

Services for Disabled Children

Pilot Testing of the Screening and Main Questionnaire

Meera Balarajan, Hayley Cripps and Margaret Blake
National Centre for Social Research



**Research Report No
DCSF-RR100**

*Services for Disabled Children:
Pilot Testing of the Screening and
Main Questionnaire*

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Contents

- ACKNOWLEDGEMENTS..... vii**
- AUTHORS' CREDITS..... viii**
- Executive Summary 1**
 - Testing the questionnaire 1
 - Screening Questionnaire 2
 - Organisation of the main questionnaire 3
 - Routing problems 4
 - Sensitivity 5
 - Summary Table 6
- 1 BACKGROUND 11**
 - 1.1 The Three Phase Research Programme 11
 - 1.2 Report Structure 12
- 2 METHODS 13**
 - 2.1 Pilot design 13
 - 2.2 Sample description 13
 - 2.3 Pilot Composition 15
- 3 SCREENING QUESTIONNAIRE 16**
 - 3.1 Question 1 16
 - 3.1.1 Findings 16
 - 3.1.2 Recommendations 16
 - 3.2 Question 2 17
 - 3.2.1 Findings 17
 - 3.2.2 Recommendations 17
 - 3.3 Question 3 17
 - 3.3.1 Findings 17
 - 3.3.2 Recommendations 17
 - 3.4 Question 4 18
 - 3.4.1 Findings 18
 - 3.4.2 Recommendations 19
 - 3.5 Question 5 19
 - 3.5.1 Findings 20
 - 3.5.2 Recommendations 20
 - 3.6 Question 6 20
 - 3.6.1 Findings 20
 - 3.6.2 Recommendations 21
 - 3.7 Question 7 21
 - 3.7.1 Findings 21
 - 3.7.2 Recommendation 22
 - 3.8 Question 8 22
 - 3.8.1 Findings 22
 - 3.8.2 Recommendations 22

3.9 Question 9	22
3.9.1 Findings	23
3.9.2 Recommendations	23
3.10 Question 10	23
3.10.1 Findings	23
3.10.2 Recommendation	23
4 MAIN QUESTIONNAIRE ABOUT YOUR CHILD	24
4.1 Question 1	24
4.1.1 Findings	24
4.1.2 Recommendation	24
4.2 Question 2	25
4.2.1 Findings	25
4.2.2 Recommendation	25
4.3 Question 3	25
4.3.1 Findings	25
4.3.2 Recommendation	25
4.4 Question 4	25
4.4.1 Findings	26
4.4.2 Recommendation	26
4.5 Question 5.....	26
4.5.1 Findings	26
4.5.2 Recommendation	27
5. MAIN QUESTIONNAIRE HEALTH SERVICES	28
5.1 Question 6	28
5.1.1 Findings	28
5.1.2 Recommendations	29
5.2 Question 7 and 8	29
5.2.1 Findings	30
5.2.2 Recommendations	31
5.3 Question 9	32
5.3.1 Findings	32
5.3.2 Recommendation	32
5.4 Question 10	33
5.4.1 Findings	33
5.4.2 Recommendations	33
5.5 Question 11	34
5.5.1 Findings	34
5.5.2 Recommendations	34
5.6 Question 12	35
5.6.1 Findings	35
5.6.2 Recommendation	35

5.7 Question 13	36
5.7.1 Findings	36
5.7.2 Recommendations	37
5.8 Question 14	37
5.8.1 Findings	38
5.8.2 Recommendations	38
5.9 Question 15	38
5.9.1 Findings	38
5.9.2 Recommendations	38
5.10 Question 16	39
5.10.1 Findings	39
5.10.2 Recommendations	39
5.11 Question 17	39
5.11.1 Findings	39
5.11.2 Recommendations	40
5.12 Question 18	40
5.12.1 Findings	40
5.12.2 Recommendations	40
5.13 Question 19	40
5.13.1 Findings	41
5.13.2 Recommendations	41
5.14 Question 20	41
5.14.1 Findings	41
5.14.2 Recommendations	41
5.15 Question 21	42
5.15.1 Findings	42
5.15.2 Recommendations	42
5.16 Question 22	42
5.16.1 Findings	42
5.16.2 Recommendations	42
6. MAIN QUESTIONNAIRE EDUCATION SERVICES.....	43
6.1 Question 23	43
6.1.1 Findings	43
6.1.2 Recommendations	43
6.2 Question 24	44
6.2.1 Findings	44
6.2.2 Recommendations	45
6.3 Question 25	46
6.3.1 Findings	46
6.3.2 Recommendations	46
6.4 Question 26	47
6.4.1 Findings	47
6.4.2 Recommendation	48

6.5	Question 27	48
	6.5.1 Findings	48
	6.5.2 Recommendations	49
6.6	Question 28	49
	6.6.1 Findings	49
	6.6.2 Recommendations	50
6.7	Question 29.....	50
	6.7.1 Findings	50
	6.7.2 Recommendations	50
6.8	Question 30	50
	6.8.1 Findings	50
	6.8. 2 Recommendations	50
6.9	Question 31.....	51
	6.9.1 Findings	51
	6.9.2 Recommendations	51
6.10	Question 32	52
	6.10.1 Findings	52
	6.10.2 Recommendations	52
6.11	Question 33	52
	6.11.1 Findings	53
	6.11.2 Recommendations	53
6.12	Question 34	54
	6.12.1 Findings	54
	6.12.2 Recommendations	54
6.13.	Question 35	54
	6.13.1 Findings	54
	6.13.2 Recommendations	54
6.14	Question 36	55
	6.14.1 Findings	55
	6.14.2 Recommendations	55
6.15	Question 37	55
	6.15.1 Findings	55
	6.15.2 Recommendations	56
6.16	Question 38	56
	6.16.1 Findings	56
	6.16.2 Recommendations	56
6.17	Question 39	57
	6.17.1 Findings	57
	6.17.2 Recommendations	57
6.18	Question 40	57
	6.18.1 Findings	57
	6.18.2 Recommendations	57

6.19 Question 41	58
6.19.1 Findings	58
6.19.2 Recommendations	58
6.20 Question 42	58
6.20.1 Findings	58
6.20.2 Recommendations	58
7 MAIN QUESTIONNAIRE SOCIAL CARE SERVICES	59
7.1 Question 43.....	59
7.1.1 Findings	59
7.1.2 Recommendations	60
7.2 Question 44	60
7.2.1 Findings	60
7.2.2 Recommendations	60
7.3 Question 45	61
7.3.1 Findings	61
7.3.2 Recommendation	61
7.4 Question 46	61
7.4.1 Findings	62
7.4.2 Recommendations	62
7.5 Question 47	62
7.5.1 Findings	63
7.5.2 Recommendations	63
7.6 Question 48	63
7.6.1 Findings	63
7.6.2 Recommendations	64
7.7 Question 49	64
7.7.1 Findings	64
7.7.2 Recommendation	64
7.8 Question 50	65
7.8.1 Findings	65
7.8.2 Recommendation	66
7.9 Question 51	66
7.9.1 Findings	66
7.9.2 Recommendations	66
7.10 Question 52	67
7.10.1 Findings	67
7.10.2 Recommendations	67
7.11 Question 53	67
7.11.1 Findings	67
7.11.2 Recommendations	68
7.12 Question 54	68
7.12.1 Findings	68
7.12.2 Recommendations	68

7.13 Question 55	68
7.13.1 Findings	69
7.13.2 Recommendations	69
7.14 Question 56	69
7.14.1 Findings	69
7.14.2 Recommendations	69
7.15 Question 57	70
7.15.1 Findings	70
7.15.2 Recommendations	70
7.16 Question 58	70
7.16.1 Findings	71
7.16.2 Recommendations	71
7.17 Question 59	71
7.17.1 Findings	71
7.17.2 Recommendations	71
7.18 Question 60	71
7.18.1 Findings	71
7.18.2 Recommendation	72
8. SUMMARY	73
8.1 The Implications of routing problems.....	73
8.2 Recommendation to address the routing problem.....	73
8.3 The implication of sensitivity.....	74
8.4 Recommendation to address sensitivity	74
BIBLIOGRAPHY.....	79
Appendix 1 Screening Questionnaire	80
Appendix 2 Main Questionnaire.....	82

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AUTHORS' CREDITS

Meera Balarajan joined the QDT Hub from academia in July 2008. She has an MPhil and PhD in Land Economy (Committee of Development Studies) from the University of Cambridge and an MA from the University of Oxford. Since joining the Hub she has worked on a range of different questionnaire design and testing projects such as the ONS Short-term migrant question development project for ONS, which involved recruiting respondents, in-depth interviews and focus groups. More recently she has been involved in questionnaire development and testing of the DCSF questions on Services for Disabled Children.

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Margaret Blake jointly heads up the QDT Hub. She has worked at NatCen since 1998, working on a wide range of surveys before moving to the QDT Hub to specialise in questionnaire design and testing. Since Margaret joined the QDT Hub she has worked on a range of different questionnaire design and testing projects including the ONS Disability question testing for DWP, the testing of the FRS material deprivation questions for older people for DWP.

Executive Summary

Background

This report outlines the results of one stage of a larger project being carried out by NatCen on behalf of the Department for Children, Schools and Families (DCSF) and the Department of Health (DH). There were three phases to this project of which the Questionnaire and Development and Testing (QDT) Hub at NatCen were involved with the second (cognitive testing using interviews) and third (pilot testing by post) phases. This report presents the findings from the pilot testing only.

The overall aim of the project is to develop a questionnaire and survey design to measure parents' experience of services for their disabled children. The survey data would feed into a performance indicator to measure the core offer (information, transparency, assessment, participation and feedback) as well as the general experience of families with disabled children.

As a result of the first phase of the project NatCen and collaborators from the Universities of Warwick and Bristol reported on a suggested survey design, screening and main questionnaire content and way of calculating the indicator. The second phase of the project involved carrying out cognitive testing of the proposed questionnaire to investigate whether respondents understood the questions as intended and whether they could answer the questions. The testing was also, to some extent, able to examine issues of acceptability and sensitivity. The third phase, reported here, pilot tested the questionnaire as a postal self completion questionnaire. This round of testing was important, as it tested the questionnaire in the form in which it will be administered in the main survey. The key aspects examined were routing, layout and missing responses.

Testing the questionnaire

The pilot testing involved testing two questionnaires:

1. Screening questionnaire designed to identify parents with one or more disabled children; and,
2. Main questionnaire to explore respondents' experience of health, education and social care service use for one of their disabled children.

Pilot testing was carried out during December 2008. One hundred respondents, who had taken part in the 2008 Childcare and After School Activities Survey and had agreed to be contacted for further research, were sent the two questionnaires in the post. In addition respondents were sent a covering letter explaining the study and asking them to fill in both questionnaires. The sample was designed to reflect the range and diversity of this population and so included parents with children of all ages, with a variety of disability types, and who had used different types of services.

Owing to the limited time available it was not possible to replicate exactly how the survey would be actually administered. It is planned that when the survey is actually conducted the screening questionnaire would be administered first. Only respondents who are identified as having disabled child from Q4 or answered yes at Q6 in the screening questionnaire would be sent the main questionnaire. In order to test the two research instruments in the limited time frame, in consultation with DCSF, it was decided that it would be most effective to send both questionnaires together. To reflect this, clear directions were provided on the main questionnaire to assist the respondent in identifying which child to focus on when answering this questionnaire.

All the questionnaires received were keyed in to a data file from which the data was transferred to SPSS for analysis.

Response

Of the 100 questionnaires we posted out, we received 28 screening questionnaires and 25 main questionnaires back. Three respondents selected themselves out from answering the main questionnaire. After the end date for keying in data for analysis, 4 screening and main questionnaires were received. They were also examined for this report but not included in the SPSS analysis.

Although response is not important for pilot testing since the aim is not to achieve a representative sample, the poor response to the postal pilot is relevant. Despite allowing three weeks in total, sending a reminder postcard after 10 days and telephoning those who had not replied after a further six days, only 28 people of the 100 responded in time for their questionnaires to be analysed. For the main stage, considerable effort will be needed to ensure that the achieved sample is representative. Cartwright's research (1986) showed that 'new mothers' are responsive to postal surveys but this research suggests parents of children in a wider age range may be less responsive. This could be because of the time pressures on this particular group (parents of disabled children). The low response to the pilot could be an indication of the sensitive subject matter deterring respondents, although we have no information about reasons for non-participation and this was not identified as a problem in the cognitive testing phase. The cognitive interviews found that the survey and the subject matter were considered sufficiently important by respondents to overcome issues of sensitivity but this may be different in a postal survey.

In the next section we highlight the main findings and problems identified from testing and we outline the key recommendations for the screening questionnaire and then the main questionnaire. Detailed wording and format changes are not included here; these can be found in the relevant section of the main body of the report. Nor do we report on questions which were found to be not problematic. A summary table of the main findings for each question is presented on page seven.

Screening Questionnaire

The screening questionnaire asks up to 6 questions about each of the respondent's children. The main problem identified with screening questionnaire was related to routing since not all questions needed to be answered for every child.

The key question in the screening questionnaire is Question 4 which will be used to identify eligible respondents for the main stage questionnaire. This question asks respondents to identify their child's disability or long standing illness. Generally, the question, worked as respondents identified their child's disability. However, there were difficulties with routing as some respondents went on to answer questions which were not relevant for them. The implication of this problem is that respondents are providing extra information. This did not reduce the effectiveness of this question as a screening question. We recommended retaining the question but making sure the *routing instructions are clear*.

Question 7 was the first of four questions in a section entitled 'Everyone Please Answer'. Question 7 sought the respondent's permission to participate in further research. To reach Q7, respondents could be routed from Q4, Q5 and Q6. Findings from the pilot testing revealed that respondents on the whole routed correctly to this question. Those who did not route correctly at this question, generally had problems with routing or just misrouted from Q6 moving directly to the main questionnaire and therefore missed Q7. As the main problem with Q7 was routing from other questions, we recommended retaining the question. We do recommend making the *routing instructions clear* from Q4, Q5 and Q6.

There were two key findings from testing Q9, which asked the respondent to check their address on the envelope and to provide their correct address if there was a mistake. Firstly the routing instructions seem to have worked overall. Secondly, although some respondents accurately provided their change of addresses others inaccurately provided their address. We have suggested amending the question to clarify who should answer this question.

We now move to look at the main findings and recommendations for the main questionnaire. We will concentrate on looking at the key issues and discuss questions which were found to be problematic here. We will not provide a question by question summary therefore.

Organisation of the main questionnaire

The main questionnaire was designed to examine parent's experience of services in three areas:

- Health care;
- Education; and,
- Social Care.

There are 60 questions in total in the questionnaire. Five questions in the background section, entitled 'About your child', 17 questions in the health care section, 20 questions in the education section and 18 questions in the social care section. As all the respondents completed the questionnaire it would appear that the length of the questionnaire did not result in respondent fatigue and the distinction and organisation between these service areas was appropriate.

However, a key finding from the pilot testing identified that it was difficult for respondents who had two or more extremely different experiences *within* the health or education service to generalise their experiences. We would recommend amending Q7 and Q8 (health) and Q24 and Q25 (education) to ask respondents '*to please tick the box which best describes your experience. If your experience has been varied with different services, please tell us about your overall experience*'. There was no indication from the pilot study that the equivalent questions in the social care section had similar problems.

It was revealed in the pilot that the instruction 'please tick one option per line' was not always followed by respondents. Where this instruction appeared respondents exhibited two answer strategies: they either followed it correctly or tended to leave the statement with a negative answer blank i.e. only ticked a line if they wanted to give an affirmative response. We recommended retaining the wording of the question but just highlight the instructions in bold. This recommendation is supported by the research by Gower and Dibbs (1989) who identified that respondents read what they think is necessary and they choose to read the boldface first and then decide to read the rest of the question in self administered questionnaires.

A consistent problem identified in the pilot with the screening and the main stage questionnaire was routing. We examine this in detail in the next section followed by a discussion of sensitivity of a self administered questionnaire.

Routing problems

This focused testing revealed the main issues in both questionnaires were related to **routing** problems. Although this was the main problem it was not found to be a consistent problem at all questions which had routing instructions. Nor did the same respondent have a consistent problem with routing generally. Rather most respondents had occasional problems with routing. The implication of misrouting in most cases in the pilot resulted in **respondents answering questions which were not applicable**. Only six of the 28 respondents routed through both the screening and the main questionnaire with no errors.

We would recommend that to assist respondents in accurately navigating through the questionnaire, **routing needs to be consistently clear**. To help address this problem we would also suggest an example is provided on the front page of the main questionnaire so respondents have an example to read before they commence filling in the questionnaire and can refer too it later. This will help comprehension and motivation in filling in the questionnaire both of which self administered questionnaires need to carefully consider (Jenkins and Dillman 1997).

The two main reasons to be concerned about routing problems are that:

- questions can be skipped in error leading to missing data
- questions can be answered in error, leading to respondent fatigue and possible satisficing¹ later in the questionnaire - this is the main concern for this questionnaire.

Whichever strategy is adopted the implications are reduction in data validity and reliability. The navigation guides if clearly presented i.e. in the same position as it is now and in bold and possibly in capital letters will all draw the respondents' eyes and follow their natural reading pattern, assisting them in routing correctly, as shown in the literature (Jenkins and Dillman 1997).

For analysis purposes it will be possible to ignore data collected by respondents who have misrouted, by setting to 'missing' any questions which should not have been answered, based on their previous answers. Although this overcomes this problem the key advice would be to make the navigation guides as clear as possible as suggested in the previous paragraph to minimise this respondent error.

¹ Satisficing is a strategy that respondents adopt to try to reduce the cognitive demands of answering a question accurately by providing what they deduce are satisfactory answers.

Sensitivity


As the questionnaire explores issues which can be viewed as sensitive by some respondents it is important the questionnaire is supported with a leaflet providing support with contact numbers for relevant organisations. It was particularly some questions in the health and education sections which were considered sensitive by respondents.

In cases where respondents found the questions sensitive this was related to having to think of services overall when they had received good and bad experiences of services. Bad experience of services made it difficult for those who had also had some good experiences to generalise from their experience in order to answer the questions. We recommend an explanation is provided on the front page to point out that some of the questions refer to the **overall experience** in the last 12 months. To support this statement we suggest adding a sentence such as: "If your experience has been varied please try and answer these questions the best you can by thinking about your overall experience".

The findings from the pilot study indicate that both the screening and the main stage questionnaire on the whole worked well. In addition the testing revealed the questions which will feed into the Disabled Children's Services performance indicator should work in a postal administered survey. However, the challenge highlighted will be to get a good response to the survey administered survey.

Summary Table

Below we present a summary table of the main findings for each question.

x= problem identified ✓= no problem identified problem with question  = Problem identified with question

Question Number	The question is not problematic overall	No Problem with question layout	No Problems with Item non-response	No missing response categories	No problems with routing to next question	No other problems indicated	Recommendation
Screening questionnaire							
SCQ1	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
SCQ2	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
SCQ3	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
SCQ4	✓	x	✓	✓	x	✓	Make routing instructions clearer - think about layout
SCQ5	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
SCQ6	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
SCQ7	✓	✓	✓	✓	x	✓	Make routing instructions clearer
SCQ8	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
SCQ9	✓	✓	✓	✓	✓	x	Amend question Add an additional answer category.
SCQ10	✓	✓	✓	✓	✓	✓	Retain Question No changes needed

Question Number	The question is not problematic overall	No Problem with question layout	No Problems with Item non-response	No missing response categories	No problems with routing to next question	No other problems indicated	Recommendation
Main questionnaire							
Q1	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q2	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q3	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q4	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q5	✓	✓	✓	✗	✓	✓	Retain Question Amend answer categories
Q6	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q7	✓	✓	✓	✓	✓	✗	Add answer category
Q8	✓	✓	✓	✓	✓	✗	Add answer category
Q9	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q10	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q11	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q12	✓	✓	✓	✓	✗	✓	Retain Question No changes needed
Q13	✓	✓	✓	✓	✓	✗	sensitivity
Q14	✓	✓	✓	✓	✓	✓	Retain Question No changes needed

Question Number	The question is not problematic overall	No Problem with question layout	No Problems with Item non-response	No missing response categories	No problems with routing to next question	No other problems indicated	Recommendation
Q15	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q16	✓	✓	✓	✓	✗	✓	Make routing instructions clearer
Q17	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q18	✓	✓	✓	✓	✗	✓	Make routing instructions clearer
Q19	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q20	✓	✗	✓	✓	✓	✓	Possible layout changes. Retain question.
Q21	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q22	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q22	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q23	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q24	✓	✓	✓	✗	✓	✓	Retain Question Amend answer category
Q25	✓	✓	✓	✗	✓	✓	Retain Question Amend answer category
Q26	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q27	✓	✓	✓	✓	✗	✓	Highlight key words in question
Q28	✓	✓	✓	✓	✓	✓	Retain Question No changes needed

Question Number	The question is not problematic overall	No Problem with question layout	No Problems with Item non-response	No missing response categories	No problems with routing to next question	No other problems indicated	Recommendation
Q29	✓	✓	✓	✓	✗	✓	Make routing instructions clearer
Q30	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q31	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q32	✓	✓	✓	✓	✗	✓	Make routing instructions clearer
Q33	✓	✓	✓	✓	✗	✓	Highlight key words in question
Q34	✓	✓	✓	✗	✓	✓	Add answer category
Q35	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q36	✓	✓	✓	✓	✗	✓	Make routing instructions clearer
Q37	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q38	✓	✓	✓	✓	✗	✓	Make routing instructions clearer
Q39	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q40	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q41	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q42	✓	✓	✗	✓	✓	✓	Retain Question No changes needed
Q43	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q44	✓	✓	✓	✓	✓	✓	Retain Question No changes needed

Question Number	The question is not problematic overall	No Problem with question layout	No Problems with Item non-response	No missing response categories	No problems with routing to next question	No other problems indicated	Recommendation
Q45	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q46	✓	✓	✗	✓	✓	✓	Retain Question No changes needed
Q47	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q48	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q49	✓	✓	✗	✓	✗	✓	Retain Question Make routing clearer
Q50	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q51	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q52	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q53	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q54	✓	✓	✗	✓	✓	✓	Retain Question No changes needed
Q55	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q56	✓	✓	✗	✓	✓	✓	Retain Question No changes needed
Q57	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q58	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q59	✓	✓	✓	✓	✓	✓	Retain Question No changes needed
Q60	✓	✓	✓	✓	✓	✓	Retain Question No changes needed

1 BACKGROUND

There is a need for robust data to measure parent's experience of accessing services for their disabled child. This report outlines the results of one stage of a larger project being carried out by NatCen on behalf of the Department for Children, Schools and Families (DCSF) and the Department of Health (DH). The overall aim of the project is to develop a self completion questionnaire and survey design to measure parents' experience of services for their disabled children. The survey data will feed into a performance indicator to measure the core offer (information, transparency, assessment, participation and feedback) as well as the general experience of families with disabled children. The survey data will collect data on parents' experiences in three service areas, which are,

- health care services,
- education services, and
- social care services.

As the information collected in the survey will feed into the Disabled Children's Services performance indicator, it is important that the questions are suitable for administration in a self-completion questionnaire and are likely to produce valid and reliable data.

1.1 The Three Phase Research Programme

The DCSF commissioned NatCen to carry out a 3 phase research project to develop a questionnaire and sample design to collect data on parental experience of services for disabled children.

Phase 1: The first stage of the project established a proposed sample design for the survey and a proposed questionnaire for asking parents about experience of services. The sample design suggested screening parents (using a questionnaire) to identify those who have a child with a long-standing illness, disability or health problem, and are thus eligible to participate in the main questionnaire asking about services.

Phase 2: The Questionnaire Development and Testing (QDT) Hub at NatCen worked on the second phase of the research which involved testing both the screening and main questionnaires using cognitive testing. In phase 2 cognitive interviews were conducted with parents with a disabled child and parents without a disabled child. This stage focussed the testing on the four distinct cognitive processes that must be completed to answer a question, namely comprehension, retrieval of the necessary information, judgement of how to answer the question and responding to the question (Tourangeau 1984) as well as sensitivity.

Phase 3: The QDT Hub carried out a postal pilot to test both the screening and main questionnaires with parents with a disabled child. The purpose of this stage was to test the questionnaire specifically in the mode in which it would be applied in the real survey, which is as a self-completion postal questionnaire. In the cognitive testing the interviewers were available to help respondents route through the questionnaire and the interviewing process ensured that questions could not be missed. This is an important difference between self-administered questionnaires and interview questionnaires (Jenkins and Dillman 1997). In addition respondents rely on the clear visual communication of the questionnaire and do not have the support of oral communication with interviewers (ibid).

This report presents the findings from just the **third phase** of the research programme i.e. the pilot testing of both the screening questionnaire and the main questionnaire (findings from phase 2 can be found in separate reports). This report outlines the problems identified with questions in both the screening and the main questionnaire. The purpose of the postal pilot was to identify problems with

- routing,
- layout of questions,
- item non-response, and
- questions with missing response categories

This report focuses on these issues. Piloting can detect overt problems that disrupt the response process but they do not necessarily provide evidence of causes of difficulties, provide evidence of hidden problems or explore the four cognitive question-answer processes. Where overt problems were identified in the pilot they are mentioned here, the other aspects were already investigated and reported in detail in phase two of this research project and are not covered in this report.

Below we discuss the report structure followed by a discussion of the methodology.

1.2 Report Structure

Chapter one (this chapter) provides an overview of the background of this research and the aims of this study.

Chapter two gives a brief overview of methodology used for the pilot testing, including a description of the sample achieved.

Chapters three to seven present the findings from the pilot testing of the questionnaires:

- Chapter Three: screening questionnaire
- Chapter Four: general section of main questionnaire
- Chapter Five: health services section of main questionnaire
- Chapter Six: education services section of main questionnaire
- Chapter Seven: social care services section of main questionnaire

Finally, Chapter Eight provides a summary of the findings for both questionnaires.

2 METHODS

2.1 Pilot design

The postal pilot was designed to test how the screening and the main questionnaire would work when administered by post. A principle concern for phase 3 of the research project was to examine how well will the questionnaires work in a postal mode.

Due to the limited time available it was not possible to replicate identically how the survey would be actually administered. It is planned that when the survey is actually conducted the screening questionnaire would be administered first. Only respondents who are identified as having disabled child from Q4 in the screening questionnaire would be sent the main questionnaire. In order to test the two research instruments in the limited time frame, in consultation with DCSF, we decided to send both questionnaires together. To help the respondent identify which child to focus on when answering the main questionnaire, clear instructions were provided on the first page of the main questionnaire. The instructions told the respondents to answer the main questionnaire for *one child* with a long standing illness, disability or health condition. We provided the instruction to respondents that this should be the child for whom they ticked at least one of the difficulties at Q4 or for whom they had ticked yes at Q6 on the screening questionnaire. If they had more than one child who fulfilled this criterion we asked them to answer the questionnaire for the child with the first name which began with a letter closest to A in the alphabet.

In addition a covering letter was sent to respondents which also included the contact details of researchers at NatCen who could be contacted for assistance. A pre-paid envelope was also enclosed for the respondents to post the questionnaires back to the organisation. A reminder postcard and phone calls were used to encourage participation in this study. The respondents were asked to send the completed questionnaires to NatCen where the data were keyed into a data file. The data was transferred from the data file to an SPSS file for analysis in SPSS. Both questionnaires were analysed to see how the layout, answer categories and routing for questions worked.

100 prospective respondents were selected and were sent both the screening questionnaire and the main questionnaire together. We received 28 screening questionnaires and 25 main questionnaires back. Three respondents selected themselves out from answering the main questionnaire. After the end date for keying in data for analysis, 4 screening and main questionnaires were received. They were also examined for this report but not included in the SPSS analysis.

Although response is not important for pilot testing, since the aim is not to achieve a representative sample, the poor response to the postal pilot is relevant. Despite allowing, three weeks sending a reminder postcard after 10 days and telephoning those who had not replied after a further six days only 32 people of the 100 responded. For the main stage considerable effort will be needed to ensure that the achieved sample is representative.

Below we discuss the sample profile in more detail.

2.2 Sample description

As mentioned above, in the main stage of this research the main questionnaire will only be sent to parents identified in the screening questionnaire as having a child with a disability or long standing illness. Therefore the pilot sample was designed to include only parents with at least one disabled child.

The sample was drawn from respondents to the 2008 Childcare and After School Activities Survey, which was carried out by NatCen for DCSF in the first half of the year. Only those who said “yes” or “maybe” to re-contact were included in the sample. Data were available on whether the parent had a child with a disability, the type of disability, whether the parent had a child with a SEN and on the ages of their children. The sample was designed to include parents who had children with different types of disabilities in a range of age groups and lived across the country. The types of disability which were included in the sample were:

- Mobility or manual dexterity
- Visual or hearing problems
- Allergy or breathing problems
- Medical needs
- Mental health problems
- Learning difficulties
- Other

The age ranges included in the sample were:

- 0-4
- 5-10
- 11-15
- 16-19

2.3 Pilot Composition

The table below presents the profile of the respondents who participated in the pilot.

Table 1: Profile of respondents who completed the Screening Questionnaire and the Main Questionnaire (describing the child for whom they completed the questionnaire)

Characteristics		Number with characteristics
Gender of child	Male	17
	Female	8
	Total	25
Age	0-4	2
	5-10	5
	11-15	15
	16-19	3
	Total	25
Disability *	Mobility or manual Dexterity	8
	Visual or hearing problems	7
	Allergy or breathing problems	8
	Medical Needs	8
	Mental health problems	4
	Learning difficulties	9
	Other	6
Total	50	
No. of disabilities	Child with one disability	8
	Child with 2 disabilities	11
	Child with 3 disabilities	4
	Child with 4 or more disabilities	2
	Total	25

* The total sums to more than 25 because some children had more than one disability. Disability calculated based on information from the 2008 Childcare and After School Activities Survey. Three respondents who completed only the screening questionnaire, were not eligible to fill in the main questionnaire because they identified none of their children as having a disability i.e. they ticked no at Q4 and no at Q6 for all their children. They correctly selected themselves out. However, they were selected to participate in the study because according to the Childcare and After School Activity Survey they had at least one child who had a disability or a long-standing illness.

3 SCREENING QUESTIONNAIRE

The purpose of the screening questionnaire is to identify parents who have a child with a long-standing illness, disability or health problem, and are thus eligible to participate in the main questionnaire which asks about services. It is important that the screening questionnaire is tested in a pilot to examine how it will work when administered as a postal questionnaire, as it will determine who is sent the main questionnaire.

The screening questionnaire asks questions about all the children in the household. On the front page of the screening questionnaire, respondents are asked to state how many children under the age of 19 live in the household. We examined all the questionnaires to see if the respondents provided details for the number of children they had stated on the front page. In this pilot all the respondents provided details of all their children recorded on the front page.

We will present below the key findings from testing the individual questions in the screening questionnaire. The findings are based on analysis of the 28 completed pilot questionnaires.

3.1 Question 1

What is this child's first name?

3.1.1 Findings

Pilot testing of this question revealed that respondents on the whole appeared not to have had problems when answering the first question in the screening questionnaire, providing just the first name as asked, for all their children. However, on occasion respondents answered the question by providing two names.

Two names

The findings from the pilot testing revealed that where respondents provided two names they did so consistently for all their children suggesting a consistent interpretation of the question. Two practices were observed where two names were given.

1. First name and a surname were given for all the children.
2. Two given names were provided and it was not clear if this was a double barrelled first name or two given names.

As respondents on these occasions have provided more information than requested, it should not affect data quality as the current question stands.

3.1.2 Recommendation

- Suggest retaining this question without modification.

3.2 Question 2

Is this child Male Female?

3.2.1 Findings

There was no evidence, such as crossing outs, on the questionnaires received to show that respondents had difficulties when answering this question for any of their children. The answers appeared to be appropriate when compared with the name given.

3.2.2 Recommendation

- Suggest retaining this question without modification.

3.3 Question 3

What was this child's age last birthday?

3.3.1 Findings

Pilot testing of this question indicated that on the whole respondents were able to provide a codeable answer. However, where this did not occur it could be inferred that this was due to a comprehension problem.

Comprehension

The pilot testing revealed that on rare occasions, the question may not have been understood. In this pilot study of 28 respondents, one respondent appears to have had a comprehension difficulty with this question. Initially she provided the last two digits of the date of birth for her first child and then crossed it out, correctly providing the child's age. However, for her second child she provided the last two digits of the date of birth. The implication of misunderstanding the question would result in invalid answers.

3.3.2 Recommendations

- Suggest retaining this question without modification to the wording of the question. To provide further clarity to the question we would suggest **age** is written in bold.

3.4 Question 4

Does this child have any long-standing illnesses, health problems or disabilities which mean that he / she has substantial difficulties with any of the areas of his / her life shown below? By long-standing we mean anything that has troubled this child over a period of at least 12 months or that is likely to affect him / her over at least 12 months. Please exclude difficulties that you would expect for a child of that age.

Please tick all that apply

Yes substantial difficulties with:

- Mobility or moving around
- Lifting / carrying
- Manual dexterity (using his / her hands)
- Continence / going to the toilet
- Eating or drinking
- Communication, speech or social skills
- Visual or hearing problems
- Memory / ability to concentrate or understand
- Ability to recognize if in physical danger
- Physical co-ordination
- Other areas of his / her life*
- I don't know, I am unsure

→ Go to **Child two** or Go to **Q7** on back page

.....
No, this child does not have substantial difficulties with any of the areas above → Go to **Q5**

3.4.1 Findings

Question 4 is the key screening question to identify which respondents should participate in the main survey. The key finding from testing this question is that the routing instructions were problematic for respondents (we discuss this in more detail below). There were three additional findings from testing this question.

- The instructions for answering this question seem to have worked as respondents were able to answer the question. The instruction 'please tick all that apply' was followed by respondents as 10 respondents ticked more than one option. Respondents also selected the 'no' answer category independently and did not select this together with other options.
- Findings from testing the answer categories revealed that all the answer categories were selected at least once. Respondents seemed able to distinguish the 'I don't know, I am unsure' answer category from the others and did not tick this one and also select other 'yes' responses.
- There is no evidence that there were problems with the layout of the answer categories.

Routing Problems

This question was the main question in the screening questionnaire which had routing problems. It is possible the routing problems identified in the pilot testing for this question, was a result of the layout of the question and the small space available for giving routing instructions.

- At this question the recurring mistake was that respondents, who should have moved onto to the next child or to Q7, missed this instruction and went on to answer Q5. This was principally observed for the first child (of the 12 respondents who misrouted at this question, 6 misrouted only for their first child) (interestingly 2 respondents made this mistake for subsequent children and not their first child) (4 respondents made the same mistake for all their children).
- Where respondents answered 'no', they generally went on to answer Q5 though one missed out Q5 and went straight onto Q6;
- One respondent did not tick anything at Q4 but went on to answer Q5 anyway; this was the second child out of three that s/he was answering for - s/he routed and answered Q5 correctly for the other 2 children - it would appear s/he simply forgot to tick the 'no' box here.

The current misrouting does not effect the use of this question as a screening question. As respondents are providing additional information, and as this questionnaire is quite short, respondent fatigue is of minimal concern. Nevertheless the routing instructions should be made as clear as possible.

3.4.2 Recommendation

- Ensure that the routing instruction after the 'yes' answer categories is clear and stands out more - the layout may need consideration.

3.5 Question 5

If child does not have substantial difficulties with any of the areas at Q4

Q5 Does this child take any medication, use any physical aids, or require any special diets or supplements for any long-standing illnesses, health problems or disabilities?

Please tick all that apply

Yes - medication

Yes - physical aid (e.g. hearing aid or respiratory support) — **→Go to Q6**

Yes - special diet or diet supplements

No medication, physical aid or special diet **→ Go to Child two or Go to Q7 on back page**

3.5.1 Findings

The main finding for Q5 was problems with routing. The answer categories were all used and the question layout was straightforward for respondents.

Routing

As discussed at Q4, there were routing problems that affected how Q5 was answered:

- It was answered by respondents who should have been routed past it (i.e. answered 'yes' at Q4);
- It was missed out by respondents who should have answered it but instead went straight on to Q6/to the next child/to Q7.

Those who correctly routed themselves to this question answered it well and did not seem to struggle with the layout at all. This question did not present problems for those routed incorrectly as it was still relevant to them. Such respondents could be routed out for analysis in the main stage. Nearly all respondents who chose 'No' correctly routed to either the next child or to Q7, one respondent misrouted and this was for their second child.

3.5.2 Recommendations

- Ensure that routing from previous questions is made clearer since the group who missed this question in error could incorrectly be screened out of the survey.
- Suggest retaining this question without modification.

3.6 Question 6

If yes at Q5

Q6 If this child did not take this medication, use this physical aid or have a special diet or supplements would he/she have substantial difficulties with any of the areas of life listed at question 4?

Yes _____

No _____

→ Go to **Child two** or Go to **Q7** on back page

3.6.1 Findings

- On the whole this question seemed straightforward for respondents; no one missed answering this question.
- The main problem with this question concerned the routing from previous questions. For example one respondent who answered 'no' at Q5 for their second child answered this question (responding no). This respondent consistently had problems with routing in the screening and the main questionnaire.

- Another strategy identified in the pilot was respondents who had answered ‘yes’ at Q4, missed out Q5 correctly and then answered Q6. It is not clear why this was. The implication of this is that further information is collected on the child and this does not affect this questionnaire acting as a screening questionnaire.

3.6.2 Recommendation

- Ensure that routing from previous questions is made clearer.

3.7 Question 7

We will be doing some further research that will help the Government to find out about the health of children and use of local services. We will treat all the information you give us confidentially. Would you be happy to take part in this research?
 Yes No

3.7.1 Findings

Pilot testing of this question revealed that respondents generally did not experience problems answering this question and gave a codable answer. However, there were on occasion problems with routing to this question.

Routing

- Question 7 is the first of 4 questions in the section entitled ‘Everyone Please Answer’. To reach this question, respondents can be routed from Q4, Q5 or Q6. Findings from the pilot testing indicated that respondents on the whole were able to follow the routing instructions and correctly routed to this question and provided an answer. Three respondents who failed to route to this question and provide an answer tended to be those who either,
 1. appeared to have problems in general with the routing in the screening questionnaire; or
 2. missed the routing to Q7 altogether, having moved straight to fill in the main questionnaire after answering Q6 for their last child.
- Two respondents failed to route from Q4 and one from Q6. By not routing to Q7, respondents were not routed to subsequent questions in the questionnaire, namely Q8, Q9 and Q10. The implication of missing Q7 is that permission to participate in further research and the verification of contact details, are not obtained. This did not matter for the pilot but for the main stage would mean the screening process would be totally ineffective as there would be no way to send them a main questionnaire since permission would not have been given.

3.7.2 Recommendations

- Suggest retaining this question without modification to the question wording.
- Suggest retaining the current routing instructions at Q4, Q5 and Q6 but ensuring that the routing instructions are clear.

3.8 Question 8

If yes at Q7

In order to help us conduct this further research, we would be very grateful if you could provide your telephone number in the box below:

Telephone number (please include the area code)

□□□□□□□□□□

We will not pass on your phone number to anyone outside the research team. We will only contact you to take part in studies relating to children's services.

3.8.1 Findings

The pilot testing revealed that this question appeared to have been straightforward for respondents. Only respondents who answered yes at Q7 answered Q8 indicating that the routing did work on Q7. All the respondents provided full phone numbers including area code when answering this question.

3.8.2 Recommendation

- Suggest retaining this question without modification.

3.9 Question 9

If yes at Q7

Please check the address on the envelope this questionnaire arrived in. If your address has changed or was incorrect please provide your address below:

House no. or name

Street

Town

County

Postcode

We will not pass on your address to anyone outside the research team. We will only contact you to take part in studies relating to children's services.

3.9.1 Findings

The pilot identified two key findings:

- The routing instruction seems to have worked as intended as only respondents who answered 'yes' at Q7 answered this question.
- Although we did have one respondent out of the 28 who returned the questionnaire, who 'correctly' filled in a change of address at this question, we found evidence of respondents filling in the address when they should not have done so. This could be because the current format does not give any indication of what to do if your address has remained unchanged and therefore people may have felt as though they were required to write something in here.

3.9.2 Recommendations

- Suggest, including a tick box for 'Address had remained unchanged'
- Suggest, altering the wording of the question so that the circumstances are clearer. For example:

Please check the address on the envelope this questionnaire arrived in. If your address has changed, was incorrect or you are planning on moving, please write in your new address below.

3.10 Question 10

If yes at Q7

So that we can contact you again please give us your full name (name of parent).

Title

First name

Surname

3.10.1 Findings

It can be inferred from the pilot testing that Q10 was not problematic, as only respondents who answered 'yes' at Q7 answered the question and they all provided their title, first name and surname as requested.

3.10.2 Recommendation

- Suggest retaining this question without modification.

4 MAIN QUESTIONNAIRE ABOUT YOUR CHILD

The main questionnaire is divided into 4 sections:

1. About your child,
2. Health services,
3. Education services and
4. Social care services.

We will examine the questions in each section in the subsequent three chapters beginning here by looking at questions in the first section, about your child. This first section of the questionnaire is composed of 5 general questions about the 'focus' child, identified by Q4 in the screening questionnaire.

4.1 Question 1

What is the child's first name?

4.1.1 Findings

Pilot testing of this question suggest that this question was generally not problematic. However, on occasion two names were provided, as in the screening questionnaire.

Two names

The same respondents who provided two names in the screening questionnaire adopted the same answer strategy when answering this identically worded question in the main questionnaire. This suggests a consistent interpretation of the question by these respondents. Two practices were observed where two names were given.

1. First name and a surname were given.
2. Two given names were provided and it was not clear if this was a double barrelled first name or two given names.

As respondents on these occasions have provided more information than requested, it should not affect data quality as the current question stands.

4.1.2 Recommendation

- Suggest retaining this question without modification.

4.2 Question 2

What is the child's date of birth? Day Month Year

4.2.1 Findings

Findings from testing this question indicate that respondents did not have problems when answering this question. All the respondents provided valid response for the day, month and year the child was born.

- All the respondents provided 2 digit answers for the day and month and 4 digit answers for the year.

4.2.2 Recommendation

- Suggest retaining this question without modification.

4.3 Question 3

Do you receive Disability Living Allowance (DLA) for your child? Please include if the child receives DLA in his / her own right Yes No

4.3.1 Findings

Pilot testing revealed that Q3 did not seem to be problematic as all the respondents answered the question and provided a codeable answer. There were no indications, such as crossing outs when the questionnaires were examined, to suggest respondents had difficulties.

4.3.2 Recommendation

- Suggest retaining this question without modification.

4.4 Question 4

To which ethnic group do you consider your child belongs?

- | | |
|-------------------------------|---|
| White | <input type="checkbox"/> |
| Mixed | White and Black African <input type="checkbox"/> |
| | White and Asian <input type="checkbox"/> |
| | White and Black Caribbean <input type="checkbox"/> |
| | Any other mixed background <input type="checkbox"/> |
| Asian or Asian British | Indian <input type="checkbox"/> |
| | Pakistani <input type="checkbox"/> |
| | Bangladeshi <input type="checkbox"/> |
| | Any other Asian background <input type="checkbox"/> |
| Black or Black British | Caribbean <input type="checkbox"/> |
| | African <input type="checkbox"/> |
| | Any other Black background <input type="checkbox"/> |
| Chinese | <input type="checkbox"/> |
| Any other ethnic group | <input type="checkbox"/> |

4.4.1 Findings

There is no evidence from the pilot testing to suggest that this question was problematic amongst the multi-ethnic sample: for example there were no crossing out or markings on the questionnaire. All the respondents appeared to have been able to find an answer category which best described their child. The sample did not include members who said they would describe their child as Black or Black British, Chinese or any other ethnic group.

4.4.2 Recommendation

- Suggest retaining this question without modification.

4.5 Question 5

Please record all the areas in which this child is currently affected or could be when his / her illness, disability or health condition flares up. Tick all that apply.

- None
- Mobility - getting about on their own outside the house or getting around inside the home
- Hand function - holding and touching
- Personal care - washing, going to the toilet, dressing etc
- Eating and Drinking - has difficulty eating or drinking by himself or herself
- Medication - has difficulty taking medication or has side effects because of medication he / she takes
- Incontinence - controlling the passage of urine and faeces
- Communication - speaking and/or understanding others
- Learning - having special educational needs
- Hearing
- Vision
- Behaviour - a condition resulting in the child getting frustrated or exhibiting socially unacceptable behaviour
- Consciousness - fits and seizures
- Diagnosed with autism, Asperger Syndrome or Autistic Spectrum Disorder (ASD)
- Palliative care needs (an active and total approach to care which focuses on enhancement of overall quality of life for the child and support for the family)
- Other (please write in other areas your child is affected) _____

4.5.1 Findings

The pilot testing revealed three key findings for Q5.

- All the respondents answered the question and all the answer codes were used by at least one of the respondents. However, closer examination identified that the top three categories were used more often. This suggests that primacy effect where the first response is selected was adopted by some of the respondents (Dillman 2007).

- There were no indications on the questionnaires when they were examined, to suggest respondents found the answer categories difficult such as crossing out answers. However, to make the answer category even more suitable respondents did on occasion amend a category they choose to highlight their child's particular issue even further, or to explain why they have chosen the option. The implication of this is that more information has been provided.
- There was also evidence to suggest respondents did not find all the areas that affected their child as they used the other category.

Other option

The other option was used by 5 respondents in this pilot study to highlight other areas that their child was affected. Their additions were:

- "Gets very down"
- "some joints get inflamed but usually still mobile, suffers more with sickness, temperatures, lethargy and lack of appetite which is a side effect of the condition"
- "hyperactivity / short attention span"
- "suffers from rhinitis, severe allergies"
- "safety".

Many of these issues are currently covered by the current options and can be catered for by amending the current categories slightly. What is not covered is 'depression' related issues related to children such as 'getting very down'. We suggest a suitably worded option is added to cover this situation.

4.5.2 Recommendations

- Suggest adding an appropriate answer category for to include 'depression, child gets down'.
- Suggest amending the answer category eating and drinking to include sickness, e.g. Eating and Drinking - has difficulty eating or drinking by himself or herself or sickness or lack of appetite.
- Suggest amending the answer category behaviour to include hyperactivity e.g. Behaviour- a condition resulting in the child being hyperactive or having a short attention span or getting frustrated or exhibiting socially unacceptable behaviour.

5. MAIN QUESTIONNAIRE HEALTH SERVICES

We now move to look at questions in the health services section of the main questionnaire. There are 17 questions in this section of the questionnaire.

5.1 Question 6

Which of the following health care services has your child used in the last 12 months?	
Please tick one box on each line	
GP	Yes <input type="checkbox"/> No <input type="checkbox"/>
Practice nurse (at the GP surgery)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Health visitor, district nurse, other community nurse	Yes <input type="checkbox"/> No <input type="checkbox"/>
Paediatrician (child health doctor) or other specialist doctor (including visiting hospital as outpatient)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Psychologist	Yes <input type="checkbox"/> No <input type="checkbox"/>
Psychiatrist or behavioural specialist	Yes <input type="checkbox"/> No <input type="checkbox"/>
Physiotherapist	Yes <input type="checkbox"/> No <input type="checkbox"/>
Speech therapist	Yes <input type="checkbox"/> No <input type="checkbox"/>
Occupational therapist (OT)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Podiatrist or chiropodist (foot specialist)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Optician or eye specialist	Yes <input type="checkbox"/> No <input type="checkbox"/>
Dentist	Yes <input type="checkbox"/> No <input type="checkbox"/>
Dietician or nutritionist	Yes <input type="checkbox"/> No <input type="checkbox"/>
Hospital as inpatient	Yes <input type="checkbox"/> No <input type="checkbox"/>
Emergency health care (e.g. A and E or minor injuries)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Palliative care (an active and total approach to care which focuses on enhancement of overall quality of life for the child and support for the family).	Yes <input type="checkbox"/> No <input type="checkbox"/>
Complementary or alternative medicine practitioner	Yes <input type="checkbox"/> No <input type="checkbox"/>

5.1.1 Findings

Piloting testing Q6, revealed three main findings, which are reported below.

- Respondents demonstrated two strategies when answering this question:
 1. they ticked one box on each line as directed or,
 2. they ticked just the yes boxes where applicable and left the other lines blank.
- Whichever strategy was adopted the respondents seemed to be clear about which answer categories to select as there were no crossing out or scribble marks on any of the questionnaires. From this we can infer that the layout and the answer categories were considered appropriate by the respondents in this pilot.
- Three respondents out of the 25 who filled in the main questionnaire in the pilot study added a response to the other category.

Other category

The other category provides an option for respondents to identify services not already covered in the answer categories. The responses provided here were:

1. neurosurgeon,
2. stay in an adolescent unit at a specialist unit, and
3. autism outreach.

On examining these respondents' answers in more detail it could be seen that in all these cases the respondents used the other category to describe one of the options they had already selected for this question. For example the respondent who wrote neurosurgeon selected yes to paediatrician or other specialist doctor. From this we can infer that respondents were providing further information on the answerable code. The findings for testing this question, suggests that the answer categories in this question are sufficiently comprehensive for respondents.

5.1.2 Recommendations

- Suggest retaining this question without modification to the question wording.
- Suggest highlighting the instruction 'tick one box on each line' in bold to remind respondents of the instructions.

5.2 Questions 7 and 8

Q7 Over the **last 12 months**, do you feel your child has received all the health care services that he or she required? Please tick one box below which best describes your experience over the last 12 months.

Did not require any health care services for my child in the last 12 months

My child received: All that he / she required

Most of what he / she required

Some of what he / she required

Little of what he / she required

None of what he / she required

Q8 Overall, how would you rate the quality of the health care services that your child has had in the **last 12 months**?

Very good

Good

Fair

Poor

Very poor

I have not used health care services for my child in the last 12 months

5.2.1 Findings

There were 2 key findings for questions 7 and 8. Firstly, there is little evidence to suggest that either question 7 or 8 were problematic as all the respondents answered these questions and provided a codeable answer. Apart from one respondent, none of the other respondents appear to have changed their answers to either question in this pilot study. In this pilot all the answer codes were used in Q7 suggesting that the answer categories are appropriate for the majority of respondents. The answer category 'very poor' in Q8 was not used at all.

The second key finding was illustrated by one respondent in this study but it highlights a challenge some respondents could have when answering this question. This respondent had a lot of difficulty answering Q7 and Q8 as her child had two extremely different experiences accessing different health care services. It was difficult for this respondent to 'average' this experience which she indicated by answering both questions for both services her child had received. She wrote the name of which service she was ticking which box for by writing it next to the answer category. The respondent telephoned the research team working on the project to discuss her concerns; she did not feel it was appropriate to average the experience because it would devalue the one excellent service her child had received and also would over-value the bad service her child had received.

This finding from testing these two questions (and also the equivalent questions in the education section Q24 and Q25) highlight the complexity of the health service experience that respondents could have to evaluate and judge in order to answer this question.

5.2.2 Recommendations

- Suggest retaining Q 7 and 8 but with further explanation provided to explain to respondents that they should consider **their overall experience**.

There are three suggestions we can provide to assist respondents to answer the question as intended.

1. Provide an explanation on the front page of the questionnaire to tell respondents that some of the questions will ask them to look at their **overall** experience in the last 12 months

*E.g. Some of the questions refer to **overall** experience in the last 12 months. If your experience has been varied please try and answer these questions the best you can, by thinking about your overall experience.*

2. Provide an explanation at the beginning of each section of the questionnaire (i.e. Health, Education and Social services) to ask respondents to think about their overall experiences over the last 12 months when answering the questions in this section.

*E.g. Some of the questions in this section refer to **overall** experience in the last 12 months. If your experience has been varied please try and answer these questions the best you can, by thinking about your overall experience.*

3. Amend Q7 and Q8 so it specifically addresses respondents with mixed experiences and tells them how to answer the question.

*E.g. Q7 Over the **last 12 months**, do you feel your child has received all the health care services that he or she required? Please tick the box which best describes your experience. If your experience has been varied with different services, please tell us about your **overall** experience.*

*E.g. Q8 Overall, how would you rate the quality of the health care services that your child has had in the **last 12 months**? Please tick the box which best describes your experience. If your experience has been varied with different services, please tell us about your **overall** experience.*

We would recommend further testing is done to see whether the suggestions provided above do successfully assist respondents with complex health service experience answer the question. In addition the testing would explore whether the changes affect how respondents who have not had conflicting experiences answer the question.

5.3 Question 9

Below are various things that parents have said in relation to information they had about their child's health condition and available health care services. Please indicate whether you agree or disagree with each of the following statements.
Tick one box on each line

	Agree	Neither agree nor disagree	Disagree	Not Applicable
We/I have been given enough useful information about my child's disability or health condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We/I have been given enough useful information about the health services my child is entitled to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We/I have been given enough information about how to get health care services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is someone we / I can go to for help and support in getting health services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.3.1 Findings

Question 9 was answered by all the respondents, who all correctly ticked one box on each line. This suggests that this question was not considered problematic. However, the pilot testing did reveal two ways of answering the question.

Answer Strategies

Two answer strategies were identified through the pilot testing. Either,

1. a different answer category was selected for the four statements, or
2. the same category was selected for all four statements (An exception to this was NA. NA was only used by one respondent who used it for three out of the four statements and the answers appeared to be contradictory).

It is not possible to know whether respondents selected the correct answer which was the same response, or the easiest option of selecting the same answer which seems suitable for all. Such a practice known as satisficing is known to occur in self administered questionnaires (Dillman 2007) (Jenkins and Dillman 1997).

5.3.2 Recommendation

- Suggest retaining question 9 without modification.

5.4 Question 10

In the **last 12 months** have you received any written or verbal information about health care services (NHS or private) for your child named at Question 1? Do not include information which you had to search for yourself. Yes → **Go to Q11** No → **Go to Q12**

5.4.1 Findings

The pilot revealed 2 key findings for question10.

- All the respondents in this pilot study answered this question providing a codeable answer. There are no indications that the respondents changed their mind when answering this question such as crossing outs. From this we can infer that respondents were confident in their answer.
- However the pilot testing did reveal respondents had problems with routing.

Routing

All the respondents who answered 'yes' at Q10 accurately went to Q11. However, two out of 16 respondents in this pilot study who answered 'no' at Q10 misrouted. They should have skipped Q11 and gone on to Q12. To understand the implication of misrouting at Q11, the answer strategies of these two respondents were examined for Q11. Both respondents have provided what appear to be plausible answers. One of the respondents selected the middle option for all the statements when answering Q11 question, namely 'yes, sometimes'. The other respondent selected a mixture of answer categories in Q11. It is not clear from the pilot testing whether these two respondents selected the wrong answer category in Q10 and therefore correctly answered Q11 or routed inaccurately to answer Q11 inaccurately. The implication of which is invalid data will be collected either at Q10 or at Q11.

5.4.2 Recommendation

As it is not clear from the pilot where the misunderstanding has arisen a suggestion would be highlight the key words in the question, to make the question even clearer.

In the **last 12 months** have you received **any written or verbal information about health care services** (NHS or private) for your child named at Question 1? Do not include information which you had to search for yourself. Yes No

5.5 Question 11

Overall, how would you describe the information you received in the **last 12 months** about health care services for your child? Please include both written and verbal information you received.

	Tick one box on each line		
	Yes, always	Yes, sometimes	No
Clear - to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relevant - to you and your child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accurate- up to date and precise information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.5.1 Findings

Only respondents who answered 'yes' at Q10 should have answered Q11.

- In this pilot testing, all the respondents (8 respondents) who selected 'yes' at the previous question correctly routed to Q11. However, as discussed above, two respondents who answered 'no' at Q10 incorrectly answered this question.
- From the pilot testing 4 answer strategies were observed.
 1. Answered all the statements with the same answer category, or,
 2. answered the first option with the first answer category only, or
 3. indicated that NA was their preferred response by writing in NA, or
 4. selected different answer categories for each statement.

The first answer strategy was the pre-dominant practice where all the respondents selected the first answer category ('yes always') on at least one occasion. The next three answer strategies were each observed on one occasion in this pilot study.

5.5.2 Recommendation

From the pilot testing it is not possible to know whether respondents selected the same answer option as it was the best answer for each statement or whether it was the easiest option.

- Suggest retaining question 11 without modification.

5.6 Question 12

In the **last 12 months**, have medical or health professionals made any **decisions** about your child's illness or disability or services that he / she should receive? Please include decisions such as whether to have an operation or change medication. Do not include routine monitoring.

Yes → **Go to Q13** No → **Go to Q16**

5.6.1 Findings

All the respondents in the pilot study answered Q12 by providing a codeable answer. The pilot study did reveal that respondents could have problems with routing at this question.

Routing

- Depending on the answer to Q12 respondents were routed to the next question or routed to Q16. On the whole respondents accurately routed when answering this question. Only one respondent in this pilot study of 25 respondents did misroute.
- The one respondent who misrouted should have answered Q16 after this question. The respondent however moved on to the next question, namely Q13. The likelihood of this error could have been increased as Q13 was on the next page so respondents had to turn over the page to check which question to answer next. To understand the implication of misrouting, this respondent's answers for Q13 to Q15 were examined. The respondent has provided codeable answers and where 'NA' was available as in Q13 the respondent did not select this category.
- It is not clear from the pilot whether the respondent has answered Q12 wrongly but by chance gone on to answer the correct questions or misrouted and just adopted a strategy known as satisficing to provide plausible answers to answer the question. The implication of either strategy is that it would affect the validity of the answers provided for this question or the subsequent three questions.

5.6.2 Recommendations

- Suggest retaining question 12 without modification to the question wording.
- Suggest adding a routing direction above question 13 to remind respondents where to route to {if yes at Q12 answer Q13, if no at Q12 answer Q16}.

5.7 Question 13

And thinking about these decisions and the questions you had to answer in the **last 12 months**, please indicate whether you agree or disagree with each of the following statements. Please include decisions such as whether to have an operation or change medication. Do not include routine monitoring.

	Tick one box on each line			
	Agree	Neither agree nor disagree	Disagree	Not applicable
We / I had to give the same information several times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We were / I was listened to and our needs were understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The decisions made were suitable for my child's needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The decisions were made at the right time for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Where necessary, the health professionals worked together to make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
On the whole we were happy with the decisions that were made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.7.1 Findings

Pilot testing for this question revealed two key findings.

- All the respondents who were routed to Q13 from Q12 answered this question and provided a codeable answer. Three answer strategies were observed in this pilot testing of this question:
 1. selected the same answer category for all six statements,
 2. selected different answer categories for all six statements and or,
 3. left a line blank and did not select any answer category for a particular statement.
- This question has the potential to be sensitive for some respondents. (We discuss this in detail below).

Statements

- The first and second statements were answered by all the respondents in this pilot and between them all the answer categories were selected. Statement three and four were skipped by two different respondents who answered the subsequent statement.
- In this pilot no respondents selected 'neither agree' nor 'disagree' for statement three and six. The answer category 'not applicable' was not selected, by any respondents when answering statement four and five.

Sensitivity of this question

- There is little evidence from crossing out or written comments to indicate that respondents were uncertain or uncomfortable in answering this question. However, one respondent in this study did have difficulties with answering this question. She annotated the statements to indicate it was difficult for her to summarise her experience and then answer this question. Nevertheless she provided codeable answers: 'disagree', for statement one, four, five and six and left two and three blank.

Sensitivity of the health care questions

- This same respondent who found it difficult to summarise her experience at Q7 and Q8 found it difficult to answer other questions in the health section. She wrote her concerns on the questionnaire as well as rang the researcher working on the project to highlight her concerns. This example highlights the sensitivity that these questions could pose for some respondents. Their experiences are valuable for the survey and important for the disability indicator. To assist these respondents to answer these questions and address the sensitivity issue of only offering them pre coded answer categories an open text box positioned strategically on this page or the next page would allow respondents to explain their views in their own words.

5.7.2 Recommendations

- Suggest retaining Q13 with its current layout and answer categories.
- We would suggest providing an open text box at the end of Q19 where respondents can elaborate on the answers they have already provided.
- It is important for this questionnaire to be supported with a leaflet or a letter providing support contact numbers so that respondents know who to contact to discuss issues which arise through filling in this questionnaire. A leaflet was provided in the cognitive testing but not for the pilot testing.

5.8 Question 14

How well do you understand the decisions that are made about your child's health care?

Very well

Fairly well

Not very well

Not at all well

5.8.1 Findings

Pilot testing this question revealed that overall the question worked. The two key points are:

- Respondents chose all the answer options at least once apart from 'Not at all well'.
- One respondent, who answered 'No' at Q12 and who therefore, should have been routed past this question, answered 'Not very well'.

5.8.2 Recommendations

- Suggest retaining this question without modification.
- Ensure that routing instructions at Q12 are clear

5.9 Question 15

Over the **last 12 months**, were you consulted or asked for your opinion when **decisions were being made** about your child's health care?

Yes, consulted a lot

Yes, consulted a little

No, not consulted at all

5.9.1 Findings

Overall the pilot testing show that this question seems to have worked. Three points were identified in the pilot, which are discussed below.

- As at Q14, the respondent who should have been routed past this question did in fact answer it.
- Another respondent who should have answered it could not and commented on the questionnaire that "*some individual practitioners have included me and others have excluded me*". She therefore felt unable to answer.
- All other respondents routed themselves correctly and chose one of the three answer categories.

5.9.2 Recommendations

- Suggest retaining this question without modification.
- Ensure that routing instructions at Q12 are clear

5.10 Question 16

Over the last 12 months, have you been asked for your opinion or feedback on the health care services your child received?			
	Yes	<input type="checkbox"/>	→ Go to Q17
No, did not receive any health services for the child in the last 12 months		<input type="checkbox"/>	→ Go to Q20
	No, not asked for opinion or feedback	<input type="checkbox"/>	→ Go to Q18

5.10.1 Findings

The main findings from testing are:

- All respondents who completed the questionnaire provided an answer, suggesting that those who followed the routing from Q12 did so correctly.
- Those who answered ‘Yes’ or ‘No, did not receive any health services for the child in the last 12 months’ correctly went on to answer Q17 or Q20 correctly. Three out of the 18 respondents who answered ‘No, not asked for opinion or feedback’ answered Q17 rather than following the routing to Q18.

5.10.2 Recommendations

- | |
|--|
| <ul style="list-style-type: none">• Suggest retaining this question without modification.• Ensure that routing instructions are clear |
|--|

5.11 Question 17

Do you think that changes were made as a result of the opinions or feedback you gave?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

5.11.1 Findings

- Testing Q17 in the pilot revealed that those respondents who incorrectly routed themselves to this question after answering ‘No, not asked for opinion or feedback’ at Q16 either answered ‘Yes’ or ‘Don't know’. It is not clear why the one respondent answered ‘Yes’.
- There was no evidence from testing this question to suggest that the answer categories did not work. In this study, respondents either chose ‘Yes’ or ‘Don't know’; no one chose ‘No’.

5.11.2 Recommendations

- Suggest retaining this question without modification.
- Ensure that routing instructions at Q16 are clear

5.12 Question 18

Over the last 12 months, has your child been asked for his / her opinion or feedback on the health care services he/she received?

- | | | |
|--|--------------------------|-------------|
| Yes | <input type="checkbox"/> | → Go to Q19 |
| No, did not receive any health services for the child in the last 12 months | <input type="checkbox"/> | → Go to Q20 |
| No, child not able to provide opinion or feedback due to young age or difficulties with learning, understanding or communication | <input type="checkbox"/> | → Go to Q20 |
| No, not asked for opinion or feedback | <input type="checkbox"/> | → Go to Q20 |

5.12.1 Findings

The main finding from testing this question was to do with routing.

- Everyone who should have answered this question did so.
- Five respondents (who did not answer 'Yes') incorrectly routed themselves to Q19.
- The pilot indicates that the answer categories are appropriate. Answer category 'No, did not receive any health services for the child in the last 12 months' was not used.

5.12.2 Recommendations

- Suggest retaining this question without modification.
- Ensure that routing instructions are clear

5.13 Question 19

Do you think that changes were made as a result of the opinions or feedback your child gave?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

5.13.1 Findings

The problem identified with this question was due routing problems.

Routing

- The two respondents who correctly routed to this question answered 'Yes' and 'Don't Know'.
- However, five respondents incorrectly routed to this question from Q18, answering a combination of 'Yes', 'No' and 'Don't Know'. These answers are not consistent with how the respondents answered Q18 and so suggests that they may have simply been picking any answer so as to move on to the next question as quickly as possible. The implication of this is that invalid data will be collected at this question for these respondents.

5.13.2 Recommendations

- Suggest retaining this question without modification.
- Ensure that routing instructions at Q18 are clear

5.14 Question 20

In the last 12 months, have you made a written complaint about a health care service you have received in relation to your child?		
Yes, to the service provider	<input type="checkbox"/>	→Go to Q21
Yes, to my Local Authority or Primary Care Trust	<input type="checkbox"/>	→Go to Q21
Yes, to other organisation (please specify)	<input type="checkbox"/>	→Go to Q21

No, I have not complained	<input type="checkbox"/>	→Go to Q23

5.14.1 Findings

- All 25 respondents answered this question. One chose 'Yes, to the service provider' - and then incorrectly wrote on the line for 'Yes, to other organisation (please specify)' *"in motion at the moment"* - indicating possible layout and comprehension problems; 1 chose 'Yes, to my Local Authority or Primary Care Trust' and 23 chose 'No, I have not complained'; no one chose 'Yes, to other organisation (please specify)'.
- The respondents who chose 'No, I have not complained' all correctly routed to Q23.

5.14.2 Recommendations

- Consider the layout of the answer categories, in particular the location of the space for writing in other organisations.
- Suggest retaining this question.

5.15 Question 21

How easy or difficult was it to find out how to make a formal written complaint?

- Very easy
- Fairly easy
- Neither easy or difficult
- Fairly difficult
- Very difficult

5.15.1 Findings

There was no evidence from the pilot testing to suggest that this question does not work. Two respondents correctly routed to this question and did not appear to have any difficulties; of the five answer categories they chose 'Fairly easy' and 'Neither easy or difficult'.

5.15.2 Recommendation

- Suggest retaining this question without modification.

5. 16 Question 22

Thinking about the complaints process, how well was your complaint dealt with?

- Very well
- Fairly well
- Not very well
- Not at all well

5.16.1 Findings

There was no evidence from the pilot testing to suggest that this question does not work. Two respondents correctly routed to this question and did not appear to have any difficulties; of the four answer categories they both chose 'Not very well'.

5.16.2 Recommendation

- Suggest retaining this question without modification.

6. MAIN QUESTIONNAIRE EDUCATION SERVICES

We now move to look at the findings from pilot testing the 20 questions in this section of the main questionnaire. This section looks at parents’ experiences of accessing education services for their disabled children in the last 12 months.

6.1 Question 23

Q23 Which of the following education services has your child (named at Question 1) used in the last 12 months?				
		Tick one box on each line		
Pre-school or nursery	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Children’s centre	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Home teaching, Portage, Private Tutor	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Mainstream school	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Special school	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Special education unit	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Hospital education service	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Support from Special Needs Teacher	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Dedicated teaching assistant / learning support assistant	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Educational psychologist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Further education college	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Connexions	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Other (please write in) _____				

6.1.1 Findings

There is no evidence from this pilot study to suggest that the layout and the answer categories did not work for this question. Below we report on the findings from testing this question.

- Respondents demonstrated two strategies when answering this question.
 1. They ticked one box on each line as directed (17 respondents) or,
 2. they ticked just the yes box where applicable, leaving the other statements unanswered (eight respondents)
- Whichever strategy was adopted the respondents seemed to be clear which answer categories to select as there was only one crossing out indicated by one respondent for this question.
- In this pilot study of 25 respondents who filled in the main questionnaire, no one added a response to the other category.

6.1.2 Recommendations

- Suggest retaining this question without modification to the question wording.
- Suggest highlighting the instruction ‘**tick one box on each line**’ in bold to remind respondents of the instructions.

6.2 Question 24

Over the **last 12 months**, do you feel your child has received all the education services that he or she required? Please tick one box below which best describes your experience over the last 12 months.

Did not require any education services for my child in the last 12 months

My child received:

All that he/she required	<input type="checkbox"/>
Most of what he/she required	<input type="checkbox"/>
Some of what he/she required	<input type="checkbox"/>
Little of what he/she required	<input type="checkbox"/>
None of what he/she required	<input type="checkbox"/>

6.2.1 Findings

Pilot testing of Q24 suggests that this question was not problematic to respondents on the whole. All the respondents in this pilot provided codeable answers and all the answer codes were used suggesting that the answer categories are appropriate for the majority of respondents. Below we examine the three key findings from testing this question.

Firstly, as in the health section (Q7), pilot testing revealed that this question could be difficult for respondents whose child has had two extremely different experiences accessing education services. One respondent wrote on her questionnaire that it was difficult for her to record her child’s experience. This respondent opted to answer the question using the middle option. This question is trying to measure a complex process for some respondents, which involves a lot of evaluation and judgement in order the answer. As suggested for Q7 and Q8 we would suggest the same three suggestions to assist respondents to answer this question as intended.

The second key finding was identified from examining the questionnaires; it could be seen that two respondents changed their mind when answering this question. This could be a minor issue such as simply of making a mistake but is mentioned here to provide a comprehensive overview of the possible problems with this question.

The final finding was that one respondent who selected the first answer category ‘did not require any education services for my child in the last 12 months’, did not answer any more questions in the education section i.e. skipped Q25 to Q42. There are no indications in the questionnaire explain why the respondent did this. It seems most likely that she considered that the remaining questions in the section would not be relevant to her. The respondent did answer all the questions in the health section and the social care section.

6.2.2 Recommendations

- Suggest retaining Q24, but with further explanation provided to explain to respondents that they should consider their **overall** experience. There are three suggestions we can provide to assist respondents to answer the question as intended.

1. Provide an explanation on the front page of the questionnaire to tell respondents that some of the questions will ask them to look at their overall experience in the last 12 months

*E.g. Some of the questions refer to **overall** experience in the last 12 months. If your experience has been varied please try and answer these questions the best you can, by thinking about your overall experience*

2. Provide an explanation at the beginning of each section of the questionnaire (i.e. Health, Education and Social services) to ask respondents to think about their overall experiences over the last 12 months when answering the questions in this section.

*E.g. Some of the questions in this section refer to **overall** experience in the last 12 months. If your experience has been varied please try and answer these questions the best you can, by thinking about your overall experience.*

3. Amend Q24 so it specifically addresses respondents with mixed experiences and tells them how to answer the question.

*E.g. Q24 Over the **last 12 months**, do you feel your child has received all the education services that he or she required? Please tick the box which best describes your experience. If your experience has been varied with different services, please tell us about your **overall** experience.*

- However we would recommend further testing is done to examine whether the suggestions provided do successfully assist respondents with complex educational experience. Also the testing would examine whether the changes affect how other respondents without conflicting experiences, answer the question.
- Consider routing those who did not require any education services for their child in the last 12 months straight to social care section to reduce respondent burden since, most questions in this section are unlikely to be relevant.

6.3 Question 25

Overall, how would you rate the quality of the education services that your child has received in the **last 12 months**?

Very good

Good

Fair

Poor

Very poor

I have not used education services for my child in the last 12 months

6.3.1 Findings

There are 2 main findings from the pilot testing.

- Pilot testing of Q25 indicates that this question was generally not problematic for respondents. All the answer codes were used in the pilot suggesting that the answer codes are appropriate. All but one respondent provided a codeable answer.
- Nevertheless pilot testing did reveal, as in the previous question, that it can be difficult for respondents to provide an overall answer when their child had two extreme experiences in the last 12 months. We propose the same three suggestions as we did for the previous question.

6.3.2 Recommendations

- Suggest retaining Q25. To assist respondents with varied experiences in the last 12 months we would advise further explanation is provided to explain to respondents that they should consider their **overall** experience. There are three suggestions we can provide to assist respondents to answer the question as intended.

1. Provide an explanation on the front page of the questionnaire to tell respondents that some of the questions will ask them to look at their **overall** experience in the last 12 months

*E.g. Some of the questions refer to **overall** experience in the last 12 months. If your experience has been varied please try and answer these questions the best you can, by thinking about your overall experience*

2. Provide an explanation at the beginning of each section of the questionnaire (i.e. Health, Education and Social services) to ask respondents to think about their overall experiences over the last 12 months when answering the questions in this section.

*E.g. Some of the questions in this section refer to **overall** experience in the last 12 months. If your experience has been varied please try and answer these questions the best you can, by thinking about your overall experience.*

3. Amend Q25 so it specifically addresses respondents with mixed experiences and tells them how to answer the question.

*E.g. Q25 Overall, how would you rate the quality of the education services that your child has had in the **last 12 months**? Please tick the box which best describes your experience. If your experience has been varied with different services, please tell us about your **overall** experience.*

- However we would recommend further testing is done to examine whether the suggestions provided do successfully assist respondents with complex educational experience. Also the testing would examine whether the changes effect how other respondents without conflicting experiences answer the question.

6.4 Question 26

Below are various things that parents have said in relation to information they had about education services for their child. Please indicate whether you agree or disagree with each of the following statements.

Tick one box on each line

	Agree	Neither agree nor disagree	Disagree	Not Applicable
We / I have been given enough useful information about my child's educational needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We / I have been given enough useful information about the education services my child is entitled to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We / I have been given enough information about how to get education services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is someone I can go to for help and support in getting education services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6.4.1 Findings

The pilot identified two key findings:

- On the whole Q26 was found not to be problematic in this testing stage. Question 26 was answered by all but one respondent (who skipped all the questions in this section of the questionnaire from Q24). All the respondents who answered this question correctly followed the instructions and ticked one box on each line. All the answer categories were used in this pilot. This suggests that this question was not considered problematic.
- The pilot testing did reveal three ways of answering the question, which could be all considered as different answer strategies.

Answer Strategies

Three answer strategies were identified through the pilot testing:

1. a different answer category was selected for the four statements (12 respondents), or
2. the same category was selected for the four statements (12 respondents), or
3. the question was not answered.

Of the 12 respondents who selected the same answer category for all four statements, 10 selected 'agree' for all their answers. It is not possible to know whether respondents choose the best answer which was the same response or the easiest option. However, it would appear from this testing that the question does work.

6.4.2 Recommendation

- Suggest retaining this question without modification

6.5 Question 27

In the **last 12 months**, have you received any written or verbal information about education services for your child named at Question 1? Do not include information which you had to search for yourself.

Yes → **Go to Q28** No → **Go to Q29**

6.5.1 Findings

There were three findings in relation to this question but only one concerns a problem with the question, namely routing.

- There is no evidence from the pilot testing to indicate that respondents found Q27 difficult. All the respondents apart from one (who missed all the questions from Q 25 onwards answered this question) provided a codeable answer to this question.
- There are no indications that the respondents changed their mind when answering this question such as crossing outs. Both the 'yes' and 'no' options were approximately equally used.
- However, the pilot testing did reveal respondents had problems with routing.

Routing

All 11 respondents who answered 'yes' at Q27 accurately went to Q28 as in the equivalent question in the health section (Q10). However, two out of 13 respondents in this pilot study who answered 'no' at this question misrouted. They should have skipped Q28 and gone on to Q29. To understand the implication of misrouting at this question, the answers given by these two respondents were examined for Q28. One of the respondents selected 'yes always' to all the statements when answering Q28; the other respondent selected a mixture

of the yes answer categories in Q28. Both respondents appear to have provided plausible answers. It is not clear from the pilot testing whether these two respondents selected the wrong answer category in Q27 but correctly routed to answer the next question or routed inaccurately to answer Q28 and have answered this question inaccurately. The implication of this error whether through misunderstanding Q27 or misrouting from Q27 to Q28 will result in invalid or unreliable answers being collected at this question or at Q28.

6.5.2 Recommendations

As it is not clear from the pilot where the misunderstanding has arisen a suggestion would be to highlight the key words in the question and provide clear routing instructions.

In the **last 12 months** have you received **any written or verbal information about education services** for your child named at Question 1? Do not include information which you had to search for yourself. Yes → **Go to Q28** No → **Go to Q29**

6.6 Question 28

Overall, how would you describe the information you received in the **last 12 months** about education services for your child named at Question 1? Please include both written and verbal information you received.

Tick one box on each line

	Yes, always	Yes, sometimes	No
Clear - to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relevant - to you and your child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accurate - up to date and precise information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6.6.1 Findings

- All the respondents (11 respondents) who selected yes at the previous question correctly routed to Q28. From the pilot testing 2 answer strategies were observed for this question.
 1. Either respondents selected different answer categories, or
 2. answered all the statements with the same answer category.
- In this pilot testing study, the answer category 'No' was not used by any respondents. Three respondents misrouted to this question from Q27. They all answered the three statements with yes options, which do not fit with their answer in Q27 which indicates they all adopted a strategy known as satisficing in which respondents select answers to progress through the questionnaire as easily as possible even if they are not correct.

6.6.2 Recommendation

From the pilot testing it is not possible to know whether respondents selected the same answer option as it was the best answer for each statement or whether it was the easiest option.

- Suggest retaining question 28 without modification ensuring the routing instructions at the previous question (Q27) are clear.

6.7 Question 29

Does your child named at Question 1 have special educational needs (SEN)?

Yes → Go to Q30 No → Go to Q32

6.7.1 Findings

The key finding from testing is that on the whole this question worked.

- Twenty four respondents answered this question - it is not clear why the 25th did not but they had also left other questions surrounding this one blank.
- All those who answered 'Yes' correctly routed to Q30. Six respondents who answered 'No' went on to Q30 rather than skipping to Q32.

6.7.2 Recommendations

- Ensure that routing instructions are clear.

6.8 Question 30

Has your child received a statement of special educational needs (SEN)?

Yes

No

6.8.1 Findings

There were two key findings from testing this question.

- All the respondents who incorrectly routed to this question logically answered 'No'.
- Other respondents were able to choose one of the two answer categories.

6.8.2 Recommendation

- Suggest retaining this question without modification.

6.9 Question 31

What type of special educational provision does your child receive?	Tick one box only
Early Years Action	<input type="checkbox"/>
Early Years Action Plus	<input type="checkbox"/>
School Action	<input type="checkbox"/>
School Action Plus	<input type="checkbox"/>
None of these	<input type="checkbox"/>

6.9.1 Findings

There were four key findings from testing this question of which two were to do with routing and two were to do with the answer categories.

Routing

There were two routing problems:

- Respondents who had answered 'No' at Q29 ignored the routing instruction and went on to answer Q30 and this question - where they all selected 'None of these'; and,
- Respondents who answered 'Yes' at Q29 answered Q30 but did not answer this question - it is unclear why this was.

Answer Categories

- There was no evidence from the pilot to suggest the answer categories do not work. Small numbers of respondents chose 'Early Years Action Plus' and 'School Action Plus', larger numbers chose 'None of these': the other answer categories were not chosen.
- We would suggest providing a 'don't know' option to prevent respondents 'guessing' or skipping the question because they 'don't know'. Research by Poe et al suggests that 'there is no appreciable differences in response error rates' when don't know options are provided on mail questionnaires (Poe et al 1988:212). So it would seem that this suggestion would not effect the data collection; if anything it may improve it, for the reason already mentioned.

6.9.2 Recommendations

- | |
|---|
| <ul style="list-style-type: none">• Ensure that routing instructions at Q29 are clear.• Consider the addition of a Don't know response |
|---|

6.10 Question 32

In the **last 12 months**, did your child named at Question 1 have a **formal assessment** of his/her particular **educational support needs**? Do **not** include standard assessments routinely provided for all children.

- Go to Q33
- Go to Q36

6.10.1 Findings

This question was generally unproblematic:

- One respondent chose 'Yes', then crossed it out and chose 'No' instead. A possible reason for this, as observed in the cognitive testing, could be that the respondent was trying to limit the number of questions answered so as to reduce the response burden.
- Only one respondent did not follow the routing correctly and went on to answer Q33-Q35 after answering 'No'.

6.10.2 Recommendations

- Suggest retaining question without modification but make the routing clear.

6.11 Question 33

Thinking about this formal assessment of your child's particular educational support needs and the decisions that were made, please indicate whether you agree or disagree with each of the following statements.

	Tick one box on each line			
	Agree	Neither agree nor disagree	Disagree	Not Applicable
We / I knew what to expect from the assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We / I had to give the same information several times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We were / I was listened to and our needs were understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The decisions made were suitable for my child's needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The decisions were made at the right time for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Where necessary, professionals worked together to make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
On the whole we were happy with the decisions that were made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6.11.1 Findings

- Respondents who answered 'yes' to Q32 were routed to Q33. In this pilot, 7 respondents answered yes to Q32. All these respondents correctly routed Q33.
- One respondent who answered no to Q32 did misroute and went on to answer Q33 selecting NA for all the statements except statements five and six when the respondent select disagree.

Misrouting

It is not possible in this pilot to know whether the one respondent who answered 'no' at Q32 made a mistake and should have answered Q33 or whether the respondent answered this question inaccurately. The implication of such misrouting in the real survey could result in over-reporting or respondent fatigue.

In addition to this, four answer strategies were observed in this pilot.

Answer strategies

1. Four respondents selected different answer categories for the seven statements.
2. One respondent selected the same answer category for the seven statements.
3. Two respondents only selected agree and when they did not they left that statement unanswered. For both these respondents they did not answer statement two.
4. A respondent answered only the first two statements.

None of the respondents in the pilot sample selected the Not Applicable answer category for any of the statements.

6.11.2 Recommendations

- The pilot revealed that further signposting is needed to assist respondents who could be misrouting or have misunderstood the previous question. We would suggest retaining the wording of the question but just highlighting the key words and the instruction **tick one box on each line** in bold.

Thinking about ***this formal assessment*** of your child's particular educational support needs **and the decisions** that were made, please indicate whether you agree or disagree with each of the following statements.

6.12 Question 34

How well do you understand the decisions that are made about which education services your child receives?

Very well

Fairly well

Not very well

Not at all well

6.12.1 Findings

There was some evidence from the pilot testing that Q34 could be inappropriate for respondents who are *awaiting* a decision about the education services their child receives:

- One respondent left this question blank, commenting on the form that “*no decision has been made yet*” -and so therefore it seems felt unable to answer this question. This respondent had answered ‘Agree’ to the first two statements at Q33 but did not answer the other statements.
- All answer categories were chosen with the exception of ‘not very well’.

6.12.2 Recommendation

- Include an extra answer category at Q34, for example ‘No decision has been made yet’ OR provide routing from Q32 so that respondents in this position are not asked this question.

6.13. Question 35

Over the **last 12 months**, were you consulted or asked for your opinion when **decisions were being made** about the education services your child receives?

Yes, consulted a lot

Yes, consulted a little

No, not consulted at all

6.13.1 Findings

This question was unproblematic: those respondents who should have answered this question did so and all others, with the exception of one, were routed past it.

6.13.2 Recommendation

- Suggest retaining question without modification.

6.14 Question 36

Over the **last 12 months**, have you been asked your opinion or feedback on the **education services your child received?**

Yes → **Go to Q37**

No, did not receive any education services for the child in the last 12 months → **Go to Q40**

No, not asked for opinion or feedback → **Go to Q38**

6.14.1 Findings

There were two key findings identified in the pilot, to do with answer categories and routing.

Answer Categories

- All respondents, with the exception of the one previously mentioned who missed out this whole group of questions, answered this question: they either chose ‘Yes’ or ‘No, not asked for opinion or feedback’ with no one choosing ‘No, did not receive any education services for the child in the last 12 months’.

Routing

- Two respondents who choose ‘No, not asked for opinion or feedback’ missed the routing to Q38 and instead went on to answer Q37.

6.14.2 Recommendations

- Ensure that routing instructions are clear.

6.15 Question 37

Do you think that changes were made as a result of the opinions or feedback you gave?

Yes

No

Don't know

6.15.1 Findings

The pilot identified two findings; the first was a problem with routing and the second finding indicated the answer categories for this question are appropriate.

- The two respondents who incorrectly routed to this question after answering ‘No, not asked for opinion or feedback’ at Q36 both answered ‘Don't know’ at this question.

The implication is the over-reporting of 'don't know', owing to this misrouting from Q36.

- All other respondents were able to provide an answer - either 'Yes', 'No' or 'Don't Know'.

6.15.2 Recommendation

- Suggest retaining question without modification.

6.16 Question 38

Over the **last 12 months**, has your child been asked for his/ her opinion or feedback on the education services he/she received?

- Yes → Go to Q39
- No, did not receive any education services for the child in the last 12 months → Go to Q40
- No, child not able to provide opinion or feedback due to young age or difficulties with learning, understanding or communication → Go to Q40
- No, not asked for opinion or feedback → Go to Q40

6.16.1 Findings

There were three key findings which were identified in the pilot:

- All respondents were able to provide an answer for this question; though no one chose 'No, did not receive any education services for the child in the last 12 months' all other answer categories were selected at least once.
- There was evidence (four respondents) that respondents who had either answered 'No, not asked for opinion or feedback missed the routing instruction and instead went on to answer Q39.
- All respondents who answer 'Yes' followed the routing instruction to Q39 correctly.

6.16.2 Recommendations

- Ensure that routing instructions are clear.

6.17 Question 39

Do you think that changes were made as a result of the opinions or feedback your child gave?

Yes

No

Don't know

6.17.1 Findings

Of those respondents who answered this question, there did not appear to be any difficulties, as all answered the question and there were no crossing out indicated in any of the questionnaires. The four respondents who misrouted to this question from Q38 answered this question with 'don't know' (three respondents) or 'no' (one respondent).

6.17.2 Recommendation

- Suggest retaining question without modification but ensure the routing instructions at Q38 are clear.

6.18 Question 40

In the **last 12 months**, have you made a written complaint about an education service you have received in relation to your child?

Yes, to the service provider (e.g. school) → Go to Q41

Yes, to my Local Authority → Go to Q41

Yes, to other organisation (please write in below) → Go to Q41

No, I have not complained → Go to Q43

6.18.1 Findings

The main finding from testing Q40 is that on the whole it worked.

- Twenty four respondents answered this question; all chose the answer category 'No, I have not complained'.
- With the exception of one respondent who answered Q41 (though not Q42), all followed the routing to Q43 correctly.

6.18.2 Recommendations

- As all the respondents, in this pilot, selected the same answer category the routing instructions from the other answer categories were not tested. From the findings from this pilot we would suggest retaining this question without modification.

6.19 Question 41

How easy or difficult was it to find out how to make a formal written complaint?

Very easy

Fairly easy

Neither easy or difficult

Fairly difficult

Very difficult

6.19.1 Findings

This question was not fully tested in this pilot. Only one respondent answered this question and they should have been routed past this question, at Q40.

- The one respondent who answered this question in error selected the answer category 'very difficult'.

6.19.2 Recommendation

- Question not tested fully; suggest retaining without modification but with clear routing instructions.

6.20 Question 42

Thinking about the complaints process, how well was your complaint dealt with?

Very well

Fairly well

Not very well

Not at all well

6.20.1 Findings

All respondents were routed past this question and therefore it has not been possible to test this question in the pilot.

6.20.2 Recommendation

- Question not tested fully, suggest retaining without modification.

7 MAIN QUESTIONNAIRE SOCIAL CARE SERVICES

This is the final section in the main questionnaire. The questions examine parents' experience of accessing social care services for their children and their families because of the particular needs of their disabled children. There are 17 questions in this section.

7.1 Question 43

Has your family used any of the following social care and family support services in the last 12 months in relation to the needs of your child named at Question 1?				
Tick one box on each line				
Home adaptations (e.g. Ramps, lifts)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Respite, foster care, short breaks	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Help at home with care for the child	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Social worker services	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Help within the home from an outside provider	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Home start or Sure Start	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Emotional support or counselling	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Direct payments (excluding benefits) or individual budget (money from local council to pay for care and support services)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Other (please write in) _____				

7.1.1 Findings

On the whole this question worked. We discuss below the four key findings which were identified and which all relate to the answer categories.

Answer categories

- Pilot testing highlighted that respondents had two strategies when answering this question.
 1. They ticked one box on each line as directed (21 respondents) or,
 2. they ticked just the yes box where applicable, leaving the other statements unanswered (four respondents).
- Whichever strategy was adopted the respondents on the whole seemed to be clear which answer categories to select as there were no crossing out on any of the questionnaires. However, one respondent indicated that he / she was not clear what 'emotional support or counselling' meant by placing a question mark in the 'no' answer category box.

- The other category, although used by one respondent in this pilot, was not used to identify other services. (It was used to describe that no one helps this respondent). This would suggest that the answer categories are comprehensive but that there was some confusion over the purpose of the space to write in other answers.
- There is no evidence from this pilot study to suggest that the layout and the answer categories did not work for this question.

7.1.2 Recommendations

- Suggest retaining this question as it is but highlight '**tick one box on each line**' in bold to remind respondents of the instructions.
- Consider layout to make it clearer what the purpose of the place to write in other is.

7.2 Question 44

Over the **last 12 months**, do you feel you and your family have received all the social care and family support services that you required in relation to your child named at Question 1? Please tick one box below which best describes your experience over the last 12 months.

Did not require any social care or family support services in relation to my child in
the last 12 months

We received:	All that he / she required <input type="checkbox"/>
	Most of what he / she required <input type="checkbox"/>
	Some of what he / she required <input type="checkbox"/>
	Little of what he / she required <input type="checkbox"/>
	None of what he / she required <input type="checkbox"/>

7.2.1 Findings

From the pilot testing it can be inferred that Q44 was not problematic for respondents. All the respondents in the pilot testing answered the question and provided a codeable answer. Between all the respondents all the answer categories were used. By examining the questionnaires it could be seen that only one respondent changed their answer, from 'we received all that he/she required' to 'did not require any social care of family support services in relation to my child in the last 12 months'. Apart from this, there were no other indications that this question was considered problematic for the respondent. Pilot testing indicates that the layout and the answer categories work in this question.

7.2.2 Recommendations

- Suggest retaining the question as it is without any modification to the wording of the question or the answer categories.

7.3 Question 45

Overall, how would you rate the quality of the social care and family support services that you received in the **last 12 months** in relation to your child named at Question 1?

- Very good
 Good
 Fair
 Poor
 Very poor
 We / I have not used social care or family support services in the last 12 months

7.3.1 Findings

Pilot testing identified three key findings:

- On the whole it was not problematic for respondents. All the respondents answered this question and provided a codeable answer.
- Examination of the questionnaires showed that two respondents did change their answers, one from 'poor' and the other from 'very poor' both to the last option, 'We/I have not used social care or family support services in the last 12 months'. The implication of this is minor as a respondent could have changed their mind. The layout of the question was clear enough for them to identify a better answer category.
- Not all the answer categories were used in this pilot study. The answer categories 'fair' and 'poor' were not used at all.

7.3.2 Recommendation

- Suggest retaining the question as it is without any modification to the wording of the question or the answer categories. As the pilot sample was small we would not suggest changing the options just because they happened not to be used here.

7.4 Question 46

Below are various things that parents have said in relation to information they had about social care and family support services for children with long standing illnesses or disabilities. Please indicate whether you agree or disagree with each of the following statements.

	Tick one box on each line			
	Agree	Neither agree nor disagree	Disagree	Not applicable
We/I have been given enough information about our social care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We/ I have been given enough useful information about the social care and family support services my <i>family is entitled to</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We/I have been given enough information about how to get social care and family support services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is someone I can go to for help and support in getting social care and family support services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7.4.1 Findings

On the whole Q46 did not appear to be problematic in the pilot testing. We report on the three main findings below.

- One respondent did not answer this question and one respondent did not answer one statement in this question, the rest of the respondents provided a codeable answer, correctly ticking one box per line. All the answer codes were used in this pilot testing. This indicates that the layout and the answer categories worked for this question.
- Testing revealed two strategies for answering this question.
 1. The same answer category was used for all four statements (17 respondents adopted this strategy and all the options were used with approximately the same frequency).
 2. Alternatively, different answer categories were used for the 4 statements. The respondent who skipped a statement (skipped statement two) adopted this strategy for the statements he / she answered.
- A minor issue but presented here for completion is that one respondent crossed out their answer which could indicate hesitancy or simply a change of opinion when answering this question

Non Response

- One respondent did not answer this question at all. There is no indication on the question to understand why the respondent did not answer this question.
- Another respondent choose not to answer statement two by leaving the line blank. Again there is no indication why the respondent adopted this strategy.

7.4.2 Recommendation

- We would suggest retaining the question as it is without changing the wording of the question or the statements, as on the whole the question worked.

7.5 Question 47

In the **last 12 months**, have you received any written or verbal information about social care or family support services in relation to your child named at Question 1? Do not include information which you had to search for yourself.

Yes → **Go to Q48** No → **Go to Q49**

7.5.1 Findings

From this pilot testing it can be inferred that Q47 was not considered problematic for respondents.

- All the respondents answered this question with a codable answer. There were no markings such as crossing outs or comments on the questionnaires to indicate the question was difficult for respondents.
- On the whole respondents were able to accurately follow the routing instructions. One respondent who should have skipped Q48 did misroute from this question and answered the following question. All the respondents who answered yes (4 respondents) at this question accurately routed to Q48.

7.5.2 Recommendation

- We would recommend retaining this question as it is without modification; ensuring the routing instructions are clear.

7.6 Question 48

Overall, how would you describe the information you received in the **last 12 months** about social care and family support services available to your family in relation to your child’s long standing illness, disability or health condition? Please include both written and verbal information you received.

	Tick one box on each line		
	Yes, always	Yes, sometimes	No
Clear - to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relevant - to you and your child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accurate - up to date and precise information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7.6.1 Findings

Below we present the three key findings revealed in the pilot, two of which related to the answer categories and one to routing.

Answer categories

- In this pilot study four respondents were routed to answer this question. All the respondents correctly ticked one box per line and gave codeable answers to each statement.
- Two answer strategies were adopted by respondents in this study:
 1. the same answer category was selected for all three statements, or
 2. different answer categories were selected for the three statements.

Routing

The one respondent in this pilot who misrouted to this question from Q47 provided codeable answers to the three statements. This respondent answered all three statements with 'yes' answers: to the first statement answered 'yes sometimes' and for the other two statements answered both 'yes always'. The respondent has provided answers which are not consistent with the previous question. The implication of this is the data collected will be invalid for this respondent.

7.6.2 Recommendations

- From the pilot testing it is not possible to know whether respondents selected the same answer option as it was the best answer for each statement or whether it was the easiest option.
- Suggest retaining Q48 without modification ensuring the routing instructions for the previous question are clear.

7.7 Question 49

In the **last 12 months**, have social care or family support services professionals such as a social worker or emotional support counsellor made any **decisions** about **your child's** illness or disability or services that you should receive? Please include decisions such as whether to be offered a new service. Do not include routine monitoring.

Yes → **Go to Q50** No → **Go to Q53**

7.7.1 Findings

From the pilot testing of this question it can be inferred that this question was not considered problematic for respondents on the whole. All but one respondent provided a codeable answer for this question. On the whole respondents were able to follow the routing instructions accurately.

Routing

In this pilot study only one respondent misrouted from this question. The respondent should have gone directly to Q53 from this question. However, they went to Q50. Another respondent indicated that they found the question problematic by placing a question mark by the answer categories. This respondent did not answer the question. From this question the respondent routed herself to Q53. As there are no further indications apart from the question mark, it is not possible to infer why this respondent found the question problematic.

7.7.2 Recommendations

- As this question on the whole was not problematic for respondents we would suggest retaining the question without modification to the wording.
- We suggest the routing instructions are clear.

7.8 Question 50

And thinking about these decisions and the questions you had to answer for your child named at Question 1, please indicate whether you agree or disagree with each of the following statements.

	Tick one box on each line			
	Agree	Neither agree nor disagree	Disagree	Not applicable
We / I had to give the same information several times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We were / I was listened to and our needs were understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The decisions made were suitable for our needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The decisions were made at the right time for us	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Where necessary, the social care professionals worked together to make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
On the whole we were happy with the decisions that were made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7.8.1 Findings

Pilot testing revealed four key findings for this question, which we present below.

Overall

- There is no evidence from the pilot testing that this question was problematic for respondents. For example there is no indication that answers were changed and no comments were provided by respondents on this question. Unlike the equivalent question in the health section (Q13), this question did not seem to be sensitive for respondents.

Answer Categories

- All the respondents who were routed to Q50 from Q49 provided a codeable answer (5 respondents). All the answer categories were used between all the respondents. 'Agree' was used 13 times (and was used by all but one respondent), 'neither agree or disagree' was used five times (three times by one respondent and twice by another respondent), 'disagree' was used eight times (seven times by one respondent) and 'NA' was used once.
- Three answer strategies were observed in this piloting testing of this question:
 1. selected the same answer category for all six statements (one respondent did this and s/he selected agree for all), or
 2. selected different answer categories for all 6 statements (three respondents); or,
 3. left a statement unanswered (One respondent did this and did not answer statement three).

Routing

- The one respondent who misrouted answered Q50 using either 'neither agree or disagree' for statements one, three and six, 'disagree' (for statement two and four) or 'not applicable' (statement five).

7.8.2 Recommendation

- Suggest retaining the question as it is without any modification.
- Suggest highlighting the instruction '**please tick one box on each line**' in bold to remind respondents about the instructions.
- To reduce the opportunities for respondents misrouting from the previous question, we would suggest an instruction is provided above this question as it is on a different page to Q49. The instruction could be: 'if yes at Q49 answer Q50 to Q52, if no at Q49 move to Q53'.

7.9 Question 51

How well do you understand the decisions that are made about the social care and family support services you receive?

Very well

Fairly well

Not very well

Not at all well

7.9.1 Findings

With the exception of one respondent who missed the routing from Q49 (and answered 'Very well', suggesting satisficing), only those respondents who were routed to this question answered it; they chose all answer categories apart from 'Not at all well'.

7.9.2 Recommendations

- Suggest retaining question without modification.

7.10 Question 52

Over the **last 12 months**, were you consulted or asked for your opinion when **decisions were being made** about your family's need for social care and family support services in relation to your child named at Question 1?

Yes, consulted a lot

Yes, consulted a little

No, not consulted at all

7.10.1 Findings

With the exception of one respondent who missed the routing from Q49 (and answered 'Yes, consulted a lot'), only those respondents who were routed to this question answered it; they chose all answer categories apart from 'No, not consulted at all'. It seems that the one respondent who misrouted displayed the primacy effect in the way they answered by selecting the first answer to the previous question and this question, just to move on to the next question. The implication of this is that invalid data will be collected on this question and the previous question by such respondents. However, by ignoring any data collected as a result of misrouting in analysis (setting to missing any questions which should not have been answered based on their previous answers) this problem can be overcome.

7.10.2 Recommendation

- Suggest retaining question without modification. However, for this question to work effectively and measure accurately what it intends too, is dependent on the clear routing at Q49.

7.11 Question 53

Over the **last 12 months**, have you been asked for your opinion or feedback on the **social care and family support services your family received** in relation to your child named at Question 1?

Yes

No, did not receive any social care or family support services in the last 12 months

No, not asked for my opinion or feedback

7.11.1 Findings

The pilot testing of Q53 identified three key findings to do with answer categories and routing which are presented below.

Answer categories

- All respondents provided an answer for this question though no one chose 'Yes'.
- One respondent ticked 'No, not asked for my opinion or feedback' before crossing this out and selecting 'No, did not receive any social care or family support services in the last 12 months': the latter answer category chosen was consistent with answers the respondent had previously given and so it would appear this was a simple error.

Routing

- Three respondents who answered 'No, not asked for my opinion or feedback' missed the routing and answered Q54 rather than going straight to Q55; they all answered 'Don't Know'.

7.11.2 Recommendation

- Suggest retaining question without modification ensuring the routing instructions are clear.

7.12 Question 54

Do you think that changes were made as a result of the opinions or feedback you gave?

Yes

No

Don't know

7.12.1 Findings

There was only one key finding from testing this question and this was due to misrouting from the previous question. The three respondents who inaccurately answered this question all logically answered 'Don't Know'. No other respondents were routed to this question.

7.12.2 Recommendation

- Question not tested fully, suggest retaining without modification.

7.13 Question 55

Over the **last 12 months**, has your child been asked his/her opinion or feedback on the social care and family support services your family received?

Yes → Go to Q56

No, did not receive any social care and family support services → Go to Q57
for the child in the last 12 months

No, child not able to provide opinion or feedback due to young → Go to Q57
age or difficulties with learning, understanding or communication

No, not asked for feedback → Go to Q57

7.13.1 Findings

The pilot identified three routing problems with this question.

Routing

- Of the respondents who answered 'No, not asked for my opinion or feedback' at Q53, most routed correctly to this question. One respondent left it unanswered however.
- No respondents answered 'Yes' and therefore ALL respondents should have been routed past Q56; however one respondent did go on to answer 'Don't Know', at Q56.
- All other respondents correctly missed out Q56 and went straight on to answer Q57.

7.13.2 Recommendation

- Suggest retaining question without modification.

7.14 Question 56

Do you think that changes were made as a result of the feedback or opinion your child gave?

Yes

No

Don't know

7.14.1 Findings

This question was not fully tested in the pilot; below are the three points which were identified.

- No respondents were routed to this question.
- One respondent answered it in error - they answered 'Don't Know'.
- Another respondent ticked 'Don't Know' and then crossed it out - this would indicate they realised they were not supposed to answer this question.

7.14.2 Recommendation

- Question not tested fully, suggest retaining without modification.

7.15 Question 57

In the **last 12 months**, have you made a written complaint about a social care or family support service you have received in relation to your child?

- | | |
|---|-------------|
| Yes, to the service provider <input type="checkbox"/> | → Go to Q58 |
| Yes, to my Local Authority <input type="checkbox"/> | → Go to Q58 |
| Yes, to other organisation (please write in below) <input type="checkbox"/> | → Go to Q58 |
| No, I have not complained <input type="checkbox"/> | → Go to Q60 |

7.15.1 Findings

The four main points examined from analysing respondents' answers to this question were related to answer categories and routing.

Answer Categories

- All respondents answered this question: one chose 'Yes, to the service provider', all others chose 'No, I have not complained'.
- Answer categories 'Yes, to my Local Authority' and 'Yes, to another organisation' were not chosen.

Routing

- The one respondent who answered 'Yes, to the service provider' correctly followed the routing to Q58 but then failed to answer Q59.
- All other respondents correctly followed the routing and so did not answer Q58 or Q59.

7.15.2 Recommendation

- Suggest retaining this question without modification.

7.16 Question 58

How easy or difficult was it to find out how to make a formal written complaint?

- Very easy
- Fairly easy
- Neither easy or difficult
- Fairly difficult
- Very difficult

7.16.1 Findings

Question 58 was not fully tested in this pilot as only one respondent was routed to this question; they answered 'Neither easy or difficult'.

7.16.2 Recommendation

- Question not tested fully, suggest retaining without modification.

7.17 Question 59

Thinking about the complaints process, how well was your complaint dealt with?

Very well

Fairly well

Not very well

Not at all well

7.17.1 Findings

This question was not answered by any respondents in this study.

7.17.2 Recommendation

- Question not tested fully. Suggest retaining without modification.

7.18 Question 60

If there is anything else you would like to tell us in relation to your child's long-standing illness, disability or health problem or their use of services, please write it in the box below

7.18.1 Findings

Question 60 is an open text box. The pilot testing revealed that this question works well. We discuss the two key findings below which can both be considered as issues on sensitivity.

Sensitivity

- Fifteen respondents provided additional information here. As this questionnaire explores sensitive issue of services for disabled children this open text box has been used by respondents to clarify their experiences of accessing health care, education and social care services. It was also used by respondents to ask for help and for respondents to highlight their difficulties and frustrations in accessing services.

Below we present a sample of comments which were provided by respondents edited to maintain the anonymity of respondents.

“I need emotional support and help with transport for [child]. Everyone I ask says no. I need help. I am sick of fighting for everything.

(Respondent with an eight year old child with multiple health conditions and who has used health and education services in the last 12 months)

“When structures work well for example moving school life is far less stressful. Being at [X school] where the staff didn’t understand [child]’s difficulties was simply awful”

(Respondent with a five year old child with multiple health conditions and who has used multiple health and education services in the last 12 months).

“We have no idea what help (if any) is available for us and our child”

(Respondent with 12 year old child with multiple health conditions and who has used health, education and social care services in the last 12 months).

“I cannot group the health service provides together because some have been excellent and others very poor”

(Respondent with 15 year old child with multiple health conditions and who has used health, education and social care services in the last 12 months)

- The type of explanations provided indicate that this questionnaire should be supported with a leaflet with contact numbers for respondents to discuss their concerns which are brought to light through answering these very detailed questions.

7.18.2 Recommendation

- | |
|---|
| <ul style="list-style-type: none">• Retain this question• Support this questionnaire with a leaflet providing phone numbers where support can be sought. |
|---|

8. SUMMARY

- The findings from the pilot study indicate that both the screening and the main stage questionnaire on the whole worked well.
- The questions which will feed into the Disabled Children's Services performance indicator should work in a postal administered survey.
- The main problem in both the screening and the main stage questionnaire was **routing**. This problem was not found to be a consistent problem at all questions which had routing instructions. Nor did the same respondent have a consistent problem with routing generally. Rather most respondents had occasional problems with routing.
- There were questions that were considered **sensitive** in the main stage questionnaire.

8.1 Routing problems

8.1.1 The implications of routing problems

- There are two main types of routing errors:
 1. questions can be skipped in error leading to missing data
 2. questions can be answered in error, leading to respondent fatigue and possible satisficing² later in the questionnaire - this is the main concern for the main stage questionnaire.
- Both type of routing error can result in a reduction in data validity and reliability.
- Most routing errors in the pilot involved **respondents answering questions which were not applicable**. In these cases, at the analysis stage it will be possible to ignore data collected by respondents who have misrouted, by setting to 'missing' any questions, which should not have been answered, based on their previous answers.
- For questions which have been skipped in error there is no analysis solution which means it is important to minimise the chances of such errors occurring through clear signposting throughout the questionnaire.

8.1.2 Recommendation to address the routing problem

- We would recommend that to assist respondents in accurately navigating through the questionnaire, **routing needs to be consistently clear**. For example, place the routing instructions in a consistent place and format to the right of the tick box and use bold and possibly capital fonts. This will all draw the respondents' eyes and follow their natural reading pattern, assisting them in routing correctly, as shown in the literature (Jenkins and Dillman 1997).

² Satisficing is a strategy that respondents adopt to try to reduce the cognitive demands of answering a question accurately by providing what they deduce are satisfactory answers.

- To help reduce routing errors we would also suggest an example is provided on the front page of the main questionnaire so respondents have an example to read before they commence filling in the questionnaire and can refer too it later. This will help comprehension and motivation in filling in the questionnaire, both of which need to be carefully considered in designing self administered questionnaires (Jenkins and Dillman 1997).

8.2 Sensitivity

8.2.1 The implications of sensitivity

- The possible implications of sensitivity are that respondents will:
 - answer questions inaccurately,
 - skip individual questions they consider to be sensitive,
 - not continue past a sensitive question,
 - not participate in the survey at all.
- In the pilot there was evidence of respondents missing individual questions but no evidence of stopping at the sensitive questions. The low response to the pilot could be an indication of the sensitive subject matter deterring respondents, although we have no information about reasons for non-participation.
- In the pilot, where respondents reported finding the questions sensitive this was related to having to think of services overall when they had had good and bad experiences of services in the last 12 months. Bad experience of services (which was a sensitive subject for the respondents) made it difficult for those who had also had some good experiences to generalise from their experience in order to answer the questions. The implication of which is that respondents may not answer the question or answer the question inaccurately.

8.2.2 Recommendation to address sensitivity

- As the questionnaire explores issues which can be viewed as sensitive by some respondents it is important the questionnaire is supported with a leaflet providing support with contact numbers for relevant organisations. It was particularly some questions in the health and education sections which were considered sensitive by respondents.
- We recommend an explanation is provided on the **front page** and at the **start of each service section** of questionnaire to point out that some of the questions refer to the **overall experience** in the last 12 months.
- To support this statement we suggest adding a sentence such as “If your experience has been varied please try and answer these questions the best you can by thinking about your overall experience” at the particularly sensitive questions namely Q7, Q8, Q24 and Q25.
- The inclusion of text boxes after sensitive questions would also assist respondents in describing their experiences and justifying their responses which could appear inconsistent if they have had diverse experience of services.

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Appendix 1 - Screening Questionnaire

Child five

1. What is this child's first name?

2. Is this child Male or Female?

3. What was this child's age last birthday? Years

4. Does this child have any long-standing illnesses, health problems or disabilities which mean that he/she has substantial difficulties with any of the areas of his/her life shown below? By long-standing we mean anything that has troubled this child over a period of at least 12 months or that is likely to affect him/her over at least 12 months. Please exclude difficulties that you would expect for a child of that age.

Please tick all that apply

- Yes substantial difficulties with:
- Mobility or moving around
 - Lifting/carrying
 - Manual dexterity (using his/her hands)
 - Continence/going to the toilet
 - Eating or drinking
 - Communication, speech or social skills Go to **Child six** on extra form or
 - Visual or hearing problems
 - Memory/ability to concentrate or understand
 - Ability to recognise if in physical danger Go to **Q7**
 - Physical coordination
 - Other areas of his/her life
 - I don't know, I am unsure

No, this child does not have substantial difficulties with any of the areas above Go to **Q5**

If child does not have substantial difficulties with any of the areas at Q4.

5. Does this child take any medication, use any physical aids, or require any special diets or supplements for any long-standing illnesses, health problems or disabilities?

Please tick all that apply

- Yes - medication
- Yes - physical aid (e.g. hearing aid or respiratory support) Go to **Q6**
- Yes - special diet or diet supplements
- No medication, physical aid or special diet Go to **Child six** on extra form or Go to **Q7**

If yes at Q5

6. If this child did not take this medication, use this physical aid or have a special diet or supplements would he/she have substantial difficulties with any of the areas of life listed at question 4?

- Yes Go to **Child six** on extra form or
- No Go to **Q7**

Everyone please answer

7. We will be doing some further research that will help the Government to find out about the health of children and use of local services. We will treat all the information you give us confidentially. Would you be happy to take part in this research?

- Yes
- No

If yes at Q7

8. In order to help us conduct this further research, we would be very grateful if you could provide your telephone number in the box below.

Telephone number (please include the area code)

We will not pass on your phone number to anyone outside the research team. We will only contact you to take part in studies relating to children's services.

If yes at Q7

9. Please check the address on the envelope this questionnaire arrived in. If your address has changed or was incorrect please write in your address below:

House no. or name

Street

Town

County

Postcode

We will not pass on your address to anyone outside the research team. We will only contact you to take part in studies relating to children's services.

If yes at Q7

10. So that we can contact you again please write in your full name (name of parent).

Title

First name

Surname

If you have more than five children please call us on 020 7549 7069 to request an additional form.

Thank you very much for your help.

The information that you have given is confidential to the research team.

Confidential

The health & well-being of children



NatCen is carrying out this study on behalf of the Department for Children, Schools and Families (DCSF) and the Department of Health (DH) to help the government improve the local services it gives to families and children

How many children aged 19 or under do you have who either live in your household, or live most or all of the time elsewhere?

Please write in

We are interested in the health and well-being of children and to make this study a success it is important that everyone fills in this questionnaire about all their children.

How to fill in this questionnaire

Please fill in a section of this questionnaire for each of your children and then go to Question 7 in the 'EVERYONE PLEASE ANSWER' section.

If you have more than five children please call us on 020 7549 7069 to request an additional form.

Please answer the questions by:

Ticking a box like this

Or writing a number in a box like this

Sometimes you will find an instruction telling you which questions to answer next like this:

Yes Go to **Q4**

No Go to **Child two**

THANK YOU FOR YOUR HELP

SN 001-006 OI 007 Card 008-000 Batch 010-014

Child one	
1. What is this child's first name? <input type="text"/>	101-104
2. Is this child <input type="checkbox"/> Male or <input type="checkbox"/> Female?	105
3. What was this child's age last birthday? <input type="text"/> Years	106-107
<p>4. Does this child have any long-standing illnesses, health problems or disabilities which mean that he/she has substantial difficulties with any of the areas of his/her life shown below? By long-standing we mean anything that has troubled this child over a period of at least 12 months or that is likely to affect him/her over at least 12 months. Please exclude difficulties that you would expect for a child of that age.</p> <p style="text-align: center;"><i>Please tick all that apply</i></p> <p>Yes substantial difficulties with:</p> <p>Mobility or moving around <input type="checkbox"/></p> <p>Lifting/carrying <input type="checkbox"/></p> <p>Manual dexterity (using his/her hands) <input type="checkbox"/></p> <p>Continence/going to the toilet <input type="checkbox"/></p> <p>Eating or drinking <input type="checkbox"/></p> <p>Communication, speech or social skills <input type="checkbox"/></p> <p>Visual or hearing problems <input type="checkbox"/></p> <p>Memory/ability to concentrate or understand <input type="checkbox"/></p> <p>Ability to recognise if in physical danger <input type="checkbox"/></p> <p>Physical coordination <input type="checkbox"/></p> <p>Other areas of his/her life <input type="checkbox"/></p> <p>I don't know, I am unsure <input type="checkbox"/></p> <p>No, this child does not have substantial difficulties with any of the areas above <input type="checkbox"/> Go to Q5</p> <p><i>If child does not have substantial difficulties with any of the areas at Q4.</i></p> <p>5. Does this child take any medication, use any physical aids, or require any special diets or supplements for any long-standing illnesses, health problems or disabilities?</p> <p style="text-align: center;"><i>Please tick all that apply</i></p> <p>Yes - medication <input type="checkbox"/></p> <p>Yes - physical aid (e.g. hearing aid or respiratory support) <input type="checkbox"/></p> <p>Yes - special diet or diet supplements <input type="checkbox"/></p> <p>No medication, physical aid or special diet <input type="checkbox"/> Go to Child two or Go to Q7 on back page</p> <p><i>If yes at Q5</i></p> <p>6. If this child did not take this medication, use this physical aid or have a special diet or supplements would he/she have substantial difficulties with any of the areas of life listed at question 4?</p> <p>Yes <input type="checkbox"/> Go to Child two or No <input type="checkbox"/> Go to Q7 on back page</p>	

Child two	
1. What is this child's first name? <input type="text"/>	101-104
2. Is this child <input type="checkbox"/> Male or <input type="checkbox"/> Female?	107
3. What was this child's age last birthday? <input type="text"/> Years	108-109
<p>4. Does this child have any long-standing illnesses, health problems or disabilities which mean that he/she has substantial difficulties with any of the areas of his/her life shown below? By long-standing we mean anything that has troubled this child over a period of at least 12 months or that is likely to affect him/her over at least 12 months. Please exclude difficulties that you would expect for a child of that age.</p> <p style="text-align: center;"><i>Please tick all that apply</i></p> <p>Yes substantial difficulties with:</p> <p>Mobility or moving around <input type="checkbox"/></p> <p>Lifting/carrying <input type="checkbox"/></p> <p>Manual dexterity (using his/her hands) <input type="checkbox"/></p> <p>Continence/going to the toilet <input type="checkbox"/></p> <p>Eating or drinking <input type="checkbox"/></p> <p>Communication, speech or social skills <input type="checkbox"/></p> <p>Visual or hearing problems <input type="checkbox"/></p> <p>Memory/ability to concentrate or understand <input type="checkbox"/></p> <p>Ability to recognise if in physical danger <input type="checkbox"/></p> <p>Physical coordination <input type="checkbox"/></p> <p>Other areas of his/her life <input type="checkbox"/></p> <p>I don't know, I am unsure <input type="checkbox"/></p> <p>No, this child does not have substantial difficulties with any of the areas above <input type="checkbox"/> Go to Q5</p> <p><i>If child does not have substantial difficulties with any of the areas at Q4.</i></p> <p>5. Does this child take any medication, use any physical aids, or require any special diets or supplements for any long-standing illnesses, health problems or disabilities?</p> <p style="text-align: center;"><i>Please tick all that apply</i></p> <p>Yes - medication <input type="checkbox"/></p> <p>Yes - physical aid (e.g. hearing aid or respiratory support) <input type="checkbox"/></p> <p>Yes - special diet or diet supplements <input type="checkbox"/></p> <p>No medication, physical aid or special diet <input type="checkbox"/> Go to Child three or Go to Q7 on back page</p> <p><i>If yes at Q5</i></p> <p>6. If this child did not take this medication, use this physical aid or have a special diet or supplements would he/she have substantial difficulties with any of the areas of life listed at question 4?</p> <p>Yes <input type="checkbox"/> Go to Child three or No <input type="checkbox"/> Go to Q7 on back page</p>	

Child three	
1. What is this child's first name? <input type="text"/>	110-113
2. Is this child <input type="checkbox"/> Male or <input type="checkbox"/> Female?	114
3. What was this child's age last birthday? <input type="text"/> Years	115-116
<p>4. Does this child have any long-standing illnesses, health problems or disabilities which mean that he/she has substantial difficulties with any of the areas of his/her life shown below? By long-standing we mean anything that has troubled this child over a period of at least 12 months or that is likely to affect him/her over at least 12 months. Please exclude difficulties that you would expect for a child of that age.</p> <p style="text-align: center;"><i>Please tick all that apply</i></p> <p>Yes substantial difficulties with:</p> <p>Mobility or moving around <input type="checkbox"/></p> <p>Lifting/carrying <input type="checkbox"/></p> <p>Manual dexterity (using his/her hands) <input type="checkbox"/></p> <p>Continence/going to the toilet <input type="checkbox"/></p> <p>Eating or drinking <input type="checkbox"/></p> <p>Communication, speech or social skills <input type="checkbox"/></p> <p>Visual or hearing problems <input type="checkbox"/></p> <p>Memory/ability to concentrate or understand <input type="checkbox"/></p> <p>Ability to recognise if in physical danger <input type="checkbox"/></p> <p>Physical coordination <input type="checkbox"/></p> <p>Other areas of his/her life <input type="checkbox"/></p> <p>I don't know, I am unsure <input type="checkbox"/></p> <p>No, this child does not have substantial difficulties with any of the areas above <input type="checkbox"/> Go to Q5</p> <p><i>If child does not have substantial difficulties with any of the areas at Q4.</i></p> <p>5. Does this child take any medication, use any physical aids, or require any special diets or supplements for any long-standing illnesses, health problems or disabilities?</p> <p style="text-align: center;"><i>Please tick all that apply</i></p> <p>Yes - medication <input type="checkbox"/></p> <p>Yes - physical aid (e.g. hearing aid or respiratory support) <input type="checkbox"/></p> <p>Yes - special diet or diet supplements <input type="checkbox"/></p> <p>No medication, physical aid or special diet <input type="checkbox"/> Go to Child four or Go to Q7 on back page</p> <p><i>If yes at Q5</i></p> <p>6. If this child did not take this medication, use this physical aid or have a special diet or supplements would he/she have substantial difficulties with any of the areas of life listed at question 4?</p> <p>Yes <input type="checkbox"/> Go to Child four or No <input type="checkbox"/> Go to Q7 on back page</p>	

Child four	
1. What is this child's first name? <input type="text"/>	117-120
2. Is this child <input type="checkbox"/> Male or <input type="checkbox"/> Female?	121
3. What was this child's age last birthday? <input type="text"/> Years	122-123
<p>4. Does this child have any long-standing illnesses, health problems or disabilities which mean that he/she has substantial difficulties with any of the areas of his/her life shown below? By long-standing we mean anything that has troubled this child over a period of at least 12 months or that is likely to affect him/her over at least 12 months. Please exclude difficulties that you would expect for a child of that age.</p> <p style="text-align: center;"><i>Please tick all that apply</i></p> <p>Yes substantial difficulties with:</p> <p>Mobility or moving around <input type="checkbox"/></p> <p>Lifting/carrying <input type="checkbox"/></p> <p>Manual dexterity (using his/her hands) <input type="checkbox"/></p> <p>Continence/going to the toilet <input type="checkbox"/></p> <p>Eating or drinking <input type="checkbox"/></p> <p>Communication, speech or social skills <input type="checkbox"/></p> <p>Visual or hearing problems <input type="checkbox"/></p> <p>Memory/ability to concentrate or understand <input type="checkbox"/></p> <p>Ability to recognise if in physical danger <input type="checkbox"/></p> <p>Physical coordination <input type="checkbox"/></p> <p>Other areas of his/her life <input type="checkbox"/></p> <p>I don't know, I am unsure <input type="checkbox"/></p> <p>No, this child does not have substantial difficulties with any of the areas above <input type="checkbox"/> Go to Q5</p> <p><i>If child does not have substantial difficulties with any of the areas at Q4.</i></p> <p>5. Does this child take any medication, use any physical aids, or require any special diets or supplements for any long-standing illnesses, health problems or disabilities?</p> <p style="text-align: center;"><i>Please tick all that apply</i></p> <p>Yes - medication <input type="checkbox"/></p> <p>Yes - physical aid (e.g. hearing aid or respiratory support) <input type="checkbox"/></p> <p>Yes - special diet or diet supplements <input type="checkbox"/></p> <p>No medication, physical aid or special diet <input type="checkbox"/> Go to Child five or Go to Q7 on back page</p> <p><i>If yes at Q5</i></p> <p>6. If this child did not take this medication, use this physical aid or have a special diet or supplements would he/she have substantial difficulties with any of the areas of life listed at question 4?</p> <p>Yes <input type="checkbox"/> Go to Child five or No <input type="checkbox"/> Go to Q7 on back page</p>	

Appendix 2 - Main Questionnaire



Children and the Use of Local Services SELF-COMPLETION QUESTIONNAIRE

P2841: Team: Pink

Please read these instructions first before completing the questionnaire

You should answer this questionnaire for only **ONE child with a long standing illness, disability or health condition**. This should be a child for whom you answered as follows on the **short blue questionnaire**:

- you ticked **at least one of the difficulties at question 4**
- OR you ticked **yes at question 6**

If you have more than one child with a long standing illness, disability or health problem you should answer this main questionnaire only for your child with a first name which begins with the letter closest to A in the alphabet. So for example if you have two children (Jack and Sarah), who both have a long standing illness, disability or health condition, you would answer this main questionnaire about Jack.

Most of the questions can be answered by ticking the box next to the answer and following the arrows which tell you which question to answer next. If there are no arrows, simply carry on to the next question.

NatCen is carrying out this study on behalf of the Department of Children, School and Families (DCSF) and the Department of Health (DH) to help the government improve the local services it gives to families and children. This questionnaire explores parents' experience of accessing services for their child.

Your participation is important as it will allow the DCSF and the DH to measure parental experiences of services and explore the impact on children's health and well-being.

Thank you for your time.

About your Child

Q1 What is the child's first name?

Q2 What is the child's date of birth?

Day

Month

Year

430-431

432-433

434-437

Q3 Do you receive Disability Living Allowance (DLA) for your child? Please include if the child receives DLA in his / her own right

Yes

No

01

02

Q4	To which ethnic group do you consider your child belongs?	Tick one box
	White	<input type="checkbox"/> _01
	Mixed	
	White and Black African	<input type="checkbox"/> _02
	White and Asian	<input type="checkbox"/> _03
	White and Black Caribbean	<input type="checkbox"/> _04
	Any other mixed background	<input type="checkbox"/> _05
	Asian or Asian British	
	Indian	<input type="checkbox"/> _06
	Pakistani	<input type="checkbox"/> _07
	Bangladeshi	<input type="checkbox"/> _08
	Any other Asian background	<input type="checkbox"/> _09
	Black or Black British	
	Caribbean	<input type="checkbox"/> _10
	African	<input type="checkbox"/> _11
	Any other Black background	<input type="checkbox"/> _12
	Chinese	<input type="checkbox"/> _13
	Any other ethnic group	<input type="checkbox"/> _14

Q5 Please record all the areas in which this child is currently affected or could be when his/her illness, disability or health condition flares up. Tick all that apply.

	None	<input type="checkbox"/> _01
Mobility - getting about on their own outside the house or getting around inside the home		<input type="checkbox"/> _02
Hand function - holding and touching		<input type="checkbox"/> _03
Personal care - washing, going to the toilet, dressing etc		<input type="checkbox"/> _04
Eating and Drinking - has difficulty eating or drinking by himself or herself		<input type="checkbox"/> _05
Medication - has difficulty taking medication or has side effects because of medication he / she takes		<input type="checkbox"/> _06
Incontinence - controlling the passage of urine and faeces		<input type="checkbox"/> _07
Communication - speaking and/or understanding others		<input type="checkbox"/> _08
Learning - having special educational needs		<input type="checkbox"/> _09
Hearing		<input type="checkbox"/> _10
Vision		<input type="checkbox"/> _11
Behaviour - a condition resulting in the child getting frustrated or exhibiting socially unacceptable behaviour		<input type="checkbox"/> _12
Consciousness - fits and seizures		<input type="checkbox"/> _13
Diagnosed with autism, Asperger Syndrome or Autistic Spectrum Disorder (ASD)		<input type="checkbox"/> _14
Palliative care needs (an active and total approach to care which focuses on enhancement of overall quality of life for the child and support for the family)		<input type="checkbox"/> _15
Other (please write in other areas your child is affected)		<input type="checkbox"/> _16

Health Care Services

The following questions are about the health care services which your child receives. This section covers both National Health Service (NHS) and private or non-NHS health care.

Q6 Which of the following health care services has your child used in the **last 12 months**?

Tick one box on each line

GP	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Practice nurse (at the GP surgery)	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Health visitor, district nurse, other community nurse	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Paediatrician (child health doctor) or other specialist doctor (including visiting hospital as outpatient)	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Psychologist	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Psychiatrist or behavioural specialist	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Physiotherapist	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Speech therapist	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Occupational therapist (OT)	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Podiatrist or chiropodist (foot specialist)	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Optician or eye specialist	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Dentist	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Dietician or nutritionist	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Hospital as inpatient	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Emergency health care (e.g. A and E or minor injuries)	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Palliative care (an active and total approach to care which focuses on enhancement of overall quality of life for the child and support for the family).	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Complementary or alternative medicine practitioner	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂
Other health services (please write in)				

01

Q7

Over the **last 12 months**, do you feel your child has received all the health care services that he or she required? Please tick one box below which best describes your experience over the last 12 months.

Did not require any health care services for my child in the last 12 months

_01

556-557

My child received:

All that he / she required

_02

Most of what he / she required

_03

Some of what he / she required

_04

Little of what he / she required

_05

None of what he / she required

_06

Q8

Overall, how would you rate the quality of the health care services that your child has had in the **last 12 months**?

Very good

_01

558-559

Good

_02

Fair

_03

Poor

_04

Very poor

_05

I have not used health care services for my child in the last 12 months

_06

Q9

Below are various things that parents have said in relation to information they had about their child's health condition and available health care services. Please indicate whether you agree or disagree with each of the following statements. Tick one box on each line

Agree

Neither agree nor disagree

Disagree

Not Applicable

We / I have been given enough useful information about **my child's disability or health condition**

_01_02_03_09

560-561

We / I have been given enough useful information about the **health services** my child is entitled to

_01_02_03_09

562-563

We / I have been given enough information about **how to get** health care services for my child

_01_02_03_09

564-565

There is someone we / I can go to for help and support in getting health services for my child

_01_02_03_09

566-567

Q10

In the **last 12 months** have you received any written or verbal information about health care services (NHS or private) for your child named at Question 1? Do not include information which you had to search for yourself.

Yes ₀₁ → **Go to Q11** 568-569
 No ₀₂ → **Go to Q12**

Q11

Overall, how would you describe the information you received in the **last 12 months** about health care services for your child? Please include both written and verbal information you received.

Tick one box on each line

	Yes, always	Yes, sometimes	No	
Clear - to understand	<input type="checkbox"/> ₀₁	<input type="checkbox"/> ₀₂	<input type="checkbox"/> ₀₃	570-571
Relevant - to you and your child	<input type="checkbox"/> ₀₁	<input type="checkbox"/> ₀₂	<input type="checkbox"/> ₀₃	572-573
Accurate - up to date and precise information	<input type="checkbox"/> ₀₁	<input type="checkbox"/> ₀₂	<input type="checkbox"/> ₀₃	574-575

Q12

In the **last 12 months**, have medical or health professionals made any **decisions** about your child's illness or disability or services that he / she should receive? Please include decisions such as whether to have an operation or change medication. Do not include routine monitoring.

Yes ₀₁ → **Go to Q13** 576-577
 No ₀₂ → **Go to Q16**

Q13

And thinking about these decisions and the questions you had to answer in the **last 12 months**, please indicate whether you agree or disagree with each of the following statements. Please include decisions such as whether to have an operation or change medication. Do not include routine monitoring.

	Tick one box on each line				
	Agree	Neither agree nor disagree	Disagree	Not applicable	
We / I had to give the same information several times	<input type="checkbox"/> ₀₁	<input type="checkbox"/> ₀₂	<input type="checkbox"/> ₀₃	<input type="checkbox"/> ₀₉	578-579
We were / I was listened to and our needs were understood	<input type="checkbox"/> ₀₁	<input type="checkbox"/> ₀₂	<input type="checkbox"/> ₀₃	<input type="checkbox"/> ₀₉	580-581
The decisions made were suitable for my child's needs	<input type="checkbox"/> ₀₁	<input type="checkbox"/> ₀₂	<input type="checkbox"/> ₀₃	<input type="checkbox"/> ₀₉	582-583
The decisions were made at the right time for my child	<input type="checkbox"/> ₀₁	<input type="checkbox"/> ₀₂	<input type="checkbox"/> ₀₃	<input type="checkbox"/> ₀₉	584-585
Where necessary, the health professionals worked together to make decisions	<input type="checkbox"/> ₀₁	<input type="checkbox"/> ₀₂	<input type="checkbox"/> ₀₃	<input type="checkbox"/> ₀₉	586-587
On the whole we were happy with the decisions that were made	<input type="checkbox"/> ₀₁	<input type="checkbox"/> ₀₂	<input type="checkbox"/> ₀₃	<input type="checkbox"/> ₀₉	588-589

Q14 How well do you understand the decisions that are made about your child's health care?

- Very well _01 590-591
- Fairly well _02
- Not very well _03
- Not at all well _04

Q15 Over the **last 12 months**, were you consulted or asked for your opinion when **decisions were being made** about your child's health care?

- Yes, consulted a lot _01 592-593
- Yes, consulted a little _02
- No, not consulted at all _03

Q16 Over the **last 12 months**, have you been asked for your opinion or feedback on the **health care services your child received?**

- Yes _01 → **Go to Q17** 594-595
- No, did not receive any health services for the child in the last 12 months _03 → **Go to Q20**
- No, not asked for opinion or feedback _02 → **Go to Q18**

Q17 Do you think that changes were made as a result of the opinions or feedback you gave?

- Yes _01 596-597
- No _02
- Don't know _08

Q18 Over the **last 12 months**, has your child been asked for his / her opinion or feedback on the health care services he/she received?

- Yes _01 → **Go to Q19** 598-599
- No, did not receive any health services for the child in the last 12 months _02 → **Go to Q20**
- No, child not able to provide opinion or feedback due to young age or difficulties with learning, understanding or communication _03 → **Go to Q20**
- No, not asked for opinion or feedback _04 → **Go to Q20**

Q19 Do you think that changes were made as a result of the opinions or feedback your child gave?

Yes _01

600-601

No _02

Don't know _08

Q20 In the **last 12 months**, have you made a written complaint about a health care service you have received in relation to your child?

Yes, to the service provider _01 → **Go to Q21**

602-625

Yes, to my Local Authority or Primary Care Trust _02 → **Go to Q21**

Yes, to other organisation (please specify) _03 → **Go to Q21**

No, I have not complained _04 → **Go to Q23**

Q21 How easy or difficult was it to find out how to make a formal written complaint?

Very easy _01

626-627

Fairly easy _02

Neither easy or difficult _03

Fairly difficult _04

Very difficult _05

Q22 Thinking about the complaints process, how well was your complaint dealt with?

Very well _01

628-629

Fairly well _02

Not very well _03

Not at all well

Education / Early Years Services

The following questions are about the education services (including pre-school education) your child receives. Please think only about education services received by **your child named at Question 1**.

Q23

Which of the following education services has your child (named at Question 1) used in the **last 12 months**?

Tick one box on each line

Pre-school or nursery	Yes	<input type="checkbox"/>	0101	No	<input type="checkbox"/>	02	651-652
Children's centre	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	653-654
Home teaching, Portage, Private Tutor	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	655-656
Mainstream school	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	657-658
Special school	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	659-660
Special education unit	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	661-662
Hospital education service	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	663-664
Support from Special Needs Teacher	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	665-666
Dedicated teaching assistant / learning support assistant	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	667-668
Educational psychologist	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	669-670
Further education college	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	671-672
Connexions	Yes	<input type="checkbox"/>	01	No	<input type="checkbox"/>	02	673-674
Other (please write in) _____							675-694

Q24

Over the **last 12 months**, do you feel your child has received all the education services that he or she required? Please tick one box below which best describes your experience over the last 12 months.

Did not require any education services for my child in the last 12 months	<input type="checkbox"/>	01	695-696
My child received: All that he / she required	<input type="checkbox"/>	02	
Most of what he / she required	<input type="checkbox"/>	03	
Some of what he / she required	<input type="checkbox"/>	04	
Little of what he / she required	<input type="checkbox"/>	05	
None of what he / she required	<input type="checkbox"/>	06	

Q25 Overall, how would you rate the quality of the education services that your child has received in the **last 12 months**?

Very good	<input type="checkbox"/>	01	697-698
Good	<input type="checkbox"/>	02	
Fair	<input type="checkbox"/>	03	
Poor	<input type="checkbox"/>	04	
Very poor	<input type="checkbox"/>	05	
I have not used education services for my child in the last 12 months	<input type="checkbox"/>	06	

Q26 Below are various things that parents have said in relation to information they had about education services for their child. Please indicate whether you agree or disagree with each of the following statements.

Tick one box on each line

	Agree	Neither agree nor disagree	Disagree	Not Applicable	
We/I have been given enough useful information about my child's educational needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	699-700
We/ I have been given enough useful information about the education services my child is entitled to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	701-702
We/I have been given enough information about how to get education services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	703-704
There is someone I can go to for help and support in getting education services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	705-706

Q27 In the **last 12 months**, have you received any written or verbal information about education services for your child named at Question 1? Do not include information which you had to search for yourself.

Yes	<input type="checkbox"/>	01	→ Go to Q28	707-708
No	<input type="checkbox"/>	02	→ Go to Q29	

Q28

Overall, how would you describe the information you received in the **last 12 months** about education services for your child named at Question 1? Please include both written and verbal information you received.

Tick one box on each line

	Yes, always	Yes, sometimes	No	
Clear - to understand	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	709-710
Relevant – to you and your child	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	711-712
Accurate - up to date and precise information	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	713-714

Q29

Does your child named at Question 1 have special educational needs (SEN)?

Yes	<input type="checkbox"/> 01	→ Go to Q30	715-716
No	<input type="checkbox"/> 02	→ Go to Q32	

Q30

Has your child received a statement of special educational needs (SEN)?

Yes	<input type="checkbox"/> 01	717-718
No	<input type="checkbox"/> 02	

Q31

What type of special educational provision does your child receive?

Tick one box only

Early Years Action	<input type="checkbox"/> 01	719-720
Early Years Action Plus	<input type="checkbox"/> 02	
School Action	<input type="checkbox"/> 03	
School Action Plus	<input type="checkbox"/> 04	
None of these	<input type="checkbox"/> 05	

Q32

In the **last 12 months**, did your child named at Question 1 have a **formal assessment** of his / her particular **educational support needs**? Do **not** include standard assessments routinely provided for all children.

Yes	<input type="checkbox"/> 01	→ Go to Q33	721-722
No	<input type="checkbox"/> 02	→ Go to Q36	

Q33

Thinking about this formal assessment of your child's particular educational support needs and the decisions that were made, please indicate whether you agree or disagree with each of the following statements.

	Tick one box on each line				
	Agree	Neither agree nor disagree	Disagree	Not Applicable	
We/I knew what to expect from the assessment	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	723-724
We/I had to give the same information several times	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	725-726
We were/I was listened to and our needs were understood	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	727-728
The decisions made were suitable for my child's needs	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	729-730
The decisions were made at the right time for my child	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	731-732
Where necessary, professionals worked together to make decisions	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	733-734
On the whole we were happy with the decisions that were made	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	735-736

Q34

How well do you understand the decisions that are made about which education services your child receives?

Very well	<input type="checkbox"/> 01	737-738
Fairly well	<input type="checkbox"/> 02	
Not very well	<input type="checkbox"/> 03	
Not at all well	<input type="checkbox"/> 04	

Q35

Over the **last 12 months**, were you consulted or asked for your opinion when **decisions were being made** about the education services your child receives?

Yes, consulted a lot	<input type="checkbox"/> 01	739-740
Yes, consulted a little	<input type="checkbox"/> 02	
No, not consulted at all	<input type="checkbox"/> 03	

Q36 Over the **last 12 months**, have you been asked your opinion or feedback on the **education services your child received?**

Yes ₀₁ → **Go to Q37** 741-742

No, did not receive any education services for the child in the last 12 months ₀₂ → **Go to Q40**

No, not asked for opinion or feedback ₀₃ → **Go to Q38**

Q37 Do you think that changes were made as a result of the opinions or feedback you gave?

Yes ₀₁ 743-744

No ₀₂

Don't know ₀₈

Q38 Over the **last 12 months**, has your child been asked for his/ her opinion or feedback on the education services he / she received?

Yes ₀₁ → **Go to Q39** 745-746

No, did not receive any education services for the child in the last 12 months ₀₂ → **Go to Q40**

No, child not able to provide opinion or feedback due to young age or difficulties with learning, understanding or communication ₀₃ → **Go to Q40**

No, not asked for opinion or feedback ₀₄ → **Go to Q40**

Q39 Do you think that changes were made as a result of the opinions or feedback your child gave?

Yes ₀₁ 747-748

No ₀₂

Don't know ₀₈

Q40

In the **last 12 months**, have you made a written complaint about an education service you have received in relation to your child?

Yes, to the service provider (e.g. school)

_01

→ Go to Q41

749-770

Yes, to my Local Authority

_02

→ Go to Q41

Yes, to other organisation (please write in below)

_03

→ Go to Q41

No, I have not complained

_04

→ Go to Q43

Q41

How easy or difficult was it to find out how to make a formal written complaint?

Very easy

_01

771-772

Fairly easy

_02

Neither easy or difficult

_03

Fairly difficult

_04

Very difficult

_05

Q42

Thinking about the complaints process, how well was your complaint dealt with?

Very well

_01

773-774

Fairly well

_02

Not very well

_03

Not at all well

775-800 Spare columns

Social Care Services

The following questions are about the social care and family support services which your family may receive in relation to your child's long-standing illness(es) or disability(ies). **Please think about services provided in relation to the child named at Question 1.** Please include services provided through your local council, as well as through independent and voluntary organisations.

Q43

Has your family used any of the following social care and family support services in the **last 12 months** in relation to the needs of your child named at Question 1?

Tick one box on each line

Home adaptations (eg. ramps, lifts)	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂	801-802
Respite, foster care, short breaks	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂	803-804
Help at home with care for the child	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂	805-806
Social worker services	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂	807-808
Help within the home from an outside provider	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂	809-810
Home start or Sure Start	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂	811-812
Emotional support or counselling	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂	813-814
Direct payments (excluding benefits) or individual budget (money from local council to pay for care and support services)	Yes	<input type="checkbox"/> ₀₁	No	<input type="checkbox"/> ₀₂	815-816
Other (please write in)					817

Q44

Over the **last 12 months**, do you feel you and your family have received all the social care and family support services that you required in relation to your child named at Question 1? Please tick one box below which best describes your experience over the last 12 months.

Did not require any social care or family support services in relation to my child in the last 12 months	<input type="checkbox"/> ₀₁	818-819
We received:		
All that he / she required	<input type="checkbox"/> ₀₂	
Most of what he / she required	<input type="checkbox"/> ₀₃	
Some of what he / she required	<input type="checkbox"/> ₀₄	
Little of what he / she required	<input type="checkbox"/> ₀₅	
None of what he / she required	<input type="checkbox"/> ₀₆	

Q45

Overall, how would you rate the quality of the social care and family support services that you received in the **last 12 months** in relation to your child named at Question 1?

Very good	<input type="checkbox"/> _01	820-821
Good	<input type="checkbox"/> _02	
Fair	<input type="checkbox"/> _03	
Poor	<input type="checkbox"/> _04	
Very poor	<input type="checkbox"/> _05	
We/I have not used social care or family support services in the last 12 months	<input type="checkbox"/> _06	

Q46

Below are various things that parents have said in relation to information they had about social care and family support services for children with long standing illnesses or disabilities. Please indicate whether you agree or disagree with each of the following statements.

Tick one box on each line

	Agree	Neither agree nor disagree	Disagree	Not applicable	
We/I have been given enough information about our social care needs	<input type="checkbox"/> _01	<input type="checkbox"/> _02	<input type="checkbox"/> _03	<input type="checkbox"/> _09	822-823
We/ I have been given enough useful information about the social care and family support services my <i>family</i> is entitled to	<input type="checkbox"/> _01	<input type="checkbox"/> _02	<input type="checkbox"/> _03	<input type="checkbox"/> _09	824-825
We/I have been given enough information about how to get social care and family support services	<input type="checkbox"/> _01	<input type="checkbox"/> _02	<input type="checkbox"/> _03	<input type="checkbox"/> _09	826-827
There is someone I can go to for help and support in getting social care and family support services	<input type="checkbox"/> _01	<input type="checkbox"/> _02	<input type="checkbox"/> _03	<input type="checkbox"/> _09	828-829

Q47

In the **last 12 months**, have you received any written or verbal information about social care or family support services in relation to your child named at Question 1? Do not include information which you had to search for yourself.

Yes _01 → **Go to Q48** 830-831

No _02 → **Go to Q49**

Q48

Overall, how would you describe the information you received in the **last 12 months** about social care and family support services available to your family in relation to your child's long standing illness, disability or health condition? Please include both written and verbal information you received.

Tick one box on each line

	Yes, always	Yes, sometimes	No	
Clear - to understand	<input type="checkbox"/> _01	<input type="checkbox"/> _02	<input type="checkbox"/> _03	832-833
Relevant - to you and your child	<input type="checkbox"/> _01	<input type="checkbox"/> _02	<input type="checkbox"/> _03	834-835
Accurate - up to date and precise information	<input type="checkbox"/> _01	<input type="checkbox"/> _02	<input type="checkbox"/> _03	836-837

Q49

In the **last 12 months**, have social care or family support services professionals such as a social worker or emotional support counsellor made any **decisions** about **your child's** illness or disability or services that you should receive? Please include decisions such as whether to be offered a new service. Do not include routine monitoring.

Yes _01 → **Go to Q50** 838-839

No _02 → **Go to Q53**

Q50

And thinking about these decisions and the questions you had to answer for your child named at Question 1, please indicate whether you agree or disagree with each of the following statements.

Tick one box on each line

	Agree	Neither agree nor disagree	Disagree	Not applicable	
We/I had to give the same information several times	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	840-841
We were/I was listened to and our needs were understood	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	842-843
The decisions made were suitable for our needs	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	844-845
The decisions were made at the right time for us	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	846-847
Where necessary, the social care professionals worked together to make decisions	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	848-849
On the whole we were happy with the decisions that were made	<input type="checkbox"/> 01	<input type="checkbox"/> 02	<input type="checkbox"/> 03	<input type="checkbox"/> 09	850-851

Q51

How well do you understand the decisions that are made about the social care and family support services you receive?

Very well	<input type="checkbox"/> 01	852-853
Fairly well	<input type="checkbox"/> 02	
Not very well	<input type="checkbox"/> 03	
Not at all well	<input type="checkbox"/> 04	

Q52

Over the **last 12 months**, were you consulted or asked for your opinion when **decisions were being made** about your family's need for social care and family support services in relation to your child named at Question 1?

Yes, consulted a lot	<input type="checkbox"/> 01	854-855
Yes, consulted a little	<input type="checkbox"/> 02	
No, not consulted at all	<input type="checkbox"/> 03	

Q53

Over the **last 12 months**, have you been asked for your opinion or feedback on the **social care and family support services your family received** in relation to your child named at Question 1?

Yes	<input type="checkbox"/> 01	→ Go to Q54	856-857
No, did not receive any social care or family support services in the last 12 months	<input type="checkbox"/> 02	→ Go to Q57	
No, not asked for my opinion or feedback	<input type="checkbox"/> 03	→ Go to Q55	

Q54

Do you think that changes were made as a result of the opinions or feedback you gave?

858-859

Yes _01

No _02

Don't know _08

Q55

Over the **last 12 months**, has your child been asked his/her opinion or feedback on the social care and family support services your family received?

860-861

Yes _01 → **Go to Q56**

No, did not receive any social care and family support services for the child in the last 12 months _02 → **Go to Q57**

No, child not able to provide opinion or feedback due to young age or difficulties with learning, understanding or communication _03 → **Go to Q57**

No, not asked for feedback _04 → **Go to Q57**

Q56

Do you think that changes were made as a result of the feedback or opinion your child gave?

862-863

Yes _01

No _02

Don't know _08

Q57

In the **last 12 months**, have you made a written complaint about a social care or family support service you have received in relation to your child?

864-865

Yes, to the service provider _01 → **Go to Q58**

Yes, to my Local Authority _02 → **Go to Q58**

Yes, to other organisation (please write in below) _03 → **Go to Q58**

No, I have not complained _04 → **Go to Q60**

Q58

How easy or difficult was it to find out how to make a formal written complaint?

866-867

Very easy 01

Fairly easy 02

Neither easy or difficult 03

Fairly difficult 04

Very difficult 05

Q59

Thinking about the complaints process, how well was your complaint dealt with?

868-869

Very well 01

Fairly well 02

Not very well 03

Not at all well

Q60

If there is anything else you would like to tell us in relation to your child's long-standing illness, disability or health problem or their use of services, please write it in the box below

870-

Thank you very much for your help.

The information that you have given is confidential to the research team.

Would you now please post both questionnaires in the pre-paid envelope enclosed to Carol Bell at the National Centre for Social Research, 101-135 Kings Road, Brentwood, Essex CM14 4LX

Thank you

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