
Promoting people's right to choice and control under the Care Act 2014.

How are local
authorities
performing?

Directed by the
Independent Living
Strategy Group,
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**“It is our choices,
Harry, that show what
we truly are, far more
than our abilities.”**

J.K. Rowling,
Harry Potter and the Chamber of Secrets

1. Introduction & Summary

1.1 Choice, control and wellbeing

Central to the Care Act 2014 is the principle of wellbeing. At the heart of the principle of wellbeing is 'control by the individual over day-to-day life, including over care and support and the way it is provided'.¹

This is because choice and control is fundamental to the core purpose of adult care and support which the Care Act guidance sees as being to 'help people to achieve the outcomes that matter to them in their life'.²

This principle is consistent with the principles and requirements of international law to which the UK is party, in particular the obligations arising out of the United Nations Convention on the Rights of Persons with Disabilities (2006).^{Ref: See: www.un.org/disabilities}

Many local authorities state they are already fully committed to the principles of choice and control.

They have worked hard in extremely trying financial circumstances not only to avoid undermining choice and control but to expand further the scope for eligible individuals requiring care and support to exercise choice and control. However, as the statutory guidance accompanying the Act acknowledges, local authorities can and sometimes do continue to exact a considerable degree of control over people's day-to-day lives.^{Ref Department for Health (2015) Care Act 2014 Statutory Guidance}

Some do so by failing to promote choice and control or by denying people access to information regarding their rights, entitlements or options. Others sometimes actively restrict people's ability to exercise choice and control, employing arbitrary spending limits on particular care and support options, placing undue restrictions on how money can be spent or by imposing burdensome monitoring to restrict choice and impede flexibility.

The statutory guidance on the Care Act 2015 is clear: such practices are wholly at odds with both the spirit and letter of the Care Act 2014.

This report brings together a range of evidence, including a new survey of social care recipients and fresh analysis of local authority guidance on the Care Act, to provide an account of local authority's performance in relation to choice and control.

It also looks specifically at the experiences of those individuals transitioning from the Independent Living Fund to local authority funded support, exploring whether there has been any reduction in the support that they receive or fresh restrictions imposed on choice and control.

To assist local authorities to meet their obligations and to support those seeking or receiving care and support to understand and secure their rights we have also produced a checklist. This is included in the annex and can also be downloaded and/or completed online at www.in-control.org.uk

¹ Care Act 2014, S1 (2) (d) Promoting individual well-being

² Care Act 2014 statutory guidance Section 1.1

1.2 Our findings

Our survey of social care recipients found that:

- Despite the emphasis on wellbeing and choice and control in the Care Act 2014, almost half (45%) of respondents to our survey said that their quality of life had reduced and almost a third (30%) said that they had experienced a reduction of choice and control over the past year.
- Half said their need for support had increased and yet only 22% had experienced a corresponding increase in paid support over the past year. Most additional support came from family and friends. Where people did receive additional support it was most likely to come from family and friends if available.
- Of the 57% of respondents who had their care package reassessed in the previous 12 months, 17% said that they had been told that there was a financial cap placed on certain types of expenditure.
- 29% of respondents reported restrictions being placed on their use of direct payments or personal budgets. 33% didn't know whether they were subject to any restrictions.
- Of those reporting that their use of direct payments or personal budgets had been subject to restrictions, stipulations regarding the tasks of personal assistants/ carers were most commonly reported (48%). 18% said that

they had had their personal support plan declined. 14% reported they had been limited to choosing from a shortlist of providers. 11% said they had been limited to using a pre-payment card.

- Of those survey respondents who are transitioning from Independent Living Fund to local authority support, 14% reported they had been told that they should expect less support in future, while the majority (56%) said they had not been told whether their support would increase, decrease or stay the same.

Our analysis of local authority guidance on the Care Act found that:

- Local authorities are generally not yet meeting their duties to ensure the provision of clear, accessible, accurate and locally tailored information regarding care and support. This means that those seeking or receiving care and support lack access to information regarding their rights and entitlements, sufficient to exercise choice and control.
- Some local authorities have produced 'quick guides' explaining the key features of the Care Act. These rarely emphasize choice and control and the universal entitlement to a personal budget.
- Local authorities are not defining personal budgets in a way that corresponds with their definition in the Care Act statutory guidance.

Whereas the guidance describes personal budgets as a mechanism for choice and control, the guidance we reviewed typically describes personal budgets only as the sum of money allocated to meet care and support needs.

- Some local authorities infer that if a person opts for their personal budget to be managed by the local authority that they should anticipate having less control over how it is spent than if they choose a direct payment. Some say, in effect, that the person will need to accept what the council chooses to provide. This does not meet the requirements of the Care Act statutory guidance which says that the option chosen should have no bearing on the ability of individuals to direct their support.

Looking beyond local authority care and support:

- In relation to NHS Continuing Care, some Clinical Commissioning Groups have adopted explicit policies which place financial limits on the amount that will be spent to support an individual to live in their own home as opposed to residential or nursing care.³ This is likely to have a particular impact on people who would previously have accessed support from the Independent Living Fund.

³ For example Mid Essex and Enfield CCG's have both adopted such policies

2. The current context for choice and control

This section provides an overview of the legal, economic and political context for choice and control in care and support.

2.1 The Care Act 2014

The Care Act 2014 embodies principles and promotes practices regarding choice and control that have evolved over the past 40 years, driven by the disabled person's independent living movement in the UK and internationally and by the wider trend towards personalised public services.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD), to which the UK is a Party, requires States to respect the individual autonomy of disabled persons, including the freedom to make one's own choices. Article 19 of the Convention – living independently and being included in the community – stipulates this principle in the context of people's living arrangements and requires that States ensure that disabled persons have a right to choice and control over where and with whom they live on an equal basis with others and that they should not be obliged to live in a particular living arrangement. (Op Cit)

Correspondingly, the Care Act 2014 requires that local authorities must promote wellbeing when carrying out any of their care and support functions in respect of a person and the concept of wellbeing includes 'control by the individual over day-to-day life (including over care and support provided and the way it is provided).' (Op Cit)

The Act further elaborates the principle of control by emphasizing the importance of beginning with the assumption that the individual is best placed to judge their own outcomes, goals and wellbeing and of ensuring that the individual's own opinions are paramount in decisions regarding their care and support. [ref 'Care Act 2014 s1 \(3\)](#) Whereas community care law previously placed local authorities under obligations to 'provide services', the obligation contained in the Care Act 2014 is to 'meet needs' sufficient to ensure a person's wellbeing. This marks a critically important shift in emphasis from a one-size-fits-all approach towards flexible, person-centred care and the ability to self-direct support.

[ref 'Care Act 2014 s8](#) To facilitate this, the Act requires that local authorities work in partnership with eligible individuals to plan their care and support, [ref Care Act 2014 s24](#) to provide everyone with a personal budget and to offer individuals a range of options regarding how their care and support is secured, including direct payments. [ref Care Act](#)

[2014 s26](#) As explained in more detail in section 3 below, the statutory guidance says that local authorities must not impose unreasonable restrictions on how personal budgets are spent, save to ensure that they are spent on meeting needs identified in the care and support plan.

2.2 The Care Act 2014

The Act and statutory guidance place particular emphasis on the provision of information and advice:

- 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. (Para 3.1)

The Care Act places obligations on local authorities to establish and maintain a service to ensure the provision of accessible, accurate, comprehensive, bespoke (and where appropriate, impartial) information and advice.

2.3 Personal budgets

At the heart of the drive towards more person-centred care and self-directed support are personal budgets. The Care Act statutory guidance says that a 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.' (para 11.3)

Personal budgets emerged in part as a response to requests from individuals or family members supporting them expressing a desire for more control but daunted by the responsibility of taking a direct payment and organising their own support. The Prime Minister's Strategy Unit report 'Improving the Life Chance of Disabled People' (2005) committed the then government to a new system of support that would include individuals being able to:

- "take some or all of their budget as a cash payment and/or to have control over the budget (with support if necessary) without actually receiving the cash"

[Prime Minister's Strategy Unit \(2005\) Improving the Life Chances of Disabled People](#)

Where the then government's 'Putting People First Concordat' (2007) HM Government strived to ensure that 30% of eligible individuals had a personal budget by 2011, the Care Act 2014 says that all eligible individuals should have one. The Act's statutory guidance says that a 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 and, with the final personal budget, having clear information about the total amount of the budget, including proportion the local authority will pay, and what amount (if any) the person will pay;
- being able to choose from a range of options for how the money is managed, including direct payments, the local authority managing the budget and a provider or third party managing the budget on the individual's behalf (an individual service fund), or a combination of these approaches;
- having a choice over who is involved in developing the care and support plan for how the personal budget will be spent, including from family or friends;
- having greater choice and control over the way the personal budget is used to purchase care and support, and from whom. (para 11.3)

Evidence from the national POET (Personal Outcomes Evaluation Tool), conducted by Think Local Act Personal (TLAP) and In Control, which concerns personal budgets across health and social care has found that personal budgets have had a broadly positive impact on the lives of those who hold them.⁴

The POET survey also found that in some significant areas of life, people who reported that they were using their personal budgets on non-traditional methods of satisfying their needs such as personal assistants and community and leisure activities reported better outcomes than when people used them to buy 'traditional' care services.

⁴ For example, the 2014 survey found that more than three quarters of personal budget holders reported their budget having a positive impact on five of the 15 areas asked about including dignity (82%), independence (78.9%), arranging support (79.9%) paid relationships (75.9%) and quality of life (81.4%). Overall, more than three quarters of personal budget holders reported their budget having a positive impact on five of the 15 areas asked about: dignity (82%); independence (78.9%); arranging support (79.9%); paid relationships (75.9%) and quality of life (81.4%). In addition at least two thirds of personal budget holders reported their budget having a positive impact on a further six of the 15 areas of life asked about: mental health (65.5%); control over life (70.6%); feeling safe (72.8%); family relationships (74.6%); friendships (67.8%); and self-esteem (73.2%). Finally more than half of personal budget holders reported their budget having a positive impact on three more areas: physical health (59.9%); with who and where you live (57.9%); and volunteering and community (54.6%).

2.3 Personal budgets

Continued

Around a quarter of personal budget holders said that aspects of the process were difficult for them in three of nine areas asked about: making changes to support (28.4%); information and advice (24.1%); and understanding restrictions placed on the use of the personal budget (23.6%).

Despite the broadly favourable experiences of those who presently benefit from a personal budget, evidence overall has pointed to a lack of progress on choice and control between 2008 and 2013.

A brief review of evidence about the impact of the 2008 Independent Living Strategy⁵, carried out by Jenny Morris found that:

- There was an increase in numbers receiving personal budgets for social care, and when delivered well, they improve outcomes.
- However, there had been significant limitations to effective delivery of personal budgets. Most have taken the form of council-managed services and there is evidence that inadequate funding and restrictions on how personal budgets/ direct payments may be used can inhibit choice and control.
- The increase in numbers using direct payments was smaller and there were also wide variations across local authority areas and service user groups. In the council with the highest percentage of direct payments users a person is 24 times more likely to get a direct payment than in the poorest performer.
- Overall, there was no evidence of significant progress in disabled people's experiences of choice and control in their lives since 2008.⁶



“I worry about the future will I just be expected to exist rather than live”

⁵ The Independent Living Strategy 2008 set out a general commitment that, by 2013: disabled people who need support to go about their daily lives will have greater choice and control over how support is provided & disabled people will have greater access to housing, transport, health, employment, education and leisure opportunities and to participation in family and community life.

⁶ Morris, J (2013) The Independent Living Strategy – a review of progress, In Control/Disability Rights UK

2.4 Public spending cuts

The backdrop to the period in question has been a policy of public spending cuts, under the rubric of 'austerity', that have fallen disproportionately on local government services, including social care at a time of rising demand from our ageing population.

Expenditure on social care by local authorities fell by £4.6 billion between 2010/11 and 2014/15 - a real terms reduction of 31%.⁷ The 2015 Spending Review has opened the door to even deeper cuts in the years to come.

This reduction in funding has led to a widespread increase in eligibility thresholds with almost nine out of 10 councils now only supporting people with 'substantial' or 'critical' needs. It has been calculated that this had led to 69,000 working age disabled adults with moderate needs and 8,000 with substantial needs losing their eligibility for social care by 2012/13.⁸ Amongst older people, the drop is even greater: almost a quarter of a million fewer older people received social care support in 2012/13 compared to 2009/10, a reduction of 26 per cent.⁹

The Health and Social Care Information Centre recently reported that of 1.85 million requests for support made in England in 2014-15, just over 650,000 received help.

Even if people are eligible for publicly funded social care, the level of support may be inadequate. Echoing concerns first raised by the Equality and Human Rights Commission, the United Kingdom Homecare Association (which represents home care providers) has expressed concern about the squeeze on the length of time that home care visits take and the amount paid by local authorities. A third of providers in their survey were worried about risks to the dignity of service users and/or the safety of the care that local councils require them to undertake for older and disabled people. Providers also reported that sometimes the level of direct payments is not sufficient.¹⁰

Anecdotal evidence suggests that where people's personal budgets are being cut it is that money previously allocated to the 'non traditional' methods of satisfying needs (for example, gym membership) that has been lost. Doing so not only narrows the scope for choice and control, it also stymies innovation and stands in the way of prevention.¹¹

Beyond the responsibilities of local authorities, some Clinical Commissioning Groups have adopted explicit policies which place financial limits on the amount that will be spent to support an individual requiring NHS Continuing Care to live in their own home as opposed to residential or nursing care.

This is likely to have a particular impact on people who would previously have accessed support from the Independent Living Fund.

⁷ ADASS (2015) Budget Survey Report

⁸ Promoting independence, preventing crisis, All Party Parliamentary Local Government Group & All Party Parliamentary Disability Group, April 2013, from modelling published by Fernandez, Snell, Forder & Wittenberg in "Implications of setting eligibility criteria for adult social care at moderate needs level", PSSRU at LSE, DP2851, 2013

⁹ Ismail, S, Thorlby, R. and Holder, H. 2014. Focus on: Social care for older people. Nuffield Foundation. <http://www.nuffieldtrust.org.uk/publications/focus-social-care-older-people>

¹⁰ Angel, C. 2012. Care is not a commodity: UKHCA Commissioning Survey 2012, United Kingdom Homecare Association. <http://www.ukhca.co.uk/downloads.aspx?ID=356>

¹¹ For example see report from Equal Lives Norfolk, forthcoming

2.5

Closure of the Independent Living Fund

The Independent Living Fund (ILF), which existed to 'top up' the funding available from local authorities in recognition that those with the highest levels of support needs required assistance that local authorities would not provide, was closed on 30th June 2015.

Although funding will be transferred to local authorities from the ILF when it closes, this will be less than that currently required to support the 18,000 people who used the ILF.

The Government's Equality Analysis concerning closure of the ILF acknowledged that:

'It is almost certain that closure of the ILF will mean that the majority of users will face changes to the way their support is delivered, including the real possibility of a reduction to the funding they currently receive. This is because the ILF funds some aspects of care that some local authorities do not and may also provide different levels of flexibility in the use of such funding.'¹²

With respect to the degree of choice and control that ILF users would enjoy in future, the Equality Analysis concluded that:

'Loss of ILF funding could mean that current ILF users will have to make different choices about their daily lives. For example, this might be because they will no longer be able to employ a personal assistant. The extent to which this will occur is impossible to calculate, given the variety of conditions and differences in local provision.'¹³

The Local Government Association and the Association of Directors of Adult Social Care have stated that:

"As ILF recipients transfer into the Local Authority system in 2015, and are subsequently reviewed against the [local authority assessment] criteria, the value of the personal budget calculated through the Resource Allocation System will generally be at a lower level than the initial ILF/LA budget."¹⁴

A survey conducted by Disability Rights UK using Freedom of Information requests found that most local authorities do not have robust plans to ring-fence resources for social care support to people who would have received ILF support.¹⁵

¹² Department for Work and Pensions (2014) Closure of the Independent Living Fund – Equality Analysis (DWP)

¹³ Ibid

¹⁴ Ibid

¹⁵ See: 'Most Councils will not ringfence ILF resources' <http://disabilityrightsuk.org/news/2014/august/most-councils-will-not-ringfence-ilf-resources>

3. What does the Care Act 2014 statutory guidance say about practices that constrain choice and control?

Some local authorities appear to place more stringent controls than others on how money devoted to care and support can be spent. The statutory guidance identifies and provides clear guidance regarding a number of ways that local authorities sometimes deliberately or inadvertently act to constrain choice and control.

3.1 Defining council-managed personal budgets as offering less choice and control than other options

In our initial analysis of local authority guidance we found that councils either failed to describe personal budgets as a mechanism for choice and control or that they suggested a 'sliding scale' of control depending on the option that a person chose to have their personal budget managed.

The Care Act 2014 guidance states that:

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. (para 10.47)

It goes on to say that:

'The person should have the maximum possible range of options for managing the personal budget, including how it is spent and how it is utilised. Directing spend is as important for those choosing the council-managed option or individual service fund as for direct payments. Evidence suggests that people using council-managed personal budgets are currently not achieving

the same level of outcomes as those using direct payments, and in too many cases do not even know they have been allocated a personal budget.' (para 11.29)

3.2 'Allowable purchases'

Some local authorities employ lists of 'allowable purchases' that determine what personal budgets can and cannot be spent on. The statutory guidance states that:

It is important that people are allowed to be very flexible to choose innovative forms of care and support, from a diverse range of sources, including quality providers but also "non-service" options such as Information and Communication Technologies (ICT) equipment, club membership, and massage. Lists of allowable purchases should be avoided as the range of possibilities should be very wide and will be beyond what the local authority is able to list at any point in time. While many authorities may choose to operate lists of quality accredited providers to help people choose (for example some authorities include trading standards-style "buy with confidence" approaches) the use of such lists should not be mandated as the only choice offer to people. Limited lists of 'prescribed providers' that are only offered to the person on a 'take it or leave it' basis do not fit with the Government's vision of personalised care and should be avoided. (para 10.48)

3.3 Pre-paid cards

'Pre-paid cards' are used by some local authorities to pay direct payments without the need for a bank account. The statutory guidance makes clear that individuals should not be obliged to receive a direct payment via a pre-paid card. Moreover, the guidance is clear that where pre-paid cards are used there should be no limits on choice and control as a consequence. For example the statutory guidance says that:

'there should not be blanket restrictions on cash withdrawals from pre-paid cards which could limit choice and control. The card must not be linked solely to an online market-place that only contains selected providers in which to choose from.' (para 12.59)

Local authorities should therefore give consideration to how they develop card systems that encourage flexibility and innovation, and consider consulting care and support user groups on any proposed changes to direct payment processes.

3.4 **Burdensome bureaucracy**

The statutory guidance makes clear that processes developed for the administration and monitoring of direct payments must not be disproportionate, with the effect that choice and control is unduly limited. Processes must not:

'...restrict choice or stifle innovation by requiring that the adult's needs are met by a particular provider, and must not place undue burdens on people to provide information to the local authority' (para 2.4)

The Care and Support (Direct Payments) Regulations 2014 demand that local authorities must not require information to be provided more often and in more detail than is reasonably required for the purpose of enabling the authority to know that making direct payment is still an appropriate way of meeting the needs, and that conditions upon which it is made are met. (para 12.4)

The Care Act statutory guidance states that:

'Local authorities should not design systems that place a disproportionate reporting burden upon the individual. The reporting system should not clash with the policy intention of direct payments to encourage greater autonomy, flexibility and innovation. For example, people should not be requested to duplicate information or have onerous monitoring requirements placed upon them.' (para 12.24)

Where a person's direct payment from a local authority is integrated with other forms of public spending, such as a personal health budget direct payments, the statutory guidance says that local authorities should work with the other public agencies to combine both payments and monitoring. This should avoid the person having to manage multiple bank accounts or to supply similar information to different public bodies.

3.5 **Arbitrary cost-ceilings**

Some local authorities appear to have adopted blanket policies to impose cost-ceilings in respect of the amount they are prepared to pay for particular care and support options. The statutory guidance clarifies that:

In determining how to meet needs, the local authority may also take into reasonable consideration its own finances and budgetary position, and must comply with its related public law duties. This includes the importance of ensuring that the funding available to the local authority is sufficient to meet the needs of the entire local population. The local authority may reasonably consider how to balance that requirement with the duty to meet the eligible needs of an individual in determining how an individual's needs should be met (but not whether those needs are met). However, the local authority should not set arbitrary upper limits on the costs it is willing to pay to meet needs through certain routes – doing so would not deliver an approach that is person-centred or compatible with public law principles. (para 10.27)

In some cases, it appears that local authorities have benchmarked such cost-ceilings in line with the costs of residential care placements. This places individuals for whom the cost of alternative care and support options is higher than that of residential care in the erroneous position of either accepting a residential care placement, or living outside of residential care without support sufficient to meet their needs. Such practices can have the effect of obliging people requiring support to accept a particular living arrangement. The Care Act statutory guidance is unequivocal that such practices are unacceptable:

Local authorities should not have arbitrary ceilings to personal budgets that result in people being forced to accept to move into care homes against their will. (11.22)



4. How well are local authorities performing with respect to people's right to choice and control under the Care Act 2014?

4.1

Our research

The message from the Care Act 2014 statutory guidance is clear: while local authorities will always need to meet their obligations in respect of the law and financial accountability, they must always strive to do so in a manner which is consistent with the aims of optimising choice, control, flexibility and innovation that lie at the heart of the Act.

The Independent Living Strategy Group conducted two pieces of research and analysis to explore the degree to which local authorities are following the spirit and letter of the Care Act and its statutory guidance in seeking to optimize choice and control.

We began by conducting a survey of those in receipt of support from their local authority regarding their experience of choice and control over the past year. Subsequently, we asked local authorities to provide us with guidance provided to the public and/or staff regarding the Care Act 2014.

I can't put anymore pressure on my husband otherwise he will be ill and needing support too

4.2

What do local authorities say about choice and control?

In July 2015 the Independent Living Strategy Group submitted a request to all of England's 155 local authorities seeking information regarding the guidance provided to the public and/or to staff regarding their rights or obligations under the Care Act 2014. A copy of the request is in the annex.

Our primary objective in seeking this information was to determine if there was any evidence of local authorities explicitly adopting policies regarding cost ceilings related to particular care and support options or imposing restrictions on how personal budgets could be spent. The information we received did not allow us to come to any firm conclusions on these matters. However, we are able to conclude that:

- Local authorities are generally not yet meeting their duties to ensure the provision of clear, accessible, accurate and locally tailored information regarding care and support. This means that those seeking or receiving care and support lack access to information regarding their rights and entitlements, sufficient to exercise choice and control.
- Some local authorities have produced 'quick guides' explaining the key features of the Care Act. These rarely emphasize choice and control and the universal entitlement to a personal budget.
- Local authority definitions of personal budgets do not correspond with their definition in the Care Act statutory guidance. Whereas the guidance describes personal budgets as a mechanism for choice and control, the guidance we reviewed typically describes personal budgets only as the sum of money allocated to meet care and support needs.
- Some local authorities advise that if a person opts for their personal budget to be managed by the local authority that they should anticipate having less control over how it is spent than if they choose a direct payment. Some say, in effect, that the person will need to accept what the council chooses to provide, and some require that there will be no choice of care provider.¹⁶ This policy and practice does not meet the requirements of the Care Act statutory guidance which says that the option chosen should have no bearing on the ability of individuals to direct their support or to choose their care provider.

Our initial assessment of the information provided by local authorities revealed a need to reinforce the central expectations of the Care Act in relation to the matters we were interested in. Care act guidance is extensive in the expectations it creates of local authorities in relation to assessment eligibility and control over support. It was clearly evident from our initial review that local authorities are not consistently communicating these to local people. Therefore we undertook to conduct a more comprehensive and systematic audit in order to comment upon the information that local authorities are making available. To provide a basis of this audit we have produced a set of 'key messages' we believe all local authorities should be communicating clearly about their new responsibilities in these areas, (appendix 5).

¹⁶ For example see Suffolk County Council www.suffolk.gov.uk/assets/suffolk.gov.uk/Care%20and%20Support/Adult/2015.06.22-Changes-to-SCC-home-care-service-booklet-v7.pdf

We hope this will be of use to them as a frame work that they can use to check the quality of their own information. Over the coming months we will use these key messages to test the quality of information local authorities are making available. Our hope is that by ensuring local authorities receive open critical feedback on the quality of their information they will be more likely to give local people the information they need. Enabling people to go through the assessment eligibility and planning of their support on a more equal footing.

We also believe the key messages will be of help to people eligible for support and to organisations who might support and advise them, so they can check that the information they are receiving conveys the spirit as well as the letter of the Care Act. The intention being to raise both the understanding and expectation of people who need support as they enter into their relationship with their local authority in a more informed and empowered way.

4.3

What are the experiences of those receiving support?

Between April and June 2015, the Independent Living Strategy Group, with the support of In Control, conducted a survey inviting respondents to answer a series of questions designed to elicit information regarding people's degree of choice and control over care and support. The methodology, survey questions and the full results are included in the annex.

The key findings of the survey are that:

Diminishing quality of life: Over 45% of respondents said their quality of life had reduced over the past year. Almost

18% said it had done so significantly

Increasing need is largely being met by informal supports: Almost 50% said their need for support had increased over the past year. However only 22% said that they had experienced an increase in paid support. 30% said they had experienced an increase in support from family and friends in the same period.

Almost a third have encountered a reduction in choice and control:

Almost 30% said that they had experienced a reduction in choice and control over their support in the past year. Only 8% said that choice and control had increased.

Some report that their local authorities are using cost-ceilings regarding particular care and support options:

57% of respondents had had their care and support package reassessed during the past year. Almost 17% had been told that there was a cap on certain types of expenditure.

Some people report facing restrictions regarding the way direct payments can be used: Just over 29% of respondents reported restrictions being placed on their use of direct payments or personal budgets. 33% said no restrictions placed. 33% didn't know.

KEY QUOTES:

'Could not use it to fund anything except personal care'

'...onorous auditing, demanding receipts for everything no matter how small. No understanding (of) the true nature of self directed support and light touch monitoring of spending of direct payment.'

The most commonly reported restrictions concern the permitted activities of personal assistants/carers:

Of those aware that their use of direct payments had been subject to restrictions, stipulations regarding the tasks of personal assistants/carers were most commonplace (48%). 18% had had their personal support plan declined. 14% had been limited to choosing from a shortlist of providers. 12% had been limited to using a pre-payment card. 31% answered 'other.'

KEY QUOTES :

'I could not use it for gym membership or strategies to lose weight'

'My personal budget can no longer be used to pay for PAs to accompany me on outings'

'(local authority) won't allow direct payments to pay for needed items they won't supply, but we can use it for items they will supply'

Some transferring from the Independent Living Fund to local authority support face a reduction in support. Most do not know what the future holds:

Of those survey respondents who are transitioning from Independent Living Fund to local authority support, 14.5% had been told that they should expect less support in future, while the majority (56.5%) had not been told whether their support would increase, decrease or stay the same.

5. Conclusions - choice and control: a solution, not a problem

5.1

Our research

Despite the coming into force of the Care Act 2014 and the clear direction provided in the statutory guidance concerning the centrality of choice and control to individual wellbeing, people have reported a loss of choice and control and a decline in their quality of life over the past year.

Local authorities are struggling to adjust to unprecedented cuts in their budgets and it seems inevitable that this will impact on the scope for choice and control of those who presently or who in future will require care and support. Central government must ensure that funding to local authorities is sufficient to enable them to meet their statutory obligations as a minimum, let alone the broader goals and aspirations of the Care Act in respect of prevention and wellbeing.

Nevertheless, our evidence also demonstrates that the impact of cuts is not uniform and that local authorities' own approach to care and support significantly influences the degree of choice and control enjoyed by those in receipt of support. There are many things that local authorities can, should – and should not – be doing, irrespective of their financial position, to promote choice and control and to strive to meet the letter and spirit of the Care Act 2014.

Writing in 2004, Charles Leadbetter noted how:

'Personalisation could be a sustaining innovation designed to make existing systems more personalised or it could be a disruptive innovation designed to put the users in the driving seat as designers and paymasters of services. It could be a programme to apply a lick of new paint to fading public services or it could be the harbinger of entirely new organisational logic.'¹⁷

The challenges facing local authorities and public services to deliver significantly more for significantly less money suggests that the time to embrace a new organisational logic has arrived. Choice and control is not a problem to be negotiated, but a much-needed solution that should be readily embraced.

¹⁷ Leadbetter, C (2004) Personalisation through participation, Demos



“My personal budget can no longer be used to pay for PAs to accompany me on outings.”

Appendix

Appendix 1

About the Independent Living Strategy Group

The informal 'Independent Living Strategy Group' includes disabled people who were part of the independent living movement from the 1970s as well as younger activists and organisations [others] concerned with the future of independent living.

The original gathering was prompted by social media discussions about welfare reform and cuts to public service funding, and their actual and potential impacts on people in the context of insufficient UK legal protections for independent living. The group has been discussing what it and others might practically do in the short, medium and long term to help protect and promote people's access to independent living.

Monitoring progress on the right to independent living forms a central part of our work.

Appendix 2

Independent Living Survey Results

Independent living survey

We wanted to reach a wide range of people who relied upon social care support, and to do so independently from organisations responsible for commissioning or providing that support. In particular we were interested in the experiences of people with a high level of support need who had been living in the community, those most likely to be effected by the transfer of the Independent Living Fund. Given the resource constraints of the project, the survey was conducted online only, using lime survey.

A link to the survey questions was circulated widely via a number of different organisations who we knew to be connected to the target group. Given the manner in which the survey was conducted the precise detail of the results should be regarded with a degree of caution however there is no reason to believe they do not provide a helpful overview of the current position.

The survey was conducted in April and May 2015 and 399 people responded, just as the Independent Living Fund was closing and funding transferred to local authorities. People from 108 different local authority areas responded to the survey.

For questions marked with a * respondents could select more than one answer so percentages are unlikely to add up to 100.

The support people get and why they get it

Respondents were asked why they needed support and what type of support they received, as tables 1 and 2 show; respondents were primarily of working age (ave.40yrs) and living in their local community rather than in residential care services, indicating the sampling approach reached the intended target group. Table 3 shows just under one quarter of respondents were in receipt of ILF money, this group were asked to complete a further set of questions relating to the transfer process.

Table 1: Why people need support

What is the main reason you have support?*	
Learning disability	37.43%
Mental health difficulties	12.30%
Old age	3.66%
Physical disability	55.76%
Other	18.06%

Table 2: The type of support people get

What paid support do you currently get?*	
Direct Payment	51.45%
Personal Budget	25.07%
Personal assistant	22.69%
Home care	10.82%
A formal service	7.65%
Support in a registered care home	3.17%
Other	29.02%

Table 3: Support funded via the Independent Living Fund

Do you receive money for your support from the Independent Living Fund?	
Yes	22.96%
No	74.67%
No answer	2.37%

Changes to living accommodation

The survey asked people where they currently lived now and where they lived a year ago to see if this had changed in the last year.

As can be seen in table 4 the vast majority of people were living in the same type of living accommodation this year as last.

Table 4: Where people lived

Which of the following best describes where you live(d)	Now	Last Year
A home that I own or have a tenancy for	53.83%	54.26%
A home of a family member or friend	25.07%	26.42%
Temporary accommodation	1.06%	0.57%
Shared lives scheme	0.00%	0.00%
Supported living or sheltered accommodation	6.33%	5.97%
Registered nursing or residential home	2.37%	3.41%
Other	7.39%	7.10%
No answer	3.96%	2.27%

Changes over the last year

The survey asked respondents about changes in their need for support, the amount of paid support they received, the amount of support they received from friends and family and the degree of choice and control they enjoyed over their support. Finally the survey asked people about changes in their quality of life.

As Table 5 shows nearly half of respondents (49%) said that their need for support had increased or increased significantly. A similar number (45%) said their quality of life had reduced. Only 15% said that their level of paid support had increased, while nearly a third (30%) said the support they received from family and friends had increased or increased significantly. Nearly a third (30%) reported that the level of choice and control over their support had reduced or reduced significantly.

Table 5: Changes over the last year

Over the last 12 months have there been changes to the following?	Need for support.	Amount of paid support you get	Support from Family & Friends	Choice and Control	Quality of life
Reduced significantly	2.56%	7.10%	5.40%	12.50%	17.61%
Reduced	3.13%	9.94%	11.08%	17.33%	27.84%
Unchanged	40.91%	59.66%	49.15%	57.39%	39.20%
Increased	35.51%	12.78%	20.45%	7.39%	9.38%
Increased significantly	13.64%	2.56%	9.66%	1.70%	3.69%
No answer	4.26%	7.95%	4.26%	3.69%	2.27%

People experience of local their authority

The survey asked people a number of questions about their experience of the local authority in relation to their support. People were asked whether they had had a review or reassessment of their needs, whether the local authority had restricted their choice and control over their support and whether their local authority had indicated that it was likely to cap the cost of certain types of service.

As table 6 shows just over half (57%) of respondents indicated they had had a review or reassessment in the last year. A small but significant minority said they had been told that there was a cap on the cost of certain types of support, just under a third (29%) said they had experienced restrictions. People reported a range of restrictions being placed on how personal budgets and direct payments could be used including most commonly the tasks carers can and cannot perform (48%), the use of a short list of preferred providers (14%) and pre-payment cards (11%). 18% of those who reported restrictions said their proposed support plan had been refused.

Table 6: People's experience of their local authority in relation to their support

	Over the last 12 months has your local authority reviewed the support you get or have they undertaken a reassessment of your needs?	During your assessment or reassessment were you told there is a 'cap' on the amount of direct payment / personal budget you could get for a particular service?	Has your local authority placed restrictions on how you can use your personal budget / direct payment?
Yes	57.10%	16.76%	29.26%
No	33.52%	48.58%	33.52%
Don't know	7.10%	32.39%	32.67%
No answer	2.27%	2.27%	4.55%

Questions aimed at recipients of the Independent Living Fund

Respondents who said they had received funds from the ILF were asked several supplementary questions focused on the transfer of their funding to the local authority.

We asked whether people had had an assessment as part of their transfer, and if so had this involved a member of the local authority. We also asked whether people had been told of any new restrictions on their support as a result of the transfer. Finally we asked whether people had been told the amount of support they could expect after the transfer.

As table 7 shows just over half (57%) of ILF recipients transferring to their local authority had not had an assessment or review. Where people had had an assessment or review the vast majority (84%) had involved someone from the local authority. A small but significant (15%) minority of recipients had been told there would be restrictions placed on the use of their direct payment.

Table 7: Question for ILF recipients

	Have you had an assessment of your support needs as part of the transfer of ILF funds?	If yes, did this involve someone from your local authority?	Have you ever been told of any new restrictions upon how you use your direct payment / personal budget now that it is not paid by the ILF?
Yes	57.89%	84.09%	15.79%
No	31.58%	13.64%	51.32%
Don't know	9.21%	2.27%	31.58%
No answer	1.32%	0.00%	1.32%

Restrictions being placed on ILF recipients included the introduction of prepayment cards and pre commissioned services, not allowing the saving of funds over time for use in a short period of intense support. Disallowing the use of money to go out and to socialise and a reduction in payment rates and an increase in eligibility were also reported. Some respondents report feeling criticised for certain types of expenditure.



“My social worker is a great support but the finance section tell me I can’t use my budget in the way I need to”

Appendix 3

Independent Living Survey

About this survey

This short survey is being carried out by a group of organisations and activists that have been meeting for the past two years to think about how to move the independent living agenda forwards. You can read more about us here

<http://www.in-control.org.uk/blog/losing-control.aspx>

We want to know about the experiences of people who access support from their local councils and find out whether choice and control over that support is changing. To help us understand these issues we would be extremely grateful if you could spare a few moments to complete this short survey to share your own experiences.

You can ask someone to help you complete this survey or they may complete it on your behalf with your agreement.

Keeping your personal information safe

The survey results will be anonymous and we will not publish any material that will identify you. You do not have to provide your name, but we very much hope you will share your email address with us so we can keep in contact and you can help us monitor people's experiences of support over time.

There are 20 questions in this survey

1. How old are you?

Please write your answer here:

2. What is the main reason you have support?

Please choose all that apply:

Learning disability

Mental health difficulties

Old age

Physical disability

Other:

3. What local authority area do you live in?

Please write your answer here:

About your Independent living fund.

4. What paid support do you currently get?

Please choose **all** that apply:

Direct Payment

Personal Budget

Personal assistant

Home care

A formal service (like a day center)

Support in a registered care home

Other:

**About your
Independent
living fund.**
(continued)

**5. Do you receive money for your support from the
Independent Living Fund? ***

Please choose **only one** of the following:

Yes

No

6. Where do you live now?

Which of the following best describes where you live

Please choose **only one** of the following:

A home that I own or have a tenancy for

A home of a family member or friend

Temporary accommodation

Shared lives scheme

Supported living or sheltered accommodation

Registered nursing or residential home

Other

About changes to your independent living.

7. Where did you live this time last year?

Which of the following best describes where you lived 12 months ago

Please choose **only one** of the following:

A home that I own or have a tenancy for

A home of a family member or friend

Temporary accommodation

Shared lives scheme

Supported living or sheltered accommodation

Registered nursing or residential home

Other

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

Please choose the appropriate response for each item:

	Reduced significantly	Reduced	Unchanged	Increased	Increased significantly
Your need for support					
Amount of paid support you get					
Amount of support you get from friends and family					
Level of choice and control you have over your support					

**About changes
to your
independent
living.**
(continued)

9. Over the last 12 months has your local authority reviewed the support you get or have they undertaken a reassessment of your needs?

Please choose **only one** of the following:

Yes

No

Don't know

10. During your assessment or reassessment were you told there is a 'cap' (a maximum) on the amount of direct payment / personal budget you could get for a particular service?

Please choose only **one** of the following:

Yes

No

Not applicable

If Yes: What was the amount of the Cap?

Only answer this question if the following conditions are met:

Answer was 'Yes' at question '10 [YC7]'
(10. During your assessment or reassessment were you told there is a 'cap' (a maximum) on the amount of direct payment/personal budget you could get for a particular service?)

Please write your answer here:

11. Has your local authority placed restrictions on how you can use your personal budget/direct payment?

Please choose **only one** of the following:

Yes

No

Don't know

If Yes: Which, if any, of the following restrictions were placed on how you use your personal budget?

Please **tick** all that apply

Only answer this question if the following conditions are met:

Answer was 'Yes' at question '12 [YC8]'
(11. Has your local authority placed restrictions on how you can use your personal budget/direct payment?)

Please choose **all** that apply:

I was required to use a pre-payment card

The tasks that my PA or carer can help me with have been limited

I had to choose from a short list of providers approved by my local authority

The local authority refused to approve my support plan as they did not agree with how the personal budget was to be spent

Other:

**About changes
to your
independent
living.**
(continued)

12. Over the last 12 months has your quality of life...

Please choose **only one** of the following:

Reduced significantly

Reduced

Unchanged

Increased

Increased significantly



“I would like to self direct my support but I am expected to check with the council for every bit even when it’s already in my support plan.”

**Future contact
with you.**

**13. Have you had an assessment of your support
needs as part of the transfer of ILF funds?**

Only answer this question if the
following conditions are met:

Answer was 'Yes' at question '5 [YF2]'
(5. Do you receive money for your support from the
Independent Living Fund?)

Please choose **only one** of the following:

Yes

No

Don't know

**If yes, did this involve someone from your
local authority?**

Only answer this question if the
following conditions are met:

Answer was 'Yes' at question '15 [FC1]'
(13. Have you had an assessment of your support needs
as part of the transfer of ILF funds?)

Please choose **only one** of the following:

Yes

No

Don't know

**Future contact
with you.**
(continued)

**14. Have you ever been told of any new restrictions
upon how you use your direct payment /
personal budget now that it is not paid by
the ILF?**

Only answer this question if the
following conditions are met:

Answer was 'Yes' at question '5 [YF2]'
(5. Do you receive money for your support from the
Independent Living Fund?)

Please choose **only one** of the following:

Yes

No

Don't know

If yes please describe:

Only answer this question if the
following conditions are met:

Answer was 'Yes' at question '17 [FC3]'
(14. Have you ever been told of any new restrictions
upon how you use your direct payment / personal
budget now that it is not paid by the ILF?)

Please write your answer here:

15. Have you been told that the amount of support you will get after transfer will change?

Only answer this question if the following conditions are met:

Answer was 'Yes' at question '5 [YF2]'

(5. Do you receive money for your support from the Independent Living Fund?)

Please choose **only one** of the following:

Yes:

I have been told I can expect more support in the future

Yes:

I have been told I can expect the same amount of support in the future

Yes:

I have been told I can expect less support in the future

No:

I have not been told much support I can expect in the future

We would like to find out if your experience of support changes over time, if you are happy for us to contact you again please provide an email address:

We will only use your email address for the purposes of this survey and we will not disclose your email address to third parties.

Please check the format of your answer.

Please write your answer here:

Thank you for answering these questions. Unfortunately we are unable to respond to individual issues, if you do have concerns about your support please contact your local authority or local advice service.

Thank you for completing this survey.

Appendix 4

Request for information to local authorities

To whom it may concern

RE: Request for information relating to care act Implementation

We are conducting a review of information provided by local authorities relating to adult social care. We are keen to understand what information is made available to local people and what policy and procedures are in place for staff to work with.

You will be aware that the Care Act places a number of new duties and powers on Local Authorities regarding the provision of care and support and the availability of personal budgets. Statutory guidance accompanying the Care Act detail how these powers and duties should be carried out.

We are particularly interested in how local authorities are communicating these new responsibilities to their staff and to local people.

In particular our review will focus on how local authorities communicate to their staff and to local people:

- entitlement to and eligibility for care and support
- entitlement to (and local authority definitions of) a personal budget
- the purpose and nature of the assessment process
- the degree of choice and control individuals can expect to exercise over their support
- any restrictions that are in place over cost, amount or nature of particular types of support
- any information specifically aimed at or relating to former ILF recipients.

We aim to review, analyse and publish our findings in the autumn and would be happy to provide you with our evaluation of the quality of the information you have submitted to us.

We hope you will see this as a helpful opportunity for a review from an independent angle. We will publish general findings but will not 'name and shame' poorer performing areas but would like to point towards areas of good practice.

We are writing to request that you provide us with all general information, and any policies and procedures relating to the above that you make available to:

- the general public
- individuals who approach your adult social care department
- staff undertaking assessment and care and support planning functions or providing support on your behalf.

Please could you send the information to:

Caroline Jowett
In Control Partnerships
Carillon House
Chapel Lane
Wythall
Birmingham
B47 6EQ

We look forward to receiving this from you by 31st July 2015.

With thanks in anticipation for your cooperation.

Julie Stansfield
CEO for In Control Partnerships

Appendix 5. Key messages check list: Things your local authority should have told you about the care act.

**These key messages
are a useful summary
of the things you
should let people know
about the care act and
the responsibilities
local authorities have
regarding; assessment,
eligibility decisions,
the definition of and
entitlement to Personal
Budgets, and the
control people should
enjoy over their support.**

They are intended to capture the spirit as well as the letter of the Care Act bringing together in one convenient summary a check list of key messages that can be used to review the information being made available by the local authority in your area.

All the messages are based on clear expectations set out in the care act statutory guidance. For presentation purposes on the first key message contains the relevant care act guidance in full, but sections of the guidance are clearly referenced under each of the following key messages.

Purpose and nature of the assessment process

The assessment is there to help you understand your needs and the support you may get (where you can't do this the Local Authority must point them out).

- The aim of the assessment is to identify what needs the person may have and what outcomes they are looking to achieve. (help people to understand their strengths and capabilities, and the support available to them in the community)-6.5
- The outcome of the assessment is to provide a full picture of the individual's needs so that a local authority can provide an appropriate response.-6.5
- The local authority should establish the impact of [need] on the individual's day-to-day life. ...must also consider whether the individual's needs impact upon their well being beyond the ways identified by the individual.- 6.14

You and your family should be at the centre of the assessment (if you can't do this the Local Authority must find an independent person to help you). You should have a copy of the assessment questions in advance and a record of the assessment afterwards.

**(Relevant care act requirements-
6.30, 6.34, 6.38, 6.98, 6.44.)**

The assessment will affect what support you get.

(Relevant care act requirements-6.44, 6.12)

Everyone has a right to be assessed (by someone able to do it well).

**(Relevant care act requirements-
6.7, 6.13, 6.28.)**

The Local Authority must think carefully about the role of your family Carers, (they can't just expect them to carry on).

(Relevant care act requirements- 6.15)

Eligibility

The eligibility decision must be based on an assessment, the assessment must consider your needs over time.

(Relevant care act requirements 6.12, 6.117)

If you do not have eligible needs you should still receive a full summary of your assessed needs, and a written explanation saying why the council is not meeting your needs.

You should expect to be given information and advice, and possibly support focused on preventing an increase in needs. If you have a high level of needs you may be entitled to NHS support, the Local Authority must inform your local NHS.

(Relevant care act requirements: 6.6, 6.100, 6.80, 10.29)

When deciding whether you are eligible the Local Authority will look at your strengths (things you can do) support available from family and local community as well as your needs (things you need help to do). If a carer is meeting your needs those needs are still eligible, but if the carer agrees to continue providing support the Local Authority does not have to meet them.

(Relevant care act requirements: 6.6, 6.10, 6.119)

The impact of your needs on your wellbeing is central to the process (wellbeing is defined in law). You should have a say how your needs effect your wellbeing.

(Relevant care act requirements: 6.10, 6.102, 6.111)

There will be a financial assessment after the assessment of needs, this must not inform the eligibility decision.

(Relevant care act requirements: 6.12)

To be eligible you must pass three tests:

- Needs are a result of disability or illness
- Your needs mean that you are unable to achieve at least two 'outcomes' related to the daily life in areas below. These are set out in law but are not the only possible areas (not an exhaustive list).
- Not achieving these 'outcomes' has a significant impact on your wellbeing

(Being unable to achieve is very broad and can just mean you need reminding or it takes you a lot longer for you than is normal, or it is very painful or risky to do so).

- managing and maintaining nutrition
- maintaining personal hygiene
- managing toilet needs
- being appropriately clothed
- being able to make use of the home safely
- maintaining a habitable home environment

- developing and maintaining family or other personal relationships
- accessing and engaging in work, training, education or volunteering
- making use of necessary facilities or services in the local community including public transport and recreational facilities or services
- carrying out any caring responsibilities the adult has for a child

(Relevant care act requirements:

**6.105, 6.106, 6.107, 6.108,
6.109, 6.110, 6.111, 6.112**

Definition of and entitlement to Personal budget

If you are eligible for long term care and support, you have a legal right to a personal budget even if you are in residential care. Your support should be arranged through a personal budget as a matter of course.

(Relevant care act requirements:

11.2, 11.7, 11.16, 10.7

You should be told before you develop a plan how much money it should take to meet your needs, and how much money the local authority will put into your personal budget.

(Relevant care act requirements:

11.3, 11.7, 11.24, 11.10, 10.3

It is you and your family who decide how the personal budget is used, regardless of where it is held.

(Relevant care act requirements:

11.7, 11.29, 11.3

You can choose how the personal budget is held, taking the money directly, asking the Local Authority or a care provider to hold it.

(Relevant care act requirements: **11.3**)

Your personal budget should be worked out in a way that you can understand.

(Relevant care act requirements: **11.4, 11.24**)

There must be enough money in the budget to meet your needs, you are free to pay more in if you choose.

(Relevant care act requirements:

11.10, 11.14, 11.24)

Degree of choice and control over support (Restrictions)

You should have help to create your own care and support plan describing the outcomes you want to achieve and how you want to be supported. The local authority will agree this with you and give you a copy.

(Relevant care act requirements:
10.2, 10.31, 10.87, 13.27)

How your needs are met is up to you.

(Relevant care act requirements:
10.47, 10.5, 10.10, 10.21)

Your needs are not just about personal care your support plan should cover other aspects of daily life and you can look at lots of different ways to meet your needs including “non-service” options such as Information and Communication Technologies (ICT) equipment, club membership, and massage’.

(Relevant care act requirements:
10.38, 10.48)

Your council should set out your options simply and clearly to help you choose how you are supported, this doesn’t mean you have to choose one of their options.

(Relevant care act requirements:
10.4, 10.33, 10.48)

The council can’t do everything certain health and housing needs are met by other organisations.

(Relevant care act requirements:**10.23**)

The council has to spend money wisely and meet everyone’s needs, this means they have some discretion when deciding exactly how to meet your eligible needs but not whether to meet them.

(Relevant care act requirements: **10.27**)

The council can’t set an upper level cost for different types of support, they must look on a case by case basis at value for money.

(Relevant care act requirements: **10.27, 10.48**)

Notes



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