



# Parent carer forum involvement in shaping health services

Working in partnership with the  
National Network of Parent Carer Forums

March 2014



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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.

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

# 1 Background

## Development of parent carer forums

Since 2008 Parent carer forums have developed across England, through support from Department for Education (DfE) funding. These forums exist to work in partnership with service leads and commissioners to improve services accessed by disabled children and their families. Membership of these is open to any parent of a disabled child so forums can provide feedback of parent carers' experiences of a range of services.

Disabled children are a relatively small proportion of the population but can have complex needs and access a wide range of different services across education, social care and health. 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 local services has been shown to be key to developing services that met families' needs and make best use of limited resources.

A National Network of Parent Carer Forums (NNPCF) has also been developed, which all parent carer forums are members of. 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.nnpkf.org.uk](http://www.nnpkf.org.uk) for more information.

Contact a Family is the delivery partner for the Department for Education to support parent carer participation in England, working in partnership with the National Network of Parent Carer Forums (NNPCF).

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.

## About the health project

At the beginning of the project, a survey was sent out which showed some parent carer forums had been successful in improving local health services by working directly with NHS managers, commissioners and clinicians. However, many parent carer forums were not aware of Local Involvement Networks (LINKs) and their role in supporting patient involvement in local health services. In a subsequent survey sent out in October 2012 more forums had tried to work with LINKs but frequently reported difficulties engaging with them. Many LINKs did not think they had a remit to work in children's services, or were primarily focused on adult services which affected the majority of their members.

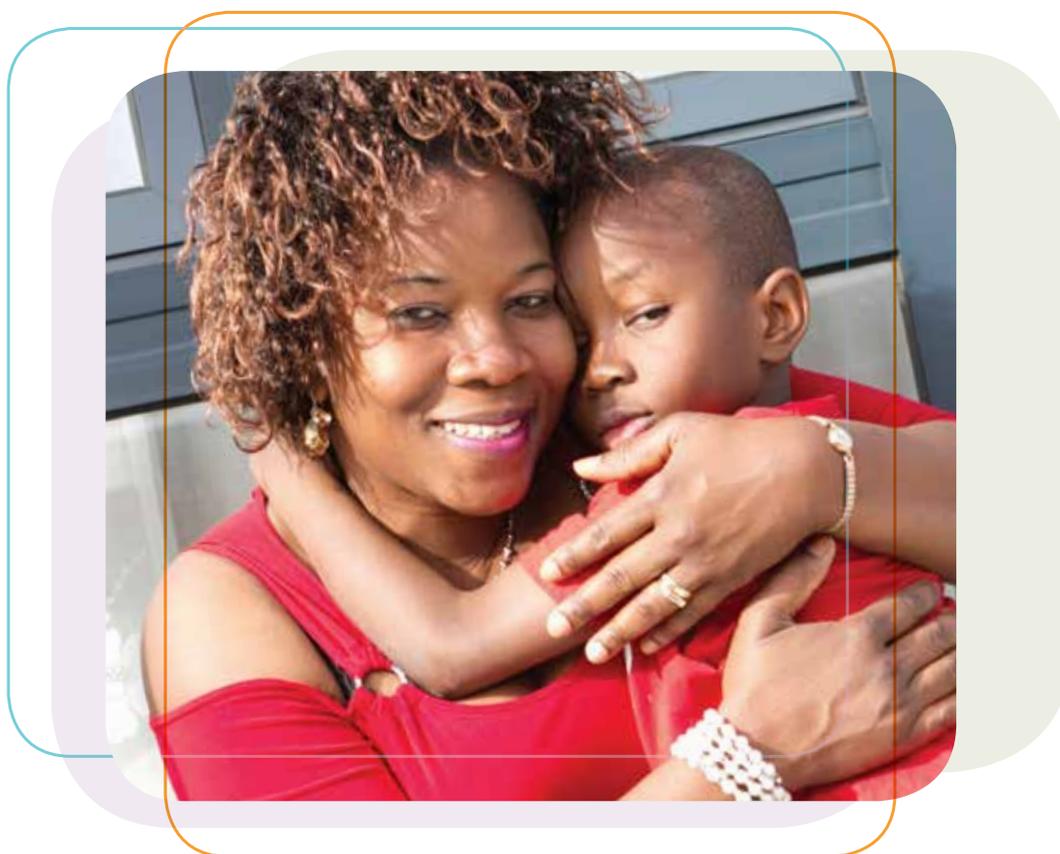
A key part of the project was to provide parent carer forums with information about the changes taking place in April 2013 and encourage them to make contact with and work with their local Healthwatch, clinical commissioning groups and health and wellbeing boards. Information materials were developed and disseminated to parent carer forums through a variety of mechanisms including presentations at NNPCF regional and national events, and running workshops for forums. The Every Disabled Child Matters (EDCM) campaign also used the information we developed about health and wellbeing boards when telling parent carer forums about the EDCM charter for health and wellbeing boards.

Information was developed for local Healthwatch to tell them about parent carer forums and disseminated by Healthwatch England at a national event.

It had been anticipated clinical commissioning groups and Healthwatch would be running in shadow form during the year 2012–13. However, clinical commissioning groups only began to become authorised in December 2013, and many local Healthwatch organisations only came into existence after April 2013.

From September 2014, major reforms are being made to how support for children with special education needs (SEN) is provided, through the implementation of the Children and Families Act 2014. This puts a requirement on local authorities and health to jointly commission support for disabled children and involve parents in developing this support. There was concern that the involvement of parent carer forums in this would have an impact on their capacity to be also involved in influencing health services.

This final report summarises the success of the project in supporting parent carer forums to become more involved in influencing how health services are delivered. It also reports on parent carer forums' involvement with clinical commissioning groups, Healthwatch and health and wellbeing boards.



## 2 Key Findings

Surveys were sent out to parent carer forums in July 2011, October 2012 and Jan 2014 asking forums about their involvement with health and who they were working with.

**105** parent carer forums out of a potential **151** responded to the final survey, compared to **73** in the previous survey. Forums responding were spread across all nine English regions.

The results show that more forums across England are working with health to improve the way services are delivered to disabled children than at the start of the project. Many forums are working in more than one health setting.

*86% per cent of parent carer forums responding to the survey were actively involved in shaping health services, and many involved in more than one setting*

### Working with health services

#### What is good

**86%** per cent of parent carer forums responding to the survey were actively involved in shaping health services, compared to 75% in the survey sent out in 2012.

Parent carer forums are frequently involved in more than one setting (specialist, universal, community, strategic) and working with a range of leads (commissioners, NHS managers, clinicians). They had been involved in a variety of ways. For example, consultations, parent representatives on project boards, members of Task and Finish groups, delivering training, working with the Overview and Scrutiny Committee.

**57%** of parent carer forums had worked with health commissioners, compared to 47% in the previous survey.

**43%** had worked with specialist lead clinicians compared to 36% in previous survey.

#### What needs addressing

In some areas parent carer forums are still struggling to find who to contact and work with when their members raise issues about specific services.

Forums found it easier to work with health where there is a lead health commissioner for children to help them make contact with the appropriate people.

## Clinical commissioning groups (CCGs)

### What is good

**93%** of forums responding knew about clinical commissioning groups (CCGs) and

**71%** described their forum as either being in contact with, or working with, a clinical commissioning group compared to 38% in the previous survey.

**32%** describe themselves as working with their CCG compared to 9% in the previous survey.

Those working with their CCG were mostly involved in supporting consultations with parent carers of disabled children. In some areas CCG staff had visited forums to gather patients' feedback. In a few areas the CCG is funding the parent carer forum to carry out consultations on their behalf.

### What needs addressing

In some areas, parent carer forums are finding it difficult to get their clinical commissioning group (CCG) to engage with them. This is likely to be because CCGs have adopted different approaches to supporting public patient engagement.

Some CCGs are engaging with the public solely through holding large public meetings where parent carer forums find it difficult to raise issues about the specific services their members are concerned about. In other areas, CCGs are mainly relying on patient participation groups within GP surgeries to feedback their experiences of acute and community services. This does not provide a ready mechanism for targeted groups such as parent carer forums to feed in their experience of services.

In some areas CCGs are happy to consult with parent carer forums about issues they have as a priority, for example out-of-hours services. However, sometimes forums find it difficult to get CCGs to engage with them about services which parents see as a priority.

Forums also regularly report being unable to attend meetings as they are held at times difficult for them, such as during school runs and school holidays.

*Sometimes forums find it difficult to get CCGs to engage with them about services which parents see as a priority.*

## Healthwatch

### What is good

**95%** of parent carer forums responding knew about Healthwatch and

**71%** described themselves as having made contact or working with them.

**36%** of parent carer forums said they were working with Healthwatch, mainly by attending meetings and supporting consultations. In a few areas, members of the parent carer forum were more actively involved in Healthwatch. By comparison, only 14% of forums were working with Local Involvement Networks (LINKs) in the previous survey. Many local Healthwatch only became operational after April 2013.

**51%** of parent carer forums thought that Healthwatch were likely to approach them if they wanted to find out about parents experiences of services for disabled children.

*A significant number of parent carer forums who have made contact with their local Healthwatch are not being able to build a relationship with them, or feel confident that Healthwatch will be able to support their work*

### What needs addressing

Only **35%** of parent carer forums responding said they were fairly or very confident that Healthwatch would be helpful in improving services for disabled children, even though 71% of parent carer forums had made contact with or were working with Healthwatch. This suggests that after making contact with Healthwatch, many forums do not feel confident in them.

Parent carer forums mentioned the following concerns about Healthwatch:

- their lack of capacity, and huge remit
- not understanding how parent carer forums work
- being focused on certain topics, for example adults, elderly, dementia, obesity
- being selective as to which organisations they will work with.

Some parent carer forums are finding that Healthwatch will not work with them.

In some local areas, Healthwatch want to work with local groups to help them target particular patient groups. In other areas, Healthwatch appear to be mainly focused on getting individuals to sign up to be volunteers or take part in public consultations through surveys.

**17%** of parent carer forums responding reported trying to make contact but had not been successful in getting Healthwatch to engage with them. A further 3% had not been able to find who to contact.

**9%** of parent carer forums thought it extremely unlikely that Healthwatch would approach them to consult about services for disabled children. This was often after having made repeated attempts to get Healthwatch to engage with them.

## Influencing the health and wellbeing board

### What is good

**85%** of parent carer forums knew about the role of the health and wellbeing board.

**12%** of parent carer forums described themselves as working with them compared to 3% the previous year.

**85%** of forums reported being in contact with either the director of children's service, director of adult service, an elected member, their clinical commissioning group or a public health lead who all have representation on the health and wellbeing board. Forums can find having contact with strategic leads helpful in getting their voice heard and affecting change.

**45%** forums had contact with three or more of these strategic leads, suggesting they are well positioned to try to get disabled children on the agenda.

Many forums mentioned their contact with joint commissioners as being helpful in influencing the health and wellbeing board.

*45% forums had contact with three or more of these strategic leads, suggesting they are well positioned to try to get disabled children on the agenda.*

### What needs addressing

**47%** of forums responding described themselves as having made contact with or working with their health and well being board, compared to 40% the previous year.

**27%** of forums had either not found who to contact, or tried to make contact and not been successful. A further 21% had not had time to try to make contact.

The health and wellbeing board is a high level strategic body with responsibility for services for the local community with many different committees and working groups reporting into it. One would not expect representatives from parent carer forums to necessarily be in direct communication with the board.

Most parent carer forums have parent representatives sitting on steering groups which are likely to feed into the work of the health and wellbeing board. 47% of forums said they were feeding into the work of their local health and wellbeing board. However, 49% of forums either did not think they were, or did not know. This could be because of a lack of understanding about how different sub-committees feed into the work of the health and wellbeing boards. This will be different in each local area.

## Implementation of SEN reforms

Some forums are making contact with their clinical commissioning group through their work on the SEN implementation.

Where clinical commissioning groups have become engaged with the SEN reforms, it is helping them understand how parent carer forums work and the benefits of working in co-production with them.

However, a significant number of forums are still reporting struggling to get health to engage with the SEN reforms and are concerned that health will not be ready for the implementation of SEN reforms being introduced in September 2014 through the Children and Families Act 2014.

*75% of forums found the GP guides and consultation toolkits helpful, 46% describing them as very helpful.*

## Support provided by Contact a Family to parent carer forums

### What is good

Contact a Family developed various materials over the course of this project to inform and support forums' involvement in health.

- 92% of parent carer forums found case studies describing forums' success in improving health services and the three-monthly Good Practice Bulletin helpful, 48% describing them as very helpful.
- 76% of forums found briefing papers explaining the roles of Healthwatch, clinical commissioning groups and health and wellbeing boards helpful, 36% describing them as very helpful.
- 75% of forums found the GP guides and consultation toolkits helpful, 46% describing them as very helpful.

Contact a Family also kept parent carer forums informed about new initiatives, for example, Department of Health good practice guidance, NICE guidelines, the NHS mandate and the Marmot review, which would support their work at a local level.

Contact a Family developed guides for GP practices and clinical commissioning groups, to help them understand what services disabled children need and how GP practices could improve the way they support disabled children.

Many parent carer forums found these helpful when making contact with their clinical commissioning group(s). In some areas clinical commissioning groups circulated these guides to all GP practices in their area. In other areas the parent carer forum enlisted its members to circulate them to all GP practices. The Royal College of GPs recommended them to their members and have included them as a resource for GPs on their website. They are also being used as a resource to train professionals.

“In my work on WHO’s World Report on Disability (2011), we identified access to healthcare as a major obstacle for disabled people. Since then, and in my work at UEA Medical School, I have looked for good resources to help train professionals to include disabled people fairly and meet their needs effectively. The Contact a Family GP practice guides are a model for the type of practical, sensible information which health professionals and families with disabled children need, and have been very helpful in my research and teaching.”

*Tom Shakespeare, Norwich Medical School, University of East Anglia*

### **What needs addressing**

Communication is not a one off event but needs to be ongoing. New parents who had recently taken on running a forum were less likely to know about the resources developed in previous years.

Parent carer forums will also need to continue to be kept informed about national initiatives relevant to their work, as well as hear about good practice examples of how other forums are improving health services.



## 3 End of Project Recommendations:

### For Healthwatch

Information should be cascaded to local Healthwatch to help them understand how parent carer forums operate and could support their work.

Local Healthwatch provide clear information about how local patient groups, including parent carer forums, can feed in their members' experiences of services to their local Healthwatch.

Local Healthwatch is asked to include in their annual report how they have involved patient groups, including parent carer forums in their area.

### For NHS England

Information should be cascaded to clinical commissioning groups to help them understand how to, and the benefits of, engaging with parent carer forums.

Examples of how clinical commissioning groups are successfully working with parent carer forums groups should be shared, to encourage other CCGs to do similar.

Consider how information such as new guidance and examples of good practice could be effectively communicated to local Healthwatch and local parent carer forums, to support their work.

### For clinical commissioning groups

Clinical commissioning groups (CCGs) nominate a lead contact, who parent carer forums can liaise with if they want to raise issues about a particular service.

Clinical commissioning groups publicise contracts due for renewal in the following year, to allow patient groups including parent carer forums to consult with their members, and inform the contents of any new service specifications.

### For health and wellbeing boards

Provide information to parent carer forums about the sub-committees which feed into the health and wellbeing board relating to children's service and how they involve parents and young people in their work.

Take responsibility for making sure plans for implementation of the SEND reforms are underway, and that all parties are involved with the process including, health and parent carer forums.

Appoint a joint commissioner, to coordinate children services between health, social care and education, and provide a link with parent carer forums.



## 4 Examples from around England

Parent carer forums can be involved in improving health services in different ways. Involvement can range from:

- simply feeding back their experience of services
- arranging meetings with service managers to find solutions to problems reported by parents
- carrying out consultations to gather evidence
- working with commissioners and practitioners to improve services, or
- working at a strategic level through the Overview and Scrutiny Committee.

Here are a few snapshots from around the country to illustrate the different ways forums are helping to improve the way services are delivered to disabled children.

**Detailed case studies and a new guide, *Sharing good practice: parent participation in health settings*, has recently been published.**

**See [www.family.org.uk/Parentcarerparticipation](http://www.family.org.uk/Parentcarerparticipation)**

### Finding solutions through dialogue

#### East Midlands: Rutland – dialogue with GP practice managers



The parent carer forum arranged a meeting with GP practice managers and a learning disability nurse to discuss problems some of their members experienced when visiting the GP. Through this meeting they discovered how they could help each other, to make sure disabled children and their families' needs are better understood and supported when they visit their GP.

#### North East: Stockton – access to Learning Disability Team/Child and Adolescent Mental Health Services (CAMHS)



After hearing about parents' issues their children had around sleep/toileting and behaviour, the forum invited the Learning Disability and CAMHS teams to meet the parent carers. Parents are now being given strategies to help them cope with these issues and know how to access support from the Learning Disability Team and CAMHS if they need it.

## Developing Information & clinical pathways

### North West: Stockport – working with the Child and Adolescent Mental Health Service (CAMHS) to increase wellbeing



The parent carer forum has worked with CAMHS to develop top tips for families for maintaining family mental health and wellbeing. They were also involved in the development of an autism spectrum disorder pathway.

### Yorkshire & Humber: North East Lincolnshire – developing diagnostic pathways



The forum has worked with health to develop the diagnostic pathways for Child and Adolescent Mental Health Services. The waiting times were over a year. The new pathway has reduced waiting times, and allows easier access back into the service if there are further issues.

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## Supporting consultations

### East of England: Norfolk – running a consultation for the clinical commissioning group



The clinical commissioning group were considering providing more support in the community to children requiring intravenous therapy and Hickman lines to receive medication. They wanted to consult with families. The forum consulted with families on their behalf, using a variety of methods (focus group, survey, telephone interview). Finally they wrote a report for the CCG with their findings.

### Yorkshire & Humber: Hull – CCG fund the forum to feed back parents experiences



NHS Hull clinical commissioning group (CCG) funds a parent participation coordinator to support the forum, facilitated by the charity 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. This year the forum helped them:

- commission a new children's wheelchair service
- develop an autism assessment and diagnostic pathway
- run a pilot to support parents carers to manage sleep and behaviour issues, and
- give feedback and suggestions for improvements to the local children's centre re accessibility and toys.

## Commissioning new improved services

### London: Redbridge – working with the Overview and Scrutiny Committee



The forum gathered evidence of the poor services disabled children were receiving, and through the director of children's services approached the Overview and Scrutiny Committee (OSC). A Children's Disability Scrutiny working group was set up and the forum was invited to be a member. After further investigation the working group made recommendations to:

- move the child development team, with all the health professionals based at one premise.
- develop integrated clinical care pathways
- designate existing staff to be key workers/lead professionals, and
- establish a Joint Commissioning Group and a child health commissioner for Redbridge.

These recommendations have now all been accepted by cabinet.

### South East: Hampshire – commissioning a new county wide therapy service



Hampshire parent carer forums approached the Overview and Scrutiny Committee with their concerns about therapy services across Hampshire. This led to Hampshire County Council inviting the forum to become a member of a project board, which investigated and helped commission a new multi-disciplinary therapist service for the whole county. The parent carer forum is going to help monitor this service.

## Co-production

### South West: Cornwall – developing a palliative care strategy



In 2012 the Primary Care Trust (PCT) offered to fund the forum 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. NHS Kernow, the clinical commissioning group for Cornwall and the Isles of Scilly, have now endorsed this strategy.



## Training of practitioners

### **West Midlands: Herefordshire – training of health visitors**



Parent Carer Voice in Herefordshire have been delivering training to health visitors where they share their experiences from when their children were babies, the difficulties they faced because of their child's additional needs, and the support provided by health visitors which they valued, as well as what was not helpful. The feedback from health visitors attending has been extremely positive.

“ Parents from the forum help deliver disability awareness training to all staff who work at the hospital ”

### **London: Kensington and Chelsea – training health staff about learning disability**



Parents from the forum sit on Chelsea Westminster hospital's Learning Disability Forum, which raises the profile of the needs of young people and adults with learning disabilities and their parent carers. This includes delivering mandatory training to all staff who work for the hospital. This is a rolling programme and includes clinicians, administration, nursing staff, trainee doctors, porters. The training has been well received by hospital staff. This led to the health commissioner inviting them to deliver similar training to GPs.

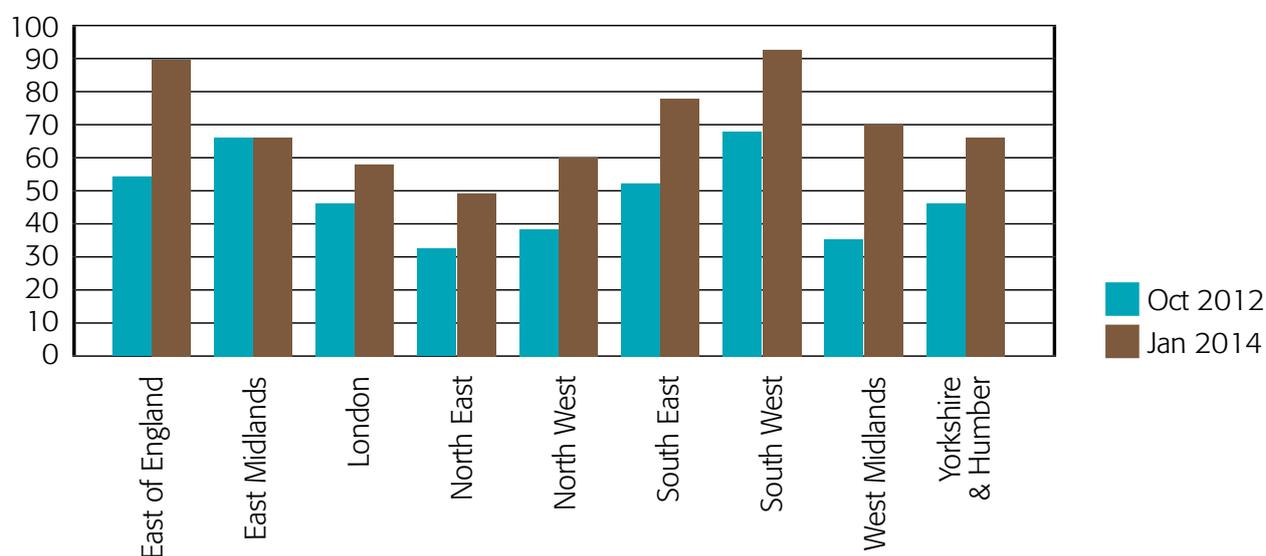


## 5 Parent carer forum involvement in health

Contact a Family sent surveys out to 151 parent carer forums at the start, half way through and at the end of the three year project to measure their involvement in health. In the final year we received 105 completed surveys from all nine regions, compared to 78 in the first and 73 in the second year.

There was an extremely high engagement from the East of England (91%) and the South West England (94%).

**CHART 1: PERCENTAGE OF AREAS RETURNING SURVEYS, BY REGION**



**TABLE 1: NUMBER OF RETURNED SURVEYS BY REGION OCTOBER 2012**

Regions	Number of LAs	October 2012		January 2014	
		Number	Percentage	Number	Percentage
East of England	11	6	55	10	91
East Midlands	9	6	67	6	67
London	32	15	47	19	59
North East	12	4	33	6	50
North West	23	9	39	14	61
South East	19	10	53	15	79
South West	16	11	69	15	94
West Midlands	14	5	36	10	71
Yorkshire & Humber	15	7	47	10	67
<b>Totals</b>	<b>151</b>	<b>73</b>	<b>48</b>	<b>105</b>	<b>70</b>

**86%** per cent of parent carer forums responding were actively involved in shaping health services, compared to 75% in the previous survey. They were involved in different ways including:

- inviting managers to meet their members for sharing of information and hear their experiences
- supporting or running consultations, to provide evidence to providers and commissioners of their members' experiences of services
- working with clinicians to develop clinical pathways
- providing parent representatives to sit on project boards, working groups, Task and Finish groups
- working with Overview and Scrutiny Committees to trouble shoot problematic services
- providing disability awareness' training to health professionals.

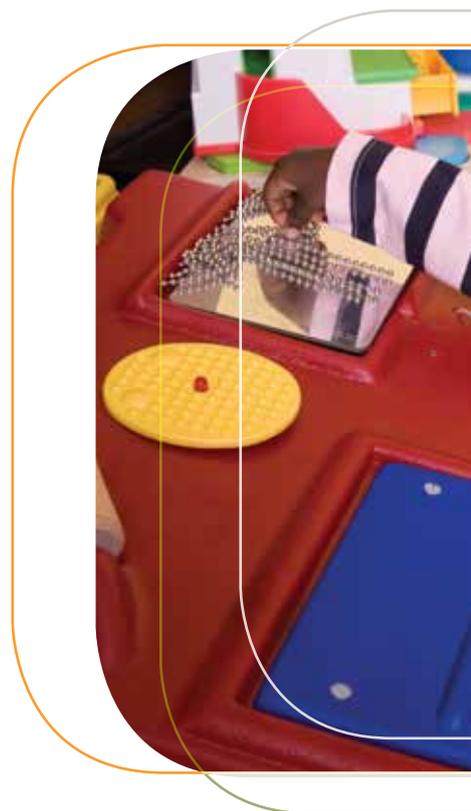
Some forums were involved in improving one particular service that parents identified as being problematic. A substantial number of forums were involved in many different strands of work.

“ We have been involved with the re designing of the Children’s Outpatients at North Devon district hospital. We have invited speakers from the NHS to question and answer sessions with parents. This is proving popular and will be continued.”

*Devon*

“ We have on-going meetings with the clinical commissioning group as a forum. We are also part of the Patient Reference Group and have links with our local Healthwatch. We invite health commissioners and other health professionals to our forums on an ongoing basis. We have also published a report, ‘Health Needs of Disabled Children’ and launched it to senior professionals in our borough with very positive outcomes. ”

*Hammersmith*



“ We work in partnership with commissioners from health, from both children and families and adult services. This work includes being part of tendering panels, training GPs, and ensuring that families of disabled children/adults have access to local acute and preventative health care. We also report on any gaps or delays we see in service provision. We sit on Chelsea Westminster hospital’s Learning Disability Forum which raises the profile of the needs of young people and adults with learning disabilities and their parent carers. In partnership with the Royal Borough of Kensington and Chelsea Adult Learning Disabilities services we are part of the mandatory training of all staff who work for the hospital. ”

*Kensington and Chelsea*

“ We have parent reps working alongside health colleagues on Project Boards, Joint Commissioning, education health and care plans and local offer work strands and the overarching project board of the Children and Families Act 2014. We have parent reps on the Palliative Care Group but this has not met recently. We were involved in a CCG project looking at community nurses services for children with long term intravenous tubes and complex nursing needs. We have had reps on the Autism Spectrum Disorder and ADHD Pathway Task and Finish groups. We have worked with the CCG and Health Scrutiny Panel on wheelchair provision (report previously shared) We have two places on the Children and Maternity Commissioning Board. ”

*Norfolk*



### Who are key contacts for parent carer forums

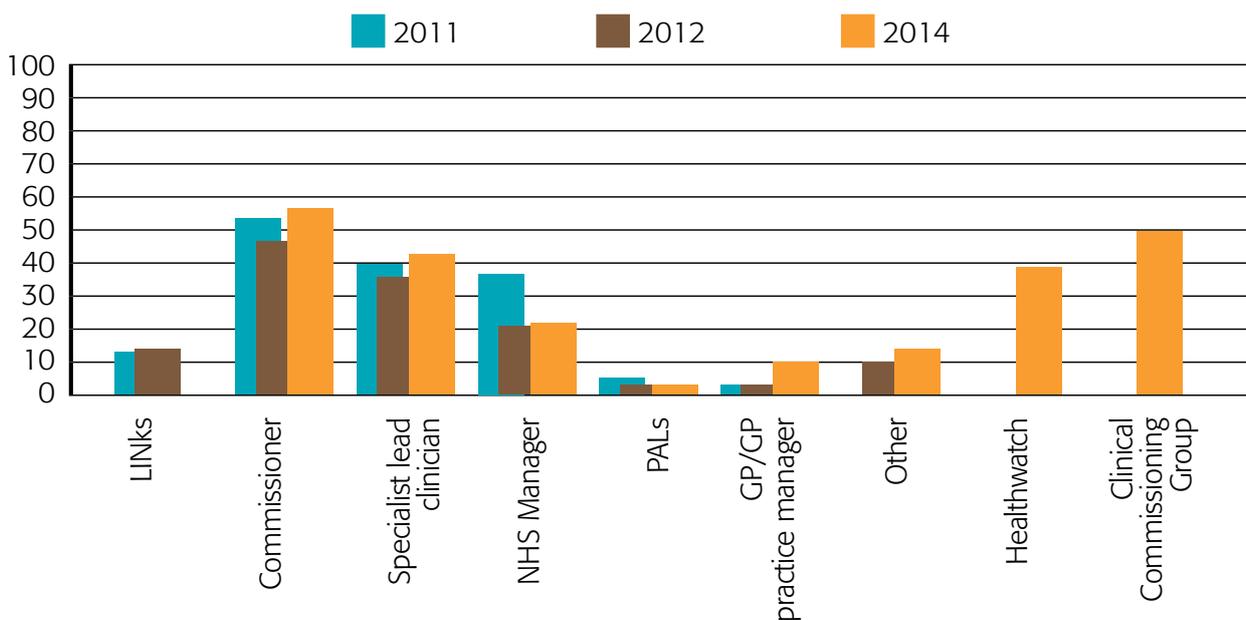
It can be difficult for parent carer forums to find who to contact, if they want to get involved in improving a particular service. Key contacts help forums make contacts with the appropriate person/department/organisation.

Over the course of the project we have been encouraging parents to make contact with the newly formed clinical commissioning groups and Healthwatch.

In the survey we asked forums to tell us who were their key contacts for their work with health.

A greater percentage of forums described commissioners (57%) and specialist lead clinicians (43%) as key contacts compared to previous years. 50% of forums described having key contacts in their clinical commissioning group and 39% in their local Healthwatch, both of whom only became operational in April 2013. By comparison in the previous year only 14% of forums described having key contacts in their LINKs.

**CHART 2: PERCENTAGE OF FORUMS WITH FOLLOWING KEY CONTACTS**



**TABLE 2: PERCENTAGE OF FORUMS WITH FOLLOWING KEY CONTACTS**

	2011	2012	2014
LINKs	13	14	
Commissioner	54	47	57
Specialist lead clinician	40	36	43
NHS manager	37	21	22
PALS	5	3	3
GP/GP practice manager	5	3	10
Other		10	14
Healthwatch			39
Clinical commissioning group			50

In the first two years the forums reported their key contacts as being mainly commissioners, specialist lead clinicians and NHS managers. Half way through the project there appeared to be a small decrease in the percentage of forums involved with commissioners, specialist lead clinicians and NHS managers to the first year. This could be due to the massive changes taking place in the NHS taking up people's time.

The final survey indicates that more parent carer forums have key contacts with commissioners and specialist clinicians than at the start of the project. Many of them are also finding their local Healthwatch and clinical commissioning groups acting as key contacts in supporting their work.

Parent carer forums mentioned other key contacts including joint commissioners, modern matrons, the local authority Overview and Scrutiny Committee, Child and Adolescent Mental Health Service, Patient's Congress and the Care Quality Commission.

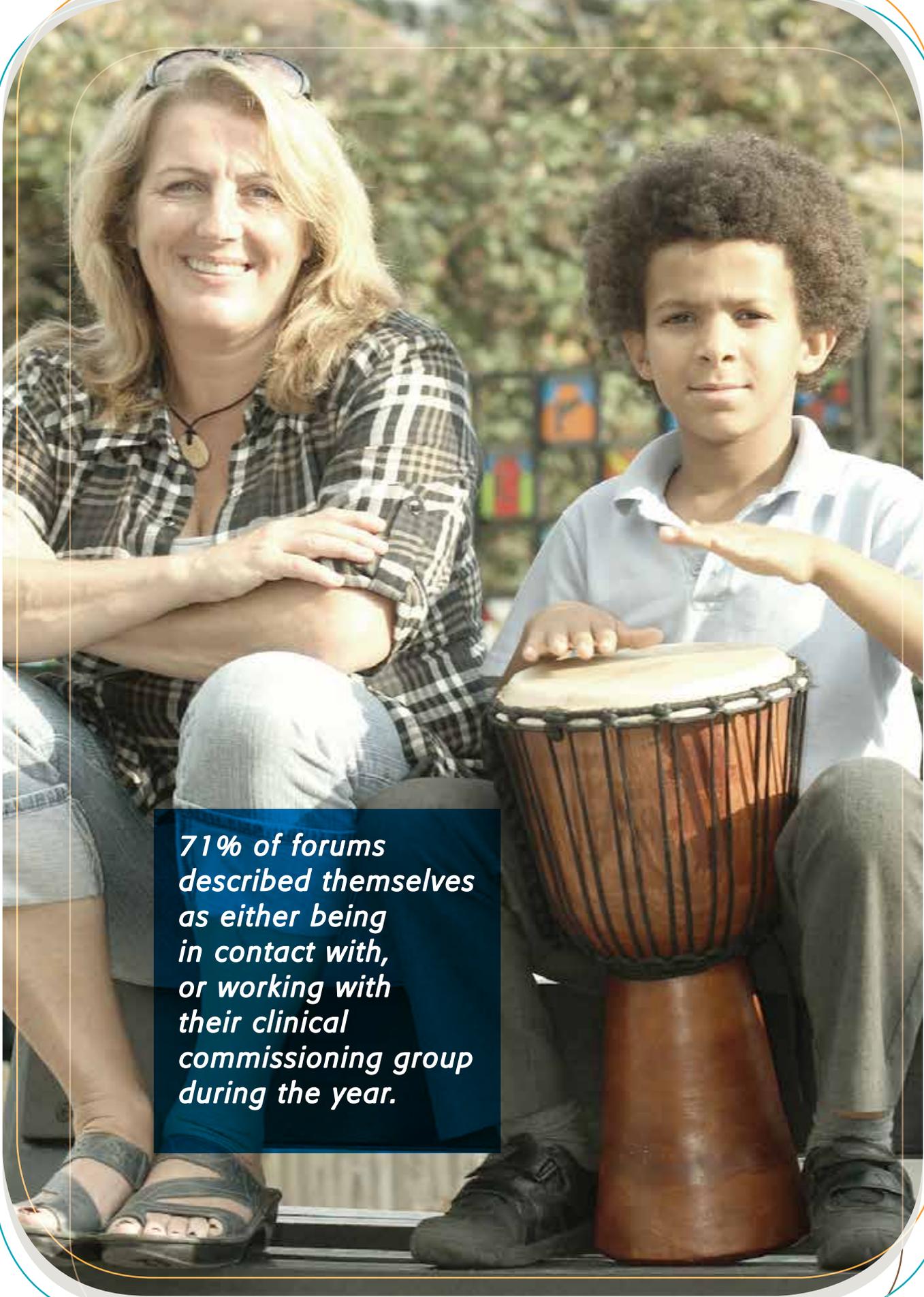
However, some parent carer forums report that they are still finding it difficult to make contact and work with health.

“Despite trying repeatedly, health still continues to avoid any engagement with the parent forum. It is virtually impossible to find the person you need to contact as no one will take responsibility and the people within the CCG and our provider arm do not seem to know either!”

“This is one area that is a real struggle to even get near to and feel there needs to be a lot more work to be done.”

“In general, health seem to make the right noises, agree that parent participation is important, but due to their long standing culture it will take a very long time, and a huge mind set shift to break them out of their current ways of working. Not sure they really understand how to work from a co-production perspective and are not really fully onboard with the benefits as a result.”

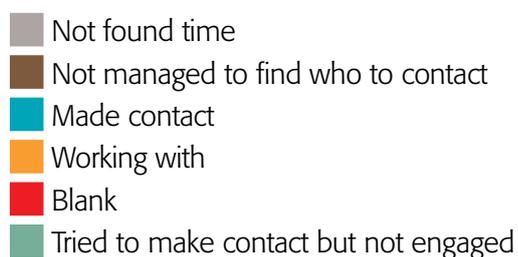
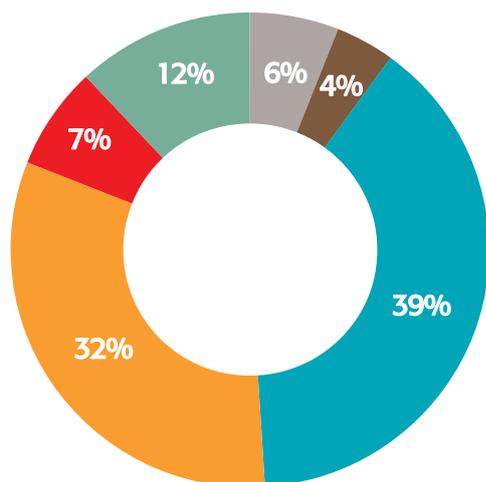
“We have had meetings with consultants, CCG commissioners, Occupational Therapy service, learning disability nurse and talked about health with local authority officers who are on the health and wellbeing board. We would not call this partnership working – just rather frustrating meetings.”



*71% of forums described themselves as either being in contact with, or working with their clinical commissioning group during the year.*

## 6 Clinical commissioning groups

**CHART 3: HAS YOUR FORUM MADE CONTACT WITH YOUR LOCAL CLINICAL COMMISSIONING GROUP?**



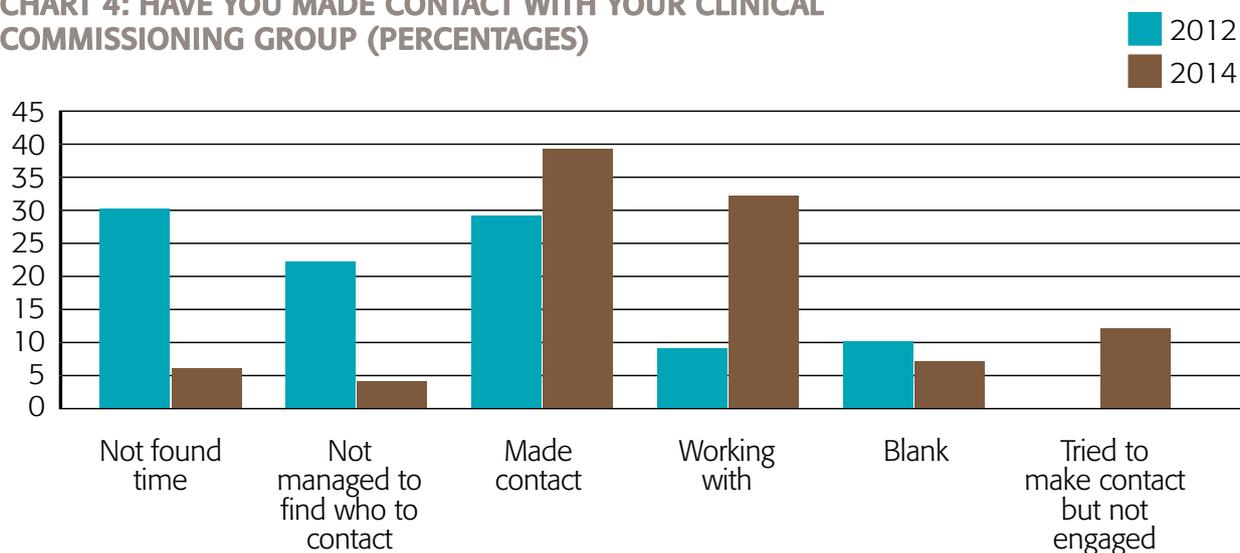
**93%** of forums responding were aware of the role of clinical commissioning groups.

In the final year survey survey we added an additional option for this question of 'tried to make contact but could not get them to engage' in response to feedback from some forums.

Seventy four (71%) forums described themselves as either being in contact with, or working with their clinical commissioning group during the year. 16% of forums had tried making contact and not been successful in getting a response or were struggling to find who to contact.

**TABLE 3: HAS YOUR FORUM MADE CONTACT WITH YOUR LOCAL CLINICAL COMMISSIONING GROUP?**

	Number	Percentage
Not found time	6	6
Not managed to find who to contact	4	4
Made contact	41	39
Working with	34	32
Blank	7	7
Tried to make contact but not engaged	13	12

**CHART 4: HAVE YOU MADE CONTACT WITH YOUR CLINICAL COMMISSIONING GROUP (PERCENTAGES)****TABLE 4: HAVE YOU MADE CONTACT WITH YOUR CLINICAL COMMISSIONING GROUP (PERCENTAGES)**

	2012	2014
Not found time	30	6
Not managed to find who to contact	22	4
Made contact	29	39
Working with	9	32
Blank	10	7
Tried to make contact but not engaged	N/A	12

More forums had found time to try to work with their CCG this year compared to the previous year. This is encouraging considering more forums have been involved in the SEN pathfinder work this year.

71% of forums were either in contact with or working with their CCG compared to 38% in the previous year. An improvement in this year's survey would be expected as clinical commissioning groups were still in shadow form and many were still being authorised.

## How parent carer forums are working with CCGs

Some forums describe themselves as only just having made contact and begun to work with their CCG.

“ We have made some contact with our CCG including joining a Patient Advisory group. As yet we have still to meet them in a meaningful way. However, they have been welcoming. ”

*Bromley*

“ Initiated contact with a presentation to CCG and due to start regular joint meetings with CCG and local authority. ”

*Hackney*

“ We are aware of them, share info with them and they have in the last month started to communicate with us. It's early days as yet but looks promising. ”

*Leeds*

“ 1) We have started to attend our local Patient, User, Carer, Public Involvement group which feeds into the CCG. I recently gave a presentation on the work of parent carer forums and what as a parent carer forum we do. We will continue to attend this on a monthly basis. 2) I have recently met with the joint commissioning manager for the CCG linked to the pathfinder and we will be doing further work together when she needs to consult with parents. She also attends the Pathfinder Project Board which I also attend. ”

*Gateshead*

In some areas the CCG have sent their own staff to attend forums meetings or consult with the parent forums steering group to understand what their issues are.

“ We also now have support at our steering group from our local patient experience officer from the clinical commissioning group. He attends steering group meetings and takes issues forward to the CCG on behalf of the forum. ”

*Blackburn with Darwen*

“ A rep from the Dorset CCG was invited and came along to our consultation coffee morning in Nov 2013. She explained the role of the CCG to parents, listened to general views and stayed for the slots on Child and Adolescent Mental Health Service (CAMHS) and Speech and Language therapy (SALT). We also gave her a list of the main areas for concern by parents in health: CAMHS, SALT, specialist dentistry, disabled children in A&E and on the wards (staff have insufficient expertise). ”

*Dorset*

“ We meet with the children's lead of the CCG every three months to discuss concerns. ”

*Hammersmith & Fulham*

In some areas the CCGs are appreciating how forums can assist their commissioning work by feeding in to them parents' experiences of services and raising awareness of disability issues. Some CCGs are funding parent carer forums to consult with parents on their behalf.

“The CCG body has been very understanding of the need now to fully consult public bodies, and find our forum a good way of accessing parent involvement, obtaining two way discussion and communication.”

*Torbay*

“We have built very good relationships with our CCG – we have been included on stakeholder forums that were developing a consultation for the future of children’s services.”

*Bedford*

“We are supplying the CCG with personal stories which are used during the health and wellbeing board meetings, and will hopefully keep the experience of families with disabled children at the top of the agenda.”

*Bolton*

“We are working with the CCG by delivering training to them. This raises their awareness of disabled children and their families and also ensures they know where to refer families to for other support.”

*Kensington and Chelsea*

“We now have funding arrangements with the CCG to deliver consultations to improve health services. To date this has included consultations on wheelchair services and the continence service. We held a focus group to support the commissioning process for Tier 2 CAMHS services, and are also working with the health trust which is new provider of Tier 3 CAMHS services to develop a service improvement plan.”

*Calderdale*

“We are also commissioned as an engagement gateway’ to provide direct parent carers’ input and views about the development and delivery of health services.”

*Brighton*



## Challenges to engagement

Some forums are finding it difficult to get their CCG to engage or are finding that the only way to engage with the CCG is through attending large public meetings where it is impossible for them to raise the issues they are concerned about. Others are finding the CCG will not talk directly to them but only through Healthwatch.

“ We have only been to public meeting no other engagement. ”

“ The CCG will not work directly with us. It works with Healthwatch and we will have to go through them. We have tried to make connection with Healthwatch. We are continuing our efforts. ”

“ We have made contact and they are aware of the forum. However nothing has materialised from this which is disappointing. ”

Parent carer forum capacity can also be an issue, especially where one parent carer forum has more than one clinical commissioning group to build links with. Forums also report some CCGs appearing stretched with their capacity.

“ Through reform work streams we have recently made contact and are pursuing this but there are five with responsibilities across county and not in touch with all yet. ”

“ Working with some CCGs in Essex but others not as much or not at all. We need more funds, people and support to engage effectively with right people in right places. ”

“ Local CCG started in March 2013 and we saw staff changes in September 2013. Whilst they appear happy to engage with us they have been somewhat stretched. ”



Parent carer forums frequently mention the problems of meetings being called at short notice and being held at time they cannot attend.

“ CCGs are also still arranging meetings at times that make it difficult for parents to attend or not giving people enough notice of meetings. ”

“ Chair attends Patient Summits but not always able to attend as events sometimes not at suitable times as she needs to return home to await son’s school transport. ”

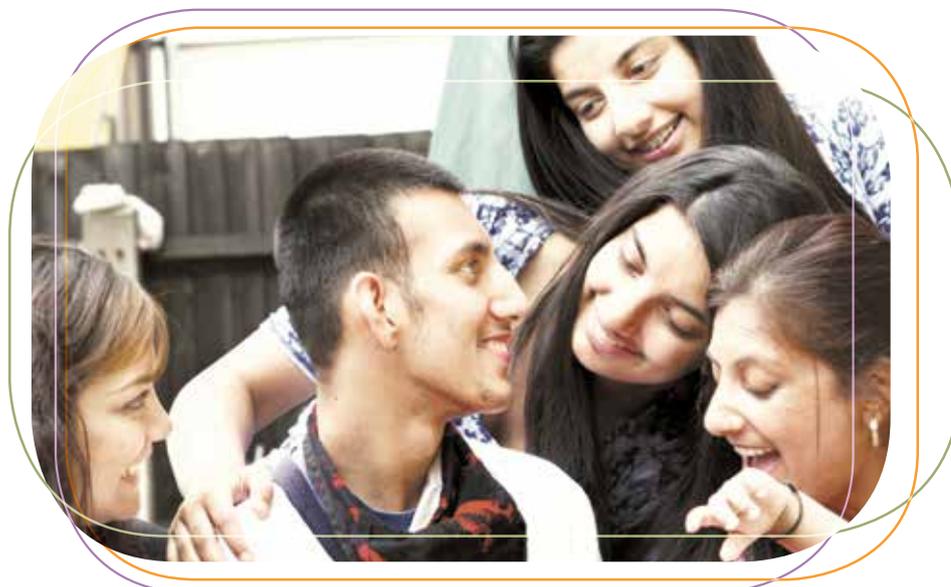
“ Chair has attended some meetings, been involved in workshops and discussions. Some meetings are called at short notice, some are cancelled at short notice, and although meetings are arranged at different times of the day (morning, afternoon, evening) some are run at times when parent carers are not available to attend. ”

Other forums spoke of clinical commissioning groups being willing to consult on their priorities, but were less willing to engage on topics which the forums wanted to prioritise.

“ We are thankful to have been included in certain areas by one commissioner already named. In all other areas where the CCG are working with Healthwatch we have been ignored, or excluded. ”

“ Our commissioner has invited us to participate to provide feedback in two of their projects which was useful and present to the CCG. However, not received any feedback and was hoping to get another invite to follow up on the work re the SEN reforms but feel I will have to contact them again and remind them. ”

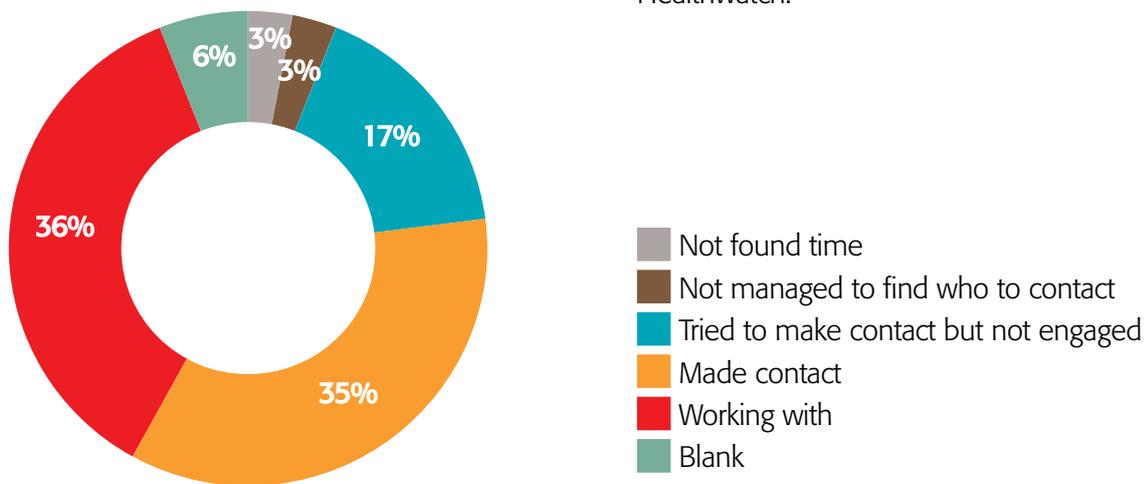
“ Our commissioner within the CCG has been helpful and informative but parents still feel that there are lots of problems in lots of areas, these are difficult to engage with. ”



## 7 Healthwatch

Parent carer forums were asked if they knew about their local Healthwatch, and to describe their forum's relationship with them.

**CHART 5: HAS YOUR FORUM MADE CONTACT WITH YOUR LOCAL HEALTHWATCH?**



**95%** of forums responding said they knew about their local Healthwatch, which shows the project was successful in keeping parent forums informed about the changes to the NHS and Healthwatch. 75% described themselves as being in contact with or working with their local Healthwatch.

**TABLE 5: HAS YOUR FORUM MADE CONTACT WITH YOUR LOCAL HEALTHWATCH?**

	Number	Percentage
Not found time	3	3
Not managed to find who to contact	3	3
Tried to make contact but not engaged	18	17
Made contact	37	35
Working with	38	36
Blank	6	6

However, 20% said they had tried to make contact but not been successful in getting Healthwatch to engage with them or not managed to find who to contact.

“ We have tried to make connection with Healthwatch. We are continuing our efforts. ”

“ So far there has been no engagement. We wrote to them to complain about some commissioning problems (incontinence pads, body supports) but we received no response. ”

“ We sent emails to Healthwatch but not had any reply to date. Not had any invites to meeting etc either. ”

“ We have been contacted by Healthwatch. They requested a meeting which we tried to arrange but there has not been a date set as they have not replied to us. ”

“ I had made contact before and they seemed disorganised, and I am still waiting for them to register the forum’s interest or make any contact. ”

Many forums said they had made contact with Healthwatch but it was early days, with their Healthwatch only just getting started.

“ Healthwatch is still in its infancy therefore they are not aware of many of the issues that our children/young people have. ”

“ The board of directors are still settling in after having to set up the company from scratch. They are finding their feet slowly as they recruit new members of staff to engage with the community. ”

“ Our Healthwatch group is still finding its feet following the transfer from LINKs. Whilst we have a parent representative who is heavily involved in Healthwatch, there has been little of particular relevance to disabled children so far. ”

## How parent carer forums are working with Healthwatch

Like clinical commissioning group, local Healthwatch differ in how they approach public and patient engagement.

Some Healthwatch are coming to meet forum meetings to consult with parents.

Some Healthwatch have champions who find out about the views of local patient groups and feed these into Healthwatch. A few forums had parent members who have become Healthwatch champions. This can be a useful way for parent carer forums to link with Healthwatch without having to attend all their meetings, which parents probably would not the capacity to take on.

“ Healthwatch regularly attend our forum and we have had several consultations with them at our offices. We were recently involved in feeding into the local account regarding transition into adult services. ”

*Knowsley*

“ Our contact at Healthwatch has been pro-active in engaging with parents and with the forum. ”

*Warwickshire*

“ We had a good working relationship with LINKs and have continued this with Healthwatch – our local rep regularly attends our consultation coffee mornings and our annual March event for all local parents. She helps by updating parents on changes and developments in the NHS and also takes parents` views to the local board and other relevant meetings. ”

*Poole*

“ Two of our members are Healthwatch champions, we also have two other parent reps for two other areas of Staffordshire. ”

*Staffordshire*

“ It is early days. We are keen to use Healthwatch as much as possible and we are Healthwatch champions. ”

*South Gloucestershire*

Other forums reported building a relationship with Healthwatch by attending their events, and inviting Healthwatch back to their events and helping with consultations.

In Peterborough the chair of the parent carer forum is also a director of Healthwatch. This has led to closer working between the two organisations. A few parents from the forum were trained by Healthwatch to inspect the children's ward at local hospitals during enter and view' inspections. Healthwatch have also asked the parent carer forum to provide parent representatives to sit on the local hospital's children's board. However, most parents carers involved in running a forum are not going to have the capacity to also take on an active role with Healthwatch.

“Very good proactive engagement-working in partnership. Healthwatch rep in all meetings. ICASS work jointly with us and has attended meetings and events.”

*Cheshire East and Chester*

“Healthwatch regularly attend our forum and we have had several consultations with them at our offices. We were recently involved in feeding into the local account regarding transition into adult services.”

*Knowsley*

“We have worked with Healthwatch, keeping each other updated with what we're doing, attending each other's events and meetings. Healthwatch and the CCG asked us to consult with parents on a proposal to change the out-of-hours service, which we did and were able to feedback responses. We are taking part in a consultation on intermediate care beds for Healthwatch. We have attended the Healthwatch Members forum. After all the work that we have done together this year, the chair of Healthwatch has now said that he wants to become formal partners of our forum.”

*Bolton*

“We have had four of the parent representatives take part in Healthwatch Peterborough training sessions and go forward to take part in enter and view work. We have been asked to look at the Emotional Health and Well being Strategy and consult on this with the wider forum. We have a seat via Healthwatch on the local hospital's children's board which we are to become involved with.”

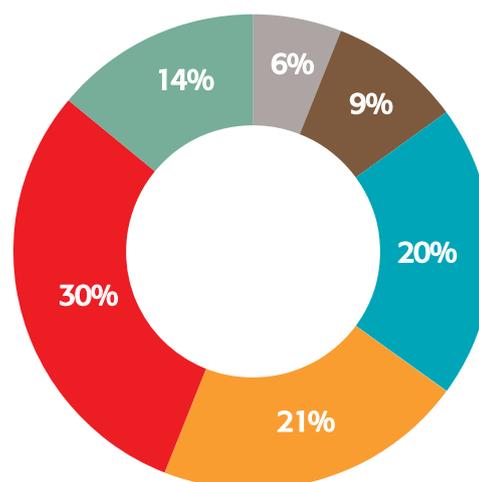
*Peterborough*

## Forums' confidence in Healthwatch

Parent carer forums were asked about how confident they were that Healthwatch would approach them to find out about parents' experiences of services for disabled children and how helpful they might be in influencing services for disabled children.



**CHART 6: HOW CONFIDENT ARE YOU THAT HEALTHWATCH WOULD APPROACH YOUR FORUM, IF THEY WANTED TO FIND OUT ABOUT PARENTS EXPERIENCES OF SERVICES FOR DISABLED CHILDREN?**

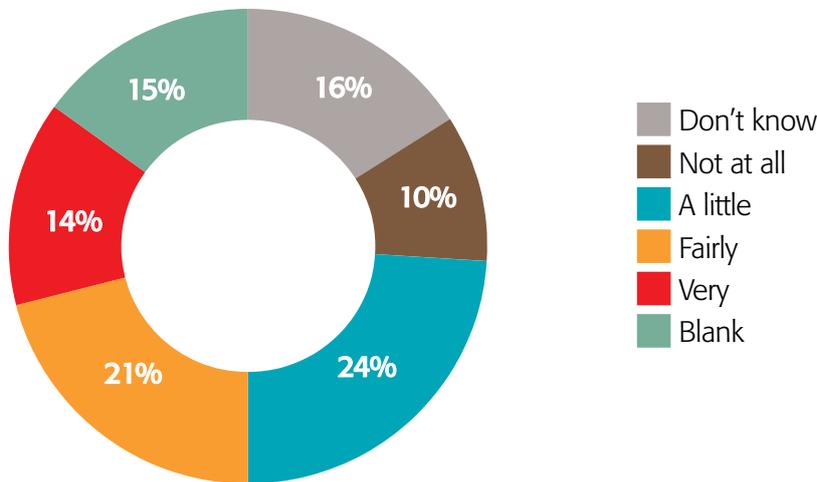


**TABLE 6 : HOW CONFIDENT ARE YOU THAT HEALTHWATCH WOULD APPROACH YOUR FORUM, IF THEY WANTED TO FIND OUT ABOUT PARENTS EXPERIENCES OF SERVICES FOR DISABLED CHILDREN?**

	Number	Percentage
Don't Know	6	6
Most unlikely	10	9
Possibly	21	20
Probably	22	21
Definitely	31	30
Blank	15	14

Although 71% of forums described themselves as having made contact with or working with their local Healthwatch, only 51% thought that Healthwatch were likely to approach them if they wanted to find out about parents experiences of services for disabled children.

**CHART 7: HOW CONFIDENT ARE YOU THAT HEALTHWATCH WILL BE HELPFUL IN INFLUENCING SERVICES FOR DISABLED CHILDREN?**



**TABLE 7: HOW CONFIDENT ARE YOU THAT HEALTHWATCH WILL BE HELPFUL IN INFLUENCING SERVICES FOR DISABLED CHILDREN?**

	Number	Percentage
Don't know	17	16
Not at all	10	10
A little	25	24
Fairly	22	21
Very	15	14
Blank	16	15

Only 35% of parent carer forums said they were fairly or very confident that Healthwatch would be helpful in improving services for disabled children.

This suggests a significant number of parent carer forums who have made contact with their local Healthwatch are not being able to build a relationship with them, or feel confident that Healthwatch will be able to support their work.

Many parent carer forums mentioned their local Healthwatch appeared to lack capacity for the huge task they have, which includes representing the views of the whole community.

“ I think there is a huge amount of work for Healthwatch to do. ”

“ Our Healthwatch seem to be struggling capacity wise. -They have not got enough volunteers. ”

“ Although we have had some contact they seem to be fairly sparse at the moment. ”

“ Get the impression that they are very overworked and under resourced. ”

“ They have promised to do more when they recruit more volunteers as at present they only have two staff. ”

Parent carer forums also reported struggling to get Healthwatch to understand the role of the forums, and how local community groups including parent carer forums could be useful in feeding in the views of targeted groups.

“ They launched in October. Good launch event - however, when I approached their info stand they asked me if I would like to volunteer for them!! ”

“ I feel that there is some way to go in establishing robust partnerships and that locally our Healthwatch service needs to be more proactive in getting out to; and understanding the role of groups including the parent forum and the value that we can bring to the work they undertake. ”

“ Whilst they are a new body, and I myself am an ambassador for them there is little or no contact with us or discussion with us. It is very much a case of them collecting individual patient comments/experiences. ”



Other parent carer forums reported that Healthwatch had other priorities and disabled children were unlikely to be on their agenda. It could be that the local authority will influence what Healthwatch prioritise as they fund them.

Forums were more likely to be confident in Healthwatch if a member of the forums was also actively involved in running Healthwatch or people working for Healthwatch were familiar with disability.

“ Have dementia, diabetes, obesity, and smoking on their agenda. Disabled children and carers didn’t feature unless we knew of parent carers who also cared for someone with dementia. Didn’t fill me with confidence. ”

“ Our local Healthwatch is very friendly and some staff are parent carers themselves with good understanding of the issues the forum is taking forward. ”  
*Reading*

“ Contact so far has led us to feel that they are most concerned with care for adults/elderly and their carer’s issues. ”

“ I am a board of director for Healthwatch. So I’m to be fully involved in sharing information. ”  
*North Lincolnshire*

“ They seem very busy and I’m not sure services for disabled children are top of mind, seems they have other challenges around care for the elderly etc. ”

“ It is still early days, but we are in contact with the chair of Healthwatch, who is always ready to listen. We have a forum member sitting on the board, so we know our views are always represented. ”  
*Worcestershire*

“ Disabilities will be on the agenda for our local Healthwatch as the management committee consists of leads for carers and young carers so we know it will always be mentioned. ”  
*Stockton*

There are concerns that some local Healthwatch appear to be selective in which organisations they will work with which is of concern, as they are meant to represent the voice of the whole community.

**“ We have been given the impression they don’t need to contact us and can go elsewhere for feedback on services our children use. ”**

**“ On asking the question of who our lead contact is in Healthwatch we were told there wasn’t one!! ”**

It is inevitable that parent carer forums experience of Healthwatch is variable.

Local Healthwatch have been set up with different legal and organisational structures, have to rely on volunteers for much of their work and are at different stages of their development. This is also true for parent carer forums, some of whom have been running for years and been actively involved in working with key strategic leads to improve services, whereas others are less developed, with their main activity being feeding into consultations.

It remains to be seen what impact organisational structure and capacity has on how effectively local Healthwatch operate.

The forum in Herefordshire was confident in their Healthwatch because a local carer support organisation, which they had strong links with, were also involved in the operation of Healthwatch. This meant it has been relatively easy for the parent carer forum to get the implementation of the Children and Families Act 2014 and disabled children put on the agenda for the health and wellbeing board through Healthwatch.

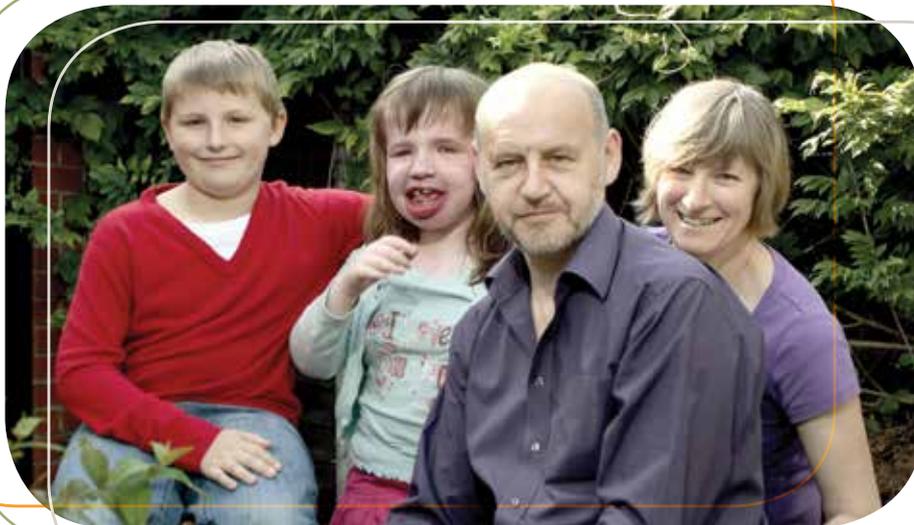
## Working with Healthwatch and influencing the health and wellbeing board

Herefordshire Voluntary Organisations Support Service and Herefordshire Carers Support were successful in a joint bid to run Healthwatch in Herefordshire. Working together in this type of partnership has helped Healthwatch build links with both local voluntary groups and people with long term conditions and their carers.

Herefordshire Carers Support provides support to Parent Carer Voice, the forum in Herefordshire for parents of disabled children. This relationship gives an easy route to parent

carers to take part in the enter and view/ programme that is run by Healthwatch which includes visits to the local hospital.

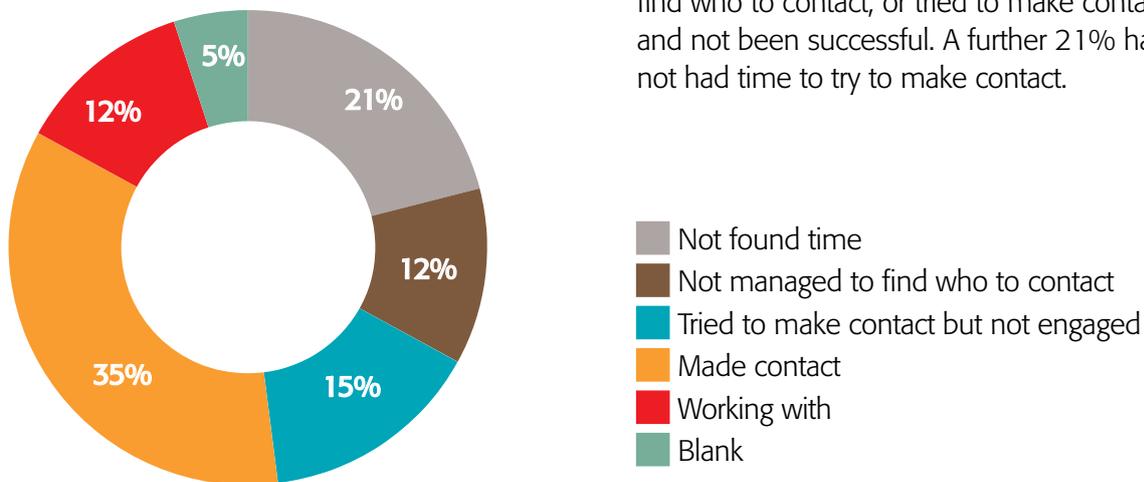
Healthwatch has put the implementation of the Children and Families Act 2014 on its agenda, recognising its role in making sure services are integrated between health and the local authority. They will also be encouraging the health and wellbeing board to sign up to Every Disabled Child Matters charter for health and wellbeing boards.



## 8 Health and wellbeing boards

**85%** of parent carer forums knew about the health and wellbeing board's role.

**CHART 8: HAS YOUR FORUM MADE CONTACT WITH YOUR LOCAL HEALTH AND WELLBEING BOARD?**



**47%** of forums responding had made contact with their health and wellbeing board but only 12% described themselves as working with them. This is an increase compared to the previous year when only 3% described themselves as working with them.

**27%** of forums had either not been able to find who to contact, or tried to make contact and not been successful. A further 21% had not had time to try to make contact.

**TABLE 8: HAS YOUR FORUM MADE CONTACT WITH YOUR LOCAL HEALTH AND WELLBEING BOARD?**

	Number	Percentage
Not found time	22	21
Not managed to find who to contact	13	12
Tried to make contact but not engaged	16	15
Made contact	37	35
Working with	12	12
Blank	5	5

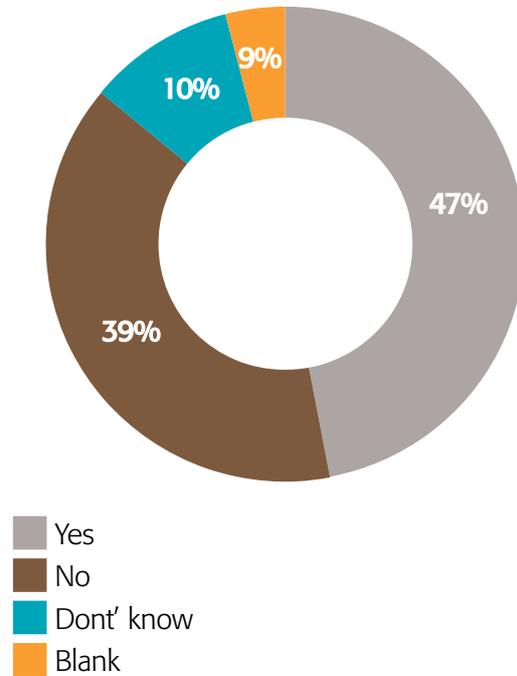
The health and wellbeing board is a high level strategic body with responsibility for the services for the local community with many different committees and working groups reporting into it. One would not expect representatives from parent carer forums to have a position on this board, or for the health and wellbeing board to necessarily be in direct communication with the forum.

Most parent carer forums have parent representatives sitting on steering groups which are likely to be feeding into the work of the health and wellbeing board. Forums also work with strategic leads who have position on the health and wellbeing boards.

Forums were asked whether they thought their work was feeding into the health and wellbeing board and which strategic leads they were in contact with who are represented on the health and wellbeing board. This included the director of children’s service, director of adult social services, an elected member, their clinical commissioning group and a public health lead.

**47%** of forums said they were feeding into the work of their local health and wellbeing board and a further 10% were not sure. This could be because they are represented on committees and working groups but are not clear about how these feed into the work of the health and wellbeing board.

**CHART 9: DOES YOUR FORUM FEED INTO THE WORK OF THE HEALTH AND WELLBEING BOARD?**



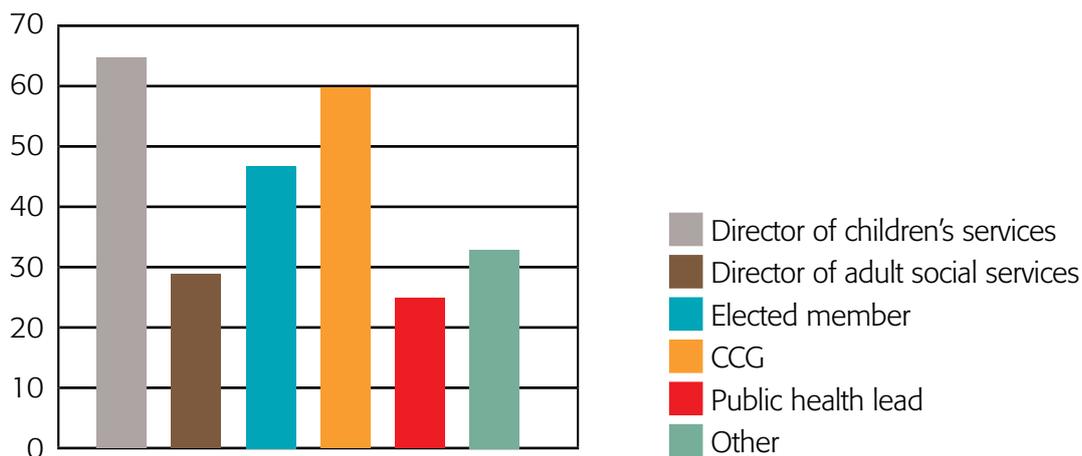
**TABLE 9: DOES YOUR FORUM FEED INTO THE WORK OF THE HEALTH AND WELLBEING BOARD?**

	Number	Percentage
Yes	49	47
No	41	39
Don't know	11	10
Blank	4	4

## Forums contact with people who can influence the health and wellbeing board

The forums were asked about their contact with people who can influence the health and wellbeing board, namely director of children's service, director of adult social services, elected member, clinical commissioning group and public health leads

**CHART 10: PERCENTAGE OF FORUMS HAVING A WORKING RELATIONSHIP WITH STRATEGIC LEADS,**



**85%** of forums responding reported being in contact with either the director of children's service, director of adult service, an elected member, their clinical commissioning group or a public health lead. 65% of the forums had contact with their director of children's services. Nearly as many forums (60%) had a contact in their CCG which is extremely promising.

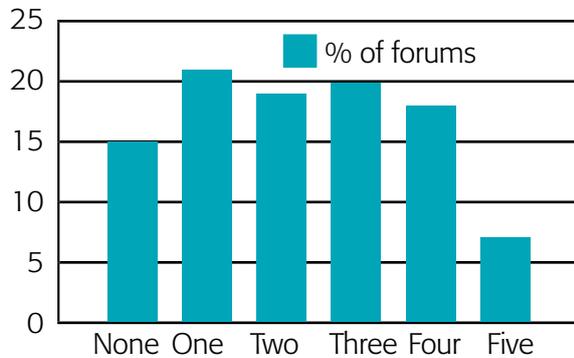
**TABLE 10: NUMBER OF FORUMS HAVING A WORKING RELATIONSHIP WITH STRATEGIC LEADS**

	Number	Percentage
Director of children's services	68	65
Director of adult social services	30	29
Elected member	49	47
CCG	63	60
Public health lead	26	25
Other	34	32

When forums were developed in 2011 it was to support the implementation of short breaks provided by children's services. It is to be expected that many forums would have a relationship with the director of children services from this. By comparison clinical commissioning groups have been operational for less than a year.

It was also indicative of the extent of forums' influence that many of them had contacts with more than one of these service leads.

**CHART 11: NUMBER OF STRATEGIC LEADS FORUMS IN CONTACT WITH**



**TABLE 11: NUMBER OF STRATEGIC LEADS FORUMS IN CONTACT WITH**

	Number	Percentage
None	16	15
One	22	21
Two	20	19
Three	21	20
Four	19	18
Five	7	7

**45%** of forums had contact with three or more of these strategic leads. This not only affects their ability to influence. Many forums find having the support of a strategic lead extremely helpful in getting their voice heard and affecting change. However, if the forums are very dependent on one lead, it can be difficult if that person leaves as they have to start afresh in building a relationship with the successor who might not be so supportive. Having leads in more than one service is good for the long term sustainability of the forum.

Many forums also mentioned that having a lead joint commissioner for children helped them in being able to influence the health and wellbeing board, as well as help them make contact with people if there were concerns about a service.



## 9 Children and Families Act 2014

Since September 2011, parent carer forums in 31 local authorities in England have been involved in pathfinder pilots for proposed changes to the special educational needs (SEN) legal framework. This includes a new single planning process to be carried out by health, education and social care. The planned date for implementation of the legislation is expected to be September 2014.

In the last year many more forums have become involved in the implementation of the reforms to SEN provision outlined in the Children and Families Act 2014 in their area. This has taken up considerable amounts of parent carer forum time and some have struggled to find parent carers to take on the additional activity and representation required by this.

There is a requirement to jointly commission services for disabled children and children with SEN with the implementation of the single planning process and access to individual budgets to provide an integrated service to families. It is imperative that health and wellbeing boards take responsibility to make sure plans for the implementation are underway. There is a requirement for health to be engaged with this process as well as parent carer forums.

Healthwatch has a representative on the health and wellbeing board to represent people living within the area. It is clear that many forums have been unable to build links with their local Healthwatch and it is unlikely that Healthwatch will be proactive in raising disabled children with the health and wellbeing board in these areas.

A comment that has come up frequently from forums involved in implementation of the SEND reforms relates to how hard it is to get health around the table to discuss the SEND reforms.

“ If Health do turn up, they appear to be unaware of their role in what they need to do, that is, joint commissioning of services, or they just don't contribute to discussions. Health appear to be drifting along without commitment. ”

“ They never attend meetings where they should have representation and have also been absent from the workshops provided by the SEND pathfinders. ”

“ the CCG seem to have little knowledge and acceptance that new services and providers need to be up to speed and take on board the SEND reforms and impact of personal budgets and education, health and care plans. ”

“ It has become clear that our local NHS organisations assume the local offer to be entirely within the local authority remit and they will let us know when it's ready. ”

“ Currently the forum is not working with any health partners with regard to the pending Children and Families Act 2014. ”

On a more positive note, other forums have made contact with their clinical commissioning group through their involvement with changes to SEN being implemented as part of the Children and Families Act 2014. They hope this work will help clinical commissioning groups start to develop a better understanding of how parents can get involved, not only through consultation but much more actively engaged working as co-partners.

“ We have met with the head of patient and public engagement, representing the CCG, and are increasingly coming into contact with CCG members at our local SEND Programme Board and Carers’ Strategy Task and Finish Group meetings. ”

*Southwark*

“ The pan-Dorset group, which is managing parent participation in developing the changes for the SEN reforms for September 2014 is chaired by a rep from the CCG and all three local parent carer forums are members – by working with health on this, we are helping to change the culture around parent participation in health, where no structure previously existed. ”

*Dorset*

“ CCG reps now attending our Pathfinder Board meetings. We have recently started working with them on a Partnership Working Group across health, adult services and children’s services looking at transformation for services as a result of the reforms. ”

*Hertfordshire*



You can read more about how parent carer forums have been working with health in our new guide *Sharing good practice: parent participation in health settings*

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



## 10 Conclusion

The project has been successful in keeping parent carer forums informed about the changes that have taken place in how health services are commissioned and supporting their engagement with health. The National Network of Parent Carer Forums (NNPCF) were key to this, by providing a mechanism to communicate with parent carer forums and share good practice.

Forums have taken this opportunity to become more engaged with health and get involved in different ways. Many forums are beginning to work with their clinical commissioning group, including some through the SEN changes being introduced through the Children and Families Act 2014. This includes a new single planning process to be carried out by health, education and social care.

Hopefully from these beginnings, clinical commissioning groups will develop a deeper understanding of how parent carer forums can help them make sure disabled children get the support they need, not only by consulting with them, but also by working with them to bring about improvements to services and make better use of limited resources.

However, there are concerns that health is not engaged enough to be ready for the implementation of SEN reforms being introduced in September 2014 through the Children and Families Act 2014.

Parent carer forums have tried to make contact and work with their local Healthwatch. It is early days but there are concerns about how Healthwatch will deliver on representing the voice of the whole community, including vulnerable groups such as disabled children on the health and wellbeing board. This is a matter of concern as disabled children should be a priority for the health and wellbeing board as they require joined up integrated services across health, education and social care.

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. ”**

The development of parent carer forums across England and their successful work with commissioners and providers of health and social care services provides a model of how we can make these aspirations a reality.

**“ To help make this vision a reality, the Government has committed to strengthening the collective voice of patients, users of care services and the public and ensuring that voice is no longer lost in the system. One of the main ways of achieving this will be through the HealthWatch arrangements. Other ways will be through duties on commissioners and providers of health and social care services to involve and consult patients and the public. ”**

***DH Healthwatch Transition plan***

## 11 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)**



# 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

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