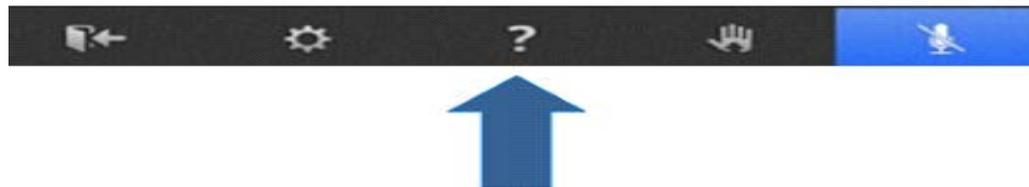


Introduction to Contact a Family webinar Participation and Health - Next Steps

- Welcome to this Contact a Family Webinar for parent carer forums and those who work with them
- This is still relatively new technology for us, so please do bear with us from a technical point of view
- Those of you joining by pc, laptop, tablet or smart phone should now be able to see this introduction slide
- As there are so many attendees with us this afternoon, it is not practical for interaction to be made verbally; therefore you will all remain 'muted' throughout

Timing & Questions

- This session will consist of a slide presentations in two parts. There will be a question and answer session after part 1 and at the end.
- We have scheduled this Webinar for 1 hour however dependent upon the number of questions raised etc. the time may be reduced or increased accordingly
- If at any point during the presentation you have question that you would like to ask, please use the question icon on your GoToWebinar tool bar on your screen
- This will allow you to type your question in to the text box and submit this to the Webinar administrator



Q&A Session

- At the end of the presentation, I will select as many relevant questions to answer as time allows, if similar questions are received I will condense these where possible
- Further relevant questions, not covered in the time allowed, will be answered and posted on the Contact a Family website along with the recording of this Webinar, details of which will be circulated early next week
- Please note that I will only consider questions relevant to forums, unfortunately I am unable to answer case specific queries
- At the end of the Webinar a short questionnaire will launch, please take the time to complete this as this will assist with future online training events

Webinar for parent carer forums Participation and Health - Next Steps

Part 1

- 1) Final Report of project: Parent carer forum involvement in shaping health services** – result of survey and key findings
- 2) Top Tips** for engaging with health
- 3) Next Steps** – plans for next year
- 4) Q&A**

Part 2 (If time)

Sharing good practice: parent participation in health settings –
some ideas to help you to do similar

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www.cafamily.org.uk/parentcarerparticipation

Celebrating Success: Making patient and carer involvement a reality

Event held May 19th to celebrate success of project and launch:

- **[Parent carer forum involvement in shaping health services](#)** – final report of project
- **[Sharing good practice: parent participation in health settings](#)** – examples from across England

Attended by DfE, DH, NHS England, Healthwatch England and parent carer forums who had provided case studies

NHS England want to help us cascade reports to CCG's

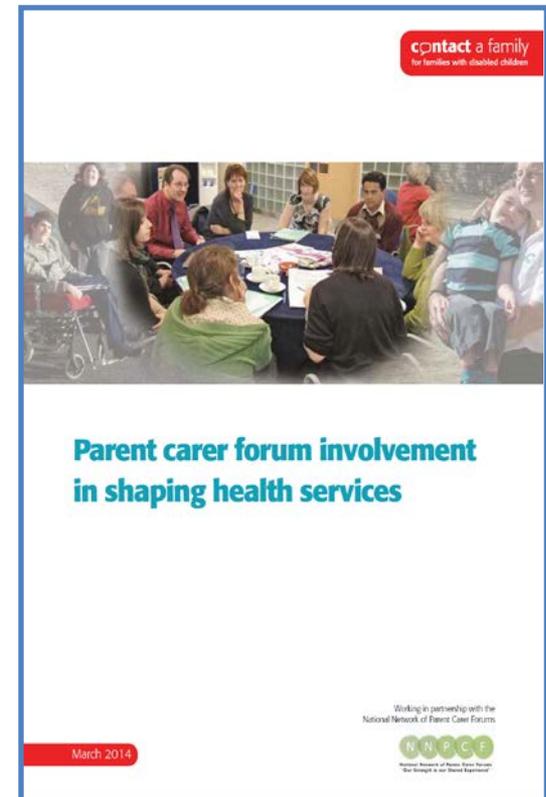
Final report of project

Results - survey of parent carer forums,
January 2014

Printed copies being sent out to all forums

Additional copies available. – email
publications@cafamily.org.uk

Includes key findings and recommendations
section



Download from Contact a Family website at
www.cafamily.org.uk/pcp/resources

Final Report of project

- High response - 105 forums compared to 73 in previous survey – thank you
- **86% per cent of parent carer forums actively involved in health,** compared to 75% in previous survey
- Parent carer forums frequently involved in more than one setting and working with different health leads
- **57% of parent carer forums worked with health commissioners,** compared to 47% in the previous survey
- **43% worked with specialist lead clinicians** compared to 36% in previous survey.

Forums still struggling to get health involved on specific issues

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

Clinical Commissioning groups – what is good

71% described their forum as being in contact with their clinical commissioning group

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

In some areas CCG staff had visited forums to gather patients' feedback

In three areas the CCG is funding the parent carer forum to carry out consultations on their behalf

CCG more likely to be carrying out **consultations** rather than working in partnership through participation or co-production

Remember they only came into operation this year

Clinical Commissioning groups

CCG set up in different ways for involving patient/carers

Some carrying out holding large public meetings where parent carer forums find it difficult to raise issues about specific services

CCG relying on patient participation groups within GP surgeries to feedback their experiences of hospital and community services. This does not provide a ready mechanism for parent carer forums to feed into

CCG happy to consult with parent carer forums about issues CCG's have as a priority, for example out-of-hours services. However, forums find it difficult to get CCGs to engage with them about services parents see as a priority

CCG not understanding about need to hold meetings in parent friendly times (not during school runs)

Healthwatch – what is good

71% of parent carer forums have made contact with Healthwatch

36% of parent carer forums 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

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

Remember many local Healthwatch only became operational **after** April 2013

Healthwatch – what needs addressing

Only 35% were confident Healthwatch would be helpful in improving services for disabled children

Your concerns included Healthwatch:

- having a lack of capacity and huge remit
- not understanding how parent carer forums work
- being focused on certain topics, e.g. adults, obesity, dementia
- being selective to which organisations they will work with

Some Healthwatch willing to work with local organisations to target particular patient groups

Others appear mainly focused on getting individuals to sign up to be volunteers or take part in public consultations

17% of parent carer forums had tried to make contact but not been successful in getting a response, a further 3% could not find who to contact

Influencing the health and wellbeing board

This is a high level strategic body with many different committees and working groups reporting into it

- Only 12% of parent carer forums described themselves as working with them
- **However 85% of forums reported being in contact with a strategic lead** with representation on the health and wellbeing board.
- 45% forums had contact with three or more of these strategic leads

Forums can find having contact with strategic leads helpful in getting their voice heard and affecting change

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

Influencing the health and wellbeing board - what needs addressing

Most parent carer forums have parent representatives sitting on steering groups which 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 it is not clear 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

Of interest

[Code of practice](#) – Designated clinical /medical officer has responsibility for co-ordinating the role of the health body in statutory assessment – *could be useful contact*

[Supporting pupils at school with medical conditions](#) – statutory guidance for governing bodies of maintained schools and proprietors of academies in England – to be implemented from September 2014 *schools not given much time to implement*

End of Project Recommendations

Information to be cascaded to Healthwatch & clinical commissioning groups to help them understand how parent carer forums operate and could support their work

Clinical commissioning groups (CCGs) nominate a lead contact for parent carer forums to liaise with. Also publicise contracts due for renewal the following year, to allow parent carer forums to consult with members to inform new service specifications

Health and wellbeing boards provide information about the sub-committees which feed into their work relating to children's service

Health and wellbeing boards appoint a joint commissioner, to coordinate children services between health, social care and education

Sharing good practice in health settings

To share with clinical commissioning groups and Healthwatch

Shows how forums work and the benefits of working with parent carer forums

Printed versions being sent out to forums

Additional copies available on request-email publications@cafamily.org.uk

Examples from different settings, provided solutions to problems reported by many families

Download electronic version from www.cafamily.org.uk/pcp/health

The image shows the cover of a publication titled "Sharing good practice: parent participation in health settings". The cover features a grid of 12 small images, each with a label: CAMHS, School Nurses, Therapy, Child development team, GP practice, Wheelchairs, Hospital, and Palliative care. The top right corner has the "contact a family" logo. The bottom left corner has a red bar with the date "March 2014". The bottom right corner has the text "Working in partnership with the National Network of Parent Carer Forums" and the "N N P C F" logo.

contact a family
for families with disabled children

Sharing good practice: parent participation in health settings
Improving services for disabled children

March 2014

Working in partnership with the
National Network of Parent Carer Forums

N N P C F
National Network of Parent Carer Forums
Our strength is our diverse experiences

Common themes from different examples :

- **finding solutions involved a dialogue** between **all** the people involved to understand each other's perspective. This included patients/carers, practitioners and commissioners and/or managers
- **authority** - needed someone with sufficient seniority to bring about change
- **monitoring** - solution included parents providing feedback of the new service, to make sure it was working and identify any further refinement needed.

Surveys to provide quantitative evidence of problem, but hearing personal stories is what motivates people to help bring about change

Rutland GP practices – wrote to GP practice managers

Hospitals – Play therapists, children's service manager, senior nurses, matrons, hospital governors

Leeds Support on sleep, behaviour e.t.c – good relationship with lead community paediatrician and head of community services

Kirklees CAMHS – commissioner for service approached them

Redbridge and Hampshire Coordinating & integrating services – overview & scrutiny committee – can bring different services together needed to consult members and gather evidence to approach them

Hull, Cornwall – good relationship with PCT, now clinical commissioning group

Forums find joint commissioners for children and young people helpful in linking with the right people. CCG's now appointing children and young people leads. Ask your key contacts for help in reaching others.

Top Tips – why it makes sense

Key messages to give to commissioners and providers

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
- Less complaints, practitioners happier when providing a good service which is good for staff retention
- Commissioners and managers know they are spending money wisely

Top Tips – use opportunities

Build relationships and get known

Disabled children are your priority but other organisations can have different priorities that are just as important to them

CCG's and Healthwatch might want to consult with parents on what they see as a priority e.g. out of hours service

If you give them opportunity to discuss this with parents for half an hour, they will be finding out more about your forum

This also provides opportunity to hear about the problems happening elsewhere.e.g. difficulty waiting, doctors not understanding child's condition is problem experienced in out of hours clinic , GP service and hospital

If you help them with their priority – it can lead to them helping you with yours

Plans for next year

NHS England want to see end of project reports and examples from health settings embedded in the system

NHS England want to work with us to help cascade information and help parent carer forums link with clinical commissioning groups

NNPCF to link with NHS England regional clinical strategic networks.

We hope to invite CCGs leads to 'Working together workshops' across England with parent carer forums and local authority leads

Following event we hope Healthwatch England will help cascade to local Healthwatch

Plans for next year

Think about your priorities, perhaps make use of one of the *Sharing good practice in health settings* examples to persuade people in your area to do similar

Please feel free to telephone or email me if you want information or advice

Thank you again for doing a brilliant job - please keep me in the loop



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Questions & Answers



Examples – this might help

GP Practices - see Rutland

At present GP practices are being encouraged to provide support for carers and register carers with their practice

GP practices often do not know which children registered with them are disabled

In Rutland the GP practice managers found the forum could help them by telling their members to identify themselves as carers

Dialogue also led to better understanding by GP practice staff in supporting disabled children's needs when visiting surgery

Try to get invited to meetings which many GP practice managers attend or invite all GP practice managers to attend one meeting

NB It is extremely difficult to get GP's to meetings, as if they miss a surgery they have to pay a locum to cover them

Hospitals – Birmingham, Manchester and Bristol case studies

Many hospitals have not got processes in place, families report dreadful experiences

Large teaching hospital more likely to have processes in place than local district hospitals

The resources developed in Manchester, Birmingham and the electronic hospital passport from Bristol could be adapted for use in other hospitals

Download resources from www.cafamily.org.uk/pcp/health

Getting staff to use them can be challenging, needs senior management buy in, hearing about families bad experiences helps motivate people to change

Examples – this might help

Sleep, behaviour, toilet training, feeding - see Leeds example

- These are common issues and many parents receive little or no advice on this. Promoting self help and supporting carer key part of NHS strategy.
- Most GP's not aware that once diagnosed children with autism/LD are discharged from child development teams
 -
 - Many child development teams only see children up to age of 5, but these can become problem area for families when their children are older.
- Some areas have behaviour support teams, sleep services, voluntary groups providing training to parents – *might be useful to map across region*

Useful lever: Recent [NICE guidelines for managing children and young people on the autism spectrum](#) says that everyone involved in the care of the child should be trained in 'positive behaviour strategies' and that families should be helped with managing sleep problems'

Examples – this might help

Child & Adolescent Mental Health Services (CAMHS) - Kirklees:

- Child & Adolescent Mental Health Services recently received a lot of adverse publicity
- Families with disabled children referred to CAMHS, are being turned away as their children are not 'bad' enough
- Those who get seen can find service not knowledgeable about supporting disabled children
- Preferred direction of travel for the NHS is to provide support in the community, and reduce the number of people referred to hospital services

Kirklees example fits in with this direction of travel, by providing more 'preventative' support 'to school staff and parents

Examples – this might help

Developing coordinated & integrated services Hampshire, Redbridge, Cornwall

- There is a desire to do this, but people often struggle to know where to begin
- Redbridge and Hampshire, gathered evidence of the problem and approached the local authority overview & scrutiny committee
- The overview & scrutiny committee set up a project board and invited the forum to have representation on it
- The project boards looked at how other areas commissioned their services
- Cornwall is a long established forum with years of working with the PCT. This led to them being funded to lead on developing a palliative care strategy.

These examples took years and required patience

Thank You



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