



## Section 4 - Starting a Parent Forum

### Subject: How to Set Up a Parent Forum

**Who this is for:** Parents and/or professional workers starting up a forum

**What this section is about:**

What is a parent forum?

How do we get one going?

How do we get recognised by local service providers?

How can we demonstrate our worth?

## 4. Starting a Parent Forum: How to Set Up a Parent Forum

### What is a Parent Forum?

It is an active group which has the specific aim to provide service providers with the views and concerns of their service user group to influence the improvement of service development, design and delivery. This is achieved through involving the forum in consultations and ensuring the parent forum has the opportunity to raise issues with children's services managers at a strategic level.

Parent forums usually take one of the following three forms:

- regular parent conferences which lead to task groups working on a specific issue
- regular meetings between parents and practitioners with agendas for discussion and action e.g. carers' forums
- independent parent-led groups sometimes called "parent forums" or "parent carer councils"

For details and examples of the three types of parent forums see section 1 - Parent Participation as a Process.

Parent forums need coordinating regardless of which form they take. They will need some kind of steering committee of parents or of parents, voluntary sector workers and professionals. This committee may be facilitated by a local voluntary organisation, a local authority or a funded parent participation worker. Alternatively, it may be run by an independent group of parent volunteers.

Successful forums are regularly involved in joint work to shape and develop services for disabled children and their families. The forum usually provides parent representatives for decision making committees and/or task groups. It is important that these representatives are able to represent a wide group of families with disabled children of different ages, conditions and community backgrounds from across their area.

### How Do We Get One Going?

Often the idea and enthusiasm may come from a parent or a professional who recognises the importance of participation.

#### Step 1

The first step is to get a group of interested people together to discuss possibilities and from this group set up a decision making or steering group. It comprises people who are willing to take an active role in shaping the forum. Many parents may be

happy to attend initially to input their views to the forum but not wish to join a steering group or committee.

Parents need to agree the composition of the committee. It can be helpful if it contains both parents and professionals, as early as possible, in the spirit of working in partnership. Professionals could be from local voluntary and/or statutory services. However, some parents may be wary of professionals being part of the steering group as they feel this affects the forum's ability to be truly independent. A compromise that many forums are happy with is to invite professionals to the steering group as non-voting (co-opted) members.

## Step 2

The steering group has to agree on how it is going to work. The first decisions to make are:

### 1 Deciding your aims

Everyone needs to agree a statement of purpose (mission statement). As this is a clear and concise statement of what the forum is for, you may want to use the mission statement in your publicity. It ensures that everyone is coming together to achieve the same overall goal from the outset. It is always helpful to look at how others have written their mission statement in deciding how you wish to frame yours.

**For example:**

#### **Hillingdon Parent Careers' Forum**

##### **Our Aims**

To represent the views of parents and carers in discussions with the local authority and, through this, to influence the way local services are delivered. We will inform the local authority of occasions when their experience of practice does not match current policy. We also want to play a more active part in service design and development by ensuring that the needs and wishes of our children and families are heard, and placed at the centre of these processes.

### 2 Deciding how you want the forum to work

This does not need to be set in stone and can be changed depending on how well it is working as the forum develops. Things to think about should include:

- how often will you meet as a committee? This may become less frequent once you are up and running
- who does the forum represent? Many successful forums have been started on the premise that every parent of a disabled child in the local authority area is

automatically a member and how much they want to be involved depends on them

### **Redbridge Parent Forum**

The Parent Forum is open to carers of children with any kind of disability (physical, learning, communication, behavioural, sensory and rare disorders) as well as children with health conditions which mean they have additional care needs.

The Parent Forum will work with existing groups but cannot take on any individual issues. The forum will need to know if there are patterns of problems or particular problems for particular groups of disabled children.

- how often will you meet with the membership? It is important to set a manageable time frame for meetings with the wider membership and to publicise these meetings well in advance
- how will you decide which issues to focus on?
- how will you make sure that these issues are addressed and fed back to the local authority or Primary Care Trust?

Every local authority area is different and what works well in one area may not in another. It may help to look at a local authority area which is similar to your own (e.g. a large rural authority or small unitary).

## Example:

### **Brighton and Hove (unitary authority)**

Having experienced a range of participation approaches over the past ten years, Amaze, the umbrella organisation supporting parent carers of children with any special need, set up a Parent Carers' Council (PaCC) in July 2008. This was in order to improve the support of parents already involved in participation, encourage new parents to get involved, increase the representation of a wider range of parents, and focus local consultation into one co-ordinated, representative group.

There is a trained steering group of about fifteen members and elected co-chairs. The group is supported by a part-time Parent Participation worker. Parent carers elect their representatives who are regular members of the Disabled Children's Strategic Board, and other key groups. Parent carers are paid for their time, which is made possible through funding from the Children and Young People's Trust and PCT.

The PaCC now has over 120 signed up members and has started to make an impact from its first report that lead to a review of therapy services. Money was released to immediately shorten the waiting list times for Occupational Therapy and Physiotherapy. Working with practitioners and managers, a full business case is about to be submitted for a transformational improvement in information, communication and training standards for therapy services for children.

## **How Do We Get Recognised by Local Service Providers?**

At this stage there is a lot of research and mapping to do. It can be bewildering working through a maze of obscure job titles and committees but it will pay dividends in the long run if you tackle this early.

### **1 Get to know the local power structure**

It is very important from the start to understand how your local authority and Primary Care Trust (PCT) work and how they are structured. Names of departments and job titles differ from area to area. Who does what? Who is responsible for making the ultimate decisions regarding services and finance?

What is the decision making process about children for your local area? What are the various strategic committees and are parents currently represented on them? If so, how were they chosen? Every area has a Children and Young People's plan (CYPP) which will be on your council website which should explain the process of consultation and planning.

This understanding will help to make sure that your forum is feeding in at the highest level and does not just become a 'talking shop'. It is useful to map the structure early

on so that you can see how the forum will link in with various committees and boards and ultimately, how it will influence any decision making processes.

## **2 Make links with local services and start to discuss possible ways of working with them**

Your aim is to establish a good working relationship with key professionals within your local authority and PCT. You want them to help spread the word about the forum and to call on your help in consulting parents. Together you can promote opportunities for parent participation and avoid duplicating consultations.

Local services you need to make contact with include:

- the Parent Partnership Service (PPS), which has a remit to support the involvement of parent carers, usually with a focus on education. Many of the staff involved in the PPS have a good working knowledge of participation and other structures
- Disabled children team - As well as linking with its head of service, check if there is a register for disabled children. Is it open to all parents of disabled children and is there a regular method for communicating with parents e.g. a newsletter?
- community child health services/child development centres as well as the local NHS Patient Advice and Liaison Service (PALS)
- local voluntary services. These range from large charities such as Barnardo's to organisations representing specific groups (e.g. Down's Syndrome, autism, sensory impairment etc.) as well as smaller, informal, local groups
- other forums and participation networks. For example, there may be a more general carers forum representing the views of all carers not just parent carers of disabled children
- is there are a designated participation officer/worker in your area? If so, it is worth linking with them to understand their role and see how their work and the proposed work of the forum can complement each other
- the county councillors who hold the relevant portfolios for children and young people and for disabilities. They make recommendations to the council and so need opportunities to listen to the issues and concerns of families with disabled children

Amongst these people there may be a local champion. In many local authorities there is a particular member of staff who goes that extra mile for families, or who has a reputation for being approachable. As well as being a useful link into the local authority or PCT, this person may also have the ability to influence others in a position of power.

## How Can We Demonstrate Our Worth?

- **by a quick win**

If at all possible, look for a quick win-win solution to a local problem.

### Example:

#### **Parent conferences at work in County Durham**

Parents in County Durham came up with the idea for a County-wide mobile phone texting service during their first all parents' conference held in May 2008. A task group of parents and professionals (The Information Focus Group) developed the idea of sending informative texts to parents about local events, leisure clubs and changes to local phone numbers/addresses. This meant that parents could choose what information they wanted to retain and what to delete. The service is now co-ordinated by The Children's Network. It went live in March 2009 and parents get about four or five texts per month. It was a quick win for everyone.

- **by demonstrating respect for the expertise of professionals and parents alike**

**Our Voice Counts!** will respect and value the breadth and depth of knowledge and expertise held by all forum members and the services/practitioners across the range of partnerships  
**Somerset Parent Forum**

### Example:

#### **Getting started in Oxfordshire**

Oxfordshire had no active forum for parents of disabled children but there were a number of voluntary sector organisations and groups (predominantly family led) supporting families with disabled children. An initial meeting was held which included representatives from these groups, an interested parent as well as key personnel from the statutory agencies, including the Parent Partnership Service. They agreed to hold a number of meetings for parents at various locations across the county as Oxfordshire covers a large geographical area.

The meetings were advertised through the voluntary sector, local groups and to schools. They were used to inform parents about the Aiming High Agenda as well as enlist parents interested in getting involved with a forum. Forty four parents registered as being interested and sixteen agreed to be part of the steering group. A subsequent joint meeting was held with both parents and professionals where two chairs, two secretaries and two treasurers were nominated so they could share the workload and responsibility for these posts. They also decided to call the forum 'Oxfordshire Family Voices.'