

Disability Sheffield Factsheet

Legal Guide and Frequently Asked Questions for Independent Living Fund (ILF) users and people with High Support Needs



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Introduction

This guide has been written to help Independent Living Fund (ILF) users understand legal and practical issues about community care assessments and support and how it will apply to them following the closure of the ILF in June 2015. It is also aimed at other adults with high support needs who may not have had support from ILF.

It has been written for people who do not have a legal background. However, any individual who is considering legal action in relation to problems with their support should not rely only on this guide but should seek specialist advice, including legal advice.

These FAQs have been prepared by Kate Whittaker¹ together with ILF users, Inclusion London and Disability Sheffield Centre for Independent Living.

Individuals and local groups are welcome to re-use extracts and are free to copy it and send it round by email. If extracts of the paper are used in other publications please state that the content was taken from this guide.

A copy of this guide is available at :

www.disabilitysheffield.org.uk/fact-information-sheets

www.inclusionlondon.co.uk/ILF

<http://ilfaction.net/info-guidance/>

You can also check there for updates to take account of future changes.

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Frequently asked Questions

1. When will changes happen to my support and how much warning will I get? Will I get enough notice to allow me to meet my employer's responsibilities?

No one should have their support cut without an assessment by their local authority.

For most ILF users this will be a re-assessment but for some Group 1 users, who have not received local authority support before, it will be the first time they have had an assessment. If this applies to you, you should seek an assessment as soon as possible so that the local authority can be aware that you have needs that the ILF has been meeting.

The assessment needs to comply with all the usual requirements for community care assessments by local authorities, but the local authority should also take account of specific guidance about ILF transfers. This includes a section in the Care Act Statutory Guidance

(www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf, paragraph 23.26 onwards) and also the Code of Practice agreed by the ILF, Association of Directors of Adult Social Services (ADASS) and Local Government Association (LGA) on the Transfer Review Programme (www.adass.org.uk/ilf-code-of-practice-nov-2014/).

Although statutory guidance does not have the force of law, local authorities are required to follow it unless there is a good reason why not – and even in such cases, they must keep any departure from it to the minimum. .

Some people will not have had a re-assessment by the end of June 2015. Many local authorities have acknowledged this and have indicated that people's funding will continue at existing levels after closure until a re-assessment has been completed, with the local authority funding the ILF element. There are likely to be some complications about maintaining this on a temporary basis pending re-assessment, for example because the system of financial contributions for ILF funding is different from that for local authority support.

A 2015 [guidance / clarification note](#) accompanying the Care Act 2014 states that it 'will usually be most pragmatic for the transition under the Care Act to take place at the point of the planned, regular review' and importantly the [Statutory Guidance](#) advises that the 'review must not be used as a mechanism to arbitrarily reduce the level of a person's personal budget' (para 13.4).

Once a re-assessment is completed, if there is a proposal to reduce or change the support, then the guidance and Code of Practice make clear that:

- This should be discussed with you: in particular the local authority should consider your opinions in relation to your wellbeing (see more about wellbeing below) and the impact of changes on both you and your family.
- People will need to be given sufficient notice and support before the change takes place, so that they can meet legal and contractual obligations, including redundancy payments and notice periods. The Code of Practice makes clear that the funding transferred to local authorities at the point of closure should enable them to meet any financial obligations that users incur as a result of the transfer.

See below about the question of whether reductions or other changes can be postponed pending the outcome of a complaint or other challenge.

2. How will the local authority go about assessing and providing me with support once ILF has closed?

In general, after closure of the ILF, the obligations owed by local authorities to assess and provide support to former ILF users will be the same as for all other users of adult social care. These are now chiefly governed by the Care Act 2014 and associated regulations and guidance. Although there is some guidance that encourages local authorities to consider particular factors for ILF users, there will be no legal obligations to treat former ILF users any differently from other users of adult social care.

So the best approach is to:-

1. Get as clued up as you can about general tips for dealing with community care assessments and decisions about eligibility and support planning, including accessing local support for people going through this process:

These are some suggestions of resources you can use for this:

- CBF/Luke Clements, Ten Top Tips (updated Care Act version available shortly – pre-Care Act version is at www.challengingbehaviour.org.uk/learning-disability-files/16---Ten-top-tips-2014.pdf): written for family carers of people with a learning disability and challenging behaviour – but is a very good overview of advice on getting and keeping a good package of adult social care (not just for people with learning disabilities)

- Scope guide to Social care and dealing with cuts or changes to your care package: www.scope.org.uk/support/disabled-people/social-care-overview
- Professor Luke Clements Care Act briefing: www.lukeclements.co.uk/whats-new/
- Powerpoint presentation on the Care Act 2014 by barrister Steve Broach (Monckton Chambers);available from Inclusion London (020 7237 3181; ellen.clifford@inclusionlondon.co.uk): This is particularly useful for analysing how key points from the Care Act (for example about eligibility, support planning, direct payments and others) are developed within the Statutory Guidance and various different sets of regulations that give detail to the Care Act.
- Carers UK guide to the Care Act: www.carersuk.org/images/publications/Factsheet_E1029_Assessments_and_the_Care_Act_updated_27_March_2015.pdf
- Luke Clements, Carers and their Rights (2015 6th edition) at www.lukeclements.co.uk/publications/
- Factsheet about eligibility for NHS funded continuing care: www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS20_NHS_continuing_healthcare_and_NHS-funded_nursing_care%20_fcs.pdf?dtrk=true

We are not trying to reproduce the content of these resources in these FAQs but urge you to use them along with the information in this guide that spells out particular tips for ILF users.

2. Think about extra arguments you can make about how your needs as an ILF user should be understood and taken into account.

This is about trying to persuade your local authority to understand your situation and the particular risks that apply. It is fundamental in all local authority social care assessments for them to look at your needs as an individual which includes the fact of you having received ILF support previously and having established ways of living a good, independent life, that you need to maintain. Some points and arguments to consider are:-

- The local authority needs to take into account the transfer review that will have been completed by the ILF (with or without input from the local

authority). They do not have to match what the ILF has provided but they have to be able to show that they have properly considered it.

- The ILF/ADASS/LGA Code of Practice on ILF transfer says that local authorities will need to give particular attention to people's wishes to remain living in the community and 'consider how they can best be supported to continue to do so, in a way which allows them to retain as much independence as possible'.
- This is in line not only with the principles of the Care Act, but also the UN Convention on the Rights of Persons with Disabilities (UNCRPD), particularly Article 19, the right to independent living. The UNCRPD has been ratified (i.e. signed up to) by the UK Government, which means the UK has obligations to work towards the 'progressive realisation' of the rights in the Convention. But the UK has not yet incorporated it directly into our national law (unlike the European Convention on Human Rights which has been incorporated through the Human Rights Act). So it does not apply directly. But legally it does have some relevance for local authorities, because they have to be mindful of the UNCRPD when dealing with issues that affect people's human rights. Under the Human Rights Act all public bodies have to act compatibly with human rights, and their understanding of what human rights mean in practice has to take account of other international obligations including the UNCRPD.
- It may be worth spelling out that to be eligible for ILF, people have been assessed as meeting certain criteria which are essentially about them (a) having particularly high support needs and (b) being at particular risk of not being able to live independently unless they receive support for this. One of the important aspects of ILF is that it has been a system (not just a pot of money) which helpfully identifies people with these needs and risks and makes sure their needs are met in such a way as to ensure they live independently. Local authorities need to be aware that without having this system of identification and specialist support, there is a danger that they will overlook how significant these needs and risks are, and will make false economies that will lead to crisis and breakdown of previously stable care arrangements and indeed placements in the community. The very stability and effectiveness of joint ILF/social care packages (and sometimes health

too) can be deceptive as to how great people's needs are and how catastrophic it can be to undermine their support in even a small way. So local authorities need to think seriously about maintaining tried and tested support that has enabled people to stay independent rather than experimenting with cuts that could be catastrophic.

- This is not an argument for giving ILF users 'more favourable treatment' than other disabled people. It is an argument that ILF users have particular needs and risks around staying independent. The Equality Act is clear that avoiding discrimination against disabled people and advancing equality of opportunity, means meeting needs that they have that others do not. For those with the highest support needs that principle must be applied just the same, so they are not discriminated against merely by virtue of having higher support needs than others.

3. What is the well-being duty in the Care Act and how can it help me argue for my independent living needs to be met?

The well-being duty is set out at the very beginning of the Care Act, as Section 1. It is very important for all adult social care users and has particular importance for people who have previously had ILF and others with high support needs and particular requirements around being able to maintain independence.

The well-being duty applies to all local authorities. It requires that in everything the local authority does under the Care Act relating to an individual, they must **promote the well-being of the individual**.

Well-being is defined (s1(2)) as including 'that individual's well-being so far as relating to any of the following –

- (a) personal dignity (including treatment of the individual with respect);
- (b) physical and mental health and emotional well-being;
- (c) protection from abuse and neglect;
- (d) control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided);
- (e) participation in work, education, training or recreation;
- (f) social and economic well-being;
- (g) domestic, family and personal relationships;
- (h) suitability of living accommodation;
- (i) the individual's contribution to society.'

As a legal duty (rather than a discretionary power) in an Act of Parliament (rather than in guidance, say), local authorities must comply with the principle of promoting well-being. The question of course, is what that means, which depends very much on the context, including the particular function that the local authority is carrying out.

Section 1 of the Care Act also sets out a lengthy list of **particular factors that local authorities must have regard to** when fulfilling the well-being duty, which is worth quoting in full because there are so many important points that may be relevant and powerful for ILF users to refer to:

- [1(3) In exercising a function under this Part in the case of an individual, a local authority must have regard to the following matters in particular –
- (a) the importance of beginning with the assumption that the individual is best-placed to judge the individual's well-being;
 - (b) the individual's views, wishes, feelings and beliefs;
 - (c) the importance of preventing or delaying the development of needs for care and support or needs for support and the importance of reducing needs of either kind that already exist;
 - (d) the need to ensure that decisions about the individual are made having regard to all the individual's circumstances (and are not based only on the individual's age or appearance or any condition of the individual's or aspect of the individual's behaviour which might lead others to make unjustified assumptions about the individual's well-being);
 - (e) the importance of the individual participating as fully as possible in decisions relating to the exercise of the function concerned and being provided with the information and support necessary to enable the individual to participate;
 - (f) the importance of achieving a balance between the individual's well-being and that of any friends or relatives who are involved in caring for the individual;
 - (g) the need to protect people from abuse and neglect;
 - (h) the need to ensure that any restriction on the individual's rights or freedom of action that is involved in the exercise of the function is kept to the minimum necessary for achieving the purpose for which the function is being exercised.'

So the well-being duty is a duty about how the local authority carries out its functions, about the factors it should constantly think about and be guided by. It

is a duty to promote well-being – not necessarily to achieve it. But nonetheless it provides some really powerful tools to argue about what is important for people in terms of social care support.

‘Well-being’ under the Care Act is therefore a very wide concept. For the purposes of the loss of ILF support, there are – arguably – two particularly important ‘principles’.

The first is ‘(a) assumption that the ‘individual’ is best placed to judge well-being’. This creates a default position (rather like the presumption of capacity in the MCA 2005) which a local authority will have to produce evidence if it wishes to rebut.

The second concerns the right to ‘independent living’ (which although absent from the Act) is expressed with force in the [Statutory Guidance](#), stating at para 1.19:

The wellbeing principle is intended to cover the key components of independent living, as expressed in the UN Convention on the Rights of People with Disabilities (in particular, Article 19 of the Convention). Supporting people to live as independently as possible, for as long as possible, is a guiding principle of the Care Act.

Some of the questions and case studies below will show how the idea of well-being comes up in the processes of assessing social care needs, determining eligibility and deciding on support to be provided, and how this can be used to highlight the types of needs that ILF users have.

4. Do I have a right to an independent advocate through the assessment process? Or other support to be able to manage the process and be properly involved?

Everyone has the right to have someone of their choice to accompany them to assessments or otherwise support them with issues around getting social care. That could be an advocate, friend or family member. Or it could be another disabled person who has been through the process before and can provide peer support. Disabled people’s organisations and other local advice and support groups can advise on options for peer support and advocacy that you can get.

Sometimes people can get free independent advocacy support for dealing with assessments and other care issues. However there is not an automatic right for everyone to be provided with this support. It depends on people’s circumstances. But there are a number of ways in which the Care Act does put stronger duties on local authorities to ensure that people have advocacy or similar support where needed, including:-

- An enhanced duty (under s4) to provide adults in need and carers with **information about care and support arrangements**, including how the adult care system operates, the care and support choices they have (including choice of providers), how to access this support and how to raise safeguarding concerns. For some people, ensuring they get this information will include receiving advocacy support.
- A **duty to involve** the person, carer and others that the person wants to be involved. Again for some people this will involve advocacy support. This duty is part of the well-being
- A duty (under s67) to provide **independent advocacy support** to specific people in set circumstances. The duty applies where the authority considers that:-

- (1) you would have ‘substantial difficulty’ in being involved in your assessment, the preparation of your care and support plan or other processes about care provision (including care reviews, safeguarding enquiries and safeguarding adult reviews; and
- (2) there is no one appropriate available to support you with the process.

‘Substantial difficulty’ in being involved means having substantial difficulty in **any one** of the following:

- understanding relevant information
- retaining information
- using or weighing the information, or
- communicating your views, wishes and feelings.

The duty to involve (using advocacy support or other means) applies from the first point of contact, request or referral (including self-referral) and at any subsequent stage of the process after that.

For it to be an ‘appropriate individual’ to facilitate the person’s involvement

- They must be able to support your active involvement
- They must not already be paid or professionally engaged in providing care or treatment to you or your carer (i.e. it is someone independent)
- The person being supported:
 - o must agree, if they have capacity to decide; or if they lack capacity, the local authority must agree; and
 - o will have a veto regardless of capacity to decide about advocacy or not.

Often there will be a family member or friend who is appropriate and willing to provide advocacy-type support, but sometimes people will not want this and may be able to insist on having independent advocacy support, if they meet the other criteria.

5. What are the most important things I need to think about to prepare for my re-assessment?

As explained above the approach the local authority will take to the re-assessment will be the standard approach that it takes to all other assessments and re-assessments for adult social care. Detailed information is available in resources such as those listed above. However here are some key points about assessments that you can find out more about in those and other resources:-

- The Care Act Guidance (para 6.38) says that local authorities must '**provide in advance, and in an accessible format, the list of questions to be covered in the assessment**'. This is a new principle which is very helpful and has certainly not been common practice so worth pushing for.
- Assessments should normally be **face to face**, not just by telephone or a self-assessment questionnaire posted to you that you cannot discuss with the assessor. The Care Act guidance suggests that in very straightforward cases it may be reasonable to have an assessment by telephone, however this is unlikely to be appropriate for ILF users.
- Although assessors need not be qualified social workers the statutory guidance emphasises that they must be '**appropriately trained**' and (para 6.88) that if an 'assessor does not have the knowledge of a particular condition or circumstance, they must consult someone who has relevant expertise'. It is important therefore to raise any concerns about the lack of expertise / ability of the assessor at an early stage if this appears to be the case.
- If there is a possibility that you have **other types of needs in addition to social care**, such as healthcare or housing then the assessor should recognise this and proactively make referrals and cooperate with other professionals and agencies, to make sure they carry out appropriate assessments promptly, and work jointly to plan and meet your needs. This is particularly relevant for ILF users many of whom may have complex health

needs and may need an assessment of eligibility for fully NHS funded continuing healthcare, or for a combined package of health and social care jointly funded by the NHS and local authority.

- The assessment should also gather information from carers, family or others who can help give information about your needs (if you agree to this). You should also be given a chance to speak to the assessor separately from your carers or family if you want to, and the same for your carers if they want to, so they can discuss their own needs as a carer.
- If family members or others are providing care free of charge, then it is very important to document through the assessment process the **extent to which the carer is willing and able to continue providing such voluntary care** (if at all), and also **whether the person being cared for wants to continue with that arrangement**. Disabled adults should not be forced into accepting free care from family or others if they do not feel that it meets their needs so as to promote their well-being and independence. Nor should family members (such as elderly parents of disabled adults) feel forced into providing care in a way that is contrary to their wellbeing or that of the disabled person, as a result of failures to recognise and meet people's eligible needs. It is vital to ensure that these factors and wishes are clearly documented in the assessment to avoid inappropriate assumptions being made that affect the support a local authority will in practice offer, to meet assessed needs.
- Under the Care Act, there are stronger rights and more detailed requirements about **assessments and support for carers** – these are discussed below.
- If the assessment identifies **very urgent needs** then the Care Act enables the authority to provide an immediate response without waiting for a full determination of eligibility (section 19(3)).
- **It is vital to get a copy of the assessment record and documentation showing what decisions have been made and why.** The Care Act and the statutory guidance oblige authorities to provide individuals with copies of their assessment (section 12(3) & para 6.98) and their care plan (section 25(9) & para 10.87).. You need to get copies of these so that you can be sure that all the necessary information has been documented in the assessment and

taken into account in the decision-making about your needs, which are eligible, and what support is going to be provided. If information is missing from the assessment record, then insist that it is added.

6. What are eligible needs?

Eligible needs are those needs which the local authority legally has to ensure are met.

The local authority assessment should clearly identify all your needs, including needs of lesser severity. There is then a process of deciding which ones are eligible, i.e. which ones the local authority must ensure are met.

There is then a further process of deciding what support is in fact going to be provided. That is a separate question from the question of which needs are eligible. Not all eligible needs will lead to the local authority providing support for them. They may be met in another way. And conversely, some needs will lead to support being provided even though they may not be eligible needs. This may be to prevent them getting worse or stop them interacting with other needs you have.

There is a very strong emphasis in the Care Act on local authorities taking **preventative steps** like this, and also on looking at the **whole person and how their needs add up** and affect their lives overall. This emphasis is not new: local authorities have long been encouraged to go beyond providing the bare minimum. And with the level of cuts to local authority budgets getting ever worse it is hard to see how local authorities are going to be able to improve on their poor track record of doing so. But it is still important to make the arguments about ‘a stitch in time’ – local authorities need to recognise that cutting support that is working and keeping people independent and included in their communities can be a huge false economy.

The issues about local authorities deciding what support you can get and planning with you how it will work are discussed further below. This section is about determining which needs are eligible, which is an essential step in getting the provision you need from the local authority.

The Care Act 2014 introduces a **new single, national eligibility framework** for all local authorities in England. This replaces the previous framework (commonly known as ‘FACS’ – Fair Access to Care Services), which allowed for significant variations between different local authorities.

The details of the new framework are set out in the Care and Support (Eligibility Criteria) Regulations 2014. To be eligible for support, you must meet three requirements (under clause 2(1) of the regulations):-

1. Your needs must be the result of a physical or mental impairment or illness (obviously the case for ILF users)
2. As a result you must be **unable to achieve two or more of the outcomes** set out in the eligibility criteria (see below), and
3. As a consequence there is, or is likely to be, a **significant impact on your wellbeing**.

The specified outcomes (clause 2(2)) are:-

- (a) managing and maintaining nutrition;
- (b) maintaining personal hygiene;
- (c) managing toilet needs;
- (d) being appropriately clothed;
- (e) being able to make use of your home safely;
- (f) maintaining a habitable home environment;
- (g) developing and maintaining family or other personal relationships;
- (h) accessing and engaging in work, training, education or volunteering;
- (i) making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and
- (j) carrying out any caring responsibilities you have for a child.

The regulations state (clause 2(3)) that you are regarded as ‘unable to achieve an outcome’ not only if you are unable to achieve it at all, but also if you:

- (a) are unable to achieve it with assistance; or
- (b) are able to achieve it without assistance but doing so causes you significant pain, distress or anxiety; or
- (c) are able to achieve it

So it should be a relatively low threshold to show you are unable to meet outcomes. However this is then balanced out by the requirement to show that there is a significant impact on your wellbeing, before your need for support to meet a particular outcome is regarded as eligible.

The Care Act Guidance says that in this context ‘significant’ should be given its ‘ordinary meaning’. But it also expands slightly on the meaning of the phrase ‘significant impact’, saying it means ‘an important effect on your **daily life, independence and well-being**’.

A vitally important principle in determining which needs are eligible for support is that the decision should be ‘carer-blind’ – **it should ignore any help you are**

getting from carers, whether paid or unpaid. This is essential so that what is assessed is the underlying need itself – not the question of how well-managed it is (or not) at any given time.

7. My needs have been reassessed and the local authority isn't offering enough support or the right support for me to live independently. How can I argue for the support plan and amount of personal budget that I need?

Once eligible needs have been identified the local authority will go on to consider what support it will provide to meet the eligible needs and any non-eligible needs that it decides to meet, eg as a preventative measure.

Needs can be met either by the local authority arranging for support services to be provided – for example by a care agency – or by the disabled person receiving a direct payment which they use to make arrangements themselves to meet the needs.

A care and support plan will be developed with you through the assessment process. This should set out all the key practical details to explain how the support is going to be provided to meet the assessed needs.

The Care Act guidance sets out what must be included in a care and support plan, including:

- a note of **all your needs** identified during the assessment
- details of which ones are **eligible needs**
- the needs that the authority is **going to meet**, and **how** it will do this – may be partly or all by a direct payment
- agreed **outcomes** you want to achieve and how support will be organised to meet them
- support which carers and others are willing and able to provide – or make clear if they or you are **not willing**
- for a carer, their desired outcomes about providing care, work, education and recreation and how support will be organised to meet them – may be by direct payments or other support to the carer or support to you
- the **personal budget**, including details of any financial contributions you will need to pay
- details of what can be done to **reduce or prevent your needs getting worse**
- amount and frequency of any **direct payments** you will get.

It is central to the principles of the Care Act (and much community care law and policy before that) that support planning should be person-centred and you should be able to be as involved as possible in thinking about what is the best way to meet your needs so that you can achieve the outcomes you want in a way that promotes your well-being.

Some (but not all) local authorities use ‘resource allocation systems’ to process details from the assessment responses at an early stage in the procedure, and generate an ‘indicative budget’ to facilitate support planning. This will not be binding (local authorities emphasise the final figure may be higher or lower) but is an estimate that is intended to be helpful in enabling disabled people to consider different options for meeting their needs that can in turn feed into the final decision about what is provided.

This approach of having an indication of the budget at an early stage so that you can be fully involved in thinking about how it will be spent on meeting your needs in the best way is a fundamental aspect of so-called ‘personalisation’ that disabled people have fought for and that can be empowering.

So it is essential to understand the extent to which your local authority can take into account its limited budget in deciding what to provide, and how this is balanced against the genuine emphasis on promoting individual well-being, choice and control over how needs are met.

Fundamentally:-

- 1) the local authority can take a strict approach to **only meeting eligible needs**, and
- 2) in choosing between different practical options for meeting your needs, **it may be able to decide to offer an option that is cheaper even though it is not your preferred option.**

So for example if you receive your support as a direct payment, the local authority may be able to offer you an amount of money to meet a particular eligible need that represents the cost of meeting that need in a relatively cheap way but that is not enough for the option for meeting it that you would choose. Even though direct payments give you flexibility about what arrangements you put in place (eg using PAs rather than a day service) that may prevent you from using your preferred option because you may not be able to afford it.

However if you are able to demonstrate that the proposed local authority funding would not be sufficient to enable you to meet your eligible needs to be met – then it would have to increase the amount accordingly.

Paragraph 10.27 of the Care Act guidance provides more insight into how this should work. It states:

'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. The authority may take decisions on a case-by-case basis which weigh up the total costs of different potential options for meeting needs, and include the cost as a relevant factor between suitable alternative options for meeting needs. This does not mean choosing the cheapest option; but the one which delivers the outcomes desired for the best value. (emphasis added)

This is a vitally important phrase to focus on in explaining in your assessment and support planning process why the support that you have had incorporating ILF funding is effective and should continue. You can use it to make a case for each element of the support you need and your support overall.

Remember also that when you are talking about **how your outcomes will be delivered, or not, by different support options:-**

- **The concept of well-being is all-important** – link everything back to that, including the specific elements of well-being listed in Section 1 of the Care Act; point out if changes or reductions will impact on your dignity, on your 'control over day-to-day life (including over care and support...)', on your emotional well-being, on the suitability of your living accommodation, on your contribution to society, and any other of the points listed. AND
- Think about the factors listed in s1 about **how the local authority should exercise its functions and promote your well-being**, including:-
 - o beginning with the assumption that you are best placed to judge your well-being;

- the importance of preventing or delaying the development of needs and reducing needs you already have;
- ensuring that you can participate as fully as possible in decisions and have full information and support to be able to do that;
- making sure that options for supporting you are the least restrictive possible.

When talking about ‘best value’ and weighing up the ‘total costs of different potential options for meeting needs’, it is worth arguing that these should include costs in the widest sense – for example if a cut to your social care will have **knock-on costs to the NHS** because of you having poorer mental health or more hospital admissions, **or to housing, or to your ability to maintain employment or that of your carers**, then make that clear.

Although there is no strict requirement for local authorities to weigh these other costs up (indeed there are perverse incentives to push responsibilities onto health authorities), local authorities are under stronger duties to promote the integration of health and social care and work cooperatively with health and other bodies. So the argument is an important one to make and get documented in your assessment.

Taking carer input into account:

It is at this support planning stage that the local authority can sometimes take into account the possibility of friends, relatives or others providing unpaid support towards some of your needs. As mentioned above, the local authority must not take account of this support in deciding which of your needs meet the eligibility criteria, but having decided what your eligible (and non-eligible) needs are, they may legitimately decide that it is not necessary to provide support to meet some of them if voluntary support is available to meet them instead. However this is **only if both the carer and the adult are willing** for this to be the case. That is why it is important to:-

- document in the assessment what your and your carers’ wishes are about the level of support they are willing to provide, and
- ensure that your care and support plan correctly specifies what assumptions have been made about any such support to be provided, and is also clear about needs that the local authority will need to provide support for.

Case Study

One of the most important cases in recent years about community care needs and local authority decision-making between different options for meeting needs, was that of Elaine McDonald, a former ballerina who received support from her local authority (Kensington & Chelsea) to meet needs following from a stroke. Ms McDonald brought a judicial review against the local authority's decision to remove night-time support she had for accessing a commode, and to instead provide her with pads, at an annual saving of some £22,000. She argued that making her incontinent in this way was an affront to her dignity. She pursued her case all the way through the UK courts up to the Supreme Court, where she was unsuccessful, and then to the European Court on Human Rights. The European Court ruled that the proposed reduction in the level of care provided did interfere in principle with Ms McDonald's right to respect for her private life (under Article 8 of the European Convention on Human Rights); however the Court found that the interference was largely justified, as it was 'satisfied that the national courts adequately balanced the applicant's personal interests against the more general interest of the competent public authority in carrying out its social responsibility of provision of care to the community at large'. Essentially the local authority's decision was accepted as a reasonable choice between different ways of meeting a need, having regard for factors including its own resources.

If this case was dealt with under the Care Act there would be some differences and the conclusion may have been different. In particular, both the eligibility decision and the decision about how to meet eligible needs would need to take account of information gathered in the assessment process about the outcomes that Ms McDonald needed support to achieve, and about the consequent impact on her wellbeing. For the outcome of 'managing toilet needs', the Care Act Guidance states (para. 6.107) that in assessing eligibility, local authorities should consider the person's 'ability to access and use a toilet and manage their toilet needs.' This is helpful for someone in Ms Mc Donald's situation but there is also a more general point to be made based on the wellbeing requirement that the authority starts from the 'assumption that the individual is best-placed to judge the individual's well-being (section 1(3) of the Care Act). That should mean accepting that Ms McDonald is best placed to say what it means for her to 'manage her toilet needs', so as to promote her wellbeing according to the factors that are most important for her. The arguments given by Ms McDonald included the effect on her dignity and relationship with her partner – both central aspects of the wellbeing principle that were of the greatest importance to her. In contrast the local authority argued that the use of pads was less of a threat to

dignity than the support of a carer and that the risk of falls would be minimised. Under the Care Act these arguments should have carried less weight than the factors highlighted by Ms McDonald which for her meant that incontinence pads would not deliver the outcome of managing her toilet needs.

Similar arguments could make a real difference to a wide variety of needs related to independent living, for example whether a need for **support with shopping** can be adequately met by internet or telephone shopping rather than having support to go out into the community. Aspects of well-being such as control by the individual over day-to-day life, social and economic well-being, as well as physical and mental health and emotional well-being, should all inform the decision-making about how outcomes such as managing nutrition and accessing facilities in the local community can be achieved in a way that meets the priorities of the individual. The same approach can be brought to even the most far reaching questions such as whether an individual's needs can be met through a **residential placement rather than support to live in your own home and employ personal assistants**. It is vital to scrutinise the different options proposed to establish whether they really are suitable and able to meet the needs in question, before deciding between them.

Remember also para. 10.27 of the guidance which says that if there are different suitable alternatives to meet needs, then although cost is a factor councils can consider in weighing up the options, it is not about choosing the cheapest option; but the one which delivers the outcomes desired for the best value.

8. My Direct Payment is not enough to pay for the support I need.

The Care Act [Statutory Guidance](#) states (para. 11.23) that the amount that the local authority calculates the personal budget to be **must be sufficient** to meet the person's needs which the local authority is **required to meet** (i.e. eligible needs of the person themselves or a carer) **or** that it **decides to meet** (i.e. non-eligible needs of the person or a carer), **and must also take into account the reasonable preferences to meet needs as detailed in the care and support plan.**

There are two main reasons why your direct payment may not be enough:

- 1) The overall budget for your care may be being restricted by wrong decisions about (a) your eligible needs and/or (b) what support options it is reasonable to provide to meet your needs.** These issues are addressed in the questions above. Or:

2) There may be failures to properly calculate the full amount of money that you need in order to make the arrangements yourself. This includes proper calculations about how much of a financial contribution you need to make to your care – direct payments are generally paid ‘net’ of the contribution that you are assessed as being able to make. (See more about financial assessments below.)

The amount of your direct payment needs to be enough to cover not just the actual help you need but all the associated costs of arranging and managing this yourself, for example:-

- recruitment costs, payroll services, CRB checks on employees
- National Insurance contributions, tax (eg PAYE), pension contributions
- VAT in some cases
- statutory holiday pay, sick pay, maternity and paternity pay and other employee benefits
- redundancy pay
- employers’ liability insurance public liability insurance
- start-up costs, training
- brokerage costs in some cases

If you have direct payments, the local authority is under just the same obligations mentioned above to provide you with copies of your assessment and support plan. Indeed it is even more vital to get these so you have a full record of your assessed needs and agreed care plan, to be clear exactly what you are entitled to and how it will work in practice. The local authority must ensure you have clear information about:-

- What is involved in managing a personal budget including your responsibilities as an employer
- What is included in your direct payment to cover all the costs adequately
- What support you can get to manage your direct payments package, both at the start and if there are difficulties.

The local authority must be able to demonstrate that the money and support provided is ‘sufficient’ for your eligible needs and outcomes to be met. So for example you may need to be able to pay staff a higher hourly rate than average for your area, in order to attract and retain suitably skilled staff. Many local authorities have standard hourly rates that they do not like to depart from. To challenge this it is important to be able to show why a higher level of skill is needed in your case, and evidence about why standard rates are inadequate to

retain good staff – eg details of past turnover of staff, or of local unskilled job vacancies that pay more.

Sometimes it can work out best to use a mixture of direct payments and provision arranged directly by the local authority. For example, you could use agency support arranged by the local authority for short pop-ins that are not economic to arrange yourself but direct payments for longer blocks of support such as for community activities. You cannot be forced to choose all of one or the other, you can mix and match if that will meet your outcomes effectively within the budget.

9. What does the Care Act say about carers? Does the Care Act give us specific rules or guidance that we can use now to stress the maintenance of current support is the only way things can work for the family as a whole and not just the disabled person?

When a disabled person is being assessed and their carer agrees to have a ‘carer’s assessment’, the process should proceed as follows:

1. Information about the adult’s needs (including their eligible needs) is gathered in their assessment.
2. The carer’s needs are identified in the carer’s assessment process. This analyses, not only the sustainability of the caring role – but also whether the carer is willing and able to carry on caring and/or providing the same level of care. The risks to sustainability can include health risks to the carer, their wishes to remain in work or return to work or undertake training, education or leisure activities and so on.
3. The assessor then measures the carer’s needs against the national eligibility criteria for carers – and determines which of these needs must be met. A support plan must then be drawn up that explains how these needs will be met.
4. Often the support the carer needs will take the form of care provided to the disabled person (eg sitting services or short breaks) and the Care Act makes it clear that such services must be provided – if the carer has an eligible need for them – even if the disabled person was not assessed as eligible (when their need was measured against the ‘adult in need’ eligibility criteria).

The process is explained in greater detail in Carers and their Rights (L Clements 2015 6th edition) at www.lukeclements.co.uk/publications/, and in the Carers UK factsheet: www.carersuk.org/files/section/4630/factsheet-e1029--assessments-and-the-care-act-after-april-2015.pdf

The introduction of national eligibility criteria for carers’ needs is a significant development under the Care Act. Previously local authorities had powers to

provide support for carers but there was no mandatory framework by which they had to do so.

The eligibility framework for carers is similar in many ways to that for individuals needing care, including a focus on the particular **outcomes** that the carer wants to achieve, and how their **well-being** will be affected if they do not have the necessary support to do so effectively. The outcomes that support may be needed to achieve include:-

- carrying out **some or all basic household activities** in the carer's home (whether or not it is also the home of the adult needing care), including preparing meals, cleaning and maintenance
- carrying out any **caring responsibilities for a child or providing care to other individuals** for whom the carer provides care
- engaging in **work, training, education, volunteering or recreational activities**,
- maintaining family or other significant **personal relationships**, and
- accessing '**necessary' facilities or services** in the community.

The points given in Question 3 above about the well-being principle and how it should be applied are just as relevant to issues of support for carers as to support for the individuals they care for. This certainly includes the requirement to take a 'whole family' approach, but also the principle of starting from the assumption that the individual (i.e. the carer) is best placed to judge their well-being and what will promote it, and also that well-being includes the key components of independent living, as expressed in Article 19 and other provisions of the UNCRPD ([Statutory Guidance](#), para. 1.19).

The Care Act guidance makes clear that carers cannot be forced to provide care, but at the same time recognises that the informal care provided by carers is a vital part of the overall system of meeting the care needs of the population particularly as demographic changes increase demand. Many ILF users with a learning disability already receive a high level of informal support from family and others and there are real risks that cuts to their support previously provided by ILF will put an unacceptable strain on family members so that the arrangements break down and this beneficial input is lost. It is important to spell out the risks of such false economies in assessments, as well as raising the important point of principle that adults with learning disabilities should not have to depend heavily on their parents for basic care if this does not promote their well-being including their independence.

Another significant change for carers under the Care Act is that there is a lower threshold for the duty to carry out a carer's assessment and consider whether support should be provided. Previously the carer had to be providing regular and substantial care, but this requirement has gone. Instead there is a focus on the nature of the relationship between the person being cared for and the carer, and this may specifically include someone who is a carer by virtue of providing **practical or emotional support**.

As before the Care Act, duties to assess and support carers are owed by the local authority in whose area the cared-for person lives, not the authority where the carer lives if that is different.

10. What do I need to know about financial assessments and contributions? What is disability related expenditure?

A comprehensive and up-to-date guide about financial assessments and the arrangements for charging for local authority adult social care is available from Age UK: www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS46_Paying_for_care_and_support_at_home_fcs.pdf?dtrk=true

This includes information (section 3.6, page 22) about how you can identify your 'disability-related expenditure' (DRE) – i.e. extra living costs that you have to pay because of your impairment / disability. The local authority must take this into account in deciding what charges you can afford to pay. So it is important to know what type of costs can be taken into account and maximise the amount of DRE that the local authority will disregard in deciding what your contribution may be.

There is no definitive list of what counts as DRE, what evidence you have to provide to prove that you have additional expenditure, or how your local authority will calculate the amount that they will disregard for different types of DRE. Different local authorities have different guidance and approaches, so it is important both to get familiar with the general rules about how local authorities have to consider DRE (for example by reading the AgeUK factsheet above) and to get information and support about what happens in your area, for example by making contact with your local disabled people's organisation (DPO). Some DPOs and other groups work to get the local authority to improve its information and policies about assessing DRE, and other policies about charging.

11. What processes can I use to challenge or complain about the local authority's decision about what support I will get?

The Care Act has introduced powers for an appeals system to be set up to deal with community care issues. However this is not yet in force. It will be set up through regulations separate from the main Care Act (like the regulations for determining eligibility, and about direct payments). Some proposals for what it will be like have been put forward and the Government is considering the consultation responses. Some of the responses have expressed concerns that having an appeals system could just make it slower for people to get a final decision from their local authority and delay them from taking the challenge further if they need to (eg to the Ombudsman). At the moment the plan is for the appeal system to come into force in April 2016 at the same time as the cost capping proposals. Nothing is certain about either of those at present. A final version of the regulations setting out the system will be published ahead of it being implemented but we don't know when this will be.

Until then the three main ways that you can challenge decisions or failures about your care are:-

- 1) the local authority complaints procedure
- 2) the Local Government Ombudsman
- 3) challenging it in court by judicial review

Often it is necessary to challenge not just the eventual decision about what support is to be provided but the way the assessment was carried out, which may (for example) have meant that relevant information about your needs was not taken into account.

Which process you use depends on the circumstances including how urgent it is and how serious the impact will be on you. But there is a strong expectation that you will use the local authority complaints procedure first and exhaust all other options before taking the legal route – except in the most serious and urgent of cases. Each local authority will have its own complaints procedure which they must provide information about, but these have to follow national rules – see below for more information. The Ombudsman can be a good option but is relatively slow and you have to have exhausted the local authority complaints process first.

There are pros and cons of the different processes including different costs that you may have to pay – including the local authority's costs if you lose a judicial review. Legal aid may be available for judicial review and in some cases for Ombudsman complaints. There are strict rules about eligibility for legal aid, including a very restrictive means test, and tests about the strength of your case. Some people have to pay a contribution to their legal aid costs. If you get legal

aid it will pay for the costs of a lawyer to advise and represent you, and it can also provide protection in case you are ordered to pay the other side's costs.

There is good information available about the different processes of challenge, including templates of complaint letters. For example:-

- www.mind.org.uk/information-support/legal-rights/complaining-about-health-and-social-care/complaints-procedure-in-england/
- www.scope.org.uk/support/disabled-people/social-care-overview: see sections on 'How to complain' and 'What next?'
- www.lukeclements.co.uk/wp-content/uploads/2015/04/5-Reduction-in-care-services.pdf: This is Luke Clements' overview on complaining about reductions to an adult social care package but also links to the Cerebra webpage below with a number of excellent precedent letters
- w3.cerebra.org.uk/research/legal-entitlements-research-project/precedent-letters/: These precedent letters have primarily been prepared for parents of disabled children but they are extremely useful for raising adult social care concerns
- www.lgo.org.uk/adult-social-care/

There is also a detailed guide available by Steve Broach and Kate Whittaker called *Using the Law to Fight Cuts to Disabled People's Services* which summarises key legal rights that disabled people have and has advice and information to help people enforce those rights, including using complaints processes and other remedies such as judicial review. It has details about support is available locally and nationally to help with community care and other issues, including including details of when legal aid may be available to help with the costs of legal advice and representation. At the end of the guide is a list of solicitors who are known to work with disabled people, with contact details. The guide is available at www.scomo.com/KWhittaker.php.²

12. Can I stop the changes happening until after my complaint or challenge has been dealt with? Can my local authority reduce my funding if I don't sign an agreement?

There is no automatic right to prevent the changes going ahead pending determination of any complaint or other challenge that you are pursuing.

² An updated version will be issued shortly but much of the information remains current

Refusing to sign an agreement for a reduced package will not prevent the local authority from making the reduction.

However depending on your circumstances you may be able to argue for the changes to be postponed for a period of time while your concerns are investigated.

For example you should point out what are the most immediate risks that will happen to you from the change going through before you have had a proper chance to seek a detailed review. If the change means that you will need to make staff redundant or reduce their hours so much that they will need to find other work, you should highlight this and ask them to avoid such irreversible steps until you have had a fair chance to make your case. You can also ask for your complaint to be dealt with on an urgent basis before the change happens.

In really exceptionally urgent situations where there is an immediate risk of harm that cannot be addressed any other way, it is possible to make an urgent application through judicial review to ask the court to make an immediate order about what the local authority should do to keep you safe. This can stay in place while the issues are investigated further. However this is rare.

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