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Working in Partnership – Family Carers and Professionals

This section of the Family Carer Advocacy Pack is about how family carers and professionals can work together, and overcoming some of the barriers to this.

Twenty years ago The Valuing People paper (March 2001) acknowledged the unique and important role of family carers:



“.....**Caring for a family member with a learning disability is a lifelong commitment, which continues even when the person is living away from the family home. Carers make a vital contribution to the lives of people with learning disabilities, often providing most of the support they need. They are a crucial resource for ensuring that people with learning disabilities can live in the community.**”

In 2020 the important role of family carers was recognised and highlighted again. Baroness Hollins, Chairperson of the Independent Care (Education) and Treatment Review (IC(E)TR) programme for people with a learning disability and autistic people in inpatient settings wrote

“**Families are being excluded in several ways, and in most cases, they are not being recognised as essential members of the team responsible for ensuring the person’s best interests are being met. They are excluded from receiving regular information and updates about the care of their family member, being unable to check that their relative is safe and being prevented from talking to or visiting them regularly, even though when they do visit, they provide comfort and reassurance to their detained relative. Many family members would welcome recognition of their own need for support, both during an admission, but also after discharge when they see more closely the long-term consequences for their relative of being a victim of a dysfunction system**”

One of her recommendations following the thematic review of Independent Care (Education) Treatment Reviews included **“to listen to patients and families, put them at the centre of care planning and ensure skilled and appropriate representation and advocacy”**.

[Read the full letter here](#)



Policy and best practice promote the need to work in partnership with family carers and in some cases, it is the law, such as in the Mental Capacity Act 2005 and the Care Act 2014. It is one of the key lines of inquiry for CQC inspections:

“Are people’s carers, advocates and representatives, including family members and friends, identified, welcomed, and treated as important partners in the delivery of their care?”

Despite this, family carers often experience barriers when trying to work in partnership with health and social care professionals to achieve the best outcomes for their relative. These include:

The system

- A ‘crisis management’ approach. For example addressing one issue then discharging which does not provide the opportunity to develop a positive working relationship
- Having to fight to access services/support
- Being promised something and it not being delivered
- Frustration at lack of progress and how long things take to happen or change. For example discharge from mental health services
- Lack of joined up working resulting in family carers often taking on the role of ‘key worker’ or having to retell their relative’s ‘story’ over and over

Lack of understanding from professionals about the role of family carers

- Not familiar with the rights of family carers to be involved in the care, support and/or treatment of their relative, instead labelling them as overprotective, difficult or interfering
- Not treating family carers as equal partners which can result in them feeling that their involvement is a ‘token gesture’
- No consideration given to making reasonable adjustments. For example, use of jargon, services being inflexible to the needs of families when planning meetings, cultural needs
- Professionals not used to being questioned or challenged which can result in family carers being considered obstructive, uncooperative, difficult and being excluded going forward

Family carer needs and experience

- Impact of tiredness, exhaustion, own physical, emotional, and mental health needs
- Not feeling listened to
- It is difficult to maintain a positive relationship with health and social care professionals who are not providing good quality care, support and/or treatment, may be presenting a barrier to discharging your relative, or involved in a safeguarding incident
- Professionals making assumptions or judgements about families, e.g. level of involvement a family carer should have in their relative’s care, support and/or treatment

- Other responsibilities (caring and work related)
- Resentment – a family carer is likely to be the only person in a meeting, representing their relative, who has had to pay their own travel costs and is not being paid for their attendance
- Being included until there is a difference of opinion
- Time constraints
- Mistrust from families (because of past experiences)
- Limited access to training about working in partnership
- Being the bearer of bad news but not the person responsible for the decision
- Other health and social care professionals not working in partnership
- Fear of raising expectations and then not being able to deliver

Professionals experience their own barriers, including:

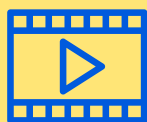
- Limited resources
- Heavy caseloads
- Lack of appropriate local services

What can family carers do to overcome some of the barriers

- Be clear about what level of involvement you want, and it can vary depending on you and your family's needs. It is your choice. You are not obliged to attend meetings, but this does not prevent you being kept up to date, receiving reports, contributing to meetings via a letter or email.
- Good communication
 - Keep communication channels open
 - Respect each other's point of view, even if there is a difference of opinion
 - Listen and reflect first before making any decisions
 - Be honest, if you don't understand something say so, ask for information in a different format, jargon free etc.
- Understand the challenges each other faces
- Acknowledge each other's expertise
- Know your rights as a family carer under Acts such as the Equality, Mental Capacity or Care
- Ask health and social care professionals to be clear about their role and responsibilities, what they will be doing and by when
- Be honest about your past experiences positive and negative, e.g. "I find it difficult to trust health and social care professionals because previously" Hopefully those you are currently working with will acknowledge this and provide reassurance
- Remind health and social care professionals, when necessary, that everyone's focus should be on positive outcomes for your relative
- Provide feedback – good and bad – and don't be afraid to raise a concern or make a complaint. Some health and social care professionals may encourage and

support you to raise a concern or make a complaint because they may be as frustrated as you at the lack of resources or the way in which they are required to work

- Identify an ally but remember to maintain boundaries, e.g. don't become over friendly or too reliant on one health and social care professional
- Ask the health and social care professionals/ organisations you are working with if they have a 'working in partnership with family carers' policy and if yes, request a copy



Visit the Challenging Behaviour Foundation Working in Partnership section and [watch Sharon \(family carer\) and Roger Banks \(psychiatrist\) talk honestly about the barriers and solutions to working in partnership.](#)

"It isn't a battle to be won... It's about working out the best solution collaboratively (together) for the person (your relative)..."

Family carers regularly have to represent their relatives in meetings. Read these ten top tips about what you can do and what should happen:

- 1.** Be prepared. Read through the notes from any previous meetings, check any outstanding actions, make sure you know where the venue is. If it is convenient, it is always better to have meetings in a neutral space. Meetings held in your home can put you under pressure, e.g. offering refreshments, feeling that you must tidy up before the meeting.
- 2.** Request all documents related to the meeting be shared in advance (ideally a minimum of 48 hours) such as the agenda (things to be discussed) or individual reports from health and social care professionals. If you have anything you would like discussed at the meeting, ask if this can be added to the agenda. You are also entitled to submit a report.
- 3.** Confirm your attendance and ask for confirmation about who else will be attending. For example, if the meeting is about your relative's discharge from a mental health service and the current barriers are adult social care funding and housing but nobody from these organisations will be attending, challenge whether it should be rearranged.
- 4.** You are entitled to ask if certain health and social care professionals can be invited to meetings, if you think their attendance will benefit your relative.

At the start of the meeting, pass round a piece of paper and ask everybody to write down:

- their name
- their role
- their contact details, including an email address. Having an email address means you can make contact at a time convenient to you. If you are unable to make contact via telephone you have an alternative and you have a paper trail of any requests you have made, etc. in case you have to raise a concern/make a complaint at a later date

- whether they have met your relative or not. They can just write yes or no. This helps you consider the usefulness of somebody's involvement, e.g. if they are employed by the service as an activities co-ordinator but haven't met your relative, how do they know what their interests are.
 - add your details to the top of the list so that if anybody wants to make a note they can.
5. It can be difficult to take notes and pay attention to what is being said. Confirm at the beginning of the meeting that there will be notes taken. This will leave you free to participate fully in the meeting, able to ask questions, challenge something if you disagree.
 6. It is always better to stay calm in meetings, but this is easier said than done, e.g. if you think somebody is preventing your relative's discharge from a mental health service or is responsible for managing a staff team which has been providing poor care, support and/or treatment.
 7. Ask for any actions to be recorded separately and ensure that each action is assigned to somebody with a completion date. Make sure you receive a copy of this.
 8. Keep a folder for all your relative's documents, e.g. notes of meetings, reports, print out any emails you may need to refer to in a meeting.
 9. Don't be afraid to ask for reasonable adjustments, e.g. timings of meetings, use of language which is jargon free. If you think that you will find a large meeting intimidating (frightening) ask for less people to attend and another professional can update them afterwards.
 10. Ask a friend to accompany you for support or check whether your area offers a family carer advocacy service. You can also contact a relevant charity organisation, e.g. the Citizens Advice Bureau. Whilst they may not be able to attend a meeting alongside you, they may be able to offer advice and help you plan

Read this self-advocacy guide from Carers UK which has been developed to help anyone with caring responsibilities gain confidence to understand their rights, communicate effectively with professionals and recognise how to be heard:

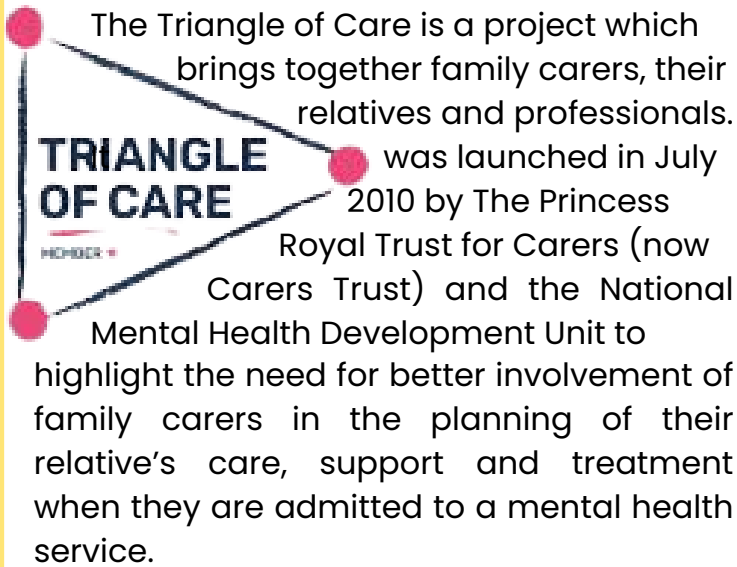


[Click here to read the guide](#)



[Click here to access a toolkit](#)

Triangle of Care



What does being a member mean?

When a mental health trust joins the Triangle of Care scheme, it is recognising the importance of involving and supporting family carers. It does this by completing a self-assessment for all its services in partnership with family carers. It then works on what needs to change to ensure family carers are a core part of the trust. As a requirement of membership, mental health providers must have family carer partners who act as critical friends to the process. The six key standards that must be met to fulfil the Triangle of Care membership include:

1. Family carers and the essential role they play is identified as soon as possible e.g. services are proactive at engaging with family carers when their relatives are admitted.
2. Staff are 'family carer aware' and trained in family carer engagement strategies.
3. Policy and practice protocols (rules) about confidentiality and information sharing are in place - the right information is shared at the right time with the right people.
4. Defined post(s) responsible for family carers are in place, e.g. Family Carer Champions.

5. A family carer introduction to a service and staff is available, e.g. information pack for family carers.
6. A range of family carer support services is available.

How the Triangle of Care can help your relative

If services are members of the Triangle of Care, they will actively look to work in partnership with you. As a family carer you are likely to be the person who has always been involved in your relative's life. You have unique knowledge about your relative e.g. their early years, the types of services they have used from education through to the current time, what has worked well and what has not, what support they need day to day.



Read the Carers Trust ['Guide to the Triangle of Care'](#)

Family Carer Involvement Contract

Some services draw up a family carer involvement contract. This is developed in partnership with the service and family carer(s) and details, for example, how communication will take place, the level of involvement family carers would like. You can ask the service your relative uses about this and even if they don't have a formal process in place, it is worth discussing and establishing how you will work together to ensure the best outcomes for your relative.

You can also discuss this with whoever commissions (pays for) your relative's care and support and/or treatment to confirm that the service your relative uses values the role of family carers. If you feel this is not happening, you can raise it as a concern or make a complaint.

Family Care Involvement Contracts should not be used as a way to limit family carer involvement or contact with their relative.

Further information



Read this guidance from Skills for Care for adult social care employers when working with family, friends and carers: <http://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-topics/Working-with-families/Working-with-families-friends-and-carers-A-framework-for-adult-social-care-employers.pdf>

Watch these 2 videos from NHS England about best practice when working in partnership with family carers whose relatives are using a secure mental health service:

1. <http://www.youtube.com/watch?v=4uFUV8HecRU>
2. <http://www.youtube.com/watch?v=433TPVRIK7I>

Read the CBF's 'Broken' report which includes the experience of family carers and how continuously having to fight for services/support contributes to their trauma: <http://www.challengingbehaviour.org.uk/news/broken-report/>

All CBF training promotes partnership working. Read more here: <http://www.challengingbehaviour.org.uk/workshops/workshops-the-benefits/>



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