

Family and Group Conferencing for Adults

Key messages from people
with lived experience

A panel of people with lived experience met to discuss key messages that they wanted to share about Family and Group Conferencing (FGC) for Adults. This resource highlights their messages, and links them with [the Standards and Guidance for Family and Group Conferencing for Adults](#).

How to use this resource: If you are looking to commission or develop an FGC service for Adults, you may find these key messages helpful in focusing on what people see as special and important in what an FGC service can offer.

These messages are linked forward to [the Standards and Guidance for Practice](#).

You may wish to consider these key messages alongside the short video, [My Experience of an FGC](#).

The Lived Experience Advisory Panel

Advisory panel for NIHR funded research on Family and Group Conferencing for Adults

Co-facilitator:

Dr Clenton Farquharson CBE. Clenton has extensive knowledge around equity and co-production in health and social care from both professional and lived experience perspectives.

Panel members:

Anna was the central person at her FGC.

Sam was a network member at her friend's FGC.

Michaela was the central person at her FGC.

Key message 1: FGCs offer choice and control – but with support

Relevant standards: **Independence of the coordinator** (Standard 1), **Preparing for uncertainty** (Standard 3), **Explaining the FGC process** (Standard 4), **Offering an advocate** (Standard 6), **Setting the right tone** (Standard 11), **Private Time** (Standard 13)

Anna: I think one of the big things is the fact that it's very much in your hands and you have the power. You decide how your Family and Group Conference looks and who you want there. You work with someone to decide on the outcomes that you want to discuss. It's very much giving you the power to decide what the journey is going to look like for you.

Michaela: Although it's your meeting, you've got other people who are going to help like the FGC coordinator. They're actually going to be there, and going to help set it up so it's not you having to do the organising.

Clenton: This is your meeting. It's about your life, your choices, your future. You're inviting the people who matter to you – not just family, but anyone who supports you.

Key message 2: FGCs get important people together

Relevant standards: **Supporting people to engage** (Standard 7), **Connecting with practitioners** (Standard 10), **Culture of mutual learning** (Standard 12), **Private Time** (Standard 13)

Sam: It was really helpful to have everybody together that really cared about this person. Family and friends, in the same room or in the same space, to talk through what they were doing, and coordinating that process.

Michaela: Everybody's doing things at the same time. Because what can happen in other scenarios is you speak to one professional, and you speak to another professional...it all takes time. They can have different ideas as well. But an FGC is definitely about having a joined-up approach to putting support in place.

Clenton: You don't need to have all the answers. Family and Group Conferencing is a safe space to figure things out together. And if you're a family member, friend, or supporter, you've been asked because you matter. It's not about the services stepping in. Professionals are there as a guest, not the organisers.

Key message 3: FGCs are person-centred and adaptable

Relevant standards: **Preparing for uncertainty** (Standard 3), **Flexibility** (Standard 5), **Venue** (Standard 9), **Setting the right tone** (Standard 11), **Culture of mutual learning** (Standard 12)

Clenton: It isn't a formal or legal process. It's about being human. And it's a relational way of working, and there's no pressure to fix anything. Just bring your honesty.

Anna: I have autism so my mind works a little bit differently. There are extra things that I needed for support, and get that extra support. Things literally are built for you. In a lot of appointments, you're seen as a patient, almost from a mould. But everyone is very different. Rather than the FGC being a very structured thing that you've got to fit into, it's a very open thing that's built for every aspect of you.

Michaela: Before the meeting started, we had a lunch, and it was a chance for people to mingle with each other and speak to each other before the actual meeting started.

Sam: One of our meetings was on a Saturday, because lots of people worked during the week. It was in my friend's house. We had a buffet lunch, and whilst eating, we were chatting. It was quite relaxed. People made tea and coffee and bought cake.

Anna: I have an eating disorder. So having a lunch style thing would have been quite daunting and difficult for me. So we just had bowls of different snacks and picky things that people could just pick up throughout the meeting, which worked a lot better because that was less stressful to me. Again, because it's personalised, you can have that aspect in a way that suits you and doesn't add extra pressure.

Michaela: The meeting's done in a circle. It helps with that feeling of hierarchy. You're at the same level of as professionals. I'm not sitting across the desk from somebody, and quite often, they've got the nice chair, haven't they?

Key message 4: Everyone contributes to the Plan – but it's not set in stone

Relevant standards: **Information sharing** (Standard 8), **Connecting with practitioners** (Standard 10), **Culture of mutual learning** (Standard 12), **Private Time** (Standard 13)

Sam: It was a practical, structured kind of plan. It was about who was going to do what and when. So when we came away, it was encouraging to know that me and my friend were going to be supported.

Anna: Professionals need to be aware that they need to be present and work with that FGC as well, because you need that kind of medical expertise and background knowledge in your meetings. That's the aspect that didn't work so well for me. It's where my support worker wasn't on board with things that I needed from them. The agenda points that I came away with from my meeting they just didn't fulfil, because they didn't really want to be a part of the FGC. So it's really important that professionals are part of it and take what you need on board.

Michaela: The plan is organic.

Key message 5: FGCs can have a long-term impact

Relevant standards: **Review and follow-through** (Standard 14)

Michaela: If the plan's not working, it can be changed after the FGC. You can have reviews of the FGC, where what's happening can be discussed and changed if necessary. A lot of what was on my plan just completely changed, because where I lived completely changed. It's knowing that's it's OK to change, no matter how much work has gone into something.

Sam: It's still going now. We know what appointment she's got and who's done what. It's been really helpful moving forward to know that there is that support and that I don't have to worry about it as much as I used to.



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