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Younger Adults' Understanding of Questions for a Service User Experience Survey

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1. Background

For some time now councils with social services responsibilities (CSSRs) have been required to conduct surveys of users' experience of social services. These have taken place nationally in three-yearly cycles. In 2002/03 the survey was for older people, in 2003/04 it was for younger adults with physical and sensory impairments, and in 2004/05 it was for children. 2005/06 marked the beginning of the second wave of the cycle.

The mandate for conducting surveys of users' experiences and satisfaction with services was first given in the white paper Modern Local Government: in Touch with the People (Department for the Environment, Trade and the Regions, 1998). In 2002 the Office of National Statistics (ONS) and SPRU developed a set of questionnaires for this purpose (Qureshi and Rowlands, 2004). Subsequent national surveys have drawn on this work to identify a set of compulsory questions for each round. User experience surveys (UESs) are regarded as an important part of the overall performance framework for social care, providing councils with information about how they might improve services locally. Local authorities are required to submit their results to government bodies so that the relative performance of the CSSRs can be judged.

Results and feedback from the first wave of UESs were mixed. The older people's UES was judged to be successful: the results were of use to councils in thinking about how they might improve their services; and work by PSSRU at the University of Kent also found evidence to support the use of the satisfaction question as a performance indicator (Netten et al., 2004). Further work is ongoing to validate this finding and the approach used. However, feedback concerning the younger adults' UES indicated that there were several shortcomings and anecdotal evidence from CSSRs suggested that there was little subsequent reflection or change in service delivery. No research was undertaken to gather evidence supporting or otherwise the use of questions as performance indicators.

There continues to be strong policy support for conducting surveys as a means to gathering the views of service users and the public. This, combined with the success of the older people's UES, has ensured continued support from the DH and CSCI for a younger adults' survey. Recognising the shortcomings of the UES from the first wave, however, the IC decided to pilot a revised version of the questionnaire. A pilot version of the UES for younger adults with physical and sensory impairment (PSI) was agreed by the advisory group and was piloted by five authorities (Barking and Dagenham, Coventry, Essex, Leicester and Warwickshire) during the months of February through April. A copy of this questionnaire is appended at the end of this

report (Appendix A). The PSSRU at Kent were asked to feed into the pilot process with a view to conducting an extension to the national survey in 2006/07. The extension would utilise the methods developed from prior work on the national UES for older people investigating the validity of performance indicators for this group (Netten et al., 2004). An integral part of this work was the development of a measure of the quality of home care.

There are therefore two key components to the work that the PSSRU at Kent are undertaking as part of their ongoing programme of work funded by the Department of Health. These are:
- feeding into the pilot of the national survey; and
- developing an extended version of the national survey for use with a sample of willing authorities.

The first component is the subject of this paper; issues relating to the second component are briefly considered here and some key findings are appended.

This report is composed of five sections. The aims and objectives of the report are outlined in the second section and the method used to gather the data is outlined in section 3. In section 4 we report on the findings from the fieldwork and draw some conclusions and recommendations for the national survey in section 5. The topic guides for the focus groups and interviews are included in the appendices along with a brief discussion of the findings from the focus groups and a copy of the final extended questionnaire.

2. Aims and objectives

The principal aim of the preliminary research, as it relates to this paper, is to feed into the pilot of the national UES for younger adults with PSI. The objective is to provide some comment on the suitability of the pilot questions as compulsory questions for the national survey. Since the pilot of the national survey will provide mainly a quantitative picture of the suitability of the survey, the aim of the work reported here is to complement this by providing a qualitative picture. We were asked to assess service users' understanding of questions and in particular the:

- interpretation by direct payments users of help they received from social services;
- interpretation of 'quite' satisfied/dissatisfied and possible replacement by 'fairly';
- interpretation of terms for members of staff such as 'care manager';
- interpretation of terms used to describe services such as 'help in your own home';
- interpretation of the term 'job'; and

- interpretation of responses to question 10 (How well does the help you get from Social Services fit in with practical help you get from family or friends?) and their relationship to answers in question 11 (Do you receive any practical help from any friends, neighbours or family members?).

3. Method

The design of the method was largely dictated by the needs of the second component of the work i.e. to develop an extended version of the national UES. There were two stages: first we conducted focus groups to explore service users' understanding of quality social services; and secondly, we conducted 30 cognitive interviews with service users in their own homes to test the suitability of the questionnaire. The rationale for this choice of methods is outlined in Appendix B. Although it is largely the cognitive interviews that are of interest to this stage of the work, the dual design also allowed us to explore some potential issues in the focus groups, in particular potential problems for direct payments users and terminology. Thus we also report here on some findings from the focus groups.

3.1 Sampling issues

Participants for both focus groups and interviews were recruited with the help of contacts within local authorities. To ensure that the sample contained as wide a variety of service users as possible, the researchers developed a set of selection criteria. The criteria were chosen on the basis that these characteristics of people may influence their experience of social services and consequently their views about what makes social services a quality service. The selection criteria were as follows:
- Age
- Gender
- Type of impairment
- Ethnicity
- Presence of informal carer
- Area of residence

Thus through a purposive sampling procedure, the researchers sought to maximise the variety of points of view. In such qualitative exploratory work with small samples, this type of sampling procedure is often more useful than representative procedures, since a wider variety of service users can be selected than might be selected randomly.

The method of recruitment of participants varied for each method. For the focus groups, contacts within local authorities recruited participants on the behalf of the researchers. The researchers gave the contacts the selection criteria for characteristics of service users and asked for groups of no greater than eight service users covering a range of these characteristics.

For the interviews, participants were recruited from the population of users receiving the pilot questionnaire. A letter was sent out with the questionnaire informing service users of this work and they were asked to respond to the letter if they wanted to participate. 29 service users responded to this letter; however several people dropped out and others had to be excluded, as they did not have a physical or sensory impairment. Further people were recruited with help from the authority contacts who assisted in setting up the focus group.

3.2 Focus groups

Three focus groups were conducted during the months of March and April 2006. Focus groups were conducted in accessible locations suggested by the liaison agency within the host authority. The sites were often within the liaison agency itself and staff from the agency were sometimes present to support the participation of some individuals in the group. This was necessary for people with communication difficulties and mild associated learning difficulties who needed someone to mediate between them and the group. Effort was taken to reassure participants of the researchers' independence and that all that was said within the room would be treated confidentially, but it was not possible to assess whether the presence of staff from the agencies influenced responses in any way. However, participants did not seem to be bothered by the presence of these staff and responses were both negative and positive and seemed to be honest expressions of participants' views. Participants were given £50 gift vouchers for their time.

The largest part of the focus group was devoted to a discussion of participants' views on what makes a quality social care service. However, there was discussion at the beginning around understanding of terms used to describe social care services and social care staff. It is this part of the focus group that is of interest here. The terms were presented to participants one by one and participants were asked what types of things they thought such a service or member of staff with such a title would do. In general the terms generated a good deal of discussion. A list of the terms tested is presented in Appendix C.

The focus groups varied in their composition. Although the aim was to have one focus group of people between the ages of 18 and 35, one between the ages of 35 and 64 and one mixed age group, in practice this was not possible, due to the pressure of time and the small size of the

population from which the sample was drawn. All focus groups were mixed ages, although one was biased towards younger service users and one focus group was composed entirely of direct payments users. The number of attendees at each group varied between nine and ten and included carers and representatives of the host agency who needed to be present to enable some service users to participate. Each group had seven service users, although some were not able to stay for the full session and either left or joined mid way through. There were always at least six service users present at any one time throughout each focus group. Table 1 shows a breakdown of the characteristics of service users present at each group.

Table 1: Characteristics of the sample of service users present at focus groups

	Number	*%*
Area composition		
Barking and Dagenham	7	33
Coventry	7	33
Essex	7	33
Gender composition		
Male	10	48
Female	11	52
Age composition		
18-24	2	10
25-34	4	19
35-44	5	24
45-54	6	29
55-64	4	19
Ethnic composition		
White	19	90
Mixed	2	10
Presence of informal care		
No	4	19
Help from outside household	9	43
Help from inside household	5	24
Help from inside and outside household	3	14

Table 1 indicates that there was quite a good mix of service users present at the focus groups. However, there were very few people from ethnic minorities recruited. This was not surprising since the three pilot areas do not have particularly large ethnic populations.

Notes detailing how participants responded to and discussed the terms for services and staff were taken both during the focus groups and after, using the tape recordings. The two field researchers also met following each focus group to discuss the issues that arose for the attendees as they discussed the terms presented (Campanelli et al., 1991).

3.3 Cognitive interviews

Thirty interviews took place during May and early June 2006. Interviews were conducted face-to-face in interviewees' homes unless they requested otherwise. Six interviewees requested to be interviewed elsewhere; four requested to be interviewed at their places of work, one by telephone and one in a church hall. Some creativity was required to conduct some interviews where participants had, for example, communication difficulties associated with their physical impairments. Care was taken to replicate as far as possible the natural situation in which the service user would be answering the questionnaire. In these cases interviews were often conducted with the main carer who was often the partner of the service user and would be the person who would help the service user to fill in the questionnaire. Participants were given a £20 gift voucher for their time.

Cognitive interviewing draws heavily on cognitive psychology and its theoretical traditions. More details about the theory of the method and how this influenced our approach are given in Appendix B and a copy of the topic guide can be found in Appendix D.

Table 2: Characteristics of the sample of service users taking part in interviews

	Number	*%*
Area composition		
Barking and Dagenham	13	43
Coventry	9	30
Essex	8	27
Gender composition		
Male	12	40
Female	18	60
Age composition		
18-24	0	0
25-44	12	40
45-64	16	53
65+	2	7
Ethnic composition		
White	27	90
Asian	1	3
Mixed	1	3
Other	1	3
Presence of informal care		
No	6	20
Help from outside household	11	37
Help from inside household	8	27
Help from inside and outside household	5	17

Table 2 shows that there was quite a good mix of service users interviewed. However, as with the focus groups there were very few people from ethnic minorities recruited. The group of those interviewed is also quite biased towards the top of the age range, with nobody within the age category 18-24 present and two people over 65. It should be noted that both of these service users had very recently turned 65 and qualified as being young adults when the project started. Since they had so recently turned 65 the researchers felt that their views were still valid. The lack of anyone younger than 24 is important since this group of people are likely to experience services quite differently. They may still be living with their parents, at university or just starting

out on their own for the first time. They do, however, represent a tiny proportion of those receiving services for this group so this omission should not be overstated.

Notes detailing understanding and responses to the questions were taken both during the interviews and after, using the tape recordings. In a similar way to the focus groups, the two field researchers met following each wave of interviews to discuss the issues that arose for the attendees as they were presented with the questions in the survey and tried to respond to them (Campanelli et al., 1991). Discussion between the researchers centred on issues that allowed insight into the interviewees thought processes as indicated by the cognitive model (Tourangeau, 1984): (i) understanding of terms, for example, expressions of reservation and confusion, and interpretations of key terms; (ii) strategies for recall, for example, use of time periods, shortcuts and so on; (iii) judgement, for example how interviewees decided to balance the events described to arrive at an answer; (iv) response categories, for example any difficulties choosing a category or any indications of interviewees moulding their answers to fit with how they wanted to be perceived.

4. Findings

This section presents the findings from both the focus groups and interviews that are relevant to the pilot of the national survey. A summary of some preliminary findings relevant to the extended survey is provided in the Appendix E.

4.1 Terminology for staff and services
The terms presented during the focus group sessions generated a good deal of discussion between participants. Findings about services are presented first followed by findings about staff terminology.

4.1.1 Terms used for services
Participants were asked to discuss their thoughts about the function of each of the services presented, in terms of the activities they undertook. It was clear from the discussions that ensued that the participants had some difficulty with several of the terms. For these terms, participants across the groups gave widely varying opinions about what such a service might do. The terms that were particularly problematic were:
- Help in your own home: Generally this was felt to be a vague term that could include help received using direct payments. However, participants noted that it excluded any help provided outside the home e.g. shopping. In general this was not understood as a

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direct service. Home care was widely understood as a direct service that provided similar types of help and care.

- Day care: Ideas about the meaning of this term ranged from care provided in the day (something similar to home care) to day centres.
- Meals: This included both meal-on-wheels services and meals cooked by care wokers.
- Family aide: There was general confusion about what was meant by this term, with many commenting that they had never heard of it. Participants' views ranged from helping the parents to look after children to help with shopping and changing light bulbs - having someone to 'fill in the gaps'.
- Resource centre: This term was not meaningful to all participants, although some identified it as similar to a day centre. However the emphasis was on the resource centre being a place to get information rather than, as a day centre is, a place to interact socially.
- Supported employment: Participants generally did not associate employment services with social services and talked quite a lot about Access to Work schemes, the Job Centre or support from charities.

Given the substantial degree of confusion present for these terms, it seems likely that these terms might cause some difficulty for people responding to the pilot questionnaire. Three of these terms (help in your own home, day care and meals) were found on the pilot questionnaire and, given these findings, attention was paid in the interviews to how people responded to these items.

It was also suggested by these groups that the terms transport, planned short term breaks and day centres may include services not provided by social services, for example local support groups may organise planned short term breaks. It was not clear from the focus groups whether this would be a problem in the context of the survey, as much may depend on how the question is presented.

More generally, participants made quite subtle distinctions between some terms. Of interest was the distinction made between home help and home care, which seemed to draw upon the history of changes to the service. The former term was seen to be associated with housework type activities and to represent the services provided in a time gone by – 'the 1970s'. The latter term was associated with care agencies and the provision of personal care activities as well as domestic type activities. It seemed that participants responded to the terms 'care' and 'help' differently, drawing upon their historical associations with types of services. During the

interview stage attention was paid to how the interviewees responded to items including either of these terms.

In summary, the groups identified difficulties with the terms 'help in your own home', 'day care' and 'meals'. The last term is problematic only if it is intended to capture meals-on-wheels services only. Understanding of these terms was tested in the cognitive interviews, along with understanding of the terms 'care' and 'help'. Alternatives to the problematic terms were also suggested by these groups as home care, day centre and meal-on-wheels, respectively. There was no support for the inclusion of terms that were dropped from the 2003/04 survey such as 'family aide' and 'supported employment' which were widely misunderstood in all of the focus groups.

4.1.2 Terms used for staff

Terms for staff were presented to participants in a similar way to those for services. Participants were asked what they thought a member of staff with such a title might do. In general, the findings were not as clear for these terms compared to those used for services.

Participants were able to classify staff into several categories, however, there was a lot of overlap between the terms and the classification did vary by focus group. The clearest classification was that of the people who provide everyday care in the service users' homes. Within this classification, care worker and care assistant were largely seen as doing the same job. They were distinguished from a personal assistant (PA), who was seen as specific to direct payments users and a carer, who could include an informal carer. Some participants also distinguished care assistants from care workers stating that the former worked in care homes and the latter in the community.

A second layer of staff were generally identified, who were seen either as responsible for arranging your entire care package or as a key contact. Social worker was always found in this classification. Support worker, specified as a community support worker, was sometimes classified here but was also identified as someone like an outreach worker who takes you outside your home. There seems to be some local variation around the use of this term, which points to the potential for widespread confusion. Key worker was also often classified in this way, but participants generally saw the term as associated with services for people with learning difficulties. Other managerial terms, such as 'case manager', were also often included in this classification. However, such staff were sometimes identified as managing the social workers, creating a third, managerial layer. Staff, such as occupational therapists (OTs), were classified separately, alone or with rehabilitation workers.

As it pertains to the survey, the terms used to apply to 'the person that arranges help for you' seem to have the potential to be understood in this way by service users. However, terms such as 'key worker' and 'rehabilitation worker' may be potentially confusing and/or misleading as they have multiple meanings to people. 'Support worker' also appears to be used differently in localities so has the potential to be a confusing term. To refer to staff that provide care in the home it would seem that both 'care worker' and 'personal assistant (PA)' should be used to cover the two possible care scenarios (where a person is employing their own PA and where a person receives a direct service). 'Carer' should not be used as it can be seen to include informal carers. In the cognitive interviews we paid attention to how the use of these terms affected responses to items.

4.2 Question wording

We first discuss some general findings and for ease of reading, we then report findings for each question followed by a discussion of the implications of these findings. Recommendations are made following the discussion of findings for each question. As discussed in section 3.3 particular attention was paid to the following areas during the interview process:

- Comprehension
- Recall strategies
- Judgement
- Response

Attention was also paid to following up on the problems identified by the focus groups.

Some general points arose from the interviews that were felt to be important by the researchers:

- Many service users commented how happy they were to see this type of work carried out. They liked to feel that they had to opportunity to express their views and very much hoped that their 'say' would change things.
- The terms 'help' and 'care' intend many meanings that can be both negative and positive and this can colour the interpretation of sentences containing these words. In general 'care' was often seen negatively as describing something done to you. 'Help' was often also viewed negatively and had a tendency to be associated with domestic tasks. Care should be taken when using these terms within a questionnaire designed to ask about social services.
- It was rare for people to answer questions about anything other than social services. However, what counted towards interviewees views of 'social services' was often quite broad and could encompass not just services for the interviewee, but also services for their children or their parents.

Question 1: Overall, how satisfied are you with the help you receive from Social Services?

Please tick [✓] one box

I am <u>extremely</u> satisfied ☐

I am <u>very</u> satisfied ☐

I am <u>quite</u> satisfied ☐

I am <u>neither satisfied nor dissatisfied</u> ☐

I am <u>quite</u> dissatisfied ☐

I am <u>very</u> dissatisfied ☐

I am <u>extremely</u> dissatisfied ☐

Interviewees were able to answer this question and respond to it in a way that reflected their feelings and experience of social services. However, there was some variety in their understanding of what counted as 'help' from 'social services'. In particular, there was some confusion for direct payments users over whether the question intended direct payments or intended more than their direct payments. It was not uncommon for interviewees to mention their contact with many branches of social services as the following quotes show:

> *"I think I've answered this first question wrongly in a way. Immediately I thought the help I receive from social services is a direct payment, but in fact there is other help I could have, or should have from social services. If you look at it that way, it's not whether I'm happy that I receive a direct payment and all that goes with it, and that's what I've answered there, but that's not what I've been asked. I have been asked about social services generally, as a whole, and I am quite dissatisfied, I would change that now… I read the cover and it said that I have been selected from social services' records and I thought I'm on social services records because I've got a direct payment…"*

The following user eventually chose to tick 'extremely dissatisfied':

"I think that's a dodgy question for me at the moment. When you say social services what branch are you talking about? The P and S team, direct payments team, the OTs...
...P&S team: fantastic, direct payments team: fantastic, the OTs: (...) well it speaks for itself..."

"Well this is what I want to clarify; I mean help in the home is done, obviously, by carers from a care agency so is that what you're actually talking about?
..Well if it's care in my home, it would relate to the care agency, which I would have thought was organised by social services, so..."

This interviewee received services from both the adults and children and families teams:
"Help from social services, do you mean because of my disability or in general, help from social services...
(Researcher asks what they take it to mean.)
... Both. If you came up to me in the street, if you didn't know me, and asked me what do you take to mean by help from social services? I would say, benefits (...) People checking up on health and children and things like that ... "

As these quotes demonstrate, for some people the difficulty in deciding what counts as 'help from social services' was immediately apparent, whilst for others it was not and only became so on direct questioning. It is clear that people make many assumptions when they answer questions and interpretations of what counts as 'social services' will make a difference to how they answer the question.

However, such difficulties did not prevent people answering the question and ticking only one box. There is some evidence that people weigh up relevant experiences in coming to their answer, although this does not seem to be true for everyone as the quotes in the previous section show. Indeed this ambivalence in feelings was not just a product of people having contact with several services, but also a product of changes in their care as the following examples demonstrate:

"This is a really difficult question to answer because up until now I had been very, very, very satisfied... Personally I am satisfied but, and there is a 'but', recently everybody has had their care package reviewed with a view to cut them... I have been put through, and it is put through, loads of assessments including a health assessment, a health needs assessment which a district nurse has to do to see if they can get any funding from health.

And it is very, very stressful to go through... Well I feel like I'm fed up with assessments. So, if you'd ask me this question 6 months ago I'd have said very satisfied, but recently I'm not very satisfied so I don't quite know what I'm going to tick there (...) Quite satisfied."

"I would say quite satisfied...
... Well the, the service is not great; I mean people do make mistakes. Erm, it's just sort of middle way, mid-way..."

"I'm one of these people who looks at both sides of it... I'm certainly glad they're there – couldn't do without them, so, but, er, I'm just on the fence with it really. It really is swings and roundabouts with social services. It really is. Some days it's brilliant and other days you just can't believe why you pay your taxes. But it is all about priority and if you don't come in that top priority then you ain't going to get support."

In these excerpts, service users seemed unwilling to express outright dissatisfaction with services and preferred to opt for either the 'quite satisfied' or 'neither satisfied nor dissatisfied' boxes. This was true even when the dissatisfying experience was quite recent and seemingly made them quite angry. In effect the two boxes ('quite satisfied' or 'neither satisfied nor dissatisfied') were used by service users to express discontent. This finding supports the cut-off of 'very' and 'extremely satisfied' for the performance indicator (Netten et al., 2004).

When judging how satisfied they were, it was not unusual for interviewees to talk in terms of their prior experiences of social services.

"Difficult one to answer (...) Now I am quite satisfied... Now...
... Although I have sufficient assistance now, it has taken a long time to get there. So, I had two years of difficulties dealing with social services, which takes away almost the pleasure of what I have now. I, at the end of it, felt quite traumatised and I constantly worried that what they'd given me would be taken away. So that is always underlying everything...
... I still worry."

"Well I would probably go for the middle one, I'm neither satisfied nor dissatisfied, because some things they do great and some things they don't do great. Some if it's affecting me and some of it's what affects others. It's a big broad spectrum and it

depends when I start judging them from. Ahh, I've got 20 years of using social services and it varies, it goes up and down and in stages and at the moment we're in a going down stage, I think."

As these quotes indicate, satisfaction is clearly related to performance and in judging performance the cumulative experience of service users with social services seemed to be important. However, as the quotes show, service users used this experience in different ways. Their experience was either used as a direct comparator for now or it tended to colour their experience of now. However, as the second quote demonstrates, judging satisfaction with services was not necessarily based entirely on personal experience and people also drew upon the experiences of others in forming their opinions. Satisfaction with social services could include how people felt about the effectiveness of social services as a whole (i.e. including children's services and services for older people) in catering for the needs of others.

When asked directly whether 'fairly satisfied' meant something different to 'quite satisfied' interviewees were largely indifferent and did not seem able to differentiate between the two terms. In addition, it was common for people to mention that it would not change how they answered the question as they often chose their response according to its position on the scale. This finding is supported by recent research by Tourangeau and colleagues (2004).

In summary, this question seems to be fairly clearly understood by participants and there were very few problems for people in choosing response boxes. There is perhaps some scope to introduce an introductory sentence to ensure people are thinking about the 'right' aspects of social services or rather to try to reduce the breadth of interpretation of 'help from social services'.

There does not seem to be any evidence to suggest that having replaced fairly with quite will change the way people respond to the question.

Question 2: Direct Payments is the option for you to purchase some or all of the services you are eligible for directly yourself, using money provided by Social Services. This should not be confused with welfare benefits that are usually paid directly into an account which are also called Direct Payments.

Has someone from Social Services informed you about <u>Direct Payments</u>?

Please tick [✓] one box

I receive Direct Payments (or have done so in the past)	☐
I have not received Direct Payments but someone from Social Services has told me about Direct Payments	☐
I have not received Direct Payments and no-one from Social Services has told me about Direct Payments	☐
Don't know	☐

This question was understood clearly and people were able to say in their own words what they thought a 'direct payment' was, including one person who had not been told about direct payments. However, we did not interview anyone who received a one-off payment.

There are no recommendations for this question.

Question 3: This question is about you and the person that arranges help for you. This could be your social worker or care manager or key worker or rehabilitation worker.

Do you feel that your opinions and preferences are taken into account when decisions are taken about what services are provided to you?

Please tick [✓] one box

Always

Usually

Sometimes

Never

This question does not apply to me because I buy all my own services using direct payments

In general, this question was understood and answered by people in a way that seemed to reflect their feelings about this area of their contact with social services. There were, however, some problems over comprehension and, although not terribly common, some interviewees interpreted this question quite broadly. It was most common for interviewees to think that this question was about the assessment and review process, but on occasion, perhaps due to the location of their care in a supported living environment, service users also thought it was about their care more generally and whether their requests were dealt with, as this quote demonstrates:

> *"The manageress here who works for social services is very good. Every time I've said something to her she's always, you know, tried to get it or nine times out of ten got it. I don't remember who my care manager is now, but every time I've called them they've always helped me out."*

Another rare but important interpretation was for interviewees to think that they were being asked about how well the CSSR consults on changes to services.

When asked directly about who they thought the 'person that arranges your care' was, most people chose either social worker or care manager. Interviewees did not seem to be distracted by the other terms and seemed to ignore them, latching onto either the term, social worker or care manager. Some direct payments users saw themselves as the person that arranges their care. However, they recognised the involvement of social services and this did not prevent them from answering the question.

The most important finding for this question was the way people receiving direct payments responded to it. It was extremely common to find direct payments users choosing to tick one of the substantive response categories rather than the 'does not apply' response specifically for them. From their discussions it was clear that they felt the question applied to them, as the following quote from a direct payments user demonstrates:

> *"Never...*
>
> *...Because I was specifically told they weren't here to assess what I (...) feel I should have but what they were able to give me. So it actually had nothing to do with my level of disability...*
>
> *...direct payments was never a problem. It was just how much time they'd give me for the help I needed. There are some things that aren't available in this area. I would have to travel to them."*

This service user had quite a strong and immediate reaction to this question and her discussion around why she chose that category seems to make sense even though she is a direct payment user. Other direct payments users were also able to provide equally valid arguments as to why the question applied to them on direct questioning, as the following quote shows:

> *"Oh yeah, to me it doesn't matter if you're a direct payment or not because to me I'm still in contact with a social worker and we have a place called X [Social Services funded] that helps us with our direct payments and they always ask me what I want and who I want. I'm the one that directs them, they don't direct me."*

There was some initial concern that this question would be difficult for people who had not had a review for a long time. We did interview one person who had not had a review for three years and had just requested a review and one person who was in the middle of their review process. Both interviewees found it difficult to answer this question, as they did not know yet whether

their opinions and preferences had been taken into account. These people had different strategies for answering this question. One person was not able to tick a box feeling that there was not a box to tick and the other drew upon other experiences to answer the question. As the quote below demonstrates the response provided is arguably at odds with the intention behind the question.

> *"Children's [services] always and with the other one because I don't know what they've given me now, because it's being reviewed now… Like I said well, like I need help with shopping and he [social worker] was like, well you don't really need help with that do you? I was like, well yeah because I can't see! What do you think I've been getting for the past three years? I'll say usually for him [social worker] because I presume that he's going to have taken notice of something, at least I hope so anyway."*

In general this question seemed to work well, but there are some categories of individuals for whom this question was problematic, notably direct payments users and those who were mid-review. In view of the fact that direct payments users seemed to think this question applied to them, it is recommended that the last response category be dropped. It is recommended that a 'don't know' category should be added for those in the middle of their reviews (or for those whose review was so long ago that they could not answer).

There was some degree of variation in interviewees' understanding of this question. Before considering whether this variation is acceptable, some clarity over the intentions behind this question needs to be sought. For example, was it intended that this question address assessment and review or was it intended that it be interpreted more broadly? Should the former be the case it is recommended that the question be reworded and retested.

Question 4: Please read the following statements and then put a tick (✓) next to each statement under the answer which comes closest to the one you want to give.

	Strongly agree	Agree	Disagree	Strongly disagree
The help I get from Social Services or using direct payments has made me more independent than I was				
It is difficult to find out from Social Services about services that might help me				

Statement 1

At a superficial level, the first statement seemed to be understood by interviewees, in that they were able to respond to it. However, it is our the opinion that this superficial 'understanding' masks misunderstanding at a deeper level caused by multiple interpretations of the term 'independence' and an ambiguity in its meaning within the context of disability. The following example demonstrate this issue and how it can affect the answers people provide:

> *"Well the care that I receive from the carers, (...) doing things for me that I'm not able to do myself, but also providing me with things to make me as independent as I possibly can be. By the provision of those things I have got to some extent some choice; whereas if I wasn't provided with those things I probably wouldn't have any choice...*
> *...Independence: to be able to do things for myself. Well, I suppose, really, I'm not independent, am I? I'm not independent, because even if I'm being provided with things to give me a certain amount of independence, I'm still not independent because I'm relying on being provided with that help, if you see what I mean. So, no, I'm not independent if you think of it that way. It gives me, to some degree, some control over my life; not a lot but some."*

As can be seen from this example, there are many ways to interpret being 'more independent'. This service user mentioned feelings of choice and control over their everyday life, and being supported to do things; but the word 'independence' conveyed more than just this. Independence was also interpreted as how the person saw themselves in their web of relationships.

"Before I come here I was stuck at my mother's house for about a year. I did have my own house, I was married, but my wife left because of my illness and I couldn't work, I was in a pretty bad way... If I wasn't here [in a supported accommodation unit] *I don't know what I'd be doing..."*

In addition, some service users who had been using services for a very long time struggled to answer this question as it was difficult for them to remember how they felt before.

In summary, the term 'independence' can be interpreted in many ways. As the examples show there is a lot of room for people to mould this statement to fit their life and agree with it. As a result it is not clear how useful this question is in providing information about how effective services are. It is recommended that this question be dropped on the basis that the term 'independence' is ambiguous and difficult in the context of disability.

Statement 2

There did not seem to be any difficulty with comprehending this statement. However, the researchers consistently found people (at all levels of aptitude) making mistakes in response to it. For example, they would go to great lengths to discuss how they thought it was actually quite easy to find out about services and then tick one of the agree boxes. Sometimes the interviewees would correct themselves, but others had to be prompted before they noticed the mistake. This suggests that the current format may lead to over-reporting of difficulty in this area. One person with some degree of cognitive impairment became very confused at this stage and it is not clear whether this person answered accurately.

Given that it was common for people to have difficulty responding to this question, due to the presence of a 'double negative', it is suggested that this question be rephrased positively or, preferably, redeveloped to be in an interrogative rather than statement format as there is some evidence to suggest that this latter format produces less polarised responses (Petty et al,. 1987).

Question 5: Please read the following statements and then put a tick (✓) next to each statement under the answer which comes closest to the one you want to give

	Strongly agree	Agree	Disagree	Strongly disagree
I have as much contact with other people as I want				
I am able to get to all the places in my local area that I want				

Statement 1

This question seemed to be quite easy to understand, in that people were able to respond to the question. However, people did seem to interpret the term 'contact with other people' in different ways. It could be interpreted very broadly to encompass not only meaningful exchanges with other people, but any occasion where other people might be seen, for example shopping. The following quotes demonstrate the range of ways people made this statement fit with their personal experience:

> *"Yeh I agree with that I suppose…*
> *…I should go out a lot more. I try and go out every single day but I can't always, I'm not always well enough or have got enough movement to go out. I really have to rely on the medicine…*
> *…I'd like to go out a lot more and do a lot more than I do but I'm very controlled by this blasted pump…*
> *…It's difficult for me to plan to go out anywhere. I like rock music, I'd like to go and see some concerts but I can never plan to go because if I buy a ticket, nine times out of ten I won't be well enough to go on the night. I have to do things very much on the spur of the moment…"*

> *"Well, strongly disagree, but that's not really down to anyone in particular. That's just the situation that I'm in, you know…*
> *…I suppose you think more of, well, friendships probably more than anything. I mean anyone who becomes disabled or cut off from the outside world; you do lose your friends.*

There's no two ways about it. Plus, you know, because the illness I've got, it saps my energy so quite often you don't feel like you've got the strength to sort of like cope with lots of visitors, you know what I mean? You just loose contact with everybody. I've got one really good mate, Caroline, and I don't know what I'd do without her. It's due to my disability that I don't get to see people, so you know…"

"Agree…
… Well I was wondering, what did you mean? Do you mean the social workers?
… I don't see much of them…
… I can't see my family because I haven't got anywhere for them to stay because my house is so small and also I use this as a bedroom, so where would I put them during the day? My family can't come…"

As the quotes demonstrate, the flexibility to interpret the meaning of this statement can become quite prohibitive when it comes to trying to understand what people's responses mean. It is very hard to see what is different in the situations of these respondents: they all report that they are prevented from seeing people as much as they would like by their circumstances, yet they all chose different responses. It seems that service users choose different ways to 'factor' their personal circumstances into their answers.

In later interviews, the interviewees were asked this question and another question designed by PSSRU to investigate the same outcome area: social life (please refer to Appendix E question 26). These interviews were particularly interesting since there were some contradictions in the interviewees' answers. Some people, who choose to agree to the statement, also choose one of the bottom two levels in the PSSRU question; in other words they choose, with the alternative PSSRU question, to express a degree of unmet need in this area. The following quote is taken from an interviewee who has quite an active life and works part-time. She chose to respond to question 6, statement 1 with 'strongly agree':

"There are times when I feel socially isolated because most of my friends… my so-called friends, disappeared when I became ill. When I was first disabled, I had a hidden impairment: it wasn't obvious what was wrong with me – I could still walk. And a lot of my friends seemed to resent the fact that I was getting some support at home – carers… Because I don't have a lot of energy and the energy I've got I'm chucking back in to supporting other people, I don't have a great deal of energy to do social things… but sometimes I just do think, it's a shame that I haven't got more friends…"

Although we cannot conclude so from the research conducted so far, it does seem likely that the two questions are actually asking different things. There is some evidence to this effect from one interviewee who was asked directly whether he thought the questions were asking the same or different things.

> *"That [question 5, statement 1] might be work, it might be leisure, it might be meaningful activities..."*

Although contact with other people is an aspect of social life, it is also an aspect of other parts of your life. The PSSRU question seems to more reliably ask people to draw on their experiences of their social situation to answer the question and allowed people to express an emotional need for company. It should be noted that both variations of the question aroused emotion within the interviewees as they talked about their reasons for giving their answers and for a number it became clear, at this point in the interview, that they were quite depressed. There is a wealth of research that shows the relationship between loneliness and depression and it may be that the alternative PSSRU question allows people to express these feelings by way of the latter two response categories. This possibility does however raise the question of how unmet need in this area should be met; is the person depressed and in need of mental health services or is their depression a result of their feelings of confinement in their own home and a result of a lack of social services to help them participate socially? This being said there is clearly unmet need in this area for a number of those interviewed and for this reason it is an important outcome for disabled people.

It was not uncommon for people to answer the question thinking about access issues in their local area. This may have been a result of where it was situated, within a grid and next to a statement about accessibility, although this is speculation. There is, however, some support for this proposition. Tourangeau and colleagues (2004) found that when items were presented in a single grid they were more highly correlated than when they were presented in two separate grids. If the questions were presented as single items they were less strongly correlated still. The effect of reversing the wording of statements meant that the reversed items were less highly correlated with the other items when they were presented in one grid compared to when they were presented the items were presented in two grids or as single items. They suggest that respondents use the proximity of items as a cue to their meaning, perhaps at the expense of reading each item carefully.

In summary, it is not terribly clear how to interpret people's answers this question meaning that the validity of the question is uncertain. The main reason for this is that there are multiple ways of interpreting the term 'contact with other people'. This can encompass social life, but also seems to extend to other areas of life, such as work, activities and can include people you see whilst shopping but do not actually have a meaningful interaction with. There are several consequences of this problem. First, it is unclear what someone who agrees with the question is expressing. Are they expressing genuine contentment with this aspect of their life or are they expressing a resigned fatalist attitude? These two possible interpretations of agreement clearly reflect different levels of welfare, with the latter implying a degree of unmet need. If the question is designed to assess the degree to which people are fulfilled in this area of life then it is likely that the question will lead to an over-reporting of fulfilment in this area. Should it be considered that it is important to measure the impact of social services in this area of outcome, it is recommended that an alternative question be used. PSSRU has cognitively tested an alternative in a similar format to question 6 that seems to capture unmet need more reliably. However, this question has not been piloted for quantitative analysis.

Statement 2

People did not seem to have any problems with either understanding or answering this question. It was clearly understood and people mentioned such barriers as dropped kerbs, inaccessible shops, limited toilet facilities, needing to be escorted every time they left the house, needing to plan everything, and the lack of affordable transport. It was also not uncommon for people to also mention the accessibility of their own house:

> *"Strongly disagree. But then again, that's because I have problems getting in and out of my home, in and out of a wheelchair, and then I am limited to how long I can spend in a wheelchair because it just gives me more pain…But it's certainly not helped by the fact that I have trouble getting in and out of the wheelchair and in and out of this house. That does confine me a lot, so… which social services could help alleviate that problem but they're being long-winded about it"*

There are no recommendations for this question.

Question 6: Which of the following statements best describes your present situation?

By 'control over daily life' we mean you have the choice to do what you want when you want to, for example having meals, going to bed and getting up, going out etc.

Please tick [✓] one box

I feel in control of my daily life ☐

Services help me to feel in control of my daily life ☐

I have some control over my daily life but not enough ☐

I have no control over my daily life ☐

This question was clearly understood by the participants in the interviews and people seemed to answer it in a way that reflected the general discussion around this question. For those people who felt their needs were met in this area, a recurrent issue was indecision over the top two categories, as they felt that both boxes applied to them. The following quote demonstrates this issue:

> *"I feel in control of my daily life... well I think they come hand in hand, the first two, absolutely... Because services help me be in control of my life really and get my life in order really, whereas, you know, with previous situations I haven't felt so in control with my life you know. I've always relied on other people to do it, you know, and at a point I am still that way, but it's on my time and I'm not having to wait around for other people to be there..."*

This service user chose the top category although clearly struggled to reject the second. It seems that the difficulty for people is that to choose the second category, whilst being factually correct, means choosing a negative identity. This was unacceptable and people choose to preserve their positive self-image rather than answer in a factually correct manner. The question was designed to try and capture different levels of welfare with respect to the area of outcome 'control over daily life'. Therefore, that this occurs is not in itself a problem since the implication from this evidence is those who choose the top level are experiencing a genuinely higher level of welfare

than those choosing the second category who feel some dependence on services. There was a real sense of empowerment amongst these service users. As one person who did not have any problems choosing the top category although he was heavily dependent on services, receiving 24 hour care, put it when questioned directly about his choice:

"Because it's me in control – it's me directing my services."

There are no recommendations for this question.

Question 7: Have you got as much information about local support groups as you want?

Please tick [✓] one box

Yes

No, I would like more information

I do not need any information

This question seemed to be understood clearly by everyone interviewed. However a consistent finding was that for some people the response categories did not seem to fit their particular situation. For example, those people who had never thought to ask for any information were often unsure how to respond as the following quotes demonstrate:

"I haven't got an awful lot of information about local support groups but that's purely because I haven't really asked for any. So, do I put yes or I do not need any information. I suppose there would be times when I need it, but... Well, yes, yeh, because then that's down to me if I need more information to ask for it."

"There again, I don't know what support groups there are...
...Like Parkinson's support groups. I know there's one of those, but I don't like mixing with people with Parkinson's disease...

...I don't want to hear about people's problems; I'd rather just ignore it, so I don't go to that. I don't know if there's any other support groups. I'm not really one for going along to classes or talking to people about problems or anything, so...

...I suppose I'd have put I've got enough information as I want [the top response]."

"I'm torn between the 'yes' and 'I don't need any information'... Well, I don't know what local support groups there would be... I've heard about some support groups that have been run in the past, but I guess, I'm tempted to go with this one [I don't need any information] because I guess I'm just not interested in support groups, whatever they might be... I guess I'm more interested in getting on with my life."

The effect of this difficulty is that it makes the interpretation of the responses unclear. For example, if someone ticks 'yes' are they saying that they have all the information they need about local support groups or are they ticking 'yes' because they had never thought to find out about support groups and by default have all the information they want? The latter possibility reflects a general lack of interest in these groups found amongst the people we interviewed; however it should be noted that this was a small and unrepresentative sample.

In summary, there was a general lack of interest displayed by interviewees towards these types of local support groups, which brings into question its value, especially as a compulsory question. However, this group was a small and representative sample and conclusions cannot be drawn about its value from this study. In addition, it is recommended that either the phrasing of the question or the response categories be changed so that the question fits with people's experiences more closely e.g. those people who have never asked and are not interested in asking. The question should then be retested.

Question 8: Are you in work at present?

Please tick [✓] one box for each option

	Yes	No
I am in full time paid work	☐	☐
I am in part time paid work	☐	☐
I am in voluntary work	☐	☐
I am on a training programme	☐	☐
I am in education	☐	☐

Unfortunately this question did not apply to the majority of people interviewed, but again this was a small and unrepresentative sample, so it is not possible to draw any conclusions about its value from this study. The question was, however, clearly understood by all participants, but for those to whom it did apply, a consistent finding was that they experienced some difficulty choosing a response category. Noted absences of categories were job seekers allowance, employment benefits, and self-employed. One person wanted to record their religious training but could not find a box to tick. Most of these absences, especially the last one, all go far beyond any concept of the word 'work', but in the context of the other categories they do make sense. It was the feeling of the researchers that the responses to this question were not entirely consistent with the question itself.

This problem was clearly exemplified during the interviews using the think-aloud technique where the interviewees led the interview by completing the questionnaire by themselves and talking about what they were doing. During these interviews it was consistently found that when at least one of the options to the question did apply to the interviewee they neglected to tick a response to all the options, ticking only the option that applied to them. In some instances this led to people missing off options that applied to them as the following quote demonstrates:

"I'm in part-time work paid, at the moment, so I didn't need to go down…

... Yeh in that scenario you're either in full-time or part-time, with me at the present it's part-time, it's going to be full-time soon. I mean I do do voluntary work so I do both, but could I tick both?

[The interviewer says he can.]

... Yeh, see I do do voluntary. I'm not in education anymore, but I don't suppose I didn't read that well enough...

[The interviewer asks at this point whether there was anything in the question that influenced the way he answered.]

...you haven't said paid work there have you? Are you in work at present? I suppose it's because I don't look at voluntary work as work as such... Voluntary work and work are completely different. Work means I get wages, voluntary work means I do it because I enjoy doing it and it might be good for my CV.

... Please tick one box. You see and then you'd have gone, 'one box' and then you're off... "

This interviewee identified two issues and this finding was supported by the dialogue of others. The first was that the word 'work' was potentially misleading and incompatible with several of the categories e.g. 'I am on a training programme'. It seems that people did not expect that these categories would follow the question. The other issue identified was with the instructions, which could be misread easily as 'Please tick one box'.

In summary, people had considerable difficulty in answering this question correctly especially when self-administered. It is the feeling of the researchers that several of the response categories are incompatible with the phrasing of the question and it is recommended that the question be rephrased so that the response categories follow from the question. Depending on the purpose of the question, it is also advisable to consider additional response categories e.g. self-employed, job seeker or perhaps 'other' to cover all eventualities. It is also recommended that the instructions be rephrased to 'For each option, please tick one box', to mitigate people filling in the form incorrectly.

Question 9: How useful have Social Services been in helping you to get a <u>paid</u> job?

<div align="right">Please tick [✓] one box</div>

I am unable to work/I am past retirement age ☐

I don't need Social Services to help me to get a job ☐

Social Services have been <u>very useful</u> in helping me to get a job ☐

Social Services have been <u>useful</u> in helping me to get a job ☐

Social Services have <u>not been very useful</u> in helping me to get a job ☐

Social Services have <u>not been at all useful</u> in helping me to get a job ☐

As with the previous question, this question did not apply to many people as they were unemployed, but again this was a small and unrepresentative sample and the same qualifications apply. However, in contrast to the last question, it was not clearly understood and for those people in a job the question also did not seem to apply. Understanding was not impeded by lack of comprehension of the term 'job' which was consistently interpreted as employment or paid employment. (This is possibly due to the qualifier 'paid' before job.) Rather it was misunderstood because, across the spectrum of employment states, people were surprised to hear that social services had a role to play here and they often discussed the Job Centre instead as the following quotes demonstrate:

> *"I don't see employment as a kind of social services role really… So I don't know (…) I mean there's the Job Centre and DEAs to support people back into work and careers advisors and that. I don't know really, that question seems a bit odd really."*

> *"(…) Well, I don't really know whether social services… Have they been any help in getting me a job? I mean I got this job sort of off my own back… and I hadn't bothered going down the Job Centre beforehand even though I know there are all the different things you can have down there… As such, though I suppose, they haven't been (…) they haven't actually been useful to me in getting a job, but then I didn't particularly need to*

help at the time. Erm (...) Yeh (...) I mean I suppose I would tick the second to bottom
one, but that's not to necessarily say that's social services fault. That's just me personally
not been down there."

One interviewee who did have help from social services, in the form of a Job Broker or
Supported Employment Advisor, to support her in employment was able to articulate the role of
social services well. However, she felt that the question asked the wrong thing and should be
about whether social services have been any help in supporting her employment rather than
helping her to get a job.

In summary, the researchers consistently found that people were surprised to see such a
question, as they did not seem to think social services had a role to play in this area. Should
the quantitative analysis of the pilot support these findings, it is recommended that this
question be dropped on the basis that useful information is unlikely to be gained from asking
this question.

Question 10: This question is about the Social Services that you receive. If you receive direct payments please answer the question about the services that you buy and any help Social Services have provided.

How well does the help you get from Social Services fit in with practical help you get from family or friends?

Please tick [✓] one box

I don't get practical help from family or friends ☐

Help from Social Services does not need to fit with practical help from family and friends ☐

Help from Social Services fits in <u>extremely well</u> with practical help from family and friends ☐

Help from Social Services fits in <u>very well</u> with practical help from family and friends ☐

Help from Social Services fits in <u>quite well</u> with practical help from family and friends ☐

Help from Social Services <u>doesn't fit in very well</u> with practical help from family and friends ☐

Help from Social Services <u>doesn't fit in at all well</u> with practical help from family and friends ☐

In general this question proved to be difficult for people, both to understand and to answer. It was common for people to struggle to make sense of it in terms of how they live their lives or to raise queries over what was meant by the term 'fit' as the following quote demonstrates.

"(...) Well I'm trying to think about how much contact my family and friends have with social services. And well apart from mother who helps me sort out quite a lot with talking

with them it's not a great deal... But how it fits in with family and friends? I suppose it, erm, it fits in pretty well, very well, erm. Yeh, I suppose quite well. Yeh, I don't really know what to answer there because I'm not, I'm not quite happy with certain... how to interpret that question into my own life."

Several service users were interviewed with family members present who also participated in the discussion. One pair consisting of the service user and a relative, who had recently become her PA, had quite a long and in-depth discussion around this question. The following quotes are excerpts from this conversation and highlight the difficulties in understanding the question, how they resolved these difficulties and the range of different ideas they had about the meaning of the term 'fit in'.

> SU: *"Prior to that [being on direct payments] the help I was getting didn't fit in with family and friends...*
> PA: *What do you mean?*
> SU: *Because, for instance, the times they would come, erm, you know, I'm sort of in the middle of the shower or my visitors arrive, or when because you were here they weren't doing the jobs they were paid for...*
> PA: *...No I think it means more the help you get from family and friends.*
> *...*
> PA: *I don't really understand what the question's asking...*
> SU: *I think I do! Wow! The help from social services, right, that would be the care package, am I right? That's how I see that. So that would be the carers I was getting. How did that fit in, my care package, with help you... that I was getting from you. Well, I mean it did and it didn't, but it... you were really put on.*
> PA: *I'm thinking more about what does it mean by fit in, does that mean you know it all came together and worked well? Is that what it's saying?*
> SU: *...Well I would assume so but it didn't because you were doing the jobs that they were supposed to be doing which delayed other things you wanted to do, so it didn't really work out well."*

As the excerpts above demonstrate the interviewees had to do quite a lot of work to arrive at an answer to this question. It is also interesting to note that both of these quotations came from direct payments users, one who found it difficult to make sense of and the other who chose to answer the question about the direct service she had recently stopped receiving. It may be that this question does not really make sense to this group of people.

Several explanations for the term 'fit in' were given in the extract between the service user and her relative/PA. Some more were given by other service users but they were broadly similar to those already noted. All the interpretations seemed to be sensible interpretations and certainly did not indicate that there will be any ambiguity when it comes to interpreting responses given by the interviewees. However, that the questions caused such difficulties does raise questions about their usefulness. In particular it may be that this area might be more usefully assessed through questions asking about the components of 'fit', for example timeliness and the behaviour of care workers or PAs.

The term 'practical help' was also found to have multiple interpretations as the following quotes demonstrate.

> *"Well it's like if they emptied an hoover, or... If they put washing out or help with shopping, rubbish, err put my medication in, got me something from the shops when I've got no bread. They're like practical things aren't they?"*

> *"Practical help... practical. I don't know. I don't know what practical means...*
> *...Practical, is just... it could be absolutely anything. It isn't personal care...*
> *...Practical is all those odd jobs that you just cannot do yourself. It could be... I don't know putting a light bulb in – that's practical. It serves purpose and it's a necessity, but..."*

> *"Well practical help, I would again, would be almost like to the physical issues. And yeh, I get my friends to empty my leg bag. I get them to... if sometimes we leave my PA at home and we go to football and they do everything, so erm... It just all depends on which friend, how willing they are, how capable they are, erm, if they've got a driving license."*

The point of contention here, as can be seen from these examples, is whether the term 'practical help' intends personal care within its meaning or whether it only includes help with purely practical household tasks such as, chopping down trees, changing light bulbs, shopping, collecting meals, taking you out and doing repairs. Taken in combination the multiple interpretations of these two terms ('practical help' and 'fit in') led interviewees to arrive at some interesting conclusions that arguably did not address the original intention of the question, as this quote demonstrates:

"Well, that's a bit of an odd one (...) I strongly believe that friends and families and PAs are separate... Because I believe that when friends and family start providing a role in your care or assistance, it changes the whole relationship and it spoils things, and they are no longer family, and to use an old-fashioned word, they are now 'carers'...

...I know there is a lot of people out there that have to rely on friends and family for care and practical support, such as dressing and bathing, but for me it's really important that those things stay for a PA, support from a PA than from friends and family. So... to answer the question, so obviously I do get some support from friends and family, dad came round and chopped down a tree for me the other day, but that's more like what friends and family would do for anybody. It's not specifically because I have a disability... So I guess it fits in extremely well, because it's separate."

In addition to these difficulties, this question was extremely hard to administer over the phone due to both the number of response categories and the length of the responses. It was very difficult for the interviewee to keep all these ideas in their mind at the same time.

In summary, people struggled to answer this question largely due to difficulties in interpreting two key terms, 'fit' and 'practical help' and in choosing a response category. In light of the recorded difficulties it is recommended that this question be dropped on the basis that it is unlikely to provide meaningful information. Should this area be considered an important area to address it is recommended that alternative questions be used that address the elements that compose 'fitting in', such as: do your care workers arrive on time, are your care workers in a rush or do your care workers do the things you want them to do? Cognitive testing of these questions indicates that they are suitable for both direct payments users and people receiving a direct service, provided that the term 'care workers' is replaced by 'care workers or PAs'.

Question 11: Do you receive any practical help from any friends, neighbours or family members?

Please tick [✓] all those that apply

Yes, from someone living in my household ☐

Yes, from someone living in another household ☐

No ☐

In general this question seemed to be clearly understood and it was answered in a way that reflected the interviewee's general discussion. However, similar problems were recorded with the interpretation of the term 'practical help' as for question 10. Potentially, this issue could make it difficult for us to interpret what it means if someone ticks a 'yes' box. Could we interpret this as meaning they receive informal care or just help with odd jobs? Is it possible that informal help with personal care tasks is left unrecorded?

If the intention of the question is to record the presence of informal care then it is possible that this question casts the net too widely, that is to say it records help with odd jobs on a very infrequent basis as informal care, as the following quote from a single man in supported living demonstrates:

> "Family and sometimes friends but that's very, very seldom...
> ... Well, they might come and visit me and they might see some washing up in the sink and they might do it for me. This sort of thing, erm, make me a cup of tea. General things. They might see a load of newspapers and clear them up. General things."

The second issue is that informal care may be under-reported since it is common for people to exclude help with personal care tasks from the term 'practical help'. In practice it is not clear to what extent the latter is likely to happen since someone providing help with personal care is also likely to provide help with domestic tasks as well and situations like this were certainly recorded during the interviews.

Although these two scenarios work in opposite directions, it is unlikely that they will cancel each other out at either the aggregate or the individual level since personal situations make this situation unlikely. The data collected so far is not adequate to make any certain conclusions regarding the questions we have raised.

Another potential issue is found for those people who employ a family member as their PA. Does this person provide them with practical help? This question was difficult for the person who employed a family member as a PA. However, it was resolved since other people also provided practical help. However we cannot be certain that this would be the case for everyone.

In summary, there is the potential for this question to both under-report and over-report informal help. Some thought should be given to rephrasing this question to improve the validity. However, much depends on the intention of the question and clarity should be sought

in this respect. Was the question designed to identify those in receipt of informal care or also those receiving often infrequent help with odd tasks? If the former was intended it is recommended that the question be rephrased to clarify this intention and retested.

Question 12: Are you male or female?

Please tick [✓] one box

Male ☐

Female ☐

Interviewees did not have any problems understanding or answering this question.

There are no recommendations for this question.

Question 13: How old are you?

Please tick [✓] one box

18-20 ☐

21-24 ☐

25-44 ☐

45-64 ☐

65 or over ☐

Interviewees did not have any problems understanding or answering this question.

There are no recommendations for this question.

Question 14: To which of these groups do you consider you belong?

Please tick [✓] one box

a) White (British, Irish, any other white background) ☐

b) Mixed (White and Black Caribbean, White and Black African, White and Asian, any other mixed background) ☐

c) Asian or Asian British (Indian, Pakistani, Bangladeshi, any other Asian background) ☐

d) Black or Black British (Caribbean, African or any other Black background) ☐

e) Chinese ☐

f) Any other ethnic group ☐

Interviewees did not have any problems understanding or answering this question.

There are no recommendations for this question.

Question 15:

Please tick [✓] all those that apply

I have a physical impairment ⬜

I have a hearing impairment ⬜

I have a visual impairment ⬜

I have some other impairment(s) (please specify) ⬜

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In general there were no major difficulties with this question, either in comprehension or responding. People seemed to answer the question in a way that reflected their discussion. However, there is some, direct and indirect, evidence to support the finding that people tick only their main impairment (usually physical) when they have less severe impairments in other areas. For example, one interviewee did not tick the visually impaired box despite not being able to read the questionnaire due to the presence of cataracts. Another interviewee stated that he only considered his main impairment when answering the question.

The difficulty here was for people with multiple impairments that are truly severe in one area to decide when to count a difficulty in another area as impairment. In some instances this could be obvious. For example, one interviewed states that he had a visual impairment based on the fact that his driving license had been revoked due to poor eyesight. It did seem that this difficulty was limited to those on the boundary of being truly impaired. For example, no one who wore glasses ticked the box, as one interviewee stated when questioned directly, "It's just normal bad eyesight". This indicates that there would only be some potentially minor under-reporting of impairments on the boundary.

It was not common for the 'other' category to be used, but examples of impairments included in this category were epilepsy and speech impairments.

There are no recommendations for this question.

Question 16: Have you received any of the following services arranged by Social Services in the past year?

Please tick [✓] one box for each service

	Yes	No
Help in your own home	☐	☐
Day care	☐	☐
Meals	☐	☐
Planned short term breaks	☐	☐
Transport	☐	☐
Equipment and adaptations	☐	☐
Other services	☐	☐

This question was clearly understood by interviewees and people also seemed to pay attention to the time period specified, rejecting to tick some boxes since they had not received the service in the past year. However, the researchers did not specifically ask the interviewees what they understood by the term 'year', e.g. were they thinking of January to December or a year from the date of interview. Experience indicates that people are likely to use both methods.

There were, however, a number of problems identified by the researchers in the way people responded to this question, which indicates that there is conceptual overlap between several of the categories. The findings support those of the focus groups. The following example is an excerpt from an interview that demonstrates the consequences of the conceptual overlap:

> Interviewer: *"Help in your own home?*
> Service user: *No, they don't come in to help me, no.*
> Interviewer: *Day care?*

> Service user: *Yes. Is it day care, when they come in and wash you?*
>
> Interviewer: *Meals?*
>
> Service user: *Don't get meals-on-wheels, no."*

In general the issues can be summarised in the following way:

- **Help in your own home**: People interpreted this quite differently and it was common for service users to understand it as help with housework only. Direct payments users also sometimes ticked this box.

- **Day care**: This was commonly misinterpreted. Some interviewees understood it to include day centres whilst other interviewees interpreted it as going out for a day or a regular planned event that could be at a day centre but could also include going to a shop. An extreme, but surprisingly common, interpretation was day care as care in the daytime. Interviewees who chose to tick day care on the basis of this interpretation of its meaning might not tick help in their own home, as they understood day care to include personal care, being given meals and being assisted in the shower. By contrast help in your own home was understood as the domestic aspects of a care package.

- **Meals**: This was again subject to several interpretations. For some people it included meals prepared by their care worker or PA but for others it only included the meals-on-wheels service. As a result a person receiving meals prepared by their care worker or PA could tick either the no or yes box. There seemed to be no pattern behind their choices.

- **Planned short-term breaks**: Some people identified this as respite care but it was common to find that people did not know what these services were.

- **Transport**: This was understood to include dial-a-ride and taxi card services. Some people also included care workers taking them out in their car, or picking up their children from school.

- **Equipment and adaptations**: This was understood without difficulty, although some people who were waiting for adaptations were unsure what to tick, sometimes choosing no and sometimes choosing yes.

- **Other services**: This box was ticked for the following reasons: for when the manager of a supported living establishment helped out with mail, etc; for an enabler (rehabilitation worker), although the interviewee wasn't sure whether this was from social services; a direct payments user ticked this box to cover the work completed by their PA (and did not tick 'help in own home' as they employed a cleaner); it was also ticked to include people taking the interviewee shopping because they did not think this was covered by 'help in your own home'.

During the focus groups some concern was raised over whether people might tick boxes for services they receive through other sources other than social services. Where there was some ambiguity, interviewees were generally able to work through their difficulties and decide whether the service was provided by social services. This is encouraging but does not entirely rule out the possibility that this might happen.

Given the lack of consistency in the way people responded to this question it is recommended that the response categories be changed. To aid this discussion, clarity needs to be sought on the intentions of using the following terms in the survey: help in own home, day care and meals. Was it intended that these terms match services delivered or match tasks delivered? Should the former be the case, it is recommended that the items be changed to 'home care', 'day centre' and 'meals-on-wheels' respectively and that new items, 'direct payments' and, perhaps, 'individual budgets', are added. This question should then be retested.

Question 17: Did you fill in this questionnaire by yourself or did you have help from someone else?

Please tick [✓] one box

I filled it in myself ☐

I had help from a care worker ☐

I had help from someone else ☐

This question was only tested in the interviews using the think-aloud method since it did not make sense to include it when the interviewer was directing the course of the interview. No problems were identified with this question during this process, although no one had help from a care worker to complete the survey since the interviewer supported them if they required help. Given the findings from the focus groups, it is possible that people who hire PAs may have difficulty choosing a box to tick, should they have had help from their PA, since direct payments users tend to regard PAs as quite different from care workers.

It is recommended that the response categories be revised to be inclusive of PAs. This could be by the addition of the term PA to the second category or perhaps the addition of a separate box to cover the possibility that a person had help from their PA.

4.3 Presentation of questions

There was a limit to the extent to which we could test this aspect of the survey as cognitive testing is not terribly useful for locating problems of this type.

Recent evidence suggests that positioning and spacing of response categories have important effects on survey response. In particular, it is important that for scales the conceptual middle is the same as the visual middle otherwise respondents can be misled about the midpoint of the scale. Tourangeau and colleagues (2004) found that respondents tend to use the visual rather than the conceptual middle of the scale as a reference point for responding. They experimented with two different survey formats. In the first, options such as 'don't know' or 'no opinion' were separated from the substantive options and in the second they were provided as a list. In the latter survey, the distribution of responses was skewed away from the conceptual middle towards the visual middle. Questions that may suffer from this problem are questions 3, 9 and 10. Other issues identified in this research were that questions presented next to each other, often in grids, tend to be interpreted as similar and consequently correlations between items are exaggerated (Tourangeau et al., 2004). This may be an issue for items in question 4 and 5.

During interviews, no issues were raised by interviewees concerning the ordering of questions. The presentation of response scales seemed to be a matter of personal taste, although it was common for people to feel that it would be beneficial to separate off the 'don't know' or 'does not apply' option from the list to aid people to find the correct response. One key issue that was identified was that interviewees tended to read the introductory sentences, for example, 'The answers to the next group of questions will be used to make sure that we have a balanced sample of service users' as applying to the question that immediately followed it or those on the same page as the section introduction. The style of the sentence also did not imply that a new section was beginning.

Several interviewees discussed the front cover. The use of the term 'enable' in the title of the survey was commented on and although not a common finding it seems important since it was noted that the word could lead someone to think that without services they might lose their home. It was suggested that the term 'support' replace it. It was also mentioned that the cover

could provide more details for people with communication problems about ways of contacting the council.

It is recommended that some changes are made to the presentation of the questions to (i) aid respondents in choosing a response category, for example ensuring that the visual middle is the same as the conceptual middle; and (ii) make the section headings stand out more clearly as section headings by considering both font changes and also including within the sentence the numbers of the questions to which the section relates.

It is also recommended that some changes are made to the front cover, changing the word 'enable' to 'support' and making the option for councils to include information about different formats a compulsion.

5. Conclusion

This report has provided a significant amount of detail about problems encountered by service users when responding to questions in the pilot survey. Several of the questions had some minor problems and we have provided recommendations as to how these questions might be altered. Some of the questions proved to be very difficult for service users and it was felt by the researchers that these questions could produce results that were difficult to interpret. In these situations a response category could be ticked by people in very different states or several response categories could be ticked by people in different states. When such a situation occurs the question does not have validity since we cannot say with any certainty what response A or B might mean. For these questions we have recommended that the question be dropped.

Where we have recommended that questions be altered we have attempted to provide some guidance as to how a more valid version of the question might be achieved. Some of these questions are taken from the extended questionnaire, a copy of which is provided in Appendix E.

Finally, the results presented here should be read in conjunction with the quantitative results from the pilot of the survey (http://www.ic.nhs.uk/TWG/ssusergroup/20062006). Cognitive testing can provide very useful information about how service users might interpret questions and arrive at their answers, but it cannot provide any clear conclusions about the distribution of responses to a question or the effects of navigational problems on responses. These answers will always be better provided by quantitative pilot work. In addition the lack of representation from

adults aged 18-24 in this work is an omission and given the poor response rate to the questionnaire from this age group it is possible that this group feels that the questionnaire does not apply to them. We recommend that further work be carried out to validate the questionnaire with this age group.

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Appendix A: Survey for pilot

Your views on help provided by [Social Services] to enable you to live in your own home

What we would like you to do
We would like you to help us by taking a few minutes to answer some questions about the help you receive from [Social Services]. If you do not wish to answer the questions, this won't affect the services you receive.

What to do if you need help
If you would like, you can ask a friend or a relative to help you complete the questionnaire. [Councils can mention here any telephone help line they have through which assistance in completing the survey can be arranged]

What to do if you have queries or would like to obtain information on the results
If you, or your friend or relative, have questions you would like to ask about the questionnaire, please ring ……………… on Monday to Friday between 10.00 am and 12.00 Noon or between 2.00 pm and 4.00 pm. [Councils can vary these hours or expand this sentence eg to say leave a message and someone will get back to you] [Councils can add a paragraph on the availability of Alternative formats of questionnaire here]

Why you were selected
Your name is just one of many that have been selected at random from [Social Services'] records.

What will be done with the results of the survey
The results of this pilot survey will be used to help decide whether to run a full survey next year and, if so, which questions to include. The results of any full survey would be used to see how happy people are with the help they get from [Social Services], to see whether

improvements need to be made to local care services and for more general research purposes. This will help the Department of Health, the Commission for Social Care Inspection, and your local [Social Services Department], who are jointly responsible for improving local care services.

Confidentiality

Your answers will be treated as confidential: they will not be passed on to your social worker or anyone else responsible for providing you with services.

If you say on the form that you are being hurt or harmed by anybody, someone (but not your care worker) [Councils can be more specific if they wish] will contact you to talk about it.

Sending back the completed questionnaire

Once you have completed the questionnaire please return it in the envelope provided by [DATE]. You don't need to put a stamp on the envelope.

Thank you for helping us by completing this questionnaire

1. **Overall, how satisfied are you with the help you receive from Social Services?**

Please tick [✓] one box

I am <u>extremely</u> satisfied   ☐

I am <u>very</u> satisfied   ☐

I am <u>quite</u> satisfied   ☐

I am <u>neither satisfied nor dissatisfied</u>   ☐

I am <u>quite</u> dissatisfied   ☐

I am <u>very</u> dissatisfied   ☐

I am <u>extremely</u> dissatisfied   ☐

2. <u>Direct Payments</u> is the option for you to purchase some or all of the services you are eligible for directly yourself, using money provided by [Social Services]. This should not be confused with welfare benefits that are usually paid directly into an account which are also called Direct Payments.

Has someone from [Social Services] informed you about Di<u>rect Payments</u>?

Please tick [✓] one box

I receive Direct Payments (or have done so in the past) ☐

I have not received Direct Payments but someone from [Social Services] has told me about Direct Payments ☐

I have not received Direct Payments and no-one from [Social Services] has told me about Direct Payments ☐

Don't know ☐

3. This question is about you and the person that arranges help for you. This could be your social worker or care manager or key worker or rehabilitation worker.

Do you feel that your opinions and preferences are taken into account when decisions are taken about what services are provided to you?

Please tick [✓] one box

Always ☐

Usually ☐

Sometimes ☐

Never ☐

This question does not apply to me because I buy all my own services using direct payments ☐

4. **Please read the following statements and then put a tick (✓) next to each statement under the answer which comes closest to the one you want to give.**

	Strongly agree	Agree	Disagree	Strongly disagree
The help I get from [Social Services] or using direct payments has made me more independent than I was				
It is difficult to find out from [Social Services] about services that might help me				

5. **Please read the following statements and then put a tick (✓) next to each statement under the answer which comes closest to the one you want to give.**

	Strongly agree	Agree	Disagree	Strongly disagree
I have as much contact with other people as I want				
I am able to get to all the places in my local area that I want				

If you have ticked "Disagree" or "Strongly disagree", please explain in the box below how Social Services could help.

6. **Which of the following statements best describes your present situation?**

By 'control over daily life' we mean you have the choice to do what you want when you want to, for example having meals, going to bed and getting up, going out etc.
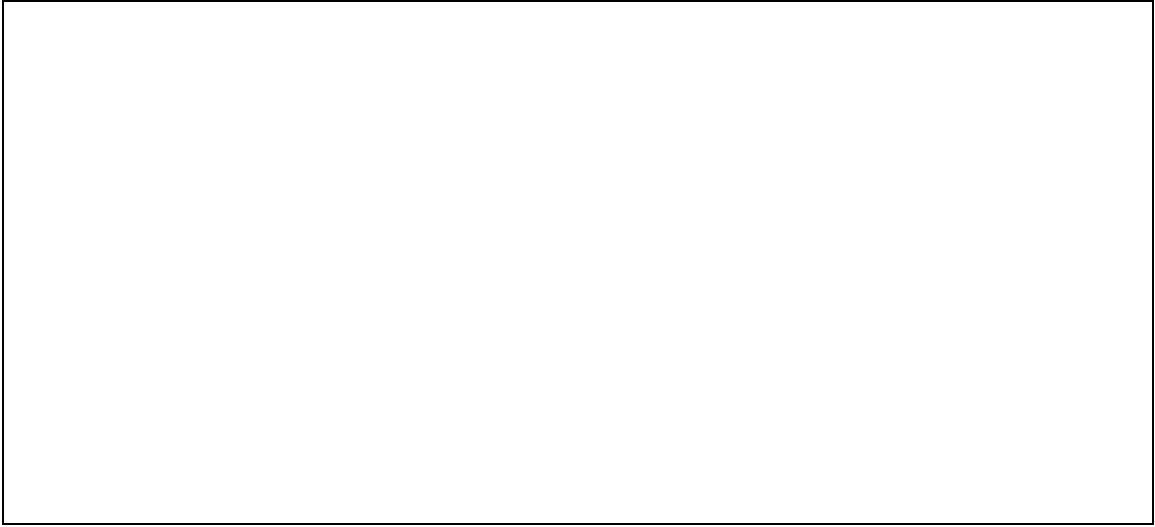
Please tick [✓] one box

I feel in control of my daily life ☐

Services help me to feel in control of my daily life ☐

I have some control over my daily life but not enough ☐

I have no control over my daily life ☐

If you have ticked "I have some control over my daily life but not enough" or "I have no control over my daily life", please explain in the box below how Social Services could help.

7. **Have you got as much information about local support groups as you want?**

Please tick [✓] one box

Yes ☐

No, I would like more information ☐

I do not need any information ☐

8. **Are you in work at present?**

Please tick [✓] one box for each option

	Yes	No
I am in full time paid work	☐	☐
I am in part time paid work	☐	☐
I am in voluntary work	☐	☐
I am on a training programme	☐	☐
I am in education	☐	☐

Please explain further in this box, if you wish.

9. How useful have [Social Services] been in helping you to get a paid job?

Please tick [✓] one box

I am unable to work/I am past retirement age ☐

I don't need [Social Services] to help me to get a job ☐

[Social Services] have been <u>very useful</u> in helping me to get a job ☐

[Social Services] have been <u>useful</u> in helping me to get a job ☐

[Social Services] have <u>not been very useful</u> in helping me to get a job ☐

[Social Services] have <u>not been at all useful</u> in helping me to get a job ☐

10. This question is about the [Social Services] that you receive. If you receive direct payments please answer the question about the services that you buy and any help [Social Services] have provided.

How well does the help you get from [Social Services] fit in with practical help you get from family or friends?

Please tick [✓] one box

I don't get practical help from family or friends ☐

Help from [Social Services] does not need to fit with practical help from family and friends ☐

Help from [Social Services] fits in <u>extremely well</u> with practical help from family and friends ☐

Help from [Social Services] fits in <u>very well</u> with practical help from family and friends ☐

Help from [Social Services] fits in <u>quite well</u> with practical help from family and friends ☐

Help from [Social Services] <u>doesn't fit in very well</u> with practical help from family and friends ☐

Help from [Social Services] <u>doesn't fit in at all well</u> with practical help from family and friends ☐

[This is where councils should add optional questions]

The answers to the next group of questions will be used to make sure that we have a balanced sample of service users.

11.   Do you receive any practical help from any friends, neighbours or family members?

Please tick [✓] all those that apply

Yes, from someone living in my household ☐

Yes, from someone living in another household ☐

No ☐

[Councils may choose to include this gender question if they are not confident of their current records]

12.   Are you male or female?

Please tick [✓] one box

Male ☐

Female ☐

[Councils may choose to include this age question if they are not confident of their current records]

13.   How old are you?

Please tick [✓] one box

18-20 ☐

21-24 ☐

25-44 ☐

45-64 ☐

65 or over ☐

14. To which of these groups do you consider you belong?

Please tick [✓] one box

a) White (British, Irish, any other white background) ☐

b) Mixed (White and Black Caribbean, White and Black African, White and Asian, any other mixed background) ☐

c) Asian or Asian British (Indian, Pakistani, Bangladeshi, any other Asian background) ☐

d) Black or Black British (Caribbean, African or any other Black background) ☐

e) Chinese ☐

f) Any other ethnic group ☐

15.

Please tick [✓] all those that apply

I have a physical impairment ☐

I have a hearing impairment ☐

I have a visual impairment ☐

I have some other impairment(s) (please specify) ☐

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16. Have you received any of the following services arranged by [Social Services] **in the past year?**

Please tick [✓] one box for each service

	Yes	No
Help in your own home		
Day care		
Meals		
Planned short term breaks		
Transport		
Equipment and adaptations		
Other services		

Please describe in this box

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17. Did you fill in this questionnaire by yourself or did you have help from someone else?

Please tick [✓] one box

I filled it in myself ☐

I had help from a care worker ☐

I had help from someone else ☐

[Councils may seek further information on who helped here if they wish. They may also insert additional questions eg about additional services the user would like to meet their needs better or seeking permission for information to be shared to follow up a particular matter]

Thank you for helping us by filling in this questionnaire.

**Please post it back to us in the envelope provided.
You don't need to put a stamp on the envelope.**

For your views to count please return this form by DATE

Appendix B: Methodological issues

The methodology chosen for this study was largely driven by the need to develop an extended survey. Following the method developed in prior work (Netten et al., 2004) the first step is to develop a sense of service users' views about quality. Although there is an increasingly wide literature around users' views of the quality of social services and what makes a quality service, this literature tends to report on the views of older people (for example Edebalk et al., 1995, Francis and Netten 2004, Qureshi and Henwood 2000, Raynes et al., 2001, Sinclair et al., 2000) and there is very little work around younger adults with physical and sensory impairments, Bamford et al., (1999) being an exception. Thus the first step was to collect primary data to develop a better appreciation of this issue.

To explore users' views of quality we chose to use focus groups. Focus groups are particularly suited to exploratory work as they provide a forum for discussion between participants where they can report on the issues they feel are relevant using their own words (Bloor et al., 2001). These features are particularly important when thinking about designing a survey as the questions need to be relevant to people and also phrased in language that they understand. The data from the focus groups was analysed thematically and the themes of quality identified were worked up into questions.

It is widely accepted that questions within questionnaires should be tested for their suitability and validity before they are included in a full scale survey. Since their inception in the 1990s, cognitive interviews have become an increasingly popular method for testing the validity of survey questions. One concern driving forward the development of the method was that the meaning of questions should be standardised for a question to be considered valid (Suchman and Jordan, 1990) and this concern remains central to the method used today.

There are two main approaches within this method and these are the 'think-aloud' and 'probing' methods. There is much disagreement in the literature as to which is better. However, it is now generally accepted that the methods can serve different purposes (Willis, 2005). The technique of concurrent probing[1] is particularly well suited to

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[1] In this method, the interviewer leads the interview usually in a face-to-face setting. The interviewer reads the question and asks the interviewee to respond. Following the response, the interviewer then asks further

developing a sense of the interviewee's understanding of the questions. For this reason it is best to use this method to begin with so that any major problems with questions can be detected early on and changed if necessary. The technique of think-aloud[2] is better suited to capturing the problems associated uniquely with self-administered surveys, such as navigational issues and formatting. For these reasons, we decided to test the items in the questionnaire in several stages. In the first stage we used the concurrent probing technique to look for any difficulties in understanding and then in the second stage we used the think-aloud technique to look for problems associated with self-completion.

Cognitive interviewing draws heavily upon cognitive psychology and its theoretical traditions. In developing the method, cognitive psychologists applied cognitive theory to the task of answering survey questions. The model proposed by Tourangeau (1984) sets out the task as composed of several mental processes that fall into the four main categories shown below:

- Comprehension
- Retrieval (from memory using strategies)
- Judgement
- Response (includes mapping the judgement to a response category and any editing of the response that may be required to present the respondent in a positive light)

These four categories refer to processes or 'components' that respondents must engage in when responding to a question. These components are used by the interviewers as a guide during the interview process to try to uncover differences in the interpretation of questions by respondents.

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questions or "probes" to determine what the interviewee understood by the question and how they came to this understanding.

[2] In this method, the interviewee leads the interview by filling in the questionnaire and talking about what they are doing as they are filling it in. The interviewer observes the person as they fill it in. Usually any difficulties are followed up by the interviewer at the end with retrospective probing.

Appendix C: Terminology explored in focus groups

The following terms for social care services were explored in the focus groups:
- Help in your own home
- Home care services
- Home help services
- A family aide
- Resource centre
- Day centre
- Day care
- Meals
- Planned short term breaks
- Transport
- Equipment and adaptations
- Direct payments
- Supported employment

The following terms for social services staff were explored in the focus groups:
- Key worker
- Rehabilitation worker
- Care worker
- Care assistant
- Personal assistant
- Support worker
- Case worker
- Occupational therapist
- Social worker
- Case manager
- Social care manager
- Carer

Appendix D: Topic guide for cognitive interviews

Introduction
- Name and organisation
- Aim of project
- Aim of interview
- How the interview works
- What to do and what not to do; reassurance
- Confidentiality and consent to record
- Any questions?

Cognitive interviewing starts…

Points to explore:
- Interpretation of questions by direct payments users – are they relevant?
- Understanding of key terms e.g. terms for social services staff and for social care services
- The interpretation by direct payments users of help they received from social services
- Interpretation of 'quite' satisfied/dissatisfied and possible replacement by 'fairly'
- Interpretation of terms such as 'care manager'
- Interpretation of terms used to describe services such as 'help in your own home'
- Interpretation of the term 'job'
- The interpretation of responses to question 10 and their relationship to answers in question 11.

Read the (relevant) instructions on the front cover to the interviewee
and give the interviewee a copy of the questionnaire.
Ask the interviewee question 1
Probe:
- What did you understand by the term 'help from social services'? In particular probe for what types of services they were thinking about. We want to understand whether this is interpreted differently by direct payments users.
- What does fairly satisfied/dissatisfied mean to you? Do you think this is different from quite satisfied/dissatisfied?

- Can you tell me what you were thinking about when you answered this question? In particular probe for incidents or stories they may have heard, perhaps media influence or influence of friends, whether they considered social services as a whole or only certain aspects ie probe for what they think and source
- Can you explain how you went about answering this question? Probe for strategies eg expectations, comparators etc

Ask the interviewee question 2
Probe:
- Can you tell me what direct payments are?
- How sure of your answer are you? The idea is to probe for what type of payments people are including in direct payments eg one-off, past, continuous etc and what it was used for to try to see if they are including things that are not direct payments.

Ask the interviewee question 3
Probe:
- Can you tell me what you were thinking about when you answered this question?
- What name would you use to describe the 'person that arranges help for you'?
- What did you think of as you tried to remember instances of decisions being taken about the services provided to you?
- Test how direct payments users respond to this.

Ask the interviewee question 4a
Probe:
- What type of help were you thinking about when you answered this question?
- What do you understand by 'independent'?
- What time period were you thinking of?
- Was it easy or difficult for you to answer? Why? In particular to probe about response categories

Ask the interviewee question 4b
Probe:
- What do you understand by 'services that might help me'? What services were you thinking about?
- What did you think of as you tried to remember?

- Was it easy or difficult for you to answer? Why? In particular to probe about response categories

Ask the interviewee question 5a

Probe:

- Can you tell me what you were thinking about when you answered this question? In particular probe for interpretation of question
- How did you decide on your answer to this question? In particular to probe about response categories

Ask the interviewee question 5b

Probe:

- Can you tell me what you were thinking about when you answered this question? In particular probe for interpretation of local area and whether 'get to' includes access to buildings or just transport issues?
- How did you decide on your answer to this question? In particular to probe about response categories

Ask the interviewee question 6

Probe:

- Can you tell me what you understand by 'control over daily life'?
- Can you tell me what 'services' you were thinking about for response 2?
- What were you thinking of as you answered this question?
- How easy or difficult was it for you to choose an answer? Why? Need to check for any perceived overlap in response categories and difficulties with this.

Ask the interviewee question 7

Probe:

- Can you tell me what you were thinking of when you answered this question?
- What do you understand by 'local support groups'?

Ask the interviewee question 8

Probe:

- What went through your mind when you answered this question?
- Do you think this list is comprehensive? Is anything missing?

- How easy or difficult was it for you to choose an answer? Why? Need to check for any difficulties with yes/no response system

Ask the interviewee question 9

Probe:

- What were you thinking about when you answered this question? Check that they are only thinking about help from social services and not other schemes.
- What do you understand by the term 'job'?

Ask the interviewee question 10

Probe:

- What went through your mind when you were answering this question?
- What do you understand by 'how well the help from social services fits practical help from family and friends'?
- Can you tell me how you decided upon your answer?
- How easy or difficult was it for you to choose an answer? Why? Need to check for any difficulties with number of categories

Ask the interviewee question 11

Probe:

- What were you thinking about when you answered this question? In particular probe for what help people are receiving, from whom and how often and what they thought counted as help
- Can you tell me what you think counts as 'practical help'?

Ask the interviewee question 12

Probe if necessary

Ask the interviewee question 13

Probe if necessary, possibly around response categories

Ask the interviewee question 14

Probe if necessary, possibly around response categories

Ask the interviewee question 15

Probe:

- How did you go about answering this question? In particular probe for what counts as an impairment for each box, including other, eg glasses as a visual impairment

Ask the interviewee question 16
Probe:
- How did you go about answering this question?
- What did you understand by <check each term>? What types of services are included in these categories ie charities etc
- What time period were you thinking of?
- Did you find this question easy or difficult to answer? Why? In particular check for yes/no answering frame

Can't ask the interviewee question 17 as it won't make any sense in the context

Questions at the end:
- This questionnaire is designed to understand how happy you are with the help you receive from social services. Do you think we have asked you the right questions?
    - o What could/should we have included?
    - o What could/should we have omitted?
- What things do you think social services need to do to improve? Explore relationship with care staff and explore assessment
- What things do you think social services do well? Explore relationship with care staff and explore assessment
- Our questions have finished. Is there anything else you'd like to say?

Appendix E: Summary of findings for the extended UES

To ground the analysis in the activity of care, we drew upon Donabedian's (Donabedian 1980) distinction between structure, process and outcome as a framework for analysis (see Figure 1). We also drew upon Pettigrew's (Pettigrew 1996) discussion of levels of analysis to separate out the different levels at which people might think about the quality of their care.

Figure 1 Framework for analysis

Outcome	quality of life or the desired outcomes of their interaction with the service (cf(Bamford *et al.* 1999)	
Process	Organisational level	quality of the (delivery of the) service
	Inter-individual level	quality of their relationship with staff
	Individual level	quality of the staff cf(Harding and Beresford 1996)

Within each analytical level we were able to identify a set of themes that constituted the meaning of quality from that perspective. The following is a list of the themes concerning quality within each analytical level. We have not included the outcome level as this has been discussed in detail elsewhere {Netten, 2005 #22}.

Quality of the service

- *Accessibility* is about providing adequate and 'user-friendly' information so that prospective and current users know what services are offered and how they can go about looking for them. However, accessibility was broader than this and also included the accessibility of the environment, including their home and buildings, such as those provided for consultation events.
- *Accountability*: an accountable service is one that seeks to ensure that users understand why and how the decisions that were taken were made. This could include decisions about general service specification as well as decisions about their specific care packages at assessment and review. Knowledge of the 'rules' or information about what types of services could be provided was essential to this understanding.

- *Continuity* referred to the continuity of care staff and the continuity of the service. Service continuity was about ensuring stability in the intensity of service receipt into the future.

- *Equity*: This referred to equitable distribution of resources between generations, but also between service users and authorities.

- *Flexibility* of the service was closely related to users feeling able to express choices, which tended to be discussed in terms of the everyday e.g. the need to be able to choose how, when and what types of activities were performed by either themselves or by the person employed to help them.

- *Participation* refers to the need to involve users in decisions about either their own care packages or services more generally. Users referred to themselves as the "experts" on themselves and felt that they were the only ones in a position to know what they needed.

- *Reliability*: this included problems such as carers not turning up, not arriving on time and not staying for the amount of time necessary.

- *Responsible*: A responsible service keeps users informed about their own service and services more generally, for example progress towards procuring a new service, more hours, or cuts in provision and changes to providers. However, ideas of responsibility are broader than those related to communication and also include the need to take steps to ensure users feel safe and prevent abuse.

- *Responsiveness*: this captures ideas about the speed with which services were able to respond to changes in situation or provision of new or different services. This theme was quite closely related to participation as users felt that if services listened to what they said they needed and wanted the service would be more responsive.

- *Value for money* was about ensuring inefficient processes were minimised and that the quality of the services reflected their cost.

Quality of the relationship

Trust was a major issue underlying their *relationship with their carer*. Users needed to know that they could trust their carers not to abuse them either physically or mentally.

They also needed to know that their carers were honest and would not steal from them. Having the feeling that carers listened to them, treated them with respect and as a "person" not an "object", and were understanding were also markers of good relationships for users.

Quality of staff

The quality of staff generally was discussed in terms of their skills and knowledge. These were closely related concepts as knowledge to an extent determines behaviour and skill. The main concern was that carers knew and understood how users' conditions affected them, so that they were not pushed to do things they could not do but it was also a safety matter since a lack of knowledge of diabetic coma could mean a carer ignored a potentially life threatening situation, thinking the person was 'just sleeping' and didn't want to get up that day.

The questions shown below constitute the questions for the extended questionnaire following analysis of the cognitive interviews.

Section 1: Overall satisfaction with Social Services
The following question asks about your overall satisfaction with the Social Services you receive to help you live in your own home. This can include your satisfaction with home care services, care from an agency, Direct Payments or any other service you receive.

1. **Overall, how satisfied are you with the help you have received from Social Services in the past year?**

<div align="right">

Please tick (✓) one box

</div>

I am extremely satisfied	☐
I am very satisfied	☐
I am quite satisfied	☐
I am neither satisfied nor dissatisfied	☐
I am quite dissatisfied	☐
I am very dissatisfied	☐
I am extremely dissatisfied	☐

Section 2: The people that help you with your daily life
Questions 2 to 13 are about the people that come into your home to help you with your daily life, including taking you out, helping you do tasks in your home, and so on. This could be a care worker, personal assistant (PA) or anyone else that is employed to care for you or help you out.

2. Do your care workers or personal assistants (PAs) come at times that suit you?

Please tick (✓) one box

They <u>always</u> come at times that suit me ☐

They <u>usually</u> come at times that suit me ☐

They <u>sometimes</u> come at times that suit me ☐

They <u>never</u> come at times that suit me ☐

3. Are your care workers or personal assistants (PAs) in a rush?

Please tick (✓) one box

They are <u>always</u> in a rush ☐

They are <u>often</u> in a rush ☐

They are <u>sometimes</u> in a rush ☐

They are <u>never</u> in a rush ☐

4. **Do your care workers or personal assistants (PAs) arrive on time?**

Please tick (✓) one box

They are <u>always</u> on time ☐

They are <u>usually</u> on time ☐

They are <u>sometimes</u> on time ☐

They are <u>never</u> on time ☐

I never know what time they're going to arrive ☐

5. **Do your care workers or personal assistants (PAs) do the things that <u>you</u> want done?**

Please tick (✓) one box

They <u>always</u> do the things I want done ☐

They <u>nearly always</u> do the things I want done ☐

They <u>sometimes</u> do the things I want done ☐

They <u>never</u> do the things I want done ☐

6. **Do your care workers or personal assistants (PAs) do things in their way rather than yours?**

Please tick (✓) one box

They <u>always</u> do things their way ☐

They <u>usually</u> do things their way ☐

They <u>sometimes</u> do things their way ☐

They <u>never</u> do things their way ☐

7. **Are your care workers or personal assistants (PAs) careless, e.g. they put things in the wrong place, are wasteful, etc?**

Please tick (✓) one box

Always ☐

Usually ☐

Sometimes ☐

Never ☐

8. **Do you feel you are treated with dignity and respect by your care workers or personal assistants (PAs)?**

Please tick (✓) one box

I am <u>always</u> treated with respect ☐

I am <u>usually</u> treated with respect ☐

I am <u>sometimes</u> treated with respect ☐

I am <u>never</u> treated with respect ☐

9. **How well do your care workers or personal assistants (PAs) understand how your condition affects you?**

Please tick (✓) one box

They completely understand ☐

They understand well enough ☐

They have some understanding ☐

They don't understand at all ☐

10. **Would you describe your relationship with your care workers or personal assistants (PAs) as…?**

Please tick (✓) one box

Excellent ☐

Good ☐

Mixed ☐

Bad ☐

11. **Do you think your care workers or personal assistants (PAs) are professional and do a good job?**

Please tick (✓) one box

Always ☐

Usually ☐

Sometimes ☐

Never ☐

12. **Do you always see the same care workers or personal assistants (PAs)?**

Yes, I <u>always</u> see the same care workers or PAs ☐

No, but I <u>nearly always</u> see the same care workers or PAs ☐

No, I <u>hardly ever</u> see the same care workers or PAs ☐

No, I <u>never</u> see the same care workers or PAs ☐

13. **Do you have as many hours with care workers or personal assistants (PAs) as you need?**

Yes, I have <u>as many</u> hours as I need ☐

No, I need a <u>few more</u> hours ☐

No, I need a <u>lot more</u> hours ☐

No, I have <u>more</u> hours than I need ☐

Section 3: Your home care service
The next question is about your home care service. This could be provided by an agency or by social services directly. If you employ your own PA then you should tick the first box.

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14. **Are you kept informed, by your home care service, about changes in your care? (e.g. your visit will be late or you'll have a different carer)**

Please tick (✓) one box

This <u>does not apply</u> to me as I employ my own PA ☐

Someone <u>always</u> lets me know about changes ☐

Someone <u>usually</u> lets me know about changes ☐

They <u>hardly ever</u> let me know about changes ☐

They <u>never</u> let me know about changes ☐

Section 4: Your contact with Social Services
The following questions from 15 to 19 are about the people you meet and talk to from Social Services. This could be your social worker, care manager or anyone else you have met or talked to.

15. **Do you feel that your opinions and preferences are taken into account when decisions are taken about what services are provided to you?**

Please tick (✓) one box

Always ☐

Usually ☐

Sometimes ☐

Never ☐

Can't say ☐

16. **Do you feel that people from Social Services understand your situation?**

<div align="right">Please tick (✓) one box</div>

Everyone understands my situation	☐
Most people understand my situation	☐
Some people understand my situation	☐
No-one understands my situation	☐

17. **Please read the following statement and then put a tick (☐) under the answer which comes closest to the one you want to give.**

	Strongly agree	Agree	Disagree	Strongly disagree
It is difficult to find out from Social Services about services that might help me				

18. <u>Direct Payments</u> is the option for you to purchase some or all of the services you are eligible for directly yourself, using money provided by Social Services. This should not be confused with welfare benefits that are usually paid directly into an account which are also called Direct Payments.

Has someone from Social Services informed you about <u>Direct Payments?</u>

<div align="right">

Please tick (✓) one box

</div>

I receive Direct Payments (or have done so in the past) ☐

I have not received Direct Payments but someone from Social Services has told me about Direct Payments ☐

I have not received Direct Payments and no-one from Social Services has told me about Direct Payments ☐

Don't know ☐

19. **Please tick the box which comes closest to describing how Social Services respond to your queries or questions.**

<div align="right">

Please tick (✓) one box

</div>

I've never contacted social services with a query ☐

Someone always gets back to me ☐

Sometimes they get back to me but sometimes I have to chase them ☐

I have to chase them but eventually someone gets back to me ☐

They never get back to me ☐

Section 5: About the type of help you receive
The following question asks about the type of help you have received from Social Services in the past year. This can include services delivered directly from Social Services or an agency or bought using Direct Payments.

20. **Which areas of life have your Direct Payments or Social Services helped <u>you</u> with in the past year?**

For each area please tick (✓) one box

	Yes	No
Feeling in control	☐	☐
Personal care	☐	☐
Meals (eg preparation, delivery of meals, etc)	☐	☐
Housework / laundry	☐	☐
Shopping	☐	☐
Personal safety	☐	☐
Seeing people socially	☐	☐
Leisure activities	☐	☐
Paid or volunteer work	☐	☐
Caring for or supporting others (eg children, husband or wife, etc)	☐	☐
Managing your household (eg paying bills, forms, etc)	☐	☐

Section 6: About your lifestyle and daily life
The following questions from 21 to 30 are about how you feel at the moment about aspects of your life and home. For each question, please tick the box that comes closest to describing how you feel.

21. **Which of the following statements best describes your present situation?**

By 'control over daily life' we mean you have the choice to do what you want when you want to, for example having meals, going to bed and getting up, going out etc.

Please tick (✓) one box

I feel in control of my daily life ☐

Services help me to feel in control of my daily life ☐

I have some control over my daily life but not enough ☐

I have no control over my daily life ☐

22. **Thinking about the way you look and feel, which of the following statements best describes your present situation?**

Please tick (✓) one box

I always feel clean and am able to wear what I want ☐

With help I always feel clean and am able to wear what I want ☐

I occasionally feel less clean than I would like or am not able to wear what I want ☐

I feel much less clean than I would like, with poor personal hygiene ☐

23. **Thinking about the meals you eat, which of the following statements best describes your present situation?**

Please tick (✓) one box

I am able to eat the meals I like when I want ☐

With help I eat the meals I like when I want ☐

I can't always eat the meals I like when I want to but I don't think there is a risk to my health ☐

I can't always eat the meals I like when I want to and I think there is a risk to my health ☐

24. **Thinking about your home, which of the following statements best describes your present situation?**

Please tick (✓) one box

My home is as clean and comfortable as I'd like it to be ☐

My home is as clean and comfortable as it can be ☐

My home could be more clean and comfortable than it is ☐

My home is not at all clean or comfortable ☐

25. **Which of the following statements best describes how safe you feel?**

Feelings of safety could be due to fear of abuse, falling or other physical harm and fear of being attacked or robbed.

Please tick (✓) one box

I have no worries about my personal safety ☐

I have support to ensure that I have no worries about my personal safety ☐

I have some worries about my personal safety ☐

I am extremely worried about my personal safety ☐

26. **Which of the following statements best describes your present situation with respect to your social life?**

Please tick (✓) one box

I have a good social life ☐

My social life is as good as it can be ☐

I have a social life but sometimes I feel lonely ☐

I feel socially isolated and often feel lonely ☐

27. **Which of the following statements best describes how involved you are in activities of your choice?**

By 'activities of your choice' we mean anything that you feel keeps you occupied including formal employment, voluntary or unpaid work, and leisure activities.

Please tick (✓) one box

I am fully occupied in activities of my choice ☐

I am occupied but not in activities of my choice ☐

I don't have enough to do to keep me occupied ☐

I have nothing much to do and am usually bored ☐

28. **Thinking about the care and support you provide to others eg children, husband or wife, etc., which of the following statements best describes your present situation?**

Please tick (✓) one box

This does not apply to me as I do not have to support anyone ☐

- - - - - - - - - - - - - - - - - -

I provide others with the kind of support that I want ☐

With help from services I can provide others with the kind of support that I want ☐

At times I find it difficult to provide others with the kind of support that I want ☐

I am not able to provide others with the kind of support I want ☐

29. **How well do you think your home is designed to meet your needs?**

Please tick (✓) one box

My home meets my needs very well ☐

My home meets most of my needs ☐

My home meets some of my needs ☐

My home is totally inappropriate for my needs ☐

30. **Please read the following statement and then put a tick (✓) under the answer which comes closest to the one you want to give.**

	Strongly agree	Agree	Disagree	Strongly disagree
I am able to get to all the places in my local area that I want				

Section 7: About yourself
The answers to the next group of questions from 31 to 40 ask you questions about yourself. They will be used to make sure that we have a balanced sample of service users.

31. **Are you male or female?**

Please tick (✓) one box

Male ☐

Female ☐

32. **How old are you?**

Please tick (✓) one box

18-20 ☐

21-24 ☐

25-44 ☐

45-64 ☐

65 or over ☐

33. **To which of these groups do you consider you belong?**

Please tick (✓) one box

a) White (British, Irish, any other white background) ☐

b) Mixed (White and Black Caribbean, White and Black African, White and Asian, any other mixed background) ☐

c) Asian or Asian British (Indian, Pakistani, Bangladeshi, any other Asian background) ☐

d) Black or Black British (Caribbean, African or any other Black background) ☐

e) Chinese ☐

f) Any other ethnic group ☐

34. Is English your first language?

Yes ☐

No ☐

35. How is your health in general?

Very Good ☐

Good ☐

Fair ☐

Bad ☐

Very Bad ☐

36. Do you need help from somebody to:

For each statement please tick (✓) one box

	Yes	No
Get dressed or undressed	☐	☐
Get in and out of bed or a chair	☐	☐
Wash face and hands	☐	☐
Prepare hot meals	☐	☐

37. **Do you receive any practical help on a regular basis from any friends, neighbours, a partner or family members?**

Please tick (✓) all those that apply

Yes, from someone living in my household ☐

Yes, from someone living in another household ☐

No ☐

38. **Have you received any of the following services arranged by Social Services in the past year?**

For each service please tick (✓) one box

	Yes	No
Direct Payments	☐	☐
Home care	☐	☐
Day centre	☐	☐
Meals on wheels	☐	☐
Planned short term breaks	☐	☐
Transport	☐	☐
Equipment and adaptations	☐	☐
Individual budgets	☐	☐
Other services	☐	☐

Please describe in this box

39. **For how long have you been receiving help from Social Services to support you to live in your own home?**

Please tick (✓) one box

Less than 6 months ☐

6 months to 1 year ☐

1 to 2 years ☐

2 to 5 years ☐

More than 5 years ☐

40. **Did you fill in this questionnaire by yourself or did you have help from someone else?**

Please tick (✓) one box

I filled it in myself ☐

I had help from a care worker or personal assistant (PA) ☐

I had help from someone else ☐

Thank you for helping us by filling in this questionnaire.

Please post it back to us in the envelope provided.
You don't need to put a stamp on the envelope.

For your views to count please return this form by DATE

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