

contact a family
for families with disabled children



Parent Carer Participation

An Overview

Working with



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 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.

Parent Carer Participation - an overview

This short guide provides examples of successful parent carer participation and :

- describes what parent carer participation is and why it is necessary
- explains the different models of parent carer forums that operate in England
- provides advice for supporting parent representatives sitting on decision making boards
- gives a few tips on developing a local participation strategy

Contents

Introduction	3
1 Information	4
2 Consultation	4
3 Participation	4
Why is Parent Carer Participation Necessary?	4
Why Parent Carer Participation is cost effective	5
Reducing the number of complaints	5
Models of Parent Carer Forums	6
1 Parent Conferences and Task Groups	6
2 Meetings between parents and children's services managers	7
3 Parent carer forums/parent carer councils	8
Supporting Parent Representatives:	10
Why have Parent Representatives?	10
Supporting Parent Representatives attending meetings	10
Confidentiality	11
Payment for parent representative	11
Golden Rules of Participation	11
Developing a participation strategy	12
The National Network of Parent Carer Forums	14

Introduction

Over the last few years there have been exciting developments in user involvement and parent carer participation. Forums for parents of disabled children developed across England under the Aiming High for Disabled Children's programme to work with professionals and improve services for disabled children and their families.

Disabled children are a relatively small proportion of the population but can have complex needs and access a wide range of different services across health, education and social care. Parent carer forums can help identify and feedback problems frequently experienced by families with disabled children and work with professionals to help them improve how services are delivered. The Department for Education have made a commitment to continue funding parent carer forums for another three years.

It is now obligatory for managers and professionals to provide families with information about services, consult with them about their experience of services, and work in partnership with them to improve services, so they better meet the needs of children and their families.

Developing parent carer participation is not easy. It involves a culture change for professionals at all levels and makes huge demands on parents' and professionals' skills, time, energy and enthusiasm, but the rewards are huge for everyone. Effective participation means that parents and their families receive services which meet their needs, and professionals do not waste resources on services that families do not want or value. As services improve, everyone involved feels a sense of achievement and confidence and all are inspired to continue to improve services through parent carer participation.

This short guide, written for service managers and commissioners, includes examples of successful parent carer participation and:

- describes what parent carer participation is and why it is necessary
- explains the different models of parent carer forums that operate in England
- provides advice for supporting parent representatives sitting on decision making boards
- gives a few tips on developing a local participation strategy

The text has been taken from a more detailed How to Guide to Parent Participation, which can be downloaded from the Contact a Family website at www.cafamily.org.uk/families/parentparticipation/index.html

Some explanations

The term 'parent' denotes 'parents or carers of disabled children'.

What does Parent Carer Participation mean?

Effective parent carer participation happens when parents have conversations with, and work alongside, professionals, in order to design, develop and improve services. This conversation benefits everyone.

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

Working with professionals helps parents understand the complexities involved and the challenges faced by the professionals who have to bring about changes to services.

Working together and sharing knowledge enables parents and professionals to find solutions that work.

There are three essential ingredients for successful parent carer participation:

- good information
- honest consultation
- effective participation.

All three elements need to be present and complement each other for meaningful and effective parent carer participation to take place.



1 Information

All parent carers need to be provided with relevant and timely information which helps them access the services and support they need to care for their disabled children. The better informed parents are, the more confident and able they are to make informed choices for their children.

A local constituency of well-informed parents develops knowledge of what works best for all disabled children and young people. Such knowledge is an essential ingredient in shaping effective services that best meet local needs and underpins successful consultation and parents' participation.

2 Consultation

Consultation is a step up from simply giving information as it requires two-way communication. Professionals may consult with parents on existing services to seek their opinions on how services can be improved, or to learn how good practice could be replicated elsewhere. Another reason for consultation could be when changes to services are planned. In this instance, as many parents as possible should be informed about proposed changes to a service and invited to give their ideas and raise any concerns about the proposals before final decisions are made.

Consultation is a two-way communication. The people carrying out the consultation need to reply to parents' responses, setting out clearly what has changed as a result of parent feedback. Where it has not been possible to make changes, those who carried out the consultation should explain why not. If they fail to do this, parents will become disillusioned with the consultation process and will not be motivated to respond in future consultations.

Many parents do not have the time, or choose not to get involved in full participation. However, all parents have opinions about the services their children receive. Consultation is an important and relatively simple way of capturing a wide range of views.



4 Parent Carer Participation an overview

3 Participation

Parent carer participation is a significant step up and requires real commitment from parents and professionals. Informed and empowered parents are enabled to become actively involved in service planning and decision making. Professionals are given the opportunity to draw on the unique skills and expertise which parents can offer. This can make a significant difference to the effectiveness and appropriateness of services. Services which have been designed taking into account all perspectives, including those of parents, are inevitably more effective and resources are not wasted on services which parents and families do not take up or value.

Why is Parent Carer Participation Necessary?

The 'Aiming High for Disabled Children' program set out the Government's commitment to improve services for disabled children and their families. The short breaks duty states:

"The Government expects all local areas to build on good practice in engaging parents of disabled children, such as parent carer forums, with the support of staff that have skills to support participation, to engage, support and train parents to influence the design and delivery of services". (Section 2.40)

Parent carer participation is also recommended as good practice in many government strategies such as the National Service Framework. There is also a new 'Duty to Involve' (Section 242 of the 2006 NHS Act) for all health services and their partner organisations, in which there is a requirement for meaningful consultation with service users. The Government's current Health and Social Care Bill (2012) aims to embed public and patient involvement at every level of the NHS.

"The Government's health and social care reforms are centred around the fundamental principle that patients and the public must be at the heart of everything our health and care services do. This will only happen if there are mechanisms in place to involve and engage people in every aspect of how services are planned, commissioned, delivered and monitored."

HealthWatch Transition Plan9, DH,
March 2011

In addition, over half the local authorities in England have signed up to the Every Disabled Child Matters Charter, thus pledging them to parent carer participation in shaping their local services.

Why Parent Carer Participation is cost effective

Parent carer participation avoids waste. When parents get involved in service planning and decision making, services more effectively meet the needs of families with disabled children. Resources are not wasted on services which parents and families do not take up or value.

“Parent participation has influenced the choice and quality of the short break services we buy, by making sure we ask the right questions in applications and interviews, and influencing processes such as the entitlement framework. So I consider the local authority to have better value services as a result of an ongoing process of parent participation.”

Commissioning Officer

Parent carer participation can help to save money. There are many examples of how it has produced simple low cost solutions to local problems.

Parent carer participation leads to realistic expectations. Parents and professionals develop a shared view of how services can best be provided to support families. Informed parents are generally realistic about their expectations and the reality of delivering services within funding limitations.

Example: Redbridge

In Redbridge parents and young people perspectives influenced the pre-commissioning process of short breaks in 2008/2009. As a result many fun, new activities were commissioned. Parent carers sat on the commissioning Panel for the first time ever and the Head of Children's Commissioning and others were really pleased with the contribution that parent carers made. This was repeated the following two years. The number of disabled children receiving short breaks in Redbridge rose from just over 300 in 2008 to nearly 800. In 2011 the number of disabled children in residential or foster placements at the request of their parents, as they no longer felt they could meet their needs at home fell from seventeen to eight.

Example: More cost effective services in Gloucestershire

As part of implementing the Aiming High agenda in Gloucestershire, professionals and parents worked together to transform the provision of short breaks. Parents told service providers that they had to wait a long time to see a social worker. They then found the core assessment process very negative and, finally, said that it often resulted in either a refusal to provide the service or else in the provision of a service which did not meet families' particular needs.

Together, parents and professionals designed a new service. Instead of involving social workers, a team of community lead professionals have been recruited to work with each individual family on what they want from a short break. Families all have differing needs and priorities. For example, they might want a fun activity for the child, or the parents may be desperate for an unbroken night's sleep. The lead professional then looks for a way to meet that need. Sometimes it can be met by integrating the disabled child into local mainstream provision rather than into specialist provision. The fundamental principle is to make no assumptions about a family and to work out individual, suitable packages in partnership with the parents.

An unexpected outcome has been that the cost of the average short break has now dropped from £10,000 per year per family to £1,600 per year per family. No family is refused help and parental satisfaction is based on the service meeting the specific need that they have identified. Services fit round the family instead of families fitting round the service.

Furthermore, as a result of listening to families, commissioners have now changed their wider approach to Short Breaks. For example, mainstream leisure weekend activities for children tend to last about two hours. However, parents of disabled children have said that they need weekend leisure activities to last a minimum of four hours. As a result, commissioners have been funding pilot weekend leisure sessions of four to five hours to see if these better meet the needs of the children and their parents.

Meeting family's needs can bring about considerable savings. The report *Impact of the Short Break Programme on the Prevention of Disabled Children Entering the Looked After System* illustrates how this programme prevented disabled children and young people entering the Looked After System. See www.cafamily.org.uk/professionals/research.html

Reducing the number of complaints

As well as helping develop services, parent carer forums can prove helpful in monitoring services and alerting commissioners and managers if problems occur. This can help reduce the number of complaints made, and the costs associated with this.

Example: Improving wheelchair services

When the parents forum, Family Voice Southend, contacted their Primary care Trust (PCT) to tell them about problems families were experiencing with the wheelchair service, the PCT asked to come and meet parents to hear their views first hand.

Locally, there was a limited choice of wheelchairs, which did not always meet the child or carers' needs. There were such lengthy waiting times, the child had often outgrown the new wheelchair before it arrived. Parents were getting little information regarding their options and how long they would have to wait for assessments and equipment.

Family Voice worked with parents and the PCT to develop a profile describing the wheelchair service they would like to see which the PCT used when inviting tenders to run the wheelchair service. The service has now been outsourced to a specialist wheelchair provider and most families are extremely satisfied with the new service.

Parents using the service are encouraged to contact Family Voice Southend if they have problems with the service. Family Voice Southend have a named contact in the PCT and, on the few occasions parents have had problems, a simple telephone call has been all that was needed to resolve the problem. This is much simpler and quicker and cheaper for the PCT than going through official complaints procedures, something parents are often very reluctant to do. The participation process also provides a mechanism for the PCT to get regular feedback about how well the outsourced wheelchair service is being delivered.



Models of Parent Carer Forums

Since 2008 parent carer forums have developed across England through support and funding from the Department of Education. These forums provide a useful resource to children's service managers wanting to involve parents of disabled children in improving services. Inevitably parent carer forums have developed in different ways and work in a variety of settings, depending on each area's own unique history, geography and structures.

Parent carer participation grows organically from small beginnings. The pace cannot be forced because it is an important learning process for both parents and professionals.

Participation has often grown out of one of three approaches:

- parents' conferences and task groups
- meetings between parents and Children's Services Managers
- parent-led groups sometimes called 'parent carer forums' or 'parent carer councils'.

6 Parent Carer Participation an overview

1 Parent Conferences and Task Groups

In some areas, conferences and task groups (sometimes called focus groups) have been used. These are coordinated by a steering group of parents. It requires strategic support from lead children service managers.

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 task groups, involving professionals and parents, are formed for each priority issue.

Durham Parent Forum holds two conferences each year for all interested parents to raise any issues. Between each conference, small focus groups consisting of parents and professionals look at the issues identified by parents at the conference. Changes are made to services and fed back to parents at the next conference. This model ensures that parents have the main influence on deciding issues and then see the outcomes. It makes good use of parents' time and promotes involvement from a wide range of parents.

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 on task groups 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 task 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.

2 Meetings between parents and children's services managers

In this approach, 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 meetings, 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 firsthand 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..

Example of meetings that worked well: Stoke on Trent – summer holiday provision

The commissioner responsible for developing short breaks met with a group of parents to ask them what type of short breaks they wanted. The parents described the types of activities their children enjoyed and mentioned how difficult holiday times were. Some parents thought special schools were the best place to hold holiday activities. Using this information, a range of different activities were organised and well attended over the summer holiday. Some of these were held at special schools and much of the scheme was a success. The commissioning team is now seeking feedback from parents and children so they can improve on this for next time.

3 Parent carer forums/parent carer councils

Some areas have a constituted parent carers' 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 is led by parents of disabled children, but might have voluntary sector workers and supportive professionals who attend meetings. 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 also 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.

Example of a constituted parent carer forum that works well: Norfolk Family Voice

Norfolk Family Voice has a steering group of parents who between them represent a range of disabilities. Most members of the steering group are in touch with other parents of disabled children through parent support groups and schools. The steering group meets regularly to discuss issues that parents bring to their attention. They run consultation events on frequently raised issues to better understand the problems.

Members of the steering groups sit on various strategic decision making committees in Norfolk and are able to feed in the views of many parents covering a range of disabilities. Each committee has at least two places for parent representatives. This means that parent representatives new to this type of work can be supported by a more experienced member.





As parent carer forums develop they often start to incorporate elements of all three approaches. The example below illustrates this. Cambridgeshire has a constituted parent's forum with representation at strategic level on many

committees. They set up a task group where a few parents worked with professionals on a time limited project to improve the experiences for families of disabled children when visiting the local hospital.

Example: Making hospital a more disabled friendly place

In Cambridgeshire, Pinpoint wanted to improve the experience for families of disabled children attending Addensbrooke hospital. They invited the children's service manager from Addensbrooke to meet with some parents. They took the manager through the fraught journey experienced by one family of a child with complex needs, from arrival in A&E by ambulance, the various problems experienced during their stay and, finally, being discharged as there was no bed in the hospital suitable for their child. Even the journey home from hospital was difficult because there were no suitable wheelchair at the hospital and the child's wheelchair had been left at home.

Other parents were also given the opportunity to mention problems they had experienced, which included having to repeatedly explain their child's medical condition and support needs again and again with different staff. This can be very distressing, frustrating and takes the parent away from being with and comforting their child.

Some of the parents agreed to work with the hospital to design a hospital passport for parents of disabled children, which would provide hospital staff with information about their child's condition and additional support needs. The Well Child nurse at the hospital agreed to coordinate the work and invited clinical staff from different departments in the hospital to work with the parents in designing this. A few families then tried using the prototype passport and parents and clinical staff gave feedback before the final version was made available to all families.

Families attending Addensbrooke say the passport has helped improve their hospital visits. One of the parents, who helped with this work, later said
"... had a trip into Addensbrooke's with [my child] on Saturday. The experience was completely different to last time. There was a special bed and we were in a room on our own. Staff lovely and very helpful."

The hospital passports can be downloaded from the 'patient information leaflets and consent forms' section of the Addensbrooke's Hospital website:
www.cuh.org.uk/addenbrookes/addenbrookes_index.html

Supporting Parent Representatives:

Why have Parent Representatives?

The role of parent representatives (reps) is to inform decision makers about the experiences of parents and to ensure that parents' views are fed into decisions about children's services at a strategic level. Through this process, parents and professionals reach a common understanding about effective services for disabled children. Their combined information and perspectives result in joint planning that leads to more effective services.

They must be able to represent all parents

To be truly representative, parent reps have the daunting task of representing the views of parents from a huge range of backgrounds whose children have a wide range of impairments. How can they hope to achieve this?

To help them, practitioners can do the following:

- ask your local parent carer forum to nominate parent reps for specific working groups. This ensures that the parents invited represent the views of a collective body of parents, are more likely to have suitable background knowledge and are trusted to speak on their behalf. If there is no existing forum, seek parent reps from a large, local multi-disability parents' support group
- allocate a minimum of two places for parents on the working group and request that their children be of different ages and have a range of disabilities. This also ensures that parents have some mutual support. Some forums have a system of experienced parent reps buddying or mentoring new parent reps

They are knowledgeable

To contribute meaningfully, parent reps need the same information as professionals on the working group about the purpose of the group and topics being discussed. It is the responsibility of the organisation setting up the group to make sure that they have this. This can be achieved in the following ways:

1. Make sure parent reps are on the mailing list for minutes and information. Check the best format for parents to receive the information; for example post, or email. Do not assume that because they have an email address that they are happy to print out all the information you send, as it can be very costly and time consuming.
2. Identify a member of the working group who will act as the key contact to meet with the parent reps beforehand to:
 - clarify the purpose of the meetings; including terms of reference, objectives and how the group fits into the overall planning structures
 - outline what the group can and cannot do, and where the boundaries and time scales are for decision making
 - let the parents know who the other members of the group are – names, job titles and departments
 - go through the agenda with the reps and discuss the issues and views they have and how to best



- raise these during the meeting
- clarify how the meeting is run; for example, formally through the chair, or by informal discussions
- answer any questions
- explain what to do if they cannot attend – may another parent rep step in?
- clarify the confidentiality policy (see below).

They are available

Parents are most often unable to participate because of the timing of meetings. You can help by:

- planning the timing of the working group meetings for when parents can attend; for example 10am–2pm, so that parents can pick up children
- avoiding school holidays
- arranging some meetings in the evenings

Supporting parent representatives attending meetings

During meetings you can help parent reps by:

- making them welcome: ask the chair to meet and greet them and introduce them to other people at the meeting
- making sure the chair asks people to introduce themselves and explain what their job involves
- asking everyone to use plain language and clarify any jargon used
- making sure the parents have a chance to input into the meeting and feel comfortable to speak openly
- clarifying what information can be shared and what is confidential to the meeting
- ensuring that the parent rep knows how agenda items are drawn up and how to ask for something to be included in future meetings.

After the meetings

You can:

- send out easy to understand minutes –including action points and deadlines – in good time
- include information about the date and time of the next meeting. It is even more helpful if a few meeting dates are set in advance

- get feedback from the reps. Was there anything that could be done to improve their experience? Do they feel able to contribute? Do they need any further information or training to help them contribute?
- thank the parents for their time and commitment

Confidentiality

At times, a strategic working group may discuss confidential matters. It is very important that parent reps are prepared for this in two ways. Firstly, the parent carer forum itself should agree a confidentiality policy and a parent representative policy. For example: 'I will hold in confidence all matters that come to my attention including information about any person or organisation that comes to my attention as a member [of the parent forum] except in those cases where there is permission to share information.'

Secondly, parent reps of such a group should be subject to exactly the same confidentiality rules as all other members of the working group.

Example: Redbridge Commissioning Short Breaks Panel

Two panels were set up to consider proposals from prospective short breaks providers, a children's panel and an adult one. There were two places for parents' representatives on the adult commissioning panel, and the parent forum (Interface) felt it important that the parent representatives had a broad perspective of issues faced by children with a range of disabilities. The parents had to follow strict rules on confidentiality before and during commissioning. This did not pose a problem, though, as the parents had been told about this in advance by Interface.

Payment for parent representatives

The recognition, reward and remuneration of parent carers for their involvement in strategic decision making is an important element for a forums sustainability. This can be a controversial area as some parents do not wish to be paid for their time – especially if it could impact on their benefits – whereas others do. It is helpful if groups can agree an overall strategy which treats all parents equally regardless of which committee they attend.

The strategy should include:

1. Basic expenses

No volunteer should be out of pocket for their work (travel costs, phone calls, photocopying and childcare). Parents appreciate having an easy way to claim expenses. Giving cash to the parent in return for completing an expenses form at the meeting is especially useful for parents on low incomes and benefits. This obviously needs to be in keeping with the law, regarding the permitted amount parents can receive on benefit. Parents need to know who is responsible for this role.

Some parent carer forums invoice service providers directly and then deal with claims from the parent reps themselves.

2. Fees and honorariums

Some service providers provide a professional fee for attending meetings; some offer an annual payment for out of pocket expenses; some give vouchers for supermarkets. Again, the policy should be consistent in all committees. However, payment can affect parents' benefits and income tax.

INVOLVE, the national advisory group supporting public involvement in NHS, public health and social care research has produced useful guides for making payments to members of the public, which includes information about how this might impact on benefits or income tax. The guides can be downloaded from the publications section of their website at: www.invo.org.uk/

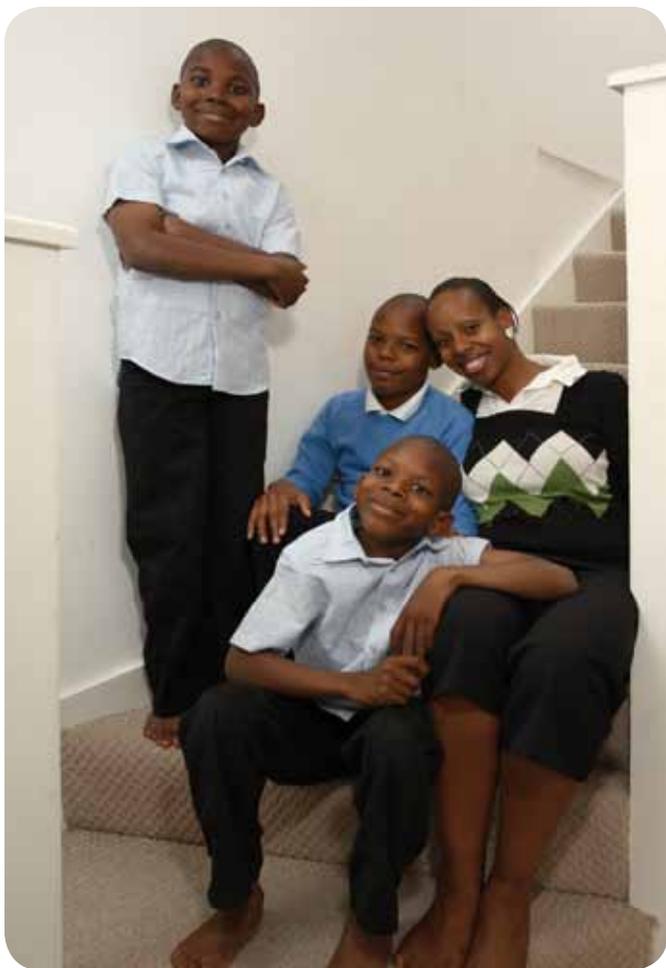
Any parent who is considering receiving payment, whether in cash or vouchers, can ring the freephone Contact a Family helpline on 0800 808 3555 to find out if, and how much, they are able to legally earn without affecting their other benefits and entitlements. Contact a Family's helpline has qualified financial advisors.

Golden Rules of Participation

There is no ideal approach to parent carer participation as it depends on local circumstances. The best starting point is to look at what exists now and to discuss how well it works and what can be built upon. Success depends on following certain golden rules in all three approaches. These are:

- parent carers, professionals and senior managers should discuss and agree what approach will be followed and their shared aim for participation
- parents and professionals can benefit from a 'quick win' to demonstrate the value of participation. This can be achieved by focusing on a specific service identified as one that can be quickly improved
- parent representatives on committees must have a mechanism to represent a wide range of views. For example, be delegated to attend by a local parent carers' forum, or belong to a local parents' multi-disability parents group





- parent representatives on committees must have a mechanism to feedback to the wider group of parents any changes resulting from their input
- parents need information, practical support and training to participate meaningfully
- parents must see the outcomes and positive changes from participating in order to feel motivated to continue.

Developing a participation strategy

Parents and professionals need to learn together what will work in their area and agree how they work in partnership. Both parties will need to think about the commitment required and what capacity they have. Participation has to lead to real change to be worthwhile for all concerned at both service delivery and strategic level. It helps if both parents and professionals have initial discussions with each other and agree a written participation strategy which is built into the Children and Young People’s Services Plan each year.

Example

Brighton & Hove city council and Amaze, the parent carer council for Brighton have agreed a parent carer partnership charter. This includes how Brighton will provide information to families and involve families in care planning for their child as well as involve parents in shaping services at a strategic level. www.amazebrighton.org.uk

The strategy needs to consider the three elements of participation (Information, Consultation, Participation), and requires an local area-wide strategy to avoid duplication, make best use of finite resources and have the best chance of success.

Parent carer forums support a dialogue between families using a service and the professionals responsible for running them. It is this dialogue which helps raise awareness of service users’ perspectives, identifies gaps in service provision and supports the improvement of local services that better meet families’ needs.

Strategy for Information

The vision:

Regardless of what service they use, parents receive essential information about all services and sources of support for families including health, social care, education, and local voluntary organisations.

What is needed?

A task group of parents and practitioners who work together to produce a central source of information and develop a programme to regularly update information and review whether it is effective.

Outcomes:

- there is a good up-to-date local directory/short summary of services and support organisations provided to families of disabled children receiving services which is made widely available through children’s centres, libraries, schools, GPs, and local authority websites
- parents who access any one service are told about support provided by other services and support organisations
- there is regular communication to most families via a newsletter or another format, providing information on a wide range of services/events/activities
- all practitioners in all services have a checklist of basic information required by parents and know the central point where they can get more information





- all practitioners receive regular e-bulletins about consultations and new services, or changes to existing services, including criteria for accessing them
- all newly-recruited practitioners are inducted on parents' needs for information by hearing from a parent carer why information matters.

Strategy for consultations

The vision:

Parents are widely consulted as their views can help inform service development or delivery.

What is needed?

A permanent task group of parents and practitioners who coordinate all consultations in the area to avoid duplication and to feed the results to strategic working groups.

Outcomes:

- services can easily consult with parents covering a wide range of disability/community/caring situations
- there are parent groups, or a parent carer forum, providing parents for focus groups
- consultations are well planned and allow parents more than one way to input their views. They are successful in reaching a large number of parents covering a wide range of disabilities/communities/caring situations
- parents living in the area hear about what has changed as a result of consultations

Strategy for participation

The vision:

A pool of skilled and confident parents, representing a wide range of backgrounds and disabilities, who are able to participate on equal terms in working groups with practitioners who welcome and support their input.

A committed group of managers exists, experienced in partnership working and who work to embed participation into practice.

What is needed?

Leadership and visible commitment from service managers is required, alongside a sustainable parent carer forum. There is an effective mechanism for ensuring that parents across the local area can be involved in shaping services and there are the means to help parents become confident and skilled participants.

Outcomes:

- there is a thriving parent carer participation structure which can represent parents' views covering a wide range of disability/community/caring situations
- parents acting as representatives on committees or small task groups are linked to planning structures so they can feed a wide range of experiences into services
- parents' views are regularly fed into the service development of social care, education and health with an auditable record of how it made a difference

- a group of commissioners, managers and practitioners who demonstrate and promote participatory working, and who value and protect this form of partnership working
- there are examples of where and how parent involvement has informed and influenced decision making about services, providing an evidence base to support future practice
- families living in the area are informed of the outcomes of this work and how they can get involved.

Parent carer participation is not a short-term fix. The cost benefits of parent carer participation are so evident that their cost should be automatically ring-fenced in the budgets for children's services. The costs involved will differ depending on the model of participation operating in the local area. However, it should be assumed that participation will grow and so budgets should be reviewed annually. For example, a parent forum may need the services of a paid worker as it grows.

Training and support

Parents and professionals will be more effective if they understand each other's perspectives and their own responsibilities in the relationship. An annual programme of joint training days built into the local training agenda, for new participating parents and newly appointed professionals on strategic committees and task groups would be relatively inexpensive and pay huge dividends.

The Parent Participation How To Guide provides more detailed information on how to develop participation. See www.cafamily.org.uk (search on parent participation).

Example: Cornwall

Cornwall Parent and Carer Council has produced a DVD of examples of good and poor practice around involving parents in meetings. The development of the DVD involved a range of professionals in Cornwall including a number of commissioners, as well as parents. As well as producing a training tool, the development of this piece of work identified a number of barriers to effective participation and supported the improvement of partnership and practice between all involved.

The National Network of Parent Carer Forums

Parent carer forums are now established in almost every English local authority area. These forums are open to parents of disabled children who want to influence how services are provided across all services, including health, education and social care.

Representatives from parent carer forums regularly meet others in their region to share information and good practice. A parent carer representative from each of the nine English regions is also a member of the steering group of the National Network of Parent Carer Forums (NNPCF). This National Network provides a co-ordinated



method of ensuring that local Parent Carer Forums are kept updated about national developments and that parent carers have a voice and are represented in national strategic planning about services and provision that affect disabled children, young people and their families. Members of the National Network represent the views of Local Parent Carer Forums on national strategic planning groups and regularly meet with the Department of Education and Department of Health.

You can read more about the National Network of Parent carer forums at www.nnpcf.org.uk

Support for Parent Carer Forums

Following the successful development of parent carer forums across England the Department for Education made a commitment to continue supporting parent carer forums until April 2015.

Contact a Family is the delivery partner for the Department for Education to support the development of parent carer participation and forums across England, working with the National Network of Parent Carer Forums. Support is provided through a grant program, regional advisers, training opportunities and additional support for some forums.

You can find contact details for local parent carer forums and more about parent carer participation and the support available to parent carer forums at the Contact a Family website www.cafamily.org.uk/families/parentparticipation

Acknowledgements

We would like to thank the National Network of Parent Carer Forums for their assistance in developing this overview.

Much of the content has been taken from a more detailed How to Guide to Parent Participation published in 2010 as part of the Aiming High for Disabled Children programme.

The full How To Guide can be downloaded from the Contact a family website at www.cafamily.org.uk/families/parentparticipation (or in separate sections from the National Network of Parent Carers website at - www.nnpcf.org.uk).

The full text of the How To Guide will be further developed and updated over the next six months.

We would like to thank the following for their assistance in developing the original How To Guide

Author: Pauline Shelley

Contact a Family staff: Sheila Davies, Carolyn Deveney, Gail Hanrahan, Claire Harding, Susan Gorse, Sarah Lee, Karen Mclean, Miranda Parrot, Kathy Rist, Gail Walshe

Parent Carer Forums

Carrie Britton, Amaze, Brighton

Anna Gill and Karen Wooddissee, Family Voice, Norfolk

Lesley Moore, Making Changes Together, Durham

Anna Walker, Parent Carer Council for Cornwall

Abbey Woolgar, Family Voice (Luton and Bedfordshire)

Thank you to Swindon Parents and Carers Advisory group for allowing the use of their image:

www.swindonparentsandcarers.org.uk/

Useful Resources on Participation

Care Quality Commission: Health care for disabled children and young people -recent research illustrating how PCTs report high levels of access and user-centred care, whilst service users report a variable level of satisfaction
<http://www.cqc.org.uk>

Council for Disabled Children: Supporting participation of disabled children and young people
www.councilfordisabledchildren.org.uk

Involve - national advisory group that supports greater public involvement in NHS, public health and social care research
<http://www.invo.org.uk/>

National Network of Parent Carer Forums - Information about and latest news from the National Network of Parent Carer Forums and resources to support parent carer participation
www.nnpcf.org.uk

NHS Institute for Innovation and improvement - resources to support engagement of patients in development of NHS services.
http://www.institute.nhs.uk/building_capability/general/engagement_and_experience.html

Participation Works - gateway for children and young people's involvement

www.participationworks.org.uk/home

Reward and recognition: the principles and practice of service user payment and reimbursement in health and social care (second edition 2006), Product Number, 276815
www.dh.gov.uk

Young, Disabled and In Control - film designed to challenge stereotypes of disability and show the positive difference when young disabled people are involved in decisions about their lives

www.councilfordisabledchildren.org.uk/getting-involved/young-disabled-and-in-control

About Contact a Family

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 advisors. 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

We produce the Contact a Family Directory – the essential guide to medical conditions and disabilities with information on over 440 conditions and UK support. Each entry provides an overview of the condition with details of support groups where available.

One-to-one support groups

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

Getting in contact with us

Helpline 0808 808 3555

Open Mon-Fri; 9.30am - 5.00pm

www.cafamily.org.uk

www.makingcontact.org

Follow us on Facebook
www.facebook.com/contactafamily

Follow us on Twitter
www.twitter.com/contactafamily

Watch our videos on YouTube
www.youtube.com/cafamily

Registered Office: 209-211 City Road,
London EC1V 1JN
Registered Charity Number: 284912
Charity registered in Scotland No. SC039169
Company limited by guarantee
Registered in England and Wales No. 1633333
VAT Registration No. GB 749 3846 82

