

INFORMATION SHEET



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

TEN TOP TIPS:

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

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

Is your relative aged 18 years or older?

Does your relative receive community care services?

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.

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.

The CBF relies on the support of our friends and colleagues to continue to provide free resources to families.

Please see below for details of how to support us.

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 http://www.edcm.org.uk/media/8260/using_the_law_to_fight_cuts.pdf

1. Get an assessment of needs

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 plan¹** explaining how these needs are going to be met (unless the disabled person is having a direct payment – 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.

Action:

- Ask for a face-to-face *care assessment²* 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. Meeting 'assessed' needs

Your local authority will decide what level of need it will meet and fund under Fair Access to Care criteria - this is known as the eligibility criteria³. When it has set this level, the law says that a disabled person's **assessed needs which meet the local authority's eligibility criteria must be met.**

NB Throughout this information sheet "meeting assessed needs" will refer to needs which meet the local authority's eligibility criteria for funding.

As long as the individual's needs meet the local authority's eligibility criteria the council cannot refuse to fund these – even if it says that its budget has been cut. A person's assessed needs 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
- Ask for a copy of your local authorities Fair Access to Care eligibility criteria
- 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 point 8)

3. Get a Care Plan

A care plan (sometimes called a 'care and support plan') must explain the 'how, who, what and when'. The care plan 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 plans and proper explanations, they are not complying with the law.

Action:

- Check your care plan to ensure that all your relative's assessed needs are being met.

4. Personal budgets

In a 'personal budget' the council tells the disabled person how much it is spending on arranging for the support services to be provided, although the money is not actually 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' monies are paid over to the person – then this is known as a '*direct payment*'⁴. Many councils are switching people to personal budgets, although the law makes no mention of 'personal budgets'. Councils **should only do this if they have fully involved the disabled person.** The new personal budget arrangement

cannot be an excuse for making a cut - 'personal budgets' are about giving individuals more choice and control about the support and services they receive and nothing more.

Action:

- If the council suggest changing the support to a personal budget arrangement ask for clear information on what is involved and what support you can get to help manage the personal budget
- The council has the same responsibility to meet your relative's assessed needs. If a personal budget results in a cut to your support when needs have not changed or been re-assessed, make a formal complaint on these grounds (see point 8).

5. Range and amount of support available

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 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.**

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.) That their care plan 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. Allocation or funding panels

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 plan 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 <http://www.lukeclements.co.uk/resources/>

7. 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’. 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 National Assistance Act 1948 (Choice of Accommodation) Directions 1992, all things being equal **a disabled person is entitled to choose the location of his or her care home – 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. Family carers must be included in a *best interests’ meeting*⁶.

8. Making a complaint

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 “When things go wrong” for information on the action that can be taken if you have a complaint or grievance:
[http://www.familycarers.org.uk/Libraries/Local/866/Docs/Resources/Safeguarding/When_Things_Go_Wrong-\(16pages\).pdf](http://www.familycarers.org.uk/Libraries/Local/866/Docs/Resources/Safeguarding/When_Things_Go_Wrong-(16pages).pdf)
- 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:
<http://www.lukeclements.co.uk/resources/> (click on ‘The Cerebra Precedent Letters’)

9. Identify some key allies

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 meet other family carers you may wish to join a carers support group or the Challenging Behaviour Foundation's family linking scheme, or email network. 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.

Action:

- Identify key allies who can support you in difficult times

10. Get more information and individual advice

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 following organisations and resources useful.

Organisations

Disability Law Service: Provides telephone or email advice on community care law. Free to disabled people and their family carers

www.dls.org.uk Tel: 020 77919800 E-mail: advice@dls.org.uk

National Autistic Society: If your relative has an Autistic Spectrum Condition you can contact the National Autistic Society Community Care Service which offers advice and information about Community Care

www.autism.org.uk Tel: 0808 800 4104 Email communitycare@nas.org.uk

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

England: Telephone: 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, (2012). Professor Luke Clements. It is available on the internet free of charge at <http://www.lukeclements.co.uk/publications/>

Disabled Children: A legal handbook (2011). Steven Broach, Luke Clements and Janet Read. It is available on the internet free of charge at <http://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 <http://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 Tel: 0808 808 1111

Action:

- Get copies of the resources listed above. Knowledge is power!
- For individual advice contact an appropriate helpline or a solicitor

Jargon Buster

1. Care plan: this is sometimes called a 'care and support 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 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: individuals needs are graded into four bands "critical", "substantial", "moderate" and "low" as set out in a document called "Fair Access to care services".

Each local authority sets its own individual eligibility criteria to decide which of the four levels of need are entitled to receive funding for social care services and support. For example, a council may decide to only fund needs which are assessed as critical or substantial.

4. Direct payments: cash payments made to individuals who have been assessed as needing services, instead of social service provisions 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']
- 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 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).

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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

Make a £5 donation by texting Cbfd05£5 to 70070

Or email us to get involved at support-us@theCBF.org.uk