

Co-production and Campaigning: Parent Carer Forums and local and national campaign groups

Parent Carer Forums and campaign groups are both working to affect change; it may be that they are working towards the same outcomes, but approach their work in different ways. Because of this, it's important to recognise the benefits of each approach so that Parent Carer Forums and campaign groups can find ways to work together to enhance each other's work, benefit the population they are representing and achieve the changes that they want to happen.

Definitions

The role of Parent Carer Forums in Co-production

Parent Carer Forums aim to work in co-production, which is an equal and reciprocal relationship where everyone's experience, knowledge and skills are used to create better outcomes. This means that Parent Carer Forums work in a solution-focused way with their local partners to find the best possible outcomes and solutions for local families, using the resources that are available – and should those resources be inadequate, Parent Carer Forums would challenge any shortfall, holding services to account. Parent Carer Forums and the local authority each sign an annual Memorandum of Understanding (MOU) regarding the way they work together with each other and with local partners, in co-production.

Using parent carers' direct, lived experience of receiving services for their children and young people with SEND, Parent Carer Forums can help to drive the local agenda highlighting where local services, processes, and commissioning is working well, and where changes or improvements need to be made. They might do this by surveying and consulting their members and compiling and submitting reports based on statistical or anecdotal case study evidence. This parental voice/opinion/evidence is fed into to local decision-making boards and work streams by representatives from the Parent Carer Forum who feedback progress or barriers to their membership. Parent Carer Forums work across services in their area on a variety of issues at any one time, as prioritised by their members. As they largely rely on volunteers, Parent Carer Forums will not have the capacity to become involved in every issue.

The SEND code of practice (paragraph 1.13) clearly defines the role that Parent Carer Forums play in co-production:

“Parent Carer Forums are representative local groups of parents and carers of children and young people with disabilities who work alongside local authorities, education, health and other service providers to ensure that the services they plan, commission, deliver and monitor meet the needs of children and families.”

The role of campaign groups

Campaign groups and charities (including Contact) seek to influence the decision-making process, or law, on specific local or national issues. A campaign might be intensive, time sensitive, and aimed at achieving a single goal. For example, campaigning against the closure of a local short breaks service, or for more accessible toilets locally.

Campaign groups might use a variety of methods such as:

- speaking at council meetings
- organising protests, rallies or petitions
- speaking to the media to publicise the issue and their campaign
- using social media to raise awareness
- involving their local MP or other public officials
- using the courts via judicial review

Campaign groups can be effective in raising the profile of the issues, galvanising public interest, raising awareness, and in gaining support for the cause.

The Charity Commission defines campaigning as follows (section 2.4 (1) Campaigning and political activity guidance for charities):

Campaigning: the commission uses this word to refer to “awareness-raising and to efforts to educate or involve the public by mobilising their support on a particular issue, or to influence or change public attitudes”. It also uses it to refer to “campaigning activity which aims to ensure that existing laws are observed.”

Why might Parent Carer Forums choose not to campaign?

There are three main reasons why Parent Carer Forums might not wish to enter into direct campaign activity:

1. Since February 2016, there have been limitations placed on the use of funds from Government contracts for campaign activity. These were written into each Government contract, including that between the Department for Education and Parent Carer Forums. Consequently, Parent Carer Forums are unable to use their DfE grant to fund any campaigning or lobbying activity.
2. Undertaking campaign activity is generally not consistent with the ethos of Parent Carer Forums whose aim is to co-produce and work alongside service providers, commissioners and policy makers in a solution-focused way. Parent Carer Forums sit at decision-making tables, their representatives drawing on the views and direct experiences of their members and contributing the impact of these into discussions, and seek to influence in this way. Therefore, Campaigning might only be considered as a last resort if collaborative influence has failed.
3. Forums that are set up as Charities or Community Interest Companies (CIC) should check that any activity they are considering does not contravene rules set for them by their regulators – for example, if they are a Charity, the Charity Commission has rules about certain types of activity, as does the office of the Regulator of Community Interest Companies for CICs.

How can Parent Carer Forums work with Campaign Groups?

Whilst their funding constraints do not prevent Parent Carer Forums from *supporting or raising awareness of local campaign activity* when it aligns closely with their objectives – forums do not actively campaign or use their DfE grant money to fund any campaigning activity.

However, a response from former Prime Minister Theresa May to the Chief Executive of the National Council for Voluntary Organisations (NCVO's) query to how a government funded group can effectively challenge or influence change makes it quite clear that:

“...it is vital that the sector's independence and freedom of speech are protected to allow charities and social enterprises to continue providing a voice for everyday people”.

She goes on to explain how these should not be deemed as 'gagging clauses' and should not stop fair criticism of government departments or policy.

With this in mind, Parent Carer Forums might choose to work with campaign groups in other ways, such as by:

- Sharing information with campaign groups about any representations or arguments the Parent Carer Forum is making to decision-makers on the same topic as campaign groups, being clear about what they can, and can't share – not breaking trust, confidentiality, confidences or compromising local area co-production agreements or MOUs, and the relationships which they may have spent years developing.
- Sharing information with campaign groups (and their strategic partners) about the impact of any planned changes or cuts to services. This can be done in a very "matter of fact" way (for example, this cut to transport services will mean that 52 children have to spend on average 45 minutes longer on school buses).
- Sharing campaign group information or petitions through the Parent Carer Forum's social media channels, making it clear they are signposting (and not endorsing) to local activity that may be of interest to their members. GDPR rules mean that unless they have specific permission, Parent Carer Forums cannot share their members' information with campaign groups as they may only contact them about issues that they have consented to receive information about.
- Inviting eligible members of campaign groups to join the Parent Carer Forum.
- Sharing information and comparing notes to maximise intelligence. Parent Carer Forums can use this to communicate with decision-makers in meetings and help them to understand how the decisions taken will affect families.
- Individual members of Parent Carer Forums may become actively involved in campaign groups or support a campaign. They are within their rights to do this so long as this is not done in the Parent Carer Forum's name or could be perceived to be on behalf of the Forum. Any Forum members doing this should be transparent with the Forum about their involvement so that any potential conflicts of interest can be managed. Forums may also have their own rules within their governing documents regarding individuals' involvement in campaign activity.

By communicating openly and transparently, and by observing each other's boundaries, Parent Carer Forums and campaign groups can either work together to complement each other's activities, or maintain a respectful understanding if working together on an issue is not possible. For example, if it would jeopardise local relationships or hamper progress on an issue that either group is already working on separately.

Managing relationships

At the heart of co-production is trust and communication. Parent Carer Forums should ensure that their members and local partners are aware of the activity they are undertaking, by:

- Being clear internally about what their governance documents (e.g. constitution, code of conduct policy) enable the Parent Carer Forum and its members to do both as a group, and as individuals.
- Being clear with campaign groups from the outset that whilst the Parent Carer Forum may share some of the same aims, as an organisation they may not actively participate in campaign activities. However, there is nothing to prevent individual members of Parent Carer Forums from joining campaign groups.
- Being open with the local authority, the CCG and any other co-production partners about what the Forum is going to be doing and explaining why they think it is the right action, i.e. to further the views of their members, and make clear that their own rules and the law enable them to do this. Be transparent and adopt a "no surprises" approach.

Summary

There are no hard and fast rules with regards to Parent Carer Forums becoming involved in campaigning.

Parent Carer Forums will need to make an informed judgement about the activities they want to engage in based on:

- what their governance documents enable them to do;
- the potential impact on key relationships,
- And, taking into account the conditions of their grant and contract with the DfE or any other funders.

If Parent Carer Forums are in any doubt, they should contact their Contact Parent Carer Participation Advisor or Regional NNPCF Steering Group Member for guidance.

How has the National Network of Parent Carer Forums worked with campaign groups?

The NNPCF is the independent national voice of Parent Carer Forums. Its vision and mission state that they aim to “create a culture of participation and co-production” to deliver better outcomes for children and young people with SEND. Campaigning activity is not within their remit because they are committed to co-productive methods to further their aims. However, they frequently work closely with campaign groups to further mutual aims. Partnering with campaign groups in this way is beneficial - the work that campaign groups do in raising public awareness helps the NNPCF to prioritise issues to take to decision makers and use their resources to extend the scale and reach of their work. Some examples include:

The NNPCF supports, but is not a member, of the *Disabled Children’s Partnership* – a campaign group of the leading children’s charities that campaign for improved health and social care for disabled children and their families. The NNPCF frequently shares information with DCP leads about what their members are telling them, what they have learnt in meetings with officials or ministers, and shares publicity and links to DCP events and campaigns, most recently the “Secret life of us” campaign.

The NNPCF is a member of the *Special Education Consortium* which is an independent group of organisations that seek to lobby and influence Government policy. The NNPCF is a member of the SEC steering group and endorse and share much of their output. For example, the NNPCF were signatories of the May 2018 letter to the press that described the scale and impact of funding cuts to services for children with SEND.

The NNPCF also supports campaigning organisations with specific requests or activities. For example, working closely with the policy team at *Contact* on their school transport campaign. The NNPCF publicised the campaign, the final report, and referenced the work that Contact had done in the NNPCF talking point on Transport. Similarly, the NNPCF often publicise information from campaign groups (including petitions) via their social media.