



How to get the right support from your local authority



A guide to the Care Act 2014 and other laws, for family carers of an adult with learning disabilities and/or autism.

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Foreword

I am delighted to have the opportunity to write a foreword for this new guide to the Care Act and other laws, for family carers to refer to.

The Care Act redefines what we mean by care and support. It offers us huge opportunities – if we know how to use them. This guide offers a roadmap to help navigate it.

As a veteran family carer of over fifty years, I have seen major changes (and challenges) in health and social care as they relate to my son, Simon. Simon, now 54, is of the generation of adults with learning disabilities and/or autism who were offered a place in a large North London long-stay hospital when they were born.

As parents, we were warned to expect little and, in effect, to ‘try again’. Of course, we rejected that option and were so fortunate in finding a charismatic paediatrician who believed that children with learning disabilities and/or autism could and should lead valued and happy lives – with the right support. He listened to family carers and he gave me a message that I have never forgotten, namely that carers can be powerful; parents can be change agents and it is up to us to change the world (and the legislation that governs it) for our relatives.

I learned rapidly that legislation matters. As Director of the Council for Disabled Children and a Commissioner with the Disability Rights Commission, I and others realised the importance of successive ‘big’ Acts. The Children Act 1989 and a range of education, legislation and successive Acts were intended to improve access to social care and support.

My son grew up; we won the battle for education and Simon eventually moved on to a house of his own, a ‘personal budget’ and access to the new technology that can revolutionise the lives of both family carers and those they support - if of course we know about it! The Care Act opened up new possibilities for us and we are making the most of them.

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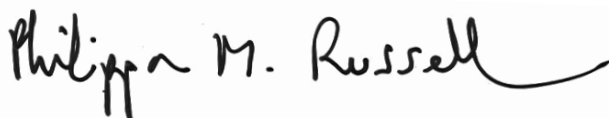
Knowledge is power, and for the first time, in the Care Act, we have legislation which should enable our relatives to lead good lives; to make choices and to feel safe and valued in their local communities.

Very importantly and also for the first time, family carers are on an equal footing with the people they support. Those of us who are family carers of people with learning disabilities and/or autism know that we can expect a lifetime of caring. Even if our sons or daughters (or any other relative) move into supported living or a care home, we still have an important role in supporting them through multiple challenges and transitions. The Care Act moves definitions of social care away from 'services' to 'wellbeing' and the kind of lives that we and our relatives want.

I once heard Acts of Parliament described as being like trees – the seeds are sown, the tree grows, but it takes time for the leaves and then the fruit to flourish. Trees need watering, care and attention in their early days. We as carers have a key role in ensuring that the Care Act is used effectively, that its big ambitions are fulfilled and that above all else it gives our relatives the best possible lives. This guide recognises the challenges, sets out the key duties within the Care Act and will enable you to make best use of the most important piece of legislation in over 60 years.

The challenge with the Care Act is how we move on from the rhetoric of personalised care and support (and a transformed social care system) to the reality of developing new patterns of care and support in an age of austerity. Family carers - and our allies like the Family Carer Support Service at Hft - have an important role to play in making the Care Act live up to its ambitions. This guide is a very good first step to achieving that goal.

Dame Philippa Russell

A handwritten signature in black ink that reads "Philippa M. Russell". The signature is written in a cursive style with a long, sweeping underline.



The Care Act was made law in 2014 and came into force in 2015. It clarifies what kind of care and support people can expect from adult social care in England. The Care Act brought together several old laws and some new ones into one modern piece of legislation. It is the most significant reform of publicly funded care and support in England in over 60 years¹.

The Care Act is accompanied by the Care and Support Statutory Guidance. They must both be followed by local authorities. We have quoted the Care and Support Statutory guidance throughout our guide, because it explains the law in detail with examples of how the law could work in practice.

In relation to that, when we use the word **must** it means that the local authority have a legal obligation under the Care Act to follow a particular course of action. When the word **should** is used, it means that the local

¹<https://www.theguardian.com/social-care-network/2014/jun/05/care-act-most-important-amendments>

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authority ought to follow a particular course of action. They are not legally obliged to, but they would leave themselves open to challenge if they chose not to comply with the guidance.

The Mental Capacity Act 2005 is accompanied by the Mental Capacity Act Code of Practice. The Mental Capacity Act is a protective piece of legislation that works to maximise people's ability to make decisions for themselves. When a person is found to lack capacity to make a particular decision, it explains the processes that must be followed to be able to make a decision on behalf of that person.

Together, the Care Act and The Mental Capacity Act are the two most important laws relating to adult social care in England. It is extremely important that family carers understand their rights and the rights of their relative under these laws.

Throughout this guide, we use the umbrella term 'local authority'. This includes the five possible types of local authorities in England: county councils; district councils; unitary authorities; London boroughs; and metropolitan districts (sometimes called metropolitan boroughs or city councils)².

We have created a glossary at the end of the guide to explain certain terms. The words included in the glossary are highlighted bold and in **purple** throughout the guide. Anything highlighted bold and in **black** is for emphasis only, and is not a glossary term.

Further Reading:

Search for your local authority by area or postcode: <https://www.gov.uk/find-local-council>

Who is this guide for?

This guide is for family carers who have a relative with learning disabilities and/or autism.

² <https://www.lgiu.org.uk/local-government-facts-and-figures/#how-is-local-government-structured>

Introduction

Our definition of a family carer is someone who has a lifelong relationship with a person who has learning disabilities and/or autism. They are usually a family member or a close friend. A family carer has an active interest in the wellbeing of that person, wherever they live.

What is this guide about?

The main focus of the guide is on the Care Act 2014 (and the accompanying Care and Support Statutory Guidance) and how it can be used to support family carers in conversations with their local authority. We have also included a section that outlines the principles of the Mental Capacity Act 2005. Throughout the guide we have given examples of how these laws can be used in practice, and we have referenced links to useful resources.

If you're reading this guide, it's likely that you have encountered a problem and are looking for ways to resolve that problem. Knowing where to start can be daunting, and so the first chapter in this guide offers general information on how to challenge when things aren't right.

The content in the rest of the guide will support your ability to promote your relative's rights, and yours as a family carer, when communicating with the local authority. It may also make you aware of rights that you didn't realise you both have.

We haven't covered all aspects of the Care Act, but we have included what we think are the most important aspects for family carers to be aware of.

- **Chapter 1** outlines different ways to challenge decisions and the support available to strengthen your case.
- In **Chapter 2** we introduce the wellbeing principle, which is the driving force behind the Care Act. It is important that families are aware that local authorities have a duty to promote their wellbeing and that of their relatives.
- **Chapter 3** explains what the Care Act says about supporting people at an early stage, to prevent people's situations from worsening.
- In **Chapter 4** we outline the local authority's duty to ensure that an information and advice service is created and maintained. This should

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make it easier for people in the area to understand the social care system and how to access it, among other things.

- **Chapter 5** explains how people can access independent advocacy and the potential benefits of doing so.
- In **Chapter 6**, we outline the principles of the Mental Capacity Act 2005 and give examples of how it should work in practice.
- **Chapter 7** explains the assessment process for adults with learning disabilities and/or autism.
- In **Chapter 8** we explain what must happen when a person with learning disabilities and/or autism is found to be eligible for local authority-funded support.
- **Chapter 9** explains the difference between a personal budget and a direct payment; how local authorities calculate how much to charge a person towards the cost of their care; and what counts as disability related expenditure.
- In **Chapter 10** we explain what should happen when people with learning disabilities and/or autism have their care and support plan reviewed and how often that should happen.
- **Chapter 11** explains the process that must be followed when assessing whether a family carer is entitled to local authority-funded support, and what must happen when a family carer is found to be eligible for support from their local authority.
- **Chapter 12** outlines how housing is treated in adult social care.

At the end of this guide we've included information about our service and the support that we offer to family carers.

Why did we write this guide?

We recognise that there is a lot of information already available about the Care Act, but feel that a lot of it is targeted at carers in general. We wanted to create a guide that is specifically for family carers who have a relative with learning disabilities and/or autism. Through our one-to-one support with family carers we speak about the most relevant laws, policies

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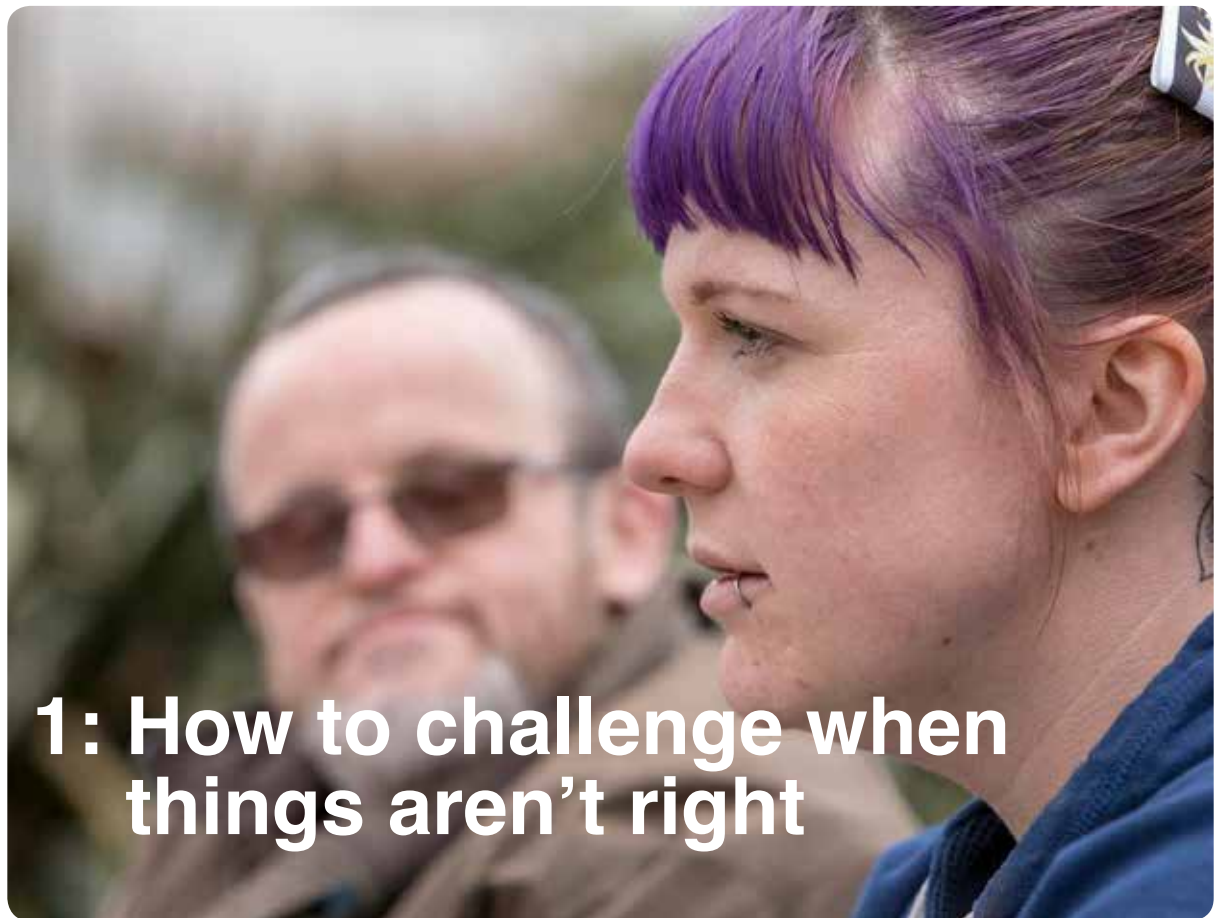
and resources to help strengthen their cases when communicating with local authorities. This guide brings that information together in one place.

We know that many people feel disillusioned by the Care Act's ability to bring change at a time when local authorities are chronically underfunded. We want our readers to remember that the Care Act is not merely guidance for a local authority - it is a law that they must adhere to, and they often do when reminded of it.

There is a lot of information in this guide. We don't expect you to read it in one sitting, but we think it would be useful to refer back to as and when you need it.



1: How to challenge when things aren't right



We often speak to family carers who are nervous about ‘rocking the boat’ by challenging or even just questioning. They worry that doing so will have a detrimental impact on the support that their relative receives. We hope that the information in this section will make speaking up a bit less daunting for family carers who aren't sure where to start.

1.1: Get support and know your rights

If you are unsure about how to approach a problem, a useful first step is to talk about what's happening. If you would like face-to-face support, your local carers' centre may be a good place to start. There are also local and national family-led support groups online with practical and supportive information.

You could speak to a charity like ours. We listen to family carers, help to unpick the issues and support them to understand their rights. We discuss strategies to get the right outcome and offer continued support. See pages 77 – 78 for further information about our service

1: How to challenge when things aren't right

Alternatively, you could seek support on social media - publically or by direct messaging a family carer activist. They are prominent on Twitter, where they speak out about social injustice towards people with learning disabilities and/or autism, and influence policy and legislation. We often retweet their campaigns and stories. You can find our Twitter handle on page 78.

1.2: Be clear about the issue and the corrective action

Describe the issue, and try to reference the relevant law or policy. State what has been done wrong and the impact it's having on your relative and your family. Spell out exactly what needs to be done to rectify the situation, by whom and by when.

1.3: Keep good records

Face-to-face and telephone communication are often the best way to resolve an issue - but it's important to keep a record of what is agreed during any meetings or calls. At meetings, it is advisable to bring someone with you to make notes. Always follow up conversations in writing to confirm what was discussed and agreed.

1.4: Offer the local authority an opportunity to resolve the issue informally

Always aim to work in partnership with the local authority. Where appropriate, try to resolve any disagreements directly.

1.5: Make a formal complaint

If you cannot resolve an issue informally, then you should consider submitting a formal complaint. Each local authority has their own complaints procedure, and they should provide you with information on how to make a complaint. This information will be available on your local authority's website or you can phone them directly.

1.6: Contact the local authority's monitoring officer

1: How to challenge when things aren't right

Monitoring officers are usually ex-solicitors or barristers. They are responsible for making sure that the local authority doesn't act in a way that might amount to 'maladministration'³. If the law hasn't been correctly followed, the monitoring officer will inform the department that they have misinterpreted it or applied an outdated policy.

List of monitoring officers in local authorities in England and Wales:
<http://www.schwehroncare.co.uk/using-the-monitoring-officer-as-a-free-and-convenient-means-to-raise-concerns-about-illegality-in-the-public-law-sense-in-adult-social-care/>

1.7: Consider going to the local government and social care ombudsman

The ombudsman is the final stage for complaints to the local authority and all adult social care providers. It is free to complain to the ombudsman. Usually you need to exhaust the local authority's complaints process before they will consider your complaint. Local authorities must publish any ombudsman findings against them.

Local Government Ombudsman website: <https://www.lgo.org.uk/>

1.8: Seek legal aid and speak to your MP

If you believe that the local authority is acting unlawfully, you should seek legal advice. Find a solicitor who is experienced in social care/health law. Your relative may be entitled to legal aid.

³ "Maladministration" is not defined in legislation. The Local Government Ombudsman's website gives some examples of "service failure", which could give rise to a valid complaint; delay, poor record keeping, failure to take action, failure to follow procedures or the law, poor communication, giving out misleading information, failure to investigate and the organisation not doing what it said it would'.

Quote from briefing paper: <http://researchbriefings.files.parliament.uk/documents/SN04117/SN04117.pdf>

1: How to challenge when things aren't right

Check if you can get legal aid: <https://www.gov.uk/check-legal-aid>

If you believe that the law needs to be changed, contact your local MP to make them aware of the situation. You can also keep an eye out for consultations on topics that affect you and your relative, and feed in to them. You may even consider starting your own petition to government and Parliament.

Create a government petition: <https://www.gov.uk/petition-government>



Further Reading:

Accessing public services toolkit: <https://www.cerebra.org.uk/help-and-information/guides-for-parents/problem-solving-toolkit/>

2: Wellbeing



The wellbeing principle is referred to in Section 1 of the Care Act. It is the driving force behind the Care Act. It applies as equally to people with learning disabilities and/or autism as it does to family carers. Importantly, it starts with the assumption that the individual is best placed to judge their own wellbeing.

The local authority must promote wellbeing when carrying out any of its functions or making decisions in relation to a person. That means it's not enough for a local authority to simply have regard for wellbeing. They must actively seek improvements in the aspects of wellbeing outlined below.

Wellbeing intentionally has a broad definition, but relates to these areas in particular:

- ✓ personal dignity (including treating the individual with respect)
- ✓ physical and mental health
- ✓ emotional wellbeing
- ✓ protection from abuse and neglect
- ✓ control by the individual over day-to-day life (including care and support and the way it is provided)
- ✓ participation in work, education, training or recreation

2: Wellbeing

- ✓ social and economic wellbeing
- ✓ domestic, family and personal life
- ✓ suitability of living accommodation
- ✓ the individual's contribution to society

2.1: How can I tell if social services are actually promoting wellbeing?

To promote wellbeing, the conversation cannot be solely about meeting needs and the services that are available to do so. Wellbeing is about much more than making sure that people are fed, watered and safe. The local authority must consider the impact of an adult or carer's needs on their wellbeing, as well as the impact that any given support route will have on that adult or carer's wellbeing.



Top tip:

For your relative, think of wellbeing as something that is important **to** them. While it may be important **for** your relative to get support with housework twice a week; what's important **to** your relative is that it's the same person every week and that the person shares similar interests.

As a family carer it may be important **for** you to get a break from caring, but what's important **to** you may be that you know your relative is being well supported during your break.



Further reading:

Determining what's important 'to' and 'for' people: <http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/sorting-important-tofor/>

Information about wellbeing: <https://www.skillsforcare.org.uk/Document-library/Standards/Care-Act/learning-and-development/introduction-and-overview/wellbeing-handout.pdf>

Wellbeing in practice: <http://www.communitycare.co.uk/2017/07/10/care-acts-wellbeing-principle-mean-practice/>

3: Supporting people at an early stage (preventing needs for care and support)



3: Supporting people at an early stage (preventing needs for care and support)

Section 2 of the Care Act refers to a local authority's duty to prevent, reduce and delay people's needs for care and support. This means that local authorities have a duty to support people at an early stage. To achieve this, local authorities need to be proactive, rather than waiting to react when people are in crisis. This duty applies to everyone in a local authority's area, including carers and adults with learning disabilities and/or autism.

The Care and Support Statutory Guidance indicates that there is no single definition for what counts as a preventative action. Preventative measures could include anything from whole-population interventions aimed at promoting health, to individual interventions aimed at one person in order to improve their skills. Interventions may include adaptations to the home or respite care, which can both be accessed under the local authority's prevention duties without the need for a Care Act assessment (see Chapter 7) or a carer's assessment (see Chapter 11).

Prevention is also referred to in the Care Act as a key consideration in the wellbeing principle. The Care Act states that when a local authority

3: Supporting people at an early stage (preventing needs for care and support)

carries out its general duty to promote an individual's wellbeing, it must also have regard for the importance of preventing or delaying needs for care and support and reducing the needs that already exist. As a concept prevention has been around for many years, but the Care Act has made it a **statutory duty**.

3.1: What does the law say about supporting carers at an early stage?

Family carers have no legal obligation to care for another adult - but they do - and in doing so they save local authorities a considerable amount of money. The economic value of the contribution made by carers in the UK is £132 billion⁴ a year. It is therefore in the local authority's interest to support carers early on, so that (where possible) carers remain willing and able to continue caring for their relative.

The Care and Support Statutory Guidance states:

'Carers play a significant role in preventing the needs for care and support for the people they care for, which is why it is important that local authorities consider preventing carers from developing needs for care and support themselves. There may be specific interventions for carers that prevent, reduce or delay the need for carers' support. These interventions may differ from those for people without caring responsibilities. Examples of services, facilities or resources that could contribute to preventing, delaying or reducing the needs of carers may include but is not limited to those which help carers to:

- *care effectively and safely – both for themselves and the person they are supporting, for example, timely interventions or advice on moving and handling safely or avoiding falls in the home, or training for carers to feel confident performing basic care tasks*
- *look after their own physical and mental health and wellbeing, including developing coping mechanisms*
- *make use of IT and other technology*

⁴ <https://carers.org/key-facts-about-carers-and-people-they-care>

3: Supporting people at an early stage (preventing needs for care and support)

- *make choices about their own lives, for example managing their caring role and paid employment*
- *find support and services available in their area*
- *access the advice, information and support they need including information and advice on welfare benefits and other financial information and about entitlement to carers' [Para 2.16].*



Example:

To prevent a family carer from becoming socially isolated, the local authority could provide information about local community activities - such as walking groups and coffee mornings.



Further reading:

Information on local authority's responsibilities for preventing need:
http://www.proceduresonline.com/resources/careact/p_preventing_needs.html

Ideas and information about linking prevention with wellbeing in practice: <https://www.scie.org.uk/prevention>



4: Information and advice

The social care system is complicated and can feel daunting to even the most experienced family carer. It can feel overwhelming when a family carer is new to caring - for example when a sibling takes over the caring role following the death of a parent, and an assessment or review is due.

Under the Care Act local authorities have a duty to establish and maintain a service to provide people in their area with information and advice relating to care and support for adults and carers. The Care and Support Statutory Guidance says:

'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].

4: Information and advice

4.1: What information should be provided?

Local authorities **must** provide information and advice on the following:

- The care and support system locally and how to access it.
- How to complain or make a formal appeal to the authority (including what those processes involve), and when independent advocacy should be provided.
- The choice of care and support and care providers available in the local authority's area – including prevention, reablement services and wider services that support wellbeing.
- How to access independent financial advice on matters relating to care and support.
- How to raise concerns about the safety or wellbeing of an adult with care and support needs (and also how to do the same for a carer with support needs).

Local authorities should also provide information on: finances; health; housing; and employment.

Local authorities must think about family carers in their own right and consider what information and advice they may need to help make their caring role easier. For example, this could include information about anything from having a break; to advice on the employment rights of working family carers.

You may wish to do your own research on the areas outlined above - in which case contacting an independent advice service early on (such as our service or your local carers' centre) can be a useful step.

4.2: Can I request information in different formats?

Yes. In addition to its information duties under the Care Act, the Equality Act 2010⁵ says that **reasonable adjustments** should be made to ensure that information is accessible to an individual with learning disabilities and/or autism. This means that information and advice needs to be

⁵ <http://www.legislation.gov.uk/ukpga/2010/15/contents>

4: Information and advice

accessible and personalised to each individual. It's no good providing easy-read documents to someone with a visual impairment. Translation and interpretation services should be made available whenever they are required.



Further reading:

Citizens Advice on reasonable adjustments: <https://www.citizensadvice.org.uk/law-and-courts/discrimination/what-are-the-different-types-of-discrimination/duty-to-make-reasonable-adjustments-for-disabled-people/>



An independent Care Act advocate is a professional advocate who has specialist knowledge of the Care Act. Their role is to support and represent a person, ensure that they are involved in Care Act processes, and help to secure their rights.

Care Act processes refer to: assessments; reviews; care and support plans (support plans for carers); and safeguarding enquiries or safeguarding adults reviews.

5.1: How do I get an independent advocate under the Care Act?

The local authority is responsible for funding independent advocates. They must refer to the Care Act to determine whether the duty to appoint an independent advocate applies. This duty applies equally to family carers and adults with learning disabilities and/or autism.

Under the Care Act, any individual who would have substantial difficulty

5: Independent advocacy

engaging in Care Act processes, and who has no appropriate person available to assist them, is entitled to an independent advocate.

Substantial difficulty simply means that a person would struggle to understand relevant information relating to Care Act processes.

An **appropriate person** is someone who is able to prioritise the opinions of the person with learning disabilities and/or autism and actively involve them in Care Act processes. An appropriate person cannot be employed to provide care. Family carers often take on the role of appropriate person for their relative – but this should not be assumed. It should be discussed and agreed with the individual and the family carer.

5.2: I'd like to be the 'appropriate person' for my relative and also have an independent advocate. Is this possible?

Yes it is, but it's at the discretion of the local authority.

The Care and Support Statutory Guidance states:

'In general, a person who has substantial difficulty in being involved in their assessment, plan and review, will only become eligible for an advocate where there is no-one appropriate to support their involvement. The exceptions are:

- *where the exercising of the assessment or planning function might result in placement in an NHS-funded provision in either a hospital for a period exceeding 4 weeks or in a care home for a period of 8 weeks or more, and the local authority believes that it would be in the best interests of the individual to arrange an advocate*
- *where there is a disagreement, relating to the individual, between the local authority and the appropriate person whose role it would be to facilitate the individual's involvement, and the local authority and the appropriate person agree that the involvement of an Independent Advocate would be beneficial to the individual' [Para 7.42].*

5.3: Why involve an independent advocate?

The role of an independent advocate is to assist a person to make the best

5: Independent advocacy

possible decision when there may be uncertainty or disagreement about the best way forward. They can help to challenge a decision or process made by the local authority.

An independent advocate must also assist the person to understand their wider rights, such as those under the Mental Capacity Act (see Chapter 6) and Human Rights Act⁶.

The involvement of an advocate or a third party brings a different dynamic to a situation. It can help to diffuse tension and encourages both sides to look at their decision from a different perspective.



Further reading:

Advocacy principles and standards: <https://www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/inclusion-empowerment-human-rights/principles-standards.asp>

Advocacy Quality Performance Mark: <https://qualityadvocacy.org.uk/>

Information about the duty to provide an independent advocate: http://www.proceduresonline.com/resources/careact/p_duty_indep_adv.html

The Care and Support (Independent Advocacy Support) Regulations 2014: http://www.legislation.gov.uk/uksi/2014/2824/pdfs/uksi_20142824_en.pdf

⁶ Legislation in full: <http://www.legislation.gov.uk/ukpga/1998/42/contents>



The Mental Capacity Act 2005 is a protective law designed to empower people and maximise their ability to make decisions for themselves. When a person is unable to make a particular decision for themselves, it provides a framework for that decision to be made on their behalf, in their best interests, and in a way that is least restrictive of their freedom.

We know that family carers can be wary of this law. Often the first time families hear about it is when they disagree with a decision about their relative being made by a professional. We also know that despite being in force since 2007 it is still widely misunderstood; so we felt it important to outline the principles of this law, with an anonymised real-life example of it being used in practice.

6.1: How do you assess a person's capacity?

You can only assess a person's capacity relating to a particular decision, at the time it needs to be made. Assessments must therefore always be decision and time specific.

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A person is considered unable to make a decision if they cannot do one or more of the following four things:

- 1.** Understand the relevant information relating to the decision;
- 2.** retain that information for long enough;
- 3.** to be able to weigh it up;
- 4.** and communicate their wishes (verbally, using sign language or by any other means).

6.2: What are the key messages of the Mental Capacity Act 2005?

There are five principles underpinning the Mental Capacity Act, which family carers should familiarise themselves with.

Principles 1 - 3 explain the process that must be taken before, and at the point of, establishing whether a person has the mental capacity to make a particular decision.

Principles 4 - 5 apply only after a person is found to lack capacity to make a particular decision. They detail the process that must be followed when making a decision on behalf of another person.

Principle 1: We must begin by assuming that the person has capacity.

Saying that a person lacks capacity in general is meaningless; capacity changes over time and depends on the decision at hand. It is not okay to assume that because an adult has learning disabilities and/or autism that they cannot make **any** decisions for themselves. While a person may struggle to make a decision relating to where they live - they may well be able to decide what they want to wear that day.

A person's ability to make a decision can be affected by lots of different factors. For example, if your relative is unwell or has recently experienced bereavement, it would not be an ideal time for a capacity assessment to be conducted.

If a professional says that your relative requires a capacity assessment, but you disagree, you should remind them that capacity must always be

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assumed, and ask them to explain why they are questioning your relative's capacity.

Principle 2: People must be supported to make a decision before anyone treats them as unable to make the decision.

All practical steps must be taken to support a person to make a decision. A person-centred approach will be needed to achieve this. Whilst easy-read information may work for one person - another person may need a family carer present to support them to understand the questions or to feel at ease.

A person does not have to be able to communicate verbally in order to communicate their wishes - though they will need to have people who know them well to help interpret what they are communicating.

Principle 3: Unwise decisions do not necessarily equate to a lack of capacity.

People with learning disabilities and/or autism have the same right to make an unwise decision as everyone else. The purpose of a capacity assessment is not to judge a person's decision, but rather to determine whether they have the capacity to make a particular decision at a particular time.

However, it's important that this principle of the Mental Capacity Act is not used as a justification for poor support. Family carers of people with learning disabilities and/or autism often spend a lifetime encouraging and challenging their relative to understand the implications of their decisions; to try to make safe and healthy choices that will improve their quality of life. However, when a family carer's relative no longer lives at home, this encouragement and challenge can sometimes be lost.

A support provider may tell a family carer that although they judge it to be an unwise decision, their relative still has the right to eat fast food every day for dinner, for example. This is true and no one has the right to force their values onto another person, but there should be encouragement and challenge to support the person to make better decisions. It would be helpful to consider what else is important to the person. Have they said they would really like to lose some weight or have more disposable income? In which case, does the person understand the implications of

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eating fast food every day in relation to those goals?

Everyone working in health and social care has a duty of care to the people they support. This means that staff must:

- always act in the best interests of individuals and others
- not act (or fail to act) in a way that results in harm
- act within their competence and not take on anything they do not believe they can safely do

For more information about the duty of care standard, see: https://www.scie.org.uk/workforce/induction/standards/cis05_dutyofcare.asp

See also OxFSN blog on choice and control versus duty of care: <https://abitmissing.wordpress.com/2017/08/31/choice-and-control-versus-duty-of-care/>

Principle 4: Decisions made on behalf of a person (who is found to lack capacity) should be made in their best interests.

This is a difficult concept. It means putting yourself in the person's shoes and imagining what that person would decide if they had the capacity, based on previous decisions and preferences they have expressed in the past. Family carers are usually central to this process because of the wealth of historical information that they hold about their relative.

This principle is sometimes referred to as a 'best interests decision' or 'best interests meeting' (though it can happen over a series of phone calls and doesn't always require a face-to-face meeting). The purpose of this process is to decide how to make a decision in the best interests of the person, in the least restrictive way (see principle 5). All options and potential outcomes in the short and long term must be considered.

Principle 5: Decisions made on behalf of a person must be made in a way that is least restrictive of the person's freedom.

This is a hugely important principle that is sometimes missed. When making a decision on behalf of another person, a number of options should be discussed - including whether intervention is necessary. Wherever

possible, the chosen option should be the one that least restricts the person's rights and freedoms.



Example:

Marie has a learning disability, she is ageing and her mobility has deteriorated. She lives in a supported living environment and has an upstairs bedroom. Her support workers are aware of her changing mobility, and with their assistance, Marie can safely get upstairs to her room. However, Marie does not want to have to wait for other people to go upstairs and continues to attempt to walk upstairs, by herself. She has subsequently fallen on two occasions.

There is a reason to question Marie's understanding of the situation, so the support provider requests a capacity assessment to be conducted by a social worker. Marie is supported before the assessment to understand why the social worker is visiting. During the assessment, Marie is supported to understand the information relevant to the situation. The capacity assessment takes place after lunch, as Marie does not process information well when she is hungry.

The social worker finds that Marie lacks the capacity to understand her limitations around stair usage. A best interests process is triggered and the social worker suggests it's in Marie's best interests to move to a bungalow owned by the same support provider, 15 miles away. Marie's family and support staff disagree that this would be in her best interests and believe that it is not what Marie would choose if she had the capacity. They explain that this has been Marie's home for 10 years; she has a good relationship with the other people who live there, and the home is close to where her family live.

Everyone agrees that not intervening is not an option, as Marie would be at risk of further falls. Marie's key worker suggests that they move her bedroom downstairs to avoid having to go upstairs. Marie's sister agrees that this will partly solve the issue but would restrict Marie's ability to use the entire house, including the upstairs communal room which she enjoys. She asks if a stair lift could be installed. It is agreed that the least restrictive option is for a stair lift to be installed - which the local authority agrees to arrange and fund.

6.3: What happens if a person is found to lack capacity to make an important decision but has no family or friends to support them?

When important decisions need to be made for a person who has been found to lack capacity, and there are no family members or friends who are willing or able to represent the person, or even to be consulted - then an independent mental capacity advocate (IMCA) **must** be appointed. IMCAs work with and support people who lack capacity; and represent their views to the people making decisions on their behalf.

Important decisions are usually those that relate to a change in accommodation or serious medical treatment, but there are other circumstances where an IMCA may be appointed - such as during a review of the person's care and support plan or in **adult protection cases**.



Further Reading:

Information about IMCAs: <https://www.scie.org.uk/mca/imca>

Navigate to Chapter 10 of the Mental Capacity Act Code of Practice for information about IMCAs: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

Our resource on the Mental Capacity Act: <https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/mental-capacity-act/>

6.4: What are appointeeship, deputyship, and lasting power of attorney?

Family carers regularly contact us having been given advice that they need to apply to become a **deputy** or **lasting power of attorney** to be able to manage (or continue to manage) their relative's affairs - usually their finances. Remember that your relative's capacity must always be assumed, and that they must be supported to make decisions for themselves before anyone can say that they are unable to make them.

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A deputy is someone who has been authorised by the Court of Protection⁷ to make decisions on behalf of another person. This is also referred to as **deputyship**. You can apply to become your relative's deputy if they lack mental capacity to make a decision for themselves at the time it needs to be made (although they may still be able to make decisions for themselves at certain times). There are two types of deputy: **personal welfare deputy**; and **property and financial affairs deputy**.

There can be considerable expense associated with deputyship, and many decisions can be made without it. For the decisions that do require a deputy (such as signing a tenancy agreement on someone else's behalf), a one-off application can be made to the Court of Protection. Family carers are not obliged to become a deputy. Other relatives or friends can do so if appropriate; and there are specialist organisations that are independent of local authorities that will act as a deputy for a fee.

A **lasting power of attorney (LPA)** is a legal document that allows attorneys to help a person make decisions, or to make decisions on their behalf, if and when they lose capacity. Lasting power of attorney can only be granted if the person has the capacity at the time of application to instruct another person to manage their affairs. An attorney can only make decisions on behalf of the person if and when they lack the capacity to make the decision themselves. There are two types of **LPA: health and welfare LPA**; and **property and financial affairs LPA**.

If your relative's income is derived only from benefits from the Department for Work and Pensions (DWP)⁸, but they are unable to manage their benefits themselves - it is likely that **appointeeship** will be all that you need. As an **appointee** you would have the right to manage your relative's benefits. Appointees are responsible for making and maintaining any benefit claims for the person they are acting on behalf of, and must spend the person's benefits money in their best interests. Family carers are not obliged to become appointees. There are specialist organisations independent of local authorities that will act as appointee for your relative for a small fee.

Many adults with learning disabilities and/or autism do not have financial

⁷ <https://www.gov.uk/courts-tribunals/court-of-protection>

⁸ <https://www.gov.uk/government/organisations/department-for-work-pensions>

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autonomy and can find it difficult to access their money. There are a whole host of reasons why this happens, including but not limited to: inaccessible banking; having to contend with a confusing benefits system; difficulty budgeting and understanding the value of money; and vulnerability to financial scams. It can be hugely empowering for adults with learning disabilities and/or autism to have control over their own money, and with the right support, lots of people have achieved this. For others, they will rely on family carers or professional organisations to manage their finances on their behalf.



Further Reading:

Appointeeship: <https://www.gov.uk/become-appointee-for-someone-claiming-benefits>

Deputyship: <https://www.gov.uk/become-deputy>

Dosh factsheet - Access to banking for adults with learning disabilities: https://www.basw.co.uk/system/files/resources/basw_13749-7_0.pdf

Dosh factsheets for family carers: <http://www.dosh.org/learn-about-money/factsheets-for-family-carers/>

Lasting power of attorney: <https://www.gov.uk/power-of-attorney>

Money support resources for people with learning disabilities: <http://www.bild.org.uk/about-bild/ourwork/money-skills/>

7: Care Act assessment for adults with learning disabilities and/or autism



The assessment for adults with learning disabilities and/or autism is one of the most important steps of adult social care (the second is the care and support plan). The assessment is the gateway to accessing local authority-funded adult social care and support. Whilst each social worker or local authority may have their own way of doing things, the Care Act is very clear on what **should** and **must** happen (see page 6) in the assessment process - which we will outline in this chapter.

7.1: What is an assessment?

The assessment for adults with learning disabilities and/or autism is referred to in the Care Act as a needs assessment; but we will refer to it as an assessment, because it covers much more than just needs. The aim is to identify what needs your relative may have, how those needs impact on their wellbeing (see Chapter 2), and the outcomes they hope to achieve in their life. The desired result of the assessment is to provide a full picture of your relative's needs so that a local authority can provide

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an appropriate response at the right time to ensure those needs are met. In order to achieve this, the assessor will ask your relative (or you, as the person supporting them) to tell them about all of the things they need support with.

7.2: How does my relative get an assessment?

The first step is to contact the local authority where your relative lives and ask to speak to the adult social care department to request a needs assessment under the Care Act. Your relative may want to contact the adult social care department themselves - but if not, you or anyone else (including a professional) can request an assessment on their behalf.

The adult social care department can be reached by phone, online, via email or by using a website referral form. If the call handler insists that you make a computer-based referral, but you struggle to use a computer, tell them that when you call.

It's very easy to be entitled to an assessment under the Care Act. Any adult with an appearance of need for care and support can have an assessment, and local authorities have a legal duty to carry one out if this condition is met. An appearance of need just means that the adult appears to have a need for care and support.

A diagnosis of learning disabilities and/or autism it is not necessary to be entitled to an assessment. The Care and Support Statutory Guidance states that local authorities '*...should base their judgement on the assessment of the adult and a formal diagnosis of the condition should not be required*' [Para 6.104]. The guidance also says that local authorities need to be aware of adults who perhaps did not receive support as a child, but may present to adult services with fairly high needs – such as young adults with autism whose needs were largely met in mainstream school.

Your relative's finances and likelihood of eligibility for local authority funding (see Chapter 7:7) are also both irrelevant at this stage. Personal finances should never be a barrier to having an assessment, and eligibility determinations can only be made after an assessment has been carried out.

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7.3: When will my relative's assessment be carried out?

The Care and Support Statutory Guidance says that the assessment should be completed within an appropriate and reasonable timescale. The guidance does not define appropriate or reasonable in this context; so we have to take them as their everyday meaning. Whilst an exact timescale is not specified, it is generally accepted that you might wait about 6-12 weeks before the assessment is carried out. If it has been longer than 12 weeks, you should chase the local authority. If nothing comes from that, consider making a formal complaint to the local authority (see Chapter 1). Local authorities should inform people of a potential timescale throughout the process.

The Care Act gives local authorities the power to meet needs where they have not completed an assessment (or review). This is particularly important in urgent or emergency situations. Once the local authority has ensured that the person's needs are met, they can consider arranging a formal assessment at a more appropriate time.



Example:

Emma is a family carer to her adult son, Harry. However, after having a painful fall she is struggling to care for him. It is agreed by Harry's social worker that more money will be added to his **personal budget** to allow Emma to pay for three more hours' of support each day from Harry's regular support worker. The extra money was provided without an assessment. A simple conversation with Emma was all that was needed, along with agreement from the social worker's manager. The arrangement is then reviewed with Emma on a regular basis, and they agree to resume the normal level of care once Emma has recovered.

7.4: Will the assessment be person-centred?

Your relative must be involved in their assessment and central to the process as much as possible, as they are best placed to judge their own wellbeing. The assessment process must also include family carers and anyone else your relative wishes to be involved.

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Assessments must always be appropriate and proportionate, and they must be person-centred and collaborative throughout. For an assessment to be appropriate it has to be accessible to the individual. For example, a telephone assessment would not be very appropriate for someone with hearing difficulties. For an assessment to be proportionate it needs to match the level of the person's needs. For example, a self-assessment would be disproportionate to the needs of an adult with learning disabilities and/or autism who gets highly distressed talking about things they need help with. A proportionate assessment for that person would be a face-to-face assessment conducted by an experienced social worker, with input from the person's family carer or independent advocate (see Chapter 5).

The initial assessment should take no less than an hour (and it could take much longer), as there will be a lot to discuss. Assessments are generally carried out at the person's home, by either a social worker or someone else who works for the local authority.

The Care Act places a legal requirement on local authorities to ensure that all assessors have the skills, knowledge and competence to carry out the assessment in question. If an assessor does not have relevant experience of learning disabilities and/or autism, local authorities have a duty to ensure that a professional with relevant expertise is available to consult. Additional professionals (such as your relative's GP) can also be consulted as part of the process.

Local authorities should consider the potential impact that the assessment process may have upon your relative and make any **reasonable adjustments** that are required. For example, if your relative finds meetings with strangers highly stressful, they may need you to speak on their behalf.

The assessor must also take a **whole family approach** to the assessment by considering the impact of your relative's care and support needs on you and any other family members. This means that local authorities need to think about your relative's needs in the context of their whole family, and identify how you and other family members might be impacted by their needs.

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7.5: How will the assessment be conducted if my relative does not communicate verbally?

When a person does not communicate through verbal means, it is essential that the assessor seeks information about their communication needs from the people who know that person best and any professionals involved in their care. The person will be communicating in their own way, so for an assessment to be truly person-centred, the assessor will need to invest the time before the assessment to make every possible effort to involve the person in their assessment. They should find out whether any communication aids, personal technology, pictures or gestures could be used to support a person. During the assessment, the assessor needs to listen to the people who know the person best, and ask about any changes in behaviour, vocal noises or facial expressions during their assessment.

It should not be assumed that your relative is unable to be involved in their assessment just because they do not communicate verbally. Often people are able to be involved in their assessment to some degree; they just need to be supported to do so.

If there is uncertainty as to whether your relative has the capacity to be involved in their needs assessment, then a capacity assessment should be carried out under the Mental Capacity Act (see Chapter 6). This will need to be completed before your relative's needs assessment can take place. Most people will be eager to have the needs assessment take place quickly, as support will not be put in place until the assessment and care and support plan has been completed – although urgent needs are treated differently (see Chapter 7.3). It is worth making the assessor aware of any concerns you have and request that both assessments happen as quickly as possible.

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7.6: How should we prepare for the assessment?

Your relative (and you, as the person supporting them) should be provided with as much information as possible about the assessment process prior to the assessment date. Local authorities have a legal duty to make **reasonable adjustments** under Section 20 of the Equality Act 2010⁹, so information must be provided in an accessible format (such as easy-read) if required. You can ask the assessor to provide your relative with a list of the questions they will be asked during the assessment to help them prepare for it.

During the assessment, the assessor will ask your relative (or you, as the person supporting them) to talk about all the things they need support with. The assessment must capture **a complete picture** of your relative's needs, **including** any needs being met by you or any other person. A good way to prepare for this is to think about what the assessor needs to know to ensure that your relative would be safe and well supported if you were unable to care for them. Often carers struggle to think about all the things they do for their relative in detail, so keeping a detailed diary for a week or two can be a very useful way to prepare for the assessment.

During the assessment, the assessor will consider your relative's support needs in relation to the outcomes on page 40 through to 41. Look at each outcome and think about whether your relative could achieve each one without additional support from another person or by using an appliance or aid. If they are unable to achieve those outcomes without support, what impact would that have on their wellbeing, safety, skills or quality of life if that support wasn't provided? Now describe that impact. The local authority needs this information to be able to accurately assess your relative, and determine what care and support needs to be put in place.

You and your relative can both prepare for their assessment by thinking about the things they wish to achieve in their life, now and in the future. For example; do they wish to find a job, go to college, or complete some training? Maybe they would like to find new friends or a partner? Are they interested in joining a drama group or a sports club? They may need to think where they want to live in the future - perhaps moving out of the

⁹ <http://www.legislation.gov.uk/ukpga/2010/15/part/2/chapter/2/crossheading/adjustments-for-disabled-persons>

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family home into supported living, or another arrangement which gives them greater independence.

Try to write a list of everything you wish to tell the assessor so you don't forget anything during the assessment. You can take resources along that you think might be useful; such as videos of your relative that illustrate how they react in particular situations, or reports from other professionals about your relative's needs and how best to meet them.

The assessment must also capture any fluctuating needs. Fluctuating needs are when a person's needs change over time due to the nature of their condition(s). If your relative's needs tend to fluctuate, and this is not obvious at the time of the assessment - be sure to make this clear to the assessor.

7.7: Will my relative be entitled to local authority-funded care and support?

Once the assessment is complete, the assessor will use the following national eligibility criteria to consider what needs your relative has and whether any of them are eligible for local authority funding. The Care Act introduced a national framework for assessing needs, so regardless of where you live in England, the same eligibility criteria will be used.

Local authorities must consider whether:

- 1.** The adult's needs arise from or are related to a physical or mental impairment or illness.
- 2.** As a result of the adult's needs, the adult is unable to achieve¹⁰ two or more of the following outcomes:
 - managing and maintaining nutrition

¹⁰ being 'unable to achieve' an outcome includes any of the following circumstances, where the adult is: unable to achieve the outcome without assistance; is able to achieve the outcome without assistance but doing so causes the adult significant pain, distress or anxiety; is able to achieve the outcome without assistance, but doing so endangers or is likely to endanger the health or safety of the adult, or of others; is able to achieve the outcome without assistance but takes significantly longer than would normally be expected.

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- maintaining personal hygiene
 - managing toilet needs
 - being appropriately clothed
 - maintaining a habitable home environment
 - being able to make use of the home safely
 - 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
3. As a consequence of being unable to achieve these outcomes, there is, or is likely to be, a significant¹¹ impact on the adult's wellbeing (see Chapter 2).

An adult's needs are only eligible for local authority-funded care and support where they meet **all three** of these conditions. The local authority also has a power to meet needs that are not eligible.

Your relative's eligible needs must be met by the local authority unless you are already providing support to meet them. This is because the local authority does not have to meet eligible needs that are already being met by a carer - but they should make no assumptions about what you are willing and/or able to do. Any support that you are prepared to provide must be considered later on during the care and support planning stage (see Chapter 8) and **not** during the eligibility process. Care being provided by you or another family carer must not affect the eligibility process. This particular point is very important.

¹¹ The term 'significant' is not defined by the regulations, and must therefore be understood to have its everyday meaning. Local authorities will have to consider whether the adult's needs and their consequent inability to achieve the outcomes will have an important, consequential effect on their daily lives, their independence and their wellbeing.

7: Care Act assessment for adults with learning disabilities and/or autism



Example:

Imran has learning disabilities and finds it difficult to get ready in the morning without support. Often his clothes are inside-out and back-to-front; and he does not shave, brush his teeth or comb his hair. Imran would fail to meet at least two of the outcomes: maintaining personal hygiene and being appropriately clothed.

As a result, this would have a significant impact on Imran's wellbeing, including: his personal dignity; protection from abuse and neglect (Imran is more likely to be targeted by members of the public because of the way he looks); participation in work, education, training or recreation (Imran is not considered appropriately dressed for the workplace); social wellbeing; personal relationships; and his contribution to society.

Imran would be eligible for local authority-funded support to ensure that he is clean, well groomed, and appropriately clothed, which in-turn will have a positive impact on his wellbeing.

7.8: What if I am unhappy with my relative's assessment?

After the assessor has written up the assessment, your relative (and anyone else they have requested to receive one) must be provided with a copy. The assessment is still in draft form at this stage, and should only be finalised when you/your relative and the assessor have agreed that it is complete. This is your opportunity to read it through to check that it is a true reflection of your relative's needs. Make sure that any care you and any other family members are providing is included and that there is enough detail to provide a **full picture of your relative's needs**.

If there are any changes required to the assessment, contact the assessor early on with your suggested amendments. While we appreciate that it can be very difficult waiting for an assessment when there is no formal support in place, try not to agree to the assessment being finalised until you are completely happy with it.

Once you are satisfied that the assessment is complete, you should inform the assessor so that they can move on to the care and support planning stage. If you are still unhappy with the assessment and have discussed this

7: Care Act assessment for adults with learning disabilities and/or autism

with the assessor to no avail, follow our suggestions in Chapter 1.



Example:

Kerri-Ann is a young woman with learning disabilities who is at risk of choking when she eats. Her father, Leroy, noticed that the assessor had only mentioned that she requires support when she eats - and not the detailed information about her choking risk and related support needs that are necessary to ensure others know how to keep her safe. Leroy contacted the assessor, who then amended the assessment to include this important information.

7.9: What if I am not available to support my relative through the assessment process?

If the assessment can be put off until another time when you will be available to support your relative, then the assessor should accommodate that. If the assessment cannot wait or you don't think you'll be available for a prolonged period of time (perhaps due to a planned stay in a hospital), try to find out whether another family member or friend who knows your relative well could support them instead. If not, it is likely that the local authority will have a duty to provide an independent advocate to support them (see Chapter 5).

8: The care and support plan for adults with learning disabilities and/or autism



8.1: What is a care and support plan?

Following the assessment and determination of eligibility: the needs of your relative and how they will be supported to meet those needs will be incorporated into a care and support plan. A plan must be created if your relative has eligible needs. The care and support planning process is the second most important step in adult social care (the first being the needs assessment).

The purpose of the care and support plan is to agree how your relative's needs should be met. There should be no restrictions on the type of information that is in the plan, so long as it's relevant to your relative's needs and/or outcomes. Your relative's needs can be met in a variety of ways, and the local authority must not place unreasonable restrictions on how it is willing to meet those needs.

The Care and Support Statutory Guidance says:

'The plan must detail the needs to be met and how the needs will be met, and will link back to the outcomes that the adult wishes to achieve in day-

8: The care and support plan for adults with learning disabilities and/or autism

to-day life as identified in the assessment process and to the wellbeing principle in the Act. This should reflect the individual's wishes, their needs and aspirations, and what is important to and for them, where this is reasonable... The local authority should encourage creativity in planning how to meet needs, and refrain from judging unusual decisions as long as these are determined to meet needs in a reasonable way' [Para 10.31].

The care and support plan must always include:

- ✓ the needs identified by the assessment
- ✓ whether the needs meet the eligibility criteria and to what extent
- ✓ the needs that the authority is going to meet, and how it intends to do so
- ✓ the outcomes the adult wishes to achieve and where care and support could be relevant to help them achieve these
- ✓ the personal budget (see Chapter 9:1)
- ✓ information and advice on what can be done to reduce the needs in question, and to prevent or delay the development of needs in the future
- ✓ where needs are being met by a direct payment, which needs will be met by the direct payment and the amount and frequency of the payments

The Care and Support Statutory Guidance also says that the plan should indicate what contingencies are in place in the event of a sudden change or emergency:

'This should be an integral part of the care and support planning process, and not something decided when someone reaches a crisis point'
[Para 10.44].

8.2: What can I expect from the care and support planning process?

Plans should be person-centred, and the process must involve your relative throughout if they wish. If you are meeting some of your relative's eligible needs at the time of the plan, you **must** be involved in the planning process. Plans can be developed jointly with the social worker, alone, or

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with family and friends – or anyone else your relative wishes to involve.

During the care and support planning stage, you will be asked what care and support you are willing and/or able to provide to your relative. If your relative has eligible needs then the local authority is required to meet them by law - **unless** you agree to do so instead. This is because the local authority is not under a duty to meet eligible needs already being met by a carer.

You are not required to meet any of your relative's needs if you are not willing and/or able to. You may have to emotionally prepare yourself for this moment; but you should never be made to feel guilty or pressured into providing care and support you are not willing and/or able to - nor should the local authority make any assumptions about what you are prepared to do.

At the start of the care and support planning stage you should be provided with an indicative budget. This is the amount of money (or hours of care and support) that the local authority thinks is required to meet your relative's eligible needs. The indicative budget is only an estimate, and will likely change throughout the care and support planning process. See Chapter 9 for more information about the budget.

Whilst the Care and Support Statutory Guidance does not provide a timescale for completion of the plan, it does state that it should be completed in a timely fashion, proportionate to the needs that are to be met.

Upon completion of the plan, the local authority must give a copy of the final plan to your relative, any other person they request to receive a copy, and (if your relative agrees) their independent advocate, if they have one. Local authorities must take all reasonable steps to come to an agreement with an adult or their carer on the plan, before they sign it off as being completed. If there is a disagreement, people must not be left without support whilst it is being resolved.

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Further reading:

Care and support planning: <http://helensandersonassociates.co.uk/person-centred-practice/care-support-planning/>

Care and support planning tool: <https://www.247grid.com/>

Personalised care and support planning: <https://www.thinklocalactpersonal.org.uk/personalised-care-and-support-planning-tool/What-is-personalised-care-and-support-planning/>

8.3: I've been told my relative's care package is going to a funding panel – what does that mean?

Funding panels are used by local authorities as a mechanism for making decisions about people's care and support. Although the Care and Support Statutory Guidance suggests that funding panels should be used for signing off large or unique care packages, it seems they are now being used routinely by local authorities¹².

The guidance states that:

'Due regard should be taken to the use of funding panels in both the timeliness and bureaucracy of the planning and sign-off process... Where used, local authorities should refrain from creating or using panels that seek to amend planning decisions, micro-manage the planning process or are in place purely for financial reasons. Local authorities should consider how to delegate responsibility to their staff to ensure sign-off takes place at the most appropriate level' [Para 10.85].

If you do not agree with a decision that has been made by a panel, you can still challenge it - but you may need to make a formal complaint or seek legal advice.

¹² <http://www.communitycare.co.uk/2018/03/21/social-workers-voice-concerns-influence-funding-panels-adults-services/>

9: Personal budgets and financial assessments for adults with learning disabilities and/or autism



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9.1: What is a personal budget?

A personal budget is the amount of money needed to meet a person's eligible needs, and also anything extra the council is willing (although not obliged) to fund. The personal budget is made up of local authority funding from adult social services. Everyone whose needs are eligible to be met by the local authority must receive a personal budget. Sometimes the budget will be presented as hours instead of a monetary value. For example: 77 hours instead of £1,077.23. However, you can ask for the budget to be presented in the way that works best for you.

The Care and Support Statutory Guidance says that the process for allocating and finalising the personal budget should be as straightforward and timely as possible. The budget allocation must be transparent so that people and/or their family carers or advocates are fully aware of how the final personal budget offer was reached. Most importantly the personal budget **must always be sufficient** to meet the person's care and support needs.

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The initial budget provided to your relative is likely to be an indicative budget. Indicative budgets can be increased or decreased depending on decisions made during the care and support planning stage. The local authority must take into account your relative's reasonable preferences as to how their needs could be met. The final signed-off personal budget will be the amount recorded in the care and support plan.

Local authorities often use computer-based resource allocation systems (RAS) to calculate people's personal budgets. These aren't designed to come up with the most generous amounts and are not particularly transparent. If you are unsure whether the budget is sufficient to meet your relative's needs, ask your relative's social worker to explain it to you, and ask them to show you what you can actually **get** with that budget before agreeing to the amount.

People should not be forced to accept specific care options against their will just because it is the cheapest option. Decisions about the budget should be based equally on all relevant considerations, including outcomes and value for money. Local authorities should take all reasonable steps to limit and resolve disputes regarding the final personal budget allocation.

9.2: How can the personal budget be paid?

Personal budgets can be paid in one of three ways:

- 1.** As a **managed account**, where the personal budget is held and managed by the local authority. There is very little flexibility with this method as the money goes straight to the support provider, through arrangements between the council and the provider.
- 2.** As an **Individual Service Fund**¹³ where the personal budget is held by a support provider, who deals with managing budgets. The individual chooses the support but does not manage the money. This type of arrangement is similar to a managed account, but it allows the provider to sub-contract elements of the care and support to other providers (after discussion with the adult and/or their family). This option allows for some flexibility in how the personal budget is spent.

¹³ <https://www.thinklocalactpersonal.org.uk/Latest/Individual-Service-Funds-ISFs-and-Contracting-for-Flexible-Support/>

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3. As a **direct payment** where the money is paid directly to the individual or someone else on their behalf. The money can be spent in a way that is flexible, as long as it is meeting the person's needs outlined in their care and support plan.

You can also choose to have the budget administered in a mixture of the above. For example, if your relative chooses a day service to have their needs met in the daytime, this cost could be paid directly to the service provider by the council as a managed account. For the hours outside of the day service, your relative could receive a direct payment to spend in a way that suits them – as long as it is being spent in a way that meets the needs outlined in their care and support plan.

The local authority might talk about the possibility of your relative being entitled to an integrated personal budget. An integrated personal budget includes both health and social care funding. If your relative is funded by health and social care, it is good to be aware that the Care Act introduced a new requirement to promote integration and ensure cooperation between local authorities and the NHS, in order to: promote the wellbeing of adults and carers; contribute to the prevention and development of needs; and, improve the quality of care for adults and carers.



Further Reading:

NHS Better Care Fund: <https://www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/>

Summary guide for different types of budgets: https://www.england.nhs.uk/wp-content/uploads/2017/06/516_Personal-budgets-integrated-personal-budgets-and-personal-health-budgets_S11.pdf

9.3: Can I manage a direct payment on behalf of my relative?

Yes, with the approval of the local authority concerned. If your relative has the ability to manage their own direct payment and they wish to do so, they can. If your relative would like a friend or family member to manage a direct payment on their behalf, they can nominate someone. This person becomes the **nominated person**. With this arrangement your

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relative would still be liable for the direct payment, including any misuse or overspending.

If your relative lacks the capacity (see Chapter 6) to manage their own direct payment, an **authorised person** could be appointed. An authorised person would take the direct payment on in their own name, with all the responsibility that will involve.

In both of these instances, the local authority must satisfy itself that the person meets certain conditions as outlined in the Care Act.

Local authorities should take all reasonable steps to provide support to whoever needs it in order for them to manage a direct payment. As the nominated or authorised person you can therefore choose to have the money paid to a third party organisation. They can either support you with managing the direct payment or manage it on your behalf.

A third-party organisation is a service that organises the payment of salaries, tax, etc. There may be a small fee for this service, to be paid by your relative, but the local authority may decide to increase your relative's personal budget to pay for it. If your relative's council isn't inclined to do that, then your relative (or you, as the person supporting them) could spend their own money to pay the fee and claim it as **disability related expenditure (DRE)** (see Chapter 9:11).

If a third party organisation is used, the overall responsibility for the direct payment still lies with the person authorised to manage the direct payment.

When paying the personal budget as a direct payment, the local authority should take into account whether there will be any essential costs associated with recruitment of staff (such as Disclosure Barring Service checks) and unavoidable overhead expenses such as: Employer National Insurance Contributions; pension contributions; holiday pay and cover; etc. If there are essential costs, the amount must be included in the personal budget. It is worth finding out what the local market rate is for employing suitably skilled staff, and reference that in conversations with the local authority when discussing the personal budget.

Where a direct payment is being used to employ personal assistants, the direct payment holder and the local authority should ensure that there are clear contingency plans in place to cover sickness (including long-term sickness), maternity/paternity pay, or holiday entitlement. The local

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authority still has a duty to ensure the individual's needs are being met, even if an individual or their family make their own arrangements through the use of a direct payment.

The direct payment will be reviewed initially within the first 6 months, and every 12 months thereafter. Reviews are intended to be light-touch, and local authorities should consider reducing monitoring requirements over time.

9.4: Will my relative be eligible for a direct payment?

Generally it is expected that direct payments are an appropriate way of meeting most care and support needs. However, if the local authority itself can purchase a service cheaper, then it is arguable that they do not have to authorise a direct payment to pay for it.

If for any reason the local authority does not agree that a direct payment is appropriate, they must provide reasons in writing, with instructions on how to get the matter reconsidered. The local authority should also continue with the care planning process to determine and agree on the best way to meet the needs, without the use of a direct payment.

9.5: Are there restrictions on what a direct payment can be used for?

There should be no unreasonable restrictions placed on how the direct payment can be spent as long as it is meeting your relative's eligible needs. However, there will be some restrictions. Generally, local authorities will have a policy that disallows direct payments to be used for a health care need that should be provided by the NHS or Clinical Commissioning Group (CCG)¹⁴, or for purchasing tobacco, alcohol or anything illegal. Most local authorities are not allowed to issue a direct payment for the purpose of securing long-term residential care.

Otherwise, the Care and Support Statutory Guidance says:

'The direct payment is designed to be used flexibly and innovatively and there should be no unreasonable restriction placed on the use of the

¹⁴ <https://www.england.nhs.uk/ccgs/>

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payment, as long as it is being used to meet eligible care and support needs' [Para 12.35].

9.6: Can I pay myself or another family member out of the direct payment?

Potentially – depending on who it is and where they live. The Direct Payment Regulations¹⁵ state that payments must not be used to pay for care from spouses and civil partners, or from a close family member who is living in the same household, except where the local authority has deemed this to be necessary. If you would like the local authority to consider this as an option, you should request it as part of the assessment and care and support planning stage and explain why it should be regarded as a necessity.

Family members can be paid for the administration and/or management of the direct payment if agreed by the local authority. The payment offered is generally the same amount that would be paid to a third-party organisation to manage the direct payment. This amount must be added on to the personal budget. The decision must be recorded in the person's care and support plan, along with the amount and frequency of the payment.

9.7: Do we have to accept a direct payment?

No. The Care and Support Statutory Guidance states:

'People must not be forced to take a direct payment against their will, but instead be informed of the choices available to them' [Para 12.5].

Further Reading:

Questions and answers on direct payments: <http://www.communitycare.co.uk/2016/10/11/questions-answered-direct-payments-care-act/>

¹⁵ <http://www.legislation.gov.uk/uksi/2014/2871/regulation/3/made>

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9.8: Should I accept a prepaid card?

Many local authorities are offering prepaid cards as a way of administering direct payments¹⁶ - and some are rolling these out as the only option. However, the Care and Support Statutory Guidance is very clear that the offer of a direct payment being paid into a bank account should always be available if the person requests it and it is appropriate to meet needs.

Prepaid cards can be beneficial to some people, as they reportedly involve less financial management and administration than a direct payment being paid into a bank account. However, they must not be used to constrain choice, for example by only allowing them to be used with a selected list of providers, or implementing blanket restrictions such as no cash withdrawals.

We would therefore advise people to do some research before accepting one. If prepaid cards are not suitable for you or your relative's needs then you do not have to accept one.

9.9: Will my relative have to pay towards their care and support?

There are certain kinds of care that local authorities are not allowed to charge for, such as: any item of equipment provided by social services or any minor adaptation costing up to £1000; reablement for 6 weeks¹⁷; or aftercare services when someone comes out of a psychiatric hospital¹⁸. However, most people will be expected to pay some sort of contribution towards their care and support. This is because social care is not free. Whilst local authorities have no obligation to charge, it is exceptional to find one that doesn't charge.

Once your relative's needs assessment is complete, their eligible needs have been determined, and care and support planning has started, the local authority will carry out a financial assessment to determine what your relative can afford to pay. They cannot be charged before this financial

¹⁶ <https://www.theguardian.com/society/2018/jun/12/councils-tighten-reins-on-personalised-care>

¹⁷ <https://www.scie.org.uk/publications/atagance/atagance54.asp>

¹⁸ <https://www.mind.org.uk/information-support/legal-rights/leaving-hospital/section-117-aftercare/#.W9B-zPZFzcs>

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assessment has happened.

If your relative lacks the capacity to take part in the financial assessment, the local authority must involve someone who is authorised to be involved with managing your relative's finances, such as an appointee or a deputy for financial affairs (see Chapter 6:4).

The charging process is different depending on what setting your relative is living in. In assessing what your relative can afford to pay, the local authority must take into account their:

- income (such as Disability Living Allowance care component, Employment and Support Allowance, and Personal Independence Payment daily living component);
- living costs (such as rent and council tax);
- capital (such as savings or valuable assets) if they have any. The value of any property that a person owns must be disregarded if the person lives there as their main or only home.

In order to help encourage people to remain in or take up employment, earnings from current employment must be disregarded when working out how much a person can pay.

Where a person's resources are below the lower capital limit of **£14,250**¹⁹, this money will not be taken into consideration during the financial assessment. People who have more than the upper capital limit of **£23,250**²⁰ will be expected to pay the full cost of their care, and are generally referred to as either 'full cost payers' or 'self-funders' depending on the setting. For people with savings or assets between the lower and upper capital limits, they will be charged a set proportion of that capital to pay towards the cost of their care and support.

It is therefore advisable that any money or assets that your relative owns which are above the lower capital limit is put into a special trust, so that the

¹⁹ See the latest local authority circular for up-to-date social care charging figures, including the lower capital limit: <https://www.gov.uk/government/collections/local-authority-circulars>

²⁰ See the latest local authority circular for up-to-date social care charging figures, including the upper capital limit: <https://www.gov.uk/government/collections/local-authority-circulars>

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money does not affect their entitlement to adult social care. Seek specialist legal advice and watch our film for more information:

<https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/what-happens-when-im-no-longer-around/>

9.10: How will the charges be worked out?

Your relative cannot be charged by the local authority to pay for their financial assessment, needs assessment, or the preparation of a care and support plan; nor can they ever be charged more than it costs the local authority to arrange their care and support.

The financial assessment must only look at your relative's finances, and not yours as a family carer. The local authority must leave an individual who is not in a residential home (see below) with enough money to live on (an amount which is set by central government).

People in a care home will contribute most of their income towards the cost of their care and support, but they must still be left with enough money to spend on clothes and other items that are not provided as part of their care package. This is known as the Personal Expenses Allowance (PEA) and is currently set at **£24.90**²¹ each week.

People receiving local authority-funded care and support in a setting other than a care home will need to be left with enough money to pay for their daily living costs such as food and bills. After charging, a person must be left with the Minimum Income Guarantee (MIG), which is currently set at **£72.40** each week for adults between the age of 18 and 25; and **£91.40** for adults over the age of 25. There are other variations on these amounts for people who are of pension credit age and/or part of a couple. People in receipt of disability premium will be allowed an additional **£40.35** on top of the MIG, and those in receipt of enhanced disability premium will be

²¹ See the latest local authority circular for up-to-date social care charging figures, including the PEA: <https://www.gov.uk/government/collections/local-authority-circulars>

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allowed **£19.70** on top of the disability premium figure²².

The charge is not directly related to the amount of care and support your relative receives. Therefore, some people who receive 9 hours of care and support each week can end up paying the same contribution as someone who receives 24/7 care, for example. However, people will only ever be asked to pay a contribution; they will not be expected to pay for the full cost of their care and support, unless they have capital over the upper capital limit (see Chapter 9:9).

The Care and Support Statutory Guidance says that local authorities should use their discretion to support the principles of care and support charging, such as:

- ✓ being person focused
- ✓ ensuring that people are not charged more than is reasonably practicable for them to pay
- ✓ being comprehensive, to reduce variation in the way that people are assessed and charged
- ✓ promoting wellbeing, social inclusion, personalisation, independence, choice and control
- ✓ being clear and transparent so people know what they will be charged

Once the financial assessment process is complete, your relative must be provided with a copy of the decision, including a breakdown of the calculations. The charges must be stated in the care and support plan. The amount they pay is known as their **financial, weekly or client contribution**. If you do not agree with your relative's contribution, you can appeal by asking for a review, or you can make a complaint. The local authority must provide clear information and advice about its complaints procedure.

²² See the latest local authority circular for up-to-date social care charging figures, including the MIG: <https://www.gov.uk/government/collections/local-authority-circulars>

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Further Reading:

Age UK factsheet about paying for care and support at home: https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs46_paying_for_care_and_support_at_home_fcs.pdf

Charging and financial assessment - Care and Support Statutory Guidance: <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#charging-and-financial-assessment>

9.11: My relative has much higher living costs because of their disabilities, so how is it fair to charge them for their social care?

If your relative receives disability benefits, the charging arrangements should ensure they get to keep enough money to cover any disability-related costs. This is known more formally as **disability related expenditure (DRE)**, and can cover anything from taking a support worker on holiday through to the cost of garden maintenance for example, as long as your relative is permitted to claim it as DRE. If you think your relative has disability related expenditure that is not being taken into consideration by adult social care, you should put forward everything you think is relevant during the financial assessment. You will need to supply evidence such as receipts or utility bills, so keep hold of any relevant paperwork.

If your relative's local authority is refusing to accept certain disability related expenditure you may be able to challenge their decision. Ask for their reasoning in writing and seek specialist advice.



Further Reading:

Examples of DRE: <http://www.real.org.uk/wp-content/uploads/2017/02/Reals-guidance-on-disability-related-expenditure-12-April-2017-PDF.pdf>

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9.12: I've been told that adult social care does not fund activities, so my relative will have to fund these themselves – is that true?

No. Providing that the activity is meeting your relative's needs as outlined in their care and support plan, and provided that a budget has been allocated for that, the local authority should not be placing restrictions on how your relative goes about that. The Care and Support Statutory Guidance states: *'Because a person's needs are specific to them, there are many ways in which their needs can be met. The intention behind the legislation is to encourage this diversity, rather than point to a service or solution that may be neither what is best nor what the person wants'* [Para 10.10].

What counts as meeting a person's needs is open to interpretation, but we would argue that most activities can be linked in some way to meeting your relative's needs and helping them to achieve their outcomes. The important thing to do is to have that discussion with the assessor at the time of your relative's care and support planning. The Care Act starts with the assumption that the individual is best placed to judge their own wellbeing. The definition of 'wellbeing' includes control by the individual over their care and support and the way it is provided. It would therefore be counterintuitive for the local authority to dictate to a person exactly what best meets their needs.

10: The review process for adults with learning disabilities and/or autism



The review process is an important part of ensuring that your relative's needs are still being met. Without regular reviews, your relative's plan could quickly become out of date, meaning that they are not receiving the care and support they need to ensure their eligible needs are met.

10.1: When should my relative have a review?

The first planned review should be light-touch, 6-8 weeks after sign-off of the original care and support plan, to check that everything is working - including the direct payment if your relative has one. After the initial light-touch review, it is expected that the local authority should conduct a review of the plan every 12 months or sooner if required.

It is the local authority's responsibility to ensure that reviews are carried out, but they may authorise a third party (such as a provider) to conduct the review instead.

Local authorities must consider all requests for reviews and decide whether

10: The review process for adults with learning disabilities and/or autism

one is necessary. The Care and Support Statutory Guidance states that in most cases it is expected that a review should be carried out, unless the local authority '*...is reasonably satisfied that the plan remains sufficient, or the request is frivolous, or is made on the basis of inaccurate information, or is a complaint; for example where a person lodges multiple requests for a review in a short period of time and there is no reason to believe that the person's needs have changed. Local authorities should clearly set out the process that will be used to consider requests*' [Para 13.23].

If the local authority refuses to carry out a review following a request, they must outline their reasoning along with information about how to pursue the matter if the adult or their carer remains unsatisfied.

10.2: What should be considered during the review?

The review process should consider the following:

- Have the person's circumstances and/or care and support needs changed?
- What is working in the plan, what is not working, and what might need to change?
- Have the outcomes identified in the plan been achieved or not?
- Does the person have new outcomes they want to meet?
- Could improvements be made to achieve better outcomes?
- Is the person's personal budget enabling them to meet their needs and the outcomes identified in their plan?
- Is the current method of managing it still the best one for what they want to achieve? For example, should direct payments be considered?
- Is the personal budget still meeting the sufficiency test?
- Are there any changes in the person's informal and community support networks which might impact negatively or positively on the plan?
- Have there been any changes to the person's needs or circumstances which might mean they are at risk of abuse or neglect?
- Are the person, carer, and independent advocate satisfied with the plan?

10: The review process for adults with learning disabilities and/or autism

A review of the plan does not necessarily mean that anything will change, but the local authority does have an ongoing duty to review what's working, what's not working, and whether anything needs to change.

As with assessments, reviews should be person-centred, outcome-focused, and proportionate to the needs to be met. If the review identifies that your relative's needs have changed, a revision of the care and support plan might be all that's necessary, rather than a full reassessment, as some changes can be made quite simply within the allocated budget.

Where a revision or reassessment is required, the local authority has to work through the same assessment and care and support planning processes as outlined throughout (see Chapters 7 and 8).

10.3: My relative has had their annual review, but their care and support has been reduced – is this allowed?

This depends on a few factors. The Care and Support Statutory Guidance states that annual reviews '*...must not be used as a mechanism to arbitrarily reduce the level of a person's personal budget*' [Para 13.4]; and '*Any reduction to a personal budget should be the result of a change in need or circumstance*' [Para 13.33]. So if your relative's needs have not changed but the budget has been reduced, the local authority needs to produce evidence of why they feel that a cut in support is justified.

On the other hand, if your relative received a lot of support with managing their toilet needs, for example, but has got to a point where they can manage this on their own without support – the local authority might be justified in reducing that support. However, it would be difficult to justify a decision to stop paying for your relative to attend a social club because the outcome in their care plan has been achieved. This is because as soon as that social activity is taken away, the need becomes unmet again.

If your relative's budget has been cut, consider the impact this will have on their wellbeing and whether any unmet eligible needs will arise as a result. If this is the case, you should approach the assessor and explain the impact to them. If they refuse to change the budget back to the original amount, you will likely have to make a formal complaint or seek legal advice.



In the previous chapter, we emphasised the importance of a needs assessment and care and support plan for adults with learning disabilities and/or autism. In this chapter we want to emphasise the importance that family carers also get a carer's assessment (and a support plan), so that they are supported in their own right.

Through our support work, we often ask family carers whether they have had a carer's assessment. Very few people say that they have - or if they do, they tell us they wouldn't bother having another one. When we ask why, we hear responses such as: 'I wouldn't be entitled to one because I don't live with my relative'; 'I don't think there's any point'; 'I had one years ago but it didn't help me'; or, 'I get Carer's Allowance²³, that's the same thing isn't it?'.

²³ A carer's assessment is not the same as Carer's Allowance, which is a government benefit paid to carers who care for an adult over the age of 16 (who is on certain benefits) for at least 35 hours each week. See our website for more information: <https://www.hft.org.uk/resources-and-guidance/benefits-and-support/carers-allowance/>

11: Carer's assessment, and support plan

We encourage all family carers to get a carer's assessment if they haven't already had one, or if they haven't had one in years. We know that carer's assessments can be worthwhile, because we've supported many family carers to prepare for them, and those carers have received personalised support from their local authority as a direct result of the assessments.

However, for carer's assessments to be worthwhile, family carers need to prepare for them - and these are some of the steps that you can take:

- Reflect on your role as a carer
- Consider what would make your caring role easier
- Ensure that you are aware of your rights, as a carer, under the Care Act
- Familiarise yourself with the assessment and support planning process

The purpose of a carer's assessment is to establish what the local authority can do to support you in your caring role; it is not an assessment to determine the quality of care you provide. You do not have to live with your relative to be entitled to a carer's assessment.

A carer's assessment must establish:

- ✓ the impact that caring has on your wellbeing
- ✓ the outcomes you wish to achieve in day-to-day life
- ✓ whether you work or wish to do so
- ✓ whether you're participating in or wish to participate in education, training or recreation
- ✓ whether you are able and willing to provide and continue to provide care

It is the responsibility of your **relative's** local authority to carry out your carer's assessment. If you live some distance away from your relative, **your** local authority may be asked to carry out the carer's assessment instead; but you should always contact your relative's local authority first, as it is up to them to arrange it.

If you have your own care and support needs, you may also be entitled to a needs assessment in your own right (not including your needs as a carer, which would be covered separately by your carer's assessment). In this case, you should follow the guidance outlined in Chapters 7 and 8.

11: Carer's assessment, and support plan

Useful information on how the NHS can support carers: <https://www.england.nhs.uk/commitment-to-carers/carers-toolkit>

11.1: I've been told I'm not entitled to a carer's assessment – is that true?

There should be very few situations where a family carer is refused a carer's assessment. The Care and Support Statutory Guidance states: *'Where an individual provides or intends to provide care for another adult and it appears that the carer may have any level of need for support (whether currently or in the future), local authorities must carry out a carer's assessment'* [Para 6.16].

Nevertheless, we have come across instances of adult social care call-handlers attempting to determine carers' entitlement to an assessment based on incorrect, irrelevant or out-of-date information, such as how many hours of care the carer provides or whether or not they live with their relative. Local authorities have a duty to ensure their staff have been appropriately trained to be able to manage such requests. So if you have been refused a carer's assessment, you can contact us or your local carers' centre for guidance.

11.2: Can I choose how my assessment is carried out?

Yes. Local authorities should consider the impact the assessment process may have on you, and be flexible with regards to the timing, location and format of the assessment.

Local authorities have different methods for how they carry out their carer's assessments: some may offer them as self-assessments, whereas others outsource them to local carers' centres. Some family carers will express a preference for a self-assessment; whereas others will prefer to be guided and supported through the process by a trained assessor.

It can be very difficult to assess yourself because what you do for your relative is everyday life, so you may struggle to see it as a 'caring role'. In this case, a conversation with another person will likely enable you to think

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about the detail. Whatever method you choose, it's important to know that you do have a choice – and the local authority must respect this.

If you live with your relative, the local authority may carry out a combined assessment where they complete your relative's assessment and your carer's assessment at the same time. This may be practical for you, particularly if you are caring for more than one person; but you can request that the assessments are carried out separately. Caring for an adult can be extremely challenging, so it's not always appropriate to have your relative present during your assessment. You may not feel comfortable being completely honest about the impact that caring has on your life, in front of your relative.

Irrespective of whether the assessments are combined or separate, a **whole family approach** must be adopted by the assessor.

11.3: Will I be eligible for local authority-funded support?

Once the assessment is complete, the assessor will use the following national eligibility criteria to consider what needs you have as a carer and whether any of them are eligible for local authority funding. Local authorities must consider whether:

1. Your needs arise as a consequence of providing necessary care to an adult.
2. As a result of your needs:
 - your physical or mental health is, or is at risk of, deteriorating, and/or
 - you are unable to achieve²⁴ just one of the following outcomes:
 - carrying out any caring responsibilities you have for a child
 - providing care to other persons for whom you provide care
 - maintaining a habitable home environment

²⁴ 'being unable' to achieve outcomes include circumstances where the carer: is unable to achieve the outcome without assistance; is able to achieve the outcome without assistance, but doing so causes or is likely to cause significant pain, distress or anxiety; is able to achieve the outcome without assistance but doing so is likely to endanger the health or safety of the carer or any adults or children for whom the carer provides care.

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- managing and maintaining nutrition
 - developing and maintaining family or other significant personal relationships
 - accessing and engaging in work, training, education or volunteering
 - making use of necessary facilities or services in the local community including recreational facilities or services
 - engaging in recreational activities
3. As a consequence, there is (or is likely to be) a significant²⁵ impact on your wellbeing (see Chapter 2).

You will have eligible needs if you meet **all three** of these conditions.

Once the eligibility determination has been made, local authorities must provide you with a copy of their decision. If the local authority finds that you do not have eligible needs, they must provide you with information and advice on what can be done to meet or reduce the needs that are not eligible; and what can be done to prevent or delay the development of those needs in the future. They may also signpost you to local support services. If you do not agree with their decision, refer to Chapter 1.

11.4: What kind of support am I likely to be offered as a carer?

It may be decided that you need support to 'maintain a habitable home environment' - in which case a weekly cleaning service would help. Perhaps it's been identified that you are unable to 'develop and maintain family or other significant personal relationships', but because you live rurally and do not drive, it is agreed that driving lessons would help you to achieve this. If you are struggling to 'access and engage in work, training, education or volunteering', it might be decided that the local authority pay

²⁵ The term 'significant' is not defined by the Eligibility Regulations, and must therefore be understood to have its everyday meaning. Local authorities will have to consider whether the carer's needs and their inability to achieve the outcomes will have an important, consequential effect on their daily lives, their independence and their own wellbeing.

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for a training course for you. Whatever support is offered, it must help you in your caring role and meet your needs in a way that works for you.

Some local authorities publish what's known as a carer's offer, which is often a variation on a pamper day for women or a pie and pint night for men. Not only does this seem presumptuous about what men and women want; it's also a token gesture compared to what carers usually need. Accept this offer if it works for you, but if you have unmet eligible needs then the local authority must provide support to meet them in a person-centred way - even if you have accepted a carer's offer. The carer's offer does not replace the local authority's duty to meet your eligible needs.

If your assessment has been carried out by a local carers' centre, they may have a restriction placed on what they can provide to you. For example, they may only be able to provide a one-off payment to carers, when in fact a monthly direct payment might be more suitable for you. Similarly, they may also have a financial cap on what they can offer you to meet your needs (for example, a limit of £200) even if you require a higher amount of support. If you think that you need something different from what they can offer you, you should speak to the local authority.

11.5: Will I receive a support plan?

Following your assessment and determination of eligibility, if the local authority decides that you have eligible needs, they must provide you with a support plan. The intention of a support plan is to determine how your needs should be met, and it must always include:

- ✓ the needs identified by the assessment
- ✓ whether the needs meet the eligibility criteria and to what extent
- ✓ the needs that the authority is going to meet, and how it intends to do so
- ✓ the outcomes you wish to achieve, and your wishes around providing care, work, education and recreation where support could be relevant
- ✓ the **personal budget**
- ✓ information and advice on what can be done to reduce the needs in question, and to prevent or delay the development of needs in the future

11: Carer's assessment, and support plan

- ✓ where needs are being met by a direct payment, which needs will be met by the direct payment and the amount and frequency of the payments

The process for support planning is exactly the same for you as it is for your relative, in that it must be person-centred, involving you throughout; it must link back to your wellbeing and the outcomes you wish to achieve; and it should reflect your wishes, needs and aspirations. Your support plan must be reviewed every 12 months or sooner if you request it.

A copy of the plan must be given to you and/or anyone else you request for it to be shared with. The local authority must take all reasonable steps to come to an agreement with you about your plan and how they should meet your eligible needs.

11.6: Will I have to pay for the support provided to me?

Whilst local authorities do have the power to charge you for the support they provide you, often they do not. The Care and Support Statutory Guidance recognises that it would be a false economy to do so and will likely lead to carers refusing support:

'When deciding whether to charge, and in determining what an appropriate charge is, a local authority should consider how it wishes to express the way it values carers within its local community as partners in care, and recognise the significant contribution carers make. Carers help to maintain the health and wellbeing of the person they care for, support this person's independence and enable them to stay in their own homes for longer. In many cases, of course, carers voluntarily meet eligible needs that the local authority would otherwise be required to meet. Local authorities should consider carefully the likely impact of any charges on carers, particularly in terms of their willingness and ability to continue their caring responsibilities' [Para 8.50].

Whilst the local authority can charge your relative a financial contribution towards their care and support (see Chapter 9:9), they cannot ask you to contribute financially towards any support that is directly provided to your relative. So if a local authority agrees to provide respite care to your relative through your carer's assessment, only your relative's finances are relevant when considering whether to charge.

11.7: Am I entitled to a personal budget as a carer?

Yes. A carer's budget is the amount paid to you to meet your eligible needs, and it can be provided to you as a one-off payment or as a regular direct payment. If you are given a one-off payment, this is usually for 12 months until the next review of your carer's assessment. Your personal budget must be an amount that enables you to meet your needs and to continue fulfilling your caring role. The way in which it will be used should be agreed as part of the planning process.

12: Housing and choice for adults with learning disabilities and/or autism



Being able to choose where we live is important to all of us - and people with learning disabilities and/or autism are no different. Determining the appropriate type of accommodation is a huge life decision. Your relative must be part of that process. The local authority should provide information and advice on housing and housing-related support options, but it is advisable to do your own research too.

If your relative has a friend or partner they might like to live with, you could all get together with the local authority to discuss options. Decisions about the suitability (and affordability) of accommodation should be made with your relative as part of their care and support planning process.

12.1: What housing options are usually offered to adults with learning disabilities and/or autism?

There are a number of housing options for adults with learning disabilities and/or autism, but the two options that you have probably heard about are residential care homes and supported living.

12: Housing and choice for adults with learning disabilities and/or autism

Social services are not legally responsible for securing housing for most people with disabilities (this falls under housing and homelessness law if a person does not have the money to buy or rent privately). However, where people's eligible needs are for personal care and accommodation together, the local authority may choose to meet this combined need by providing accommodation in a residential care home.

OxFSN guide to finding the right support – tips for looking for support providers and questions to ask: https://www.oxfsn.org.uk/wp-content/uploads/2015/01/Moving-into-Adulthood-series_Finding-the-Right-Support-guide.pdf

OxFSN film about adults with learning disabilities moving out of the family home: <https://www.youtube.com/watch?v=L40yPP06qJw&t=>

Residential care homes are a way of providing housing and care and support in one contractually integrated package, which covers everything from care and support, to rent, utilities and food. Care homes can have any number of people living in them (usually a minimum of 4), with staff providing a mixture of one-to-one support (support provided to one individual from one staff member) and shared support (support provided to more than one individual from one staff member), depending on each of the individual's care and support plans. The local authority will cover the full cost of residential care if it has been agreed that it meets the individual's eligible needs. This is usually paid directly from the local authority to the care provider. It is the responsibility of the local authority to ensure the individual's needs are being met and that the care home is fulfilling their Care Act duties.

Some people view residential homes as institutional, as people are often living in a large home separate from their community. It is also sometimes felt that the people living in them have very little control or say over what happens in the home and over who comes and goes. Whilst there are good arguments against large residential homes, it is important to acknowledge that some people may still choose this kind of home as their preferred and most suitable option. Some residential homes feel less institutionalised than some supported living arrangements - so it is

12: Housing and choice for adults with learning disabilities and/or autism

important that people have a genuine choice over where they live, and that the choice is not driven purely by ideology.

Care Quality Commission (CQC) website for care home ratings: <https://www.cqc.org.uk>

Supported living can take many different forms, but ultimately it involves people either living on their own or with other people, with support, where they pay for their rent, food and utilities out of their own income. Any eligible care and support is paid for by the local authority, which can either be paid directly to the provider or to a direct payment holder (see Chapter 9.2).

It is not necessary that the landlord and support provider are separate (in legal terms) as long as the tenancy and the care arrangements are separately provided for. However, it is still considered best practice that the landlord and care provider are different. A written tenancy agreement is considered best practice for tenants in supported living, and the rent is usually paid for by housing benefit²⁶.

Supported living is also referred to as independent living. These descriptions can alarm some family carers as it sounds like their relative will be expected to live independently, and will not get the level of support that they need compared to a residential home. However, independent living does not mean that people are self-sufficient. Your relative should receive the support that they need and the local authority has a duty to meet your relative's eligible needs wherever they live.

Information on tenancy agreements for people with learning disabilities: <http://www.housingandsupport.org.uk/tenancy>

NDTi's 'The real tenancy test' which applies to supported living: <https://www.ndti.org.uk/uploads/files/TheRealTenancyTestFINAL.pdf>

²⁶ <https://www.gov.uk/housing-benefit>

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REACH standards: http://www.livewellcare.co.uk/images/guide_to_supported_living.pdf

Shared Lives is a scheme where adults with learning disabilities and/or autism are matched to Shared Lives carers and families who have a spare room to offer. After some time to get to know each other, the person either moves in with them or visits on a regular basis in the daytime or for overnight breaks.

Information about Shared Lives:
<https://sharedlivesplus.org.uk/home/about-shared-lives>

In any situation where the accommodation is being funded by the local authority, local authorities must ensure that individuals have a genuine choice of accommodation - with at least one accommodation option available and affordable within the person's **personal budget**.

12.2: Other options

Some families are in a position to buy a flat or home for their relative. If your relative is entitled to care and support, the premise would be exactly the same as supported living: they would still receive their local authority-funded package of care, and would be expected to pay for their food and bills out of their income. Your relative may be able to claim housing benefit if they live in a separate self-contained property to you. It cannot be denied merely because a relative is the landlord, but it must be a commercial arrangement.

See Learning Disability England's website for information about renting to a relative: <http://www.housingandsupport.org.uk/renting-accommodation-to-relatives>

12: Housing and choice for adults with learning disabilities and/or autism

Some people with learning disabilities and/or autism may have their housing needs met by the housing department as opposed to adult social care. If this does happen, and your relative falls under the duty of the housing department, they will have to apply for council housing. Adult social care staff should still take steps to enable them to access the support to which they are entitled, by reporting on their needs in order to elevate their priority to the maximum allowed under the local lettings policy or homelessness law²⁷.

Government information on council housing: <https://www.gov.uk/council-housing>

12.3: Can my relative live at home with me?

Yes, if that's what you both want, although you don't have an obligation to house your relative. If your relative isn't ready to move out of the family home they can still have their eligible care and support needs met through a personalised care package – in the same way as people living more independently. Just remember, you need to be clear with the local authority about what you are willing and able to do for your relative whilst they remain at home, as they do not have to meet eligible needs that are being met by a carer. You are not obliged to do anything by way of care and support just because you accommodate your relative.

If your home requires adaptations for your relative, you may be entitled to receive this for free. Minor adaptations up to the cost of £1000 must be provided for free. Anything above that will require an assessment and funding from the Disabled Facilities Grant.

Apply for a Disabled Facilities Grant: <https://www.gov.uk/disabled-facilities-grants>

²⁷ https://england.shelter.org.uk/housing_advice/homelessness/rules/priority_need

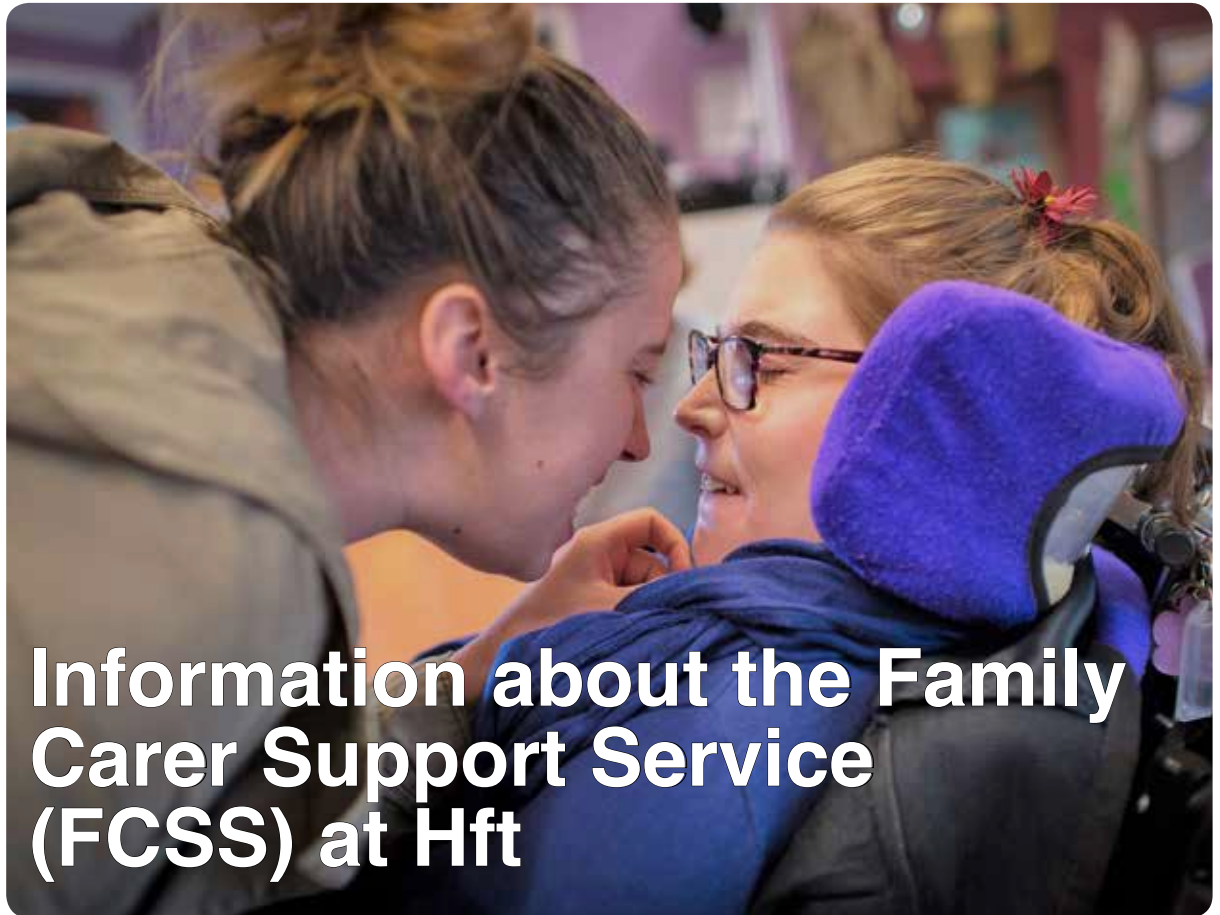


Further Reading:

Age UK's factsheet for information about tenancy rights: https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs68_tenancy_rights_security_of_tenure_fcs.pdf

Learning Disability England's website for useful information about housing: <http://www.housingandsupport.org.uk/home>

Mencap's website for the pros and cons of different housing options: <https://www.mencap.org.uk/advice-and-support/housing/housing-faqs>



We hope that you found this guide useful and that having read it, you feel better informed of your rights as a family carer and the rights of your relative.

If you would like to speak to us about your individual situation, please do call us on our freephone number **0808 801 0448** or e-mail: familycarersupport@hft.org.uk

The Family Carer Support Service (FCSS) is a free national service for family carers in England who have an adult relative with learning disabilities and/or autism. As one of Hft's charitable projects, we are funded exclusively through voluntary donations and grants.

We support family carers to understand and exercise their rights, and to navigate statutory services including social care, health, education and welfare. We offer:

- one-to-one support by phone, email and letter
- regular workshops on topics affecting carers

Information about the Family Carer Support Service (FCSS) at Hft

- a wide range of family carer focused resources
- monthly e-news bulletins to people who have signed up to our mailing list

We occasionally respond to government consultations affecting family carers. We send information about these consultations to our members and incorporate their feedback in our response.

We also share lots of useful information on our social media channels.

- [Twitter: /HftFamilyCarers](https://twitter.com/HftFamilyCarers)
- [Facebook: /familycarersupport/](https://www.facebook.com/familycarersupport/)
- [Youtube: /user/familycarersupport](https://www.youtube.com/user/familycarersupport)

For more information or to see our other resources, please visit:

<https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/>

Glossary

Adult protection cases – a formal enquiry into suspected abuse or neglect of an adult.

Appointee/appointeeship – an appointee is someone who has been appointed by the Department for Work and Pensions to deal with a person's benefits because they are unable to manage them. Appointees are responsible for making and maintaining any benefit claims, and spending the person's benefits money in their best interests.

Authorised person – a person appointed to take on a local authority-funded direct payment on behalf of an adult who lacks capacity to manage it themselves.

Disability related expenditure (DRE) – costs that arise from a disability or long-term health condition.

Deputy/deputyship – a deputy is someone who has been authorised by the Court of Protection to make decisions on behalf of another person who lacks capacity. There are two types of deputy: **personal welfare deputy**; and **property and financial affairs deputy**. Personal welfare deputies can make decisions about the person's medical treatment and how that person is looked after. Property and financial affairs deputies can make decisions about the person's money and property.

Financial, weekly or client contribution – the amount of money an adult has to contribute towards the cost of their local authority-funded care and support.

Lasting power of attorney (LPA) – a legal document that allows 'attorneys' to help a person make decisions, or to make decisions on their behalf, if and when they lose capacity. Lasting power of attorney can only be granted if the person has the capacity at the time of application to instruct another person to manage their affairs. There are two types of LPA: **health and welfare LPA**; and **property and financial affairs LPA**. Health and welfare LPA gives attorneys the power to make decisions

Glossary

about the person's medical treatment and how that person is looked after. Property and financial affairs LPA gives attorneys the power to make decisions about the person's money and property.

Nominated person – a person nominated by an adult to manage their local authority-funded direct payment on their behalf. Under this arrangement the adult is still responsible for the direct payment.

Personal budget – the amount of money needed to meet a person's eligible needs, and also anything extra the local authority is willing (although not obliged) to fund. The personal budget is made up of local authority funding from adult social services.

Reasonable adjustments – a legal duty under the Equality Act 2010, whereby employers and public sector organisations must take all reasonable steps to ensure that people with disabilities are not placed at a substantial disadvantage compared to people without disabilities. Examples of reasonable adjustments include a school ensuring that it is fully accessible to students who use wheelchairs, or a GP offering double appointments to people with learning disabilities and/or autism.

Statutory duty – a law that a government organisation, or the staff members of that organisation, must obey.

Whole family approach – this is when local authorities think about a person's needs in the context of their whole family, and identify how other family members might be impacted by their needs.



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