



CAMHS



School  
Nurses



Therapy



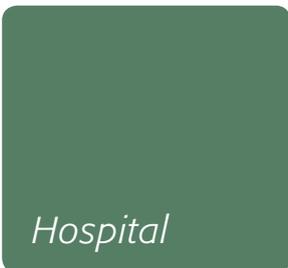
Child  
development  
team



GP practice



Wheelchairs



Hospital



Palliative  
care



# Sharing good practice: parent participation in health settings

Improving services for disabled children

Working in partnership with the  
National Network of Parent Carer Forums

March 2014



## Acknowledgements

I would like to thank the following for their help in developing this guide:

- The National Network of Parent Carer Forums (NNPCF), including all the parent carers who have worked so hard to improve the way health services are delivered to disabled children and shared their success stories, to encourage others to do similar.
- All the commissioners, senior managers and practitioners who listened to parents and worked with them, to bring about improvements to the way they provide services to disabled children.
- The Department of Health for funding this work through the Voluntary Sector Investment Programme Innovation, Excellence and Strategic Development Fund.
- The Department for Education for their continuing support of parent carer forums.
- The Strengthening Parent Carer Participation Team and other colleagues at Contact a Family for their help and support for this project

### **Sheila Davies**

Parent Carer Participation manager (health)

[sheila.davies@cafamily.org.uk](mailto:sheila.davies@cafamily.org.uk)

**contact a family**  
for families with disabled children

Contact a Family provides advice, information and support to all UK families with disabled children, regardless of the disability or health condition. Through a national helpline and family support service, we provide advice on any aspects of caring for a disabled child, including help with benefits and educational issues. We help families get in touch with others in similar situations.

We have supported the development of parent carer forums across England, where parent carers work with professionals to improve how services are delivered in their local area.

# Contents

<b>1 Forward</b>	<b>4</b>
<b>2 Background</b>	<b>5</b>
<b>3 The participation process</b>	<b>6</b>
<b>4 Working with hospitals</b>	<b>8</b>
Royal Manchester Children's hospital (RMCH) – improving the experience for children with autism	8
Birmingham Children's hospital – improving the experience of children with learning disability	10
<b>5 Working in community settings</b>	<b>12</b>
Kirklees PCAN – redesigning Child and Adolescent Mental Health Service (CAMHS) service for children with a learning disability	12
Hull – clinical commissioning group funding forum for feedback on services for disabled children	14
Leeds EPIC – support for families on common issues, for example behaviour, toilet training	16
<b>6 Working with GP practices</b>	<b>18</b>
Rutland Parent Carer Voice – finding solutions through dialogue	18
<b>7 Co-production in developing integrated services</b>	<b>20</b>
Hampshire Parent Carer Network and Hampshire County Council – redesigning the therapy service across the county	20
Redbridge Interface – transformational change for the child development centre	22
Cornwall Parent Carer Council – co-production to develop a palliative care strategy	24
<b>8 Further Information</b>	<b>26</b>

# 1 Forward

The NHS reforms proposed in the White Paper Equity and Excellence: Liberating the NHS set out the government's vision for the future of the NHS. It said that the NHS would:

“be genuinely centred on patients and carers and ‘give citizens a greater say in how the NHS is run’.”

Those providing and commissioning health services are now expected to involve and consult with patients and their carers to inform their planning and development of services.

The examples contained within this publication are all from paediatric health settings around England. They illustrate the diverse ways commissioners, health practitioners and service providers can learn about the experiences of parents of disabled children, and with that knowledge improve the way services are delivered to disabled children.

The examples come from a variety of settings and cover a range of different services. Some came out of one-off consultation events, while others came about from an ongoing dialogue between parents, health professionals, managers and commissioners. They all illustrate how patient and carer participation can be made to work effectively in health settings.

I recommend this publication as a useful starting point to people wanting to know more about participation and understand how it can be helpful in improving the way services are provided.



**Dr Jacqueline Cornish**

OBE FRCP(Lond) Hon FRCPCH DSc(Hon)

National Clinical Director Children, Young People and Transition to Adulthood

Medical Directorate, NHS England

*The examples in this publication illustrate the diverse ways commissioners, health practitioners and service providers can learn about the experiences of disabled children and their families*



## 2 Background

Since 2008 parent carer forums have been developed across England with funding from the Department for Education. Any parent, or person with parental responsibility for a disabled child or young person can become a member of their local parent carer forum. Forums are pan disability. They exist to work in partnership with service leads to improve services for disabled children and their families.

A National Network of Parent Carer Forums (NNPCF) has been developed and its membership is made up of parent carer forums. There are forums in almost every local authority area in England, with a reach of over 63,000 parent carers between them. The National Network provides a mechanism for the experiences of parents of disabled children in parent carer forums from across England to be fed back at a regional and national level.

Disabled children are a relatively small proportion of the population but can have complex needs and access a wide range of different services. Parent carer forums help identify and feedback problems frequently experienced by families with disabled children and work with professionals to help improve how services are delivered.

Involving parent carer forums in commissioning and improving local services has been shown to be key to developing services that met families' needs and make best use of resources.

Contact a Family was funded from April 2011 to March 2014 through the Department of Health's Innovation Excellence and Service Development Fund, to support the involvement of parent carer forums in commissioning and improving local health services for disabled children. Part of the work included writing up case studies of successful work, to share with others.

This guide includes examples from across England of how parents and professionals have worked together to improve services for disabled children.

More detailed case studies can be downloaded at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success)



*Parent carer forums help identify and feedback problems and work with professionals to help improve how services are delivered.*

## 3 The participation process

This guide illustrates the different ways parent carers have helped bring about improvements to the way services are provided to disabled children. Parent carers were not only involved in feeding in their experiences through consultations, but often more actively involved working alongside professionals.

Sometimes the work began after parent carer forums approached commissioners and service leads to tell them about problems their members frequently encountered.

In other examples, practitioners or commissioners realised there was a problem and approached parents, asking for their help so they could understand what was going wrong and work with them to find solutions.

In Rutland and Stockton, solutions were found simply by having a meeting with all the parties concerned. In Leeds, when the community paediatrician could not provide a solution from his own service, he was proactive in arranging a meeting and getting representatives from other services to attend, which led to a solution being found.

In Kirklees, the commissioner consulted with parents at an event organised by the parent carer forum, to identify what changes needed to be done to the Child and Adolescent Mental Health Service (CAMHS) specifications for children with a learning disability. In Hull the clinical commissioning group is funding the parent carer forum to find parents for consultations, participation and monitoring of a range of different services.

In Hampshire and Redbridge, the process of improvement took longer as the solution required a redesign and commissioning of a new service. Having parents involved in the entire process helped make sure the new services were designed to meet their children's needs.

In Birmingham and Manchester implementation took a long time as new ways of working had to be rolled out across an entire hospital. They found that sharing families stories helped motivate hospital staff to change the way they worked.

In Cornwall the parent carer forum was so well-established and trusted that it took the lead in developing a strategy for palliative care for the whole county, working with all the agencies who support children and young people with a life limiting or life threatening condition.

All these different examples had the following in common:

- they involved parents talking about their experiences of services, to help professionals understand what needed to improve. Their stories were useful for people wanting to motivate others that change was needed
- finding solutions involved a dialogue between all the different people involved to understand each other's perspective. They then worked together to find solutions and implement them. This included patients/carers, practitioners and commissioners and/or managers and required someone with sufficient seniority to be able to bring about change
- the solution included parents providing feedback of the new service, to make sure it was working and identify any further refinement that was needed.

Improving services for disabled children and young people bring about benefits for everyone:

- children and young people receive the support they need early on, so they can achieve their potential and lead more independent lives in adulthood
- families feel supported and have a more positive relationship with the practitioners involved in their care
- practitioners are happier when providing a good service and which is also good for staff retention
- commissioners and managers know they are spending money wisely.



*Practitioners or commissioners realised there was a problem and approached parents, asking for their help so they could understand what was going wrong and work with them to find solutions.*



## 4 Working with hospitals

### Royal Manchester Children's Hospital (RMCH) – improving the experience for children with autism

#### Working with hospitals: consultation and participation

People involved: hospital therapeutic and specialised play services, parents of children/young people with autism, multi-disciplinary group of hospital staff, Salford university.

“Most people will not think that accessing medical services for disabled children is stressful, but for a child with complex needs, autism, learning difficulties and speech problems the whole experience for both the child and their carers can be daunting and frightening when doctors and nurses do not have the knowledge and understanding of autism.”

*Parent*

#### Background

A large proportion of children being referred to the Therapeutic & Specialised Play Services for refusing to comply with medical treatment had a diagnosis of Autism or Asperger. Health Play Specialists thought hospital staff did not understand or have the knowledge and skills about autism and how to communicate and support these children and young people while they were in hospital.

#### The participation process

The Health Play Specialists submitted a proposal to the hospital clinical governance team and equality and diversity committee to explore this further. A multi-disciplinary group (ASIG) was set up to lead the work to improve the quality for children and young people with autism. Members of the group included a surgeon, dentist, radiologist, play specialists, registered nurses and parents.

They asked parent carers of children and young people with autism to share their experiences of attending hospital and invited senior colleagues to these events. The patients' stories helped them gain a much better understanding of the challenges and difficulties faced by families and why action was needed.

The Health Play Specialists worked with parent carers to develop questions to identify a child's individual needs, such as what might upset their child and prove difficult. The questions were used to develop a person centred assessment.

ASIG also worked collaboratively with Salford University to develop a designated Royal Manchester Children's hospital autism standard and protocol/pathway, so children with autism are identified and their needs supported when they visit the hospital. A communication 'Dos and Don'ts' list was also developed for hospital staff to provide top tips for success.

Hospital wards/departments were given access to resources such as pictorial communication tools, which can be used to familiarise children with what to expect and create 'social stories'.

ASIG helped disseminate the new procedure to their clinical teams. This included explaining to

staff the problems children and young people and their families had experienced and how this new process could lead to a better experience, not only for the children and young people and their families, but also for staff. Champions were identified to take on the role of local experts.

The autism project lead visited local parent groups, professional teams and forums to tell them about the process and ask them to encourage parents/carers to request a personal assessment for their child.

All parent carers of children with autism attending hospital are asked to complete a service user evaluation about their experience. This is used to find further ways to improve the service. The local National Autistic Society is to provide mystery shoppers to check the processes are working.

## Outcomes

- The scheme has helped staff to understand and improve how they support children and young people with autism.
- Children with autism receive a personal assessment to identify their individual needs and what might upset them while in hospital.
- Families are also offered a hospital 'pre-visit' to explore the areas of the hospital they will encounter on their admission/clinic day.
- Children and young people with autism have a much better experience when visiting the hospital.

“We had pictures of the ward and staff which had been sent to me by the hospital play services which helped me explain to Marley what different staff did.”

*Parent*

## Why this worked

- Parents helped develop the questions which are used in the assessment process.
- The steering group included staff from across the hospital, so they could make sure the processes would work in different departments. These staff were also useful in rolling the scheme out to different sections in the hospital.
- Local parent groups and teams working with disabled children were approached and asked to let parents know about the new processes. The hospital also uses this as an opportunity to improve their assessment form by asking parents if they are asking all the right questions.
- The hospital uses evaluation forms to check with families about their experiences and refine their processes if needed.

### For more information

A more detailed case study can be found at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success)

The personal assessment form and communications 'Do's and Don'ts' for hospital staff can be downloaded at [www.cafamily.org.uk/pcp/health](http://www.cafamily.org.uk/pcp/health)



## Birmingham Children's hospital – improving the experience of children with learning disability

### Working with hospitals: consultation and participation

A steering group including hospital staff, Child and Adolescent Mental Health Service (CAMHS), local voluntary groups, parent carer forum, parents of children with learning disabilities. Young people with learning disabilities.

### Background

Following the Mencap 'death by indifference' report, Birmingham Children's hospital decided to review and improve the experience of children who have a learning disability who come to the hospital.

### The participation process

They formed a steering group, which included representatives of hospital governors and staff, Child and Adolescent Mental Health Service (CAMHS) and parents of children with learning disabilities, including representatives from ICAN a local parent carer forum. The steering group also included members from the voluntary sector including Mencap.

The steering group sought feedback from parents, children and young people about their experiences of visiting hospital. They invited young people who have learning disabilities to carry out an audit of the hospital. They were given the freedom to visit any department and ward and comment on how friendly the staff were and how well they felt they could support children and young people with additional needs.

This feedback provided evidence of what needed to change.

A learning disability nurse was appointed to develop resources and work with hospital staff to improve how children and young people with learning disabilities and their families were supported.

They developed a hospital passport for parents to fill in, which alerts hospital staff about what might upset the individual child while at hospital.

“ The hospital passport is amazing. It is simple, short and sweet and gets everything that needs to be said across in a very simple way. I don't just use it at the hospital – I use it everywhere I go, including school. It is so much easier to use this little book than the realms of notes that I used to carry around before. ”

*Parent*

Resources were developed to support staff to communicate with and carry out assessments of children and young people with learning disabilities.

A one day disability awareness training course was developed where hospital staff hear about the problems families experienced when they visited the hospital. Children and young people with learning disabilities join for part of the day to explain to hospital staff how they like to be communicated with.

Hospital processes were amended so hospital staff find out about each child's additional needs and know how to accommodate them. For example, surgical teams let learning disability patients be first on the list for surgery if possible.

The hospital have implemented 'quality walkabouts', where the learning disability nurse, her manager, and a representative from Mencap walk around the hospital and ask children with learning disabilities and their families about their experiences.

## Outcomes

Children and young people who have learning disabilities and their families find visiting the hospital less stressful. This is because the hospital can plan ahead to make sure arrangements are in place to adequately support them. This makes life easier for everyone including hospital staff.

“ Paediatric nurses have considerable clinical expertise but might not receive training about learning disability. My role is to share my expertise with them, so they can incorporate this in their clinical work.”

*Raj Jhamat, Learning Disability Liaison Nurse, Birmingham Children's Hospital*

## Why this worked

The steering group included parents, representatives from hospital senior management and people with expert knowledge of learning disability. Young people with learning disabilities were also involved.

The hospital funded a learning disability nurse to support the work on developing resources and training for hospital staff.

The disability awareness training includes telling hospital staff about families' experiences, which motivates staff to want to improve how they support these families.

The hospital continues to check with families about their experiences of visiting the hospital.

## For more information

A more detailed case study can be found at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success) or contact:

**Raj Jhamat, Birmingham Children's hospital**

[raj.jhamat@bch.nhs.uk](mailto:raj.jhamat@bch.nhs.uk)

[www.bch.nhs.uk/story/parents-and-carers/learning-disabilities](http://www.bch.nhs.uk/story/parents-and-carers/learning-disabilities)

**Parent carer forum: Solihull - CAN**

[info@solihullcan.org](mailto:info@solihullcan.org)

[www.solihullcan.org](http://www.solihullcan.org)



## 5 Working in community settings

### Kirklees PCAN – redesigning Child and Adolescent Mental Health Service (CAMHS) service for children with a learning disability

#### Working in the community - consultation

People Involved: Commissioner, PCAN parent carer forum, ICARUS (an external consultancy).

#### Background

The NHS commissioner for Kirklees Child and Adolescent Mental Health service (CAMHS) heard that parents of children with learning disabilities were unhappy with the existing CAMHS service.

Children with learning disabilities and mental health issues were being offered either:

- a Tier 2 service, for children with less severe mental health issues, mainly provided through school
- a Tier 3 service, for children with more severe mental health problems, which was provided through CAMHS but which did not focus on their learning disability.

#### The Participation process

The commissioner asked Parents of Children with Additional needs (PCAN), the local parent carer forum in Kirklees, for help to get parents' input into the design of a new CAMHS /learning disability service.

The forum planned and advertised a Saturday morning event to parent carers.

The event involved a dozen parents of children with learning disabilities and mental health issues in a structured dialogue with the commissioner and a colleague. This was facilitated by Icarus, a consultancy with expertise in this area.

The dialogue was structured to ask about pressure points in the child's life and the impact these had on both the child and their family. Parents were also asked what would be helpful for their children and for themselves.

A detailed report was written up from the consultations and this informed how service specifications for a new Tier 2 and Tier 3 service were drawn up.

## Outcomes

Kirklees decommissioned the Tier 2 and 3 CAMHS service, and drew up new service specifications using information provided by the parents. Two new contracts have been awarded.

The new service includes focusing on the child's holistic needs, working in partnership with the child or young person and their families and carers. It includes linking with other services involved with the child/young person, and bringing these elements together in a more coordinated way for the benefit of the child/young person.

Tier 2 staff are going into schools and working with the SENCO and other school staff to help them gain a better understanding of a child's needs, and develop strategies that will help the child. They are also supporting parents of children with learning disabilities, so they can receive support and training to help them understand their child's emotional needs and learn strategies to help them cope with their child's behaviour.

The Tier 3 service specification for children with learning disabilities and mental health issues has been designed around what parents asked for regarding access, information and being listened to. The core team for the new service includes a learning disabilities nurse, a mental health nurse and a number of hands-on flexible support workers, supplemented with access to psychologist and psychiatrists.

## Why this worked

The focus group was held on a Saturday, making it easier for parents to attend.

The use of an independent facilitator enabled a constructive dialogue to take place.

The commissioners listened to parents, taking into account the stresses which can contribute to a child developing mental health issues as well as their experience of the service.

Instead of commissioning more of the same, they designed a service around the child and families needs.

### For more information

A more detailed case study can be found at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success) or contact:

#### Parent carer forum: PCAN – Kirklees

[www.pcankirklees.org](http://www.pcankirklees.org)

#### Icarus

Richard Sorton

[richard@icarus.uk.net](mailto:richard@icarus.uk.net)

#### NHS Commissioner

Debi Hemingway

[Debi.Hemingway@Kirklees.nhs.uk](mailto:Debi.Hemingway@Kirklees.nhs.uk)



## Hull – clinical commissioning group funding forum for feedback on services for disabled children

### Working in the community-consultation and participation

People Involved: Parent carer forum, KIDS (voluntary sector organisation), clinical commissioning group, lead health commissioner.

### Background

NHS Hull clinical commissioning group (CCG) funds a parent participation coordinator to support the parent carer forum, facilitated by KIDS. In return, the forum agrees to carry out engagement and consultation with their members on their views and experience of health services when requested. There is a lead health commissioner for children's services who the forum has a good working relationship with.

### The Participation process

#### Wheelchairs

The forum consulted with families about the children's wheelchair service. Two parent representatives were then involved in the procurement of a new service.

#### Assessment and diagnosis of children with autism

The CCG identified the need to review services for the assessment and diagnosis of children with autism. They wanted to develop a remodelled service and clinical pathway so that children would be seen, assessed and parents receive the results of the assessment within 20 weeks of referral. Parents were cynical that this could be achieved but agreed to help in developing the new pathway.

#### Sleep

The forum worked in partnership with KIDS, the CCG and the local authority to look at the extent of the difficulties parents face and what can be done to support them. The forum reported to commissioners that parents wanted more support to help them manage their child's sleep and behaviour. The local authority, health services and KIDS agreed to investigate what they could do to help families. They formed a strategy and a sleep implementation group. The parent carer forum helped monitor two different sleep interventions piloted in Hull, sleep workshops and face-to-face support by sleep practitioners.

#### The children's centre

Parents from the forum gave feedback and suggestions for improvements at the local children's centre where a range of community health, social care and education services for children with special educational needs, disabilities and/or additional health needs are delivered. Parents identified a range of issues, including a lack of suitable toys for children and sensory area, difficulty around access, especially for people with wheelchairs/buggies, lack of parking spaces, lack of hoists and changing places and walls not adequate to maintain patient confidentiality.

## Outcomes

### Wheelchairs

This led to an improved service with reduced waiting times and a more efficient maintenance and repair service. The forum receives much fewer complaints from parents about the wheelchair service, and if problems do occur, they know who to contact and the problem is usually quickly resolved.

### Assessment and diagnosis of children with autism

More children are being diagnosed earlier and appropriate support is being offered to parents. New referrals are being processed using the new pathway and the CCG has developed targets for clearing the waiting list with the provider. The commissioner meets bi-monthly with the forum and provides updates and information showing how the service is performing.

### Sleep

The CCG discovered that some parents could successfully implement cognitive and behavioural approaches learnt from attending workshops, but others needed more intensive one-to-one support. These approaches were less likely to work well if the child was on medication that interfered with sleep. This is common for children with ADHD and epilepsy. The CCG have now provided more intensive training to sleep practitioners which also includes sessions on the physiology of the brain, the impact of medication (including on children with epilepsy and ADHD). The forum will help monitor this service.

### Improving the children's centre

Since the consultation the children's centre was flooded. Parents are now working with the estate manager to plan how to refurbish and improve the centre.

## Why this worked

- By helping fund a parent carer forum, the CCG can easily consult with parents of disabled children to hear their experiences of services, and involve parents in helping with to improve services and monitor how effective they are.
- KIDS a local charity supporting families of disabled children employs the participation worker who supports the parents in running the forum.
- Feeding back to the parents data showing how the assessment and diagnosis of children with autism has improved will motivate parents to get involved with similar work in the future.
- Having a lead commissioner for children's health helps by providing a single point of contact for both the forum and the CCG.

### For more information

A more detailed case study can be found at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success) or contact Sue Wilson

**KIDS Parent Participation Coordinator**

01482 467540



## Leeds EPIC – support for families on common issues, for example behaviour, toilet training

### Working in the community - consultation and participation

People Involved: Parent carer forum, community paediatrician, head of community services, special school nurses.

### Background:

Parents told the forum they wanted advice on how to support their children around issues such as sleep, behaviour, toilet training, eating and sexuality. The child development team did not have enough resources to support parents on this.

### The participation process

The parent carer forum asked Dr Arnab Seal, the lead community paediatrician and Sue Wilkinson, General Manager of NHS Leeds Community Healthcare, for help to find a solution.

Dr Arnab Seal and Sue Wilkinson set up a small working group inviting the head of community care and representatives for special school nurses, therapists and parents to join.

The forum said parents did not think it necessary to be seen by a consultant paediatrician on these issues. They were happy for someone else to provide advice.

The working group discovered that school nurses working in special schools could provide advice to parents on these issues. The school nurses were already doing this on an adhoc basis to parents who approached them. However, many parents did not know they could go to the school nurse for this type of advice.

The working group decided to put this service on a more formal basis. It was agreed that school nurses would spend one day a week providing an advice service to parents.

The forum helped publicise this to parents to let them know they can telephone the school nurses for an appointment. Children who are in main stream schools and registered as disabled can also access this service.

The community paediatricians also agreed to hold some clinics in the special schools with special school nurses also attending.

## Outcomes

- Parents are receiving advice from specialist nurses with a wealth of experience of working with disabled children. They can provide strategies to parents to help them cope with these issues.
- Consultant paediatrician's time has been freed up so they can spend more time concentrating on medical matters.
- Children do not have to be taken out of school so frequently to attend clinical appointments.

## Why this worked

- The paediatrician and NHS manager for community services took a proactive role in getting the right people round the table, who between them came up with a better way of working.
- The forum are helping to make sure parents hear about where they can go for support on these issues.

### For more information

**Parent carer forum EPIC Leeds**

[www.epicleeds.org.uk](http://www.epicleeds.org.uk)  
[epicleeds@gmail.com](mailto:epicleeds@gmail.com)



## 6 Working with GP practices

### Rutland Parent Carer Voice – finding solutions through dialogue

#### Working with GP practices - consultation and participation

People involved: Parent carer forum, GP practice managers, learning disability nurse.

#### Background:

Rutland is a small unitary authority just outside Leicestershire. A few parents of children on the autistic spectrum reported experiencing problems when visiting their GP practice. The forum thought this might be common for other parents of children with additional needs.

#### The participation process:

The forum consulted with their members to find out more about their experiences of visiting the GP.

They wrote a letter to all four GP practice managers in Rutland asking them if they would be willing to meet with a few parents to hear their experiences.

The forum also invited the Learning Disability Primary Care Liaison Nurse to attend.

The chair of the parent forum began by reading an email from one parent describing the wonderful service she received when attending her GP surgery. She said that this was how the majority of Rutland parents and carers felt but there were one or two issues they would like to discuss with the GP practice managers to see if solutions could be found.

The GP practice managers were aware of some of the issues the parents wanted to raise and

were already taking steps to address them. For example, wheelchair access.

#### The GP practice managers heard from parents that:

- children and young people were unhappy about being referred to the 'baby clinic' for blood tests
- receptionists often did not recognise that the child/young person had additional needs
- GP practice staff did not seem to understand how they could make visits less stressful for patients with learning disability/autism
- parents wanted to be able see the same doctor, so the child would see a familiar face when visiting the GP practice and so the doctor could become familiar with their child and their child's condition
- the GP surgeries were not recognising that the parents were also carers.

#### The parents heard from GP practice managers that:

- the GP surgeries had a system on their computer to alert receptionists if a patient had a disability, but they did not know which children registered with their practice had disabilities
- all the surgeries were keen for patients to be able to see the same GP on most visits, but why this can be difficult at times
- they had a system for registering carers with their GP practice and needed carers to identify themselves to the practice
- All GP surgeries had a Patient Participation Groups and they would welcome having a parent of a disabled children represented on these to

continue to let them know how patients and carers experienced their service.

**The learning disability nurse told them about:**

- training on learning disability/autism awareness which GP practice staff could attend
- training courses for carers around Health Action Plans, Traffic Light Booklet (useful if you need to attend a hospital) and Emergency Grab Sheet (useful to take with you everywhere).

## Outcomes

**The GP practice managers have:**

- renamed the 'baby clinic' to something more appropriate
- sent some staff on the disability awareness course provided by the learning disability team
- put processes in place to make visiting the surgery less fraught. For example, parents can wait in their car with their child until the doctor is ready to see them.

**The forum has:**

- encouraged their members to register their child's additional needs with the GP practice and also let them know they are carers
- told their members about the carers courses which many parent carers have now attended
- advised parents that if there is a problem when visiting the GP practice, they simply need to mention it and the surgery will do their best to address it.
- the forum has helped find a parent of a disabled child to sit on some of these surgeries Patient Participation Groups.

“ I visited the GP with my son for a flu jab. When I got there I discovered there a was going to a be a long wait. I approached the receptionist and explained that my son had autism and if possible could someone come and get us when it was our turn. Unexpectedly I was quickly fast tracked to the front of the queue.”

*Parent*

## Why this worked

On hearing about problems from a few parents, the forum consulted with their members to find out if this was common and whether there were other problems their members experienced.

The parents began the meeting by saying what was good about the service, which made the atmosphere more amicable.

Everyone was willing to listen and understand what the problems were for the other people in the room, and find solutions that worked or everyone.

Having a parent of a disabled child on GP Patient Participation Groups provides a mechanism for the conversations to continue.

### For more information

A more detailed case study can be found at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success) or contact:

**Parent carer forum - Rutland Parent Carer Voice**

[jacqui\\_price1@yahoo.co.uk](mailto:jacqui_price1@yahoo.co.uk)  
[www.rutlandenfamilies.co.uk/rutland-parent-carer-voice](http://www.rutlandenfamilies.co.uk/rutland-parent-carer-voice)



## 7 Co-production in developing integrated services

### Hampshire Parent Carer Network and Hampshire County Council - redesigning the therapy service across the county

#### Working at a strategic level to integrate services - co-production

People involved: Parent carer forum, Overview and Scrutiny Committee (health), Hampshire County Council, steering group including commissioners, therapists, two GP leads from the clinical commissioning group and representatives of the parent carer forum.

After consultation with a range of organisations, the Overview and Scrutiny Committee reported on the problems and asked Hampshire County Council Children's Services to report back on how they intended to respond.

Hampshire County Council set up a Children's Therapies Programme Board to better understand what the problems were and agree on what a new service should look like. Hampshire Parent Carer Network was invited to sit on this board as well as therapists and two GP leads for children with disabilities from the clinical commissioning groups.

#### Background

Hampshire had numerous different Health Trusts providing children's therapy services across the county. This led to a postcode lottery of services. Hampshire Parent Carer Network, the local parent carer forum heard from members about long waiting times, poor coordination between different therapists and children not receiving regular reviews. Hampshire County Council (HCC) had also been receiving a high volume of complaints around inequity of access to the service.

The board looked at how therapy services were provided in other areas including a model used in Wiltshire. The model was presented to various parent/carers groups and other stakeholders for feedback and Hampshire Parent Carer Network ensured that their views were expressed.

The health commissioners negotiated with the five clinical commissioning groups in Hampshire to commission a joint contract for children's therapy services. Tender documents, including the specification for the service, were developed based on the recommendations from the Paediatric Therapies Programme Board. Parent representatives from Hampshire Parent Carer Network were involved in scoring specific parts of the tenders received and interviewing suppliers as part of the tendering process.

#### The participation process

Hampshire Parent Carer Network consulted with their members and submitted a report to the Hampshire County Council and Health Overview and Scrutiny Committee.

Hampshire Parent Carer Network will be involved in monitoring the new service to make sure it is meeting the standards set in the service specification.

## Outcomes

A new multi-disciplinary therapy service has been commissioned for the whole of Hampshire.

There will be a single point of referral and referrals can be made by either practitioners or parent/carers.

There will be a telephone helpline manned by qualified therapists with a triage type service to expedite referrals and minimise waiting times.

The new service is to be delivered by a multidisciplinary team working from the same centre.

Children and young people are expected to be seen within set waiting times, receive regular reviews and have their plans updated.

## Why this worked

Parent carers were involved right from the start and through the whole commissioning process so they could influence what was included in the specification.

The programme board also included practitioners and GPs representing the CCG, so their expertise was also input to the process.

The programme board not only looked at what was not working, but also looked at how services are delivered elsewhere, before making their recommendations.

The parent carer forum understood that the process of bringing about change takes time and remained engaged. The whole process took three years from raising the issue with the Overview and Scrutiny Committee to seeing the new service being commissioned.

### For more information

A more detailed case study can be found at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success) or contact:

**Parent carer forum - Hampshire Parent/Carer Network (HPCN)**

[info@hpcn.org.uk](mailto:info@hpcn.org.uk)  
[www.hpcn.org.uk](http://www.hpcn.org.uk)



## Redbridge Interface - transformational change for the child development centre

### Working at a strategic level to integrate services - co-production

People involved: Parent carer forum, Overview and Scrutiny Committee, strategic leads.

### Background

The parent carer forum in Redbridge, Interface, was set up by parent carers who were concerned about the health services being provided to their children with SEN and disabilities. This was leading to poor outcomes for the health and wellbeing of both children and families.

Interface took whatever opportunity arose to talk to everyone at all levels within the local authority and health, including commissioners and providers, which led over the years to a number of things including reviews of service, and input to the Joint Strategic Needs Assessment (JSNA). This brought about a few small improvements but not the transformational change that was needed.

### The participation process

The forum had a good relationship with the Director of Children Services (DCS). The forum wrote to her and asked her to seek a strategic review of the health service in relation to disabled children because of a number of systemic problems.

In their letter they used evidence gathered from previous consultations with members about the current situation in Redbridge as well as national evidence supporting their case for improvement.

The Director of Children Services approached the local authority Overview and Scrutiny Committee (OSC) and asked them to set up a Children's Disability Scrutiny working group to investigate further. The OSC agreed to this.

Parents from Interface were invited to present to the working group. They developed a powerpoint presentation which included how the current system was letting families down and the role of the local authorities and clinical commissioning groups in commissioning health services following recent changes and national initiatives which supported their case. Following this the working group co-opted two parent representatives from the forum to be members of the group.

The working group visited the premises where the child development centre is based. They also visited the Ark, a neighbouring child development centre where different health professionals (paediatricians, therapists, nurses) work together from the same purpose built building. The Ark showed the subgroup the clinical pathways and protocols they have in place. This helped the councillors understand how a well run child development team operates.

The working group ran their own consultation of parents or carers of children with disabilities in Redbridge asking them about their views of the standards of care they received. The forum encouraged their members to respond to this consultation.

The working group invited key leads to attend meetings and answer questions, including leads from the clinical commissioning group, the local child development centres as well as the local authority.

Finally the sub-group wrote a report with recommendations and an action plan, requiring certain actions to be met by a certain date and identifying the organisations responsible for this. These recommendations were then approved by the Overview and Scrutiny Committee and cabinet.

## Outcomes

- The child development unit is to move to different premises with all health professionals based in the one premise
- Integrated clinical care pathways are to be developed which meet the NICE guideline regarding 18 weeks.
- Data collection will be streamlined, to gather more accurate numbers of on disabled children.
- Certain existing staff are to be designated as keyworkers /lead professionals
- A Joint Commissioning Group is to be established as well as a child health commissioner for Redbridge.
- Development of a code of practice for disabled children's service will be included in the Special Educational Needs (SEND) single assessment (EHC) and local offer.
- Establishment of a health working group to take work forward which includes parent representatives.
- The views of parents and families are to be used in monitoring the services.

## Why this worked

The parent forum was structured, consistent and persistent.

They regularly gathered evidence from their members through consultations and focus groups and used this to evidence their reports and presentations.

Their communications were well thought out and tailored for different audiences.

After struggling to make inroads into health they approached a strategic lead in the local authority with whom they had good relations with and asked their assistance.

Parent representatives will continue to be involved in the work taking this forward and be involved in monitoring the new service.

“ I am very grateful to representatives from the Redbridge Interface parent carers forum, who played an integral role in the development of this work and hope that parents and carers of children and young people with disabilities will see clear links between our recommendations and their experiences.”

*Councillor Elaine Norman, Chair, Health Needs of Disabled Children Working group*

### For more information

A more detailed case study can be found at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success) or contact:

#### Parent carer forum - Interface

[info@interface-parentforumredbridge.org.uk](mailto:info@interface-parentforumredbridge.org.uk)  
[www.interface-parentforumredbridge.org.uk](http://www.interface-parentforumredbridge.org.uk)



## Cornwall Parent Carer Council – co-production to develop a palliative care strategy

### Working at a strategic level to integrate services: co-production

People Involved: Parent carer forum, all agencies involved in supporting children and young people with a life limiting or life threatening condition in Cornwall and the Isles of Scilly.

### Background

In 2012 the Primary Care Trust (PCT) offered to fund the Cornwall Parent Carer Council, the parent carer forum for Cornwall, to develop a palliative care strategy, working with all the agencies involved in supporting children and young people with a life limiting or life threatening condition in Cornwall and the Isles of Scilly. The purpose of the strategy was to improve the outcomes and experiences of these children and young people, by having a choice and range of services available to enable them to live as full a life as possible. To deliver this would require a fully integrated approach among the key delivery partners in Cornwall and Isles of Scilly from both statutory and voluntary sectors.

### The participation process

The Parent Carer Council for Cornwall employed three parent carers to work on this, including one parent whose child had a life limiting condition with complex needs, and another whose child had died from a life limiting condition.

When they found it difficult to reach parents of children with life limiting conditions, they set up a Facebook page called the Palliative Care Network. This allowed parents to self-identify that this work was relevant to them. It also

meant parents were able to communicate with other parents who have children with a life limiting or life threatening condition.

As previous consultations had been carried out with parents and professionals, information was collected from these to identify themes requiring improvement.

A questionnaire was put together for parents and professionals, asking them to rank which theme would be their highest priority, and which would be their lowest priority. They consulted with parents and staff from all agencies involved about contents of questionnaire.

The questionnaire was then sent out to families and professional workers asking them to say what they thought the priorities should be.

A conference was organised attended by parents and professionals from all the agencies involved. They heard parents and professionals talk about children's end of life experiences. A film was shown with a life limited teenager and his siblings expressing their views. After this questionnaires were distributed to all attendees.

The results of the survey showed interesting differences between what the parents and the professionals thought should be a priority in the strategy. For example the parents had not seen nursing care as a priority as they were happy with the service they received. However, the professionals saw it as a priority as they were aware of how stretched these teams were.

The parents had financial hardship as a priority high on their list but professionals placed it very low. This might be because the professionals did not fully understand the huge impact financial pressures have on families' resilience and ability to cope.

The national charity Together for Short Lives had recently produced a framework for the development of integrated multi-agency care pathways for children with life threatening and life limiting conditions (2011). There are five standards within this pathway and all of the priorities the consultation identified fitted within these standards. The parents used this framework to develop the strategy, seeking feedback from relevant agencies for different sections.

Once it was written the full strategy was sent out for consultation to all stakeholders. A few minimal changes were needed as a result of this consultation.

## Outcomes

Actions were agreed for each of these five standards, including the agencies involved in each, and the expected benefits and outcomes and when they should be achieved, based on the priorities agreed by parents and professionals.

Recommendations were also made about continuing to have Cornwall and Isles of Scilly Children's Palliative Care forum meetings at the local hospice attended by all agencies that provide support to children and families, including parents. The network will be able to steer the strategy to ensure outcomes for children and families improve.

In April 2013, the NHS Kernow clinical commissioning group become responsible for commissioning palliative care and the PCT was disbanded. NHS Kernow have now endorsed the strategy and are in the process of implementing it.

Some improvement in service have already been seen:

- the new Facebook page for parents of children with life limiting conditions allows them to communicate with each other and gain advice and support

- work between GPs and out-of-hours' services has improved to ensure better communication, so children dying at home can easily have the pain relieving medication they require.

## Why this worked

- The strategy was developed in co-production with families, professionals and key delivery partners from both statutory and voluntary sectors.
- There was a commitment to the strategy by all partners.
- The forum found parents with direct experience of these services to help lead the work. They were persistent in reaching affected families when this initially proved difficult.
- The consultation included all the different people involved in receiving and delivering the service, so different perspectives were heard and understood.
- The forum avoided duplication of effort by making use of previous consultations and the framework developed by Together for Short Lives.
- They made efficient use of people's time by working closely with relevant people for different sections of the strategy and then allowing everyone to comment on the final draft.

### For more information

A more detailed case study can be found at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success) or contact:

**Cornwall parent carer council**

[www.parentcarercouncilcornwall.org.uk](http://www.parentcarercouncilcornwall.org.uk)

## 8 Further Information

### Parent Carer Participation

You can read more about parent carer participation on the Contact a Family website at

**[www.cafamily.org.uk/parentcarerparticipation](http://www.cafamily.org.uk/parentcarerparticipation)**

The Contact a Family parent carer participation good practice newsletter is sent out electronically every three months. It provides examples of how parent carer participation is improving services for disabled children.

**You can sign up on our website to receive this e-newsletter at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success).**

### The National Network of Parent Carer Forums (NNPCF)

The National Network of Parent Carer Forums (NNPCF) was launched in 2011 and its membership is made up of parent carer forums. There are forums in almost every 151 local authority areas in England, with a reach of over 63,000 parent carers between them. This provides a mechanism to feed in the experiences of parents of disabled children in parent carer forums from across England at a regional and national level.

**See [www.nnpcf.org.uk](http://www.nnpcf.org.uk) for more information.**

Contact a Family and the National Network of Parent Carer Forums (NNPCF) produce a joint information bulletin. This bulletin contains key information about the development of parent carer participation, important changes across Health Education and Social Care in England, news for local forums, the latest news from the NNPCF and opportunities for forums to participate.

**You can sign up to receive this bulletin at [www.cafamily.org.uk/parent-carer-forums](http://www.cafamily.org.uk/parent-carer-forums)**

### Finding your local parent carer forum

You can find contact details of local parent carer forums on the Contact a Family website at

**[www.cafamily.org.uk/parent-carer-forums](http://www.cafamily.org.uk/parent-carer-forums)**

and on the National Network of Parent Carer Forums' website at

**[www.nnpcf.org.uk](http://www.nnpcf.org.uk)**

This booklet has been produced as part of a project funded April 2011 to March 2014 through the Department of Health's Innovation Excellence and Service Development Fund

# About Contact a Family

## Campaigning

We campaign for rights and justice for all families with disabled children.

## Freephone helpline

Our freephone helpline for parents and professionals across the UK is staffed by trained parent advisors. It provides information and advice on a wide range of issues including welfare rights, education, short breaks, local services and local support.

## Publications

We produce a wide range of publications including newsletters, parent guides and research reports, helping parents and professionals to stay informed.

## Linking families

We put families in contact with others whose child has the same condition for support. We link them through existing support groups, our online social networking sites or using our one-to-one linking service.

## Medical information

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

## One-to-one support groups

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

## Local, regional and national offices

Contact a Family has a number of offices around the UK providing local newsletters, information, workshops and support.

## Parent carer participation

Contact a Family supports the involvement of parents in shaping services (health, education and social care).

**contact a family**  
for families with disabled children

☎ 020 7608 8700

✉ [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

🌐 [www.cafamily.co.uk](http://www.cafamily.co.uk)

📘 [www.facebook.com/contactafamily](https://www.facebook.com/contactafamily)

🐦 [www.twitter.com/contactafamily](https://www.twitter.com/contactafamily)

📺 [www.youtube.com/cafamily](https://www.youtube.com/cafamily)