

Independent Living Survey 2016

Published by

In Control on behalf of the Independent Living Strategy Group

Personal dignity

Social and
economic
wellbeing

Protection from
abuse and neglect

Domestic, family
and personal
relationships

Control by the
individual over
day-to-day life

Contribution to
society

Suitability of
living
accommodation

Physical and
mental health and
emotional
wellbeing

Participation in
work, education,
training or
recreation

The individual aspects of wellbeing or outcomes above are those which are set out in the Care Act, and are most relevant to people with care and support needs and carers. There is no hierarchy, and all should be considered of equal importance when considering 'wellbeing' in the round.

Foreword



**Baroness Campbell
of Surbiton DBE**

In April 2015 the Care Act became law in England. It radically changed the way in which care and support services were to be organised. The act now places local authorities under a powerful obligation which has the potential to help thousands of disabled people to enjoy what most people take for granted – ‘Independent Living’. Today,

Local Authorities are charged with actively ‘promoting’ an individual’s well-being, not simply “having regard for”. Now, all decisions taken by local authorities when exercising their powers under the act, must meet this general duty – it’s the law!

The Care Act could potentially be the most exciting, creative and positive move forward in the history of local authority care and support services. The question is, is it working in practice? If not, what do we need to do to improve its future progress. This survey attempts to answer some of these questions based on the real-life experience of those using its services.

The Act is far reaching in the areas of life it covers, for example ‘personal dignity’ to ‘control over daily life’. The list is impressive and encompasses the things that people in the independent living movement have been campaigning for, for decades. In addition, many of the obligations the government has signed up to under the **UN Convention on the Rights of Persons with Disabilities** are contained within. So as well as being comprehensive and powerful, it is a long awaited list with a compelling provenance.

Exciting times with all to play for one might think, however successful implementation is up against a massive problem. This new duty is being placed on local authorities at a time of unprecedented cuts to their funding, when the population of older and disabled people is rising. The demand for social care services is mounting. It is estimated that Local Authorities have had to **make £3.53 billion budget savings** over the last four years. In addition The Independent Living Fund (ILF) closure, has meant local authorities assimilating 18,000 disabled people into their organisational structures and policies, the Independent ILF bursaries that came with each individual was not ring fenced, so many local authorities used the extra money to plug the hole in other services leaving a shortfall in the independent living budget.

So what is the effect of all this for disabled people living in England today? Has the level and quality of the support people receive survived the abolition of the ILF? Are the new powers and duties enshrined in the Care Act making a difference to peoples everyday lives? Or is the idea of well-being and all that it encompasses just an idea being swamped by the ongoing funding cuts?

In the spirit of ‘nothing about us without us’ the Independent Living Strategy Group, which I have the privilege to chair, resolved to find out. This survey and report starts to offer some vital answers to these important questions - answers from the people directly affected, disabled people themselves. I hope that you find the report both challenging and useful. Please don’t read the findings without considering what you can do, to ensure the spirit of the Care Act to promote people’s well-being materialises into action, not words, after all, it is the law.

Summary of key findings

Choice and control

- Just under half (48%) of all respondents reported that the choice and control they enjoyed over their support was poor or very poor.
- A third of respondents (33%) said that the level of choice and control they enjoyed over their support had reduced or reduced significantly.
- Significant numbers of people reported a range of different restrictions being placed on how they could use the money available for their support: for example 50% of respondents reported support was restricted to personal care tasks only.

Quality of life and wellbeing

- Well over half (58%) of respondents reported that their quality of life had reduced or reduced significantly over the past twelve months.
- A quarter of respondents (25%) said the hours of work or volunteering they could do had reduced or reduced significantly.
- Almost two out of five (38%) reported they are having to rely more on family and friends for support.
- More than a quarter (27%) of respondents reported an increase or a significant increase in the amount of money they have to contribute towards the cost of their support.

Quality and amount of support

- About the same numbers of respondents rated the quality of their support as good or very good (41%) as rated it poor or very poor (40%).
- However, the amount of support was rated as poor or very poor by 44% of respondents compared to 30% saying the amount of support they had was good or very good.

Experiences of assessments and reviews

- The majority (86%) of people reported that when their Local Authority had assessed their needs they had listened or partly listened to them.
- Of those respondents who said their support had been reviewed in the last twelve months, just under two thirds (63%) did not know how much money was available for their support.
- 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.

Experiences of former Independent Living Fund recipients

- Two out of five (41%) former ILF recipients reported that the amount of their support had decreased or decreased a lot, and one third (33%) said that the quality of support had got worse or a lot worse.
- Around one third (34%) of former ILF recipients reported new restrictions being placed on their support.
- Information and advice
- Over a third of respondents (37%) struggle to find the information and advice they need.
- Most commonly people rely on friends and family (33%) and user led organisations (22%) for information and advice.
- Only 16% used their local authority's website for information.
- In terms of what people need advice and support with, just under a half (45%) said they needed help understanding their rights under the Care Act and a third (34%) solving problems with their local council.
- Over half (51%) of direct payment recipients reported that the information, advice and support they get to manage their direct payment was poor or very poor.

Introduction

In October 2015, shortly after the Care Act had come into force in England, the Independent Living Strategy Group published a report '**Promoting people's rights to choice and control**' looking at the extent to which local councils were exercising their new powers and meeting new duties. The report highlighted a number of points of concern, including:

- A reduction in quality of life reported by people who need support
- A lack of good information and advice available to people who need support
- Restrictions on how people were able to use their personal budget

The group resolved to monitor the situation as it developed and to this **end** we have undertaken a survey of people who have support about their experiences of their support and their dealings with their local council. This report presents some of the findings **from** the survey and we hope our work is both a challenge and a help to local councils who are charged with promoting the wellbeing of people who need support and respecting people's rights to live independently and to be included in the community.

Who are the independent living strategy group?

We are a network of disabled people's organisations and their allies that exists to protect, promote and ensure the fulfilment of disabled people's right to independent living in England. We have been meeting and sharing information about all aspects of independent living since 2013. The group is chaired by Baroness Jane Campbell, and includes disabled people who were part of the independent living movement from the 1970s as well as younger activists, other individuals and organisations concerned with the future of independent living. Through coordinated action we aim to: frame debates and shape new agendas; influence emerging policy and legislation; and ensure effective implementation of existing law and policy. A full list of our members is in Appendix 1

Survey findings

Survey methodology is described in appendix 2. In total 485 responses were analysed, the results of this analysis are presented below. Not all respondents answered all the questions, some questions and some of the questions allowed for more than one answer, so the total number of responses will not necessarily add up to these numbers. Where provided, percentages are of those people who responded to that question.

Who responded to the survey?

The average age of respondents was 48: (51%) were aged between 46 and 65 and just under a third (30%) were aged between 26 and 45 years.

Table 1. How old are you?

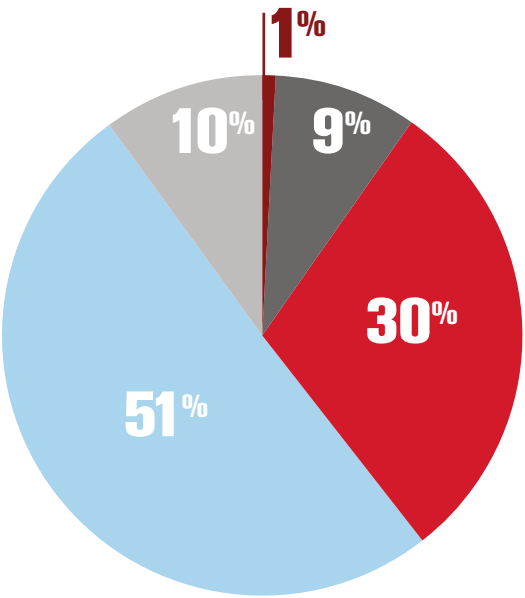
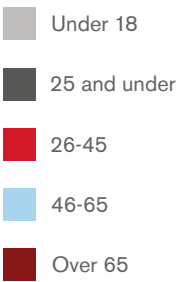
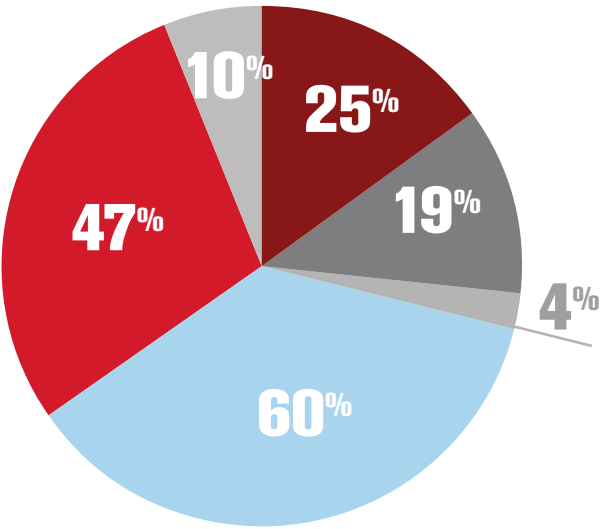
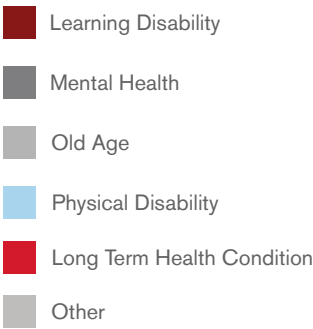


Table 2. What is the main reason you have support?



As table 2 shows, the majority of respondents reported that the main reason they needed support was physical **disability** (60%) and that just under half of the respondents said they had a long term health condition. Only a small proportion (4%) of respondents said they needed support because of old age. These proportions are not numerically representative of the wider population of people receiving adult social care, notably as older people are under-represented. However the group profile given its age, reason for support and type of support used is likely to present a 'best case' scenario in many of the areas we asked about.

We also asked people what local authority area they lived in. As can be seen in table 3, respondents came from all regions in England and were broadly evenly spread across the nine regions of the country.

Table 3. What local authority area do you live in?

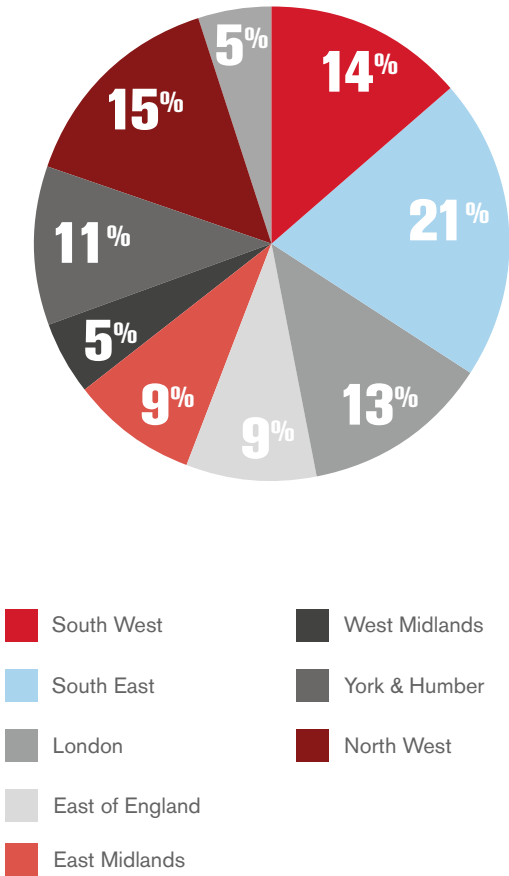
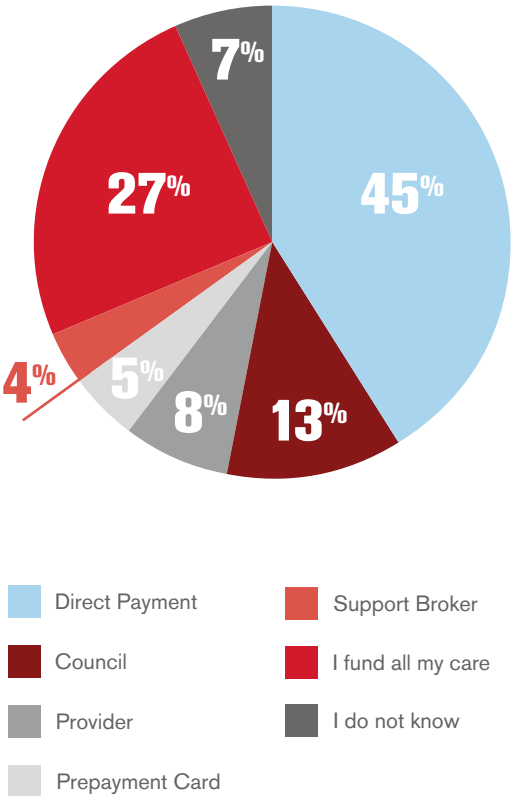


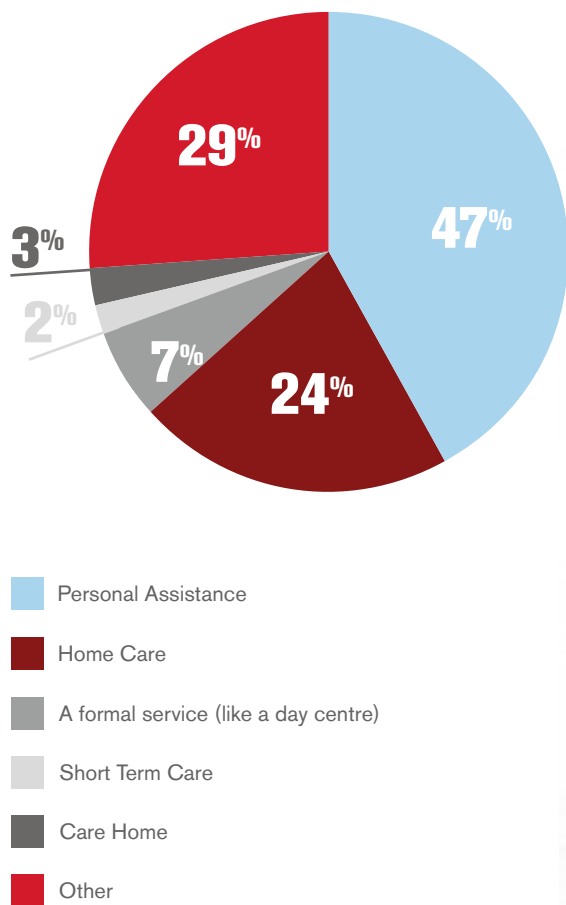
Table 4. How is the money for your support managed?



The survey provided a brief explanation of a personal budget and respondents were asked to say how the money for their support was managed. As table 4 shows, nearly half the respondents to the survey held a direct payment (45%). Small numbers used prepayment cards (5%) or a service broker (4%).

Respondents were asked what support they currently received. Table 5 shows that nearly half (47%) of the survey respondents were supported by a personal assistant, just under a quarter (24%) received home care, and small numbers used formal care services such as day centres or care homes.

Table 5. What paid support do you currently get?



Experience of direct payments

We asked those respondents who said they received a direct payment a number of additional questions specifically about their experience of direct payments. We asked people to rate different aspects of their direct payment.

Table 6 shows that more respondents rated their direct payment as good or very good than rated their direct payment as poor or very poor in 3 of the 7 areas we asked about; amount of money, control over the direct payment, and meeting your needs. In one area, the ease and appropriateness of

financial monitoring, the same proportion of respondents rated their directed payment as poor or very poor as rated their direct payment as good or very good. In the two aspects relating to being an employer, more respondents rated their direct payment as poor or very poor than rated their direct payment good or very good.

Table 7 shows that over half (51%) 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%) rated this aspect good or very good.

The information, advice and support you get to manage your direct payment

A key role in ensuring that people are given relevant and timely information about direct payments, so that they can make a decision whether to request a payment, and, if doing so, are supported to use and manage the payment appropriately. 12.5 Care act statutory guidance

Over half (51%) 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%) rated this aspect good or very good.



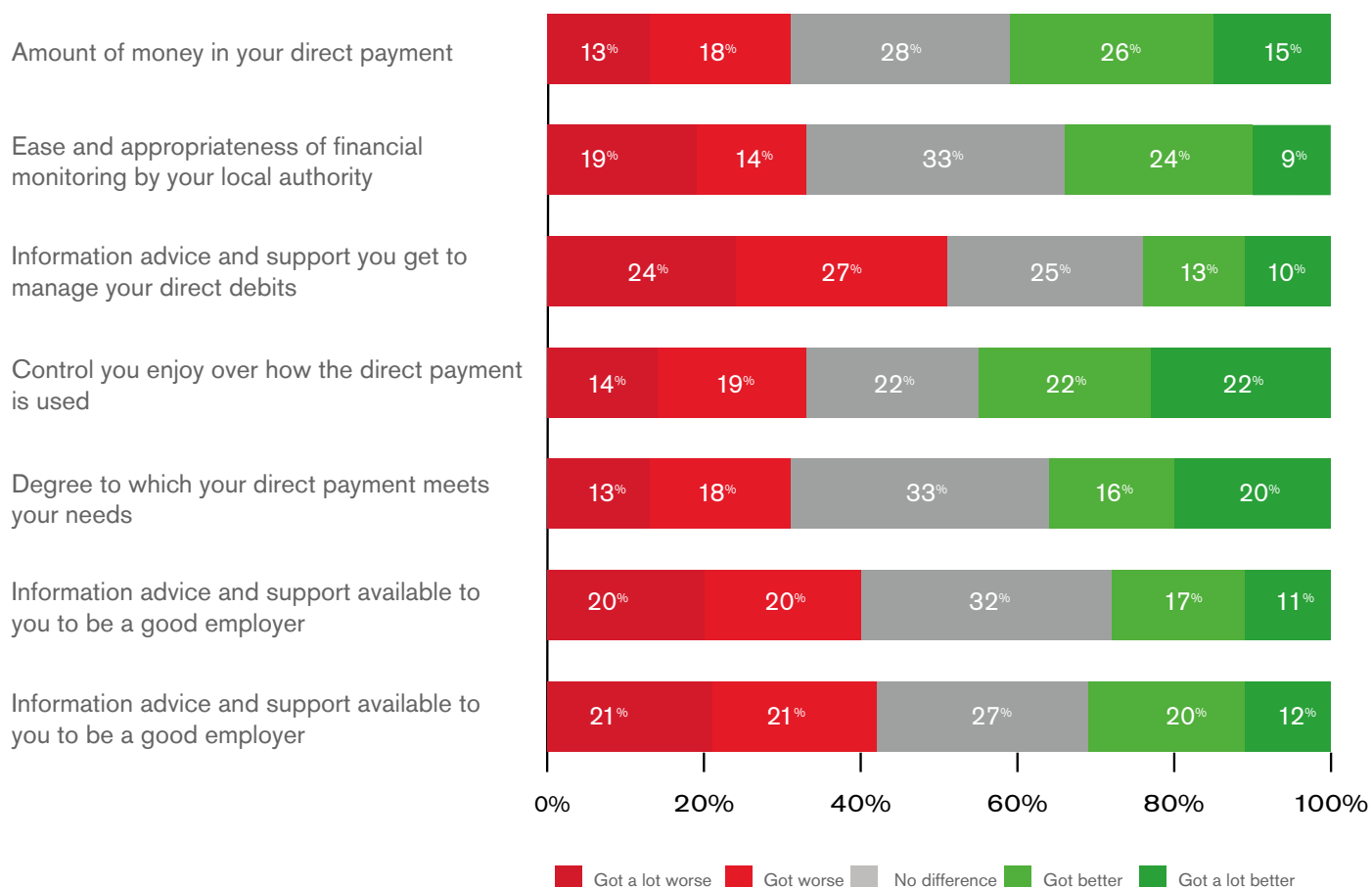


Table 6. How would you rate the following aspects of your direct payment?

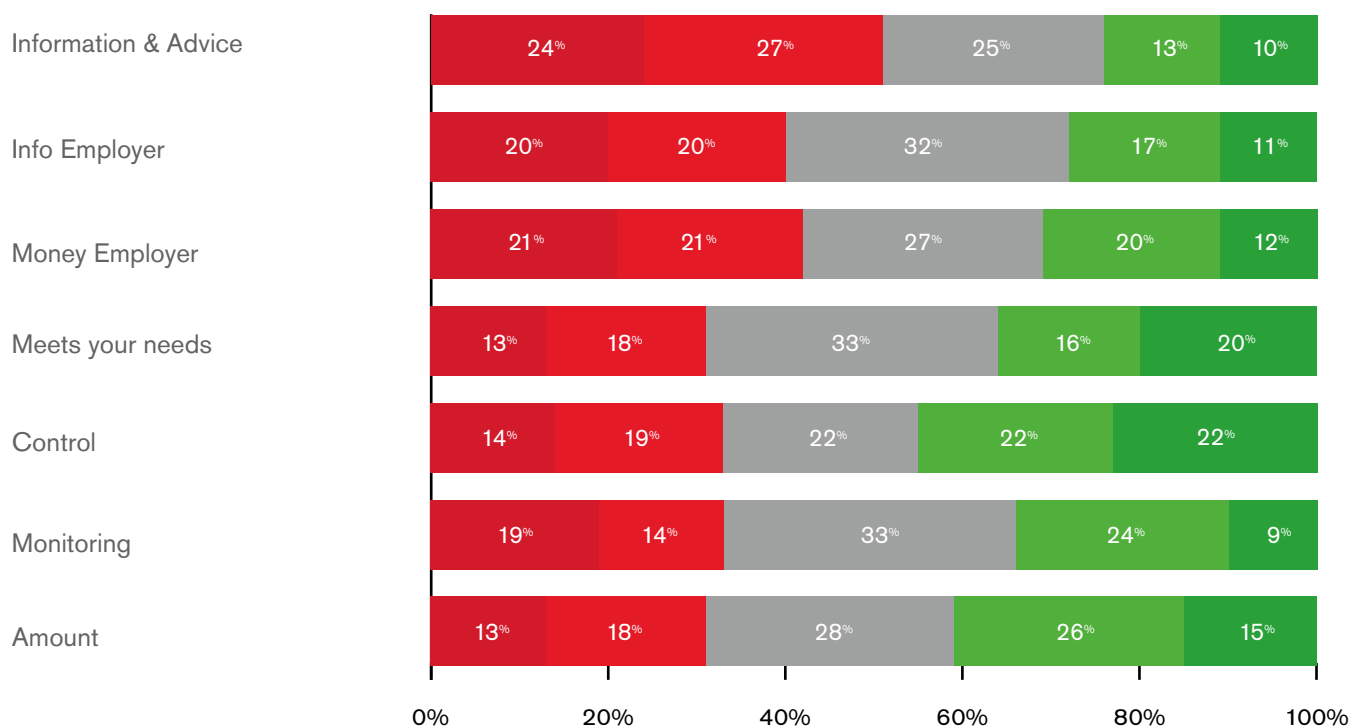


Table 7. The experience of direct payment recipients

Experience of former Independent Living Fund recipients

The survey asked people whether or not they had previously received money for their support from the **ILF**. Survey respondents who had previously received money from the ILF were asked a set of additional questions about their experience of the transfer process and their current support arrangements. As table 8 shows, 95 people responding to the survey had formerly received money from the ILF.

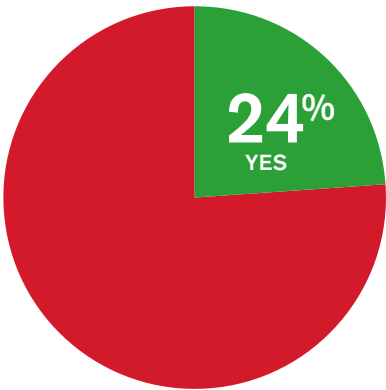
Three quarters (76%) of this group said they had had an assessment as part of the transfer of their funding. Over a third (34%) of former ILF recipients reported that new restrictions over how the money for their support could be used. Approaching one half two out of five of this group (41%) said that the amount of support they received had decreased or decreased a lot. Just under a third (32%) said their support had got worse since transferring from the **ILF**.

Experience of former ILF recipients

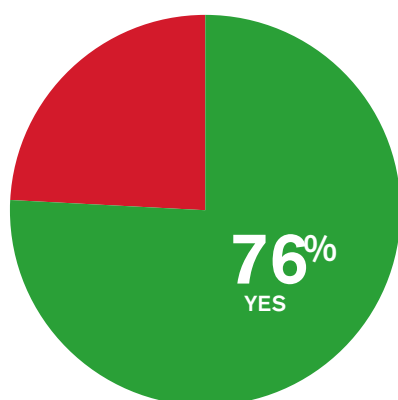
However the person chooses to have their needs met, whether by direct payment, by the provision of local authority-arranged or directly provided care and support, or third-party provision, or a mix of these, there should be no constraint on how the needs are met as long as this is reasonable. 10.47
Care Act statutory guidance

- 34% of former Independent Living Fund recipients reported new restrictions being placed on their support
- 41% of former Independent Living Fund recipients reported that the amount of their support had decreased or decreased a lot.
- 33% said that their support had got worse or a lot worse.

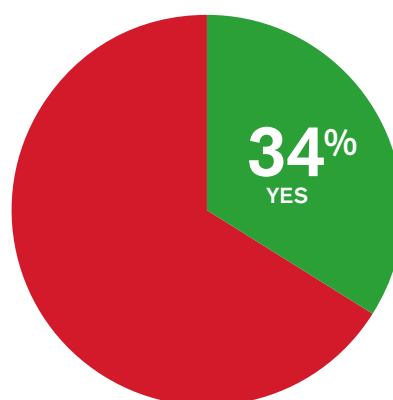
Did you previously receive money for your support from the Independent Living Fund?



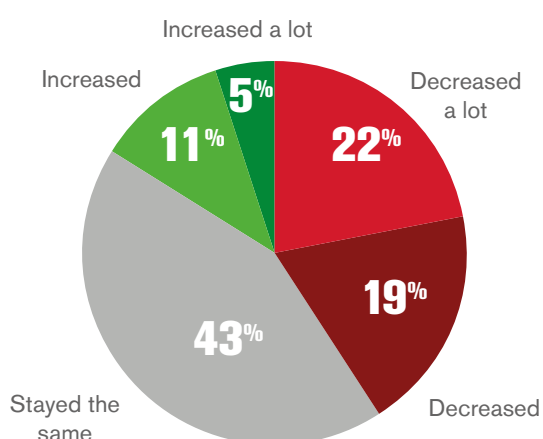
Did you have an assessment of your support needs as part of the transfer of Independent Living Funds?



Since your Independent Living Fund transferred to the local authority, have you been told of any new restrictions on how you can use the money for your support?



Now that you no longer receive money from the Independent Living Fund has the amount of support you get changed?



Since your Independent Living Fund was transferred to your local authority has your day to day support you get changed?

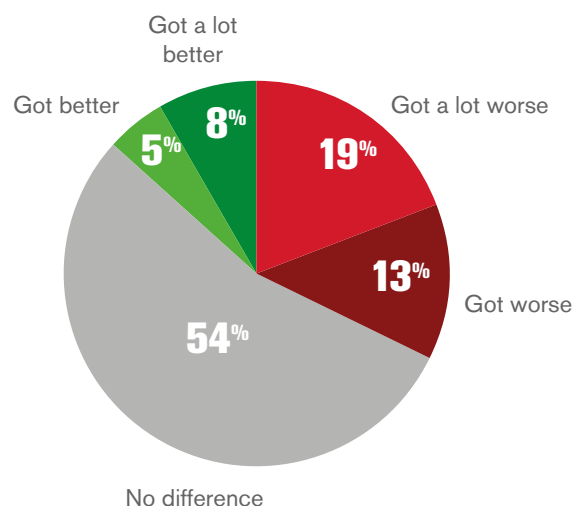


Table 8. The experience of former recipients of the Independent Living Fund

Choice and control

This is a planning tool designed for Local Authorities to use in partnership with interested parties locally. It draws together the key findings from our survey highlighting these and contrasting them against the requirements of the Care Act as they are set out in the statutory guidance. The intention is to focus local action and foster joint working between local authorities and user led organisations to address the issues highlighted in this report in whatever way is most appropriate locally.

Care act requirements

However the person chooses to have their needs met, whether by direct payment, by the provision of local authority-arranged or directly provided care and support, or third-party provision, or a mix of these, there should be no constraint on how the needs are met as long as this is reasonable. 10.47 Care and support statutory guidance

Survey findings	Local position	Action required
48% choice and control over support poor. 33% choice and control over support reduced A range of different restrictions being placed on use of money for support:	What is the local goal?	<ul style="list-style-type: none"> • • • •
Who else needs to be involved		
How we will know we have achieved this		

Experiences of assessments and reviews

Care act requirements

The assessment and eligibility process is one of the most important elements of the care and support system. The process must be person-centred throughout, involving the person and supporting them to have choice and control. 6.1

Local authorities should not ignore or downplay the importance of a person's own opinions in relation to their life and their care. Where particular views, feelings or beliefs (including religious beliefs) impact on the choices that a person may wish to make about their care, these should be taken into account. 1.14 1a

The personal budget means; 'knowing, before care and support planning begins, an estimate of how much money will be available to meet a person's assessed needs..' 11.3

Survey findings	Local position	Action required
47% people reported LA had only partly listened to them 14% that the LA had not listened at assessment. 63% not know how much money available for their support when planning.	What is the local goal?	<ul style="list-style-type: none"> • • • •
Who else needs to be involved		
How we will know we have achieved this		

Information and advice

Care act requirements

Information and advice is fundamental to enabling people, carers and families to take control of, and make well-informed choices about, their care and support and how they fund it 3.1

The availability and provision of information and advice, whether more general information about the way the system operates in the local authority area or more personalised information on a person's specific needs, are essential building blocks to all of the reforms and many of the specific duties the Act introduces. 3.7

The local authority has an active and critical role in the provision of information and advice and must take an active role 3.3

Survey findings	Local position	Action required
37% struggle to find information & advice. Only 16% used their local authority's website for information. People need advice and support with, understanding their rights (45%), solving problems with local council (34%) 51% Information advice and support to manage their direct payment was poor.	What is the local goal?	<ul style="list-style-type: none">••••
Who else needs to be involved		
How we will know we have achieved this		

Quality & Wellbeing

Care act requirements

The core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life. 1.1 Care and support statutory guidance

Local authorities must promote wellbeing when carrying out any of their care and support functions in respect of a person. 1.2

Survey findings	Local position	Action required
<p>58% quality of life reduced over the past 12 months. 25% hours of work or volunteering reduced.</p> <p>Same numbers rated quality of support as good (41%) as rated it poor (40%).</p> <p>The amount of support was rated as poor by 44% compared to 30% rating the amount as good.</p>	What is the local goal?	<ul style="list-style-type: none"> • • • •

Where people live

The survey asked people to say where they live now and where they were living twelve months ago. As can be seen from table 9, the vast majority of people reported that they were living in the same type of accommodation as they were a year ago.

Which of the following best describe where you live?	Family or friend	Owner/ Tenancy	Reg. Care Home	Supported Living	Temporary Accommodation
Now	62	263	7	28	4
12 Months Ago	76	261	7	24	1
Change	-14	2	0	4	3

Table 9. Which of the following best describes where you live?

Changes over the last year in people's lives and their experience of support

The survey asked people a number of questions about their life and their support over the last year and whether these had reduced, stayed the same or increased.

As can be seen from table 10, well over half (58%) of the respondents said that their quality of life had reduced or reduced significantly over the last 12 months. Over half of the group (60%) said their need for support had increased or increased a lot, while nearly a quarter (24%) reported a reduction or

a significant reduction in the support they received.

Well over a third (38%) reported that the support they get from friends or family had increased or increased significantly. A third (33%) of respondents said that the amount of choice and control they have over their support had reduced or reduced significantly over the last 12 months. More than a quarter (27%) of respondents reported an increase or a significant increase in the amount of money they contribute towards the cost of their support. A quarter of the group (25%) said the hours of work or volunteering they could do had reduced or reduced significantly.

Changes over the last year

The core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life. 1.1 Care and support statutory guidance

Local Authorities must promote wellbeing when carrying out any of their care and support functions in respect of a person. 1.2 Care and support statutory guidance

Well over half (58%) of the respondents said that their quality of life had reduced or reduced significantly over the last 12 months.

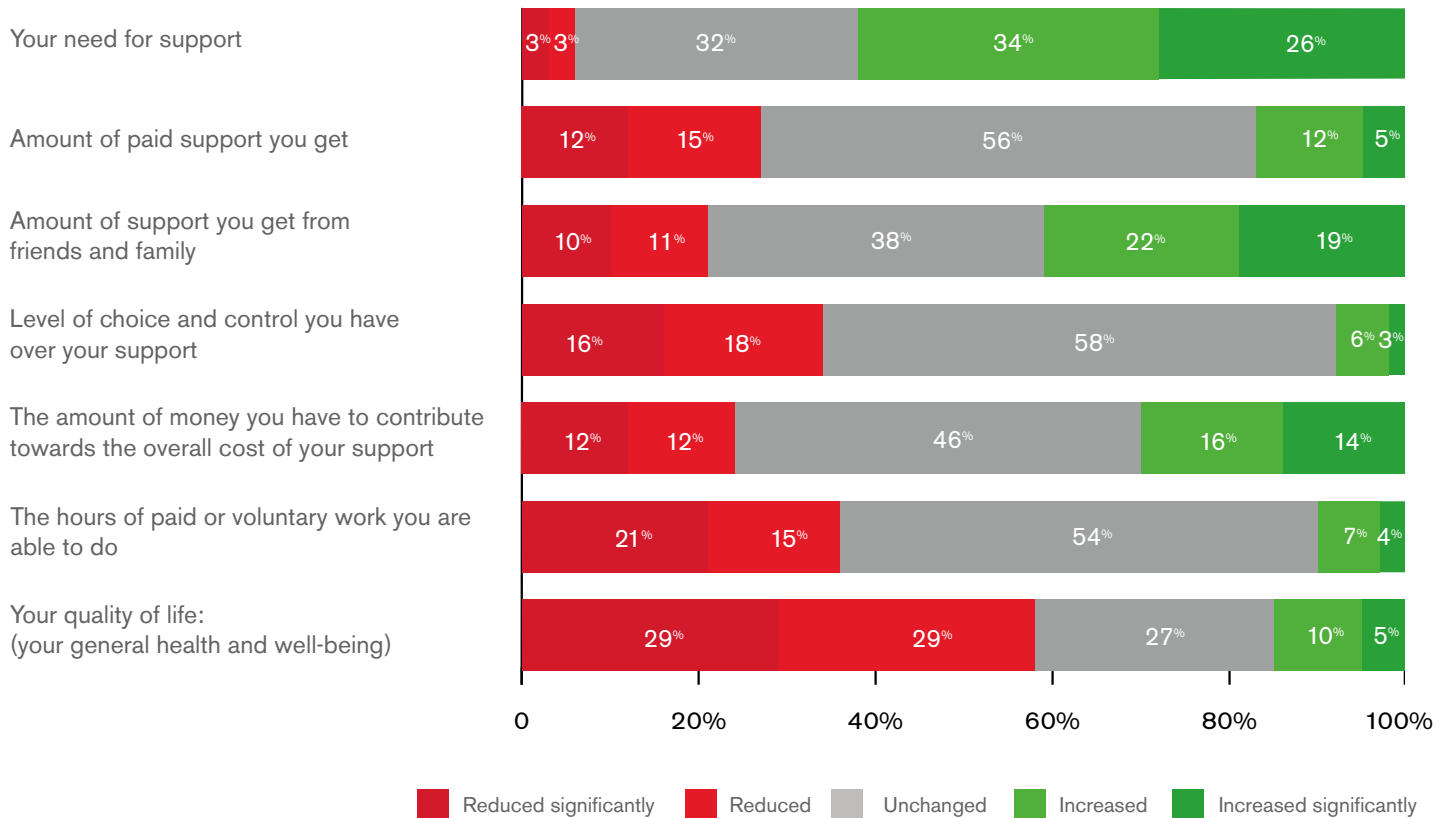


Table 10. Over the last 12 months have there been changes to the following?

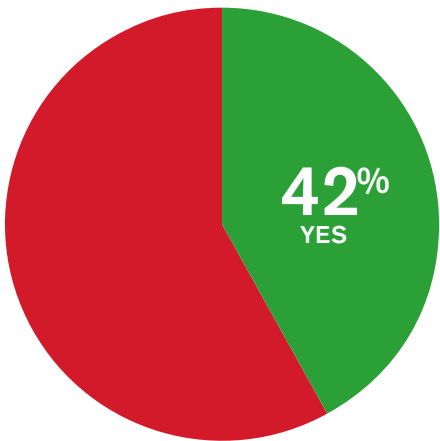
People's experience of their local authority

The survey asked people a number of questions about their experience of their Local Authority in relation to their support. People were asked if they had had an assessment or a review of their support within the last 12 months and, if so, to what extent the local authority had listened to them. The survey also asked people whether they were told how much money was available for their support as part of the planning and support process.

Just under half the group (42%) reported that they had undergone an assessment of their needs in the last 12 months and just under half (41%) reported their local authority had either reviewed or helped them plan their support over the past 12 months. The vast majority (86%) of people reported that when their local authority had assessed their needs they had listened or partly listened to them. Of those respondents who said their support had been reviewed in the last 12 months, just under two thirds (63%) did not know how much money was available for their support.

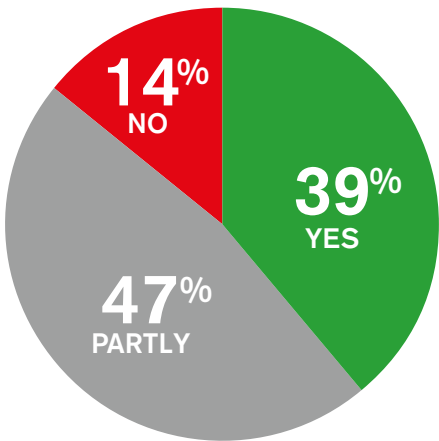
Table 11. People's experience of their local authority in relation to their care and support

Over the last 12 months has your local authority assessed your needs?



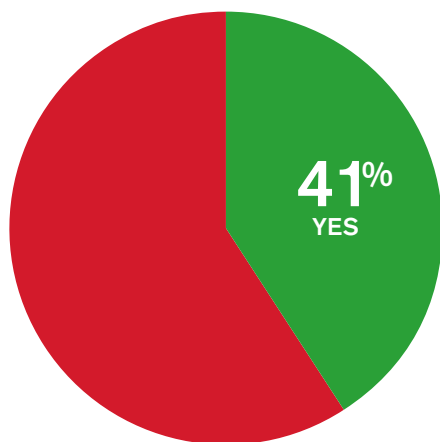
Size 350
 Yes 148 42%

Did your local authority listen to you when they assessed your needs?



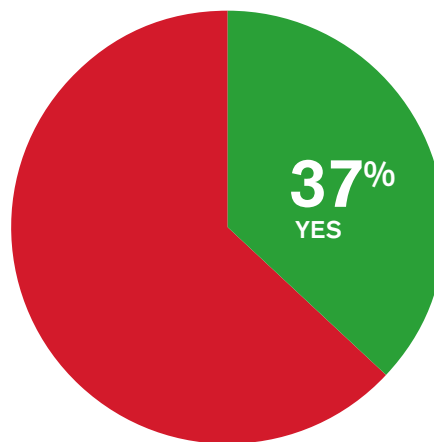
Size 191
 Yes 74 39%
 Partly 90 47%
 No 27 14%

Over the last 12 months has your local authority reviewed or helped you plan your support?



Size 329
Yes 136 41%

When your local authority reviewed your support or helped you plan, did you know how much money was available for your support?



Size 363
Yes 89 25%

The personal budget is the mechanism that, in conjunction with the care and support plan, or support plan, enables the person, and their advocate if they have one, to exercise greater choice and take control over how their care and support needs are met. It means: knowing, before care and support planning begins, an estimate of how much money will be available to meet a person's assessed needs

11.3 Care and support statutory guidance

People's experience of their local authority

Two thirds (63%) of people who had reviewed or developed their support plan in the last 12 months were not told how much money was available for their support.

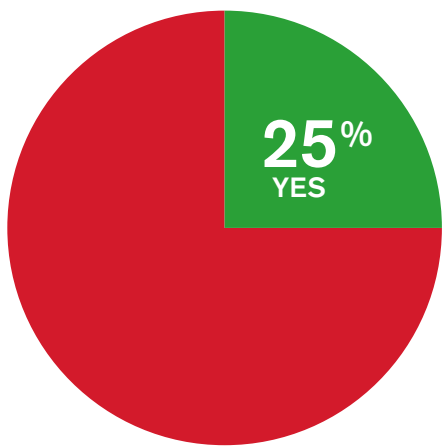
As well as asking general questions about people's experience of assessment and planning, the survey also asked people whether or not the council had told them that there was a cap on the cost of certain services and or whether their support would be reduced because of the saving councils are

seeking to make to the cost of care. Table 10 shows that a quarter of people had been told their support would be reduced because of cuts/savings (25%) **and/or** there is a limit to the amount of money you can get for a particular service (25%).

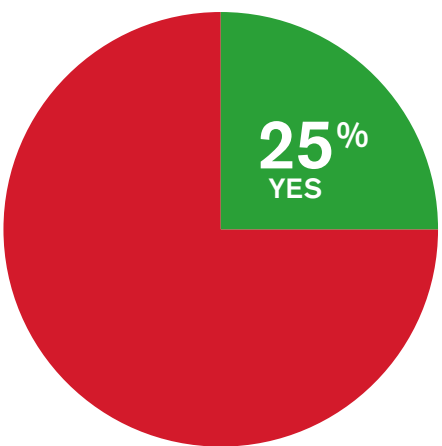
Over the last 12 months has your Local Authority told you either of the following:

There is a limit to the amount of money you get for a particular service

That your support (or the money available for your support) would be reduced because of cuts/savings



Size 363
Yes 89 25%



Size 363
Yes 91 25%

The survey asked people whether the local authority had placed restrictions on how they could use the money available for their support and, if so, what kinds of restrictions had been imposed. Table 12 shows significant numbers of people reported a range of different restrictions being placed on how they could use the money available for their support. Most commonly restricting support to personal care tasks (50% of people reporting restrictions), a third

of people (33%) who reported restrictions reported a cap on how much they could pay per hour. Who can be paid, when support can be provided and where support can be provided were all reported by a quarter of those who said restrictions had been put in place by the local authority. Other restrictions included the imposition of pre-payment cards (13%) and a refusal to approve care plans containing support the local authority had proscribed (17%).

Over the last 12 months has your local authority placed any restrictions on how you can use the money available for your support?

How much that can be paid per hour	49	33%
Who can be paid (approved care provider, only scheduled support described in care plan)	37	25%
What support can be paid for (only personal care, only scheduled support described in care plan)	75	50%
When support can be provided (no overnight support at home, no flexible use of hours)	38	26%
Where support can be provided (no support to go out and about in local area)	38	26%
I was required to use a pre-payment card	19	13%
LA refused to approve support plan: did not agree with how the personal budget was to be spent	25	17%

Table 12. Over the last 12 months has your local authority placed any restrictions on how you can use the money available for your support?

However the person chooses to have their needs met, whether by direct payment, by the provision of local authority-arranged or directly provided care and support, or third-party provision, or a mix of these, there should be no constraint on how the needs are met as long as this is reasonable. 10.47 Care and support statutory guidance

Local authority restrictions

Significant numbers of people reported a range of different restrictions being placed on how they could use the money available for their support. Most commonly restricting support to personal care tasks (50% of people reporting restrictions).

Other restrictions included the imposition of pre-payment cards (13%)

Whilst the use of such cards can be a useful step from managed services to direct payments, they should not be provided as the only option to take a direct payment. The offer of a 'traditional' direct payment paid into a bank account should always be available if this is what the person requests and this is appropriate to meet needs. 12.58

The survey asked people to rate their support over the last twelve months in relation to the amount of support, its quality and the choice and control they have. As table 13 shows, in terms of quality of support equal numbers of respondents rated their support as poor and very poor (40%) as did good or very good (41%). The amount of support was rated

as poor or very poor by 44% of respondents compared to 30% saying the amount of support they had was good or very good. Just under half (48%) of respondents said the choice and control they had over their support was poor or very poor compared to a third (33%) who said the control over their support was good or very good.

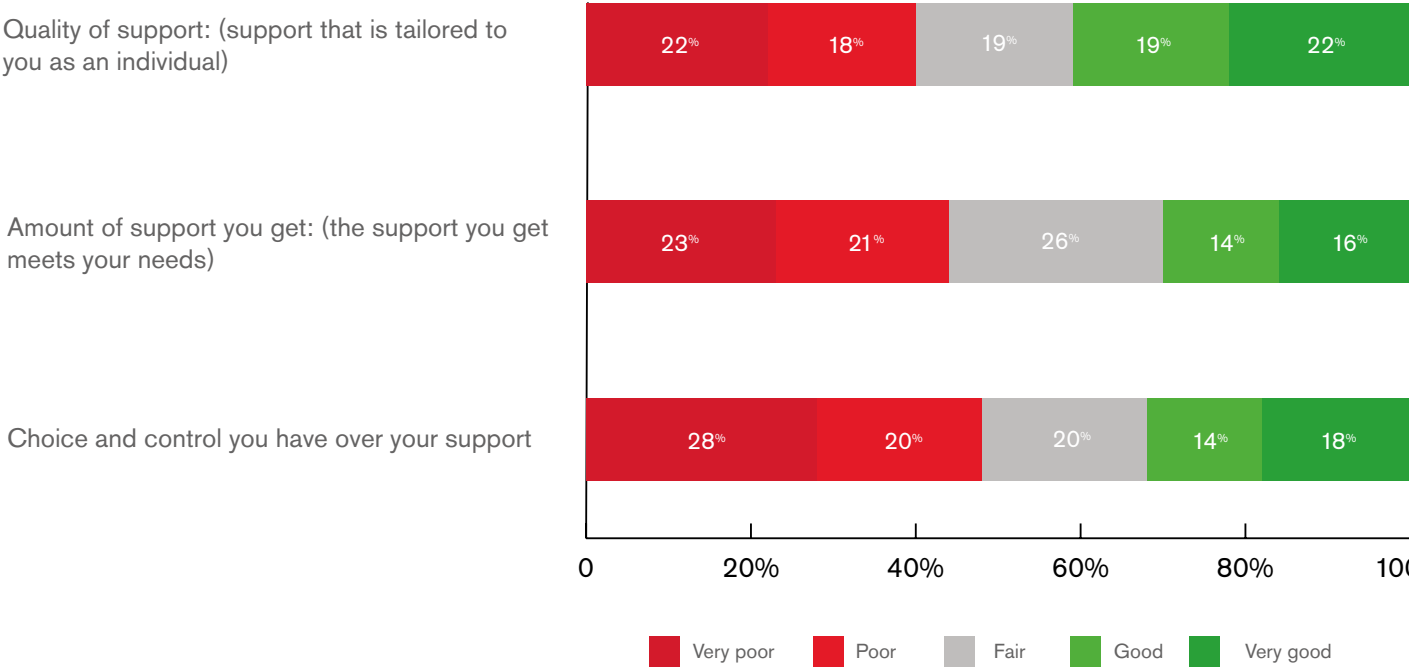


Table 13. What do you think about these areas of your support over the last 12 months?

Information and advice about support

Finally, as table 14 depicts the survey asked people about where they go for information and advice to help manage their support, and what topics they need advice and information on. Most commonly people relied upon friends or family (46%) for information and advice about support. Just under a third looked to user led organisations (30%) or local charities (30%). Small numbers used the Local Authority website (16%), a telephone advice line

(6%) or a local brokerage service (4%), while over a third of people (37%) said they struggled to find good information and advice.

In terms of what areas people needed advice and support in, nearly two thirds (61%) of people said **they** needed help understanding their rights under the Care Act and just under a half (47%) said **they** needed help **sorting** out problems with their local authority.

**15. Where do you go if you need good information or advice regarding your support?
Available for your support?**

Friends and family	162	46%
I struggle to find good information and advice	131	37%
User led organisation / carer groups etc.	110	31%
Websites of large national charities	105	30%
Other people that I know who also need support	95	27%
Social media such as Facebook pages	88	25%
Care providers / agencies	61	17%

16. What areas do you need information and advice on?

Your rights and entitlements to support under the Care Act 2014	281	61%
Sorting out problems with my local authority	166	47%
Employing a personal assistant	94	26%
Managing a direct payment	70	20%
Choosing a local service	64	18%
Other	63	18%

Table 14. Information and advice about support

Information and advice about support

Information and advice is fundamental to enabling people, carers and families to take control of, and make well-informed choices about, their care and support and how they fund it. Not only does information and advice help to promote people's wellbeing by increasing their ability to exercise choice and control, it is also a vital component of preventing or delaying people's need for care and support. 3.1 Care and support statutory guidance

Over a third of people (37%) said they struggle to find good information and advice. Nearly two thirds (61%) of people said they needed help understanding their rights under the Care Act.

Conclusion and Recommendations

It is clear from our findings that Local Authorities need to do more to meet the expectations of the Care Act. We have provided a planning template for use locally that highlights key areas that our survey shows needs to be addressed. We would strongly urge local user led organisations, support providers and Local Authorities to agree together what further action is required in their locality to address the issues highlighted in this report.

To assist in this at the center of the report we have included a planning tool designed for Local Authorities to use in partnership with interested parties locally. The planning tool draws together the key findings from our survey highlighting these and contrasting them against the requirements of the Care Act as they are set out in the acts statutory guidance. The intention is to focus local action and foster joint working between Local Authorities and user led organisations to address the issues highlighted in this report in whatever way is most appropriate locally. We would invite people using the planning tool to let us know so we are aware of and can share examples of activity that is being taken forward.



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Appendix 1.

The independent living strategy group are:

Baroness Jane Campbell, Chair
Baroness Tanni Grey-Thompson
Baroness Celia Thomas
Beatrice Barleon, Mencap
Sue Bott, Disability Rights UK
Gary Bourlet, Learning Disability England
Philipa Bragman, CHANGE
Don Brand
Steve Broach
Kevin Caulfield, Hammersmith and Fulham Campaign Against Cuts
Ellen Clifford, Inclusion London
Neil Crowther
John Evans
Lorraine Gradwell, Greater Manchester Coalition of Disabled People
Clare Gray, Shaw Trust
Catherine Hale, Spartacus Network
Mark Harrison, Equal Lives
Chris Hatton
Richard Huggins, Justice for LB
John Kelly, Merton Centre for Independent Living
Simon Legg, Spinal Injuries Association
Ian Loynes, Spectrum
Becki Meakin, Shaping Our Lives
Jenny Morris
Martin Routledge
Michelle Scattergood, Breakthrough UK
Andrew Shipley, Aspire
James Taylor, Scope
Philipa Thompson, Independent Lives
John Waters, In Control
Oliver Lewis, Mental Health and Disability Advocacy Centre
Gary Bourlet, Learning Disability England
Alicia Wood (supporting Gary Bourlet)
Clare Gray, Shaw Trust
Andrew Shipley, Aspire
Lyla Adwan-Kamara, Merton CIL



Appendix 2.

Methodology

We wanted to know about the day-to-day experiences of people who need support, whether people felt they had enough support, where that support was coming from and had this changed in the last year. We wanted to know what people thought about the way in which their local council had carried out its duties under the Care Act and whether or not councils were recognising people's rights to live an independent life.

To this end the survey questions explored the relationship people have with their local council in regard to their support, and the extent to which this was a trusting and empowering relationship. In particular we were keen to understand whether or not councils were providing people with appropriate levels of support and good quality information. Finally we wanted to know whether or not councils were promoting or restricting the choice and control people have over their support.

The survey asked people about:

- The information, advice and support they receive
- The amount and quality of support people are receiving
- People's quality of life
- Whether or not there had been changes to people's living arrangements over the last year
- Whether or not key aspects of the care and support process were being carried out in line with the requirements of the Care Act

In addition, the survey also explored the experience of two specific sub-groups with additional questions for people in those groups - recipients of direct payments and former recipients of ILF money. Direct payment recipients' questions looked at peoples' experience of managing the direct payment and in particular the additional responsibility of being a good employer. Questions aimed at former ILF recipients asked about the process of transferring to council funded support whether or not an assessment had been undertaken, whether the amount of support had changed and whether any new restrictions had been put in place over the use of money by the local council taking on funding responsibility.

The areas of investigation were agreed by the Independent Living Strategy Group and the survey

questions were designed and written by group members. The survey was undertaken online using 'lime survey', with additional easy-read paper versions available on request. Potential respondents were identified by members of the Independent Living Strategy Group through the various networks that group members were part of. Members of the Independent Living Strategy Group invited respondents to take part, sending a link to the survey via email. The survey was open between May and September 2016.

Before completing the survey, respondents were told that the survey was designed for disabled and older adults who need help and support with independent living, and were given a brief explanation of some of the terms used in the survey. That the survey was being carried out by the Independent Living Strategy Group. That the survey was a follow up to a similar survey carried out last year in order to find out about the experiences of people who access support from their local authority to find out whether choice and control over that support is changing. Respondents were told they could ask someone to help them complete the survey and, finally, respondents were told their personal data would be stored securely, not shared and that answers would be anonymised.

Once responses had been collected via the online survey, a number of incomplete returns were removed from the data. All responses that included answers in the survey sections concerning experience of support and experience of the local authority were retained. Having removed a number of partial returns, 485 responses were retained and analysed. The results of this analysis are presented below. Not all respondents answered all the questions and some of the questions allowed for more than one answer, so the total number of responses will not necessarily add up to these numbers. Where provided, percentages are of those people who responded to that question.

1

Adult social care funding: 2014 state of the nation report Local Government Association Association of Directors of Adult Social Services

Full survey results

1. How old are you?

Size 466

Under 18	25 or Under	26 - 45	46 - 65	over 65
3	43	141	236	46
1%	9%	30%	51%	10%

2. What is the main reason you have support?

Size 453

Learning Disability	Mental Health	Old Age	Physical Disability	Long Term Health Condition	Other
113	86	17	272	212	45

3. What local authority area do you live in?

Size 385

South West	South East	London	East of England	East Midlands
52	80	51	35	33
14%	21%	13%	9%	9%
West Midlands	York & Humber	North West	North East	
19	41	56	18	
5%	11%	15%	5%	

4. How is the money for your support managed?

Size 401

Direct Payment	Council	Provider	Prepayment Card	Support Broker	I fund all my care	I do not know
182	52	33	19	18	107	28
45%	13%	8%	5%	4%	27%	7%

4.1 How would you rate the following aspects of your direct payment?

Amount of money in your direct payment

Size 174

Very poor	Poor	Fair	Good	Very Good
22	32	49	45	26
13%	18%	28%	26%	15%

**4.2 How would you rate the following aspects of your direct payment?
Ease and appropriateness of financial monitoring by your local authority**

Size 165

Very poor	Poor	Fair	Good	Very Good
32	23	55	40	15
19%	14%	33%	24%	9%

**4.3 How would you rate the following aspects of your direct payment?
Information advice and support you get to manage your direct payment**

Size 166

Very poor	Poor	Fair	Good	Very Good
40	45	42	22	17
24%	27%	25%	13%	10%

**4.4 How would you rate the following aspects of your direct payment?
Control you enjoy over how the direct payment is used**

Size 166

Very poor	Poor	Fair	Good	Very Good
24	32	37	36	37
14%	19%	22%	22%	22%

**4.5 How would you rate the following aspects of your direct payment?
Degree to which your direct payment meets your needs**

Size 168

Very poor	Poor	Fair	Good	Very Good
22	30	56	27	33
13%	18%	33%	16%	20%

**4.6 How would you rate the following aspects of your direct payment?
Information advice and support available to you to be a good employer**

Size 152

Very poor	Poor	Fair	Good	Very Good
31	31	48	26	16
20%	20%	32%	17%	11%

**4.7 How would you rate the following aspects of your direct payment?
Information advice and support available to you to be a good employer**

Size 158

Very poor	Poor	Fair	Good	Very Good
33	33	42	31	19
21%	21%	27%	20%	12%

5. What paid support do you currently get?

Size 396

Personal Assistant	Home Care	A formal service (like a day centre)	Short Term Care	Care Home	Other
187	96	28	9	13	116
47%	24%	7%	2%	3%	29%

6. Did you previously receive money for your support from the Independent Living Fund?

Size	396	Yes	95	24%
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6.1 Did you have an assessment of your support needs as part of the transfer of Independent Living Funds?

Size	95	Yes	72	76%
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6.2 Since your Independent Living funding transferred to the local authority, have you been told of any new restrictions on how you can use the money for your support?

Size	95	Yes	32	34%
------	----	-----	----	-----

6.3 Now that you no longer receive money from the Independent Living Fund has the amount of support you get changed?

Size 83

Decreased a lot	Decreased	Stayed the same	Increased	Increased a lot
18	16	36	9	4
22%	19%	43%	11%	5%

6.4 Since your Independent Living funding was transferred to your local authority has your day to day support you get changed?

Size 83

Got a lot worse	Got worse	No difference	Got better	Got a lot better
16	11	45	4	7
19%	13%	54%	5%	8%

7. Which of the following best describes where you live

Size 377

	Family or friend	Owner/tenancy	Reg. Care home	Supported living	Temporary accom
Now	62	263	7	28	4
12 Months ago	76	261	7	24	1
Change	-14	2	0	4	3

8. Over the last 12 months have there been changes to the following?				
Your need for support				
Size 351				
Reduced significantly	Reduced	Unchanged	Increased	Increased significantly
11	10	114	119	93
3%	3%	32%	34%	26%
Amount of paid support you get				
Size 340				
Reduced significantly	Reduced	Unchanged	Increased	Increased significantly
38	45	173	37	14
11%	13%	51%	11%	4%
Amount of support you get from friends and family				
Size 347				
Reduced significantly	Reduced	Unchanged	Increased	Increased significantly
33	36	124	70	62
10%	10%	36%	20%	18%
Level of choice and control you have over your support				
Size 342				
Reduced significantly	Reduced	Unchanged	Increased	Increased significantly
53	60	192	19	9
15%	18%	56%	6%	3%
The amount of money you have to contribute towards the overall cost of your support				
Size 336				
Reduced significantly	Reduced	Unchanged	Increased	Increased significantly
38	36	143	49	42
11%	11%	43%	15%	13%
The hours of paid or voluntary work you are able to do				
Size 315				
Reduced significantly	Reduced	Unchanged	Increased	Increased significantly
47	33	121	15	9
15%	10%	38%	5%	3%
Your quality of life: (your general health and well being)				
Size 350				
Reduced significantly	Reduced	Unchanged	Increased	Increased significantly
100	102	94	35	16
29%	29%	27%	10%	5%

9. Over the last 12 months has your local authority assessed your needs?			
Size 350	Yes	148	42%

10. Did your local authority listen to you when they assessed your needs?			
Size 191	Yes	74	39%
	Partly	90	47%
	No	27	14%

11. Over the last 12 months has your local authority reviewed or helped you plan your support?			
Size 329	Yes	136	41%
11.1 When your local authority reviewed your support or helped you plan, did you know how much money was available for your support?			
Size 126	Yes	46	37%

12. Over the last 12 months has your local authority told you either of the following:			
There is a limit to the amount of money you can get for a particular service			
Size 363	Yes	89	25%
That your support (or the money available for your support) would be reduced because of cuts/savings			
	Yes	91	25%

13. Over the last 12 months has your local authority placed any restrictions on how you can use the money available for your support?		
Size 149	Yes	%
How much that can be paid per hour	49	33%
Who can be paid (approved care provider only, can't pay family for support)	37	25%
What support can be paid for (only personal care, only scheduled support described in care plan)	75	50%
When support can be provided (no overnight support at home, no flexible use of hours)	38	26%
Where support can be provided (no support to go out and about in local area)	38	26%
I was required to use a pre-payment card	19	13%
LA refused to approve support plan: did not agree with how the personal budget was to be spent	25	17%

14. What do you think about these areas of your support over the last 12 months? Quality of support: (support that is tailored to you as an individual)				
Size 326				
Very poor	Poor	Fair	Good	Very Good
72	59	61	63	71
22%	18%	19%	19%	22%
Amount of support you get: (the support you get meets your needs:)				
Size 331				
Very poor	Poor	Fair	Good	Very Good
75	70	87	45	54
23%	21%	26%	14%	16%
Choice and control you have over your support				
Size 323				
Very poor	Poor	Fair	Good	Very Good
91	64	63	46	59
28%	20%	20%	14%	18%

15. Where do you go if you need good information or advice regarding your support? Available for your support?		
Size 355		
Friends and family	162	46%
I struggle to find good information and advice	131	37%
User led organisation/carer groups etc	110	31%
Websites of large national charities	105	30%
Other people that I know who also need support	95	27%
Social media such as facebook pages	88	25%
Care providers/agencies	61	17%
The local authority website	58	16%
A telephone advice line	20	6%
Local Brokerage services	15	4%

16. What areas do you need information and advice on?

Size 351

Your rights and entitlements to support under the Care Act 2014	218	61%
Sorting out problems with my local authority	166	47%
Employing a personal assisitant	94	26%
Managing a direct payment	70	20%
Choosing a local service	64	18%
Other	63	18%