

## Meeting the challenge **3**

What if it is getting difficult to support my family member at home or in their current service?



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# What if it is getting difficult to support my family member at home or in their current service?

This factsheet will provide you with information about what can happen when it becomes difficult to support a family member at home, or in their current service and they require more specialist assessment and support.

Words in **purple** are explained in more detail in the glossary at the end of the factsheet.

If it is getting more difficult to support your family member at home it is important to ask for help as soon as possible. This also applies to those care or health providers who are supporting someone. In this way you might be able to stop a crisis developing that would be distressing for everyone.

- When asking for extra support, it is always worth highlighting the point that support early on can help **avoid a crisis**.
- Remember- it is never too late to look into getting more support in times of difficulty.

It is important to ask the question – why are things becoming more difficult?:

- Is it because your family member is not getting the right support? (see factsheet 2)  
OR:
- Is it because their needs are changing and the support they have is not right any more?

**“Where children, young people and adults need specialist support the default position should be to put this support into the person’s home through specialist community teams and services.”**

Transforming Care report <sup>1</sup>

**“What Simon needed was more support in the residential care home where he lived... Social services wouldn’t provide the funding for a few extra hours a day for the care he needed. So things got worse for Simon, and he was sent to an assessment unit.”**

Simon’s mum, Out of Sight report <sup>2</sup>

<sup>1</sup>Transforming Care: A national response to Winterbourne View Hospital, Department of Health, 2012

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf)

<sup>2</sup>Out of Sight, Mencap and the Challenging Behaviour Foundation, 2012

[www.mencap.org.uk/outofsight](http://www.mencap.org.uk/outofsight)



## Top Tip

Is your family member getting good support? – ask yourself these questions:

- Do they have an up to date care and support plan?
- Have they had a functional assessment? Do they have a Positive Behaviour Support Plan?
- Do they spend their days doing things they enjoy / are they active?
- Do they have good physical and mental health support?
- Are the staff working with them trained to meet their individual needs?
- Do they live in an environment that suits their needs? (e.g. it is not too noisy, there is enough space, they have chosen who they live with)
- Is the support they receive individualised and holistic to meet their specific needs?

See factsheet 2 for more information on what good support looks like.

## Support for your family member

It is important that the needs of your family member are understood. This should be achieved by having a thorough needs assessment – see factsheet 2 for more information on this.

Your family member may already have had an assessment and be getting some support. You should always ask for a **reassessment** if you feel that your family member's needs are changing and they require additional support.

## Support for yourself as a family carer

You may already have had a carer's assessment (see factsheet 2 for more on carers' assessments). If you have not, you should ask for one by contacting your local authority. You should ask for a reassessment if you feel that your needs are changing and you require additional support.

## Should services make changes to meet the needs of your family member?

- Your family member may be receiving care and support from different services. For example, in the family home and/or **short breaks (or respite) services**. Or they may live in **supported living** or **residential care**. Whatever the service is, if they are finding it difficult to meet the needs of your family member, they should tailor the way they provide support to the person. This might include:
  - Offering their staff more specialist training around managing challenging behaviour e.g. how to implement positive behaviour support plans
  - Ensuring there is an appropriate **level of staff support** e.g. 1:1 support at home and 2:1 support in the community
  - Bringing in specialist support from outside e.g. professionals in the community such as psychologists or learning disability nurses who have expertise in managing behaviour that challenges.

Some of the changes that services need to make will need extra funding and local commissioners (the people who buy services) might not agree to pay more. This is where it is important to record the day-to-day support needs of your family member to use as evidence of their changing needs.

It is vital that the current support service seeks to make the adjustments that will meet the needs of your family member. However, it may become apparent that, even after adjustments have been made, they cannot adequately meet those needs, for whatever reason. They should work with you and your family member to find different provision that is more suited to their individual needs. This will need to include the relevant professionals in the discussions e.g. social worker, psychologist etc.



### Top Tip

If your family member lacks the **mental capacity** to make their own decision about next steps, then you should ask for a **'best interests' meeting** to be held. This should look at the difficulties the service is having and ensure any decision made is in the person's best interest.

Find out more about capacity, best interests and the Mental Capacity Act and decision making:

Guide to the Mental Capacity Act (for family and friends of people with learning disabilities) (HFT)

[www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act/](http://www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act/)

Mental Capacity Act resource pack for family carers (Mencap)

[www.mencap.org.uk/mental-capacity-act-resource](http://www.mencap.org.uk/mental-capacity-act-resource)

Mental Capacity Act 2005: A brief guide for providers of Shared Lives and other community services (Local Government Association, NHS England, Care Provider Alliance)

[www.local.gov.uk/documents/10180/6869714/L14-393+MCA+guides\\_09.pdf/e95b1230-88b3-44dc-8cb9-4672c5d1ce3d](http://www.local.gov.uk/documents/10180/6869714/L14-393+MCA+guides_09.pdf/e95b1230-88b3-44dc-8cb9-4672c5d1ce3d)

### What are the options for support when it becomes more difficult for you to meet the needs of your family member?

As described above, you should ask for a reassessment of their needs. Your family member's care and support plan and positive behaviour support plan may need to be changed to reflect the person's changed needs and that they need more support. See factsheet 2 about what good support looks like.

Most people should be able to get the assessment and behaviour support they need in the community, either in the place they are living or in another suitable community placement. Only in very rare cases should it be necessary to go into an assessment and treatment unit or other inpatient unit - e.g. for the assessment and treatment of a serious mental health problem.

If you are not confident that all of the options for assessing and treating the person you care about in the community have been explored, ask for an urgent meeting with your family member's social worker, care manager and commissioner, involving the people with the right expertise in managing behaviour that challenges in the community - e.g. psychiatrist, psychologist. You may want to speak to a solicitor.



### Top Tip

If you are finding your family member's behaviour more challenging - keep a record of what is happening day to day. Gather evidence and prove that additional support is required. Keep a note of what happened, how it started and what happened as a result of the behaviour.

You could use an ABC record chart to do this (see page 9 of the Challenging Behaviour Foundation's 'Supporting Change' factsheet):

[www.challengingbehaviour.org.uk/learning-disability-files/10\\_Challenging\\_Behaviour\\_Supporting\\_Change\\_2008.pdf](http://www.challengingbehaviour.org.uk/learning-disability-files/10_Challenging_Behaviour_Supporting_Change_2008.pdf)

### Take Control of the Money

An alternative to an admission into an inpatient unit might be to take control of the social care / health money that is being used to provide services for your family member and buy in the support you want instead. See factsheet 2 for more on personal budgets.



### More Information

**In Control – helpline and information about direct payments and personal budgets**

[www.in-control.org.uk](http://www.in-control.org.uk)

**Personal Health Budgets: Including People with Learning Disabilities (Think Local Act Personal)**

[www.thinklocalactpersonal.org.uk/\\_library/Reports/TLAPIncludingLD.pdf](http://www.thinklocalactpersonal.org.uk/_library/Reports/TLAPIncludingLD.pdf)

### What if the professionals say my family member should go into a unit?

A person should only ever go into an inpatient unit if they have needs that can only be met in a unit (see factsheets 2 and 4). Every possible alternative to inpatient care for assessment or treatment should be explored first, and admission for treatment should be based on a clear treatment plan with planning for discharge starting at the point of admission.



## Top Tip

The Mental Health Act Code of Practice is clear that, before it is decided that admission to hospital is necessary, consideration must be given to whether there are alternative means of providing the care and treatment which the patient requires, including consideration of whether there might be other effective forms of care or treatment which the patient would be willing to accept. This might include management in the community, including at crisis point, through the support of professionals in the community who have expertise in supporting people with learning disabilities who display behaviour that challenges (see factsheet 2 for more). The Code of Practice also states that the patient's wishes and views of their own needs should be taken into account.

Ask the professionals who are working with your family member these questions:

- Why does the proposed assessment or care and treatment have to take place in an inpatient setting?
- What is the 'clinical reason' for my family member being admitted and what is the proposed treatment?
- What alternative options to detention in an inpatient unit have been considered?

The Mental Health Code of practice can be found here:

[www.gov.uk/government/publications/code-of-practice-mental-health-act-1983](http://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983)

If a period of time within an inpatient unit is required, this should ideally be a small local service, allowing people to stay close to family and friends. Unfortunately we know that, in many areas, there is a lack of this sort of service. This may mean your family member is being sent to one that is far away from home. If you are unhappy with the location of an alternative provision, make it clear that you are unhappy with the location and say why. Make sure that your objection is recorded on file. Talk to the people responsible for commissioning your family member's support. If you don't know who they are – ask! You may want to speak to a solicitor.

See **Meeting the challenge: Frequently asked questions about the law** written by Irwin Mitchell Solicitors for more information about your family member's legal rights: [www.irwinmitchell.com/meetingthechallenge](http://www.irwinmitchell.com/meetingthechallenge)

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## Glossary

### Short breaks (respite) services

The term 'short breaks' or 'respite' is used to describe the time off that family carers and people with a learning disability can receive. Services come in different forms. Some families access short breaks centres or some may receive direct payments to buy their own support. Breaks are an essential part of the support needed by the whole family. They provide time off for the carer to rest and focus on other activities and family members, and a chance for those they care for to spend time with others and take part in different activities.

### Supported living

This is an approach based upon the principle that a person with a disability should get the support they need to live in their own home, with the support they need. It allows people to choose where they want to live, who they want to live with, how they want to be supported, and what happens in their home. Supported living is not one model – it can look very different for different people.

### Residential care

Care and support that is provided in a group care home setting, with 24 hour staffing.

### Level of staff support

This refers to the number of staff caring for a single person, usually written as a ratio i.e. 2 (number of staff): 1 (person).

### Mental capacity

'Mental capacity' is the ability to make decisions for yourself. The Mental Capacity Act is the law designed to protect and empower people who may lack capacity to make decisions, for example decisions about their own care and support, property or finances, because of a mental health condition, learning disability, brain injury or illness. The law applies to people aged 16 or over.

### Assessment and treatment unit

(ATU): a type of inpatient unit designed to facilitate the assessment and treatment of people, where this cannot be done safely in

community based settings. There are different types of inpatient units available for people with learning disabilities who require assessment and treatment; which sort of unit will depend on their individual need.

### Best interests meeting

The Mental Capacity Act says that adults have the right to make their own decisions wherever possible. If they are unable to make their own decision (because they lack the 'mental capacity' to do so) then others may make a best interest decision for them but the person must still remain at the centre of any decisions made. A best interests meeting is a way of bringing together the people who know the individual well to discuss a particular decision to be made in order to ensure this is done in their best interests.

### Personal budgets

A Personal Budget means that the person is allocated a pot of money to choose and pay for the care and support they want.

For more information visit  
[www.mencap.org.uk/meetingthechallenge](http://www.mencap.org.uk/meetingthechallenge)

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