

Newcastle Adult Services: Social Care User Experience Survey 2012 / 13

Central Policy Unit Central Divisions

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Introduction

Purpose of the survey

This report presents the findings from the statutory national 2012/13 Adult Services User Experience Survey, which was created by the NHS Information Centre¹. This was carried out to explore the views of service users about the care and support services they receive from councils with adult social service responsibilities (CASSRs). The purpose of the survey is described by the Information Centre as:

"The main purpose of the Adult Social Care Survey (ASCS) will be to provide assured, consistent and benchmarkable local data on care outcomes. It will be the most significant pool of personal outcome information for those receiving adult social care. The ASCS will be used to:

- Support transparency and accountability to local people, enabling people to make better choices about their care.
- Help local services to identify areas where outcomes can be improved in a very challenging financial climate, and support their own initiatives with an assured vehicle for obtaining outcome information.

It will also be used to populate six outcome measures in the Adult Social Care Outcomes Framework."

This survey updates the findings from the earlier 2010/11 and 2011/12 Social Care User Experience surveys. These are designed to be outcome-focussed, measuring the effect that services have on the quality of people's lives. A full list of the questions asked in the survey can be found in Appendix 1 on p. 39.

This report focuses upon the key findings from the 2012/13 survey and how they compare to the 2010/11 and 2011/12 survey. A subsequent report will compare the findings to those for the UK as a whole in 2012/13, once this information is available.

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Methodology

Questionnaires were sent out to a random stratified sample of people who were receiving care and support services from Newcastle Adult Services, during the period 1st September – 31st December 2012 (the "eligible population"). All types of care and support service users were included in the sample, which comprised people receiving: residential care, nursing care, home care, care in day centres, meals at home, short-term residential care (not respite care), direct payments, personal budgets, professional support, and equipment or home adaptations.

¹ The NHS Information Centre website is here: http://www.ic.nhs.uk/article/2215/User-Experience-Survey-Adult-Social-Care-Guidance-2012-13 (URL dated 9 January 2013).

In 2012/13, as in 2011/12, the eligible population was divided into four groups, or strata, as follows:

- 1. People of all ages with a learning disability
- 2. People aged 18-64 with no learning disability
- 3. People aged 65 and over with no learning disability, in residential care
- 4. People aged 65 and over with no learning disability, who receive community-based services

We then drew a random sample from each stratum, based upon the response rates from people in each stratum in 2011/12. Out of a total of 5291 people in the eligible population, we drew a random sample of 1227, based on the assumption that we would achieve a response rate of 33% in total, as we did in 2011/12. Two people in the survey were replacements for others who were removed from the original sample for reasons of incapacity or because they had died or gone into care very shortly before the survey began. Questionnaires were sent out on 28 January 2013, with reminders going out on 11 February. The fieldwork period for the entire survey was 28 January to 8 March 2013.

Responses and margin of error

We received 497 returned questionnaires out of 1227 sent out, giving a response rate of 41%. This gives a margin of error² for the entire survey of +/- 4.18 percentage points, given that the total number of service users we drew our random sample from was 5291. This is within the maximum margin of error specified by the NHS Information Centre of +/ 5.00 percentage points.

This means that we can consider that the results from the survey are representative of the entire population of 5291 people who are receiving care and support services from Newcastle City Council, to within 4.18 percentage points either way. For example, the percentage of people in the survey who feel that they have adequate control over their daily lives is 45%, so the "true" figure for the population as whole lies between 41% - 49% (figures have been rounded).

Equality and diversity

In 2013, nearly everyone who took part in the survey did so by returning a questionnaire, apart from two people who had telephone interviews, and two people who had face-to-face interviews. Most had help from another person, such as a friend or family member, to complete the questionnaire (see p.35 for details).

We strove to ensure that everyone was able to participate in the survey, using 14-point Arial font for the printed surveys to maximise ease of reading. Additionally, before sending out the questionnaires, we checked service users' Carefirst records to determine if they had any special communication requirements such as large print or other language. People requiring large print surveys were sent them on yellow paper in the font size they had specified (or, if no font size was specified, in 18 point font). The Information Centre

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² The margin of error is a figure calculated using statistics theory to show how close the percentages calculated from the data collected in the survey are to the "true" satisfaction percentages. The "true" percentage is the figure we would get if we could ask every single person who received care and support services this question and receive their answer.

supplied us with Easy Read versions of the questionnaires for use by people with learning disabilities. No-one took part in the survey via an advocate.

In 2012/13 there were twelve people who had sensory impairments; where possible, we checked with the support workers of people known to have communication needs to confirm their requirements. People who required audio cassettes, Braille or very large print (such as 30-point font or above) were contacted by telephone to confirm if they would like to take part in the survey, and, if so, whether they preferred to have the survey in the form of a telephone interview, a face-to-face interview, or an audio cassette. Two people with visual impairments took part via a telephone interview, one had an interview in person, and one person asked to be sent an audio cassette.

People who use British Sign Language were sent a letter in simple English, followed by a reminder, with a form they could use to indicate if they wanted to take part by having a Sign Language interpreted interview. One person took part in this way.

We checked the requirements of people in this group whose first language is not English. In all cases, they were either known to be able to read English, or to have arrangements in place (such as a trusted friend or family member) to help them deal with correspondence in English. We also offered all respondents the option of having a translated questionnaire, or a telephone or face-to-face interview with an interpreter and the researcher if this was what they wanted. No-one chose to do this.

Safety, wellbeing and confidentiality

Where a person gave a reply or made a comment which indicated that there was a reason to be concerned for their personal safety or wellbeing (for example "I am extremely worried about my personal safety"), their details were passed on to Stuart Pattinson, Team Manager in Wellbeing, Care and Learning Directorate, for appropriate action to be taken to safeguard their wellbeing. This is permissible under the terms of the confidentiality guarantee offered to everyone who takes part in the survey:

"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. You will not be personally identified... However, if any of your replies cause us to be concerned about your safety or well-being, someone not directly involved with providing you with services will contact you to discuss this. This is the only circumstance under which it will be used to identify you".

Key Findings

Generally speaking, respondents to the survey were happy and satisfied with their care and support services, including different aspects of the service such as how they had been treated. The most common ways in which care and support services helped people were either with control over their daily lives, or their personal safety.

There has been relatively little statistically significant change in levels of satisfaction, or responses to questions about people's quality of life, since the survey was last run in 2010/11 and 2011/12. Three areas where there have been statistically significant changes are as follows:

Overall satisfaction (ASCOF 1)

• There has been a drop in overall satisfaction with care and support services since last year, from 69% extremely or very satisfied in 2011/12, to 63% extremely or very satisfied in 2012/13. Note that this figure was 65% in 2010/11, so it may be the case this figure fluctuates year on year. We will monitor in in the 2013/14 survey.

Food and drink

- Fewer people replied that they were able to get all the food and drink they wanted compared to last year: 65%, compared to 72% in 2011/12. However, this was matched by an increase in people replying "I get adequate food and drink at okay times", and we should note that 65% of people said this in 2010/11, so this does not suggest a trend. There has not been an increase in people replying that they do not get adequate food and drink.
- On the other hand, since 2011/2012 there has been an **increase** in people saying that care and support services help them to get food and drink, from 63% to 70%. (The question was not asked in 2010/11.)

Information and complaints

- There has been a decrease in the percentage of service users who said that information was very easy to find: 19%, compared to 24% in 2011/12 and 23% in 2010/11.
- These percentages include people who said that they had never tried to find
 information or advice. Fewer people said this in 2012/2013, and so the decrease in the
 percentage of service users who said that information was very easy to find has been
 matched by increases in the percentages who said it was quite easy to find, and who
 said it was very or quite difficult.
- For the first time, we asked if service users would use **email** if they wanted to make a complaint: **8%** replied that they would.

People were generally quite positive about finding information or advice, and about feeling they knew how to make a complaint and could do so if they wanted to. Complaining by telephone or via a representative, such as a family member, was the preferred method for just over half of respondents, as it was in previous years. A third said they would use an online complaints form to make a complaint if one was available, which again is consistent with the previous two years.

For each question about people's quality of life, such as getting food and drink, having enough social contact with others, the majority of people replied that things were either "good" or "adequate". However, for questions about control over daily life, social contact with others, and personal time, there were substantial minorities who gave more negative answers, and this is a pattern that has been seen in previous years' surveys.

When asked who they would talk to if they felt unsafe or were worried about something that had happened to them, the majority of people replied that they would speak to a family member. Other common responses were that people would speak to a care worker, keyworker or Personal Assistant, or a friend, neighbour or colleague. Nearly half of the people in the survey said that their health was fair. However, over half said that they had moderate pain or discomfort, and nearly half said that they were either moderately or extremely anxious or depressed.

The majority of people could get around indoors, get in and out of bed, and feed themselves without any assistance, although in each case a substantial minority of people either had difficulty doing this or could not do so without help. Similarly, the majority could use the toilet, and wash their hands and face without assistance. Half could get dressed and undressed without assistance. However, over half either had difficulty with washing all over and dealing with their finances and paperwork, or could not do these actions at all without help.

The majority of people thought that their home either met their needs very well or that it met most of their needs. Over a third said that they could get to all the places in their local area that they wanted to; however, the majority either found it difficult to get to all the local places they wanted to, were unable to do this, or did not leave their homes. Most people did not buy in extra care and support, but a majority were receiving practical help and support on a regular basis either from someone else in their household (such as a partner) or from someone in another household (such as a friend or family member).

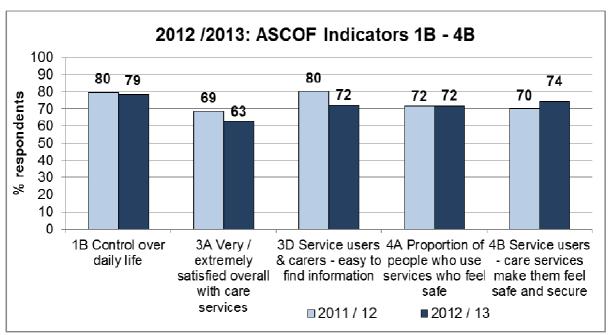
ASCOF Indicators

Quality of Life Indicator

Newcastle City Council's score for the ASCOF 1A indicator about people's overall quality of life was:

NI127 19.2 = out of a possible maximum of 24 expressed as a percentage 80.0% = 0 of the maximum possible score

In 2011/12, the total score was **19.4** (**80.8%**), and in 2010/11, it was **18.9** (**78.7**% of the maximum possible score). The change from 19.2 to 19.4 is very small and not statistically significant. The other ASCOF indicators are shown in the chart below; full details can be found in Appendix 2 on p. 42.



Action Points

Areas which may require attention are as follows. These are the same as in previous years; there has been no significant change in these findings since the 2010 / 11 and 2011 / 12 surveys:

- **Complaints**: 21% of respondents said that they did not know how to make a complaint, and this percentage seems to be staying the same across the years. We also found this in surveys run earlier than 2010 / 2011, such as the older home care users survey or home equipment users survey.
- Control over daily life: 22% said that they had either some control over their daily life but not enough, or no control at all.
- **Depression or anxiety**: 48% said that they had either moderate or extreme depression or anxiety.
- **Finances and paperwork**: Over half of respondents (59%) said that they could not manage their finances or paperwork without help.
- **Getting around outside the home**: 66% of people in the survey either found it difficult to get to all the places in their local area that they wanted to, could not get to all the local places they wanted to, or did not leave their homes.
- **Health**: Only 36% of people in the survey described their health as good or very good. 18% described it as bad or very bad.
- Pain or discomfort: 63% said that they either had moderate or extreme pain or discomfort.
- **Personal time**: 30% either did not do any of the **things they wanted to do** with their time, or did some things that they wanted but not enough. This question had the lowest "most positive" response of all questions about people's quality of life: only 35% of respondents said that they were able to do all the things they wanted to do.
- Social contact with people: 21% said that they had either little social contact with people, or not enough contact.
- Taking part in the survey: 9% of people had had someone else answer the questionnaire for them, without asking them the questions.

Summary of findings

Below is a summary of the main findings of the survey. Full frequency tables and can be found in the "Frequency tables" section on p. 12. A full list of the questions asked can be found in Appendix 1 on p. 39, and comments analysis can be found in Appendix 3 on p.45.

Satisfaction with care and support services

- 59% of respondents without learning disabilities were extremely or very **satisfied overall** with the care and support they receive³. Of people with learning disabilities, 83% replied "I am very happy with the way staff help me, it's really good".
- 90% said that either **having help** made them think and feel better about themselves (53%) or did not affect how they thought about themselves (37%).
- 92% said that **the way they were helped** and treated either made them feel better about themselves (59%) or did not affect how they felt about themselves (33%).

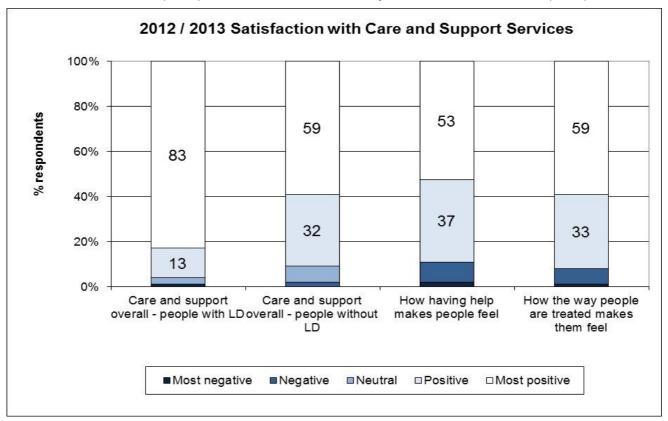


Chart 1: Satisfaction with care and support services

Quality of life

• 29% of respondents without learning disabilities said that their **quality of life** was either very good or so good, it could not be better. If people who replied simply "good" (28%) are included, this gives a total of 57% (figures have been rounded). Of people with learning disabilities, 33% replied "My life is really great" and 46% replied "My life is mostly good". 91% of all respondents said that care and support services helped them to have a better quality of life.

³ People with a learning disability received a version of the questionnaire in which the options were different and not comparable. This means that their answers cannot be included in this total and are reported separately.

- 79% of all respondents (both with and without learning disabilities) said that either they
 had as much control as they wanted over their lives (34%) or adequate control (45%).
 84% said that care and support services helped them to have control over their daily
 lives. Chart 2 (on the next page) shows respondents' relative levels of happiness with
 different aspects of their lives.
- 59% said that they felt **clean** and were able to present themselves the way they liked. 71% said that care and support services helped them with this.
- 65% said that they got all the **food and drink** they liked when they wanted. 70% said that care and support services helped them with this.
- 65% said that their **homes** (including care homes for people in residential care) were as **clean** and comfortable as they liked. 65% said that care and support services helped to keep their homes clean and comfortable.
- 72% said that they felt as **safe** as they wanted. 74% said that care and support services helped them with feeling safe.

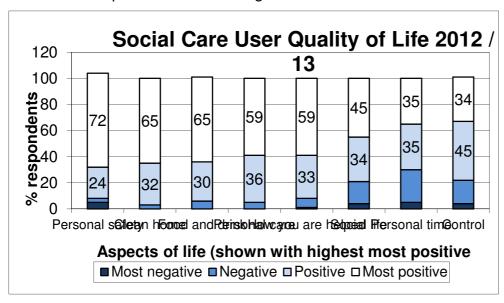


Chart 2: Quality of life

• 79% of people said that either they had as much **social contact** as they wanted with people they liked (45%) or that they had adequate social contact (34%). 63% said that care and support services helped them with having social contact.

• When people were asked about how they **spent their time**, 70% said that they were either able to spend their time as they wanted (35%), or that they were able to do enough of the things they valued and enjoyed (35%). 61% said that care and support services helped with the way they spent their time.

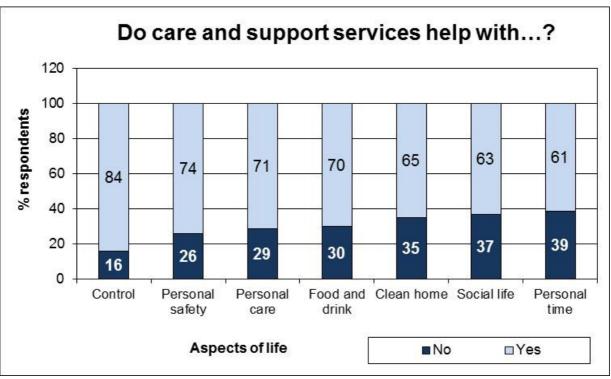


Chart 3: Contribution of care and support services to different aspects of peoples' lives **Information**, safety, and complaints

- Around a quarter of people (24%) had never tried to find **information** or advice about support, services or benefits. Of those who had, 76% said it was very or quite easy.
- Three-quarters of respondents (75%) said that if they were worried about something that had happened to them, or they felt unsafe, they would speak to a **family member**.
- The majority of people (71%) said that they both knew how to make a **complaint** and felt they could do this if they wanted to.
- Just over half of all respondents (52%) said that they would make a complaint by telephone, with the next two most popular options being either complaining in person, or via an advocate or other representative such as a family member (34% for each option).
- A third of people in the survey (33%), said that they would use an **online complaints form** to make a complaint, if one was available.

Health and wellbeing

Health

- The largest percentage of respondents, nearly half (46%), described their **health** as "fair".
- The majority of respondents (63%) said that they had moderate or extreme pain or discomfort
- Just less than half of all respondents (48%) said that they had either **moderate or extreme anxiety** or depression.

Doing things in the home

- Over three-guarters of respondents (80%) could easily **feed** themselves without help.
- Just under two-thirds of respondents (62%) could easily get in and out of **bed** or a chair by themselves without help.
- Just over half of respondents (59%) said that they **could not** deal with **finances** or paperwork without help..
- Just over half of respondents (54%) said that they could get around easily **indoors** by themselves without help.

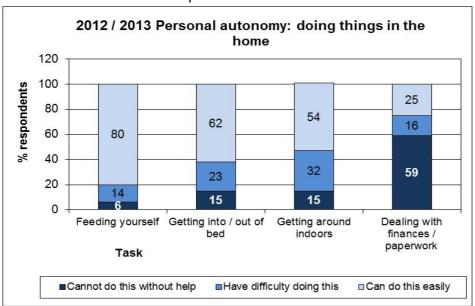


Chart 4: Doing things in the home without help Personal care

- Over three-quarters of respondents (79%) said that they could easily **wash** their hands and face without help.
- The majority of respondents (72%) said that they usually managed to use the **toilet** by without help.
- Half of all respondents (54%) said that they could easily get **dressed** and undressed by without help.
- The largest single percentage of respondents said that they **could easily** wash all over by themselves (39%); the next largest said that they **could not** do this without help (35%).

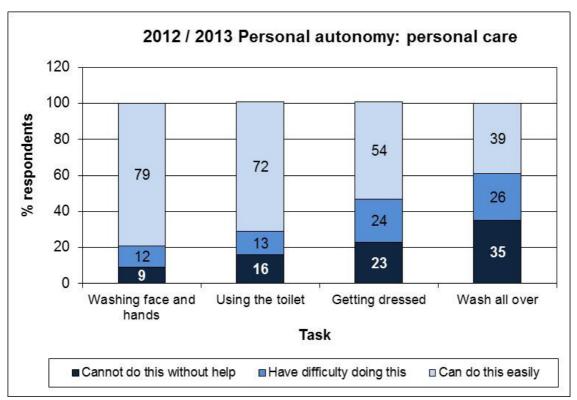


Chart 5: Personal autonomy: personal care

Home, local area and extra care services

- The majority of respondents (68%) did not buy in any additional care and support services.
- Over half of respondents (60%) said that their **home** met their needs very well.
- Just over half of respondents (57%) **received practical help** on a regular basis from someone living in another household (such as an adult son or daughter, friend or neighbour).
- The largest single percentage of respondents (34%) said that they could get to all the
 places in their local area that they wanted to. However, 66% of respondents had
 difficulty doing this, could not get to all the local places they wanted to go to, or did not
 leave their homes.

Taking part in the survey

- The largest percentage of respondents (36%), **had help** with writing their answers in the questionnaire from someone living outside their household. 30% did not have help from anyone else.
- The largest percentage of respondents (44%) who had had help, had had someone else read the answers to them. Of some concern is the fact than 40 people (9%) had had someone else answer for them, without asking them the questions. This may imply that the covering letter for the survey needs to be revised, to indicate that the questionnaire should only be completed using the responses from the person it is addressed to.

What people told us

When we asked people if they had any comments they wanted to make about their care and support services, the most common themes in their comments were:

- Generally happy with care and support services, including residential care
- Unhappy with aspects of care services, including residential care
- Description of what care does for the person receiving it
- Friends and family, including spouses, provide support
- Cannot go out alone and have to have help to do this
- Person needed help to complete questionnaire
- Would like more care and support

More information about what respondents told us can be found in Appendix 3 on p. 45.

About the respondents

The **profile** of the respondents, in terms of whether they receive care in the community or in a residential setting, whether they have a learning disability or not, and their gender, age group and ethnicity, is generally similar to that of the wider population of all adults receiving care and support services from Newcastle City Council. Combined with the margin of error of +/-4.18 percentage points, this means that we can be generally confident that the results are representative of the population as a whole.

The sampling method was deliberately designed to ensure that people in each of the four strata:

- 1. People with learning disabilities
- 2. People without learning disabilities aged 18-64
- 3. People without learning disabilities aged 65 and over, in residential care
- 4. People without learning disabilities aged 65 and over, receiving community-based care. were represented in the sample in the same proportions that they are present in the population. For more details about this, see below under 'Frequency Tables'.

The majority of respondents (62%) took part using a **questionnaire** designed for people receiving services in the community and which was not an "easy read" questionnaire.

The majority of people in the survey:

- Were **female** (59%)
- Were aged **65 and over** (63%)
- Were from a **white** ethnic background (94%)
- Described their religious beliefs as **Christian** (87%)
- Were in the primary client group "**physical disability**, frailty and / or sensory impairment" (64%).
- Care at home was the service received by the largest percentage of people in the survey (48%), bearing in mind that around 13% of people in the survey were receiving more than one service (for example, care at home and home equipment).

Frequency Tables

Strata response rates

As described above in the Methodology section (p. 1), the sample was divided into four strata:

- 1. People of all ages with a learning disability
- 2. People aged 18-64 with no learning disability
- 3. People aged 65 and over with no learning disability, in residential care
- 4. People aged 65 and over with no learning disability, who receive community-based services

The numbers and percentages of people in these strata were as follows:

Strata		% People in this stratum in the responses	% people in this stratum in the sample	% people in this stratum in the population
1. LD - All ages	76	15	13	15
2. Non LD, 18-64	124	25	26	21
3. Non-LD, 65+, In Residential Care	92	19	23	20
4. Non-LD, 65+, Community Based Services	205	41	39	44
Total	497	100	100	100

This table shows that the percentage of **respondents** from each stratum is roughly proportional to the percentage of people in each stratum in the **population** as a whole. It can also be seen that the percentages of people in the strata in the sample are slightly higher or lower than the percentages of people in the strata in the population. This is because we know from previous years' surveys that the response rates for some strata tend to be lower than others, and thus we include proportionally more people from these strata in the sample to compensate for this. This is an advantage of stratified sampling – it enables us to compensate for expected lower response rate from some groups of people.

Percentages and weighting

This year, as in 2011/12, the social care survey results have been weighted. This is due to the use of stratified sampling, as described above. Weighting is used to ensure that the results reported are representative of the entire population. For example, it could be the case that we received a very high number of responses from people in one stratum (for example, people with learning disabilities), and a very low number of responses from people in another (for example, people aged 65 or over in residential care).

If we reported the results without weighting them, this would mean that the views of people in the stratum with a higher response rate were over-represented in the findings, and the view of people in the stratum with a lower response rate were under-represented. Weighting the results corrects this, so that the results reported are "as if" the numbers of respondents from each stratum are exactly proportional to the number of people in each stratum in the eligible population.

The weighting is calculated as follows (from the official guidance):

"This is ...done by dividing the number of people in each stratum in the eligible population by the number of returned questionnaires in each stratum. This has

the effect of weighting for both the sample design and non-response at the same time."

The actual numbers of respondents have been included in the tables below for reference. However, the percentages shown are the **weighted percentages**. This means that any percentages calculated from the numbers in the tables will not be exactly the same as the percentages in the tables, and should not be used. Only the weighted percentages should be quoted.

Response rates for each stratum are as follows:

Strata	No. in population	No. in sample	No. respondents	Response rate	Weight
1 People with learning disabilities of all ages	769	155	78	49%	(769 / 78) 9.86
2 People without learning disabilities, aged 18-64	1129	312	117	38%	(1129 / 117) 9.65
3 People without learning disabilities, aged 65 and over, in residential care	1043	277	92	33%	(1043 / 92) 11.34
4 People without learning disabilities, aged 65 and over, receiving community-based services	2350	483	210	44%	(2350 / 210) 11.19
Totals	5291	1227	497	-	-

Section 1: Overall satisfaction with your social care and support

Q1. Overall, how satisfied or dissatisfied are you with the care and support services you receive? People without a learning disability

Q1 Overall satisfaction with care and support	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %	Valid Percent 2010/11 %
Extremely satisfied	96	24	32	26
Very satisfied	144	35	36	38
Quite satisfied	127	32	25	31
Neither satisfied nor dissatisfied	27	7	5	4
Quite dissatisfied	7	2	1	2
Very dissatisfied	2	0	1	0
Extremely dissatisfied	1	0	1	0
Total	404	100	100	100
People with a learning disability	<i>78</i>	•	•	
Missing	15			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

59% of respondents without a learning disability were extremely or very satisfied overall with their care and support services, compared to 68% in 2011/12 and 64% in 2010/11. A further 32% were quite satisfied. 10 people replied "quite dissatisfied", "very dissatisfied" or "extremely dissatisfied".

People with a learning disability

Q1 Overall satisfaction with care and support – people with a learning disability	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %	Valid Percent 2010/11 %
I am very happy with the way staff help me, it's really good	63	83	76	70
I am quite happy with the way staff help me	10	13	18	25
The way staff help me is OK	2	3	7	5
I don't think the way staff help me is that good	0	0	0	0
I think the way staff help me is really bad	1	1	0	0
Total respondents	76	100	100	100
People without a learning disability	404			
No response	2			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

83% of respondents with a learning disability were very happy with how staff helped them, compared to 76% in 2011/12 and 70% in 2010/11. Please note that the number of people

in the survey with a learning disability is relatively small, so percentages can change considerably from year to year with only relatively small changes in the *number* of people choosing different responses.

The reason why the results for this question for people with and without learning disabilities cannot be combined is that they have different numbers of answer options: seven for people without a learning disability, five for people with a learning disability. This is because: "[research showed that] those [people] with learning disabilities found it very difficult to answer questions where the number of response categories was more than five, and therefore a few of the questions in the easy-read version have a different number of responses to those in the main questionnaire. Therefore, these will not be comparable between the different versions and the results for learning disabled service users will be reported separately." [From the official guidance.]

There are seven options for the question for people who do not have a learning disability because previous years' surveys have shown high levels of satisfaction, and low levels of dissatisfaction. It is therefore useful to have seven options, as it allows for respondents to choose one of three different levels of satisfaction, allowing us to distinguish between different groups within the survey.

Section 2: Your quality of life

Q2a. Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole? People without a learning disability

Q2a Quality of life	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %	Valid Percent 2010/11 %
So good, it could not be better	16	4	6	4
Very good	105	25	22	23
Good	114	28	29	29
Alright	143	34	32	35
Bad	27	6	7	8
Very bad	9	2	3	1
So bad, it could not be worse	2	1	2	0
Total	416	100	100	100
Missing	3			
People with a learning				
disability	<i>78</i>			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

4% of respondents to the survey who did not have a learning disability said that their quality of life was so good, it could not be better. 53% replied either "very good" (25%) or "good" (28%), compared to 51% in 2011/12 and 52% in 2010/11. The largest single percentage replied "alright" (34%). 38 people replied either "bad", "very bad" or "so bad it could not be worse".

People with a learning disability

Q2a Quality of life – people with a learning disability	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %	Valid Percent 2010/11 %
My life is really great	26	33	61	38
My life is mostly good	36	46	28	41
My life is OK, some good things, some bad things	15	19	11	21
My life is mostly bad	0	0	0	0
My life is really terrible	1	1	0	0
Total respondents	78	100	100	100
People without a learning disability	419			
Missing	0			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

33% of respondents with a learning disability thought that their lives were really great (26 people), compared to 61% in 2011/12 (28 people) and 38% in 2010/11 (21 people). Again, please note that the number of people in the survey with a learning disability is relatively small, so percentages can change considerably from year to year with only relatively small changes in the number of people choosing different responses. 46% of respondents with a learning disability thought that their lives were mostly good. One person replied "my life is really terrible".

Q2b Care and support services help with quality of life	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %
Yes	441	91	89
No	43	9	10
Total	484	100	100
Missing	13		
Total	497		

^{*} This question was not asked in 2010/11. The percentages shown are those with a weighting factor.

91% of respondents said that care and support services helped them to have a better quality of life, comapred to 89% in 2011/12.

Q3a. Which of the following statements best describes how much control you have over your daily life?

Q3a Control over daily life	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I have as much control over my daily life as I want	166	34	36	31
I have adequate control over my daily life	218	45	43	45
I have some control over my daily life but not enough	86	18	16	20
I have no control over my daily life	18	4	4	3
Total	488	100	100	100
Missing	9		_	
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The largest single percentage of respondents, 45%, said that they had adequate control over their daily life, which is not significantly different from 2010/11 and 2011/12. 34% had as much control as they wanted over their lives. 22% had some control over their lives but not enough, or no control at all.

Q3b. Do care and support services help you in having control over your daily life?

Q3b Care and support services help with control over daily life	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %
Yes	403	84	86
No	78	16	14
Total	481	100	100
Missing	16		
Total	497		

^{*} This question was not asked in 2010/11. The percentages shown are those with a weighting factor

84% of respondents said that care and support services helped them to have control over their lives, compared to 86% in 2011/12.

Q4a. Thinking about your personal care, by which we mean being clean and presentable in appearance, which of the following statements best describes your situation?

Q4a Personal care	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I feel clean and am able to present myself the way I like	293	59	62	58
I feel adequately clean and presentable	175	36	33	38
I feel less than adequately clean or presentable	24	5	4	4
I don't feel at all clean or presentable	0	0	1	1
Total	492	100	100	100
Missing	5	-		
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The majority of people, 59%, said that they felt clean and were able to present themselves the way they liked. This compares to 62% in 2011/12 and 58% in 2010/11. 36% felt adequately clean, and 24 people said they felt less than adequately clean.

Q4b. Do care and support services help you in keeping clean and presentable in appearance?

Q4b Care and support services help with cleanliness and appearance	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %
Yes	345	71	68
No	141	29	33
Total	486	100	100
Missing	11	_	
Total	497		

^{*} This question was not asked in 2010/11. The percentages shown are those with a weighting factor

71% of respondents said that care and support services helped them to keep clean and presentable in appearance, compared to 68% in 2011/12.

Q5a. Thinking about the food and drink you get, which of the following statements best describes your situation?

Q5a Food and drink	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I get all the food and drink I like when I want	318	65	72	65
I get adequate food and drink at okay times	144	30	23	31
I don't always get adequate or timely food and drink	27	6	4	3
I don't always get adequate or timely food and drink, and I think there is a risk to my health	2	0	2	1
Total	491	100	100	100
Missing	6			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The majority of people, 65%, said that they got all the food and drink they liked when they wanted, compared to 72% in 2011/12 and 65% in 2010/11 – a statistically significant change. 30% said that they got adequate food and drink at acceptable times. 29 people said that they did not get adequate or timely food and drink.

People who replied that they do not always get adequate or timely food and drink and who thought that there was a risk to their health had their details passed on in confidence to Adult Social Care Direct, so this could be discussed with them.

Q5b. Do care and support services help you to get food and drink?

Q5b Care and support services help with getting food and drink	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %
Yes	346	70	<i>63</i>
No	145	30	37
Total	491	100	100
Missing	6		
Total	497		

^{*} This question was not asked in 2010/11. The percentages shown are those with a weighting factor

70% of respondents said that care and support services helped them to get food and drink, compared to 63% in 2911/12 – again, a statistically significant change.

Q6a. Which of the following statements best describes how clean and comfortable your home is?

Q6a Cleanliness of home	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
My home is as clean and comfortable as I want	320	65	67	64
My home is adequately clean and comfortable	154	32	29	31
My home is not quite clean or comfortable enough	17	3	4	4
My home is not at all clean or comfortable	2	0	0	1
Total	493	100	100	100
Missing	4			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The majority of people, 65%, said that their home is as clean and comfortable as they would like, compared to 67% in 2011/12 and 64% in 2010/11. 32% said that their home was adequately clean and comfortable, and 19 people said that either their home was not quite clean and comfortable enough, or that their home was not at all clean and comfortable.

Q6b. Do care and support services help to keep your home clean and comfortable?

Q6b Do care and support services help to keep your home clean and comfortable?	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %
Yes	317	65	59
No	171	35	41
Total	488	100	100
Missing	9		
Total	497		

^{*} This question was not asked in 2010/11. The percentages shown are those with a weighting factor

65% of respondents said that care and support services helped them to get food and drink, compared to 59% in 2011/12.

Q7a. Which of the following statements best describes how safe you feel?

Q7a Personal safety	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I feel as safe as I want Generally I feel adequately safe , but not as safe as I	350	72	72	64
would like I feel less than adequately	116	24	24	29
safe	16	3	2	4
l don't feel at all safe	8	5	2	2
Total	490	100	100	100
Missing	7	-		
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The majority of people, 72%, said that they felt as safe as they wanted, the same as in 2011/12, and higher than in 2010/11 (64%). 24% said they generally felt adequately safe, but not as safe as they would like. 24 people said that either they felt less than adequately safe, or that they did not feel at all safe.

People who replied that they did not feel at all safe had their details passed on in confidence to Adult Social Care Direct, so this could be discussed with them. One person commented:

"I do not feel safe when I am ill with my epilepsy, for example when I have prodromes [a feeling that a seizure is about to occur] and auras [sensory disturbances]".

Q7b. Do care and support services help you in feeling safe?

Q7b Care and support services help with feeling safe	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %
Yes	361	74	70
No	125	26	30
Total	486	100	100
Missing	11		
Total	497		

^{*} This question was not asked in 2010/11. The percentages shown are those with a weighting factor

74% of respondents said that care and support services helped them to feel safe, compared to 70% in 2011/12.

Q8a. Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?

Q8a Social contact	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I have as much social contact as I want with people I like	224	45	51	43
I have adequate social contact with people	162	34	31	38
I have some social contact with people, but not enough	85	17	14	16
I have little social contact with people and feel socially isolated	20	4	4	3
Total	491	100	100	100
Missing	6			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

45% of respondents said that they had as much social contact as they wanted with people they liked, compared to 51% in 2011/12 and 43% in 2010/11. 34% had adequate social contact. 21% had either some social contact but not enough, or little social contact and felt socially isolated.

Q8b. Do care and support services help you in having social contact with people?

Q8b Care and support services help with having social contact	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %
Yes	313	63	61
No	177	37	39
Total	490	100	100
Missing	7	•	
Total	497		

^{*} This question was not asked in 2010/11. The percentages shown are those with a weighting factor

63% of respondents said that care and support services helped them to have social contact with people, compared to 61% in 2011/12.

Q9a. Which of the following statements best describes how you spend your time?

Q9a Leisure time	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I'm able to spend my time as I want , doing things I value or enjoy	174	35	37	32
I'm able to do enough of the things I value or enjoy with my time	169	35	35	32
I do some of the things I value or enjoy with my time but not enough	122	25	22	32
I don't do anything I value or enjoy with my time	26	5	6	5
Total	491	100	100	100
Missing	6			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The majority of people's responses to the question about how they spent their time were evenly split between the "top two" options, with 35% of respondents respectively choosing the options: "spending time as I want, doing things I value or enjoy" or "I'm able to do enough of the things I value...". This is similar to the results in the previous two years. 5% of people said that they do not do anything they value or enjoy with their time, which is in line with previous years.

Q9b. Do care and support services help you with the way you spend your time?

Q9b Care and support services help with the way you spend your time	Frequency	Valid Percent* 2012/13 %	Valid Percent* 2011/12 %
Yes	300	61	57
No	187	39	42
Total	487	100	100
Missing	10		
Total	497		

^{*} This question was not asked in 2010/11. The percentages shown are those with a weighting factor

61% of respondents said that care and support services helped them to spend their time the way they wanted to, compared to 57% in 2011/12.

Q10. Which of these statements best describes how having help to do things makes you think and feel about yourself?

Q10 How does having help make you feel?	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
Having help makes me think and feel better about myself	254	53	56	50
Having help does not affect the way I think or feel about myself	173	37	34	35
Having help sometimes undermines the way I think and feel about myself	44	9	8	15
Having help completely undermines the way I think and feel about myself	9	2	2	1
Total	480	100	100	100
Missing	17			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

Just over half of all respondents said that having help makes them think and feel better about themselves: 53%, compared to 56% in 2011/12 and 50% in 2010/11. 37% said it did not affect how they felt. 11% said that it either sometimes undermined how they thought and felt about themselves or completely undermined this.

Q11. Thinking about the way you are helped and treated, and how that makes you think and feel about yourself, which of these statements best describes your situation?

Q11 Way of being helped and treated	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
The way I'm helped and treated makes me think and feel better about myself	286	59	59	54
The way I'm helped and treated does not affect the way I think or feel about myself	158	33	32	38
The way I'm helped and treated sometimes undermines the way I think and feel about myself	34	7	8	8
The way I'm helped and treated completely undermines the way I think and feel about myself	4	1	2	1
Total	482	100	100	100
Missing	15			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

Over half of all respondents to the survey said that the way they are helped and treated makes them think and feel better about themselves: 59%, compared to 59% in 2011/12

and 54 % in 2010/11. 33% said it did not affect how they felt, and 8% said that it either sometimes or completely undermined how they thought and felt about themselves.

Section 3: Knowledge and information

Q12a. In the past year, have you found it easy or difficult to find information and advice about support, services or benefits?

Q12 Ease of obtaining information	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
Very easy to find	91	19	24	23
Quite easy to find	189	39	33	34
Quite difficult to find	57	12	11	13
Very difficult to find	33	7	3	3
I've never tried to find information or advice	113	24	29	27
Total	483	100	100	100
Missing	14			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

24% of respondents had never tried to find information or advice about support, services or benefits. 58% said that they had found it very or quite easy, compared to 57% in 2011/12 and 2010/11. If the people who had not tried to find information are removed from the totals, the percentage of people who had tried to find information, and had found it very or quite easy, is **76%**, with 24% finding it very or quite difficult.

Q12b. Thinking about the care and support you receive, if you felt unsafe or were worried about something that had happened to you, who would you talk to?

Q12b Who would you talk to about your worries or if you did not feel safe?	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
Family member	363	75	79	79
Care worker, keyworker, or Personal Assistant	174	35	33	39
Friend, neighbour or colleague	89	18	22	21
Care manager or social worker	89	18	15	20
Manager of your care home or day	85	17	21	24
service			— ·	24
Someone else	26	5	6	/
Don't know	10	2	2	1
No-one, I wouldn't say anything	3	1	2	2
Total	488	-	-	-
Missing	9			
Total	497			

^{*} Respondents could choose as many options as they wanted to, so percentages do not total 100. The percentages shown are those with the weighting factor applied.

The majority of respondents (75%) said that they would tell a family member about something that had happened that worried them, or if they felt unsafe; this was also the most common answer in previous years. Most people who replied "other" told us who they would speak to, and this is shown in the table below:

Other – who else?	Frequency 2012/13	Frequency 2011/12	Frequency 2010 / 11
Manager at my workplace	3	0	0
Support worker	3	0	0
Clinical psychologist	2	1	0
Sheltered housing warden / officer	2	2	2
Unable to speak	2	0	0
Church pastor or priest, or a church leader	1	1	1
Concierge, sheltered housing office, landlord, or manager of apartment building	1	3	0
Doctor (GP or doctor at a hospital)	1	4	0
Enablers	1	0	0
Nurse (such as a district nurse or specialist heart or mental health nurse)	1	6	2
Senior carer at care organisation	1	0	0
Support organisation such as Henshaw's Society	1	0	0
Teacher	1	0	0
Cafe supervisor (Capabilities)	0	1	1
Occupational therapist	0	1	1
Police	0	1	0
Psychiatrist	0	1	1
Total people who commented on 'other'	20	20	16
Not specified	6	3	8
Total	26	23	24

It can be seen here that (as in previous years) medical professionals, such as doctors, nurses, and psychologists, were commonly mentioned in the context of people that service users would trust to discuss their worries or concerns about not feeling safe with. Other people mentioned were managers in the workplace, or support workers.

Q12c. If you wanted to make a complaint about the care services you receive, do you know how to?

Q12c Making a complaint	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
Yes, and I feel I could if I wanted to	340	71	74	71
No, I do not know how to make a complaint	38	21	16	20
Yes, but I do not feel I could if I wanted to	98	8	10	9
Total	476	100	100	100
Missing	21	-		
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The majority of respondents (71%, compared to 74% in 2011/12 and 71% in 2010/11) said that they both knew how to make a complaint, and felt that they could if they wanted to. There has been an increased in the percentage of people who replied "Yes, but I do not feel I could if I wanted to". It is not clear at present if this is a change or a random variation in this year's survey, but we will check to see if this change persists in the 2013/14 survey.

Q12d. If you wanted to make a complaint, which of the methods below would you be most likely to use?

Q12d Preferred method of making a complaint	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
Telephone	244	52	52	50
Via an advocate or other representative (such as a family				
member)	202	34	40	45
In person	160	34	30	29
Letter	77	16	19	15
Complaints form	50	10	11	11
Email	39	8	-	-
Councillor or MP	26	6	4	5
Other (not specified)	1	0	2	2
Total	474	-	-	-
Missing	23		_	
Total	497			

^{*} Respondents could choose as many options as they thought applied, so percentages do not total 100. The percentages shown are those with the weighting factor applied. "Email" was not an option in earlier surveys.

Half of all respondents said they would prefer to complain by telephone (52%, compared to 52% in 2011/12 and 50% in 2010/11), with the next most popular options being complaining in person or via an advocate or other representative such as a family member. Most people commented that they would ask their family to deal with complaints; others said that they would speak to a care worker, care home manager, or social worker. One person commented:

"Most or any complaints I have are dealt with by my mother, social worker or carer in the day centre."

Q12e. [People receiving services in the community only] We want to develop an online complaints form so that people who want to complain about care services can complain using the Newcastle City Council website. If you wanted to make a complaint, would you use this method if it was available?

Q12e Online complaints form	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
Yes, I would use it	124	33	32	26
No, I would not use it	200	56	68	74
Don't know	40	11	-	-
Total	364	100	100	100
Not an option*	112			
Missing	21			
Total	497			

^{*} This question was not included in the questionnaires sent to people receiving residential care. The percentages shown are those with the weighting factor applied. 'Don't know' was not an option in 2010/11 and a 2011/12.

Just over a quarter (33%) of people in the survey who were receiving care and support services in the community said that they would use an online complaints form if one was created, in line with the previous year's results (33%, compared to 26% in 2010/11).

Section 4: Your health

Q13. How is your health in general?

Q13 General health*	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
Very good	55	11	10	7
Good	123	25	22	25
Fair	221	46	46	47
Bad	71	14	16	17
Very bad	18	4	6	4
Total	488	100	100	100
Missing	9		-	
Total	497			

^{*} This was question no. 17 in the questionnaires sent to people receiving residential services, and question no. 18 in the questionnaires sent to people receiving community-based services. The percentages shown are those with the weighting factor applied.

The largest percentage of respondents, nearly half (46%), described their health as "fair", which is the same as the previous two years' results (46% in 2011/12, 47% in 2010/11). 18% described it as bad or very bad, and 36% described it as good or very good.

Q14. By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

a. Pain or discomfort

Q14a Pain or discomfort	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I have no pain or discomfort	170	34	30	29
I have moderate pain or discomfort	260	51	57	54
I have extreme pain or discomfort	58	12	14	18
Total	488	100	100	100
Missing	9			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

Half of all respondents (51%) said that they had moderate pain or discomfort, compared to 57% in 2011/12 and 54% in 2010/11. One person commented:

"I am heavily medicated for pain relief."

b. Anxiety or depression

Q14b Anxiety or depression	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I am not anxious or depressed I am moderately anxious or	247	52	51	50
depressed	211	43	40	43
I am extremely anxious or depressed	25	5	8	7
Total	483	100	100	100
Missing	14			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

Half of all respondents (52%) said that they were not anxious or depressed, which is consistent with 2011/12 (51%) and 2010/11 (50%). One person commented:

"I have rheumatoid arthritis and am depressed. I have trouble using my hands, walking, sitting for long, sometimes I don't leave my room."

Q15. Please place a tick in the box that best describes your abilities for each of the following questions labelled from a to d.

a. Do you usually manage to get around indoors (except steps) by yourself?

Q15a Getting around indoors	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I can do this easily by myself	267	54	57	52
I have difficulty doing this myself	152	32	28	32
I can't do this by myself	72	15	15	16
Total	491	100	100	100
Missing	6			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

Just over half of respondents (54%) could get around easily indoors by themselves without help, which is consistent with 2011/12 (57%) and 2010/11 (52%).

b. Do you usually manage to get in and out of a bed (or chair) by yourself?

Q15b Getting in and out of bed	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I can do this easily by myself	307	62	63	56
I have difficulty doing this myself	109	23	21	27
I can't do this by myself	75	15	16	17
Total	491	100	100	100
Missing	6		-	
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

Just less than two-thirds of respondents (62%) could easily get in and out of bed by themselves without help. which is consistent with 2011/12 (63%) and higher than 2010/11 (56%).

c. Do you usually manage to feed yourself?

Q15c Feeding yourself	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I can do this easily by myself	395	80	81	84
I have difficulty doing this myself	68	14	15	12
I can't do this by myself	30	6	5	5
Total	493	100	100	100
Missing	4			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

Over three-quarters of respondents (80%) could easily feed themselves without help, in line with previous years' results (81% in 2011/12 and 84% in 2010/11).

d. Do you usually deal with finances and paperwork – for example, paying bills, writing letters – by yourself?

Q15d Dealing with finances or paperwork	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I can do this easily by myself	121	25	28	28
I have difficulty doing this myself	80	16	18	13
I can't do this by myself	290	59	<i>55</i>	59
Total	491	100	100	100
Missing	6			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The majority of respondents (59%) said that they could **not** deal with finances or paperwork without help, in line with previous years' results (55% in 2011/12 and 59% in 2010/11).

Q16. Please place a tick in the box that best describes your abilities for each of the following questions labelled from a to d.

a. Do you usually manage to wash all over by yourself, using either a bath or shower?

Q16a Washing all over	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I can do this easily by myself	196	39	40	36
I have difficulty doing this myself	124	26	26	27
I can't do this by myself	168	35	34	37
Total	488	100	100	100
Missing	9			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The largest single percentage of respondents said that they could easily wash all over by themselves (39%); the next largest said that they could not do this without help (35%). This is in line with previous years' results: 40% could do this without help in 2011/12; 36% in 2010/11).

One person commented in relation to these questions:

"On many of these questions they ask if I can do stuff, but none ask if I can do them when I am at my lowest, which is very often in these situations."

b. Do you usually manage to get dressed and undressed by yourself?

Q16b Getting dressed	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I can do this easily by myself	265	54	51	49
I have difficulty doing this myself	113	24	27	28
I can't do this by myself	109	23	22	24
Total	487	100	100	100
Missing	10			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

Just over half of all respondents (54%) said that they could easily get dressed and undressed without help, in line with previous years' results (51% in 2011/12 and 49% in 2010/11).

c. Do you usually manage to use the WC / toilet by yourself?

Q16c Using the toilet	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I can do this easily by myself	350	72	69	68
I have difficulty doing this myself	62	13	17	18
I can't do this by myself	76	16	14	14
Total	488	100	100	100
Missing	9			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The majority of respondents (72%) said that they usually managed to use the toilet without help, in line with previous years' results (69% in 2011/12 and 68% in 2010/11).

d. Do you usually manage to wash your face and hands by yourself?

Q16d Washing face and hands	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I can do this easily by myself	385	79	79	81
I have difficulty doing this myself	58	12	11	12
I can't do this by myself	46	9	9	7
Total	489	100	100	100
Missing	8			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

Over three-quarters of respondents (79%) said that they could easily wash their hands and face without help, in line with previous years' results (79% in 2011/12 and 81% in 2010/11).

Section 5: About your surroundings

Q17. How well do you think your home is designed to meet your needs?

Q17 Does your home meet your needs?	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
My home meets my needs very well	292	60	59	56
My home meets most of my needs	157	32	31	34
My home meets some of my needs	33	7	7	8
My home is totally inappropriate for my needs	8	2	3	2
Total	490	100	100	100
Missing	7			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

Over half of respondents (60%) said that their home met their needs very well, in line with previous years' results (59% in 2011/12 and 56% in 2010/11).

Q18. Thinking about getting around outside of your home, which of the following statements best describes your present situation?

Q18 Getting around in your local area	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
I can get to all the places in my local area that I want	169	34	39	35
At times I find it difficult to get to all the places in my local area that I want	119	24	26	24
I am unable to get to all the places in my local area that I	00	20	20	22
want	98		20	
I do not leave my home	101	22	20	19
Total	487	100	100	100
Missing	10			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The largest single percentage of respondents (34%) said that they could get to all the places in their local area that they wanted to, which is similar to previous years' results (39% in 2011/12 and 35% in 2010/11). However, this means that 66% of respondents had difficulty doing this, could not get to all the local places they wanted to go to, or did not leave their homes. One person commented:

"When I say I do not leave my home, I go out in my own wheelchair with my family, as I am unable to walk without support outside."

Section 6: About you

Q19. Do you receive any practical help on a regular basis from your husband or wife, partner, friends, neighbours or family members?

Q19 Practical help from others	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
a. Yes, from someone who lives in another household	169	57	53	53
b. Yes, from someone living in my household	271	34	40	40
c. No , I do not receive any help	92	19	20	18
Total	485	-	-	-
Missing	12			
Total	497			

^{*} Respondents could choose both 'yes" options if this applied to them, so percentages do not total 100. The percentages shown are those with the weighting factor applied.

Just over half (57%) of respondents said that they received practical help from someone who lived in another household, such as a friend or neighbour, which is in line with previous years' results (53% in both 2011/12 and 2010/11).

Q20. Do you buy any additional care or support privately or pay more to 'top up' your care and support?

Q20 Purchase additional care and support	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
Yes, with my own money	124	27	24	30
Yes, my family pays for this	34	7	8	6
No , I do not have any additional care or support	324	68	72	65
Total	476	-	-	-
Missing	21			
Total	497			

^{*} Respondents could choose both 'yes" options if this applied to them, so percentages do not total 100. The percentages shown are those with the weighting factor applied.

The majority of respondents (68%) did not buy in any additional care and support services, either with their own money, or with their family paying for it, which is in line with previous years' results (72% in 2011/12 and 65% in 2010/11). One person commented:

"We have a cleaner once a month."

Q21. Did you write the answers to this questionnaire by yourself or did you have help from someone else?

Q21 Did you have help?	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
Yes, I had help from someone living outside my household	148	36	32	33
No, I wrote the answers myself	100	30	30	31
Yes, I had help from a care worker	70	20	20	16
Yes, I had help from someone living in my household	170	14	18	20
Total	488	100	100	100
Missing	9			
Total	497			

^{*} The percentages shown are those with the weighting factor applied.

The largest percentage of respondents (36%), had help with writing their answers in the questionnaire from someone living outside their household, which is in line with previous years' findings (32% in 2011/12 and 33% in 2010/11). 30% did not have help from anyone else.

Q22. What type of help did you have?

Q22 Help with questionnaire	Frequency	Valid Percent* 2012/13 %	Valid Percent 2011/12* %	Valid Percent 2010/11 %
Someone else read the questions to me	211	44	43	41
Someone wrote down the answers for me	172	36	36	37
None , because I wrote the answers myself	134	28	27	31
I talked through the questions with someone else	125	26	23	26
Someone else translated the questions for me	73	15	11	14
Someone answered for me , without asking me the questions	40	9	7	7
Total	473	-	-	-
Missing	24	- -		
Total	497			

^{*} Respondents could choose as many options as applied to them, so percentages do not total 100. The percentages shown are those with the weighting factor applied.

The largest percentage of respondents (44%) had had someone else read the questions to them, which is line with previous years' results (43% in 2011/12 and 41% in 2010/11). Of some concern is the fact than 70 people (9%) had had someone else answer for them, without asking them the questions. This has been an issue in the two previous years, when 7% of people who returned questionnaires had had this done for them.

About the respondents

1. Types of questionnaire

There are four different questionnaires used in the survey. Please note that these do not correspond to the four strata, as the person's age does not determine what type of questionnaire they are sent; questionnaires are sent out based upon where the person lives and whether they have a learning disability. The percentages of people who responded using them are as follows:

Тур	pes of questionnaire	Number sent out	Number returned	% 2012/13 <u>response</u>	% 2011/12 response
1	Questionnaire for residents in their own				
	home	<i>759</i>	313	41	34
2	Questionnaire for residents in care homes	313	106	34	27
3	Questionnaire for adults with a learning disability in their own homes	138	72	52	36
4	Model questionnaire for adults with a learning disability in residential care	17	6	35	8
Tot	al respondents and non-respondents	1227	497	=	-

The majority of questionnaires returned were questionnaires sent to people receiving community-based services (living in their own homes). The highest response rate, 52%, was for adults with a learning disability living in the community.

2. Gender

Gender	Frequency	2012 / 13 %	2011/12 %	% in sample	% in population
Male	204	41	37	41	40
Female	293	59	63	59	60
Total	497	100	100	100	100

The majority of respondents were female (59%), in line with the proportions of men and women in the sample.

3. Age

Age groups	Frequency	2012 / 13 %	2011/12 %	% in sample	% in population
18-24	19	4	3	4	4
25-34	23	5	6	6	5
35-44	19	4	4	6	6
45-54	52	11	8	9	9
55-64	74	15	13	11	10
65-74	67	14	11	12	13
75-84	110	22	27	23	24
85 and over	133	27	29	28	28
Total	497	100	100	100	100

The single largest percentage of respondents were **aged 85 and over** (27%). The majority (67%) were aged 65 and over. The percentage of respondents in the different age groups was in line with the proportions of people in these groups in the sample.

4. Ethnic origin

Ethnic origin	Frequency	2012 / 13 %	2011/12 %	% in sample
White	464	94	96	94
Asian or Asian British	11	2	2	2
Black or Black British	2	0	1	1
Other	2	0	1	0
Not stated	7	1	1	2
Mixed	5	1	0	0
Chinese	3	1	0	1
Total	494	100	100	100
Missing	3	-	-	-
Total	497	-	-	-

The majority of respondents were from a White background (94%). The percentage of respondents in the different ethnic groups was in line with the proportions of people in these groups in the sample.

5. Religion

Religion	Frequency	2012 / 13 %	2011/12 %	% in sample
Christian	213	87	90	86
None	24	10	7	9
Muslim	4	2	2	3
Other	3	1	1	1
Buddhist	1	0	0	0
Hindu	1	0	0	0
Jewish	0	0	1	0
Total	246	100	100	100
Missing	251	-	-	1
Total	497	-	-	-

The majority of respondents about whom we had information on their religion said that their religion was Christian (87%). The percentage of respondents who said they followed different religions, or none, were in line with the proportions of people in these groups in the sample.

Primary client groups

Primary client groups	Frequency	2012 / 13 %	2011/12 %	% in sample	% in population
Physical disability, frailty and / or sensory		_	-	-	-
impairment	293	64	72	64	64
Mental health	100	21	11	21	19
Learning disability	76	13	15	13	15
Vulnerable people	12	2	1	1	1
Substance misuse	6	1	1	2	1
Total	497	100	100	100	0

The majority of people belonged to the client group "Physical disability, frailty and / or sensory impairment" (64%). The percentage of respondents in the different client groups were in line with the proportions of people in these groups in the sample.

6. Types of care services received by respondents

It is somewhat difficult to determine the extent to which respondents are representative of the wider population in terms of the services they received, as many respondents received more than one type of service (161 - 13% of the sample), giving many different possible combinations.

If we consider this in terms of the individual services and how many people receive them, the table below shows that the respondents were generally representative of the people in the sample in terms of how many of them received each type of service.

Type of care	Frequency	Percent %	% of people in the sample receiving this service	Difference: response / sample
Home care	239	48	44	4
Personal budgets	96	19	18	1
Residential care	78	16	19	-3
Equipment or home adaptations	64	13	13	0
Direct Payments	65	13	11	2
Day care	58	12	10	2
Professional support	48	10	12	-2
Nursing care	35	7	8	-1
Meals at home	19	4	3	1
Short-term residential care	1	0	1	-1
Other services	0	0	0	0

Appendix 1 – Questions asked, and information about respondents

Questions

Section 1: Overall satisfaction with your social care and support

1. Overall, how satisfied are you with the care and support services you receive?

Section 2: Your quality of life

- 2a. Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?
- 2b. Do care and support services help you to have a better quality of life?
- 3a. Which of the following statements best describes how much control you have over your daily life?
- 3b. Do care and support services help you in having control over your daily life?
- 4a. Thinking about your personal care, by which we mean being clean and presentable in appearance, which of the following statements best describes your situation?
- 4b. Do care and support services help you in keeping clean and presentable in appearance?
- 5a. Thinking about the food and drink you get, which of the following statements best describes your situation?
- 5b. Do care and support services help you to get food and drink?
- 6a. Which of the following statements best describes how clean and comfortable your home is?
- 6b. Do care and support services help you in keeping your home clean and comfortable?
- 7a. Which of the following statements best describes how safe you feel?
- 7b. Do care and support services help you in feeling safe?
- 8a. Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?
- 8b. Do care and support services help you in having social contact with people?
- 9a. Which of the following statements best describes how you spend your time?
- 9b. Do care and support services help you in the way you spend your time?

- 10. Which of these statements best describes how having help to do things makes you think and feel about yourself?
- 11. Thinking about the way you are helped and treated, and how that makes you think and feel about yourself, which of these statements best describes your situation?

Section 3: Knowledge and information

- 12a. In the past year, have you found it easy or difficult to find information and advice about support, services or benefits?
- 12b. Thinking about the care and support you receive, if you felt unsafe or were worried about something that had happened to you, who would you talk to?
- 12c. If you wanted to make a complaint about the care services you receive, do you know how to?
- 12d. If you wanted to make a complaint, which of the methods below would you be most likely to use?
- 12e. We want to develop an online complaints form so that people who want to complain about care services can complain using the Newcastle City Council website. If you wanted to make a complaint, would you use this method if it was available?

Note: This question was not used in the questionnaires (standard and easy read) for people in residential care.

Section 4: Your health

- 13. How is your health in general?
- 14. By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.
- a. Pain or discomfort
- b. Anxiety or depression
- 15. Please place a tick in the box that best describes your abilities for each of the following questions labelled from a to d.
- a. Do you usually manage to get around indoors (except steps) by yourself?
- b. Do you usually manage to get in and out of a bed (or chair) by yourself?
- c. Do you usually manage to feed yourself?
- d. Do you usually deal with finances and paperwork- for example, paying bills, writing letters by yourself?
- 16. Please place a tick in the box that best describes your abilities for each of the following questions labelled from a to d.
- a. Do you usually manage to wash all over by yourself, using either a bath or shower?
- b. Do you usually manage to get dressed and undressed by yourself?
- c. Do you usually manage to use the WC / toilet by yourself?
- d. Do you usually manage to wash your face and hands by yourself?

Section 5: About your surroundings

- 17. How well do you think your home is designed to meet your needs?
- 18. Thinking about getting around outside of your home, which of the following statements best describes your present situation?

Section 6: About you

- 19. Do you receive any practical help on a regular basis from your husband or wife, partner, friends, neighbours or family members?
- 20. Do you buy any additional care or support privately or pay more to 'top up' your care and support?
- 21. Did you write the answers to this questionnaire by yourself or did you have help from someone else?
- 22. What type of help did you have?
- 23. If you would like to tell us anything else about your life, about the services you receive, or about any of the issues raised in this questionnaire, please write this down in the space below.
- 24. Would you be happy to be invited to take part in more research?
- 25. Please tick this box if you would like to receive information about the findings of this survey.

Information known about the people in the sample (metadata)

- 1. Gender
- 2. Age
- 3. Ethnicity
- 4. Religion
- 5. Primary client group (physical disability, frailty and sensory impairment; mental health; learning disability; substance misuse; vulnerable people)
- 6. Care and support services being received:
 - a. Residential care
 - b. Nursing care
 - c. Day care
 - d. Meals at home
 - e. Short-term residential care (but not respite care)
 - f. Direct payment
 - g. Personal budget
 - h. Professional support
 - i. Equipment or adaptations
 - j. Other services

Appendix 2 – ASCOF Indicators

The data return sheet provided by the NHS Information Centre calculates the ASCOF Quality of Life Indicators as follows:

Weighted Results	Numerator	Denominator	Indicator	2011/12
(1A) Social care - related quality of life	93907.3	4895.3	19.2 out of a maximum possible 24.0 (80%)	19.4
(1B) The proportion of people who use services who have control over their daily life	4083.0	5195.7	78.6	79.7
(3A) Overall satisfaction of people who use services with their care and support	3201.0	5107.6	62.7	68.6
(3D) The proportion of people who use services and carers who find it easy to find information about services	2970.1	3921.1	72.0	80.3*
(4A) The proportion of people who use services who feel safe	3736.5	5216.8	71.6	71.7
(4B) The proportion of people who use services who say that those services have made them feel safe and secure	3833.1	5171.8	74.1	70.2

^{*} Note that this figure is not comparable to the 2012/13 figure, as the 2011/12 figure does not contain the views of carers.

ASCOF Definitions

(1A) Enhancing quality of life for people with care and support needs

This measure represents an average quality of life score for a person based on the responses of those that completed the Adult Social Care Survey. It is a composite measure using responses to questions from the survey covering eight domains: control, dignity, personal care, food and nutrition, safety, occupation, social participation and accommodation. These questions and the domains they cover are shown here:

Qn	Question	Domain
3a	Which of the following statements best describes how much control you have over your daily life?	Control
4a	Thinking about keeping clean and presentable in appearance, which of the following statements best describes your situation?	Personal care
5a	Thinking about the food and drink you get, which of the following statements best describes your situation?	Food

Qn	Question	Domain
6a	Which of the following statements best describes how clean and comfortable your home is?	Accommodation
7a	Which of the following statements best describes how safe you feel?	Personal safety
8a	Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?	Social life
9a	Which of the following statements best describes how you spend your time?	Occupation
11	Which of these statements best describes how the way you are helped and treated makes you think and feel about yourself?	Dignity

Numerator: Each respondent is assigned a score based on their answers to questions 3 to 9, and 11. Each of the questions has four answers which are equated with having either no unmet needs in a specific life area or domain, having needs adequately met, having some needs met and having no needs met. The scores are assigned as follows:

- No needs met (the last answer option for each question)	= 0
- Some needs met (3rd answer option)	= 1
- Needs adequately met (2nd answer option)	= 2
- No unmet needs (1st answer option)	= 3

The numerator is then a sum of the scores for all respondents who have answered questions 3 to 9 and 11. Those respondents who were sent the version of the questionnaire for people with learning disabilities will be treated in the same way, as this questionnaire has been designed to be equivalent to the non-learning disabilities version.

Denominator The number of respondents who answered all the questions 3a to 9a

and 11.

Exclusions Any respondents who failed to answer all the questions 3a to 9a and

11 are excluded from the calculation of the indicator. For example, a respondent who answered questions 3a to 8a and 11 but did not answer Q9a will be excluded from the indicator calculation.

The calculation table for 2012/13 is:

	No unmet	Needs adequately	Some	No needs	
	needs	met	needs met	met	Total
Q3a	1657.5	2197.3	877.3	163.1	4895.3
Q4a	2873.5	1804.5	217.3	0.0	4895.3
Q5a	3143.2	1462.8	279.6	9.6	4895.3
Q6a	3204.8	1527.8	141.8	20.8	4895.3
Q7a	3487.2	1170.6	155.5	82.0	4895.3
Q8a	2227.5	1645.5	835.4	186.8	4895.3
Q9a	1684.8	1743.7	1201.1	265.7	4895.3
Q11	2886.9	1631.6	335.0	41.7	4895.3
Total	21165.6	13183.8	4043.0	769.8	4895.3

Score	63496.7	26367.6	4043.0	0
000.0	00 10017		10 1010	•

Numerator	Denominator	1A
93907.3	4895.3	19.2

(1B) The proportion of people who use services who have control over their daily life

Enhancing quality of life for people with care and support needs.

People manage their own support as much as they wish, so that they are in control of what, how and when support is delivered to match their needs.

Numerator In response to Question 3, those individuals who selected the

response 'I have as much control over my daily life as I want and "I

have adequate control over my daily life".

Denominator All those who respond to the question.

(3A) Overall satisfaction of people who use services with their care and support

Ensuring people have a positive experience of care and support.

People who use social care and their carers who are satisfied with their experience of care and support services.

Numerator In response to Question 1, those individuals who selected the

response "I am extremely satisfied" or "I am very satisfied" and for the easy read version for those with learning disabilities, those individuals who selected "I am very happy with the way staff help me, it's really

good".

Denominator All those who responded to the question.

(3D) The proportion of people who use services and carers who find it easy to find information about services

Ensuring people have a positive experience of care and support.

People know what choices are available to them locally, what they are entitled to, and who to contact when they need help.

Numerator In response to Question 12, those individuals who selected the

response "Very easy to find" and "fairly easy to find".

Denominator All those who responded to the question.

(4A) The proportion of people who use services who feel safe

Safeguarding people whose circumstances make them vulnerable and protecting from avoidable harm.

Numerator In response to Question 7, those individuals who selected the

response "I feel as safe as I want".

Denominator All those who responded to the question.

(4B) The proportion of people who use services who say that those services have made them feel safe and secure

Safeguarding people whose circumstances make them vulnerable and protecting from avoidable harm.

Numerator In response to Question 7b, those individuals who selected the

response "yes".

Denominator All those who responded to the question.

Appendix 3 – Respondents' comments

132 people gave us their views, in response to the question: "If you would like to tell us anything else about your life, about the services you receive, or about any of the issues raised in this questionnaire, please write this down here." Of these, 10 commented only that they were completing the form on behalf of someone else, and they have been removed from the analysis. This section summarises the themes in respondents' comments and compares them to the previous year's survey findings. A full list of all comments is available on request from Louise Reeve in the Central Policy Unit at: louise.reeve@newcastle.gov.uk.

Theme	2012 / 2013	2011 / 2012
Happy with care and support services	27	21
Happy with care and support services in general	11 6	14
Happy with care workersHappy with residential care	6	7
Unhappy with aspects of care services • Unhappy with residential care	22 5	14
Description of what care does for the person receiving it	13	11
Friends and family, including spouses, provide support	10	10
Cannot go out alone, have to have help to do this	6	3
Person needed help to complete questionnaire	6	-
Would like more care and support	6	9
Equipment helps with aspects of life such as getting around and bathing	5	-
Have severe sensory impairment	5	-
Need care services for all aspects of life	5	-
Changing care companies has led to decline in service standards	4	-
Care services help with social life and accessing information	3	-
Concerned about implications of financial cuts to services	3	2
Ability to do tasks mentioned in survey varies from day to day	2	-
Care workers do not do everything that is asked of them	2	-
Care workers need to be reliable	2	2
Concerned at possibility of services closing	2	-
Could not answer due to dementia	2	-
Happy with my life	2	2
Have severe mobility issues	2	-
Limitations caused by illness or disability is frustrating and depressing	2	-
Sickness cover for social workers needs to be improved	2	-
Sometimes have problems getting information in a suitable format (such as large print or Braille)	2	-
Waiting for services	2	-
Would like to have more social activities	2	-

^{*} Several people commented on more than one aspect of care, support, and quality of life – hence the number of comments is larger than the number of people who replied to this question.

Comparison with 2011/2012

The main themes in respondents' comments in 2011/12 were:

- Happy with care workers / support services
- Unhappy with aspects of care services
- Description of care received
- Care is mainly provided by family carers
- Would like more care and support services

and similar comments were received in 2010/11. The themes in the list above were, again, the most common in 2012 / 2013, and we also received comments from people who said they could not go out alone without help, and who needed help to complete questionnaire.

As in 2011/12, we received comments about people's concern about cuts to service, or possible closing-down of facilities, for example:

"My parents are doing all they can to make sure Castledene remains my respite centre, because they know how stressed and unhappy I would be if I went somewhere else."

"I am concerned that when the Independent Living Fund stops this will impact immensely on my quality of life."

Happy with care workers / support services (27 comments)

This was also the most common theme in respondents' comments in 2011/2012 (21 comments) and 2010/11 (30 comments). Comments included:

"Social Services helped me when I needed the help to get up and down the stairs in my home, with a Stannah stairlift. All I can say is that thanks to them my standard of life is much improved."

"My life has improved greatly since I went into residential care."

"I am bedbound in my care home. I would just like to say this is a wonderful home. The staff are so very kind and caring, and show such dignity and respect for all people in here. The food is excellent, all aspects of the home are always so very clean and neat."

"My care worker is first class, nothing is too much trouble for her."

"The care and support provided to me during the very difficult life I have led means a lot to me. I am most grateful for all the care, time and empathy provided to me. Without this help, I would have been dead decades ago."

Unhappy with aspects of care services (14 comments)

This was also a common theme in respondents' comments in 2011/12 (14 comments) and 2010/11 (21 comments). Themes in people's comments included:

- Unhappy with meals at home service
- Unhappy with food in residential care
- Unhappy with mental health support services
- Unhappy with quality of residential care

Comments included:

"I don't feel I get enough support from carers in my home. They do very little that is asked of them and I don't get my full support that is mentioned in my care plan, as I only get 20 minutes, which is not long enough as there are a lot of tasks left."

"I have a small concern that other residents wander in and out of my mam's room, it happens when I am there, so it must happen when I am not."

"I have had times when my carer has not turned up and I have had to ring the agency, then ask my daughter for help."

"I stopped having care from the council because the carers never came on time and were not allowed to help me, as I need to be supported whilst standing and lifted at times. I now have a private care worker once a week."

"Meals at home were cold and the portions were small, I was not happy with them."

"Since the changeover of care companies nothing has run smoothly, despite my daughter chasing them up."

"The problem I find is the agencies ...they send different people all the time, with dementia this is a no-no!"

"There is no dedicated chef to prepare meals, the food in residential care could be better."

Description of what care does for the person receiving it (13 comments)

13 people described what their care services provided for them, such as:

- Allowing their regular carer to have a break.
- Helping with housework and cleaning
- Helping to get food

Friends and family, including spouses, provide support (10 comments)

10 people commented on how their family and friends provided them with support, for example helping with:

- Collecting benefits or pension payments, and paying bills
- Dealing with problems
- Shopping

One person, who helped their mother to complete the questionnaire, commented:

"I am my mother's carer. She has vascular dementia. Thank God I and my family are here to take care for her. I feel sorry for those who have no family!"

Cannot go out alone, have to have help to do this (6 comments)

Several people commented on this, probably because we ask several questions in the survey about getting around inside and outside the home. Comments included:

"I can get around my flat with a trolley by myself, but I need a wheelchair and a relative or care worker with me outside."

"I am too weak to go out alone. This is really difficult. I cannot go out unaided, I have to have someone push my chair as the electric one is for use only inside the house."

Person needed help to complete questionnaire (6 comments)

Six people made comments on this, sometimes made by the person who helped them complete the questionnaire, for example:

"[The person who was sent this questionnaire] has expressive aphasia and required help to complete the questionnaire."

"I need everything broken down into small pieces of information in order to understand. I am unable to read and fill in the questionnaires on my own."

Would like more care and support services (6 comments)

We also received nine comments about this in 2011/12 and 2010/11. Comments included:

"I do have a reasonable care package but could do with extra care, as I go a long time without food or drink in the day."

"I need overnight stays as I find going to the commode very unsteady and fall quite a lot."

"It would be a good arrangement to have a permanent help, such as a housekeeper paid by the client at a reasonable charge, possibly subsidised to allow persons to live in their own home. This would reduce costs to the city council caused by using care homes, which must be costly to maintain, especially in these days of major cutbacks."

Appendix 4 Social Care User Experience Survey 2012/13 Comments Themes – Word Cloud

The diagram below is a "word cloud", a representation of how often each theme was mentioned in respondents' comments. The themes which were mentioned most often appear in larger text, proportional to how often they appeared. (For more information about word clouds, please see the Word It Out website: http://worditout.com/).

Completed form on behalf of person it was sent to

Happy with care and support services Cannot go out alone, have to have help to do this Happy with care workers

Unhappy with aspects of care services

Unhappy with residential care Would like more care and support

Happy with residential care Have severe sensory impairment

Friends and family provide support
Person needed help to complete questionnaire

Description of what care does for the person

Changing care companies has led to decline in service standards