

The Care Act 2014

Survey Results

**Exploring the impact of the
Care Act on the lives of people
with care and support needs.**

June 2017



Acknowledgements

Think Local Act Personal (TLAP) thanks all those who completed the survey, members of the Steering Group who contributed to the design of the survey, and the Department of Health for supporting the work throughout.

Note about the Survey

The survey aims to explore the impact of selected features of the Care Act on the lives of people with care and support needs, particularly those most relevant to personalisation and community-based support.

TLAP carried out the survey described in this report within strict time and resource limitations during September 2016. The survey was developed and available only for online use in order to meet time and budget requirements. It is acknowledged that for some people, this may have caused difficulties. TLAP is grateful to all those who overcame difficulties arising from the limitations of online surveys to make their contributions, and to the organisations who assisted them in many cases.

Note on the statistics

The survey statistics quoted in this report are a selection only. The pie charts featured in this summary report are the overall results to survey questions from all respondents. The text underneath the charts provides some breakdown according to demographics. The full data tables, including the results according to different by demographics, can be downloaded from www.thinklocalactpersonal.org.uk/browse/careact2014

Other Resources

A short review of relevant studies was carried out in parallel with the survey to provide context and comparison of knowledge about progress with the implementation of the Care Act. A selection of government statistics relevant to personalised care and support was also reviewed. A summary of these can be seen as an annex to this report at the TLAP website www.thinklocalactpersonal.org.uk/browse/careact2014

Foreword

Since launching in 2011, Think Local Act Personal (TLAP) has worked hard to embed personalisation in policy and legislation. Uniquely, we have united partners from across health and social care – including those who commission, provide, use and regulate services and support their development – to tackle tough implementation challenges in delivering personalised, community-based care and support. We have achieved this because we share the values and vision set out in our Partnership Agreement.

In 2016, the Department of Health commissioned TLAP to find out about the experiences of people with care and support needs a year after the Care Act 2014 came into effect. A survey of this scope had never been done before and was run for one month (September 2016) and received responses from around 1100 people; 60 per cent of those were carers.

We asked questions on a variety of topics including whether people felt it was easy to get information and advice, or did they have choice and control of their care and support. The survey results have shown us that in many areas, implementation of the Care Act is yet to make a difference. There has been some good progress but this must be carefully balanced by looking at areas of major concern including access to support, the effectiveness of the support received and how greatly people's experiences vary depending on whether they are using council funded care and support or paying for that care themselves.

Many won't be surprised by this. These findings are similar to those found in other recent surveys including the Independent Living Survey 2016¹ published by InControl on behalf of the Independent Living Strategy Group, the State of Caring Survey 2016² published by Carers UK and Independent Age's report³ on how councils are performing when it comes to providing information and advice.

Somewhat interestingly, the results show a marked difference between council's perceptions of Care Act implementation,⁴ and the experiences of people and carers directly themselves.

TLAP works hard to support its partners to achieve our shared vision for personalised care and support. But the results of this survey, alongside the challenging economic environment, changing expectations of the NHS Five Year Forward View⁵ and Association of Directors of Adult Social Services (ADASS) work on why Social Care Matters,⁶ means people's experiences of personalisation aren't as they should and could be.

TLAP will be working with its partners to take the results of this survey to inform plans for our work in 2017 and beyond. We strongly encourage all our partners and those working across health and social care that are focused on delivering better lives for people who need support and their carers to do the same so we can achieve the aspirations of the Care Act – that is to help people to achieve the outcomes that matter to them in their life by promoting their wellbeing.

Key survey findings



Information and Advice

51% found it "quite" or "very" difficult to find information.



23% who had looked for information in the last year said it was easy to find.



67% Respondents who didn't receive any support found it harder to access information and advice about support than people who did receive support.



Involvement in support planning

25% felt that the council always or frequently listened to their wants and needs.



49% reported that their choices are always or frequently respected.



54% were involved as much as they wanted in arranging their care or support.



70% said the council sometimes, rarely or never listened to their want or needs.



Advocacy

11% were offered and received help from an advocate.



3% wanted, but were refused help from an advocate.



68% were not offered an advocate.



Wellbeing and Health

69% overall said their care and support made a positive difference to health.



23% said support made no difference or worse and 8% said much worse.



Wellbeing – feeling safe and secure

48% said care and support helped in feeling safe or secure.



51% said support made no difference or made them feel less safe.



Wellbeing and daily living

58% overall said support made daily living better.



42% of carers said that support made their daily living activities better, compared to 74% of people who need care or support.



Quality of Care and Support

27% were not happy with the quality of care. Carers and people funding their own support were less likely to be happy with quality.



56% said they were happy with the quality of care.



29% said quality had improved over the last year.



25% said it had got worse in the last year.



“One thing I would change...” by people with care and support needs

40% wanted easier access to, or more care.



21% wanted better quality, more flexibility or less complexity in arranging support.



14% wanted to reduce the pressure on carers.



10% wanted to see more easily accessible/good quality information and advice.



Introduction

Following the first year of implementation of the Care Act in 2015, TLAP commissioned a survey to find out how people who have care and support needs have experienced some of the changes brought about by the Act.

The survey was open to all people with care and support needs during September 2016, and was completed by 1,181 people aged 18 and over. The majority that replied were receiving support of some kind. Of these, 391 were people who need care and support for themselves, and 643 were carers. 64 were both carers and receiving support and the remaining 83 people did not declare their position. TLAP's partner organisations were closely involved in developing and promoting the survey.

Methodology

Survey questions were focused on aspects of personalisation, and wherever possible, based on questions that had been used and tested by partner organisations in other surveys or evaluations, including the Personal Outcomes Evaluation Tool developed by In Control and The University of Lancaster.

Completion of the online survey was assisted and encouraged by members of the Partnership through their individual organisations during September 2016. The detailed survey questions can be found on TLAP's website, www.thinklocalactpersonal.org.uk/browse/careact2014, with tables of the results and a review of other related studies and surveys. TLAP carried out the survey described in this report within strict time and resource limitations. The survey was developed and available only for online use in order to meet time and budget requirements. It is acknowledged that for some people, this may have caused difficulties. TLAP is grateful to all those who overcame difficulties arising from the limitations of online surveys to make their contributions, and to the organisations who assisted them in many cases.

Survey Results overview: who responded?

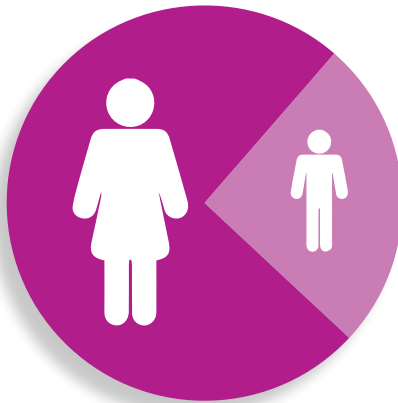


The survey was completed by 1,181 respondents aged 18 and over from locations across all **nine English regions**.

Of these, **455** were people who needed care and support for themselves, and **643** were carers.



There were four respondents aged less than 18 years, all providing unpaid care, and one stated that they also needed care or support for themselves. Of all respondents, 84.9 per cent were people receiving council funding, and 11.7 per cent were self-funding.



The survey respondents were **25.5% male** and **73.4% female**.

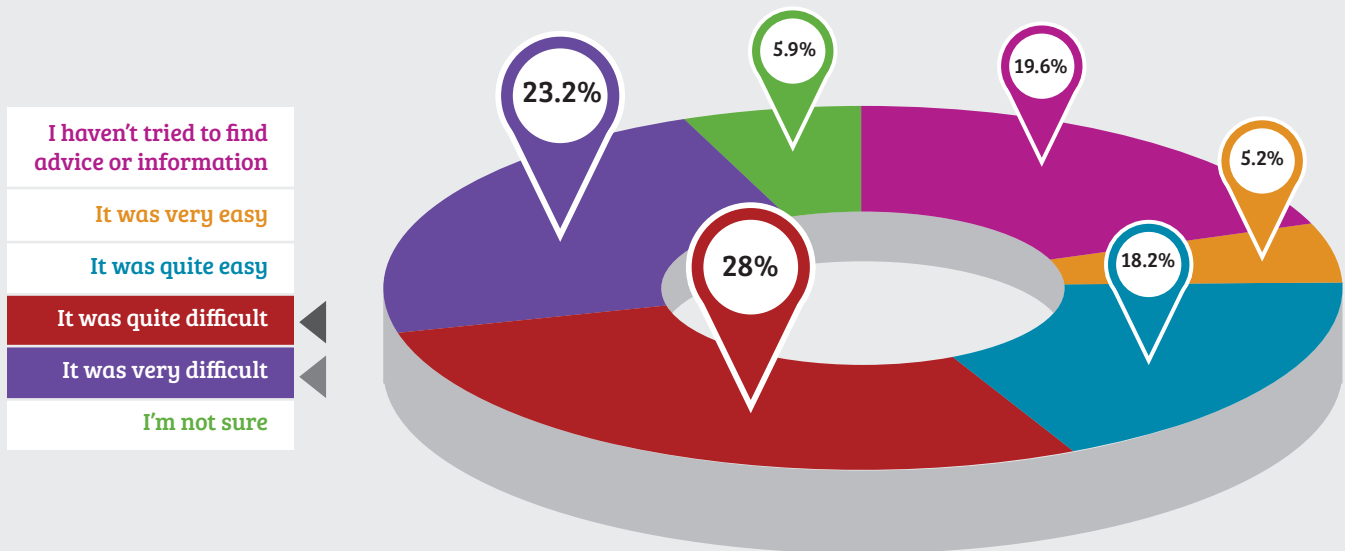
It should be noted that people who responded were not proportionally representative of the population of people receiving adult social care. For further details about respondents, please see the TLAP website.

The pie charts featured in this summary report are the overall results to survey questions from all respondents. The text underneath the charts provides some breakdown according to demographics. The full data tables, including the results according to different by demographics, can be downloaded from www.thinklocalactpersonal.org.uk/browse/careact2014

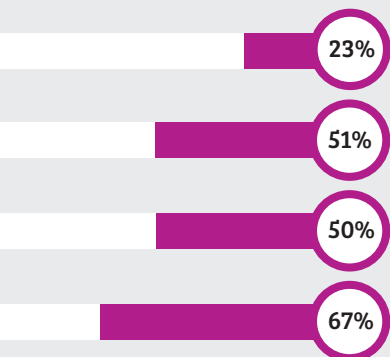
Detailed Findings⁷

INFORMATION: Is access to advice and information improving?

WE ASKED: Over the last year, how easy or difficult was it to find advice or information about support, or how to pay for it?



Breakdown of results and other results of interest



Overall, less than a quarter of people who had looked for information in the last year said it was easy to find.

Just over half found it "quite" or "very" difficult to find.

People funding their own support (50%) were more likely to report that it was difficult to find information than those who had council-funded support (39%).

Respondents who didn't receive any support (67%) found it harder to access information and advice about support than people who did receive it (32%).

Other Evidence



Examples of good practice from other studies show that progress towards the Act's information requirements can be achieved.⁸



Finding information appears to be easier for people already "in the system" and getting support. The Adult Social Care Survey⁹ of people who use services and carers, which forms part of the statutory adult social care collections managed on behalf of the Department of Health by NHS Digital, and which feeds into the Adult Social Care Outcomes Framework showed that 74% of people who responded found it fairly, or very easy to find information and advice about support, services or benefits.



What do people with care and support needs want to see change?

Six people commented on ways that they thought information and advice should improve. These included simpler ways of finding information, for example, through a single common point for health and care: more pro-active help and advice from the agencies, more personalised or in-depth advice, and more clarity and accuracy about entitlements to support, the costs and how to meet them.

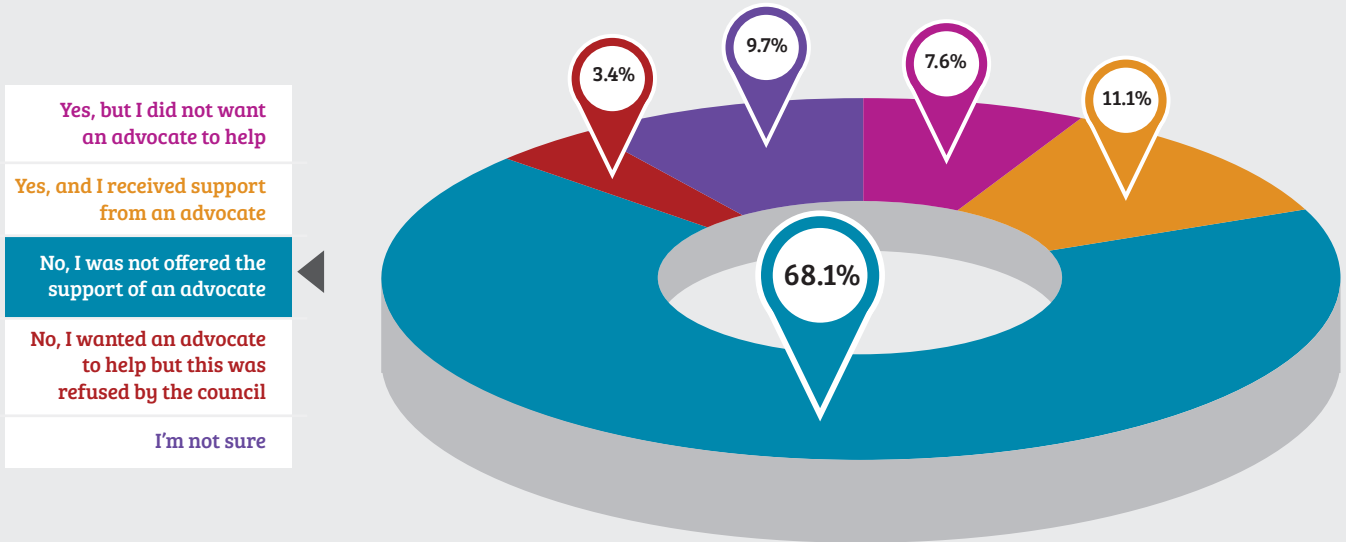
"A system which pulls all information together, so as a carer you do not spend your time ringing adult care services and NHS and Council services e.g. housing etc."

"Was told as I did not need financial help they could not open a case on us so have been left to sort ourselves out."

"Having someone to ... explain all the options without the red tape of being told "I can't tell you that."

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

WE ASKED: Has the council offered you help from an advocate to help you take part fully in the decisions about your care and support?



Breakdown of results and other results of interest

- 68%** Just over two thirds were not offered the support of an advocate.
- 11%** Overall, 11 per cent who responded were offered and received help from an advocate.
- 3%** A small number of people wanted an advocate but were refused.
- 8%** Eight per cent of respondents were offered but did not want an advocate to help.

Other Evidence



In some areas, a “wait and see” approach may be limiting the effective use of advocacy.¹⁰



Local commissioning of advocacy services appears to be tentative, uncertain or reducing.



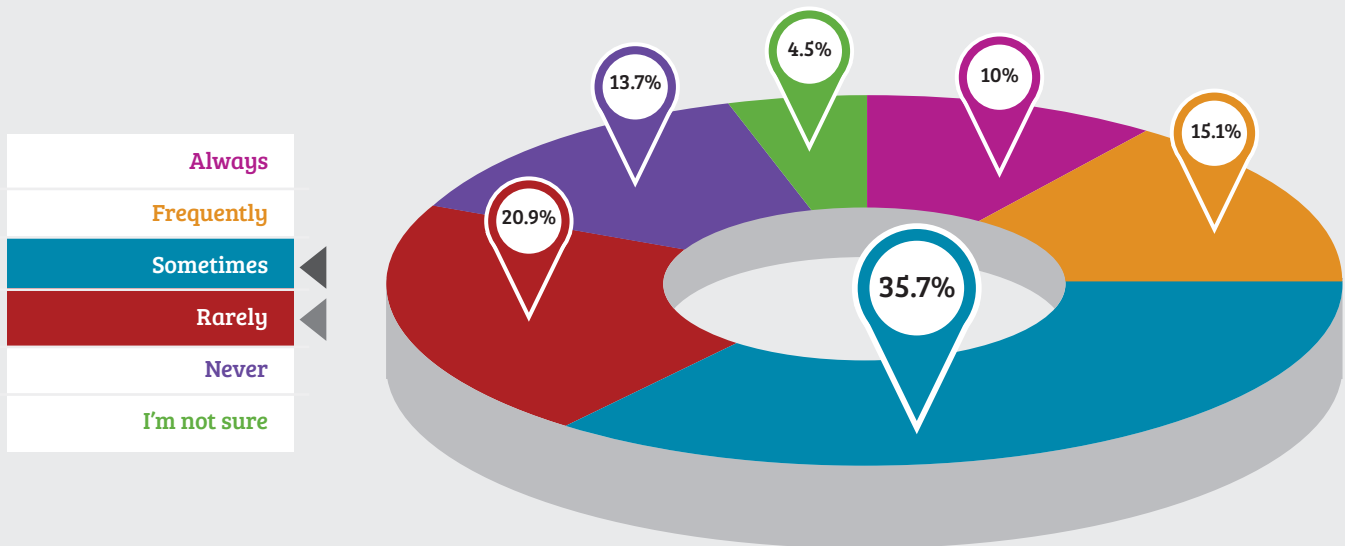
Whilst provision of advocacy is not compulsory, such a low uptake and apparent offer may indicate caution should be noted.

In some cases, people undertaking the assessments may have identified that advocacy (as defined by the Care Act) was not needed.

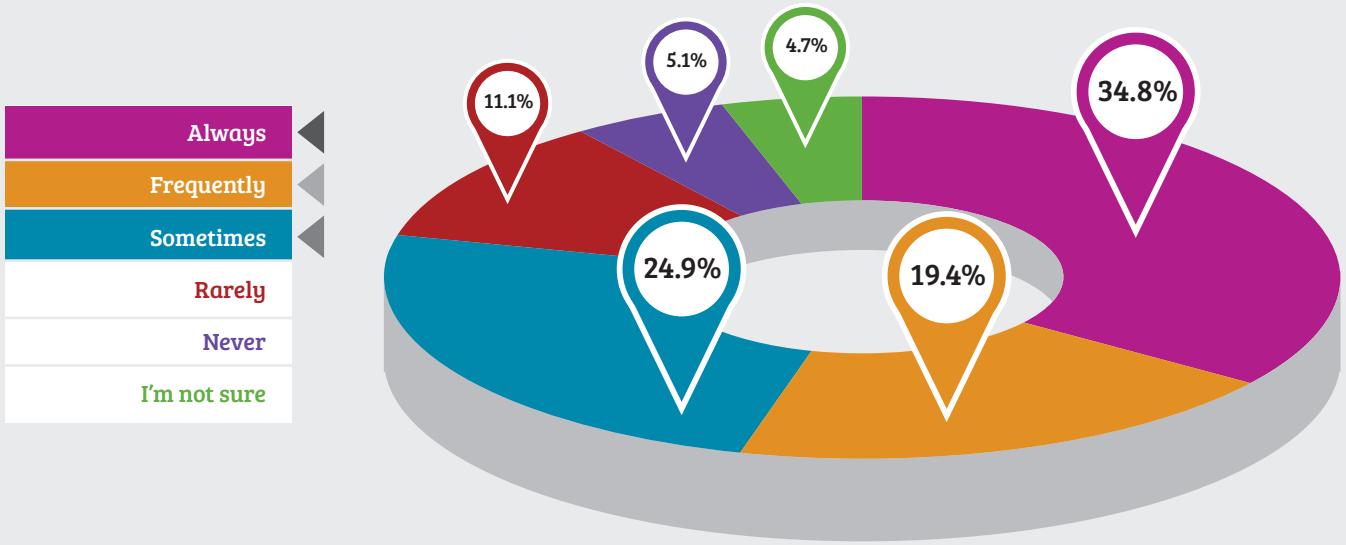
NEEDS ASSESSMENT AND SUPPORT PLANNING: How do people experience assessment and care planning?

WE ASKED: About respondents' experience of assessment and care planning, if they had been in contact with the council to arrange or change support. The survey asked them to rate their experience against the following aspects:

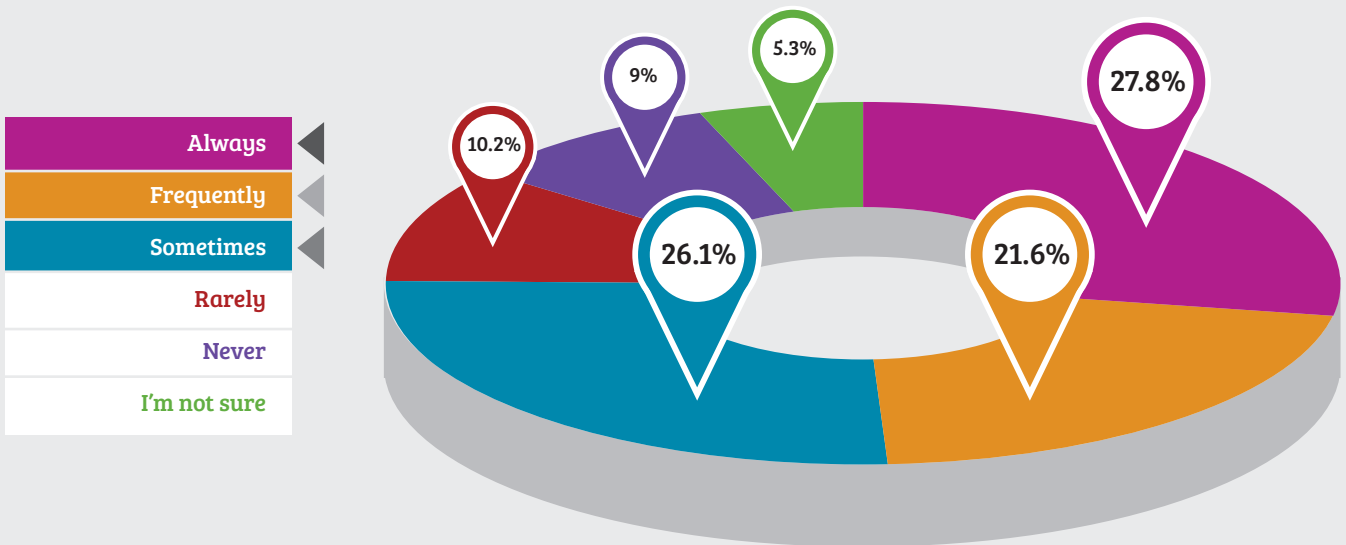
1) The council has listened to me and understands what I want and need.



2) I have been involved as much as I want in arranging my care or support?



3) My choices have been respected in arranging care or support?



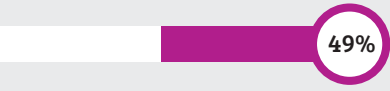
Breakdown of results and other results of interest



The majority of respondents said the council sometimes, rarely or never listened to them, but just over a quarter of respondents felt that the council always or frequently listened to their wants and needs.



More than half were involved as much as they wanted in arranging their care or support.



Just under half felt that their choices are always or frequently respected.



Carers were less likely to feel listened to (74%) than people who need care and support themselves (65%).

What do people with care and support needs want to see change?

Some survey respondents described in their own words changes they wanted to see to the processes of arranging care and support:

“The first step towards receiving care and support is an assessment. The way that Councils avoid meeting their duties under the Care Act is by making it as difficult as possible for assessments to be carried out ... It means care and support needs go unreported and unrecognised.”

“Councils are changing the carers assessments ... and reducing what is available and the criteria are very high now so worried about next year.”

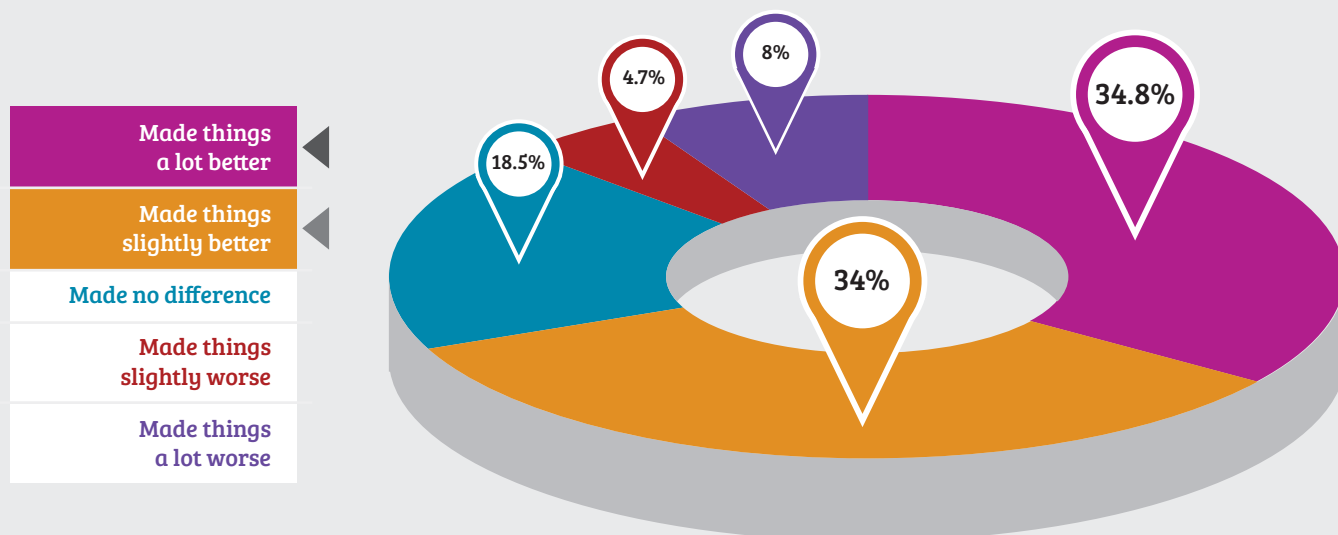
“Better communication between the different professionals. I often feel like I am the Care co-ordinator as I have the greatest awareness of need.”

“Too exhausted and fed up with the system to look into the changes and to contact anyone regarding support. It is always laborious and there are so many obstacles/reports/assessments.”

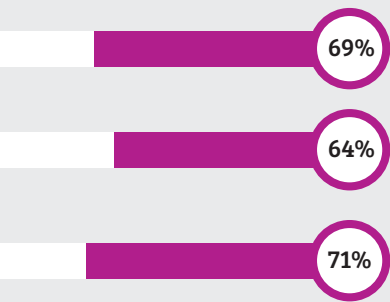
WELLBEING: How do care and support make a difference to wellbeing?

WE ASKED: What difference support had made to aspects of people’s lives over the last year.

1) Health



Breakdown of results and other results of interest

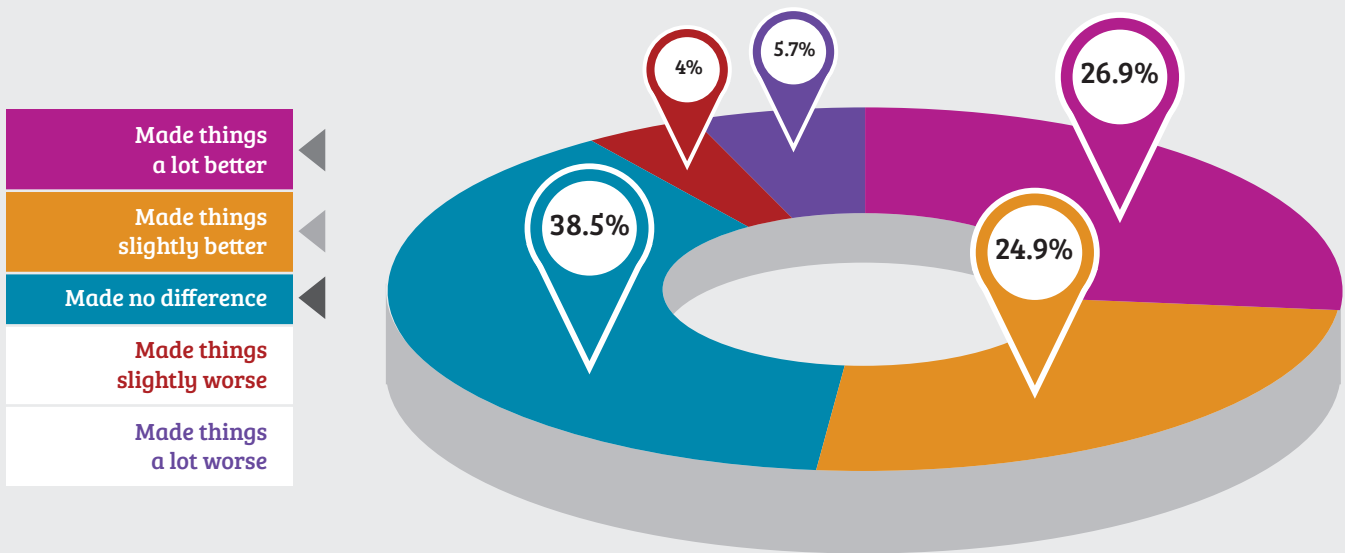


Overall, more than two thirds said their care and support made a positive difference to their health. Of these:

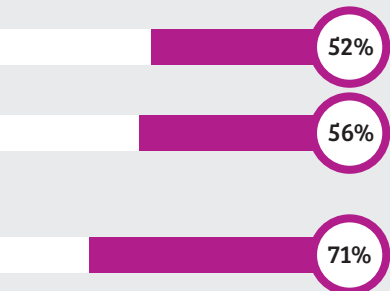
Carers were less likely to report improvement in their health (64%) than people who need support for themselves (72%).

People funding their own support (71%) were less likely to report a positive effect on their health than people receiving full financial support from the council (80%).

2) Taking part in your community, doing things you enjoy



Breakdown of results and other results of interest

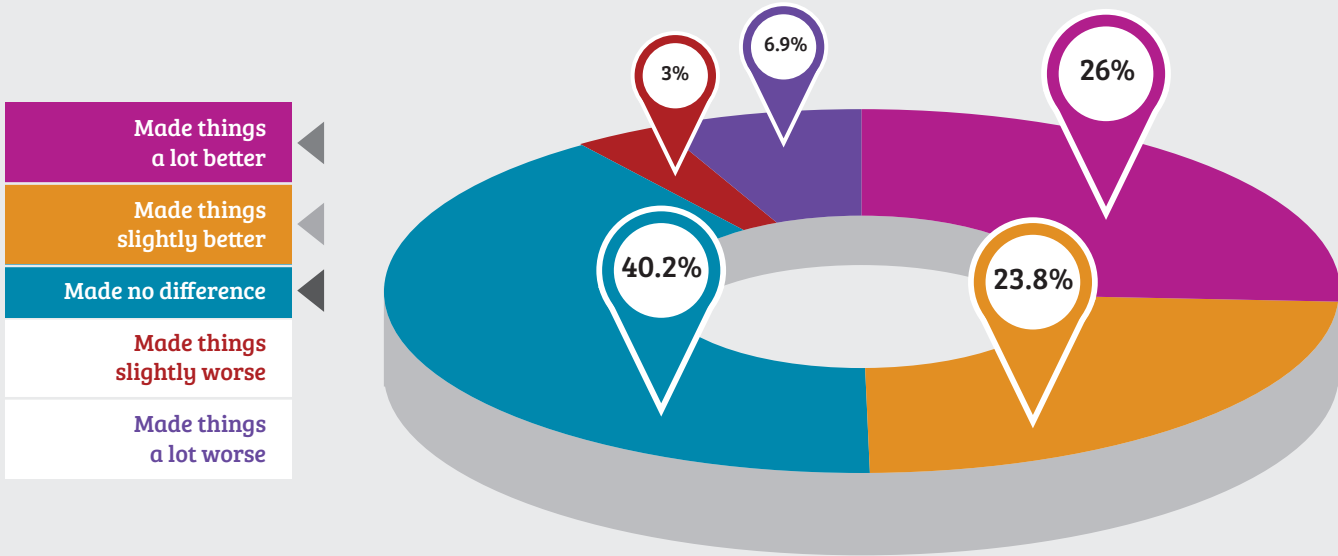


Just over half found that support made taking part better.

Over half of carers said it made no difference to taking part, or made things worse, but fewer people with support needs felt like this.

71% of people funding their own support said that support made no difference or made things worse – compared to 40% of people who had council funding.

3) Spending time with family and friends



Breakdown of results and other results of interest



Overall, one half (50 per cent) said that support made spending time with friends and family better. Of these:



Younger adults (18-35yrs) were much more likely than all other age groups (24%) to say that support made spending time with friends and family a lot better.

Other Evidence

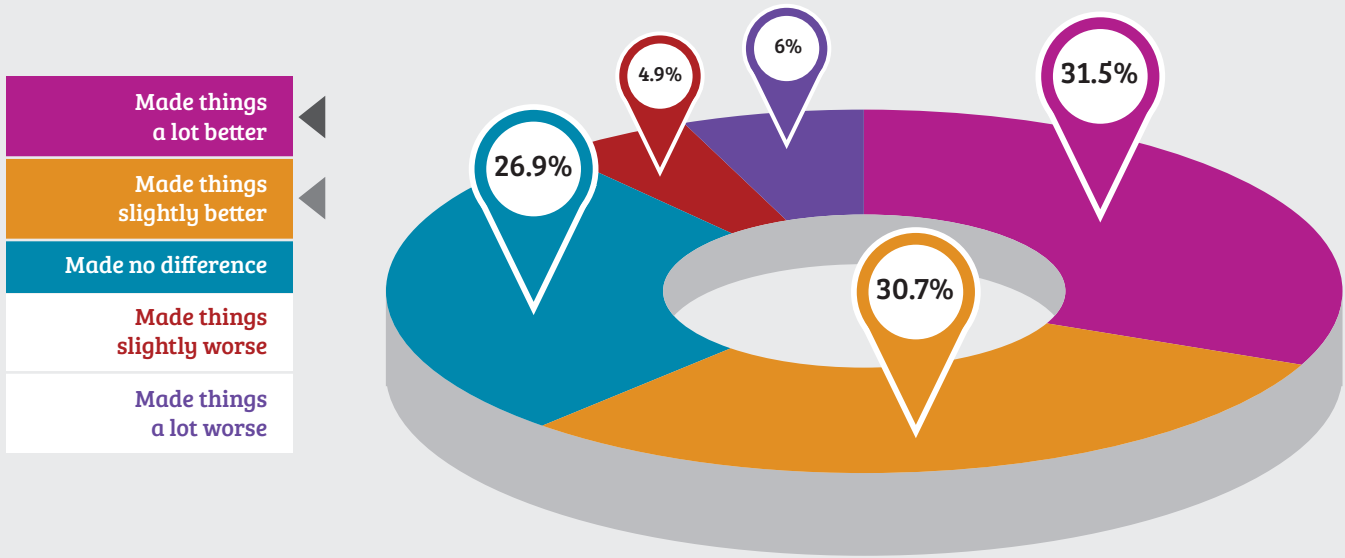


NHS Digital statistics for 2015-16 showed an increase in the proportion of people who said they had little social contact and feel socially isolated.¹¹

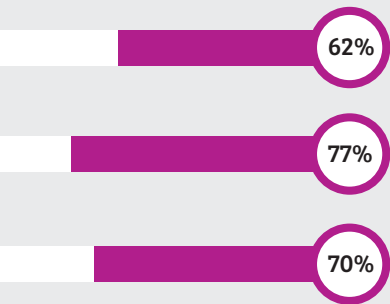


From the same source, the proportion of respondents who said they had adequate social contact in 2015-16 (32.6 per cent) reduced from the level reported in 2014-15.

4) Your home (being happy where you live)



Breakdown of results and other results of interest

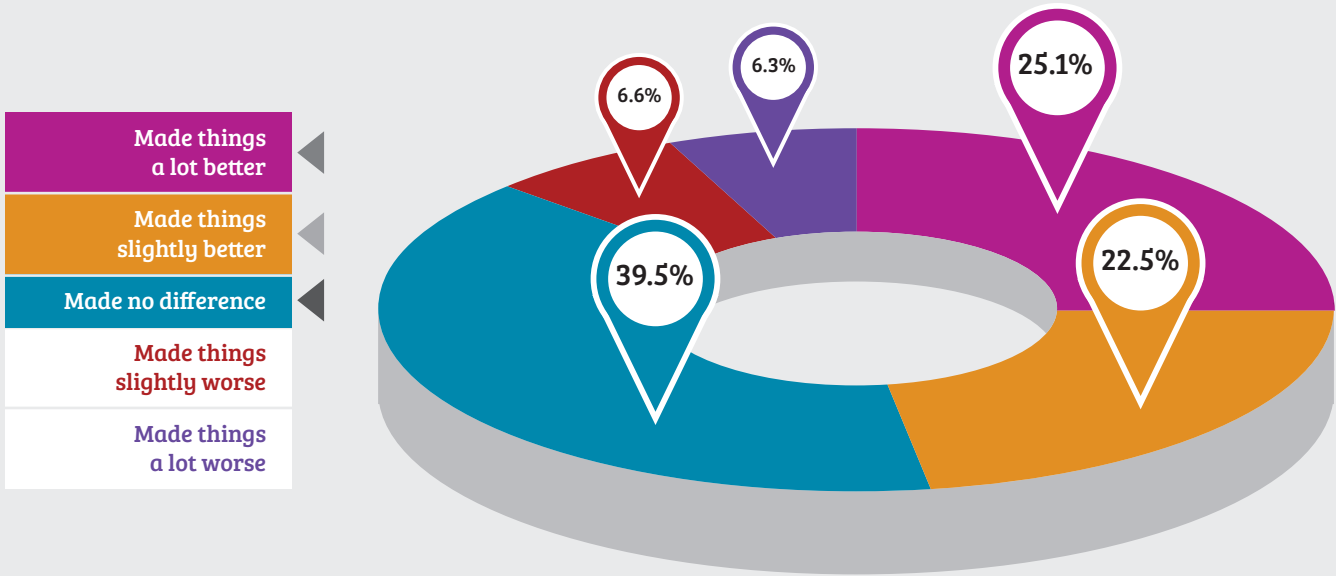


Nearly two thirds said their support made being happy with their home better. Of these:

The majority of people who pay for their own support reported that they were happy where they live.

Fewer of those who have council support reported that they were happy where they live.

5) Feeling safe and secure



Breakdown of results and other results of interest

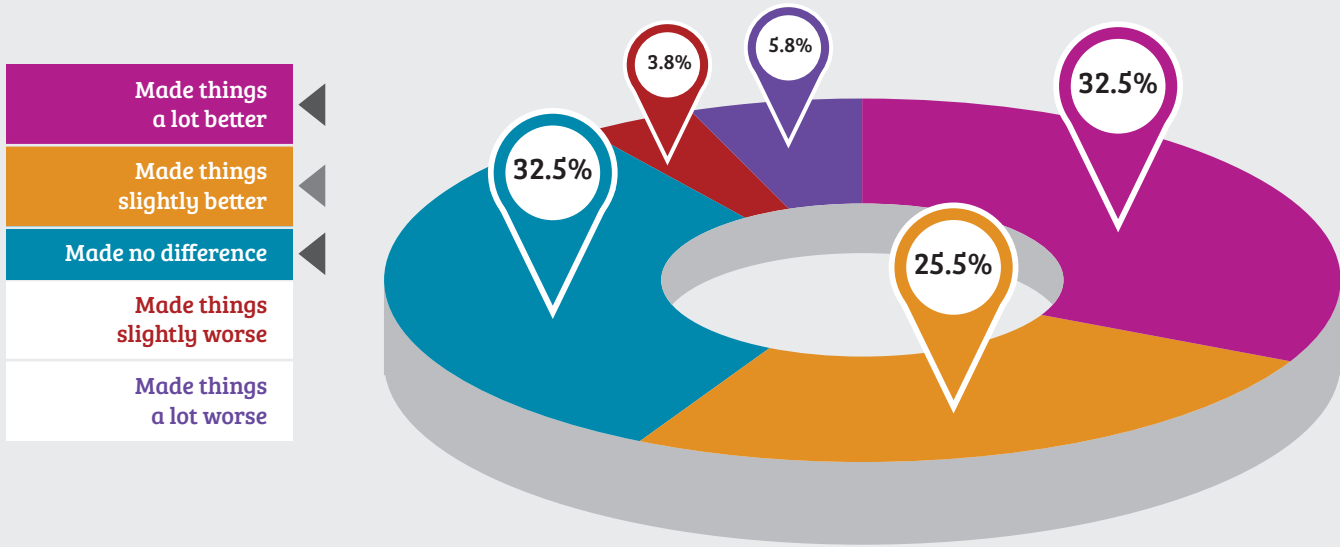


Just less than half said their care and support improved their feeling of safety or security.

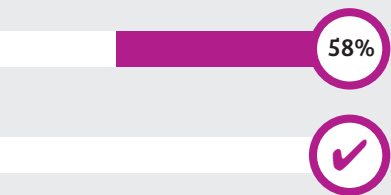
Over half said support made no difference or made them feel less safe.

Carers were more likely to report that support made no difference – just over a third said support made feeling safe and secure better.

6) Daily living activities



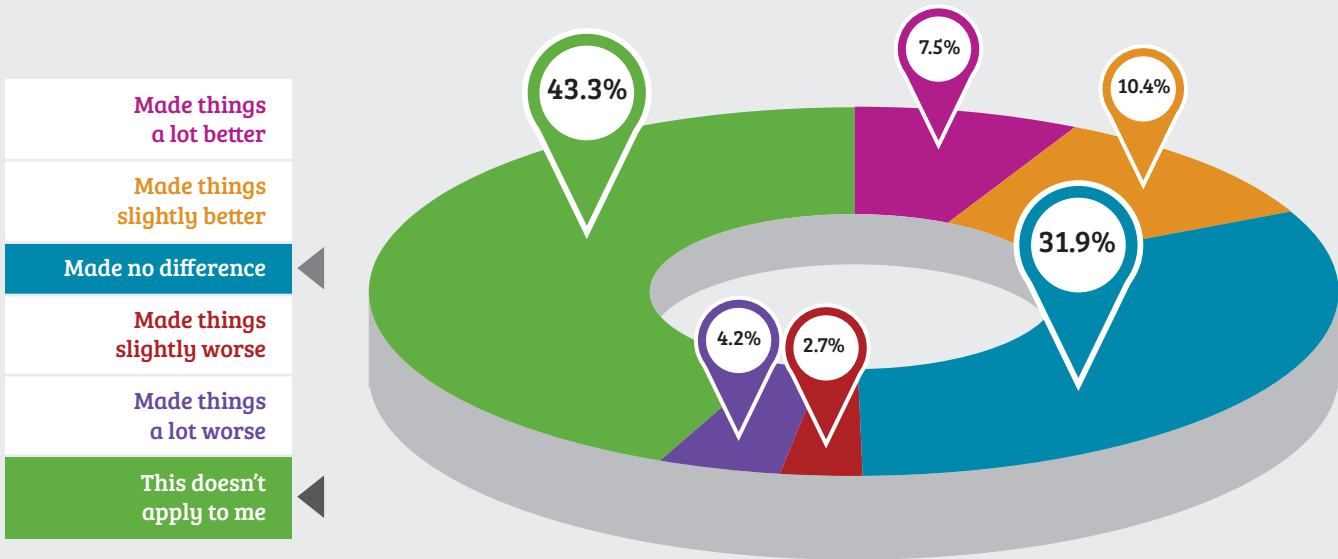
Breakdown of results and other results of interest



Over half said that support made the activities of daily living better – and this rises to three quarters for younger adults aged 18 to 35 years.

People who need support for themselves were three times more likely than carers to say that support made daily living activities a lot better.

7) Finding work or continuing to work



Breakdown of results and other results of interest

Less than a quarter said that their support helps them 'a lot' or 'slightly' when finding or continuing to work; a third said it made no difference at all.

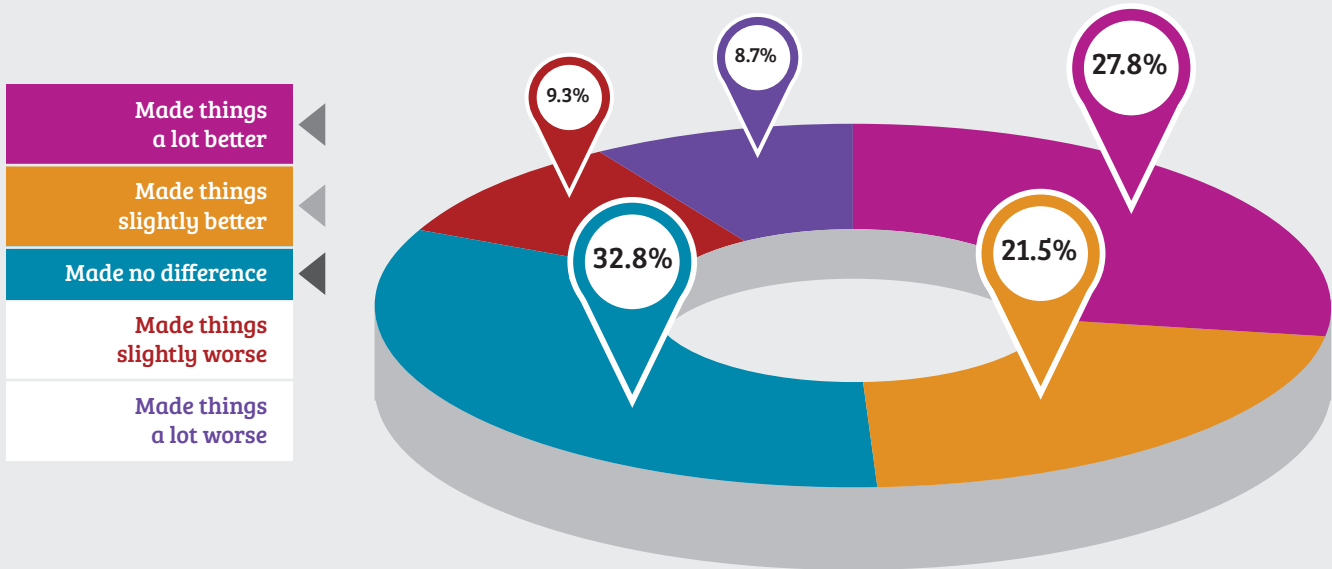
18%

43% said this question didn't apply to them. Only 17% of the overall respondents to this question were over the age of 65. A high proportion of this age group answered that this question did not apply, but as too did a high proportion of people across all other age group. No further data is available to help better understand this response.

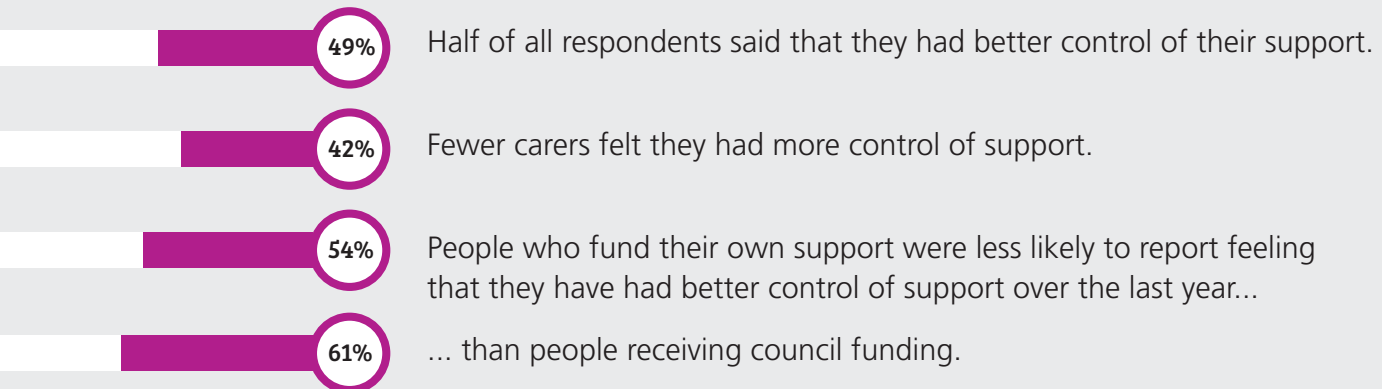
43%

8) Choice and control of support

WE ASKED: Whether having choice and control over when people were supported, and by whom, made a difference.

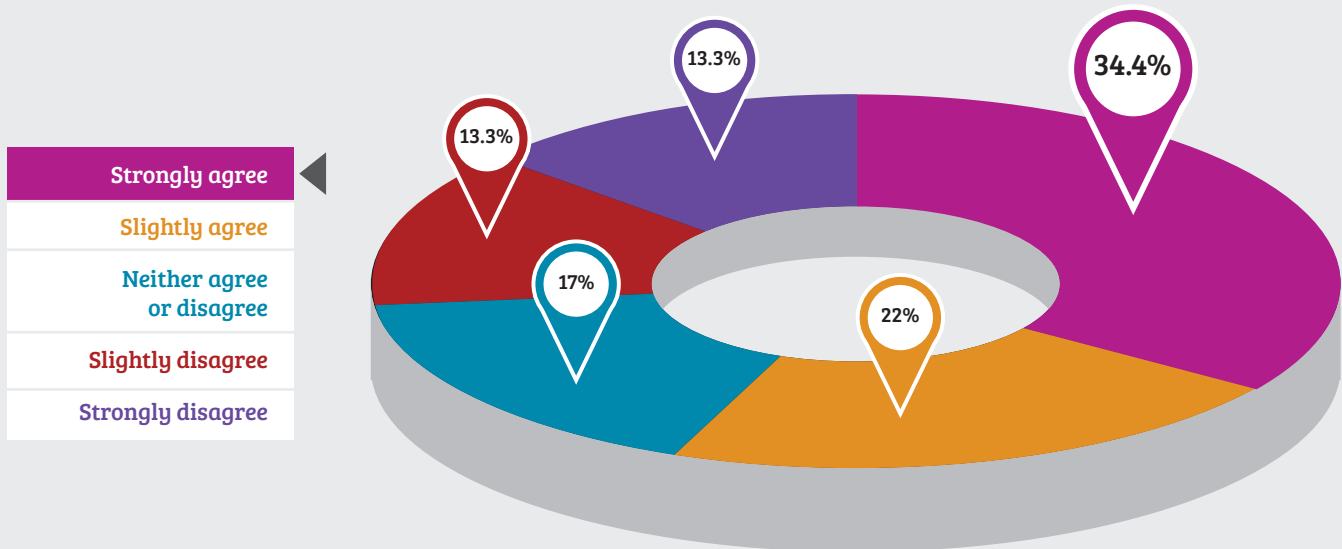


Breakdown of results and other results of interest

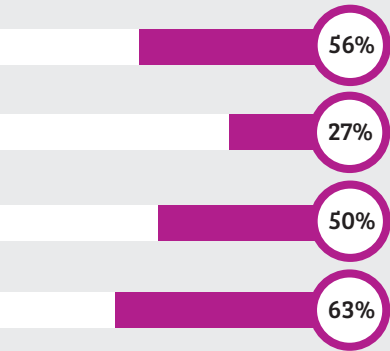


QUALITY OF CARE AND SUPPORT

WE ASKED: Survey respondents if they were happy now with the quality of their care and support.



Breakdown of results and other results of interest



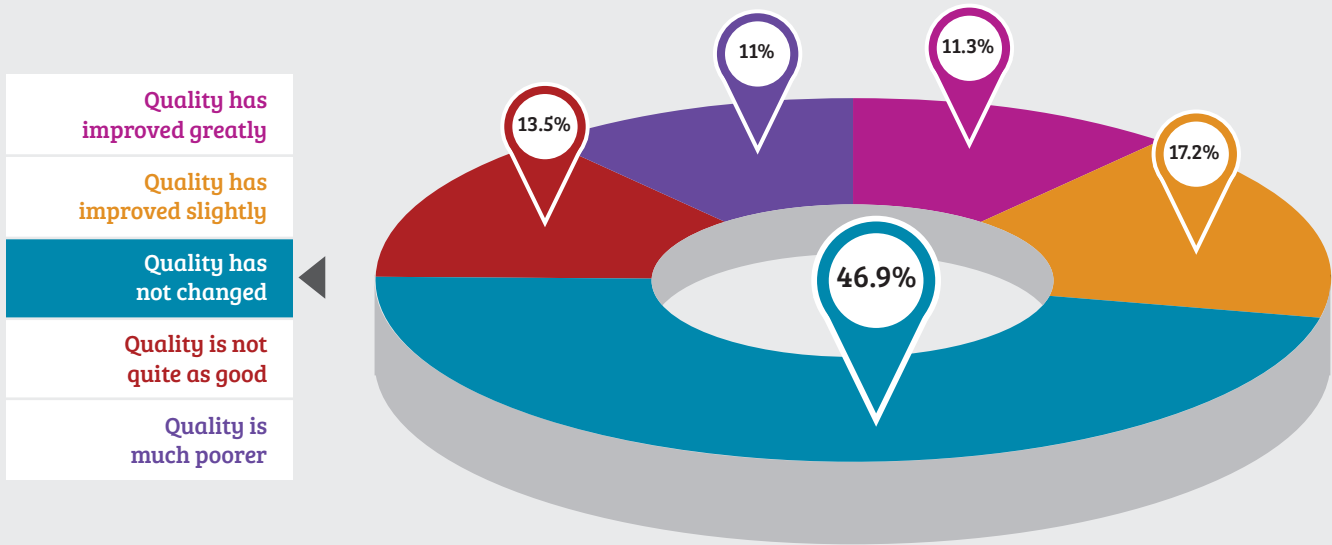
More than half said they were happy with the quality of care.

Over a quarter were not happy with the quality of care.

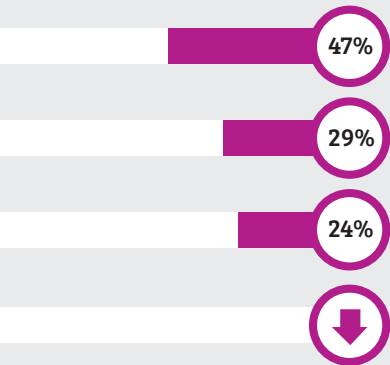
Carers were less likely to be happy with the quality of care (50%) than people needing care for themselves (62%).

People who fund their own support were less likely to be happy with the quality (63%) than those who have council funding (66%).

WE ALSO ASKED: Whether the quality of support had changed over the last year.



Breakdown of results and other results of interest



Overall, just under a half said quality had not changed.

Over a quarter said quality had improved.

Just under one quarter said quality was poorer.

People who pay for their own care were less likely to report improved quality than people who have council funded support.

What did respondents say about the quality of care or support?

237



Some 237 people responded to this question. A number praised the qualities of care workers, or personal assistants. There was particular satisfaction from a small number of people using direct payments who organised their own support, stayed in control of recruitment and the management of day-to-day support plans. Concerns about self directed support usually related to the levels of available council budgets (through direct payments), or to the high costs of care for people who fund their own support.

There were also more critical comments about the quality of support: including lack of respect, inconsistency where there are multiple carers, and communication problems with the companies supplying care workers.

Please note that the quotations are as extracted from the survey: no attempt has been made to correct any apparent language errors. In some places editing has been carried out to protect privacy or for brevity and is represented by 3 dots (...).

Being treated with dignity and respect, person centred support

16 people commented positively on this aspect. For example:

“Staff support me in a person centred way. I am respected and given choices. My needs and wishes are taken into consideration when planning my time table which I am involved in.”

“The support and care I get from my carer is amazing, she goes and does things that are beyond her contract. Nothing is rushed we do things when I’m ready, she is kind and always has a smile.”

Less positively, 20 people reported different experiences:

“Some (carers) are not very respectful some are always in a hurry and cut down on the time they should be in for.”

“The actual Carers who care for my husband are very pleasant people but they are not always really engaged in his needs. They often rush the call ... My husband has Parkinson’s and often becomes very stiff ... and I find that many of the Carers are not aware of this and complain that he is stubborn!”

“All care agencies do not have English speaking carers so it’s very hard to get carers to understand what you want ... this needs to change!”

“It is vital that officers within the council and any decision makers don’t adopt a ‘one size fits all’ scenario. We are all different and our needs are specific and personal.”

Skills and knowledge of care and support workers or Personal Assistants (PAs)

15 people made positive comments on skill and knowledge levels:

“The people who support me are equipped with the relevant skills and knowledge to ensure that I am safe ... and there is an ongoing programme of refresher training.”

“I particularly like people who can sign (bsl) around me, and especially male staff, I like it when they can drive and we can go out in the car.”

Rather more people (32) had criticisms relating to the competencies of care and support workers:

“It’s been especially difficult to obtain appropriate care with a fluctuating, unpredictable, hidden disability. ... They are also not adequately trained or staying in the job long enough to benefit training them so it’s been impossible to provide quality care...”

“Never know who will turn up, new untrained people who only last a couple of days, do what is essential if they are able, fortunately usually one of the pair know what to do ... I have been injured ... just by people being careless. Get no support for anything other than personal care, never go out, or support with activities.”

“The care company I use from time to time send lots of different carers some of whom are very good, others are not. All are respectful and reliable, but some lack very basic knowledge and skills, such as how to wash their hands and what is hygienic and what isn’t (in areas like food prep and washing up).”

“Home carers are all different many don’t have skills or knowledge of my condition to care for me correctly (I’m hemiplegic following massive stroke) care times vary and can be very late in mornings getting me up I cannot have a bed call as my agency doesn’t have calls after 8.30pm and it’s too early for me to go to bed at that time luckily I can put myself to bed.”

Adequacy of resources to meet needs (qualifying for support, levels of direct payments, costs of self-funded support)

There were many reported worries about the adequacy of care and support affecting the quality of life, but also two positive comments:

“Since I pay an agency for my husband’s care I have quite a bit of control over the quality of care I get. My carers are excellent... However; although we are not wealthy we have been thrifty and have some savings so I have to pay for care and for respite when I need it. I feel that carers in my position should get some financial help with the high costs of care. It worries me that our savings are getting depleted. I worry for my future. I am 78 and feel my life slipping away whilst there are still ‘a lot’ of things I would like to do but can’t.

“We receive paid respite ... through direct payments. The carers we employ through this scheme have vast experience with children and young adults with additional/special needs. We are very happy with the respite we receive for our child ... Its valuable and much needed for us”.

The 44 concerns expressed were typically about the absence of support, or inadequate levels of support and the impact this makes on the quality of life, both for carers and people who need support for themselves:

“My carer is wonderful but my council is trying to make cuts I am strongly resistant to changes.”

“I am a carer for my husband who needs 24/7 care. Social workers do not fully understand how badly Parkinson’s Disease affects my husband. I do everything for him apart from two carer’s calls to shower him and put him in bed. He has constant falls and falls out of bed but will not provide a bed with cot sides. We pay nearly all funding for care. Although I have just been granted more breaks, I do not take them because they insist he is sent to the worst care home that doesn’t suit his needs as it is the cheapest in the area ... The stress of looking after him ... has had an impact on my health. I hardly ever see family and friends anymore. I feel isolated and imprisoned. He has needed to be in full time care for a long time but says he will not go so I will be looking after him until I die.”

“Despite clearly needing it I receive no support of any kind from my county.”

“The biggest stress in my life is from Council funding and keeping my carers.”

Choice and control over support

Of the 21 positive comments about choice and control, a high proportion of people reported positively on the ways that direct payments contributed to the quality of support, even though this might involve a lot of effort to maintain. For example:

“I receive direct payments and this is crucial to me, I use the freedom to choose to get the care I need when I want it, from carers I like, can rely on and trust. It has however taken ‘a lot’ of work to keep this working well. I have had helpful social workers but find it annoying they have to close the case and you have to start again with a new person every time there is a change, inevitably these happen as health deteriorates and the condition progresses.”

“Being able to go onto direct payments has enabled me to employ my own staff team, whereas before I had 24 hour live in care from a direct service and it caused difficulties at home, now I am my own boss and feel in control of my own life.”

“I have moved from the restrictions of council provided agency care to direct payments which has made a vast improvement and allows me to be me again.”

Conversely, some difficulties were also reported, often in relation to the available budgets, or inability to control the timing or frequency of support:

“The quality of care provided by independent providers to the person I care for has normally been and remains good but the quality of care offered ... for me as a carer has become very significantly poorer as a result ... of the awarding of a contract for provision of a Carers’ Service to a remote organisation whose staff appear to have no knowledge of what being a carer involves and no skills in relating to carers.

“The quality of care I receive varies according to which carers come. Though I receive a list of the carers I should have for the week in advance, this can’t be relied on. I have had money stolen and though I told the provider about this and the police were called in, I never received the money back. If I am going to return home late for any reason, I tell the carers and the organisation, but sometimes they don’t act on this and when I do get home the carers have already been and I won’t have any tea or help to get to bed.”

Quality of service commissioning and service providing organisations

Seven people made positive comments about the organisations that were responsible for arranging or providing care or support:

“We were fortunate to be able to access a reputable domiciliary care agency from the outset. For a limited period, we had the benefit of employing a PA. For some years we have benefitted significantly from the support of the carer centre in the county and also from a dependable sitting service, providing short respite breaks. Very rarely have we experienced disappointing quality of support from the workers involved.”

“I talked to the staff about moving to supported living, they helped me arrange for assessment with social worker and got me an advocate. I have now found a flat and will be moving soon. Staff are supporting me to use trains alone for when I move.”

There were 36 less positive comments, many about agency unreliability, and often related to the pressures agencies experience in supplying an adequate number of trained workers to meet the needs of people using the services.

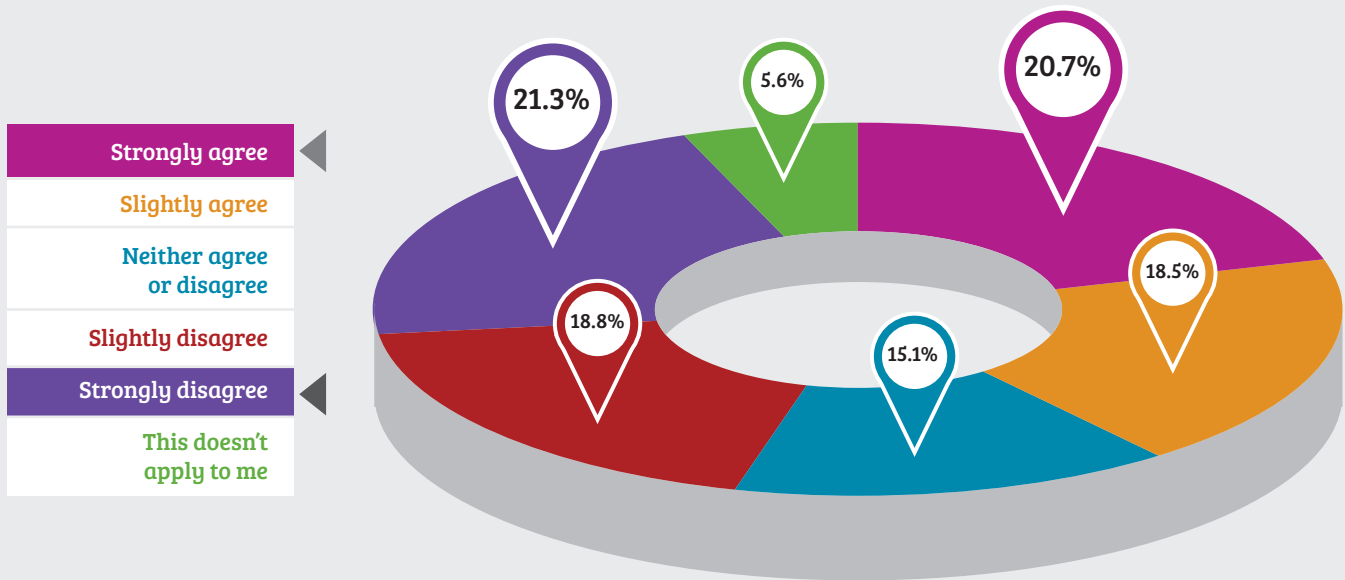
“Yes my social worker is great I can phone her anytime ... but the care company that does my care are not that good there is no communication and I have to phone them at least once a week to find out where the carer is ... I get a rota sometimes it does not turn up till the middle of the week. They change the time of the carer call without commenting with me and sometimes they have only two days training ... all I ask is to be keep informed of what is happening.”

“The person I care for is quite often let down by the care agency who find it difficult to find replacement care while I am working at the shop. This means I am unable to go into work to volunteer, at short notice. Also, I am now expected to pay for travel costs as personal budget will no longer pay for travel.”

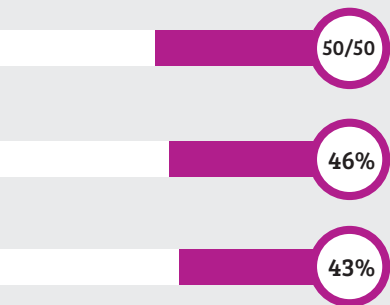
“I am self funding for care. I have knowledge of the act anyway and notice that assessors don't have a great deal of knowledge on benefits such as pension credit regulations or council tax benefits here in (a county council area). They give incorrect information. Also they hound residents for detail of where/how they spend their own money even when the resident is self funding. I am not eligible for help and am offended and annoyed. Why did they want bank statements from 5 years ago? I am not a criminal. Hounding people under the guise of social care should be illegal.”

LOCAL SERVICES

WE ASKED: Respondents to rate how easy or difficult it had been to find the kind of care or support that they wanted in their local area over the last year?



Breakdown of results and other results of interest



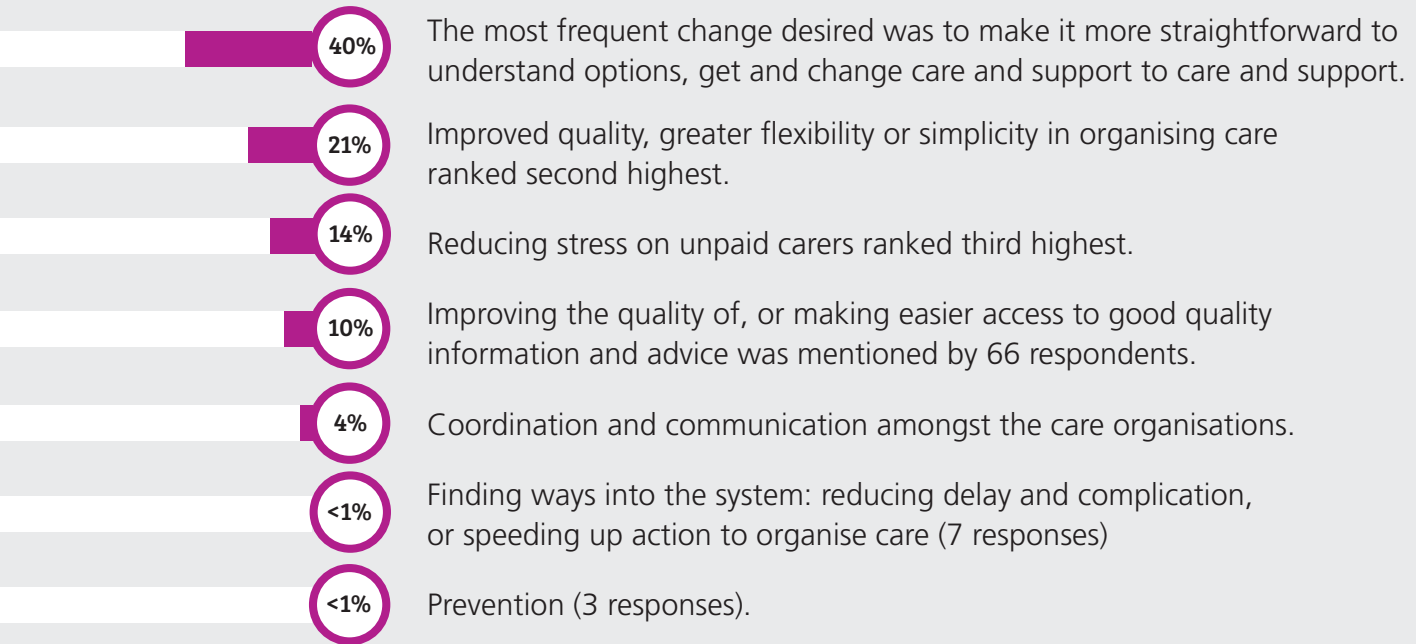
Overall, people who responded were about evenly divided in finding it easy or difficult to find the care they wanted locally.

Carers were more likely to report difficulty finding local care and support (46%) than people who need support for themselves (35%).

People whose support is funded by councils were much more likely to agree (43%) than people who fund their own support (36%).

Changes sought by people with care and support needs

WE ASKED: If there was one thing about your care or support that you could change, what would it be? There were 741 responses, all of which were analysed and classified into groups by theme:



These topics are considered in turn: please note that about nine per cent of responses were not classifiable by theme and are not included in this section.

40% **ACCESS TO SUPPORT: Absence or inadequacy of care and support (273 responses)**

This topic was the most prevalent among the responses. Typically, anxieties or concerns expressed were about:

- Not getting any support at all.

- The lack of assessment or follow up with support after assessment.
- The access obstacles represented by assessment.
- High thresholds to qualify for support (eligibility for council funded help).
- Reductions in existing levels of support, or fears about this happening in the future.
- The costs of support (for people who pay for their own support).

“As well as being a carer for my mother, I am a healthcare professional and therefore know what to expect ... what would I change?? The local authority, my mother’s GP, the local NHS mental health services have not been in contact, carried out a review or offered/provided any support now for 2 and 1/2 years; it would be good to think the Care Act made a difference but it appears not.”

“I would like to find reliable caring help for myself but it is almost impossible in (a Council area). Council cutbacks mean there is no money available unless one is terminally ill.”

“I wish they wouldn’t threat to cut my budget. I’m worried I will be stuck at home with no support.”

“Making the ‘system’ easier! It is such a huge battle to get support that sometimes it is not worth even trying. The energy it takes to fight the system is phenomenal.”

21%

Quality of care and support: Listening, a more person or family-centred approach: lack of continuity, or inflexibility (147 responses)

Many people described changes they wanted in the way support and care were provided, or to its qualities. These are summarised as follows:

- A more person-centred, or family-centred approach.
- A more compassionate approach by council representatives with assessment responsibilities.
- Greater flexibility to vary the “who, what and when” of support (including direct payments).
- Better continuity or consistency of care.
- Higher levels of skill, (including specialised skills or knowledge) competency or professionalism among support and care workers.

“I would like an inclusive plan that supports my whole family and myself as a parent. I would also like to be able to have support so I can go outside my house. I would like to live as a (...) woman without being made to feel like a baby in nappies and be able to access a toilet when needed not when told. I would like to be able to eat and drink knowing that I can go to the bathroom if needed. Lastly I would like support to be out as a family and do normal activities like cinema or shop for boys’ birthdays or Christmas or go to events and for my husband to receive some respite before we have no marriage left to save.”

“Ad hoc care rather than permanent care would be really useful on a pay-as-you-go basis to give my partner a break occasionally.”

“I have a personal budget, but would like to be able to be more flexible. If I want to have less care and save money when I am feeling not too bad, I would like to use the money for extra care when my condition is worse. However, money not used will be taken back by the council.”

“... that the company informed me when they change my time slot”

“A new personal assistant with better skills and a professional attitude.”

“I am on the Autistic Spectrum (Aspergers) and I need routine, structure, stability and continuity and since the death of my Mother I no longer have this and I find it very difficult to function.”

“My son is in supported living. More consistency in terms of staff would mean that less mistakes were made. I have been forced to become his care co-ordinator more and more and I am not getting any younger. This also applies when dealing with clinical professionals who often don't have his notes or haven't read them, contradict each other.”

14%

Carers: Relief from stress and exhaustion (97 responses)

Responses from carers described carer stress, exhaustion, loss of income and quality of life. One person receiving support wrote that he wanted change that would:

“... take stress off my wife ... I am slowly watching her work her way into the grave. She works as a full time nurse on the local cardiac unit dealing with life and death decisions each day. When she is off work she is caring for me. The only carer support she received was 2 hours cleaning a week which has been removed in my review in June. When the cleaning was done it was the only time I saw a smile on her face I don't know how much more she can take. To be honest I can't help feeling she would be better off without me.”

Carers responding were amongst the most critical about the care and support available: mostly about the lack of support.

The changes mentioned by carers can be summarised as follows:

- Relief from the physical and mental strain of caring without support.
- The (adverse) financial consequences for families of full time caring, from loss of earned income to the levels of benefits.
- The need for respite or other breaks to prevent the breakdown of health.
- Contact with people who can advise on care and give emotional support.

- Surprise and frustration that carers' entitlements through assessment are either not clearly understood or advertised by councils.
- Anxiety about who will care if the carer is no longer able to do so.

“More physical, emotional and financial support for my carer, who is my husband and has to work 2 jobs, one full and one part-time, to support us. This has taken a toll on his own health, both physically and mentally, which in turn has an effect on me and my health.”

“As a carer, it is difficult to combine the needs of my aunt ... despite support from various agencies ... with my career as a senior mental health worker, and my private life having recently married. The constant demands leave little satisfactory time for rest and recuperation ... let alone fun.”

“I would actually like some support! The council/government does not appreciate what carers have given up in order to care. I've given up my career, my pension pot, my future all for £62.10 a week. I'm expected to be a nurse, carer, housekeeper, cook, nutritionist, health expert, advocate ... Continuing Healthcare (CHC) are trying to get away with as little as possible! I'm continually fighting. It shouldn't be like that!”

“Recognition that as a carer, we are continually running on an empty tank ... With no chance of refuelling. Respite should be available for carers on a regular basis. Instead we are left to our own devices...”

10%

Information and Advice (66 responses)

The improvement of local information and advice is a major objective of the Care Act and prompted varying comments from people completing the survey. The changes sought by respondents can be summarised as:

- Simpler ways of finding advice and information, for example, through a single common point: or better still, more pro-active help from the agencies.
- More personalised or in-depth advice for example about care and support options.
- Greater clarity and accuracy about entitlements to support, the costs and how to meet them.

“It would be useful to know what other options are available to me and the information needs to be put out there in a way that is easier to find.”

“Help from social services. Was told as I did not need financial help they could not open a case on us so have been left to sort ourselves out.”

“Knowing how to pay for long term care when I am unable to look after my disabled son. It is impossible to plan as the government has reneged on its capping policy.”

“Someone to listen to me and help me sort out what to do NOT someone who tells me to go somewhere else that then leads up a blind alley.”

“A system which pulls all information together, so as a carer you do not spend your time ringing adult care services and NHS and Council services ... People who properly listen and don't pass you from pillar to post. Services where staff get back to you when they say they will...”

“Having someone to turn to in order to explain all the options without the red tape of being told “I can't tell you that”... Having someone to co-ordinate things so if you phone for help and are passed on, you can go from one person to another and end up where you started. Nobody takes responsibility.”

4%

Coordination and communication amongst the care organisations (32 responses)

The main issues noted were:

- Having to tell the same story to different professionals numerous times.
- Professionals apparently not communicating with one another.
- Lack of clarity about agency responsibilities – mainly between health and social care.
- Being unable to find the right person to talk to: “going from pillar to post”.
- Finding care after a stay in hospital.

Typical examples of changes sought include the following:

“Not being ping ponged back and forth between council adult services and NHS ... resulting in absolutely nothing, just the usual exhaustion from the effort and finding out it was pointless.”

“Better communication between the different professionals. I often feel like I am the care co-ordinator as I have the greatest awareness of need”.

“To be able to find a phone number and not be passed to several people having to explain the problem over and over again.”

<1%

Finding ways into the system: Reducing delay and complication, or speeding up action to organise care (7 responses)

Some people who answered found the processes to access care and support complicated. The key changes sought are summarised as follows:

- Prompt assessment and follow up, especially at times of crisis.
- Simpler, less complicated access to assessment and support.
- Simpler administration of Direct Payments.
- More flexibility to vary support quickly when needs or circumstances change.

"I am living with my wife who is also totally blind and hearing impaired. She was admitted to hospital on 9 August, and I contacted xxxx social services dept., with which we are both registered. They said they would send somebody to assess her and my needs. Today, 30 Sept. I am still (waiting) for them to call!!!"

"The first step towards receiving care and support is an assessment. The way that Councils avoid meeting their duties under the Care Act is by making it as difficult as possible for assessments to be carried out. ... assessments should be carried out by individuals and by organisations independent of local authorities so they can't limit access to them as a means of rationing care."

"I would improve the time it took me to receive a response from both health services and the Council. Health services didn't take my needs seriously until I reached breaking point – and even then the support I received was limited. During this time, I was asked if I would like a Cares Assessment. The council then took almost a year to get in touch to offer me one."

"Too exhausted and fed up with the system to look into the changes and to contact anyone regarding support. It is always laborious and there are so many obstacles/reports/assessments before at the end of it the nightmare that is direct payments is offered to you and then repeat with a whole new set of obstacles/hassles and professionals to meet."

"That carer's assessments were carried out promptly – waited 9 months last year and am now 3 months overdue this year. Also that my son's social worker remains in contact – haven't heard from anyone for months since his named social worker went on long term sick. My son has autism and can present challenging behaviours so it's hard."



<1%

Prevention (3 responses)

A few respondents identified changes that described how prompt or earlier action to provide support would help prevent personal or family situations from worsening.

“They would have to step in at a moment’s notice if I became too ill to care 24/7. Why not try to make things easier by providing respite without delay or quibble now?”

“I would improve the time it took me to receive a response from both health services and the Council. Health services didn’t take my needs seriously until I reached breaking point – and even then the support I received was limited. During this time, I was asked if I would like a Cares Assessment. The council then took almost a year to get in touch to offer me one.”

Appendix 1:

Steering Group Members

With thanks to the following past and present members of the Care Act Survey Steering Group who helped us complete this work:

Phillippa Ashcroft, *Voiceability*

Fredi Attwood, *Care and Support Alliance*

Mike Beazley, *Care Performance Partners*

Anna Davies, *Independent Age*

Linda Doherty, *Think Local Act Personal*

Carl Evans, *Department of Health*

Clenton Farquharson, *National Coproduction Advisory Group*

Alvin Kinch, *Healthwatch*

Jean King, *Department of Health*

Jaimee Lewis, *Think Local Act Personal*

Stephen Lowe, *Age UK*

Ciaran Osborne, *Independent Age*

Louise Newport, *Department of Health*

Andy Payne, *Healthwatch*

Don Redding, *National Voices*

Isaac Samuels, *National Coproduction Advisory Group*

Lynda Tarpey, *Think Local Act Personal*

Debbie Turnbull, *Think Local Act Personal*

Martin Walker, *Think Local Act Personal*

John Waters, *InControl*

Martin Yates, *National Coproduction Advisory Group*

Sara Zmertych, *Think Local Act Personal*

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Think Local Act Personal

Think Local Act Personal (TLAP) is a national partnership of more than 50 organisations committed to supporting the continued implementation of personalisation and community-based health, care and support.

web: www.thinklocalactpersonal.org.uk

email: info@tlap.org.uk

twitter: @tlap1