

FAMILIES PARTICIPATING CONFIDENTLY

The personalisation project worked with six families not from the East Midlands. They contacted the CBF's family support workers because they were concerned their relative's current arrangements were not meeting their needs.

The project learned that families have to be very persistent if they are to achieve anything and also that they have to be confident



Families Working in Partnership with Commissioners

The project manager aimed to support families to engage in confident and positive communication with the commissioners. It was not easy: families had to be persistent. Some commissioners appeared to think families were unreasonable in asking for personalised arrangements for their relatives. The families' aim to reduce the likelihood of their relative's challenging behaviour and improve their current unacceptable quality of life seemed not to be understood.

The project manager talked with families about what to say to the commissioners and how to say it. They were encouraged to be confident and not apologetic or aggressive. The skills families needed were those which commissioners acquire by working in large organisations, assisted by training on assertiveness, negotiation skills and communication skills generally.

This led the project manager to wonder whether there are easily accessible courses for families to help them engage positively with commissioners.

Family –led Commissioning or Monitoring

The other relationship in which families need to be confident is with service providers when spending direct payments, participating in service reviews, challenging if quality is not satisfactory or posing other queries about the service.

One parent became labelled as difficult because of the persistent challenges made to a care home. The care home was apparently responsible for the following matters in relation to the care of the parent's relative¹ -

- An injury to the leg was explained by care staff as being due the relative leaning against a radiator – yet if the radiator was so hot as to cause injury, this was a

¹ the relative had no speech and the ability to make decisions similar to a person at 18 months of age

failure of care. This was raised as a concern with the manager who responded angrily to the parent for raising the matter

- An injury was explained by bed springs sticking through the mattress. A care worker said the parent should buy a new mattress. This was raised with the manager who eventually agreed to replace the mattress.
- The home accused the parent of buying poor quality clothing for the relative: they said the parent was allowing their relative to look like a tramp. Yet the parent had bought almost exactly the same clothes for a sibling who lived at home and the clothes were still in good condition. The problem was the laundering at the care home e.g. wrong temperature, use of bleach. This was raised with the manager
- The parent witnessed a resident being kissed against their wishes by another resident. When this was mentioned to the manager, the family was told to give notice of their visits so a manager could be present
- Soon after the above incident, the home accused the family of causing injuries to the relative on a home visit and a safeguarding investigation was undertaken though found to be without any real foundation

Eventually, notice was given to the relative to leave the home within 28 days. No information was made available to the new placement and no transition visits to the care home by the staff of the new placement were allowed. The manager told the commissioner that the relative was difficult and hysterical and this was repeated to the project manager as a fact by the commissioner.

Families Participating Confidently– Tips for Meetings with Professionals

Confidence does not mean being pushy – it means speaking your truth clearly so you are heard. No-one can argue with your truth – it is an important piece of the jigsaw. Only you hold that piece.

Some people find that in meetings they end up being passive – they are not sure what to say when or how to say it; they worry they might lose their temper, or they think people will be shocked if they say what they really feel. So they end up saying nothing even though plenty needs to be said. How many times have you found yourself thinking “I should have said.....I wish I’d said”.

Some people find they end up being confrontational in meetings - aggressive and pushy - perhaps because they panic when they need to speak in public which might be because they think people are against them. Perhaps they are! But start by assuming they are not.

Some people find that in meetings they end up being manipulative, putting things as though they are asking people for ‘favours’ when there is no need to; being overly familiar even though the relationship is not a friendship; trying to make professionals feel sorry for them to get more help which can make professionals lose respect if it is not true

Some of us just go blank in meetings! So - before the meeting

- Think through what you need to say before you are in the situation – prepare yourself. Jot down a few ideas.
- Practice what you'd like to say in the mirror or with a trusted person who understands you. Ask them how it sounds. Don't get a rigid script though – there might not be the right moment to say it – but at least try out some of your ideas
- If you think it is going to be a difficult meeting, ask to speak to a professional before the meeting to talk about how it will be run and when you can speak – make sure you know the 'rules' about the meeting

Because there is not always time for everything in meetings, before you go think through

- which things you must say and
- which things you would like to say but that are not essential this time
- what you want to say on your behalf. Don't speak for others unless they have asked you to. If you and your partner or other relative are both going to the meeting, agree how you will avoid this. The closest couple can have different views - try not to find out your differences in the meeting! And you can both put forward your views – with respect for one another

When you speak in meetings, try to make sure you speak

- at the right volume: not too loud, not too quiet
- at the right speed: don't rush, take your time. But also don't take too long!

If you need adjustments to the way the meeting is run to make yourself understood or so you can understand, ensure the person arranging the meeting knows straight away whether this is to do with your hearing, speaking voice or language

At the beginning of the meeting, make sure the person running the meeting (usually called the chair) knows you want to say something at the right time. It is their job to make sure everyone gets a chance to speak. As the meeting rolls on and you want to say something, ask the chair when it will be your turn to contribute

If you find that you keep going to meetings and come away feeling that you have not said the things you wanted to or let your temper get out of control or made a fool of yourself in some way, ask to speak to a professional about the meeting – ideally the chair - and how it could have been better. Tell them you don't feel you are getting your points across and ask for their advice.

You might need to spend quite a bit of time to develop these skills. Most people do.

Here are some websites about being confident – there are lots on the internet. Have a look around for one you like

<http://www.assertiveness.org.uk/>

<http://www.mindtools.com/pages/article/Assertiveness.htm>

<http://www.teamtechnology.co.uk/assertiveness/how-to-be-more-assertive.html>

<http://crucialhabits.com/assertive-communication-skills.html>

Parents Participating Confidently

Medway parents and carers forum run a course called “Parents Participating Confidently”. It is funded by a grant from the Department of Education, which is received by all parent forums. See the next page for the flyer sent out to inform people about the course

“We run two courses a year – one in Spring and another in the Autumn. The courses are designed for no more than 12 people at a time. The parents and carers have to have a young person with an additional support need, in the age group 0-25. We are looking for some of those parents to become trainers themselves.

The proof of the effectiveness off the course is that of the ten committee members we have, 9 attended the course before they joined the committee!”

If you know of any other courses about participating confidently that are available to families – they don’t have to be specific to the families of disabled people, the CBF would be very pleased to hear about them – please send details to – info@thecbf.org.uk

Here is an example of the kind of course which can help families develop the necessary skills for leading or participating in commissioning support



Parents Participating Confidently Parent Course

Date: Thurs 20th & 27th September 2012
Time: 9.30 am to 2.30 pm (9.15 am for coffee)
Venue: Rainbow Court
Danecourt School
Hotel Road, Watling Street
Gillingham, Kent ME8 6AA

To book a place

or for more information contact
Medway Parents & Carers Forum
at
medwaypcf@googlemail.com

or Phone 07813 123984

Lunch will be provided, so please
advise of any dietary needs at
time of booking.

Why should I take part?

- It is very important that parents are involved in the planning of services for children. Agencies are now involving parents at all stages
- It is also important that you feel fully involved in decisions about your child
- This course aims to help strengthen your knowledge and skills to be able to feel confident in participation

How will I learn?

- In a comfortable and informal setting
- By doing activities and having discussions
- By having fun
- By receiving and giving information

What will I learn?

- What is meant by the word 'Participation'
- What the specific activities are that this might involve
- How to identify the barriers that might make taking part difficult
- New communication skills to enable you to feel confident when expressing your views
- Tips and strategies for coping with difficult situations.

What will I be able to do at the end of the course?

- Understand the different types of participation
- Use the skills you have learnt to prepare for meetings effectively
- Feel confident to give your views
- Be able to express or challenge a different view confidently and positively