

The Care Act 2014
Survey Results Annex:

Background Research and Statistics





Introduction

This document accompanies the report of a survey carried out by Think Local Act Personal (TLAP) between September-October 2016, to find out how the Care Act 2014 has made a difference to the lives of adults who need care or support.

To provide context for the survey, TLAP also reviewed related research and statistics relevant to its work on the Care Act and personalisation. This annex brings together material from the review, and covers a number of the Act's key changes in:

- The delivery of local information and advice.
- Assessment and support planning.
- Promoting wellbeing.
- The quality of care and support.

The report of the survey, alongside a set of tables with the results for all survey questions, is available at www.thinklocalactpersonal.org.uk/browse/careact2014

Information and Advice

Is access to advice and information improving?

Research evidence

There is recent and wide-ranging evidence in the report from Independent Age: Information and advice since the Care Act – how are councils performing? published in January 2016¹. The methods used, scale of the research, and the independent standing of the researchers give confidence in the findings.

The research reviewed all English local authority websites and a mystery shopping exercise involving 151 councils, to judge how well they were able to respond to calls enquiring about care and support information scenarios.

There were some examples of good, comprehensive information being offered in a supportive manner. However, only 45 councils out of 152 provided all the online information that is required by the Act.

The majority were providing a minimum level of information and advice through their websites, but more than two thirds were not able to demonstrate that they had sufficient online information in all the areas required by the Act.

Just over half gave a good response to the questions asked; one in three did not give a satisfactory answer to the question posed by the caller and one in twenty gave only a partial response.

¹ Independent Age (2016) Information and advice since the Care Act – how are councils performing? (online) www.independentage.org/policy-research/research-reports/information-and-advice-since-care-act-how-are-councils-performing

In nearly a quarter of cases, the researchers found it very difficult to find the relevant number to call on the council website, and in a significant minority of cases (9 per cent), the caller was not able to get through to the council at all.

Carers UK produced their State of Care Report² in May 2016, based on a survey of 3000+ carers. Findings relevant to the TLAP Care Act Survey report include:

Just over a third of those having an assessment in the last year "were told how to get all the information and advice about their caring role they felt they needed".

Less than a quarter said they received "little or no helpful information or advice and felt they did not know where to go for support with caring".

The Independent Living Survey 2016³ also included information in its survey, which was responded to by 485 people. Some of the findings about information were focused on people who use direct payments, and included the following:

Over half of respondents rated "information, advice and support you get to manage your direct payment" as poor or very poor, while less than a quarter, 23 per cent, rated this aspect good or very good

Wider information questions prompted the following responses:

Struggle to find information and advice.

Less than a fifth used their local council's website for information.

Need advice and support to understand their rights.

Solve problems with local council.

16%

45%

34%

² Carers UK (2016) State of Caring Survey 2016 www.carersuk.org/news-and-campaigns/state-of-caring-survey-2016

³ In Control/Independent Living Strategy Group (2016) Independent Living. Online: www.in-control.org.uk/news/in-control-news/report-on-the-independent-living-survey-2016.aspx

Statistical evidence

Statistical evidence from the Health and Social Care Information Centre (HSCIC) provides a contrast to the findings described above. In its annual **Adult Social Care Survey for 2015-16**⁴ published in September 2016, people who have council funded support were asked: "In the past year, have you generally found it easy or difficult to find information and advice about support, services or benefits?" The finding is based on a sample of 66,555 respondents in 2014-15 and 68,765 in 2015-16.

The results over two years are shown below, and suggest that around three quarters of people found it fairly or very easy to find information. The HSCIC found that the variation between the two years was not statistically significant (meaning that the changes over time could be explained by normal variations between the samples that were drawn in each year).

Responses	2014-15	2015-16
Very easy to find	28.1	28.2
Fairly easy to find	46.3	45.3
Fairly difficult to find	17.2	17.6
Very difficult to find	8.3	8.9
No of respondents	49,850	51,610

Source: Adult Social Care Survey: Health and Social Care Information Centre: Sept 2016

⁴ Health and Social Care Information Centre (September 2016) Adult Social Care Survey http://content.digital.nhs.uk/catalogue/PUB21630

Advocacy

Is advocacy being extended to help people with assessment and care planning decisions?

Research evidence

A report was published by the **Advocacy Action Alliance (AAA)**,⁵ a coalition of advocacy providers across England and Wales. AAA commissioned the Mental Health Foundation to survey advocacy providers in the summer of 2015. Some 101 responses were received covering 72 local authority areas.

The survey does not focus specifically on the experiences of people who use services or carers, but it is helpful in assessing progress towards the aim of increasing the availability of advocates to help them navigate a path towards personalised care and support.

The AAA survey focuses on respondents' role as provider of independent advocacy under the Care Act: the type of contract held to provide Care Act advocacy, the length of contracts, and expenditure on advocacy.

Almost two thirds of contracts for independent advocacy were for 12 months or less. The AAA believes that some local authorities had not commissioned any Care Act advocacy in time for April 2015. Around a half of respondents reported that their contracts and contracts held by other organisations to provide advocacy had been reduced or ended since April 2015, suggesting a reduction in the provision of advocacy in many local authority areas.

⁵ Advocacy Action Alliance/Mental Health Foundation (2015) Commissioning independent advocacy under the Care Act 2014 https://opaal.org.uk/app/uploads/2015/12/Care-Actmonitor-survey-report-FINAL.pdf

Follow-up research (unpublished) by Birmingham University, the Social Care Institute for Excellence and the University of Central Lancashire in June 2016 confirms that these issues were not just the result of uncertainties during initial implementation of the Care Act.It was found that over half of contracts were for twelve months or less, a quarter for 12 to 24 months, and just 16 per cent were for more than 24 months. Five per cent of contracts had not been let.

A number of barriers to effective commissioning were identified in the study:

- Limited needs assessment and consideration of diversity.
- Lack of understanding of advocacy (adult social care teams, commissioners).
- Reliance on spot purchasing.
- Out of area clients who takes responsibility?
- Increasing demand in light of reducing resources.
- Complexity of advocacy landscape.
- The market limited choice of provider(s).

According to the Local Government Association and the Association of Directors of Adult Social Services in their quarterly stock-take in November 2015,⁶ independent advocacy was arranged for 11,000 people – about 2 per cent of people assessed and eligible for care. The Government's own impact assessment estimated that 7 per cent would qualify for support.

The journal Community Care⁷ also obtained figures from 80 councils in England, under the Freedom of Information Act. It found that advocates were provided to 2.1 per cent of 253,000 people assessed under the Care Act between April and September 2015.

⁶ LGA (2016) Stocktake 5 www.local.gov.uk/care-support-reform/-/journal_content/56/10180/6341378/ARTICLE

⁷ Community Care 2016: www.communitycare.co.uk/2016/01/13/social-workers-urged-review-practice-given-low-care-act-advocacy-case-numbers

Needs Assessment and Support Planning

How do people experience assessment and care planning?

Research evidence

The Independent Living Survey 2016⁸ was published by In Control on behalf of the Independent Living Strategy Group in October 2016. The findings included a section on the experience of assessment. The relevant findings were:

86%

Reported that when their Local Authority had assessed their needs, they had listened or partly listened to them.

63%

Of those respondents who said their support had been reviewed in the last twelve months, just under two thirds did not know how much money was available for their support.

1/4

One in four people had been told their support would be reduced because of cuts/ savings and/or there is a limit to the amount of money you can get for a particular service.

The National Audit Office (NAO) noted in its report of June 2015 that there had been a fall of 14 percent in the number of people aged 65 or over receiving social care assessments between 2005 and 2013: and a 30 per cent fall in the number of people aged 65 or over receiving social care services between 2005 and 2013.9

⁸ In Control/Independent Living Strategy Group (2016) Independent Living. Online: www.in-control.org.uk/news/in-control-news/report-on-the-independent-living-survey-2016.aspx

⁹ National Audit Office(2015): Care Act First Phase Reforms: Report by the Comptroller and Auditor General

According to the ADASS Budget Survey Forecast for 2016,¹⁰ data on the expected numbers of people who receive services "tentatively suggests that the numbers of older people have remained virtually flat (- 0.1per cent change) despite demographic growth; whilst growth in the numbers of people aged 18-65 and carers using services was around five per cent".

From the October 2015 **Department of Health Stocktake**,¹¹ it was reported that at national level, 1.65m social care assessments were "expected in 2015/16 (+56,000 from 2014-15) and the percentage of assessments that meet the eligibility threshold is estimated to marginally increase by two per cent (or 72,000) to 65." It should be remembered that any increases anticipated are based on the major reductions of the preceding eight years.

However, the Independent Age report on information and advice¹² found, in its survey of information and advice services, a number of examples where local authorities were "not clear that care assessments are available regardless of level of need or finances".

The Carers Trust¹³ evidence on assessment highlighted examples of good practice but concluded overall that "Carers' assessments are not yet working properly under the Care Act". Amongst the findings of their survey, it was found that:

Carers had not had assessments.

Felt the assessment was "Not helpful".

Had not received a letter or a support plan after assessment.



¹¹ Local Government Association (2016) Care Act Stocktake. www.local.gov.uk/care-support-reform/-/journal_content/56/10180/6341378/ARTICLE

¹² Independent Age (2016)Information and advice since the Care Act – how are councils performing? www.independentage.org/policy-research/research-reports/information-and-advice-since-care-act-how-are-councils-performing

¹³ Carers Trust (2016). Care Act for carers: one year: lessons learned, next steps. (online) https://carers.org/care-act-carers-one-year-commission.

In the same report, councils were reported as generally positive about progress, with 50 per cent (12 councils) reporting that "things were better under the Care Act". They reported that the process had been "embedded well, that assessments are now more thorough, and that assessors now have to follow the guidance provided by the Care Act".

Carers UK¹⁴ produced their State of Care Report in May 2016, and this also asked carers about their experience of assessment. Across the UK, just under a third of carers who responded said they had had an assessment of the impact of their caring role on them in the previous year. Only a minority of those having an assessment in the last year (35 per cent) were told how to get all the information and advice about their caring role they felt they needed, with 1 in 5 (22 per cent) saying they" received little or no helpful information or advice" and felt they did not know where to go for support with caring.

In Control's¹⁵ survey results produced a figure of 57 per cent of respondents whose care package had been reassessed in the previous 12 months: and of these 17 per cent said that they had been told that there was a financial cap placed on certain types of expenditure.

The Independent Age assessment of progress with information and advice posed the question for testers reviewing council websites: "Can you find information on getting an assessment? Is it clear how you would go about doing this?"

The results were mixed. Three of the sample of councils tested "did not seem to have any information" but there were also a few good examples. Most websites had "...just a number to ring, and the testers would have liked more information about what was involved in the assessment process".

¹⁴ Carers UK: State of Caring 2016: online at www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016

¹⁵ Independent Living Strategy Group/ In Control (2015) Promoting people's right to choice and control under the Care Act 2014. How are local authorities performing?

A study carried out by **Revitalise**¹⁶ (a national charity providing respite care) was published in June 2016 following Freedom of Information requests to English councils. It found that:

"...local authorities gave fewer Needs Assessments for disabled people during the first year of the Care Act than in the year before it, and half (48 per cent) had carried out an average of 22 per cent fewer Carer Assessments during the same period".

Statistical evidence

National statistics no longer tell us directly about the number of assessments carried out by councils. However, the **Health and Social Care Information Centre's Adult Social Care Survey**¹⁷ tells us something about the extent to which people who receive a service feel in control of daily life.

The survey asked people with council funded support: 'Which of the following statements best describes how much control you have over your daily life?' (Note that this question is asking about daily life and is **NOT** asking about choice and control of the support they receive). The focus is on the outcome of support, rather than the process of assessing and deciding what is delivered and how.

The sample was from 68,210 respondents in 2014-15 and 71,355 in 2015-16. The results for the two years 2014-15 and 2015-16 are shown in the following chart.

¹⁶ Revitalise (2016); Care Act Fails in First Year http://revitalise.org.uk/news/care-act-fails-in-first-year-finds-revitalise-study/

¹⁷ Digital NHS: Health and Social Care Information Centre (2016). Adult Social Care Survey: Sept 2016, NHS Digital.



Source: Adult Social Care Survey: Health and Social Care Information Centre: Sept 2016

The proportion of respondents who reported that they had no control over their daily lives increased from 5.1 per cent in 2014-15 to 5.6 per cent in 2015-16; the HSCIC notes that this is a statistically significant increase.

A further important change has been in the reducing number of reviews. Reviews may be used to adjust levels of support to their needs, as these change over time. According to NHS Digital statistics, some 843,000 reviews for existing clients were completed in 2013-14: this was four per cent less than in 2012-13 and 39 per cent less than in 2008-09.

¹⁸ *HSCIC:* Community Care Statistics: Social Services Activity, England 2013-14 www.content. digital.nhs.uk/catalogue/PUB21934

Wellbeing

How do care and support make a difference to wellbeing?

Research evidence

The Independent Living Strategy Group's survey report,¹⁹ published by In Control, was conducted in the spring of 2016 and analysed responses from 485 people. Amongst other findings it found that:



More than half of respondents "reported that their quality of life had reduced or reduced significantly" over the past twelve months.



A quarter of respondents said the hours of work or volunteering they could do had reduced or reduced significantly.

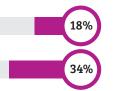


Almost two out of five reported having to rely more on family and friends for support.



More than a quarter of respondents reported an increase or a significant increase in the amount of money they have to contribute towards the cost of their support.

The Spinal Injuries Association carried out a small scale (unpublished) survey with 82 respondents, and of these:



12 of the 68 who answered this question reported that the limitation on the amount of care they get is putting their life at risk.

Reported that limitation on care is putting their health at risk.

Reported that their ability to work is stopped or put at risk.

¹⁹ In Control/Independent Living Strategy Group (2016): Independent Living Survey 2016. (online) www.in-control.org.uk/media/243039/independent%20living%20 survey%202016%20v2.pdf



Reported being stopped from taking part in family &/or community life.



18 of 76 reported their care had been reduced in the last two years. Of these, 46 per cent reported having their life put at risk, compared with just 6 per cent of those with no unreduced care.

Statistical evidence

The Adult Social Care Survey²⁰ results for 2015-16 offer insights from large scale samples into the wellbeing of people with care and support needs. It should be remembered that this survey only included people who receive a council-funded service.

Overall satisfaction with council funded services remained fairly stable over the last two years, with around 80 per cent (of samples of 67,000 and 71,000 respondents respectively) reporting that they were "extremely, very, or quite satisfied" with their care and support.

There was a small increase in the proportion of respondents reporting that "having help makes them think and feel better about themselves" (now at 61.3 per cent). The change is statistically significant.

In assessing their overall quality of life in 2015-16, over 71, 000 people who responded reported that:

31.1%

Respondents reported that life was so good it could not be better, or was very good.

31.2%

Felt that life was good.

28.9%

Reported that life was alright.

5.7%

Felt that life was bad.

3.1%

Reported that life was very bad or so bad it could not be worse.

²⁰ Digital NHS: Health and Social Care Information Centre (2016). Adult Social Care Survey: Sept 2016, NHS Digital.

Health

The survey showed no statistically significant differences between self-perceived health between 2014-15 and 2015-16. With respect to physical health in 2015-16:



Respondents reported having no pain or discomfort.

Reported having moderate pain or discomfort.

Respondents reported being in extreme pain or discomfort.

In respect of mental health:

The results were similar to those reported for 2014-15, with no statistically significant changes. In 2015-16:



Respondents reported they were not anxious or depressed.

Reported feeling moderately anxious or depressed.

Respondents reported feeling extremely anxious or depressed.

Social needs



The proportion of respondents who reported that they had adequate social contact in 2015-16, 32.6 per cent, represents a statistically significant reduction of 1.0 percentage points when compared to the 33.6 per cent who responded in 2014-15.



A further finding was that the proportion of respondents who had little social contact with people and felt socially isolated increased from 5.1 per cent in 2014-15, to 5.6 per cent in 2015-16. This change is also statistically significant.

Mobility

Just 30 per cent of people who use services (from samples of 66,770 respondents in 2014-15 and 69,390 in 2015-16) reported that they were "able to get to all the places in their local area that they wanted".



Over a quarter of respondents reported that they "did not leave their homes". For 2015-16 these figures are a statistically significant reduction and increase respectively, compared to 2014-15.

There was also statistically significant increase in the percentage of people who use services who reported they "can't usually manage to get around indoors (except steps) by themselves".

Feeling at home



The proportion of respondents who reported that "their home meets most of their needs" in 2015-16. This is a reduction of 1.1 percentage points from the 31.8 per cent reported in 2014-15 and is a statistically significant reduction.

Daily Living

Nearly a quarter of respondents reported not being able or having difficulty with feeding themselves, and this did not change statistically from the previous year: but a higher proportion of respondents were unable to dress, or to use the toilet independently.



Just over two thirds of respondents reported they were usually not able to "deal with finances and paperwork (such as paying bills and writing letters)" for themselves. This compares to 64.3 per cent in 2014-15 and is reported to be a statistically significant increase. Additionally, 18.7 per cent of respondents reported that they were able to deal with their finances and paperwork for themselves; this is a statistically significant reduction compared to 2014-15.

Feeling Safe



The proportion of respondents who reported that care and support services helped them in feeling safe increased from 84.5 per cent to 85.4 per cent – a statistically significant change.

Quality of Care and Support

Research evidence

The most comprehensive source of independent evidence about the quality of care is the Care Quality Commission (CQC). CQC published its **Annual Report for 2015-16**²¹ in October 2016.

In 2015, CQC reported continuing improvement, but also concerns about the "sustainability of provision, due to the increasing complexity of people's care needs, significant cuts to local authority budgets, increasing costs, high vacancy rates, and pressure from local commissioners to keep fees as low as possible". Updating this position in 2016, CQC commented that:

"...much good care is being delivered and encouraging levels of improvement are taking place. However, the sustainability of this position is in doubt. We are also beginning to see some evidence of deterioration in quality, and some providers who are struggling to improve their rating beyond 'requires improvement."

²¹ Care Quality Commission (2016). The state of health care and adult social care in England 2015/16. Online: www.cgc.org.uk/content/state-of-care

CQC believes that quality in this sector...

"...may be approaching a tipping point. The combination of a growing and ageing population, people with more long-term conditions and a challenging economic climate means greater demand on services and more problems for people in accessing care."

It should be remembered that the relatively small number of personal assistants who are directly employed by individuals through direct payments fall outside the scope of CQC inspection and regulation.

Statistical evidence

The Adult Social Care Survey includes a general question about the effect of services on the way respondents feel about themselves – a related aspect of quality. At 61.3 per cent, there was a percentage point increase in 2015-16 in the proportion of service users who reported that having help makes them think and feel better about themselves; this change is statistically significant.

Respondents to the Independent living Survey 2016 reported similar proportions of people rating the quality of their support as poor and very poor (40 per cent) as good or very good (41 per cent).

Local Services

Is it getting easier to find a good range of local care and support?

Research and statistics

Little overall research (since the Care Act) or specific statistics on recent changes to the local availability of care services was found. However, one study was published in July 2016 by **HESTIA**,²² a charity working with adults and children in crisis and which has supported people with personal budgets for five years in Richmond, Newham and Wandsworth. One finding from its survey and focus group activity was that "of the people with a direct payment and/or managed account who knew where to look, 87 per cent were able to find tailored care and support".

A source of potential information on planned local changes in the supply of services may be found in councils' local Market Position Statements, which are often published, but their analysis is beyond the scope of the present work.

²² Hestia (2016): Personal budgets – A Lived Experience www.hestia.org/wp-content/uploads/2016/07/Hestia_Personal_Budgets_2016_Final-1.pdf

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