



National Network of Parent Carer Forums
'Our Strength is our Shared Experience'

contact a family
for families with disabled children



Findings from Parent Carer Forums in pathfinder areas

A report commissioned by The National Network of Parent Carer Forums and Contact a Family

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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.

The National Network of Parent Carer Forums (NNPCF) is a parent carer led organisation, whose membership is made up of all of the Parent Carer Forums who are eligible to receive a parent participation grant from the Department for Education. The NNPCF Steering Group is made up of parent carers from each region who are able to represent the voice of parent carers in their regions and ensure information about national developments is disseminated and that parent carer participation is strengthened, and embedded. The role of the NNPCF is to ensure parent carers are able to have a voice and work as partners as services, strategies and legislation concerning disabled children, young people and their families is developed locally, regionally, and nationally.

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1. Background

1.1

In March 2011, the Government published its consultation Green Paper on special educational needs and disability. The purpose of this paper was to test a range of proposals designed to respond to existing failings and frustrations within the system. A tender process resulted in grants being awarded to 31 Local Authorities in England, who formed 20 SEND Pathfinders with their PCT partners. There was no national 'blueprint' for how things should be done, so it was up to individual Pathfinder areas to design new arrangements, pilot them and test how well they work in practice to better support life outcomes for children and young people; to give parents confidence by giving them more control; and to transfer power to professionals on the front line and to local communities.

1.2 Aims of the Pathfinder Programme

The 20 SEND Pathfinders are working towards the following common objectives:

To develop a new **0-25 assessment process and a single plan** which

- a. brings together the education, health and social care services on which children and young people who are disabled or have SEN and their families rely; and
- b. focuses on improving outcomes;
 - To explore how the voluntary and community sector could explore access to specialist expertise and introduce more independence to the process;
 - To ensure the full engagement of children, young people and their parents and families, schools and colleges;
 - To improve choice and control for children, young people and their families through the use of personal budgets and direct payments.¹

All the pathfinders had to evidence how they would engage with parents and carers in their bid to become a pathfinder, and so this report charts the success with which they have done that.

2. Background to this report

2.1

All the pathfinders had to evidence how they would engage with parents and carers in their bid to become a pathfinder, and so this report charts the success with which they have done that.

2.2

All forums in pathfinder areas have been offered a small amount of additional support from Contact a Family, as the delivery partner for the Department for Education.

Forums have also reported back to their regional network meetings which are part of the National Network of Parent Carer Forums and some have attended some of the Mott McDonald Learning Events. However, there was no clear understanding of the range of experiences of forums in pathfinder areas, and consequently, the learning that could be taken from that. As such, Contact a Family and the National Network of Parent Carer Forums jointly devised and commissioned this piece of research to evidence some of the learning from forums in pathfinder areas that would be useful for non pathfinder areas to consider as they begin to develop their own transformation programmes.

2.3

A questionnaire was sent to all the pathfinder parent carer forums in December 2012. Because of the short timescale and already heavy workload, a Parent Carer Participation Associate was commissioned to interview the forum representatives by telephone, using the questionnaire as a guide rather than asking parent carer forum representatives to complete it. A copy of the questionnaire is in Appendix 1.

2.4

Contact was made with all 31 pathfinders, but it was only possible to complete it with 24 of the parent carer forums. However, as this represents 77% of the forums, it was felt that this would be a representative sample.



¹ Adapted from Mott MacDonald SEND Pathfinder Programme Summary May 2012

3. 24 pathfinders consulted

3.1

The 24 parent carer forums which completed the questionnaire were:

Bexley; Bromley; Calderdale; Devon; Gateshead; Greenwich; Hartlepool; Hertfordshire; Leicester City; Lewisham; Manchester; Medway; North Yorkshire; Solihull; Surrey; Trafford; Wigan; Wiltshire; SE7 Pathfinder, which includes Brighton & Hove, East Sussex, Hampshire, Kent, Medway and West Sussex.

3.2

From these forums, 11 Chairs of Forums, 6 parent members, 6 Parent Participation workers who were also parent carers, 3 Parent Partnership officers, and one manager who was not a parent carer were spoken with. In some areas, more than one representative contributed and were spoken with.

3.3

Throughout this report, Parent Carer Forums are referred to as such, or just as forums.

4. Involvement in the bid

4.1

The first question to be asked in this survey was whether the parent carer forum had been involved in developing the bid to be a pathfinder.

4.2

Only 5 forums (22%) responded that they were involved. One forum did not respond.

4.3

Following the success of the bid, 17 forums (73%) said that they were involved immediately or very soon afterwards in working with the Local Authority, leaving 6 forums that became involved later.



4.4

It is noticeable that in the areas that became involved with the local authority quickest, the extent of their involvement in the work streams was much greater. Therefore, out of the 17 forums that were involved soon after the bid was successful, 11 said that their role involved coproduction of the group. This suggests that early involvement in the work will lead to a higher level of involvement throughout.

4.5

In the 6 forums who responded that they were not involved soon after the bid succeeded, all responded that their involvement is on the basis of participation and being informed. Two forums reported that their involvement has been considerably delayed, with only two becoming involved after August 2012.

4.6

11 forums identified that their involvement included coproduction.

4.7

It is notable that all of the first case studies on the Mott MacDonald Website (<http://www.sendpathfinder.co.uk/foodforthought/>) are from these areas, and suggests that involvement of parent carers in coproduction in the pathfinder provides evidence of this as good practice.

4.8

In the SE7 Regional Framework for Parent Carer Participation, coproduction is a core theme of all work streams and SE7 defined coproduction in the following way:

“Coproduction happens when all team members together co-produce decisions, plans, actions and materials as a collective with shared responsibility. This process develops over time, blends a range of expertise and perspectives, is driven by a solution focussed approach from all participants and requires strong leadership. Communication that is transparent and open, relationships that are equitable and respectful help the team overcome complex challenges and continue the process of learning together.”

4.9

One forum responded that they thought their meetings were coproduced, until they found out about a separate decision making meeting to which they were not invited. This would mean that their involvement was on the basis of participation.

4.10

The NNPCF and CaF have also produced guidance entitled “Markers of good practice in building Parent Carer Participation”, which is in Appendix 2.



5. Challenges

5.1

Forums were asked about the challenges in enabling the participation of the forum in the work, and 6 Forums responded as follows:

- The forum was only just set up when the pathfinder started.
- The local authority set up governance early on, then invited us to join.
- There was a new director in post who did not know about the forum. First contact was in March 2012.
- We had a strong forum. We followed progress, and knew that our authority had become a pathfinder early on. Ongoing challenges – lack of communication with forum. We were constantly asking to be involved, and it took months before we were.
- The pathfinder has taken a lot of time to get involved with us, and there is still not much involvement. Some local authority workers do not see the point of involving parents.
- It was hard to get involved. We had help from an associate from Contact a Family. We also made links with Mott MacDonald.

6. Remunerating or resourcing the activity

6.1

15 forums (65%) responded that they were remunerated for their involvement in the groups, with some receiving substantial grants to provide specific workers. One Forum received a grant to provide administrative support for 10 hours per week. Other grants ranged in value from £1,600 to £30,000

6.2

For the other 8 forums, they provided funding and support to their parent carers from their budget, with no additional pathfinder monies.

6.3

12 of the forums have an agreed payment policy, while 8 do not (4 did not respond). These policies vary widely, with some including an hourly rate for attending meetings, some including travel expenses, parking and childcare. Some of these payments come from the forums own budget, and some forums have received additional monies. None of the forums pay for travel time, which in some areas can be up to 5 hours return journey.

6.4

In 8 forums, an hourly rate for attendance at meetings is paid. This is in the range from £4 - £12.50 per hour. Some forums were reluctant to go down this route because of the impact on benefits payments. One forum has set up a system of Time Credits, whereby credits can be used to 'buy' services, such as time at a leisure centre. In all forums, travel expenses are paid, and in 16 forums (66%), child care expenses are paid.

6.5

21 of the forums said that paying parents to attend meetings was essential. Some of the responses included:

- Costs could have been met from Department for Education grant, but it would have been tight.
- Payments to parents do make a difference.
- Good to get something back for time.
- It reflects the amount of time spent.
- Some parent carers would not have been able to participate without payment, and extra events needed resourcing.
- Commitment any way. But travel expenses helped.

- It helps get people along and give a regular commitment. It is hard work.
- If there was more money, then we may be able to reach a wider cross section of parents and attract new parents.

6.6

11 of the forums received financial support in advance of the activity, and the remainder after the activity. A few experienced significant delays in receiving this.

6.7

The survey asked the forums to encapsulate the amount of time spent taking part in the work streams. Some local authorities have up to 12 work streams, but the majority has 5 or 6. Out of 24 forums, forums responded that they attend a total of 106 work streams, excluding any additional parent carer forum meetings. Some of the work streams were meeting fortnightly initially, with most meeting monthly, and some meeting quarterly. It is common for more than one parent to attend each meeting, and so with meetings lasting a minimum of 2 hours, the picture becomes clearer of the amount of time that parent carers are contributing to the pathfinders to help them succeed. There is a wide range of time spent at these meetings, from one forum that has one work stream which has taken 32 hours for parents to attend, to another forum which has 8 work streams and has taken parent carers 472 hours to attend. Considering that only 8 forums pay parent carers to attend, it is evident that parent carers are investing an enormous amount of time in this work.

6.8

It is important to point out that high attendance of parent

carers at meetings is not solely determined by being remunerated, as there are several forums with numerous work streams that also have parents attending regularly who are not paid an hourly rate. However, it is unclear how sustainable this level of activity and attendance would be.

6.9

It should also be noted that the estimate of the time taken to attend meetings excludes preparation time, and so the time taken is likely to be grossly underestimated.

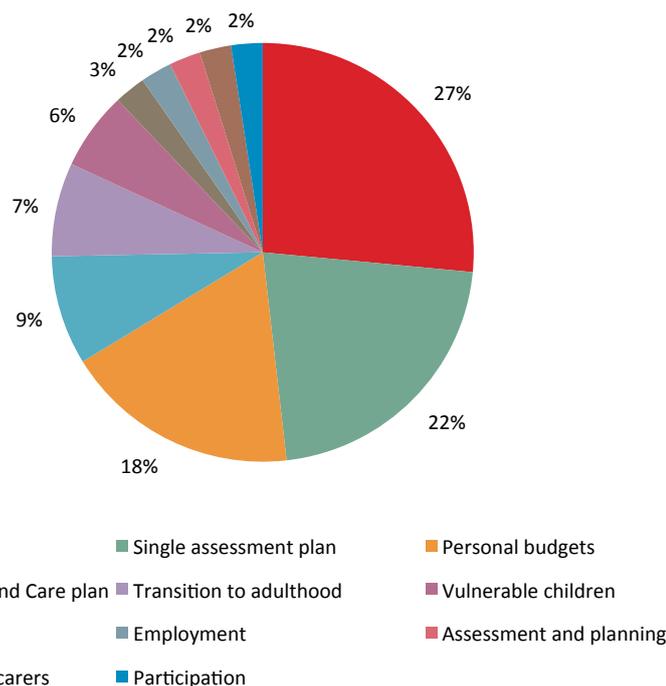
7. Work streams

7.1

Many Local Authorities had local Change Boards that coordinated the Pathfinder activity and from which the following work streams were developed. Forums were either part of these work streams, or involved in them:

- 22 forums had a work stream on the local offer
- 18 forums had a work stream on the single assessment plan
- 15 forums had a work stream on personal budgets
- 7 forums had a work stream on the Education, Health and Care plan
- 6 forums had a work stream on transition to adulthood
- 5 forums had a work stream on vulnerable children
- 2 forums had a work stream on Early Years
- 2 forums had a work stream on employment
- 2 forums had a work stream on assessment and planning
- 2 forums had a work stream on support for parent carers
- 2 forums had a work stream on participation

Work streams in the pathfinders



7.2

Other work streams included:

- Data and information
- Education Transport
- Keyworker
- Resource allocation
- Commissioning

None of the forums reported being involved in the work stream on recruiting and supporting the pathfinder families.

8. What has not gone well

8.1

8 forums responded about the difficulty with times of meetings:

- Timing of meetings, and requests e.g. feedback from one of the streams was requested in July, just before the holidays, which is impossible time for parents.
- Constant change of date and time of meetings with no notice. Two meetings attended that had been changed.
- Some meetings were held in the summer holidays and no child care was paid.
- Cancelling meetings at short notice.
- Double scheduling of meetings.
- Timing of meetings is challenging.
- Timing of meetings.
- Location of meetings.
- A meeting perspective – professionals seem to view meetings casually, in that sometimes they go, and sometimes they don't.

8.2 Decisions

3 forums referred to their concerns that decisions were being made elsewhere:

- Decisions are often made elsewhere, and not in meetings where parents are represented.
- Decision making meeting takes place with no parent rep.
- Some decisions are taken without involving parents.

8.3 Involvement

4 forums identified that not being involved at the beginning has made their involvement difficult:

- Not invited at the beginning.
- Lack of involvement from the beginning.
- Not involved from the beginning.
- At the beginning, the pathfinder leads were not good at working with parents and being challenged by parents.

8.4 Organisational

8 forums identified organisation difficulties, both in terms of their own forum, as well as with the local authority:

- The way the local authority works.
- Wrong perception of roles and what the workers job is.
- Time involved, but we have a good committed group of parents, but caring responsibilities may get in the way.
- Hard to get parents actively involved.
- Those who know about the pathfinder know about us, but not anyone else.
- Hard to attend so many meetings.
- Minutes not very good.
- Not able to influence selection of families.

8.5 Cultural change needed

4 forums recognised that involvement of parent carers may involve a change of culture, which can be challenging for staff:

- Trying to enforce change in a climate of not wanting to change.
- System development and embedding good practice.
- Initial enthusiasm was good, but some staff have left, and we could be cut out of the loop.
- Cultural change is slow.



8.6 General feedback

There were many additional comments from the forums, included here as they are also important, but each point has been made by one forum, rather than a few:

- Practitioners don't like taking instruction from parents.
- Since the new draft legislation, the direction is now unclear, as there is a lot in the draft that was not in the Green paper e.g. there is nothing that enforces health or care services to get involved in the process.
- Severe lack of communication with parents.
- The parents' forum missed the timescale to work with the local authority. They have been told that they are welcome, but take up has been poor.
- We need more guidance to forums about parents working with professionals.
- Local authority staff did not hear parents' comments about the single plan, and put into it what they wanted. Parents responded strongly to this, and it was changed. There is a danger that we are not listened to because we are too friendly with the local authority officers.
- Poor leadership.
- Not enough people know about the work entailed, including schools and parents.
- Capacity – volume of work.
- Trying to get it right before trying it out.
- For the personalisation work, not much movement for a huge amount of work.
- At first, the council had outside consultants, and it felt process driven, and not driven by focusing on the customers. The pace was slow and drawn out.
- Some difficulties from some parents giving feedback from meetings they attended.
- Not carrying forward action by parents.
- Parents recruited outside of committee.
- It took a long time to get started, and now challenges the capacity of the forum.
- Disorganisation in the local authority - Project lead keeps changing.
- There is a concern that the needs of children with less complex impairments are not being addressed.
- Communication about the content of the work streams.
- Lack of communication within the consortium
- Few parents to attend meetings.
- Not paid for our time, but they want our expertise. We want something back, not necessarily monetary.
- No link to health.
- Hit and miss with professionals, many are dismissive of parents.

9. What has gone well

Forums were asked what they felt had gone well as a result of being part of a pathfinder.

9.1 Raising the profile of parent participation and the Forum

5 forums talked about the way the pathfinder has successfully raised the profile of the forum itself e.g. one forum said:

“We are able to recruit more parents with our raised profile”

9.2 Involved and appreciated

17 forums talked about the importance of being involved, and how their contribution was appreciated. Given that most parents are contributing in their own time as volunteers, this is a significant vote of confidence for the whole process of engaging with parents e.g.

- We have been involved in developing the local offer.
- We have organised and spoken at the local pathfinder event.
- We have influenced pathfinder.
- Represented in all work groups.
- Number of different parents involved.
- Parents involved from the beginning.
- Actively involved in meetings – and appreciated.
- Involved at strategic level.
- Better understanding of parents' perspective with parents on the pathfinder core team.
- The local authority have changed the times of meetings to suit us.

9.3 Good relationships

16 out of the 24 forums referred to the good relationship that they developed with their local authority partners:

- Improvement in working together and working with parents. Seen more as equal partners by most.
- Good communication with the local authority and PCT.
- Cultural change within the local authority, enabling professionals to work alongside parents /carers in a culture where parental involvement was previously negligible.
- Language has changed from 'helping clients/patients/pupils and families' to 'working alongside children and families'.
- Broken down barriers between parents and professionals.
- More respectful working relationships.
- Good leadership. We have had an excellent pathfinder manager who listens well and does not take things personally.



9.4 Additional resources

3 forums commented on the fact that they received extra funding to support this work:

“We are better resourced now. We have dedicated time for the pathfinder”

“We have funding and support for an admin worker”

“A coordinator has been appointed to identify parents and field replacements”

9.5 General feedback

There was also some general feedback about what has gone well, including:

- Enthusiasm of parents.
- Ensuring feedback is truly representative.
- Parents supporting other parents.
- Single format for the single plan achieved.
- Work on the single plan.
- Support from Mott MacDonald to produce newsletter.
- Calendar events, booked for 6 months, helps booking childcare.
- Timings changed after parent feedback.
- Having a central telephone number helps.
- ‘You said, we did’ meeting.

10. What has been the impact of having parent carers involved strategically?

10.1 Positive impact

Many of the forums referred to the positive impact of having parent carers involved strategically:

- Now seen as credible strategic partners.
- Always focused on parents and young people.
- We have made points that the professionals would not have realised.
- We have injected practical reality into the discussions.
- We rise above the internal politics and challenge it.
- Helping to make local authority policies parent friendly.
- It has changed the way parents perceived.
- Training parents to participate in meetings has helped.
- We are slowly making a difference. Parents talking about the reality and professionals are beginning to listen.

10.2 Additional positive impacts

15 forums commented that local authority workers had greater respect for them, having met them at meetings.

- Greater respect for parents.
- Ensuring parents are asked their views.
- Valued members, not just done to. Our area is always good at working with parents.
- Changed professional perceptions of parents in a positive way.

- Respected and known that we represent a large section of parents.
- Professionals see parents as equals, and think of the children holistically, not just in terms of educational or health needs.
- Even better communication with the local authority. They run everything passed us, and we now have a closer working relationship.
- If involving parents is maintained, then it can continue to be an excellent resource for the local authority. Parents are keen to participate, and it is representative, giving 'real life' information.
- We can develop policies and services that are more workable
- It has opened doors for other participation activities, especially with health and education.
- Helped us get involved in other areas.
- Building relationships which were previously more confrontational.
- Parents "keep it real".

10.3 Culture

Several people responded that the culture of the local authority would have to change in order for services to change, and this concept is particularly true in relation to the local authorities engaging with parents as full partners. One parent carer said that:

"The local authority has to listen to the views of parents, and this can take more time as a result, and so it needs a change of culture."

10.4 Negative impact

Although the majority of responses were very positive, there was some concern about the extra work of the pathfinder taking over, and also some concern about what the end result will be:

- There is a heavy workload on the forum to make sure that parents are represented, but we are not sure of the impact. E.g. many parents responded regarding the local offer, but it is unclear if the local authority have looked at and included the responses.
- Taking away from what we do elsewhere.
- Number of meetings – capacity.



10 Findings from Parent Carer Forums in pathfinder areas

11. Have there been any changes in relationships or ways of working?

11.1 Maintaining positive relationships

Two forums said that they had always had good relationships with their local authority partners:

- We already had good relationships and communication.
- We always had a good, strong working relationship with SEN leads.

11.2 Challenges in working relationships

Three forums reported that:

- Some meetings happen without parents being informed. Personnel changes disrupt partnership working.
- Sometimes staff close ranks, because of pressures.
- No, there have not been any changes, and they are friendly, but they do not treat us as professionals.

11.3 Improved relationships

The majority of forums (22) reported much improved relationships with the local authority:

- Parents are now more able to negotiate. There seems to be a greater level of mutual respect.
- Parent carer representatives are now on email lists along with the professionals, so there is a greater air of openness. Professionals do not see parents as so threatening.
- We have better relationships with education and health workers.
- Positive changes. There are no barriers, just equal status between parents and professionals.
- There have been improvements from some professionals of their perceptions of parents.
- Invited onto boards that we did not know existed.
- Yes – professionals have been easier to contact. The 'fight' element is being reduced. We now run a training course on navigating the system which is co led.
- Named as strategic advisor.
- Greater respect and improved communication.
- Closer working relationship.
- Yes, from both sides. Parents better understand why professionals say they can't have services.
- The professional's consideration of parents' voices has improved, and sharing information not previously discussed.
- Certain local authority staff will come for advice where they would not have done before.
- We feel we are listened to and taken seriously.
- Improved relationships with the wider professional network.
- Relationships have been improved with a number of people, specifically:
 - Children with disabilities social work team
 - Head of pupil services
 - Head of commissioning
 - 2 special schools

11.4 Working with wider range of partners

5 forums commented that being part of the forum has enabled them to work with a wider range of local services:

- The pathfinder work has made people come to the table who would not usually.
- It has helped us get involved in other areas, but we don't know what is happening regionally.
- The director of children's services recently came to a conference we held.
- The pathfinder has brought people together, and we have met people who we would not otherwise have met.

Yes, we have recently had a positive meeting between us and other local voluntary groups that was enabled by being part of the pathfinder.



12. The three biggest challenges

12.1

The respondents were asked what have been the three biggest challenges. Their responses, along with suggested solutions are documented below:

What have been the three biggest challenges?	Solutions
Capacity	
Capacity and managing additional work	Listening and understanding each others perspective
Capacity – we are a small group trying to do a lot	Decide which meetings are essential and match experience and interest
Capacity – identifying parents who can commit the time. 50% of what we are doing is related to the pathfinder	We keep the forum updated, and so keep in touch with the members
Capacity for forum to be available, and capacity for professionals to undertake engagement work	Raise profile of this work within agencies
Capacity – needing more parents, and keeping parents interested	Raising the profile of the group helps it to recruit more parents
Culture	
Challenging entrenched local authority decision making	Parent reps ask for parent views and feed this back to the group
Cultural change in practice	Longer term plans are needed. People tend to think in 4 to 5 year plans
Cultural change	Coproduction shows parents as equals and aids the cultural change needed
Culture change for staff and parents. Some staff are reluctant to abandon the old ways	Person centred training for staff (could be parent led)
Strategic planning and their approach. The local authority has asked us to manage parents' expectations. Our role is to voice parents concerns, but funding comes from the local authority, so do they think they own us?	Being clear about our role
Ensuring we get the widest group of parents involved from across the borough	Awareness raising. We target specific groups of parents e.g. parents with a disability, & parents for whom English is a second language.
Timescale – lack of early guidance	In contrast to Aiming High, the pathfinders are very loose
Economic climate; local authority staff morale is low	Local authorities have to take parent carers seriously
Mechanism for monitoring care provider	Talking to people

Organisational cultures. The way bureaucracy can make things difficult e.g. our supporting organisation can book a taxi on account, but cannot pay a bus fare as they have no petty cash	Timing of meetings – reinforce the message about being flexible with location, paying for a taxi / providing catering
Time and Timing of meetings	
Time is needed to attend meetings, and timings need to be improved – one person arrived for a meeting to be told it had been cancelled. Meetings are still held in holidays	Convenient time for parents.
Having meetings at times that are suitable for parents	Constantly reminding professionals to have meetings in school hours
Timing of meetings	assertiveness
Time involved, not enough parents	Sharing responsibility with neighbouring authority, doing feedback to them, identifying parents and approaching parents on 1:1 basis
Timing and making meetings more parent friendly	Being part of regional forum, and being briefed by national organisations, and attending meetings
Timescale	Having parents and professionals round a table, get to understand parent perspective
Training issues – need more time, especially for continued professional development	If not paid, then parents need to get more 'rewards' for assisting
Ensuring meetings observe the 5 Fs of participation: Fun, food, flexibility, focus & feedback	Reminding people of improvements that came out of Aiming High programme
Involvement	
Being included – we have parents who want to be involved	Hard to reach all families
Getting the right parents involved	Support from Contact a Family and the National Network for Parent Carer Forums helped
Getting people to listen to us and take us seriously	Being open and honest
Parents anxieties about the new system	Austerity programme as backdrop to all the work being undertaken
Health involvement	
Pan disability – need to be proportionate on the forum	
Getting people from health involved	Examples of good practice from other areas, but community health care team very good
Health are not engaged Hard to see how parents can use direct payments when services are block commissioned. May be better to be awarded hours rather than budget	
Other comments	
Sharing workload	Recruit more widely
Communication within the network	Need buy in
Resistance from education to this open way of working	Slowly slowly getting to know the people
Getting the message about the pathfinder to the wider group of families	Going out to schools, publishing a newsletter
Engaging parents	Newsletters and conference (one in January)
Getting people to accept change	Parent conference
Understanding what we are doing, given that we joined late	We keep abreast of changes by attending meetings elsewhere

We have had to consolidate and set up the organisation from scratch in the same timeframe.	We work very hard, and take up all offers of help from parents
Communication	Survey – feeding in to joint Commissioning board
Being recognised as equal partners	By example
Maintaining parental involvement	Keeping a high profile by advertising, newsletter, Facebook page, and training days
Real participation by parents and payment for the parents	Start again in 2013, with Parent participation officer more involved
Confusion over meetings and the purpose of meetings	Ensure clarity about work streams and who is involved
One of the most important Bills currently, yet parents are being held at arms length. How do I stop the parents from feeling let down	Discuss selection process for pilot families – focus is on children with complex needs, so what about the majority of children with SEN, especially in mainstream schools
Professional attitude	The more we work together, the more it changes. We need to sit and listen.
Parents have to see themselves as skilled and professional	Training
Forums need more resources to set up for longer	
Some profs still feel they know best	Showing how participation can save money, save time, and give publicity e.g. wrong kind of hoist in a leisure centre
Trying to understand what is happening and the implications and getting the right information to the right people e.g. post 16 should not just be for special schools	Improving communication – we have many areas with no internet or broadband or mobile connection, so we have to post information
Concern that autistic children will not get the help they need	Hard to get information to all families

12.2

It is clear that there have been considerable challenges to overcome in order to enable the input of parent carers, and their commitment to finding solutions is evident. Sustaining this level of involvement may also be a challenge and will require further investment from everyone involved.



13. The impact of the extra pathfinder work on the parent carer forums

13.1 Additional workload

The majority of forums commented on the extra workload resulting from involvement, and the difficulty of addressing other issues at the same time as being involved in the work of the pathfinder:

- We have had to attend additional pathfinder meetings, awareness meetings, training and other related activities.
- Capacity. We have a small core group which has been a strength. (12 people)
- It has helped the forum to grow, from 2 staff to 6.
- Massive. No time to do anything else. No time for building the blocks of the forum, since it has been swamped by this. There are 8 people on the steering groups. It is hard work.
- Less time for other issues, but the benefits outweigh the negatives.
- More work, more meetings. One big meeting, every other month, for 4 hours.
- It has stretched our capacity and has affected the formal setting up of the forum.
- It has limited other activity. Sit on other boards now. Hard without additional funding.

- 50% more work for Parent participation worker; more forum meetings; Consulted by others; Austerity measures hitting NHS and youth services; we are distracted from our other priorities.
- We know what we want to achieve as a forum, and need to ensure that the pathfinder does not completely take over.
- We have added an agenda item to each forum for feedback and discussion. We are spread thinly, having to attend many more pathfinder related meetings.
- Stopped us focusing on outreach.
- Adding to the work of the core group means that they have less time to work on other things.
- It has taken over. We have little room to do anything else.
- Increased volume of work; Need to keep it fresh.
- Not enough time for non-pathfinder work e.g. Housing strategy not responded to, and Carers Rights day postponed.
- Conflicting with other work.

13.2

- As well as the difficulties, some of the forums described more positive impact:
- The voice of the parent is better heard.
- Opportunity to publicise the forum.
- Building confidence especially with the local offer.
- Other professionals have seen the value.
- It gives us motivation and structure to measure change and what is not working and makes us transparent.
- We have been involved with senior officers in shaping services.



14. Main concerns for the next 18 months

14.1 Keeping parents motivated

9 forums commented on the difficulty of keeping parents engaged for a further 18 months:

- Involving more families.
- Sustainability.
- Maintaining parental involvement over a longer period of time, as they need to see a positive difference.
- Consultation fatigue and parents deciding to withdraw.
- Impact of continuing to work at this capacity.
- Parental disengagement, especially if they can't see results.
- May have drained enthusiasm of parents, parents too overloaded, and wont sit on other groups.
- Become independent and a recognised body.
- Keeping parents positive.

14.2 Will feedback from the pathfinder be used?

8 forums questioned the impact of their involvement, and whether it would be evidenced in the local outcome:

- SEN pathfinder – is all this work for nothing?
- Big changes – concerns, will it work?
- What will the outcome be? It is not known.
- Funding – will it remain?
- Concern that if there is not specific education plan, then enforcing additional support for health or care needs may not be feasible any more.
- Changes in health / social care / education due to austerity measures.
- Concern that all work done wont be used.
- Parents are worried about the changes and when the single plan will come in. what if they don't use any of the feedback from the pathfinder.
- Ensuring input makes a difference.

14.3 Increasing membership of forum

14 forums mentioned the importance of continuing to promote the parent carer forum, and involve new parents, and the challenges of that:

- More people on the forum.
- We want to build up the forum.
- Enough parents to attend.
- Maintaining a positive image of the forum at a time of great challenge.
- Reaching out to wider group of parents to enable their participation.
- Developing forum, so not just pathfinder led.
- Getting right parents involved.
- Keeping parents involved.
- Keeping momentum.
- Pathfinder will continue to take over, no capacity for other issues.

- Keeping people interested with the extension of the pathfinders
- Recruiting new committee members.
- Productive to have parents in the mix, but danger of overload and exhaustion.
- Keeping parents involved.

14.4 Roll out of the programme

Other comments were focussed on the roll out of the programme:

- Rolling it out.
- Concerned how system will be brought in.
- What support will there be for children already in the system
- Need to see evidence of the change in working, and then sustaining that change.
- Training and development of the workforce.
- More families to pilot personal budget need training.
- The service targets children with complex needs. Children with autism are not eligible for many services.
- The legislation is now diluted. We need to be clear on what we 'must' do, and what we are meant to do.
- Communication needs to be clearer, especially timelines and hierarchy in council.
- What will the local offer be, and what does local mean? E.g. Town or region – some areas served by different local councils.
- Home to school transport. If there is no choice of school, then opting out will be very expensive because of the cost of transport.

15. What Parent Carer Forums, Local Authorities and partners need to consider as they begin to work on the proposed changes

15.1 Working together

14 forums identified working together as the most important thing to do:

- Working together. Listen to each other, consider other views and respect them.
- Working at a pace that takes parents with us. Ensuring parents have a real voice and influence.
- Getting into the room and being part of the discussion.
- Include parents as much as possible.
- Working together properly and equally informed. There is a gulf between pathfinders and non pathfinders.
- Meaningful dialogue. Would like to continue to work together to make it for purpose. Not them and us.
- Working together.
- Embedding coproduction and joint working between the parent forum, education and health and social care.
- Clear communication – more face to face interaction, working together; Payment for parents.

- Working together and a shared understanding of each others roles.
- Working together – listening to each other. Limited funds.
- Understanding parents views, and for the local authority to understand the proposed changes, and everyone to appreciate the financial restrictions.
- Respect and understanding for other people's position. Working together. Common sense.
- Think long term. Invest sensibly and bravely to reap rewards later on. Work together, share accountability.

15.2 Communication

- Clear timely communication to all parents, schools (including mainstream).
- Adequate training to enable change of mindset, not tweak what they already have.
- Communication is open and views of parents listened to and parents consulted.
- Reaching out to parents. Two road shows have already been organised to inform parents about the proposed changes and find out their views. More road shows will be needed as further changes occur.

15.3 Other comments

- Keep the child and family at the centre of the picture.
- What we have worked on is achievable, and that the parents' voice is heard and acted on.
- The needs of children with SEN and disabilities must be taken into account, as there is a huge diversity of need. Is this about parents getting less?
- Need to scrap current system and start again, rather than try to alter current system. Something produced that will work for 30 families, but will it work for all?
- Clarifying what the local offer will be. If it is as good as possible, then the education, health and care process will not be so significant.
- Training and development.

15.4 Where to complain

- Accountability – where do you complain, who to, and what about.
- Accurate information – so the local offer needs to be clear about what needs to be provided by schools. Mechanisms for finding solutions.
- Sustaining changes and children who do not meet criteria will still get support.





16. Key elements in the revised Code of Practice relating to parent carer forums, and pathfinder learning

Forums were asked to identify if there were any key elements that they felt should be included in the revised Code of Practice.

16.1 Requirement to work with parent carer forums

18 forums said that there should be a requirement for local authorities to involve Parent Carer Forums with their strategic service development, just as there is a requirement for the Parent Partnership Service to be established in every local authority.

- There should be a requirement for parent carer forums to be involved from the beginning.
- Ensuring continuing influence of parent carer forums, similar to parent partnership officers – mentioned in a similar way in the Code of Practice so that they become embedded in the structure.
- Parent participation should be mandatory.
- Recognition of value of parent carer forum and local authorities must demonstrate they have a parent carer forum which is parent led.
- To be included in the legislation, like the PPS, rather than being briefly alluded to.
- The Code of Practice needs to be underpinned by statutory status. Just as in the current SEN Code of practice, there needs to be words used such as 'must' and 'should' to denote the requirements.
- Coproduction written in, through parent forums.
- Formal recognition and expectation that the Parent Carer Forum will always be involved strategically, especially in education, who need to be forced to the table.
- The local authority should value parents, and not see them as token, as we have a lot to contribute.

- To have effective parent carer forum to inform and participate. The lines of communication and areas of responsibility of the local authority to the forum need to be clear. In our area, the forum is partly funded by Big Lottery funding.
- Involvement with Parent Forums at local authority level. Local authorities should have to work with them.
- Must be accountable if the procedures are not followed e.g. nothing happened to an LEA when they did not attend mediation, and no penalty was given.
- Language too passive – need to define what is law and what is best practice. Legal obligation to hold education accountable, but not health and social care. Health and wellbeing board – want to be represented on this.
- Treat parents as experts and give them the same authority as professionals.
- Solution focused mechanisms across sectors, not just at tribunal stage, but earlier. Parent carer forums must be part of the strategic mechanism and associated with duty to liaise with statutory agencies.
- The local authority has to involve parent carer forums.
- Recognition of Parent Carer Forums and that local authorities must work in partnership with them, with support provided by the National Network of Parent Carer Forum. We keep it real.
- Voice of parents and children, engaged and need to have mechanism for maintaining parents as equal partners. Facilitating the voice of parents – the local authority should be able to evidence participation.

16.2 Other comments

- Clarify who will be eligible for a single plan, and what support will be available for those not eligible.
- Coproduction as the way forward. Involving parents meaningfully and parent forums need support to do that, with CaF and NNPCF.
- Focus should not be just at schools, but outside of school so that health and social care can focus on the child's needs, and not educational needs. Services should focus on the whole child. E.g. one child could not go to after school club because the school transport could only take the child home at 3.30pm.
- Getting views of children is very hard. Listen and do not close ranks.
- Most important thing is for the Code of Practice to be agreed through Parliament as before with 2001 Code of Practice, as currently it will belong to the secretary of state only, which will mean that it can be changed more easily.
- Easy to understand – perhaps have a shortened version with key elements.
- Work together to same target.
- Clarity about what a parent carer forum should be e.g. constituted group, who should be involved, should it be parent led.
- Education for children with SEN should be holistic, so the worker may need practical and vocational skills.

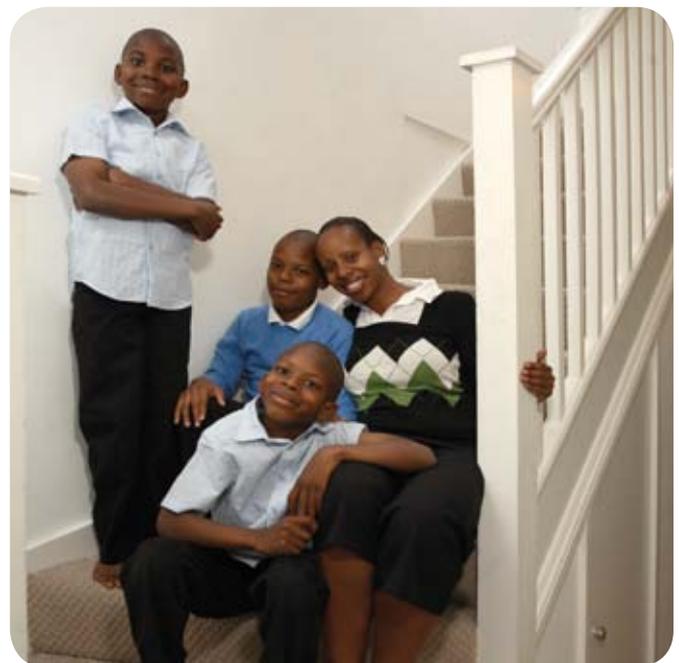
17. Messages to be fed back directly to the Department for Education about the pathfinder work

The questionnaire asked parent carer forums to feedback any messages about the pathfinder work. All responses are included:

- Please listen to parents and involve them in the process, don't just tell them afterwards.
- Coproduction – Inviting parents may change some people's lives. Listen and hear what parents are saying and act on it.
- Importance of ensuring that parents can have their views heard and that the Department for Education will be open to reviewing and revising the proposals in light of parents' responses.
- Parent participation should be mandatory. Focus should not be just at schools, but outside of school so that health and social care can focus on the child's needs, and not educational needs. Services should focus on the whole child. E.g. one child could not go to after school club because the school transport could only take the child home at 3.30pm.
- Give the change the chance to work. Still many children not subject to person centred planning – this looks at whole child, not just education.
- Please appreciate the time and effort put into this. We would like the guidance to be written into the Code.
- We would like to reinforce the endorsement that there needs to be continued and evidenced joint working with parents. It needs to be understood that work has increased as a result of the pathfinder, and it needs to be resourced.
- We want to see support for our children broadening, not being restricted, but it does not feel that it is going this way.
- Coproduction works well. Don't have compulsory mediation.
- Listen to what people have asked for, and what they have said, and what their concerns are.
- If you want parent participation, you need to set it out from the inception, and it must be enforced. Local authorities need to accept accountability, rather than it just being about individual families fighting in their corner. The Department for Education need to ensure that they are getting value for money. Perhaps, if a local authority is being inspected, then parents from the parent forum could be used.
- Consider pathfinder funding going directly to forums, instead of via the local authority. So many have had £30000. We would like to employ someone ourselves as coordinator.
- Good information received from the Department for Education, and they seem keen to get it right. Would be good if the Department for Education could put pressure on the Department of Health to be equal partner.
- Working together idea is excellent. Parent carer forums need resources to function, and clear line of

communication if they are going to make a difference.

- Thanks for the opportunity that it has given us to work with parents and learning from that.
- Schools would benefit from standard SEN training, and training for all on Equalities Act and Human Rights Act.
- Remember that professionals are paid, whereas parents and carers are firstly carers, so commitment to family. Don't put too much on staff. Please consider feedback from parent carer forum in any decision.
- One size does not fit all. What works in urban areas does not work in rural areas.
- No diminishing of parental rights – more evidence of this needed than ministerial letter.
- We are a small area, and use many resources across counties, so counties need to work together. There needs to be a focus on the needs of the whole family. Some families with two children with SEN face particular problems with school transport, especially if one child gets it, and another does not. Multidisciplinary working on single plan – suggestion that the single plan is held online as a live document that can be securely accessed by those involved.
- Make sure you listen to parents, as parents know best. Don't take away any rights that we already have.
- London centric feeling about the process- all meetings in London.
- Relieved that it is extended.
- Don't lose the holistic focus – it is not just about education.
- Keep it clear and concise and avoid misinterpretation. Need to strike a balance between striving forward and using parents without raising anxieties.
- Parents are not fully involved.
- It was wise to extend the timeframe. Be clear on legislation and accountability. The Department for Education needs to work more closely with the Department of Health. Reconsider thresholds for apprenticeships.



18. Conclusion

There is overwhelming evidence that involving parent carer forums in the pathfinder areas has been a very productive way to ensure that services remain focused on meeting the needs of disabled children and families, as it is these parents who can bring the reality of looking after a disabled child, or child or young person with additional needs to the table. Parent carer forum members were all clear that it is their role to represent all parents, and not just their own children, which is a frequent criticism when involving parents in this way. All the forums had mechanisms in place to consult with their members about the plans being made, and most arranged additional meetings, conferences and consultation sessions, as well as sending out questionnaires to their membership to inform themselves.

Identifying parents to attend meetings has needed considerable organisational skills, as well as ensuring that those representatives feed back to the wider group and continue to represent the views of all parents.

Remunerating parents for their time and expenses is well received, but it appears that the commitment to contribute to the developments is more important, so where parents have not been paid, their attendance is still exemplary given the number of work streams and meetings arranged, although how realistic this commitment would be on a longer term basis is unclear.

The parent carer forum representatives mostly reported back that they feel appreciated and fully involved in the pathfinders, and there was a lot of evidence that relationships with local authority workers and with some voluntary organisations has improved. The parent carers have found that they have been invited to meetings that they did not know existed, and often treated as equals. Having parent carers coproducing the meetings mean that the parent carers have a greater sense of being treated as equal partners, and is an example of good practice, but does require a cultural change in local authorities that do not have a history of engaging well with parents and carers.

However, not all forums in pathfinder areas were able to participate in this research, and it may be that those who either were not able, or did not want to participate in this may be because they felt unable to respond to the questions. This is an area we will explore for the future.

One of the things that has been particularly difficult about the meetings is their timing. Many forums said that meetings were held late in the afternoon, and during holidays, and they have had to be very assertive to change this to enable the parents to attend. Several forum members had attended for meetings which had been cancelled without their knowledge, and others talked about attending meetings which were not well attended by the professionals. In addition, three forums identified that the decisions about the pathfinder are taken in a separate meeting which parents do not attend, and so they question the value of their contribution. However, as the parents have the opportunity to take part in changes that effect the lives of their children, and parent carers like them, so they come up with solutions

for the difficulties that arise, and in this way, their approach to participation can be seen to be completely professional.

For example, in one forum, the parent identified that they needed more parent carers to become involved, and they needed to keep parent carers interested. They recognised that raising the profile of this work helped them to recruit more parents.

Several forums identified that the extent to which they are involved can depend on the project lead and individual people, and when these people leave, it can be hard to convince the new worker of the importance of their role unless it has been embedded within the local authority. This kind of cultural change can be slow to take effect, so the forums making most progress in this area tend to the ones that already have a history of engagement with parent carers.

The forums were mostly positive about the impact of being involved strategically in the pathfinder. For example, one parent said:

“We have made points that the professionals would not have realised.”

Another said:

“We rise above the internal politics and challenge it.”

Another positive outcome is that in 15 forums, comments were made that local authority workers had greater respect for them.

One significant challenge facing the majority of parent carer forums is the lack of capacity to field parents for all the different work streams, and the danger that the pathfinder work takes over from everything else in which they are involved. This will be something that the forums continue to struggle with as the pathfinders have now been extended.

Similarly, 22 of the forums reported that their relationships with the local authority had improved as result of their involvement. One parent said:

“Parent carer representatives are now on email lists along with the professionals, so there is a greater air of openness. Professionals do not see parents as so threatening.”

Another parent said:

“We feel we are listened to and taken seriously.”

Attendance and involvement has also given parent carers an insight into how decisions are made about resources, and one parent said:

“Parents better understand why professionals say they can’t have services.”

Because the pathfinder has now been extended, the forums were asked about their concerns over the next 18 months. 9 forums commented on the challenge of keeping parents motivated, now that the end is not in sight, and the deadline has been moved. They particularly emphasised the concerns raised by some parents about not seeing the results of their effort, and in 8 forums, the parent carers have been questioning if all the work is for nothing, and if the changes are going to be brought in. One parent summed this up:

“Parents are worried about the changes and when the single plan will come in. What if they don’t use any of the feedback from the pathfinder?”

In considering the future, over half of the forums (14) said that working together is the most important thing to do. In addition, the forums said that keeping communication flowing would be essential, as well as making sure that parents and children know to whom they may complain if they are dissatisfied.

The questionnaire asked forums to comment on the key elements in the revised Code of Practice. Not surprisingly, given the positive experiences that most forums have had, 18 of the forums recommended that there should be a requirement for a local authority to involve a parent carer forum in their service development.

Finally, parent carer forums were asked if they wanted to feedback anything directly to the Department for Education. Most of the forums reiterated the importance of listening to and acting on the views of parent carers, particularly given the amount of effort that has been put into ensuring that their views have been included in the pathfinders. One suggestion was for some of the additional pathfinder resource to be provided directly to them rather than through the local authority. Concern was raised about the involvement of health authorities in the programme, and there is evidence of some involvement, but not extensively. A few forums commented on the difference experienced in the larger county councils, and how having a rural population needs to be catered for as well as urban communities.

19. Key learning points

1. Funding to enable participation in the pathfinders has helped to enable parent carers to attend and feel valued, and not be out of pocket as a result
2. Coproduction requires a cultural shift, but has proved effective in enabling full parental engagement and improving relationships between parent carer forums and range of managers and commissioners.
3. Involvement in the pathfinder has helped to raise the profile of parent carer forums, and consequently boost their membership and make them even more representative
4. The commitment of parent carer forums to participate fully in the pathfinders is commended. For some, it has meant an enormous amount of time has been spent coordinating the involvement, as well as participating. A few areas have had substantial help and have been able to employ someone to assist with this, and many have been able to remunerate parent carers for their time at meetings, in addition to travel expenses, and occasionally child care costs. However, this report shows that the ability and commitment of parent carers to act as critical friends is present irrespective of being paid for their expenses, or being paid for their time.
5. Parent carers need to be involved in all decision making meetings, else their attendance can appear tokenistic
6. Because of the extension of the programme, some parent carers are concerned about whether the feedback from the pathfinders will be used.
7. Parent carers feel that it should be a requirement to involve parent carer forums in the onward development and improvement of services in the revised Code of Practice.
8. Parents will need to know what action they can take if they do not agree with the outcome of an assessment of their child’s needs in the revised Code of Practice.
9. The child’s holistic needs should be addressed, encompassing health and social care as well as education.
10. There have been considerable challenges to overcome in order to enable the input of parent carers in some areas, and their commitment to finding solutions is evident. Sustaining this level of involvement may be a challenge and will require further investment from everyone involved.



Appendix 1 Questionnaire sent to all Pathfinder Parent Carer Forums

QUESTIONNAIRE FOR PARENT CARER FORUMS IN PATHFINDER AREAS

We are eager to gather and understand the main learning points from parent carer forums involved in current Pathfinders. We need to do this now in order for this learning to influence decisions about Pathfinders and the Code of Practice.

A Contact a Family Associate Justin Simon, will be trying to contact you over the next two weeks to talk through this questionnaire, so whilst you do not need to complete this yourself, it will be helpful for you to review this and consider the full implications of the Pathfinder experience for you and your forum. We appreciate this is asking for more of your time, but your input will be invaluable for the future, and to enable other non pathfinder areas to consider the best ways to work with forums.

Name of Parent Carer Forum			
Local Area			
Name of Interviewee			
Role in Forum		Parent/Carer	Yes/No
If No - role of interviewee			
Date			

1. Was the Parent Carer Forum involved in developing the bid to be a pathfinder area? Yes No
2. If so, what level of involvement did you have with the bid?

No involvement	
Involved after the bid was completed	
Consulted about the bid	
Actively participated in considering the bid	
Co-produced the bid	
Date	

3. Following the success of the bid, was the parent forum immediately involved in working with the Local Authority Yes No
4. If No – what were the challenges in enabling the participation of your forum in the work?

5. Estimating how much extra work has been involved, by how many parents

Activity	Duration How long did it take (hours)?	How many parent reps involved?	Frequency (weekly, fortnightly, monthly etc)	State whether expenses met, and or payment per hour	Informing or Consultation or Participation or Coproduction
Local Change Boards (Strategic Pathfinder planning group)					
Specific work streams					
▪ Education health and Care Plan					
▪ Local offer strategic groups					
▪ Single Assessment process					
▪ Recruiting and supporting pathfinder families					
▪ Other (please specify)					
Additional parent carer forum meetings to train, support and ensure communication with new rresp					

6. Remunerating or resourcing the activity

Was extra funding/support given to support this work?	Yes/No
If yes, how much was this?	
Was this paid in advance or after activity?	
Was this paid following an agreed payment policy?	
Do you think resourcing your involvement has been essential to ensure effective participation or coproduction?	Yes/No (any additional comments)
If No - would additional resource have supported your involvement?	

7. What has gone well and why – can you give examples?

8. What has not gone well and why – can you give specific examples?

9. What has been the impact of having parent carers involved strategically?

10. Have there been any changes in relationships or ways of working? Can you give examples?

11. What have the biggest 3 challenges been?

1.	
2.	
3.	

12. What are your solutions to these?

1.	
2.	
3.	

13. What has the impact of the extra Pathfinder work been on your forum?

14. What are your 3 main concerns for the next 18 months?

1.	
2.	
3.	

15. What in your opinion is the most important thing forums, Local Authorities and partners need to consider as they begin to work on the proposed changes?

16. Do you have any key elements you want to see in the revised Code of Practice relating to parent carer forums, and any pathfinder learning?

17. Are there any messages you would want to be fed back directly to the Department for Education about the pathfinder work?

Finally, a huge THANK YOU to you and your forum for your hard work.

We would like to invite Pathfinder Forums to meet together at the Department for Education to consider the learning from being part of a pathfinder which will be held on February 8th 2013 hosted at the Department for Education. We will be in touch with you shortly in relation to this.

For further advice, assistance or information regarding parent carer participation please contact: Sue North, Director of Operations, Strengthening Parent Carer Participation, Contact a Family, sue.north@cafamily.org.uk tel 0207 7608 8778, 209-211 City Road, London, EC1V 1JN www.cafamily.org.uk or Co-chairs, National Network of Parent Carer Forums, email: info@nnpf.org.uk c/o S North, 209-211 City Road, London, EC1V 1JN www.nnpf.org.uk

About the National Network of Parent Carer Forums

- Promoting Parent Carer Participation
- Ensuring the voices of parent carers are heard nationally with Departmental and Strategic Partners across Education, Health and Social Care
- Empowering and supporting parent carer participation developments across England
- Working with Regional Parent Carer Forum Networks across England
- Producing information and updates for Parent Carer Forums
- Producing responses to national consultations based upon the views of the membership.

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