



**The Challenging
Behaviour Foundation**

making a difference to the lives of people with severe learning disabilities



Adult Social Care (England)

**Support options, housing, personalisation
and living a good life**

CONTENTS

	Page
1. <u>INTRODUCTION</u>	3
2. <u>UNDERSTANDING YOUR RELATIVE’S RIGHTS</u>	5
3. <u>ASSESSING NEEDS AND CARE PLANNING</u>	9
4. <u>CHOICES</u>	14
5. <u>PLANS</u>	20
6. <u>FUNDING</u>	25
7. <u>REVIEWS, RE-ASSESSMENT AND REVISIONS</u>	33
8. <u>FREQUENT CHALLENGES</u>	34
9. <u>SAFEGUARDS</u>	38
10. <u>WHO CAN HELP?</u>	42
11. <u>APPENDIX 1: QUESTIONS TO ASK SUPPORT PROVIDERS</u>	44
12. <u>APPENDIX 2: CHECKLIST OF PLANS</u>	48

Case studies are fictional but based on real life situations and the Family Support Service’s casework.

Thank you to everyone who has contributed to this information pack and checked its accuracy.

1. INTRODUCTION



If your relative has a severe learning disability, it's likely that you'll be in contact with your local social care team to get the support and care needed for them or for yourself as a family carer.



You might already be working with a social worker but feel that your relative's needs or situation have changed

recently. It's important to make sure that their needs are recognised and properly addressed.

Family carers of adults with severe learning disabilities often want peace of mind knowing their relative's needs are fully understood and being met. You're not alone in wanting the best for them!

However, navigating adult social care can be overwhelming, that's why we've created this friendly and comprehensive guide to help you every step of the way.

Our aim is to provide you with the knowledge and tools you need to make the best decisions and ensure your relative gets the care they deserve. Whether you're just starting out or looking to expand your understanding, this guide covers everything you need to know about resources, rights, and responsibilities.

Inside, you'll find easy-to-follow advice on care assessments, eligibility, finances, and specialised services. We've broken down complex information into simple steps to make it easier for you to secure the right support for your family member.

The purpose of this pack is to provide information specific to the needs of families caring for individuals with severe learning disabilities who are described as displaying behaviours that challenge. It is hoped that it will provide the information families require as they navigate care and support for their relative.

If you are looking for information for children or young adults who are transitioning to adult services please see this dedicated guide:

<https://www.challengingbehaviour.org.uk/information-and-guidance/person-centred-support/resource-planning-for-adulthood/>

We hope the information in this pack is helpful.

If you need further support you can contact the Challenging Behaviour Foundation's Family Support Team who offer casework support to families navigating adult social care.

Contact us

- You can call the Family Support Service on 0300 666 0126
- Or email us at support@theCBF.org.uk

We are open at the following times:

- Monday – Thursday: 9am – 5pm
- Friday: 9am – 3pm

2. UNDERSTANDING YOUR RELATIVE'S RIGHTS

There are several pieces of legislation (Acts) which will be relevant to families who are supporting a relative with a severe learning disability. Knowing more about these Acts may help you when supporting your relative to use Adult Social Care Services. The [CBF Family Carer Advocacy Resource](#) also contains information on the relevant pieces of legislation.

The Care Act 2014

This law sets out how adult social care in England should be provided. Its focus is on wellbeing and prevention, promoting choice and control over how services are delivered. The accompanying [Care and Support Statutory Guidance](#) explains how the Care Act should work in practice.

Human Rights Act 1998

Human rights are basic rights and freedoms that belong to everyone. Having knowledge of the Human Rights Act will ensure you can identify if the care and support your relative receives breaches their rights and what you can do to take action.

Equality Act 2010

The Equality Act provides a legal framework to protect the rights of individuals and ensure equality of opportunity for all. The Equality Act protects individuals from unfair treatment.

Mental Capacity Act 2005

The Mental Capacity Act (MCA) applies to anyone aged 16 years and over. It protects people who have been assessed as lacking the mental capacity to make their own decisions about their care and support or treatment. It covers decisions about day-to-day things like what to wear or eat and other more complex life changing decisions like whether to move into a care home or supported living.

Autism Act 2009

The Autism Act placed a legal obligation on the Government to have a strategy for improving services for autistic adults, underpinned by providing statutory guidance to Local Authorities (LA).

MAKING DECISIONS

When an individual with learning disabilities becomes an adult, their family should still be involved in making decisions for them but the law no longer allows them to do so in the same way as when they were under 16. Most day-to-day decisions will be made by a family carer or paid support worker and will not usually be formally recorded, but bigger or more contentious decisions should follow a more formal process.

The Mental Capacity Act (2005):

- Applies to everyone over the age of 16
- Assumes that everyone can make their own decisions unless it is proved otherwise (i.e. they have the capacity to make decisions)
- Says that a person must be given appropriate support to help them make decisions, ensure that his/her wishes are taken into account and that preferred communication methods are used to explain the options available
- Says no one should be stopped from making a decision, just because someone else thinks it is unwise
- Looks at each decision a person needs to make separately. It may be that the person lacks capacity to make a particular decision e.g. where they should live, but this does not necessarily mean that the person lacks the capacity to make any decisions at all e.g. what to eat, wear and do each day
- Outlines the process for deciding whether someone has the capacity to make a specific decision.

The Act states:

- Professionals must consult with family members and take their views into account to make a best interest decision. Family members have the right to challenge professionals if they feel they are not consulted.
- If it is decided that someone lacks the capacity to make a decision and a decision is made for them, it must be in the person's Best Interest
- Best Interest meetings should be chaired by an appropriate person and a formal record should be kept of the process of working out the best interests of the person, it should provide details of how the decision was reached and what was taken into consideration.

continued:

- When a best interest decision is made for someone who lacks capacity, the decision must be the least restrictive option possible for the person e.g. locking a knife drawer instead of preventing access to the kitchen
- Ultimately families can ask for decisions to be referred to the Court of Protection and can apply for Legal Deputyship if they feel their involvement is limited.

ANNUAL HEALTH CHECKS

People with learning disabilities over the age of 14 are entitled to an NHS Annual Health Check in recognition that they may find it harder to communicate their symptoms or recognise changes in their body if they are becoming unwell. If your relative lives with you it is your responsibility to make sure they receive an annual health check. If they live in a registered care home, supported living service or their own home, it is the care provider's responsibility.

SOCIAL CARE ASSESSMENT

If your relative is 18 years or older and has an appearance of need for social care support, an assessment of their needs can be requested from the Local Authority social care team.

CARER'S ASSESSMENTS

Unpaid carers including family members have the right to request an assessment of needs for themselves. A carers assessment will consider what support carers might need to continue in their caring role.

ADVOCACY

There is a legal duty on Local Authorities to provide independent advocacy if no one appropriate is able to support an individual with a severe learning disability to be involved with their assessment, care and support planning or review of a care plan. Information about advocacy can be found in the [CBF Family Carer Advocacy Resource](#).

FURTHER INFORMATION

- **Making decisions: a guide for family, friends and other unpaid carers** (OPG 602) visit [OPG602 \(ouh.nhs.uk\)](https://ouh.nhs.uk/OPG602).
- **Using the Mental Capacity Act (2005). A resource for families and friends of people with learning disabilities.** Home Farm Trust. visit [Hft | Family Carer Support | The Mental Capacity Act](#) or telephone 0117 906 1700
- **Deputyship** [Deputyship - Challenging Behaviour Foundation](#)
- **Health Information** [Health - Challenging Behaviour Foundation](#)
- **Accessing Support with a Carers Assessment** [Accessing Support with a Carers Assessment](#)
- **CBF Family Carer Advocacy Guide** provides information for family carers who are advocating for or alongside their relative (aged 16 or over) [Family Carer Advocacy Resource - Challenging Behaviour Foundation](#)

3. ASSESSING NEEDS AND CARE PLANNING

If your relative is 18 years or older and has an appearance of need for social care support, an assessment of their needs can be requested from the Local Authority social care team.

WELLBEING

The **Wellbeing Principle** in the **Care Act (2014)** is central to the legislation's approach to adult social care in England. It emphasises promoting and safeguarding the wellbeing of individuals when making decisions about their care and support. The principle highlights that Local Authorities must consider the physical, mental, and emotional wellbeing of people needing care and their carers in all actions.

The act says, 'Wellbeing' is a broad concept which relates to the following areas:

- Personal dignity (including treatment of the individual with respect)
- Physical and mental health and emotional wellbeing
- Protection from abuse and neglect
- Control by the individual over day-to-day life (including over care and support provided and the way it is provided)
- Participation in work, education, training, or recreation
- Social and economic wellbeing
- Domestic, family, and personal relationships
- Suitability of living accommodation
- Contribution to society

Local Authorities have a legal duty to promote a person's wellbeing whenever they make a decision about their care and support.

ASSESSMENT

The Care Act (2014) sets a relatively low threshold for assessments, obligating Local Authorities to assess any adult who may require care and support. Typically, adults with severe learning disabilities are likely to meet these criteria.

Local Authorities must conduct assessments that are both proportionate and appropriate. Individuals with severe learning disabilities are entitled to request a face-to-face assessment, along with any other necessary reasonable adjustments.

Such assessments should be performed by either a social worker or a competent member of the social care team.

The assessment process is designed to collect information. You have the right to request a copy of the questions that will be asked during the assessment in advance. This can be particularly beneficial for those supporting someone with a severe learning disability, as it allows for adequate preparation. Keeping a diary of needs, including those currently met by unpaid carers, for a week or so before the assessment can be helpful.

It's crucial to communicate all the assistance, support, or prompting an individual with a severe learning disability requires, especially for activities that cause pain, distress, or anxiety. The Local Authority must document all areas where the individual requires assistance, as this affects funding eligibility.

Family carers should clearly articulate the extent of care they provide and whether they are willing and able to continue this support. It's important to note that Local Authorities cannot insist that family members provide care and support.

KEY POINT

Some Local Authorities may refer to a Needs Assessment by other names such as a Care Act Assessment, a Strengths and Needs assessment or a What Matters Assessment.

They may present the assessment paperwork in different formats, however, they should all identify eligible needs (see below for information on Eligibility Criteria).

ELIGIBILITY

The Local Authority must provide care and support for people who are assessed as eligible for such support under the Care Act (2014) **Eligibility Criteria**.

When assessing your relative, the Local Authority will look at ten key areas, or 'outcomes.' To qualify for support, your relative's needs must arise from or be related to **a physical or mental impairment or illness** and they must **be unable to achieve two or more of these outcomes**.

If your relative is unable to meet two or more outcomes, and it **significantly impacts their wellbeing**, these are '**eligible needs**'.

Outcome	Considerations
1. Managing and maintaining nutrition	Does the adult have access to food and drink to maintain nutrition, and is the adult able to prepare and consume the food and drink?
2. Maintaining personal hygiene	Is the adult able to wash themselves and launder their clothes?
3. Managing toilet needs	Is the adult able to access and use a toilet and manage their toilet needs?
4. Being appropriately clothed	Is the adult able to dress themselves and to be appropriately dressed, for instance in relation to the weather to maintain their health?
5. Being able to make use of the home safely	Is the adult able to move around the home safely, which could for example include not burning themselves with hot water from the tap or using kitchen facilities? This should also include the immediate environment around the home such as access to the property, for example steps leading up to the home.
6. Maintaining a habitable home environment	Is the condition of the adult's home sufficiently clean and maintained to be safe? A habitable home is safe and has essential amenities. An adult may require support to sustain their occupancy of the home and to maintain amenities, such as water, electricity and gas.
7. Developing and maintaining family or other personal relationships	Is the adult lonely or isolated, either because their needs prevent them from maintaining the personal relationships they have or because their needs prevent them from developing new relationships?

Outcome	Considerations
8. Accessing and engaging in work, training, education or volunteering	Does the adult have an opportunity to apply themselves and contribute to society through work, training, education or volunteering, subject to their own wishes in this regard? This includes the physical access to any facility and support with the participation in the relevant activity.
9. Making use of necessary facilities or services in the local community including public transport and recreational facilities or services	Is the adult able to get around in the community safely? Can they use such facilities as public transport, shops or recreational facilities and how might this impact on their wellbeing? Local Authorities do not have responsibility for the provision of NHS services such as patient transport, however they should consider needs for support when the adult is attending healthcare appointments.
10. Carrying out any caring responsibilities the adult has for a child	Does the person have any parenting or other caring responsibilities? The adult may for example be a step-parent with caring responsibilities for their spouse's children.

If your relative's needs meet the Care Act (2014) Eligibility Criteria, the Local Authority is legally obligated to ensure they receive the necessary support, regardless of budget cuts. Any needs that aren't being met by family or friends must be met by the Local Authority. This can be done either by arranging appropriate support services or through a 'direct payment.' See [page 26](#) for information about Direct Payments.

CARE PLANNING

Deciding how to meet your relative's needs happens during the Care Planning stage. You and your relative where possible, should be actively involved in this process, where you can discuss and explore various support options.

The Local Authority will also provide details of your relative's personal budget, which is the amount they've calculated to cover the cost of care and support. It's important to note that this budget must be sufficient to fully meet your relative's assessed needs.

Care Planning will result in the development of a Care and Support plan (see Part 5 of this resource).

If you are unhappy with your relative's assessment or eligibility decision see Part 6 below for information about how to complain.

KNOW YOUR RIGHTS

During the Care Planning stage, the Local Authority must follow the Mental Capacity Act (2005) and complete the plan in line with the Human Rights Act (1998).



BROKERAGE

Brokerage is a way people can be helped to navigate the social care system. Through brokerage people can be helped to gain access to, funding for and receive the care and support they need or can be helped to identify how these needs might best be met and at what cost.

Brokerage should ensure that the individual is fully involved and in control of choosing their own care package and its delivery. This is independent of whether people fund their own care or are supported in some measure by their Local Authority.

Brokerage can be provided by people who are specifically trained and employed as brokers or by members of the individual's family or friends who may not be paid to undertake the role. To find out more information about the Support Brokerage Network visit their website [About the Support Brokerage Network | Imagineer](#).

Some Local Authorities have their own Brokerage Team. Their role is the same as an independent broker and you should still be involved in planning how to meet your relative's needs. Information about how brokerage should work is here: [A short guide on brokerage and the role of brokers in relation to social care | Disability Rights UK](#).

4. CHOICES



HOUSING

Individuals with a severe learning disability who display behaviour described as challenging can, with the right support and adaptations, live successfully in a range of housing. This includes individual self-contained properties, housing networks, group homes,

and shared accommodation schemes and they can benefit from the full range of accommodation options, from renting to home ownership.

Probably the biggest decision you will need to make is whether a registered care home, supported living or staying in the family home is the best option for your relative. The main advantages and disadvantages of each are set out below:

Residential Care Homes

In the past, a residential care home was virtually the only option available to people with severe learning disabilities and behaviour described as challenging, apart from living with their families. A common approach was for the Local Authority to search for an existing residential home that had a vacancy and was willing to take the individual. However, the culture of 'fitting the person into what is available' has gradually been changing, and forward thinking residential care home providers are much more flexible and person-centred than they were in the past.

A residential care placement provides a 'complete' service of accommodation and care support.

The **advantages** of this approach include:

- A complete, 'all-in-one' package
- The service is usually up and running and can be viewed
- There is a contract with the Local Authority specifying what is provided
- The home is inspected regularly by the Care Quality Commission (CQC) against a range of standards

The **disadvantages** of this type of service include:

- If there are any difficulties, the service provider can terminate the contract and the person has to move out
- The individual is unlikely to have any say over who else lives there

- The individual is likely to have to share facilities with others who live there e.g. kitchen, bathroom, lounge etc
- The service provider determines the future direction of the service (e.g. expanding, closing, changing)
- The Local Authority will require the individual to contribute most of his/her benefit income to cover the cost of food, bills, and housing. As a result the individual will be left with a small personal allowance

If you are considering a residential care home placement for your relative, you should obtain a copy of the contract with the Local Authority to ensure you are aware of what should be provided, and a copy of the most recent CQC inspection report. CQC inspection reports are available from the CQC website: www.cqc.org.uk.

Supported Living

Supported Living is an individualised approach that enables people to choose where they live, how they live and who supports them. Supported Living means that an individual's accommodation is separate from their care support.

The **advantages** of this approach include:

- The accommodation and the care support required can be tailored to specific individual need
- The accommodation is the individual's own home, either by tenancy or ownership/shared ownership ([Shared ownership is a scheme whereby people part buy and part rent the property they live in](#)).
- The individual can claim housing benefit and other benefits
- The individual can choose who provides their care support
- The individual is in greater control of both their accommodation and their care support. As accommodation and care are separate, it means that the person can have security of tenure, cannot be moved against their will, and may be able to change their care provider if they so wish

The **disadvantages** of this approach include:

- It can be daunting/difficult to make it happen
- It can take time and effort to set it up and find suitable accommodation and a provider that can meet your relative's needs
- This is not a complete package; accommodation and care support are provided separately
- Some Supported Living services cluster people together and insist they all receive care from the same provider

Staying in the Family Home



Many young people do not move out of their family home at 18, and it is likely many individuals with severe learning disabilities and their families will choose to remain living together at least for a few years. This may involve using care services to provide support within the family home. It may also involve some minor or even major adaptations to the family home.

The **advantages** of remaining in the family home include:

- It may be the preferred and most logical option for everyone
- The individual will already be familiar with the environment
- It will allow the benefits and comforts of family life to continue alongside funded support

The **disadvantages** of remaining in the family home include:

- Uncertainty as to what will happen when relatives get older
- It can feel intrusive to have paid carers working to support your relative in your family home
- There may be a negative impact on other members of the family

Deciding where your relative lives is a very personal decision: it is important that the person is treated as an individual, they are supported to contribute as much as possible to the decision and the situation is constantly reviewed with the individuals' needs to make sure they are being met.

When you are choosing and visiting potential providers of services, or have identified a potential care provider, we have co-produced a list of questions to ask support providers – see Appendix 1 below.

FURTHER INFORMATION

Housing Support

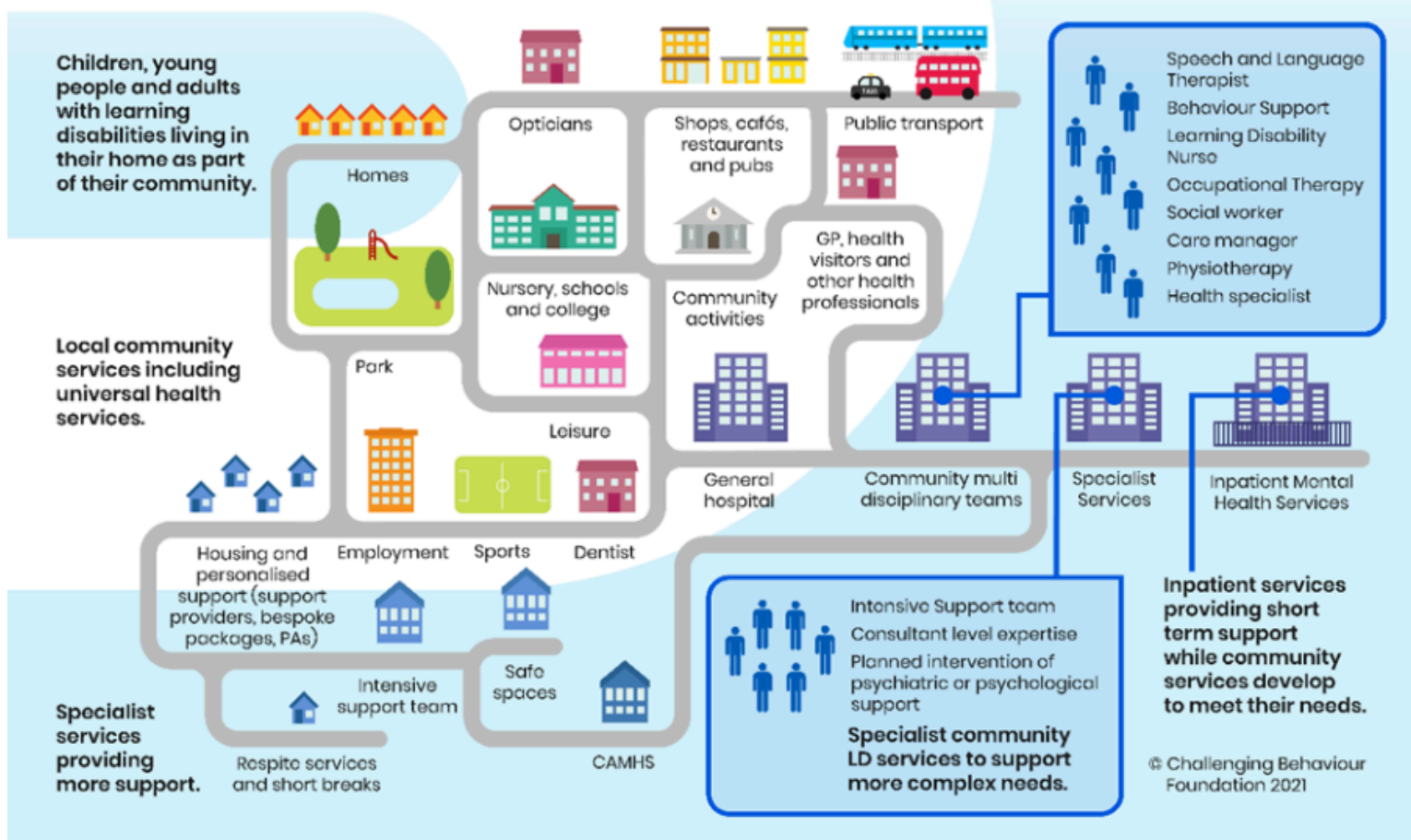
- [8 Ways to get a house](#) and [Planning your house](#): Two guides to help you with thinking about types of accommodation and planning living arrangements.
- [Challenging behaviour: a guide for family carers on getting the right support for adults/teenagers](#): Two guides produced by the SCIE and CBF that cover what family carers should expect from local services. Available from the Challenging Behaviour Foundation. Free to family carers. Telephone 01634 838739, e-mail info@thecbf.org.uk or visit www.challengingbehaviour.org.uk.
- [Learning Disability England](#): A national charity with a range of housing resources.
- Behaviour: A guide for family carers on getting the right support for adults: [Hft](#) Provides local support services for people with learning disabilities throughout England.
- [CBF and PBS Academy resources: Questions to ask to check Positive Behavioural Support \(PBS\) is being used well](#): Includes a PBS checklist for family carers which can be used when considering a school, a Local Authority, a day service or any other setting that could potentially provide PBS to support an individual with learning disabilities.
- [CBF Resource: Everybody Matters DVD](#): Colleen and Shaun's stories show that everyone can be supported to live a full and active life in their community.
- [Advance Housing & Support for People with a Disability or Mental Health Condition](#) (advanceuk.org): provide housing, support and other community related services, specialising in supporting people with learning difficulties and mental health conditions.
- [Mencap](#): Find out about housing advice, support and services you can access.
- [Shared lives plus](#): A scheme where an adult or young person who needs long term support is matched with a carefully approved Shared Lives carer, by their local Shared Lives scheme which are run or commissioned by the Local Authority's adult social care services.
- [Local Government Association](#): Housing for people with a learning disability or autistic people.



ACCESSING THE COMMUNITY AND DAY SERVICES

Individuals with learning disabilities have the same rights as everyone else including accessing community services such as the doctors, shops and restaurants. Appropriate support should be provided in order for individuals to exercise those rights.

Good community support for children, young people and adults with learning disabilities is...



There are traditional day services which offer a range of support activities in the local community. However, all services in the community have a duty under the **Equality Act 2010** to make reasonable adjustments to enable people with disabilities to access them. Your relative's care and support plan should include community-based activities and the practical help and support required to access them.

There are also clubs and events that are specifically designed for people with learning disabilities. These include:

- Sports clubs
- Art and music groups
- Autistic friendly cinema screenings and theatre performances
- Nightclub events

KNOW YOUR RIGHTS

The **Equality Act (2010)** gives disabled people important rights of access to everyday services provided by local Local Authority, doctors' surgeries, shops, hotels, banks, pubs, post offices, theatres, hairdressers, places of worship, courts and voluntary groups such as play groups. Access to services is not just about physical access, it is about making services easier to use for everybody. Service providers have an obligation to make **reasonable adjustments** to premises or to the way they provide a service. To find out more go to www.equalityhumanrights.com.

FURTHER INFORMATION

Support with leisure activities:

- [Mencap](#): Local Mencap groups offer support and activities.
- County Sports Partnership: You can contact CSP about local sporting and volunteering opportunities. Visit activeblackcountry.co.uk
- [Parasport](#): where you can search for disability sport and physical activity in the local area.
- [UK Sports Association For People With Learning Disability \(SportExcel UK\)](#).
- [Stay up Late](#): learning disability campaign promoting access to nightlife – because life doesn't stop at 9pm.
- [Books Beyond Words](#): run book clubs for people with learning disabilities, to enjoy books without words in a social environment.

5. PLANS

CARE AND SUPPORT PLANS

The assessed needs of your relative must be accompanied by a Care and Support Plan which clearly states what their needs are and how their needs will be met.

A copy of the Care and Support Plan should be shared with you as your relative's representative as this is nearly always in the individual's best interests (see above for information about making best interests decisions). A copy should always be shared with your relative's advocate.

The Care and Support Plan written by Adult Social Care is a legal document. If a Local Authority fails to provide Care and Support Plans and proper explanations, they are not complying with the law.

A Care and Support Plan (sometimes called a 'care plan') must explain:

- What care is to be provided
- Who will provide the care
- How it will be provided
- When it will be provided.

Local Authorities can't have blanket policies that they don't do certain types of social care support services (e.g. 'we don't provide help with bathing unless this need is verified by a doctor's note' or 'we don't provide travel support anymore' or 'we don't provide evening (or weekend) services' and so on).

The law requires that a person's eligible assessed needs have to be met. Personal Budgets cannot be used to impose limitations of this nature – so Local Authorities cannot have 'upper limits' on the amount of financial support that can be provided: a person's assessed needs must be met, regardless of their cost.

However, you should bear in mind that the Local Authority can take the cost of services into account when commissioning services. For example, if there are two services that can meet your family member's assessed needs, the Local Authority could choose the cheaper option. If this happens and you think that the more expensive service would be better for your family member, you would need to prove that it would meet the needs of your relative and that the cheaper option would not, or that the more expensive option offers better value for money.

KEY POINTS

Look through your family members Care and Support Plan to ensure all of your relative's assessed needs are included.

Check the Care and Support Plan and think about how it might affect their wellbeing. If there is anything in their care plan that will have a negative effect on their wellbeing, you can challenge it.

If you are unhappy with your relative's Care and Support Plan, see Chapter 6 below for information about how to complain.

SUPPORT PLANS (NOT TO BE CONFUSED WITH CARE AND SUPPORT PLANS!)

If your relative is supported by carers in the home, at a day centre, in a residential care setting or supported living service, the care provider should also have a Support Plan. This is not a legal document; however, it should provide details of your relative's needs and how they should be met on a daily basis. Depending on the setting where your relative is receiving support, it should contain important information such as;

- their communication needs,
- details of their likes and dislikes,
- support to ensure their dietary needs are met,
- leisure activities they enjoy or places to avoid due to 'triggers'
- their morning, evening and nighttime routines,
- how personal care needs are supported (preferences for baths or showers, how they have the have their hair or nails cut).

It may help if you start writing down everything your relative needs their support team to know, to ensure it is all contained within the plan.

The Support Plan should be written in collaboration with you and those who know your relative well. The support team should have access to the plan to ensure they have knowledge and understanding of your relative's needs and some care providers have a 'read and sign' system which provides evidence that the team have read the plan for the person they are supporting.

The Support Plan should also be regularly reviewed as your relatives circumstance and preferences can change.

POSITIVE BEHAVIOUR SUPPORT PLAN (PBS PLAN)

A positive behaviour support plan is a written plan based on a functional assessment of behaviour which contains different strategies designed to alter the environment and teach new skills to reduce challenging behaviours and increase quality of life.

The plan should reflect the person's needs and contain both proactive and reactive strategies to manage behaviour safely and to ensure that the least restrictive strategies are used.

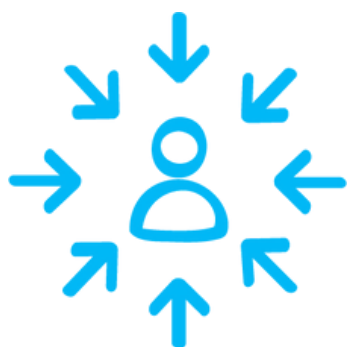
Everybody supporting your relative should follow the behaviour support plan to ensure a consistent approach across all settings (eg. home, day centre, respite centre). There should be regular reviews of the plan. For more information see the CBF's Positive Behavioural support webpage [here](#).

EDUCATION HEALTH AND CARE PLAN (EHCP)

Your relative may have an Education Health and Care Plan if they remain in education over the age of 18 years with SEN or disabilities. The EHCP should contain details of their education, health and care needs and Section H of the plan may contain details of social care that they are receiving.

For more information on Special Educational Needs and Disabilities system, please read the CBF's information on [Getting an Education, Health and Care Plan \(England\)](#).

PERSON CENTRED PLAN (PCP)



What is a PCP?

A PCP ensures that an individual remains central to any plans made for their life, including their transition to adulthood. The PCP process is owned and controlled by the person (and sometimes their closest family and friends). It begins with the needs of the individual, and not with the availability of services.

What should a PCP include?

It includes a positive 'vision' of what life should look like for the individual, focusing on the individual's strengths, abilities and preferences. A PCP should also include the support needed to achieve the vision, maintain it, evaluate and review it. The plan can then be used to help obtain the services, and support, that the individual requires to achieve their 'vision'. The plan should be regularly reviewed and added to over time to keep it relevant and useful.

Why is a PCP so important?

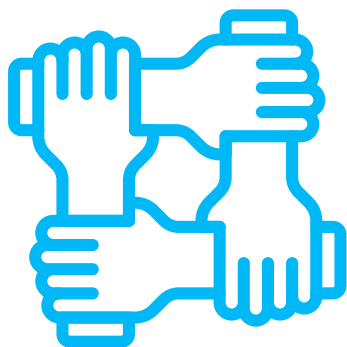
It focuses on core human rights such as having choices about the way an individual lives, being able to live as independently as possible and feeling included in society. Person-centred planning moves away from the philosophy of labelling an individual and instead focuses on their strengths, aspirations and quality of life.

Who should be involved in developing a PCP?

A range of people should be involved in creating the plan, including family, friends, support staff, an advocate and social worker as well as the individual themselves.

Your Social Worker or Care Manager will be a key person who can co-ordinate the process and ensure that all those who should be involved are included. They will be able to provide information about local services, support and opportunities. Should you have any concerns about your son/daughter's current support and services, they will be the best people to contact in the first instance. If you do not feel that your concerns have been adequately dealt with then you should raise this with their manager.

Your local **Learning Disability Partnership Board** oversees all Learning Disability services in your area (your Local Authority will be able to provide you with the Learning Disability lead contact who will have information about the Partnership Board). Your Partnership Board is responsible for ensuring that people with Learning Disabilities are included in the Local Authority's plans and are receiving the services they are entitled to.



CIRCLES OF SUPPORT

It is useful to have a circle of support when putting person centred planning in motion. This is where people who care about the individual such as family and friends can meet together, to discuss what's working and not working in a person's life.

The meetings are often informal and personalised to the needs of the individual and the group. They provide a great way of focusing on the personal needs of the individual, as well as improving communication between families and professionals.

KEY POINTS

The key points to remember when you are trying to champion local individualised services or support for your family member are:

1. **Aim high.** Engage your relative in any way that is meaningful and appropriate and think about what an 'ideal' scenario for your relative would be. It may be that not all aspects of this vision will be achieved, but at least some will be.
2. **Identify allies** that can help and support you (The CBF is one!).
3. **Think creatively.** Don't accept that you can only choose from what is currently available.
4. **Don't give up** if you encounter barriers - barriers can be overcome.
5. **Find out what other families have done.** The CBF [Family Carers' Email Network](#) enables you to be in touch with a number of families around the UK. You can share experiences, information and receive support - without any obligation to reply or to identify yourself.

FURTHER INFORMATION

- [Circles of Support - Do I have to go this alone?](#)
- The National Autistic Society: [Making transition decisions](#)
- [Helen Sanderson Associates](#) or email: info@helensandersonassociates.co.uk
- [Foundation for People with Learning Disabilities](#)
- [CBF Family Carer Advocacy Resource](#) provides information for family carers who are advocating for, or alongside their relative (aged 16 or over)

6. FUNDING

There are a range of ways that your relative's care and support might be funded across education, health and social care. Your relative's support may be funded by one or more sources and their Social Worker should be able to explain the options available.



PERSONAL BUDGETS (SOCIAL CARE)

The Local Authority has a duty in law to meet an individual's eligible social care and support needs. The sum of money provided in order to do this is called a Personal Budget. Since the Care Act (2014) came into force, the Local Authority must give everyone who has eligible needs a personal budget, giving people greater

choice and power to make their own decisions about how their needs are met. The Local Authority will tell you how much they think you are entitled to (this is known as an indicative budget) before you look at the Care and Support plan being created.

The final allocation of the Personal Budget will be decided through the planning process and when the plan is 'signed off' by the Local Authority. Everyone involved should have transparent information about how the Personal Budget is calculated and how much money is in it. The money must be able to fund support to meet all individual's eligible needs – this means that the final amount may be more than the indicative budget.

You should also have a choice about how this Personal Budget is managed. There are several options:

- The money can be managed by the Local Authority who will purchase and organise the care and support, in line with the individual's needs and wishes.
- A third party known as an Individual Service Fund (ISF) can also be chosen to manage the personal budget. The person (and/or their family, advocate or carer) can choose an organisation to manage the budget on their behalf and work with them to plan care and support services and activities that will help them to meet their eligible social care needs. You can find more information [here](#).

- It can be managed directly by the individual or by someone on their behalf, like a family member, if the person does not have the capacity to manage their care package. This is known as a Direct Payment, for more information about Direct Payments, see below.
- It can be decided that the personal budget is a “mixed package”: a combination of any of the three – whatever works best for the person to get their needs met!

KNOW YOUR RIGHTS

The **Care Act (2014)** states that Care and Support Plans for people over 18 must include a personal budget

DIRECT PAYMENTS

Part, or all, of the personal budget can be made available to the individual (or a relative if the person lacks the capacity to manage it) so they can plan and finance their support themselves. You can do this by requesting a Direct Payment, and Local Authorities should support people in making such a request. This means that the person and/or their family or circle of support is given the money, purchases the support they want and is in control of the services providing support. You cannot be forced to accept Direct Payments and can only be prevented from doing so in very specific situations. However, the Direct Payments can only be used to meet your relative’s eligible care and support needs.

If you use a Direct Payment to purchase care directly and employ Personal Assistants, you may become an employer. This could include paying wages and arranging contracts with employees. Any extra legal costs incurred by becoming an employer should be included in the personal budget. This can be appointed to a third party, such as a family member, who can organise the ‘business’ end. The Local Authority should support people to use and manage their direct payments to commission and buy the care they need.

If someone lacks the mental capacity to request direct payments in order to meet their care needs, another person such as a family member or friend can request direct payments on their behalf.

DIRECT PAYMENTS FOR ADULTS LACKING THE CAPACITY TO CONSENT

All Local Authorities have a duty to offer direct payments to eligible adults who lack the capacity to consent to receive them. When an adult lacks capacity to consent, a Direct Payment can be made to a willing and appropriate ‘**suitable person**’, such as a family member or friend.

This person must be deemed as someone who will act in the person's best interests, be capable of managing the payments, and of using the funding to meet the individual's needs. The family member or friend then receives and manages the payments on behalf of the person who lacks capacity.

The **Mental Capacity Act (2005)** must be followed when Direct Payments are arranged for someone who is unable to make decisions about how their care is funded. The Mental Capacity Act (2005) is explained in more detail in the [CBF Family Carer Advocacy Resource](#).

The Local Authority can also agree to make the funding available to a Trust or a Deputy appointed by the Court of Protection.

- **A Trust** is a legal arrangement of a group of at least three people 'the Trustees' who will own and manage money and/or property for the benefit of another person. Trustees take responsibility for organising, managing and monitoring a person's funds on behalf of a person who lacks capacity to receive and manage a Direct Payment. Trustees set up a bank account in the Trust's name to receive payments and have legal obligations to fulfil. Trustees can only act jointly and unanimously in decisions regarding trust funds.
- A Property and Affairs **Deputy** is someone appointed by the Court of Protection to make decisions in the best interests of people who lack capacity. This type of Deputy can make specific on-going decisions as set out by the Court on behalf of the person e.g. to manage their bank accounts, to sign tenancy/mortgage forms or to receive a Direct Payment. One or more family member can take on this role, or another responsible person appointed by the Court. Additional information can be found in the [CBF's guide to Deputyship](#).

CONTINUING HEALTHCARE (NHS) FUNDING

Continuing Healthcare funding is provided solely from NHS as part of a care package for anyone outside of hospital who has a continuing primary health need. This funding is used to meet health and related social care needs such as residential home costs, therapy, personal care etc. Eligibility for NHS Continuing Healthcare is determined through the use of a Decision Support Tool which looks at your relative's level of need in 12 domains.

KNOW YOUR RIGHTS

The Decision Support Tool Guidance with details of the 12 domains can be found at [NHS Continuing Healthcare Decision Support Tool Guidance](#)

The NHS is divided into local Integrated Care Boards (ICB) who plan and pay for local healthcare so you may hear CHC funding referred to as ICB funding.

PERSONAL HEALTH BUDGETS

A personal health budget is an amount of NHS money that is allocated to support your relative's health and wellbeing needs. If they are eligible, your relative (or a family member or carer), will work with your local NHS team to plan how to spend the money and get the care they need. A personal health budget allows you to manage your relative's healthcare and support such as treatments, equipment and personal care, in a way that suits them.

If your relative is eligible for Continuing Healthcare, a personal health budget works in a similar way to the personal budget in Social Care, where a care plan is devised with the person that identifies how this money will be used to meet their health needs. The money can be managed in a range of ways including by the NHS, a third party or in the form of direct payments. Personal Health Budgets are available for people who do not receive Continuing Healthcare if they have other health needs at the discretion of the ICB.

JOINT FUNDING

There may be some people who will have eligible social care needs and eligible health needs that both need to be met. In such cases, these people will be eligible to have care packages funded jointly by the NHS and their Local Authority. The introduction of Personal Health Budgets, similar to Personal Budgets in social care, means that it is much easier to pool these budgets together.

The Local Authority should provide information to the individual about the possible benefits of joint funding, as well as drive integration with health professionals to combine funding when possible. Joint funding should not lead to duplicate processes or increased monitoring. In cases where an individual's care package is jointly funded, the Local Authority should 'take the lead' to oversee monitoring and assurance. The Local Authority should agree with the NHS how integration should occur, and to what extent.

For example, the proportion each funding body provides can be equal, or different.

Integrated Care Boards (ICBs), are encouraged to develop Integrated Personal Commissioning where all health and social care support will be fully joined up. More information on the IPC sites can be found [here](#).

DISABLED FACILITIES GRANT (DFG)

A person with a disability who owns the property they live in, or is a tenant, may qualify for a disabled facilities grant. This can go towards the cost of providing adaptations and facilities that enable the disabled person to live independently and safely in their home, as well as to make caring for them easier. Such grants are given by Local Housing Authorities.

For a person under 19 years the grant is not means tested, but a financial assessment will be conducted for those 19 or over. If the disabled person is on certain benefits, they will not normally have to make a contribution.

Contact your local Housing or Environmental Health department of your local Local Authority for more information or visit their website [here](#).

BENEFITS

- [Universal Credit](#) – payment to help with living costs if you are on a low income, out of work or you cannot work.
- [Employment and Support Allowance \(ESA\)](#) – a benefit for people who have a disability or health condition that affects how much they can work.
- [Personal Independent Payments \(PIP\)](#) – available for 16–64 year-olds to help cover the costs of long-term ill health and disability.
- [Carers Allowance](#) – if you care for someone at least 35 hours a week and they get certain benefits.

Employment can affect the benefits an individual receives, and there are regulations about the type and amount of work someone can do without losing out financially. The Jobcentre Plus can give you more information about the regulations. See their [website](#) or telephone your local office.

CHARGING AND FINANCIAL ASSESSMENTS

If your relative is funded by Continuing Healthcare they will not need to contribute towards the cost of their care. This is because NHS services are free at the point of receipt.

If your relative is funded by the Local Authority, they will need to carry out a financial assessment of your family member's income and assets.

They will calculate how much an individual can afford to pay towards the cost of their care and support. Your family member must still be left with some money for themselves:

- **Personal Expenses Allowance (PEA)** is a minimum weekly amount an individual living in a care home is assumed to need for personal expenses.
- **The Minimum Income Guarantee (MIG)** is the amount of money an individual can keep to cover living costs if they live in another setting other than a care home eg. Supported Living Accommodation.

These amounts can change each financial year.

Your relative will only ever have to pay as much as they are assessed as being able to contribute. For example if your relative must contribute £50 this will stay the same regardless of whether the cost of their care is £50 or £5000.

If your relative's income changes you should ask for a new financial assessment.

KNOW YOUR RIGHTS

For more up to date information on Personal Expenses Allowance and Minimum Income Guarantee see Chapter 8 of the [Care and Support Statutory Guidance](#).

You can also obtain information [here](#).

DISABILITY RELATED EXPENDITURE (DRE)

As part of the financial assessment carried out by the Local Authority, consideration should be given to extra costs that arise as a result of your family member's disability. For example, if your relative needs several changes of clothes each day and has additional costs for laundry, wear and tear to clothing or the washing machine and tumble drier.

The Local Authority must take these costs into account when deciding how much your family member must pay towards the care costs.

In practical terms this means that these costs will be deducted from the total amount your relative will be required to pay.

The Care Act (2014) and the Care and Support Statutory Guidance from the Department of Health and Social Care does not provide an exhaustive list of what should be considered as DRE but costs could include:

- Cost of specialist items
- Entry to specialist activities
- Accessing local amenities that promote inclusion if stated in the Care Plan
- Additional cleaning materials/laundry detergent due to soiling/urinating
- Above average usage of gas/electricity/water due to additional laundry
- Special clothing/special bedding
- Cost of special dietary products
- Cost of replacement items caused by challenging behaviour.
- Transport costs to places specified in your relative's care plan

The amount of DRE deducted from your care costs should be based on your actual costs, not a standard allowance that is given to everyone with care and support needs.

KNOW YOUR RIGHTS

For more up to date information on Disability Related Expenses see the [Care and Support Statutory Guidance Annex C](#)

For more information and to make sure Disability Related Expenses are being considered when the Local Authority completes their assessment, the CBF has an [information and resource sheet](#). There is also a [template letter](#) you can use to request a DRE assessment.

FURTHER INFORMATION

- [Personal Budgets and Direct Payments nhs.co.uk](#)
- [Direct payments: frequently asked questions](#) available free from, the Social Care Institute for Excellence ([SCIE](#))
- [Independent Lives](#) provide a range of support services to help manage direct payments including advisors and payroll services for personal assistants

Continued.

- [Penderels Trust](#) offers a number of services to support people make the most of their personal budget/direct payment, from advice and guidance when employing a personal assistant to money management and training. Email enquiries@penderelstrust.org.uk
- Information on Deputies and The Court of Protection including information booklets and application forms is available from [The Office of The Public Guardian](#)
- Becoming a Deputy: information sheet '[Getting legal authority to make decisions about money](#)' available from the CBF
- [Support Brokerage Network](#): Support Brokers act as independent facilitators working alongside people, supporting them to plan to live the life of their choice
- [Citizens Advice Bureau](#) can advise you about what benefits you are entitled to .

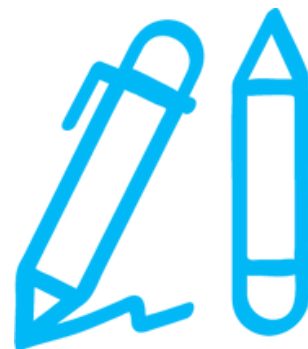
7. REVIEWS, RE-ASSESSMENT AND REVISIONS

REVIEWS

Once the Care and Support Plan is in place, it should be kept under review 'generally'.

The Care and Support Statutory Guidance states that the Local Authority:

- should conduct a periodic review of all care plans no later than every 12 months, whether a request is made or not;
- must also carry out a review when information or evidence arises that suggests that the person's circumstances have changed in a way that might affect the appropriateness of the care plan;
- should consider a 'light touch' review 6-8 weeks after a care plan is agreed and signed off.



REASSESSMENTS

If the circumstances, support or services change, your family member's needs should be re-assessed.

If a re-assessment of needs has been completed. Family carers should be consulted over this.

REVISIONS

Following a re-assessment the Care and Support Plan should then be revised.

If a re-assessment has not been completed, you can challenge any cuts as it is unlawful to reduce (revise) support or services without a re-assessment.

Your family member should not be left without support whilst a dispute is being resolved.

8. FREQUENT CHALLENGES



It is important to ensure that the process of developing appropriate adult services is well-planned and carefully managed and brings together all the people who have an interest in the individual. However, this can be a complex process, particularly for people with who may display challenging behaviour. There are many reasons for this, and the table below shows some of the most common difficulties you may face – with some of the keys to tackling each issue set out alongside.

For support challenging any of these issues, contact the CBF Family Support Service on 0300 666 0126 or email us at support@thecbf.org.uk

The 'problem'	The solution
Encountering a 'fit the person into what's available' approach rather than a person-centred approach.	Challenge this! There are many examples where a person-centred approach has proved to result in an improved quality of life for individuals with complex needs, and the law says the individual's aspirations and needs must be taken into account when planning their care and support.
Lack of appropriate choice in existing housing opportunities.	There are a number of organisations who can advise on a range of housing opportunities. Visit Transform Housing & Support or Shelter . Also check your Local Offer.
Lack of funding to meet high costs of support.	The law says that a disabled person's assessed needs which meet the national eligibility criteria must be met. Use the CBF Family Carer Advocacy resource to advocate for your relative.
Lack of adequate support to access mainstream Further Education opportunities.	People with disabilities have the same rights as everyone else to continued education. Local Authorities have responsibility to improve the range of further education opportunities for young people with learning disabilities up to their 25th birthday. IPSEA have information here: Young people (aged 16-25) (IPSEA) Independent Provider of Special Education Advice . Ask what action is being taken in your area.

The 'problem'	The solution
Lack of appropriate daytime opportunities including employment.	By using personal budgets and direct payments, people can be supported to access existing community facilities and employment opportunities. You can also ask your Local Authority to address gaps in their local offer. This would involve commissioning new, more specialised services.
Lack of appropriate choice in care support opportunities.	There are a number of ways to address this: many care provider organisations will work with you to find flexible and person-centred solutions, or you can employ your own staff team using direct payments.
Difficulty for families to get their relative's health needs met or to get reasonable adjustments made	Parents can challenge this by referring to their legal entitlements. If your relative does not have mental capacity, parents have the right to be involved in decisions regarding their health. Also refer to the Equality Act (2010) which states services must make reasonable adjustments if there are barriers to accessing that service.

CHALLENGING A LACK OF APPROPRIATE SERVICES OR SUPPORT

Local authorities are responsible for developing support and services to meet the specific needs of their communities. However, it's often quicker and easier for Local Authorities to place people in existing, generic services rather than create individualised local care and support options. When a disabled person's needs can be best met by local services, Local Authorities must actively work to make those services available. This could involve, for example, urgent discussions with private providers to expand the availability of suitable local options.

In cases where Local Authorities claim there is no appropriate service within the area, they cannot simply say, "You'll have to use a service outside our area or arrange something on your own with a Personal Budget."

OUT-OF-AREA PLACEMENTS

When there aren't local services available, Local Authorities often place people in specialist services outside the local area. While these placements might meet the individual's needs, they can have significant consequences:

- They may impact family contact and involvement due to distance.
- They can prevent the growth of local expertise and the development of inclusive services.

With person-centred approaches now widely recognised, it is increasingly possible for people with severe learning disabilities and complex needs to receive quality support within their local communities. A Local Authority committed to person-centred support should be prepared to develop specialised, local options that meet the specific needs of each individual. If the only option you are offered is out-of-area, consider challenging this decision.

Conversely, some Local Authorities may pressure disabled individuals in out-of-area placements to return locally, even if they are settled and prefer to remain where they are. This can also arise if a Local Authority refuses to fund care outside its area, such as respite care, even if it is ideally suited to the person's needs. For those in out-of-county placements, this location is their home under Article 8 of the European Convention on Human Rights, and under the Care and Support and Aftercare (Choice of Accommodation) Regulations 2014, individuals have the right to choose—or, if they lack capacity, have chosen on their behalf—the location of their care home, supported living arrangement, or Shared Lives placement, even if it is outside the Local Authority's jurisdiction.

HOSPITAL PLACEMENTS AND THE MENTAL HEALTH ACT

There are some situations where your relative may be placed in an inpatient unit. There are different ways an individual may end up in a hospital placement:

- They have been detained under the [Mental Health Act \(1983\)](#) ('sectioned').
- They have agreed to enter as a voluntary/informal patient for assessment and treatment.
- Placed in a hospital with a Deprivation of Liberty Safeguards authorisation in place. This applies when the individual lacks capacity but detention under the Mental Health Act (1983) is inappropriate.

Although a hospital placement may be helpful short term for specific reasons, it is not a suitable, long-term home.

FURTHER INFORMATION

- [Meeting the Challenge: My family member has been sent to an inpatient unit – what do I need to know?](#)
- [Building the Right Support](#): A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. It has been developed jointly by NHS England, Local Government Association and the Association of Adult Social Services

HOW TO COMPLAIN

If you need to complain about your Local Authority adult social care department you should contact them either online or by writing to them. Most Local Authorities have a complaints form you can complete and submit online.

Once they have received your complaint, the Local Authority should give you information about the complaints process, explain what will happen to the complaint and how long the process will take.

Sometimes the Local Authority will ask for additional time to investigate a complaint and you may need to provide documents or further information. Alternatively, you can contact the Monitoring Officer at your Local Authority. They have a duty to ensure Local Authority fulfil its statutory duties. Details for the Monitoring Officer can usually be found on your Local Authority's website.

If you are not happy with the response you receive from the Local Authority, you can complain to the Local Government Ombudsman (LGO). You should usually complain to the LGO within 12 months of becoming aware of the problem.

For more information on complaining to the LGO and details of what they can and cannot do, see the LGO webpage [How to complain about adult social care and support](#).

If providing feedback, raising a concern or making a complaint has been unsuccessful in bringing about change or the law is not followed, there may be a need to involve a solicitor to ensure your relative's and your (family carer) rights are met. For more information about Making a legal challenge please see the Family Carer Advocacy resource pages [When things go wrong](#).

9. SAFEGUARDS



Individuals with severe learning disabilities whose behaviour is described as challenging are at increased risk of abuse. Abuse can take many forms, from the more obvious e.g. physical abuse to the less obvious e.g. financial or emotional abuse. The risks are increased because:

- They are likely to have poor communication skills
- Their behaviour is described as challenging
- They are likely to be dependent on others for day-to-day support

It is therefore essential that services and supports for individuals who have severe learning disabilities who display challenging behaviour are person-centred and understand why the person behaves as they do.

Different service providers may have different approaches to supporting people who display challenging behaviour. It is important that you check out the approach used by any service that you are considering using by asking for a copy of any policies relating to behaviour before you agree that it is suitable for your relative.

Services should have appropriate monitoring mechanisms in place to minimise the risk of abuse, detect potential abuse, highlight indicators of abuse and be aware of and prevent closed cultures. In addition, a number of other safeguards can be put in place to protect individuals.

STATUTORY REQUIREMENTS

1. Policies & procedures

The following policies and procedures should be in place and regularly reviewed and updated, with copies available on request:

- A comprehensive adult protection policy
- Behaviour management policy
- Physical intervention policy
- Risk assessments

In addition, there should be a clear complaints procedure. Complaints should be formally investigated, and findings acted upon.

2. Monitoring and Inspection

Services are checked by agencies to ensure correct procedures are in place to protect vulnerable individuals. Services for adults are inspected by the [CQC](#) (Care Quality Commission). Services for children (e.g. residential schools) are inspected by [Ofsted](#) (the Office for Standards in Education, Children's Services and Skills). Families should report concerns to the CQC. The CQC inspection framework consists of four key lines of enquiry:

- Is the service safe?
- Is the service effective?
- Is the service caring?
- Is the service responsive?
- Is the service well led?

Services can then be given one of four ratings; outstanding, good, requires improvement or inadequate. Inspection are available.

3. Staff checks

The Disclosure and Barring Service (DBS) is a UK agency that helps employers make safer recruitment decisions and prevent unsuitable people from working with vulnerable groups, including children. The DBS process requests criminal records checks and decides whether a person should be placed on or removed from a barred list. The DBS was created as a replacement for the Criminal Records Bureau and the Independent Safeguarding Authority.

By making statutory checks against the list, providers of care must not offer anyone on the list employment in care positions. Checks are requested as part of disclosures from the Disclosure and Barring Service.

OTHER SAFEGUARDS

Separating housing and care provision

People whose behaviour is described as challenging who are placed in a registered care home are vulnerable to exclusion if problems arise. This could mean that a person is given notice to leave the service. However, if the housing provision is separate from the care provision, the individual can remain in their home, and the care provider can be changed if necessary. This situation enables the individual to have greater control of his/her life because they can change their care provider without losing their home.

Independent Advocacy

An advocate is someone who helps make the wishes and opinions of an individual known, and often families act as powerful advocates for their family member. However, there may be conflicts of interest at times, and sometimes family carers are not aware of all the opportunities that are available. Independent advocacy aims to be an effective way to help the person with a learning disability to have a stronger 'voice', and you should ask about advocacy services available in your area.

However, it is important to note that advocacy for someone with severe learning disabilities whose behaviour is described as challenging is a skilled role and will require a great deal of time, commitment and expertise if it is to be done effectively.

There are different types of advocacy and their availability and funding for them varies. For more information, see the CBF's [What is Advocacy?](#) resource.

Families rightly feel they should have a role advocating for their relative, and professionals often have a professional duty to advocate. An individual is best supported where families, professional carers, and independent advocates, all recognise their separate roles, but work together.

KNOW YOUR RIGHTS

According to the **Care Act (2014)**:

- If an adult needing care would experience substantial difficulty in participating in their social care assessment and/or the preparation of their care and support plan, or a safeguarding investigation, then the Local Authority must make sure they have someone suitable to help.
- If the Local Authority is satisfied that there is some other person who is a suitable representative (e.g. a family member or friend) they will not need to provide an advocate.
- Local Authorities must also provide an advocate for carers if they feel that the carer needs help to be fully involved in the preparation of their carers assessment or support plan.

People with severe learning disabilities should be cared for in ways that promote their independence, well-being and choice. However sometimes people with severe or profound learning disabilities are deprived of their liberty for treatment or care because this is in their best interests to protect them from harm. Where an adult has continuous supervision and/or is not free to leave their home or place they are staying, then a Deprivation of Liberty Safeguards (DoLS) authorisation will need to be put in place if they live in a registered care home or are in hospital. If they are living in their own home or in the family home, an application will need to be made to the Court of Protection for a Deprivation of Liberty Order. A DoLS is also needed for other specific restrictions on the person and family carers should be consulted as part of the process.

FURTHER INFORMATION

- CBF Family Carer Advocacy Resource:
<https://www.challengingbehaviour.org.uk/information-and-guidance/rights-and-the-law/00-family-carer-advocacy-resource/>
- [Deprivation of liberty safeguards: resources - GOV.UK](#) gives clear information about the Deprivation of Liberty Safeguards to ensure the correct process is followed when someone needs to be deprived of their liberty.

10. WHO CAN HELP



There are a range of people that may be available to provide you with advice. Any of these could be a starting point to signpost you to sources of support.

VOLUNTARY ORGANISATIONS

Voluntary organisations provide a range of information, support and advice. Some provide general information (e.g. Mencap, Contact, etc), and some provide more specialised information for people with specific needs.

The Challenging Behaviour Foundation

The CBF aims to work closely with family carers, professionals and commissioners in order to promote and develop small, individualised, high quality local services and support for people who have severe learning disabilities and behaviour described as challenging.

We are keen to work with those who want to achieve better outcomes for individuals with behaviour described as challenging and their families and carers, facilitating equality of access to local education and participation in the wider community.

Ways in which we may be able to help include:

- Talking through your options with you (call the Family Support Service to speak to a Family Support Worker: 0300 666 0126)
- Linking you with other families who have relatives who have severe learning disabilities and are described as having challenging behaviour (join the Family Carer Email Network)
- Linking you with people who can help you achieve the future of your choice for your relative,
- Providing information and support to both families and professional carers around understanding challenging behaviour and supporting behaviour change.

Mencap

The leading voice of learning disability, they work in partnership with people with learning disabilities to help them live life as they choose, eg help them to find employment, offer advice and deliver residential day services, etc.

Provides:

- A website which features the latest learning disability news, campaigns and a large amount of information related to learning disability,
- Services including housing, support, learning, employment and leisure. Local Mencap groups offer support and activities.

Telephone: 0808 808 1111

Website: www.mencap.org.uk

Learning Disability England

Campaigns for better housing, support and rights for people with learning disabilities. Working with people with learning disabilities, families, advocacy organisations, housing and support providers and commissioners.

Provides:

- Membership and advice,
- Information and resources on housing, support, funding and rights,
- Hosts conferences and events,
- Identifies and shares good practice.

Telephone: 0300 1110444

Website: www.learningdisabilityengland.org.uk

Whether you are accessing social care for the first time or trying to change services or support for your relative, we know what a lengthy and difficult process it can be. There are times when you will forge ahead and other times when progress will seem painfully slow – and it may feel easier to ‘stay the same’ rather than try to change things. Don’t give up! Ask for help if you need it. At the CBF we know how hard it can be, and we will do all we can to support you.

Remember: It’s never too soon to start – and it’s never too late to change for the better!

APPENDIX 1: QUESTIONS TO ASK SUPPORT PROVIDERS

If you are considering a support provider for your relative, there are a number of questions you could ask to help you decide if they are suitable. Listen out for the red flags in the providers response and ask more questions if you hear them:

Questions	Red flags
Person centred approach • Can you provide an example of how you have changed your practice to meet the needs of an individual? • Can you tell me how you ensure that you always adopt a person centred approach? • How are Person Centred Plans used and updated over time? • What adaptations will you make to accommodate my relative's needs? • How will you encourage my relative to develop his / her skills? • Can you tell me how you will support my relative to express their individual personality / identity?	Comments that suggest your relative will need to fit in with staff/what already goes on E.g.. 'Of course we can support your son with the activities he enjoys, obviously day staff finish at 7/8/9pm but I presume he'd be home by then' 'Oh don't worry. Our staff will do all the cleaning and washing so your son won't need to learn any of that.' 'The bedroom has just been decorated but next time we decorate she can choose the colours she wants.'
Activities and choices • What will be a typical weekday / weekend look like for my relative? • How will you support my relative to access community facilities? • How will you support my relative in trying new activities? • What transport is available to enable my relative to access community facilities? • How will you ensure my relative has transport at the time it's needed, to access community facilities? • Are activities organised on a group or individual basis, or combination of the two?	Comments that suggest a fixed timetable of activities that everyone has to do (regardless of whether they enjoy them) E.g. 'Everyone in the house does the same activity to encourage them to socialise, everyone loves horse riding' 'We don't have enough staff to support people to go out on their own so we always go as a group' Comments that suggest capacity to decide whether to go out or stay home will be assumed without a mental capacity assessment

Questions	Red flags
• If a group activity is arranged that my relative does not wish to participate in, what will you do? • What sorts of choices will be offered? (ranging from breakfast cereal to activities and everything in between!) • Will my relative be able to access the internet? • How will you support my relative with nights out (and staying out late)? • How will you support my relative with long day trips?	E.g. 'If your daughter refuses to come to an activity, we just won't take her even if it's something we know she enjoys, it's her choice' Comments that suggest your relative will need to fit in with staff rotas E.g. 'Of course we can support your son to visit theme parks, we don't mind a long drive, obviously day staff finish at 7/8/9pm but I presume he'd be home by then'
Family • How do you support families to be actively involved in their relatives' lives? • As a family member, if I wanted to, could I actively be involved in support e.g. interviewing staff? • Can you put me in touch with other families of people you support so that I can hear their views? • Can I visit / contact my relative at any time? • Can I visit without an appointment? • Are parents consulted / involved in reviewing policies? • How will you keep me involved in changes about my relative's care?	Any suggestion of rigid rules around contact especially in the first few weeks or months E.g. 'We tell everyone not to visit for three months, your daughter will need to settle in and understand she lives here now' Any reluctance to help you speak to other families or evidence of filtering feedback E.g. 'I don't think we can put you in touch, but we have some reviews from families that I can share' Any evidence that you won't be welcome and involved in your relative's support E.g. 'We like people to visit at the same time every week and let us know when they are on their way' 'Your son will be so busy you won't need to worry about visiting every day/week/month (whatever you have indicated you'd like to do)'

Questions	Red flags
Behaviour Support • Can I see your behaviour management/ physical intervention/ adult protection policy? • How will you meet the behavioural needs of my relative? • What professionals will my relative have support from? (in-house & external) • Do you have a behaviour specialist / consultant or a behaviour team? • Do you use a positive behavioural support approach? (the recommended approach for challenging behaviour) Can you give me examples of this? • Do you use physical restraint? Are all your staffs trained to use this, and is the training accredited by the British Institute of Learning Disabilities? • Do you use PRN (given as needed) medication as a way of managing challenging behaviour? How many people living here take medication to manage challenging behaviour?	Any indication that the staff member (regardless of their seniority) doesn't know where to find policies E.g. 'I can ask my manager if we have one/where to find that for you' Any indication that the person doesn't know what Positive Behaviour Support is E.g. 'Oh we are always really positive when supporting behaviour, we use reward systems like sticker charts' Any indication of over use of physical intervention or no training in doing this safely E.g. 'Don't worry we have some strong men who can get involved if they need to' 'Oh no, none of our staff are trained, we never use physical intervention.... In an emergency we'd just have to do our best'
Support staff • Will my relative be able to choose his/her staff support? • How will you guarantee continuity of staff, ensuring that my relative has: 1. appropriately fully-qualified staff at all times 2. staff with whom he / she is familiar? • Do you use agency staff? • What induction, training and ongoing support do your staff receive? (Look out for PBS / MCA training – can you give examples of this?) • Do all the staff that will support my relative have a good standard of spoken English?	Any suggestion that you or your relative will not be involved in staff selection and the recruitment process may be unsafe E.g. 'There's a staffing crisis at the moment so we can't afford to be too picky, I'm not sure we can let you daughter pick her staff' 'Most people we employ have never worked in care before but we train them up' 'We always use the same agency but we can't guarantee they will send the same staff, they just send who is available'

Questions	Red flags
• What appropriate support will be put in place if English isn't my relative's first language? • How will you ensure staff that support my relative have the appropriate communication skills? What alternative communication methods are used? • If my relative doesn't like a particular member of staff, how will you manage this?	Comments suggesting training is sparse or unrealistically thorough (clarify if these are short awareness courses or in-depth training) E.g. 'Everyone has the mandatory training they need to be a support worker' 'Everyone has completed training in PBS, the Mental Capacity Act (2005), autism, communication and active support so they know exactly what they are doing'
Other • How will you ensure my relative's health needs are monitored and met? • What does your complaints procedure involve? • How many safeguarding alerts were raised here in the last year? • How will you prepare my relative for moving in? • How will you prepare my relative if new people move into the residence? • How will you support my relative in maintaining friendships and making new ones?	Comments that suggest little contact with professionals outside of the service (institutionalisation) E.g. 'We have our own psychiatrist and psychologist and a registered nurse on site so you don't really need to worry about seeing the GP' Comments that suggest little understanding about formal complaints procedures and/or safeguarding E.g. 'Just send any issues to me on WhatsApp and I will sort them out for you, it's quicker' Comments that appear to not see the need to prepare your relative for significant change E.g. 'I don't think other residents would cope with you daughter visiting' 'If your son uses a visual timetable we can just add photos to that on the day'

With thanks to the families who contributed to the questions for service providers.

APPENDIX 2: CHECKLIST OF PLANS IN ADULT SOCIAL CARE (ENGLAND)

☐ **Care and Support Plan**

- Clearly states the individual's assessed needs and how they will be met.
- Should be shared with the person's representative and advocate.
- Must include:
 - What care is provided
 - Who provides the care
 - How and when it is provided
- Should be regularly reviewed and revised as needed.

☐ **Support Plan**

- Created by the care provider (eg, carers, day centre, residential care, supported living).
- Not a legal document, but details daily support needs, routines, preferences, and important information for staff.
- Written collaboratively with family and those who know the person well.
- Should be regularly reviewed and updated.

☐ **Positive Behaviour Support Plan (PBS Plan)**

- Based on a functional assessment of behaviour.
- Contains strategies to reduce challenging behaviours and improve quality of life.
- Includes preventative and reactive strategies.
- Should be followed by all support staff and regularly reviewed.

☐ **Education, Health and Care Plan (EHCP)**

- A legal document for individuals over 18 in education.
- Details education, health, and care needs.
- LA must complete an annual review and send a cease to maintain letter before stopping education.

☐ **Person Centred Plan (PCP)**

- Not a legal document but ensures the individual is central to all planning.
- Focuses on strengths, aspirations, and quality of life.
- Developed with family, friends, support staff, advocate, and social worker.

Tip: Each plan should be regularly reviewed and updated to reflect changes in needs or circumstances.