

INFORMATION SHEET



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

Getting the best support package: TEN TOP TIPS

For family carers on ensuring good support and services for adults with severe learning disabilities whose behaviour is described as challenging.

Ten Top Tips of Luke Clements, Professor of Law and Social Justice at the School of Law, University of Leeds:

www.law.leeds.ac.uk/people/staff/clements/

This information sheet has been written for family carers whose relative has severe learning disabilities and behaviour described as challenging.

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback:

www.surveymonkey.co.uk/r/cbfresources.

Is your relative aged 18 years or older?

Does your relative receive funding from the Local Authority?

If the answer is yes this information sheet is for you. Outlined below are ten top tips to help you get the right support for your family member.

If your relative is under 18 see:

- Disabled Children: A legal handbook. Luke Clements. Free to download: www.lukeclements.co.uk/publications/
- Using the law to fight the cuts to disabled children's services. Free to download: www.edcm.org.uk/media/8260/using_the_law_to_fight_cuts.pdf

If your relative is over 18 and receives funding from the NHS see:

- NHS Choices webpages: www.nhs.uk/conditions/social-care-and-support-guide/pages/nhs-continuing-care.aspx
- What so I need to know about NHS Continuing Healthcare? Alison Giraud-Saunders. Free to download: www.learningdisabilities.org.uk/content/assets/pdf/publications/NHS_CHC.pdf

Words in *italics* are explained in the Jargon Buster at the end of this information sheet.

1. **Get an assessment of needs**

In all but the most simple cases, a disabled person has a right to a face to face **assessment** with a skilled member of social services, who must identify that person's 'needs' for social care support, equipment, etc. These needs must be clearly stated and the disabled person and his or her carer / representative must be given a copy of this. The assessed needs must be accompanied by a *Care and Support Plan*¹ **explaining how these needs are going to be met** (unless the disabled person is having a *Direct Payment*⁴ – in which case there must be a detailed explanation as to why the sum paid is sufficient to meet the needs that have been assessed). If your council says that they don't do face to face assessments and instead send out 'self assessment' forms, this is unlawful.

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Action:

- Ask for a face-to-face *Care Assessment*² carried out by a professional from social services
- If you are only offered a self assessment form ask for a face to face assessment

2. Make sure your family member's 'assessed' needs are met

Your local authority must provide care and support for people who are assessed as eligible for such support under the Care Act 2014 *Eligibility Criteria*³. The law says that a disabled person's **assessed needs which meet the *Eligibility Criteria*³ must be met.**

NB Throughout this information sheet "meeting assessed needs" refers to needs which meet the Care Act *Eligibility Criteria*³ for funding. In order to eligible for support, the person being assessed must be unable to achieve **two or more** of the ten 'outcomes' listed in the table below unless they have support from others:

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?
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.

The criteria are explained in the [Care and Support Statutory Guidance](#) issued by the Government, chapter 6 (see Further Information section at the end of this information sheet).

If the individual's needs meet the Care Act *Eligibility Criteria*³, the council must ensure that these needs are met – even if it says that its budget has been cut. A person's assessed needs which are not being met voluntarily by family or friends, must be met by the council either (1) arranging for support services to be provided, or (2) by the disabled person receiving a '*direct payment*⁴' (i.e. where the person actually receives a cash payment from the council which is used to meet the assessed needs).

Action:

- Ensure all needs (and the level) are clearly identified - otherwise they will not be funded
- Check the Care Act *Eligibility Criteria*³
- If you think that the assessment is incorrect you should first speak to your family member's social worker. If you are unhappy with the response you receive, you could make a formal complaint to your Local Authority or to the ombudsman (see Tip 9).
- Under the Care Act 2014 Local Authorities now have a legal duty to promote a person's wellbeing whenever they make a decision about them. Look through your family members care 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 your relative's wellbeing, you can challenge it (see Tip 9)
- If your support or services change, check that a re-assessment of needs has been completed- family carers should be consulted over this.
- If a re-assessment has not been completed, challenge any cuts as it is unlawful to reduce support or services without a re-assessment (see Tip 9)

3. Get a Care and Support Plan¹

A *Care and Support Plan*¹ (sometimes called a 'care plan') must explain the 'how, who, what and when'. The *Care and Support Plan*¹ is used as a means of checking whether or not the identified needs are being met. *Personal Budgets*⁵ don't change this at all and if a council fails to provide *Care and Support Plans*¹ and proper explanations, they are not complying with the law.

Action:

- Check your *Care and Support Plan*¹ to ensure that all your relative's assessed needs are being met.

4. Find out about Personal Budgets⁵

In a *Personal Budget*⁵ the council tells the disabled person how much it is spending on arranging for the support services to be provided, although the money need not actually be handed to the person. The council is then supposed to encourage that person to become more involved in using the money in a way that enables them to have a better life. If the *Personal Budget*⁵ monies are paid over to the person – then this is known as a '*direct payment*⁴'. A *Personal Budget*⁵ must be based on the cost of meeting your family member's needs and cannot be used as an excuse for making a cut - *Personal Budgets*⁵ are about giving individuals more choice and control about the support and services they receive and nothing more.

Action:

- If you are offered a *Personal Budget*⁵ arrangement ask for clear information on what is involved and what support you can get to help manage the *Personal Budget*⁵
- If a *Personal Budget*⁵ results in a cut to your support when needs have not changed or been re-assessed, make a formal complaint on these grounds (see Tip 9).

5. Make sure that the range and amount of support offered meets your family member's assessed needs

Councils 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 assessed needs have to be met.** *Personal Budgets*⁵ cannot be used to impose limitations of this nature – so councils 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.

Action:

- If your relative is denied access to a particular type of support or a cap is placed on the amount of support they can get, check that
 1. your relative's needs are clearly described in their *Care Assessment*²
 2. their *Care and Support Plan*¹ states how their needs will be met.
- Challenge any blanket bans or upper limits on the amount of financial support that is provided. The council has a legal duty to meet your relative's assessed needs.

6. Check if your Local Authority uses an allocation or funding panel

Many local authorities use 'panels' of various types (sometimes termed 'allocation panels', 'funding panels' or 'purchasing panels') as a means of rationing services. Often a social worker will have spent a considerable amount of time assessing a disabled person's needs and will propose a *Care and Support Plan*¹ to a panel, only for the panel to refuse. This is generally unlawful – since assessed needs must be met – regardless of resources.

Action:

- Request a written response from the panel which details how the council will fulfil its duty to meet the assessed need.
- For more detail on this see 'Council funding panels' at www.lukeclements.co.uk/resources/

7. Challenge any lack of appropriate services and support

Councils should develop local support and services to meet local need but it can be easier and quicker to 'put people' in 'ready-made' services rather than develop local individualised packages of care and support. Where the disabled person's needs are best addressed by local support services, then the council must be able to demonstrate that it is taking active steps to arrange or commission such services (for example, that it is having urgent discussions with the independent sector to increase the availability of suitable services etc). In such cases local authorities cannot simply say 'we don't have anything suitable, so you will either have to use a service outside our area or you will have to arrange this yourself using a *Personal Budget*⁵. In a court case known as *R v. Islington LBC ex p Rixon* (1996) the court held that **local authorities had to adjust provision to meet need and not the other way around.**

Some local authorities try to force disabled people, who they are funding in 'out of county' placements, to move back into the local authority area – even where the disabled person has settled happily and wants to remain. This can also arise where a council refuses to fund a care need, because the provider is outside its area (e.g. a respite care facility) even though it is exactly what the disabled person needs. If a disabled person is living in such an out of county placement in a care home, then this is their 'home' for the purposes of article 8 European Convention on Human Rights and in any event under the Care and Support and Aftercare (Choice of Accommodation) Regulations 2014, all things being equal **a disabled person is entitled to choose the location of his or her care home, their supported living arrangement or their 'Shared Lives' placement– even if it is located outside the council's area.** If the person lacks sufficient mental capacity to make this decision, then a 'Best Interests' decision will have to be taken – which must place particular emphasis on that person's wishes as well as those interested in his or her welfare (i.e. family and friends).

Action:

- If nothing suitable is available locally for your relative ask for evidence that your council is taking steps to arrange or commission a new service
- Local authorities must adjust provision to meet your relative's needs – not the other way round. Ask how they will adjust provision to meet the needs of your relative.
- Disabled people are entitled to choose where they live – even if it is located outside the council's area. If your relative lacks capacity to decide where they live ask for a *Best Interests' Meeting*⁶. Family carers must be included in a *Best Interests' Meeting*⁶.

8. Get a carers assessment

Councils must provide care and support for disabled people who are assessed as being eligible for support under the Care Act 2014 *Eligibility Criteria*³. Even if the disabled person is not eligible for support, the law says that any carer who has eligible needs themselves must have their needs met. This can include providing care (e.g. respite or short break care, now referred to as 'replacement care') to the disabled person. This means it is very important for the carer(s) of a disabled person to have 'carers' assessment(s)'. Under the Care Act 2014, carers have exactly the same rights as disabled people when it comes to having assessments and having their needs met.

Action:

- Ensure that all people providing care for the disabled person (on an unpaid basis) have a face to face 'carers assessment'
- Ensure the carer is provided with a copy of the assessment and the care support plan for all eligible needs (the law requires that this be done) and that all the carer's needs (and the level) are clearly identified - otherwise they will not be funded
- Ensure that the support plan for the carer explains clearly how the carer's eligible needs will be met. If you believe that either the assessment, or eligibility decision or the support plan is flawed – consider making a complaint (Tip 9 below).

9. Make a complaint if you think the Council has acted unlawfully

If you believe that the Council has acted unlawfully, you should make a formal complaint to try to reach a positive outcome for you and your relative.

Action:

- See "Making a Complaint" for information on the action that can be taken if you have a complaint or grievance: www.mencap.org.uk/get-involved/campaigns/what-we-campaign-about/social-care/cuts/cuts-faqs/making-complaint
- Ask for a copy of the Council complaints procedure and make sure you follow it
- A template letter to help you structure your complaint is available from: www.lukeclements.co.uk/resources/ (click on 'The Cerebra Precedent Letters')

10. Seek out some key allies and gather information

Caring can be a profoundly hard and isolating experience and it may be helpful to identify some key allies who you can draw on to support you. Many families find talking to other family carers an invaluable source of information and emotional support. To be put in touch with other family carers you may wish to join a carers support group or the Challenging Behaviour Foundation's *Family Linking Scheme*⁷, or *Family Carers' Email Network*⁸. If you believe your local authority are not fulfilling their duties to you or your relative you may wish to contact your local councillor or MP and ask that they write a letter of support.

It may be helpful to find out more or you may need to get individual advice on legal issues as appropriate. Whilst the Challenging Behaviour Foundation is happy to provide general information we are unable to provide legal advice. You may find the below organisations and resources useful.

Action:

- Identify key allies who can support you in difficult times
- Get copies of the resources listed below. Knowledge is power!
- For individual advice contact an appropriate helpline or a solicitor

Further Information

Organisations:

Disability Law Service: A charity that provides free telephone and email advice to people with disabilities and their carers, including advice on Community Care Law. They also have a number of information sheets that can be downloaded for free from their website.

Telephone: 020 7791 9800

Email: advice@dls.org.uk

Website: www.dls.org.uk

Disability Rights UK: This charity has an advice service that provides information for individuals and organizations on Personalisation/Self-Directed Support. It provides appropriate information on: getting social care funding in relation to the care needs of a disabled person, *Direct Payments*⁴ and *Personal Budgets*⁵.

Telephone: 0300 555 1525

Email: selfdirectedsupport@disabilityrightsuk.org

Website: www.disabilityrightsuk.org

Mencap Learning Disability Helpline: Provides advice and information on community care in England, Wales & Northern Ireland.

England: 0808 808 1111

Email: help@mencap.org.uk

Northern Ireland: 0808 808 1111

Email: mencapni@mencap.org.uk

Wales: 0808 808 1111

Email: information.wales@mencap.org.uk

Resources:

Carers and their Rights, (2015). Professor Luke Clements. Available on the internet free of charge at www.lukeclements.co.uk/publications/

Disabled Children: A legal handbook (2015). Steven Broach, Luke Clements and Janet Read. Available on the internet free of charge at www.lukeclements.co.uk/publications/

Using the Law to Fight Cuts to Disabled People's Services, (2011). Doughty Street Chambers and Irwin Mitchell Solicitors. Available on the internet free of charge www.edcm.org.uk/resources/resources-for-supporters

Get your rights: What to do if your service is cut? (2011). MENCAP. Available on the internet free of charge www.mencap.org.uk/node/6675
Tel: 0808 808 1111

The Care Act 2014 Care and Support Statutory Guidance (2014) can be accessed at www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation

Jargon Buster

1. Care and Support Plan: this is sometimes called a 'care plan'. It is a written statement of individual assessed needs identified during a Care Assessment. It sets out what support you should get, why, when, and details of who is meant to provide it. Individuals are entitled to a copy of their Care and Support Plan.

2. Care Assessment: also known as an 'assessment of needs' is carried out by the Social Services department of an individual's local council and is the first step towards getting help and support with care. The assessment looks at an individual's needs and determines what services and support a person is entitled to.

3. Eligibility Criteria: This is set out in the Care Act 2014. Top Tip 2 above explains how a disabled person's needs may meet the Eligibility Criteria. There is a separate set of criteria for Carers and these are generally considered to be more generous than those for disabled people. These are explained in detail in Professor Clements' 'Carers and their Rights' book (2015) – see above.

4. Direct Payments: cash payments made to individuals who have been assessed as eligible for support. They are an alternative to the social services department making the arrangements e.g. day centre placement

5. Personal Budgets: "A Personal Budget may be taken:

- in the form of a direct (cash) payment, held directly by the person, or where they lack capacity, by a 'suitable person' [Legally this is known as a 'direct payment' - see above]
- by way of an 'account' held and managed by the council in line with the person's wishes, that is to pay for community care services which are commissioned by the council, or as an account placed with a provider. This can be the means by which someone who does not opt for a direct payment can draw on existing or new contracts to suit their needs without taking on direct budget management responsibilities.
- as a mixture of the above"

(ADASS 2009)

6. Best Interests' Meeting: A Best Interest Meeting can be arranged when an individual lacks the capacity to make a decision for themselves. The people at the meeting should discuss what the best course of action is for the individual who lacks capacity. It should not be the personal views of the people; instead they should consider the current and future interests of the individual who lacks capacity, weigh them up and decide which course of action is, on balance, the best course of action. The meeting must consider many factors including the individuals wishes and feelings and also those of anyone engaged in caring for the person or interested in his welfare (s4 Mental Capacity Act 2005).

7. Family Linking Scheme: The Family Linking Scheme can match you with a family carer Link Volunteer to speak to on the phone regularly. We try to match people based on the age of their relative and the kind of situation they are in. Link Volunteers are trained to provide emotional support. Having also been in a similar situation, they may be able to offer information and useful ideas. Link volunteers are not expected to advise, produce solutions or answers to all questions. If you are interested in using the Family Linking Scheme, please email support@theCBF.org.uk or call 01634 838739 to ask for an application form.

8. Family Carers' Email Network: The Challenging Behaviour Foundation's Family Carers' Email Network puts you in touch with a large number of families around the UK. You can share experiences, information and receive support - without any obligation to reply or to identify yourself. All questions and comments are posted anonymously. If you are interested in joining the Family Carers' Email Network, please email network@theCBF.org.uk or call 01634 838739 to ask for an application form.

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The Challenging Behaviour Foundation

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@thecbf.org.uk, or visit our website: www.challengingbehaviour.org.uk

If you have found this information useful, please consider making a donation.

You can show your support at www.challengingbehaviour.org.uk/support-us.

Make a £5 donation by texting CBF DN05 to 70085

Or email us to get involved at support_us@thecbf.org.uk