

parent participation

improving services for disabled children

professionals' guide

**COUNCIL FOR
DISABLED
CHILDREN**

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for families with disabled children

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Contact a Family was founded in 1979. It is a UK wide voluntary organisation providing support advice and information to families with a disabled child across the UK. Contact a Family provides this help regardless of the medical condition of the child, including the most rare.

Contact a Family's main aim is to empower parents of disabled children to obtain the best possible care for their children and families.

Its objectives are:

- ◆ to provide information to families on any disability and any aspect of caring for a disabled child
- ◆ to foster parent mutual support groups and parent networks at national, regional and local level
- ◆ to link families together whose child has a rare condition where there is no existing group
- ◆ to publish and disseminate useful information for parents and for the professionals who work with them
- ◆ to raise awareness of families' needs and press for improved services based on parent's experiences

The charity has offices in Wales, Scotland and Northern Ireland, as well as regional offices in England and local offices in parts of London. A network of volunteer Local Area Reps, all of whom are parent, provide information in local areas.

There is a national freephone helpline on 0808 808 3555 (10am-4pm, Monday to Friday). The service is free and confidential. Textphone users should dial 0808 808 3556. E-mail enquiries can be sent to helpline@cafamily.org.uk or write to 209-211 City Road, London, EC1V 1JN.

The **Council for Disabled Children** (formerly the Voluntary Council for Handicapped Children) was established in 1974. It is an independently elected, multidisciplinary consortium operating under the aegis of the National Children's Bureau.

The Council for Disabled Children (CDC) promotes collaborative work and partnership between various agencies, parents and children, and provides a national forum for the discussion, development and dissemination of a wide range of policy and practice issues relating to service provision and support for children and young people with disabilities and special educational needs.

CDC's broad-based membership and our contacts with an extensive network of individuals and agencies, both large and small, national and local, gives us a unique overview of current issues and assists us in promoting quality services and support for children and their families.

CDC aims to:

- ◆ raise awareness of the needs of disabled children and their families;
- ◆ contribute to the development of policy and practice in central and local government;
- ◆ promote the participation of disabled children and their families in all decision making about their lives; and
- ◆ provide an independent national forum for the discussion and resolution of issues relating to children and disability.

The specific objectives of CDC include:

- ◆ identifying and disseminating information on current policy and practice, research and training;
- ◆ advising and working with government and local authority departments, health authorities and NHS trusts, schools and voluntary organisations;
- ◆ responding to new directions in the development of services and legislation; and
- ◆ advising on gaps and overlaps in service provision and encouraging inter-agency working.

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foreword

Parents of disabled children and young people care passionately about the services they receive. Parents have strong views on the services they get; whether agencies are working together and most of all whether the needs of their child are truly being met.

All services are now expected to consult with parents and involve them in planning and development. But the concept of 'parent participation' means different things to different people. How do we ensure that parent participation is effective and meaningful for parents? This guide has been produced by Contact a Family and the Council for Disabled Children to address these issues and to help and support the many parents and professionals who want to work together to improve services.

There is mounting evidence to support parent participation as a successful way of providing better services. Evidence also shows that parents who are involved in planning and developing services are more contented and empowered parents.

The guide offers an array of practical examples and suggestions to help professionals and parents become effective participators. It also offers an opportunity to welcome and reflect on a changing culture within public services that now places such importance on the input of service users.

Inviting parents to participate in the planning and delivery of services poses many challenges for us as professionals. Yet it is only through working with parents that we understand how to deliver the services they need. Parents observe and experience the system at close quarters and their knowledge and expertise is unique.

We believe that good participation leads to empowered parents, empowered children and empowered services. This is undoubtedly a win-win situation for disabled children, their families and the professionals who work with them – what more could we want?



Francine Bates, Chief Executive, Contact a Family



Christine Lenehan, Director, Council for Disabled Children

1 introduction

A great deal of recent legislation and guidance on health, education and social care highlights the need for user participation. This is leading to some imaginative and cost-effective developments in local services, based on what works for families.

The principle of parent participation has increasingly been accepted and is being turned into practice through a variety of participation activities by many service providers. However, problems arise when commitment to participation isn't translated effectively into practice. Participation needs to be a meaningful experience for parents as well as an integral part of organisational practice.

This guide draws on work carried out by Contact a Family and the Council for Disabled Children with hundreds of parents and professionals. Staff from both organisations have helped parents and professionals develop a constructive dialogue with each other through parents forums and consultation meetings. In addition, we have gathered evidence from parents and professionals on the principles that underlie effective participation and the good practice that results. This guide pulls together the knowledge from this work.

The ideas in this guide have been tested with professionals and parents in workshops in Halton, Sunderland and Sutton. Views on the guidance have also been sought from parents' groups, individual parents and professionals across the UK. We are grateful to everyone who has helped us by providing examples and giving us feedback. All the examples we use have been provided and approved by parents who benefit from the good practice they describe.

This guide outlines principles and good practice for workers on consulting with parents. It is accompanied by a separate guide for parents who take part in consultation and planning of services.



The guide is intended for staff at all levels, from front-line staff to managers and directors – because consultation only works when there is commitment to it at the highest level and it is embedded throughout the culture of the service. It is relevant to staff in health, education, social services, leisure, youth, and transport departments, as well as Sure Start and other local services. The guide is written for anyone who wishes to seek the views of parents in ways that are meaningful to both parents and professionals.

The aims of the guide are to

- ◆ improve access to participation in services for parents and families of disabled children
- ◆ provide support to services that involve parents and families of disabled children in service planning and development.

The objective of the guide is to

- ♦ give service providers a tool to develop and enhance their work with parents of disabled children.

What's in the guide

The seven chapters in this guide can be read and referred to separately, and sections may be photocopied and used in training or meetings.

- ♦ Chapter 1 introduces the guide and sets out its aims and objectives.
- ♦ Chapter 2 defines participation and looks at the benefits that parent participation can bring to services.
- ♦ Chapter 3 looks at some of the common issues and challenges of undertaking consultation with parents and carers of disabled children.
- ♦ Chapter 4 outlines the key principles involving parents in service planning and development. This chapter is divided into four sections. Each section examines a key principle.
- ♦ Chapter 5 looks at monitoring and evaluation and provides a summary of the main ideas in the guidance together with a checklist of indicators with which to measure success in achieving them.
- ♦ Chapter 6 outlines the relevant legislation and guidance for England and Wales, Scotland and Northern Ireland.
- ♦ Chapter 7 provides lists of contacts, further information and the references mentioned in the guide, along with suggested further readings.

A note about the four UK nations

This guidance was written primarily for the development of services in England, but the principles will apply in all four nations. In general, the language refers to settings in England, although there are corresponding services in Northern Ireland, Scotland and Wales. Advice on where to get further information on settings and legislation and guidance can be found in Chapter 6. Information about services in Northern Ireland, Scotland and Wales is available from Contact a Family offices in each country; see Chapter 7 for contact details.

A note about language

For ease of reading, the following terms are used throughout the guide.

- ♦ **Professionals** This refers to all paid staff, practitioners and others who work for the service provider. We appreciate that this term does not always accurately describe the people who work with parents and who might be involved in developing parent participation. However, it is the term that most fully represents the wide range of people who work with the parents of disabled children.
- ♦ **Disabled children** This means all children and young people who have any disability, special or additional needs, long-term health condition and/or challenging behaviour.

- ◆ **Parents** This means parents and/or carers of disabled children and young people.
- ◆ **Forums** These refer to those structures and settings where parents, or parents and workers together, meet to discuss issues and services.
- ◆ **Social services** This term includes all social work settings, including some services provided by voluntary organisations.

2

background

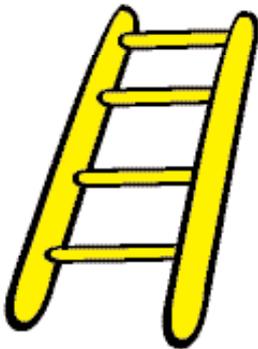
This section defines participation and describes the way in which it helps to improve services. Parents of disabled children often have contact with a range of services. Therefore, it's important that they are able to participate in a way that is useful for them and also effective in developing services.

The concept of service users participating in the planning of services has become a central issue across the public service sector and much recent legislation and guidance on health, education, social care and early years mentions the need for user participation.

What is participation?

The purpose of participation in this context is to ensure better outcomes for families of disabled children and to improve services for all users. It's about the involvement of parents with a wide range of professionals and local service managers in the planning stages of service delivery.

Participation is a multi-layered concept that includes the level of participation, the nature of the participation activity, the frequency and duration of participation, and the content of the decision-making (Kirby *et al* 2003). The level of participation is often seen in terms of the power dynamic between the parties. The different levels at which service users can be involved in decisions about service provision have been depicted as steps on a 'ladder of participation', a useful model for illustrating the type of participation relevant to a particular situation and the power balances involved (Wilcox 1994). This model of participation can be used by service providers to measure where they are currently on the ladder and to help them work out where they aim to be. Practical examples of the differences are given in Chapter 4.



Research by the Audit Commission that formed part of its study of Disabled Children's Services (Audit Commission 2003a) found that parents noticed a tendency for professionals to talk to each other, using language that parents could not understand. Parents often felt their own knowledge and expertise in caring for their child and knowing his or her needs was being overlooked in favour of fixed professional views and procedures. Families felt they could improve services if given some input into how they were managed and delivered. Few of the parents spoken to in the study mentioned being consulted about services or being offered an opportunity to contribute their views. However, the study did indicate that a number of small-scale consultation initiatives were being undertaken by local service providers. This Audit Commission study highlights the need for parents and professionals to work more closely together to develop a common language. It also highlights parents' frustration and their desire for greater participation in service planning.

In the past, parent participation has tended to be done in an ad hoc manner, usually as consultation at one-off events around a new service or new policy. It has been noted that in the provision of education services:

« ... parents' views have been sought retrospectively as part of evaluation of provision. » (Wolfendale 1998).

In effect, this does not enable parents to participate in the planning of services, as it is little more than an information exercise. Parent participation needs to be a regular and routine part of service design and delivery. This will require an organisational and cultural change in the way that services are provided. Parents need to be involved in the development of services from the planning stage to ensure that services are designed to meet their needs effectively. The key principles set out in Chapter 4 outline methods and techniques for doing this.

When developing strategies for enabling parent participation, professionals need to recognise that parents may find it very hard to get involved in service planning due to practical issues such as childcare, time and money, and also



because they may feel they will not be listened to anyway and it will be a waste of their time

(Ball 1997, page 21). The issue of providing practical support to parents is looked at in Key Principle 3. It has been noted that: 'While many councils reported sending out questionnaires to families about services, very few reported on the return rate or the quality of information gathered' (Council for Disabled Children 2001). This shows that such methods of consultation are not appropriate or could be improved and services need to develop more accessible formats of consultation and participation.

The benefits of parent participation

There are a number of reasons why providers need parents to participate in service planning. As well as helping to create services better designed to meet the needs of users, participation helps parents to be active agents as opposed to passive recipients in caring for their children (Beresford 1994, page 114). Being involved empowers parents and helps them to feel they have some control over their own and their child's lives, which can lead to lower levels of stress for families and better use of services. Participation not only helps develop better services, it also improves relationships between professionals and parents and helps parents to be active participants in planning for their children's lives.

Parent participation can be a time-consuming activity and difficult to fit into an already busy schedule. However, in the long term it is likely to save time and money, as parents will be more content with services which are designed to better meet their needs.

The purposes of children and young people's participation has been set out as being to help create better services, and to promote citizenship, social inclusion, personal and social education, and development (Kirby *et al* 2003). Parent participation to a certain extent shares these purposes, but it would be useful to add that one of the main purposes of parent participation is to improve the lives of families with disabled children.

An in-depth study of 20 families carried out in the 1990s found that stress was a major problem for families with disabled children. Much of the stress was caused not directly by the disabled child, but was associated with having a disabled child. Many stresses came from encounters with professionals and dissatisfaction with service provision. The study found that many parents had had some sort of confrontation with health, education or social services. This study also found that ‘the extent to which a parent feels supported by services is as much a product of satisfaction with services for the child as with satisfaction with parent support services’ (Beresford 1994, page 39). These findings further emphasise that parent participation in service planning will improve services as well as the lives of families with disabled children.

There is a growing body of evidence which suggests that effective parent participation in service planning improves provision for families with disabled children. The Audit Commission’s report *Services for Disabled Children* (2003b), identified four critical components that together would make up truly effective services for disabled children:

- ♦ services meet families’ needs
- ♦ families participate in everyday life
- ♦ services recognise that children grow and move on
- ♦ services recognise, recruit and develop the right people
(Audit Commission 2003b, page 4).

In preparing its report, the Audit Commission assessed current provision against these components and identified the challenges for leaders at all levels. The report recommended that services can meet families’ needs when commissioners, managers and practitioners understand what families want and need, and use this to commission and deliver the right services (Audit Commission 2003b).

Research in Northern Ireland into support for disabled children and their families found that ‘service providers need to more actively involve parents and children in the planning process and listen to their views’ (Kelly and Montieth 2003).



The reform, improvement and modernisation of public services which has taken place over the last few years provides structural support for the development of effective parent participation. In addition, providers need to enable users to participate in service design because of particular developments: funding systems have changed; new forms of public-private mix have been adopted; and new systems of inspection and evaluation have been created. These developments mean that expectations have changed and providers now need to offer both choice and high standards. One way of doing this is to provide what service users want; parent participation is the ideal method of achieving this (see examples on pages 41–42).

Participation is becoming an integral part of all service planning and delivery. Legislation requires public service providers to consult with parents to ensure they are providing services that users want. Service providers need to develop a culture of participation in which parents are automatically involved in the planning process.

As research on children and participation has shown: ‘organisations that are

successful in involving children and young people are those that see participation as a wider concept, reaching beyond specific events to include a whole or overarching approach, leading to the development of a participatory culture’ (Kirby *et al* 2003, page 13).

Legislation and guidance



The good practice described in this guide is underpinned by statutory legislation and guidance across education, health and social care. The Children Act 1989 is still one of the major pieces of legislation affecting children’s services, but more recent legislation and guidance reinforces the need to involve parents in the process of service delivery and development. In health, the NHS Plan 2000 introduces the need for providers to consult with service users. In education, the SEN Code of Practice, issued in 2001, outlines the need for LEAs and schools to develop effective parent participation. In social services, the Carers and Disabled Children Act 2000 encourages service providers to work with parents.

Relevant legislation and guidance covering England and Wales as well as Scotland and Northern Ireland are discussed in detail in Chapter 6.

3 setting the scene

This chapter addresses some basic questions about involving parents in service development and examines the challenges of developing parent participation. It demonstrates the need for a change in the culture of participation in order that organisations can achieve successful and effective outcomes. It also shows why parent participation is beneficial for providers and service users.

Why involve parents?

It is important to involve parents in service development and delivery for the following reasons:

- ♦ to draw on parents' expertise and knowledge about their disabled children
- ♦ to achieve family-centred services
- ♦ to create flexible, personalised and responsive services
- ♦ to reach groups which are traditionally excluded and include them in service provision
- ♦ to develop good relationships through partnership working which can feed into other relationships between families and services
- ♦ to give parents an opportunity to express views and wishes in a positive and receptive environment
- ♦ because informed and involved parents are more likely to have realistic expectations of services and some shared ownership of choices and priorities
- ♦ because parents can be useful resources to support professionals in their work
- ♦ because involving parents will create more responsive services which will, in turn, be more cost effective.

Professionals providing front-line care to families generally have excellent relationships with them. They know about families' experiences, including those of the most marginalised and unrepresented parents. This relationship, built over time, is important to professionals and parents. In order to effectively use what they learn from parents about what makes for effective services, professionals need an ongoing process of consultation to provide an evidence base for any changes they make in service planning and delivery. Managers can support this by helping front-line staff to create positive and effective participation, so that professionals and parents can work together as allies, as one parent hoped for:

« I believe that professionals go into the caring professions because they want to help us and then they find that they have to defend a system that they have no control over. I feel like the system plays us off against each other and makes us enemies and wastes all our energies. But professionals are our natural allies and when we work together we are very powerful partners! »

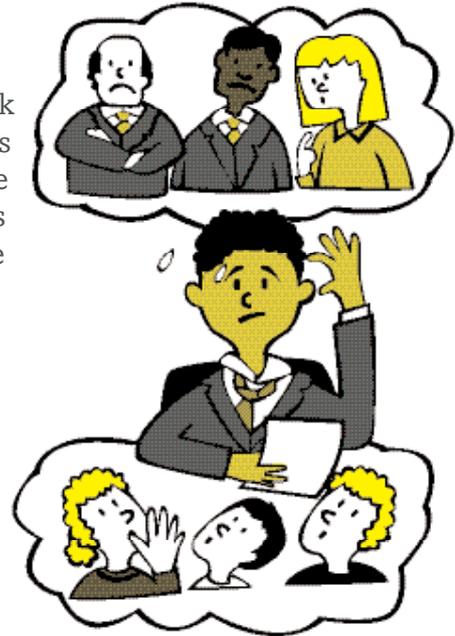
A parent from Sheffield

The challenges to parent participation

Challenges for professionals

When professionals and parents work together on planning groups and forums they can achieve useful and positive outcomes. However, common difficulties for professionals that can make the process less effective include:

- ◆ lack of skills and experience in developing effective participation practice and strategies
- ◆ insufficient time to nurture confidence and skills in parents
- ◆ lack of support from managers and/or peers
- ◆ feeling they are not able to fully participate in service planning and yet being expected to develop parent participation
- ◆ lack of clarity about what they can offer to parents
- ◆ high or unmanageable expectations on the part of families
- ◆ fears that agendas will be dominated by a few powerful parents who are not necessarily representative of all parents in the area
- ◆ lack of power to bring about desired changes
- ◆ no multi-agency strategy, hence a lack of communication among agencies about consulting, leading to 'consultation fatigue' among parents
- ◆ lack of a transparent mechanism for involving and selecting parents
- ◆ difficulties in persuading a representative range of parents to participate
- ◆ lack of resources, such as sufficient time, administrative support and budget.



Some workers address these difficulties by selecting a few 'known' parents to sit on a variety of planning bodies. These are willing parents who spend a great deal of time trying to get involved and influence services. They are often very knowledgeable and have a great deal to offer. However, they cannot represent the views of all local parents and they can sometimes deter other parents from getting involved. A move away from this limited approach to parent participation is needed, towards an inclusive one that can produce more reliable results for parents and services. There can also be problems because of the way such 'known' parents are viewed by other parents: that is, as the ones who are always involved, friendly with professionals and taking up all opportunities.

In some local authorities, practitioners have set up regular forums where parents and professionals can meet to discuss services. While some of these forums are very effective and have helped services to develop, some parents have commented that:

- ◆ the professionals who attend keep changing
- ◆ professionals control what goes on the agenda
- ◆ nothing happens, and meetings come and go with no outcomes.

When planning participation activities with parents, professionals should

remember these comments. Parents should feel they are active participants in decision-making. Staff attending events should be consistent so that parents can build up a relationship with representatives of the service. And staff should report back to parents the outcomes of meetings, giving reasons why any requests were not addressed and outlining future steps to implement them. This will enable parents to see the benefits of their participation. For many organisations or services, this will require changes in the way that parents are involved. Participation will be most effective if it eventually becomes a routine part of the way that decisions are made and information is shared; deadlines and timescales therefore need to take this into account.

The provider's commitment to participation will be further enhanced and demonstrated if a senior manager attends some meetings or events and hears parents' views first-hand.

Challenges for parents

There are numerous reasons why parents may find it hard to participate. Some of these are:

- ◆ too many complicated caring responsibilities
- ◆ lack of confidence to speak out in the presence of others
- ◆ lack of practical support, such as childcare expenses or crèche facilities
- ◆ difficulty getting to meetings because of timing or transport problems
- ◆ being put off by language or jargon used or lack of interpreting support
- ◆ intimidated by the formal settings in which meetings are held
- ◆ worried they will be seen as obstructive or demanding and their child's services will suffer
- ◆ feeling they cannot personally speak for all parents
- ◆ parents' sensory or other impairments are not taken into account.

How services can improve when parents are involved



aMAZE is a group in Brighton which provides support and advice to parents of children with special needs. It was asked to nominate a parent representative to work with a multi-agency group reviewing the local Incontinence Service, as changes had to be made because of a large overspend.

Parent focus groups were organised and, as a result, aMAZE was able to offer practical and constructive suggestions for improving the service. For example, the service was divided to create separate adult and children's services, both of which have benefited from the change. The children's

service was positively renamed the Paediatric Continence Service so that the focus shifted and placed more emphasis on helping children to manage their continence. Feedback about continence products provided the option for parents and young people to choose from a broader range of products, including opting for fewer, more expensive products that suit their child's individual needs. The university training course for nurses now includes a module on paediatric continence, part of which is delivered by a parent, and a handbook for parents is being written.

Some parents can overcome these difficulties but are then put off because of:

- ◆ being consulted too often
- ◆ boredom and absence of fun or enjoyment in the process
- ◆ lack of choice about how they can contribute their views
- ◆ feeling they have no real power
- ◆ lack of feedback when they do get involved.

Professionals can feel like this about meetings as well, so creating better, more accessible meetings would benefit everyone.

Summary

Participation can be difficult for both parents and professionals when they lack time and resources to engage in the process effectively and when both parties lack power to create change as a result of their work. This chapter has looked at the benefits that effective participation can bring to service providers and families, and has shown that a shift in the culture of participation is needed to overcome the many challenges that are involved in the process. There are a number of ways of working through these issues: the next chapter gives practical guidance on how to meet these challenges.

4 key principles

The following key principles provide guidance for:

- ◆ staff who work with families on a daily basis and who are often charged with carrying out consultation
- ◆ service managers and directors who will be supporting them.

In writing this guidance, we consulted with parents and practitioners involved in participation in a wide range of arenas. It was clear from this that, although there are many local variations and mechanisms for developing effective participation, there are four key principles which underlie successful participation and involvement. They are:

- ◆ Key Principle 1: Defining what participation means
- ◆ Key Principle 2: Using a variety of approaches
- ◆ Key Principle 3: Overcoming an imbalance of power and control
- ◆ Key Principle 4: Visible action.

The following sections provide details of these key principles and how they can be approached, along with practical examples. Everyone who has provided us with a good practice example is willing to be contacted for further information; their details can be found in Chapter 7.

At the end of each section is a practical exercise, headed *What do you think?*. This can be used by a team of colleagues or by a multi-agency group, with parents or individually, to generate discussion and thinking around developing effective participation strategies and activities. You may prefer to use examples relating to issues in your area and adapt the discussion points accordingly.

It is essential that professionals are clear and honest about what is being offered to parents so that they believe their participation is worthwhile. Each time parents are asked to participate in consultation, whether it's a working party or a one-off event, it's good practice to start by clarifying how much influence this exercise or group will have on service development. Professionals may find it helpful to clarify for themselves where this activity fits into strategic planning and what weight parents' views will have relative to other influences and interests in the process. It will then be easier to convey this to parents and avoid misunderstandings and unrealistic expectations.

Consultation is often mistaken for participation, but it is part of the whole process of participation. Participation is about parents playing a full part in the decision-making process and is usually a continuous exercise. This requires practitioners to create the right environment for this to happen (this is addressed by other key principles). Participation occurs at different levels, described as a 'ladder of participation' (Wilcox 1994): at the lowest level parents have little influence, at the highest level they are significantly empowered. Different models have described the ladder with varying levels of participation, but in this guide we describe three levels of participation, or three rungs on the ladder. Different rungs are appropriate to use at different times or in different settings.

Deciding which level is appropriate

Before deciding which level to work at, it's helpful to think about the capacity of the service and the purpose of the exercise. The three rungs are outlined below with discussion on when and in what situations to use them and what each approach can achieve. It is likely that eventually all three approaches would be used together to keep parents informed, ensure they are satisfied and enable them to be involved in new developments.



Information

You are giving parents information about a service development and not asking for feedback. This lets parents know about changes that have already taken place, or about new services that have already been developed or have to be developed to meet government guidelines.

For example, your local authority could be setting up a new Children's Trust to promote multi-agency working. It's important that parents understand what this will mean for services for disabled children. Giving information is very important as a first step in involving service users and can lead to more active involvement at a later stage.

To inform, remember:

You should be clear that this is not a consultation. However, you should inform parents that there will be a chance for consultation and participation in planning about the new Children's Trust services at a later stage.

	<i>Typical process</i>	<i>Typical methods</i>	<i>The stance of the resource holder</i>
Information	Presentation and promotion	Leaflets, newsletters, displays	'Here's what we are going to do'
Consultation	Communication and feedback	Surveys, meetings	'Here are our opinions – what do you think?'
Participation	Partnership building	Working groups/ forums	We want to make decisions together



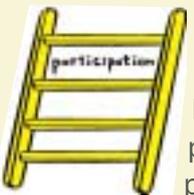
Consultation

You are offering parents some limited choices about what you are going to do. You have a fairly clear vision and some plans but wish to consult on problems, offer some options, invite comment and take feedback.

For example, you may have set up an early years family centre and would like views from parents of disabled children about some of its activities.

When consulting, remember:

- Only consult if you are able to take notice of what parents say.
- Let parents know the limitations of this exercise. Be very clear about your own role and about who makes the ultimate decisions, and how and when this will be done. Parents can then make informed decisions about whether they want to invest their time and energy in responding. Those who do decide to invest in the exercise will not feel cheated.
- Make it clear how you will inform parents about the final decisions.



Participation

In a situation where true participation takes place, parents are given a significant voice in the planning and decision-making processes. This is only appropriate where no pre-determined decisions have been made or when the agency is willing to be led or significantly influenced by the views of parents. Parents might participate, for example, in the shaping of fully inclusive after-school clubs or accessible playgrounds in the local authority.

Spelthorne Children with Disabilities Forum: Short breaks and leisure



This forum is open to all parents who wish to attend.

Typically about ten parents attend, not always the same ones. A few parents on the forum pointed out that short breaks were a major problem in Spelthorne and so a group of around four parents were given permission by the forum to develop a mini-project investigating the families' needs. As a result of parents' expressed needs, the forum then commissioned a larger study from Royal Holloway College. This study showed clearly that parents wanted a residential centre – for which money was not going to be available. But it also raised issues about other forms of short breaks, including the need for leisure services for disabled children. A subgroup formed to start an after-school club, which has been running successfully for two years with parents on its management committee. The club has the support of all services and the main strategy group.

Clarifying what is on offer

It is essential for professionals to clarify how much influence parents will have. A general protocol or set of standards can be very helpful in establishing this at the outset. An example of a basic protocol is shown below. Forums and parent groups will need to adapt and develop this to meet the needs of the individual group.

Example of basic protocol/guidelines for a group or forum

Value statement

- ◆ what the forum/board/group believes in
- ◆ aims of the forum/board/group
- ◆ honesty and clarity

Participation – a definition

- ◆ equal status of parents and professionals

Principles for involvement

- ◆ eligibility and representation
- ◆ responsibilities of parents
- ◆ responsibilities of service providers

Good practice guidelines

- ◆ purpose of groups or meetings attended to be clearly stated
- ◆ timescales to be clearly stated
- ◆ arrangements for feedback mechanisms to be agreed
- ◆ regard to equality of access to events in terms of venues and meeting times, expenses for parents etc

Quality assurance

- ◆ written agreements between parents and any providers or services

Developed from protocols and guidelines from Somerset Impact and Cheshire Disabled Children's Partnership Board

Summary

This section has looked at what participation is and outlined the different levels of participation, including information and consultation. The next section, Key Principle 2, describes the types of activities that can be carried out at each level of participation.



What do you think?

You are one of several professionals concerned about some of the ways your service involves parents of disabled children in ongoing service planning. You sometimes feel that consultations are merely a 'tick box' exercise and that parents actually have very little real say on how services develop. You feel uncomfortable about exploiting parents who really want to be involved and also feel that you are wasting your own energies.

Discussion points

- 1 What could you and your colleagues do to make the participation process more transparent and meaningful?
- 2 If you drew up a participation strategy, what would it say?
- 3 How would you tell parents about your new strategy?

This section examines the need for a variety of approaches to engage parents from different backgrounds and circumstances. It also looks at practitioners' need for time, resources and support from managers to make participation meaningful and effective.

Parents are all different; they have different abilities and preferences. Their views should be captured at whatever level they prefer, be it through questionnaires, in meetings or through individual feedback. Engaging with a range of parents is more effective in the long run than relying on a limited number of parents who are confident and comfortable with the more formal approaches.

Adopting different approaches takes time and so it helps to know who else is asking parents to participate, to avoid unnecessary duplication. For example, parents sometimes say they are asked to fill in the same questionnaires by different people at different times. A central database of recent and current consultations in your own and in other organisations would prevent some unnecessary duplication. For example, two agencies may be consulting separately about leisure provision: rather than carrying out two separate consultations, it would be more efficient and cost effective to carry out just one, in partnership. Other ways of avoiding duplication would be contacting the co-ordinator for the area's Children's Disability Register or the Early Years' Partnership, or recording all consultation exercises with a local parents or voluntary sector forum.

Having decided to involve parents in the development of a service, a service, decide

what approaches to use and clarify what is being offered to parents on the ladder of participation.



Information

Below are some methods of providing parents with information.

The aim of providing information is to inform parents about a new service development. Methods that can be used include public meetings, written information and attending existing parent groups.

Public meetings

What it does

- ◆ Allows for immediate discussion and opportunities to clear up misunderstandings
- ◆ Provides a gauge of parents' likely responses to the idea
- ◆ Brings together a range of groups and people
- ◆ Open and transparent

Issues to think about

- ◆ Limited numbers will attend
- ◆ Can be intimidating

Tips

- ◆ Avoid complex presentations
- ◆ Use a good facilitator who can think quickly, is clear and does not use jargon
- ◆ Explain that this is information only and say when and if consultation is likely to happen

	<i>Typical process</i>	<i>Typical methods</i>	<i>The stance of the resource holder</i>
Information	Presentation and promotion	Leaflets, newsletters, displays	'Here's what we are going to do'
Consultation	Communication and feedback	Surveys, meetings	'Here are our opinions – what do you think?'
Participation	Partnership building	Working groups/ forums	We want to make decisions together

- ◆ Use a community venue, not service-related
- ◆ Timing – avoid school runs and early evening

Cost

- ◆ Hire of hall, refreshments, crèche, parents' travel costs, facilitator and interpreter

Written information

What it does

- ◆ Ensures that basic information is received by lots of parents
- ◆ May prompt local groups to engage in future consultations

Issues to think about

- ◆ May not be accessible to all parents because of language and literacy barriers

Tips for reaching parents

- ◆ Present information so parents can see immediately if it is relevant to them
- ◆ Carry out a plain English test to check it is readable: www.plainenglish.co.uk.
- ◆ Mailings to all parents of children in special and mainstream schools, including those in out-of-area placements where appropriate
- ◆ Articles in newsletters read by parent carers
- ◆ Avoid over-glossy materials as they can be too formal and intimidating
- ◆ Information on local authority website
- ◆ Link workers for families who do not speak English can be used to disseminate information

Cost

- ◆ Printing of leaflets and letters, stamps, administration, time, translations



Consultation

The aim of consulting is to tell parents about a new service or a change in services and offer some options on a limited range of choices. Techniques that can be used include questionnaires, focus groups/workshops, meetings, fun events, and using existing parents' groups/networks.

Some methods of consultation are outlined below, along with the benefits and issues of each approach. Using a variety of these approaches will ensure that different voices are heard.



Questionnaires

Benefits

- ◆ A range of views from people who may not attend meetings
- ◆ Some parents prefer being anonymous

Issues to consider

- ◆ Can be time-consuming
- ◆ Low returns – 20% is good; ideally enclose a stamped addressed envelope
- ◆ Not good for areas with low literacy levels
- ◆ Some parents dislike or cannot fill in forms
- ◆ Multiple choice questions easy to analyse but may be too restrictive and must be piloted first.

One-off focus groups (see following page for more detail on this method)

Benefits

- ◆ In-depth valuable ideas and discussion
- ◆ Friendly and informal
- ◆ Attracts new parents who may stay involved
- ◆ Identifies possible conflicts of views early

Issues to consider

- ◆ May not represent entire community
- ◆ Can be time-consuming to set up, facilitate and write-up.
- ◆ Can also be intimidating – needs experienced facilitator

Fun events

Benefits

- ◆ Draws in families from a range of communities who would not attend formal events
- ◆ Generates positive feelings
- ◆ Friendly and informal atmosphere

Issues to consider

- ◆ Time consuming and costly – need entertainment for children, etc.

Individual feedback by phone, email or suggestion boxes or at drop-ins

Benefits

- ◆ Enables front-line staff, including link workers, to feedback views from families they know
- ◆ Gives flexibility to parents on when to respond

Issues to consider

- ◆ Time-consuming – takes time to collate views from different sources
- ◆ Limited numbers

Attend existing parent groups

Benefits

- ◆ Cohesive group on its own territory
- ◆ Meet parents who may not go to meetings organised by professionals
- ◆ Time is convenient for group

Issues to consider

- ◆ Limited numbers
- ◆ May represent only one disability
- ◆ Invitation from the group is usually needed
- ◆ The group may require a fee or expenses



Technique tip Focus groups

A really effective method of involving parents is to run one-off focus groups. These are excellent for getting a depth of information that cannot be achieved through surveys or written comments. An ideal number is six to ten parents. Discussion on a particular topic provides a range of views and perspectives, which enable the future direction of the service to be planned most effectively for the greater majority of users.



Focus groups are a good way to seek views from parents who have not been involved in consultations before. Several focus groups addressing one topic are more likely to identify common themes. It is best to hold these in different locations at different times to enable more people to take part.

Focus groups are also a good way of engaging with minority communities. For example, a focus group for Asian parents set up by a trusted worker or Asian parent volunteer and using a recognised neighbourhood centre in the community will encourage parents who may not otherwise be involved in using or commenting on services.

Seek out parents through as many channels as possible; for example:

- ◆ (in England) through mailing lists of Parent Partnership Officers, Disability Registers
- ◆ through local voluntary groups such as Contact a Family or local NCH or Barnardo's children's disability projects
- ◆ through letters home via special and mainstream schools.

A two- or three-hour well-structured session for each group is ample for a focused discussion. Be very clear about what questions you are asking. It helps to break into small groups for part of the time to provide variety and ensure everyone has a say. It is vital to have an experienced facilitator and at least two note-takers to capture all the views. It helps the discussion flow if parents can just talk and not have to write down their thoughts as well.

Feedback after the event is vital if you are to retain the confidence of parents who attended. The report of the meeting should be sent to all participants with an indication

about when decision will be made about the service and how parents will be informed.



Technique tip **One-off general meetings**

One-off general meetings with parents are good method for enabling parents to participate in the planning of a new service or changes to an existing service. They enable those parents to participate who cannot make a long-term commitment to a forum but who are interested in having some involvement.

To ensure that a meeting is a meaningful form of participation, parents should be provided with background information beforehand so they have an opportunity to understand the implications for their family. Parents' suggestions and views should be recorded in the meeting, and minutes or notes should be circulated to parents after the event to give them a chance to agree that their views have been recorded accurately.

Parents also need to be informed at a later date about what will be done and if their views and wishes have not been met, why this was not possible and what the service provider will do to work towards this in the future. If there are any suggestions or ideas from parents that are not feasible, the reasons should be explained to parents. If parents are informed at each stage of the process about developments and why, in terms of funding and efficiency, certain developments are not possible, they are more likely to understand.



Participation

The aim of participation is to give parents a significant voice in the design of a new service and the development of a service over time. Parent membership of an ongoing working group or children's forum is an effective way for parents to be involved in service planning and delivery.

Forums which include parents chosen to reflect a range of views, and where they have an opportunity to influence decisions, are a

powerful tool for developing family-centred services. The parents must be there at the outset and help draw up the reference rules or protocols (see Key Principle 1, page 21) for the group. The advantages of such forums are that parents develop skills and knowledge along with the group.

Forums allow parents to keep informed about new developments and be involved at all stages. They also represent an informed group of parents with whom professionals can consult on a regular basis. Such forums are run by parents or by a local voluntary or statutory worker and give local parents a voice in the provision of local services. Such forums may be dominated by one or two individual parents but this situation can be avoided if forums have clear terms of reference and are run openly. The practical example on page 27 shows the terms of reference developed by a working group in Gateshead when it was set up by a paid worker.

There may, however, be issues about whether the parents in the group are representative of other parents. There is also the possibility that the group becomes dominated by professionals and the views of the parents are overpowered (see Key Principle 3, which deals with issues of power and control).

Some groups are traditionally under-represented in both accessing services and participating in their development.



Technique tip **Working with hard-to-reach groups**

Hard-to-reach groups may include:

- ♦ communities which are isolated because of language or cultural differences
- ♦ parents who work, especially fathers, and become excluded from participation.

The following possible approaches may encourage participation of hard-to-reach groups.

- ♦ Try snowballing: one parent provides the name of another parent, who then provides the name of another parent and so on.
- ♦ Work through an established community organisation, such as local cultural and community groups (for example, there are Somali community organisations in many

London boroughs), local playgroups or toy libraries.

- ◆ Hold evening and/or Saturday meetings.
- ◆ Encourage front-line staff who visit people's homes to get feedback from families.
- ◆ Hold multicultural fun events.

Issues to consider include:

- ◆ potential bias in working through personal contacts as well as issues of confidentiality when reporting views
- ◆ community groups may not be in touch with many parents of disabled children
- ◆ allow more time for planning
- ◆ interpreters may be needed.

Consulting with Asian parents, Sparkbrook, Birmingham



In 2001 a steering group met, made up of representatives from Birmingham Community Health, Birmingham Social Services, Sparkbrook Regeneration Team, Health Promotion, Compare Community Business and three voluntary sector agencies. The aim was to consult Asian parents of disabled children in Sparkbrook about their preferred means of support and help. Local professionals were asked to identify as many parents as possible, and any parent taking part was to be given a shopping voucher as a thank

you. Thirty-three parents were visited at home by community parents from Compare who had participated in a brief training session. The parents were asked about current and preferred sources of help. Afterwards, all participating parents were invited to an event. Taxis, a crèche and interpreters were provided and attendance was high (71 parents attended). The findings were disseminated verbally at the event in various language focus groups (Urdu, Punjabi, Bengali and Arabic) and the parents asked to feedback and comment.

Using a variety of methods to provide information, to consult and to involve parents



In 2003, Contact a Family was commissioned by the Canterbury Children's Fund to find out what services disabled children and their parents most wanted the service to pay for and to identify parents who would ensure that the new service would be parent-led.

Information was provided by

- ◆ a short explanatory bulletin sent out to parents through the special schools and specialist units

Consultation took place with a wide range of parents through

- ◆ a postal questionnaire
- ◆ three focus groups in three different locations with parents who had never given their views before
- ◆ three family fun events held in the holidays at three different locations
- ◆ participants being all asked to bring the views of their whole family on their ticket of admission to these

- ◆ telephone interviews with individual parents
- ◆ teachers asked to seek views of children in special schools
- ◆ KIDS and Mencap focus groups with another two groups of young people
- ◆ Key professionals in all services who were contacted for their views in person and by phone.

Participation took place by

- ◆ a number of individual parents who volunteered to be on a steering group which met regularly to design a new service based on parents' wishes

Outcome

- ◆ Parents' top wishes were for an information service for themselves and leisure activities for their children and accordingly a parent-led project was funded to meet these needs.

Gateshead Children's Forum



What we will do – 2003/2004 (Terms of reference)



Who will be members of the Forum?

- ◆ Service users/Parents/Carers – have an open invitation to attend
- ◆ Service planners
- ◆ Specialist workers
- ◆ Other people can join as and when required

How often will we meet?

We will meet on a regular basis, at least every two months. This can be changed if we need to meet more often. Venues and meeting times will be arranged for the convenience of parents/carers.

How will we record what happens at the meetings?

Notes of the meeting will be made and kept on file. These notes will be sent to Forum members and to other people who may be interested in finding out more.

Who will we report to?

The Forum will feed into and seek feedback from the Children and Young People's Partnership Board, the Learning Disability Partnership Board, the Children's Trust Project Team/Board and the Gateshead Network of Children with Disabilities (via the Network newsletter, Information Exchange). This is a two-way process.

Who will lead the Forum?

The Forum will have an elected Chair and Vice-Chair for a period of 12 months.

What will we be responsible for doing?

- 1 Giving parents/carers a voice to express ideas and issues.
- 2 Helping to co-ordinate work around services for children with disabilities in Gateshead, including the Children's Trust.
- 3 Making sure that information about disabled children is communicated properly to service users, parents/carers and statutory and voluntary agencies. This is a two-way process.
- 4 Identifying gaps in service and working with partners to address these.
- 5 To help with commissioning of services by informing decision makers about identified needs and opportunities.
- 6 Making sure that the objectives of Government initiatives Quality Protects and Valuing People are met through the Forum.
- 7 Responding to the National Service Framework agenda for children with disabilities.
- 8 Having joint ownership of the Gateshead Network of Children with Disabilities and being committed to its work.
- 9 Making sure that service users and parent/carers are involved in and consulted on service developments.
- 10 Promoting inclusion.
- 11 Making sure that the Forum is kept up to date about national and regional research and best practice.
- 12 Developing a database of interagency training and parents/carers who have a special interest in children with disabilities.
- 13 Setting targets and identifying review dates to measure the effectiveness of the Forum.

Summary

Key Principle 2 describes a variety of approaches that can be used when involving parents in service planning and development. Different methods that can be used for informing and consulting with parents have been outlined in this section, and the benefits and issues of each approach discussed.



What do you think?

You and your colleagues are members of a multi-agency planning group representing health, education and social services. You have agreed to develop a key worker scheme for your area. The group has examples of models tried in other local authorities and you wish to involve parents in developing a scheme that will work in your area with your population of disabled children. Your local population includes a sizeable Chinese community.

Discussion points

- 1** How will your group inform parents of the new plans?
- 2** What elements of the scheme are open for parents to debate and give views on?
- 3** How will you gather those views so that they are representative of local families?
- 4** How will you enable parents to have an ongoing role in designing the service?

This section focuses on the issue of whether parents and professionals are on a level playing field. It is about changing the culture of the service or organisation so that the views of parents are heard throughout and their presence on committees and working groups is not just tokenistic.

Here are some of the things parents have said about participating in working groups.

« There are lots of them and only me representing parents. They keep changing and I never know who half of them are. »

« I went once to a meeting to represent parents' views and was never asked back. I felt humiliated by this – was there something wrong with me? »

« I have no idea what they are talking about sometimes but I just pretend I do so they won't think I am stupid. »



There are many practical ways in which parents can be supported and enabled to be confident partners and allies in improving services. Most of these relate to an attitude of mind and cost relatively little to implement in comparison to the pay-off you get in return. It is vital that parents' power and status is recognised so that their voices are heard and heeded. Five steps that can be taken to achieve this have been identified and are outlined below.

These five steps are about increasing the status and power of parents so that their views count as much as professional views do. Professionals may feel that this is unreasonable because parents do not have to pay for or deliver the actual service. But that service affects the quality of parents' and children's everyday lives and their ability to cope with never-ending demands. As one parent said;

« They can leave their job and go for a trip round the world – but we cannot. They move on but we are always here. »



Five steps to creating a level playing field

- 1** Build a constituency of parents.
- 2** Work towards the same access to information that professionals have.
- 3** Provide practical support.
- 4** Seek ways to build parents' confidence and skills.
- 5** Provide support for professionals within a culture of participation.



Level playing field step 1

Build a constituency of parents

One of the many differences between parent and professional members of working groups is that the professional has a network of colleagues to feed back to and bring ideas from. Parents without a similar reference group or constituency can feel isolated, undermined and open to the criticism that they are just representing their own views. Of course, individual parents can legitimately be there as well, but everyone needs to be clear that they are giving an individual perspective and that parents representing other parents carry more weight.

It's a good idea, therefore, to seek parents who are active in a local parent-led multi-disability group or forum as members who can undertake to be a conduit of information. Remember that such voluntary groups and forums cannot absorb the task of communicating with and supporting parent representatives without resources. Members of such groups are likely to be volunteers with many other responsibilities, e.g. looking after children or working, so the more notice and practical support you can offer, the more likely it is they can provide members willing to be part of working groups.

Wolverhampton Parents' SEN and Disability Forum



« Six of us parents in Wolverhampton were frequently asked to attend local planning and strategy groups to represent parents' views. One day, we were asked by the Parent Partnership Officer to consider how that role could be developed to provide more effective consultation with parents. It was then we formed the Parents' Forum, which was aided with start-up funding and support from the

Parent Partnership and subsequently with a grant from the Community Chest.

After 18 months we have a membership of over 70 parents and have distributed an information leaflet across the city about the representation we can offer. We tell them what is going on and ask for their views as well as feeding back what happens in these meetings. »

A parent who helped develop the Forum

Below are some suggestions and examples of seeking representative parents.

- ♦ Channel all requests for parent representatives through an existing local, parent-led parents' forum which works well with a range of professionals and parents.

parents or provide a professional who has dedicated time and skills to set up a forum.

- ♦ Seek parents' views through a local voluntary sector forum where parents meet with professionals.

Leicester Parents and Carers Council



This Council, with its membership of over 1,000 parents across Leicester City, Leicestershire and Rutland, identifies and supports parent representatives to sit on several planning groups across the three local authorities. It also brings large numbers of parents together on behalf of agencies which need to carry out consultations. The Council keeps its members informed of opportunities and policy changes, and also gives feedback through its regular newsletter and support and information meeting, as well as to the many local groups to which their representatives belong.

- ♦ Appoint individual parents who can demonstrate that they meet with a range of parents of children with different disabilities – for example, through volunteer work for a voluntary organisation – and who agree to use established networks to seek views and feedback.
- ♦ Consider setting up consultation forums with a view to them becoming parent led. Commission a local voluntary agency trusted by parents to work with willing

South Gloucestershire Parents and Carers Advisory Forum



This regular forum is an opportunity for parents and carers to get together to share their experiences of statutory services and find out about current issues. Around 350 parents, who are on the children's disability register, receive the forum's quarterly Network Newsletter produced by staff from health, social services, education, the voluntary sector and parents. The newsletter gives feedback from the forum meetings and parent reps report from work groups. All interested parents are invited to give their views at regular meetings where they can identify common concerns about gaps in services. Members can become involved in the work groups of the Children's Joint Strategy Group.

The Parent and Carers Advisory Forum is facilitated by the Care Forum, a registered charity whose members are voluntary and community groups with a particular interest in health and social care.

Parents can choose to receive the information in Braille, audio-tape, large print and plain English.

- ◆ Approach black and minority ethnic carer support groups to encourage their members to participate.
- ◆ Have a strategy for reaching traditionally excluded groups – such as disabled parents and parents from black and minority ethnic groups.

Lessons from Sure Start, Nuneaton



We have used interpreters at consultation but the cost of interpreters and the pace of word-for-word interpretation can be problematic in terms of the time it takes. We now find that using bilingual volunteers and our own bilingual staff members is a better way of cascading information about the programme outside the Partnership Board Forum.



What do you think?

Just as professionals move on and change jobs, so some parents will also, at times, want to withdraw from active participation and consultation. It is very important to keep recruiting and nurturing the process in order to maintain strong and varied parental input.

Discussion points

- 1 Are your current parent members representative of the local population?
- 2 How could you encourage change while maintaining continuity?
- 3 How can you ensure that they are representative of other parents?



Level playing field step 2

Equitable access to information

Parents can bring a huge amount of knowledge and insight, built on personal experience and discussion with other parents, to meetings and consultations. As well as personal experience, some parents seek out information through local networks, voluntary work, attending conferences and information events and via libraries, books and the internet, and are often experts in particular subject areas.

Nevertheless, there is likely to be a wide disparity between the opportunities and information resources readily available to parents and to professionals, so agencies wishing to engage with parents on anything like a level playing field need to take active steps to redress this imbalance. This is particularly necessary for parents who join working groups and professional-led forums. In order to have any hope of functioning effectively, parents need information. They also need time to read it before meetings.



Some practitioners worry about overloading parents with reams of incomprehensible paperwork. However, busy practitioners and busy parents are equally unlikely to read a mass

of paperwork. All participants work more effectively with clear papers and bullet points. More organised meetings with clear information will benefit all attendees and will help to produce effective outcomes.

Other vital information needs can be easily overlooked and yet can make all the difference to ensuring everyone can participate meaningfully. For example, when parents are invited to join a working group, they will need to make a decision about whether this is a good use of their time, how effective their contribution will be and what they might gain from it. The checklist on the right sets out points to help parents and professionals think about this.

Checklist

About the working group

Its membership

- ◆ who is on the committee: their names and titles
- ◆ who is the Chair: his/her background; how is the Chair chosen
- ◆ how are members selected – are they representatives of their organisations or are they there because of personal interest and commitment?

Its remit and power

- ◆ the role, purpose, terms of reference and powers
- ◆ how it links with other overlapping groups and services (a diagram would be useful)
- ◆ how it disseminates information to other groups
- ◆ what it has achieved.

Its ways of working

- ◆ who sets the agenda; how do parents get an item on the agenda
- ◆ when and where it meets
- ◆ use of plain language
- ◆ how people address each other
- ◆ what is confidential and what can be shared outside the meetings
- ◆ encouraging team working – e.g. 'away days', training or socialising together.

About parent representation

- ◆ how parent members are chosen
- ◆ how many parent members there are
- ◆ how long they are expected to stay on the committee
- ◆ the role of the parent rep – an individual voice or representing a wide body of parental views?
- ◆ the induction process and ongoing training
- ◆ expenses and other access issues
- ◆ practical help such as provision of folders.

Many parents who came to the workshops run to trial the ideas in this guide gave their responses to this guidance when it was being drafted and told us that the idea of this checklist is particularly helpful. They added some other ideas which they felt would help them participate more meaningfully. These were:

- ◆ the provision of one-page summaries of new legislation or background information to provide the context for discussions
- ◆ a 'jargon buster' sign which they could hold up in meetings when they do not understand jargon
- ◆ pre-meetings with the chair of the working group, especially for new members, to brief them about the way it works
- ◆ information offered in Braille, audio or large print.

The Leicestershire schools example highlights the need to make sure that parents who are involved in decisions about a service have access to information which could inform their decisions. Parents, just like professionals, need information to help them understand the context and the background.

Leicestershire schools



Parents in Leicestershire were consulted in 2003 about proposed Schools' SEN Delegation of Funding. Although the information given was thorough, written in plain English and supported by road shows and presentations, parents felt they could not make informed judgements without knowing the amount of money being delegated. Upon receiving this comment, the Leicestershire Education Authority circulated to parents a full list of proposed delegated funding within the county. Parents felt not only that they had been listened to but also that significant information had been released, therefore confirming a culture of mutual respect and openness.



What do you think?

The services provided by the local Child Development Centre are being reviewed. There are questions about whether some of the services should be delivered in different ways. You and some colleagues and a few parents are invited to sit on the multi-agency review group.

Discussion points

- 1 What information would you need in order to participate confidently in this group?
- 2 What information would you need form a view about the future of the service?
- 3 How does this compare with the information that parent members are given?
- 4 How could any imbalance be redressed?



Level playing field step 3

Practical support

Parents need practical support to participate as demonstrated by the following comments.

« You look around the room and you know that everyone except you is there in their work time, with their mileage allowances. »

« There's a SEN group I'm supposed to be on, but it meets at 4.15 so I can never get to it. »

« Our local authority said it was consulting about respite care. It offered a public meeting at 6pm which is about the worst time for any parent! Parents were furious. Yet we have about 40 parents who regularly attend our Saturday leisure club and chat while children play, so why did they not ask to visit us there? »

Parents who respond to invitations to consultation meetings or working groups often do so as volunteers, in their own time and almost always at some inconvenience. Practical support would seem the simplest to solve, but it is still common for parents to be expected to contribute not only their precious time and unique insights and expertise, but to do so at their own expense. We outline below some basic ways in which to level the playing field.

Expenses

Expenses should be offered to all parents attending a participation event. Not only does this help to level the playing field it also makes the event accessible to a wider group of parents. However, some parents are unable to accept expenses in the form of money, as this can affect their benefits. In some situations, these parents have been reimbursed with vouchers of their choice. The issue of expenses should be discussed with parents so that a satisfactory, long-term arrangement can be agreed. If in doubt, parents should seek advice.

When arranging a participation event, service providers should:

- ♦ have a budget to cover parents' fees or expenses
- ♦ be proactive in offering to cover costs – e.g. send out a claim form with the

meeting agenda

- ♦ set up a simple, speedy way to process claims: could small sums – e.g. car park or taxi fare – be reimbursed on the day in cash.

In some instances a local voluntary organisation or parents' forum have secured small funds to reimburse parents; as they are in a position to refund parents' expenses more efficiently and sensitively.

Childcare

aMAZE, Brighton



aMAZE is a local parent-led voluntary organisation which works with families of disabled children. The group sometimes acts as a clearing house for requests for parents to sit on planning groups. Parents are offered fees for their time; for example, between £10 and £20 an hour is provided for tasks such as contributing to working groups, helping to draft documents or participating in influential strategic or commissioning groups like the one developing the new Children's Trust.

Where possible offer a crèche or childcare on site or be creative in helping parents find suitable childcare, if they haven't got anything set up. Again, a simple, speedy way to



process claims makes a big difference to how parents feel about claiming these.

Timing

Remember:

- ♦ think about parents' daily timetable and plan accordingly: during the school day or in the evening is likely to suit most: is it possible to alternate meeting times?
- ♦ avoid religious festivals
- ♦ avoid school holidays.

Gateshead Disabled Children's Forum



This forum meets every six to eight weeks in the morning, as this suits most people, but it is also committed to holding at least two meetings a year in the evening or at weekends, and in rural as well as city locations.

Other access issues

Remember to think about:

- ◆ physical access to the venue
- ◆ interpreters – and extra time to allow for interpreting to take place
- ◆ sign language interpreters
- ◆ materials in large print and other formats and in languages other than English.

Sure Start, Nuneaton



A few months after the Sure Start local programme started in Nuneaton, an Asian parent of a disabled child was encouraged to chair the Parents' Forum, which in turn nominates parents to sit on the Sure Start Partnership Board. The parent arranged for interpreters to attend Parents' Forum meetings. This encouraged other Asian parents to attend. Interpreters wrote down everything that was said and then explained it verbally. The meeting paused while the Asian parents caught up and in this way they felt totally included. The Asian parents felt valued and were able to give their views about how the service could develop.

Creating the right environment

Parents can feel overwhelmed when juggling many demands and may forget meetings or lose confidence in their ability to participate in them. Some parents may therefore find it helpful if a friendly worker telephones them beforehand to remind them of the meeting and check they can attend.

Other things which can help are:

- ◆ a neutral venue – use a range of venues acceptable to all sectors of population
- ◆ a comfortable environment – but avoid grand venues which parents may criticise as a waste of public money
- ◆ refreshments or lunch – as before, good standard but not excessive
- ◆ some fun – such as outings, family events and seasonal parties.



What do you think?

Your colleagues from other services have mixed views and mixed policies about paying expenses to parents who sit on working groups. Some of the groups pay childcare expenses, two offer a thank you voucher and one group pays a fee. Parents are beginning to comment on the inconsistent policies.

Discussion points

- 1 How could your service, in partnership with others, develop a consistent way of paying parents?
- 2 What expenses should be covered and at what rates?
- 3 Should parents be paid a fee for the time spent on working groups?
- 4 Would you ask parents for their views?



Level playing field step 4

Building parents' confidence and skills

« I am a special needs teacher and used to dealing with a range of distressing medical conditions, giving medication and going with pupils to hospital. So I should have been prepared when my own son began having seizures at eight weeks old. How wrong could I be? I was totally devastated. Nothing can prepare you when it is your own child. »

Parent from Birmingham

In addition to grief and anxiety when they have a disabled child, many parents experience a profound loss of confidence. Strengths and resources can be undermined by implied criticisms from family ('It's not my side of the family') loss of friends who feel uncomfortable with disability, negative comments from doctors ('He will never walk or talk') and well meaning but hurtful comments from neighbours and acquaintances.

Yet parents have their own histories of achievements, skills and resources. Many parents relish opportunities to develop themselves and to turn their new knowledge of disability into helping other parents and, as one parent said, 'changing the world for our disabled children'. Parents from quite different backgrounds have developed dynamic parents' groups, trained as social workers, gone to work in the social care field or set up leisure provision for disabled children.

Building confidence through respect and support

There are many ways in which professionals can help increase parents' confidence and skills so that they can operate on a more equal footing. These range from holding pre-meetings to prepare parents for large committee groups, to ensuring that rooms are laid out informally, using first names for workers and ensuring that coffee and tea is easily available to any latecomers. Such small acts of thoughtfulness give powerful messages to parents about how they are respected. Professionals should also think



about their use of language, as some parents have reported that they have felt a lack of respect from professionals who make throwaway comments about parents in general rather than acknowledging parents on a more individual basis.

Many of the following examples are policies developed by the Leicester Parents and Carers Council, others are suggestions made by individual parents.

- ◆ Provide or pay for training for parents. This could be for individual parent representatives, for an interested parents' group or for the consultation forum as a whole.
- ◆ Offer peer support by always ensuring there is a minimum of two parents on every statutory-led working group. Facilitate introductions between the parents.
- ◆ Have a link person/mentor for a new parent joining a working group (who could be a parent or a professional, or both) and where possible, ensure they can accompany the parent to the first few meetings.
- ◆ Provide funding to a voluntary organisation to pay the expenses for a local volunteer parent who will be supported by his or her parent body.
- ◆ Draw up a job description or an agreement/contract which clearly states obligations to support the parent.
- ◆ Provide a parent ID badge – as well as being the only unpaid person around the table, the parent member is usually also the only one not wearing an official badge. Create an 'X-town parent representative' badge or ask the parent group to provide one.

Building confidence through developing skills

Some service providers set up specialist subgroups of main groups to focus on

subjects such as leisure or transport. These smaller working groups allow parents to follow their particular interests and provide excellent confidence-building steps to participating in higher-level strategic groups, as they tend to be more informal and less intimidating.

St Helen's Action Research Project (SHARP)



St Helen's services and parents are keen to develop an integrated service for disabled children and their families across education, social services, health and local voluntary groups. Using an action research model, parents met to 'wish on a star' for their ideal service and a Project Support Group was set up. This was made up of 50% parents and 50% professionals. A stakeholder launch was held (again 50:50 participation). Parents undertook an accredited training programme in research methods and skills in order to investigate good practice elsewhere, interview local service providers and use their personal examples as case studies. The Together from the Start self-evaluation tool was used to check out over 30 local services. A 50:50 action learning set incorporated all the research findings into a model of what the St Helens' integrated service will look like. This model is now being shared with as many parents as possible in order to get their comments. An action plan for implementation is being drawn up.

The parent researchers found the programme exciting and empowering. They have grown in confidence and skills and will share ownership of the vision of the integrated service as it develops.

Building confidence through training

A growing number of local authorities in the north of England and in Scotland are sponsoring parents to go on training courses inspired by the Partners in Policy Making Courses, first set up by the North West Training and Development Team. The courses

are designed to help parent-carers and people with learning disabilities to gain the skills needed to influence services. Course participants learn about the history of disability, the social model of disability and the policy context for services. They also acquire skills such as public speaking in order to be able to comment on service delivery.

Here is how one graduate described the impact which the course had on her:

« I learned how to think about things in a different light. How to work with people as a team to achieve a mutual goal. How to work with service providers. How to let go of my inhibitions. I could always put on a confident face when I felt anything but confident. Now when I look confident it is because I am, I have a contribution to make and I have been trained to do it effectively. I am proud to be a Partners in Policymaking Graduate Liverpool 1999. »

Parent, Liverpool

Building confidence through parents taking the lead: parent-led forums and councils

In a number of local authorities there is an established Parents and Carers Council or parents' forum, which has usually been started by parents who are keen to work constructively with providers. The councils or forums provide great opportunities for many parents to develop skills and confidence in working with professionals. They are also extremely useful for professionals who wish to consult about services because they can provide a pool of willing and well-supported volunteers for strategy groups, they can provide lots of parents for one-off consultations, and they can communicate effectively and positively with their large parent membership about new developments.

Some examples of such consultative forums are:

- ◆ Calderdale Parents and Carers Council
- ◆ Kirklees Parent Carers Forum
- ◆ Leicester Parents and Carers Council
- ◆ Rochdale Parents Forum
- ◆ Sheffield Parents/ Family Forum
- ◆ Wolverhampton Parents SEN and Disability Forum.

These forums are so successful that they are inspiring parents in neighbouring counties and boroughs to start them as well. They all receive enquiries from parents for help and guidance on setting up similar organisations.

The forums need funding to get going, as well as ongoing support from professionals and service providers. The history of these forums shows that in the early stages they can manage on small amounts of neighbourhood funding (to pay expenses) and a lot of volunteer help. However, when they take off and grow beyond the capacity of volunteer parents, they need statutory agencies to provide secure joint funding for a worker (hopefully a parent) to develop the forum – for example, by supporting lay representatives to sit on planning groups and using the membership to gather views for the local statutory agency.

The benefits of such a forum for local parents and service providers are massive and hence the development of such forums should be encouraged and assisted. The value of having parents as allies is huge and should be considered when thinking about costs.

How parents' groups develop partnerships with workers



Calderdale Parents & Carers Council was started in 2001.

A group of parents attended a meeting held by social services and listened to a talk by a parent from Leicester Parents and Carers Council. They were inspired to start their own council along similar lines. Thanks to statutory funding, the group now has two parent paid workers and an administrator and provides opportunities for parents to have their say about services through consultation meetings and on-going working groups. Calderdale Parents & Carers Council also regularly meets with parents groups from neighbouring counties who are keen to adopt a similar model.



What do you think?

You have recently taken over as chair of a multi-agency working group. The group's membership comprises 15 professionals and three parents. The meetings are held monthly, for a couple of hours, in the boardroom of a local hospital around a huge, formal table. A couple of the health professionals are very vocal compared to the rest of the professionals present and the three parents tend to say very little. All three parents rarely get to the same meeting and a couple of them occasionally arrive a little late. Latecomers miss out on tea and coffee, which is served before the meetings start.

Discussion points

- 1 What could you do to make all group members more likely to join in discussions?
- 2 What steps could you take to help the parents feel more comfortable and confident in the meetings?



Level playing field step 5

Support for professionals who consult within a culture of participation



Professionals need support from managers to make participation happen. This section looks at ways that they can be supported that will help level the playing field.

« You asked me how we created the right conditions in Leicester for genuine consultation with parents to flourish. Well, firstly, Leicester has a history of successful partnership working across health, social services and education. Our strategic partnership is a multi-agency body to which I report. Secondly, we use a consumer-oriented approach to all our services. And very important, I am supported by the Director of Social Services who tells me that how my colleagues and I work alongside families is right and is important. It could not happen without his commitment and support. »

Manager of Children's Services, Leicester

Professionals charged with consultation are often working on the front line. They cannot operate effectively in isolation, any more than a parent can. Their work has to take place within a wider culture of participation and be supported from the very top as well as by their peers and managers. For many services this will require changing the way people work. This can be difficult, but most people's doubts, fears and scepticism will fade if they can see enough benefits in the new ways of working. The change must be driven by the director of the service and senior managers.

Alder Hey Children's Hospital Parents and Carers Council



« Twenty-four parents met at an open day with the Chair of the Trust, the Executive Director of Nursing, the Patient Advice and Liaison Service (PALS), a consultant psychologist and four trained Trust facilitators to explore how they would like this parents' forum to develop. The staff involved have given their commitment to support the group for as long as needed, but the aim is for the parents themselves to take ownership of the Parents and Carers Council.

PALS is instrumental in bringing the Councils together but the commitment demonstrated by the Chair and senior management is crucial to their success and to ensuring that children and families really do influence developments and change at Alder Hey. »

Senior PALS Officer

Here are some of the ways in which senior staff can support front-line practitioners who are developing participation.

- ◆ Information
 - use staff newsletters to disseminate information about local and neighbouring initiatives that illustrate the benefits of consultation
 - encourage open, two-way communication within the agency's hierarchies
 - invite enthusiastic parent and professional speakers to speak at staff meetings
 - send out memos about legislation and guidance on consultation.
- ◆ Identify 'consultation champions' within the service who are influential and persuasive staff members and ask them to work with colleagues in a planning group to develop a consultation strategy.
- ◆ Build information and awareness about consultation into all staff job descriptions, staff inductions, staff supervisions and appraisals
- ◆ Provide funding for all workers to have training in disability equality, in facilitating

and chairing groups, and in other techniques such as carrying out surveys.

- ◆ Create a dedicated post and budget to enable sufficient time to be given to developing consultation.
- ◆ Ensure that front-line workers are up to date with consultations and participation and their outcomes, even if they have not been personally involved in them. This will encourage workers to feel the process is important and enable them to give feedback to individual families.
- ◆ Provide professional rewards such as praise, publicity, awards.
- ◆ Senior managers and director should attend at least one consultation event or group each year where they are given the opportunity to listen to parents' experiences. This provides a powerful message to front-line staff and parents that strategic managers value the consultation process.
- ◆ Work with multi-agency partners to establish a central database of all consultations in the county or borough and encourage staff to use it.

Summary

Key Principle 3 has described ways to overcoming imbalances of power and control. Five steps that can be used to help level the playing field have been outlined.

- 1 Build a constituency of parents.
- 2 Work towards the same access to information that professionals have.
- 3 Provide practical support.
- 4 Seek ways to build parents' confidence and skills.
- 5 Provide support for professionals within a culture of participation.

The methods and ideas described for each step can be used by staff working with parents to ensure that parents and workers are working together equally, with neither group having an unfair share of the power or control.

Key Principle 4 looks at the need for visible action to make sure parents remain engaged with the process of participation.



What do you think?

As the newly appointed service manager of children's services you are keen to improve participation of parents in planning services for disabled children. You review the existing systems and various consultations that have been going on and you are struck by how ad hoc and uncoordinated it all is. You want a participation strategy and you are determined to find the resources to support it.

Discussion points

- 1 What is your vision for a participation strategy?
- 2 What will you need to put into place to implement it?
- 3 Who are your allies to help you deliver it?
- 4 What outcomes do you anticipate?

« The success of initiatives to involve users and carers should be judged not by how many people take part but by the amount of change that takes place in the services people receive and the quality of their lives. »

Joseph Rowntree Foundation 1995,
Social Care Summary 3



Without visible changes, parents and workers will simply disengage. If services do not develop and improve both parties will feel powerless and helpless. Staff are less likely to feel positive about their work if they are unable to improve services for children and families.

Parents can accept that change and improvement can take a long time, but they need to see that there are processes in place to make things happen. Informing parents about initiatives to improve services will help them to see that action is being taken.

Providing feedback

Feedback to parents is essential, at all levels of information, consultation and participation. Feedback should be about actions and outcomes and not just a set of minutes. For example, some agencies send reports saying: 'This is what you said and this is what we will do about it.' This lets parents know that they have been listened to and action will be taken.

♦ **Feedback from meetings**

To keep parents on board, provide information about meetings before they happen and then send as many parents as possible a summary of what was said, as well as publishing it in newsletters, local papers and on websites.

♦ **Feedback from consultation events**

Use a variety of ways to give parents a report of the event, a summary of the views expressed by parents, a timetable for decisions and a timetable for action. Use the same routes to feedback decisions and then the action itself. Remember to include those who could not attend the event. If possible, a thank-you letter to those who attended is always appreciated.

If some expectations have not been met, acknowledge this openly and explain the

reasons. Share parents' disappointments rather than defending the negative decision.

♦ **Provide some quick wins**

This will show parents that their input can make a difference. It will also encourage parents to continue their involvement and participation.

The examples below outline visible actions that have come about with the help of parent participation.

Calderdale Parents and Carers Council (PCC) Leisure and the Accessible Play Spaces Project



Calderdale PCC asked members about their most important issues, and leisure was one of them. Accordingly, five PCC parent members worked for 18 months to raise issues about inclusive leisure. This resulted in the following:

- ♦ The Children & Young People's Management Board is providing funding to set up a Disabled Young People's Forum to comment on accessible leisure and link more positively into the Calderdale Youth parliament
- ♦ The PCC wrote a report on accessible play spaces and has worked with the Leisure Department to provide a piece of fully accessible equipment for a local park, with more to follow.
- ♦ The Leisure Department has set up a group called Park Pals – the idea of the parents – and this group will implement inclusive policies.
- ♦ In February 2004, the PCC held a huge event for libraries, museums, parks, leisure, youth groups, music, drama etc to all share good practice in inclusion.

Wraparound Parents Forum, Northern Ireland



Wraparound is a scheme to improve services for disabled children and their families in the Southern Health and Social Services Board's area. Parents have created a Parents Forum to ensure that the voices of parents are heard when services are planned. Although the Parents Forum is new, it has already started developing an information guide for parents. The idea came from a mother at the Wraparound Stakeholders Forum. A parent has been asked to facilitate the production of the guide. He has met with the Parents Forum and they shortlisted the top ten topics for the guide.

Devon Parent Carers Forum Shaping the Children's Fund



« Parents and carers have played an important role in shaping the Children with Special Needs theme of the Devon Children's Fund.

The Devon Parent Carers Forum, in consultation with parents and carers across the county, was instrumental in planning the direction of services within this theme. They wanted the work to focus on three areas: enabling, playschemes, and support for siblings, alongside of services for their special needs brothers and sisters. In the locality areas parents and carers have influenced what and how the services have developed. In Teignbridge, for example, the project's steering group is chaired by a parent carer and their views inform the service direction. The Devon Children's Fund is looking at ways of both widening involvement generally and linking with the local Parent Carer Forums, which are a different stages of development. »

Programme Development Officer

Rochdale Parents Forum Improving swimming pools



At the first meeting of the Rochdale Parents' Forum, parents agreed that the most important thing which could convince them it was worthwhile being involved was seeing results. Access to leisure facilities, and particularly swimming, was a major concern. Parents were critical of changing facilities, safety equipment, water temperature and suitable designated sessions. Forum members met with the Children's Fund Manager and Manager of Leisure Services, with immediate positive results.

The major pools in the local authority have had essential facilities introduced, including changing tables, bins and lockers, with a pilot scheme of a self-contained lockable changing room for families at one pool. A grant from the Children's Fund paid for the installation of hydraulic tables at three pools and parents learned about the possibility of being trained as special needs swimming instructors. Best of all, feedback from the Leisure Services Manager shows that use of the pools by disabled children and their families has never been higher. And of course, the Forum is keeping an eye open to see that these standards are maintained.

Such feedback demonstrates to parents and workers the value of parental involvement. Some quick wins help sustain everyone when progress of change seems slow.

Sutton parents

Shaping services in Sutton



Parents have been involved with the development of Sutton's Joint Strategy for disabled children, young people and their families from its early days. Initially, the local authority commissioned Contact a Family, as an independent body, to consult with two focus groups of local parents. The parents shared their experiences of local services and their ideas about how things could be made better, and then fed back their key points to professionals from health, education, social services, and the play and youth service. All the views expressed during the consultation were written up into a consultation report. This report was used by Sutton to inform their Joint Strategy, which later became the foundation for Sutton's application to become a pathfinder Children's Trust focusing on disabled children and young people. From consultation to successful pathfinder status took a little under three years.

After the consultation, and during the three-year period, parents contributed to various planning groups, made

presentations at the launches of two local authority and other agency partnerships, and regularly participated in a Parents Steering Group facilitated by Contact a Family, which fed back to the local authority. Some of the outcomes of this long partnership between parents and the local authority and others include:

- ◆ the development of an inclusive, summer youth scheme run along childcare lines
- ◆ a project to develop information and support resources for parent carers and professionals who work alongside them
- ◆ promotion of a key worker service for parent carers (funding has recently been secured for a three-year project to develop a service)
- ◆ partners on the application to become a Children's Trust.

And currently, six parents sit on the management board of Sutton Children's Trust board, having the same number of places as each sector represented on the board – e.g., health, education, social services and the voluntary sector.

Summary

Key Principle 4 has outlined the importance of providing feedback to parents who have participated. Feedback on results should be provided, as well as information about what

developments are being planned and why some changes will go ahead in the future rather than immediately.



What do you think?

Your service has consulted parents about a number of service developments over the last year. You have made several changes based on parents' views. Some quick small changes have come about through one-off consultations with parents and other more profound changes have developed out of long-term working groups in which parents have played a role. The participants are all proud of their efforts and yet both the parents and the professionals often

meet parents who are unaware of these developments and grumble that the parent voice is not heeded.

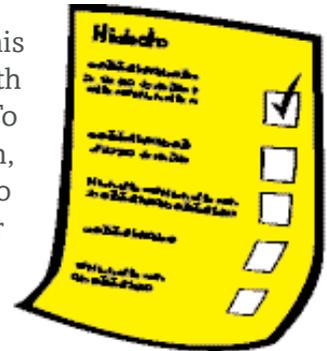
Discussion points

- 1 How could you find ways of communicating the beneficial changes to parents at large?
- 2 How could you raise awareness among parents of this effective working partnership between parents and professionals?

5 does participation work? monitoring and evaluation

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This chapter summarises the main ideas in this guidance in the form of a checklist of indicators with which to measure success in achieving them. To develop meaningful and effective participation, workers and managers can use these checklists to make sure they are applying the key principles to their practice.



Key principle 1 Defining what participation means

For professionals

- All public meetings and consultation exercises with parents state clearly whether parents are being informed, or being consulted on a limited range of choices, or being asked to help shape a service.
- Likewise, all public written communications to parents about services state clearly whether it is offering information, consultation or participation.
- All forums and meetings have protocols or guidelines.

Key principle 2 Using a variety of approaches

For professionals

- Parents are given information about new service developments for disabled children.
- Information about services is disseminated through mainstream and specialist health, social services, early years, education and relevant voluntary sector networks and parent groups (including local black and minority ethnic groups).
- Mailing lists and newsletters reach as many parents as possible.
- Consultation is carried out using oral and written methods in a range of formats in order to reach different people.
- Ongoing consultation groups advertise for parents to join them via health, social services, education and early years networks.

For managers

- Specific staff time, people and budgets are allocated to develop consultation.

Building a constituency of parents

For professionals

- A minimum of two parent representatives sit on any one planning group.
- Parent representatives have been nominated to represent a constituency of parents such as a local parents' group or parent-led forum.
- Parent representatives represent a range of disabilities and additional needs and ages of children.
- Ongoing working groups liaise with local community and black and minority ethnic groups to ensure that link workers are informed about developments and can encourage parents to attend.
- Interpreters and sign language interpreters are provided for parents who need help to participate in working groups.
- Worker-led forums advertise themselves as open and welcoming to all interested parents and willing to provide support.

For managers

- Funding is provided to a parent-led forum/parent council if one exists (or if parents are keen to develop one) to enable them to develop their membership, training and peer support to parent representatives.
- One-off consultations are contracted out to large parent-led forums with funding (if they wish to take these on).

Equitable access to information

For professionals

- Parents are given information about the working group and committee, including its membership, remit and ways of working (see checklist on page 32).
- Parents are provided with summaries of relevant legislation or policies.

Practical support

For professionals and managers

- A crèche is provided at meetings.
- Meetings take place at times parents choose.
- Meetings are held in convenient and safe venues with sufficient parking and good public transport links.
- Agendas and minutes are jargon-free, in plain English and size 14 print.
- Parents are given out-of-pocket expenses, e.g., for childcare and travel, and consideration is given to paying parents a fee for their time.
- Refreshments are provided.
- Meetings finish on time.

Confidence and skills

For professionals

- New parents on the group are supported by a mentor – preferably an experienced parent.
- Parents are encouraged and enabled to put items on the agenda.
- An official name badge is provided for parents.
- Parents are given folders or files to store papers.

For managers

- Training for parents is provided or paid for.
- A contract is provided, setting out the rights and responsibilities of all group members.

Support for professionals**For managers**

- A consultation strategy is drawn up and endorsed by senior staff.
- The service director and senior manager attend at least one consultation meeting or group per year to hear parents' experiences.
- All staff are expected to be committed to consultation as part of their job description, induction, approach to work, supervision and appraisals.
- News of good practice and successful consultations are disseminated through staff newsletters, websites and staff meetings.
- A multi-agency consultation/participation database is in use.

Key principle 4 Visible action**For professionals**

- A written report is distributed to all parents after meetings, summarising the information through mainstream and specialist networks.
- A report summarising parents' views and feedback is sent to parents following consultation events, with a timetable for decisions and likely action.
- A further report is sent to parents when the new service starts.
- Publicity is distributed widely, detailing the role that parents played in developing the service.

For managers

- Professionals are encouraged to keep up to date with consultation and participation and pass outcomes on to the families they see.
- Quick wins which will clearly benefit all families of disabled children are identified and acted on promptly by the service provider.
- Services change and develop to meet families' expressed needs.

6 legislation and guidance



The good practice in this guide is underpinned by legislation and guidance. In this chapter, various key pieces of legislation are outlined to explain how they impact on the need for parent participation.

This guidance was written primarily for the development of services in England, but the principles will apply in all four nations. We have, therefore, indicated which country each piece of legislation or guidance covers. We have also included details of where to get more information about legislation for Wales and Northern Ireland. A section at the end of this chapter covers the relevant legislation and guidance for Scotland.

Health

Health and Social Care Act 2011 (England and Wales)

The Health and Social Care Act 2011 places a duty on health authorities, primary care trusts and NHS trusts to involve and consult 'persons to whom those services are being or may be provided' on 'the planning of the provision of those services, the development and consideration of proposals for changes in the way those services are provided, and decisions to be made by that body affecting the operation of those services' (Section 11).

The NHS Plan 2000 (England and Wales)

- « All NHS trusts, primary care groups and primary care trusts will have to ask patients and carers for their views on the services they have received. »
- « A Patients' Forum will be established in every NHS trust and primary care trust to provide direct input from patients into how local NHS services are run. »

The NHS Plan 2000 introduced the need for health care providers to consult with patients on the services they provide. There are a number of new initiatives in health provision to increase participation in service design and delivery. Members of Patient and Public Involvement (PPI) forums will be provided with training and development opportunities to enable them to participate effectively. The Commission for Patient and Public Involvement in Health, set up in January 2003, has a remit to ensure that the public is involved in decision-making about health and the provision of health services. Its aim is to work to ensure that the voice of both the public and patients are heard in health matters. It will offer links to health-related organisations and provide development and learning opportunities (Department of Health 2000b). There will be a PPI forum for each NHS trust and primary care trust in England, made up of patients and members of the public. PPI forums will provide parents of children with disabilities a way to get their needs and views of services heard. More information about the NHS plan can be found at: www.nhs.uk/nationalplan.

Building on the Best: Choice, Responsiveness and Equity in the NHS (UK)

This Department of Health consultation report, published in 2003, further stresses the need to ‘listen to what patients and the public are telling us’. (Department of Health 2003, page 18)

Social services

The Children Act 1989 (England and Wales) The Children Order 1995 (Northern Ireland)

« In making any such decision a local authority shall give due consideration to such wishes and feelings of any person mentioned in subsection (4)(b) to (d) [parents or any person who is not a parent of his but who has parental responsibility for him] as they have been able to ascertain. » (Section 22:5)

The 1989 Children Act emphasises the importance of the role of parents in their children’s lives. There is further mention of parent participation in the regulations and guidance on children with disabilities that accompanied the Act, which includes a section on the planning of services in partnership with parents and children. A key theme in the Act is ‘that of partnership with parents’ (Section 6:1). ‘Participation will be a token exercise unless careful consideration is given to supporting and informing children and parents about the consequences of any decision being taken – and about the options which they need to consider in making a preference’. While this refers to parents participating in decisions about their children, it also applies to participation in planning of services in a more general sense.

Regulations and guidance for the Children Act 1989, Volume 2, states that ‘partnership with parents ... is the guiding principle for the provision of services within the family home and where children are provided with accommodation under voluntary arrangements. Such arrangements are intended to assist the parent and enhance, not undermine, the parent’s authority and control’ (Department of Health 1991, para 2.1).

The NHS and Community Care Act 1990 (England and Wales)

This Act also emphasised the need to consult with service users. ‘In carrying out any of their functions, local authorities shall consult such voluntary organisations as appear to the authority to represent the interests of persons who use, or are likely to use, any community care services within the area of the authority.’ (Section 46, General Provisions)

Carers and Disabled Children Act 2000 (England and Wales) Carers and Direct Payments Act (NI) 2002

This Act came into force in England in April 2001 and in July 2002 in Wales. It was introduced in Northern Ireland as the Carers and Direct Payments Act in 2002. It makes provision for the assessment of parents and carers. The Act places a duty on service providers to make assessments if carers ask for one. It encourages service providers to work with parents to look at the options available to them.

National Inspection of Services to Disabled Children and their Families: Social Services Inspectorate 1994 (England)

The 1994 Social Services Inspectorate report on services to disabled children and their families recommended that ‘social services departments should consult more widely with parents about the quality of services and changes in service provision’ (Department of Health 1994, page 8). The Inspectorate found there was ‘no routine method of involving parents in the evaluation of the quality of the service they received in any of the authorities’ (ibid, page 21) and it suggested that ‘one important way of involving parents is in the planning and development of future services’ (ibid).

Assessing Children in Need and their Families: Practice Guidance (England 2000, Wales 2001)

This Department of Health practice guidance states that: ‘Families require clear information about the focus of any assessment and about available services providing support. Parents should be clearly informed that their views and priorities are important and they should be encouraged to contribute to the process’ (Department of Health 2000a, 3:17).

Education

Education legislation

The 1980 Education Act states that parents have to be represented on schools governing bodies. The 1986 Education Act and the Education Reform Act 1988 changed the composition and roles of governing bodies, and promoted the idea of equal partnership between parents, the local education authority (LEA) and the local community. Education Acts in 1993, 1996, 1997 and 2002 amended and updated the laws regarding the working and constitution of governor bodies. They extended the occasions when governors are required to consult parents before making a decision. Now schools must consult before drawing up and reviewing the behaviour policy of the school and the home–school agreement (Advisory Centre for Education 1999).

Special Educational Needs Code of Practice 2002 (England) Special Educational Needs Code of Practice for Wales (2002)

« One of the fundamental principles that inform the Code is that ‘parents have a vital role to play in supporting their child’s education. » (Section 1:5)

« To make communications effective professionals should acknowledge and draw on parental knowledge and expertise in relation to their child. » (Section 2:13)

The Special Educational Needs (SEN) Code of Practice states that LEAs need to ensure that they are accessible and welcoming, and that they value the views and involvement of parents. Clearly, with regard to children with special needs, LEAs and schools need to develop effective parent participation to meet the regulations set out in the Code of Practice.

This guidance also outlines the requirement for all LEAs to make provisions for Parent Partnership Services.

« All LEAs must make arrangements for Parent Partnership Services. It is essential that parents are aware of the Parent Partnership Service so that they know where they can obtain the information and advice they need. LEAs must therefore inform parents, schools and others about the arrangements for the service and how they can access it. »

(Department for Education and Skills 2001a, 2:16)

Parent Partnership Services help to ensure that parents can participate in their child's education. Most LEAs now have a well-developed parent partnership service. There is a great deal of good and interesting practice being carried out by the services.

SEN Toolkit 2002 (England & Wales)

The SEN Toolkit states as a critical success factor that professionals and parents work in partnership and professionals take account of parents' views. It also states that LEA SEN policies must describe ways to develop partnership with parents (Department for Education and Skills 2001b, S.1). Section 2 of the toolkit explains how schools, LEAs and all who support pupils with SEN should actively seek to work with parents (ibid, S.2).

Removing Barriers to Achievement: The Government's Strategy for SEN (England)

« Parents of children with SEN are often much under pressure and relationships with local services can be difficult, particularly where views differ about what provision would be most appropriate. »

(Department for Education and Skills 2004a, page 79)

This strategy emphasises the need for local services to work in partnership with parents of children with SEN. It refers to the section in the SEN Code of Practice, which states the expectation that all professionals will work actively with parents and value the contribution they make. This document is further endorsement of the case for increasing levels of parent participation across services.

Joint settings

The Children Act 1989 (England and Wales) The Children Order 1995 (Northern Ireland)

« The authorities should agree on the arrangements for seeking views from all interested parties and individuals. »

Children Act 1989

This quote relates to early years settings and is a clear illustration of the responsibility of local authorities to consult with parents. The Children Act 1989 Section 19.7 concerns the duty placed on local authorities and local education authorities together to review the day care available in the area and says that they should 'have regard to any representations made by health authorities and any other representations' (Ball 1997).

Together from the Start 2003 (England)

Regarding provision of services for the early years, this guidance states that:

« Professionals should approach work in this area with the expectation that they must work in partnership with families, with parents fully involved in any decision-making processes effecting the provision of support to their child. »
(Department for Education & Skills and Department of Health 2003, 4.1).

This guidance also recommends that ‘opportunities and mechanisms for the full engagement of families as consumers of services should be maximised in the review and planning processes’ (Department for Education & Skills and Department of Health 2003, 5.8).

Every Child Matters: Next Steps (England)

This report outlines the findings from consultation on the Every Child Matters Green Paper. It highlights the importance of organising services around the child, young person or family and working in partnership (Department for Education and Skills 2004b).

The Children’s Bill (England)

The Children’s Bill is now before Parliament and will provide the foundations for the principles outlined in *Every Child Matters* to be built upon across all services.

Developing Accessible Play Space: A Good Practice Guide (England)

« Parents of disabled children report that being consulted about the nature of a play space and involved in its development is one of the factors which increase the likelihood that they will take their children there. »
(Office of the Deputy Prime Minister 2003, page 24)

This guide outlines the benefits of consulting and engaging disabled children and families in developing services.

National Service Framework (England)

The National Service Framework (NSF), due out in 2004, will set expectations for all health care services and social care services. One of the themes at the heart of the NSF is participation. It will provide guidance on multi-agency strategies to:

- ♦ provide information to families
- ♦ involve children and families in decisions on their treatment, care and support
- ♦ involve children and families in strategic planning of services
- ♦ promotion of Patient Advice and Liaison Service (PALS) and patient forums
- ♦ provide advocacy and interpreting services
- ♦ include children with high communication needs.

The Children’s NSF in Wales is due to be launched for consultation in September 2004.

Code of Practice on Consultation (England)

In 2004 the Cabinet Office published a code of practice on consultation in which Tony Blair writes that ‘effective consultation is a key part of the policy making process’ and that ‘people’s views can help shape policy developments and set the agenda for better public services’ (Cabinet Office 2004).

NORTHERN IRELAND AND WALES

Further information about legislation and guidance for Northern Ireland can be found on at: www.northernireland-legislation.hmso.gov.uk, and for Wales at www.wales-legislation.hmso.gov.uk.

Information about legislation and guidance for all four nations is also available from www.childpolicy.org.uk.

SCOTLAND

Health

Partnership for Care White Paper, 2003

This describes the Scottish Executive’s plans to improve health, modernise services and deliver the highest quality of care. Key proposals include:

- ♦ patients/parents/carers to be partners in decision-making
- ♦ a new Scottish Health Council which will involve the public
- ♦ a new guarantee of treatment on time.

NHS Quality Improvement Scotland (NHS QIS) The Voice of Parents and Carers, 2004

The NHS QIS has been established to promote and lead quality improvement initiatives in Scottish health services. A study looking at children’s services found that parents’ experience of services was poor:

« Parents repeatedly used the term ‘fight’ to describe their dealings with health care professionals. They were perceived as ‘battle-hardened veterans of the system’ and there was a genuine sense of a ‘them’ and ‘us’ between parents and health care professionals. »

The report concludes that the voice of parents and carers needs to be taken much more seriously.

SIGN – Scottish Intercollegiate Guidelines Network

The Scottish Intercollegiate Guidelines Network (SIGN) was formed to improve the quality of health care for patients in Scotland by reducing variation in practice and outcome, through the development and dissemination of national clinical guidelines containing recommendations for effective practice. SIGN is clear about the important role of parents/carers in its key development groups.

Social services

The Children (Scotland) Act 1995 Scotland's Children – Regulations and Guidance

« Children and their families who are currently using or receiving services should be consulted, together with those who have been in receipt of services. » (Vol. 1, p.11)

Services for children with disabilities and those affected by disability are covered by the Children (Scotland) Act 1995 and the three volumes of guidance that cover its implementation. A key aspect highlighted in *Scotland's Children*, the Scottish Executive guidance, is the need to plan effectively for these services. The guidance states that parents must be consulted and involved in this planning process.

Education

Scottish parents have the right to be consulted over a range of decisions about education provision in their area, including decisions about school closures, re-locations and opening new schools, as well as about meeting the needs of pupils with additional support requirements.

The Standards in Scotland's Schools etc (Scotland) Act, 2000 Circular 2/2001

This includes many provisions to make sure parents are consulted at both school and education authority levels.

Effective Provision for Special Educational Needs (EPSEN)

« Parental involvement: the rights and responsibilities of parents are respected and they are actively encouraged to be involved in making decisions about the approaches taken to meet their children's special educational needs. » (page 9)

EPSEN, the Scottish Executive Education Department's key publication on meeting the additional needs of pupils, highlights the involvement of parents in decision-making.

Manual of Good Practice in SEN

'All those involved in the education of children should, if possible, build a constructive relationship with parents as early as possible, listen to and act on their views, and actively encourage and support them to participate fully in the planning and provision of programmes to meet their children's special educational needs.' (page 16)

This manual highlights good practice in the education of pupils with additional support needs. It states that good practice requires the effective participation and involvement of parents.

***The Education (Additional Support for Learning) (Scotland)
Act 2004 Code of Practice***

This Act replaces the system of assessment and provision of services in Scotland for pupils with additional support needs and fully supports the involvement of parents at all stages of decision-making in relation to service development for their children.

7 contacts, further information and references

Contacts for practical examples

Statutory agencies

Devon Parent Carers Forum

The chair is a Contact a Family local parent volunteer, Margaret Ladbury, who can be contacted via Contact a Family's national office. More information about the Children's Fund consultation is available from Amanda Trafford
Email atrafford@devon.gov.uk



Gateshead Children's Forum

Draws on a pool of about 40 parents, with about 20 attending a typical meeting. For more information, contact:
Jessica Moore
Network Coordinator
Community Based Services
Gateshead Council
Civic Centre, Regent Street
Gateshead NE8 1HH
Tel 0191 433 2480
Email jessicamoore@gateshead.gov.uk

Patent Advice and Liaison Services (PALS)

There are currently six PALS services located in specialist children's hospitals. They belong to their own paediatric PALS network, as well as to their respective regional PALS networks in London, Sheffield, Bristol, Birmingham, Manchester and Liverpool. All six are keen to share their experiences with PALS services which have little contact with children and their parents. For more information, contact:
Jean Pownceby
Senior PALS Officer
Royal Liverpool Children's NHS Trust (Alder Hey)
Email PALS@rlch-tr.nwest.nhs.uk

SNAP and Asian parents

A full report of the Birmingham consultation with Asian parents is lodged with Contact a Family because their West Midlands development officer was on the steering group. The Sure Start example was supplied by Rizwana Pathan, Contact a Family volunteer local rep in Nuneaton.
Email pauline.shelley@cafamily.org.uk

St Helens Star Children's Centre

The SHARP Report will be written up in detail during 2004. To find out more, contact:

Cathy Hamer
 SHARP Project Manager
 The Star Centre
 College Street
 St Helens WA10 1UH
 Tel 01744 453 073
 Email starchildrenscentre@sthelens.gov.uk

Voluntary Action in Spelthorne

For more information contact:
 Sarah Clarke on 01784 446 358
 Email Sarahclarke-va@lineone.net

Northern Ireland Wraparound

For more information about Wraparound, contact Dr. Brid Farrell, on: (028) 3741 4564 or email bridfa@shssb.n-i.nhs.uk
 Information is also posted on the Southern Health Board's site:
 www.shssb.org

Voluntary organisations

aMAZE

The group can be contacted at:
 Community Base
 113 Queen's Road
 Brighton BN1 3XG
 Tel 01273 772 289
 Email info@amazebrighton.co.uk

Contact a Family

Further information about Contact a Family's experiences of consulting with parents (including information about local Contact a Family volunteers and the Sure Start example) can be obtained from:
 Pauline Shelley
 Contact a Family
 Email pauline.shelley@cafamily.org.uk

Somerset Impact

For a full copy of the Somerset Impact guidance, standards on consultation with parent/carers and the voluntary sector, and parent/carer involvement and participation, contact:
 Janet Disney
 Somerset Impact
 10 Castle Street
 Bridgwater
 Somerset TA6 3DB
 Tel 01278 444 794
 Email janet.disney@somimpact.freeserve.uk

South Gloucestershire Parents and Carers Advisory Forum

For more information contact:
 Elley Reinhart
 South Gloucestershire Children's Voluntary Sector Co-ordinator
 The Care Forum
 The Vassall Centre
 Gill Avenue

Fishponds
Bristol BS16 2QQ
Tel 0117 958 9307
Email elleyreinhart@thecareforum.org.uk

Sutton Parents

For more information about the steering group, contact:
Jo Winsloe
Contact a Family Development Officer
Email sutton@cafamily.org.uk

Parent-led forums and councils

The Calderdale Parent and Carers' Council

The group has consulted with parents about their top issues for 2004 and have several examples of successful work with service providers. This includes the parents' report on meeting the needs of children who use non-verbal communication. The Council now has three part-time workers (all parents of disabled children). Contact them at:
The Parent & Carers Council
Hanson Lane Enterprise Centre
Halifax HX1 5PG
Tel 01422 343 090
Email cpcc@btconnect.com

Leicester, Leicestershire and Rutland Parents and Carers Council

Formed in 1999 and committed to multi-agency partnership working. Has invested heavily in training of parent representatives who provide mentoring, support and representation to over 1,000 members. Also provides a forum for consultation and an information network. Has produced a consultation contract for service providers; badges for their representatives who sit on groups; and floats for parents to cover their costs. Also produce newsletters and an annual report. They have funding now for two part-time paid workers. Contact:
Sue Harrison
Parent and Carers Council
c/o Fosse Neighbourhood Centre
Mantle Road
Leicester LE3 6ZJ
Email parentsC@aol.com
Website wwwparentcarercouncil.co.uk

Rochdale Parents' Forum

Contact a Family North West was commissioned by social services to help parents set up their own parents' forum to facilitate consultation. A report about this process and the birth of the forum (Involving and consulting parents of children and young people with disabilities in Rochdale: a report of the early stages of the development of a parents' forum, Mary McBride, 2002) is available from Contact a Family.
Rochdale Parents Forum covers Rochdale, Heywood, Middleton. It can be contacted at:
PO Box 412
Rochdale OL11 5ZW
Tel 07901 812532

Wolverhampton Parents SEN and Disability Forum

More information is available from:

PO Box 3236

Wolverhampton WV4 4ZX

Tel 07986 528 879

Email wolverhamptonpf@hotmail.com

and from:

Wendy Wallis

Wolverhampton PPS

Education Department

The Jennie Lee centre

Lichfield Road

Wednesfield WV11 3HT

Tel 01902 556 345

Email ppservice@wolverhampton.gov.uk

Training**Partners in Policymaking**

For information about Partners in Policymaking courses, contact:

Lynne Elwell or Sue Canavan

NW Training and Development Team

St James Square

Accrington

Lancs BB5 0RE

Tel 01254 306 850

Email lynne.partners@virgin.net

Courses are also run by Merseyside Partners in Policymaking

New Century Halls

Heathcote Road

Walton

Liverpool L4 6BX

Tel 0151 287 7977

Email merseysidepartners@policymaking.fsnet.co.uk

Partners in Policymaking (Scotland)

Scottish Human Services (SHS)

SHS Trust

1a Washington Court

Washington Lane

Edinburgh EH11 2HA

Tel 0131 538 7717

Textphone 0131 477 3684

Email email general@shstrust.org.uk

Website www.shstrust.org.uk

SHS also produces a set of booklets, Checklists for meetings, available from the address above or they can be downloaded from:

http://www.shstrust.org.uk/publications_reports.htm

Open University

The Open University
PO Box 188
Milton Keynes MK7 6DH
Tel 01908 858 786
Website www.open.ac.uk

Equal People is a pack about learning disability for people with learning difficulties, staff and their carers in community, residential, advocacy and educational settings. It can be studied individually, with a partner or in groups. Written accessibly, using pictures, videos and audio tapes, Equal People looks at better ways of working together, controlling and planning change, and what people with learning difficulties can do with the right opportunities. Topics include: finding out about the past and the present, recognising and dealing with discrimination, local policies and services, making choices and good communication. The pack was produced in collaboration with Mencap and People First.

Further information**Techniques**

The section on consultation techniques was based on material written by NSW Public Health in Australia. The full document, with more detailed guidance, can be seen at www.health.nsw.gov.au/public-health/crcp/hib/publications/toc.html

Consulting hard-to-reach groups:

LARIA stands for Local Authorities Research and Intelligence. For a seminar report and full Trescom Research article see: www.laria.gov.uk/content/features/68/feat1.htm

Children and young people's participation**4 Nations Child Policy Network**

www.childpolicy.org.uk

This website contains information on the latest policy developments relating to children and young people in all parts of the UK. By facilitating greater access to policy information and consultation with policy-makers, the network hopes to empower its users to contribute to and influence policy decisions affecting the lives of children, their families and those who work with them. There are links to numerous resources that have been developed to assist in involving children and young people in the decision-making process.

Involving children

Produced for the Department of Health (DH) by the Council for Disabled Children and Triangle (2002), this part of the DH website lists publications and resources for enabling disabled children to be involved in planning and consultation.

<http://www.doh.gov.uk/integratedchildrenssystem/involvingchildren>

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