Research Report DCSF-RR216

Parental experience of services for disabled children:

Findings from the second national survey

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ISBN 978 1 84775 720-3

March 2010

Content

EXECUTIVE SUMMARY

This report draws on the findings of the second national survey of parents' views on services for disabled children in England. The survey was conducted by TNS-BMRB on behalf of the Department for Children, Schools and Families (DCSF). The survey was primarily designed to generate an overall indicator and set of sub-indicators which measure parental views on the five elements of the *Core Offer* as set out in the government's report *Aiming High for Disabled Children*[1]*.* These comprise: *Information*; *Transparency*; *Assessment*; *Participation*; and *Feedback*. Sub-indicators have been calculated for each of these elements within the three service areas of *health, education* and *care & family support*. Thus, there are a total of 15 sub-indicators which are also combined to form an overall indicator reported at the national and local level.

The survey represents the second wave of three to be conducted over the financial years 2008-09, 2009-10 and 2010-11. The first wave was smaller in scale and the sample was limited to provide a national indicator score and local area results in 30 local authorities which had the indicator as part of their local area agreement in 2008-09 and 21 coterminous Primary Care Trusts (PCTs) (NI54 for LAs and VSC33 for PCTs). In 2009-10 the sample was expanded to allow local indicator scores to be calculated in the large majority of LAs and PCTs.

Background (Chapter 1)

In 2009-10, there were a total of 31,466 respondents who completed the main questionnaire. Of these, 7,199 were panel respondents who had also taken part in the 2008-09 survey[2.] The remaining 24,267 were recruited fresh via the same two stage postal survey process used in year one.

In 2009-10, for the fresh sample, 712,048 parents with a school-aged child sampled from the National Pupil Database were sent a short screening survey. Where a household containing a disabled child according to the 1995 Disability Discrimination Act (DDA) was identified a second longer questionnaire was mailed. A total of 56,332 main stage questionnaires were sent out (12,226 from the 2008-09 sample and

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[1] http://www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer/

[2] A panel was used to increase efficiencies and help ensure continuity of the sample

44,106 identified via the fresh screening exercise) with 31,466 returned, the final response based on all eligible to take part was 56%.

Parents were asked a number of detailed questions about their experiences of services received in the last 12 months across the three sectors of health, education and care & family support. Within each of these three sectors, there were questions pertaining to the five Core Offer elements; 15 sub-indicators in total. Each sub-indicator was calculated on the basis of the proportion of parents who had received an “acceptable” level of service within each sector/Core Offer topic. The threshold for receipt of an “acceptable” level of service was set separately for each sub-indicator and is detailed in the main body of the report. Respondents who had no experience of the relevant services in the past 12 months were generally excluded from the sub-indicator for that section.

Profile of disabled children (Chapter 2)

The sample of disabled children included in the 2009-10 survey had a broadly similar profile at a national level to the 2008-09 survey sample.

- Three in ten parents with a disabled child (29%) were in receipt of Disability Living Allowance (DLA) on behalf of their child, while one in ten (11%) of the whole sample received it at the higher rate either for care or mobility.

- Two fifths (41%) of children had a special educational need (SEN) and 23% of all included in the survey were in receipt of a statement of SEN. In addition, 23% of children had both a special educational need (with or without statement) and were also in receipt of DLA.

- Conditions affecting cognitive function – including learning, behaviour and communication – were the most common types of problems reported by parents. This was followed by conditions affecting personal care, eating and drinking and mobility.

- Three in ten parents (30%) reported a single area of difficulty while 49% reported multiple difficulties (the remainder reported no difficulties at the time of the main stage survey[3]). Multiple difficulties were especially prevalent when the child was in receipt of higher level DLA (97% of this group reported 2+ difficulties and 78% 5+ difficulties).

- The use of healthcare and educational services was almost universal and 25% of parents reported using care & family support services.

- Specialist health care and care & family support services were most commonly used by children in receipt of DLA; and specialist educational services by those with a statement of SEN.

Overall indicator scores (Chapter 3)

The overall indicator is calculated by taking the average of each of the 15 sub-indicator scores. The baseline overall national indicator score for 2009-10 is **61 out of 100,** a rise from 59 out of 100 since 2008-09. A higher score denotes greater satisfaction with services. Across the 145 local areas and 150 PCTs[4], scores ranged from 55 to 68.

The groups most strongly associated with a **higher** national indicator score (indicating greater satisfaction with services) were as follows:

- children for whom parents reported a single area of difficulty arising from their condition (score of 63 for 1 area of difficulty compared with a score of 58 when children had 5+ areas of difficulty);

- children with a condition related to consciousness (score of 63) or sensory impairment such as vision, hearing (score of 62);

- girls (score of 62 compared with a score of 60 for boys);

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[3] These were parents who reported difficulties at the screener stage but not at the main stage – around half of them had indicated at the screener stage that their child's condition was controlled by medication (section 2.3)

[4] A proportion of LAs and PCTs are coterminous

- younger children of pre-school age (score of 64 compared with 61 on average);

- black children (score of 63 compared with 61 for white children and 58 for children from mixed or other races).

The groups associated with a **lower** national indicator score (indicating lower levels of satisfaction with services) were as follows:

- children with special educational needs but no statement (score of 54);

- when children suffered depression or conditions affecting cognitive function such as learning, communication, autism & behaviour (scores in the range 52-59);

- children from mixed or "other" ethnic backgrounds (score of 58);

- children with 5+ areas of difficulty associated with their condition (score of 58).

There was no difference in the overall level indicator score between all disabled children (score of 61) and children in receipt of any DLA (score of 61) or higher rate DLA (score of 61). The overall score was one point higher (62) where respondents reported a statement of SEN. Differences on these measures were observed within many of the sub-indicators (see further below).

Sub-indicator breakdowns (Chapter 4)

The 15 sub-indicator scores, shown for the two survey years, are shown in figure E1 below.

Figure E1

SUB-INDICATOR SCORES, 2008-09 AND 2009-10

	Health		**Education**		**Care & family support**	
	2008-09	2009-10	2008-09	2009-10	2008-09	2009-10
Information	68	69	69	70	60	69
Assessment	75	76	76	77	62	67
Feedback	12	12	22	20	11	12
Transparency	96	96	92	92	86	89
Participation	60	61	50	48	52	53

The sub-indicators largely remained stable over the two survey years (which might be expected given the short time-scale between the two surveys). However, there were some temporal differences within the care & family support sub-indicators: rises were observed within Assessment, Information and Transparency sub-indicators. There were, however, some differences between the 2008-09 and 2009-10 questionnaires in relation to care & family support, which should be borne in mind when interpreting the sub-indicator scores (see appendix 2 for a full discussion of these).

Transparency was the area yielding the highest satisfaction rates from parents across all three service sectors, while *Feedback* was the lowest rated. Within *Assessment* and *Transparency*, care & family support attracted lower rating levels compared with the other two sectors. Within *Participation*, health services were better rated than education and care & family support. Within *Feedback*, education was rated better in comparison to the other service domains.

- **Information:** This sub-indicator was based on all respondents (health and care & family support)/all who had received relevant services for their child in the last 12 months (education) and covered: perceived sufficiency of information on child's needs; services entitled to; how to access services; sourcing support; and clarity, relevance and accuracy of information. In general, parents were most satisfied with information provided when their children were of pre-school age. For health and care & family support, there was also clear evidence that parents of children in receipt of DLA (both higher and lower rate) or with a statement of SEN were less likely to be happy with the quality of information received.

- **Assessment:** This sub-indicator was based on all parents who said that professionals had made a decision about the services their child had received. Compared with education and health, parents were less satisfied that during their assessments for care & family support, they were listened to and their needs understood; that the decisions made were suitable and delivered at the right time; and that they were happy with the decisions made. Educational assessments were better regarded than health and care & family support assessments in terms of joined-up working and information sharing.

- **Feedback:** This sub-indicator was largely based on all who had received relevant services for their child in the past 12 months. The score was based on the extent to which feedback from parents and children (where possible) was both elicited and acted upon; in addition the Feedback score comprised parents' experience of complaints handling among the small proportion who had made a complaint (4% in the case of health, 5% in the case of education and 2% in the case of care & family support).

  The score for Feedback was very low compared with other Core Offer areas, and the main reason for this was that parents said that they and their children were generally not asked for feedback. In only a small proportion of cases was feedback elicited, but not acted upon. The results also suggest that parents are not always happy with processes for accessing information about how to complain, and how complaints are handled.

- **Transparency:** This sub-indicator was based on all parents who said that professionals had made a decision about the services their child had received. The large majority of parents across all sectors understood the decisions that had been made. Ratings were slightly higher for health compared with the other two sectors.

- **Participation:** This sub-indicator was based on all parents who said that professionals had made a decision about the services their child had received. The sub-indicator reflects the extent to which parents felt consulted over the decisions made – across the three sectors between 48% and 61% said that they were consulted "a lot" over decisions made.

Variation in sub-indicators by survey subgroups (Chapter 4)

Differences that occurred across survey groups for the overall level indicator have been noted above. However, at the sub-indicator level much greater variation by survey group was found. Across the 15 sub-indicators, some general patterns emerge:

- **Age**: across most sub-indicators, parents of younger pre-school children tended to be more satisfied than parents of older children. However, within education, scores for 16-19s were often higher than average, especially within *Assessment, Information and Participation.*

- By **ethnicity** of the child, there was strong evidence that parents of black children were more satisfied than average with services related to health, and this was particularly noticeable within *Feedback* and *Participation*. Parents of Asian children were particularly happy with care & family support Assessments.

- **Receipt of DLA**, particularly higher level receipt (which can be a useful proxy for severity of disability), was associated with higher levels of satisfaction across some of the sub-indicators. This was particularly noticeable within *Feedback.* However, for *Information* the pattern was reversed for care & family support and health. Within these domains, parents in receipt of higher levels of DLA were much less happy with the quality of information received.

- In general, within the education sub-indicators, parents of a child with a **special educational need** in receipt of a statement were the most satisfied. This difference was particularly marked within *Feedback.* Although they were less satisfied in relation to *Information.*

- Some patterns by type of health condition/disability also emerge. **Depression** is generally the condition which is associated with lower than average scores across nearly all sectors and service elements.

- Within *Assessment* and *Information*, there was a tendency for conditions affecting cognitive function (**behaviour and autism**) to be associated with lower than average ratings within health and care & family support.

- There was also evidence of a general trend towards parents of children suffering a sensory impairment (hearing and/or vision) having higher levels of satisfaction across many of the Core Offer areas and service domains.

Other general experience of services (Chapter 5)

There were additional questions asked in the survey that were not directly used in the calculation of the overall indicator, either because they were ‘filter’ questions or because they did not relate to specific Core Offer elements. However they still provided useful insight into parents’ experience of services. For instance:

- Of the three service domains, parents were most likely to have experienced professionals making decisions about the services their child should receive in relation to health care services (44%). This compares with 32% in relation to a formal assessment of educational needs and 9% with respect to care & family support services.

- A quarter (25%) of those who considered they had a care & family support need said they received little or none of the services they required over the last twelve months. This compares with 6% and 9% respectively in relation to health and educational service needs.

- Parents were asked a single question asking them to rate the quality of services they had received for each of the three sectors. On the basis of this, the majority of service users rated the service received as at least “good” but this did vary by service domain: 80% for health care, 73% for education and 57% for care & family support services. Conversely, one in six (16%) of those receiving care & family support services rated the service they did receive as poor or very poor. This compared with 4% and 7% for health and education respectively. However, it should be borne in mind that parents’ ratings of services in this context are based on a single question and may not incorporate all factors included in the calculation of the overall composite indicator.

Further issues raised by parents (Chapter 6)

In addition to the questions which directly fed into the indicator scores, parents were also given the opportunity to comment freely on the services that their child had received across the three service domains, as well as their experience of other local services. Comments were distilled into a set of themes and a summary is given below.

- **Health care**: A little over a third of parents (37%) commented on this service area. Of these parents, a third (36%) gave positive comments as part of their feedback (usually relating to generic healthcare services but also more specifically towards hospital staff and the GP). Negative feedback included reference to poor communication & information (22% of those who commented); being unhappy with health care services received (21%); difficulty accessing services (18%); and not receiving services required (18%).

- **Education**: A third (34%) commented on this service area and, of these comments, 39% were positive, rising to 48% of parents with a child who had a statement of SEN. Where negative comments were made this centred on lack of services available (29% of those commenting – this comment was more prevalent when children had SEN but no statement, 38%); difficulty accessing services (18% - again more prevalent when children had SEN but no statement, 33%); and negative comments about services received (18%). Compared with the other two service areas, there was a smaller proportion of negative comments about poor communication and information.

- **Care & family support**: One in five (20%) commented on this service area. Among those making comments, the level of positive feedback was lower compared with the other service areas (15%). Negative comments were largely dominated by lack of services available (25% of all commenting) and poor communication and information (23%).

- **Other local services:** Only 16% of parents made comments relating to other local services for children and young people. Parents commenting here tended to use this question to make more generic comments about their child’s condition or services received. Of those making comments, the two principal specific comments made were a need for more information about their child’s condition (16% of those providing feedback); and a lack of available help (15%).

1. BACKGROUND

1.1 Aims of the study

This report provides the main findings of the second national survey of parents' views of services for disabled children in England. This survey is the second of three surveys funded by the Department for Children, Schools and Families (DCSF) aimed at providing an indicator for local authorities and primary care trusts on the provision of services for disabled children. The concept of the indicator was first introduced in the Aiming High for Disabled Children (AHDC) report published in May 2007[5]. It forms part of a performance framework aimed at improving the quality of services for disabled children. Aiming High for Disabled Children is a joint delivery programme between the DCSF and the Department of Health (DH).

Surveys in this series were carried out by TNS-BMRB. The second survey was conducted between July and November 2009 (to cover the financial year 2009-10) whilst the first was conducted between January and April 2009 (to cover the financial year 2008-09). A national baseline was established in 2008-09 and this report provides details of the 2009-10 survey.

The study's primary purpose is to measure parental experience of services for disabled children in 2009-10. The secondary purpose is to provide 2009-10 figures for the large majority of local authorities (LAs) and Primary Care Trusts (PCTs). This includes a second tranche of scores for the 30 local authority areas (and the PCT areas that have boundaries exactly coterminous with these LA areas) that took part in the 2008-09 survey.

1.2 Development of the indicator

Aiming High for Disabled Children brought together general principles for service delivery into the Core Offer, a statement of the standards which families with disabled children could expect across the country from local services. The five elements of the Core Offer are *Information*, *Transparency*, *Assessment*, *Participation* and *Feedback*. The standards set out in the Core Offer make clear how disabled children, young

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[5] http://www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer

people and their families can expect services to be delivered, and how they should experience those services. The indicator was then based on these five elements to provide a measure against these standards. This was further developed by the DCSF using findings from the National Centre for Social Research's (NatCen) feasibility study conducted for them in 2008[6].

1.3 Roll-out of the indicator survey

The 2008-09 survey generated a baseline national indicator, together with local authority level indicators for 30 authorities which had included the indicator in their Local Area Agreement (LAA) or as a local target for 2008-09. The 2009-10 survey provided a national score and scores for the large majority of local authorities and PCTs in England. The third survey, covering the financial year 2010-11, will be conducted in Summer 2010 to be reported in Winter 2010.

1.4 Survey method

In order to meet the requirements of a large scale national survey, a two-stage paper-based questionnaire methodology was employed. The first was a short 'screening questionnaire' to identify parents with disabled children as defined by the DDA (see below). The second was a longer questionnaire, sent only to parents of disabled children, designed to collect information on their experiences of local services. In 2009-10, there was also a panel element to the sample, with parents who had taken part in 2008-09 invited to participate in the second phase of the survey. This was intended to maximise the efficiency of the sample by directly contacting families known to have a DDA disabled child and therefore reduce the extent of additional screening required.

The responses to the second questionnaire were then used to calculate the indicator score. The indicator is based on an intended minimum sample of 200 parents of disabled children in each local area. The definition of a disabled child/young person used was as defined by the Disability Discrimination Act (DDA) 1995: "a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day to day activities".

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[6] http://www.dcsf.gov.uk/research/data/uploadfiles/DCSF-RR053v1.pdf

In 2009-10 a total of 31,466 completed main stage questionnaires were received. More detail on survey methodology and response is set out in appendix 2, and more information on the demographic profile of disabled children is provided in chapter 2. The following two chapters focus on the indicator scores and the constituent sub-indicators, looking at parents' overall satisfaction with local services and what makes up their satisfaction or dissatisfaction. Chapter 5 looks at other useful perceptions of local services, which were not covered by the overall indicator. The final chapter looks at further issues that parents highlighted with respect to the services their child had received. The structure is as follows:

- Profile of disabled children (Chapter 2)
- Overall indicator scores (Chapter 3)
- Sub-indicator breakdown (national level) (Chapter 4)
- Other general experiences of services (Chapter 5)
- Further issues raised by parents (Chapter 6)

2. PROFILE OF DISABLED CHILDREN

CHAPTER SUMMARY

The sample of disabled children included in the 2009-10 survey had a broadly similar profile at a national level as the 2008-09 survey.

Three in ten parents with a disabled child (29%) were in receipt of Disability Living Allowance (DLA) on behalf of their child, while one in nine (11%) of the whole sample received it at the higher rate either for care or mobility. Two fifths (41%) of children had a special educational need (SEN) and 23% of all included in the survey were in receipt of a statement of SEN. In addition, 23% of children had both a special educational need (with or without statement) and were also in receipt of DLA.

Conditions affecting cognitive function – including learning, behaviour and communication – were the most common types of problems reported by parents. This was followed by conditions affecting personal care, eating and drinking and mobility. Three in ten parents (30%) reported a single area of difficulty while 49% reported multiple difficulties (the remainder reported no difficulties). Multiple difficulties were especially prevalent when the child was in receipt of higher level DLA (97% of this group reported 2+ difficulties and 78% 5+ difficulties).

The use of health care and educational services was almost universal and 25% of parents used care & family support services.

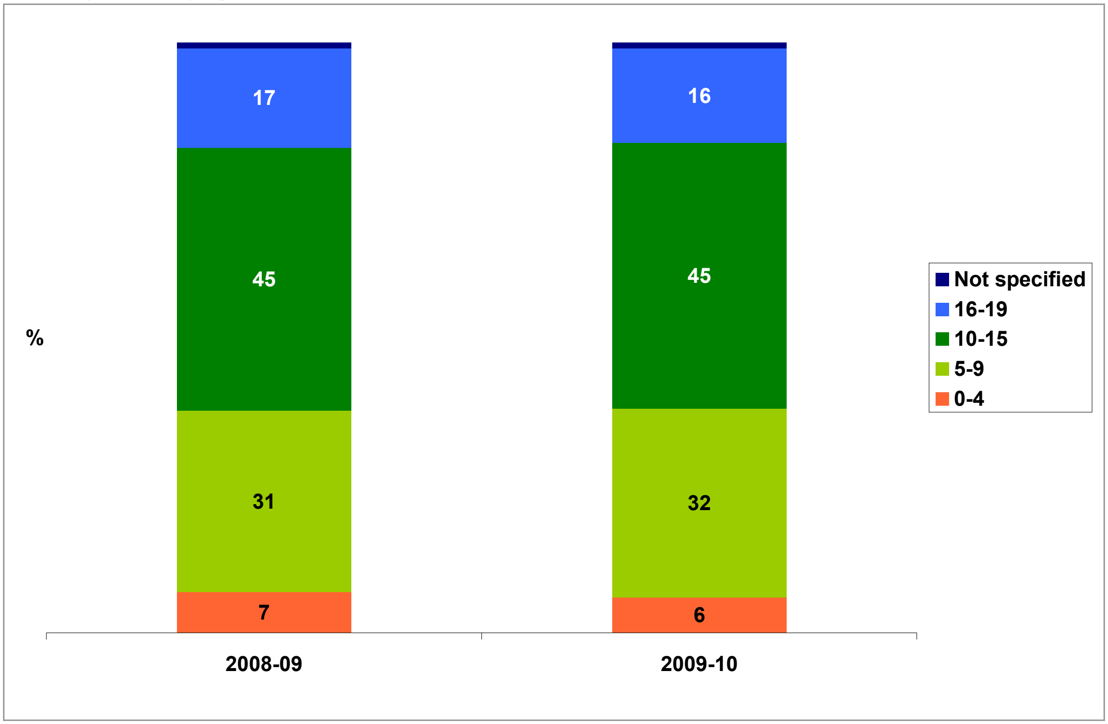
Specialist health care and care & family support services were most commonly used by children in receipt of DLA; and specialist educational services by those with a statement of SEN.

This chapter covers information regarding the profile of the sample in terms of demographics such as age; ethnicity; disability type; receipt of DLA; statement of SEN; and services used. This helps provide a context for the detailed findings.

2.1 Demographics

As in the 2008-09 survey the large majority of parents answered questions in relation to school age children. The age profile of children referred to was very similar to that obtained in 2008-09 (see figure 1).

Figure 1 Age profile of children



Base: All children: 2008-09: (12,226); 2009-10: (31,466)

Twelve per cent of the children were from a minority ethnic group: 4% Asian, 2% black, 5% mixed ethnicity and 1% from another ethnic origin.

2.2 Level and type of disability

Whether the parent receives Disability Living Allowance (DLA) on behalf of their child (or whether the child receives it in their own right) can be used as a useful proxy for the severity of disability. The profile was, again, very similar to that achieved in the 2008-09 survey (see figure 2).

Figure 2

LEVEL OF DLA RECEIPT IN SAMPLE

	2008-09	**2009-10**
	%	%
High rate DLA for care or mobility	12	11
Any DLA receipt	29	29
Not in receipt	71	70
Care component received	27	28
- at highest rate	10	10
- at middle rate	14	15
- at lowest rate	3	3
Mobility component received	18	18
- at higher rate	7	7
- at lower rate	11	11
Base (n): All children	*12,226*	*31,466*

The proportion of children classified by parents as having a special educational need (SEN) was also very similar to that found in 2008-09 (see figure 3).

Figure 3

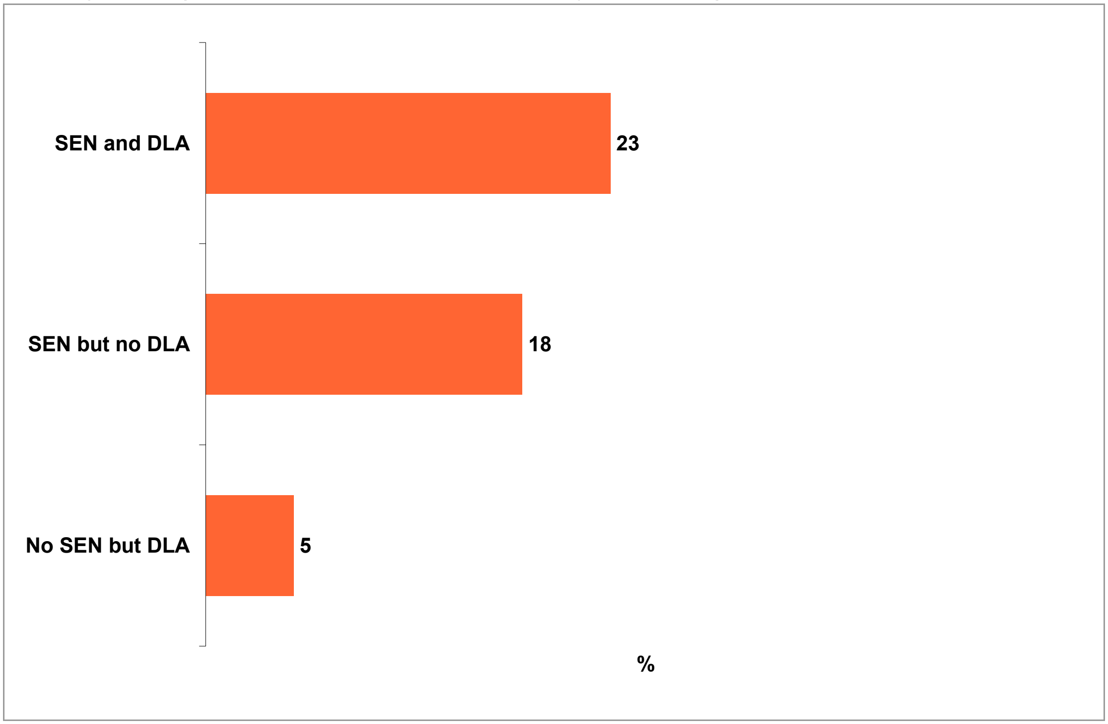
SPECIAL EDUCATIONAL NEEDS STATUS

	2008-09	**2009-10**
	%	%
Any SEN	42	41
- With statement	25	23
- Without statement	14	13
- Don’t know/ Not specified	4	5
No SEN	52	54
No educational services used	5	3
Base (n): All children	*12,226*	*31,466*

Around four in ten (41%) parents reported that their child had SEN, with around one quarter (23%) having a statement of SEN.

Figure 4 demonstrates considerable overlap between receipt of DLA and identification of SEN amongst respondents. One quarter (23%) reported that their child had a SEN and were in receipt of any level of DLA. One in five (18%) children in the sample had a SEN but were not in receipt of DLA, while 5% had no SEN but were in receipt of DLA. Half (49%) of parents reported that their child had no special educational need and that they did not receive DLA. Figure 70 in appendix 1 provides a more detailed breakdown by level of DLA receipt and SEN.

Figure 4 Special educational needs status by DLA receipt status†



Base: All children (31,466)

†Results shown only for children with SEN or in receipt of DLA

The breakdown of reported illness, disability or condition was broadly similar to that seen in the 2008-09 survey (see figure 5 below). The most common area in which children were affected was learning (34%), followed by behaviour (30%) – both of which are cognitive functions. The areas of difficulty least commonly reported were depression, conditions resulting in fits and seizures (consciousness) and those giving rise to palliative care needs. Around one in five parents (19%) indicated in the main survey that their child did not have an illness, disability or health condition – however they were eligible for the survey based on their answers to the screening questionnaire which they had completed previously. This group is considered in more detail in sub-section 2.3 below.

Figure 5 also shows prevalence of each illness, disability or health condition within each age group and within respondents in receipt of DLA or having a statement of SEN.

Figure 5

AREAS IN WHICH CHILD IS AFFECTED[†] AS A RESULT OF ILLNESS, DISABILITY OR CONDITION, BY AGE, RECEIPT OF DLA AND STATEMENT OF SEN

	Age				**Receives DLA**	**Statement of SEN**	**2008-09**	**2009-10**
	0-4	**5-9**	**10-15**	**16-19**				
	%	%	%	%	%	%	%	%
Learning – having special educational needs	21	34	37	33	70	86	35	34
Behaviour	20	31	33	25	61	62	31	30
Communication	36	31	25	25	61	68	27	28
Personal care	23	26	22	20	63	58	23	23
Mobility	19	16	18	21	52	47	18	18
Eating & drinking	23	15	12	12	34	28	14	14
Vision	14	16	12	10	17	19	13	13
Incontinence	15	16	11	8	27	26	13	12
Medication	10	10	13	16	31	21	13	12
Autism/Asperger/ASD	7	13	16	14	36	38	13	14
Hand function	12	12	11	12	28	28	12	11
Hearing	12	12	8	8	12	13	10	10
Depression	*	1	6	11	8	6	5	5
Consciousness	5	4	5	7	12	11	5	5
Palliative care	1	1	1	1	3	3	1	1
Other condition	18	18	22	24	18	14	19	20
No illness, disability or condition indicated in main survey, however:	22	18	19	21	1	1	18	19
– An illness, disability or condition indicated in screener survey	14	10	10	10	*	*	10	10
– medication, physical aid or special diet or supplements successfully used to manage an illness, disability or conditions reported in screener survey	8	8	9	12	*	*	8	9
Base (n)	*1,875*	*9,821*	*14,866*	*4,588*	*12,642*	*11,417*	*12,226*	*31,466*

[†] Responses selected from a pre-defined list, parents could select as many responses as applied

The nature of areas of difficulty was related to the age of the child. Problems with communication and eating and drinking were, not surprisingly, more common among younger children than older. In line with expectations, depression was very much a condition that affected older rather than younger children.

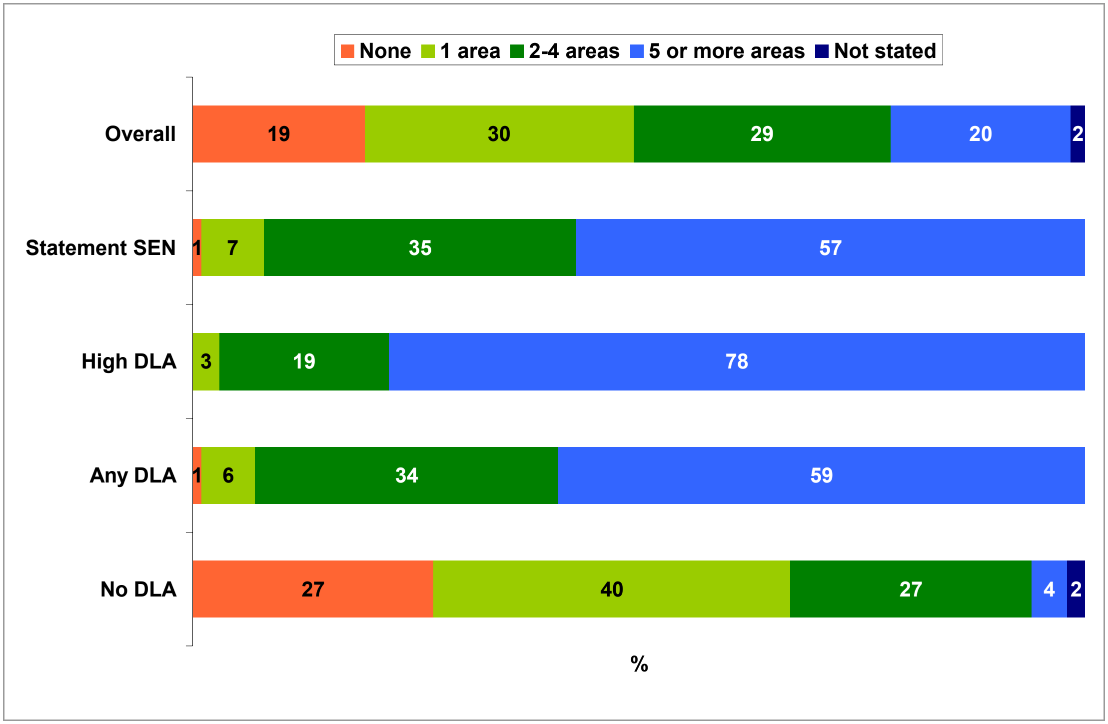
There were some differences in the areas of difficulty reported by those who were in receipt of DLA compared with those whose children had a statement of SEN. Unsurprisingly, learning difficulties were reported by the large majority of parents whose child had a statement of SEN (86%). This is compared with seven in ten (70%) parents of children in receipt of DLA. Two-thirds (68%) of parents whose child had a statement of SEN reported communication as another area of difficulty compared with 61% of those in receipt of DLA.

Parents in receipt of DLA for their child were more likely to report that their child had difficulties with personal care, mobility, eating and drinking and taking medication or having side effects because of them, compared with parents of children with a statement of SEN. Overall, however, both of these sub-groups were much more likely than average to report that their child had difficulties with the areas of life listed in figure 5.

Multiple health conditions

Since parents were asked to report all areas in which their child was affected as a result of their illness, disability or condition it is also useful to examine the number of areas of difficulty reported. Figure 6 shows that one in three (30%) parents reported that their child had a single area of difficulty, while half (49%) recorded multiple areas of difficulty.

Figure 6 Number of areas child is affected as a result of illness, disability or condition from main survey



Base: All children (31,466); Statement SEN (11,417); High DLA (5,407); Any DLA (12,642); No DLA (18,577)

There was a clear difference in the number of areas of difficulty reported by receipt of DLA or identification of a SEN. If the child had a statement of SEN, the proportion of parents who reported that their child had multiple areas of difficulty rose to 92%. Almost all (97%) of those in receipt of higher rate DLA for either the care or mobility component reported multiple areas of difficulty. Those not in receipt of DLA were more likely to report one area of difficulty or none at all (67%).

2.3 Parents reporting no illness, disability or condition

As stated earlier, 19% of parents recorded at the main stage that their child was not affected in any way by illness, disability or condition. Figure 5 showed that just under half of this group (9% of the overall sample) indicated at screener stage that their child required medication, physical aids or a special diet or supplements to successfully manage an illness, disability or condition (and would have difficulties if they did not take the medication). In line with the DDA definition of disability, these children were included in the main stage survey.

The remaining parents who indicated that their child was not affected by an illness, disability or condition in the main stage survey *did* report a long standing illness, health problem or disability at the screener survey (10% of the entire sample) which is why they were eligible for the main stage survey. This group will be investigated further and eligibility criteria for inclusion into the survey may be reviewed as part of a subsequent methodology review.

The majority of respondents selecting ‘not affected in any way’ at the main stage reported no special educational needs (89%) and were not in receipt of DLA (99%). They were also more likely to be of a non-white ethnic origin i.e. mixed, Asian, black or an other ethnic group (16% compared with 12% on average).

It should be noted that previous research has indicated that the complexities of identifying and defining disability are considerable. For example, parents may not know or remember their child’s diagnosis, or there may be some uncertainty about it (Hutchison & Gordon 2005). Parents may be uncertain about whether the diagnosis indicates a long-standing condition, whether it is susceptible to treatment/therapy or whether the child may grow out of it.

2.4 Services used

Health and educational services were used by nearly all parents in the last twelve months (98% and 96% respectively). Thirteen per cent of parents of under fives said they did not use education services compared with three per cent of parents of children aged five or over. Care & family support services were used by a much smaller proportion of all families (25%).

Health care services

The most commonly used health care services were GPs (78%) and dentists (68%). Half (48%) of parents had seen a paediatrician or another specialist doctor. Overall the pattern of services used remained largely unchanged from the 2008-09 survey (see figure 7).

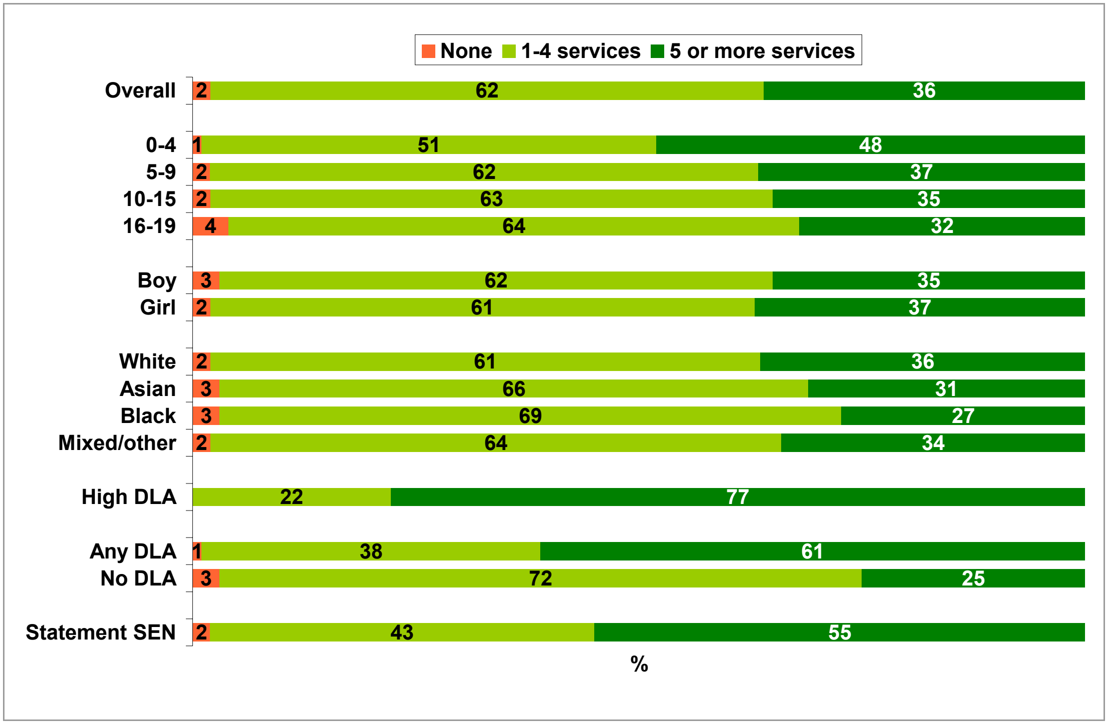
Figure 7

HEALTH CARE SERVICES USED IN LAST 12 MONTHS

	2008-09	**2009-10**
	%	%
GP	79	78
Dentist	68	68
Paediatrician or other specialist doctor	48	48
Optician or eye specialist	39	41
Practice nurse	28	30
Speech & language therapist	20	20
Emergency health care/A&E	16	17
Hospital in-patient	16	16
Health visitor, district or community nurse	12	12
Psychologist	12	12
Occupational therapist	10	11
Psychiatrist/behavioural specialist	11	11
Physiotherapist	11	11
Dietician or nutritionist	8	9
Podiatrist or chiropodist	6	6
Community equipment & wheelchair services	5	5
Complementary/alternative medical practitioner	3	3
Palliative care	*	*
Other health services	9	10
None used	2	2
Base (n): All children	*12,226*	*31,466*

Around one-third (36%) of parents reported that their child had used five or more health care services in the past twelve months (see figure 8). Younger children (those aged 0-4) were more likely to have used five or more health care services (48%) compared with the average.

Figure 8 Number of health care services used in last 12 months



Base: All children (31,466); 0-4 (1,875); 5-9 (9,821); 10-15 (14,866); 16-19 (4,588); Boy (19,958); Girl (11,304); White (26,727); Asian (1,418); Black (1,100); Mixed/other (1,873); High DLA (5,407); Any DLA (12,642); No DLA (18,577); Statement SEN (11,417)

Parents of children in receipt of higher rate DLA were over twice as likely to have used five or more health care services in the past twelve months (77%) compared with the average (36%). Six in ten parents of children in receipt of any rate of DLA (61%) had used five or more health care services in the past twelve months. Children in receipt of a statement of SEN were also associated with an increased use of multiple (5+) health care services in the past twelve months (55%), although this rate was lower than those in receipt of higher rate DLA.

Education services

Three-quarters (73%) of parents mentioned that their child used a mainstream school in the last twelve months. One in five children had support from a special needs teacher (21%) and a similar proportion (19%) had a dedicated teaching assistant

(TA) or learning support assistant (LSA). Figure 9 lists all of the education services used by disabled children in the last twelve months – the pattern of usage has changed little since the 2008-09 survey.

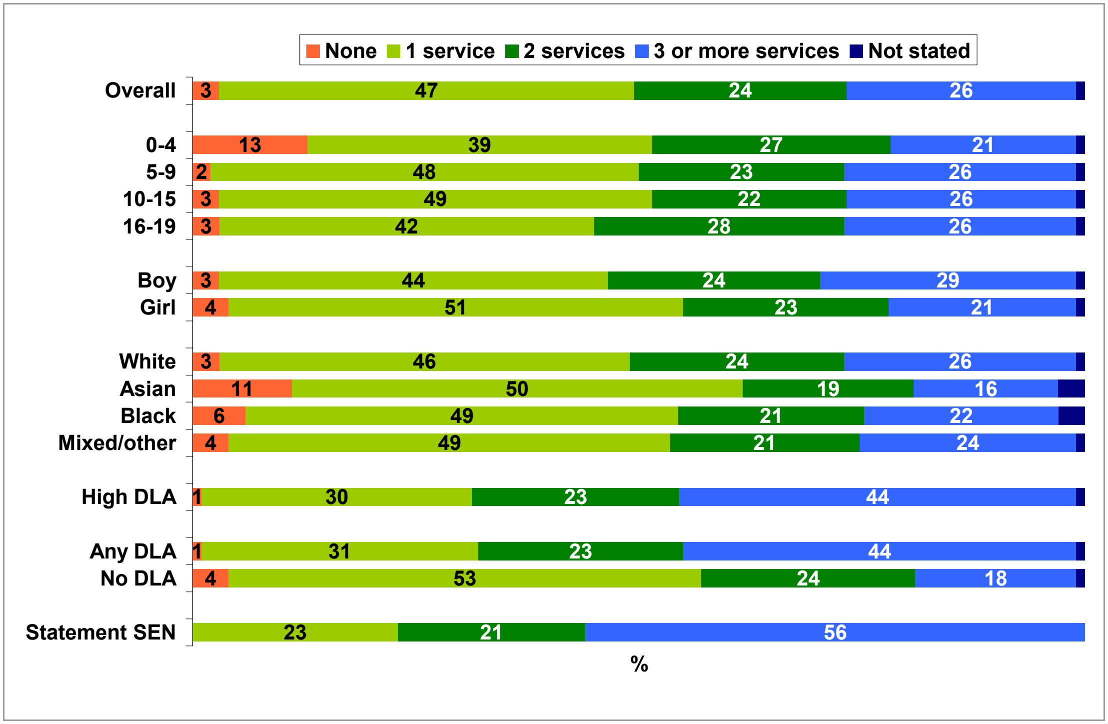
Figure 9

EDUCATION SERVICES USED IN LAST 12 MONTHS

	2008-09	**2009-10**
	%	%
Mainstream school	70	73
Support from Special Needs Teacher	21	21
Dedicated TA/LSA	19	19
Extended school services (breakfast, after-school clubs)	11	12
Special school	11	10
Educational psychologist	11	10
Connexions	11	10
Pre-school or nursery	8	8
FE college	7	8
Home teaching, private tutor	4	5
Special education unit	4	4
Children's Centre	3	3
Hospital education service	1	2
Other	5	6
None used	4	3
Base (n): All children	*12,226*	*31,466*

One quarter (26%) of parents reported that their child had used three or more education services in the past twelve months (see figure 10).

Figure 10 Number of education services used in last 12 months



Base: All children (31,466); 0-4 (1,875); 5-9 (9,821); 10-15 (14,866); 16-19 (4,588); Boy (19,958); Girl (11,304); White (26,727); Asian (1,418); Black (1,100); Mixed/other (1,873); High DLA (5,407); Any DLA (12,642); No DLA (18,577); Statement SEN (11,417)

Children under five were less likely to have used education services in the past twelve months (13% used no education services, compared with 3% on average), which is unsurprising given that most of these children had not reached the statutory school age. Older children, so those 16 or over, were slightly more likely to use more than one education service compared with younger children (54% and 49% respectively).

There was also a difference by the child's gender and ethnicity: boys were more likely to have used three or more education services in the past twelve months (29%) compared with girls (21%). Black and Asian children were slightly less likely to have used education services in the past twelve months (6% of black and 11% of Asian children not using education services compared with 3% of white children).

Over four in ten (44%) parents of children in receipt of any rate of DLA reported their child had used three or more education services in the past twelve months. The subgroup most likely to have used three or more education services in the past twelve months were children with a statement of SEN (56%).

Care & family support services

As in the 2008-09 survey, the proportion of parents who said they used care & family support services in the past twelve months was lower than those using health and education services. This is not surprising given that care & family support comprises more specialist services. Social worker services were used by 9% of families whilst 8% used emotional support or counselling services (see figure 11).

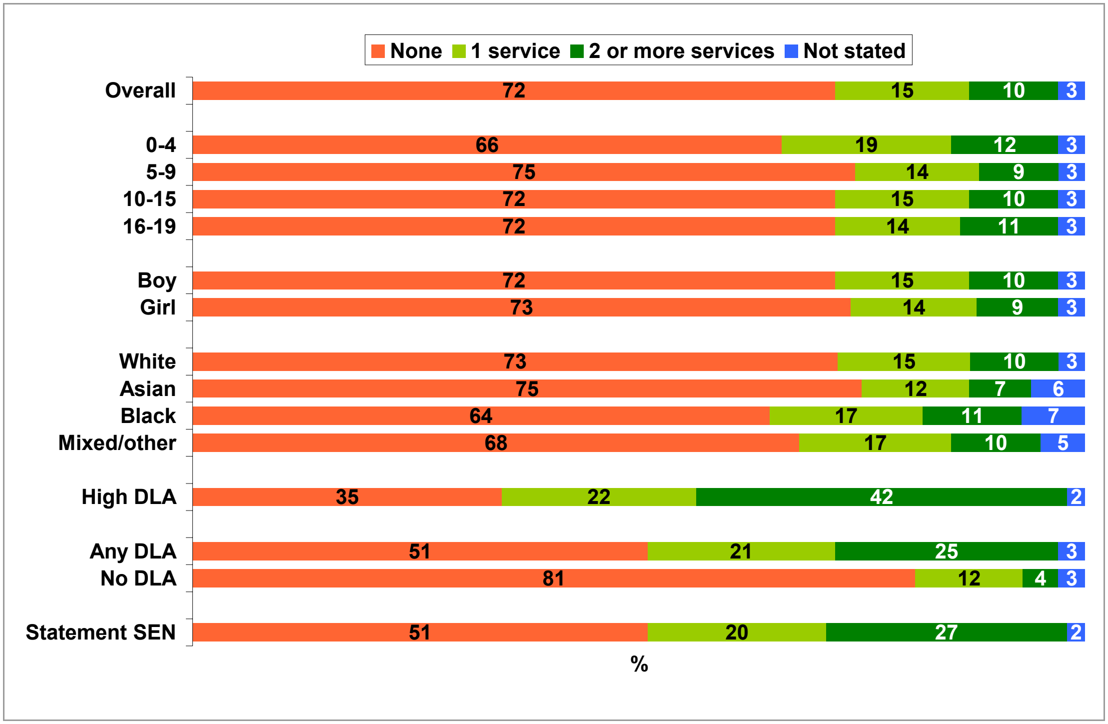
Figure 11

CARE & FAMILY SUPPORT SERVICES USED IN LAST 12 MONTHS

	2008-09	**2009-10**
	%	%
Social worker services	9	9
Emotional support or counselling services	7	8
Respite, foster care, short breaks	4	5
Direct payments or individual budget	4	4
Childcare & play provisions	3	4
Home adaptations (e.g. lifts, ramps)	2	3
Help at home with care	2	2
Home start or Sure Start	2	2
Help within home from outside provider	2	2
Other	2	4
No services used	74	72
Base (n): All children	*12,226*	*31,466*

One in ten (10%) families reported using two or more care & family support services in the past twelve months (see figure 12).

Figure 12 Number of care & family support services used in last 12 months



Base: All children (31,466); 0-4 (1,875); 5-9 (9,821); 10-15 (14,866); 16-19 (4,588); Boy (19,958); Girl (11,304); White (26,727); Asian (1,418); Black (1,100); Mixed/other (1,873); High DLA (5,407); Any DLA (12,642); No DLA (18,577); Statement SEN (11,417)

Families with disabled children under five were more likely to have used at least one care & family support service – this is driven by a greater proportion of these families using childcare and play provisions (10%) compared with families with older children (3%).

Half (51%) of families that received DLA for their child said that they did not use care & family support services in the past twelve months. This is compared with seven in ten (72%) families overall not using services. The proportion falls to just one in three (35%) when looking at families in receipt of higher rate DLA.

If the child had a statement of SEN, half (51%) of families said that they did not use care & family support services in the past twelve months.

3. OVERALL INDICATOR SCORES

CHAPTER SUMMARY

The overall indicator is calculated by taking the average of each of the 15 sub-indicator scores and thus represents a composite measure. The overall national indicator score for 2009-10 was **61 out of 100** which represents a rise of 2 points since 2008-09. The overall scores ranged from 55 to 68 points across local authorities and PCTs.

Higher than average scores (denoting higher than average satisfaction) were observed among parents of the following subgroups: children for whom parents reported a single area of difficulty arising from their condition; children with hearing or vision needs or affected by fits or seizures; disabled children under 5; and black and Asian children.

Lower than average scores were observed among parents of: children with SEN but no statement; children with cognitive or behavioural problems/depression; and children with multiple areas affected as a result of their illness or disability.

The overall indicator is calculated by taking the average of each of the 15 sub-indicator scores. The individual sub-indicators, and the questions which make up each of these, are discussed in detail in this chapter and the next. A minimum threshold of ‘acceptable’ service was developed for each sub-indicator and respondents were classified as having received either ‘acceptable’ or ‘non-acceptable’ levels of service in each area. The overall indicator is a composite measure and represents an average of the percentage of parents receiving an ‘acceptable’ level of service across each of the 15 sub-indicators.

3.1 The national indicator score

The overall national indicator score for 2009-10 was **61 out of 100.** The overall national indicator score for 2008-09 was 59 out of 100 – an increase between the two survey periods. The scores represent a composite of services received in the five Core Offer areas (Information, Assessment, Transparency, Participation and Feedback) across the three service domains of health, education and care & Family Support. Overall scores were calculated on a 0-100 scale with higher scores denoting greater satisfaction with services.

3.2 Indicator scores, by local area

Figure 68 in appendix 1 displays the indicator scores for 145 local authorities (LAs) from the 2009-10 survey. The overall scores ranged from 55 to 68 points across LAs. Also included are a second tranche of scores for the 30 LAs with National Indicator 54 (NI 54) as part of their Local Area Agreements or local target in 2008-09.

Figure 69 in appendix 1 displays the indicator scores for 150 Primary Care Trusts (PCTs) from the 2009-10 survey. The overall scores also ranged from 55 to 68 points across PCTs.

3.3 Indicator scores by key demographics and service experience

As the overall indicator score is essentially a measure of satisfaction with local services it is possible to examine satisfaction among various subgroups of interest. A summary of the scores is presented in figure 13.

Figure 13

PARENTAL EXPERIENCES OF SERVICES PROVIDED TO DISABLED CHILDREN: OVERALL SCORES IN 2009-10, BY SUBGROUP

	Overall score	Base
Overall	**61**	***31,466***
High DLA	61	*5,217*
Any DLA	61	*12,165*
No DLA	60	*17,559*
SEN with statement	62	*11,162*
SEN without statement	54	*3,999*
No SEN	61	*12,750*
Boy	60	*19,023*
Girl	62	*10,722*
0-4	64	*1,567*
5-9	60	*9,526*
10-15	61	*14,275*
16-19	61	*4,309*
White	61	*25,622*
Mixed/Other	58	*1,737*
Asian	62	*1,310*
Black	63	*969*
Number of health services used in last 12 months		
None	60	*565*
1-4	62	*17,259*
5 or more	60	*12,041*
Number of education services used in last 12 months		
None	62	*432*
1	62	*12,326*
2	59	*7,119*
3 or more	59	*9,909*
Number of care & family support services used in last 12 months		
None	60	*19,982*
1	60	*4,897*
2 or more	63	*4,293*
Area affected as a result of illness, disability or condition		
Consciousness	63	*2,008*
Vision	62	*4,291*
Hearing	62	*3,127*
Incontinence	61	*4,721*
Palliative care needs	60	*410*
Medication	59	*4,472*
Mobility	59	*7,525*
Personal care	59	*9,543*
Hand function	59	*4,660*
Learning	59	*14,118*

Communication	58	*11,374*
Eating and drinking	58	*5,235*
Autism/Asperger Syndrome/ASD	57	*6,006*
Behaviour	57	*11,578*
Depression	52	*1,576*
Other	58	*5,679*
No illness, disability or condition indicated in main survey, however:		
– An illness, disability or condition indicated in screener survey	66	*2,204*
– medication, physical aid or special diet or supplements successfully used to manage an illness, disability or conditions reported in screener survey	64	*1,878*
Number of areas affected as a result of illness, disability or condition		
1	63	*7,445*
2-4	59	*9,290*
5 or more	58	*8,758*
Extent to which parents felt their child had received all of the health care services required over last 12 months		
All that he/she required	69	*14,881*
Most of what he/she required	60	*8,108*
Some of what he/she required	46	*4,096*
Little/none of what he/she required	33	*1,865*
Extent to which parents felt their child had received all of the school and education services required over last 12 months		
All that he/she required	71	*12,993*
Most of what he/she required	61	*8,733*
Some of what he/she required	49	*4,949*
Little/none of what he/she required	37	*2,864*
Extent to which parents felt their family had received all of the care & family support services required over last 12 months		
All that they required	76	*4,520*
Most of what they required	67	*4,644*
Some of what they required	54	*3,896*
Little/none of what they required	38	*4,719*

Parents of children with multiple areas affected as a result of their illness, disability or condition appeared to be less satisfied.

There were variations in satisfaction with local services by the areas in which a child was affected by their illness, disability or condition. There was higher than average satisfaction when the child's hearing or vision was affected and also if they were affected by fits and seizures (problems with consciousness). Lower than average satisfaction levels were exhibited by parents of children with behaviour problems, Autism/Asperger Syndrome/Autistic Spectrum Disorder (ASD) and depression.

Parents of children who have SEN but do not have a statement were one of the most dissatisfied groups with an overall score of 54 (seven points lower than average).

There appeared to be a difference in satisfaction levels for parents of disabled girls compared with disabled boys – the former group being more satisfied with local services than the latter. This might be explained by demographic differences observed between the two groups – parents of disabled boys made up six in ten (61%) of the sample and these boys tended to be affected in a greater number of ways by their illness, disability or condition (shown earlier to be linked to higher dissatisfaction). The disabled boys in the sample were also more likely to be in receipt of DLA. However, the disabled boys in the sample were also more likely to have SEN, both with a statement and without. These two factors were shown earlier to have an opposite effect on satisfaction so these effects may cancel each other out overall.

Local services were rated more highly than average by parents of under 5s and it appeared that Asian and black ethnic groups were more satisfied as well.

Heavier health and education service users (as measured by the number of different types of services used in the last twelve months) tended to be more dissatisfied than on average. The opposite was true of care & family support service users where those who used two or more services were more satisfied compared with those who used one or none.

Finally, a clear and consistent picture emerges in respect of the variation of the national indicator by the level of service parents felt they had received. Indicator scores were consistently low (ranging from 33 to 38) when parents felt their child had a service need that was not met at any level, the indicator rising steeply to between 69 and 76 when parents felt all service needs were met. Further analysis of the extent to which parents felt their child had received all of the services required in the last twelve months is detailed in section 5.2.

4. SUB-INDICATOR BREAKDOWN (NATIONAL LEVEL)

CHAPTER SUMMARY

This chapter looks at each sub-indicator in turn – for each, there is first an explanation of how the sub-indicator has been calculated and then the questions that make up each sub-indicator are analysed. Sub-indicators are cross-analysed by key variables and are done across the three service domains.

This box represents an overall summary of the variation of the sub-indicators across all five Core Offer areas within the three service domains. The following summarises some general patterns that emerged across the 15 sub-indicators.

Across most sub-indicators, parents of younger pre-school children tended to be more satisfied than parents of older children. However, within education, scores for 16-19s were often higher than average, especially within the areas of *Assessment, Information and Participation.* There was strong evidence that parents of black children were more satisfied than average with services related to health, and this was particularly noticeable within *Feedback* and *Participation*. Parents of Asian children were particularly happy with care & family support assessments.

In general **receipt of DLA** and in particular higher level receipt (which can be a useful proxy for severity of disability) was associated with higher levels of satisfaction across some of the sub-indicators. This was particularly noticeable within *Feedback.* However, for *Information* the pattern was reversed for care & family support and health. Within these domains, parents in receipt of higher levels of DLA were much less happy with the quality of information received.

In general, within the education sub-indicators, parents of a child with a **special educational need** who was in receipt of a statement of SEN were the most satisfied and this difference was particularly marked within *Feedback.*

Some patterns by type of health condition/disability also emerged. **Depression** was generally associated with lower than average scores across nearly all sectors and service elements. Within *Assessment* and *Information*, there was a tendency for conditions affecting cognitive function (**behaviour and autism**) to be associated with lower than average ratings within health and care & family support. There was also evidence of a general trend towards parents of children suffering a sensory impairment (hearing and/or vision) having higher levels of satisfaction across many of the Core Offer areas and service domains.

The remainder of this chapter now details the headline and detailed findings for the five Core Offer areas: Assessment, Information, Feedback, Transparency and Participation.

4.1 Assessment: national sub-indicator breakdown

SECTION SUMMARY

The Assessment sub-indicators for 2009-10 are 76 for health, 77 for education, and 67 for care & family support. The sub-indicators have remained stable for health and education, although there has been a rise of five points in the care & family support sub-indicator.

The health and education sub-indicators were high (over 70) for all groups of parents. While the overall composite indicator did not vary much by receipt and level of DLA, there was considerable variation in relation to this across some of the sub-indicators. Parents of children in receipt of the higher level of DLA were the most satisfied in terms of educational assessments, although the reverse was true for care & family support assessments.

Parents of Asian children were particularly likely to be satisfied with education and care & family support assessments, with respective scores of 84 and 87. The latter score was particularly notable; the equivalent care & family support score among parents of white children was 66.

There was variability by nature of the child’s disability or health condition. Across all three service areas, scores were lower than average when the child or young person suffered depression – this is also borne out in the overall composite indicator. Assessments for children with palliative care needs were higher than average within education, but lower than average within health and care & family support. There was evidence of higher levels of satisfaction when the child suffered a sensory impairment. Assessments related to hearing disorders scored highly within the care & family support service domain, while those related to vision disorders scored highly within the health service domain.

In this and the following four sections we look at the sub-indicator scores and the detailed responses for the questions which make up each sub-indicator. This section details the scores for **Assessment**. Where relevant, sub-indicators have been cross-analysed by key variables including: receipt and level of DLA; age of child; ethnicity of child; disability type; whether child has a statement of special educational need; and other relevant questionnaire variables.

Similar sets of questions were asked in each of the three sections of the questionnaire, but tailored accordingly to health, education and care & family support. Sub-indicators were generally only calculated for respondents who had used the services relevant to that particular sub-indicator. Thus the base sizes vary by question according to the question filters applied.

4.1.1 Background

The Aiming High for Disabled Children's Core Offer standard for Assessment sets out the expectation that: *"Disabled children and young people receive child-centred multi-agency co-ordinated services from the point of referral through identification and assessment to delivery"*

Disabled children, young people and families should expect assessments that are:

- Holistic, multi-agency and co-ordinated, undertaken as far as possible in the same place at the same time, and be provided as early as possible with minimum waiting times
- Proportionate to the apparent need, guided by the views of the child and family, and centred on meeting their needs rather than on the pattern of current services
- Based on the necessary consent to share information and an understanding of the purpose and possible outcomes of the assessment
- Based on shared information, increasingly the Common Assessment Framework, as a platform for more specialist assessments, ensuring that families do not have to provide the same information time and time again
- Focused on promoting the welfare of the child in the family context and recognising that the needs of the family change over time
- Undertaken by staff with the right skills for onward referral or diagnosis, assessment, treatment and ongoing care and support.

4.1.2 How the Assessment sub-indicator was calculated

This sub-indicator was based on 6 questions (7 in the case of education). All were based on a simple *agree/neither agree nor disagree/disagree/not applicable* scale.

Any *disagree* on these questions counted as a "negative" in terms of the sub-indicator, with the exception of one statement "*We had to give the same information several times"* where an *agree* counted as a negative contribution to the sub-indicator (figure 14).

All Assessment sub-indicators were based on parents who said that professionals had made a **decision** about the services their child had received. In the case of health this related to medical or health professionals making decisions about the child's illness or disability and the services they should receive; in the case of care & family support this related to care & family support professionals making decisions about services received; and in the case of education this related to receipt of a formal assessment of educational support needs or an annual review of SEN.

If at least two scores were rated negatively then a respondent did not pass the threshold to be scored as receiving an acceptable level of service. Some respondents were excluded from the sub-indicator if they declined to answer a certain number of questions; if the number of questions with missing data meant that an acceptable/unacceptable verdict could not be reached these respondents were excluded from the calculation[7].

This information is summarised below in figure 14.

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[7] The minimum threshold for receiving an **unacceptable** level of service was 2 negative responses; and to receive an **acceptable** level of service the minimum threshold was 6 (education); and 5 (health and care & family support) positive responses respectively. So if, for example, only 2 questions of the 6 health questions were answered, one positively and one negatively, neither minimum threshold was reached and the respondent would be excluded from the base when calculating the sub-indicator.

Figure 14

QUESTIONS WHICH CONSTITUTE THE "ASSESSMENT" SUB-INDICATOR AND EXPLANATION FOR SCORING SYSTEM

	Response categories	Positive/ negative	Base (health)	Base (education)	Base (care & family support)
We/I knew what to expect from the assessment	Not applicable	Positive	NOT ASKED	All having formal assessment or annual review of SEN in last 12 months	NOT ASKED
	Agree				
	Neither agree nor disagree				
	Disagree	Negative			
We/I had to give the same information several times	Not applicable	Positive	All who have had decisions made on child's behalf in last 12 months	All having formal assessment or annual review of SEN in last 12 months	All who have had decisions made on child's behalf in last 12 months
	Disagree				
	Neither agree nor disagree				
	Agree	Negative			
We were/I was listened to and our needs were understood	Not applicable	Positive	All who have had decisions made on child's behalf in last 12 months	All having formal assessment or annual review of SEN in last 12 months	All who have had decisions made on child's behalf in last 12 months
	Agree				
	Neither agree nor disagree				
	Disagree	Negative			
The decisions made were suitable for my child's needs	Not applicable	Positive	All who have had decisions made on child's behalf in last 12 months	All having formal assessment or annual review of SEN in last 12 months	All who have had decisions made on child's behalf in last 12 months
	Agree				
	Neither agree nor disagree				
	Disagree	Negative			
The decisions were made at the right time for my child	Not applicable	Positive	All who have had decisions made on child's behalf in last 12 months	All having formal assessment or annual review of SEN in last 12 months	All who have had decisions made on child's behalf in last 12 months
	Agree				
	Neither agree nor disagree				
	Disagree	Negative			
Where necessary, the professionals worked together to make decisions	Not applicable	Positive	All who have had decisions made on child's behalf in last 12 months	All having formal assessment or annual review of SEN in last 12 months	All who have had decisions made on child's behalf in last 12 months
	Agree				
	Neither agree nor disagree				
	Disagree	Negative			
On the whole we were happy with the decisions that were made	Not applicable	Positive	All who have had decisions made on child's behalf in last 12 months	All having formal assessment or annual review of SEN in last 12 months	All who have had decisions made on child's behalf in last 12 months
	Agree				
	Neither agree nor disagree				
	Disagree	Negative			

Level of service received on Assessment sub-indicator deemed ***acceptable*** if at least 6 of the above were scored positively for education; at least 5 scored positively for health and care & family support

Level of service received on Assessment sub-indicator deemed ***unacceptable*** if at least 2 of the above were scored negatively

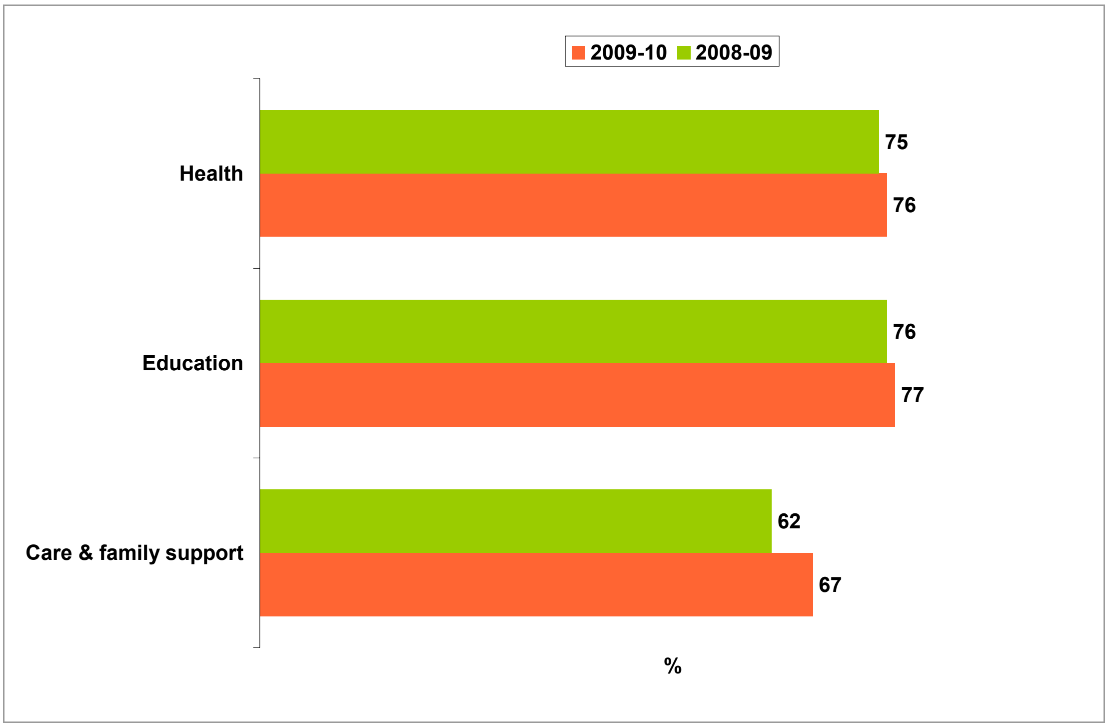
If a respondent eligible to answer these questions does not answer sufficient questions to determine the above classification they are excluded from the sub-indicator calculation

Sub-indicator is calculated as the proportion of eligible respondents who give an acceptable rating, based on the above scoring system

4.1.3 Sub-indicator scores: Assessment

The sub-indicators for the three service areas are shown in figure 15 below for 2008-09 and 2009-10. The health and education sub-indicators have remained roughly stable since 2008-09 but there has been a rise of five points in the sub-indicator for care & family support Assessment.

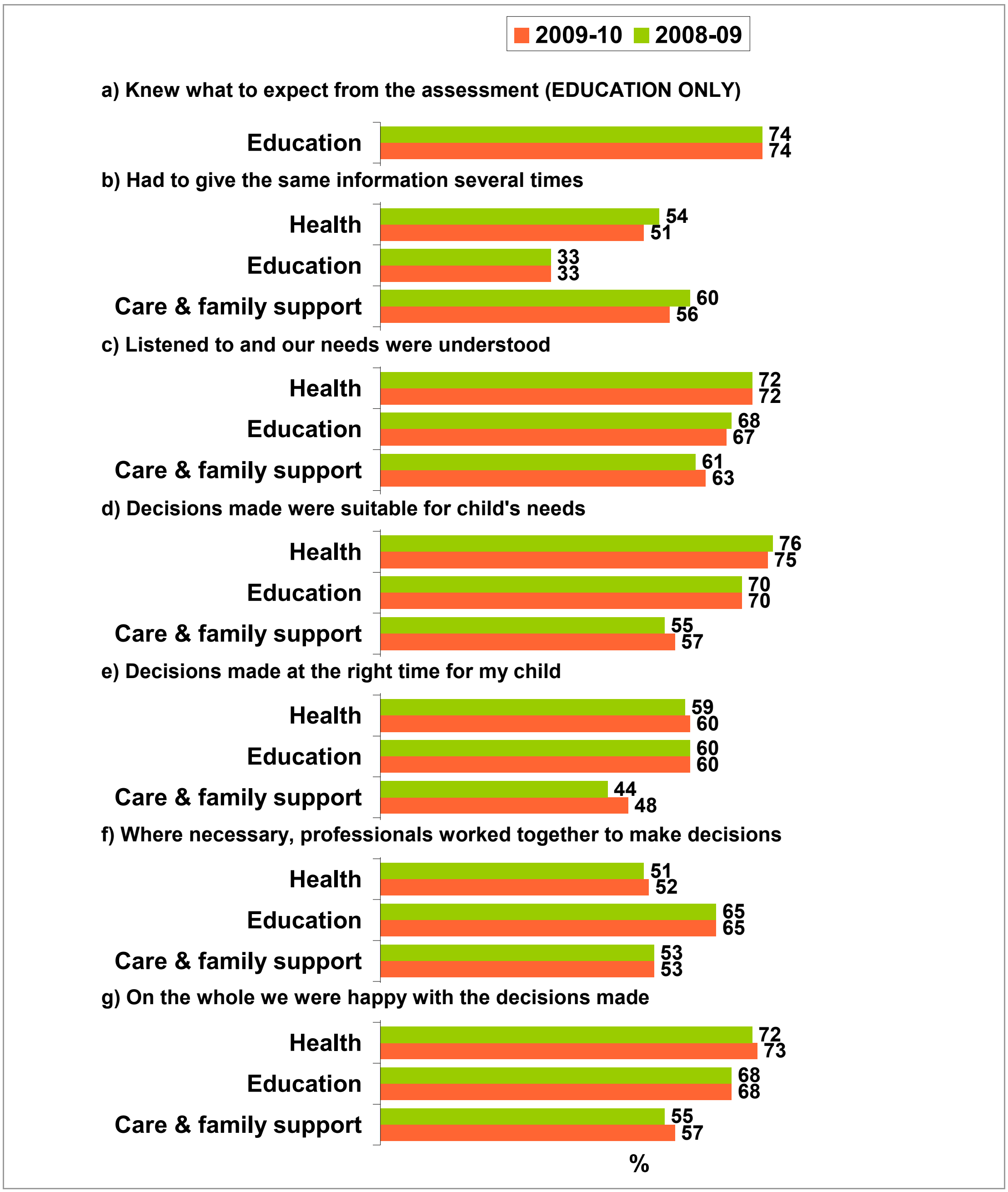
Figure 15 ASSESSMENT sub-indicator scores for the three service areas 2008-09 & 2009-10



Bases 2008-09: *Health (5,047), Education (4,580), Care & Family Support (1,181)*
Bases 2009-10: *Health (13,238), Education (13,135), Care & Family Support (3,700)*

The composition of the Assessment sub-indicators in terms of the constituent questions is displayed in Figure 16. As in 2008-09, in comparison with education and health, parents were less satisfied that during their assessments for care & family support, they were listened to and their needs understood; that the decisions made were suitable and delivered at the right time; and that they were happy with the decisions made. Compared with health and care & family support assessments, parents were less likely to consider in educational assessments that they had to repeatedly give the same information and were more likely to agree that the professionals worked together.

Figure 16 Breakdown of responses to the seven questions which constitute the ASSESSMENT sub-indicator: 2008-09 & 2009-10



Bases 2008-09: *a) Education (4,681) b) Health (5,097); Education (4,579); CFS (1,207) c) Health (5,148); Education (4,655); CFS (1,207) d) Health (5,171); Education (4,673); CFS (1,205) e) Health (512); Education (464); CFS (1,190) f) Health (5,145); Education (4,658); CFS (1,189) g) Health (5,198); Education (4,663); CFS (1,194)*
Bases 2009-10: *a) Education (13,379) b) Health (13,360); Education (13,158); CFS (3,743) c) Health (13,405); Education (13,271); CFS (3,764) d) Health (13,463); Education (13,318); CFS (3,754) e) Health (13,358); Education (13,228); CFS (3,737) f) Health (13,383); Education (13,294); CFS (3,731) g) Health (13,470); Education (13,335); CFS (3,744)*

The rise in the care & family support sub-indicator between 2008-09 and 2009-10 may be linked to a reduction in the proportion of people who felt in 2009-10 that they had to give the same information several times and a small increase in the proportion who felt that timely decisions were made. There were, however, some differences between the 2008-09 and 2009-10 questionnaires in relation to care and family support, which should be borne in mind when interpreting the sub-indicator scores for care & family support (see appendix 2 for a full discussion of these).

4.1.4 Variation in sub-indicator scores by survey subgroups

It is also useful to view the sub-indicator scores by certain survey groups, in order to find out which groups of parents are most and least satisfied with the service received. When interpreting the scores, it should be remembered that a higher sub-indicator score indicates a higher level of satisfaction with the service received, according to the number of positive ratings given out of the six/seven contributing questions[8].

Health assessments

Figure 17 displays the variation in health assessment sub-indicator score by survey subgroup for 2009-10.

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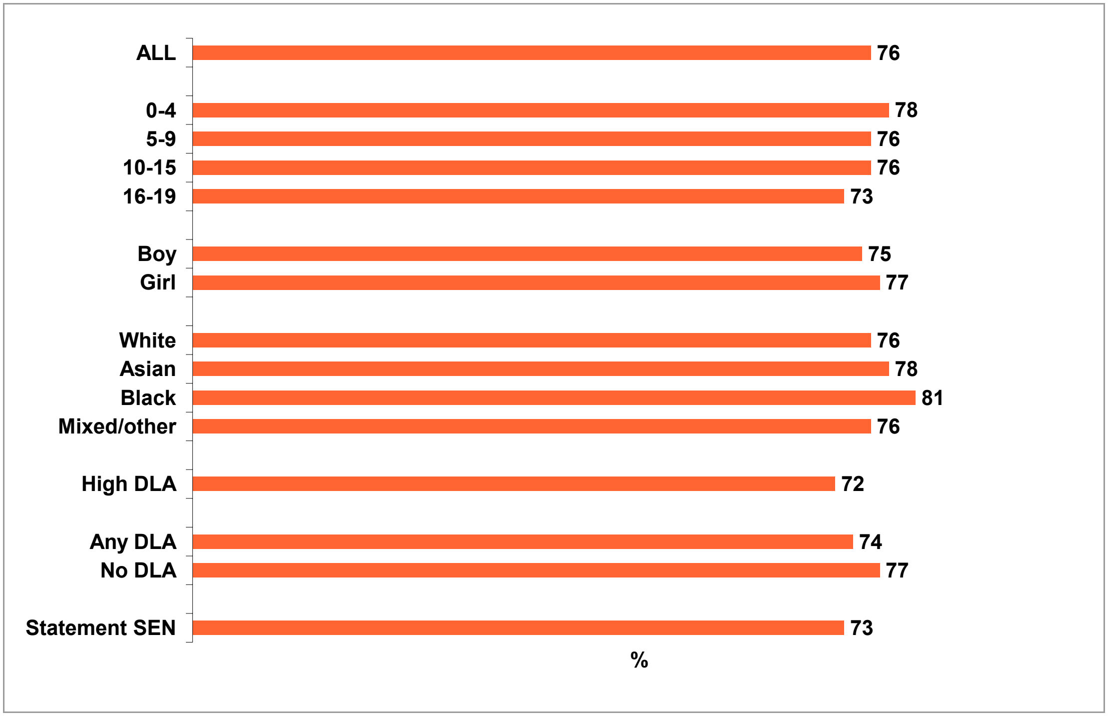
[8] As explained in section 4.1.2, for one of the questions '*We/I had to give the same information several times'* a high level of agreement with this statement was scored as a negative rating, the reverse scoring to the other questions contributing to the sub-indicator.

Figure 17 HEALTH ASSESSMENT sub-indicator scores by survey subgroup



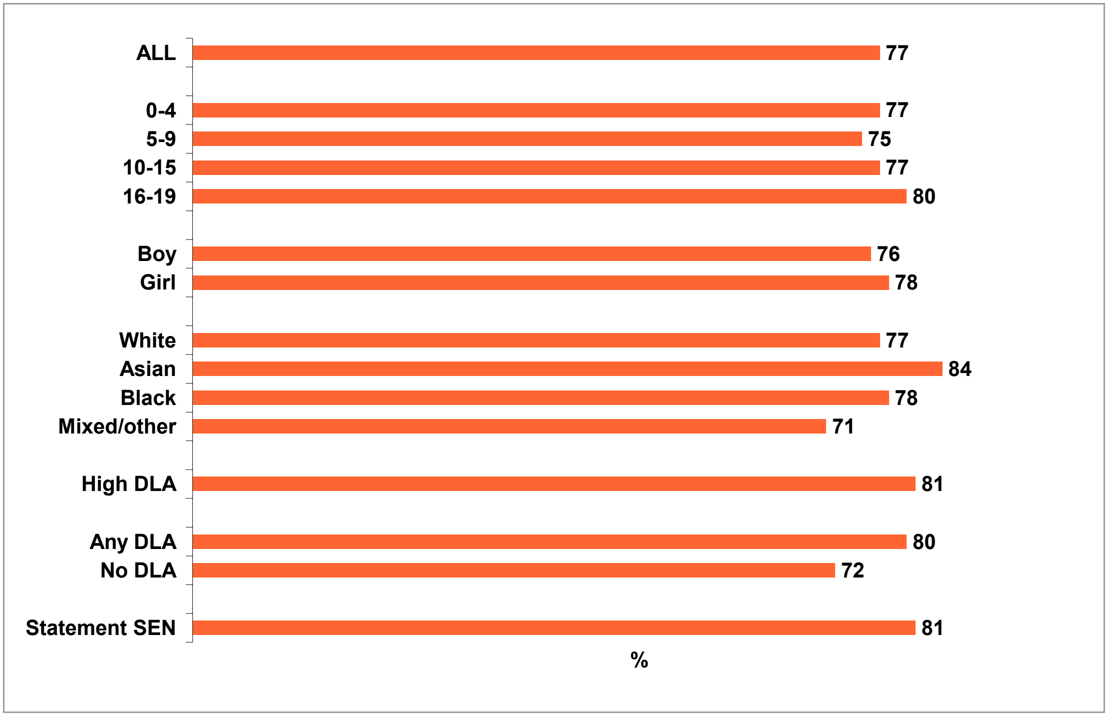
Bases 2009-10: *All (13,238); 0-4 (1,021); 5-9 (4,329); 10-15 (5,994); 16-19 (1,775); Boy (8,172); Girl (4,974); White (11,485); Asian (453); Black (363); Mixed/other (812); High DLA (3,187); Any DLA (6,282); No DLA (6,870); Statement SEN (5,139)*

There was relatively little demographic variability in the health assessment sub-indicator although subgroups that stood out as being slightly more satisfied than their counterparts included parents of black children (score of 81 compared with 76 among parents of white children) and parents of pre-school children (score of 78 among parents of 0-4s compared with a score of 73 among parents of 16-19s). The lowest scores were found among those with children who were in receipt of high level DLA (score of 72). The score for health assessments is universally high across all survey subgroups, indicating that this is an area which delivers high levels of satisfaction across all parents.

Education assessments

Figure 18 displays the variation in education Assessment sub-indicator score by survey subgroup for 2009-10.

Figure 18 EDUCATION ASSESSMENT sub-indicator scores by survey subgroup



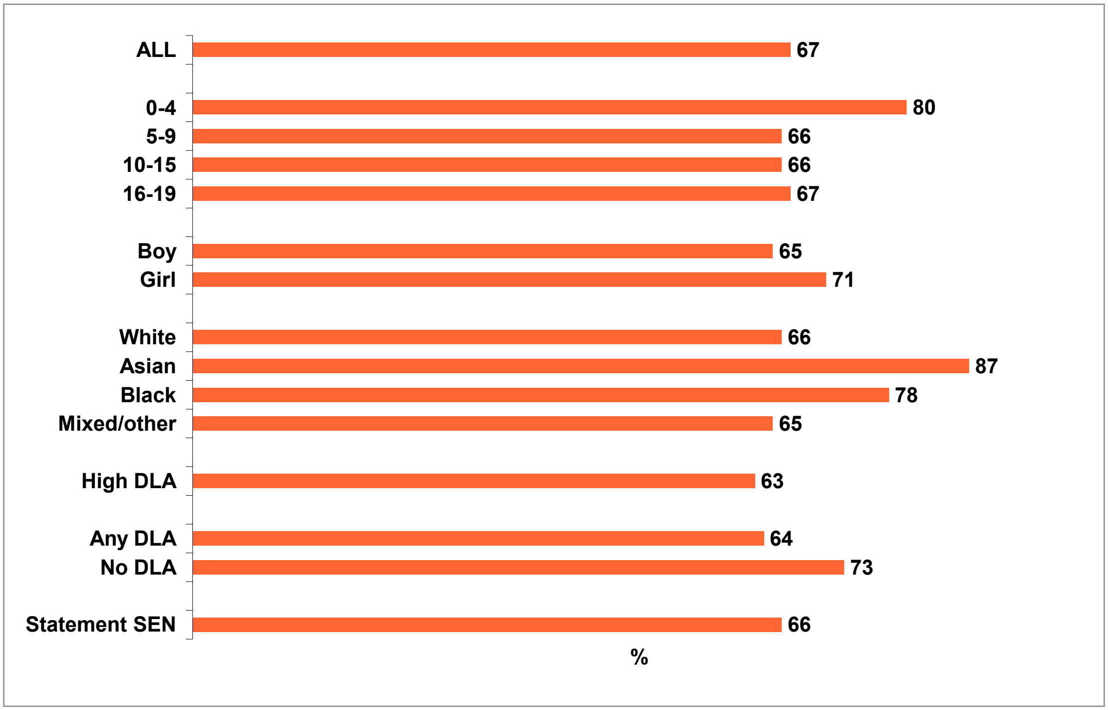
Bases 2009-10: *All (13,135); 0-4 (414); 5-9 (4,159); 10-15 (6,750); 16-19 (1,711); Boy (9,183); Girl (3,852); White (11,431); Asian (478); Black (396); Mixed/other (694); High DLA (4,181); Any DLA (8,998); No DLA (4,045); Statement SEN (9,980)*

As with health, scores for educational assessments were high across all subgroups, although slightly lower than average scores were observed among parents of children from mixed or other ethnic groups (score of 71) and parents not in receipt of any DLA for their child (score of 72). At the other end of the scale, parents of Asian children were particularly likely to be satisfied with educational assessments received by their child (score of 84) as were parents of children in receipt of higher level DLA (score of 81) or a statement of SEN (score of 81).

Care & family support assessments

Figure 19 displays the variation in care & family support Assessment sub-indicator score by survey subgroup for 2009-10.

Figure 19 CARE & FAMILY SUPPORT ASSESSMENT sub-indicator scores by survey subgroup



Bases 2009-10: *All (3,700); 0-4 (198); 5-9 (988); 10-15 (1,792); 16-19 (687); Boy (2,396); Girl (1,267); White (3,163); Asian (144); Black (119); Mixed/other (230); High DLA (1,811); Any DLA (2,873); No DLA (790); Statement SEN (2,681)*

In general scores for care and family support assessments were lower relative to educational and health assessments, although peaks of satisfaction were found among parents of Asian children (score of 87) and parents with pre-school children (score of 80). In contrast to educational assessments, parents of children in receipt of higher level DLA were less satisfied than average (a score of 63).

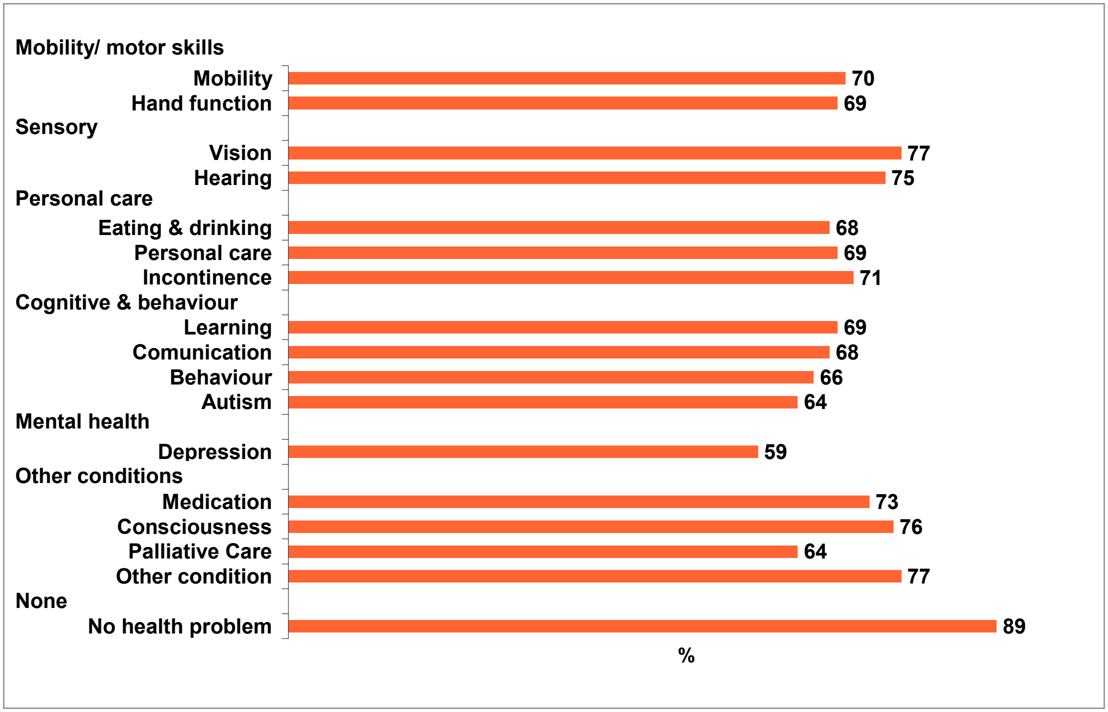
4.1.4.1 Assessment sub-indicator by type of disability

In addition to the above subgroups it is also of interest to explore the relationship between level of satisfaction with assessment and type of disability.

Health assessments

Figure 20 displays the health assessment sub-indicator by type of disability.

Figure 20 HEALTH ASSESSMENT sub-indicator scores by nature of child's disability



***Bases 2009-10:** Mobility (4,301); hand function (2,721); vision (2,197); hearing (1,684); eating & drinking (3,260); personal care (5,195); incontinence (2,840); learning (6,381); communication (5,449); behaviour (5,580); autism (2,664); depression (940); medication (3,184); consciousness (1,456); palliative care (283); other condition (2,912); no health problem (1,172)*

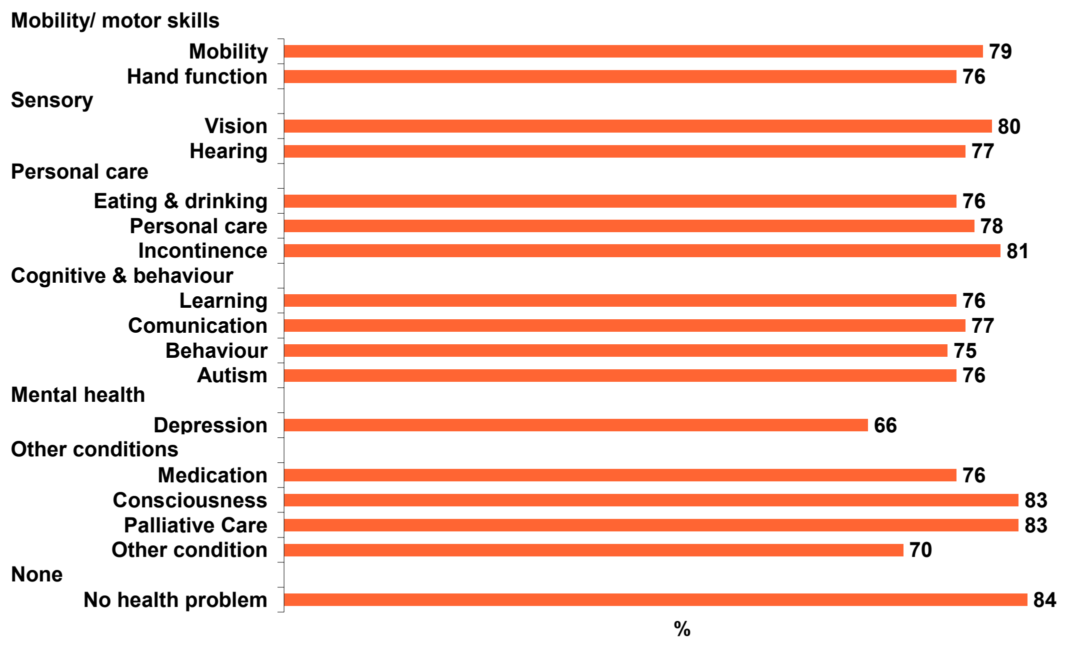
The highest levels of satisfaction with health assessments were observed when the child had a sensory impairment (respective scores of 77 and 75 for vision and hearing) and when the child suffered from a condition related to consciousness (score of 76).

On the other hand, scores were lower than average when the child suffered from a behavioural disorder or autism (scores of 66 and 64 respectively) or when the child had palliative care needs (score 64). However, as was also observed in 2008-09, the health assessment score was markedly low when the child or young person suffered from depression (59).

Education assessments

Figure 21 displays the education assessment sub-indicator by type of disability.

Figure 21 EDUCATION ASSESSMENT sub-indicator scores by nature of child's disability



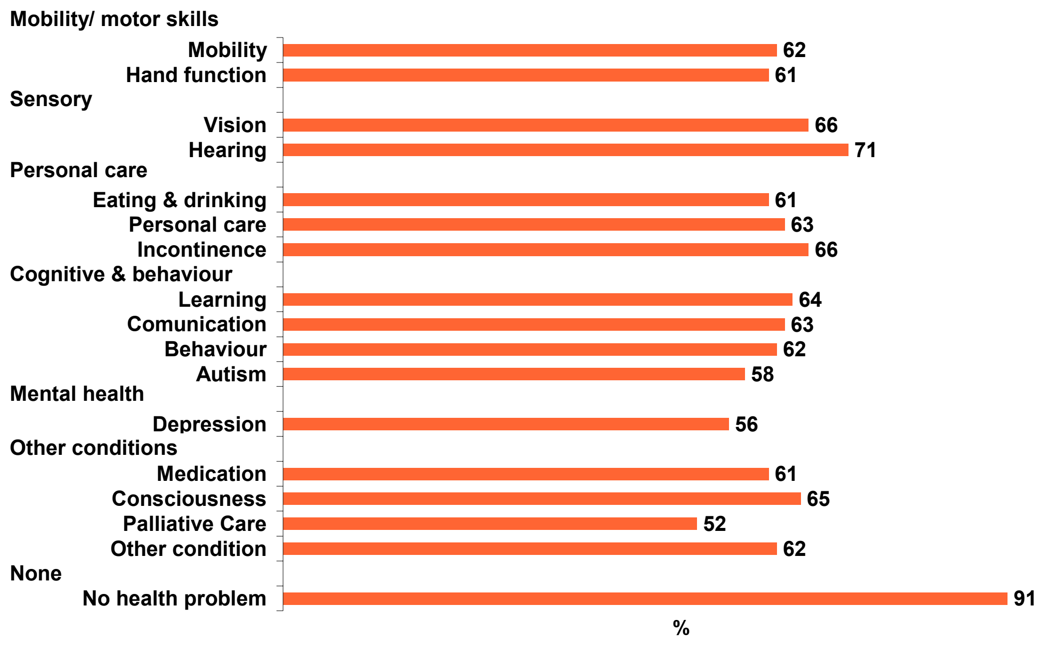
Bases 2009-10: *Mobility (5,626); hand function (3,485); vision (2,360); hearing (1,677); eating & drinking (3,477); personal care (7,041); incontinence (3,178); learning (10,544); communication (8,333); behaviour (7,702); autism (4,573); depression (691); medication (2,709); consciousness (1,350); palliative care (294); other condition (1,988); no health problem (236)*

Scores for educational assessments were high across the board with the exception of a relatively low score when the young person suffered from depression (66). In reverse to the pattern noted in health assessments above, parents of children with palliative care needs showed higher than average satisfaction levels for educational assessments (score of 83).

Care & family support assessments

Figure 22 displays the care & family support assessment sub-indicator by type of disability, grouped by type of impairment.

Figure 22 CARE & FAMILY SUPPORT ASSESSMENT sub-indicator scores by nature of child's disability



Bases 2009-10: *Mobility (2,117); hand function (1,311); vision (827); hearing (477); eating & drinking (1,490); personal care (2,567); incontinence (1,423); learning (2,903); communication (2,565); behaviour (2,452); autism (1,326); depression (322); medication (1,228); consciousness (646); palliative care (168); other condition (651); no health problem (89)*

When the assessment related to care & family support, the variability by type of disability was relatively low although, as with health assessments, palliative care stood out as attracting lower levels of satisfaction from parents. When children had a hearing problem, ratings for care & family support assessments were higher than average (score of 71).

4.2 Information: national sub-indicator breakdown

SECTION SUMMARY

The Information sub-indicators for 2009-10 are 69 for health, 70 for education, and 69 for care & family support. The sub-indicators have remained stable for health and education, although there has been a rise of nine points in the care & family support sub-indicator.

In general, parents were most satisfied with information provided when their children were of pre-school age. This is one of the factors why the overall composite indicator is higher for parents of children of pre-school age.

While the overall composite indicator was the same for parents of children regardless of receipt and level of DLA, significant variation was observed in relation to this across some sub-indicators. For example, for health and care & family support, there was strong evidence that parents of children in receipt of DLA or with a statement of SEN were less likely to be happy with the quality of information received; but the level of satisfaction for these groups were higher than average in feedback.

Across the three service domains, there was a general pattern by nature of disability. Parents were less satisfied than average when their child suffered a cognitive impairment (especially conditions related to behaviour/autism) or suffered depression. On the other hand, information was rated better than average when the child suffered a sensory impairment (hearing or vision).

This section details the scores for **Information**. It should be noted that there were some important changes to the questionnaire in 2009-10 that affected care & family support sections of the questionnaire, and in particular questions relating to the care & family support information sub-indicator. These are discussed in more detail in appendix 2.

Where relevant, sub-indicators have been cross-analysed by key variables including: receipt and level of DLA; age of child; ethnicity of child; disability type; whether child has a statement of special educational need; and other relevant questionnaire variables.

Similar sets of questions were asked in each of the three sections of the questionnaire, but tailored accordingly to health, education and care & family support. In some cases, sub-indicators were only calculated for respondents who had used the services relevant to that particular sub-indicator. Thus the base sizes vary by question according to the question filters applied.

4.2.1 Background

The Aiming High for Disabled Children's Core Offer standard for Information sets out the expectation that: *"The information provided should be tailored to the individual needs of children and their parents and be readily accessible in a range of formats."*

Providing information and greater transparency about decision making will empower families to find their own ways to meet the needs of their disabled child, their other children and themselves.

Disabled children, young people and their families should expect information which is:

- Accessible: using everyday language, alternative formats, the internet and community languages as necessary
- Available: "to hand" without delay in places where families with children routinely go, including schools and colleges, health centres and GP surgeries and Sure Start Children's Centres
- Relevant and accurate: appropriate for every stage of a child's life and up-to-date with what is actually provided
- Joined-up: co-ordinated across local authorities, schools and colleges, PCTs, provider trusts and the voluntary and independent sector
- User-focused: always focusing on the desired outcome i.e. families know where, and how, to get help and support.

4.2.2 How the Information sub-indicator was calculated

This sub-indicator was based on 7 questions (figure 23). The first four documented below were based on a simple *agree/neither agree nor disagree/disagree/not applicable scale*. Any *disagree* on these questions counted as a "negative" in terms of the sub-indicator. The last three questions about written and verbal information were based on a simple *always/sometimes/never* scale where a response of *never* counted as a negative. Where a respondent was not eligible to answer the latter three questions because they had not received any written or verbal information this was given an assumed rating of "positive".

If at least two scores were rated negatively then a respondent did not pass the threshold to be scored as receiving an acceptable level of service. Some respondents were excluded from the sub-indicator if they declined to answer a certain number of questions; if the number of questions with missing data meant that an acceptable/unacceptable verdict could not be reached these respondents were excluded from the calculation[9].

Information concerning the calculation of the Information sub-indicator is summarised below in figure 23.

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[9] The minimum threshold for receiving an **unacceptable** level of service was 2 negative responses; and to receive an **acceptable** level of service the minimum threshold was 6 positive responses. So if, for example, only 2 questions of the 7 were answered, one positively and one negatively, neither minimum threshold was reached and the respondent would be excluded from the base when calculating the sub-indicator.

Figure 23

QUESTIONS WHICH CONSTITUTE THE "INFORMATION" SUB-INDICATOR AND EXPLANATION FOR SCORING SYSTEM

	Response categories	Positive/ negative	Base (health)	Base (education)	Base (care & family support) †
We have been given enough information about my child's health condition/educational needs/care & family support needs	Not applicable	Positive	All respondents	All receiving education services for their child in last 12 months	All respondents
	Agree				
	Neither agree nor disagree				
	Disagree	Negative			
We have been given enough useful information about the health/education/care & family support services my child is entitled to	Not applicable	Positive	All respondents	All receiving education services for their child in last 12 months	All respondents
	Agree				
	Neither agree nor disagree				
	Disagree	Negative			
We have been given enough information about how to get health/education/care & family support services for my child	Not applicable	Positive	All respondents	All receiving education services for their child in last 12 months	All respondents
	Agree				
	Neither agree nor disagree				
	Disagree	Negative			
There is someone we/I can go to for help & support in getting health/education/care & family support services for my child	Not applicable	Positive	All respondents	All receiving education services for their child in last 12 months	All respondents
	Agree				
	Neither agree nor disagree				
	Disagree	Negative			
How often was information received **clear** to understand?	No written/ verbal info in last 12 months	Positive	All respondents	All receiving education services for their child in last 12 months	All respondents
	Always				
	Sometimes				
	Never	Negative			
How often was information received **relevant** to you and your child?	No written/ verbal info in last 12 months	Positive	All respondents	All receiving education services for their child in last 12 months	All respondents
	Always				
	Sometimes				
	Never	Negative			
How often was information received **accurate** and up to date?	No written/ verbal info in last 12 months	Positive	All respondents	All receiving education services for their child in last 12 months	All respondents
	Always				
	Sometimes				
	Never	Negative			

†Note change in base and impact on sub-indicator calculation – see appendix 2 for further details

Level of service received on Information sub-indicator deemed ***acceptable*** if at least 6 of the above scored positively

Level of service received on Information sub-indicator deemed ***unacceptable*** if at least 2 of the above scored negatively

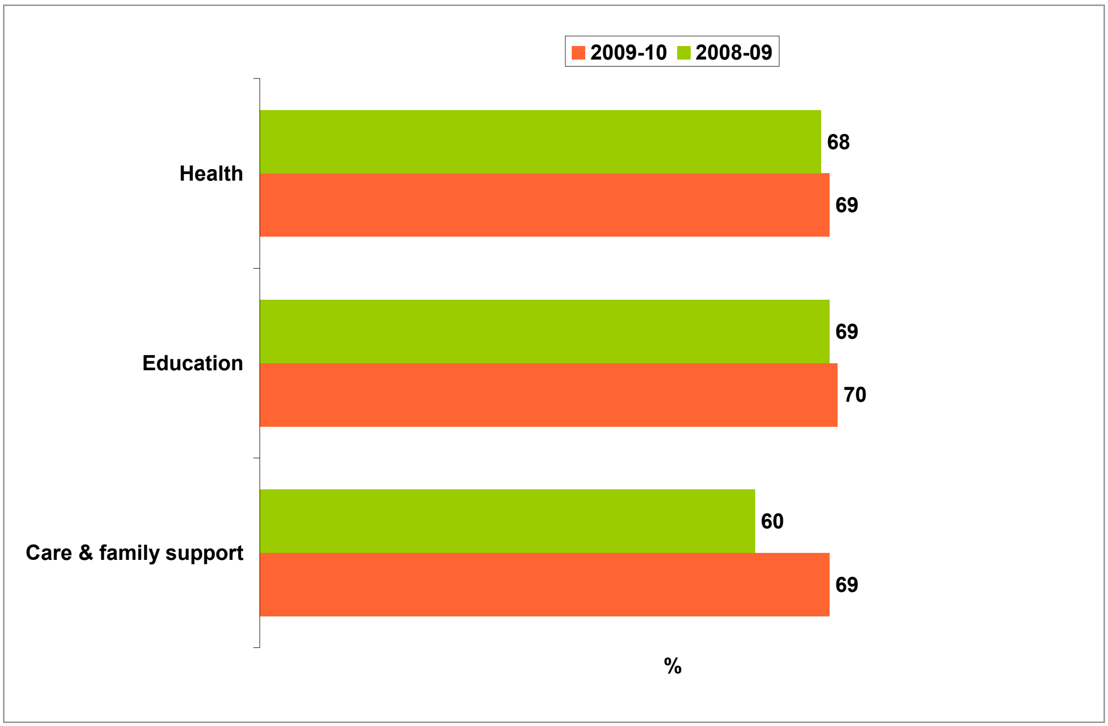
If a respondent eligible to answer these questions does not answer sufficient questions to determine the above classification they are excluded from the sub-indicator calculation

Sub-indicator is calculated as the proportion of eligible respondents who give an acceptable rating, based on the above scoring system

4.2.3 Sub-indicator scores: Information

The sub-indicators for the three service areas are shown in figure 24 below for 2008-09 and 2009-10. There was little change in the sub-indicators for health and education since 2008-09. However there has been a rise of nine points in the sub-indicator for care & family support Information.

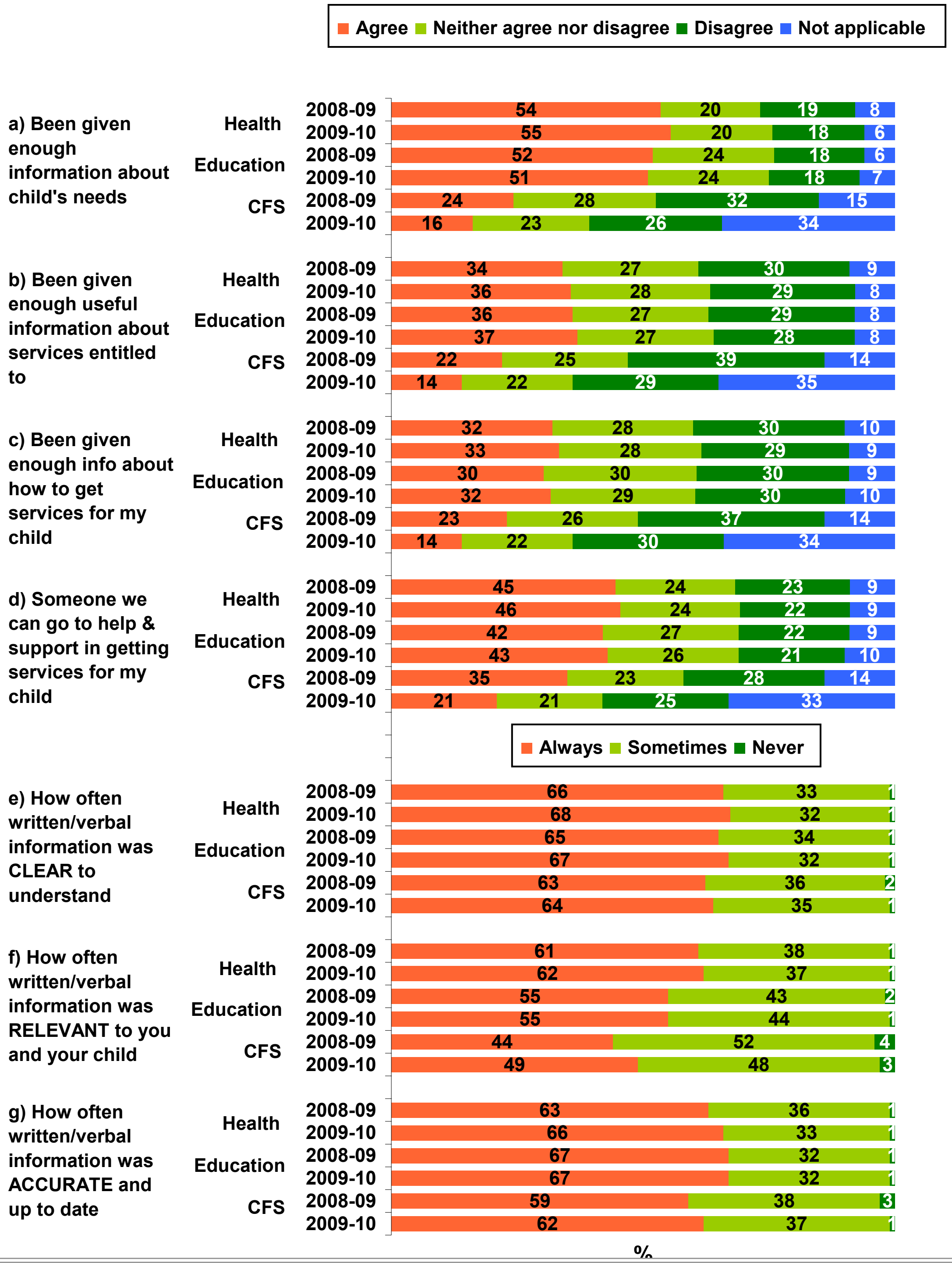
Figure 24 INFORMATION sub-indicator scores for the three service areas 2008-09 & 2009-10



Bases 2008-09: *Health (11,241), Education (10,923), Care & Family Support (3,612)*
Bases 2009-10: *Health (29,340), Education (28,526), Care & Family Support (29,503)*

The composition of the Information sub-indicators in terms of the constituent questions is displayed in Figure 25 below. There has been no change over time in the pattern of responses within these questions for health and education. The high proportion of respondents selecting 'not applicable' in response to the first four questions relating to care and family support reflect the questionnaire changes discussed in appendix 2.

Figure 25 Breakdown of responses to the seven questions which constitute the INFORMATION sub-indicator: 2008-09 (top bar for each core area) & 2009-10 (lower bar for each core area)



Bases 2008-09: *a) Health (11,980); Education (11,350); CFS (3,751) b) Health (11,763); Education (11,278); CFS (3,742) c) Health (11,718); Education (11,250); CFS (3,732) d) Health (11,714); Education (11,244); CFS (3,735) e) Health (3,834); Education (4,438); CFS (1,466) f) Health (3,620); Education (4,270); CFS (1,392) g) Health (3,525); Education (4,190); CFS (1,355)*

Bases 2009-10: *a) Health (30,891); Education (29,750); CFS (30,198) b) Health (30,591); Education (29,501); CFS (30,046) c) Health (30,535); Education (29,437); CFS (30,023) d) Health (30,532); Education (29,391); CFS (30,011) e) Health (10,452); Education (12,372); CFS (4,931) f) Health (9,876); Education (11,903); CFS (4,728) g) Health (9,613); Education (11,706); CFS (4,636)*

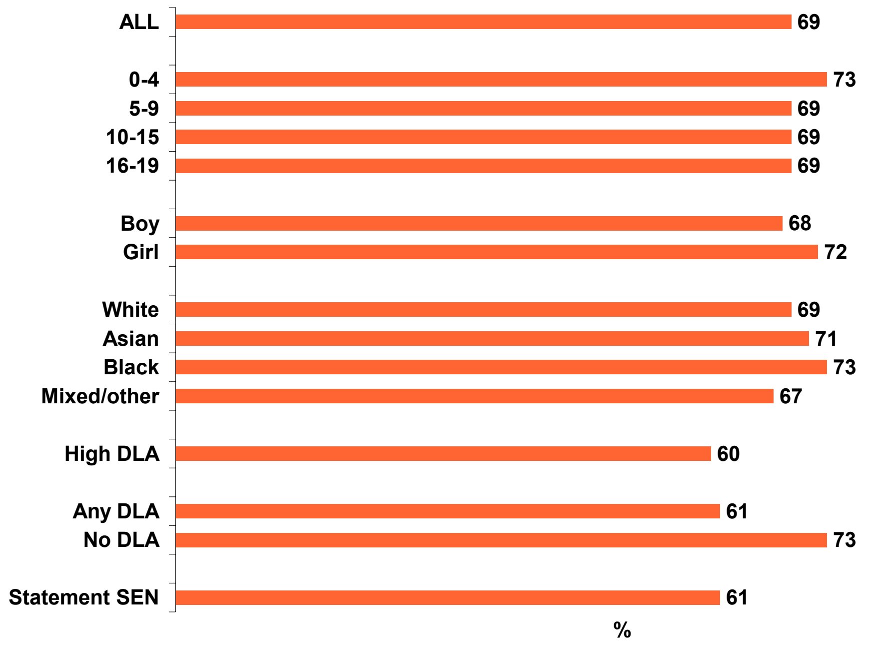
4.2.4 Variation in sub-indicator scores by survey subgroups

It is also useful to view the sub-indicator scores by certain survey groups, in order to find out which groups of parents are most and least satisfied with the service received. When interpreting the scores, it should be remembered that a higher sub-indicator score indicates a higher level of satisfaction with the service received, according to the number of positive ratings given out of the seven contributing questions.

Health information

Figure 26 displays the variation in health Information sub-indicator score by survey subgroup for 2009-10.

Figure 26 HEALTH INFORMATION sub-indicator scores by survey subgroup



Bases 2009-10: *All (29,340); 0-4 (1,752); 5-9 (9,186); 10-15 (13,864); 16-19 (4,273); Boy (18,652); Girl (10,500); White (25,193); Asian (1,243); Black (916); Mixed/other (1,721); High DLA (5,039); Any DLA (11,830); No DLA (17,316); Statement SEN (10,669)*

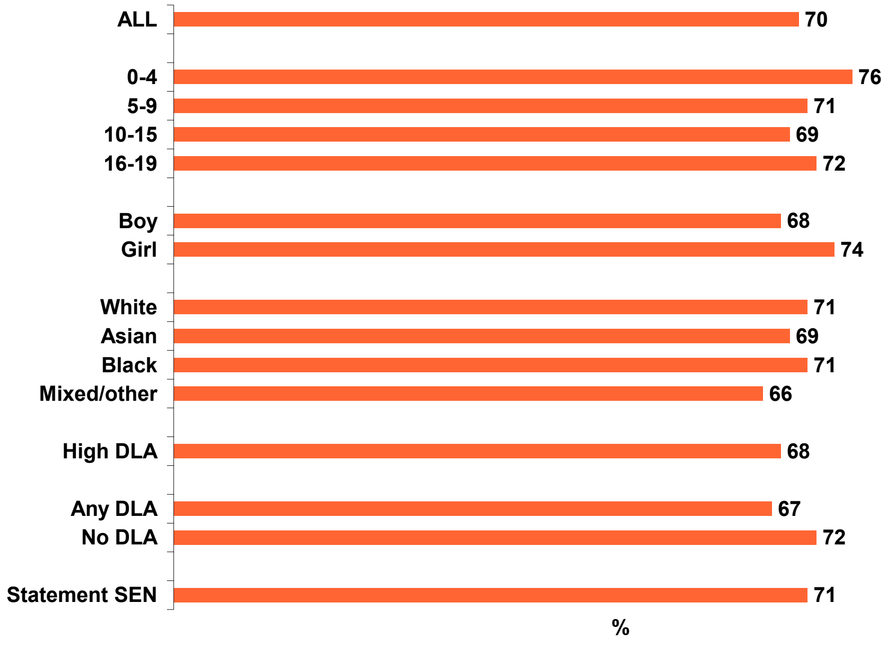
The results for health show that parents gave a slightly higher relative rating compared to the average score (69) when their child is under 5 years old (score of 73). In addition, parents of black children tended to give slightly higher ratings than average (also score of 73).

Satisfaction regarding information given in relation to health services was strongly related to level of disability – both receipt of and level of DLA. Those whose child received DLA had a lower relative score (61) than those whose child did not receive it (73) indicating that the more disabled the child the greater degree of dissatisfaction. The score among children with high level DLA was even lower (60).

Education information

Figure 27 displays the variation in education Information sub-indicator score by survey subgroup for 2009-10.

Figure 27 EDUCATION INFORMATION sub-indicator scores by survey subgroup



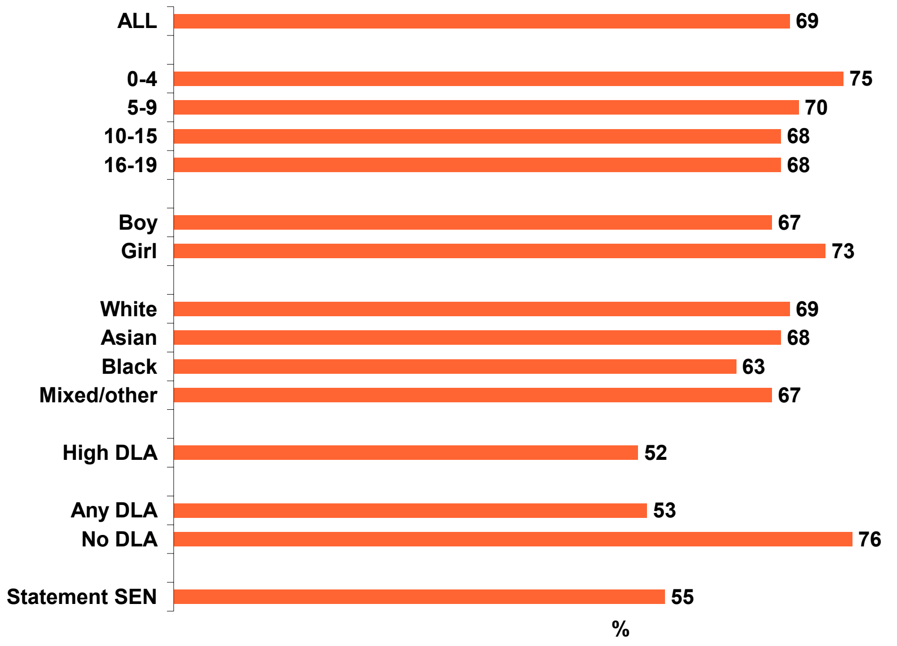
Bases 2009-10: *All (28,526); 0-4 (1,484); 5-9 (9,140); 10-15 (13,622); 16-19 (4,056); Boy (18,173); Girl (10,171); White (24,611); Asian (1,153); Black (848); Mixed/other (1,648); High DLA (4,968); Any DLA (11,630); No DLA (16,710); Statement SEN (10,679)*

In terms of information provided about education services, parents of younger pre-school children tended to give higher ratings (score of 76) compared with the national average (score of 70). Parents of girls were slightly more satisfied with the quality of education information than parents of boys (scores of 74 and 68 respectively).

Care & family support information

Figure 28 displays the variation in care & family support Information sub-indicator score by survey subgroup for 2009-10.

Figure 28 CARE & FAMILY SUPPORT INFORMATION sub-indicator scores by survey subgroup



Bases 2009-10: *All (29,503); 0-4 (1,749); 5-9 (9,269); 10-15 (13,948); 16-19 (4,276); Boy (18,742); Girl (10,581); White (25,368); Asian (1,260); Black (891); Mixed/other (1,722); High DLA (5,130); Any DLA (11,966); No DLA (17,346); Statement SEN (10,800)*

As with the other sub-indicators for Information, those giving the most positive ratings were parents of younger pre-school children (score of 75 compared with the national average of 69); and those not in receipt of DLA (score of 76). By contrast, those in receipt of high level DLA were significantly less likely to be satisfied with the quality of care and family support information received (score of 52).

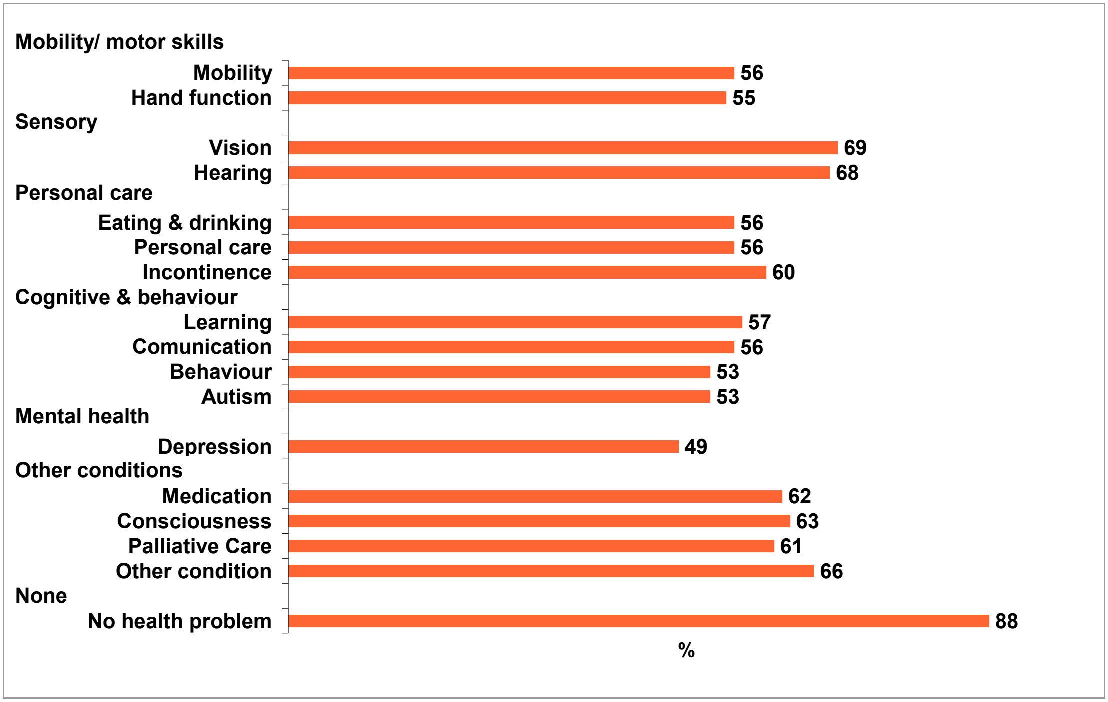
4.2.4.1 Information sub-indicator by type of disability

In addition to the above subgroups it is also of interest to explore the relationship between level of satisfaction with information and type of disability.

Health information

Figure 29 displays the health Information sub-indicator by type of disability, grouped by type of impairment.

Figure 29 HEALTH INFORMATION sub-indicator scores by nature of child's disability



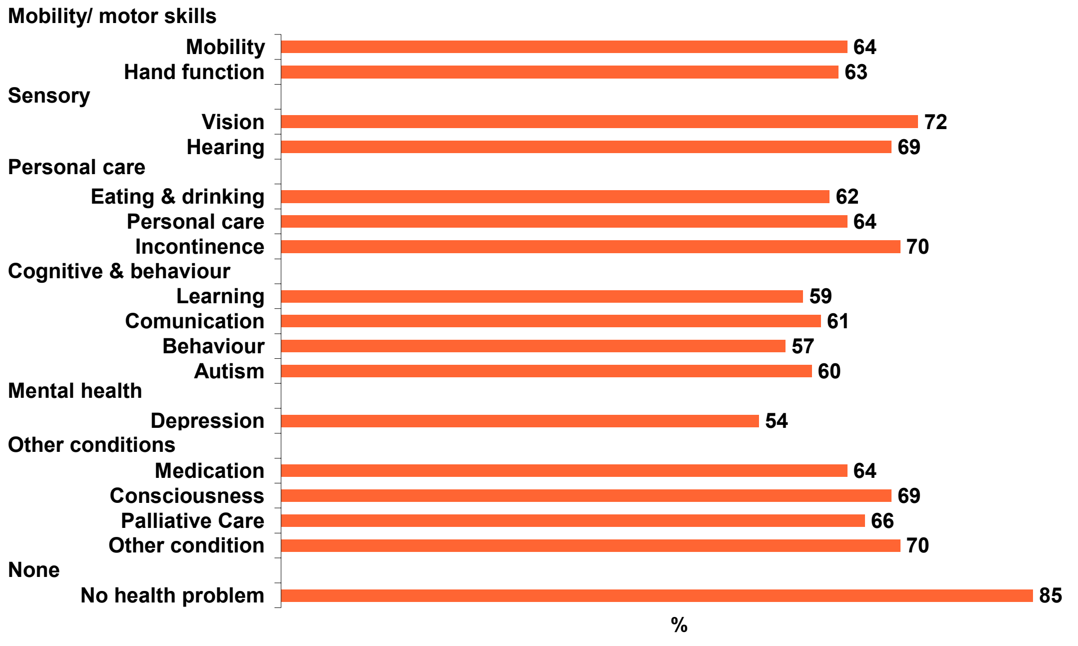
Bases 2009-10: *Mobility (7,342); hand function (4,553); vision (4,168); hearing (3,062); eating & drinking (5,155); personal care (9,263); incontinence (4,621); learning (13,664); communication (11,122); behaviour (11,300); autism (5,893); depression (1,577); medication (4,382); consciousness (1,938); palliative care (390); other condition (5,575); no health problem (4,046)*

For health information, the scores for parents of children with conditions relating to personal care, mobility/motor skills and cognitive or behavioural conditions were all low relative to the average score. On the other hand, the scores for children with sensory impairments were notably high in comparison. As has been noted elsewhere, parents who have a child suffering from depression were particularly likely to be unhappy with the quality of health information received.

Education information

Figure 30 displays the education information sub-indicator by type of disability.

Figure 30 EDUCATION INFORMATION sub-indicator scores by nature of child's disability



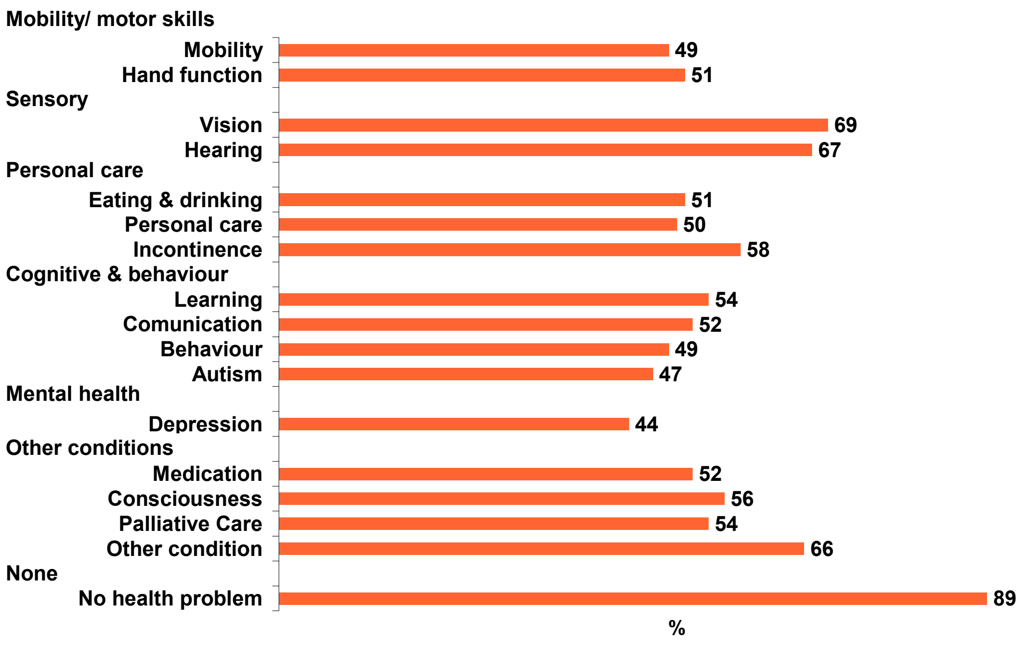
Bases 2009-10: *Mobility (7,233); hand function (4,481); vision (4,084); hearing (2,974); eating & drinking (5,009); personal care (9,155); incontinence (4,548); learning (13,556); communication (10,945); behaviour (11,172); autism (5,817); depression (1,513); medication (4,255); consciousness (1,903); palliative care (375); other condition (5,421); no health problem (3,784)*

Within education, the lower relative scores for children who experience a condition related to cognitive function or behaviour are particularly notable, as is the low score for children who suffer depression.

Care & family support information

Figure 31 displays the care & family support information sub-indicator by type of disability, grouped by type of impairment.

Figure 31 CARE & FAMILY SUPPORT INFORMATION sub-indicator scores by nature of child's disability



Bases 2009-10: *Mobility (7,433); hand function (4,594); vision (4,191); hearing (3,094); eating & drinking (5,198); personal care (9,367); incontinence (4,645); learning (13,785); communication (11,208); behaviour (11,409); autism (5,925); depression (1,570); medication (4,413); consciousness (1,974); palliative care (403); other condition (5,599); no health problem (4,068)*

Similar to education information, the lowest scores for care and family support information provision tended to be found among parents of children with cognitive/ behavioural disorders and depression, although the scores for mobility/motor skills and personal care also tended to be lower than average. By contrast, scores were much higher when children suffer a sensory impairment and once again this reflects a more general trend for increased satisfaction within this group that has been observed elsewhere.

4.3 Feedback: national sub-indicator breakdown

SECTION SUMMARY

The Feedback sub-indicators for 2009-10 are 12 for health, 20 for education, and 12 for care & family support. The sub-indicators have remained stable since 2008-09. These relatively low scores stem from the fact that the large majority of parents and their children were not asked to give feedback. In the rare cases when feedback was elicited, it was usually either acted upon or the feedback was positive.

Within health and education, the feedback sub-indicators were higher than average among parents of children from a black ethnic origin, in receipt of higher level DLA and statement of SEN. Scores for care & family support also rose when the child received high level DLA or SEN statement. Variations by DLA should be viewed in the context of the overall indicator, which remained the same for DLA recipients and non-recipients.

There was some variability by nature of the child's disability or health condition. In general, Feedback scores were highest for the more serious disabilities such as problems relating to consciousness or when the child had palliative care needs.

This section details the scores for **Feedback**. Where relevant, sub-indicators have been cross-analysed by key variables including: receipt and level of DLA; age of child; ethnicity of child; disability type; whether child has a statement of special educational need; and other relevant questionnaire variables.

Similar sets of questions were asked in each of the three sections of the questionnaire, but tailored accordingly to health, education and care & family support. Sub-indicators were generally only calculated for respondents who had used the services relevant to that particular sub-indicator. Thus the base sizes vary by question according to the question filters applied.

4.3.1 Background

The Aiming High for Disabled Children's Core Offer standard for Feedback sets out the expectation that: *"Disabled children want staff to listen to them, ask them for their ideas, take notice of what they say and give them choices… Involvement of children and their parents in planning services leads to more appropriate services".*

Disabled children, young people and their families should expect:

- Feedback to be routinely and systematically
  - sought from all children and families regardless of impairment
  - analysed by socio demographic factors and by nature of impairment
  - reported in everyday language to local parents forums and to meetings
  - acted upon so that the views of families requiring support demonstrably influence future provision
- Support to be available to enable disabled children and young people to provide feedback, for example, advocacy
- A clear and well-publicised complaints procedure for all families who are not happy with the services they are receiving
- Complaints to be dealt with promptly, fully, fairly and at an appropriate level, with findings fed back to parents and carers.

4.3.2 How the Feedback sub-indicator was calculated

This sub-indicator was based on four measures compiled from six questions. Two of the measures were composite measures based on two questions. Thus, parents were asked whether they had been asked for feedback, and – if yes - whether the feedback had been acted upon. These questions were combined to give a single measure: *feedback elicited and acted upon; feedback elicited and not acted upon; feedback elicited but no need for action as feedback was positive; and feedback not elicited*. A "negative" score was recorded where feedback was elicited but not acted upon, or where no feedback was sought at all.

The same set of questions was asked in relation to children i.e. whether children's views were sought and acted upon. However, in this case some extra categories were included in the composite measure: *service did not have the communication skills to obtain child's feedback* and *child unable to provide feedback due to young* *age or other problems (e.g. communication problems)*. A “negative” score was recorded where feedback was elicited but not acted upon, where no feedback was sought at all, or where the service lacked the necessary communication skills to elicit feedback from the child.

Finally two questions were asked in relation to complaints handling. A negative score was recorded where dissatisfaction was observed on either measure. A satisfied or neutral response counted as “positive”. In addition all who had not made a complaint at all (the large majority) were imputed a “positive” score.

The Feedback questions were based only on parents who have received the relevant health/education/care & family support services on behalf of their child, whereas the complaints questions were based on all respondents for health and care & family support. If at least one measure out of the four was rated negatively then a respondent did not pass the threshold to be scored as receiving an acceptable level of service. Some respondents were excluded from the sub-indicator if they declined to answer a certain number of questions; if the number of questions with missing data meant that an acceptable/unacceptable verdict could not be reached these respondents were excluded from the calculation[10].

This information is summarised below in figure 32.

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[10] The minimum threshold for receiving an **unacceptable** level of service was 1; and to receive an **acceptable** level of service the minimum threshold was 4. So if, for example, only 2 of the 4 health measures were recorded, two positively and zero negatively, neither minimum threshold was reached and the respondent would be excluded from the base when calculating the sub-indicator.

Figure 32

QUESTIONS WHICH CONSTITUTE THE "FEEDBACK" SUB-INDICATOR AND EXPLANATION FOR SCORING SYSTEM

	Response categories	Positive/ negative	Base (health)	Base (education)	Base (care & family support)
In last 12 months have you been asked for your opinion on services child received? / Have changes been made as a result?	Feedback elicited & changes made	Positive	All who have received health services for their child in last 12 months	All who have received education services for their child in last 12 months	All who have received care & family support services for their child in last 12 months
	Feedback elicited but no need for change as feedback positive				
	Feedback elicited & changes not made				
	Feedback not elicited	Negative			
In last 12 months has your child been asked for their opinion on services child received? / Have changes been made as a result?	Feedback elicited & changes made	Positive	All who have received health services for their child in last 12 months	All who have received education services for their child in last 12 months	All who have received care & family support services for their child in last 12 months
	Feedback elicited but no need for change as feedback positive				
	Child unable to provide feedback as too young or other problems				
	Service lacked communication skills to obtain child's feedback	Negative			
	Feedback elicited & changes not made				
	Feedback not elicited				
When complaint made, how well was complaint dealt with?	No complaint made	Positive	All who have received health services for their child in last 12 months	All who have received education services for their child in last 12 months	All who have received care & family support services for their child in last 12 months
	Very well				
	Fairly well				
	Not very well	Negative			
	Not at all well				
When complaint made, how easy or difficult was it to find out how to make a formal written complaint?	No complaint made	Positive	All respondents	All who have received education services for their child in last 12 months	All respondents
	Very easy				
	Fairly easy				
	Neither easy nor difficult				
	Fairly difficult	Negative			
	Very difficult				

Level of service received on Feedback sub-indicator deemed ***acceptable*** if at least 3 of the above were scored positively

Level of service received on Feedback sub-indicator deemed ***unacceptable*** if at least 1 of the above was scored negatively

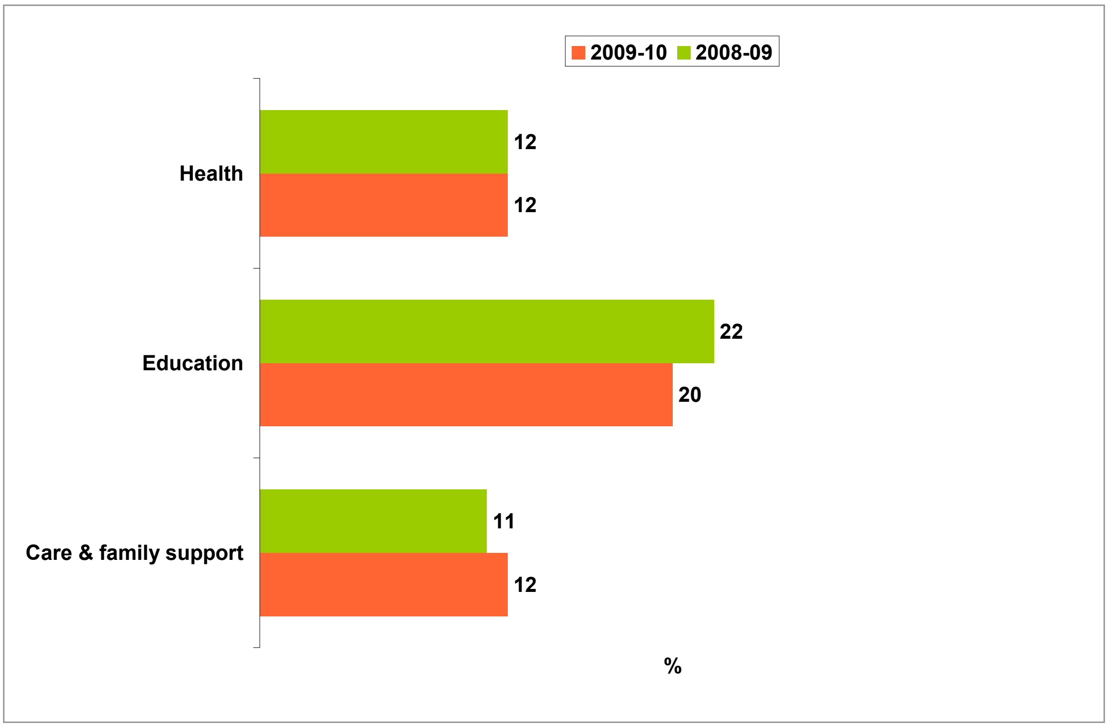
If a respondent eligible to answer these questions does not answer sufficient questions to determine the above classification they are excluded from the sub-indicator calculation

Sub-indicator is calculated as the proportion of eligible respondents who give an acceptable rating, based on the above scoring system

4.3.3 Sub-indicator scores: Feedback

The sub-indicators for the three service areas are shown in figure 33 below for 2008-09 and 2009-10. There have been no substantive changes between the two survey years.

Figure 33 FEEDBACK sub-indicator scores for the three service areas 2008-09 & 2009-10



Bases 2008-09: *Health (11,272), Education (11,493), Care & Family Support (4,359)*
Bases 2009-10: *Health (29,321), Education (29,933), Care & Family Support (13,773)*

The composition of the Feedback sub-indicators in terms of the constituent questions is displayed in Figure 34 below.

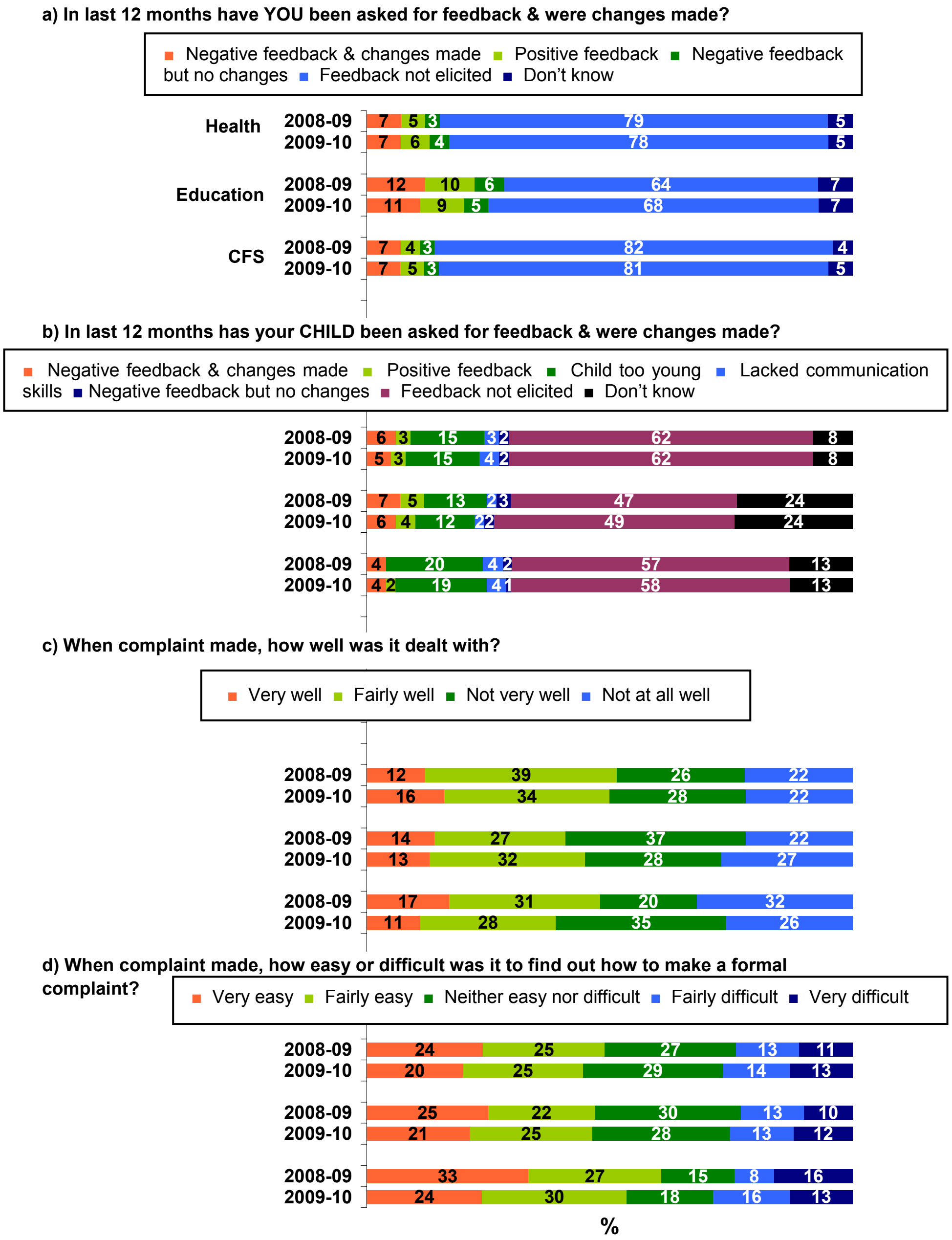
As in 2008-09, feedback from parents on behalf of the child was most likely to be elicited in the case of education (24% compared with 16% for health and 15% for care & family support). In the majority of cases where feedback was elicited, changes were either made or the feedback was positive so no changes were necessary. In only a small proportion of cases (3% for care & family support; 4% for health; 5% for education) was feedback elicited but not acted upon. Thus, the main contributor to the low sub-indicator score from this measure was failure to elicit feedback at all (68% for education; 78% for health; and 81% for care & family support).

Parents were also asked about whether feedback was elicited from children. Some parents indicated that their child was too young or unable, due to other problems, to provide feedback (between 14% and 23% across the three service sectors). Across the remaining respondents, then once again the main contributor to the low sub-indicator score was failure to ask the child for feedback. Feedback was elicited from children in only 7% of cases for care & family support, 10% for health and 12% for education. Across the three service domains, 2% or fewer reported feedback being elicited but not acted upon. On these feedback measures, there were no significant changes over time.

Complaints were still rare: 4% in the case of health, 5% in the case of education and 2% in the case of care & family support. However, when complaints were made, at least half of parents were not happy with the way it was dealt with (51% of those making complaints in the case of health, 55% for education and 61% for care & family support). The latter finding represents a slight increase over time: in 2008-09 52% of care & family support complainants were unhappy with the way it was dealt with compared with 61% in 2009-10.

Around half of complainants said it was very or fairly easy to find out how to go about making a formal complaint (45% for health, 46% for education and 53% for care & family support). The proportion finding it difficult varied in the range 26% to 29%. From 2008-09 to 2009-10 the proportion of care & family support complainants who found it “very easy” to find out how to make a complaint fell from 33% to 24%.

Figure 34 Breakdown of responses to each of the questions which constitute the FEEDBACK sub-indicator: 2008-09 & 2009-10



Bases 2008-09: *a) Health (11,313); Education (11,561); CFS (4,372) b) Health (11,141); Education (11,514); CFS (4,277) c) Health (486); Education (733); CFS (241) d) Health (487); Education (746); CFS (248)*
Bases 2009-10: *a) Health (29,451); Education (30,084); CFS (13,798) b) Health (29,014); Education (30,099); CFS (13,580) c) Health (1,313); Education (1,891); CFS (691) d) Health (1,304); Education (1,881); CFS (685)*

Further information about the profile of those who had made a complaint can be found in figure 71 in appendix 1.

In general, if the child had a statement of SEN or was in receipt of DLA, the parent was more likely to have made a complaint about a health, education or care & family support service in the last twelve months. Also, parents of children from non-white ethnic groups appeared to be slightly more prone to making complaints about a service used.

Making a complaint was related to the number of services used in the last twelve months. Generally the more services used, the greater likelihood of having made a complaint (see figure 72 in appendix 1).

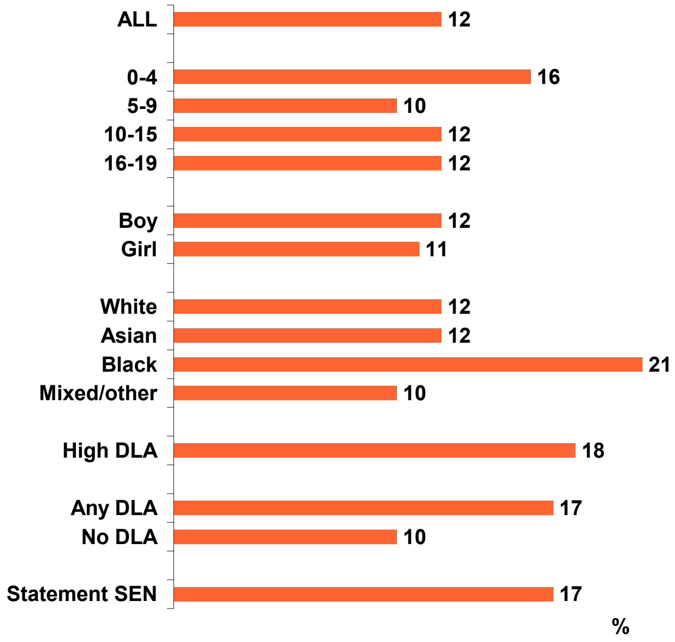
4.3.4 Variation in sub-indicator scores by survey subgroups

It is also useful to view the sub-indicator scores by certain survey groups, in order to find out which groups of parents are most and least satisfied with the service received. When interpreting the scores, it should be remembered that a higher sub-indicator score indicates a higher level of satisfaction with the service received, according to the number of positive ratings given out of the four contributing measures.

Health feedback

Figure 35 displays the variation in health Feedback sub-indicator score by survey subgroup for 2009-10.

Figure 35 HEALTH FEEDBACK sub-indicator scores by survey subgroup



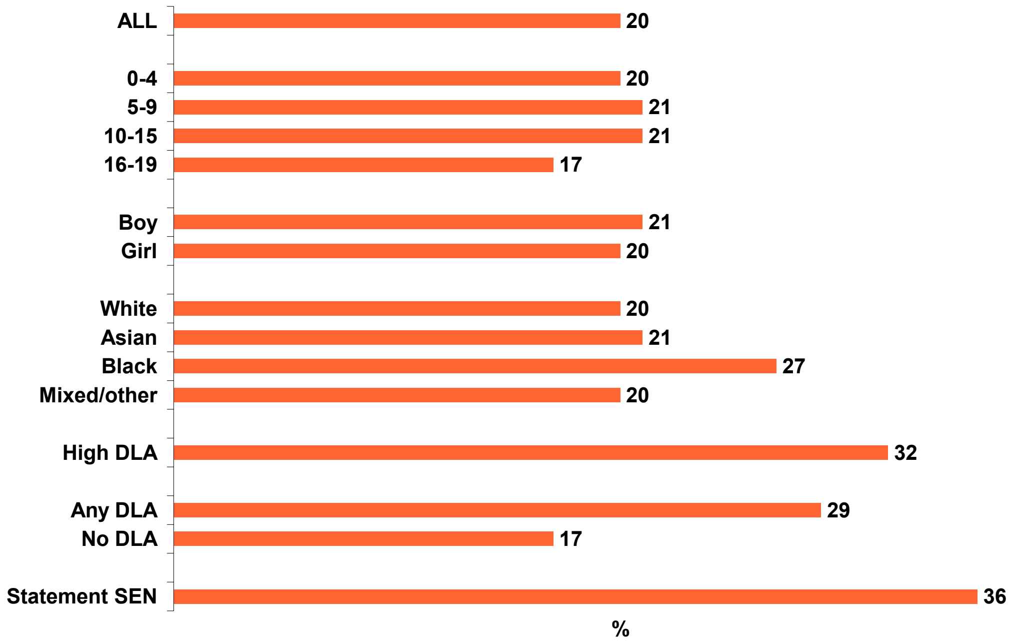
Bases 2009-10: *All (29,321); 0-4 (1,787); 5-9 (9,291); 10-15 (13,784); 16-19 (4,183); Boy (18,483); Girl (10,651); White (25,131); Asian (1,243); Black (947); Mixed/other (1,715); High DLA (5,207); Any DLA (12,017); No DLA (17,096); Statement SEN (10,696)*

The health Feedback score was relatively low across all subgroups, although a peak was observed among parents of black children (score of 21). Where a child was in receipt of higher level DLA feedback scores were higher compared with children not in receipt of DLA (scores of 18 and 10 respectively). Finally, there was evidence that feedback was more often elicited and acted upon when the child was of pre-school age compared with older children.

Education feedback

Figure 36 displays the variation in education Feedback sub-indicator score by survey subgroup for 2009-10.

Figure 36 EDUCATION FEEDBACK sub-indicator scores by survey subgroup



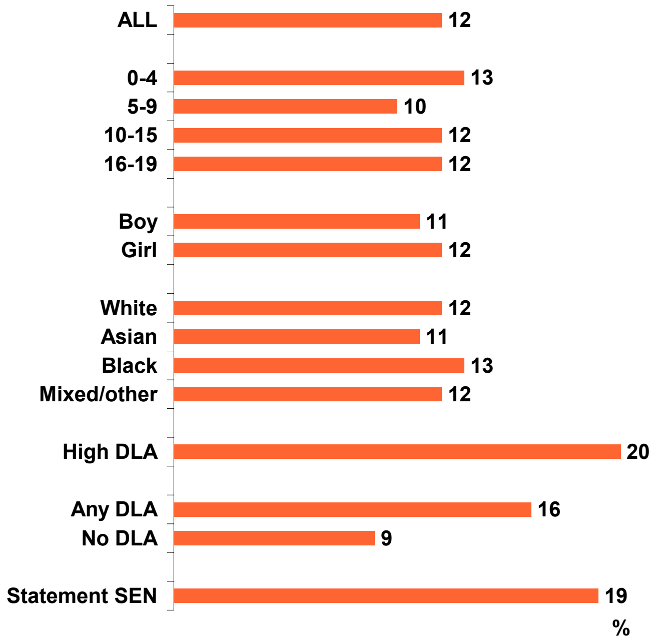
Bases 2009-10: *All (29,933); 0-4 (1,567); 5-9 (9,526); 10-15 (14,275); 16-19 (4,309); Boy (19,023); Girl (10,722); White (25,622); Asian (1,310); Black (969); Mixed/other (1,737); High DLA (5,217); Any DLA (12,165); No DLA (17,559); Statement SEN (11,162)*

As with health, feedback scores rose when the child was black (score of 27 compared with 20 overall) and when the child was in receipt of high level DLA (score of 32). However, the highest score for educational Feedback was observed when children were in receipt of a statement of SEN (score of 36).

Care & family support feedback

Figure 37 displays the variation in care & family support Feedback sub-indicator score by survey subgroup for 2009-10.

Figure 37 CARE & FAMILY SUPPORT FEEDBACK sub-indicator scores by survey subgroup



***Bases 2009-10:** All (13,773); 0-4 (832); 5-9 (4,102); 10-15 (6,601); 16-19 (2,088); Boy (8,893); Girl (4,775); White (11,553); Asian (647); Black (503); Mixed/other (888); High DLA (3,880); Any DLA (7,623); No DLA (6,031); Statement SEN (6,699)*

Within care & family support, there was relatively little variation by age or ethnicity, although higher level DLA receipt and statement of SEN were once again associated with higher levels of satisfaction with feedback.

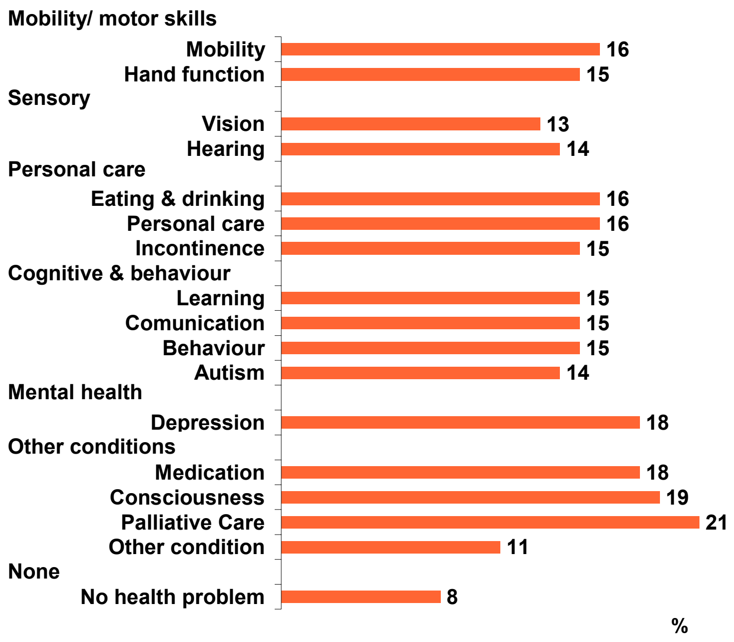
4.3.4.1 Feedback sub-indicator by type of disability

In addition to the above subgroups it is also of interest to explore the relationship between level of satisfaction with feedback and type of disability.

Health feedback

Figure 38 displays the health Feedback sub-indicator by type of disability.

Figure 38 HEALTH FEEDBACK sub-indicator scores by nature of child's disability



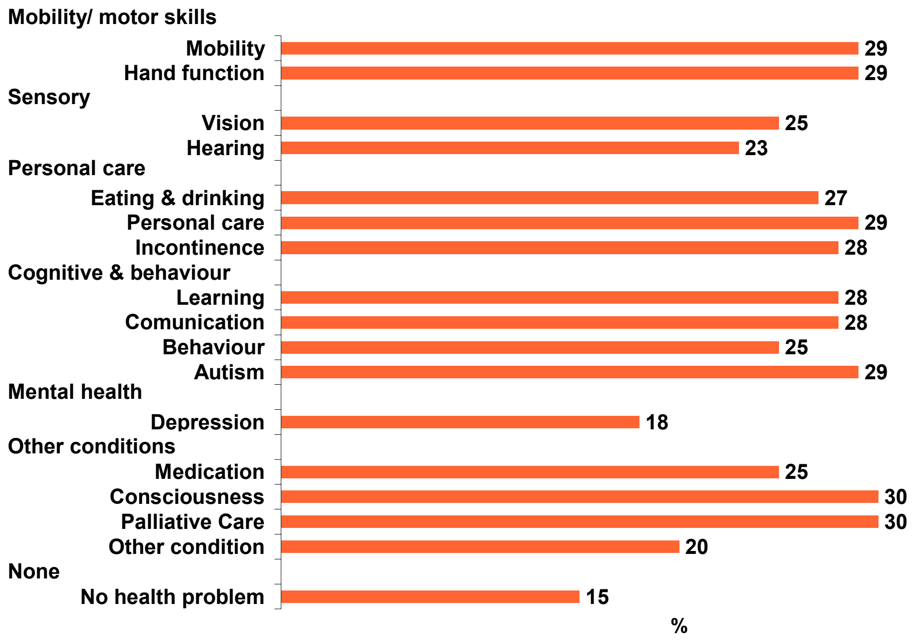
***Bases 2009-10:** Mobility (7,493); hand function (4,622); vision (4,259); hearing (3,150); eating & drinking (5,266); personal care (9,435); incontinence (4,724); learning (13,637); communication (11,140); behaviour (11,357); autism (5,757); depression (1,588); medication (4,540); consciousness (2,037); palliative care (420); other condition (5,658); no health problem (3,962)*

There was relatively little variability across the feedback scores by type of impairment. Scores were slightly higher than average within some of the more serious disabilities such as when children had palliative care needs (score of 21) and problems related to consciousness (score of 19).

Education feedback

Figure 39 displays the education Feedback sub-indicator by type of disability, grouped by type of impairment.

Figure 39 EDUCATION FEEDBACK sub-indicator scores by nature of child's disability



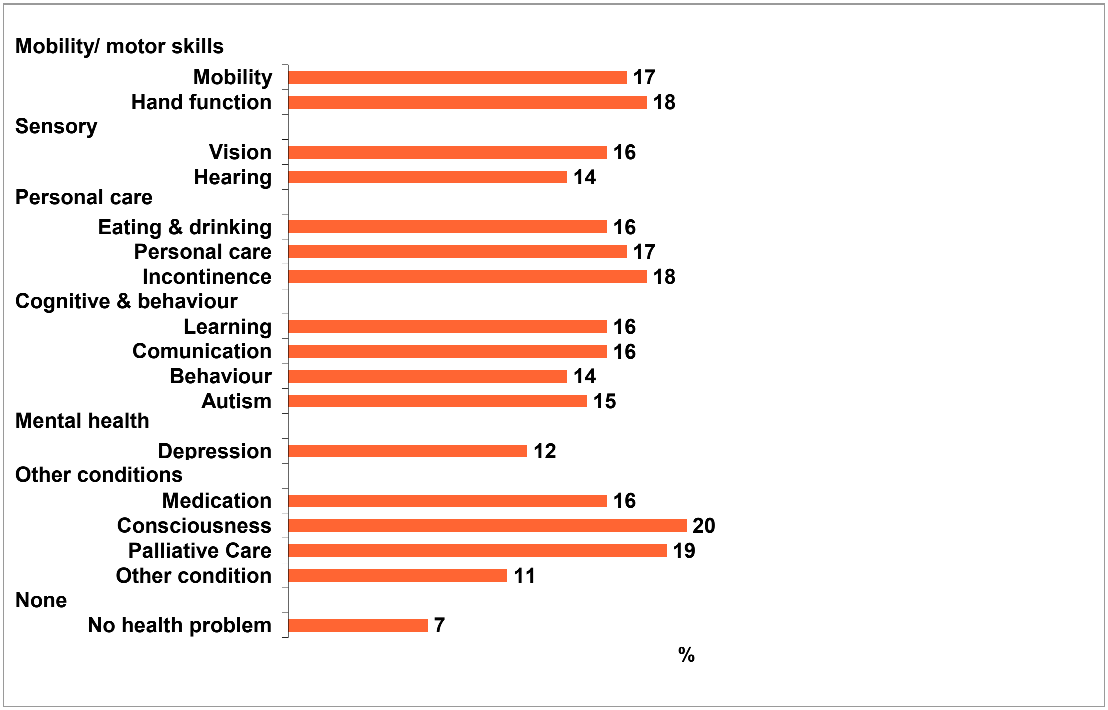
Bases 2009-10: *Mobility (7,525); hand function (4,660); vision (4,291); hearing (3,127); eating & drinking (5,235); personal care (9,543); incontinence (4,721); learning (14,118); communication (11,374); behaviour (11,578); autism (6,006); depression (1,576); medication (4,472); consciousness (2,008); palliative care (410); other condition (5,679); no health problem (4,083)*

Within education, the highest scores were observed among the more serious conditions once again - palliative care and consciousness - indicating that feedback in these situations is more likely to be elicited and acted upon. Relative to these high scores, the score for depression was low reflecting the pattern seen elsewhere in this report.

Care & family support feedback

Figure 40 displays the care & family support Feedback sub-indicator by type of disability.

Figure 40 CARE & FAMILY SUPPORT FEEDBACK sub-indicator scores by nature of child's disability



Bases 2009-10: *Mobility (5,002); hand function (3,080); vision (2,272); hearing (1,586); eating & drinking (3,563); personal care (6,216); incontinence (3,211); learning (8,083); communication (6,784); behaviour (7,075); autism (3,538); depression (1,061); medication (2,990); consciousness (1,391); palliative care (350); other condition (2,532); no health problem (1,056)*

The pattern here was similar to the other two areas, with problems relating to consciousness attracting higher than average Feedback scores; while depression was associated with lower relative scores.

4.4 Transparency: national sub-indicator breakdown

SECTION SUMMARY

The Transparency sub-indicators for 2009-10 are 96 for health, 92 for education, and 89 for care & family support. The sub-indicators have remained stable for health and education, although there has been a rise of three points in the care & family support sub-indicator.

The scores across all of the three service domains show that Transparency was the highest rated of the five Core Offer areas.

There was little variation in sub-indicator scores between different groups of parents.

4.4.1 Background

The Aiming High for Disabled Children's Core Offer standard for Transparency sets out the expectation that disabled children, young people and their families should expect transparency about:

- How overall resources are decided and have changed over time
- How resources are allocated, with criteria based on need, which are fair, understandable, and take account of the impact of disability
- The purpose of an assessment, the process which will take place, the time it may take and the possible outcomes
- How services work together to promote good outcomes, for example, care pathways for children with specific conditions, multi-agency involvement in statutory assessment of SEN and appropriate support for transition to adulthood
- How services are commissioned. This should be on the basis of a rigorous, up-to-date, published needs analysis of the local population of disabled children, with an integrated inter-agency plan to meet the support needs of families
- How the Local Authority, the PCT and their partners work together, through Children's Trust arrangements

- How the Children and Young People's Plan (CYPP) is produced and how communities can influence the Plan
- How the CYPP delivers the statutory requirements regarding disability equality
- How feedback is sought, analysed, reported and acted upon
- The quality of local services, including performance measures and inspection reports
- How their legal entitlements are being met and how to complain if necessary.

4.4.2 How the Transparency sub-indicator was calculated

This sub-indicator was based on one question. Where decisions were made about the child's health care/education/care & family support services received, parents were asked how well they **understood** the decision that had been made. The scale was based on *very well/fairly well/not very well* and *not at all well*. A response of *not very well* or *not at all well* was regarded as a "negative" in terms of the sub-indicator.

Thus, all Transparency sub-indicators were based on parents who say that professionals have made a **decision** about the services their child has received. In the case of health this relates to medical or health professionals making decisions about the child's illness or disability and the services they should receive; in the case of care & family support this relates to care & family support professionals making decisions about services received; and in the case of education this relates to receipt of a formal assessment of educational support needs or an annual review of SEN.

If *not very well* or *not at all well* was recorded then the respondent did not pass the threshold to be scored as receiving an acceptable level of service. Respondents were excluded from the sub-indicator if they declined to answer the question.

This information is summarised in figure 41.

Figure 41

QUESTIONS WHICH CONSTITUTE THE "TRANSPARENCY" SUB-INDICATOR AND EXPLANATION FOR SCORING SYSTEM

	Response categories	**Positive/ negative**	**Base (health)**	**Base (education)**	**Base (care & family support)**
Over past 12 months how well do you **understand** the decisions that have been made about your child's health care/ education/care & family support services?	Very well	Positive	All who have had decisions made on child's behalf in last 12 months	All who have had a formal assessment or annual review of SEN in last 12 months	All who have had decisions made on child's behalf in last 12 months
	Fairly well				
	Not very well	Negative			
	Not at all well				

Level of service received on Transparency sub-indicator deemed **acceptable** if question was scored positively

Level of service received on Transparency sub-indicator deemed **unacceptable** if question was scored negatively

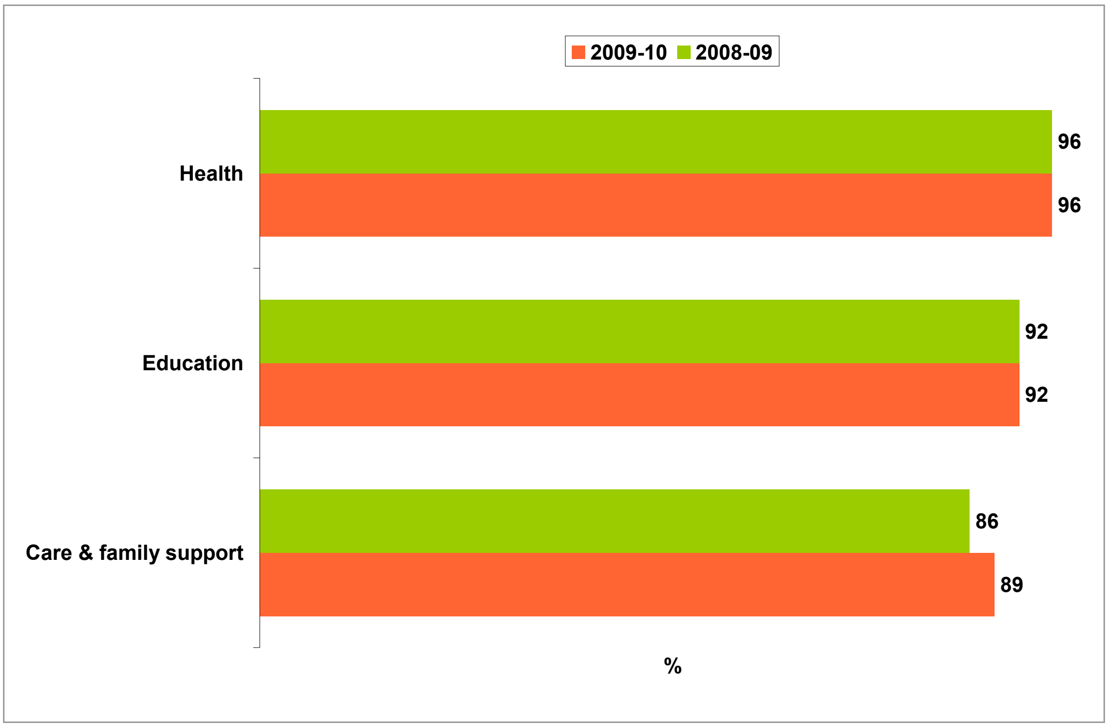
If a respondent failed to answer the question they were excluded from the sub-indicator calculation

Sub-indicator is calculated as the proportion of eligible respondents who give an acceptable rating, based on the above scoring system

4.4.3 Sub-indicator scores: Transparency

The sub-indicators for the three service areas are shown in figure 42 below for 2008-09 and 2009-10. The sub-indicators for health and education have remained at the same level since 2008-09. There has been a rise, however, of three points in the sub-indicator for care & family support Transparency since 2008-09.

Figure 42 TRANSPARENCY sub-indicator scores for the three service areas 2008-09 & 2009-10

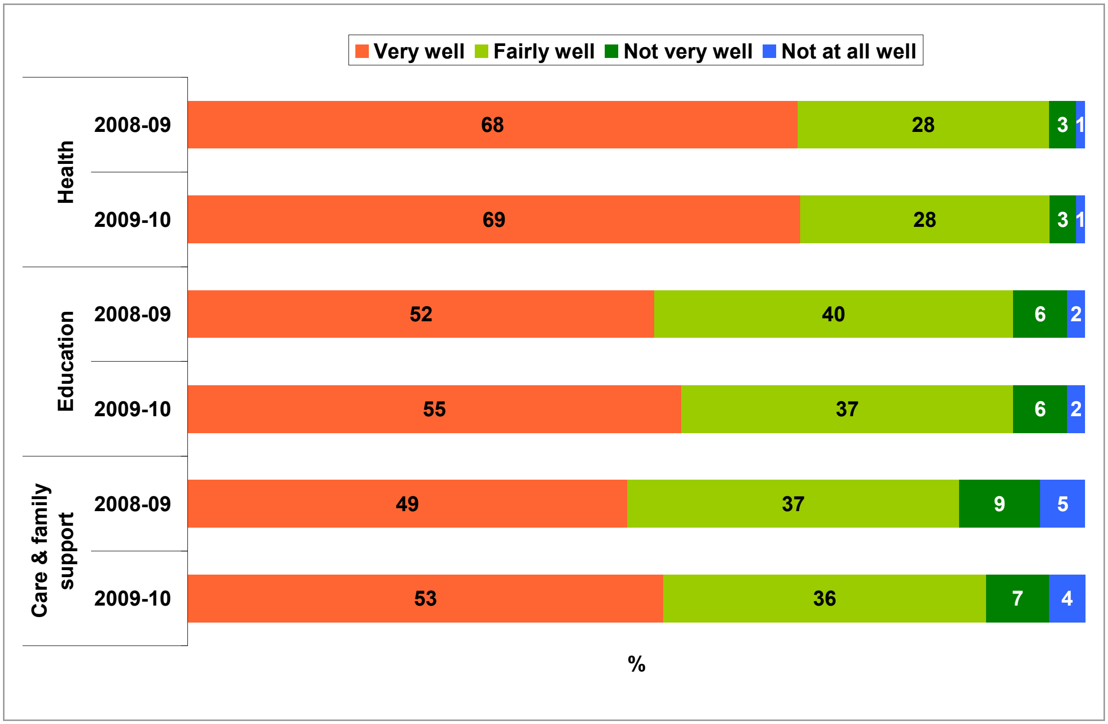


Bases 2008-09: *Health (5,330), Education (4,738), Care & Family Support (1,229)*
Bases 2009-10: *Health (13,720), Education (13,424), Care & Family Support (3,809)*

The composition of the Transparency sub-indicators in terms of the constituent questions is displayed in figure 43 below. As also shown by the sub-indicator scores, health continued to be the service area where Transparency was given the highest ratings, with seven in ten (69%) parents saying that they understood the decisions made very well. Within education and care & family support, comprehension levels were slightly lower, although the sub-indicator scores remain high (92 and 89 respectively).

Figure 43 Full breakdown of responses to the question which constitutes the TRANSPARENCY sub-indicator: 2008-09 & 2009-10

Over the last 12 months, how well do you understand the decisions that have been made about your child's health care/education/care & family support services?



Bases 2008-09: *Health (5,330), Education (4,738), Care & Family Support (1,229)*
Bases 2009-10: *Health (13,720), Education (13,424), Care & Family Support (3,809)*

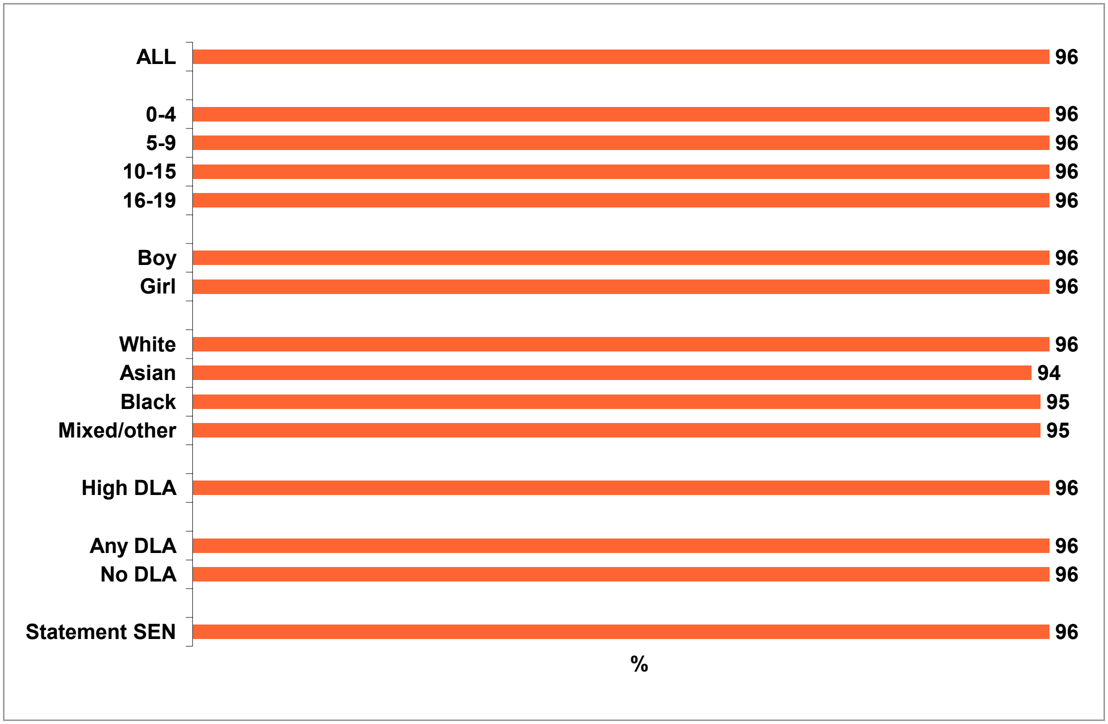
4.4.4 Variation in sub-indicator scores by survey subgroups

It is also useful to view the sub-indicator scores by certain survey groups, in order to find out which groups of parents are most and least satisfied with the service received. When interpreting the scores, it should be remembered that a higher sub-indicator score indicates a higher level of satisfaction with the service received.

Health transparency

There was very little demographic variation in the sub-indicator scores as most scores were close to 100. Figure 44 displays the Transparency sub-indicator score for health by survey subgroup for 2009-10.

Figure 44 HEALTH TRANSPARENCY sub-indicator scores by survey subgroup

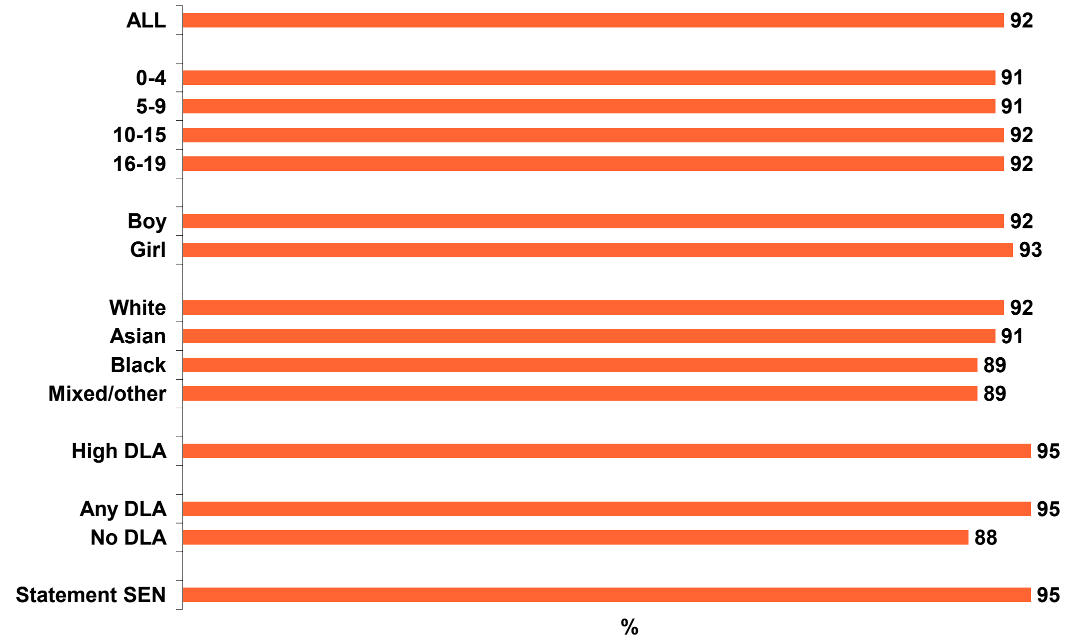


Bases 2009-10: *All (13,720); 0-4 (1,050); 5-9 (4,461); 10-15 (6,216); 16-19 (1,865); Boy (8,490); Girl (5,132); White (11,828); Asian (496); Black (406); Mixed/other (853); High DLA (3,297); Any DLA (6,530); No DLA (7,090); Statement SEN (5,351)*

Education transparency

Although the score was uniformly high, there were some differences in satisfaction for education Transparency (see figure 45). Parents of children in receipt of high level DLA or with a statement of SEN tended to have the highest levels of satisfaction in this area (a score of 95 in both cases).

Figure 45 EDUCATION TRANSPARENCY sub-indicator scores by survey subgroup



Bases 2009-10: *All (13,424); 0-4 (423); 5-9 (4,245); 10-15 (6,882); 16-19 (1,765); Boy (9,367); Girl (3,956); White (11,631); Asian (511); Black (430); Mixed/other (708); High DLA (4,262); Any DLA (9,194); No DLA (4,128); Statement SEN (10,181)*

Care & family support transparency

Figure 46 displays the variation in the care & family support transparency sub-indicator score by survey subgroup for 2009-10.

Figure 46 CARE & FAMILY SUPPORT TRANSPARENCY sub-indicator scores by survey subgroup

Bases 2009-10: *All (3,809); 0-4 (211); 5-9 (1,021); 10-15 (1,831); 16-19 (705); Boy (2,460); Girl (1,312); White (3,225); Asian (155); Black (134); Mixed/Other (246); High DLA (1,857); Any DLA (2,942); No DLA (825); Statement SEN (2,738)*

Scores showed very little variation between different subgroups. The one marked exception to this was parents of black children who reported much lower satisfaction (score of 78) compared with the average (89).

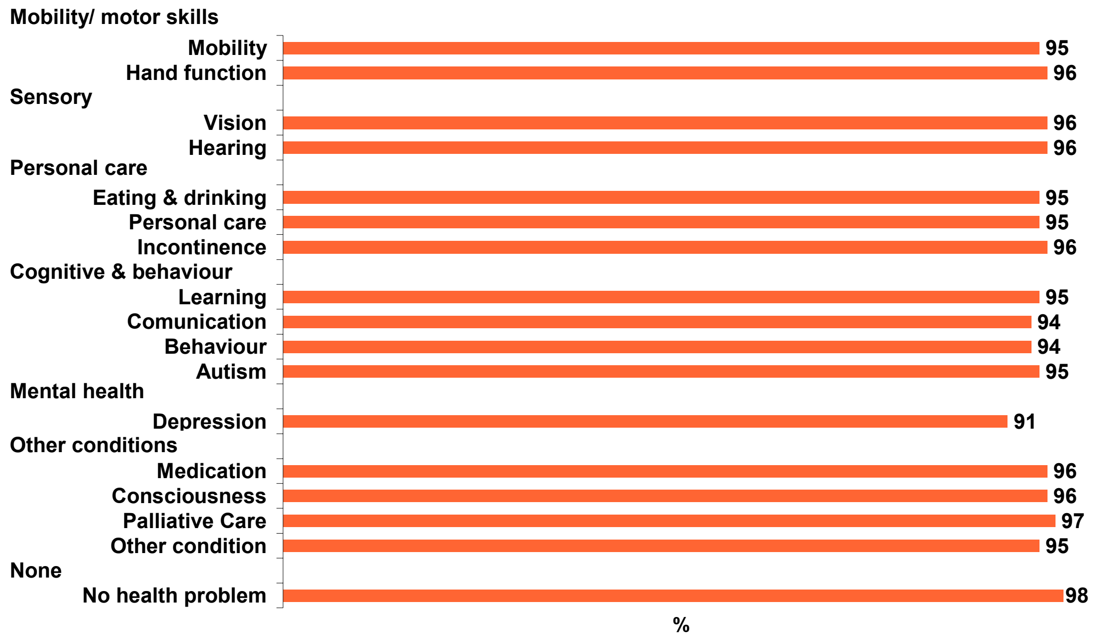
4.4.4.1 Transparency sub-indicator by type of disability

There was also very little variation in the sub-indicator scores by the areas in which a child was affected by their illness, disability or condition. There were some differences, however, that were noted.

Health transparency

Figure 47 displays the variation in health transparency sub-indicator score by type of disability for 2009-10. The scores ranged from 91 to 98 across the subgroups shown.

Figure 47 HEALTH TRANSPARENCY sub-indicator scores by nature of child's disability



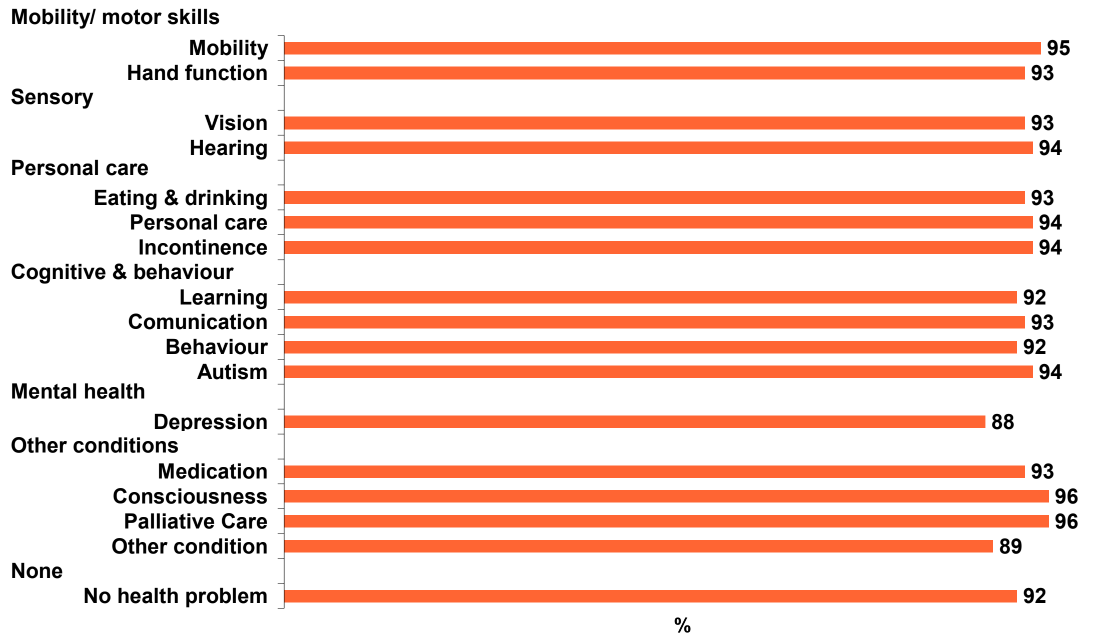
Bases 2009-10: *Mobility (4,433); Hand function (2,808); Vision (2,278); Hearing (1,750); Eating & Drinking (3,371); Personal care (5,382); Incontinence (2,937); Learning (6,636); Communication (5,633); Behaviour (5,777); Autism (2,746); Depression (969); Medication (3,286); Consciousness (1,507); Palliative care (297); Other condition (3,013); No health problem (1,221)*

The Transparency score for health was lower than average when the child suffered from depression (91 compared with 96 on average). There were no other marked differences by type of disability.

Education transparency

Figure 48 displays the education transparency sub-indicator by type of disability.

Figure 48 EDUCATION TRANSPARENCY sub-indicator scores by nature of child's disability



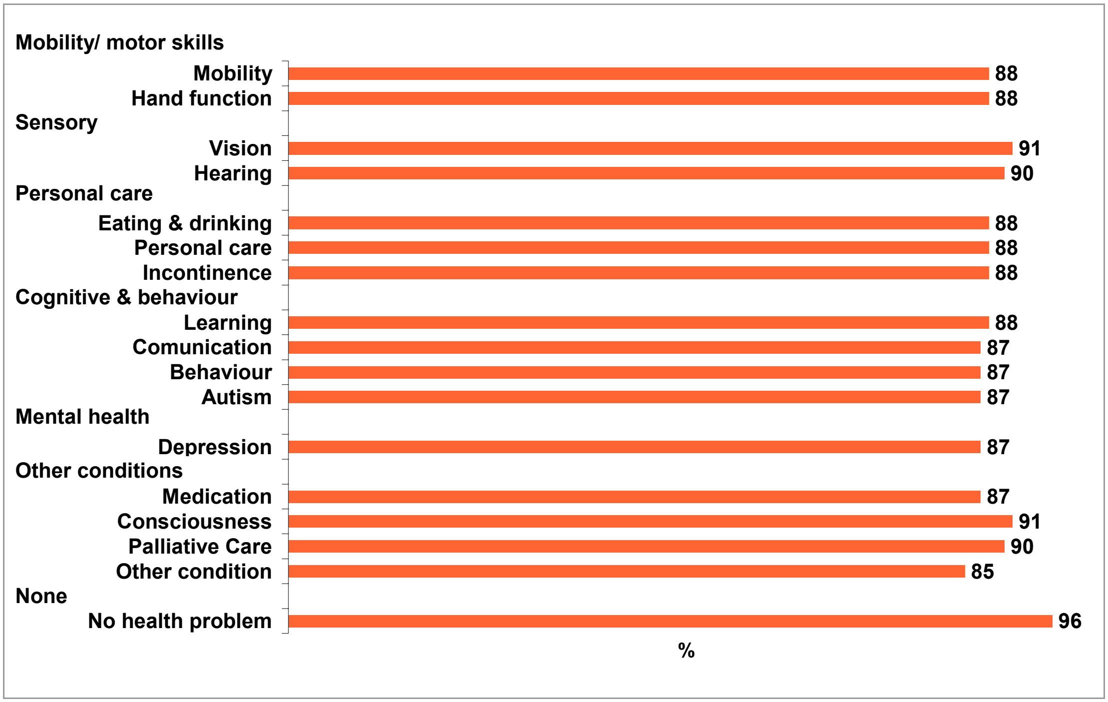
Bases 2009-10: *Mobility (5,739); Hand function (3,538); Vision (2,423); Hearing (1,704); Eating & Drinking (3,547); Personal care (7,172); Incontinence (3,237); Learning (10,763); Communication (8,483); Behaviour (7,839); Autism (4,646); Depression (703); Medication (2,755); Consciousness (1,378); Palliative care (304); Other condition (2,019); No health problem (252)*

The scores ranged from 88 to 96 across all of the subgroups shown; very little differences between them. However, as with the health sub-indicator, the education sub-indicator was lower than average when the child suffered from depression (score of 88 compared with 92 on average). The absolute values are still high however so overall it appears to be a strong area of satisfaction for parents.

Care & family support transparency

There was very little variation in the care & family support sub-indicator score by the areas in which a child was affected by their illness, disability or condition (see figure 49).

Figure 49 CARE & FAMILY SUPPORT TRANSPARENCY sub-indicator scores by nature of child's disability



Bases 2009-10: *Mobility (2,159); Hand function (1,337); Vision (847); Hearing (485); Eating & Drinking (1,519); Personal care (2,617); Incontinence (1,455); Learning (2,965); Communication (2,607); Behaviour (2,497); Autism (1,342); Depression (323); Medication (1,258); Consciousness (662); Palliative care (172); Other condition (672); No health problem (94)*

Parents who reported that their child was not affected in any way by an illness, disability or condition were more satisfied with this aspect of care & family support services compared with the average (score of 96 compared with 89 on average).

4.5 Participation: national sub-indicator breakdown

SECTION SUMMARY

The Participation sub-indicators for 2009-10 are 61 for health, 48 for education, and 53 for care & family support. The sub-indicators have increased by one point for health and care & family support, although there has been a fall of two points in the education sub-indicator.

The health and education sub-indicators were higher than average for parents of children in receipt of DLA or with a statement of SEN. This difference was not observed for the care & family support sub-indicator.

Parents of black disabled children were particularly likely to be satisfied with participation in health and educational decisions, with respective scores of 66 and 55. They were slightly less satisfied with participation in decisions about care & family support services received (score of 50).

An age pattern emerged across the service domains with parents of 16-19 year olds being more satisfied with education Participation and care & family support Participation (scores of 52 and 58 respectively). The reverse was true of health Participation with parents of 16-19 year olds less satisfied than average (score of 54).

There was variability by nature of the child's disability or health condition. For health and care & family support, scores were lower than average when the child or young person suffered depression.

4.5.1 Background

The Aiming High for Disabled Children's Core Offer standard for Participation sets out the expectation that *"Disabled children and young people and their families are routinely involved and supported in making informed decisions about their treatment, care and support, and in shaping services."*

Disabled children, young people and families should expect participation through:

- Choice over the support provided to them through full involvement in assessment and design of their packages of care
- The option of participating from the beginning in decisions about local service development, in particular drawing up the Children and Young People's Plan
- Arrangements in all areas for parents of disabled children so that they can fully participate in shaping local universal and specialist services at both strategic and operational levels, these may be through parent forums or Local Involvement Networks (LINks)
- Tailor-made opportunities using a creative range of methods to ensure disabled children and young people can meaningfully participate in service planning and development
- Opportunities for involvement in drawing up the disability equality scheme and monitoring its effectiveness in eliminating discrimination.

4.5.2 How the Participation sub-indicator was calculated

This sub-indicator was based on one question. Where decisions were made about the child's health care/education/care & family support services received, parents were asked how well they were consulted or asked for their opinion when decisions were made. The scale was based on *Yes - consulted a lot/Yes – consulted a little/No – not consulted at all*. A response of *Yes – consulted a little* or *No – not consulted at all* was regarded as a "negative" in terms of the sub-indicator.

Thus, all Participation sub-indicators were based on parents who say that professionals have made a **decision** about the services their child has received. In the case of health this relates to medical or health professionals making decisions about the child's illness or disability and the services they should receive; in the case of care & family support this relates to care & family support professionals making decisions about services received; and in the case of education this relates to receipt of a formal assessment of educational support needs or an annual review of SEN.

If *consulted a little* or *not at all* was recorded then the respondent did not pass the threshold to be scored as receiving an acceptable level of service. Respondents were excluded from the sub-indicator if they declined to answer the question.

This information is summarised in figure 50.

Figure 50

QUESTIONS WHICH CONSTITUTE THE "PARTICIPATION" SUB-INDICATOR AND EXPLANATION FOR SCORING SYSTEM

	Response categories	**Positive/ negative**	**Base (health)**	**Base (education)**	**Base (care & family support)**
Over past 12 months were you consulted or asked for your opinion when **decisions** were made about your child's health care/ education/care & family support services?	Yes, a lot	Positive	All who have had decisions made on child's behalf in last 12 months	All who have had a formal assessment or annual review of SEN in last 12 months	All who have had decisions made on child's behalf in last 12 months
	Yes, a little	Negative			
	Not at all				

Level of service received on Participation sub-indicator deemed **acceptable** if question was scored positively

Level of service received on Participation sub-indicator deemed **unacceptable** if question was scored negatively

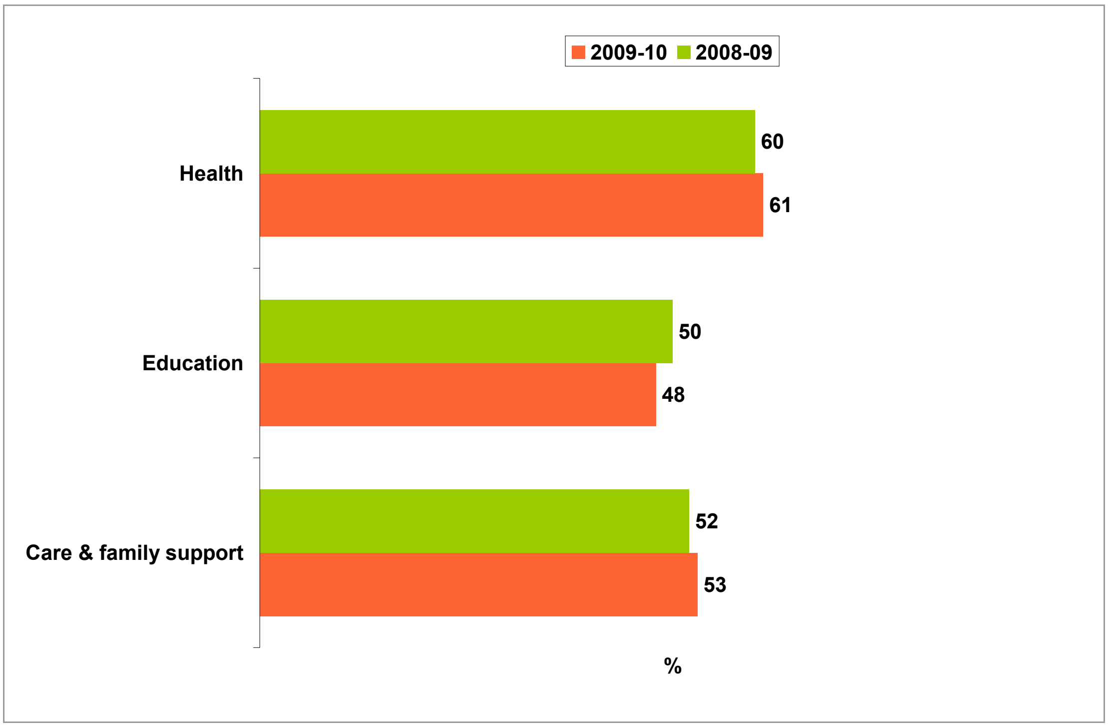
If a respondent failed to answer the question they were excluded from the sub-indicator calculation

Sub-indicator is calculated as the proportion of eligible respondents who give an acceptable rating, based on the above scoring system

4.5.3 Sub-indicator scores: Participation

The sub-indicators for the three service areas are shown in figure 51 below for 2008-09 and 2009-10. There was very little change in the sub-indicator scores across all of the three service domains since 2008-09.

Figure 51 PARTICIPATION sub-indicator scores for the three service areas 2008-09 & 2009-10

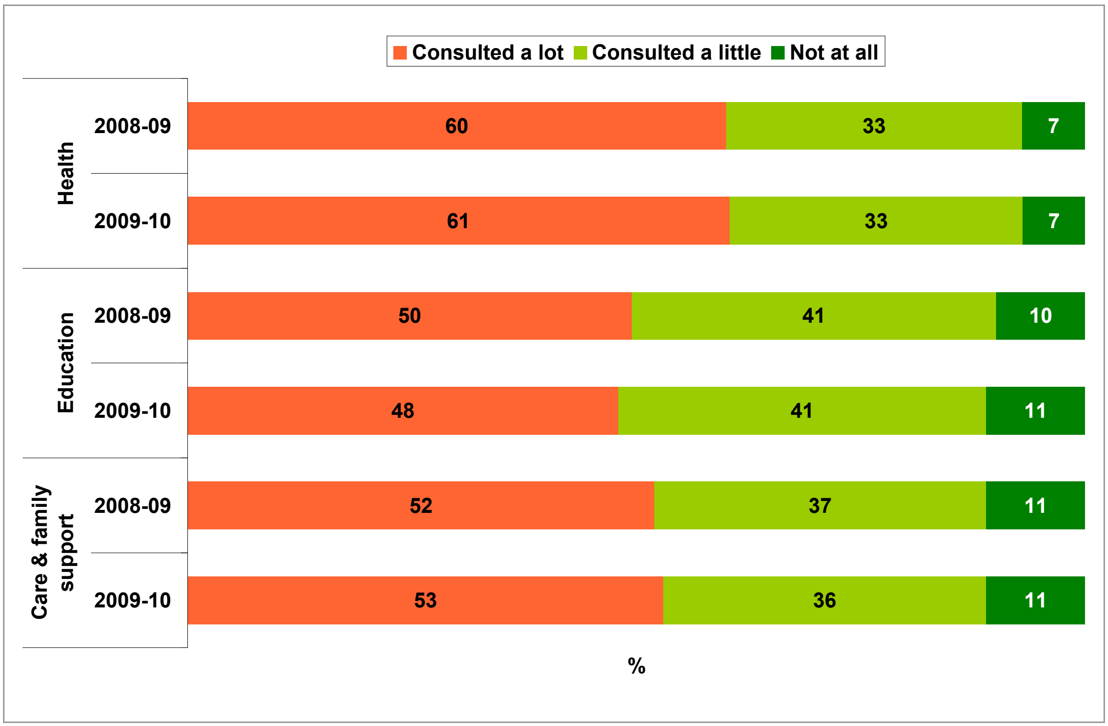


Bases 2008-09: *Health (5,313), Education (4,768), Care & Family Support (1,225)*
Bases 2009-10: *Health (13,698), Education (13,435), Care & Family Support (3,808)*

The composition of the Participation sub-indicators in terms of the constituent questions is displayed in figure 52 below. There was very little difference in parents' responses in 2009-10 compared to 2008-09. The pattern of responses for Participation was very similar for the three service domains, with between 48 and 61 per cent of parents saying that they were consulted a lot over decisions made.

Figure 52 Full breakdown of responses to the question which constitutes the PARTICIPATION sub-indicator: 2008-09 & 2009-10

Over the last 12 months, were you consulted or asked for your opinion when decisions were being made about your child's health care/education/care & family support services?



Bases 2008-09: *Health (5,313), Education (4,768), Care & Family Support (1,225)*
Bases 2009-10: *Health (13,698), Education (13,435), Care & Family Support (3,808)*

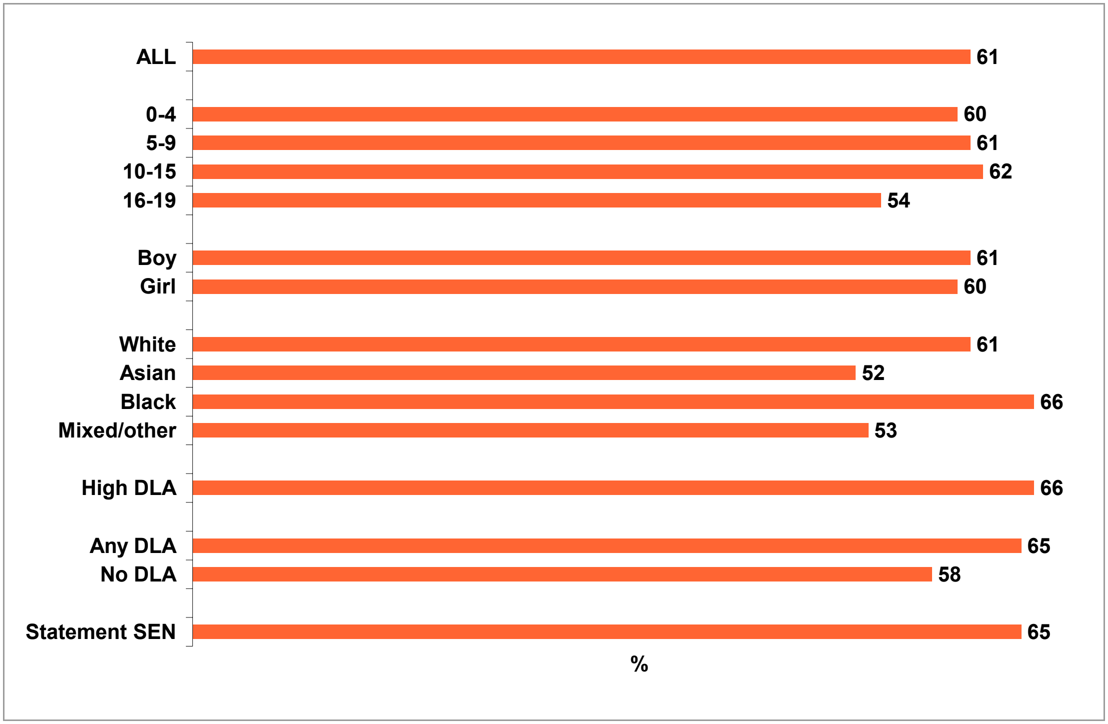
4.5.4 Variation in sub-indicator scores by survey subgroups

It is also useful to view the sub-indicator scores by certain survey groups, in order to find out which groups of parents are most and least satisfied with the service received. When interpreting the scores, it should be remembered that a higher sub-indicator score indicates a higher level of satisfaction with the service received.

Health participation

Figure 53 displays the variation in health Participation sub-indicator score by survey subgroup.

Figure 53 HEALTH PARTICIPATION sub-indicator scores by survey subgroup



Bases 2009-10: *All (13,698); 0-4 (1,047); 5-9 (4,454); 10-15 (6,210); 16-19 (1,860); Boy (8,471); Girl (5,129); White (11,819); Asian (490); Black (402); Mixed/other (850); High DLA (3,293); Any DLA (6,526); No DLA (7,073); Statement SEN (5,344)*

Parents with disabled children at the higher end of the age continuum (16-19) were less satisfied on the Participation measure than average, with a score of 54. This mirrored the finding from 2008-09.

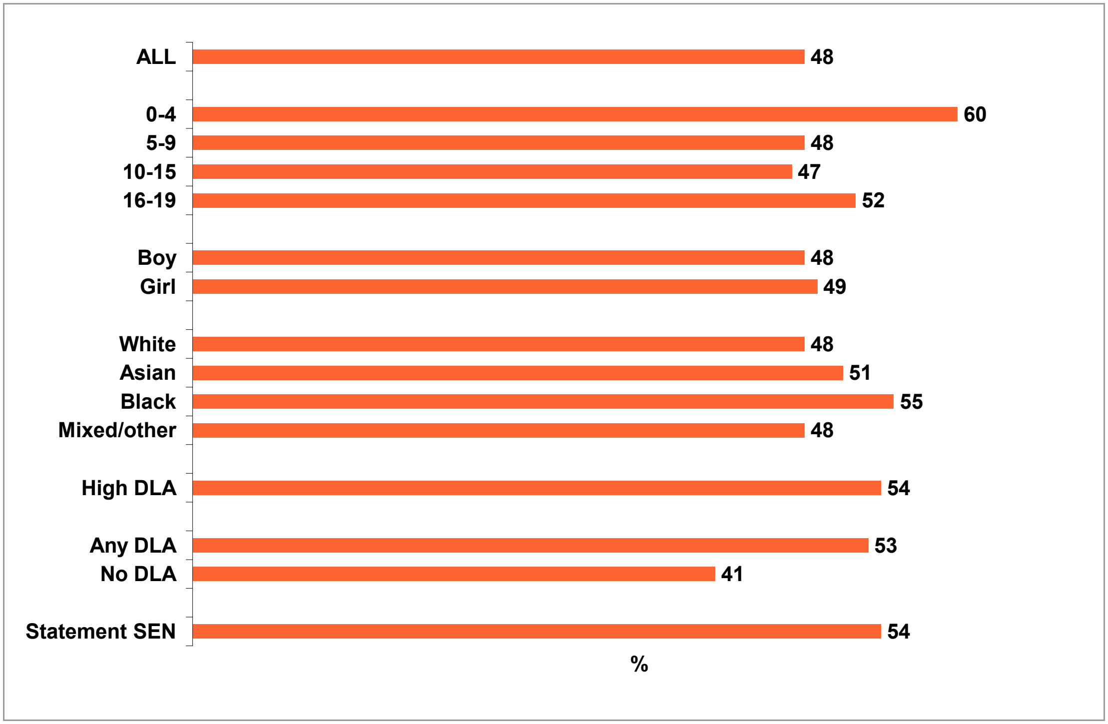
In addition, parents with Asian children or children from a mixed ethnic origin were slightly less satisfied on this measure than parents of white children (scores of 52 and 53 against 61 for white children). Contrary to the finding from 2008-09, parents of children from a black ethnic origin were now more likely to be satisfied on this measure with a score of 66 in 2009-10 compared with 55 in 2008-09.

Parents of children in receipt of DLA and also those who had a child with a statement of SEN were also more likely to show higher levels of satisfaction with Participation (both with scores of 65 compared with 61 on average).

Education participation

There were similar subgroup differences to the health sub-indicator when looking at the education Participation sub-indicator scores by the same groups (see figure 54).

Figure 54 EDUCATION PARTICIPATION sub-indicator scores by survey subgroup



Bases 2009-10: *All (13,435); 0-4 (420); 5-9 (4,258); 10-15 (6,883); 16-19 (1,764); Boy (9,380); Girl (3,954); White (11,638); Asian (510); Black (431); Mixed/other (710); High DLA (4,255); Any DLA (9,189); No DLA (4,142); Statement SEN (10,183)*

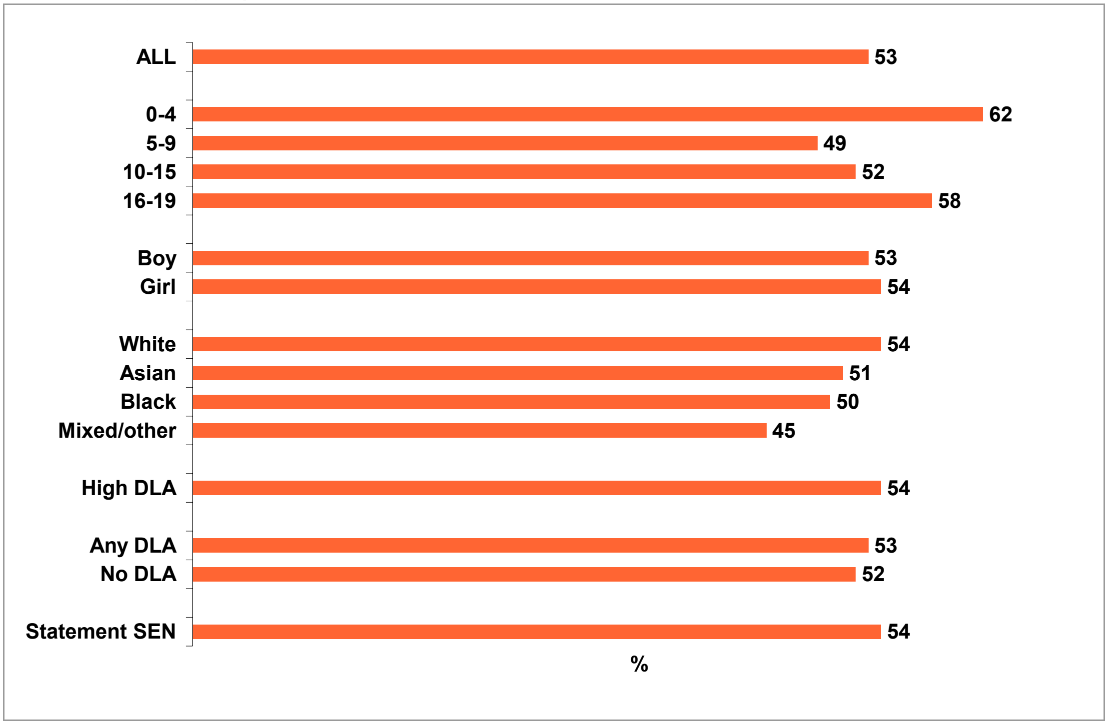
Parents of black children were more likely to be satisfied on this measure (score of 55) compared with average (score of 48). Parents of children in receipt of higher rate DLA or with a statement of SEN were also more likely to be satisfied with the extent to which they were able to participate in decision making about services for their child. Both of the above groups scored 54.

Unlike the health Participation scores, parents of children at either sides of the age continuum were more satisfied on the education Participation measure than average (score of 60 for parents of under 5s and a score of 52 for parents of 16-19 year olds).

Care & family support participation

Differences in the care & family support Participation sub-indicator scores can be seen in figure 55 and were evident across a few subgroups. In particular, parents of children at either sides of the age continuum were more satisfied on this measure than average (score of 62 for parents of under 5s and a score of 58 for parents of 16-19 year olds).

Figure 55 CARE & FAMILY SUPPORT PARTICIPATION sub-indicator scores by survey subgroup



***Bases 2009-10:** All (3,808); 0-4 (210); 5-9 (1,014); 10-15 (1,836); 16-19 (706); Boy (2,459); Girl (1,311); White (3,225); Asian (152); Black (134); Mixed/other (245); High DLA (1,854); Any DLA (2,945); No DLA (820); Statement SEN (2,741)*

The only other noticeable difference was among ethnic groups. Those with children from a non-white ethnic background (so Asian, black, mixed and other ethnic groups) were less satisfied with participation in decisions affecting care & family support services compared with parents of children from a white ethnic background (scores of 48 and 54 respectively).

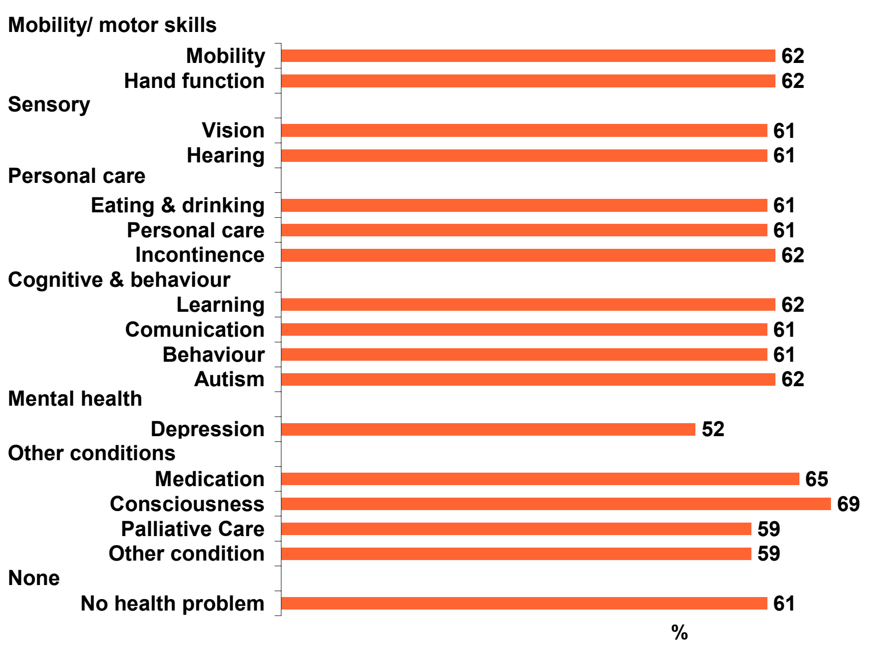
4.5.4.1 Participation sub-indicator by type of disability

In addition to the above subgroups it is also of interest to explore the relationship between level of satisfaction with Participation and the areas in which a child was affected by their illness, disability or condition.

Health participation

Figure 56 displays the variation in Participation sub-indicator score for the health service domain by type of disability for 2009-10.

Figure 56 HEALTH PARTICIPATION sub-indicator scores by nature of child's disability



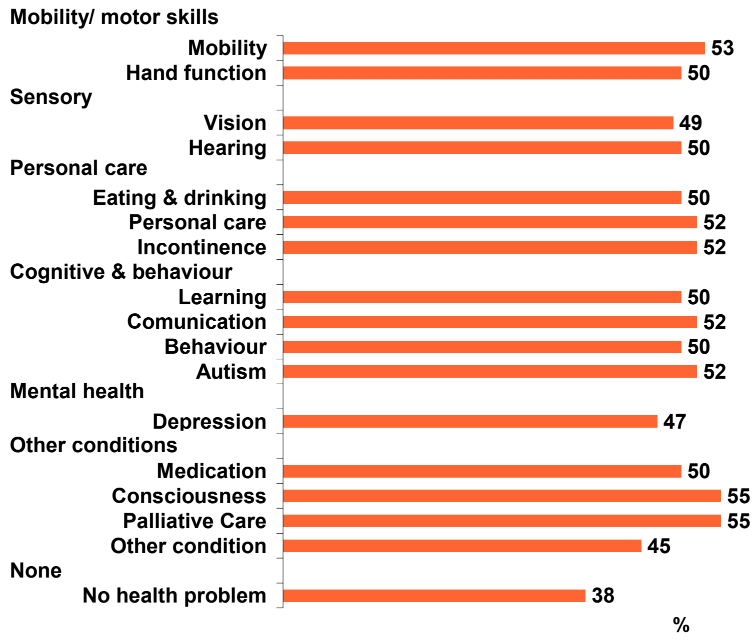
Bases 2009-10: *Mobility (4,426); Hand function (2,806); Vision (2,271); Hearing (1,744); Eating & Drinking (3,361); Personal care (5,378); Incontinence (2,933); Learning (6,627); Communication (5,629); Behaviour (5,768); Autism (2,747); Depression (969); Medication (3,276); Consciousness (1,502); Palliative care (294); Other condition (3,001); No health problem (1,220)*

There were some differences apparent in the health sub-indicator scores by disability type. As noted for other sub-indicator scores, if the child suffered from depression satisfaction tended to be lower and this was the case with health Participation – a score of 52 compared with the average of 61. Parents of children who suffer from fits and seizures (consciousness) were the most highly satisfied group with a score of 69.

Education participation

There was less variation in the education sub-indicator scores by type of disability (see figure 57).

Figure 57 EDUCATION PARTICIPATION sub-indicator scores by nature of child's disability



Bases 2009-10: *Mobility (5,734); Hand function (3,541); Vision (2,416); Hearing (1,708); Eating & Drinking (3,547); Personal care (7,172); Incontinence (3,236); Learning (10,775); Communication (8,487); Behaviour (7,851); Autism (4,648); Depression (706); Medication (2,752); Consciousness (1,376); Palliative care (304); Other condition (2,023); No health problem (253)*

Scores ranged from 45 to 55 across the disability types, although the lowest satisfaction score was given by parents who indicated that their child did not have an illness, disability or condition but were eligible for the survey based on their answers to the screening questionnaire[11] (score of 38). Higher satisfaction ratings in this area were given by parents of children who had palliative care needs or problems with consciousness (both with scores of 55).

Care & family support participation

The care & family support sub-indicator for Participation was similar to the education sub-indicator, with little variation across the list of affected areas (see figure 58).

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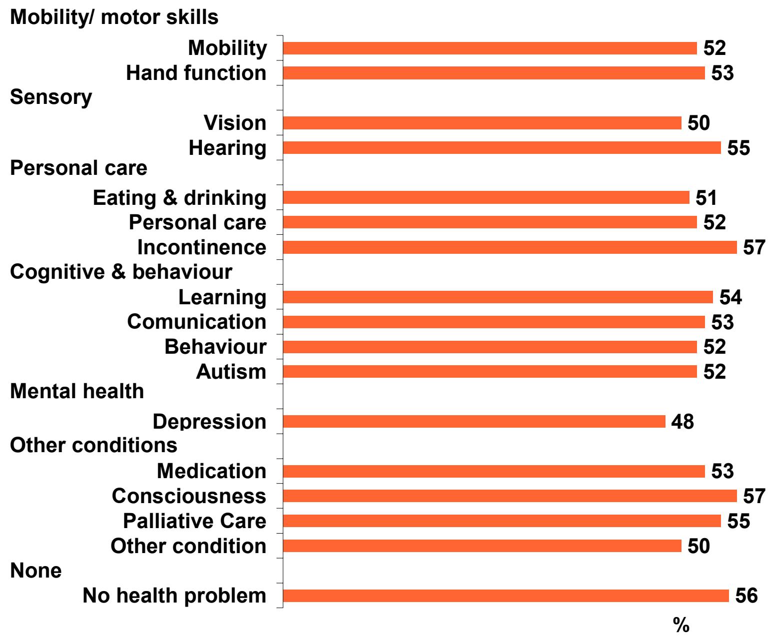
[11] In the screener survey which they had completed previously they had either said that their child did have an illness, disability or condition or that their child required medication, physical aids or a special diet or supplements to successfully manage an illness, disability or condition (see section 2.3).

Figure 58 CARE & FAMILY SUPPORT PARTICIPATION sub-indicator scores by nature of child's disability



Bases 2009-10: *Mobility (2,160); Hand function (1,341); Vision (845); Hearing (485); Eating & Drinking (1,516); Personal care (2,618); Incontinence (1,453); Learning (2,967); Communication (2,607); Behaviour (2,499); Autism (1,339); Depression (323); Medication (1,254); Consciousness (661); Palliative care (174); Other condition (677); No health problem (94)*

Scores ranged from 48 (depression) to 57 (consciousness and incontinence) across the disability types.

5. OTHER GENERAL EXPERIENCES OF SERVICES

CHAPTER SUMMARY

Approaching half (44%) of all parents had experienced professionals making decisions about the health care services their child should receive; 32% said this in relation to formal assessment of educational needs; and 9% in relation to decisions about receipt of care & family support services.

Eight in ten (81%) parents requiring health services and three-quarters (75%) of those requiring educational services said that they received all or most of the services they required in the previous 12 months. For those with care & family support needs, a lower proportion (55%) said that their child's needs had been fully or mostly met. In general, when children were in receipt of DLA or had a statement of SEN, parents were less likely than others to feel that their child's needs had been fully or mostly met.

The majority of service users rated the service received as at least "good" but this did vary by service domain: 80% for health, 73% for education and 57% for care & family support. It should be noted that these ratings were garnered from a single question asked upfront in the relevant questionnaire section, before parents were asked the specific questions around the Core Offer areas, which fed into the calculation of the overall composite indicator.

This chapter covers parents' more general experience of services including: experience of decisions made; how parents rated the services they had received for their child and; the extent to which they felt their children's service needs were met.

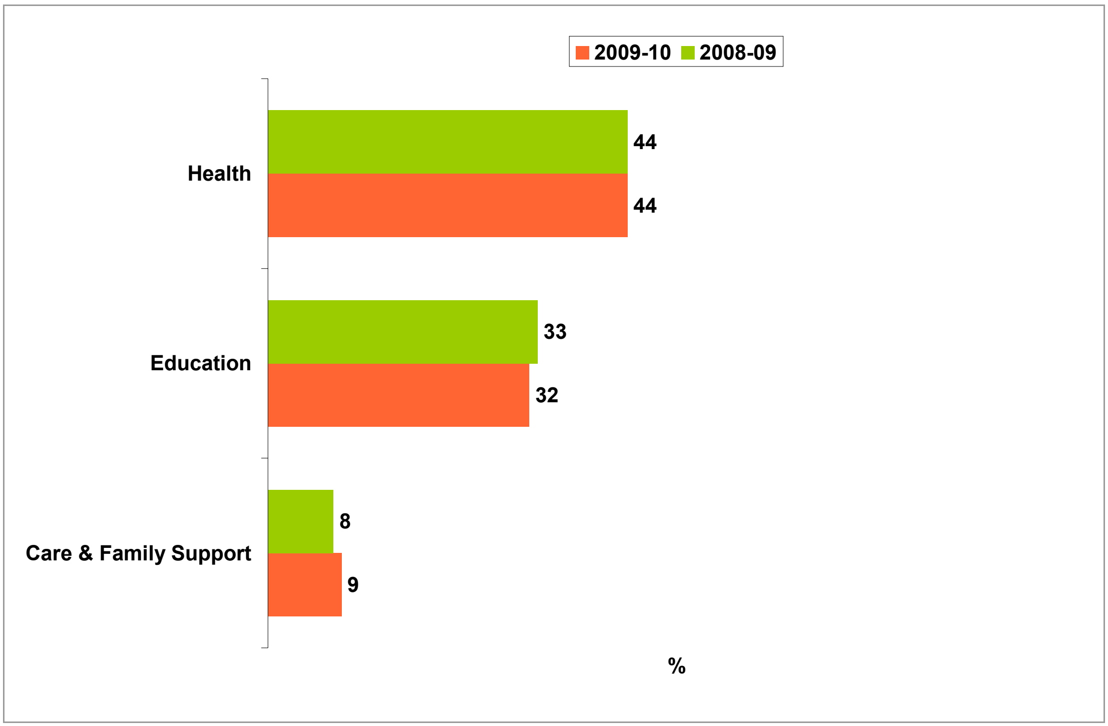
The questions reported on in this chapter were not used in the calculation of the overall indicator but provide further contextual information about parents' experience of services. More specifically, the questions about decision making were mainly present to filter the appropriate respondents so that they could be used in the relevant sub-indicator calculations. However, the questions also provide some useful background information in their own right.

Parents' ratings of health care services, education services and care & family support services reported in this chapter were each based on a single question asked upfront in the relevant questionnaire section, before they were asked the specific questions around the Core Offer areas. Thus it should be borne in mind that parents' ratings of services in this section may not be based on all factors included in the calculation of the overall composite indicator (further information about how the overall composite indicator is comprised can be found in chapter 4).

5.1 Decisions made about services

Three of the sub-indicators used to derive the overall indicator (Assessment, Transparency and Participation) were based on all parents who had experienced professionals making decisions about the services their child should receive. In figure 59 it can be seen that, overall, 44% of parents said that medical or health professionals had made decisions about their child's condition or services their child should receive in the last twelve months, unchanged from 2008-09. One-third (32%) of parents using education services said that their child had had a formal assessment of his/her educational support needs or an annual review of SEN (33% in 2008-09). Fewer than one in ten (9%) parents said that care & family support services professionals such as a social worker had made any decisions about their child's condition or services they should receive (8% in 2008-09).

Figure 59 Whether have had decisions made about child's condition or services by professionals (health and care & family support) in last 12 months; whether have had a formal assessment of educational support needs or annual review of SEN in last 12 months



Bases 2008-09: *Health (12,226), Education (11,757), Care & Family Support (12,226)*
Bases 2009-10: *Health (31,466), Education (30,544), Care & Family Support (31,466)*

Experience of medical or health professionals making decisions about their child's condition or services their child should receive was higher where the child was under five (57%) and where the parent received DLA for the child (54%).

Two-thirds (66%) of those in receipt of DLA had had a formal assessment of their educational support needs in the last twelve months.

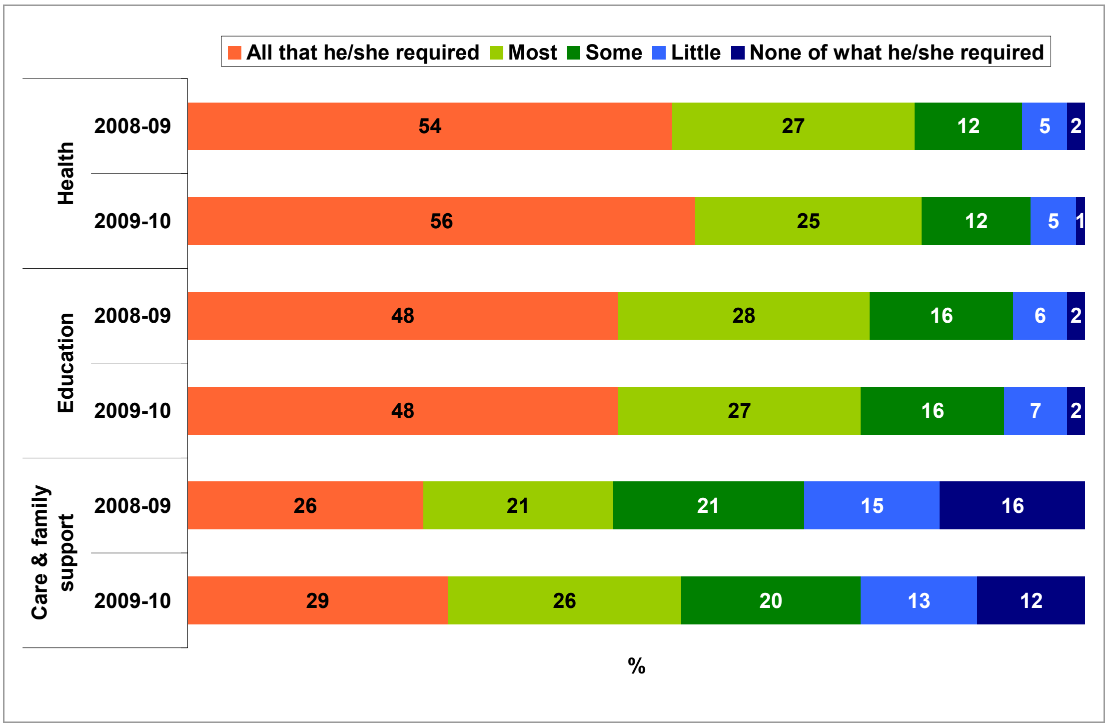
Experience of care & family support professionals making decisions about their child's disability or services their child should receive was higher where the child had a statement of SEN (23%) and where the parent received DLA for the child (21%).

5.2 Rating of services and levels of unmet need

For each of the three service domains, all parents (regardless of service use) were asked to what extent they considered that their child had received all the services they required over the previous twelve months. Parents' responses in both the 2008-

09 survey and 2009-10 survey are summarised in figure 60. This shows the proportions based on those who say that their child required each service.

Figure 60 Extent to which parents feel child has received all the services they required in last 12 months



***Bases 2008-09:** All requiring services: Health (11,657), Education (11,617), Care & Family Support (5,230)*
***Bases 2009-10:** All requiring services: Health (30,270), Education (30,292), Care & Family Support (18,440)*

Parents generally felt that their child's needs were being met to a greater extent in health and education services compared with care & family support services, a pattern observed in the 2008-09 survey.

Eight in ten (81%) parents said that their child had received all or most of the health care services they had required, with three-quarters (75%) saying they had received all or most of the school and other education services they had required. Just over half (55%) said they had received all or most of the care & family support services they had required over the last twelve months.

Parents of children with SEN were less likely to say that their child had received all or most of the health services they required over the last twelve months (75%). Those in receipt of DLA were also less likely to say this (77%).

Parents of children with a statement of SEN were only slightly less likely than average to say that their child had received all or most of the school and education services they required over the last twelve months (72%). However where the child had a SEN without a statement this perception fell to 51%.

Parents of children in receipt of DLA were less likely than others to feel that they had received all or most of the care & family support services they required in the last twelve months (48% and 60% respectively).

Parents of children with SEN, regardless of whether they were in receipt of DLA, were also less likely to think that their care & family support service needs were being met with 45% saying that they had received all or most of what they required.

In the 2008-09 survey, views on whether *all* service needs were being met were found to vary by ethnicity with Asian, black and other ethnic groups being less assured than parents of white children. A similar picture emerged in the 2009-10 survey (see figure 61).

Figure 61

EXTENT TO WHICH PARENTS FEEL CHILD HAS RECEIVED ALL THE SERVICES THEY REQUIRED IN LAST 12 MONTHS, BY ETHNICITY

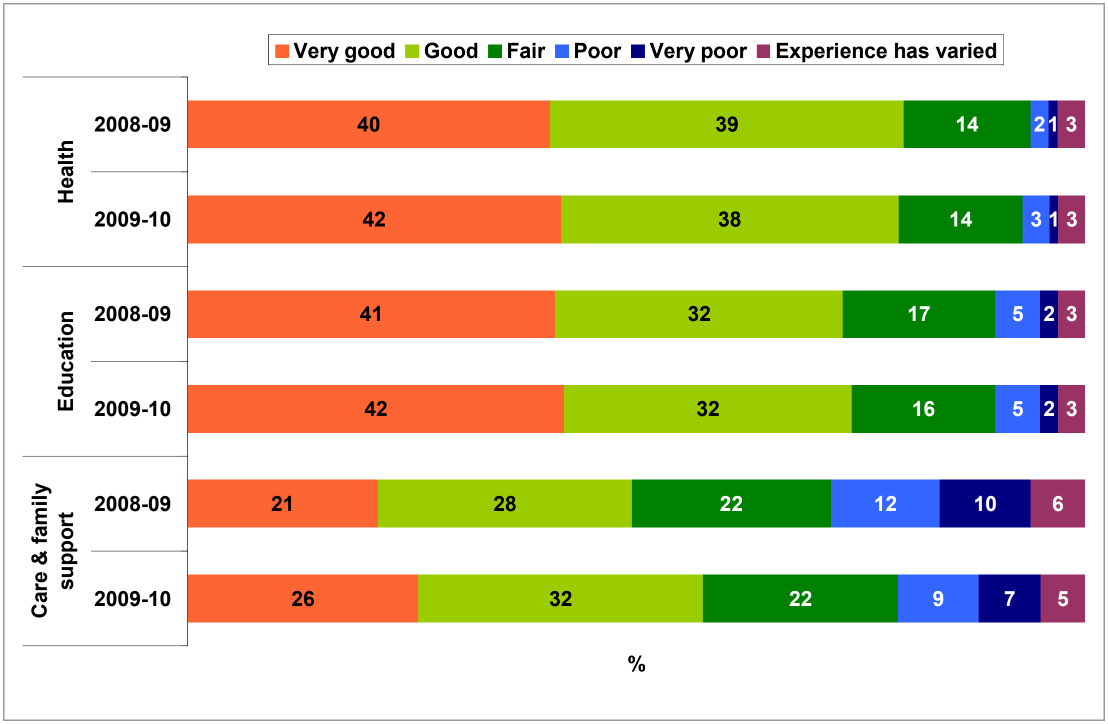
	Health		**Education**		**Care & family support**	
	2008-09 %	2009-10 %	2008-09 %	2009-10 %	2008-09 %	2009-10 %
Overall	54	56	48	48	26	29
White	56	57	49	49	28	30
Mixed	48	54	41	45	18	26
Asian	38	41	42	40	19	19
Black	41	42	35	40	16	15
Other	36	43	39	40	8	24

Bases 2008-09 (n): *All requiring services: Health (11,657); White (10,265); Mixed (454); Asian (411); Black (319); Other (83); Education (11,617); White (10,221); Mixed (453); Asian (417); Black (315); Other (86); Care & Family Support (5,230); White (4,539); Mixed (231); Asian (193); Black (159); Other (42)*
Bases 2009-10 (n): *All requiring services: Health (30,270); White (25,886); Mixed (1,387); Asian (1,293); Black (1,006); Other (397); Education (30,292); White (25,891); Mixed (1,377); Asian (1,300); Black (1,013); Other (403); Care & Family Support (18,440); White (15,627); Mixed (903); Asian (775); Black (644); Other (272)*

Across all three service sectors, parents of children from a mixed ethnic background appeared to be more assured compared with the 2008-09 survey that their child had received all of the services they required in the last twelve months.

When asked to rate the quality of the services they had received in the last twelve months parents were generally very positive (see figure 62), although again ratings for care & family support services were comparatively lower than for health and education services. As noted in the introduction to this chapter, parents' ratings of services in this section were based on one direct question asked about each of the three service domains. Parents may have considered other factors important to them, which were not represented in the composite indicator score.

Figure 62 Parents' rating of the quality of services their child has used in last 12 months



Bases 2008-09: *All using services in last 12 months: Health (11,717), Education (11,757), Care & Family Support (3,900)*
Bases 2009-10: *All using services in last 12 months: Health (30,357), Education (30,544), Care & Family Support (14,277)*

Eight in ten (80%) rated health care services received in the last twelve months as good or very good. The equivalent figure for education services was 73%. Both were very similar to previous ratings from the 2008-09 survey. Ratings for care & family support services, however, have increased since the 2008-09 survey. The proportion of parents rating them as good or very good increased from 49% to 57%.

Parents in receipt of DLA for their child rated health care services slightly less highly than parents not in receipt of DLA (36% of the former group rated them very good compared with 44% of the latter group).

Around six in ten (57%) parents of children under five rated the education services their child had received in the previous twelve months as very good compared with four in ten (41%) parents of older children. Where the child has SEN without a statement only one quarter (25%) rated the education services their child had received over the last twelve months as very good.

The ratings of services, from these single measures, did mirror the composite indicator scores for certain subgroups. Parents of pre-school aged children were more likely to rate education services and care & family support services as very good or good (87% and 66% respectively compared with averages of 73% and 57% respectively).

Parents who reported that their children had five or more areas of difficulty associated with their illness, disability or condition were less likely to rate services as very good or good compared with average (70% for health; 67% for education; 49% for care & family support).

6. FURTHER ISSUES RAISED BY PARENTS

CHAPTER SUMMARY

When given the opportunity to comment freely on the services that their child had received, a mixture of positive and negative comments were received, although responses were more weighted towards the negative.

In relation to health care services, one in three (36%) parents who commented gave positive feedback about services received while four in ten comments (39%) made in relation to educational services were positive. There was, however, less spontaneous positive feedback about care & family support services with 15% of comments made about care & family support falling in this category.

Where parents highlighted negative issues in relation to the three service domains, these tended to be around the areas of poor communication and information, difficulties with access to services or feelings that there was a general lack of services available.

Parents were also invited to give feedback not directly related to one of the three service areas but about other local services they had used in the last twelve months. The common themes that emerged included an overall need for more information on their child's condition, a general feeling that there was a lack of help available and complaints about a lack of funding for local services. What was particularly evident, however, was the sheer variety of issues that arose, reflecting the fact that concerns were very particular to individual family circumstances.

This chapter explores the responses given by parents to a number of open questions included in the questionnaire. Given the wide-ranging issues covered by this research it was important that parents had the chance to express their views freely without being restricted by pre-defined answers on the questionnaire. Parents were given the opportunity, at the end of each section of the questionnaire, to write any additional comments they had about the health, education and care & family support services their child had received. In addition to commenting about the three service domains covered by the survey, in 2009-10 parents were given the opportunity to comment on their experience of any other local services that were not covered elsewhere in the survey.

Comments from all of the questions were coded into common answers and these coded responses were further grouped under a set of sub-headings to allow for a clearer analysis. For comments relating to the three service areas of health, education and care & family support, the sub-headings used were the same as those used in 2008-09 to allow direct comparison.

It was found that parents sometimes used the final open-ended question, which was intended to capture parents' experiences of other local services, to make comments directly relating to health, education and care & family support services. Where this occurred, the results were merged with the appropriate service section and removed from the analysis of their experience of other local services.

In reading the following chapter it should be noted that not all parents decided to comment on the services that their child had received. Figure 63 shows the proportion of parents that gave a comment about the respective service areas. The lower level of comments relating to care and family support is likely to reflect the lower number of service users in this category.

Figure 63

PROPORTION OF PARENTS WHO COMMENTED ON THE SERVICES THEIR CHILD HAD RECEIVED

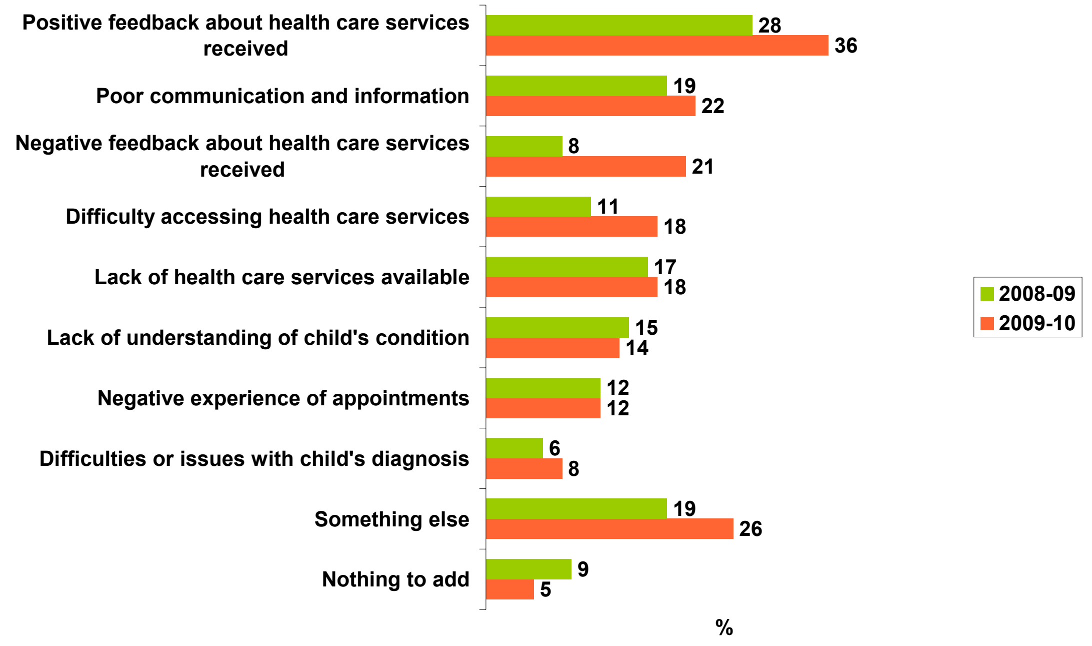
	Number of parents who commented	**Percentage (%)**
Health care services	*11,833*	37
Education services	*11,258*	34
Care & family support services	*7,311*	20
Other local services	*5,608*	16

Most of the following analyses focus solely on parents who commented about local services. Further analyses are conducted within the sub-headings where common coded responses were grouped.

6.1 Comments made about health care services

Figure 64 shows the most common types of issues raised by parents about health care services. Encouragingly, as in 2008-09, the most frequent type of comment made by parents was a positive reference to health care services received (36% of parents who commented).

Figure 64 Topics for comments on health care services 2008-09 and 2009-10



Bases: All who commented 2009-10 (11,833); 2008-09 (4,080)

One-fifth (22%) of parents raised concerns about poor communication and information and a similar proportion (21%) gave negative feedback about health care services received.

Compared with 2008-09, a higher proportion of parents made positive comments about health care services (36% in 2009-10 compared with 28% in 2008-09). However this was also true of negative comments (21% in 2009-10 compared with 8% in 2008-09) and for difficulties accessing services (18% in 2009-10 compared with 11% in 2008-09). The higher proportion of responses given across the board in 2009-10 reflects the fact that parents tended to give an answer covering more than one theme.

Of those who gave positive feedback about health care services received, three in ten (29%) simply said that the health care services were good. In relation to specific services, parents commented on hospital staff or hospital services being good and that the GP or GP's surgery was good (17% and 15% respectively). These mirror the most common responses in the 'positive feedback' subgroup given in 2008-09. Other comments within this category included positive references to a wide variety of other individual services. The full breakdown of responses given by parents can be found in figure 73 in appendix 1.

Positive feedback about health care services received

Health care services are good

Hospital staff/ service is good

GP/ GP's surgery is good

One in five parents (19%) who made comments in relation to poor communication and information said they needed more information on their child's condition. Another common response (made by 17% of parents commenting in this category) was that health care professionals should realise that the parent knows their child best. Other answers under this theme included the feeling that there was not enough communication between everyone involved (16%), not being sure what help or benefits were available to them (16%) and complaints that they had to see numerous different health professionals (9%).

Poor communication and information

Need more information on child's condition

Health professionals should realise that parent knows child best

Not enough communication between everyone involved

The most common piece of negative feedback given by parents in relation to health care services received was that the GP or GP's surgery was poor (19%). Around one in eight parents (12%) said they thought the hospital staff or service was poor, with one in nine (11%) saying that Child and Adolescent Mental Health Services (CAMHS) were poor. Other parents giving a negative comment about health care services felt the quality of services overall was erratic (14%). Parents made negative references to a wide variety of other individual services; a full listing is detailed in figure 75 in appendix 1.

Around one in five parents (18%) who made comments in relation to health care services cited difficulties in accessing services; with half of these parents (53%) saying they had found progress difficult or frustrating. Other common responses in this category included the process taking too long (21%) and parents having to find health care services themselves (13%).

Of those parents who felt there was a lack of available health care services, one in five (21%) said they had to resort to private health care. Parents also said there was a general lack of support available for their child (15%) and problems with funding (11%). Other comments that made up this category related to inadequate provision of a particular health service, for example speech and language therapy, occupational therapy etc – a detailed breakdown of responses is displayed in figure 77 in appendix 1.

There was a feeling amongst some parents who commented (14%) that those responsible for providing their child's health care services lacked a proper understanding of their child's condition. They felt their child had not received the most appropriate services (35% of comments in this category), that action or non-action had affected the child badly (25%) and that their child's condition was not taken seriously (17%).

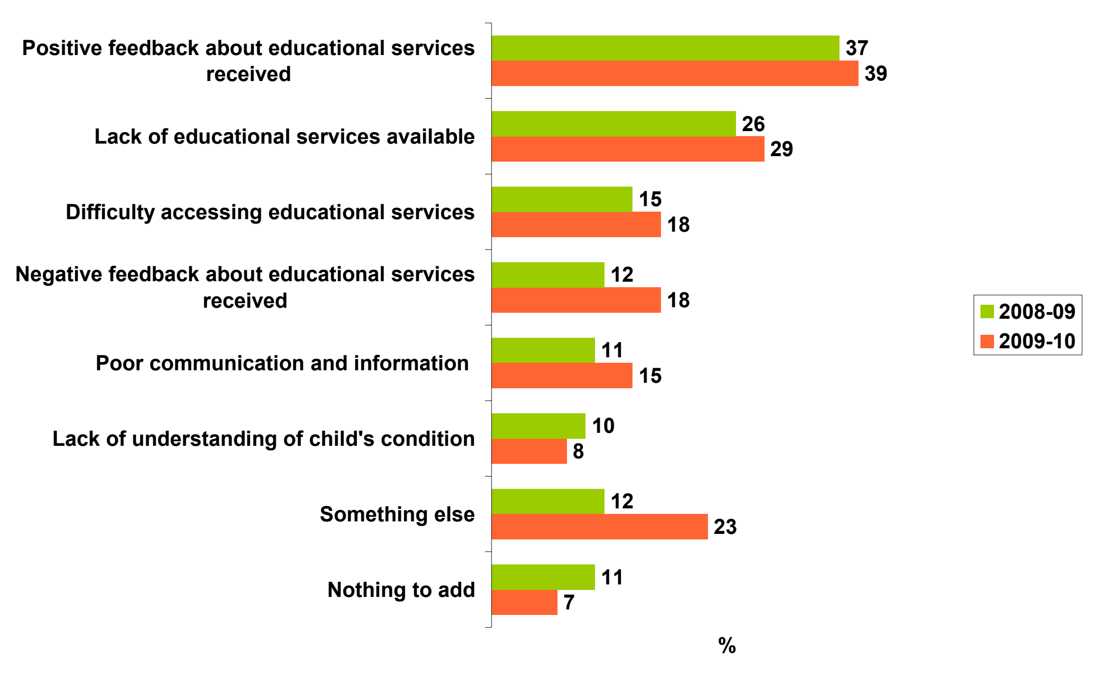
One in eight (12%) parents who commented had specific negative comments to make in relation to health care appointments. Of these the majority (62%) complained about the length of time taken to arrange appointments.

A full list of all coded responses given in relation to health care services can be found in figures 73-81 in appendix 1.

6.2 Comments made about education services

Around four in ten (39%) comments made by parents in relation to education services were positive (see figure 65).

Figure 65 Topics for comments on education services 2008-09 and 2009-10



Bases: All who commented 2009-10 (11,258); 2008-09 (4,163)

Parents whose child had a statement of SEN were much more likely to give positive feedback (48%) compared with those whose child had SEN without a statement (32%) and those whose child had no SEN (38%).

However three in ten (29%) parents who commented felt that there was a lack of educational services available, one in five (18%) reported difficulties in accessing these services and the same proportion gave negative feedback about an educational service their child had received. Parents of children with SEN without a statement, in particular, were more likely to report difficulties accessing services and a lack of educational services available (33% and 38% respectively). Overall the additional feedback given by parents in relation to educational services was broadly similar to 2008-09.

Of those parents who gave positive feedback about an educational service received, over half (55%) said that they were pleased or happy with their child's school while three in ten (30%) said that the school was supportive. A smaller proportion of this positive feedback was to do with their school being helpful (17%). The full breakdown of positive feedback given by parents is shown in figure 82 in appendix 1.

Positive experience of education services

We are pleased/ happy with the school

The school is supportive

Those parents who felt there was a lack of educational services available most commonly mentioned that their child needed more help or support from the school (45%). Some argued that there was not enough money put aside for special needs (12%). Several parents also complained that specific needs were not met, for example speech therapy, signing, large print etc. Further details of these can be found in figure 83 in appendix 1.

Lack of education services

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

Three in ten (31%) parents who mentioned difficulties in accessing educational services complained that help was only given on parents' initiative or that they had to fight for help to be given. One quarter (23%) reported difficulties in getting a statement of SEN for their child. Other comments within this group included problems in getting help from their SEN service/SENCO (15%) or from their local authority (17%).

Parents who gave negative feedback about educational services their child had received tended to feel that their child had been let down by their school or by the education system (29%). Some were concerned that their child was being bullied or struggling socially (16%) while the same proportion said they had to move their child to another school as the previous one had been inadequate.

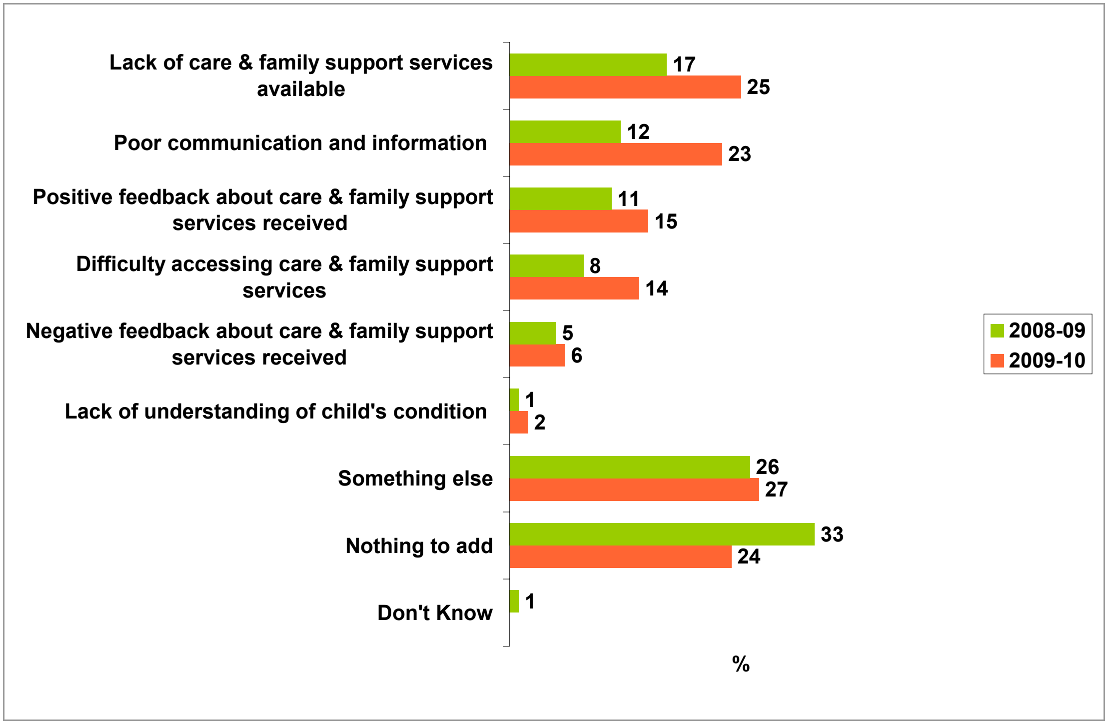
Parents who raised concerns about poor communication and information felt there was a lack of communication from the school about their child (37% of comments in this category) and that they needed more information on services their child was entitled to (25%). A further quarter of comments (24%) related to parents judging that those providing educational services were not interested in parents' views or did not listen enough to parents.

A full list of all coded responses given in relation to education services can be found in figures 82-88 in appendix 1.

6.3 Comments made about care & family support services

Figure 66 shows the general themes that came out of parents' comments in relation to care & family support services their child had received. As in 2008-09, the most common issue mentioned by parents was the lack of these services available to them. A quarter (25%) of all comments received fell in this category.

Figure 66 Topics for comments on care & family support services 2008-09 and 2009-10



Bases: All who commented 2009-10 (7,311); 2008-09 (3,526)

Another common theme to come out of parental comments was the poor level of communication and information parents had received – present in 23% of comments. Around one in seven (15%) parents reported positive experiences of using care & family support services, but a similar proportion (14%) mentioned difficulties in accessing these services. Only a small proportion of parents who commented made negative comments about a care & family support service their child had used (6%).

Lack of care & family support services available

No help or support available

Support is needed for the whole family

Parents felt there was a general lack of care & family support services available to them, with some specifically concerned that help should be available to the whole family – this concern was present in 15% of comments in this category. The full breakdown of responses given by parents is shown in figure 89 in appendix 1.

In relation to poor communication and information, the majority of comments in this area were to do with parents not knowing what help was available or what they were entitled to (70%). Other concerns included a lack of follow-up or reviews by care & family support services (16%) and there not being enough communication between everyone involved (8%).

Where parents wrote about positive experiences, the most common feedback was that services in general were good (29% of comments in this area), that particular individuals in care & family support had been excellent (28%) and some parents felt there was plenty of help and support available to them (27%).

Those parents who had difficulty accessing care & family support services most commonly mentioned they were frustrated that they had to find information and organise things themselves (34%) and that it often took a long time (32%). Other parents remarked that they had had to fight to receive the care & family support services they felt they needed (18%).

Half (48%) of parents who gave negative feedback about care & family support services their child had received said they felt let down by social care services. A full list of all coded responses given in relation to care & family support services can be found in figures 89-95 in appendix 1.

6.4 Comments made about other local services

A number of issues emerged from parents' comments that were not specifically related to health, education or care & family support services. On the whole these tended to be references to their child's condition or general comments about their experiences. Some common answers have been grouped into themes and are shown in figure 67.

Figure 67

TOPICS FOR COMMENTS ON OTHER LOCAL SERVICES FOR CHILDREN AND YOUNG PEOPLE

	%
Need more information on child's condition/help available	16
Lack of help available	15
Resource issues in relation to local services	7
Problems with bureaucracy/ accessing services	5
Need more provision for leisure activities	5
Positive references to services in general	5
Issues with child's diagnosis	4
Issues with appointments	4
Lack of understanding of child's condition	4
Issues with benefits	3
Issues with travel/transport	2
Other	47
No/nothing/not applicable	13
Base (n): All who commented	*5,608*

The most common theme to emerge was an overall need for more information on the child's condition and what help or benefits the family may be entitled to (16% of comments made). A number of parents expressed a general sense that there was a lack of help available (15%) – the more specific comments in this category included references to help being needed for the whole family and for young people over the age of 18 (22% and 7% of comments in this category respectively).

Parents mentioned a lack of funding and resources in local services (7%), with a minority of these making specific references to a lack of equipment for disabled children (6% of comments in this category). As was the case in relation to specific services, some parents expressed frustration in the processes and bureaucracy involved in accessing services, making up 5% of comments made about other local services.

An additional theme to emerge was the need for better provision of leisure activities (mentioned in a further 5% of comments). This included social activities for children and young people and after school clubs (59% and 42% of comments in this category respectively).

The specific comments that parents gave in relation to positive references to services in general (5%), issues with appointments (4%), issues with the child's diagnosis (4%) and lack of understanding of the child's condition (4%) tended to mirror those given in relation to specific services. Some parents mentioned problems in relation to benefits (3%), most prominently the Disability Living Allowance (DLA), which comprised almost three quarters (72%) of comments about benefits. Of the 2% of parents who had issues with transport most referred to having to travel to a non-local facility as appropriate services were not available in their area (61% of comments made that fell under this sub-heading).

What is, perhaps, the most revealing aspect about parental comments made in this section is the sheer variety of comments made about other local services. This is reflected in the very large proportion of comments that could not be grouped together under a common theme (47%).

Some of the comments were largely not related to the question asked, for example, around one in five (18%) comments in this residual category were about the child's health condition. This suggests that parents' concerns about local services are very wide-ranging and largely individual to their own circumstances. The complete list of additional comments given by parents under 'Anything else to add about local services' is shown in figures 96-107 in appendix 1.

REFERENCES

Campbell-Hall, V., Coulter, A. and Joyce, L. (2009) *Parental Experience of Services for Disabled Children: Qualitative Research (Phase 2) – Exploring the Findings from the National Survey*. DCSF-RR161 www.dcsf.gov.uk/research

Department for Children, Schools and Families. *Aiming High for Disabled Children*. http://www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer

Grant, C. and Hamlyn, B. (2009) *Parental Experience of Services for Disabled Children: National Survey*.DCSF-RR146 www.dcsf.gov.uk/research

Hutchison T., and Gordon, D., (2005) Ascertaining the prevalence of childhood disability. *Child: Care, Health and Development*, Volume 31, Issue 1, pp99-107. Blackwell Publishing Ltd

National Centre for Social Research. et al. (2008) *Development of a Survey on Services for Disabled Children*. DCSF-RR53 www.dcsf.gov.uk/research

Slade, Z., Coulter, A. and Joyce, L. (2009) *Parental Experience of Services for Disabled Children: Qualitative Research*. DCSF-RR147 www.dcsf.gov.uk/research

APPENDIX 1 – ADDITIONAL TABLES

Figure 68

PARENTAL EXPERIENCES OF SERVICES PROVIDED TO DISABLED CHILDREN: OVERALL SCORES IN 2008-09 AND 2009-10, BY LOCAL AUTHORITY

	2008-09[12]		2009-10[13]	
	Overall score	Base	Overall score	Base
ENGLAND	59	*12,226*	61	*31,466*
NORTH EAST				
Darlington	..	..	62	*163*
Durham	..	..	61	*224*
Gateshead	..	..	64	*195*
Hartlepool	..	..	66	*116*
Middlesbrough	..	..	65	*191*
Newcastle Upon Tyne	..	..	64	*200*
North Tyneside	..	..	67	*198*
Northumberland	..	..	67	*202*
Redcar and Cleveland	61	*255*	62	*169*
South Tyneside	..	..	63	*156*
Stockton-On-Tees	..	..	60	*187*
Sunderland	..	..	62	*186*
NORTH WEST				
Blackburn with Darwen	..	..	64	*152*
Blackpool	..	..	57	*159*
Bolton	..	..	62	*148*
Bury	62	*328*	62	*184*
Cheshire[14]	..	..	60	*415*
Cumbria	..	..	62	*193*
Halton	..	..	62	*141*
Knowsley	..	..	61	*97*
Lancashire	..	..	62	*586*
Liverpool	..	..	60	*136*
Manchester	..	..	61	*197*
Oldham	56	*224*	59	*149*
Rochdale	..	..	58	*168*
Salford	..	..	62	*143*
Sefton	..	..	62	*204*

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[12] The 2008-09 scores were first published by DCSF in May 2009. However eighteen LAs subsequently had their overall scores for 2008-09 revised from those originally published. It was identified that survey responses had been allocated to the LA of the school that the child attended rather than the LA in which they were resident. The 2008-09 scores presented here are the revised scores published in December 2009.

[13] There were five LAs where an indicator score for 2009-10 could not be produced due to low base sizes (Rutland, City of London, Kensington and Chelsea, Westminster and Isles of Scilly).

[14] These figures were reported on the pre-April 2009 Local Authority structure. In April 2009, Cheshire was replaced by the new LAs of ‘Cheshire East’, and ‘Cheshire West and Chester’.

St Helens	..	..	63	*154*
Stockport	..	..	61	*200*
Tameside	..	..	61	*145*
Trafford	..	..	60	*201*
Warrington	..	..	64	*179*
Wigan	..	..	64	*171*
Wirral	..	..	63	*215*
YORKSHIRE AND THE HUMBER				
Barnsley	61	*367*	62	*224*
Bradford	..	..	57	*163*
Calderdale	..	..	63	*188*
Doncaster	..	..	62	*174*
East Riding of Yorkshire	56	*396*	60	*247*
Kingston Upon Hull, City of	..	..	57	*171*
Kirklees	..	..	62	*190*
Leeds	..	..	59	*205*
North East Lincolnshire	63	*254*	63	*187*
North Lincolnshire	61	*325*	64	*180*
North Yorkshire	..	..	62	*252*
Rotherham	..	..	60	*214*
Sheffield	..	..	61	*248*
Wakefield	..	..	56	*203*
York	64	*335*	63	*203*
EAST MIDLANDS				
Derby	61	*274*	63	*153*
Derbyshire	57	*425*	68	*266*
Leicester	59	*199*	60	*160*
Leicestershire	..	..	63	*229*
Lincolnshire	..	..	60	*237*
Northamptonshire	..	..	60	*217*
Nottingham	..	..	60	*142*
Nottinghamshire	..	..	64	*441*
Rutland	..	..	-	*55*
WEST MIDLANDS				
Birmingham	..	..	57	*470*
Coventry	..	..	61	*179*
Dudley	..	..	59	*191*
Herefordshire	..	..	60	*234*
Sandwell	..	..	61	*146*
Shropshire	..	..	63	*210*
Solihull	59	*257*	63	*180*
Staffordshire	..	..	62	*387*
Stoke-On-Trent	..	..	61	*161*
Telford and Wrekin	..	..	59	*198*
Walsall	..	..	61	*195*
Warwickshire	..	..	62	*205*
Wolverhampton	..	..	64	*152*
Worcestershire	60	*278*	62	*201*
EAST OF ENGLAND				
Bedfordshire[15]	..	..	62	*388*

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[15] These figures were reported on the pre-April 2009 Local Authority structure. In April 2009, Bedfordshire was replaced by the new LAs of ‘Bedford’ and ‘Central Bedfordshire’.

Cambridgeshire	59	*393*	63	*254*
Essex	..	..	58	*735*
Hertfordshire	54	*367*	57	*408*
Luton	58	*289*	60	*176*
Norfolk	60	*470*	64	*339*
Peterborough	60	*272*	63	*163*
Southend-on-Sea	..	..	62	*169*
Suffolk	..	..	63	*362*
Thurrock	..	..	57	*170*
LONDON				
INNER LONDON				
Camden	..	..	62	*136*
City Of London	..	..	-	*3*
Hackney	58	*171*	61	*169*
Hammersmith and Fulham	..	..	58	*102*
Haringey	..	..	58	*177*
Islington	..	..	59	*168*
Kensington and Chelsea	..	..	-	*64*
Lambeth	..	..	58	*181*
Lewisham	55	*169*	58	*211*
Newham	..	..	59	*152*
Southwark	..	..	60	*181*
Tower Hamlets	..	..	61	*128*
Wandsworth	..	..	61	*160*
Westminster	..	..	-	*81*
OUTER LONDON				
Barking and Dagenham	58	*242*	61	*214*
Barnet	..	..	60	*232*
Bexley	59	*229*	59	*270*
Brent	58	*130*	55	*179*
Bromley	..	..	59	*314*
Croydon	..	..	60	*231*
Ealing	..	..	60	*200*
Enfield	..	..	60	*209*
Greenwich	..	..	58	*197*
Harrow	..	..	61	*195*
Havering	..	..	58	*237*
Hillingdon	..	..	58	*241*
Hounslow	..	..	61	*194*
Kingston Upon Thames	..	..	62	*232*
Merton	..	..	60	*210*
Redbridge	..	..	59	*190*
Richmond Upon Thames	..	..	60	*220*
Sutton	..	..	57	*243*
Waltham Forest	..	..	60	*181*
SOUTH EAST				
Bracknell Forest	..	..	61	*191*
Brighton and Hove	58	*270*	62	*175*
Buckinghamshire	..	..	58	*226*
East Sussex	..	..	60	*434*
Hampshire	..	..	57	*265*
Isle Of Wight	..	..	57	*244*
Kent	..	..	59	*434*
Medway Towns	..	..	59	*215*
Milton Keynes	..	..	60	*189*
Oxfordshire	..	..	63	*228*
Portsmouth	..	..	61	*190*

Reading	..	..	59	*173*
Slough	..	..	65	*107*
Southampton	..	..	60	*185*
Surrey	..	..	57	*242*
West Berkshire	..	..	61	*175*
West Sussex	..	..	61	*219*
Windsor and Maidenhead	62	*217*	60	*181*
Wokingham	..	..	61	*201*
SOUTH WEST				
Bath and North East Somerset	62	*336*	64	*207*
Bournemouth	..	..	60	*184*
Bristol, City of	..	..	62	*239*
Cornwall	..	..	57	*225*
Devon	57	*422*	61	*282*
Dorset	..	..	61	*248*
Gloucestershire	60	*348*	62	*217*
Isles Of Scilly	..	..	-	*7*
North Somerset	..	..	61	*250*
Plymouth	..	..	61	*217*
Poole	59	*256*	58	*182*
Somerset	..	..	62	*237*
South Gloucestershire	..	..	62	*233*
Swindon	..	..	62	*202*
Torbay	57	*240*	62	*162*
Wiltshire	..	..	61	*252*

Figure 69

PARENTAL EXPERIENCES OF SERVICES PROVIDED TO DISABLED CHILDREN: OVERALL SCORES IN 2008-09 AND 2009-10, BY PRIMARY CARE TRUST

	2008-09[16]		**2009-10[17]**	
	Overall score	Base	Overall score	Base
ENGLAND	59	*12,226*	61	*31,466*
NORTH EAST Strategic Health Authority (SHA)				
County Durham PCT	..	..	61	*224*
Darlington PCT	..	..	62	*163*
Gateshead PCT	..	..	64	*195*
Hartlepool PCT	..	..	66	*116*
Middlesbrough PCT	..	..	65	*191*
Newcastle PCT	..	..	64	*200*
North Tyneside PCT	..	..	67	*198*
Northumberland Care Trust	..	..	67	*202*
Redcar and Cleveland PCT	61	*255*	62	*169*
South Tyneside PCT	..	..	63	*156*
Stockton-on-Tees Teaching	..	..	60	*187*
Sunderland Teaching PCT	..	..	62	*186*
NORTH WEST SHA				
Ashton, Leigh and Wigan PCT	..	..	64	*171*
Blackburn with Darwen PCT	..	..	64	*152*
Blackpool PCT	..	..	57	*159*
Bolton PCT	..	..	62	*148*
Bury PCT	62	*328*	62	*184*
Central & Eastern Cheshire PCT	..	..	57	*207*
Central Lancashire PCT	..	..	60	*203*
Cumbria PCT	..	..	62	*193*
East Lancashire PCT	..	..	63	*164*
Halton & St. Helens PCT	..	..	62	*295*
Heywood, Middleton & Rochdale PCT	..	..	58	*168*
Knowsley PCT	..	..	61	*97*
Liverpool PCT	..	..	60	*136*
Manchester PCT	..	..	61	*197*
North Lancashire PCT	..	..	59	*219*
Oldham PCT	56	*224*	59	*149*
Salford PCT	..	..	62	*143*
Sefton PCT	..	..	62	*204*
Stockport PCT	..	..	61	*200*

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[16] The 2008-09 scores were first published by DCSF in May 2009. However thirteen PCTs subsequently had their overall scores for 2008-09 revised from those originally published. It was identified that survey responses had been allocated to the PCT of the school that the child attended rather than the PCT in which they were resident. The 2008-09 scores presented here are the revised scores published in December 2009.

[17] There were two PCTs where an indicator score for 2009-10 could not be produced due to low base sizes (Kensington and Chelsea PCT and Westminster PCT).

Tameside with Glossop PCT	..	..	61	*152*
Trafford PCT	..	..	60	*201*
Warrington PCT	..	..	64	*179*
Western Cheshire PCT	..	..	63	*208*
Wirral PCT	..	..	63	*215*
YORKSHIRE AND THE HUMBER SHA				
Barnsley PCT	61	*367*	62	*224*
Bradford & Airedale PCT	..	..	57	*163*
Calderdale PCT	..	..	63	*188*
Doncaster PCT	..	..	62	*174*
East Riding of Yorkshire PCT	56	*396*	60	*247*
Hull PCT	..	..	57	*171*
Kirklees PCT	..	..	62	*190*
Leeds PCT	..	..	59	*205*
North East Lincolnshire Care Trust Plus	..	..	63	*187*
North Lincolnshire PCT	..	..	64	*175*
North Yorkshire & York PCT	..	..	62	*455*
Rotherham PCT	..	..	60	*214*
Sheffield PCT	..	..	61	*248*
Wakefield District PCT	..	..	56	*203*
EAST MIDLANDS SHA				
Bassetlaw PCT	..	..	58	*181*
Derby City PCT	61	*274*	63	*153*
Derbyshire County PCT	..	..	68	*259*
Leicester City PCT	59	*199*	60	*160*
Leicestershire County & Rutland PCT	..	..	64	*284*
Lincolnshire PCT	..	..	61	*242*
Northamptonshire PCT	..	..	60	*217*
Nottingham City PCT	..	..	60	*142*
Nottinghamshire County Teaching PCT	..	..	64	*260*
WEST MIDLANDS SHA				
Birmingham East & North PCT	..	..	58	*179*
Coventry PCT	..	..	61	*179*
Dudley PCT	..	..	59	*191*
Heart of Birmingham PCT	..	..	57	*104*
Herefordshire PCT	..	..	60	*234*
North Staffordshire PCT	..	..	65	*187*
Sandwell PCT	..	..	61	*146*
Shropshire County PCT	..	..	63	*210*
Solihull Care Trust	59	*257*	63	*180*
South Birmingham PCT	..	..	59	*187*
South Staffordshire PCT	..	..	63	*199*
Stoke on Trent PCT	..	..	61	*162*
Telford and Wrekin PCT	..	..	59	*198*
Walsall PCT	..	..	61	*195*
Warwickshire PCT	..	..	62	*205*
Wolverhampton City PCT	..	..	64	*152*
Worcestershire PCT	60	*278*	62	*201*
EAST OF ENGLAND SHA				
Bedfordshire PCT	..	..	62	*388*
Cambridgeshire PCT	59	*393*	63	*254*

East & North Hertfordshire PCT	..	..	60	*224*
Great Yarmouth & Waveney PCT	..	..	61	*195*
Luton Teaching PCT	58	*289*	60	*176*
Mid Essex PCT	..	..	60	*262*
Norfolk PCT	..	..	64	*257*
North East Essex PCT	..	..	58	*205*
Peterborough PCT	60	*272*	63	*163*
South East Essex PCT	..	..	62	*202*
South West Essex PCT	..	..	56	*217*
Suffolk PCT	..	..	62	*249*
West Essex PCT	..	..	59	*188*
West Hertfordshire PCT	..	..	60	*184*
LONDON SHA				
Barking and Dagenham PCT	58	*242*	61	*214*
Barnet PCT	..	..	60	*232*
Bexley Care Trust	59	*229*	59	*270*
Brent Teaching PCT	58	*130*	55	*179*
Bromley PCT	..	..	59	*314*
Camden PCT	..	..	62	*136*
City and Hackney PCT	..	..	61	*172*
Croydon PCT	..	..	60	*231*
Ealing PCT	..	..	60	*200*
Enfield PCT	..	..	60	*209*
Greenwich PCT	..	..	58	*197*
Hammersmith and Fulham PCT	..	..	58	*102*
Haringey PCT	..	..	58	*177*
Harrow PCT	..	..	61	*195*
Havering PCT	..	..	58	*237*
Hillingdon PCT	..	..	58	*241*
Hounslow PCT	..	..	61	*194*
Islington PCT	..	..	59	*168*
Kensington and Chelsea PCT	..	..	-	*64*
Kingston PCT	..	..	62	*232*
Lambeth PCT	..	..	58	*181*
Lewisham PCT	55	*169*	58	*211*
Newham PCT	..	..	59	*152*
Redbridge PCT	..	..	59	*190*
Richmond and Twickenham PCT	..	..	60	*220*
Southwark PCT	..	..	60	*181*
Sutton and Merton PCT	..	..	58	*453*
Tower Hamlets PCT	..	..	61	*128*
Waltham Forest PCT	..	..	60	*181*
Wandsworth PCT	..	..	61	*160*
Westminster PCT	..	..	-	*81*
SOUTH EAST COAST SHA				
Brighton and Hove City PCT	58	*270*	62	*175*
East Sussex Downs & Weald PCT	..	..	60	*220*
Eastern & Coastal Kent Teaching PCT	..	..	58	*205*
Hastings & Rother PCT	..	..	60	*214*
Medway PCT	..	..	59	*215*
Surrey PCT	..	..	57	*237*
West Kent PCT	..	..	60	*229*

West Sussex PCT	..	..	61	*219*
SOUTH CENTRAL SHA				
Berkshire East PCT	..	..	64	*484*
Berkshire West PCT	..	..	57	*549*
Buckinghamshire PCT	..	..	58	*228*
Hampshire PCT	..	..	57	*265*
Isle of Wight PCT	..	..	57	*244*
Milton Keynes PCT	..	..	60	*193*
Oxfordshire PCT	..	..	63	*222*
Portsmouth City PCT	..	..	61	*190*
Southampton City PCT	..	..	60	*185*
SOUTH WEST SHA				
Bath and North East Somerset PCT	62	*336*	64	*207*
Bournemouth & Poole PCT	..	..	59	*366*
Bristol Teaching PCT	..	..	62	*239*
Cornwall & Isles of Scilly PCT	..	..	58	*232*
Devon PCT	57	*422*	61	*282*
Dorset PCT	..	..	61	*248*
Gloucestershire PCT	60	*348*	62	*217*
North Somerset PCT	..	..	61	*250*
Plymouth PCT	..	..	61	*217*
Somerset PCT	..	..	62	*237*
South Gloucestershire PCT	..	..	62	*233*
Swindon PCT	..	..	62	*202*
Torbay Care Trust	57	*240*	62	*162*
Wiltshire PCT	..	..	61	*252*

Figure 70

SPECIAL EDUCATIONAL NEEDS STATUS BY LEVEL OF DLA RECEIPT

	%
Statement of SEN and high level DLA receipt	8
Statement of SEN and medium or low level DLA receipt	9
Statement of SEN but not in receipt of DLA	5
SEN without statement and high level DLA receipt	2
SEN without statement and medium or low level DLA receipt	4
SEN without statement but not in receipt of DLA	13
No SEN but in receipt of DLA	5
No SEN and not in receipt of DLA	49
No educational services used	3
Not specified	2
Base (n): All children	*31,466*

Figure 71

WHETHER PARENT HAS MADE A FORMAL WRITTEN COMPLAINT ABOUT A SERVICE THEIR CHILD HAS RECEIVED IN LAST 12 MONTHS

	Health	**Education**	**Care & family support**
	%	%	%
2009-10	4	5	2
2008-09	4	5	1
Age of child			
0-4	5	2	1
5-9	4	5	1
10-15	4	7	2
16-19	3	4	2
Sex of child			
Male	3	6	2
Female	4	5	1
Ethnicity			
White	3	5	2
Asian	7	6	2
Black	6	7	5
Mixed/other	6	8	3
Receipt of DLA			
High DLA	8	8	6
Any DLA	6	8	4
No DLA	3	4	1
Statement of SEN	6	8	4

Bases (n): *2009-10 (31,466); 2008-09 (12,226); 0-4 (1,875); 5-9 (9,821); 10-15 (14,866); 16-19 (4,588); Boy (19,958); Girl (11,304); White (26,727); Asian (1,418); Black (1,100); Mixed/Other (1,873); High DLA (5,407); Any DLA (12,642); No DLA (18,577); Statement of SEN (11,417)*

Figure 72

WHETHER PARENT HAS MADE A FORMAL WRITTEN COMPLAINT ABOUT A SERVICE THEIR CHILD HAS RECEIVED IN LAST 12 MONTHS, BY LEVEL OF SERVICE USAGE

	%	**Base (n)**
	Health	
Overall	4	*31,466*
None	2	*658*
1-4 services used	2	*18,155*
5 or more services used	7	*12,557*
	Education	
Overall	5	*31,466*
None	1	*859*
1 service used	4	*12,859*
2 services used	5	*7,317*
3 or more services used	8	*10,175*
	Care & family support	
Overall	2	*31,466*
None	*	*20,886*
1 service used	3	*5,123*
2 or more services used	8	*4,454*

Figure 73

COMMENTS THAT MAKE UP THE TOPIC OF POSITIVE FEEDBACK ABOUT HEALTH CARE SERVICES RECEIVED

	All giving positive feedback about health care services
	%
Health care services are good	29
Hospital staff/service is good	17
GP/GP's surgery is good	15
Health professionals are helpful	9
Child is improving/doing well	7
Paediatrician is good	5
Health care professionals are good	5
Service/care has now improved	4
Health care services are helpful	4
Speech and language service is good	4
Child and Adolescent Mental Health Services (CAMHS) are good	4
Opticians/eye service is good	3
Dentist is good	2
A&E/emergency service is good	2
ENT/audiology service is good	2
Diabetic service is good	2
The physio/physio service is good	2
Occupational therapist/Occupational therapy service is good	2
Out-patient nurses are good	2
Great Ormond Street Hospital/Addenbrookes is good	1
Health care services are professional	1
All positive references to appointments	1
Asthma is service good	1
Psychiatrist is good	1
Community nurses are good	1
Positive references to care being age-appropriate	1
Health visitor is good	1
Allergy service is good	1
The school nurse is good	1
Good communication between everyone involved	1
The dietician/dietician service is good	1
Nurse at GPs surgery is good	1
Health care professionals consider/support parents/whole family	*
Autism service is good	*
Enuresis service is good	*
Child is treated as an individual/listened to	*
Epilepsy service is good	*
Base (n)	*3,946*

Figure 74

COMMENTS THAT MAKE UP THE TOPIC OF POOR COMMUNICATION AND INFORMATION IN RELATION TO HEALTH CARE SERVICES RECEIVED

	All citing poor communication and information in health care services
	%
Need more information on child's condition	19
Health professionals should realise that parent knows child best	17
Not enough communication between everyone involved	16
Not sure what help/ benefits are available	16
Child/ we see numerous different health professionals	9
Services had to be found by myself	7
Mixed communication	7
Still don't know what caused problem/not been referred on	6
Lack of information (no detail)	5
Issues with notes/reports/records being lost/unavailable	5
Still waiting for someone to get back to us	4
Had to do own research	3
Parents/carers not always included (in decisions)	3
Require more support/information about dyslexia	2
The GP is uncommunicative	1
The GP/GP's surgery does not have enough time to listen	1
Require more support/information about dyspraxia	1
Health professionals ignore child/discuss unsuitable matters in front of child	*
Base (n)	*2,665*

Figure 75

COMMENTS THAT MAKE UP THE TOPIC OF NEGATIVE FEEDBACK ABOUT HEALTH CARE SERVICES RECEIVED

	All giving negative feedback about health care services
	%
GP/GP's surgery is poor	19
Quality of services erratic	14
Hospital staff/service is poor	12
Child and Adolescent Mental Health Services (CAMHS) are poor	11
Have complained/involved other agencies or governing bodies	7
Speech and language service is poor	7
Paediatrician is poor	4
Dentist/dental service is poor	4
Occupational therapist/Occupational therapy service is poor	4
Need single point of contact/ one person to oversee	4
Service/care is poor (all other negative references)	3
Could complain/have had cause to complain	3
A&E/emergency service is poor	3
Autism service is poor	2
Health professionals do not consider parents/ whole family	2
Service is/appears overstretched	2
The health visitor/health visitor service is poor	2
Negative references to care being age-appropriate	2
GP just gives us a prescription/recommends paracetamol	2
Psychologist service is poor	1
Asthma service is poor	1
Optician/optician’s service is poor	1
Physio/physio service is poor	1
ENT/audiology service is poor	1
Allergy service is poor	1
Dietician/dietician service is poor	1
Diabetics/diabetes service is poor	1
Enuresis service is poor	1
School nurse/school nurse service is poor	1
Feel let down by healthcare services	1
We get passed around	1
Problems/issues with out of hours service	*
Complaints are not dealt with properly	*
Epilepsy service is poor	*
ADHD service is poor	*
Do not see consultant/only see locum/junior doctor/registrar	*
Orthotics service is poor	*
Base (n)	*2,614*

Figure 76

COMMENTS THAT MAKE UP THE TOPIC OF DIFFICULTIES ACCESSING HEALTH CARE SERVICES

	All citing difficulties or issues accessing health care services
	%
Frustrating/difficult progress	53
Lengthy process/all takes so long	21
Health care services had to be found by myself	13
Health professionals have not helped with finding suitable services	8
Told we would receive further help but then nothing happens	7
Availability of services is a postcode lottery	5
Problems/issues when health professional left or retired	3
Problems/issues with obtaining medication	2
Issues with respite care	1
Issues with red tape/bureaucracy/administration	1
Would like access to alternative treatments	1
Issues with child physically accessing health care	*
Base (n)	*2,358*

Figure 77

COMMENTS THAT MAKE UP THE TOPIC OF LACK OF HEALTH CARE SERVICES AVAILABLE

	All citing lack of health care services available
	%
Had to resort to private healthcare	21
No support provided for child	15
In need of/need more speech & language therapy	14
Problems/issues with funding	11
Negative references to family being left alone	10
Services not available locally	7
In need of/need more occupational therapy	6
Health care services have been cut or reduced	6
In need of/need more physiotherapy	5
Service/care does not continue for long enough	5
In need of/need more Child and Adolescent Mental Health Services (CAMHS)	4
Shortage of staff	3
Do not receive enough care/often enough	3
Problems/issues with DLA	2
Issues with equipment	2
Lack of equipment available for child	2
Not enough funding for equipment for child	1
Physical problems catered for but not mental/ emotional	1
Need help in the home	1
In need of/need more ADHD services	*
In need of/need more dental services	*
Base (n)	*2,327*

Figure 78

COMMENTS THAT MAKE UP THE TOPIC OF LACK OF UNDERSTANDING OF THE CHILD'S CONDITION BY HEALTH CARE SERVICES

	All citing a lack of understanding of the child's condition
	%
Not received best/most appropriate services	35
Action/non-action has affected child badly	25
Child's condition not properly understood	23
Child's condition is not taken seriously	17
Health professionals have pre-conceived ideas about child's condition	7
Negative references to child being discharged/signed off	6
Situation has to get desperate before action taken	4
Base (n)	*1,676*

Figure 79

COMMENTS THAT MAKE UP THE TOPIC OF DIFFICULTIES/ISSUES ARRANGING APPOINTMENTS WITH HEALTH CARE SERVICES

	All citing difficulties/issues arranging appointments
	%
Appointments take a long time to be arranged	62
All other negative references to appointments	15
Not contacted about follow-up appointment	14
Hospital appointments often changed/delayed/cancelled	10
Appointments often late	7
Not re-contacted about cancelled appointments	1
Base (n)	*1,468*

Figure 80

COMMENTS THAT MAKE UP THE TOPIC OF DIFFICULTIES/ISSUES WITH CHILD'S DIAGNOSIS

	All citing difficulties/issues with child's diagnosis
	%
Difficulty getting child referred for diagnosis	33
Child has not been officially diagnosed	24
Annoyed child's condition only acknowledged recently	21
Issues with diagnosis	18
Child only diagnosed recently	8
Base (n)	*865*

Figure 81

COMMENTS THAT MAKE UP THE TOPIC OF OTHER COMMENTS ABOUT HEALTH CARE SERVICES RECEIVED

	All citing other issues about health care services
	%
All references to child's health condition	25
All references to child's health care services regime	16
I'm happy on the whole/in general (but...)	10
The School is good	9
On-going situation/no further forward	7
The school is poor	6
Service/care has stopped	6
Child has minor health problems	6
Care depends on parents (knowledge/profession)	5
Issues with transition from paediatric to adult services	5
Receive (more) help from charities/support groups	4
Other answers	4
Child has open access/can refer back if necessary	2
Issues with transition from primary to secondary	2
All negative references to the questionnaire	2
Child does not fit criteria	2
It is expensive travelling to appointments	1
Child refuses help/service	1
Cost is put before child's/family's needs	1
Problems/issues with social services	1
Issues with vaccinations	1
Negative references to buildings/facilities	1
Child was diagnosed/treated abroad	1
Child is foster child/looked-after child	*
No longer attend hospital/ clinic as no progress being made	*
Had to/we changed Health professional or health service	*
Base (n)	*3,020*

Figure 82

COMMENTS THAT MAKE UP THE TOPIC OF POSITIVE FEEDBACK ABOUT EDUCATION SERVICES RECEIVED

	All giving positive feedback about education services
	%
Pleased or happy with the school	55
The school is supportive	30
The school is helpful	17
Child has improved or done well at this school	13
Receive excellent SEN support/good advice from SENCO	7
The School is good	6
Local Authority excellent/get help from them	2
Connexions have given help and support to my child	1
Child attends private/very good nursery with support	1
Hospital school/educational service beneficial to child	1
My child pleased with after school activities/holiday	1
Transition between schools went smoothly/had good support	1
Positive reference to S&L therapy /educational psychologist	*
Hours allocated for SEN are used correctly for my child	*
Happy with educational services received	*
Positive mention of Ofsted report/assessment/inspection	*
Library services excellent	*
Excellent support from Autism Outreach	*
Equipment has been provided by school/services	*
Base (n)	*4,550*

Figure 83

COMMENTS THAT MAKE UP THE TOPIC OF LACK OF EDUCATION SERVICES AVAILABLE

	All citing lack of education services available
	%
The child needs more help or support at the school	45
The child's needs were not met	17
There is not enough money for special needs	12
School does not have the right specialist skills	7
Lack of support or help from headteachers/ senior teachers	7
School says child doesn't need extra support/ won't give all	6
Child does not receive (enough) one to one support	4
Lack of support for special needs in post-16 education	4
Medical/medication needs are not met	3
No/insufficient after school clubs	3
No provision locally/had to travel to another borough	2
Child has IEP in place but reviews/action do not take place	2
Have had to pay for extra tuition/one to one provision	2
The school does not have enough time for the child	2
Child needs to attend special needs school	2
Lack of equipment for special needs	1
Recommendations made at annual reviews not being actioned	1
Childs statement/placement/assistant stopped without warning	1
Special dietary needs are not met in school	1
School makes promises and then does not deliver	1
Need schools that are between mainstream schools and special needs schools	*
The school needs new facilities for disabled children	*
Annual reviews/assessments do not take place/are irregular	*
No support/funding/testing - Dyslexia, ADHD, Aspergers, Attention span disorder	*
Shortage of staff (include all references)	*
The school & educational services require more resources	*
Base (n)	*3,262*

Figure 84

COMMENTS THAT MAKE UP THE TOPIC OF DIFFICULTIES ACCESSING EDUCATION SERVICES

	All citing difficulties or issues accessing education services
	%
Parent had to fight for help to be given	31
Difficulty with getting a statement of SEN	23
LEA obstructive/no help from LEA	17
SEN service very poor/no support from SENCO	15
Takes too long to be assessed	14
Not been able to get a statement of SEN	12
Difficulty getting/not enough special school places	6
Child's education suffered due to late assessment	6
Problems obtaining EMA funding/disability grants	1
Special transport needed to join activities/school trips	*
Problems finding a nursery place	*
Colleges are unhelpful to children are applying/attending with special needs	*
School not helpful/refused child an IEP	*
School discourages applying for funding/suitable placement	*
Base (n)	*2,222*

Figure 85

COMMENTS THAT MAKE UP THE TOPIC OF NEGATIVE FEEDBACK ABOUT EDUCATION SERVICES RECEIVED

	All giving negative feedback about education services
	%
Feel child has been let down by the school/ education system	29
Child is bullied or struggling socially	16
Moved to another school as previous school inadequate	16
Parent does not like the school/thinks it is not very good	13
The school is poor	8
Had to make formal complaint/go to tribunal	7
Child is unhappy at school	7
Delayed action/appointments/waiting lists have affected child	5
Connexions service poor/lack of help from them	4
School/LEA unhelpful with extra work/tutoring when child absent from school	3
Constant staff changes/ no continuity of teachers	3
Unhappy with OT, S&L therapist, educational psychologist	3
School more concerned with results/Ofsted than children’s needs	2
Treatment of child dependent on whether teacher likes them	2
Schools need to relook at curriculum/have regular training	1
Large amount of teaching by unqualified teaching assistants	1
Negative references to educational services	1
Child receives too much homework	*
Autism Outreach Service poor/ do not receive help from them	*
Poor discipline/behavioural policy within the school	*
Base (n)	*2,022*

Figure 86

COMMENTS THAT MAKE UP THE TOPIC OF POOR COMMUNICATION AND INFORMATION IN RELATION TO EDUCATION SERVICES RECEIVED

	All citing poor communication and information in education services
	%
Lack of communication from school to parents about the child	37
Need more information on services child is entitled to	25
Not interested in parent's views/do not listen to parents	24
Lack of communication within school about the child's needs	14
Education, health & social services do not co-operate	5
No feedback/follow up received on educational progress	2
Lack of information about college/university	2
Need more guidance/advice regarding career choices	1
Base (n)	*1,650*

Figure 87

COMMENTS THAT MAKE UP THE TOPIC OF LACK OF UNDERSTANDING OF THE CHILD'S CONDITION BY EDUCATION SERVICES

	All citing a lack of understanding of the child's condition
	%
Lack of knowledge or understanding at school about child's condition	99
Child needs more hours on their statement/SEN/special needs	1
Base (n)	*792*

Figure 88

COMMENTS THAT MAKE UP THE TOPIC OF OTHER COMMENTS ABOUT EDUCATION SERVICES RECEIVED

	All citing other issues about education services
	%
Have received lots of information about services	10
Poor/need support with transition to next school (general)	10
Child educated privately/has better education at private school	8
In process of applying/waiting for an assessment	8
Other answers	8
Child not stretched/pushed enough to reach full potential	7
Child has no special educational needs	7
Have had to pay for assessments privately/privately funded	5
Child off to/ at University/College	4
Child educated at home/better education at home	4
Help is focused on disruptive children	4
Child is/has been excluded on number of occasions	3
Problems/have issues with transport	3
Class sizes too big	3
Issues with transition -primary/secondary school	2
Regular training/updates for teachers of special needs	2
Not enough homework	2
School Action/Action Plus (all mentions)	1
Issues with transition -secondary school/university	1
Gifted & Talented children (all mentions)	1
Child needs more/being seen by/having/OT, S&L therapy	1
Need more help/support when moving to mainstream schools	1
Child attends mainstream school with special needs resources	1
Parent Partnership more knowledgeable/helpful than the school	1
All mentions of Behavioural problems	1
Should be specific schools for special needs	1
Child is not attending school (all mentions)	1
The child has been given extra hours and time for exams	1
Child is reluctant/refuses help/support that is available	1
No problems with transition -primary/secondary school	1
School closures/merging/being rebuilt caused disruption to child	1
Parent works in education so can access services	1
Need regular training/updates for teachers of special needs	1
Child has learning difficulties (non specific)	*
Child attends a residential/boarding school	*
No problems with transition -secondary school/university	*
Child has problems mixing with their peers	*
Child has mental health problems	*
The school property has maintenance/building problems	*
Child has/is involved in reviews	*
Base (n)	*2,571*

Figure 89

COMMENTS THAT MAKE UP THE TOPIC OF LACK OF CARE & FAMILY SUPPORT SERVICES AVAILABLE

	All citing lack of care & family support services available
	%
No help or support available	32
Feel in need of support with child's health problem	23
Support/help is needed for the whole family	15
Need more respite care	10
Not enough funding available	7
We have no allocated social worker	5
Services unable to recognise our needs	4
Have obtained services at personal expense	4
Shortage of staff	3
Support is/services are limited	3
Our social care services have been withdrawn/cut back	3
Not enough support available in our area	3
Insufficient support/do not get enough	3
Insufficient support for young adults	3
Services overstretched	2
Rely on/only manage with support from family/friends	2
No support/help from social worker	1
Respite care withdrawn/reduced	1
Need support during school holidays	1
Lack of provision of social inclusion opportunities	1
Lack of speech/language therapy	*
Lack of suitable provision of leisure activities	*
Base (n)	*2,095*

Figure 90

COMMENTS THAT MAKE UP THE TOPIC OF POOR COMMUNICATION AND INFORMATION IN RELATION TO CARE & FAMILY SUPPORT SERVICES RECEIVED

	All citing poor communication and information in care & family support services
	%
Don't know what help is available/entitled to	70
No feedback/follow-up received/no reviews	16
Not enough communication between everyone involved	8
Need to listen to parents/do not listen to parents	7
Need more information about 'out of school' clubs	2
More help/information required from Family Support	2
Social services hard to get in touch with	1
Support/services often withdrawn at short notice	*
Base (n)	*1,723*

Figure 91

COMMENTS THAT MAKE UP THE TOPIC OF POSITIVE FEEDBACK ABOUT CARE & FAMILY SUPPORT SERVICES RECEIVED

	All giving positive feedback about care & family support services
	%
Excellent/good/no complaints	29
Individuals have been excellent/good	28
Plenty of help and support available	27
Good support/help from school	18
Respite care excellent (all positive references)	8
Good support from social worker	2
Visits to social care professional had a positive effect	2
Dealing with the same people/good continuity of care	1
Child enjoys visits to see social care professional	1
Wide range of therapies available	*
Base (n)	*1,203*

Figure 92

COMMENTS THAT MAKE UP THE TOPIC OF DIFFICULTIES ACCESSING CARE & FAMILY SUPPORT SERVICES

	All citing difficulties or issues accessing care & family support services
	%
Have to find out about/organise services yourself	34
It takes a long time to get the assistance that we are entitled to	32
Had to fight for social care services	18
Turned down for respite care	6
If you appear/are able to cope alone, it can be difficult	4
Services difficult/impossible to access (no detail)	4
Refused/not entitled to DLA	3
Services are difficult to access because of distance or opening hours	3
Too many forms to complete	2
Too much red tape/bureaucratic process	2
Appealing for/still waiting to hear about respite care	2
In need of home adaptations/service is poor	2
Base (n)	*1,170*

Figure 93

COMMENTS THAT MAKE UP THE TOPIC OF NEGATIVE FEEDBACK ABOUT CARE & FAMILY SUPPORT SERVICES RECEIVED

	All giving negative feedback about care & family support services
	%
Feel let down by social care services	48
Have complained /made a complaint	15
Poor service received (no detail)	14
Don't always have the same social worker	10
Could complain/had cause to complain	10
Infrequent visits from social worker	7
Cannot trust social/support services	1
Base (n)	*501*

Figure 94

COMMENTS THAT MAKE UP THE TOPIC OF LACK OF UNDERSTANDING OF THE CHILD'S CONDITION BY CARE & FAMILY SUPPORT SERVICES

	All citing a lack of understanding of the child's condition
	%
Lack of understanding of specific needs/services not tailored	58
Lack of understanding of Aspergers/ASD/Autism	35
Lack of understanding of ADHD	8
Base (n)	*191*

Figure 95

COMMENTS THAT MAKE UP THE TOPIC OF OTHER COMMENTS ABOUT CARE & FAMILY SUPPORT SERVICES RECEIVED

	All citing other issues about care & family support services
	%
Never had need for social services/no dealings with them	22
Have to rely on/good support from charities/support groups	12
Need more support/help from school	9
Only support received by GP/hospital/medical services	8
We do not meet the criteria/threshold	8
Awaiting assessment/just going through the process	7
Hard to get/still waiting for direct payments	7
Other answers	6
Transition period difficult/concerned about transition	5
All negative references to questionnaire	3
We need help financially	3
Receive direct payments/direct payments working well	3
I am the foster carer	3
Service good now but had to reach crisis point before help given	2
Had to wait too long for counselling	2
Child refuses help/support available	2
Social services have been judgemental	2
Care we receive is good but would like more	1
Parenting courses would be beneficial	1
Transport services unsatisfactory	1
Appeals process takes a long time	*
Base (n)	*1,933*

Figure 96

COMMENTS THAT MAKE UP THE TOPIC OF NEEDING MORE INFORMATION ABOUT CHILD'S CONDITION (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing needing more information about child's condition
	%
Not sure what (additional) help/benefits are available	61
Need/would like more information re child's condition	23
Need more information on services child is entitled to	15
No information/lack of information (no detail)	11
Base (n)	*962*

Figure 97

COMMENTS THAT MAKE UP THE TOPIC OF LACK OF HELP AVAILABLE (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing a lack of help available
	%
No support provided for child (no specific service)	29
Support/help is needed for the whole family	22
Need more help/support (No detail)	16
Have been told we would receive help but nothing happens	9
More help/support required for 18+ people	7
Feel isolated/alone/unsupported	7
Child's situation has to get desperate before action taken	5
Little/no support for working parents	5
Lack of/no (local) services available (No detail)	3
If you appear/are able to cope alone it can be difficult to get support	2
Base (n)	*871*

Figure 98

COMMENTS THAT MAKE UP THE TOPIC OF RESOURCE ISSUES IN RELATION TO LOCAL SERVICES (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing resource issues in relation to local services
	%
Problems/issues with funding	87
Lack of equipment available for child	6
Not enough funding for equipment for child	6
Shortage of staff	4
Lack of professional/qualified staff	1
Base (n)	*430*

Figure 99

COMMENTS THAT MAKE UP THE TOPIC OF PROBLEMS WITH BUREAUCRACY/ ACCESSING SERVICES (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing problems with bureaucracy/ accessing services
	%
Lengthy process/all takes so long	90
Too much red tape/bureaucratic process	11
Base (n)	*302*

Figure 100

COMMENTS THAT MAKE UP THE TOPIC OF NEEDING MORE PROVISION OF LEISURE ACTIVITIES (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing needing more provision of leisure activities
	%
Need more things for children/teenagers to do	59
No/insufficient after/out of school clubs	42
Should have special play equipment for disabled children	3
Leisure facilities should be free/no charge to use them	3
Park (equipment) should be improved	1
Base (n)	*361*

Figure 101

COMMENTS THAT MAKE UP THE TOPIC OF POSITIVE REFERENCES ABOUT SERVICES IN GENERAL (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing positive references about services in general
	%
Plenty of help and support available	43
I'm happy on the whole/in general but...	35
Service/care is good now/has improved/was poor originally	14
Good support from Parent Partnership Office	5
Receive direct payments/direct payments working well	3
Excellent/have lots of opportunities for inclusion support services	1
Base (n)	*332*

Figure 102

COMMENTS THAT MAKE UP THE TOPIC OF ISSUES WITH APPOINTMENTS (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing issues with appointments
	%
Appointments take a long time to be arranged	80
Not contacted about a follow-up appointment	13
Prefer appointments out of school hours	5
Appointments often late	2
Not re-contacted about cancelled appointments	1
Base (n)	*241*

Figure 103

COMMENTS THAT MAKE UP THE TOPIC OF ISSUES WITH CHILD’S DIAGNOSIS (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing issues with child’s diagnosis
	%
Difficulty getting child referred for diagnosis	38
Child has not been officially diagnosed	30
Annoyed child's condition only discovered/acknowledged recently	21
Still don't know what caused the problem/not been investigated	17
Base (n)	*209*

Figure 104

COMMENTS THAT MAKE UP THE TOPIC OF LACK OF UNDERSTANDING OF THE CHILD'S CONDITION (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing a lack of understanding of the child's condition
	%
Child's condition is not taken seriously	50
Lack of understanding/provisions for Aspergers/ASD/Autism	43
Lack of understanding of ADHD	9
Base (n)	*225*

Figure 105

COMMENTS THAT MAKE UP THE TOPIC OF ISSUES WITH BENEFITS (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing issues with benefits
	%
Problems/issues with DLA	72
All negative references to not being able to claim benefits	13
Direct payments not working well (all negative references)	7
Problems with getting a Blue Badge	7
Problems/issues with EMA	3
Base (n)	*146*

Figure 106

COMMENTS THAT MAKE UP THE TOPIC OF ISSUES WITH TRAVEL/TRANSPORT (OTHER COMMENTS ABOUT OTHER SERVICES)

	All citing issues with travel/ transport
	%
Have to travel for services not available locally	61
Issues with transport	36
It is expensive travelling to appointments	8
Base (n)	*141*

Figure 107

COMMENTS THAT MAKE UP THE TOPIC OF OTHER COMMENTS ABOUT OTHER LOCAL SERVICES

	All citing other issues about other local services
	%
All references to child’s health condition	18
Receive (more) help from charities/support groups	12
All negative references to the questionnaire	11
Not enough communication between everyone involved	9
Other answers	9
Action/non-action has affected child badly	8
Child has minor/mild health problems	7
All references to child’s health care services regime	5
Child is improving/doing well	5
Good/poor care depends on parents (knowledge/work)	4
Postcode lottery/services/care not available in all regions	4
Excellent (holiday) activities now available	4
Issues with transition from paediatric to adult services	4
Erratic services/care some good, some poor	3
Could complain/have/had cause to complain	2
On-going situation/no further forward	2
No longer requires support/care/services	2
Parents health affected by worry of children	2
Parents/carers not always included	2
No communication between services	2
Service/care has stopped/child has been signed off	1
Should have a central allocated professional to contact	1
Child does not receive (enough) one to one support	1
Service/care does not continue for long enough	1
Do not receive help from charities/support groups	1
Service/care is poor	1
I am the foster carer	1
‘Every Child Matters’ does not seem to apply	*
Little/no opportunities for inclusion with other children	*
Would be helpful to have a Parents Support Group	*
Child has open access/can refer back if necessary	*
No problems with transport/lots of help with transport	*
No longer attends hospital/clinic as no progress being made	*
Have applied for a friend/buddy for child	*
Base (n)	*2,577*

APPENDIX 2 – TECHNICAL ANNEX

Survey method

In 2009-10, to identify extra parents eligible to complete the indicator survey, the screening survey was sent to 712,048 households of school aged children in England. These households were identified from the National Pupil Database (NPD)[18] which holds details of all school-aged children and includes details of whether they have a special educational need (these households were over-sampled compared with other households).

As a result of the screening survey, 36,801 families with disabled children aged 0-19 were identified, according to the DDA definition. These families were further contacted by post with a more detailed questionnaire asking them about their experiences in the last twelve months of the services they received. Where families had more than one disabled child separate questionnaires were sent. As a result 44,106 questionnaires were sent.

In addition to this new screening exercise, where a family had completed the 2008-09 main stage survey for their disabled children, they were sent a copy of the 2009-10 questionnaire to fill in asking about their experiences of local services in the previous twelve months. A further 12,226 questionnaires were sent.

In total, out of the 56,332 questionnaires sent out, 31,466 questionnaires were returned representing a response rate of 56%. This was an increase on the response rate achieved in the 2008-09 main stage survey of 54%.

Although the primary method of completion was by post, parents had the option to complete the surveys online, although take-up of this was comparatively low (6% of

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[18] The eligibility criterion for the survey was defined as disabled children aged 0-19. However the NPD excludes pre-school aged children (under 5) and those who have left school (from age 16). The NPD also does not cover children in independent schools. However, the decision to use the NPD was felt to be the most pragmatic solution given restrictions in access to other data sources at the time of the survey. Siblings of NPD-listed children who fall within the excluded age groups will have had a chance of selection though because information on all children in the household was requested on the screener questionnaire. Therefore although this sampling method had the limitation of not representing the full range of children aged 0-19, it could be addressed through weighting.

main questionnaires were completed online). The surveys were also offered to parents in various languages in order to reach a wide range of parents with disabled children. Reminder letters were sent at various intervals to maximise response at each stage.

How the indicator is measured

The identified sample of parents was sent a questionnaire to assess their general experience of services for disabled children (aged 0-19 years old) and the extent to which services for disabled children were delivered across the health, care & family support and education service sectors according to the five elements of the Aiming High for Disabled Children Core Offer. The elements of the Core Offer are: good provision of *Information*; *Transparency* in how the available levels of support are determined; integrated *Assessment*; *Participation* of disabled children and their families in local services; and accessible *Feedback* and complaints procedures.

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 broad service areas of health, education and care & family support. Thus there are five sub-indicators covering Information, Transparency, Assessment, Participation and Feedback respectively for health; education; and care & family support areas.

Each of the fifteen sub-indicators was calculated based on responses to the relevant section in the questionnaire. Responses to each section of the questionnaire were used to identify whether respondents had received an 'acceptable level' of experience of the relevant services in the past twelve months.

Respondents that had not had experience of relevant services in the past twelve months were excluded from the calculation of the sub-indicator.

Differences between 2008-09 and 2009-10 questionnaires: Care & family support

There were some differences between the 2008-09 and 2009-10 questionnaires which should be borne in mind when comparing indicator scores. These changes occurred within the care and family support section. There were two changes to the section: one change related to question wording and the other to question routing. The first of these potentially affected the calculation of all care and family support sub-indictors at Year 2. The second affected specifically the care and family support Information sub-indicator at Year 2. Further details are provided below.

Changes to question wording

In 2008-09, the final section of the questionnaire was titled “Social Care Services” and the wording used throughout this section when asking questions referring to information, assessment, feedback and so on was “social care and family support”. However, upon analysis of 2008-09 data, it was thought that the number of users taken through this section had been undercounted based on comparisons with official statistics of service users. It was thought that the term ‘social care and family support’ may have been misleading for some respondents, who may have interpreted it more narrowly than was intended. In particular, it was thought that people may have thought the section related only to ‘social work’ rather than the broader range of services including, for example, childcare and play provision.

In 2009-10, therefore, it was decided to rename this section “Care and family support services” and all references to “Social care and family support” were replaced with this term i.e. removing the word “social”. It was hoped that this would encourage more service users to answer questions relevant to them.

For the purposes of the indicator, and to be consistent with 2008-09, all respondents answering the appropriate codes at relevant questions were included in the calculation of the sub-indicators.

Despite the changes described above the actual change in the care & family support sub-indicators for assessment, participation, feedback and transparency have been small. The main change between 2008-09 and 2009-10 has been within the Information sub-indicator for this core area and this is discussed further below.

Changes to question routing

In addition to the above change, a key change was also made to the routing in the care & family support section. In 2008-09, the key question set which contributed to the care & family support Information sub-indicator was asked of all who did not say

“No care & family support services used”. In 2009-10, this filter requirement was removed and all respondents were asked the “information” questions. The reason for this was to ensure that all potential service users were included in the sub-indicator, rather than omitting service users for whom information might have been useful even if they did not go on to receive a service.

This routing change affected the base upon which the care and family support sub-indicator was calculated. In 2008-09 only service users were included in the calculation while in 2009-10 all respondents were included. Analysis shows that the non-service users routed through this question were more likely to select ‘not-applicable’ to the four information questions.

A decision was made at the start of the survey series to include “not applicable” as a positive contribution to the sub-indicator (chapter 4 has more detail on how respective sub-indicators were calculated). This was because, by default, they had not had a problem with the information received. This means that the change in the questionnaire routing discussed above resulted in more respondents being attributed a positive rating for the care and family support information sub-indicator.

These changes to routing and wording will have had some influence on the care and family support sub-indicator values, and the change in score to the care and family support information sub-indicator in particular should be viewed in light of this. However, it is not possible to quantify the combined impact of these changes.

Ref: DCSF-RR216

ISBN: 978-1-84775-720-3

www.dcsf.gov.uk/research

Published by the Department for
Children, Schools and Families

Registered Charity no. 313392

department for
children, schools and families