to attend?'			
Town / City / Area	Numbers who replied	Yes	No
Cumbria	4	1	3
Darlington	2	1	1
Durham	24	4	20
Gateshead	14	1	13
Hartlepool	6	3	3
Middlesbrough	1		1
Newcastle	66	24	42
North Tyneside	25	5	20
Northumberland	33	11	22
Redcar	2		2
South Tyneside	8	6	2
Stockton	14	1	13
Sunderland	15	7	8

Written comments from people who said their child **did attend** activities in the community:

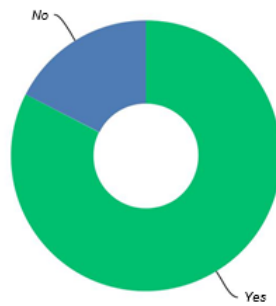
- 12 people said yes there was choice, but more for school children than adults with a learning disability and / or autism
- 8 people said whilst their children did access community activities but their children's 'behaviour' made it difficult
- 7 people said there was lots of choice
- 1 person says their daughter already does enough
- 1 person said most activities seemed to cater for older children
- 1 person spoke about the good quality of their short breaks
- 1 person said yes but that mainstream activities were not very flexible

The most popular written comments from people who said their child **did not attend** activities in the community:

- 7 people said that travel was an issue
- 4 people said there were not enough opportunities for people with profound and multiple learning disabilities
- 4 people said there was not enough opportunities for people with autism
- 3 people said there was not enough information on activities
- 3 people said that activities were not flexible enough to support people in their own home

Q16 Are there any barriers to your child/young person attending an activity?

Answered: 223 Skipped: 14



ANSWER CHOICES	RESPONSES	
Yes	82.51%	184
No	17.49%	39
TOTAL		223

Regional differences in responses to the questions 'Are there any barriers to your child / young person attending an activity?'			
Town / City / Area	Numbers who replied	Yes	No
Cumbria	4	4	
Darlington	2	1	1
Durham	24	19	5
Gateshead	13	13	
Hartlepool	6	4	2
Middlesbrough	1	1	
Newcastle	66	55	11
North Tyneside	27	23	4
Northumberland	37	27	10
Redcar	2	2	
South Tyneside	8	8	
Stockton	14	12	2
Sunderland	15	14	1

The most popular written comments describing barriers are:

- 11 people talked about problems with transport, especially if people were reliant upon families to travel
- 9 people talked about their child's 'challenging behaviour'
- 9 people talked about how stressful noisy environments were for people
- 8 people talked about the difficulty in employing suitable support, often via a Direct Payment
- 8 people talked about problems of staff awareness of the needs of people with a disability

- 8 people talked about their child's levels of stress, anxiety and lack of confidence
- 7 people talked about their child being uncomfortable in crowds
- 4 people talked about the physical accessibility issues of venues
- 4 people talked about the need for families to support all of their children and other family commitments
- 4 people talked about the cost of activities

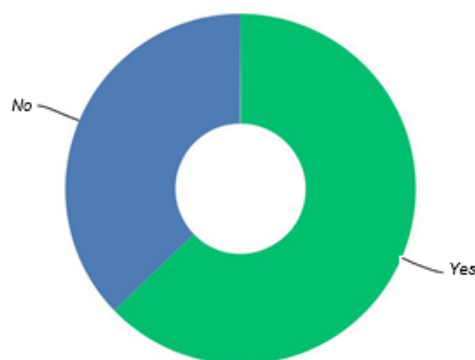
**Parent / Carers described how they found out about activities from a variety of sources;**

- 43 people talked about the importance of Social media, mostly Facebook
- 32 people talked about getting information from other parent / carers and friends. The phrase 'word of mouth' was commonly used.
- 17 people talked specifically about support and information received from parents support groups
- 14 people received their information from teachers at school or college
- 13 people received information directly from service providers that their children were involved with
- 8 parent / carers described being fully reliant when finding out about different activities
- 4 parent/ carers mentioned awareness of the Local Offer

**The local offer**

*Q18 Have you heard of the Local Offer?*

Answered: 223 Skipped: 14



ANSWER CHOICES	RESPONSES	
Yes	62.78%	140
No	37.22%	83
TOTAL		223

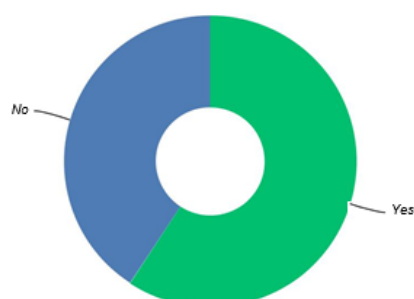
82% of professionals are aware of the Local Offer and 74% signposted people to the Local Offer. 63% of Parent / Carers are also aware of the Local Offer. It is therefore very surprising that throughout all of the returns, barely a handful of carers mentioned using the Local Offer.

## Support for Parent / Carers

### Belonging to a Parent / Carer Group

Q19 Are you part of a parent/carers support group?

Answered: 216 Skipped: 21



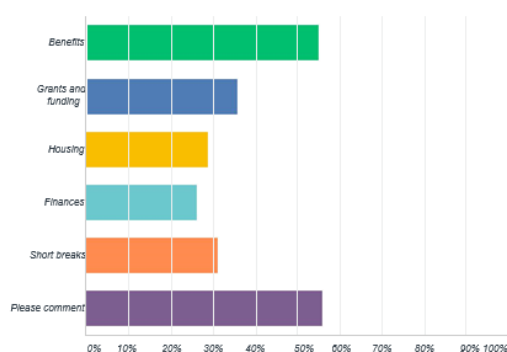
ANSWER CHOICES	RESPONSES	
Yes	59.26%	128
No	40.74%	88
TOTAL		216

From the 47 written comments received, 32 people directly belong to a group and 12 people belong to a Facebook group. The Facebook option was seen as practical for people who struggle with time.

### Understanding where to obtain support

Q20 Do you know where to find support or advice and guidance for the following issues?

Answered: 198 Skipped: 39



ANSWER CHOICES	RESPONSES	
Benefits	55.05%	109
Grants and funding	35.86%	71
Housing	28.79%	57
Finances	26.26%	52
Short breaks	31.31%	62
Please comment	56.06%	111
Total Respondents: 198		

It is clear from the graph Q20, that there is a significant issue for parents / carers around finding advice and guidance. In particular;

- 74% would not know where to find financial advice
- 71% would not know where to go for housing advice

The most common area, benefits advice, still meant that 45% of people would not know where they had to go for advice and guidance.

93 people filled in the comment section around the question where to obtain support. Some interesting data returned was:

- 42 people said they had no idea where to go for advice and guidance
- 7 people said they used the Citizens Advice Bureau. 4 of these people were from Northumberland.
- 9 people used Facebook and other social media
- 4 people said they used a Social Worker

“No, nobody has been able to help”

What was most noticeable regionally was the variation **in the those saying they didn’t know where to go for any advice;**

25 % of respondents from Newcastle (7 out of 28 comments). This was the lowest rate.

64% from Northumberland (14 out of 22 comments). This was the highest rate.

“the local offer but it...is...rather limited in Northumberland - I am a good resource gatherer but others will be more isolated and struggle”

The difference between Newcastle and Northumberland is stark, whatever the reason.

Other areas:

- 31 % from Durham (5 out of 16 comments)
- 43 % from South-Tyneside (3 out of 7 comments)
- 66% from Gateshead (4 out of 6 comments)
- 71% from Sunderland (5 out of 7 comments)

“Navigating the system is hard”

Another quite stark finding is that only 4 out of 93 people mentioned using the Local Offer.

“The 'Local Offer' just led to the Citizens Advice”

## Receiving support

### Q21 Have you accessed support for these issues?

Answered: 211 Skipped: 26



ANSWER CHOICES	RESPONSES	
Yes	47.39%	100
No	52.61%	111
TOTAL		211

The percentage of people across the region who have received support for the issues mentioned in Q21 is 47 %.

48 people filled in the comment section for this question.

The only statistic that stood out was the amount of people in Newcastle who had received welfare support.

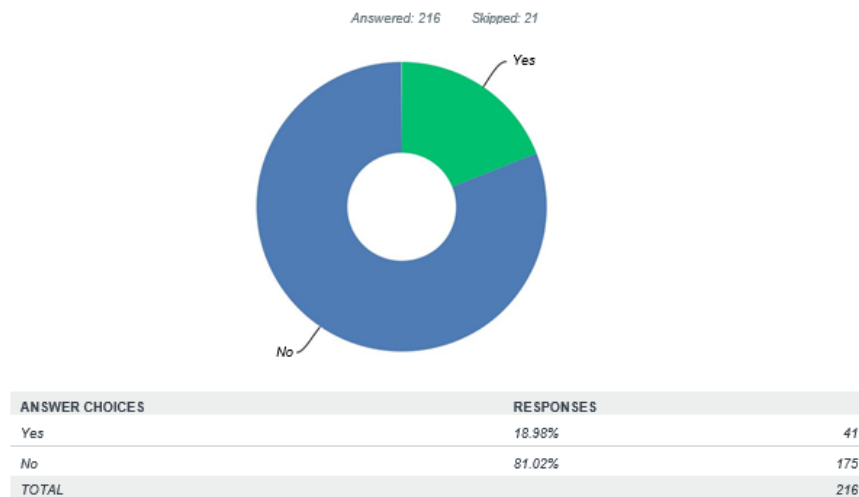
- 50 % (8 people out of 16)
- Northumberland was also 50% (3 out of 6) but the other areas were statistically too low to be meaningful.

‘Still coming to terms with diagnosis and struggling to get referral for other child who I suspect has same condition. Overwhelmed with managing behaviour and the “invisibility” of daughter’s disability and feeling that we won’t seem entitled to, or deserving of, extra support’

‘It appears to be a very limited choice unless parents investigate every possible opportunity and work endlessly to find a workable solution ensure their children have a happy, fulfilled and safe life’

## Emotional Support

Q22 Have you received any emotional support for yourself as a carer?



The issue of emotional support, anxiety, stress was mentioned on many occasions during the comments sections on the questionnaire. However:

**81% of parent / carers state that they receive no emotional support.**

Regionally the results are very consistent regarding the percentage of parent / carers who have not received emotional support;

- 83% from Durham (19 out of 23)
- 100% from Hartlepool (4 out of 4)
- 85% from Newcastle (53 out of 62)
- 81% from North Tyneside (21 out of 26)
- 81% from Northumberland (21 out of 26)
- 100% from South Tyneside (8 out of 8)
- 79% from Stockton (11 out of 14)
- 77% from Sunderland (10 out of 13)

## Training that would have help parent / carers in their role

- **Supporting behaviour said to challenge**

From the written comments received regarding what training and support would be most useful for parent / carers, the overwhelming priority was support around learning to manage 'challenging behaviour'. Over 20 people mentioned the need for support with this



issue and it is clearly supporting their children in the best possible during stressful periods is an area of major concern.

‘Control //minimising impact of aggressive behaviour with all preparations meltdowns still happen - what to do for person experiencing a meltdown?’

‘Yes, training on managing teen meltdowns and how to safely restrain in dangerous situations’

- **Emotional support for parent / carers**

11 mentioned some kind of emotional support for parent / carers.

‘Emotional resilience would be beneficial. As would calming techniques with a moody teenager’

‘Anything would help. Sometimes being a carer is overwhelming, lonely, relentless’

‘Counselling as standard for parents of disabled children’

Other areas of training mentioned:

- Understanding autism was requested several times
- Speech and language training, including Makaton training was mentioned several times

Mentioned on one or two occasions were:

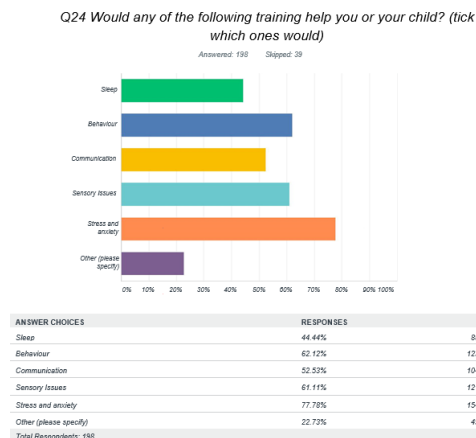
- Managing finances on behalf of your child including Power of Attorney
- Support to be an effective advocate
- Sensory difficulties

Beyond specific training several people valued having more parent support groups, carers assessments and general advice work-shops.

‘It’s very lonely being ...(a)...parent you don’t meet other parents at the school gates. Class numbers are small you have to force yourself to get out and meet people it’s difficult to find babysitters in the evening so therefore it was good to have mother and child groups clubs activities you could do together’

## Response to the question:

### Would any of the following training helped you in your role?

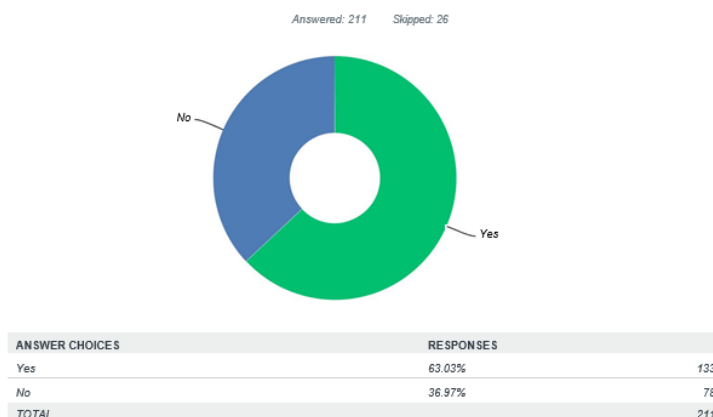


It is clear from the responses that stress and anxiety are a major area of concern for carers.

When asked if there were any other areas that might be considered for training, the most popular, with 4 comments, was dealing with 'violence' which was specifically mentioned and 'challenging behaviour,' again mentioned by 4 people.

## Experience of professional support

Q25 Does your child receive support from other professional?  
For example, Portage, Health Visitor, Child and Adolescent Mental Health Services, Children and Young People Service, or Social Worker

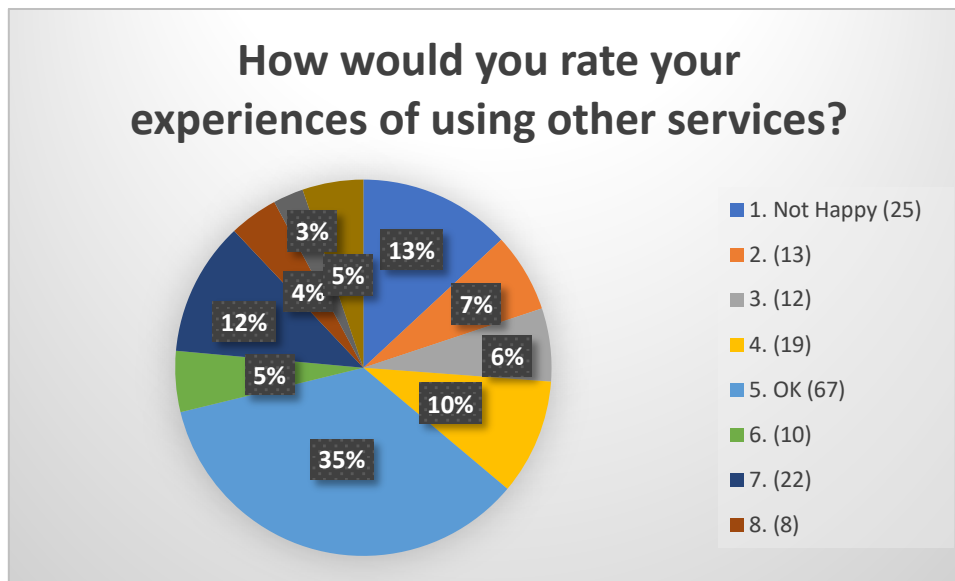


From across the region – those that filled in the comments section indicated:

- 33 people had a Social Worker
- 24 people were supported by Children and Young People service (CYPs)

- 21 people were supported by CAHMS
- 7 people had a Health Visitor
- 6 people had Portage
- 2 people saw a Physiotherapist
- 1 person was supported by Speech and Language Therapy

### Experience of working with professionals



From the Chart we can see that:

- 50% of people rated their experience as average or very close to average (the average mark added to the two adjacent scores)
- 21 % of people rated their experience as poor or very close to poor (Poor + the adjacent score)
- 8 % of people rated their experience as positive (Positive + the adjacent score)

### The written comments about peoples experience of working with professionals

The comments indicated no distinct regional patterns such as an identifiable excellent or poor service.

### 14 comments praised good services and support, usually around individual roles;

‘We had support from the health visitor. She was approachable and friendly  
(name removed) paediatrician is great’

‘I have been lucky to have been very well supported and my son has a great life’

It has become clear how the skills and qualities of individual staff made a huge difference to peoples experience and outcomes.

‘It really depends on the individual professionals, their knowledge of how to access services on your sons behalf, their interpretation of your child’s needs and the dynamics of your family setup’.

The importance of individual quality staff perhaps explains the two comments regarding concerns over staff turn-over;

‘Staff turnover meant she never developed a relationship with her worker and when the last one left she was discharged not because her issues were resolved but because they didn't have anyone to do the work with her’

**35 comments were more critical of services, but again no distinct patterns were shown across different localities. The most commented upon areas were:**

- 8 comments regarding long waiting times
- 5 comments relating to issues with bureaucracy and poor communication

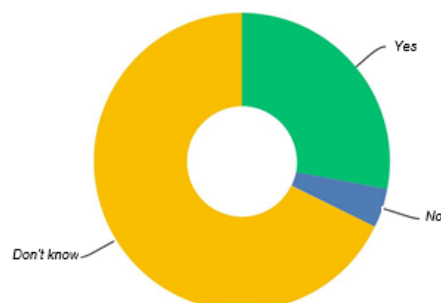
‘Can be stressful and feel like you're going around in circles sometimes’

‘Feel like we have just been left to get on with it’

‘We don’t really use other services as they are not offered and everything is such a fight that it's not worth the bother to be honest’

*Q27 Are there any services that would help your child that are not available in your area?*

Answered: 211 Skipped: 26



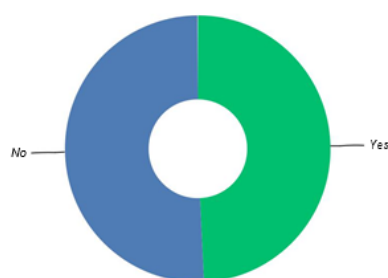
ANSWER CHOICES	RESPONSES	
Yes	27.96%	59
No	4.27%	9
Don't know	67.77%	143
TOTAL		211

There was no strong regional variation in the written comments about Q27.

- 7 people wanted more leisure and social groups
- 5 people wanted more availability of Speech and Language therapy
- 4 wanted more counselling services
- 4 wanted sensory needs training

Q28 Do you feel your voice has been listened to in terms of your child/young persons plan/care?

Answered: 203 Skipped: 34



ANSWER CHOICES	RESPONSES	
Yes	49.26%	100
No	50.74%	103
TOTAL		203

From the written comments on Q28, those who thought they were not listened to said:

- 16 people said the staff didn't listen or understand their children's needs
- 5 people said mainstream schools don't understand people with disabilities
- 3 people said schools didn't support the person to have a plan
- 3 people said it was about 'box ticking'

From the written comments, which are unreflective of the graph above, those who thought they were listened to said:

- 8 people said they were listened to but had to fight for this
- 4 people said yes but it was inconsistent
- 3 people praised supportive staff

**The types of services professional's think have been most effective in their own region at supporting parents/carers and people with a Learning Disability and/or Autism?**

- 15 professionals said the wider third sector

- 10 professionals said parent support groups
- 10 professionals said local Community Learning Disability Teams
- 6 people said school specialists including Specialist Educational Needs Coordinator (SENCO)
- 4 professionals said speech and language therapists
- 4 professionals said the local authority
- 4 professionals said children's support groups
- 3 professionals said an autism hub
- 2 professionals said work placements
- 2 professionals said occupational therapy
- 2 professionals said outreach workers
- 1 professional said parenting program
- 1 professional said children's mental health services

Regionally only the following areas had 3 or more professionals from the same area identifying the same service as most effective

- 7 professionals from Newcastle said the 3<sup>rd</sup> sector / voluntary sector. 5 people specifically mentioned Skills for People
- 5 professionals from Newcastle specifically mentioned local social work teams
- 5 professionals from North Tyneside specifically mentioned local social work teams
- 4 professionals from Cumbria said Speech and Language Therapy
- 3 professionals from Newcastle said Specialist Educational Needs Coordinator (SENCO)

**Services that professionals felt would benefit parent / carers that *are not available in their area***

- 9 professionals said support groups for people with autism
- 4 professional said support group for parents after diagnosis
- 4 professionals said post diagnostic counselling for parents/carers
- 4 professionals said more advocacy services
- 4 professionals said more children's mental health support
- 2 professionals said more information on benefits and rights
- 2 professionals said more information on specialist support in schools

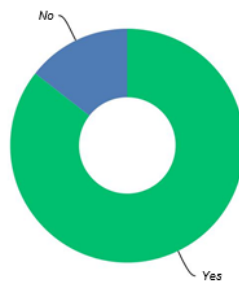
Regionally only the following areas had 3 or more professionals from the same area identifying the same service as most effective

- 4 professionals from Durham said support groups for people with autism three professionals
- 3 professionals from Gateshead said support groups for people with autism
- 3 professionals from Newcastle said support more support for children's mental health

## The parent/ carer voice in the development of services

Q29 Are you confident about speaking up on behalf of your child to professionals?

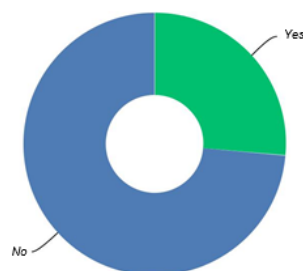
Answered: 208 Skipped: 29



ANSWER CHOICES	RESPONSES	
Yes	85.58%	178
No	14.42%	30
TOTAL		208

Q30 Do you think the wider services listen to parents/carers?

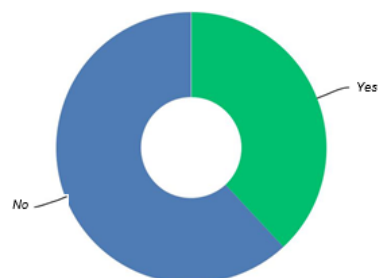
Answered: 197 Skipped: 40



ANSWER CHOICES	RESPONSES	
Yes	26.40%	52
No	73.60%	145
TOTAL		197

Q31 Are you involved in any groups, forums or networks designed to give parent carers a voice?

Answered: 210 Skipped: 27



ANSWER CHOICES	RESPONSES	
Yes	38.10%	80
No	61.90%	130
TOTAL		210

38% of respondents are part of a network or group designed to give parents a stronger voice in the influencing and development of services and wider society.

Across the region some of the interesting returns are;

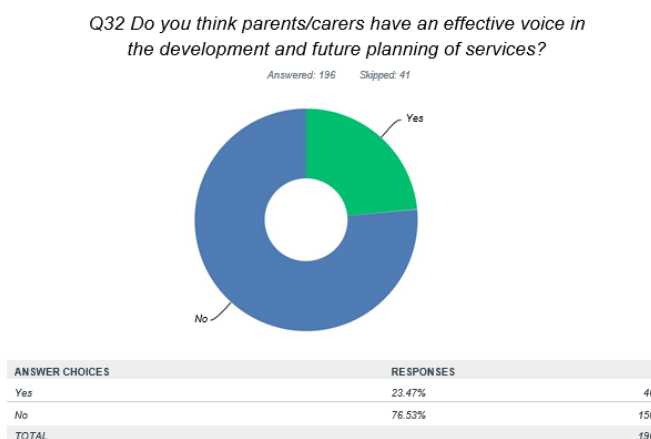
- Durham, Gateshead and Newcastle with the highest returns reported 36% of people engaged in a network.
- North Tyneside with 24 returns has 24% of people involved in a network
- Sunderland with 14 returns have 21% of people involved in a network.

Of the 43 written comments we received in this area, 31 people attended groups and 12 people relied upon Facebook.

“I’m on Facebook as I’m working so time is limited” reflects several of the comments we received.

Of the 186 people who answered the question:

**Do you think patient/carers have ineffective boys in development and future planning of services?**



Just under 77% said no.

There are some quite sharp regional disparities around this question;

- Newcastle with 57 returns had the highest positive response (for statistically useful numbers) with 32 % feeling carers / parents had an effective voice
- Northumberland with 30 respondents had only 10% of people feeling they had an effective voice.



- Sunderland with 14 returns had only one person, 7 %, feel they had an effective voice
- North Tyneside with 23 returns had 17 % feel they had an effective voice
- Gateshead with 14 returns had 14 % feel they have an effective voice
- North Tyneside with 23 returns and 17% feel they have an effective voice

The main written comments around the effectiveness of a strategic parent / carer voice were:

- 7 people believing austerity had impacted on a successful carer voice
- 7 people believing consultation was often 'tokenistic' and used 'to tick boxes' books.

" Sometimes we are just used as a tick box to say parents have been consulted when really nobody was actually interested in what we had to say"

"It seems that services really do not listen to parents and families at the very best they are only paying lip service"

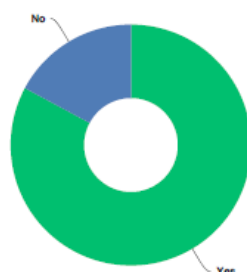
We did received two comments that were unequivocally positive about having an effective voice however the rest of the more positive comments tended to be caveated e.g. five people said much more could be done and others stressed an effective voice was only possible because of the strong carers.

"There is no one better out there who can be a voice for a disabled child than the parent who's been through the struggles of having to fight for the most basic of things"

## The professional view of meaningful carer engagement

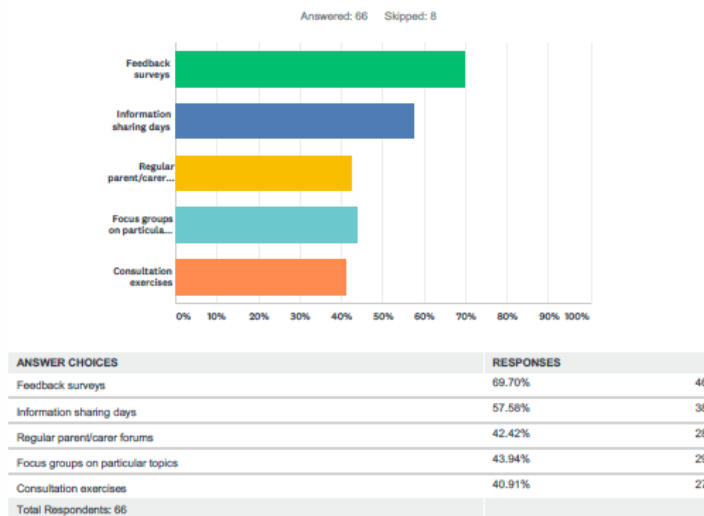
Q19 Do you feel the services you work in has an effective parent/carers engagement strategy that encourages active and meaningful involvement?

Answered: 70 Skipped: 4



ANSWER CHOICES	RESPONSES
Yes	82.86% 58
No	17.14% 12
TOTAL	70

Q20 What methods of engagement for parent/carers does your service support?



The largest gap between the parent /carers and professional is over how effective the parent / carer engagement is in giving people a meaningful voice. 83% of professionals see the engagement as meaningful.

Many examples of changes in response to the voice of parent / carers was given. A few examples are:

- An improved autism hub
- An independent travel scheme
- A new referral form for next day appointments
- Training in positive behavioural support
- Neuro diversity pathways
- Disability awareness training
- A new building and redeveloped rooms
- Holiday activities
- Emergency health care plans

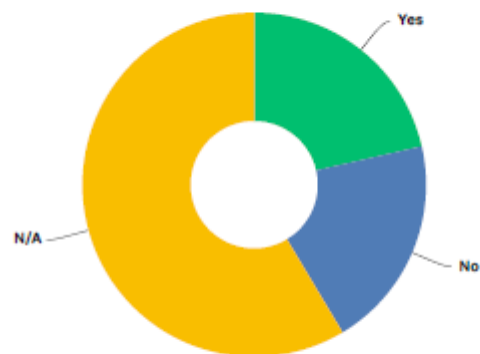
When asked what types of training might be further developed for parents/carers the following was given:

- 7 people said positive behavioural support
- 5 people talked about training for parents in crisis and resilience training
- 5 wanted specific training for people around autism
- 3 three people wanted speech and language therapy training
- 3 people wanted more training in managing sleep

## Professional views on the Long stay Hospitals

Q17 If you have had experience of supporting people who have been in long stay hospitals for reasons of assessment and behavioural issues are there any types of services or approaches that could have stopped the admission?

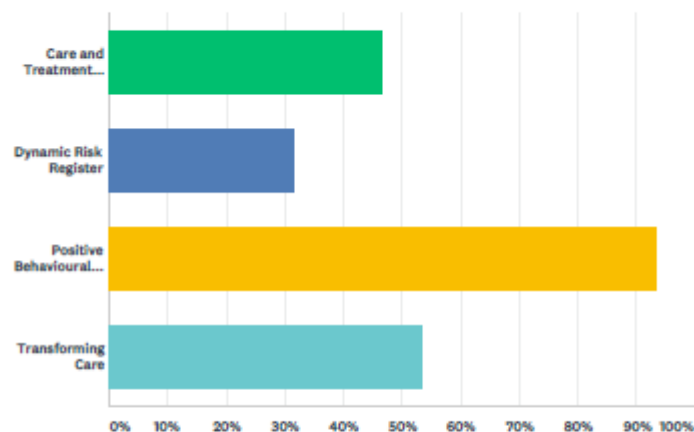
Answered: 70 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	21.43%	15
No	20.00%	14
N/A	58.57%	41
TOTAL		70

Q18 Please tick the boxes that you have an understanding and awareness of:

Answered: 60 Skipped: 14



ANSWER CHOICES	RESPONSES	
Care and Treatment Review	46.67%	28
Dynamic Risk Register	31.67%	19
Positive Behavioural Support	93.33%	56
Transforming Care	53.33%	32
Total Respondents: 60		

**Answers to the question: If you have had experience of supporting people who have been in long stay hospitals for reasons of assessment and behavioural issues are there any types of services or approaches that could have stopped the admission?**

- 5 professionals said, no there were no other types of services that could've stopped the admission
- 4 professionals said more support for community-based crisis support
- 3 professionals said more short breaks / respite support
- 1 professional said enhance community support around well-being
- 1 professional said better planning around transition
- 1 professional said the training for parents/carers
- 1 professional said earlier intervention
- 1 professional said better care support
- 1 professional said home treatment
- 1 professional said behavioural support pathways for people with autism
- 1 professional said access to Positive Behavioural support and other psychological interventions

Report by Skills for People, April 2019