

Parent Carer Forums - How they work

Models of Parent Carer Forums

Parent Participation often begins with one of three approaches:

- 1 Parents' conferences and focus groups
- 2 Parent-led groups sometimes called 'parent forums' or 'parent carer councils'
- 3 Meetings between parents and children's services managers

Though parent carer participation often begin with one of these models, as they develop they frequently being to incorporate elements from other models. e.g. a focus or task group might be formed after a particular issue is raised in meetings between parents and children services, or a parent carer council might decide to run a large conference to get feedback from parents about their priorities.

1 Parents' conferences and focus groups

Parents are invited to attend a large conference type event usually once or twice a year to discuss and agree issues they want prioritised. Following the conference, small focus or task groups, involving professionals and parents are formed for each priority issue. The task groups meet regularly for a limited period of time to reach a more detailed understanding of the problem and look for practical solutions. Their conclusions and any actions taken as a result are fed back to the next parents' conference and strategic decision makers.

Why this works

Parents are focused on an issue of interest to them and only have to commit their involvement on a short-term basis. It is easier to arrange meetings with a small number of people at times convenient to all. Having a small number of people makes it less daunting for everyone to join in discussion.

What might stop it working?

There is a danger that some parents' views will not be represented. The parents' representatives on the focus groups will need to have a system for collecting a wide range of views and will need the skills to act as informed representatives of the wider group.

An example of this approach that works well is Durham Making Changes Together described in more detail on page 4.

2 Parent-led groups sometimes called ‘parent forums’ or ‘parent carer councils’

Some areas have a constituted parents’ forum which is a parent membership group that consults with parent carers to get their views of services and raises issues with services at a strategic level.

It has a coordinating committee or steering group which manages the work of the forum. The coordinating committee might be made up solely of parents of disabled children or might be made up of a mixture of parents, voluntary sector workers and supportive professionals. The forum usually provides parent representatives for strategic decision making committees and/or task groups who are able to represent the views of a wide range of parents.

Why this works

It provides a clear and accessible mechanism for providers to find out parents’ views of services as well as allowing parents to raise concerns. The parents on the committee hear about experiences from different parent groups whose children have a range of impairments, resulting in a better understanding of the differing needs of families. This is invaluable when presenting parents’ views to service providers and allows experienced parents to mentor parents who have not been involved before. Providers can commission the forum to undertake consultation on their behalf which can lead to the reduction in numbers of consultations and offers the possibility of income generation opportunities to sustain the forum.

What might stop it working?

Running the forum can take up a lot of time and energy. There needs to be a strong and committed steering or management group. If there are not many parents involved, the same parents can be asked to sit on lots of committees and they can quickly become exhausted and disengage. Additionally, the forum may lose credibility if providers are not seeing a range of parents. The work of the forum can snowball and funding is needed for admin support and ongoing parent expenses.

An example of this approach that works well is Norfolk Family Voice and is described in more detail on page 6

3 Meetings between parents and children’s services managers

Parents are invited to meet, usually on a regular basis, to discuss

their experiences of services. This could be a large public meeting or a smaller group of parents who between them can represent other families' experiences. The group may also be called a forum. It may be run by parents, a paid worker or a by a local voluntary organisation. Service managers and sometimes commissioners also attend, either regularly or by invitation, so that parents can raise issues with them and they in turn can ask for parents' views on topics relevant to them. This requires good facilitation skills by whoever chairs these meetings.

Why this works

Parents do not feel obliged to attend every meeting. It is easy to opt in and out depending on family circumstances or whether the issue is of interest to the individual parent. Managers and Commissioners hear first hand how parents experience services.

What might stop it working?

Parents who cannot get to meetings do not get the opportunity to input their views. Parents can disengage if they do not see changes as a result of their input. Managers can feel threatened by parents who are critical of them. There might be a conflict about what needs discussing if an agenda is not agreed beforehand.

An example of this approach that works well is Shropshire and is described in more detail on page 10

Profile: A large Rural Authority
Led by: Parents and Voluntary Sector Organisation
Facilitates: Participation

The Durham Model - Making Changes Together <http://www.mctdurham.co.uk/>

Initially a parent Steering Group was set up by parents working with Contact a Family's North East Regional Manager and County Durham's' Parent Partnership Officer. Co Durham is a large local authority with a rural and ex heavy industry population spread.

The Steering Group met regularly over a two month period. Meetings were financially supported by the local authority through the Disabled Children's Implementation Group – a strategic senior management group of staff.

The Steering Group meetings formulated an ambitious plan to engage with parents of disabled children from all walks of life, across a widely spread community to ensure their views led to practical, positive change.

How it is structured

There are TWO Conferences each year – in spring and autumn, focusing on issues affecting families with disabled children in Co Durham. Parents and carers also receive updates about changes happening as a result of their involvement.

Between each Conference focus groups look at issues raised at the conference in detail. Each focus group is made up of interested parents and professionals. Meetings between Conferences depend on the amount of work needed; information sharing, transport, lead professional and early years were the initial focus groups.

Should the Local Authority secure funding for a service for disabled children a 'one off' Focus Group can be set up to decide use of the grant.

Strengths of this model

This system creates a 'Catherine Wheel' effect – Parents see visible change driven by their views and experiences – word of mouth encourages increased parental attendance at each conference.

Conferences and focus groups 'grow' clearer understanding between parents and professionals about the challenges of navigating the current systems and offers solutions based on clear feedback and mutual collaboration.

In placing emphasis on the parent conference as the main influential force it provides an inclusive platform open to **all** families. The Parent Steering Group *only decide* the conference structure which ensures that no one parent becomes the driving force nor

becomes responsible for representing the wider constituency of parents views as a token parent invited to professional meetings.

This model works well as parents and professionals see innovative change and it reverses the concept of parents being invited to join Boards/Strategic Partnerships as here, professionals are invited to join Focus Groups - which in turn creates a 'level playing field' of planning and negotiation.

It makes very efficient use of parents' time.

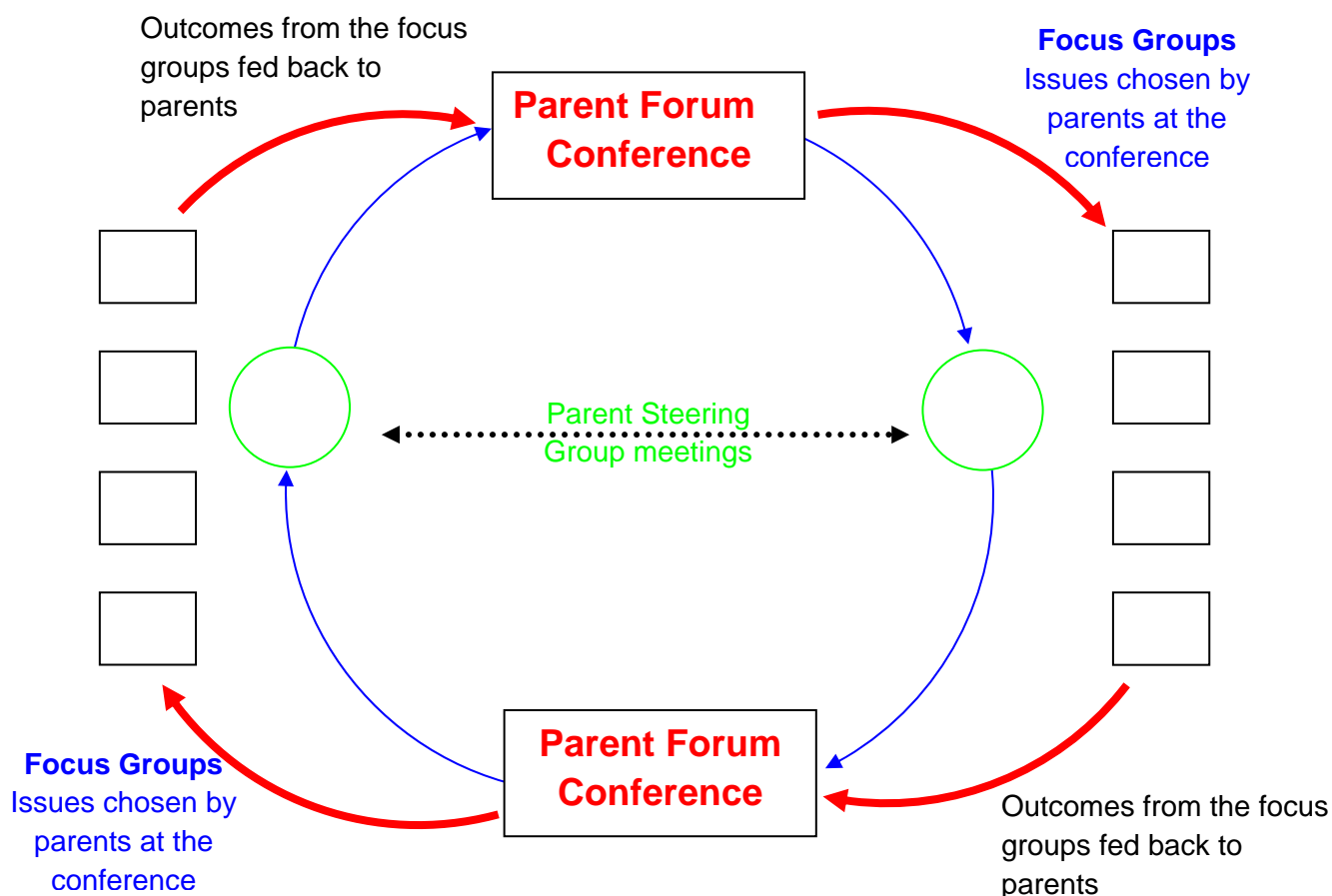
It does not ask for an ongoing commitment, which is difficult for many parents, and therefore promotes involvement from a wider population of parent carers.

This model is still evolving.

Outcomes to date

Parent carers have input into the role requirements and descriptions of Lead Professionals.

There is real two-way communication between parents and professionals leading to better understanding on both sides: professionals now have a much clearer picture of the experience of parents and parents have an understanding of the decision making process around the provision of services.



Profile: A Large Rural Authority
Led by: Parents
Facilitates: Consultation and participation

Family Voice - Norfolk <http://www.familyvoice.org.uk/>

How it was set up

About 8 years ago two parent governors were invited by the then LEA to join the 'Best Value Review' Steering Group. On attending an event one of them heard presentations from parents from Leicestershire and Calderdale's Parent Carers councils. At the time, in Norfolk there was not sufficient parent led activity to successfully set up a similar forum. A while later some parents became involved as parent co-trainers as part of the Early Support Programme. Through this they met other like minded parents and built good relationships with LA and PCT managers. As a result they felt more confident about setting up a parent carer's council in Norfolk.

With the help of Contact a Family they formed Family Voice which now has approximately 180 members. It started with two open meetings, one in the evening and one during the day. The meetings were advertised widely through as many varied contacts as possible and over 30 interested parents attended. The county gave them a £2,000 grant to get started and they formed a Steering Group.

How it is structured

Family Voice runs meetings open to all parents approximately three times a year. These meetings are issue based. Topics covered recently include the new draft Disabled Children's Strategy and consultation around SEN reorganisation.

Family Voice has two committees that feed into the steering group which manages the organisation. One committee responsible for administration and marketing and the other to look at issues parents raise. The committees meet in different venues, including the Parent Partnership offices, in each others houses or in coffee shops, mainly around Norwich, which acts as a central point to a very large rural county.

How it links with Children's Services

Norfolk County Council has continued to finance the administration and travel costs of setting up the organisation. The council and the PCTs ask Family Voice to provide parent representatives to sit on many different steering or strategy groups. These include county-wide and specific specialist committees.

Amongst these at present are the Disabled Children's Strategy Group, the SEN Strategy project board, the Positive Handling Group, Norfolk Carers' Council, Parenting Strategy, the Paediatric Network, the short breaks Pathfinder communication group and a parent member chairs the county wide multi-agency ASD Steering Group.

Parent reps are drawn from the steering group, committees and wider membership. Usually parents who want to get more involved initially become a member of a committee, to help them build up their knowledge of other parents' experiences before becoming parent reps.

Family Voice often asks to have two parent reps on a committee. This allows parents new to being a representative to be mentored by a more experienced parent representative. Larger consultation events on such issues as the Statementing review or SEN Review are of course opened as far and wide as possible.

Following the example set by the Early Support Programme, Family Voice has recently agreed a payment policy also adopted by the council. Parent reps attending steering groups will be paid £10.75 an hour, plus travel costs plus child care if needed. It was also agreed that members will not be paid for attending any Family Voice meetings as all this work is voluntary.

Parents all sign up to the Family Voice parent participation policy before becoming a rep and all the Steering Group sign a Data Protection Policy.

How it reaches other parents

Family Voice has three types of membership:

- Full - for individual parents/foster parents/wider family members
- Affiliate - for the various parent groups in Norfolk including condition specific groups
- Associate - for professionals working with families of disabled children who are supportive of the work of Family Voice

Family Voice produces a newsletter that is either emailed or posted to members (at member's preference). The newsletter informs parents about what is going on and advertises events / focus groups / consultations.

Family Voice reaches out and finds new parents by:

- Members giving out leaflets to groups / at meetings / to parents they meet
- Sending flyers inviting parents to join to schools / libraries / Children's Centres
- Running focus groups on specific issues and inviting parents who attend to join
- Inviting parents who attend Early Support Parent Workshops that are being offered around the county

Strengths of this model

Family Voice successfully facilitates the input of a large number of families with disabled children into strategic decision making within the large rural authority.

The structure enables parents to respond to requests for parents input on particular issues.

The Administration & Marketing committee enables the organisation to recruit new parents on an ongoing basis and respond to their need for information.

Outcomes to date

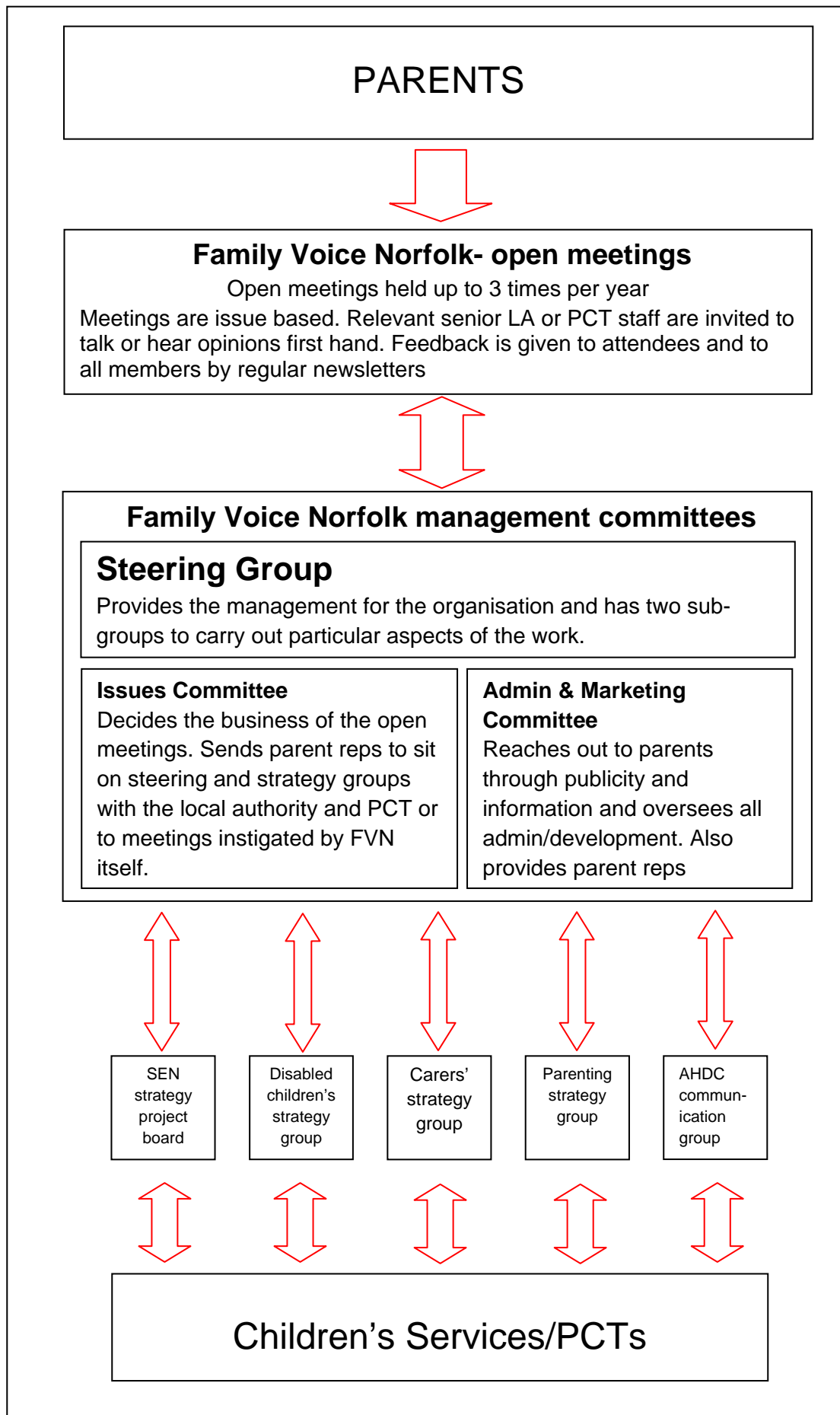
Family Voice Norfolk is a relatively new organisation but already feels that it has been instrumental in changing the way parent carers are involved in looking at change. Parents are now involved in inputting to the working and focus of all relevant strategy documents and are no longer just presented with a final version. An example of this is the work that is being undertaken to develop the short breaks service. There was an innovative proposal that the county could work on the basis of assumed need for some short breaks amongst families of children receiving high and middle rate DLA. Parent reps strongly supported this idea and asked for it to be adopted, which it now has been.

As a result of work undertaken by Family Voice, a new and comprehensive Continence Guide has been published and distributed by the PCT.

As an organisation they have also been key in developing parents' confidence to speak out and get involved in shaping services.

Future developments

Family Voice is working towards forming five satellite groups to feed into the steering group across Norfolk to reach more parents and enable them to have an input into the decision making process.



Profile **A unitary Authority**
Led by **Parent Partnership Service and Parents**
Facilitates **Consultation and Participation**

Parent and Carer Council – Shropshire www.paccshropshire.org.uk

How it was set up

There was a meeting organised in 2005 by a local group of professionals and parents known as the Special Needs Interest Group (this unfortunately no longer meets) at which a speaker from Leicestershire explained what they had achieved there. As a result a group of parents began to meet, and were supported by staff from the Parent Partnership Service. It took some time for the group to settle down to having a regular membership, but by 2007 was able to form a committee and agree a constitution. The Parent Partnership Service continues to provide support and information and guidance from Contact a Family has been very useful.

How it is structured

The Parent and Carers Council Committee (PACC) has regular monthly meetings. The current committee has recently grown from 6 to 10. Recently the meetings themselves have focused on planning and development rather than on issues.

We also maintain a database of members, who are not able to come to committee meetings but wish to be informed about opportunities for participation and consultation.

We have had a small grant (£750.00) from the local Community Council which has paid for printing and admin costs, and some volunteers expenses. We have also had financial support from Shropshire Council services to pay for participation events and mailshots, but this has not been formalised.

How it links with Children's Services

When Children's services want to consult with parents of disabled children they ask PACC to send out the information to its membership. It is then the choice of parents to respond to the consultation on an individual basis.

Where there is the opportunity for a parent representative to be involved by sitting on a working group Children's Services ask PACC for a parent. This opportunity is also advertised to the membership and parents asked to get involved if this is a service or issue which they feel they can represent others on.

How it reaches other parents

We use existing networks (Parent Partnership Service, Record of Children with Disability, Special School distribution) to distribute our leaflets inviting people to become members. Notices are put in PPS and Record Newsletter and on the PPS website.

We maintain a database of our members kept securely by PPS. PPS also administer mailshots (email and by post) and charge PACC for materials used and postage (not time). We send out mailshots with information about consultation and participation opportunities. We also produce regular newsletters with feedback and reports from those people who have joined committees and panels.

We aim to organise two events per year at which members can meet one another. One is a more formal Open Forum, which professionals attend and are invited to take questions from the floor. The other is our AGM and Open event, at which parents can join workshops to share concerns and ideas. We take forward ideas from both events.

We are establishing good links with existing support groups, as we recognise that for many parents/carers attendance or involvement with a local support group is as much as they can manage to take part in, and for PACC this is a really good opportunity to get views and share ideas and news.

Strengths of this model

As many people as possible have been given the opportunity to take part. Of those who have joined, we can say that they have all been given the information about opportunities to share their views. We hope that not only does this ensure that as wide a range of views as possible is presented, but also protects those people who do take part from a criticism that they are not representative.

We realise that there are other opportunities to participate and consult which do not come through PACC, but we do hope that now local services do know where to go to get parents and carers views and be confident that there is a structure in place.

Outcomes to date

We are now represented on a wide range of committee's and panels, and we have also consulted with members about a range of issues. The following are examples of some of the changes to services which have resulted:

Parents' views are now represented on the majority of the joint commissioning groups in Shropshire.

It was confirmed at the recent Joint Commissioning Group that Shropshire local authority and PCT have both now signed up to the Every Disabled Child Matters Charters directly as a result of the issue being raised and discussed by PACC and its members.

The lack of Saturday / holiday provision and the need to be able to participate in community based activities were picked up by the Short Breaks Working Group. Pilot

schemes to increase holiday provision and to support inclusion community activities are being developed.

Funding has been agreed to provide moving and handling training for parents and carers.

Funding has been allocated for additional sessions of Makaton training for professionals and parents.

PACC was asked for ideas for the use of the Parent/Carers room at the new multi-agency room, many of which were taken on board.

Future developments

PACC will be holding further Open Forum events aimed at engaging with more parents carers in the county and providing feedback to existing members.

In order to recruit more members and offer more flexible opportunities for participation and consultation PACC also aims to develop a website. This is particularly important as Shropshire is a large rural county and the problem of travelling to meetings can exclude many families. Online participation will enable involvement from a greater number of families. It is also intended the website will be offered as a platform for support groups. PACC is aware that it could be doing more to engage with local groups and use the opportunities that they offer for informal participation.

