

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

# National AHDC results

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 local areas 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 national average findings based on the 31466 questionnaires which were completed by parents of disabled children across England. Within the report, \* shows a value less than 0.5 but not 0, **n/a** indicates a question was not asked in a given category and **n=** shows the base, or number of respondents, for a given result.

## Contents

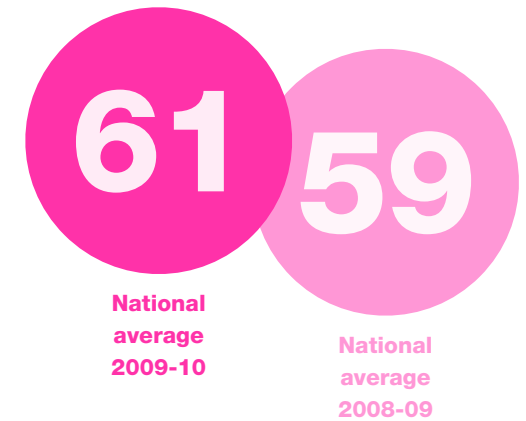
1.1	Introduction	2
1.2	The indicator	3
<b>2</b>	<b>The five core offer areas</b>	<b>4</b>
2.1	Information	5
2.2	Assessment	7
2.3	Transparency	8
2.4	Participation	8
2.5	Feedback	9
<b>3</b>	<b>Additional feedback</b>	<b>10</b>
3.1	Health care services	11
3.2	Health care comments	12
3.3	Education services	13
3.4	Education comments	14
3.5	Care & family support services	15
3.6	Care & family support comments	16
<b>4</b>	<b>Demographics</b>	<b>17</b>

## 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 local areas where an indicator score was produced, scores ranged from 55 to 68. The national rating was 59 in 2008-09.

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>

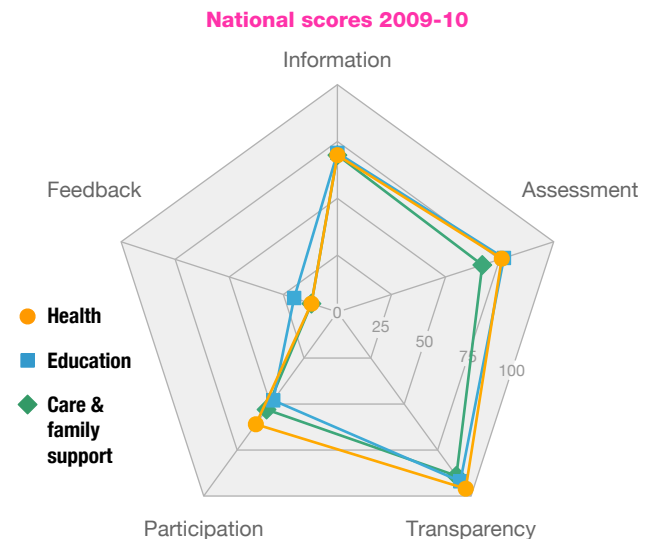


### 1.1 National scores

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



## 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

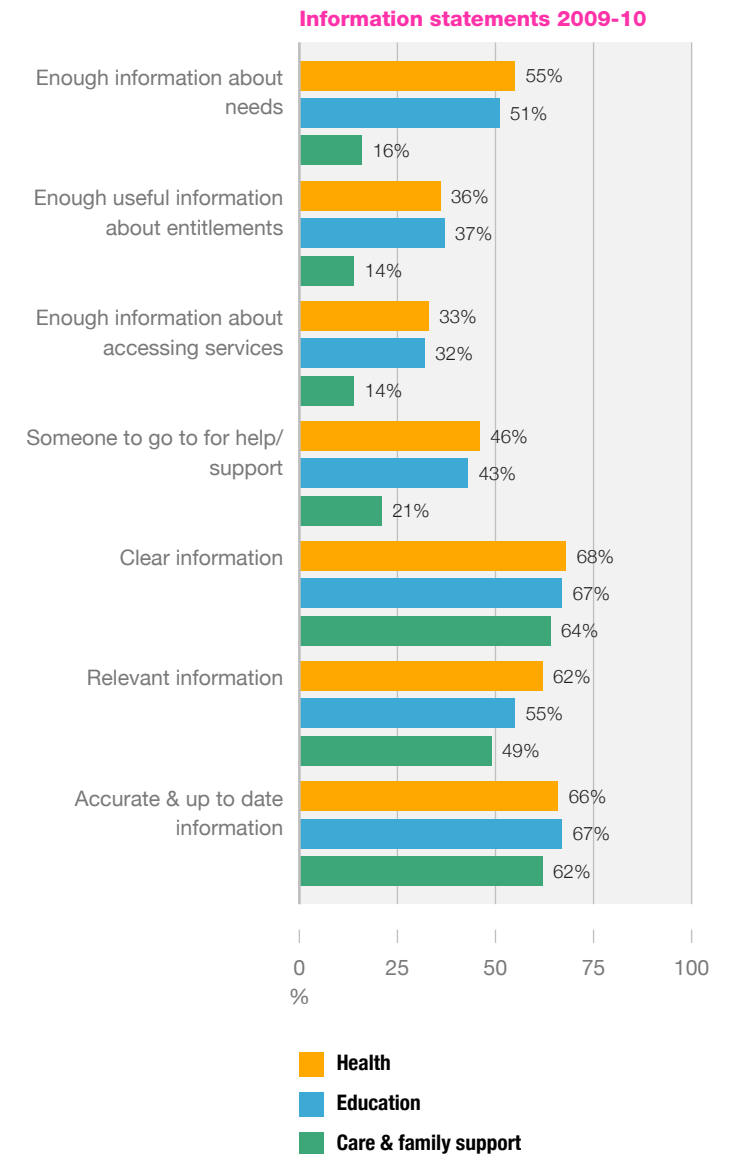
Parents were asked to give their opinion about the information they had received about health, education and care & family support services. Those who had received information were asked how often the information was clear to understand, relevant and accurate.

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

	Health		Education		Care & family support	
	2009-10	2008-09	2009-10	2008-09	2009-10	2008-09
	Shaded: All areas, 2008-09					
We/I have been given enough information about my child's disability or health condition/educational needs/our care & family support needs	55%	54%	51%	52%	16%	24%
	n=30891	11910	n=29750	11350	n=30198	3751
We/I have been given enough useful information about the health/education/care & family support services my child/family is entitled to	36%	34%	37%	36%	14%	22%
	n=30591	11763	n=29501	11278	n=30046	3742
We/I have been given enough information about how to get health/education/care & family support services for my child	33%	32%	32%	30%	14%	23%
	n=30535	11718	n=29437	11250	n=30023	3732
There is someone we/I can go to for help and support in getting health/education/care & family support services for my child	46%	45%	43%	42%	21%	35%
	n=30532	11714	n=29391	11244	n=30011	3735

Base: All parents of disabled children



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

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
	In the last 12 months, how often was the information you received about health/education/care & family support services clear to understand?	68% n=10452	66% 3834	67% n=12372	65% 4438	64% n=4931
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?	62% n=9876	61% 3620	55% n=11903	55% 4270	49% n=4728	44% 1392
In the last 12 months, how often was the information you received about health/education/care & family support services accurate and up to date?	66% n=9613	63% 3525	67% n=11706	67% 4190	62% n=4636	59% 1355

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.

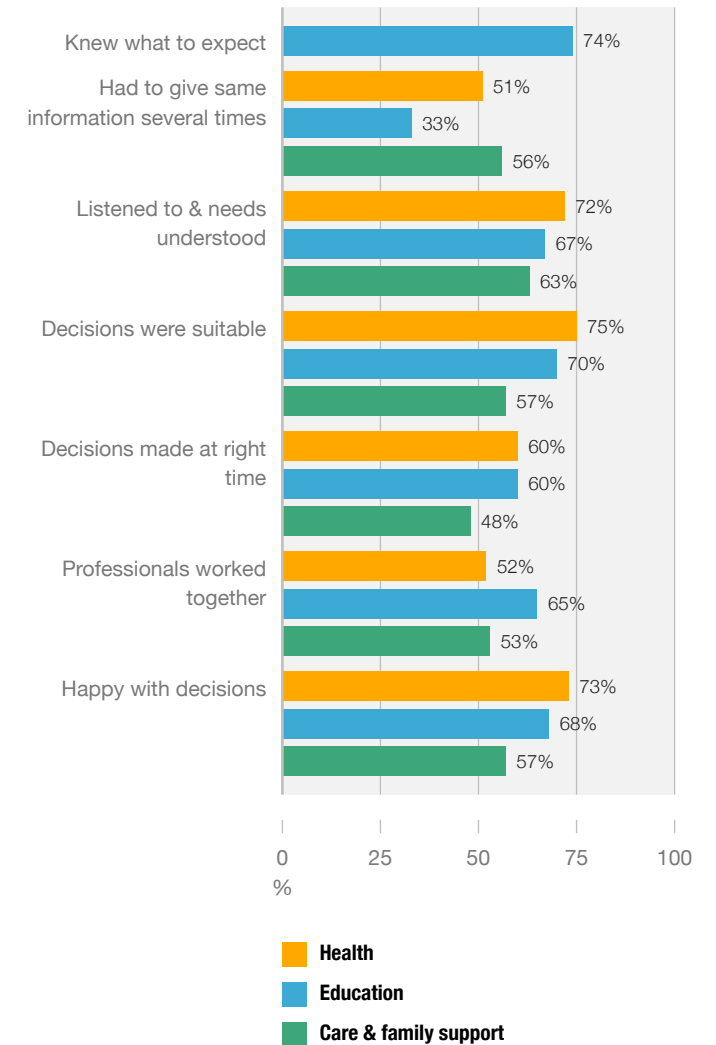
It should be noted that agreement with statement two ‘We/I had to give the same information several times’ represents a negative response.

### 2.2.1 Assessment statements – percentage agreeing

All areas, 2009-10	Health		Education		Care & family support	
	Shaded: All areas, 2008-09					
	2009-10	2008-09	2009-10	2008-09	2009-10	2008-09
We/I knew what to expect from the assessment	n/a	n/a	74%	74%	n/a	n/a
			n=13379	4681		
We/I had to give the same information several times	51%	54%	33%	33%	56%	60%
	n=13360	5097	n=13158	4579	n=3743	1207
We were/I was listened to and our needs were understood	72%	72%	67%	68%	63%	61%
	n=13405	5148	n=13271	4655	n=3764	1207
The decisions made were suitable for my child’s needs	75%	76%	70%	70%	57%	55%
	n=13463	5171	n=13318	4673	n=3754	1205
The decisions were made at the right time for my child	60%	59%	60%	60%	48%	44%
	n=13358	5129	n=13228	4640	n=3737	1190
Where necessary the health/education/care & family support professionals worked together to make decisions	52%	51%	65%	65%	53%	53%
	n=13383	5145	n=13294	4658	n=3731	1189
On the whole we were happy with the decisions that were made	73%	72%	68%	68%	57%	55%
	n=13470	5198	n=13335	4663	n=3744	1194

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

Assessment statements 2009-10



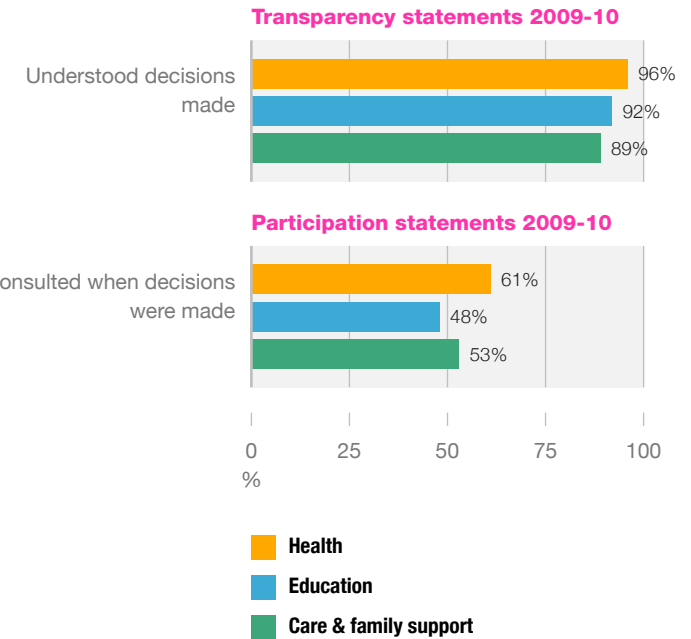
## 2.3 Transparency

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’

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
	How well do you understand the decisions that have been made about which health/education/care & family support services your child receives?	96% n=13720	96% 5330	92% n=13424	92% 4738	89% n=3809

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

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
	Over the last 12 months, were you consulted when decisions were being made about the health/education/care & family support services your child receives?	61% n=13698	60% 5313	48% n=13435	50% 4768	53% n=3808

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



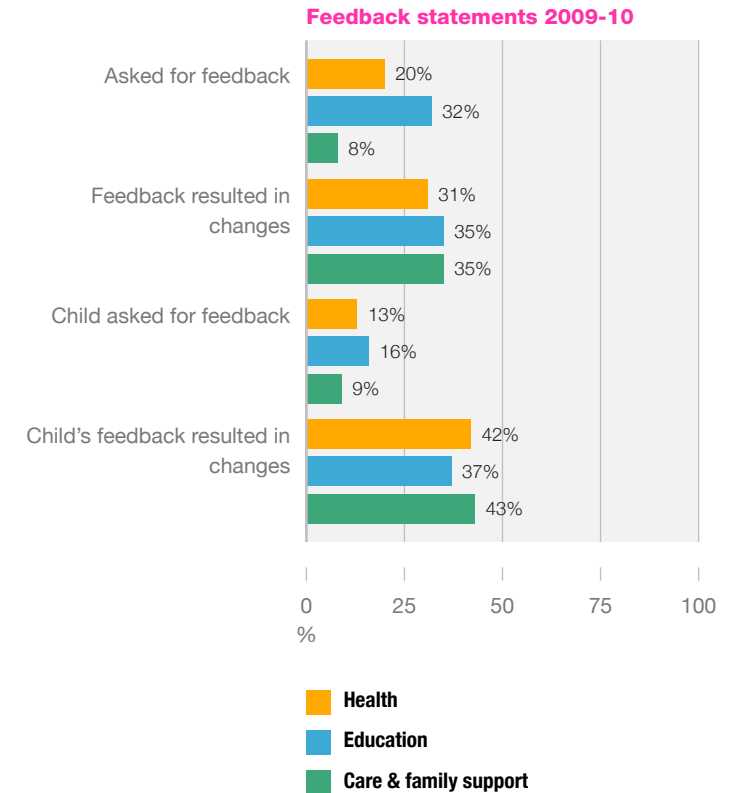
## 2.5 Feedback

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'

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
	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>	20% n=31058	19% 11963	32% n=30084	36% 11561	8% n=30569
Do you think that changes were made as a result of the feedback you gave? <sup>2</sup>	31% n=6938	33% 2411	35% n=10559	35% 4102	35% n=3062	38% 881
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>	13% n=29014	13% 11141	16% n=30099	18% 11514	9% n=13580	9% 4277
Do you think that changes were made as a result of the feedback your child gave? <sup>2</sup>	42% n=3606	44% 1400	37% n=5337	37% 2148	43% n=1225	46% 398

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.**



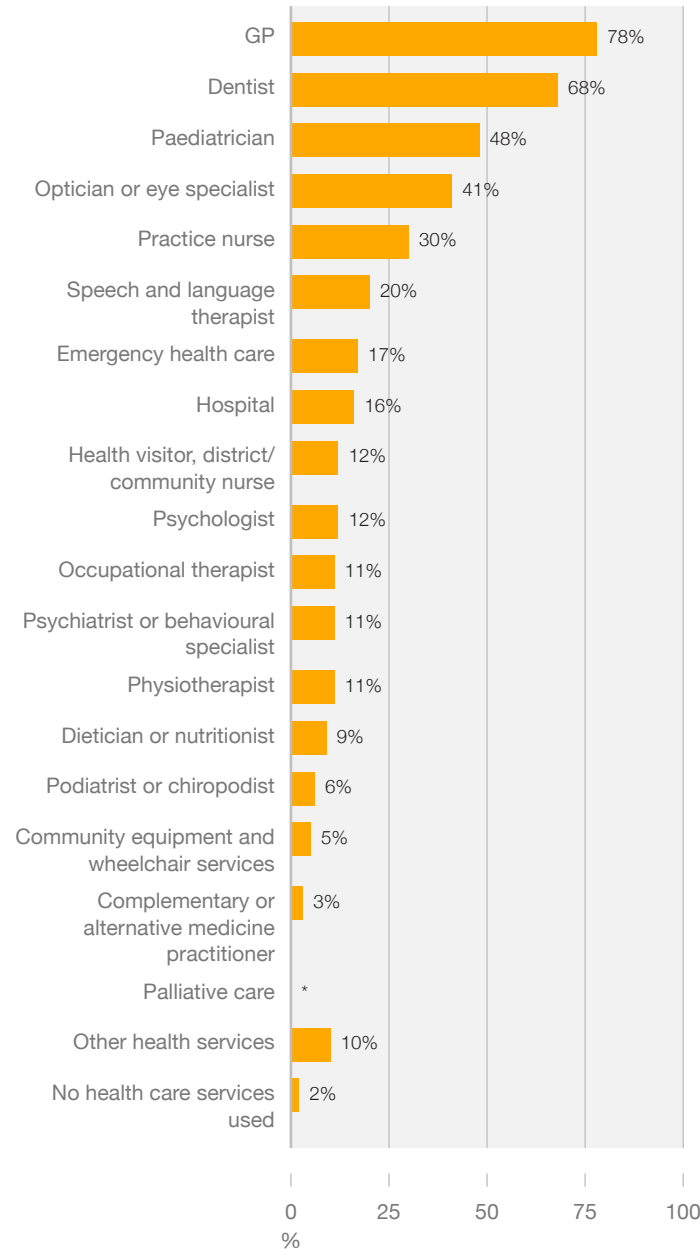
### 3.1 Health care services

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.

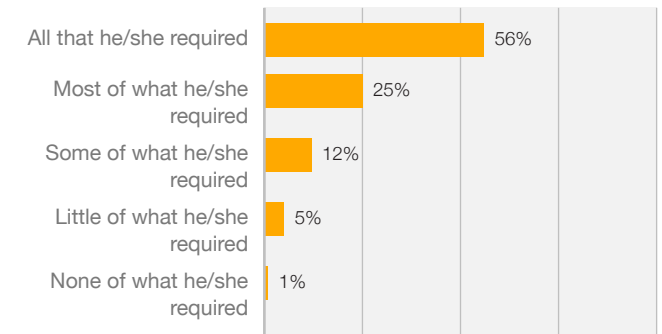
3.1.1 Health care services used in the last 12 months

Base: all parents of disabled children (n=31466)



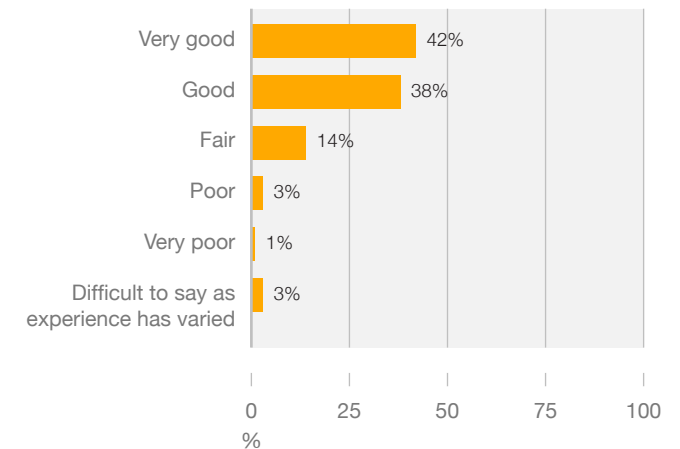
3.1.2 Level of health care services received for child over the last 12 months

Base: all who required a service (n=30270)



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

Base: all who had used services (n=30357)



## 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

All areas, 2009-10	Total
Positive feedback about the Health Care Services received	36%
Poor communication and information	22%
Negative feedback about the Health Care Services received	21%
Difficulties/issues when accessing Health Care Services	18%
Lack of Health Care Services available	18%
Lack of understanding of child's condition	14%
Difficulties/issues arranging appointments	12%
Difficulties or issues with child's diagnosis	8%
Other	26%
No/Nothing/Not Applicable	5%
Don't know	*
Base: all who commented	11833

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

Healthcare services are good  
 Hospital staff/service is good  
 GP/GP's surgery is good  
 HPs are helpful

#### Topic 2 Poor communication and information

Need more information on child's condition  
 HPs should realise that parent knows child best  
 Not enough communication between everyone involved  
 Not sure what help/benefits are available

#### Topic 3 Negative feedback about the Health Care Services received

GP/GP's surgery is poor  
 Quality of services erratic  
 Hospital staff/service is poor  
 CAMHS is poor

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

Frustrating/difficult process  
 Lengthy process/all takes so long  
 Healthcare services had to be found by myself  
 HPs have not helped with finding suitable services

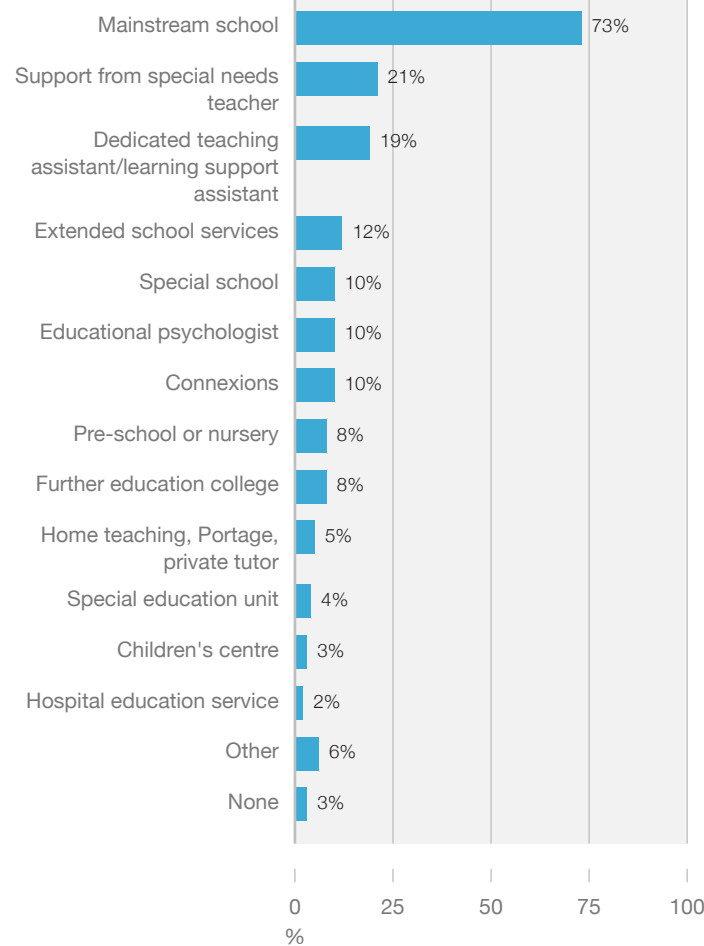
### 3.3 Education services

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.

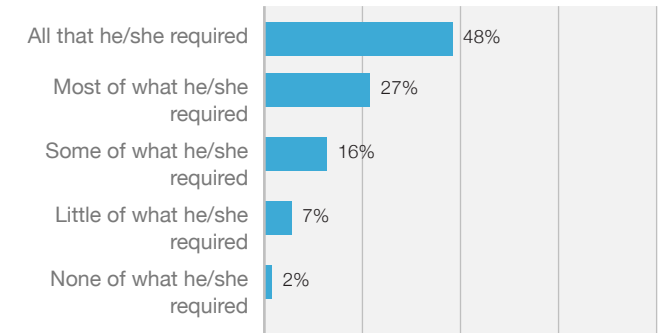
3.3.1 Education services used in the last 12 months

Base: all parents of disabled children (n=31466)



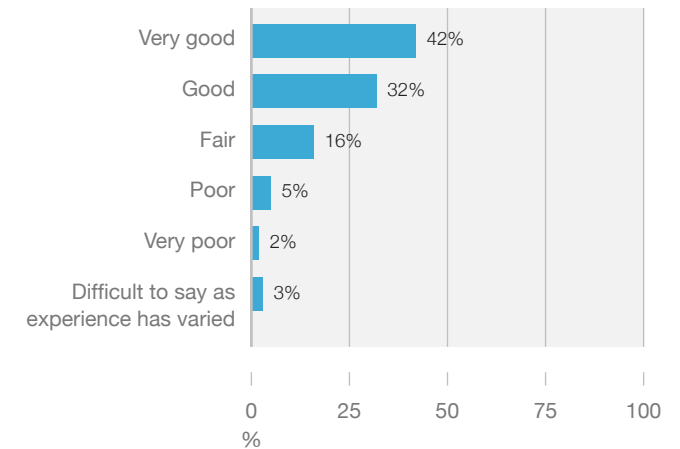
3.3.2 Level of education services received for child over the last 12 months

Base: all who required a service (n=30292)



3.3.3 Quality of education services received in the last 12 months

Base: all who had used services (n=30544)



## 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

All areas, 2009-10	Total
Positive feedback about the Education Services received	39%
Lack of Education Services available	29%
Difficulties or issues accessing Education Services	18%
Negative feedback about the Education Services received	18%
Poor communication and information	15%
Lack of understanding of child's condition	8%
Other	23%
No/Nothing/Not Applicable	7%
Don't know	*
Base: all who commented	11258

#### 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  
 There is not enough money for special needs  
 School does not have the right specialist skills

#### Topic 3 Difficulties or issues accessing Education Services

Parent had to fight for help to be given  
 Difficulty with getting a statement of SEN  
 LEA obstructive/no help from LEA  
 SEN service very poor/no support from SENCO

#### Topic 4 Negative feedback about the Education Services received

Feel child has been let down by the school/ education system  
 Child is bullied or struggling socially  
 Moved to another school as previous school inadequate  
 Parent does not like the school/thinks it is not very good

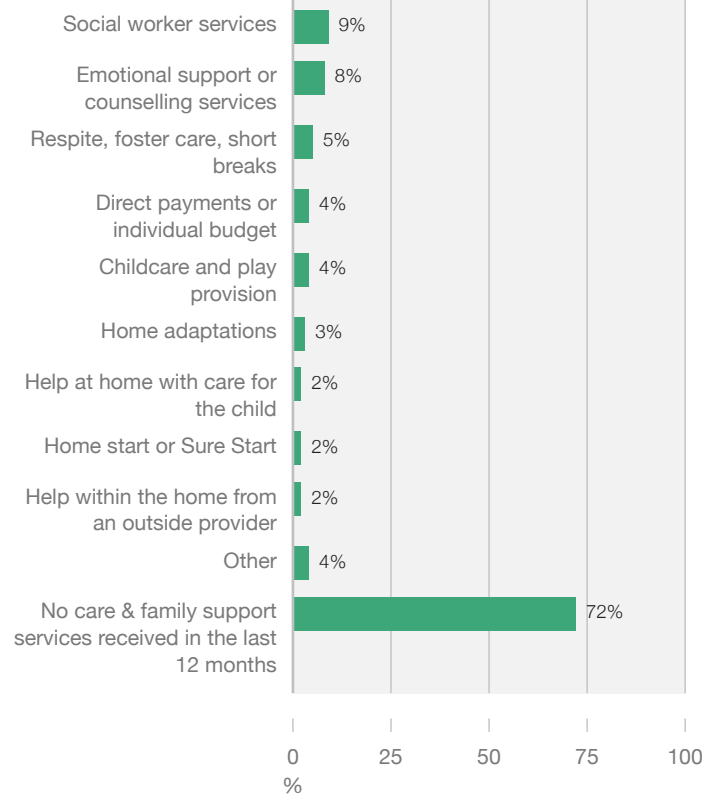
### 3.5 Care & family support services

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.

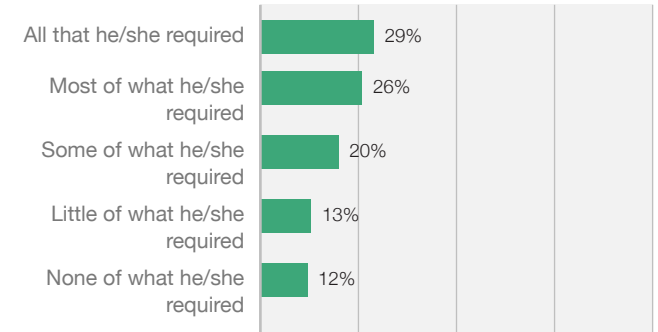
3.5.1 Care & family support services used in the last 12 months

Base: all parents of disabled children (n=31466)



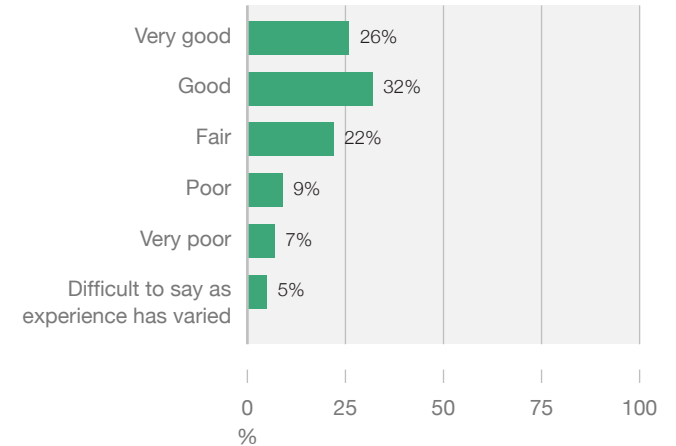
3.5.2 Level of care & family support services received over the last 12 months

Base: all who required a service (n=18440)



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

Base: all who had used services (n=14277)



## 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

All areas, 2009-10	Total
Lack of Care & Family Support Services available	25%
Poor communication and information	23%
Positive feedback about the Care & Family Support Services received	15%
Difficulties or issues accessing Care & Family Support Services	14%
Negative feedback about the Care & Family Support Services received	6%
Lack of understanding of child's condition	2%
Other	27%
No/Nothing/Not Applicable	24%
Don't know	*
Base: all who commented	7311

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

No help or support available  
 Feel in need of support with child's health problem  
 Support/help is needed for the whole family  
 Need more respite care

#### Topic 2 Poor communication and information

Don't know what help is available/ entitled to  
 No feedback / follow-up received / no reviews  
 Not enough communication between everyone involved  
 Need to listen to parents/ do not listen to parents

#### Topic 3 Positive feedback about the Care & Family Support Services received

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

#### Topic 4 Difficulties or issues accessing Care & Family Support Services

Have to find out about/organise services yourself  
 It takes a long time to get the assistance that we are entitled to  
 Had to fight for social care services  
 Turned down for respite care

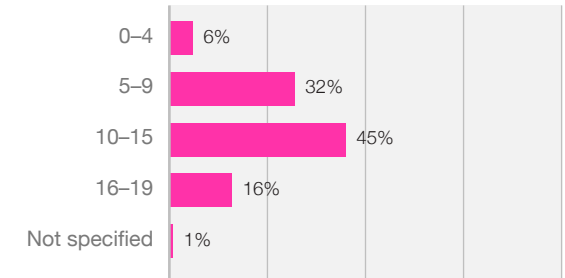


# 4 Demographics

#### 4.1 Age of child

All areas, 2009-10	Total
0-4	6%
5-9	32%
10-15	45%
16-19	16%
Not specified	1%
<hr/>	
Base: all parents of disabled children	31466

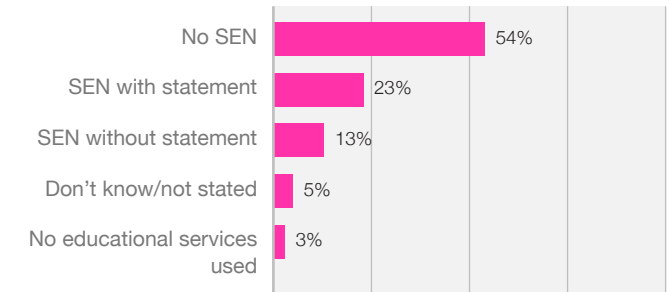
#### 4.1 Age of child



#### 4.2 Special educational needs of child

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

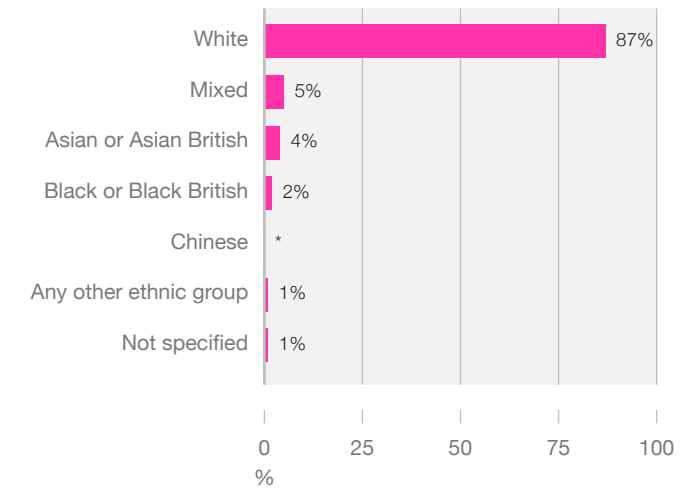
#### 4.2 Special educational needs of child



#### 4.3 Ethnic group of child

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

#### 4.3 Ethnic group of child



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

All areas, 2009-10	% of those receiving DLA	% of those with SEN	Total
Learning	70%	74%	<b>34%</b>
Behaviour	61%	56%	<b>30%</b>
Communication	61%	54%	<b>28%</b>
Personal care	63%	44%	<b>23%</b>
Mobility	52%	34%	<b>18%</b>
Autism/Asperger Syndrome/ASD	36%	31%	<b>14%</b>
Eating and drinking	34%	23%	<b>14%</b>
Vision	17%	16%	<b>13%</b>
Incontinence	27%	19%	<b>12%</b>
Medication	31%	17%	<b>12%</b>
Hand function	28%	22%	<b>11%</b>
Hearing	12%	12%	<b>10%</b>
Consciousness	12%	8%	<b>5%</b>
Depression	8%	6%	<b>5%</b>
Palliative care needs	3%	2%	<b>1%</b>
Other	18%	17%	<b>20%</b>
No illness, disability or condition indicated in main survey, <sup>1</sup> however:	1%	2%	<b>19%</b>
<i>a. an illness, disability or condition indicated in screener survey</i>	*	1%	<b>10%</b>
<i>b. medication, physical aid or special diet or supplements successfully used to manage an illness, disability or conditions reported in screener survey</i>	*	1%	<b>9%</b>
Not specified	*	1%	<b>2%</b>
Base: all parents of disabled children in category. (1) A full analysis of this group at national level is provided in the main research report.	12642	17200	<b>31466</b>

#### 4.5 Level of DLA receipt

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

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

All areas, 2009-10	% of those receiving DLA	% of those with SEN	Total
None	1%	2%	<b>19%</b>
1 health problem/condition	6%	15%	<b>30%</b>
2 to 4 health problems/conditions	34%	39%	<b>29%</b>
5 or more health problems/conditions	59%	43%	<b>20%</b>
Not specified	*	1%	<b>2%</b>
Base: all parents of disabled children in category	12642	17200	<b>31466</b>