

parent participation

improving services for disabled children

**parent participation
in health settings**

contact a family
for families with disabled children
incorporating
The Lady Hoare Trust

published by
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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 parents' 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 parents, 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 parents & paediatricians together project

This three year project, which began in April 2004, is a joint initiative being led by Contact a Family, working together with the Royal College of Paediatrics and Child Health (RCPCH).

The project has two aims.

- ♦ To ensure that every parent across the UK whose child is born or diagnosed with a disabling medical condition or rare disorder is automatically put in touch through health professionals with Contact a Family.
- ♦ To open up new opportunities for parents of disabled children to influence child health services across the UK, by creating new frameworks for co-operation between parents and paediatricians.

Contact a Family will continue to collect successful examples of parent participation in paediatric settings over the lifetime of the project and publish them on its website at www.cafamily.org.uk/papt.html



contact a family

**Parents and Paediatricians together –
a joint project between Contact a Family and
The Royal College of Paediatrics and Child Health (RCPCH)**

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- ◆ The Big Lottery which funds the Paediatricians and Parents Together Project

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- ◆ Pauline Shelley, National Development Manager
- ◆ Paul Soames, Director of UK Operations

Foreword

Those providing health services are now expected to consult with parents and users and to involve them in the planning and development of services. However the concept of parent participation can mean different things to different people. How do we ensure that parent participation is effective, meaningful and manageable? How do we find parents willing to get involved, who will represent the wider community and also recognise the very real economic limitations that restrict the services we can deliver? Yet it is only through working with parents, finding out from them the problems they experience, that we can plan to better meet their needs.

The examples contained within this publication are all from paediatric health settings around the UK and illustrate the diverse ways medical professionals can learn about the experiences of parents of disabled children, and from this knowledge improve the way services are delivered. They come from a variety of settings and cover a range of different services. Some of the examples came out of one off consultation events; others came about from an ongoing dialogue between parents and health professionals. They all illustrate how parent participation can be made to work effectively in health settings.

In the Introduction there is also useful advice on how to find parents, and keep them involved in participation work. I recommend this publication as a useful starting point to paediatric professionals who want to involve parents in participation.

Professor Alan Craft
President, RCPCH
March 2005

1 Introduction

This report is a summary of some successful attempts by paediatricians and their health and social care colleagues to consult with parents of disabled children in order to improve the ways they deliver their services.

It has been produced by Contact a Family as part of the Paediatricians and Parents Together Project. This three year project (2004 to 2007) is a collaboration between Contact a Family and the Royal College of Paediatrics and Child Health. Its main aims are to ensure that parents receive helpful information and support from paediatric staff in caring for their disabled children as well as to encourage health professionals to consult with parents about the services they deliver.

1.1 Why parent participation matters

A great deal of recent legislation and guidance on health and social care highlights the need for user consultation and participation. Recent examples in England and Wales are the Health and Social Care Act 2001, The NHS Plan 2000, Carers and Disabled Children Act 2000 and the National Service Framework for Children which will drive the direction of health and social care in England and Wales for the next decade. In Scotland examples are Partnership for Care White Paper 2003 and NHS Quality Improvement Scotland (The Voice of Parents and Carers 2004). There are similar imperatives contained within the Children Order, Northern Ireland 1995 and the Children (Scotland) Act 1995.

There are good reasons for the legislation and guidance. There is a wealth of research that shows that parents of disabled children have similar needs. This includes needs for information about caring for their children in the community and for professionals to provide more family centred services. By encouraging parents and children to give feedback about how they experience services, paediatricians and their health colleagues can use this information to develop services that better meets families' needs. There is growing evidence that this in turn leads to more contented parents and a more cost effective service, with parents making fewer avoidable demands on health services.

For example, if paediatricians and their colleagues provide parents with good information they will cope better; so it is cost effective to have a system for providing information that meets parents' needs. By asking parents what information is needed, professionals can ensure that what they provide does meet these needs.



However it is a challenge to overloaded paediatricians and their colleagues to find effective ways of working which make the best use of their time and of parents' knowledge and insights. The examples in this report illustrate the different ways that it has been done.

Each example contains a brief summary. More detailed descriptions as well as further examples, can be found on our website at www.cafamily.org.uk/papt.html

More examples will be added to the website over the three years of the project.

1.2 Lessons learned

One size does not fit all Consultation and participation are both helpful in developing of services that better meet the needs of families. If possible it is preferable to use both methods.

- ◆ Consultation – where parents are given the opportunity to give feedback on how they experience services to inform planning of service development.
- ◆ Participation – where parents sit on committees and take an active part in decision making.

Many parents of disabled children will not be able to make the time commitment to participate in committees on a regular basis. One-off consultation events provide parents with the opportunity to input their views. A larger number of parents giving feedback leads to a more accurate picture of how services are working.

Finding parents to consult with The examples in this document show a variety of ways which include:

- ◆ Tapping into groups of parents who meet regularly e.g. in Scarborough CDC the Task Force heard from the parent group via the parent representatives about problems parents were experiencing and took action to address this by changing working practices. One off meetings can also attract new parents willing to get involved in further consultation or participation work. In Doncaster and Carlisle, parents from a one off meeting volunteered to become members of a committee.
- ◆ In two of the examples, the paediatricians called a meeting with groups of parents using their services and the parents went on to form a group of allies who worked closely with them – for example ADD+UP in Essex and Umbrella in S Derbyshire.
- ◆ Not all parents will attend meetings and there are other ways by which their views can be collected. In the Carlisle CDC example a questionnaire is sent out with the centre brochure, so that the views of new parents are collected on an ongoing basis. Patient exit interviews, suggestions boxes, reviewing complaints and listening to individual parent's experiences are other ways of getting parent feedback.

Finding parents to participate and keeping them on board The examples contain some vital principles which made them a success.

- ◆ They had more than one parent on a committee so that that they would feel more confident and be more effective. Many of these examples, such as Fife SNIP, involved large numbers of parents in order to even up the power balance.
- ◆ They drew parent representatives from parent groups to ensure that they are they not just representing themselves – for example Wraparound.
- ◆ They visibly acted upon what parents said – producing, for example, an information guide based on parent input or a modification of service in response to their views. Minutes and action plans were circulated after meetings.
- ◆ The paediatricians worked with other colleagues and this ensured the commitment of all relevant staff to the process. In the Wrexham example, the paediatrician also included the junior doctors to ensure changes on the ward worked.
- ◆ They took care of essential practical details which are so important to parents – such as convenient meeting times, accessible locations, expenses and a welcoming atmosphere.

Doncaster | information directory and information days

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NSF Framework for Children, England (2004)

Timely, appropriate, accessible and accurate information is provided to enable children and young people, parents or carers to make choices about the treatment, care and services they wish to use.

Identified need Parents attending the Child Development Centre had problems finding information on where to go for help and support in their local area and needed better information to help them care for their children.

Objective To provide easily accessible information to parents of disabled children in Doncaster.

People involved Paediatrician, parents of children attending centre, committee including representatives from health, social services, education, the voluntary sector and parents.

The participation process

- 1 'One off' meeting with Consultant Paediatrician Dr Mukhlis Madlom, professionals from other agencies and families of children attending the Centre. Many families reported problems in finding appropriate information.
- 2 A committee was formed, called 'Route 2000' to produce a local directory of information for families with disabled children and to run information days. The committee has representatives from education, social services, health, the voluntary sector as well as parents.
- 3 Parents are encouraged to give feedback on what other information they would like to see in the directory via a feedback form within the directory.
- 4 Information days are held annually, and parents attending will be invited to suggest topics for the next information day via feedback forms.

Outcomes

- 1 A directory of local services which contains information parents need has been produced. Funding from selling the directory (£10 professionals, £1 parents) is being used to keep the directory up to date and ensure updates are sent to parents annually.
- 2 Information days have been held for parents and other professionals on *Managing challenging behaviour*, *Moving and handling of children with physical disabilities*, *Childhood epilepsies – management and practical issues* and *Families with disabilities – the way forward?*

More detailed information:

www.cafamily.org.uk/papt.html

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2.2

Parent participation in community settings

Carlisle | design of brochure/ongoing feedback of services

NSF Framework for Children, England (2004)

Disabled children and their parents are routinely involved and supported in making informed decisions about their treatment, care and services, and in shaping services.

Identified needs Parents needed information about the services provided at the Child Development Centre (CDC) and what to expect when initially referred. The CDC also wanted a mechanism to get feedback from parents on their experiences of the services.

Objectives To develop an information brochure about the centre and develop ongoing evaluation process of services provided.

People involved Parents' group and multi-agency professionals from the CDC.

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The participation process

- 1 A drop-in parent group meets monthly at the centre, facilitated by the nursing coordinator. Professionals attend occasionally at request of parents to provide information e.g. behavioural management, therapeutic play.
- 2 The parent group discussed their experiences on first visiting the centre and what information they would have found helpful. From this discussion the parents decided what should be included in a new brochure for the centre.
- 3 The parents helped design a feedback form to go in the brochure to provide ongoing evaluation of how well services meet families' needs. This form also includes feedback on how sensitively diagnosis is handled and how well standards set by the CDCs' mission statement are being met.
- 4 Parents from the group are invited to participate on various working groups. Also parents of children aged 0 to 3 attending the centre were invited to a one off conference to discuss the Early Years Support material and how it might be used. At this event four parents volunteered to sit on the working group which is rolling out Early Years Support across Cumbria.

Outcomes

- 1 Parents have somewhere to meet, access helpful information and provide each other with mutual support.
- 2 A brochure about the centre containing information which parents need, written in a style they understand.
- 3 A questionnaire that provides ongoing feedback from families, to help the centre evaluate their services.
- 4 Parent representatives sitting on working groups and using their experiences to help develop services that better meet families' needs.

More detailed information:
www.cafamily.org.uk/papt.html

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Flintshire/Deeside | speech and language therapy

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NSF Framework for Children, Wales (2004)

Families will have:

- practical support to assist them in caring for their child
- advice on how to maximise their child's development.

Identified need To reduce long waiting times for speech and language therapy following referral.

Objective To develop a system or timeline that could be employed to minimise the time between referral, assessment and intervention.

People involved Parents of both pre-school and school aged children whose children were about to receive or are receiving a therapy from the Community Paediatric Speech and Language Therapy Service, speech and language therapists, speech and language therapy assistants and the Development Officer of Afasic Cymru.

The participation process

- 1 Four sessions arranged: two for Flintshire parents and two for Wrexham parents. Approximately 200 parents invited to each of the four sessions.
- 2 A pro-forma of questions was devised for all sessions to provide consistency. Questions were on parents' experience of referrals system; experience of first appointment; waiting list options related to a timeline of 12 months; appointments outside working hours; experience of therapy.
- 3 The sessions were held at various venues during mornings when children were at school. The parents were split into groups at each session led by speech and language therapists and their assistants plus the Development Officer from Afasic Cymru.
- 4 Parents were asked to give feedback by completing an evaluation form at the end of each session.

Outcomes

Parents asked for support, advice and information whilst their child was waiting for therapy. They suggested the following which is being acted upon with input from parents:

- 1 Support from the health visitor. Information sessions for health visitors have taken place on the identification of speech and language problems, the referral process and what advice health visitors could be in a position to offer to parents waiting for an assessment.
- 2 Parent information pack to include helpful hints and activities for parents to work on with children who are waiting for a date for an assessment.
- 3 More information about the length of the waiting list after referral.
- 4 Activities to work alongside their child at home while waiting.
- 5 Review of waiting times on a monthly basis.
- 6 Information sessions on identifying speech and language problems to be rolled out to school nurses and staff at playgroups and nurseries.

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3.1

parent participation in hospital settings

Wrexham Maelor Hospital | Children's ward practices

NSF Framework for Children, Wales (2004)

Agencies employ creative and imaginative approaches including the use of new technologies and multimedia or non-verbal communication to provide information and to ensure that the views of disabled children and their families are heard.

Identified needs Informal feedback from parents indicated a number of deficiencies in aspects of the care of children with severe disability who are relatively frequent attenders on the ward.

Objectives To identify deficiencies in resources, equipment available, skills of the staff and the processes of care during the admission of children with severe and complex disability.

People involved An invited group of parents of disabled children attending the ward; a nurse, a play specialist, junior doctors and Consultant Paediatrician Dr P Minchom.

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The participation process

- 1 Parents were invited to a meeting with the nurse, play specialist and a doctor. An agenda with issues already identified was used to ensure key subjects were covered. Specific time was given for parents to raise further issues. Detailed minutes were taken.
- 2 Areas identified for attention were: the process of admission to the ward, availability of appropriate specialised equipment, play resources, disability awareness, access and parent accommodation.
- 3 An action plan was drawn up. This listed the points made by parents, grouped them into overall areas of need and identified possible strategies to meet those needs. This was circulated with the minutes of the meeting to all participants.

Outcomes

- 1 A number of rapid responses included: successful application for funding to upgrade facilities for disabled children and their parents on the ward; a successful bid to maintain and develop the ward admissions unit; an increase in play specialist time for the ward.
- 2 Parents specifically found it traumatic and distressing to have to repeat details of their child's history, on each admission, for new staff who were unfamiliar with their child. A single sheet outline of the child's history, condition, treatment and special needs was developed, piloted with parents and is now to be implemented. Parents will hold one copy, and another copy will be in the notes, so the ward has ready access.

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Yorkhill Children's Hospital | hospital facilities

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Partnership for care, Scotland White Paper (2003)

Understanding the wants and needs of patients, whether children, adults or older people will lead to more effective and high quality health care and must be a core activity of the health service.

Identified needs Variety of concerns expressed by parents and carers who use the hospital, ranging from disabled parking and catering to pre-admission issues (but not clinical care).

Objective To provide a forum where the views of parents and carers are considered and valued and which provides an opportunity for parents and carers to be involved in Trust initiatives.

People involved Members of the public, children, young people, voluntary organisations, Senior Nurse for Patient Services (SNPS), (lay) Chair of the Family Council and relevant managers from different departments.

The participation process

- 1 Initial consultation through survey of 250 voluntary organisations with regard to frequency, venue and timing of meetings.
- 2 Quarterly evening meetings held plus monthly visits by SNPS to clinical areas on rotating basis to collect individual views.
- 3 Views collected from meetings and visits inform an action plan which is updated after each of the above.
- 4 Action plan circulated at the evening meetings.
- 5 Relevant managers are involved according to the issues raised.
- 6 Other issues which are highlighted in the action plan are fed back to the appropriate departments for action.
- 7 Update in the form of a short article published in Talk Back (PFPI newsletter), circulated to the hospital and database of 250 voluntary organisations.

More detailed information:

www.cafamily.org.uk/papt.html

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Outcomes

- 1 Resolution of various issues e.g. refurbishment of outpatients in Child Psychiatry, provision of snack trolley-service for resident parents.
- 2 Articles in *Talk Back* (PFPI newsletter).
- 3 Input to evening meetings from various speakers, nurse practitioner for the pre-admission programme, youth worker and activities coordinator for young people, voluntary services manager and play services manager.
- 4 Concerns can be voiced and parents and other participants at the evening meetings gain fuller understanding of the issues even where there is no immediate solution.

4.1

Scarborough | ongoing dialogue between parents and professionals

NSF Framework for Children, England (2004)

Disabled children and young people and their families are routinely involved and supported in making informed decisions about their treatment, care and support, and in shaping services.

Identified needs Problems encountered when children with disabilities were admitted as inpatients or had visited Accident and Emergency.

Objective To provide services that better meet the needs of families of children with disabilities.

People involved Paediatrician, Child Development Centre Co-ordinator, parent support groups, multi-agency task groups including parent representative, hospital staff.

The participation process

- 1 A family room in the Child Development Centre (CDC) is available for a variety of parent groups to meet, facilitated by the CDC Co-ordinator, herself a parent of a disabled child. Groups include multi-disability, autism and transition. The family room holds information for families including literature, videos and internet access.
- 2 The CDC Co-ordinator proactively seeks feedback on problems encountered by families and feeds these back to Dr Lwin, Consultant Paediatrician at the Centre or to the matron at the local hospital.
- 3 A parent representative sits on a multi-agency task force group for each clinical setting, e.g. disability, autism, hearing impairment. The parent representative also meets with at least one of the parent groups thus providing an ongoing two way communication between families and task force groups.
- 4 'One off' meetings are occasionally held at the CDC with professionals and parents to discuss particular issues that parents have raised.
- 5 Parents from the autistic group meet with staff at the hospital to explain the problems posed when they have to visit hospital.

Some of the outcomes

- 1 Parents have an easily accessible place for information and support.
- 2 New procedures, put into place by hospital ward staff and AandE, to alleviate problems encountered when children with autism have to go to hospital.
- 3 Parents of children with autism gave feedback on a job description for a Family Link Worker so the post better met their needs.
- 4 Parent groups lobbied PCT for more funding to increase the number of autism clinics and reduce waiting times for children needing assessment.
- 5 Hospital staff are working to improve the provision of hospital care of children with physical disabilities and difficulties around communication.
- 6 Material has been developed to help prepare children with communication problems before visiting the dentist.

More detailed information:

www.cafamily.org.uk/papt.html

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4.2

parent participation in hospital/community settings

South Derbyshire | information and support to families of disabled children

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NSF Framework for Children, England (2004)

Disabled children and young people and their families are routinely involved and supported in making informed decisions about their treatment, care and support, and in shaping services.

Identified need Parents had problems finding information on where to go for help and support in their local area.

Objective To support the needs of families with disabled children in South Derbyshire.

People involved Paediatrician, parents of children attending centre and Umbrella, a voluntary agency supporting families of children with disabilities.

The participation process

- 1 A 'one off ' meeting in 1985 organised by Consultant Paediatrician Dr Richard Morton and families of children attending his clinic. Many families reported great problems in finding appropriate information.
- 2 A committee was established to help meet this need, made up of parents and professionals working in social services, health and education. The name Umbrella was adopted as the name was perceived to 'cover all' disabilities/additional needs.
- 3 Umbrella became a parent led charity, developed its services and now has 23 salaried posts and over 100 volunteers. Most of the management committee and staff are themselves parents of children with additional needs.
- 4 Umbrella is frequently asked to consult its members on services offered by health, social services and education.

Outcomes

- 1 An information/phone-in service set up at the Child Development Centre which is easily accessible to families attending clinic and by phone.
- 2 Development of the Umbrella Handbook on children's services which helps families' access services to support them and their children.
- 3 Development of many other services to help support families with disabled children including a baby sitting service, leisure and play schemes for the children, outreach workers and disability awareness training.
- 4 An easily accessible source of families for agencies to consult with around services.

More detailed information:
www.cafamily.org.uk/papt.html

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NHS Quality Improvement Scotland (2003)

Ensuring that people have the information that they require to be involved in decisions about their own care and to participate fully.

Identified need Parents valued the resource available from the Special Needs Information Point (SNIP) at the Royal Hospital for Sick Children in Edinburgh and wanted access to a similar information resource locally.

Objective To provide easily accessible information and support to parents of children with additional support needs and staff working with them in Fife.

People involved Fife advisory group including parents, Co-ordinator of Pre-school Community Team (PSCT) RNIB Information Officer, Carers' Centre manager, social worker; management committee SNIP; consultant paediatrician; Local Health Community Council (LHCC) manager.

The participation process

- 1 Three parents identified the need and approached PSCT Co-ordinator with their ideas.
- 2 These three parents were invited to a meeting, facilitated by PSCT Co-ordinator to discuss their ideas and working group formed. Briefing paper and action plan produced.
- 3 Other agencies invited to form advisory group from original working group (50% parents and professionals). More parents identified through professionals' and parents' networks. Decision made to approach SNIP with a view to the Fife model becoming a local outreach from an established organisation. SNIP accepted subject to funding being identified.
- 4 Consultant paediatrician facilitated links within local hospital regarding accommodation.
- 5 Successful application made to Health Improvement Fund for funding to carry out consultation with parents and staff regarding the range of services to be offered.

Outcomes

- 1 Agreement reached on Fife as local outreach from SNIP.
- 2 Consultation with parents and staff has been carried out.
- 3 Work is on-going regarding accommodation and funding with a target date of 2006.

More detailed information:

www.cafamily.org.uk/papt.html

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5.1

parent participation in multi-agency settings

London borough | protocol for assessment and management of ADHD

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NSF Framework for Children, England (2004)

There are arrangements which encourage multi-agency strategic planning or services for disabled children, possibly through a Children's Trust, including the joint commissioning and delivery of services.

Identified needs Parents felt that school staff had a poor understanding of the needs of children with ADHD and as a result their children were often labelled as being 'naughty'. There was a lengthy wait from children being referred for assessment to being diagnosed and receiving support.

Objectives To develop an agreed protocol for the assessment and management of children with ADHD to provide better support to families and improve co-ordination of services.

People involved Representatives from health, social services and education and the local parent support group.

The participation process

- 1 A one off meeting organised by consultant paediatrician Dr. Puvanundran for parents of children with ADHD attending his clinic, led to the formation of a parent support group called ADD+UP.
- 2 ADD+UP approached the health authority and told them about the problems their children commonly faced. This led to the formation of a multi-agency committee to develop a protocol for the assessment and management of children with ADHD, including parent representatives from ADD+UP.
- 3 The committee continued to meet to monitor the protocol and review it. Parents from ADD+UP and professionals using the protocol gave feedback leading to minor amendments.

Outcomes

- 1 Formation of ADD+UP which provides opportunities for parents to meet and gain information about ADHD and the practical and financial help families may be entitled to, as well as holding leisure events for children with ADHD and their siblings (including a very successful summer play scheme).
- 2 Development of a multi-agency protocol for the identification, assessment and management of children with ADHD. Professionals from the different disciplines work more effectively together.
- 3 The average time taken from referral to diagnosis was reduced from 18 months to 6 months.

More detailed information:
www.cafamily.org.uk/papt.html

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5.2

parent participation in multi-agency settings

Fife | implementation of key worker scheme

NHS Scotland: Quality Improvement Standards (2005)

We believe that all improvements made to NHS Scotland must be sensitive to the needs and wishes of patients, carers and the public.

Identified need Co-ordination of services for families where children are involved with two or more service providers.

Objective To streamline referrals and ensure service co-ordination through multi-agency pre-school community teams and a key worker system.

People involved PSCT steering group including parents, community paediatrician, senior managers from health, education and social work, consultant therapy manager, paediatric nurse manager, area deputy educational psychologist, educational home visiting service manager, integrated community schools manager. Six community teams including representatives from services/agencies, community paediatrician, integration manager. Key workers from various services working with families. Jointly managed (Fife Council/NHS Fife) Co-ordinator.

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The participation process

- 1 Consultation with 40 parents and 40 staff from child development centres in Fife through separate focus groups facilitated by an external agency (Interconnections). Report written.
- 2 Multi-agency working group considered the report and recommendations.
- 3 Service co-ordination/key working model agreed.
- 4 Steering group formed – parents invited to join.
- 5 Community teams set up with single entry referral pathway.
- 6 Parents attend meetings to discuss which services will meet the needs of their child and family.
- 7 Core teams of professionals working closely with families formed and key workers identified.
- 8 Key worker training course held – participants included professionals and parents.
- 9 Parent and two professionals attended training for trainers' course.
- 10 Parent and professionals deliver key worker training – all courses involve parents as participants as well as parent trainers.

Outcomes

- 1 Service co-ordination/key working system established.
- 2 Families central to process.
- 3 Key worker training in place with parent trainer involvement.

More detailed information:
www.cafamily.org.uk/papt.html

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Northern Ireland Southern Board | multi-agency working

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Wraparound: the Health Impact Assessment Summary Report (2002)

The participation of service users will impact greatly on the development of services.

Identified need Parents and professionals identified a number of issues with service provision and accessing appropriate local information. A more inclusive and coherent approach was needed to meet their needs.

Objective To set up an inclusive scheme called 'Wraparound' in order to develop multi-agency, multi-professional working.

People involved Parents, children and young people, multi-agency professionals and child care services in the Southern Health and Social Services Board Area, Northern Ireland.

The participation process

- 1 A Health Impact Assessment was carried out in order to review how Wraparound would effect the health and well being of everyone directly or indirectly involved, over its lifetime and beyond.
- 2 Task groups and a stakeholder forum were established that included parents, children and young people.
- 3 A manifesto which identified agreed standards for agencies working with disabled children and their families was developed in consultation with the task groups and local Trusts.
- 4 Parents made presentations outlining their experiences and concerns.

Outcomes

- 1 The establishment of a Parents' Forum of 180 members, with several sub groups contributing to improving specific aspects of service delivery.
- 2 A directory of local services designed by the Parents' Forum which contains local information parents need.
- 3 Significant changes to the organisation and delivery of services to disabled children, young people and their families in the area. The model of service delivery promoted can be replicated in other parts of Northern Ireland or other healthcare settings.
- 4 The offer of disability awareness training, providing information and developing 'parent friendly' models of service delivery.

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Craigavon Area Hospital | parent/child held health care record

Wraparound: the Health Impact Assessment Summary Report (2002)

It's one way of re-adjusting the perspectives of professional and carers alike and moving to more of an understanding of the others position.

Identified need Professionals, parents and young people felt that there was no appropriate document/booklet that could be used from birth to adulthood. Children/young people with specific waiting difficulties were delayed inappropriately in adult A and E departments.

Objective To develop and implement a new parent/child held Health Care Record and Fast Track card for use by children and young people with complex needs.

People involved Multi-agency professionals, young people and parents of children with a range of disabilities and disorders.

The participation process

- 1 Parents highlighted the issues and took it to the Quality and Patient Support (QPS) Manager in Craigavon Area Hospital who helped them set up a sub group. Several parents from the Wraparound Parents Forum then volunteered to contribute to the groups' work.
- 2 Parents and professionals work on an equal basis and all contribute to gathering of information and co-opting additional members to the group as needed.
- 3 Notes are taken and disseminated to the group members by the QPS Manager.
- 4 Parents were offered travel, childcare and attendance costs to all meetings.

Outcomes

- 1 The establishment of a firm action plan to work to achieve these objectives. Fast track record and parent held health record to be finalised by Autumn 2005.
- 2 The process of dialogue between parents and professionals brought about a better understanding of disability issues.
- 3 Improved relationships between parents and the professionals they work with.
- 4 Increased disability awareness among staff throughout the hospital.

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Daslⁿe I epidemiological research

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National Service Framework for Children, England (2004)

Local Authorities, Primary Care Trusts and NHS Trusts ensure that: Specific information pertinent to particular conditions is provided.

Identified need There was an absence of data available on the epidemiology of autism spectrum disorders in the North East and how they affect families and individuals.

Objective To develop a database of children with autism spectrum disorder, for planning service provision and suggesting priorities for research.

People involved Child Health Team at the University of Newcastle upon Tyne, parents of children with autism spectrum disorders, voluntary groups and members of the research team.

The participation process

- 1 The North East regional office of Contact a Family was asked by the research team to find parents who would be willing to assist with the project.
- 2 These parents helped design the information, consent form and questionnaires to be sent out to other parents. Parents ensured the literature was written in a style parents would be comfortable with, which would answer their questions and convince them of the value of the project.
- 3 Contact a Family, local parent groups and community professionals advertised the database and appealed for parents to register.
- 4 Parents helped make arrangements for the official launch of the database and spoke on the day, showing their enthusiasm for the project.
- 5 Meetings continue to be arranged with parents registered on the database, to discuss how they want the data used to influence research and services.
- 6 Parents receive a newsletter on the progress of the database, with invitation to help write and edit it.
- 7 Parents contribute to various committees to support the work of the database, including the steering group.

Outcomes

- 1 A database of families within the area of Northumberland, Tyne and Wear with data on the number and needs of families with children with ASD, which can be used for research purposes and to help plan services.
- 2 An on-going commitment to the project by parents, paediatricians and staff.

More detailed
information:

www.cafamily.org.uk/papt.html

Contact
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RCPCH | patient leaflet for children/ young people with CFS/ME

National Service Framework for Children, England (2004)

Timely, appropriate, accessible and accurate information is provided to enable children and young people, parents or carers to make choices about the treatment, care and services they wish to use.

Specific information pertinent to particular conditions is provided.

Identified need The Association of Young People with ME (AYME) received calls to its helpline which indicated many young people and their families were not getting appropriate advice at diagnosis.

Objective To develop a leaflet for young people recently diagnosed with CFS/ME, to help them better understand and manage their condition.

People involved Paediatricians, parents, young people with CFS/ME, a head teacher and representative from AYME, Royal College of Paediatrics and Child Health (RCPCH) whilst also developing clinical guidelines for paediatricians.

The participation process

- 1 A small committee was formed (with email access) made up of a paediatrician, a parent, a young person recovered from CFS/ME, a head teacher and a representative from AYME who acted as chair. The committee had experience between them of the whole range of severity of CFS/ME.
- 2 Examples of leaflets already written were used to generate discussion and ideas. Young people with CFS/ME were consulted via the AYME internet message board to find out what topics they wanted included.
- 3 The chair produced an initial draft and members of the committee helped redraft contents until everyone was happy with the content and layout. A young patient provided illustrations for the leaflet. This process was carried out relatively easily by using email.
- 4 A RCPCH research officer also checked the draft, to ensure the patient leaflet would conform with the clinical guideline being produced.
- 5 The final draft was circulated to a few young patients, parents, condition support groups and other health professionals for their input.

More detailed
information:
www.cafamily.org.uk/papt.html

Contact
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The leaflet can be
downloaded from
www.rcpch.ac.uk/publications

Outcomes

Medical information suitable for doctors to give to young people with CFS/ME, is now available through the RCPCH and AYME:

- written in a language young people understand and including information the patients wanted.
- suitable for the very young and more severely affected patients.
- including sections on education and friends, as well as symptom control and condition management
- encourages the child/young person to manage their condition.

Further information

Contact a Family will continue to collect successful examples of parent participation in paediatric settings over the lifetime of the parents & paediatricians together project and publish them on its website at www.cafamily.org.uk/papt.html

If you have an example that other health professionals might find useful please let Contact a Family know about them. There are two leaflets available which health professionals can give to parents, one telling them about the different ways Contact a Family supports families and the other providing guidance to parents on judging the reliability of medical information found on the internet.

For any of the above, or to find out more about Contact a Family and how they can help with participation work please contact one of the five Paediatric Project Officers.

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Wales Martin Davies 029 2049 8001 martin.davies@cafamily.org.uk

Further reading

- *Parent Participation: Improving services for disabled children – professional guide* (2004) Contact a Family
- *Parent Participation: Improving services for disabled children – parents guide* (2004) Contact a Family
- *Making a difference: how parent groups can use the Children's NSF to influence local services* (2005) Contact a Family

References

- National Service Framework for Children and Young People and Maternity Services – Standard 8 (2004), Department of Health
- National Services Framework for Children, Young People and Maternity Services in Wales, 2004 Welsh Assembly
- NHS Quality Improvement Scotland – Patient Focus and Public Involvement (2003)
- Partnership for Care: Scotland's Health White Paper, Scottish Executive
- Wraparound: the Health Impact Assessment of the all inclusive Wraparound Scheme-Summary Report, August 2002, SHSSB, The Institute of Public Health in Ireland