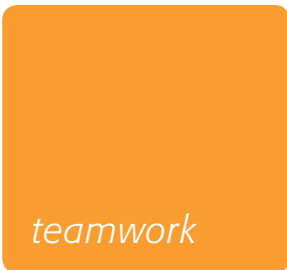




getting started



managing finances



teamwork



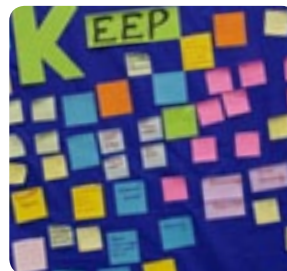
improving services



managing conflict



charity or social enterprise?



Parent carer forum handbook

A how-to guide for people setting up or running a parent carer forum

Contact a Family working with

Introduction

Forums across the nation are at different stages in their development. Each and every forum is unique, but they also have many things in common. Some forums are well established and others are beginning again for a variety of reasons, including becoming independent of the local authority or a voluntary organisation and 'going it alone'.

We do not expect you to read this handbook sequentially, but to dip into different sections as and when needed.

Whatever stage your forum is at, there will be something useful for you in this guide.

If you are just starting, or restarting a forum

The information in this guide should help you get your forum up and running.

We suggest you start by reading *Section 1.1 Getting started*.

It is not likely that you would make the decisions about your legal structure until you have been up and running for a while. However, the information in *Section 1 – Legal structures* will help you to understand your options at the beginning, when writing your constitution, to describe how your forum will work.

We recommend you spend time early on in agreeing policies as this can prevent problems occurring later on. You might find it helpful to download templates of the policies described in *Section 1.3 Policies* from the Contact a Family website and adapt for your own purpose.

If your forum has been running for a while

There are likely to be sections in the guide that could help you make the forum more effective. These might help you to identify steps that you previously missed out.

You might want to start by reading *Section 2.2 Working as a team* and run an annual health check on your forum to help prioritise your work and identify areas for future development. Other sections that might be of interest include:

Section 1.2 Governance – if you are considering becoming a charity or social enterprise.

Section 1.4 Financial management – if you want to understand the implications of paying parent carers for their time on forum work.

We hope you find this handbook useful.

Using this guide

This handbook contains interactive elements. If reading on screen it is best viewed in Adobe Acrobat – which can be downloaded free here:

www.adobe.com

Moving around the guide

This guide has been designed so you can find what you need, when you need it. It comes in five sections, and each section is broken down into short chapters.

On the index (page 4)

Click on the section titles for more detail of what is included in that section.

Click on the chapter titles to go straight to that chapter.

On any page

At the bottom of the page click on 'Parent Carer Participation Handbook' to take you back to the index.

At the top of the page click the section header to go to the section contents page.

On the section contents pages

Click on the chapter title to go straight to that chapter.

Websites

Click on any website name in this document to go straight to that web page.

NB When we refer to 'parents' or 'parent carers' in this guide we mean this as an inclusive term which encompasses parents, grandparents, foster parents, adoptive parents or anyone with parental responsibility caring for a disabled child.

NB When we refer to 'disabled children' in this guide we mean this as an inclusive term which encompasses children with a disability, long term health condition and children with additional or special educational needs.

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1 Getting started

1.1 Setting up a parent carer forum

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1.1 Setting up a parent carer forum

How parent carer forums began

Parents with disabled children can need to use lots of different services to get support for their child and themselves. This can include getting additional support for their child's education, being seen by different health services and getting help from social care services so their child can take part in fun activities while their families can have a break from caring.

When parents with disabled children meet other parents they often find they are facing similar problems in accessing services. Nearly ten years ago parents in a few areas in England decided to start a forum, sometimes called a parent carer council, to improve how services were run in their area. They decided to approach their local authority and health services, and offer to work with them to try and improve services.

They were successful in doing this and the professionals they worked with realised that the parents' knowledge and experience of using services was useful to them. It helped them understand what was not working well and improve services so they better met families' needs.

Since 2008 parent carer forums have been set up in most local authority areas of England, with help from the Department for Education, who provide a small grant to parent carer forums and fund a team at Contact a Family to support them. The forums have been successful in improving services for disabled children. You can see examples of this at:

www.cafamily.org.uk/pcp/success

In some areas parent carer forums became active and then later on stopped functioning when the parents running them moved on and other parents had not wanted to take on their roles.

This section of the guide is written for:

1. parent carers wanting to start a parent carer forum from scratch
2. parent carer forums wanting to improve how they run their forum.

Step 1: Setting up a steering group

The first step is to get other parents involved to work with you and set up a 'steering group' to get things up and running. This might later be called the management committee. You might find it helpful to approach groups that are already in your local area to see if they have people who would be interested in working with you. These include local parent support groups, carers' centres and the Information and Advice and Support Services for SEND (formerly called Parent Partnership Services). Your local Family Information Service and local library should be able to give you contact details for these.

If there has previously been a forum in the area then it might be useful to link with parent carers who were involved and see if they will work with you.

It is important that you start sharing tasks among each other right from the beginning and avoid the situation where one or two people are having to do most of the work.

It will help to find out from each other your skills and strengths so tasks can be allocated to people to make best use of people's strengths.

At this stage you will find it helpful to nominate someone to act as:

- ▶ **Chair** – to chair meetings, encourage discussion and support the group to make decisions.
- ▶ **Secretary** – to take brief notes of what was agreed at meetings and who is responsible for taking them forward.

Step 2: Agreeing aims and objectives

The first step is for everyone to agree and be clear about what the forum aims and hopes to achieve. This is important as it ensures everyone involved in the forum understands its purpose.

It can be useful to come up with a mission statement which sets out the forum's aims and what they hope to achieve. This can be useful to display on leaflets, websites and newsletters – to give a clear message to people about the purpose of the forum.

You will need to think about who is eligible to be a member of the forum.

In England, to receive the Department for Education grant, parent carer forums have to be open to all parents or carers with a disabled child living in the local authority area. They also have to be pan-disability, meaning all parent carers with a disabled child can become a member, regardless of the nature of their child's disability or medical condition.

You will need to decide on what age range to include. Some forums restrict membership to parent carers of children aged 0-19, but many are open to parent carers of young people up to the age of 25, in line with the Children and Families Act 2014.

Below are some examples from parent carer forums which might help you when deciding on your own.

Examples

- ▶ **Waltham Forest** – We are a friendly, voluntary group of parents and carers of disabled children and young people aged from 0 to 25 in the London Borough of Waltham Forest. Our aim is to provide feedback on the development and direction of services for disabled children and young people in the borough to key policy makers.
- ▶ **Sheffield** – We are a group of parent carers of children with a wide range of disabilities. Our aim is to give parent carers in Sheffield a voice in influencing local developments that affect their children.
- ▶ **Norfolk Family Voice** – a collective of parents and carers of children with special and additional needs working voluntarily and 'Aiming High'. Our aim is to make sure that parents' voices are heard when it comes to planning and decision making about services for our children in Norfolk.

Step 3: Planning how the forum will work

This step requires careful thought to make sure it will work for your local area. It is important to consider the geographical area you cover and any existing parent groups that you could link in with.

If your local authority covers a very small area it is relatively easy to organise meetings and events that most parents can attend. You might decide to hold monthly or three monthly meetings of the forum which last a couple of hours.

However, if your local authority covers a large county area this is not going to be practical. You might instead want to invite parents from existing parent groups across the county to sit on the steering group, so they can feed in their members' experiences to the forum.

Some forums may prefer to hold one or two large events per year, to which they invite all of their members. The events provide an opportunity for parents to say what issues they want the forum to prioritise over the coming months. They also enable the forum to feedback any progress and changes that have arisen as a result of the forum's involvement, to the wider parent group.

As the steering group is having discussions about this it might be helpful to start drafting Terms of Reference which sets out the purpose and structure of the forum.

Terms of reference might include:

- what the forum hopes to achieve
- roles and responsibilities (that is, who will take part in it, what they will do)
- how often meetings will be held
- who will attend
- how representatives will be selected
- how decisions will be made.

An example Terms of Reference can be downloaded from the Contact a Family resources page:

www.cafamily.org.uk/runaforum

Your forum will also need to set up a bank account which will need at least two people's signatures to write cheques.

Step 4: Decide on a name and let people know about you

While you are discussing how you are going to work it would be good to also think about what you are going to call your forum. It helps to come up with a name that will explain to other people what you do and encourage parents to want to join.

Examples of names other forums have used include Family Voice Norfolk, Parent Carer Council for Cornwall, Sheffield Parent Carer Forum, PIPS (Parents In Partnership Stockport), Middlesbrough Parents4Change.

Next steps

You will want to start telling people about what you are doing and hold your first meeting. The following sections in this handbook are helpful for this:

2.1 Making it work – Attracting and keeping members

3.1 Communication – Getting the basics right

5.2 Improving services – Building relationships

Top Tips

- ▶ Try to include parents in the steering group whose children have different conditions and levels of severity and who live in different areas so you represent a wider range of experiences.
- ▶ Share the workload as much as possible to avoid parents leaving because they find they have too much to do.
- ▶ Find out what people's strengths are and allocate tasks within the group which best suit them.
- ▶ Agree a mission statement so everyone is clear about the purpose of the forum.
- ▶ Take time to think about how the forum will operate. Consider how big an area you cover and what other groups/organisations might link into your forum.

1.2 Governance and legal structures

What is meant by governance

Governance – the term used to describe how an organisation operates. It includes what it hopes to achieve, how it will achieve it and how it will be held accountable.

It is important to have written processes agreed so that everyone is clear about how the parent carer forum works. This can be done gradually as your steering group discusses and agrees how the forum will operate.

Having clear information written down helps prevent misunderstandings.

i *Anna Gill has been involved in establishing and running a local forum, and helping forums establish in other local areas. Listen to her advice on setting up a forum:*

www.cafamily.org.uk/pcp/resources

In *Section 1.1* we talked about developing and agreeing:

Mission statement – explaining the purpose of your forum and what it hopes to achieve.

Terms of reference – setting out the purpose and structure of the forum and describing the activities the forum will take to reach its aims.

You will need to think about how decisions are made and how you will manage the finances. This is usually set out in what is called a constitution. A constitution is the 'rule book' for an organisation. It should set out:

- the mission and values of the organisation
- the organisation's aims
- who is allowed to be a member
- when members meet
- how decisions will be taken. For example, by committee, Annual General Meeting (AGM)
- how individual members can call an Emergency General Meeting
- the membership of the management committee, and individual roles and responsibilities. For example Chair, Treasurer, Secretary

- meetings of the management committee – how often they will take place and how they will be recorded
- how decisions can be made and how they will be recorded
- the powers of the management committee
- how the management committee will be accountable to the membership
- how the finances of the organisation will be managed
- how the constitution can be changed
- how the organisation will be wound up if it closes.

i An example of a simple constitution can be found on the Contact a Family website:

www.cafamily.org.uk/runaforum

When you write your constitution you will want to consider what type of legal structure you want to eventually become. You can then adapt a model constitution provided for that type of legal structure. This will save you work later on, when you are ready to go ahead and adopt a legal structure.

Having no legal structure – unincorporated associations

An ‘unincorporated association’ is an organisation set up through an agreement between a group of people who come together for a reason other than to make a profit, for example a voluntary group or a sports club. When you first start your forum it is likely to be an ‘unincorporated association’. This isn’t a legal structure, so the association won’t be recognised by law. This means that individual members are personally responsible for any debts and contractual obligations made by the group. However, the forum can take out insurance to protect their members against this.

Even if you are a small group and do not think of yourselves as a charity, you will still be charitable in the eyes of the law if you have ‘charitable purpose’. Whether this is the case will depend on your forum’s purpose and how this is described in your constitution. You can read more about charitable purpose on the Charity Commission website:

www.gov.uk/government/organisations/charity-commission

Charities fall under the jurisdiction of the Charity Commission whether they are registered or not, and they should abide by charity law.

A small charitable organisation with an income that does not exceed £5,000 can enjoy some of the benefits of charitable status by registering with Her Majesty’s Revenue and Customs (HMRC) for tax relief. To do this you will need to have a separate bank account

for your group and provide statements as proof. You can read more on the HMRC website:

www.hmrc.gov.uk/charities/tax/recognition.htm#1

An HMRC registration can be used as evidence of your charitable status.

Note – if your annual income exceeds £5,000 a year and your forum has ‘charitable purpose’ then you should register as a charity.

Choosing a legal structure

Not having a legal structure limits the activities that your forum can take on and can prevent you from applying for some sources of funding. You cannot employ people and if you enter into contracts (for example hiring a venue, ordering stationery, leasing office space) the individual signing the contract is personally responsible for the contract and not the forum.

To address this, your forum is likely to consider one of the following:

- running under the umbrella of a local voluntary organisation
- registering as a charity
- becoming a social enterprise, such as a community interest company.

This document provides a basic overview of these options and where to go for further information. Before adopting a legal structure you will want to take advice and consider your options carefully - choosing an unsuitable legal structure can cause problems later on.

Details of organisations that can provide further advice, including your local Council for Voluntary Service (CVS), are at the end of this section. You might also find it helpful to talk to other forums about which option they took, how easy they found the process and whether it turned out to be the right option for them.

To help decide the best option you will want to think about the different types of activity your forum might want to carry out.

These might include:

- applying for grants from charitable trusts and fundraising
- employing members of staff to work for the forum
- entering into contracts to provide services, for example running consultations of their members.

There will be certain administrative tasks associated with whatever legal structure you choose. You will want to find out what they are and consider how time consuming they will be.

Running under the umbrella of a local voluntary organisation

Some forums opt to run under the umbrella of a local voluntary sector organisation such as a local carers organisation. This can be useful, as you do not have to register as a legal organisation in your own right which will save lots of administrative tasks. It may be possible for the voluntary organisation to employ someone to provide support for the forum. This can be a great help for parent carer forums still in the early stages of development. However, if you are taking this approach you will need to clarify with the voluntary organisation from the outset each other's responsibilities, including decisions about how money will be spent, how decisions are made and any charges by the voluntary organisation for their services.

Registering as a charity

The Charity Commission website has information on starting a charity which will help you decide whether becoming a charity is the right option for your forum.

If you want to apply to charitable trusts for funding or carry out fundraising activities then you might find it advantageous to register as a charity.

However, you cannot become a charity unless you have a charitable purpose. Your charity's 'purpose' is what it is set up to achieve. It is important that your mission statement and constitution shows the forum has a 'charitable purpose' if you wish to become a charity. You can read more about what is considered charitable purpose on the Charity Commission website:

www.gov.uk/government/organisations/charity-commission

Example of charitable purpose

from Sheffield Parent Carer Forum (charitable company limited by guarantee):

The objects of the Company ('the objects') are to relieve the needs of children and young people, including their parents, carers and families, who have disabilities and/or special educational needs in the Sheffield area, in order to improve their quality of life, promote their inclusion in their local communities and to help and support them to reach their full potential.

When you register as a charity you will be given a charity number. Having a charity number can raise the public's confidence in your group, help you attract more volunteers and fundraise. Many trusts and businesses will only give money to registered charities.

Registered charities may also:

- get relief from some taxes, such as VAT concessions
- become eligible for schemes such as Gift Aid and payroll giving (Give As You Earn). Both of these schemes will enable your group to claim the tax on donations from tax payers. The value of such schemes varies depending on donors' income tax rates.

If you decide to register as a charity you will need to:

- select a board of trustees. These are normally unpaid volunteers who are responsible for applying the group's constitution and managing it
You do not need a huge number of trustees but should have at least three: a Chair, a Secretary and a Treasurer
- draw up and formally adopt a constitution through a formal meeting of your members
- once registered, hold an Annual General Meeting (AGM) each year and submit an annual return (a report showing your annual income and expenditure) to the Charity Commission
- if your income is greater than £10,000 your annual return will need to include a summary of your accounts. For example annual income, expenditure, assets. If your income is greater than £25,000 you will also have to have your accounts audited.

Role of trustees

Trustees have overall control of a charity and are responsible for making sure it's doing what it was set up to do. In some forums the members of the steering group involved in running the forum are the trustees.

Other forums have appointed trustees who are not parent carers of disabled children, or involved in running the forum. This can be a useful way of bringing in people with additional expertise to advise on running the forum, for example someone with business management or fundraising expertise. However, this approach would mean additional work for the forum management committee in writing reports for and attending trustee meetings. It is also possible that the trustees might sometimes have different priorities than the steering group.

i You can read more about trustees on the Charity Commission website:

www.gov.uk/government/organisations/charity-commission

Types of charity

There are four types of charity to choose from:

- unincorporated association
- charitable incorporated organisation (CIO)
- charitable company, and
- trust.

Trusts are unlikely to be suitable for parent carer forums as they have a small membership and their sole purpose is to donate money to others. Below is a brief overview of the other three types of charity.

Unincorporated association and registered charity

You can remain an 'unincorporated association' (see page 15) and register as a charity. This is suitable for charities with a membership but relatively small income and assets. If you take this option your forum is still not a recognised legal structure, so the forum has still not got the legal capacity to enter into contracts in the name of the forum.

► **This means**

- You have a charity number which can be helpful for fundraising and applying for charitable grants.

► **To think about**

- Trustees will be liable for what your charity does but the forum can take out insurance to protect them from this.
- This is not really suitable if you want to employ staff or enter into business contracts to deliver services. For example, sign an agreement where the forum is paid by the local authority to provide a service such as training staff or running consultations events.
- You will need to submit an annual return to the Charity Commission if your income is greater than £10,000, and if your income is greater than £25,000 you will also need to provide audited accounts.

Charitable Incorporated Organisation(CIO)

CIOs were introduced in 2012 by the Charity Commission. They are suitable for small charities who want to employ people and enter into contracts. There are two types of CIO:

- an association CIO is suitable for organisations where there is a wider membership who can vote on decisions at AGMs, which is likely to be the case for forums
- a foundation CIO is suitable for organisations where the only members are trustees – so not likely to be suitable for a forum.

► **This means**

- You have a charity number which can be helpful for fundraising and applying for charitable grants.
- Trustees (or directors) are protected in most circumstances against contractual liabilities. For example, if the charity cannot meet its debts the trustees are not personally responsible to meet the shortfall.
- The forum can employ staff and enter into business contracts to deliver services. For example, sign an agreement where the forum is paid by the local authority to provide a service such as training staff or running consultations events.

► **To think about**

- You will need to submit an annual return to the Charity Commission if your income is greater than £10,000, and if your annual income is greater than £25,000 you will need to submit audited accounts as well.
- You will need to keep a register of members and trustees.
- You will need to keep a record of meetings of trustees and any decisions made.

Charitable Company limited by guarantee

This option is more suitable for large organisations.

► **This means**

- You have a charity number which can be helpful for fundraising and applying for charitable grants.
- Trustees (or directors) are protected in most circumstances against contractual liabilities.
- The forum can employ staff and enter into business contracts to deliver services.

► To think about

- Registering and administering a CIO is a simpler process than becoming a charitable company limited by guarantee.
- You must register your charitable company with both the Charity Commission and Companies House. You will need to provide both of these with detailed information on your finances and activities each year.

Top Tips

- If you decide to register as a charity make use of the model constitution provided by the Charity Commission for the type of charity you choose.
- Charities have various legal obligations, including showing details of their charity registration on all their information material. For example letters, leaflets, websites.

i More information on starting and running a charity can be found on the Charity Commission website:

www.gov.uk/government/organisations/charity-commission

Social enterprises and Community Interest Companies

Social enterprises

Social enterprises are businesses trading for social and environmental purposes. Any profits they make have to be reinvested into the business. They are run by directors who can be, but do not have to be paid.

A Community Interest Company (CIC) is a type of social enterprise company suitable for small organisations. A CIC can employ people and enter into contracts.

Compared with a charity a CIC has:

- greater flexibility in terms of activity
- no trustees and no trustee control
- directors who can be paid, but this is regulated.

Community Interest Company

Suitable for small organisations who want to employ people and enter into contracts.

► This means

- The forum is protected in most circumstances against contractual liabilities.
- The forum can employ staff and enter into business contracts to deliver services.

► To think about

- You do not have the benefits charities have around fundraising and claiming tax benefits.
- You will need to produce annual reports to the regulator of Community Interest Companies (CICs), reporting on activities and annual returns.
- When writing your constitution, known as 'articles of association', consider how much of a say you want members to have in decisions regarding the running of the forum.

Top Tip

The regulator of Community Interest Companies provides various model templates to use when developing your constitution. Some of these templates are suitable for organisations where the directors make most of the key decisions in running the organisation. Other templates are suitable for organisations where the directors make most of the day to day decisions about the company's business, but give members a strong role in controlling the overall governance of the company. This needs careful consideration when choosing which template to use.

i More information on setting up a social enterprise can be found at:

www.gov.uk/set-up-a-social-enterprise

We recommend you take further advice before deciding on a legal structure. Details of organisations who can help with this are provided overleaf.

Useful organisations and further information

- ▶ **Charity Commission** – information on setting up, registering and running a charity:
www.gov.uk/government/organisations/charity-commission
- ▶ **Community Interest Companies** – the processes you need to follow, and the documents you need to submit, when you are a community interest company or you wish to form one:
www.gov.uk/government/organisations/office-of-the-regulator-of-community-interest-companies
- ▶ **Contact a Family** – Group Action Pack: Role of trustees - description of the role of trustees:
www.cafamily.org.uk/media/533721/group_action_pack_the_role_of_trustees.pdf
- ▶ **Get Legal** – free, online reference and decision-making tool for charities, social enterprises and co-operative organisations. Get Legal has been developed by the National Council for Voluntary Organisations (NCVO), with support from Bates, Wells & Braithwaite, leading lawyers for charities and social enterprises, to enable organisations and their advisers to access clear information and guidance on the most appropriate legal form and governance structure for delivering their goals:
www.getlegal.org.uk
- ▶ **The Governance Hub** – provides support for good governance in the voluntary and community sector in England. They produce a range of information and resources for trustees, chairs and management committees:
www.governancehub.org.uk
- ▶ **LawWorks** – offers free legal information and advice to community groups like forums, in England and Wales:
<http://lawworks.org.uk/community-groups>
- ▶ **Local infrastructure organisations** – (such as Councils for Voluntary Action, or Councils for Voluntary Service) offer information and advice on charity registration and other issues to voluntary and community groups. To find your nearest local infrastructure organisation contact the National Association for Voluntary and Community Action (NAVCA) on 0114 278 6636:
www.navca.org.uk
- ▶ **Small Charities Coalition** – is free to join and offers advice on running a small charity:
www.smallcharities.org.uk

1.3 Policies

Why are policies and procedures important?

Having clearly written policies and procedures helps ensure that everyone involved in the work of the forum has guidelines on how to deal with situations when they occur.

A little time invested at the beginning when the forum is being formed can save a lot of time and effort later on. Some forums have developed policies after finding themselves in a difficult situation. These forums now realise it would have been easier if there had been policies in place before the problem arose.

Policies do not need to be complex or lengthy documents.

There are a range of sample policies available on the Contact a Family website that could be adapted for your own forum. They can be downloaded from:

www.cafamily.org.uk/runaforum

Policies that a parent carer forum will find useful include:

- code of conduct
- equality and diversity
- safeguarding
- data protection
- social media
- financial policies – covered separately in *Section 1.4 Finance management and paying parents*.

i *The National Network of Parent Carer Forums have also developed their own policies which forums might find useful to adapt. These can be found on the useful information section of their website:*

www.nnpf.org.uk

Code of conduct

The forum should agree a code of conduct to help make sure its actions are transparent, that its representatives act with integrity and give people confidence in the organisation.

This could include sections on:

- ▶ **Behaviour** – treating people courteously and with dignity and respect.
- ▶ **Confidentiality** – following agreed rules for confidentiality after attending meetings. Not sharing information about individuals unless the individual has given permission to share, or there are child protection or legal issues arising.
- ▶ **Conflict of interest** – so members must declare any actual or potential conflict of interest. For example, if a member of the steering group runs a training company that is offering to provide training to the forum.

The code of conduct should require representatives of the forum including committee members to sign up to abide by the code.

It is also important that there is a clear process for what action will be taken in the event of an individual not abiding by the code.

You might find it helpful to read the National Network of Parent Carer Forums' code of conduct.

Parent carer representatives

You might want to include a separate code of conduct for parents representing the forum on working groups or strategic boards. This would include that they feed in the views of the wider parent carer group at meetings, even if they do not agree with those views – something that not all people are able to do. Parent carer representatives need to be clear about what would be expected of them when they are representing the forum.

- ❗ *An example of a Code of Conduct and parent carer representatives' agreement form can be found on the Contact a Family website:*

www.cafamily.org.uk/runaforum

Equality and diversity

This should state the forum's policy in promoting equality around issues such as:

- race
- disability
- religion or belief
- gender, sexual orientation or gender reassignment
- age.

i You can download a template for an equality and diversity policy from:

www.cafamily.org.uk/runaforum

Safeguarding

Safeguarding children is vital for parent carer forums as they have a duty of care towards the children with whom they have contact. Having safeguards in place within an organisation not only protects and promotes the welfare of children but also gives confidence to the management committee, any staff that are employed, volunteers, parents/carers and the general public.

It shows the forum's commitment to protecting children, giving clear signals that the forum takes safeguarding children seriously in all aspects of its activity. The development and implementation of a clear and concise Safeguarding Children policy supported by clearly described procedures is a key requirement of any organisation working with children and families.

i Contact a Family has produced a safeguarding policy template that you may wish to draw on for your forum:

www.cafamily.org.uk/runaforum

Data protection

The Data Protection Act 1998 requires organisations processing personal data to register with the Information Commissioner's Office (ICO) unless they are exempt. If your organisation was established for not-for-profit purposes and does not make a profit, you are exempt from registration.

The Information Commissioner's Office has an online self-assessment to check if your forum needs to register or not:

http://ico.org.uk/for_organisations/data_protection/registration/self-assessment

If you handle personal information about individuals, your forum will still have a number of legal obligations to protect that information under the Data Protection Act 1998.

Some key principles about data collection are as follows:

- information must be collected and used fairly and inside the law
- information must only be held and used for the reasons given
- it must not be kept longer than is necessary for the registered purpose
- the information must be kept safe and secure. This includes keeping the information backed up and away from any unauthorised access.

A forum's information data protection policy should be written with these key points in mind.

It is also important to think about data in the form of photographs and to include in the policy the permission requirements for using photographs of members of the forum and/or their children, for example photos taken at parent forum events.

i *Contact a Family has produced a template for the development of a data protection policy:*

www.cafamily.org.uk/runaforum

i *You can read more about the eight principles of data protection and download a plain English guide from the Information Commissioner's Office website:*

http://ico.org.uk/for_organisations/data_protection/the_guide

Social media

Services such as Facebook, Instagram, Flickr, YouTube and Twitter are social media. Social media services like these are designed to encourage social interaction through the creation and sharing of content among groups and the wider world. They can be a very useful element of a parent carer forum's communication strategy.

However, when a forum decides to use social media it is important to remember that once something is posted on the internet it cannot be taken back (even if it is not visible). Any content posted on social media will be publicly accessible and will represent your organisation. So it is important to have a policy on this.

Your social media policy should cover:

- staying within legal frameworks – libel, defamation, copyright, data protection
- safeguarding children
- posting content
- permission to post information on behalf of the forum
- personal responsibility for content posted on social media
- requirement to use a standard disclaimer
- acceptable conduct on social media
- moderation of content
- action to be taken regarding 'inappropriate content'.

i *Contact a Family has produced a template for development of a data protection policy:*
www.cafamily.org.uk/runaforum

Further reading

i *Contact a Family Group Action Pack – Social networking. Search for 'Group Action Pack – Social networking' on our website:*
www.cafamily.org.uk

1.4 Finance management

Financial policy

It helps to have a financial policy that outlines:

- what money can be spent on and who can authorise it
- who will record money coming in and going out (income/expenditure)
- how frequently the management committee will monitor finances to make sure there is enough money to carry out all the planned activities.

A financial policy helps protect the parent carer forum and the individuals who run it. It aids you in monitoring your finances, helps ensure you obtain value for money and is good practice for any organisation in receipt of a grant.

- i** *Contact a Family has an example of a financial control policy for parent carer forums which can be downloaded from our website:*

www.cafamily.org.uk/runaforum

Usually the treasurer or bookkeeper has overall responsibility for ensuring the forum's accounts are correct and up to date. Many people are nervous about handling money in any quantity. If you don't have someone on the management committee who feels confident about this aspect of the forum's work, find a forum member familiar with book keeping or accounts who will be prepared to help. This could be by helping the treasurer or bookkeeper set up systems to record income and expenditure on.

Forums will find it helpful to keep their accounts on a spreadsheet, such as Microsoft Excel. A spreadsheet allows you to calculate sub totals and totals more easily. It also enables information about proof of expenditure to be presented clearly, and cross referenced with the actual receipts.

Members of the committee might also want to consider attending a training course to help them with this role. There are many free local classes and quite possibly a parent/carer within the forum will be able to help with training.

- i** *Contact a Family has developed a spreadsheet to assist with recording a forum's spending throughout the financial year, which will also help with the grant monitoring process. This can be found on the grant and monitoring section of the website:*

www.cafamily.org.uk/parentcarerparticipation

Why it is important to budget

Budgeting is planning how to spend the forum's available funds. It helps to have a budget in place from the start of the financial year or funding period. Without a plan the forum risks:

- spending its money too soon in the year, leaving too little for the later months
- spending money on the wrong things.

You can develop a budget simply by deciding on headings for the things you need to cover, for example events, publicity, training, and deciding on how much money from the total you have available to devote to each.

During the year the treasurer or bookkeeper should keep the budget under review by making sure spending is staying in line with planning. It makes sense to do this regularly, say at least once a term, through reports to the management committee.

Preparing a budget also forces people to plan ahead and may act as a reminder of work to be done. Some tips for budgeting are:

- if appropriate, base your budget on previous years' accounts but include an amount to cover rising costs
- be realistic about expenses and remember that many quotations do not include VAT
- make sure everyone knows the budget and keeps within it.

Payment of parents' expenses

No parent carer carrying out work on behalf of the forum should be out of pocket for their activity (travel costs, phone calls, photocopying and childcare). Parents with disabled children often have to give up their work to care for their child. This can have a huge impact on their income and many will rely on benefits.

If their expenses are not paid promptly, parents who rely on benefits might be prevented from taking an active part in the forum. This could prevent families who rely on benefits because their children have the most complex needs, from being an active member of the forum.

It is useful to have a remuneration policy which explains what expenses people can claim for when carrying out tasks for the forum. This might be within the financial policy or written as a separate policy.

The policy should include:

- ▶ **Travel expenses** – what can be claimed for different modes of transport, for example train, bus, mileage of private cars, when it is appropriate to use a taxi.
- ▶ **Childcare** – you might want to consider whether to have a maximum hourly rate. Some parent carers will need 2-1 care for their child which is expensive. But refusing to pay above a particular rate could prevent some parents from being involved.
- ▶ **Refreshments** – expenses for refreshments when parents are on forum business, including maximum amount that can be claimed.
- ▶ **General expenses** – such as stationery and postage, and the costs of telephone calls when parents carry out activities for the forum.
- ▶ **Receipts** – parent carers claiming expenses will need to provide receipts for audit purposes or sign claim forms for expenses, if it is not possible to provide receipts For example car mileage.

Having a record of receipts also provides evidence to the Inland Revenue that parent carers are being paid expenses, rather than being paid for work which would be treated as taxable income.

If parents are paid more in expenses than they've actually spent ('above out of pocket expenses') then this would be treated as taxable income and could affect their benefits.

- ❗ *The Inland Revenue website has information on the maximum rate that can be claimed for travel expenses, including car mileage:*

www.hmrc.gov.uk/rate/travel.htm

Parent carers appreciate having an easy way to claim for expenses, and carers need to know who is responsible for paying them their expenses. Giving cash to the parent carer in return for completing an expenses form at the meeting is especially useful for parent carers on low incomes or benefits.

Paying people for their time (remuneration)

You might find that some members of the committee are putting in a considerable amount of time supporting the work of the forum.

Parents representing the forum on strategic working groups can find themselves working for considerable amounts of time in an unpaid capacity alongside paid professionals doing similar work. Other parent carers might find themselves spending a large amount of their time carrying out administrative tasks in running the forum or organising forum events.

It is not reasonable to expect people to contribute a huge amount of their time and expertise for no financial reward. You might want to explore agreeing a policy to reimburse parent carer representatives with the local authority/health service for their time and expenses for their work on strategic working groups.

Some forums like to offer parent carers payments for their time, skills and expertise.

This can be a difficult area as some parents do wish to be paid for their time and others do not. Receiving payment can affect parent carers who are on benefits or can impact on tax. It is helpful if the forum can agree an overall strategy which offers all parent carers the same for similar work.

This strategy would state what type of work the forum would offer payments for and at what rate. This might include attending meetings, giving presentations at events, organising events. It would also include how these activities will be reimbursed, evidence of parent carers' involvement (for example feedback forms from attendance of meetings) and timescales for claiming and reimbursement.

i You can download an example of a financial and expenses remuneration policy and procedure from the Contact a Family website:

www.cafamily.org.uk/runaforum

One-off payments

It is possible to make a payment to a parent carer for a one-off involvement activity which takes place on one day only within one financial year. This payment is viewed as a thank you gift. It could be paid to parent carers to feedback their views in a consultation. The payment should be a reasonable amount for the activity and there should be no prior involvement within the same financial year (from 6 April). It could be given as a voucher which will be easier for the forum to provide an audit trail. This could be paid as an incentive and thank you to parent carers attending a focus group for the day.

People on benefits should inform Jobcentre Plus but it should not affect a person's entitlement to welfare benefits (provided the amount does not take their savings above the capital limit for benefits). Tax and National Insurance do not usually apply to one-off payments and should not be deducted. Notifying Her Majesty's Revenue and Customs (HMRC) about one-off payments is not required, provided they are for one day only in the financial year.

Honorarium and vouchers

Rather than pay an hourly rate, forums sometimes consider paying parent carers a single payment (honorarium), or giving them vouchers for a complete piece of work. For example running a consultation, writing a report. Both of these would be considered as taxable income by the Inland Revenue and could affect parent carers' benefits.

Important things to consider

If you are going to offer to pay parent carers for specific tasks you first need to consider:

- whether the Inland Revenue might consider the forum as an employer and the implications if this happens
- the responsibility of parent carers being paid as self-employed to notify the Inland Revenue
- the possible impact for parent carers who are on benefits.

When the forum is the employer

If a parent carer has a job description or is paid for an activity for a fixed number of hours on a regular basis the Inland Revenue might consider this as paid employment. In this case the forum paying the parent carer would be responsible for paying any tax and National Insurance (NI) contributions due, and other entitlements such as holiday pay. If the organisation did not deduct tax and NI contributions as it should have done the Inland Revenue would hold them responsible for any back tax and National Insurance that should have been deducted.

i HMRC has a series of questions to help determine whether a role should be categorised as employed or self employed:

www.hmrc.gov.uk/calcs/esi.htm

Forums are advised to seek clarification from their local tax office if in doubt.

Responsibilities of parents being paid as self employed

If the forum wants to pay for a specific task, for example organise an event or run a training session, it is most likely that they will choose to pay a parent carer for their time on a self-employed basis. If this is the case the parent carer will need to provide a signed statement for each payment saying they will be responsible for paying any tax and NI contributions due.

Parent carers might want to take advice about how any payment for their involvement would affect their tax/NI contributions before agreeing to receiving payments.

i *The HMRC website has useful information about thresholds for paying tax, NI contributions and completing self assessment returns:*

www.hmrc.gov.uk/individuals/index.shtml

Impact on benefits for parent carers

Any money earned may affect any income related benefits that people receive.

Parent carers on benefits are required to inform the Department for Work and Pensions (DWP) of any income they are receiving. Earnings might also affect benefits claimed from the local authority such as Housing and Council Tax Benefit.

It is not possible to write simple guidance on how much a parent carer could earn before affecting their benefits as it is very much dependant on the individual's financial situation.

The safest option for any parent carer who is considering receiving payment, by money or by voucher, is to call the Contact a Family freephone helpline to find out if their benefits would be affected if they are paid, and how much they can earn without affecting their other benefits and entitlements. Contact a Family's helpline has qualified financial advisers who can help parents with this on freephone 0808 808 3555.

 You might want to make sure parent carers on benefits are aware of the following:

Averaging rule – the benefits system limits the amount a person receiving benefits can be paid. This usually applies on a weekly basis. This rule allows more than the weekly disregard or limit to be paid for involvement in one week, if no paid involvement takes place in other weeks. The involved person must ask Jobcentre Plus in advance if they will treat payments as averaged.

It is the individual person's responsibility to find out about their benefits conditions and notify the Jobcentre Plus of their intentions to take up an offer of involvement.

Example**Averaging Rule**

Susan has been told she can earn up to £75 a week without affecting her benefits.

In May she received £100 from the forum for work carried out in week one, but did not receive any payment for the rest of the month. If the £100 was taken as weekly income it would affect her benefits. However, by averaging the payment over a four week period she had received an average of £25 a week, so her benefits were not affected.

The Welfare Reform Act 2012

The Welfare Reform Act 2012 introduced a number of changes to the welfare benefits system for service users who are working to improve services through user involvement.

If people receiving Universal Credit accept a fee for service user involvement, it will be classed as earned income and will be taken into account when calculating their entitlement to Universal Credit. But:

- any reimbursed out of pocket expenses will not be treated as earnings
- they will be able to accept a fee lower than that offered or turn down payment for involvement and their entitlement to Universal Credit will not be affected.

i Further information can be found in Chapter H3 in the *Advice for decision making: staff guide*:

www.gov.uk/government/publications/advice-for-decision-making-staff-guide

Further sources of information

i *Contact a Family Group Action Pack – Fundraising for local and national support groups:*

<http://tinyurl.com/puauawt>

i *Department of Health: Reward and Recognition – Principles and practice of service user payment and reimbursement in health and social care (2006):*

www.dh.gov.uk/en/index.htm

i *HM Revenue and Customs Employment Status Indicator – has a series of questions to help determine whether a role should be categorised as employed or self employed:*

www.hmrc.gov.uk/calcs/esi.htm

i *HM Revenue and Customs – table showing personal tax allowances:*

www.hmrc.gov.uk/rates/it.htm

i *Payment for Involvement – a guide for making payments to members of the public actively involved in NHS, public health and social care research:*

www.invo.org.uk/posttypepublication/payment-for-involvement

1.5 The Department for Education grant to support parent carer forums

For the last six years, the Department for Education has made a small grant available to one parent carer forum in each local authority area in England. The grant is available each financial year and provides the resource to support forums with basic costs that are incurred to enable them to continue to function and run.

The Conditions of Grant

There are 'Conditions of Grant' and every application needs to meet these. The main conditions are:

The grant must be used to strengthen the forum to ensure the active participation of parents in the service planning and decision making processes within each local area.

However, there are other conditions that also apply to the grant:

- Forums that apply must be pan-disability. This means their membership must be open to any parent carer of a child or young person with a special educational needs or disability living in the local authority area. They must not be restricted to families whose children have a specific disability or medical condition.
- Forums should participate across education, health and social care – so groups whose remit is to work with only one service can't apply. For example, a group only interested in health will not be eligible to apply for the grant.

The grant amount has varied between £10,000 and £15,000 and there are some restrictions about the activities that it can be used for. The grant is specifically to support activity relating to participation and should not be used for activities that relate to providing short breaks or family support. Whilst these are often much needed services in local areas, they should be resourced from other sources, and not from the participation grant.

Contact a Family approve, monitor and manage the grant process on behalf of the Department for Education and recommends approval of application forms and monitoring. The Department for Education makes the payments directly to parent carer forums.

If a forum or forum members are applying for the grant for the first time, there is a range of information available online, including videos explaining the process and what to consider. First time applicants should also talk to their parent carer participation advisor. You can find their contact details by going to www.cafamily.org.uk/pcp/supportforforums

The application process

Applications are made for each financial year from April – March and the relevant documents are available on the Contact a Family website at:

www.cafamily.org.uk/pcpgrants

Documentation is usually available from the end of January, including the closing date for applications. There are comprehensive guidance notes to support you to make your application, which are revised and updated each year.

As the grant process has been in place for some time, in most local areas there is an established forum that applies for the grant. The application form asks how the application will build on previous work in the area.

In a few areas each year, the established forum may cease to exist for various reasons and a new forum may be established.

If in any one area applications are received from more than one group or forum, we would seek to work with both groups to encourage them to work together and develop a shared application. However, if this is not possible, we will consider the applications and approve the application we feel most meets the Conditions of Grant and will enable parent carer participation in the local area.

Forums need to have their own bank account to be able to apply for the grant, or to be supported by another organisation that will hold the grant for them.

Forums are also expected to have a financial policy that describes how they determine how funds are spent, and what their processes are for ensuring this is done in a way that safeguards both the funds of the forums, and the individuals who are involved in the forum. Information on how to develop a financial policy can be found in *Section 1.4 Finance management*. Some forums use part of their grant to pay for an accountant to manage their finances for them, which is an acceptable use of the grant.

What information do forums need to provide in their application?

Forums are asked to provide a range of information within the application, so it is worth making sure you plan enough time to collect all of the information you need. If you submit your application without all of the necessary information, it will delay your application as we will have to come back and ask you for missing information.

The information you will need to have for your application includes:

- bank account details
- contact details of the forum, and parent carer representatives within the forum
- the kind of organisation your forum is
- how many parent carers are involved at different levels in your forum.
For example, the steering group, representatives, forum members you communicate with
- if your forum receives any other funding or financial support.

The largest part of the application form asks you about the outcomes and outputs you hope to achieve through using the parent carer participation grant. By this we mean:

- ▶ **Outcomes** – what outcomes or changes the forum expects to bring about as a result of their work. For example, having parent carer representatives influence and work with different strategic groups in the local authority to support service evaluation. Or become more representative by involving more parents from targeted ‘seldom heard/harder to reach’ groups’.
- ▶ **Outputs** – what outputs or activities the forum expects to carry out (for example attending meetings, workshops, website development, consultation events, newsletters or events) to bring about these outcomes.
- ▶ **Budget** – a financial breakdown of how the forum plans to spend the grant to achieve these outputs and outcomes.

Forums who have experience of completing their application recommend that your forum considers your outcomes first, then work out what outputs you need to achieve this, and then consider how to allocate your budget to achieve this.

When we look at your grant application form, we will look at how your budget spend links to your outcomes and outputs.

Contact a Family have developed a spreadsheet to assist forums with recording their forum’s spending through the financial year. This will also assist with the grant monitoring

process. You can download this spreadsheet, the grant monitoring form, and guidance on completing your grant monitoring from the Contact a Family website at:

www.cafamily.org.uk/pcpgrants

There is always the opportunity to adjust your budget throughout the year if your forum's circumstances or activities need to change. To do this you need to talk to your parent carer participation advisor who will complete a grant variation with you. Depending on the size of the variation they will either be able to agree it, or ask a manager to agree to it. If you change your planned spend without doing this, you may be challenged about this when your grant spend is monitored and this can cause some difficulties.

Support for your application

Once your application is complete, we ask that you seek support from the partners you intend to work with. This does not mean that forums have to ask these partners to support the details of their application or even see the application (although forums may wish to share it). The forum itself needs to determine its priorities and what it aims to achieve throughout the year.

However, as the purpose of the forum is to work with statutory partners and other organisations to participate, we need to know that those organisations do recognise and are willing to work with the forum.

As such the wording of the signatures of support is:

"I support this forum to make this application, and will work with them as the voice of parent carers in this area."

We ask forums to seek support from their local authority, health partners, and other key partners, including other local parent groups and other groups who work with parent carers, for example their local Information Advice and Support Service (formerly called Parent Partnership Service). This can also be a good opportunity for forums to make sure they are linking with these groups, and in turn the partners can promote the forum to the parent carers they are working with.

You can ask your parent carer participation advisor to check your application before sending it in, or for advice on filling in the form.

The process

Once the completed application form has been sent to Contact a Family you should receive notification within a few days that it has been received. A few weeks later you should receive notification of whether your application has been successful, and when the money should be received. The grant is usually paid in two parts.

1. The first part is normally applied for from set dates between March and June, and paid after 1 April, once the application has been approved.
2. The second grant payment is normally applied for from set dates between September and November, and paid once the monitoring from the previous year has been approved (see below).

Grant monitoring and reporting

At the end of each financial year, a parent carer forum that has received a grant will need to provide Contact a Family with details of how it has been spent. This usually consists of a completed monitoring form which shows:

- proof of how the grant has been spent
- the outputs and outcomes achieved
- information about the development of the forum, and their working relationships with key strategic partners.

These have to be submitted by a set date, usually around the end of April.

It is important that forums can account for how they have spent public money, and to ensure that it has been spent in the way that was agreed in line with their application.

The monitoring also provides important information from forums about their activity, about how effective that has been, the challenges that they have experienced throughout the year, and the successes that have been achieved through the participation of the forum.

This information is invaluable for being able to evidence the impact that parent carer participation has on local services and why forums should continue to receive the funding and support they need to continue running and be sustainable.

The information also helps other people who are developing groups to understand the true costs involved and help future planning of the grants programme.

Proof of grant spent

Parent carer forums will be expected to submit proofs of expenditure. These will be invoices, receipts, petty cash vouchers and any other documents that prove how the grant has been spent. For example:

- ▶ **Invoices** – these might be for goods or services ordered from companies (venue hire, outside caterers), or raised by individuals such as admin support, childcare, speakers.
- ▶ **Receipts** – received when purchasing goods such as refreshments, stationery, equipment.
- ▶ **Petty cash vouchers** – these can be purchased at local stationers. They are assigned by people when they have made a small one-off expenditure, such as parents' travel expenses, teas/coffees for small meetings.
- ▶ **Expense forms** – these provide a brief description when money is spent on a number of items, to which the receipts can be attached.

It is important that forums have considered this when they receive the grant, and have a clear plan for how they collect and keep this information so it is readily available for them at the end of the financial year when they need to submit it. The spreadsheet mentioned in the application section on page 29 can be a useful tool.

- i** *We have quick tips to support forums to keep the financial side of things flowing. They can be downloaded at:*

www.cafamily.org.uk/pcpgrants

Outcomes and outputs

We also ask forums to provide clear information about the outputs (what they have done) and the outcomes (what has been achieved by their activity). It can often be difficult at the end of the year to remember everything that your forum has been involved in and achieved. Forums that have been completing the monitoring for some time recommend that forums have a way to record throughout the year the activity they have been involved in, and the outcomes that they have achieved – even if this is just keeping notes in a book, or having a slot in each of their steering group meetings to record this. This makes completing the monitoring less difficult at the end of the financial year.

Whilst it is always good to see how forums have worked with lots of organisations, we particularly want to hear about the difference their participation has made to service delivery, improvement or evaluation. It can be difficult sometimes to articulate how having parent carer representatives working with partners has made a difference, so it can be worth asking those you are engaged with what difference they think the involvement of the forum has made.

It is also important to remember that when we review the monitoring form we have to consider how much the forum has spent, against their outcomes. So if a lot of the grant has been spent in one area but has led to no outcomes, we may need to ask you about this.

If forums do not provide the relevant information in their monitoring form, this may mean we have to come back and ask you for more details and this can delay the final approval of your monitoring.

Although completing the monitoring form can be time consuming, it is vital to ensure the continued funding and support for forums. It also gives the opportunity for forums to share the successes and challenges they have experienced throughout the year with the Department for Education.

Information about the development of the forum and their working relationships with key strategic partners

The grant monitoring form also asks forums to provide a range of information about:

- the way they work
- how their membership is made up
- how they seek to work with and represent parent carers who may face additional barriers to engaging
- how they link with other parent groups in your local area, and
- their working relationships with key stakeholders, including education, health and social care.

There are some specific questions in relation to elements of work where there is a legal (statutory) duty to work with parent carers – the short breaks duty, and the local offer.

This information is really important to enable forums to provide evidence locally about who they represent, and how they link with the broader parent carer community. It is also very important to provide evidence of how statutory partners may be working with local forums, and to identify if there are common challenges and successes that forums across England are experiencing.

The anonymised results of all forums' monitoring in relation to these aspects are published every year so that forums can then see the national picture.

i Further information

All of the information and guidance about the parent carer participation grant is on our website. It includes a short video explaining the grant application process, with useful tips from forums about how to approach the application form and ideas about what to include. Visit:

www.family.org.uk/pcpgrants

Please contact either the local parent carer participation adviser or the Contact a Family grants team for further information or advice. Their contact details can be found at:

www.cafamily.org.uk/pcp/supportforforums

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2.1 Attracting and keeping members

Advertising the forum

Your parent carer forum will want to attract as many parents as possible to become members.

Having a large number of members helps you to:

- hear about and be able to represent the experiences of families with a range of conditions/disabilities when you talk to and work alongside service providers/commissioners
- provide evidence that an issue affects a large number of families. This will help you make the case that improvement is needed
- be recognised as an organisation that is representative of families with disabled children.

Parents might be put off joining the forum if they think it is going to involve lots of work. They are more likely to join if they know that they can decide on how little, or how much, involvement they have. For example, they might want to receive information/input into surveys/attend occasional meetings but not wish to be a parent carer representative on strategic decision making boards.

You may find it helpful to have a leaflet that you can give to parents telling them about the forum and how they can join.

It is worth spending time on designing this leaflet to make sure it explains:

- in simple English, what the purpose of the forum is (your mission statement, or aims and objectives)
- how parent carers can make contact with the forum and become a member
- how parent carers can contribute their views
- why it is important that parents join – to make positive changes to the services that affect their families.

Make sure it has an attractive and eye-catching style and the wording will encourage parents to read it.

It is also helpful to have information to give out showing how the forum has helped improve services in your area.

Keeping information about your members

Some forums have designed their leaflet to include a membership form as a tear-off strip, so people can fill in their details and return directly to you at an event or meeting. However, you might prefer to have a separate membership form to collect members' contact and address details.

When taking down details of new members, you might also want to ask for:

- details of their child's age and condition – this will help you target members for consultations about particular services. It will also show that the forum is representative of a wide and varied range of ages and disabilities
- how parents prefer to receive communications – it is much more cost effective to communicate electronically, but not all parents will have an email address
- information about parents' ethnicity/geographical area – to help ensure that the forum membership is representative of the local community and if not, get to know which groups you need to target.

TOP TIP

Before getting a leaflet printed ask a few parents who know nothing about the forum to read it and say whether it makes sense, and would encourage them to join.

i You can read more about producing information in:

Section 3.1 Communications – Getting the basics right

Reaching parents

There are various methods you can use to tell parents about the forum. Choose the methods that work best for you. Try to get other parents involved in spreading the word.

▶ Visit local parent carer groups, including specific condition groups

Many parents opt to join a local parents group which specialises in one disability such as autism, ADHD, Down syndrome or hearing impairments. These parents may not realise that many of the problems they experience are also experienced by other families whose children have a different condition.

Some parent carer forums have found it effective for a member of the forum to visit local parent carer groups where they meet, to tell them about the forum, why it was set up and how they can join.

If you invite a member of the parent carer support group to join the forum's steering group this will provide an effective way for parents in this group to feed their experiences in to the forum.

▶ Leaflets at places which families visit

You could ask centres that families with disabled children visit to give out your leaflet and include information about the forum in newsletters they send out.

These might include:

- Information, Advice and Support Services for SEND (formerly called parent partnership service)
- GP surgeries/health centres
- child development team/centre
- the local carers centre or other local voluntary organisations with an interest in disabled children
- toy library
- schools
- children's centres
- hospital departments accessed by families with disabled children.

You are more likely to be successful in getting parents to become involved if you can persuade staff at the centre to give out the leaflets to parents, rather than simply leave them on display in a waiting room.

One enterprising forum in a rural area persuaded the drivers of the school transport to give leaflets out to parents at their homes as they dropped their disabled children off after school.

► Information stalls at events

You can ask to have a stall at events which parents with disabled children are likely to attend.

This might include:

- school parents' evenings or annual fêtes
- disability-specific events and conferences
- family fun days
- local shows
- supermarkets/shopping centres.

You might want to order some pull up banners and pop-up stands to make your stall more interesting. You could also attract people to your stall by running a free raffle or lucky dip.

► Ask schools to tell parents about the forum and how to join

You could approach people at the local school (for example, the SENCO) and ask them to give your leaflet out to parents of children with special educational needs (SEN).

► Using local media

It can be highly effective to use local media to reach parents, particularly when launching a new parent carer forum or telling people about a recent success. Local radio, television and papers are all potentially interested in local human interest stories. Not everyone will be confident enough to talk to the local media and this often needs to be done at short notice. All media will want a story to hook the reader and so parents will also need to feel comfortable about telling their own story about why they joined the forum.

You might want to get a shortlist of parent carers who are willing to speak to the media and feel comfortable talking about why they joined the forum and what they get out of it.

- i** For more information on talking to the media read the *Contact a Family Group Action Pack – Speaking to the media*:

www.cafamily.org.uk/media/435005/gapspeakingtothedia_finaloct2010.pdf

► *Ask people working with disabled children to let parents know about you*

Contact those who work with disabled children in your area to ask them if they would be willing to hand out your literature to families accessing their services.

These could include:

- community paediatricians and child development teams
- early years workers such as health visitors, portage workers, pre-school teachers who work with children at home
- Information, Advice and Support Service for SEND (formerly Parent Partnership Services)
- special schools and SENCOs in mainstream schools
- local voluntary organisations and carers' centres. For example, Barnardos, Carers Trust (formerly the Princess Royal Trust for Carers), Mencap
- social workers and family support workers
- children's therapy teams such as occupational therapy, physiotherapy and speech and language therapy
- support workers and social workers in Child and Adolescent Mental Health Services (CAMHS).

Running your own events

These can include large formal events or small informal meetings, such as:

► *Coffee mornings/drop in sessions*

You may want to consider running coffee mornings/drop ins in different parts of the area you cover and inviting parents to come and have coffee, cake and share their experiences. This will help you find out what issues are affecting parents, which might help the forum prioritise its work. These are really useful for those parent carers who do not wish to attend formal meetings but would like to feed in their views. Sometimes they act as a stepping stone to more active forum involvement. Some areas ask professionals to attend the sessions so that they can capture feedback on their services directly from parents.

► *Focus groups or workshops*

You might decide to run an event which focuses on a particular topic of interest to parents. You may invite service providers to speak on this topic, for example transition, speech and language therapy, Information Advice and Support Service for SEND (formerly Parent Partnership Service). You could also use it as an opportunity to consult parent carers about their experiences of this service, to help gather evidence about why improvements are needed.

► *Information events*

One well tested way is to hold an information event for families of disabled children. Ask staff from local services as well as local support and carers groups to man information stands where families can find out about how they support families with disabled children. For example benefits, education, short breaks, transition.

These kinds of events should always be free of charge, and held in an accessible venue, with good transport links. You might want to consider holding it during the day, preferably in term-time between 10am to 2pm, as well as in the evening or weekend to allow working parents to attend.

Use this as an opportunity to tell parents about the forum and encourage them to join.

► *Road Shows*

This can work in large or rural areas where taking information to parent carers enables them to travel shorter distances to meet you. You could consider doing this in partnership with a range of other stakeholders to increase the appeal and share the costs.

► Conference

When holding a conference, the forum can set the agenda to include topics and key-note speakers which are of interest to parent carers. Conferences can be an excellent way to both share information and gather feedback from parents, which can then be fed back to local service managers. They can also attract media attention which will mean more people hear about the forum. Conferences can be costly and some forums hold joint conferences with their local authority which they have co-produced and co-fund.

► Specific activities

Organising activities such as a dads' pub night or a picnic in the park are cheap and easy ways to encourage parent carers with similar interests to come together in a relaxed environment, where they can talk comfortably about issues that are affecting them.

Make sure the feedback gathered at these events is written up and fed into forum steering group meetings. Follow up with attendees and let them know if anything changes as a result of them telling you about what is important to them.

TOP TIP

Consider the amount of effort involved in organising these, what they are likely to achieve and the costs involved when deciding on what type of event(s) to run.

Being inclusive

Try to make events and meetings accessible to as many people as possible:

- consider having events at different times of the day, including evenings and weekends so more parents can attend
- choose dates that do not clash with religious festivals and holidays
- make arrangements for people with special dietary requirements, including religious ones
- choose venues that are as culturally neutral as possible
- if running an all day event be aware some members may need to worship at different times of the day and a separate room or area may be required for this.

i Useful resources

Further information about religious festivals and holidays and calendars of religious festivals can be found at:

www.interfaithcalendar.org

www.bbc.co.uk/religion/tools/calendar/

Information on cultural dietary requirements can be found by visiting:

www.faithandfood.com

You can check school holidays for your areas on your local authority website.

Targeting 'hard-to-reach' groups

At some stage you will want to review your membership to find out if there are particular groups of parent carers who you have not yet reached.

These might include:

- parents from minority ethnic groups, including parent carers who do not speak or read English
- parents of children with very complex needs, who might find it difficult to leave the house
- parents who live in geographically isolated areas
- parents whose children are 'under the radar' because their children are in mainstream settings
- parents who move round a lot and/or are in temporary accommodation
- parents with low levels of literacy and/or learning disabilities
- families from the armed forces
- teenage mothers
- parents with mental health problems or fathers
- single parents
- parents who work
- disabled parents.

Families from hard-to-reach groups often have the most trouble accessing services.

To identify the groups you want to target, start by looking at information about your current membership, such as the postal address, child's disability, age and ethnic origin.

You will then need to consider what groups there are in your area who you are not reaching. For example, families in social housing, or those from different ethnic origins.

Each local area is different in terms of its community – or demography. It should be possible to get demographic information about your local area from websites such as:

Office for National Statistics – neighbourhood statistics:

www.neighbourhood.statistics.gov.uk/dissemination

Office for National Statistics – ethnic breakdowns by local authority (search on 'ethnic background local authority census'):

www.ons.gov.uk

Make contact with people already working with a community

It is helpful to get to know more about the group you want to engage with and what might make it difficult for them to engage with your forum. For example language, cultural beliefs.

Rather than expecting parents from different communities to come to you, you might want to try to meet with them in settings where they already meet. They are more likely to agree to meet with you if you are introduced to them by someone they trust. Try to make links with organisations in your area who work with a particular community. Your local voluntary action groups should be able to help you with this. You can find their details at www.navca.org.uk

Alternatively, many communities have leaders or elders who are trusted by members of the community or speak on their behalf. Try to meet them and ask for their help in making contact with families who have disabled children.

i *You might find it helpful to read about how the parent carer forum in Gloucestershire increased their membership and reached minority groups:*

www.cafamily.org.uk/pcp/success

Retaining members

Once you have enthusiastic parents joining the parent carer forum you need to keep them engaged. If, having joined the forum or attended a meeting they hear nothing for many months then they are likely to become disillusioned with the forum and may leave.

Parents are more likely to stay interested and want to become more actively involved if they think the forum is going to be successful in improving services for disabled children.

It is important therefore, to have a communications strategy and to make sure that members receive regular communications to tell them about what the forum has been involved in. This might be through emails/newsletters/social media/or developing a website.

Ask parents what they think are the priority issues for the forum to work on. If you have consulted with parents about a service, write up a report on your findings and send out to parents as well as the local authority/health service.

Make sure members hear about any successes you have in improving services. For example, if your forum carried out a survey of parents on the continence service, wrote a report summarising the findings, discussed the results with the service provider which led to more choice in continence products, then make sure everyone hears about it. You can also use the opportunity to thank all parents who took part in the survey.

You might find it helps to produce a short 'You said, we did' style newsletter summarising what parents said and the actions you have taken.

i *For more information on how to do this see:*

Section 3 .3 Communications – Publicising the forum's work

2.2 Developing the team

Personalities and leadership styles

Most parent carer forums are run by a steering group of parent carer volunteers, who manage the day to day running of the forum (this might be called the forum management committee). Members of the steering group usually have different roles and responsibilities. For example Chair, Treasurer, Secretary, Communications.

i You can read more about this in Section 1 *Getting Started* and Section 2.2 *Making it work – Developing the team*.

The members of the forum steering group are likely to be very committed parents who are passionate about what they are doing and want to achieve. They might have very different experiences of services and different views on what changes are most needed. They will also have different personalities. Some parents might appear very confident and tend to be quite directive. Others might find it difficult to challenge when they disagree with what others are saying.

The steering group will be more effective if it works in a collaborative way, where everyone has a chance to put forward their views, and decisions are taken by the whole group. If parents feel they are not being listened to they may become disillusioned and leave. This will mean there are fewer parents to share the workload.

It can be useful to agree a few ground rules for meetings and remind people of them at the start of each meeting.

For example:

- listen, and respect the views of others
- share 'air time' evenly
- avoid interrupting
- keep discussions to the point and try not to repeat
- respect the confidentiality of the meeting.

Research has shown that teams work best when they are 'owned' by the group not by an individual. Making sure each member of the group has a specific area on which they lead can be a good approach.

The role of Chair

The group is likely to need a Chair whose role is not to lead the forum but to support the steering group to make decisions. The Chair has an important role in making sure everyone has the opportunity to put forward their view, that decisions are made by the whole group, and that the meeting ends on time. Having a relaxed and friendly style also makes people feel comfortable and happier to take part in the meeting.

When chairing a small group meeting it helps to:

- ▶ **Be prepared** – circulate an agenda in advance so everyone knows what will be discussed.
- ▶ **Make a good start** – begin by welcoming everyone and if there are new people, invite everybody to introduce themselves.
- ▶ **Ask someone to take notes** – these can be brief but need to include decisions made and who is to action them. Do not be tempted to try to do this as well as chair the meeting.
- ▶ **Outline the agenda** – and allow people to suggest items for Any Other Business (AOB) at the beginning, so you know to leave time for this at the end if necessary.
- ▶ **Keep to the agenda** – it is very easy for people to move away from the item being discussed and start to talk about a completely different topic. If this occurs and it is something that needs to be discussed, suggest putting it on the agenda for the following meeting.
- ▶ **Encourage discussion** – remain impartial, make sure everyone has the opportunity to contribute, invite people who have not contributed to give their opinion, then summarise what people have said.
- ▶ **Agree decisions** – as a group, make sure decisions are taken and noted so everyone is clear about what has been decided and what action is to be taken and by whom. Important decisions should be made democratically by taking a vote, with the chair having a casting vote in the event of a tie.
- ▶ **End on time** – this is really important, especially as parents might have caring responsibilities to attend to.

Chairing meetings is a real skill and there are training courses to help people to become more effective in this role.

Sharing the workload – making use of people’s skills

Sharing the workload between members of the steering group ensures that everyone has a part to play and feels involved. It also prevents all the effort and work falling to one or two people. This is vital in order to avoid burn out.

It can help to find out what skills individual members of the group have and how much time they have available for forum work. Then tasks can be shared within the group according to what each person can manage. You might do this by carrying out a skills audit and identify areas which committee members might like to get training in.

Carrying out a skills audit

Start by deciding as a group what skills you think you will need:

- ▶ **Organisational skills** – planning and running events, for example.
- ▶ **Administration** – maintaining the membership database, recording meetings, producing and sending out newsletters.
- ▶ **Facilitation skills** – consulting with parents about their experiences of services.
- ▶ **Negotiating skills** – knowing how to talk to people to get a result that both parties are happy with.
- ▶ **Meeting skills** – to be a parent carer representative on strategic groups or work streams.
- ▶ **IT skills** – to update/moderate social media or the forum’s website.
- ▶ **Budget management** – monitoring spend and making sure you are not going over budget.
- ▶ **Time management** – balancing forum work with other demands of personal and family life.

Next, invite each member of the group to say on a scale of 0-5 how comfortable they are in performing different tasks. This will help to build a profile of the skills available to you and highlight any areas where there are gaps. You will then be able to make enquiries about what training is available in your area. This might be through individuals attending training courses run in your area, or by paying a trainer to provide one day’s training to members of the steering group.

Some parents might not want to sit on a committee but are quite happy to be responsible for certain tasks. For example, taking leaflets to schools, helping to organise an event, maintaining the membership list.

If there are not enough people on the group to do all the work, think about setting up small working groups that could be chaired by a committee member, where other willing parent carer members of the forum do some of the work.

The steering group might find itself in the position where there are lots of areas of work that they want to get involved in, but they don't have enough capacity to take it all on. If this is the case it is important to prioritise and concentrate on the areas the forum can manage. It may be possible to pick up the other issues later.

There may be occasions when, due to the demands of personal or family life, the forum work becomes too much for one member. This is perfectly understandable, and members should be encouraged to think about their personal wellbeing before that of the forum. Sometimes taking a brief break from the work will be enough, but at times other members may need to stand down for a time, cease active forum work or even resign from the committee. Individual members should be encouraged to consider all of the options available and do what is right for them.

Parent carer representatives

Forums will want to nominate parent carer representatives to sit on local authority and health service strategic boards, committees, or task and finish groups so that parents' voices are heard and acted upon when decisions are being made about services affecting their children.

You can read more about these committees in *Section 4.1 Working in partnership – How local government works* and *Section 4.2 Working in partnership – How local health services are provided*.

It is important that parent carer representatives are able to feed in not only their own experiences and views but also those of others, even if they personally do not agree with them.

You might want to consider developing a code of conduct for parent carer representatives, so they understand what is expected of them when representing the forum. This will include how they are going to report back to the forum and what is expected of them around issues of confidentiality. This helps to promote a professional image of the forum's work and will help the forum to gain credibility with services.

You will want to make sure parent carer representatives report back to you about their work. You might find the sample parent carer representative feedback form on the Contact a Family website helpful:

www.cafamily.org.uk/runaforum

You might also want to discuss with the local authority/health service some minimum standards for the involvement of parent carer representatives in their meetings. For example, reasonable expenses; accessible meetings, times and venue; papers provided in good time before meetings.

Some forums find it helpful to have a minimum of two parents on a steering group.

This has the following advantages:

- it may enable the forum to represent a wider group of experiences, for example early years/primary/secondary/transition, learning disability/physical/complex needs
- it is less intimidating for parents
- new parent carer representatives can be supported by more experienced parents
- if one parent carer is unable to attend a meeting, the other parent carer can cover.

Some forums are structured so that all parent carer representatives are also members of the forum steering group. This is not always possible, especially if the local authority/health service invite the forum to provide parent carer representatives for lots of different working groups and committees.

Professionals sometimes invite individual parents who are not members of the forum to sit on their working groups or committees as parent carer representatives. When this occurs, it is not always clear how these parents represent experiences other than their own.

It can be helpful to meet with these professionals to tell them about the forum and explain how you would like to work with them. You might also invite the parent carer representatives on these committees to become a member of the forum.

Forums might find it helpful to invite parent carer representatives from all the different committees to meet with each other occasionally. This will provide a useful opportunity for the parent carer representatives to talk about any issues they might be experiencing in their role. It also provides an opportunity to invite parent carer representatives who are not members of the forum along and encourage them to become members of the forum.

It will also help the steering group to identify which are the key committees and boards they want a presence on and prioritise these, see *Section 4.1 Working with your local authority*, and *4.2 How local health services are provided in England*.

Managing conflict

It is almost inevitable that at some point in time there will be differences of opinion within the steering group over some aspect of the forum's work.

This might be because of disagreement over:

- who holds key positions in the forum
- which areas of work to prioritise
- how money is spent
- how to handle situations with local authorities or health services.

It can also be caused by:

- one person wanting to do things their way
- personality clashes
- inappropriate conduct by one or more member of the committee.

Conflict can be minimised by making sure that at meetings everyone is encouraged to express themselves openly and honestly and that decisions are made collectively and transparently. It also helps to have clear guidelines on how meetings will be conducted and what is deemed unacceptable behaviour or language.

Managing conflict calmly is key to neutralising or resolving it.

i For more advice watch the video 'Managing conflict for parent carer forums':

www.cafamily.org.uk/runaforum

If the conflict cannot be resolved by the group it may be helpful to involve a third party to mediate. They will:

- listen to all sides of an argument
- encourage individuals to move from their fixed positions or interests
- help people focus on what is needed in order to move beyond the issue
- encourage the group to find a solution which is owned and acceptable to all parties

- write an agreement which everyone must stick to
- enable the forum to refocus their attention on the positive outcomes they are trying to achieve.

Often just being given the opportunity to speak uninterrupted, and have someone listen to what the issues are and how they affect the other person, can be a major step towards the resolution of a conflict. People are often so caught up in how something affects them or their child that they do not consider the bigger picture or think about how the same issues may affect others in very different ways.

The services of a trained mediator do not come cheaply. You may be able to find someone you know who is impartial to assist, and negotiate between parties to help them reach an amicable solution.

TOP TIPS: *Managing conflict*

- ▶ Develop team 'ground rules' that commit to respecting the views of others.
- ▶ Allow people to express frustration or anger openly and respectfully, otherwise it can come out indirectly.
- ▶ Openly and calmly discuss differences before they develop into major conflict.
- ▶ Try to find solutions that incorporate any different viewpoints, if possible.
- ▶ Thank people for their contribution to the discussion.
- ▶ Ensure that decisions are made collectively – by vote if necessary, and are recorded.
- ▶ Ensure you have a code of conduct so there are agreed processes for managing very difficult situations before they occur.

Annual MOT – how are we doing?

It is easy to concentrate most of your efforts on activities which the forum has prioritised and forget to keep an eye on other things that also need your attention. This is why it can be helpful for the steering group to take time out to reflect on how they are doing and to reassess what their priorities are. This could be done once a year, to allow the group to plan what they hope to achieve, and how they will do it, during the coming year.

Topics the steering group might want to consider:

- ▶ **Membership** – retaining members/recruiting new members and targeting particular groups.
- ▶ **Marketing/communications** – do parents and professionals hear about your work?
- ▶ **Influencing services** – what was successful, what was not, what do you need to work on?
- ▶ **Building relationships** – with key people such as service leads/managers/commissioners/other groups and stakeholders.
- ▶ **Finance** – review your budget and check that spending is in line with your planning or any grant applications.
- ▶ **Capacity** – do you need to prioritise certain activities above others?

It can be really useful to do this with the help of a facilitator, so that all members of the forum steering group, including the Chair, are able to participate and reflect equally.

2.3 Planning for the future

It is inevitable that at some point in time, parent carers involved in the running of the forum will leave. This can be for many reasons, including:

- a parent carer needs to spend more time with their child or family if they are going through a difficult patch
- their personal circumstances change
- a parent carer goes back to work and no longer has time to be actively involved in the forum
- a parent's child moves into adult services
- parents find that being involved is too heavy a commitment on their time
- a family moves to another local authority area.

It is therefore important to:

- prioritise and spread the forum's workload so that parents do not get burnt out and leave – see *Section 2.2 Developing the team*
- make sure parent carers know that their work is appreciated, and feel that their time is usefully spent
- avoid becoming dependant on one or two parents – be continually recruiting and up-skilling new parents, and plan for succession (who will take over when parents leave).

Prioritise

Families with disabled children access many different services. The forum might want to be involved in improving many of these services. The forum may also receive requests from service managers wanting to involve them in their work. You may feel obliged to accept these requests for your involvement.

However, if you already have a full workload, you risk putting too much strain on people's time. The forum will need to carefully prioritise its work and concentrate on the tasks you have agreed are important, and that you have the capacity to complete without putting too much pressure on your members.

You might want to consult with members at your annual general meeting (AGM), to find out what their priorities are for change and concentrate on these.

Show appreciation and check people are OK

Do not take it for granted that people are happy with the role they have been asked to carry out. Take the time to check how people are finding the work. Give everyone the opportunity to talk about what is going well, and what they are finding difficult. If they are struggling, ask if they would benefit from attending a training course to increase their confidence and ability to perform a particular role. Find out if there is someone else who would be happy to share some of the work, mentor them, or if they are still not happy with that role, offer them something which is more suitable for their skill set.

Have processes in place if you have parent carer representatives who sit on committees but are not members of the steering group. Make sure they have someone on the forum they can contact if they begin to find this work difficult or if they have any questions. You may wish to arrange an induction for all parent carer representatives so that they know what is required of them, agree to the code of conduct, and the support available to them when carrying out their role. It may be useful to draw up a role description and to have a 'parent carer reps' agreement. Arrange for any new parent carer representative to go through the same induction and provide a mentor if necessary until they are confident in carrying out the role on their own.

Avoid 'founder syndrome'

Sometimes members of forum steering groups may have a tendency to do everything themselves and appear reluctant to involve other people. This can be because they feel new people would not fit in to the existing group or they would have too much to learn to get up to speed, or on a basic human level, the members of the founding group feel that they 'own' the forum. This is a well-known phenomenon that happens with groups, and it is understandable. It is sometimes referred to as 'founder syndrome'.

Indicators of 'founder syndrome' include:

- a founder who is at the centre of all decision-making with little input from others
- a steering group that rarely meets, or has constant turnover, or is made up of friends and family who have little input
- an organisation in which there is little thought for succession planning (who will take over from the initial group members)
- a founder who has few other interests or projects, devoting nearly all his/her time to the organisation
- a founder who has tried to leave, but always comes back
- comments such as, "I don't know what would happen without me".

Founder syndrome can happen to extremely talented and dedicated individuals.

How to avoid 'founder syndrome':

- building a strong steering group or management committee where everyone has a part to play
- planning regular reviews of the forum's work and who does what
- planning some team social events to help develop the group as a team
- welcoming and taking up offers of help from other committee members
- encouraging new members of the forum to get involved in working groups to gain experience that might lead to them becoming members of the committee
- developing a succession plan
- limiting the amount of time officer roles on the committee can be held by the same person.

Recruit parent carers and develop their skills

Parent carers who are new to the forum might lack the confidence to volunteer to help. They may feel that they don't know enough or that others know more than they do.

Try to provide opportunities for new parents to volunteer on small tasks which provide them with an opportunity to get to know you better. If they feel welcomed, they are more likely to volunteer to take on more work.

Other ways to include new members might be to:

- run regular training courses on parent carer participation and/or being a parent carer representative, for parents who are thinking of becoming involved
- have clear role descriptions for parent carer representatives and members of the steering group which includes what is required of them
- provide a list of training courses that parents can attend to skill them up for a role. For example, chairing a meeting, presentation skills, accounts or minute taking
- have two parent carer representative places on each committee, so parents new to the work can shadow more experienced parent carer representatives.

Finally, you are more likely to attract and retain new parents if:

- you show respect for each other
- your meetings are well managed and keep to time
- you occasionally take time out to socialise and get to know each other outside of forum meetings. For example, a group meal out or a team building exercise which can help the forum to gel.

Plan for succession

As part of your annual health check (see *Section 2.2 Developing the team*) ask everyone:

- how they are finding their roles
- if they are happy with their work, and
- if they have any plans they might have for the future, which might affect their ability to take part in forum work.

It is always useful to 'up-skill' other members of the steering group or wider forum, so they are prepared to take over a role in the event of another parent having to leave.

If you are aware that a member is going to leave the forum, ask them to mentor another parent so that they can learn about the role from the experienced parent ahead of their departure. This does not always work as people sometimes leave suddenly. This is why it is sensible to have well-trained parent carers who are able to fulfil a variety of roles until new members can be recruited.

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3.1 Getting the basics rights

House styles

It helps to decide from the start on a 'house style' for consistency in all your communications. This will make your forum appear more professional and any of your literature or publications will be instantly recognisable as having come from you. Having an attractive house style will also help generate interest and attract more parents to join your forum.

Choose a colour for your forum, a name, a logo and a typeface. Use the house style in all your communications including posters, flyers, newsletters, PowerPoint presentations, your website and social media.

Example

Read how Gloucestershire Parent Carer Forum doubled its membership after improving its publicity and promotional material:

www.cafamily.org.uk/pcp/success

Tips for written material

Make your headlines attention grabbing

Consider the power of headlines and try to come up with a title that will attract parents' interest.

Parents attention is not likely to grabbed by phrases such as 'Influencing services', 'Parent participation' or 'Strategic committees'.

They are more likely to respond to phrases that appeal to them personally, such as:

- does your child have additional needs?
- are you getting the support and help you need?
- help us improve services for disabled children.

Keep it simple

Stick to the vital information and keep the language simple but not patronising. Busy parents are not going to take time to wade through dense and dry text. Give some thought to your local community. It helps to have written information accessible to the widest possible audience. For example, do some of your target audience speak English as a second language?

When producing promotional leaflets make sure you include:

- the name of the forum
- your aims or mission statement
- brief description of what you do
- why it is important for parents to join
- how to make contact – try to give at least two contact names, email, telephone number, address, and links to your website and social media if you have them.

If you are all volunteers working from home, consider buying a dedicated mobile phone for the forum and avoid giving out someone's private telephone number.

Producing flyers to advertise events – make sure you include:

- the purpose of the meeting
- who the event is for
- the date and time
- the place
- any costs involved
- the availability of help with travel and childcare costs
- where to get more information and how to book places.

If you are a registered charity or a social enterprise, do not forget there are legal obligations to include details of your registration on all your information material.

If you receive funding from another organisation, there might also be requirement to acknowledge their support and include their logo.

Design tips

- ▶ Do not squeeze too much onto a page – empty space helps readability.
- ▶ Use a clear font at 12pt or above.
- ▶ CAPITALS ARE FINE for short headings but not for long sections of text.
- ▶ It's better to use bold text rather than underlining for emphasis.
- ▶ Use left justified text as it is easier for the eye to follow.
- ▶ Use photographs, illustrations and text boxes to break up large areas of text.
- ▶ Leave a reasonable space between the text and the lines of a text box.

Photos and illustrations

A positive picture of a child often catches people's attention. Some parents are happy for their child's photos to be used for the publicity of causes they support. It is important that photos represent children from as many ethnic groups in your local community as possible so that all parents carers feel welcome.

Whenever using photos of 'real' people you must get their written permission to do so. If the images are of a child you will need their parent or guardian's permission.

Write a simple 'photo permission' form. Have tick boxes to say where the photos can be used, for example, on your website, for media campaigns, in publications.

Let people choose on the form how long they will allow you to use their images for. This is important if parents allow you to use pictures of their children. When children become teenagers they may not want photos of themselves as a child used on the forum's website or elsewhere.

If it is not possible to use photos of local families, you can buy images from online photo libraries, for example www.shutterstock.com and www.istockphoto.com

Printing and publishing

A desktop publishing package may make this job easier but many forums have made effective leaflets using a simple word processing package such as Microsoft Word.

Your options for printing include:

- using your own computer printer
- using a photocopier
- commercial printing company.

Some computer printers are much slower than photocopiers. If you are printing a large number of leaflets or flyers you might find it quicker and easier to use a photocopier. This might also be cheaper as ink cartridges for computer printers can be expensive. Using a higher-quality paper will also make the final product look more professional.

It is also worthwhile finding out how much it would cost to get your material printed by a commercial printing company. This is likely to provide a higher-quality print, and with advances in technology is getting cheaper.

If you use a commercial printing company, check with them which format you should use to send your publication to them. You might want to use a professional designer to lay out the leaflet. If you do this make sure you get the final version back, so that you can use it as a template to produce publications in the future.

Telephones

Forums should consider buying a mobile phone to provide a main contact number for members of the public wanting to contact the forum. Avoid giving out parents' personal telephone numbers as main contacts for the forum. If you do this, parents might find themselves receiving telephone calls about the forum at inconvenient times. For example evenings, weekends, or when they are in meetings. Parents can always put the forum's mobile phone on divert, but might be reluctant to do this with their personal number, especially if they might need to be contacted if their child has a problem.

Also if the parent carer changes role within the forum, or stands down, it is easy to give the mobile phone to another person who is taking over their role.

If no-one's available to take calls, it helps to have a friendly voice mail message which encourages callers to leave a message, and saying someone will return their call soon.

Emails

Email is a very useful form of communication. It is simple to use, fast, cheap and you can use it to send bulk communications such as newsletters to most of your membership. But there can be downsides to using email.

It is important that you follow some basic guidelines if your forum uses email to communicate with its members:

- before using email, consider whether a phone call, a letter or a face-to-face meeting would be more appropriate
- use a courteous greeting/sign-off – as well as 'please' and thank you'
- check over what you've written to avoid misunderstandings – it can help to read the email out loud to make sure the tone is as you intended
- be aware of punctuation – an email's intended message or tone may change drastically if a comma, for example, is in the wrong place
- be aware that what you send out in an email is in writing and cannot be taken back
- keep emails brief and to the point
- make sure attachments are of a reasonable size and in a software/software version commonly held by users
- acknowledge emails in a timely manner

- if your forum only checks their emails periodically, you may wish to have a holding message letting parents know that you will be in touch soon, or provide a telephone number if they would like a quicker response
- during school holidays you may wish to set up an out-of-office message that lets people know when you will be resuming forum work.

Things to avoid in emails

- ▶ Do not say in an email anything that you would not say in a letter or in person.
- ▶ Do not bombard your members with emails, they will get sick of receiving them and stop reading them.
- ▶ If sending out emails to publicise events to your members do not allow everyone's email addresses to show. Use blind copy (BCC). This is a serious privacy issue.
- ▶ Never use a forwarded or an old email, hit reply and start typing about an entirely new topic. It may contain information that you or someone else does not want to be shared. Begin a new message thread for each new person or topic.

3.2 Websites

A website is an effective way of informing many people of the existence of your forum and its work. You can use a website to:

- tell people about your forum and how to contact you
- tell parents about meetings, consultations and opportunities to get involved
- keep people up to date with what is going on, for example success stories, results of consultations and details of what the forum is currently involved in
- attract parents who do not like using telephones and cannot get to, or don't wish to, attend meetings
- link to local networks, for example parent carer groups, local services and useful information, including the 'local offer'
- set up online forums to enable parents to contribute their views on local services when they cannot get to meetings so they still have their voice heard
- raise your forum's profile amongst service managers and professionals.

Setting up a website – issues to consider

This is not intended to be an exhaustive guide to setting up a website. However, here are a few practicalities to consider:

► What will it cost?

You will need to think about whether you want to pay a web designer or whether you have someone in the forum with the skills to set it up. Alternatively, you may be able to get a volunteer from outside of the forum to help you (see table on page 73).

There may be software or hardware computer costs and training costs. You will need to pay the cost of registering your domain name and an annual registration fee.

► What should it contain?

Your website will want to include information about:

- the forum's purpose and who can join
- how the forum is run and how often it meets
- how parents can join and get involved
- contact details for people wanting more information
- what the forum is currently involved in
- how the forum has been successful in improving services.

You will also want to advertise forum meetings, events and consultations.

Community Website Builder

The Community Website Builder allows registered UK charities, non-profit making organisations and volunteer-led groups or organisations to build and maintain their own website free of charge. To qualify for use of the free service your organisation must be from the United Kingdom, provide a clear benefit to the local community, and be one of the following:

- a registered charity
- a non-profit making organisation
- a volunteer-led group.

If you are unsure if your organisation qualifies, you can check your eligibility by sending full details of your organisation and its intended use of the website to e-mailsupport@ik.com or call 08700 112850. To start using the Community Website Builder go to:

www.btck.co.uk/

IT4Communities

IT4Communities is a national IT volunteering programme that:

- helps charities and community/voluntary groups to find volunteers to help with their IT needs
- helps IT professionals to find suitable IT volunteering opportunities
- provides support for volunteering projects from project definition to project completion:

www.it4communities.org.uk/it4c/home/index.jsp

► Should we have an online forum?

Online forums allow parents to comment on particular issues, as well as creating an on-going dialogue with parents who may not attend forum meetings in person. An online forum is also helpful to parent carer representatives who sit on steering groups and committees as they are able to represent the views of as wide a range of parents as possible.

However, if parents are adding their views, someone needs to be responsible for responding to them and moderating any inappropriate content.

Online forums need guidelines on appropriate use so it is worth making contact with other groups who already have an e-forum to find out how they are monitored. You may wish to develop a social media policy. See *Section 1.3 Getting started – Policies*.

► Naming your website

Your forum will need to settle on a name you all feel happy with. Having your own domain name is something to aim for. Most groups opt for a .org.uk domain (the use of the word .org denotes a charitable or not-for-profit organisation) but some choose the more global org.com.

Once you have registered the address it is yours for as long as you pay the annual fee. You can move the site to a different Internet Service Provider (ISP) and keep the same address.

i Nominet.uk gives clear information about domain names. Nominet is officially recognised as the .uk domain name registry by the internet industry, users and the UK Government. Nominet ensures that each domain is only used once and all the other providers have to register through them:

www.nominet.org.uk

► Maintaining your website

It gives a bad impression of an organisation if their website has not been updated for some time. Unfortunately a lot of websites fail because there is no one with the time or expertise to maintain it.

When you set up your website make sure you choose software that is going to be easy for members of the committee to use to keep the web up to date. If possible choose software that allows more than one person to update content, so you do not have to rely on only one person.

Next steps

When you have thought about these issues, the next step is to seek or get advice from someone who knows about website construction.

Some forums will have members who can help with this. However, it can be relatively cheap to pay someone to build a website and this might be the better option if parents are going to be too busy to commit time to put in the work. If you go down this route, make sure that it is going to be relatively simple for parents to keep the website updated once it has been built.

i *Many forums have already developed excellent websites. Have a look at as many as you can to get ideas. Some examples can be found at:*

www.swindonparentsandcarers.org.uk

www.interface-parentforumredbridge.org.uk/

www.in-it-together.org.uk

Publicising your website

There are ways that you can make sure parents and professionals find out about your website including:

- putting your website address on all your publicity for the forum
- ensuring your correct details are included in your Local Offer
- publicising it in local newsletters which are distributed by schools, local charities and/or Disability Register
- thinking about what key words people will use to find the forum and use them prominently on the home page to aid searches
- keeping your design simple and clear so there is less clutter for search engines
- links to your site are a key source of ranking. Compile a list of relevant websites and ask them if they will add a link to your website on theirs – for example, the section on the council's website page for families with disabled children).

3.3 Social media

The rapid growth of social media, such as Facebook, YouTube and Twitter, in recent years enables forums to reach many more people. It has several benefits:

- it is a low-cost way of sharing information and publicising your forum
- it provides a way for your members to share their thoughts, ideas and experiences
- you can reach parents who perhaps cannot attend meetings because of caring or financial constraints.

Facebook

Many forums have set up their own Facebook page to share news of events and keep in touch with other parent carer forums.

Some forums opt to have a public Facebook page, which anyone can see, as well as a closed Facebook page which only members of the forum can see and post comments.

- the public Facebook page is used to promote the forum, its purpose, and events and consultations they are involved with
- the closed Facebook page provides a private place where parent carers who are members of the forum can comment on their experiences. This can be a useful way to gather evidence that many people are affected by the same problem.

It can be helpful to have a statement on your Facebook page explaining its purpose, what is considered acceptable conduct and how inappropriate messages will be moderated. See social media policy in *Section 3.1 Getting started – Policies*.

The National Network of Parent Carer Forums have set up a national Facebook page which allows forums to keep in touch with each other. This provides an easy mechanism for forums to share information, resources and experiences with each other.

i *Some parent carer forum Facebook pages:*

www.facebook.com/PODSForumTelford

www.facebook.com/pipstockport/info

www.facebook.com/groups/181544370100/?fref=nf

Example

Stockport Parents in Partnership had a website, a Facebook page attracting on average 200 hits a week, and a Twitter account. They used £300 of their grant money to fund one day's training in social media for 15 parent carers, who were either members of their steering group, or parent carer representatives for the forum.

The training included information on how to present information on Facebook and how regularly posting messages would increase the forum's visibility and popularity on Facebook.

Now the forum's work on social media is shared amongst a larger group of parent carers. Using the information provided on the training course led to them increasing the number of hits on their Facebook page to an average of 10,000 hits a week.

Twitter

Twitter can be useful for:

- posting brief messages to give people up-to-date information about the forum
- finding and making contact with key people such as commissioners or strategic leads in your area.

Training in social media

There are many things to consider when setting up social media including:

- making sure it is used in a way that gives the forum a professional image
- agreeing who can send messages and post information on behalf of the forum
- developing people's skills so as not to rely on just one person
- finding how to increase the number of people who will find you via social media
- what to do if someone posts something that is inappropriate or offensive.

It can be really helpful to buy in training for the forum on using social media, to help address all of these issues.

3.4 Keeping people informed

Making sure that people know about your work and achievements is really important. It can help to:

- give people confidence in the forum
- boost morale – make people feel good about being part of the forum
- attract membership and support
- attract funding
- promote the forum to other parents, services and groups.
- let parents and professionals hear about your achievements.

If parent carers see that the forum is representing their views and working to improve services for disabled children, they are more likely to become members and perhaps be motivated to take on a more active role.

If parent carers hear very little about the work of the forum they are likely to become disillusioned, and lose their motivation to remain members or be involved.

If professionals or organisations hear about the successful work of the forum they are more likely to want to involve the forum in their work and to work in partnership.

It is, therefore, important to regularly update people about the forum's work, especially any success stories.

Newsletters

Newsletters can be a useful way of keeping people informed. You could ask other organisations who send newsletters out to parents with disabled children if you could have a regular item in their newsletter. For example, the local authority, parent partnership service or Healthwatch.

You could decide to produce your own newsletter and ask a member to take responsibility for producing it. The newsletter can then be added to your website and emailed to members.

Things to consider when developing a newsletter:

- ▶ **Design** – you might want to pay a graphic designer to design a template for the first newsletter which can be edited by you for later issues. This will make it look more professional. If you want to print copies on your own printer, stick to an A4 format and avoid too many deep colours – they will use a lot of ink.
- ▶ **Length** – have a maximum number of pages and stick to that. Keeping it short and simple means more people are likely to read it.

- ▶ **Content** – you might decide to include information of interest to parents; for example, holiday activities for disabled children. This could attract more parents to read the newsletter. However if you do this, make sure the newsletter still gets its main message across, which is informing parents about the forum’s work and the difference it has made to developing local services.
- ▶ **Frequency** – agree how frequently you are going to send out the newsletter. It is better to opt to send it out less regularly, (say each term), rather than say you are going to send it out more frequently and fail to do so.
- ▶ **Printing** – it will be much cheaper and less work to email the newsletter to people. However having a printed copy can be useful to give out at events and meetings. You might also want to mail printed copies to families who do not have internet access.
- ▶ **Planning** – from your planned distribution date work backwards to include time for gathering articles, checking articles, proof reading, including your forum’s contact details, and printing.

Reports of consultations /events

You might want to consult your members about their experience of a particular service and write this up as a report. This can be a useful way of providing evidence of a problem to agencies, and asking them to agree to work with you to find a solution.

When writing reports include:

- **quantitative evidence (numbers).** For example: 80% of families were dissatisfied with the choice of continence pads available, and
- **qualitative evidence (how it affects individuals).** For example: a parent carer at the meeting said ‘the pads my son is supplied with leak at night – so we are continually having to change him and his bedding in the middle of the night’.

Add a summary or ‘key findings’ section at the front for people who are not likely to have time to read the full report.

As well as submitting your reports to the agencies responsible for the service, put them on your website so people can see what you have been doing, and the influence that you have had.

Talking to the media

Talking to the local media about your forum provides an opportunity to reach out to more parents and raise the profile of your group with potential funders, partners, policy makers and other organisations.

Local papers are often on the look out for a story, especially if you can send them photos to go with the article. Local radio stations are often interested in events in their area for inclusion in features such as 'What's on' slots, news bulletins, longer features or as part of a social action/community programme.

The media prefer human-interest stories and will probably want a personal angle. If you do this, it is important to consider issues of confidentiality before being interviewed. It is important to think carefully about what your key messages are and how to describe the problems that are taking place while still putting across a positive image of disability.

i *You can read more about this in:*

Contact a Family Group Action Pack – Speaking to the media

Contact a Family Group Action Pack – Writing a news release

TOP TIP

MPs often want to have the opportunity to be seen in the local press. If you invite your local MP or portfolio member councillor to a forum event or meeting, then also invite the local press. This way your forum gets some local publicity as well as the MP/councillor.

It also provides you with an opportunity to raise your MP's awareness of the work of the forum and the issues affecting families with disabled children.

4 Working in partnership

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4.1 How local government works in England

'Local government' is the collective name for local councils – often called local authorities. Local councils are made up of councillors (elected members) who are voted for by the public in local elections, and paid council staff (officers) who deliver services.

Most council services are statutory. This means the council must provide them because they have a legal duty to do so (see page 94). Some council services are tightly controlled by central government, so there is a similar level of service across England (for example, Housing Benefit payments). But councils have some choice over the level and type of some services they provide (for example, short breaks for disabled children).

When councils have more money they can provide a greater range of services that go beyond their legal duties. But when the budget is tight, they often only provide services they have a legal duty to provide, rather than services they could provide but don't have a legal duty to do so.

Local government structures

The type(s) of council in your area will depend on where you live.

Some councils have two tiers:

- Tier 1: County and city council – responsible for services across the whole of a county or city, such as education, transport and social care
- Tier 2: District and borough councils – cover a smaller area, often a town or rural area, and are usually responsible for services like rubbish collection and recycling, leisure services and housing.

Other councils have one tier of local government which provides all services. They are called unitary authorities but might confusingly be called city councils, borough councils, metropolitan borough councils, or just councils.

Funding

Local government has three main sources of income:

- grants from central government
- council tax
- other locally generated income. This includes income from fees, charges for services and rent for social housing.

Councils are heavily dependent on the grants they receive from central government and are limited in how they can increase income from local sources.

The council decides how the income it receives will be spent to provide the different services it is responsible for, and has a legal duty to provide. The council will get advice from officers working for the council when it makes these decisions.

A few of the grants from central government will be 'ring fenced', meaning they can only be spent on providing a specific service. For example, the dedicated Schools Grant can only be used to pay for running schools under local authority control.

Decision making – councillors

Each local authority has a cabinet, made up of councillors who act as an executive board. The cabinet is responsible for drawing up policies, plans and strategies, and recommending them to the overall council.

The cabinet will be led by either the leader of the council, or in some areas by an elected mayor. Usually, each member of the cabinet is responsible for one aspect of the council's work; for example education, children's services, adult services and culture. They will have a 'portfolio' of work they are responsible for.

Members of the cabinet and the leader of the council may have a lot of influence and are useful people for the forum to make contact with to let them know about the forum's work.

Lead member for children and young people

This is an elected councillor who is responsible for working with officers to make sure that services for children and young people are fit for purpose. As elected officials, they are accountable to voters, including parent carers, who live in their area. They are also likely to sit on the key, strategic decision-making boards and groups for children and young people in your local area. They can be invaluable allies to parent carer forums.

TOP TIP

Councillors, Mayors and Lead Members often like to receive invitations to speak at events, as it may provide an opportunity for them to have positive press coverage.

Inviting them to speak at one of your events gives you the opportunity to tell them about the forum, encourage them to support your work, and also get publicity about the forum in the local press as well.

Decision making – committees /sub-committees

Each local authority is set up in different ways, and might call some of their decision making and strategic groups something slightly different. This summary is a general outline of the way many operate.

There will be a number of committees and sub-committees preparing papers to take to cabinet for approval, and making decisions relating to how services are run.

You might want to build links with people who chair or sit on these committees so that you can keep them informed about the issues experienced by children and young people with special educational needs and disabilities, and their families.

Members of these committees will often include members of staff working for the council. These committees are usually chaired by a member of the cabinet or a senior member of council staff with responsibilities for this area.

The services of most interest to forums are likely to be those involved in:

- children's services (including education and children and families services)
- adult service (including social care services for disabled people).

In some areas services for disabled children, young people and adults have been, or are being, merged into one service, usually called a 'People's Directorate'. There is still likely to be an individual with specific responsibilities for children and young people. You should be able to find out who this is from your local authority's website.

The following may have slightly different names in your area but are of particular interest to forums:

- ▶ **Children, Young People and Families Board** – a strategic board meeting where issues for all children and young people in the area are considered, planned and reviewed. It is usually attended by a range of multi-agency partners.
- ▶ **Learning Disability Partnership Board** – a strategic group that considers issues for adults with learning disabilities. It usually includes issues around transition and preparing for adulthood.
- ▶ **Health and Wellbeing Board** – a strategic board responsible for coordinating services between health and the local authority. Its membership includes the director of children’s services, director of adult social care, a representative of the clinical commissioning group and a representative from Healthwatch. There is a Healthwatch in every local authority area. It supports public and patient involvement in local health and social care services.

The Health and Wellbeing Board will also take a lead in relation to the Joint Strategic Needs Assessment.

A Joint Strategic Needs Assessments (JSNAs) is carried out by the local authority every few years to analyse the health needs of the local population and guide how it commission health, wellbeing and social care services. The information gathered from this is used for the health and well-being strategy, for the area. This influences how funding is allocated and which services are prioritised for improvements.

i *There are briefing papers on the Contact a Family website which will provide more detailed information, including:*

- *The role of Healthwatch and Healthwatch England*
- *How local Healthwatch and parent carer forums can help each other*
- *Health and Wellbeing Boards’ role in promoting integrated services*
- *Why Health and Wellbeing Boards should target disabled children services.*

They can all be downloaded from:

www.cafamily.org.uk/pcp/NHS

Overview and Scrutiny Committees

Every local authority in England has a process where elected members can question the people who sit on the council's Cabinet and council employees. They can also question representatives of certain other organisations and make recommendations to them.

Most councils do this through an Overview and Scrutiny Committee. Their members are made up of councillors who are not on the Executive Committee or Cabinet of that council. In some areas, the Overview and Scrutiny committees will have sub-committees which focus on a particular topic; for example health.

The Overview and Scrutiny committee can review issues of relevance to local people and make recommendations to decision makers, including NHS commissioners and the council. Committees can investigate any issue which affects their area and the people who live there, whether or not it is the direct responsibility of the council.

They have the right to refer matters back to the full council if they believe decisions have been made which breach the council's budget or strategy.

Some forums have found it helpful to approach their Overview and Scrutiny Committee when they have been unhappy with a particular service and have been unable to influence it through their involvement and participation with officers.

i You can read about how two forums successfully improved services by approaching their Overview and Scrutiny committee:

www.cafamily.org.uk/pcp/success

See: Hampshire: Improving therapy services across Hampshire – commissioning a new multidisciplinary therapist service.

Redbridge bringing about transformational change – developing a coordinated and integrated child development service.

Find out more

The strategic groups that meet should have their minutes, or a summary of the discussions, available to the public on the council's website. They usually have the terms of reference of the groups there too.

Parent carer representation on committees

It may be unlikely that your forum would be invited to have parent carer representation on high level strategic boards. These boards only spend a small proportion of their time discussing services for disabled children. Members of the board are expected to read lots of papers before going to meetings, and many of them won't be relevant to children with special educational needs and disabilities. Being a parent carer representative on these boards can be time consuming.

Forums might prefer to have parent carer representatives on sub-committees that have a particular focus on disabled children.

Forums should make their own decisions about which are the key strategic groups and meetings they want to be part of. They will want to consider the benefits and challenges of each one, and which are likely to lead to the best outcomes in terms of influencing decision making, and making links with key partners.

Example: influencing short breaks

The parent carer forum in Middlesbrough holds conferences twice a year which attract about 60 to 70 parents. Key leads such as the director of children services, the Mayor and local MPs regularly attend.

Parents frequently give presentations about their experiences – which helps everyone attending appreciate the difference services can make to people's lives.

At one event attended by the Mayor, five parents each gave a two-minute presentation on the difference short breaks made to their children's lives.

Following this, the Mayor made a commitment not to reduce spending on short breaks. This commitment was made at a time the council were having to make cuts to services because of a reduction in their funding from central government.

Useful people to build a working relationship include:

Director of children's services – this will be the person who is ultimately responsible for the children and young people's services in your local area.

Forums will also find it useful to link with the director, or lead for the special educational needs and disabilities (SEN or SEND) teams in the local authority. These will usually be individuals responsible for the support and quality of provision for children with SEND.

You may also want to find out who the lead is for children's social care, and the disabled children's team. Building strong working links with these individuals will help your work.

Example: decision-making process in short breaks

Activity	People with influence
Officers working for the council put proposals to strategic meetings, then the cabinet, about the short breaks service provisions and budget required.	Director of children's services, manager of disabled children services, committees making decisions affecting short breaks, short break commissioners, councillor with lead for children's services.
The cabinet considers proposals and makes recommendations to the Overview and Scrutiny Committee.	Leader of the council, Mayor, councillor with lead for children's services.
The Overview and Scrutiny Committee either accepts recommendations, or send them back to cabinet with comments for further consideration, or refers them for decision by full council.	Members of the Overview and Scrutiny Committee.
Once the budget is allocated, children's services are responsible for deciding how to spend the money allocated to them for short breaks.	Director of children's services, manager of disabled children's services, committees making decisions affecting short breaks, short break commissioners, councillor with the lead for children's services.

How government policy affects services run by local authorities

It can be useful for forums to be aware of government guidance for local authorities about services for disabled children, including any legal requirements or good practice guidelines.

If the guidance says the local authority 'must' provide a service, this will mean that a law has been passed in Parliament which says local authorities have to provide that service. This is known as a 'statutory duty' and it is illegal for the local authority not to provide that service. For example, the Education Act 1996 says local authorities must provide school-to-home transport for eligible disabled children.

If the guidance says local authorities 'should' provide a service, this usually means it is considered good practice but it is not a legal requirement.

Steve Broach, a barrister who specialises in the law around disabled children, has produced seven videos for parent carer forums. These videos give the current legal context for school transport, school funding, short breaks, personal budgets and direct payments, recent health developments, welfare reform, Housing Benefit and Council Tax Benefit, and the Children and Families Act 2014 for parent carer forums.

i Watch these videos on at:

www.cafamily.org.uk/runaforum

Next Steps

You can find information about your local authority structure and information about cabinet members and committees on your local authority's website.

If you cannot easily find this from the local authority home page, try entering searches on their website for key words like 'cabinet' and 'committees'.

i You can find out your local authority's website by going to:

www.gov.uk/find-your-local-council

4.2 How local health services are provided in England

There are two organisations responsible for providing local health services:

- clinical commissioning groups (CCGs) – providing community and hospital services for the local community
- NHS England – providing primary care services such as GPs, dentists and chemists.

NHS England also commission some services at a regional or national level including:

- some services for members of the armed forces and their families
- services for prisoners or people in custodial settings
- some specialised services usually required by only a few people, delivered by highly specialised staff or requiring extremely expensive equipment.

How health services are funded

The Treasury allocates money to the Department of Health. The Department of Health allocates money to NHS England. The Department of Health retains a proportion of the budget for its running costs and the funding of bodies such as Public Health England.

NHS England allocates money to the clinical commissioning groups (CCGs) to enable them to commission services for local populations. NHS England retains some of this money to pay for its running costs and the services it commissions directly: primary care (including GP services), specialised services, offender and military healthcare.

CCG budgets are allocated on a 'weighted capitation' basis. This means that budgets are set based on the size of the population, and adjusted for other factors, including the age profile of the population, the health of the population, and the location of the population.

The CCG then pays other organisations to provide hospital and community health services for people living in their area. They pay commissioners to help with managing this.

Organisations providing services can include NHS Foundation Trusts, NHS Hospital Trusts and NHS Community Trusts. It can also include private healthcare companies, voluntary organisations and social enterprises.

Clinical commissioning groups (CCGs)

The CCG is responsible for providing local hospital and community services for people living in their area. All GP practices have to be a member of a clinical commissioning group (CCG).

Some local authorities have only one CCG for their area. County councils covering a large geographical area are likely to have more than one CCG.

Clinical commissioning groups are managed by a governing body, which includes GPs, a registered nurse, a secondary-care specialist and at least two lay members.

The governing body will make final decisions on how the income they receive from central government will be spent. They have to consider all the health services that their local population needs.

Some members of the governing body will take the clinical lead for a particular area – for example, learning disabilities, children and young people, mental health. Not all CCG governing bodies include a clinical lead for children, though. One lay member is likely to have a lead role in championing patient and public involvement.

Members of the public can attend governing body meetings and submit questions to the committee in advance of the meetings. Papers for these meetings can be found on the clinical commissioning group website. Forums might find it useful to attend one of these meetings, in order to:

- gain a better understanding of how the governing body works
- identify individuals who might be useful contacts
- submit a question to bring a topic to the CCG's attention.

CCGs, GPs and public and patient involvement

Each GP practice has a patient participation group, made up of patient representatives who attend that GP practice. These representatives provide feedback to the GP practice about the services they provide, to help them improve.

CCGs also have a duty to involve the public and patients in their work when commissioning local community and hospital services. The methods used by CCGs to involve the public vary in each area. These methods can have advantages and disadvantages.

Ways CCGs might carry out public and patient involvement

Method	Advantage	Disadvantage
The CCG invites the local community to public patient engagement events.	The CCG get feedback from a large number of people through running one event.	Some patient groups might find it difficult to attend. The event may clash with the school run, for example, or carers cannot attend because of their caring responsibilities. It is difficult to feedback experiences of minority groups, such as families with disabled children, as most people at the event will have different priorities.
The CCG asks patient representatives from GP practices to feed into the CCG their experience of accessing local hospital and community services.	The CCG gets feedback from people across the whole geographical area.	The patient representatives might only reflect their own personal experience, and may not be aware of how services are experienced by other patient groups.
The CCG invites individuals living in the area to sign up to feedback their views through surveys.	It is easy to send out surveys and for individuals to feedback their experiences.	Individuals can get deluged with requests to complete surveys about health services they are not interested in and disengage. The survey might not pick up problems experienced by minority patient groups if they are only made up a small percentage of the sample.
The CCG builds links with patient groups/forums/charities in the local area and consult with them when changes are being planned that will affect services they use, such as the wheelchair service, the learning disability service, or mental health services.	The CCG has ready mechanisms to get feedback from patients/carers on specific services when decisions are being made about them. Patients/carers are only asked to become involved with services that are important to them so are more likely to stay engaged.	They might miss the views of the wider community.

i You can find contact details of CCGs for each local authority from:

www.cafamily.org.uk/pcp/NHS

If you search your local CCG website you can find:

- names of members of the governing body
- information about governing body meetings
- details of how the public and patients can be involved in the CCG's work.

Useful contacts might include:

- contact details for individuals/groups wanting to engage in public and patient involvement work
- clinicians on the governing body with an interest in services frequently used by disabled children
- lay members on the governing body leading on public and patient involvement.

Example

Hull parent carer forum – working with their CCG

NHS Hull clinical commissioning group (CCG) funds a parent participation coordinator to support the forum, facilitated by the charity KIDS.

In return, the forum agrees to carry out engagement and consultation with their members on their views and experiences of health services, when requested.

In 2013/14 the forum helped the CCG:

- commission a new children's wheelchair service
- develop an autism assessment and diagnostic pathway which meets NICE guidelines and has helped clear the one-year waiting list for this service
- run a pilot to support parents carers to manage sleep and behaviour issues
- gave feedback and suggestions for improvements to the local children's centre regarding accessibility and toys.

NHS England

NHS England is a national independent organisation set up to work at arm's length from the government:

www.england.nhs.uk

The main aim of NHS England is to improve the health outcomes for people in England.

As well as commissioning some services (primary, armed forces services, prisoners' services, and specialised), NHS England is responsible for:

- improving how health care is delivered across England
- overseeing the operation of clinical commissioning groups (CCGs)
- allocating resources to CCGs.

NHS England has 26 area teams, working across four regions, the north of England, London, the Midlands and east of England, and south of England.

The area teams act as 'local arms' of NHS England overseeing the operation of CCGs and commissioning local primary services. They might be useful to talk to if:

- you would like help from them in improving how GP services support disabled children and their families across the area they cover
- you want to share good practice from one local area (primary, community or hospital), especially if there is a 'post code lottery' of services across the region.

i You can find details of your regional and local area team on the NHS England website:

www.england.nhs.uk/about/regional-area-teams/

TOP TIP

Each NHS England area team covers more than one local authority, so you might want to work with neighbouring parent carer forums on this.

Example**Stockport - using social media to make links with key contacts**

The forum set up a twitter account and started to follow Kath Evans Twitter: @kathevens2.

Kath is NHS England Head of Patient Experience – Maternity, Newborn, Children and Young People, and has lots of people in health follow her.

The forum chair looked at who from Stockport was following Kath (people with the word Stockport in their Twitter identity).

This helped them identify the clinical commissioning group lead for children and various health commissioners for their area.

The forum started to follow them on Twitter and sent them a message telling them about the forum. This contact led to them building a working relationship with them.

Now the commissioners and health leads are following the forum on Twitter.

Working with organisations providing health services

The day-to-day running of the NHS can be split into two major functions:

- commissioning services for people
- providing services.

You can read more about how services are commissioned in *Section 4.3 Understanding and influencing service commissioning*.

Almost all organisations providing health services are expected to improve their service by listening to the people who use their service.

Many parent carer forums have found that approaching the organisations responsible for providing the service, and explaining to them the problems their members experienced, was all that was needed to bring about an improvement.

i *Almost all hospitals have websites with details of how patients and the public can get involved with improving services. You can find them on the NHS Choices website:*

www.nhs.uk/service-search

Useful contacts could be hospital matrons, lead paediatricians, Patient Advice and Liaison Services (PALS), senior staff on hospital wards, or the hospital governor (might be called Non-Executive Director) with the remit for public and patient involvement.

If the organisation is unhelpful, then the parent carer forum's next step might be to approach the clinical commissioning group who is paying for the service.

Example**Peterborough: Improving inpatient stay – working directly with hospital practitioners**

Family Voice Peterborough invited senior ward staff from the children's ward at their local hospital to attend their annual conference. This provided an opportunity for staff to hear first hand from parents about their experiences when their children were inpatients on the ward.

Many of the difficulties families faced related to needing support which took into account their child's disability. For example, children with autism were being put on wards with other children rather than in a single room. The noise and activity from the people around them was causing these children to become very distressed, which triggered challenging behaviour.

Following this event the senior nurse invited parents to a follow up meeting to discuss these issues further.

This led to changes being made so disabled children or children with additional needs were better understood and supported when staying in hospital:

www.cafamily.org.uk/pcp/success

Making use of clinical guidance and standards

Commissioners have to consider clinical guidance, including guidance set by National Institute of Clinical Excellence (NICE) and the Royal College of Paediatrics and Child Health (RCPCH), when they commission services.

NHS England is currently developing a range of tools to support effective commissioning. This will include setting service standards, model care pathways, commissioning guidance and standard contracts which will all be based on what is written in clinical guidelines.

You will find it helpful to know what these guidelines say when discussing these services with managers and commissioners.

i You can read more about these in our briefing paper called 'Making use of clinical guidance and standards', which can be downloaded from:

www.cafamily.org.uk/pcp/NHS

Example**Guidelines which might be of particular interest to parent carer forum include:**

- NICE: Attention deficit hyperactivity disorder: diagnosis and management of ADHD in children young people and adults
- NICE: Autism diagnosis in children and young people: recognition, referral and diagnosis of children and young people on the autism spectrum
- NICE: Autism: the management and support of children and young people on the autism spectrum
- NICE: The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care
- NICE: Spasticity in children and young people with non-progressive brain disorders: management of spasticity and co-existing motor disorders and their musculoskeletal complications
- RCPCH: Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management
- NICE: Antisocial behaviour and conduct disorders in children and young people: recognition, intervention and management.

i *All these and more can be found at:*

www.nice.org.uk/Guidance

4.3 Understanding and influencing service commissioning

Local authorities, clinical commissioning groups and NHS England will pay commissioners to commission local services for them.

There are generally four stages involved in commissioning a service:

- 1 **Needs assessment** – assessing the needs of the local population for the service. For example, the number of disabled children requiring a wheelchair service.
- 2 **Specification** – drawing up a specification of what the service will provide and the outcomes it should deliver. For example, all children referred for assessment should be seen within six weeks.
- 3 **Procurement** – the process by which organisations are selected to deliver the service. This often involves a tendering process, where different organisations compete to win the contract to deliver the service.
- 4 **Contract management** – drawing up a contract between the organisation paying for the service and the organisation(s) who will provide the service. Meetings are also held with providers to make sure they are meeting their contractual obligations.

Contracts are usually made for the organisation to deliver the service for a number of years. Then the whole commissioning cycle begins again.

Parent carer forums will find they can be most effective in improving a service by getting involved at the start of the commissioning cycle and remaining involved throughout all the stages.

Needs assessments – how forums can help

Before commissioning a service, commissioners are expected to listen to the experiences of patients and carers using the existing service and consider the needs of the local population.

Commissioners also have to take into account any national guidelines that set standards for services.

Parent carer forums can help provide evidence of need. For example, running a consultation of their members to gather evidence that children are going without a service, or waiting a long time to be seen by a service.

i It can be useful to compare what the current service provides with what is set in national guidelines for that service. You can read more about this in the Contact a Family briefing paper *Making use of clinical guidance and standards*.

Service specifications – how forums can help

Commissioners develop a service specification which describes what services will be provided, such as:

- where the service is to be provided – for example in one centre, in children’s centres or in people’s homes
- the types of health professionals required to deliver the service and their level of knowledge and experience
- which other services or health professionals they have to liaise with – for example GPs, physiotherapists, schools
- maximum waiting times between referral and being treated
- what treatments or equipment will be offered, and
- which patients will be eligible to receive treatment.

If parent carer forums influence what is written in the service specification, then the service is more likely to work for families.

Example

Commissioning a wheelchair service for south east London.

A new wheelchair service was to be commissioned for six local authority areas in south east London. Parent carer forums for these areas came together to run a workshop which the commissioner attended to hear about how families found the existing service.

This highlighted a few issues, including the need for better information for families about the service, and the importance of being able to choose from a range of wheelchair manufacturers and models to meet children’s needs.

i Read the full report:

www.cafamily.org.uk/pcp/health

It can be timely at this stage to run a workshop or focus group to find out how members experience the existing service. This will help identify what should be included in the new service specification to improve the service.

Procurement – how forums can help

This is the process by which organisations are selected to deliver the service. It often involves a tendering process where different organisations compete to win the contract to deliver the service.

Information events are usually held to explain the application process to organisations interested in providing the service. Sometimes parent carer forums have had the opportunity to talk at these events to explain their priorities for the service to potential providers.

Parent carer forums can also provide parent carer representatives to sit on the panel selecting the successful organisations.

Example

When Redbridge commissioned their short breaks service they involved children and young people as well as parents in the procurement process. You can read more about this at:

www.cafamily.org.uk/pcp/success

Contract management – how forums can help

The service specification will also include information about how commissioners will monitor that the service is being delivered to a sufficient standard. This often used to focus on the number of complaints about a service, but commissioners are increasingly asking service providers to show evidence of patient satisfaction with the service they deliver, as well as evidence of patient involvement in improving the service.

Commissioners hold regular review meetings with organisations providing services, to make sure they are delivering the service as set out in the contract.

Example**Southend: Improving wheelchair and transport services**

The parent carer forum in Southend contacted the commissioners and told them about problems with the existing service.

The forum worked with the commissioners to draw up a new service specification which would better meet children's needs.

Parents were encouraged to contact the forum if they had problems with the new service.

This would be fed back to the commissioner and often the problem would be quickly resolved. This also provided a ready mechanism to help the commissioners monitor the service.

This is much simpler, quicker and cheaper for everyone than having to go through official complaints procedures – something parents are often very reluctant to do:

www.cafamily.org.uk/pcp/success

Parent carer forums can feedback to commissioners any dissatisfaction with the service that they hear about from their members and ask them to discuss it with the provider at the meeting.

Commissioners will not know about families' problems with services unless someone tells them they are happening.

Making contact with commissioners

Commissioners can be extremely useful contacts for forums, but tracking them down can be difficult.

Commissioners might be employed by the local authority/clinical commissioning group, or work for an organisation which provides commissioning support to the local authority/clinical commissioning group.

Commissioners who specialise in children's services can be extremely knowledgeable in their field and be useful allies for forums. In some areas there are joint children's commissioners who are responsible for children's services across both health, and the

local authority. Parent carer forums appear to find it much easier to get involved when there is a joint commissioner for children's services.

Commissioners are, however, sometimes asked to commission services for which they have no previous experience. For example, a commissioner with no previous experience might be asked to commission a children's wheelchair service. Parent carer forums should not assume that a commissioner has in-depth knowledge of an existing service. Be willing to explain to them what is good and bad about the way a service currently works.

Commissioning Support Units (CSU)

There are eighteen commissioning support units across England. They provide commissioning support services to NHS commissioners, including local clinical commissioning groups (CCGs), NHS England, acute trusts and local government. For details of these see:

www.england.nhs.uk/ourwork/commissioning/comm-supp/csu/

Tracking down commissioners

Parent carer forums might find it helpful to build good relations with people who can help them to find out which commissioner is responsible for a particular service. People who might help with this include:

- local authority: director of children's services, senior managers, councillor (lead for children)
- health: clinical commissioning group's lead for children, designated medical officer
- commissioners: if you have a good relationship with one commissioner, they will often try to help you find out who is responsible for commissioning another service.

5 Improving services

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5.1 Listening to parent carers

If forums provide feedback to service providers that only reflects the views of a small number of parent carers there is a risk that:

- the feedback they are providing is not a true picture of how services are working
- the forum will be criticised for not being representative of families living in the area.

This is why, wherever possible, the feedback you give to local service providers should reflect the views of your wider membership, and not just a few parent carers.

Consulting with your members

You will want to consult with your members to:

- 1) find out what services work well – and what needs changing – to help you prioritise the forum's work
- 2) gather evidence that change is needed to submit to the local authority/health service.

You can get informal feedback from your members:

- at meetings, such as coffee mornings, drop-ins, parent support groups, forum meetings
- through social media by, for example inviting members to make comments via Facebook, Twitter, online forums.

You might want to carry out a more formal consultation on a service that parents are unhappy with, and write a report to submit to the local authority and/or health service.

It is best to offer parents a variety of ways to input into consultations so that you are able to capture the views of as many parents as possible.

Focus Groups

You could run a focus group and invite parents to meet and feedback their experience of a particular service. This is a useful way to generate discussion to find out what part of a service is not working well and why. It also provides an opportunity to identify solutions to problems, by asking parents to tell you what a good service would look like.

Example

Using a focus group to improve the wheelchair service

Contact a Family, working with local parent carer forums, ran a consultation with parents in South East London whose children used the wheelchair service. They used a simple exercise to find out from parents which aspects of the service they were happy with and where improvement was needed. Most parents were happy with the assessment process but a few were very unhappy. This was because their children were on the autism spectrum and the wheelchair assessors did not understand their particular needs.

i You can download *Listening to parents experiences* which describes the exercise used to get initial feedback at:

www.cafamily.org.uk/pcp/health

It could be adapted for consulting on any service.

When advertising your focus group – use the tips in *Section 3.1 Communications – getting the basics right*.

TOP TIPS: Running a focus group

- ▶ You might want to consider using an experienced independent facilitator. They can set a friendly tone and encourage everyone to have their say.
- ▶ Plan the session, with timings and think about the questions you want to ask.
- ▶ A visible 'parking space' on the wall with post-it notes placed on tables are great ways for those who find it difficult to speak up in a room full of people to have their say. They might have some really useful suggestions to contribute.
- ▶ Parents often find it easier to talk in a small group. You might want to split up into smaller working groups for some of the session.
- ▶ You will need at least one person to take notes, and more when you have split up into smaller groups.
- ▶ Use tools such as voting stickers on a 'democracy wall' for each parent carer to register individual views. This ensures that each vote is visible and carries the same weight, including the views of people who do not say anything.
- ▶ You might want to run more than one focus group, and target different parts of the community, such as a minority ethnic communities. You might want to check to see if interpreters are needed.
- ▶ Focus groups should run at times to suit parents. The middle of the day is often ideal, but remember those who can only make it in the evenings or at weekends.
- ▶ Offering refreshments, travel and childcare expenses makes it more attractive to attend.
- ▶ At the end, say what is going to happen next, how you will let them know, and thank everyone for coming and giving their time.
- ▶ Afterwards - send a short report to everyone who participated, summing up the views and saying how you are going to take this forward. Remember that feeding back is vital as it keeps parents interested.

Surveys

Surveys are a useful way of gathering numeric data to show that lots of people are being affected by a poor service, and how.

Websites like Survey Monkey can be used to create surveys which your members can complete on the internet. This is much more efficient than sending out surveys on paper as:

- you can email the survey to your members, and advertise it on your website and through social media, rather than sending out by post
- parent carers type their responses onto the computer, saving you the time involved in entering data manually
- totals are automatically added up for you, saving you time and less risk of being inaccurate
- responses are immediately available once submitted
- you do not have to rely on people posting surveys back to you, or waiting for them to arrive.

You can also download people's responses from the internet into a single Excel spreadsheet.

If you want to give parents alternative options for completing the survey, you can:

- send paper copies to members without internet access
- ask people to complete surveys when attending meetings, events
- offer telephone interviews where parents answer the survey questions over the telephone.

Telephone interviews can be useful for reaching isolated families, such as those who find it difficult to leave home because of their child's complex needs. They can provide an opportunity for isolated parents to talk to someone about their concerns and also provide stories about families' experiences.

All these additional responses can then be entered manually onto the Excel spreadsheet downloaded from Survey Monkey, and the final totals calculated in Excel.

The data that you collect and collate can provide hard evidence to present to providers about their services.

TOP TIPS: Designing a survey

- ▶ If you keep surveys short, simple and easy to fill in, people are much more likely to complete them.
- ▶ Explain at the top why you are sending out the survey and what you will be doing with the results.
- ▶ Use a few 'closed' questions, which allow people only a few options which can be used to generate hard-hitting statistics. For example the question:

How satisfied are you with the service? (Pick the best description)

very satisfied / satisfied / dissatisfied / extremely dissatisfied

could generate the following statistic:

"90% of parents said they were dissatisfied or extremely dissatisfied with the service."

- ▶ Use a few 'open' questions to find out how the poor service is affecting disabled children and their families. For example:

Please tell us how is this affecting you and your child?

Quote some of these in your report, as this will help motivate people to want to improve the service.

- ▶ Before sending out the survey, ask a few parent carers to test it and let you know if they found anything difficult to understand.
- ▶ At the end, thank people for completing it, and remember to tell them where to send the survey.
- ▶ Give a realistic, clear deadline for replies and mention how, when and where parents will be able to see the results.

Report writing

Once you have completed your consultation(s) you will want to write up the results.

Try to find people within the forum who have some experience in:

- Excel – for totalling the data, converting it to percentages and generating graphs/pie charts. You can also do this within SurveyMonkey
- writing reports in plain English.

It might make sense to share the work between two people, to make best use of people's strengths and to spread the workload.

i Visit the Plain English Campaign website at www.plainenglish.co.uk for more information and tools to help with writing in plain English.

TOP TIPS: Writing reports of consultations

- ▶ **Keep it short** – people are put off by long reports.
- ▶ **Introduction** – don't assume readers know about your forum, give a brief explanation.
- ▶ **Key findings** – put a summary near the front of the report with some hard hitting facts.
- ▶ **Recommendations** – the report needs to suggest recommendations that are reasonable and will resolve the problem, rather than simply be a list of what is wrong.
- ▶ **Graphs and tables** – put tables showing the data next to the graphs/pie charts. Some people prefer to look at graphs, others prefer numbers.
- ▶ **Acknowledgements** – say thank you to everyone who has helped, including the parents who fed into the consultation.

As well as sending the final report to the commissioners and manager of the service, you will want to add it to your website, and also consider sending it to other key contacts in the area who might be interested in reading it. For example, your local MP or councillor.

5.2 Building relationships with key people

The forum will find it helpful to build a working relationship with the senior professionals responsible for managing and commissioning services.

These people can help you be included when decisions are being made about the services that disabled children access.

In *Section 4* we talked about how services work and identify some of these key people. These include:

- local authority – director of children’s services, disabled children’s service manager, short breaks leads, special educational needs (SEN) leads
- health - designated medical officer for SEN, clinical commissioning group (CCG) lead for children and young people, service managers, hospital matrons, lead paediatrician
- commissioners – commissioners responsible for children’s services, especially joint commissioners.

It can also be beneficial to build links with local councillors responsible for children and local MPs. They can also be useful in helping you find the right people to talk to and introduce you to them.

When you first start your forum you will probably want to target just one or two of these people. This might be an individual who you have heard is supportive of parent carer participation, or it could be an individual who manages a service that your forum particularly wants to focus on.

You will want to think about how to approach these people in a way that will make them want to work with you.

Initial approaches

Always try to make your first contact positive. It might not be the right time to take a list of requests or difficulties to a first meeting. But it is an opportunity to discuss how you can work together, how to build trust, and how to work together to find solutions.

Your first approach might be by sending a letter, an email, or making a telephone call. You will want to:

- keep it short and friendly
- include a sentence to explain the purpose of the forum and that you are representing the views of many parents, not just your own
- acknowledge that you understand they have limited budgets
- mention any national policy that might make them want to work with you
- ask to meet to explore how you can support each other's work.

If you have already have a good working relationship with someone who knows this person, ask them if they could help pave the way for you by introducing you to them.

Example letter to introduce the forum

Dear

We are writing to you in our capacity as **[chair / co-chairs / secretary]** of **[name of forum]**, the parent carer forum for **[name of local authority]**. Our membership is made up of **[X number]** of parents with disabled children.

The forum's purpose is to work with local services, to help bring about improvements in services for disabled children and young people and those with special educational needs.

We understand that in the current financial climate, budgets are restricted and authorities face significant challenges. Evidence demonstrates that working directly with people who use and access services to plan, commission and evaluate them leads to services that are:

- targeted where they will have the best impact
- better quality
- fit-for-purpose, and will
- improve outcomes for children and families.

The Children and Families Act 2014 places a legal duty to involve parent carers in how services for disabled children are delivered. Working with **[name of parent carer forum]** can support you to meet this duty.

We would welcome the opportunity to have a meeting with you to explore how we might work together.

Your sincerely

Planning for meetings

Having managed to arrange a meeting, you need to plan for the meeting. It is likely that you will have a limited time, and lots to say. Strategic leads tend to have very full diaries which means that if they have only allocated you half an hour, that is all you will get. If you take up longer than the time allocated, they may be less willing to want to meet you again.

Identify the key messages you want to get across, and the outcomes you hope to get out of the meeting. Try to stick to them and don't drift off onto other topics.

One important outcome is that they go away from the meeting wanting to continue to work with you. They are more likely to do this if:

- you come across as friendly and approachable – rather than angry and demanding
- you appear willing to listen and try to understand their perspective
- you offer solutions and not just problems
- everyone is clear about the actions that you will both take following the meeting.

It might be helpful to take one or two parents to talk about their personal experiences. Listening to personal stories can really motivate professionals to want to bring about change. However, if you do this make sure:

- the manager or commissioner understands that many other families are experiencing similar situations
- the parent carer does not talk for so long you run out of time to have meaningful discussion
- you are not there to complain but want work with them to try to find a solution.

You might find it helps to have a rehearsal / dry run before the actual meeting.

At the end of the meeting, try to agree actions for taking things forward, with a suggested time scale.

Presentation skills

At some stage you might be invited to present to a committee or board. Delivering a good presentation can help persuade people at a senior level to work with you to improve a service.

Many people are nervous about public speaking, but you might find some members of the steering group have experience of this. You might also want to consider sending people for training on presentation skills, so that you will be prepared if offered the opportunity.

i *Contact a Family have a YouTube video with Tips on presentations and public speaking:*

www.cafamily.org.uyj/pcp/runaforum

Redbridge – Bringing about transformational change in health

Interface were invited to present to the children's disability scrutiny working group. They developed a PowerPoint presentation for this.

Following this, the working group co-opted two parent carer representatives from the forum to be members of the Group. See more at:

www.cafamily.org.uk/pcp/success

Making use of networks

Building up contacts with others working in the field of disability can be really useful. These might include:

- local voluntary organisations – for example, local carer centres
- Information and Advice and Support Services (formerly called Parent Partnership Services)
- practitioners supporting disabled children, for example paediatricians, community nurses, short breaks, special educational needs (SEN) teams.
- Healthwatch.

Although these people are not responsible for managing and commissioning services, they might know the people who are and help you make contact with them.

You might also find advantages to working together to discuss an issue, gather evidence and explore possible solutions, which can then be taken as proposals to senior managers and commissioners.

5.3 Bringing about change

Parent carer participation

Listening to parent carers' and young peoples' views and experiences helps service managers and commissioners understand what is working well and where improvement is needed.

However, working out how to improve services requires a conversation, which includes the perspectives of parent carers, young people, practitioners as well as managers and commissioners. Each brings their own expertise:

- parents and young people can bring their own experiences and share the experience of others using the service including its shortfalls
- practitioners have specialist skills and knowledge, and understand what is required to deliver a service
- managers have expertise on matters, such as budgets, workforce and legal responsibilities
- commissioners bring skills in service specification, procurement and contract management.

All of these people working together, acknowledging each others' expertise, helps develop services that run more effectively. It requires a willingness by all parties to listen to and try to understand each other's perspective.

Working with parents and young people helps professionals understand what needs to happen to develop services that meet families' needs.

Working with professionals helps parents and young people understand the complexity involved and the challenges faced by professionals in bringing about change.

Working together and sharing knowledge enables everyone to find solutions that work and make best use of limited resources. These conversations can take place through:

- 'task and finish groups', where all the parties concerned meet to look at how a particular service works, and find ways to improve it
- parent carer representatives becoming members of steering groups and decision making boards.

TOP TIPS: task and finish groups

- ▶ Task and finish groups usually work better if they are kept small. This makes it easier to arrange meetings, as well as being less daunting for people to join in the discussion.
- ▶ Try to have a few parent carer representatives, who between them can represent a range of situations (for example age, severity of child's condition, geographical location).
- ▶ They need representatives of the different practitioners and services involved, as well as parent carers.
- ▶ The group also needs at least one senior manager with authority to support the implementation of any changes the group recommends.
- ▶ Arrange meetings at times and venues that make it easy for parents to attend.

Example**Leeds EPIC task and finish group**

The parent carer forum approached the lead paediatrician and said parents wanted more help on issues such as sleep, behaviour, and toilet training.

The paediatrician agreed to set up a small working group and invited the head of community services, special school nurses, therapists and parents.

They met a few times to explore the problem to try to find a solution. This led to the special school nurses agreeing to offer a service one day a week to provide advice to parents on these issues.

i For more information see *Leeds support for families on common issues*:

www.cafamily.org.uk/pcp/success

Parent carer representatives

Having parent carer representatives on steering groups and decision-making boards makes sure the parents perspective is considered when decisions are made about the services their children use.

Being a parent carer representative on a committee can be extremely daunting, especially if other committee members are not welcoming. Providing parent carer representatives with information, practical support and training will help them to participate meaningfully. Some forums feel that it is important to have two parent carer representatives attend wherever possible. This can be particularly helpful if you are attending a large meeting.

Some forums and local authorities have found it helpful to agree ground rules which make it less daunting for parent carers and makes sure their time is spent effectively.

What might be included in the ground rules:

- parent carer representatives on committees have a way to represent the views of other parents' experiences, and not just their own
- a minimum of two places for parent carers so they can support each other, and more experienced parent carer representatives can support new parent carer representatives
- someone acts as key contact for parents, and meets new parent carer representatives before their first meeting to clarify the purpose of the meetings, explain how the meetings are run and any policy around confidentiality
- agendas are distributed with the appropriate papers in sufficient time for parent carers to be able to read and digest them. Parents are not likely to have printers at home capable of printing large volumes and might prefer to have printed copies sent out
- everyone uses plain English and avoids abbreviations and jargon, or if this cannot be avoided explain what they mean
- parent carer representatives on committees feedback to the forum changes resulting from their input
- parents receive remuneration for expenses promptly. You might want to consider when parents should be reimbursed for their time.

To motivate parent carers representatives to carry on working with you, make them feel valued and that their work is useful.

Reporting success

Parent carers are only going to stay involved in the forums if they believe the forum is making a difference. This is why it is so important that parents hear how the forum has helped improve services.

As the forum grows and more parents are involved in different committees it is easy to be so involved in bringing about change, that parents forget how important it is to communicate what is happening to their members.

That is why it helps to ask parent carer representatives to report back to the steering groups about their work, and any successes – as well as if they feel their time is not being spent effectively.

i You can find an example of a parent carer representative feedback form at:

www.cafamilyorg.uk/runaforum

This can be used to feed into communications/newsletters/web updates being sent to members.

You can read more about this in Section 3.3: Publicising the work of the forum.

5.4 Co-production

What is co-production?

Having parent carers at the heart of strategic decision-making helps to bring parents and services together to form a shared vision, make a difference, and to bring about real change. Successful parent carer participation is underpinned by:

- ▶ **Information** – providing parent carers with clear, comprehensive and timely information which enables them to make informed decisions and choices.
- ▶ **Meaningful consultation** – that ensures parents' voices are heard and listened to when services are being developed or reviewed.
- ▶ **Parent carer participation happens when parent carer representatives:**
 - attend strategic working groups or task and finish groups to put forward the views of the wider parent carer group (see *Section 5.3 Bringing about change*), or
 - are involved in the commissioning process or in interviewing the workforce (see *Section 4.3 Understanding and influencing service commissioning*).

This facilitates two-way communication between the forum and services.

- ▶ **Co-production** – takes the concept of meaningful participation further. It happens when service providers recognise the benefits of working in true partnership with other practitioners and service users. They adopt this process 'from the start', when planning, developing, implementing or reviewing a service. It means that all the right people are around the table right from the beginning of an idea, and that they are involved equally to:
 - shape, design, develop, implement, and review services
 - make recommendations, plans, actions, and develop materials.

working together right from the beginning, through to the end.

Co-production may evolve as a natural progression from participation.

Co-production - improving existing services

Forums might want to consult with their wider parent carer group to provide evidence to the local authority that a service is not working or requires improvement. They may ask the local authority to work in co-production to redesign the service.

Example

Improving children's therapy services across Hampshire

The parent carer forum in Hampshire consulted with their members about access to therapy services, and submitted their findings to the local authority Overview and Scrutiny Committee.

Hampshire County Council set up a Children's Therapies Programme Board to better understand what the problems were and agree on what a new service should look like.

Hampshire Parent/Carer Network was invited to sit on the Programme Board as well as therapists and two GP leads for children with disabilities from the Clinical Commissioning Group.

After agreeing what the new service should look like, the Programme Board worked with the commissioner to procure a service which met these requirements.

i For more information see:

www.cafamily.org.uk/pcp/success

Co-production when planning a service

The local authority or health board might be planning a new service, or conducting a service review to overhaul an existing service. If they were practising co-production they would:

- seek the opinion of the parent carer forum, as well as other stakeholders (practitioners, service managers, commissioners) on the process from the start
- work together to carry out a consultation of young people, parents and other stakeholders' views
- sit round the table with the forum and other stakeholders to discuss the feedback
- work together to plan and agree a constructive way forward
- keep all stakeholders involved in the design, implementation and review of the service.

This is more likely to happen where local services have had a good experience of working with the parent carer forum, perhaps through previous consultation and participation work.

Example

SE7

Seven local authorities in the South East of England (SE7) agreed to work together to test the special educational needs and disability reforms.

The SE7 Regional Steering Group was made up of key representatives from each local authority area, education, social care and health leads, the strategic health authority, national and local representatives from the community and voluntary sector and parent carer representatives.

They included parent carers in the strategic decision making process as full partners from the start, and included them in all steps of the process.

i For more information see:

www.se7pathfinder.co.uk/what-who-is-se7

Making co-production work

For co-production to be successful it requires buy-in from the top. It needs senior managers and strategic leads to understand how participation and partnership working works, and be committed to it. There also needs to be real commitment from all stakeholders to make it work.

Working together with parent carers from the outset and giving them an equal voice might be challenging for services as they are held to account, made to look at issues from different perspectives and may be asked to work in different ways. Similarly, working in co-production helps parent carers better understand the constraints and limitations placed on services, particularly around budgets and legislative requirements.

Co-production is a learning curve for all involved. It can work effectively, and its rewards can outweigh any initial difficulties. Partners are often able to find ways around problems or sticking points, to make more effective use of the resources available, and to find realistic and workable solutions.

Co-production is sometimes viewed as the difficult option as it can take time to get right. It may involve some initial time and effort, yet it saves time wasted in investing in the wrong services. It ensures a better take up of the services that are developed, as they meet the needs of families better.

Contact a Family's video of parents and strategic leads from pathfinder areas, *Working Together – our experience of co-production*, produced with SE7, Mott MacDonald and the National Network of Parent Carer Forums, highlights the benefits of co-production in terms of being able to put the right services in place that meet families' needs. The people involved found working in co-production was well worth the time investment, transformation and culture shift required. Providers also describe evidence-based co-productive practice as efficient and effective once in place.

They declare that there is no way back now they have changed the way they work. They hold the firm belief that by working together, shared solutions can be achieved. Those involved in co-production are in agreement that the tokenistic representation of parents has to become a thing of the past.

By working in co-production many areas have changed their working culture, embedded a structure for working together from the start, built this into practice and considered how they will review it going forward.

With the recent special educational needs and disability reforms owing to the implementation of the Children and Families Act 2014, parent carer forums all over England have been involved in co-producing local authority local offers, Education, Health and Care plans and service specifications. Now that the new system is in place it is imperative that parent carer forums remain as partners in reviewing how the changes are working, and providing constructive challenges as active partners to local authorities and health.

Remember that co-production encompasses:

Co-design Co-production Co-delivery Co-evaluation

i *There are some useful resources on co-production on the Social Care Institute for Excellence website:*

www.scie.org.uk

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Sheila Davies

Contact a Family Parent Carer Participation Manager

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Contact a Family provides advice, information and support to all UK families with disabled children, regardless of the disability or health condition. Through a national helpline and family support service, we provide advice on any aspects of caring for a disabled child, including help with benefits and educational issues. We also help families get in touch with others in similar situations.

We have supported the development of Parent Carer Forums across England, where parent carers work with professionals to improve how services are delivered in their local area.



The National Network of Parent Carer Forums (NNPCF) is a parent carer-led organisation, whose membership is made up of all of the Parent Carer Forums who are eligible to receive a parent participation grant from the Department for Education. The NNPCF Steering Group is made up of parent carers from each region who represent the voice of parent carers in their regions, ensure information about national developments is disseminated, and that parent carer participation is strengthened and embedded.

The role of the NNPCF is to ensure parent carers are able to have a voice and work as partners as services, strategies and legislation concerning disabled children, young people and their families are developed locally, regionally, and nationally.

Disclaimer

This guide is for information purposes only. It is not intended to be a source of legal advice and must not be relied upon as such. Although great care has been taken in the production of this guide, Contact a Family cannot take any responsibility for any errors or omissions. Listing of other organisations' resources does not constitute endorsement by Contact a Family.



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- Promoting Parent Carer Participation
- Ensuring the voices of parent carers are heard nationally with departmental and strategic partners across education, health and social care
- Empowering and supporting parent carer participation developments across England
- Working with Regional Parent Carer Forum Networks across England
- Producing information and updates for Parent Carer Forums
- Producing responses to national consultations based upon the views of the membership.

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Campaigning

We campaign for rights and justice for all families with disabled children.

Freephone helpline

Our freephone helpline for parents and professionals across the UK is staffed by trained parent advisers. It provides information and advice on a wide range of issues including welfare rights, education, short breaks, local services and local support.

Publications

We produce a wide range of publications including newsletters, parent guides and research reports, helping parents and professionals to stay informed.

Linking families

We put families in contact with others whose child has the same condition for support. We link them through existing support groups, our online social networking sites or using our one-to-one linking service.

Medical information

Contact a Family has information on hundreds of conditions, and details of support groups where possible. Visit www.cafamily.org.uk/medical-information, or call our freephone helpline for anything not listed on our website.

One-to-one support groups

We offer practical and emotional support on a one-to-one basis to families with disabled children, through our family support service, volunteer parent carer representatives and through our local offices.

Local, regional and national offices

Contact a Family has a number of offices around the UK providing local newsletters, information, workshops and support.

Parent carer participation

Contact a Family supports the involvement of parents in shaping services (health, education and social care).