

## **Aiming High for Disabled Children (AHDC) – November 2009**

# AHDC results for Cumbria PCT

Prepared by TNS-BMRB for the Department for Children, Schools and Families and the Department of Health

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## 1.1 Introduction

Aiming High for Disabled Children (AHDC) is the Government's strategy to improve the quality of services for disabled children and their families. One of its commitments was to measure performance and progress at a local level, by tracking parents' perceptions, and in May 2007 an indicator was proposed to enable their views to be measured at a local and national level. The new indicator therefore plays a central part in improving the quality of services for disabled children.

The first wave of the survey, conducted in April 2009, was used to calculate a national baseline indicator, together with local authority indicators for 30 local authorities which had included the indicator in their Local Area Agreement (LAA) or as a local target for 2008-09.

A short screener questionnaire was used to identify parents of disabled children. Those parents willing to take part were then contacted again with a more detailed questionnaire about their experiences of services for disabled children.

In 2008-09, over 12,000 main stage surveys were returned by parents. These parents were invited to take part again as part of the 2009-10 survey, along with additional parents identified as part of a new screening exercise. Over 31,000 main stage surveys were returned for 2009-10 covering the vast majority of PCTs in England.

Details of how the indicator is calculated and copies of the screener and main stage questionnaires can be accessed here: <http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/coreoffer/coreofferandni/>

This report presents the survey findings for Cumbria PCT where 193 questionnaires were completed by parents of disabled children.

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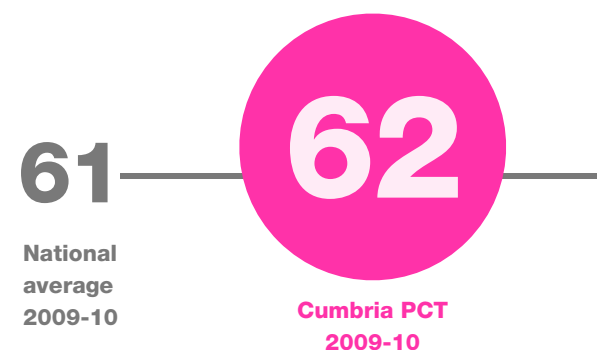
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## 1.2 The indicator

The overall score is based on an average of fifteen sub-indicators which each cover an element of the core offer in one of the three service sectors of health, education, and care & family support services. The five core offer standards are: information, assessment, transparency, participation and feedback; hence there are five sub-indicators for each service sector reflecting these core offer standards. A higher score denotes greater satisfaction with services.

At an overall national level parents rated the services received by their disabled child as 61 out of 100. Across all PCTs where an indicator score was produced, scores ranged from 55 to 68. In Cumbria PCT parents rated the services received by their disabled child as 62 out of 100. This figure represents a baseline from which to track progress or changes in perceptions and experience in future years.

There were some important differences between the 2008-09 and 2009-10 questionnaires, which should be borne in mind when comparing scores.<sup>1</sup>

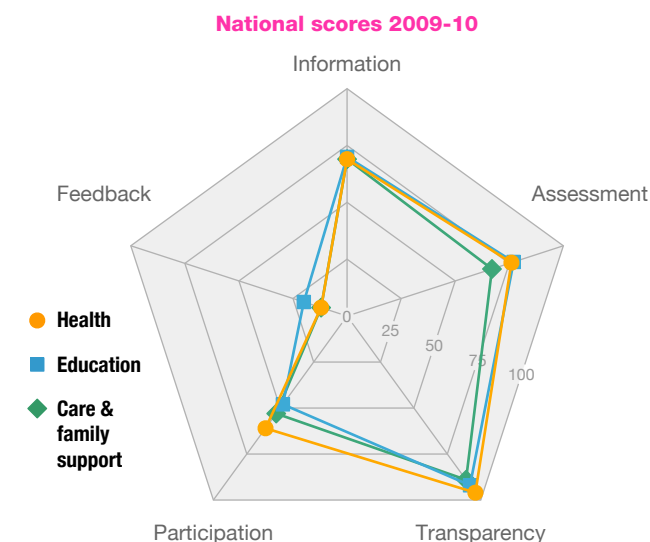


### 1.1 National scores

All areas, 2009-10 Shaded: All areas, 2008-09	Health		Education		Care & family support	
	2009-10	2008-09	2009-10	2008-09	2009-10	2008-09
Information sub-indicator score	69 n=29340	68 11241	70 n=28526	69 10923	69 n=29503	60 3612
Assessment sub-indicator score	76 n=13238	75 5047	77 n=13135	76 4580	67 n=3700	62 1181
Transparency sub-indicator score	96 n=13720	96 5330	92 n=13424	92 4738	89 n=3809	86 1229
Participation sub-indicator score	61 n=13698	60 5313	48 n=13435	50 4768	53 n=3808	52 1225
Feedback sub-indicator score	12 n=29321	12 11272	20 n=29933	22 11493	12 n=13773	11 4359

Scores: derived from relevant statements

(1) See the national report for a full discussion of changes in the questionnaire between 2008-09 and 2009-10. These affected care & family support sections of the questionnaire, and in particular questions relating to the care & family support information sub-indicator.



## 1.2 Local scores

### Cumbria PCT, 2009-10

	Health	Education	Care & family support
Information sub-indicator score	68 n=181	69 n=181	64 n=177
Assessment sub-indicator score	93 n=80	78 n=92	• n<30
Transparency sub-indicator score	96 n=83	89 n=99	• n<30
Participation sub-indicator score	62 n=83	52 n=100	• n<30
Feedback sub-indicator score	11 n=179	19 n=189	16 n=85

Scores: derived from relevant statements

### Key to symbols and codes used in this report

**n/a** indicates a question was not asked in a given category

**\*** shows a value less than 0.5 but not 0

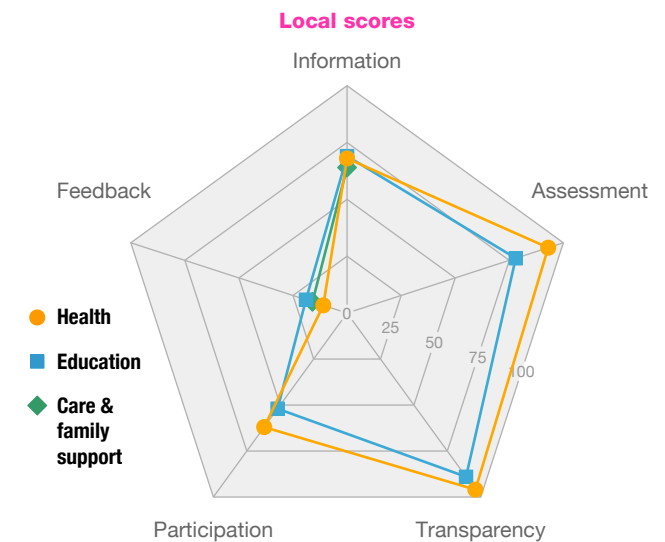
**–** means exactly 0

**n=** shows the base, or number of respondents, for a given result

**⚠** indicates the result should be treated with caution as the base is below 50

**•** replaces a value not shown because fewer than 30 people responded

**NB:** where figures have been excluded from a table they have also been excluded from the related chart



## 2 The five core offer areas

This section outlines parents' views of the health, education and care & family support services around the five core offer areas of information, assessment, transparency, participation and feedback. Questions reported here contributed to the calculation of the indicator score for 2009-10. More detail of how indicator scores were calculated can be accessed in the national research report and via <http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/coreoffer/coreofferandni/>

## 2.1 Information

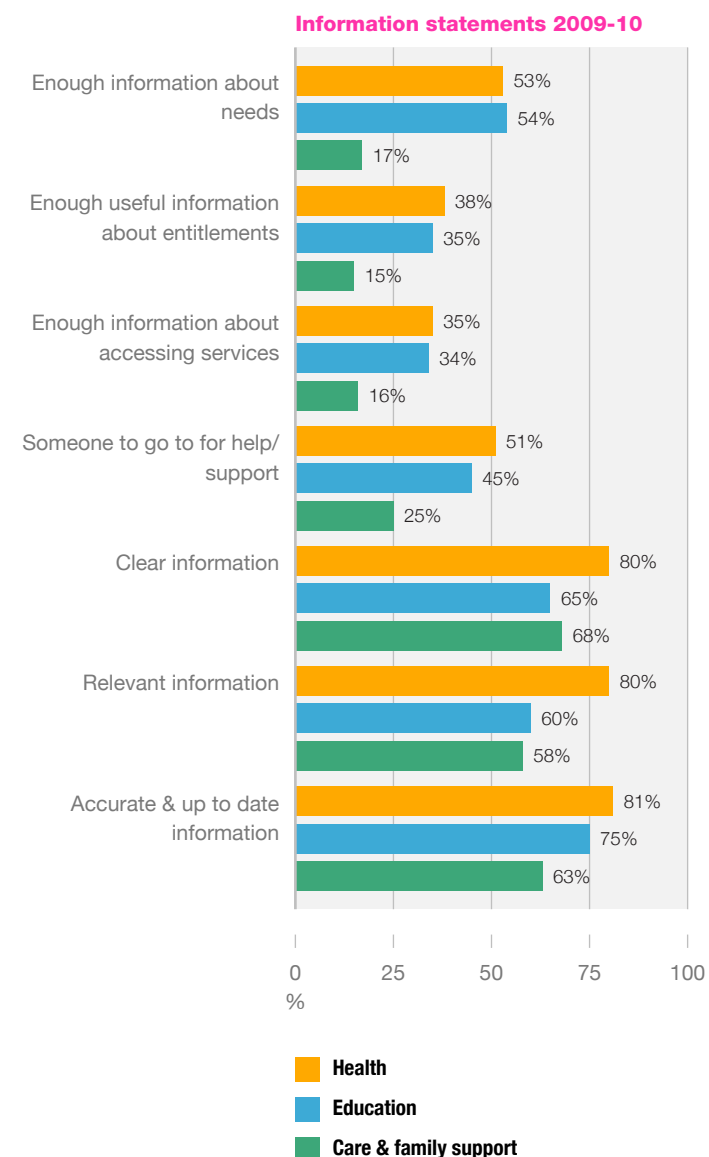
Parents were asked to give their opinion about the information they had received about health, education and care & family support services. Those who had received information were asked how often the information was clear to understand, relevant and accurate.

Table 2.1.1 below shows the percentage of parents who agreed with each of the four statements, and table 2.1.2 shows the percentage of parents who said that the information they received was always clear, always relevant or always accurate.

### 2.1.1 Information statements (1) – percentage agreeing

Cumbria PCT, 2009-10	Health	Education	Care & family support
We/I have been given enough information about my child's disability or health condition/educational needs/our care & family support needs	53% n=192	54% n=186	17% n=185
We/I have been given enough useful information about the health/education/care & family support services my child/family is entitled to	38% n=189	35% n=186	15% n=185
We/I have been given enough information about how to get health/education/care & family support services for my child	35% n=190	34% n=185	16% n=185
There is someone we/I can go to for help and support in getting health/education/care & family support services for my child	51% n=188	45% n=183	25% n=185

Base: All parents of disabled children



### 2.1.2 Information statements (2) – percentage choosing ‘always’

Cumbria PCT, 2009-10	Health	Education	Care & family support
In the last 12 months, how often was the information you received about health/education/care & family support services clear to understand?	80% n=60	65% n=80	68% ⚠ n=36
In the last 12 months, how often was the information you received about health/education/care & family support services relevant to you and your child?	80% n=59	60% n=76	58% ⚠ n=31
In the last 12 months, how often was the information you received about health/education/care & family support services accurate and up to date?	81% n=58	75% n=78	63% ⚠ n=32
Base: All who had received information			

## 2.2 Assessment

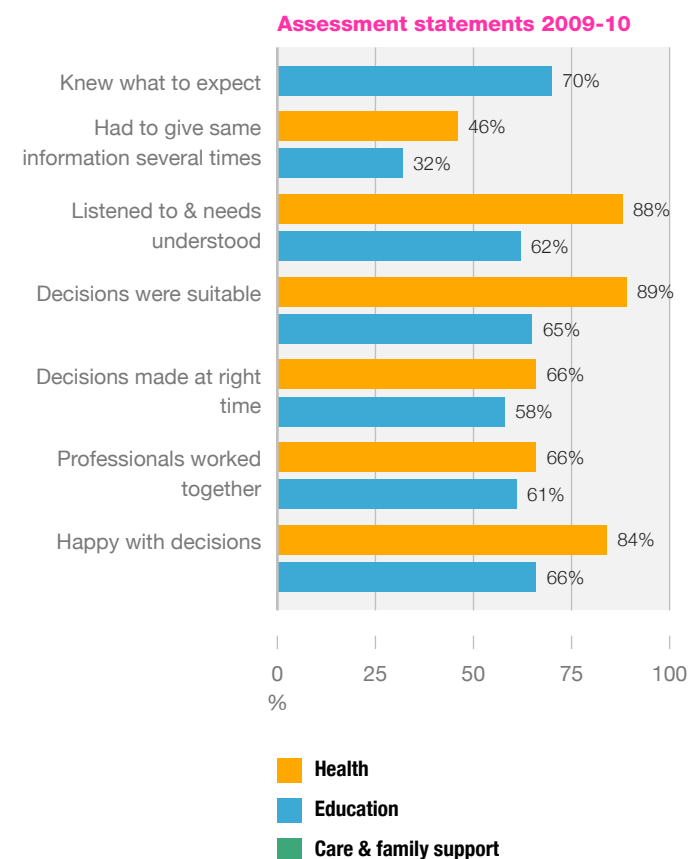
Parents were asked their opinions about the assessment process used for making decisions about the services their child would receive. The table below shows the percentage of parents agreeing with each statement about the assessment process.

It should be noted that agreement with statement two 'We/I had to give the same information several times' represents a negative response.

### 2.2.1 Assessment statements – percentage agreeing

Cumbria PCT, 2009-10	Health	Education	Care & family support
We/I knew what to expect from the assessment	n/a	70% n=98	n/a
We/I had to give the same information several times	46% n=81	32% n=94	• n<30
We were/I was listened to and our needs were understood	88% n=82	62% n=95	• n<30
The decisions made were suitable for my child's needs	89% n=82	65% n=93	• n<30
The decisions were made at the right time for my child	66% n=82	58% n=92	• n<30
Where necessary the health/education/care & family support professionals worked together to make decisions	66% n=82	61% n=95	• n<30
On the whole we were happy with the decisions that were made	84% n=82	66% n=97	• n<30

Base: All who had an assessment or decisions made about their child





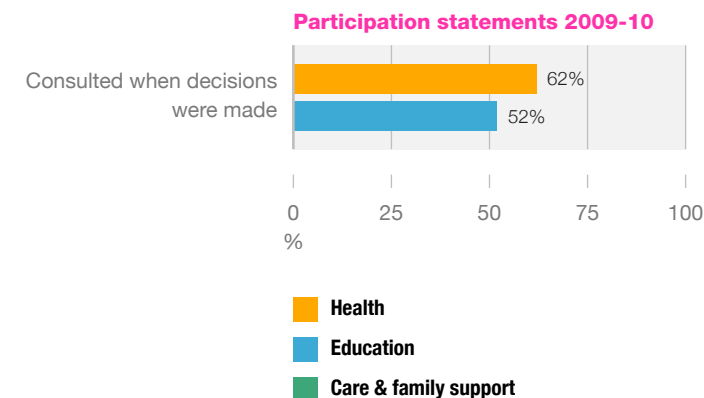
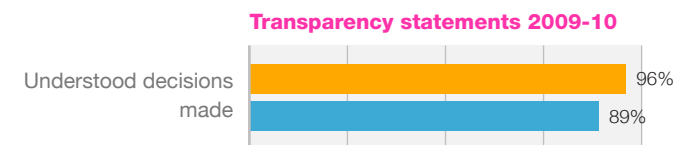
## 2.3 Transparency

Providing greater transparency about decisions is one of the elements of the core offer. To measure this element parents were asked how well they understood the decisions that were made about the services their child received.

### 2.3.1 Transparency statements – percentage choosing ‘very’ or ‘fairly well’

Cumbria PCT, 2009-10	Health	Education	Care & family support
How well do you understand the decisions that have been made about which health/education/care & family support services your child receives?	96% n=83	89% n=99	• n<30

Base: All who had an assessment or decisions made about their child



## 2.4 Participation

Participation is another element of the core offer and parents were therefore asked to what extent they felt they were consulted or asked for their opinions when decisions were being made about their child. The table below shows the percentage of parents who felt they were consulted a lot when decisions were made about their child.

### 2.4.1 Participation statements – percentage saying they were consulted a lot

Cumbria PCT, 2009-10	Health	Education	Care & family support
Over the last 12 months, were you consulted when decisions were being made about the health/education/care & family support services your child receives?	62% n=83	52% n=100	• n<30

Base: All who had an assessment or decisions made about their child

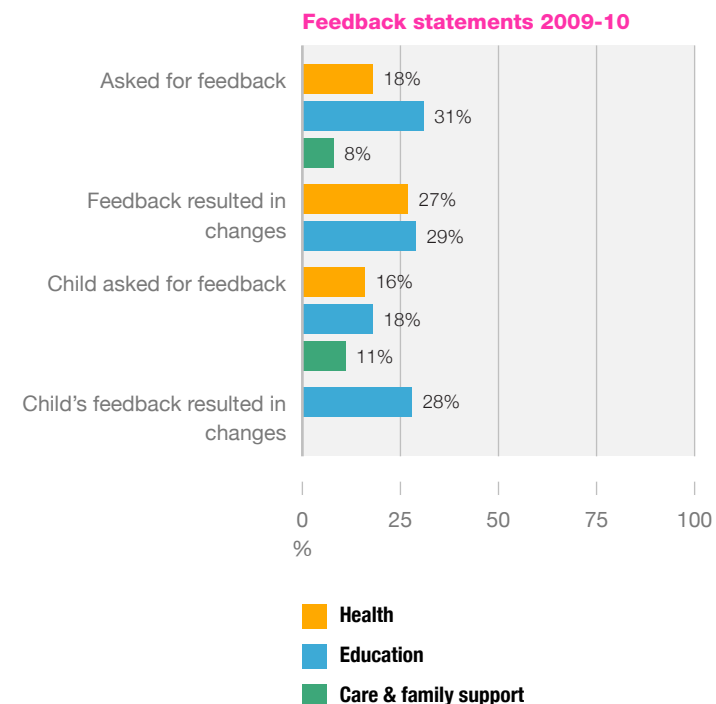
## 2.5 Feedback

As in the 2008-09 survey, feedback was shown to be an area where the indicator showed particularly low scores. Parents were asked in the survey whether they or their children were asked for their opinion or feedback about the services they received and if so whether they thought changes were made as a result of the feedback they gave. The table below shows the percentage of parents who answered 'yes' at these questions. Parents were also asked about the complaints process but so few parents had complained that there were not sufficient responses for analysis.

### 2.5.1 Feedback statements – percentage choosing 'yes'

Cumbria PCT, 2009-10	Health	Education	Care & family support
Over the last 12 months, have you been asked for your opinion on the health/education/care & family support services your child received? <sup>1</sup>	18% n=191	31% n=190	8% n=187
Do you think that changes were made as a result of the feedback you gave? <sup>2</sup>	27% ▲ n=39	29% n=73	● n<30
Over the last 12 months, has your child been asked for their opinion on the health/education/care & family support services he or she received? <sup>1</sup>	16% n=173	18% n=190	11% n=82
Do you think that changes were made as a result of the feedback your child gave? <sup>2</sup>	● n<30	28% ▲ n=43	● n<30


Base: (1) All parents of disabled children, (2) All who were asked for feedback



# 3 Additional feedback

Parents were also asked additional questions about whether their child had received all the services that they required and how parents themselves rated the quality of the services their child had received.

This section gives details about which services parents had used, whether they felt they received the services they needed, how they rated these services and any additional comments parents wanted to make about the services they had received.



**A spreadsheet containing a more detailed list of comments is attached here in the electronic version of this report.**

## 3.1 Health care services

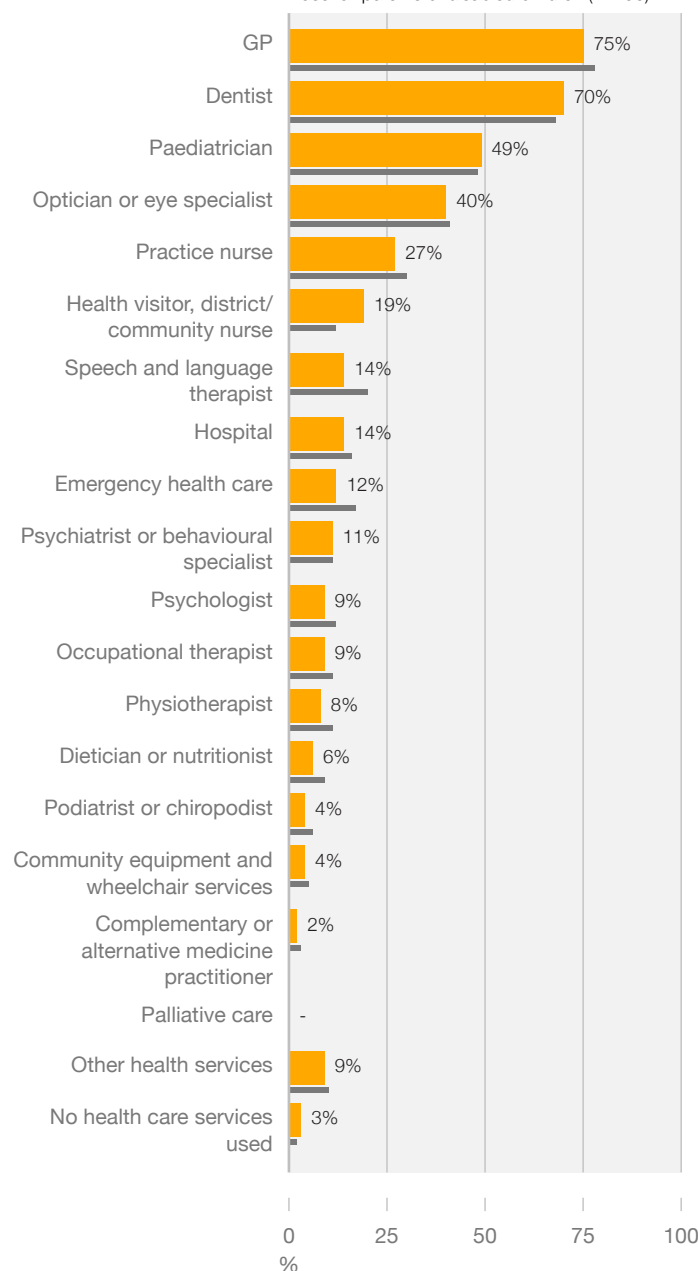
Parents were asked to indicate which health services they had used in the last 12 months for their child. Chart 3.1.1 shows the proportion of parents who had used each service.

In addition to the questions used to create the national indicator, the survey also asked parents whether their child had received all the health care services that they required and how parents themselves rated the quality of the health care services their child had received.

■ Cumbria PCT  
■ National

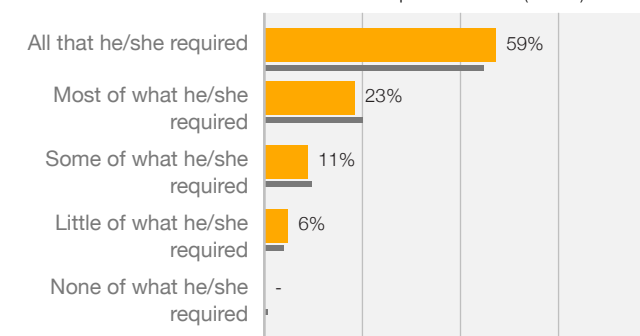
3.1.1 Health care services used in the last 12 months

Base: all parents of disabled children (n=193)



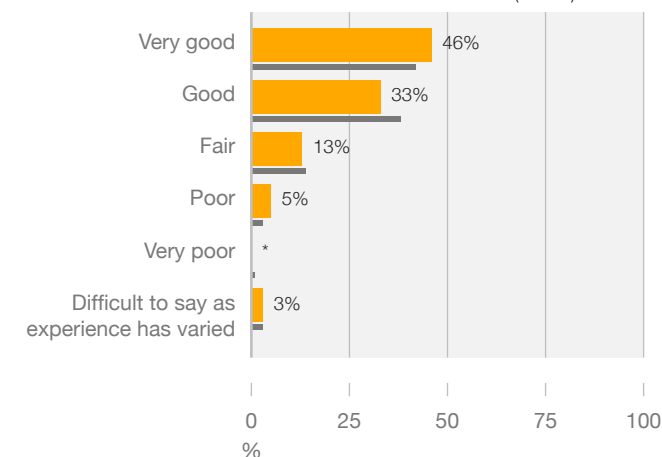
3.1.2 Level of health care services received for child over the last 12 months

Base: all who required a service (n=185)



3.1.3 Quality of health care services received in the last 12 months

Base: all who had used services (n=188)



## 3.2 Health care comments

Parents were asked if there was anything else they would like to say about the health care services their child had received that had not been covered in the survey. Parents' individual comments were summarised and grouped into key topic areas and these are shown in Table 3.2.1.

The tables to the right provide greater insight into the specific comments parents made about the health care services their child received. The most frequently mentioned comments for the top four topic areas are listed.

### 3.2.1 Topics for comments on health care services

Cumbria PCT, 2009-10	Total
Positive feedback about the Health Care Services received	45%
Negative feedback about the Health Care Services received	26%
Lack of Health Care Services available	20%
Difficulties/issues when accessing Health Care Services	18%
Poor communication and information	16%
Lack of understanding of child's condition	15%
Difficulties/issues arranging appointments	12%
Difficulties or issues with child's diagnosis	7%
Other	19%
No/Nothing/Not Applicable	3%
Don't know	-
Base: all who commented	74

#### Topic 1 Positive feedback about the Health Care Services received

GP/GP's surgery is good  
Healthcare services are good  
Hospital staff/service is good  
Community nurses are good

#### Topic 2 Negative feedback about the Health Care Services received

Quality of services erratic  
CAMHS is poor  
Paediatrician is poor  
Dentist/dental service is poor

#### Topic 3 Lack of Health Care Services available

Services not available locally  
Had to resort to Private healthcare  
No support provided for child  
Healthcare services have been cut or reduced

#### Topic 4 Difficulties/issues when accessing Health Care Services

Frustrating/difficult process  
Lengthy process/all takes so long  
Availability of services a postcode lottery  
Healthcare services had to be found by myself

### 3.3 Education services

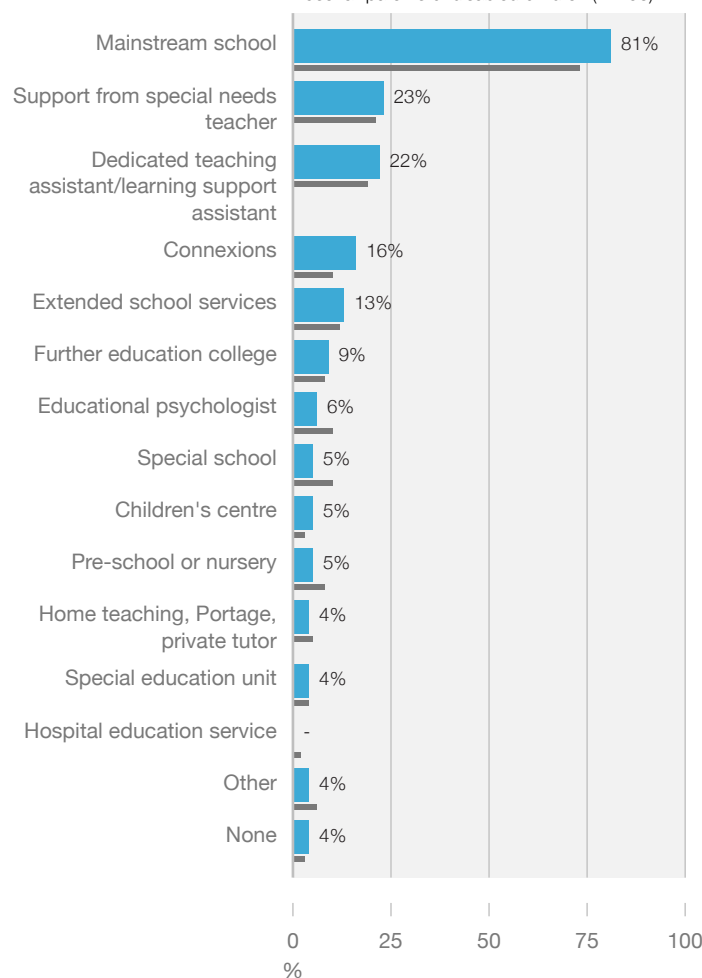
Parents were asked to indicate which education services they had used in the last 12 months for their child. Chart 3.3.1 shows the proportion of parents who had used each service.

In addition to the questions used to create the national indicator, the survey also asked parents whether their child had received all the education services that they required and how parents themselves rated the quality of the education services their child had received.

■ Cumbria PCT  
■ National

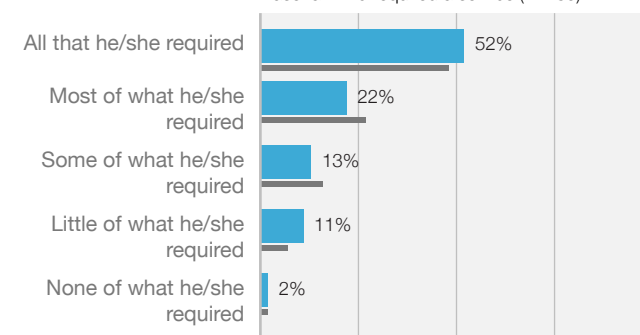
3.3.1 Education services used in the last 12 months

Base: all parents of disabled children (n=193)



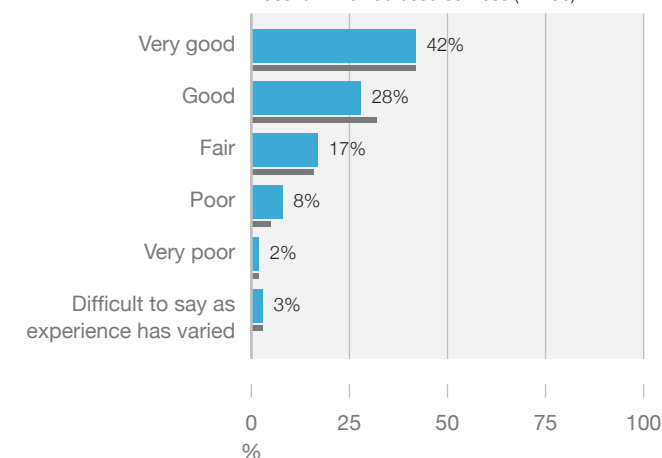
3.3.2 Level of education services received for child over the last 12 months

Base: all who required a service (n=185)



3.3.3 Quality of education services received in the last 12 months

Base: all who had used services (n=190)



## 3.4 Education comments

Parents were asked if there was anything else they would like to say about the education services their child had received that had not been covered in the survey. Parents' individual comments were summarised and grouped into key topic areas and these are shown in Table 3.4.1.

The tables to the right provide greater insight into the specific comments parents made about the education services their child received. The most frequently mentioned comments for the top four topic areas are listed.

### 3.4.1 Topics for comments on education services

Cumbria PCT, 2009-10	Total
Positive feedback about the Education Services received	44%
Lack of Education Services available	30%
Negative feedback about the Education Services received	21%
Poor communication and information	17%
Difficulties or issues accessing Education Services	15%
Lack of understanding of child's condition	12%
Other	15%
No/Nothing/Not Applicable	6%
Don't know	-
Base: all who commented	77

#### Topic 1 Positive feedback about the Education Services received

Pleased or happy with the school

The school is supportive

The school is helpful

Child has improved or done well at this school

#### Topic 2 Lack of Education Services available

The child needs more help or support at the school

The child's needs were not met

Lack of support for special needs in post-16 education

Medical/medication needs are not met

#### Topic 3 Negative feedback about the Education Services received

Feel child has been let down by the school/ education system

Parent does not like the school/thinks it is not very good

Moved to another school as previous school inadequate

Child is bullied or struggling socially

#### Topic 4 Poor communication and information

Lack of communication from school to parents about the child

Need more information on services child is entitled to

Lack of communication within school about the child's needs

Education, Health & Social Services do not co-operate

## 3.5 Care & family support services

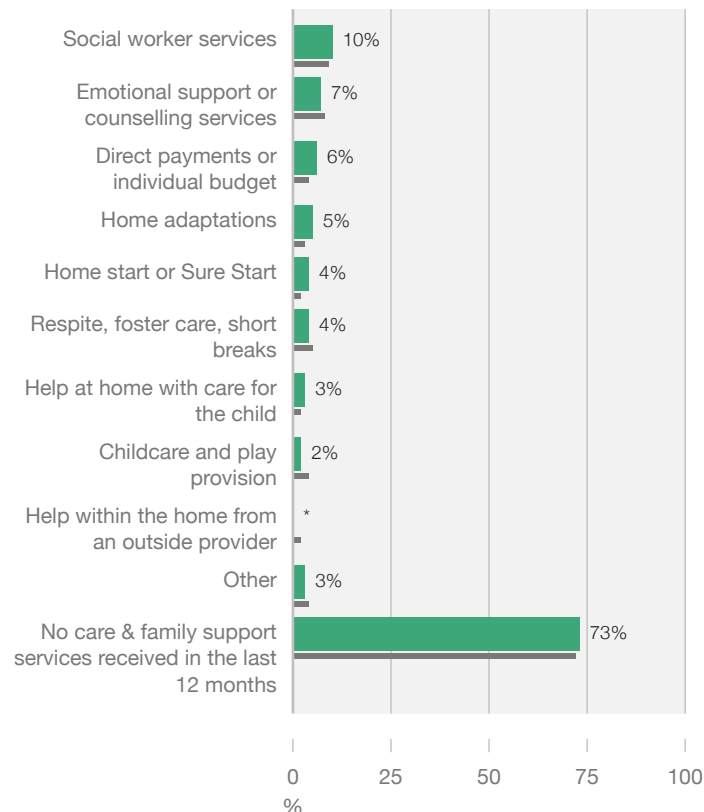
Parents were asked to indicate which care & family support services they had used in the last 12 months for their child. Chart 3.5.1 shows the proportion of parents who had used each service.

In addition to the questions used to create the national indicator, the survey also asked parents whether they and their family had received all the care & family support services that they required and how parents themselves rated the quality of the care & family support services their family had received.

■ Cumbria PCT  
— National

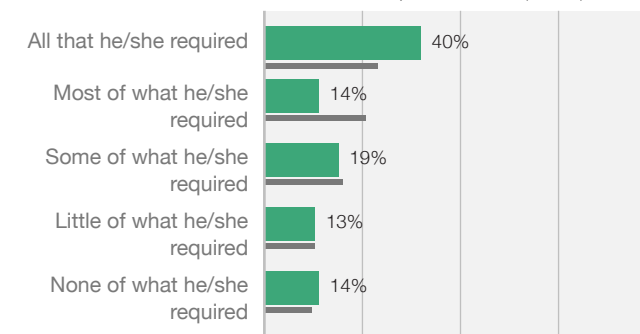
### 3.5.1 Care & family support services used in the last 12 months

Base: all parents of disabled children (n=193)



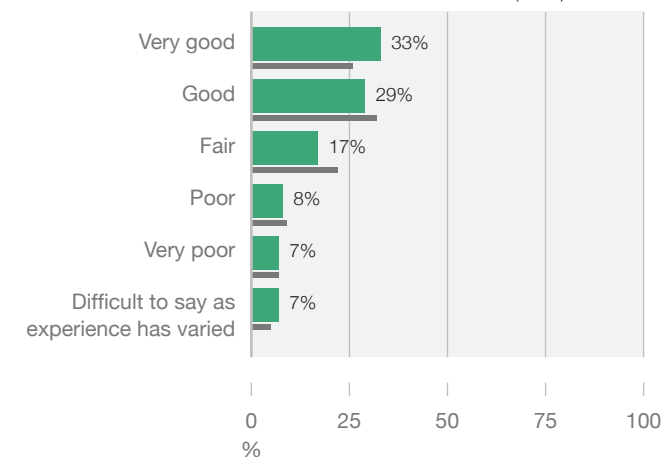
### 3.5.2 Level of care & family support services received over the last 12 months

Base: all who required a service (n=116)



### 3.5.3 Quality of care & family support services received in the last 12 months

Base: all who had used services (n=97)





## 3.6 Care & family support comments

Parents were asked if there was anything else they would like to say about the care & family support services their child had received that had not been covered in the survey. Parents' individual comments were summarised and grouped into key topic areas and these are shown in Table 3.6.1.

The tables to the right provide greater insight into the specific comments parents made about the care & family support services their child received. The most frequently mentioned comments for the top four topic areas are listed.

### 3.6.1 Topics for comments on care & family support services

Cumbria PCT, 2009-10	Total
Lack of Care & Family Support Services available	13%
Difficulties or issues accessing Care & Family Support Services	13%
Poor communication and information	12%
Positive feedback about the Care & Family Support Services received	11%
Lack of understanding of child's condition	9%
Negative feedback about the Care & Family Support Services received	8%
Other	31%
No/Nothing/Not Applicable	29%
Don't know	-
Base: all who commented	43

#### Topic 1 Lack of Care & Family Support Services available

No help or support available  
Not enough funding available  
Shortage of staff  
Need more respite care

#### Topic 2 Difficulties or issues accessing Care & Family Support Services

Had to fight for social care services  
It takes a long time to get the assistance that we are entitled to  
Too much red tape / bureaucratic process  
If you appear / are able to cope alone, it can be difficult

#### Topic 3 Poor communication and information

Don't know what help is available/ entitled to  
No feedback / follow-up received / no reviews

#### Topic 4 Positive feedback about the Care & Family Support Services received

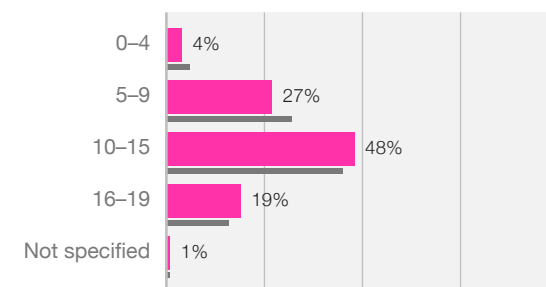
Individuals are / have been excellent / good  
Excellent / good / no complaints  
Good support / help from school  
Plenty of help and support available

# 4 Demographics

#### 4.1 Age of child

Cumbria PCT, 2009-10	Total	All areas
0-4	4%	6%
5-9	27%	32%
10-15	48%	45%
16-19	19%	16%
Not specified	1%	1%
Base: all parents of disabled children	193	31466

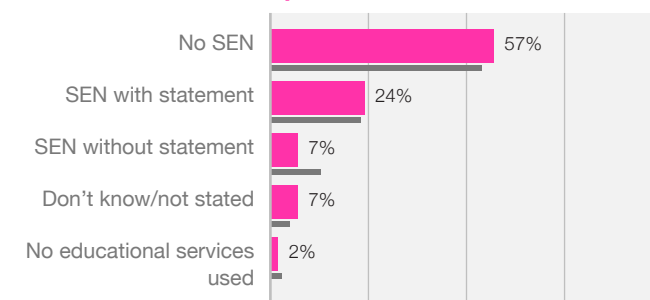
#### 4.1 Age of child



#### 4.2 Special educational needs of child

Cumbria PCT, 2009-10	Total	All areas
No SEN	57%	54%
SEN with statement	24%	23%
SEN without statement	7%	13%
Don't know/not stated	7%	5%
No educational services used	2%	3%
Base: all parents of disabled children	193	31466

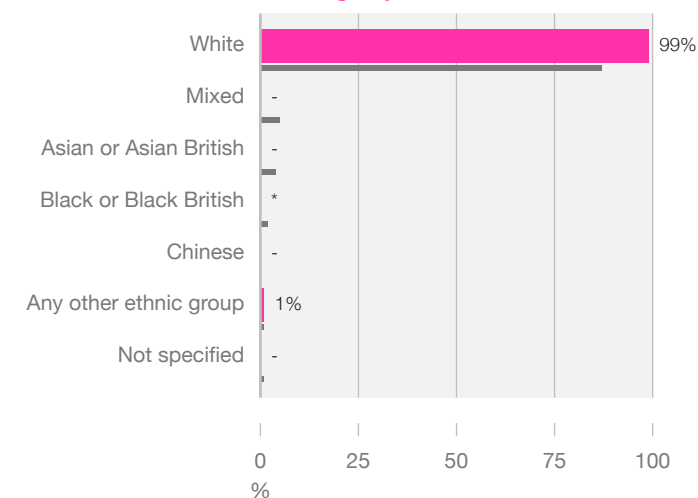
#### 4.2 Special educational needs of child



#### 4.3 Ethnic group of child

Cumbria PCT, 2009-10	Total	All areas
White	99%	87%
Mixed	-	5%
Asian or Asian British	-	4%
Black or Black British	*	2%
Chinese	-	*
Any other ethnic group	1%	1%
Not specified	-	1%
Base: all parents of disabled children	193	31466

#### 4.3 Ethnic group of child



#### 4.4 Areas in which child is affected by illness, disability or condition

Cumbria PCT, 2009-10	% of those receiving DLA	% of those with SEN	Total	All areas
Learning	60%	77%	<b>32%</b>	34%
Behaviour	52%	47%	<b>30%</b>	30%
Personal care	63%	47%	<b>29%</b>	23%
Communication	51%	60%	<b>26%</b>	28%
Mobility	46%	32%	<b>18%</b>	18%
Medication	27%	7%	<b>16%</b>	12%
Incontinence	30%	20%	<b>15%</b>	12%
Eating and drinking	27%	19%	<b>13%</b>	14%
Hand function	24%	19%	<b>11%</b>	11%
Vision	14%	14%	<b>11%</b>	13%
Hearing	10%	16%	<b>10%</b>	10%
Autism/Asperger Syndrome/ASD	24%	25%	<b>10%</b>	14%
Consciousness	12%	6%	<b>5%</b>	5%
Depression	12%	6%	<b>5%</b>	5%
Palliative care needs	1%	1%	<b>1%</b>	1%
Other	15%	15%	<b>20%</b>	20%
No illness, disability or condition indicated in main survey, <sup>†</sup> however:	-	1%	<b>14%</b>	19%
<b>a.</b> an illness, disability or condition indicated in screener survey	-	1%	<b>9%</b>	10%
<b>b.</b> medication, physical aid or special diet or supplements successfully used to manage an illness, disability or conditions reported in screener survey	-	-	<b>5%</b>	9%
Not specified	-	*	<b>*</b>	2%
Base: all parents of disabled children in category. (†) A full analysis of this group at national level is provided in the main research report.	84	109	<b>193</b>	31466

#### 4.5 Level of DLA receipt

Cumbria PCT, 2009-10	Total	All areas
High DLA	<b>12%</b>	11%
Any DLA	<b>34%</b>	29%
No DLA	<b>66%</b>	70%
Not specified	-	1%
Base: all parents of disabled children	<b>193</b>	31466

#### 4.6 Number of illnesses, disabilities or conditions child affected by

Cumbria PCT, 2009-10	% of those receiving DLA	% of those with SEN	Total	All areas
None	-	1%	<b>14%</b>	19%
1 health problem/condition	12%	23%	<b>33%</b>	30%
2 to 4 health problems/conditions	45%	40%	<b>36%</b>	29%
5 or more health problems/conditions	43%	36%	<b>17%</b>	20%
Not specified	-	*	*	2%
Base: all parents of disabled children in category	84	109	<b>193</b>	31466