

Services for Disabled Children Questionnaire Testing

Meera Balarajan, Alice McGee and Margaret Blake
National Centre for Social Research



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*Services for Disabled Children:
Questionnaire Testing*

Meera Balarajan, Alice McGee and Margaret Blake

National Centre for Social Research

The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Children, Schools and Families.

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Abbreviations

ADHD	Attention-Deficit Hyperactivity Disorder
AHDC	Aiming High for Disabled Children
AS	Autistic Spectrum
CAF	Common Assessment Framework
CB	Child Benefit
DDA	Disability Discrimination Act
DLA	Disability Living Allowance
FGD	Focus group discussion
FRS	Family Resources Survey
LA	Local Authority
NPD	National Pupil Database
OT	Occupational Therapy
PAF	Postcode Address File
PCT	Primary Care Trust
PI	Performance Indicator
SEN	Special Educational Needs

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). 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 stage 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 stage of the project reported on here involved carrying out cognitive testing of the proposed questionnaire to investigate whether respondents understand the questions as intended and whether can answer the questions. The testing was also, to some extent, able to examine issues of acceptability and sensitivity.

Testing the questionnaire

The cognitive testing involved testing two questionnaires:

1. Screening questionnaire designed to identify parents with one or more disabled children¹; and,
2. Main questionnaire exploring experience of service use for one of their disabled children.

Cognitive question testing was carried out during September 2008 by five interviewers across the country and involved 32 interviews with parents with disabled children. 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.

This executive summary highlights main findings of the testing and outlines the key recommendations in terms of (1) which questions to retain and (2) the key changes which should be made to questions. Detailed wording and format changes are not included here; these can be found in the relevant section of the main body of the report.

Organisation of the questionnaire

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

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

¹ The results of testing the screening questionnaire have been reported on separately. This report focuses on the findings for the main questionnaire.

Respondents were generally clear about the distinctions between these service areas and regarded the split as appropriate and reflecting the way in which they think about and receive services. A few services were felt to fall into two or more of the service areas. For example occupation therapy was seen as both a health care and a social care service. However, for most specific services parents agreed that they fell into the groups used in the questionnaire. We would recommend that this way of organising the questionnaire is retained but that the order is changed so that the questionnaire covers health, education and social care, in this order. Social care services were used by the smallest group (in the cognitive interview sample) and are also the services used by the whole family, meaning that when education followed this section respondents found it difficult to retain a focus on the named child.

One issue which arose throughout the questionnaire was whether non NHS health services, particularly complementary and alternative therapies should be included when thinking about health services; the client should advise on this.

The 12 month reference period

The questionnaire was based around a 12 month reference period, asking parents to think back over the last 12 months when answering the questions. Evidence on how well this worked was mixed. The timing of the cognitive interview fell in September, at the start of the school year, and made it relatively easy for parents to think about the last 12 months (although occasionally parents considered only this calendar year (2008) or the last complete calendar year (2007)). Even where parents understood the correct time period, at times they could mention events which happened outside that time period which they felt were important (evidence of 'telescoping'). Parents did not find the reference period too long. We would recommend retaining the 12 months reference period. In some questions it could be made more prominent (for example by bolding or underlining the text) and clarification should be provided about what it means (for example "that is from September 2007 to September 2008). In addition the covering letter could explain to respondents why they should think only about the last 12 months when completing the questionnaire.

Age range

The questionnaire is intended to cover respondents with children in a wide age range from 0 to 19. Children and young people have a wide variety of needs in terms of service use. Consideration could be given to splitting the sample and providing two or three versions of the questionnaire appropriate to different age groups. However it could be difficult to identify an appropriate age cut off.

Background questions

Respondents were asked questions about the nature of their child's disability to provide a context for the questionnaire; these questions will not feed into the indicator. Questions about difficulties the child had (Q3/ A4) and about whether the respondent considered their child to be disabled (Q4/A5) were problematic for respondents and therefore we would recommend dropping them.

The question about the way in which the child is affected (Q5/ A6) did have some problems and amendments need to be made but we believe this question is important for DCSF and DH as without it there will be limited information on the nature of the named child's disability. Some of the answer categories need to be clarified.

Questions on the ethnic origin of the named child (A3) and on receipt of Disability Living Allowance (A6) were not cognitively tested as they are standard questions. **Consideration should be given to the importance of including the ethnic question (in the absence of other background demographic questions).** The question on DLA (A6) should only be included if needed for sampling purposes.

Health care services

Question 6 (H1) on the services used in the last 12 months is a useful question both for analysis and for directing respondents to understand what is included. It should be retained but with some modifications to make it clearer.

The DCSF and DH need to advise on whether non NHS services and complementary and alternative therapies should be included here.

Question 7 (H2) provides data for general experience and thus should probably be retained. However there is an issue that parents felt they did not know what their child needed and also the answer 'all that he / she needed' covered a wide variety of experiences. The question about quality of services (H3) was not included in the cognitive testing.

Question 8 (H4) and the questions with that format throughout the questionnaire generally worked. **Respondents were confused by the word access used in some statements. We would like the client to advise on what is meant by access in these statements so appropriate changes can be made.**

We advise removing the last two statements which confused respondents and also reducing the answer categories to three (agree, neither agree nor disagree, disagree) rather than five because respondents did not find the distinction useful and reducing to three has no impact on the indicator calculation. The recommendation to reduce to three categories applies to all such questions throughout the questionnaire.

Question 9 (H5) needs a routing question about whether the respondent received any information since the current layout does not work. **Respondents were unclear about whether information received should include information which they had to seek out; advice is needed from the client on this.**

Question 10 (H6) was used for routing to Question 11. Respondents were inconsistent in their understanding of the term 'decision' being unclear whether to include only major decisions or whether decision such as continuing with current treatment should be counted. Where respondents were unsure, a quick look at Question 11 (which routed from the yes answer) assisted them in choosing 'no' in order to complete the questionnaire more quickly. This routing question is therefore essential but clarifying what is meant by 'decision' may reduce the risk, and problems associated with, 'shortcutting'. **DCSF and DH should advise on what types of decisions they would like considered here.**

Question 11 (H7) should be retained with minor amendments to make the wording more consistent. Consideration should be given to dropping some of the statements to reduce the overall questionnaire length (e.g. statement 6 which overlaps with Question 12 and also statement 7).

Question 12 (H8) was felt to be repeat of Statement 6 at Question 11. By dropping statement 6 Question 12 can be retained and feeds into the transparency indicator.

Question 13 (H9) presented problems for respondents who did not have a consistent understanding of what 'involved' meant. **Clarification is needed from the client on what is meant by 'involvement' so that the question can be reworded.** Respondents were unclear whether involvement meant being kept informed or whether it meant having some control over decisions and they also differed on what level was appropriate for parents.

Question 14 (H10) was confusing since respondents found it difficult to know what professionals think and were also confused about what 'interested in' referred to. Consideration should be given to dropping this question, although this will impact on middle aspect of the participation indicator.

At Question 15 (H13) respondents were unclear about what 'feedback' meant. Clarification needs to be provided on the meaning of 'feedback' or the alternative wording used for the parents version of this question (H11) adopted, which asked "have you been asked your opinion?". Parents found it hard to give an answer to Question 16 (H14) about whether changes are made as a result of feedback. We would recommend dropping this question but retaining the equivalent question for parents (H12) since it covers an important aspect of feedback, namely whether respondents believe things change in response to their feedback. We would recommend that the parent question (H12) is modified to ask about changes made as a result of feedback given by that parent, rather than more generally, though this means it should only be asked of those who have been asked for feedback at H11.

Question 17 to 19 did not present any particular problem in the cognitive testing, though very few were asked questions 18 and 19. Based on findings from other questions there is a potential for respondents to be confused about the intended meaning of Question 19. The question refers to the 'way in that your complaint was dealt with', however since the question asks how happy they are there is a risk that respondents may think about how happy they are with the outcome of the complaint rather than the process. **We would welcome a discussion with the client on what this aspect of the core offer is intended to cover (complaints process or outcome of complaint) and also whether this question could be dropped.**

Questions 20 (S1) and 24 (E1) are important questions in helping respondents understand what is included in social care (S1) and education (E1) and should be retained. Modifications are needed to clarify the meaning of some answer categories. Additional missing answer categories can be considered and are suggested in the main report but we would caution against adding many more categories so agreement will be needed on the priorities. We recommend retaining the use of the term 'social care and family support services' in Question 20 (S1) since some respondents saw them as different but those who saw them as the same were not confused by the use of both terms. Evidence was found of negative feelings about the term 'social services' so we would recommend it is not used.

Questions 21 to 23 and 25, 26 and 28 were similar to questions covered in the health section and the same recommendations would be made.

Question 27a (E6) was not well understood: partly because parents were not very familiar with School Action and the other terms referred to but also because the way the question was set out and worded was confusing. Parents were not sure what 'level' referred to and misunderstood the slash (/) in the answer categories. The question was also perceived as doubled-barrelled. We have recommended a restructuring of this question so that the different elements of the question are separated out.

Question 27b (E7) referred to 'assessment' rather than 'decision' which had been used for H7 and S7. Respondents did not have consistent understandings of the term 'assessment'. In contrast to 'decision' where respondents tended to say 'no' if they were not sure, at this question respondents considered the term too broadly and ticked 'yes' incorrectly, thus being routed to Q28. This may in part have been because the questionnaire layout here meant the follow-up question was on the following page and so parents did not use it to help them answer Q27b). ***We would recommend that the term 'assessment' is explained to respondents and would welcome advice from the clients on what should be covered here.***

Open ended questions

In places respondents felt frustrated that they could not fully express their feelings about their disabled child's use of services or the experiences they had had. This is because the questionnaire takes a very closed format. We would recommend that after certain key questions or at the end of the questionnaire respondents are offered an open ended question for them to explain their answers or express issues which are not covered by the closed questions. These questions need to be worded such that respondents do not feel either that they have to answer them or that they are going to form a key part of the analysis.

Questionnaire presentation

Since the questionnaire will be a self-completion form, without the assistance of an interviewer, it is essential that it is accessible to **all** respondents. Almost half of disabled children in Britain live with a parent with a DDA-defined disability (Read et al 2007²) and therefore their needs should be taken into account in terms of the presentation of the core instrument (a paper questionnaire), in alternative formats which are offered and in support available to respondents during the fieldwork period.

² Read, J., Spencer, N., & Blackburn, C. (2007) *Can we count them? Disabled children and their households*. Full Research Report. End of Award Report, REC-000-22-1725. Swindon: ESRC.

1 BACKGROUND

The DCSF commissioned NatCen to carry out a project to develop a questionnaire and sample design to collect data on parental experience of services for disabled children. The data collected will feed into the Disabled Children's Services performance indicator. The indicator is intended to measure the core offer to disabled children and their families in five areas plus their general experience.

The first stage of the project resulted in a proposed sample design for the survey and a proposed questionnaire for asking parents about experience of services. The sample design involves 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.

The Question Development and Testing Hub at NatCen have been working on the second stage of the research which involves testing both the screening and main questionnaires. This is the second report, which presents the findings of testing the main questionnaire; the first report focussed on the testing of the screening questionnaire. A brief summary of the purpose of testing the screening questionnaire is given below followed by the background of testing the main questionnaire.

It is important that the screening questionnaire is fully tested to explore whether respondents understand the questions as intended and are able to answer them. The screening questionnaire identifies who is eligible to be sent a main questionnaire so it is essential that the screening questionnaire fulfils its role of correctly identifying respondents with a child with a long standing illness, disability or health problem (see Interim Report: Findings from testing the screening questionnaire for more information about this aspect of the study).

The main questionnaire on services, which is the focus of this report, has been cognitively tested to identify whether there is a match between the intended meaning and respondents' understanding. The cognitive interview process allows us to test how parents understand the questions and their ability to answer them, as well as issues of layout, routing and response. It is important that the main questionnaire is tested to explore how well questions work in practice and specifically whether respondents understand and are able to respond to the questions in the way the researchers intended.

The cognitive interviews uncovered the processes involved in responding to the questions. This was a particularly important step for this project because the aim of the questionnaire is to gather information on quite abstract concepts such as "information", "transparency" and "assessment" and for this information to feed into a measurable indicator of acceptable level of provision of service. The questionnaire covered three main service areas, namely: health care services, social care and education and early year services. For each of the three main service areas the questionnaire examined the five aspects of the core offer:

1. Information
2. Assessment
3. Transparency
4. Participation
5. Feedback

Thus, there are fifteen sections in the questionnaire and from each section a series of problem scores per respondent can be calculated which will feed into the performance indicator.

The cognitive interviews probed these 15 areas and the findings are presented in the report.

1.1 Aims of the Study

The overarching aim of testing the main questionnaire is to assess whether the questions in the questionnaire work. The emphasis was on checking that key questions which could feed into the disability indicator are clearly understood by respondents and whether respondents could accurately answer the question using the code answers provided.

The Main questionnaire (See Appendix A) asked respondents to fill in details for one specific child identified in the screening questionnaire. The child who was the focus of the main questionnaire was identified because he or she had a long standing illness, disability or health problem and thereby came under the broad definition of the Disability Discrimination Act 1995 and was 19 years old or younger.

The specific aims of the testing were to investigate:

- 1) Whether respondents understand each of the terms used, namely health care services, social care services and education and early year services
- 2) Whether the specific questions can be easily understood.
- 3) The list of specific areas for focus within health care services, social care services and education and early year services were appropriate in coverage.
- 4) Whether the questions asked can realistically be answered by respondents either because they know the answer or can easily find out the answer.
- 5) Whether the questions asked are acceptable to respondents, particularly because some of the questions asked could be sensitive for some respondents.
- 6) Whether parents feel motivated to complete the main questionnaire.
- 7) Whether the questionnaire was effective in collecting details about the specific children.

The best way at exploring respondents' understanding of questions and the terms, their ability to answer questions and any judgements or shortcuts involved in answering questions is through cognitive testing.

1.2 Structure of the Report

This report presents the research findings to examine if the main questionnaire works. An overview of the research methods will be presented in the next section. The next chapter will present the findings and recommendations.

1.3 Research Methods

The main questionnaire was evaluated through cognitive testing in September 2008. Although the questionnaire is a paper self completion it was administered in a face to face cognitive interview. Respondents were given the main questionnaire at the time of the interview by the interviewer. The respondents were encouraged to think aloud while answering the questionnaire. Specific probes were used by interviewers at specified points to retrospectively probe respondents to explore specific aspects of the question and answer process for key questions. The questionnaire included a total of 28 questions. As the questionnaire is long not all the questions were probed in detailed. Key questions which were considered problematic or questions which will feed into the indicator were the focus of the cognitive interview.

All cognitive interviews were carried out face-to-face, on a one-to-one basis. All the interviews were conducted by five experienced cognitive interviewers from NatCen's core team and panel in the respondent's home, to ensure respondent confidentiality. The interviews lasted approximately 90 minutes of which 60 to 75 minutes were spent on the main questionnaire. Respondents were given a £20 High Street Voucher as a thank you for taking part in the interview. The face-to-face cognitive testing took place in four areas in England. These were

1. Oldham, Bolton and Manchester
2. Birmingham area
3. Crewe and Cheshire
4. York and Huddersfield area
5. Nottingham and Derby area

1.4 Sample design and recruitment

A purposive sample design was used for the study in order to reflect the range and diversity of the population in relation to how people would approach answering the questionnaires. The sample comprised of 32 face-to-face interviews with parents who had a disabled child or a child with a long standing illness or health condition.

The sample of parents was designed to cover parents with a range of characteristics in terms of the age of their disabled child, the nature of the child's disability and the services used by that child. Quotas were set to ensure the sample represented children aged 0-4 years (pre-school), 5-10 years (primary school), 11-15 (secondary school) and 16-19 (transitional) who had used either special health services, special education services or social care/family services or no services in the last 12 months. The sample was designed to include parents with children who had different disability types, namely: mobility or manual dexterity, visual or hearing problems, allergy or breathing problems, medical needs, mental health problems, learning difficulties and other types of disabilities.

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 was 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.

Table 1: Sample Characteristics

Characteristics		Number with characteristics
Gender of child	Male	23
	Female	9
	Total	32
Age	0-4	8
	5-10	9
	11-15	10
	16-19	5
	Total	32
Disability	Mobility or manual Dexterity	5
	Visual or hearing problems	9
	Allergy or breathing problems	12
	Medical Needs	6
	Mental health problems	3
	Learning difficulties	4
	Other	9
Total	48*	
No of disabilities	Child with one disability	19
	Child with 2 disabilities	9
	Child with 3 or more disabilities	4
	Total	
Service Used in the last 12 months	special health services	8
	special education services	10
	social care/ family services	5
	no services used	8
	multiple Services Used	1
Total	32	

* The total sums to more 32 because some children had more than one disability

1.5 Recruitment

Potentially eligible respondents identified from the childcare study were sent an advance letter explaining the study and informing the respondent that they would soon receive a call. NatCen's telephone unit, which is based in our Brentwood offices, made contact with respondents and conducted a short telephone interview to explain the purpose of the study, to seek co-operation and to check the respondent's contact details. Although most of the information needed for meeting quotas for the sample of parents with disabled children was available from the 2008 Childcare Study, a screening question about use of services in the last 12 months was required to ensure a mix of service users were included. This was to allow the questions to be relevant and fully tested in the cognitive interviews.

Once the respondent had agreed to take part, the NatCen's telephone unit sent out a confirmation letter to the respondent giving a short written explanation about the nature and purpose of the study and specifying the name of the interviewer who would be conducting the interview. This mailing also included a copy of the screening questionnaire and instructions for the respondent to complete it before the cognitive interview. Respondent details were passed over to the cognitive interviewers who then arranged an appointment to interview the respondent at a date and time of their choosing.

1.6 Analysis

Interviews were analysed using a content analysis approach based on Framework, an analytic tool developed by the Qualitative Research Unit at NatCen. This involved devising a matrix which listed the respective test questions across the page and cases down the page. The matrix included a summary of the child's characteristics (age and type of disability) and characteristics of the family (e.g. whether there are other disabled children in the household). Under each question a summary was made of each respondent's understanding of the question, judgements made in formulating an answer, any problems the respondent had in answering the question and the answer provided. This approach allowed a systematic analysis, whereby data could be read horizontally as a complete case record for an individual, or vertically by question, looking across all cases. Once the matrix was complete data was reviewed. In reviewing the matrix the full range of problems with questions was explored.

2 GENERAL VIEWS OF THE QUESTIONNAIRE AND BACKGROUND QUESTIONS

In this chapter we first outline the general findings about the main questionnaire and findings about the background questions. This and subsequent findings chapters will focus on specific questions and will cover:

1. The question that was cognitively tested;
2. An outline of the findings at that question(s); and,
3. Final recommendations for improvement.

The findings from the cognitive testing will provide evidence as to where problems exist and the possible reasons for them; however the cognitive testing is not able to quantify the size or extent of these errors. To do this would require a larger scale experimental pilot which is planned for later this year.

2.1 General Views of the Questionnaire

In this section we present the general views of respondents to the main questionnaire.

2.1.1 Findings

Questionnaire Structure

The questionnaire was structured around three different types of services:

- Health care
- Social care
- Education

It was therefore important to explore respondents' understanding of these three different types of services. For the questions in each section to work effectively respondents need to both understand what is included within each term and able to distinguish between the three service areas. In this chapter we explore the issue of how respondents view the three service areas in relation to each other. Findings on respondent comprehension of each service area are presented in the relevant sections, later in the report.

Instructions

The majority of respondents did not read the instructions. They saw the first question and started to fill in the questionnaire. Respondents exhibited this behaviour for two main reasons:

- The first reason is they felt they had a lot of experience of filling in questionnaires regarding their child so knew what to do, as a consequence they only read instructions which they think they need to.

- Secondly, they saw standard questions which they could easily answer straight away and they wanted to get going. Respondents who were asked to read the instructions all found the instructions to be clear. Respondents appreciated being thanked for their time in the instructions.

Which Child to focus on?

Where respondents had more than one child with a disability (identified from the screening questionnaire) agreement was reached between the respondent and interviewer over which child should be the subject of the questionnaire. Where respondents were asked to give a view on which child should be covered by the questionnaire respondents exhibited different strategies, choosing either.

1. the eldest child (this was most common);
2. the child in most need of services (This may not have been the child with a disability);
3. the child who they felt would be most interesting; or,
4. the youngest child.

This shows that respondents had varying views on who the questionnaire should be covering. In the main stage it is essential that the instructions at the start should be very clear about which child is to be the focus on the entire questionnaire. Since respondents were also found not to read instructions, the information about which child to focus on should be repeated in several places to ensure it is noted (for example in the advance letter, in front page of instructions and perhaps a note within the wording of the first question directing them to check the name of the child from the advance letter).

Although all respondents started the interview thinking about one named child they did not always retain this focus throughout the questionnaire. Strategies varied according to the questions and section. For example, education was often answered with all the respondent's school age children in mind. Since this section followed the social care section in which respondents were asked to think about their family as a whole the loss of focus on the named child is not surprising.

The wide scope of the questionnaire

The questionnaire currently tries to seek information from respondents from a wide age range of children: aged 0 months old to 19 years of age and with a range of disabilities. This wide scope has meant that some questions did not work as well for all respondents because the child was too young or too old. For example, the child may not have entered education or may have left education (affecting education section). For younger children they may be too young to do things on their own which impacts on questions about the effects of their disability on their day to day life.

The sample also included parents with children with a wide variety of disabilities in terms of the severity of the disability and its impacts on the child's life. As a consequence some questions were considered difficult for respondents because the issue did not affect their child.

One general solution to address the wide age range of the questionnaire is to have at least two versions of the questionnaire: one for respondents with young children and one for respondents with older children. This would be possible in the main stage as information about the ages of the respondent's children would be available from the screening questionnaire. However, there is an issue over the appropriate ages to cut off each questionnaire. Pre-school children may be in some form of education so it is not appropriate to remove education questions for this age group. In terms of children's need for parental assistance, regardless of whether they have a disability, this depends on the child and the type of access being considered (this is discussed more fully in the section on question 3).

Open Ended Questions

Respondents understandably felt committed to the topic of the questionnaire and on occasions felt limited by the closed answer options. To address this, an open ended text box could be provided at strategic points in the questionnaire or at the end of the questionnaire to give respondents the opportunity to express their views more fully. There is an issue over how and whether these data would be used as it would be hard to analyse them and respondents should not be misled into thinking they would form part of the main analysis.

Questionnaire presentation

Since the questionnaire will be self-completion without the assistance of an interviewer it is essential that it is accessible to respondents. For the cognitive testing the instructions and questions in the questionnaire were written in Arial script, font size 11 in black. Headings were demarcated in black or red font with font size varying from 14 to 11 depending on the importance of the heading.

Almost half of disabled children live with a parent with a DDA-defined disability (Read et al 2007³) and their needs should be taken into account. The questionnaire should be laid out in line with RNIB guidelines to assist those with sight impairments and ideally a professional with experience in this area involved in revising the questionnaire. The questionnaire could be offered in an audio format and or Braille as well as in key minority languages. We would recommend that for the mainstage of the research a professional designer is employed (as was done for the screening questionnaire prior to cognitive testing). For those who may need help in completing the questionnaire assistance could be provided via a telephone help line.

During the cognitive testing a respondent with a sight impairment was interviewed. The interviewer had to read out all the questions and the interview had to be conducted over two sessions. With appropriate assistance this respondent was keen to participate. The key is making available such assistance to facilitate the participation of respondents regardless of their needs.

³ Read, J., Spencer, N., & Blackburn, C. (2007) *Can we count them? Disabled children and their households*. Full Research Report. End of Award Report, REC-000-22-1725. Swindon: ESRC.

2.1.2 Recommendations

- Consider involving a graphic designer to design the layout of the questionnaire so it is visually appealing and user friendly
- Consider highlighting the instructions by writing it in red and placing it in a box with a pale background to make the instructions more visually eye catching (advice is needed from organisation such as RNIB on this)
- Consider indicating that respondents should read the instructions before answering the questions
- Consider making the instructions more explicit about which child is to be focus of the questionnaire and remind respondents throughout the questionnaire.
- Consider providing open ended text box at strategic points or at the end of the questionnaire

For example:

Please read these instructions first before completing the questionnaire

We would like you to **focus *only* on the named child** indicated in the covering letter when answering this questionnaire.

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.

Thank you for your time.

2.2 Gathering Basic Information (Questions 1 and 2)

Although respondents did not have real problems answering Question 1 and 2, the cognitive interviewing did reveal the question and answer process and highlighted possible problematic areas.

2.2.1 Questions 1 and 2

Q1 What is the child’s name?

Q2 What is the child’s date of birth? Day MonthYear

2.2.2 Findings

The difficulty that respondents had when answering question 1 related to the lack of clarity over whether they should give the full, or just the first, name of the child. The majority of respondents gave the first and last name because the form looked formal (more so than the screening questionnaire) or there was more space which indicated to the respondent that they should provide the surname. The appropriate answer strategy depends on the purpose of this question. If it is to be used to uniquely identify the child who is the subject of a main questionnaire and to ensure the parent was thinking of the right child, in most households first name would be sufficient. In complex households there might be two children with the same first name or children may have a different surname to the parents suggesting a need for surname to be collected. However this is less important than in the screening questionnaire.

Question 2 was generally fine. One respondent gave the wrong year but realised their mistake when the interviewer pointed it out. If the instructions at the start are clearer about which child to focus on, such respondent errors could be reduced by reducing ambiguity for the respondent.

2.2.3 Recommendation

- Consider rewording question 1 to “What is this child’s first name”? or “What is this child’s name (give first and surname)?” depending on the purpose of collecting the name (*client to advise*)

2.3 Difficulties due to illness, disability or health problem (Question 3)

2.3.1 Question 3

Q3(A4)	Does your child have more difficulties than other children of their age, doing any of the following due to their illness, disability or health problems?	Please tick one box on each line	
1	Using public transport	Yes <input type="checkbox"/>	No <input type="checkbox"/>
2	Getting about in their own home	Yes <input type="checkbox"/>	No <input type="checkbox"/>
3	Using school buildings and facilities	Yes <input type="checkbox"/>	No <input type="checkbox"/>
4	Using health service buildings and facilities	Yes <input type="checkbox"/>	No <input type="checkbox"/>
5	Using local council social service buildings and facilities	Yes <input type="checkbox"/>	No <input type="checkbox"/>
6	Using public parks and leisure facilities (e.g. playgrounds, swimming pools etc)	Yes <input type="checkbox"/>	No <input type="checkbox"/>
7	Joining activity groups or clubs (e.g. cubs, guides, sports groups)	Yes <input type="checkbox"/>	No <input type="checkbox"/>

2.3.2 Findings

General answer strategies

Respondents were, on the whole, able to provide answers to this question though some expressed doubt as to whether they were doing so correctly.

Respondents tended to work their way through the list, ticking yes or no for each category. Respondents considered things their own child found difficult on a day to day basis and so the process of answering this question was fairly personal and specific to that particular child and the difficulties they experience in every day life. Respondents thought in general terms about their child's experiences rather than of specific instances, though in some cases respondents gave examples of particular occurrences.

Only one respondent was unsure about what she was meant to do at this question. For this respondent the question appeared to make more sense worded the other way round, first stating 'due to their illness, disability or health problem' and then 'does you children have more difficulties than other children of their age, the question mark coming after 'of their age?'

Answer categories

All seven valid answer categories were ticked at least once. One respondent selected category 8 'Has no illness, disability or health problems'. The seven valid answer categories themselves were not particularly problematic though it should be noted that respondents took these categories and applied them to their own very personal experiences, meaning they were open to wide interpretation. To give some examples, one respondent thought about how her child had difficulty reading signs (ticked 'Yes' at categories 3, 4, 5 and 7). Another respondent thought about her child's hearing impairment and how it affected his balance and communication with other children (categories 1, 3, 4, 5, 6 and 7). A third respondent, who ticked categories 1, 3, 4 and 5, thought about how her child behaved in public and that he could use these services or do these activities until he "*cannot get his own way*" (16-19 years, Allergy or breathing problems). This respondent would have liked a 'Sometimes' option as it depended on the circumstances on that particular day. This is discussed in more detail later on.

In terms of the answer categories themselves, respondents did not have problem understand them in general. Some commented that 'Buildings and facilities' was a fairly vague and loose term. Others suggested that the three categories for different types of buildings and facilities (school, health service and social service) should be combined. However combining them would make the categories more general and also mean that the questionnaire could not distinguish between access issues for the different service areas.

The think aloud technique highlighted that respondents were not clear whether these categories were asking whether their child would know what to do in the building or asking about getting around physically in the building.

Age range and diversity

Respondents' children ranged in age from infants (the youngest child was aged 2) to adults (the eldest aged 18). This age group is thus extremely diverse, spanning children and young people (CYP) with varying needs, abilities and behaviours. Additionally, not only did the questionnaire need to be applicable to such a wide age gap, it also needed to apply to CYP with a wide variety of disabilities or conditions. These challenges meant that (a) some categories were simply inappropriate for, or inapplicable to, respondents and (b) where categories were ticked these could have indicated very different problems depending on the age of the child - for instance one respondent thought about circumstances in which her daughter might need to use her inhaler (ticked Yes at category 6) whilst another thought about the difficulties of taking a small child or baby to health services buildings, rather than necessarily about a disability, (ticked category 4).

Not applicable

Respondents commented that some of the answer categories did not apply to their child and thus they were unsure whether to (a) leave both boxes blank or (b) tick 'No'. This tended to occur where the respondent had young children who either did not visit these places or did not do so alone or the child did not do that type of activity such as swimming. In practice both strategies were adopted meaning two problems came into play: (1) where the boxes were left blank there would be no way to tell if the respondent thought the question was inapplicable or if they had simply missed it, and (2) where the respondent ticked 'No' this could indicate (a) that this category **did** apply to their child but they do not have any problem with it or (b) the category was **not** applicable to their child.

Assistance

Further confusion arose surrounding whether to tick 'Yes' or 'No' in relation to assistance. Respondents said that their child did not experience difficulty with the tasks or activities when someone was there to help them, often this being the parent, but they would experience difficulty if they were alone. In effect, the difficulty for the child themselves had been removed due to the presence of a helper but, in fact, their need for a helper was related to their disability or condition. Occasionally respondents would tick 'No' giving the false impression that the child would not have more difficulties than other children of their age. One respondent said it was clear in her mind that her child had many more difficulties than other children but because she was there to carry him or push him everywhere these difficulties were removed. This respondent felt that the question assumed public transport services were used when in fact this might not be possible. Other comments included that young children might find these tasks difficult anyway and one example was that navigating a pram or pushchair was just as problematic as a wheelchair and so it really depended on the circumstances.

Middle category

There was a desire for a middle category as in occasionally respondents wanted to tick a 'Sometimes' box as the problem did not always occur. One respondent commented that this does still, however, mean 'Yes' but others did not employ this reasoning and became stuck, undecided whether to tick 'Yes' or 'No' or simply to leave both boxes blank.

Comprehension of key terms: Illness, disability or health problem

Respondents were asked to describe 'illness, disability and health problem' in their own words. On the whole respondents took these terms separately and defined each one. One respondent described all three as:

"Anything that might affect him (her son)"
(A mother with a 14 year old son with hearing loss)

Disability

Definitions of disability focused upon physical or mental limitations:

"Something physically permanent"
(A respondent with a 5 year old son who has medical needs)

"It is something that is stopping you doing something, like a physical disability, not walking properly, a limb problem, like not standing properly because of limb problems."
(A respondent with a 5 year old son who has an 'other disability')

Health problem

Definitions of health problems were less specific but centred on less permanent conditions or those that were not seen as being as 'serious', for instance Asthma. One respondent described this as:

"not being a well person"
(A respondent with a 14 year old son who has an 'other disability')

Illness

Illnesses were defined as being ill, poorly or sick (e.g. more like flu or something temporary as opposed to something more chronic or permanent).

Comparing with 'other children of their age'

Respondents were asked to compare their child's difficulties with 'other children of their age'. During probing respondents were asked to explain how they went about making this comparison and who they thought of as 'other children of the same age'. In general respondents fell into two categories:

1. Those who thought of other children with **no** disability, health problem or condition. Respondents described these children as:
 - Children with no problems
 - Other children in the same class at school
 - Peers or siblings (when they were the age the child is now) who do not have the condition.

Examples of respondents' descriptions were:

"[An] average child for [the] age group"
(11-15 years, Mental health problems, Learning difficulties)

"Difficulties would mean he would have more problems with any kind of activity, than a 'normal' child."
(A respondent with an 8 year old child with mobility or manual dexterity disability)

This last quotation raises the issue of the word 'normal'. Some respondents felt strongly that this word was unhelpful and should not be used in any kind of description or definition relating to their child (i.e. that they were not 'normal').

2. Those who thought of other children **with** a disability or health problems rather than without

These findings show that respondents were not consistent in their understanding of 'other children', meaning the comparisons were not systematic across respondents. Both children with and without disabilities were considered.

Time period

Although the question does not include a specific time period, respondents were probed during the cognitive interviews about whether they thought of a certain time period when considering their answer. Respondents had, in fact, thought about a range of time periods, these were:

- Since birth, always or in general
- The last few years
- The last year
- Now or currently (the last few months).

Feelings about answering

Due to concerns about the sensitive nature of this question, respondents were also probed about how they felt about answering it. While respondents reported no problem answering the question, on occasion they said they found it difficult to answer as the task of defining disability itself could be difficult for respondents from an emotional point of view. Comments included:

- The question appeared a little abruptly and did not naturally follow on from the previous question
- The question raised negative emotions and could make respondents feel 'sad'.

"[It made me feel sad] but with any chronic problem, you just get on with it"

(A respondent who has a 14 year old son with an 'other disability')

"[I] don't think of him as disabled but I know he is"

(A respondent with a 5 year old son with Allergy or breathing problems, Medical needs, Learning difficulties and an 'other disability')

2.3.3 Recommendations

- Consider dropping this question as it does not feed into the performance indicator
- If the question needs to be retained, consider rewording the question, so the phrase, due to their illness, disability or health problem' comes first then 'does your child have more difficulties than other children of their age?
- Should the question include the term 'unassisted' or 'without assistance'?
- Add NA category
- Add a Sometimes category
- Make explicit that the control/comparison group is children without disabilities?
- Do not include a time period as respondents will consider their own and unlikely to make a difference

2.4 Whether consider child to be disabled (Question 4)

2.4.1 Question 4

Q4(A5) Do you consider your child to be disabled?

Yes 1 → Go to Q5

No 2 → Go to Q6

2.4.2 Findings

Answer strategies

This question was felt by respondents to cover two concepts: (1) whether the child was disabled and (2) whether the parent considered the child to be disabled. Where these two concepts matched, parents were able to answer clearly. However, where there was discord or disagreement between the two in the respondent's mind, this led to problems in providing an answer. Essentially respondents could be classed as being one of four types:

1. Respondents who firmly considered their child **not** to be disabled and provided this answer immediately ('No'). It should be noted that, this did not necessarily mean that their child was not disabled, they may have been classed as 'disabled' but the parent was unable to accept this fact or allow the label to be applied to their child. Despite the mismatch between the 'official' view and their own view, they were still able to answer the question thinking about their **own** opinion on the matter.

"No, not at all...It is not a disability. It could improve as he gets older, even though he will always have it...It does not stop him from doing anything."

(Respondent who has a 5 year old son with Medical needs)

"A child is handicapped or can't do certain things. Like can't walk. It wouldn't mean like my child."

(Respondent who has a 3 year old son with Allergy or breathing problems)

"Unless it's really, really bad - her asthma - I wouldn't consider it to be any kind of disability because she can do what other people can do"

(Respondent with a (AGE?) daughter with asthma or breathing problems)

"It's not his fault, it's not a disability, it's something that he can't control. I don't see him as disabled. We talk to him about it being something 'not fusing right,' but not in a bad way; just something 'not gelling' right. We never say he is disabled."

(A respondent with a 11 year old son with Allergy or breathing problems)

NB: Despite this comment, this respondent went on to refer to her child as disabled throughout the interview.

"There are ways of dealing with his problem, so, if there are such ways, it is not a disability... his eyesight is very poor, without his glasses. But, with his glasses he is fine...it is not a disability."

(A respondent with a 5 year old son who has medical needs)

2. Respondents who accepted that their child **was** disabled and answered affirmatively (i.e. there was no mismatch). Respondents found this easier to answer where their child had been 'registered' or 'classified' as disabled or that it was 'official'. This meant that they may receive benefits for their child due to their disability. In these cases it made it easier for respondents to say that their child was disabled as it was the 'right' or 'appropriate' word to describe this.

"Diabetes is classed as a disability. He gets his Disability Living Allowance. If he wasn't classed as disabled he wouldn't get that."

(A respondent with an 18 year old son with Medical needs and mental health problems)

"I consider it a disability because his day to day life often requires outside help. He needs to have an escort to go for a walk or to go to the shops."

(A respondent with a 10 year old son with Allergy or breathing problems and other disabilities)

3. Respondents who did not want to say that their child was disabled but knew 'inside' or 'deep down' that they were (i.e. there was a mismatch between their own opinion and what they considered the truth or 'official' opinion to be). In these cases respondents would answer affirmatively. For this group, this question was very problematic as it presented them with an emotionally difficult question and one they did not wish to think about and answer. In cases it seemed that the respondents had not thought about this beforehand as it was too difficult for them and this may have been the first time they were asked plainly for their own opinion and confronted with Yes / No boxes. These problems make this question a very murky area as in practice both 'Yes' and 'No' are applicable: 'Yes' in that the respondent thinks their child is disabled 'inside' or 'technically' and 'No' in that they do not, from an emotional point of view, want to think this or have this opinion.

"... no-one wants their child to be disabled."

(A respondent with a 14 year old son with Visual or hearing problems)

4. Respondents who were not sure whether or not their child was disabled and struggled with this question, debating the point with themselves in their head or out loud. This group ended up choosing either 'Yes' or 'No' after some debate or in some cases were unable to answer. For this group, this question was again very emotive and parents could say the question was not clear enough or did not contain enough clarity about what was meant by 'being disabled'. This was a particular problem for respondents who felt their child's problems to be fairly mild, less significant than other peoples, or worse at particular times. For instance one respondent said she would have answered 'Yes' a few months ago but things were better now so she chose 'No'. For these respondents the question was not specific enough about what 'disabled' meant. It was also difficult for parents who found it hard to define disability where the child has psychological rather than physical problems

"For us it is not a significant impairment, so then I do not consider him disabled, as I would consider other children as disabled."

(A respondent with a 14 year old son with Visual or hearing problems)

"Attending a Special school would imply being mentally disabled..so, he's not disabled, but has learning difficulties, so maybe the question is not specific enough."

(A respondent with a 14 year old son with Other difficulties)

Indecision and 'changing your mind'

An important finding that emerged from the cognitive interviews was that respondents could decide they would carry on filling in the form and come back to this question, if later on they felt their child's situation had not been properly reflected or represented.

"If they haven't asked me the right Qs and I felt that they hadn't appreciated the problems we have because I couldn't put them across, then I would think that nothing's going to improve for us because they're not asking the right kinds of Qs for the problems we've got... We're used to fighting for everything, but the services are not there, because they don't ask the right Qs. It would become another 'nail in the coffin' of disappointment."

(A respondent with a 14 year old son with Other difficulties)

'Having a disability' vs 'Being disabled'

Defining disability is clearly a thorny area and respondents differed in their preferred terminology. A preferred term was voiced: 'having a disability' (i.e. does your child have a disability?), rather than being 'disabled' (i.e. is your child disabled?). One respondent was able to explain this distinction quite clearly: for a person who has a disability, it is not always a 'problem' and thus does not necessarily 'disable' him or her. But for other people, the perception is that, the disability is a problem and the public perception of the word is quite different to the reality of having a disability. Another term which was more preferable was 'less able'.

"Depends on what they mean by 'disabled.' She's not disabled really; she's got a disability. Being disabled means somebody who has got a disability, like being handicapped...don't know, really...They need to word things properly, so that I can really understand it."

(A respondent with a 11 year old daughter with Allergy or breathing problems and an 'other disability')

NB: This respondent, after debating the question out loud and looking at the list at Q5 decided to tick 'Yes'.

Feelings about answering

Again, due to concerns about the sensitive nature of this question, respondents were asked about how they felt answering it. Two main categories emerged:

1. Respondents who felt the question appeared rather abruptly following a discussion about things their child **was** able to do and that it raised emotive issues for parents and was upsetting for parents to answer. No parent likes to think of their child as being disabled and having to enter it on a form could be upsetting and frustrating. The terms 'label' and 'stigma' formed part of the discussion here and the negative connotations associated with them.
2. The second group contained respondents who felt that, although it was a difficult issue, this was a necessary question for the survey and were happy to answer. However, as mentioned earlier, there was some concern that confusion existed between the two concepts of 'whether the child was disabled' and the parents' opinion on whether this was so.

"There's no problem with the actual question, it does need to be asked."

(A respondent with an 8 year old child with mobility or manual dexterity problems)

2.4.3 Recommendations

- We would recommend removing this question since it does not feed into the performance indicator.
- If the question is to be retained we would recommend rephrasing it to ask whether the parent considers their child to 'have a disability' but since this is covered in the screening questionnaire we would not recommend this.

2.5 Areas the child is affected (Question 5)

2.5.1 Question 5

Q5(A6)	Please record all the areas in which this child is affected:	
1	None	<input type="checkbox"/>
2	Mobility - getting about the house and beyond	<input type="checkbox"/>
3	Hand function - holding and touching	<input type="checkbox"/>
4	Personal care - washing, going to the toilet, dressing etc	<input type="checkbox"/>
5	Incontinence - controlling the passage of urine and faeces	<input type="checkbox"/>
6	Communication - speaking and/or understanding others	<input type="checkbox"/>
7	Learning - having special educational needs etc	<input type="checkbox"/>
8	Hearing	<input type="checkbox"/>
9	Vision	<input type="checkbox"/>
10	Behaviour - a condition resulting in socially unacceptable behaviour	<input type="checkbox"/>
11	Consciousness - fits and seizures	<input type="checkbox"/>
12	Diagnosed with autism or Asperger Syndrome - diagnosed by a qualified medical practitioner as having classical autism or Asperger Syndrome. Do not include children who have merely been identified as having an Autistic Spectrum Disorder (ASD) eg. by their school. This can be associated with the behaviour and learning categories above	<input type="checkbox"/>
13	Palliative care needs	<input type="checkbox"/>
14	Other (please write in) _____	<input type="checkbox"/>

2.5.2 Findings

A number of issues were identified with Question 5. Despite these issues there were respondents who had no problems and did not find the question sensitive. They found the question and answer categories easy to understand and were sure of their answers. Respondents did express surprise that the question was very specific, as earlier questions had not been but this was not a problem.

Comprehension of the answer categories

There were two main types of problems related to the meaning of the answer categories. Firstly, respondents were not always familiar with the terms used. Almost universally, respondents (including health workers) did not know what Palliative care was but felt certain that they would know if their child had this type of care and so opted not to tick that option. Secondly, although respondents understood the categories they were unsure what was intended in the context of the question and sometimes felt they did not accurately capture their child's situation. The main problems arose with mobility (2), learning (7) and behaviour (10).

1. Mobility - getting about the house and beyond.

A respondent pointed out that her child did have a problem outside the house but not in the house. She did not know how to answer this question and decided to come back to this question at the end of the questionnaire so as to use other questions as a tool to understand how she should answer the question. Another respondent who had a deaf child, considered her child needed support outside the home and therefore had difficulties with mobility because of his disability but he did not have problems with his physical mobility.

2. Learning - having special educational needs etc.

One respondent pointed out that her child was very bright and as a result has special educational needs. However she was not sure if her son's situation is what this category covered and so was unsure how to answer.

3. Behaviour - a condition resulting in socially unacceptable behaviour

The term 'socially unacceptable behaviour' was felt to suggest someone being naughty. As a result parents could feel this category did not cover a child's frustration (with their disability). As a respondent pointed out, her daughter is not naughty but she sometimes gets frustrated so loses her temper. For a young child this may be the only way to express her anxiety with her condition.

Other parents were surprised to find this category since they did not associate this with disability or illness.

Changing situations and multiple conditions

Where the respondent's child had more than one condition the parent could find this question confusing since they had to think about multiple areas pertaining to multiple conditions. Respondents were able to answer this question.

The situation in relation to a child's disability can change over time and this caused respondents problems in answering in two main situations:

1. When their child's condition was currently stable but their child could have problems in some of these areas when their child is not well. Respondents tended to answer the question based on the situation on the day but the think aloud indicated which areas the child was affected when he/she was not well. If the question is trying identify the areas which the child's disability affects this should be clarified.
2. When their child's disability has been addressed and therefore is not a problem any more but had been in the past.

Routing and other problems

There was evidence of respondents who were inaccurately routed after question 4 (going to question 5 even when they had said no to question 4). Since they felt their child did not have a disability and were surprised to see the question but they were able to use the option 'none' and answer the question.

Respondents sometimes used the space under 'other' to explain earlier choices and not to select another condition which suggests this question may be a candidate for a box allowing respondents to record an open ended response (as has been suggested elsewhere in this report).

Where the space under 'other' was correctly used respondents identified gaps in the current list of areas affected. Respondents pointed out there were no options for:

1. tumours and their effects (however this is something very specific so probably cannot be added)
2. problems associated with medication, whether it is difficulty taking medication or side effects related to medication
3. difficulties with eating and drinking

It was suggested that there is no need for the definition associated with autism or Asperger Syndrome, because parent's whose child is affected by this condition will know about it and will not need the definition.

Problems related to age rather than disability

As was found with Question 3 respondent were unsure how to answer if their child was very young. A respondent pointed out that her child could have problems moving around on his own outside the house but he never goes out unaccompanied because he is too young rather than because of his disability.

Recommendations

- Although this question is problematic it should probably be retained to provide information about the type of disability affecting the child.
- Consider re-wording the question so it covers conditions that fluctuate

Please record all the areas in which this child is currently or could be affected when their illness / disability / condition flares up?

- Consider adding the following options to give respondents more accurate options to select from:
 - Eating and Drinking - has difficulty eating or drinking by himself / herself
 - Medication - has difficulty taking medication or has side effects because of medication he / she takes
- Consider rewording options to make them more appropriate

Suggested amendments to answer codes

- Mobility - getting about on their own outside the house or getting around inside the home
- Behaviour - a condition resulting in the child getting frustrated or exhibiting socially unacceptable behaviour.
- Consider removing the definition of Asperger syndrome. Consider whether ASD diagnosed at school which is specifically excluded should be included under the learning category.
- Consider providing a definition of palliative care needs
- Consider defining 'Other' so it reads Other (please write other areas your child is affected in)

Client to advise on:

- what should be covered by mobility (physical mobility or a broader definition), special educational needs, behaviour***
- whether school diagnosed ASD should be included under learning***

Other questions not tested in cognitive testing

Questions about the child's ethnicity (A3) and receipt of disability living allowance (DLA) were not included in the cognitive testing. ***We would like the clients to consider whether the question of ethnicity should be included*** in the questionnaire given the pressure on space and the lack of other demographic questions. We will consult with NatCen statisticians on the role of the DLA question for sampling. If it is not required for sampling or weighting purposes we would recommend dropping it.

3 HEALTH CARE SERVICES

3.1 Meaning of Health Care Services

Respondents were generally clear about their understanding of the term health care services. All were able to provide an explanation or definition of the term. Although the precise definitions varied, at their core was a consistent understanding of the term. Respondents described the term as:

- Connected with doctors or GPs / nurses / hospitals
- Connected with medical staff
- Services you need for health / well being
- Services provided by the NHS
- Services within the local authority

A question arose over whether complementary or alternative therapies should be included in the definition and whether respondents should be reporting their experiences with these types of services.

Respondents generally agreed that the list of health services provided at question 6 fitted in with how they would define health services themselves. However the services listed at question 6 focus very much on the physical side of health; some respondents saw health care services as covering mental health as well.

3.1.1 Question 6

Q6(H1)		Which of the following health care services has your child used in <i>the last 12 months</i> ?		Please tick one box on each line	
1	GP	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Practice nurse (at the GP surgery)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Health visitor, district nurse, other community nurse	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Paediatrician (child health doctor) or other specialist doctor	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
5	Psychologist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
6	Physiotherapist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
7	Speech therapist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
8	Occupational therapist (OT)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
9	Podiatrist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
10	Optician or eye specialist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
11	Dentist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
12	Dietician or nutritionist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
13	Hospital as inpatient	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
14	Palliative care	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
15	Other health services (please specify) _____	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

3.1.2 Findings

Approaches to answering the question

Question 6 was considered a key question to explore in the cognitive interviews, in order to see whether this question was easily understood, had the appropriate coverage of health services and could be easily and accurately answered by respondents. Respondents tended to just read the first question and not the heading on the page or the explanation below it and just jumped into answering the question.

The cognitive interviews found that respondents adopted two main strategies when answering this question. Those who:

1. Ticked one box on each line (notably the majority of respondents in the same); and,
2. Were unsure whether to tick just the yes boxes and leave a line blank if the answer was no and thereby indicate only the services they have used.

It was also noted that respondents could find it frustrating to be limited to Yes and No boxes when they were not sure, particularly if they did not understand the service being described. Where respondents did not understand a term some just left the line blank, while others ticked no because they assumed they would know what the service was if they had used it. If the purpose of the question is to find out parents' experiences of accessing services for their child capturing this information could be useful to highlight ambiguity in particular service area. However, if this question is simply to understand which services have definitely been used the question would not need to be re-worded although the number of options may want to be limited to reduce respondent frustration.

Time Frame

The cognitive interviews showed that the time frame of 12 months was easy for most respondents to think about. This study was conducted in September which is a key month in a child's school calendar being the start of the school year. Respondents pointed out other key events such as changes in family circumstances exactly 12 months ago to show their confidence in thinking about 12 months. Such key landmarks in the year made the recall period easier for respondents to define. Respondents could use a reference period from January 2008 the start of the year or answer the question thinking about the last complete year i.e. 2007, or they could miss the 12 months reference period all together and just think about the question generally. There was a possibility of telescopic recall influencing the question and answer process of respondents since respondents wanted to mention things which they felt were important but which had not happened in the last 12 months..

Clarity and Comprehension

Respondents were probed on their understanding of the different health care services listed in question 6. Respondents did understand the majority of health care services. However, a few descriptions were confusing for respondents. As in question 5, 'Palliative care' was not understood by the majority of respondents. In addition respondents wondered why Palliative care was on the list because they associated this with 'old people'. 'Podiatrist' was also not clear to respondents who asked why not simply write, a foot doctor or chiropodist, rather than use specialist terms such as Podiatrist. Where respondents did not understand a term they either left the line blank or ticked no assuming they would know if their child received palliative care or had used Podiatrist services in the last 12 months.

The interviews found that respondents were surprised to see optician but thought that 'of course' it should be there. Respondents were not sure however, whether eye tests are included in this question. If it is to be included this needs to be made more explicit.

While the specialist terms could confuse respondents, on the flip side the terms used on some occasions were not focussed enough for respondents, for example a respondent questioned whether psychologist meant "educational" psychologist for example.

Apart from the issue of whether a respondent can answer the question if they do not know the terms used, another issue is that is respondents are presented with questions they do not understand it can make them feel 'thick'. This can make them feel negative about the questionnaire, impacting on their response and the way in which they approach the questions.

Missing options

Respondents were probed to examine whether they felt particular health care services were missing from the list. Respondents pointed out that there was no option for **ADHD specialist**, **chiroprapist** (though this may be covered by podiatrist), **emergency health care services** and **out-patient services** (though these could be covered by each of the options mentioned). A respondent pointed out that health visitor is missing but in fact it is provided as an option, suggesting it is not visible enough.

Another issue that was highlighted in the interviews was that the list focussed on professionals dealing with physical disabilities and not mental health or behavioural conditions. To address this gap in the list of answer codes could be altered to give recognition to these conditions while not lengthening the current list which could over burden respondents. However adding additional examples to existing answer categories can result in respondents not seeing all the services listed.

Respondents were probed specifically to find out if they thought the provision of equipment should be included in this question; respondents either had no views on the matter as they had no experience of needing equipment or they felt that it was covered by the question because each relevant service would provide appropriate equipment. This could be equipment from an occupational therapist or could be glasses from an eye specialist.

3.2.3 Recommendation

- Consider making the heading and definition more visually prominent for example by writing the text in red and placing it in a box with a shaded area behind.

Health Care Services

The following questions are about the health care services which your child receives.

- Consider amending question 6 to cover additional areas such as psychiatrist, chiroprapist, emergency health care and Hospital as an out patient
- Consider simplifying the answer code 9 podiatrist to refer to foot specialist
- Consider increasing the visibility of answer code 3 'health visitor' by making it a separate code from district nurse and other community nurse
- Consider adding an explanation to code 14 'palliative care' in order to make the question more user friendly.
- ***Client to clarify whether non NHS and or complementary and alternative therapies should be included here***

Suggested New Question

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

- GP
- Health Visitor
- Practice nurse (at the GP surgery)
- District nurse and / or other community nurse
- Paediatrician (child health doctor) or other specialist doctor (inc visiting the Hospital as an out patient)
- Psychiatrist and a behavioural specialist
- Hospital as in patient
- Emergency health care
- Psychologist
- Physiotherapist
- Speech therapist
- Occupational therapist
- Foot specialist
- Optician or eye specialist (including eye tests)
- Dentist
- Dietician or nutritionist
- Palliative care (an approach that improves the quality of life of patients and their families facing the problems associated with complex illness)
- Other health services (please specify *any other services*).....

3.3 Accessing Needed health Services (Question 7)

3.3.1 Question 7

Q7(H2)	Over the past 12 months, do you feel you have had all the health care services your child needed? Did you receive...
1	All that he / she needed <input type="checkbox"/>
2	Most of what he / she needed <input type="checkbox"/>
3	Some of what he / she needed <input type="checkbox"/>
4	Little of what he / she needed <input type="checkbox"/>
5	None of what he / she needed <input type="checkbox"/>
6	Did not need any health care services for my child in the past 12 months <input type="checkbox"/>

3.3.2 Findings

Question 7 was not considered difficult to answer by respondents in the sample however cognitive interview did highlight inconsistencies in the way the question was interpreted by respondents. As a consequence respondents used different strategies to answer the question depending on how they understood the question.

Inconsistency and meaning

Question 7 was interpreted inconsistently by respondents. Respondents questioned the meaning of 'have had', 'needed' and 'did you receive' in the context of the question. They were not sure if the question was asking about health care services which were used in the last 12 months but no longer used i.e. the course of treatment / medication has been completed *or* treatment and/or medication still currently received. The second ambiguity related to the use of the word 'needed'. Respondents either felt they could not accurately answer this question because they did not know all that the child needed because they were not a medical professional. In some cases respondents in this situation did feel that their child had received all that they knew about or was available to them at the time. Respondents were not clear how to interpret 'did you receive' in the context of the question. They were not sure if it included receiving information about health services or whether it actually referred to receiving a health service. The final confusion was the last code (code 6) which did not make sense to the respondents in light of the way the question was worded.

Answer Process

The answer codes were also used inconsistently by respondents. For example code one was used by respondents who had a variety of experiences, if they:

- had received 90% of what they needed
- had pushed and then got what they wanted

- had received all their child needed overall but not from any particular provider. For example one respondent felt they had not received what they needed from her GP but she had gone to the hospital herself with her child and then they had received all that she needed for her child.

It was suggested by a respondent that it would be easier to answer the question with a yes or no box, however this would group respondents even further and make it less easy to distinguish between how well needs had been met. Other respondents found the answer options were appropriate and found answering the question easy.

Time Frame

The majority of respondents found it was easy to reflect on 12 months. Occasionally respondents missed the time frame and answered the question more broadly.

3.3.3 Recommendations

- Consider dropping this question or the untested question on quality (H3) (which feed into general experience) depending on client needs. ***Client to advise on importance of general experience.***
- Consider clarifying the question to address respondents' difficulty with the word needed. We would be happy to advise on an alternative question. Below is a suggested alternative though it should be noted that the term 'required' has not been tested and may present the same problems as 'needed' and we have not tested how respondents would interpret 'overall':

Suggested New Question

Over the ***past 12 months***, did 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 your child receive?

1. All that he / she required overall
2. Most of what he / she required overall
3. Some of what he / she required overall
4. Little of what he / she required overall
5. None of what he / she required overall
6. No health care services because he / she did not need any

3.4 Information about Child’s Condition (Question 8)

3.4.1 Question 8

Q8(H4)		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 tick the box that best describes how much you agree or disagree with each statement.				
		Agree Strongly	Agree	Neither agree nor disagree	Disagree	Disagree Strongly
1	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"/>	<input type="checkbox"/>
2	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"/>	<input type="checkbox"/>
3	I have been given enough information about <i>how to access</i> health care services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	There is someone I can go to for help and support in accessing health services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	I have only been able to get information about health care services by word-of-mouth/from other parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	I get passed around from person to person when I try to find out information about health care services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.4.2 Findings

Question 8 was probed in detail by interviewers because it was considered a key question. This question is one of a pair of questions which will be used to calculate acceptable level of service for accessing information on health care services. This question is paired with question 9. It was therefore important to ensure that the question is consistently understood by respondents and they answer the question the same way to ensure comparability. The probes explored whether respondents understood the question, statements and the answer process. The findings will be presented in this order below.

The question

For the majority of respondents question 8 was clear. However, respondents could find it a long question which needed pauses, such as commas to break it down. It was also considered a long question as it had six separate questions within.

The six statements

The statements were well received in general. For example respondents thought it was good to ask about 'useful' information and health services the child was entitled to because it indicated a child's *right* to services. Generally it was considered the statements were clear and specific. The cognitive interviews found that the majority of respondents understood the question, knew how to answer the question and were accurately able to answer the question. However, occasionally respondents did think statement 1 and 2 and 3 meant the same thing.

Statement 3 and 4

A respondent showed hesitancy in answering statement 3 as she was not sure they had received enough information because they may not have been told everything. Other respondents were unsure what 'access' meant in statement 3 and 4 whether it meant physically how to visit a place or knowing key persons who can organize access. As a consequence, respondents either did not answer or chose to disagree with statement 3 or 4 as an indication they did not understand the question. 'Think aloud' strategy used by the interviewers to explore how respondents answered the questions indicated that respondents generally interpreted access to mean knowing the phone number of GPs or a point of contact who could organise health care services. As a consequence feedback from respondents suggested that not relevant box should be given for question 3 and 4 because they did not need guidance on how to access getting an appointment with the doctor. Question 4 was considered inconsistent with the other statements and earlier questions in that it referred to 'health services' and not 'health **care** services'.

Answer Process

Respondents' reaction to the answer process varied. Respondents could feel that the answer codes enabled them to answer the question accurately. Others felt three codes would be sufficient: agree, neither agree nor disagree and disagree, as "you either agree or you don't", to quote the respondent. In the interview debrief it was suggested that a true and a not true option would have made it easier for respondents to answer the individual statements. Another point raised in the debrief that respondent error could arise because the statements change from positive to negative (statement 5 and 6) in sentiment and respondents may assume that agreeing with a statement implies a positive answer. Furthermore for statement five there was disagreement over what would constitute a positive answer in that relying on word of mouth could reflect poor levels of formal information or could be seen a good thing in that the parent has an informal information network.

It was suggested that the question could benefit from an open text box where a respondent could optionally write why they strongly disagree or agree with the question.

3.4.3 Recommendations

- Retain the current question. This question can be used to calculate the problem score for health care services - information.
- Consider formatting key words in italics in statement 1 and 2 so each statement can be clearly distinguished. Question 3 will be examined separately in the following recommendation.
- Consider adding NA

Suggested amendments to the statement

Statement 1

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

Statement 2

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

- Consider clarifying statement 3 and 4. ***Client to advise on what is meant by access in these statements so appropriate changes can be made.*** Our current suggestions are below, an alternative would be to replace 'access's with 'get'.

Statement 3

I have been given enough information about how to contact health care services for my child

Statement 4

There is someone I can go to for help and support in arranging appointments, visits and contact details of health care services for my child

- As statements 5 and 6 are difficult for respondents to answer and it is covered by earlier statements we would suggest considering dropping these two statements.
- Consider adding an open text box to allow respondents to add any extra information

3.5 Information about Child’s Condition (Question 9)

3.5.1 Question 9

Q9(H5)		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.		
		Please tick one box on each line		
		Yes, always	Yes, sometimes	No
1	Clear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Relevant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Accurate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	I have not received any information about health care services available to my child in the last 12 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.5.2 Findings

Although on the whole respondents understood the question, they were not always comfortable in answering the question as it currently stands. This is an important finding as this question will be used to calculate acceptable service in providing information on health care services. The problematic area was the fifth option which did not associate easily with the answer options. ‘Clear, relevant and accurate’ were correctly understood by all the respondents, although not all the respondents were confident that they had understood the meanings accurately. Verbal and written were also clearly understood. Respondents were probed to find out if they would include information from the world-wide-web as written information in this question. Respondents were mixed in their response: some would have included it, others would not because this would be information they had sought on their own and had not received.

Respondents who found the question confusing pointed out they did not know if the question covered information about services already received or information about services generally. Another issue was confusion over the types of services covered by the question. For example, a respondent was confused because half the information she had received was to do with alternative therapies. She found it difficult to know whether to include information about these type of services when answering this question. This respondent opted to answer all the statements with yes sometimes. The direction ‘please tick one box on each line’ on occasion was missed, with the consequence respondents were confused how to answer the question. These respondents left the relevant line blank. Respondents were also confused by the last statement which did not fit easily with the question or the answer codes, yes always, yes sometimes and no.

3.5.3 Recommendation

Consider breaking down the question into two parts. First ask the respondent whether they have received any information; if they have then ask the respondent to indicate what they thought of the information. This would simplify the question and answer process for the respondent. We have provided below a suggestion for the two questions. Respondents were unclear about whether information received should include **information which they had to seek out; advice is needed from the client on this as well on the issue of whether information about non NHS and or complementary and alternative therapies should be included. This will affect the bracketed wording suggested below.**

Suggested New Question

Q9A In the last 12 months have you received any information (or found information independently) about health care services (within the NHS and externally) for your child named at question 1?

Yes → Please go to question 9B

No → Please go to question 10

Q9B Overall, how would describe the information you have received in the last 12 months about any health care services (from the NHS) for your child?

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

3.6 Decisions regarding the child’s health (Question 10)

3.6.1 Question 10

Q10(H6)	In the past 12 months, have medical or health professionals made any <i>decisions</i> about your child’s illness or disability or services that he / she should receive?		
	Yes	<input type="checkbox"/>	¹ ➔ Go to Q11
	No	<input type="checkbox"/>	² ➔ Go to Q12

3.6.2 Findings

Question 10 was included as one of two questions to examine health care services assessment (the other question is question 11).

Comprehension

There were cases where respondents found the question unclear. These respondents were confused by the phrase ‘should receive’. Like question 7, respondents were not sure they had the full information to be able answer this question. The strategy used to overcome this was to answer the question with reference to all the services the child needed.

The cognitive interviews identified two main ways that the word ‘decisions’ was interpreted by respondents in this question:

1. Only big decisions were being included such as an operation, change in medication, treatment or equipment and not decisions that took place in an ordinary visit to the doctors, dentists or opticians. These respondents considered that just monitoring or observing a condition to be “no decision had been taken” because no medication had been received and that being referred to a specialist was being given advice, rather than a decision being made.

“A decision would be about going into hospital, or something and no-one has said anything like that...”
(A parent with a child aged 5-10, with an allergy or breathing problems).

2. Any decision that had been taken in the last 12 months was included when answering this question including routine decisions to just monitor a condition

The interviews also showed how question order effects influenced this question since the answer given at question 10 affects subsequent routing. One way of deciding on an answer was for respondents to see question 11 and realising that it was a long question deciding to answer Question 10 ‘no’ in order to be routed to question 12 and thereby avoid answering Question 11.

“Too many questions too complicated, too much on the page, too many boxes. No, no more”
(A mother with a son aged 11 with ADHD)

3.6.3 Recommendations

- **Client to advise on what type of decision should be covered by this question and how to describe it.**

- Consider rewording the question depending on the purpose of the question either:

In the past 12 months, have medical or health professionals made any decisions about your child's illness or disability or services that he / she should receive. Or

In the past 12 months, have medical or health professionals made major decisions about your child's illness or disability or services that he / she should receive (though use of the term 'major' may lead to respondents excluding some relevant decisions)

- If the question is slightly amended as suggested above it could be used as one of two questions on which a problem score for health care service assessment is calculated.
- If possible place question 11 on the following page so respondents are not influenced by it when answering question 10 (this arrangement was used for the equivalent question about assessment in the education section and the problem of short cutting was not observed there).

3.7 Making decisions about child's health care (Question 11)

3.7.1 Question 11

Q11(H7)		And thinking about these decisions and the questions you had to answer in the last 12 months, please indicate how much you agree or disagree with each of the following statements.				
		Agree Strongly	Agree	Neither agree nor disagree	Disagree	Disagree Strongly
1	We had to give the same information several times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	We were listened to and our needs were understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	The decisions made were suitable for my child's needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	The decisions were made at the right time for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	The relevant professionals worked together to make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	We/I understood how the professionals had come to their decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	On the whole the decisions that were made were fair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	No decisions were made by health professionals in relation to my child in the past 12 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.7.2 Findings

Question 11 is the second of two question (question 10 is the other question) which will feed into the disabled children's services indicator looking at acceptable service in health services assessment. It is important this question is clearly understood and the answer codes work to ensure respondent's can easily answer this question examining assessment.

Answer strategies

Respondents approached this question by working their way through the list, line by line, sometimes reading out the statements. Where respondents felt a statement was irrelevant to them they either (a) ticked nothing on that line or (b) ticked the middle category ('Neither agree not disagree'). When asked how they approached the task, respondents said they thought about the situation and whether or not they agreed: "...*deciding how I felt about the decisions they had made and answering*" (A respondent with an eight year old with Visual or hearing problems)

Answer categories

All five of the answer categories were chosen at least once, the first three answers (Agree Strongly, Agree and Neither agree not disagree) more popular than the latter two (Disagree and Disagree Strongly). Views about the wording of, and number of, answer categories were mixed.

Wording of answer categories

Respondents could find it difficult to differentiate or choose between 'Agree Strongly' and 'Agree'. For example one respondent said she thought the answer was a simple Yes or No. Another said "*I'm sure so I just agree*" (A respondent with an 11 year old son with Visual or hearing problems)

Other rationales for choosing between the two were:

Ticking 'Agree Strongly'

- Where there had been no problems
- Where there had been a very positive feeling
- Where something had happened repeatedly

"There were no problems with anything about how they kept us informed and what was to happen, everything was great"
(A respondent with a 5 year old son with Medical needs)

"Where I had received a positive reaction and help from the various services I put 'strongly'"
(A respondent with a 14 year old son with medical needs and an 'other disability')

Ticking 'Agree'

- Where the respondent did not feel completely satisfied with what had occurred but was relatively content with the decisions that had been made
- Where the respondent felt they could have been more involved

"There were times we were not part of the decision making process, so didn't feel 'strongly'"

(A respondent with a 5 year old son with Visual or hearing problems and allergy or breathing problems)

Number of answer categories

Respondents did not have overly strong opinions on the number of answer categories. There were some comments that three boxes might be easier to absorb than five, but this did not seem to have been a problem. However, as the decision to pick 'Strongly Agree' or 'Agree' did not seem to be a particularly clear one it may be simpler to move to a three box format. More importantly respondents made two other requests:

- That a 'Not applicable' category be included, as occasionally respondents had not formed an opinion or had not reached a point where they were able to give a clear answer (e.g. if it was fairly early on in the decision making process about their child's condition). In these cases respondents either ticked the middle category ('Neither agree nor disagree') or left the whole line blank.
- That space is included for respondents to make comments or explain their answer. As these questions are so personal and emotive to respondents they would like to be given the chance to expand on their answer.

Statements

Respondents were asked about their understanding of the seven statements and whether there was any overlap between them. On the whole respondents found the statements clear, the problem being that their experiences varied so widely (even over the last 12 months) that it was difficult to know which box to tick. Where this happened respondents tended to choose the middle category. Below are findings for specific statements.

We had to give the same information several times (Statement 1)

This statement was misunderstood by one respondent who at first thought it referred to information she had received. Other than this, respondents understood the statement. One respondent gave the example of having to provide the same information on a repeated basis at a hospital, comparing this unfavourably with the local GP or Dentist where this would not occur.

The decisions were made at the right time for my child (Statement 4)

This statement proved problematic in a few cases. One respondent considered the timing of appointments and how they had had to wait a long time for follow up, which referred more to bad management than decision making regarding treatment. A second respondent likened the process to being on a 'see saw' with good then bad decisions (this R did think about the last 12 months).

The relevant professionals worked together to make decisions (Statement 5)

Respondents did not feel the wording of this statement to be very clear. The process was described as complicated, meaning it was difficult to answer the statement in its current form. For instance some children could have a number of different disabilities or conditions and it would not have been relevant for the different health professionals to work together; in these cases it was not clear who should be considered. This statement also brought about the following comments from respondents, regarding their personal experiences:

“Even though various professionals have been involved with my son’s diagnosis and treatment, the ‘big guy’, the hearing specialist, made the decision”

(A respondent with 14 year old son with Visual or hearing problems)

“Well I’m just thinking of the nurse and the doctor. That’s all she sees”

(A respondent with a 16 year old daughter with allergy or breathing problems)

“Usually, you see at least two or three different professionals at any one time. Sometimes you see one and they tell you one thing. Then you see someone else and they are only concerned with their particular area and they don’t overlap or consult with each other because they’re outside each others areas”

(Respondent with a 10 year old son with Allergy or breathing problems and other disabilities)

On the whole the decisions that were made were fair (Statement 7)

This statement could be confusing, mainly because of the use of the word ‘fair’. It is not completely clear what is meant by this. One respondent did not understand what was implied by this word, stating *“At the time it was the only option that was viable”* (Respondent with a 10 year old son with Allergy or breathing problems and Other disabilities)

No decisions were made by health professionals in relation to my child in the past 12 months (Statement 8)

Respondents picked up on the irrelevance of this option: firstly because Q10 deals with this (and so respondents for whom the question would not apply are routed past it) and secondly because the answer categories, as they stand, do not apply or make sense. One respondent described it as being a *“double negative”* (A respondent with a 5 year old son with other disabilities)

It seemed that respondents’ choice of answers to the statements in this question depended largely on (a) way the health services reacted to respondents’ circumstances and (b) respondents ability to ‘take in’ what is being told to them. The more engaged the respondent seemed with the decisions that had been made regarding their child’s condition, the more positively they answered these statements here.

Overlap

Taking the question as a whole, one respondent said she thought it overlapped with Q9 and because of this, if on her own, she probably would not answer properly, perhaps instead even make a pattern of ticks across the boxes. This respondent said that the questionnaire was too long and should be cut down to only three pages as then people would be more willing to complete it.

Statements respondents felt overlapped were:

- Statements 1 and 2
- Statements 3 and 4
- Statements 5 and 6

It was also suggested that the statements were re-ordered so that statement 7 appeared before 5 and 6.

Time period

Respondents were asked about the time period they thought about when answering this question. In the few places this was probed on, respondents said they had thought about the last 12 months and that this had been fairly easy to do. When asked exactly what they had considered during that time, a mixed response was given. Respondents either thought generally over the past year or considered a more specific one-off incident in that time. It was very easy for respondents to focus on one incident where this had happened recently and so this question depended very much on what had taken place in the recent past with the individual child in terms of their health care.

3.7.3 Recommendations

- Consider re-wording the question 'And thinking about these decisions and the information you have had to give health professionals in the last 12 months, please indicate whether you agree or disagree with each of the following statements'
- Move to 3 answer categories - Agree, Neither agree nor disagree, Disagree
- Add a N/A category
- Add space to write in comments (even if can't be used in analysis)
- Use we or I consistently
- Use professionals or health professionals consistently
- Statement 5: Where necessary, the health professionals worked together to make decisions
- Statement 6: We understood how the health professionals reached their decisions - consider dropping this statement as there is considerable overlap with question 12. Question 12 is the only question that measures transparency in the indicator, so is a key question.
- Amend or drop statement 7: On the whole, we were happy with the decisions that were made
- Statement 8: One answer box or drop altogether as these answer categories do not apply and the respondents do notice.
- If the above considerations are accepted this question could be used to measure a problem score for health service assessment.

3.8 Understanding decisions (Question 12)

3.8.1 Question 12

Q12(H8)	How well do you understand how decisions are made about which health care services your child receives? Do you understand this	
	Very well	<input type="checkbox"/>
	Fairly well	<input type="checkbox"/>
	Not very well	<input type="checkbox"/>
	Not at all well	<input type="checkbox"/>

3.8.2 Findings

Question 12 was an important question to test as it is the only question which will look at transparency of health care services in the indicator. In addition the equivalent question in social care services and education was not tested. Below we look at issues identified in the cognitive interview, namely answer strategies and specific problems and overlap.

Answer strategies

Respondents were able to provide answers to this question, with answers ranging from ‘Very well’ to ‘Not very well’. The final category ‘Not at all well’ was not selected. Answers were concentrated on the positive end of the spectrum. As with the previous question (question 11), and perhaps as expected, there was a tendency to focus on very specific instances that had involved decisions as this is an emotive and very personal topic area, particularly where decisions are yet to be made.

Specific problems and overlap

There were specific problems with this question in a few cases. There was a feeling that there was overlap between this question and the previous question (question 11), that in fact it had already been covered there at Statement 6. One respondent confused ‘decisions’ with ‘instructions’ for medication (e.g. leaflets, medicine slips). Another was confused by what the question was asking and eventually chose ‘fairly well’.

Answer categories

The four answer categories appeared to work well: no-one had a problem choosing an answer and no additional answer categories were suggested. Respondents were probed on how they went about selecting their answer; some examples are given below:

Very well

Respondents answered ‘Very well’ if they felt everything had been clearly explained and they were happy with the decisions that had been made.

“Everything with the health care services, everything been understood by me well and if I didn’t understand it, they would explain it”
(Respondent with an 18 year old son with Medical needs and Mental health problems)

Fairly well

Respondents answered ‘Fairly well’ if they had understood most, not understood absolutely everything (100%), of what they had been told or had read, or if they had a good knowledge of the area.

“Well, when you read leaflets you find some of the words you can’t understand so that’s why I put ‘fairly well’.
(Respondent with a 16 year old daughter with Allergy or breathing problems)

“I say fairly well as in - I know what’s available. I watch the news”
(Respondent with a 4 year old daughter with Allergy or breathing problems and Medical needs)

Health care services

Respondents were also probed about their understanding of ‘health care services’. Respondents tended to think about the services most used by their child or anyone that needed to be involved in their child’s life or who they needed to see. These included a wide range of individuals including:

- Doctors and paediatricians
- Nurses
- Professionals
- Specialists
- Physiotherapists
- Occupational therapists
- Statutory health services
- Child and adolescent mental health services
- Everything from child services
- Teams that go into schools
- People who ‘look after’ a child’s ‘welfare’, or who have their ‘best interests at heart’

3.8.3 Recommendations

- Reflecting that statement 6 in question 11 and question 12 was found to be repetitious for respondents we would recommend that question 12 is strengthened by removing statement 6 in question 11.
- We would recommend that this recommendation is applied to the relevant questions in social services and in education.
- Retain answer categories as they are
- Re-word question to make shorter and remove double 'how'.
- Suggested wording - 'How well do you understand the decisions that are made about your child's health care...?'

3.9 Involvement in decision making (Question 13)

3.9.1 Question 13

Q13(H9)	Over the past 12 months, how much have you been involved in decision making about your child's need for health care services?										
	<table><tr><td>A lot</td><td><input type="checkbox"/></td></tr><tr><td>A little</td><td><input type="checkbox"/></td></tr><tr><td>Not much</td><td><input type="checkbox"/></td></tr><tr><td>Not at all</td><td><input type="checkbox"/></td></tr><tr><td>No decisions were made by health professionals in relation to my child in the past 12 months</td><td><input type="checkbox"/></td></tr></table>	A lot	<input type="checkbox"/>	A little	<input type="checkbox"/>	Not much	<input type="checkbox"/>	Not at all	<input type="checkbox"/>	No decisions were made by health professionals in relation to my child in the past 12 months	<input type="checkbox"/>
A lot	<input type="checkbox"/>										
A little	<input type="checkbox"/>										
Not much	<input type="checkbox"/>										
Not at all	<input type="checkbox"/>										
No decisions were made by health professionals in relation to my child in the past 12 months	<input type="checkbox"/>										

3.9.2 Findings

Question 13 and question 14 have been identified for measuring participation in the indicator. The equivalent of question 13 was not tested in the Social care and education section. It was therefore very important to test this question and to see how it would work.

Answer categories

Respondents appeared to understand this question and were able to choose between the four answer categories. Answers were generally positive (either 'A lot' or 'A little'). One respondent commented that very often parents are actively involved in decisions relating to their child's health care and so it is not necessarily enough to say they were involved 'A lot'. One respondent wanted to be able to say: *"I am completely involved, completely"*, rather than just 'A lot' (A respondent with a 14 year old son with Mental health problems, and Learning difficulties).

Problems interpreting the answer categories

There are fundamental problems with the answer categories as they exist as the answer wraps together two concepts: (1) how involved respondents were in decision making; and (2) to what extent they agreed with the health professional about the decision.

Although all respondents managed to tick an answer category, they did on occasion deliberate over choosing one and this occurred where they had simply accepted the decision made by the professional. In these situations they had been 'consulted' but had not needed to argue against the decision. Thus, where respondents agreed with, or were happy to leave decisions to the experts could tick 'Not at all' without any negative connotations. Likewise, ticking 'A lot' could indicate a parent had disagreed with the doctor regarding the best treatment for their child, or in fact the opposite, that they agreed with the doctor but felt very involved with the decision.

"Whatever she's needed I've been asked about. Whether I want to go down that route. I've always felt that I've had a choice. I didn't want her to wear a patch. They gave me the reasons why she should but it's my decision"
(Respondent with a 4 year old daughter who has Allergy or breathing problems and Medical needs)

"Basically, whatever they've told me, I've agreed to it... The people who have told me are professionals. When a professional tells you something you don't have to agree with them"
(A respondent with a 3 year old daughter with Allergy or breathing problems)

Involvement

Respondents were asked to describe what was meant by 'being involved' in decision making. Somewhat linked with the problems described above, there again appeared to be confusion between two concepts: (1) being 'fully **informed**', 'in the loop' or 'updated' about professionals decisions; and (2) being consulted or actually **involved** in these decisions. One respondent summed this up quite well stating that this came down to whether or not one agreed with the professionals. This respondent chose *"a little involved, because they have the expertise and one should take their advice"* (A respondent with a 14 year old son with Visual or hearing problems). Other definitions of 'involvement' that fell into these two categories were:

(1) Being 'informed'

- Receiving a full explanation
- Seeing the paperwork

(2) Being 'involved'

- To be asked for your opinion and for it to be taken into account.
- An opportunity to sit down and have a discussion and, importantly, for there to be adequate time for this
- To be fully involved in the decisions
- Having an involvement in the care plan
- Decisions not being made without both parent and child present
- Being there and being listened to.

“played a part”

(A Respondent with a 5 year old son with Allergy or breathing problems, Medical needs, Learning difficulties and Other difficulties)

“having a say”

(A Respondent with a 5 year old son with Allergy or breathing problems, Medical needs, Learning difficulties and Other difficulties)

Overlap with other illnesses

One problem that emerged during cognitive testing was that of other illnesses. Occasionally respondents would not restrict their thinking to their child’s disability or condition and would include other illnesses (e.g. bowel problems or issues surrounding puberty). This occurred where something very recent had taken place relating to these illnesses and thus these other illnesses were at the forefront of the respondent’s mind.

Time frame and ‘telescoping’

With earlier questions we found that respondents thought about a mixture of time periods, some thought generally about their child’s condition, others were able to restrict their thinking to only the last 12 months. However, during probing at this question the problem of ‘telescoping’⁴ raised itself, whereby respondents wished to report their experiences even when they were outside the 12 month time frame. This problem may be particularly salient for these kinds of questions, where the respondent feels very emotional about the topic and thus want to ‘have their say’. This finding indicates that at question 10 respondents may tick ‘Yes’ and go on to answer questions about decision making, even when it falls outside of the 12 month time frame, as they do not want to miss out on answering the questions. This finding also shows that, while our concern was initially that respondents do not notice the 12 month time frame, respondents occasionally employing this answer strategy can actually spot it, but choose to ignore it. Respondents admitted that, at this question, they tended to focus more generally on the past and how involved they had been in decision making generally, rather than sticking rigidly to the last calendar year.

Emotive nature of topic area

To follow up on this, respondents were also probed about whether they considered their involvement in decision making in general or if they had focused on a specific incident when formulating their answer. Respondents provided a mixture of responses to this probing: some had focused generally on their involvement in decision making and others had thought of particular instances that had occurred. Where parents had had negative experiences, the experience of going back over them and remembering them could be upsetting and raise emotions during the interview. In one particular case there had been an incident where the parents’ views had not been taken into account and treatment for their child had been delayed. Due to the recall of how upsetting this had been the interview needed to be paused for a while. Importantly, this experience had coloured this respondent’s entire attitude towards healthcare and it must be recognised that when answering these types of questions emotional issues could ‘take over’. It was in cases difficult to remain focused on the questions as they asked about such emotive topics. This is a potential problem for the entire questionnaire.

⁴ See Sudman,S, Bradburn.N, and Schwarz, N. (1996) Thinking About Answers The Application of Cognitive Processes to Survey Methodology, John Wiley & Sons Inc

3.9.4 Recommendations

- The current questions would benefit from being re-worded. This would help it to feed better to the participation problem score.
- Separate out/clarify these entwined concepts by adding two follow up questions (these would then need to be analysed in tandem with Q13 in order to properly interpret it)
- Re-word: ‘Over the past 12 months, how involved have you been involved decision making about your child’s health care?’ Very involved, Fairly involved, Not very involved, Not at all involved, No decisions made... ***Client to clarify what is meant by ‘involved’ in the context of the performance indicator.***
- Insert follow up question ‘Over the past 12 months, would you have liked to be more involved in decision making about your child’s health care?’ Yes, I would have liked to be more involved, No, I am happy with how involved I was. However given the shortage of space adding an additional question may not be possible.
- Alternatively, depending on what DCSF would like covered by the idea of “involved” Q13 could be reworded to make the level of involvement clearer: ‘Over the past 12 months, were you consulted or asked for your opinion when decisions were being made about your child’s health care?’ Yes, I was consulted a lot, Yes, I was consulted to some extent, No, I was not consulted.

3.10 Health Professional interest in Parent’s views (Question 14)

3.10.1 Question 14

Q14(H10)	How interested do you think that health professionals are in the views of parents, about how health care services for children could be improved? Would you say they are ...
Very interested	<input type="checkbox"/>
Fairly interested	<input type="checkbox"/>
Not very interested	<input type="checkbox"/>
Not interested at all	<input type="checkbox"/>

3.10.2 Findings

Question 14 is the second of two questions which will be used to calculate a problem score in participation for each respondent (the other question is question 13). The equivalent question in the social care and education services was not tested. This was therefore a key question to test in the cognitive interviews. We discuss our findings below.

Answer strategies

All respondents, with the exception of one, were able to provide an answer to this question. This one respondent said this type of question should not be included.

“That’s a complicated sentence, too long and does not make sense. I’ve read it 5 times now and is it asking about the views of parents or the views of consultants? Really weird. How do I know about these things?”
(Respondent with a 11 year old son with Allergy or breathing problems)

The confusion between whether the question was asking about parents’ views or professionals views was not confined to this respondent. Confusion also existed surrounding what professionals were interested in; this was confused with whether they were interested in the children themselves. It appears that the question was too long and wordy and included too many concepts to be clear.

It became apparent that the question was very much dependent on respondents’ own personal experience of health professionals and that these experiences coloured their view on the topic. Variety of experience was also key; some professionals were interested and others were not, which led to difficulty in choosing a category as it was impossible to convey this variety.

“It all depends on how friendly you are with the doctor”
(A respondent with a 14 year old son with an ‘other disability’)

Lastly, respondents commented on the problem of time; the professionals probably would be interested if time permitted. One respondent referred to the *“bigger picture”* (A respondent with a 14 year old son with an ‘other disability’) within the Health service and that while professionals would like to be interested in parents’ views there simply is not time.

Answer categories

Answers ranged from very interested to not very interested. Some examples of how respondents explained their choice of answer category are given below:

Very interested

“They try to help every family, every child, in my own experience. They listen to what we have to say”
(A respondent with a 5 year old with an ‘other disability’)

Fairly interested

“They like to hear feedback and request your views and if there is a decision to be made about improving services, it’s taken into consideration but it’s not the be all and end all of those improvements”
(A respondent with a 10 year old son with Allergy or breathing problems and an ‘other disability’)

“I think they do care about parents’ views but I think they’re also trying to get the job done”
(A respondent with a 4 year old daughter with Allergy or breathing problems and Medical needs)

“It would not be an over-riding feature, although they would take it into consideration”

(A respondent with a 14 year old son with an ‘other disability’)

“A lot of the time I am not listened to as a mum and some of the professionals are not interested”

(A respondent with a 7 year old son with Visual or hearing problems, Medical needs, Learning difficulties and an ‘other disability’)

Not very interested

“cos when you do go to the doctor or the hospitals they don’t really ask you what you think. They just give you information”

(A respondent with a 3 year old daughter with Allergy or breathing problems)

Health professionals

Respondents were asked who they thought of as ‘health professionals’. A variety of different people were considered:

- Only the doctor
- Nurses
- Anyone the child has needed to see or anyone caring for your child
- Specialists
- Health visitors
- Opticians

“think you would normally answer this question on who you normally see, in my case the Doctor...” (A respondent with a 14 year old son with Mental health problems and Learning difficulties)

Suggestions respondents made for improvement of the question were:

- Include some examples as it was not clear who the question referred to
- Use the term ‘health specialists’ rather than ‘professionals’ as the latter term covers a huge body of people that have anything at all to do with health.

3.10.3 Recommendations

- Consider re-wording the existing question, to ‘Do you think health care professionals are interested in the views....?’ Yes always, Yes to some extent, No.
- If retain existing answer categories include a middle category - ‘Some are and are not’ - otherwise respondents choose a middle category to try and display the mix (doesn’t tell the story adequately)
- If retain existing answer categories consider altering the final one to ‘Not at all interested’ for consistency
- If the above recommendations are adopted question 14 could be used to contribute to a problem score for participation of health care services. An alternative would be to drop this question which means that the middle aspect of the participation indicator would not be covered.
- We would recommend that these suggestions are adopted for the equivalent question in the social care and education section.

3.11 Feedback from children (Question 15)

Next respondents were asked whether their child had been asked to give feedback on the health care they had received over the last year and whether they felt changes were made as a result of feedback from children.

3.11.1 Question 15

Q15(H13)	Over the past 12 months, has your child been asked for feedback on the health care services he / she received?
	Yes <input type="checkbox"/>
	No <input type="checkbox"/>
Did not receive any health care services in the past 12 months	<input type="checkbox"/>
Child not able to provide feedback due to young age or learning/cognitive difficulties	<input type="checkbox"/>

3.11.2 Findings

There are currently 7 questions which are proposed to feed into the feedback problem score. Five of these questions were tested in the health care section (questions 15-19). The feedback questions were not tested in the social care and education section. It was therefore important to test meaning and routing of questions 15-19. We present the findings for the respective questions in their own section.

Whether child has been asked for feedback

Only three respondents answered 'Yes' at this question. The remaining answers were either 'No', or that the child was unable to provide feedback due to being too young or due to a learning or cognitive difficulty. Occasionally respondents missed this box and ticked 'No' in error. No respondent selected the third option 'Did not receive any health care services in the past 12 months'.

Respondents showed considerable surprise at being asked about this topic though were pleased to be asked as they felt it to be an important one.

"but of course the answer is no"

(A respondent with a 8 year old son with mobility or manual dexterity disability)

Understanding of 'feedback'

The question does not specify whether this feedback should be written or verbal and so occasionally respondents were confused about what they should include. One respondent did not understand the word 'feedback'. In fact the three respondents that chose 'Yes' gave questionable answers: one chose 'No' and then 'Yes', saying it was both, though it did not seem that the feedback was directed at the child, more the parent and of an informal nature. The second 'Yes' focused on the health professional asking the child if liked his glasses which, during probing, the respondent decided was not actually 'feedback', that would be more to do with the services he received when he came to visit. The third 'Yes' was also a mistake *"this one is a bit tricky, I don't understand the word feedback"* (A respondent with a 5 year old son with Other disabilities). When probed on this word the respondent said he thought it was asking about results or what they thought about the case or medication. There was only evidence of one true experience of children being asked to provide feedback and this was one respondent saying that in a hospital she had once seen questionnaires for children to fill in.

When asked to define 'feedback' respondents gave the following responses:

- Children being asked what they thought of the services, whether they liked them or not and why
- Children being asked to give information about their treatment back to the health services and professionals
- Children being contacted directly to give their thoughts and opinions on what has happened
- Children asked to fill in a questionnaire (like this one)
- Children's comments being used to help improve services

"Feedback is about how you feel about the services you've received"

(A respondent with a 14 year old son with visual or hearing problems)

"The experience that she's had and how she felt about it"

(A respondent with a 4 year old daughter with Allergy or breathing problems and Medical needs)

Appropriateness of children providing feedback

Respondents gave their opinion on whether or not it was appropriate for children to give feedback and there was a wide mix of views. These views fell into two main categories:

1. Respondents that thought it was important for children to give feedback and for these views to be heard.

“They always ask adults but not the children themselves and they should do more often”

(Respondent with a 14 year old son with Medical needs and an ‘other disability’)

2. Respondents that thought it was inappropriate for young children to be asked these questions as they would not know how to respond or be unable to answer. In these cases the adult would need to step in and provide the feedback instead.

“[The questions would go] straight over her head”

(A respondent with a 4 year old daughter with Mobility or manual dexterity, visual or hearing problems and medical needs)

Time period

Respondents were asked about the time period they had considered. It appeared that respondents were able to consider the last 12 months, but arguably this is irrelevant as there was no evidence of any of the children having been asked to give feedback at all.

3.11.3 Recommendations

- To encourage respondents to read the longer answer codes, these should come first followed by the simpler answer codes, namely Yes and no
- Possibly consider adding the answer code “communication difficulties” to the category explaining why child is not able to provide feedback.
- Consider providing a better description/definition of what is meant by feedback, for example does it include written and/or verbal, and consider providing some examples to clarify this for respondents.
- Alternatively use the phrase ‘asked for their opinion’ which was used in the draft equivalent question for parents (H11)
- It should be noted that the equivalent question about feedback from parents (H11) which was not cognitively tested should be included in the main questionnaire with a definition of feedback.

3.12 Whether changes are made as a result of children’s feedback (Question 16)

3.12.1 Question 16

Q16(H14)	Do you think that changes are made as a result of the feedback children give?
	Yes, always <input type="checkbox"/>
	Yes, sometimes <input type="checkbox"/>
	No <input type="checkbox"/>
	Don’t know <input type="checkbox"/>

3.12.2 Findings

Despite all four answer categories being ticked at least once, the overwhelming response to this question was that respondents’ simply did not know whether changes were made as a result of children’s feedback. The two most popular response options were: ‘Don’t Know’ and ‘Yes’, sometimes, though at this latter category, respondents often said they did not really know. Thus, it appeared that answers to this question were not based on much other than a general feeling, rather than anything more substantive.

“I’d like to say yes but I really don’t know. I would hope they would... Every child is different and it would be very important to get an overall view of what children think about things”

(A respondent with a 14 year old son with Visual or hearing problems)

“I don’t think many people listen to what children have to say”

(A respondent with a 4 year old daughter with Mobility or manual dexterity, visual or hearing problems and medical needs)

“Yes, I feel, especially at the children’s hospital. I think they have listened to children. And they’ve changed the environment accordingly”

(A respondent with a 4 year old daughter with Allergy or breathing problems and Medical needs)

Despite answering ‘No’ to the previous question, one respondent mentioned at this second question that her son had attended group therapy sessions where he was asked to give feedback and that this was important in making him feel he has something to give. It was not clear why this respondent had answered ‘No’ at the previous question and not included this experience as ‘feedback’. This gives more support to the argument that the term ‘feedback’ is misunderstood and respondents are unclear about what to include and how to answer.

3.12.3 Recommendations

- Drop question as respondents do not know the answer, it's more based on a feeling rather than anything evidence based
- Or route out if answer at previous question is not 'yes'
- If retained, give examples of feedback to help clarify what this is, say whether we mean written or verbal feedback etc. Alternatively, if the term 'opinion' is used in previous question consider wording this question in line with that.
- For the equivalent question (H12) about parental feedback consider asking about changes made as a result of the respondent's own feedback (routing accordingly from H11) rather than asking about feedback given by parents in general.

3.13 Making a formal complaint (Question 17, 18 and 19)

3.13.1 Question 17, Q18 and 19

Q17(H15) In the past 12 months, have you made a formal complaint about a health care service you have received in relation to your child?

Yes, to the service provider	<input type="checkbox"/>
Yes, to my Local Authority or Primary Care Trust	<input type="checkbox"/>
Yes, to other organisation (please specify) _____	<input type="checkbox"/>
No, I have not complained → Go to Q20	

Q18(H16) How easy or difficult was it to find out how to make a formal complaint?

Very easy	<input type="checkbox"/>
Fairly easy	<input type="checkbox"/>
Neither easy or difficult	<input type="checkbox"/>
Fairly difficult	<input type="checkbox"/>
Very difficult	<input type="checkbox"/>
Have not complained	<input type="checkbox"/>

Q19(H17) How happy were you with the way that your complaint was dealt with?

Very happy	<input type="checkbox"/>
Fairly happy	<input type="checkbox"/>
Neither happy nor unhappy	<input type="checkbox"/>
Fairly unhappy	<input type="checkbox"/>
Very unhappy	<input type="checkbox"/>
Have not complained	<input type="checkbox"/>

3.13.2 Findings

Answer categories

Respondents were able to answer this question as on the whole the answer was 'No'. Only a few respondents in the sample had respondents actually made a formal complaint.

Respondents disliked the fact that there was no tick box for 'No', it broke the pattern of ticking a box at each question and meant that they were unsure about what they were meant to do (this was an typing error and not intended). In some cases this meant that respondents missed the routing and went on to answer the next question which did not apply to them.

"No complaint so need a no box to fill in, three yes boxes and no no box!"
(A respondent with a 15 year old daughter with an 'other disability')

"It would be nice to have some indication about what I'm supposed to be doing, if that's my answer."
(A respondent with a 14 year old son with other disability)

As so few respondents in the sample had made complaints it was not possible to fully evaluate the wording of the first two answer categories and how appropriate these were. Respondents who had ticked 'Other organisation' had complained to (1) their local MP and (2) a hospital care organisation.

'Formal complaint'

Respondents were asked to explain what they understood by 'formal complaint'. The main characteristics of a formal complaint were:

- That is was physical, i.e. in writing
- Something official
- Filling in a 'complaint form'
- Following a formal procedure
- Complaining to a superior about someone (going over someone's head)

- The next step after making a verbal complaint and nothing happening or being unsatisfied with the outcome

Respondents were also asked about the difference between a formal and informal complaint and respondents seemed fairly clear about this distinction. The difference appeared to be telling someone you were not happy (informal), compared with making a complaint in writing (formal). Where respondents said they had complained informally (e.g. to a nurse), they had still ticked 'No' at this question because this was not seen as a formal complaint.

Other organisations

Respondents were also asked during probing about what 'other organisations might be'. Examples respondents gave included:

- Voluntary organizations or support groups (e.g. SENSE or the Cerebral Palsy group)
- Dentists
- Opticians
- Orthodontists
- Management
- One of the governing bodies

Making a formal complaint and satisfaction with outcome

As so few respondents in the sample had actually made a formal complaint it was not possible to fully evaluate Q18 and Q19. Those who had made a complaint said at Q18 that it was easy or neither easy nor difficult and did not elaborate. Those who answered Q19 did not have any problems with the question or answer categories.

3.13.3 Recommendations

- Consider retaining question 17, 18 and 19 as they could feed into a problem score on feedback.
- At Question 17 'No' category should be clearer, first option maybe so the routing arrow is clearer and there should definitely be a tick box
- Could ask whether have made a complaint in writing as this would be clearer than 'formal'.
- Since only a minority are asked Q18 and 19 consideration could be given to dropping these two questions to save space, however this would impact on the feedback aspect of the performance indicator.

Based on findings from other questions there is a potential for respondents to be confused about the intended meaning of Question 19. The question refers to the 'way in that your complaint was dealt with', however since the question asks how happy they are there is a risk that respondents may think about how happy they are with the outcome of the complaint rather than the process. ***We would welcome a discussion with the client on what this aspect of the core offer is intended to cover (complaints process or outcome of complaint) and also whether this question could be dropped.***

4. Social Care Services Used

4. 1 Meaning of Social Care Services

Respondents were asked a similar set of questions about experience of services for ‘social care services’. Respondents were given a description of these 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 illnesses or disabilities. Please include services provided through your local council, as well as through independent and voluntary organisations.’). The cognitive interviews explored what respondents understood these services to mean and what they felt were covered by these terms. The way in which respondents interpreted these social care and family support services varied and there was a less consistent understanding than in the section on health services. Respondents tended not to have experience of these types of services and felt the services were not relevant for them because their child’s disabilities were not serious enough.

When thinking about the phrase as a whole (“social care and family support”) respondents saw this as:

- being different from health care services (though some health professionals were seen as providing social care services e.g. health visitors and OTs),
- being home based / outside hospital
- supporting people in dealing with their whole situation rather than just medical needs
- caring for social side / well being

Where respondents saw a distinction between “social care” and “family support” they saw them as outlined below:

Social care

- Provided by social services
- Provided by council
- Social workers
- More serious/ provided where needs are serious

Family support

- Provided by voluntary organisation or charity
- Less serious - available before social workers get involved
- Providing emotional support
- For families
- Subset of social care

The terms “social services” and “social worker” were used by respondents in discussing the meaning of social care. Respondents held both positive and negative attitudes towards social services, seeing them either as a source or support or associating social services with taking children away from parents.

“When people hear of Social Care they immediately think of ‘the Social’ which would mean that Social Services i.e. a social worker is involved, and that must be serious”.

(Respondent with one child, 14 year old son with visual or hearing problems).

“Social Care’ still means ‘Social Services’ in people’s minds and putting ‘social workers’ at the top is not a good idea, because of the ‘bad press’ they, often, have. It would block me off, from wanting to answer anything here”

(Respondent with three children, her son aged 11 has ADHD).

The use of two terms: “social care” and “family support” in the question did not confuse respondents whether they saw them as meaning the same thing or two different types of services.

Although education was mentioned in discussing social care and family support services and some health professionals were seen as providing social care support, generally respondents successfully distinguished social care and the other types of services. In this sense the introductory sentence was effective, though it should be noted that some respondents only read the introduction when prompted to by the interviewer and this would not happen when completing a self-completion questionnaire. Respondents’ understandings of what “social care and family support” services covered were diverse. However the inclusion of question 20 provides clarification to respondents about what the term includes in the context of this questionnaire.

We will now move to look at individual questions which were tested in this section.

4.2 Use of Social Care Services

4.2.1 Question 20

Q20(S1)	Has your family used any of the following social care and family support services in <i>the last 12 months</i> ?	Please tick one box on each line			
1	Social worker services	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Home adaptations (eg. ramps, lifts)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Respite, foster care, short breaks	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Help at home with care for the child	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
5	Help with housework	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
6	Emotional support or counselling	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
7	Direct payments (excluding benefits) or individual budget	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
8	Other (please specify) _____ - _____	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

4.2.2 Findings

Although respondents did not seem to have any real problems when answering this question, the cognitive testing did identify inconsistent meaning of social care and family support services and problematic answer categories.

Instructions and Meaning of Terminology

Respondents who were routed at question 17 to question 20 exhibited two broad practices, they literally routed to question 20 and did not read the instructions on the top of the page or they did read the instructions. Although not probed it appears that the three respondents who were not routed did not read the instructions on the top of the page. As in previous sections the instructions are not visually drawing respondents to read the instructions.

The cognitive interviews identified that respondents did realise that this section was looking at services used by the family but many respondents failed to realise the question was focussed on services used by the family in relation to the named child’s disability. The think aloud process identified that respondents picked up that this section was looking at long-standing illnesses or disabilities and not health problems. It would help respondents to think about the named child’s disability or long standing illness if this is included in the wording of the question.

The instructions were clear to respondents and they realised they had to tick one box per line. Feedback from the interviewer debrief suggests that many respondents had no experience with these services. To prevent respondent fatigue the question could be broken down to only ask those who have had experience with any of the services to identify which services they have used. However, occasionally respondents used the list to decide whether or not they had used those types of services at all.

Comprehension of answer categories

Respondents who had not used social care and family support services spoke generally and thought the list was comprehensive although surprised to see housework on the list, sometimes interpreting it to mean children or neighbours helping with household chores. To address this code 5 needs to be clarified (e.g. help within the home from an outside provider). Respite was understood in this context. The question was easy but respondents found the answer process repetitive.

A problematic answer category for all types of respondents, whether or not they had used social care services was 'direct payments'. Two aspects were highlighted in the cognitive interviews

1. They did not understand what it meant
2. They wanted to include their benefits and did not know why they were excluded

As in the health section this answer category needs clarification if it is to be included. As it stands respondents who receive financial assistance do not relate to this answer category. Another problematic area was the placement of emotional support and counselling in social care services. Findings from the interviews suggest that some respondents considered this service as a health service.

Missing options

Respondents who had used social care services found the list very specific but incomplete in coverage. Respondents drew on their own experience to identify services they would have indicated if present on the list. The services missing from the list were:

1. Support Groups - which provide specialised support relating to particular illness, disabilities and health problems of children
2. Support Groups - which deal with complaints
3. Charities and Voluntary Groups which provide support for disabled children
4. Home Start and Sure Start

Respondents did not identify these services which they considered were missing in the list in the 'other' open text section because they were not sure if it was covered in the wording of the question. This suggests that respondents realised the specific focus of the question examining social care and family support services but were more comfortable using the answer codes than writing text.

4.2.3 Recommendations

- Consider highlighting the instructions in a consistent manner to earlier recommendations, such as placing the text in a box with a shaded background.
- Consider moving social worker services to below Help at home with care for the child
- Consider defining direct payments in the context of this section

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 disability(ies), long-standing illness(es). Please include services provided through your local council, as well as through independent and voluntary organisations.

Q20 Has your family used any of the following social care and family support services in the last 12 months?		Please tick one box on each line		
1	Home adaptations (eg. ramps, lifts)	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
2	Respite, foster care, short breaks	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
3	Help at home with care for the child	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
4	Social worker services	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
5	Help within the home from an outside provider	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
6	Home Start and/or Sure Start	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
7	Emotional support or counselling	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
8	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"/>
9	Other (please specify) _____	Yes	<input type="checkbox"/>	No <input type="checkbox"/>

4.3 Information Received (Question 21)

4.3.1 Question 21

Q21(S5)		Overall, how would you describe the information you received in the last 12 months about social care and family support services available to you? Please include both written and verbal information you received.		
Please tick one box on each line				
		Yes, always	Yes, sometimes	No
1	Clear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Relevant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Accurate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	I have not received any information about social care and family support services available to us in the last 12 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.3.2 Findings

Question 21 is one of a pair of questions which will be used to calculate a problem score for the provision of information about social care services for respondents. The partner question was not included in the test questionnaire to be cognitively tested as it is similar to question 8. It was important that this question was cognitively tested to see if it worked and could be used to feed into the disability indicator. The answer codes, ‘clear, relevant and accurate’ were understood by respondents. The cognitive interviews identified that some respondents had difficulties understanding how to answer the question. This is discussed below examining issues of comprehension and clarity.

Comprehension

The interviews found that the respondents understood what the question was about but they exhibited differences in who they included in the question. They either thought just about the named child who is the focus of this questionnaire or about all their children “it’s a motherly-thing to include both children, to see what there is for both of them” (A respondent with a 14 year old child with hearing or visual problems). The question has to be specific to direct respondents appropriately on how they should go about answering this question. This inconsistency will affect how data can be interpreted during the analysis stage.

Clarity

Respondents questioned why they should answer question 21 if they answered no to all the options in question 20. This could be rectified by routing them to question 22. Respondents who had not received any information found this question problematic to answer. They exhibited three practices

1. Left the question blank;
2. Answered no to code 1, 2, 3 and 4; or,
3. Answered code 4 but were unsure.

Respondents did not feel code 4 was clear and they found it difficult to understand in the context of the answer options. By introducing the new question before question 21 to ask respondents if they have received any information this would route respondents who had not received information so they did not have to answer this question. Code 4 would then be unnecessary.

Respondents who had received information also found option 4 problematic for this same reason. They demonstrated two strategies in answering this question

1. Left code 4 blank
2. Ticked a box generally no.

As a reflection of the length of this questionnaire a danger for any question is respondent fatigue. This can be increased by a difficult question. A respondent exhibited this with this question because she felt this question was long winded.

“To be honest, I’d just tick a box to be over-and-done-with”
(A mother with an 11 year old son who has ADHD)

The problem score for this question is calculated only on the no options. It is therefore important that respondents have answered this question correctly, especially the way the no boxes are chosen.

4.3.3 Recommendations

- Consider adding a screening question so only respondents who have received information are asked a subsequent question to describe the information, however there is a risk of respondents using this question to take a 'short cut' past Q21.
- Consider re-wording the question so it is more specific.
- Consider removing code 4 as an option or rewording it as it easier for respondents. In the suggested new question below we have proposed a modified version of code 4 to identify respondents who have inaccurately routed and prevent them choosing an inappropriate answer code.

Suggested New Question

In the last 12 months have you received any information about social services and family support services available to your family in relation to **your child's** long standing illness, disability or health condition? Please think of your child named at Q1. Please include both written and verbal information.

YES → Go to Q21B NO → Go to Q22

Q21B(S5) Overall, how would you describe the written and verbal information you have received in the last 12 months about social services and family support services available to your family in relation to **your child's** long standing illness, disability or health condition?

Please tick one box on each line

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

4.4 Social Care / Family support decisions (Question 22)

4.4.1 Question 22

Q22(S6)	In the past 12 months, have social care/family support services professionals made any decisions about your child’s illness or disability or services that you should receive?	Yes	<input type="checkbox"/>	1	→ Go to Q23
		No	<input type="checkbox"/>	2	→ Go to Q24

4.4.2 Findings

Question 22 and question 23 will be used to calculate non-acceptable service in social care assessment.

Comprehension

The think aloud process identified that respondents could view professionals as associated with health professions because the question asked specifically about the child’s disability or illness. Those who did find it difficult to understand what was being asked of them. Reflecting this confusion, respondents thought question 22 was repeating an earlier question (question 10).

Respondents who had answered no to question 20 and question 21 wondered why they were being asked to answer this question which was irrelevant to them. They did answer the question nevertheless with a ‘no’ response. The cognitive interview highlighted that respondents were not always clear whether to answer the question pertaining just to the named child with a disability, illness or health condition or to all their children. Only two respondents in the sample answered yes to this question, of which one answered this question relating to medical decisions so had misunderstood the question.

Question order effects

On the other hand there was evidence that respondents could find this question was easy because they had already answered a similar question or they found it clear and therefore easy to answer.

The influence of question order was also seen in the way respondents decided how to answer question 22. To avoid question 23, a long question, respondents decided to answer no to question 22. Only two respondents in the sample answered yes to question 22.

4.4.3 Recommendation

- Consider providing an example of a social care/family support services professional to help respondents understand the question
- Consider routing respondents who have answered no to previous questions to question 24.
- Consider setting out the questionnaire so question 23 is not on the same page as question 24.
- If the above considerations are accepted question 22 could be used to define the base when calculating the social care services assessment score.

Suggested New Question

Q22 (S6)	In the past 12 months, have social care / family support services professionals such as a social worker or an emotional support counsellor made any decisions about your child's illness or disability or services that you should receive?		
	Yes	<input type="checkbox"/>	1 → Go to Q23
	No	<input type="checkbox"/>	2 → Go to Q24

4.5 Social Care / Family support decisions (Question 23)

4.5.1 Question 23

Q23(S7)		And thinking about these decisions and the questions you had to answer, please indicate how much you agree or disagree with each of the following statements.				
		Agree Strongly	Agree	Neither agree nor disagree	Disagree	Disagree Strongly
1	We had to give the same information several times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	We were listened to and our needs were understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	The decisions made were suitable for our needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	The decisions were made at the right time for us	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	The relevant professionals worked together to make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	We/I understood how the professionals had come to their decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	On the whole, the decisions that were made were fair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	No decisions were made by social care/family support services professionals in relation to my family in the past 12 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.5.2 Findings

Question 23 is the second half of two questions which will be used to calculate the social services assessment problem code. The cognitive interview explored whether respondents understood the question and could answer the question the way they wanted too.

Initial Impression

The layout of question 23 is off-putting for some respondents with 2 respondents in the sample answering the previous question 'no' to avoid having to read this question.

“could not face all that stuff”
(A respondent with a 11 year old son with ADHD)

The answer process

In general respondents found this question straight forward to answer. It was what they expected; the statements were clear, did not overlap and were easy to answer. It was indicated that three level answer scale would be sufficient for this question namely agree, neither agree or disagree or disagree. One respondent did not understand the question and answered the question for other members of the family including their partner and not for the child who is the focus of the questionnaire.

4.5.3 Recommendations

- Consider retaining this question, statements and answer codes. This question could be used to calculate non-acceptable service of social care assessment
- Consider setting question 23 on a separate page to avoid ‘shortcutting’.
- Consider re-wording the question

Suggested New Question

Question 23 And thinking about these decisions and the questions you had to answer for this named child please indicate whether you agree or disagree with each of the following statements.

5 Education Services

5.1 Meaning of Education Services

The cognitive interviews identified that when respondents first thought about education services the first thing they thought about were schools. Respondents didn't always think beyond schools while on occasion thought it could include services offered through the school rather than just at school. Education services could also include colleges and universities. We now will look at the individual questions tested in this section.

5.2 Education / Early Years Services

5.2.1 Question 24

Q24(E) Which of the following education services has your child had in <i>the last 12 months</i> ?		Please tick one box on each line	
1	Pre-school or nursery	Yes <input type="checkbox"/>	No <input type="checkbox"/>
2	Children's centre	Yes <input type="checkbox"/>	No <input type="checkbox"/>
3	Portage or home teaching	Yes <input type="checkbox"/>	No <input type="checkbox"/>
4	Mainstream school	Yes <input type="checkbox"/>	No <input type="checkbox"/>
5	Special school	Yes <input type="checkbox"/>	No <input type="checkbox"/>
6	Hospital education service	Yes <input type="checkbox"/>	No <input type="checkbox"/>
7	Support from Special Needs Teacher	Yes <input type="checkbox"/>	No <input type="checkbox"/>
8	Dedicated teaching assistant/learning support assistant	Yes <input type="checkbox"/>	No <input type="checkbox"/>
9	Educational psychologist	Yes <input type="checkbox"/>	No <input type="checkbox"/>
10	Further education college	Yes <input type="checkbox"/>	No <input type="checkbox"/>
11	Connexions	Yes <input type="checkbox"/>	No <input type="checkbox"/>
12	Other (please specify) _____	Yes <input type="checkbox"/>	No <input type="checkbox"/>

5.2.2 Findings

Although respondents did not seem to have any real problems when answering this question, the cognitive testing did reveal what respondents were thinking and how they were going about answering the questions.

Meaning of Education Services

Respondents had a broad understanding of education services describing it as main stream school, providing special education needs, the provision of education not normally available in normal schools, meeting a child's education needs, including pre-school and nursery education, government policies relating to education and home work club. The sample selection for this study meant that nearly all the respondents have involvement with education through their children who are of school or college age. The consequence was that all the respondents found this question easy to answer.

Answer process

As this question was in a similar style to Q6 and Q20, respondents found it easy to answer because it was familiar. Respondents did not feel that this question was repetitive because it looked a different area, namely education. They clearly indicated the services they used by ticking the appropriate box. However, when a service was not used, respondents demonstrated two practices, either to correctly tick the no box or a minority of respondents left the line blank. When a respondent did not understand the meaning of an option he/she tended to leave the line blank. This was primarily seen in reference to 'Connexions' and 'portage'. The 'other' option, if not filled in with a written explanation, this box was left blank. It was considered that the answer codes 'yes' and 'no' were inappropriate for the 'other' category. On the whole respondents were able to identify options that matched what they wanted to answer. However, on occasion there was no appropriate answer category. For example, a respondent whose child attended a main school with a specialist education unit attached, both of which he uses, answered the question by selecting code 4 and 8. This suggests the need to add this as an option to appropriately understand the education services used by disabled children.

Inclusion of all their children

There was evidence of respondents automatically assuming that the question was about all their children and not just the child who was the focus of the questionnaire. It was suggested that this should be made explicit in this section as this would not be as obvious as in the health section where questions were asking about an illness, disability or health problems so respondents could infer the questions were about the child named on the front page. Education and early year services could be relevant to all the respondent's children.

Meaning

Respondents were probed to explore whether they understood the education services currently listed in question 24. Respondents could either explain 'dedicated teaching assistant' or did not know the meaning of this answer code in the context of this question. The think aloud process identified that respondents were not clear about whether they should include teaching assistants who happened to be in their child's classroom but were not there particularly to help their child when answering this question. If this provision of support is to be included this would need to be specified in the question. The term 'dedicated' was included to clarify this but it was obviously not understood as respondents were confused about the difference is between a teaching assistant and a dedicated teaching assistant. Interpretations included:

- class room assistant,
- non-specialist teachers,
- someone who provides one to one teaching in the class room,
- individual who provides support for disabled children in class.

Respondents did not understand code 3 'portage' but could infer a meaning from home teaching. In addition respondents could be surprised to see 'Connexions' assuming it was related to providing support to find a job. Respondents could also be unsure what it meant, however respondents whose child used this service correctly answered the question.

Missing options

Respondents identified a number of answer codes which were missing and which they felt should be added to this question. These were:

- Specialist education unit
- Speech therapist
- Diversity Services
- Inclusion Services
- Qualified teachers for the Visually Impaired and hard of hearing
- Private Tutor
- LEA support worker
- Before and after school clubs

Respondents did not include these missing options in the other category. Only two respondents in the sample wrote in the 'other' answer code. One respondent identified after school club and the other respondent added her son had a scribe for the exams. As in earlier questions the 'other' option did not work well as respondents were more comfortable using pre-coded answer codes. .

5.2.3 Recommendations

- Consider amending the question to help respondents to understand that they should focus only on their child who has a disability, illness or health problems perhaps referring to them as ‘your child named at question1’.

Suggested new question

Thinking about your named child for this questionnaire, which of the following education services has he/she used in the last 12 months?

- Consider removing the term ‘portage’ as home teaching is understood
- Consider adding additional options
 - Qualified teachers for the Visually Impaired and hard of hearing
 - Diversity and/or Inclusion Services
 - Specialist education unit
 - Speech therapist
 - Private Tutor (include with home teaching)
 - Before and/or after school clubs or other clubs
 - LEA support worker

However adding all these would make the question too long so discussion is needed with DCSF over which are the priorities.

If the ‘other option’ is to be retained consider rewording it and removing the Yes and No box from other option.
 - Other (please tell us about other education services your child has used here).

5. 3 Education Services (Question 25)

5.3.1 Question 25

Q25(E2)	Over the past 12 months, do you feel you have received all the education services your child needed? Did you receive	
1	All that he / she needed	<input type="checkbox"/>
2	Most of what he / she needed	<input type="checkbox"/>
3	Some of what he / she needed	<input type="checkbox"/>
4	Little of what he / she needed	<input type="checkbox"/>
5	None of what he / she needed	<input type="checkbox"/>

5.3.2 Findings

Respondents generally indicated that they had no problems with answering question 25. The probes used in the cognitive interviews did identify some problematic aspects which can be broadly considered as not accurately understanding the question and incomplete answer codes available.

Comprehension

Generally speaking respondents understood the essence of the question but not all the respondents realised which child to focus on when answering this question. Three strategies were shown by respondents. They:

1. Answered the question for the named child;
2. Answered the question for all their children who are of school age; or,
3. Answered the question for the non-named children in the household because it is considered the named child has nearly finished at school

The different strategies used will produce inaccurate data. The general introduction to the education/early year section was not remembered by respondents when they answered question 25. Either this introduction needs to explicitly state that the named child on the questionnaire should be the focus of all the questions in this section or this needs to be explicitly stated in question 25. Respondents generally found it easy to answer the question as they understood it.

The cognitive interviews did identify that education services were not understood by all the respondents. The previous question had not influenced how all the respondents thought about education services. The findings from the cognitive interviews showed that respondents could consider education services as information sent to their children. This misunderstanding of education services arose because of the word 'received' in the question led them to think of 'receiving information'.

The interviews also indicated that respondents may not feel that they have the information to answer the question. The interviews identified that this question to be involves two concepts, and respondents may have incomplete knowledge of both:

- which education services are available
- which services their child needs

Respondents then had to calculate which answer was the most appropriate. Parents who were unsure tended to answer the question based on what they *thought* their child required.

Answer Codes

The answer codes were considered good and comprehensive. Respondents either decided on an answer and then found their answer was available or used the answer codes to decide on their answer. Answer codes 3 and 4 were considered not problematic which indicates that this aspect of the question will be fine for the calculation of acceptable level of participation in education and early years services. The interviews did find that code 1 (all that he / she needed) was used in two situations:

1. Accurately reflected what the respondent thought
2. Closest matched for situations where the respondent felt their child was receiving 'too much attention' rather than being allowed to develop at their own speed.

Time Frame

Respondents said they found it easy to think about the last 12 months.

5.3.3 Recommendations

- This question could feed into the education and early year service performance indicator in the area general experience but it does not feed into the core offer performance indicator. Consideration could be given to dropping this and the subsequent untested question about quality (E3) if general experience is not needed for the indicator.
- Consider adjusting the question to remind respondents to focus on the named child when answering this question and what are education services. For example the question could read:

Suggested New Question

Thinking about the previous question do you feel that your child named at Question 1 has received all the education services he / she required over the past 12 months?

Or

- Thinking about the previous question do you feel that the your child named at Question 1 has **had** all the education services he / she required over the past 12 months?

Consider using the term 'required' to be consistent with the equivalent health question.

Q25(E2) Thinking about the previous question do you feel that the named child has had all the education services he/she required over the past 12 months?

- | | | |
|---|--|--------------------------|
| 1 | All that he / she needed (or required) | <input type="checkbox"/> |
| 2 | Most of what he / she needed | <input type="checkbox"/> |
| 4 | Some of what he / she needed | <input type="checkbox"/> |
| 5 | Little of what he / she needed | <input type="checkbox"/> |
| 6 | None of what he / she needed | <input type="checkbox"/> |

5.4 Information (Question 26)

5.4.1 Question 26

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

	Please tick one box on each line		
	Yes, always	Yes, sometimes	No
Clear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relevant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accurate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have not received any information about education services available to my child in the last 12 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.4.2 Findings

Respondents tended to find this question easy and quick to answer. This question will feed into the feedback section of the performance indicator for education and early year services. The negative responses will be used in the calculations. The interviews highlighted that respondents again showed some variation in the interpretation of the question. This will be discussed below.

Interpretation

Respondents varied in whom they included when answering the question. For example, respondents could just focus on the named child or consider all their children. Another area which was interpreted differently was where the information on education services was received. Occasionally respondents included information only sent from the school whereas others included information passed verbally by their child to them from the school. This influenced how they answered the question. For example where a respondent had focussed just on information received from the school she left the question blank because she had not received any such information. The question needs to be re-worded and the answer codes made more appropriate to help respondents who do have difficulties with this current question.

Answer Codes

Respondents had experience of this style of question from earlier sections. This they found eased the process of answering the question and it was not repetitive because it looked at a different area. The cognitive interviews did highlight some problematic aspects with this question nevertheless and this does have implication for the role of this question in measuring unacceptable service in feedback in education and early year services.

Respondents felt that the option 'no' should read 'not' to make the question clearer. Another finding was 'clear, relevant and accurate' were generally considered easy to use answer codes. Where they were not understood a box was not ticked on that line. The only code that was occasionally misunderstood in the context of the question was 'relevant'.

Code 4, as in previous similar questions was problematic for respondents. Code 4 did not seem to make sense with the answer process. The implication was that respondents could be either confused by the whole question or just confused by this last option. If respondents fell in the latter category they tended to leave the line blank.

Consistency

To be consistent with recommendations for question 9 it would be recommended that this question is divided into 2 parts: firstly to identify if a respondent received information, if they have route them to the second part which asks them to describe the information they have received.

5.4.3 Recommendation

- Consider adding a proceeding question to identify respondents who have received information.
- Consider re-wording question 26 to specify which child the respondent should focus on and which sources of information to include when answering the question.
- Consider re-moving code 4
- ***Client to clarify whether this question should include information which the respondent had to seek out. If it includes this then the term 'received' should be reconsidered.***

Suggested New Question

In the last 12 months, have you received any written or verbal information about education services for your child named at question 1? Please include both written and verbal information.

Yes → Go to Q26b

No → Go to Q27a

Q26b(E5) Overall, how would you describe the written and verbal information you received in the last 12 months about education services for your named child?

Please tick one box on each line

		Yes, always	Yes, sometimes	Not
1	Clear - to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Relevant - to you and your child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Accurate - up to date and precise information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. 5 Special Education Need (Question 27a)

5. 5.1 Question 27a

Q27(E7)	In the past 12 months, did your child have an assessment of his / her educational needs?	Yes	<input type="checkbox"/>	1	→ Go to Q28
		No	<input type="checkbox"/>	2	→ Go to Q29

5. 5.2 Findings

Q27a was not considered a sensitive question but it was a problematic question for respondents. The cognitive interview showed that respondents had comprehension difficulties with the questions and/or the answer codes.

Question Comprehension

Respondents showed three levels of understanding when answering this question.

1. They understood the terminology ‘special education need’ and ‘level’ and what the question was asking.
2. They understood the terminology ‘special education need’ or ‘level’ but not both and therefore were confused with the question.
3. They did not understand any of the terminology in the question.

Respondents were not clear on the association of School Action Plan and School Action Plus with having SEN or with having a statement. This difficulty was exhibited by parents who had a child who had a statement and those who did not. This was not clarified by the answer code wording (this will be discussed in detail in the next section). The consequence of this lack of clarity generally resulted in the question not being answered or answered no when in fact in the think aloud process it was clear that the child had a statement.

The think aloud process used in cognitive interviews identified that the question was difficult for respondents to answer irrespective of whether their child was receiving education provision. This was because the question involved understanding of a variety of terms, some of which were misunderstood. For example the term ‘level’ could apply to schooling level (early years or school; or primary school or secondary school) or could refer to the action level (Action or Action Plus)

To address some of these difficulties mentioned above, the question could be split so only respondents whose child has a special education need are asked to state at what level. This would simplify the current question. The question regarding level could be clarified by asking at what level at school.

Answer Comprehension

Findings from the interview indicated that Codes 2 and 3 could be made clearer for respondents. The current wording adds to the respondents' confusion. Respondents did not see the slash that separated 'School' and 'Early Years Action' or saw the slash but misinterpreted the purpose, understanding code two to mean 'Yes, at school or at early years action' rather than 'yes, at school action or early years action'. Recommendations on the rewording will depend on whether the question is to be revised. If revised the codes could simply be broken down so they read:

1 Yes, at School Action or Early Years Action

2 Yes, at School Action Plus or Early Years Action Plus

Alternatively they could be split into four categories.

Respondents were not clear at which ages the different levels operate. For example whether early years were associated with toddlers and not at the primary school level, of whether it included both. Respondents whose child was too young to have this kind of assessment are not currently provided with an answer code.

5.5.3 Recommendations

- Consider splitting the question to first ask the respondent if their child has an SEN and if they answer yes then follow this up to ask the level of the statement. If they answer no route the respondent to question 27b.
- Consider adding more answer codes.
- If the question is not key to this survey consider dropping this question and making it appropriate for respondent involves lengthening it and taking up valuable questionnaire space.
- This does not feed into the indicator.

Suggested New Questions

Does your child have special educational needs?

Yes → Go to 27a:1

No → Go to 27b

Q 27a:1 Has your child received a statement of SEN?

Yes → Go to 27a:2

No → Go to 27b

Client to advise on the question below (e.g. can you 'receive' Early Years action). The terms 'provision' and 'level' were not understood.

Q 27a:2 Does your child currently receive? (Tick one only)

- 1. Early Years Action
- 2. Early Years Action Plus
- 3. School Action
- 4. School Action Plus
- 5. None of these

5.6 Education Assessment (Question 27b)

5.6.1 Question 27b

Q27b(E7)	In the past 12 months, did your child have an assessment of his / her educational needs?
	<p>Yes <input type="checkbox"/> ¹ → Go to Q28</p> <p>No <input type="checkbox"/> → Go to Q29</p>

5.6.2 Findings

This question is important as it routes respondents to question 28 which will be used to calculate unacceptable level of service in the assessment of education and early year services. If respondents are inaccurately routed this will have implication for the accuracy of the measurement of problem score at question 28. Respondents were not confused which child to focus on when answering this question, unlike previous questions in this section. Respondents did not find this question difficult to answer although the cognitive interview did highlight the wide discrepancy in how 'assessment' was interpreted in this question. We discuss these different interpretations in the following section.

Meaning

Respondents interpreted the meaning of 'assessment' in the question in seven different ways when answering this question:

- a formal process which addresses a child's need or problem. It is conducted by professionals in a formal manner and supported with documentation of their findings, with conclusions and what will be done for the child provided.
- a measurement of their child against other children of a similar age generally. The assessment would indicate what the child was able to do or not do, compared to these other children, what help would be required and what will be provided.
- a variety of events where feedback was provided on their child such as parents evening.
- to include home visits by 'teachers' before a child joined a nursery school to discuss the child's health needs.
- tests such as SATs, end of year tests or end of term tests
- end of year nursery report as it included cognitive skills component in the report.
- an assessment of special educational needs (linking it to the previous question).

Although respondents did not feel the question was difficult the wide variety of interpretations has affected how respondents answered this question. This suggests that the question needs to be more specific. The definitions used included general assessments which all children would receive as well as special assessments related to their child's needs or disability.

Sensitivity

This question was universally deemed as acceptable. However, concerns were raised that 'some people' may not feel uncomfortable answering such a question if their child had a behavioural problem, had a special educational need or choose to ignore their children's special needs so would not know how to answer this question.

5.6.3 Recommendation

- Consider re-wording the question so it is more focussed.

Suggested New Question and Answer Code

In the past 12 months, did your child have a formal assessment of his/her educational needs conducted by an educational psychologist?

Client to advise on whether only assessments by educational psychologists would be of interest. Advise on meaning of assessment.

Continue to place Q28 on a separate page.

- (Consider adding an additional answer code I do not know →Go to Q29)

Q27	In the past 12 months, did your child have a <i>formal assessment</i> of his/her particular educational support needs conducted by educational psychologist? Do not include standard assessments routinely provided for all children.
Yes	<input type="checkbox"/> 1 → Go to Q28
No	<input type="checkbox"/> 2 → Go to Q29
I do not know	<input type="checkbox"/> 3 → Go to Q29

5. 7 Education Assessment and Decisions (Question 28)

5.7.1 Question 28

Q28(E8) Thinking about this assessment and the decisions that were made, please indicate how much you agree or disagree with each of the following statements

		Agree Strongly	Agree	Neither agree nor disagree	Disagree	Disagree Strongly
1	We knew what to expect from the assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	We had to give the same information several times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	We were listened to and our needs were understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	The decisions made were suitable for my child's needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	The decisions were made at the right time for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	The relevant professionals worked together to make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	On the whole, the decisions that were made were fair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	We / I understood how the professionals had come to their decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	My child did not have an assessment of his / her educational needs in the past 12 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. 7.2 Findings

This question is the key question which will be used to measure problem score in educational assessment. The main difficulty respondents had with the question was that they did not understand 'assessment' and were being routed to this question because they misunderstood the question 27b and had answered yes in error.

Comprehension

The nine statements and how to answer the question were clearly understood by respondents. Two strategies were broadly used to answer this question.

1. The respondents clearly understood the question and were able to easily answer the question.
2. Respondents who did not understand a problematic term such as assessment used in the question often opted for the middle option neither agree nor disagree or on fewer occasions answered code 9. The think aloud process identified that respondents would have preferred to have code 9 at the top as this would have prevented them having to go through each of the statements and this would have helped to clarify how to answer the question. These respondents could be routed past to question 28 if question 27b is clarified.

As discussed for Question 27b the term 'assessment' was not understood. If question 27b is clearer the comprehension difficulties identified in question 28 would be addressed. Beyond the issues raised in the previous question, assessment was also interpreted in this question by one respondent to include this questionnaire which had just been answered. The difficulty here arose due to the inaccurate routing due to not understanding the previous question and had answered 'yes' in error. Another interpretation of assessment was a measure of how the child would cope in the 'real world'. Respondents whose child had never had an assessment because they were only just entering the education system were not familiar with educational assessments.

5.7.3 Recommendation

- Consider slightly amending Q28 so that it is clearer for respondents.
- This question could be used to measure educational assessment problem score if the term assessment is clarified. The statements are clear and respondents understand how to answer this question.
- Consider moving code 9 so it becomes code 1 or drop this since Q27b provides the routing if it Q27b was improved respondents should not be routed to Q28 in error.
- Drop code 8 which overlaps with a question which was not tested (E9) and should be included because it feeds into the transparency indicator.
- Drop code 7 in line with similar recommendation for Q11 (H7)

Suggested New Question

Q28(E8) Thinking about this formal assessment of your son's/daughter's particular educational support needs and the decisions that were made associated with this, please indicate how much you agree or disagree with each of the following statements

		Agree	Neither agree nor disagree	Disagree
1	My child did not have an assessment of his / her educational needs in the last 12 months <input type="checkbox"/> Go to Q29	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	We knew what to expect from the assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	We had to give the same information several times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	We were listened to and our needs were understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	The decisions made were suitable for my child's needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	The decisions were made at the right time for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	The relevant professionals worked together to make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	On the whole, the decisions that were made were fair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	We / I understood how the professionals had come to their decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. GENERAL VIEWS OF THE QUESTIONNAIRE

In this section of the report we provide a summary of the general views of the questionnaire, focussing on the relevance and importance of the questionnaire as a whole followed by a discussion of the acceptability of this questionnaire for respondents. This section concludes with a summary of the findings of the distinction of the three services, health, social care and education services in the questionnaire.

Relevance and importance of questionnaire as a whole

Respondents felt that the questionnaire was relevant and covered important issues which research should investigate. It was felt that in order for the right services to be provided information needs to be collected from parents. This was expressed by parents in two main ways:

- the general value of collecting information on this topic,
- the hope that by answering such questions services would be improved for their children or other children like them.

Those who said they might not be willing to respond if the questionnaire came by post cited reasons such as being busy and not being able to face a long form. Respondents did not say they would not respond because it was not worthwhile.

The cognitive interviews for testing this questionnaire were longer than average (many were 1.5 to 2 hours long). Bearing in the mind the other commitments the respondents had (all had at least one disabled child) their co-operation with the cognitive interview reflects how important the topic was felt to be.

Acceptability

Respondents did not report finding the interview sensitive or making them feel uncomfortable. The sample for the cognitive testing ranged from parents who did not consider their children to be disabled to parents with one or more children with multiple and in some cases profound disabilities. Even where the questionnaire may have raised difficult issues respondents were willing to answer the questions.

It was suggested that some other respondents might be embarrassed answering social care questions but none of the respondents interviewed reported that they had any problem with them (though few had used these types of services).

Relevance of individual sections

Although none of the respondents questioned the importance of the questionnaire as a whole, those who had not used particular services (especially social care or education) felt those particular sections were not relevant to them. The questionnaire was designed with minimal routing to make it easier to navigate through the questionnaire but in places this did mean respondents were being asked questions which they felt were not relevant to them.

Reference period

The questionnaire is based on a reference period of 12 months. Only one respondent in the sample reported that she had felt frustrated by this reference period since she sometimes wanted to report things which had happened in the last 2 to 5 years since they were relevant for the survey. Generally respondents were able to think about the last 12 months when answering individual questions although on occasions respondents answered a question in general terms. This was not a consistent practice with the same respondents adopting the same interpretation consistently for all the questions, but rather respondents considered each question on its own terms and varied how they interpreted 12 months. This testing took place in September which is a key month in a child's calendar with the start of the new school year. The cognitive interviews did identify that such landmark events did make recall easier for respondents. In general terms 12 months did work as a good reference period for question where a reference period was given namely questions 6,7,9,10,11,13,15,17,21,22,24,25,26 and 27b.

Respondent views on the distinction between health, social care and education services within the questionnaire

The distinction between the three types of services was generally clear to respondents, although a few services such as health visitor or occupational therapist were seen as potentially falling under more than one category. The division of the questionnaire into the three sections made sense to respondents and reflected the way in which they received services and the way in which their child was assessed. Respondents did not report difficulties in thinking about the three areas separately.

Views on the best order for the three service areas varied and suggestions for amended ordering covered most possible orders. The only consensus was that the questionnaire should not start with social care. Opinions were divided over whether health or education should be first and whether social care or education should be third.

We would recommend that the report is structured such that health section is followed by education then social care. Health services are most likely to have been used in the last 12 months, followed by education and with social care being used by relatively few respondents. Furthermore, including education first may help respondents understand that social care services are not intended to include education services in the context of these questions.

APPENDIX A: Fieldwork documents: Main Questionnaire



Children and the Use of Local Services SELF-COMPLETION QUESTIONNAIRE

P2841: Team: QDT

Serial	<input type="text"/>	PNo	<input type="text"/>	<input type="text"/>								
Name	<input type="text"/>							Interviewer	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Completing the questionnaire

This questionnaire is exploring how respondents experience answering these questions. Most of the questions can be answered simply 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. Your feedback to the interviewer will help us in designing a questionnaire which will be used to look at parental experience of services for children. Thank you for your time.

About your Child

Q1(A1) What is the child's name?-

Q2(A2) What is the child's date of birth? Day Month Year

Q3(A4) Does your child have more difficulties than other children of their age, doing any of the following due to their illness, disability or health problems? Please tick one box on each line

1	Using public transport	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Getting about in their own home	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Using school buildings and facilities	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Using health service buildings and facilities	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
5	Using local council social service buildings and facilities	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
6	Using public parks and leisure facilities (e.g. playgrounds, swimming pools etc)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
7	Joining activity groups or clubs (e.g. cubs, guides, sports groups)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

Q4(A5) Do you consider your child to be disabled?

Yes ¹ → Go to Q5

No ² → Go to Q6

Q5(A6) Please record all the areas in which this child is affected:

- | | | | |
|----|--|--|--------------------------|
| 1 | | None | <input type="checkbox"/> |
| 2 | | Mobility - getting about the house and beyond | <input type="checkbox"/> |
| 3 | | Hand function - holding and touching | <input type="checkbox"/> |
| 4 | | Personal care - washing, going to the toilet, dressing etc | <input type="checkbox"/> |
| 5 | | Incontinence - controlling the passage of urine and faeces | <input type="checkbox"/> |
| 6 | | Communication - speaking and / or understanding others | <input type="checkbox"/> |
| 7 | | Learning - having special educational needs etc | <input type="checkbox"/> |
| 8 | | Hearing | <input type="checkbox"/> |
| 9 | | Vision | <input type="checkbox"/> |
| 10 | | Behaviour - a condition resulting in socially unacceptable behaviour | <input type="checkbox"/> |
| 11 | | Consciousness - fits and seizures | <input type="checkbox"/> |
| 12 | | Diagnosed with autism or Asperger Syndrome - diagnosed by a qualified medical practitioner as having classical autism or Asperger Syndrome. Do not include children who have merely been identified as having an Autistic Spectrum Disorder (ASD) eg. by their school. This can be associated with the behaviour and learning categories above | <input type="checkbox"/> |
| 13 | | Palliative care needs | <input type="checkbox"/> |
| 14 | | Other (please write in) _____
_____ | <input type="checkbox"/> |

Health Care Services

The following questions are about the health care services which your child receives.

Q6(H1)

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

Please tick one box on each line

1	GP	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Practice nurse (at the GP surgery)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Health visitor, district nurse, other community nurse	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Paediatrician (child health doctor) or other specialist doctor	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
5	Psychologist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
6	Physiotherapist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
7	Speech therapist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
8	Occupational therapist (OT)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
9	Podiatrist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
10	Optician or eye specialist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
11	Dentist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
12	Dietician or nutritionist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
13	Hospital as inpatient	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
14	Palliative care	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
15	Other health services (please specify) _____	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

Q7(H2)

Over the past 12 months, do you feel you have had all the health care services your child needed? Did you receive...

- | | | |
|---|--|--------------------------|
| 1 | All that he / she needed | <input type="checkbox"/> |
| 2 | Most of what he / she needed | <input type="checkbox"/> |
| 3 | Some of what he / she needed | <input type="checkbox"/> |
| 4 | Little of what he / she needed | <input type="checkbox"/> |
| 5 | None of what he / she needed | <input type="checkbox"/> |
| 6 | Did not need any health care services for my child in the past 12 months | <input type="checkbox"/> |

Q8(H4)

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 tick the box that best describes how much you agree or disagree with each statement.

		Agree Strongly	Agree	Neither agree nor disagree	Disagree	Disagree Strongly
1	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"/>	<input type="checkbox"/>
2	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"/>	<input type="checkbox"/>
3	I have been given enough information about <i>how to</i> access health care services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	There is someone I can go to for help and support in accessing health services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	I have only been able to get information about health care services by word-of-mouth/from other parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	I get passed around from person to person when I try to find out information about health care services for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q9(H5)

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.

Please tick one box on each line

		Yes, always	Yes, sometimes	No
1	Clear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Relevant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Accurate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	I have not received any information about health care services available to my child in the last 12 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q10(H6)

In the past 12 months, have medical or health professionals made any *decisions* about your child's illness or disability or services that he / she should receive?

Yes ¹ → Go to Q11

No ² → Go to Q12

Q11(H7)

And thinking about these decisions and the questions you had to answer in the last 12 months, please indicate how much you agree or disagree with each of the following statements.

		Agree Strongly	Agree	Neither agree nor disagree	Disagree	Disagree Strongly
1	We had to give the same information several times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	We were listened to and our needs were understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	The decisions made were suitable for my child's needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	The decisions were made at the right time for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	The relevant professionals worked together to make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	We / I understood how the professionals had come to their decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 7 On the whole the decisions that were made were fair
- 8 No decisions were made by health professionals in relation to my child in the past 12 months

Q12(H8) How well do you understand how decisions are made about which health care services your child receives? Do you understand this

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

Q13(H9) Over the past 12 months, how much have you been involved in decision making about your child's need for health care services?

- A lot
- A little
- Not much
- Not at all
- No decisions were made by health professionals in relation to my child in the past 12 months

Q14(H10) How interested do you think that health professionals are in the views of parents, about how health care services for children could be improved? Would you say they are ...

- Very interested
- Fairly interested
- Not very interested
- Not interested at all

Q15(H13) Over the past 12 months, has your child been asked for feedback on the health care services he/she received?

Yes

No

Did not receive any health care services in the past 12 months

Child not able to provide feedback due to young age or learning/cognitive difficulties

Q16(H14) Do you think that changes are made as a result of the feedback children give?

Yes, always

Yes, sometimes

No

Don't know

Q17(H15) In the past 12 months, have you made a formal complaint about a health care service you have received in relation to your child?

Yes, to the service provider

Yes, to my Local Authority or Primary Care Trust

Yes, to other organisation (please specify)

No, I have not complained **→ Go to Q20**

Q18(H16)

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

Very easy

Fairly easy

Neither easy or difficult

Fairly difficult

Very difficult

Have not complained

Q19(H17)

How happy were you with the way that your complaint was dealt with?

Very happy

Fairly happy

Neither happy nor unhappy

Fairly unhappy

Very unhappy

Have not complained

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 illnesses or disabilities. Please include services provided through your local council, as well as through independent and voluntary organisations. Thank you.

Q20(S1)

Has your family used any of the following social care and family support services in *the last 12 months*?

Please tick one box on each line

1	Social worker services	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Home adaptations (eg. ramps, lifts)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Respite, foster care, short breaks	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Help at home with care for the child	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
5	Help with housework	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
6	Emotional support or counselling	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
7	Direct payments (excluding benefits) or individual budget	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
8	Other (please specify) _____ _____	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

Q21(S5)

Overall, how would you describe the information you received in the last 12 months about social care and family support services available to you? Please include both written and verbal information you received.

Please tick one box on each line

		Yes, always	Yes, sometimes	No
1	Clear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Relevant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Accurate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	I have not received any information about social care and family support services available to us in the last 12 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q22(S6)

In the past 12 months, have social care / family support services professionals made any decisions about your child's illness or disability or services that you should receive?

Yes ¹ → Go to Q23

No ² → Go to Q24

Q23(S7)

And thinking about these decisions and the questions you had to answer, please indicate how much you agree or disagree with each of the following statements.

		Agree Strongly	Agree	Neither agree nor disagree	Disagree	Disagree Strongly
1	We had to give the same information several times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	We were listened to and our needs were understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	The decisions made were suitable for our needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	The decisions were made at the right time for us	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	The relevant professionals worked together to make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	We/I understood how the professionals had come to their decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	On the whole, the decisions that were made were fair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	No decisions were made by social care / family support services professionals in relation to my family in the past 12 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Education / Early Years Services

The following questions are about the education services (including pre-school education) your child receives.

Q24(E1) Which of the following education services has your child had in *the last 12 months*? Please tick one box on each line

1	Pre-school or nursery	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
2	Children's centre	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
3	Portage or home teaching	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
4	Mainstream school	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
5	Special school	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
6	Hospital education service	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
7	Support from Special Needs Teacher	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
8	Dedicated teaching assistant / learning support assistant	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
9	Educational psychologist	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
10	Further education college	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
11	Connexions	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
12	Other (please specify) _____	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

Q25(E2)

Over the past 12 months, do you feel you have received all the education services your child needed? Did you receive.....

- | | | |
|---|--------------------------------|--------------------------|
| 1 | All that he / she needed | <input type="checkbox"/> |
| 2 | Most of what he / she needed | <input type="checkbox"/> |
| 3 | Some of what he / she needed | <input type="checkbox"/> |
| 4 | Little of what he / she needed | <input type="checkbox"/> |
| 5 | None of what he/she needed | <input type="checkbox"/> |

Q26(E5)

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

Please tick one box on each line

- | | | Yes, always | Yes, sometimes | No |
|---|--|--------------------------|--------------------------|--------------------------|
| 1 | Clear | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 | Relevant | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3 | Accurate | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4 | I have not received any information about education services available to my child in the last 12 months | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Q27a(E6)

Does your child have a 'special educational need' (SEN), and if so, at what level is he/she receiving provision?

- | | | |
|---|--|--------------------------|
| 1 | No, does not have SEN | <input type="checkbox"/> |
| 2 | Yes, at School / Early Years Action | <input type="checkbox"/> |
| 3 | Yes, at School / Early Years Action Plus | <input type="checkbox"/> |
| 4 | Yes, has a statement of SEN | <input type="checkbox"/> |
| 5 | Yes, has SEN but I don't know what level | <input type="checkbox"/> |

Q27b(E7) In the past 12 months, did your child have an assessment of his / her educational needs?

Yes 1 ➔ **Go to Q28**

No ➔ **Go to Q29**

Q28(E8) Thinking about this assessment and the decisions that were made, please indicate how much you agree or disagree with each of the following statements

		Agree Strongly	Agree	Neither agree nor disagree	Disagree	Disagree Strongly
1	We knew what to expect from the assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	We had to give the same information several times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	We were listened to and our needs were understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	The decisions made were suitable for my child's needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	The decisions were made at the right time for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	The relevant professionals worked together to make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	On the whole, the decisions that were made were fair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	We/I understood how the professionals had come to their decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	My child did not have an assessment of his/her educational needs in the past 12 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q29 ➔

Thank you very much for your help.

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

Would you now please post the questionnaire in the pre-paid envelope enclosed

Thank you

Probe Sheet



Probe Sheet for Interviewers

The Main Aim

- To examine R's experience of the screening questionnaire through retrospective Probing
- To examine R's experience of filling in the main self-completion questionnaire

The Main Objectives for the interview

- To examine parents' understanding of the questions in both questionnaires
- To examine parents' ability to answer the questions in both questionnaires
- To examine issues of layout, routing and response in both questionnaires

Introduction

Aim: To introduce yourself and gain informed consent

- Introduce yourself, the National Centre, and the study
- We are developing some questions to ask parents about services they have used for their children. The purpose of this interview is to check that the questions are understood as intended and that respondents are able to answer them
- Explain that you will be asking them to answer a series of questions in a paper questionnaire and at various points throughout the questionnaire you will then be asking them to tell you how they went about answering the survey questions.
- We are not just interested in the answers they give but also in what they understand the questions to mean and the process by which they arrive at their answer
- Remind them that participation is voluntary.
- Stress the confidentiality of the process; all the findings will be reported anonymously. Make sure they understand this.
- Explain that you will be recording the interview so that you don't have to make lots of notes during the interview. Check this is ok with the respondent.
- As the interview will explore issues pertaining to a child in the family please check with the R if they are comfortable to answer questions in the presence of the child or not and check that the child is comfortable with whatever arrangement is made.
- Ask whether they have any questions before you start

Stage 1: Screening Questionnaire

Aim: To understand if the screening questionnaire works

ASK THE R IF THEY HAVE RECEIVED AND FILLED IN THE QUESTIONNAIRE

(If they have not received the form or not filled it in please give them the screening questionnaire (version A or B) and ask them to fill it.

General probes

Appearance of the questionnaire

- What do you think of the look of the questionnaire?

For R's who answered the questionnaire:

- Was there anything on the questionnaire that convinced you to participate?
- Were the instructions on the form easy or difficult to understand? (please note any difficult areas)

For Rs who did not answer the questionnaire:

- Was there anything on the front page that put you off filling in the form?
- Were the instructions on the form easy or difficult to understand? (please note the areas that were difficult if there were areas)

SHOW THEM THE VERSION OF THE FORM THEY DID NOT RECEIVE. ASK THEM TO TAKE A LOOK AND GET THEIR FIRST IMPRESSIONS OF THE FORM.

- Is there a difference between the two versions? What is different?
- Do you prefer the look of one? (please explore why, do the rows or columns make a difference)
- Which form do you think you would prefer to fill in? (Acknowledge that they are only seeing the other version for the first time at the interview so it is not easy)

Question 4

- How easy was it to answer this question?
- How did you go about answering this question?
- Were there any children for whom you were unsure what to answer? Why?
- What do you think 'disability' meant in this question?
- How did you understand 'health problem' here?
- Was the explanation of long standing illness easy or difficult to understand?
- How did you know which arrow to follow?

THE RESPONDENTS WHO ANSWERED NO:

- Was it clear what you should do next?

Question 6 (if applicable)

- What did you understand 'substantial difficulties' to mean in this question?
- Were there any answer categories you were unsure about? Why?

Question 7

- Could you explain in your own words what you understood Question 7 to mean?

Questions 8, 9

- What did you do after you answered question 7 for the first child? Was it clear what you should do?
- What did you do after answer

If respondent answered 8 and 9 on back page

- How did you get to these questions?
- How did you know you were meant to answer them?
- What did you understand by the term 'further research?'

If respondent did not answer Q8 and Q9 on back page:

- Did you see question 8 and 9 on the back page?
- Did you think they applied to you or not?
- Do you think you would have known to answer them in the other version of the screening questionnaire?

Completing questionnaire for all children

- How many children do you have?

If number is different from number completed on questionnaire

- How did you decide which children to include in the questionnaire?

For all respondents

- Were there any children who you were unsure whether to include on the questionnaire?
- Why? How did you decide whether or not to include them?
- Was it easy or difficult to know when to move to the questions for the next child and to find where they were?

INTERVIEWER:

If respondent classified at least one of their children as disabled (said yes at Q4) then give them version A of the main questionnaire. If respondent said no at question 4 for all their children give them version B with the pink front cover.

Stage 2: How the questions in the main questionnaire work

Aim: To see if Rs understand the questions and are able to answer them

Please ask respondents to **think aloud** while they are answering the questions

INTERVIEWER:

- Please explain to the respondents that the previous questionnaire is what we call a screening questionnaire so we can give the right questionnaire to the right people.
- Explain that you will spend the rest of the interview going through the main questionnaire. Please give them the questionnaire.
- They should complete it themselves and you will tell them when to answer each question because you will be stopping to discuss their answers as they go through.
- Please ask the R to tell you what they are thinking when they answer the questions. Use the windows example or another example if you find it helpful.
- Use the probes to illicit specific information that we are looking for.

ASK RESPONDENT TO ANSWER QUESTIONS 1-3 (Questions 1 and 2 are for information and should not be probed.)

Question 3 (Probe if you have time)

“Does your child have more difficulties than other children of their age, doing any of the following due to their illness, disability or health problems?”

- Did you find it easy or difficult to answer Q3?
- What do you think the term ‘illness, disability or health problem’ meant in this question?
- What do you think ‘more difficulties than other children of their age’ meant in this question?
- What time period were you thinking of when answering this question?
- Were you thinking of the general situation or of particular incidents?

For any categories they said yes to ask:

- What type of difficulties were you thinking of when you answered this?

All

- How did you feel about answering this question?

ASK R TO ANSWER Q 4 - Q 5

Question 4

“Do you consider your child to be disabled?”

- Did you find it easy or difficult to answer Q4?
- How did you feel about answering this question?

Question 5

“Please record all the areas in which this child is affected:”

- How did you go about answering question 5?
- How easy was the list In Q 5 to use?
- Were any areas unclear to you? Which?
- Are there areas that you were surprised to see on the list?
- Are there areas missing from the list?

ASK R TO ANSWER Q6

Question 6 (KEY QUESTION TO PROBE ON)

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

- What did you understand by the term ‘health care services’ in this question?
- How did you go about answering this question? (find out whether they read each line in turn and ticked yes or no or whether they used it as a list and then just ticked those that applied)
- In your view are there any services missing from this list?
- Were there any services you were surprised to see on the list?
- Do you think that all the services on the list were health services?
- How easy or difficult was it to remember the services that your child used?
- How easy was to generalise about your experiences of health services? For example your experiences with health professionals.
- Do you think equipment provision should be included on a list like this?
- Were there any services which you weren’t sure about? (*please explore what these issues were - didn’t know what it meant or not sure if their child had used that service*)
- What time period were you thinking about when answering this question?

Check that respondent has ticked a yes or no in every row. If not ask:

- You have not ticked an answer for...Can you tell me why.

ASK R TO ANSWER Q7- Q9

Question 7

“Over the past 12 months, do you feel you have had all the health care services your child needed? Did you receive...”

- What did you understand by ‘all the health care services your child needed’?
- How easy was it remember all the health care services your child needed
- How did you work out your answer for Q7?
- What time period were you thinking about?
- How confident are you about the answer you gave at Q7? *(Please explore if not covered already in the probes what their concerns are, if any)*

Question 8

“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 tick the box that best describes how much you agree or disagree with each statement.”

- Were there any statements in Q8 which were not clear?
- How did you decide whether to agree or disagree with each statement in Q8?
- How did you decide when to choose ‘strongly agree’ or ‘strongly disagree’?
- Probe on understanding of any statements respondent seems unsure about
- Did any of the statements seem to overlap?

Question 9

“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.”

- When you answered Q9 what did ‘clear’, ‘relevant’ and ‘accurate’ mean to you in the context of this question?
- How did you go about answering each aspect of this question?
- Do you include written and verbal information in your answer?
- Should we be asking about any other aspects of information received?
- How confident are you of the answers you have given at Q9?

If respondents answered I have not received any information about health care services available to my child in the last 12 months please ask them:

- How easy was it to find a response box?

General probe on Questions 7-9

- How easy or difficult was it to answer these three questions?

ASK RESPONDENT TO ANSWER Q10- 12

Question 10

“In the past 12 months, have medical or health professionals made any *decisions* about your child’s illness or disability or services that he/she should receive?”

- How did you arrive at your answer for Q10?
- What did you understand by the word ‘decisions’ in this question?
- How did you decide which arrow to follow in Q10?

Question 11 (KEY QUESTION TO PROBE ON)

“And thinking about these decisions and the questions you had to answer, please indicate how much you agree or disagree with each of the following statements.”

- Were there any statements that you felt overlapped with another statement?
- How did you decide whether to agree or disagree with each statement in Q11?
- How did you decide when to choose ‘strongly agree’ or ‘strongly disagree’?
- What time period were you thinking about when you answered Q11?
- Were there any statements in Q11 that were not clear? Which?
- Were there any other aspects of the decision making process we should include in this question?

Question 12

“How well do you understand how decisions are made about which health care services your child receives? Do you understand this”

- What does ‘health care services’ mean to you in the context of Q12?
- How easy or difficult was it to choose one answer?
- Did the answer categories given match the answer you wanted to give?

ASK R TO ANSWER Q13- Q16

Question 13

Over the past 12 months, how much have you been involved in decision making about your child's need for health care services?

- In this question (Q13) what did the word 'involve' mean to you?
- How did you go about answering Q13?
- What time period were you thinking of?
- Was there a particular incident that you used in answering this question or did you think of the whole 12 months in general?
- Did the answer categories given match the answer you wanted to give?

Question 14

"How interested do you think that health professionals are in the views of parents, about how health care services for children could be improved? Would you say they are ..."

- Do you think the term 'health professional' is clear in this question? - what does this mean to you?
- Were you thinking of children in general or of your own particular child when answering this question?
- How did you go about answering Q14? (*did R think of one particular incident or about their general experience? Did they base it on their own experience or the experience of others?*)
- Did you use the answer boxes to choose an answer or decide the answer then choose the closest box?
- Did the answer categories given match the answer you wanted to give?

Question 15

"Over the past 12 months, has your child been asked for feedback on the health care services he / she received?"

- What do you think 'feedback' meant in this question?
- What time period were you thinking about when answering the question?
- If this question was not relevant was it clear how you should answer it?

Question 16

“Do you think that changes are made as a result of the feedback children give?”

- What do you think ‘feedback’ meant in this question?
- Were you thinking of children in general or of your own particular child when answering this question?
- What type of changes were you thinking of when answering this question?
- Did the answer categories match the answer you wanted to give?

ASK RESPONDENT TO ANSWER Q17-19 (Allow respondents to follow routing themselves)

Question 17

“In the past 12 months, have you made a formal complaint about a health care service you have received in relation to your child?”

- What do you understand a ‘formal complaint’ to be in this question?
- How do you feel about answering this question?
- What ‘other organisations’ were you thinking of when answering the question?

Question 18 (if applicable)

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

- Could you answer this question (Q 18) using the answer boxes provided? (*please explore if R said no, what the issues were*)

Question 19 (if applicable)

“How happy were you with the way that your complaint was dealt with?”

- Could you answer this question (Q 19) using the answer boxes provided? (*please explore if R said no, what the issues were*)

ASK R TO READ INTRODUCTION TO SOCIAL SERVICES SECTION

General social services introduction (KEY PROBES)

- Please could you tell me what social care means in your own words?
- What would you say family support services are?
- Are social care and family support services the same or different? How are they different?
- How did you understand this in the context of this questionnaire?
- What type of services would they include?
- Is there another term or word you use to describe these services?

ASK R TO ANSWER Q 20

Question 20 (KEY QUESTION TO PROBE ON)

“Has your family used any of the following social care and family support services in *the last 12 months?*”

- Did you understand ‘social care and family support services’ the same way as in the introduction?
- Were you able to find all the services that your family has used in the last 12 months? *(if no please explore whether they knew which box to tick)*
- Are there any services here which should be on the list and are currently not?
- Do you think that all the services on the list were social services?
- How easy was to generalise about your experiences of social services?
- How could this have been made easier?
- How can we improve this list?
- How did you feel about answering this question
- What time period were you thinking of when answering this question?
- Were there any options that you were not sure whether to answer yes or no too? Why? Was it because you weren’t sure what they meant?
- What did you understand ‘...’ to mean *(use this probe for services they say yes to)*.
- Did you answer yes to services used by other members of your family (not just your disabled child)?

ASK R TO ANSWER Q 21-23

Question 21

“Overall, how would you describe the information you received in the last 12 months about social care and family support services available to you? Please include both written and verbal information you received.”

- When you answered Q21 what did ‘clear’, ‘relevant’ and ‘accurate’ mean to you in the context of this question?
- How did you go about answering each aspect of this question?
- Do you include written and verbal information in your answer?
- Should we be asking about any other aspects of information received?
- How confident are you of the answers you have given at Q9?

If respondents answered I have not received any information about social care and family support services available to my child in the last 12 months please ask them:

- How easy was it to find a response box?

Check that respondent has ticked a yes or no in every row. If not ask:

- You have not ticked an answer for...Can you tell me why.
- What time period were you thinking about when answering this question?

Question 22

“In the past 12 months, have social care / family support services professionals made any decisions about your child’s illness or disability or services that you should receive?”

- How did you arrive at your answer for Q22?
- What did you understand by the word ‘decisions’ in this question?
- How did you decide which arrow to follow after answering this question?

Question 23 (KEY QUESTION TO PROBE ON)

“And thinking about these decisions and the questions you had to answer, please indicate how much you agree or disagree with each of the following statements.”

- Were there any statements that you felt overlapped with another statement?
- How did you decide whether to agree or disagree with each statement in Q23?
- How did you decide when to choose ‘strongly agree’ or ‘strongly disagree’?
- What time period were you thinking about when you answered Q23? (*Time is not mentioned in the wording of the question*)
- Were there any statements in Q23 that were not clear? Which?
- Were there any other aspects of the decision making process we should include in this question?

More general social support probes

Now that you have answered a few questions on social care and family support services do you think there is a difference between what you thought this section of the questionnaire was going to be about and what the questions actually asked?

ASK R TO READ INTRODUCTION TO EDUCATION / EARLY YEARS SERVICES SECTION

General education section probes (KEY PROBES)

- Please could you tell me what 'educational services' means in your own words?
- How did you understand this in the context of this questionnaire?

ASK R TO ANSWER Q24

Question 24 (KEY QUESTION TO PROBE ON)

"Which of the following education services has your child had in *the last 12 months*?"

- What did you understand by the term 'education services' in this question?
- How did you go about answering this question? (*find out whether they read each line in turn and ticked yes or no or whether they used it as a list and then just ticked those that applied*)
- In your view are there any services missing from this list?
- Were there any services you were surprised to see on the list?
- How easy or difficult was it to remember the services that your child used?
- Were there any services which you weren't sure about? (*please explore what these issues were - didn't know what it meant or not sure if their child had used that service*)
- Do you think that all the services on the list were education or early year services?
- What did dedicated teaching assistant mean to you?

CHECK THAT RESPONDENT HAS TICKED A YES OR NO IN EVERY ROW. IF NOT ASK:

- You have not ticked an answer for...Can you tell me why.
- What time period were you thinking about when answering this question?
- By seeing similar questions does it make it easier or harder to answer the questionnaire (*explore if it is boring/ hard to concentrate*)

ASK R TO ANSWER Q25-28

General probes Q25-28

- How easy or difficult was it answer these questions asking about the educational services your child use?
- How confident are you about your answers?
- Now that you have answered a few questions on educational services do you think there is a difference between what you thought this section of the questionnaire was going to be about and what was actually covered?

Question 27a (KEY QUESTION TO PROBE ON)

“Does your child have a ‘special educational needs’ (SEN), and, if so at what level are they receiving provision?”

- What do you understand by a 'statement of special education needs'?
- What do you understand by 'School/ early years action plus'?
- Are these terms which you would use or would you usually describe SEN in a different way?
- What do you understand by the phrase 'at what level is he/she receiving provision'?
- If they don't know the level, ask why they do not know what level.
- How do you feel about answering this question?
- Do the answer categories include the answer you wanted to give?

Question 27b

“In the past 12 months, did your child have an assessment of his/her educational needs?”

- What do you think ‘assessment’ means in this question?
- How did you feel about answering this question?

Question 28

“Thinking about this assessment and the decisions that were made, please indicate how much you agree or disagree with each of the following statements”

- What did you understand by the word “assessment” in this question?
- Were there any statements that you felt overlapped with another statement?
- Were there any statements in Q28 that you were not sure about? Why was this?
- Were there any statements that you found difficult to answer? - why was this?
- How easy was to generalise about your experiences of education or early year services? How could this have been made easier?

NOW ASK RESPONDENT TO THINK ABOUT THE WHOLE QUESTIONNAIRE

General probes for whole questionnaire

- Do you think it is useful to get peoples views of the health, social and educational services that your children use?
- Is there one type of service, which you are more comfortable in answering questions on? Why is this?
- Are there any areas you are less comfortable with? Why?
- How easy was to generalise about your experiences of health services, social care and education and early year services in answering the questions?
- The questionnaire has split up the questions about the three types of services. Does this make sense to you?
- Does this split reflect the way you receive services?
- Does your child receive assessments for all the areas together? (*if yes, explore this further*)
- Would it have been easier to answer the questions if they had been arranged in another way?

Please thank them for their help, reassure confidentiality and END

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