

Newcastle People Directorate: Social Care User Experience Survey 2018 / 2019



Policy and Communications Team Assistant Chief Executive's Directorate

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Introduction

Purpose of the survey

This report presents the findings for Newcastle City Council from the statutory national 2018/19 Adult Social Care Services User Experience Survey, which has been 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:

"Data collected through the Personal Social Services Adult Social Care Survey (ASCS) by local authorities are sent to NHS Digital and are used as the basis of analyses that are included in national level Official Statistics reports. Data are also used to populate several measures in the Adult Social Care Outcomes Framework (ASCOF). These data are expected to be used to inform policy and decision-making at both the local and national level, and to improve care, services and outcomes for local populations."

This survey updates the findings from the earlier 2010/11, 2011/12, 2012/13, 2014/15, 2015/16, 2016/17 and 2017/8 Adult 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.57.

This report focuses upon the key findings from both the mandatory questions and our own questions from the 2018/19 survey, and how they compare to the 2010/11, 2011/12, 2012/13, 2013/14, 2014/5, 2015/16, 2016/17 and 2017/18 surveys. A subsequent report will compare the findings for Newcastle to those for the UK in 2018/19, once this information is available.

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¹ The NHS Digital website is here: https://digital.nhs.uk/data-and-information/datacollections-and-data-sets/data-collections/social-care-user-surveys/social-careuser-survey-2018-19 (URL dated 05 June 2019).

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 2018 (the "eligible population"). The sample was extracted on 14th November 2018. 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. In 2018/19, as with previous years, 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 the previous survey in 2017/18. Out of a total of **4,113** people in the eligible population, we drew a total sample of **1,293**. 283 people in the survey were replacements for people in the original survey sample who had been removed from the sample on the advice of a care home manager, due to incapacity to give consent to take part.

Questionnaires were sent out on 19 February 2018, with reminders going out on 5 March. This is later than ideal, as the first questionnaires are intended to be sent out in January but was unavoidable due to the work commitments of the analyst and Digital Print. The fieldwork period for the entire survey was 19 February to 25 May 2018. 31.5% responded to the questionnaire (compared to 69% in 2017/18 and 87% in 2016/17), with 28.8% responding to the original request and a further 2.7% responding to the reminder.

Responses and margin of error

We received **407** returned questionnaires out of **1,293** sent out, giving a response rate of **31.5**%. This response rate gives a margin of error² for the entire survey of **+/- 4.93** percentage points, given that the total number of service users we drew our random sample from was 4,113. This is inside 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 generally representative of the entire population of 4,113 people who are receiving care and support services from Newcastle City Council, to within 4.93 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 41%, so the "true" figure for the population as whole lies between 35.9% - 45.9% (figures have been rounded).

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.

Equality and diversity

In 2018, everyone who took part in the survey did so by returning a questionnaire. There were no face-to-face interviews undertaken. Nearly 8 out of 10 had help from another person, such as a friend or family member, to complete the questionnaire (see p.48 for details).

We strove to ensure that everyone could 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 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 2018/19 there were 26 people known to have sensory impairments (not including people requiring large print - 53). Where possible, we checked with their support workers 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. Only one person asked for the questionnaire in Braille format. There were no requests for 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 (there was also the option for them to participate by having a friend or family member translate the printed form for them, and record their answers). No-one 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 take up this option.

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 Linda Gray, Service Manager in People 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

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. As in previous years, the most common ways in which service users said that care and support services helped them were either with the quality of their lives, with control over their daily lives, or with their personal safety. This section presents statistically significant differences between the 2017/18 and 2018/19 results.

An overview

Most service users in the survey were satisfied with their care and support services, and with their quality of life. For each question about people's quality of life, such as getting food and drink, having enough social contact with others, most 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 (even though the sampling method changed in 2014/15). Most respondents said that care and support services helped with these aspects of their lives.

Respondents were generally quite positive about the ease of finding information or advice. The most popular ways of finding out information about care and support services were by letter or face-to-face. The majority said that they felt they knew how to make a complaint could do so if they wanted to. Complaining by telephone or via a representative, such as a family member, was the preferred method for over half of respondents, as it was in previous years.

When asked who they would talk to if they felt unsafe or were worried about something that had happened to them, just under half of respondents replied that they would speak to a family member. The largest percentage of the people in the survey said that their health was fair. However, half said that they had moderate pain or discomfort, and half also said that they were either moderately or extremely anxious or depressed.

Two thirds of people could get around indoors, get in and out of bed, and most people could feed themselves without any assistance. A third of people either had difficulty doing this or could not do so without help. Similarly, the two thirds could use the toilet, and most could wash their hands and face without assistance. Four out of ten either had difficulty with getting dressed and undressed, and three out of ten had difficulty washing all over. Most people responded that they had difficulty dealing with their finances and paperwork or could not do these actions at all without help.

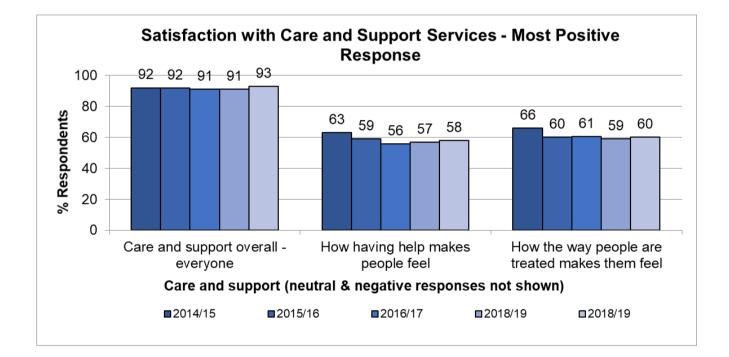
Two thirds of people thought that their home either met their needs very well or that it met most of their needs. A third said that they could get to all the places in their local area that they wanted to; however, the majority either found it difficult to get to all the local places they wanted to, were unable to do this, or did not leave their homes.

Most people did not buy in extra care and support, but the 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). Most people thought that Newcastle City Council care and support services had stayed the same over the previous year.

Key Findings – Differences compared to the previous year

Satisfaction with Services

- ASCOF 3A Overall satisfaction everyone: 69% of all service users replied that they were 'extremely' satisfied in response to this question compared to 68% in 2017/18 and 62% in 2016/17. This is in line with earlier years' responses and is not a statistically significant difference.
- ASCOF 3A Overall satisfaction people with a learning disability: A lower number (83%) of service users with a learning disability replied with the most positive response: "I am very happy with the way staff help me, it's really good" compared to 85% in 2017/18. It should be noted that the total number of people with learning disabilities in the survey is relatively small, therefore this percentage can change from year to year.

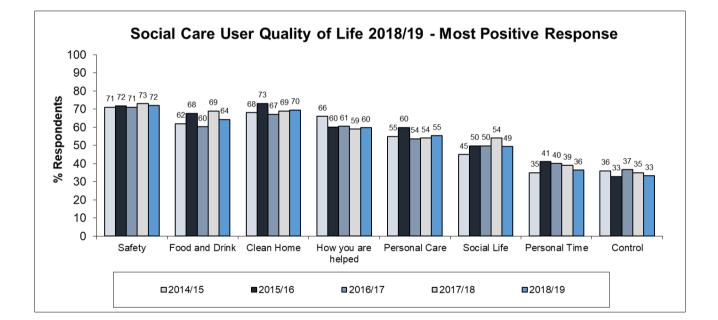


Quality of Life

- Quality of life: 37% of service users with a learning disability replied, "My life is really great", compared to 38% in 2017/18. This is not a statistically significant difference. There was also a decrease in the percentage replying: "My life is mostly good": from 43% in 2017/18 to 38% in 2018/9.
- Food and drink: There is a decrease in the number of respondents (64%) saying that they "get all the food and drink they like when they want", compared to 69% in 2017/18. Those respondents replying "I get adequate food and drink" increased from 25% to 32% in 2018/19.

Overall

As shown in the chart below, in 2018/19, the percentages of respondents giving the most positive response to the questions were generally like previous years. There is an increase in the percentage of people who responded with the most positive answer in having a clean home, how they are helped and personal care, yet a decrease in getting all the food and drink they want, social life, personal time and being in control of their daily life.



Information and complaints

• Making a complaint: A lower percentage of respondents say that they know how to make a complaint and feel that they can (61%), compared to 72% in 2017/18 and 62% in 2016/17.

Health and personal autonomy

• **Pain and discomfort**: 38% of respondents say that they do not have pain and discomfort compared to 39% in 2017/19.

ASCOF Indicators

Quality of Life Indicator

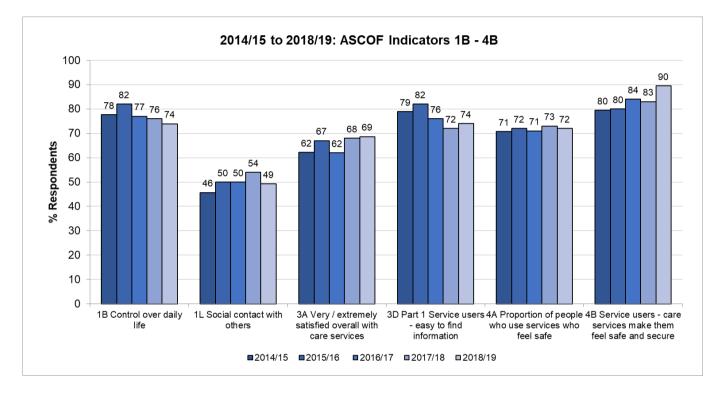
Newcastle City Council's score for the ASCOF 1A indicator about people's overall quality of life was:

ASCOF 1A

19.2 = out of a possible maximum of 24.0 **80.0**% = of the maximum possible score

expressed as a percentage:

Looking at previous years, in 2017/18 the score was 19.2, in 2016/17 it was 19.4 and 19.7 in 2015/16. The other ASCOF indicators are shown in the chart below:



In **2018/19**, only one indicator was significantly different to the previous year. There has been an increase in social care users who feel that care services make them feel safe and secure (ASCOF 4B), increasing from 83% in 2017/18 to 90% in 2018/19 and an increase of 10% over the last five years.

- ASCOF 1B 74% of Care and support service users feel they have control over their daily lives, compare to 76% in 2017/18
- ASCOF 1L 49% of users have social contact with others, a decrease from 54% in 2017/18 yet in-line with previous years.
- ASCOF 3A 69% of respondents are extremely or very satisfied with their social care and support services overall, compared to 68% in 2017/18 and 62% in 2016/17.
- ASCOF 3D part 1 74% of social care users say it is easy to find information about services and benefits, compared to 72% in 2017/18.
- **ASCOF 4A** there is a 1 percentage point decrease in the proportion of people who use services who **feel safe**, from 73% in 2017/18 to 72% in 2018/19.

• **ASCOF 4B** – the proportion of people who use services who say that those services have made them **feel safe and secure**: 90%, a 7 percentage points increase from the previous year. This is recognised as a significant increase.

Action Points

Areas which may require attention are as follows:

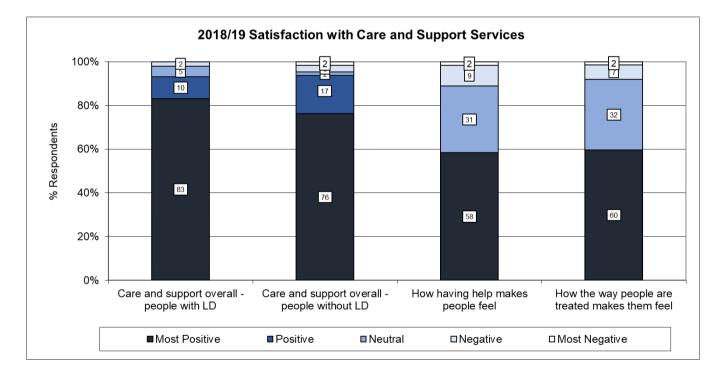
- **Control over daily life**: 26% said that they had either some control over their daily life but not enough, or no control at all. This question had the lowest "most positive" response of all questions about people's quality of life with only 34% of respondents saying that they felt that they had control of their life.
- **Depression or anxiety**: Half of the respondents (50%) said that they had either moderate (42%) or extreme (8%) depression or anxiety.
- Feeling Safe: 5% of respondents don't feel safe in their home, with 1.4% of respondents not feeling safe at all.
- Getting around outside the home: 7 out of 10 (71%) of people in the survey either found it difficult to get to all the places in their local area that they wanted to or could not get to all the local places they wanted to. Over a quarter (26%) said that they did not leave their homes.
- **Health**: Only 38% of people in the survey described their health as good or very good. 21% described it as bad or very bad, a 2 percentage points increase from 2017/18.
- **Pain or discomfort**: Over two-thirds of respondents (62%), said that they either had moderate or extreme pain or discomfort.
- **Personal time**: Over a third (33%) of respondents 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 second lowest "most positive" response of all questions about people's quality of life with only 37% of respondents saying that they could do all the things they wanted to do.
- Social contact with people: 19% of respondents said that they had either very little social contact with people, or not enough contact, with 6% having little social contact and feeling socially isolated.
- Think and feel good about yourself: 11% of respondents felt that they way they are helped either sometimes undermines the way they think and feel about themselves (9%) or completely undermines the way they think and feel about themselves (2%).
- **Taking part in the survey**: 11% 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.16. A full list of the questions asked can be found in Appendix 1 on p.57.

Satisfaction with care and support services

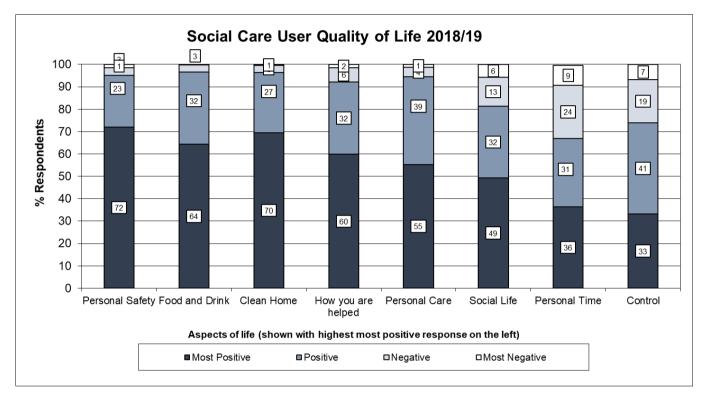
- 76% (a 12 percentage points increase from last year) of respondents without learning disabilities were extremely or very satisfied overall with the care and support they receive³. Of people with learning disabilities, 83% replied "I am very happy with the way staff help me, it's really good" (2 percentage points decrease). This is summarised in the chart below. The figure for everyone in the survey, both with and without learning disabilities, was 69%, an increase of 1 percentage point from 2017/18.
- 89% (a 3 percentage points increase from 2017/18) said either that **having help** made them think and feel better about themselves (58%) or that it did not affect how they thought about themselves (31%).
- 92% (90% in 2017/18) said that **the way they were helped** and treated either made them feel better about themselves (60%) or did not affect how they felt about themselves (32%).



³ People with a learning disability received a version of the questionnaire in which the options were different.

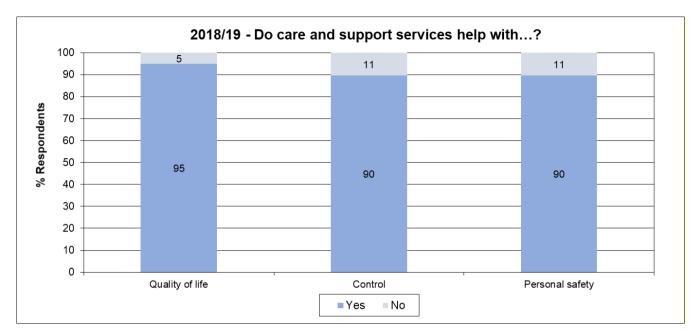
Quality of life

29% (3 percentage points more than last year) 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" (26%) are included, this gives a total of 55% (a 2 percentage points increase from 2017/18). Of people with learning disabilities, 37% replied "My life is really great" and 38% replied "My life is mostly good". 95% of all respondents said that care and support services helped them to have a better quality of life, an increase of 3%.



- People receiving care in a **community setting** (both with and without learning disabilities) were asked if they thought they had enough **choice** over the social care and support services they receive. 66% (3 percentage points down from last year, although not a statistical significance) said they had enough choice, 29% (8 percentage points increase from 2017/18) said they did not have enough choice, and 5% said they did not want or need choice.
- 74% (2 percentage points decrease from 20171/18) of all respondents said that either they had as much control as they wanted over their lives (33%) or adequate control (41%). The chart above shows respondents' relative levels of happiness with different aspects of their lives.
- 55% (1 percentage point more than last year) said that they felt **clean** and could present themselves the way they liked.
- 64% (5 percentage points decrease from last year) said that they got all the food and drink they liked when they wanted.
- 70% said that their **homes** (including care homes for people in residential care) were as **clean** and comfortable as they liked.
- 72% (1 percentage point down from 2017/18) said that they felt as **safe** as they wanted.

- 81% of people said that either they had as much **social contact** as they wanted with people they liked (49%) or that they had adequate social contact (32%).
- When people were asked about how they **spent their time**, 67% (4 percentage points decrease from 2017/18) said that they were either able to spend their time as they wanted (36%), or that they could do enough of the things they valued and enjoyed (31%).



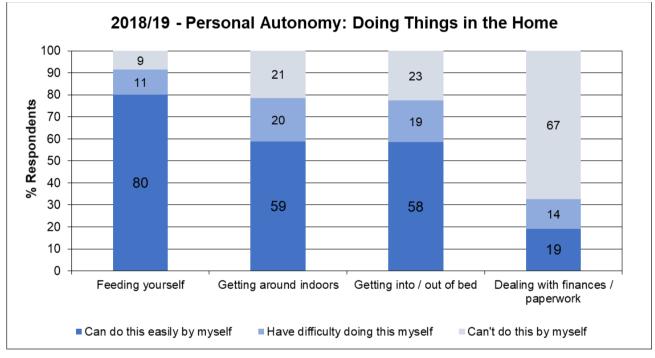
Information, safeguarding, and complaints

- We also asked if people had encountered problems seeking information or advice about services. 20% of respondents had never tried to find information or advice about support, services or benefits. 74% responded saying that they found it either fairly easy or very easy.
- We asked people about their **preferred method of receiving information** about care and support services, benefits, and so on. Over half (52%) said they preferred to receive information by letter, followed by 44% saying they preferred to receive it by leaflet/handbook then 42% preferring face to face.
- 78% respondents said that if they were worried about something that had happened to them, or they felt unsafe, they would speak to a **family member**.
- Two thirds of respondents (61%) said that they both knew how to make a **complaint** and felt they could do this if they wanted to. 19% said that they knew how to make a complaint but did not feel like they wanted to.
- Almost half of respondents (47%) said that they would **make a complaint** by telephone, with the next two most popular options being either complaining via an advocate (39%) or in person (26%).

Health and Personal Autonomy

Health

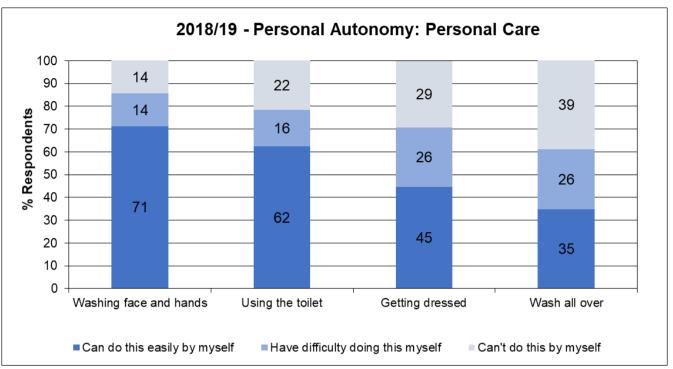
- The largest percentage of respondents (41%) described their health as "fair".
- Most respondents (62%) said that they had moderate (50%) or extreme (13%) pain or discomfort.
- Over two thirds of all respondents (62%) said that they had either **moderate** (50%) or **extreme** (13%) **anxiety** or depression.



Doing things in the home

- 8 out of 10 of respondents (80%) could easily feed themselves without help.
- Nearly two-thirds of respondents (59%) said that they could get around easily **indoors** by themselves without help.
- Nearly two thirds of respondents (58%) could easily get in and out of **bed** or a chair by themselves without help.
- 67% of respondents said that they could **not** deal with **finances** or paperwork without help.

Personal Care



- Around three-quarters of respondents (71%) said that they could easily **wash** their hands and face without help.
- Over two thirds respondents (62%) said that they usually managed to use the **toilet** by without help.
- Just under half of all respondents (45%) said that they could easily get **dressed** and undressed by themselves without help.
- 39% of respondents said that they **could not wash all over** by themselves without help.

Home, Local Area, Extra Care Services and Comments

- Most respondents (64%) did not buy in any additional care and support services.
- Over half of respondents (57%) said that their home met their needs very well.
- 41% **received practical help** on a regular basis from someone living in their household (such as a partner or parent). 53% **received practical help** on a regular basis from someone living in another household.
- 29% of respondents said that they could **get to all the places in their local area** that they wanted to. However, 71% of respondents had difficulty doing this, could not get to all the local places they wanted to go to (44%), or did not leave their homes (27%).
- When asked for their views, many respondents made positive comments about their care and support services, although there were some who reported having negative experiences. Others commented on their quality of life, or on services they would like to receive one issue raised was that some respondents would like to have control of their own money. Some comments were received from family carers who had helped the person they care for to complete the questionnaire.

Taking part in the survey

- The largest percentage of respondents (34%), **had help** with writing their answers in the questionnaire from someone living outside their household. 18% did not have help from anyone else.
- 43%, of respondents had **someone else read** the answers to them. Of some concern is the fact that 40 people (11%) had had someone else answer for them, without asking them the questions.

About the respondents

The **profile** of the respondents, in terms of whether they receive care in the community or in a residential or nursing 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 **+/-4.6 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'.

Most respondents:

- Were from a **white** ethnic background (95%)
- Described their religious beliefs as Christian (79%)
- Received care and support services in a **community setting** (62%).
- Were **female** (57%)
- Were receiving care and support services for the primary support reason **physical support** (43%).
- Were receiving care and support services via Local Authority (LA)-managed personal budget (43%).

Frequency Tables

Strata response rates

As described above in the Methodology section (p. 2), 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

Strata	Number of respondents	% 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	110	27	22	24
2. Non-LD, 18-64	63	15	17	18
3. Non-LD, 65+, In Residential Care	86	21	34	25
4. Non-LD, 65+, Community Based Services	148	36	27	34
Total	407	100	100	100

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

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 (such as stratum 3) 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 with previous years, 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.

From the 2014/15 survey onwards, the weighting has been calculated as follows (from the official guidance):

"For 2014-15 onwards, a unique set of weights are calculated for each question by dividing the eligible population, at stratum level for the local authority (as before), by the count of usable responses to that question, at stratum level for the local authority. Although the impact of the change is minimal, this calculation produces more accurate results."

The actual numbers of respondents have been included in the tables below for reference, but please note that, the percentages shown in the tables in the rest of the report are the **weighted percentages**. (This means that any percentages calculated from the numbers of respondents in the tables will not be exactly the same as the weighted percentages which are used for reporting.) Only the weighted percentages should be quoted.

Strata	No. in population	No. in sample	No. respondents	Response rate %	Q1 no of answers	E.g. of weight for Q1
1. LD – All ages	993	284	110	27	101	9.832
2. Non-LD, 18-64	722	222	63	15	63	11.460
3. Non-LD, 65+, In Residential Care	1009	434	86	21	86	11.733
4. Non-LD, 65+, Community Based Services	1389	353	148	36	146	9.514
Totals	4113	1293	407	100	396	-

An example of response rates for each stratum and weightings for Q1 are as follows:

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?

All respondents in five bands

Q1 Overall satisfaction with care and support	No.	2018 / 19 %*	2017 / 18 %*	2016 / 17 %*	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
Extremely or very satisfied / Very happy with the way staff help me, it's really good	271	69	68	62	67	67	64	63	69	69
Quite satisfied / Quite happy with the way staff help me	97	24	23	29	25	25	28	29	24	27
Neither satisfied nor dissatisfied / The way staff help me is OK	17	4	5	6	5	5	5	6	5	3
Quite dissatisfied / Don't think the way staff help me is that good	9	2	2	2	2	2	2	2	1	1
Extremely or very dissatisfied / Think the way staff help me is really bad	2	0.5	2	1	1	1	1	1	1	0
Total	396	100	100	100	100	100	100	100	100	100

* Percentages shown are those with a weighting factor applied.

This question is designed so that the responses for people with and without learning disabilities can be combined into five satisfaction bands. As shown above, most service users (69%) were extremely or very satisfied with their social care and support services, which is significantly higher than two years ago (62%). 11 service users replied that they were quite, very or extremely dissatisfied with care and support services.

People without a learning disability

Q1 Overall satisfaction with care and support	No.	2018 / 19 %*	2017 / 18 %*	2016 / 17 %*	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
Extremely & Very satisfied	48	76	64	59	63	60	62	59	68	68
Quite satisfied	11	18	27	33	28	30	29	32	25	25
Neither satisfied nor dissatisfied	1	2	6	5	5	6	5	7	5	5
Quite dissatisfied	2	3	2	3	3	3	3	2	1	1
Extremely & Very dissatisfied	1	2	2	1	2	0	1	0	2	2
Total		100	100	100	100	100	100	100	100	100
People without a learning disability	63									
Missing	0									
Total	407									

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

76% of respondents without a learning disability were extremely or very satisfied overall with their care and support services, compared to 64% in 2017/18 and 59% in 2016/17. A further 18% were quite satisfied.

4 service users replied, "neither satisfied nor dissatisfied", "quite dissatisfied", "very dissatisfied" or "extremely dissatisfied".

People with a learning disability

Q1 Overall satisfaction with care and support – people with a learning disability	No.	2018 / 19 %*	2017 / 18 %*	2016 / 17 %*	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I am very happy with the way staff help me, it's really good	84	83	85	73	82	69	77	83	76	70
I am quite happy with the way staff help me	10	10	10	18	14	28	20	13	18	25
The way staff help me is OK	5	5	2	9	4	3	3	3	7	5
l don't think the way staff help me is that good	2	2	2	0	0	0	0	0	0	0
I think the way staff help me is really bad	0	0	0	0	1	0	0	1	0	0
Total respondents		100	100	100	100	100	100	100	100	100
People with a learning disability	110									
No response	9									
Total	407									

* 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 85% in 2017/18 and 73% in 2016/17. Two respondents replied with 'I don't think the way staff help me is that good'.

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?

Q2a Quality of life	No.	2018 / 19 %*	2017 / 18 %*	2016 / 17 %*	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
So good, it could not be better or very good / My life is really great	113	29	28	29	31	39	30	30	32	35
Good / My life is mostly good	119	30	32	32	32	24	32	30	39	28
Alright / My life is OK, some good things, some bad things	128	32	31	29	27	29	31	32	39	30
Bad / My life is mostly bad	25	6	7	7	6	6	6	6	6	6
So bad, it could not be worse or very bad / My life is really terrible	9	2	3	3	3	3	2	2	4	1
Total	394	100	100	100	100	100	100	100	100	100
Missing	13									
Total	407									

All respondents in five bands

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

This question is designed so that the responses for people with and without learning disabilities can be combined into five bands describing people's quality of life. As shown above, most service users said that their quality of life was either very good, or quite good: 59%, which is similar to 2017/18 (60%). 34 service users (20 more than 2017/18) said that their quality of life was very or extremely bad.

In the five years since the 2014/15 survey, the percentage of service users who said their life was really great has decreased by 10 percentage points from 39% to 29%, and the percentage of service users who said their life was mostly good has increased from 24% to 30%.

People without a learning disability

Q2a Quality of life	No.	2018 / 19 %*	2017 / 18 %*	2016 / 17 %*	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
So good, it could not be better or Very Good	18	29	26	29	30	31	28	29	28	27
Good	16	26	27	26	29	24	31	28	29	29
Alright	18	29	35	33	30	35	33	34	32	35
Bad	7	11	9	9	8	7	6	6	7	8
Very bad or so bad, it could not get any worse	3	5	3	4	3	4	2	3	5	1
Total	62	100	100	100	100	100	100	100	100	100
Missing	1									
People without a learning disability	63									
Total	407									

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

29% 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 or was very good. This is 3% higher than in 2017/18. 26% replied that it was "good" and 29% "alright".

10 people replied their quality of life was either "bad", "very bad" or "so bad it could not be worse", compared to 32 in 2017/18.

People with a learning disability

Q2a Quality of life – people with a learning disability	No.	2018 / 19 %*	2017 / 18 %*	2016 / 17 %*	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
My life is really great	38	37	38	28	39	40	38	33	61	38
My life is mostly good	39	38	43	54	43	33	37	46	28	41
My life is OK, some good things, some bad things	24	23	17	18	16	25	19	19	11	21
My life is mostly bad	2	2	2	0	1	1	2	0	0	0
My life is really terrible	0	0	0	0	1	0	5	1	0	0
Total respondents	103	100	100	100	100	100	100	100	100	100
People with a learning disability	110									
Missing	7									
Total	407									

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

37% of respondents with a learning disability thought that their lives were really great (38 people), compared to 38% in 2017/18 and 28% for 2016/17. 38% of respondents with a learning disability thought that their lives were mostly good which compares to 43% in 2017/18. No-one replied, "My life is really terrible".

Q2b Care and support services help with quality of life	No.	2018 / 19 %*	2017 / 18 %*	2016 / 17 %*	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %
Yes	367	95	92	94	92	92	94	91	89
No	20	5	8	6	8	8	6	9	10
Total	387	100	100	100	100	100	100	100	100
Missing	20								
Total	407								

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

95% of respondents said that care and support services helped them to have a better quality of life, compared to 92% in 2017/18.

Q2c. How much choice do you have over the social care and support services you receive?

Q2c Choice over care and support services	No.	2018 / 19	2017 / 18	2016 / 17*
I do have enough choice over care and support services	128	66	69	66
I don't have enough choice over care and support services	56	29	21	28
I don't want or need choice about care and support services	10	5	10	6
Total	194	100	100	100
Missing	10			
This question does not apply	203			
Total	407			

* This question was not asked before 2016/17 and is only included in the questionnaire versions sent to people receiving care services in a community setting.

Just over two-thirds of respondents (66%) said that they had enough choice over their social care and support services, compared to 69% in 2017/18.

Q3a Control over daily life	No.	2018 / 19 %*	2017 / 18 %*	2016 / 17 %*	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
l have as much control over my daily life as I want	131	33	37	37	33	36	36	34	36	31
l have adequate control over my daily life	160	41	40	40	49	41	40	45	43	45
l have some control over my daily life but not enough	75	19	19	19	15	18	19	18	16	20
l have no control over my daily life	25	7	4	4	3	5	5	4	4	3
Total	391	100	100	100	100	100	100	100	100	100
Missing	29									
Total	407									

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

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

The largest single percentage of respondents, 41%, said that they had adequate control over their daily life, which is in line with the results of the last two surveys. 33% had as much control as they wanted over their lives. 26% had either some control over their lives but not enough, or no control at all, which is 2 percentage points more than 2017/18.

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	No.	2018 / 19 %*	2017 / 18 %*	2016 / 17 %*	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %
Yes	337	90	88	92	91	90	89	84	86
No	41	10	12	8	9	10	11	16	14
Total	378	100	100	100	100	100	100	100	100
Missing	29								
Total	407								

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

90% of respondents said that care and support services helped them to have control over their lives, compared to 88% in 2017/18 and 92% in 2016/17. This is not a significant difference compared to the previous year.

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	No.	2018 / 19 %	2017 / 18%	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I feel clean and am able to present myself the way I like	221	55	54	54	60	55	59	59	62	58
l feel adequately clean and presentable	153	39	39	43	34	38	36	36	33	38
l feel less than adequately clean or presentable	17	4	6	4	6	4	4	5	4	4
l don't feel at all clean or presentable	5	1	1	0	1	1	1	0	1	1
Total	396	100	100	100	100	100	100	100	100	100
Missing	11									
Total	407									

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

Just over half of respondents, 55%, said that they felt clean and were able to present themselves the way they liked. This compares to 54% in the previous two surveys. 39% felt adequately clean, 22 people said they felt less than adequately clean, five of which replied, "I don't feel at all clean and presentable".

Q5a Food and drink	No.	2018 / 19 %	2017 / 18%	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
l get all the food and drink I like when I want	254	64	69	60	68	62	66	65	72	65
l get adequate food and drink at okay times	123	32	25	36	28	29	29	30	23	31
l don't always get adequate or timely food and drink	12	3	6	4	4	6	5	6	4	3
I don't always get adequate or timely food and drink, and I think there is a risk to my health	1	0.3	1	0	1	2	1	0	2	1
Total	390	100	100	100	100	100	100	100	100	100
Missing	17									
Total	407									

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

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

Over two thirds of people (64%) said that they got all the food and drink they liked when they wanted, which is a decrease compared to 69% in 2017/18. 32% said that they got adequate food and drink at okay times (a 7 percentage points increase from 25% in 2017/18), and 13 people said that they did not get adequate or timely food and drink. The one person 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 staff in Newcastle People Directorate, so this could be discussed with them.

Q6a Cleanliness of home	No.	2018 / 19 %	2017 / 18%	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
My home is as clean and comfortable as I want	273	70	69	67	73	68	70	65	67	64
My home is adequately clean and comfortable	102	27	26	28	24	29	26	32	29	31
My home is not quite clean or comfortable enough	12	3	5	5	3	3	3	3	4	4
My home is not at all clean or comfortable	2	1	0	0	1	1	1	0	0	1
Total	389	100	100	100	100	100	100	100	100	100
Missing	18									
Total	407									

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

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

Most service users, 70%, said that their home is as clean and comfortable as they would like. This is not significantly different to the previous year's results. 27% said that their home was adequately clean and comfortable, and 14 people said that either their home was not quite clean and comfortable enough, or that their home was not at all clean and comfortable.

Q7a Personal safety	No.	2018 / 19 %	2017 / 18%	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I feel as safe as I want	285	72	73	71	72	71	69	72	72	64
Generally I feel adequately safe , but not as safe as I would like	94	23	20	23	24	25	25	24	24	29
l feel less than adequately safe	14	3	5	5	3	3	5	3	2	4
I don't feel at all safe	6	1	2	1	1	2	2	5	2	2
Total	399	100	100	100	100	100	100	100	100	100
Missing	8									
Total	407									

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

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

Most people, 72%, said that they felt as safe as they wanted, which is generally in line with previous years' findings. 23% said they generally felt adequately safe, but not as safe as they would like which is a 3 percentage points increase from 2017/18. 21 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.

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	No.	2017 / 18%	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I have as much social contact as I want with people I like	193	49	54	50	50	45	51	45	51	43
I have adequate social contact with people	126	32	27	32	35	36	33	34	31	38
I have some social contact with people, but not enough	50	13	13	14	12	12	13	17	14	16
I have little social contact with people and feel socially isolated	23	6	6	4	3	5	4	4	4	3
Total	392	100	100	100	100	100	100	100	100	100
Missing	15									
Total	407									

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

Nearly half (49%) of respondents said that they had as much social contact as they wanted with people they liked, which is a 5 percentage points decrease from 2017/18. 32% of respondents had adequate social contact, and 19% had either some social contact but not enough, or little social contact and felt socially isolated.

Q9a Leisure time	No.	2018 / 19 %	2017 / 18%	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I'm able to spend my time as I want , doing things I value or enjoy	144	36	39	40	41	35	36	35	37	32
I'm able to do enough of the things I value or enjoy with my time	120	31	32	30	31	34	38	35	35	32
I do some of the things I value or enjoy with my time but not enough	94	24	22	23	21	24	22	25	22	32
I don't do anything I value or enjoy with my time	34	9	7	7	7	6	5	5	6	5
Total	392	100	100	100	100	100	100	100	100	100
Missing	15									
Total	407									

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

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

39% of respondents replied, "I'm able to spend time as I want, doing things I value or enjoy", followed by 31% replying "I'm able to do enough of the things I value or enjoy with my time". This is in line with the results from previous years. 7% of people said that they do not do anything they value or enjoy with their time, which is in line with previous years.

Q10 How does having help make you feel?	No.	2018 /19 %	2017 / 18%	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
Having help makes me think and feel better about myself	226	58	57	56	59	63	63	53	56	50
Having help does not affect the way I think or feel about myself	117	31	29	35	32	27	28	37	34	35
Having help sometimes undermines the way I think and feel about myself	36	9	11	7	8	10	8	9	8	15
Having help completely undermines the way I think and feel about myself	7	2	3	2	1	1	2	2	2	1
Total	386	100	100	100	100	100	100	100	100	100
Missing	21									
Total	407									

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

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

58% of service users said that having help made them think and feel better about themselves, compared to 57% in 2017/18 and 56% in 2016/17. This is not a significant change compared to the previous year's results.

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	No.	2018 / 19 %	2017 / 18%	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
The way I'm helped and treated makes me think and feel better about myself	223	60	59	61	60	66	61	59	59	54
The way I'm helped and treated does not affect the way I think or feel about myself	120	32	31	32	33	26	32	33	32	38
The way I'm helped and treated sometimes undermines the way I think and feel about myself	23	6	9	6	6	7	7	7	8	8
The way I'm helped and treated completely undermines the way I think and feel about myself	6	2	2	1	1	1	0	1	2	1
Total	372	100	100	100	100	100	100	100	100	100
Missing	35									
Total	407									

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

Two thirds of all respondents (60%) to the survey said that the way they are helped and treated makes them think and feel better about themselves, with 32% saying it did not affect how they felt. 8% (29 people) said that it either sometimes or completely undermined how they thought and felt about themselves. This is generally in line with the previous years' findings.

Section 3: Knowledge and information

Q12a. Ease of obtaining information	No.	2018 / 19*	2018 / 19 % with 'never tried' removed	2017 / 18 *	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
Very easy to find	73	20	27	20	21	19	22	25	19	24	23
Fairly easy to find	128	35	47	33	36	42	35	37	39	33	34
Fairly difficult to find	54	15	20	12	12	9	11	10	12	11	13
Very difficult to find	19	5	7	8	5	4	4	5	7	3	3
l've never tried to find information or advice	86	25	-	28	26	25	27	23	24	29	27
Total	360	100	100	100	100	100	100	100	100	100	100
Missing	47										
Total	407										

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

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

25% of respondents had never tried to find information or advice about support, services or benefits (compared to 28% in the previous year). 55% said that they had found it very or fairly easy, which is 2 percentage points more than last year (53%). 20% found it either very or fairly difficult.

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 fairly easy, is 74%, with just over a quarter (27%) finding it very or fairly difficult.

We also asked our own questions at the end of the survey about how people would prefer to receive information about care and support services (Q23) and whether they had had any problems getting hold of information in the right format for them. The results are shown on the next page.

Q23. How would you prefer to find out information about care and support services?

Q24. Find information about care and support services?	No.	2018 / 19*	2017 / 18*	2016 / 17*	2015 / 16 %	2014 / 15 %	2013 / 14 %
Letter	189	52	54	48	59	52	48
Leaflet or handbook	160	44	36	31	59	40	39
Face to face/ Meeting Someone	151	42	45	46	42	45	51
Telephone	52	14	14	14	14	13	13
Support group	44	12	9	8	9	8	9
Email	32	9	6	6	8	4	7
Online	23	6	5	4	6	4	3
Something else	9	2	3	6	3	4	4
Total	660	-	-	-	-	-	-
Missing	45						
Total	407						

* The percentages shown are those with the weighting factor applied. This question was not asked before 2013/4. Respondents could choose more than one option.

Most respondents said they preferred to find out information about care and support services either letter (52%) a leaflet/handbook (44%) and then face to face (42%). This is in line with previous years' results.

Q12b. Please tell us what we can do to make it easier for you to find information and advice about support services or benefits.

We asked service users to give us their views on how we can do to make it easier for you to find information and advice about support services or benefits. Comments included:

"More literature should be made available for people with disabilities i.e. Telephone number for social adult services and what help and information can be given. Even useful telephone numbers about services for the disabled. Made more really available."

"Family have been passed around loads of different social work numbers as I am not an open case. Cannot get key safe number for health staff and people visiting bang on my door when I cannot get up."

"Postal information, clear & easy to understand."

"Publicise these more widely in readily available sources." "It would be nice for my husband to have one person to contact rather than individual services. Too much time is spent on hold phoning council. A booklet with contacts would help especially if people answered the phone & not automated messages saying no one was able to take the calls."

Q12b: Comments from people		No. of pe	ople who	said this	
who have had problems getting hold of information	2018/19	2017 / 18	2016 / 17	2015 / 16	2014 / 15
I have had no problems finding information	12	7	7	30	12
My support worker helps me get information	9	4	-	-	-
My family help me get information	9	12	5	10	7
I do not know who to talk to about finding information	7	5	5	4	2
When you call to get information, you are passed around	4	3	-	-	-
I cannot get information myself	4	2	-	-	-
My partner helps me get information	3	2	-	-	-
Leaflets and Letters of what is available	13				
Other (one comment only)	16	33	-	-	-

Q12c. 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?

	Q12c W	/ho wou	ıld you t	alk to a	bout yo	ur worri	es or if	you did	not fee	safe?
Who would you talk to?	No.	2018 / 19 %	2017 / 18%	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
Family member	304	78	75	74	76	76	76	75	79	79
Manager of your care home or day service	126	33	24	21	20	15	18	17	21	24
Care manager or social worker	77	21	19	17	19	14	18	18	15	20
Friend, neighbour or colleague	63	16	12	15	11	17	21	18	22	21
Care worker, key worker, or Personal Assistant	54	13	39	36	37	36	36	35	33	39
Someone else	15	4	7	7	8	8	6	5	6	7
Don't know	7	2	4	4	2	2	3	2	2	1
No-one, I wouldn't say anything	15	4	1	1	2	2	1	1	2	2
Total	661	-	-	-	-	-	-	-	-	-
Missing	17									
Total	407									

* 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.

78% of respondents said that they would tell a family member about something that had happened that worried them, or if they felt unsafe. This is in line with previous years.

Q12d. If you wanted to make a complaint about the care services you receive, do you know how to and do you feel you could if you wanted to?

Q12d Making a complaint	No.	2018 / 19%	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
Yes, and I feel I could if I wanted to	227	61	72	62	71	68	78	71	74	71
Yes, but I do not feel I could if I wanted to	79	19	5	7	6	7	9	8	10	9
No , I do not know how to make a complaint, but I am confident I could find out how to if I wanted to	35	9	12	16	13	19	14	24	10	20
No, I do not know how to make a complaint, and I am not sure how I would find out how to do this	11	3	5	6	6	6	14	21	16	20
Don't know	27	8	6	10	5	-	-	-	-	-
Total	379	100	100	100	100	100	100	100	100	100
Missing	28									
Total	407									

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

** In previous surveys, there was one single "no" option.

*** In previous surveys, there was no "don't know" option.

Two thirds of respondents (61%) said that they both knew how to make a complaint and felt that they could if they wanted to. This is a 11 percentage points decrease from the previous year.

Comments included:

"Complaints are not always listened to."

"I have a lack of capacity."

"I haven't had to make a complaint."

"Mum has dementia so is unable to communicate her feelings - I would have to notice something not right & act on her behalf." "Where would one start."

		Q12e Preferred method of making a complaint										
Preferred method	No.	2018 / 19 %	2017 / 18%	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %		
Telephone	185	47	44	44	51	47	53	52	52	50		
Via an advocate or other representative	151	39	40	41	37	39	40	34	40	45		
In person	95	26	39	33	31	34	32	34	30	29		
Letter	56	14	13	12	12	14	18	16	19	15		
Email	32	9	7	9	9	8	5	8	-	-		
Printed complaints form	22	6	4	7	5	5	6	10	11	11		
Other***	13	4	2	1	2	1	3	0	2	2		
Online complaints form	12	3	4	4	3	2	3	-	-	-		
Don't know or not sure**	11	2	7	7	5	3	-	-	-	-		
Councillor or MP***	9	2	4	3	3	3	2	6	4	5		
Total	562	-	-	-	-	-	-	-	-	-		
Missing	27											
Total	407											

Q12e. If you wanted to make a complaint, which of the methods below would you be most likely to use?

* 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.

** "Don't know or not sure" was not an option in earlier surveys.

*** These were not options in the Easy Read versions of the questionnaire.

The largest single percentage of all respondents said they would prefer to complain by telephone (47%), followed by 39% who would prefer to complain by using an advocate or other representative, then in person (26%).

Section 4: Your Health

Q13 General health*	No.	2018 / 19 %	2017 / 18%	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
Very good	49	12	14	11	16	11	13	11	10	7
Good	104	26	27	26	24	25	24	25	22	25
Fair	161	41	41	45	42	45	45	46	46	47
Bad	67	17	15	14	14	14	14	14	16	17
Very bad	17	4	4	4	4	5	4	4	6	4
Total	398	100	100	100	100	100	100	100	100	100
Missing	9									
Total	407									

Q13. How is your health in general?

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

As in previous years, the largest percentage of respondents (41%), described their health as "fair" (the same as 2017/18). 22% described it as bad or very bad (a 3 percentage points increase from 2017/18), and 38% described it as good or very good (3 percentage points lower than last year).

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

Q14a Pain or 2018 / 2017/ 2016 / 2015 / 2014 / 2013 / 2012 / 2011/ 2010/ discomfort No. 19 % 18 % 17 % 16 % 15 % 14 % 13 % 12 % 11 % I have no pain or 149 38 39 34 40 32 37 34 30 29 discomfort I have **moderate** 191 50 48 54 48 57 51 51 57 54 pain or discomfort I have extreme 13 48 13 12 12 11 13 12 14 18 pain or discomfort Total 388 100 100 100 100 100 100 100 100 100 Missing 19 Total 407

a. Pain or discomfort

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

Half of all respondents (50%) said that they had moderate pain or discomfort, compared to 48% in 2017/18. 38% said that they have no pain or discomfort.

b. Anxiety or depression

Q14b Anxiety or depression	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
l am not anxious or depressed	192	50	43	47	48	51	47	52	51	50
l am moderately anxious or depressed	165	42	46	45	43	43	46	43	40	43
l am extremely anxious or depressed	29	8	11	9	9	6	7	5	8	7
Total	386	100	100	100	100	100	100	100	100	100
Missing	21									
Total	407									

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

50% of all respondents said that they were not anxious or depressed, which is 7 percentage points more than 2017/18. There is a decrease of 4 percentage points from 46% in 2017/18 to 42% in 2018/19 of all respondents replying that they are moderately anxious or depressed.

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

Q15a Getting around indoors	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I can do this easily by myself	237	59	59	57	55	56	54	54	57	52
I have difficulty doing this myself	78	20	24	26	27	25	29	32	28	32
l can't do this by myself	80	21	17	18	18	19	17	15	15	16
Total	395	100	100	100	100	100	100	100	100	100
Missing	12									
Total	407									

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

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

Nearly two thirds of respondents (59%) could get around easily indoors by themselves without help, in line with 2017/18 figures. 20% replied saying that they had difficulty getting around indoors themselves, which is 4 percentage points better than 2017/18.

Q15b Getting in and out of bed or a chair	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I can do this easily by myself	237	58	58	58	58	56	57	62	63	56
I have difficulty doing this myself	73	19	24	22	20	23	26	23	21	27
l can't do this by myself	85	23	18	20	21	21	17	15	16	17
Total	395	100	100	100	100	100	100	100	100	100
Missing	12					-				
Total	407									

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

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

Just over half of respondents (58%) could easily get in and out of bed by themselves without help, which has been the case for the last four years. 19% said that they had difficulty getting in and out of bed (or chair) themselves, which is a 5 percentage points improvement from 2017/18.

c. Do you usually manage to feed yourself?

Q15c Feeding yourself	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I can do this easily by myself	316	80	78	79	82	80	78	80	81	84
I have difficulty doing this myself	44	11	13	14	12	13	16	14	15	12
l can't do this by myself	32	9	9	7	6	7	6	6	5	5
Total	392	100	100	100	100	100	100	100	100	100
Missing	15			-						
Total	407									

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

8 out of 10 respondents (80%) could **easily** feed themselves without help, compared to 78% in 2017/18 and 79% in 2016/17. There has been no significant change.

	-	-		-	-	-	-	-	-	-
Q15d Dealing with finances or paperwork	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
l can do this easily by myself	76	19	16	20	25	20	19	25	28	28
I have difficulty doing this myself	53	14	13	16	10	13	18	16	18	13
l can't do this by myself	264	67	71	64	66	67	63	59	55	59
Total	393	100	100	100	100	100	100	100	100	100
Missing	14									
Total	407									

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

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

Over two-thirds of respondents (67%) said that they could **not** deal with finances or paperwork without help, which is 4 percentage points better than 2017/18. 19% of respondents said that they can deal with finances easily, compared to 16% last year.

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

Q16a Washing all over	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I can do this easily by myself	140	35	33	32	35	35	36	39	40	36
I have difficulty doing this myself	104	26	28	28	28	23	26	26	26	27
l can't do this by myself	148	39	39	40	37	42	39	35	34	37
Total	392	100	100	100	100	100	100	100	100	100
Missing	15									
Total	407									

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

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

The largest single percentage of respondents said that they could **not** easily wash all over by themselves (39%). However, the next largest said that they could do this **easily** (35%), which is 2 percentage points more than in 2017/18. There has been no statistically significant change.

Q16b Getting 2018 / 2017 / 2016 / 2015 / 2014 / 2013 / 2012 / 2011 / 2010 / dressed No. 19 % 18 % 17 % 16 % 15 % 14 % 13 % 12 % 11 % I can do this **easily** 180 45 45 44 47 47 51 54 51 49 by myself I have difficulty 103 26 30 28 29 24 22 24 27 28 doing this myself I can't do this by 110 29 26 28 25 29 28 23 22 24 myself Total 393 100 100 100 100 100 100 100 100 100 14 Missing Total 407

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

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

Just under half of all respondents (45%) said that they could easily get dressed and undressed **easily** by themselves, which is in line with the previous year's results. There has been no statistically significant change.

	anaye	to use				uiseii:				
Q16c Using the toilet	No.	2018 / 19 %	2017 / 18 %				2013 / 14 %			
I can do this easily	251	62	64	65	68	64	67	72	69	68

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

by myself I have difficulty doing this myself I can't do this by myself Total Missing Total

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

Most respondents (62%) said that they can **easily** to use the toilet without help, which is in line with the previous year's results. 22% of respondents replied saying that they can't use the toilet by themselves which is 4 percentage points more than in 2017/18.

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

Q16d Washing face and hands	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I can do this easily by myself	285	71	72	74	77	73	73	79	79	81
I have difficulty doing this myself	56	14	18	14	13	13	14	12	11	12
l can't do this by myself	55	14	10	12	11	14	13	9	9	7
Total	396	100	100	100	100	100	100	100	100	100
Missing	11	-								
Total	407									

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

Just under three-quarters of respondents (71%) said that they could easily wash their hands and face without help. This is in line with previous years. 14% (4 percentage points more than in 2017/18) said that they can't do this by themselves.

Section 5: About your surroundings

Q17 How well does your home meet your needs?	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
My home meets my needs very well	221	57	62	62	63	59	63	60	59	56
My home meets most of my needs	127	33	24	25	27	32	27	32	31	34
My home meets some of my needs	34	9	12	9	7	9	10	7	7	8
My home is totally inappropriate for my needs	8	2	3	3	3	1	1	2	3	2
Total	390	100	100	100	100	100	100	100	100	100
Missing	17	-							-	
Total	407									

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

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

As in 2017/18, over half of respondents (57%) said that their home met their needs **very well (**which is a 5 percentage points decrease from the previous year), followed by 33% saying that their home meets **most** of their needs.

Q18 Getting around in your local area	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
l can get to all the places in my local area that I want	114	29	33	32	33	31	32	34	39	35
At times I find it difficult to get to all the places in my local area that I want	81	21	19	23	24	22	23	24	26	24
I am unable to get to all the places in my local area that I want	89	23	27	19	22	23	23	20	20	22
l do not leave my home	100	27	21	26	22	23	22	22	20	19
Total	384	100	100	100	100	100	100	100	100	100
Missing	23									
Total	407									

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

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

Nearly a third of respondents (29%) said that they could **get to all the places** in their local area that they wanted to. This is 4 percentage points less than 2017/18. This means that 70% 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.

Section 6: About you and the help you receive

Q19 Practical help from others	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
a. Yes , from someone who lives in another household	161	41	36	33	49	47	52	57	53	53
b. Yes, from someone living in my household	204	53	47	51	40	36	41	34	40	40
c. No , I do not receive any help	62	16	25	23	19	25	16	19	20	18
Total	427	-	-	-	-	-	-	-	-	-
Missing	20									
Total	407									

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

* 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.

A lower percentage of respondents replied "**No**, **I do not receive any help**" in 2018/19 (16%), compared to 25% in 2017/18 and 23% in 2016/17. 41% said "Yes, they received help from **someone who lives in another household**", which is 5 percentage points more than 2017/18.

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	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
Yes, with my own money	115	29	26	27	29	27	26	27	24	30
Yes, my family pays for this	33	9	7	8	7	8	10	7	8	6
No , I do not have any additional care or support	237	64	69	67	65	67	67	68	72	65
Total	385	100	-	-	-	-	-	-	-	-
Missing	32									
Total	407									

* 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.

64% of all respondents **did not buy** in any additional care and support services, compared to 69% in 2017/18. There has been no significant change from previous years.

Q21 Did you have help?	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
I had help from someone living outside my household	126	34	36	36	33	36	35	36	32	33
l had help from a care worker	61	16	29	23	23	25	22	30	30	31
l had help from someone living in my household	111	27	18	16	20	15	20	14	18	20
No , I did not have help	92	23	18	16	24	24	22	20	20	16
Total	390	100	100	100	100	100	100	100	100	100
Missing	17									
Total	407									

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

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

As in previous years, the largest single percentage of respondents (34%), had help with writing their answers in the questionnaire from someone living **outside** their household, 16% had help from a **care worker** and 27% had help with someone **living** in their household.

Q22. What type of help did you have?

Q22 Help with questionnaire	No.	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %	2010 / 11 %
Someone else read the questions to me	167	43	45	45	50	47	46	44	43	41
Someone wrote down the answers for me	141	36	38	38	38	44	36	36	36	37
I talked through the questions with someone else	113	29	23	23	25	44	26	26	23	26
Someone else translated the questions for me	71	17	18	18	20	17	15	15	11	14
None , I did not have any help	82	21	23	23	23	24	22	28	27	31
Someone answered for me , without asking me the questions	40	11	11	11	7	7	12	9	7	7
Total	614	-	-	-	-	-	-	-	-	-
Missing	22									
Total	407									

* 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 (43%) had had someone else **read the questions to them**, which is line with previous years' results. Of some concern is the fact than 40 people (11%) had had **someone else answer for them, without asking them the questions**. This has been an issue in previous years.

Q24. 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.

We asked people if there was anything else they wanted to say about their care services, quality of life, or anything else they wanted to discuss. The main themes of their comments are shown below, with the most common themes being people saying that they were happy with their services:

	Number of comments							
Q24 General comments – themes	2018 / 19	2017 / 18	2016 / 17	2015 / 16	2014 / 15			
I am happy with care services and staff	34	13	10	32	30			
I had help from my family to complete this form	9	3	3	-	-			
Survey difficult to complete	6	-	-	-	-			
No consistency in Carers/ Social Care staff	5	-	-	-	-			
I am happy with my care home	4	10	6	3	4			
I would like to go out of my house more, offered trips, day centres etc	4	3	-	-	-			
I am not happy with my care and support	3							
I have difficulty getting out	2	2	-	-	-			
I would like control of my own money	2	-	-	-	-			
Not happy paying for care and support	2	-	-	-	-			
Would like more information about services	1	-	-	-	-			
Other (one person making the comment)	27	96	111	-	-			

Comments included:

"Since I have been getting help it has restored my faith in humanity just really happy helpful caring people." "I have 3 to 4 hospital app etc every month and I or a family member always give 7 days notice for an early morning call for a carer to come to my home to help me out of bed, dress & make breakfast, the last 2 or 3 times no carers have turned up when I have booked them for a certain time and have had to phone a family member to help me up etc to get to my appointment on time." "My carers are excellent. I manage very well with them." "Get less time now carers private & not 'care at home' (when I came out of hospital). More things new carers not allowed to do (such as take sample pots to GP so I do not get my tablets). New carers don't tidy up as well after making meals. Don't like having to get up at 7am." "The direct payments that I receive helps me to meet friends & family, who don't live close to me, take up new hobbies and keep my hobbies that I already have, visits to places of interest to me and breaks from stresses of daily life with dementia. It's been a great life line to me and my wife." "I would like to get out more meet you people, maybe a day centre." "I am not happy/about the amount I have to pay to Cassa it is £71-92 I used to have 4 carers coming in but I only have 2 now and I still have to pay £71-92 I disagree in paying that amount of money one comes in the morning and one at 7-30 at night I think it should be half the price I only get paid every 2 weeks I phone to ask if they could put the payments to every 2 weeks and they said no I cannot afford to pay monthly." "It helps me to go out and do things which are important to me. I cannot go out by myself so the support is a life saver for me!" "The difficulty is knowing who is coming and at what times (they can vary by $1\frac{1}{2}$ hours) the carers are not given our precise location & have to ring for directions each time someone new comes despite office being given detailed directions."

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 the service users' care setting, their age, and whether they have a learning disability. The percentages of people who responded using them are as follows:

	es of stionnaire	No. sent out	No. return ed	% 2018 / 19 respo nse	% 2017 / 18	% 2016 / 17	% 2015 / 16	% 2014 / 15	% 2013 / 14	% 2012 / 13	% 2011 / 12
1	Residents in their own homes	284	110	39	35	55	40	39	36	41	34
2	Residents in care homes	222	63	28	27	22	26	34	28	34	27
3	Adults with a learning disability in their own homes	434	86	20	40	22	36	42	40	52	36
4	Adults with a learning disability in residential care	353	148	42	10	2	44	25	50	35	8
and	al respondents non- condents	1293	407	31	-	-	-	-	-	-	-

The largest number of questionnaires returned, and the highest response rate was received from adults with learning disabilities living in residential care (Strata 4), followed by residents receiving services in their own home (Strata 1).

2. Gender

Gender	Frequency	2018 / 19 %	2017 / 18 %	2016 / 17 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	% in sample	% in population
Male	166	41	43	43	43	43	40	43	43
Female	241	59	57	57	57	57	60	57	57
Total	407	100	100	100	100	100	100	100	100

As in previous years, most respondents were female (59%), in line with the proportions of men and women in the sample.

Age groups	Frequency	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	2011 / 12 %
18-24	28	7	4	4	5	1	4	4	3
25-34	33	8	5	6	6	5	8	5	6
35-44	25	6	6	5	8	4	5	4	4
45-54	31	8	9	9	11	12	9	11	8
55-64	48	12	18	10	11	14	11	15	13
65-74	49	12	15	16	16	11	11	14	11
75-84	78	19	20	21	20	27	26	22	27
85 and over	115	28	24	30	24	26	26	27	29
Total	407	100	100	100	100	100	100	100	100

3. Age

Most respondents (59%) were aged 65 and over. This is the same as 2017/18 but less than previous years.

4. Ethnic origin

Ethnic origin	Frequency	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	% in 2018 /19 sample
White	386	96	96	95	96	94	95	94	95
Asian or Asian British	0	0	2	3	2	3	2	2	0
Black or Black British	1	0	1	1	0	1	1	0	0.2
Not stated	0	0	1	1	1	1	2	1	0
Other	17	4	0	0	0	0	0	0	5.3
Total	404	100	100	100	100	100	100	100	100
Missing	3								
Total	407								

Most respondents were from a White background (96%), as in previous years.

Religion	Frequency	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15 %	2013 / 14 %	2012 / 13 %	% in 2018 / 9 sample
Christian	187	80	84	82	84	86	85	87	79.4
None	31	13	10	10	11	9	10	10	13.4
Other	5	2	3	2	2	1	1	1	1.5
Hindu	3	1	2	1	1	0	1	0	0.5
Jewish	0	0	1	1	0	0	2	0	0.1
Muslim	7	3	1	4	2	3	1	2	0.3
Total	233	100	100	100	100	100	100	100	100
Missing	174							-	-
Total	407							-	-

5. Religion

Most respondents, about whom we had information on their religion, said that their religion or belief was Christian (80%), as in previous years. The percentage of respondents who said they followed different religions or beliefs, or none, were in line with the proportions of people in these groups in the sample.

Primary support reasons

Primary client groups	Frequency	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	% in sample	% in population
Physical Support	192	47	48	45	48	43	42
Learning Disability Support	110	27	25	16	24	22	24
Mental Health Support	37	9	10	15	9	13	11
Support with Memory and Cognition	37	9	10	13	10	13	13
Social Support	21	5	9	9	9	8	8
Sensory Support	10	2	2	2	1	2	2
Total	407	100	100	100	100	100	100

* Note that in previous years, service users were grouped by "Primary Client Group" (five categories), not "Primary Support Reason". These percentages therefore cannot be meaningfully compared with previous years.

The largest client group was 'Physical support' (47%), followed by 27% with 'Learning Disability Support'. The percentage of respondents in the different client groups were in line with the proportions of people in these groups in the sample.

Support setting

Support setting	Frequency	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	% in sample	% in population
Community	301	74	69	73	76	61	62
Residential Care	79	19	20	18	6	25	25
Nursing Care	27	7	11	10	18	14	14
Total	407	100	100	100	100	100	100

Most survey respondents received care in a community setting (74%). The percentages of respondents in the different support settings were generally in line with the proportions of people in these groups in the sample.

Mechanism of delivery

Mechanism of delivery*	Frequency	2018 / 19 %	2017 / 18 %	2016 / 17 %	2015 / 16 %	2014 / 15%	% in sample
LA-commissioned support only	0	0	43	7	17	22	1.5
LA-managed personal budget	225	56	39	69	54	57	43
Direct payment only	76	19	17	17	20	15	18
Part direct payment	0	0	0	6	9	6	1
Not Applicable	103	25	-	-	-	-	38
Total	404	100	100	100	100	100	100
Missing	3						
Total	407						

* We did not collect this information in the years prior to 2014/15.

The percentages of respondents in the different groups were significantly different from those in previous years, but were in line with the proportions of people in these groups in the sample.

Reported Health Condition: Autism (excluding Asperger Syndrome or High-Functioning Autism)

Reported Health Condition: Autism	Frequency	2018 / 19 %*		2016 / 17 %	% in sample
Yes	12	3	3	1	4
No	395	97	97	99	96
Total	407	100	100	100	100

* We did not collect this information in the years prior to 2016 / 17.

3% of participants had autism, which is in line with the proportions of people in this group in the sample.

Reported Health Condition: Asperger Syndrome or High-Functioning Autism

Reported Health Condition: Asperger Syndrome or High-Functioning Autism	Frequency	2017 / 18 %*	2016 / 17 %	% in sample
Yes	2	0.5	0	0.6
No	405	99.5	100	99.4
Total	407	100	100	100

* We did not collect this information in the years prior to 2016 / 17.

Two people had Asperger Syndrome / High-Functioning Autism, which is in line with the proportions of people in these groups in the sample.

Appendix 1 – Questions asked, and information about respondents

Questions

Section 1: Overall satisfaction with your social care and support

1. Overall, how satisfied or dissatisfied 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 keeping 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. Have you had any problems in getting hold of information about care and support services, such as not knowing who to talk to, or not being able to get information in the right format (such as large print)? If so, please tell us here:

12c. 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?

12d. If you wanted to make a complaint about the care services you receive, do you know how to and do you feel you could do this?

12e. If you wanted to make a complaint, which of the methods below would you be most likely to use?

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 (care) 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 have any help from someone else to complete this questionnaire?

22. What type of help did you have?

Section 7: About your care and support, information, and personal safety

23. How would you prefer to find out information about care and support services, benefits and so on?

24. Could you tell us which of the following aspects of your life help you to feel safe in your home?

25. 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.

26 Would you be happy to be invited to take part in more research?

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 or belief
- 5. Primary support reason
- 6. Support setting
- 7. Mechanism of delivery

Appendix 2 – ASCOF Indicators

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

			Indicat or 2018/1	2017 /	2016 / 17	2015 /	2014/	2013/
Weighted Results	Numerator	Denominator	9	18		16	15	14
(1A) Social care - related quality of life	79008.1	4113	19.2	19.2	19.4	19.7	19.2	19.3
(1B) The proportion of people who use services who have control over their daily life	3038.4	4113	73.9	76%	77.0%	81.9%	77.6%	77%
(1I) Proportion of people who use services and carers, who reported that they had as much social contact as they would like* **	2027.5	4113	49.3	54%	49.7%	49.8%	45.7%	51%
(3A) Overall satisfaction of people who use services with their care and support	2822.6	4113	68.6	68%	62.4%	66.9%	62.2%	64%
(3D part 1) The proportion of people who use services who find it easy to find information about services**	2601.9	4113	73.8	72%	76.3%	82.1%	78.9%	80.2%
(4A) The proportion of people who use services who feel safe	2960.3	4113	72.0	73%	70.7%	71.9%	70.7%	69%
(4B) The proportion of people who use services who say that those services have made them feel safe and secure	3679.5	4113	89.5	83%	84.1%	80.2%	79.5%	78%

*These are the final figures, calculated using weighted data from the Newcastle Social Care Users Survey 2017/18, according to the official guidance.

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
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 2018/19 is:

	No unmet needs	Needs adequately met	Some needs met	No needs met	Total
Q3a	1402.1	1716.1	802.7	192.1	4113.0
Q4a	2300.1	1619.9	146.4	46.6	4113.0
Q5a	2685.8	1276.9	150.3	0.0	4113.0
Q6a	2933.3	1085.7	83.2	10.8	4113.0
Q7a	2928.4	975.0	141.3	68.2	4113.0
Q8a	1990.9	1361.3	538.3	222.4	4113.0
Q9a	1488.3	1277.1	1036.9	310.7	4113.0
Q11	2466.0	1321.4	257.3	68.2	4113.0
Total	18194.9	10633.5	3156.5	919.1	4113.0

Score 54854.6 21267.0 3156.5 0

Numerator	Denominator	1A
79008.1	4113.0	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.

(11) The proportion of people who use services and their carers who have as much social contact as they would like

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

There is a clear link between loneliness and poor mental and physical health. A key element of the Government's vision for social care is to tackle loneliness and social isolation, supporting people to remain connected to their communities and to develop and maintain connections to their friends and family. This measure will draw on self-reported levels of social contact as an indicator of social isolation for both users of social care and carers.

Where, for 1I part 1 (users):

Numerator: In response to Question 8a of the ASCS, those individuals who selected the response "I have as much social contact as I want with people I like".

Denominator: All those that responded to the question.

For both the numerator (X) and denominator (Y), weighted data should be used to calculate the measure.

(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 part 1) The proportion of people who use services 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.

Standard questionnaire	%	Easy Read questionnaire	%	Combined	%
I am extremely satisfied		I am very happy with the way staff help me, it's really good		I am extremely or very satisfied	
I am very satisfied					
Subtotal					
I am quite satisfied		I am quite happy with the way staff help me		I am quite satisfied	
I am neither satisfied nor dissatisfied		The way staff help me is OK		I am neither satisfied nor dissatisfied	
I am quite dissatisfied		I do not think the way staff help me is that good		I am quite dissatisfied	
I am very dissatisfied		I think the way staff help me		I am extremely or very	
I am extremely dissatisfied		is really bad		dissatisfied	
Subtotal					





This report was prepared by Policy and Communications Team Assistant Chief Executive's Division July 2019